PROMOTING ADVANCE CARE PLANNING EDUCATION AND ADVANCE DIRECTIVE COMPLETION IN THE COMMUNITY SETTING

By

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A scholarly project submitted in partial fulfillment of the requirements for the degree of Doctor of Nursing Practice

In

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DEDICATION

This DNP project is dedicated to my family. To my father who taught me that sometimes an extreme sacrifice, on your own terms, is worth the extra time with the people you love. To my mother who taught me strength and resilience through great loss. My deepest, heartfelt thanks to my family who has supported me unwaveringly throughout this project, it would not have been possible without you. Thank you.
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ABSTRACT

The United States population is aging due, in part, to western medicine’s ability to prevent, treat, and cure disease which has allowed the prolongation of life. End-of-life care has become more invasive and, despite the continued focus on patient autonomy, rates of advance directive (AD) completion remain low. Increased knowledge may increase the community dwelling adult population’s ability to plan for end-of-life, have end-of-life conversations, complete ADs, and increase individual’s autonomy at end-of-life. **Purpose:** The purpose of this project was to educate community-dwelling adults about the purpose and importance of ADs, encourage conversation about end-of-life planning, encourage completion of ADs in community-dwelling adults of all ages and in doing so, promote personal autonomy. **Method:** A sample of N=16 community-dwelling adults participated in an educational intervention that contained information on end-of-life planning with a focus on ADs. Pre- and post-intervention surveys were used to gather demographic information, assess AD knowledge and examine participant views on importance of understanding health information and autonomy. Descriptive statistics, qualitative description, and paired-sample t test was used to analyze the data. **Outcome:** The sample consisted of 16 community-dwelling adults between ages 30 and 84-years old. The five questions assessing AD knowledge Pre- and Post-intervention were scored as correct or incorrect for each participant and total correct responses were computed into a mean score. The results of the paired sample t-test indicates that there was a significant difference between scores for pre-intervention survey (M= 63.75, SD = 22.84) and post-intervention survey (M= 90.0, SD= 10.9, t(4)=3.015, p=.039). **Conclusion:** The project results indicate that this intervention was effective in increasing AD knowledge, although, the impact on actual AD completion rates was not assessed. Further research is needed to identify successful methods of increasing ACP and AD knowledge in the community-dwelling adult population and also to identify the impact of such programs on actual AD completion.
INTRODUCTION

Background

The United States (U.S.) population is aging. In 2015 there were 47.8 million people age 65 and older in the U.S., accounting for 14.9% of the population (Iriondo & Jordan, 2018). This number is expected to grow to 98.2 million or almost 25% of the expected population by 2060 (Iriondo & Jordan, 2018). By 2030 the entire baby boomer generation will be over age 65, which means 1/5 of U.S. citizens will have reached retirement age (Iriondo & Jordan, 2018). Life expectancy in the U.S. was 50 years or less in 1900 (National Institute on Aging, 2011) and by 2017 had increased to 78.8 years (Centers for Disease Control and Prevention, 2017). The increase in the aging population is partially due to improvements in western medicine and technology that allow providers to prevent, diagnose, manage or even cure conditions that have caused mortality in the past.

Healthcare providers now have more tools than ever to artificially prolong life, but they are not always able to maintain the person’s quality of life (Rummans, Bostwick & Clark, 2000). Along with the increase in life expectancy, more people are living with chronic disease (Rao, Anderson, Lin, & Laux, 2014) and death is a certainty all people eventually face. In the U.S., care at the end-of-life has become more invasive. Malcolm, Tung, Baum, Parikh, and Ashamalla, (2015) examined intensive care unit (ICU)
admissions in a person’s last month of life and reported that, in the prior 10 years, ICU admissions had almost tripled and the movement of people throughout multiple care settings within their last three months of life had also increased threefold. At end-of-life people are frequently not in control of their care, pain is common, and the death itself often occurs in an institution (Cassel & Demel, 2001) despite most people in the U.S. wishing to pass away in their homes (Wilkinson, Wenger, & Shugarman, 2007).

A person’s independence, or autonomy, is one of the most important Western bioethical principles (Sedig, 2016; Wilkinson et al., 2007). Patient autonomy was legally established by case law in 1914 by requiring consent before an invasive medical procedure (Wilkinson et al., 2017). Patient autonomy is commonly defined as persons who have decision-making capacity having the right to make their own medical decisions (Varelius, 2006). Making informed medical decisions requires a certain level of health literacy, or basic literacy skills along with knowledge on the health related topic that is being addressed (U.S. Department of Health and Human Services, 2017). Health literacy is the ability of an individual to obtain, process, and understand basic health information and use this information to make appropriate decisions about their health care (U.S. Department of Health and Human Services, 2017). To truly assure autonomy for their patients, providers must also make sure the person understands the risks, benefits and alternatives of each proposed option of treatment (Sedig, 2016). How can providers respect peoples’ wishes and ensure people receive appropriate end of life care if the person cannot speak for themselves?
Advance care planning (ACP) includes understanding the different life-sustaining treatments available, deciding what treatments would or would not be wanted, sharing these values with loved ones, and completing an advance directive (AD) to put these wishes in writing (National Hospice and Palliative Care Organization, 2006). The original advance directive (AD) was developed in 1960 to protect terminal patients from aggressive and futile treatment and give patients a voice in their care (Sabatino, 2010). In 1990 the Patient Self Determination Act (PSDA) was enacted by Congress. The PSDA required health care facilities to ask people if they have completed an AD, provide people information on their rights to autonomy in care, and make AD forms available if a person did not have them completed (Wilkinson et al., 2007).

A person’s wishes for end-of-life care may vary significantly from one person to the next. Some people wish their healthcare providers to exhaust all possible treatment options, some wish to refuse all treatment, while most lie somewhere along the spectrum between these two poles. Without a completed AD in which a person’s preferences are made known, healthcare providers often provide every life-sustaining intervention (Wilkinson et al., 2007). This may increase cost of care, and prolong life without necessarily improving quality of life. Advance directives allow people to maintain their autonomy and communicate their wishes, even when a medical event prevents them from speaking for themselves.

Advance directives contain two legal documents, a living will and a medical power of attorney. The living will allows a person to state which medical interventions they would and would not want if they are unable to communicate for themselves. This
document instructs health care providers about their healthcare goals and treatment preferences and indicates when (or if) the person would like to cease treatment (Wilkinson et al., 2007). The medical power of attorney/durable power of attorney for health care lets a person appoint someone they trust to speak for them in a medical crisis when a person is unable to speak for themselves. Currently, ADs are accepted throughout the U.S. and used, not only to determine end-of-life care preferences, but also to guide care throughout disease progression and aging (Wilkinson et al., 2007). Despite their importance the AD completion rate remains low, with only 18 to 30% of Americans having completed these documents (Rao, Anderson, Feng-Chang, and Laux, 2014; Moorman & Inoue, 2012; Wilkinson et al., 2007).

Advance care planning increases completion of ADs, increases family and clinician understanding of a person’s wishes, increases the person’s quality of life, increases the likelihood that the person’s wishes will be complied with by family and clinicians, and increases the likelihood that individuals will pass away in the setting they prefer (Detering, & Silveira, 2017). Advance care planning may decrease end of life hospitalization and invasive end-of-life treatment if this is the person’s preference. There is also a reported increase in satisfaction with quality of care and a lower risk of stress, anxiety, and depression for surviving relatives when the deceased has completed an AD (Detering & Silveira, 2017). Silveira, Kim, and Langa (2010) found that people who had ADs were most likely to receive care consistent with their wishes. People are more likely to complete an AD if they were older, Caucasian, have a history of chronic disease, have a higher socioeconomic status, and have a higher level of education. People are also more
likely to complete an AD if they have been educated about end of life care options and ADs (Detering & Silveira, 2017). This project was designed to provide an educational intervention to adults in the community setting to improve health literacy in regard to ADs, and also open and begin to normalize the conversation about end-of-life preferences.

**Purpose Statement**

Advance directive completion rates remain low despite legislation and evidence-based research exhibiting their value to people, health care providers, and the healthcare system. The purpose of this project was to educate community-dwelling adults about the purpose and importance of ADs, encourage conversation about end-of-life planning, encourage completion of ADs in community-dwelling adults of all ages, and, in doing so, promote autonomy.

**Significance of the Project**

There have been many programs developed to increase advance directive completion. Legislation and evidence-based research has exhibited the value of ADs to individuals, health care providers, and the healthcare system. Despite this, AD completion rates remain low and many adults have not had ACP conversations. This indicates a need for further program development and implementation of interventions
focused on ACP and AD completion. Improved AD knowledge may increase the community-based adult population’s ability to have end-of-life planning conversations, complete ADs, and increase end-of-life autonomy (Wilkinson et al., 2007). The information gained in completion of this community-based education project could be used to improve such programs in the future.

**Theoretical Framework**

Holistic and preventative care is embedded in the nursing profession. Nurses are committed to caring for not only a person’s physical health, but also to considering the person’s beliefs, values, and spiritual health to improve their quality of life. Nurses care for, and support, the whole person from birth until death. In her theory of caring, Swanson proposed that good nursing care must include caring for a person’s biopsychosocial and spiritual wellbeing (Swanson, 2010). The primary purpose of Swanson’s theory is to assist nurses in delivering care that “fosters dignity, respect and empowerment” (Masters, 2015, p. 324) with the ultimate goal of increased wholeness. Swanson’s (2010) theory includes six concepts; caring, maintaining belief, knowing, being with, doing for, and enabling that, when combined, encompass the holistic, interconnectedness of nurse-driven health care.

Advance care planning and the completion of ADs not only addresses the physical disease process, but also the psychosocial and spiritual care of the person and their families. Swanson’s theory is well suited to guide this project in that it calls for nurses to
provide holistic treatment of the person, which is a critical component in advance directive and end-of-life conversations.

Swanson defined her concept of “caring” as a “nurturing way of relating to a valued other toward whom one feels a personal sense of commitment and responsibility” (Swanson, 1991, p. 162). The focus of ACP is to allow people to state for themselves what they believe would be best possible care for themselves in given situations. A person’s idea of what constitutes best care can be influenced by a “complex interplay of a genetic heritage, spiritual endowment and the capacity to exercise freewill” (Masters, 2015, p.322). Providers must be able to explore what each individual values in their care to provide the best possible healthcare to each person.

The concept of caring was utilized throughout the design of the educational intervention. A personal sense of commitment and responsibility was felt by the student towards the community members who participated in the intervention. The educational intervention and surveys were designed to be a nurturing experience that would, in theory, reach the goal of allowing these community members to go forward with increased confidence that their wishes for end of life care would be honored and their experience at end-of-life would be the best possible according to each individual participant. The concept of caring was also utilized during the presentation in the expression of gratitude for the value of the participant’s time and the opportunity the participants provided to the graduate student. This was clarified in the introduction of the presentation by thanking participants for their participation and again at the close.
Swanson defined “maintaining belief” as “sustaining faith in the other’s capacity to get through an event in the life of the other’s capacity and holding him or her in high esteem, maintaining a hope-filled attitude, offering realistic optimism, helping to find meaning” (Swanson, 1991, p. 162). Swanson (1991) felt this should be done “no matter the situation” (p.162). Swanson’s concept of maintaining belief was utilized in the discussion portion of the project by acknowledging that the participants were held in high esteem and acknowledging that they have the ability to discuss ACP. The intervention was designed to provide encouragement, increase knowledge, and encourage participants to examine what ACP could mean to them. Assisting people with ACP can offer people realistic optimism by allowing people to be informed and involved in their care. Advance care planning can promote open dialogue between a provider, their patients, and the patient’s loved ones about realistic expectations for a disease processes/aging. This conversation may assist people in finding meaning in a challenging situation.

Swanson defined her concept of “knowing” as “striving to understand the meaning of an event in the life of the other, avoiding assumptions, focusing on the person cared for, seeking cues, assessing meticulously and engaging both the one caring and the one cared for in the process of knowing” (Swanson, 1991, p. 162). AD discussions allow mutual engagement between the person completing the directive and anyone they choose to include in these conversations. AD discussions require a willingness to try to understand what the end-of-life process means to a person without making assumptions.

The project was meant to provide knowledge to participants, but mutual engagement in the learning process was achieved through the question and answer
segment at the end of the presentation. This provided an opportunity to turn focus to the participants and allowed the graduate student to learn and increase understanding of the focus population. The concept of knowing was further utilized in design of the pre and post surveys, especially the comment section.

The concept of “being with”, in relation to Swanson’s theory, was defined as “being emotionally present to the other. It includes being present in person, conveying availability, and sharing feelings without burdening the one cared for” (Swanson, 1991, p. 162). Throughout the introduction, presentation, and question and answer portion of the project it was imperative that the graduate student convey that she was fully present throughout the process, and was there to understand and learn from the participants as much as she was there to provide education. This was also addressed by having a clear schedule after the presentation to allow as much time as necessary to address participant questions and suggestions.

“Doing for”, defined as “doing for others what one would do for oneself, including anticipating needs, comforting, performing skillfully and competently and protecting the one cared for while preserving his or her dignity” (Swanson 1991, p. 162) relates to this project in the ability of advance directives to preserve dignity at end of life and assist providers in anticipating a person’s needs. This project was conceived in recognition of the need to improve end of life care and protect the autonomy and dignity of people in a vulnerable period of life.

The AD documents provided to participants, when completed, guide providers in assisting and facilitating the person’s passage through life transitions. Providers cannot
do “for others what one would do for oneself” literally and expect to preserve autonomy. Despite a health care provider’s ability to perform skillfully and competently and protect those they care for, the relevance of “doing for” in relation to ACP is it allows providers to follow the person’s wishes for care as they would hope their own wishes would be respected. Preserving dignity at end-of-life is completed more easily if wishes are known and the graduate student reiterated that advance directives help primary care providers (PCPs) maintain dignity as well as protect people when they are most vulnerable and can’t speak for themselves.

Swanson defined “enabling” as “facilitating the other’s passage through life transitions and unfamiliar events by focusing on the event, informing, explaining, supporting, validating feelings, generating alternatives, thinking things through, and giving feedback” (Swanson, 1991, p. 162). The concept of enabling was used to guide the development of the PowerPoint presentation used during the educational intervention. The PowerPoint presentation was developed to inform, explain, and discuss the many alternative options in end of life care. The environment was designed to be a supportive setting where feelings could be validated.

Swanson’s six concepts work together within her theory of caring to promote holistic treatment of the person which is an integral component in advance directive and end-of-life conversations. This theory was utilized to guide the development and delivery of the project, throughout the project implementation, especially during the development and delivery of the educational presentation, the question-answer session at the close of the educational intervention and in review of the survey results.
CHAPTER TWO

REVIEW OF THE LITERATURE

This chapter includes a summary of the literature on health literacy, advance directives, advance directive utilization, effects of advance directive utilization, and prior interventions focused on improving AD completion rates in the community setting. The literature review was conducted using the Montana State University Library database, Google Scholar, PubMed, CINAHL and the Agency for Healthcare Research and Quality’s National Guideline Clearinghouse. The Medical Subject Headings (MeSH) terms utilized for the literature review were *end of life, planning, adult, promoting end of life conversations, clinical practice guidelines for advance care planning, advance directives, interventions, advance directive completion rates,* and *living will.* Inclusion criteria were articles from 2000 to present written in English. Articles prior to 2000 and articles that focused exclusively on critically ill patients were excluded.

**Health Literacy**

Health literacy is the ability of an individual to obtain, process, and understand basic health information and use this information to make appropriate decisions about health care (U.S. Department of Health and Human Services, 2017). Health literacy requires a basic understanding of health related topics. Health literacy impacts the ability to communicate with health care providers, navigate the healthcare system, and engage in
the management of their health conditions. Health literacy may be influenced by communication skills, previous knowledge about health topics, the situation, the context, and the person’s culture (U.S. Department of Health and Human Services, 2017). Over 30% of the United States (U.S.) population is functionally health illiterate, 14% of U.S. adults have below basic health literacy, and only 12% of U.S. adults have proficient health literacy skills (The U.S. Department of Education, National Center for Education Statistics, 2013). Poor health literacy scores have been linked to poor health outcomes, less preventative care, lower rates of health insurance and higher healthcare costs; while adults with higher health literacy scores report better overall health (U.S. Department of Health and Human Services, 2017). The responsibility for improving health literacy lies with health professionals and the healthcare system. Health-related content is engaging for adults when it is relevant to their lives and health professionals can work with educators to develop programs that increase health literacy in this population (U.S. Department of Health and Human Services, 2017).

Berkman, Sheridan, Donahue, Halpern, and Crotty (2011) conducted a systematic review of literature to assess the relationship between low health literacy and health care use, outcomes, costs, and disparities in people of all ages. They found low health literacy was associated with increased hospitalizations and use of emergency care. They also found low health literacy was associated with lower utilization of preventative services such as mammography screening and influenza vaccination, poor medication management and ability to interpret medication labels, decreased overall health status,
and higher all-cause mortality rates (Berkman, Sheridan, Donahue, Halpern, and Crotty, 2011).

Kobayashi, Wardle, Wolf, and Von Wanger (2016) conducted a systematic review and meta-analysis to assess the association between age and health literacy and cognitive function in adults over 50 years old. A total of 70 analyses from 60 studies were reviewed, 29 of these were included in the meta-analysis. They found that only 12% of US adults have proficient health literacy skills. They also found older age to be strongly associated with limited basic health literacy skills that are required for successful healthcare interactions, such as reading comprehension, reasoning, and numeracy skills. They found vocabulary-based health literacy, however, to remain more stable with age (Kobayashi et al., 2016). Limited health literacy puts older adults at risk for poor chronic disease management and decreased use of preventative health services (Kobayashi et al., 2016). Based on the results of this review, the authors recommended that interventions in this population focus on utilizing previously learned knowledge and facts or crystallized cognitive ability, such as generalized knowledge and vocabulary, which remain more stable with age (Kobayashi et al., 2016). They also recommended that outcome measurement be selected wisely (Kobayashi et al., 2016).

In 2013 Waite et al. conducted a study to examine the relationship between functional health literacy and AD completion in community dwelling adults. The authors conducted face-to-face structured cognitive interviews to assess health literacy, cognitive function, physical health status, mental health, and health-related behaviors. There were 803 participants age 55 to 74 who received healthcare at any of five health centers in
Chicago, Illinois. Nearly one third of study participants were noted to have limited health literacy as measured by the Test of Functional Health Literacy in Adults (TOFHLA). The authors found that participants with low health literacy, independent of race, income, education, and age, were less likely to have an AD and AD completion significantly increased as health literacy increased. They found that less than half of their sample (41.2%) had completed an AD. Factors other than health literacy that had increased AD completion were white race, older age, higher education, higher income, and fewer chronic conditions (Wait et al., 2013). Based on the results of this study, the authors suggested interventions to improve AD completion should be simplified and discussions about AD may reduce health literacy barriers related to advance care planning (Waite et al., 2013).

**Advance Directive Utilization**

Wilkinson, Wenger, and Shugarman (2007) conducted a systematic review of peer-reviewed research evidence focused on AD completion published from 2004 to 2007 and utilized this to update a previous systematic review including articles from 1990 to 2004. They found that AD completion rates remained low despite multiple decades of advocacy and legislation encouraging their completion. They also found that often ADs don’t drive patient care, especially when families intervene at end-of-life. The authors noted multiple obstacles people had to completing AD including inadequate knowledge, the perception that AD completion and execution would be difficult, the
perception that the AD would not be followed, reluctance to broach the topic of death, and that an AD would not be necessary because their family would know what they would want. They also found limitations of ADs; such as coverage of a limited set of medical situations, lack of context, and difficulty predicting future treatment preferences. Wilkinson et al. (2007) also found ADs were limited by lack of access, with many physicians not being aware of completed ADs.

Wilkinson and colleagues (2007) found no evidence of negative psychological impact due to discussing ACP. Many participants reported feeling that they needed more information to complete end-of-life planning. The authors recommended that interventions promoting ACP address the limitations of ADs. They also recommended family members and caregivers be involved in ACP conversations as early and often as possible due to the reported frequency of disagreements between patients, families and caregivers in regards to end-of-life health care interventions. Their recommendations included peer mentoring, comprehensive interventions targeted at community dwelling elderly, facilitated ACP programs, efforts to increase patient/family/provider shared decision making, and providing AD materials that make completion easy. They stated that both intensive interventions which included formally structured education sessions, and community wide interventions showed positive results which included increased ACP conversation, increased AD completion and decreased healthcare surrogate decision-making stress. Optimally, advance care planning would take place in a series of interactions so people are educated, have the opportunity to ask questions and clarify
information, and have time to include, or at least inform, their families of their plans (Wilkinson et al., 2007).

Rao, Anderson, Feng-Chang, and Laux (2014) analyzed data from adults who participated in the 2009 or 2010 HealthStyles Survey which was designed to represent the U.S. population. They examined associations between ADs, demographic data, socioeconomic variables, health status, and end of life concerns. They found that 67.8% of participants reported concerns about end-of-life care. These concerns included cost, pain, comfort, and dignity at end of life. Despite these concerns only 48.6% reported having conversations about the treatment they would want at end-of-life and only 26.3% had an advance directive. The most frequently reported reason for not having an AD was lack of awareness and the second most reported reason was that the participants felt their family knew and would respect their wishes. They found respondents who had not had discussions about end of life care were five times less likely to have completed an AD (Rao et al., 2014).

Cummins, Prislin, Nguyen, Encinas, and Vigneron (2011) completed a retrospective review of ADs among patients aged 18-65 years old. They reviewed data from 497 in-patient records and examined AD completion and admitting diagnosis. They found a lower than expected rate of AD utilization in this population, at only 7.6%. They concluded that AD completion in younger age groups was significantly lower than that of the older population. They also stated that people in their 20s-30s who often have not considered filling out advance directives are often the “most controversial and
heartbreaking” cases when family must attempt to make end-of-life decisions (Cummins et al., 2011, p. 24).

Moorman and Inoue (2012) conducted a cross-sectional internet survey with a convenience sample of 1,075 couples (2,150 participants) aged 18-64 years old. They found 55% had discussed ACP with another person and only 28% had completed an AD. They found that death avoidance was the predominant reason this sample had not had ACP conversations and that those in poor to fair health were significantly more likely to have these conversations than those who felt their health was good to excellent. Using a rating scale ranging from 0 (no life-prolonging treatment) to 10 (all possible life-prolonging treatment), they found the majority of the participants preferred a moderate amount of treatment at end of life, scoring 5.23 out of total of 10. Their partners estimated their treatment preference slightly higher, at an average score of 5.51. The authors found only 28.8% of partners were accurate when predicting their partner’s preferences. The authors concluded that advance care planning completed only at the end of life loses much of its meaningful potential and having these conversations in this age group increases partner awareness and opens the topic to further discussion (Moorman & Inoue, 2012).

DiJulio, Firth, and Brodie (2015) reviewed data from the 1,202 adults, aged 18 years or older, who participated in the Kaiser Health Tracking Poll. They found ACP discussions occurred more frequently with those over the age of 75 and those with chronic medical conditions, but the majority of participants of any age wanted to discuss advance planning and end-of-life care. More than eight in ten participants stated that they
would feel comfortable having conversations about end-of-life care with their partner and almost half reported they would feel comfortable having those conversations with their children, parents, close friends and/or physician. A majority of the participants in the poll also indicated they would like to discuss ADs with their provider (DiJulio, Firth, & Brodie, 2015).

Advance Directive Impact

Enguidanos and Ailshire (2017) reviewed Health and Retirement Study survey data from 9,164 respondents and found that 3,810 (45%) had completed an advance directive prior to death. The Health and Retirement study included exit interviews with 2,904 healthcare proxies for participants who passed away prior to completion of the study. The investigators focused on data from participants who had completed advance directives. The total sample consisted of 2,904 participants after excluding 906 cases with missing information or data and those with proxy interviews completed more than 3 years after death. They found that only 5.35% of participants wanted prolonged, aggressive care. They found that timing of AD completion significantly impacted the participant’s end of life preferences. Only 1.8% who had completed ADs 5 to 10 years prior to death wanted prolonged aggressive care. The percentage of those who wished for prolonged aggressive care increased to 5.0% when ADs were completed 7-24 months prior to death and increased again to 12% in those who completed ADs in the last 3 months of life. The
percentage then fell again, to 3.9% in participants who completed ADs within the last month of life.

Auer (2008) conducted a case study focused on end-of-life planning with primary care patients who had chronic illnesses. She found that advance directive conversations allowed the opportunity for those living with chronic illness to discuss their wishes in relation to their current health status. She also found advance care planning conversations allowed people to retain control of their care, discuss what was important to them personally at the end-of-life, and establish realistic expectations for the course of their disease and treatment (Auer, 2008).

Detering, Hancock, Reade and Silvester (2010) conducted a randomized controlled trial to investigate the impact ACP had on end of life care of elderly patients. There were 309 participants who were followed for 6 months or until death. The participants were randomly assigned to receive usual care (n=155) or facilitated ACP (n=154) which involved formal ACP from a trained facilitator using the Respecting Patient Choices model. The participant’s doctor also participated in the ACP discussion if participants needed assistance in understanding their prognosis and treatment options. Participants in the intervention group were assisted in reflecting on their goals, values, and beliefs. They were encouraged to document their future healthcare choices and appoint a surrogate. Participants in the intervention group were also encouraged to include family members, especially their surrogate decision makers, in discussions about end-of-life care choices. The aim was to complete ACP documentation with participants before discharge. Outcomes that were studied were if the participants’ wishes were
known and respected, as well as participant and family satisfaction and response to the hospital stay. Detering et al. (2010) found that involving family and friends in ACP discussions reduced symptoms of stress, anxiety, and depression throughout the end-of-life decision process. They also found those in the intervention group had a much higher chance of their end of life wishes being followed and higher patient and family satisfaction (Detering et al., 2010).

**Interventions to Increase AD Completion**

Jezewski, Meeker, Loralee, and Finnell (2007) completed a systematic literature review focused on the effectiveness of interventions to increase AD completion. They found didactic interventions increased AD completion at a significantly lower rate than interactive interventions in which participants were able to ask questions.

Bravo, Trottier, Arcand, and Dubois (2016) conducted a randomized trial comparing two interventions aimed at increasing AD completion rates in community-dwelling, competent adults. One intervention consisted of two home visits by a trained facilitator and a group session providing information on ADs (n=118) and the other included only the group session (n=39). They found that after one month, 80% of the multi-session group completed ADs compared to 82% of those who attended only the group session and that both groups had similar variation in wishes regarding end of life care. The investigators concluded that single-session ACP interventions may increase AD
completion at similar rates as multiple session interventions, however further research was indicated (Bravo et al., 2016).

Kossman (2014) conducted a literature review of articles published from 2008 to 2013 with a focus on AD prevalence, implications for patient care, and impact of interventions on AD completion. She found that advance directive completion was dependent on how information was communicated to the person and the family and that providing information was not enough. She found that, to develop health literacy, people need to understand the information provided.

Kossman (2014) found that educational interventions provided the highest completion rates. Increased documented detail in AD choices, such as specific situational care, lead to outcomes more in line with the person’s preferences. Choosing a surrogate (healthcare POA) also increased the value of AD in providing care in line with the person’s wishes. She also found that people with completed ADs were less likely to have feeding tubes placed at end of life and less likely to die in the hospital setting (Kossman, 2014).

Splendore and Grant (2017) implemented a multimodal interactive workshop to increase AD completion. In the literature review conducted prior to the intervention, they found that AD completion was lowest in individuals who felt they had good overall health. They found multimodal interventions were most effective in increasing AD completion. They also found that presentations by a trained facilitator in a nonthreatening environment stimulated ACP discussions with individuals and family members and increased participant autonomy. They advertised their workshop with flyers, church
bulletins, newspaper, and word-of-mouth and delivered the workshop to a convenience sample of 40 community-dwelling adults in a rural community setting. They assessed the effectiveness of their intervention using pre and post-intervention surveys and found improvement in knowledge and completion post-intervention. They found that their intervention increased ACP, understanding of ADs, and AD completion one month post-intervention.
CHAPTER THREE

METHODS

The purpose of this project was to educate community-dwelling adults about the purpose and importance of ADs, encourage conversation about end-of-life planning, encourage completion of ADs in community-dwelling adults of all ages, and, in doing so, promote patient autonomy. The purpose was addressed by planning and implementing an educational intervention with a small group of adults in one rural community.

Montana State University Institutional Review Board Approval

Submission of the project for Montana State University Institutional Review Board (IRB) approval was completed on January 11th 2018. The project was designated as exempt from IRB review on January 31st 2018. See appendix A, page 52, for IRB documentation. There was minimal risk involved in this project. All participant demographic information was kept confidential by the numbering of pre- and post-intervention surveys to connect them without the use of personal identifying information. Information was also kept confidential by the student storing completed surveys in a locked file cabinet until completion of the data analysis. When all data had been converted to excel formal and a backup of the data was stored on an external hard drive, surveys were destroyed.
Setting

The intervention was implemented on June 7th, 2018 at 6:00 PM at the Public Library in a rural community in Western Montana. The town is a county seat and is surrounded by two mountain ranges. This setting provides many outdoor recreational activities to residents and visitors alike. The library is governed by a board of trustees and has been housed at the current location since 1916, with an enlargement completed in 1988. There is an upper floor that houses books and computers for public use. This project’s educational intervention was presented in the library’s daylit basement which is reserved for meetings, community events, and educational programs. The basement, as well as the rest of the library, is handicap accessible.

The room utilized for the presentation was equipped with a podium, laptop computer, projector and wall-mounted projection screen. The room was set up with two rows of tables. Chairs were positioned facing the podium and projector screen. Coffee, tea and water were available for participants. Each participant was provided a folder and pen on arrival.

Population and Sample

The most recent United States Census Bureau (2016) population estimate for this community was 42,088 with 24.6% of the population 65 years or older (a 5.4% increase
from the 2010 census). The population per square mile is 16.8 and is 95.9% white, 3.4% Latino or Hispanic. In this community 91.9% of the population 25 years and older have a high school or higher education, while 24.4 have a bachelor degree or higher. Of the population under 65 years, 19.3% do not have health insurance and 14.9% of the population live in poverty. The median household income in this community is $39,480 (United States Census Bureau, 2016). The sample population for this project was community-dwelling adults (18 years and older) in this rural Montana community. Inclusion criteria were age 18-years or older, community dwelling, English speaking, male or females of any ethnicity in the selected rural community.

Participants were a convenience sample of adult community members who presumably responded to the posted flyers or announcements and voluntarily attended the presentation. Sixteen community dwelling adults attended the educational intervention and all who attended participated in the pre- and post-survey.

**Development of Intervention**

The DNP student utilized multiple resources in development of the educational intervention. Atul Gawande’s (2014) book *Being Mortal* was used for applicable quotes at the beginning and close of the presentation. The Merriam Webster online dictionary (2011) was used to ascertain accurate definitions.

Wilkinson et al. (2007) and the National Hospice and Palliative Care Organization (2006) were used to explain concepts and define terminology throughout the presentation.
Information from these resources was utilized in the discussion about living wills and healthcare POAs. These resources were also utilized in development of the discussion about decision-making capacity and when an AD goes into effect.

Engage With Grace, a project designed by those impacted by end-of-life care to “get the conversation started” (Holt and Drane, 2018), was introduced as one option to help initiate ACP discussions with family members and/or loved ones.

The National Hospice and Palliative Care Organization (2018) was referenced for information on what must be done to make an AD legal in Montana. Goetting, Fox, and Knerr (2014) compiled a guide for Montana’s end-of-life registry. This guide included definitions, the registration form, and contacts for further information. The guide was used when discussing the registry during the educational intervention. Information regarding POLSTs was retrieved from the National POLST Paradigm (2018).

Many resources noted the death, divorce, decade, diagnosis and decline as 5 suggestions about when to review advance directives (Hospice Partners, 2018) and The American Bar Association Commission on Law and Aging (Siegel, 2012). Detering, & Silveira (2017) and AARP Education & Outreach (2010) were resources used when discussing the impact of ADs on end-of-life care and the experiences of loved ones.

Delivery of Intervention

Adult community members were invited to participate in an educational intervention regarding ACP. Advertising of this project was supported by the public
library. The adult services librarian agreed to have the educational intervention offered through the library’s community educational events program and assisted in development of promotional flyers. The content of the flyers included the target audience, a brief description of the intervention, the location, the date, the time, and a brief introduction of the student presenter. To access and recruit participants the education intervention flyers were distributed throughout the community at multiple different settings including local coffee shops, churches, gyms, and multiple restaurants. The program announcement was also placed on the library’s online event calendar and was sent out as part of the voluntary monthly email which alerts community members to library programs. See appendix B, page 54, for the flyer.

Participants were asked to complete a pre-survey, participate in the educational intervention, and then complete the post-intervention survey. Upon arrival at the Public Library, community participants were given the option to participate, or decline participation in the pre-intervention and post-intervention survey portion of this project. It was stated that declining participation in the survey portion would have no impact on their ability to participate in the educational intervention and they would still receive all educational materials. Individuals who agreed to participate were given a pre-intervention survey to complete to assess their baseline knowledge on the topic.

The educational intervention was an in-person presentation with utilization of Microsoft PowerPoint in the Public Library’s community classroom by the doctoral student. The presentation was scheduled at 6 PM. The DNP student provided each participant with a folder containing documents related to the educational intervention on
arrival. The Montana AD document (The National Hospice and Palliative Care Organization, 2018) and the Montana end-of-life registry guide (Goetting, Fox, and Knerr, 2014) were included in each participant’s packet, along with information on accessing these resources online. The “one slide” from the Engage With Grace project (Holt and Drane, 2018) was also included. See Appendix F through H, pages 76-87, for these documents. Ten minutes were given at the beginning for participants to complete the pre-intervention survey and for late arrivals to get settled. The DNP student began by thanking participants for attending and introducing the topic of end-of-life planning.

The student stated the purpose of the presentation as an introduction to the subject. The student explained that, due to the breadth of the subject, the presentation would only be an introduction. The presentation took approximately 35 minutes. Time was provided at the close for participants to ask questions prior to completion of the post-survey. After the questions participants completed the post-intervention surveys and turned them in to the student as they left the library. The time from the scheduled start of the intervention to completion of post-intervention surveys was approximately an hour.

The content of the educational intervention included reasons to discuss end-of-life planning and steps involved in end-of-life planning. The student discussed what to consider when discussing end-of-life planning, including physical, mental, and emotional needs. The student addressed the importance of having these conversations, even if loved ones may have different values. The Engage With Grace One Slide content was introduced as one way to approach the topic and open the conversation with family members.
The importance of communicating wishes and values led to the topic of advance directives. ADs were explained, including both the living will and health care power of attorney. The positives of ACP were discussed, such as retained autonomy and reported stress in those family members or loved ones. Negative aspects of the living will document such as a lack of space for specific directions were also mentioned. The student also made clear that an AD is a legal document. The importance of the accessibility of these documents, once completed, was stressed. The Montana End of Life Registry was discussed as an option to increase accessibility. Physician Order for Life Sustaining Treatment was also briefly discussed at this time. The DNP student reiterated that ADs are a “living document” which can be updated at any time. The DNP student also discussed the recommendations for when AD documents should be reviewed and updated if needed. In closing the DNP student discussed the impact of advance care planning and why it is important to discuss it sooner than later. The student also provided resources that could be utilized for further information such as Caring Info.org and the Montana Department of Justice End of Life Registry. See appendix E, page 63, for the educational intervention PowerPoint.

Data Collection

Surveys were used to identify any changes in the participants’ AD knowledge from pre-intervention to post-intervention. Participants were informed that completion of the survey portion was voluntary and the choice to complete, or not complete the surveys,
would have no impact on their ability to participate in the educational intervention. The two surveys were pre-numbered to be easily matched at the conclusion of the intervention while preserving confidentiality of the participants. Surveys were designed in 14-point, Times New Roman font. The pre-intervention survey consisted of 16 questions. Copies of the surveys are included in Appendices C and D.

Participants who chose to participate in the survey portion were asked to complete the pre-intervention survey immediately and this survey was collected by the student prior to initiation of the presentation. Pre-intervention surveys were utilized to gather demographic data and assess the participants’ baseline knowledge of ADs. Demographic data included gender, age range, and level of formal education. In the pre-intervention survey the participants were asked about the importance of being informed of health, importance of autonomy in their health care and their understanding of health information. Participants were also asked if they had previously had a conversation with their primary care provider about advance directives and if they have a completed advance directive. Pre-intervention surveys were used to assess participants’ baseline knowledge on the educational intervention topic. Knowledge of advance directives was measured utilizing 5 questions on the pre-intervention survey and reassessed utilizing those same questions in the post-intervention survey. See appendix C, page 56, for the pre-intervention survey.
The five questions used to assess AD knowledge were:

1) How old do you need to be to complete a legal advance directive?
   a) 18
   b) 25
   c) 50
   d) 65

2) What do you need to do to make an advance directive legal in Montana?
   a) It must be notarized
   b) You must have 2 witnesses
   c) It must be completed by a lawyer
   d) It must be completed with your primary care physician

3) When can you change your advance directive?
   a) With any change in health
   b) When you make an appointment with your physician
   c) Anytime
   d) This document can’t be changed

4) When does an advance directive take effect?
   a) When you enter the hospital
   b) When your family believes you are no longer making the correct choices
   c) When the doctor in charge of your care determines you are in a terminal condition
   d) When you can no longer participate in decisions regarding your medical treatment as determined by the doctor in charge of your care
   e) When the doctor in charge of your care determines you are in a terminal condition AND that you can no longer participate in decisions regarding your medical treatment

5) Are an Advance Directive and a Provider Order for Life-Sustaining Treatment the same?
   a) Yes
   b) No
   c) Unsure

Post-intervention surveys were distributed and completed immediately following
the presentation and discussion. The post-intervention survey was used to provide
information on the impact of the educational intervention. The post-intervention survey
included the same 5 questions to assess AD knowledge. The post-intervention survey
included questions about if participants felt more knowledgeable about ADs after the presentation and how likely they were to complete an AD in the next 3 months. A space was also provided on this survey for free-text comments and suggestions for improvement of the intervention. See appendix D, page 60, for the post-intervention survey.

Post-intervention surveys were collected as participants left the library and attached to the participant’s pre-intervention survey by identification number. All participants who completed a pre-intervention survey also completed the coordinating post-intervention survey.

Data Analysis

All pre- and post-intervention data from the paper surveys was coded and manually entered into Microsoft Excel by the student to prepare for statistical analysis. Demographic information from the pre-intervention survey were organized into table format using Microsoft Excel. Responses on the 5 questions assessing AD knowledge on the pre- and post-intervention surveys were scored as correct or incorrect. Tables were generated utilizing the data and organized using subheadings based on each survey question.

Data from Likert scale responses on the pre-intervention survey was analyzed and graphic representations were generated. The percent change from the 5 questions assessing AD knowledge from pre-intervention survey to post-intervention survey was
calculated. Correlational analysis was completed to examine association between demographic data and baseline AD knowledge. Change in AD knowledge from pre- to post-intervention was assessed by utilizing a paired t-test to compare mean total scores from questions 11, 12, 13, 15, 16 on the pre-intervention survey and questions 1 through 5 on the post-survey. Qualitative responses on question 8 on the post-intervention survey question addressing comments about the educational intervention were reviewed and summarized.
CHAPTER FOUR

RESULTS

The purpose of this project was to educate community-dwelling adults about the purpose and importance of ADs, encourage conversation about end-of-life planning, encourage completion of ADs in community-dwelling adults of all ages, and, in doing so, promote autonomy. A sample of 16 community-dwelling adults participated in an educational intervention focused on end-of-life planning and ADs. Pre- and post-intervention surveys were used to gather demographic information and opinions about autonomy in healthcare, and to assess AD knowledge. The DNP student utilized Microsoft PowerPoint for the presentation portion of the educational intervention. The PowerPoint presentation went smoothly with no technical challenges. PowerPoint slides functioned as anticipated to engage the participants in the presentation content. Participants appeared engaged throughout. After the presentation the DNP student designated time for participants to ask questions and provide comments.

Sample Description

Demographic data collected from the pre-intervention survey included gender, age, and highest level of education (Table 1). As can be seen in Table 1, most of the 16 participants were women. All participants reported being between ages 30 and 84-years old and all participants had some type of post-secondary education.
Table 1. Demographic Data

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total N</td>
<td>16</td>
<td>100</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>5</td>
<td>31.25</td>
</tr>
<tr>
<td>Female</td>
<td>11</td>
<td>68.75</td>
</tr>
<tr>
<td>Age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>18-29</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>30-44</td>
<td>2</td>
<td>12.5</td>
</tr>
<tr>
<td>45-64</td>
<td>8</td>
<td>50</td>
</tr>
<tr>
<td>65-84</td>
<td>6</td>
<td>37.5</td>
</tr>
<tr>
<td>85 or older</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Highest Level of Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than high school or equivalent</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>High school diploma or equivalent</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Trade-school, Associate, or other 2-year degree</td>
<td>4</td>
<td>25</td>
</tr>
<tr>
<td>Bachelor’s degree</td>
<td>9</td>
<td>56.25</td>
</tr>
<tr>
<td>Master’s degree</td>
<td>3</td>
<td>18.75</td>
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<tr>
<td>Doctorate degree</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Survey Results

All participants (N=16) completed the pre-intervention survey and questions 1 through 7 of the post-intervention survey. Only 7 of the 16 participants chose to answer the final open-ended question in the post-intervention survey.

Qualitative Data

When asked “How important do you feel it is that you are informed about your health care?” 87.5% of participants reported it was very important and 12.5% reported it was important. No participants, with or without a completed AD thought being informed about their healthcare was not important or somewhat important. Of the participants that
reported having a completed AD, 83.33 % felt it was very important and 16.66% thought it was important. All 4 of the participants who had not completed an AD reported they felt it was very important that they were informed about their healthcare.

When asked how often they understood information given regarding their healthcare, only one of the 16 participants responded always. Eleven of the participants responded that they understood this information most of the time, and 3 participants reported they understood this information some of the time. One participant out of 16 reported that they only understood information given regarding their healthcare half of the time.

Participants were in agreement that having control over their healthcare was very important (87.5%) to important (12.5%). No participants reported that autonomy was somewhat important or not important. See appendix C, page 56, for the pre-intervention survey.

Pre- and Post-intervention AD Knowledge

Participants were asked 5 questions to assess their AD knowledge on the pre- and post-intervention surveys. Responses for each of the 5 questions were scored as correct or incorrect. A summary of the total number of correct responses is provided in Figure 1. Total correct answers were calculated for all participants (N=16) and a mean score was computed. A higher mean score indicated a greater understanding of ADs (Table 2).
The percentage of participants who were able to correctly answer each question ranged from 37.5% to 93.75% on the pre-intervention survey and 68.75% to 100% on the post-intervention survey (Table 2). The Mean pre-intervention score was 63.75% and the mean post-intervention score was 90%, with a mean difference of 26.25% (Table 2). A paired-samples t-test was computed to compare the mean scores obtained on the 5 survey questions pre- and post-intervention. The results of the paired sample t-test indicates that there was a significant difference between scores for pre-intervention survey (M= 63.75, SD = 22.84) and post-intervention survey (M= 90.0, SD= 10.9, t(4)=3.015, p=.039) See Table 3 for a summary of results.

Figure 1. Pre-intervention and Post-intervention Comparison
Table 2. Percentage of Correct Answers on AD Knowledge Questions, Pre- and Post-intervention

<table>
<thead>
<tr>
<th>Question #</th>
<th>Pre-Intervention</th>
<th>Post-Intervention</th>
<th>Difference</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>93.75%</td>
<td>100.00%</td>
<td>6.25%</td>
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<tr>
<td>2</td>
<td>37.50%</td>
<td>93.75%</td>
<td>56.25%</td>
</tr>
<tr>
<td>3</td>
<td>81.25%</td>
<td>93.75%</td>
<td>12.50%</td>
</tr>
<tr>
<td>4</td>
<td>37.50%</td>
<td>68.75%</td>
<td>31.25%</td>
</tr>
<tr>
<td>5</td>
<td>68.75%</td>
<td>93.75%</td>
<td>25.00%</td>
</tr>
<tr>
<td>Mean Scores</td>
<td>63.75%</td>
<td>90.00%</td>
<td>26.25%</td>
</tr>
</tbody>
</table>

Table 3. Summary of Paired Samples t test

<table>
<thead>
<tr>
<th>Measure</th>
<th>T value</th>
<th>P value for Paired t test</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean scores on AD knowledge questions pre- and post-intervention (N=16)</td>
<td>3.015</td>
<td>.039</td>
</tr>
</tbody>
</table>

Demographic Data and AD Completion

Twelve participants (75%) reported having completed ADs prior to attending the presentation, and 4 participants (25%) had not completed an AD. The 2 participants in the youngest age group in attendance (30-44) did not have a completed advance directive. Only 1 participant from 45-64 years-old and 1 participant in the age range of 65-84 had not completed an AD. Six participants reported having had an AD conversation with their primary care provider. The 2 participants in the 30-44 age range and the 1 participant in the 45-64 age range who did not have a completed AD also reported not having a conversation about ADs with their PCP (Figure 1). All male participants (n=5) reported
having a completed AD on the pre-intervention survey. Four of the 11 female participants (36.36%) reported not having a completed AD. Of the 4 participants without completed ADs, 3 reported their highest level of education as a Bachelor’s degree and one reported a Master degree.

Figure 2. Advance Directive Conversations with Primary Care Provider

Evaluation Questions

The post-intervention survey contained 3 question to gather information about the intervention (See Appendix D, Questions 6, 7, and 8). Based on responses to survey question #6, 100% of participants reported they felt more knowledgeable about advance directives after the presentation. In response to question #7, 3 of the 4 participants who did not have a completed AD upon arrival to the presentation, reported that they would be very likely to complete an AD in the next 3 months and 1 of the 4 reported being unsure. The participant who reported being unsure had further questions about “specific treatments a person could accept or reject” when answering Question 8, the open-ended final survey question.
Seven participants chose to answer Question 8: “What information do you feel should have been included in this presentation that was not included?” Three participants noted that they would have liked the presentation to include more information on specific medical options/treatments that could be included in an advance directive document. Four participants requested information be included on the impact/legality of this document while traveling, both in the U.S. and abroad. Two participants provided a general comment that the presentation contained good information.

Participant Discussion

At the end of the PowerPoint the student opened the discussion to the participants. Participant discussion included transferability of AD documentation when traveling to other states or out of the country. The DNP student was not able to answer this question fully as some states will accept another’s AD, some will not consider it a legal document and the student was not aware of other country’s laws in regards to ADs. The DNP student used this line of discussion to reiterate the importance of having ACP conversations with family and loved ones so wishes are known, with or without documentation. Participants also asked about the level of detail that can be included in AD documentation which led to review of the Montana “My Choices” advance directive form (National Hospice and Palliative Care Organization, 2018) where there is a section referencing special directions in relation to chronic illness or serious disability. The DNP
student discussed that in regard to specific directions, it would be beneficial to involve the person’s own PCP in the discussion.

Four participants stated they had completed ADs prior to the intervention but would utilize the information from the presentation to review and update these documents. One participant stated they had not considered the importance of discussing wishes with their family and would make this a priority. One participant stated they would like an extra folder to take to their husband, this was provided by the DNP student. Multiple participants voiced their appreciation for the presentation content. When participants had no further questions or comments the DNP student thanked them again for their time and participation.
The Patient Self Determination Act (PSDA) was enacted by congress in 1990, amending titles XVII (Medicare) and XIX (Medicaid) of the Social Security Act, with a goal of increasing patient autonomy in care (Patient Self Determination Act, 1990) by empowering people to complete ADs. The PSDA requires health care providers to ask people if they have completed an AD, provide people information on their rights to autonomy in care, and make AD forms available if needed. Despite this act and the published data on low AD completion rates in community-dwelling adults, there is a lack of published literature describing community-focused interventions which make a significant, positive impact on AD conversation and completion. The purpose of this project was to educate community-dwelling adults about the purpose and importance of ADs, encourage conversation about end-of-life planning, encourage completion of ADs in community-dwelling adults of all ages, and, in doing so, promote patient autonomy. This project implemented an educational intervention focused on end-of-life planning, specifically ADs with a group of adults in one rural community. The impact of the educational intervention was measured by comparing participants’ pre- and post-intervention survey results, specifically five questions evaluating AD knowledge. All participants demonstrated an increase in their perceived AD knowledge following the intervention. Examining the strengths and weaknesses of the intervention and project
design may allow improved results in future projects with similar goals of increasing AD knowledge and completion in community-dwelling adults.

**Discussion of the Results**

All participants in this study reported that they felt it was important to very important that they are informed about, and in control of, their health care. Despite this, only 35.5% reported having an AD conversation with their PCP. The likelihood of having had a conversation about ADs with the participants’ PCP was lower among the younger participants, with neither of the 2 participants in the 30-44 age range having a completed AD or having had an AD conversation with their PCP. This aligned with the findings of Cummins and colleagues (2011) of a much lower AD utilization rate in 18 to 65 year olds when compared with those over 65.

Based on 75% of participants in this project reporting completed ADs on the pre-intervention survey, it was likely that many of the participants came to the intervention with prior AD knowledge. Scores for AD knowledge were calculated based on total correct answers to five questions. The mean pre-intervention score was 63.75%. The mean post-intervention score was 90.00%. This change in scores was statistically significant based on a paired t test at p = < .05. All participants also reported a perceived increase in AD knowledge. Based on these results, the goal of improving AD knowledge was met. Research has shown that single-session ACP interventions increased AD completion, especially when combined with a question and answer session (Bravo et al.,
Although post-intervention AD completion was not assessed in this project, it is possible that an increase in AD knowledge contributes to subsequent AD completion.

**Limitations of the Project**

Addressing ACP in the community setting was, as anticipated, a challenging task. Several limitations are acknowledged in this project. One limitation was that the effectiveness of the intervention was unknown. The intervention was developed by the graduate student based on the literature and implemented for the first time in this project. Developing a new intervention was necessary due to the lack of published guidelines or literature on effective methods to increase AD knowledge and completion as well as to stimulate ACP conversation in the community setting.

The small sample size (N=16) drawn from one rural community was another limitation. This limitation decreased the generalizability of the project’s findings to a larger population or different location. Selection bias was a potential limitation, as all who attended the educational intervention were volunteers and some were friends or family members of the graduate student. The participants were fairly homogeneous with respect to race and educational level, therefore, the results of this project cannot be generalized to other, more diverse, populations. Due to the one-time presentation in this specific community, implementation of this project in other communities may be significantly different.
The compressed frame of the intervention was also a potential limitation. The short time frame may have impacted this project in two ways. The pre-intervention survey was directly followed by the educational intervention, which was then directly followed by the post-intervention survey. Due to the short time between the pre-intervention and post-intervention survey, scores on the post-intervention survey may have reflected experience with the test rather than an increase in knowledge due to the intervention. The graduate student had originally planned to survey participants 3 months post-intervention to assess subsequent AD completion. This was not completed due to time constraints and the fact that a majority (75%) of the participants had completed an AD prior to attending the educational intervention.

**Implications for Clinical Practice**

This project demonstrated that this topic can be approached in a way that educates community-dwelling adults and encourages them to advocate for the care they desire at end-of-life. Healthcare providers should support and implement community-based programs such as this to increase community-member knowledge about ACP. The PowerPoint slides included in Appendix E could be used as is or revised by others to supplement a community presentation.

It is critical that providers make a greater effort to address ACP as part of the yearly primary care visit with all adults, not just those 65 and older. Patient and family satisfaction with care is higher in those who have completed ACP (Detering et al., 2010).
Most people would like to have conversations about ACP with their PCP (DiJulio, Firth, & Brodie, 2015). Primary care providers could initiate family visits, where the family join the patient in-office, for ACP discussions. A group office visit would be beneficial as it would allow the provider to educate more than one person at a time and it would open the conversation within the family which has been shown to reduced symptoms of stress, anxiety, and depression (Detering et al., 2010).

Providers also have the responsibility to educate the patient on the ability for ACP to adapt as the patient’s condition changes or as their desires evolve. Enguidanos & Ailshire (2017) found that patient’s preferences change as they approach end-of-life. It is important for providers to emphasize that AD documents can be changed as often as a patient wishes to reassure patients that these documents will not commit them to a care path they may wish to change in the future. Providers also need to educate patients that these documents will not go into effect until they are unable to advocate for themselves.

All participants in this project reported that they felt it was important to very important that they are informed about, and in control of, their health care. Advance care planning and ADs increase the likelihood that a person’s wishes will be followed by family and clinicians (Detering, & Silveira, 2017). Understanding health information is crucial for completing an AD because, to do so, people need to understand their current health status, estimated progression of illness/ disability (if applicable) and their health care options. Primary care providers should also consider this finding throughout their practice as a whole and provide their patients with education regarding their diagnoses and treatment options, as well as the risks and benefits associated with each option.
In this project, it was also found that there is a lower AD completion rate and AD conversation rate with PCPs among the younger participants. All 3 participants who were 64 and younger had not had a conversation about ACP or ADs which is not surprising considering research has shown that ACP discussions occur more frequently with those over 75 (DiJulio, Firth, & Brodie, 2015). The young adult age group is at high-risk for unintentional injury, violence, and mental health disease (Wong, Merchant, & Moreno, 2014). Cummins et al (2011) found that younger people have not considered completing ADs. The most common reason given by people for not completing an AD is a lack of awareness (Rao et al., 2014). Primary care providers could make a significant impact in this area. One way to do this is to have AD conversations take place as a standard part of a primary care visit beginning when people turn 18-years old. Due to young adults infrequent utilization of healthcare when compared to children and older adults, initiating ACP in this population at primary care visits may not be sufficient (Wong, Merchant, & Moreno, 2014). Providers may need to think outside the box to disseminate important health information to this age group within their communities. Approximately 90% of this age group is active on social media and previous studies have shown young adults are interested in receiving health information on social media (Wong, Merchant, & Moreno, 2014). One way providers may reach this age group is establishing a social media presence as a provider which has the potential to expand the reach of their educational efforts.
Relation of Project to Nursing Theory

Swanson’s Theory of Caring was utilized to guide this scholarly project. This project’s focus was the community-dwelling adult population. The goal of the project was to increase patient autonomy by providing information about the purpose and importance of ADs, encourage conversation about end-of-life planning and encourage completion of ADs in community-dwelling adults of all ages. The goal, design, and implementation process of this project were consistent with Swanson’s theory and her belief that providers should deliver care that empowers the individual, fosters dignity, and respects the individual’s values (Masters, 2015). The educational intervention was designed to empower participants to direct their end-of-life care in a way that they felt respects their personal values and maintains their dignity.

Recommendations for Future Research and Scholarly Projects

There is currently insufficient evidence about how to design and implement interventions that significantly impact community-dwelling adult knowledge and completion of ADs. Future research could examine comparative effectiveness of different intervention designs on AD knowledge and completion. Further research on strategies increasing attendance to community-based educational interventions could positively impact not only this project but potentially many other educational interventions. Despite the limitations of this project, the results demonstrated that an increase in AD
understanding is possible with a one-time educational intervention. Interventions such as this, which incorporate discussion and time for questions and answers have been shown to increase AD completion when compared to didactic-only interventions (Jezewski et al., 2007). This project and the current limited AD completion rates demonstrate the need for increased education relating to ADs and end-of-life planning in the community-dwelling adult population. Research has shown, however, that optimal ACP would take place in a series of interactions, allowing people to clarify information, and include family members in planning (Wilkinson et al., 2007). A community-based educational intervention that was designed as a series, or even one interaction with a follow-up session may improve on this project’s outcomes.

This project could be replicated on a larger scale. This could include multiple communities and/or a larger sample of participants. An increased sample size and/or a more diverse sample may show a more meaningful difference in AD awareness, knowledge, and completion. A subsequent project could include post-intervention follow-up to assess if participants without prior ADs subsequently complete them.

It would be beneficial to involve participants’ PCP in interventions to promote ACP and AD and AD conversations. With PCP involvement realistic expectations for the course of disease and treatment could be established and clarified (Auer, 2008). A series of interactions including a community educational intervention such as the one in this project, as well as conversations with the person’s PCP and loved ones would allow people to ask questions and clarify information.
Conclusion

To respect patient autonomy, it is critical that health care providers are aware of people’s wishes for end-of-life care. One way to address this is by completion of ADs. While post-intervention AD completion was not assessed in this project, 100% of participants reported feeling more knowledgeable about advance directives. There was also a significant increase in participant’s ability to correctly answer the five AD knowledge questions on the post-intervention survey when compared to the pre-intervention survey. Further research and scholarly projects are needed to establish the most effective interventions for improving AD knowledge and completion in the community setting. Until results of such research or projects are available, community-based interventions such as this can be utilized to increase awareness and knowledge of AD and end-of-life planning in the community setting.
REFERENCES CITED


APPENDICIES
APPENDIX A

IRB APPROVAL LETTER
INSTITUTIONAL REVIEW BOARD
For the Protection of Human Subjects
FWA 00000165

960 Technology Blvd. Room 127
c/o Microbiology & Immunology
Montana State University
Bozeman, MT 59718
Telephone: 406-994-6783
FAX: 406-994-4303
Email: cheryl@montana.edu

MEMORANDUM

TO: Mary Smith and Jean Shreffler-Grant
FROM: Mark Quinn
Chair, Institutional Review Board for the Protection of Human Subjects
DATE: January 31, 2018
RE: "Improving Advance Directive Completion in the Adult Rural Population" [MS013118-EX]

The above research, described in your submission of January 11, 2018, is exempt from the requirement of review by the Institutional Review Board in accordance with the Code of Federal regulations, Part 46, section 101. The specific paragraph which applies to your research is:

   (b) (1) Research conducted in established or commonly accepted educational settings, involving normal educational practices such as (i) research on regular and special education instructional strategies, or (ii) research on the effectiveness of or the comparison among instructional techniques, curricula, or classroom management methods.

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

   (b) (3) Research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior that is not exempt under paragraph (b)(2) of this section, if: (i) the human subjects are selected or appointed public officials or candidates for public office; or (ii) federal statute(s) without exception that the confidentiality of the personally identifiable information will be maintained throughout the research and thereafter.

   (b) (4) Research involving the collection or study of existing data, documents, records, pathological specimens, or diagnostic specimens, if these sources are publicly available, or if the information is recorded by the investigator in such a manner that the subjects cannot be identified, directly or through identifiers linked to the subjects.

   (b) (5) Research and demonstration projects, which are conducted by or subject to the approval of department or agency heads, and which are designed to study, evaluate, or otherwise examine: (i) public benefit or service programs; (ii) procedures for obtaining benefits or services under those programs; (iii) possible changes in or alternatives to those programs or procedures; or (iv) possible changes in methods or levels of payment for benefits or services under those programs.

   (b) (6) Taste and food quality evaluation and consumer acceptance studies, (i) if wholesome foods without additives are consumed, or (ii) if a food is consumed that contains a food ingredient at or below the level and for a use found to be safe, or agricultural chemical or environmental contaminant at or below the level found to be safe, by the FDA, or approved by the EPA, or the Food Safety and Inspection Service of the USDA.

Although review by the Institutional Review Board is not required for the above research, the Committee will be glad to review it. If you wish a review and committee approval, please submit 3 copies of the usual application form and it will be processed by expedited review.
APPENDIX B

POSTER ADVERTISING ADVANCE CARE PLANNING PRESENTATION
Complete an Advanced Directive Workshop

Thursday, June 7
6:00-7:00 pm
meeting room
Bitterroot Public Library
where programs are always free

Mary Smith, Bachelor of Science in Nursing
Doctorate Student, Montana State University - College of Nursing
6 years of Medical-Surgical and Neurologic-Rehabilitation Nursing experience.

- Learn about advance directives, their components, and why they are important.
- Learn about the importance of discussing advance directives and your wishes with family and your healthcare POA.
- Learn how to complete your advanced care directive and register your choices with Montana’s End-of-Life Registry.

306 State Street, Hamilton, MT 406 363-1670
APPENDIX C

PRE-INTERVENTION SURVEY
1) Are you:
   a) Male
   b) Female

2) What age group do you fit in?
   a) 18-29
   b) 30-44
   c) 45-64
   d) 65-84
   e) 85 or older

3) What is the highest level of education you have completed?
   a) Less than high school or equivalent
   b) High school diploma or equivalent
   c) Trade-school education, Associate, two-year degree
   d) Bachelor’s degree
   e) Master’s degree
   f) Doctorate

4) How important do you feel it is that you are informed about your health care?
   a) Not important, my doctor manages my health concerns
   b) Somewhat important
   c) Important
   d) Very important

5) How often do you understand the information given to you regarding your health?
   a) Rarely
   b) Some of the time
   c) Half the time
   d) Most of the time
   e) Always

6) How important is it that you have control (autonomy) over your health care?
   a) Not important, my doctor manages my health concerns
   b) Somewhat important
   c) Important
   d) Very important
7) Have you had a conversation about advance directives with your primary care provider (doctor)?
   a) Yes
   b) No
   c) Unsure
   d) I don’t have a primary care provider

8) Do you have an advance directive?
   a) Yes
   b) No
   c) Unsure

9) If you do not have an advance directive, why have you not completed one?
   a) I don’t know what an advance directive is.
   b) I don’t feel that I have enough information to complete an advance directive
   c) I don’t feel that I am ready to complete an advance directive
   d) I don’t feel it is important to have an advance directive
   e) Other:

10) How likely is it that you will complete an advance directive in the next 3 months?
    a) I already have an advance directive
    b) Very unlikely
    c) Unsure
    d) Likely
    e) Very likely

11) How old do you need to be to complete a legal advance directive?
    a) 18
    b) 25
    c) 50
    d) 65

12) What do you need to do to make an advance directive legal in Montana?
    a) It must be notarized
    b) You must have 2 witnesses
    c) It must be completed by a lawyer
    d) It must be completed with your primary care provider
13) When can you change your advance directive?
   a) With any change in health
   b) When you make an appointment with your primary care provider
   c) Anytime
   d) This document can’t be changed

14) Have you heard of the End-of-life registry?
   a) Yes
   b) No

15) When does an advance directive take effect?
   a) When you enter the hospital
   b) When your family believes you are no longer making the correct choices
   c) When the doctor in charge of your care determines you are in a terminal condition
   d) When you can no longer participate in decisions regarding your medical treatment as determined by the doctor in charge of your care
   e) When the doctor in charge of your care determines you are in a terminal condition AND that you can no longer participate in decisions regarding your medical treatment

16) Are an advance directive and a Provider Order for Life-Sustaining Treatment the same?
   a) Yes
   b) No
   c) Unsure
APPENDIX D

POST-INTERVENTION SURVEY
1) How old do you need to be to complete a legal advance directive?
   a) 18
   b) 25
   c) 65

2) What do you need to do to make an advance directive legal in Montana?
   a) It must be notarized
   b) You must have 2 witnesses
   c) It must be completed by a lawyer
   d) It must be completed with your primary care provider

3) When can I change my advance directive?
   a) With any change in health
   b) When I make an appointment with my primary care provider
   c) Anytime
   d) This document can’t be changed

4) When does an advance directive take effect?
   a) When you enter the hospital
   b) When your family believes you are no longer making the correct choices
   c) When the doctor in charge of your care determines you are in a terminal condition
   d) When you can no longer participate in decisions regarding your medical treatment as determined by the doctor in charge of your care
   e) When the doctor in charge of your care determines you are in a terminal condition AND that you can no longer participate in decisions regarding your medical treatment.

5) Are an Advance Directive and a Provider Order for Life-Sustaining Treatment the same?
   a) Yes
   b) No
   c) Unsure

6) Do you feel more knowledgeable about advance directives after this presentation?
   a) Yes
   b) No
7) How likely is it that you will complete an advance directive in the next 3 months?
   a) I already have an advance directive
   b) Very unlikely
   c) Unsure
   d) Likely
   e) Very likely

8) What information do you feel should have been included in this presentation that was not included?
   a) ______________________________________________________________
       ______________________________________________________________
       ______________________________________________________________
       ______________________________________________________________
   b) ______________________________________________________________
       ______________________________________________________________
       ______________________________________________________________
       ______________________________________________________________

If you do not mind being contacted by email with a follow-up 2-question survey please leave your email below (this will be removed from your survey to keep answers anonymous).

__________________________________________________________________

Thank you for your time and participation!
APPENDIX E

ADVANCE CARE PLANNING POWERPOINT
Planning for our Final Chapter

Mary Smith
Montana State University
DNP-FNP

we all have an idea of what a “good life” entails...
We share our stories
but, in our culture,
we have forgotten something
that is critically important;
The ending
Optimism:

to anticipate the best possible outcome
~Merriam-Webster Dictionary

How can you communicate your wishes?
WHAT IS IT THAT MAKES LIFE MEANINGFUL?

What is worth giving up to keep on living?

And, just as importantly,

What isn’t?

CONSIDER THESE THREE AREAS:

• Physical
• Mental
• Emotional
CAN YOU AND YOUR LOVED ONES ANSWER THESE QUESTIONS?

1. On a scale of 1 to 5, where do you fall on this continuum?
   1. Let me die without medical intervention
   2. Medical intervention recommended
   3. Medical intervention possible
   4. Medical intervention required
   5. Medical intervention essential

2. If there were a choice, would you prefer to die at home, or in a hospital?
3. Could a loved one correctly describe how you'd like to be treated in the case of a terminal illness?
4. Is there someone you trust whom you've appointed to advocate on your behalf when the time is near?
5. Have you completed any of the following: written a living will, appointed a healthcare power of attorney, or completed an advanced directive?

ADVANCED DIRECTIVE

- Living Will
- Healthcare (Medical)
  Power of Attorney
DECISION-MAKING CAPACITY

LIVING WILL
HEALTHCARE POWER OF ATTORNEY

Significant other?
Child?
Family member?
Friend?
Lawyer?

Most importantly:
A person you trust

Montana Advance Directive

MONTANA ADVANCE DIRECTIVE

More information available at
The National Hospice and Palliative Care Organization
http://www.caringinfo.org/140/pages/index.cfm?pageid=3289
What do I do with my completed advance directive?

https://app.mt.gov/registry/
I COMPLETED AND FILED MY ADVANCE DIRECTIVE...

NOW I NEVER HAVE TO THINK ABOUT IT AGAIN!
A living document

5 D’S
- Decade
- Death
- Divorce
- Diagnosis
- Decline

POLST
Physician Orders for Life Sustaining Treatment
* ~Will it make any impact?~ *

A problem for my future self....
You only die once
~ Atul Gawande
APPENDIX F
PARTICIPANT PACKET HANDOUT: MY CHOICES ADVANCE DIRECTIVE
Full Name: ____________________________________________

Please print

These directions apply only in situations when I am not able to make or communicate my health care choices directly. Put an X through any sections you are not completing at this time.

1. Terminal Conditions (Living Will)

I provide these directions in accordance with the Montana Rights of the Terminally Ill Act. These are my wishes for the kind of treatment I want if I cannot communicate or make my own decisions. These directions are only valid if both of the following two conditions exist:

- I have a terminal condition, and
- in the opinion of my attending physician, I will die in a relatively short time without life sustaining treatment that only prolongs the dying process.

I authorize my Representative, if I have appointed one, to make the decision to provide, withhold, or withdraw any health care treatment.

General Treatment Directions

Check the boxes that express your wishes:

☐ I provide no directions at this time.

☐ I direct my attending physician to withdraw or withhold treatment that merely prolongs the dying process.

I further direct that (check all boxes that apply):

☐ Treatment be given to maintain my dignity, keep me comfortable and relieve pain.

☐ If I cannot drink, I do not want to receive fluids through a needle or catheter placed in my body unless for comfort.

☐ If I cannot eat, I do not want a tube inserted in my nose or mouth, or surgically placed in my stomach to give me food.

☐ If I have a serious infection, I do not want antibiotics to prolong my life. Antibiotics may be used to treat a painful infection.

I have attached additional directions regarding medical treatment to this form:

☐ Yes  ☐ No
2. Chronic Illness or Serious Disability (Optional)

My chronic illness or disability can complicate an acute illness, but should not be misinterpreted as a terminal condition.

Diagnosis _____________________________________________________________

Consult my physician _________________________________________________
Name ___________________________ Phone ________________________________

Special directions (use additional pages if necessary) ______________________

3. Health Care Representative (Power of Attorney for Health Care)

My Representative may make all health care decisions for me as authorized in this document and shall be given access to all my medical records. This appointment applies whether I am expected to recover or not.

I wish to appoint a Representative ☐ Yes ☐ No

A. Primary Representative

I appoint __________________________________________ as my Representative.
Print Representative's Full Name ________________________________

Representative's Address
City ___________________________________________ State ______ Zip ______
Home Phone __________________ Work Phone ______________________

My Representative’s authority is effective when I cannot make health care decisions or communicate my wishes. I may revoke this authority at any time I regain these abilities (unless my attending physician and any necessary experts determine I am not capable of making decisions in my own best interest).

If, for any reason, I should need a guardian of my person designated by a court, I nominate my Representative, or Alternate Representative(s), named below.

B. Alternate Representative(s)

If: 1. I revoke my Representative's authority; or
    2. My Representative becomes unwilling or unable to act for me; or
    3. My Representative is my spouse and I become legally separated or divorced,
I name the following person(s) as alternates to my Representative in the order listed:

1. Print Alternate Representative’s Full Name __________________________
   Address _________________________________________________________
   City __________________ State ______ Zip ______
   Home Phone __________ Work Phone ______________________

2. Print Alternate Representative’s Full Name __________________________
   Address _________________________________________________________
   City __________________ State ______ Zip ______
   Home Phone __________ Work Phone ______________________

Revised 03/14
4. Signing and Witnessing this Advance Directive

A. Your Signature

Ask two people to watch you sign and have them sign below. If you can, it’s best to sign this document in front of a Notary Public.

1. I revoke any prior health care advance directive or directions.
2. This document is intended to be valid in any jurisdiction in which it is presented.
3. A copy of this document is intended to have the same effect as the original.
4. Those who act as I have directed in this document shall be free from legal liability for having followed my directions.
5. If my attending physician is unwilling or unable to comply with my wishes as stated in this document, I direct my care be transferred to a physician who will.

I sign this document on the ___________ day of _________________, 20__________

Signature

Print Full Name

Address

City State Zip

Home Phone Work Phone

B. Ask Your Witnesses to Read and Sign

I declare that I am over the age of 18 and the person who signed this document is personally known to me, and has signed these health care advance directives in my presence, and appears to be of sound mind and under no duress, fraud or undue influence.

1. Signature Date 2. Signature Date

Printed Name Printed Name

Address Address

City State Zip City State Zip

C. Notarizing This Document

STATE OF _________________ COUNTY OF _________________

On this __________ day of _________________, 20__________, the said known to me (or satisfactorily proven) to be the person named in the foregoing instrument, personally appeared before me, a Notary Public within and for the State and County aforesaid, and acknowledged that he or she freely and voluntarily executed the same for the purposes stated therein.

____________________________

Notary Public for the State of ________________________

Residing at ________________________________

My commission expires ________________________
5. Special Directions

A. Spiritual Preferences
   My religion ____________________________ My faith community ____________________________
   Contact person ________________________ I would like spiritual support ☐ Yes ☐ No

B. Where I Would Like to be When I Die
   ☐ My home  ☐ Hospital  ☐ Nursing home  ☐ Other ____________________________

C. Donation of Organs at My Death (check one of the following):
   ☐ I do not wish to donate any of my body, organs, or tissue.
   ☐ I wish to donate my entire body.
   ☐ I wish to donate only the following (check all that apply):
       ☐ Any organs, tissues, or body parts  ☐ Heart  ☐ Kidneys  ☐ Lungs
       ☐ Bone Marrow  ☐ Eyes  ☐ Skin  ☐ Liver  ☐ Other(s)

D. After-Death Care (care of my body, burial, cremation, funeral home preference)

E. Additional Directions (use additional pages if necessary) ____________________________

Signature ____________________________ Date ____________________________

F. Distributing this Advance Directive
   I plan to deposit this Advance Directive in the Montana End-of-Life Registry: ☐ Yes ☐ No
   I plan to send copies of this document to the following people or locations:

   Physician: ____________________________
   Name ____________________________
   Address ____________________________
   City __________________ State __________________ Zip __________________
   Home Phone __________________ Work Phone __________________
   Hospital: ____________________________
   Name ____________________________
   Address ____________________________
   City __________________ State __________________ Zip __________________
   Home Phone __________________ Work Phone __________________

   Family Member: ____________________________ Relationship ____________________________
   Name ____________________________
   Address ____________________________
   City __________________ State __________________ Zip __________________
   Home Phone __________________ Work Phone __________________

Revised 03/14
APPENDIX G
PARTICIPANT PACKET HANDOUT: MONTANA’S END-OF-LIFE REGISTRY
Montana's End-of-Life Registry

by Marsha A. Goering, Ph.D., CFP®, CFCS, Professor and Extension Family Economics Specialist, Montana State University Bozeman; Tim fox, Montana Attorney General; Virginia Kneer, CCA, MSU Extension Agent, Broadwater County

This MontGuide answers commonly asked questions about the Montana End-of-Life Registry, Living Wills, Comfort Ono and POLST.

Introduction
The Montana Legislature authorized the Attorney General’s Office to establish and maintain an End-of-Life Registry Web site for Montana citizens. The goal was to provide a place for citizens to securely store their advance directive online and to give authorized health care providers immediate access to them. This MontGuide answers commonly asked questions about the Montana End-of-Life Registry.

What is an advance directive?
An advance directive is a document that expresses how you would want to be treated if you were seriously ill and unable to make decisions for yourself. It provides instructions about what you would want done or not done about life-sustaining treatment and other health care issues. You may order that your life be prolonged as long as possible. Or, you may order that your attending physician withhold or withdraw treatment that would only prolong the process of dying. Examples of advance directives include health care directives, living wills (called a declaration in Montana), health care (medical power of attorney), and provider orders for life-sustaining treatment (POLST).

How do I file an advance directive?
First, complete an advance directive that meets the requirements of Montana law, found in Section 50-9-103 of the Montana Code Annotated. A form that meets these requirements is available from the End-of-Life Registry at www.endolife.mt.gov.

MSU Extension also has a declaration (living will) form that is included in the MontGuide, Montana Rights of the Terminally Ill Act (MT1992H10). This publication is available through your local County Extension Agent or online at www.montana.edu/extensionplanning. Scroll down to Montana Rights of Terminally Ill Act.

A POLST form is available from your physician or other healthcare provider or you can download a copy online at www.polst.mt.gov.

Second, complete the Montana End-of-Life Consumer Registration Agreement. A copy of the agreement is on page 2 of this MontGuide. The form is also available from the End-of-Life Registry at www.endolife.mt.gov.

Once you have completed your advance directive and consumer registration agreement, make a copy of each so you will have a record of your submission. Then send the original forms to:

Montana End-of-Life Registry
Office of Consumer Protection
P.O. Box 201410
Helena, MT 59630-1410

What are the legal requirements for an advance directive?
Regardless of the format, Montana law requires that a person (called a declarant under the Montana Rights of the Terminally Ill Act) executing an advance directive is at least 18 years of age. Two witnesses must observe your signing of the form and then sign the forms themselves. Your signature and those of the two witnesses do not have to be notarized.

You may have another individual sign for you if you are unable to sign the form yourself.

Example A: Jane has Parkinson's disease and can no longer hold a pen to sign documents although she is mentally competent. Jane asked her attorney to sign on her behalf in the presence of two witnesses.

Who can witness my advance directive?
Friends, acquaintances and business associates can serve as witnesses during the signing of your advance directive. While Montana law allows family members to be witnesses, you may choose not to have relatives as witnesses to avoid questions regarding impartiality.

Example B: Ralph did not want any of his children to serve as witnesses because he is aware that they may disagree with his wish to stop life sustaining treatment for his terminal cancer.

What if I change my mind about my advance directive?
You can always make changes to your advance directive stored in the registry. Simply complete a new advance directive and a new Consumer Registration Agreement and mail both new forms to the Office of Consumer Protection. Indicate on the Consumer Registration agreement that you wish to replace your existing directive with a new one. You cannot file or change your advance directive online.
Montana Department of Justice  
Office of Consumer Protection  

MONTANA  
END-OF-LIFE REGISTRY  
www.endoflife.mt.gov  

Consumer  
Registration  
Agreement  

PO Box 201410, Helena, MT 59620-1410  
Phone: (406) 444-0960 or (866) 975-3314  
E-mail: endoflife@mt.gov  

This form indicates your desire to store an advance directive in the Montana End-of-Life Registry, to replace or remove an Advance Directive already in the Registry, or to request a replacement wallet card.  
• Read this Agreement carefully and fill in Sections A through C completely.  
• Attach your witnessed Advance Directive.  
• Return this Agreement with your Advance Directive to the Office of Consumer Protection at the address above.  
• Your Consumer Registration Agreement will be processed within three weeks. You will receive further information in the mail.  

Section A  

<table>
<thead>
<tr>
<th>Prefix</th>
<th>First Name</th>
<th>Middle Name or Initial</th>
<th>Last Name</th>
<th>Suffix</th>
</tr>
</thead>
<tbody>
<tr>
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<table>
<thead>
<tr>
<th>Gender</th>
<th>Date of Birth (Month/Day/Year)</th>
<th>Mother's Maiden Name</th>
<th>Social Security Number</th>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
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<table>
<thead>
<tr>
<th>Mailing Address</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cty</td>
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</tr>
</tbody>
</table>

Section B  

Pick a level of privacy:  

- Standard Privacy: If the information on my wallet card is unavailable, in addition to health care providers, people who enter my Social Security Number, date of birth and mother's maiden name can view my advance directive.  
- Higher Privacy: Only people who have the information from my wallet card and health care providers can view my advance directive.  

I want to:  

- Store an advance directive in the Registry.  
- Replace an advance directive in the Registry with a new one.  
- Add an Addendum to my current directive  
- Remove my advance directive from the Registry.  
- Request a replacement wallet card.  

Section C  

I am providing this personal information along with my advance directive, with the understanding that my personal information will be stored in a secure Department of Justice database and will not be available to the public. I certify that the advance directive that accompanies this Agreement is my current effective advance directive and was duly executed, witnessed and acknowledged in accordance with Section 50-5-103 of the Montana Code Annotated.  

I understand that:  

- my advance directive will be entered in the Montana End-of-Life Registry free of charge;  
- this authorization is voluntary;  
- this authorization to store my advance directive in the Montana End-of-Life Registry will remain in force until I revoke it;  
- I may revoke this authorization at any time by giving written notice of my revocation to the address listed above, and no agency, provider or individual may be held liable for any action based on this authorization before a written notice of revocation has been entered into the Registry.  

Signature of Person Signing This Agreement: ____________________________  
Date: ____________________________  

If the person named in the advance directive is unable to sign this form, and you have legal authority to sign for that person, please check the source of your authority and provide proof thereof.  
- Durable Power of Attorney  
- Court Appointed Guardian  

Revised 02/18
When does my advance directive become effective?
Your advance directive becomes effective only when the attending health care provider determines that you are in a terminal condition and can no longer participate in decisions regarding your medical treatment. Your advance directive will not be used provided you are able to express your own decisions on whether to accept or refuse medical treatment. You may make decisions regarding life-sustaining treatment for yourself as long as you are able to do so.

What is the difference between an advance directive and a Comfort One form?
Comfort One gives you the opportunity and the right to limit the care you receive in a medical emergency only. Comfort One is designed for persons in an emergency situation outside the hospital. It provides immediate identification to rescuers that you do not want to be resuscitated. You will only be provided comfort care and be allowed to die in the natural course of your illness. Enrollment is limited to those who have a terminal illness or those whose physician has ordered “do not resuscitate.” By displaying a Comfort One form, wallet card or bracelet (these are the only credentials approved by the Montana Department of Health & Environmental Sciences) to emergency medical service personnel, you can avoid all efforts of resuscitation. Unless you have one of these Comfort One credentials, EMT personnel will attempt to resuscitate you. Comfort One is being replaced by POLST.

What is the difference between Comfort One and POLST?
POLST is the Provider Orders for Life-Sustaining Treatment (POLST) program in Montana. The POLST form helps assure that patient wishes to have or limit specific medical treatments are respected near the end of life by all providers. The POLST form (www.polst.mt.gov) is an official documentation of medical orders on a standardized form coupled with a promise by health care professionals to honor those wishes. The Comfort One is for EMT personnel only and they will still honor your wishes. But gradually the POLST will replace Comfort One because the form applies to all health care providers.

Who are health care providers?
A health care provider is a person who is licensed, certified or otherwise authorized by the laws of Montana to administer health care in the ordinary course of business or practice of a profession.

What is the cost of filing an advance directive?
It's FREE! The Montana End-of-Life Registry stores your advance directive online without charge to encourage every Montanan to participate.

Who can access my advance directive?
You can specify whom you want to have access to your advance directive in Section B of the Consumer Registration Agreement. Section B offers two levels of privacy: standard or high.
* Standard Privacy allows you to access your advance directive anytime. Health care providers who have registered with the Attorney General's Office can also access your advance directive 24 hours a day. Anyone with your Social Security number, birth date and mother's maiden name, or with your name and access code can also access your advance directive online under this option.
* High Privacy allows access online only by the person who filed the advance directive, registered health care providers or anyone with your name and access code.

How will I know if my advance directive has been entered in the End-of-Life Registry?
Within three weeks of receiving your advance directive the Office of Consumer Protection will send you a letter indicating that your advance directive has been entered in the Montana End-of-Life Registry. The letter will also confirm your identifying information. You will also receive:
• A wallet card that contains the access code you use to check your advance directive through the online Montana End-of-Life Registry service.
• Four labels that can be placed on the back of your driver's license, health insurance card, automobile insurance card, or other important locations.

What if my advance directive is rejected?
If the Office of Consumer Protection determines that your advance directive does not meet Montana's legal requirements, your form and the Consumer Registration Agreement will be returned to you with a letter indicating what additional information is needed.

Who should know that I have an advance directive?
Provide a copy of your advance directive to your physician or other health care providers. These health care professionals are required to make your advance directive a part of your medical record and follow its provisions.

If you have designated another individual (termed a designee) to make decisions for you governing the withholding or withdrawal of life-sustaining treatment, provide your designee with a copy of your advance directive. When you name a person as your designee, the attending physician or other health care provider is required to follow the designee's instructions regarding end-of-life care.

Let your family members know you have an advance directive and encourage family members to place their advance directives in the Montana End-of-Life Registry.

Who can I contact for further Information about the Montana End-of-Life Registry?
Staff of the Montana Attorney General's Office and the Office of Consumer Protection cannot provide legal advice about advance directives or provide legal services such as writing an advance directive for you. However, they can answer questions you may have about the registry. You can contact the registry staff via email at endofliferegistry@mt.gov or call the registry's toll-free number, 1-866-675-3314, 24 hours a day.

Who should I ask about advance health care directives?
Your doctor, attorney or others who specialize in end-of-life care issues can answer your questions about advance directives.
Further information is available online from a number of government and non-profit organizations such as:

**Aging with Dignity**
P.O. Box 1661
Tallahassee, FL 32302-1661
Phone: 888-594-7437  Fax: 850-681-2481
E-mail: five wishes@agingwithdignity.org
www.agingwithdignity.org

**Association of Montana Health Care Providers (MHA)**
P.O. Box 3119
Helena, MT 59620
Phone: 406-442-1911  Fax: 406-443-3894
E-mail: mike@mha.org
www.mtha.org

**Compassion and Choices**
P.O. Box 101810
Denver, CO 80250-1810
Phone: 800-247-7421
www.compassionandchoices.org

**Caring Connections**
1700 Diagonal Road, Suite 625
Alexandria, VA 22314
Phone: 800-658-6958
E-mail: caringinfo@vlhpc.org
www.caringinfo.org

**National Hospice and Palliative Care Organization**
1731 King Street, Suite 100
Alexandria, VA 22314
Phone: 703-837-1300  Fax: 703-837-1233
www.nhpco.org

**Senior & Long-Term Care Division**
111 North Sanders, Room 301
Helena, MT 59620-4210
Phone: (406) 444-5622  Fax: (406) 444-1970
www.dphhs.mt.gov/dltc

**Montana Board of Medical Examiners**
Department of Labor and Industry
P.O. Box 200513, 301 South Park
Helena, MT 59620-0513
Phone: 406-841-2202  Fax: 406-841-2305
E-mail: dlhhamed@mt.gov

**FREE**

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**Summary**
Montanans can securely store their advance directives online. An advance directive provides instructions about your health care in the event you are unable to make these decisions yourself. The End-of-Life Registry is free to Montanans. Immediate access can be provided to authorized health care providers and family members. You can change your advance directive anytime you choose; however you cannot file or change your advance directive online.

**Disclaimer**
The material appearing in this fact sheet is presented for informational purposes only. The objective is to help you develop an understanding of the Montana End-of-Life Registry. The contents should not be considered as legal advice on advance directives or be used as such. For legal information specific to a health care (medical) power of attorney, contact an attorney.

**Acknowledgment**
Appreciation is expressed to the following for reviewing this Montana Guide for accuracy:
- Elderly Assistance Committee, State Bar of Montana
- Businesses, Estates Trusts Tax and Real Property Section, State Bar of Montana
- Office of Consumer Protection, Attorney General's Office
- Montana Board of Medical Examiners

**Website downloads**
- POLST form: www.polar.mt.gov
- Declaration (Direct Physician to Withhold) and Declaration (Designating Another Individual to Make Decisions) forms: www.montana.edu/estateplanning scrawl down to Montana Rights of Terminally Ill Act

To order additional publications, please contact your county or reservation MSU Extension office, visit our online catalog at www.store.msuextension.org or e-mail orderpubs@montana.edu

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**Montana State University Extension**

File under: Family Financial Planning (Estate Planning)
Revised February 2014  214SA
APPENDIX H

PARTICIPANT PACKET HANDOUT: ENGAGE WITH GRACE: ONE SLIDE

PROJECT POWERPOINT SLIDE
Can You and Your Loved Ones Answer These Questions?

1. On a scale of 1 to 5, where do you fall on this continuum?

   1 - Let me die without medical intervention
   2
   3 - Don’t give up on me no matter what, try any proven and unproven intervention possible
   4
   5

2. If there were a choice, would you prefer to die at home, or in a hospital?
3. Could a loved one correctly describe how you’d like to be treated in the case of a terminal illness?
4. Is there someone you trust whom you’ve appointed to advocate on your behalf when the time is near?
5. Have you completed any of the following: written a living will, appointed a healthcare power of attorney, or completed an advanced directive?

engagewithgrace.org

The One Slide Project
APPENDIX I

PARTICIPANT PACKET HANDOUT: END-OF-LIFE CARE SPECTRUM
Where do you fit on the spectrum for each question about end-of-life care?

<table>
<thead>
<tr>
<th>Only want to know the basics</th>
<th>Want to know as much as possible about your care</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ignorance is bliss</td>
<td>Want to know every detail</td>
</tr>
<tr>
<td>Want the doctors to just do what they think is best?</td>
<td>Want a say in any decision</td>
</tr>
<tr>
<td>Live as long as possible no matter what</td>
<td>Quality of life is more important than quantity</td>
</tr>
<tr>
<td>Mind living in a nursing/skilled facility</td>
<td>Living independently is a huge priority</td>
</tr>
<tr>
<td>Your loved ones should follow your wishes exactly</td>
<td>Your loved ones should follow what brings them peace</td>
</tr>
<tr>
<td>Want to be alone at the end</td>
<td>Want to be surrounded by loved ones</td>
</tr>
<tr>
<td>Keep health issues private</td>
<td>Loved ones should know everything about your health</td>
</tr>
</tbody>
</table>