

Effect of a Multimodal Intervention on Advance Directive Completion Rates

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Abstract

Advance care planning (ACP) could be working better both in the primary and hospital settings. When a patient is admitted in the hospital, there are several questions asked during admission regarding ACP but little screening on ACP is done in the primary care setting. Existing research supports ACP as a benefit to quality of death and health care costs, however, there is limited research on how to apply it in the primary care setting. Most of the research regarding ACP and end-of-life (EOL) care focuses on the process in the hospital or in nursing homes.

The goal of this project was to apply translational research to ACP within the primary care setting as a way of improving quality of care related to death and health care costs. The purpose of this project was to identify a sustainable program to assist primary care offices in the advancement and promotion of ACP. The intervention program utilized a multimodal approach to enhance advanced directive (AD) completion rates, and to identify influential factors affecting AD completion to tailor patient education based on these factors. The project yielded no participants. The basis of no participants is not likely a result of lack of interest but a reflection of the inadequacy of the recruitment process. The patient-initiated recruitment process was not effective in this setting because patients are not likely to think about the need for EOL care and advanced directive decision-making without being prompted to do so.

Future research should be conducted to identify appropriate and effective methods to engage patients in the ACP process through other recruitment methods such as direct-provider contact and continuous follow-up either by phone, mail, or electronic in the primary care setting. Other research opportunities are to examine the multi-modal approach to AD completion in community settings such as within faith-based organizations and health fairs.

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Advance care planning (ACP) is a recognized process for patients to communicate their preferences for medical care during critical illness if they lose their capacity to make medical decisions or express their wishes. Benefits of ACP include patient empowerment, autonomy, and reduced resource utilization. Research suggests that ACP can aid in making more patient-centered decisions, and contributing to better end-of-life (EOL) care and outcomes (Bischoff, Sudore, Miao, Boscardin, & Smith, 2013; Brinkman-Stoppelenburg, Rietjens, and van der Heide, 2014). Furthermore, research suggests that these interventions can help better allocate healthcare resources and contribute to cost containment (Dixon, Matosevic, & Knapp, 2015; Klingler, Schmitten, & Marckmann, 2015).

Completion of the advance directive (AD) is a fundamental element of the ACP process. However, AD completion rates remain low, both nationally and locally, despite the established benefits (Ramsaroop, Reid, & Adelman, 2007). The most effective method of promoting patients and their families to participate in this process has not been established (Ramsaroop, Reid, & Adelman, 2007; Landry, Kroenke, Lucas, & Reeder, 1997). The purpose of this capstone project was to evaluate if implementation of a multimodal intervention ACP program improves AD completion rates for Medicare patients aged 65 or older over a 2-month period in one Midwest primary care practice. Barriers and facilitators of the ACP process were identified to help tailor education and promotion methods to enhance future patient likelihood of AD completion.

Scope and Significance of Problem

The lack of ACP is a concern in both the primary and hospital care settings. Patients suffer unnecessary medical interventions, including cardiopulmonary resuscitation (CPR) and intubation, which they may not choose otherwise if given the opportunity. These missed

opportunities to protect patients' right to autonomy lend to poor health outcomes and loss of valuable health care resources. Families often are faced with difficult decisions regarding a loved one's EOL care that raise ethical concerns and cause emotional strain. A study conducted by the National Institute of Nursing Research showed that having no AD is the most notable factor contributing to family stress in hospitalized dying patients following withdrawal of aggressive medical treatments. Such stressors lead to intrusive psychological symptoms such as disturbed sleep and waves of strong emotions (Tilden, Tolle, Nelson, Thomson, & Eggman, 1999).

As technology has improved and the ability to artificially prolong life expanded markedly, so has the need to address EOL concerns. Studies show the ineffectiveness of cardiopulmonary resuscitation in most instances. Approximately only 2% of adults who have an out-of-hospital cardiac arrest and receive CPR ever recover fully, (Hagihara, et al., 2012) and only 18% of seniors who receive CPR in the hospital ever survive to be discharged (Ehlenbach, et al., 2009). Despite this, the natural default response in American hospitals often is rescue medicine.

The cost of interventions performed during EOL care often exceeds all the lifelong medical care. The average spending per patient for EOL care is \$33,500, nearly four times more than the typical cost for patients not dying in the same year (Kaiser Family Foundation, 2016). These costs will result in critical deficits in finances as health care supports an increasing aging population in the wave of the grey tsunami of baby boomers (Klingler, Schmitt, & Marckmann, 2015).

In reality, more patients die from chronic illness than from acute events. More than 90 million Americans live with at least one chronic illness, and 70% of Americans die from chronic disease. This figure is even higher among the Medicare population, with nine out of ten deaths

being associated with chronic illness. The last two years of life for patients with chronic illness account for nearly 32% of total Medicare spending, most going towards physician and hospital fees related to repeated hospitalizations. However, this is not what patients often want. Research completed by the Robert Wood Johnson Foundation suggests that most patients with serious illness prefer to die at home; yet, the majority (55%) end up dying in the hospital (Dartmouth Atlas of Health Care, 2016).

ADs provide a way to ensure patients' wishes are granted to provide a quality of EOL care while optimizing health care dollars and resources. Hamlet, et al., (2010) stated a total savings of \$5.95 million in Medicare costs could be realized by providing telephonic EOL counseling as an ancillary Medicare service. Zhang, et al. (2009) demonstrated not only cost savings of \$1041 per patient for those who reported EOL discussions, but also patients who did not have EOL discussions had worse quality of death in their final week (Pearson product moment correlation partial $r = -0.17$, $P=0.006$). Bischoff, Sudore, Miao, Boscardin, & Smith (2013) showed that ACP resulted in improved quality of care at the EOL, including less in-hospital deaths (adjusted RR 0.87, 95% CI 0.80-0.94), and increased hospice use (adjusted RR 1.68, 1.43-1.97).

Furthermore, current societal trends show that ACP is a concern for patients. A poll done by Kaiser Health showed that 9 out of 10 adults believe providers should discuss EOL concerns with their patients, but only 17% have ever had such discussions. Among those who have not had discussions with their providers, over half said they would like to and most believe (81%) Medicare should pay for these discussions (Kaiser Family Foundation, 2016). Consistent to endorsements from a range of stakeholders and bipartisan members of Congress, the Centers for Medicare and Medicaid Services (CMS) has begun paying for ACP discussions between patients

and their health care providers as of January 2016 (Centers for Medicare and Medicaid Services (CMS), 2015). These societal trends and economic influences identify ACP as a health concern facing a window of opportunity for a change in practice.

The Federal Patient Self-Determination Act (PSDA) of 1991 first brought attention to the importance of ADs. The 1995 Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT) demonstrated that a large proportion of patients receive prolonged aggressive treatments despite wishing for more palliative care (SUPPORT Principal Investigators, 1995). Since then, little has been done to educate, encourage, and enforce the PSDA supporting the need for directed efforts to improve techniques and interventions that increase AD completion rates. Regulatory agencies, such as the Joint Commission and CMS, require staff be educated to inform patients about ADs. The recent legislation allows providers to bill Medicare for ACP as a separate and individualized service to cover these discussions (CMS, 2015). Directing the focus on AD completion rates in the primary care setting before hospitalization could help improve EOL care and reduce health care costs.

Existing research supports ACP as a benefit to quality of death and health care costs, however, there is limited research applying this to the primary care setting. Most of the research regarding ACP and EOL care focuses on the process in the hospital or in nursing homes. The goal of this capstone project is to translate research to bring ACP in the primary care setting to improve quality of care related to death and health care costs before a crisis occurs. The recent passage of legislation by CMS to pay for ACP discussions and the rising public interest shown by current poll surveys demonstrates that ACP now faces a unique window of opportunity to mobilize a change in practice.

The primary care setting is an appropriate setting to focus on completion of ADs. The most successful interventions to increase AD completion rates are interactive discussions involving repeated conversations (Spoelhof & Elliott, 2012). Surveys found that most adults would prefer to discuss ADs while they are well, preferably with their primary doctor who has known them over time (Cugliari, Miller, & Sobal, 1995; Stetler, Elliott, & Bruno, 1992). Having a dedicated provider facilitates trust and rapport with the patient that would likely translate into a better understanding of patient preferences, beliefs, and wishes regarding EOL wishes. Having a long-term relationship with a patient allows the provider to explore what is meaningful to the patient over time to gain understanding of what quality of life is to that person and how this can be best interpreted in terms of death and illness decisions. This research suggests that focusing interventions within the primary care setting will be the most beneficial to enhance AD completion rates.

Concepts

Advance Care Planning (ACP)

ACP is the process of considering and communicating plans for future medical care and goals over time that is aligned with personal preferences, especially in the setting of serious illness or as the end of life approaches.

Advance Directive (AD)

AD is the legal document describing preferences for future care and appointing a surrogate to make health care decisions in the event of incapacity. It typically consists of a health care durable power of attorney (HCPOA) and a living will.

Health Care Durable Power of Attorney (HCPOA)

HCPOA is a legal document that appoints an “agent” to make future medical decisions. It becomes effective only when the patient is incapacitated.

Living Will

Living will is a document that details an individual’s wishes prospectively regarding initiating, withholding, and withdrawing certain life-sustaining medical interventions. It is effective only when the patient becomes incapacitated and with certain medical conditions.

Target Population and/or Stakeholders

The target population for this policy proposal was Medicare patients over age 65 years. This target population is a priority because they are likely to be the most immediately affected by EOL care decisions. This population group is also most important to address for the not-for-profit health system partnering with this project and the Centers for Medicare and Medicaid as these entities look for ways to uphold and improve quality of care while meeting financial demands. Additional stakeholders to consider in implementing this policy include palliative and hospice organizations, medical organizations including American Medical Association, members of the administration board including the Vice Presidents of Quality/Performance Improvement, Patient Care Services, and Medical Affairs, and members of the professional advisory council specific to legal affairs.

Problem Statement

Many programs and interventions have been tested since the PSDA was enacted in 1992; some of these programs have increased rates and others have had little or no impact. Studies estimate that only 5% to 15% of adults in the United States have completed ADs since the passage of the PSDA twenty years ago (Jones, Moss, & Harris-Kojetin, 2011). The low

prevalence of AD completion indicates a need for programs to educate and motivate patients and providers to ensure ADs are completed. Therefore, this capstone project intended to use written materials and face-to-face discussions to motivate patients to complete their ADs.

Second, research indicates that the preference for having an AD can be influenced by individual attitudes, cultural beliefs, health conditions, and trust in health care professionals (Jones, Moss, & Harris-Kojetin, 2011). Reasons individuals give for completing ADs include the opportunity to exercise autonomy and control, and relieve the burden on loved ones (Ernecoff, Keane, & Albert, 2016). Factors associated with completion of ADs include older age, length of time patient has been seen in the primary care practice, white race, married, and provider has an AD (Ramsaroop, Reid, & Adelman, 2007). This project also aimed to identify the barriers and facilitators that influence patients in the primary care setting to complete their ADs.

Purpose of the Project

The purpose of this project was to evaluate if implementation of a multimodal ACP program improves advance medical directive completion rates in the primary care setting for Medicare patients aged 65 and older over a 2-month period. Barriers and facilitators to completion of the AD were identified.

Clinical Question

Will implementing a multimodal advance care planning program in a primary care practice have an effect on AD completion rates for Medicare patients aged 65 or older?

Outcomes

- Advance medical directive completion rates will increase following implementation of an advance care planning program.
- Barriers and facilitators influencing the completion of the ACP process will be identified.

Review of the Literature

Relevant literature was reviewed to evaluate interventions that have been used in the past and what can be done to increase completion rates in the primary care setting. The history of PSDA and the SUPPORT study highlight the need for focused improvements in the area of ADs. The optimal setting for AD completion was also examined with a review of the literature to support the primary care office. The literature review demonstrated the need for improvement in practice and discussed the motivating factors and interventions that may assist in improving AD completion rates in the primary care setting.

The research identified the following key beliefs: acceptance of the nearing of death, EOL situations within the patient's realm of imagination, trust in the person assisting in the ACP process, and need for control aid in the ACP process (Piers, et al., 2013). According to Duke, Thompson, and Hastie (2007), the strongest influential factors for completion of an AD in hospitalized patients were spouses, family members, and sense of spirituality. Most learned about ADs from family, friends, personal attorneys, and others, while less than 25% learned about ADs from their health care providers. The number one reason cited for completing an AD were not wanting to be burden on their family (Duke, Thompson, & Hastie, 2007). By identifying influencing factors and facilitators, primary care clinicians will be more suited to educate patients and potentially enhance the likelihood of AD completion.

Evidence shows that ACP makes sense both economically and in quality of care. Three comprehensive systematic reviews demonstrated the economic savings and improvement in quality of EOL care supported by ACP. ACP was determined to reduce life-sustaining treatment, improve hospice and palliative care use, and deter hospitalization (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). Secondly, evidence suggests that ACP may lead to healthcare

savings with a net cost savings ranging from \$1041 to \$64,827 per patient (Dixon, Matosevic, & Knapp, 2015; Klinger, Schmitt, & Marckmann, 2015). Specifically, cost reductions of \$64,827 could be realized for terminally hospitalized patients (Chambers, Diamond, Perkel, & Lasch, 1994), \$56,700 for high-cost, low-income Medicare beneficiaries over 6 months of EOL care (Hamlet, Hobgood, Hamar, Dobbs, Rula, & Pope, 2010), \$11,500 for decedents living with dementia in the community during the last 6 months of life (Nicholas, Bynum, Iwashyna, Weir, & Langa, 2014), and \$1041 in hospital charges for decedents with cancer over the last week of life (Zhang, et al., 2009).

Moreover, Chambers, et al. (1994) demonstrated the average inpatient charge for patients without a documented AD was more than three times those with such documentation (\$95,305 vs. \$30,478). Hamlet, et al., (2010) stated a total savings of \$5.95 million in Medicare costs could be realized by providing telephonic EOL counseling as an ancillary Medicare service. Zhang, et al. (2009) demonstrated not only cost savings of \$1041 per patient for those who reported EOL discussions, but also patients who did not have EOL discussions had worse quality of death in their final week (Pearson product moment correlation partial $r = -0.17$, $P=0.006$), suggesting that higher costs and more interventions related with poorer quality of deaths. Last, Bischoff, Sudore, Miao, Boscardin, and Smith (2013) showed that ACP resulted in improved quality of care at the EOL, including less in-hospital deaths (adjusted RR 0.87, 95% CI 0.80-0.94), and increased use of hospice (aRR 1.68, 1.43-1.97). These studies suggest that ADs would offer substantial improvements in the allocation of health care resources towards interventions that are more grounded in fiscal responsibility and outcome measures.

The literature on interventions to improve AD completion rates was reviewed. Patient and provider influences, as well as educational influences were discussed in the review. Focus was

placed on motivating factors to AD completion rates. Interventional studies were evaluated. Multimodal interventions were found to have the biggest impact in improving AD completion rates.

Review of Literature Method

The review was conducted using a health information systems database including Medline, CINAHL, and the Cochrane Database. The Medical Subject Headings (MeSH) terms used were: ACP, ADs, intervention, education, completion, and primary care. Inclusion criteria included articles written in the English language, the years 1996 to present, peer-reviewed, research articles, high levels of evidence, intervention or outcome to support completion of AD, and age groups 65+ years. Exclusion criteria included letters to editor, articles related to feelings, perceptions, or understanding of life-sustaining treatments, articles related to mental health disorders, dementia, cancer, hospice, palliative care, or long-term care. One article on hospitalized patients was included because it cited factors that may influence completion of an AD that could be similar to ambulatory care patients in primary care. The search yielded 35 articles for review, eight were chosen for review. These eight were specifically chosen based on relevance and level of research. The setting in which the study was implemented was also taken into account, with seven of the studies conducted in the primary care setting (see Figure 1).

A variety of interventions were implemented. Of these eight articles: one was a systematic review of the literature, two were quasi-experimental, one a retrospective analysis, one an experimental pilot study, one a prospective cohort study, one a cross-sectional descriptive study, and one a qualitative exploratory study.

Review of Literature Results

The research studies were rated based on levels of evidence outlined by Polit and Beck (2012). This allowed for consistency in rating throughout all of the research studies reviewed and chosen for inclusion. The studies on AD completion described patient and provider influences; educational factors, and interventions to increase AD completion including mailings, computer reminder alerts to prompt providers, group educational sessions, and individual counseling with face-to-face discussion.

Motivational influences.

Piers, et al. (2013) conducted a qualitative exploratory study (level IV evidence) using semi-structured interviews in terminally ill or frail older adults to elicit the interviewees' personal narratives on 1) what was important in their life at that moment, and 2) their wishes and attitudes towards planning for EOL. Thematic analysis was done using the qualitative analysis database Nvivo 8 for framework development and coding. Three themes were identified as motivating factors who discussed EOL planning: 1) an acceptance of dying in near future; 2) feeling entitled to plan EOL care; and 3) motivations leading to plan or not plan EOL care. Motivational factors to planning included trust in surrogate decision-makers, good experiences with death and dying, and desire to maintain control and relieve loved ones from burden of decision-making (Piers, et al., 2013).

Duke, Thompson, and Hastie (2007) completed a level III, cross-sectional, descriptive study to evaluate characteristics and factors influenced by hospitalized patients to complete ADs. The barriers to initiating the discussion regarding ADs during hospitalization were similar to barriers in the outpatient setting. Barriers identified included lack of knowledge, confusing paperwork, and vagueness regarding who should initiate the discussion and who is educated to have the discussion. A convenience sample was selected from two acute care facilities in East

Texas using the following criteria: English-speaking, completed ADs, willingness to be interviewed or use the written tool, alert and oriented to person, place, and time.

The Advance Directive Assessment Tool (ADAT) was used, which was a 39-item questionnaire developed to gather information from patients. Sixty-four percent of the patients who completed the ADAT indicated they had ADs. The most influential reasons for having ADs were influences from spouses or loved ones and not wanting to be a burden to their family. Thirty-six percent of the patients who completed the ADAT indicated they had significant health issues, but seventy percent indicated their health status did not affect their decision to complete an AD (Duke, Thompson, & Hastie, 2007).

Understanding motivational factors to completing ADs is an important step to enhancing overall completion rates. Some of the motivational factors are out of the control of the primary care provider, such as emotional factors of trust and acceptance of death. The influential factor that could be influenced most by the primary care provider is the patients desire to relieve loved ones of the burden of decision-making. The primary care provider may elect to educate patients on this benefit when approaching the subject to motivate patients to complete ADs.

Interventions.

Simple and cost effective interventions are important in the primary care setting to improve AD completion rates. Interventions included handing out of written materials, having face-to-face discussions, a computer-based reminder program, group medical visits, and computer-based modeling. A systematic review done by Ramsaroop, Reid, and Adelman (2007) indicated that multimodal interventions were the most employed. The level I used meta-analysis to evaluate absolute rate differences in completion rates between intervention and control groups. Eighteen studies were examined, including twelve random control studies, two quasi-

experimental, one retrospective cohort, one observational, and two prospective. Ages of sample population ranged from eighteen to ninety in a variety of settings (e.g. Veteran's Affairs Medical Center, primary care clinics, internal medicine clinics, and geriatric clinics) and variety of interventions (e.g. patient-directed, physician-directed, and combined). Effect sizes ranged from -.05 to 2.48 with most (5) achieving an effect size between 0.5-0.8, indicating a moderate overall effect favoring AD interventions. The most successful intervention incorporated direct patient-healthcare professional interactions. More-effective strategies also used iterative interactions over multiple visits. Common barriers to completing ADs included lack of time, provider education, patient health literacy, lack of privacy for the discussion, and the perception the patient was "not sick enough" (Ramsaroop, Reid, & Adelman, 2007).

Wissow, Belote, Kramer, Compton-Phillips, Kritzer, and Weiner (2004) examined efficient ways to promote ADs among heterogeneous populations of elderly ambulatory patients within five Baltimore medical center groups of Kaiser Permanente. The prospective quasi-experimental study included an intervention group that involved pre- and post-visit reminder letters for ADs and a "Planning Ahead" brochure, educational presentations to medical and support staff by the chief of internal medicine on ACP and a "desk book" for reference, and organizational components consisting of a task checklist, preprinted reminder stickers, and reinforcement steps. The control group was selected from a sixth medical center. The sample size was 2,120 patients along with 29 medical providers. Inclusion criteria included patients 65 years or older who were continuously enrolled in one of the five medical centers or the comparison center during the study period and who had scheduled a health maintenance visit during the study year. A modest increase in AD completion rates was achieved in the provider-centered intervention group, 67 patients (7.8%) completed new ADs versus 9 (<1%) in the comparison

center ($p < .001$). Semi-structured debriefing interviews of providers revealed time constraints and unwillingness to press discussions with patients as barriers to conducting AD discussions with patients. The mechanism responsible for the increase was not provided by the study, such as how the discussions were framed or the frequency of AD discussions (Wissow, Belote, Kramer, Compton-Phillips, Kritzler, & Weiner, 2004).

Tung, Vickers, Lackore, Cabanela, Hataway, and Chaudhry (2011) conducted a level III retrospective analysis of an administered intervention to a cohort group representative of a population of patients seeking care at Mayo Clinic Rochester over a 23-week period. Inclusion criteria included patients 60 years or older, those seeking a health maintenance exam (HME) appointment, who did not have a current AD on file, and were identified at increased risk of health deterioration by the Generic disease management (GDSM). Exclusion criteria included non English-speaking and nursing home residents. The intervention group contained 574 patients with 146 in the control group. The intervention involved a multimodal approach of mailing an ACP educational packet and using a clinical decision support system (CDSS) to help remind clinicians to follow-up at the HME. AD completion rates were found to be significantly higher (17.5%) from 4.1% to 21.6% ($p < .0001$) when an organized patient education process such as a pre-visit resource mailing and CDSS that electronically prompted providers to counsel patients about their ADs. Forty-three percent of the patients surveyed by a post-intervention survey stated they decided to complete their AD because of receiving the packet. Surveyed patients preferred written materials to electronic ones when learning about ACP. The most common barrier cited for not completing an AD was not being sure of wishes (38.7%) (Tung, Vickers, Lackore, Cabanela, Hataway, & Chaudhry, 2011).

Duffield and Podzamsky (1996) conducted a quasi-experimental, level III study to determine if discussions about and distribution of AD forms in a rural, private primary health care office in Illinois would increase AD completion rates. The forms were distributed for one month and yielded a sample size of 195 patients, ranging in age from 21 to 88, with an average age of 54. Patients that did not complete ADs were used as the control group. Logistic regression analysis was used to determine if independent variables (e.g. age, provider, length of time in practice, marital status, acceptance of death, having a will, and attendance of religious services) had an effect on returning an AD form. T and chi-square tests were used to compare the characteristics of subjects who returned a completed AD and those who did not. The intervention involving discussion and distribution of AD forms in the primary care office resulted in a 45% increase in return rates. Older patient age ($P=.001$), longer length of time in practice ($P=.039$), less education ($P=.025$), and physician provider ($r=.002$) were associated with higher completion rates (Duffield & Podzamsky, 1996). This study, although dated, was used because it was similar in nature and provided a conceptual base for conducting this project.

Ernecoff, Keane, and Albert (2016) conducted a prospective cohort level III study employing agent-based modeling (ABM) to simulate actions and interactions of autonomous agents that would accurately reflect the rates at which individuals complete the ACP process. ABM design was based on the Transtheoretical Model (TTM) of behavior change using barriers (e.g. emotional and psychological readiness, having necessary materials), facilitators (increasing the salience for the need to develop an ACP, social support); and behavioral variables (susceptibility, baseline distribution) (Ernecoff, Keane, & Albert, 2016).

The ABM was used to predict how agents would move through the steps of the TTM in response to exposure to barriers, facilitators, and behavioral variables. Systematic manipulation

of these variables was done to determine the weight with which they may influence agents based on observed population rates. The model suggested structural interventions, e.g. increased access to ACP materials in primary care clinics, in addition to improved methods of data collection for behavioral studies, e.g. incorporating longitudinal data to capture behavioral dynamics had the largest effect on enhancing behavioral change to ACP completion (Ernecoff, Keane, & Albert, 2016).

Last, Lum, et al. (2016) conducted a level III, longitudinal experimental pilot study of five cohorts for eight months to examine if implementing group medical visits in a geriatric clinic at the University of Colorado Hospital would facilitate ACP conversations. Of 80 patients approached, 32 participated (40%) in at least one session. Mean age of participants was 79 years of age, 59% were women, and 72% were White. A Wilcoxon-signed rank test was used to test significance of change from pre to post-intervention. Patients reported an overall increase in ACP conversations with enough details that the patient felt confident that their loved ones knew their wishes (from 19% to 41%, $P=0.02$). Of 24 patients (75%) who reported having had an ACP conversation, 92% felt comfortable, 58% felt prepared, and 38% felt somewhat prepared. Patient retention was 84%, with 27 of 32 patients participating in both sessions. Qualitative analysis was also done to identify themes of the GMV experience using a mixed inductive and deductive approach. Key discussion themes showed patients shared personal values and challenges related to ACP and discussed a broad range of patient-raised topics related to ACP (Lum, et al., 2016).

Synthesis of Review of Interventions

There are many reasons why AD completion rates have not increased since the passage of the PSDA in 1992. Reluctance to initiate the conversation, time constraints, assumptions that the patient is too healthy, and unwillingness to press patients have all been cited by providers as

barriers to AD completion (Duke, Thompson, & Hastie, 2007; Wissow, Belote, Kramer, Compton-Phillips, Kritzler, & Weiner, 2004; Ramsaroop, Reid, & Adelman, 2007). Patient-cited barriers to completion are more varied, but common themes include deferring to family or planning to do it later (Ramsaroop, Reid, & Adelman, 2007), not being sure of their wishes (Tung, Vickers, Lackore, Cabanela, Hathaway, & Chaudhry, 2011), and non-acceptance of death as a likely outcome (Piers, et al., 2013). Piers, et al. (2013) also identified trust in their families and physicians to make good EOL care decisions for them and having good experiences with death and dying as barriers to proceeding with ACP. The most cited reason for completing an AD was not wanting to burden family with EOL decision-making (Duke, Thompson, & Hastie, 2007; Piers, et al., 2013). Other motivating factors identified by the literature included limited trust in family members to respect patient wishes, bad experiences with death and dying, fears regarding specific outcomes, and desire to control (Piers, et al., 2013). Despite barriers, patients still showed an interest in completing their AD. The study done by Lum, et al. (2016) engaging patients in a primary care office in ACP through group medical visits had a high participation rate of 40% and a retention rate of 84%, indicating that patients are interested, willing to participate, and desired to engage in conversations.

ACP is shown to save money and improve quality of EOL care. Interventions that are aimed at increasing ACP and AD completion will enhance the future of health care. Multimodal interventions have been shown to increase completion rates with a specific focus on face-to-face discussions with trained healthcare professionals (Ramsaroop, Reid, & Adelman, 2007). Having the opportunity to ask questions and receive compassionate, educated answers led patients to completing their AD forms. Ramsaroop, Reid, and Adelman (2007) identified iterative

interactions over multiple visits as the most effective method to enhance AD completion. This finding supports the primary care provider as the best suited for ACP discussions.

Multimodal interventions have been shown to have the biggest impact in increasing AD completion rates (Ramsaroop, Reid, & Adelman, 2007). One form of communication and interaction with a patient is insufficient when addressing such a complex discussion. In this review, several studies have employed multimodal interventions for AD completion including interventions that focused on provider education with organizational reminders (Wissow, Belote, Kramer, Compton-Phillips, Kritzler, & Weiner, 2004), a computerized clinical decision support system with written materials (Tung, Vickers, Lackore, Cabanela, Hataway, & Chaudhry, 2011), group medical visits with written educational materials (Lum, et al., 2016); all which resulted in statistically significant increases in AD completion rates. Ernecoff, Keane, and Albert's (2016) ABM suggest structural interventions such as increasing access to ACP materials in primary care clinics may be influential to motivate patients to complete AD. Tung, Vickers, Lackore, Cabanela, Hataway, and Chaudhry (2011) identified that patients prefer written materials to electronic ones when learning about ACP.

Current evidence supports an intervention that is multimodal and uses face-to-face discussions. Duffield and Podzamsky (1996) showed that providing a simple multi-modal intervention of AD forms and a discussion increased the AD completion rate by almost half within a primary care office. This increase was achieved without increasing the amount of provider time spent at each visit. Older people who had a longer relationship with their PCP were more likely to complete directives, again lending to the conclusion that PCP in a primary care setting are the most suitable for completing ADs and discussing ACP. This research supports the

implementation of a multimodal intervention utilizing written materials for education coupled with face-to-face discussions in a primary care setting as a way to enhance AD completion rates.

Theoretical Framework

A practical and ethical challenge of finding interventions that promote ACP completion rates is controlling and intervening in human behavior. To enhance ACP completion rates, it is necessary to understand and identify how best to motivate individuals towards ACP through the integration of complex behavioral patterns that aim at reducing barriers and increasing facilitators. One such model that aims to illustrate an individual's migration of change in association with a health-related behavior is the Transtheoretical Model of behavior change (TTM) (Ernecoff, Keane, & Albert, 2016).

The TTM, developed by Prochaska and colleagues, is widely used as a theoretical framework for conceptualizing behavior change. The TTM places individuals in a stepwise series of readiness states for completing a behavior, where different interventions may be applicable at different stages of readiness. Based on TTM's framework, individuals move through different stages-encountering different barriers and facilitators -to potentially alter a behavior (Ernecoff, Keane, & Albert, 2016).

The four stages include pre-contemplation, contemplation, preparation, and action-maintenance. At pre-contemplation, individuals have never considered ACP either because they have never been introduced to the concept or did not find ACP to be a worthwhile or relevant behavior. At contemplation, individuals begin to think about their treatment preferences and values, however are not yet ready to talk about their thoughts or take action to plan behaviors. Barriers at this stage include perceived irrelevance due to health status or religious beliefs that determinations are left to God. At preparation, individuals have decided ACP would be an

advantageous behavior to adopt so they begin planning to formally discuss their EOL decisions with their surrogate decision makers and healthcare team. Barriers at this stage include lack of resources or education to execute the process as well as emotional and psychological barriers affecting willingness to discuss their wishes with loved ones. Perception of health may affect one's follow-through if ACP behavior ranks lower in relation to other aspects of their lives. Last, action-maintenance is the stage of completion and continuance to maintain and update the ACP. These individuals have had active discussions with their families and physicians. Barriers to this stage include lack of potential surrogate decision makers, lack of emotional readiness or willingness of loved ones or healthcare providers to discuss EOL wishes, or desire to not burden loved ones. With respect to maintenance, some individuals may not be aware of the need to review and update ACP (Ernecoff, Keane, & Albert, 2016). The TTM can be applied to ACP behavior to reflect how individuals complete the ACP process and how individuals respond to barriers, facilitators, and behavioral variables that aim to increase completion rates.

Assessment of Organization

The project was implemented in a Midwest primary care practice located in a large Midwestern city. It is part of the not-for-profit health system. The practice is located in a census tract with a population of 9,389 people in an area of 507,625 square miles. The median age of residents in this region is 40.2, with a mode between 50 and 54. The dominant race is Caucasian with 92% being White. Most residents live in family households (81.4%) with an average income of \$116,250. Many have a college education with 98.3% having a high school degree or higher (Census, 2014). This demographic is a well-appointed group for needing ACP. There are 44,384 Medicare beneficiaries in Douglas County (County Health Rankings, 2013), 608 within primary care clinic's practice. Of these, 368 have ADs on file (Partnering Clinic, 2016).

Assessment of the organization included readiness for change, barriers and facilitators, and risks and/or intended consequences of implementation of the new practice proposed by this capstone project. The ACP intervention involved utilization of both written educational materials and time to conduct face-to-face meetings. The written materials required little time from the organization and only a minimal amount of resources in paper and supplies. The face-to-face meetings required provider time. Reimbursement for provider time for 30 minutes of counseling on ACP is \$86 for the initial and \$75 for each additional 30-minute session (Robeznieks, 2015).

The not-for-profit health system has showed interest in the development of ADs through the annual sponsorship of an ambulatory clinic for community members to participate in ACP on National Healthcare Decisions Day (NHDD), April 16th. The ambulatory clinic allowed for members of the community to come in and address any questions and receive assistance in preparing their AD documents.

The partnering primary care practice is between contemplation and preparation since small steps to promote ACP have been made but a wide practice change or system adaptation has not been implemented. For instance, there are clinic signs that encourage writing a living will, as well as a clinical decision support tool that alerts the provider when a patient does not have an AD. However, the providers do not follow the suggestions of the clinical decision support tool, and when asked were not aware that one existed. Some providers realize the benefits of ADs as evidenced by their discussions with patients. One common goal of this program was to educate providers and patients on the benefits versus costs of having an AD to help motivate them into preparation and action stages.

The number one anticipated barrier to implementing this project was provider time constraints, followed by financial concerns. Reimbursement for ADs is billable only at \$172 (\$86

per 30-minute discussion) for an hour of physician time. One useful inclusion in the CMS reimbursement plan is allowing physician assistants, nurse practitioners, and registered nurses to help in initiating the conversation and follow-up (Robeznieks, 2015).

Methodology

Setting

The program was implemented with one internal medicine doctor at a primary care practice in a Midwestern city. The practice has six family medicine physicians, seven internal medicine physicians, one doctor osteopathic medicine, and three advance practice nurses. The practice also employs a large office staff including nurses, medical assistants, secretaries, an office manager, and an informatics technician. The practice has more than 1000 patients and over 500 are Medicare (Partnering Clinic, 2016).

The provider agreed to be a clinical partner in this project. The clinic manager granted use of the clinic to conduct data collection for support of this study. The clinic manager granted access to the DNP student to access clinic electronic charts to gather data to support the study. The health system compliance officer granted access to the DNP student for use of the electronic medical record on patients eligible for participation during the project implementation period according to health privacy protection policy.

Sample

The sample was a convenience sample with patients who were scheduled for an appointment during the project implementation period. Inclusion criteria included Medicare patients aged 65 or older. Exclusion criteria included patients expressing no interest in formulating their AD, those diagnosed with dementia, and any vulnerable groups (e.g. prisoners). The population was accessed through a recruitment flyer (Appendix D) distributed to patients

who had an appointment with the clinical partner and who met inclusion criteria. The clinical partner determined which patients met inclusion and exclusion criteria and distributed recruitment flyers to the appropriate patients.

Design

This was a quality improvement project designed to evaluate if implementation of an ACP program enhanced AD completion rates in a primary care practice. The aim of the project was to improve AD completion rates through the implementation of a multi-modal intervention program. The multi-modal intervention involved written educational materials provided to participants in an ACP packet and a face-to-face discussion with the DNP student.

Timeline

The quality improvement project implementation took place from March 4, 2017 to May 30, 2017 with education materials prepared in February 2017.

Data Collection

The National Guideline Clearinghouse developed a guideline for improving ADs compliance for geriatric patients. This is the most applicable quality measure for this study since it focused on an older adult population. The major outcome was to increase the number of ADs completed in the primary care setting (Ramsey & Mitty, 2003). AD completion rate was determined by the number of ADs completed during the project implementation period. The sample number was determined by the number of eligible patients who contacted the PI and agreed to participate. A post-evaluation survey (Appendix K) would have been given at the face-to-face discussion meetings to assess barriers and facilitators of the ACP process using a modified version of the ADAT tool along with several demographic questions. Data was to be

collected throughout the implementation period on a rolling basis as participants enrolled and completed the program.

Instruments

Five Wishes.

The “Five Wishes” tool was obtained for use to assist patients in formulating their EOL care wishes for their living will portion of their AD, as well as the appointment of a health care proxy for their medical care power of attorney (see Appendix G). This document is published by the Aging with Dignity organization and is available for purchase. The Aging with Dignity website promotes its use by organizations for ACP needs of employees, members, and customers. This tool was included in all packets given to patients that agreed to participate. Permission to use the tool was requested and granted through the Aging with Dignity Organization (see Appendix J).

Post-evaluation Survey.

The post-evaluation survey (see Appendix K) was composed by the PI using four demographic questions, five questions taken from the Advance Directive Assessment Tool (ADAT) tool, and two questions evaluating reasons for not completing an AD and usefulness of the program. The 11-item questionnaire was designed as multiple-choice to collect demographic data and identify barriers and facilitators in the AD process. The five questions taken from the ADAT tool were chosen because they pertained to patients rather than clinicians and pertained to the objectives of this project to identify influential factors that may affect one’s formulation of an AD. The influential factors included how participants became aware of ADs, who assisted in completing, who had the most influence in formulating, what was the most important factor in deciding to (or not to), and did sense of spirituality affect the decision to have an AD. The last

question involving usefulness of the program was included to evaluate if participants found the multimodal interventions of the project helpful in completing their ADs.

The original ADAT instrument was not published or tested since most of the items were nominal level data, and test-retest was not possible due to difficulties in obtaining retest on the same patients. The tool was not conducive to internal reliability testing for the same reasons noted above. Peer review experts (all RNs with PhD degrees and experts in research and EOL care) reviewed the original tool for content validity with 100% agreement of items for relevance and measurement of variables (Duke, Thompson, and Hastie, 2007). Permission to use this tool in its modified form was received from the original author, Gloria Duke, and is included (see Appendix I).

Procedures for Implementation

The ACP packets that would have been constructed included a letter of intent (see Appendix E), informed consent (see Appendix H), Frequently Asked Questions regarding ADs (see Appendix F), and the “Five Wishes” template form used to formulate participants’ ADs (see Appendix G). The clinic partner distributed recruitment flyers (see Appendix D) to participants who met the inclusion criteria for the study. The recruitment flyer (see Appendix D) instructed patients interested in participating in the program to contact the PI. The initial contact with the patient via the recruitment flyer yielded no response calls from the patient to the PI to enroll and participate in the study.

The rest of procedures were not implemented because no participants responded to the recruitment flyer. The PI would have scheduled face-to-face discussion meetings and mailed the ACP packet to participants after they made the initial contact. The ACP packet (see Appendices E through H) more specifically explained the intent of the program and identified the project

investigator, as well as provided informed consent and gave participants instructions on completing the AD process (precontemplation/contemplation phase). Participants would have been advised to review the documents with their loved ones to help guide them on their EOL care decisions (preparation stage). The PI also would have obtained contact information from the participant to follow-up for any questions and any potential changes to the schedule.

During the face-to-face meetings, participants would have signed the informed consent and be assisted in completing their AD forms (action stage). Following the discussion, post-evaluation surveys (see Appendix K) would have been distributed and completed. Participants that completed their AD and the post-evaluation survey would have completed the program.

The potential location for the face-to-face discussions was an exam room at the clinical partner's office. Two witnesses, an employee of the Midwest primary care practice, and the principal investigator, would have witnessed the participant's signature on the AD documents to formalize the documents. The results of the face-to-face discussion and signing of the AD would have been documented in the electronic medical record.

Participants unable to complete their AD at the face-to-face discussion would have been allowed to do so with their provider. Additionally, if participants would have requested the assistance of their usual primary care provider or if questions arose that were unable to be answered by the principal investigator, another in-office discussion would have been set up with the provider, billable under ACP coverage.

Ethical

Computer Permission.

Computer access to the partnering clinic was obtained from the campus manager of the not-for-profit health system for the purpose of data collection on the project and began at the start of the program upon approval.

Integrity of the Data.

There was no data collected involving protected health information in this project because no contact with patients was obtained through the recruitment process.

Conflict of Interest.

There was no conflict of interest to declare related to this project. The principal investigator had no relevant financial or nonfinancial relationships to disclose. Investigator is an employee of the Midwest not-for profit health system on the cardiac unit and did not receiving any compensation for the project or for completion of ADs. The letter of intent explained the purpose of the research and the role of the student researcher in the study (see Appendix E). The informed consent document explained to the patient that declining to participate or withdrawing at any time during the project did not affect the provider-patient relationship or any right to health care or other eligible services (see Appendix H).

Informed consent.

This research project involved no more than minimal risk to subjects and included an informed consent, which detailed these risks to subjects.

Institutional Review Board.

This project was approved by the Nebraska Methodist College Institutional Review Board (IRB) and presented for comments to the members of the Doctorate of Nursing Practice Capstone Committee of Nebraska Methodist College. The IRB of the partnering not-for-profit health system also approved the project plan and evaluation methods.

Data Analysis

There were no patients enrolled through the recruitment process. The lack of participants affected data analysis in terms of evaluating the effectiveness of the multi-modal intervention to enhance AD completion as well as understanding demographics of the population in relation to AD completion. If participants had been obtained, descriptive statistics including percent and frequency would have been used to analyze demographic data. Characteristics of the sample population, including age, gender, race, and length of time in the medical practice would have been summarized using a table to analyze if any of these factors affected likelihood of AD completion. Barriers and facilitators in the ACP process would have been identified through the use of the post- evaluation survey. Barrier and facilitator factors would have been reported as percentages based on responses to the survey.

To analyze the effectiveness of the intervention program, total AD completion rates would have been reported in percentages based on the total sample population. The percentages of patients with completed ADs would have been calculated based on the total number of patients who agreed and contacted the PI and those patients who ultimately completed ADs. The denominator would be based on the number of patients who agreed to participate and contacted the PI. The numerator would be the number of patients with a completed AD at the face-to-face discussion. These percentages would be displayed in a bar chart to show comparisons between national averages and the population from which the sample group was taken. These percentages would be compared to the AD completion rates within the medical practice 60% (368 of 608 Medicare patients), as well as to the national estimated average of 51% among individuals 65 years of age and older. This national average is based on survey respondents of the 2009 and

2010 HealthStyles Survey, a mail panel survey designed to be representative of the U.S. population (Rao, Anderson, Lin, & Laux, 2014).

The post-evaluation survey (Appendix K) would have been used to analyze barriers and facilitators to AD completion facilitating factors and potential barriers to writing an AD. If participants had enrolled and completed the survey, the totals for each response would have been tallied and overall percentages reported to determine which factors, if any, were most helpful in influencing one's decision to complete the ACP process in the primary care setting. These factors would have been reported in a chart form and pie graph to depict the most significant influential factors to AD completion rates.

Results

The study yielded no participants who enrolled in the program to complete their AD. The clinical partner identified twenty-four potential patients as candidates for the program. These twenty-four patients were given recruitment flyers with the intent to contact the PI for enrollment in the program. None of these patients initiated contact with the PI following their visit with the clinical partner. The PI met with the clinical partner to discuss time constraints to enroll patients in the program and to offer suggestions to encourage enrollment. At this meeting, the clinical partner advised a follow-up call would be helpful to serve as a reminder of the program and prompt participation. A follow-up call was not possible in this study under the IRB approval agreement.

Discussion/Conclusions

The recruitment method in this study was not effective for the target population. The patient-initiated recruitment process was not effective in this setting because patients are not

likely to think about the need for EOL care and advanced directive decision-making without being encouraged to do so. Most participants in the studies identified in the literature review were selected and recruited based on non-randomized design through identification and recruitment by their provider and/or the researchers. Direct contact by the researchers in the form of questionnaires (Duffield & Podzamsky, 1996; Duke, Thompson, & Hastie, 2007), mailings (Tung, Vickers, Lackore, Cabanela, Hataway, & Chaudhry, 2011), interviews (Piers, et al., 2013; Wissow, Belote, Kramer, Compton-Phillips, Kritzler, & Weiner, 2004), and group visits (Lum, et al., 2016) were utilized to characterize influences promoting AD in various settings including primary care. Participants were contacted throughout the study by researchers and/or their provider to enhance retention.

The IRB limitations placed on the recruitment of subjects impacted the ability of the PI to enroll participants in the project. Additionally, the length of time for the IRB process along with graduation deadlines hindered the PI's ability to adapt the study and reapply for IRB approval. The IRB required that participants contact the PI instead of the initial contact coming from the PI. Participant-initiated contact was required by the IRB to eliminate the potential for participant coercion. Also, the informed consent document was modified to encourage participants to discuss ADs with an attorney. The IRB modifications limited the applicability as well as the scope of the project by restricting participation and the ability of the PI and clinical partner to assist patients in the ACP and in the formation of their ADs.

Many studies have demonstrated the role the PCP should have in the ACP and in knowing patients EOL care wishes. The Kaiser Health poll identifying 90% of adults would prefer providers discuss EOL concerns with them exemplifies the paradigm shift of ACP from a legal to a medical practice (Kaiser Family Foundation, 2016). The basis for this shift is that

health providers are able to discuss the implications of these decisions, in terms of their medical disease, co-morbidities, prognosis, interventions, and health-related behaviors to offer practical advice and alternatives of care. Consistent to patient preference, the CMS now pays for ACP discussions between patients and their health care providers as of January 2016 (CMS, 2015).

The IRB required statement in the informed consent to contact an attorney about the AD demonstrates the current societal factors that hinder health providers from taking an active role in ACP and EOL care. These opposing forces impede the progression of ACP to guide quality EOL care.

Nursing Implications for Practice

The capstone experience provided a practical example of translating research into practice. Despite the limitations of the project, the conclusions from implementation of the intervention provided valuable insight into future research. The lack of subject participation using the patient-initiated recruitment process indicates the difficulty in changing health-related behaviors without ongoing follow-up by the healthcare team. Although patients desire to have input in their end-of-life care, initiating these conversations and prompting healthcare providers is challenging due to a lack of urgency and sensitivity of the topics. Patients may view death as an unlikely or long-term outcome, diminishing their likelihood in engaging and completing their advanced medical directives. Consequently, it may be necessary to implement an approach that involves routine follow-up by the healthcare team to engage patients in completing their advanced directives. Universally, providing follow-up may be an important aspect in all

interventions that target health-related behaviors. This is an important application to consider when aiming to impact population health on any level that targets health-related behaviors.

Over the last two decades, the U.S. health care delivery system has undergone fundamental shifts in emphasis from inpatient acute care of illness focused on the individual with fragmented care via independent institutions to outpatient primary care agencies focused on wellness and prevention using managed care via system integration and continuum of services (Shi and Singh, 2015). Healthy People 2020's vision is a society where people live long, healthy lives. Its overarching goals are to attain high-quality longer lives free of disease, disability, injury, and premature death, to promote quality of life across all life stages, and eliminate disparities (Healthy People 2020, 2016).

However, what about in death? Should there be a quality factor applied towards dying and EOL care? Would advance care planning, as a means to enhance quality of death, be an important application of population health? Providing quality EOL care that encourages wellness, cohesion, and continuum of services requires a paradigm shift that nurtures the view of the patient and allows for collaborative medical decision-making. This is best supported by ACP interventions in the primary care setting.

The implications of ACP to EOL care should be important to patients of all ages. Systematic research has demonstrated the economic importance, as well as the benefits to health outcomes. This study was limited to an older adult population; however, ADs are not just for the elderly. Efforts to target younger individuals should be made to educate and promote AD completion in all populations. A term known as nudging has been shown to have application in many health-related behaviors such as smoking, alcohol consumption, diet, and physical activity. Nudging refers to an intervention that alters a person's behavior in a predictable way without

forbidding any options or significantly changing the economic incentives (Marteau, 2011). Nudging could have an important application in ACP. Instead of being an opt-in system, ACP could be implemented in primary practice as an opt-out system, where patients would automatically be prompted to create an AD unless they chose to opt-out of doing so. This would apply ACP to all patients to enhance AD completion rates.

Knowledge of the characteristics of individuals who have prepared ADs including factors that influenced their decisions and resources used can guide health care providers to facilitate this process for others to enhance AD completion rates (Fairchild, 1998). In Duke, Thompson, and Hastie's research not wanting to be a burden to family was the most common reason for signing an AD. A second motivating factor was health status since 36% of participants who formulated their AD stated they were experiencing significant health problems at the time they signed their AD. However, the goal of ACP is pre-crisis preparation of EOL care wishes (Duke, Thompson, & Hastie, 2007).

Pre-crisis preparation enhances autonomous health care decision-making when individuals are best able to make a conscious, rational, and personal decision about EOL issues (Duke, Thompson, and Hastie, 2007). Suggestions for future research to provide pre-crisis preparation would be to offer ACP in the community setting. Two possibilities for the community approach include local faith-based organizations and health fairs.

Plan for Sustainability

In order to be sustainable, a project must be technically feasible, value acceptable within the community, have tolerable costs, anticipated public agreement, and a reasonable chance for stakeholder buy-in (Hinshaw & Grady, 2011). This capstone project met all the criteria, however failed to produce results due to a breakdown in the recruitment process. The project was

technically feasible, having been established as a value within the community through poll surveys, had tolerable costs in that it is payable through CMS, was anticipated to have public agreement, and was a reasonable extension of the application of legislation passed by CMS to cover ACP discussions.

The target population for this project was Medicare patients over age 65 years. This target population was a priority because they were most likely to be immediately affected by EOL care decisions. Future applications of this project would be to expand ACP to include younger patients and other settings. Additionally, it would be suggested to repeat the project in the same setting using a different recruitment method to identify if ACP would be enhanced using the multi-modal approach.

Stakeholders that could potentially be involved in the future development of the project include other health care providers and other clinics as the program expands throughout the health system, as well as to other health systems. It would be important to include members of the billing department to help train staff in CMS coding and billing for AD discussions. Also, CMS and private insurance groups would be a major stakeholder in expanding reimbursement benefits. Additionally, it would be important to include members of professional organizations including the American Medical Association (AMA), the National Patient Safety Foundation, National Healthcare Decisions Day (NHDD), AARP, American Hospital Association, National Hospice and Palliative Care Organization, and governmental agencies such as the Agency for Health Research and Quality and Centers for Medicare and Medicaid Services. These agencies would support ADs as a means of improving quality of care related to death, as well as improving the use of healthcare resources.

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Appendix A: Letter granting permission for data collection



November 11, 2016

To Whom It May Concern:

Maria Douthett has permission to conduct data collection regarding Advanced Care Planning within Dr. Mark Omar's patient population. The data collection will be an unidentified survey given to patients who agree to participate.

Respectfully,

A black rectangular redaction box covering the signature of Stacy Roberts.

Stacy Roberts
Campus Manager

Methodist Physicians Clinic
Internal Medicine HealthWest
16120 West Dodge Road
Omaha, Nebraska 68118
Phone: 402-354-0560
Fax: 402-354-0555

Appendix B: Letter granting electronic medical record access from clinic



November 11, 2016

To Whom It May Concern:

Maria Douthett will have continued EMR student access while conducting her research project within Dr. Mark Omar's patient population. Access will be necessary to determine who is qualified for the study. Maria will be meeting with patients and assisting them with advanced directives.

Respectfully,

Stacy Roberts
Campus Manager

Methodist Physicians Clinic
Internal Medicine HealthWest
16120 West Dodge Road
Omaha, Nebraska 68118
Phone: 402-354-0560
Fax: 402-354-0555

Appendix C: Letter granting electronic medical record access from compliance officer



Methodist IRB
8303 Dodge Street
Omaha, NE 68114

December 19, 2016

To IRB Committee:

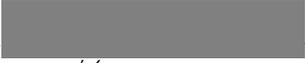
The Methodist College graduate student Maria Douthett is an investigator involved in a research project entitled: "Effect of a Multimodal Intervention on Advance Directive Completion Rates".

The investigator needs access to the Methodist Electronic Health Record (EHR) for completing the data tool form in the IRB application.

The project will begin January 9, 2017 and will end May 5, 2017; however access to the Methodist EHR will be done (dates) January 9, 2017 through May 5, 2017.

Pending Methodist IRB approval of this study, the Methodist only investigator has approval to access the Methodist EHR using her current Nebraska Methodist College DNP student sign-on. A letter dated November 11, 2016 signed by the campus manager of Methodist Physicians Clinic HealthWest also has been obtained granting permission to use the student sign-on. If the investigator is an employee, they are not to use their current employee sign-on user name and password for this study.

If you have any questions, please let me know.


Tracy Durbin, MPA, CHCO
Chief Compliance Officer
Nebraska Methodist Health System



Give the gift of planning!

Completing a living will or an advanced directive is one of the best gifts you can give yourself and loved ones to guide your health care at the end of life.

Having an advanced directive is a means to communicate your healthcare wishes in the event you cannot. Take time to plan for the future by completing your advanced care directives.

You have the opportunity to participate in a research project allowing you to complete your **Living Will** and **Health Care Proxy** with the help of a Doctoral Nurse Practitioner student from Nebraska Methodist College free of charge. In order to participate, you must be age 65 or older and have the desire and ability to make decisions regarding your advance directives. You may still participate if you already have an advance directive and desire to update your wishes. Participation involves contacting the student listed below for further information so that an advance care planning packet can be mailed to you to assist in formulating your advanced care directives. When you contact the student, you will also set up a face-to-face meeting (about 30 minutes), which will be held at your usual Methodist physician clinic to discuss your directives. Following the discussion, you will be asked to complete a short survey regarding your experience. At the end of the meeting, you will have the proper advanced directive documents completed and documented in your medical record, as well as the originals for your personal file.

Please contact the student directly at:
Maria Douthett, DNPc
(402) 201-3989
Maria.Douthett2@methodistcollege.edu



Letter of Intent

Spring, 2017

Dear Patient,

You are receiving this letter because you are scheduled for an annual physical or follow up appointment today at Methodist Physicians Clinic HealthWest and have agreed to participate in an advance care planning program to complete your advance directive.

I am a Family Nurse Practitioner and Doctor of Nursing Practice student through Nebraska Methodist College who will be implementing a project this semester. My goal of the project is to evaluate if having the advance care planning program in place at this clinic will benefit Advance Directive completion rates through education, support, and guidance in completing the appropriate paperwork. As such, part of the program will be the use of an information packet to discuss your end-of-life care wishes with your family and bring in with you to a face-to-face discussion where we will formulate your wishes into a formal document. You will have the opportunity to sign these documents in front of two witnesses at the face-to-face meeting for legal application.

In this packet you will find an Informed Consent to read through and sign, Frequently Asked Questions regarding advance directives, and the Five Wishes document to review, complete, and bring to the face-to-face discussion. Please take time to review these forms, discuss them with your family members, and complete them as much as possible for your face-to-face discussion. We will discuss any questions you may have and any areas left blank at this meeting, so that you may feel comfortable that these documents express your intended wishes. The Five Wishes document will become legally binding when your Health Care Power of Attorney and Living Will documents are completed and witnessed either by a notary public or 2 witnesses. You will have the opportunity to make these legally binding at the face-to-face meeting.

If you are uncertain or uncomfortable completing the forms at any time, please bring them with you to our face-to-face discussion appointment and we can discuss the benefits, any concerns you may have, and what the next steps may be.

I appreciate your time in assisting me with completing my Capstone Project and I look forward to working with you over the next few months.

Sincerely,

Maria Douthett, DNP student

Appendix F: Frequently asked questions

Frequently Asked Questions

1. What is an Advance Directive?
2. What is a Living Will?
3. What is a Power of Attorney for Health Care?
4. Can I appoint more than one person to share the responsibility of being my Power of Attorney for Health Care?
5. When do Advance Directives take effect?
6. Can I have both?
7. Do I have to make an Advance Directive?
8. What if I change my mind after I sign an Advance Directive?
9. What choices should I make in my Advance Directive?
10. Does an Advance Directive have to be signed and witnessed?
11. If I have an Advance Directive in one state, will it be followed in a different state?
12. What do Advance Directives NOT include?
13. How do I make my wishes known regarding organ and tissue donation?
14. What should I do with my Advance Directive if I choose to have one?
15. Does Medicare cover it?

1. What is an Advance Directive?

An Advance Directive is a written statement in which you state your choices for health care, or name someone to make such choices for you, if you become unable to make your own decisions about medical treatment. The two most common forms are:

2. Living Will

Power of Attorney

What is a Living Will?

In a Living Will document you state the kinds of medical treatments you want, or do not want, when you are terminally ill and unable to make your own decisions. It is called "Living Will" because it takes effect while you are still living but unable to communicate your choices. It is important to understand that a Living Will is authoritative; that means that it cannot be overridden by the wishes of family members who might not agree with everything you have decided about your medical care.

3. What is a Power of Attorney for Health Care?

In a Power of Attorney for Health Care document you name another person to act as your "attorney in fact" or your "representative". This person will make medical decisions for you, if you become unable to make them for yourself.

Your representative can be:

- A family member or
- A close friend.

Your representative cannot be:

- Your doctor
- An employee of your doctor or your health care provider (unless he/she is your relative) or
- Any person already serving as Power of Attorney for Health Care for 10 or more people (unless he/she is your relative).

Your representative is guided by your instruction about any medical treatment you want or do not want.

4. Can I appoint more than one person to share the responsibility of being my Power of Attorney for Health Care?

You should appoint only ONE person to be your attorney in fact, but you may appoint others as your alternates.

5. When do Advance Directives take effect?

Your Advance Directive takes effect only after you can no longer make personal decisions about medical treatment. As long as you can make your own decision, your health care providers will rely on your judgment about what to do.

6. Can I have both?

Yes. In fact, it is often a good idea to have both written instructions about what medical care you do and do not want provided to you if you are terminally ill (a Living Will) and the name of a person to make decisions on your behalf about care when you are unable to do so (Power of Attorney for Health Care).

7. Do I have to make an Advance Directive?

No. It is entirely up to you whether you want to prepare an Advance Directive. The main advantage of an Advance Directive is to express your wishes if you become unable to state them yourself.

8. What if I change my mind after I sign an Advance Directive?

You can revoke it. At any time, if you want, you can make a new one. If you are a patient, tell your doctor or nurse that you want to change your Advance Directive. It is best to destroy the old one.

9. What choices should I make in my Advance Directive?

You decide what to include in your Advance Directive. You should consider the circumstances in which you want life-prolonging medical treatments started, continued or stopped. You may wish to discuss this decision with your family, close friends, health care providers, clergy and others. Nebraska Medicine will follow your advance directive within the limits of the law and the hospital's capabilities.

10. Does an Advance Directive have to be signed and witnessed?

Yes, you sign and date both a Living Will and a Power of Attorney for Health Care in order for them to be legally valid.

Your signature on a Living Will can be witnessed by either:

1. Two qualified adults
 - Cannot be your life or health insurance provider
 - Only one witness may be an employee of your health care provider
2. A notary public

Your signature on a Power of Attorney for Health Care can be witnessed by either:

1. Two qualified adults

Cannot be:

- Your spouse, parent, child, grand- child, brother or sister
- Any person entitled to your estate
- Your doctor
- Your Power of Attorney for Health Care or their alternates
- An employee of your life insurance or health insurance provider and
- Only one witness may be an employee of your health care provider

2. A notary public

11. If I have an Advance Directive in one state, will it be followed in a different state?

Yes. Under Nebraska law an Advance Directive that is properly prepared according to another state's laws may be honored in Nebraska.

12. What do Advance Directives NOT include?

A Living Will is not the same as a Last Will and Testament.

Power of Attorney for Health Care is not the same as Power of Attorney for financial issues.

A Living Will is not the same as "Do Not Resuscitate" (DNR) order. A DNR is generated only by a physician order at your request.

13. How do I make my wishes known regarding organ and tissue donation?

You may request a donor card and make your wishes known to your family.

14. What should I do with my Advance Directive if I choose to have one?

If you have a Living Will or Power of Attorney for Health Care, give a copy to a family member, your doctor, and your representative, if you have named one. Tell your doctor to make the Advance Directive part of your permanent record. Keep the original of your Advance Directive in a safe place where it can easily be found by others if it is needed. If you ever need to go into the hospital, you should bring a copy of your Advance Directive with you.

15. Does Medicare cover it?

Starting January 1, 2016, Medicare began covering advance care planning as a separate service provided by physicians and other health professionals (such as nurse practitioners who bill Medicare using the physician fee schedule). Medicare now covers advance care planning provided in medical offices and facility settings, including hospitals. As with most other physician services, beneficiaries are subject to cost sharing for advance care planning provided by their physician or health professional. If Medicare beneficiaries desire advance care planning during their annual wellness visit, physicians and other health professionals may provide it during the visit and bill Medicare separately for it. However, beneficiaries will not have any cost sharing liability for advance care planning provided in conjunction with their annual wellness visits.

Additional Resources

If you want more information about Advance Directives or these forms, you can contact the principle investigator at (402) 201-3989.

Adapted from:

Nebraska Medicine. (2016). Advance Directive (Living Will). Retrieved from <http://www.nebraskamed.com/patients/advance-directive>

Kaiser Family Foundation. (2016). 10 FAQs: Medicare's role in end-of-life care. Retrieved from <http://kff.org/medicare/fact-sheet/10-faqs-medicares-role-in-end-of-life-care/>

Appendix G: Five Wishes

The image shows a 'Five Wishes' form with a large, diagonal 'SAMPLE' watermark and an 'IES' logo. The form is on a light blue background and contains the following text and fields:

- At the top, there are four blue checkmarks.
- The text 'SH FOR:' is followed by a blue checkmark.
- The text 'b Make Can Decision' is followed by a blue checkmark.
- The text 'Medical Treatme' is followed by a blue checkmark.
- The text 'How Comfor' is followed by a blue checkmark.
- The text 'How I' is followed by a blue checkmark.
- The text 'Wha' is followed by a blue checkmark.
- At the bottom, there is a blue line for 'print your name' and a white box for 'birthdate'.

Five Wishes

There are many things in life that are out of our hands. This Five Wishes document gives you a way to control something very important—how you are treated if you get seriously ill. It is an easy-to-complete form that lets you say exactly what you want. Once it is filled out and properly signed it is valid under the laws of most states.

What Is Five Wishes?

Five Wishes is the first living will that talks about your personal, emotional and spiritual needs as well as your medical wishes. It lets you choose the person you want to make health care decisions for you if you are not able to make them for yourself. Five Wishes lets you say exactly how you wish to be

treated if you get seriously ill. It was written with the help of The American Bar Association's Commission on Law and Aging, and the nation's leading experts in end-of-life care. It's also easy to use. All you have to do is check a box, circle a direction, or write a few sentences.

How Five Wishes Can Help You And Your Family

- It lets you talk with your family, friends and doctor about how you want to be treated if you become seriously ill.
- Your family members will not have to guess what you want. It protects them if you become seriously ill, because they won't have to make hard choices without knowing your wishes.
- You can know what your mom, dad, spouse, or friend wants. You can be there for them when they need you most. You will understand what they really want.

How Five Wishes Began

For 12 years, Jim Towey worked closely with Mother Teresa, and, for one year, he lived in a hospice she ran in Washington, DC. Inspired by this first-hand experience, Mr. Towey sought a way for patients and their families to plan ahead and to cope with serious illness. The result is Five Wishes and the response to it has been

overwhelming. It has been featured on CNN and NBC's Today Show and in the pages of *Time* and *Money* magazines. Newspapers have called Five Wishes the first "living will with a heart and soul." Today, Five Wishes is available in 27 languages.

Who Should Use Five Wishes

Five Wishes is for anyone 18 or older — married, single, parents, adult children, and friends. More than 19 million people of all ages have already used it. Because it

works so well, lawyers, doctors, hospitals and hospices, faith communities, employers, and retiree groups are handing out the document.

Five Wishes States

If you live in the **District of Columbia** or one of the **42 states** listed below, you can use Five Wishes and have the peace of mind to know that it substantially meets your state's requirements under the law:

Alaska	Illinois	Montana	South Carolina
Arizona	Iowa	Nebraska	South Dakota
Arkansas	Kentucky	Nevada	Tennessee
California	Louisiana	New Jersey	Vermont
Colorado	Maine	New Mexico	Virginia
Connecticut	Maryland	New York	Washington
Delaware	Massachusetts	North Carolina	West Virginia
Florida	Michigan	North Dakota	Wisconsin
Georgia	Minnesota	Oklahoma	Wyoming
Hawaii	Mississippi	Pennsylvania	
Idaho	Missouri	Rhode Island	

If your state is not one of the 42 states listed here, Five Wishes does not meet the technical requirements in the statutes of your state. So some doctors in your state may be reluctant to honor Five Wishes. However, many people from states not on this list do complete Five Wishes along with their state's legal form. They find that Five Wishes helps them express all that they want and provides a helpful guide to family members, friends, care givers and doctors. Most doctors and health care professionals know they need to listen to your wishes no matter how you express them.

Do I Choose To Five Wishes?

You already have a living will or a durable power of attorney for health care. If you use Five Wishes instead, all you need to do is fill out and sign a new Five Wishes document. As soon as you sign it, it takes away any advance directive you had before. To make sure the right form is used, please do the following:

- Destroy all copies of your old living will or durable power of attorney for health care. Or you can write "revoked" in large letters across the copy you have. Tell your lawyer if he or she helped prepare those old forms for you. *AND*
- Tell your Health Care Agent, family members, and doctor that you have filled out a new Five Wishes. Make sure they know about your new wishes.

WISH 1

The Person I Want To Make Health Care Decisions For Me When I Can't Make Them For Myself.

If I am no longer able to make my own health care decisions, this form names the person I choose to make these choices for me. This person will be my Health Care Agent (or other term that may be used in my state, such as proxy, representative, or surrogate). This person will make my health care choices if both of these things happen:

- My attending or treating doctor finds I am no longer able to make
- Another health care provider agrees this is true.

If my state has a way of finding that I am not able to make health care decisions, then my state's way should be followed.

The Person I Choose As My Health Care Agent Is:

First Choice Name

Phone

Address

State/Zip

If this person is not able or willing to make these choices, I am divorced or legally separated from me, OR this person has died, then these people are my choice:

Second Choice Name

Second Choice Name

Address

Address

City/State/Zip

City/State/Zip

Phone

Phone

Picking The Right Person To Be Your Health Care Agent

Choose someone who knows you very well, understands you, and can make difficult decisions. A spouse or family member may be a good choice because they are too personally involved. Sometimes they are the best choice you know best. Choose someone who can stand up for you so that your wishes are followed. Also, choose someone who is likely to be nearby so that they can help when you need them. Whether you choose a spouse, family member, or friend as your Health Care Agent, make sure you talk about these wishes and be sure that this person agrees to respect

and follow your wishes. Your Health Care Agent should be **at least 18 years or older** (in Colorado, 21 years or older) and should **not** be:

- Your health care provider, including the owner or operator of a health or residential or community care facility serving you.
- An employee or spouse of an employee of your health care provider.
- Serving as an agent or proxy for 10 or more people unless he or she is your spouse or close relative.

WISH 2

My Wish For The Kind Of Medical Treatment I Want Or Don't Want.

I believe that my life is precious and I deserve to be treated with dignity. I am very sick and am not able to speak for myself, I want the following w directions I have given to my Health Care Agent, to be respected and followe.

What You Should Keep In Mind As My Caregiver

- I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means that I will be drowsy or sleep more than I would otherwise.

I do not want anything done or omitted by my doctors or nurses with the intention of ending my life.

I want to be offered food and fluids and kept clean and w

What "Life-Support Treatment" Means To Me

Life-support treatment means any medical procedure, device or medication to keep me alive. Life-support treatment includes: medical devices put in me to help me breathe and water supplied by medical devices; cardiopulmonary resuscitation (CPR); surgery; blood transfusions; dialysis; and other treatments. If I write the meaning of life-support treatment. I write this limitation in the space below. I want to make very clear what I want and under what conditions.

In Case Of An Emergency

If you have a medical emergency and ambulance personnel arrive, they may look to see if you have a **Do Not Resuscitate** form or bracelet. Many states require a person to have a **Do Not Resuscitate** form filled out and

signed by a doctor. This form lets ambulance personnel know that you don't want them to use life-support treatment when you are dying. Please check with your doctor to see if you need to have a **Do Not Resuscitate** form filled out.

Here is the kind of medical treatment that I want or don't want in the four situations listed below. I want my Health Care Agent, my family, my doctors and other health care providers, my friends and all others to know these directions.

Close to death:

If my doctor and another health care professional both decide that I am likely to die within a short period of time, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

In A Coma And Not Expected To Wake Up Or Recover:

If my doctor and another health care professional both decide that I am in a coma from which I am not expected to wake up or recover, and I have brain damage, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

Permanent And Severe Brain Damage And Not Expected To Recover:

If my doctor and another health care professional both decide that I have permanent and severe brain damage, (for example, I can open my eyes, but I can not speak or understand) and I am not expected to get better, and life-support treatment would only delay the moment of my death (Choose *one* of the following):

- I want to have life-support treatment.
- I do not want life-support treatment. If it has been started, I want it stopped.
- I want to have life-support treatment if my doctor believes it could help. But I want my doctor to stop giving me life-support treatment if it is not helping my health condition or symptoms.

In Another Condition Under Which I Do Not Wish To Be Kept Alive:

If there is another condition under which I do not wish to have life-support treatment, I describe it below. In this condition, I believe that the costs and burdens of life-support treatment are too much and not worth the benefits to me. Therefore, in this condition, I do not want life-support treatment. (For example, you may write "end-stage condition." That means that your health has gotten worse. You are not able to take care of yourself in any way, mentally or physically. Life-support treatment will not help you recover. Please leave the space blank if you have no other condition to describe.)

The next three wishes deal with my personal, spiritual and emotional wishes. They are important to me. I want to be treated with dignity near the end of my life, so I would like people to do the things written in Wishes 3, 4, and 5 when they can be done. I understand that my family, my doctors and other health care providers, my friends, and others may not be able to do these things or are not required by law to do these things. I do not expect the following wishes to place new or added legal duties on my doctors or other health care providers. I also do not expect these wishes to excuse my doctor or other health care providers from giving care as asked for by law.

WISH 3 My Wish For How Comfortable I Want to Be.

(Please cross out anything that you don't agree with.)

- I do not want to be massaged with warm blankets.
- I wish to have my hair combed as often as possible until I die.
- If I show signs of breath, or halitosis, I wish to have perfume or mouth clipping used.
- I wish to have a long life.
- I wish to have my loved ones by my side.
- I want my lips to stop dryness.
- I wish to have my hair kept fresh and clean at all times.

WISH 4 My Wish For How I Want People To Treat Me.

(Please cross out anything that you don't agree with.)

- I wish to have people by my side when possible.
- I want to be treated with kindness and cheerfulness, and not sadness.
- I wish to have pictures of my loved ones in my room, near my bed.
- If I am not able to control my bowel or bladder functions, I wish for my clothes and bed linens to be kept clean, and for them to be changed as soon as they can be if they have been soiled.
- I want to die in my home, if that can be done.
- I wish to have others by my side praying for me when possible.
- I wish to have the members of my faith community told that I am sick and asked to pray for me and visit me.

WISH 5

My Wish For What I Want My Loved Ones To Know.

(Please cross out anything that you don't agree with.)

- I wish to have my family know that I love them.
- I wish to be forgiven for hurt my family, friends, and friends to love me.
- I wish to have my family and others know that I forgive them they may have hurt me in my life, including me. This will help me live a meaningful life in my final days.
- I wish for my family and friends to get counseling if they have trouble with death. I want memories of my death to bring them joy and not sorrow.
- I wish for all of my family to make peace with each other after death, if they can.
- I wish for my family and friends to think about what I was like before I got seriously ill. I want them to remember me in this way after my death.
- After my death, I would like to be buried in a cemetery.
- My body should be donated to a medical school.
- I would like to have a memorial service.

If anyone asks how I want to be remembered, please say the following about me:

If there is to be a memorial service for me, I wish for this service to include the following (list music, songs, readings or other specific requests that you have):

(Please use the space below for any other wishes. For example, you may want to donate any or all parts of your body when you die. You may also wish to designate a charity to receive memorial contributions. Please attach a separate sheet of paper if you need more space.)

Signing The Five Wishes Form

Please make sure you sign your Five Wishes form in the presence of the two witnesses.

I, _____, ask that my family, my doctors, and other health care providers, my friends, and all others, follow my wishes as communicated by my Health Care Agent (if I have one and he or she is available), or as otherwise expressed in this form. This form becomes valid when I am unable to make decisions or speak for myself. If any part of this form cannot be legally followed, I also revoke any health care advance directives I have

Signature: _____

Address: _____

Phone: _____ Date: _____

Witness Statement • (2 witnesses needed):

I, the witness, declare that the person who signed or acknowledged this form (hereafter referred to as the person) appears to be of sound mind and under no duress, fraud, or undue influence.

I also declare that I am over 18 years of age and am NOT:

- The individual appointed as (agent/proxy/surrogate/patient advocate/representative) by this document or his/her successor,
- The person's health care provider, including owner or operator of a health, long-term, or other residential or community care facility, serving the person,
- An employee of the person's health care provider,

(Some states may have fewer rules about who can be a witness. Unless you know your state's rules, please follow the above.)

Signature of Witness #1	Signature of Witness #2
Printed Name of Witness #1	Printed Name of Witness #2
Address	Address
Phone	Phone

• **Notarization** is only required for residents of Missouri, North Carolina, South Carolina and West Virginia

- If you live in Missouri, only your signature should be notarized.
- If you live in North Carolina, South Carolina or West Virginia, you should have your signature, and the signatures of your witnesses, notarized.

STATE OF _____ COUNTY OF _____

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

My Commission Expires: _____
 10 _____ Notary Public

What To Do After You Complete Five Wishes

- Make sure you sign and witness the form just the way it says in the directions. Then your Five Wishes will be legal and valid.
- Talk about your wishes with your health care agent, family members and others who care about you. Give them copies of your completed Five Wishes.
- Keep the original copy you signed in a special place in your home. Do NOT put it in a safe deposit box. Keep it nearby so that someone can find it when you need it.
- Fill out the wallet card below. Carry it with you. That way people will know where you keep your Five Wishes.
- Talk to your doctor during your next office visit. Give your doctor a copy of your Five Wishes. Make sure it is put in your medical record. Be sure is wi other
- If yo take that i our medical record.
- I hav er following people copies my com

Residents of Wisconsin must attach the _____
 More information and the notice state _____ or 1-888-594-7437.

Residents of ALABAMA, ARIZONA, ARKANSAS, CALIFORNIA, COLORADO, CONNECTICUT, DELAWARE, FLORIDA, GEORGIA, ILLINOIS, INDIANA, IOWA, KANSAS, KENTUCKY, LOUISIANA, MAINE, MARYLAND, MASSACHUSETTS, MICHIGAN, MINNESOTA, MISSISSIPPI, MISSOURI, MONTANA, NEBRASKA, NEVADA, NEW HAMPSHIRE, NEW JERSEY, NEW MEXICO, NEW YORK, NORTH CAROLINA, NORTH DAKOTA, OHIO, OKLAHOMA, OREGON, PENNSYLVANIA, RHODE ISLAND, SOUTH CAROLINA, SOUTH DAKOTA, TENNESSEE, TEXAS, UTAH, VERMONT, VIRGINIA, WASHINGTON, WEST VIRGINIA, WISCONSIN, WYOMING.
Witnessing Rules.
 If you live in one of the states listed above, you may use this form. If you live in a nursing home or care facility, a home for the mentally retarded or developmentally disabled, you may have to follow special rules. For further information, please contact _____

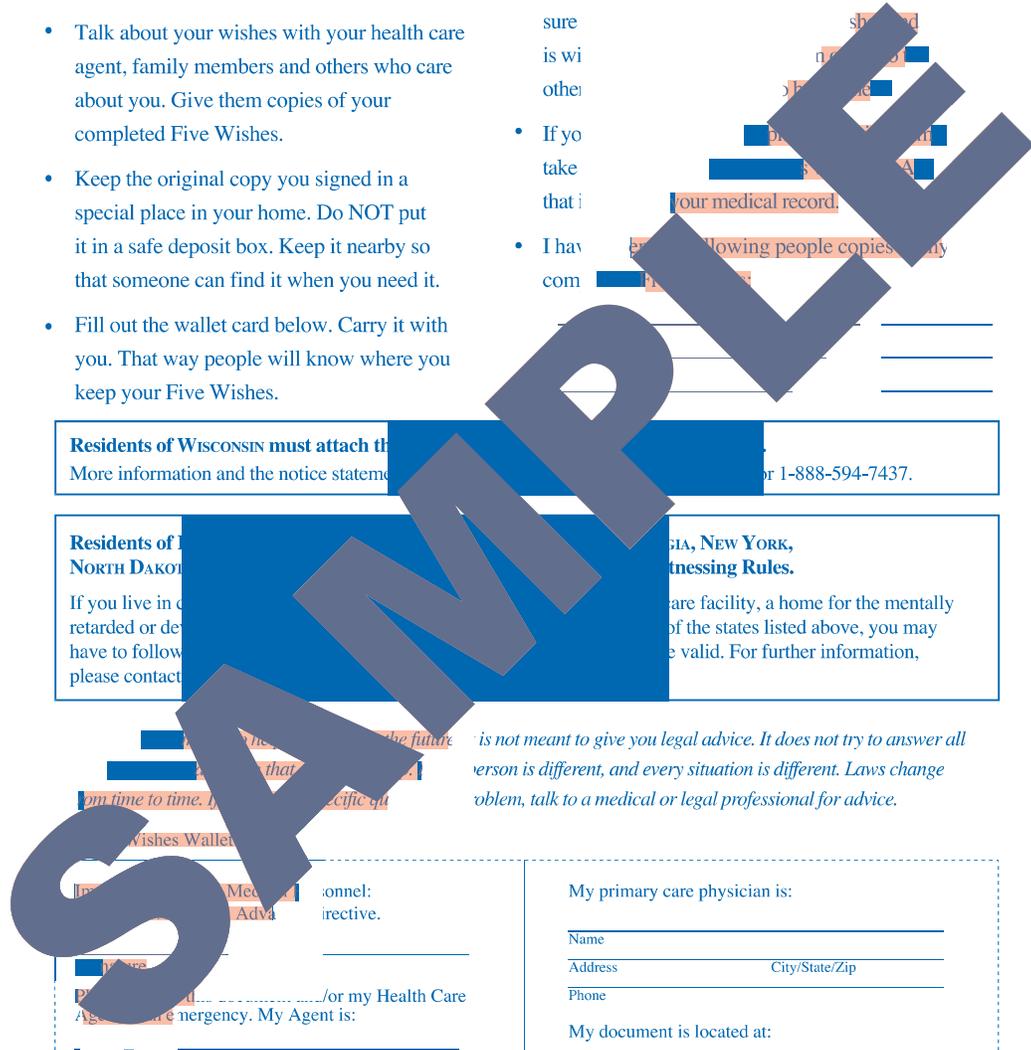
_____ is not meant to give you legal advice. It does not try to answer all questions. Every situation is different. Laws change from time to time. If you have a specific question, talk to a medical or legal professional for advice.

My primary care physician is:

Name _____
 Address _____ City/State/Zip _____
 Phone _____

My document is located at:

Cut Out Card, Fold and Laminate for Safekeeping



Here’s What People Are Saying About Five Wishes:

“It will be a year since my mother passed on. We knew what she wanted because she had the Five Wishes living will. When it came down to the end, my brother and I had no questions on what we needed to do. We had peace of

“I must say I love your Five Wishes. It helped me address all the issues of medical care, but on top of that, it was a relief for me and my husband.”

“I don’t want my children to have to make decisions for me. I never knew that there were so many options available in a sensitive and caring form. I can

well on the conc
In W.
staff, Arizona
s I am having to make for my mother
ns to be considered. Thank you for
and have it on file for my children
Diana
Hand

To Order:

Call (888) 5-WISHES to purchase more copies of Five Wishes, the Five Wishes DVD, or Next Steps guides. Ask about the “Family Package” that includes 10 Five Wishes, 2 Next Steps guides and 1 DVD at a savings of more than 50%. For more information visit Aging with Dignity’s website, or call for details.

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Appendix H: Informed consent

Title of EBP project: Advance care planning in the primary care setting**Introduction**

You are invited to participate in a study looking at an advance care planning program within your primary care provider's office. You have been selected to participate because you are 65 years or older and have been recognized by your primary physician as a candidate for advance care planning based on your ability to participate and lack of having completed this process. This study will evaluate if providing written materials about advance directives and a follow-up discussion with someone knowledgeable about advance directives will improve the likelihood of subjects completing the advance directive process. The steps of the program will assist you in completing your own living will and health care power of attorney.

What is involved in the study?

If you choose to participate, you will receive an information packet providing you with more details about the research study. The research study includes an explanation of the “Five Wishes” document to explore your end-of-life wishes and guide your discussion with family and friends. As part of the study, you will also be invited to participate in a face-to-face discussion with the principal investigator to discuss your selections on the document and ensure they express your intended end-of-life care wishes. You will have the opportunity to finalize this document during the face-to-face discussion in the presence of two witnesses. The time it will take to review the forms with your family is approximately 1 to 2 hours. The face-to-face discussion with the principal investigator will take approximately 30 minutes. Finalization will take another 10 minutes. At the conclusion of the discussion, you will be asked to complete a post-evaluation survey, which will take 15 minutes. In all, your time commitment for the study will be 55 minutes plus driving time. This is separate from the time needed to discuss the forms with your family as this time may vary significantly based on your preferences.

Risks and Benefits

This study involves only minimal risks to subjects. Minimal risks would involve emotional factors related to dealing with and discussing end-of-life-related topics and time commitments. You are free to skip any questions on the post-evaluation survey that you prefer not to answer. If you experience emotional distress related to any of the topics; you may discuss these with the principal investigator, your primary health provider, a spiritual advisor, or the 24-hour Crisis Line at 402-717-4673 or 402-546-0770. Benefits of the study would include having formal documents that express your wishes and participating in research that may assist in others in implementing an advance care planning process. The Five Wishes document is one method to indicate your advance directives. You should contact an attorney about your advanced directives in addition to completion of the Five Wishes.

Confidentiality

The following steps will be taken to keep information about you confidential and protect it from unauthorized disclosure, tampering, or damage: only limited demographic information will be collected in a post-survey, including your age, gender, length of time within this medical practice, prior exposure to advance directives, and your evaluation of the process. This data will

be coded using subject numbers and kept in a locked cabinet only accessible by the principal investigator and maintained for a minimum of 5 years. The study results will be disseminated in a scholarly project with the potential of being published in nursing journals and nursing research seminars. Results will be presented in an aggregate manner and all personal information will be de-identified.

Your rights as a study participant

Your participation in this research is voluntary. If you choose not to participate, or change your mind later, your decision will not affect your relationship with your doctor or your right to health care or other services you may be eligible for. You have the right to withdraw from the study at any time simply by notifying either the principal investigator or your primary care provider that you no longer wish to participate. You will receive a copy of this consent document once signed at the face-to-face discussion meeting.

You can contact the principal investigator, Maria Douthett at [REDACTED] or by email at [REDACTED] if you have any questions about the study, problems during participation, or have anything unexpected occur during the study that you feel is as a result of the study or affects your ability to participate. You may also contact the faculty mentor, Dr. Fran Henton by email at [REDACTED] if you have any concerns regarding the principal investigator.

Consent of Subject

Signature of Subject

Date

Printed Name of Subject

Signature of Principal Investigator
Maria B. Douthett

Date

[REDACTED]

Appendix I: Permission to use ADAT

From: "Douthett, Maria" [REDACTED]
Subject: FW: ADAT tool
Date: October 1, 2016 at 11:25:56 AM CDT
To: "mariabsandoval@gmail.com" [REDACTED]

From: Gloria Duke [REDACTED]
Sent: Saturday, October 01, 2016 11:16 AM
To: Douthett, Maria
Subject: Re: ADAT tool

Hello Maria!

Of course, you are more than welcome to use this tool. I'm glad you are only using part of it since the tool in general needs work to improve internal consistency. I hope your research goes very well, and never hesitate to let me know if I can help with anything! Take care, Gloria

Gloria Duke, PhD, RN
Professor and Associate Dean, CNHS Office of Research
Bart Brooks Professor of Ethics & Leadership
Chair, UT Tyler Institutional Review Board
3900 University Blvd
Tyler, TX 75799 Office 903-566-7023 Fax 903-565-5533

I embrace honor and integrity. Therefore, I choose not to lie, cheat, or steal, nor to accept the actions of those who do.
(The UT Tyler Honor Code)

From: Douthett, Maria [REDACTED]
Sent: Friday, September 30, 2016 3:02 PM
To: Gloria Duke
Subject: ADAT tool

Hello Ms. Duke,

I am a FNP/DNP student at Methodist College in Omaha, Nebraska and am doing my project on advance care planning in the primary care setting. As part of my research, I want to evaluate the biggest influencing factors in patients that complete advance directives versus those that do not. I came across your Advance Directive Assessment Tool (ADAT) and thought it would be helpful

for my research. I plan to only use a portion, that which is listed in your research article, "Factors influencing completion of advance directives in hospitalized patients," as well as the addition of one question directed to those that did not complete the process as to what was the primary reason for not. The purpose of my email is to ask for permission to utilize this modified version of the ADAT. I can provide you with the results of my study at its conclusion next year in May if you would like.

Thank you in advance for your good research stewardship,
Maria Douthett

This message and any included attachments are from Nebraska Methodist Health System and its affiliates and are intended only for the addressee. The message may contain privileged, confidential and/or proprietary information intended only for the person(s) named. Unauthorized forwarding, printing, copying, distribution, or use of such information is strictly prohibited and may be unlawful. If you are not the addressee, please promptly delete this message and notify the sender of the delivery error by e-mail or you may call Nebraska Methodist Health System and its affiliates in Omaha, Nebraska, U.S.A at [REDACTED].

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Appendix J: Permission to use Five Wishes

Your Five Wishes inquiry re obtaining Five Wishes

Ed Towey [REDACTED]

To: Douthett, Maria

Ms. Douthett:

Monday, October 03, 2016 10:06 AM

Thank you for contacting Aging with Dignity about obtaining Five Wishes. Yes, you may use Five Wishes as you describe, but you don't need our permission to do that. We do not allow photocopying of the blank Five Wishes, so you'll need to obtain 20-25 of them yourself or obtain them from a third party. The \$5 individual copy price drops to just \$1 each when you order 25 or more, so 25 copies would be \$25. You can order by mail and pay by check or money order and send to Aging with Dignity, P.O. Box 1661, Tallahassee, FL 32301, or you can use your credit/debit card when ordering by phone at (888) 5-WISHES or when visiting our website shopping cart at: www.agingwithdignity.org/shop. All orders ship out the next business day.

We'd love to hear how your project fares! Best wishes,

Ed Towey Vice President

On 9/30/2016 2:37 PM you wrote:

I am a Family Nurse Practitioner and Doctor of Nursing Practice Student at Nebraska Methodist College doing my final capstone project on enhancing advance care planning practices in the primary care setting. I am interested in using "The Five Wishes" booklet as a tool to assist in the advance care planning process for patients at a local primary care practice office. By using your tool, I plan to secure the advance care directives for 20-25 Medicare patients within the practice. I am writing to request permission for the use of the booklets as a tool in my research to

complete advance directives.

Appendix K: Post Evaluation Survey

Post-evaluation survey

Please indicate just one selection for each question. If you select other, please provide an answer to the question.

Age

- 65-79
- 70-74
- 75-79
- 80-84
- 85 or older

Gender

- Male
- Female

Race

- Hispanic or Latino
- White
- African American
- Pacific Islander or Asian
- Other _____

Length of time with this medical practice

- Less than 1 year
- 1-4 years
- 5-9 year
- 10-14 year
- Greater than 15 years

How did you first become aware of advance directives?

- Family member
- Friend
- Primary care provider
- Nurse
- Social worker
- Other _____

Who assisted you in completing your AD?

- Family
- Health care provider
- Attorney
- Friend
- Self
- Other _____

Who influenced you the most to formulate your AD?

- Spouse
- Child
- Other family member
- Self
- Friend
- Health care provider
- Other _____

What was the biggest factor in deciding to formulate an AD?

- I do not want to be a burden to my family
- I desire to have control over medical interventions
- I want to have piece of mind
- I do not trust my family to be able to carry out my end-of-life wishes
- I have had bad experiences with death of loved ones in the past
- My health status

Did your sense of spirituality affect your decision to have an AD?

- Yes
- No

If you did not formulate your AD, what was the biggest factor in not being able to do so?

- I do not know my wishes
- I do not accept death as an outcome
- I trust my family to be able to make decisions for me
- I have had good experiences with death in the past
- Death seems so far away from me

Whether you completed an AD or not, how helpful was this program to you in learning about advance directives and exploring your end-of-life care plan?

- 4-Extremely helpful
- 3-Very helpful
- 2-Somewhat helpful
- 1-Not helpful

Review of Literature Matrix

Table 1

Review of literature results

Article Citation Level of Evidence PICOT question	Purpose of Research Conceptual Framework or Theory Design Used	Measurement Tools	Sample & Size	Results of Research	Comments:
<p>Brinkman-Stoppelenburg, A., Rietjens, J.A., & van der Heide, A. (2014). The effects of advance care planning on end-of-life care: A systematic review. <i>Palliative Medicine</i>, 28(8), 1000-1025. doi: 10.1177/0269216314526272</p> <p>Level of Evidence: Systematic review of randomized controlled and observational studies, Level I (Polit & Beck, 2012).</p>	<p>The purpose of this research was to present an overview of studies on the effects of advance care planning (ACP) and gain insight in the effectiveness of different types of advance care planning. The aim is to investigate which aspects of EOL care, such as medical treatment, place of care, and quality of life, are affected by the use of different types of ACP.</p> <p>Electronic databases were used to locate research articles that</p>	<p>Meta-analysis was performed using the numbers of studies in which ACP was associated with a decrease or increase in certain outcomes, the number of studies in which no significant association was found and the number of studies that showed mixed results.</p> <p>Four types of</p>	<p>N=113 6 experimental , 107 observational ; 91 in the US, 5 in Canada, 13 other; 9 community, 37 nursing home, 37 hospital (not ICU), 18 ICU, and 1 mixed; 52 DNR, 16 DNH, 45 AD, 20 complex; 13 0-100 patients in</p>	<p>Meta-analysis showed ACP was often found to decrease life-sustaining treatment, increase use of hospice and palliative care, and prevent hospitalization. Complex ACP interventions seem to increase compliance with patients' end-of-life wishes.</p>	<p>The effects of different types of ACP were studied in various settings and populations using different outcome measures, showing evidence that ACP positively impacts the quality of EOL care. Complex ACP may be more effective in meeting patients' wishes than documents alone. Study limitations include difficulty in finding an adequate search strategy, omission of studies with ACP as a component of a larger intervention (e.g. palliative care consultation), and limitations in inferences that can be drawn due to a lack of examination of details regarding types of ACP. The limitations in analysis are related to lack of standardization of outcome measures and ACP interventions. Implications for</p>

<p>PICOT Question: What are the effects of ACP on end-of-life care?</p>	<p>included both experimental and observational studies comparing empirical research on the effects of ACP in which a comparison was made between patients who did and who did not participate in ACP. Effects had to pertain to medical tx, compliance with EOL wishes, place of care/death, satisfaction of care, and prevalence or severity of symptoms.</p> <p>Three researchers extracted from articles and graded the level of evidence using the criteria proposed by Higginson et al.</p> <p>Systematic review</p>	<p>ACP types were analyzed: DNR, DNH, AD/living will/HCPOA; and complex ACP intervention</p>	<p>study, 35 101-500, 16 501-1000, and 49 >1000. These samples were compared to see how outcomes varied with each different type of ACP implemented in the various settings.</p>		<p>nursing practice include the potential advance care planning can offer to promote end-of-life care and quality of death, but further research is needed that focuses on experiences of the patients and their families. Future research to support ACP as an intervention should use an experimental design to compare standardized ACP interventions and outcome measures in order to recommend a specific ACP intervention that will improve outcomes.</p>
<p>Klinger, C., Schmitt, J., & Marckmann, G. (2015). Does facilitated advance care planning reduce</p>	<p>The purpose of this research was to conduct a systematic review based on the Preferred Reporting Items for Systematic Reviews</p>	<p>Data analysis was done using a narrative synthesis to describe study results. Mean</p>	<p>7 empirical studies were identified based on inclusion criteria</p>	<p>Six of the 7 studies found reduced costs, 3 of them statistically significant (p-</p>	<p>This systematic review was well written with limited flaws in regards to data analysis. The problem was thoroughly described and the search for data was done appropriately and in depth.</p>

<p>the costs of care near the end of life? Systematic review and ethical considerations. <i>Palliative Medicine</i>, 1-11. doi: 10.1177/0269216315601346</p> <p>Level of Evidence: Systematic review of randomized controlled trials, before-after studies, and cohort studies, Level I (Polit & Beck, 2012).</p> <p>PICOT question: Will comprehensive ACP programs have an effect on overall expenditures and cost containment?</p>	<p>and Meta-Analyses using randomized controlled trials, before-after studies, and cohort studies on the cost implications of advance care planning programs, as well as discuss ethical considerations arising in this context.</p> <p>Electronic databases were used to locate empirical studies that investigated the cost implications of ACP programs involving professionally facilitated end-of-life discussions.</p> <p>A systematic review was conducted based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Statement (PRISMA) recommendations. A data extraction tabloid was developed and tested. One researcher</p>	<p>and median costs were provided with AD discussion and without in each study. Data pooling was considered inappropriate due to study heterogeneity in design, intervention, setting, and outcome measure.</p>	<p>assessing the costs of care with ACP in comparison with standard care without an ACP, years ranging from 1994 to 2010. 4 studies were RCTs, 1 a before-after design, and 2 used a cohort design (1 prospective and one retrospective)</p>	<p>value <0.05). One study showed a non-significant gross cost reduction, while the remaining 2 studies did not report whether the cost reductions reached statistical significance. The one that did not have an effect on cost reduction was the SUPPORT RCT conducted in 1995. Reported cost reductions ranged from USD1041 to USD64,827 per patient. The highest cost reductions, both absolute and refractive, were achieved in sicker patient populations who</p>	<p>Sample, data extraction, quality of data, and data analysis were described in the article. The quality of data was not assessed using a referenced work and was assessed by two researchers (C.K. and G.M.); data extraction was also done by C.K. and verified by G.M. The results showed 6 of the 7 studies demonstrated cost savings through ACP ranging from 1041 to 64,830 per patient, depending on the study period and the cost measurement. Program implementation costs were small compared to savings realized, amounting to 6%, 11%, and 15% of gross savings.</p> <p>Problems: Comparison (or pool analysis in a meta-analysis) is not possible because the studies differ substantially in regard to costs included in the calculation, the time frame of analysis and the patient population, setting, and intervention chosen. Limited application of the data due to: ACP not being examined in most of the studies in isolation; limited sample size; limited evidence base; and lack of generalizability.</p> <p>Implications for future research include studying ACP using a</p>
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	<p>(C.K.) extracted data from studies meeting inclusion criteria and assigned study quality; one researcher (G.M.) reviewed her decisions. The study quality was assessed in levels of evidence ranging from I (RCT) over II (other interventional studies) to III (observational studies). The 7 studies varied regarding study design, setting and participants, details of the intervention, and cost components.</p> <p>Systematic review</p>			use more hospital care.	comprehensive, validated ACP approach to accurately assess program costs, cost savings, and clinical outcomes; using a standardized reporting indicator such as that published in 2013 by Husereau, Drummond, Petrou, et al. for health economic evaluations; and using clearly defined and described ACP interventions to allow an assessment of which elements determine ACP effectiveness. Ethically, the research challenges whether reducing cost of care should be a reason for implementing ACP interventions. However, this is supported by the positive outcomes to patient autonomy and improvement in quality of care.
<p>Dixon, J., Matosevic, T., & Knapp, M. (2015). The economic evidence for advance care planning: Systematic review of evidence. <i>Palliative Medicine</i>, 29(10), 869-884. doi: 10.1177/0269216315586659.</p>	<p>The purpose of this research is to use a systematic review of academic literature to review and summarize economic evidence on advance care planning (ACP).</p> <p>Electronic database search to locate empirical studies that</p>	<p>Results were based on whether the ACP intervention showed a positive, negative, or mixed effect on economic outcomes.</p>	<p>N=18. 5 randomized designs (RCTs and cluster RCT) and 13 observational studies (3 non-randomized and 10</p>	<p>Study findings are mixed. Of the 8 studies that explore the impact of ACP in general, just over half (5) report a statistically significant association between ACP and healthcare</p>	<p>This systematic review was well written with limited flaws. The problem was thoroughly described and the search for data was done appropriately and in depth. Sample, quality of data, data extraction, and data analysis were described in detail. The only aspect that was not described was what researcher was responsible for doing data extraction and sample selection or if all were, and</p>

<p>Level of Evidence: Systematic review of randomized controlled trials and observational studies (3 non-randomized controlled designs and 10 natural experiments), Level I (Polit & Beck, 2012).</p> <p>PICOT question: What are the economic outcomes potentially associated with ACP?</p>	<p>report on economic outcomes potentially associated with ACP, published between 1990 and 2014.</p> <p>Two researchers selected articles based on inclusion and exclusion criteria, descriptive data including year of publication, country, type of ACP activity or intervention, target population and setting, sample and sample size, study design, economic outcome measures used, and results was extracted. The level of evidence was graded according to the schema used by Brinkman-Stoppelenburg et al. in their systematic review of (non-economic) outcomes associated with ACP, which was adapted from criteria originally proposed by Higginson</p>		<p>natural experiments), evaluating varying types of ACP interventions in a variety of settings including nursing homes, hospitals, a home-based telephone counseling intervention, and a complex care and coordination program through the VAMC. Six of the studies used Medicare charges as their cost measure; 3 of used direct charges made to the patient or the</p>	<p>savings. Of the 10 intervention studies, exactly half (5) report a statistically significant association between the intervention and healthcare savings. Of the 5 RCTs, over half (3) report a statistically significant association between ACP and reduced healthcare costs, while just over half (7) of the 13 observational studies found a statistically significant association. Cost savings ranged from \$64,827 for terminally hospitalized \$1041 for decedents with cancer.</p>	<p>how discrepancies were handled. Problems: Small number of relevant studies, the lack of cost-effectiveness studies, various methodological limitations, and the fact that studies were highly heterogeneous limits the ability to draw firm conclusions and pool data about the economic outcomes associated with ACP. Implications for nursing practice include a potential for showing a positive correlation of ACP on reducing healthcare costs. Future research should focus more on experimental designs, research that targets populations and circumstances with the greatest potential for cost-effectiveness using possibly a mixed methods approach.</p>
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	et al. Systematic review		insurer; 7 used accounting costs; and 2 estimated costs using nationally calculated average unit costs. Eight of the studies are non-intervention studies and 10 focus on specific interventions (e.g. counseling and support services).		
Ramsaroop, S.D., Reid, M.C., & Adelman, R.D. (2007). Completing an advance directive in the primary care setting: What do we need for success? <i>Journal of the American Geriatrics Society</i> , 55(2), 277-283. doi:	The purpose of this study is to systematically review studies designed to increase advance directive completion in the primary care setting using meta-analysis to quantify their effects. Literature review based on inclusion and	Meta-analysis was performed calculating absolute rate differences (i.e. differences in completion rates between intervention and control groups) for each study. Individual study	N=18 12 were RCTs, 2 quasi-experimental , 1 retrospective cohort, 1 observational , and 2 prospective. Ages of	Most studies employed multi-modal interventions. The most common was educational materials coupled with a patient-healthcare provider	The majority of studies demonstrated statistically significant effects associated with the intervention(s). Effect sizes ranged from -.05 to 2.48, with most (5) achieving an effect size between 0.5-0.8, indicating a moderate overall effect favoring AD intervention. The unadjusted pooled effect size was 0.50 (95%CI=0.17-0.83). The adjusted pooled effect size increased to

<p>10.1111/j.1532-5415.2007.01065.x</p> <p>Level of Evidence: Systematic review of randomized controlled trials (12), quasi-experimental (2), prospective trials (2), observational study (1), and retrospective cohort study (1), Level I (Polit & Beck, 2012).</p> <p>PICOT question: What interventions will increase AD completion in the primary care setting?</p>	<p>exclusion criteria of English-language literature published from January 1991 to July 2005.</p> <p>Three authors independently abstracted information (e.g. design, study duration, types of interventions employed) and AD completion rates for each intervention.</p> <p>Systematic review with meta-analysis</p>	<p>and pooled-effect sizes were also calculated using Cohen's d with 95% CIs. Qualitative analysis was done on studies that identified factors associated with completion of AD.</p>	<p>sample population ranged from 18 to 90 and older, mostly female, varied substantially in ethnicity, in a variety of settings (including VA primary care clinics, geriatric clinics, HMO primary care clinics, internal medicine clinics, and primary care offices), and variety of interventions (patient-directed, physician-directed, and combined).</p>	<p>interaction in a group or individual setting. Absolute differences in completion rates varied from high of 44% to low -2%. Effect sizes could be calculated for 15 of 18 studies. The pooled effect size was 0.50 (95% CI=0.17-0.83), indicating a moderate overall effect in favor of the intervention.</p>	<p>1.15 (95% CI=0.52-1.77). The most successful intervention incorporated direct patient-healthcare professional interactions. More-effective strategies also used iterative interactions over multiple visits. In contrast, passive education using written materials was found to be the least effective. Barriers were also identified to AD completion. Future research includes intervention studies that measure and analyze results based on patients' reasons for the visit and duration of patient-physician relationship and degree of rapport, as well as ascertaining participants' comprehension of completed AD, as well as level of congruence between patients' wishes and proxies' understanding of those wishes. The implications of this research include a focus on completion of AD in the primary care setting, where most adults receive longitudinal care; use of meta-analysis to ascertain individual and pooled effect sizes for studies conducted over a 14-year observation period; and support for use of iterative patient-provider discussion over multiple</p>
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					visits to enhance AD completion.
<p>Tung, E.E., Vickers, K.S., Lackore, K., Cabanela, R., Hathaway, J., & Chaudhry, R. (2011). Clinical decision support technology to increase advance care planning in the primary care setting. <i>American Journal of Hospice and Palliative Medicine</i>, 28(4), 230-235. doi: 10.1177/1049909110386045</p> <p>Level of Evidence: Retrospective analysis of a cohort study, Controlled cohort studies, Level III (Melnik & Fineout-Overholt, 2015).</p> <p>PICOT question: Will a multimodal patient education intervention targeting patients at increased risk of health deterioration increase</p>	<p>The purpose of this research is to examine if a multimodal patient education intervention targeting patients at increased risk of health deterioration would increase patient understanding of the ACP process and motivate them to complete a written AMD.</p> <p>The theoretical base and review of literature were clearly stated with a conceptual framework; concept definitions included AMD and description of the ACP intervention. The study proposes that despite the importance, AMD completion rates remain low and no established research has shown the most effective method. Researchers hypothesize that a</p>	<p>The primary outcome of interest was the proportion of participants who completed and turned in an AMD during the pilot. Secondary outcomes included identification of patient preferences for type of educational resources and identification of resources that most motivated patients to complete the AMD. Also, obstacles preventing completion of AMD were explored for those not completing an AMD.</p> <p>The intervention</p>	<p>Size of N=574, Control group=146</p> <p>Inclusion criteria include patients 60 years or older, seeking an HME appointment, who did not have a completed AMD electronically stored, and identified at increased risk of health deterioration by the Generic disease management system (GDMS) on the basis of stored clinical data.</p>	<p>The overall effect of the multimodal education intervention revealed a 17.5% increase in AMD completion rates (4.1% vs. 21.6%) (P<.0001). Of the 574 patients sent follow-up surveys, 72 (12.5%) returned a completed survey. In all, 41 (57%) survey respondents completed their AMD and shared this plan with their PCP at the time of data analysis; 43% decided to complete their AMD because of receiving the packet. Surveyed patients</p>	<p>AMD completion rate was significantly higher when an organized patient education process such as a previsit resource mailing was done in addition to a clinical decision support system like GDMS that electronically prompted physicians to counsel patients about ACP. Patients prefer these educational materials be written and that these materials enhance the likelihood of AD completion rates. The clinical significance is the combination of a pre-visit educational material on ACP can help primary care providers raise awareness and enhance AD completion rates. The study is somewhat limited in its applicability and generalizability due to the biasedness in study group versus the control group. The study group was generally younger, and more physically active than those scheduled for acute visits. Also, the participants were mostly white and high school graduates. The educational materials provided also would not effectively reach patients with low literacy or vision impairment. Last, the low response</p>

<p>patient understanding and motivate them to complete a written AMD?</p>	<p>multimodal approach of offering a mailed ACP educational packet with information systems and the care team approach could help in completion of AD by alleviating time constraint barriers.</p> <p>Retrospective analysis of an administered intervention to a cohort group representative of a population of patients seeking care at Mayo Clinic Rochester over a 23 week pilot study</p>	<p>and control groups were compared with a 2x2 table and the Fisher exact test P value. Comparison of AMD completion and demographic, functional status, and comorbidity information was made using SAS version 9.1. SPSS software was used to analyze patient follow-up survey data.</p>	<p>Samples were selected from two (of 4 total) randomly chosen primary care internal medicine (PCIM) sites. Exclusion included non English-speaking and nursing home residents.</p>	<p>preferred written materials to electronic ones when learning about ACP. The most common barrier listed was not being sure of their wishes (38.7%).</p>	<p>rate in the follow-up survey limits the applicability of this data to a more generalized population.</p>
<p>Lum, H.D., Jones, J., Matlock, D.D., Glasgow, R.E., Lobo, I., Levy, C.R., Schwartz, R.S., Sudore, R.L, & Kutner, J.S. (2016). Advance care planning meets group medical visits: The feasibility of promoting</p>	<p>The purpose of this research is to examine if a primary care-based group visit model focused on advance care planning is feasible to facilitate advance care planning conversations.</p> <p>Concept definitions were included group</p>	<p>RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) used to evaluate the pilot demonstration</p> <p>Patient evaluation</p>	<p>N=32 who participated, and n=48 who were approached but did not participate. Selection method was based on referral or assignment.</p>	<p>Patients reported an overall increase in ACP conversations with enough details that the patient felt confident that their loved ones knew their wishes (19% to 41%, P=0.02).</p>	<p>The study is somewhat limited in its applicability and generalizability due to the limited number of participants. The high participation rate (40%) suggests that patients are interested and willing to participate. Future studies should increase the population size and expand the demographics to include patients with sensory, cognitive, and functional limitations to broaden</p>

<p>conversations. <i>Annals of Family Medicine</i>, 14(2), 125-132. doi: 10.1370/afm/1906</p> <p>Level of Evidence: Longitudinal pilot study of 5 cohorts between November 2013 and June 2014, Controlled cohort studies, Level III (Melnyk & Fineout-Overholt, 2015).</p> <p>PICOT: Will a group visit facilitate discussion about ACP and increase patient engagement in a geriatric clinic among patients over 65 over 8 months?</p>	<p>medical visits (GMVs) as a strategic approach. The important role primary care clinics serve to engage patients in ACP was discussed within the context of recent societal and political influences (e.g. the IOM “Dying in America” report, CM reimbursement for ACP).</p> <p>Experimental pilot demonstration study implementing the Conversation group medical visits (GMV) in 5 cohort study groups within the Seniors Clinic at the University of Colorado Hospital between November 2013 and June 2014</p> <p>Experimental pilot longitudinal study</p>	<p>survey to collect demographic information, perspectives on GMV using a 5-point Likert scale, and assess impact on ACP conversations (from The Conversations Project).</p> <p>A Wilcoxon signed rank test was used to test for change in detailed ACP conversations before and after the GMV.</p> <p>Qualitative analysis was also done to identify themes of the GMV experience using a mixed inductive and deductive approach, and open coding</p>	<p>Of 80 patients approached, 32 participated (40%) in at least 1 session. Mean age of participants was 79 years, 59% were women, and 72% were white.</p>	<p>Of 24 patients (75%) who reported having had an ACP conversation, 92% felt comfortable, 58% felt prepared, and 38% felt somewhat prepared. Patient retention was 84%, with 27 of 32 patients participating in both sessions. Key discussion themes showed patients shared personal values and challenges r/t ACP and discussed a broad range of patient-raised topics r/t ACP.</p>	<p>the study’s applicability. Overall Comments on validity and reliability: The study procedures and process were clearly laid out, contributing to the overall reliability of the study. The study measured what it intended to measure, the effect on engagement before the intervention and after the intervention to engage in ACP conversations, indicating its validity.</p>
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		using constant comparison to identify consistent themes and triangulation of the data.			
<p>Wissow, L.S., Belote, A., Kramer, W., Compton-Phillips, A., Kritzler, R., & Weiner, J.P. (2004). Promoting advance directives among elderly primary care patients. <i>Journal of General Internal Medicine</i>, 19(9), 944-951.</p> <p>Level of evidence: Quasi-experimental trial in 5 suburban and urban health centers, Controlled cohort studies, Level II (Melnyk & Fineout-Overholt, 2015).</p> <p>PICOT question: Will targeting doctor</p>	<p>The purpose of this research is to determine efficient ways of promoting advance directives among heterogeneous populations of elderly ambulatory patients.</p> <p>Intervention took place in 5 Baltimore medical center groups of Kaiser Permanente. The allocation of patients to the intervention or control group depended on the site where they received primary care. Patient intervention consisted of pre- and post-visit reminder letters for ADs and a “Planning Ahead” brochure. Provider interventions consisted</p>	<p>ICD-10 codes reflected patient diagnoses</p> <p>Semi-structured debriefing interview of providers following training.</p> <p>Intervention and control groups were compared using multiple logistic regression models calculated using generalized estimating equations with provider as the clustering variable and with intervention sites represented as</p>	<p>Selection of the sample group was determined based on non-randomized design. Size of N=2,120</p> <p>Providers were targeted within the department of internal medicine (22 internists, 2 family MDs, 5 NPs).</p> <p>Inclusion criteria include patients 65 years or older who were</p>	<p>A modest increase was achieved, 67 (7.8%) of patients at the intervention centers completed new ADs, vs. 9 (<1%) at the comparison center (P<.001). Patients 75 and older were twice as likely (OR, 2.0; 95% CI 1.2-3.3) as those 65 to 74 to file a new AD, and the odds were twice as great (OR, 2.6; 95% CI 1.4-4.6) at centers serving communities</p>	<p>The clinical significance is the use of a provider-centered intervention was successful at making modest increases in AD completion rates, however the mechanism of this increase was unknown.</p> <p>The results are overall valid, however a limitation is that the mechanism by which the intervention had an effect is unknown. The frequency of AD discussion, who raised the questions, what kinds of directives were proposed, how the discussions were framed, or if resulting directives were truly “new” or revised.</p> <p>The comparison group was a relatively affluent community of mostly Whites with a higher than average median income. The intervention center communities have lower income levels and larger proportion of African Americans (2.5% to 73.3%).</p>

<p>behavior to initiate discussion of AD during health maintenance visits through oral and written education and patient prompts to discuss AD increase the use of AD among a socioeconomically heterogeneous group of ambulatory, elderly patients?</p>	<p>of presentations to medical and support staff by the chief of internal medicine and a “desk book.” Organizational components included a task checklist, preprinted reminder stickers, and reinforcement steps.</p> <p>Prospective, quasi-experimental (nonequivalent control group)</p>	<p>dummy variables to analyze for differences among the intervention sites.</p>	<p>continuously enrolled in 1 of the 5 Baltimore-area centers or the comparison center during the study period and who had scheduled an “extended health maintenance visit (a 45-minute visit to cover both preventive and chronic issues) during the study year.</p>	<p>with median household income over the state median. Adjusting for non-related factors (e.g. gender, ER visits, recent hospitalization, and number of chronic conditions), the intervention resulted in a 20-fold increase (95% CI, 10.4-47.8) in the odds of creating a new AD. Doctors reported barriers of time and unwillingness to press discussions with patients.</p>	<p>Higher response rates were seen in centers serving communities with the highest income so this would skew the data to reflect more of the affluent population and could have misrepresented the control group results. This would affect both the reliability and validity of the study.</p>
<p>Piers, R.D., van Eechoud, I.J., Van Camp, S., Grypdonck, M., Deveugele, M., Verbeke, N.C., & Van Den Noortgate, N.J. (2013). Advance care</p>	<p>The purpose of this research was to gain insight into the views of elderly on ACP.</p> <p>A narrow literature review was provided; conceptual</p>	<p>Data concerning demographics, terminal disease and comorbidities, functional dependence, and cognitive status</p>	<p>Sample included 38 persons with a median age of 81, recruited from 3 different</p>	<p>3 themes identified of older adults (terminally ill or frail) who talked about EOL care planning influencing</p>	<p>Risk of pseudo-participation in ACP if participant did not acceptant death as a possible outcome. This may result in EOL decisions not reflecting patient’s true wishes. Before engaging in ACP conversations, providers should explore if patient accepts</p>

<p>planning in terminally ill and frail older persons. <i>Patient Education and Counseling</i>, 90, 323-329.</p> <p>Level of evidence: Qualitative exploratory study, observational analytical, Level IV (Joanna Briggs Institute, 2014).</p> <p>PICOT questions: 1) If older frail and ill persons in Dutch-speaking Belgium are ready or willing to engage in ACP and 2) What motivates whether or not they proceed to planning EOL care.</p>	<p>underpinnings involve the rise in disease chronicity and poor quality of care in the final phase of life in the geriatric population. ACP may bridge the gap provided an understanding of perceptions and motivations is developed.</p> <p>Qualitative exploratory study using semi-structured interviews averaging 50 minutes to elicit the interviewees' personal narratives on 1) what was important in their life at that moment and 2) their wishes and attitudes towards planning for end of life.</p>	<p>(MMSE) also collected. Semi-structured interviews used to explore questions. Themes identified and a framework was developed and codes assigned. Codes analyzed using qualitative analysis database (Nvivo 8).</p>	<p>geriatric care settings. New participants taken until data saturation achieved. Inclusion criteria included age over 70 with a limited life expectancy (6 months), able to participate in 1-hour interview, and Dutch native language.</p>	<p>ACP: 1) acceptance of dying in near future as likely outcome; 2) feeling entitled to plan EOL care; and 3) motivations leading to plan or not plan EOL care. Model constructed based on the 3 major elements influencing ACP. (scales diagram)</p>	<p>dying as a likely outcome. Also, the experiences and fears concerning death and dying, trust, and need for control should be assessed.</p> <p>Patients selected by healthcare providers, which could result in possible selection bias since providers knew that the interview contained questions about death and dying. Patients who have difficulty accepting their terminal illness likely would have refused participation, further leading to skewedness. Also, only native Dutch speakers were interviewed, affecting the generalizability of the research. Overall, the research seemed credible and dependable with sufficient rigor and detail provided to reproduce results and study the same phenomenon in other groups. It would be interesting to apply this knowledge and research analysis to other groups of elderly, for example here in Omaha to see if the same themes were produced.</p>
<p>Duffield, P., & Podzamsky, J.E. (1996). The completion of</p>	<p>The purpose of this research is to determine whether discussion about and distribution</p>	<p>Questionnaire to determine educational level, marital</p>	<p>Selection of the sample group was determined</p>	<p>The discussion about and distribution of AD forms in the</p>	<p>The clinical significance is providing AD forms and discussion increased the rates by almost half within a primary care</p>

<p>advance directives in primary care. <i>The Journal of Family Practice</i>, 42(4), 378-383.</p> <p>Level of evidence: Quasi-experimental, non-randomized, pre-post intervention, Level II (Melnyk & Fineout-Overholt, 2015).</p>	<p>of advance directive forms in a rural, private primary health care office would increase the number of patients who complete and return these forms.</p> <p>The theoretical base and review of literature including concept definitions on advance directive and the Patient Self-Determination Act.</p> <p>1-month of forms were distributed in a private family practice office in rural Illinois community to address the study questions. The group that did not complete AD was used as the control group. The two groups were analyzed using logistic regression analyses to see if independent variables of age, provider, length of time in practice, marital status, acceptance of</p>	<p>status, previous experience with illness, religion and attendance of religious services, frequency of contact with immediate family members, and previous questioning regarding AD To determine acceptance of death, the Death Acceptance dimension of the Life Attitude Profile-Revised (LAP-R)</p>	<p>based on non-randomized design. Size of n=195, ranging in age from 21 to 88, with an average age of 54. Inclusion criteria include at least 21 years of age, no AD, seen in office during the month of March 1994. Exclusion included developmental delay, dementia, or severe illness, or seen in office first time.</p>	<p>primary care office resulted in a 45% return rate. Older patient age (P=.001), longer length of time in practice (P=.039), less education (P=.025), and physician provider (r=.002) were associated with higher completion rates</p>	<p>office. This increase was achieved without increasing the amount of provider time spent at each visit. Older people who had a longer relationship with their PCP were more likely to complete directives, again leading to the conclusion that PCP in a primary care setting are the most suitable for completing ADs and discussing ACP.</p> <p>Research was older and type of study and methods were not as clear as some of the more recent studies. I chose this study though because I thought that some of the methods I could use for my capstone.</p> <p>Applicability: The study is applicable in the primary care setting. One limitation is that it was only conducted in one rural primary care office with one family physician and two family NPs. This limits the generalizability of the findings to other settings.</p>
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	<p>death, having a will, and attendance of religious services altered the dependent variable of returning an AD form. The t and chi-square tests used to compare the characteristics of subjects who returned a completed AD and those who did not. Participant responses to LAP-R were summed. The 0.05 level of significance was chosen.</p> <p>Interventional pre-post study</p>				
<p>Ernecoff, N.C., Keane, C.R., & Albert, S.M. (2016). Health behavior change in advance care planning: an agent-based model. <i>BMC Public Health</i>, 16(193). doi: 10.1186/s12889-016-2872-9.</p> <p>Level of Evidence:</p>	<p>The purpose of this research was build an agent-based model that accurately reflects the rates at which individuals and the population complete the ACP process, barriers (emotional and psychological readiness, having necessary materials), facilitators (increasing</p>	<p>Ran 2 types of experiments systematically to simulate different dynamics: 1) a model where all agents developed an ACP, and 2) models in which agents developed ACP under the influence of each</p>	<p>Sample included a simulated population based on statistics for a population age 65 and older using NetLogo v5.0.4 beginning with a</p>	<p>Two simulation ABM models were able to accurately reflect ACP behavior and decision-making using the TTM stages of change, successfully incorporating ACP barriers, facilitators, and</p>	<p>ABM is a useful method for representing dynamic social and experiential influences on ACP decision-making process. The model suggests structural interventions, e.g. increasing access to ACP materials in primary care clinics, in addition to improved methods of data collection for behavioral studies, e.g. incorporating longitudinal data to capture behavioral dynamics. ABM may allow for</p>

<p>Prospective cohort design, Level III (Melnyk & Fineout-Overholt, 2015).</p> <p>PICOT question: Will ABM accurately predict reflect the rates at which individuals and the population complete the ACP process, barriers, facilitators, and behavioral variables?</p>	<p>the salience of the need to develop an ACP; social support); and behavioral variables (susceptibility, baseline distributions).</p> <p>Agent-based modeling (ABM) uses computers to simulate actions and interactions of autonomous agents in order to examine behavioral dynamics with a computer before implementation in the field. The ABM designed applies the Transtheoretical Model of behavior change to ACP as a health behavior to accurately reflect: 1) the rates at which individuals complete the process, 2) how individuals respond to barriers, facilitators, and behavioral variables, and 3) the interactions between these variables.</p>	<p>other, ICU stay, and loved ones' illness or death, visits to primary care clinics and the addition of local networks. The first experiment was designed to represent how transitions between stages would occur in an ideal situation. The second experiment was designed to mimic observed population rates of ACP in the TTM. For each, systematic manipulation of 5 sets of variables in the model and the parameters to determine the weight with which they may influence agents.</p>	<p>distribution of stages of change for ACP empirically found in other behaviors. Each stage agents have a score from 0-100, with higher scores representing greater likelihood of advancing to the next stage.</p>	<p>other behavioral variables. The resulting distributions across the stages of change replicated those found in literature, with approximately half of participants in the action-maintenance stage in both the model and the literature.</p>	<p>testing of ACP interventions prior to implementation as a way of testing for effectiveness prior to allocation decisions. Strengths of the model: ACP model offers a generalizable method for integrating the TTM into an ABM. ABM can also be applied to other health behaviors by adjusting the barriers and facilitators affecting movement through the stages of change. The strength of the model is its high internal validity because agents behave according to model assumptions. The dependability is also high since the model successfully integrates, varies, and tests potentially causal factors of a behavior to recreate at least some of the empirical results. However, it is unknown if the mechanism in the model drives ACP behavior, therefore affecting its causality. The credibility is acceptable but could be improved by having more empirical research to integrate into the ABM. Many variables were not currently available in literature, therefore estimates from the literature had to be used. The credibility of the model could be enhanced by integrate additional</p>
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		Baseline values were determined based on literature.			empirical research to give a more clearer picture of the model. Also, the integration of additional barriers and facilitators of ACP would help the model better reflect population-level decision-making.
<p>Duke, G., Thompson, S., & Hastie, M. (2007). Factors influencing completion of advance directives in hospitalized patients. <i>International Journal of Palliative Nursing</i>, 13(1), 39-43.</p> <p>Level of Evidence: Cross sectional descriptive design, Level IV (Melnik & Fineout-Overholt, 2015).</p> <p>PICOT question: What factors influence the decision by hospitalized patients to complete</p>	<p>The purpose of this study was to describe factors that influenced the decision by hospitalized patients to formulate an AD.</p> <p>Descriptive study examined factors affecting completion of ADs by inpatients of 2 East Texas acute care facilities using a convenience sample and conducted interviews.</p>	<p><i>Advance Directive Assessment Tool (ADAT)</i> is a 39-item investigator-developed questionnaire originating from information elicited from patient interviews, querying them on how and why they formulated an AD. Tool was not conducive to internal consistency testing since test-retest on the</p>	<p>N=47 Convenience sample of patients included those who: Spoke English Completed an AD Willing to be interviewed and/or complete written tools Were oriented to time, place, and person.</p>	<p>Spouses, family members, and sense of spirituality were strongest influential factors for AD completion. Spirituality was a strong influencing factor among 45%. Most learned about ADs from family, friends, personal attorneys, and others, while only 23% learned about ADs from health providers. Not</p>	<p>Not wanting to be a burden to family was the most common reason for signing an AD, and this finding is consistent with limited existing literature (Douglas and Brown, 2002; Libbus and Russell, 1995). Knowledge of the characteristics of individuals who have prepared ADs along with factors that influenced their decision to formulate and the resources used can guide health care providers to facilitate this process for other individuals to advance AD completion rates (Fairchild, 1998). A second motivating factor found in Duke, Thompson, and Hastie's research was health status since 36% of participants who formulated their AD stated they were experiencing significant health problems at the time they signed their AD.</p>

AD?		same patients was not possible. Content validity was verified using an expert panel of 3 nurse consultants holding PhDs with expertise in nursing research and end-of-life care and a hospice chaplain.		wanting to be a burden on family members (45%) was the major reason cited for AD completion, followed by wanting to control their own medical care (17%).	However, the goal of advance care planning is pre-crisis preparation of end-of-life care wishes. Pre-crisis preparation could enhance autonomous health care decision-making when individuals are best able to make a conscious, rational, and personal decision about end-of-life issues. The role of having the primary care provider initiate discussions on AD formulation is to allow for pre-crisis preparation. Limitations of this study include use of a new tool without established internal consistency, a small convenience sample of Caucasian patients, and no comparison of patients without ADs.
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Note. Review of literature results for advance care planning interventions, outcomes, and influential factors affect AD completion rates.

Literature Search

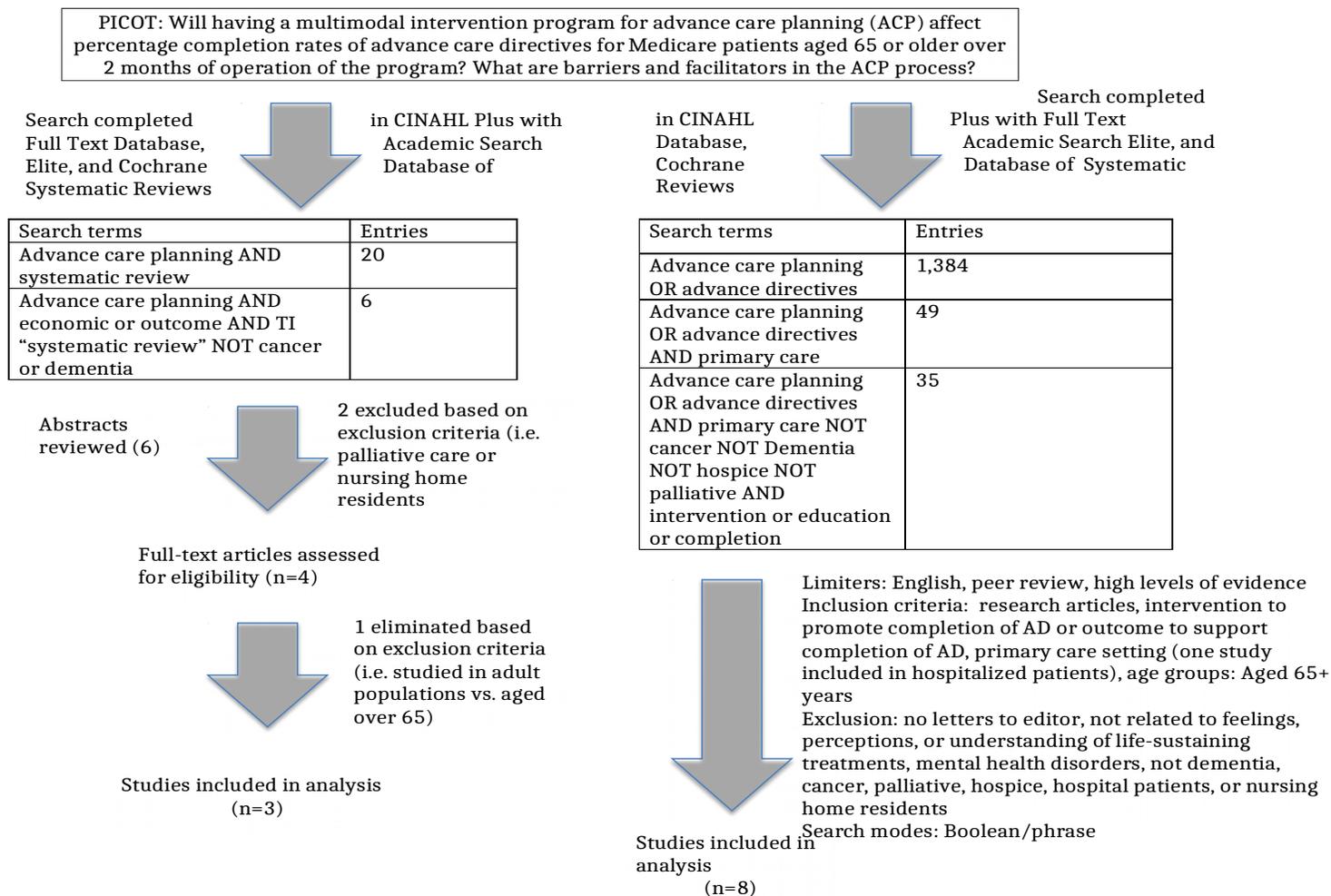


Figure 1. Literature search for advance care planning outcomes, economic, and interventions in primary care.

