

RESPECTING END OF LIFE WISHES: DEVELOPMENT AND IMPLEMENTATION
OF AN EVIDENCE-BASED INTERVENTION TO INCREASE THE
COMPLETION OF ADVANCE DIRECTIVES

by

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A scholarly project submitted in partial fulfillment
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of

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DEDICATION

I have been fortunate to have had the support of loved ones throughout the completion of this project and degree who without I would not have been able to succeed. I would like to dedicate this paper to my husband Bernie, my Mother in law Cris and Father in law Dino. They have been at the frontline providing continued support, motivation and love that kept me moving forward. I would not have gone down this adventurous road if I didn't know my girls were with their unconditionally, loving "Nana and Papa" during clinical days, classes, and long hours of homework. They have shown me the true meaning of family in so many ways and I will be forever grateful. To my daughters Sylvia and Norah, who have been my motivation to work hard and to my brother Dave, whose ambition to take on any challenge and not stop until you succeed has been a guiding inspiration throughout this journey. I will forever be thankful for these special people in my life.

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ABSTRACT

With an aging population and medical advancements people are living longer. With advanced age often come chronic conditions making it increasingly important to communicate end of life (EOL) care preferences to family, loved ones, and healthcare providers. However, despite the proven benefits that advance care planning (ACP) can provide for patients, families, and providers, it remains a challenge to initiate such conversations and advance directive (AD) completion rates remain low. The purpose of this project was to analyze the current process of discussing EOL care preferences, completing and accessing ADs in a rural family practice clinic and identify areas in need of improvement. The primary goal is to increase completion of ADs with a secondary aim to increase healthcare provider accessibility to ADs. Development and implementation of an ACP intervention consisting of a standard visit for a provider-initiated ACP discussion with patients 65 years and older. Pre and post AD knowledge surveys before and after the visit, augmented with a census medical record review (MMR) were used to evaluate the intervention. A total of 26 patients, 4.42% of the eligible population chose to participate. The project found that the majority 69.23% (n=18) of the participants reported having an AD, however 55.56% (n=10) were not documented in the EMR. Further, 37.50% (3) of participants reported not having one but was found to have had a Physician Orders for Life Sustaining Treatment (POLST) during both pre and post intervention periods. The MMR found 81.72% (n= 733) of patients from both time periods did not have an AD in their electronic medical record (EMR). None of the intervention participants were found to have completed an AD following the intervention, however, it proved to be informative and somewhat influential on their thoughts surrounding EOL preferences and discussing them with others. The intervention had no effect on the completion of ADs as reflected by the proportion of ADs found in the EMR in the post intervention period. In fact, the proportion of ADs found in this period decreased. Overall, the intervention was beneficial as it further identified challenges in the current process recognizing provider accessibility to ADs as the bigger issue as well as the need for additional patient and provider education.

INTRODUCTION

Background

The American population aged 65 and older is projected to double over the next three decades, increasing from 48 million to 88 million by 2050 (United States Census Bureau, 2016). This is in part due to the aging baby boomers and longer life spans (Centers for Disease Control and Prevention [CDC], 2013). Advances in medicine have contributed to a shift in the leading cause of death from infectious diseases and acute illness to chronic diseases (CDC, 2013). Thirty-six percent of the U.S. population has a chronic condition (Institute of Medicine [IOM], 2014) and two out of every three older Americans have multiple chronic conditions (CDC, 2013). With advances in medicine and the management of one or more chronic conditions, healthcare providers and patients have more treatment options than ever before. This makes discussing and documenting end of life (EOL) care preferences an increasingly important aspect of healthcare (Malpas, 2011).

Advance care planning (ACP) is an ongoing process in which a person's values, beliefs and EOL care preferences are discussed with friends, family, and healthcare providers. It often includes the completion of an Advance Directive (AD), although documented EOL care preferences should be routinely revisited and should never replace open, continuous EOL care discussions (IOM, 2014).

Problem and Rationale for Project

Silveria, Kim, and Langa (2010) found through an analysis of survey data of 3,746 subjects from the Health and Retirement Study, that more than a quarter of elderly adults may need surrogate decision making before death, but only 67.5% of these individuals have an AD completed. Without an AD it can be difficult for family and or healthcare providers to guess what a person's EOL care preferences may be (IOM, 2014). In fact, when EOL care preferences are not known, and put in the hands of the healthcare provider, aggressive care is most often provided (Escher, Perneger, Rudaz, Dayer & Perrier, 2014).

According to Sharp, Moran, Kuhn, and Barclay (2013) only “2-29% of frail older people had discussed some form of EOL care plans with a healthcare professional” (p. 659). The lack of EOL care discussions and the low completion rate of ADs is not specific to one area of healthcare. Wright et al. (2008) found that only 37% of cancer patients reported having EOL discussions with healthcare providers and another study by Van Scoy and Sherman (2013) found that only 17% of patients that die in an intensive care unit have an AD. In the primary care setting providers often find it difficult to identify the right time to initiate EOL care discussions (Glaudemans, Moll van Charante, & Willems, 2015)

Primary care providers (PCP) care for patients across a lifespan, and manage many chronic illnesses through the coordination of patient care across multiple specialties, and are often the most familiar with patients and their families (IOM, 2014). The IOM considers primary care an ideal setting for ACP discussions. However,

implementing an iterative process of discussing one's EOL preferences continues to be a challenge and there is limited knowledge on its effectiveness in the primary care setting.

Purpose of the Project

The purpose of this project was to analyze the current process of discussing EOL care preferences, completing and accessing ADs in a rural family practice clinic, and identifying areas in need of improvement. Identified areas for improvement in the current process included the lack of a standard time/visit for healthcare providers to initiate EOL care conversations including the completion of ADs and healthcare provider access to these documents when needed. The information obtained was utilized in the development and implementation of an intervention involving provider-patient ACP communication. One of the IOM (2014) recommendations is that any organization that establishes quality standards should also develop standards for clinician-patient communication. Utilizing IOM (2014) recommendations and other supportive literature, an evidence based intervention was developed. The intervention included, in combination with written educational materials a provider initiated ACP and AD conversation with patients 65 years and older during a primary care visit.

The primary goal of the intervention was to increase the completion of ADs as reflected by the proportion of ADs found in medical records pre and post intervention. The implementation of this intervention was considered the first phase of an iterative model of ACP. With an aging population, establishing an effective ACP process is essential now more than ever to better understand and respect one's EOL wishes.

Secondary aims included increasing healthcare provider accessibility to ADs which was done through the promotion of the Montana End of Life Registry (MEOLR) and to identify any correlation between age, comorbidities, number of visits to the clinic, or type of health care provider with completion of ADs.

REVIEW OF LITERATURE

A review of literature was completed to better understand ACP, ADs, the purpose of such documents, facilitators and barriers to their use, their role in primary care, and interventions to increase their use. Cumulative Index to Nursing and Allied Health Literature (CINAHL), Medical Literature Analysis and Retrieval System Online (MEDLINE), COCHRANE, and Google scholar databases were searched. All articles were written in the English language. Due to limited studies, specifically randomized control trials on ACP and ADs, there was no limit on year of publication. Search terms included advance directives, advance directives and barriers, advance directives and timing, advance care planning, advance care planning in primary care, end of life care, and end of life decisions.

Advance Directives and Advance Care Planning

The Patient Self Determination Act (PSDA), passed in 1991, was an attempt to protect patient autonomy in healthcare decision making. The PSDA requires health care institutions and health maintenance organizations participating in Medicare and Medicaid programs to provide patients with written information regarding their right to make health care decisions and ADs (Maxfield, Pohl, & Colling, 2003; Zager, & Yancy, 2011). Unfortunately, many healthcare settings fulfill the minimum requirement by asking patients if they have an AD, and checking a box without discussing their EOL preferences. Gordon and Shade (1999) reported that one third of seniors had an AD on file, but only 15% were asked about end of life preferences.

Advance directive is an umbrella term for several documents that make a person's preferences for healthcare intervention known when he or she is unable to do so. They take effect and become the primary basis of decisions only when the patient loses the capacity to make decisions on their own. These include a living will (LW) and a Durable Power of Attorney for Health Care (DPAHC). Healthcare providers legally have to respect these directives and to accept the decisions made by of proxies (Olick, 2012).

A LW is an instructive directive that documents the medical interventions a person desires at the EOL if they are no longer able to speak for him or herself. Durable Power of Attorney for Health Care (DPAHC) is the designation of a person to make medical decisions for another person who is unable to make decisions for him/herself. Due to ease of use and the ability of the proxy to respond to a patient's current circumstance without having to interpret a LW, a DPAHC has become one of the most widely used AD (Olick, 2012).

ACP and ADs have been found to have several benefits. Silveria et al. (2010) reported that "among 435 incapacitated subjects who had prepared LWs and who had expressed a preference for or against all care possible, there was strong agreement between their stated preference and the care they received" (p.1215). Bischoff and colleagues (2013) revealed that having an AD decreased a person's chances of an extended hospitalization in the last month of life by 69% and correlated with hospice admissions and longer length of stay in hospice.

Facilitators and Barriers to Advance
Care Planning and Advance Directives

In order to assure that patients receive care consistent with their wishes ACP discussions are critical; however, there remain several challenges to implementing a process of discussing patient preferences (Ahluwalia et al., 2014). One study by Alano et al. (2010) found that

healthcare professionals can play a major role in improving the AD rate of completion in older patients by approaching them about ADs, explaining the importance of the role of ADs, and most importantly, asking them to complete ADs (p.274).

Furthermore, a survey study involving 700 community dwelling older adults by Morrison and Meier (2004) reported that predictors of AD completion involved “established primary care providers, personal experience with mechanical ventilation, knowledge about the process of ACP, and physicians’ willingness to effectively initiate such discussions” (p.2421).

Malcomson and Bisbee (2009) found that “elders express readiness and eagerness to take part in ACP discussions and believe that periods of relative wellness are the ideal time for these discussions” (p.19). Often, the elderly are interested in having ACP discussions to avoid being a burden to adult children and other loved ones (Malcomson & Bisbee, 2009). Elders have recognized that limited time, inconsistency in health care providers caring for them, and the large focus on treatment and cure play a role in whether or not an ACP discussion will take place (Malcomson & Bisbee, 2009).

According to the IOM (2014), there are many barriers to clear communication on people’s EOL care preferences. These include hesitation in discussing death by not only

patients and families, but clinicians as well. Limited time and initiation of these conversations in a crisis situation does not allow for quality communication.

Additionally, a lack of system or organizational support for ACP including clinician training, payment, and record keeping can effect communication of EOL care preferences (IOM, 2014).

In regards to hesitation in discussing death, 96% of the patients in a study by Tulsky, Fischer, Rose, and Arnold (1998) thought an EOL discussion was beneficial and 95% of patients thought it is a good idea for doctors to have such discussions and only 7% felt uncomfortable. Additionally, Wright et al. (2008) revealed that EOL conversations did not cause a person psychological distress. In fact, “in 52.9% of cases it helped patients accept their illness and focus on medical treatments involving pain management and comfort over life extending therapies” (p.1668).

A literature review by Ramsaroop, Reid, and Adelman (2007) reported that for providers, lack of time is one of the most common barriers to initiating ACP discussions. There are often many competing goals to be addressed in a primary care visit and an ACP discussion is rarely the first on the list (Nelson & Nelson, 2014). Tulsky et al. (1998) found that the median AD discussion lasted 5.6 minutes. However, for patients, one of the most commonly recognized reasons for not discussing EOL preferences was they were either leaving it up to family or putting it off until later (Ramsaroop, Reid, & Adelman, 2007). Unfortunately, if physicians don't have time, and patients don't want to ask about ACP, then EOL preferences will remain unknown (Ramsaroop et al., 2007).

Financial concerns and the question of reimbursement have historically been recognized as barriers to ACP discussions (IOM, 2014). However, effective January 1, 2016 Medicare has created ACP current procedural terminology (CPT) codes that provide reimbursement for ACP discussions. These codes are eligible to be used at an annual wellness exam and when medically necessary, for example a change of medical condition (Centers for Medicare & Medicaid Services [CMS], 2015). The documentation and accessibility of ADs have also been found to affect EOL preference communication. In a study by Bergman-Evans, Kuhnel, McNitt, and Myers (2008) surveying a variety of healthcare professionals on the usefulness and barriers of ADs across the care continuum, “40% of 412 healthcare professionals recognized lack of an AD on the chart as the most commonly encountered logistical issue” (p. 350).

Lastly, when it comes to preparing for the EOL, limited awareness of cultural differences is an identified barrier to the completion of ADs (Zager & Yancy, 2011). Standard AD forms do not incorporate cultural differences in regards to patient preferences and values; therefore, according to Zager and Yancy (2011) “dialogue that is culturally sensitive may help when discussing end-of-life issues with culturally diverse individuals” (p.210).

Advance Care Planning Timing

When is the most appropriate time to initiate ACP discussions? The answer to this question depends on the person you ask as well as their experiences. Unfortunately, despite supporting evidence, determining the appropriate time to initiate ACP discussions

remains a challenge. O'Sullivan and colleagues (2015) conducted a study in a family practice in Canada with a sample size of 800 patients that revealed the desired timing for ACP discussions to take place were greatly affected by a person's perceived importance of ADs.

Patient Perspective

When asked about the most appropriate timing for an ACP discussion, in a study by Barnes and colleagues (2007) with purposive sampling of 22 palliative care and oncology patients, relatives, and user group members the majority of participants wanted the opportunity to discuss EOL issues on more than one occasion. This would allow time to think about EOL care preferences, and update them as they change. In fact, the remoteness of a completed AD has been found to affect a healthcare provider's care decisions, specifically in emergency situations (Burkle, Mueller, Swetz, Hook, & Keegan, 2012).

A literature review by Auriemma et al. (2014) revealed that patient wishes change over time. EOL care preferences were found to be more stable among inpatients and seriously ill outpatients. Those with higher education and who had taken part in ACP and had an AD were found to have greater preference stability (Auriemma et al., 2014). The fact that EOL care preferences change over time makes the continuous aspects of ACP in discussing values, beliefs, and care preferences especially important.

Provider Perspective

According to Tulsky et al. (1998), 95% of physicians felt comfortable discussing EOL preferences and ADs, but there remains differing views on the most appropriate timing for these discussions to take place. A study by Otte, Jung, Elger, and Bally (2014) interviewing 23 Swiss general practitioners reported that general practitioners prefer to

initiate the first conversation about ADs early, when the patient is still healthy, to gain a clear understanding of a patient's desires in terms of their medical care, update AD preferences as these can change over time, and reaffirm a patient's wishes as their illness and medical care progress (para. 43).

Additionally, when asked when the most appropriate timing for initiating conversations on ADs, 205 out of 412 surveyed healthcare professionals from a variety of healthcare settings said the annual/ routine checkup (Bergman-Evans et al., 2008).

Tulsky and colleagues (1998) reported that 61% of physicians would rarely discuss this topic in the outpatient setting. A concern with this finding is that when EOL wishes are not discussed and documented, they often end up being addressed during a hospitalization. However, during a hospitalization patients may be in pain, have feelings of anxiety and other emotions as well as potential effects of medications which can all interfere with decision making (Maxfield, Pohl, and Colling, 2003). Also, when ACP is addressed in a hospital setting, patients may receive AD information from hospital staff whom they are not familiar with versus their primary care provider where there is often a trusted relationship. Despite varying findings in regard to the most appropriate timing for ACP discussion to take place, the overall consensus is that the decision to accept or refuse life- sustaining treatment should not be made under pressure in a time of crisis,

indicating that the primary care setting may be ideal for ACP discussions (Maxfield et al., 2003).

Advance Care Planning in Primary Care

Primary care providers manage the preventative, acute and chronic care of patients across the lifespan (IOM, 2014). This established patient-provider relationship makes the primary care setting desirable to initiate ACP discussions and continue open communication as health status changes. In fact, a study by Ahluwalia and colleagues (2014) interviewing 20 providers at a large Veterans Affairs (VA) facility reported that both primary and acute care providers felt that ACP would be best when initiated in the primary care setting due to the level of knowledge the primary care provider (PCP) has of their patients. However, the limited time was quickly acknowledged and recognized as a significant barrier (Ahluwalia et al., 2014). Additionally, Duffield and Posamsky (1996) reported that having previously established care showed a clinically significant increase in completion of ADs. Bergmans-Evans et al. (2008) found that

the initiation and/or review of ADs at annual or routine visits gives the patient and the provider an opportunity to discuss this serious matter in a less threatening environment than waiting for serious illness, injury or procedure (p. 352).

Unfortunately, despite these findings in support of implementing ACP in the primary care setting, it is not consistently being done. A structured literature review of 10 articles by Glaudemans, Moll van Charante, and Willems (2015) exploring ACP in primary care revealed that in this setting, ACP is mainly focused on Alzheimer's disease,

cancer or other terminal illness and “of all patients who died of a non-sudden death, only one-third had ACP” (p.20).

Interventions for Improvement

A variety of ACP interventions have been developed and trialed in practice as an attempt to better support the goals of the patient self-determination act (PSDA) with varying success. A study by Duffield and Poszamsky (1996) completed in a rural private family practice with patients seen in the clinic showed a 45% increase in the completion of ADs. The findings of this study were attributed to the simplicity of the questionnaire as well as a 3-5 minute conversation between the provider and patient. In a systematic review of 9 randomized control trials, Weathers et al. (2016) found that “ACP interventions decreased hospitalizations, use of resources and increased patient and family satisfaction with care and increased the use of ADs” (p. 106). Additionally, families and patients reported an increase in ACP knowledge, EOL wishes were more closely followed, and understanding of EOL preferences were improved (Weathers et al.).

The designs of ACP interventions vary immensely. Gordon and Shade (1999) found that having EOL preferences simply addressed by a nurse or a physician increased the chance of having an AD on file almost 3 times compared to those that did not have their EOL preferences addressed. A survey of 72 participants in a study to increase the completion of AD's, revealed that most respondents preferred written materials to electronic materials (Tung et al., 2011). In addition, Durbin, Fish, Bachman, and Smith

(2010) conducted a systematic review of randomized control trials to evaluate the effectiveness of educational interventions for improving AD completion and found that interventions that included written and verbal materials were more effective than written materials alone in increasing the number of newly completed ADs.

In a review of literature by Weathers et al. (2016), most of the ACP interventions were informative utilizing a variety of educational materials from written, verbal and videos, and in some cases were combined with a discussion about EOL care preferences. A review of 18 studies intended to increase the completion of ADs by Ramsaroop et al. (2007) also supported a combination of written materials and EOL care discussions. This review of literature found that AD education in the form of written materials alone was ineffective and the most successful interventions included direct patient-healthcare provider interactions (Ramsaroop et al., 2007).

Summary

This review of literature highlights the benefits of ACP and completion of ADs, but acknowledges several barriers to the implementation of ACP discussions as well as increasing the completion of ADs. Efforts have been taken to improve the prevalence of ACP discussions and the completion of ADs to better respect one's EOL wishes. Initiating ACP and AD discussions in the primary care setting is supported by the literature due to the established patient-provider relationship and during a relatively healthy state and non-crisis situation. The most successful ACP interventions have been

shown to include both written materials as well as an ACP discussion between healthcare providers and patients.

THEORETICAL UNDERPINNING

The Theory

The theoretical framework that guided this project is the Human-to-Human Relationship Model by Joyce Travelbee. This theory focuses on the establishment of a trusting relationship that can only be established through a specific interaction process. The first phase is the original encounter, then visibility of personal/emerging identities, and developing feelings of empathy. Travelbee (1964) describes empathy as an “intellectual and emotional comprehension of another person, important and desirable because it helps us to predict that person’s behavior and to perceive accurately his thinking and feeling” (p.68). Following empathy come feelings of sympathy, and finally establishing mutual understanding (Current Nursing, 2012). There is rapport established by the final stage of the relationship which Travelbee considers a prerequisite to achieving a genuine human-to- human relationship (Current Nursing, 2012). Travelbee (1963) believes rapport is

composed of a cluster of inter-related thoughts, and feelings: interest in, and concern for, other; empathy, compassion, and sympathy; a nonjudgmental attitude, and respect for each individual as a unique human being (p.70).

Travelbee goes on to say “rapport is a process, a happening, an experience between two persons” (p.70).

Rationale

Studies have shown that a facilitator for ACP discussions is an established and trusting relationship (Duffield et al., 1996; Maxfield et al., 2003). Each phase of the process in which relationships are established parallels key components of an effective ACP process. An ACP process that encompasses more than completing an AD, but incorporates a continuous communication process to better understand a person's beliefs, values and EOL preferences over time. Five of the seven concepts of the Human -to - Human relationship model helped guide the development and implementation of this intervention.

These concepts include meaning, communication, nursing, suffering and hope. Meaning is how one defines experiences. Communication and meaning are the basis for understanding others and contributing to a relationship. Nursing helps individuals and families find meaning in experiences of life, illness, and suffering. Suffering is unique to everyone. It can include physical and mental unease with different intensity, duration and depth that vary with each day and experience. There are several characteristics of hope as defined in the human-to-human relationship model that are pertinent to ACP. Hope is thought to be future oriented; involving the desire to have an experience, and having confidence in others that they will be there when needed (Current Nursing, 2012).

Studies by Ahluwalia et al. (2014) and Morrison & Meier (2004) have found that a person's EOL preferences are impacted by experiences which are unique to each individual and involve varying amounts of suffering and hope. The characteristics of hope are all very pertinent to the thoughts, and feelings that go into discussing ACP and

completing ADs. The healthcare provider provides the aspects of nursing in these conversations throughout this critical process.

METHODS

Introduction

An assessment of the current process of discussing, completing and utilizing ADs was completed through observation, discussions with the facility's chief operating officer (COO), the chief executive officer (CEO), medical director and a physician practicing in the rural family practice clinic. In addition, a short questionnaire was provided to healthcare providers at the clinic to further assess this process and identify areas for improvement. At the time of the assessment, there were 5 full-time providers practicing in the clinic. Three out of five providers completed the questionnaire. All providers reported that it was challenging to find ADs when they needed them and each provider had different practices on when, how and with whom they had ACP discussions. When asked what improvements could be made to the current process, all providers suggested having a standard time/visit to discuss these topics as well as a consistent place to retrieve them when necessary. When asked what aspects of ACP and ADs they would like further education on, they requested AD information specific to MT.

Ethical Issues and Human Rights

Montana State University Institutional Review Board reviewed and approved this project. Medical record review and data collection was completed by this student. Patient names were replaced with a random ID number and Excel spreadsheets used for data analysis were password protected on a password protected computer. This student was

the only one with access to IDs linked to patient identifiers. The participants in the project read and signed informed consent that was provided by clinic staff prior to the intervention. Participation in the intervention was voluntary and there was no incentive provided for participation. Risks include the inconvenience of completing the pre and post survey each taking approximately 5 minutes or less to complete, and take part in, what can be an uncomfortable conversation for some people. Privacy of information was of utmost importance, and Health Insurance Portability and Accountability Act (HIPAA) laws were followed at all times.

Sample and Setting

Location of Data Collection and Intervention

The setting for this project was a family practice clinic located in a rural community with a population of approximately 900 people in Southwestern Montana. The clinic is staffed with two secretaries, 3 full time physicians, 3 physician assistants, an in-house patient care coordinator, and a variety of visiting specialists. There is one medical assistant per provider each day. The clinic provides primary care to an average of 7,400 patients per year with 48% of the patient population being Medicare age.

Prior to the implementation of this intervention, the clinic had recently hired a COO who supported a culture of continuous growth and improvement. It was the collaboration of the COO and a champion physician in the clinic who strives to provide high quality, evidence based care that made this project possible through encouragement

and continuous support. The intervention period began May 18, 2016 and ended September 16, 2016 over a period of approximately 4 months.

Sample Characteristics

The original intent of this project was to include all Medicare patients aged 65 years and older that were being seen in the clinic for an annual exam (AE) during the intervention period. However, all patients 65 years and older seen for any reason were included to increase sample size. A total of 83 patients aged 65 and older who were seen for AEs from May 18th to September 30th, and 505 patients aged 65 and older who were seen for other reasons during that time period. Of the 588 eligible patients, 30 chose to participate. Unfortunately, one participant was 55 years old, and 3 participants completed the pre and post AD knowledge surveys, but did not sign consent form, so 26 patients were included in the analysis. Of these, there were 5 seen for an AE, 5 for a medication review and 16 seen for other reasons. Inquiry about race and ethnicity was not included in this project.

Intervention Design

The Intervention

The intervention consisted of the implementation of a standard visit for a provider initiated conversation regarding ADs, in combination with written educational materials, and additional support in discussing and completing forms upon request by the in-house patient care coordinator. Initially, it was decided that this conversation would take place at every AE for all Medicare patients aged 65 years and older. As the first phase of an

iterative ACP process, that would allow for ADs and ACP discussions to take place on a reoccurring basis at least annually, if not sooner, depending on each specific patient's health status in a non-threatening environment (Bergman-Evans et al., 2008; Otte et al., 2004). However, in order to increase the sample size, this ACP and AD conversation was later initiated during visits with all patients aged 65 years and older. This change was not ideal, but had the potential to be beneficial in evaluating the effectiveness of initiating these conversations in the primary care setting in general.

According to the IOM committee (2014), the ACP process can begin at any age or state of health and should center on frequent conversations with family members and care providers. Additionally, primary care is a desired setting for such conversations due to the non-threatening environment, in comparison to an unexpected hospitalization, and an established relationship with the providers (Bergmans-Evans et al., 1996; Morrison et al., 2004).

A provider checklist was created to guide and document the conversation. The original intent was to create a form within the electronic medical record (EMR) that served not only as a reminder to providers to initiate these conversations, but also a way to document such conversations. In a study by Hayek and colleagues (2014) evaluating the effectiveness of an EMR based reminder in improving AD documentation rates, physician education and one time reminders to discuss AD alone had limited effect on the completion rates of AD. Instead, this study showed that having an easily accessible dedicated section for AD documentation in the EMR showed a 76% completion of AD in those patients with AD on the problem list in comparison to 11.5% of those without AD

on the problem list (Hayek et al., 2014). The CEO of the facility at the time of planning and implementation of the project preferred that the use of the EMR was excluded from the project. Therefore, a paper checklist was created and utilized for this project.

Physician Orders for Life-Sustaining Treatment (POLST). In the planning phase of this project, the DNP student, in collaboration with the champion physician, discussed which form would be the focus of the conversation with the long term goal of standardizing the form that is completed at the clinic. The POLST form was considered because it is one page in length and can be filled out fairly quickly. However, the POLST form is not an AD, and is only recommended for those who are seriously ill where their current medical condition requires standing medical orders to direct care in the case of an emergency. A POLST form should not replace an AD, but be completed in addition to an AD in some circumstances (National POLST Paradigm, 2016).

Five Wishes. The five wishes document is an AD that addresses not only a person's medical treatment preferences and legal aspects of care, but personal and spiritual preferences (Aging with Dignity, 2016). The five wishes document is written in everyday language and has been shown to be helpful in starting and guiding EOL care conversations with loved ones (Aging with Dignity). Although, it requires more time to complete than the POLST form, it was decided that this form would be discussed in the provider initiated conversation during the intervention period in hopes that this form might increase ACP conversation among patients, loved ones, and healthcare providers.

Montana End of Life Registry (MEOLR). The MEOLR is a secure data base managed by the attorney general that provides authorized healthcare providers twenty-four-hour access to ADs (Office of Consumer Protection, 2016). The MEOLR was selected to be part of the ACP conversation during the intervention to address the concern of AD availability. Education about the registry, and how to use the registry was discussed with the long term goal of improving accessibility, however, tracking and analyzing the utilization of this registry following the intervention was beyond the scope of this project. The IOM (2014) reported that electronic storage of AD and other related documents has the potential to improve access and effectiveness of these documents.

Steps of the Intervention

The DNP student was responsible for planning and initiating the intervention. However, without the continued support of the clinic administration and staff, this project would not have been successful. The steps of the DNP project following the initial assessment were as follows:

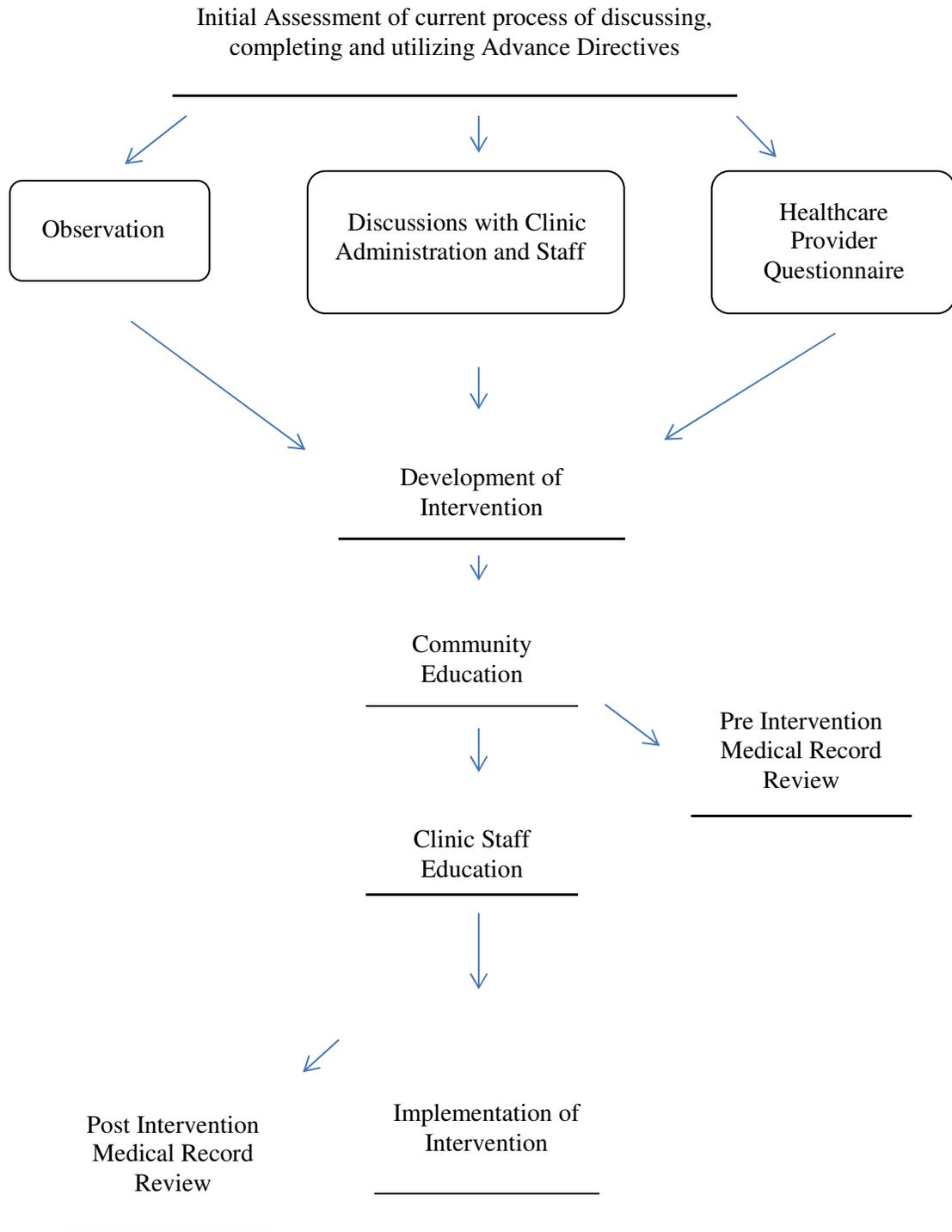


Figure 1: Steps of the DNP project following the initial assessment.

Community Education. Prior to this project, there have been infrequent informational meetings offered in the community on ADs. In order to increase awareness of AD and educate the community on the importance of ACP and ADs, two educational in-services were offered to community members at the local senior center. The hope was that these educational in-services would augment the intervention educating patients prior to potentially participating and being more likely to complete an AD. Promotion of the educational sessions was done by the DNP student through flyers throughout the community including local businesses, library, medical center, and the post office. These in-services covered ACP, what it entails and why it is important and also included basics of ADs including what they are, different forms, and details specific to MT. Each in-service was approximately 20 minutes long with time for questions. Unfortunately, there were only a total of two attendees. Formal evaluation of these educational sessions was out of the scope of this project.

Staff Education. Due to the staffing matrix, it was challenging to get all clinic staff and providers together at one time. Therefore, all clinic staff was informed of the project in person by the DNP student on a one-to-one basis. In addition, a PowerPoint presentation was sent via email to all staff and available throughout the clinic so it was easily accessible and could be used as a resource.

The PowerPoint highlighted the who, what, and why of the project and included the process of implementation. Based on the educational needs recognized in the initial assessment, the PowerPoint included AD basics and legalities specific to MT as well as several resources for additional information. The PowerPoint also included information

on the ACP CPT codes for Medicare reimbursement and when to use them. The in-house patient clinical coordinator was also available to providers to answer questions regarding these ACP CPT codes and for guidance on when to use these codes.

Implementation. The DNP student collaborated with clinic staff to discuss the best approach to implementation. It was determined that in order to fit best into the current workflow of the clinic, the medical assistants (MA) would provide all eligible patients a project packet, explain the project, and answer questions. This packet included IRB approved consent forms explaining the study, and risks and benefits associated with the project. An AD pre and post knowledge survey was included, as well as written educational resources, including information on (1) POLST (2) Montana End of Life Registry and (3) Five wishes basics. A five wishes document was available upon request. Envelopes were located throughout the clinic in secure work stations for completed intervention documents.

Continued support was provided to the clinic staff throughout the 4-month intervention period. The DNP student would check in every 2 weeks, and as needed, to monitor progress, pick up surveys, and address any concerns the clinic staff was having with the intervention and implementation. Barriers to successful implementation were identified and addressed throughout the intervention period. Barriers included:

1. Intervention packets not consistently being provided to eligible patients. This was addressed with additional education and visible reminders in areas staff felt would be beneficial as well as email reminders to all clinic staff.

2. Failure to complete or return intervention documents. Unfortunately, some subjects would partially complete the packet or take it home and report that they would return it to the clinic later. Therefore, it is unknown how many additional patients actually received the intervention ACP discussion.
3. Small sample size. Despite continuous monitoring sample size remained low at which point the DNP student spent a few days in the clinic introducing the project to eligible patients and explaining each step of the process. In addition, the DNP student reviewed the provider schedule for several days in advance and labeled packets with provider initials and appointment time of eligible patients. These packets were left in the works space of the designated MA. This proved to be the most effective in addressing all three barriers to successful implementation.

Instruments for Data Collection

Instruments for data collection included the initial provider questionnaire assessing the current ACP process, an ACP intervention checklist for providers, a pre and post AD knowledge survey and a census medical record review.

ACP Intervention Checklist for Providers. This checklist (appendix A) included whether or not the subject had an AD completed, if so which form, and whether or not the clinic had a copy. It also had a place to document when AD basics were reviewed; the five wishes document was reviewed as well as the MEOLR. There was also space for any additional notes/comments. This checklist was approved by the COO and the champion

physician to ensure it included appropriate content, and would fit into the current workflow at the clinic.

Pre and Post AD Knowledge Surveys. The effectiveness of this intervention was evaluated through pre and post AD knowledge surveys (appendix B and C). The surveys were adapted from “Evaluation of Advance Directives Video Education for Patients,” by C. Toraya, 2014. Refer to Toraya, 2014. The pre knowledge survey assessed whether the patient had discussed their healthcare wishes with their healthcare provider or loved ones, how familiar they are with ADs and if they have completed one. The post knowledge survey evaluated whether or not the conversation during their visit changed their knowledge level, desire to complete an AD and rated the effectiveness of the conversation.

Medical Record Review (MRR). Medical records of patients 65 and older were reviewed for all visits to the clinic pre intervention from January 1 to May 17, 2016. The intervention took place May 18 through September 16, 2016, and all medical records were reviewed post intervention for all patients 65 and older seen in the clinic from May 18 through November 30, 2016.

The primary purpose of the MRR was to determine the proportion of patients with ADs in their EMR and assess for any differences in this proportion pre and post intervention. This was especially important because of the potential of additional participants in the intervention where paper work was not completed and/or returned. A patient was considered to have AD if one was found in the EMR at any visit during the

data collection period. Each patient's age, gender, reason for visit, code status, type and location of AD (if available), the presence or absence of specific comorbidities and the provider type were collected for each visit. Comorbidities collected included hypertension (HTN), coronary artery disease (CAD), atrial fibrillation (AFIB), heart failure (HF), cerebral vascular accident (CVA), diabetes (DM), high cholesterol (chol), cancer (CA), chronic obstructive pulmonary disease (COPD), and dementia. These specific comorbidities were selected because many of them are included in the current literature (Barnes et al. 2007; Brazil et al. 2015; Wright et al. 2008) surrounding ADs and ACP and those that are not included in the literature are some of the more common conditions in the patient population aged 65 years and older.

A code status was either a Full code (F), a do not resuscitate (DNR), or was not documented in the EMR (N). Having a code status documented means that a person had their resuscitative preferences addressed and documented in the EMR for healthcare providers to have access to. In this study a documented DNR was of particular focus. The post intervention MRR also included whether or not the AD was completed during the intervention period, and if so if it was following a hospitalization (A) or clinic visit (C).

Due to the clinic's current code utilization practices, it was challenging to review charts based on codes. It was found that reviewing by code gave a falsely low population size. Therefore, in order to get a more accurate population and to maintain consistency throughout the MRR, all medical records were reviewed based on the entered chief complaint. Annual exam and medication review were of particular significance and highlighted in the results because they are both supported by literature as appropriate

visits to initiate ACPs as they both occur on an annual basis (Duffield et al., 1996; Otte et al., 2004).

Quality Assurance

The majority of assessment tools used in this project were created specifically to identify, investigate and analyze a problem specific to this rural family practice clinic. Therefore, with the exception of the pre and post AD knowledge surveys, the reliability of these assessment tools were not tested prior to the intervention. In general, surveys have some degree of bias due to the tendency for respondent to provide an answer they think is correct rather than their natural response (Moran, Burson, & Conrad, 2014).

The MRR was completed as an evaluation tool in addition to the post knowledge survey to ensure accuracy of results. To ensure accuracy of the data collected the MRR was completed by one person, the DNP student, and reviewed for errors on multiple occasions throughout the analysis process.

Analysis

Analytical Methods

Data analysis was completed throughout the project by the DNP student with the assistance of the Montana State University Statistical Consulting and Research Services (SCRS). Results were presented by the SCRS in tables and graphs summarizing the intervention participants and their survey responses, as well as the MRR. Descriptive statistics were utilized to summarize the collected data including percentages, median and mean. The effects of timing of AE visits were considered through the collection and

analysis of pre intervention and post intervention data. Logistic regression was used on patients seen for an AE during both time periods to estimate the odds of having an AD while controlling for other variables including age category, number of visits to the clinic, number of comorbidities, time period pre or post, sex, documented code status, and provider type. Clinical inferences were identified through the review of tables and graphs.

RESULTS

Pre and Post AD Knowledge Survey

Of the 26 intervention participants, ages ranged from 65-89 years of age. The largest representation 53.84% of intervention participants was aged 65-75. The average age was 75.04 and the median age was 75. The majority of the population was under the age of 80 and 25% was less than age 68. Of the intervention participants, there were more females 57.69% (n=15) than 42.31% (n=11) males. The average age of female participants was 74.13 and males 76. 27. See figure 2.

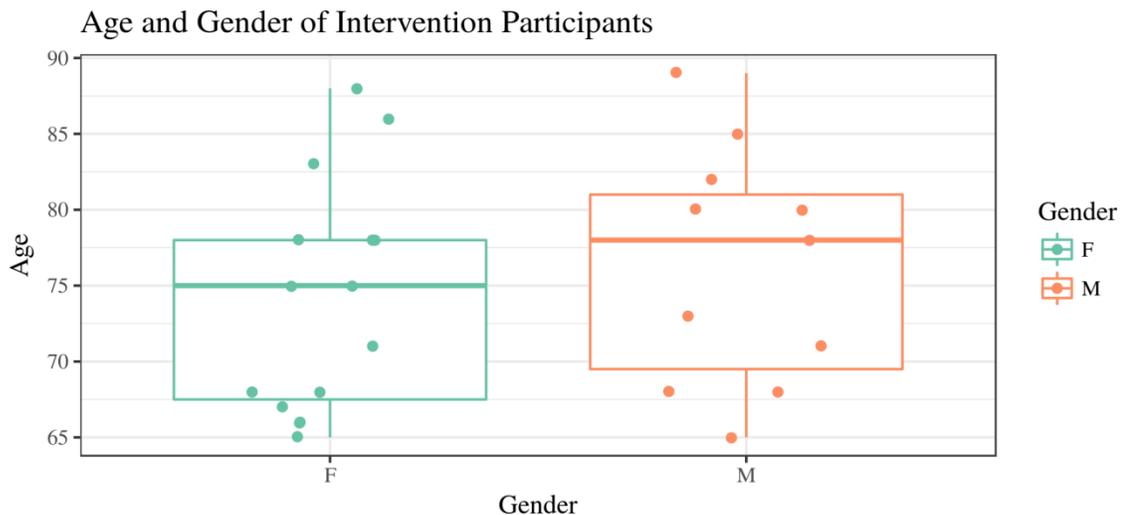


Figure 2: Plot of age by sex for intervention participants. The box plots use horizontal lines to show the 1st quartile (25% percentile), median (50% percentile) and 3rd quartile (75% percentile) of the ages and the vertical lines show the age range. The points represent the individual patients, and have been jittered right to left to reduce overlap. (Figure and caption from MSU SCRS report, adapted with permission.)

The majority, 69.23% (18 of the 26 participants), of the intervention participants reported having an AD and 30.77% (8 of the 26 participants) reported no AD. Through a

medical record review (MRR), intervention participant survey responses were compared to whether they had an AD available in their EMR at any visit during the data collection period. Only 44.44% (8 of the 18 participants with a reported AD) of those who reported having an AD completed had this document in their EMR. The participants who reported not having an AD, 37.50% (3 of the 8 participants with no reported AD) had an AD available in their EMR by the end of the data collection period. Each of these documents was found to be a POLST form completed during a hospitalization. See figure 3.

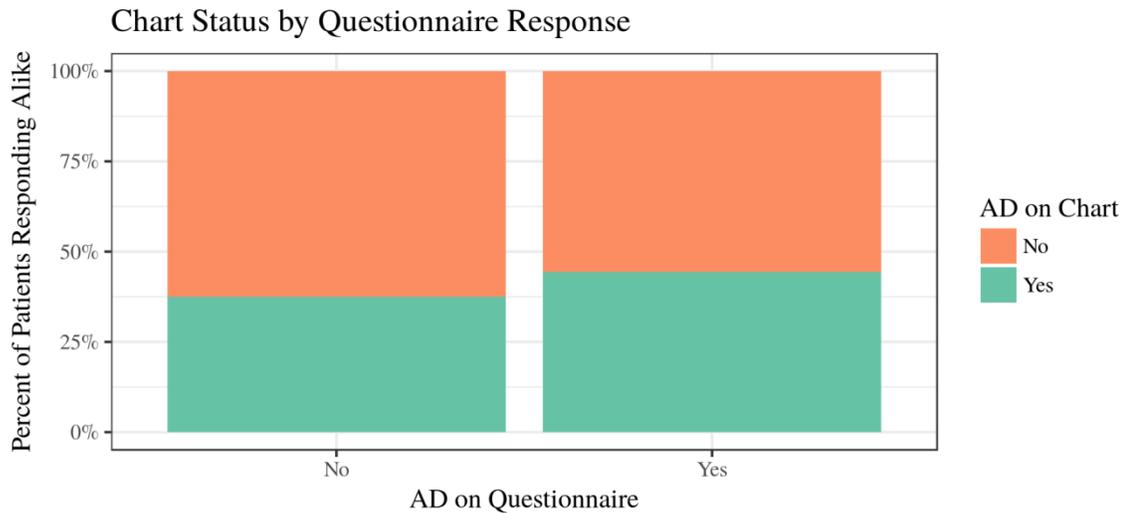


Figure 3: Plot showing the percent of intervention participants with an AD on the chart at any visit during the data collection period within participants who reported having or not having an AD on the pre AD knowledge survey. (Figure 5 and caption from MSU SCRS report, adapted with permission.)

A larger proportion of females, 73.33% (11 out of 15 females), than males, 63.64% (7 out of 11 males), were found to have a reported AD. See figure 4. Of the intervention participants who reported having an AD the most commonly completed form was a DPAHC, 34.62% (9 of the 18 reported ADs), LW, 11.54% (3 of the 18 reported

ADs), and 3.85% (1 of the 18 reported ADs) five wishes. However, 19.23% (5 of the 18 reported ADs) of those who reported having an AD did not specify the document type. None of the intervention participants reported having a POLST. See figure 5.

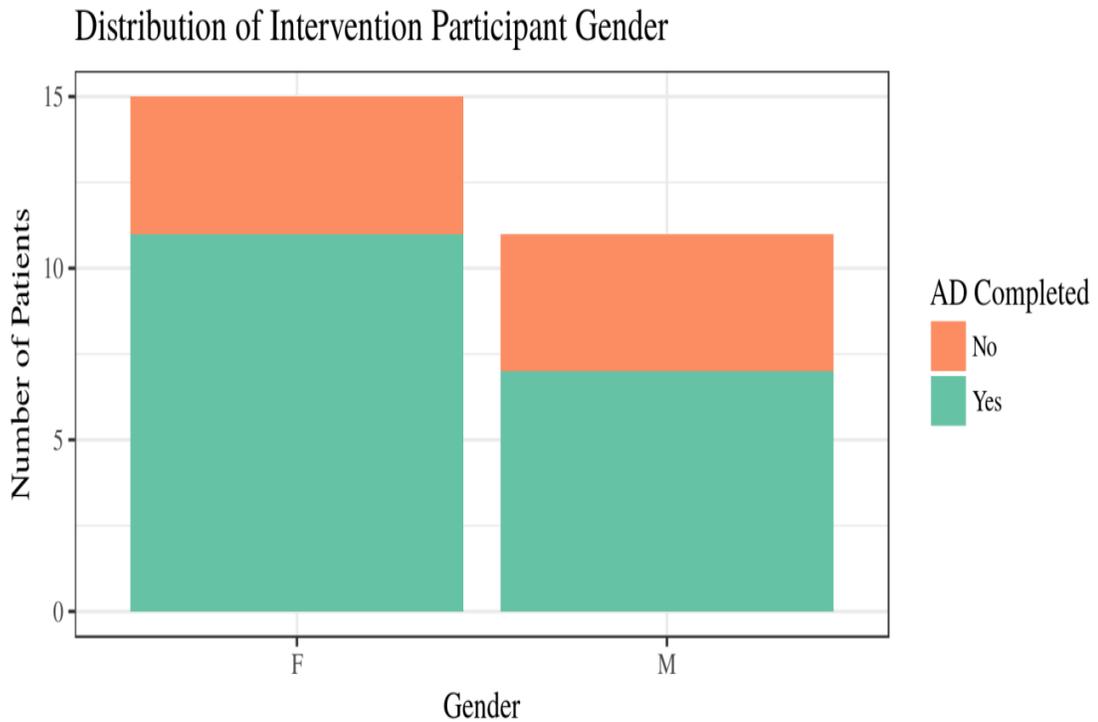


Figure 4: Distribution of intervention participant gender, colored whether they indicated on the pre AD knowledge survey that they had completed an AD. (Figure 2 and caption by MSU SCRS, adapted with permission.)

Distribution of Reported AD Types

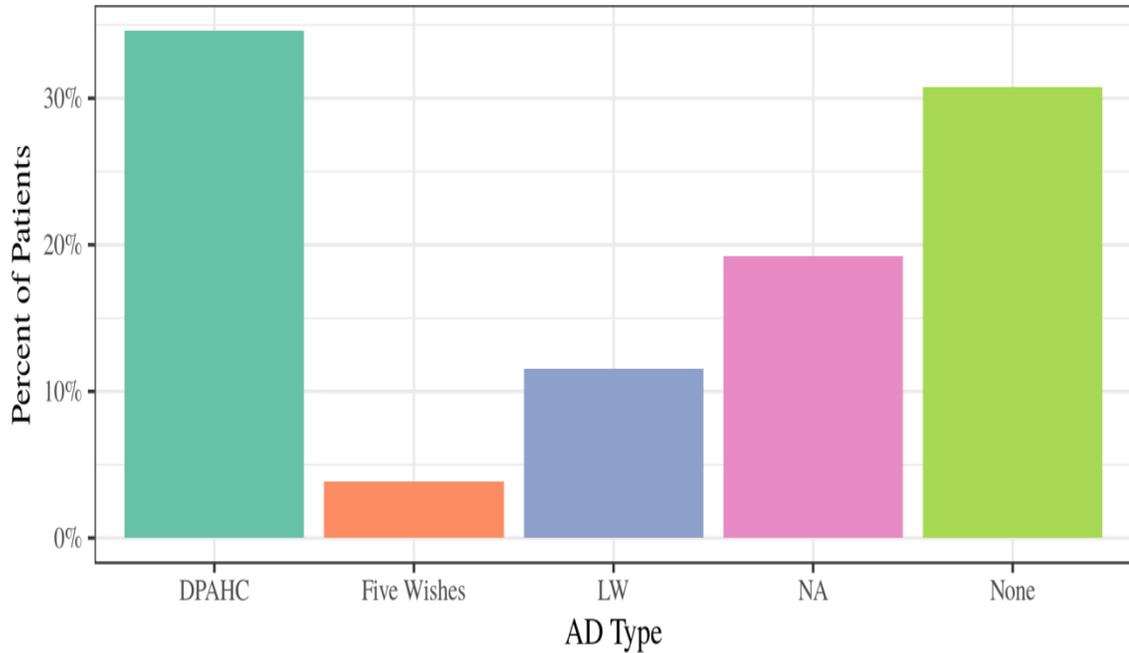


Figure 5: Percent of intervention participants reporting each AD type on the pre AD knowledge survey. The AD type labeled as unavailable (NA) represents those who reported having an AD, but that did not specify the type. (Figure 3 and caption from MSU SCRS report, adapted with permission.)

Helpfulness of the Conversation

The helpfulness of the provider initiated ACP conversation was evaluated on a scale from one to ten. Nine participants provided ratings, and the average rating was 8.33. The majority, 75%, rated the helpfulness less than a 10, and 25% rated it less than an 8. The highest rating was a 10, and the lowest was a 5. See figure 6.

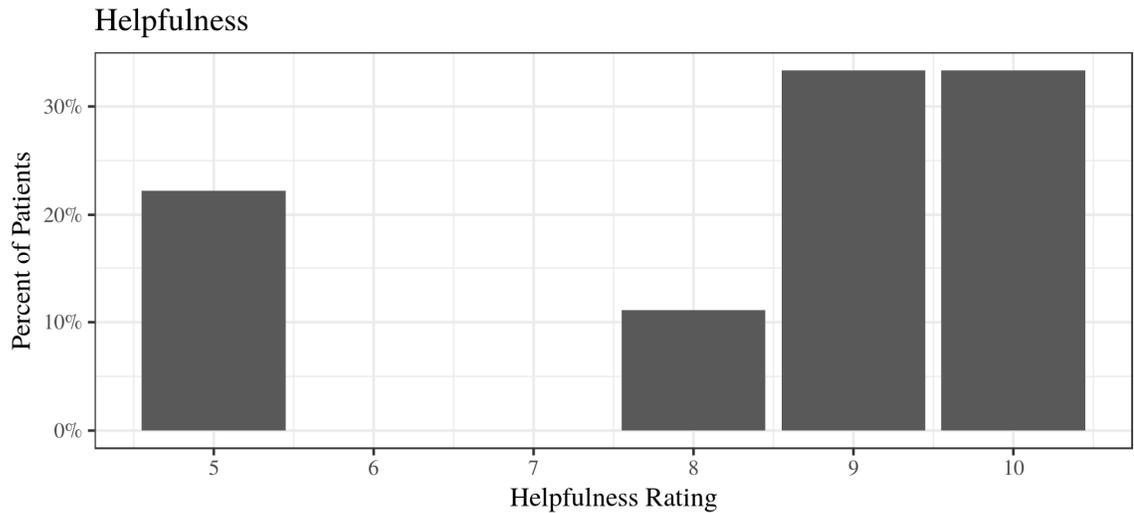


Figure 6: Plot showing the percent of intervention participants who gave each helpfulness ratings within the 9 patients who provided ratings. One being not helpful and ten being extremely helpful. (Figure 9 and caption from MSU SCRS report, adapted with permission.)

When asked if the conversation during the intervention changed anything about their future EOL wishes or discussing their wishes with loved ones, 3 out of the 18 intervention participants that reported having an AD did not respond to this question. Of the participants that responded, 100% (15 of the 15 participants) responded no. Of the 8 participants that reported no AD, 1 participant did not respond to this question. Of those that did respond, 71.42% (5 of the 7 participants) responded no and 28.57% (2 of the 7 participants that responded) responded yes to this question. Further, when asked if they plan to complete an AD because of this conversation, of the participants without a reported AD, the majority 62.50% (5 of the 8 participants without an AD) were undecided (UD), 25% (2 of the 8 participants without an AD) responded yes, and 12.50% (1 of the 8 participants without an AD) responded no.

Of the intervention participants 73.08% (19 of the 26 participants) had already discussed EOL preferences with family and loved ones and 23% (6 of the 26 participants) had discussed them with their doctors. Most of the participants 65.38% (17 of the 26 participants) reported having a good understanding of ADs prior to the conversation, 26.92% (7 of the 26 participants) somewhat understood ADs and only 7.69% (2 of the 26 participants) did not. Of the participants that responded when asked if they have enough information to start the process of discussing EOL preferences and completing forms, 71.42% (15 of the 21 participants) responded yes, 28.57% (6 of the 21 participants) responded no, and 5 were left blank.

Comorbidities

Less than 40% of participants with each specific comorbidity reported having an AD. The exception to this was DM in which 60% (3 of the 5 participants with DM) of participants with this condition had reported an AD and 100 % (1 of the 1 participant with CVA) of those with a CVA had a reported AD. See figure 7. To explore the association of comorbidities on the completion of ADs further, the relationship of having one or more comorbidities on the completion of an AD was considered. It was found that 22.22% (4 of the 18 participants with an AD) of intervention participants who had an AD had no comorbidities, 33.33% (6 of the 18 participants with an AD) had 1 comorbidity, 38.89% (7 of the 26 participants with an AD) had 2 comorbidities, and 5.56% (1 of the 26 participants with an AD) had 3. In comparison, of those intervention participants who reported no AD, 37.50% (3 of the 8 participants with no AD) had no comorbidities, 37.50% (3 of the 8 participants with no AD) had 1 comorbidity, 12.50% (1 of the 8

participants with no AD) had 2 comorbidities, and 12.50% (1 of the 8 participants with no AD) had 3 comorbidities. See figure 8.

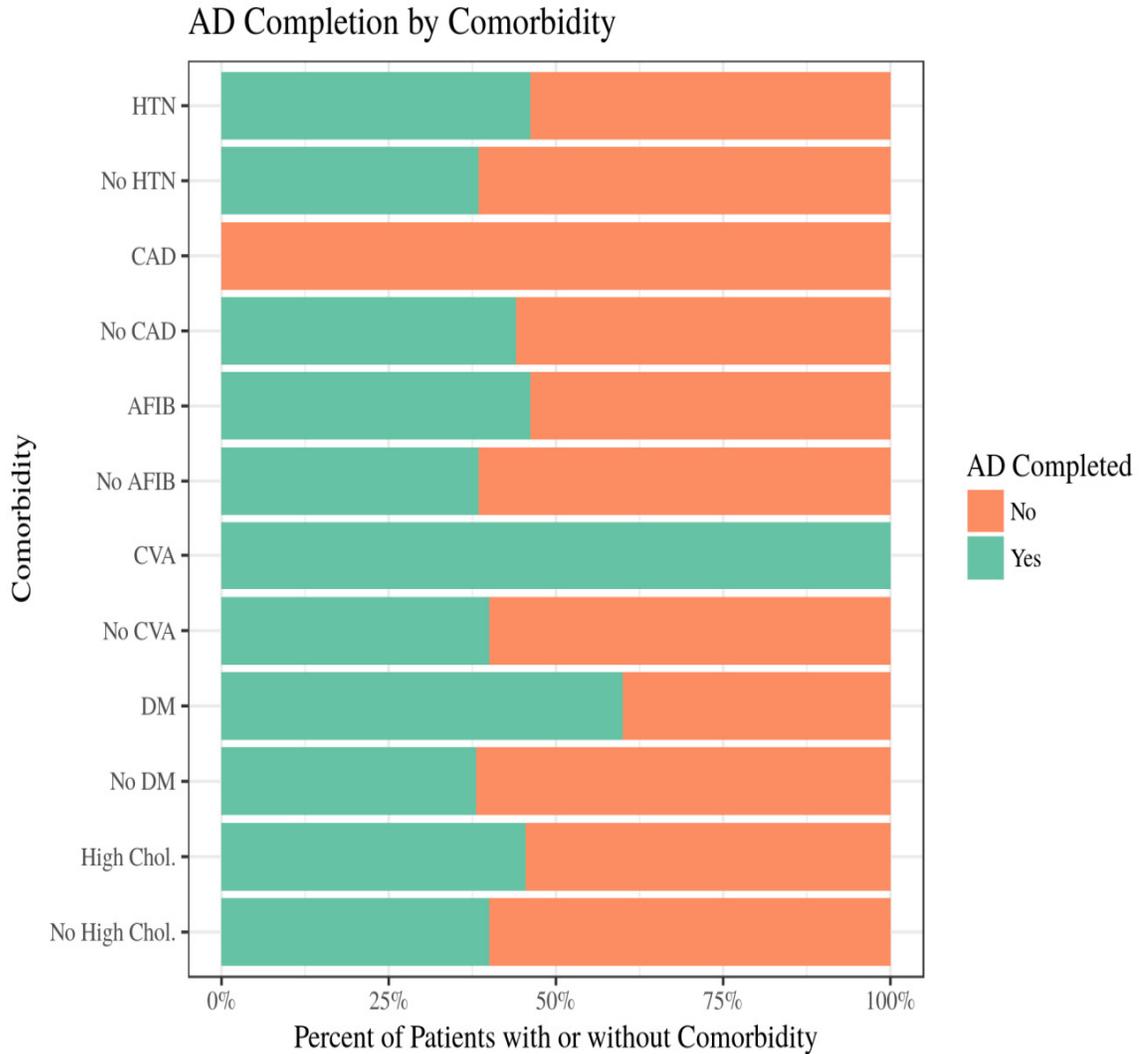


Figure 7: Plot showing the percent of intervention participants who reported having an AD, within those with and without each comorbidity. Note that each participant is counted six times on this plot because each individual either has or does not have each comorbidity. (Figure and caption from MSU SCRS report, adapted with permission.)

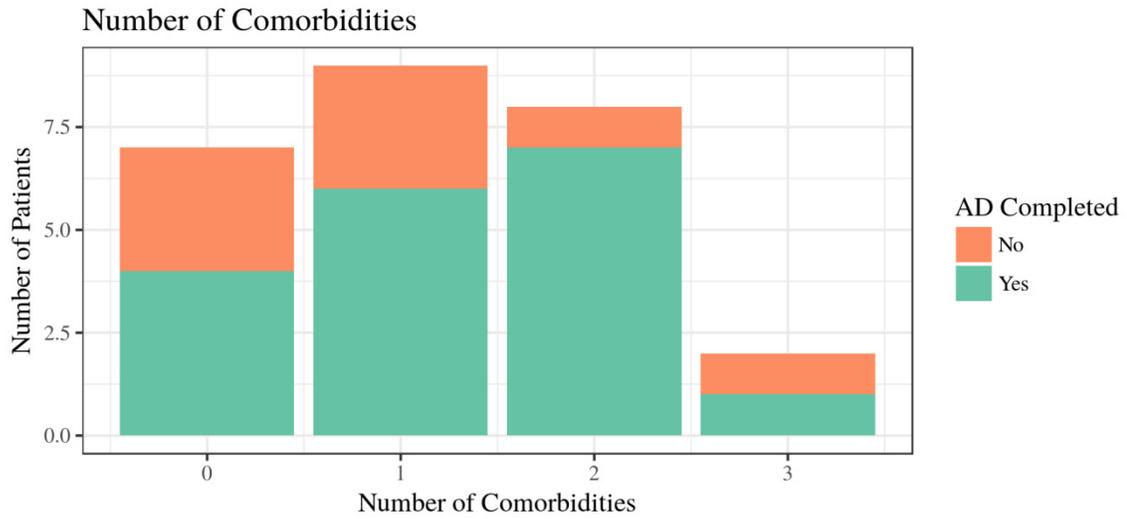


Figure 8: Plot showing the number of intervention participants with each number of comorbidities, colored by whether the individual reported having or not having a preexisting AD. (Figure and caption from MSU SCRS report, adapted with permission.)

ACP Intervention Checklist for Providers

The ACP intervention checklist for providers was completed 25 of the 26 appointments. Unfortunately, 15 of these checklists were separated from the surveys, so the provider and patient responses cannot be linked. It was found that providers reviewed AD basics in 96% (24 of the 25 conversations the checklist was completed) of the discussions. Five wishes and MEOLR were both reviewed in 80% (20 of the 25 conversations the checklist was completed) of the discussions. Documented reasons for not reviewing five wishes and MEOLR included patient was an advocate for aging with dignity which is the organization that promotes the five wishes document, lost interest after AD basics, and not a MT resident so the MEOLR did not pertain to these participants.

Medical Record Review

A total of 2,317 charts for 897 patients were reviewed. There were 862 visits by 473 patients during the pre-intervention period and 1,455 visits by 722 patients during the post-intervention period. A total of 298 patients were seen in the clinic during both pre and post intervention periods. The post intervention time period was found to have more visits by more patients, and a smaller proportion of patient had an AD in the post time period.

Reason for Visit

Of the 2,317 medical records reviewed during the data collection period, 11.65% (n=270) of total visits were for an AE, 6.91 % (n=160) for a medication review, and 81.44% (n= 1887) were for other reasons. During the pre-intervention period 14.27% (123 of the 862 pre intervention visits) visits were for an AE and 5.80% (50 of the 862 pre intervention visits) were for medication reviews compared to 10.10% (147 of the 1,455 post intervention visits) and 7.56% (110 of the 1,455 post intervention visits) respectively in the post intervention period. See figure 9.

Advance Directives

The majority, 81.72% (733 of the 897 patients), of patients from both time periods did not have an AD in their EMR. Of the overall patient population, 395 patients had multiple visits and did not have an AD at their first visit, 4.56 % (18 of the 395 patients) of these patients had an AD in their EMR at their last visit during the data collection

period. Two of these were intervention participants, one with an AD in their EMR prior to the intervention and one during the intervention.

Of patients seen in the pre intervention period, 127 had multiple visits and did not have an AD their first visit, but 4.72% (6 of the 127 patients) of these patients had an AD by their last visit in the pre intervention period. During the post intervention time period 260 patients had multiple visits and did not have an AD at their first visit during this period, however 2.31% (6 of the 260 patients) of these patients had an AD by their last visit in this time period. The remaining 6 patients had no AD at their last or only visit in the pre intervention period but had an AD at their first or only post intervention visit.

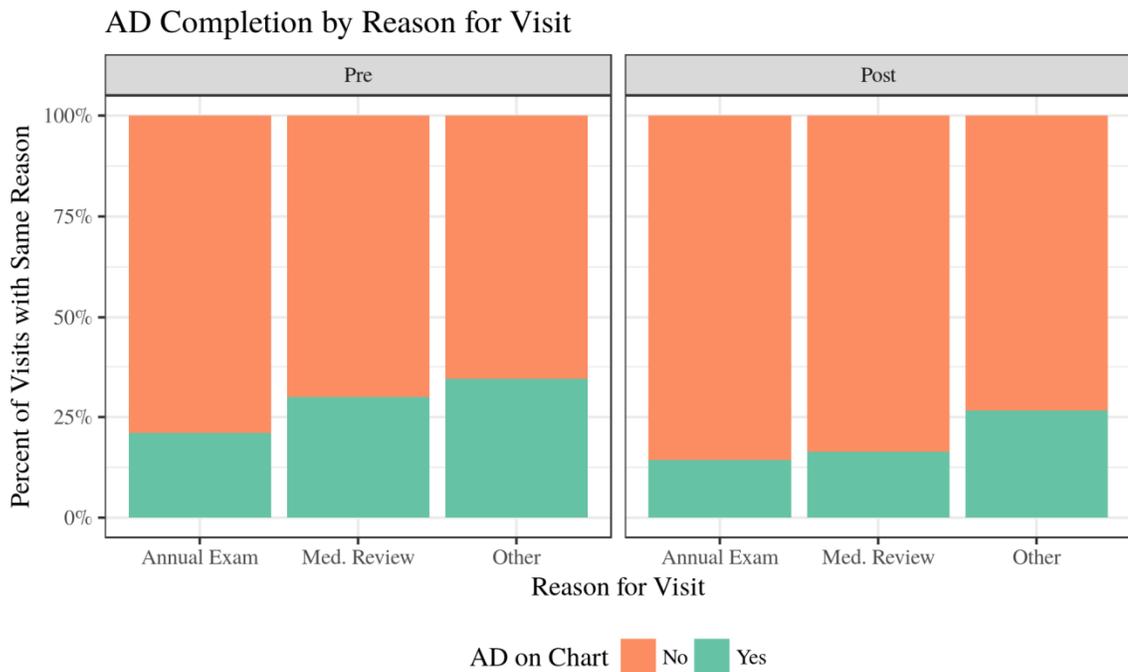


Figure 9: Plot showing the percent of visits where an AD was charted within all visits for the same reason in the same time period. (Figure 29 and caption from MSU SCRS report, adapted with permission.)

Of these 18 patients, 50% (9 of the 18 patients) of the ADs appeared in the EMR during the intervention period. It was confirmed that 22.22% (2 of the 9 ADs that appeared during the intervention period) of them were following a conversation with a provider; however, neither of these were intervention participants; 33.3% (3 of the 9 ADs that appeared during the intervention period) appeared in the EMR during a hospitalization and were all POLST forms and 44.44% (4 of the 9 ADs that appeared during the intervention period) were unable to be linked to either and one of these were an intervention participant.

In the overall population, of the 18.28% (164 of the 897 patients) of patients that did have a documented AD, the majority (67.68%, 111 of the 164 patients with an AD) had a POLST, 23.78% (39 of the 164 patients with an AD) had a LW; 5.49% (9 of the 164 patients with an AD) had a DPAHC, and 3.05% (5 of the 164 patients with an AD) had five wishes in their EMR. After examining the proportion of each type of AD between pre and post intervention time periods, there were minimal differences identified. See figure 10.

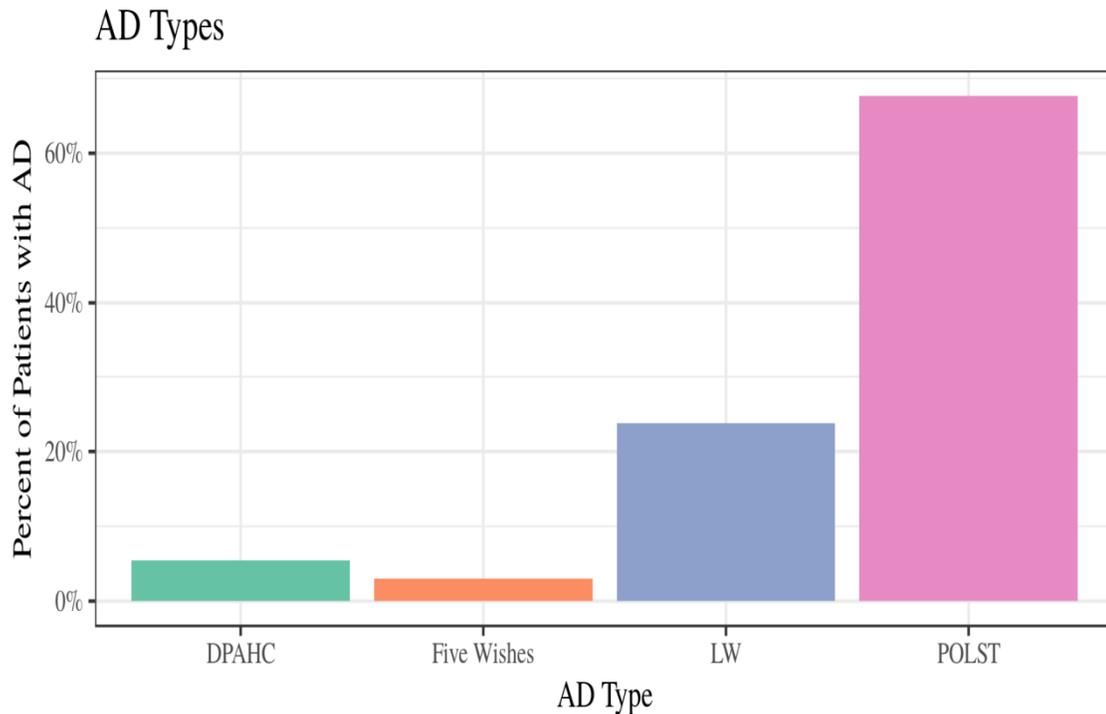


Figure 10: Plot showing the percent of patients with each type of AD charted, within patients who had any type of AD charted at any time during data collection. (Figure 20 and caption from MSU SCRS report, adapted with permission.)

Age and Visits

The majority 65.55% (588 of the 897 patients) of the overall patient population was between the ages of 65-75, 25.08% (225 of the 897 patients) was 76-85, and 9.36% (84 of the 897 patients) >85. Of those aged 65-75, 11.73% (69 of the 588 patients) had an AD, of those aged 76-85, 23.56% (53 of the 225 patients) had an AD, and 50% (42 of the 84 patients) of those >85 had an AD. When comparing the pre and post intervention time periods there was judged to be no significant difference in the proportion of patients aged 65-75. The post intervention period had slightly more 27.15% (196 of the 722 patients) patients compared to 23.26% (110 of the 473 patients) age 76-85, but the pre intervention

had more 12.05% (57 of the 473 patients) patients >85 compared to 9.42% (68 of the 722 patients). See figure 11.

Visits were evaluated by whether a patient had 1, 2 and > 2 clinic visits during the data collection period. Of the overall patient population, 44.26% (397 of the 897 patients) of patients had 1 visit. Of these, 10.33% (41 of the 397 patients with 1 visit) had an AD; 21.74% (195 of 897 patients) had 2 visit, of these 16.41% (32 of the 195 patients with 2 visits) had an AD; 34% (305 of the 897 patients) had >2visits; of these, 29.84 % (91 of the 305 patients with >2 visits) had an AD. A similar relationship between number of visits and having an AD were identified in both time periods. See figures 12 and 13.

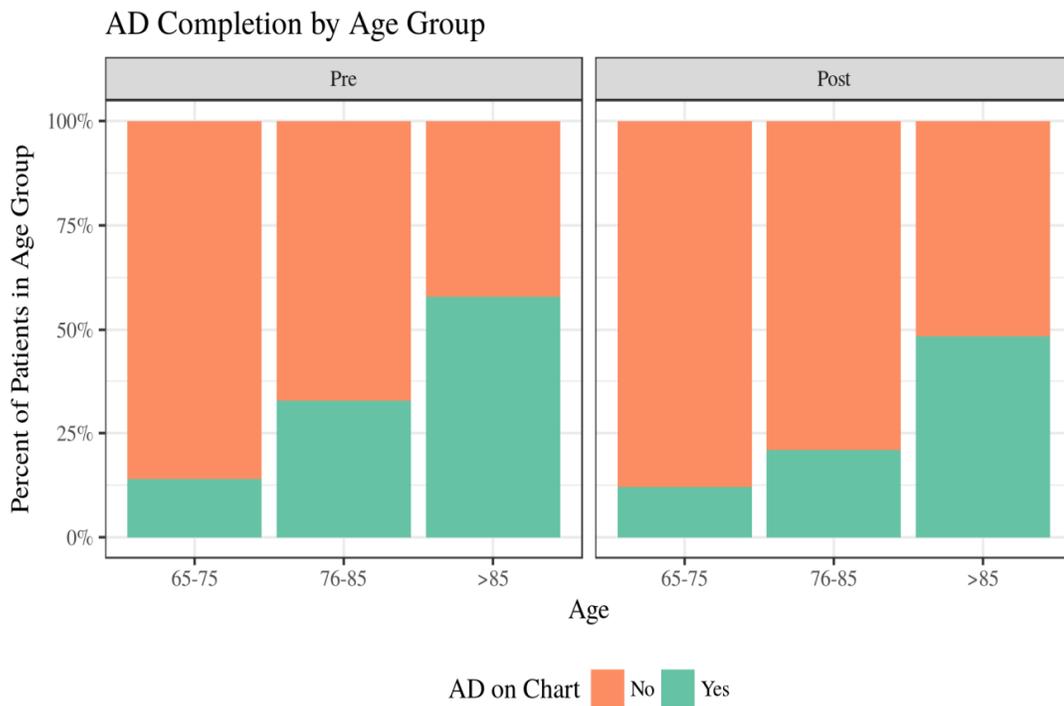


Figure 11: Percent of patients with an AD within all patients in each age group seen in each time period. (Figure 33 and caption from MSU SCRS report, adapted with permission.)

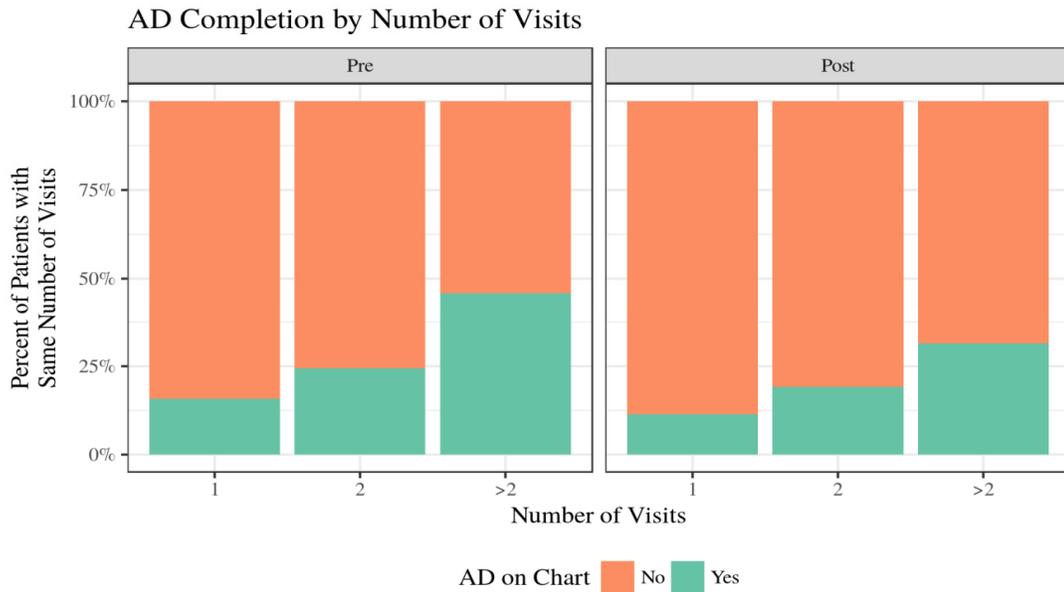


Figure 12: Percent of patients with ADs versus the number of times the patient visited in each time period. (Figure 35 and caption from MSU SCRS report, adapted with permission.)

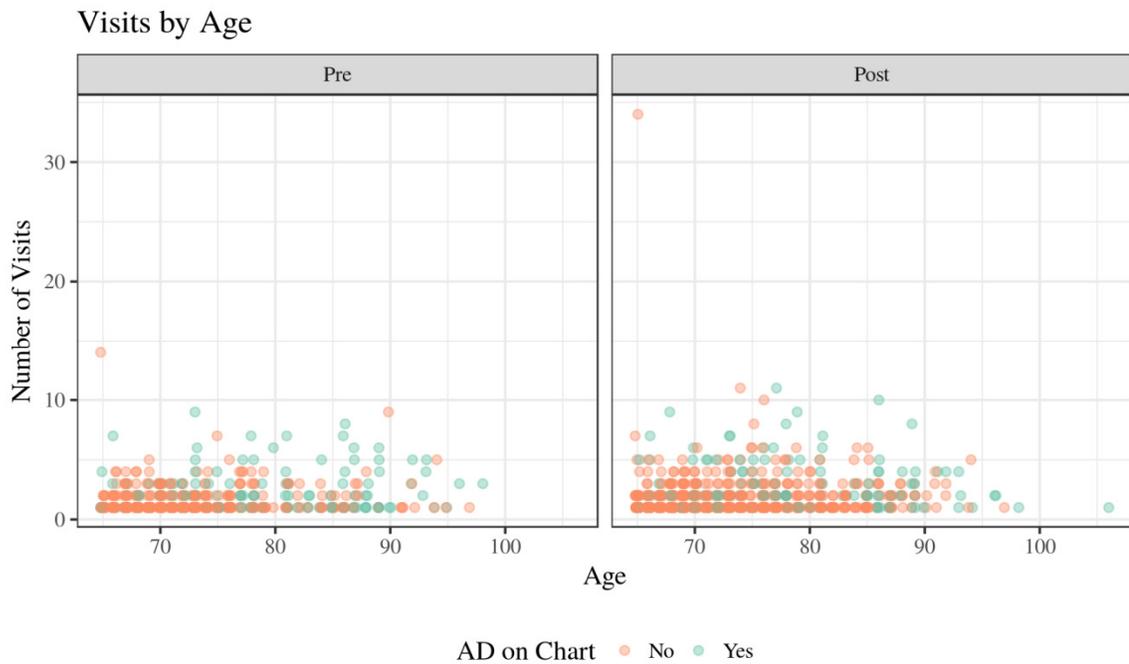


Figure 13: Number of visits by patient age, for each period separately. (Figure 36 and caption from MSU SCRS report, adapted with permission.)

Gender

The majority 51.73% (n=464) the overall patient population were males and 48.27% (n=433) female. There was a higher prevalence of females 21.48% (93 of the 433 females) with ADs when compared to males 15.30% (71 of the 464 males). The majority of the pre intervention period were males 51.37% (243 of the 473 patients) and the majority of the post intervention period were females 50.69% (366 of the 722 patients). Females were found to have more ADs in both time periods. See figure 14.



Figure 14: Distribution of the gender of all patients seen in each time period, colored by AD completion. (Figure 30 and caption from MSU SCRS report, adapted with permission.)

Code Status

In the overall patient population, a DNR was found in 6.35% (57 of the 733 patients with DNR or No code status documented) of the EMRs. Of those, only 8.77% (5 of the 57 patients with a DNR) did not have AD also documented in their EMR. There was no significant difference found in this between time periods. See figure 15.

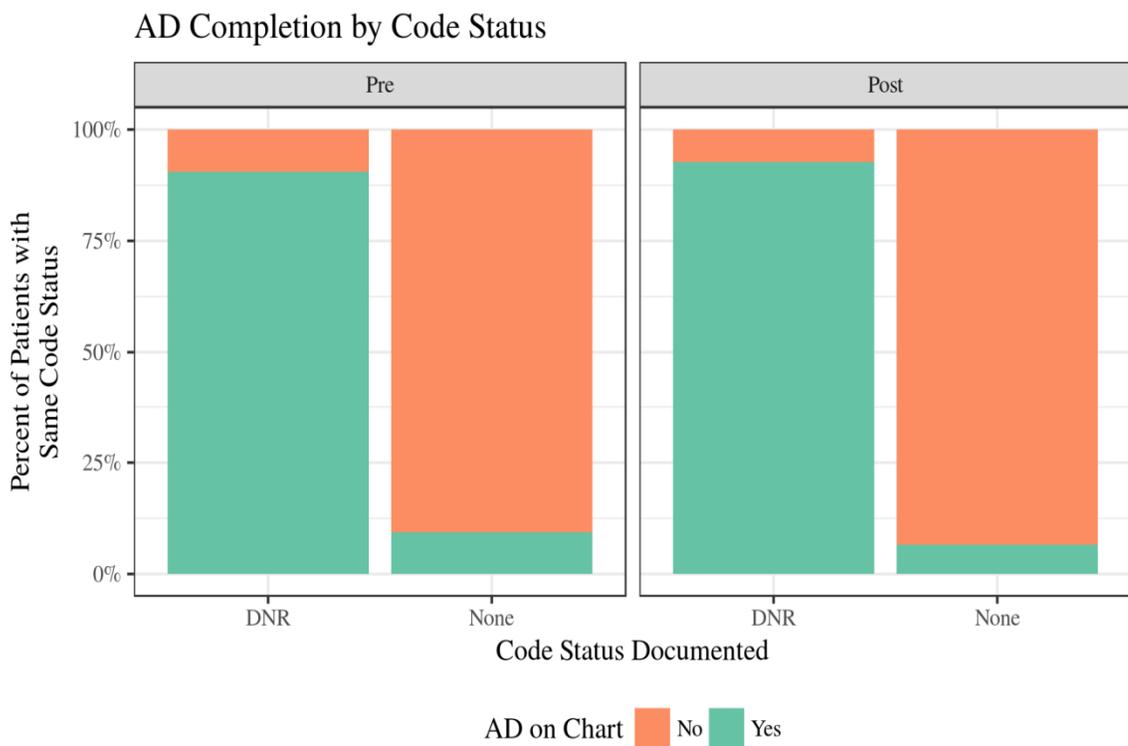


Figure 15: Plot showing the percent of patients with and without advance directives in each time period, within all patients seen in each time period who had a DNR on file and who never had a code status recorded. (Figure 40 and caption from MSU SCRS report, adapted with permission.)

Provider Type

It was found that in the overall population as well as in comparing pre and post intervention periods MDs saw slightly more patients with ADs than PAs with the exception of the pre intervention period where PAs were found to have seen slightly more patients with ADs than MDs. The scope of this project did not include identifying which provider type actually initiated the ACP discussion if any that led to the completion of these ADs. For future studies it would be helpful to identify which providers are actually having ACP discussions that led to the completion of an AD. See figure 16.

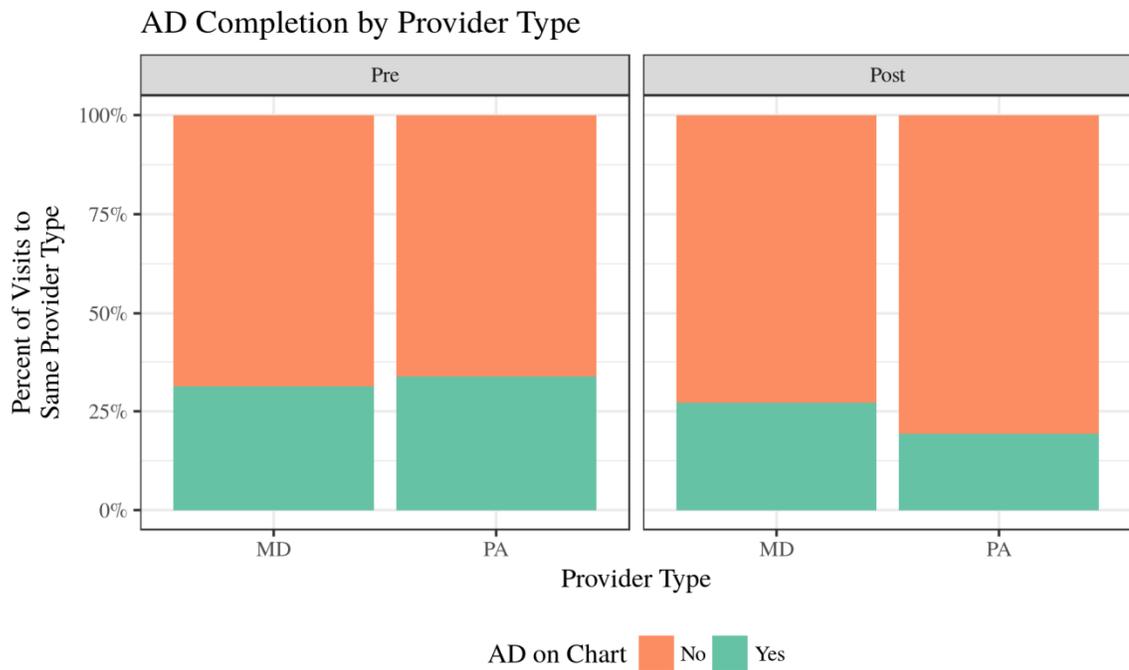


Figure 16: Plot showing the percent of visits where an AD was charted within all visits to each provider type in each time period. (Figure 42 and caption from MSU SCRS report, adapted with permission.)

Comorbidities

In the overall patient population, as well as pre and post intervention time periods the most prevalent comorbidities were HTN, Afib, and high cholesterol. It was found in the overall population and both time periods that patients with a specific comorbidity were slightly more likely to have an AD than if they did not have that specific comorbidity. The two comorbidities found to have the most significant impact on AD completion were HF and CVA. In all periods it was found that approximately 60-70% of patients with HF had an AD as well as approximately 65-75% of those who had suffered a CVA had an AD. See figure 17.

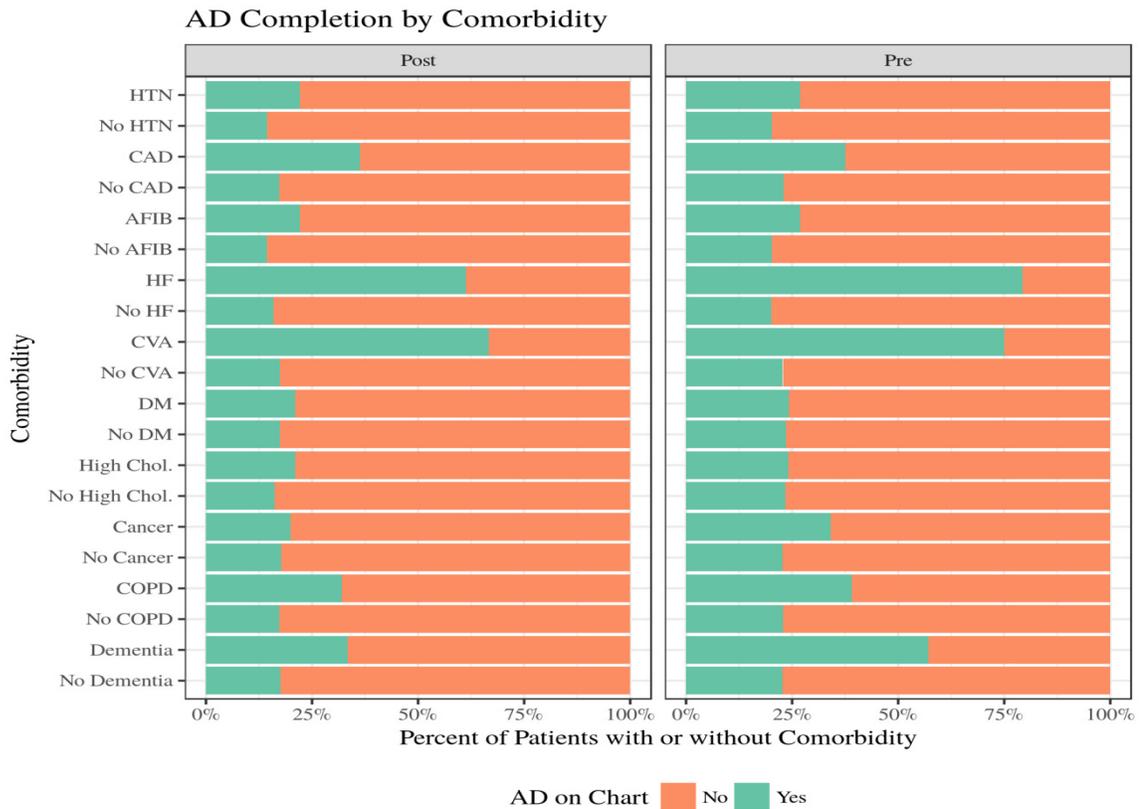


Figure 17: Plot showing the percent of patients who ever had an AD charted within all patients with and without each comorbidity seen in each time period. (Figure 39 and caption from MSU SCRS report, adapted with permission.)

Logistic Regression

Logistic regression was used to compare the patients seen for an AE during the pre-intervention time period to those seen for an AE in the post intervention time period while controlling for age group, number of visits, number of comorbidities, time period, gender, documented code status and provider type. The eight patients had 2 AE charts; these were omitted from the data analysis as they were most likely data entry errors. A total of 254 patients were included in the analysis: 115 with AEs in the pre intervention period and 139 with AEs in the post intervention period. The final analysis did not find any interactions between time period and other predictors, and the analysis of deviance shows no evidence (p-value=0.7327) that the odds of having an AD differ between the two time periods (table 1). However, it did show evidence of an interaction between age and number of comorbidities specifically in the age group > 85. See table 1, figures 18 and 19.

Table 1: Estimated logistic regression coefficients, standard errors, odds ratios, and 95% confidence intervals for the odds ratios. The odds ratio for categorical variables are the relative to the baseline level of each variable (marked with an asterisk). The odds ratios reported for the number of visits and the number of comorbidities are, respectively, the multiplicative effect of one additional visit and one additional comorbidity on the odds of having an AD. (Table 53 and caption from SRCS report, adapted with permission.)

	Estimate	Std. Error	OR	OR 95% CI
Age 65-75*				
Age 76-85	1.2445	0.8866	3.4713	0.6107 to 19.7311
Age >85	0.3579	1.8328	1.4303	0.0394 to 51.9442
Number of Visits	0.0550	0.1729	1.0565	0.7529 to 1.4826
Number of Comorbidities	-0.5751	0.3608	0.5626	0.2774 to 1.1411
Period Pre-Intervention*				
Period Post-Intervention	-0.1518	0.4439	0.5626	0.3599 to 2.0507
Gender Female*				
Gender Male	-0.0110	0.4346	0.9890	0.4220 to 2.3180
Code Status None*				
Code Status DNR	4.9892	1.5624	146.8168	6.8684 to 3138.3320
Code Status F	2.0717	0.4399	7.9386	3.3518 to 18.8025
Provider Type MD*				
Provider Type PA	2.0717	0.6374	1.1039	0.3165 to 3.8505
Age 65-75, Number of Visits*				
Age 76-85, Number of Visits	-0.4059	0.2627	0.6664	0.3982 to 1.1151
Age >85, Number of Visits	-0.8678	0.5955	0.4199	0.1307 to 1.3490
Age 65-75, Number of Comorbidities*				
Age 76-85, Number of Comorbidities	0.3135	0.4436	1.3682	0.5735 to 3.2640
Age >85, Number of Comorbidities	1.9503	0.8539	7.0308	1.3188 to 37.4821
Number of Visits, Number of Comorbidities	0.1258	0.0813	1.1340	0.9669 to 1.3300

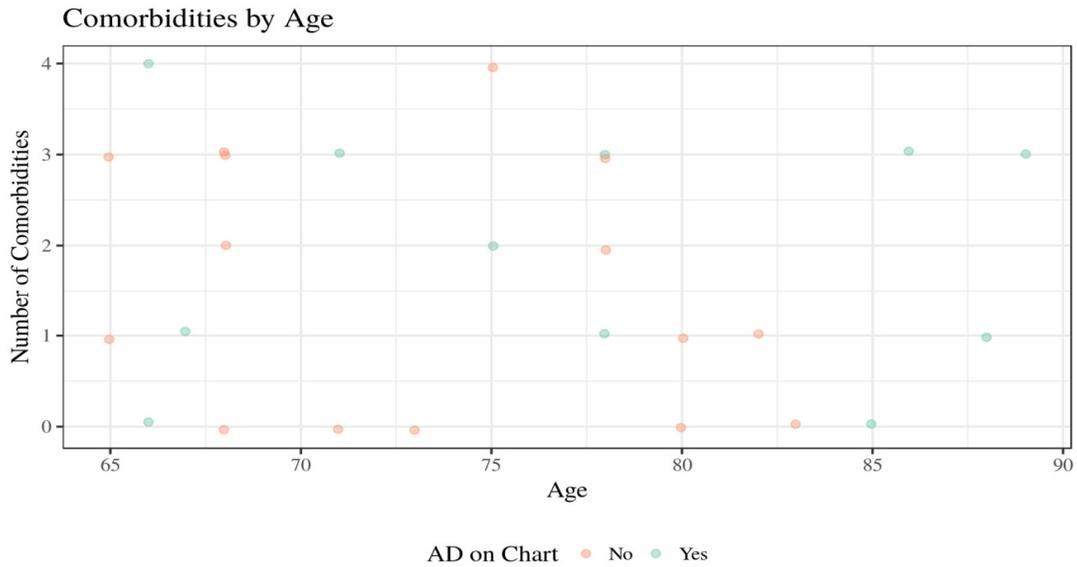


Figure 18: Plot of number of comorbidities by patient age and colored by AD status, for all intervention participants. The points are semitransparent and jittered slightly so that overlapping points are more visible. (Figure 8 and caption from SRCS report, adapted with permission.)

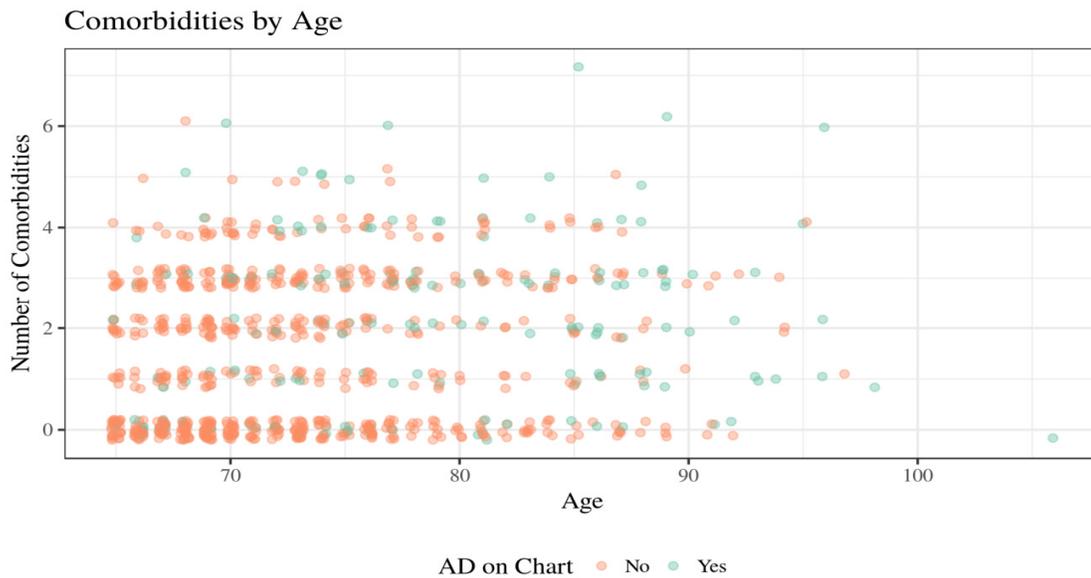


Figure 19: Plot of number of comorbidities by patient age and colored by AD status, for all patients. The points are semitransparent and jittered slightly so that overlapping points are more visible. (Figure 23 and caption from SRCS report, adapted with permission.)

DISCUSSION

Intervention

While only 34.62% (9 of the 26 participants) rated the overall effectiveness of the intervention, 71.42% (15 of the 21 participants) felt equipped with enough information to start the process of discussing wishes and completing ADs. Those that reported no AD, 25% (2 of the 8 participants) were interested in completing an AD following the intervention and 62.50% (5 of the 8 participants) were undecided. The fact that the majority of those without an AD were undecided after the intervention may suggest a lack of information, or unanswered questions. Additional time during a patient visit to discuss ACP may be needed to address both of these concerns as lack of time is recognized as one of the most common barriers to ACP conversations (Ramsaroop et al., 2007). It is important to consider that the initial intent of the project was to have these conversations at AEs which would have potentially allowed for additional time and reimbursement if ACP codes were utilized correctly.

Most participants, 65.38% (17 of the 26 intervention participants), had a good understanding of ADs prior to the intervention. In regards to EOL wishes and the desire or lack thereof to discuss these wishes with others following the intervention, 28.57% (2 of the 7 participants), of those without an AD responded yes and all participants who reported an AD responded no. These findings indicate that the intervention may have been more beneficial to those who reported no AD in comparison to those that had an AD. Therefore, one might be tempted to exclude those with an AD from future

interventions; however, having a completed AD is only one aspect of ACP. The intervention addressed other important aspects of ACP including importance of discussing EOL wishes with others and making them accessible.

The majority, 69.23% (18 of the 26 participants), of intervention participants reported having a completed AD. However, more than half, 55.56% (10 of the 18 participants with an AD), of reported ADs were not available in the EMR. These findings suggest that AD accessibility may be a bigger issue than completion of ADs. Further, 37.50% (3 of the 8 participants) of those that reported no AD were found to have one in their EMR by the end of the data collection period. While the explanation for these 3 ADs that became available in EMR could have been in part due to the intervention, instead, it was determined that these participants all had a POLST in their EMR following a hospitalization. In fact, it was found that the majority of POLST forms found in the EMR were following hospitalizations. Further, no intervention participants reported having a POLST form and all 3 of these patients had the form in their EMR in pre and post intervention visits indicating that the intervention had no effect on the completion of these forms.

The fact that POLST forms were in their medical record, but patients were unaware of their existence is concerning. While it is important to complete a POLST during a hospital admission, it should be recognized that it is for that admission only and should be updated with any change of condition and that it should not replace an AD. The majority of patients with an AD in their EMR only have a POLST. However, an admission to the hospital is not an ideal place to discuss EOL care preferences for the

first time (Maxfield et al., 2015). These findings support the need for additional patient and provider education on ADs, POLST, and ACP.

It was found that 76.92% (20 of the 26 participants) had not discussed EOL preferences with their doctors, and 27% (7 of the 26 participants) of participants had not discussed them with family and loved ones. These findings indicate some improvement compared to a study by Salmond and David (2005) who reported “95% (n=76) never had any discussions with their physicians’ regarding EOL care and more than half of the participants, 51% (n=41), never had any EOL discussions with their families.” (p. 124).

Medical Record Review

The purpose of the MRR was to compare proportions of AD in pre and post intervention time periods. Overall, 81.72% (733 of the 897 patients) of the patient population did not have an AD in their EMR. Of those that did, 67.68% (111 of the 164 completed ADs) had a POLST. In the overall patient population, a DNR was found in only 6.35% (57 of the 897 patients) of the EMRs. However, only 8.77% (5 of the 57 patients with a DNR) of these did not have an AD also documented in their EMR indicating that in general, patients with a DNR also had an AD.

The MRR revealed a smaller proportion of patients who had an AD in their EMR during the post intervention period, confirming that the intervention did not have the intended effect on the proportion of ADs in the EMR. Unfortunately, these findings are not consistent with literature supporting this type of ACP intervention in increasing the completion of ADs (Alano et al., 2010; Ramsaroop et al., 2007; Weathers et al., 2016).

Although there is no one intervention alike, the length of the interventions ranged from 1-24 months long with the average follow up being done at 3 and 6 months' post intervention (Alano et al., 2010; Ramsaroop et al., 2007; Weathers et al., 2016).

However, it is important to consider that there were more visits by more patients in the post intervention period. Additionally, 14.27% (123 of the 862 pre-intervention visits) of visits during the pre-intervention period were for AEs and 5.80% (50 of the 862 pre-intervention visits) medication reviews compared to 10.10% (147 of the 1,455 post intervention visits) AEs and 7.56% (110 of the 1,455 post intervention visits) medication reviews in the post intervention period. These findings should be considered in the explanation for the decrease in proportion of completed ADs as fewer patients in the post intervention period were seen for visits that are more appropriate to discuss ACP. The method of evaluation should also be considered in the explanation of these findings. Using the number of ADs in the EMR pre and post intervention as the primary outcome measure fails to differentiate between actual AD completion and accessibility to these documents. Therefore, the MRR was not the best tool to evaluate the effect the intervention had on completion of ADs.

Additionally, a post knowledge AD survey immediately following the intervention was not ideal. What would have been more effective in pinpointing a cause and effect would be to conduct a follow up survey over the phone a few months later. This follow up would not only confirm the number of ADS completed following the intervention, but additional information on the effectiveness of the intervention could have been collected as well. It would also allow the patient to ask further questions and

serve as an additional reminder to complete an AD. This was the original intent; however, due to time constraints it was not realistic, but should be considered in future studies.

The MRR revealed that 4.56% (18 of the 395 patients) of patients with multiple visits in both time periods who did not have an AD at their first visit had one at their last visit. Of these 18 patients, 50% (9 of the 18 patients) appeared during the intervention period. Only 22.22% (2 of the 9 ADs that appeared during the intervention period) was following an AD conversation with a provider confirmed in the provider's notes. Due to some of the challenges met in the implementation of the intervention, it was a possibility that providers were initiating the ACP discussion, but documentation was not completed. Further, 33.33% (3 of the 9 ADs that appeared during the intervention period) were completed during a hospitalization and 44.44% (4 of the 9 ADs that appeared during the intervention period) were unable to be connected to either a clinic visit or hospitalization as there was no documentation indicating an ACP discussion had taken place in the provider notes or a recent hospitalization.

This project found that among intervention participants 73.33% of females (11 of 15 females), were more likely than 63.64% (7 of the 11 males) of males, to have an AD. This trend was identified in pre and post time periods as well. This is consistent with a study by Douglas and Brown (2002) that found women were more likely than men to have completed ADs, however, Van Scoy et al. (2014) reported no difference in gender. Additionally, Van Scoy et al. (2014) found that health care utilization including visits to primary care and hospital admissions in a year had no impact on a whether or not a

patient had a health care proxy. However, in this project, as the number of visits increased so did the proportion of ADs for those that were seen for 1, 2 and >2 visits.

This project found that the likelihood of having an AD increased with age in both time periods. This is consistent with a study by Alano et al. (2010) in which the completion of ADs increased after the age of 75 to 35% and even more to 96% completion after the age of 85. Additionally, logistic regression showed evidence of an interaction between age and number of comorbidities specifically in the age group > 85. Van Scoy et al. (2014) also reported that older patients as well as those with more comorbidities were more likely to have a LW.

Hanson & Rodgeman (as cited by Salmond & David, 2005) found that patients with chronic illness, such as diabetes, liver disease, or heart disease, had completion rates below 10% in contrast with those with cancer, who had a completion rate of 16.4%. However, in all time periods it was found that patients with heart failure (HF) and a history of a cerebral vascular accident (CVA) were more likely to have an AD when compared to other conditions. Approximately 60-70% of patients with HF had an AD and approximately 65-75% of those who had suffered a CVA had an AD. In general, less than 40% of patients with other comorbidities had an AD. These findings indicate that having a specific comorbidity does not have an overwhelming effect on the completion of AD and having 1 and 2 comorbidities may have some effect on the completion of ADs; however, having >2 comorbidities showed less of an effect.

Of those with cancer, 20-35% had an AD in this project indicating minimal differences in those with cancer to those with other comorbidities. These findings are not

surprising being that in a cohort study investigating attitudes of hospitalized cancer patients toward ADs, it was found that only 5% of this population had already completed an AD and only 10% were interested in completing one after a one-on-one discussion with the study physician (Kierner, Hladschik-Kermer, Gartern, &Watzke, 2010).

Limitations

A number of limitations are identified with this project. First, due to a small sample size there is potential for sampling error. Having to rely on clinic staff to invite and inform eligible participants was not ideal. Although approved and supported by staff throughout its implementation, participant recruitment was not consistent throughout the study and greatly affected the sample size. Measures taken to address this problem throughout the implementation were further discussed in methods.

Second, the design and timing of the project evaluation limited the quality of study findings. As discussed above the results were affected by administering the post AD knowledge survey immediately following the provider- initiated ACP conversation versus a month or two later via phone. As well as utilizing the proportion of ADs found in the MRR as a primary outcome measure. Third, personal bias should be considered in the selection of articles for the literature review, development of the intervention and interpretation of data though measures were taken to minimize this.

Many aspects of this project contribute to its limited effectiveness and have the potential to affect its generalizability. However, the model and goals of this project can be generalized to any primary care setting if the setting is evaluated to tailor the

intervention to the specific setting. Despite limited measurable gains, and while ACP conversations may continue to be initiated at no specific time or interval, this project provided education to providers and may serve as a reminder to initiate ACP conversations in the future.

In addition, through discussion of the purpose and rationale for this project, a practice change involving standardizing the location of AD's in the EMR was implemented in the early planning phases of this project. This change will help increase accessibility to these documents. The clinic is also in the developing stages of an annual wellness visit program that will include some aspects of ACP. The results of this study will be presented to guide this and other future interventions.

CONCLUSION

The initiation of an ACP discussion in the primary care setting continues to be a challenge. There remain limited studies specifically, randomized control trials (RCT), on the effectiveness of ACP discussions in this setting. Considering a RCT design may be most beneficial when considering future studies. This would allow the effects of an ACP intervention to be evaluated more effectively through the comparison of differences in an intervention and control group.

Although unsuccessful in meeting its primary goal of increasing the proportion of ADs in the EMR, overall, this project was not without benefit. As a pilot project with a small sample size and limited prior literature, this project has provided a look into some of the challenges and potential solutions to successful implementation of an iterative model of ACP in the primary care setting. There were several unexpected challenges met through the implementation of this project. Changes to the project design made along the way, as well as the project findings have contributed to the current literature and provided opportunity for future studies.

This project not only proved to be informative for participants with and without ADs, it identified the need for future studies on accessibility of ADs. The findings of this project suggest that accessibility may be as big or a bigger issue than AD completion. However, further studies are needed to differentiate between completion and accessibility of ADs. This project also identified the need for additional staff and potentially more time to effectively initiate ACP discussions and provide the support needed to answer patient's questions and assist with completion of documents as needed.

Considering the utilization of aspects of the evidence based ACP respecting choices program may be helpful in addressing these limitations. The respecting choices program utilizes a trained designated facilitator to guide the patient, family and interdisciplinary team through an iterative model of ACP (Forlini & Goldberg, 2014). Having a designated facilitator could have the potential to provide increased consistency in the recruitment process as well as allow additional time to answer questions and assist patients with the completion of forms.

A need for additional patient, as well as provider, education was also recognized. Future education should include ACP, ADs, as well as the use of ACP codes to ensure reimbursement. In order to have better success with future educational seminars, some incentive to attend such as food may be beneficial. Also, the presence of a healthcare provider may also motivate more people to attend. Both should be included in the advertising of the educational seminars. This project provided education on the proper use of ACP codes and coordinated in house support for providers in their use if needed, however it was out of the scope of this project to track the use of such codes. Therefore, future studies on the appropriate use of ACP codes and how it affects the initiation of ACP and the completion of ADs would be beneficial.

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APPENDICES

APPENDIX A

ADVANCE CARE PLANNING INTERVENTION

CHECKLIST FOR PROVIDERS

Question	Response
Advance Directive completed	Yes____ No____
If yes, what document?	Yes____ No____
If yes, does the clinic have a copy?	Yes____ No____
Where is the copy in the EHR?	
Advance Directive Basics Reviewed	Yes____ No____
<ul style="list-style-type: none"> • What are they • Why it is important • Different types 	
Five Wishes Document Reviewed	Yes____ No____
Montana End of Life Registry Reviewed	Yes____ No____
Additional Notes/Comments:	

APPENDIX B

SURVEY QUESTIONS PRIOR TO MEDICARE

INITIAL OR ANNUAL EXAM

Participation is voluntary, you can choose to not answer any questions you do not want to answer and you can stop at any time.

Question One)	Possible Responses (Circle)
1. Have you discussed your health care wishes with family/loved ones in case you ever get seriously ill or injured and cannot communicate your wishes?	Yes/No
2. Have you discussed these wishes with your doctor?	Yes/ No
3. Are you familiar with with the Five wishes form?	Yes/Somewhat/NO
4. Do you feel that you understand the purpose of a healthcare directive, living will, and/or DPOA form? Yes/Somewhat/No	
5. Have you completed a POLST, Five wish form or other healthcare directive or DPOA form? If so, which one?	Yes/No
6. If you answered yes to question 5. Where do you keep the completed document?	

*****DOPA= durable power of attorney for health care*****

POLST: Physician Orders for Life-Sustaining Treatment a form that includes a patient's values, beliefs, and goals for care, and the healthcare provider presents the patient's diagnosis, prognosis, and treatment alternatives, including the benefits and burdens of life-sustaining treatment.

Five Wishes is an advance directive or living will. It is a form that lets your loved ones know your health care choices if you are too sick to make them yourself.

Adapted from "Evaluation of Advance Directives Video Education for Patients," by C.Toraya, 2014, *Journal of Palliative Medicine*, 17, 8, p.942-946. Copyright 2014 by Mary Ann Liebert, Inc.

APPENDIX C

SURVEY QUESTIONS POST MEDICARE ANNUAL EXAM

Participation is voluntary, you can choose to not answer any questions you do not want to answer and you can stop at any time.

Question (Circle one)	Possible Responses
1. Did the discussion with your healthcare provider during your Medicare initial or annual exam change anything about your future health care wishes or about discussing your wishes with your family/loved ones and your doctor?	Yes/No Comments:
2. Did you attend an Advance Directive educational session provided free in your community?	Yes/No
3. If you answered yes to question 2. Do you plan to complete a POLST, Five wishes or other healthcare directive form because of the educational session? If so, which document?	Yes/No/Undecided
4. Do you plan to complete a POLST, Five wishes or other healthcare directive form because of the discussion with your health care provider during your Medicare initial or annual exam? If so, which document?	Yes/No/ Undecided
5. Do you feel that you have enough information to start the process of discussing your wishes and completing forms? If not, what additional information would be helpful?	Yes/ No
6. How helpful was the discussion with your healthcare provider?	Rank 1-10 (See scale Comments:

7. How helpful was the educational session if attended?

Rank 1-10

Comments:

***** Ranking scale*****1=not helpful, 10= extremely helpful.

POLST: Physician Orders for Life-Sustaining Treatment a form that includes a patient's values, beliefs, and goals for care, and the healthcare provider presents the patient's diagnosis, prognosis, and treatment alternatives, including the benefits and burdens of life-sustaining treatment.

Five Wishes is an advance directive or living will. It is a form that lets your loved ones know your health care choices if you are too sick to make them yourself.

Adapted from "Evaluation of Advance Directives Video Education for Patients," by C.Toraya, 2014, *Journal of Palliative Medicine*, 17, 8, p.942-946. Copyright 2014 by Mary Ann Liebert, Inc.

APPENDIX D

IRB APPROVAL AND CONSENT FORM



INSTITUTIONAL REVIEW BOARD
For the Protection of Human Subjects
FWA 00000165

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 Montana State University
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MEMORANDUM

TO: Christine Fanelli and Jennifer Sofie

FROM: Mark Quinn *Mark Quinn CJ*
 Chair, Institutional Review Board for the Protection of Human Subjects

DATE: January 21, 2016

SUBJECT: "Respecting End of Life Wishes: Development and Implementation of an Evidence Based Intervention to Increase the Completion of Advance Directives" [CF012116]

The above proposal was reviewed by expedited review by the Institutional Review Board. This proposal is now approved for a period of one-year.

Please keep track of the number of subjects who participate in the study and of any unexpected or adverse consequences of the research. If there are any adverse consequences, please report them to the committee as soon as possible. If there are serious adverse consequences, please suspend the research until the situation has been reviewed by the Institutional Review Board.

Any changes in the human subjects' aspects of the research should be approved by the committee before they are implemented.

It is the investigator's responsibility to inform subjects about the risks and benefits of the research. Although the subject's signing of the consent form, documents this process, you, as the investigator should be sure that the subject understands it. Please remember that subjects should receive a copy of the consent form and that you should keep a signed copy for your records.

In one year, you will be sent a questionnaire asking for information about the progress of the research. The information that you provide will be used to determine whether the committee will give continuing approval for another year. If the research is still in progress in 3 years, a complete new application will be required.

SUBJECT CONSENT FORM FOR PARTICIPATION IN HUMAN RESEARCH AT MONTANA STATE UNIVERSITY

Respecting End of Life Wishes: Development and Implementation of an Evidence Based Intervention to Increase the Completion of Advance Directives.

Purpose

You are being asked to be part of a study. The goal is to increase the number of Advance Directives completed. The purpose is to respect one's end of life wishes. The study includes all Medicare patients 65 years and older who are being seen for their Medicare initial or annual exam.

Procedure

If you agree to be part of the study you will be asked to complete a survey prior to your doctor's visit. Your healthcare provider will talk about the completion of an Advance Directive. This will include the purpose of such a document, your options, and help in its completion as needed. You will then complete a survey after your visit. **Participation is voluntary. You can choose to not answer any questions you do not want to answer and/or you can stop at anytime.**

Risks

Talking about end of life wishes and Advance Directives can be hard. This is a conversation that your healthcare provider will have with you at some point. It will take place at this visit as part of the study. There are no risks other than the time spent filling out each survey and taking part in what can be an uncomfortable conversation for some people.

Benefits

The benefits of the study include a chance to have questions you may have answered. Assistance with the completion of an Advance Directive, and your end life wishes known.

Funding

There is no cost involved in this study or cost to the subjects.

Confidentiality

Your records will be treated with professional standards of confidentiality. Medical records will be reviewed to find the number of Medicare patients with completed Advance Directives. There will be no identifying personal information collected for this study. If you have questions about the study, you can call Christine Fanelli at 720-202-8763. If you have additional questions about the rights of human subjects you can contact the Chair of the Institutional Review Board, Mark Quinn, (406) 994-4707 [mquinn@montana.edu].

APPROVED

AUTHORIZATION: I have read the above and understand the discomforts, inconvenience and risk of this study. I, _____ (*name of subject*), agree to participate in this research. I also agree that my health information can be collected and used by the researchers and staff for the research study described in this consent form. I understand that I may later refuse to participate and that I may withdraw from the study at any time. I have received a copy of this consent form for my own records.

Signed: _____

Investigator: _____

Date: _____

APPENDIX E

LITERATURE REVIEW MATRIX

Literature Review Matrix

Citation	Design/ Methods	Sample/Setting	Measurement/ Tools	Results	Rationale	Pertinent Outcomes/ comments	LOE
Ahluwalia, S.C., Bekelman, D.B., Huynh, A.K., Prendergast, T. J., Shreve, S., & Lorenz, K.A. (2015). Barriers and strategies to an iterative model of advance care planning communication. <i>American Journal of Hospice & Palliative Medicine</i> , 32, 817-823.	Interview: 2 focus groups, 3 semi structured interviews	20 providers at large VA Medical Center.	None	Barriers include: variation among providers, in approaches to ACP, lack of useful information about patient values, ineffective communication. Promoted increased role of PCP, Conclusion: Increased communication among providers, utilize EHR. Link pt experience to their values.	Characterize barriers and strategies for realizing an iterative model of ACP patient-provider communication		VI
Alano, G.J, Pekmezaris, R., Tai, J.Y., Hussain, H.J., Jeune, J., Louis, B, El-Kass, G., Ashraf, M.S., Reddy, R., Lesser, M., & Wolf-Klein, G.P. (2010). Factors influencing older adults to complete advance directives. <i>Palliative and Supportive Care</i> , 8, 267-275	Direct interviews	200 subjects Hospitalized and community dwelling cognitively intact patients 65years and older in NY.		63% had completed ADs. Increased completion with age 35% 75y, 96% by 85 years old. HCP play major role in improving AD completion rate, by approaching them, about ADs,explaining importance of ADs, and asking them to complete ADS.	Determine factors which influence AD completion among older adults		VI

<p>Allen, J. Y., Hilgeman, M. M., & Allen, R. S. (2010). Prospective end-of-life treatment decisions and perceived vulnerability: Future time left to live and memory self-efficacy. <i>Aging & Mental Health, 15</i>(1), 122-131. doi: 10.1080/13607863.2010.50522</p>	<p>Cross-sectional Interview-style in one of six randomly assigned counterbalanced orders using response cards to facilitate participant understanding.</p>	<p>81 older adults recruited from single family dwellings, two assisted living facilities, and one senior citizen center.</p>	<p>Sociodemographic, physical health, cognitive status, and depression: Depression Subjective health Cognitive assessment Depressive symptomatology PRECEPTIONS : Future time perspective Memory self-efficacy</p>	<p>Participants with more perspective of future time, less perceived change in memory, greater perceived memory capacity and more depressive symptoms, as well as African Americans desired treatment more often.</p>	<p>Hypothetical preferences about treatment decisions may not be a great depiction of real world situation. Small study sample using convenience sampling. Previous experience with life sustaining treatment was not evaluated in this study.</p>	<p>These are factors that can affect a person's end of life decisions and wishes. It is thought identifying perceptions related to end-of-life treatment preference might improve interventions that facilitate quality care through patient autonomy.</p>	<p>VI</p>
<p>Barnes, K., Jones, L., Tookman, A. & King, M. (2007). Acceptability of an advance care planning interview schedule: a focus group study <i>Palliative Medicine, 21</i>, 23-28.</p>	<p>Interviews in focus groups Purposive sampling to obtain balanced sample</p>	<p>22 oncology patients, user group members and relatives.</p>	<p>Tape recordings of focus groups transcribed verbatim. Thinking about issues, Timing of advance care planning, Recognizing individuality, person conducting conversation</p>	<p>Most felt that these issues should be discussed on more than one occasion. For some, initiating these discussion prompted them to discuss their wishes with family</p>	<p>Explore acceptability of an interview schedule</p>		<p>VI</p>

<p>Bergman-Evans, B., Kuhnel, L., McNitt, D., Myers, S. (2008). Uncovering beliefs and barriers: Staff attitudes related to advance directives. <i>American Journal of Hospice & Palliative Medicine</i>, 25 (5), 347-353.</p>	<p>Surveys handed out at weekly meetings.</p>	<p>650 surveys 412 completed 63.3% Jan to March 2007.</p>	<p>Brief Survey about staff attitudes related to advance directives.</p>	<p>50% said annual exam good time to talk about AD and admission to hospital. 40% of AD were not found on chart.</p>	<p>Explore the health care professionals and staff perceptions of usefulness and barriers to advance directives across the care continuum.</p>		<p>VI</p>
<p>Bischoff, K.E., Sudore, R., Miao, Y., Boscardin, W.J., & Smith, A.K. (2013) Advance care planning and the quality of end of life care in older adults. <i>Journal of American Geriatric Society</i>, 61, 209-214.</p>	<p>Exit interviews At death of HRS respondents exit interview with HC proxies within 24 months of death.</p>	<p>43394HRS respondents who were Medicare beneficiaries and died btwn 1993 and 2007. The nationally representative HRS.</p>	<p>Hospital admission in the last month, in hospital death, more than 14 days in the hospital during the last month of life, ICU admission in the last month, more than one ER visit, hospice admission and length.</p>	<p>Most older adults take part in ACP multiple years before death, increased after 1997, DPOA more common. ACP is associated with a lower rate of in hospital death and greater hospice use.</p>	<p>Determine whether advance care planning influences quality of end of life care</p>	<p>Large sample size. ACP associated with less in-hospital deaths and greater use of hospice.</p>	<p>VI</p>

<p>Booth, M., Nash, S., Banks, C. & Springett, A. (2014). Three approaches to delivering end-of-life education to care homes in a region of south east England. <i>International Journal of Palliative Nursing</i>, 20,(1).</p>	<p>Discussion of the implementation of three different educational programs surrounding end of life care.</p>	<p>Three different end of life care initiatives to 383 care homes over 3 year period.</p>	<p>Action learning project A six step to success care home program. A Gold Standards Framework for Care home program.</p>	<p>This review did not provide solid evidence as to which program was most effective, but stimulated conversation on the pros and cons of current end of life education.</p>	<p>This article discussed pros and cons to these education programs after they were initiated limiting the value of information provided.</p>	<p>This introduces 3 potential educational programs that may be effective in improving end of life knowledge. However, more research around these initiatives is needed to prove their efficacy.</p>	<p>VII</p>
<p>Bravo, G., Dubois, M, Wagneur, B. (2008). Assessing the effectiveness of interventions to promote advance directives among older adults: A systematic review and multi-level analysis. <i>Social Science & Medicine</i>, 67, 1122-1132. doi: 10.1016j.socscimed.2008.06.006.</p>	<p>Systematic review</p>	<p>1985-2005 55 studies</p>	<p>Multilevel analysis, meta-analysis approaches.</p>	<p>Providing oral and written information on AD, assistance with completion, over multiple visits leads increased completion</p>	<p>What intervention works best and in whom in promoting ADs</p>		<p>V</p>

Brazil, K., Carter, G., Galway, K., Watson, M., & Van der Steen, J.T. (2015). General practitioners perceptions on advance care planning for patients living with dementia. <i>BMC Palliative Care</i> . Doi: 10.1186/s12904-0019-x.	Cross sectional postal survey to evaluate care of dementia	Facilities caring for at least 30 dementia pts in a year identified through the QOF data. 138 completed surveys.	The care for dementia patients at the end of life survey instrument.	Conversations should be initiated by provider, but not necessarily at time of dx.	Describe attitudes and practice preferences of GPs working within the UK's NHS regarding communication and decision-making for patients with dementia and their families.		VI
Brickman-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> 1(26) doi: 10.1177/0269216314526272	Systematic Review	113 papers reviewed	Compared ACP to basic advance directives and DNR.	Advance care planning was found to decrease life-sustaining treatment, increase use of hospice and palliative care and prevent hospital stays. Complex advance care planning interventions seem to increase compliance with patients' end-of-life wishes.	ACP varied from different studies, search criteria was difficult,	Good evidence on ACP and its effects need more research on community level vs in patient.	V
Brown, J.B., Beck, A., Boles, M., Barrett, P.(1999). Practical methods to increase use of advance medical directives. <i>Journal of General Internal Medicine</i> , 14, 21-26.	Population based, randomized controlled trial Written materials and video mailed to half and just written materials. Follow up 3 months later with record review	Kaiser Permanente members aged 75 years and older.	Proportion of subjects who placed a AD in their medical record for the first time.	65.4% increase in written group and 72.6% in video group	Evaluate effectiveness of educational material mailed to patient home on completion rates of AD.		II

<p>Burkle, C.M., Mueller, P.S., Swetz, K.M, Hook, C.C. & Keegan, M.T. (2012). Physician perspectives and compliance with patient advance directives: the role of external factors play on physician decision making. <i>BMC Medical Ethics</i>, 13(31).</p>	<p>Survey of Attendees of two Mayo clinic continuing medical education courses. Three hypothetical patient scenarios based in part on previously court-litigated matters assessed external factors and perceived pt preferences on physician compliance with patient-articulated wishes regarding resuscitation</p>	<p>388 surveys completed.</p>	<p>Scantron survey based system.</p>	<p>Provider decisions are greatly impacted by the specific situation, without legal liability concern, and the majority would consider family wishes over AD. Remoteness of AD and reversibility of the immediate condition played a role in the decision.</p>	<p>Impact of external factors and perceived patient preferences on physicians' decisions to honor or forgo previously established ADs. Physicians' views regarding legal risks, concerns of patient's ability to comprehend complexities involved with their care. Impact of the cost of end of life care.</p>	<p>VI</p>
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<p>Chao, S. (2011). Functional disability & psychological well-being in later life: Does source of support matter? <i>Aging & Mental Health, 16</i>(2), 236-244. doi: 10.1080/13607863.2011.596809</p>	<p>A random effect modeling was utilized with data from a nationwide longitudinal study in Taiwan. Collection of data from the Survey of Health and Living Status of the Elderly in Taiwan.</p>	<p>6722 observations from 2856 elders over a seven-year period served as subjects of this study.</p>	<p>Increasing functional disability Psychological well-being: depression and LS Social support.</p>	<p>Instrumental support from family members and formal organizations as well as emotional support from families' friends, and formal organizations was significantly associated with better psychological well-being among the elderly in Taiwan. Also support from family.</p>	<p>Explore differences in source of support</p>	<p>This article does not directly related to advance directives; however this was selected to explore a person's functional ability and psychological well-being, level of life satisfaction and depression and how it can potentially contribute to end of life decisions and coping.</p>	<p>VI</p>
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<p>Decker, I.M. & Reed, P.G. (2005). Developmental and contextual correlates of elders' anticipated end-of-life treatment decisions. <i>Death Studies</i>, 29, 827-846, doi: 10.1080/07481180500236743</p>	<p>Interviews via questionnaires</p>	<p>210 elders 60years or older, able to live independently or semi independently and able to read and comprehend questionnaire.</p>	<p>4 developmental factors: integrated moral reasoning, self-transcendence, past experience with life threatening illness and age 5 contextual factors: education level, gender, ethnicity, current health status, and completion of living will.</p>	<p>Overall the elders preferred less aggressive EOL treatment. It was influenced by previous experiences with illness.</p>	<p>Survey vs live interview, varied interpretation of questions</p>	<p>This will is a great article for determining what factors related to the individual have an impact on end of life decisions.</p>	<p>VI</p>
<p>Detering, K.M., Hancock, A.D., Reade, M.C. & Silvester. W. (2010) The impact of advance care planning on end of life care in elderly patients: randomized controlled trial. <i>BMJ</i>.doi:10.1136/bmj.c1345</p>	<p>Randomized control trial Patients assessed on 3rd day of admission: medical record reviewed. And brief interview. Intervention group received formal trained facilitator. Control: received usual medical care but no ACP.</p>	<p>309 legally competent medical inpatients aged 80 or more and followed for six months or until death.</p>	<p>Respecting Patient Choices model. Discharge questionnaire. Telephone follows up at 3 and 6 months. If death occurred family was interviewed.</p>	<p>84% in control group completed AD and or proxy 86% of EOL wishes were followed compared to 30%. Family of those intervention group had less stress.</p>	<p>Investigate the impact of ACP on end of life care in elderly patients.</p>		<p>II</p>

<p>Diaz-Montes, T.P., Johnson, M.K., Giuntoli, R.L., Brown, A.J. (2012). Importance and timing of end-of-life care discussions among gynecologic oncology patients. <i>American Journal of Hospice & Palliative Medicine</i>, 30, 59-67.</p>	<p>Questionnaire</p>	<p>122 gynecologic oncology patients regardless of type, stage or disease progression OBGYN Oncology center</p>	<p>SPSS using descriptive statistics</p>	<p>Most patients were familiar with AD, addressing EOLC is an important part of treatment. Designating a DPOA was significantly related to disease status. Optimal timing with disease progression or with no further available treatment.</p>	<p>To assess the importance and desired timing of EOL care discussions among women with OBGYN CA.</p>		<p>VI</p>
<p>Douglas, R., & Brown, H.N. (2002). <i>Patients' attitudes toward advance directives</i>. <i>Journal of Nursing Scholarship</i>. 34(1), 61-65.</p>	<p>Convenience sample. Interviewed. Data collected over 3 weeks from an oncology and medical telemetry unit at a teaching hospital Interviewed 62 patients were asked and 29 declined. 30 participated</p>	<p>62 patients were asked and 29 declined. 30 participated</p>	<p>Nolan and Bruder's advance directive attitude survey.</p>	<p>Many hospitalized 75% had heard of and received information on AD, but AD completion was 43%. Most likely to complete AD were Caucasian, female and over age 65.</p>	<p>Explore hospitalized patients' attitude toward advance directives and reasons for completing them and demographic differences.</p>		<p>VI</p>
<p>Duffield, P. & Poszamsky, J.E. (1996) The completion of advance directives in primary care. <i>Journal of Family Practice</i>, 42, 4, 378-388.</p>	<p>Survey</p>	<p>Private family practice office in rural Illinois. 195 subjects. Ages 21-88 who visited office in a one month period.</p>	<p>None.</p>	<p>45% subjects returned completed AD. Discussion was 3-5 minutes, easy forms. Subjects reported that they prefer to have PCP discuss these issues with them while they are still healthy. Older patients, longer length of time in the practice, less education, physician provider were all associated with higher completion rates</p>	<p>Determine whether discussions about and distribution of AD forms would increase the number of completed and returned AD.</p>		<p>VI</p>

Durbin, C.R., Fish, A.F., Bachman, J.A., & Smith, K.V. (2010). Systematic review of educational interventions for improving advance directive completion. <i>Journal of Nursing Scholarship</i> , 42(3), 234-241.	Systematic Review Same day surgery, Cardiac rehab, senior housing, medical practice, discharged outpatients	12 randomized and 4 non randomized studies. 1991 - 2009.	None.	No strong evidence in effectiveness of educational interventions, but written and verbal better than just written.	Compare educational programs to improve AD completion		V
Escher, M., Perneger, T.V., Rudaz, S., Dayer, P., & Perrier, A. (2014). Impact of advance directives and a health care proxy on doctors' decisions: A randomized trial. <i>Journal of Pain and Symptom Management</i> , 47(1), 1-11.	Cross sectional mail survey including randomized vignettes describing clinical situations involving medical decisions	861 GPs, general internists, and internists with any sub specialty	Created patient vignettes	Combination AD and proxy had a stronger influence than either alone. Both the hand written note and formalized document led the doctors to forgo hospitalization. In absence of documentation all doctors would have admitted the patient.	Quantify the influence of advance directive and proxy opinions on doctor's decisions.		IV
Gaw, A., Doherty, S., Hungerford, P., & May, J. (2012). When death is imminent. <i>Australian Family Physician</i> , 41(8).	Retrospective review of hospital records.	43 of the 80 patient deaths were reviewed. 55 ER patient records were reviewed.	Medical records of patients that died at Tamworth Rural Referral Hospital from Jan 1 to March 31 2011. As well as a review of unplanned admission through the ED during the same period	77% of patients had their first documented end of life discussion 3 days before death. 82% of the ER patients had no documentation of end of life discussions.	. To compare the EOL decisions of those at EOL to those that were thought to be nearing EOL.	Although an extremely small sample, it does show that most people do not have important conversations with their families prior to the need for them.	VI

<p>Gillian, P., der Riet, P. v., & Jeong, S. (2013). End of life care education, past, and present: A review of the literature. <i>Nurse Education Today</i>, 34, 331-342, doi:10.1016/j.nedt.2013.06.009</p>	<p>Literature review</p>	<p>18 research papers published between 1984 and 2012</p>	<p>Two main themes: Modes of End of Life Education Delivery and End of Life Care Education Initiatives</p>	<p>Lack of end of life content in textbooks, as well as in nursing curriculum.</p>	<p>Modes of EOL education</p>	<p>This is a great article to get started in the hunt for an effective mode of education for health care providers. It recommends end of life simulation to help prepare nursing students to provide better end of life care. This could potentially be translated into education for all healthcare providers.</p>	<p>V</p>
<p>Glaudemans, J.J., Moll van Charante, E. P., Willems, D.L. (2015). Advance care planning in primary care, only severely ill patients? A structured review. <i>Family Practice</i>, 16-26, doi:10.1093/fampra/cm u074</p>	<p>Structured review of literature to explore current practice on ACP in primary care</p>	<p>10 articles</p>	<p>None.</p>	<p>More in alzheimer's dx, cancer and terminal illness. Difficult for PCPs to judge best time. Patients would like these conversations when they are still healthy.</p>	<p>Provide overview of actual practice of ACP in primary care.</p>		<p>V</p>

<p>Gordon, N.P., Shade, S.B. (1999). Advance directives are more likely among seniors asked about end of life care preferences. <i>Arch Intern Med</i>, 159, 701-704.</p>	<p>Cross sectional survey</p>	<p>5365 Random 65 years olds HMO members</p>	<p>AD completed, Conversation with clinician</p>	<p>1/3 seniors had AD only 15% had talked with a clinician about EOLCP. Age was associated with increased AD and talking about EOLP. Having been asked was significantly associated with completion of AD.</p>	<p>Estimate the proportion of seniors in a large HMO who have been asked about end of life preferences by a clinician.</p>	<p>Large sample supports intervention.</p>	<p>VI</p>
<p>Hayek, S. Nieva, R., Corrigan, F., Zhou, A.,Mudaliar, U., Mays, D., Massoomi, M., Ilksoy, N.(2014). End-of-life planning: Improving documentation of advance directives in the outpatient clinic using electronic medical records. <i>Journal of Palliative Medicine</i>, 17(12), doi: 10.1089/jpm.2013.0684 .</p>	<p>Prospective QI study Two test change based on physician interview: Change 1 paper education material provided to pt and email sent to provider with education and general reminder to address AD. Change 2:AD put in problem list of specific pts with documentation encouraged</p>	<p>Chart review of 100 randomly selected charts pre intervention. 588 charts reviewed after first change, 157 charts met criteria for change 2 7 residents.</p>	<p>Rates of completed AD.</p>	<p>End of life preferences rarely documented in resident run clinic, physician education and one-time reminders on counseling and discussing AD have limited impact, EMR use effective</p>	<p>Assess effectiveness of an EMR based reminder in improving AD rates</p>		<p>IV</p>

<p>Hickman, S. E., Nelson, C. A., Perrin, N. A., Moss, A. H., Hammes, B. J., & Tolle, S. W. (2010). A comparison of methods to communicate treatment preferences in nursing facilities: Traditional practices versus the physician orders for life sustaining treatment program. <i>The American Geriatrics Society</i>, doi: 10.1111/j.1532-5415.2010.02955.x.</p>	<p>Retrospective observational cohort study.</p>	<p>1711 living and deceased nursing facility residents aged 65 and older with a minimum 60 day stay.</p>	<p>Life sustaining treatment orders, pain, shortness of breath and related treatments in 7 day increments and POLST use over a 60 day period.</p>	<p>Although more documented treatment preferences, patients with POLSTs had no different symptom management or assessment. POLST were associated with less life sustaining treatment.</p>		<p>Study found advantages to the use of POLST in communicating life sustaining preferences.</p>	<p>IV</p>
<p>Huang, H., Chiu, T., Lee, L., Yao, C., Chen, C., & Hu, W. (2012). Family experience with difficult decisions in end-of-life care. <i>Psycho-Oncology</i>, 21, 785-791. doi: 10.1002/pon.3107.</p>	<p>Cross-sectional survey that employed the systemic random sampling method. Surveys were mailed, from 1999-2000. Data collection during 2003-2005. Telephone follow up for those that did not fill out survey.</p>	<p>Bereaved families of 500 patients who died of cancer. 180 hospice patients and 320 non hospice. Final study only included 302 bereaved family caregivers.</p>	<p>Questionnaire with five parts: Knowledge of palliative care. Knowledge of the natural death act. Beliefs related to the natural death act. Difficulty of decisions.</p>	<p>Most difficult decisions were related to truth telling, place of care, and alternative treatments. Better communication is thought to decrease negative perceptions of the Natural Death Act and in turn decrease psychological distress.</p>	<p>Evaluate family experience with difficult decisions in EOL care.</p>	<p>Although this does demonstrate families' struggles with difficult end of life decisions, it is not as helpful because 180 of the participants were already in hospice which major decisions whether or not to treat or not is mainly already made.</p>	<p>VI</p>

<p>Kemp, K.R., Emmons, E. & Hayes, J. (2004). Advance directives and do-not-resuscitate orders on general medical wards versus the intensive care unit. <i>MILITARY MEDICINE</i>, 169,(6).</p>	<p>Retrospective review of medical records.</p>	<p>335 records of patients admitted to the general medicine wards and to the ICU at Brooke Army Medical Center.</p>	<p>Completed advance directives and completed do-not-resuscitate orders.</p>	<p>No difference in the average length of stay, presence of advance directives, or documentation of advance directives in ward vs ICU.</p>	<p>Compare completion of AD and DNRs on medical floors vs ICU.</p>		<p>IV</p>
<p>Kierner, K.A., Hladschik-Kermer, B., Gartner, V., Watzke, H.H. (2010). Attitudes of patients with malignancies towards completion of AD. <i>Supportive Care Cancer</i>, 18, 367-372.</p>	<p>Cohort study Basic AD information was provided. Provided the option to complete AD in hospital now, later or outpatient. All were screen for anxiety and depression.</p>	<p>108 hospitalized cancer patients.</p>	<p>Hospital Anxiety and Depression Scale. Number of patients willing to issue an AD after receiving the information provided.</p>	<p>10% of hospitalized patients wish to issue an AD: 32% no specific reason, 22% had full confidence their MD would make the right decision, 15% felt it wasn't important and too young. 8 % were afraid it would lead to under treatment</p>	<p>Investigated attitudes toward AD in hospitalized patients with malignant disease.</p>		<p>IV</p>
<p>Lind, R., Nortvedt, P., Lorem, G., & Hevroy, O. (2012). Family involvement in the. Care of competent intensive care patients. <i>Nursing Ethics</i>, 20(1), 61-71. doi: 10.1177/0969733012448969.</p>	<p>All interviews were conducted by the first author an experienced ICU nurse and a trained researcher. Most took place in the participant's home; they lasted for 60–90 min, were recorded digitally and transcribed</p>	<p>interviews with 27 relatives of 21 deceased patients from four Norwegian ICUs. Inclusion criteria included: age >18 years for both patient and relative, daily visits by the relative and a decision to withdraw treatment documented in the patient record</p>	<p>The questions addressed interaction with health-care personnel, experiences of the communication in the EOL discussions and the content of the conversations.</p>	<p>relatives Narrate about a strong relationship with the patient. they viewed their presence as crucial provide support and protect the patient, and safeguarding his values and interests. decision making varied from active participation in the decision-making process to acceptance of the physicians' Decision or just receiving information.</p>	<p>.</p>	<p>models of informed shared decision making should be utilized and optimized in intensive care, where nurses and physicians work with both the patient and his or her family and regard the family as partners in the process</p>	<p>VI</p>

<p>Lum, H. D., Brown, J.B., Juarez-Colunga, E., & Betz, M, E. (2015). Physician involvement in life transition planning: a survey of community-dwelling older adults. <i>BMC Family Practice</i>, 16, doi: 10.1186/s12875-015-0311-0.</p>	<p>Surveys, anonymous, voluntary, paper based mail.</p>	<p>457 surveys Single independent living facility.>55</p>	<p>ACP,Driving, finances, housing</p>	<p>Open communication with physicians on ACP and driving were accepted. Finances and housing not as much. Room for improvement in these discussions within healthcare system.</p>	<p>Examine older adults' experiences and opinions concerning ACP, driving, finances, and housing.</p>		<p>VI</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 conversations. <i>Annals of Family Medicine</i>, 14,125-132.</p>	<p>Interview, pilot of ACP group visit. 2 sessions 2 hours each.</p>	<p>32 participated in 5 group visit cohorts Senior clinic at University of Colorado, GMV 65 years and older</p>	<p>Considering personal values, ACP, choosing surrogates</p>	<p>Most agreed it was better than discussing AD in usual clinic visit. Increase in conversations at home.</p>	<p>Effectiveness of a group visit to discuss ACP</p>		<p>VI</p>

<p>Malcomson, H., & Bisbee, S. (2009). Perspectives of healthy elders on advance care planning. <i>Journal of the American Academy of Nurse Practitioners</i>, 21, 18-23.</p>	<p>Interview and questionnaires</p>	<p>A convenience sample of 20 healthy men and women, aged 60–94 years old from one community senior center and two assisted living facilities.</p>	<p>1) What forms of communication have healthy elders had regarding advance care planning? (2) What is the comfort level of healthy elders regarding discussion of end-of-life preferences? (3) What factors contribute to and impede communication and comfort on the issue of advance care planning?</p>	<p>ACP is influenced by concern for others. Elders assume that their preferences are known, Elders value a healthcare system that supports provider time, focus, and continuity. Elders express readiness and eagerness to engage in advance care planning discussions.</p>	<p>Explore perspective of healthy elderly individuals on ACP.</p>		<p>VI</p>
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<p>Matsui, M. (2010). Effectiveness of end-of-life education among community-dwelling older adults. <i>Nursing Ethics</i>, 17(3), 363-372. doi: 10.1177/0969733009355372.</p>	<p>Quasi-experimental design Intervention group received 90-minute educational program consisting of watching a video and listening to a lecture with handout and discussion with other participants</p>	<p>121 older adults aged 65 years and older who were members of senior citizen centers in West Japan. 60 intervention participants from three units, each of which had 20 members and 61 control participants from six sites.</p>	<p>Pre and post analysis, 1 month follow up exploring attitude about advance directives and initiating discussion. As well as preferences on life sustaining treatment.</p>	<p>Intervention group's attitudes became more favorable towards advance directives. They had less preference in life-sustaining tx Such as artificial nutrition. More acceptance of intervention overall.</p>	<p>Effectiveness of EOL education.</p>	<p>Interesting finding: Few participants actually filled out living wills at follow up, however twice as many in intervention group discussed end of life matters with family members and/or physician.</p>	<p>III</p>
<p>Morrell, E.D., Brown, B.P., Qi, R., Drabiak, K., & Helft, P.R. (2008). The do-not-resuscitate order: associations with advance directives, physician specialty and documentation of discussion 15 years after patient self-determination act. <i>Journal of Medical Ethics</i>, 34, 642-647.</p>	<p>Retrospective chart review</p>	<p>All Deaths at Indiana University Hospital in 2005 284 charts analyzed</p>	<p>None.</p>	<p>There remains a difference between medical and surgical specialties in timing of completion of DNR. Correlation in completion of DNR orders and provider documentation in chart</p>	<p>Determine effectiveness of PDSA</p>		<p>IV</p>
<p>Morrison, S.R., & Meier, D.E. (2004). High rates of advance care planning in new York city's elderly population. <i>Arch Intern Med</i>, 164, 2421-2426.</p>	<p>Survey 51 item survey that assessed attitudes, beliefs, and practices regarding ACP</p>	<p>34 randomly selected NYC senior centers 700 adults 60 and older</p>	<p>NONE.</p>	<p>Predictors of AD completion involve established PCP, personal experience with vent, knowledge about ACP, PCP willingness to initiate conversation.</p>	<p>Explore factors that may influence patient's willingness to engage in ACP</p>		<p>VI</p>

O'Sullivan, R., Mailo, K., Angeles, R., & Agarwal, G. (2015) Advance directives: Survey of primary care patients. <i>Canadian Family Physician</i> , 61, 353-355.	Cross- sectional analytical study.	Any adult 18 and older who attended teaching clinic. 800 completed survey.	Logistic regression	Pt's preference to have family md initiate was correlated with patient's higher ranking of its importance.	Establish prevalence of pts with AD in family practice and to describe pt perspectives on family doctors initiating discussions about AD.		VI
Otte, I.C., Jung, C., Elger, B.S., Bally, K. (2014). Advance directives and the impact of timing: A qualitative study with swiss general practitioners. <i>The European Journal of Medical Sciences</i> . doi: 10.4414/smw.2014.14035.	Interview	23 Swiss general practitioner	None.	Initiate conversation early when healthy to gain full understanding of patient's desire, Update regularly, reaffirm when illness progresses	GP perspectives regarding timing of EOL conversations.		VI
Ramsaroop, S.D., Reid, M.C., & Adeknabm R.D. (2007). Completing an advance directive in primary care setting: What do we need for success? <i>The American Geriatrics Society</i> , 55, 277-283.	Systematic literature review	Literature from Jan 1991-2005 18 Studies 12 RCT 2 Quasi 1 retrospective 1 observational 2 prospective	None.	Most successful interventions involved direct patient-HCP communication over multiple visits. Written materials only ineffective. Lack of time biggest barrier and no desire to initiate. Patients with lots of health issues less likely to discuss in routine visit d/t other concerns. Or new PCP.	Review studies designed to increase AD completion.	Length of studies vary 1-32 months.	V

<p>Rao, J. K., Anderson, L. A., Lin, F. C., & Laux, J. P. (2014). Completion of advance directives among u.s. consumers. <i>American Journal of Preventative Medicine</i>, 46(1), 65-70. doi: 10.1016/j.amepre.2013.09.008.</p>	<p>Review of data collected through a survey.</p>	<p>adults aged 18 years and older who participated in the 2009 or 2010 HealthStyles Survey, a mail panel survey designed to be representative of the U.S. population</p>	<p>Likelihood ratio tests were used to examine the associations between advance directive completion and demographic and socioeconomic variables including: education, income, & employment. Also, presence of a chronic condition; regular source of health care; and self-reported EOL concerns or discussions.</p>	<p>Of the 7946 respondents, 26.3% had an advance directive. The most frequently reported reason for not having one was lack of awareness. Respondents with advance directives also were more likely to report having a chronic disease and a regular source of care. Advance directives were less frequent among those who reported not knowing if they had an EOL concern</p>	<p>AD completion rates</p>	<p>This is good study to get an idea of what people outside of health care facilities know about EOL and if and why they fill out advance directives. This</p>	<p>VI</p>
<p>Salmond, S.W., & David, E. (2005). Attitudes toward advance directives and advance directive completion rates. <i>Orthopaedic Nursing</i>, 24(2), 117-129</p>	<p>Descriptive correlational study. Data Jan to March 2003. Daily census was reviewed x8 weeks and candidates identified by charge RN and approached.</p>	<p>Convenience sample Adult hospitalized patients admitted to medical/surgical units. 80 patients</p>	<p>Adaptive version of advance directive attitude survey</p>	<p>Majority hadn't discussed AD with provider, regardless of educational materials AD rates low.</p>	<p>Identify the significant attitudes and factors that influence the completion of Ads .</p>		<p>VI</p>

Silveria, M. J., Scott, K., & Langa, K. M. (2010). Advance directives and outcomes of surrogate decision making before death. <i>The New England Journal of Medicine</i> , 362(13), 1211-1218.	Data from a biennial longitudinal survey	3746 Individuals 60 years of age or older who died between 2000-2006 and whom proxy had answered a study related exit interview after the participant's death.	Data was used from the Health and Retirement Study, a biennial longitudinal survey of a nationally representative cohort of U.S. adults 51 years of age or older.	42.5% required decision making, 70.3 % lacked decision making ability, and 67.6% had advance directives. Patients who had prepared advance directives received care related to their preferences.	Determine outcomes of surrogate decision making.	The findings of this study support the use of advance directives.	VI
Toraya, C. (2014). Evaluation of advance directives video education for patients, <i>Journal of Palliative Medicine</i> , 17 (8),doi: 10.1089/jpm.2013.0585 .	Prospective, non randomized, pre/post survey 12 minute video including planning for future healthcare wishes.	37 outpatients and 8 in patients. 4 months providers and medical staff offered patients the option to view the video during their clinic visit or in the hospital.	Pre and post survey questions.	The video was helpful and increased awareness	Evaluate the effectiveness of an educational AD video to determine whether it increased patient understanding regarding discussions of future health care wishes		VI
Tulsky, J.A., Fischer, G.S., Rose, M.R., Arnold, R.M. (1998). Opening the black box: how do physicians communicate about advance directives? <i>Annals of Internal Medicine</i> , 129(6), 441-449.	Prospective, audiotaped physician-patient communication about EOL from April 1994 to Oct 1994. Observation and coding of real time patient provider discussions	Primary care providers in Durham, NC, and Pittsburg, PA. General medicine practices. Patients 65 years and older. 56 conversations were observed.	Physicians completed survey. Code Book created to analyze discussions.	MDs discuss black and white scenarios. They were short. Most patients found conversations useful.	To describe how physicians discuss advance directives with patients.		VI

<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 & Palliative Medicine</i>, 28, 230-235, doi: 10.1177/1049909110386045.</p>	<p>Retrospective Review. Intervention and control groups Packet sent to intervention group</p>	<p>Primary care settings at Mayo clinic</p>	<p>None</p>	<p>Well timed, targeted, multimodal educational intervention increased completion of AMDs by 17.5%. Less time utilized by providers, educational materials mailed in advance.</p>	<p>Determine the effectiveness of clinical decision support.</p>		<p>III</p>
<p>Van Leuven, K.A. (2012). Advance care planning in health service users. <i>Journal of Clinical Nursing</i>, 21, 3126-3133. doi.10.1111/j.1365-2702.2012.04190.x</p>	<p>Chart review, observation, residents residing in 3 SNFs</p>	<p>272 charts, aged 35-100 years of age</p>	<p>Presence of AD, what time and timing. RC/AL SAS tool: social engagement and GIF : health status</p>	<p>90.44% entered SNF w/o AD. 69.11 remained without one.</p>	<p>Examine the use of AAD in patients actively using health services.</p>	<p>Promotes more conversations.</p>	<p>IV</p>

<p>Van Scoy, L.J., Green, M.J., Dimmock, A.EF., Bascom, R., Boehmer, J.P., Hensel, J.K., Hozella, J.B., Lehman, E.B., Schubart, J.R., Farace, E., Stewart, R.R., & Levi, B.H. (2016). High satisfaction and low decisional conflict with advance care planning among chronically ill patients with advanced chronic obstructive pulmonary disease or heartfailure using an online decision aid: A pilot study. <i>Chronic Illness</i>, 12 (3), 227-235. Doi: 10.1177/174395316633511..</p>	<p>Surveys Participation in online ACP course Make your wishes known</p>	<p>24 HF and 25 COPD</p>	<p>Surveys used in previous studies to evaluate intervention</p>	<p>90% highly satisfied with an accurate AD created. Lower decisional conflict and knowledge scores rose by 18%</p>	<p>Explore how patients with COPD and HF experience ACP using an online decision aid.</p>		<p>VI</p>
<p>Van Scoy, L.J., Howrylak, J., Nguyen, A., Chen, M., Sherman, M. (2014). Family structure, experiences with end-of-life decision making, and who asked about advance directives impacts advance directive completion rates. <i>Journal of Palliative Medicine</i>, 17, doi:10.1089/jpm.2014.0033.</p>	<p>Interviews 1:1. And verified with chart review</p>	<p>130 inpatients of urban university hospital.</p>	<p>Demographics, healthcare utilization, disease entity, experiences with death and dying or end of life decision making.</p>	<p>Older patients more likely to have AD. No impact of increased healthcare utilization. Just asking about AD increases completion. Increased comorbidities lead to increased AD.</p>	<p>Investigate factors associated with completion of advance directives.</p>	<p>Includes ages, comorbidities, and healthcare utilization.</p>	<p>VI</p>

<p>Vleminck, A. D., Houttekier, D., Pardon, K., Deschepper, R., Van Audenhove, C., Stichele, R.V., & Deliens, L. (2013). Barriers and facilitators for general practitioners to engage in advance care planning: A systematic review. <i>Scandinavian Journal of Primary Health Care</i>, 31, 215-226.</p>	<p>Systematic Review of Literature</p>	<p>1990-2011 16 articles</p>		<p>Barriers including GP experience, knowledge, and confidence. Finances. Increased in cancer patients. Timing discussed briefly.</p>	<p>Determine barriers and facilitators for GPS to engage in ACP.</p>		<p>V</p>
<p>Vo, H., Pekmezaris, R., Guzik, H., Nouryan, C., Patel, C., Vij, B., Tai, J., & Wolf-Klein, G. (2011). Knowledge and attitudes of health care workers regarding molst (medical orders for life-sustaining treatment) implementation in long-term care facilities. <i>National Gerontological Nursing Association</i>, 32(1), 58-62. doi: 10.1016/j.gerinurse.2010.11.002.</p>	<p>Anonymous survey during regular scheduled meetings at the respective nursing facilities across all shifts. 75-100 surveys were distributed in each facility. Each facility was either a high or low prevalence facility.</p>	<p>RNs, medical attending, residents/fellows, LPNs, social workers, and NPs employed at 6 targeted health system affiliates were recruited for study.</p>	<p>11 questions about experience and knowledge, 11 questions about attitudes and 9 questions about demographics. The Chi-square test was utilized for categorical variables. The spearman rank correlation was used to describe ordinal variables.</p>	<p>35% response rate. 169 surveys reviewed. Younger employees were more actively involved in the completion of the MOLST form. Employees working at the same facility for a long time were stock in past practices. HP more often thought that LTC residents should have a MOLST. Also recognizing it's benefits.</p>	<p>Evaluate the impact of knowledge and attitudes of physicians, nurses and social workers in nursing facilities of the the MOLST implementation</p>	<p>This is a good article in recognizing that the type of facility and type of staff can affect the use of advance directives positively or negatively.</p>	<p>VI</p>

<p>Weathers, E., O’Caoimh, R., Cornally, Cornally, N., Fitzgerald, C., Kearns, T., Coffey, A., Daly, E., O’Sullivan, R. & McGlade, C. (2016). Advance care planning: A systematic review of randomized controlled trials conducted with older adults. <i>Maturitas</i>, 91, 101-109.</p>	<p>Systematic review of RCTs related to ACP interventions with older adults</p>	<p>9 articles different settings</p>	<p>Symptom management, quality of care and healthcare utilization.</p>	<p>Need for more RCT examining economic impact. Decreased hospitalization and resource use, increased knowledge, understanding of EOL preferences</p>	<p>Impact of ACP interventions on several outcomes.</p>		<p><i>I</i></p>
<p>Wheatley, E., Huntington, M.K. (2012). Advance directives and code status documentation in an academic practice. <i>Family Medicine</i>, 44(8), 574-578.</p>	<p>Chart review December 2008 to Jan 2009</p>	<p>121 randomly selected 65 years or older seen in the last year at Family medicine residency program</p>	<p>Living environment, age, level of physician training</p>	<p>Overall geriatrics above national average 44% in AD completion. And 55% in documented code status. Independent living elders had lowest rates of 25%. Improvement is necessary in the 65-69 ranges.</p>	<p>Determine proportion of geriatric patients with ADs or code status recorded</p>	<p>Includes code status, and ages.</p>	<p><i>IV</i></p>

<p>Wright, A.A., Zhang, B., Ray, A., Mack, J.W., Trice, E., Balboni, T., Mitchell, S.L., Jackson, V.A., Block, S.D., Maciejewski, P.K., & Prigerson, H.G. (2008). Associations between end-of-life discussion, patient mental health, medical care near death, and caregiver bereavement adjustment. <i>Journal of American Medical Association</i>. 300(14)</p>	<p>Prospective, longitudinal, cohort study .Interview. Patient recruitment from Sep 2002 – Feb 28th 2008</p>	<p>638 Cancer patients>20 years old, presence of informal care giver, and stamina to complete interview.</p>	<p>EOLD, survival of two groups</p>	<p>37 % of cancer patients had EOLD. Pts with EOLD had lower performance status, higher symptom burden and shorter survival times. EOLD had no relationship with depression, sad, terrified, worried or meeting criteria for a mental dx. They were more likely to accept their illness. Better for caregivers.</p>	<p>Examine associations between end of life discussion with physicians and the medical care that terminally ill cancer patients receive near death. And to examine relationship between discussions and patients' psychological distress, quality of life near death and caregivers bereavement outcomes.</p>	<p>Less aggressive care and earlier hospice was related to better quality of life and less than one week of hospice was same quality of life as no EOLD.</p>	<p>VI</p>
<p>Zager, S., & Yancy, M. (2011). A call to improve practice concerning cultural sensitivity in advance directives: A review of the literature. <i>Worldviews on Evidence-Based Nursing</i>, doi: 10.1111/j.1741-6787.2011.00222.x.</p>	<p>Comprehensive review of the literature</p>	<p>Selection of articles included qualitative and quantitative studies.</p>	<p>The evidence was evaluated and synthesized for information related to cultural sensitivity and Ads.</p>	<p>Healthcare provider (HCP) awareness, communication, and education concerning cultural differences and advance care planning (ACP) assisted in meeting the needs for end-of-life planning in the current era of increased globalization. Education for HCP on cultural differences and how to lead discussions promoted ACP.</p>	<p>Assess cultural factors related to AD.</p>	<p>Initiating conversations about ACP can be facilitated by using open-ended questions that respect the values and beliefs of various cultures.</p>	<p>V</p>

<p>Zhang, W. (2013). Olders adults making end of llife decisions: An application of ro'ys adaptation model. <i>Journal of Aging Research</i>, doi: 10.1155/2013/470812.</p>	<p>Model-testing design & pathway analysis Extracted data from previously completed surveys and implemented it into Roy's adaptation model which provides framework for identifying variables that influence individual's responses to stressful situations. Focusing on: Focal, contextual, and residual stimuli. The adaptive mode and response.</p>	<p>938 participants: Noninstitutionalize d US citizens aged 55 or older who had previously participated in the 1994 SOA II and the 1998 decedent file.</p>	<p>Using Roys Model they focused on focal contextual and residual stimuli. Contextual stimuli, adaptive modes and adaptive response.</p>	<p>The final path model showed physical impairment, self- rated health, continuing to work and family structure had direct and indirect effects on the completion of advance directives.</p>	<p>Identify and analyze factors influencing AD completion in an older population. . The influence of demographic, family structure, and health status variables on advance directive completion were analyzed</p>	<p>Great article utilizing Roy's Adaptation model that put the concepts of interest of this study into perspective and guided the analysis of how each variable influenced other variables.</p>	<p>V</p>
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