

Patient Engagement in Advance Care Planning in Primary Care

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Abstract

Advance care planning is a process that allows individuals to define their preferences and goals for future medical care through a series of behaviors and actions. Early advance care planning allows patients time to process their feelings about future end-of-life care, decreases healthcare spending, and reduces caregiver, patient, and provider distress. This quasi-experimental, evidence-based quality improvement project aimed to increase patient engagement in advance care planning behaviors in the primary care setting over five months. Patients 50 years of age and older who are English-speaking and have two or more chronic conditions were provided access to PREPARE educational materials and completed the four-item Advance Care Planning Engagement Survey. Twenty-seven participants completed the survey at a federally qualified healthcare center in the Midwest. The primary outcome measured was patient engagement in advance care planning by gender and age. The project found that patients 50 years of age and older are contemplating engaging in advance care planning behaviors. Primary care clinics are the ideal setting to provide patients with educational materials to aid in increasing engagement in advance care planning.

Keywords: advance care planning, primary care, advance directive, engagement, Advance Care Planning Engagement Survey, PREPARE, quality of life

Patient Engagement in Advance Care Planning in Primary Care

Advance care planning (ACP) is a process of identifying personal values and one's perception of quality of life to determine future healthcare preferences. Advance care planning is a sensitive undertaking for patients due to the complex interplay of personal, cultural, spiritual, and institutional values that influence a person's wishes for end-of-life care. Implementing measures to increase patient engagement in ACP in the primary care setting can reduce healthcare spending, increase patient and family satisfaction with care, and allow patients adequate time to engage in the ACP process (Ramsaroop et al., 2007; Royal College of Physicians of London et al., 2009).

Significance

Patients often only discuss their healthcare wishes regarding end-of-life care once they are seriously ill or too late. Times of illness cause significant distress to the patient, family, and those caring for the patient (Jimenez et al., 2018; Ramsaroop et al., 2007). Patients' loved ones may face complex medical decisions without knowing the medical treatment their family member would prefer. Without knowing a patient's preferences, patients may receive treatments they would never have wanted.

In 1991, the Federal Patient Self-Determination Act (PSDA) brought attention to the value that advance care documents (ACDs) and ACP offer patients in protecting their right to make their own healthcare decisions (Teoli & Ghassemzadeh, 2022). It has been determined that patients engage in many different behaviors that express and verbalize their healthcare preferences. Patients partake in ACP by discussing their preferences with their healthcare provider, appointing a medical surrogate, and documenting their healthcare decisions (Sudore et al., 2013; Sudore et al., 2018b). Advance care documents include living wills, advance

directives, and a durable power of attorney (American College of Physicians [ACP], n.d.). Advance care planning and ACDs guide providers in maintaining patient autonomy and dignity and allow healthcare workers to ensure they provide care that aligns with patient goals. Early advance care planning has been shown to protect patient autonomy and decrease healthcare costs by reducing emergency room visits, hospitalizations, and unwanted procedures and treatments (Kendall et al., 2020; Ramsaroop et al., 2007).

The Centers for Disease Control and Prevention (CDC) estimated that over 70% of Americans do not have an ACD (Center for Disease Control and Prevention, 2017). A systematic review found that in adults who did not have an existing ACD, 61-91% expressed interest in discussing advanced directives and their end-of-life preferences. However, only 2-29% of these patients discuss ACP with their providers (Nelson-Brantley et al., 2019). Medicare was the largest insurer for end-of-life care in 2014, with 80% of patients who died that year on Medicare (Kaiser Family Foundation, 2015). Studies on Medicare spending revealed that 25% of total spending is attributed to beneficiaries during their last year of life (Kaiser Family Foundation, 2015). Engagement in ACP lowers healthcare spending at the end-of-life by ensuring patients receive care consistent with their values and medical preferences and avoiding unwanted medical treatment (Nelson-Brantley et al., 2019). Early engagement in ACP in primary care is essential to ensure patients address their medical preferences before becoming seriously ill (Rietjens et al., 2017).

Local Issue

Data on local ACD rates for Missouri is unavailable. A federally qualified healthcare center in Missouri, serving as the improvement project site, cares for a large older adult population. Less than 10% of these patients are predicted to have an ACD. The primary care

clinic is located in a small rural town with patients who predominately identify as Caucasian. This project site is an underserved healthcare community, and many patients are uninsured, on Medicaid, or utilize the clinic's sliding fee program.

Diversity Consideration

Ethnic and racial backgrounds influence how patients make end-of-life care decisions. Patient engagement in ACP among ethnic minorities ranges from 0-29% (Hong et al., 2018). Individuals least likely to engage in ACP are those of Korean, Vietnamese, and Chinese descent. Latinos seem to engage in ACP the least compared to their Caucasian counterparts (Hong et al., 2018). Cultural values, including family-centered decision-making, influence ACP engagement among ethnic minority groups. Individuals with greater acculturation are more likely to engage in ACP and complete an ACD (Hong et al., 2018). Approximately 26% of Americans have completed an ACD (Rao et al., 2014).

Problem

According to the United States Census Bureau (2018), in 2030, the number of adults over 65 will outnumber youth for the first time in U.S. history. The growing older adult population poses a unique challenge to the healthcare system. With over 60% of adults older than 65 managing two or more chronic conditions, the current health system must grow to support the aging adult and meet the goals of the aging patient during the end-of-life (U.S. Department of Health and Human Services [USDHHS], 2020). Chronic diseases significantly increase the risk of additional health complications and death. The annual cost of chronic diseases in the United States is \$3.7 trillion (Hayes & Gillian, 2020). Advance care planning reduces healthcare spending by identifying treatment goals early and helping providers avoid unwanted medical treatments and hospitalizations (Jimenez et al., 2018; Ramsaroop et al., 2007; Rietjens et al.,

2017). Advance care planning allocates medical expenses to treatments congruent with the patient's desired care. Patients who do not engage in ACP risk losing autonomy over their medical care if they become incapacitated. Healthcare providers and families face an ethical dilemma when forced to make medical decisions without knowing the patient's wishes. Despite the benefits of ACP, only one in three adults in the United States has completed a formal advance directive (Blackwood et al., 2019). The lack of ACP makes patients vulnerable when faced with a healthcare crisis.

Problem Statement

When making end-of-life care decisions without previously engaging in advance care planning behaviors, patients often experience a loss of autonomy, dissatisfaction with quality of life outcomes, and unwanted healthcare treatment. Currently, no standardized tool exists to identify patients ready to discuss advance care documents with their provider or educate patients on advance care planning in primary care, the ideal setting to engage in advance care planning (Rietjens et al., 2017; Royal College of Physicians of London et al., 2009).

Purpose Statement

This quality improvement project proposal aimed to increase patient engagement in ACP in the primary care setting.

Review of Evidence

Inquiry

In patients over the age of 50 with two or more chronic conditions, does an ACP Engagement Survey combined with PREPARE educational materials increase patient engagement in ACP over five months in the primary care setting?

Literature Search Strategies

The literature search for this project included research that utilized the ACP Engagement Survey, addressed ACP barriers, and conducted interventions to increase engagement in ACP. Inclusion criteria included peer-edited journals or primary sources, an adult patient population, and the primary care or community health setting. Literature was included if it applied to the chosen inquiry, addressed the adult patient, or focused on ACP for the aging patient. The databases included PubMed, CINAHL, and MEDLINE (see Appendix D). Google Scholar was also utilized in the literature search. Keywords included advance care planning, engagement in advance care planning, advance directive, barriers, and primary care. Eight level I, seven level II, four level III, five level IV, seven level VI, and one level VII studies were included in the synthesis of evidence (see Appendix A). The research designs for the studies varied and included five systematic reviews, three control trials without randomization, seven randomized control trials, four qualitative studies, three quantitative descriptive studies, one quasi-experimental study, four cohort designs, one cross-sectional study, and one metasynthesis.

Synthesis of Evidence

The analysis of evidence included a synthesis of the findings from the literature search (see Appendix A). Five themes were present within the evidence related to the inquiry: engagement in ACP, facilitators of ACP, barriers to ACP, conceptualizing wishes, and outcomes of ACP.

Engagement in ACP

Two evidence-based clinical practice guidelines recommend that providers initiate ACP discussions with all patients who have long-term conditions (Rietjens et al., 2017; Royal College of Physicians of London et al., 2009). Clinical guidelines also recommend initiating ACP

conversations in the primary care setting, where patients are more likely to participate in the ACP process (Royal College of Physicians of London et al., 2009).

Interventions to Increase Patient Engagement in ACP

Several studies have been conducted on interventions aimed at increasing patient engagement in the primary care setting. Four systematic reviews determined that direct patient and provider communication has the most significant impact on increasing patient engagement in ACP behaviors (Blackwood et al., 2019; Jimenez et al., 2018; Ramsaroop et al., 2007; Risk et al., 2019). Provider communication in intervals as short as three to five minutes has successfully increased engagement in the clinic setting (Ramsaroop et al., 2007). Visits with a nurse care coordinator or social worker to discuss ACP also increase patient participation (Holland et al., 2017). One study utilized highly visible banners in the electronic health record (EHR) to notify providers of patients who did not have an ACD on file and remind providers to discuss ACP measures with these patients (Sandoval et al., 2019). Another study increased patient participation in ACP by implementing an online messaging system through the health system's online health portal (Brungardt et al., 2019). Passive educational materials, without direct counseling, are less effective at engaging patients in ACP (Freytag et al., 2020; Ramsaroop et al., 2007). Educational materials coupled with access to a contact person who can address patient questions increase ACP engagement more than educational materials alone (Ramsaroop et al., 2007). Overall, the literature indicates that when patients are provided with an ACP tool, they are likely to engage in behaviors of ACP (Howard et al., 2020; Howard et al., 2021; Ramsaroop et al., 2007).

Patients who utilized PREPARE, a website that offers mixed methods of learning about ACP, engaged in more conversations with their healthcare providers about ACP and were more

likely to ask questions, express concerns, and assert their preferences in future medical care (Freytag et al., 2020; Howard et al., 2020). The PREPARE program increases behavior change process scores using audio, visual, and written education materials (Howard et al., 2020). Three studies found that PREPARE facilitated patient engagement better than offering patients an easy-to-read ACD (Shi et al., 2019; Sudore et al., 2017a; Sudore et al., 2018b). *Speak Up* workbooks designed to walk patients through the steps of ACP increased patient engagement in asking questions to their providers but did not increase other ACP behaviors (Howard et al., 2021). One study compared the effectiveness of several ACP workbooks and education tools, including *Speak Up*, PREPARE, and *Conversations Matter*, and found that all three tools increased patient engagement in ACP (Howard et al., 2018).

Measuring Engagement in ACP

Several studies showed that the ACP Engagement Survey identifies patients ready to engage in ACP behaviors (Freytag et al., 2020; Howard et al., 2016; Shi et al., 2019). The ACP Engagement Survey also detects behavior changes following interventions to increase patient engagement in ACP (Howard et al., 2016; Howard et al., 2021; Sudore et al., 2013; Shi et al., 2019). The ACP Engagement Survey measures four subscales of behavior change: knowledge, contemplation, self-efficacy, and readiness (Lum et al., 2018; Sudore et al., 2013). Four studies found that the ACP Engagement Survey can detect small but meaningful changes in patient behavior that indicate readiness or participation in ACP (Shi et al., 2019; Sudore et al., 2013; Sudore et al., 2017b; Sudore et al., 2018b). The ACP Engagement Survey has been validated in three randomized control trials and three quasi-experimental studies (Freytag et al., 2020; Lum et al., 2018; Sudore et al., 2013; Shi et al., 2019; Sudore et al., 2017b; Sudore et al., 2018b). This survey has been validated in English, Spanish, Dutch, Chinese, and Japanese, with high levels of

internal consistency in identifying patient engagement in ACP (Okada et al., 2021; Shi et al., 2019; Sudore et al., 2018b; van der Smissen et al., 2021). One study determined that the 82, 55, 34, 15, nine, and four-item ACP Engagement Surveys can detect behavior changes. The longer-item surveys have slightly higher internal consistency and validity (Sudore et al., 2017b).

Facilitators of ACP

Ramsaroop et al. (2007) found that patients are more likely to engage in ACP if the provider they see has their own ACD. Risk et al. (2019) attributed higher AD completion rates among patients whose provider has an ACD to the provider's philosophical commitment to ACP. Four studies found that patients prefer that their primary care provider initiate ACP conversations (Abu Al Hamayel et al., 2019; Jimenez et al., 2018; Kendell et al., 2020; Ramsaroop et al., 2007). Provider-led ACP conversations increase patient engagement in ACP (Jimenez et al., 2018; Kendell et al., 2020; Ramsaroop et al., 2007). This preference was attributed to patients' established trust with their primary care provider, which made patients comfortable discussing sensitive subjects such as end-of-life care (Kendell et al., 2020). One systematic review and one expert panel determined that it is crucial to tailor ACP interventions to the patient's readiness level (Risk et al., 2019; Sudore et al., 2017c). The study conducted by Kendell et al. (2020) found that patients preferred to have ACP conversations face-to-face. Patients felt better prepared to engage in ACP when provided with detailed information regarding their medical status to facilitate the ACP process (Kendell et al., 2020). Clinical practice guidelines recommend providing patients with prognosis information and clarification on medical diagnoses to facilitate the ACP process (Abu Al Hamayel et al., 2019).

Two studies found that patients prefer to contemplate ACP decisions with their families and community (Freytag & Rauscher, 2017; Jimenez et al., 2018). Family openness about death

has been associated with increased engagement in ACP (Freitag & Rauscher, 2017). Higher education levels are also associated with the completion of ACDs (Ramsaroop et al., 2007; Rao et al., 2014). Patients with severe health conditions are more likely to engage in ACP than patients who do not have health concerns (Jimenez et al., 2018; Rao et al., 2014). Three systematic reviews found that patients were more likely to engage in ACP in older age, which may be attributed to the prevalence of chronic health conditions in the older adult (Jimenez et al., 2018; Ramsaroop et al., 2007; Risk et al., 2019). Frequent offerings of ACP increase patient engagement, suggesting patients should be routinely screened for readiness to engage in ACP (Combes et al., 2021; Risk et al., 2019).

Barriers to ACP

Four systematic reviews found that the most significant barrier to engaging patients in ACP in the primary care setting is the lack of time providers can offer to assist with planning measures (Blackwood et al., 2019; Jimenez et al., 2018; Ramsaroop et al., 2007; Risk et al., 2019). Three studies also found that providers need more time to engage in in-depth discussions to facilitate ACP in the primary care setting (Bernard et al., 2020; Hafid et al., 2021; Kendell et al., 2020). Hafid et al. (2021) found that 58% of primary care providers did not feel they could incorporate ACP into their clinical routine. Additionally, many healthcare establishments need systems to facilitate ACP at an institutional level (Jimenez et al., 2018). One systematic review, which included 54 RCTs, found that ACP is perceived as unimportant to the healthcare provider if there is a lack of performance monitors or incentives involving ACP (Risk et al., 2019).

Jimenez et al. (2018) found that the lack of a clear legal framework for ACDs hinders ACP implementation. Differing state laws on adopting ACDs contributes to provider and patient knowledge gaps related to ACP. Providers' perception of patients' low health literacy is a barrier

to ACP (Ramsaroop et al., 2007; Risk et al., 2019). A systematic review addressed patients' lack of knowledge regarding clinical considerations at the end-of-life as a barrier to patients engaging in ACP behaviors (Risk et al., 2019). Ambiguity over who should initiate ACP conversations contributes to poor patient engagement in ACP (Bernard et al., 2020; Risk et al., 2019). Providers may feel uncomfortable discussing end-of-life care or lack confidence in ACP conversations (Blackwood et al., 2019; Risk et al., 2019). Lack of patient preparedness to discuss ACP has been identified as a barrier to planning, stressing the importance of identifying patients ready to engage in ACP (Abu Al Hamayel et al., 2019; Jimenez et al., 2018).

Several studies discussed the disparity between Caucasians and other racial groups in ACP. Caucasians are more likely to engage in ACP behaviors and have a completed ACD than patients of Hispanic or Black ethnicity (Hong et al., 2018; Jimenez et al., 2018; Ramsaroop et al., 2007). Persons with lower education levels and low socioeconomic status are also less likely to engage in ACP (Ramsaroop et al., 2007). Two systematic reviews found that patients may lack trust in the healthcare system, particularly those of Black ethnicity, leading to poor engagement in ACP (Hong et al., 2018; Risk et al., 2019). Distrust of healthcare professionals by the Black community stems from years of medical mistreatment based on their race (Hong et al., 2018). Some patients find ACP and naming a medical surrogate stressful and burdensome (Blackwood et al., 2019; Jimenez et al., 2018; Ramsaroop et al., 2007). Preconceived ideas about ACP and ACDs can hinder ACP interventions in the primary care setting (Freytag & Rauscher, 2017). Many patients reported confusion between hospice and palliative care and concern that ACP may lead them not to receive desired treatments (Freytag & Rauscher, 2017). One study reported that patients often felt too young to participate in ACP, the topic was too emotional, and ACP was not a priority (Bernard et al., 2020). Another study aimed to engage frail older adults in ACP and

found that patients felt ACP was rarely relevant to their lives despite self-reported poor health (Combes et al., 2021).

Conceptualizing Wishes

One evidence-based practice guideline recommends that providers facilitate a patient's exploration of personal values and goals for future care to aid in the ACP process (Rietjens et al., 2017). A qualitative study found that patients reported personal values to have the most influence on shaping their medical preferences (Abu Al Hamayel et al., 2019). Patients prefer to discuss their values, perception of quality of life, and concerns with their healthcare providers and family before completing an ACD (Freitag & Rauscher, 2017; Jimenez et al., 2018). When engaging in ACP, patients consider where they want to die and whom they want present (Abu Al Hamayel et al., 2019). Patients draw from previous healthcare experiences, both personal and individuals they know, to form their preferences for end-of-life care (Abu Al Hamayel et al., 2019).

Outcomes of ACP

Outcome Measures of ACP Interventions

Documented discussion of ACP in the EHR was used as an outcome measure for patient engagement in several studies (Howard et al., 2016; Ramsaroop et al., 2007; Sudore et al., 2013; Sudore et al., 2017a). One study found that measuring ACD completion rates alone as an outcome for ACP interventions limits measuring the full scope of ACP behaviors that patients may engage in—deeming the intervention unsuccessful (Sudore et al., 2013). Patients engage in ACP by exploring end-of-life care options, identifying a medical surrogate, and sharing their preferences with people important to them (Sudore et al., 2013; Sudore et al., 2018b). Measurement of ACD completion without analysis of other ACP behaviors would not account for the numerous activities that patients may engage in throughout the ACP process. One

evidence-based practice guideline recommends using process, action, quality of care, and healthcare outcomes as outcome domains for ACP to ensure that changes in behaviors and engagement in the process of ACP can be evaluated (Sudore et al., 2018a). Documentation of treatment preferences in the EHR is an additional outcome of patients engaging in the ACP process (Sudore et al., 2018a).

Benefits of ACP

Patients who engage in ACP behaviors are more likely to have healthcare providers and their families incorporate their wishes into future treatment decisions (Bernard et al., 2020; Freytag & Rauscher, 2017; Howard et al., 2020; Sudore et al., 2018a). Although care consistent with goals is a relevant metric in ACP interventions, no standardized or reliable method is present to measure this outcome (Sudore et al., 2018b). One systematic review found that patients who participate in ACP benefit from preserved autonomy in medical decision-making (Jimenez et al., 2018). Patients and families experience more peace and less moral distress when healthcare wishes have been discussed prior to serious illness (Freytag & Rauscher, 2017; Jimenez et al., 2018). Two systematic reviews and one evidence-based practice guideline acknowledged that ACP decreases unnecessary utilization of health services and healthcare costs (Jimenez et al., 2018; Ramsaroop et al., 2007; Rietjens et al., 2017).

Summary of Evidence

The research shows that the ACP Engagement Survey can detect patients who are in the contemplation stage of ACP and measure changes in ACP behaviors (Lum et al., 2018; Shi et al., 2019; Sudore et al., 2013; Sudore et al., 2017a; Sudore et al., 2017b; Sudore et al., 2017c). Identifying patients contemplating ACP is essential so that the patient-provider relationship can be respected and maintained (Royal College of Physicians of London, 2009). Patient and

provider discussion about ACP and end-of-life care is the most successful method to increase patient engagement in ACP because patients can ask questions and contemplate how their values influence their healthcare preferences (Ramsaroop et al., 2007; Risk et al., 2019). Many other interventions have been studied to increase patient engagement in ACP because of the barriers to implementing direct patient and provider communication. Educational materials that utilize various learning methods have shown to engage patients in ACP behaviors (Howard et al., 2018; Ramsaroop et al., 2007; Shi et al., 2019; Sudore et al., 2017a; Sudore et al., 2018b).

Literature Discussion

Evidence Alignment and Strength

The literature provides evidence validating the use of the ACP Engagement Survey in the primary care setting. Evidence from five level II studies found that the ACP Engagement Survey identifies a patient's readiness to engage in ACP (Lum et al., 2018; Shi et al., 2019; Sudore et al., 2013; Sudore et al., 2017a; Sudore et al., 2018b). When used in the primary care setting, the ACP Engagement Survey can identify a change in patient behavior patterns (Lum et al., 2018; Shi et al., 2019; Sudore et al., 2017a; Sudore et al., 2017b; Sudore et al., 2018). Four level I systematic reviews were identified that reviewed the evidence concerning facilitators and barriers associated with ACP in the primary care setting (Blackwood et al., 2019; Hong et al., 2018; Ramsaroop et al., 2007; Risk et al., 2019). Many different engagement strategies have been utilized to increase ACP in primary care. Four systematic reviews found sufficient evidence to suggest that providers do not have adequate time to engage in ACP in the primary care setting with their patients (Blackwood et al., 2019; Jimenez et al., 2018; Ramsaroop et al., 2007; Risk et al., 2019). Several studies with high levels of evidence found that mixed methods of learning increased patient engagement in ACP (Howard et al., 2020; Jimenez et al., 2018; Ramsaroop et

al., 2007; Shi et al., 2019; Sudore et al., 2017a; Sudore et al., 2018b). The Royal College of Physicians of London (2009) comprised a level I evidence-based clinical practice guideline recommending ACP occur in the primary care setting before patients become acutely ill.

Limitations, Weaknesses

Limitations exist within the research related to the inquiry. There are no systematic reviews pertaining to the ACP Engagement Survey, resulting in lower levels of evidence to support the survey. Additionally, the ACP Engagement Survey was created by Rebecca Sudore, the founder of PREPARE, which may present bias or validity concerns within study results (Sudore et al., 2013; Sudore et al., 2017a; Sudore et al., 2017b; Sudore et al., 2018b). Written education materials do improve patient engagement in ACP but were found not to be the most effective method to engage patients in the primary care setting (Freytag et al., 2020; Ramsaroop et al., 2007). This weakness caused by institutional barriers, including short appointment visits and lack of support systems, largely influenced the success of ACP interventions in the research (Blackwood et al., 2019; Bernard et al., 2020; Hafid et al., 2021; Jimenez et al., 2018; Kendell et al., 2020).

Gaps

No gaps existed within the literature addressing the barriers and facilitators associated with ACP or ACD clinical guidelines. No studies were published evaluating the long-term use of the ACP Engagement Survey to identify patients ready to engage in ACP. Similarly, studies that implemented PREPARE in the primary care clinic ranged from three to 15 months in length (Howard et al., 2018; Howard et al., 2016; Shi et al., 2019; Sudore et al., 2017b; Sudore et al., 2018b). Further research is needed to evaluate the sustainability of PREPARE tools in the primary care setting.

Theory

The Theory of Human Becoming was selected for application to the quality improvement project (see Appendix F). The Theory of Human Becoming was developed by Rosemarie Parse and is a middle-range nursing theory that focuses on human wholeness, the relationship between the human and the universe, and the nature of one's health (Parse, 1992). The theory aims to describe and understand each individual's connection with their environment, experiences, and health to create a lived reality and perspective of health and wellness that is unique to each person (Parse, 1992). The central concept of the Theory of Human Becoming is quality of life (Morris, 2006; Parse, 1994). The theory defines quality of life as what each patient says quality of life is to them based on personal lived experiences and perceptions (Parse, 1994). Parse states that quality of life is subjective, an *umbrella term*, and may change based on an individual situation and the meaning they choose to give to their life (Parse, 1994). The Theory of Human Becoming describes how individuals apply meaning, rhythmicity, and transcendence to their lives (Parse, 1999).

Quality of life is a crucial term both patients and providers must define throughout the ACP process. Determining a patient's perception of quality of life is critical so that providers can educate patients on care that aligns with their values. Patients must understand what they consider to be a quality life to participate in ACP behaviors. The current project intervention guides patients through activities that aid in identifying important beliefs that providers and caregivers should honor in end-of-life care (PREPARE For Your Care, n.d.). No studies on improving ACP engagement within the primary care setting utilizing the Theory of Human Becoming were identified. Despite this knowledge gap, the literature has depicted many examples of the theory's application to evaluate quality of life from the patient's perspective.

Methods

IRB and Ethics

This project was reviewed by the University of Missouri Kansas City (UMKC) Institutional Review Board and deemed to be quality improvement (see Appendix L). Patient privacy was maintained using computer-generated randomized coding at the time of administration of the survey tool. Only basic demographic information, including gender, race, and age, was obtained from the participants. Patient and provider interactions remained confidential due to the sensitivity and privacy of ACP. This project was partially funded by the UMKC Retiree's Association. The project lead had no conflicts of interest to report.

Setting and Participants

The improvement initiative was implemented at a federally qualified health center in the Midwest. The primary care clinic is located in a rural town and cares for patients of low socioeconomic status. The clinic serves many older adult patients with multiple comorbid conditions such as hypertension, hyperlipidemia, heart failure, chronic obstructive pulmonary disease, and diabetes. Consecutive sampling was used to identify patients that were 50 years of age or older, had two or more chronic conditions, and could read and speak English. Patients who had ACDs were included in the project to analyze the change process patients undergo throughout ACP.

Evidence-Based Practice Intervention

Printed and online education materials from PREPARE were implemented as the project intervention. The PREPARE program aids individuals in making medical decisions for their future selves and facilitating patient and provider communication regarding ACP (PREPARE for Your Care, n.d.). Licensing was obtained in the Summer of 2022 for quality improvement

purposes (see Appendix J). Participants were provided printed educational materials from PREPARE. In addition, patients were educated on how to access PREPARE online, where they can use the program to guide them through choosing a medical surrogate, learn how to communicate their wishes best, and complete advance care documents (ACD).

Procedure

Before project implementation, the primary care practice's nurse practitioner (NP) and medical assistant (MA) were educated on the ACP Engagement Survey and the PREPARE educational resources. Clinic staff was educated on the proper administration and scoring of the ACP Engagement Survey and had the opportunity to use the PREPARE online resources. This education time allowed the nurse practitioner provider and clinic staff to become familiar with the survey tool and ask questions regarding ACP.

The MA and NP at the primary care clinic were responsible for identifying patients who met inclusion criteria and initiating the screening with the ACP Engagement Survey. Patients were administered the four-item ACP Engagement Survey by the MA during rooming and triage. The MA calculated the survey score and reported the behavior change stage to the provider prior to seeing the patient. All project participants were provided with PREPARE educational materials and the URL to the PREPARE website. At the end of the patient's visit, the NP provided the patient with printed PREPARE educational materials and educated the patient on access to PREPARE online. Patients had the opportunity to ask questions and discuss ACP topics if appointment time allowed. Patients who had additional questions outside the standard visit time were advised to schedule an appointment to discuss ACP.

Patients were contacted one-month following their initial clinic visit where they were provided with PREPARE materials. This time period allowed patients to engage with the

PREPARE website and participate in ACP behaviors. Participants were contacted via email or mail for follow-up. The follow-up included completion of the ACP Engagement Survey and encouragement to bring their ACDs to the primary care clinic to be added to their EHR. After the initial five months of project implementation, data were analyzed to identify relationships between age or gender and ACP behaviors (see Appendix H & I).

Barriers

A potential barrier to the project was the project lead's lack of rapport with patients at the project site locations. Advance care planning is a sensitive topic that patients may only feel comfortable discussing with their established healthcare providers. To overcome this barrier, the project leader established a need for change and excitement among the healthcare team who have rapport with their patients. Healthcare team members may not see the importance of ACP, particularly in the primary care setting, and disengage patients from participating in the project. Additionally, healthcare team members may find the ACP Engagement Survey administration burdensome or an extra task to complete. It was essential that the project lead educate the healthcare team on the benefits of ACP in the primary care setting and integrate the survey into the clinic workflow seamlessly.

Facilitators

The educational tools from PREPARE offer many supportive resources for patients and healthcare providers. The PREPARE for Your Care (n.d.) website is easy to navigate and includes a video educating users on using their computer, tablet, or smartphone to participate in ACP. Providers and patients can utilize these free resources anytime, further facilitating ACP.

The project was partially funded by the University of Missouri – Kansas City Retirees

Association. Funds assisted in coverage of the licensing fee for PREPARE, printed surveys, and education materials to facilitate project implementation.

Sustainability

A potential lack of patient interest in ACP threatened the project's sustainability. When patients are not prepared to participate in ACP, it is challenging to determine the usefulness of the intervention on ACP engagement. The brief length of the ACP Engagement Survey, totaling four questions, simplifies the tool's integration into the primary care setting. It is known that providers have limited time to spend with their patients due to institutional pressures (Blackwood et al., 2019; Ramsaroop et al., 2007). The tool provides a simple method to identify patients prepared to engage in ACP and addresses institutional time constraints that healthcare providers encounter. The ease of use and minimal time commitment to screen patients with the ACP Engagement Survey led to sustainability of use after project completion.

Evidence-Based Practice Model

The Stetler Model of Evidence-Based Practice is a model that defines the steps to find, sort, and evaluate evidence, followed by recommending and implementing change based on the findings (Stetler, 2001). This model aligns with the project because the steps outlined in the model are similar to the actions in the QI project. Phase I of the evidence-based practice (EBP) model includes identifying a problem or area of less-than-best practice (Stetler, 2001). This project was conducted because patients benefit from ACP before becoming acutely ill, but ACP in primary care is not routinely seen in practice (Royal College of Physicians of London, 2009). Phase II and phase III of the model focus on accumulating, critiquing, and synthesizing the evidence and deciding, based on the strength of the evidence, whether to recommend the findings

for use in practice. The final phases, IV and V, are when the practitioner translates their findings through implementation into their practice, followed by an evaluation of outcomes.

Organizational Change Process

Kotter and Cohen's Model of Change comprises eight steps that lead to organizational change (Kotter Inc., 2018). This model is based heavily on appealing to members of an organization's emotions to empower them to enact change. This change model was selected for the project because the emotional impact ACP has on patients and their families can be used to encourage change among the healthcare team. This model also stresses measuring short-term goals to maintain momentum for change. Patients express many behaviors while engaging in ACP, and it is crucial to measure short-term goals such as identifying a medical surrogate or discussing end-of-life care with a provider to measure project successes.

Project Design

This doctoral project is an evidence-based, QI initiative using a quasi-experimental, pre-post approach conducted over five months. The project used the four-item ACP Engagement Survey to identify patients' behavior change stage. Outcomes measured included patient engagement in ACP utilizing patients' behavior change stage (pre and one-month post-intervention) and behavior change stage by age and gender (pre-intervention).

Validity

Several factors support the internal validity of the quality improvement project. The project was conducted with no selection bias in the patients asked to participate. All patients that met the criteria were offered the opportunity to participate in the project. The benefits of ACP make it unethical to withhold tools from patients in the form of a prospective control group. The validity of the ACP Engagement Survey supports the internal validity of the project (Sudore et

al., 2017). This project was designed to address the typical barriers that patients and providers face with ACP in primary care, including lack of time during patient encounters, low levels of health literacy, and incorporation of the various ways individuals learn new information.

Ensuring that the project design addresses real-world issues in ACP contributes to the usefulness of this evidence-based quality improvement project and the transfer of the intervention to other sites.

Primary Outcome

The primary outcome was to determine if PREPARE educational materials increase patient engagement in ACP in the primary care setting. Engagement in ACP was measured using the ACP Engagement Survey. Secondary outcomes measured included patient likelihood to engage in ACP by age and gender.

Measurement Instrument

The measurement instrument utilized was the ACP Engagement Survey (see Appendix M). This tool measures the complex process of behavior change that patients undergo throughout the ACP experience and was used to measure patient engagement in ACP (Sudore et al., 2017). The four-item survey tool uses the average score from a five-point Likert scale to assess patient readiness, self-efficacy, and behavior changes in ACP. Cronbach's alpha for the four-item survey is 0.86. The test-retest reliability for the survey using the intraclass correlation is 0.70, and the Pearson correlation coefficient is 0.89. Participants in the project were asked to complete the survey on paper upon initial patient encounters. The survey took patients a total of five to eight minutes to complete. Survey scores were calculated by the clinic's MA. Patients were contacted and asked to repeat the survey one-month after their initial clinic visit. The ACP Engagement Survey was available without cost for use throughout the project.

Quality of Data

To establish a baseline of patient engagement in ACP behaviors, patients completed the ACP engagement survey before interacting with the PREPARE learning materials. Participants were encouraged to be honest in their answers to ensure an accurate representation of their unique ACP experience. The total project implementation time was five months, with data collection ongoing throughout the project's entirety. Patients repeated the ACP engagement survey one month after their initial encounter with PREPARE materials.

Calculations for sample size were completed using G*Power (Faul et al., 2007). The sample size required to complete a power analysis using a paired t-test was 27 with a power of .80, effect of .50 (medium), and error probability of .05. A sample size of 30 was required to complete a power analysis with a repeated measures ANOVA with a power of .80, effect of .50 (medium), and error probability of .05.

Howard et al. (2020) conducted a pre-post multisite study over 15 months implementing PREPARE and measuring patient engagement in ACP utilizing the ACP engagement survey. The study recruited 136 participants across two primary care clinics. The mean behavior change score calculated from the ACP engagement survey at baseline data collection was 2.9 and 3.5 on follow-up. The mean change between the pre-post intervention behavior change scores was .6, producing a moderate effect size (Cohen $d = .75$).

Statistical Analysis Tests

Statistical analysis was completed using Jamovi (see Appendix N). The collected demographic information (age, gender, race) was analyzed using descriptive analysis. Pre-intervention ACP Engagement Survey scores were compared by gender, age, and race. The age of participants was separated into categories of 50-59, 60-69, 70-79, and 80 years of age and

older for data analysis. Age and pre-intervention ACP Engagement Scores were analyzed using Spearman's correlation test.

Results

Setting and Participants

Implementation began in October 2022. Post-intervention follow-up surveys were completed in March 2023. The project took place at a primary care, federally qualified healthcare center in the Midwest. The project recruited 27 participants that met inclusion criteria (pre-intervention $n=27$). Post-intervention follow-up resulted in six participants completing the ACP Engagement Survey after interacting with PREPARE materials (post-intervention $n=6$). All participants were Caucasian. Female participants accounted for 63.0% ($n=17$) of project participants, and males represented 37.0% ($n=10$) of the sample. The participant age range was 50 to 93 years of age. The average age of participants was 68.4 years of age ($M=68.4$).

Intervention Course

Pre-intervention surveys were completed by participants at the primary care clinic from October through December of 2022. Following completion of the pre-intervention ACP Engagement Survey, participants were given PREPARE handout materials and educated on accessing PREPARE's interactive website. Thirty-three participants originally completed pre-intervention surveys, but six were excluded from data analysis for a substantial amount of missing data. Post-intervention surveys were mailed or emailed to participants approximately one month after being provided with PREPARE materials from December 2022 through March 2023. Participants who did not complete follow-up surveys when initially delivered were sent reminder correspondences to engage with PREPARE materials and complete the post-intervention survey. Reminder emails were scheduled weekly for three weeks if post-intervention

surveys still needed to be received from the participant. Printed reminder correspondences were sent in the mail if the participant had not responded within three weeks of the initial follow-up survey being sent and no email address had been provided to the project team. A total of nine participants returned post-intervention surveys, but three were excluded due to missing data. The data analysis was conducted in March 2023.

Outcome Data

Pre-intervention and Gender

Both males and females in the pre-intervention group were in the contemplation phase of behavior change (female $M=2.97$, male $M=2.80$, overall $M=2.91$). Males and females were least likely to participate in discussions about their future medical care with their healthcare provider compared to engaging in other ACP behaviors. Males expressed less interest than females in talking with their primary care provider about their care. The ACP behavior females were most likely to engage in was discussing their medical care with their medical decision-maker ($M=3.24$). Males expressed equal interest in signing official paperwork naming a medical decision maker ($M=3.10$) and speaking to their medical decision maker about their healthcare preferences ($M=3.10$).

Pre-intervention and Age

Pre-intervention participants who were 60 or older were in the contemplation phase of behavior change. Participants aged 60-69 were most likely to engage in ACP behaviors ($n=6$; $M=3.54$). The data revealed that patients aged 60-69 were considering signing official papers naming a medical decision-maker within the next thirty days ($n=6$; $M=4.0$). Patients 50-59 years old were in the pre-contemplation behavior change stage and least likely to participate in ACP ($n=6$; $M=2.25$). Patients aged 50-59 years were least likely to discuss their future medical care

with their healthcare provider compared to all age groups and other ACP behaviors ($n=6$; $M=1.50$). The Spearman Correlation test showed no correlation between age and pre-intervention ACP Engagement Survey scores.

Primary Outcome and Missing Data

The primary outcome of the project, determining if PREPARE materials increased patient engagement in ACP behaviors, was unable to be measured due to the small post-intervention sample size of six. Data missing from both the pre and post-intervention groups that resulted in participant exclusion was due to participants marking either *not sure* or *refused* on the four-item ACP Engagement Survey. See Appendix O for the completed statistical analysis table.

Discussion

Successes

Most participants in the project were in the contemplation behavior change stage before interacting with PREPARE. Patients contemplating ACP are more likely to interact with intervention materials and be open to discussing ACP. Participants were contemplating completing a variety of ACP behaviors within the upcoming six months, including signing official papers, naming a medical surrogate, discussing their care with their medical decision-maker, and talking with their healthcare provider about future medical care. Older adults contemplating ACP behaviors accept educational materials regarding ACP and are likely to partake in these behaviors in the next six months.

Project Strengths

The organizational culture of the primary care clinic led to the project's success. The clinic averages 14 patient visits per day, allowing ample time to discuss ACP and educate patients on PREPARE resources. The nurse practitioner at the clinic had experience

implementing quality-improvement initiatives at the project site and offered expertise and input throughout the implementation process. The intervention tool, PREPARE, provided many materials that assisted in training the clinic staff before project implementation. Additionally, PREPARE has ready-to-print pamphlets and handouts for clinic use that were utilized throughout the project. The resources provided by PREPARE supported the project leader, clinic staff, and participants from project planning to completion.

Identifying patients that qualified for project participation was successful with the recruitment of 33 participants. The MA and LPN staff at the clinic assessed each patient for inclusion criteria and asked permission from the patient to participate in the quality improvement project. The completed pre-intervention surveys were stored responsibly and collected by the project leader at weekly site visits. The project leader utilized the Research Electronic Data Capture (REDCap) software to enter pre-intervention demographic and ACP Engagement Survey data and schedule post-intervention follow-up surveys to be sent out one month after the participant was given PREPARE materials. Using the REDCap software allowed the project to successfully store pre-intervention data and schedule and send post-intervention follow-up surveys in a secure and timely manner.

Comparison to the Literature

The project results were similar to published studies in the literature. The study conducted by Howard et al. (2016) recruited patients in the primary care setting who were 50 or older and measured engagement in ACP. Participants demonstrated a baseline behavior change score in the contemplation phase ($M=3.0$, $SD=0.6$; Howard et al., 2016). Similarly, another study in the primary care setting showed that patients 55 years old with two or more chronic conditions

were in the contemplation phase of behavior change before intervention with PREPARE materials ($M=2.6$; Sudore et al., 2018b).

Two studies had varying results from this QI project. A study by Sudore et al. (2013) showed that patients 55 years of age or older were in the preparation phase of behavior change in relation to ACP ($M=3.7$). Another study demonstrated that patients 50 years or older were in the preparation phase of behavior change ($M=4.0$; Howard et al., 2020). Although the literature had varying results identifying patients' behavior change stage in the primary care setting, all studies showed that patients were contemplating engaging in ACP behaviors within the next six months or less.

Limitations

Internal Validity

Attrition bias posed a threat to the internal validity of the project. The attrition rate from pre to post-intervention was 78%. The ACP engagement from pre and post-intervention was not evaluated due to the small post-intervention sample size. A confounding factor that could impact the project results is the participants' individual healthcare habits. Patients that partake in various health behaviors such as healthy eating, exercise, and home monitoring of their chronic conditions may be more likely to engage in other healthcare habits such as ACP. Another factor that impacts internal validity is individuals understanding of medical treatments, the course of their chronic conditions, and comfort level with discussing end-of-life care. Patients with different experiences with healthcare may express varying levels of interest in ACP behaviors.

External Validity

The participants all identified as Caucasian, impacting the validity of transfer of the intervention experience to other patient populations of different racial backgrounds to foster

improvements. Although the sample was not representative of the U.S. population, the sample is generalizable to many other rural Midwest towns that have limited racial diversity. Due to the clinic's rural location, the QI intervention may not be transferrable to suburban or urban patient populations that have access to different healthcare and varying life experiences that impact how they view quality of life.

Sustainability

To sustain the implementation of PREPARE materials at the primary care clinic, educational pamphlets and handouts will be stationed in each patient exam room. Placing PREPARE materials in each exam space will allow the healthcare provider easy access to the materials for distribution. The only expense to maintain PREPARE materials in the clinic setting is the low-cost printing fees, increasing sustainability of education materials in the clinic setting. The greatest obstacle to the sustainability of the clinic continuing to encourage patients to engage in ACP behaviors is maintaining the urgency and importance of ACP within the institution. The four-item ACP Engagement Survey takes minimal time for patients to complete and can be used to identify patients in the contemplation behavior change of ACP. Primary care clinics can use the survey as a screening tool and provide patients in the contemplation phase with printed PREPARE education materials. The project lead recommends that the clinic ask patients if they have ACDs at each visit to ensure that important documentation is added to EHR.

Minimization of Limitations

Throughout project implementation, all participants were provided with the same educational materials that introduced the topic of ACP and the various ways individuals can participate in ACP behaviors. By administering consistent educational materials to all participants, all participants had the same baseline understanding of ACP prior to interacting

with PREPARE and completing the post-intervention survey. Education materials and an introduction to PREPARE resources were provided by the clinic NP, who had an established relationship with project participants. Both mail and email follow-up were implemented so participants could be reached by whichever method best suited them.

The primary project outcome of change could not be measured due to the small post-intervention sample size. Therefore, the project did not conclude whether using PREPARE in the primary care setting increased patient engagement in ACP behaviors. Results from the project are reflective of Caucasian patients' opinion on ACP that reside in the rural Midwest but do not reflect how various cultures and patients of different racial backgrounds engage in ACP or in different settings.

Interpretation

Expected and Actual Outcomes

The project expected to increase patient engagement in ACP by providing access to PREPARE. Although a comparison could not be completed to determine if PREPARE increased patient engagement, patients considering engaging in ACP were accepting of healthcare support related to ACP and educational materials. The project leader anticipated that older patients would be more likely to engage in ACP behaviors than younger adults. The data showed no correlation between age and ACP behaviors. The difference between the expected and actual outcome of age and increased engagement in ACP may be due to the small sample size of patients who were 80 or older.

Intervention Effectiveness

The project was unable to conclude the effectiveness of the PREPARE program in increasing patient engagement in ACP behaviors due to the small post-intervention sample size. The four-item ACP Engagement Survey was easy to administer to participants and required

minimal time for patients to complete. The four-item survey is a convenient way to screen patients in a fast-paced primary care clinic for their interest in ACP behaviors, as evidenced by the successful pre-intervention survey phase of the project. The support of a doctorate-level nurse practitioner at the project site was beneficial throughout the project's implementation phase. The nurse practitioner provided valuable QI experience to the project when obstacles arose, including addressing decreased post-intervention participation. The rural, federally qualified healthcare center was the ideal setting for project implementation. The institution prioritized the quality and quantity of time patients and providers could interact, which benefited the distribution of PREPARE materials to patients.

Intervention Revisions

In future implementation or replication of this project, extended follow-up time is suggested to allow more participants to contemplate ACP. The contemplation stage of the behavior change process is classified as having an interest in acting on a behavior within the next six months. The project's planning process delayed project implementation, which shortened the allotted post-intervention follow-up time. Extending patient follow-up would allow participants more time to interact with PREPARE materials, contemplate their future medical care, and complete an ACD.

Another recommended revision to the intervention steps is incorporating in-person follow-up to the post-intervention data collection plan. Obtaining a sufficient number of participants to complete post-intervention follow-up was a limitation of this project and the evaluation of the project's primary outcome. The follow-up ACP Engagement Survey could be completed by participants at follow-up visits at the primary care clinic for management of their chronic conditions. Adjusting how participant follow-up is conducted by seeing individuals in-

person ensures that the project team will contact the participant again, leading to a larger post-intervention sample size.

Impact on the Health System

The findings from the project demonstrate that patients 50 years of age and older who suffer from chronic medical conditions are contemplating ACP behaviors. Patients contemplating ACP behaviors are likely to be encouraged to participate in ACP when provided with support from their healthcare provider and educational materials. The PREPARE education materials address institutional barriers to assisting patients in ACP by providing an interactive learning environment in the comfort of a patient's home.

The estimated budget for the project was under the actual cost of the implementation and dissemination (see Appendix B). The project was partially funded by UMKC's Retiree's Association, and the project team leader covered additional costs. Conference and associated professional membership fees totaled more than initially anticipated for the project. Fortunately, the licensing fee for using PREPARE resources only applies to QI or research. Primary care and other healthcare institutions can utilize the PREPARE educational resources without cost, if not for research. The PREPARE program offers educational materials in several languages that clinics can download, with printing fees the only cost to the institution. The accessibility of PREPARE materials is a significant contributor to the sustainability of the intervention tool.

Conclusion

The online platform of PREPARE is a useful ACP education tool for patients and their families. PREPARE grants patients access to ACP resources conveniently, allowing patients to participate in planning at their own pace. Providing engaging multimodal education to patients addresses the barrier of provider time constraints to discuss ACP in primary care. Future

outcome studies for PREPARE include qualitative data collection measuring patients' feelings towards ACP and worry about end-of-life care after interacting with the resources.

Implementation of PREPARE in the future includes specialty clinics such as cardiology, nephrology, and pulmonology, where patients are often treated for chronic conditions with poor health outcomes.

Following the implementation of this evidence-based QI project, the study findings were presented to UMKC and the project site. The project was also presented at the Midwest Nursing Research Society's annual conference in Des Moines, Iowa. Project findings will also be submitted for publication in a peer-edited journal and disseminated at a regional healthcare conference.

Clinical practice guidelines recommend that providers assess their patients' readiness to engage in ACP and support ACP behaviors in the primary care setting (Rietjens et al., 2017; Royal College of Physicians of London et al., 2009). Many patients rely on their healthcare provider to begin the conversation about ACP (Bernard et al., 2020; Risk et al., 2019). Implementation of the ACP Engagement Survey will assist healthcare providers in identifying patients who are ready to engage in ACP. The PREPARE provides patients with multiple learning methods to engage in ACP behaviors. Using the ACP Engagement Survey with supplemental PREPARE resources in the primary care setting can increase patient engagement in ACP behaviors, improve ACD completion rates, and respect patients' preferences in future medical care.

References

- Abu Al Hamayel, N., Isenberg, S. R., Sixon, J., Smith, K. C., Pitts, S. I., Dy, S. M., & Hannum, S. M. (2019). Preparing older patients with serious illness for advance care planning discussions in primary care. *Journal of Pain and Symptom Management*, 58(2), 244–251.
<https://doi.org/10.1016/j.jpainsymman.2019.04.032>
- American College of Physicians [ACP]. (n.d.). *Advance care planning – Implementation for practice*. Retrieved from https://www.acponline.org/system/files/documents/practice-resources/business-resources/payment/medicare/advance_care_planning_toolkit.pdf
- Bernard, C., Tan, A., Slaven, M., Elston, D., Heyland, D., & Howard, M. (2020). Exploring patient-reported barriers to advance care planning in family practice. *BMC Family Practice*, 21(1), 1–9.
<https://doi.org/10.1186/s12875-020-01167-0>
- Blackwood, D. H., Walker, D., Mythen, M. G., Taylor, R. M., & Vindrola-Padros, C. (2019). Barriers to advance care planning with patients as perceived by nurses and other healthcare professionals: A systematic review. *Journal of Clinical Nursing*, 28(23–24), 4276–4297.
<https://doi.org/10.1111/jocn.15049>
- Brungardt, A., Daddato, A. E., Parnes, B., & Lum, H. D. (2019). Use of an ambulatory patient portal for advance care planning engagement. *The Journal of the American Board of Family Medicine*, 32(6), 925–930. <https://doi.org/10.3122/jabfm.2019.06.190016>
- Center for Disease Control and Prevention [CDC]. (2017). Give Peace of Mind: Advance Care Planning. Retrieved from <http://www.cdc.gov/aging/advancecareplanning>
- Combes, S., Forbes, G., Gillett, K., Norton, C., & Nicholson, C. (2021). Development of a theory-based intervention to increase cognitively able frail elders' engagement with advance care

planning using the behaviour change wheel. *BMC Health Services Research*, 21(1), 1–16.

<https://doi.org/10.1186/s12913-021-06548-4>

Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39, 175-191.

Freytag, J., Street, R. L., Barnes, D. E., Shi, Y., Volow, A. M., Shim, J. K., Alexander, S. C., & Sudore, R. L. (2020). Empowering older adults to discuss advance care planning during clinical visits: The PREPARE randomized trial. *Journal of the American Geriatrics Society*, 68(6), 1210–1217. <https://doi.org/10.1111/jgs.16405>

Freytag, J., & Rauscher, E. A. (2017). The importance of intergenerational communication in advance care planning: Generational relationships among perceptions and beliefs. *Journal of Health Communication*, 22(6), 488–496. <https://doi.org/10.1080/10810730.2017.1311971>

Hafid, A., Howard, M., Guenter, D., Elston, D., Fikree, S., Gallagher, E., Winemaker, S., & Waters, H. (2021). Advance care planning conversations in primary care: A quality improvement project using the serious illness care program. *BMC Palliative Care*, 20(1), 122.

<https://doi.org/10.1186/s12904-021-00817-z>

Hayes, T. & Gillian, S. (2020). Chronic Disease in the United States: A Worsening Health and Economic Crisis. <https://www.americanactionforum.org/research/chronic-disease-in-the-united-states-a-worsening-health-and-economic-crisis/>

Holland, D. E., Vanderboom, C. E., Dose, A. M., Ingram, C. J., Delgado, A., Austin, C. M., Green, M. J., & Levi, B. (2017). Nurse-led patient-centered advance care planning in primary care: A pilot study. *Journal of Hospice & Palliative Nursing*, 19(4), 368–375.

<https://doi.org/10.1097/NJH.0000000000000358>

- Hong, M., Yi, E.-H., Johnson, K. J., & Adamek, M. E. (2018). Facilitators and barriers for advance care planning among ethnic and racial minorities in the U.S.: A systematic review of the current literature. *Journal of Immigrant and Minority Health, 20*(5), 1277–1287.
<https://doi.org/10.1007/s10903-017-0670-9>
- Howard, M., Allatt, P., Bernard, C., Klein, D., Elston, D., Tan, A., Slaven, M., Barwich, D., You, J. J., Sudore, R., Arora, N., Mroz, L., Heyland, B., Mueen, M., & Heyland, D. (2018). Efficacy of advance care planning interactive web sites and workbooks to improve patient engagement in primary care: The results of tool evaluations. *Journal of Pain and Symptom Management, 56*(6), e42–e43. <https://doi.org/10.1016/j.jpainsymman.2018.10.465>
- Howard, M., Bonham, A. J., Heyland, D. K., Sudore, R., Fassbender, K., Robinson, C. A., McKenzie, M., Elston, D., & You, J. J. (2016). Measuring engagement in advance care planning: A cross-sectional multicentre feasibility study. *BMJ Open, 6*(6), e010375.
<https://doi.org/10.1136/bmjopen-2015-010375>
- Howard, M., Robinson, C. A., McKenzie, M., Fyles, G., Hanvey, L., Barwich, D., Bernard, C., Elston, D., Tan, A., Yeung, L., & Heyland, D. K. (2021). Effect of “Speak Up” educational tools to engage patients in advance care planning in outpatient healthcare settings: A prospective before-after study. *Patient Education and Counseling, 104*(4), 709–714.
<https://doi.org/10.1016/j.pec.2020.11.028>
- Howard, M., Robinson, C. A., McKenzie, M., Fyles, G., Sudore, R. L., Andersen, E., Arora, N., Barwich, D., Bernard, C., Elston, D., Heyland, R., Klein, D., McFee, E., Mroz, L., Slaven, M., Tan, A., & Heyland, D. K. (2020). Effect of an interactive website to engage patients in advance care planning in outpatient settings. *Annals of Family Medicine, 18*(2), 110–117.

Jimenez, G., Tan, W. S., Virk, A. K., Low, C. K., Car, J., & Ho, A. H. Y. (2018). Overview of systematic reviews of advance care planning: Summary of evidence and global lessons. *Journal of Pain and Symptom Management*, 56(3), 436-459.e25.

<https://doi.org/10.1016/j.jpainsymman.2018.05.016>

Kaiser Family Foundation. (2015). Medicare's Role in End-Of-Life Care. Retrieved from <http://files.kff.org/attachment/fact-sheet-10-faqs-medicares-role-in-end-of-lifecare>

Kendell, C., Kotecha, J., Martin, M., Jorgensen, M. & Urquhart, R. (2020). Patient and caregiver perspectives on early identification for advance care planning in primary healthcare settings. *BMC Family Practice*, 21(1), 1–9. <https://doi.org/10.1186/s12875-020-01206-w>

Kotter Inc. (2018). *8 steps to accelerate change in your organization*.

<https://www.kotterinc.com/research-and-insights/8-steps-accelerating-change-ebook-2020/>

Lum, H. D., Barnes, D. E., Katen, M. T., Shi, Y., Boscardin, J., & Sudore, R. L. (2018). Improving a full range of advance care planning behavior change and action domains: The PREPARE randomized trial. *Journal of Pain and Symptom Management*, 56(4), 575-581.e7.

<https://doi.org/10.1016/j.jpainsymman.2018.06.007>

Morris, D. (2006). *Parse's theory of nursing: Human becoming theory*. Springer Publishing Company.

Okada, H., Takenouchi, S., Okuhara, T., Ueno, H., & Kiuchi, T. (2021). Development of a Japanese version of the Advance Care Planning Engagement Survey: Examination of its reliability and validity. *Palliative and Supportive Care*, 19(3), 341–347.

<https://doi.org/10.1017/S1478951520001108>

Parse, R. (1992). Human becoming: Parse's theory of nursing. *Nursing Science Quarterly*, 5(1), p. 35-42.

Parse, R. (1999). *The human becoming theory in practice and research*. Jones and Bartlett Publishers.

Parse, R. (1994). Quality of life: Sciencing and living the art of human becoming. *Nursing Science Quarterly*, 7(1), p. 16-21.

PREPARE For Your Care. (n.d.). *Get started!* <https://prepareforyourcare.org/en/entry>

Nelson-Brantley, H., Buller, C., Befort, C., Ellerbeck, E., Shifter, A. & Ellis, S. (2019). Using implementation science to further the adoption and implementation of advance care planning in rural primary care. *Journal of Nursing Scholarship*, 52(1), p. 55-64.

Ramsaroop, S. D., Reid, M. C., & Adelman, R. D. (2007). Completing an advance directive in the primary care setting: What do we need for success? *Journal of the American Geriatrics Society*, 55(2), 277–283. <https://doi.org/10.1111/j.1532-5415.2007.01065.x>

Rao, J. K., Anderson, L. A., Lin, F.-C., & Laux, J. P. (2014). Completion of advance directives among U.S. consumers. *American Journal of Preventive Medicine*, 46(1), 65–70. <https://doi.org/10.1016/j.amepre.2013.09.008>

Rietjens, J. A., Sudore, R. L., Connolly, M., van Delden, J. J., Drickamer, M. A., Droger, M., van der Heide, A., Heyland, D. K., Houttekier, D., Janssen, D. J., Orsi, L., Payne, S., Seymour, J., Jox, R. J., Korfage, I. J., & Care, E. A. for P. (2017). Definition and recommendations for advance care planning: An international consensus supported by the European Association for Palliative Care. *The Lancet. Oncology*, 18(9), e543–e551. [https://doi.org/10.1016/s1470-2045\(17\)30582-x](https://doi.org/10.1016/s1470-2045(17)30582-x)

Risk, J., Mohammadi, L., Rhee, J., Walters, L., & Ward, P. R. (2019). Barriers, enablers and initiatives for uptake of advance care planning in general practice: A systematic review and critical interpretive synthesis. *BMJ Open*, 9(9), e030275. <https://doi.org/10.1136/bmjopen-2019-030275>

- Royal College of Physicians of London, Clinical Standards Department, Conroy, S., Turner-Stokes, L., & Higgins, B. (2009). *Advance care planning: National guidelines*. Royal College of Physicians.
- Sandoval, M. B., King, J. G., Hart, V., & Repp, A. B. (2019). Increasing advance care planning in primary care practices: A multi-site quality improvement initiative. *Journal of General Internal Medicine*, 34(6), 809–811. <https://doi.org/10.1007/s11606-018-4800-4>
- Shi, Y., Barnes, D. E., Boscardin, J., You, J. J., Heyland, D. K., Volow, A. M., Howard, M., & Sudore, R. L. (2019). Brief English and Spanish survey detects change in response to advance care planning interventions. *Journal of Pain and Symptom Management*, 58(6), 1068-1074.e5. <https://doi.org/10.1016/j.jpainsymman.2019.09.004>
- Stetler, C. B. (2001). Updating the Stetler Model of research utilization to facilitate evidence-based practice. *Nursing Outlook*, 49(6), 272–279. <https://doi.org/10.1067/mno.2001.120517>
- Sudore, R. L., Boscardin, J., Feuz, M. A., McMahan, R. D., Katen, M. T., & Barnes, D. E. (2017a). Effect of the PREPARE website vs an easy-to-read advance directive on advance care planning documentation and engagement among veterans: A randomized clinical trial. *JAMA Internal Medicine*, 177(8), 1102–1109. <https://doi.org/10.1001/jamainternmed.2017.1607>
- Sudore, R. L., Heyland, D. K., Barnes, D. E., Howard, M., Fassbender, K., Robinson, C. A., Boscardin, J., & You, J. J. (2017b). Measuring advance care planning: Optimizing the Advance Care Planning Engagement Survey. *Journal of Pain and Symptom Management*, 53(4), 669-681.e8. <https://doi.org/10.1016/j.jpainsymman.2016.10.367>
- Sudore, R. L., Heyland, D. K., Lum, H. D., Rietjens, J. A. C., Korfage, I. J., Ritchie, C. S., Hanson, L. C., Meier, D. E., Pantilat, S. Z., Lorenz, K., Howard, M., Green, M. J., Simon, J. E., Feuz, M. A., & You, J. J. (2018a). Outcomes that define successful advance care planning: A Delphi Panel

consensus. *Journal of Pain and Symptom Management*, 55(2), 245-255.e8.

<https://doi.org/10.1016/j.jpainsymman.2017.08.025>

Sudore, R. L., Lum, H. D., You, J. J., Hanson, L. C., Meier, D. E., Pantilat, S. Z., Matlock, D. D., Rietjens, J. A. C., Korfage, I. J., Ritchie, C. S., Kutner, J. S., Teno, J. M., Thomas, J., McMahan, R. D., & Heyland, D. K. (2017c). Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi Panel. *Journal of Pain and Symptom Management*, 53(5), 821-832.e1. <https://doi.org/10.1016/j.jpainsymman.2016.12.331>

Sudore, R. L., Schillinger, D., Katen, M. T., Shi, Y., Boscardin, W. J., Osua, S., & Barnes, D. E. (2018b). Engaging diverse English- and Spanish-speaking older adults in advance care planning: The PREPARE randomized clinical trial. *JAMA Internal Medicine*, 178(12), 1616–1625.

Sudore, R., Stewart, A., Knight, S., McMahan, R., Feuz, M., Miao, Y. & Barnes, D. (2013). Development and validation of a questionnaire to detect behavior change in multiple advance care planning behaviors. *PLoS ONE*, 8(9), e72465–e72465.

<https://doi.org/10.1371/journal.pone.0072465>

Teoli, D., & Ghassemzadeh, S. (2022). Patient Self-Determination Act. In *StatPearls*. StatPearls Publishing. <http://www.ncbi.nlm.nih.gov/books/NBK538297/>

United States Census Bureau. (2018). *Older people projected to outnumber children for the first time in U.S. history*. <https://www.census.gov/newsroom/press-releases/2018/cb18-41-population-projections.html>

U.S. Department of Health and Human Services [USDHHS]. (2020). Older adults. *Healthy People 2030*. [https://www.healthypeople.gov/2020/topics-objectives/topic/older-adults#:~:text=In%202014%2C%2014.5%25%20\(46.3,\(98%20million\)%20by%202060.&text=Aging%20adults%20experience%20higher%20risk,2%20or%20more%20chronic%20conditions](https://www.healthypeople.gov/2020/topics-objectives/topic/older-adults#:~:text=In%202014%2C%2014.5%25%20(46.3,(98%20million)%20by%202060.&text=Aging%20adults%20experience%20higher%20risk,2%20or%20more%20chronic%20conditions)

van der Smissen, D., van der Heide, A., Sudore, R. L., Rietjens, J. A. C., & Korfage, I. J. (2021).

Measuring advance care planning behavior in Dutch adults: Translation, cultural adaptation and validation of the Advance Care Planning Engagement Survey. *BMC Medical Research*

Methodology, 21(1), 1–8. <https://doi.org/10.1186/s12874-021-01389-5>

**Appendix A
Evidence Table**

Topic, Theme, Subtopic	First Author, Year	Title, Journal	Purpose	Research Design	Level of Evidence	Sample & Sampling, Setting	Measures & Reliability (if reported)	Results & Analysis Used	Limitations & Usefulness
Engagement in ACP	Brungardt et al., 2019	Use of Ambulatory Patient Portal for Advance Care Planning Engagement <i>Journal of the American Board of Family Medicine</i>	Increase ACP outcomes by engaging older adults in ACP through web-based ACP tools	Quantitative descriptive	Level VI	Patients 65 and older, seen in the primary care clinic within last 18 months, must have a portal account and internet access Convenience sampling Primary care geriatric clinic	Composite ACP action within one year Use of online health portal Documented ACP discussion with provider	16% engagement rate	Small sample size Relatively low read rate of online portal messages
Engagement in ACP	Freytag et al., 2020	Empowering Older Adults to Discuss Advance Care Planning During Clinical Visits: The PREPARE Randomized Trial <i>Journal of the American</i>	Compare patient participation in ACP with PREPARE and an easy to read AD versus easy to read AD only	RCT	Level II	English or Spanish speaking, 55 years of age or older, two or more chronic conditions Random sampling	ACP Engagement Survey “Utterances”	PREPARE engaged 41% more patients in ACP than AD alone	Increased engagement was associated with higher levels of completed ACDs PREPARE with ACD engaged more patients in

		<i>Geriatrics Society</i>				Primary care clinic			ACP than AD alone Measured engagement in utterances
Engagement in ACP	Holland et al., 2017	Nurse-Led Patient-Centered Advance Care Planning in Primary Care: A Pilot Study <i>Journal of Hospice and Palliative Nursing</i>	Evaluate the feasibility of a nurse-led ACP intervention in primary care	Cohort study	Level IV	Community dwelling adults with an ACD who had multiple health conditions Convenience sampling Large primary care clinic in the midwest	Patient and nurse satisfaction with intervention	X ² , Kruskal Wallace test, Fisher exact test Mean satisfaction scores were satisfied to very satisfied	Patients and nurses were both satisfied with nurse-led interventions aimed to increase ACP
Engagement in ACP	Howard et al., 2018	Efficacy of Advance Care Planning Interactive Web Sites and Workbooks to Improve Patient Engagement in Primary Care: The Results of Tool Evaluations <i>Journal of Pain and Symptom Management</i>	Evaluate the efficacy of seven ACP tools (Speak Up, Conversations Matter, PREPARE, etc.) to improve ACP engagement in primary care patients in Canada	Control trial without randomization	Level III	50 years of age or older, English-speaking, cognitively able Convenience sampling Primary care clinic	Increased engagement as measured by the ACP Engagement Survey	Behavior process and action scores significantly increased from baseline at 6-week follow up	ACP workbooks and websites improve patient engage in ACP

Engagement in ACP	Howard et al., 2016	Measuring Engagement in Advance Care Planning: A Cross-Sectional Multicentre Feasibility Study	To assess feasibility of the ACP Engagement Survey in various health care settings	Cross-sectional	Level IV	50 years or older in primary care; 80 or older or 55 and older with clinical markers of advance disease in the hospital; 19 and older in cancer and dialysis clinics Convenience sampling	Feasibility, acceptability and clinical sensibility of the ACP Engagement Survey	Kruskal Wallace test High levels of action and process mean scores	ACP Engagement Survey shows feasibility in outpatient setting Survey does not seem feasible in inpatient settings
Engagement in ACP	Howard et al., 2020	Effect of an Interactive Website to Engage Patients in Advance Care Planning in Outpatient Settings <i>Annals of Family Medicine</i>	Evaluate changes in ACP behaviors among patients in outpatient clinics following the use of PREPARE	Cohort study	Level IV	50 or older in primary care; 18 or older in cancer clinic; not cognitively impaired Primary care clinic, cancer clinic	Behavior change score/ACP Engagement Survey	Mean action score was 4.0 at baseline and 5.2 at follow-up Effect size was moderate (0.75)	Implementation of PREPARE increased patient engagement in ACP Evaluated concurrent with cancer patients, limiting application to primary care use
Engagement in ACP	Howard et al., 2021	Effect of “Speak Up” Educational Tools to Engage Patients in Advance Care	Evaluate the effectiveness of the Speak Up campaign on ACP with patients in	Cohort study	Level IV	50 years of age in primary care; 18 years of age in cancer center, communicate	Score on the ACP Engagement Survey	Mean Behavior Change Process scores: 2.9 at baseline, 3.5 at follow-up (mean change 0.6, 95% confidence)	Public tools may have utilization for engaging patients in ACP

		<p>Planning in Outpatient Healthcare Settings: A Prospective Before-After Study</p> <p><i>Patient Education and Counseling</i></p>	<p>outpatient clinics</p>			<p>in English, internet access</p> <p>Primary care clinic, cancer clinic</p>		<p>interval 0.5 to 0.7; large effect size of 0.8)</p> <p>Mean Action Measure score: 3.7 at baseline; 4.8 at follow-up (mean change 1.1, 95% confidence interval 0.6–1.5; small effect size of 0.2)</p>	<p>Evaluated concurrent with cancer patients, limiting application to primary care use</p>
<p>Engagement in ACP</p>	<p>Lum et al., 2019</p>	<p>Improving a Full Range of Advance Care Planning Behavior Change and Action Domains: The PREPARE Randomized Trial</p> <p><i>Journal of Pain and Symptom Management</i></p>	<p>Compare effectiveness of PREPARE + easy to read AD versus easy to read AD only on the behavior change process</p>	<p>RCT</p>	<p>Level II</p>	<p>60 years of age +, primary care, 2 or more comorbidities</p>	<p>Behavior change process/ACP Engagement Survey</p>	<p>PREPARE resulted in increased behavior change processes on all subscales (p < 0.005)</p>	<p>PREPARE and easy-to-read AD both increase engagement in ACP</p>
<p>Engagement in ACP</p>	<p>Okada et al., 2021</p>	<p>Development of a Japanese Version of the Advance Care Planning Engagement Survey: Examination of</p>	<p>Development and validity testing of the ACP Engagement Survey in Japanese</p>	<p>Quantitative Descriptive</p>	<p>Level VI</p>	<p>65 years of age or older, admitted or visiting a hospital in San Francisco or Canada, Japanese</p>	<p>ACP Engagement Survey</p>	<p>No behaviors exhibited ceiling effects, some behaviors exhibited floor effects</p>	<p>Overall good reliability for both internal consistency and test-retest reliability</p>

		its Reliability and Validity <i>Palliative and Supportive Care</i>				speaking and reading Persons visiting a hospital Convenience sampling		Cronbach's alpha 0.94	Floor effects noted on some behavior processes causing concern for certain behavior measure validity
Engagement in ACP	Ramsarop et al., 2007	Completing an Advance Directive in the Primary Care Setting: What Do We Need for Success? <i>Journal of the American Geriatrics Society</i>	Review studies implemented to increase ACP in the primary care setting and quantify their effect	Systematic review	Level I	Adult patients	Individual and pooled effect size	Pooled effect size 0.50, moderate overall	The most successful ACP intervention is direct patient-provider interaction Passive education materials are the least effective ACP intervention
Engagement in ACP	Royal College of Physicians of London et al., 2009	<i>Advance care planning: National guidelines.</i> Royal College of Physicians	Establish recommendations for clinicians for ACP	EBPG	Level I	Adult patients	Developed with Appraisal of Guideline Research and Evaluation criteria		Recommend to offer ACP in routine primary care visits Providers should initiate ACP discussion in patients with chronic conditions

Engagement in ACP	Sandoval et al., 2019	Increasing Advance Care Planning in Primary Care Practices: A Multi-Site Quality Improvement Initiative <i>Journal of General Internal Medicine</i>	Incorporate ACP into daily practice at 9 primary care clinics	Cohort study	Level IV	All patients 18 years of age or older who are cognitively intact Convenience sampling 9 primary care clinics	Increased AD forms completed and documented in the EHR	Rate of ACP form completion was 4.16 (95% CI 2.32, 7.46) times higher post intervention	Quality initiatives targeted at increasing ACP in the primary care setting can be implanted and successful Large health system initiative with large institutional support
Engagement in ACP	Shi et al., 2019	Brief English and Spanish survey detects change in response to advance care planning interventions. <i>Journal of Pain and Symptom Management</i>	Determine whether shorter versions of the ACP survey are valid	RCT	Level II	50 years of age or older, English-speaking, cognitively able Primary care clinic Convenience sampling	ACP Engagement Survey	Unpaired t test and chi square test intraclass correlations of the 82-item to shorter versions were high (0.78 - 0.97) and this remained consistent among all survey groups	All versions were able to detect behavior changes
Engagement in ACP	Sudore et al., 2013	Development and Validation of a Questionnaire to Detect Behavior Change in Multiple Advance Care	Develop and validate a survey that measures the full ACP process	RCT	Level II	English-speaking, 55 years of age or older, At VA, nursing home, or community, must score 8 or higher on	Behavior change process measures	Cronbach's alpha (0.94) Test retest-- Process Measures intraclass correlation, 0.70;	All process measure subscales were validated and able to be used individually as well

		Planning Behaviors <i>PLoS ONE</i>				mental assessment (SPMSQ)		Action Measures, 0.87	Detect small, but meaningful differences in behavior change
Engagement in ACP	Sudore et al., 2017a	Effect of the PREPARE Website vs an Easy-to-Read Advance Directive on Advance Care Planning Documentation and Engagement Among Veterans: A Randomized Clinical Trial. <i>JAMA Internal Medicine</i>	Compare effectiveness of ACP versus easy to read AD at increasing AD engagement	RCT	Level II	Womens, geriatrics, or general VA clinic; 60 years or older; 2 or more chronic conditions; 2 or more visits with their provider in previous 2 years General health clinic	ACP documentation in EHR ACP Engagement Survey	Unpaired t test, chi square, fisher exact test Using the original 82 item survey as reference/comparison, all survey versions had a Pearson correlation coefficient with P < 0.001 – meaning the survey versions are very comparable to one another	ACP was higher in the PREPARE group than AD alone Participants were compensated for completion of interviews which may cause validity concerns with the study’s results
Engagement in ACP	Sudore et al., 2017b	Measuring Advance Care Planning: Optimizing the Advance Care Planning Engagement Survey <i>Journal of Pain and Symptom Management</i>	Creation/validation of modified/shortened versions of the ACP Engagement Survey	Quasi experimental	Level III	English or Spanish speaking Convenience sampling Primary care, inpatient, and cancer clinics	Measurement of ACP behaviors and level of patient engagement	Pearson correlation coefficient, test retest reliability	Four and nine item surveys are psychometrically sound and can be used for QI initiatives Internal consistency and construct validity is slightly

									higher in longer versions
Engagement in ACP	Sudore et al., 2018	Engaging diverse English and Spanish speaking older adults in advance care planning: The PREPARE randomized clinical trial <i>Journal of the American Medical Association.</i>	Comparison of the PREPARE method of ACP versus traditional ACP methods. The “advance care planning Engagement Survey” was utilized as a tool to measure patient engagement among both groups	RCT	Level II	986 participants 55 years of age or older who spoke English or Spanish well and had two more chronic conditions Participants were from 4 primary care facilities in the San Francisco Health Network All patients with a 5 th grade reading level who met inclusion criteria were sent a letter for recruitment	Advance care planning Engagement Survey involving a 5-point Likert scale	In the PREPARE group, 98.1% reported increased engagement using the “advance care planning engagement survey” 89.5% of the AD only group reported increased engagement Of the 986 participants, 27.3% had prior AD documentation ACP documentation increased in the PREPARE group (43% vs 32%; p < 0.001)	The 4-point “advance care planning Engagement Survey” is able to detect changes in patient engagement involving ACP in both the English and Spanish speaking population groups Both patient groups benefited from ACP as evidenced by increased engagement and completion of an AD Measurement of ACP discussion with provider as an outcome demonstrates that patients engage in many

									different ACP behaviors Demonstrates an increase in ACP among low-income, diverse, Spanish speaking adults (a group with historically low ACP engagement)
Engagement in ACP	Van der Smissen et al., 2021	Measuring Advance Care Planning Behavior in Dutch Adults: Translation, Cultural Adaptation and Validation of the Advance Care Planning Engagement Survey <i>BMC Medical Research Methodology</i>	Translate and validate ACP Engagement Survey into dutch	RCT	Level II	Comparison of adults 60 years of age or older versus under the age of 60	ACP Engagement Survey	Cronbach's alpha: 0.97 reproducibility with intraclass correlation: 0.88	People with chronic disease engaged in more ACP than those who did not have health concerns
Facilitators of ACP	Kendall et al., 2020	Patient and Caregiver Perspectives on Early Identification for Advance Care Planning in Primary	Identify patient and caregiver perspective on early initiative of ACP in the primary care setting	Qualitative study	Level VI	65 years of age or older with declining health and a caregiver 65 years of age or older with	Evaluation of a semi-structured interviews		Patients prefer to have an existing relationship with provider, have family or support

		Healthcare Settings <i>BMC Family Practice</i>				declining health			present, prefer to have detailed and specific info regarding the status of their health condition
Facilitators of ACP	Jimenez et al., 2018	Overview of Systematic Reviews of Advance Care Planning: Summary of Evidence and Global Lessons <i>Journal of Pain and Symptom Management</i>	Synthesize ACP research and identify relevant contextual elements, program features, and impacted outcomes from policies and practice	Metasynthesis	Level I		Overview of systematic reviews using the Cochrane Handbook of Systematic Reviews of Interventions		Successful ACP implementation include whole-system, strategic approach, successful ACP program features, innovations for ACP support Unable to identify a gold standard for ACP
Facilitators of ACP	Risk et al., 2019	Barriers, Enablers and Initiatives for Uptake of Advance Care Planning in General Practice: A Systematic Review and	Identify barriers and enablers to ACP in primary care	Systematic review	Level I	Primary care/general practice setting			Determining readiness to engage was an important step prior to initiative of ACP discussions

		Critical Interpretive Synthesis. <i>BMJ Open</i>							Limited information provided on grading of evidence and process of literature review
Facilitators of ACP	Sudore et al., 2017c	Defining Advance care Planning for Adults: A Consensus Definition from a Multidisciplinary Delphi Panel. <i>Journal of Pain and Symptom Management,</i>		Expert opinion	Level VII		Delphi method (multiple rounds of peer feedback)		ACP should be tailored to patient readiness
Barriers to ACP	Blackwood et al., 2019	Barriers to Advance Care Planning with Patients as Perceived by Nurses and Other Healthcare Professionals: A Systematic Review <i>Journal of Clinical Nursing</i>	Identify barrier to ACP discussions as reported by nurses and other HCPs	Systematic review	Level I		Guided by PRISMA		ADs do not fully ensure good decision-making that align with patient values, so ACP was a newly adopted term

Barriers to ACP	Bernard et al., 2020	Exploring Patient-Reported Barriers to Advance Care Planning in Family Practice <i>BMC Family Practice</i>	Assess the barriers faced by older adults patients in talking to their families and PCPs about ACP	Qualitative study	Level VI	50 years of age or older, read/write English, no cognitive impairment Convenience sampling	Thematic analysis		Patients often feel that they are too young to engage in ACP, that it is not a priority, or that it is too emotional A large portion of those who completed the survey responded that they did not know what ACP was, which may lead to poor result validity
Barriers to ACP	Freytag & Rauscher, 2017	The importance of Intergenerational Communication in Advance Care Planning: Generational Relationships Among Perceptions and Beliefs <i>Journal of Health Communication</i>	Examine the relationship between patient family members and family openness about death, death anxiety, perceived knowledge of surrogate decision making, and self-efficacy in ACP	Control trial without randomization	Level III	Students at a University who were in a communications course and their family members (no randomization)	Online survey using Likert scales	RMSEA	Poor validity due to students being required to complete surveys for their grade Only 10% of interviews were called to confirm as being filled out by appropriate subjects

Barriers to ACP	Hafid et al., 2021	Advance Care Planning Conversations in Primary Care: A Quality Improvement Project Using the Serious Illness Care Program <i>BMC Palliative Care</i>	Assess implementability and sustainability of ACP in the primary care setting.	Control without randomization	Level III	Physicians conducted conversations after receiving training on ACP to patients 65 years of age or older with one or more chronic conditions or frailty expected to shorten life expectancy	Pre- and post-SICP self-assessments	Shapiro-Wilks test Wilcoxon Sign-Rank tests two-tailed p-value	ACP could not be implemented in the primary care clinic during routine visits, physicians reported SICP to be helpful in improving their skill in conducting conversations about serious illness
Barriers to ACP	Hong et al., 2018	Facilitators and Barriers for Advance Care Planning Among Ethnic and Racial Minorities in the U.S.: A Systematic Review of the Current Literature <i>Journal of Immigrant and Minority Health</i>	Systematically review the empirical literature of ACP with ethnic and racial minorities	Systematic review	Level I	Asians, Koreans, Latinos, Hispanics, Blacks, Chinese adults	Modified version of framework synthesis method		Ethnic populations vary in their engagement levels in ACP Further research is needed to determine what ACP interventions are successful in these populations
Barriers to ACP	Rao et al., 2014	Completion of Advance Directives Among U.S. Consumers	Characterize US adults that do not have an AD and factors	Quantitative descriptive	Level VI	18 years of age or older who participated in a survey	Factors associated with high AD rates	Likelihood ratio tests	Racial and ethnic disparities noted in ACP

		<i>American Journal of Preventive Medicine</i>	associated with completion			Online recruitment	versus low AD rates		Recruitment online may lead to poor generalizability of results
Barrier to ACP	Combes et al., 2021	Development of a Theory-Based Intervention to Increase Cognitively Able Frail Elders' Engagement with Advance Care Planning Using the Behaviour Change Wheel <i>BMC Health Services Research</i>	Develop an intervention designed to increase frail elderly patient's engagement in ACP (comprised of video content and verbal education)	Qualitative study	Level VI	Pertinent stakeholders including frail older adults, family members, and health care providers	Increase engagement as evidenced by patient and stakeholder interviews Semi-structured interviewing	Thematic analysis using the behavior change wheel as a theoretical framework	Older frail adults do not feel the need to engage in ACP despite self-reported poor health
Conceptualizing Wishes	Abu Al Hamayel et al., 2019	Preparing Older Patients with Serious Illness for Advance Care Planning Discussions in Primary Care. <i>Journal of Pain and Symptom Management</i>	Explore older patient perspectives on ACP discussions with family and primary care providers	Qualitative study	Level VI	60 years of age or older, no AD, scheduled annual visit with their PCP (convenience sample)	Patient interviewing	Thematic analysis: 1) the relevance/importance of ACP as a whole; 2) independently conceptualizing wishes and preferences for the future; 3) the process of engagement in ACP discussions; and 4) different outcomes of ACP discussions	Mailed educational materials and reminders to engage in ACP increases patient participation Patients biggest influence on ACP is their personal values

Outcomes of ACP	Rietjens et al., 2017	<p>Definition and Recommendations for Advance Care Planning: An International Consensus Supported by the European Association for Palliative Care</p> <p><i>The Lancet. Oncology</i></p>	Develop an accepted definition for ACP and present recommendations for providers, law makers, and researchers	EBPG	Level I		5 round Delphi study		<p>Recommend:</p> <ul style="list-style-type: none"> - exploring patient's values - medical information should be clarified where appropriate - tailor ACP communication to the patient's learning style - engage in ACP at any stage of life, revisit often
Outcomes of ACP	Sudore et al., 2018a	<p>Outcomes that Define Successful Advance Care Planning: A Delphi Panel consensus.</p> <p><i>Journal of Pain and Symptom Management</i></p>	Create outcome constructs for ACP	EBPG	Level I		Delphi panel consensus Literature analysis		<p>Outcome domains:</p> <p>Process, Action, Quality of care, Healthcare outcomes</p>

¹ LOE from Melnyk, B. M., & Fineout-Overholt, E. (2019). Evidence-based practice in nursing and healthcare (4th ed.). Wolters Kluwer.

Appendix B**Cost Table**

Item	Item Description	Quantity	Anticipated Cost
Printing	Laminated survey tools	4	\$20
	Brochures and educational materials	75	\$75
Team Members	NP educational luncheon	1 hour	\$45
	MA educational luncheon	1 hour	\$15
Intervention tools	PREPARE licensing cost	1	\$500
Dissemination	Poster	1	\$150
	Conference	1	\$200
Total Cost			\$1,005

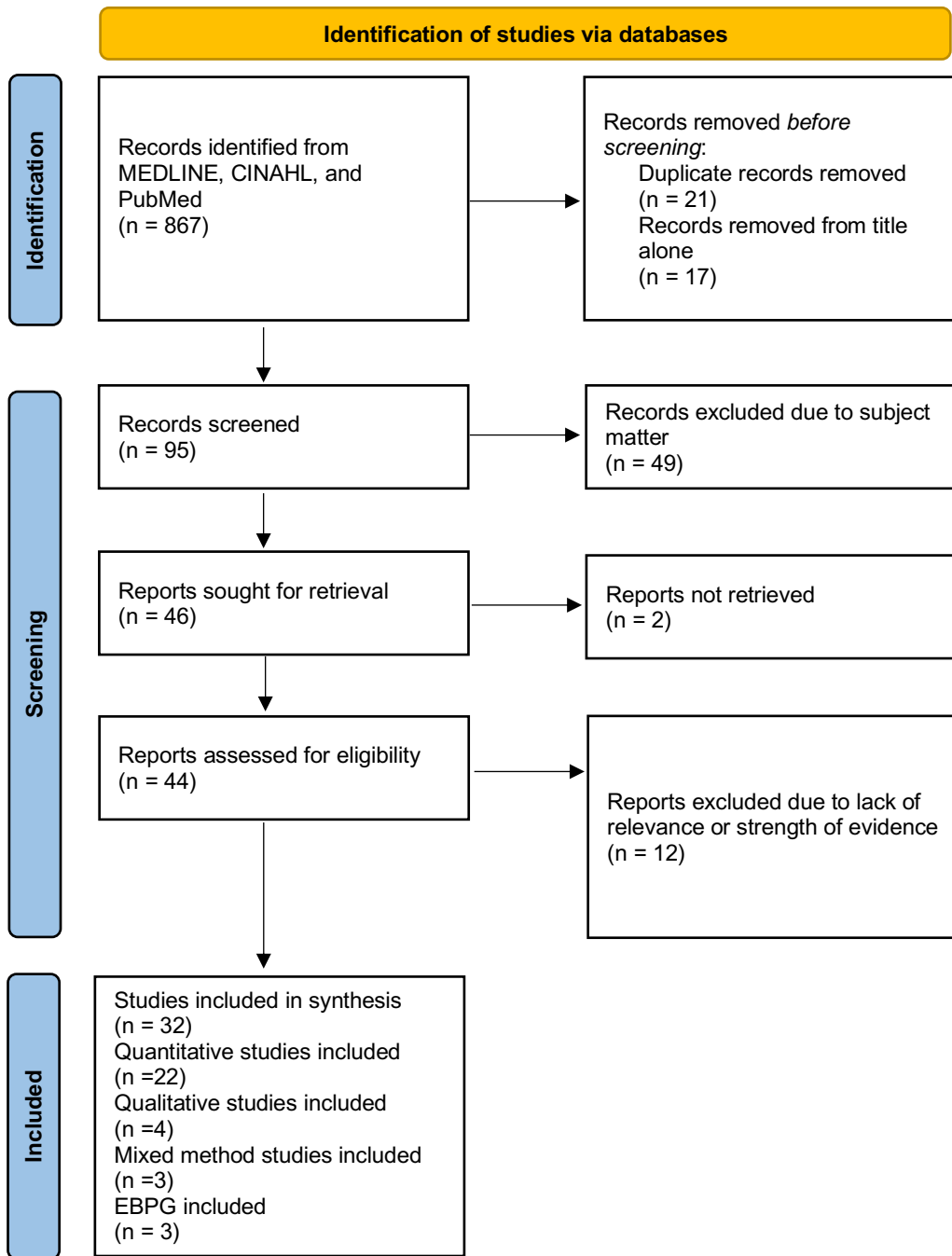
Appendix C

Definition of Terms

Term	Definition
Advance care planning (ACP)	Process of identifying personal values and perceptions of quality of life to determine future healthcare preferences
Advance care documents (ACD)	Legal documents including living wills, advance directives, and a durable power of attorney that outline patient medical preferences
Medical surrogate	Designated individual to make healthcare decisions in place of the patient when they are unable to do so themselves
Quality of life	Perception of one’s position and outlook on life

Appendix D

PRISMA Flow Diagram



From: Page MJ, McKenzie JE, Bossuyt PM, Boutron I, Hoffmann TC, Mulrow CD, et al. The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ* 2021;372:n71. doi: 10.1136/bmj.n71

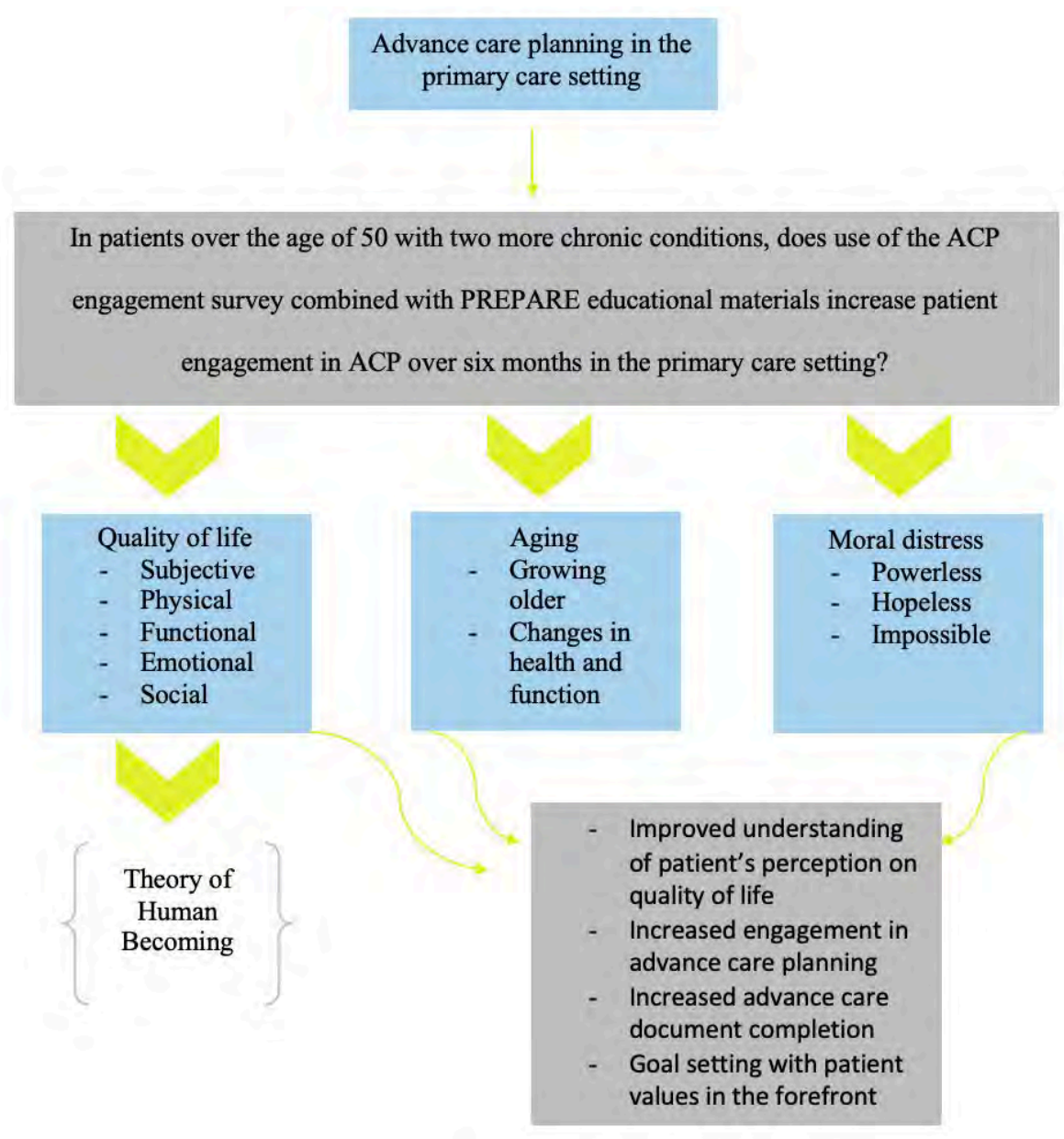
Appendix E
Evidence Grid

	Engagement in ACP	Facilitators of ACP	Barriers of ACP	Conceptualizing Wishes	Outcomes of ACP
Abu Al Hamayel, N. (2019)		X	X	X	X
Blackwood, C. (2020)		X	X		
Brungardt, A. (2019)	X				
Bernard, C. (2020)			X		X
Freytag, J. (2017)		X	X		X
Freytag, J. (2020)	X				
Hafid, A. (2021)			X		
Holland, D. (2017)	X				
Hong, M. (2018)			X		
Van der Smissen, D. (2021)	X				
Sudore, R. (2017b)	X				
Howard, M. (2016)	X				
Ramsaroop, S. (2007)	X	X	X		X
Kendell, C. (2020)		X	X		
Howard, M. (2018)	X				
Howard, M. (2020)	X				X
Jimenez, G. (2018)		X	X		X
Lum, H.D. (2018)	X				
Howard, M. (2021)	X				
Okada, H. (2021)	X				
Rao, J.K. (2014)		X			
Sudore, R. (2013)	X				X
Rietjens, J.A. (2017)				X	X
Risk, J. (2019)		X	X		
Royal College of Physicians of London (2009)	X				
Combes, S. (2021)		X	X		
Sandavol, M.B. (2019)	X				
Shi, Y. (2019)	X				
Sudore, R. (2017a)	X				
Sudore, R. (2018a)					X
Sudore, R. (2017c)		X			

Sudore, R. (2018b)	X				X
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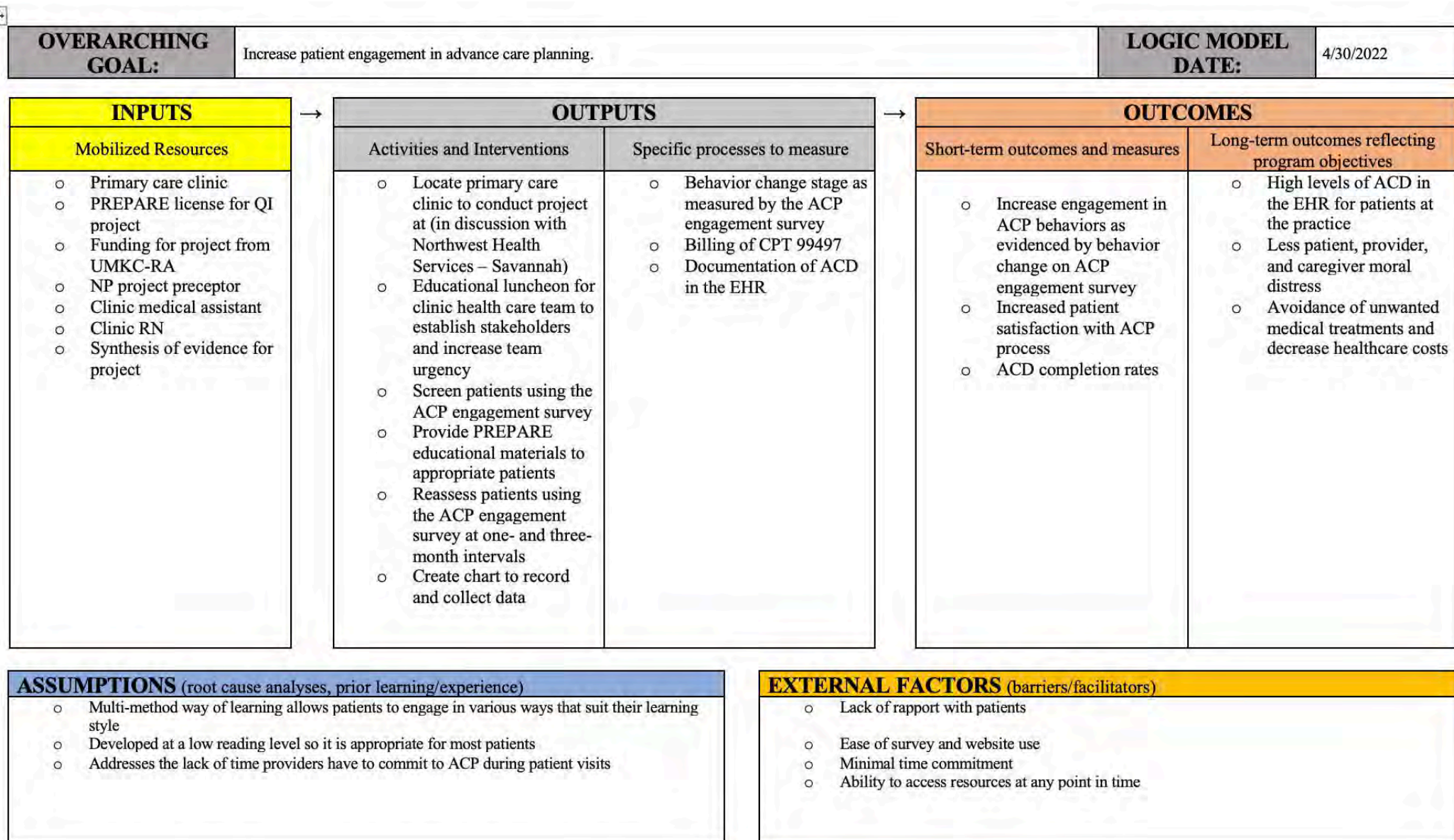
Appendix F

Theory to Application Diagram



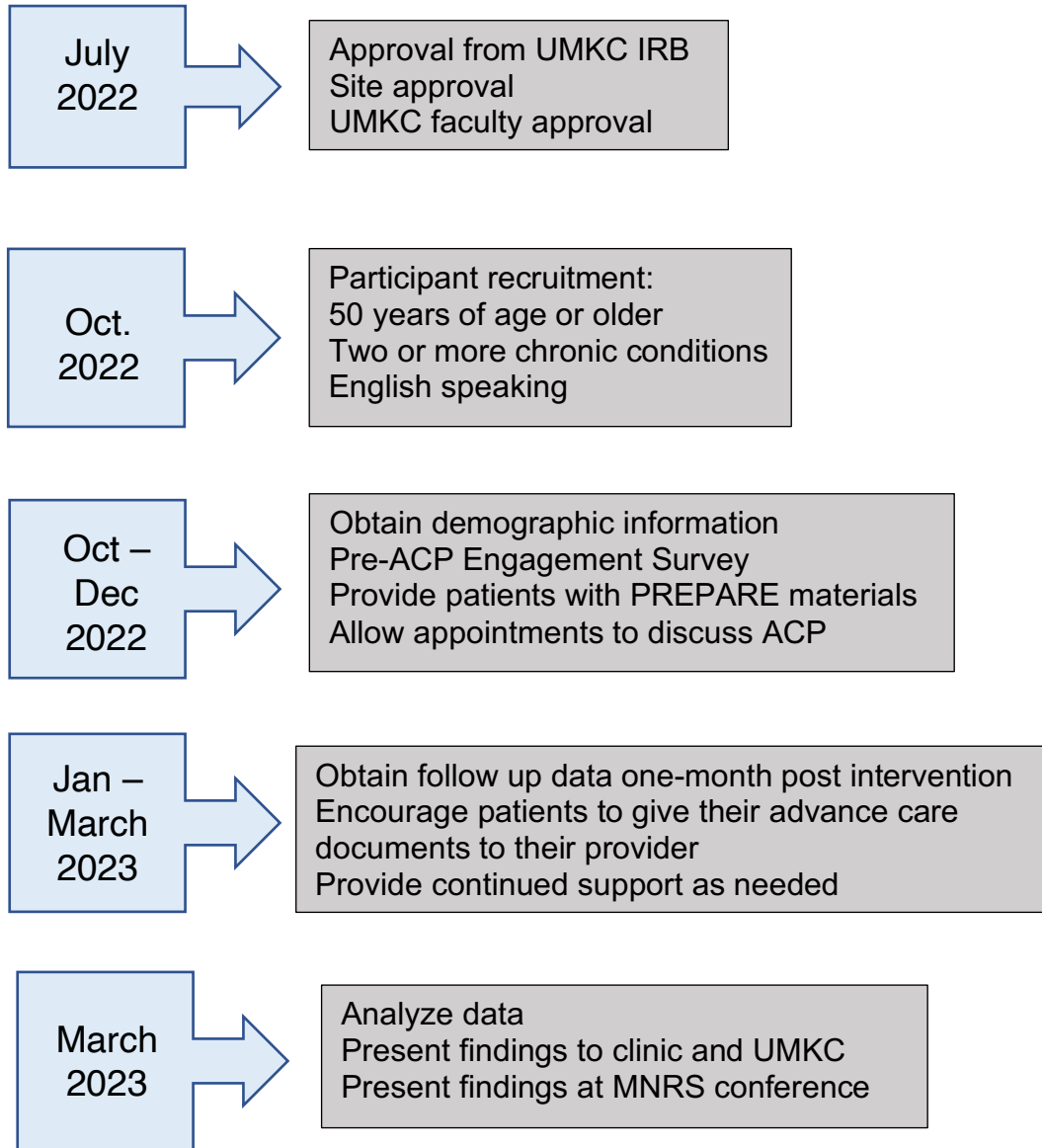
Appendix G

Logic Model



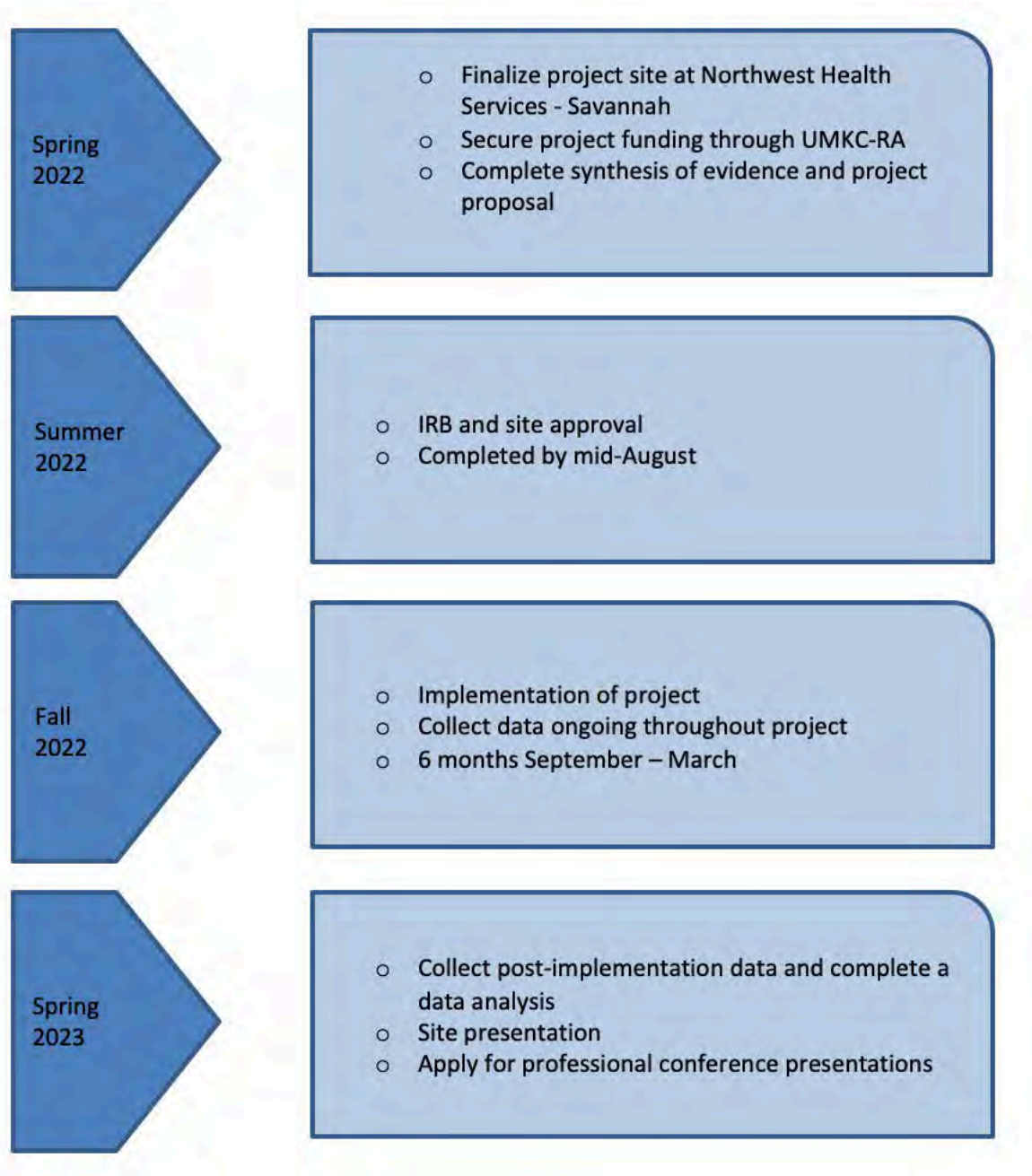
Appendix H

Intervention Flow Diagram



Appendix I

Project Timeline



¹ Baseline data includes measurement of patients' behavior change stage. Patients may be in the precontemplation, contemplation, preparation, action, or maintenance behavior change stage.

Appendix J

Permission for Tools

NONEXCLUSIVE LICENSE AGREEMENT

This Nonexclusive License Agreement (“Agreement”) is made and entered into as of September 29, 2022 (“Effective Date”) by and between THE REGENTS OF THE UNIVERSITY OF CALIFORNIA, a California constitutional corporation (“The Regents”), acting on behalf of the University of California San Francisco, and through the Office of Technology Management & Advancement, University of California San Francisco, 600 16th Street, Suite S-272, San Francisco, California, 94143 and The Curators of the University of Missouri on behalf of the University of Missouri- Kansas City located at 2464 Charlotte St, Kansas City, MO 64108, hereinafter called “Licensee.”

Whereas, The Regents is the proprietor of the content, including, without limitation, text, graphics and video, on the websites designated as www.prepareforyourcare.org and subdirectories thereof (“PREPARE”); and

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- c. The Licensee has the right at any time to terminate this Agreement by providing a Notice of Termination to The Regents. Termination of this Agreement will be effective sixty (30) days from the effective date of such notice. If the Licensee fails to perform or violates any term or covenant of this Agreement, then The Regents will have the right to terminate this Agreement by providing five (5) days written notice of termination to Licensee.
- d. Any termination or expiration of this Agreement will not affect the rights and obligations set forth in Articles 4, 5, 6, 7, 8 and 9.

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IN WITNESS WHEREOF, the parties hereto have executed this License Agreement on the date and year first written above.

Appendix K

Faculty Approval Letter

July 9, 2022

UMKC DNP Student: Payton Wolff

Congratulations. The UMKC Doctor of Nursing Practice (DNP) faculty have approved your DNP project proposal, *Increasing Patient Engagement in Advance Care Planning in Primary Care*.

Sincerely,

Cheri Barber, DNP, RN, PPCNP-BC, FAANP

Clinical Assistant Professor

DNP Program Director

UMKC School of Nursing and Health Studies barberch@umkc.edu

Lyla Lindholm, DNP, RN, ACNS-BC

Clinical Assistant Professor, DNP Faculty

MSN-DNP Program Coordinator

UMKC School of Nursing and Health Studies lindholml@umkc.edu

Debbie C. Pankau DNP, APRN, FNP-BC

Clinical Assistant Professor

DNP Project Course Faculty

UMKC School of Nursing pankaud@umkc.edu

DNP Faculty Mentor: Marti Anselmo

Appendix L**IRB QI Determination Letter**

Institutional Review Board
University of Missouri-Kansas City
5319 Rockhill Road
Kansas City, MO 64110
816-235-5927
umkcirb@umkc.edu

July 20, 2022

Dear Lyla Jo Lindholm,

A member of the UMKC Research Compliance Office screened your QI project #2092316 entitled "Increasing Patient Engagement in Advance Care Planning in Primary Care" and made the following determination: QI Determination:

The project has been determined to be a quality improvement activity not requiring IRB review.

If you have any questions regarding this determination, please feel free to contact our office at 816-235-5927, umkcirb@umkc.edu, or by replying to this notification.

Note Regarding Publications: It is appropriate to disseminate and replicate QI/program evaluation successes, including sharing the information external to an organization. This may include presentations and publications. The mere intent to publish the findings does not require IRB review as long as the publication does not refer to the activity as research.

Thank you,
UMKC Institutional Review Board

Appendix M
Measurement Tool

Four-item Advance Care Planning Engagement Survey

Email address/address: _____

How old are you? _____

What gender do you identify with?

- | | |
|---------------------------------|---|
| <input type="checkbox"/> Male | <input type="checkbox"/> Other |
| <input type="checkbox"/> Female | <input type="checkbox"/> Prefer not to answer |

What racial or ethnic group describes you?

- | | | |
|--|--|--|
| <input type="checkbox"/> White | <input type="checkbox"/> Asian/Pacific | <input type="checkbox"/> Prefer not to |
| <input type="checkbox"/> Black | <input type="checkbox"/> Islander | <input type="checkbox"/> answer |
| <input type="checkbox"/> Hispanic/Latino | <input type="checkbox"/> Other | |

Advanced Care Planning Engagement Survey

We will ask about your experiences and opinions. We may ask about things that you have already done, or have not thought about at all. Just answer as honestly as you can.

The following question asks about medical decision makers. A medical decision maker is a family member or friend who can make decisions for you if you were to become too sick to make your own decisions.

1. How ready are you to SIGN OFFICIAL PAPERS naming a person or group of people to make medical decisions for you?

- | | |
|---|---|
| <input type="checkbox"/> I have never thought about it | <input type="checkbox"/> I have already done it |
| <input type="checkbox"/> I have thought about it, but I am not ready to do it | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> I am thinking about doing it in the next 6 months | <input type="checkbox"/> Refused |
| <input type="checkbox"/> I am definitely planning on doing it in the next 30 days | |

The following questions are about specific medical treatments that people may or may never want if they were very sick or at the end of their life. For instance, some people know they would want to be on a breathing machine. Other people know they would never want to be on a breathing machine. There are no right or wrong answers.

3. How ready are you to talk to your DECISION MAKER about the kind of medical care you would want if you were very sick or near the end of life?

- | | |
|---|---|
| <input type="checkbox"/> I have never thought about it | <input type="checkbox"/> I have already done it |
| <input type="checkbox"/> I have thought about it, but I am not ready to do it | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> I am thinking about doing it in the next 6 months | <input type="checkbox"/> Refused |
| <input type="checkbox"/> I am definitely planning on doing it in the next 30 days | |

4. How ready are you to talk to your DOCTOR about the kind of medical care you would want if you were very sick or near the end of life?

- | | |
|--|---|
| <input type="checkbox"/> I have never thought about it | <input type="checkbox"/> I have already done it |
| <input type="checkbox"/> I have thought about it, but I am not ready to do it | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> I am thinking about doing it over the next few visits | <input type="checkbox"/> Refused |
| <input type="checkbox"/> I am definitely planning to do it at the next visit | |

5. How ready are you to SIGN OFFICIAL PAPERS putting your wishes about the kind of medical care you would want if you were very sick or near the end of life?

- | | |
|---|-----------------------------------|
| <input type="checkbox"/> I have never thought about it | <input type="checkbox"/> Not sure |
| <input type="checkbox"/> I have thought about it, but I am not ready to do it | <input type="checkbox"/> Refused |
| <input type="checkbox"/> I am thinking about doing it in the next 6 months | |
| <input type="checkbox"/> I am definitely planning on doing it in the next 30 days | |
| <input type="checkbox"/> I have already done it | |

We encourage you to utilize the PREPARE resources to assist in planning for your future health care. You can access PREPARE for free at www.prepareforyourcare.org.

Please look out for follow up surveys. Follow up surveys will be sent to your email and be used for quality improvement purposes.

Information collected is confidential. Survey data will be utilized for a quality improvement project in partnership with the University of Missouri – Kansas City.

Appendix O

Statistical Analysis Results Tables

Frequencies of Gender

Gender	Counts	% of Total	Cumulative %
Female	17	63.0 %	63.0 %
Male	10	37.0 %	100.0 %

Frequencies of Age

Age	Counts	% of Total	Cumulative %
50-59	6	22.2 %	22.2 %
60-69	6	22.2 %	44.4 %
70-79	12	44.4 %	88.9 %
80 +	3	11.1 %	100.0 %

Descriptives Engagement Survey by Gender

	Gender	Q1	Q2	Q3	Q4	Pre Ave.
N	Female	17	17	17	17	
	Male	10	10	10	10	
Mean	Female	3.12	3.24	2.59	2.88	2.97
	Male	3.10	3.10	2.20	2.80	2.80
Standard deviation	Female	1.62	1.52	1.50	1.62	1.49
	Male	1.73	1.73	1.62	1.62	1.50

Descriptives Engagement Survey by Age

	Age	Q1	Q2	Q3	Q4	Pre Ave.
N	50-59	6	6	6	6	
	60-69	6	6	6	6	
	70-79	12	12	12	12	
	80 +	3	3	3	3	
Mean	50-59	2.50	2.50	1.50	2.50	2.25
	60-69	4.00	4.00	3.00	3.17	3.54
	70-79	3.08	3.08	2.58	2.92	2.94
	80 +	2.67	3.33	2.67	2.67	2.83
Standard deviation	50-59	1.64	1.64	0.837	1.64	1.32
	60-69	1.55	1.55	1.67	1.47	1.36
	70-79	1.56	1.56	1.56	1.68	1.53
	80 +	2.08	1.53	2.08	2.08	1.89

Appendix P

Executive Summary

Problem

By 2030, the number of adults over 65 in the United States will exceed the number of youth. The increasing older adult population poses a challenge to the healthcare system as older adults often have chronic conditions that increase the risk of additional health complications, increased healthcare spending, and risk of death. Advance care planning (ACP) effectively reduces healthcare costs by allocating medical expenses to treatments that align with the patients' desired care and helps providers avoid unwanted medical treatments and hospitalizations. Completion of an advance care document (ACD) ensures that patients receive end-of-life care that aligns with their values and preferences. However, despite the benefits of ACP, only one in three adults in the United States has completed a formal advance directive, leaving them vulnerable in the event of a healthcare crisis.

Purpose

This evidence-based quality improvement project aimed to increase patient engagement in ACP in the primary care setting by implementing the Engagement Survey and PREPARE educational materials.

Methods

The project was implemented at a federally qualified health center (FQHC) in a rural town that serves patients of low socioeconomic status, many of whom have multiple chronic conditions. Patients aged 50 or older with two or more chronic conditions were identified using consecutive sampling by the clinic's medical assistant and nursing staff. Participants were administered the ACP Engagement Survey and provided with PREPARE educational materials.

The clinic's nurse practitioner encouraged the participants to interact with the ACP learning materials before the end of their visit. One month after being provided with PREPARE materials, project participants were contacted through email or mail and asked to complete the ACP Engagement Survey for comparative analysis.

Results

The project recruited 27 total participants with an average age of 68.4 years. The pre-intervention data showed that male and female participants were in the contemplation phase of behavior change (female $M=2.97$, male $M=2.80$, overall $M=2.91$). Female participants were more likely than males to engage in ACP behaviors, such as discussing medical care with their medical decision-maker ($M=3.24$). Participants aged 60-69 were most likely to engage in ACP behaviors ($n=6$, $M=3.54$), while those aged 50-59 were less likely to participate ($n=6$, $M=1.50$). There was no correlation between age and pre-intervention ACP Engagement Survey scores. The primary outcome could not be measured due to the small post-intervention sample size ($n=6$).

Recommendations

The PREPARE online platform is a useful ACP education tool for patients and their families, providing access to ACP resources they can use at their own pace. The platform addresses the barrier of provider time constraints in discussing ACP in primary care. Healthcare providers are recommended to assess patients' readiness for ACP using the ACP Engagement Survey to identify patients ready to discuss their future medical care. Primary care clinics should prioritize proper storage of patients' ACDs and ask their patients at each visit to provide these documents to ensure they receive care congruent with their wishes.