

COMMUNITY ENGAGEMENT TO IMPROVE ADVANCE CARE PLANNING  
KNOWLEDGE WITH HEALTHY ADULTS

by

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## ABSTRACT

**Purpose.** This quality improvement (QI) project aimed to improve advance care planning (ACP) knowledge and comfort level in end-of-life (EOL) discussions of healthy adults through an online community engagement session teaching ACP education and playing an EOL conversation game *Hello*.

**Background.** ACP is highly underutilized, with only 25% of Americans having an advance directive (Weathers et al., 2016). ACP helps people receive care consistent with their values and preferences, which improves quality of EOL care (Weathers et al., 2016). It also reduces healthcare costs by the decreasing utilization of futile healthcare services and burdensome transitions of care (Institute of Medicine [IOM], 2015; Kelley & Bollens-Lund, 2018; Smith et al., 2012). Barriers to ACP include lack of awareness and the belief that it only applies to older, sicker individuals. The coronavirus 2019 (COVID-19) pandemic, however, gave reason for people of all health-states and ages to voice their healthcare priorities in the case of a life-threatening illness. This provided an opportunistic time to normalize ACP, especially for people living near the first COVID-19 outbreak.

**Methods.** Participants were ages 18 to 45, lived within 45 minutes of Bothell, WA, and were self-identified as healthy. Flyers were posted at local businesses and on social media, and disclosure forms and the invitation to an online Zoom meeting were sent to those who volunteered. Pre and posttest surveys via SoGoSurvey were sent to assess baseline and post-engagement session knowledge and comfort level regarding ACP and EOL conversations and assess the stage of change from the transtheoretical model in regards to ACP behavior. Data analysis occurred on Excel.

**Results.** The project was implemented over a 60-minute Zoom meeting. Data analysis showed an increase in ACP knowledge and comfort level discussing EOL, and a forward shift in the stage of change. Seminar evaluation revealed that participants viewed the seminar as worthwhile.

**Conclusions.** Effective dissemination of ACP information and exposure to EOL conversations targeted towards healthy, community-dwelling adults can be successfully accomplished through an online engagement session for the community of Bothell, Washington. Future studies should include participants from a wider variety of locations and results from multiple online sessions.

## INTRODUCTION

### Background

Advance care planning (ACP) is an important, ongoing discussion regarding future healthcare decisions and end-of-life (EOL) care where individuals express how they want to be cared for, what they most value, and whom they want to make decisions on their behalf if they are too ill or can no longer speak for themselves to make their wishes known (Weathers et al., 2016). This active and intentional process involves individuals, family members, loved ones, and healthcare professionals. It allows for communication about care goals and preferences when afflicted with a life-limiting condition or at the end-of-life (EOL), use of life-sustaining measures, choosing a healthcare proxy, and completing legal documentation of healthcare preferences called advance directives (AD) (Houben, Spruit, Groenen, Wouters, & Janssen, 2014). Despite mounting evidence that suggests ACP and ADs increase the quality of EOL care and provide care more aligned with patient and family wishes, only 25% of Americans have a documented AD (Weathers et al., 2016). Because of the lack of ACP, decisions about life-sustaining treatments are often crisis-oriented, may not be in concordance with patients' preferences for EOL care, and may cause distress in loved ones (Houben et al., 2014).

The lack of ACP has significant implications on the quality of life (QOL) at the end-of-life (EOL), creating emotional burdens and moral distress for family and caregivers and increasing healthcare expenditures for futile treatments (Houben et al., 2014). In the absence of ACP, the current culture of American medical practice utilizes life-prolonging and life-sustaining treatments no matter what the cost is to the patient and the family's QOL (Institute of Medicine [IOM], 2015). This is highly mismatched with what most people want, as over 70% of the

Medicare population expresses a desire for treatment that focuses on comfort and alleviating suffering over living longer at the end-of-life (Bernacki & Block, 2014). Most with serious illnesses prefer to receive care where they are most comfortable, at home, especially near the end of their life (World Health Organization [WHO], n.d.). Despite this fact, evidence suggests that one in four adults age 65 and older die in an acute care setting (Bernacki & Block, 2014). The last few months of life are exceptionally costly, not because existing symptoms become even more distressing and pronounced, but because of the lack of ACP and no indication of EOL preferences (Bernacki & Block, 2014; IOM, 2015; Scibetta, Kerr, McGuire, & Rabow, 2016). As most people value quality over quantity of life (QOL) at the end-of-life (EOL) or in the event of a severe or terminal illness, ACP and the presence of an AD reduces utilization of futile healthcare services, burdensome transitions of care, and hospital deaths (IOM, 2015; Kelley & Bollens-Lund, 2018; Smith et al., 2012), while providing care more congruent with patient wishes, improving the quality of care, and enhancing family satisfaction with care (Houben et al., 2014).

Low AD completion rates and participation in ACP is multifactorial and involves barriers created by both providers and the patient. Our culture avoids conversations about death and dying; therefore, people are not used to having such discussions and may not be open or comfortable doing so (Kalish, 2019). On the provider side, there is no shortage of evidence suggesting that healthcare professionals lack practical communication skills and the ability to execute proper EOL discussions (IOM, 2015). Evidence suggests that many providers feel inadequately prepared due to lack of education or resources to conduct productive, skillful discussions regarding disease realities or EOL, which is essential in ACP (Bernacki & Block,

2014). Medical curricula must match the current healthcare demands, which expect non-palliative care clinicians to provide high-quality palliative care and EOL discussions. Finally, one of the most significant barriers to ACP is simply the lack of knowledge among lay people (Kermel-Schiffman & Werner, 2017; Rao, Anderson, Lin, & Laux, 2014). Individuals must be adequately informed to demonstrate effective health behaviors; as medical professionals are underprepared to educate patients, ACP completion rates continue to be low despite its potential benefits. Increasing the knowledge, comfort level, and attitude towards conversations about death and EOL on the patient side must begin with interventions at the local and national levels, to validate death and dying as a normal, universal process, and to normalize the communication and planning of future healthcare events. People rely on medical professionals to provide them with the necessary information, especially with health promotion and wellness. ACP discussion should be integrated into routine care in the same way providers integrate preventative healthcare such as mammograms and vaccines. Lack of ACP awareness must be realized as a significant threat to humane and high-quality EOL care. It will take the work of national stakeholders and healthcare leaders to incorporate ACP discussions into routine practice.

There have been national movements to upstream and normalize advance care planning (ACP) and conversations about death. However, this has not resulted in increased ACP completion rates or clinically significant changes in EOL care (Teno, Freedman, Kasper, Gozalo, & Mor, 2015). New strategies are needed to engage individuals in conversation about death and dying to increase knowledge and improve attitudes toward ACP and EOL (Van Scoy, Reading, Scott, Green, & Levi, 2016). Community-based interventions promoting EOL discussions have shown success in increasing comfort in talking about EOL wishes with loved ones and eliciting

ACP behaviors (Abba, Lloyd-Williams, & Horton, 2019). Some of these interventions include workshops and presentations to increase awareness about EOL planning benefits and provide people with the tools to facilitate EOL discussions with loved ones (Abba et al., 2019). Although these methods have been proven successful, there is nothing particularly innovative about these approaches that would elicit interest in those who are hesitant or uncomfortable talking about death and EOL. A novel intervention, created by the *Conversation Project* and the Institute of Healthcare Improvement (IHI), took a rather morbid and stressful topic of death and incorporated it into an enjoyable and light conversation game called *Hello* (Van Scoy, Green et al., 2017). Studies utilizing *Hello* had success in promoting participation in ACP as evidenced by an increased rate of ACP behaviors in the three months following the game (Van Scoy, Green et al., 2017; Van Scoy, Reading et al., 2017; Van Scoy, Reading, Scott et al., 2016). These findings suggest that using a game format may be a useful way to motivate people to perform essential ACP behaviors.

### **Local Climate Regarding ACP and EOL**

The outbreak of the coronavirus 2019 (COVID-19), the novel coronavirus which emerged from Wuhan, China, was declared a pandemic by the World Health Organization (WHO) on March 11, 2020 (WHO, 2020). Washington State had the first confirmed case of death from COVID-19 in the United States (US), followed by the first major confirmed US outbreak of the disease at a nursing home in Kirkland, Washington (WA), which sent shockwaves nationwide (Arentz et al., 2020). With the ever-climbing death rates, the diminishing supply of personal protective equipment (PPE), inadequate number of needed ventilators, and the insidious nature in which this disease spreads, COVID-19 has instilled fear and uncertainty in us

all, even in young, healthy adults. To slow the spread of disease, Governor Jay Inslee of Washington State declared a state of emergency on February 29, 2020, which started the state's shelter-in-place order where only essential businesses are allowed to operate (Inslee, 2020).

Although it should not take such an extraordinary circumstance to elicit interest in ACP, this is a highly opportunistic time to normalize conversations about EOL and ACP when death and dying are at the forefront of many of our minds, especially people living in this local area. In the current state with the COVID-19 pandemic, ACP has also never been more pertinent. People of all health-states and ages have great reason to voice their healthcare priorities and goals in case of an acute, life-threatening illness such as the COVID-19. As the COVID-19 pandemic continues to be the topic at every dinner table and of every media outlet in America, there is no better time than now to normalize conversations about EOL and ACP. Engaging people in these conversations when it feels the most applicable may be the solution to making a change in our society's attitude about death at large.

Having the engagement of volunteers from the epicenter of the US COVID-19 outbreak is a valuable perspective that can add to our knowledge of the local climate. It would be worth investigating whether the pandemic brought forth the lack of EOL discussions and ACP knowledge as a concern for healthy adults.

### **Intended Improvement**

#### **Project Purpose**

This doctor of nursing practice (DNP) quality improvement (QI) project aims to increase ACP knowledge and comfort level in EOL discussions of community-dwelling healthy adults by providing a combination of ACP education and playing an EOL conversation game called *Hello*

by the *Conversation Project*. This community engagement, in which discussions about death, end-of-life, and healthcare preferences took place, provided individuals with an opportunity to speak about death and EOL in a non-threatening, game-like environment. Studies show that when given an opportunity, 95% of individuals are willing to talk about their EOL preferences and wishes, and 53% even state a sense of relief in discussing such material with their loved ones (IHI, 2019). As leaders in the community, healthcare providers have the responsibility of engaging the community in essential health conversations which they may not have otherwise. This especially applies to EOL discussions, as only 32% have engaged in such conversations even though 92% believe it is a meaningful conversation (IHI, 2019).

### **Project Question**

In community-dwelling healthy adults (P), does the combination of an interactive EOL conversation game along with ACP education (I) increase the comfort level (C) to discuss matters surrounding end-of-life and knowledge of ACP (O) compared to pre-intervention?

### **Project Objectives**

Aim 1: Educate community-dwelling healthy adults about ACP and engage in meaningful conversation about end-of-life, death, and dying in a light, enjoyable manner.

Aim 2: Increase participants' comfort level in EOL discussions and readiness to participate in ACP behaviors.

## **Theoretical Framework**

### **The Transtheoretical Model**

The transtheoretical model (TTM) developed by Prochaska and DiClemente (1983) is an influential change model applicable to behavioral health change. This model highlights key

theoretical constructs necessary for understanding how individuals think about change and behavioral modification (Prochaska, Prochaska, & Levesque, 2001). The TTM makes no assumptions about an individual's readiness for change because not everyone is prepared to make permanent behavioral adjustments (Velicer, Prochaska, Fava, Norman, & Redding, 1998). Such an assumption would lead to interventions that do not reflect people's needs and level of readiness to change (Levesque et al., 2001; Velicer et al., 1998). In the TTM, a person moves through five sequential stages of change over time (Prochaska & DiClemente, 1983). These stages include the precontemplation, contemplation, preparation, action, and maintenance stages, and each stage is associated with different processes that can help individuals progress to the next stage of change (Prochaska & DiClemente, 1983). Through the TTM lens, change requires time and is not tied to a single event (Velicer et al., 1998), in the same way that people cannot acquire the comfort or the readiness to discuss EOL related topics and perform ACP activities overnight. The TTM is a model focused on understanding the process in which intentional behavioral changes occur in individuals. It helped guide this project in the development and implementation of the intervention.

### **Stages of Change**

#### **Precontemplation**

The first stage in the TTM is precontemplation (Velicer et al., 1998). Individuals in this stage may be unaware or lack the knowledge of ACP and may have never even considered participating in ACP behaviors (Ernecoff, Keane, & Albert, 2016; Velicer et al., 1998). This may be from lack of exposure to the ACP process or being under-informed about its relevance to the individual (Ernecoff et al., 2016). In this stage, negative consequences of their inactions toward

ACP are not yet realized, and denial for the need to change exists (Levesque et al., 2001).

Individuals are not ready to participate in ACP activities such as discussion surrounding end-of-life and death. The cons of behavioral change, such as having to participate in uncomfortable, high-stress conversations about death, outweigh the pros of ACP from an individual perspective at their current knowledge state (Velicer et al., 1998).

### **Contemplation**

Individuals in the contemplation stage of change may be considering changing their health behavior in the foreseeable future, specifically in the next six months (Velicer et al., 1998). In this stage, individuals are acutely aware of both the pros and cons of modifying their behavior, which creates hesitation and uncertainty (Velicer et al., 1998). Consciousness-raising is a process used in this stage to gather more information and become more aware of the problem at hand (Prochaska et al., 2001). Individuals may seek information about ACP, AD, and selecting a healthcare proxy, and may start thinking about their preferences and values related to end-of-life (Ernecoff et al., 2016). A common barrier in participating in ACP behavior in this stage may be one's health state, specifically of healthy individuals, who may not recognize how ACP can benefit them and their loved ones. The widespread assumption that ACP occurs only when afflicted with a life-limiting illness or when death is imminent limits ACP's potential (Lambert South, Elton, & Lietzenmayer, 2020).

### **Preparation**

The preparation stage consists of those who have already taken small steps toward ACP behaviors by having a plan of action such as the intent to talk to loved ones about their goals of care at end-of-life (EOL) or knowing whom they would want to choose as their healthcare proxy

(Ernecoff et al., 2016). Individuals in this stage are ready to change their behavior, specifically in the next 30 days, but have not taken overt actions due to lack of knowledge or resources on the ACP process (Ernecoff et al., 2016; Levesque et al., 2001). If they have the know-how, they may be failing to prioritize ACP behaviors above other aspects of their lives, especially if they are in a good health state (Ernecoff et al., 2016; Velicer et al., 1998).

### **Action**

Individuals in the action stage of change have committed to altering their behavior, leading to participation in the ACP process in the last six months (Velicer et al., 1998). Examples of ACP behaviors include communication with loved ones and healthcare providers about EOL care goals and preferences, choosing a healthcare proxy, and completing an AD (Fried et al., 2012; Velicer et al., 1998). The positive consequences of ACP engagement outweigh the cons, and behavioral changes have led to observable actions (Velicer et al., 1998). By this stage, individuals are comfortable having discussions surrounding EOL as they recognize death as a universal human experience that is inevitable.

### **Maintenance**

The maintenance stage is where individuals work to prevent relapse to previous stages of change (Velicer et al., 1998). Individuals can revisit and update their ADs, review and modify their preferences for EOL care, and have an ongoing discussion with their surrogate decision-makers to ensure healthcare decisions made on their behalf will be congruent with their wishes. Sustaining at this stage of change is challenging, with the expectation of several regressions before establishing permanent behavior change (Levesque et al., 2001).

Studies have found that 80% of people, before the implementation of a change initiative, are at either the first stage of precontemplation, or the second stage of contemplation (Prochaska et al., 2001; Velicer et al., 1998). In these two stages, the denial of the need to change and resistance predominate; it is no wonder that when change is imposed on unprepared, unmotivated individuals, a decrease in participation and an increase in conflict is seen (Prochaska et al., 2001). Later stages of change are associated with a higher readiness for change, and acknowledging the level of preparedness is vital in creating stage-matched interventions that would be effective and appropriate (Prochaska et al., 2001). With that said, interventions guided by the TTM are appropriate for participants at any level of readiness for change (Fried et al., 2016). Such interventions have a broad appeal and generally have higher participation rates than traditional health promotion programs that do not account for the variability in the readiness or needs of individuals (Fried et al., 2016).

It would be expected that the average volunteer of this project would be in the contemplation stage of change. These individuals volunteered to participate in this project, which shows that they want to learn more about ACP and, when given the opportunity, want to have open conversations about death and EOL.

## **Literature Synthesis**

### **Evidence Search**

A literature search was conducted for all English-language studies on interventions aimed to increase EOL conversations, ACP knowledge, and ACP behaviors. The search was conducted on PubMed and Embase databases. The keywords utilized in the searches were “advance care planning,” “end of life,” “community,” “education,” “adults,” and “game.” A variety of

combinations of these terms were used to search for the most relevant articles on the topic. The search yielded 274 results.

The following inclusion criteria further refined the search: full-text, peer-reviewed, English language, and published between the years 2015 and 2020. Exclusion criteria included studies done outside of Western countries, studies with narrow foci on participants under the age of 18, inpatient or outpatient interventions, and studies with outcomes focused on the medical staff. After applying the inclusion and exclusion criteria, along with excluding articles that were duplicates or irrelevant to the inquiry question, 18 articles which were found to be the most applicable were included in the literature synthesis. The following section will discuss the common themes found through these selected articles, which can also be found in Appendix G.

### **Strength of Community-Based ACP Interventions**

Only an estimated one-fourth of US adults have completed an AD (Teno et al., 2015). Health education must begin at microsystems, penetrate communities, and increase the dissemination of ACP knowledge and normalization of conversations about death and EOL care preferences (Teno et al., 2015; Weathers et al., 2016). Within this literature review, community-based ACP interventions were deployed by a variety of health-related professionals such as social workers, bilingual patient navigators, community health workers, nurses, and nurses practitioners, and in community-based sites including churches, libraries restaurants, a university campus, medical clinics, research centers, community centers, and places of residence (Bravo et al., 2016; Fink et al., 2020; Hendricks Sloan et al., 2016; Lambert South et al., 2020; Litzelman et al., 2017; Rabow, McGowan, Small, Keyssar, & Rugo, 2019; Radhakrishnan, Van Scoy, Jillapalli, Saxena, & Kim, 2019; Splendore & Grant, 2017; Sulmasy et al., 2017; Sun et al., 2017;

Van Scoy, Green et al., 2017; Van Scoy, Reading et al., 2017; Van Scoy, Reading, Scott, Chuang et al., 2016; Van Scoy, Reading, Scott, Green et al., 2016). Healthy community-dwelling adults, compared to persons with serious illnesses or comorbidities, have fewer opportunities to express their EOL preferences and would benefit from community-level exposures to information and education about ACP (Bravo et al., 2016; Fink et al., 2020; Fried, Zenoni, & Iannone, 2017; Hendricks Sloan et al., 2016; Lambert South et al., 2020; Splendore & Grant, 2017).

The literature review revealed that community-based interventions could be tailored to increase applicability to the populations that it serves. Many study interventions were minority-centered and culturally sensitive or neutral, making it appropriate for implementation in rural areas rich in diversity (Fink et al., 2020; Hendricks Sloan et al., 2016; Radhakrishnan et al., 2019). Facilitators of the community interventions such as community health workers were in a unique position to better understand and relate to people of the local community as they shared the same language, ethnic background, and socioeconomic status (Fink et al., 2020; Hendricks Sloan et al., 2016; Radhakrishnan et al., 2019). As ethnic minorities and populations of lower socioeconomic status may have less trust in the American medical system and have less access to traditional healthcare settings, great value was seen in community ACP interventions for promoting buy-in and engagement of local groups and increasing access to otherwise inaccessible resources (Fink et al., 2020; Hendricks Sloan et al., 2016; Radhakrishnan et al., 2019). As the older minority population is expected to grow substantially in the next several decades, community-level ACP interventions are now more important than ever in mitigating health disparities currently found in EOL care of minorities, including higher symptom burden,

more suffering, and increased healthcare utilization (Fink et al., 2020; Hendricks Sloan et al., 2016)

### **Strength of Innovative Approaches to Increase EOL Conversation and ACP Behaviors**

When given the opportunity, studies suggested that the majority of adults desired to talk about scenarios surrounding death, EOL care, and preferences for future medical treatment (Houben et al., 2014; Weathers et al., 2016). However, reluctance and discomfort in initiating and facilitating conversations about death and EOL was a common finding (Lambert South et al., 2020; Litzelman et al., 2017; Radhakrishnan et al., 2019). Innovative ACP tools have emerged to increase communication about EOL and to increase ACP behaviors, such as the card game *Go Wish*, the conversation game *Hello* (previously called *My Gift of Grace*), the booklets *Five Wishes* and *My Preferences*, and a conversation facilitating event called *Death over Dinner*. Utilization of these tools showed success in creating meaningful conversations about death, EOL and QOL between patients and their loved one; enhanced the healthcare surrogate's knowledge of patient preferences, values, and goals of care for EOL through open and honest communication; increased ACP behaviors such as discussions and completion rates of AD; and enhanced attitudes and comfort level toward ACP (Bravo et al., 2016; Lambert South et al., 2020; Radhakrishnan et al., 2019; Splendore & Grant, 2017; Van Scoy, Green et al., 2017; Van Scoy, Reading et al., 2017; Van Scoy, Reading, Scott, Green et al., 2016). Most notably, the game-based approach to conversations was noted by participants to be uplifting, interactive, and fun, and allowed for serious and unpleasant conversations to take place in a non-threatening, informal manner (Litzelman et al., 2017; Radhakrishnan et al., 2019; Van Scoy, Green et al., 2017; Van Scoy, Reading et al., 2017; Van Scoy, Reading, Scott, Chuang et al., 2016; Van Scoy,

Reading, Scott, Green et al., 2016). These tools are not only innovative but were cost-effective as the participants were able to implement the interventions without a facilitator (Lambert South et al., 2020; Radhakrishnan et al., 2019; Van Scoy, Reading et al., 2017; Van Scoy, Reading, Scott, Green, et al., 2016).

### **Weakness**

Many studies investigating people's thoughts, attitudes, and behaviors toward ACP activities entail study designs deemed lower in quality. Examples of common study designs seen in this literature review were qualitative descriptive studies, such as thematic analysis, pre-/post-study designs typically without probability sampling or the use of control groups, and some quasi-experimental designs without extensive randomization of participants or allocation of intervention. Although these designs may lack the methodological components deemed essential for the highest-quality evidence, not all types of clinical questions are best answered by all study designs (Aslam, Georgiev, Mehta, & Kumar, 2012). The exploration of beliefs and attitudes toward death and EOL care is highly individualistic. It necessitates the assessment and understanding of human constructs – without which, the interpretation of our project question is not possible. Deliberately focusing on varying study designs and not just prioritizing the level of evidence is necessary as the concept of sickness, death, and dying explores complex human conditions. Evidence drawn from real patients, real thoughts, and honest reflection of their lived experiences can be a powerful tool in guiding clinical practice. Experiential knowledge holds a high level of real-world applicability and value and should be explored when seeking to understand complex human conditions such as ones dealt with in ACP.

## **Gaps and Limitations**

Key components of ACP include designating a healthcare proxy, choices for the use of life-sustaining measures, and documentation of AD (Houben et al., 2014; Weathers et al., 2016). However, studies have shown that filling out documents merely covers hypothetical medical situations, and these activities alone do not translate to patients receiving EOL care aligned with their preferences (Bravo et al., 2016; Johnson, Butow, Kerridge, & Tattersall, 2018). Also, healthcare proxies are shown to hold inaccurate assumptions about the patient's EOL preferences, either through misinformation or overestimation of their ability to make decisions congruent with that of the patient (Bravo et al., 2016; Fried et al., 2017). For these reasons, along with the importance of emphasizing death as a universal and natural human process, the most crucial aspect of ACP is arguably the quality of communication held between the patient and their surrogate about the patient's care goals and preferences for EOL (Abbott, 2017; Fried et al., 2017). Quality conversations will help to normalize and destigmatize the subject of death and dying, increase uptake of ACP behaviors, increase the healthcare proxy's confidence in the challenging surrogate decision-making, and increase the likelihood of patients' wishes being honored at the EOL (Bravo et al., 2016; Fink et al., 2020; Hendricks Sloan et al., 2016; Lambert South et al., 2020; Litzelman et al., 2017; Rabow et al., 2019; Radhakrishnan et al., 2019; Splendore & Grant, 2017; Sulmasy et al., 2017; Sun et al., 2017; Van Scoy, Green et al., 2017; Van Scoy, Reading et al., 2017; Van Scoy, Reading, Scott, Chuang et al., 2016; Van Scoy, Reading, Scott, Green et al., 2016). For quality conversations to take place, most people need ACP interventions that simply present them with the opportunity for conversations, especially ones that flow naturally, to have help facilitating meaningful dialog, and to feel as comfortable as

possible in an inherently uncomfortable situation. Using a game-based EOL conversation game, such as *Hello* discussed previously, along with ACP education, would be an economically feasible, resource-conscious, and enjoyable ACP intervention that should be explored further. It can attract awareness and curiosity to death conversations, increase knowledge of ACP, and help increase and facilitate quality EOL conversations between loved ones in the community setting.

## **METHODS**

### **Project Design**

This DNP project utilized a framework of quality improvement (QI) to systematically implement an educational, community-engagement intervention to improve the knowledge and attitudes about ACP and EOL discussions in community-dwelling healthy adults. Pre- and post-engagement surveys were implemented to compare if the intervention leads to measurable improvements, as evidenced by an increase in ACP knowledge and comfort level in discussing topics surrounding EOL. The survey responses were designed to demonstrate a shift in participants' stage of change as modeled by the TTM.

### **Model for Implementation**

This project utilized the Model for Improvement by Langley et al. (2009) and endorsed by the Institute for Healthcare Improvement (IHI) to assess the implementation of ACP education and an EOL conversation game called *Hello* by the *Conversation Project* on a group of healthy adult volunteers. The Model for Improvement focuses on accelerating improvement by answering three fundamental questions and testing the change using the plan-do-study-act (PDSA) cycle (IHI, n.d.). The three questions focus on identifying the project aim or goal, establishing measures, and selecting the change that can lead to improvement (IHI, n.d.). The

aims of this project are to (1) educate community-dwelling healthy adults about ACP and engage in meaningful conversations about EOL within one educational online engagement session, (2) present pre- and post-engagement survey results to compare baseline and post-intervention ACP knowledge, comfort level in EOL discussions, and readiness for change in regards to ACP behaviors. The pre- and post-engagement surveys provided quantifiable measures to identify the change in ACP knowledge as well as the change in comfort level on communicating about topics surrounding EOL. The change made by this project is simple: providing a fun and welcoming environment conducive to open and honest conversations about EOL between healthy adult community members. Increasing the uptake of ACP will start with destigmatizing death. It will take novel approaches to alter people's thoughts and beliefs deeply embedded in our culture and society. Although talking about death can be grim, it is a natural process of life, and having open discussion could empower community members to feel more open and comfortable with the topic.

The change in ACP knowledge and attitude toward EOL communication after implementing a community engagement session can be documented using the PDSA cycle. The cycle is ongoing – it analyzes and learns lessons from the change being tested and adapts changes for the next set of the PDSA cycle. The “Plan” was to implement a one-session online community engagement intervention to educate and open people's minds on how pertinent ACP is at any stage in life, regardless of their health state. Another objective was to increase awareness that avoiding speaking about death only perpetuates the fear, unknown, and uncertainty even more, and talking and processing feelings surrounding EOL can be eye-opening and liberating. The expectation was that the engagement session will increase individuals'

knowledgebase of ACP, increase comfort levels in speaking about end-of-life, and help individuals to be more ready for change as exhibited by their advancement in the stage of change modeled by the TTM. The second stage of the PDSA cycle, “Do,” is where the project will take place. There will be documentation of unexpected problems, barriers, and facilitators to the project aims. Examples would be, missing information from the pre- or post-engagement surveys, lack of connection between participants, lack of interest in topics discussed, or how interested they were. Analysis of such data will begin while the project takes place. The “Study” phase will compare expected outcomes to actual outcomes and will finalize data analysis. Perhaps one session will not be enough to transform people’s beliefs about EOL conversations or increase comfort level regarding death. Reflecting on what was learned from this intervention will be valuable in the “Act” phase. Future QI projects, or even research, could apply what was learned from this project to help further understand the applicability of a game-based intervention in helping facilitate serious health conversations within a healthy urban community population.

### **Setting and Stakeholders**

This community engagement session took place on an online video conferencing platform called Zoom (Zoom Video Communications, 2020), with volunteer participants from the Bothell, WA area. Although the engagement platform was online and provided the opportunity to recruit participants from any location, Bothell is only 15 minutes away from Kirkland, WA, where the first confirmed outbreak of COVID-19 in the US occurred. Therefore, it was an unanticipated opportunity to get the perspective of adults living in one of the first areas in which the COVID-19 pandemic began.

The following data were obtained from Data USA, a comprehensive website with public government data (Data USA, n.d.). Bothell, WA is a city located 25 minutes north of Seattle, WA with a population of 130,925, and a median age of 37.2 within the public use microdata area encompassing Bothell, Mill Creek, and Silver Firs. The ethnic composition of Bothell, WA, is predominantly made up of Caucasians (69.6%), followed by Asians (16.5%) and Hispanics (6.53%) which, in comparison with the ethnic composition of the entire US, represents a population of more Whites, significantly more Asians, and fewer Hispanics. Bothell has 1.3 times more foreign-born residents and 1.7 times higher average household income than the entire US.

The above data shows that residents in Bothell are of higher socioeconomic status than the average person in the US. There is no shortage of evidence suggesting that higher socioeconomic status is associated with higher educational level, higher health literacy, better health status, and better health-related outcomes (Stormacq, Van den Broucke, & Wosinski, 2018). There is also a lack of ethnic diversity as Caucasians and Asians make up 86% of Bothell residents (Data USA, n.d.). The types of people who occupy Bothell should be considered during data analysis. Education level, income, and ethnicity all have a part in how health concepts and death are understood.

There were several stakeholders in this project. First, the owners of the local businesses who permit posting of the project flyer in their establishments played a role in gaining participants. Second was the healthy adult community members of the Bothell area. This community engagement project explored how an online educational intervention allowed people to learn and grow their knowledge and to realize that there is no easy way to become comfortable

with the uncomfortable other than confronting it head-on. To destigmatize and normalize EOL discussions and increase ACP behaviors at large will take the buy-in and support of many other stakeholders such as medical providers, healthcare staff, educators of higher learning, and national organizations. Targeting community-dwelling members and invoking their curiosity and interest on a local level can build momentum and change from the bottom up.

### **Intervention**

The intervention of this project consists of two parts. The ACP education, which took place at the beginning of the online session, was disseminated from a PowerPoint presentation on the components of ACP. The slides from the PowerPoint presentation can be viewed in Appendix E. This included education about healthcare proxies, advance directives, legalizing ACP documentation, and types of life sustaining measures (such as intravenous fluids, tube feedings, parenteral nutrition, cardiopulmonary resuscitation, & mechanical ventilation). A discussion took place about patient preferences and what QOL can mean to different individuals. The presentation provided participants with helpful ACP resources that can be used to gain further knowledge or to help them take steps toward ACP completion if they so choose. The PowerPoint slides were screen shared by the investigator on Zoom. This presentation took approximately 15 minutes.

The second part of the intervention was the interactive conversation game *Hello. Hello* facilitated conversations to individuals in a way that was non-threatening and light-hearted (Van Scoy, Green et al., 2017). Utilizing the conversation game booklet encompassing 32 thought-provoking questions, one question was screen-shared at a time for everyone to answer. The investigator read the screen-shared question out loud, and then the participants were given a few

minutes to write down their responses on a piece of paper. Each participant was given the opportunity to share their answers or to pass their turn. There were 45 minutes allotted to play the game.

### **Participants and Recruitment**

A convenience sample was utilized to recruit healthy adult volunteers in the Bothell area for this QI project. This decision was made based on convenience sampling's ability to produce expedited data collection, as well as ease of recruitment and economic feasibility. The inclusion criteria used for participants were the following: (a) between the ages of 18 to 45, (b) English speaking, (c) lives within 45 minutes of the Bothell area, and (d) is self-identified as being a healthy individual. These criteria were chosen because of the aim to target healthy, community-dwelling adults that would not be categorized as "elderly." The abundance of available literature on ACP and EOL studies subjects who are older, in poor health states, or both (Bravo et al., 2016; Kastbom, Milberg, & Karlsson, 2017; Weathers et al., 2016). It is important to explore the impact of ACP interventions on younger, healthy adult populations to understand better, how people think and behave when preparing for future healthcare decisions while in optimal health states.

Participants for this QI project were recruited using flyers (Appendix B). The flyers were posted around local businesses as well as posted online on the PI's personal social media outlets such as Facebook and Instagram. The flyer briefly discussed the project purpose, participant inclusion criteria, project implementation, and the presenter's contact information for any questions. Volunteers were asked to contact the principal investigator (PI) via email. From there,

the PI communicated with the volunteers via email with the necessary information to move forward with participation in the project.

### **Consent and Ethical Considerations**

The project was reviewed and approved by the Institutional Review Board (IRB) through the University of Arizona before recruitment and data collection for this project occurred. The IRB approval letter can be viewed in Appendix H. Participants were given the disclosure form (Appendix A) which describe consent as being implied if they voluntarily continued to participate in the project.

The protection of the project participants is of the highest priority. The ethical principles of *respect for persons*, *beneficence*, and *justice* were employed throughout the planning, implementation, and evaluation of this project. Respect for persons were exhibited by the understanding that participants are all autonomous beings who, given the appropriate information, have the capacity and the right to make their own decisions (Miracle, 2016). Additional protection was planned to be given to vulnerable persons, such as participants with mental illnesses, to ensure they have the cognitive capacity to understand what is at stake (Miracle, 2016). The project disclosure form clearly stated that participation is voluntary, the option to withdraw at any time if desired, and refusal to participate will result in no penalty. The project met the beneficence principle by ensuring that all possible measures were taken to reduce the risk of harm to the participants. Email addresses were the only discernable participant identifier collected in this project and were stored in a password-protected device only accessible to the student. The only identifiable harm in participating in the online educational session and completing the pre- and post-engagement surveys was the psychological risk of emotional

distress or sadness when discussing EOL and death. There were steps in place to minimize this risk such as having an investigator competent in handling emotionally difficult conversations and adept in therapeutic communication. The principle of justice was deployed by treating every participant equally and hosting the educational session fairly by giving all participants an equal opportunity to speak. The criteria for participation were carefully established to exclude as few participants as possible while understanding that limitations do exist, and project aims must be met through the inclusion and exclusion of volunteers.

### **Data Collection**

This project recruited participants using a flyer (Appendix B), which was distributed at local businesses and on the PI's social media platforms, specifically Instagram and Facebook. The recruitment flyer asked any interested volunteers to contact the student via email. This allowed the investigator to collect the volunteers' email addresses, which was used to send links to the pre- and post-engagement surveys (Appendix C & D) from the online survey software, SoGoSurvey, as well as the link to an online video conferencing platform called Zoom.

Eleven volunteers who responded with interest in participating in this project received a link to the online pre-engagement survey via email one week before the engagement session day. Once they clicked on the pre-engagement survey link, the project disclosure form (Appendix A) was the first item stating the session's purpose, the time required to complete different components of the project, and the voluntary nature of participation. This was followed by the pre-engagement survey, which was filled and submitted anonymously through a feature on SoGoSurvey (SoGoSurvey, 2020), which de-linked responses from participant-identifying information including email addresses, dates and time of participation, and internet protocol

addresses. The 11 participants were asked to complete the pre-engagement survey at any time before the engagement session. The 11 participants were asked to email the student once they completed the pre-engagement survey, at which point they were sent the link to the Zoom meeting where the engagement session took place. On the day of the engagement session, 11 participants logged into the Zoom meeting online at the specified time and date using the link sent by the presenter. The session began with a brief introduction of the presenter and an overview of ACP through a screen-shared PowerPoint presentation as described previously.

Next, the conversation game *Hello* was introduced and explained. The game has 32 thought-provoking questions about living, dying, and individual preferences at the EOL, all of which was not utilized due to time constraints and the size of the project sample. Once the student picked a question out of the *Hello* game for everyone to answer, the participants were given a few minutes to write down their answers. They could either choose to share or to pass. Forty-five minutes were allotted for the game to be played. After the game, each participant was asked to fill out the online post-engagement survey, which the link was sent out to their email soon after the Zoom session ended. Participants were asked to complete the post-survey within one week of the session. The participants were asked to notify the student via email when they have completed the post-engagement survey. A \$10 Amazon gift card was sent to the 11 participants who stated completion of the post-survey, as stated on the recruitment flyer.

### **Surveys**

Sudore et al. (2017) have created a validated 9-item ACP engagement survey, which has been assessed for internal consistency and construct validity on the ability to detect a change in people's behavior in regards to ACP (Sudore et al., 2017). These nine questions are a part of the

pre- and post-engagement surveys utilized in this project. Answered on a 5-point Likert scale, each answer option to these questions correlate with a stage of change in the TTM. For example, one of the questions reads, “How ready are you to talk to your provider about the kind of medical care you would want if you were very sick or near the end of life?” The answers range from, “I have never thought about it,” to “I have already done it.” A group average of the stage of change was assessed for each question from the pre-engagement survey. This will indicate whether the type of intervention provided was appropriate for the participants’ stage of change. Secondly, comparing the results from the pre-engagement surveys to the post-engagement surveys can reveal several factors. One, to see if individual participants moved in stages of change after the project intervention, and two, to see whether the intervention can facilitate a move forward in the average stage of change of participants as a collective group.

The pre-engagement survey collected demographics of participants, including their age range, gender, and education level, as well as their history with ACP. The post-engagement survey had an additional three questions to the 9-item ACP engagement survey from Sudore et al. (2017). These questions evaluated the engagement session quality, and its ability to increase ACP knowledge and comfort level in discussing end-of-life.

The sections with the patient demographics, the history with ACP, and the seminar evaluation were developed by Murphy (2019), and permission was obtained by the author to utilize for this DNP project. Pre- and post-engagement surveys can be viewed in Appendix C and D.

## **Data Analysis**

Data evaluation utilized the software program Microsoft Excel (Microsoft Corporation, 2017) for analysis. The tables demonstrate the participant demographics, history with ACP, and seminar evaluation questions. For each question from the 9-item ACP engagement survey by Sudore et al. (2017), the central tendency was measured by assessing the average stage of change for the group, and the results from before and after the educational intervention were compared. The participants' thoughts on whether the session improved their knowledge of ACP and increased their comfort level in having EOL discussions was assessed by the seminar evaluation questions, which were answered on a 5-point Likert scale. An example being, "I feel more comfortable in discussing my end-of-life wishes with my family and friends," with an answer from "strongly agree" to "strongly disagree." The percentage of people who answer "agree" or "strongly agree" is presented in a table. The percentages show the proportion of participants who demonstrated our expected outcome of increased knowledge and increased comfort level.

## **RESULTS**

### **Outcome**

A total of 11 participants responded with interest to the recruitment flyer. All 11 participants completed the pre-engagement survey, attended the educational Zoom session on August 22, 2020, and completed the post-engagement survey within one week of the Zoom session. For a detailed timeline of the project, view Appendix F.

Participant demographics can be viewed in Table 1. Most participants were females (N=9, 81.8%), and the most common age group was between 26-35 years (N=10). The highest

level of education for most was a bachelor's degree (N=9), with one participant having an associate's degree and another having a master's degree.

**Table 1**

*Participant Demographics*

<b>Demographics (n=11)</b>			
<b>Age, (%)</b>		<b>Education, (%)</b>	
18-25	0	Some High School	0
26-35	90.9	High School	0
35-45	9.1	Associates	9.1
<b>Gender, (%)</b>		Bachelors	81.8
Female	81.8	Masters	9.1
Male	18.2	PhD/Doctorate	0

The participants' history with ACP was collected and can be viewed in Table 2. All participants had heard of a living will, and most had heard of an AD (N=9) and a medical power of attorney (N=8). When participants were asked if they have thought about how they would like to be cared for at the EOL, four responded with "I have never thought about it," three responded with "I am thinking about it, but not sure how to talk about it" and two responses each for "I have thought about it, but not ready to discuss it" and "I have thought about it, and have talked to my family and friends." Lastly, when asked if the COVID-19 pandemic made them more aware of the lack of ACP knowledge and EOL discussions as a concern, 55% of participants answered either "strongly agree" or "agree," 18.2% stated "neither agree nor disagree," and 27.3% answered they "disagree."

**Table 2***History with ACP*

Pre-Education Information			
Heard of AD, (%)		Thought about EOL care, (%)	
Yes	81.8	Never	36.3
No	18.2	Yes, but not ready to discuss	18.2
Heard of Living Will, (%)		Yes, but not sure how to discuss	27.3
Yes	100	Yes, and have talked to family/friends	18.2
No	0	Already made plans for EOL care	0
Heard of MPOA, (%)		More aware of lack of ACP because of COVID-19, (%)	
Yes	72.7	Strongly agree	9
No	27.3	Agree	45.5
Completed ACP documents, (%)		Neither agree or disagree	18.2
AD	0	Disagree	27.3
Living Will	0	Strongly disagree	0
MPOA	0		

Abbreviations: ACP, advance care planning; AD, advanced directive; COVID-19, coronavirus 2019; EOL, end-of-life; MPOA, medical power of attorney

The first aim of this project was to educate community-dwelling healthy adults about ACP and to engage in meaningful conversation about EOL. This project provided a community engagement Zoom session where ACP education was provided along with the facilitation of a light-hearted EOL conversation game. Participants openly discussed their thoughts and perspectives of death and dying in an environment that was as open and free from judgment as possible.

The post-engagement survey included a seminar evaluation question to understand participants' perceptions of the increase in knowledge. All seminar evaluation questions can be viewed in Table 3. The percentage that answered either "agree" or "strongly agree" is displayed in the table. The questions, "The education that was provided increased my knowledge about advance care planning," were answered as either "agree" or "strongly agree" by all (100%) of participants. A part of the second aim was to increase participants' comfort level in EOL

discussions. The seminar evaluation question, “I feel more comfortable in discussing my end-of-life wishes with my family and friends,” received an answer of “agree” or “strongly agree” by 81.8% of participants. The participant’s perception of the Zoom meeting’s value was evaluated with the question, “The time spent at this seminar was worthwhile,” which received an “agree” or “strongly agree” by all (100%) of participants.

**Table 3**

*Seminar Evaluation Questions*

Questions, (%)	Agree	Strongly Agree	Total
The education that was provided increased my knowledge about ACP	81.8	18.2	100
I feel more comfortable in discussing my EOL wishes with my family and friends	63.6	18.2	81.8
The time spent at this seminar was worthwhile	54.5	45.5	100

Abbreviations: ACP, advance care planning; EOL, end-of-life

Another part of the second aim was to increase participants’ readiness to partake in ACP behaviors. To assess this, the group mean of each question from the 9-item ACP engagement questions was measured and compared between the pre- and post-surveys as displayed in Table 4. Answered on a 5-point Likert scale, each answer option correlated with a stage of change in the transtheoretical model as follows: (1) *precontemplation*, (2) *contemplation*, (3) *preparation*, (4) *action*, and (5) *maintenance*. An increase in the group mean showed advancement in the stage of change and indicated a positive outcome from the Zoom session. As compared to pre-survey, there was an increase in post-survey means of all nine questions from the ACP engagement survey. The largest increase in group mean of 1.28 points between pre- and post-surveys was produced from the question, “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?” and

smallest increase in group mean of 0.18 points was produced from the question “How confident are you that today you could talk with your provider about the care you would want if you were very sick or near the end of life?” Assessing the shift in the collective group’s stage of change demonstrated that the participants started in the contemplation stage (M=2.46) then shifted to the preparation stage (M=3.18) after the engagement session.

**Table 4**

*Comparison of pre- and post-engagement survey results*

ACP Engagement Questions	Pre- Engagement, mean	Post- Engagement, mean
Readiness to discuss with medical provider EOL wishes	1.64	2.55
Readiness to tell HCP whom MPOA is	2.18	2.64
Readiness to discuss EOL wishes with MPOA	1.82	3.1
Readiness to document EOL wishes	1.64	2.55
Readiness to sign documents appointing MPOA	1.73	2.45
Level of readiness to formally ask someone to be MPOA	2.82	3.63
Confidence discussing EOL preferences with MPOA	3.09	4.09
Confidence level asking someone to be MPOA	4.36	4.63
Confidence level discussing EOL care with HCP	2.82	3
Overall group score	2.46	3.18
<b>Number Correlated with Stages of Change</b>		
1 - Precontemplation		
2 - Contemplation		
3 - Preparation		
4 - Action		
5 - Maintenance		

Abbreviations: EOL, end-of-life; HCP, health care provider; MPOA, medical power of attorney

## DISCUSSION

### Summary

A short, online community engagement session, which took little to no cost in preparation, increased ACP knowledge, and increased comfort in EOL discussions as measured

subjectively per participants' report. The ACP education session revealed that most had heard of different advance directive documentation names yet knew no details about what they entailed. Participants learned about the different life-sustaining measures, comfort measures, and had conversations about what a "good death" can mean to different individuals. Every volunteer fully participated in the EOL conversation game and was engaged in meaningful conversations.

The aim to improve knowledge and comfort level in EOL discussions was accomplished by providing healthy community-dwelling adults with exposure to ACP education and an opportunity to play an EOL discussion game that facilitated the expression of EOL goals and care preferences. The seminar evaluation results validated this outcome as evidenced by all (100%) participants answering that they "agreed" or "strongly agreed" that the Zoom session improved their ACP knowledge and was worthwhile, and 81.8% stating increased comfort level in discussing EOL matters with family and friends.

Each answer to the ACP engagement questions was correlated to a stage of change in the transtheoretical model by Prochaska and DiClemente (1983), as shown in Table 4. As anticipated, the participants were collectively in the contemplation stage of change before the engagement session; this makes sense as they volunteered to participate in this project, which meant they sought more information about ACP. The expected outcome was a positive upward shift in the stage of change after the engagement session, which would suggest an increase in readiness to perform ACP behaviors. Results showed a shift in group mean scores from the contemplation stage ( $M=2.46$ ) to the preparation stage ( $M=3.18$ ), demonstrating our expected outcome.

## **Interpretation**

Consistent with previous study findings, participants were willing to discuss their thoughts and preferences about end-of-life when given the right opportunity (IHI, 2019). They reported positive experiences with the conversation game, *Hello*, which allowed stressful conversations to take place organically in a game-based atmosphere. This project created an environment where death was highlighted as a natural and universal human process, EOL conversations were normalized, and serious discussions about future medical care were had without the pressure of an imminent health concern. These healthy community-dwelling adult volunteers were exposed to ACP information, perhaps formally for the first time.

## **Implications**

### **Practice**

This project provided implications for future practice, especially for primary care. Unless acutely ill, healthy adults have no contact with inpatient healthcare settings. This, along with the fact that the type of conversation needed for ACP is better suited in the primary care setting indicates that the dissemination of ACP information and EOL care conversations need to occur in the outpatient setting. There are, however, real-life limitations of appointment times and complexities of ACP conversations. As seen in this project, the impact of ACP education can inform clinicians that incorporating even the simplest of ACP education into patient visits can increase knowledge. An educational pamphlet is an example of education that patients can take home and refer to if they desire to learn more. This way, healthy patients are made aware of ACP and their benefits earlier on and can begin to think and have conversations with their loved ones who could become their healthcare proxy in the future.

## **Education**

There is no shortage of evidence suggesting that healthcare professionals lack practical communication skills and cannot execute proper EOL discussions due to the lack of education in academia (IOM, 2015). The overall quality of patient-provider communication regarding serious illness is low, specifically in discussing prognosis due to concern of inflicting emotional and spiritual distress to the patient and family members (IOM, 2015). There is a deficit of palliative care and ACP content integrated into the academic curricula of medical, nursing, and pharmacy schools (IOM, 2015). This leads to professionals entering practice unprepared to discuss basic ACP with limited understanding of practical communication skills needed to talk about end-of-life (Bernacki & Block, 2014). In a study of medical residents, 88% reported not having received or having very little training on EOL care during residency (Schmit et al., 2016).

Improving providers' skill and comfort with EOL discussion starts with an intervention in academia to require EOL and communication training in their curricula to match the current healthcare demands, which expect non-palliative care clinicians to provide high-quality palliative care and EOL discussions. As the goal is for ACP to occur regardless of age or health state, proper EOL training for providers is vital in the primary care setting, which has the most access to healthy individuals.

## **Research**

Most of the available literature on ACP and EOL conversations works with older subjects, in poor health states, or both (Bravo et al., 2016; Kastbom et al., 2017; Weathers et al., 2016). We now know ACP is most optimal when done earlier in life when individuals are healthy, with intact cognition, and able to make decisions for themselves without the pressure of

an imminent threat to health (Prince-Paul & DiFranco, 2017). Studying how younger, healthier individuals think about death and their understanding, perception, and behavior towards ACP would be informative. It would be interesting to study how the home lives and conversations surrounding death, and their cultural background, influence beliefs and comfort with discussing death.

### **Policy**

On January 1, 2016, the Centers for Medicare and Medicaid Services (CMS) approved two current procedural terminology (CPT) codes that would reimburse providers for face-to-face conversations about ACP in the inpatient and outpatient settings (Barwise, Wilson, Sharp, & DeMartino, 2020). The ability to reimburse providers for ACP discussions, which can be a time-consuming process, ultimately benefits the patients and the families by increasing access and occurrence to ACP conversations. This change will likely increase the uptake of ACP, with the primary goal of improving the delivery of care at the EOL by providing care congruent to patient values and preferences (Barwise et al., 2020). In turn, a decrease in the national healthcare costs should result in avoiding unwanted healthcare utilization and futile medical care at the EOL. While the introduction of these CPT codes was a significant step forward, clinician reimbursement for ACP only covers Medicare patients, which vastly limits the patient populations benefited by this change, explicitly excluding healthy younger adults. However, further monitoring of billing practices, rates of ACP and AD completions, and health metrics related to EOL care quality would be needed to support future policy interventions to include patients covered by other insurance plans.

### **Limitations**

Several limitations can be identified in this study. First, the study sample could not accurately reflect the population of the immediate community and was heavily representing females (N=9, 81.8%) and those between the ages of 25-35 (N=10, 90.9%). This may be because most of the recruitment was accomplished through the investigator's social media platforms due to the pandemic discouraging people from visiting local businesses to decrease infection spread. Ten out of the 11 participants held a bachelor's degree or higher, reflecting as an advantage in medical literacy and knowledge. It therefore must be taken into consideration when interpreting results. Secondly, the sample size is small and therefore undermines internal validity and ability to extrapolate data. Finally, the COVID-19 pandemic did affect this project. The original plan was to have community-dwelling older adults participate in an educational session in an elderly apartment community. This was quickly deemed unfeasible as Washington State went into a mandated stay-at-home order where any gatherings were prohibited. Even without this order, it would have been unsafe to promote a medically vulnerable population to gather for this project. Therefore, the project was altered to an online setting with healthy adults between the ages of 18-45. The change from an in-person to an online platform changed the target population as older individuals may not know how to utilize technology and web-based programs.

### **DNP Essentials Addressed**

This DNP project addressed components of the DNP essentials in its development and implementation. The *DNP Essential III: Clinical Scholarship and Analytical Methods for Evidence-Based Practice* applied greatly to what was accomplished. First, critical appraisal of relevant literature about ACP education in the community setting and novel approaches to EOL

conversations was conducted to better understand the current research gaps. Secondly, a need for ACP education and discussion among healthy adults was identified. A community engagement session was designed, directed, and evaluated to promote health and wellness and discuss death as a universal process, an unmet need in our society. Although not generalizable, the project findings were nevertheless knowledge-generating in the context of our given participant sample and project design. Early ACP introduction benefits far outweigh any risks that can be identified, including healthcare overhead cost of implementing ACP initiatives, especially if there are the appropriate compensations for providers through policy changes.

This project's aims aligned greatly with the *DNP Essential VII: Clinical Prevention and Population Health for Improving the Nation's Health*. This essential speaks to improving populations' health status with risk reduction, illness prevention, and health promotion of aggregates such as the community. This project promoted and normalized EOL discussions, fostered patient autonomy through ACP education, helped honor personal preferences and values regarding future medical care and EOL, reduced the risk of possible unnecessary healthcare utilization, and validated the importance of individualized EOL care. This project utilized a care delivery model of disseminating education through an online outlet that is readily available across various cultures, socioeconomic dimensions, and communities. It showed that access to education and healthcare could be accomplished through web-based devices and impact health outcomes.

### **Conclusions**

Currently, discussions about EOL care goals, preferences, or documentation are not prioritized in the American healthcare system. Lack of ACP is a multi-factorial and deeply

systemic issue that must be addressed to improve EOL care quality by honoring what is most important to each individual. Providing EOL care congruent with the patient's preferences is a part of providing compassionate and humane care. Arguably, providing a "good" death is just as important and impactful for the remaining loved ones who express less guilt and more peace when patient's wishes were followed at the EOL, and they are not left to make decisions on their behalf (Houben et al., 2014; Sulmasy et al., 2017). No matter what age and state of health, discussions about living, dying, and what matters most should occur, both in the home and in the healthcare setting. Changes can start as small as in the community setting, where individuals can connect and share thoughts with others alike or as widely-spread with digital platforms for promotion and education of ACP. Understanding the full effect of ACP on the biopsychosocial state of populations and the effects on our healthcare economics should motivate policymakers and healthcare stakeholders to mobilize efforts and resources to improve the care of the dying.

### **Plan for Sustainability**

The most significant benefit of utilizing an online platform, such as Zoom, is implementing community education that requires minimal cost. Eliminating the financial barrier makes such interventions extremely feasible and sustainable in the long-term. Also, an online platform eliminates geographical barriers and allows dissemination of information to all those with access to the internet. Future QI projects that wish to take this project design to implement ACP education and community engagement could modify their project to include various demographics from one location or multiple sites, depending on the targeted sample base and the project aims.

**Plan for Dissemination**

Unlike other QI projects, this project did not collaborate with a local healthcare facility. Therefore, dissemination of findings will occur through future submissions for national healthcare journals and at local medical conferences. Dissemination of findings will be reflected in the PI's clinical practice by bringing ACP awareness to all wellness visits and promoting AD documentation.

APPENDIX A:  
THE UNIVERSITY OF ARIZONA INSTITUTIONAL REVIEW BOARD DETERMINATION  
LETTER


 Human Subjects  
 Protection Program

 1618 E. Helen St.  
 P.O.Box 245137  
 Tucson, AZ 85724-5137  
 Tel: (520) 626-6721  
<http://rgw.arizona.edu/compliance/home>

**Date:** August 05, 2020  
**Principal Investigator:** Yuiho Walker Mrozinski  
**Protocol Number:** 2007862245  
**Protocol Title:** Community Engagement to Improve Advance Care Planning Knowledge with Healthy Adults

**Determination:** Approved  
**Expiration Date:** August 03, 2023

**Documents Reviewed Concurrently:**

**Data Collection Tools:** *Hello Game 32 questions.docx*  
**Data Collection Tools:** *Mrozinski\_AcpEducation (1).pdf*  
**Data Collection Tools:** *post-engagement survey.docx*  
**Data Collection Tools:** *pre-engagement survey.docx*  
**HSPP Forms/Correspondence:** *application\_v2019-12 Yui Mrozinski1 EDIT.pdf*  
**HSPP Forms/Correspondence:** *Mrozinski appendix\_waiver.pdf*  
**HSPP Forms/Correspondence:** *Mrozinski list\_of\_research\_personnel\_v04-2020 (1) YMrozinski.pdf*  
**Informed Consent/PHI Forms:** *Disclosure Form.docx*  
**Informed Consent/PHI Forms:** *Disclosure Form.pdf*  
**Other Approvals and Authorizations:** *COI Certification Complete for 2007862245.msg*  
**Recruitment Material:** *Flyer.docx*

**Regulatory Determinations/Comments:**

- The project is not federally funded or supported and has been deemed to be no more than minimal risk.
- The project listed is required to update the HSPP on the status of the research in 3 years. A reminder notice will be sent 60 days prior to the expiration noted to submit a 'Project Update' form.

This project has been reviewed and approved by an IRB Chair or designee.

- The University of Arizona maintains a Federalwide Assurance with the Office for Human Research Protections (FWA #00004218).
- All research procedures should be conducted according to the approved protocol and the policies and guidance of the IRB.
- The Principal Investigator should notify the IRB immediately of any proposed changes that affect the protocol and report any unanticipated problems involving risks to participants or others. Please refer to Guidance Investigators [Responsibility after IRB Approval, Reporting Local Information](#) and [Minimal Risk or Exempt Research](#).
- All documents referenced in this submission have been reviewed and approved. Documents are filed with the HSPP Office.

APPENDIX B:  
CONSENT DOCUMENT (DISCLOSURE AND CONSENT FORM)

## Community Engagement to Improve Advance Care Planning Knowledge with Healthy Adults

### **Principal Investigator: Yuiho Mrozinski**

The purpose of this project is to engage members of the community, specifically healthy adults, to learn about advance care planning (ACP) and to participate in meaningful conversations about end-of-life preferences. This project will provide ACP education and invite participants to play an end-of-life conversation game called *Hello* through a facilitated online Zoom session. The goal is to provide a welcoming and fun environment where individuals can have open and honest conversations about end-of-life and healthcare preferences utilizing a game-based approach and in the comfort of their own homes.

If you choose to take part in this project, you will be asked to fill out an online pre-and-post session survey which includes your demographics, knowledge about ACP, and your thoughts about end-of-life conversations.

This online community engagement session will collectively take approximately 1 hour and 10 minutes with the following breakdown of the session time: 5 minutes for pre-engagement survey, 60 minutes for the online Zoom session (15 minutes for the ACP education, 45 minutes for the conversation game), and 5 minutes for the post-engagement survey. First, an educational overview of ACP will be given through a screen-shared PowerPoint presentation, then the conversation game *Hello* is introduced and explained. The Zoom session will not be recorded, and you will not be identified in any report or publication of this study. Even though we will tell all participants in the study that the comments made during the focus group should be kept confidential, it is possible that participants may repeat comments outside the group. There may be some psychological risk of emotional distress or sadness when discussing end-of-life and death, and you will receive the immediate benefit of gaining knowledge about ACP and improving comfort in discussing end-of-life subjects. Survey responses are anonymous; your name will not be collected or linked to your answers. Your email address will be stored in a password protected device only accessible to the principal investigator, and will be deleted upon completion of this study.

All participants will be compensated with a \$10 Amazon gift card upon completion of the post-survey. To receive the gift card, participants must email the PI indicating completion of the post-survey, at which point the gift card will be emailed directly to their email address.

If you choose to participate in the project, participation is voluntary, refusal to participate will involve no penalty or loss of benefits to which you are otherwise entitled. You may withdraw at any time from the project. In addition, you may skip any question that you choose not to answer. By participating, you do not give up any personal legal rights you may have as a participant in this project. Participation will mean you agree to have your responses used for this project.

An Institutional Review Board responsible for human subjects' research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable

state and federal regulations and University policies designed to protect the rights and welfare of participants in research.

The information that you provide in the study will be handled confidentially. However, there may be circumstances where this information must be released or shared as required by law. The University of Arizona Institutional Review Board may review the research records for monitoring purposes. By submitting your survey responses and participating in the meeting, you are consenting to your survey data being used for this research. Information collected about you will not be used or shared for future research studies.

For questions about your rights as a participant in this study or to discuss other study-related concerns or complaints with someone who is not part of the research team, you may contact the Human Subjects Protection Program at 520-626-6721 or online at <http://rgw.arizona.edu/compliance/human-subjects-protection-program>.

For questions, concerns, or complaints about the project, you may contact:

Yuiho Mrozinski, RN, BSN, CPHON  
DNP-FNP Student  
Phone: 425-891-3573  
Email: [ymrozinski@email.arizona.edu](mailto:ymrozinski@email.arizona.edu)

APPENDIX C:  
RECRUITMENT MATERIAL (RECRUITMENT FLYER)



**AUGUST 22, 2020**

**4 - 5PM**

**Join our Zoom meeting!**

Come learn about advance care planning and participate in a light-hearted end-of-life conversation game!

**Let's Talk About**

**E n d o f L i f e**



**Did you know...**

That 92% believe that having a meaningful end-of-life conversation is very important...

...but only 32% of Americans have engaged in conversations about their end-of-life wishes with their loved ones!

**Let's normalize end-of-life conversation!**

**Are you...**

- A healthy adult between ages 18 to 45 years old?
- Live within 45 mins of Bothell, WA?

**Bring your friends and family!**

**Participate in our zoom meeting!**

\*This is a research protocol, and by attending the Zoom session, you are participating in research.

**All participants will receive a \$10 Amazon gift card!**



**Questions and Registration:**

Contact [ymrozinski@email.arizona.edu](mailto:ymrozinski@email.arizona.edu)

An Institutional Review Board responsible for human subjects research at The University of Arizona reviewed this research project and found it to be acceptable, according to applicable state/federal regulations and University policies designed to protect the rights and welfare of participants in research.

APPENDIX D:

EVALUATION INSTRUMENTS (ADVANCE CARE PLANNING PRE-ENGAGEMENT  
SURVEY/DEMOGRAPHIC INFORMATION/PRE-EDUCATION SURVEY/ENGAGEMENT  
SURVEY/POST-ENGAGEMENT SURVEY AND EVALUATION)

## ADVANCE CARE PLANNING PRE-ENGAGEMENT SURVEY

The purpose of this questionnaire is for you to provide some basic background information about yourself and your experience with advance care planning. Please complete the following demographics and pre-education questionnaire.

### **Demographic Information**

1. Gender: Female \_\_\_\_\_ Male \_\_\_\_\_
2. Age: 18-25 \_\_\_\_\_ 26-35 \_\_\_\_\_ 35-45 \_\_\_\_\_
3. Highest level of Education:
  - a. Some High School \_\_\_\_\_
  - b. High School \_\_\_\_\_
  - c. Associates \_\_\_\_\_
  - d. Bachelors \_\_\_\_\_
  - e. Masters \_\_\_\_\_
  - f. PhD/Doctorate \_\_\_\_\_

### **Advance Care Planning Pre-Education**

4. Have you heard of any of the following?
  - a. Advance Directives: Yes \_\_\_\_\_ No \_\_\_\_\_
  - b. Living Will: Yes \_\_\_\_\_ No \_\_\_\_\_
  - c. Medical Power of Attorney: Yes \_\_\_\_\_ No \_\_\_\_\_
5. Have you completed any documentation listed above? Yes \_\_\_\_\_ No \_\_\_\_\_
  - a. If yes, which documentation have you completed?
    - i. Advance Directive: \_\_\_\_\_
    - ii. Living Will: \_\_\_\_\_
    - iii. Medical Power of Attorney: \_\_\_\_\_
6. Have you thought of how you would want to be cared for at the end-of-life?
  - a. I have never thought about it
  - b. I have thought about it, but not ready to discuss it
  - c. I am thinking about it, but not sure how to talk about it
  - d. I have thought about it, and have talked to my family and friends
  - e. I have already made plans for my end-of-life care
7. The COVID-19 pandemic made you more aware of the lack of ACP knowledge and end-of-life discussions as a concern
  - a. Strongly agree
  - b. Agree
  - c. Neither agree or disagree

- d. Disagree
- e. Strongly disagree

### Advance Care Planning Engagement Survey

1. How ready are you to talk to your provider about the kind of medical care you would want if you were very sick or near the end of life?
  - a. I have never thought about it
  - b. I have thought about it, but I am not ready to do it
  - c. I am thinking about doing it over the next few visits
  - d. I am definitely planning to do it at the next visit
  - e. I have already done it
2. How ready are you to talk with your provider about who you want your medical decision maker to be?
  - a. I have never thought about it
  - b. I have thought about it, but I am not ready to do it
  - c. I am thinking about doing it over the next few visits
  - d. I am definitely planning to do it at the next visit
  - e. I have already done it
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?
  - a. I have never thought about it
  - b. I have thought about it, but I am not ready to do it
  - c. I am thinking about it in the next 6 months
  - d. I am definitely planning to do it in the next 30 days
  - e. I have already done it
4. How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life?
  - a. I have never thought about it
  - b. I have thought about it, but I am not ready to do it
  - c. I am thinking about it in the next 6 months
  - d. I am definitely planning to do it in the next 30 days
  - e. I have already done it
5. How ready are you to sign official papers naming a person or group of people to make medical decisions for you?
  - a. I have never thought about it
  - b. I have thought about it, but I am not ready to do it
  - c. I am thinking about it in the next 6 months
  - d. I am definitely planning to do it in the next 30 days
  - e. I have already done it

6. How ready are you to formally ask someone to be your medical decision maker?
  - a. I have never thought about it
  - b. I have thought about it, but I am not ready to do it
  - c. I am thinking about it in the next 6 months
  - d. I am definitely planning to do it in the next 30 days
  - e. I have already done it
  
7. How confident are you that today you could talk with your medical decision maker about the care you would want if you were very sick or near the end of life?
  - a. Not confident at all
  - b. A little confident
  - c. Somewhat confident
  - d. Fairly confident
  - e. Extremely confident
  
8. How confident are you that today you could ask someone to be your medical decision maker?
  - a. Not confident at all
  - b. A little confident
  - c. Somewhat confident
  - d. Fairly confident
  - e. Extremely confident
  
9. How confident are you that today you could talk with your provider about the care you would want if you were very sick or near the end of life?
  - a. Not confident at all
  - b. A little confident
  - c. Somewhat confident
  - d. Fairly confident
  - e. Extremely confident

## ADVANCE CARE PLANNING POST-ENGAGEMENT SURVEY AND EVALUATION

The purpose of this questionnaire is to evaluate if the Advance Care Planning education that was provided made an impact on your knowledge, comfort levels in communicating and documenting your end-of-life wishes.

### Advance Care Planning Engagement Survey

1. How ready are you to talk to your provider about the kind of medical care you would want if you were very sick or near the end of life?
  - a. I have never thought about it
  - b. I have thought about it, but I am not ready to do it
  - c. I am thinking about doing it over the next few visits
  - d. I am definitely planning to do it at the next visit
  - e. I have already done it
  
2. How ready are you to talk with your provider about who you want your medical decision maker to be?
  - a. I have never thought about it
  - b. I have thought about it, but I am not ready to do it
  - c. I am thinking about doing it over the next few visits
  - d. I am definitely planning to do it at the next visit
  - e. I have already done it
  
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?
  - a. I have never thought about it
  - b. I have thought about it, but I am not ready to do it
  - c. I am thinking about it in the next 6 months
  - d. I am definitely planning to do it in the next 30 days
  - e. I have already done it
  
4. How ready are you to sign official papers putting your wishes in writing about the kind of medical care you would want if you were very sick or near the end of life?
  - a. I have never thought about it
  - b. I have thought about it, but I am not ready to do it
  - c. I am thinking about it in the next 6 months
  - d. I am definitely planning to do it in the next 30 days
  - e. I have already done it
  
5. How ready are you to sign official papers naming a person or group of people to make medical decisions for you?
  - a. I have never thought about it
  - b. I have thought about it, but I am not ready to do it

- c. I am thinking about it in the next 6 months
  - d. I am definitely planning to do it in the next 30 days
  - e. I have already done it
6. How ready are you to formally ask someone to be your medical decision maker?
- a. I have never thought about it
  - b. I have thought about it, but I am not ready to do it
  - c. I am thinking about it in the next 6 months
  - d. I am definitely planning to do it in the next 30 days
  - e. I have already done it
7. How confident are you that today you could talk with your medical decision maker about the care you would want if you were very sick or near the end of life?
- a. Not confident at all
  - b. A little confident
  - c. Somewhat confident
  - d. Fairly confident
  - e. Extremely confident
8. How confident are you that today you could ask someone to be your medical decision maker?
- a. Not confident at all
  - b. A little confident
  - c. Somewhat confident
  - d. Fairly confident
  - e. Extremely confident
9. How confident are you that today you could talk with your provider about the care you would want if you were very sick or near the end of life?
- a. Not confident at all
  - b. A little confident
  - c. Somewhat confident
  - d. Fairly confident
  - e. Extremely confident
10. The education that was provided increased my knowledge about advance care planning
- a. Strongly agree
  - b. Agree
  - c. Neither agree or disagree
  - d. Disagree
  - e. Strongly disagree
11. I feel more comfortable in discussing my end-of-life wishes with my family and friends
- a. Strongly agree

- b. Agree
- c. Neither agree or disagree
- d. Disagree
- e. Strongly disagree

12. The time spent at this seminar was worthwhile

- a. Strongly agree
- b. Agree
- c. Neither agree or disagree
- d. Disagree
- e. Strongly disagree

Additional comments:

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APPENDIX E:  
PARTICIPANT MATERIAL (ADVANCE CARE PLANNING POWERPOINT EDUCATION  
SLIDES)

## ACP EDUCATION SLIDES



### “Let’s Talk End-of-Life!”

Increasing knowledge and destigmatizing death



Highly individualistic

No right or wrong answers



Answers evolve with time and circumstance

Know your options

## What is a “good” death?

- Who – family, friends, mentors, etc.
- What – music, objects
- Where – at home, somewhere comfortable
- How – quantity or quality, or little of both?



## Advance Directives

Documents that state your wishes for medical care in an emergency and at the end-of-life

- **Healthcare Power of Attorney**
  - Choose a person to make medical decisions on your behalf
- **Living Will**
  - Emergency treatments you want/don't want
  - Under which circumstances these apply

**Must have 2 witnesses to legalize documents**

## Treatment options

- **CPR:** Restore your heartbeat if your heart stops or is in a life-threatening abnormal rhythm
- **Ventilator:** Machines that help you breathe
- **Artificial nutrition and hydration:** Tube feeding, IV nutrition, IV fluids
- **Comfort measures:** Goal to relieve suffering and pain – limited medical testing, managing distressing symptoms, emotional/spiritual support



## Resources

The screenshot shows the Washington State Coronavirus Response (COVID-19) website. The main heading is "Mental and emotional well-being". Below it, there is a sub-heading "WHERE CAN I FIND SUPPORT FOR MY MENTAL HEALTH AND WELL-BEING?" followed by a paragraph: "This can be a stressful time. It is normal that you or your loved ones might feel anxious, sad, scared or angry. You are not alone. It is okay to seek out and ask for help. The resources here are a good place to start." Below this, it says "If you are experiencing excess stress due to COVID-19 call 888-681-0211 for support and resources." There are two main sections: "IN A CRISIS?" and "YOU".

**IN A CRISIS?**

- Suicide Prevention Lifeline: 800-273-8255
- Crisis Connections: 866-4-CRISIS (866-427-4747)
- Crisis Text Line: Text HOME to 741741
- Crisis Connections connects people to physical, emotional and financial crisis to services through 24-Hour Crisis Line, Teen Line, WA Recovery Help Line, and WA Migrant Line
- Disaster Distress Helpline: 800-985-5990 or text "T&WHELP" to 66746

**YOU**

- Care for Your Coronavirus Anxiety Toolkit
- Care for your coronavirus anxiety - a project by Shine

- **The National Institute of Aging**
- **End of Life Washington**
- **WA State Coronavirus Response**
  - Mental and emotional well-being support page
  - Crisis hotlines
  - <https://coronavirus.wa.gov/information-for-you-and-your-family/mental-and-emotional-well-being>

APPENDIX G:  
PROJECT TIMELINE

Date	Project
7/20/2020	IRB application submission
8/5/2020	IRB application approval
8/6/2020	Posted recruitment flyers
8/16/2020 – 8/21/2020	Sent disclosure forms and link to pre-test and Zoom session
8/22/2020	Project Implementation; sent out post-surveys
8/29/2020	All post-surveys received
8/20/2020 – 10/15/2020	Data analysis and outcomes
11/10/2020	DNP project presentation to committee

APPENDIX G:  
LITERATURE REVIEW GRID

Author's Last Name; Pub. Year	Title of Publication	Type of Study	Main Outcomes or Findings	Support for and or link to project
Bravo et al., 2016	Promoting advance care planning among community-based older adults: A randomized controlled trial	RCT	<p>A multimodal ACP intervention elicited 80% of experimental participants to complete documentation of their preference regarding future healthcare decisions through a booklet called <i>My Preferences</i>. The intervention did not help to increase the concordance of health-related decision making between the patient and the proxy in hypothetical health situations. Proxies often overestimated the older adult's desire for medical treatment and underestimated the desire for comfort care.</p> <p>Study involved community-dwelling older adults in relatively good health state.</p>	<ul style="list-style-type: none"> <li>• Documentation tools elicit older adults to document their wishes</li> <li>• Communication between the patient and the healthcare proxy is imperative in increasing the likelihood of surrogate decision making that is congruent to patient's wishes</li> <li>• Patients benefit from ACP interventions that allow the opportunity for important conversations about EOL care and medical care preferences to take place</li> </ul>
Fink et al., 2020	Community-based conversations about advance care planning for underserved populations using lay patient navigators	Case series	<p>A state-wide implementation of community-based, culturally-tailored ACP initiatives conducted by bilingual patient navigators reached medically underserved, community-dwelling adults of Colorado. Out of the participants who completed the postsession survey (47%), more than half stated intent for ACP engagement in the next 6 months and 98% expressed satisfaction with the ACP session.</p>	<ul style="list-style-type: none"> <li>• Healthy community-dwelling adults, compared to persons with serious illnesses or comorbidities, have less opportunities to express their EOL preferences and would benefit from a community-level exposure to information and education</li> <li>• Community-based interventions implemented in rural areas can reach ethnically diverse and lower socioeconomic populations who have less access to traditional healthcare settings.</li> <li>• Promoting ACP engagement at the community level is important to</li> </ul>

Author's Last Name; Pub. Year	Title of Publication	Type of Study	Main Outcomes or Findings	Support for and or link to project
				<p>promote buy-in, increases awareness, and opening up meaningful conversation</p>
Fried, Zenoni, & Lynne Iannone, 2017	A dyadic perspective on engagement in advance care planning	Qualitative cross-sectional study.	Interview of veteran-surrogate dyads revealed disagreements about whether ACP activities or communication had taken place (on average, >39%). The most common reason contributing to disagreements, where the veteran thought the conversation occurred but the surrogate did not, was because the surrogate expressed lack of knowledge of the veteran's preferences and goals of care. Surrogates were more inclined to believe the ACP activity had taken place when the veteran believed it did not in situations where the surrogates felt they knew the veteran well enough to know their wishes without having been told explicitly.	<ul style="list-style-type: none"> <li>• 81% of surrogates were either spouses or children, underlining the importance of clear and detailed communication regarding medical preferences and goals of care, even with loved ones who know each other best</li> <li>• Many assumptions are made, increasing the likelihood of discordant care to patient preferences</li> </ul>
Fried, Zenoni, Lynne Iannone, O'Leary, & Fenton, 2017	Engagement in advance care planning and surrogates' knowledge of patients' treatment goals	Cross-sectional cohort study	Veterans and their healthcare proxy (legal or hypothetical) were interviewed separately to determine how much the completion of ACP activities correlated with surrogate's knowledge of patient's treatment goals. Based on three hypothetical health states (severe physical and cognitive impairment, and being under severe pain), completion of communication regarding QOL was most associated with increased surrogate	<ul style="list-style-type: none"> <li>• ACP needs to include communication between the patient and their proxy about what health outcomes matters most to patients</li> <li>• Filling out documentation is inadequate in preparing surrogates to make decision aligned with patient wishes</li> </ul>

Author's Last Name; Pub. Year	Title of Publication	Type of Study	Main Outcomes or Findings	Support for and or link to project
			<p>knowledge of what the patient would want. However, this study revealed that the completion of ACP activities such as communications about life-sustaining treatment, appointing a healthcare proxy, and completion of AD does not necessarily correlate with increased surrogate knowledge of patient's treatment goals.</p>	
Hendricks et al., 2016	Church-based health promotion focused on advance care planning and end-of-life care at black baptist churches: a cross-sectional survey	A Cross-Sectional Survey	Surveys administered in two Baptist churches serving black congregations revealed that black parishioners valued EOL care and expressed desire for church-based ACP education.	<ul style="list-style-type: none"> <li>• The older minority population will grow substantially in the next several decades</li> <li>• Minorities are found to have disparities in EOL care with higher symptom burden and increased healthcare utilization at EOL</li> <li>• Culturally-tailored ACP interventions can increase buy-in and participation in ACP activities</li> </ul>

Author's Last Name; Pub. Year	Title of Publication	Type of Study	Main Outcomes or Findings	Support for and or link to project
Lambert South, Elton, & Lietzenmayer, 2020	Communicating death with humor: Humor types and functions in death over dinner conversations		Death over Dinner is an uplifting and interactive approach to facilitate conversations about death and EOL in a non-threatening, informal environment with family and friends. Utilizing Death over Dinner, the use of humor was assessed during dinner conversations. Various types of humor were utilized, some being more effective and beneficial than others at facilitating satisfactory conversations about death. Humor helps relieve tension during heavy, uncomfortable conversations and helps to build bond between members.	<ul style="list-style-type: none"> <li>• Having conversations about death should not only be reserved for when death is imminent</li> <li>• Death is a universal experience; denial of death is unhealthy</li> <li>• Novel ACP interventions and approaches are needed, such as this that allow for conversations about EOL to occur in a fun, light-hearted manner</li> <li>• What we are currently is not enough to increase ACP behaviors or awareness</li> </ul>
Litzelman et al., 2016	Enhancing the prospects for palliative care at the end of life: a statewide educational demonstration project to improve advance care planning	Quasi-experimental	Education to improve EOL conversations and AD documentation was provided to healthcare providers and organizations. Survey results showed that providers felt their EOL communication skills were improved and expressed more comfort with ACP conversations post education.	<ul style="list-style-type: none"> <li>• Providers are underprepared in their education to facilitate effective ACP and lack confidence</li> <li>• Providing ACP education opportunities through continuing education, or enhancing existing medical programs to include mandatory EOL communications skills should be considered</li> </ul>
Litzelman et al., 2017	Clarifying values and preferences for care near the end of life: the role of a new lay workforce	Mixed methods design, Pre-post longitudinal design	Community health workers can effectively engage older adults in ACP activities. Use of the Go Wish card game stimulated positive and meaningful conversation about EOL preferences otherwise not discussed, and helped participants in priority-setting in regards to what is important at the EOL	<ul style="list-style-type: none"> <li>• Community health workers are in unique positions to better understand and relate to people of the local community.</li> <li>• With shortage in palliative care professionals, community health workers are valuable in reaching</li> </ul>

Author's Last Name; Pub. Year	Title of Publication	Type of Study	Main Outcomes or Findings	Support for and or link to project
				and effectively engaging with community-dwelling older adults
Rabow, McGowan, Small, Keyssar, Redwing, & Rugo, 2019	Advance care planning in community: an evaluation of a pilot 2-session, nurse-led workshop	Two-session, nurse-led ACP workshops for patients and their family caregivers.	ACP education through nurse-led workshops in the community setting was well-received by participants and their family members. Completion of validated 4-question ACP engagement surveys pre- and post intervention revealed increase in ACP readiness post intervention (P = 0.001).	<ul style="list-style-type: none"> <li>Community education is important to increase access to healthcare knowledge and effects health outcomes by encouraging beneficial health behaviors such as completion of AD.</li> </ul>
Radhakrishnan, Van Scoy, Jillapalli, Saxena, & Miyong, 2019	Community-based game intervention to improve South Asian Indian Americans' engagement with advanced care planning	A pretest-posttest design	<p>My gift of grace, a conversation game now called "Hello", was found to be cultural appropriate and effectiveness in facilitating a fun and educational conversations about death and EOL care preferences in South Asian Indian Americans.</p> <p>Participants expressed that the conversation game was satisfying, realistic, and high in quality. This community-based intervention lead to an increase in ACP behavior such as creating living wills (18%) and updating preferences of preexisting ADs (80%).</p>	<ul style="list-style-type: none"> <li>Cultural-appropriateness is important</li> <li>Easy to use, easy to understand, game based approach helps people to open up and engage more</li> <li>Increasing awareness improved ACP behaviors</li> </ul>

Author's Last Name; Pub. Year	Title of Publication	Type of Study	Main Outcomes or Findings	Support for and or link to project
Splendore & Grant, 2017	A nurse practitioner–led community workshop: Increasing adult participation in advance care planning	A pre–post repeated measures design	Community-dwelling older adults participated in a one-day NP led workshop utilizing Five Wishes, a legal living will document. The workshop was well received by participants. 48% of those who did not previously have an AD completed one by 1 month post intervention, with 86% of those individuals utilizing the Five Wishes booklet from the meeting. 93% of participants who had completed a AD by one month after workshop engaged in discussion about their AD to their loved ones, and 13% had disseminated their AD.	<ul style="list-style-type: none"> <li>• Community engagements led by trusted community healthcare leaders establishes trust</li> <li>• Utilizing an already established documentation such as Five Wishes facilitates easier and proper dissemination of information and necessary documentation</li> <li>• The step-by-step approach provided by the Five Wishes documentation makes it easy for participants to gather information necessary for a AD documentation</li> </ul>
Sulmasy et al., 2017	The trial of ascertaining individual preferences for loved ones' role in end-of-life decisions (tailored) study: A randomized controlled trial to improve surrogate decision making	RCT	<p>The intervention of nurse-facilitated EOL discussion between patients and their healthcare proxy lead to increased desire for mutual surrogate decision-making in both the patient and the proxy where patient's preferences and what the proxy believes is best for the patient is both considered. Control patients demonstrated a 40% reduction in endorsement of mutual surrogate decision making and increased endorsement of substituted judgement, where decisions are made solely by the surrogate's judgment.</p> <p>EOL discussion lead to the surrogates reporting less stress and more satisfaction.</p>	<ul style="list-style-type: none"> <li>• Increasing open communication between patient and proxy is very important in having congruent goals of care</li> <li>• Improving surrogate decision making can decrease burden and stress</li> <li>• Improving surrogate knowledge of patient's preferences increases quality of EOL care</li> </ul>

Author's Last Name; Pub. Year	Title of Publication	Type of Study	Main Outcomes or Findings	Support for and or link to project
Sun et al., 2017	Efficacy of a church-based, culturally tailored program to promote completion of advance directives among Asian Americans	Pilot study, with single group pre- and post-intervention design	Culturally-appropriate two-session educational program about AD was successful in increased AD-related knowledge and behaviors, resulting in 71.8% completing their AD and 25.0% having a conversation with their healthcare proxy within 3 months of intervention.	<ul style="list-style-type: none"> <li>• Culturally-targeted interventions involving a group of people in the same community may foster positive health behaviors through peer support, increased knowledge, and guidance from community</li> <li>• Creating awareness improves health behavior and therefore can improve health outcomes</li> </ul>
Van Coy et al., 2017a	Community game day: Using an end-of-life conversation game to encourage advance care planning	Convergent, mixed methods design	Utilizing an engaging group activity to discuss uncomfortable topics such as death/dying and advance care planning can create a positive and enjoyable experience for patients and caregivers to discuss EOL preferences and increase completion rates of ACP.	<ul style="list-style-type: none"> <li>• A game-based approach is effective in engaging the community to talk about EOL, and may make people more open and comfortable talking about the care they would want at EOL. This may lead to increased knowledge, comfort, and ultimately completion of ACP, which is the goal of this project</li> <li>• This study demonstrates the type of implementation I hope to be able to do in the community and the type of response I hope to receive</li> </ul>

Author's Last Name; Pub. Year	Title of Publication	Type of Study	Main Outcomes or Findings	Support for and or link to project
Van Coy et al., 2017b	Can playing an end-of-life conversation game motivate people to engage in advance care planning?	Exploratory pilot study	EOL conversation game can promote a behavior change in participants to complete ACP within 3 months of intervention. This change in behavior is reflected in the movement between stages of change based on Prochaska's transtheoretical model of behavior change. EOL conversation game can increase people's openness and comfort in the subject of death and EOL and increased knowledge in the importance of ACP for the individual and their family members. Advancements in stage of readiness was seen in 78% of participants who performed at least one ACP behavior in the 3 months following the conversation game.	<ul style="list-style-type: none"> <li>Results supports the effectiveness of game-based approach in discussing topics seen as uncomfortable or unpleasant and producing meaningful results (increased ACP behaviors) that will impact the community</li> </ul>
Van Scoy et al., 2016a	Conversation game effectively engages groups of individuals about death and dying	Mixed methods study	Participants engaged in the Conversation Game to discuss death, dying and EOL care. Experience and quality of the game-based approach was recorded using pre-post tests and postgame focus groups. Participants felt game provided positive experience and enjoyed listening to others EOL values. Mixed emotions were present regarding playing with family members versus strangers. Game provided prompted EOL discussions that were uncomfortable, yet realistic.	<ul style="list-style-type: none"> <li>Results support reason to do my project, as project goal is to get people in the community to talk about EOL and ACP in a fun yet productive manner and increase knowledge and attitude toward ACP</li> </ul>

Author's Last Name; Pub. Year	Title of Publication	Type of Study	Main Outcomes or Findings	Support for and or link to project
Van Scoy et al., 2016b	Exploring the topics discussed during a conversation card game about death and dying: A content analysis	Qualitative content analysis	A group of participants played the EOL conversation game, "My Gift". Participants were open and willing to speak about sensitive issues surrounding EOL when given the opportunity and the right environment. Participants expressed positively to their experience with the conversation game.	<ul style="list-style-type: none"> <li>• Game-based approach to stressful conversations may be an appropriate way to facilitate hard conversations</li> <li>• People need to be provided with the opportunity to speak about death</li> <li>• ACP interventions can occur without a facilitator which shows that such interventions can be cost effective</li> <li>• The game-based conversation approach fostered clinically relevant conversations to occur in a non-stressful environment.</li> </ul>
Weathers et al., 2016	Advance care planning: A systematic review of randomised controlled trials conducted with older adults	Systematic review	<p>ACP interventions decreased hospital admissions, use of medical resources, increased patient and family satisfaction with care and increased use of AD. There was an increased ACP discussions post interventions. Study was unable to determine if ADs improve quality of EOL care.</p> <p>Patients usually want to talk about end-of-life care and can discuss their preferences regarding life-sustaining treatments.</p>	<ul style="list-style-type: none"> <li>• ACP shows overall increase in quality care indicators such as less hospitalizations and increased patient/caregiver satisfactions with care</li> </ul>
ACP=advance care planning; RCT=randomized control trial; AD= advance directive; EOL= end-of-life; NP= nurse practitioner				

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