ADVANCE CARE PLANNING: COMMUNITY EDUCATION TO IMPROVE

END-OF-LIFE KNOWLEDGE AND COMMUNICATION

by

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As members of the DNP Project Committee, we certify that we have read the DNP project

prepared by *Jacqueline Lorriene Murphy*, titled *Advance Care Planning: Community Education*

to Improve End-of-Life Knowledge and Communication and recommend that it be accepted as

fulfilling the DNP project requirement for the Degree of Doctor of Nursing Practice.

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STATEMENT BY AUTHOR

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SIGNED: <u>Jacqueline Lorriene Murphy</u>

ACKNOWLEDGMENTS

DEDICATION

Dedicated to my guardian angel and granddaddy -

Adrian Joseph Bain

The passion behind this project,

forever in my heart

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ABSTRACT

The research and development of new technologies within modern medicine allow patients to live longer with chronic diseases. For some patients, quantity of life does not always equal quality of life and may increase suffering at the end-of-life (EOL). Advance Care Planning (ACP) and EOL discussions amongst family members and medical providers can contribute to patient's experiencing a more peaceful death. Despite the benefits of ACP, only 30% of United States citizens have documented their EOL wishes. The purpose of this project was to improve comfort levels discussing EOL preferences; and increase participant knowledge and willingness to complete ACP documents. Utilizing a quality improvement design, participants were recruited from a 55 and older bible study group at Mission Community Church, and neighboring churches in Gilbert, Arizona. The three-hour educational seminar included a combination of ACP education, and the EOL communication game *Hello.* Data was obtained from pre-educational and post-educational surveys which included the ACP Engagement Survey. This was used to identify baseline and post-education stage of change, based on the Transtheoretical Model. Significant changes were found within three out of the nine questions on the ACP Engagement Survey. This included participants' readiness to communicate with their healthcare provider whom their appointed medical power of attorney (MPOA) is: pre- (M=3, SD 1.60); post- (M=3.75, SD 0.8864); t= 2.393, p= 0.047; readiness to document their EOL wishes: pre- (M= 2.875, SD 1.126); post- (M= 4.0, SD 0.5345); t= 3.211, p= 0.0148; readiness to sign documents appointing a MPOA: pre- (M=3.0, SD 1.195); post- (M= 3.625, SD 0.9161); t= 2.376, p= 0.0492). Extremely significant findings were obtained from the overall ACP Engagement survey: pre- (M= 3.431, SD 0.5698); post- (M= 4.125, SD 0.6409); t=6.799, p = 0.0001). Participants

believed the information that they received during the seminar improved their comfort levels

discussing EOL wishes, and ACP knowledge. Despite low attendance (N=8), there is significant

evidence to support ACP community education and the EOL communication game *Hello*, does

improve knowledge and comfort levels in discussing EOL preferences. Further research should

include studies with multiple educational seminars, and/or larger scale study.

INTRODUCTION

Background

Advancements in modern medicine have assisted in extending life expectancies from 47.3 years in 1900 to 77.8 years in 2015 (United States Department of Health and Human Services [HHS], 2017). Extensive and invasive interventions within intensive care units (ICU) have not only reversed immediate death, but for some prolonged life at the cost of increased suffering (McDermid & Bagshaw, 2009). For patients with advanced chronic diseases, approximately 62% die each year, due to chronic obstructive pulmonary disease, heart disease, stroke, cancer, and diabetes (Centers for Disease Control and Prevention [CDC], 2017a). Complex symptoms and acute exacerbations are often the primary cause of frequent hospitalizations during the last years of life (CDC, 2015).

Conversations regarding disease progression, life expectancy and advance care planning (ACP) are important to discuss with patients prior to a medical crisis (Davies, 2015). Conversations with healthcare providers and loved ones regarding end-of-life (EOL) wishes can often be challenging for patients (McMahan, Knight, Fried, & Sudore, 2013). The Patient Self-Determination Act of 1990 was created to allow competent patients to communicate their preferences of treatments that are life sustaining, prior to becoming incapacitated (Thobaben & Proctor, 1996). The creation of the law protects patients' rights and the provider's ability to withdraw invasive therapies based on the patient's wishes (Thobaben & Proctor, 1996). This law also requires medical facilities and healthcare providers to educate patients about advanced directives (AD), disease prognosis and progression (Davies, 2015; Thobaben & Procter, 1996). ACP includes three important elements: the "designation of healthcare durable power of attorney,

completion of an AD, and out of hospital resuscitation orders" (Dahlin & Wittenberg, 2015, p. 96). ADs consist of the legal documentation that are implemented when one becomes incapacitated. This documentation serves as a guide to medical treatments such as cardiopulmonary resuscitation, mechanical ventilation, artificial feeding and EOL care (Dahlin & Wittenberg, 2015).

National Problem

Even though there are protective policies in place, only 30% of United States citizens have completed ADs (Aldrich, 2012; CDC, 2017b). Current survey data does not differentiate ACP completion rates per state, and each state carries their own specific laws pertaining to ACP documentation (American Bar Association, 2018). According to the CDC (2017a), there are barriers associated with patients completing ADs. These barriers include: lack of awareness, denial, confusion, and cultural differences (CDC, 2017a). Lack of awareness about AD's is related to communication issues between patients and healthcare providers, as well as lack of a current process to share patients' wishes electronically (CDC, 2017a). Denial related to death and dying in the United States is a real problem. It is a sensitive and difficult discussion that is ignored until medical crises occur (CDC, 2017a). Patients are often confused or fearful that they will not be medically treated if they have completed an AD; instead it provides a clear direction for care (CDC, 2017a). Respecting and understanding cultural differences and educating patients from different cultural backgrounds may provide a clear direction to their EOL care (CDC, 2017a). Improving ACP documentation rates and normalizing EOL conversations can improve the quality of life for patients that are suffering with chronic debilitating or terminal diseases.

Project Purpose

The purpose of this project is to educate community members within the Phoenix metropolitan area, 50 years and older about ACP. The primary outcome goal of this project is to improve participant comfort levels discussing EOL preferences with healthcare providers and family members. The interactive conversation game *Hello* will be played to allow participants the ability to practice sharing their personal EOL values and preferences. The secondary outcome goal is to increase participant knowledge and willingness to complete ACP. Results of current research studies have found that the use of an interactive game alone does not improve ACP knowledge (Van Scoy, Reading, et al., 2017). It is recommended to incorporate ACP education prior to implementing an interactive EOL game to increase ACP knowledge and completion rates. This project was formulated based on treating patients with chronic diseases within a medical ICU that do not have ADs or an appointed MPOA. Often, these patients are unable to communicate personal EOL wishes, and difficult treatment decisions are left to family members to make during a medical crisis. Treatment decisions that are placed on distraught family members often cause unnecessary psychological distress and prolonged grief (McMahan, Knight, Fried, & Sudore, 2013; Walczak et al., 2017). Key stakeholders for this project include the support and partnership from Hospice of the Valley, leaders at Mission Community church, community members, as well as the local medical community.

Study Question

In community members 50 years and older (P), does ACP education, and an EOL conversation game (I) increase knowledge and comfort levels with EOL discussions (O) compared to baseline pre-education results (C)?

THEORETICAL FRAMEWORK

The Transtheoretical Model

Theories are conceptualized as a process to view and understand experiences (Moran & Burson, 2014). They are utilized within many areas of nursing research such as social, behavioral, and psychology to support the findings of broad ideas (Reed, 2011). The Transtheoretical Model (TTM) or the Stages of Change Model, was created in 1977 by Prochaska and DiClemente (Lamarte, 2016). This model assumes that humans do not change their behaviors immediately. Instead, behavior change occurs within a cyclic process (Lamarte, 2016). The movement within the six stages allows for progression to maintenance of change (Prochaska & DiClemente, 1992).

Stages of Change

There are six stages of change within this model: precontemplation, contemplation, preparation, action, maintenance, and termination (Lamarte, 2016). The stage of termination is typically not used within programs of health promotion due to individuals staying within the maintenance stage of change (Lamarte, 2016). As we move through each stage or process of change the application of cognitive, affective, and evaluative processes occur (Lamarte, 2016). As each stage of change is completed, one can exit or re-enter within a process (Lamarte, 2016). This is dependent upon the person's commitment to the change (Lamarte, 2016). When an individual reaches the action stage there is modification of their behavior and increased commitment to the change (Norcross, Krebs, & Prochaska, 2011). The ACP process is more beneficial and effective when individuals are actively prepared before they are faced with a medical crisis (Moorman & Inoue, 2013). The TTM will provide this project a framework of

supportive behavioral stages that can be used to evaluate the readiness for change in participants attending the educational seminar.

Precontemplation

The precontemplation stage of change is the earliest level of change (Prochaska & DiClemente, 1992). At this stage, individuals are not aware or are not willing to discuss or participate within ACP. The precontemplation stage of change supports the idea of denying or ignoring death in the United States (Aldrich, 2012). Those within this stage can become defensive when approached with the idea of changing their behavior (Prochaska & DiClemente, 1992). They do not believe that consequences related to not preparing for EOL will affect them. The likelihood of this group being exposed to negative EOL experiences is small, and they deny the process of death. There is no considerable thought to change within the near future, and their ability to move past this stage is to acknowledge that death is inevitable (Prochaska & DiClemente, 1992).

Contemplation

The second stage of the TTM is contemplation (Prochaska & DiClemente, 1992). Within this stage, there is active thought about the change in behavior. Individuals that are actively contemplating ACP would include those that are seeking answers to their own EOL values. They may not have experienced death at a personal level, but they may have heard stories from others and their personal experiences in relation to death. At this stage there is active information seeking, and reevaluation of personal values about the specific behavior (Prochaska & DiClemente, 1992). Individuals within this stage are not prepared to actively change, but they are reviewing their options and evaluating their own EOL values (Prochaska & DiClemente, 1992).

In order for this group to move to the next stage of change they would have to actively decide to engage in ACP (Prochaska & DiClemente, 1992).

Preparation

   The third stage of change is preparation. In this stage of change, the individuals' attitude and behavior changes towards preparing to complete ACP (Prochaska & DiClemente, 1992). There is a plan to actively make the changes within the near future. Individuals within this stage may have experienced EOL with a close friend or family member. This experience has caused one to reflect on their own personal values. It has caused them to think about how they would want to be cared for, or whom they would appoint to make decisions for them if they became incapacitated. This group of individuals will be researching ACP or attending educational seminars.

Action

   The fourth stage of change within this model is action. In this stage, individuals are actively involved in completing the stage (Moorman & Inoue, 2013; Prochaska & DiClemente, 1992). In relation to ACP, one would actively participate in conversations, and complete documentation of their wishes with family, friends, and healthcare providers. These individuals are actively communicating with others about their wishes and are not afraid to discuss death. Those within this stage of change are unable to move onto maintenance unless they revisit and modify their ADs as values or wishes change (Moorman & Inoue, 2013; Prochaska & DiClemente, 1992).

Maintenance

The stage of maintenance is the continued work that is needed to prevent relapse in behavior (Norcross, Krebs, & Prochaska, 2011). The stage would be the continued review, and updating of changes if needed, of one's AD or MPOA. Sustaining behavioral change is difficult, as individuals lead active and busy lives. Unless they are maintaining and updating their advanced care documents on a regular basis, making changes based on their current values and wishes, and discussing these wishes with loved ones and healthcare providers, individuals will fall back into the action stage. This stage requires the individual to sustain the behavior of change every six months for up to three years to prevent relapse (Prochaska & DiClemente, 1992)

This model has been used to guide a variety of research studies, which include measuring smoking cessation, as well as addressing ACP (Ernecoff, Keane, & Albert, 2016; Moorman & Inoue, 2013; Prochaska & DiClemente, 1992). Further research completed by Prochaska and DiClemente (1992), using the TTM, was to identify prevention of cancer, promotion of health, treatment for alcoholics and interventions within psychotherapy.

Ernecoff et al. (2016) utilized the TTM to create an agent-based model. The agent-based model is a simulation of the general population within the United States, which allowed the researchers to examine potential behavior patterns to complete ACP. Although this is a computer-generated program, the researchers inputted data from other studies that identified barriers, facilitators and readiness to complete ACP amongst older adults (Ernecoff et al., 2016). Ernecoff et al. (2016) believe that their model provides a basic representation of behavior change in relation to ACP. Limitations include the influential barriers that are impactful to completion of

ACP. These limitations are related to previous personal experiences with EOL and ACP that a computerized model may not be able to replicate (Ernecoff et al., 2016).

Moorman and Inoue (2013), studied ACP issues amongst married couples. They evaluated couples between the ages of 18 to 64 years old, as they believe that over the age of 65 it is too late to discuss meaningful EOL planning (Moorman & Inoue, 2013). The TTM was applied to their study to identify the relationship between completion rates of ADs, and EOL conversations with age and health status of participants (Moorman & Inoue, 2013). Moorman and Inoue (2013) also wanted to identify the influence of spouses' personal preferences of EOL plans compared to their partners' wishes. The results of their study found that decreased health and older age influenced the behavioral stage of change in the participants from the contemplation stage into action or maintenance stage (Moorman & Inoue, 2013). Barriers related to decreased adherence in younger couples was related to avoidance about death, believed that they were too healthy, or lack of ACP information (Moorman & Inoue, 2013). Moorman and Inoue (2013) also found that the completion of ACP did not alter their ability to interpret EOL wishes for their spouse and serve as their decision maker. It is this author's belief that the ACP studies utilizing the TTM provide the supporting evidence needed for this project. This model supports the purpose of this project by identifying if educating the community about ACP will increase their knowledge and comfort levels to discuss EOL planning. Pre-education surveys were utilized to identify current stage of change, and post-education surveys were used to identify a change in stages.

Concepts

The TTM framework was applied to this project through understanding participants' baseline ACP behavior. This author's goal was to educate individuals that are within the contemplation, preparation, action, and maintenance stage of change. By engaging and educating participants within these levels of behavior change, the likelihood of moving on to the next stage of behavior change will improve. Community members that are currently within the precontemplation stage could potentially move to the contemplation stage when they hear or read about the ACP project through community advertisement. Those within the contemplation stage may participate within the ACP education project, but not act on the information that is received. They will use the information to ask others about EOL experiences. Community members within the preparation stage will use past experiences to guide their own EOL values. They could utilize the education provided to think about how they would discuss their EOL values with family, friends, and healthcare providers. They may also consider whom they would appoint as a potential MPOA. Participants within the action stage will use the education to confirm their personal EOL values and apply this to ACP documentation. Those within this stage will be willing to complete ACP documentation by the end of the educational session. Participants within the maintenance stage will bring their current ACP documents to the educational seminar and will apply the information obtained to update them. Despite the stage of change the participants are within prior to receiving ACP education, it was this author's goal to ensure that the community has improved levels of knowledge and comfort to discuss EOL wishes.

SYNTHESIS OF EVIDENCE

Literature Review

To find supporting evidence of ACP education and the benefits of EOL communication, a search was conducted using the electronic databases PubMed, CINAHL and Embase. Key search terms included: "advance care planning," "end-of-life care," "communication," "community education," and "advance directives. Inclusion criteria for this search included: systematic reviews, randomized controlled trials, meta-analysis, observational studies, articles within the past five years and English language. Search results obtained from PubMed included 97 articles, CINAHL provided 13 articles, and Embase 33 articles. After further review, a total of 20 articles were selected for analysis. Those that were excluded were due to duplication of articles, irrelevance to ACP education, in-patient only interventions, or education directed towards healthcare providers only. Included articles can be reviewed within Appendix A. Due to the lack of studies that integrate improving EOL communication and ACP education within one interventional study, this literature review will discuss the strengths of each intervention separately and the weaknesses together.

Strengths of EOL Communication

Current research has evaluated the use of interventions that improve EOL communication amongst patients, family members, and healthcare providers. With the limited availability of documented ACP and time constraints within outpatient medical facilities it is recommended that patients initiate these conversations to ensure that their EOL preferences are addressed (Finkelman, 2018). Interventions used to address improving EOL communication range from the *My Preferences* educational booklet, educational seminars, and interactive games

such as *Go Wish* and *My Gift of Grace* (now known as *Hello*). Consistency was found across

multiple studies that support the use of tools to improve EOL conversations with positive

outcomes which include: increasing participant comfort levels, facilitating EOL discussions,

guiding participant EOL preferences, evaluating personal values, and practicing difficult

conversations (Abba, Byrne, Horton, & Lloyd-Williams, 2013; Austin, Mohottige, Sudore,

Smith, & Hanson, 2015; Bravo et al., 2016; Houben, Spruit, Groenen, Wouters, & Janssen, 2014;

Litzelman, Cottingham, Griffin, Inui, & Ivy, 2016; Oczkowski, Chung, Hanvey, Mbuagbaw, &

You, 2016; Van Scoy, Reading, Scott, Green, & Levi, 2016). Other studies evaluating

communication tools found that ACP conversations reduced hospitalization rates (10%), the use

of palliative chemotherapy (5%), ICU admissions (6%) and emergency department use (7%)

(Rocque et al., 2017).

Three separate studies performed by Van Scoy et al. (2017a); Van Scoy et al. (2017b);

and Van Scoy et al. (2016), evaluated the effectiveness of the interactive conversation game *My*

Gift of Grace. The purpose of their studies was to evaluate if the game would increase EOL

conversations, increase motivation to complete ACP, and increase engagement in ACP (Van

Scoy et al., 2017a; Van Scoy et al., 2017b; Van Scoy et al., 2016). The results from their studies

found improved motivation and engagement to complete ACP with 78% increasing EOL

discussion with family and healthcare providers, 21% increase in ACP completion rates, and

19% appointing a MPOA (Van Scoy et al., 2017a). The use of interactive games provided

participants realistic conversations and the ability to evaluate personal EOL values, preferences,

and improved understanding of ACP (Van Scoy et al., 2017b; Van Scoy et al., 2016). Other

positive findings of their studies included increased readiness to change by participants, with

67% of participants moving from the contemplation stage to the action stage of change (Van

Scoy, Reading et al., 2017).

Strengths of ACP Education

Studies focusing on ACP education have been implemented because previous research

has found that there is confusion regarding how to complete it, the therapies to select, and with

whom to share their wishes (Houben et al., 2014). Interventions implemented within this

literature review included the use of educational videos, websites, written and verbal instruction,

and in-home ACP navigators. The results from the studies that investigated ACP education found

that there was an increased rate of documented ACP post-intervention ranging from 10.8% to

80% (Austin et al., 2015; Bravo et al., 2016; Houben et al., 2014; Sudore et al., 2017a; Weathers

et al., 2016). Other pertinent findings of these studies included that patients with a support

system are more likely to complete ACP, EOL care correlated with documented wishes, previous

exposure to medical experiences increased willingness to participate, and reduced psychological

distress within family members during bereavement (Ko, Lee, & Hong, 2016; Martin, Hayes,

Gregorevic, & Lim, 2016; McMahan et al., 2013; Weathers et al., 2016). Four studies found that

there was a higher rate of readiness to complete ACP when patients perceived themselves to be

ill or near death (Ko et al., 2016; Martin et al., 2016; Rocque et al., 2017; Sinclair et al., 2017).

ACP education has also been associated with reduced hospital admission rates ranging from 9 to

26%, reduction in healthcare costs of $2097 per patient, and increased out-of-hospital deaths

(11%) (Martin et al., 2016).

Sudore et al. (2017a) designed a randomized comparative effectiveness trial within a

Veterans Affair (VA) clinic. The intent of their research was to validate the effectiveness of

PREPARE, an interactive ACP website, along with an easy-to-read AD to increase completion rates and behavior change (Sudore et al., 2017a). Two-hundred and nine veterans were assigned to the AD group, and 205 veterans were allocated to the PREPARE website and AD group (Sudore et al., 2017a). Participants were assessed at baseline, one week, three months and six months using the Patient Health Questionnaire (PHQ-4), and the ACP Engagement survey (Sudore et al., 2017a). The results of their research found that participants within the PREPARE group had higher completion rates compared to the AD only group (37% versus 27% p= 0.04) (Sudore et al., 2017a). The findings from their research demonstrate that the use of interactive educational programs along with user friendly ADs increase engagement and documentation. These findings could be applied at the community or population level to improve understanding of ACP and increase documentation rates.

Weaknesses of ACP Education and Communication Tools

There was consistency across many of the research studies in which the findings were considered low-quality evidence. Low-quality of evidence is because the design of studies typically researched within this specialty are observational or cohort design (Abba et al., 2013; McMahan et al., 2013; Oczkowski et al., 2016; Walczak, Butow, Bu, & Clayton, 2016). Yet when randomized control trials were implemented the researchers experienced high levels of attrition rates related to mortality, high risk of bias due to the lack of concealed allocations, the inability to blind patients or therapists participating within the study (Abba et al., 2013; Houben et al., 2014; Kirchhoff, Hammes, Kehl, Briggs, & Brown, 2012; Sinclair et al., 2017; Walczak et al., 2017; Weathers et al., 2016). There is a limited amount of randomized control studies with high levels of evidence that support a specific communication tool or form of ACP education.

Within the randomized control studies that provide strong evidence supporting either intervention, their study sample is too small and further research is needed in a larger study (Kirchhoff et al., 2012). Bravo et al. (2016) discussed their interventional ACP education program compared to their control group health education program but did not provide results or discuss the outcomes of the control group. Other limitations include participants denying death and considering themselves to be too healthy to consider how they wish to be treated when they are incapacitated (Moorman & Inoue, 2013). Future research should include implementing communication tools and ACP education together since ACP documentation alone does not prepare patients and families for complex medical decision making (McMahan et al., 2013).

Rationale for Project

After analyzing the literature, there is clear evidence to support educating community members about ACP and utilizing an interactive communication tool to improve comfort levels with discussing EOL wishes. There are limited studies that have implemented an educational program and an interactive game together despite the supporting evidence of the individual interventions. The benefits of preparing for EOL with ACP far outweigh the weaknesses of current research. Gaps to patients completing ACP documentation include the lack of education and support that patients and families need to make difficult EOL decisions (Houben et al., 2014). ACP community education promotes shared-decision making and collaborative conversations within families and healthcare providers (McCusker et al., 2013). Furthermore, the Institute of Medicine (IOM) (2014) recommends ACP education should be provided to the community by healthcare providers, faith-based organizations, and community-based organizations to advocate for patient-centered care. In summary, community education should

present evidence-based information regarding treatment options and encourage EOL

communication that elicits individual values and preferences (IOM, 2014).

METHODS

Design

This DNP project used a quality improvement (QI) design focusing on patient-centered

care. Patient-centered care includes: respect for patients' values, preferences and expressed

needs; coordination and integration of care; information, communication, and education;

physical comfort; emotional support; and involvement of family and friends (Finkelman, 2018).

The primary element of patient-centered care is individualized based on the patient's personal

values, preferences, and respecting their expressed needs (Finkelman, 2018). This element

supports the need for educating the community about ACP and EOL discussions. Education

provided the community information needed to document their values, beliefs and wishes. It also

ensured that their voice is heard, even when they are no longer able to speak for themselves. The

use of the patient-centered care model in this QI project provided community members the

confidence and communication skills to discuss their EOL wishes with family, friends, and

healthcare providers. The ability to communicate these wishes, and actively participate in

healthcare decisions will build trusting relationships, and improve quality of life (Finkelman,

2018).

Participants

Criteria for inclusion in this QI project include: (a) adult community members 50 years

and older, (b) English speaking, (c) and live within the Phoenix metropolitan area. Participants of

the project were not limited by race, sex, comorbidities, educational background, or financial

status. These criteria were chosen because the aim of this study is to provide education to community members about ACP regardless of economic or social background. In addition, it is imperative for community members to plan and discuss their EOL values and wishes with others, and this should be reviewed prior to facing a medical crisis. To achieve the aims of this project, the goal was to recruit a minimum of 20 participants. Despite this goal, a total of 8 community members attended the seminar.

Setting

The location of the educational seminar was held at Mission Community Church in Gilbert, Arizona. This church is non-denominational, with an average weekly attendance of 5,000 (Mission Community Church, n.d.) The church location was selected due to the capability of reaching participants prior to entering EOL. It is this author's belief that educating the community prior to a severe medical diagnosis, will allow for future planning before a medical crisis. Issues with attempting to reach community members under the age of 75 include: denial of death, denial of future medical illnesses, and those within the precontemplation and contemplation stages of behavior change (Prochaska & DiClemente, 1992).

Hospice of the Valley (HOV) has been providing services to the Phoenix metropolitan area for over forty years (HOV, 2018). The services that they provide to the community include: hospice and palliative care, in home health care, supportive assistance for patients with dementia and pulmonary disease, grief and family caregiver support, mindfulness classes, comfort therapies, and community education (HOV, 2018). In partnership with HOV, participants from surrounding east valley churches were invited to attend the ACP educational seminar. The 55 and older bible study group, located on the church campus was also invited to attend the seminar.

Participant recruitment began two weeks prior, which included advertisement at other church campuses, as well as brief meetings with the bible study group. This partnership assisted this author in advertising to the community, ACP education and ACP documents during the seminar. The advertisement informed the community that the seminar is a QI project and led by this doctoral student at the University of Arizona.

The day of the seminar, participants received a project disclosure, and the pre-education survey upon entry to the educational seminar. The project disclosure informed the participants about the purpose of the project, the time required to complete the surveys, and the voluntary and anonymous nature of their participation. Participants were instructed that there is no penalty, or risk to them if they wish to withdraw from the project. This disclosure can be reviewed within Appendix B. Instruction was given on how to complete the survey, and that a post-education survey will be handed out at the end of the seminar. The educational seminar began with a brief introduction to ACP, and the background on this project. The ADs and healthcare power of attorney documents were discussed in detail by the HOV liaison. Additional education discussing mechanical ventilation, cardiopulmonary resuscitation, artificial hydration, and nutrition was presented. Previous research has found that these areas are known to cause increased confusion in the community (Houben et al., 2014).

Next, the *Hello* game was introduced. This is an interactive game that provides participants an opportunity to think about and discuss difficult decisions in EOL care (Common Practice, 2017). The combination of an interactive game, along with ACP education was chosen because of the positive outcomes in the individual interventions. There is also a lack of research studies that have used a combination of education and an interactive game. Participants were

invited to sit at tables in groups of four to allow for open discussion about EOL preferences and

values. Due to the small size of participants, 30 minutes was allotted for the participants to play.

A question booklet, and five 'thank you' tokens were provided to each participant. The thank

you tokens were to be given to other participants anytime they felt that someone shared an

answer that was appreciated or difficult to discuss. Participants were invited to take turns reading

the questions aloud, share their answers, or opt to pass if they preferred. The goal of the game is

to allow participants to evaluate and practice discussing their personal values and EOL wishes.

This discussion about EOL care allows for realistic conversations and guides the direction of

ACP with family and healthcare providers (Van Scoy, Green et al., 2017; Van Scoy et al., 2016).

These difficult and realistic questions allowed the participants the ability to review EOL wishes

that may not have been previously thought of. Participants were encouraged to take home their

booklets and use them as a guide to discuss their wishes with family, friends, and healthcare

providers. ACP documentation was provided to all participants by the HOV liaison.

Data Collection

Pre- and-post educational questionnaires were used to obtain data from participants. The

ACP Engagement survey was used for pre- and-post educational evaluation with permission by

Dr Rebecca Sudore. Dr Sudore is the lead researcher in a three-year study that developed and

validated the ACP Engagement survey (Sudore et al., 2017b). This nine-item survey is a reduced

version of the original 82-item survey and has been proven to be just as effective but with less

time constraints as the original (Sudore et al., 2017b). The data obtained from this survey

provided an evaluation of the participant's readiness for change. It also allowed this author the

ability to identify their stage of change. The pre-educational questionnaire included minimal

non-identifying background information as well as a baseline ACP Engagement survey. This can

be reviewed in Appendix C. The post-education questionnaire included the ACP Engagement

survey along with an evaluation the educational seminar. This can be reviewed in Appendix D.

Utilizing the ACP Engagement survey pre-and-post education provided the data required to

validate the effectiveness of ACP community education.

Data Analysis

To evaluate the outcomes of this study, data received from the pre-and-post educational

surveys was inputted into GraphPad, a statistical software. The paired t-test was used to compare

the information obtained from the pre-education and post-education surveys. For a paired t-test

to be valid there must be two paired measurements from the same participant, such as data

received from pre- and post-test surveys; the measures that are compared are normally

distributed; and the measurement scale must be interval, ratio, or sometimes ordinal (Kellar &

Kelvin, 2013). The comparative analysis of the data obtained from these surveys was used to

determine if the education provided increased the likelihood of the participants' behavior change.

Mean scores were used to determine if there was an increase in knowledge about ACP and their

ability to communicate EOL wishes with ease. Data obtained from the demographics was used to

evaluate the background and age of participants willing to attend ACP education.

Ethical Considerations

The ethical principles: respect for persons, beneficence, and justice were implemented to

protect the participants of this DNP project.

Respect for Persons

Respect for persons was met by understanding that everyone has their own perspective and values for EOL, and that they are entitled to these values. Participants were provided the opportunity to openly discuss EOL preferences and values with other participants or choose not to without fear of penalty. Participants were provided a disclosure for the project and were entitled the freedom to engage or withdraw from any activities administered.

Beneficence

Beneficence was met by ensuring that the identity of the participants is protected and participating in this project did not cause undue harm. Information obtained from the pre-and-post-surveys were non-identifying and did not place the participants at risk of vulnerability. Participating within the educational seminar and an interactive conversation game did not expose participants to harm.

Justice

Justice was met by educating community members 50 years and older, as previous research has determined that everyone should complete ACP documentation and communicate their wishes with loved ones. Minimal restrictions were made on participant requirements to ensure that all willing older adults can attend. All participants were treated equally and had the opportunity to interact and ask questions during the seminar as needed. This author did not research vulnerable populations; no special needs are not necessary to address. The application for human research was required to complete this DNP project due to the evaluation of ACP education provided to community members.

RESULTS

Findings

The ACP educational seminar was conducted at Mission Community Church as a three-hour event on a Saturday morning. Participant characteristics are shown in Table 1. Basic demographic data was obtained from the pre-educational questionnaire. A total of eight participants attended the seminar. Their ages ranged from less than 50 years old (n=2), 60 to 69 years old (n=5), and 70 to 79 years old (n=1). Seventy-five percent of participants were female Caucasians. Educational background included: high school graduate (n=4), associate's degree (n=3), and bachelor's degree (n=1). Lastly, basic medical history was obtained which ranged from no medical conditions (n=1), cardiac disease (n=2), pulmonary disease (n=3), hepatic disease (n=1), and other (n=4). The responses for other included: epilepsy, stroke, Crohn's disease, diverticulitis, and diabetes.

Next, baseline ACP data was obtained; this data can be viewed in Table 2. About 75% of participants had heard of ADs and living will, while 100% of participants had heard of MPOA. Yet, only 50% (n=4) of the participants had completed ACP documentation. Of those who had completed ACP documentation, 25% completed AD and/or living will, and 50% had previously appointed a MPOA. The majority (n=6), had not discussed their EOL wishes with their family, friends, or healthcare provider. Only two participants had been appointed as a MPOA for a loved one but, had not been in a situation where they were required to make difficult healthcare decisions. Baseline pre-education data also found that participants had been thinking about how they would want to be cared for at the EOL or facing a terminal illness but were unsure how to

talk about their wishes. They had also thought about whom they would appoint as a MPOA but
were unsure how to talk about it.

TABLE 1. *Participant characteristics*.

Demographics (N=8)			
Age, n (%)		Education, n (%)	
<50	25	Some High School	0
50-59	0	High School	50
60-69	62.50	Associates	37.50
70-79	12.50	Bachelors	12.50
80+	0	Masters	0
Gender, n (%)		PhD/Doctorate	0
Female	75	Medical History, n (%)	
Male	25	None	12.50
Race, n (%)		Cardiac Disease	25
Hispanic	12.5	Pulmonary Disease	38
African American	0	Hepatic Disease	12.50
Native American	0	Renal Disease	0
Asian	12.50	Cancer	0
White	75	Other	50
Other	0		

TABLE 2. *Pre-education data*.

Baseline ACP Knowledge and Communication			
Heard of AD, n (%)		Discussed wishes with HCP, n (%)	
Yes	75	Yes	37.50
No	25	No	62.50
Heard of Living Will, n (%)		MPOA for a loved one, n (%)	
Yes	87.50	Yes	25
No	12.50	No	75
Heard of MPOA, n (%)		Completed ACP documents (N=4)	
Yes	100	AD, n (%)	25
No	0	Living Will, n (%)	25
Discussed wishes with family, n (%)		MPOA, n (%)	50
Yes	37.50	Baseline EOL Preferences	
No	62.50	Thought about EOL care, mean	3.25
Abbreviations: ACP, advance care planning; AD, advance directive; MPOA, medical power of attorney; HCP, health care provider; EOL, end-of-life		Terminal illness EOL care, mean	3.125
		Whom to appoint as MPOA, mean	3.375

This DNP project had two outcome goals. The primary outcome goal was to improve
participant comfort levels discussing their EOL preferences with healthcare providers and family
members. The secondary outcome goal was to increase participant knowledge and willingness to

complete ACP documents. Data obtained from the ACP Engagement survey was evaluated using a comparative analysis of pre- and post-education questionnaires. The confidence interval (CI) was set to 95% with a significance level of 0.05. Out of the nine individual questions, there were significant differences within three areas. These areas included: readiness to communicate with a healthcare provider the name of appointed MPOA; readiness to document EOL wishes; and readiness to complete documents appointing MPOA. The evaluation of participants' readiness to communicate with their healthcare provider whom their appointed MPOA is: pre-education (M=3, SD 1.60) and post-education (M=3.75, SD 0.8864); t= 2.393, p= 0.047. The participants' readiness to document their EOL wishes: pre-education (M= 2.875, SD 1.126) and post-education (M= 4.0, SD 0.5345); t= 3.211, p= 0.0148. Finally, the participants' readiness to sign documents appointing a MPOA: pre-education (M=3.0, SD 1.195) and post-education (M= 3.625, SD 0.9161); t= 2.376, p= 0.0492). Although the findings for readiness to appoint MPOA and communicate with a healthcare provider about MPOA were considered a significant difference compared to pre-education findings, the results are marginal. Finally, the overall means of pre-education and post-education data were analyzed. The pre-education (M= 3.431, SD 0.5698) and post-education (M= 4.125, SD 0.6409); t=6.799, p = 0.0001). The results of overall t-test correlate with extremely significant difference between pre-and-post education results. The pre-and-post education paired t-test results can be viewed in Table 3.

TABLE 3. *Paired t-test results*.

ACP Engagement Question	Pre-Education M/SD	Post-Education M/SD	t-test	P value
Readiness to discuss with medical provider EOL wishes	2.875/1.642	3.50/0.7559	1.667	0.1395
Readiness to tell HCP whom MPOA is	3.0/1.60	3.75/0.8864	2.393	0.0479
Readiness to discuss EOL wishes with MPOA	3.125/1.553	3.875/0.6409	1.821	0.1114
Readiness to document EOL wishes	2.875/1.126	4.0/0.5345	3.211	0.0148
Readiness to sign documents appointing MPOA	3.0/1.195	3.625/0.9161	2.376	0.0492
Level of readiness to formally ask someone to be MPOA	3.625/1.302	4.125/0.6409	1.528	0.1705
Confidence discussing EOL preferences with MPOA	4.0/1.069	4.375/0.9161	1.426	0.1970
Confidence level asking someone to be MPOA	4.25/1.035	4.50/0.7559	0.7977	0.4512
Confidence level discussing EOL care with HCP	4.125/0.9910	4.50/0.7559	1.158	0.2849
ACP Engagement survey overall	3.431/0.5698	4.028/0.3738	6.799	0.0001

Abbreviations: ACP, Advance Care Planning; M, mean; SD, standard deviation; EOL, end-of-life; HCP. Health care provider, MPOA, medical power of attorney

Participants were also asked to evaluate the ACP seminar based on increasing their knowledge about ACP, improving comfort levels discussing their EOL wishes, and if they felt that the seminar was worth their time. The Likert scale was used to rate the seminar, *strongly agree=1* to *strongly disagree=5*. All three questions were answered with an average score of *strongly agree* to *agree* (Question #10 M=1.5, #11 M=1.125, #12 M=1.125). The seminar evaluation results, which includes additional participant comments can be viewed within Table 4.

TABLE 4. *Seminar evaluation*.

	Strongly Agree	Agree
Q #10: The education that was provided increased my knowledge about ACP, n (%)	50	50
Q #11: I feel more comfortable in discussing my EOL wishes with my family and friends, n (%)	87.50	12.50
Q #12 The time spent at this seminar was worthwhile, n (%)	87.50	12.50
Additional Comments:		

Helped my wife, that is what is important

Strongly believe that I need to revise my directives sooner rather than later and have the conversation with my loved ones.

More baby boomers facing the advance directives is needed, especially the 55+ bible study students are recommending this.

Thank you. This was very helpful, I appreciate receiving the forms as well as the teaching.

Was very informative, thank you!

Good job! Lots of helpful information

DISCUSSION

Utilizing the TTM or Stages of Change theory, the ACP Engagement survey questions were evaluated to determine each participant's behavior change. The level of each stage was numbered '1' thru '5': precontemplation (1), contemplation (2), preparation (3), action (4), and maintenance (5). Despite, the statistical outcomes of the paired t-test there was evidence of behavior change within each individual question. Movement between each level of change can be viewed within Figure 1. The participant's overall pre-education stage of change was equivalent to the preparation stage (M=3.43). In comparison, the overall post-education stage of change for all participants was equivalent to the action stage (M=4.02).
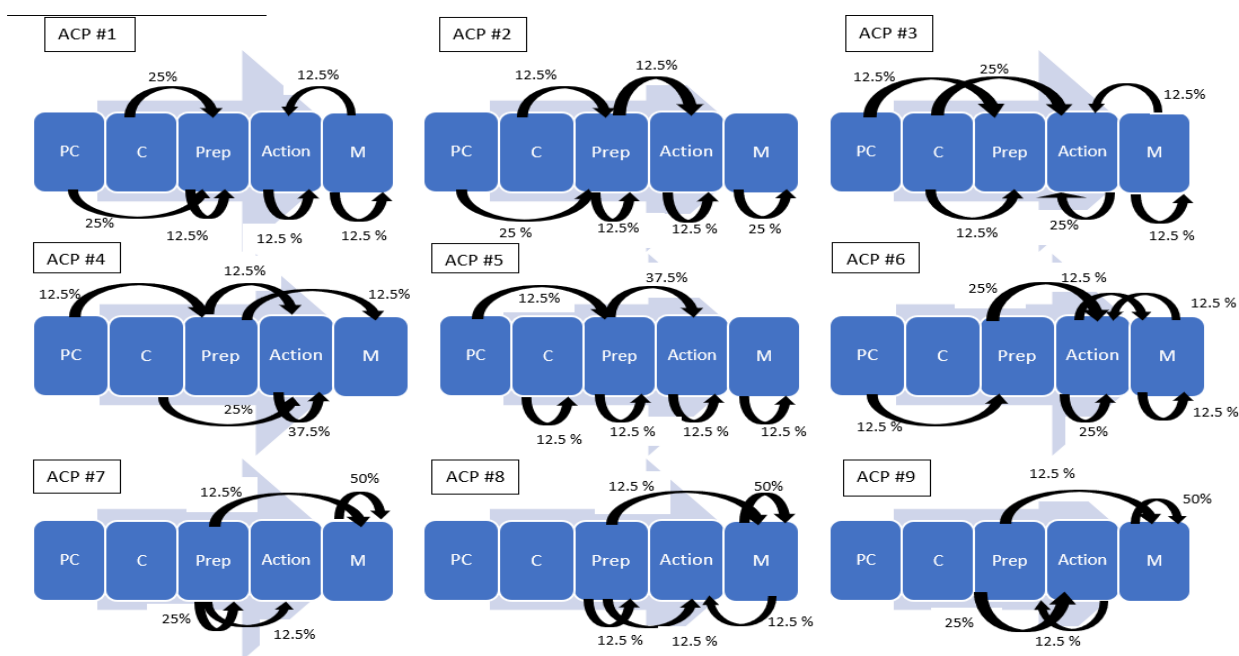

FIGURE 1. Stages of change.

The first outcome goal of this project was to increase comfort levels discussing EOL values and preferences with family, friends, and healthcare providers. Unfortunately, the individual ACP survey data did not support this outcome goal. There was significant evidence to

support that the participants did feel more comfortable discussing who they have appointed as

their MPOA with their healthcare provider. Yet, they were not ready to discuss their EOL wishes

with anyone at this time. The secondary outcome goal was to improve ACP knowledge and

willingness to complete documents. This outcome goal was obtained as evidence by the

significant findings that the participants were ready to complete ACP documentation specifying

their EOL wishes and appointing a MPOA. The seminar evaluation did provide strong evidence

that the participants strongly agreed that the education did increase their knowledge and comfort

levels. The overall ACP survey data did provide extremely significant findings (p =0.0001) that

community education about ACP does improve participant knowledge and comfort levels. This

information does support and confirm this author's project outcome goals. Despite the findings

of significant change only being found within one-third of the individual ACP Engagement

questions, this author believes that there is sufficient evidence to suggest that community

education, and a communication game can increase ACP documentation and improve comfort

levels discussing EOL wishes.

Limitations

Although, two out of the eight participants were 50 years old or younger, their survey

data was kept within this project's outcomes. The decision to include their data was made

because it is this author's belief that everyone over the age of 18 should be prepared for EOL. By

advertising and providing community education to all ages there is an increased chance of

younger adults actively planning, documenting, and communicating their EOL preferences. This

project also had a low rate of participation, (N=8) which some may conclude that the positive

findings are unsubstantiated. Due to small sample size, the outcomes of this project may not be

have the same significant findings in a larger study. All participants willingly obtained ACP documentation to take home with them, and some chose to take extra copies for their family and friends. However, this project did not follow-up with participants to verify if they had completed ACP documentation, or discussed their EOL wishes.

Implications for Future Research

Future research is needed within the area of community education in ACP and EOL communication. Larger studies that implement ACP education and communication tools are necessary. Current research studies support the individual interventions, but future research should focus on combining these interventions to increase ACP knowledge and EOL communication skills within the community. One can educate the community about the ACP documentation, but if individuals do not communicate their wishes or provide copies of their documented wishes to loved ones, it is difficult to abide by their EOL preferences. It is this author's dream to be a part of a larger study that implements both interventions within the community. Doing so could reduce EOL suffering on the individual and reduce psychological stress on their loved ones.

Implications for Practice

By starting the conversation about ACP with patients on a daily basis, it will hopefully increase patient engagement to plan for EOL. It is also important to understand that these conversations may not fit within a standard clinic appointment. Active participation with community groups such as HOV, may help expand the conversation outside of the medical clinic. As a future nurse practitioner, the research, planning, and implementation of this project will guide this author on how to discuss and educate the community about ACP. Further research

and ACP interventions can help guide healthcare providers practice in discussing EOL plans

with patients and change the current practice of EOL discussions.

APPENDIX A:

EVIDENCE APPRAISAL TABLE

Project question: In community members 50 years and older (P), does ACP education, and an EOL conversation game (I) increase knowledge and comfort levels with EOL discussions (O) compared to baseline pre-education results (C)?

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
Abba, Byrne, Horton, & Lloyd-Williams (2013). Interventions to encourage discussion of EOL preferences between members of the general population and the people closest to them- a systematic literature review	Which EBP is effective in encouraging the general population to evaluate, and discuss EOL preferences?	None	Systematic literature review	Studies (n=5), UK (n=4), Japan (n=1)	Data extraction and analysis reported using PRISMA guidelines	Limited availability of current research that has studied interventions that improve EOL conversations. Primary outcomes: Increased engagement when presented in a public forum; low quality of evidence due to observations made. Engagement, attendance, and participant views: The use of an educational booklet aided in the facilitation of ACP workshops. Workshops improved comfort levels to discuss EOL treatments. Public lectures improved the perceptions of the possibility of dying at home.

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
Bravo et al. (2016). Promoting ACP among community-based older adults: A RCT	If a multimodal ACP intervention motivates community based older adults to document their wishes regarding future care, and guides proxies in making hypothetical health related decisions that match those of their relatives.	None listed	RCT	70 years or older; French speaking; live within Eastern Townships of Quebec; not institutionalized; deemed free of cognitive deficits; agrees to designate a potential proxy and is willing to participate as a co-participant (n=235) Experimental group - ACP education program (n=118) Control - Health education program (n=117)	Concordance assessments (baseline, 1st month following intervention and 6 months later). SAS Proc GENMOD-to test the effect of health states on desire for treatment and comfort care. *My preferences* booklet	Baseline-comparable findings **Intervention**: 94/118 (80%) completed *My preferences* booklet, with 84/94 (89%) preferring comfort measures over life sustaining/prolonging measures. When comparing patient wishes with health proxy, health proxy would decide on further treatment when patient would not desire treatment-baseline Unsuccessful in improving proxies' ability to predict older adults' choices/ **Control:** No data provided
Houben et al. (2014). Efficacy of ACP: A systematic review and meta-analysis	ACP interventions increase completion of AD as well as occurrence of EOL discussions. ACP interventions can improve other outcomes, such as quality of communication	None listed	Systematic Review and Meta-analysis	56 studies: 15 inpatients; 37 outpatients; 4 both	PEDro scale: Score of <6 = low quality trials, >6= high quality trials. N=31 <6 N=25 >6	Interventions that included education about AD directives AND communication about ACP increased completion rates. Patients that were in intervention groups

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
	about EOL care, and concordance between preferences of EOL care and delivered care.					received care that corelated with EOL wishes. ACP interventions are most likely to improve other outcomes, such as quality of communication.
Kirchhoff et al. (2012). Impact of a disease-specific ACP intervention on EOL care	Does the use of a Patient-Centered ACP (PC-ACP) identify patient EOL choices, and does EOL care correlate with patient wishes?	none	RCT	Patients with CHF stage II, III, or IV (n=179) or ESRD(n=134) Total(n=313) and their caregivers (n=313) Intervention: PC-ACP (n=160) Control: usual care (n=153)	Pre-study surveys to assess ADLs, ADs, EHR review,	**High rate of death before end of study (n=110), did not complete study (n=23), died prior to end of intervention (n=2)** Patient preferences of less aggressive care: Not statistically significant Patient preferences vs EOL care: 74% (n=81), able to verbalize preferences until death, lack of significance between control and intervention

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
Ko, Lee, & Hong, (2016). Willingness to complete ADs among low-income older adults living in the USA	Explore willingness to complete ADs and examine the role of social support and other factors impacting willingness among low-income older adults.	Health Behavior Model	Cross-sectional qualitative study	N=204; participants whom have not completed an AD Homeless participants (N=65, 31.9%), living within homeless shelter (N=51, 24.9%), and lived within transitional housing (N=30, 14.6%), lived with family or friends (N=97, 47.3%).	Face-to-face interviews using EOL care preference questionnaire; Advance decision-making questionnaire; Lubben support network scale.	Willingness to complete ADs was associated with attitudes towards advance decision making (t [202] =2.26, p=0.02), and social support (t [202] =2.11, p=0.04). Reduced health increased participants willingness to complete ADs (OR= 1.43, 95% CI =1.07-1.90).
Litzelman, Cottingham, Griffin, Inui, & Ivy (2016). Enhancing the prospects for palliative care at the EOL: A statewide educational demonstration project to improve ACP	To provide education and coaching to individuals, healthcare providers, and organizations with the intent to facilitate EOL conversations, documenting and honoring wishes and preferences of care during the final stages of life.	Adult learning theory	Quasi-experimental	Community members (n=2266), Community health workers (n=590), HCP (n=2010) Total (n=4866)	Education style survey data collected at the end of each event using Likert scale	**Community members:** 4/5 Likert scale: Participants felt the information provided allowed for open conversations, reflection on their personal values and good conversation regarding EOL. **Community health workers:** 4.8/5, believed that their communication skills were improved and felt more comfortable

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
						discussing EOL wishes with patients and families **HCP:** 4.2/5 Likert scale, felt knowledge obtained will change their current practice towards EOL, and felt more comfortable discussing EOL with patients
Litzelman et al. (2017). Clarifying values and preferences for care near the EOL: The role of a new lay workforce	Does the use of the game *Go Wish* engage community members in ACP conversations, and improve ACP experiences?	None	Pre-post longitudinal design	Total participants (n=392)	15 semi-structured interviews	Engaged in ACP (n=306); no goal setting (n=306), goal setting started (n=42), goal setting completed (n=44) goal setting completed= reduced hospital admissions Goal setting started vs not for inpatient stays (HR 0.27, 95% CI 0.09–0.08) No significant difference between completed and not started (HR 1.49, CI 0.84, 2.66). **Importance of ACP conversations**: "helpful and important", game

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
						easy to use and discuss with lay person, difficult to discuss with family. Usability of game: helpful to stimulate discussion on difficult topics Highest priority using cards: Ability to attend to spiritual and religious concerns, and preparing for the end of life, and maintaining personal wholeness
Martin, Hayes, Gregorevic, & Lim, (2016). The effects of ACP interventions on nursing home residents: A systematic review	Identify the effects of ACP interventions on nursing home residents	None listed	Systematic Review	13 studies, (5 studies evaluating educational programs; 5 studies introducing or evaluating a new ACP form; 2 studies introducing an ACP program with a PC initiative; 1 observing the effect of DNR orders on medical treatments of respiratory infections.	GRADE system (high quality:1; moderate quality: 2; low quality: 8; very low quality: 2)	**Hospitalization & costs**: Decreased admissions rates 9-26% less. Costs $1772 intervention vs $3869 control (hospital usage costs); $3400 intervention vs $5239 control (total healthcare costs). **Place of death**: ACP increased # patients dying within nursing home instead of hospital (29%-40% compared to control)

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
						Consistency with resident's wishes: ACP increased in consistency with wishes (13%-29% compared to control) **Use of life-sustaining treatments:** 4 out of 24 hospitalizations were for the use of life-sustaining treatments, which reflect the possibility of ACP to be ignored. **Quality of life and satisfaction**: Improved QOL (p=0.034), physical discomfort (p=0.017), and existential distress (p=0.38) **Mortality:** ACP not associated with higher mortality rates 30.4 vs 41.6 per 100 beds (p=0.0425).

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
McMahan, Knight, Fried, & Sudore (2013). ACP beyond ADs: Perspectives from patients and surrogates	To understand what steps best prepare patients and surrogates for decision making	None listed	Qualitative research study	65 years or older, had a primary care physician, and had a serious chronic illness, English, or Spanish speaking (n=38) Surrogates-18 years or older, and have made serious medical decisions for someone else, English, or Spanish speaking. (n=31)	Focus groups – 7 patient only and 6 surrogates only focus groups	**Use of ADs alone is not sufficient**: ADs do not prepare patients and surrogates to prepare for complex medical decisions **Identifying values based on past experiences and quality of life:** Previous experiences influence personal decision making with complex medical decisions and quality of life. **Choosing surrogates and verifying their understanding:** Important to consider selecting someone that can be trusted, make sound decisions, emotionally stable, ask questions, and be there when needed. **Considering whether to grant surrogates leeway in decision making:** Participants respecting

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
						surrogates personal values and ability to make decisions with their best judgement. **Informing family and friends about one's wishes:** Communication with family and friends about one's wishes is important to alleviate surrogate burden and reduce conflict.
Oczkowski, Chung, Hanvey, Mbuagbaw, & You (2016). Communication tools for EOL decision making in ambulatory care settings: A systematic review and meta-analysis	To determine the impact of communication tools for EOL decision making with adult patients in ambulatory care settings on the completion of ADs, patient wishes vs medical orders, care desired vs care received at EOL	None listed	Systematic review and meta-analysis	Studies completed within the outpatient setting (n=67; 46 RCT, 21 observational studies), US (93%), Asia (3%), Europe (3%), Australia (1%). Adults w/o specific medical condition (n=39, 58%), Cancer (n=12), Cardiac disease (n=8), Renal (n=8), COPD (n=7), neuro (n=3), dementia (n=2), HIV (n=2). Control=Usual Care	Standardized, piloted online forms, studies evaluated using GRADE	**Completion of ACP:** Risk ratio 1.92, 472 vs 250/1000 completed documentation with communication tools **Concordance of AD vs medical orders for care**: Risk ratio 1.18, 916 vs 776/1000 with communication tools **Care desired vs care received:** Risk ratio 1.17, 612 vs 490/1000 with communication tools **Patient preference**

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
						for life-prolonging treatments: Communication tools reduced desire for life-prolonging treatments (risk ratio 0.62, 95% C=0.41-0.94, p=0.02) **Quality of communication patient and family:** Tools improved quality of communication- (SMD 1.12, 95% CI = 0.62–1.62, p<0.001). **Quality of communication patient and HCP:** Tools improved quality of communication (MD 3.02, 95% CI = 1.26–4.78, P<0.001; I2 = 51%). **EOL/ACP knowledge:** Tools improved knowledge scores (SMD 0.56, 95% CI = 0.26–0.86, p<0.001; I2 = 52%). **Healthcare utilization:** Inconclusive findings with three

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
						showing reduction of ICU and hospital admissions that were low risk of bias; those with high risk of bias had mixed findings **EOL satisfaction:** No significant difference found with tools
Rocque et al. (2017). Implementation and impact of patient lay navigator-led ACP planning conversations	Can trained lay navigators increase the number of ACP conversations, and effect the utilization of EOL care	none	Convergent, parallel mixed-methods design	ACP navigators (n=50) Patients (n=1319),	Documented conversations via electronic records, Navigator questionnaire, Medicare claims data, face-to-face interviews	**ACP conversation timing**: Completed ACP conversation (n=481), decline (n=366), were still in process at analysis (n=472 **EOL utilization outcomes**: Hospital utilization 46% vs 56%, (p=0.02), chemotherapy use 14% vs 19% (p=0.17), ICU admission 18% vs 24% (p=0.07) ER visits 46% vs 53% (p=0.08). **Barriers to navigator led ACP**: Health literacy, lack of readiness, lack of comfort and timing initiating conversation, lack

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
						of stakeholder buy-in, compared to death panels **Facilitators to navigator led ACP**: Previous exposure to ACP, established rapport, patient readiness, physician buy-in
Sinclair et al. (2016). ACP uptake among patients with severe lung disease: A randomised patient preference trial of a nurse-led, facilitated ACP intervention	Primary: If a systematic nurse-led, facilitated ACP intervention is effective in increasing ACP readiness and uptake among patients with advanced respiratory disease.	TTM	Multi-centre open-label RCT with preference arm	Patients with respiratory malignancy, COPD, or interstitial lung disease, >18, English speaking and without previous AD (n=149)\n\n**Intervention:** (N=106) Nurse-led facilitated ACP that provides EOL communication skills for patients and loved ones\n\n**Control:** (N=43) Usual care	Chart audits to assess AD documentation; interviews, EQ-5D-5L: 5 dimensions of health-related quality of life	**ACP uptake and readiness:** 54/106 (50.9%) with increased likelihood of completing ACP at 6 months, compared to 6/43 (14%). **Informal ACP uptake baseline-6 mo:** Inter: 33/106, 31.1%- 76/106, 71.7%, (p <0.001) Control: 12/43, 27.9% vs 20/43, 46.5% (not significant). **ACP discussions at 3 mo**: Inter: 62% vs 77%, (p<005) Control: 50% vs 73%, (p=0.06)

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
Sudore et al. (2017a). Effect of the PREPARE website vs an easy to read AD on ACP documentation and engagement among veterans: A RCT	Can a patient-facing, interactive ACP website called PREPARE plus an easy-to-read AD increase ACP documentation compared with an AD alone?	TTM	Single blind, parallel group Randomized comparative effectiveness trial	415 veterans from VA clinics AD-only (n=209) PREPARE Plus AD (n=205)	ACP Engagement survey	**Primary**: New ACP documentation: Higher rates of completion with PREPARE group 37% compared to 27% p=0.04 **Secondary**: Knowledge, contemplation, self-efficacy & readiness to change utilizing ACP engagement survey: Mean ACP engagement scores using linear regression models showed increased engagement in those using PREPARE site. Prepare plus AD (0.59 to 0.68 SD for process scores,0.49 to 0.59 SDs for action scores) and were small for the AD-only arm (0.24 to 0.39 for process scores, 0.20 to 0.39 SDs for action scores).

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
Van Scoy et al. (2016). Conversation game effectively engages groups of individuals about death and dying	Playing the conversation game *My gift of Grace* would result in satisfying and realistic conversations about EOL	none	Mixed methods study	English speaking adults from Pennsylvania (n=57), and Kentucky (n=13) Games played (n=18)	Pre-survey using PANAS-X measure, Post-surveys, Post-game focus groups	Participants felt game provided positive experience, enjoyed listening to others EOL values. Mixed emotions regarding playing with family members vs strangers Game provided prompted EOL discussions that were uncomfortable, yet realistic
Van Scoy et al. (2017). Can playing an EOL conversation game motivate people to engage in ACP?	Does the use of the game "My gift of Grace" motivate participants to engage in ACP behaviors	TTM	Exploratory Pilot study	18 games (n=70) participants from Pennsylvania (n=57), from Kentucky (n=13)	Pre/Posttest surveys (Process of change questionnaire), and phone interviews	Updated AD's or initiated further EOL discussion (78%) Increased behavior changes at 3 months (73%) Increased completion rates of living will and healthcare proxy
Van Scoy et al. (2017). Community game day: Using an EOL conversation game to encourage ACP	Does the use of an interactive EOL game motivate patients and caregivers to engage in ACP, and is it acceptable to use in community settings?	none	Convergent mixed methods study	22 games (n=93 participants). Patients with chronic disease (n=49), caregivers/surrogates (n=44)	Pre-survey using 55 item ACP engagement survey Post survey using 9 item ACP engagement survey, and ACP behavior survey Post game focus	**Behavioral outcomes**: 75% completed one or more ACP (completing AD, updating AD, or discussing EOL wishes with family or HCP)

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
					group	43/93 had not completed AD prior to study, post intervention 19/43 completed AD within 3 months. Participants felt empowered by hearing others EOL values, and allowed them to reflect on their own EOL wishes Learned new perspectives to other participants EOL wishes and values
Walczak, Butow, Bu, & Clayton (2016). A systematic review of evidence for EOL communication interventions: Who do they target, how are they structured, and do they work?	Assess the evidence for interventions that targets EOL communication and targeted stakeholders within EOL communication	None listed	Systematic review	(N=45) Patient focused interventions (N=6), Caregiver focused interventions (N=3), Multi-focal interventions (N=12), Healthcare professional interventions (N=24)	QualSyst standard assessment criteria to evaluate research studies	**Patient focused interventions:** Interventions r/t EOL and ACP with the greatest impact on outcomes, EOL preferences and improved discussion/communication EOL. **Caregiver focused interventions:** Structured EOL family conference and bereavement reduced grief and psychological distress **Multi-focal**

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
						interventions: Significant improvements in studies with question prompt list for EOL preferences, increased comfort in pt asking questions regarding prognosis, EOL and reduced unmet needs. **Healthcare professional interventions:** No significance in length of training days to improve comfort with EOL discussions, yet improvement in empathetic communication behaviors were seen.
Walczak et al. (2017). Encouraging early discussion of life expectancy and EOL care: A randomised controlled trial of a nurse led communication support program for patients and	Compared to control groups, participants will engage in conversation with providers regarding prognosis, and EOL preferences. Participants will report increased self-efficacy when communicating,	Self-determination theory of health-related behavior change	Single blinded, parallel group RCT	English speaking, adults with various cancer diagnoses with a 2-12-month life expectancy. CSP (n=61) Control (n=49)	Perceived efficacy in physician/patient interactions scale (PEPPI), FACT-G health related QOL, CISQ and Degner CPS	Impact of the intervention: Intervention group with significantly higher outcomes overall. (p=0.000). **Consultation length**: No significant difference **Communication**

Author/Article	Research Question	Framework	Design	Sample	Data Collection	Findings
caregivers	discuss EOL preferences, and have improved QOL					**self-efficacy**: no significant difference **Preferences for information and decision making**: no significant difference **Quality of life:** no significant difference High level of attrition Small sample size
Weathers et al. (2016). ACP: A systematic review of randomised controlled trials conducted with older adults	Examination of the impact of ACP and the outcomes of symptom management, quality of care and healthcare utilization, in adults older than 65 across all health care settings.	None listed	Systematic review	9 RCTs (3,646 individuals 65 years or older)	Oxford five-point scoring system scores greater than 3 = free of bias, Cochrane EPOC review group	ACP interventions decreased hospitalization and use of resources, increased patient and family satisfaction with care and increased use of advanced care directives. Increased ACP discussions post interventions. Unable to determine of ADs improve quality of EOL care.

ACP=Advance care planning; RCT=randomized control trial; AD= Advanced Directive; EOL= End-of-life; PC=Palliative Care; DNR= Do not resuscitate; QOL= Quality of Life; HCP= Healthcare provider, EPOC=Effective practice and organization of care; CISQ= Cassileth information styles questionnaire; CPS=control preferences scale; PC-ACP= Patient-Centered ACP; GRADE= Grading of recommendation assessment, development, and evaluation; PEDro= Physiotherapy Evidence-Based Database

APPENDIX B:

PROJECT DISCLOSURE

ADVANCE CARE PLANNING: COMMUNITY EDUCATION TO IMPROVE END-OF-LIFE KNOWLEDGE AND COMMUNICATION
Principal Investigator Jacqueline L. Murphy

The purpose of this project is to educate community members 50 years and older about Advance Care Planning, and to improve communication about end-of-life wishes.

If you choose to take part in this project, you will be asked to attend an educational seminar about advance care planning, play an interactive group game, engage in difficult conversation, and complete a pre-education and post education survey. It will take approximately 5 minutes to complete each survey. There is a risk of emotional distress associated with participating in this project as you think about your personal end-of-life values and preferences. There will be no immediate benefit from your participation, but you may use the information obtained from this seminar to complete Advance Care Planning. Survey responses are anonymous.

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.

For questions, concerns, or complaints about the project, you may email Jacqueline L Murphy, BSN RN at jmurphy04@email.arizona.edu

APPENDIX C:

PRE-EDUCATION SURVEY

ADVANCE CARE PLANNING PRE-EDUCATION 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: less than 50_____ 50-59_____ 60-69 _____70-79_____80 and over_____
3. Highest level of Education:
   - a. Some Highschool_____
   - b. Highschool_____
   - c. Associates_____
   - d. Bachelors_____
   - e. Masters_____
   - f. PhD/Doctorate_____
4. Please specify your ethnicity:
   - a. Hispanic or Latino _____
   - b. Black or African American _____
   - c. Native American or American Indian _____
   - d. Asian or Pacific Islander_____
   - e. White or Caucasian _____
   - f. Other _____
5. Past medical history *(select all that apply)*
   - a. Never diagnosed with a medical condition _____
   - b. Heart disease (*High blood pressure, coronary artery disease, congestive heart failure, previous Heart attack)* _____
   - c. Lung disease (*Asthma, Chronic Obstructive Pulmonary Disease, Emphysema, Chronic Bronchitis)* _____
   - d. Liver disease (*Hepatitis, Chronic liver disease)* _____
   - e. Kidney disease (*Kidney failure, Chronic kidney disease, dialysis)* _____
   - f. Cancer _____
   - g. Other _____

Advanced Care Planning Pre-Education

6. Have you heard of any of the following?

   a. Advanced Directives: Yes_____ No _____

   b. Living Will: Yes_____ No _____

   c. Medical Power of Attorney: Yes_____ No _____

7. Have you completed any documentation listed above? Yes_____ No_____
   - a. If yes, which documentation have you completed?
     - i. Advanced Directive: _____
     - ii. Living Will: _____
     - iii. Medical Power of Attorney: _____
   - b. Have you discussed your wishes with family or friends? Yes _____ No_____
   - c. Have you discussed your wishes with a medical provider? Yes _____ No_____

8. Have you ever been in a situation where you were required to make medical decisions for a loved one when they were no longer able to?
   - a. Yes_____ (*if yes please answer #9)*
   - b. No _____

9. Did you feel that the decisions you made for your loved one reflected their wishes?
   - a. Yes_____
   - b. Unsure, we never discussed this prior _____
   - c. Other: _____

10. 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

11. If you were diagnosed with a terminal illness, debilitating disease, or were in a life-threatening motor vehicle accident, have you thought of how you would want to be care for?
      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 this type of situation

12. Have you thought of whom you would want to make medical decisions for you if you were unable to communicate your wishes?
      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 this type of situation

Advance Care Planning Engagement Survey

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

APPENDIX D:

POST-EDUCATION SURVEY AND EVALUATION

ADVANCE CARE PLANNING POST-EDUCATION SURVEY

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.

<u>Advance Care Planning Engagement Survey</u>

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