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Technology-Based End-of-Life Planning for an Underserved Population

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For an Underserved Population

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Abstract

Problem: Research indicates a low-income status and ethnic and racial diversity is a barrier to ACP engagement.

Context: This project took place at a Federally Qualified Heath Center located in Northern California which serves approximately 200,000 diverse and economically disadvantaged patients.

Methods: The primary intervention was dissemination of an email to patients 50 and older, via their health system email account. The email included a direct link to PREPARE, an online advance care planning technology tool. A secondary intervention was a presentation to primary care providers that focused on end-of-life-care planning tools and communication strategies.

Results: The email was distributed to 22,296 patients and received a total of 895 clicks on the link to PREPARE. Pre- and post-email data did not show a significant change in ACP engagement. The provider presentation pre-and post-survey results revealed an increase in mean scores for comfort with ACP discussions, best practices for ACP discussion, and communication resources.

Conclusions: Engaging patients in ACP is a persistent challenge for primary care providers working with diverse groups within healthcare systems. As the U.S. geriatric population becomes larger and more diverse, advance health care planning needs to be prioritized in a culturally sensitive manner.

Technology-Based End-of-Life Planning

For an Underserved Population

Section II: Introduction

Problem Description

The Hospice and Palliative Nurses Association (HPNA) holds the position that "advance care planning is a central tenet of person-centered care," and "patients have the right to receive care that is consistent with their values and preferences" (HPNA, 2017). Unfortunately, the majority of individuals with a terminal illness or life-threatening condition have not documented their end-of-life-care preferences. Only one third of sick adults in the United States have completed an advance directive, indicating a general lack of attention to end-of-life-care planning (Reuters, 2017).

Hirschman, Kapo, and Karlawish (2006) estimated that only 5% to 15% of the United States population have a completed advance health directive. Yet, 70% of people report they would prefer to die at home, but 76% of individuals actually die within an institution (Wilson, Kottke, & Schettle, 2014).

By 2050 there will be an estimated 33 million African American, Hispanic, Asian, American Indian or Alaskan Natives age 65 years and older in the U.S. These racially and ethnically diverse groups will represent approximately 40% of the total population for this age group (Ortman, Velkoff & Hogan, 2014). Nurses and nurse practitioners are increasingly at the frontline of primary and geriatric care for diverse and underserved populations; hence, there is a great need for evidence-based interventions for advance care planning (ACP) with diverse and underserved populations (Spetz & Muench, 2018).

The National Consensus Project for Quality Palliative Care (2018) has identified culturally appropriate end-of-life-care planning as a U.S. national priority. It is well documented that diverse populations are less likely to both engage in end-of-life-care planning and have an advance directive (Pecanac, Repenshek, Tennenbaum, & Hammes, 2014). One study found that only 18% of diverse patients had completed an advance directive compared to 34% of Caucasians (Rao et al., 2014). Health care providers conduct end-of-life discussions less often with diverse patients (Kulkarni, 2011).

The literature denotes diverse populations are less likely to have an advance directive when compared to Caucasian groups (Pecanac, Repenshek, Tennenbaum, & Hammes, 2014). Hong, Yi, Johnson, and Adamek (2018) in an attempt to identify challengers and promotors of advance care planning (ACP), conducted a systematic review of the current literature surrounding advance care planning among ethnic and racial minorities in the U.S. Their review identified four categories of facilitators and barriers to advance care planning for diverse groups: (a) socio-demographic factors; (b) health status, literacy, and experiences; (c) cultural values; and (d) spirituality (Hong et al, 2018). Socio-demographic factors influencing ACP engagement were age, income, and education. Ethnic and racially diverse groups more often reported low health literacy about ACP and knowledge of how to complete an advance health directive (Hong et al., 2018). This research indicates low income status, being less educated, and ethnic and racial diversity is a barrier to ACP engagement This makes end-of-life-care planning a challenge for diverse and underserved patient populations.

Setting. The setting for this DNP project was a Federally Qualified Health Center (FQHC) located in Northern California. This health system serves approximately 200,000

patients and has over 640,000 health related visits per year (cchealth.org, 2018). The patient

demographics include multiple ethnic and racial backgrounds with a low-income status.

In addition to the medical center, there are eleven outpatient clinics providing both

primary care and specialty services i.e. rheumatology, gastroenterology, neurology, dermatology,

oncology, nephrology, orthopedics and gynecology. There is a palliative care clinic with one

provider. The majority of her consults are done in the inpatient setting and per her report, the

palliative care clinic is under-utilized and is only available two-half days a month in one

ambulatory clinic (Palliative care physician lead, personal communication, February 14, 2019).

Each patient has the option to sign up for the secure email system offered through the electronic

medical record (EMR).

The EMR utilized by this FQHC notes whether a patient has a documented advanced

health directive (AHD). The number of patients who have an AHD is not tracked, and the

institution has not made advance health planning a meaningful use priority. There are no primary

care end-of-life-planning programs being implemented in this healthcare system, and the

ambulatory EMR has not promoted any smart-phrases or templates to assist with end-of-life-

planning visits in the ambulatory setting.

Meeker and Jezewski (2004, 2005) report that patients prefer to discuss advance care

planning with their primary care provider while they are in good health, and that providers

should initiate the conversation. Unfortunately, family members often serve as surrogates, but

are typically ill prepared to make medical decisions on their family member's behalf (Meeker &

Jezewski, 2005). In a report generated by the California HealthCare Foundation in collaboration

with Coalition for Compassionate Care of California (2012), it is reported that 56% of

Californians have not communicated their end-of-life wishes to anyone. However, 80%

responded they would like to talk to a healthcare provider about their end-of-life-wishes but only

7% have done so. Advance care planning is optimal patient care that should be happening sooner

in everyone's life and preferably within the primary care setting.

Available Knowledge

PICO question: The following PICO question drove the search for evidence for this

project: In primary care patients, 50 and older, seen within an integrated county healthcare

system in Northern California, how effective is a technology-based end-of-life-planning tool,

compared to current practices, at increasing advance care planning engagement?

Search methodology. The literature search was conducted from November 2017 thru

November 2019, and the following databases were searched: Cochrane, CINAHL, Academic

Search Complete, PubMed, and Science Direct. Search terms included *end-of-life-care-planning,*

advance care planning interventions, advance health directives, advance care planning

programs, relationship, diverse patient populations, and *minority.* The author also reviewed

several reference lists from advance care planning research articles.

Evidence. This review included peer-reviewed, primary research articles that were

written in English and conducted in the United States, that were published within the past five

years, and that implemented an intervention specifically directed toward diverse ethnic and racial

groups residing in the United States. Several articles reported a lack of ACP engagement in

diverse groups. If the article did not test a specific intervention aimed at diverse groups in order

to increase ACP engagement, it was excluded. Articles were still included if advance directive

completion was not assessed because that is only one measure of ACP engagement. This

exhaustive search yielded 13 articles that were grouped into two categories related to ACP interventions: community focused programs and institutional based interventions. All of the evidence in this review is summarized in Appendix A.

Community Focused Advanced Care Planning Interventions

Lee, Hinderer, and Friedmann (2015) implemented a community-based program aimed at an urban Chinese American population. A seminar tailored to Chinese Americans was conducted on two occasions at a Chinese community center (n=72). The seminar consisted of a bilingual presentation on advance directives and a tutorial on completion of an advance directive as a family process. Using pre and post-test surveys, mean knowledge scores were 7.11 prior to the seminar and 9.20 immediately following the seminar showing a significant positive change in ACP knowledge for this sample of Chinese Americans.

Huang et al. (2016) reported about the discrepancies in end-of-life planning for African Americans specifically from the southern U.S. They recognize this population has multiple co-morbidities in addition to low health literacy, making them a particularly vulnerable population. Conducting a mixed-method randomized control trial they examined the Thinking Ahead Project (TAP). TAP is a single-session, 90-minute intervention that employs motivational interviewing, Respecting Choices ACP facilitation program, The First Steps ACP protocol, and a revised advanced directive (AD) form that is written at a fifth-grade literacy level. The study population consisted of 30 community dwelling African Americans; 15 were randomized to the intervention group and 15 to the control group. The control group received educational materials on AD and were asked to review them. A majority of the intervention group, 86.7%, reported feeling "very much" prepared to make decisions regarding end-of-life care, while only 66.7% of those in the

control group reported the same level of preparedness. Lastly, 100% of both groups reported an increase in their intention to complete an AD.

Pecanac, Repenshek, Tennenbaum, and Hammes (2014) similarly utilized the Respecting Choices model of AD planning. They conducted a study with a retrospective chart review design to evaluate the Respecting Choices program with a racially diverse population. Initially, the Respecting Choices program's effectiveness had only been tested with a mostly Caucasian population. Respecting Choices is a program which includes AD patient education materials for the community, AD facilitators working in all healthcare institutions within the community, standardization of policies regarding documentation and maintaining ADs, and performance improvement methods for each intervention.

The researchers reviewed the medical records of 732 deceased patients from 2005 to 2010 comparing what was written in an AD versus the actual end-of-life treatment received (Pecanac et al., 2014). Upon chart review, the authors found a significant increase post intervention in the percentage of advance directives for racially diverse patients, 25.8% to 38.4%, but no statistically significant increase for the white population, 46.7% to 47.3%. This finding would indicate the Respecting Choices program had a potentially larger impact on racially diverse populations, although the specifics of the diverse population were not given in terms of exact breakdown of race and ethnicity.

Wilson, Kottke, and Schettle (2014) sought to increase ADs throughout the Minneapolis metropolitan area. Recognizing the success of the Respecting Choices program, the researchers sought to increase ACP documentation within a more complex and diverse population. Honoring

Choices Minnesota (HCM) was an intervention used to recruit all the healthcare systems within

the Minneapolis Metropolitan Area.

According to Wilson et al. (2014), HCM consisted of three phases of implementation.

Phase I, which included strategy and planning, involved a three-year process of forming

committees from various backgrounds including social workers, clinicians, and healthcare

administration. Phase II was implementation of HCM. Several interventions were accomplished

including the design of a website, online newsletter for health organizations, development of

seven pilot teams, a conference giving the opportunity to share experiences with HCM, and

televised documentaries of ACP experiences on a local public television station. Phase III

consisted of refinement and dissemination of the HCM plan. Six other communities across the

nation adopted the HCM model. As of 2013, eight large metropolitan healthcare systems have

implemented the HCM program. These efforts resulted in AD documentation rates ranging from

15.1% to 31.7%, reported from seven systems utilizing HCM (Wilson, 2014).

Sun et al. (2017) recognized insufficient end-of-life-care planning among Asian

Americans. They conducted a single group pre- and post-intervention study which evaluated a

culturally-tailored education intervention. Study participants were recruited through their

churches using announcements and telephone calls. Inclusion criteria were self-identifying as

Chinese or Vietnamese, and age 35 or older. Exclusion criteria were involvement with the

project and prior completion of an AD. Program development involved nine individual

interviews with church leaders and participating church members. Sun et al. concluded the

following regarding intervention content:

(a) materials should be language-concordant; (b) health professionals should deliver

messages; (c) sessions should be focused on patient rights to reduce the stigma associated

with AD, and (d) enough time (four weeks) should be provided between sessions to allow

discussion between participants and family members. (p. 3)

Two educational sessions, 4 weeks apart, were conducted within four churches, two

Chinese Protestant and two Vietnamese Catholic churches. The first session was an endorsement

of AD by a church official and AD explanation by a physician. The second education session

focused on AD explanation and completion. Pre- and post-intervention questionnaires were

completed. The primary outcomes of the study were completion of an AD and a proxy

conversation about AD. Descriptive statistics were computed. At three months post-intervention

71.8% of participants had completed an AD and 25% had a proxy conversation (Sun et al.,

2017).

Nedjat-Haiem et al. (2017) conducted a prospective, pre/post-test, two group, randomized

pilot trial. The researchers examined the feasibility and satisfaction with a community-based

ACP intervention in southern New Mexico, targeting older Latinos. Acknowledging their study

was part of a larger research project, the authors sought to evaluate feasibility and satisfaction

with the ACP-1 Plan. Study participants were recruited using methodology from a sociocultural

framework. Inclusion criteria were Latinos/Hispanics living in southern New Mexico, age

greater than 50, and having one or more chronic illnesses. A total of 74 subjects were enrolled.

Participants were randomly assigned to usual care or treatment intervention group. The usual

care group was given general advance directive education about ACPs and ADs. The treatment

group received motivational interviewing counseling and client-centered supportive care

regarding ACP engagement. The qualitative data indicated overall satisfaction with ACP-1 and feasibility of recruitment and the intervention.

As part of the same study, Nedjat-Haiem et al. (2019) randomized 74 chronically ill Latinos 50 and older to usual care including ACP education, or the treatment group that included ACP education with motivational interviewing. AD completion was significantly greater in the treatment group. However, the treatment group was significantly less likely to discuss ACP with healthcare providers or family members. This unanticipated finding indicates more research is needed to determine other factors influencing the patient-provider relationship and barriers to ACP family discussions.

Institution-based advanced care planning interventions. Bonner et al. (2014), conducted a pilot study examining an advance care treatment plan (ACT-Plan) with family members that were African American dementia caregivers. Their group-based education intervention was conducted within five adult day care centers located in an urban setting. A two group, pre- and post-test design was utilized. Sixty-eight African American caregivers of relatives with dementia participated in one of two groups: a four-week ACT-Plan condition group (n=35), or an attention control condition group focused on health promotion topics including hypertension, diabetes, exercise, and advance directives (n=33). Randomization of participants did not occur.

Using a standard training protocol, each group session was conducted by an advance practice nurse. Using descriptive statistics, primary outcome measures were knowledge about dementia; knowledge about cardiopulmonary resuscitation (CPR); mechanical ventilation (MV); tube feeding (TF); and self-efficacy on decisions made for CPR, MV, and TF. The authors

concluded that knowledge of dementia and self-efficacy were increased for the ACT-Plan group.

Comfort with knowledge of CPR, MV, and TF decreased in the ACT-Plan group, but remained

unchanged in the attention control group, suggesting more knowledge about these topics could

make caregivers more uncomfortable about making decisions regarding these interventions

(Bonner et al., 2014). Finally, there was a significant decrease in the decision to use CPR, MV,

and TF in the ACT-Plan group, but not in the attention control group (Bonner et al., 2014).

Song et al. (2016) conducted a secondary data analysis from a randomized control trial

comparing an ACP intervention entitled Sharing Patient's Illness Representations to Increase

Trust (SPIRIT) to standard care. Specifically, they examined dyad congruence on goals of care,

surrogate decision-making confidence, a combination of the two, and patient decisional conflict

(Song et al., 2016). Another comparison was made between the results of African Americans and

Caucasians. Patients were recruited from 20 dialysis centers in eight counties in North Carolina.

The SPIRIT arm participated in two sessions that discussed the participant's prognosis and

values regarding end-of-life care. A goals-of-care document was completed with a surrogate

decision maker. Session two was a review of the goals-of-care (Song et al., 2016).

The SPIRIT intervention had a significant effect on the number of dyads (patient and

surrogate) with congruence about treatment goals, surrogate decision-making confidence,

improving preparation for end-of-life decision making, and post-bereavement outcomes for

African Americans. SPIRIT did not have a significant effect on Caucasians for the same

outcomes, indicating this program may be more aligned with African American cultural values

than those of Caucasians (Song et al., 2016).

Sudore et al. (2014) developed the PREPARE Website in an attempt to "reconceptualize" ACP, especially for ethnically and racially diverse groups. PREPARE is a web-based tool that was designed to teach skills required to communicate end-of-life care wishes to surrogate decision makers and primary care providers. The education materials are written at a fifth-grade level with a 14 point or larger font. There are five steps in PREPARE:

1) choose a medical decision maker and ask them to serve in that role; 2) decide what matters most in life and for medical care…; 3) decide on leeway for the surrogate decision maker…; 4) communicate wishes with surrogates, clinicians, and other family and friends; and 5) ask doctors the right questions to make informed medical decisions. (Sudore et al., 2014, pp. 676-677)

Sudore et al. (2014) conducted a pilot study to test PREPARE's ability to engage a racially and ethnically diverse geriatric population in ACP. Forty-three participants were recruited of which 65% were non-white, and were asked to view PREPARE on their own within the senior center. Engagement in ACP was the primary outcome and it was measured with the ACP Engagement Survey. ACP engagement was found to significantly increase at one week after the intervention.

PREPARE was further tested by Sudore et al. (2017) within primary care clinics of the Veterans Affairs Health Care System. A randomized-controlled trial was done to compare PREPARE with an easy- to- read advanced directive. Participants were randomized to either PREPARE plus an AD, or an AD alone. New ACP documentation at nine months was the primary outcome measure. There was a total of 414 participants, 43% of whom were non-white. New ACP documentation was 25% in the AD only arm, and 35% in the PREPARE plus AD

arm. These findings suggest that PREPARE and an easy to read AD are capable of improving

ACP engagement and documentation, specifically in resource- challenged clinics.

PREPARE was again tested via a single-blind, parallel-group, comparative efficacy trial

design with randomization (Sudore et al., 2018). English-speaking and Spanish-speaking older

adults were randomized to PREPARE and an easy-to-read advance directive intervention, versus

an easy-to-read AD alone. The measurable outcomes were ACP documentation of legal forms

and ACP discussions. A total of 986 older adults with two or more chronic illnesses from four

primary care clinics were enrolled into the study. Similar to the RCT done at the Veterans

Affairs Institution using PREPARE, the PREPARE group in this trial had higher new

documentation of ACP (legal forms and ACP discussions) at 15 months.

Zapata et al. (2018) utilized the PREPARE movie version within a group visit setting,

involving a diverse population of patients from a safety-net health system. This feasibility pilot

included two 90-minute group visits that involved 22 participants viewing the PREPARE

website movie while attending an ACP group visit. The majority of participants (73%) were

nonwhite with limited health literacy. Knowledge about surrogate designation went from 46%

pre-intervention to 85% post-intervention. The authors concluded there was an increase in

surrogate designation and AD completion. Participants rated the group visits and PREPARE

program a mean score of eight on a ten-point acceptability scale. Zapata et al. concluded that

utilization of the PREPARE movie for ACP, during group visits in the primary care setting, is

feasible for use with diverse adults.

Rationale

The conceptual framework guiding this project was comprised of Knowles's adult learning theory (Knowles, 1973), Parse's human becoming theory (Parse, 2010), and Chochinov's dignity-conserving care model (Chochinov, 2007). Each theory and model offered elements pertinent to this project.

Adult learning theory is based on two concepts: andragogy and self-directed learning (Sanchez & Cocknell, 2017). *Andragogy* focuses on adults as learners, while *self-directed learning* presumes adults are responsible for their own learning, which allows them a more in depth understanding of themselves (Sanchez & Cocknell, 2017). Four key characteristics are pertinent to adult learning theory:

adults have life experiences that they use to direct and comprehend their learning, adults are internally motivated and problem driven, adults expect the knowledge obtained to be immediately applicable, adults are independent and responsible for the time, place, and method of learning. (Sanchez & Cooknell, 2017, p.17)

Parse's human becoming theory deems patients as experts in their own life, and their health results from their perspective of quality of life (Parse, 2010). Parse recognizes the importance of human dignity and outlines four ethical tenets of the human becoming ontology about human dignity as follows (a) reverence is solemn regard for human presence, (b) awe is beholding the unexplained of human existence, (c) betrayal is violation of human trust, and (d) shame is humiliation with dishonoring human worth (Parse, 2010).

Chochinov (2007) developed his dignity-conserving care model from a qualitative study looking at dignity in relation to dying patients. His findings revealed three themes including (a)

illness-related concerns, (b) dignity-conserving concerns, and (c) social dignity concerns. He

further detailed four major ideas within his framework which are attitude, behavior, compassion,

and dialogue. Both Parse's theory and Chochinov's model entrust the patient to know what is

best for them when making end-of-life-care choices.

This project incorporated each of these theories and Chochinov's model described above.

By allowing patients to view the AD material on their own and at their own pace, they are

allowed to be adult learners in control of their personal learning process. Advance care planning

embodies the ideas of Parse (2010) and Chochinov (2007) by presenting patients with an

opportunity to reflect on their personal values and providing a platform to convey their end-of-

life care wishes so that care is in sync with a patient's unique moral principles.

Specific Aims

The purpose of this project was to improve end-of-life-planning for an underserved and

diverse patient population, using a technology tool. The AIM statement is as follows: By

December 2019 develop, implement, and evaluate an end-of-life-care planning technology

project at a Federally Qualified Health Center in Northern California.

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Section III: Methods

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Context

Stakeholders. End-of-life-care and advance health directives involve multiple

stakeholders. At present, many healthcare systems within the United States are failing at

obtaining information about a patient's preferences for end-of-life care as evidenced by

persistent low advance directive rates in the U.S. Yadav et al. (2017) conducted a systematic

review revealing only one in three U.S. adults complete an advance directive. Often, an advance

directive is not acknowledged or known to exist by the healthcare community. This leads to

potential unwanted--and likely expensive--patient care.

Those with an interest in improving end-of-life care planning are patients and their

families, providers, healthcare systems, and the community at large. Patients have a right to have

their wishes known and respected, especially when unable to speak for themselves. According to

The Conversation Project (2019), 80% of individuals would like to have an end-of-life-care

discussion with their healthcare provider if they become seriously ill. However, only 7% have

had the conversation (The Conversation Project, 2019).

Health care systems must recognize they are providing unwanted care that is not

congruent with patients' values. Coppola, Ditto, Danks, and Smucker (2001) reported that

hospital-based physicians had a significant lack of accuracy about end-of-life care wishes

without an advance directive for guidance. Further, end-of-life care is a significant driver of

healthcare costs which creates a financial burden on healthcare systems and tax payers, with

Medicare as the biggest payer. Bekelman, Halpern, and Blankart (2016) reported twice as many

intensive care unit admissions in the U.S. for cancer patients 65 years and older at the end of

their life, compared to Belgium, Canada, England, Norway, Germany, and the Netherlands.

Providers need tools to promote ACP discussions with patients and equip them to advocate on

their behalf.

This healthcare institution for which this project was conducted is a stakeholder in this

problem because the majority of their patients are on a government supported health plan and

come from diverse backgrounds. Knowing each of their patient's end-of-life preferences would

allow for more patient-centered care, better trust, less suffering from patients and family, and

savings on healthcare costs allocated to end-of-life care. Fortunately, administration from the

institution recognizes the need for better advance care planning for this diverse and underserved

population, and the committee responsible for approval unanimously agreed to implementation

of this project (see Appendix B for approval letter).

A lack of attention to advance care planning was widely evident in this organization

given the low rate of documented advance care planning engagement and minimal use of

palliative care services. This project was inspired by a patient encounter involving an attempted

end-of-life discussion during a primary care visit. The author was unable to identify patient

resources or access EMR tools tailored to the primary care setting.

Gap analysis. A gap analysis was conducted on end-of-life-care-planning in this

organization revealing the healthcare institution does not have a program that addresses end-of-

life-care. Further, the agency is not collecting data regarding Physician Orders for Life-

Sustaining Treatment (POLST) or advance directive completion. The ambulatory charts do not

include smart sets for end-of-life-care discussions.

The purpose of this project is to promote end-of-life-care planning using a technology

tool. Using an education technology tool that targets the patients directly and increasing

provider knowledge on ACP engagement, will facilitate a change in practice by promoting more

ACP discussions in the primary care setting. This will encourage ACP engagement to become a

standard of care in the primary care clinic.

Maxfield, Pohl, and Colling (2003) identify ten barriers to advance care planning which

include patient and provider reluctance, time constraints, assumptions, denial and

procrastination, unrealistic expectations, delaying until a crisis, discomfort with palliative care

planning, lack of documentation, and cultural and health system barriers. However, multiple

programs attempting to increase awareness, discussion with patients, and completion of

advanced directives are present in the literature. Butler, Ratner, McCreedy, Shippee and Kane

(2014) report that the PREPARE model utilized much less resources when compared to other

advance care planning decision aids, while still increasing AHD documentation within the EMR,

through primary care clinics. Thus, indicating, the PREPARE model could be a viable option for

communities and institutions with limited resources. In essence, the literature indicates that the

use of end-of-life decisions aids is helpful, primary care is the optimal setting for discussions

about end-of-life-care planning, and adequate ACP documentation is lacking. Therefore, an

education program that encourages patients and caregivers to have this discussion within the

primary care setting and that promotes clear and concise documentation is warranted (see

appendix E).

Interventions

The primary intervention was an email that was sent to patients via their healthcare email

account. The DNP candidate/author in collaboration with the IT committee and the palliative

care department of the institution constructed the email. Several drafts were proposed which

included graphics intended to market advance care planning. However, due to technical

constraints discovered just prior to distribution, no graphics were allowed in the email. The final

draft used for the project was approved by the IT and communication steering committees of the

institution. Email content included basic information regarding end-of-life-care-planning, a link

to prepareforyourcare.org, and information on how to schedule an appointment with your

primary care provider. PREPARE is an interactive web tool that provides simple end-of-life-

care-planning information with video examples of end-of-life discussions between individuals

and a healthcare provider or family member, information on creating an advance directive, and

more resources for advance care planning (see Appendix C).

PREPARE was developed by researchers from the University of California. The content

is derived from 13 focus groups of diverse, English and Spanish- speaking older patients and

surrogate decision makers with experience making serious medical decisions (Sudore et al.,

2014). Based in Social Cognitive Theory, PREPARE focuses on preparation for end-of-life

planning discussions with surrogate decision makers and clinicians (Sudore et al., 2014).

PREPARE utilizes a five-step process. These five steps are 1) choose a medical decision maker

and ask them to serve in that role; 2) decide what matters most in life and for medical care; 3)

decide on leeway for the surrogate decision maker; 4) communicate wishes with surrogates,

clinicians, and other family and friends; and 5) ask healthcare providers the right questions to

make informed medical decisions (Sudore et al., 2014). PREPARE is available in both English

and Spanish. A license to use PREPARE in this format was required and obtained by the DNP

student/project manager on behalf of the institution (see Appendix D).

The email was structured using the *power of 3* for patient education. The *power of 3*,

based on adult learning theory, allows patients to review the patient education material when

they deem themselves ready and at their own pace (Sanchez & Cooknell, 2017). This validated

tool was originally developed for post-operative care of open-heart surgery patients. The *Power

of 3* utilizes a mnemonic alliteration that pertains to a certain health condition (Sanchez &

Cooknell, 2017). The rationale behind the tool is that patients with low health literacy recall an

average of 2.5 words out of seven (McCarthy et al., 2012). This simplified approach is necessary

to gain patient awareness for end-of-life planning, as research indicates low health literacy and lack of formal education is a barrier to completion (Hong et al, 2018).

A secondary intervention was a twenty-minute education session for primary care clinicians working in the institution. The presentation given by the DNP student/project manager focused on end-of-life-care planning tools, resources, methods for productive discussions on advance care planning, and the DNP project.

GANTT. A GANTT chart was developed to provide a timeline for this project and can be viewed in Appendix F. The timeline begins with writing the prospectus, which was completed May 2019. The next major milestones are then listed with approximate dates when the tasks were to begin and end. These milestones included a thorough gap analysis, intervention development, toolkit development, implementation of the intervention, evaluation of the project with data analysis, project write-up, and final presentation. Each milestone for the DNP project was completed as proposed and on schedule.

SWOT Analysis. The SWOT analysis involves an examination of the strengths, weakness, opportunities, and threats related to a phenomenon from the perspective of both internal and external influences. See Appendix G for the SWOT analysis of this end-of-life-care-planning project.

There are several internal strengths and weaknesses pertaining to this project. The strengths include support from administration, available staff to sustain the project, very low cost to both initiate and sustain the project, and an existing technology infrastructure needed to implement the intervention. An external strength is the existing technology tool that has been proven effective in similar settings (Sudore et al., 2014) and an awareness in the healthcare

culture of this organization about the need for better staff and patient education for end-of-life-planning. Internal weaknesses are (a) advance health directives are not a current prime measure within this institution, and (b) this topic tends to be challenging for both patients and healthcare staff to address. External weaknesses include (a) cultural barriers to discussing end-of-life-care that can be more prevalent in underserved populations, and (b) lack of community awareness regarding end-of-life-planning (Sudore et al., 2014).

Opportunities and threats were also considered for the SWOT analysis. This project provided opportunities for implementing a low-cost program addressing this issue where such a program currently does not exist, an increase in revenue for billable advance care planning visits, and providing a platform that encourages end-of-life-care discussions with patients and primary care providers. Further, this intervention may serve as a model for other institutions serving underserved populations. An internal threat to the project is only being able to reach patients with an active healthcare email account. Another internal threat is ACP documentation is not a prime measure tracked by this institution and minimal resources may be available for implementation and ongoing support. Lastly, lack of patient and staff interest may also influence sustainability of the project.

Work breakdown structure. A work breakdown structure for an end-of-life-care-planning program was done using the tabular view (see Appendix H). Included are three levels of work going from broad to detailed information. Level one is the overall objective of the project, which was creating a technology-based end-of-life-planning program for an underserved and diverse patient population. Level two is broken down into five categories which include the following: initiation of pre-qualifying project requirements, planning, qualifying project (N749

course), project intervention, evaluation and closeout of the project. Each of these five categories are further broken down into tasks, deliverables, and milestones related to the project.

The first level two category, initiation-pre-qualifying project, had level three tasks that were required prior to enrollment in the qualifying project (N749 course). For the purposes of this project, the *DNP Student Responsibility Agreement, DNP Milestone Approval Form, and DNP Statement of Non-Research Determination Form* were submitted to the DNP student advisor prior to enrollment into N749.

The second level two category, planning, had several level three jobs. These were reviewing available technology tools; exploring options for dissemination of the technology tool and information; discussion of the project idea with the medical director, nurse manager, and chief information officer; researching target age for end-of-life planning; and obtaining the data report for pre-intervention statistics.

The third category, enrollment into qualifying project (N749 course), had level three tasks that were completion of licensing application to use prepareforyourcare.org; development of marketing plan; prospectus; manuscript; preparation and submission of manuscript to USF Scholarship Repository and possibly to a journal; and to complete a data report prior to the intervention.

Level four, project intervention, entailed two main tasks. These tasks were staff training on the intervention and dissemination of prepareforyourcare.org information to patients.

The final step (level five), evaluation and closeout of the project, involved obtaining post-intervention data, completing a follow-up survey for staff, overall project evaluation, manuscript, and submission of an article to an academic journal.

Project budget. The estimated total cost of the project was approximately $22,950. This is based on an average nurse practitioner hourly wage of 70 dollars per hour. The personal time hours were based on a three-credit course with one credit hour equal to 45 hours of work. Staff development time is allotted to the DNP student/project manager at her place of employment, and is two hours per week. An IT person was utilized to distribute the information. See Appendix N for a detailed budget.

Communication matrix. See Appendix O for a copy of the communication matrix. Most communication was initiated and directed by the DNP student/project manager. Project planning efforts were updated and communicated to the DNP advisor, chief of communications, and the director of palliative care at the healthcare institution. Status updates on plans of implementation and IT involvement were communicated to the provider staff during the monthly staff meetings that were done face-to-face and by phone conference. One month prior to project implementation, all clinic staff were informed during an all- provider staff meeting. The DNP advisor was updated monthly regarding project progress by way of Zoom sessions and email.

Cost/benefit analysis. The potential for revenue is significant with the possibility of more advance care planning engagement and avoidance of ER and ICU admissions along with decreases in ICU lengths of stay. As mentioned above, the total approximated cost to implement this project was $22,950. Reimbursement from Medicare for an ACP visit is approximately $86 dollars and $69.59 dollars from Medi-cal (CMS.gov, 2019). More revenue is possible from ACP billing codes, if there is an increase in ACP discussions among patients and their provider.

Research has shown that hospice use in the last year of life can reduce Medicare costs significantly. One study showed a cost savings of $2,309 per hospice user (just over $20,000)

enrolled 53 to 105 days prior to death. Non-hospice users had an approximate cost of just under

$25,000 for the same enrollment period (Coalition for Compassionate Care, 2012). This DNP

project has an approximate cost of $22,000. There is a cost benefit if this evidence-based

intervention promotes hospice utilization for just ten patients with an approximate cost savings

of $23,000, based on the research just mentioned. The intervention (approximately $22,000) is

also cost effective if it avoids one ICU admission for one patient, which is estimate to be $31,679

per stay (Chin-Yee, D'Egidio, Thavorn, Heyland, & Kyeremanteng, 2017) (see Appendix N).

Study of the Interventions. The gap analysis revealed the institution did not have

adequate resources or training for primary care providers to provide end-of-life-care planning.

Further, it was also found that patient education resources were scarce and under-utilized, and

advance care planning was not being measured. Baseline data was difficult to obtain, given ACP

was not prioritized by the institution. After identifying these gaps, it was decided to try to create

a project to improve advance care planning in this underserved and diverse population. At

inception, the project manager approached medical staff to gather information on feasible project

ideas. After discussions with the clinical nurse manager, clinic medical director, and director of

palliative care, it was determined that a patient education tool and staff training could improve

ACP in this institution.

Initially, group visits for patients interested in ACP were considered as an intervention by

the DNP student. However, the institution was not supportive of group visits due to financial

constraints and lack of resources. In fact, all group visits were discontinued during the planning

phase of this project. Therefore, a patient education tool was considered that could be easily

accessed by patients in a cost-effective way. After reviewing patient education tools within the

institution, the decision was made to research more culturally sensitive materials regarding ACP.

After reviewing several potential free products, PREPARE was chosen. The literature has

validated PREPARE in several studies including a randomized- controlled trial whose study

populations were also diverse and underserved.

Once the education tool was chosen, it was necessary to determine a cost-efficient means

for dissemination. The IT department was approached to inquire about utilizing the patient email

system for distribution of the tool. The project had to be presented to the communications

committee for approval. This was accomplished in February 2019. The licensing obtained for

PREPARE allowed for the email to include the link only. No other data could be obtained

regarding patient interaction with the tool.

Measures

ACP engagement measures. Measurement of effectiveness was assessed with pre- and

post-intervention data extrapolated from the EMR. A data report was requested from the IT

department once the intervention was complete and included percentages of ACP outcome

measures three months prior and three months post-implementation. ACP engagement included

(a) scanned ACP documents into the medical record, (b) use of ACP note types within primary

care, and (c) use of ACP ICD-10 codes. Data was obtained for all eleven ambulatory clinics

within the health system. At the time of project implementation, PREPARE had a validated ACP

engagement measurement tool. However, it was not feasible for use by this institution given lack

of staff and financial resources.

Pre and post-presentation questionnaire. A provider presentation was designed and

implemented to a small group of primary care providers that work in one ambulatory care clinic

within the organization. An author-developed Pre- and Post-Presentation Questionnaire

consisting of nine items was developed that utilized a Likert scale (ratings from 1 *strongly*

disagree to 5 *strongly agree* was given to determine if primary care providers agree that ACP

should happen in primary care and if they have adequate resources to do so. See Appendix I for a

copy of these questionnaires. Again, a validated tool to measure PCP confidence in doing ACP

and degree to which one agrees with ACP in the primary care setting did not exist at the time

project planning or implementation, so an author-developed tool was used for data collection.

Analysis

      Email data analysis. All email related data was obtained through the health system's

EMR by request from the IT department. Engagement data was collected three months prior to

the email distribution, August 24th, 2019 to November 23rd, 2019. The email was disseminated

on November 24th, 2019, and data was also collected November 24th to February 24th, or three

months after circulation of the PREPARE email. Reports were developed containing pre and post

percentages of ACP engagement. As mentioned above, ACP engagement included scanned ACP

documents into the medical record, use of ACP note types within primary care, and use of ACP

ICD-10 codes.

      Other email data included number of email clicks by week, from the date of distribution.

Four weeks of data regarding number of email clicks on the PREPARE link was collected from

the communications department of the health system.

      Patient education access and engagement in regards to traditional in-person patient

education sessions were also collected for the same week of email circulation. This data was

attained from an ambulatory clinic director working within the health system, and included

number of patient education appointments scheduled, number of missed appointments, and number of appointments attended.

Provider presentation data. An advance care planning presentation for primary care providers was conducted on September 19th, 2019 at one ambulatory clinic within the health system. Each provider was given a pre- and post- questionnaire which utilized a Likert scale. This data was then entered into an Excel spreadsheet where the means for each question response were calculated for both pre- and post-questionnaires. The standard deviation for each pre- and post-questionnaire response mean score was calculated within an Excel spreadsheet.

Ethical Considerations

Participant protection. There were multiple ethical issues to consider at the inception of this project. First, after a review of the project prospectus by the DNP Committee, the project was declared to be a change of practice and not research. See Appendix J for the Statement of Non-Research Determination. Second, the agency's administration had concerns regarding the end-of-life information being given to patients, without a provider being present. It was decided to present the project proposal to the Communication Committee for approval.

The Communication Committee was comprised of staff from various departments including medical records, registration, nursing, medicine, and IT. The committee also included a patient from the health system. When the project was proposed to the committee, there was a unanimous vote to move forward with the project because ACP was deemed to be an important topic that needs more attention. The Communication Committee further decided that the content of the email must include instructions on how to schedule an appointment with a primary care provider if the patient desired to do so.

The project participants included patients aged 50 and older with a health system email account and primary care providers from one ambulatory clinic site. Patients receiving the email were identified by the IT department and not the project manager. Data obtained by the DNP student/project manager, for the distributed email and the provider presentation, did not contain any type of participant identification. Email data was reported in percentages of ACP engagement per IT and did not include any patient record information. The provider presentation surveys were done anonymously, and the project manager did not have any participant identification information.

Jesuit values and ANA Ethical Standards. The intent of this project was to provide an efficient and effective method that enables patients to obtain knowledge on end-of-life-care planning, so that their values and wishes can be respected by the health system. The overall goal of ACP is that patients are provided care that is concordant with their values. This program was designed specifically for an underserved patient population, which is in-line with the Jesuit values of helping the less fortunate and contributing to a more humane community.

Advance care planning incorporates cura personalis, or care of the whole person. Every individual will face death, and unfortunately those from underserved and diverse populations are more often subjected to healthcare interventions that may be not be aligned with their values. By offering more culturally appropriate ACP information and resources, healthcare institutions are helping their underserved and diverse patients to have more autonomy at the end of their lives.

The American Nurses Association (2018) has provided a document that outlines the code of ethics for the nursing profession, entitled "Code of Ethics for Nurses with Interpretive

Statements." There are nine provisions and provision one specifically states "The nurse

practices with compassion and respect for the inherent dignity, worth, and unique attributes of

every person" (ANA.org, 2018, page 1). This provision offers five guidelines and the fourth

guideline is "The right to self-determination" (ANA.org, 2018). In their statement, they declare

a patient has the right to "accept, refuse, or terminate treatment without deceit, undue

influence, duress, coercion, or prejudice" (ANA.org, 2018, page 2). This project mirrors the

provision by enabling patients to make choices for their end-of-life care, and for this

information to be acknowledged and documented. As outlined in provision 6.1 from the ANA

code of ethics, the environment and moral virtue (ANA.org, 2018) the healthcare system has a

moral obligation to provide a safe environment for ACP and nurses can be a primary driver in

this effort. California nurse practitioners are increasingly at the frontline of primary and

geriatric care for diverse and underserved populations, making this topic ever more significant

for the entire healthcare system (Spetz & Muench, 2018).

Section IV: Results Demographics

As of November 2019, the number of patients enrolled in the institution's health plan age

50 and older was 23,347 (CCHS, 2019). The percentage of those with five or more chronic

illnesses was 45.74% which was a total of 10,680 patients (CCHS, 2019). Eighty-eight different

languages are spoken by patients enrolled in this health plan. A majority of them speak English

(>50%), Spanish (19.91%), or Tagalog (4.46%) (CCHS, 2019).

Digital use among the health system's population. According to a report published by

the health system, as of September 2018 more than 36,000 patients were enrolled in the medical

record email program, *my*cclink. Forty percent of patients seen in primary care from October

2017 through September 2018 had a *my*cclink account (CCHS, 2019). Also included in this

report were results from a survey utilized to obtain data regarding use of technology by this

patient population. Data received from the survey was based on a total of 501 respondents.

Accessibility of technology revealed that 82% of patients own a smartphone, 75% have an email

address, and 68% have used the internet to learn about health issues (CCHS, 2019). Fifty-five

percent of Spanish speaking patients have an email address compared to 85% of English-

speaking patients. Daily internet use was reported by 70% of respondents, and was more

prevalent among English-speakers at 65% versus Spanish-speakers at 44% (CCHS, 2019).

Internet access via a smartphone was reported by the majority (66%) of those surveyed, and

Spanish speakers age 50 to 59 were more likely to use their smartphone for the internet when

compared to English speakers, 69% versus 54%. Further, not knowing how to use technology

tools (computers, smartphones, and tablets) and cost of internet service were the top two reasons

for lack of internet use (CCHS, 2019).

Provider presentation

A provider presentation was conducted in September 2019 regarding: (a) advance care

planning in primary care, and (b) how this DNP project aims to improve it. The presentation was

done during a staff meeting at a primary care clinic within the health system. Material covered

included advance care planning in underserved populations and in primary care, information on

advance care planning resources for providers and patients, and the DNP project being

implemented at the institution. The ACP in Primary Care Questionnaire was given to each

provider attending the presentation, both pre- and post-presentation. The questionnaire utilized a

Likert scale for each question. Providers were asked to rate information on a scale of one to five,

with one meaning, *strongly agree*, two *disagree*, three *un-decided*, four *agree*, and five *strongly agree*.

Nine primary care providers attended the presentation and nine questionnaires were administered, but only six pre- and post-questionnaires were completely finished. Two questionnaires included responses to the pre-questionnaire questions only, and another questionnaire had one response to one pre-questionnaire question. Data from these three questionnaires was not included in the analysis. Data analysis of questionnaire results was done on the six completed ACP in Primary Care Questionnaire.

Overall, the presentation increased awareness of advance care planning practices and resources. Specifically, there was an increase in the belief that primary care providers are preferred by patients for ACP discussions with a pre-mean score of 2.5 and post-mean score of 4.33. However, there was slight decrease in the post-mean score for the question asking if ACP conversations should take place in primary care with a mean pre-education score of 4.17 and a mean post-education score of 4 (see Appendix K).

Email intervention data

On November 24, 2019 the advance care planning email was distributed to over 22,296 patients. It was targeted to patients 50 and older, who were seen within primary care in the past year and who have an active email account with the institution. As noted before, the health system has 23, 347 patients 50 and older enrolled in the health plan, indicating 95% of them have an active email account.

The actual number of those who both opened the email and clicked on the prepareforyourcare.org link was obtained. Eleven clicks were from testing the link one week

prior to distribution of the email to patients and were not used. During the week of distribution, there was a total of 543 clicks, the largest number of responses to the email. Week two had 149 clicks and 74 clicks during week three. Weeks four through eight had a total of 129 clicks. A total of 895 clicks were calculated, indicating an overall 4% response rate to the email. See Appendix L for a graph showing the distribution of email clicks per week.

During the week of November 24, 2019, there were a total of 71 patient education appointments scheduled for the entire 191,000 patients enrolled in the health plan. Thirty-four patients were seen with the remaining 37 patients missing their appointment. The technology tool had 543 clicks out of 22, 296 emails sent, for that same week. Therefore, patient education appointments reached 0.01% of the patient population for which appointments were available, while the email patient education reached 2.4% of those who received the email.

Pre-and post-intervention data

Advance care planning engagement was measured pre- and post-email distribution (see Appendix M). Again, ACP engagement is defined as scanned advance care documents, use of an ACP note type, and use of ACP ICD-10 codes. Data was reported in percentages per each clinic site for two time periods including August 24th through November 23, 2019 and November 24th through February 24th, 2019. The pre-email data was based on a higher number of patients than the post-email data. This drop in the number of patients enrolled that were over 50 is thought to be related to lack of plan renewals at the beginning of the year. Overall, there was a slight increase in the percentage of patients with advanced care scanned documents post intervention, 4.94% (n=14,347) and 5.01% (n=13,489) respectively. Use of an ACP note type and ACP ICD-

10 codes had a small decrease in the post intervention percentages. However, as mentioned the sample number changed from pre to post-intervention.

Section V: Discussion

Summary

  Key findings. The purpose of this project was use of a technology tool to progress end-of-life-planning for an underserved and diverse patient population. The AIM statement guiding this DNP project was: By December 2019 develop, implement, and evaluate an end-of-life-care planning technology project at a Federally Qualified Health Center in Northern California. A presentation on advance care planning and the DNP project, for primary care providers working within the institution, was completed. Overall, the aim of the DNP project was achieved with successful distribution of the technology tool to the defined patient population and completion of the provider presentation.

  In brief, an email containing information on advance care planning and a link to prepareforyourcare.org, a web-based tool for ACP, was disseminated to patients 50 and older who were registered for the medical record email system, *cc*link. Over 22,000 patients received the email on November 24, 2019. One month after dissemination, 4% of the project population had opened the email and clicked on the prepearforyourcare.org link.

  Pre-and post-intervention data regarding ACP documentation was obtained. ACP documentation, for the purposes of this project, was defined as a documented advance health directive, use of an advance care planning note type, and utilization of ACP ICD-10 codes. Three ambulatory clinics throughout the health system had an increase in ACP documentation post-intervention, while the remaining clinics saw stable or a slight decrease in documentation rates.

ACP documentation overall was nearly equal both pre- and post-intervention for primary care

and specialty clinics.

The number of patients who clicked on the prepareforyourcare.org link was a much

greater volume when compared to traditional patient education clinic appointments and actual

patients seen for those appointments. The data indicates a readiness of a subset of patients 50 and

older to utilize technology tools for patient education. It further signifies patient interest in end-

of-life-care planning for patients 50 and older who are part of this diverse and underserved

population.

Successful changes and future possibilities. As a result of this project, there is a greater

interest in advance care planning from administration. Advance care planning is now considered

a major entity of the social determinants of health by the health system. As such, since project

implementation, an EMR patient navigator for advance care planning is being examined and

prioritized as an ACP technology tool. Further, a grant has been awarded to improve palliative

care services in primary care within this institution. This grant opportunity is a direct result of

this project showing the importance of advance care planning in primary care for underserved

and diverse patient populations and the lack of resources for both patients and providers. The

grant implementation plan will assist with project expansion by optimizing technology and EMR

advance care planning tools, and educating primary care providers about generalist palliative

care and the available tools tailored to a primary care workflow.

Advanced Nursing Practice Implications. The American Nurses Association (2018)

has provided a document that outlines the code of ethics for the nursing profession, entitled *Code

of Ethics for Nurses with Interpretive Statements*. There are nine provisions and provision one

specifically states, "The nurse practices with compassion and respect for the inherent dignity, worth, and unique attributes of every person" (ANA.org, 2018, page 1). This provision offers five guidelines and the fourth guideline is "The right to self-determination" (ANA.org, 2018). The Code declares a patient has the right to "accept, refuse, or terminate treatment without deceit, undue influence, duress, coercion, or prejudice" (ANA.org, 2018, page 2). This project mirrors this provision in that it is enabling patients to make their choices regarding care be known and documented by the health system.

The healthcare system has a moral obligation to provide culturally appropriate advance care planning, and nurses can be a primary driver in this effort. Nurse practitioners are increasingly at the frontline of primary and geriatric care for diverse and underserved populations, making this topic ever more significant for the NP workforce. By optimizing ACP technology tools, advanced care planning can be better integrated into primary care. This in turn will increase opportunities for advance care planning with underserved and diverse populations.

Interpretation

Comparison and impact. The results of this intervention revealed multiple important findings. Just under 900 patients, or 4% of the project population, engaged with a patient education technology tool, indicating there is an interest from patients to use this method of patient education and in advance care planning. When compared to more traditional patient education modalities, specifically an in-office patient education appointment, the technology tool reached a significantly larger number of patients, while using fewer financial resources.

The literature regarding advance-planning interventions that target diverse and underserved populations overwhelmingly indicates that when a culturally appropriate ACP

intervention is utilized, there is an increase in ACP engagement. The email was written using the

power of 3 philosophy, a validated process in the literature, and that utilizes very simple terms

with three pieces of information. Numerous studies have validated PREPARE as an effective

tool for increasing ACP engagement in diverse and underserved populations (Sudore et al., 2014,

2017, 2018). Although there was not a significant change in ACP engagement, there appears to

be an interest in ACP in this patient population as evidenced by patients clicking on the email

link.

Observed versus anticipated outcomes. Project approval was granted February 2019,

but the email was not distributed until November 24, 2019. The original distribution date was

September or October 2019. However, due to other technology demands of the health system,

this project was delayed several times. The IT department did not have enough staff during the

fall 2019 time period due to EMR upgrade rollouts. The DNP student/project manager requested

the email be sent prior to January 2020, but was not notified of the distribution until one week

after the email had been sent to patients.

The email format itself went through many transformations. When the project was

proposed to the communications committee, the DNP student/project manager was informed that

graphics could be included in the body of the email. The initial draft was completed through a

collaboration with the palliative care physician lead, a social worker, and the DNP

student/project manager. When presented to the communication committee it was rejected

because the committee felt it was not patient friendly. Of note, there is a patient on the

committee who also agreed with the above statement. Therefore, the project manager

collaborated with an outside marketing firm to help devise a more visually appealing product that

abided by the *power of 3* patient education theory. However, due to technical constraints of the

EMR, graphics were not able to be included in the body of the email and this information was

discovered just prior to distribution. A link to the flier created by the graphic designer was all

that could be used. It was decided this would be too confusing to patients, and the decision was

made to only include text in the email.

Costs. Patient education appointments are offered at five out of 11 ambulatory clinics.

Each patient education appointment requires one hour of nursing time to complete. The

distribution of PREPARE via email required approximately two hours of work for a single IT

associate. As previously noted, during the week of the email distribution, 71 patient education

appointments were scheduled which required 71 hours of registered nursing time. The

technology tool reached over 22,000 patients and was utilized by 543 patients during the same

time frame, at a fraction of the cost.

Leadership of change. It is essential to note patient education appointments offer

services that a technology tool used in this capacity cannot. Technology tools of this manner are

not able to replace nursing intervention, but could be thought of as another modality of reaching

patients with education tools and resources. However, patients need to be given the opportunity

to follow up with a nurse educator and primary care provider to allow patient questions and for

assessment that the material was adequately understood. This too could be done with technology,

such as video conferencing or email chat. Nursing staff could potentially reach more patients and

provide education to other clinics that currently do not offer patient education on site. With

technology, a nurse educator could potentially offer services to multiple clinics versus one. This

would be a stream-lined use of nursing staff resources.

Assumptions. The DNP student/project manager made multiple assumptions when designing this project. First, it was assumed that patients utilizing the health services of this institution have an interest in ACP. A second assumption was the institution has adequate technical capabilities and support staff to accomplish a project of this nature. Thirdly, there was a notion that a large number of patients have access to email and the internet. Finally, a presumption was made that if the email was sent, patients would click on the link. This in turn would potentially increase ACP engagement for this institution.

Assumptions were also made about primary care providers and ACP. The DNP student/project manager assumed primary care providers would view ACP as a non-primary care responsibility, and patients prefer to have ACP discussions with non-primary care providers. Based on the questionnaire results from the provider presentation, these assumptions were correct with a pre-presentation mean score of 2.5 regarding the belief that patients prefer primary care providers for ACP discussions.

Findings, Inferences, and Implications. The conceptual framework guiding this project included Knowles's adult learning theory (Knowles, 1973), Parse's human becoming theory (Parse, 2010), and Chochinov's dignity-conserving care model (Chochinov, 2007). The results from the email intervention supported the conceptual framework. PREPARE allows for self-guided adult learning, and it was presented to an adult population where a number of patients showed an interest as evidenced by the number of email clicks. Further, this interest supports Parse's human becoming theory. When patients have a platform to voice their values as it pertains to end-of-life care, they recognize reverence from the health system caring for them. Chochinov (2007) has four major ideas within his framework which are attitude, behavior,

compassion, and dialogue which were all demonstrated in this project. The behavior exhibited by

patients receiving the email reveals a need for compassion and a desire for dialogue regarding

ACP.

The overall results of this project have led to an increased awareness of the importance

and necessity for ACP in this patient population. Now recognized as a priority, there is

administrative support to increase ACP resources and services within the institution. Further,

grant dollars have been awarded to specifically offer training on ACP for primary care providers

and to increase EMR tools for ACP in primary care. Other ACP patient resources and

opportunities are also being considered. Finally, ACP is seen as an integral part of the social

determinants of health model which is guiding primary care for many California FQHCs.

Healthcare systems, especially those serving underserved and vulnerable patient

populations have a responsibility to recognize the ACP challenges in these populations and offer

services to accommodate their specific end-of-life care needs. As the results of this project

indicate, providers recognize the importance of ACP, but it continues to be a challenging topic in

which to engage patients. The literature specifies that patients prefer to have these ACP

discussions with their primary care provider. As such, more resources and visit work flow tools

are needed to make end-of-life care planning more feasible. Further, nurses are in a prime

position to have these discussions with their patients and need more training and resources to be

equipped to prioritize and accomplish ACP. As the findings of this project and the literature

overall indicates, ACP continues to lack the attention it requires in many healthcare

organizations. Patients continue to receive care that may not be in line with their personal values.

The culture of ACP within healthcare continues to evolve and more staff training and resources are needed to continue to improve this process.

Limitations

Multiple limitations existed regarding this project. ACP can be a challenging topic to present and obtain patient engagement, especially in the underserved. It would have been optimal if the email could have allowed graphics to better present the topic and "market" ACP to this particular population. The timing of the email was also potentially sub-optimal. It was distributed November 24th, 2019, which was the week of the Thanksgiving holiday. This tends to be a particularly busy time of year, and end-of-life planning may not be prioritized. Further, it was not possible for the IT department to distinguish unique clicks of the email. It is probable some patients clicked on the link more than once, which also limits the accuracy of the data analysis.

Licensing had to be obtained to disseminate PREPARE in this format. The DNP student/project manager was granted a one-time student license that expired December 31, 2019. Any further licensing would cost the institution approximately $15,000, which is not currently being considered. This cost limits repetition to see if patient engagement improves with the technology tool. Another limitation was lack of follow up on patient perspectives of the email and technology tool. This also could not be accomplished due to lack of institutional resources.

Limitations on the data and analysis also existed. At time of implementation, a validated tool to measure provider knowledge and opinions on ACP did not exist. A tool had to be created by the DNP student/project manager. Further, the provider sample size was small and so it was not possible to determine the significance of findings.

PREPARE offers validated tools to measure ACP engagement, but these were not feasible for use in the institution. The tool requires significant staff for distribution and analysis which was not available at the time of implementation. The pre- and post-data analysis was also limited by a changing sample size from pre-implementation to post-implementation. The number of primary care patients 50 and older was less when compared to the post intervention sample. This number is constantly fluctuating as patients change insurance or have a lapse in coverage.

Another major limitation of this project was limited access to primary care providers for training. The institution has eleven ambulatory clinics throughout a large Northern California County. The project manager did not have enough resources to reach all eleven clinics to do ACP training and for this reason one clinic was selected. This significantly impacted provider training and therefore the ability to increase awareness of ACP in primary care providers.

Conclusions

There is a persistent lack of ACP in underserved and diverse patient populations. Caucasian groups continue to have higher rates of advance directive completion when compared to diverse groups (Bullock, 2011; Huang et al., 2016; Pecanac et al., 2014). Further, there is limited research on ACP engagement in underserved and diverse populations, with a restricted number of randomized- controlled trials on the topic. Although there is little research on ACP interventions in ethnically and racially diverse populations, the few published studies do demonstrate that evidence-based interventions can improve ACP engagement and documentation. More research on how to engage diverse and underserved patients in ACP is warranted for our increasingly diverse aging population.

Patients need assistance with ACP as they often are not aware of end-of-life-care

planning or do not understand how to navigate ACP. This is especially true for diverse and

underserved populations. There is ample opportunity for healthcare institutions to strategize

culturally sensitive ACP programs for the communities they serve. Compounding the lack of

ACP engagement in diverse populations is a lack of practitioner preparedness to have these

discussions and to guide culturally diverse patients through the ACP process. Although

PREPARE has been shown to significantly impact ACP engagement through a randomized-

controlled trial (Sudore et al., 2017) indicating it could be a viable option for communities and

institutions with diverse patient populations, it also requires significant financial resources.

The outcomes of this DNP project reflect the findings in the literature that more

healthcare staff education is needed, and underserved and diverse patient groups are difficult to

engage for end-of-life planning. As healthcare resources continue to be limited, ACP technology

tools should be considered as adjunct to traditional patient education modalities and integrated

into ambulatory workflows. Kelley, Wenger, and Sarkisian (2010) found that Latinos are

receiving more aggressive medical care even though research indicates they prefer less

aggressive treatment, and they are dying more often in the hospital, rather than at home or in

hospice when compared to non-Hispanic whites.

The status quo of ACP is not ethically sound care and there is a critical need for ACP

education for diverse and underserved patients and their healthcare providers. ACP engagement

tools tailored to diverse primary care populations are essential to successful end-of-life-care

discussions between patients, caregivers, and providers. It is imperative that more advance health

care planning templates within EMRs be made available; there is also need for better access to

multi-lingual tools, medical interpreters and other resources for both patients and providers, and

longer visit time to allow practitioners to engage these complex discussions. As the U.S.

population continues to age and becomes more diverse, end-of-life-care planning education will

become critically important for all stakeholders of ACP engagement.

Section VI: Other Information

There are no outside funding sources to report for the design, implementation, and

analysis of this DNP project.

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Section VIII: Appendices

Appendix A

Evidence Evaluation Table

Citation	Conceptual Framework	Design/ Method	Sample/ Setting	Variables Studied and Their Definitions	Measurement	Data Analysis	Findings	Appraisal: Worth to Practice
Bonner, G.J., Wang, E., Wilkie, D.J., Ferrans, C.E., Dancy, B., & Watkins, Y.J. (2014). Advance care treatment plan (ACT-Plan) for African American family caregivers: A pilot study. *Dementia(London), 13(1),* 1-17. doi: 10.1177/1471 30121244940 8	None stated	Pilot program: group-based education intervention. Two groups: ACT-Plan and attention control group. Subjects were not randomized	N=68, AA caregivers of relatives with dementia. Conducted in 5 adult day care centers in an urban setting.	Independent variable: ACT-Plan Dependent variable: knowledge about dementia, CPR, mechanical ventilation, tube feeing, and self-efficacy on decisions made.	Rate of AHD prior to respecting choices im-plementation 2005-2007	Descriptive statistics including means, frequencies, and standard deviations were utilized	ACT-Plan group: Increase in knowledge of dementia and self-efficacy; decrease in comfort with knowledge of CPR, MV, and TF; decrease in the decision to use CPR, MV, and TF.	**Strengths:** High attrition rate **Limitations:** Pilot study, subjects were not randomized **Critical Appraisal Tool & Rating:** John Hopkins nursing evidence-based practice research evidence appraisal tool: 2B
Huang, C.H.S., Crowther, M., Allen, R.S., DeCoster, J., Kim, G., Azuero, C.,	None stated	Mixed-method randomized controlled trial	N=30, African American, age 45 or older, no cognitive deficits	Dependent variables: Feasibility, knowledge, intention to complete an AD,	Feasibility-program satisfaction survey; knowledge- 12 item scale; intention- single	Quantitative analysis SPSS22.0. ANCOVAs intervention knowledge, comparison of	Feasibility- more than 80% reported TAP intervention helped "very much" Knowledge-significant increase	**Strengths:** RCT focused on an underserved, diverse group. **Limitations:** small sample size,

Ang, X., & Kvale, E. (2016). A pilot feasibility intervention to increase advance care planning among African Americans in the deep south. *Journal of Palliative Medicine, 19(2),* 164-173. doi: 10.1089/jpm.2015.0334				Preference for an AD form In-dependent variable: TAP intervention	item question; Preference- single item question	means for primary outcomes using paired sample t-tests	in intervention group Preference- both groups reported preference for adaptive AD form Intention- 100% increase	geographic specificity **Critical appraisal tool:** John Hopkins nursing evidence-based practice research evidence appraisal tool:1B
Lee, M. C., Hinderer, K. A., & Friedmann, E. (2015). Engaging Chinese American adults in advance care planning. *Journal of Gerontological Nursing,* 41(8), 17-21. doi: 10.3928/00989134-20150406-01	None stated.	Pilot program	N=72	Dependent Variable: ACP knowledge Independent variable: Culturally sensitive, 1-hour nurse-led seminar conducted in a Chinese community center	ACP knowledge scores were significantly increased immediately following the seminar (mean=7.11-9.20)	Used a p value of <0.01	ACP knowledge scores were significantly increased immediately following the seminar (mean=7.11-9.20)	**Strengths:** Large sample size **Limitation:** Pilot program. No control group, convenience sampling **Critical Appraisal tool:** John Hopkins nursing evidence-based practice research evidence appraisal tool:

Nedjat-Haiem, F.R., Carrion, I.V., Gonzalez, K., Quintana, A., Ell, K., O'Connell, M., Thompson, B., & Mishra, S.I. (2017). Implementing an advance care planning intervention in community settings with older Latinos: A feasibility study, *Journal of Palliative Care, 20*(9), 984-993. doi: 10.1089/jpm.2016.0504	None stated.	Prospective, pretest/post-test, two group, randomized, community-based pilot.	N=74, >50, living in Southern New Mexico, having one more chronic diseases, Hispanic/Latino. Subjects were excluded if there was any possibility of limited cognitive functioning	Independent variables: ACP-I plan and usual care. Dependent variables: Satisfaction and feasibility of ACP-I	Pre/post-test surveys, Qualitative interviews	Mixed quantitative and qualitative methods utilized. "measures of feasibility were calculated." Satisfaction was measured by "acceptance of and retention in the program." Qualitative interviews were reviewed for recurrent themes. .	ACP-I was deemed feasible and helpful.	**Strengths:** Randomization of subjects to intervention and usual care. Good sample size for this type of study. **Limitations:** Convenience sampling, no pre-ACP knowledge assessment. **Critical appraisal tool:** John Hopkins nursing evidence-based practice research evidence appraisal tool:1B
Pecanac, K.E., Repenshek, M.F., Tennenbaum, D., & Hammes, B.J. (2014). Respecting choices and advance directives in a diverse community.	None stated.	Retrospective chart review	N=732, decedents from 2005-2010, in 300 bed Midwestern metropolitan hospital.	Independent Variable: Respecting choices program Dependent Variable: Completion of AHD after respecting choices training	Rate of AHD prior to respecting choices im-plementation 2005-2007 rate of AHD after implementation of respecting choices 2008-2010.	Stata's TEFFECTS program was utilized to determine treatment effect of Respecting Choices	Significant increase in AHD in diverse groups after implement-tation of respecting choices 25.8%-38.4 no significant change for whites	**Strengths:** Retro-spective design **Limitations:** Selection bias, Other influences besides respecting choices **Critical Appraisal Tool & Rating:**

Journal of Palliative Medicine, 17(3), 282-287. doi: 10. 1089/jpm. *of Palliative Medicine, 17(3)*, 282-287. doi: 10. 1089/jpm.								John Hopkins nursing evidence-based practice research evidence appraisal tool: 2B
Song, M., Ward, S.E., Lin, F., Hamilton, J.B., Hanson, L.C., Hladik, G.A., & Fine, J.P. (2016). Racial differences in outcomes of an advance care planning intervention for dialysis patients and their surrogates. *Journal of Palliative Medicine, 19*(2), 134-142. doi: 10.1089/jpm. 2015.0232	None stated.	A secondary data analysis of an RCT examining an ACP intervention (SPIRIT) versus usual care.	N= 420 participants with 210 surrogate dyads recruited from 20 dialysis centers	Independent variable: SPIRIT ACP intervention Dependent variable: dyad congruence on goals of care, surrogate decision making confidence, composite of the two, patient decisional conflict, surrogate bereavement outcomes	Outcomes were compared for African Americans versus whites	Descriptive statistics were used to summarize participant characteristics, $x2$ and t were preformed to compare group difference within race and to compare African Americans with whites in baseline characteristics	SPIRIT had a significant impact on African Americans for dyad congruence, surrogate decision-making confidence, and the composite-post intervention, and reducing bereavement depressive symptoms. It did not have a significant effect on the above for whites.	**Strengths:** based on an RCT, large sample size **Limitations:** exploratory analytic approach, as the original study was not designed to assess effects of race on SPIRIT, original study was done in one specific region of the U.S. and may not be applicable to other areas **Critical Appraisal Tool & Rating:** John Hopkins nursing evidence-based practice research evidence appraisal tool: 1B

Sudore, R.L., Knight, S.J., McMahan, R.D., Feuz, M., Farrell, D., Miao, Y., & Barnes, D.E. (2014). A novel website to prepare diverse older adults for decision making and advance care planning: A pilot study. *Journal of Pain and Symptom Management, 47(4),* 674-686.	Social Cognitive Theory, Interpersonal Communication Competence Model, Behavior Change Theory	Pilot test of the PREPARE website for feasibility and ACP engagement	N=43, recruited from 3 low-income senior centers in San Francisco, English speaking only, 65% were non-white	Independent variable: PREPARE website Dependent variable: engagement in ACP	ACP engagement was measured with the ACP Engagement Survey.	Behavior Change Process Measures increased (Likert scores 3.1-3.7), significant decrease in precontemplation	Change from baseline to 1 week later (after exposure to PREPARE) were assessed with Wilcoxon signed rank sum test for continuous variables and McNemar's test for dichotomous variables	**Strengths:** PREPARE was rated as easy to use by diverse older adults **Limitations:** small sample, convenience sampling, tested in one region of the U.S., no control group **Critical Appraisal Tool & Rating:** John Hopkins nursing evidence-based practice research evidence appraisal tool: 2B
Sudore, R.L., Boscardin, J., Feuz, M.A., McMahan, R.D., Katen, M.T., & Barnes, D.E. (2017). Effect of the PREPARE website versus an easy-to-read advance directive on advance care	None stated- "previously published."	Single-blinded, parallel-group, randomized comparative Effectiveness Trial	N=414 recruited from VA Established in primary care as measured by 2 clinic visits in past year 2 chronic illnesses Exclusion criteria dementia, cognitive impairment, blindness, delirium, psychosis, active drug or ETOH abuse, plans of leaving town within 3 months, inability to answer	Independent variable: Easy to read AD and PREPARE Dependent variable: New ACP docu-mentation at 9 months	New ACP documentation in EMR at 9 months after study enrollment Secondary outcomes: Validated, patient-reported ACP engagement Survey at 1 week, 3 months, and 6 months	Participant characteristics Fisher exact tests Intention to treat analysis using SAS stat software Mixed-effects logistic and linear regression with fixed effects	ACP documentation Higher in PREPARE plus AD group with p value of .04.	**Strengths:** RCT **Limitations:** Only 9% were women PREPARE must be seen on computer which may limit use at home Implications: Importance of facilitator for ACP documentation, ACP documents

planning documentation and engagement among veterans. *JAMA, 177(8),* 1102-1109. doi: 10.1001/jamainternmed.2017.1607			informed consent teach-back questions within 3 attempts, no phone					written at 12th grade level are less effective than ongoing education by health care professional **Critical appraisal tool:** John Hopkins nursing evidence-based practice research evidence appraisal tool:1A
Sudore, R.L., Schillinger, D., Katen, M.T., Shi, Y., Boscardin, W.J., Osua, S., & Barnes, D.E. (2018). Engaging diverse English-and Spanish-speaking older adults in advance care planning. *JAMA Internal Medicine, 178(12),* 1616-1625. doi: 10.1001/jamai	None stated.	Randomized control trial	N=986 participants, limited health literacy, and 45.1% were Spanish speaking, recruited from 4 safety-net, primary care clinics in San Francisco	Independent variables: PREPARE plus and easy-to-read advance directive Dependent variables: New ACP documentation and ACP engagement	New ACP documentation in the medical record at 15 months, post-intervention. ACP Engagement Survey was utilized to measure ACP engagement of participants at 1 week, 3 months, 6 months, and 12 months	Documentation of ACP: mixed-effects logistic regression with fixed effects for time, group, and group-by-time interaction	ACP documentation was higher in the PREPARE group. An increase in behavior change and action scores in the PREPARE group for both English and Spanish speaking participants.	**Strengths:** RCT, large diverse sample size **Limitations:** Study conducted only in San Francisco, limiting generalizability. Participants could not be blinded, staff support could have also influenced ACP documentation. **Critical appraisal tool:** John Hopkins nursing evidence-based practice

nternmed.2018.4657								research evidence appraisal tool:1A
Sun, A., Bui, Q., Tsoh, J., Gildengorin, G., Chan, J., Cheng,J., Lai, K., Stephen, M., & Nguyen, T. (2017). Efficacy of a church-based, culturally tailored program to promote completion of advance directives among Asian Americans. *Journal of Immigrant and Minority Health, 19(2),* 381-391. doi: 10.1007/s10903-016-0365-7	Theory of Reasoned Action	Single group pilot study	N=174, self-identified as Chinese or Vietnamese, age 35 years or older.	Independent variable: two 2-hour group education sessions about advance directives. Session 1-endorsement of AD by a church leader, explanation of AD by a physician. Session 2-step-by-step instruction on completing an AD Dependent variable: AD-related knowledge, beliefs, attitudes, and intentions; AD completion, and conversation with a healthcare proxy	Surveys were conducted pre-intervention and post- intervention immediately after and at 3 months.	SAS version 9.3. descriptive statistics including means, standard deviations and percentages-both separately for Chinese and Vietnamese and total sample	Significant increase in AD-related knowledge, intentions, and supportive beliefs about AD. 71.8% AD completion and 25% had a proxy conversation	**Strengths:** Culturally targeted intervention for AD completion shown to be effective. Large sample size. **Limitations:** No control group, convenience sampling. **Critical appraisal tool:** John Hopkins nursing evidence-based practice research evidence appraisal tool: 3B

| Wilson, K.S., Kottke, T.E., & Schettle, S. (2014). Honoring choices Minnesota: Preliminary data from a community-wide advance care planning model. *Journal of American Geriatric Society, 62,* 2420-2425. doi: 10.1111/jgs.13136 | None stated. | Pilot project | 8 large health care systems in a major metropolitan area | Independent variable: Honoring Choices Minnesota

Dependent variable: ACP document-tation | Self-reported data from each institution regarding ACP documentation | None stated. | 27,000 individuals visited the website, the HCD form was downloaded 2200 times, two smallest healthcare systems had the highest rates of inpatient HCDs. | **Strengths:** Intervention was implemented in several health systems

Limitations: pilot study with no control group, self- reported data from institutions

Critical appraisal tool: John Hopkins nursing evidence-based practice research evidence appraisal tool: 3C |
| Zapata, C., Lum, H.D., Wistar, E., Horton, C., & Sudore, R.L. (2018). Feasibility of a video-based advance care planning website to facilitate groups visits among diverse adults from a safety-net health system. | None stated. | Feasibility pilot | N=22, greater than or equal to 50 years of age, two more chronic disease. Group visits (GV) conducted in two primary care clinics in Northern California | Independent variable: prepareforyourcare.org video presented in a GV setting

Dependent variable: ACP knowledge, surrogate designation, completed AD | Pre and post-multiple-choice questionnaire, ACP Engagement Survey | Intercooled Stata, version 13. Percentages or means were calculated and compared using Fisher's exact tests or t-tests. | Surrogate decision knowledge improved from 46% to 85%, surrogate designation increased 48% to 85%, AD completion 9% to 24%, significance for feasibility | **Strengths:** First study to only use a video for ACP education in a group setting- no provider facilitator.

Limitations: No control group, small sample size

Critical appraisal tool: John Hopkins nursing evidence-based practice |

Journal of Palliative Medicine, 21(6), 853-857. doi: 10.1089/jpm.2017.0476								research evidence appraisal tool: 3B

Appendix B

Letter of Approval

Sent: Friday, March 8, 2019 9:03 AM
To: Haley Kirkpatrick
Subject: Letter of support for Haley Kirkpatrick project

To whom it may concern,

This is a letter of support for Haley Kirkpatrick to implement her DNP Project at Contra Costa Health Services.

chair the committee that oversees our online patient poortal. The committee approved Haley's proposal to send messages to patients on the portal educating them about advanced-care planning at its Feb. 13 meeting.

Please let me know if you need more information. We're looking forward to working with Haley on her project.

Appendix C

PREPARE Website

Click the video above to learn more.

Appendix D

PREPARE License

WITNESSETH:

Whereas, The Regents is the proprietor of the content, including, without limitation, text, graphics and video, on the websites designated as www.prepareforyourcare.org and subdirectories thereof (collectively "PREPARE");
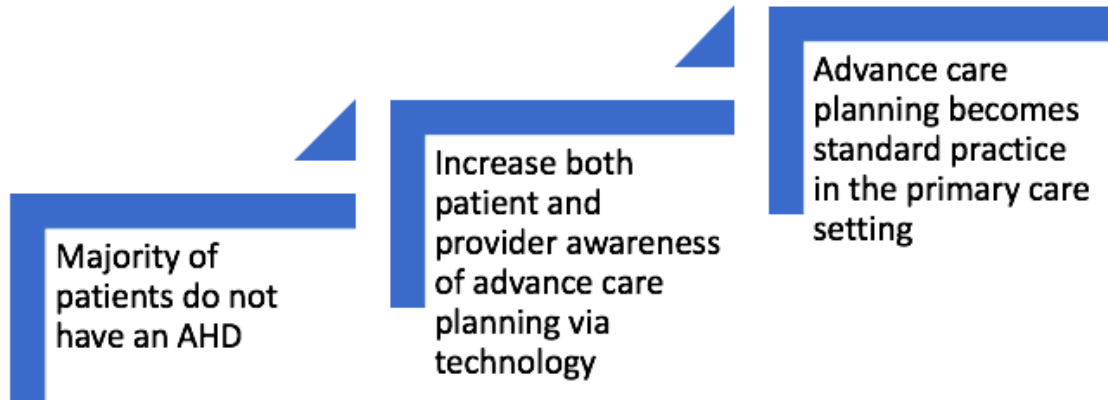
Whereas, Licensee desires to obtain from The Regents a license use PREPARE;

NOW, THEREFORE, in consideration of the mutual covenants, conditions, and terms hereinafter set forth, and for other good and valuable consideration, the parties hereby agree as follows:

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Appendix E

Gap Analysis

Majority of patients do not have an AHD

Increase both patient and provider awareness of advance care planning via technology

Advance care planning becomes standard practice in the primary care setting

Appendix F

GANTT Chart

Project Timeline for End-of-Life-Planning with a Technology Intervention
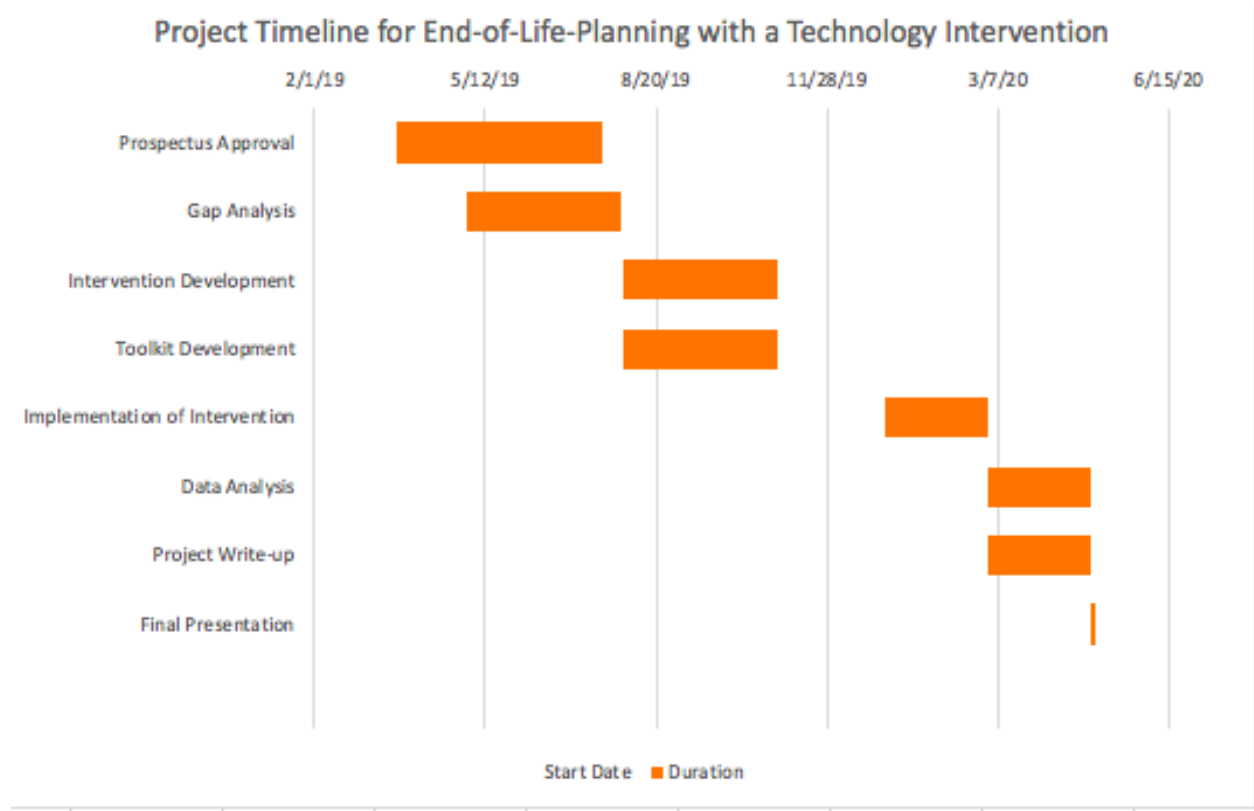
Appendix G

SWOT Analysis

Strengths

Technology Tool proven effective
Technology infrastructure already exists
Space and staff are available for group visits
Low cost intervention and program
Administration is supportive

Weaknesses

Not a prime measure
Cultural barriers to discussing death
Low interest from staff and patients

Opportunities

Low cost intervention
Increase in revenue from end-of-life-planning visits
Platform for patients to discuss with PCP
Improvement of end-of-life-planning in primary care
Pilot program at Antioch Health Center

Threats

CCC will not allow email platform
Limited resources due to not being a prime measure
Patient resistance due to cultural barriers
Staff resistance due to low priority to other health maintenance issues

Appendix H

Work Breakdown Structure

Level 1	Level 2	Level 3
1 End of Life Planning using a Technology Tool 2 Provider presentation on ACP in primary care	1.1 Initiation-Pre-Quals	1.1.1 Quals memo 1.1.2 IRB course and certificate 1.1.3 Milestone form 1.1.4 Deliverable: Statement of determination 1.1.5 Preliminary data meeting with chief information officer
	1.2 Planning	1.2.1 Review available technology tools for end-of-life-planning 1.2.2 Explore options for dissemination of information 1.2.3 Discuss project idea with the medical director and nurse manager 1.2.4 Discuss project with chief information officer of Contra Costa County (CCC) 1.2.5 Research target age for project 1.2.6 Deliverable: Data report for advance health care documentation at CCC in primary care, pre-intervention
	1.3 Quals N749	1.3.1 Completion of licensing application to use prepareforyourcare.org 1.3.2 Development of marketing plan for the prepare website within the Antioch Health Clinic (AHC) of CCC i.e. webpage 1.3.3 Prospectus 1.3.4 Manuscript 1.3.5 Development of presentation for Antioch primary care providers about prepareforyourcare.org
	1.4 Project Intervention	1.4.1 Staff education: information session and tool kit 1.4.2 Disseminate prepareforyourcare.org information to patients- via email
	1.5 Closeout	1.5.1 Data collection on number of patients accessing prepareforyourcare.org 1.5.2 Data advance health care planning documentation 1.5.3 Follow up survey of staff 1.5.4 Project evaluation 1.5.5 Final Manuscript 1.5.6 Submission for publication to academic journal

Appendix I

Pre/Post Presentation Questionnaire

PRE-TEST

1-Strongly disagree (SD), 2-Disagree (D), 3-Undecided (U), 4-Agree (A), 5-Strongly agree (SA)	▢	▢	
1) PCPS are the correct practitioners to discuss advance health directives with their patients.	1. 2. 3. 4. 5.		
2) I am comfortable talking to patients about advance health directives and end of life care.	1. 2. 3. 4. 5.		
3) I routinely ask about end of life care requests for patients 50 years and older.	1. 2. 3. 4. 5.		
4) I know the best practices for discussing advance health directives and POLST with underserved and ESL (English as second language) patient populations.	1. 2. 3. 4. 5.		
5) I know how to complete an advance health directive and POLST.	1. 2. 3. 4. 5.		
6) I am comfortable discussing end of life care with underserved and ESL patient populations.	1 2. 3. 4. 5.		
7) I recommend that patients complete an advanced health directive and POLST.	1 2. 3. 4. 5.		
8) I believe AHD conversations should happen in the primary care setting rather than in the hospital.	1 2. 3. 4. 5.		

Comments:

_____

_____   _____

POST-TEST

1-Strongly disagree (SD), 2-Disagree (D), 3-Undecided (U), 4-Agree (A), 5-Strongly agree (SA)		
1) PCPS are the correct practitioners to discuss advance health directives with their patients.	1. 2. 3. 4. 5.	
2) I am comfortable talking to patients about advance health directives and end of life care. _____	1. 3. 4. 5. 1.	
3) I routinely ask about end of life care requests for patients 55 years and older. _____	1. 2. 3. 4. 5.	
4) I know the best practices for discussing advance health directives and POLST with underserved and ESL (English as second language) patient populations _____	1. 2. 3. 4. 5.	
5) I know how to complete and advance health directive and POLST.	1. 2. 3. 4. 5.	
6) I am comfortable discussing end of life care with underserved and ESL patient populations.	1. 2. 3. 4. 5.	
7) I recommend that patients complete an advanced health directive and POLST.	1. 2. 3. 4. 5.	
8) I believe AHD conversations should happen in the primary care setting rather than in the hospital.	1 2. 3. 4. 5.	

Comments:

_____

_____

_____

Appendix J

State of Determination

DNP Statement of Non-Research Determination Form

Student Name:

HaleyKirkpatrick_____

Title of Project:

End-of-Life-Care Planning for an Underserved Population with the use of technology

Brief Description of Project:

The majority of individuals with a terminal illness or life-threatening condition do not have an advance directive. Seventy percent of people report they would prefer to die at home, but 76% of individuals actually die within an institution (Wilson, Kottke, & Schettle, 2014). Further, minorities are less likely to have an advance health directive (AHD) when compared to Caucasian groups (Pecanac, Repenshek, Tennenbaum, and Hammes, 2014). Contra Costa County(CCC) has over 640,000 health related visits per year and serves over 100,000 patients (ccchealth.org, 2018). The patient demographics include multiple ethnic and racial backgrounds with a low-income status. Currently, CCC does not have an end-of-life-care planning program. This project is intended to take place within a primary health clinic located in Antioch, California. The intervention includes making a web page regarding end-of-life-planning, that will be distributed to

patients through their cclink email account. Within this web document, there will be a

link directing patients to prepareforyourcare.org. This website includes an instructional

video and allows for patient participation in end-of-life-care-planning. This interactive

web tool provides information on a very basic level and is also available in Spanish. The

intervention will be supplemented with a group visit for end-of-life-care-planning; and

provider training on end-of-life-care-planning and prepareforyourcare.org.

A) Aim Statement:

By December 2019, develop, implement, and evaluate an end-of-life-care-planning web-

based project at the Antioch Health Clinic.

B) Description of Intervention:

Development of a webpage that will be forwarded to patients via their cclink/email

account through CCC. The webpage will provide basic information regarding end-of-

life-care-planning and ask the "five whys" of end-of-life-care. This webpage will then

provide a link to prepareforyourcare.org, which is an interactive web tool that

provides simple end-of-life-care information about planning. Included are videos of

individuals having this discussion with their healthcare provider and family. A group

visit will also be offered for patients wanting more information regarding end-of-life-

care.

C) How will this intervention change practice?

Currently, there is no program at CCC for end-of-life-care planning within the primary

care setting. The purpose of this project is to increase awareness among this patient

population and to facilitate end-of-life-care planning for patients and their primary

care providers.

D) Outcome measurements:

1) How many patients open the email to the webpage

2) How many patients attend the group visit

3) How many primary care visits at the Antioch Health Clinic bill for end-of-life-
   planning pre and post intervention.

To qualify as an Evidence-based Change in Practice Project, rather than a Research Project, the

criteria outlined in federal guidelines will be used:

(http://answers.hhs.gov/ohrp/categories/1569)

☐   This project meets the guidelines for an Evidence-based Change in Practice Project as

outlined in the Project Checklist (attached). Student may proceed with implementation.

☐This project involves research with human subjects and must be submitted for IRB approval

before project activity can commence.

Comments:

EVIDENCE-BASED CHANGE OF PRACTICE PROJECT CHECKLIST *

Instructions: Answer YES or NO to each of the following statements:

Project Title:	YES	NO
The aim of the project is to improve the process or delivery of care with established/ accepted standards, or to implement evidence-based change. There is no intention of using the data for research purposes.	x	
The specific aim is to improve performance on a specific service or program and **is a part of usual care**. ALL participants will receive standard of care.	x	
The project is **NOT** designed to follow a research design, e.g., hypothesis testing or group comparison, randomization, control groups, prospective comparison groups, cross-sectional, case control). The project does **NOT** follow a protocol that overrides clinical decision-making.	x	

The project involves implementation of established and tested quality standards and/or systematic monitoring, assessment or evaluation of the organization to ensure that existing quality standards are being met. The project does **NOT** develop paradigms or untested methods or new untested standards.	x	
The project involves implementation of care practices and interventions that are consensus-based or evidence-based. The project does **NOT** seek to test an intervention that is beyond current science and experience.	x	
The project is conducted by staff where the project will take place and involves staff who are working at an agency that has an agreement with USF SONHP.	x	
The project has **NO** funding from federal agencies or research-focused organizations and is not receiving funding for implementation research.	x	
The agency or clinical practice unit agrees that this is a project that will be implemented to improve the process or delivery of care, i.e., **not** a personal research project that is dependent upon the voluntary participation of colleagues, students and/ or patients.	x	
If there is an intent to, or possibility of publishing your work, you and supervising faculty and the agency oversight committee are comfortable with the following statement in your methods section: *"This project was undertaken as an Evidence-based change of practice project at X hospital or agency and as such was not formally supervised by the Institutional Review Board."*	x	

ANSWER KEY: If the answer to **ALL** of these items is yes, the project can be considered an

Evidence-based activity that does NOT meet the definition of research. **IRB review is not**

required. Keep a copy of this checklist in your files. If the answer to ANY of these questions is

NO, you must submit for IRB approval.

*Adapted with permission of Elizabeth L. Hohmann, MD, Director and Chair, Partners Human

Research Committee, Partners Health System, Boston, MA.

STUDENT NAME (Please print):

Haley Kirkpatrick_____

Signature of Student:

_____**DATE__11/21/18_____**

SUPERVISING FACULTY MEMBER (CHAIR) NAME (Please print):

_____

Signature of Supervising Faculty Member (Chair):

_____**DATE_____**

Appendix K

Questionnaire Results Data

Column1	Pre-survey means	Post-survey means
Question 1	2.5(0.69)	4.33(1.49)
Question 2	3.83(1.07	4(1)
Question 3	2.5(0.96)	4.17(0.69)
Question 4	2.17(0.90)	4(0.82)
Question 5	2.83(1.34)	4(1.41)
Question 6	2.67(0.94)	4.17(0.69)
Question 7	3.67(1.11)	4.17(1.07)
Question 8	4.17(0.69)	4(1.46)

Appendix L

Email Clicks Data Table

Number of Email Clicks By Week
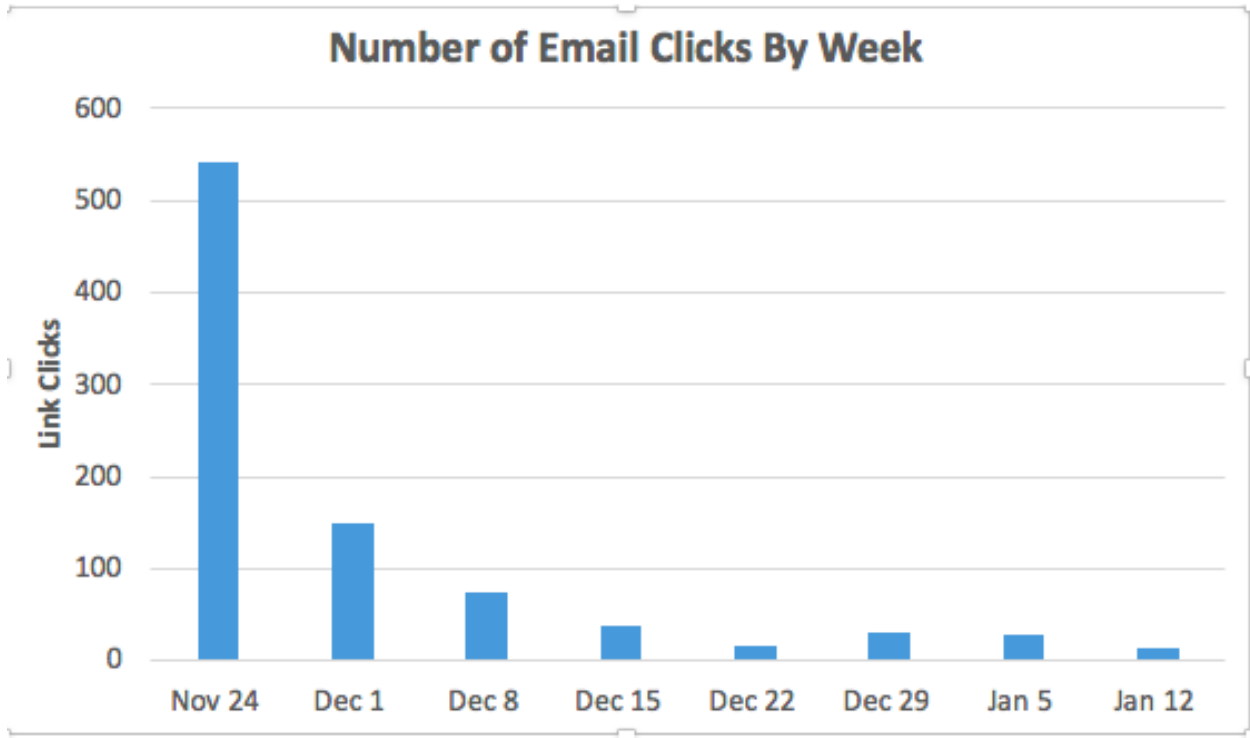
Appendix M

ACP Engagement Data Table

Percent of Patients Encountered with ACP Before and After Email Intervention
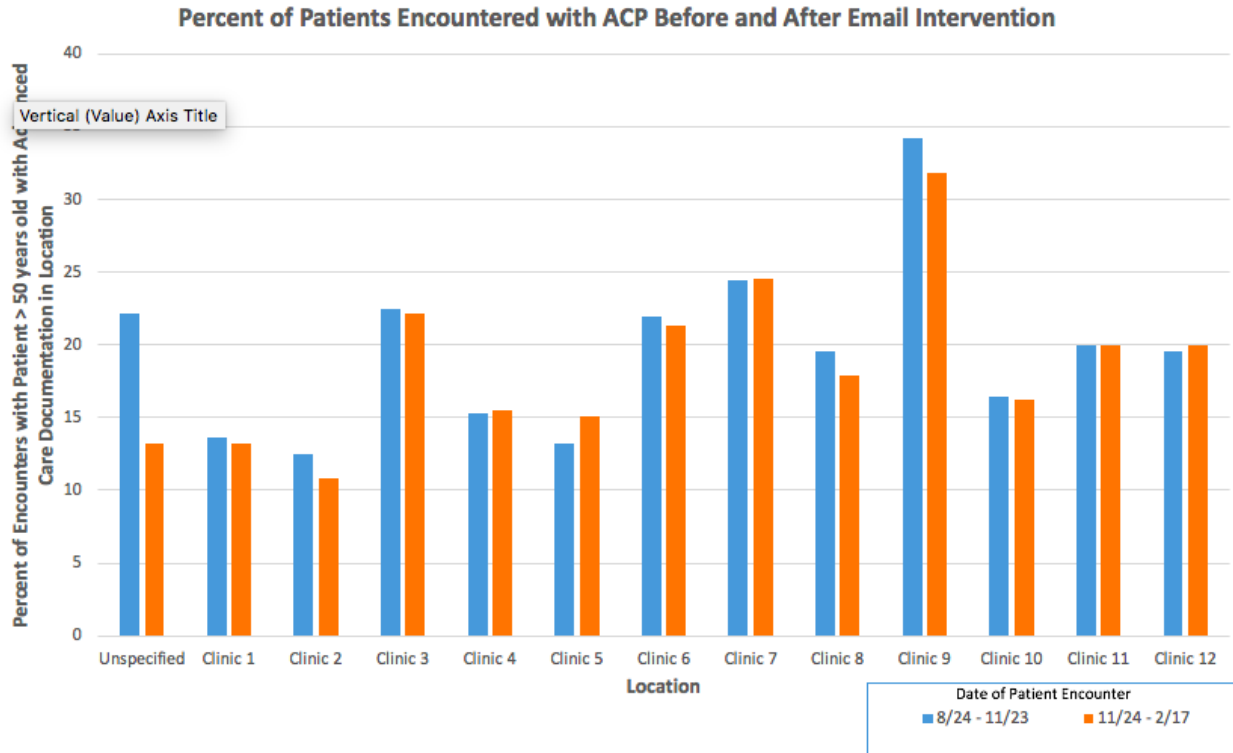
Appendix N

Project Budget

Project Costs	Amount
Personal time value cost	18,900
Staff development/Administration time	3,360
Vital Talk conference	450
1 FTE for provider ACP presentation	140
IT	100
Approximate total Costs	22,950
Potential revenue sources	
Medicare reimbursement for end-of-life-care primary care clinic visit	86
Medical reimbursement for end-of-life-care primary care clinic visit	70
Potential cost-avoidance examples	
ICU length of stay shortened x 1 patient	6100
ICU admission avoided x 1 patient	38,000

Appendix O

Responsibility/Communication Matrix

Event	Target Audience	When	How	Responsible
Project planning	DNP Advisor	Monthly and as needed	Zoom sessions and email	DNP student
Project planning	Antioch clinical nurse manager, Dr. Julie Freedman-director of Palliative care for CCC	Monthly and as needed	Face-to-face meetings and email	DNP student
Status updates on plans for group visits and IT involvement for project implementation	Primary care providers at Antioch Health Clinic	Monthly	Staff meetings	DNP student
Project Implementation	Antioch clinical nurse manager, Dr. Julie Freeman, Antioch staff, and DNP advisor	Once	Presented at all staff meeting, one month prior to implementation	DNP student
Data Analysis	Antioch clinical nurse manager, Dr. Julie Freeman, Antioch staff, and DNP advisor	once	Approximately four months after implementation of intervention	DNP student
Presentation	DNP advisor	Monthly	Zoom sessions and	DNP student