Advance Care Planning Engagement Among Devoted Polish Roman-Catholics

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Date: December 30, 2019
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Abstract

**Purpose:** This quality improvement project aimed to examine the efficacy of a nurse-driven, culturally tailored Advance Care Planning (ACP) education, in a church-based setting. ACP and Advance Directives (AD) are vital for the End-of-Life (EOL) decision-making. Despite this critical fact, in the US, ethnic minority groups are less likely to be engaged in the ACP process than White Americans. Being unprepared for death decreases EOL quality care, creates decision-making burden for family, exposes to undesirable medical treatments, and increases cost.

**Methodology:** The intervention utilized Five Wishes AD to increase ACP knowledge and promote behavior change related to AD adaption among Polish Roman-Catholics. The project used a convenience sample as a single group pre-post-post measure design for Polish participants \((n=40)\) from a Roman-Catholic church. Measured domains included demographic factors, individual EOL preferences, and ACP engagement.

**Results:** Although limited, the project findings revealed that a nurse-led culturally tailored ACP education program was beneficial to the Polish ethnic minority group. The success was evident by a marked increase in participant’s level of readiness to engage in the ACP process \((p<0.05)\) and 70% AD completion rate.

**Implication for Practice:** The results encourage nurse-driven faith-based ACP education as it offers an opportunity to meet the holistic needs of the ethnic group and allow for incorporating faith into nursing practice. Acknowledging the dynamic transformations in population demographics and current healthcare economics, nurses in all fields of practice have a key role to play in assisting the public to make informed EOL decisions prior to a crisis, regardless of an individual’s age, health status or religious views.

**Keywords:** advance care planning, advance directives, culturally tailored education
Advance Care Planning Among Devoted Polish Roman-Catholics

Death epitomizes the great certainty in life. Such a powerful statement frequently prowls in the back of human’s minds, exerting its influence on their subconscious level (Bindeman, 2017). Utterly ignorant of mortality, people think that death will come to other individuals, never to them. However, the act of birth begins the relentless journey toward demise and ultimately drives all that people commit to do, whether eating, sleeping, shaping meaningful relationships, or nurturing children. What matters to individual’s changes overtime and the promise of death illuminates these changes. The younger generations have a cognitive awareness that demise will eventually happen. However, this mindfulness does not trigger any emotional connection to their occurrence of mortality. The older populations realize their unavoidable mortality and demonstrate that coming to terms with one’s death involves reflection on its importance in one’s life. Hence, they consider more meaningful principles that provide life with its meaning.

Unfortunately, life-threatening illness and the chaotic demonstration of death, marked by the cessation of all bodily biological functions can occur abruptly despite an individual’s age. Being unprepared for death exposes the affected person to medical treatment he/she may or may not wish to receive. Additionally, events like this subject the family members to a situation where specific and immediate critical healthcare decisions must be made to care for the sick person. For example, sometimes the healthcare decisions include termination of care, especially in the case of the near-death scenario or prolonged comatose. In such circumstances discussing Advance Care Planning (ACP) prior to a crisis becomes a necessity to help ease out the burden of decision-making away from the family members. At the same time, ACP allows the opportunity to fulfill the wishes of the sick individual who is no longer capable of making healthcare decisions. Moreover, having an ACP discussion ingrained in a cultural approach further enhances
individual’s preferences, personal values, and beliefs.

The purpose of this project was to deliver a culturally tailored educational program to 18 years and older, non-English speaking, Polish Roman-Catholics, residing in Northern New Jersey. The provision of the culturally sensitive intervention is essential to meet the needs of the population whose culture markedly differs from the Americans. According to Liu et al. (2012), utilizing routine or standardized educational material such as pamphlets, brochures, videos, and internet resources does not meet the cultural needs of minority groups due to their cultural belief and language barrier. Therefore, understanding and integrating cultural preferences, values, and beliefs into ACP educational sessions increase the overall participant’s engagement in the process (Fang, Sixsmith, Sinclair & Horst, 2016; Lee, Hinderer & Friedmann, 2015) and improve the Advance Directive (AD) adoption rate among constituents (Sun et al., 2017).

**Background and Significance**

**Landmark Cases**

While some individuals welcome the life-prolonging medical interventions, others remain skeptical about being kept alive by noise-making technology in the complex care environment (Backes, Erdmann, & Büscher, 2015). The fight for life perspective resulted in prominent bitter court cases that relied on the United States (U.S.) legal system to resolve disputes between family members or treatment facilities and loved ones to detach the incapacitated individuals from life support measures and ultimately establish the AD concept (Aulisio, 2016).

The case of Terri Schiavo, a 41-year old female from Florida, who remained in a vegetative state for the 15 years after an unexpected series of medical events represents a classic example (Fins & Bernat, 2018). Terri’s husband accepted the diagnosis of her irreversible condition and based on the recalled statement made by his wife that she would never desire to be
maintained alive on a breathing apparatus, declined further life-prolonging measures on his wife’s behalf. However, her parents never acknowledged their daughter’s poor diagnosis and robustly resisted their son-in-law's decision as it was not aligned with their religious beliefs. Seven years of litigation resulted in a dual tragedy, Terri’s death and the dissemination of a family unit.

Similarly, the case of Nancy Beth Cruzan became a focal point of a passionate debate about when and how can the family decide to withhold nutrition or medical treatment from a family member. In 1983, Nancy was left in a vegetative state due to severe brain damage sustained after a car crash. In 1987, her parents presented a petition to the court to remove her feeding tube and allow her to die in a peaceful and dignified manner. After a stressful and difficult court battle, the U.S. Supreme Court authorized Nancy’s parents as her legal guardians and permitted the nourishment withdrawal (Aulisio, 2016). Interestingly, the U.S. Supreme Court expressed a preference for written AD over oral communication as it provides much greater evidence of one’s end-of-life (EOL) desires.

Perhaps the court case of Karen Ann Quinlan (Karen Ann Quinlan Hospice, 2019) was one of the landmark court debates on the true definition of life and the right to die. In 1975, Karen Ann, a New Jersey native, suddenly lapsed into a coma requiring full life support, including mechanical ventilation. Knowing that Karen Ann would not want to be kept alive by breathing machines, her parents found themselves wrestling with fundamental questions of life and death. The petition filed before the New Jersey Superior Court resulted in Karen Ann’s father being appointed as her legal guardian, giving him the ability to determine her medical treatment, including discontinuation of the extraordinary measures.
Health Policy and Advance Care Planning

The need for written documents allowing people to express their wishes regarding EOL care became very apparent after the development of the discussed court cases of the healthy, young individuals who were stricken by a sudden life-threatening illness and denied the possibility of a dignified death. In response to the case of Nancy Cruzan, the Patient Self-Determination Act (PSDA) was signed into law as a component of the Omnibus Budget Reconciliation Act. This was to ensure that U.S. residents are provided with information about AD and they have the full authority to accept or refuse extraordinary treatment modalities (Miller, 2017; Pope, 2013). The law ultimately engaged the public in autonomous decisions regarding EOL wishes. After multiple revisions the PSDA went into effect on December 1991 and consisted of three significant mandates including (a) Medicare and Medicaid funded facilities must ask all newly admitted patient if he/she has an AD, provide written information about one, assist with completion of an AD if desired, and provide education on AD; (b) all states must have laws related to AD with a clear definition of a surrogate, providing a way for citizens to make their medical treatment wishes known in advance, and (c) the Federal Department of Health and Human Services (FDHHS) to conduct a study on what the PSDA’s impact could be toward patients and to educate the public about AD (Miller, 2017).

The pressing need for ACP discussions has been also vigorously addressed in the Dying in America: Improving Quality of Life and Honoring Individual Preferences Near the End of Life report (Institute of Medicine [IOM], 1997). The report called for a thorough reform of the current healthcare system and strongly recommended improvement in the specific and important ACP areas to enhance the quality of EOL and increase public ability to choose their preference treatment.
According to the U.S. Department of Health and Human Services (USDHHS; 2017), approximately 2.6 million Americans passed away in 2014 and about 10% of them were Medicare beneficiaries. On average, EOL Medicare spending totaled $34,529 per recipient which translates as four times higher disbursement rate than the median expenditure per each elderly individual who did not expire in 2014 (Kaiser Family Foundation, 2016). Moreover, 50% of the entire Medicare spending for individuals who pass away in each year goes toward inpatient hospitalization, while nursing home facilities and hospice services account only for 20% of expenditure. A recent Kaiser Family Foundation (2015) survey concluded that 89% of Medicare beneficiaries want the healthcare providers to discuss EOL options with their patients and 81% of adults 65 and older mentioned that Medicare should finance dialogue between healthcare providers and their patients about EOL treatment choices.

**End of Life Healthcare Cost**

Aldridge and Kelley (2015) demonstrated in their study that the EOL population significantly drives the U.S. healthcare spending. Of the $1,627 billion expenditure in 2011, roughly $205 billion was entirely dedicated to the care of the persons in their last six months of life. In 2013, the U.S. had approximately 23% of EOL individuals dying in the inpatient setting, which is significantly lower than Canada, Germany, Belgium, and England. However, the extensive use of the healthcare resources such as Intensive Care Unit (ICU) was documented in 40.3% of Americans during their final weeks of life compared with less than 18% in the previously mentioned nations (Emanuel & Bekelman, 2016). A thorough breakdown of the EOL health care cost distribution at the national, state and county level is presented elsewhere in the paper.

As the intensity of care in the final months of life is trending up, the aggressive care at
the EOL detracts from, rather than improves, an individual’s quality of life (The Dartmouth Institute, 2016). The proportion of Medicare decedents enrolled in hospice care within three days of their deaths varies more than fourfold across U.S. territories with the current national average of 16.8%. However, the referrals are often done too late and do not reflect true individual preferences, which favor comfort measures over aggressive medical interventions (The Dartmouth Institute, 2016).

Moreover, the care that people receive at the EOL frequently does not fulfill their wishes and is often more aggressive and invasive than desired (Weathers et al., 2016). The engagement in independent healthcare decisions has a potential of decreasing healthcare cost as the pertinent individual may choose less aggressive and invasive treatment options (Brinkman-Stoppelenburg, Rietjens & Van Der Heide, 2014). The emerging study conducted by Bond et al. (2018) demonstrated an overall reduction in hospitalization costs ranging from $1,748 to $9,500 due to decrease in healthcare utilization without any significant increase in mortality (Lilly, Swami, Liu, Riker & Badawi, 2017; Liu, Dawod & Wonnapharhown, 2017).

**Role of Nurses in ACP**

The American Nurses Association (ANA; 2015) Code of Ethics expects healthcare professionals such as registered nurses to engage the public in ACP and advocate for their legal right to self-determination based on their cultural and spiritual beliefs, personal values, and preferences. Understanding the genesis of AD and choices available to the public can help practitioners purposefully and confidently address individual ACP needs (Miller, 2017). The nurses in all fields of practice, including doctoral prepared nurses, have a critical role to advocate for citizens’ autonomy and adoption of AD, guaranteeing quality care for all individuals, despite their age, health status, culture, language, or religious views.
If the nurses can engage in and communicate the importance and significance of ACP to their patients, in a pertinent and meaningful approach, the discussions would occur before the crisis and could result in higher AD adoption rates. However, the postponed ACP discussions usually happen too late when the individual is no longer able to express his/her preferences and have them acknowledged by their appointed decision maker. Therefore, the ACP community initiatives can ensure a meaningful increase in the ACP community awareness and engagement, and ultimately address the historically low rates of ACP.

Building effective community engagement to drive sound outcomes requires a strong process. To underpin this project, the Five Wishes AD, known for its unique personal, emotional and spiritual approach in this arena, will be used.

**Improving ACP Engagement**

Five Wishes is a comprehensive, easy-to-use, and individualized AD form which guides the ACP challenging discussion among individuals, their families, surrogates, healthcare professionals, and faith communities (Wenger, Fink, Asakura & Oman, 2012). Five Wishes, a legal document written in everyday language, changes the current way of discussing ACP. The AD allows individuals to express their EOL preferences, indicating what the individual wants his/her loved ones to know, expressing medical treatment preferences and choices for comfort, discussing important spiritual elements, and designating a surrogate decision-maker. According to Aging with Dignity (2019), Five Wishes effectiveness has been shown in various settings such as healthcare systems, skilled facilities, clinics and faith-based initiatives. Five Wishes (2019) states that the high applicability of the document is contributed to its customizable based on the needs of the served population or settings. The Five Wishes form is available in 28 languages, including Polish.
Problem Statement

Despite the support of federal law, CMS ACP reimbursement and a wide range of national and state ACP initiatives the rate of AD completion has not increased, nor have those programs addressed the needs of the non-English-speaking population (Pope, 2013). Therefore, this leaves the Polish community as a disadvantaged population when it comes to ACP options and opportunities.

Needs Assessment

National Level

The World Health Organization (WHO; 2015) reported that the number of people over age 65 will increase from an estimated 524 million in 2010 to almost two billion in 2050 in most developing countries. Similarly, the U.S. Census Bureau (2018) projected that by the year 2025 there will be approximately 78 million individuals older than 65 years. Even though federal law requires healthcare organizations and providers to offer AD forms to patients, most of them do not complete this requirement. As a result, only 32% of the U.S. population have AD; 92% of Americans acknowledge the importance of discussing the EOL wishes; and 95% say they would be willing to talk about their wishes (Institute for Healthcare Improvement [IHI], 2019; Rao, Anderson, Lin & Laux, 2014; Wenger et al., 2012). Some of the facts associated with limited ACP can be minutely evaluated using retrospective data.

For example, the Dartmouth Atlas Project (2019) demonstrated that roughly 32% of total Medicare expenditure in 2012 went towards doctors and hospital fees associated with recurrent EOL hospitalizations. Additionally, the same source further denoted that 74,286 of U.S. Medicare decedents, 65 or older, experienced at least 1.425 hospital admissions per 1,000 deaths during the last six months of life. Additionally, 23% spent an average of seven or more days in
the ICU and 28% die during hospitalization. Such an extensive utilization of acute EOL care resulted in $22,933 of national spending per decedent.

State Level

Currently, over one million New Jersey residents are 65 or older (USDHHS; 2016). Interestingly, only three in 10 adults in New Jersey are even aware of the AD existence, while 61% are comfortable discussing EOL issues (Yadav et al., 2017). Nearly 40% of New Jersey residents have never engaged in ACP and an overwhelming 60% lack a written document to validate EOL wishes (NJHCQI, 2018b). The profound lack of ACP discussion on the state level underscores the importance of innovative approaches to EOL care. It also helps to ensure that individuals and their families meaningfully engage in discussion of their EOL preferences before the crisis. Subsequently, the Dartmouth Atlas Project (2019) connects the lack of ACP with about 34,451 Medicare decedents of age 65 or older. The reported data reflect a spending link to approximately 1.4 hospital admissions per 1000 deaths among these individuals during their last six months of life. This includes an average of 12 days of inpatient stay, 5.486 days of ICU care and a 25% rate of hospital death incidence. Ultimately, such a high consumption of acute EOL care resulted in $20,419 state expenditure per decedent.

County Level

Approximately 10% of New Jersey’s population over the age of 65 resides in the Passaic County township, New Jersey (Data USA, 2017). Interestingly, the U.S. Census Bureau (2018) estimates that 18% of Polish immigrants in the U.S. are currently 65 or older and 20.2% of those individuals reside in New Jersey. Although, there is no statistical data available regarding Polish population of 65 or older residing in Clifton, New Jersey, it is known that currently 8.9% of town’s population is Polish (Data USA, 2017). Unfortunately, current published data do not
differentiate ACP completion rates per county, including non-English speaking Roman-Catholics.

Though there exists a lack of evidence to support the management of ACP among Passaic residents, the Dartmouth Atlas Project Report (2019) links the absence of ACP discussions to one and a half hospital visits among 1,632 of the county’s Medicare decedents age 65 or older, within their last six months of life. Each inpatient admission resulted in a length of stay of 12 days, including five days of ICU care and a 28.5% rate of deaths occurrence. Such significant findings are not congruent with the conclusions of the Institute for Alternative Futures report (2012) that most individuals prefer a conservative EOL care and desire to die at home. Furthermore, the use of inpatient healthcare resources equated in $23,640 spending per decedent (Dartmouth Atlas Project, 2019).

**Barriers Associated with Low ACP Rates**

The low ACP participation rate is mainly attributed to a lack of awareness of ACP, deficiencies in understanding the purpose of the AD form, culture, and religion (Hutchison, Raffin-Bouchal, Syme, Biondo & Simon, 2017). Also, low healthcare literacy may hinder understanding of the AD document (Miller, 2017), as well as the personal assumption that EOL wishes are known to family members (Miller, 2017; Rao et al., 2014). Most importantly, families often feel discomfort, sadness, and emotional distress while discussing EOL synopsis with the healthcare provider (Johnson, Butow, Kerridge, Bell, Tattersall, 2017) and healthcare providers often feel unprepared (Chan et al., 2016; Hutchison et al., 2017) to discuss such an emotional topic with the patient and his/her family. According to Centers for Disease Control and Prevention (CDC; 2017), understanding and respecting cultural differences and educating different cultural backgrounds may present a clear direction to their EOL care, increase their
engagement in ACP process and normalize these difficult conversations.

**Cultural Impact on ACP and AD**

Minority groups presently include one-third of the U.S. population with about 65% of the Americans identifying themselves as White, 13% Black, 13% Hispanics, 4.5% Asian-Pacific Islander, 1.5% American-Indian/Alaskan native and 2.5% Bi-ethnic (U.S. Census Bureau, 2017). The current U.S. healthcare model, which tenets autonomy in medical decision-making, cannot be effortlessly applied to members of some ethnic minorities (Zolkehli, 2017). For example, the legal documents such as AD, are specific examples of strategies to extend self-governance in circumstances in which individuals are no longer speak for themselves. However, many non-Western cultures, especially those that emphasize beneficence over autonomy, perceive the documents as isolating rather than empowering (Carr, 2012; Zolkehli, 2017). These cultures believe that communities and relatives, not individuals alone, are affected by severe illness and death, and should accompany crucial medical decisions. Moreover, Carr (2012) and Pope (2013) suggest that due to specific cultural factors, the ethnic minorities exhibit greater variability in the EOL preferences, response to healing, suffering, and medical-decision making process.

Huang, Neuhaus, Chiong (2016) and Hong, Yi, Johnson, Adamek (2018) discuss essential cultural motives responsible for the ACP hesitance and low AD completion rates among minority communities. These include (a) discussions of death may be viewed as impolite and disrespectful to the principle that God determines individual faith; (b) open ACP discussions may provoke unnecessary depression or anxiety; (c) direct disclosure of EOL wishes may eliminate hope; (d) speaking about conditions, illness or death plans make death real due to the power of spoken words, and (e) survival alone may be an essential validation of spiritual faithfulness. Undoubtedly, the above cultural and ethnic drives must be considered while
discussing ACP among various minority groups.

**ACP Discussions Among Roman-Catholics**

In order to support the ACP initiative among Roman-Catholics residing in Northern New Jersey, assessing its cultural needs is paramount. Nevertheless, discussing ACP in this community can be challenging. Although there are no specific taboos around the concept of death, many Poles may hesitate to voice their personal experiences associated with death and chronic illness. Because such discussions are associated with death and dying, they may also elicit strong negative feelings such as sadness, depression or crying (Hutchison et al., 2017; Johnson, Butow, Kerridge, Tattersall, 2018). While delivering ACP education, great consideration must be given to appropriately tailored information to respectfully address the psychosocial factors of the participating individual.

Undoubtedly, improving ACP documentation rates and encouraging the spread of the conversation throughout our culture, can result in enhanced quality of life for individuals who suffer from chronic or terminal illnesses. In consideration of conducting a community-based project a SWOT analysis was conducted.

**Strengths**

Polish residents of Clifton, New Jersey have a culture with values and a deep sense of belonging in a family, to a church, and to various organizations. Such variables present the significant strengths of the community and are the critical avenues assisting in ACP discussions as well as willingness to complete the AD. According to Sun et al. (2017) the participants adopt AD when bounded by identified support systems such as family or friends, within their adopted social system such as faith-based organization or community center, and through endorsement by the church leader.
Weaknesses

Currently, Clifton township lacks sufficient resources to match the community’s ACP desire to better meet the needs of the residents and their families. Additionally, Polish residents experience a profound language and health literacy barrier, which greatly prevent them from the AD adoption (Culturally Responsive Palliative Care [CRPC], 2014). According to Hoover et al. (2015), to address the racial and ethnic disparities in U.S. communities, attending to language barriers should be readily achievable as it does not require much effort but results in targeting a well-known source of disparities among minority populations.

Unfortunately, Passaic County also has a limited number of healthcare professionals who speak Polish and are willing to participate in community outreach. Although these professionals understand the need for ACP conversations and view them as necessary, they also feel unprepared to initiate such important discussions resulting in their discomfort when discussing EOL issues (Chan et al., 2016). Additionally, Sharp, Malyon, Barclay and Sharp (2018) vigorously demonstrate in their study that minority healthcare providers are concerned about raising unrealistic expectations such as difficulty ensuring that the individual wishes will be respected.

Opportunities

Federal agencies such as Center for Medicare and Medicaid Services (CMS) and numerous organizations, and foundations are engaged in the opportunities to strengthen the understanding and acceptance of ACP by healthcare professionals, patients, seriously ill individuals, people at the EOL, and their families. Prompted by the recommendations of IOM, known now as the National Academy of Medicine, Division of Health and Medicine, Medicare established financial incentives for healthcare providers to conduct widespread effort to educate
the constituents on the advantages of the ACP and ultimately the ability of the citizens to decide their own direction of EOL treatment (The Commonwealth Fund, 2015). The establishment of such regulatory action marked a crucial step towards increasing the number of ACP conversations and encouraging doctors and Medicare beneficiaries to discuss the challenges associated with the ACP process (CMS, 2018).

Additionally, the Conversation of Your Life (COYL) community-driven program, created by NJHCQI, further focuses on the improvement and increase of EOL awareness and care planning among New Jersey residents from a community perspective (NJHCQI, 2018a). After a successful 2015 pilot in the townships of Gloucester, Tenafly and Princeton, the COYL program expanded into Bergen, Camden and Mercer, Burlington, Monmouth, Middlesex, and Somerset Counties.

Undoubtedly, the Polish community would benefit from the ACP initiatives such as COYL campaign or local focus groups. Unfortunately, the COYL campaign has not yet reached Passaic County and it is tentatively scheduled to be implemented only in the Fall of 2019 (NJHQI, 2018b). Taking into consideration a growing trend toward more personalized health care services, the healthcare providers are in a crucial position to support the community in focusing on providing more effective and efficient ACP services. According to NJHCQI (2018b), the active engagement of community healthcare professionals ensures that expert guidance is continuously available and that resources are well appropriated in support of vulnerable communities. The above findings provide a perfect opportunity for the trained minority healthcare providers, to assume a key role in educating residents and their families about AD as the cornerstone to not only EOL care but to any aspect of the care continuum.
Threats

The recent establishment of the COYL campaign in Bergen County may potentially possesses a threat to the success of this project as the Polish community in Passaic may develop a misconception about the ACP concept. However, the COYL initiative does not provide a culturally tailored approach. Therefore, its threat level is low.

The lack of readily available ACP process puts the Polish community at risk for receiving EOL care that may not be wanted or go against their values and wishes. Weathers et al. (2016) demonstrate that such a disparity results in lower EOL quality care, increased family distress, and elevated healthcare cost.

Clinical Question

The research question guided this quality improvement project was as follows “How does a culturally tailored ACP education session impact awareness and completion of AD in devoted, non-English speaking Polish Roman-Catholics?”

Objectives and Aims

The goal of this quality improvement project is to increase ACP engagement and improve AD completion amongst devoted, non-English speaking Polish Roman-Catholics. The above aims were achieved through three specific objectives.

- Provision of two, 90 minute, culturally tailored ACP education sessions via utilization of multimodal approach. Strategies included a power point presentation, video screening, introduction to Five Wishes form, and discussion focused on personal EOL values and preferences.

- Evaluation of the participants’ level of ACP readiness to engage in the ACP process through the four-item Advance Care Planning Engagement Survey.
(ACPES) administered immediately before, after and two weeks post intervention

- Determination of the number of participants that adapted the ADs during the second ACP session. This was measured by comparing the number of completed Five Wishes forms to the actual number of attendees present at the session. While determining the adoption of ADs among this population, the socio-demographic factors including age, sex, possession of children, education, marital status, religiosity defined as the number at the occurrence of church service attendance (e.g. daily, weekly, bi-weekly, monthly), and length of U.S stay, were taken into consideration.

**Literature Review**

In order to find supporting evidence of ACP culturally tailored education and its effectiveness in the AD adoption process, a comprehensive evidence-based literature search was performed using four electronic databases such as CINAHL, PubMed, Medline, and Google Scholar. The key search terms included *advance care planning, advance directives, culturally tailored education, ACP and Polish Americans, Five Wishes, advance care planning AND Five Wishes*, and *end-of-life care*. The inclusion criteria for this search included meta-analysis, systematic reviews, randomized controlled trials, correlational and retrospective studies, and peer-reviewed articles within the past seven years written in English and Polish languages. The initial search yielded 98 articles; however, only 35 studies fit the inclusion criteria for analysis. Twenty articles were retained for appraisal using the John Hopkins Research Appraisal Tool for research and non-research sources and included in the evidence-based tables (see Appendix A).
ACP Discussions Among Polish Roman-Catholics

While there are no taboos associated with the concept of death, discussing ACP among Polish Roman-Catholic community can be challenging. Poles value autonomy in medical decision making but hesitate to converse about their personal experiences associated with death, chronic illness or EOL preferences (CRPC, 2014). Such sensitive dialogs often elicit strong feelings such as sadness, helplessness, depression and crying (Hutchison et al., 2017; Johnson et al., 2017; Schrijvers & Cherny, 2014). Additionally, the low completion rates of AD among ethnically diverse individuals, including Polish immigrants, suggest that there are significant reasons that may impact the decision not to adapt the AD. Carr (2012) and Hutchison et al. (2017) state that the constituents’ ACP educational experience and concept awareness greatly depend on independent psychosocial variables such as personal values, beliefs, community, culture and religion. Congruently, Ko & Berkman (2012) and Kwak, Ko & Kramer (2014) imply that the ACP engagement process may be also affected by low EOL healthcare literacy level, language barrier and family support.

Factors Influencing ACP Awareness and Engagement

**Personal values and beliefs.** Individuals differ in terms of what makes life worth living and what is important to them at the EOL. Numerous studies imply that although death is viewed as inevitable, people are reluctant to discuss and plan for it (Carr, 2012; Dobbs, Park, Jang & Meng, 2015). Moreover, people exhibit both positive and negative attitudes toward ACP and EOL care. For example, Huang et al. (2016) noted that Black-Americans find ACP discussions critical however, an essential life value rooted in a validation of spiritual faithfulness prompts them to prolong life, even in a case of severe illness. As a consequence, they are more likely than White-Americans to favor aggressive EOL treatments (Portanova, Ailshire, Perez, Rahman,
Enguidanos, 2017). Likewise, Korean-Americans value life as an essential virtue and recognize the AD practicality but avoid ACP discussions as they may result in death (Ko & Berkman, 2012; Sun et al., 2017). Intriguingly, the same group desires a hospital death due to a common perception that it is less burdensome to the family than a peaceful death at home (Ko & Berkman, 2012). Similarly, Roman-Catholics believe that life must be protected, respected, valued, and used for the glory of God till the last breath (United States Conference of Catholic Bishops [USCCB], 2018). Consequently, they do not feel obligated to avoid or undergo procedures that preserve life. It is crucial to recognize that the views and attitudes of older Polish immigrants may have been preserved despite the changes of practices in Poland or attitudes of the younger generation (CRPC, 2014). As these values and perspectives may not apply to all Polish speaking members of the community, it is imperative not to make any generalization or presumptions about community member’s beliefs and principles.

**Family influence.** A family is paramount to Polish Roman-Catholics, and it is challenging to overstate the implication of family presence in the ACP process. The concept of the family participation in the EOL care is robustly endorsed in the literature (Carr, 2012; Hong et al., 2018; Ko, Roh, Higgins, 2013; Kwak et al., 2014). For instance, Van Scoy, Howrylak, Nguyen, Chen, Sherman (2014) provided substantial evidence that a strong family structure significantly impacts possession of AD. The study participants who were asked by a family member to complete AD were 68.6 times more likely to adapt the document compare to 10.8% times in those lacking family support. Similarly, 21.9% of older Korean Americans were able to engage their families in the ACP process and discussed the EOL preferences with their spouse and children (Ko et al., 2013). Indisputably, both studies suggest the necessity of family-targeted ACP educational programs for ethnic minorities.
**Death and dying.** Though minority group members agree to reveal their EOL preferences to their loved ones, they also discourse how challenging it is to have such conversations. Carr (2012) pointed out that White-Americans are almost three times as likely as African-Americans or Hispanics to discuss their treatment preferences with their significant others. This finding is congruent with their decision-making autonomy and self-determination tenets (Zolkfli, 2017). The African-Americans and European-Americans described the EOL family discussions as emotional processes which ultimately force the family members to fully accept the participant’s mortality (Egbert, Child, Lin, Savery & Bosley, 2017). Moreover, the family members often experience overwhelming tension, anxiety, and apprehensions about what and how to conduct such delicate and complex dialogues (Keeley and Generous, 2017). As anticipated, Ko and Berkman (2012) showed that Korean-Americans have difficulty initiating EOL family conversations due to their children’s resistance.

Another study conducted by Carr (2012) discovered that Hispanic and Asian-Americans were more likely than Caucasians to openly admit that they were not sure how to initiate the discussion. Also, Fisher, Sauaia, Min and Kutner (2012) disclosed that even though 45% of the hospitalized Latin-Americans reported having the ACP conversations with their families, only 39% had a durable power of attorney and only 27% essentially adapted AD. The study provided strong evidence that the existing ACP federal mandates are unsuccessful and ineffective. Furthermore, even if the ACP education is provided on each hospital admission, it is not fully understood by the patients (Fisher et al., 2012).

**Health literacy and language.** Evidence suggests that profound language and health literacy are responsible for disengagement in ACP process among ethnic minorities (Carr, 2011; Howard et al., 2018; Ladin, Buttaforro, Hahn, Koch-Weser, & Weiner, 2018). A cross-sectional
study by Ng and Chong (2013) disclosed that even the trained ACP facilitators, including nurses, doctors, social workers, and case managers, had difficulty to meaningfully engage their participants in the ACP process. Profound 50% of individuals lacked the fundamental understanding of specific ACP terminology, and 48% owned their inability to comprehend the provided ACP information to the language barrier. Likewise, Fisher et al. (2012) confirmed that the same barriers prevented Latino hospitalized patients from AD adaption and resulted in only 29% AD completion rate compared with the rate of 54% in Caucasians. Moreover, the inability to understand EOL information prompted Latino participants to express preferences for more specific life-prolonging measures. Another valuable study conducted by Ladin et al. (2018) disclosed that low health literacy rate among elderly dialysis patients, including frequent misunderstanding of EOL terminology, produced a profound reluctance to ACP engagement process and resulted in only 13% EOL discussion rate.

The above research provided convincing evidence that in order to help spreading advocacy for and practice of ACP, careful consideration for devoted ACP facilitators is needed for successful implementation of ACP (Fisher et al., 2012; Ladin et al., 2018; Ng & Chong, 2013).

**Acculturation.** The level of acculturation within different minority groups is vital to the ACP awareness and AD adaption. Various studies found that acculturation is a predictor of AD completion (Dobbs et al., 2015; Gao, Sun, Ko, Kwak, & Shen, 2015; Wright et al., 2013). The analysis of the study conducted by Wright et al. (2013) showed that greater acculturation among White-Americans is highly associated with increased ACP awareness and EOL preferences (AOR = 0.68, 95% CI:0.49–0.99). Likewise, the cross-sectional study of Korean Americans showed that health insurance ownership, female gender, married status, and higher education are
considerably correlated with the improved AD awareness and completion (Dobbs et al., 2015). Such association was determined by the Spearman correlation coefficient of 0.53 and $p < 0.001$. Additionally, Gao et al. (2015) proved that willingness to forgo care, preference for EOL wishes disclosure and ACP shift toward western values as Chinese-American elders acculturate (OR=6.87, $p < 0.01$). Consistently, all studies suggest that the level of acculturation must be taken into considerations while developing and disseminating ACP educational programs (Dobbs et al., 2015; Gao et al., 2015; Wright et al., 2013).

**Recommendations to ACP Engagement**

Giving the rising needs for cultural competence in EOL care, consistent evidence of the low level of ACP awareness and low AD completion rates, multiple studies provide useful recommendations on how to meaningfully engage the ethnic groups in the ACP process (Dobbs et al., 2015; Ko & Berkman, 2012). These suggestions include (a) building trust among diverse groups; (b) respecting value orientations and cultural norms; (c) inclusion of family and appointing a surrogate decision-maker; (d) providing support during the illness and suffering period, and lastly (e) providing culturally appropriate education (Dobbs et al., 2015; Ko & Berkman, 2012; Kwak, Allen & Haley, 2011; Kwak et al., 2014).

**Culturally Tailored Education Among Minority Groups**

The implementation of culturally tailored education to increase the ACP awareness and engagement among minority groups, cannot be overemphasized. Ko et al. (2013) vigorously debate that implementing ACP conversations established on the important cultural values, free of direct reference to death and dying concept, increase participant’s comfort level. Moreover, establishing rapport and building a strong relationship with the community members, assist the individuals with real-time ACP decisions (Kwak et al., 2014). Furthermore, the practical support
and advocacy for EOL care consistent with ethnic group’s preferences are fundamental components of culturally sensitive ACP process (Kwak et al., 2011; Kwak et al., 2014). The efficacy of community-based programs conducted in various community settings, including churches, senior centers, adult day cares, is adequately discussed in the latest literature (Dobbs et al., 2015; Ko & Berkman, 2012; Lee et al., 2015; Sun et al., 2017).

**Asian-Americans.** The research conducted by Sun et al. (2017) and Lee et al. (2015) demonstrated that while discussing ACP process, recognizing the degree to which cultural values shape one’s thinking about death and dying is critical. As predicted, the culturally targeted and language-concordant education, allowed both researchers to achieve meaningful behavior changes among Asian-Americans regarding the ACP process. Although Hong et al. (2018) revealed that spirituality could be considered a barrier to AD adoption, Sun et al. (2017) proved tremendous usefulness of a church-based ACP promotion model in the AD adoption among Asian minority. The organized step-by-step AD guidance permitted the researchers to achieve a 72% completion rate of AD and 25% increase in surrogate ACP conversations among Chinese Protestants and Vietnamese Catholic participants. Additionally, the spiritual endorsement of the ACP program by the church leaders further increased the community ACP engagement (Sun et al., 2017).

Similarly, a one-hour, nurse-led, culturally tailored seminar empowered Lee at al. (2015) to obtain a remarkable increase in ACP knowledge \((t [70] = -8.380, p<0.05)\) and 93% increased intention to complete the AD among urban, community-dwelling Chinese American adults. Congruently, Sun et al. (2017) and Lee et al. (2015) validated the statement that approaching ACP concept in a culturally sensitive manner helps to normalize the discussion among ethnic minority groups and moves the culture toward becoming one in which raising the topic of death
does not only occur when it is imminent (Lee et al., 2015; Sun et al., 2017). Furthermore, the findings confirmed beyond doubt that the acceptance of AD by participant’s, their families, church members, and church leaders create a subjective norm which emphasizes the collectivist decision-making process. Therefore, providing considerations for family presence during the ACP conversations is imperative to further facilitation of difficult EOL discussions (Dobbs et al., 2015; Ko & Berman, 2012; Kwak et al., 2014; Sun et al., 2017).

**African-Americans.** The promotion of AD completion through culturally tailored education has also been very successful in African-American church communities. For instance, in the mix-method randomized controlled trial, Huang et al. (2016) examined the feasibility of 90-minute culturally fitted ACP intervention as an avenue to addressing the low AD completion rates and barriers to ACP engagement among Southern minority groups. The implementation of the Respecting Choices program, known for honoring an individual’s ACP goals and values, resulted in high satisfaction with the intervention, increased ACP knowledge and ultimately intensified demand to complete the AD ($p = 0.01$). As anticipated, there was no substantial variance in the control group.

Similarly, Lyon et al. (2019) focused on strengthening EOL care for African-Americans with HIV and their surrogates through culturally competent FAmily-CEntered (FACE) education. The study results showed profound positive effect of the program, evidenced by a significant increase of AD documentation from only 13% at baseline to 59% in the intervention group as opposed to 17% in the control group ($p < 0.0001$). As a result, 59% of participants randomized to the program, had adapted AD compared to only 20% of the control group ($p < 0.0001$).

Lyon et al. (2019) and Huang et al. (2016) have not only raised ACP awareness among vulnerable communities but also validated the common understanding that addressing the
cultural factors is crucial to successful ACP engagement among minority groups. Their research also produced substantial evidence that the cultural indicators such as ethnicity, religiosity, gender, age, socioeconomic status affect all individuals and ultimately go a long way toward respecting what matters most to them at the EOL (Adams & Warshaw, 2017; Hong et al., 2018; Portanova et al., 2017).

**Hispanics and Latinos.** Respectively, the culturally contextualized ACP intervention has also shown to be very useful in the underserved Latino population with a life-limited illness. Fischer, Cervantes, Fink, Kutner (2015), provided the Latino participants with linguistically matched ACP materials and bicultural, and bilingual navigator home visitations. As a result of this community intervention, the ACP rates were significantly greater in the intervention group (47%) versus the control group (25%). The rigorous study method provided evidence that for terminally ill individuals, the ACP is a much more complicated process than just an intellectual or administrative task. Undoubtedly, the ethnically sensitive program provided valuable insight to the intensely ACP human process in which participants are encouraged to contemplate on their mortality or worsened health condition, and called to make plans for future, various EOL treatment options (Hong et al., 2018).

Ultimately, the analyzed studies demonstrate that the provision of culturally-sensitive ACP programs challenge the Hispanic ethnic participants to see new ways of understanding and attending the ACP concerns, prepare them to make future ACP care decisions and equip them in confidence to complete the AD form (Carr, 2012; Fischer et al., 2015).

**Caucasians.** The value of ethnically appropriate nursing-driven AD and ACP education has been very successful amongst the Caucasian population. For example, the 90-minute, nurse-led, community-based ACP/AD session, allowed Hinderer and Lee (2014) to achieve tremendous
improvement in the AD completion rates (97.7%) and increase in the ACP engagement process (82.6%) among adults from Wicomico County, Maryland and Sussex County, Delaware. Analogously to Dobbs et al. (2015); Ko & Berkman (2012); Kwak et al. (2014) and Sun et al. (2017), the above quasi-experimental study proposes that effective ACP education must focus on active family participation as its presence directly correlates with AD completion rate.

Similarly, a one-time, nurse practitioner-led ACP workshop conducted by Splendore and Grant (2017), has shown high feasibility of initiating the ACP discussions in the community setting located in Pittsburg, Pennsylvania. Ultimately, the study resulted in overall participant positive response, remarkable completion of AD (93%) and boosted understanding of ACP and dissemination of AD.

Likewise, the Respecting Choices program in the retrospective study by Pecanac, Repenshek, Tennenbaum and Hammes (2014) not only lead to a substantial increase in AD prevalence (25.8% to 38.4%) among community members of La Cross County, Wisconsin, but also allowed to prove the agreement between treatment choices stated in the adopted AD and the care delivered at the EOL. The program deepened the common understanding that addressing the cultural myriad of characteristics, experiences, and influences is an essential and reliable tactic for vulnerable communities ACP engagement.

Also, Livingston et al. (2013) revealed that the repeated ACP educational sessions based on tradition, beliefs, and culture were instrumental in a Jewish, dementia community in London. The culturally-sensitive educational program resulted in a streaking rise in the AD adoption rate from 25% to 75% and enhanced family satisfaction. Likewise, Kirchhoff, Hammes, Kehl, Briggs and Brown (2012) allowed the ill Protestant individuals and their surrogates to elicit EOL preferences through utilization of patient-centered ACP (PC-ACP). Analogous to the study
performed by Fischer et al. (2015), the trained ACP facilitator assisted the participants in the
documentation of individualized treatment wishes, supported the designated decision-maker in
understanding the participant’s EOL choices and prepared proxies to make decisions that
integrate those preferences. As a result, 74% of the control group made their EOL treatment
choices and faced future decisions in a prepared and more cognizant way.

The analysis of the above ACP studies has raised a significant observation that
routinizing the ACP conversations require the designation of an appropriately trained individual
who is comfortable conducting the discussion, permits time to ask and answer challenging
questions studies (Hinderer & Lee, 2014; Kirchhoff et al., 2012; Livingston et al., 2013; Pecanac
et al., 2014; Splendore & Grant, 2017). The ACP facilitators should also periodically check if the
AD preferences have changed (Kirchhoff et al., 2012; Schrijvers & Cherny, 2014).

ACP Outcome Measures

With the propagation of various ACP initiatives and tools, assessing the success of the
ACP programs is imperative (Sudore et al., 2018). The traditional method of assessing the
effectiveness of the ACP intervention has been measured by the adoption of AD (Carr, 2012;
Dobbs et al., 2015; Lee et al., 2015; Sun et al., 2017; Van Scoy et al., 2014). However, the
standardized outcomes that define effective ACP are still deficient (Sudore et al., 2018). Sudore
et al. (2017) proposed the Advance Care Planning Engagement Survey (ACPES) to assess (a)
ACP process measures defined by attitudes toward ACP or EOL preferences; (b) action
measures through ACP conversations; (c) quality measures via participant satisfaction, and (d)
healthcare measures through healthcare utilization. The ACPES tool was utilized to detect ACP
behaviors and domains by multiple studies, including Ko and Berkman (2012) and Sun et al.
(2017).
Utilization of Five Wishes

It is imperative to note that the Fives Wishes form (Aging with Dignity, 2019) has been frequently utilized in the ACP tailored approaches as the AD discussion tool (Hinderer & Lee, 2014; Lee et al., 2015; Splendore & Grant, 2017). The application of this accessible and easy-to-understand document served as a practical hands-on guide to promote the challenging ACP process that facilitated high AD adaption rates and increased level of ACP awareness.

Wiener (2012) published a study evaluating Five Wishes form as an AD document. The majority of the young adult participants reported that this simple and effective way to guide EOL decision-making process was either helpful or very helpful to themselves (95%) and to others (90%). In conclusion, the above research highlighted the fact that Five Wishes AD allows compassionate, autonomous care, support, and consolation before and after death (Wiener, 2012).

Research Uniformity

Notably, consistency was found across all studies supporting the hypothesis that culturally tailored, community-based educational interventions successfully and effectively promote AD adaption and ACP engagement among ethical and religious groups. Initiating ACP conversations early, increasing education efforts, strengthening strategies, and providing tailored information are essential interventions that facilitate and guarantee AD adoption. Also, various ACP culturally-sensitive programs such as Respect Choices, Five Wishes, FACE, PC-ACP and nurse-led seminars provided a valuable insight to the intensely ACP human process in which participants were deeply encouraged to contemplate on their mortality or worsened health condition and called to make plans for exploring various EOL treatment options (Hinderer & Lee, 2014; Lee et al., 2015; Splendore & Grant, 2017). Finally, the studies
proved that partnerships with community organizations, faith-based institutions or community-dwelling establishments hold a definite promise to a successful facilitation of EOL care conversations, ACP engagement and AD adoption before an imminent health crisis may occur (Fischer et al., 2015; Lee et al., 2015; Livingston et al., 2013; Lyons et al., 2019; Splendore & Grant, 2017).

**Theoretical Framework**

As exhibited by the analysis of the pertinent literature, the ACP planning process is profoundly encumbered by the presence of deep beliefs, attitudes, and spiritual views held by each family and community. Bearing that in mind, shifting the traditional ACP approach to more explicit, culturally appropriate and transparent method and bringing the successful application of ACP process change across multi-sector populations and communities can be quite challenging.

The Knowledge-to-Action (KTA) model was utilized as a guiding theoretical framework for this project to enhance the implementation efforts and to address the existing knowledge-practice gap between the proven ACP benefits and low rates of ACP engagement in the Roman Catholic community (see Appendix B). The model developed by Graham et al. (2006) is a hypothesized process which assumes a system perspective, places knowledge creators and users within a model of knowledge that is receptive, adaptive, and unforeseeable. The framework operates on the presumption that there are two distinct but interrelated elements: (a) Knowledge Creation and (b) Action Cycle. These stages are represented by a cycle, suggesting that the process of moving new evidence into practice is not static but rather dynamic, interactive and involved. The process of knowledge generation is represented by the funnel component of the KTA model which is further broken down into three distinctive phases such as knowledge inquiry (i.e., primary studies), knowledge synthesis (i.e. secondary studies), and the creation of
feasible knowledge tools such as clinical guidelines, protocols or decision aids (Graham et al., 2006).

The action cycle, represented by various activities necessary for knowledge implementation, was initiated by identification of ACP knowledge gap and appraisal of literature applicable to the studied community: Polish Roman-Catholics. The barriers to community engagement in the ACP process were identified and analyzed, and a strategy to bring the proposed change, was developed (i.e. the culturally tailored ACP education). Once the knowledge translation strategy was delivered, its effect was monitored and achieved outcomes evaluated. Lastly, the recommendations for future replications of comparable interventions were provided to attain the sustainability of the project.

Methodology

Project Design

The above quality improvement project utilized a quasi-experimental with pre, post, post study design in a single cohort. The recruited participants attended two 90-minute ACP sessions - (1) an ACP Seminar and (2) an ACP Booster Session. Both sessions were scheduled two weeks apart. The ACP Seminar was solely focus on delivering ACP information to the recruited cohort. The appropriately chosen survey tools were administered in-person immediately before and after the planned ACP intervention. The tools were discussed in detail later in the paper. The Booster Session was exclusively dedicated to step-by-step Five Wishes guidance. Prior to the adaption of AD, the participants had an opportunity to ask questions and seek clarifications related to the ACP concepts encountered during the initial session. In addition, a follow-up survey was administered at the completion of the second ACP session. The subsequent sections further address the detailed specifics of project methodology.
Setting

The ACP intervention was delivered at the Roman-Catholic church located in Northern New Jersey. The parish is a flourishing community of devoted Roman-Catholics with approximately 882 families. Roughly 85% of church members declare themselves as Polish (Maria Matrys, personal communication, January 15, 2019) and either speak only Polish or are bilingual. This faithful community includes first generation of Polish immigrants and their children and grandchildren who belong to the same parish and attend the same church services.

A church priest, who is a main stakeholder in this quality improvement project, shares similar cultural values and beliefs as the community. All church services are currently delivered in English and Polish.

Study Population

This quality improvement project focused on Polish-American Roman-Catholic adults residing in Clifton city, New Jersey and the town’s vicinity. Based on the recent data provided by U.S. Census Bureau (2018) approximately 20.2% of New Jersey residents are Polish and 14.6% of them reside in Clifton, New Jersey. Although, there is not specific age data among Polish immigrants living in Clifton, it is known that approximately 66% of town residents are above age 65 and 40.7% of them are disabled (U.S. Census Bureau, 2018). Additionally, 33% of town citizens are high school graduates, 4.6% hold associate degree and 7.6% possess graduate or professional degree. The average median household income of an average Cliftonian is $71,830 (Data USA, 2017).

As discussed previously the intensity of hospital care in the last six months of life, the rates of hospital deaths and the inpatient healthcare spending among Passaic county residents, exceeds the national benchmarks, with the equivalent of approximately 21,000 hospital days,
28.5% inpatient death rate and $23,640 of spending per decedent (Dartmouth Atlas Project, 2019).

For this quality improvement project, a convenience sample of Polish-American adults from the Roman-Catholic parish served as the intervention population. Based on the established inclusion and exclusion criteria, and the previous experience with a similar project, the projected sample size was 40 participants. The participation inclusion criteria comprised of Polish-American ethnicity, Roman-Catholic religion, age 18 or older, and self-reported ability to read, write and communicate in the native Polish language. The exclusion criteria included age younger than 18 and 90 or older, as well as those self-reporting a physical (e.g. blindness) or cognitive impairment which may prevent full participation in the ACP intervention.

Subject Recruitment

The project participants were recruited directly from the designated church site. The church members were allowed to invite some other non-church eligible members such as relatives or friends, to participate in the intervention. This snowballing approach was allowed to increase the program exposure. The event was advertised to all potential participants through verbal announcements (see Appendix C) during church mass, church bulletin reminders (see Appendix D) and event flyer (see Appendix E) for three weeks prior to the intervention. The initial verbal announcements were presented in both English and Polish by the church priest. The church priest also assisted in the recruitment process through telling the potential participants about the ACP seminar and inviting the eligible participants to attend the intervention. The primary investigator (PI) assessed the eligibility of the interested participants and registered the qualified individuals following the church masses for three consecutive Sundays prior to the ACP intervention.
**Consent Procedure**

The informed consent (see Appendix F) was obtained from the Rutgers Institutional Review Board [IRB] portal and translated into Polish by the IRB designated translation services (N. Desai, personal communication, April 8, 2019). The Polish version consent was presented to each eligible participant in-person at the time of event registration. Only the PI, a Polish native fluent in both Polish and English, administered the informed consent to each participant and assisted with the completion of the form. During the registration process, the prospective participants were permitted to utilize the church hall for one hour, where they thoroughly reviewed the informed consent and discussed any concerns before signing it. At the same time all subjects were provided with the primary investigator’s (PIs) phone number and the email address in anticipation of any other concerns related to the offered intervention. All completed consent forms were retained by the PI and were secured in the home locked cabinet. Each study subject was given a copy of the consent to retain for their personal record.

A registration sheet (see Appendix G) was utilized to maintain an accurate and appropriate record of all participants and their pertinent information such as first and last name, phone number and the consent status. This step ensured that all subjects completed the consent form prior to the ACP intervention. In a case where a participant has not registered for the ACP event but decided to attend it, she/he was given an opportunity to register for it and signed the informed consent immediately prior to the initial ACP session.

**Project Risks and Harms**

A risk of harm associated with the project involvement was minimal. Potential risks consisted mostly of emotional, psychological and spiritual distress resulting from the deliberate and purposeful dialogues reflecting on death and dying process, as well as recalling
uncomfortable experiences (Hutchison et al., 2017; Johnson et al., 2017; Schrijvers & Cherny, 2014). To alleviate such risk, all the participants were made aware that they may completely withdraw from the intervention at any time. In addition, the church priest was readily available to provide emotional and spiritual support to the affected individual. Also, all subjects were educated that if for any unknown reason they became uncomfortable with the administered survey questions, they may either skip the questions or not complete the survey.

The project also had a minimal potential for a breach in data security. To mitigate such risk, the participants were informed that no personal identifiers were obtained during the intervention but rather identification number was assigned for each participant. All other security and safeguard measures is discussed later in this paper.

**Subject Costs and Compensation**

The recruited participants have not incurred any cost associated with the ACP intervention as the ACP materials and refreshments were provided free of charge. Each participant who attends both ACP sessions received a $5.00 Dunkin Donuts gift card at the conclusion of the ACP Booster session.

**Study Intervention**

The ACP intervention consisted of two ACP sessions-(1) the ACP Seminar and (2) the ACP Booster Session, held two weeks apart and proceeded by advertisement and subject recruitment processes. The entire intervention was conducted in Polish language which is the native language of the PI.

**ACP seminar.** The first ACP session included sign-in of participants and the administration of the pre-survey. Upon completion of the pre-test, the following activities were administered-(a) EOL video watching; (b) overview of ACP concepts through PowerPoint
presentation delivered by the PI; (c) introduction of Polish-English version of Five Wishes; (d) group discussion related to personal EOL experience, and finally (e) the administration of the post-survey. Upon completion of the ACP Seminar, the participants were voluntarily asked to identify a healthcare decision-maker and invite the chosen individual to the ACP Booster Session. Additionally, all the participants were informed that the PI will contact them by phone one week prior to the ACP Booster Session to remind them about the event.

*Advertising and recruitment.* The ACP program advertising was initiated three weeks prior to the ACP Seminar event date. The event flyer was displayed on the bulletin board located in the back of the church and inserted into the weekly church bulletin. Additionally, a written announcement was posted in the church bulletin. Also, a verbal announcement about the incoming ACP event was made by the church priest during all church services. The recruitment process is discussed in detail elsewhere in this paper.

*Sign-in process and refreshments.* A sign-in table was designated in the church hall where the intervention took place. On arrival, each recruited participant signed next to their name on the registration sheet, confirming the accuracy of the information provided. Upon verification of the informed consent completion, the PI provided each participant with the copy of the signed informed consent and the folder containing ACP materials with an assigned corresponding participant identification (ID) number. Potential eligible participants who did not register for the event in advance and did not complete the informed consent, were required to provide their personal information on the registration sheet and completed informed consent upon admittance to the intervention. Adequately, the ID number was provided. During the entire event, light refreshments were provided.

*Event materials.* Each participant was provided with a folder containing seminar
materials at the time of sign-in. The seminar folder included-(a) Seminar agenda (see Appendix H); (b) demographic survey (see Appendix I); (c) pre-intervention survey (see Appendix J); (c) copy of the power-point slides (see Appendix K); (d) ACP pamphlet adapted from NJHCQI (see Appendix L); (e) copy of the POLST (see Appendix M); (f) Five Wishes form (see Appendix N); (g) the post-intervention survey (see Appendix O), and (h) program evaluation (see Appendix P). All the above materials, except informed consent, pre-intervention surveys, post-intervention survey, follow-up survey and Five Wishes, were provided in English. In order to achieve better project outcomes, the excluded materials were translated into Polish by the PI (N. Desai, personal communication, 4/8/2019).

**Introduction and pre-intervention survey.** At the beginning of the ACP Seminar, the PI welcomed all the participants and provided a thorough description of the seminar. Also, the spiritual leader offered his blessings to all the gathered individuals. Afterwards, the participants were asked by the PI to fill out the pre-intervention survey, using the assigned ID number. The welcoming and completion of the tool took no longer than 15 minutes. All the surveys were collected by the PI upon completion. Detailed information about the pre-intervention survey is provided elsewhere in this paper.

**EOL film and refreshments.** After 15 minutes of the event opening, a short film “Anna’s Story” was played. This 15-minute film, produced by Atlantic Health with support of Horizon Blue Cross Blue Shield of New Jersey, is a fictitious story used for educational purposes. The movie portrays an EOL experience through the lenses of a dying individual, her loved ones and the healthcare providers. Hypothetically, the film stipulated all the participant with a deeper understating of the ACP process as it exposed the complexity of the EOL decisions and illustrated the significance of family involvement in the ACP process. Bekker et al. (2013)
demonstrated that personal stories such as the one portrayed in “Anna’s Story” movie, make individual ACP decisions more effective. At the same time Carr and Luth (2017) discuss that educational videos along with other appropriate tools, greatly enhance ACP decision-making process. During the viewing of the film, light refreshments were provided.

**Discussion on EOL experience.** After the viewing of the “Anna’s Story” film, the participants were prompted to reflect on the information presented. Consequently, the individuals were allowed to share their personal EOL experience. Zwakman et al. (2018) demonstrated that participants’ openness, ambivalence and readiness to share personal EOL stories with the group, play an important role in their willingness and ability to participate in the ACP conversation. The discussion lasted no longer than 15 minutes.

**PowerPoint presentation.** A culturally-sensitive, 30-minute ACP slide show presentation was delivered to the participants in Polish by the PI who is a Polish native fluent in both Polish and English. The presentation included an overview of ACP concepts, particularly (a) defining ACP and AD; (b) the need for AD; (c) the utilization of CPR, breathing machines and feeding tubes when an individual becomes very sick; (d) Roman-Catholic Church teaching about withdraw and withholding lift-sustaining treatments; (e) strategies on how to initiate ACP conversation with the loved ones and with healthcare provider; (f) utilization of palliative care and hospice; and finally (g) Five Wishes introduction.

The content of the presentation was chosen based on the recommendations provided by reputable sources such as NJHCQI and the IHI. Additionally, the PowerPoint content was developed based on the reviewed ACP literature and the feedback of a Rutgers DNP student who developed a similar project. Upon the conclusion of the presentation, the participants were offered an opportunity to ask questions pertaining to the presented content.
Post-intervention surveys. At the completion of the program, all participants were encouraged to complete a five-minute post-intervention survey, using the previously assigned ID number. All filled-out surveys were collected by the PI. In addition, the participants were asked to complete the program evaluation survey to evaluate the usefulness of the intervention. The completion of both tools took no longer than 15 minutes. Detailed information about the four-item ACPES and the program evaluation survey are discussed elsewhere in the paper.

Upon the completion of the ACP Seminar, participants were invited by the PI to attend the ACP Booster Session scheduled two weeks post the ACP Seminar. However, the participants were asked to identify a healthcare decision-maker and, if possible, invite the chosen individual to the ACP Booster Session. The partakers were also informed that the PI will contact them by phone, one week prior to the ACP Booster Session, to remind them about the incoming event. The phone script is available in Appendix Q.

**Booster session.** The follow-up ACP Booster Session occurred two weeks post ACP Seminar and included signing-in of all the returning participants in a similar manner as the ACP Seminar session. The registration sheet utilized for the ACP seminar was also utilized for the ACP Booster Session. Upon arrival each participant stopped by the sign-in table to confirm their participation in the session by placing a check mark in the “Attended Booster” column.

The agenda for the Booster Session (see Appendix R) included (a) welcoming statement; (b) ACP “Before I Leave” icebreaker (see Appendix S); (c) questions and answers; (d) a step-by-step guidance to adaptation of Five Wishes; (e) completion of follow-up survey (see Appendix S), and (f) closing statement and distribution of $5.00 Dunkin Donuts gift cards.

**Welcoming statement and icebreaker.** At the beginning of the Booster Session, the PI welcomed all the returning participant and invited them to verbalize what they would like to
achieve before they die. For this purpose, the “Before I Leave” board served as an ice-breaker. The board was obtained from NJHCQI a week before the event and displayed by the main entrance to the church hall on the day of the scheduled session. By writing the bucket list items on the board, the participants started to contemplate death, reflected upon their current life and considered what matters to them the most. This simple 15-minute exercise brought some positive energy to the participants and permitted some creative reflections flow freely.

**Questions and answers.** The 20-minute question and answer portion of the seminar focused on providing answers to any possible questions presented by the participants. In addition, the following queries were used to guide the conversation (a) May a husband and wife fill out Five Wishes together and authorize their children to make their healthcare decisions? (b) Can I change my EOL wishes? (c) Will my healthcare providers follow all my EOL personal wishes and will my pain be adequately managed? (d) When might I request care? and (e) Will my burial and memorial service wishes be respected? The above questions were adapted from Five Wishes Presenter’s Guide (Aging with Dignity, 2010) and aimed to further assist the participants in the EOL decision-making process. Light refreshments were served during the question and answer segment of the program.

**Adoption of Five Wishes.** The adoption of Five Wishes occurred through a 35-minute step-by-step AD guidance approach. The discussion started with the recollection of the concept of “healthcare agent” and “living will” which addressed Wish one and two, respectively. The participants were able to choose the best foreseen scenarios that best reflect their beliefs and wishes. Wishes three, four and five, were tackled by asking participants what would be most important to them if they become very sick. A focus was placed on how comfortable they would like to be at the EOL, how they want to be treated at the EOL, and what they want their loved
ones to know. Upon the completion of Five Wishes, the participants were advised to complete the “Signing the Five Wishes Form” section, read the statement carefully, ask two witnesses to be present, and signed the Five Wishes in front of witnesses. Additionally, the participants were reminded to make copies of the completed Five Wishes for the family, friends, healthcare agent, healthcare provider and family attorney, and discuss the completed wishes with them. Also, the individuals were instructed to keep the completed Five Wishes at home readily available. The detailed description of Five Wishes form is elsewhere in the paper.

**Follow-up survey.** At the end of the workshop, the participants were asked to complete the follow-up four-item ACPES survey (see Appendix T) to determine if the ACP intervention had a sustained impact on ACP engagement among the partakers. The completion of the tool took no longer than 15 minutes. The four-item ACPES is discussed elsewhere in the paper.

**Closing statement.** At the end of the Booster Session the PI thanked all of the partakers for participation in the ACP quality improvement. Additionally, each participant who attended both ACP sessions received a $5.00 gift card to Dunkin Donuts.

**Measured Outcomes**

The effectiveness of the ACP intervention on ACP engagement was measured through the utilization of a four-item ACPES tool. The survey measured the participant’s ACP engagement at three points (a) immediately before intervention, (b) immediately post intervention, and c) follow up two weeks after the intervention. Additionally, the program feedback, gained through nine evaluator questions, allowed to assess the quality of the intervention, its cultural appropriateness, as well as suggestions for future improvements.

**Pre-intervention survey.** The pre-intervention survey was divided into three distinctive parts (a) seven demographic questions, (b) three EOL perspective questions, and (c) the four-
Demographic questions. The specific demographics were comprised of the participant’s spoken language, gender, age, marital status, presence of children, education level, religiosity level and the length of U.S. stay. These specific questions allowed the PI to learn the characteristics of the studied population. The utilization of demographic data in this project improvement is discussed elsewhere in the paper.

EOL preference questions. The three-item EOL preference survey focused on gaining participants' perspective on EOL care, including length of treatment, care concerns and disposition. The above questions were adapted from the Conversation Project kit dedicated to helping individuals to talk about their wishes for the EOL and provide a shared understanding of what matters to individuals during their final days (IHI, 2019). The analysis of the participants’ responses meaningfully guided the discussion during the Booster session. Such an approach made it easier to make decisions when the time comes (IHI, 2019).

ACP engagement survey. The ACP engagement survey utilized in this quality improvement project was the ACPES tool developed by Sudore et al. (2017). The survey measured specific variables associated with engagement, such as identification of values, choosing a healthcare surrogate, engaging in ACP conversations with the loved ones and the provider and ultimately adapting the AD. According to Sudore et al. (2017), since all these variables strongly relate with the changes in ACP behavior ($r = .91, p < .001$), the tool is appropriate to gauge the impact of ACP intervention (Sudore et al., 2017).

For the purpose of this quality improvement project, the four-item ACPES tool was utilized for the pre, post and follow-up. The tool was validated in a diverse cohort of 664 participants and resulted in a Cronbach’s alpha of 0.84 for the English version (Sudore et al.,
This short survey focused on the readiness to engage in a meaningful ACP discussion in two domains- (a) quality of life (QOL), and (b) medical decision maker (DM). The tool utilized Likert scale responses scored on a five-point scale. It took approximately five minutes to complete the ACPES tool. Permission to use the survey for the project was obtained from the author and is attached in Appendix U (R. Sudore, personal communication, May 12, 2019).

As mentioned earlier in the paper, the ACPES tool was translated into Polish by the PI. It was expected that the tool may not preserve its validity post translation. However, the completion of the tool psychometric testing was not expected for this project (Edna Cadmus, personal communication, March 30, 2019).

**Pre-intervention survey.** The four-item version of ACPES was utilized as the pre-intervention tool. The survey allowed to assess the participant’s baseline ACP readiness to engage in ACP discussion.

**Post-intervention surveys.** The four-item version of ACPES was used as the post-test survey. The tool allowed to detect any changes in ACP behavior from baseline to post ACP intervention exposure. In addition, nine questions were included in the post survey to evaluate the quality of the seminar to further customize the program in the future and assist in prospective replication of the project with analogous audience. The evaluation questions were adopted from Sample Workshop Evaluation Questionnaire developed by WGBH Boston, & Corporation for Public Broadcasting (2002). It took approximately five minutes to provide answers to the post-survey.

**Follow-up survey.** To further determine changes in ACP action and ensure consistency of the outcomes, the same ACPES was utilized as the follow-up tool. The survey was administered to the participants during face-to-face session two-weeks post ACP intervention.
Project Timeline

The ACP project timeline reflected all activities related to the development of ACP project proposal through the project findings dissemination (see Appendix V). The development of ACP project proposal took place from January 2019 through May 2019 where submission of the ACP project to IRB took place from June 2019 through July 2019. Upon IRB approval, the subject recruitment took place in September 2019 and project implementation lasted till the middle of October 2019. Consequently, data analysis and completion of DNP dissertation were accomplished by the end of November 2019. Lastly, the initial dissemination of findings was completed by December 2019.

Resources and Economic Considerations

The PI was responsible for all the project expenses such as printing of educational and advertising materials, surveys, material and consent translation, folders, pens, audio-visual equipment and refreshments. Some of other materials, for example the Polish-American version of Five Wishes form was donated by the NJHCQI (A. Perez, personal communication, February 1, 2019). The project space was provided free of charge by the church where the ACP seminar will take place. A detailed project budget is included in Appendix W.

Evaluation Plan

Data Analysis

The evaluation section addressed all previously discussed outcome measures which included ACP engagement, EOL perspective, program quality and adaptation of AD. The demographic measures collected during seminar session such as age, gender, spoken language, marital status, presence of children, education level, church attendance rate, and length of U.S. stay, were analyzed utilizing correlational statistics to define the sample. Consequently,
descriptive statistics were applied for the demographic data where the median was calculated for subject age and the percentage of male and female participants will be calculated for age, sex, education level, presence of children, church attendance, and length of U.S. stay. Additionally, the program quality feedback included in post-intervention survey, was analyzed in regard to the number and percentage of responses in each respective category. Similarly, the open-ended questions were reviewed and grouped according to the emerged themes.

The four-item ACPES tool established foundation for statistical analysis of ACP engagement among recruited participants. The data collected immediately before the intervention and immediately after the intervention was compared to detect any increase in the ACP engagement level from the baseline to post intervention. Additionally, the post-intervention data was compared to the follow-up data to detect if the involvement in the ACP Booster Session further enhanced the participants’ readiness to engage into ACP discussion. The Wilcoxon Rank Sum test was utilized for this purpose.

The AD adaptation rate was determined by a physical count of participants who completed Five Wishes AD against those who have not signed the document.

**Data Maintenance and Security**

During the seminar, data completed on paper was collected at three specific points: pre-intervention (e.g. demographic survey and ACPES), post-intervention (ACPES and evaluation survey) and follow-up (ACPES). To ensure the personal confidentiality and security of the collected data, the following measures took place. Each subject was assigned an ID number which substituted personal information and was used for all survey completions. The assigned ID number was linked to the participant’s personal information collected during the registration process. In order to further assure personal data confidentiality, all survey data collected was
entered into the data management system such as SPSS electronic spreadsheet and stored on a password protected personal computer. Then the data was backed-up on the cloud password protected account with a two-step verification. All SPSS files were secured in the same manner. The log linking the sensitive personal information with the participant’s ID was in the sole possession of the PI and remained in a home locked cabinet until all the data were collected, entered into SPSS and analyzed. As mentioned elsewhere in the paper, the log was destroyed approximately one month after the completion of the ACP intervention. The de-identified data and the signed informed consents will be kept for at least three years following the project’s completion, in the office of the DNP Project Team Chair located at 180 University Avenue, Newark, New Jersey, 07102.

**Results**

Data collection for the intervention tests, including demographics, EOL preference survey, the ACPES pre-intervention and post-intervention, and the program evaluation, occurred during ACP Seminar, on September 15<sup>th</sup>, 2019. Accordingly, data collection for the follow-up ACPES intervention survey happened during the Booster Session, on September 29<sup>th</sup>, 2019. Upon completion of data collection, all information was entered the SPSS Statistics Software Version 26 and analyzed utilizing the same statistical application.

**Descriptive Statistics**

The convenience sample of 40 participants was recruited directly from the designated church site, based on the previously established inclusion and exclusion criteria. Beforehand, three individuals were eliminated from the project participation due to medical diagnosis of dementia (n=1) and hearing deficit (n=2). Also, three (n=3) individuals were randomly removed by the PI due to the approved sample size. All eliminated individuals were permitted to attend
the ACP intervention and received the same ACP resources as the consented group but were exempted from the completion of the intervention surveys. The consented individuals \((n=40; 100\%)\) attended the ACP Seminar session and completed the entire set of pre- and post-intervention surveys. However, 35 out of 40 participants returned for the two-week follow-up ACP Booster Session and all completed the respective follow-up ACPES survey. The sociodemographic and the EOL preference data collection tools aimed to describe the cohort and determine its personal EOL preferences. The readiness to engage in ACP process data were collected using the validated ACPES instrument to measure the effect of culturally tailored ACP education on AD adaptation among faith-based community members.

**Demographics.** The cohort was distributed as follows: Polish-Americans \((n=40, 100\%)\) with the Polish language as the primary language spoken at home \((n=38, 87.5\%)\). The participants were female \((n=28, 70\%)\) and male \((n=12, 30\%)\) who ranged in age from 35-89 with a mean age group of 56-64. The \(n=25 (62\%)\) of the partakers were married, \(n=38 (95\%)\) had children, \(n=28 (70\%)\) attended church weekly, and \(n=16 (40\%)\) reported completion of high school education. Participants ranged in length of time living in the USA from 5 to 55 years with the same mean acculturation time of 26-35 years. The sample’s socio-demographics are presented in Table 1 (Appendix X).

**ACP Engagement**

The ACPES was administered immediately before intervention (Readiness1), immediately post-intervention (Readiness2), and two-weeks post-intervention (Readiness3). The surveys focused on measuring the effectiveness of the ACP education on participant’s readiness to engage in a meaningful ACP discussion in two domains – (a) QOL and (b) DM (Sudore et al., 2017). Each ACPES consisted of four identical questions using a Likert scale represented by 1-
not at all ready to engage in ACP, 2-not very ready to engage in ACP, 3-not sure if ready to engage in ACP, 4-somewhat ready to engage in ACP, and 5-very ready to engage in ACP.

In order to determine whether there was a statistically significant mean difference in participant’s perceived readiness to engage in the ACP process, the ACPES pre, post and follow up survey scores were compared using the Wilcoxon Signed-Rank test with the expected $p$ value at $<0.05$. The median of differences between the total score of the pre-intervention test (Readiness1) and the total score of the post-intervention test (Readiness2) shown that participation in the ACP Seminar contributed to participant’s ACP awareness and readiness to engage in ACP ($z=2.422, p=0.015$). Similarly, the median of differences between the total score of the post-intervention test (Readiness2) and total score of follow up-intervention test (Readiness3) demonstrated that the involvement in the ACP Booster Session contributed to a further increase in participant’s readiness to engage in ACP ($z=2.287, p=0.022$). The ACPES results are reported in Table 2 (Appendix X).

**EOL Preferences**

The three-item EOL preference survey focused on gaining participants’ perspectives on EOL care, including treatment length, final EOL care, and disposition. The survey showed that $n=36$ (50%) of participants avowed that quality of life is far more vital to them than its length. Congruently, participants ($n=27, 67.55\%$) admitted being concerned about receiving over aggressive EOL care, and $n=31$ (77.5%) would want to spend their last days at home. The EOL preferences results are reported in Table 3 (Appendix X).

**Completed AD**

At the end of the ACP Booster session, participants ($n=28, 70\%$) signed the AD. The AD adaption rate was determined by a physical count of those individuals who signed the Five
Wishes document. The high rate of AD adaption demonstrated superior applicability and customizability of the document to the specific needs of Polish Roman-Catholic population.

Program Evaluation

The nine-question program effectiveness survey focused on the assessment of the quality of the ACP program, with the intent to improve future prospective projects with a comparable audience. The first part of the survey consisted of six questions using a Likert scale represented by 1-not at all effective, 2-not very effective, 3-not sure if effective, 4-somewhat effective, and 5-very effective. The program participants reported that the nurse-led, culturally tailored ACP program definitely met \( n=26, 65\% \), and prepared \( n=31, 77.5\% \) them to apply the acquired knowledge in the future. As a result, the cohort members would very likely \( n=36, 90\% \) recommend the seminar to others. Despite the sensitivity of the topics, the partakers stated that the presented information was very appropriate \( n=35, 87.5\% \), very easy to understand \( n=34, 85\% \), and very relevant \( n=36, 90\% \) to them and their families. The above findings are shown in Table 4 (Appendix X).

The next part of the survey focused on future ACP seminar improvements where cohort members were asked to select all that applied from seven options. In providing feedback on how to improve the program, \( n=2 \) (5%) participants recommended the reduction of the amount of information while \( n=9 \) (22.5%) individuals recommended an increase in the amount of information during future events. Additionally, \( n=8 \) (20%) partakers shared that the program was too short and suggested lengthening the seminar time while \( n=6 \) (15%) individuals perceived the seminar as too long and proposed shortening its time in the future. Also, \( n=1 \) (2.5%) individual suggested that improvement of the instructional methods should be taken into consideration.
while conducting prospective ACP education, \( n = 1 \) (2.5%) participants proposed provision of better information and \( n = 2 \) (5%) individuals recommended more detailed information.

The last part of the survey encouraged respondents to provide answers to three open-ended questions- (a) What did they like the best in the seminar? (b) What other related programs would they recommend in the future? and (c) Provide additional comments and suggestions? In relating what the participants liked the most about the program, the participants reported that the seminar was “clear,” “informative,” and “concise.” The utilization of “meaningful examples” allowed them to “share personal,” “real-life experiences,” which provoked a fruitful discussion, elicit “difficult” questions, and incited the “clear” answers. The participants also commented on the presenter’s excellent communication skills, especially confidence, listening, empathy, calming tone of voice, respect, and open-mindedness. In providing feedback on what other similar programs they would like to see in the future, the cohort members stated that they would be interested in seminars discussing care of the terminally ill individuals, pro-life dialogues, health maintenance, and disease prevention education. Not a single participant expressed emotional distress during both sessions, though some individuals were crying when sharing their personal stories. The participants expressed gratitude for providing the ACP education and in the copies of Five Wishes AD in their native language. Finally, participants (\( n = 20 \), 50\%) refrained from providing any specific recommendations or suggestions for future ACP programs.

**Discussion**

This scholarly project sought to examine the impact of the culturally tailored ACP education session on readiness to engage in ACP dialogue and AD adaptation in devoted Polish Roman-Catholics. As discussed elsewhere in this paper, the lack of ACP discussions among minority groups and the absence of AD often lead to extreme and life-prolonging EOL
treatments (The Dartmouth Institute, 2016), frequently incongruent with the individual preferences. As anticipated by the PI, the nurse-led culturally tailored ACP education conducted in a faith-based setting, was associated with increased ACP readiness to engage in EOL conversation and ultimately resulted in the AD adaptation among ethnic minority (Dobbs et al., 2015; Lee et al., 2015; Sun et al., 2017). The increase in AD adaptation is concomitant with ethics (Carr, 2012; Dobbs, Park, Jang & Meng, 2015), increase in EOL quality care (Weathers et al., 2016) and decrease in financial strain on the USA healthcare system (Bond et al., 2016; Kaiser Family Foundation, 2016).

Considering the ACP knowledge gained among Polish Roman-Catholics, one can stipulate that the KTA framework had enhanced the success of the project. In addition, the knowledge generation was supplemented using evidence appraisal, identification of the population of interest and evaluation of the needs of both, the population and the faith-based organization endorsing the project.

At the time of the project implementation there were no previously established programs addressing the lack of AD among Polish Roman-Catholics. As discussed in the findings section, the analysis of the socio-demographic survey revealed a reasonable homogenous sample based on the median result (Table 1, Appendix X). The similarity of language, gender, age, marital status, having children, education level, religiosity, and acculturation was not surprising since the participants were recruited from a specific minority population. As anticipated, the cohort represented the single faith churchgoers of Roman-Catholic denomination in a distinct region that consisted of individuals with the same beliefs, values, and life perspectives (CRPC, 2014).

As a result, the ACP intervention supported the project clinical question that culturally-tailored ACP education may impact awareness and completion of AD among the faith-based
community. The above statement was demonstrated in the statistical findings of the ACPES for readiness to engage in ACP dialogue (Table 2, Appendix X) and the high rate of signed AD. Such findings were also congruent with the study results provided by Ko et al. (2013), Kwak et al. (2011), and Kwak et al. (2014) that implementation of ACP conversation, established on the cultural values, provide participants with real-time ACP decision opportunity. Although some participants showed dissatisfaction with the repetitive use of the ACPES survey, the obtained outcomes postulated the intervention was successful and useful for those recruited into the project.

The theoretical framework underpinning the project facilitated the choice of an appropriate project design to successfully deliver the intervention. For example, the inclusion of a Booster Session to the culturally designed ACP education intervention may have been associated with the participants’ readiness to sign the AD. This finding strongly resonates with the study outcomes presented by Sun et al. (2017) that the organized step-by-step AD guidance approach to AD permits to achieve an increase in AD adaption rate among minority groups.

Similarly, all participants declared Polish as their primary language spoken at home. The provision of the language-concordant intervention may have improved the participants’ EOL literacy. As demonstrated by Carr (2011), Howard et al. (2018), Ladin et al. (2018) and Sun et al. (2017), it might have ensured the subject’s meaningful behavior change and further enhanced their readiness to engage in the ACP process.

Moreover, the project findings (Table 3, Appendix X) strongly resonate with the research conclusions made by Backes, Erdmann, & Büscher (2015) that individuals value the quality of life far more than quantity, as life is only worth leaving if an individual is in good health. Also, the results illustrate that the project participants remained skeptical about being kept alive by
noise-making technology (Portanova et al., 2017). Likewise, they were concerned about receiving over aggressive EOL treatment; paradoxically, dying individuals often receive more invasive than desired care in the last days of their life (Brinkman-Stoplenburg et al., 2014; Weathers et al., 2016). Moreover, the majority of project participants would like to spend their final days at home, but as proven by the latest evidence base studies, the expiring individuals often spend their last days in a complex hospital environment (Emanuel & Bekelman, 2016), away from the loved ones.

**Project Strengths**

This project suggests that there are some strengths that should be considered in future quality improvement projects. For example, the ACP Booster Session shown tremendous usefulness in the achievement of a high rate of signed AD as it offered organized step-by-step guidance to bilingual Five Wishes AD. Similar research outcomes were found in studies demonstrated by Lee et al. (2015) and Sun et al. (2017). Additionally, the incorporation of active participation of everyone in the session through collective analysis of all AD wishes, incorporation of practical EOL examples, and the provision of Q & A session may have added value to the intervention. Moreover, the time between the intervention and the Booster Session provided sufficient prospects for participants to translate newly acquired knowledge into meaningful action- AD adaptation (Lee et al., 2015; Sun et al., 2017). The novice linguistically and culturally matched ACP approach, facilitated by the trusted healthcare professional who was perceived as “their own” (Fischer et al., 2015) and the endorsement of the intervention by the priest, further enhanced the success of the project (Fisher et al., 2012; Ladin et al., 2018; Ng & Chong, 2013). Taken together, these findings suggest that ACP is a complex, intense human
process, and step-by-step AD guidance, discussion facilitation, and exchange, and views and information should be given high priority.

Project Limitations

Despite the after-mentioned strengths of the project, there are perhaps some limitations associated with it. For example, the convenience sample being composed of Polish Roman-Catholics naturally created a limitation to the project as the project cohort is not representative of all Polish-speaking members of the community. Caution must be taken while making any generalization of assumptions about the community’s principles, values, and attitudes. In addition to the issue of a non-representative convenience sample, the limited sample size restricted the statistical power of the project.

Also, the four–item ACPES survey, developed by Sudore et al. (2017), was utilized in the project to gauge the impact of the ACP intervention on participants’ readiness to engage in a meaningful ACP dialogue. As discussed elsewhere in the paper, the validated American ACPES version was translated into Polish by the PI, who is the native Polish speaker. However, the translated questions may not have been equivalent across both linguistic groups. Although the psychometric tool testing was not tested for this population, the cross-language survey validity, through the back-translation method, was provided to preserve the tool validity. Nevertheless, the language differences in survey responses may have existed. Consequently, the survey data may have been affected by what would pose a significant project drawback.

Project Facilitators

Furthermore, the KTA model fostered a platform for collaborative implementation of evidence-based efforts to address the existing ACP gap and delivery of translation strategies to
the faith community level. It also allowed the provision of currently garnered ACP knowledge to fit local context.

The Roman-Catholic church, located in Northern New Jersey, offered excellent access to the population in need, in an environment where the participants felt comfortable, safe, and supported. The secured organizational support, through a formal written agreement and endorsement from the priest, further led to positive project attainments. The church’s infrastructure, such as free of charge event space and parking, and availability of audiovisual support, assured that the intervention occurred efficiently, smoothly and cost-efficiently. Also, the familiarity of the PI with the community values, beliefs, religion, culture, ability to communicate in their native language, and professional association with the parish leadership further promoted the successful completion of the project goal. The recruitment process and strategies were coordinated with the church activities, including Sunday services and annual church picnic, which was critical to the assurance of maximum event participation of the church members. Importantly, both- the ACP Seminar and Booster Session occurred immediately after Sunday morning mass what was very convenient for the interested individuals. The ACP intervention was ingrained into religious beliefs and grounded in God’s Word, which was not only well-received by the participants but also potentially promoted their spiritual growth and deepened their understanding of faith and population health as interrelated concepts.

The provision of the Booster Session allowed the PI to cover the desired content in-depth, including the incorporation of various learning tools, such as group discussion, ACP conversation initiation, and personal experience sharing. Such an approach increased the participants’ engagement and permitted them to grasp the ACP concepts better.
Project Barriers

The KTA model supported the identification and assessment of ACP barriers at the implementation site. For example, the recruitment process, had been affected by many various factors. Although the project’s informed consent was culturally appropriate, translated by a native speaker, understandable to the participants, and written at a sixth-grade level, the elderly individuals expressed great hesitance signing it. Additionally, the individuals expressed a general sense of unease toward the concept of project improvement, precisely deception of collecting additional, undisclosed information without permission and withholding or hiding it. Likewise, the potential subjects articulated skepticism when providing personal information, such as names and phone numbers. The identified obstacles arose from the fact that the elderly population, including minority groups, is now an attractive target for identity theft and various scams. In assisting the individuals to make an informed decision about whether to enroll in the project, the PI devoted a long time to review the information presented in the informed consent and explained, in great detail, the role of Rutgers IRB in DNP project approval. Besides, a thorough explanation of the project’s risks, benefits, and project methods was offered to foster a sense of trust among community members.

In addition, the project implementation process was impacted by seasonal activities, precisely vacation time. Unfortunately, during summertime, not many church members attended Sunday services, resulting in a profound negative effect on the recruitment of the projected sample. That fact required the PI to pushed back the recruitment, implementation, and evaluation process by approximately four weeks in order to maximize project participation.

The project also faced some difficulties associated with the allocation of extra project day. The vast number of prospective subjects exhibited discontent with the fact that the project
participation necessitates partaking in two consecutive sessions- ACP Seminar and Booster Session. Although the provision of Booster Session surfaced to be very beneficial for the participants and crucial to the success of the project, it was an additional scheduled session, which potentially resulted in the respondent drop out ($n=5; 12.5\%$).

The provision of language-concordant intervention and resources required the PI to translate necessary documents and materials into Polish to ensure the achievement of maximum project outcomes. Although very rewarding, the pursuit also appeared to be extremely time-consuming. Additionally, to safeguard the validity of the PI’s translation, the back interpretation into American-English was provided by the certified American-Polish translator, which proved to be costly.

**Unintended Consequences**

One of the unforeseen consequences of the project may be an unintentional ability of the PI, as the prominent community leader, to influence participant’s behavior outside of their awareness. This assumption could certainly explain the high rate of program participation. Also, since subjects criticized the repetitiveness of the survey, their responses to the pre-intervention survey could automatically influence the subsequent questionnaires or even misinterpretation of survey questions. Similarly, the participants’ judgment can be anchored when dealing with the Likert scale due to difficulty in deciding the appropriate answer or even misinterpretation of scale.

Additionally, healthy, young participants perceived signing AD as a deliberate act of terminating ones’ lives. The individuals verbalized their opposition between the right of the individual to complete AD and the societal obligation to protect lives to the very end. Such a statement suggests that alternative tools of ACP education should be consider in younger
generation. Although ACP might seem premature in younger adults, educating them with the ACP concept may be beneficial in making healthcare decisions for their loved ones when appropriate (Kavalieratos, Ernecoff, Keim-Malpass & Degenholtz, 2015).

**Process Evaluation**

In terms of evaluating the project goal, objectives and activities, it is safe to conclude that the program has produced desired results, delivered expected benefits and generated desired behavior change. The participants increased their readiness to engage in ACP process, improved understanding of importance of possessing AD and finally took proactive participation in decision making process in the form of adapting Five Wishes AD. The KTA model guided the evaluation of project outcomes and development of suggestions for future project replications.

**Implications**

At the time of the project implementation, there was no known published research discussing the effectiveness of ACP community programs among the Polish minority group. The results of this quality improvement project support the advancements in clinical practice for healthcare providers, research, healthcare policy, education, and quality and safety. The implications apply to providers, state and national organizations, and are discussed below.

**Clinical Practice and Research**

The results of the ACP program demonstrate that the active support of minority groups with ACP discussions requires healthcare professionals not only to possess thorough clinical expertise but also ability to understand one’s culture, values, and religious beliefs. The ACP intervention portrayed in this project can be safely adapted for use in other ethnically diverse groups with various EOL literacy levels and different community settings such as libraries, senior citizen centers, or residential healthcare facilities. However, the project highlights the need
for more research on the variables that genuinely affect readiness to engage in the ACP process in the promotion of the EOL dialogue that is sensitive to the participant’s culture and beliefs. Further studies are needed to assess the influence of individual ACP community interventions to increase EOL knowledge within the population. One can indeed educate the community about the importance of AD documentation, but if the community members do not share their EOL desires with their loved ones or primary providers, it is difficult to assess the effect of the intervention on a large scale.

**Healthcare Policy**

The community-based ACP educational intervention introduced in this quality improvement project prospectively ensures that the recruited minority subjects will receive EOL care consistent with the personal preferences, provides guidance to the families and most importantly, it will reduce their decisional burden. Such intervention lays the ground for policy makers to increasing community efforts, strengthening ACP strategies and providing culturally-sensitive information that facilitate and guarantee AD adaption.

Promoting and improving ACP practice will require comprehensive changes across the entire healthcare system and among healthcare providers. As the culturally-tailored ACP intervention portrayed in this project, clearly does not fit within a standard of a typical clinic visit (Hutchison et al., 2017), the healthcare professionals need to advocate for better ACP reimbursements to facilitate EOL public education. The project results offer convincing evidence that in order to help spreading advocacy for and practice of ACP, careful consideration for linguistically prepared and culturally sensitive ACP facilitators are needed for successful execution of ACP (Fischer et al., 2015). The likelihood of reducing racial disparity in ACP endeavors, encompasses the need to include multiple collaborative strategies to increase diversity
in nursing. Thus, the role of minority nursing organizations in increasing ACP equity and the preparation of ethnic minority nurses to assume more significant leadership roles, cannot be overemphasized, and should remain a national priority. It is fundamental to create and support policies to ensure workforce diversity, but also it is critical to provide funding to nurse-led community efforts. Consequently, the “research mistrust” concept, encountered in this project, needs be efficiently addressed to facilitate widespread research engagement among unique ethnic groups. Moreover, the federal guidelines and IRBs policies ought to be appropriately reevaluated to address Limited English Proficiency (LEP) to enable research participation by minority groups.

Additionally, to comply with the recommendation of the IOM report (IOM, 1997), specific EOL policies should be in place to mandate healthcare providers to have ACP discussions with particular populations such as terminally and chronically ill, and minority groups. Healthcare professionals need to support the evidence base research focused on the establishment of the best ACP guidelines and the best EOL practices to incorporate the education of such sensitive and complex topic among general and minority populations. As discussed elsewhere in this paper, the PSDA law requires AD documentation in Medicare and Medicaid funded facilities, despite individual’s age, language or religious orientation. Similarly, on the State Level, the New Jersey Advance Directives for Health Care Act (N.J.S.A. 26:2H-53 et seq.), encourages the public to plan ahead for EOL decisions through utilization of AD. Analogously, on the Professional Level, the Code of Ethics (ANA; 2015) obligates registered nurses to engage public in ACP discussions to promote the self-determination right.

Notably, faith-based organizations are in a crucial position to be reliable clinical partners for population health by collaborating in various nursing projects. As proven by this quality
improvement project, the student gained a good understanding of integrating ethical issues with the faith and culture of those they are serving, whereas members of the faith-based setting obtain very much needed health promotion services.

**Quality and Safety**

The above ACP intervention empowered the participating healthcare consumers to start important EOL conversation and enabled them to express their EOL preferences. When healthcare wishes are clearly stated in writing, the guilty feeling and family disagreements may be avoided. Moreover, having completed the Five Wishes AD, assist healthcare providers in respecting the individual beliefs in case of life-limiting illness and results in enhanced overall EOL care satisfaction among involved parties. Moreover, the individuals nearing the EOL may clearly state how they want to be treated, how their pain needs to be managed and decide what their family members and other are to know. Therefore, the open ACP discussion dramatically improves quality of life at the EOL, promotes affected individual’s self-reliance, reduces uncertainty and fear, and reinforces trust among involved parties (Hutchison et al., 2017).

The ACP intervention findings demonstrated the applicability of the ACPES tool in measuring the readiness of the Polish minority group to engage in ACP discussion and allowed them to express their EOL wishes. Further EOL discussions with the loved ones and primary care physician, based on the adapted AD, aim to ensure that the individual EOL wishes are respected. The open-minded ACP discussions reduce the fear associated with death and dying concept and reinforce trust among partakers (Hutchison et al., 2017).

Perhaps, NJHQI could incorporate the four-item ACPES tool during current and future COYL events, to assess the impact of their programs on public readiness to engage in ACP
discussions. The organization may consider the development of culturally-tailored interventions to address the complex needs of various minority groups residing in New Jersey.

**Education**

The project demonstrated that ACP education and training were the primary facilitators of ACP discussion. However, lack of education and training among healthcare professionals has been reflected in numerous studies (Chan et al., 2016; Hutchison et al., 2017). Perhaps, incorporation of comprehensive EOL care education should be integrated into undergraduate and graduate curriculum to assist providers with knowledge and skills to address ACP disparities. Additionally, the ACP re-education is essential to community nurses as they have a key role in providing EOL community care and are the central facilitators of ACP process.

Perhaps, providing ACP competency training for spiritual leaders to become more knowledgeable about ACP is essential to designing an effective ACP approach within the faith-based communities. Priests, chaplains and community clergy have the potential to minimize the existing AD completion gap through a natural spread of ACP information till it eventually becomes the norm in the society.

**Economic Implications**

The ACP community-based initiative portrayed in this quality project improvement enhanced the ACP awareness and engaged Polish-American minority group in EOL conversations by providing accessible resources. The promising new partnership between the community and the religious system emerged with the explicit goal of increasing AD rates among the studied ethnic group and allowed the underserved population informatively to express their EOL wishes and preferences before an imminent crisis occur. Many aggressive interventions may leave individuals confined to nursing homes, dependent on feeding tubes for
survival, comatose or vegetative state, and as a result it exposes the stakeholders to an overwhelming financial burden. The ACP intervention has a potential of decreasing aggressive EOL medical care among the studied population and ultimately reduce the economic burden to the participating taxpayers, their families and to Medicare and other insurance companies. Additionally, the cost of the aggressive EOL care can be offset through cost savings related to less aggressive EOL care congruent with individual preferences (Brinkman-Stoppeleburg et al., 2014). The emerging study conducted by Bond et al. (2018) demonstrated an overall reduction in hospitalization costs ranging from $1,748 to $9,500 per individual, due to decrease in healthcare utilization without any significant increase in mortality (Lilly et al., 2017; Liu et al., 2017).

**Sustainability of the Project**

The successful execution of the project does not always lead to long-term program sustainability and naturally requires action alignment of dedicated leaders to extend the program beyond the initial outcomes. The KTA framework steered the sustainability of the project through the dissemination of project findings. The author of this project plans to actively support all parish educational events where ACP discussion might be appropriate. In addition, the primary investigator will assist the NJHQI in rolling out the Passaic COYL campaign which is tentatively scheduled for implementation in the Fall of 2019 (NJHQI, 2018b).

**Plans for Dissemination of Professional Reporting**

To build upon the existing ACP knowledge base related to the enhancement of ACP engagement among Polish-American Roman-Catholics, the dissemination of the obtained findings is paramount. The propagation of the accomplished outcomes will happen through the formal presentation of project findings before the designated DNP committee, Rutgers poster presentation and manuscript publication in *Christian Nursing, Geriatric Nursing, Age and Aging,*
The World Among Us and Journal of Pain and Symptom Management scholarly magazines. Additionally, the project findings are expected to provide a solid recommendation for future ACP programs among similar population and therefore, the results of the project will be shared with NJHCQI, Passaic COYL task force and Dr. R. Sudore.

**Conclusion**

ACP is the process by which individuals reflect upon their personal EOL preferences and values, document their wishes in AD and share their choices with loved ones, friends, primary care provider, and spiritual leader. Unfortunately, the care at EOL is becoming more intense with the increased use of the inpatient facilities, specifically ICU. Within the community context, especially the Polish minority groups, the readiness to participate in a meaningful ACP process requires culturally appropriate ACP intervention to elicit the EOL discussion before crises occur. The project lends support to the value of a nurse-facilitated ACP intervention in a supportive church setting, where the individuals are provided with an opportunity to appreciate the usefulness and applicability of ACP. As a result, the conversation naturally happens earlier and permits the individuals to find a better path to the EOL journey, congruent with their values and desires.
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doi: https://doi.org/10.3399/bjgp17X694145

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Nurse Practitioners*, 29(9), 535–542.

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You, J. J. (2018). Original article: Outcomes that define successful advance care
245–255. doi: https://doi.org/10.1016/j.jpainsymman.2017.08.025


### Table of Evidence

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<tr>
<th>Article #</th>
<th>Author &amp; Date</th>
<th>Evidence Type</th>
<th>Sample Size &amp; Setting</th>
<th>Study findings that help me answer my EBP Question</th>
<th>Limitations</th>
<th>Evidence Level &amp; Quality</th>
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</thead>
<tbody>
<tr>
<td>1</td>
<td>Carr, D. (2012)</td>
<td>Non-experimental, cross-sectional study</td>
<td>National sample data</td>
<td>Analyses of Asian, White, Black, and Asian-Black married and cohabiting couples show that fewer Asian-Americans than Whites have EOL conversations, but more often adapt ADs.</td>
<td>Only basic demographics, socioeconomic status, and one health indicator examined in the study.</td>
<td>Level: III Quality: Good</td>
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<td>2.</td>
<td>Dobbs, D., Park, N. S., Jang, Y., &amp; Meng, H. (2015)</td>
<td>Non-experimental, cross-sectional study.</td>
<td>n=675 Korean-American older adults. Community-dwelling settings, including senior centers and housing, elder associations and churches.</td>
<td>Study analysis showed that female gender (95% CI = 1.06–2.51), married status (95% CI = 1.21–4.17), higher education level (95% CI = 2.40–8.25), and health insurance ownership are associated with AD engagement and awareness. 82% of participants revealed acculturation score of 17.8 ± 7.6, one-fifth had AD awareness and 18.6% adapted AD post intervention. Higher level of education correlated to ACP engagement and AD completion (Spearman correlation coefficient = 0.53, p &lt; .001).</td>
<td>Cross-sectional study design made impossible to draw causal relationship between predictors and outcomes. Descriptive ACP awareness and AD completion questions failed to address complex ACP concepts.</td>
<td>Research Level: III Quality: High</td>
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<td>3.</td>
<td>Fischer, S. M., Sautuaia, A., Min, S.-J., &amp; Kutner, J. (2012).</td>
<td>Non-experimental, prospective observational cohort study.</td>
<td>n=458 Caucasian and Latino hospitalized adults. Veteran’s Affairs organization, academic medical center and safety net hospital.</td>
<td>Only 29% of Latino participants reported AD discussions, compared to 54% of Whites ($p = 0.0002$). 24% of participants (25% Latino and 26% Caucasians) included AD in their health record. However, the $p$ value noted not to be significant. No significant difference noted between Latinos and Caucasians in regard to AD completion and inclusion in medical record (OR 1.44, CI 0.73–2.85).</td>
<td>Only acutely ill and recently hospitalized individuals included in the study. The research unable to determine if the AD conversations actually happened since the medical records were the only evidence of AD existence. The AD rates have not reflected individuals who had adapted them in another setting but had not included them in their medical record</td>
<td>Research Level: III Quality: Good</td>
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<td>4.</td>
<td>Fischer, S., Cervantes, L., Fink, R., &amp; Kutner, J. (2015).</td>
<td>Experimental, pilot randomized controlled trial.</td>
<td>$n=64$ English and Spanish speaking Latino adults with serious illness. Community dwelling setting in Denver, Colorado.</td>
<td>81% of participants assigned to the intervention group experienced at least one culturally tailored education and home visit with the community navigator. ACP rate noted to be higher in the intervention group (47%) than the control group (25%, $p=0.06$) Hospice enrollment noted to be similar between intervention and control groups ($n=7$ vs. $n=6$).</td>
<td>Limited study generalizability due to low enrollment rate. Not all the participants received the same number of interventions. Missing data for 11 participants who lacked follow-up clinical encounters.</td>
<td>Research Level: I Quality: High</td>
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<td>5.</td>
<td>Hinderer, K., Lee, M. C. (2014).</td>
<td>Experimental, pilot study utilizing a quasi-experimental study.</td>
<td>$n=86$ English-speaking Caucasian and other race adults. Community-dwelling, Wicomico County, Maryland and Sussex County, Delaware.</td>
<td>82.6% of attendees found the ACP seminar very useful. 97.7% reported the intent to adapt the AD and plan to participate in ACP discussions with their families. The AD attitudes noted to be high throughout the study sample. Older women adapted AD more often compared to younger female participants. In general females were more likely than men to engage in ACP discussions.</td>
<td>Homogeneous study with limited size sample. Pre-seminar AD baseline unknown but would have been very helpful. Difficult to generalize study finding since AD and ACP laws and regulations vary from state to state.</td>
<td>Research Level: II Quality: High</td>
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| 6.       | Hong, M., Yi, E.-H., Johnson, K. J., & Adamek, M. E. (2017). | Experimental, systematic review with quasi-experimental method. | 26 studies, including qualitative research. | Evaluated studies reported the ACP engagement among ethnic minority groups from 0 up to 29%.  
All research piloted among racial minority groups with any disease revealed 40%–59.1% ACP engagement after appropriate ACP intervention.  
Variables that facilitated or impeded ACP engagement and awareness were recognized. These include socio-demographic status, health outcomes, ACP literacy level, spirituality and cultural values. | All literature review studies utilized convenience sampling, making the findings difficult to generalize to all ethnic groups.  
Unable to establish the causality between some of existing barriers and ACP engagement due to inclusion of quantitative studies.  
Also, unable to establish clear distinctions between ethnicities. | Research  
Level: I  
Quality: High |
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<td>7.</td>
<td>Huang, C., Crowther, M., Allen, R., Decoster, J., Kim, G., Azuero, C., Kvale, E. (2016)</td>
<td>Experimental, mixed-method randomized controlled trial.</td>
<td>$n=30$ African-American English-speaking adults. Multiple rural community-dwellings located in South Carolina, Mississippi, Florida, Alabama, Georgia, Louisiana and Texas.</td>
<td>All 30 study participants reported high satisfaction with the ACP intervention (SD = 0.44) and enhanced intent to adapt an AD post program. A substantial rise in AD knowledge from pre- to post- intervention was noted in the intervention group ($p = 0.01$). As expected, no substantial difference was noted in the control group. The primary barriers to ACP discussions were identified as mistrust of doctors, lack of ACP information, and avoidance of death discussions.</td>
<td>Limited sample size and geographical specificity restricted the study findings generalizability. Inability to simulate ACP response in the control group was noted since no ACP educational material was offered.</td>
<td>Research Level: I Quality: High</td>
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<td>8.</td>
<td>Ko, E., &amp; Berkman, C. S. (2012).</td>
<td>Non-experimental, exploratory, qualitative study with focus groups.</td>
<td><em>n</em> = 25, 65 and older Korean American adults. Two senior centers and one primary care practice in New York City Neighborhoods.</td>
<td>Most participants reported increased ACP awareness, had a positive attitude toward completing AD and acknowledged the benefits of doing so. 50% participants agreed that AD is not necessary because their family will be able to make decisions for them. The majority of participants acknowledge that AD may be necessary even when there is a good relationship between doctor and patient. Three-quarters of participants believed that a health care proxy is not needed when there are trusted family members who can make decisions for them. Also, slightly more than half agreed that a health care proxy is not needed when there is a good relationship with the doctor.</td>
<td>Limited study generalizability due to small sample and selection bias (senior center’s residents who reported good health condition).</td>
<td>Research Level: III Quality: Good</td>
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<td>9.</td>
<td>Kwak, J., Ko, E., &amp; Kramer, B. J. (2014).</td>
<td>Non-experimental, exploratory study.</td>
<td>(n=24) case managers and supervisors of care management teams. Wisconsin County Department of Family Care.</td>
<td>Four main barriers to ACP awareness and engagement were identified: cultural taboo; belief that act of death is beyond human control; shared decision-making obligation; and preparation for EOL care defined as an unknown concept. Participants recommended to tackle these barriers through development of community trust, propagation of cultural knowledge, respect for ethical values; promotion of surrogate; culturally tailored education of families and community leaders.</td>
<td>Limited study generalizability due to small sample size, sample selection and small geographical area. The view and interpretations introduced in the study are based only on a specific sample rather than ethnically diverse elders and their loved ones. The study lacked the discussion on strategies to engage families in ACP discussions with the elders.</td>
<td>Research Level: III Quality: High - Good</td>
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<td>10.</td>
<td>Kirchhoff, K., Hammes, B., Kehl, K., Briggs, L., &amp; Brown, R. (2012).</td>
<td>Experimental, randomized controlled trial.</td>
<td>n=313 Caucasian adults with heart failure and renal disease and their surrogate healthcare decision-makers. Wisconsin community associated with clinics and dialysis units.</td>
<td>Post ACP intervention, 74% of study participants continued to make their own EOL decisions. The intervention group had less (1/62) events in which individual’s EOL preferences were not honored than in the control group (6/48). Due to greater ACP awareness, more individuals from the intervention group withheld from hemodialysis treatment than the controls.</td>
<td>Limited generalizability due to mostly Caucasian sample, only one state involvement and only two chronic illnesses utilization. Quality of collected data effected by a) surrogates not seeing themselves as decision-makers; b) difficulty gaining access to medical records from non-study locations; c) some participants lacked medical record since they passed away at home. ACP intervention given only once without a booster.</td>
<td>Research Level: I Quality: High</td>
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<td>11</td>
<td>Ladin, K., Buttafaro, K., Hahn, E., Koch-Weser, S., &amp; Weiner, D. E. (2018).</td>
<td>Non-experimental, qualitative/descriptive study.</td>
<td>n=31 dialysis patients. Two dialysis centers, Boston, MA.</td>
<td>13% of participants discussed their EOL wishes with physician at baseline and 25% openly indicated that they had never contemplated EOL wishes. Post ACP intervention, 50% of participants acknowledged increased ACP awareness which prompted them to discuss their EOL preferences with their support system. Less than 30% of individuals were not able to properly define EOL terminology used during EOL ACP discussions. Study analyses generated five arguments in regard to low AD adoption: (1) misinterpretation of EOL terminology; (2) physicians hesitant to EOL discussions; (3) participants fitting into socially composed roles; (4) disagreeing expectancies and treatment care delivered; and (5) integrating EOL principles and care opportunities.</td>
<td>Limited study generalizability due to specific sample. Sample bias since the participants were recruited from areas of high healthcare market competition and exhibited high education levels. Probability that some participants have not fully shared their experiences due to the topic sensitivity. Possibility that other themes may arise in other settings.</td>
<td>Research Level: III Quality: Good</td>
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<td>12.</td>
<td>Lee, M. C., Hinderer, K.A., Friedmann, E. (2015).</td>
<td>Quasi-experimental study utilizing a single group pre- and post-intervention design.</td>
<td>$n=72$ Chinese American adults. Urban community-dwelling center, Washington, DC.</td>
<td>69.4% of participants reported they have not had AD before intervention and 20% of them adapted the AD a month after the intervention. 62.5% of participants have not had any prior ACP discussions and 35.6% of them stated having an ACP conversations.</td>
<td>Convenience sample limited finding generalizability. All instruments utilized during the study were not validated in any other research. The level of acculturation was not measured.</td>
<td>Research Level: II Quality: Good</td>
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<td>13.</td>
<td>Livingston, G., Lewis-Holmes, E., Pitfield, C., Manela, M., Chan, D., Constant, E., Livingston, G. (2013)</td>
<td>Quasi-experimental study utilizing a single group pre- and post-intervention design.</td>
<td>n=30 Jewish home residents their families and staff. Dementia nursing home, London, UK.</td>
<td>Significant increase in AD documentation aroused due to participants and their relatives’ engagement in EOL conversations with health professionals. Also, significant growth noted in DNR orders among 16 participants (73%, ( p &lt; 0.001 )), dying in home settings (76%) versus to inpatient setting (47%; ( p &lt; 0.02 )). Moreover, the general satisfaction of family members has improved from 7.5 (SD = 1.3) at baseline to 9.1 (SD = 2.4) post-intervention.</td>
<td>Limited generalizability due to small sample size and motivated/ atypical nursing staff. Low staff turnover. Recent changes in dementia policy may influence the generalizability of the study.</td>
<td>Research Level: II Quality: Good – Low</td>
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<td>14.</td>
<td>Lyon, M. E., Squires, L., D’Angelo, L. J., Benator, D., Scott, R. K., Greenberg, I. H., Wang, J. (2019).</td>
<td>Experimental, longitudinal, blinded, two-arm, randomized controlled trial with intent-to-treat design.</td>
<td>$n=233$ African-Americans, American Indian/Alaska Natives, White/Caucasian adults with HIV and their surrogate decision-makers. Community-dwelling, Washington, DC.</td>
<td>Three months post FACE intervention the AD adoption in the intervention groups increased to 59% from 13% at baseline as opposed to 17% in the control groups ($p &lt; 0.0001$). Additionally, the probability of having an AD was seven times greater in the randomized group than the non-intervention group ($p &lt; 0.0001$). Additionally, 58% of African-Americans had adapted AD compared to 20% of controls ($p &lt; 0.0001$).</td>
<td>Limited study sample due to inability of the 92% of potentially eligible participants to identify a surrogate. Absolute blinding was hard to preserve at the study sites. Moreover, the RA-Assessors have not received formal ACP training to minimize bias. Additional bias was potentially introduced through face-to-face assessments.</td>
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<td>Pecanac, K., Repenshek, M., Tennenbaum, D., &amp; Hammes, B. (2014).</td>
<td>Experimental, retrospective study.</td>
<td><em>n</em>=732 retrospective chart reviews of racial minorities. Midwestern Metropolitan Hospital, La Crosse County, Wisconsin.</td>
<td>The post intervention AD occurrence improved significantly for ethnic minorities from 25.8% to 38.4%, resulting in a significant average treatment effect (<em>p</em> = 0.011). The improvement in AD occurrence for Caucasians was minimal (0.6%), and the average treatment effect was not significant (<em>p</em> = 0.648). There was an increase in AD prevalence (35.9% to 42.9%), although the average treatment effect was not statistically significant (<em>p</em> = 0.069).</td>
<td>Study design limits generalizability. It is unknown if decedents were personally affected by the program as groups were assessed before and after intervention. Both groups were also composed of different decedents. Other possible influences or secular trends, aside from the intervention, may have influenced the results. Some of the measures included smaller sample sizes due to infrequency of occurrence.</td>
<td>Research Level: II Quality: High</td>
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<tr>
<td>Article #</td>
<td>Author &amp; Date</td>
<td>Evidence Type</td>
<td>Sample Size &amp; Setting</td>
<td>Study findings that help to answer my EBP Question</td>
<td>Limitations</td>
<td>Evidence Level &amp; Quality</td>
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<td>17.</td>
<td>Splendore, E., &amp; Grant, C. (2017).</td>
<td>Quasi-experimental study with a single group pre- and post-intervention design.</td>
<td>n=40 Caucasian, English-speaking adults. Rural-dwelling community, Pittsburgh, Pennsylvania.</td>
<td>Post intervention, 15 participants testified having a completed AD. 13 participants stated that the Five Wishes form utilized at the seminar was very useful. Additionally, 93% of participants had discussed their ACP preferences with their loved ones and 13% had disseminated their AD to the appropriate parties.</td>
<td>Participation based on convenience effecting the finding’s generalizability Homogenous study. Study instruments not validated. None of the participants disseminated AD to their provider. The study resources were known to the research leader and may have had an impact on participated individuals.</td>
<td>Research Level: II Quality: Good</td>
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<td>Article #</td>
<td>Author &amp; Date</td>
<td>Evidence Type</td>
<td>Sample Size &amp; Setting</td>
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<td>18.</td>
<td>Sudore, R. L., Heyland, D. K., Lum, H. D., Rietjens, J. A. C., Korfage, I. J., Ritchie, C. S., You, J. J. (2018).</td>
<td>Non-Research, Consensus Panel</td>
<td>52-member Delphi panel from four nations and various disciplines.</td>
<td>Establishment of Organizing Framework outcome domains: process, actions, quality of care, and health care utilization. The major five consensus outcomes included 1) reliable care based on EOL goals, 2) surrogate designation, 3) surrogate documentation, 4) EOL discussion with surrogates, and 5) EOL preferences documented, recorded and easily accessible.</td>
<td>Study has not generated valid measurement methods for the highest rated outcomes, especially reliable care consistent with EOL goals. Delphi panel experts were recruited from only four countries. Therefore, self-selection and information bias may have occurred. Patients and family members may have various ACP perspectives and must be included in ACP research.</td>
<td>Non-Research Level: IV Quality: High</td>
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<tr>
<td>Article #</td>
<td>Author &amp; Date</td>
<td>Evidence Type</td>
<td>Sample Size &amp; Setting</td>
<td>Study findings that help to answer my EBP Question</td>
<td>Limitations</td>
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<td>19.</td>
<td>Sun, A., Bui, Q., Tsoh, J. Y., Gildengorin, G., Chan, J., Cheng, J., Lai, K., McPhee, S., Nguyen, T. (2017).</td>
<td>Quasi-experimental study utilizing a single group pre- and post-intervention design.</td>
<td>n=174 Chinese and Vietnamese English-speaking adults. Two Chinese Protestant and two Vietnamese Catholic churches, California.</td>
<td>Culturally-sensitive education and guidance significantly increased participants' AD-related knowledge and intentions. Study findings showed 71.8% AD adaption, and 25.0% EOL conversation with proxies among participants. The intervention also increased in supportive AD beliefs and attitudes.</td>
<td>Absence of a control group limited the findings. Convenience sampling may have introduced bias. Knowledge measure did not stipulate that AD was effective only when individuals unable to communicate their EOL preferences. Limited sample size enabled to evaluate the value of each intervention’s element.</td>
<td>Research Level: II Quality: Good</td>
</tr>
<tr>
<td>Article #</td>
<td>Author &amp; Date</td>
<td>Evidence Type</td>
<td>Sample Size &amp; Setting</td>
<td>Study findings that help to answer my EBP Question</td>
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<td>20.</td>
<td>Van Scoy, L. J., Howrylak, J., Nguyen, A., Chen, M., &amp; Sherman, M. (2014).</td>
<td>Non-experimental, prospective cross-sectional study with structured interviews.</td>
<td>( n = 130 ) hospitalized adults. Urban University Hospital.</td>
<td>Study findings showed that patients with AD were older ((p &lt; 0.001)), possessed higher level of religiosity ((p = 0.04)), had offspring ((p = 0.03)), and were widowed ((p &lt; 0.001)) compare to the patients without AD. Participants were approximately 11 times more likely to adapt an AD when asked and guided by medical personnel, or family and friends, compared to those who were not coached. Participants with prior EOL experience and ACP knowledge were approximately three times more likely to adapt an AD and four times more likely to possess an AD than those without experiences.</td>
<td>Small sample size with predominantly female and black participants. Study has not confirmed the assumption that age, race, and gender have an impact on AD and EOL preferences. Although, the study showed the low rate of AD adaptation, it is a consistent finding with the national literature. Reported variables were grounded in patients’ personal EOL recollections and may be biased.</td>
<td>Research Level: III Quality: Good – Poor</td>
</tr>
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Appendix B

Conceptual Framework Map
Appendix C

ACP Seminar Verbal Announcement

ACP Seminar Verbal Announcement

Medical advances bring new and complex questions regarding medical treatments and moral decision making. Our Catholic faith offers both a long tradition of reflection and Church teaching to help to guide us through these issues. Please join us for the Advance Care Planning Seminar, hosted by a Doctoral student of Rutgers School of Nursing, Anna Wagner, to learn about preparing for end-of-life healthcare decisions. The Primary Investigator of this research study is Dr. Edna Cadmus who can be reached at 973-353-1428 or emailed at ednacadm@sn.rutgers.edu.

The seminar is for Polish-speaking adults, age 18-89, and those who are caregivers for parents or the loved ones will find the event very meaningful. The eligible participants will attend two-90 minutes free of cost study sessions — Seminar and Booster Session, held two weeks apart. The seminar research study activities will include completion of demographic and pre-intervention surveys, viewing of “Anna’s Story” short film, discussion on end-of-life experience, Advance Care Planning PowerPoint presentation and completion of post-intervention survey. Similarly, the Booster session will include the “Before I Leave” icebreaker, end-of-life question and answer segment, adaptation of Five Wishes and completion of follow-up and program evaluation surveys.

Light refreshments will be provided. Please register for the event with Anna Wagner on XXXXX/19, XXXXX/19 and XXXXX/19 after 10 am church service.
Appendix D

ACP Seminar Church Bulletin Advertisement

ACP Seminar Church Bulletin Advertisement
Sunday, XX/XX/19 and XX/XX/19 11:30-13:00 pm: Advance Care Planning Seminar prepared by a Doctoral student of Rutgers School of Nursing. Learn how to plan for end-of-life care, talk about it and discuss this important concept with your loved ones, and your healthcare provider. Upon the conclusion of the seminar, all attendees will have an opportunity to complete an Advance Directive if they choose. All interested participants, please register for the event with Anna Wagner on XX/XX/19, XX/XX/19 and XX/XX/19 after 10 am church service. Light refreshments will be provided during both events. Please register after church this week!
Appendix E

Event Flyer

“Life is pleasant. Death is peaceful. It’s the transition that’s troublesome.”

Isaac Asimov

“ADVANCE CARE PLANNING ENGAGEMENT AMONG DEVOTED POLISH ROMAN-CATHOLICS”

A health crisis may hit ANY of us, ANYTIME, at ANY age..... Are you ready to engage in Advance Care Planning?

WHO: Polish-American Roman-Catholic adults age 18-89 with ability to speak, write and communicate in Polish are invited to participate in an Advance Care Planning research study. 40 eligible participants will attend two 90 minutes study sessions – Seminar and Booster Session, at no cost.

WHY: The purpose of the research is to engage Polish-American community in a meaningful conversation about Advance Care Planning and discuss the values and treatment choices at the end-of-life. The benefit of taking part in this research study includes access to various information and materials that can greatly assist you and your family in planning for end-of-life. The Advance Care Planning research study will consist of the following research study activities:
- Completion of demographic, pre-intervention, post-intervention and follow-up surveys.
- Viewing of “Anna’s Story” film, discussion on end-of-life experience, Advance Care Planning PowerPoint presentation, end-of-life question and answer session and adaptation of Five Wishes

YOU WILL LEARN:
- Roman-Catholic Church teaching about withdrawal and withholding life-sustaining treatments, palliative care and hospice
- Advances of medicine such as resuscitation, breathing machines, and feeding tubes
- Different types of Advance Directives, how to identify the surrogate decision maker and how to adapt Five Wishes for yourself
- Various strategies to initiate the end-of-life conversation with your loved ones and healthcare provider

WHERE: XXX Roman-Catholic Church, 49 Speer Ave, Clifton, NJ 07013 Ph# 973-779-4102

WHEN: XX/XX/2019 and XX/XX/2019

CONTACTS: For registration and information, please contact
Primary Investigator: Dr. Edna Cadmus [redacted] Email: [redacted] Project Coordinator: Anna Wagner Email: [redacted]
Appendix F

Informed Consent

CONSENT TO TAKE PART IN A RESEARCH STUDY

TITiLE OF STUDY: Advance Care Planning Engagement Among Devoted Polish Roman-Catholics.

Principal Investigator: Edna Cadmus, PhD, RN, NEA-BC, FAAN
Project Coordinator: Anna Wagner, BSN, RN, CCRN

STUDY SUMMARY: This consent form is part of an informed consent process for a research study and it will provide information that will help you decide whether you want to take part in this study. It is your choice to take part or not. The purpose of the research is to provide you with an opportunity to engage in a meaningful conversation about Advance Care Planning. If you take part in the research, you will be asked to complete pertinent surveys and attend (a) the Advance Care Planning Seminar and (b) the Advance Care Planning Booster Session. Both events will be hosted two weeks apart. Your total time in the study will take three hours — (a) 90-minutes for the Advance Care Planning Session and (b) 90-minutes for the Advance Care Planning Booster Session. Possible harms or burdens of taking part in the study may be emotional, psychological and spiritual distress resulting from the purposeful dialogues reflecting on death and dying process, as well as recalling uncomfortable end-of-life experiences. The spiritual leader will be readily available to provide emotional and spiritual support in case you experience any emotional discomfort. Additionally, to alleviate such risk, you can withdraw from the intervention completely at any time. The possible benefits of taking part in the study may be access to various information and materials that can greatly assist you and your family in planning for end-of-life care. Your alternative to taking part in the research study is not to take part in it.

The information in this consent form will provide more details about the research study and what will be asked of you if you choose to take part in it. If you have any questions now or during the study, if you choose to take part, you should feel free to ask them and should expect to be given answers you completely understand. After all of your questions have been answered and you wish to take part in the research study, you will be asked to sign this consent form. You are not giving up any of your legal rights by agreeing to take part in this research or by signing this consent form.

Who is conducting this research study?
Anna Wagner, a Rutgers School of Nursing Doctoral student is the Project Coordinator (PC) of this research study who has the overall responsibility for the conduct of the research. She will ask you to sign this informed consent. You will be given a copy of the signed consent form to keep.
Anna Wagner may be reached at phone # [redacted]. If you have any questions about your rights as a research subject, please contact the Newark Institutional Review Board Director at 973-353-1090 or by mail at Ackerson Hall, Room 220, 1800 University Avenue, Newark 07102. You may also contact the committee chair, Dr. Edna Cadmus at 973-353-1428 or email at ednacadm@sn.rutgers.edu.

What is Advance Care Planning?
It is a process that enables you to make plans about your end-of-life care. The process specifically seeks to ensure that you take necessary steps to discuss and document personal preferences and values regarding medical care in the case of serious or life-limiting disease. It also warrants that you receive the desired end-of-life care in the setting of your own choices.

What is Advance Directive?
It is a legal document that allows you to describe your specific end-of-life preferences in the event of a serious illness, injury, or age-related decline. The document will guide your family and healthcare providers through the medical treatments that you wish to receive if you are no longer able to communicate your wishes.

Why is this study being done?
The intention of this research is to increase Advance Care Planning engagement and improve Advance Directive completion among devoted, non-English speaking Polish Roman Catholics. The intervention will allow you and your family to engage in a meaningful conversation about Advance Care Planning and discuss your values and your treatment choices at the end-of-life. The purpose of this research study is also to determine the efficacy of the program.

Who may take part in this study and who may not?
In order to participate in the study, you must be of Polish-American ethnicity, Roman-Catholic religion, age 18-89, and have the ability to read, write and communicate in the native Polish language. You must not have any physical (e.g. blindness) or cognitive impairment which may prevent your full participation in the Advance Care Planning intervention.

Why have I been asked to take part in this study?
You are invited to participate in the study to evaluate the impact of the Advance Care Planning intervention on the Advance Care Planning engagement among Polish Roman Catholics. You will be one of approximately 40 study participants.

How long will the study take and how many subjects will take part?
A convenience sample of Polish-American adults from your Roman-Catholic parish will serve as the study population. The projected study sample size will be 40 participants. As an eligible participant you will commit to attend two-90 minutes free of cost study sessions (a) the Advance Care Planning Seminar and (b) the Advance Care Planning Booster Session. The sessions will be conducted two weeks apart. The overall length of the study will be two weeks.
What will I be asked to do if I take part in this study?
You will be asked to attend two 90-minute Advance Care Planning sessions (a) the Advance Care Planning Seminar and b) the Advance Care Planning Booster Session. The sessions will be held two weeks apart.

During the Advance Care Planning Session, you will be asked to complete a demographic survey and the Advance Care Planning Engagement Survey. It will take approximately 10 minutes to complete both surveys. After you complete the questioners, you will attend a one-hour educational session, including (a) end-of-life video watching, (b) overview of Advance Care Planning concepts through PowerPoint presentation, (c) introduction of Polish-English version of Five Wishes, and (d) group discussion related to personal end-of-life experience. At the end of the seminar you will be asked to complete the program evaluation survey and the Advance Care Planning Engagement Survey. It will take approximately 10 minutes to complete both questioners.

In two-weeks, you will be asked to return for the 90-minute Advance Care Planning Booster Session, which will include (a) welcoming statement, (b) ACP icebreaker, (c) questions and answers, and (d) a step-by-step guidance to adaptation of Five Wishes. You will be also provided with an opportunity to complete your own Five Wishes form. At the end of the Advance Care Planning Booster Session you will be asked again to complete the Advance Care Planning Engagement Survey. It will take approximately five minutes to complete the questioner.

What are the risks and/or discomforts I might experience if I take part in this study?
A risk of harm associated with the project involvement is minimal. It may consist mostly of emotional, psychological and spiritual distress resulting from the purposeful dialogues reflecting on death and dying process, as well as recalling uncomfortable end-of-life experiences. To alleviate such risk, please be aware that you can withdraw from the intervention completely at any time. In addition, the spiritual leader will be readily available to provide emotional and spiritual support in case you experience any emotional discomfort. Also, all if for any unknown reason they became uncomfortable with the administered survey questions, you may either skip the questions or not complete the survey.
There is also a minimal potential for a breach in data security. To mitigate such risk, please noted that no personal identifiers will be obtained during the study but rather identification number will be assigned to you.

Are there any benefits to me if I choose to take part in this study?
The benefits of taking part in this study include access to various information and materials that can greatly assist you in planning for end-of-life care for you and your family. You will also contribute to knowledge about effectiveness of the Advance Care Planning intervention on the Advance Care Planning engagement in Polish Roman-Catholics.
What are my alternatives if I do not want to take part in this study?
There are no alternatives available. You may withdraw your participation in the study or you may choose not to take part in it.

Will there be any cost to me to take part in this study?
There is no cost associated with the project to you or your family.

Will I be paid to take part in this study?
You will not be paid to take part in this study but you will receive a $5.00 gift card to Dunkin Donuts if you attend the Advance Care Planning Seminar and the Advance Care Planning Booster Session.

How will information about me be kept private or confidential?
All efforts will be made to keep your personal information in your research record confidential. The paper data will be stored in a secured computer after it is entered. You will be given an assigned personal information number so your personal information such as first name, last name and phone number will not be stored on the paper surveys. The PC is the only person who will see your individual responses and the results. Approximately a month after the completion of the study, the list that links your personal information with your assigned identification number, will be destroyed.

What will happen if I do not wish to take part in the study or if I later decide not to stay in the study?
It is your choice whether to take part in the research. You may choose to take part, not to take part or you may change your mind and withdraw from the study at any time.

If you do not want to enter the study or decide to stop taking part, your relationship with the study staff will not change, and you may do so without penalty and without loss of benefits to which you are otherwise entitled.

How the findings will be used?
The findings of the study will be used to evaluate the impact of the Advance Care Planning intervention on Advance Care Planning engagement among Polish Roman-Catholics. Its results will be presented at Rutgers University School of Nursing and published in an academic journal.
AGREEMENT TO PARTICIPATE

1. Subject Consent:

I have read this entire consent form, or it has been read to me, and I believe that I understand what has been discussed. All of my questions about this form and this study have been answered. I agree to take part in this study.

Subject Name:__________________________________________

Subject Signature:_______________________________________ Date:___________

2. Signature of Investigator/Individual Obtaining Consent:

To the best of my ability, I have explained and discussed all the important details about the study including all of the information contained in this consent form.

Investigator/Person Obtaining Consent (printed name):________________________

Signature:_______________________________________ Date:___________
Appendix G

Registration Form

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<th>ID NUMBER</th>
<th>FIRST NAME</th>
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Date:

Version #1 3.11.19

[Image of Rutgers eIRB Approved notice]
Appendix H

ACP Session Agenda

Advance Care Planning Seminar Agenda

11:15 - 11:30 - Sign-in
11:30 - 11:40 - Welcoming statement - Anna Wagner
  Spiritual blessing – Fr. Waclaw Sokolowski
11:40 - 11:50 - Surveys
11:50 - 12:10 - Anna’s Story film viewing
12:10 - 12:20 - End-of-life group discussion
12:20 – 12:50 - Advance Care Planning PowerPoint presentation
12:50 – 13:00 - Surveys
13:00 - Closing statement

Light refreshments will be provided

ADVANCE DIRECTIVES: 3 EASY STEPS

1
THINK
about what
you want.

2
WRITE
it down.

3
SHARE
with others.

Version #1  5.11.19

RUTGERS eIRB
APPROVED

IRB ID:  Pro2019001226
Approval Date:  7/2/2019
Expiration Date:  7/1/2020
Appendix I

Pre-Intervention Demographic Survey

Identification Number:

Survey 1: Demographics

Part 1 Instructions:
Please do not write your name on this survey but utilize the identification number assigned for you to use this form. Kindly answer the following questions by circling the appropriate response. The answers will assist in the analysis of today’s Advance Care Planning Seminar.

1. What is your gender?
   Male    Female

2. What is your age?
   18-24    25-34    35-44    45-55    50-64    65-74    75-89

3. What language do you speak at home?
   Polish    English

4. What is your marital status?
   Single    Married    Divorced    Separated    Widowed

5. Do you have children?
   Yes    No

6. What is your highest education level?
   Grade school    High School    Vocational/Technical
   Collage (Associate or Bachelor)    Graduate (Master’s/Doctorate)

7. How often do you attend church service?
   Every Day    Weekly    Twice a week    Monthly    Annually

Version #1 5.11.19
8. How long have you lived in the U.S?

5-15 years   16-25 years   26-35 years   36-45 years   46-55 years or more

Part 2 Instructions:
Please do not write your name on this survey but utilize the identification number assigned for you to use this form. Kindly answer the following questions by circling the appropriate response. The answers will be utilized to understand your perspective on end-of-life care.

9. How long would you like to receive medical care at the end-of-life?

Indefinitely, no matter how uncomfortable treatments are  Quality of life is more important to me than quantity

10. What are your concerns about end-of-life treatment?

I am worried that I will not get enough care  I am worried that I will get overly aggressive care

11. What are your preferences about where you want to be during your final days?

I would not mind spending my last days in a healthcare facility  I want to spend my last days at home

Thank you for completing the survey

Version # 1  5.11.19
Appendix J
Pre-Intervention ACPES

Identification Number:

Survey II: Pre-Intervention Advance Care Planning Engagement Survey

Instructions:
Please do not write your name on this survey but utilize the identification number assigned for you to use this form. Kindly answer the questions as honestly as possible and confirm your response by circle the appropriate number. Please note that your answers will be utilized to evaluate your readiness to engage in the Advance Care Planning.

1 (not at all) 2 (not very) 3 (not sure) 4 (somewhat) 5 (very)

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<td>1.</td>
<td>How ready are you to sign official papers naming a person or group of people to make medical decisions for you?</td>
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<td>2.</td>
<td>How ready are you to talk to your decision-maker about the kind of medical care you would want if you were very sick or near the end of life?</td>
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<td>3.</td>
<td>How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life?</td>
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<td>4.</td>
<td>How ready are you to sign official papers putting your wishes about the kind of medical care you would want if you were very sick or near the end of life?</td>
<td>1</td>
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Thank you for completing the survey

Version #1 5.11.19
Appendix K

PowerPoint Presentation

Advance Care Planning Engagement Among Devoted Polish Roman-Catholics

Anna Wagner
Rutgers School of Nursing

Objectives

- Understand:
  - Advance Care Planning (ACP) and Advance Directives (AD)
  - Advancements of today’s medicine and their implication
  - Roman-Catholic Church end-of-life (EOL) teaching
  - POLST and Five Wishes Advance Directives (AD)

- Learn:
  - Strategies to initiate ACP conversation

Unprepared...

- We are completely unprepared for something that is predictable
- We plan for the big and little things in life... birthdays, holidays, weddings...
  - How about death...
  - What if unexpected happens... car accident, injury or illness...
- How would you feel if you are unable to communicate with anyone and there are things that you really want or you do not want...
- How would anybody know your wishes if...
  - you do not talk about it...
  - you do not have it written down...
Types of legal documents...

- **A Living Will**: A document declaring an individual’s wishes and directing the physician to refuse certain life sustaining procedures when the death is imminent due to a terminal condition or when the individual is in a persistent vegetative state.

- **Power of Attorney for Healthcare (POA-HC)**: A document that authorizes another person (called the “agent”) to make healthcare decisions for the person executing the document (called the “principal”), consistent with the terms of the document and based on the wishes of the individual. Document is effective when the person is unable to make healthcare decisions.

- **Do Not Resuscitate (DNR) order**: A DNR order may only be issued by an attending physician and only applies to a “qualified individual” (an adult who has a terminal condition or would suffer pain or harm from resuscitation or when resuscitation would be unsuccessful). The qualified individual must also request the DNR order, consent to it, and sign the written order.

(Institute for Healthcare Improvement, 2019)

---

**Talking About Death is...**

- **Weird**
- **Taboo**
- **Bad Luck**
- **Morbid** — a part of life.

**Death...**

“Life is pleasant. Death is peaceful. It’s the transition that’s troublesome.”

- Isaac Asimov

- It is one of the concepts we do not want to discuss, yet it impacts each and every individual.
- Talking about death is difficult but imperative.
- Being prepared for death ensures that your final wishes are being followed.

---

**Advancements of Today’s Medicine...**

Conventional medical care: goal is to keep individual alive and cure or manage disease (prolong life):

- Cardio-pulmonary Resuscitation (CPR)
- Breathing machine
  - Feeding tubes
Roman-Catholic Church Teaches...

- Fundamental underpinnings of Roman-Catholic faith derived from the Sacred Scripture called the Holy Bible (USCCB, 2018)
  - Human life is a sacred gift provided by God and created in His image (Ethical and Religious Directive [ERD] 33)
  - It must be protected, respected, valued and used for His glory (ERD 33)
- Humans should never intentionally and directly use or avoid medications, devices or treatments that reject God’s gift and ultimately cause death (ERD 56)
- We are not obligated to avoid or undergo procedures that preserve life either (EDR 56)

Roman-Catholic Church Teaches...

- Every human
  - must be clearly and accurately informed about a proposed course of treatment, its risks, benefits, cost, and alternatives (ERD 55)
  - has a right to receive or not receive morally-reasonable care (ERD 56)
  - has a moral obligation to use ordinary, meaning proportionate, treatments with a reasonable hope to preserve life (ERD 56)
- Morally unreasonable care means which are extraordinary, clearly futile, and often bothersome, may no to be used (ERD 57)
- Morally reasonable care such as nutrition and hydration, may be optional. The medically assisted nutrition or hydration is voluntary when it only prolongs life, causes an excessive financial burden or physical discomfort (ERD 60)

Roman-Catholic Church Teaches...

- Good death preparation process is imperative (ERD 55), especially when human life is in danger of death such as advanced age or terminal illness
  - Individuals need to be provided with information that will allow them to understand their condition and encourage them to discuss their end-of-life wishes with families, healthcare providers and spiritual leaders
Advance Care Planning (ACP)

The process of planning for the future...reflection and communication...

- Seeks to ensure that an individual takes steps to discuss and document personal preferences and values regarding medical care in the case of serious or life-limiting disease
- Ensures that individuals receive the desired EOL care in the setting of their own choices
- Lifts the burden from the loved ones

(Aging with Dignity, 2010)

Let’s initiate the ACP conversation...

- “I need your help with something...”
- “Remember how someone in the family died—was it a “good death or a “hard” death? How will yours be different...?”
- “I was thinking about what happened to ______, and it made me realize...?”
- “Even though I am ok right now, I am worried that ______, and I want to be prepared.”
- “I need to think about the future. Will you help me?”
- “I just answered some questions about how I want end of my life to be. I want you to see my answers. And I am worried what your answers would be?”

(Institute for Healthcare Improvement, 2019)

Advance Directive (AD)

A legal document that is written in advance of an illness, injury, or age-related decline in which an individual states specific EOL treatment preferences

- Increases likelihood that your wishes are respected.
- Reduces end-of-life hospitalization
- Reduces decision-burden of your family members
- Reduces moral distress among healthcare providers

(Aging with Dignity, 2010)
Did you know that ...

- Only 32% of the U.S. population has AD
- 92% of Americans acknowledge the importance of discussing the EOL wishes
- 95% say they would be willing to talk about their wishes (IHI, 2019; Rao, Anderson, Lin & Laux, 2014; Wenger et al., 2012)
- 40% of New Jersey residents have never engaged in ACP
- 60% lack a written document to validate EOL wishes (NJHCO, 2018b)
- There is no evidence to support the management of ACP among Passaic residents

  * Result: 1.5 hospital visits among 1,632 of the Passaic county’s Medicare decedents age 65 or older, within their last six months of life (The Dartmouth Atlas Project Report, 2019)
  * Each inpatient admission had a length of stay of 12 days, including five days of ICU care, 28.5% rate of deaths occurrence and $23,640 spending per decedent (The Dartmouth Atlas Project, 2019)

Which type of AD is right for you...

- **Advance Directives**
  - Helps you to make a healthcare decision when you are unable to do so
  - Appropriate at any age
  - Should be shared with surrogate decision-maker, family, friends and healthcare provider
  - Should be reviewed and updated regularly
  - Available in Polish

- **POLST**
  - Appropriate for those at the end-of-life or those who suffer from a life-limiting illness (cancer)
  - Honored in any emergency situation
  - Should be reviewed and updated regularly
  - Not available in Polish

(Aging with Dignity, 2010)

POLST Advance Directive...
Five Wishes Advance Directives...

- Comprehensive, easy-to-use, and individualized ACP program that guides the ACP challenging discussion among individuals, their families, surrogates, healthcare professionals, and faith communities (Wenger, Fink, Asakura & Oman, 2012)
- A legal document written in everyday language
- Meets legal requirements for an AD in 42 U.S. states and District of Columbia
- Five Wishes form is available in 28 languages, including Polish

(Aging with Dignity, 2010)

My Wish # 1:

The person I want to make care decisions for me when I cannot...

- Allows you to name a “health agent”, “durable power of attorney for healthcare” or surrogate decision-maker such as spouse, child or friend
- Choose the person who will honor your wishes and stand up for you
- The surrogate decision-maker must be at least 18 years old, not your healthcare provider or employee of the healthcare provider

(Aging with Dignity, 2010)

My Wish # 2

The kind of medical treatment I want or I do not want...

- This part is known as a “living will”
- Allows you to define what life support treatment means to you – Yes life support, No life support, Stop life support if it was started or Do a total life support treatment
- It is not a Do-Not-Resuscitate order
- Clarifies your wishes in several scenarios such as terminal condition, coma, severe brain damage

(Aging with Dignity, 2010)
My Wish # 3

How comfortable I want to be when you are dying...

- This question stresses that you want your pain to be managed properly
- You can express your choices for types of care, such as having a cool, moist cloth placed on your forehead if you have a fever or having your favorite music played
- It also asks you to give information about hospice and comfort care

(Aging with Dignity, 2010)

My Wish # 4:

How I want people to treat me...

- Informs your loved ones what they should keep in mind if you become sick:
  - If you want people around
  - If you want your hand to be held
  - If you want prayer
  - Having pictures of loved ones in your room

(Aging with Dignity, 2010)

My Wish # 5:

What I want my loved ones to know...

- Unique part that deals with “closure” matters
- Encourages you to express matters of deep importance in an age when families often live apart
- Allows you to offer love and forgiveness to those who may have hurt you
- Communicates practical matters such as preferences for memorial or burial

(Aging with Dignity, 2010)
Palliative Care and Hospice Care...

**Palliative Care:** the goal is to maximize quality of life and comfort while continuing conventional medical care. Death viewed as a natural part of life.

**Hospice Care:** the goal is to maximize the quality of life and comfort to relieve suffering resulted from life-limiting illness such as cancer. Helps the ill individual and the family to prepare for death.

Advance Care Planning...

**Advance Directives: 3 Easy Steps**

1. **Think** about what you want.
2. **Write** it down.
3. **Share** with others.

Thank you for your participation in ACP seminar...
References


Appendix L

ACP Pamphlet
We understand that advance care planning can be daunting—not only because it is difficult for many of us to think about aging and death, but also because there are a lot of terms and forms that can complicate the process. This checklist simplifies things for you, so you can start—and finish—your advance care planning journey.

1. Consider.
- Consider your own priorities for end-of-life care.
- Consider what might happen if you don’t discuss end-of-life care and become unable to make healthcare decisions for yourself.

2. Communicate.
- Communicate your end-of-life care wishes with your loved ones and doctors.

3. Create.
- Designate your healthcare agent (the person who can legally make decisions for you if you are incapable of making them on your own), and formalize this relationship by signing your Proxy Directive.
- Put your end-of-life care wishes in writing. There are several options. You do not need to fill out all of these forms. Take a look at them and decide what is right for you.
  - New Jersey Instruction Directive
  - 5 Wishes
  - POLST (requires signature of attending doctor or nurse practitioner)
- Share your advance directives with loved ones and your healthcare providers.
- Keep your advance directives in an accessible and secure location.
- Revisit your advance directives and end-of-life conversations every few years.

Advance Care Planning: Useful Terms

Advance Directive:
An advance directive is a legal document that allows you to spell out your decisions about end-of-life care ahead of time. Each state’s advance directive varies. In New Jersey, you do not need a lawyer to complete an advance directive. If you choose to get your advance directive notarized, you don’t need additional witnesses; if you choose not to get your advance directive notarized, you must sign and date it in front of two adult witnesses who must also sign and date the document. The form can be updated and/or cancelled at any time. In New Jersey there are two parts to the Advance Directive—the Living Will (Instruction Directive) and the Power of Attorney (Proxy Directive).

Living Will (Instruction Directive):
A living will is a written, legal document that spells out medical treatments you would and would not want to be used to keep you alive, as well as other decisions such as pain management or organ donation. Have conversations with your primary care doctor, family, friends, and anyone you feel comfortable with to determine your personal wishes regarding these issues.

Durable Power of Attorney for Health Care (Proxy Directive):
The proxy directive is where you name a person to make decisions for you when you are unable to do so. This person can be anyone—family or friend—except for your personal doctor. The Proxy Directive will only go into effect if you are no longer able to speak for yourself.

Five Wishes:
The Five Wishes is an alternative form that is acceptable as an Advance Directive in the state of New Jersey. The Five Wishes form is written in everyday language and has become the most popular Advance Directive in America.

Practitioner Orders for Life-Sustaining Treatment (POLST):
A POLST form is a medical order indicating your preferences for end-of-life care. In most states, this form is intended for use only during the final stages of life. In New Jersey, the POLST form can be filled out at any time. It is filled out with your doctor or nurse practitioner based on the contents of your directives, discussions with your doctor or nurse practitioner, and your treatment preferences.

POLST forms are intended for people who have already been diagnosed with serious illness, so even if you have one before, it is important to speak with your doctor or nurse practitioner regularly and update your POLST form as your preferences change as you age. The POLST serves as practitioner-ordered instructions—not unlike a prescription—to ensure that, in case of an emergency, you receive the treatment you prefer. A POLST travels with you, at whatever facility you are being cared for.

Hospice
Hospice offers medical care toward a different goal: maintaining or improving quality of life for someone whose illness, disease or condition is unlikely to be cured. Each patient’s individualized care plan is updated as needed to address the physical, emotional and spiritual pain that often accompanies terminal illness. Hospice care also offers practical support for the caregivers during the illness and grief support after the death. Hospice is something more that is available to the patient and the entire family when curative measures have been exhausted and life prognosis is six months or less.

Palliative Care
A comprehensive approach to treating serious illness that focuses on the physical, psychological and spiritual, and existential needs of the patient. Its goal is to achieve the best quality of life available to the patient by relieving suffering and controlling pain and symptoms. Palliative care may be given at any time during a patient’s illness, from diagnosis on.
Appendix M

POLST AD

---

**HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY**

**Physician Orders** for Life-Sustaining Treatment

<table>
<thead>
<tr>
<th>Last Name - First Name - Middle Initial</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date of Birth</td>
</tr>
</tbody>
</table>

**Medical Conditions/Patient Goals:**

**Agency Info/Sticker**

---

**A. CARDIOPULMONARY RESUSCITATION (CPR):** Person has no pulse and is not breathing.

- [ ] CPR/Attempt Resuscitation
- [ ] DNAR/Do Not Attempt Resuscitation (Allow Natural Death)

Choosing DNAR will include appropriate comfort measures and may still include the range of treatments below. When not in cardiopulmonary arrest, go to part B.

---

**B. MEDICAL INTERVENTIONS:** Person has pulse and/or is breathing.

- [ ] COMFORT MEASURES ONLY
  - Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. Patient prefers no hospital transfer: EMS contact medical control to determine if transport indicated to provide adequate comfort.

- [ ] LIMITED ADDITIONAL INTERVENTIONS
  - Includes care described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation or mechanical ventilation. May use less invasive airway support (e.g., CPAP, BiPAP).
  - Transfer to hospital if indicated. Avoid intensive care if possible.

- [ ] FULL TREATMENT
  - Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated.
  - Transfer to hospital if indicated. Includes intensive care.

**Additional Orders:** (e.g., dialysis, etc.)

---

**C. SIGNATURES:** The signatures below verify that these orders are consistent with the patient's medical condition, known preferences and best known information. If signed by a surrogate, the patient must be decisionally incapacitated and the person signing is the legal surrogate.

<table>
<thead>
<tr>
<th>Discussed with:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient</td>
</tr>
<tr>
<td>Legal Guardian</td>
</tr>
<tr>
<td>Sponsor/Other:</td>
</tr>
</tbody>
</table>

**PRINT — Physician/ARNP/PA-C Name**

<table>
<thead>
<tr>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
</tr>
</tbody>
</table>

**PRINT — Patient or Legal Surrogate: Name**

<table>
<thead>
<tr>
<th>Phone Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
</tr>
</tbody>
</table>

**Patient or Legal Surrogate Signature (mandatory)**

**Person has:**

- Health Care Directive (living will)
- Durable Power of Attorney for Health Care

Encourage all advance care planning documents to accompany POLST.

---

**SEND ORIGINAL FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED**

**Revised 2/2011**

Photocopies and faxes of signed POLST forms are legal and valid. May make copies for records.
Appendix N

Five Wishes AD
Appendix O

Post-intervention ACPES

Identification Number:

Survey III: Post-Intervention Advance Care Planning Engagement Survey

Instructions:
Please do not write your name on this survey but utilize the identification number assigned for you to use this form. Kindly answer the questions as honestly as possible and confirm your response by circle the appropriate number. Please note that your answers will be utilized to evaluate your readiness to engage in the Advance Care Planning.

1 (not at all)  2 (not very)  3 (not sure)  4 (somewhat)  5 (very)

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>How ready are you to sign official papers naming a person or</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>group of people to make medical decisions for you?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>How ready are you to talk to your decision-maker about the</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>kind of medical care you would want if you were very sick or</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>near the end of life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3</td>
<td>How ready are you to talk to your doctor about the kind of</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>medical care you would want if you were very sick or near the</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>end of life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4</td>
<td>How ready are you to sign official papers putting your wishes</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
</tr>
<tr>
<td></td>
<td>about the kind of medical care you would want if you were very</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>sick or near the end of life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Thank you for completing the survey

Version #1  5.11.19

[Approval stamp]
Appendix P

Program Evaluation

Identification Number:

Survey IV: Effectiveness of the Advance Care Planning Seminar

Instructions:
Please do not write your name on this survey. An identification number will be assigned for you to use this form. Kindly answer the following questions by circling the appropriate response. Please note that your answers will be utilized to evaluate the effectiveness of today’s Advance Care Planning seminar.

1 (not at all)  2 (not very)  3 (not sure)  4 (somewhat)  5 (very)

1. How well this seminar met your expectations?
   1  2  3  4  5

2. How ready are you to apply what you have learned in this seminar?
   1  2  3  4  5

2. How easy was to understand the presented information?
   1  2  3  4  5

3. How appropriate was the information provided?
   1  2  3  4  5

4. How likely would you recommend this seminar to others?
   1  2  3  4  5

5. How relevant was the information to you and your family?
   1  2  3  4  5

6. What recommendations would you make to improve this seminar?

   ___ Reduce the amount of information
   ___ Increase the amount of information

Version #1  5.11.19
7. What did you like the best in the seminar?

8. What other related programs would you like to see in the future?

9. Additional comments and suggestions.

Thank you for completing the survey

Version #1  5.11.19
Appendix Q

Phone Script for ACP Booster Session

Good Morning/Good Afternoon Mr./Mrs. ____. This is Anna Wagner, Rutgers student. I would like to remind you about our Advance Care Planning Booster Session held on XX/XX/19 after the 10:00 am church service. Once again, thank you very much for your participation in the research study and I look forward seeing you on Sunday. Best regards.
Appendix R

Booster Session Agenda

Advance Care Planning Booster Session Agenda

11:30 - 11:40 - Sign-in
11:40 - 11:45 - Welcoming statement - Anna Wagner
11:45 – 11:55 - “Before I Leave” icebreaker
11:55 - 12:15 - Questions and answers
12:15 - 12:45 – Five Wishes adaptation
12:45 - 12:55 – Follow up and program evaluation surveys
12:55 – 13:00 – Closing statement

Light refreshments will be provided

As You Wish

ADVANCE CARE PLANNING

Version #1  5.11.19
Appendix S

“Before I Leave” Icebreaker

Before I Leave...
Appendix T

Follow-up ACPES

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<th>Identification Number:</th>
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<td><strong>Instructions:</strong></td>
<td>Please do not write your name on this survey but utilize the identification number assigned for you to use this form. Kindly answer the questions as honestly as possible and confirm your response by circle the appropriate number. Please note that your answers will be utilized to evaluate your engagement in the Advance Care Planning.</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>1 (not at all)</th>
<th>2 (not very)</th>
<th>3 (not sure)</th>
<th>4 (somewhat)</th>
<th>5 (very)</th>
</tr>
</thead>
<tbody>
<tr>
<td>How ready are you to sign official papers naming a person or group of people to make medical decisions for you?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How ready are you to talk to your decision-maker about the kind of medical care you would want if you were very sick or near the end of life?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>How ready are you to talk to your doctor about the kind of medical care you would want if you were very sick or near the end of life?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>How ready are you to sign official papers putting your wishes about the kind of medical care you would want if you were very sick or near the end of life?</td>
<td>1 2 3 4 5</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*Thank you for completing the survey*
Appendix U

Permission Letter

Letter Seeking Permission to Use Advance Care Planning Engagement Survey

Date 04/05/2019

Name: Anna Wagner
Institution: Rutgers University
Department: Leadership
Address: 9 Sipp Avenue
City/State/Zip: Clifton, NJ, 07013

Dear [Name],

I am Anna Wagner, a Doctoral student from Rutgers University, School of Nursing. I am currently working on my DNP project titled *Advance Care Planning Engagement Among Devoted Polish Roman-Catholics*, under the direction of my project chair, Dr. Edna Cadmus, phone 973-353-1428 and email address ednacadm@sn.rutgers.edu. The project proposal will be presented to Rutgers Institutional Review Board (IRB) for approval. In advance, I am seeking your permission to use the Advance Care Planning Engagement Survey instrument in my research study. The tool will be utilized and printed under the following conditions:

- The survey will be solely used for the research study.
- Inclusion of the copyright statement will be printed and visible on all copies of the instrument.
- Upon completion of the project, a copy of the completed research study will be sent, via email, to your attention.

Please advise on these terms and conditions by responding to the following e-mail address: wagneraw@sn.rutgers.edu. Also, for further details, The Rutgers School of Nursing IRB Director can be contacted at 973-353-1090 or by mail at 1800 University Avenue, Ackerson Hall Room #220, Newark, NJ 07102.

Thanking you in advance for your assistance.

Sincerely,

Anna Wagner, BSN, RN, CCRN
## Appendix V

### Project Timeline

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<th>No.</th>
<th>ACP Project Timeline</th>
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<td>Jan 7, 2019</td>
<td>May 15, 2019</td>
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<td>3</td>
<td>Subject Recruitment</td>
<td>Sep 1, 2019</td>
<td>Sep 15, 2019</td>
<td>15</td>
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<td>4</td>
<td>Project Implementation</td>
<td>Sep 22, 2019</td>
<td>Oct 6, 2019</td>
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<tr>
<td>5</td>
<td>Data Analysis</td>
<td>Oct 7, 2019</td>
<td>Oct 30, 2019</td>
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<td>6</td>
<td>Project Completion</td>
<td>Nov 1, 2019</td>
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<tr>
<td>7</td>
<td>Result Dissemination</td>
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<td>IRB Application</td>
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<td></td>
<td>Subject Recruitment</td>
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<td>Project Implementation</td>
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<td></td>
<td>Data Analysis</td>
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<td>Project Completion</td>
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<tr>
<td></td>
<td>Result Dissemination</td>
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*Note: The table includes a visual representation of the timeline with bars for each project stage.*
## Appendix W

Project Budget

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<tr>
<td><strong>Total</strong></td>
<td><strong>$1,350.00</strong></td>
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</tbody>
</table>
Appendix X

Project Findings

*Table 1.* Socio-demographic data

<table>
<thead>
<tr>
<th>Factor</th>
<th>Total Sample</th>
<th>Percent</th>
</tr>
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<tbody>
<tr>
<td><strong>Age Group</strong></td>
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<tr>
<td>35-44</td>
<td>5</td>
<td>12.5</td>
</tr>
<tr>
<td>45-55</td>
<td>11</td>
<td>27.5</td>
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<tr>
<td>56-64</td>
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<tr>
<td>65-74</td>
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<td>75-89</td>
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<tr>
<td><strong>Gender</strong></td>
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<tr>
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<td>30</td>
</tr>
<tr>
<td>Female</td>
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<tr>
<td><strong>n</strong></td>
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<tr>
<td><strong>Language</strong></td>
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<tr>
<td>Polish</td>
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<tr>
<td>English</td>
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<tr>
<td>Other</td>
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<tr>
<td><strong>Marital Status</strong></td>
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<tr>
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<tr>
<td><strong>Children</strong></td>
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<tr>
<td>No</td>
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<td>5.0</td>
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<tr>
<td><strong>n</strong></td>
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<td>100</td>
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<tr>
<td><strong>Education</strong></td>
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<tr>
<td>College</td>
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<td><strong>Church Attendance</strong></td>
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<td>Weekly</td>
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<tr>
<td>Twice a Week</td>
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<tr>
<td><strong>Acculturation</strong></td>
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<td>5 - 15</td>
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<tr>
<td>16 - 25</td>
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<td>27.5</td>
</tr>
<tr>
<td>26 - 35</td>
<td>13</td>
<td>32.5</td>
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<td>36 - 45</td>
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<td>46 - 55</td>
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Table 2. Wilcoxon Signed-Rank model

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<tr>
<th>Hypothesis</th>
<th>Test</th>
<th>Total N</th>
<th>Test Statistic</th>
<th>Standard Error</th>
<th>Standardized Test Statistic</th>
<th>Asymptotic Sig. (2-Sided Test)</th>
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<tbody>
<tr>
<td>1 The median of differences between Readiness 1 and Readiness 2 equals 0</td>
<td>Related Samples Wilcoxon Signed Rank Test</td>
<td>40</td>
<td>200.5</td>
<td>30.551</td>
<td>2.422</td>
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<tr>
<td>2 The median of differences between Readiness 2 and Readiness 3 equals 0</td>
<td>Related Samples Wilcoxon Signed Rank Test</td>
<td>40</td>
<td>247.0</td>
<td>36.949</td>
<td>2.287</td>
<td>0.022</td>
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</table>
Table 3. EOL personal preferences

<table>
<thead>
<tr>
<th>EOL Question</th>
<th>Answer</th>
<th>Frequency</th>
<th>Percent</th>
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</thead>
<tbody>
<tr>
<td>How long you would like to receive medical care at EOL?</td>
<td>Indefinitely</td>
<td>4</td>
<td>10</td>
</tr>
<tr>
<td></td>
<td>Quality of life</td>
<td>36</td>
<td>90</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>40</td>
<td>100</td>
</tr>
<tr>
<td>What are your concerns regarding EOL treatment?</td>
<td>Worried will not get care</td>
<td>13</td>
<td>32.5</td>
</tr>
<tr>
<td></td>
<td>Overly Aggressive care</td>
<td>27</td>
<td>67.5</td>
</tr>
<tr>
<td></td>
<td>Total</td>
<td>40</td>
<td>100</td>
</tr>
<tr>
<td>What are your preferences about where you want to be during your final days?</td>
<td>Healthcare facility</td>
<td>9</td>
<td>22.5</td>
</tr>
<tr>
<td></td>
<td>Home</td>
<td>31</td>
<td>77.5</td>
</tr>
<tr>
<td></td>
<td>Total</td>
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</table>
Table 4. Program evaluation

<table>
<thead>
<tr>
<th>Question</th>
<th>Not at all N</th>
<th>Not at all Percent</th>
<th>Not Very N</th>
<th>Not Very Percent</th>
<th>Not Sure N</th>
<th>Not Sure Percent</th>
<th>Somewhat N</th>
<th>Somewhat Percent</th>
<th>Very N</th>
<th>Very Percent</th>
<th>Total N</th>
<th>Total Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>How well this seminar meets your expectations?</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
<td>1</td>
<td>2.5%</td>
<td>13</td>
<td>32.5%</td>
<td>26</td>
<td>65%</td>
<td>40</td>
<td>100.0%</td>
</tr>
<tr>
<td>How ready are you to apply what you have learned in this seminar?</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
<td>9</td>
<td>22.5%</td>
<td>31</td>
<td>77.5%</td>
<td>40</td>
<td>100.0%</td>
</tr>
<tr>
<td>How easy was to understand the presented information?</td>
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<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
<td>6</td>
<td>15%</td>
<td>34</td>
<td>85.0%</td>
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<tr>
<td>How appropriate was the information provided?</td>
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<td>0</td>
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<td>0</td>
<td>0.0%</td>
<td>5</td>
<td>12.5%</td>
<td>35</td>
<td>87.5%</td>
<td>40</td>
<td>100.0%</td>
</tr>
<tr>
<td>How likely would you recommend this seminar to others?</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
<td>0</td>
<td>0.0%</td>
<td>4</td>
<td>10.0%</td>
<td>36</td>
<td>90.0%</td>
<td>40</td>
<td>100.0%</td>
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