

A Community-Based Advance Care Planning Intervention for the
Adult Children of Older Adult Korean Americans

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Abstract

Purpose: This quality improvement project aimed to increase engagement in advance care planning (ACP) and ACP behaviors among Korean Americans in New Jersey (NJ) by implementing a culturally-relevant ACP intervention targeted toward the adult children of Korean American older adults.

Methodology: A single session ACP training event was held at an English-speaking Korean American church in central NJ. The training consisted of a short film about a woman's end-of-life journey, and an overview by a registered nurse of ACP concepts and how to use the Korean-English version of the "Five Wishes" advance directive to guide ACP conversations with a parent or loved one. The project used a pre- post- post-test design to measure ACP actions (i.e. ACP documentation and ACP conversations) and Advance Care Planning Engagement Survey (ACPES) scores before, immediately after (ACPES only), and two months after the intervention.

Results: The convenience sample ($n = 13$) of participants was primarily female (54%), Korean American (85%), with a mean age of 40.5 years. Participants' aggregate ACPES scores increased 23% from baseline to two-month follow-up, ($M = 3.31$, $M = 4.07$). At two-month follow-up, 23% of participants had had a new ACP conversation with their parent or loved one, and 31% had completed a new ACP action. Additionally, after the intervention, 39% of participants reported not having completed an ACP action they previously reported before the intervention, suggesting a shift in participants' understanding of advance directives and ACP conversations following the intervention.

Implications: Korean American older adults have low rates of ACP, placing them at increased risk for poor end-of-life care outcomes in a state that provides the most aggressive end-of-life medical care in the nation. The family unit plays a key role in ACP for Korean American older

adults. This quality improvement project demonstrates that an ACP intervention by nurses to support adult children of older adult Korean Americans in engaging in semi-structured ACP conversations may help improve families' engagement in ACP and increase discussion of ACP wishes and values.

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Although traditionally Koreans hold a preference for a natural home death (Shin et al., 2016), Korean Americans have low rates of engagement in advance care planning (ACP) (Dobbs, Park, Jang & Meng, 2015). An expert consensus panel defined ACP as “a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care” (Sudore, Lum et al., 2017, p 826). ACP is an important component of quality end-of-life (EOL) care (Institute of Medicine [IOM], 2015) — care that is patient and family-centered, effective, timely, and minimizes harm to patients and families. Individuals who participate in ACP are more likely to receive care at the EOL that aligns with their goals and values (Detering, Hancock, Reade & Silvester, 2010; Morrison et al., 2005). Conversely, a lack of ACP is associated with higher rates of aggressive medical care at the end of life, even though most adults report a preference for less aggressive treatments and care settings in their final days (Dartmouth Institute, 2018).

Minority populations in the U.S. are less likely to participate in ACP and more likely to face additional barriers to good EOL care (Johnson, 2013; Rao, Anderson, Lin, & Laux, 2014). The literature has identified a number of barriers to EOL care planning for Korean Americans, such as resistance of providers or family members to discussing ACP, and a lack of ACP information presented in a way that harmonizes with the expected role of the family in Korean culture (Ko & Berkman, 2010; Ko & Berkman, 2012; Kwak & Salmon, 2007). New Jersey’s growing Korean American population is especially vulnerable to having a “bad death” because of the state’s poor indicators for EOL care compared to the rest of the country (Dartmouth Institute, 2018). Outreach and education on ACP must be targeted to Korean Americans in New Jersey in a relevant and meaningful way in order to improve this population’s engagement in ACP and EOL care outcomes.

Background and Significance

A rapid advancement in medical technology has improved the healthcare system's ability to keep acutely ill patients alive in emergencies, but the system has not kept pace in preparing patients, families, and clinicians to thoughtfully navigate the increasingly complex healthcare decisions at the end of life that have resulted from this technology. This is especially a problem in New Jersey, where Medicare data shows that residents receive some of the most aggressive EOL care in the nation (Bynum, Meara, Chang & Rhoads, 2016). New Jersey has rates well above the national average in intensive care unit (ICU) stays in the last six months of life, feeding tube placements for patients with advanced dementia, and hospice referrals occurring late—in the last three days of life (Bynum et al., 2016). Although over 80% of adults report a desire to stay out of the hospital at the very end of life, over a quarter of New Jersey residents were in a hospital when they died in 2014 (compared to 21% nationwide) (Dartmouth Institute, 2018). Add to these short-comings an aging U.S. population, with over 20% expected to be 65 or older by the year 2030, compared to 13% in 2010 (Ortman, Velkoff & Hogan, 2014), and the problem becomes even more dire.

Diversity and EOL Care

The increasing diversity of the nation (Ortman et al., 2014) adds another layer of complexity to the future of EOL care because of disparities in access and quality of palliative care for non-White populations (Faigle, Ziai, Urrutia, Cooper, & Gottesman, 2017; Johnson, 2013). Further, racial minority populations discuss EOL issues with family and providers less often than non-Hispanic Whites, tend to have lower health literacy around EOL topics, and utilize hospice care at lower rates (IOM, 2015). Multiple studies have documented a preference for more aggressive terminal care in minority populations (Baker, 2002; Barnato, Anthony,

Skinner, Gallagher & Fisher, 2009), which some suggest is a result of factors such as gaps in knowledge and health literacy (Vollandes et al., 2008), a mistrust of the healthcare system, and a lack of culturally-relevant engagement on ACP (Johnstone & Kanitsaki, 2009).

Improving EOL Care Through ACP

ACP is promoted as a strategy to improve the quality of EOL care by ensuring that when patients lack the capacity to make healthcare decisions at the end of life, as 70% of older adults do, their preferences for care will be honored (Silveira, Kim, & Langa, 2010). Indeed, in randomized control trials, ACP has been shown to improve outcomes not only for patients, but also for caregivers (Weathers et al., 2016). As Weathers et al.'s (2016) systematic review found, patients who received ACP interventions were more likely to receive the care they preferred and had fewer hospitalizations. Patients' healthcare proxies had a better understanding of patients' wishes, patients and families were more satisfied with care, while caregivers coped better and reported a better quality of life (Weathers et al., 2016).

The Patient Self-Determination Act, passed in 1991, required healthcare settings to take new action on advance directives as legal written records concerning patients' wishes for medical care and/or their appointed healthcare proxy (Omnibus Reconciliation Act of 1990; Silveira et al., 2010). Analysis of deaths among a national cohort of older adults found that individuals with advance directives who were unable to make decisions were likely to receive the kind of care they had indicated on their directives (Silveira et al., 2010). Nevertheless, concerns have been raised about the shortcomings of advance directives; they are not always available or found in medical records (or are sometimes ignored even if they are), they are not actionable in an emergency, and they are underutilized by adults who are younger, poorer, are a minority, or have less education (Meghani & Hinds, 2015). New Jersey, among other states, has introduced

the Practitioner Orders for Life-Sustaining Treatment (POLST) form for individuals near the end of life as a solution to some of these shortcomings (National POLST Paradigm, 2018). The POLST records patients' care preferences as actionable medical orders (National POLST Paradigm, 2018). A move to create a digital registry for POLST forms is anticipated to help remedy the problem of availability (National POLST Paradigm, 2018). Experts advocate incorporating advance directives into a larger process of ACP, rather than relying on them as a stand-alone document (IOM, 2015; Sudore, Lum et al., 2017).

Improving ACP Engagement and Quality

Sudore et al. (2008) described five phases in the ACP process: pre-contemplation, contemplation, preparation, action, and maintenance. The action phase includes discussion with family and friends, discussion with the healthcare team, and documentation. Sudore et al. (2008) found that individuals who had talked about their care preferences with loved ones were more likely to also discuss the matter with their healthcare team and go on to document their preferences. For this reason, ACP interventions that focus on helping participants progress through the contemplation and discussion phases of the ACP process are recommended (Sudore et al., 2008). Rather than approaching ACP as a one-time event, the IOM's (2015) Life Cycle Model for ACP recommends that individuals visit the ACP process at various milestones throughout life, such as getting a driver's license and marriage, as well as during changes in health status.

A number of evidence-based tools exist to help individuals engage in ACP such as living will templates like "Five Wishes" (Splendore & Grant, 2017), official state POLST forms, discussion tools like those from the Conversation Project (Lum, Dukes, Church, Abbot, & Youngwerth, 2018), and educational programs for organizations, like Respecting Choices

(Detering et al., 2010), or for individuals, like PREPARE (Sudore, Boscardin et al., 2017). A systematic review by Weathers et al. (2016) of ACP interventions in the literature yielded mainly informational interventions that aimed to increase completion of ADs and improve healthcare proxies' decision-making. There is also some evidence that communication tools for ACP, such as structured discussions and/or written tools, can increase ACP conversations, increase AD completion, and increase agreement between patients' wishes and their medical orders or care received (Oczkowski, Chung, Hanvey, Mbuagbaw, & You, 2016). Sudore, Heyland, Lum et al. (2017) engaged in an expert consensus panel and agreed in recommending that ACP quality be measured by the following outcomes: (a) EOL care is consistent with stated goals, (b) a surrogate decision-maker is designated, (c) patient's choice of surrogate(s) is documented, (d) patient discussions with surrogate(s), and (e) documents and recorded wishes are accessible when needed.

Diversity and ACP

However, despite the availability of tools and growth in the use of advance directives, non-White populations still lag behind in their adoption of ACP (Rao et al., 2014). Both Johnson (2013) and Johnstone & Kanitsaki (2009) point out that Western values such as autonomy and self-determination have traditionally dominated the ACP landscape, with a lack of attention to non-Western values (e.g. collectivism vs. autonomy, partial disclosure vs. full disclosure of prognosis, etc.), that non-White populations bring to EOL concerns. They argue that this contributes to a concept of ACP that diverse populations may find irrelevant or even offensive, and contributes to disparities in EOL care. However, whereas the use of advance directives as a stand-alone document emphasizes the Western value of autonomy (Johnstone & Kanitsaki, 2009), the process of ACP is more nuanced, allowing room for individuals to make the process

their own, and need not be in conflict with non-Western values and priorities. Best practices for ACP must be translated into culturally-relevant interventions, tools, and programs that effectively engage diverse populations in the ACP process.

Needs Assessment

A need for the project was identified through several sources. Demographic information was retrieved from U.S. Census reports. Data on national, state, and local EOL outcomes was gathered through the Dartmouth Atlas of Health Care and information on the EOL care and care planning needs of Korean Americans was drawn from the experiences and expertise of state and local stakeholders, including the Holy Name Korean Medical Program, the New Jersey Healthcare Quality Institute's Conversation of Your Life (COYL) program, and a local Korean American church in Middlesex County, New Jersey. The findings are presented below.

Nationally

According to the most recent U.S. Census data, Asian Americans comprise the fastest growing population in the U.S (Hoeffel, Rastogi, Kim, & Shahid, 2012). California, New York, Texas, and New Jersey, the four states with the highest Asian American populations, are also among the states with the highest intensity of hospital care in the last two years of life (Dartmouth Institute, 2018; Hoeffel et al., 2012). Nationally, the Korean American population grew just over 33% between 2000 and 2010, making up the fifth largest Asian American population in the nation, estimated at over 1,463,000 in 2010 (Hoeffel et al., 2012). The northeastern U.S. is home to over one quarter of the nation's Korean Americans (Hoeffel et al., 2012).

New Jersey

Nearly 6% of Korean Americans in the U.S. reside in New Jersey (Hoeffel et al., 2012). The growth of New Jersey's Korean American population surpassed that of the nation between 2000 and 2010 (i.e. 43.4% vs. ~33%), making up roughly 13% of the state's Asian population (Wu, 2012). New Jersey was home to nearly 100,000 Korean Americans in 2010, with Middlesex County home to the second largest Korean American population in the state, after Bergen County (Wu, 2012). The older adult Korean population in New Jersey has been increasing since 2005, when 4.1% were 65 or older (n= 3,408), whereas 14.4% were 65 or older as of 2016 (n= 13,129) (U.S. Census Bureau, 2018). Korean Americans in New Jersey have created a vibrant community. A Google search of "Korean church NJ" quickly yields over fifty Korean Christian congregations in Central and North Jersey on the first four search pages alone. Additional searches yield two Korean Community Centers, four Korean schools in North and Central Jersey, as well as many Korean-speaking healthcare providers.

The Korean Medical Program (KMP), established by a New Jersey hospital to accommodate the needs of the growing Korean American population, expanded significantly since its founding ten years ago to include 85 Korean-speaking primary care and specialty physicians, serving over 45,000 patients each year (Holy Name Medical Center, 2018). Patients who utilize the KMP are primarily first-generation immigrant families who face barriers to healthcare because of language and cultural differences (Holy Name Medical Center, 2018). The KMP engages in outreach events to the Korean American community, and has incorporated information-sharing about EOL resources such as hospice care and legal services into events with Korean churches, senior centers, senior housing, and cultural organizations (C. Kim, personal communication, February 13, 2018). A representative from the KMP related that although the Korean American community considers discussion of EOL topics unusual and

uncomfortable, many Korean Americans are open to discussing EOL topics, and in fact the KMP is planning a campaign in partnership with COYL to help improve the Korean American community's engagement with EOL care planning (C. Kim, personal communication, February 13, 2018).

Middlesex County

As discussed earlier, New Jersey compares poorly to the rest of the nation in EOL care outcomes, spending more on care and providing more aggressive care to the dying. The New Brunswick referral region in Middlesex County has the 5th highest intensity of hospital care in the last six months of life in the nation, ranking behind two other regions (i.e. Hackensack and Paterson) within the state (Dartmouth Institute, 2018). COYL, a program of the New Jersey Healthcare Quality Institute, promotes culture change around EOL care planning. COYL recently formed a task force in Middlesex County to expand outreach to Middlesex residents. Middlesex County is one of the most diverse counties in New Jersey, with Asian Americans comprising nearly a quarter of the population, and 43% of residents speaking a language other than English (DataUSA, n.d.). COYL has an expressed goal of expanding program outreach to Asian American populations including Korean Americans (D. Levine, personal communication, January 10, 2018).

Because of the importance of religious communities to Korean Americans in New Jersey, a Korean American church was selected as an appropriate site to implement the project. Discussion with local faith-community leaders in a primarily Korean American congregation uncovered a need for information on ACP for church members, many of whom are beginning to take on caregiver roles as the adult children of older adult Korean Americans (D. Choi, personal communication, January 9, 2018). The English-speaking church is located in an urban area of

Middlesex County and is comprised mostly of young families, with roughly 100 adult members. Although the majority of adult members are college-educated, there is a lack of individuals in the church who may have expertise in EOL matters, either through work experience in health-related professions or personal experiences caring for a loved one (D. Choi, personal communication, January 9, 2018). There were a number of reputable resources and programs to promote ACP, including local community-based programming through COYL. However, there was a lack of programming tailored toward a Korean American audience that could address the congregation's specific needs as potential caregivers.

Problem Statement

There is a lack of ACP outreach that is relevant to the local Korean American population. Culturally-relevant interventions to increase engagement in ACP are needed to help improve the quality of EOL care this population experiences.

Clinical Question

The project sought to answer the question: will a culturally-sensitive ACP program for the adult children of older adult Korean parents increase ACP engagement and action toward ACP?

Aims and Objectives

This project aimed to develop and evaluate the effectiveness of a culturally-sensitive program for Middlesex County Korean American adults with older adult Korean parents or loved ones that will promote health literacy about EOL decisions and increase engagement in ACP. A secondary aim of the project was to lay a foundation for future COYL programming with Korean American populations. The objectives of this project included:

- creating a culturally-sensitive ACP program for Korean American adult children.

- measuring the program's impact using the Advance Care Planning Engagement Survey (ACPES) pre and post-intervention.
- conducting a survey after the program implementation to evaluate the program's effectiveness.
- increasing the number of Korean American families who have taken ACP action (i.e. ACP conversations with family, friends, or healthcare providers, completed an AD).

Review of Literature

A review of the relevant literature was performed using the following databases: CINAHL, Medline, Pubmed, and Google Scholar. Search terms included *advance care planning*, *Korean American*, and *Korean*. For Google Scholar only, the terms *advance care planning*, *intervention*, and *Korean American* were used with data parameters set to 2014 through 2018. The search yielded 108 articles and an additional five articles were included from review of the references of relevant sources. After exclusion criteria were applied, 21 articles were included in the review. For a graphic depiction of the search strategy, see the included PRISMA diagram (see Appendix A). After exclusion criteria were applied, 20 sources were appraised and included in the table of evidence (see Appendix B).

Korean Americans and ACP

Korean Americans have lower rates of advance care planning awareness and participation, with only 18.6% of older adult, community-dwelling Korean Americans having completed an advance directive, compared with 51.2% of community-dwelling older adults nationwide (Dobbs et al., 2015; Rao et al., 2014). A number of factors have been associated with this phenomenon, including lower health literacy around EOL issues, cultural factors, and a lack of culturally-appropriate information on ACP (Dobbs et al., 2015; Ko & Berkman, 2012; Kwak & Salmon, 2007). Both health literacy or experiences and cultural values are significant

facilitators (or barriers) to ACP engagement for ethnic minorities (Hong, Yi, Johnson, & Adamek, 2017).

ACP awareness and acculturation. Awareness of ACP is significant, as several studies have identified a link between ACP awareness and ACP engagement (Dobbs et al., 2015; Jang, Chiriboga, Allen, Kwak, & Haley, 2010; Ko & Lee, 2009; Lee et al., 2018). Ko and Lee (2009) found that level of knowledge about ACP, more than race, contributed to older adults' likelihood to have ACP discussions. Acculturation may influence ACP awareness, as demonstrated in a survey of nearly 700 community-dwelling older adult Korean Americans (Dobbs et al., 2015). A study by Jang et al. (2010) found that Korean Americans who had prior awareness of hospice care were more willing to use it, as were those who had higher levels of acculturation to U.S. culture. In contrast, the use of palliative and hospice care remains uncommon in South Korea except for terminal cancers, and no standard AD form exists (Shin et al., 2016). In fact, in a survey of 295 older adult South Koreans, none of those surveyed had completed an AD, and less than 30% had heard of ADs prior to the study (Lee et al., 2018). Shin et al. (2016) described that although most South Koreans would prefer to die naturally at home, two thirds of the population die in a hospital, often using life-sustaining treatments until the very end of life.

Cultural values and attitudes toward ACP. The literature suggests that Korean Americans have both positive and negative attitudes toward ACP and palliative or hospice care. A common Korean value rooted in Confucianist beliefs is a desire not to burden one's family (Shin et al., 2016). Some Korean Americans stated a preference for hospital death because of a perception that it would be less burdensome to their family than a home death (Frank et al., 1998). This value also impacted Korean Americans' attitudes toward ACP in studies which found that participants viewed ADs or ACP as potentially helpful for reducing the burden on

family members who are responsible for EOL decision-making (Ko & Berkman, 2012; Kwak & Salmon, 2007). Ko, Roh, and Higgins (2013) found that older adult Korean Americans who shared this view were more likely to have discussions about EOL care.

Another traditional cultural value, filial piety, is “the moral obligation of an adult child to respect and obey their parents and provide support for them in old age” (Shin et al., 2016, p 412). Filial piety has been viewed as both in support of and against ACP and palliative or hospice care (Kwak & Salmon, 2007; Shin et al., 2016). Interestingly, a study by Kim and Foreman (2011) found that while the adult children of Korean American older adults tended to have positive attitudes toward ACP, they also tended to believe that their parents would want life-sustaining treatment at the end of life. Indeed, Korean American older adults predicted this phenomenon, explaining that their children would feel obligated to do everything they can to save their lives out of filial piety, regardless of what their care preferences were (Frank et al., 1998; Kwak & Salmon, 2007; Phipps, True, & Murray, 2003). However, Kim and Foreman (2011) also found that adult Korean American children who were more acculturated to U.S. culture were less likely to think their parents would want life-sustaining treatment. Also, about half of the Korean American caregivers (n= 8) who participated in Kwak and Salmon’s 2007 study cited filial piety as a rationale for choosing palliative care for their parents in a hypothetical scenario because they wished to honor what they perceived as their parents’ preferences.

The role of family in EOL decision-making. A strong theme in the literature is the role of the family, specifically adult children, in decision-making about EOL care for Korean American older adults. In a qualitative case report by Frank et al. (1998), the authors sought to clarify findings from a larger study which found that while Korean American elders stated a preference for less aggressive care, they nevertheless tended also to say that children should

pursue life-sustaining treatment for their parents. The qualitative analysis shed light on this perceived conflict when the interviewee explained that to her, the children's role in decision-making is more important than her own personal wishes, and that the values of filial piety and *tori* (i.e. duty, or the right thing to do) necessitate life-saving measures.

Other studies corroborate this view. In focus groups conducted by Kwak and Salmon (2007), Korean American elders stated that the family is expected to make final EOL decisions. However, in focus groups of Korean American older adults by Ko and Berkman (2010), while some adults wanted their children to make EOL decisions for them or felt that it was the inevitable course, others stated a desire to remain in control of their own decisions as much as possible. A literature review by Kwak and Haley (2005) found that Asian Americans were more likely to desire collective decision-making around EOL care choices.

Family influence on ACP. Noting the significant role family plays in EOL decision-making for Korean Americans, it is not surprising that a number of studies had findings related to the family's influence on having EOL conversations or appointing a healthcare proxy. In a cross-sectional study with Native Hawaiians and Asian Americans, Katoaoka-Yahiro, Conde, Wong, Page, and Peller (2010) found that both groups preferred discussing EOL issues with family over healthcare workers, legal professionals, clergy, or friends. A survey of Korean American elders in New York City found low rates of EOL communication (21.9%), but that those who had EOL discussions did so most frequently with family. Ko and Lee (2009) also found that older adults (both Korean American and non-Hispanic Whites) were more likely to talk about ACP with family than with healthcare providers or others. This relates to findings by Van Scoy, Howrylak, Nguyen, Chen, and Sherman (2014), who found that hospital inpatients were 68.6 times more likely to complete an AD when asked to do so by family or friends, than

when not asked at all, and 18 times more likely to choose a healthcare proxy. Family and friends had a much greater influence on ACP engagement than healthcare providers, whose requests to patients to complete an AD yielded a 10.8 times higher likelihood of them doing so than if they were not asked (Van Scoy et al., 2014).

Difficulty talking about death and dying. However, although patients may be more willing to discuss ACP in family than others, they also stress how difficult it is to have EOL conversations. Carr (2012) found that both Asian Americans and Latinos were more likely than non-Hispanic Whites to say they were not sure how to bring up the topic. Ko and Berkman (2012) described a common sentiment among Korean American elders with mainly Korean American physicians, that it was hard to discuss ACP with their doctor because the provider did not seem to want to bring up the topic. A similar population of older adult Korean Americans reported difficulty talking about EOL care planning with their children because of the children's resistance to the topic (Ko & Berkman, 2010). Kwak and Salmon (2007) described the difficulty of EOL communication for Korean American adults and caregivers alike.

The cultural expectation of *noon chi*, or indirect communication, may contribute to difficulty with EOL communication among many Korean American families (Kwak & Salmon, 2007). Some Korean American elders preferred to refer to EOL topics only indirectly, presuming that the family will know what to do by *noon chi*, making explicit discussion unnecessary (Ko & Berkman, 2012). Additionally, traditional Korean values may suggest that planning for dying is antithetical to living, and inappropriate (Ko & Berkman, 2012). Ko et al. (2013) and Ko and Lee (2009) both found that when EOL communication occurred in a Korean American and a mixed White and Korean American sample, it tended to be quite general rather than about specifics.

Recommendations for ACP Engagement

The literature provides recommendations for engaging ethnic minorities, specifically Korean Americans in ACP. Kwak and Haley (2005) provided recommendations from the literature that can be broadly applied to minority populations as (a) avoid expecting all members of an ethnic group to have similar attitudes or beliefs, (b) work on building trust, and (c) focus on understanding and respecting diverse beliefs as the foundation for work with diverse populations. Kwak et al. (2014) also gave broadly applicable advice for work with diverse older adults, based on the experiences of professional care managers. The study reiterated the foundational concepts of building trust and respecting different views, and further advised building rapport over time, moving toward ACP discussions by starting with more general conversations about health decision-making in general, and to focus on encouraging adults to appoint a healthcare proxy (Kwak et al., 2014).

Family and provider involvement. The importance of involving the family in EOL discussions and interventions is strongly endorsed in the literature (Frank et al., 1998; Jang et al., 2010; Kataoka-Yahiro et al., 2010; Kim & Foreman, 2011; Ko & Berkman, 2010; Ko & Berkman, 2012; Ko et al., 2013). Because of a frequent preference for collective decision-making in Korean American families, it is difficult to overemphasize the significance of family inclusion in ACP (Kwak & Haley, 2005). Despite a strong focus in the literature on family involvement in ACP, there is also support for provider-led initiatives. Shin et al. (2016) argue that the POLST paradigm may be effective for ACP engagement in South Korea, because of physician involvement in POLST completion and the particular weight of physicians' guidance on Korean patients' care decisions. Ko et al. (2013) as well as Kwak and Salmon (2007) advocated provider involvement in initiating ACP with Korean immigrant patients.

Interventions to increase provider initiation of ACP conversations should be considered, particularly with Korean American physicians (Kwak & Salmon, 2007).

ACP outreach. Another common recommendation is the implementation of educational interventions to increase awareness of and engagement in ACP (Dobbs et al., 2015; Jang et al., 2010; Ko & Berkman, 2012; Ko et al., 2013). Community-based programs were especially recommended, with senior centers and churches as a suggested sites (Dobbs et al., 2015; Ko & Berkman, 2012; Ko et al., 2013). Hong et al. (2018) found that spirituality can be a barrier toward ACP for some minority groups. However, spirituality may also be used to facilitate ACP engagement, as in a church-based ACP program for Asian Americans (i.e. Chinese and Vietnamese) without ADs, which resulted in 73% of participants completing an AD, and 25% initiating an ACP conversation with family (Sun, Bui, Tsoh et al., 2017). The researchers held interviews and focus groups with stakeholders prior to program design to make the programming culturally appropriate, and included a “spiritual endorsement” of ACP by local faith leaders as part of the program (Sun et al., 2017).

In addition to guidance on setting, the literature cites additional considerations for ACP interventions. Ko and Berkman (2012) and Jang et al. (2010) advocated the inclusion of family members in ACP education to facilitate EOL conversations. Jang et al. (2010) further advise incorporating cultural beliefs like filial piety and filial expectations into the program design, and conducting programming in participants’ preferred language. According to Ko and Berkman (2012), ACP outreach should include instruction for adults and their families on “how to communicate with health care providers and family members about their preferences for information about diagnosis, prognosis, and treatment, and how to complete an AD” (p 498). Ko and Berkman (2012) recommended that social workers assess Korean American patients’

individual preferences related to EOL discussions. A South Korea-based study by Koh, Kim, and Kim (2016) recommended a similar protocol for healthcare professionals initiating EOL care discussions with cancer patients, which included systematically assessing patients' decision-making ability, how they view their condition, whether or how much they want to know, the family dynamic, and readiness for ACP conversations. Although these examples focus on health and service professionals, this concept could be applied on a wider level with both professionals and trained lay persons working on ACP engagement in a community-based setting.

Recommended outcome measures. As discussed briefly above, Sudore, Heyland, Lum et al. (2017) recommend measuring the success of ACP using process measures (e.g. attitudes toward ACP or life-sustaining treatment), action measures (e.g. ACP discussions), quality measures (e.g. patient satisfaction), and health care measures (e.g. care utilization). In regards to measuring outcomes related ACP outreach, the studies reviewed focused mainly on process and action measures. A number of studies examined attitudes toward ACP or life-sustaining treatment before and after ACP interventions (Kataoka-Yahiro et al., 2010; Kim & Foreman, 2011; Ko & Berkman, 2012; Sun et al., 2017). Measures of rates of AD completion or EOL discussions was another commonly used measure (Carr, 2012; Dobbs et al., 2015; Kataoka-Yahiro et al., 2010; Ko et al., 2013; Lee et al., 2018; Sun et al., 2017; Van Scoy et al., 2014).

Theoretical Framework

The project was guided by the Knowledge to Action (KTA) framework, which is useful for translating evidence into a local practice context. The KTA framework was developed by Graham et al. (2006) and consists of two main components: the knowledge funnel and the action cycle. The process of knowledge generation is depicted by the knowledge funnel to describe how knowledge is created, then synthesized, and then refined into easy-to-use formats like tools (e.g.

practice guidelines, care pathways) (Graham et al., 2006). The action cycle takes knowledge from the funnel and applies it to practice, starting with the identification of a problem, and taking steps to plan and implement a change using the knowledge, and finally evaluating and sustaining the change (Graham et al., 2006).

For this project, a plan was developed based on the KTA framework to address a knowledge-practice gap that exists between the known benefits and need for ACP and low rates of ACP engagement in the Korean American population. A conceptual framework was developed to provide a pictorial description of the KTA process as applied to this project (see Appendix C). Relevant knowledge was appraised for quality and its applicability to the target population: the adult children of Korean American older adults. Barriers to adoption of ACP behaviors were identified, and a plan to disseminate the knowledge (i.e. the ACP intervention) was developed. Further steps included implementing the intervention and monitoring the intervention's effect on ACP, evaluation of the intervention's outcomes and quality, and providing recommendations for future reiterations of similar interventions with the population to enhance the project's sustainability. At the conclusion of the project, formal evaluation of findings and recommendations were disseminated more widely to contribute evidence to the knowledge funnel.

Methodology

The project was a pilot evidence translation project for performance improvement. The project used a quasi-experimental pre-post measurement design in a single cohort. Surveys were administered in-person before and after an advance care planning educational intervention, and an electronic survey was administered at two months follow-up to evaluate the test of change. The following sections address further details of the project methodology.

Setting

The ACP program was delivered in partnership with the Middlesex County COYL Task Force and took place in a Korean American church in central New Jersey. The church had a congregation of roughly 100 adult members. Members were primarily Korean American and English-speaking or bilingual. Church services are conducted in English. The congregation was comprised mainly of young families whose older adult parents do not attend the same church. The church's pastor was a key stakeholder for the improvement project.

The hospital referral region where the intervention took place exceeds national benchmarks for intensity of hospital care in the last six months of life and rates of hospital deaths, with the equivalent of an additional 16,368 hospital days and 355 more hospital deaths compared to the 2014 national benchmark (Dartmouth Atlas, 2018). In 2016, nearly one third of all patients who died in one of the area's hospitals received palliative care services (A. Holmes, personal communication, March 6, 2018). Only 3.8% of patients receiving palliative care were Asian (A. Holmes, personal communication, March 6, 2018). This is a low proportion considering that Asians make up nearly a quarter of the local population of the city (U.S. Census Bureau, 2018).

According to the most recent U.S. Census data, there were approximately 7,400 Middlesex County residents who identified as Korean (U.S. Census Bureau, 2018). Of Korean residents who were 18 or older (n= 6,195), 12% (n= 739) were 65 or older, and three percent (n= 179) were 75 or older (U.S. Census Bureau, 2018). This aligns with the overall Middlesex County population, of which 12.3% were 65 or older (U.S. Census Bureau, 2018). As of 2016, Middlesex County households had a median income of \$80,716, and 89% of adults aged 25 and

older had at least a high school diploma, with 41.5% holding at least a bachelor's degree (U.S. Census Bureau, 2018).

Project Population

The population of focus was Korean American adults in Middlesex County, New Jersey. Based on the most recent U.S. Census data, there were approximately 6,150 Korean American adults between 18-90 years of age in Middlesex County. For the purposes of the pilot performance improvement project, a convenience sample of Korean American adults from one Middlesex County church served as the project population. The expected sample size was approximately 25 participants.

This project's inclusion criteria for participation included self-declared comfort with reading, writing, and communicating in English, age 18 or older, access to email for administration of the follow-up survey, and being a member of the church or invited by a church member. Exclusion criteria included age 90 or older, and disabilities that prevented participation in an educational program (e.g. blindness, cognitive limitations that preclude learning). Non-Korean American members were not excluded from participation in the ACP intervention, however, their responses were separated from the sample in data analysis to determine if it impacted overall results.

Subject Recruitment

The project used purposeful sampling of participants. Participants were recruited directly from the church site. Snowballing was also allowed so that church members may invite non-church members to participate, however no participants were recruited this way. The ACP intervention was advertised to adult church members through verbal announcements during church services, written reminders in the church bulletin, as well as website and email

announcements. The primary investigator engaged site stakeholders to determine how programs and events are typically advertised to the congregation. The content of announcements and advertising materials are included in the appendices (see Appendix D). Church leaders, including the pastor, assisted in telling potential participants about the program and invited interested members to see the primary investigator for follow-up and assessment of eligibility for participation. The primary investigator participated directly in recruitment by being present to register participants following the church service for two weeks prior to the intervention.

Consent Procedure

The primary investigator administered the informed consent form to participants; no other study team members were involved in obtaining informed consent. The consent form was completed on paper and participants were given a copy of the form to keep (see Appendix F). Informed consent was obtained by the primary investigator in-person at the church during registration of participants on the two Sundays prior to the ACP intervention. Any registered participants who did not complete the informed consent prior to the day of the intervention did so immediately prior to the ACP intervention. The same process applied to participants who did not pre-register for the program but showed up for the ACP intervention. The primary investigator used the sign-up sheet to maintain a list of registered participants and the status of their consent to ensure that any subjects lacking a completed consent form completed the process prior to admittance to the program (see Appendix E). Subjects had the opportunity to speak with the primary investigator during the consent process, and were also be given the investigator's phone number and email address so that they could contact the investigator with any concerns. The primary investigator retained completed consent forms.

Risks or Harms

A risk of minimal harm was expected from involvement in the project, including a risk of psychological, emotional, or spiritual distress resulting from reflection on death and dying. A further risk of project involvement was recalling memories of difficult or upsetting experiences related to death and dying. To help mitigate this risk, participants were notified that they could leave the program at any time, and that church leaders were available during and immediately after the intervention to provide spiritual and emotional support if needed. Participants were also informed that they may skip survey questions or withdraw from the project completely at any time and for any reason. Additionally, participants in the project faced a risk of minimal harm related to the potential for a breach in data security. This risk was mitigated through the use of participant identification numbers in place of personal identifiers, as well as the use of data security measures. This is covered in more detail in the section entitled “Data Maintenance and Security”.

Subject Costs and Compensation

Subjects did not incur any costs from participation in the project. Refreshments and ACP materials were provided free of charge. Among participants who completed the two-month follow-up survey, one participant was selected at random to receive one \$50 gift certificate to Amazon.

Project Interventions

The project consisted of an advance care planning workshop with the administration of surveys before and after the workshop, as well as a final survey administered two months after the workshop. The intervention took place in the building that the church rented for services, and was held after a Sunday church service. The intervention included advertising and recruitment for the event, a pre-test survey, sign-in of participants and confirmation of completed con-

sent. The event included a light lunch and a viewing of a 20 minute video about a patient's end-of-life experience, a presentation delivered by the primary investigator providing an overview of ACP topics and instruction in how to use the bilingual Korean-English version of the "Five Wishes" AD, and a voluntary take-home assignment. There was also a question and answer period in which participants could ask questions. Surveys were administered on paper prior to the workshop and after the workshop. The follow-up survey was administered via SurveyMonkey through an email hyperlink.

Advertising. Advertising for the ACP program began approximately two months prior to the event date, with a written announcement in the church bulletin and the church's weekly email announcements. Two weeks before the event through the week of the event, a verbal announcement was made during the church service. All advertising materials and scripts may be found in the Appendices (see Appendix D). A flyer and script for social media announcements were also prepared for the purposes of advertising the event, however they were not used. During the two Sundays leading up to the event date, the primary investigator was present following the church service to register participants for the event. Further details regarding recruitment are available under "Subject Recruitment" above.

Pre-test survey. A pre-test survey was administered prior to the start of the ACP workshop. The primary investigator administered the survey on the two Sundays leading up to the ACP workshop when she was present to recruit participants after the site's church services. The survey was administered to participants who signed-up for the workshop after obtaining informed consent. Participants were assigned an ID number and were instructed to fill out the survey using the assigned ID number. For individuals who elected to register for the workshop on the day of the event, the survey was administered immediately following registration and in-

formed consent, prior to the start of the program. The survey took 5-10 minutes to complete and was collected by the primary investigator when completed. Contents of the survey are discussed below under “Outcome Measures.”

Sign-in and program materials. A sign-in table was set up at the entrance to the room where the intervention took place. A volunteer from COYL assisted participants in signing in. Participants signed next to their name on the registration sheet and the volunteer checked the registration sheet to confirm that informed consent was previously obtained and the pre-test survey was completed. If consent and the pre-test were already completed, the participant was given a workshop folder containing workshop materials marked with their name and corresponding participant ID number. Participants who did not pre-register, or who do not complete the informed consent prior to the intervention were required to complete the consent, obtain an ID number and complete the pre-test survey prior to admittance to the program. Any questions regarding the program, consent or pre-test were referred to the primary investigator.

Each registered participant received a folder containing workshop materials when he or she signed-in for the workshop. The workshop folder contained the following materials: (a) a workshop schedule, (b) a copy of the slideshow presentation, (c) the Korean-English version of "Five Wishes", (d) a pamphlet about the POLST from NJHCQI, (e) a pamphlet on ACP steps from PREPARE, (f) a sample copy of the English version of the POLST, (g) a list of additional helpful resources by topic, and (h) the post-test survey. A copy of all workshop materials that were contained in the workshop folder are available in the Appendices (see Appendix G).

Refreshments and short film. A light lunch was provided for participants. At the start of the program, the primary investigator welcomed participants and described the schedule of events. The investigator encouraged participants to discuss the following question over lunch

(displayed on the projector screen): “When you think about health care for your parent or loved one, what do you worry about: getting too much care, not enough care, or something else?”

About twenty minutes after the event start time, the short film, *Anna’s Story*, was played. *Anna’s Story* is a fictional story depicting an EOL experience from the perspective of a dying patient, family, and various members of the healthcare team. The film was produced by Atlantic Health with support from Horizon Blue Cross Blue Shield of New Jersey to be used for educational purposes (Hicks, 2009). A study by Volandes et al. (2008) demonstrated that educational videos may help improve informed decision-making around EOL topics, compared to verbal instruction alone. The *Anna’s Story* film was intended to give participants a baseline understanding of the complexity surrounding EOL decisions and care, and to underscore the significance of engaging in ACP with family members.

Presentation. An educational presentation on ACP was delivered by the primary investigator, who is a registered nurse and member of the Middlesex County COYL Task Force. The presentation was supplemented by a slideshow presentation and included an overview of ACP topics and instruction in use of the Korean-English version of the "Five Wishes" AD to guide and document ACP conversations with family. A copy of the presentation slides is available in the Appendices (see Appendix G). ACP topics covered included a definition of ACP, types of medical care at the EOL, types of ACP documents, how to select the appropriate ACP document, how to start ACP conversations, and how to talk with healthcare providers about care options and decisions.

Topics were selected based on discussion with stakeholders from the project site (i.e. the church pastor and two church members with personal experience as caregivers) and published educational materials from the COYL program of the NJHCQI, and other reputable sources in-

cluding the New Jersey Hospital Association, PREPARE, and the Conversation Project. Finally, the presenter gave participants a voluntary take-home assignment to use the Korean-English version of "Five Wishes" in the following 60 days to begin an ACP conversation with a parent or other individual for whom they are a caregiver (excluding a child). Participants were informed that the investigator would follow-up in two months to see if any additional ACP actions have been taken. The presentation lasted about 45 minutes, and concluded with a question and answer period (approximately 15 minutes) in which participants asked questions of the presenter and a COYL volunteer who was a hospital chaplain. The program script is available in the appendices (see Appendix H).

Post-test survey. Immediately following the educational presentation, participants completed a short post-test survey. The post-test survey was included in the workshop folder and was pre-marked with the participant's ID number. Contents of the survey will be discussed under "Outcome Measures" below. Participants handed in their surveys to project volunteers upon completion.

Follow-up survey and raffle. A follow-up survey was administered to participants two months after the workshop. A link to the electronic survey was delivered to the email address provided by each participant upon registration. The survey was anonymous; participants entered their ID number on the survey. A personalized email was sent to each participant with a reminder of their ID number prior to administering the survey. Details regarding the content of the survey are described under "Outcome Measures" below. Participants who completed the follow-up survey were entered into a raffle to win a \$50 gift card to Amazon, and one participant was selected at random to win the gift card, which was delivered by email.

Additional considerations. Participants with children were advised that free childcare was provided by church volunteers in a dedicated room during the workshop. Children were picked up by parents after the program.

Outcome Measures

To evaluate the program's impact, the following outcome measures were used: the 15-item ACPES, feedback on program quality, and self-report of ACP actions. The ACPES was administered in both the pre-test, post-test, and follow-up surveys in order to measure the ACP intervention's impact on ACP engagement. Feedback on program quality was collected in the post-test survey to measure the perceived cultural appropriateness and quality of the intervention, as well as suggestions for improvement. Self-reported information on ACP actions taken were collected in the pre-test survey as well as the two-month follow-up survey to determine if the program contributed to an increase in ACP actions taken by participants. A copy of the pre-test, post-test, and follow-up surveys may be found in the appendices (see Appendix I).

Pre-test survey. The pre-test survey contained questions related to participants' demographics, ACP actions taken, and the 15-item version of the ACPES. Demographic information included sex, age, marital status, ethnicity and education level. Demographic questions were repeated in subsequent surveys. The survey took participants 5-15 minutes to complete. The following sections describe the remaining survey components in more detail.

ACP actions. Participants were asked about whether they cared for a parent or loved one, or were likely to care for one in the future. During the pre-test survey and the two-month follow-up survey, participants were asked about what prior ACP actions (i.e. ACP conversations and ACP documentation) they had taken. This measure is modeled after findings from a study by Sudore, Schickedanz et al. (2008), which found ACP discussions to be a significant area for

ACP interventions to target in addition to the traditional focus on AD completion. Subjects were asked about ACP actions they had taken personally, as well as actions they had taken with their parent(s) or other individuals for whom they were caregivers (see Appendix I). Survey questions measuring ACP actions were developed by the primary investigator and reviewed for clarity and specificity by a co-investigator with experience in quality improvement and program evaluation.

ACP Engagement Survey. The ACPES was developed by Sudore, Heyland, Barnes et al. (2017), and includes four validated versions, each with progressively fewer questions (i.e. 55-item, 34-item, 15-item, nine-item, and four-item versions). The ACPES measures factors related to ACP engagement including identifying values, selecting a healthcare decision-maker, engaging in ACP discussions with decision-makers and the healthcare team, and documenting care wishes (Sudore, Heyland, Barnes et al., 2017). Because changes in ACPES scores correlate closely with changes in ACP behaviors ($r = .91, p < .001$), the tool is well-suited to measuring the impact of ACP interventions (Sudore, Heyland, Barnes et al., 2017).

The tool was validated in a diverse cohort of 1,165 individuals over two phases, six percent of which were English-speaking Asian or Pacific Islander (Sudore, Heyland, Barnes et al., 2017). The validation study demonstrated a Cronbach's alpha of 0.92 for the English version of the 15-item survey (Sudore, Heyland, Barnes et al., 2017). The ACPES uses Likert scale responses. The ACPES is scored on a five point scale, with the 15-item version demonstrating an average score of 3.16 during the validation study in a cohort with an average age of 64.9 years (Sudore, Heyland, Barnes et al., 2017). Permission to use the survey for the performance improvement project was obtained from the tool's corresponding author (R. Sudore, personal communication, March 7, 2018).

Post-test survey. The post-test survey repeated the 15-item version of the ACPES and also included questions regarding the workshop's quality. Questions related to program quality were used for program evaluation purposes to help tailor the program for future reiterations with similar audiences. Workshop evaluation items in the post-test survey were adapted from the "Sample Workshop Evaluation Questionnaire" developed by WGBH Boston and the Corporation for Public Broadcasting (n.d.) for use in evaluating educational workshop programming. The survey took about 5 minutes to complete.

Follow-up survey. A follow-up survey was administered electronically two months after the workshop. The online survey platform SurveyMonkey.com was used to create and deliver the survey via email. According to SurveyMonkey, the follow-up survey took participants less than 5 minutes to complete. Participants had about two weeks from the survey's delivery to complete the survey. Participants were asked to enter their assigned ID number on their survey to allow linking of their data to the previous surveys. One reminder was sent to participants to complete the follow-up survey toward the end of the survey window.

In order to determine changes in ACP actions taken and ACP engagement since the intervention, the follow-up survey repeated questions relating to ACP actions and the 15-item version of the ACPES. The same survey items used in the pre-test survey was used in the follow-up survey to help ensure consistency. The ACPES was measured at three points (i.e. before, immediately after, and one month after the ACP intervention) to help determine if the ACP program had a sustained impact on ACP engagement. To encourage completion of the follow-up survey, participants who completed the survey were entered to win a \$50 gift card to Amazon.

Project Timeline

The project timeline was guided by the phases of the KTA cycle: (1) problem, (2) adapt, (3) barriers, (4) select, tailor and implement, (5) monitor, (6) evaluate, and (7) sustain. Project activities related to preparing the proposal and submission to the Institutional Review Board were included in steps one through four of the KTA cycle; which took place from January 2018 through June 2018. Implementation also took place during step four, and evaluation and dissemination of results occurred in steps five through seven of the KTA cycle. Implementation lasted four months from September through December 2018. Evaluation took place from November 2018 through January 2019, and initial dissemination of findings was completed by May 2019. A Gantt chart is included for a detailed timeline (see Appendix J).

Resources Needed/Economic Considerations

The project required several resources, including materials for participants, space and equipment for the educational intervention, and services such as child care. The primary investigator was responsible for project costs, however, some services and resources were provided in kind or donated. Project materials included a copy of the Korean-English “Five Wishes” document for each participant as well as folders, pens, and other documents (i.e. consent form, surveys, educational materials, advertising materials). Technological resources included a subscription to SurveyMonkey to administer the follow-up survey, and a copy of SPSS statistical software for data analysis. Space and audiovisual equipment was provided by the church where the intervention took place. Church member volunteers also provided childcare during the intervention. A light lunch was provided by the primary investigator, and serving supplies and beverages were provided by the church. The project budget is included in the Appendices (see Appendix K).

Sustainability

The final phase of the KTA cycle is sustaining the knowledge application. The project was intended to be a one-time event, and there are not plans to repeat the workshop in the same church or to continue further COYL programming within the same church after the project's conclusion. However, the project was used to help inform future COYL programming with Korean American and/or other Asian American populations. The evaluation feedback was used to refine the workshop programming, and to help model future COYL programming with similar populations. Efforts were also taken to disseminate the project's findings through a presentation of findings, a poster presentation, and preparation of a manuscript for journal submission so that it may build upon the existing knowledge base related to increasing advance care planning engagement and action in Korean American populations.

Evaluation

This section will address the evaluation of the following outcome measures which were previously described: ACP engagement, ACP actions, and program quality. Demographic measures, including age group, sex, race, marital status, education, and caregiver status, were analyzed using descriptive statistics to describe the sample. The mean and median age of the sample and the percentage of male and female participants were calculated for age and sex. For race, the percentages of Korean and "other" race participants were calculated. The percentage of participants in each education level were calculated. The percentage of participants who identify as a caregiver was also calculated using responses to pre-test survey question number 8 (see Appendix I). ACP actions were reported as the percentage of participants who have an AD, who have had ACP conversations, participants whose loved one had an AD and participants who had an ACP conversation with their loved one. Quality feedback questions from the post-test survey

were analyzed by determining the number and percentage of responses in each category. Responses to open-ended questions were reviewed, summarized, and analyzed for themes.

Statistical analysis was performed on the sample as a whole to compare ACP actions, namely ACP discussions (both personal and as a caregiver), and ACP documentation (both personal and as a caregiver), before the intervention and at follow-up using McNemar's Exact test. ACP engagement, as measured with the ACPES, was compared at three time points: before the intervention, immediately following the intervention, and at follow-up after the intervention. ACPES scores were calculated using the ACPES tool. The 15-item version of the ACPES tool has a total potential score of 75. The ACPES score were first calculated on each survey by tallying the total score and dividing by 15 to provide a score between one and five. This allows the score to be compared to other versions of the ACPES with fewer or more items. ACPES scores were compared both pre and post-intervention, and at post-intervention and follow-up to determine if the intervention increased levels of ACP engagement, and if increases in engagement were sustained over time.

Data Maintenance and Security

Data was collected at three points, including two surveys completed on paper, and one completed electronically over the internet. The following measures were taken to ensure confidentiality and data security. Participants were assigned an identification (ID) number which they entered on their surveys in lieu of their names. Participants' names and email addresses were collected and linked to their ID number on a log which was held by the primary investigator. All data collected was entered into an electronic spreadsheet in SPSS and stored on a password protected computer as well as backed up on the cloud in a password protected account with two-step verification. All SPSS files for analysis were secured in the same manner. The primary investi-

gator retained the log linking participants to their ID number until all data was collected and entered into the data management system (i.e. SPSS) or Numbers spreadsheet (for open-ended responses), at which time the log was destroyed. This took place about one month after the close of the follow-up survey.

The paper surveys were retained by the primary investigator until data analysis was complete, and original surveys were stored in a secured filing cabinet until they were destroyed following the completion of data analysis. SurveyMonkey was used to create, administer, and gather responses to the follow-up survey. Data was secured via the use of a password protected SurveyMonkey account. According to SurveyMonkey, survey response data is encrypted and stored in physically secured U.S.-based servers (SurveyMonkey, 2017). Information on additional data security measures taken by SurveyMonkey is available at <https://www.surveymonkey.com/mp/policy/security/>. Data from the electronic survey was entered into SPSS for analysis. Access to individual survey responses was limited to members of the DNP team as needed for data analysis. De-identified data is to be retained at 180 University Avenue, New Brunswick, New Jersey in the office of the DNP Team Chair for at least three years following the project's close-out.

Results

Data collection occurred between October 7-21, 2018 for pre-test and post-test data, and from December 15-31, 2018 for follow-up data. Data analysis was performed using SPSS version 25. A convenience sample of 26 participants were recruited from the church, representing approximately 25% of the total adult congregation of about 100 members, however, only 13 completed all components (pre-post, and follow-up).

Descriptive Statistics

Of the 26 consented participants, 20 attended the ACP training intervention, and 18 participants returned post-test surveys after the ACP intervention. The final sample of 13 participants completing all three components was used for data analysis. The participants were primarily Korean American (84.6%), female (53.8%) married (76.9%), and all had at least a college education. Participants ranged in age from 26 to 55 with a mean age of 40.5 years. All 13 participants identified as current or future caregivers to a parent or other loved one other than a child. The sample's demographics are presented in Table 1 (see Appendix L).

ACP Actions

ACP actions taken by participants and their parent or loved one were compared. For questions whose listed responses included “yes”, “no” and “not sure”, the categories “no” and “not sure” were combined for analysis. The question regarding whom participants had talked with about their own EOL care wishes was dichotomized to “yes” or “no” for whether they had had a conversation for comparison before and after the intervention. A summary of these results are highlighted below, and are fully presented in Tables 2 (see Appendix L).

Before the intervention, participants (n=13) were most likely to have discussed their care wishes with family or friends (69%) or to have never discussed them before (30.1%). No participants reported having discussed their own EOL care wishes with a healthcare professional. Participants reported an increase in ACP conversations at follow-up— both personal conversations about participants' own wishes, and conversations with a parent or loved one about their wishes for EOL care. An unexpected finding was that five participants at follow-up (38.5%) reported that they had not completed an ACP action that they previously reported they had done, with one participant reversing two ACP actions at follow-up (e.g. on pre-test reporting having completed

an AD, but reporting no AD at two-month follow-up). Results are reported in Table 3 (see Appendix L).

Engagement

Results related to engagement scores are reported in Table 4 (see Appendix L). The 15-item ACPES, which was administered during the pre-test, post-test, and follow-up surveys consisted of 15 survey questions using a Likert scale format where 1= very ready/confident, and 5= not at all ready/confident. The tools were reverse scored on a 5-point scale, so that a score of 1.00 reflects low ACP engagement, and a score of 5.00 reflects high engagement. Surveys were scored manually two times, and any conflicting scores were resolved to ensure accuracy. Two outliers were detected among pre-test ACPES scores that were more than 1.5 box-lengths from the edge of the box in a boxplot. Outliers were determined to be a measurement error (i.e. Likert scale was used backwards). This was reported by one participant and was determined to be the case with the second outlier due to extreme difference between pre and post scores in an illogical direction. The two outlier scores were altered by reverse scoring to capture the intended responses.

ACPES scores were compared between the pre-test and post-test surveys and the pre-test and follow-up surveys using a paired samples t-test. Participation in the ACP workshop contributed to a moderate increase in ACPES scores immediately after the intervention compared to before the training, $M = 0.459$, 95% CI $[-0.031, 1.048]$, $t(12) = 2.053$, $p = .063$, $d = 0.57$. There was also a moderate increase between ACPES scores at two-month follow-up compared to before the intervention, $M = 0.581$, 95% CI $[-0.137, 1.299]$, $t(12) = 1.762$, $p = .103$, $d = 0.49$. This increase in engagement was sustained through the two-month follow-up period, as demonstrated

by a lack of a significant difference between post-test and follow-up scores according to the Wilcoxon Signed Rank test ($z = 1.02, p = .306$).

Program Evaluation Feedback

Results related to program evaluation are reported in Tables 5 through 7 (see Appendix L). Reflected through responses to 5-point Likert-style questions, participants reported that the ACP program met their expectations somewhat well, that they were somewhat ready to apply what they learned in the session, that the information was very easy to understand, and that they were somewhat likely to recommend a similar program to others. Two questions sought to evaluate the program's cultural relevance: how relevant the information was to participants and/or their family, and how much participants agreed with the statement "the workshop addressed sensitive topics in an appropriate way". Participants felt that the program was very relevant, and dealt very appropriately with sensitive topics.

Participants were asked to select all that applied from 11 options addressing how the program could be improved. In order of the number of responses, the most frequent responses were related to the information provided (e.g. cover more information, include greater detail), instructional methods (e.g. increase interaction, include more case examples), and the length of the program (i.e. make the program shorter or longer). Participants were also invited to respond to three open ended questions and were given room for additional comments. Participants shared what they liked best about the program, what they would change to improve upon the program, future programming related to ACP that they would like to see for a Korean American audience, and comments related to the program's personal significance and suggestions for the presenter for improving public speaking skills and survey clarity.

In relating what they liked best about the program, participants reported that the program provided a good overview of ACP topics and that they liked the program material including discussion of ACP documents, real life examples, the question and answer time, and the *Anna's Story* film. Participants particularly found the discussion of the "Five Wishes" tool to be helpful and reported that they felt having a bilingual Korean-English copy to be very valuable, as captured by the comment, "Very informative. Five Wishes was excellent and translation is key". Comments also addressed the program's organization, tempo and tone.

In providing feedback on how to improve the program, participants underscored their desire for incorporating more interaction into the session. "More time on Q&A and review of practical examples", "allotting time to review one wish [of the Five Wishes] collectively might be helpful", "add role playing", "discussion of what attendees feel/think/know about their or their loved ones' ACP and needs" are a sampling of comments related to this topic. Participants also suggested including an attorney in the program as a speaker, discussing the pros and cons of different decisions or ACP choices in more detail, providing more case examples, and speaking more directly about participants' concerns, needs, and challenges with ACP as Korean Americans, including how to address these specific issues. For future programming, participants made suggestions that clustered around two themes: programming that targeted native Korean speakers, and practice-based interactive programming where participants could develop ACP conversation skills.

Discussion

The primary investigator hypothesized that because the family plays a key role in ACP for Korean American older adults, that the intervention, intended to support adult children in discussing ACP with their Korean-American parents, would help increase ACP conversations with-

in the family unit. Three participants, representing 23% of the follow-up sample (n=13), reported having had a new ACP conversation with their parent or adult loved one for whom they were a caregiver, for a total of 54% of participants (n=7) reporting an ACP conversation with their parent/loved one. Further, an additional two participants commented that they intended to use the bilingual “Five Wishes” in the near future to initiate a conversation with their parent.

At the time of writing, there were no known published results of ACP programs targeted to support Asian American families by reaching out to adult child caregivers. Despite cultural and structural barriers to ACP for Korean Americans that were documented in the literature and discussed earlier, the results of this project suggest that adult children who self-identify as caregivers for Korean-speaking parents or loved ones desire to proactively support their loved ones in navigating EOL care. Although the project was associated with a modest increase in both personal and family ACP actions (i.e. participants’ ACP conversations about their own and their parents’ EOL care wishes), the intervention was not enough on its own to fully overcome participants’ barriers to family ACP.

Participants reported their parents’ resistance to discussing death and dying as a large barrier to ACP, and expressed concern during the question and answer period over what would happen to their parents if they did not have documented or known wishes for EOL care. This phenomenon is expressed in the literature, as in Kwak and Salmon’s 2007 study of Korean elders’ attitudes and preferences for end-of-life care. Kwak and Salmon’s (2007) findings reflected elders’ preference for indirect communication (i.e. *noon chi*) and discomfort discussing end-of-life care planning with family. Kwak and Salmon (2007) also noted participants’ reports that physician-initiated ACP discussions facilitated communication about ACP. This resonates with participants’ requests for ACP programming by a healthcare professional targeted directly to-

ward Korean-speaking older adults. Participants expressed both verbally and in writing that a similar program for native Korean-speaking older adults would be beneficial in helping families discuss this sensitive topic more openly and directly by helping to make it more socially and culturally acceptable.

Particularly, participants considered a community-based and/or faith-setting based program similar to this project to be desirable due to accessibility and promoting the social acceptability of the topic through implicit endorsement by faith leaders' hosting the program. This is also supported by the results of a similarly structured ACP program described by Sun et al. (2017). The program was likewise held in a church, and included a faith-based endorsement of ACP by a religious leader, explanation of ACP by a healthcare professional, and instruction in how to complete an AD form (Sun et al., 2017). The program resulted in a large increase in AD completion among older adult participants to whom it was targeted, with participants who had family support for having an AD being over 15 times more likely to discuss ACP with a decision-maker than those without family support (Sun et al., 2017). This suggests that pairing ACP interventions targeted to adult child caregivers and older adults may both help increase family support for ACP and reduce elders' resistance toward discussing ACP with the family.

The project's findings support the use of the bilingual "Five Wishes" as a foundation for teaching Korean American adult child caregivers how to initiate ACP within their family. The Korean-English "Five Wishes" was widely valued by participants through verbal and written feedback. "Five Wishes" has been utilized in this fashion to guide conversations about EOL care wishes in other patient groups. The *Family Journal: Counseling and Therapy for Couples and Families* published an article which advocated for couples to use the "Five Wishes" as a script to discuss ACP, and shared a case study of one couple who used the tool to talk about their wishes

and values for EOL care and document their preferences (Eckstein & Mullener, 2010). The “Five Wishes” has also been used to create an AD tailored to adolescents and young adults with serious medical conditions to assist them in sharing their wishes with their families (Wiener, Zadeh, Battles et al., 2012).

Project Facilitators

The application of the Knowledge to Action (KTA) Cycle to this project promoted the project’s organization, implementation, evaluation, and consideration of sustainability. After defining the problem and the evidence base to address lower rates of ACP among Korean Americans, the KTA cycle guided adaptation of evidence to the project, assessment of barriers, development and implementation of the intervention. The KTA cycle further guided monitoring and evaluation of project outcomes, and work to sustain results through developing recommendations for future programming. Finally, the model facilitated work aimed at contributing to the knowledge funnel through dissemination of project findings.

The delivery of the intervention within a faith community facilitated the project’s success. The DNP student’s prior relationship with the faith community through a close contact supported the site’s buy-in for the project. The project benefitted from endorsement from the church’s Pastor and influential peers, as well as the logistic and practical support of the church in providing space, audio visual support, and childcare. The DNP student attended church services for two weeks leading up the ACP training, and recruited participants in person for the intervention. The physical presence of the DNP student served as a strong reminder for interested individuals to register for the program, allowed participants to ask questions, and encouraged conversation among members about the upcoming training program. Spending time with the con-

gregation prior to the event also allowed the DNP student to build relationships and rapport with participants.

Although time constraints were an issue for the training, the time and location of the training intervention was convenient for participants, many of whom do not live locally to the church. Incorporating story-telling into the intervention helped participants engage with the material, as expressed in written and verbal feedback following the training. *Anna's Story*, a short film about a woman's end of life journey, a participant's sharing how having discussed end of life wishes helped during a difficult experience, and the DNP student's sharing of personal and professional experiences related to ACP, death and dying, and EOL care resonated with participants. The use of the bilingual Korean-English version of the "Five Wishes" AD was well received by participants.

Project Barriers

Recruitment may have been impacted by difficulties with advertising the ACP training. The program was not advertised as frequently as was intended due to miscommunication between the DNP student, site contact, and the individuals responsible for updating the communication channels used by the church (i.e. church bulletins, weekly emails with announcements, the church website, and social media). Further, a recruitment flyer developed for the training event was not able to be distributed due to the timing of a required IRB modification. The timing of the intervention and follow-up may have limited the increase in ACP conversations with parents following the intervention, as participants verbalized reticence to initiating a potentially disruptive conversation during the Thanksgiving and Christmas holiday season. Two months may also have been an insufficient time period for some participants to prepare for and initiate a conversation with their loved one. The timeframe of the follow-up survey (i.e. the week before Christmas

through New Year's Eve) may also have resulted in a lower survey response rate, as participants may have been busy with seasonal activities.

Although it did not appear to deter interested participants from registering for the training intervention, the length of the pre-test survey was a barrier for this project. Some participants expressed frustration with the ACPES tool, commenting on the perceived repetitiveness of the questions and reporting confusion on the difference between similarly worded questions. Additionally, the ACPES tool utilized in the project surveys contained a formatting error which was not recognized until after surveys were administered. While Sudore, Heyland et al. (2017) included more detailed descriptions for each Likert response (e.g. 1 = "not at all" or "I have never thought about it" depending on question type) in the published ACPES, the primary investigator administered the tool with a simplified Likert scale ranging from "not at all ready/confident" to "very ready/confident". This limitation should be considered in interpreting results related to ACPES scores in this project, however, mean ACPES scores were in line with previously published average scores (Sudore, Heyland et al., 2017).

More interactive workshop-like programming was set aside for a content-heavy program in order to provide participants with a necessary basic foundation in ACP in the limited time available. The ACP training was limited to a single two hour session due to time constraints with the church's use of rented space for services, as well as in consideration of feedback from church representatives during planning of the program, who advised that a single session would be preferred. As a result, the DNP student was not able to cover content in as much depth as was desired by the student and participants. Additionally, time constraints limited the types learning tools that were able to be incorporated, such as story-telling, group discussion, role playing, etc., which might have increased participants' engagement with and grasp of the subject matter.

Finally, difficulty engaging church representatives early on in the project's planning stages limited the DNP student's ability to tailor the intervention to the needs of the congregation. Some guidance was obtained from three church representatives including the church Pastor and members who had experienced the death of a parent they had helped care for, however, these perspectives were not necessarily representative of those of the greater congregation. While a focused discussion with or short survey of potential participants' baseline knowledge and learning goals would have been helpful for planning the intervention, this was not feasible due to constraints in communicating with potential participants prior to IRB approval of the project.

Unintended Consequences

The finding at two-month follow-up that participants reported lower rates of advance directive completion was unexpected and on the surface, paradoxical. However, this finding may be related to initial misconceptions about what an AD is, resulting in participants reevaluating whether the manner in which they had documented their EOL wishes was adequate. Another possibility is that participants may have interpreted the question "have you put your wishes for end of life medical care in writing?" differently during the pre-test and follow-up surveys. For instance, participants may have interpreted the question at follow-up to be asking about actions specifically taken since the intervention, rather than action taken generally in the past. Regardless of the phenomenon behind this finding, it is possible that the reversal of participants' responses may have masked a significant effect of the intervention on personal ACP behaviors.

Implications

The findings, barriers and facilitators of this project have implications for clinical practice, healthcare policy, quality and safety, education, and the cost of healthcare. Implications

apply to the work of individual clinicians, larger groups such as the COYL task force, as well as state and national entities. These are described below.

Clinical Practice

Professionals engaging in community outreach for ACP should consider stacking interventions within a faith community to target different individuals in a family unit to improve family support for ACP and reduce stigma surrounding discussing death and dying for elders. Professionals should strive to facilitate ACP behaviors within the family unit for Korean American families to improve the cultural relevance of interventions. To better support Korean American families in having difficult conversations about death and dying, future ACP outreach should consider combining ACP programming geared directly toward adult child caregivers with skills-based programming where attendees can practice using the “Five Wishes” for ACP conversations, and programming with similar content to that of this project held in Korean for native Korean-speaking older adults.

A number of recommendations arise from this project’s experience with measuring project outcomes. If possible, any measurement tools to be used in tracking the impact of interventions should be trialed in the target audience prior to use. While the ACPES tool proved a useful and valuable tool for measuring the impact of the intervention, shorter versions may be more well received by users, while still having a high degree of internal consistency (Sudore, Heyland et al., 2017). Indeed, Sudore, Heyland et al. (2017) recommend using the 9 or 4-item tools for quality improvement projects and where research resources are limited. Finally, professionals should not rely solely on the ACPES tool when targeting the ACP behaviors of a participant’s parent or the family unit as a whole as the ACPES is intended to measure personal engagement

in ACP and does not apply directly to ACP as a family unit. A measure of ACP actions taken is a helpful complementary measure for family-based ACP.

Healthcare Policy

Targeting ACP interventions toward families rather than individuals alone could be an effective model for expanding engagement in ACP for families with non-Western values and traditions. Healthcare institutions should thoughtfully consider a policy of asking patients if they want their family to be involved in the ACP process when discussing or offering information about ACP. If the model is demonstrated to be effective across larger samples and wider populations, state or federal policy through Medicaid and Medicare could require hospitals, home care and hospice agencies, and primary care providers' practices to inquire if patients would like their family to be involved in the ACP process when discussing ACP with patients.

Quality, Safety and Education

This project demonstrated the usefulness of the ACPES in measuring the quality of ACP outreach programs as well as the value of ACP interventions targeting caregivers and families particularly for non-White populations. The Middlesex County Conversation of Your Life (COYL) task force should consider incorporating the short four-item version of the ACPES into the standard COYL event evaluation survey for all future COYL programming to better assess the impact of programming on ACP engagement. Because it is typically not feasible to follow-up with event attendees to assess for changes in behaviors (e.g. completing an AD), ACP engagement is a helpful surrogate marker of program impact. COYL should also consider incorporating more ACP interventions geared toward caregivers and/or families into programming, particularly for programming taking place with East Asian American populations. This is timely due to cur-

rent outreach underway to partner with organizations in the South Asian and Korean American communities.

Economic Implications

Improving families' engagement in ACP has the potential to decrease aggressive medical interventions when they are unwanted by patients and their families, thus decreasing the economic burden to Medicare and taxpayers represented in the cost of care over the last two years/six months of beneficiaries' lives. A gross cost analysis by O'Sullivan, Murphy, O'Caoimh and colleagues (2016) estimated that widespread uptake of an ACP program consisting of advance directives and palliative care in long-term care (LTC) settings would result in an annual cost reduction between 17.7 and 42.2 million Euros (i.e. about 20.8 and 48.6 million U.S. dollars) related to a reduction in hospital admissions and inpatient days, based on findings from three LTC centers. Further, the cost of ACP can be offset through cost savings related to less aggressive EOL care in keeping with patients' preferences. An Australian study by Nguyen, Sellars, Agar and colleagues (2017) estimated that a nationwide primary care-based ACP program for adults 65 and older would be cost-effective if adopted by at least 50% of adults.

Sustainability/Plans for Future Scholarship

The outcomes of future similar ACP interventions should be rigorously analyzed with larger samples to better assess the impact of ACP programming targeted toward Korean American caregivers. Further research should be done to assess the value of targeting ACP interventions to family units rather than individuals alone, and to determine promising ACP interventions toward this end. Future scholars should also consider adapting the ACPES for use in assessing ACP engagement within a family unit to provide a more rigorous tool to assess the impact of ACP training with caregivers. In view of the Knowledge to Action framework, the author will

seek to disseminate the findings of this quality improvement project through inclusion in a scholarly journal in order to contribute to the knowledge funnel by building on the current knowledge on this subject.

Conclusion

Koreans have traditionally valued a natural death at home (Shin et al., 2016). However, irregardless of personal preferences, older adult Korean Americans in NJ are likely to experience an EOL journey that involves medical intervention. NJ ranks above all other states in the U.S. for rates of hospital admissions in the last six months of life (1,424.87 per 1,000 Medicare enrollees in 2015), with up to 28% of Medicare enrollees spending at least a week in the ICU at the EOL and dying in a hospital, according to the Dartmouth Institute (2019). Engaging in ACP behaviors as a family unit can enable Korean American families to support elders' values and preferences for EOL care.

A nurse-led, community-based ACP program for the adult children of Korean American adults provided a foundation in ACP for participants to support their parents and loved ones in ACP. Participants showed higher rates of ACP engagement, and engaged in more ACP conversations about both their own wishes and those of their parents after the intervention. The Korean-English "Five Wishes" advance directive serves as a valuable template for individuals to consider their own EOL values and to engage their family in ACP discussions. A continued focus on community-based ACP outreach to Korean American older adults and adult child caregivers will help increase adoption of ACP behaviors and support positive EOL experiences in Korean American families.

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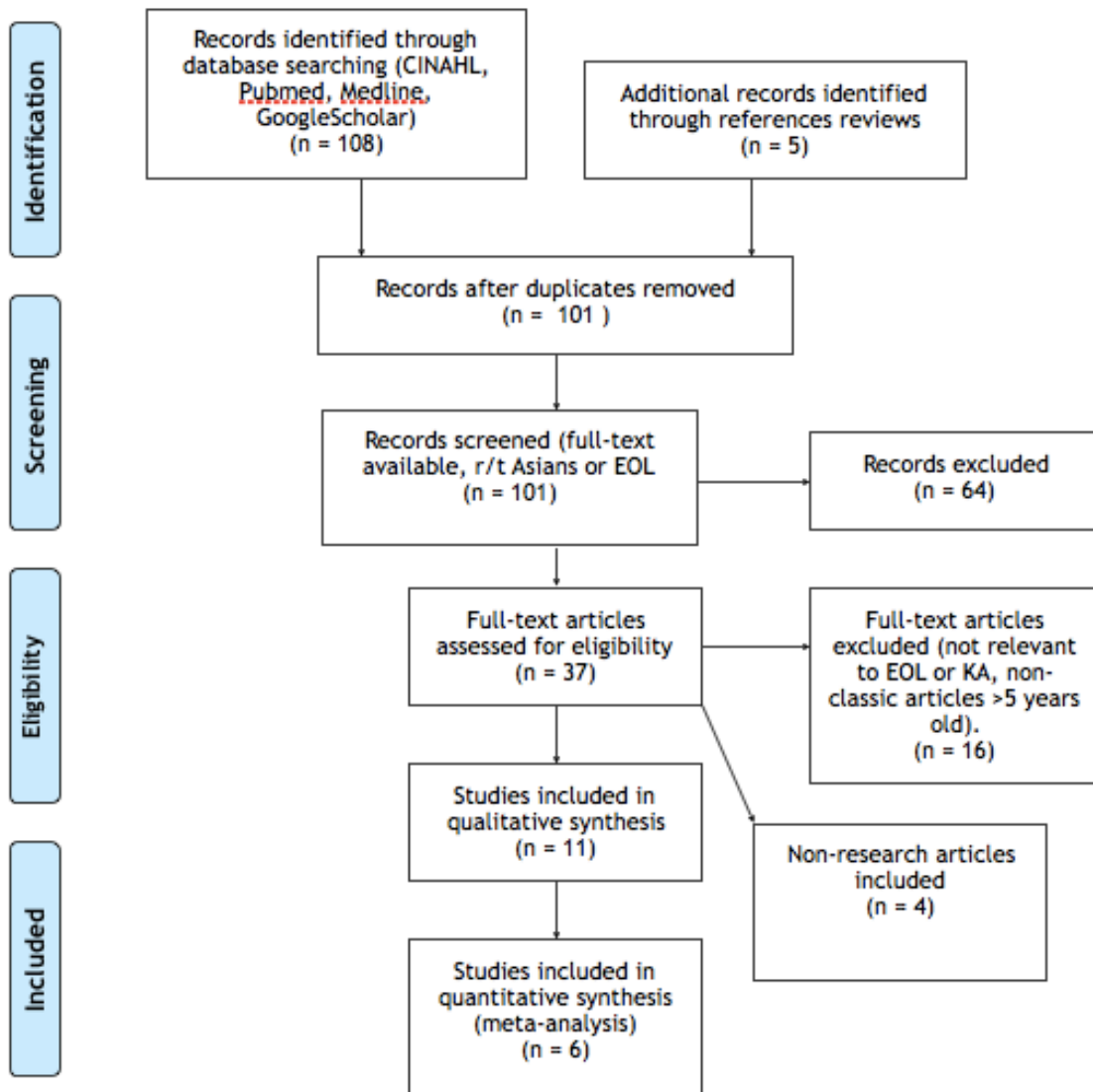
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Appendix A

Prisma Diagram



Adapted from Moher, Liberati, Tetziaff, & Altman (2009).

Appendix B

Evidence Table

EBP Question: Will a culturally-tailored ACP program for the adult children of older adult KA's increase participants' engagement in ACP, as measured by their engagement in ACP and their rates of ACP discussions with family members before and after the program?
Date: February 11, 2018

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
1	Carr, D. (2012).	cross-sectional survey, non-experimental	n= 2,111 married/cohabiting adults 18-64 y/o, national	<p>Asians were less likely to report EOL discussions than Whites (OR= 0.58, p <.01), but more likely to have a living will.</p> <p>Asians were most likely to cite the following reasons for not having a living will: it would not affect treatment, and they do not want to think about dying.</p> <p>Asians and Latinos were more likely than others to say that they were not sure how to bring up the topic of EOL care.</p> <p>Author note- barriers based more on "denial and avoidance...and less on cognitive or knowledge obstacles" (p. 938).</p>	<p>Generalizability limited by sample focused only on married or cohabiting adults.</p> <p>Non-English speakers were excluded, may have resulted in Asian and Latino sample with higher levels of acculturation than populations.</p> <p>Analysis focused on demographics, SES, and limited health info, but did not consider religion, cultural factors, or experiences</p>	<p>Research Level: III</p> <p>Grade: Good</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
2	Dobbs, D., Park, S.N., Jang, Y., & Meng, H. (2015)	Cross-sectional observational survey (quantitative), non-experimental	n= 675 community-dwelling older Korean-American adults (literate in written Korean)	<p>Roughly 1/5 of sample were aware of AD, and 18.6% had completed an AD; the two measures correlated (spearman $\rho=0.53$, $p<.001$).</p> <p>Acculturation and older age were associated with both awareness and completion of AD. 60% of those aware had completed an AD.</p> <p><i>"individuals with a low level of acculturation should be prioritized in intervention efforts to increase awareness and completion of ADs"</i></p> <p><i>"given success of churches as recruitment sites...this would be a recommended venue for ... intervention"</i></p> <p><i>"awareness alone is not enough to promote completion of ADs in Korean-American older adults"</i> (p 567).</p>	<p>Not able to demonstrate directionality of correlation (cross-sectional design).</p> <p>Specific focus on awareness and completion as yes or no- does not give insight into population's experiences and contributing factors to awareness and AD completion.</p>	<p>Research Level: III</p> <p>Grade: High</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
3	Frank, G., Blackhall, L. J., Michel, V., Murphy, S. T., Azen, S. P., & Park, K. (1998)	Case report providing qualitative insight to a previous quantitative study	n = 1, typical respondent from larger sample of 200 KA from 800 person sample in previous study	<p>Perceived conflict in larger study between KA's wishes for less aggressive care at EOL and their stated view that children should pursue LST at the EOL is explained by the KA interviewee's view that the children's role in decision-making is of greater importance than personal preferences</p> <p>Perception that filial piety and tori (right thing to do) dictate that LST should be requested to do everything to save family member's life</p> <p>Interviewee perception that dying in hospital is less burdensome to family- value of not wanting to burden family overrides her value of natural death at home</p>	<p>Very small sample; although representing what researchers found to be a "typical" response, cannot be generalized</p> <p>Classic article, but possibly outdated, with influence of changes in Korean culture around EOL customs (in Korea), may result in changing views</p>	<p>Research Level: V</p> <p>Grade: High</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
4	Jang, Y., Chiriboga, D. A., Allen, J. Y., Kwak, J., & Haley, W. E. (2010)	Cross-sectional survey, non-experimental	n= 675 KA adults (60+), Florida community-dwelling, convenience sample recruited from community and telephone book	<p>About 1/2 of sample had heard of hospice, and almost 3/4 were willing to use it</p> <p>Prior awareness of hospice resulted in the greatest odds of willingness to use hospice (OR 4.43, 95% CI = 2.85-6.90) among KA elders</p> <p>Acculturation and chronic conditions also significantly increased odds of willingness to use hospice among Korean-A elders</p> <p>Author recommendations- programs to increase awareness of EOL options; inclusion of family (not just older adults); address cultural beliefs like filial piety and filial expectations in programming; use preferred language</p>	<p>Study in single geographic area (FL), not random sampling, key measure measured as yes/no without qualifying data- limits generalizability</p>	<p>Research Level: III</p> <p>Grade: Good</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
5	Hong, M., Casado, B. L., Lee, S. E., & Pruchno, R. (2018)	Systematic review with quasi-experimental, mixed method, and qualitative studies included	26 articles included in study	Facilitators and barriers to engaging ethnic minorities in ACP: four categories- 1) socio-demographic factors, 2) health status, literacy and experiences, 3) cultural values, and 4) spirituality	Conclusions for some minority groups based on small number of studies Design of included studies limits rigor of review findings	Research Level: III Grade: Poor
6	Kataoka-Yahiro, M. R., Conde, F. A., Wong, R. S., Page, V., & Peller, B. (2010)	Descriptive, cross-sectional survey, non-experimental	n= 50, convenience sample from HD centers in Hawaii - native Hawaiians and Asian Americans	The chronically ill participants had positive attitudes about ACP, but only 40% had an AD Stated preference for EOL conversations with family over health/legal professionals/clergy/friends	Small, geographic sample Asian American ethnicity not specified, all participants viewed as single group Attitude tool not validated	Research Level: III Grade: Poor

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
7	Kim, M., & Foreman, M.D. (2011)	Correlative cross-sectional survey (quantitative)	n= 115 adult Korean American children (18-64), recruited through churches and 1 KA community center and snowball approach	<p>Children tended to believe parents' wishes were for life-sustaining treatment at EOL</p> <p>Children had generally positive attitudes toward EOL care planning (8-item Blackhall et al scale)</p> <p>Negative correlation between children's views on parents' wishes for life sustaining tx (using Life-Support Preference Questionnaire) and children's older age and high acculturation</p> <p>Higher education level, higher acculturation and lower level of familism positively correlated with positive attitude toward care planning</p>	<p>Convenience sample. 25/146 original sample declined to participate</p> <p>Most of sample was born in Korea, higher Korean culture</p> <p>acculturation- may not be generalizable to non-immigrant KA adult children</p> <p>Does not take into consideration parents' actual preferences for comparison</p>	<p>Research Level: III</p> <p>Grade: Good</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
8	Ko, E., Berkman, C.S. (2010)	Qualitative focus group	n= 23 older adult Korean Americans in 3 focus groups recruited through a PMD office in NY	<p>Themes identified: whether children are resistant/receptive to EOL discussions, whether the older adult or their children should make EOL care decisions, whether decision making should fall to eldest son or all children, whether children would carry out parent's wishes for care</p> <p>Children play a key role in decision-making at EOL, and participants universally reported difficulty discussing EOL issues with children</p>	<p>Not broadly generalizable because of small qualitative nature.</p> <p>Looks at feelings/ views about AD and decision-making process, but does not give insight into care preferences of the group.</p> <p>Does not give insight into children's views about EOL decision-making with/for their parents.</p>	<p>Research Level: III</p> <p>Grade: Good</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
9	Ko, E., & Berkman, C.S. (2012)	Individual structured interviews and focus groups	n= 26 individual interviews, 3 focus groups (n=9, 8, 6) KA 65+ in NYC	<p>Themes identified: AD are helpful for avoiding unwanted tx at EOL and for reducing burden on family for decision-making</p> <p>Misunderstandings by older adult KA about ADs. Participants desired education on topic in a community setting, particularly in church.</p> <p>Suggested use of media-video for teaching</p> <p>Perception that health providers may not want to initiate discussion about EOL care (most had Korean physicians)</p> <p>View by some that ACP is in conflict with living (focus on living rather than thinking about dying)</p> <p>Conflict in views: most participants did not think it was good to wait until a health crisis occurs for ACP, but over half said that designating a proxy is unnecessary bc family will know what to do</p> <p>Author recommend culturally-competent AD education about EOL care and discussing preferences with family and</p>	<p>Small convenience sample, exploratory study, probable selection bias for individuals more willing to discuss EOL issues</p> <p>Generalizability cautiously limited to similar population-older adult KA in NYC metro area who are community-dwelling, in good health</p>	<p>Research Level: III</p> <p>Grade: Good</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
10	Ko, E., & Lee, J. (2009)	Descriptive study, focus groups	n= 217 community-dwelling elders, 1/2 NWH, 1/2 KA in urban Eastern U.S.	<p>Individuals were more likely to discuss EOL CP with family (children, spouse) than healthcare providers or others</p> <p>When discussed, tended to discuss wishes more in general terms than specific</p> <p>Participants with more knowledge about EOL care and ACP were more likely to have EOL discussions</p> <p>Ethnicity (KA vs non-Hispanic Whites) did not have a significant effect on EOL communication when knowledge level was included in analysis- knowledge may mediate relationship btwn ethnicity and EOL communication</p>	<p>Nonprobability sampling used; recruited only from senior centers</p> <p>Scales/tools used were modified and translated, which may have affected their validity</p>	<p>Research Level: III</p> <p>Grade: Good-poor</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
11	Ko, E., Roh, S., & Higgins, D. (2013).	Cross-sectional survey, non-experimental	n= 195 older adult Korean immigrants from NYC senior centers	<p>EOL communication was measured on likert scale (very specifically, generally, only indirectly, or not at all)</p> <p>Communication was most frequent with family, and was mostly general (21.9% had had discussions)</p> <p>Older adults who placed greater importance on the idea of being a burden to family were more likely to have EOL communication (this was greatest effect measured)</p> <p>More religious adults were less likely to have EOL communication (second greatest effect measured)</p> <p>Authors recommendations for community-based education on ACP and providers' having EOL discussions with patients and family</p>	<p>Nonprobability sampling used; recruited only from 2 senior centers in NYC- not homebound or isolated</p> <p>Cross-sectional design does not account for changes in views/ behaviors over time</p>	<p>Research Level: III Grade: Good</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
12	Kwak, J., & Haley, W. E. (2005)	Non-research, literature review & recommendations. Classic study	n = 33 empirical studies addressing race/ethnicity and EOL care planning	<p>Non-White groups were less aware of AD and less likely to support their use</p> <p>Asians were more likely to prefer collective decision-making around EOL decisions</p> <p>Four domains discussed- AD possession, AD knowledge, AD attitudes, and life support use and preferences</p> <p>Authors recommendations- studies should include attention to other factors - e.g. SES, acculturation, language proficiency, and cultural values, attitudes and behaviors as distinct concepts</p> <p>Avoid expecting uniform beliefs/ attitudes/etc. in ethnic group, build trust, seek to understand and respect diverse beliefs</p>	<p>Studies were too variable to form strong consensus findings</p> <p>Findings pertain mainly to future research and not specifically to practice</p>	<p>Research Level: V</p> <p>Grade: Good</p>

13	Kwak, J., et al. (2014)	Non-experimental, qualitative study	n = 7 in-depth interviews with care managers/supervisors, and n=24 care managers in 2 focus groups in a Milwaukee care management organization	<p>Care managers for diverse, frail older adult patients reported four main challenges: 1) death and dying are taboo topics, 2) the “dying process is beyond human control”, 3) patients’ family and others have responsibility for making care decisions, 4) clients see planning for death as a foreign concept</p> <p>Care managers recommended:</p> <ul style="list-style-type: none"> gaining trust with diverse elders to make discussion of difficult topics more acceptable- ACP discussions should occur over time to establish a rapport and trust Approach discussion of ACP by asking about health decision-making in general to better understand and be respectful of different values Encourage patients to appoint a health care proxy if instructional directives are inconsistent with the cultural norms for family decision-making Focus education about ACP on family and lay leaders Community-based group education 	Findings based on care managers’ (expert) experiences with diverse elders near the EOL- amounts to expert opinion, but is not tested and views are as “outsiders”	Research Level: III Grade: High
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Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
14	Kwak, J. and J. R. Salmon (2007)	Non-experimental, qualitative pilot study. Classic study	n= 36 KA (20 older adults, 16 caregivers) in four focus groups in FL	Older adults and caregivers' responses yielded 6 themes: 1) there was a lack of knowledge and misunderstandings about AD and hospice care, 2) the family is expected to make final EOL decisions, but AD viewed as helpful for guiding decision-making, 3) filial piety can be interpreted as pro- and against hospice care, 4) bringing up EOL topics is uncomfortable and difficult for older adults and caregivers alike, older adults tend to prefer indirect communication (<i>noon chi</i>), 5) physicians are important in bringing up ACP, 6) home death is traditionally valued, but can be seen as burdensome to family	Sample not representative of larger population- in limited geographic area, higher than average education level for population (and acculturation) - most applicable to an educated and acculturated KA population	Research Level: III Grade: Good

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
15	Lee, J. E., Shin, D. W., Son, K. Y., Park, H. J., Lim, J. Y., Song, M. S., . . . Cho, B. (2018)	Cross-sectional survey, non-experimental	n= 295 South Koreans 60 + (in South Korea), community-dwelling	<p>Participants who had higher education, lower economic status, and were married were more likely to have a positive attitude toward AD</p> <p>Participants who had EOL discussion with family were more likely to have positive views of ADs</p> <p>Nearly 80% felt ADs were necessary, but 0% had completed one, and only 29.15% had heard of one prior to study</p> <p>More positive views on ADs among individuals wit lower functional status and comorbidities hypothesized by authors to be r/t desire not to burden family</p>	<p>Attitudes and experiences with ADs/ ACP assessed with unvalidated tool developed by the authors</p> <p>Limited geographic region of Korea, convenience sampling- may not be representative of larger population</p> <p>Findings did not reach level of significance</p>	<p>Research Level: III</p> <p>Grade: Poor</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
16	Phipps, E. J., True, G., & Murray, G. F. (2003)	Non-research, Consumer preference/experience	Forums and focus groups with ethnic communities in Philadelphia: KA, African American, and Latino; number of participants not identified	<p>KA churches played key role in organizing forum and connecting with community and providing health promotion. Churches served as “cultural and social centers, information and referral sources...” and helped with physical needs (i.e. transport to appts).</p> <p>Lack of knowledge n focus groups about hospice and ACP/ADs, life-sustaining treatments</p> <p>Focus groups found topic of ACP complicated by value of filial piety, but most expressed desire to not have LST at EOL. Concern expressed that children may not be able to honor wishes because of filial piety because may be seen as dishonoring parents to not pursue treatment.</p>	<p>Focus group recruitment and facilitation not described.</p> <p>Non-research; limited generalizability, simply one community's experience with ACP outreach</p>	<p>Non-research Level: V</p> <p>Grade: Good</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
17	Shin, D. W., et al. (2016)	Non-research, literature review & recommendations	South Korea	<p>Provides review of state of EOL care and ACP in South Korea, useful for context for less acculturated KAs.</p> <p>2/3 population die in hospitals despite a majority preferring home death. A recent law encourages ACP.</p> <p>Use of hospice and palliative care is uncommon, except for cancer diagnoses.</p> <p>No legal or standard AD form exists in Korea.</p> <p>Five themes influenced by traditional Confucianist beliefs impact attitudes toward EOL care and ACP: 1) opting for natural death, 2) desire not to burden others, 3) preference for family involvement and trust in doctor, 4) avoiding discussion of death, and 5) filial piety</p> <p>Author perceives POLST as a feasible model in Korea bc of MD involvement</p>	Did not discuss appraisal of quality of sources or search strategy.	<p>Non-research</p> <p>Level: V</p> <p>Grade: Low-good</p>

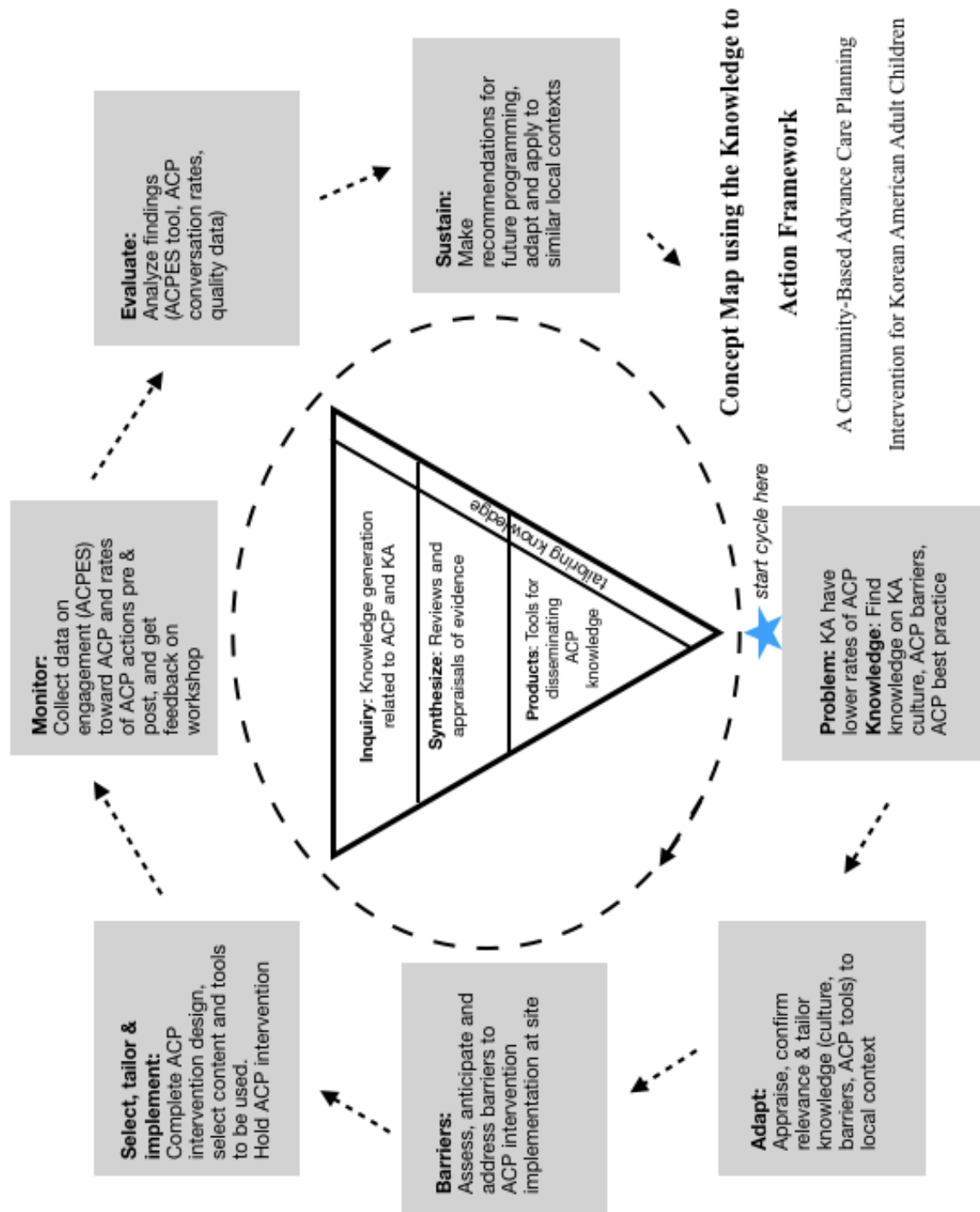
Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
18	Sudore , R. L., Schillinger, D., Knight, S. J., & Fried, T. R. (2010)	Descriptive, cross-sectional survey, non-experimental	n= 205 chronically ill adults 50+ in CA, White, Af rican , American, Latino & Asian/Pac. Islander	<p>Forty-five % of participants were uncertain (somewhat sure or less) about their care decisions regarding LST in a described hypothetical EOL situation.</p> <p>Latino and Asian or Pacific Islander patients were more likely to be uncertain than Whites.</p> <p>Patients with lower health literacy (on s-TOFHLA) and poorer health were also more likely to be uncertain. Language and acculturation may be involved- with those whose first language was not English and those born outside the U.S. more uncertain.</p> <p>Recommendations: Pay attention to cultural appropriateness and literacy-level appropriateness of ACP interventions.</p>	<p>Asians were only 9% of sample (n=19). Convenience sampling from a single site in San Francisco presents possible bias.</p> <p>Could not separate effect of uncertainty about scenario from possible confusion about the wording.</p> <p>May underestimate level of uncertainty—more care was taken to verbally describe scenario than in practice, where pts often <u>receive</u> written information</p> <p>Does not consider <u>affect</u> of reviewing decisions with family/friends- imp. for AA</p>	<p>Research Level: III</p> <p>Grade: High</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
19	Sun, A., Bui, Q., Tsoh, J. Y., Gildengorin, G., Chan, J., . . . Nguyen, T. (2017)	Quasi-experimental, pre-test/post-test, single group-pilot study	n = 174 participants from 4 Asian American churches-Chinese and Vietnamese	<p>Educational intervention to increase AD completion- 2 sessions, with a pre-test, immediate post-test, and 3 month f/u. Measured AD knowledge, beliefs, attitudes, and completion, as well as ACP discussion with a proxy.</p> <p>Church staff helped with recruitment- announcements, phone calls. Required age 35+, and either Chinese or Vietnamese. Excluded those who already had an AD.</p> <p>To culturally tailor the intervention, researchers had interviews with church leaders and focus groups with members prior to design.</p> <p>Findings: 1) materials in preferred languages, 2) health professionals give talks, 3) focus on patient rights (to reduce AD stigma), 4) allow time between sessions (4 wks) to have ACP discussions</p> <p>Session 1: "spiritually-based endorsement of AD by church leader, health prof. education on AD and how to complete, with forms given in preferred language.</p>	<p>(findings cont.) Staff available to assist with completion.</p> <p>Session 2- Reminders given prior. Second spiritual endorsement message. More detail on how to complete AD, and assistance given in completion of forms. Participants took home completed form with 2 copies for MD and proxy.</p> <p>Results: Beliefs and attitudes used ADAS + part of Brief Systems of Belief Inventory + 1 original question.</p> <p>73% completed AD, 25% had a ACP conversation w/ family</p>	<p>Research Level: II</p> <p>Grade: Good-low</p> <p>Limits: Modified eval. tool, not validated. Convenience sampling, no control.</p>

Article #	Author & Date	Evidence Type	Sample, Sample Size, Setting	Study findings that help answer EBP Question	Limitations	Evidence Level & Quality
20	Van Scoy, L.J., Howrylak, J., Nguyen, A., Chen, M., Sherman, M. (2014)	Cross-sectional survey, non-experimental	n= 130; urban hospital inpatients	<p>Patients were 68.6 times more likely to complete an AD if asked by friends or family (95% CI 13.0-361.3), compared to 10.8 x if asked by medical staff, and 46.5 x if asked by legal staff, than if not asked at all.</p> <p>Patients were 18 x more likely to appoint a healthcare proxy if asked by family and friends, 1.68 x for medical staff, and 4.34 x for legal staff— than if not asked.</p>	Convenience sampling; inpatient population may not be generalizable to community-dwelling adults. Did not look at race/ethnicity as a factor.	<p>Research Level: III</p> <p>Grade: Good-poor</p>

Appendix C

Concept Map



Appendix D

Advertising Materials

Email Announcement Blurb, Church Bulletin Blurb

Sunday, 10/21/18 12:30-2:30 pm: Advance Care Planning Workshop from Rutgers School of Nursing and Conversation of Your Life. Learn how to plan for end-of-life healthcare decisions and how to talk to your family about this important topic. Register for the workshop with Morgan Park on 10/7 or 10/14 after church.

Church Bulletin Insert (Flyer)

Advance Care Planning Workshop

Sunday, October 21st 12:30-2:30 PM

You've prepared for life after death, but what about death itself? Rutgers School of Nursing and the NJ Healthcare Quality Institute's *Conversation of Your Life* program are hosting a workshop at _____ about planning for healthcare decisions at the end of life.

The fact is, you may need to make healthcare decisions for your loved ones when they are at the end of their lives. Are you ready to make decisions that enable them to live their final days in a way that is meaningful to them and the family? Learn about the basics, and how to talk to your loved ones about this important topic.

The workshop is open to all English-speaking adults 18-89 years old, non-church members are welcome. A light lunch and child care will be provided. Please register for the workshop with Morgan Park on 10/7 or 10/14 after church.

Social Media Post Script 1

(to be published one to two weeks before event)

You've prepared for life after death, but what about death itself?

Come to the Advance Care Planning Workshop (hosted by Rutgers School of Nursing and Conversation of Your Life) to learn about preparing for healthcare decisions at the end of life. The workshop is for all English-speaking adults, but those who are—or will be—caregivers for parents or other loved ones will find it especially helpful.

Light lunch and child care provided. Sunday, 10/21 12:30-2:30 pm. Register after church this week!

Social Media Post Script 2

(to be published one week or less before the event)

A meaningful death takes some planning.

Remember to stay after church this Sunday (12:30-2:30 pm) for the Advance Care Planning Workshop from Rutgers School of Nursing and Conversation of Your Life! The workshop is open to all English-speaking adults, but will be especially helpful for those who help (or will help) care for parents or other loved ones. A light lunch and child care will be provided.

Appendix E

Registration and Sign-In Sheet Templates

Advance Care Planning Workshop Registration Sheet

Participant ID #	Name	Email	Consent (check)	Pretest (check)
001				
002				
003				
004				
005				
006				
007				

Advance Care Planning Workshop Sign-in

Please sign next to your name and check to make sure your information is correct.

ID #	Name	Email	Signature	INTERNAL USE Consent & Pretest Complete
001				
002				
003				
004				
005				
006				
007				

Appendix F

Consent Form



Informed Consent Form

Project Title: Evaluating the Impact of a Community-Based Advance Care Planning Intervention for Korean American Adult Children

You are being asked to participate in a quality improvement project that is being conducted by Morgan Park at the Rutgers University. This is a quality improvement project to increase participation in advance care planning.

PURPOSE OF THE PROJECT:

The purpose of this project is to evaluate the impact of an advance care planning program. You will be one of approximately 25 participants from (or invited by a member of) _____ Church.

WHAT WILL BE DONE?:

You will complete three surveys, and attend an educational workshop about advance care planning.

You will complete the first survey before the workshop, and it will take 5 to 10 minutes to complete. The survey includes questions about your feelings and beliefs about advance care planning, your demographics, and steps you may have taken toward planning for end-of-life care.

After you complete the questionnaire, we will hold an educational program on advance care planning which will take about 2 hours. You will complete a short survey after the education program, which will take about 10 minutes to complete. The second survey will ask questions about your feelings and beliefs about advance care planning, and your opinions about the program.

In two months you will receive a link in your email to a follow-up questionnaire. The follow up survey will take about 5 minutes to complete, and will ask questions about your feelings and beliefs about advance care planning, and steps you may have taken toward planning for end-of-life care.

We expect the project to last about two months, including the advance care planning program at _____ Church, and the online follow-up survey in two months. Participation in this project is voluntary. The only alternative to this project is not to participate.

RISKS OR DISCOMFORTS:

Minimal risks are anticipated from taking part in this project. Risks include feelings of sadness, discomfort, or distress related to discussion of death and dying. The educational program may

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Approval Date: 6/29/2018
Expiration Date: 6/28/2019



cause you to remember upsetting experiences. Church leaders will be available during and immediately after the educational program for spiritual and emotional support. There is also a risk of a breach of confidentiality if there is a breach in data security. Steps will be taken to keep your data safe, including the use of an identification number in place of your personal information, and measures to securely store your data. More information on how your data will be kept safe is below.

If you feel uncomfortable with a survey question or during the educational program, you can skip that question or withdraw from the project altogether. If you decide to quit at any time before you have finished the questionnaire, your answers will NOT be recorded.

BENEFITS OF THIS PROJECT:

Benefits from participating in this project include access to information and materials that can help you plan for end-of-life care for yourself or loved ones. You will also be contributing to knowledge about effective ways to increase engagement in advance care planning for Korean American families.

CONFIDENTIALITY:

Your responses will be kept strictly confidential. The paper/digital data will be stored in a secure computer after it is entered. Your personal identifiers (*such as name, email address*) will not be stored with data from your survey. You will be given a participant identification (ID) number which will be entered on your survey instead of your name. The researchers will see your individual survey responses and the results.

After we have finished data collection, the list that links your name and email address to your participant number will be destroyed.

COMPENSATION:

You will not receive any financial compensation for participating in this project. Participants who complete the follow-up survey will be entered into a raffle to win one \$50 gift card to Amazon. The winner will be selected at random after the follow-up survey is closed, and the gift card will be delivered via email to the email address specified during sign-up for the workshop.

WITHDRAWAL:

Your participation is voluntary; you are free to withdraw your participation from this project at any time. If you do not want to continue, you may turn in a blank survey. You also may choose to skip any questions that you do not wish to answer.

HOW THE FINDINGS WILL BE USED:

The results of the project will be used to evaluate the impact of an advance care planning program. The results from the project will be presented at Rutgers University School of Nursing, and the results might be published in an academic journal.

CONTACT INFORMATION:

If you have concerns or questions about this research project, please contact Morgan Park at (xxx) xxx-xxxx or hennesmo@sn.rutgers.edu or co-investigator Edna Cadmus at (973) 353-1428 or ednacadm@sn.rutgers.edu.

If you have questions about your rights as a research subject, please contact the IRB Director at (973)-972-3608 Newark.

By beginning the survey, you acknowledge that you have read this information and agree to participate in this research, with the knowledge that you are free to withdraw your participation at any time without penalty.

AGREEMENT TO PARTICIPATE

1. Participant 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.

Participant Name: _____

Participant 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

Workshop Materials

HOW IS POLST DIFFERENT FROM AN ADVANCE DIRECTIVE?

POLST complements an Advance Directive and does not totally replace that document. You may still need an advance directive to appoint a legal healthcare administrator. It is recommended that all adults have an advance directive regardless of their health status. If there is a conflict between the documents, have a conversation with your practitioner as soon as possible to determine the most current preferences.

The promise of POLST is that it empowers you to make the important decisions about your end-of-life care. Have the POLST conversation with your medical professional.








POLST

PRACTITIONER ORDERS FOR LIFE-SUSTAINING TREATMENT

THE PROMISE OF POLST:

TAKING CHARGE OF YOUR HEALTHCARE TREATMENT AT THE END OF LIFE




THE PROMISE OF POLST: TAKING CHARGE OF YOUR HEALTHCARE TREATMENT AT THE END OF LIFE

Talking about your wishes during a serious, life-altering illness can be difficult, emotional and, and for some of us, is a conversation we would rather avoid. But it's a conversation you must have as an important and necessary part of good medical care. You have the right to participate fully in all your healthcare decisions – and that's even more important near the end of life.

The best way to make your preferences known is by talking with your healthcare provider and filling out the Practitioner Orders for Life-Sustaining Treatment form, or POLST. POLST is a medical order form that empowers individuals by carefully detailing their personal wishes regarding end-of-life care. POLST can help you make meaningful personal choices regarding your care – and ensure that every member of the healthcare team understands and respects those choices. Individuals fill out the POLST form together with their physician or advance practice nurse. It's signed by all of you and then becomes a permanent part of your medical record. Your POLST form will travel with you and must be honored in all his/her healthcare settings. And you can modify your POLST form at any time.



GOALS OF CARE

This section details how you want to live your life in the time you have left. What is most important to you as you deal with a life-limiting illness? Do you have personal goals or family milestones you would like to reach? How much do you want to know about your illness? How much does your family know about your priorities and wishes? These are all issues you should consider. Your POLST form will allow you to make known any personal, cultural or spiritual practices related to your care.

MEDICAL INTERVENTIONS

The form also will allow you to work with your medical professional to clearly define the types of medical interventions you want – or don't want. For example, you may specify that you want comfort measures only, which is medical treatment intended to eliminate pain and suffering. You may specify an array of other treatment options such as intravenous fluids or antibiotics. Or you may state your wishes for full treatment, including all options available to sustain your life which could include a feeding tube and cardio pulmonary resuscitation.



YOU SHOULD HAVE A POLST FORM IF YOU ARE:


- Seriously ill with a life-limiting advanced illness
- Frail and weak and have trouble performing routine daily activities
- Afraid of losing the capacity to make your own healthcare decisions in the near future
- Living in a nursing home or hospice.

MAKE YOUR WISHES KNOWN: CHOICES TO DISCUSS WITH YOUR HEALTHCARE PROFESSIONAL

There are two very important parts of the POLST form for you to describe your goals and wishes at the end of life your "goals of care" and the medical interventions that you do and do not want.



A program to help you make medical decisions for yourself and others



Step 1 Choose a medical decision maker.

Step 2 Decide what matters most in life.

Step 3 Choose flexibility for your decision maker.

Step 4 Tell others about your medical wishes.

Step 5 Ask doctors the right questions.

www.prepareforyourcare.org

Step 1 Choose a Medical Decision Maker

Choose someone you trust to help make decisions for you in case you become too sick to make your own decisions.

A good decision maker will:

- ask doctors questions
- respect your wishes

If there is no one to choose right now, do Steps 2, 4, and 5.

How to say it:

"If I get sick in the future and cannot make my own decisions, would you work with my doctors and help make medical decision for me?"

OR

"I do not want to make my own medical decisions. Would you talk to the doctors and help make medical decisions for me now and in the future?"



Step 2 Decide What Matters Most in Life

This can help you decide on medical care that is right for you.



Five questions can help you decide what matters for your medical care:

1. What is most important in life? Friends? Family? Religion?
2. What experiences have you had with serious illness or death?
3. What brings you quality of life? Quality of life is different for each person. Some people are willing to live through a lot for a chance of living longer. Others know certain things would be hard on their quality of life.
4. If you were very sick, what would be most important to you:
 - To live as long as possible even if you think you have poor quality of life?
 - Or, to try treatments for a period of time, but stop if you are suffering?
 - Or, to focus on quality of life and comfort, even if your life is shorter?
5. Have you changed your mind about what matters most in your life over time?

Step 3 Choose Flexibility for Your Decision Maker

Flexibility gives your decision maker leeway to work with your doctors and possibly change your prior medical decisions if something else is better for you at that time.

How to say it:

Total Flexibility:

"I trust you to work with my doctors. It is OK if you have to change my prior decisions if something is better for me at that time."



Some Flexibility:

"It is OK if you have to change my prior decisions. But, there are some decisions that I never want you to change. These decisions are..."



No Flexibility:

"Follow my wishes exactly, no matter what."



Step 4 Tell Others About Your Medical Wishes

This will help you get the medical care you want.

How to say it:

To your decision maker and doctors:

"This is what is most important in my life and for my medical care..."

To your doctor and family and friends:

"I chose this person to be my decision maker and I want to give them (TOTAL, SOME, or NO) flexibility to make decisions for me."

Your doctors can help you put your medical wishes on an advance directive form.



Step 5 Ask Doctors the Right Questions

- Write down questions ahead of time.
- Bring someone with you.
- Tell doctors at the **start of the visit** if you have questions.



How to say it:

If your doctor recommends something, ask about the:

- **Benefits** – the good things that could happen
- **Risks** – the bad things that could happen
- **Options** for different kinds of treatment
- **What your life will be like after treatment**

Make sure you understand:

"What I'm hearing you say is... Is this right?"

Your Action Plan

Action Plan

By _____
I will _____



Helpful Resources for caregivers and advance care planning

On Talking to Loved Ones

- *Your Conversation Starter Kit* by the Conversation Project and the Institute for Healthcare Improvement (IHI)

<https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-ConvoStarterKit-English.pdf>

- *Your Conversation Starter Kit (For Families and Loved Ones of People with Alzheimer's Disease or Other Forms of Dementia)* by the Conversation Project and IHI

<https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-StarterKit-Alzheimers-English.pdf>

On Talking to Healthcare Providers

- *How To Talk To Your Doctor* by the Conversation Project and IHI

<https://theconversationproject.org/wp-content/uploads/2017/02/ConversationProject-TalkToYourDr-English.pdf>

On Healthcare Proxies

- *How to Choose a Health Care Proxy & How to Be a Health Care Proxy* by the Conversation Project and IHI

<https://theconversationproject.org/wp-content/uploads/2017/03/ConversationProject-ProxyKit-English.pdf>

On the Practitioner Orders for Life-Sustaining Treatment (POLST) Form

- FAQ's, POLST form downloads, POLST educational pamphlet: <http://www.state.nj.us/health/advancedirective/polst/>

Other Resources

- PREPARE for your care: A user-friendly website with advance care planning training videos, easy to read advance directive and advance care planning workbook (question guide)

<https://prepareforyourcare.org>

- *A Caregiver's Guide to the Dying Process* by the Hospice Foundation of America

https://hospicefoundation.org/hfa/media/Files/Hospice_TheDyingProcess_Docutech-READERSPREADS.pdf

Finding and choosing good healthcare facilities:

- Home Care Agencies: <https://www.medicare.gov/homehealthcompare/search.html>
- Nursing Homes: <https://www.medicare.gov/nursinghomecompare/search.html?>
- Hospitals: <https://www.medicare.gov/hospitalcompare/search.html?>

ADVANCE CARE PLANNING WORKSHOP



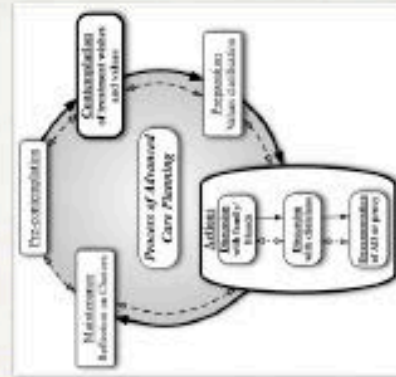
MWC's Conversation of Your Life

RUTGERS
UNIVERSITY

WHY SHOULD I TALK WITH MY FAMILY ABOUT THE END OF LIFE?

DON'T WORRY, IT'S A PROCESS

- One step at a time
- Where are you starting?
- Where do you want to go?
- Keep it up



Stuckey, Schneider et al., 2008

OVERVIEW

WHAT WE'LL COVER

- What is advance care planning (ACP)?
- What types of care options are there at the end of life?
- What are the different ACP documents/forms?
- How to choose the "right" ACP form for your family.
- How to start ACP conversations and ask clinical questions.
- How to use the Five Wishes tool.
- Q&A
- Challenge

BACKGROUND

WHAT IS ADVANCE CARE PLANNING?

- Preparing (in advance) for decisions about healthcare that may need to be made when a person is very sick and close to dying
- What is important to you at the end of life?
- Who do you want making decisions if you cannot?
- What kind of care do you want (or not want)?

TYPES OF END OF LIFE CARE

- Conventional medical care: goal is to keep patients alive and cure or manage disease(s) (prolong life)
- Palliative care: goal is to maximize quality of life and comfort while continuing conventional medical treatment (complements conventional care). Views death as a natural part of life.
- Hospice care: goal is to maximize quality of life and comfort to relieve suffering caused by non-curable disease(s). Chronic diseases (e.g. diabetes) and curable conditions (e.g. wounds or infections) are still treated. Helps patients and loved ones prepare for death.

MORE ON HOSPICE

- For individuals who have a life-limiting illness (healthcare provider estimates about 6 months of life- can be extended)
- Covered by Medicare Part A and most insurance
- Comes with extra services (physical, emotional, spiritual care)
- Medical treatments are focused on promoting comfort and well-being, rather than to "cure" non-curable diseases

ACP BASICS

ACP DOCUMENTS

- Living will: (legal, not medical orders) describes one's wishes for end of life care.
- Healthcare Power of Attorney/Healthcare Proxy: (legal) appoints a healthcare decision-maker for when one is not able to make decisions.
- Advance directive: (legal, not medical orders) describes healthcare wishes and appoints a healthcare proxy. Each state has a specific form.
- Practitioner Orders For Life Sustaining Treatment (POLST): (medical orders, legally binding) a medical document filled out with one's doctor/nurse practitioner that serves as actionable medical orders. Also has option to appoint a healthcare proxy and record one's goals of care.

WHICH TYPE IS RIGHT FOR MY FAMILY?

ADVANCE DIRECTIVE VS. POLST

- Advance directive
 - Appropriate for any age and stage of life
 - Should be shared with healthcare proxy, family/friends, and your doctor
 - Can be used to help make care decisions when you are unable (but cannot be used in an emergency)
- POLST
 - Most appropriate for those near the end of life (i.e. frail or fragile health, or those whose "doctor would not be surprised if they passed away in about a year") or those who have a serious illness, but can be filled out at any time
 - Will be honored in an emergency in any setting
 - Should be reviewed and updated regularly with your provider as health and/or wishes change

[ALSO AVAILABLE
IN KOREAN]
NEW JERSEY
POLST

The image shows a New Jersey POLST (Practitioner Orders for Life Sustaining Treatment) form. It is a green document with white text and a red cross symbol. The form is titled "NEW JERSEY POLST" and includes sections for "PATIENT INFORMATION", "PHYSICIAN INFORMATION", "POLST DECISIONS", and "SIGNATURES". The form is designed to be filled out by a healthcare provider and the patient or their surrogate decision-maker. It includes checkboxes for "Do Not Resuscitate", "Limit Resuscitation", and "Full Resuscitation". It also includes checkboxes for "Do Not Intubate", "Limit Intubation", and "Full Intubation". The form is a standard document used in New Jersey to document a patient's wishes regarding end-of-life care.

STARTING THE CONVERSATION

GETTING STARTED ACP CONVERSATIONS

- Prepare
 - Why is this conversation important to you?
 - Consider a practice run. "What matters to me is..."
 - Who, when, where.
- Act
 - Process not an event
 - Opening "lines"
 - Ask what/how much they would like to know



TALKING TO HEALTH CARE PROVIDERS

ASKING QUESTIONS

- Write down your questions before your visit/call.
- Bring someone along: A support person can help with asking questions, sharing important information, and making decisions.
- Tell your provider up front that you have questions to ask (during the small talk).
- Ask about:
 - Benefits
 - Risks
 - Options
- Clarify: "What I am hearing you say is..., is that right?"

ACP TOOL FIVE WISHES

WISH ONE

THE PERSON I WANT TO MAKE CARE DECISIONS FOR ME WHEN I CAN'T

- Designate a healthcare proxy (decision-maker)
- Does not take effect unless the individual is not able to make decisions (as determined by their physician)
- Choose a proxy (can be more than one person with a "leader")
- What kind of decisions do you want proxy to make?
- Changing your proxy



Photo: cdc.gov

WISH TWO

THE KIND OF MEDICAL TREATMENT I WANT OR DON'T WANT

- Life support: "any medical procedure, device or medication to keep me alive"
- Potential health situations: close to death, coma-not expected to recover, permanent severe brain damage, other
- Yes life support
- No life support
- Stop life support if it was started
- Do a trial of life support treatment



Photo: Getty Images photo of a medical monitor with a small inset photo of a person in a hospital bed.

WISH THREE

HOW COMFORTABLE I WANT TO BE

- What would make you feel comfortable and comforted when you are dying.
- Things your loved ones, healthcare team, or spiritual support persons can do for you to make you feel physically comfortable.
- Examples: brush my hair everyday, play my favorite hymns when I am near death, bring me kittens to pet



Photo: Getty Images photo of a person's hand being gently held by another person's hand.

WISH FOUR

HOW I WANT PEOPLE TO TREAT ME

- What would help you feel emotionally and spiritually at peace when you are dying?
- Things your loved ones, healthcare team, or spiritual support persons can do for you.
- Examples: hold my hand and talk to me even if I seem asleep, help me die at home if possible, I do not want to be alone, I want church members to visit me



Photo: Getty Images photo of a person lying in a hospital bed, being attended to by a healthcare professional.

SIGNING AND SHARING WHAT TO DO WITH FIVE WISHES

- Benefits of documenting your conversation/wishes
- Making the form an "official" advance directive
- Sign with two witnesses (must also sign)
 - Healthcare proxy cannot be one of the witnesses
- Does NOT need to be notarized

CARING CHALLENGE

BRINGING FIVE WISHES HOME

WISH FIVE

WHAT I WANT MY LOVED ONES TO KNOW



Photo: iStock.com

- What would you want your family and close loved ones to know if you could not tell them?
- Seeing to unfinished business.
- Examples: I want my family to respect my wishes for care, I want my sister to know that I love and forgive her, I want to be buried/cremated, I want you to read ___ at my funeral

SIGNING AND SHARING WHAT TO DO WITH FIVE WISHES

- Using the completed form
- Guide conversations with loved ones, proxy(ies), healthcare providers
- Sharing copies
- Limitations
- NOT for an emergency situation
- Consider also completing a POLST if appropriate

Q&A

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Appendix H

Advance Care Planning Workshop Script

- I. Welcome, Introduction
 - A. Instructions for event
 - 1. Lunch
 - 2. Encourage lunch discussion: “When you think about healthcare at the end of life for yourself or a loved one, which do you worry about: getting too much care, not getting enough care, or something else?”
 - B. Introduction to Anna’s Story film
- II. Transition to workshop presentation
 - A. Advance care planning (ACP) Workshop
 - B. Presented in partnership with Rutgers School of Nursing and NJ Healthcare Quality Institute’s Conversation of Your Life Middlesex County Task Force
- III. Why should I talk with my family about the end of life?
 - A. Recap of Anna’s Story
 - B. Opportunity for group to share from their discussions or share personal story related to ACP or the EOL
 - C. Goal of today’s program is to help you and your family do what you **can** do to set the stage for a death that is full and meaningful.
- IV. ACP Process
 - A. One step at a time: ACP is a process
 - B. Where are you starting?
 - C. Where would you like to go?
 - 1. Stages of ACP
 - a) Pre-contemplation
 - b) Contemplation
 - c) Preparation
 - d) Action
 - e) Maintenance
 - D. Keep it up (continual process/cyclical)
- V. Overview of presentation (what we’ll cover)
 - A. What is ACP?
 - B. What types of care options are there at the end of life?
 - C. What are the different ACP documents/forms?
 - D. How to choose the “right” ACP form for your family.
 - E. How to start ACP conversations and ask clinical questions.
 - F. How to use the "Five Wishes" tool.
 - G. Question and answer period, time permitting.
 - H. Challenge.
- VI. Background
 - A. What is advance care planning?

1. Definition
 2. What is important to you at the end of life?
 3. Who do you want making decisions if you cannot?
 4. What kind of care do you want (or not want)?
 - B. Types of end of life care
 1. Conventional medical care definition and goals
 2. Palliative care definition and goals
 3. Hospice care
 - a) Who is hospice for
 - b) Insurance coverage for services
 - c) Hospice services
 - d) Goals of care
- VII. ACP basics
- A. ACP documents
 1. Living will
 2. Healthcare power of attorney/healthcare proxy
 3. Advance directive
 4. Practitioner Orders for Life Sustaining Treatment (POLST)
 - B. Choosing the appropriate ACP document(s)
 1. Advance directive
 - a) Any age and stage of life
 - b) Sharing your advance directive
 - c) Use and interpretation
 2. POLST
 - a) For those near the end of life or with serious illness
 - b) Applied in any care setting
 - c) Review and update regularly with your provider
 - d) Where to find more information
- VIII. Starting the conversation
- A. Getting started
 1. Prepare
 - a) Why is this important to you
 - b) Hold a practice run
 - c) Determine details: who, when, where
 2. Act
 - a) Process, not a one-time event
 - b) Using opening “lines”
 - c) Asking what/how much your loved one would like to know about their prognosis/health or how involved in their decision-making they would like to be

B. Talking to healthcare providers

1. Write down questions before visit/call
2. Bring/be a support person
3. Tell provider up front that you have questions
4. Things to ask about
 - a) Benefits of recommended treatment
 - b) Risks
 - c) Other treatment options
5. Clarify: "What I am hearing you say is..., is that right?"

IX. Using an ACP tool: "Five Wishes"

A. Wish One: The person I want to make care decisions for me when I can't

1. Designate healthcare proxy (decision-maker)
2. When proxy takes effect
3. How to choose a proxy
4. Choosing what/how much responsibility proxy will have
5. Changing your proxy

B. Wish Two: The kind of medical treatment I want or don't want

1. Describing what you want your caregiver to keep in mind
2. Defining what "life support" means to you
3. Choosing level of care in different types of medical scenarios
 - a) Scenarios
 - (1) close to death
 - (2) coma and unlikely to recover
 - (3) permanent brain damage and unlikely to recover
 - (4) other
 - b) Care options
 - (1) I want life support
 - (2) No life support
 - (3) Do a trial of life support

C. Wish Three: How comfortable I want to be

1. What would make you feel comfortable and comforted when you are dying
2. How others can promote your physical comfort at the end of life
3. Instructions for how to fill in this part of "Five Wishes"

D. Wish Four: How I want people to treat me

1. What would help you feel emotionally and spiritually at peace when you are dying
2. How others can help you
 - a) Who
 - b) Examples
3. Instructions on how to fill out this part of form

- E. Wish Five: What I want my loved ones to know
 - 1. What would you want you family and loved ones to know if you could not tell them
 - 2. Seeing to unfinished business
 - a) Example
 - b) Example
 - 3. Instructions for how to fill in this part of "Five Wishes"
- F. Signing and sharing the "Five Wishes" form
 - 1. Benefits of documenting wishes
 - 2. How to make the form "official" (signing instructions)
 - 3. How to use the document
 - a) Guide conversations
 - (1) Family/loved ones
 - (2) Healthcare providers
 - b) Document your wishes
 - c) Limitations
 - (1) Not for use in emergency
 - (2) Reminder on use of POLST
- X. Caring challenge
 - A. Instructions for challenge
 - 1. Hold an ACP discussion with a loved one using "Five Wishes"
 - a) Plan your conversation (Who, when, where)
 - b) Start your conversation
 - 2. Follow-up instructions
 - a) Follow-up survey to be delivered by email in approximately 60 days
 - b) Incentive for filling out follow-up survey (one gift card randomly awarded)
- XI. Question and answer period (time permitting)
- XII. References
 - A. Available on slides (see slides attached),
 - B. Copy available to participants from PI on request
- XIII. Wrap up
 - A. Thank you for attending
 - B. Instructions for completing post-test survey

Appendix I

Survey Instruments

ID #: _____



Survey I

You will be assigned an ID number to use for this survey. Please do not write your name on this survey. Answer the following questions to the best of your ability. You may skip questions or quit at any time, for any reason. Your responses will be used to help evaluate the effectiveness of the Advance Care Planning Workshop.

Part I

Please clearly circle your response.

1. What is your sex?

Male Female

2. What is your age?

3. What is your marital status?

Single Married Divorced/Separated Widowed

4. What is your ethnicity? (*Nationality of your ancestors*) Select all that apply.

Korean Other: _____

5. What is the highest level of education you have completed?

Grade 8 or less Some high school High school/GED Some college

Technical/vocational College (Associate or Bachelor's) Graduate (Master's or Doctorate)

Part II

Please clearly circle your response.

6. Have you put your wishes for end of life medical care in writing?

YES NO Not Sure

Version Number: 01
Version Date: 6/10/18

 **RUTGERS** | eIRB
APPROVED
IRB ID: Pro2018001040
Approval Date: 6/29/2018
Expiration Date: 6/28/2019

ID #: _____



Survey I

7. Have you ever had a conversation about what kind of medical care you would want when you are very sick and close to dying? If so, who have you talked to about this? Select all that apply.

Family/friends Healthcare Provider Have not talked about it

Questions 8-10 ask about care you may provide to your parents or loved ones.

For these questions, a *parent or loved one* includes a parent, parent-in-law, step-parent or other loved one. Do not include a child under 18 years old or anyone you care for as part of your job. If there is more than one person, think of the person that you spend the most time caring for (or who you think may need your help first).

Care includes any tasks, duties or activities that the person would otherwise do for themselves if they were able. Some examples are making appointments, housework, paperwork, driving, etc.

8. Do you have a parent or loved one that you help take care of, or who you may help take care of in the future?

YES NO

If you answered NO, please skip questions 9 and 10.

9. As far as you know, has this person put their wishes for end-of-life medical care in writing?

YES NO Not Sure

10. Have you talked with this person about the kind of medical care they would want when they are very sick and close to dying?

YES NO Not Sure

ID #: _____



Survey I

Part III

For the next 15 questions, use the following scale to describe how ready or confident you are about different aspects of planning for medical care at the end-of-life. Please circle one response for each question.

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

1.	How ready are you to formally ask someone to be your medical decision maker?	1	2	3	4	5
2.	How ready are you to sign official papers naming a person or group of people to make medical decisions for you?	1	2	3	4	5
3.	How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life?	1	2	3	4	5
4.	How ready are you to sign official papers putting your wishes in writing?	1	2	3	4	5
5.	How confident are you that today you could ask someone to be your medical decision maker?	1	2	3	4	5
6.	How confident are you that today you could talk with your doctor about how much flexibility you want to give your medical decision maker?	1	2	3	4	5
7.	How confident are you that today you could talk with your doctor about the care you would want if your were very sick or near the end of life?	1	2	3	4	5

Version Number: 01
Version Date: 6/10/18


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 Approval Date: 6/29/2018
 Expiration Date: 6/28/2019

ID #: _____



Survey I

8.	How confident are you that today you could talk with your medical decision maker about the care you would want if you were very sick or near the end of life?	1	2	3	4	5
9.	How confident are you that today you could talk with your decision maker about how much flexibility you want to give them?	1	2	3	4	5
10.	How confident are you that today you could ask the right questions of your doctor to help make good medical decisions?	1	2	3	4	5
11.	How ready are you to talk to your doctor about how much flexibility you want to give your decision maker?	1	2	3	4	5
12.	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?	1	2	3	4	5
13.	How ready are you to talk to your doctor about who you want your medical decision maker to be?	1	2	3	4	5
14.	How ready are you to talk to your decision maker about how much flexibility you want to give them?	1	2	3	4	5
15.	How ready are you to ask to your doctor questions to help you make a good medical decision?	1	2	3	4	5

Thank you for completing the survey.

Version Number: 01
Version Date: 6/10/18


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 IRB ID: Pro2018001040
 Approval Date: 6/29/2018
 Expiration Date: 6/28/2019

ID #: _____



Survey II

DO NOT START THIS SURVEY UNTIL AFTER THE WORKSHOP

Your ID # may be found on the front of your program folder. Please do not write your name on this survey. Please answer the following questions to the best of your ability. You may skip questions or quit at any time, for any reason. Your responses will be used to help evaluate the effectiveness of the Advance Care Planning Workshop.

Part I

Please answer the following questions about the program you just attended. Please circle your response.

1= not at all, 2= not very, 3= neutral, 4= somewhat, 5= very

1. How well did this workshop met your expectations?

1 2 3 4 5

2. How ready do you feel to apply what you learned in this workshop?

1 2 3 4 5

3. How easy to understand was the information?

1 2 3 4 5

4. How likely would you be to recommend a similar workshop to others?

1 2 3 4 5

5. How relevant was the information to you and/or your family?

1 2 3 4 5

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6. How much do you agree with the following statement: The workshop addressed sensitive topics in an appropriate way. 1 2 3 4 5

7. What would you do to improve this workshop? Select all that apply.

☐ Reduce the amount of information covered in the workshop.

☐ Increase the amount of information covered in the workshop.

☐ Update the information covered in the workshop.

☐ Improve the instructional methods.

☐ Change the speaker.

☐ Improve workshop organization.

☐ Allot more time for the workshop.

☐ Shorten the time for the workshop.

☐ Provide better information before the workshop to help participants prepare.

☐ Make the information more simple.

☐ Make the information more detailed.

7. What did you like best about workshop?

8. What would you change, get rid of or add to make the workshop better?

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Survey II

9. What kind of future programming about advance care planning would you like to see for Korean Americans (if applicable)?

10. If you have any additional comments, you may write them here.

Part II

For the next 15 questions, use the following scale to describe how ready or confident you are about different aspects of advance care planning. Please circle one response for each question.

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

	1 (very) 2 (somewhat) 3 (neutral) 4 (not very) 5 (not at all)	
1.	How ready are you to formally ask someone to be your medical decision maker?	1 2 3 4 5
2.	How ready are you to sign official papers naming a person or group of people to make medical decisions for you?	1 2 3 4 5

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3.	How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life?	1	2	3	4	5
4.	How ready are you to sign official papers putting your wishes in writing?	1	2	3	4	5
5.	How confident are you that today you could ask someone to be your medical decision maker?	1	2	3	4	5
6.	How confident are you that today you could talk with your doctor about how much flexibility you want to give your medical decision maker?	1	2	3	4	5
7.	How confident are you that today you could talk with your doctor about the care you would want if your were very sick or near the end of life?	1	2	3	4	5
8.	How confident are you that today you could talk with your medical decision maker about the care you would want if you were very sick or near the end of life?	1	2	3	4	5
9.	How confident are you that today you could talk with your decision maker about how much flexibility you want to give them?	1	2	3	4	5
10.	How confident are you that today you could ask the right questions of your doctor to help make good medical decisions?	1	2	3	4	5

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Survey II

11.	How ready are you to talk to your doctor about how much flexibility you want to give your decision maker?	1	2	3	4	5
12.	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?	1	2	3	4	5
13.	How ready are you to talk to your doctor about who you want your medical decision maker to be?	1	2	3	4	5
14.	How ready are you to talk to your decision maker about how much flexibility you want to give them?	1	2	3	4	5
15.	How ready are you to ask to your doctor questions to help you make a good medical decision?	1	2	3	4	5

Thank you for completing the survey. Please hand in before leaving.

ID #: _____



Survey III

Your ID # may be found on the front of your program folder and in the email sent by Morgan Park with the subject "ID Number for Follow-up Survey". Please do not write your name on this survey. Please answer the following questions to the best of your ability. You may skip questions or quit at any time, for any reason. Your responses will be used to help evaluate the effectiveness of the Advance Care Planning Workshop.

Part I

For the next 15 questions, use the following scale to describe how ready or confident you are about different aspects of advance care planning. Please circle one response for each question.

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

	1 (very) 2 (somewhat) 3 (neutral) 4 (not very) 5 (not at all)	
1.	How ready are you to formally ask someone to be your medical decision maker?	1 2 3 4 5
2.	How ready are you to sign official papers naming a person or group of people to make medical decisions for you?	1 2 3 4 5
3.	How ready are you to talk to your decision maker about the kind of medical care you would want if you were very sick or near the end of life?	1 2 3 4 5
4.	How ready are you to sign official papers putting your wishes in writing?	1 2 3 4 5
5.	How confident are you that today you could ask someone to be your medical decision maker?	1 2 3 4 5

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Survey III

6.	How confident are you that today you could talk with your doctor about how much flexibility you want to give your medical decision maker?	1	2	3	4	5
7.	How confident are you that today you could talk with your doctor about the care you would want if your were very sick or near the end of life?	1	2	3	4	5
8.	How confident are you that today you could talk with your medical decision maker about the care you would want if you were very sick or near the end of life?	1	2	3	4	5
9.	How confident are you that today you could talk with your decision maker about how much flexibility you want to give them?	1	2	3	4	5
	1 (very) 2 (somewhat) 3 (neutral) 4 (not very) 5 (not at all)					
10.	How confident are you that today you could ask the right questions of your doctor to help make good medical decisions?	1	2	3	4	5
11.	How ready are you to talk to your doctor about how much flexibility you want to give your decision maker?	1	2	3	4	5
12.	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?	1	2	3	4	5
13.	How ready are you to talk to your doctor about who you want your medical decision maker to be?	1	2	3	4	5

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Survey III

14.	How ready are you to talk to your decision maker about how much flexibility you want to give them?	1	2	3	4	5
15.	How ready are you to ask your doctor questions to help you make a good medical decision?	1	2	3	4	5

Part II

1. Have you put your wishes for end of life medical care in writing?
YES NO Not Sure
2. Have you ever had a conversation about what kind of medical care you would want when you are very sick and close to dying? If so, who have you talked to about this? Select all that apply.
Family/friends Healthcare Provider Have not talked about it

Questions 8-10 ask about care you may provide to your parents or loved ones.

For these questions, a *parent or loved one* includes a parent, parent-in-law, step-parent or other loved one. Do not include a child under 18 years old or anyone you care for as part of your job. If there is more than one person, think of the person that you spend the most time caring for (or who you think may need your help first).

Care includes any tasks, duties or activities that the person would otherwise do for themselves if they were able. Some examples are making appointments, housework, paperwork, driving, etc.

3. Do you have a parent or loved one that you help take care of, or who you may help take care of in the future?
YES NO

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Survey III

If you answered NO, please skip questions 4 and 5.

4. As far as you know, has this person put their wishes for end-of-life medical care in writing?

YES NO Not Sure

5. Have you talked with this person about the kind of medical care they would want when they are very sick and close to dying?

YES NO Not Sure

6. If you have talked with this person about their wishes for end-of-life medical care, did you use the Five Wishes form?

YES NO

7. If you have any additional comments, you may record them here.

Thank you for completing the survey.

Project Timeline

[illegible]

[illegible]

Appendix K

Project Budget

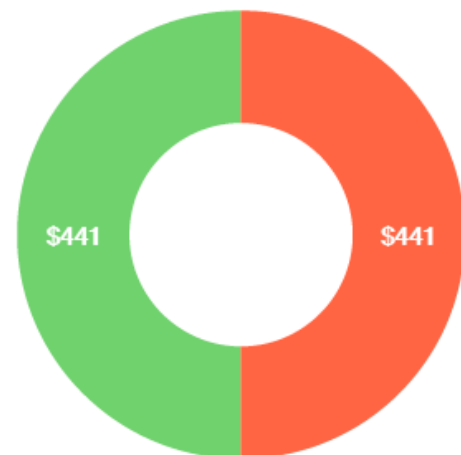
Project Budget

MONEY IN	
Researcher funding	\$441
TOTAL INCOME	\$441

MONEY LEFT OVER	
Income minus expenses	\$0

PROJECT EXPENSES	
Presentation space	\$0
AV equipment	\$0
Childcare services	\$0
Five Wishes	\$50
Folders, pens	\$20
Printing and printing supplies	\$50
Anna's Story DVD	\$0
SPSS	\$89
laerd.com subscription for data analysis	\$12
SurveyMonkey subscription	\$60
Refreshments (Light Lunch)	\$160
TOTAL EXPENSES	\$441

Income/Expenses



● Income minus expenses
 ● Total expenses
 ● Total income

Appendix L

Data Tables

Table 1 <i>Sample Demographics</i>		
Characteristic	n= 13	%
Gender		
Male	6	46.2
Female	7	53.8
Ethnicity		
Korean American	11	84.6
Other Asian American	2	15.4
Marital status		
Married	10	76.9
Single	3	23.1
Widowed/Divorced	0	0
Highest level of education completed		
College (2 or 4 year)	8	61.5
Graduate school	0	0
Other		
Self-identified as a caregiver		
Yes	13	100
No	0	0
Age		
18-28	1	7.1
29-39	6	46.2
40-50	4	30.8
51-61	2	15.4
62 +	0	0

Table 2

Advance Care Planning Actions Before and After Intervention

Actions Taken	N= 13 Pre-intervention n / %	N= 13 Follow-up n / %	McNemar Test Statistic	Significance
Put own wishes in writing	5 / 38.5	3 / 23.1	0.5	$p = .500$
Talked about own end-of-life wishes	9 / 69.2	10 / 76.9	0.0	$p = 1.00$
Parent/loved one completed an advance directive	4 / 30.8	2 / 15.4	0.5	$p = .500$
Talked about parent/loved one's end-of-life wishes	5 / 38.5	7 / 53.8	0.25	$p = .625$
Any new ACP action taken	0 / 0	5 / 38.5	2.25	$p = .125$

Table 3 <i>Advance Care Planning (ACP) Actions Taken by Participants</i>				
ACP Actions Taken n = 13	Baseline n	Follow-up n	New ACP Action n	New “No” n
Put own wishes in writing	5	3	0	2
Talked about own end-of-life wishes	9	10	2	1
Parent/loved one completed an advance directive	4	2	0	2
Talked about parent/loved one’s end-of-life wishes	5	7	3	1
<i>Note:</i> The “New ‘No’” column captures instances where participants reported not having done an ACP action they previously reported doing.				

Table 4 <i>Advance Care Planning Engagement Survey (ACPES) Scores Pre-Post and Follow-up</i>				
n= 13	Pre-intervention	Post-intervention	Follow-up	% Change Pre- to Follow-up
Mean	3.31	3.99	4.07	23
Median	4.07	4.13	4.20	3
Range	4.00	2.67	3.00	N/A

Table 5

Program Evaluation Feedback: Likert Scale Questions

Evaluation question	Mean Likert Score
Program met my expectations.	4.2
I am ready to apply what I have learned.	4.1
The information was easy to understand.	4.7
How likely are you to recommend a similar program to others?	4.3
How relevant was to information to you and/or your family?	4.5
The workshop addressed sensitive topics in an appropriate way.	4.7

Table 6

Program Evaluation Feedback: Ways to Improve

Evaluation question	Frequency of response
Reduce the amount of information covered.	0
Increase the amount of information covered.	4
Update the information covered.	0
Improve the instructional methods.	3
Change the speaker.	1
Improve workshop organization.	0
Allot more time for the workshop.	2
Shorten the time for the workshop.	2
Provide better information before the workshop to help participants prepare.	4
Make the information more simple.	1
Make the information more detailed.	3

Note: Questions were adapted from WGBH Boston, & Corporation for Public Broadcasting, (n.d.).

Table 7

Program Evaluation Feedback: Comments

Evaluation question	Related comments
What did you like best about the workshop?	1) The accompanied short film. 2) Good overview of ACP options & questions to consider. 3) Well-organized. Practical. Great tempo. Doesn't drag on. Not too fast. Not too emotional. Not callous. 4) Your personal story, real life example. 5) "You do yours-siblings do theirs. Then ask parents" (<i>describing a helpful comment referring to AD's and how to encourage resistant parents to engage in topic</i>). 6) Timely topic. Well organized/basics well presented. Good case examples. Helpful material. 7) As a beginner, providing the basic questions to ask & consider. 5 Wishes is a great tool introduced. 8) Learning about the 5 Wishes- it simplifies the process especially for older people. 9) Very informative. 5 Wishes was excellent and translation is key. 10) Forms, scenarios/questions to think about. 11) Presentation of various types of legal documents.
What would you change, get rid of or add to make the workshop better?	1) More time on Q&A and review of practical examples. 2) More feedback on any Asian American needs or concerns and how to address. Workshop was targeted to Korean Americans but it did not speak to any Korean American issues, challenges, etc. 3) Presentation felt a bit slow. 4) More on how to have conversations or start conversations with parents who may not want to discuss this issue. 5) [Include an] attorney as part of the presentation. 6) Break for questions before 5 Wishes as topics are naturally separated. Allotting time to review 1 wish collectively might be helpful, keep the audience engaged. 7) Add role playing. 8) Brief discussion of what attendees feel/think/know about their/loved ones' ACP & needs. 9) More interaction. 10) Pros/cons of certain decisions/choices.
What kind of programming about advance care planning would you like to see for Korean Americans (if applicable)?	1) Community programs/services available to families & patients for elderly on good/poor deaths. 2) A little more interaction, but within a certain time frame. 3) It'd be great to have this presentation made directly to older Korean-generation. 4) Discussion/practice-based conversation. 5) More translated documents. 6) Information on where Korean-speaking older generation can get some information. A directory of contacts. 7) An initiative to educate the older demographic in Korean to discuss the positivity of ACP. 8) Offer this to senior citizens :) 9) One that makes it easier to talk with Korean-native speaking loved ones.