

By Morgan Park

Increasing Advance Care Planning Conversations Among Korean Americans through a faith community Nurse Intervention

ABSTRACT: Minority populations have lower rates of advance care planning (ACP) than the general population. Faith community nurses (FCNs) can facilitate ACP training to improve end-of-life care outcomes for patients and caregivers. A nurseled ACP training delivered to a primarily Korean American faith community increased the number of families who discussed end-of-life care values and wishes. Considerations for ACP outreach to Korean Americans and implications for FCNs are discussed.

KEY WORDS: advance care planning, advance directives, end-of-life care, faith community nursing, Korean Americans, nursing

dvancements in medical technology have led to lifesaving treatments, but also have increased the complexity of treatment decisions that individuals and their families face at the end of life (EOL). To glimpse the dizzying experience of chronically ill patients at the EOL, picture spending your last months of life going to more than 26 doctor appointments and staying 8.5 days in the hospital (including 3.6 in the intensive care unit). This was the average experience for Medicare patients who died in 2017 (The Dartmouth Institute [Dartmouth], 2020). These figures demonstrate an improvement in EOL care outcomes, reflecting a nationwide trend toward less aggressive care more in line with what most patients say they prefer at EOL (Dartmouth, 2020; Goodman et al., 2013). More patients and families are choosing hospice care and are receiving care sooner. In 2016, 54% of patients facing death chose hospice for an average 25 days of care (Dartmouth, 2020).

Despite these trends, overall Medicare spending in the last 2 years of life continues to rise, and patients navigate care with 10 or more physicians in their last months of life (Dartmouth, 2020). Nevertheless, more spending and care are not *more* when it comes to EOL care outcomes or providing care that lines up with patients' goals and preferences (Fisher et al., 2003a, Fisher et al., 2003b). Further, despite an overall upward trend, EOL quality outcomes differ from state to state and hospital to hospital (Goodman et al., 2013). The healthcare system continues to struggle to meet the needs of the nation's aging population, including helping patients and families navigate the complicated decisions about care in the final years of life. Faith community nurses can take a meaningful role in cultivating conversations and participation in advance care planning, especially for minority groups.

ADVANCE CARE PLANNING

Advance care planning (ACP) is "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). Upward of 70% of older adults lose their ability to make decisions for themselves at the EOL, introducing added stress and uncertainty for loved ones who must make decisions (Silveira et al., 2010).

Advance care planning has been linked to better quality EOL care for patients and families (Detering et al., 2010). In a review of the impact of ACP interventions (Weathers et al., 2016), patients were more likely to receive the

care they preferred and less likely to be hospitalized. Further, healthcare proxies, or patient-selected surrogate decision-makers, had a better grasp of the care patients wanted. Satisfaction with care was higher for both patients and their families, and caregivers reported a better quality of life.

Despite the known benefits of ACP, many adults do not consider or discuss their values and preferences for medical care with others. Only 25% of U.S. adults have documented their wishes for EOL care in an advance directive (AD) (Rao et al., 2014). This is especially true for American



Morgan Park, DNP, RN, has designed, led, and assisted with community-based advance care planning programs through a community task force under the New Jersey Health Care Quality Institute.

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minority populations who face additional barriers to quality EOL care than do non-Hispanic Whites (Johnson, 2013; Rao et al., 2014). According to the Institute of Medicine (2015), non-White populations are less likely to discuss EOL wishes with family and healthcare providers, often have less knowledge about EOL issues, and enroll in hospice at lower rates than the general population. Additionally, individuals from non-White ethnic groups may not find ACP concepts relatable because concepts often are presented through the lens of traditionally Western values such as autonomy and self-determination. This can give minority families the impression that ACP is not useful or relevant.

KOREAN AMERICANS AND ACP

Asian Americans are the fastest growing population in the United States (Budiman & Ruiz, 2021). In the 2020 census, Korean Americans were the fifth largest Asian American population in the United States. The

states with the largest Asian American populations—California, New York, Texas, and New Jersey-are also known for providing the highest intensity of hospital care at the EOL (Dartmouth, 2020) As a group, Korean Americans have low rates of ACP. One study found that only 18.6% of community-dwelling Korean American older adults had completed an AD (Dobbs et al., 2015). Lower rates of ACP among Korean Americans have been linked to health literacy, cultural factors, and accessibility of information about ACP (Dobbs et al., 2015; Ko & Berkman, 2012; Kwak & Salmon, 2007).

To help overcome barriers to ACP, outreach to Korean Americans must be culturally appropriate and relevant. Because of the importance of the family's role in EOL decision-making and its influence on ACP behaviors, family-based interventions are recommended (Jang et al., 2010; Kataoka-Yahiro et al., 2010; Kim & Foreman, 2011; Ko & Berkman, 2012; Ko et al., 2013). Community-



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based settings such as faith communities, and senior or cultural centers are recommended venues because of accessibility to learners (Dobbs et al., 2015; Jang et al., 2010; Ko & Berkman, 2012; Ko et al., 2013). Finally, cultural values and norms have implications for ACP outreach.

For example, some Korean Americans may prefer or presume that loved ones intuitively understand their wishes for EOL care through the Korean concept of noonchi, which can be described as indirect communication or emotional intelligence (Kwak & Salmon, 2007; Wang, 2018). This can present challenges and resistance to discussion of ACP in Korean American families and requires that ACP outreach be approached with sensitivity. Culturally, many families and even Korean American healthcare providers may find it difficult to discuss death and dving (Ko & Berkman, 2010; Ko & Berkman, 2012; Kwak & Salmon, 2007). Building trust and rapport while gradually progressing from general discussion of making decisions about health to the topic of ACP may be helpful (Kwak et al., 2014). (See Sidebar: Death and Dying: Cultural Norms of Korean Americans.)

IMPROVING ENGAGEMENT

A quality improvement (QI) project to improve rates of ACP among Korean Americans was undertaken in urban New Jersey in partnership with the local Conversation of Your Life (COYL) chapter, a community-based task force focused on changing the culture around EOL care in New Jersey. A nurse-led ACP training was held at a church comprised of primarily Korean American members. The program targeted the adult children of older adult Korean Americans and sought to prepare participants to initiate ACP conversations within their families. The QI project was approved and overseen by the Rutgers University Institutional Review Board, and informed consent was obtained from all participants.

Sidebar: Death and Dying: Cultural Norms of Korean Americans

To provide culturally appropriate end-of-life care and support for Korean Americans, Western-oriented healthcare providers and faith-based nurses need understanding of this group's cultural beliefs and practices.

The role of the family at the end of life is a significant cultural distinction of Korean Americans. Described as *filial piety* (Koh-Kreinke, 2019), this can be defined as the "moral obligation of an adult child to respect and obey one's parents and provide support for them in old age" (Kwak & Salmon, 2007, p. 1,869). As the elders become infirm or frail, their adult children become their caregivers in a reversal of the parent-child hierarchy in earlier family life. This cultural norm typically results in multigenerational households where elderly parents live with their children and grandchildren; this is considered a benefit to all the family members. Koh-Kreinke (2019) stated that "Koreans venerate the aged not only because we feel a moral obligation to do so, but also because we value the wisdom and familial bond that we share with our elders" (p. 16). Koreans, Koh-Kreinke said, face the distress of the oncoming death of their aged parents by caring for their elders. As a result of their intergenerational relationships, Korean Americans often are more open than some cultures—with the entire adult family present—to discussion about advance directives and hospice care (Kwak & Salmon, 2007).

Three essential concepts that influence how Koreans view their death and dying are han, jeong, and nun-chi. Han may be exhibited as suppressed emotion; Koreans generally do not express emotion overtly. Jeong embodies a strong familial connection or relationship of trust and empathy (Koh-Kreinke, 2019). Nun-chi (or noonchi) is literally defined as "eye measure" and is described as an "awareness of and sensitivity to another person's nonverbal cue" (Kwak & Salmon, 2007, p. 1,869). Adult children may depend on nun-chi when discerning their elder parent's concerns about death rather than having a frank discussion of the topic. Koh-Krienke (2019) notes that this demonstrates Koreans' cultural style of implicit, subtle, and nonverbal communication.

Korean Americans are most likely to choose dying at home with their family rather than in a hospital. Hospice care has been slow to gain acceptance in Korean American families as their understanding of the concept is obscured by believing that hospice means giving up hope or participating in physician-assisted suicide or euthanasia (Koh-Kreinke, 2019).

Nurses who desire to support Korean Americans at the end of their lives can be appreciated advocates by practicing culturally competent communication and understanding.

-Karen Schmidt, BA, RN, JCN Contributing Editor

Sample and Outcome Measures

Twenty-two participants attended the ACP training, and 13 completed all administered surveys and were included in the QI project sample (N = 13). Participants were all Asian American while 11 were Korean American; 6 were males and 7 were females and all had at least a college education. The mean age was 40.5 years; 7 participants were under age 40. All self-identified as caregivers of older adult parents (see Table 1: Sample Demographics online as supplemental digital content at http://links.lww.com/NCF-JCN/ A86). Participants completed anonymous surveys before, immediately after, and 2 months after the training. The project tracked three outcomes of engagement in ACP using scores on the Advance Care Planning Engagement Survey (ACPES), changes in ACP actions, and program evaluation feedback. Participants completed pre- and post-test surveys on paper at the church site before and after the intervention; the follow-up survey was administered 2 months later via SurveyMonkey. As an incentive, participants who returned the follow-up survey were entered to win one \$50 Amazon gift card. Only data from participants who returned

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all three surveys (N = 13) were included in analysis of the project.

Quality Improvement Intervention

A free lunch and training seminar about ACP were held following a Sunday morning church service. Lunch was provided by the nurse presenter and church volunteers offered child-care. The 1.5-hour training included a) a 20-minute film, *Anna's Story*; b) an overview of ACP concepts; c) a step-by-step discussion of how to use the *Five Wishes* AD to guide semistructured ACP discussions with a parent or loved one; and d) a question-and-answer period.

While participants ate lunch, they watched *Anna's Story*. The fictional film shows Anna's EOL journey from her own perspective, as well as from those of her closest relative and the health-care professionals they encounter in Anna's final days (Hicks, 2009). The film is intended to stimulate thought and conversation about one's personal values about end-of-life care.

Following the film, the nurse presenter provided an overview of ACP concepts. The ACP process was described, including precontemplation, contemplation, preparation, action, and maintenance (Sudore et al., 2008). Advance care planning was then compared with different approaches of EOL care, including conventional medical treatment, palliative care, and hospice care. Participants learned to distinguish between different ACP documents such as a Living Will and a POLST (portable medical orders) (National POLST, 2021), how to talk to providers about treatment options, and received recommendations from The Conversation Project about starting an ACP conversation. Training topics were selected based on a review of the scholarly and gray literature on ACP outreach and included recommendations from The Conversation Project (2021) and Prepare for Your Care (2020).

Five Wishes was selected for use as an AD because it is easy to read and available in a bilingual Korean-English version. The AD lends itself to guiding

Table 2. 15-Item Advance Care Planning Engagement Survey (ACPES) Scores* Pre- and Post-intervention and at Follow-up (*N* = 13)

	Preintervention	Postintervention	2-month 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		

Note. ACPES Scores can range from 0 to 5, indicating low engagement to high engagement in advance care planning.

discussion of EOL by delineating ACP into five wishes: appointing a health-care decision-maker, medical treatment, physical comfort at the EOL, emotional and spiritual needs, and additional information loved ones should know (Aging With Dignity, 2020). Participants received a copy of the presentation notes as well as Korean-English and English-only versions of *Five Wishes*. The nurse presenter and a hospital chaplain from COYL answered questions following the seminar.

Results

Engagement with ACP was measured before and after the intervention and at 2 months follow-up using the 15-item version of the Advance Care Planning Engagement Survey (ACPES) (Sudore, Heyland et al., 2017). The ACPES includes questions about readiness to complete specific ACP actions, such as appointing a healthcare proxy or discussing EOL with a provider. The ACPES is scored on a five-point scale, with 0.0 indicating low engagement and 5.0 high engagement with ACP and has been shown to correlate with ACP behaviors. Aggre-

gate ACPES scores increased in participants by 23% from pretest to follow-up (see Table 2).

Participants responded "yes" or "no" to four questions about ACP actions. Table 3 displays the surveyed actions and participants' responses. At followup, 31% of participants had completed a new ACP action. A new ACP conversation with a parent was the most frequently reported action (see Table 3). Participants provided feedback on the quality of the program and relayed answers to open-ended questions regarding what they liked best and how to improve the intervention (see Table 4: Program Evaluation Feedback and Table 5: Open-Ended Responses about the ACP Program online as SDC at http://links.lww. com/NCF-JCN/A86).

DISCUSSION

This QI project showed an increase in family conversations about EOL care wishes and a shift in how participants understood ADs. Sun et al. (2017) reported the results of a church-based ACP program with an Asian American population. That

Table 3. Advance Care Planning (ACP) Actions Taken by Participants (N = 13)

ACP Actions Taken	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

Note: The "New 'No'" column captures instances where participants reported not having done an ACP action they previously reported doing.

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two-session intervention was targeted toward older adults and included time for participants to work on their AD with assistance from research staff. About 70% of participants had completed an AD after the program, and 25% had discussed their wishes with a healthcare proxy (Sun et al., 2017).

There were both similarities and differences between Sun et al.'s (2017) ACP program and this project. Both were hosted by Asian American

between participants in the two programs, as the older adults which Sun et al.'s program (2017) targeted were more likely overall to complete ADs (Rao et al., 2014) and this program reached younger adults. However, incorporating skills-based training, such as dedicated time to work on ADs or to practice ACP discussions, could improve rates of ACP behaviors. Future ACP outreach should consider layering programs geared toward adult children with

It was not clear why or how participants' perceptions about ACP documentation changed in this project. Participants may have considered legal documentation such as estate planning when initially responding regarding AD completion. Alternatively, participants' wishes may have changed after learning more about EOL care, or participants may simply have considered prior documentation inadequate after the training program. Regardless, this finding emphasizes the misconceptions and confusion that individuals have around ACP documents. ACP outreach should clarify the differences between types of ACP documents and provide one or more examples of easy-to-use ADs.

As many as 70% of older adults lose their ability to make decisions for themselves at the EOL.

churches and endorsed by faith community leaders. Both programs used ADs to teach participants about ACP, with both seeing an increase in ACP behaviors among participants. However, where the current project saw an increase in ACP conversations but no increase in AD completion, Sun et al.'s program saw a large increase in AD completion and an increase in ACP discussions that was comparable to this project.

The difference in AD completion is likely related to the age difference

programming targeted toward older adults to determine if a layered approach could help improve rates of both ACP conversations and documentation in families. In addition, participants in this project wanted more interactive discussion in this intervention (e.g., Q&A, role playing) and greater focus on when there is resistance to ACP.

Interestingly, compared with before the intervention, fewer participants reported that they or their parent had documented EOL wishes at follow-up.



Faith community nurses (FCNs) can play an important role in helping patients and families engage in ACP and improve EOL outcomes. Nurses can access various evidence-based, free, or affordable resources to plan and implement ACP outreach to faith communities. Nurses also can help dispel myths about ACP and address concerns of individuals and families. By engaging in ACP outreach, FCNs can equip families in a practical way to follow the biblical directive of honoring one's father and mother (Exodus 20:12; Ephesians 6:2) through thoughtful planning for the last stage of life.

Both ACP discussions and documentation are important and complementary components of preparing for EOL care. The evidence-based PREPARE program stresses familybased ACP that incorporates discussion of and documentation of wishes (Sudore, Boscardin et al., 2017). Appointing and discussing values and preferences about EOL care with a healthcare proxy (or proxies) is a key element in the PREPARE program. For FCNs looking to learn about the topic of ACP or who want a preprepared, evidence-based program to share with their faith community, the onlinebased PREPARE program is a helpful resource.



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Web Resources

- Aging With Dignity https://agingwithdignity.org/
- Five Wishes https://fivewishes.org
- National Hospice and Palliative Care Organization https://www.nhpco.org/patientsand-caregivers/?pageid=3277
- National POLST https://polst.org/professionalspage/?pro=1
- PREPARE for Your Care www.prepareforyourcare.com
- The Conversation Project https://theconversationproject. org/

A "patient-facing" or easy-to-read AD can assist individuals and families in talking about EOL care and recording wishes. The ADs from *Prepare for Your Care* and *Five Wishes* are two examples written in everyday language. Five Wishes is available in bilingual versions in nearly 30 languages and includes wishes about personal, spiritual, medical, and legal decisions associated with the EOL (Aging With Dignity, 2020). This can be a helpful guide for families to use for semistructured ACP conversations or to discuss their wishes with healthcare providers.

ADDRESSING MISCONCEPTIONS AND CONCERNS

Misconceptions about ADs are common, ranging from simple confusion about the types of ACP documents to more serious fears that documenting wishes means giving up one's right to make health decisions or that healthcare providers will not provide any treatment (Sabatino, 2015). The FCN, as a trusted and accessible healthcare provider, is well positioned to help address individuals' and families' misconceptions and questions. Individuals may also have spiritual concerns related to EOL decisions that the FCN can help them navigate in partnership with faith leaders, chaplains, or counselors.

The faith community is a potential setting for health outreach to families as

multiple generations are sometimes part of the same faith community. Furthermore, Jesus' rebuke of religious leaders who were neglecting God's commandment through Moses to "honor your father and mother" provides a strong spiritual basis for the inclusion of ACP and navigating caring for aging or disabled family members in an FCN program (Mark 7:8-13). As discussed above, including the family unit in ACP efforts to Asian Americans and other minority groups is a recommended strategy. Resistance to discussion of EOL issues by both adult children and older adult parents is a common barrier to ACP in Korean American families. Family-based outreach through faith communities may be a helpful approach to overcoming this resistance by making EOL topics more immediately relevant and more socially and culturally acceptable to families.

Discussing loved ones' preferences, values, and goals surrounding EOL care can help families ensure that their loved one receives the care he or she prefers and reduce the distress that caregivers experience when a loved one is at the EOL (Weathers et al., 2016). Overall, minority populations tend to be less prepared for EOL care decisions and may approach ACP with different needs and values than White Americans. This church-based QI project helped increase the number of ACP conversations within the church's Korean American families and demonstrated how FCNs can serve their own communities by assisting members to engage in ACP.

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- There's only one correct answer for each question. A passing score for this test is 7 correct answers. If you pass, you can print your certificate of earned contact hours and access the answer key. If you fail, you have the option of taking the test again at no additional cost.
- For questions, contact Lippincott Professional Development: 1-800-787-8985.
- Registration deadline is September 1, 2023.

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