



Achieving advance care planning in diverse, underserved populations

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Executive Summary

There remains a gap in meeting the palliative and end-of-life (EOL) care needs, including advance care planning (ACP) needs of ethnic minority, under-resourced, veterans, and lesbian, gay, bisexual, transgender, and queer (LGBTQ) Americans, as well as persons with disabilities and residing in geographically isolated regions. Intersecting socially constructed characteristics influence the lived experience of marginalized communities, including their health-care experiences. These persistent gaps pose a serious barrier to achieving high-quality care, including palliative and EOL care, across the life span of members of these growing populations. The American Academy of Nursing supports efforts to systematically study and translate research into best practices and policies supporting underserved, marginalized communities so that all Americans enjoy high-quality palliative and EOL care.

Background

Although considerable evidence demonstrates important gains in palliative care (PC) and EOL care in the United States for some populations, persistent gaps in ACP threaten the national goal of compassionate, affordable, sustainable, and high-quality health care in many communities ([Institute of Medicine \[IOM\], 2014](#)). Gaps include challenges with completing an advance directive, living will, and durable power of attorney and routinely discussing EOL care. In its landmark report, *Dying in America: Improving Quality and Honoring Individual*

Preferences Near the End of Life, the National Academy of Medicine (formerly the [IOM, 2014](#)) called for person-centered, family-oriented, and evidence-based approaches to EOL care. Delivering this level of care requires embracing as indicators of patient- and family-centered care the intersecting influence of culture, socioeconomic status, ethnicity, ability, geography, gender identity, and sexual orientation on the experience of living with illness, dying, and decision-making about ACP at the sociostructural level.

Public and private stakeholders struggle with achieving this goal for all Americans, including for citizens living in U.S. possessions and territories. Although the National Hospice and Palliative Care Organization ([National Hospice and Palliative Care Organization, 2016](#)) provides downloadable advance directives for residents of the 50 states and the District of Columbia, similar documents are not available for residents of U.S. territories and possessions. How do we, as a nation, communicate convincingly to the public across geography and intersecting demographic characteristics that ACP is a process designed to support patients' and their family's health-care decisions? In 2016, the Association of Health Care Journalists (AHCJ) acknowledged that journalists could help elevate the discussion of ACP in the United States, beyond prominent cases such as those of Nancy Cruzan and Terri Schiavo, to engage and educate the public ([Seegert, 2016](#)). Stories such as Amy Berman's ([Berman, 2015](#)), a nurse who published an Op-Ed in the Washington Post to the Centers for Medicare and Medicaid Services (CMS) about her battle with stage IV inflammatory breast cancer, provided the public the opportunity to understand first-hand the need for high-quality ACP discussions. Too often, however, members of marginalized populations do not have these critical

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conversations. Just over one-quarter of all adults have given EOL wishes little or no thought, and less have documented them in a durable power of attorney or living will (IOM, 2014). Perhaps, America as a nation has reached a tipping point, given that many baby boomers and their families will experience the need for conversations and decisions around PC and EOL care (IOM, 2014). What can nurses and other stakeholders do to take advantage of this historical opportunity to institutionalize high-quality ACP, as has occurred in the United Kingdom, Australia, and the seven other nations who outrank the United States in this area of health care? Moreover, how do we acquire the evidence needed to document the most effective approaches available to support ACP for the diverse citizens served by the U.S. health-care system?

Before obtaining evidence to support ACP for all Americans, there is the need to examine how the lack of evidence-based, theory-guided, patient- and family-centered ACP widens the health disparity gap for marginalized populations. Data suggest that same-sex couples may experience barriers to participating fully in a partner's care, including ACP, because traditional definitions of family inform hospital policy and influence staff behavior (Center for American Progress, 2011). This example is notable because an estimated 9 million Americans self-identify as LGBT (Gates, 2011), and in one study, 56% of lesbian, gay, or bisexual patients and 70% of transgender and gender nonconforming patients reported that they had experienced discrimination during health-care encounters (Lambda Legal, 2010). Persons with disabilities also experience ACP disparities. Nearly one in five U.S. citizens report a disability (U.S. Census Bureau, 2012). In a study sampling 53 persons with disabilities, a common theme reported was the desire to have greater control over their ACP, a finding suggesting providers may exclude them from or limit their involvement in discussions about these critical health-care decisions (National Hospice and Palliative Care Organization, 2009). Consistent evidence also indicates that completion rates for advance directives among African Americans and Hispanic Americans are considerably less than for Caucasians (Portanova, Ailshire, Perez, Rahman, & Enguidanos, 2017). Cultural variations in EOL decision-making among these groups include a preference for family or group decision-making and for receiving aggressive life-prolonging treatments, even when there is no medical hope of recovery (Barnato et al., 2007; Kwak & Haley, 2005).

Because Americans living in rural communities often lack local ACP resources, the Department of Veteran's Affairs developed a program to foster ACP discussions between groups of veterans and an interdisciplinary team of health-care providers (U.S. Department of Veterans Affairs Office of Rural Health, 2017). Diverse and often under-resourced citizens and nationals residing in U.S. territories and possessions grapple with geography as well as geopolitics, which challenges high-quality ACP and EOL care. U.S. nationals and citizens living on 5 of the 16 permanently inhabited island possessions and territories do not have access to the ACP

and EOL resources afforded to Americans residing in the 50 states. Although 20,000 men and women from these islands serve in the U.S. military (Calahan, 2017), recent federal cases affirm that these possessions are essentially colonies and are subject to congressional oversight with little to no right to self-determination (Newkirk, 2016). Populations affected include residents of Puerto Rico, the U.S. Virgin Islands, Guam, the Northern Mariana Islands, and American Samoa.

Efforts encouraging completion of ACP and implementing advance directives among patients and families from culturally and ethnically diverse backgrounds—particularly among populations reflecting diverse racial, ethnic, religious, and socioeconomic backgrounds, gender identities, sexual orientations, and geographies—have been largely unsuccessful perhaps because they lack an evidence base. Between 1997 and 2010, an estimated \$432.93 million federal dollars supported PC and EOL research. Although a 10-fold increase in federal funding occurred during this period, private dollars decreased significantly (National Institute of Nursing Research [NINR], 2013). In 2011, the National Institutes of Health (NIH) dedicated less than 1% of its budget to PC research (Smith & Brawley, 2011). A comprehensive approach would include an examination of the intersecting impact of multiple social characteristics on the living and dying process and therefore on ACP initiatives to meet the goal of person-centered, family-oriented care.

Responses and Policy Options

A series of targeted, interdisciplinary campaigns led by the NINR (2013, 2017a, 2017b), reflect an ongoing federal commitment to enhancing EOL care across the life span and in various health-care settings. Other federal agencies such as the U.S. Department of Health and Human Services (2008), as well as the National Academy of Medicine (formerly the IOM, 1997, 2003) have also long advocated initiatives and developed reports supporting ACP for all Americans. Similar efforts, position statements, and reports have also been released by non-profit organizations, including the Robert Wood Johnson Foundation (2005) and Aspen Institute (2016). These reports, however, do not offer evidence-based recommendations for improving the ACP and EOL care for marginalized, underserved populations with various intersecting social characteristics. Public and private grant funders, including the Agency for Health Care Research and Quality (2014), the Patient-Centered Outcomes Research Institute (PCORI, 2017), and the Robert Wood Johnson Foundation (2005), are advocating for evidence-based approaches and reimbursement to address the ACP needs of these underserved Americans.

Although CMS has recently begun reimbursing physicians for ACP discussions and other payers will likely follow suit, many health-care providers lack a framework for understanding the complex, intersecting social

facets of identity that influence the wishes, priorities, and plans of diverse individuals. Grounding research, clinical practice, and health policy in the intersectionality theory—which focuses on the multiple competing social factors that influence health inequities—provide a framework for exploring and meeting these needs (Bowleg, 2012). Unfortunately, providers will likely focus on efficiency rather than thoroughness during these conversations if the quality of these conversations is not incentivized (Berringer & Lowers, 2015). For the best outcomes, studies assessing the quality and effectiveness of these discussions from the perspective of patients, families, and payers are needed.

The Academy's Position

The American Academy of Nursing (2015); Tilden et al., 2015) has long supported increased access to PC and EOL care, including ACP, for all Americans, especially for underserved populations. Therefore, the lack of evidence-based initiatives that meet the needs of persons with intersecting realities, including disabilities, ethnic minority groups, LGBTQ, and geographically isolated Americans living in U.S. island territories and rural communities are of great concern. This position recognizes the importance of delivering ACP, which embraces the personal decisions of diverse populations about their current illness, values, beliefs, and personal preferences for PC and EOL care (Cohen, Germain, & Poppel, 2003; Song et al., 2010; Sudore & Fried, 2010).

The Academy will collaborate with other nursing, health-care professional, nonprofit, and consumer organizations to advocate for the expansion of federally and privately funded research initiatives designed to develop, test, and ultimately translate ACP best practices into routine health-care practices and health policies for all U.S. citizens. These efforts must take into account the intersecting social characteristics and experiences that contribute to the health-care preferences and outcomes of underserved, marginalized communities.

Recommendations

1. Advocate that CMS obtain input from a broad group of clinician and consumer groups, such as the American Nurses Association, the Institute for Health Care Improvement, the American Association of Retired Persons (AARP), and the Consumer Coalition for Quality Health Care, in developing quality measures that tie reimbursement of ACP conversations to documentation specifying the inclusion of information about patients' values, beliefs, and personal preferences. CMS should review and revise quality measures as best practices emerge from analysis of quality data and ongoing research.
2. Encourage federal research grant-awarding agencies such as the NIH, CDC, and PCORI, as well as private funders, to make ACP research a priority, increasing funding for studies examining the influence of intersecting social characteristics on the experiences of and interventions to improve outcomes for underserved, marginalized communities. Although three NIH institutes—the National Cancer Institute, the NINR, and the National Institute on Aging—have led ACP research initiatives, funding for this critical research is insufficient. This research is crucial because every generation of every American family will face multiple ACP experiences and because diversity in this country is growing and becoming more complex.
3. Advocate that federal funding agencies, such as the NIH, including the NINR, as well as PCORI and private funders, such as the Gordon and Betty Moore Foundation, the Robert Wood Johnson Foundation, and the Josiah Macy Jr. Foundation, focus on complex intersecting characteristics of the American population in studies to better understand ACP preferences among marginalized, underserved communities. Research teams that include community members representing marginalized populations and studies that explore similarities and differences in PC and EOL preferences of these families should receive funding priority. Because groups that create research and policy agendas seldom include representatives of these communities, the products that emerge could unintentionally create secondary marginalization (Bauer, 2014).
4. Collaborate with nursing and other health profession organizations, clergy, traditional healers, and relevant consumer advocacy organizations such as AARP and the National Alliance for Caregiving to create and disseminate public service messages that inform the public of the need for PC and EOL research, initiatives, and policies to improve the health-care outcomes of all Americans. Including the language and thoughts of patients and families in ACP affirms the importance of their points of view. Collaborating with traditional community healers, such as American Indian medicine men and women and Spanish *curanderos* and *santeros*, is paramount because these providers, who are often lay people, may be the individuals trusted to provide ACP information and support to patients and their families (R. Spector, personal communication). These public service messages should be updated to reflect current evidence and to include actors representing diverse members of marginalized communities and diverse family structures. A campaign that informs diverse, marginalized, underserved, older adults about Medicare coverage for ACP conversations is a logical first initiative.
5. Partner with the American Nurses Association, state nurse associations, and the AHCA to release news stories describing state-specific laws related to ACP and how they differ from nearby states for diverse families, including those who are marginalized and underserved. Seegert (2016) has suggested that stories

can also include interviews with families and providers with ACP experiences and their perceptions about why these decisions influenced their experiences. Also, stories about families who lost a loved one but did not have ACP, why they did not have them, and whether they would make a different decision after the loss of their loved one are needed. News stories should include families reflecting intersecting social characteristics and family types. The partnership should release these stories during National Healthcare Decisions Day and National Hospice and Palliative Care month held annually in November (Seegert, 2016).

6. Work with interdisciplinary health professions and relevant consumer advocacy organizations, such as the American Nurses Association, the National Coalition for Hospice and Palliative Care, the American Health Lawyer Association, AARP, and the National Family Caregiving Alliance, to create a speaker's bureau that conveys evidence-based, clear, and compelling messages and fact sheets advocating the need for ACP for diverse communities. This bureau can provide the names of qualified professionals and community experts who can effectively and accurately disseminate information to local and state governments exploring policy initiatives focused on ACP for diverse constituents and employers developing human resource policies to support workers facing ACP decisions.
7. Partner with nurses and health ministers working in the U.S. territories, possessions, and organizations such as the American Bar Association, the Virgin Islands Bar Association, the American Samoa Bar Association, Marshall Islands Judiciary, the Commonwealth of the Northern Mariana Islands Bar Association, and national advocacy organizations, to develop and add territory-specific ACP resources to the National Hospice and Palliative Care Organization website.

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