

Policy Brief

June 2023

UNDERSTANDING DIVERSITY: INTERCULTURAL EDUCATION FOR HEALTHCARE PRACTITIONERS ON ADVANCE CARE PLANNING

2 out of 3

U.S. adults have
not completed an
advance directive



JAMA. 2020 Jul 20. Completion of Advance Directives and Documented Care Preferences During the Coronavirus Disease 2019 (COVID-19) Pandemic
Accessed at: <https://candc.link/357FCIP>

Executive Summary

Advance care planning (ACP), including advance directives and discussion of end-of-life wishes, is critical to quality end-of-life care. ACP completion by racial and ethnically diverse communities remains extremely low, leading to a lower quality of care and increased use of invasive treatments that cost families and the country millions of dollars annually. The federal government needs to sponsor ACP education for healthcare providers that honors patients' and carers' cultural backgrounds so doctors can properly engage diverse communities in ACP to avoid unnecessary costs.

Keywords: Disparities, Inclusion, Race, Ethnicity, End-of-life Care

IMPORTANCE

Culturally competent ACP is necessary for the growing diversity of the U.S. population. The number of Black, Indigenous, and people of color (BIPOC) is substantially increasing in the U.S. By 2045, just over 50% of older adults living in the U.S. will be persons of color.¹³ The increase in BIPOC populations will lead to higher end-of-life costs due to the lack of advance care planning (ACP) with providers among BIPOC adults. Blacks, Hispanics, and Asian Americans have been shown to complete ACP at 2-3 times lower rates than Whites.⁷

ACP includes formal documents such as a living will or surrogate decision-maker, as well as conversations with loved ones about the care you wish to receive at the end of life if you are unable to speak for yourself.

ACP is a critical component of high-quality end-of-life care.⁹

Almost 50% of individuals at the end of life will be unable to make medical decisions due to incapacitation.²¹

“As native Americans, we have a deep connection to our traditions and cultural practices, which often involve end-of-life care. Advance care planning allows us to honor these traditions while also making informed medical decisions.” Dr. Donald Warne

By 2030 BIPOC older adults will account for nearly half (42.7 million) of all Medicare beneficiaries,⁵ and BIPOC patients spend 30-50% more on end-of-life care than White

patients,^{4,11} making spending on BIPOC older adults end-of-life care a substantial cost to Medicare that will only increase.⁴

The COVID-19 pandemic has only exacerbated social inequalities at the end of life between Whites and BIPOC groups in the U.S. Access to healthcare has been identified as one of the most significant problems facing BIPOC communities.²⁵

Chronic diseases, including COVID-19 infections, disproportionately burden BIPOC adults.²⁵ COVID-19 has provided us with a unique opportunity to identify disparities between Whites and BIPOC populations and address these disparities in end-of-life care.

“As a person of color, we often face healthcare disparities and injustices, so it’s important for us to have a voice in our own medical decisions. Advance care planning allows us to do that.” Dr. Regina Davis Moss

The increased cost of end-of-life care among BIPOC populations is due to use of aggressive non-beneficial treatments at the end of life.^{15,19} These include increased hospitalization and repeat emergency room visits, increased use of feeding tubes, ventilators, cardiopulmonary resuscitation (CPR), and decreased use of hospice and palliative care.²³

These invasive and painful treatments are detrimental to the BIPOC population's end-of-life quality assessment by individuals, families, and caregivers.^{15,19} These treatments *do not* prolong life and, in some cases, shorten it.^{10,24}

A variety of factors are associated with aggressive and costly end-of-life care among BIPOC populations, including healthcare discrimination, distrust of healthcare providers and decreased

understanding of treatment options.¹⁷

Culturally competent training will ensure that healthcare providers are able to acknowledge and address patients' diverse values and beliefs and tailor healthcare delivery to meet the patient's needs and eliminate disparities. Cultural competency includes adapting healthcare services to reduce barriers, such as providing interpreters and forms in languages other than English.^{1,25}

What is culturally Competent Care?¹

- (1) Respects the cultural background and identity of others
- (2) Providing equal access to care
- (3) Promotes understanding of your own values and patients' values
- (4) Develops self-awareness of your values to effectively communicate across cultures
- (5) Allows for language imperfections and provides extra time for patients to express themselves
- (6) Intercultural learning is a lifelong process

COMPELLING RESEARCH

Research in BIPOC communities demonstrates that culturally competent community engagement strategies work and are desired.¹⁸ If physicians engaged in culturally component ACP, it would decrease costs to the nation and reduce the burden for BIPOC older adults and their caregivers. However, BIPOC groups are often hindered by a healthcare system that does not consider culture, religion, and differing beliefs.

Studies have shown that BIPOC populations are more likely to have misconceptions about ACP due to a lack of understanding,⁶ which may delay end-of-life care discussions with physicians and lead to care that is incongruent with patients' end-of-life treatment goals. Loved ones are

then forced to make decisions in stressful situations with little to no context.

Increasing ACP among BIPOC groups has the potential to increase caregiver competence in decision-making and ensure that patients and caregivers do not suffer needlessly.²⁶ Culturally competent ACP will ensure all people die with the autonomy and dignity they deserve.

Educating healthcare workers in providing culturally competent ACP with BIPOC patients and communities will: ²³
(1) Respond to changing demographics
(2) Eliminate disparities in health care at the end of life by increasing ACP
(3) Increase hospice and palliative care use
(4) Decrease hospitalizations, invasive treatment, and unwanted care saving millions in Medicare spending
(5) Decrease complicated bereavement among caregivers ²⁷
(6) Improve end-of-life quality for patients, caregivers, and loved ones

A study completed in 2022 found that physicians were most likely to avoid conversations about end-of-life care with BIPOC populations and cited patient barriers and not physician barriers as the reason for nonengagement.² These findings demonstrate a need for greater physicians' understanding of how to engage in ACP conversations and to negate stereotypes.

Physicians will often opt for all treatment when ACP has not been completed. Even when advance directives have been documented in the medical records, doctors often assume patients want all care.⁸

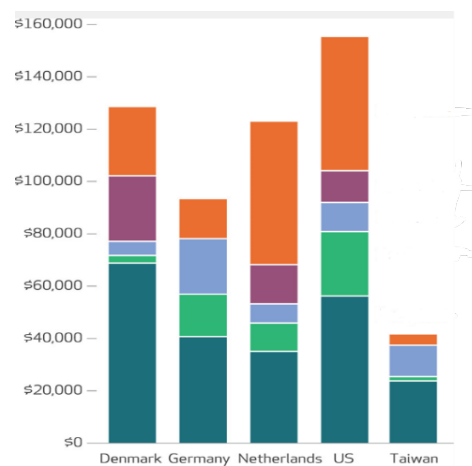
Physicians must be trained to engage in ACP conversations with racial and ethnically diverse populations to ensure a shared understanding of wishes.

Despite physicians' shortcomings in executing wishes at the end of life, they are still uniquely positioned to facilitate ACP discussions. Healthcare providers are often the first to discuss ACP with BIPOC adults.

BIPOC populations are more likely to have chronic conditions such as dementia, diabetes, and heart disease.²³ These conditions put them at a greater risk of hospital use. During these critical contacts doctors can discuss ACP with BIPOC older adults.

Increasing BIPOCs' understanding of ACP by combating misconceptions and ensuring healthcare providers are trained to provide unbiased education will increase ACP and subsequently enhance healthcare's ability to care for people at the end of life.

The United States spends more on end-of-life care than any other country in the world.¹² We must act now to reduce healthcare spending.

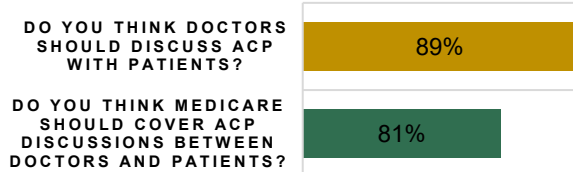


Spending in Last Year of Life¹²

Despite extensive research in the past 30 years on ACP, why BIPOC older adults complete ACP at lower rates is still poorly understood, and racial and ethnic populations are still woefully underrepresented in end-of-life research.¹⁴

Surveys show that almost 90% of adults in the United States over the age of 18 believe that doctors should have discussions with patients about ACP and that Medicare should cover ACP conversations.²⁰

PERCENTAGE OF ADULTS AGE 18 AND OVER WHO ANSWERED 'YES'²⁰



POLICY CONTEXT

The Patient Self-Determination ACT (PSDA) was enacted by the United States Congress in 1990 as an amendment to Title XVIII of the Social Security Act and went into effect on December 1, 1991.¹⁶ The PSDA requires healthcare providers to inform adult patients (18 and over) in writing about their right to make decisions about their end-of-life medical care. Physicians are required to document and respect these decisions. The PSDA applies to all healthcare providers participating in Medicare and Medicaid programs.

The PSDA originally included a provision to educate healthcare professionals to ensure that staff and the community were informed on ACP.

Federal institution involved in Medicare and minority health and disparities include The National Institute on Aging- Resource Centers for Minority Aging Research, The National Institute on Minority Health and Health Disparities, The United States Department of Health and Human Services- Office of Minority Health, Indian Health Service: The Federal Health Program for American Indians and Alaska Natives. Finally, The Center for Medicare and Medicaid would implement the amendment to the PSDA.

Leading organizations committed to culturally competent ACP include national non-profits such as The National Hospice and Palliate Care Organization: Diversity Advisory Council, American Society on Aging- Generations focusing on ACP and equality, and the AARP, which promotes diversity, equity, and inclusion.

POLICY RECOMMEDATION

To develop, implement, and evaluate a culturally competent ACP education program for providers by implementing the original PSDA educational component that required providers to ensure that healthcare staff and the community are educated on ACP. Adding culturally competent training to the PSDA Act will ensure that people of all backgrounds are respected.



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