



FAST FACTS AND CONCEPTS #204

PALLIATIVE CARE IN THE AFRICAN AMERICAN COMMUNITY

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Background African Americans face a disproportionate burden of morbidity and mortality from many serious illnesses (1). As in other areas of healthcare, the experience of palliative and end-of-life care for African Americans differs from that of white patients (2,3). This *Fast Facts* summarizes racial differences in the quality of palliative care, discusses beliefs which may be more common among African Americans, and offers recommendations for clinicians. Clinicians should not make assumptions about individual patients based on this discussion and should always elicit values and preferences specific to the patient.

Care Differences Between African Americans and Whites

- **Pain Management:** African Americans are less likely to have pain adequately assessed and treated across care settings and are more likely to live in areas where pharmacies do not stock opioids (4,5).
- **Communication:** African Americans are more likely to report poor quality communication, and discussions with providers are less likely to lead to care that is aligned with preferences (6-8).
- **Satisfaction:** African Americans are less satisfied with the quality of end-of-life care (6,9).
- **Advance Care Planning (ACP):** African Americans are less likely to participate in formal or informal ACP, have less knowledge of advance directives and are less likely to complete them (10-12).
- **Hospice:** African Americans have less knowledge of hospice, are less likely to enroll in hospice, and are more likely to disenroll from hospice to seek disease-modifying therapies (13-17).

Differences in Beliefs and Preferences Between African Americans and Whites

- **Preferences:** A greater minority of African Americans prefer life-prolonging care even when prognosis is poor (18-19). This has been cited as a barrier to hospice use.
- **Spiritual Beliefs:** African Americans more often rely on religious community support for medical decision-making (20). Spiritual beliefs may influence care preferences, including beliefs in divine intervention or miracles, that suffering is redemptive, and God alone determines life and death (21).
- **Family:** African Americans often desire a family-oriented approach to decision-making in advanced illness over ACP within an autonomous framework (10,20,22,23). They may be more likely to believe that family should make treatment decisions for them and more likely to involve distant relatives and nonrelatives in decision-making (10-12).
- **Mistrust:** Given past injustices and ongoing disparities, not surprisingly, African Americans report greater mistrust in the healthcare system (11). This mistrust may impact decision-making.

Opportunities to Improve Care The recommendations that follow are an attempt to address beliefs, preferences, and values which may be more common among African Americans. However, these recommendations are broadly applicable to the care of any seriously ill patient.

- **Elicit cultural beliefs that may influence care:** Ask patients' and families' about their cultural beliefs regarding illness and death, socioeconomic contexts, decision-making styles, and support resources (24). A willingness to listen and direct care in a culturally-attuned manner builds trust (25).
- **Address spiritual needs:** Ask patients about the role of spirituality in decision-making. Clinicians should be open to clergy or religious community involvement in care. Clergy, for example, may help mitigate religious misunderstandings and longstanding mistrust (26). For patients well-supported by their religious communities, spiritual support from the medical team may improve the quality of end-of-life care (27).
- **Respect preferences for family involvement:** Caregivers' trust in clinicians, mediated in part by the quality of communication, can influence treatment decisions (28). Elicit and respect preferences for family (including distant relatives and nonrelatives) involvement in decision-making (22).
- **Provide information and document preferences:** Inform patients about the range of care options, including hospice and palliative care. Explore beliefs, and dispel myths. Even if African Americans choose not to complete advance directives, document treatment preferences and encourage them to identify a trusted decision-maker.

- **Address issues of mistrust:** Eliciting values, providing information about care options, respecting preferences, expressing empathy, and engaging in shared decision-making are all ways to build trust (29). Addressing issues of mistrust directly with patients and families, including asking about past and current experiences may also improve communication (24).
- **Respect preferences:** Because of a greater preference for aggressive care even when prognosis is poor, conflict may occur between African Americans and their clinicians (19,30). In the event of conflict, clinicians should respectfully negotiate shared goals and focus on the needs of the patient (11,24,31). Time-limited trials based on preferences may be helpful as may compassionate recommendations about what is felt to be the best medical care for a patient given the prognosis, options, and goals. See *Fast Facts* #183 and #184 for more information on conflict resolution.

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