

Palliative Care in the African American Community #204

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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 health care, the experience of palliative and end-of-life care for African Americans differs from that of white patients.²⁻⁴ This *Fast Fact* summarizes racial differences in the quality of palliative care, discusses beliefs that 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.⁵⁻⁷
- 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.⁸⁻¹¹
- Satisfaction: African Americans are less satisfied with the quality of end-of-life care.^{8,11}
- 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.¹²⁻¹⁴
- 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.^{13,15-20}

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.^{21,22} 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.²³ Spiritual beliefs may influence care preferences, including beliefs in divine intervention or miracles, that suffering is redemptive, and that God alone determines life and death.²⁴
- Family: African Americans often desire a family-oriented approach to decision making in advanced illness over ACP within an autonomous framework.^{12,23,25,26} 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.¹²⁻¹⁴
- Mistrust: Given past injustices and ongoing disparities, not surprisingly, African Americans report greater mistrust in the health care system.¹³ This mistrust may impact decision making.

Opportunities to Improve Care

The recommendations that follow are an attempt to address beliefs, preferences, and values that 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.²⁷ A willingness to

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listen and direct care in a culturally attuned manner build trust.²⁸

- 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.²⁹ For patients well supported by their religious communities, spiritual support from the medical team may improve the quality of end-of-life care.³⁰
- Respect preferences for family involvement: Caregivers' trust in clinicians, mediated in part by the quality of communication, can influence treatment decisions.³¹ Elicit and respect preferences for family (including distant relatives and nonrelatives) involvement in decision making.²⁵
- 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.³² Addressing issues of mistrust directly with patients and families, including asking about past and current experiences, may also improve communication.²⁷
- Respect preferences: Because of a greater preference for aggressive care even when prognosis is poor, conflict may occur between African Americans and their clinicians.^{19,33} In the event of conflict, clinicians should respectfully negotiate shared goals and focus on the needs of the patient.^{13,27,34} 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.

References

1. Meyer PA, Penman-Aguilar A, Campbell VA, et al.: Conclusion and future directions: CDC Health Disparities and Inequalities Report—United States, 2013. *MMWR Surveill Summ* 2013;62:184–186.
2. Abdollah F, Sammon JD, Majumder K, et al.: Racial disparities in end-of-life care among patients with prostate cancer: A population-based study. *J Natl Compr Canc Netw* 2015;13:1131–1138.
3. Miesfeldt S, Murray K, Lucas L, et al.: Association of age, gender, and race with intensity of end-of-life care for Medicare beneficiaries with cancer. *J Palliat Med* 2012;15:548–554.
4. Johnson KS: Racial and ethnic disparities in palliative care. *J Palliat Med* 2013;16:1329–1334.
5. Shavers VL, Bakos A, Sheppard VB: Race, ethnicity, and pain among the U.S. adult population. *J Health Care Poor Underserved* 2010;21:177–220.
6. Green CR, Ndao-Brumblay SK, West B, Washington T: Differences in prescription opioid analgesic availability: Comparing minority and white pharmacies across Michigan. *J Pain* 2005;6:689–699.
7. Morrison RS, Wallenstein S, Natale DK, Senzel RS, Huang LL: “We don’t carry that”—failure of pharmacies in predominantly nonwhite neighborhoods to stock opioid analgesics. *N Engl J Med* 2000;342:1023–1026.
8. Welch LC, Teno JM, Mor V: End-of-life care in black and white: Face matters for medical care of dying patients and their families. *J Am Geriatr Soc* 2005;53:1145–1153.
9. Loggers ET, Maciejewski PK, Paulk E, et al.: Racial differences in predictors of intensive end-of-life care in patients with advanced cancer. *J Clin Oncol* 2009;27:5559–5564.
10. Mack JW, Paulk ME, Viswanath K, Prigerson HG: Racial disparities in the outcomes of communication on medical care received near death. *Arch Intern Med* 2010;170:1533–1540.
11. Rhodes RL, Teno JM, Connor SR: African American bereaved family members' perceptions of the quality of hospice care: Lessened disparities, but opportunities to improve remain. *J Pain Symptom Manage* 2007;34:472–479.
12. Torke AM, Garas NS, Sexson W, Branch WT: Medical care at the end of life: Views of African American patients in an urban hospital. *J Palliat Med* 2005;8:593–602.
13. Johnson KS, Kuchibhatla M, Tulsy JA: What explains racial differences in the use of advance directives and attitudes toward hospice care? Racial differences in beliefs about end-of-life care. *J Am Geriatr Soc* 2008;56:1953–1958.
14. Jones AL, Moss AJ, Harris-Kojetin LD: Use of advance directives in long-term care populations. *NCHS Data Brief* 2011:1–8.
15. Rhodes RL, Batchelor K, Lee SC, Halm EA: Barriers to end-of-life care for African Americans from the providers' perspective: Opportunity for intervention development. *Am J Hosp Palliat Care* 2015;32:137–143.
16. Rhodes RL, Teno JM, Welch LC: Access to hospice for African Americans: Are they informed about the option of hospice? *J Palliat Med* 2006;9:268–272.
17. LoPresti MA, Dement F, Gold HT: End-of-life care for people with cancer from ethnic minority groups: A systematic review. *Am J Hosp Palliat Care* 2014. [E-pub ahead of print.]
18. Wicher CP, Meeker MA: What influences African American end-of-life preferences? *J Health Care Poor Underserved* 2012;23:28–58.
19. Johnson KS, Kuchibhatla M, Tanis D, Tulsy JA: Racial differences in hospice revocation to pursue aggressive care. *Arch Intern Med* 2008;168:218–224.
20. U.S. Medicare Payment Advisory Commission: Hospice Services. In: Report to Congress: Medicare Payment Policy. 2013. http://www.medpac.gov/documents/reports/mar13_ch12.pdf?sfvrsn=0 (last accessed January 17, 2016).
21. Zheng NT, Mukamel DB, Caprio T, et al.: Racial disparities in in-hospital death and hospice use among nursing home residents at the end of life. *Med Care* 2011;49:992–998.
22. Barnato AE, Anthony DL, Skinner J, Gallagher PM, Fisher ES: Racial and ethnic differences in preferences for end-of-life treatment. *J Gen Intern Med* 2009;24:695–701.
23. Song MK, Hanson LC: Relationships between psychosocial-spiritual well-being and end-of-life preferences and values in African American dialysis patients. *J Pain Symptom Manage* 2009;38:372–380.
24. Johnson KS, Elbert-Avila KI, Tulsy JA: The influence of spiritual beliefs and practices on the treatment preferences

- of African Americans: A review of the literature. *J Am Geriatr Soc* 2005;53:711–719.
25. Dilworth-Anderson P, Williams SW, Cooper T: Family caregiving to elderly African Americans: Caregiver types and structures. *J Gerontol B Psychol Sci Soc Sci* 1999;54: S237–S241.
 26. Perkins HS, Geppert CM, Gonzales A, et al.: Cross-cultural similarities and differences in attitudes about advance care planning. *J Gen Intern Med* 2002;17:48–57.
 27. Kagawa-Singer M, Blackhall LJ: Negotiating cross-cultural issues at the end of life: “You got to go where he lives” *JAMA* 2001;286:2993.
 28. Darnell LK, Hickson SV: Cultural competent patient-centered nursing care. *Nurs Clin North Am* 2015;50: 99–108.
 29. Arriola KR, Perryman JP, Doldren MA, et al.: Understanding the role of clergy in African American organ and tissue donation decision-making. *Ethn Health* 2007;12: 465–482.
 30. Balboni TA, Balboni M, Enzinger AC, et al.: Provision of spiritual support to patients with advanced cancer by religious communities and associations with medical care at the end of life. *JAMA Intern Med* 2013;173:1109–1117.
 31. Watkins YJ, Bonner GJ, Wang E, et al.: Relationship among trust in physicians, demographics, and end-of-life treatment decisions made by African American dementia caregivers. *J Hosp Palliat Nurs* 2012;14:238–243.
 32. Tulsy JA, Arnold RM, Alexander SC, et al.: Enhancing communication between oncologists and patients with a computer-based training program: A randomized trial. *Ann Intern Med* 2011;155:593–601.
 33. Breen CM, Abernethy AP, Abbott KH, Tulsy JA: Conflict associated with decisions to limit life-sustaining treatment in intensive care units. *J Gen Intern Med* 2001;16:283–289.
 34. Mitnick S, Leffler C, Hood VL: Family caregivers, patients and physicians: Ethical guidance to optimize relationships. *J Gen Intern Med* 2010;25:255–260.

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