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## FAST FACTS AND CONCEPTS #204

**Author(s):** Mythili Raghavan, Alexander Smith MD, MS, and Robert Arnold MD

**Background** The care African Americans receive at the end-of-life, as well as African Americans' attitudes towards end-of-life care, differ in some ways from the general US population. Clinicians' poor understanding of these differences may lead to ineffectual communication and patient dissatisfaction. This Fast Fact outlines research findings on differences in end-of-life care and values between African Americans and the population as a whole. **Note:** the differences discussed here represent broad trends and the full spectrum of values and practices within African American communities is diverse and not captured by the following discussion. Clinicians are advised not to make assumptions about individual patients based on population data, and to always explore each patient's values and wishes.

**End-of-Life Practices** With respect to European American cohorts, African Americans are:

- Less likely to complete advance directives (14, 19), enroll in hospice (15), receive appropriate symptom management at the end-of-life (3, 9), or be satisfied with the quality of end-of-life care and communication (20).
- More likely to receive aggressive treatment at the end-of-life (including artificial nutrition and hospitalization) (2, 4, 5, 16), to stop hospice care to seek life-prolonging treatment (11), and to die in a hospital (6, 13). Over recent decades, while there have been more opportunities for patients to die outside of hospitals, rates of in-hospital deaths have declined for European Americans; a similar decrease has not been observed for African Americans (8).

**Reasons for these differences** have been researched extensively and likely include:

- *Preferences/Values* – In general African Americans are more likely to want life-prolonging and aggressive treatments; to associate treatment limitations and hospice care with 'giving up;' and have less interest in completing advance directives (relying more on verbal communication of their wishes with family) (6, 9, 10, 18). These differences are not solely due to mistrust or educational and economic status (similar trends are seen with African American physicians) (3), although they can be attenuated by explicit advance care planning in some instances (19). They likely also reflect deep cultural values stemming in part from the strong religious faith of many African Americans; for instance a trust that 'death is in God's hands' may underlie a reluctance to discuss or plan for terminal care needs (3, 10, 12).
- *Health Care Disparities and Trust* – Historic and current racism and health care inequalities, and the resultant mistrust of health care providers and institutions, likely drive these differences as well (3). African Americans are less likely to be offered hospice care and pharmacies in minority neighborhoods are less likely to stock opioid analgesics (1, 3). There is some evidence that differences in end-of-life care are attenuated where health care is distributed more equitably (such as in the Veterans Health Administration) (7).

## Recommendations for Communication

- Ask the patient and family about their perspectives about end-of-life care and decision-making prior to making recommendations. *Have you thought about getting sicker? What happened when your dad got sick and died? Are you the kind of person who makes decisions on your own or do you want your family to be involved?* This allows you to understand the patient's/family's beliefs about end-of-life care and make suggestions that are consistent with their values (see also *Fast Facts* #17 and 26).
- Ask about spirituality and religious beliefs (see *Fast Fact* #19). Offer to involve a chaplain or the patient's

personal spiritual advisor.

- Frame the discussion positively. Focus on meeting shared goals, not on what you are not going to do. *I want to help you live as best you can, given how sick you are becoming.*
- Look for issues of trust and address them openly. Seek to understand any mistrust, avoid labeling the patient (e.g. as 'irrational'), and redress any grievances within your power. Build trust through offering time, careful communication, and close follow-up.
- If there is conflict, recognize that we all bring our own values and culture to the bedside, and our conception of what constitutes a 'good death' may genuinely differ from our patients'. Seek shared goals and values, focused on the needs of the patient, and recommend what you feel is the best medical care for a patient given their prognosis, options, and goals.

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**Fast Facts and Concepts** are edited by Drew A Rosielle MD, Palliative Care Center, Medical College of Wisconsin. For more information write to: drosiell@mcw.edu. More information, as well as the complete set of Fast Facts, are available at EPERC: www.eperc.mcw.edu.

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**Medical College of Wisconsin**

8701 Watertown Plank Road, Milwaukee, WI 53226

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