

# End-of-Life Planning Designed to Encourage, Motivate, and Engage African Americans

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Big Mama had a stroke and is in the hospital. What should we do? What does she want us to do? Should we keep her on life-support? Can we care for her at home? What if she does not survive?

These questions often arise when families, friends, and doctors avoid end-of-life discussions. Conversations surrounding death may not be easy; however, the reality of aging, illness, and death is a fact. There are dire consequences, such as aggressive medical interventions, expensive treatments, pain, and suffering when patients do not express their end-of-life wishes. Various reasons for this lack of planning may exist. Still, the assumed responsibility shifts to others, usually family members, who may be uninformed, reluctant, or not interested in accepting this responsibility (Sheng et al., 2019).

## Key Messages

The medical community encourages the completion of advance directives to document health care wishes should one become incapacitated; however, planning and discussing one's end-of-life wishes involves more than checking a box on a provided form. The process involves gaining knowledge about the types of available care, such as palliative, hospice, live-in aid, nursing home, or assisted living. Other choices may include obtaining life insurance, selecting charities for planned-giving commitments, completing one's bucket list, or making amends with estranged family members. Finally, proactive life planners may want to consider, decide, and share their views and feelings on traditional burials, cremations, or environmentally-friendly disposal methods to rest in eternal peace.

The general problem is that African Americans and many people of color shy away from vital healthcare services due to systemic racism, medical mistrust, religious convictions, or cultural differences. Conflicting perspectives on end-of-life care, dying, and death is an ongoing disconnect; healthcare providers may view a prolonged life filled with pain and suffering as inhumane, while many people of color view pain and suffering as another struggle to overcome. Medical professionals often find this reluctance challenging, but the issue for the patient is deciding whom to trust or finding someone to listen to their concerns. Most patients want accurate information in a comfortable, non-threatening setting that allows ample time for essential questions and clear, comprehensible answers. This disconnect prevents consensus building, active communication, and an alignment of expectations which drives this research question about how to encourage, motivate, and engage communities of color to participate in end-of-life planning activities.

## Purpose

This study aimed to understand how the underlying aspects of medical mistrust, health disparities, social determinants of health, and systemic racism affect end-of-life planning in communities of color (Collins et al., 2018; Collins et al., 2021; Powell et al., 2019). The evidence suggests that these underlying conditions contribute to health disparities in underserved populations. The prevailing thought is that public health initiatives using evidence-based programs (EBPs) are critical to addressing health disparities (O'Mara-Eves et al., 2015; Ramanadhan et al., 2020). The research strategy was to identify, understand, and interpret EBPs that effectively reduce health disparities and stimulate end-of-life planning and discussions.

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### **Key Findings**

- Systemic racism began over 400 years ago when medical communities rationalized that people of African descent were less than human to justify slavery and their use as medical research subjects (Thomas & Casper, 2019).
- The enactment of the Self-Determination Act of 1991 shifted end-of-life decision-making responsibilities from medical professionals to patients. Requirements included educating staff, patients, and the community on ethical issues related to the Act and Advance Directives (Congress, n.d.).
- Cultural humilities combined with cultural competencies provide patient-centered care that decreases healthcare disparities. Cultural humilities involve the clinician's willingness to develop a nurturing relationship with the patient that emphasizes respect for others' beliefs, customs, and values (Stubbe, 2020).
- Health disparities are entrenched in society today, as evidenced by the effects of systemic racism on communities of color, most notably in the social determinants of health (SDOH). SDOH describes where people are born, live, and work, including the forces that shape the systems of daily life (Groos et al., 2018; Warren, 2020). These environmental forces touch on unemployment, food insecurity, housing instability, social injustices, and health care inequities.
- Faith-based and community-based organizations develop programs to address the needs of their community, which may or may not include evidence-based scientific research for decision-making. These organizations may use evidence-based research programs, models, and interventions when designed to affect behavioral changes in the community as long as the process is not a burden (Ramanadhan et al., 2020).
- Collaborative partnerships between medical providers and the community can incorporate evidence-based data into programs designed to support the community's health-related needs (McDonnell & Idle, 2020).

### **Recommendations**

A community-led, medically-driven health intervention strategy that promotes awareness, planning, and discussions is the best practice to encourage, motivate, and engage people of color to plan, discuss, and choose the path for their end-of-life journey (Van Scoy et al., 2020). Intervention programs operated by respected pastors, community leaders, or non-medical personnel increase participant buy-in, trust, and involvement. These delivery models fulfill the need to receive detailed information from trusted sources in a comfortable, supportive environment. Collaborating with medical professionals allows sharing of reliable, accurate health-related information. When providing services to their community, this strategy combines the medical professional's knowledge, skills, and education with the community leaders' reliability, credibility, and integrity.

Two other effective community-based delivery models use non-medical personnel that includes evidence-based solutions to encourage engagement with the targeted population in their community. Conversational-style gameplay is one example that has successfully increased individual participation (Van Scoy et al., 2016). Another consideration is hosting a dinner party with family and friends to discuss end-of-life choices (South & Elton, 2017). Both intervention strategies can use a variation of the Van Scoy et al. (2016) game questions to start the conversation. These examples are practical, inexpensive, and easy-to-

disseminate intervention tools to provide accurate information to many people who enjoy playing games or prefer dining with family and friends.

### Conclusion

These recommended solutions aim to increase the number of community members who engage in end-of-life planning, discussions, and decision-making activities, including completing documentation to legalize their healthcare wishes. The flexibility of these delivery models, including the scope and timing, will only be limited by the inputs established by the community leaders, participants, and medical partners. Each solution allows the participants to reflect, discuss, and share their intimate thoughts surrounding the often-feared topics of end-of-life care, dying, and death. The participants will learn to evaluate available end-of-life plans, consider personal values, and voice their preferences for the type of end-of-life care they desire.

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