What Can I Do?
5 Ways to Promote Advance Care Planning

Advancing Advance Care Planning for African Americans

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Introduction

Far too many Americans are reaching the end of life without having sufficiently planned for their healthcare wishes to be executed. Even fewer African Americans are represented among those with an advance care plan. Critical to advance care planning is both a conversation and a written document. Increasing advance care planning among African Americans will require systemic changes that not only build trust but also increase access to information and culturally appropriate care.

In this presentation Dr. Sullivan addresses historical explanations while emphasizing current systemic issues in the contemporary health care system which contribute to the current state. These include scientific racism, health care disparities and a need for increased community education and cultural appropriateness. While systemic issues must be addressed, there is much that healthcare providers can do. The provider - patient relationship can be a key mitigating factor that can build trust through better communication and advocacy.
Missed Opportunity

- Only one third to one half of Americans have engaged in advance care planning (ACP).

- Multiple studies confirm that African Americans are much less likely to engage in advance care planning than whites.

- Whites are two to three times more likely:
  - To have a Living Will
  - To have appointed a durable power of attorney
  - To have discussed their preferences with a loved one.
Why does this matter?

Neglecting to plan may mean we will receive treatments we would not want or not receive treatment we would want.
Scientific Racism & Health Care Disparities

Tuskegee Study of Untreated Syphilis in the African American Male, a longitudinal study of the clinical course of untreated syphilis was conducted by the U.S. Public Health Service between 1932 and 1972. Untreated syphilis was known to lead to heart disease, blindness, mental problems, or death. The goal of the study was to see if the course of the illness in Black men was the same as in white men.

These men trusted the health care system.

Henrietta Lachs and her family also trusted the healthcare system.

She died at Johns Hopkins of ovarian cancer but not before physicians removed some of her cells for research without her knowledge or permission. That was 60 years ago, but hers are the first “immortal” human cells grown in a culture - still alive today. Her daughter asks “... if her mother was so important to medicine, why couldn’t her children afford health insurance?
70+ Years After Tuskegee and HeLa, Racial Health and Health Care Disparities Persist, Rooted in Systemic Injustice.

Studies consistently show that African Americans receive poorer quality health [and mental health] care than Whites over the life course.” (Smedley, Stith, Nelson 2003).

Research is beginning to show better outcomes for African Americans when treated by a Black physician. (NYT 9/3/20)

Studies are showing that when you control for socioeconomic status, education and insurance the disparities in engagement in ACP persist.

We need to focus more on the contemporary health care system and how it can reduce disparities in care rather than focus exclusively on the attitudes of Black patients.

“If George Floyd had died of Covid-19, the world would not know his name. If he had lived another thirty years and died of cardiovascular disease, the world would not know his name…. Yet, ... if he had died at age seventy-four from diabetes-related complications - the underlying cause of death would be the same: racism.”

Role of Religion on End-of-Life Decisioning

Appreciate

Cultural/Religious Beliefs

- Religion or faith plays an important role in the lives of many African Americans.
- Religious Traditions may offer perspectives on:
  - Suffering
  - Ordinary vs Extraordinary means
  - Provision of hydration and nourishment
  - Withdrawing life-sustaining equipment

- Acknowledge the importance of faith and family.
- There may be greater concern about how the illness and the associated costs will burden the Black family.
  
(Carr, 2003)

- Does the patient ascribe more control to God than the individual?
- Holding on to hope has helped African Americans cope with atrocities and struggles for generations.
How can health care providers build trusting relationships with African-American patients?

Relate!

► Establish good Communication. Studies show African Americans more likely to report poor communication with their provider.

► Many African Americans are unaware of or uninformed of hospice care.

► See: “Conversation Starters: Research Insights from Clinicians and Patients on Conversations About End-of-Life Care and Wishes”

Advocate!

► Raise your voice and raise your hand in your organization re: inequities, disparities in care, access, patient and community education, etc.

► Work with other professionals and the community re these issues.

► Participate in the life of the community.

Martha A Sullivan, DSW, MA
“Speak of death [and incapacity] in the time of Life.”