NHPCO Project ECHO  
*Equity Where It Matters*

**Key Takeaways**
**Supporting African American Patients**

February 2, 2023

**Key points:**

- **Disparity in Hospice Utilization:** A racial disparity in hospice utilization and Medicare decedents who use hospice exists, and this is influenced by the social determinants of health (SDOH). Barriers to considering hospice may include family reluctance to release their own care, misconceptions around hastening death, mistrust of the healthcare system due to past experimentation, and spiritual and religious beliefs.

- **The Role of Faith:** In the Black/African American population, faith often plays a major role in decision making and there may be a strong presence of faith beliefs in the illness experience where God is recognized as in charge and the Pastor’s role is fundamental. Hope for a miracle is a common sentiment.

- **Advance Directives:** For some African American communities, completing advance directives is less likely to occur and choosing the aggressive treatment prevails. In addition, health providers are less likely to discuss goals of patient treatment, and even if those conversations do occur, African American patients’ goals are less likely to be respected nor followed. Coupled with a lack of knowledge of prognosis and the timing of disease, advance directives for African American patients can be difficult to attain.

**Actionable Steps:**

- Create a practical Cultural Sensitivity Training for Providers which includes tangible steps for providers to take to center the role of cultural consciousness when discussing hospice to patients.

- Utilize mixed media resources to educate patients and their families, such as videos, brochures, etc. Determine the best possible communication method for each respective patient.

- When possible, include members of the patient’s trusted community into the hospice plan (i.e., pastor or spiritual leaders).

**Conversation Starters:**

- How can providers sustainably build gradual trust with Black/African American patients when discussing end of life care?

- In what ways can my organization bolster our cultural sensitivity training to ensure that it is reflective of the unique considerations of Black/African Americans when determining medical decisions?

- How can, I on an individual level, ensure that a patient’s needs are being respected in a situation where the patient may feel unheard?
Participant Perspectives:

- “Embrace and lean into the faith traditions of our patients that give them strength.”
- “Use faith to build bridges, not barriers.”
- What strategies should be used when trying to forge relationships with churches, especially in the African American community?
  - Focus on engaging faith leaders, as opposed to just churches
  - Start discussions about advanced directives without focusing only on hospice care.
  - “Our supportive care team has been reaching out to pastors in our community to offer free educational coffee talks at their church about advance care directives.”
  - “Working with the health ministries at the church is a great way to get the conversation started, particularly providing info about advance care planning.”
- “In both palliative and hospice care, focusing on the supportive nature of the care that follows the lead and supports the decisions of the patient and their loved ones rather than coming in and directing the care, is key to gaining trust.”
- Healthcare providers need to use caution in respecting patients’ preferences without overstepping boundaries. It is important for providers to understand that spirituality and faith can play a major role in patients’ decisions about their treatments.
- “Trust is a key component of communication.”
- “We need to empower our patients, families, and communities with information.”
- Hospice and palliative care providers must be sensitive to the fact that often by the time Black/African American patients come to hospice and palliative care that they may be experiencing fear and mistrust based on their past experiences.
- “There are multiple areas of need that can be addressed when families are empowered with information that prepares them for encounters with doctors and other providers. Hospices can engage in cultural and faith-based outreach that is founded in deep listening and humility - NOT for referrals.”

References:

• Epps, Fayron; Moore, Miranda; Chester, Mia; Gore, Janelle; Sainz, Mayra; Adkins, Aisha; Clevenger, Carolyn; Aycock, Dawn. Nursing Administration Quarterly, Volume 46, Number 1, January/March 2022, pp. 72-80(9) https://www.ingentaconnect.com/content/wk/naq/2022/00000046/00000001/art00010
• Dr. Fayron Epps https://www.nursing.emory.edu/faculty-staff/fayron-epps
• Source: Nursing Administration Quarterly, Volume 46, Number 1, January/March 2022, pp. 72-80(9)
• NHPCO Diversity Tools and Resources https://www.nhpco.org/education/tools-and-resources/diversity
• Culturally and Linguistically Appropriate Services (CLAS) https://thinkculturalhealth.hhs.gov/clas
• Leave No One Behind: Equity and Access in Palliative Care https://wfrtds.org/report-on-access-to-palliative-care/
• NHPCO Caring Info www.caringinfo.org