

Team Reflection

No. 14 - Home Hospice and the Black Community

Sharrita Berry was a 52-year-old woman living in Oakland, Calif. She had been coughing heavily and struggling to breathe. Doctors diagnosed her with COPD and the condition was rapidly advancing. Physician specialists and intensivists struggled to connect with Ms. Berry, and she lacked trust in what they were saying, until one encounter.

When Dr. Jessica Zitter met Ms. Berry, she began by leaving aside medical lingo and the technicalities and instead invited Ms. Berry to share her experiences and aspects of her life. After generously listening to the patient, Dr. Zitter asked Ms. Berry about a breathing machine. She said, "I'm afraid I wouldn't get off [the ventilator]." The physician agreed and began to tell her about home hospice. Ms. Berry's daughter seemed relieved by her mom's desire to forgo aggressive life-sustaining interventions. "My mama knows I don't like seeing her in the hospital. She knows I'm more comfortable with her being with me and closer to me." [14.1]

Ms. Berry's decision for home hospice was relatively unusual for a Black patient facing a terminal condition. Sadly, due to historic wounds of medical abuse by white physicians and administrators, racial inequities appear in end-of-life care today, resulting in mistrust particularly in Black communities across the U.S. Studies show when facing end-of-life situations, people of color are more likely to request high-intensity treatments and tend to die more often on machinery in facilities and away from their homes. [14.1]

Palliative and hospice care possess the specialization to support the patient's holistic needs whether physical, social, emotional and/or spiritual. Spending what may likely be one's final months in one's own community and home can be a source of great comfort for many, rather than surrounded by unknown professionals in a foreign, sterile and untrustworthy place. In contrast, home hospice, can provide greater comfort, and less painful options, all at lower costs and with significant support.

Home care entails identifying support and the participation of the community. Throughout the COVID-19 pandemic faith communities emerged as one important partner. This is especially true with African American and other racial/ethnic





communities. Faith communities often hold trust with parishioners and provide community support.

Dr. Shawnee Daniels-Sykes, a Black Catholic bioethicist and nurse, describes how "Black people hail from a culture of deep religious roots; they have found meaning in pain and suffering through the black spirituals and reflection of the paschal mystery of the Black Jesus." [14.2] She envisions health care to the Black community to be holistic, communal, spiritual and humanistic. Clinicians may find this vision at odds with the values of autonomy and agnosticism. Yet, tapping into spiritual care resources and faith communities in the neighborhoods beyond the hospital, the vision and the desires of those like Ms. Berry can be achieved.

Consider

- Recall a recent situation with a patient when you listened whole-heartedly to her or his experience?
- What did you notice about what they were deeply seeking?
- Are there ways that you or your organization partner closely with faith communities or other key leaders in nearby neighborhoods?
- How does your organization involve faith leaders from those organizations, and do they have convenient and frequent access to the residents of long-term care facilities and in-patient settings?
- How do you greet them and help foster a connection with the people / patients you serve?

Let us pray together,

God of time and eternity,

Be close to your people especially those whose numbered days are fewer and drawing to an end. Help us to imitate your gentle love in remaining close to them, in listening with supple hearts to their needs and desires, so that we might support the comfort they need, sustain family and loved ones, and entrust them at last to your eternal care. Amen.





[14.1] https://centerforhealthjournalism.org/fellowships/projects/racial-disparities-end-life-care-how-mistrust-keeps-many-african-americans-away

[14.2] Shawnee Daniels-Sykes, "Code Black: A Black Catholic Liberation Bioethics," *The Journal of Black Catholic Theology* 3 (Fall): 29-59. 2009.

