

Dying in community: The black church and hospice care

by [Amy Frykholm](#) in the [August 7, 2013](#) issue



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The American hospice movement is thriving. Forty-two percent of all Americans who died in 2010 were in hospice care—up from 22 percent in 2000. The number of organizations providing hospice care has grown steadily, up 13 percent from 2006—from 4,500 to over 5,000—as has the length of time that patients spend in

hospice care. More people are spending their dying days experiencing the holistic medicine and dignified care that hospice seeks to provide.

But the growth in the hospice movement has tended to neglect African Americans. African Americans constitute 13 percent of the U.S. population, but only 8 percent of hospice patients are African American—even though blacks have the highest cancer rates of all ethnicities and are more likely to die from cancer than whites.

In recent studies on ethnicity, race and death, researchers found that blacks are only half as likely as whites to have advanced-care plans. Blacks are almost twice as likely as whites to choose “full-code” status—that is, they are more likely to request that all medical means be used to preserve their lives. Blacks are also half as likely to opt for withdrawal of life support when faced with a terminal illness.

One explanation for this gap is the general lack of equality in access to medical care. Blacks have less contact with the medical establishment throughout their lives, make fewer visits to clinics and are less likely to have a primary care physician. They are almost twice as likely as whites not to have health insurance. It’s not surprising then that when faced with terminal illnesses, African Americans are less aware of all the options for care.

Another factor is African Americans’ deeply embedded distrust of the medical establishment. Officials at the Duke Institute for Care at the End of Life cite the case of an African-American man who was asked about his preferences for cardiac resuscitation and hospice care. “Do you ask all your patients these things?” he asked suspiciously.

Etta McGregor Jones, director of Amani Community Health Corporation, a nonprofit organization associated with Trinity United Church of Christ in Chicago, sees this suspicion among people in her community. “As a black person,” she said, “there is a feeling that hospice might be one of those experiments they want to do, like Tuskegee: they want to cut off the procedures and cut back on the medication; they want to practice on you and see how long it takes you to die.” After a presentation on African Americans and hospice care at the National Medical Association, civil rights activist and comedian Dick Gregory quipped, “So now they want us to get comfortable with dying?”

This skepticism is compounded by the fact that few African Americans hold leadership positions in the nation’s 5,500 hospice care organizations. Shareefah

Sabur, chief quality and education officer for the Hospice of the Western Reserve in Cleveland, remembers attending a national meeting of hospice care providers 20 years ago and realizing that she was one of only a few African Americans in the room. At a statewide meeting more recently, she was one of only two African Americans present.

Religious faith is a decisive element in African Americans' approach to hospice. Blacks are almost twice as likely as whites to say that faith plays an important role in their decision making. They are more likely than whites to belong to a religious community, to pray and to request prayers. Prayers for and belief in healing play a significant role in African-American churches. These factors build a resistance to the idea of hospice.

Jones said that some people in her community believe that "if you refer a family member to hospice, that means you don't have enough faith in God. If you really believed, if you prayed hard enough, God would heal that family member."

Aaron McLeod, a community liaison for Vitas, the nation's largest hospice care corporation, said he has heard prayers for healing that were inappropriate in the medical situation. "Some clergypersons who come into a hospice situation and pray prayers of healing and prayers of deliverance [are] totally misappropriating the whole enterprise of what it is to be at the end of one's life."

McLeod believes that the gap between hospice and African-American churches is primarily a matter of education. In an effort to close that gap, he teaches groups and churches about end-of-life issues.

Studies show that 80 percent of African Americans have heard of hospice, but only 15 percent know that Medicare pays for it. "There is no reason for them not to take this important service," said McLeod. "They're paying taxes and paying insurance premiums for this service but are not using it."

Exclusion from medical care, suspicions of the medical establishment and theological reservations may explain why blacks tend not to use hospice. But Otis Moss, pastor at Chicago's Trinity United Church, sees another problem. Hospice organizations work out of a clinical model, he said, and have trouble understanding the "theological and spiritual and cultural language" of the African-American community. When communication breaks down, hospice organizations "end up dismissing the community and claiming that there are 'cultural barriers,' when in

fact they have not done the legwork necessary for understanding community. [They are] not taking the time to develop . . . the unique aspects of the community they want to engage.”

Part of the clinical model that Moss refers to is the requirement that every hospice organization work with an interdisciplinary team of care providers, also called a “circle of care.” This circle usually includes a doctor, a nurse, a home health-care worker and volunteers as well as a chaplain, clergyperson or counselor who provides spiritual care for the dying person and the family. This team approach is at the heart of the hospice effort to provide holistic care. It is a response to the overmedicalizing of death that occurs in the hospital, which disconnects people from their loved ones at the time of death.

This approach is a great improvement on an exclusively medical approach, but it can unintentionally sideline pastors who might already be connected to a family. Perhaps ironically, assigning a professional team of strangers to an individual institutionalizes the idea that dying is an individualistic process rather than a communal one. The spiritual-care person on a team is typically hired by the hospice organization and trained to deal with a wide variety of cases, spiritual and religious communities and backgrounds.

In fulfilling the requirement to have a “pastoral or other counselor,” hospice organizations increasingly turn to people whom they themselves have hired and trained. Because the spiritual counselor has to serve patients with a wide variety of needs, she provides a generic form of spiritual care. If a patient already has a pastor, the spiritual care person’s job might be to coordinate and communicate with the patient’s religious community. This can work well, but in the case of African Americans who are part of religious communities, the hospice team can create another layer of bureaucracy at a time when patients most need to be surrounded by their community. A spiritual counselor cannot replace the pastor or deacon who has baptized your children, aided you in times of trouble and been at your side throughout your life.

In the early 2000s, Trinity UCC decided to establish a church-based, community-centered hospice program. Trinity’s pastor at the time, Jeremiah Wright, had observed the hospice care his parents had received, and he wanted his parishioners to have access to similar care, grounded in the Trinity community. With the help of several parishioners, he started Amani (the Swahili word for “healing, wholeness and

eternal life with God”). The goal was to create a distinctively African-American hospice that would especially honor African-American traditions.

Traditionally, death is a communal event for African Americans. Instead of funerals, many African-American churches hold “homegoing celebrations,” rituals that reach back deep into African-American tradition.

“We celebrate the life and the gathering of the community,” observed Moss, “lifting up the life and legacy of an individual. They are now home with others who have gone before them. You have tears, shouts, laughter, fellowship, food, more food.

“It eases the grief when someone has prepared the greatest sweet potato pie anyone has ever tasted as they tell the story of how Grandma used to grow tomatoes. The food, the stories, the sharing of people’s favorite songs—that helps people remember that this is not the end of the story. This is just the beginning of the story. It changes how you experience death because it is not final for you. In the African tradition, your ancestors speak to you and are with you all of the time. The people who go before you make a way for those who are living and for those who are not yet born.”

Wright wanted Amani’s hospice program to be built on this communal foundation. Church members who were dying would be cared for by other members who were trained to help patients communicate with the medical establishment, make choices at the end of life and navigate the medical system. In many ways, Amani’s vision and that of the hospice movement were alike. Both wanted to surround the dying with support, love and multiple levels of care. In Amani’s case, the church was to be the communal vehicle for this care, partnering with the medical establishment.

In 2003 Amani was up and running with a training and volunteer program. Rosalyn Priester, its first director, and staff trained more than 90 volunteer church members, and the group was exploring how to become a licensed hospice organization. Priester tried to provide missing services by establishing formal partnerships with licensed hospice services. But these partnerships fell through. Apparently the kind of integrated partnership that Amani imagined was all but impossible.

In order to fulfill federal requirements, hospice organizations must have their own stable of volunteers and their own spiritual care providers. Hospice organizations wanted to draw Trinity’s volunteers into their own ranks, but this did not match Amani’s vision.

From 2003 to 2009, several partnerships were begun and then faltered. Eventually Amani decided it could no longer continue hospice services, and it turned to other programs. (It has taken on issues of school violence, breast cancer awareness and caregiver support.)

Today when members of Trinity sign up for hospice care, they receive visits from church deacons and congregation members, but the church is not formally linked to a licensed hospice program. It does not have the partnership that Wright and his colleagues envisioned. The church benefits from having trained hospice workers in the congregation, but few of them volunteer outside of the church. They are not eager to show up at a random hospital and be assigned to patients with whom they have no relationship.

Sabur, the hospice executive in Cleveland, observes that issues of race, culture, ethnicity and religion all come into play in end-of-life care. Whites may feel more comfortable with whites, and blacks with blacks.

“It’s just a human tendency,” she said. But she believes that community-based models that rely on affiliation with religious communities can thrive.

In Cleveland, volunteers from Catholic churches are assigned to a particular hospice organization, but they are trained as part of the church. The hospice can then assign Catholic volunteers to Catholics, although the volunteer may not be from the same parish as the patient. This is a step toward creating a less generic and richer form of spirituality in hospice care.

If hospice organizations are serious about overcoming the gap between African Americans and hospice, they will need not only to educate African Americans about hospice care but also to learn about the communal shape of dying in the African-American community and how to integrate that tradition into its work. Such an approach calls for a different model of partnership—one in which, as Moss said, “the hospice organization wouldn’t bring all the resources. It would recognize that the faith community has resources.”