
Key Topics on End-of-Life Care for African Americans

The Case Study

“African Americans have been caring for their loved ones at home since the beginning of time. It was never called HOME CARE. They have cared for their dying relatives equally as long. It was never called HOSPICE. Relatives come home from various parts of the country to relieve the caregivers, and it was never called RESPITE CARE. They come to give relief to mama, papa, sisters, brothers, aunts, uncles, cousins, grandma and grandpa. They talk with each other, share experience[s] and give advice and counsel. It is never called NETWORKING. Last, but not least, they serve as volunteers in their own communities, in their own churches, and on their own streets. They wear no uniforms, record no hours and receive no awards. Nor do they expect to be rewarded. It is family caring for family, neighbors caring for neighbors and communities caring for each other.”

—Bernice Catherine Harper, MSW, MSH, PhD

The Last Miles of the Way Home, a National Conference to Improve End-of-Life Care for African Americans, was held in February 2004 in Atlanta, Ga. The powerful climax of the conference was the Town Hall Meeting moderated by renowned journalist Mr. George Strait. Mr. Strait designed a role-playing scenario in which a group of distinguished national experts and conference participants engaged in theatrical dialogue about an African American family facing end-of-life care decision making. The Town Hall Meeting, “**Bringing the Message Back Home: Taking Action, Making Changes,**” examined how one African American family moved quality end-of-life care from concept to reality.

Moderator:

- **George A. Strait Jr.**
Assistant Vice Chancellor, Public Affairs, University of California, Berkeley, CA
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Panelists/Performers:

- **Beny Primm, MD**
Director, Addiction Research & Treatment Corporation
- **Gwendolyn London, DMin**
President, London & Associates
- **Glenda Hodges, PhD, JD, MDiv**
Director, Program in Spirituality and Medicine, Howard University College of Medicine
- **Richard Payne, MD**
Director, Duke Institute on Care at the End of Life
- **LaVera Crawley, MD**
Medical Ethics Researcher and Lecturer, Stanford University
- **Aranthan Jones**
Former Senior Health Advisor
Congresswoman Donna M. Christian-Christiansen, MD
US Virgin Islands
- **Darryl Crompton, JD, MPH**
Vice President, Research and Program Development
MasiMax Resources Inc.

The Road Home: A Father and Daughter's Journey

Mr. Beny Primm is a successful 75-year-old African American business owner and widower with one child, daughter Gwendolyn, who is a registered nurse. Mr. Primm lives alone in the home he shared with his wife of 52 years; she passed away several years ago. He is a very independent, spiritually rooted man who has been an active member of his community for more than 40 years.

Mr. Primm is a well known and highly regarded individual in his community and his home church. Mr. Primm has developed and maintains a strong relationship with his former classmate and attorney, Darryl Crompton, and his long-time pastor, Rev. Glenda Hodges. Mr. Primm regularly seeks their legal counsel and spiritual guidance.

Mr. Primm has a loving relationship with his daughter; however there are strained periods in their interactions on a daily basis. Recently he is feeling vulnerable about his loss of control over his life and concerned about his overall quality of life. Gwen is feeling the stress of having to support and deal with issues related to her father's care, while raising her three teenage daughters. Gwen's husband runs the family business started by her father.

Mr. Primm is forgetful and has experienced some loss of function over the past few years. After his third car accident in a year's time, his daughter confiscated his car keys. Since his last car accident, Mr. Primm has moved in with his daughter and her family.

Mr. Primm has developed an intermittent palsy on his left cheek, and he is aphasic at times. He is on blood pressure medication but does not like how the medication makes him feel. Mr. Primm also suffers from diabetes and has recently had his left leg amputated.

Over the course of the last six months, Mr. Primm has been diagnosed with a rare blood disorder; his health is declining rapidly. Dr. Payne, the family physician of more than 20 years, has informed Mr. Primm and his daughter that the disease can only be treated with an expensive bone marrow transplant.

Although Dr. Payne and his colleague, Dr. Crawley, passionately advocate on Mr. Primm's behalf for the transplant, Mr. Aranthan Jones, director with the Center for Medicare/Medicaid Services has emphatically denied the request for the transplant. Dr. Payne has informed Mr. Primm and his daughter that based on the progression of his illness and Medicare's decision, he should consider other options of care, such as hospice.

While Dr. Payne would like to refer Mr. Primm to hospice immediately, Mr. Primm and Gwen are still very reluctant to give up the fight. At this stage, the family meets with the principals in Mr. Primm's life (his pastor, doctor, and attorney) to discuss his options for care. Gwen is concerned about the quality of her father's remaining time. As a nurse Gwen is very familiar with the under treatment of pain and the reports that pharmacies in predominately Black and Hispanic communities are not stocking the proper pain medications. As Mr. Primm's illness advances, Gwen would like his cultural preferences acknowledged and respected. Because of the conflict that has developed between the two of them, Gwen would also like to be reassured that his psycho-social concerns are met.

In previous conversation with Rev. Hodges and Dr. Payne, Mr. Primm revealed that his primary concerns are that he will be in severe pain, weak and addicted to pain medications as his condition progresses. He also states that it is important that he not become a burden to this daughter. He expresses that hospice care means giving up and that his quality of care will decrease once he submits to hospice. Mr. Primm is also worried about his life-long business and he wants to make sure that everything "is in order" for his son-in-law to fully take over the business once he relinquishes control of the company.

Gwen strongly expresses her frustration and anger to Rev. Hodges and Dr. Payne that she was not brought into the conversations about her father's health earlier on given that she is his primary caregiver. Dr. Payne and Rev. Hodges acknowledge Gwen's frustration, and they reassure her that the lines of communications will be open to her regarding her father's continuous medical and spiritual care.

Rev. Hodges informs Gwen and Mr. Primm that hospice care will allow them to have the quality time they are both seeking and not overburden Gwen with his daily medical and personal care. Gwen states in no uncertain terms to Rev. Hodges and Dr. Payne that in considering hospice care for her father it does not mean that she giving up her role as his primary caregiver. Rev. Hodges informs Mr. Primm that hospice is comfort care and that accessing the services does not mean giving up; she assures him that his unquestionable faith and spiritual beliefs will guide him through his journey.

Because the hospice program is run by their church, Rev. Hodges informs Mr. Primm and Gwen that his home church is an extension of his family; members of the church and the community will be at his side throughout his need for care. Rev. Hodges states that the church fully recognizes the cultural norms and perspectives of the community they service; it is vowed by Rev. Hodges that should Mr. Primm and his daughter elect to utilize hospice services, his cultural needs and preferences will be honored and respected. In addition, Rev. Hodges tells Gwen that hospice will also address her father's psycho-social and spiritual needs. Rev Hodges comforts Mr. Primm with song and prayer during their meeting together.

Mr. Primm's attorney, Mr. Crompton, suggests that Mr. Primm give his daughter power of attorney over his legal and financial affairs and reviews the advance directive document with Gwen and Mr. Primm. He also discusses the legal matters Mr. Primm will need to attend to in the very near future concerning his company. Mr. Primm is comfortable with his attorney's advice and he agrees that all legal matters relating to his medical care and financial business should be taken care of immediately with his daughter and son-in-law by his side.

Mr. Primm and his daughter reviewed their options for care together, affirming and reaffirming the full conversations. At the end of the meeting, confident that they have exhausted all options for curative measures and that their questions and concerns were fully acknowledged and addressed, they requested that Dr. Payne refer them to hospice care services.

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The two-hour session provided a stimulating and insightful view into how an African American family addresses the end-of-life care issue for a family member. Mr. Primm and his daughter Gwen wanted their concerns to be heard and questions responded to before making any final decisions about beginning hospice care. In the end, Mr. Primm and his daughter took the action and made the change to ensure that Mr. Primm's final journey home was one of comfort, dignity, and respect and that his cultural preferences, spiritual needs, and psycho-social needs would be met.

During the theatrical scenario, the panelists/performers explored various topics such as:

- Understanding the cultural needs and preferences of diverse populations seeking end-of-life care
- Acknowledging the traditions of care for African Americans from its historical and cultural perspectives
- The importance of listening to the patient and family member(s); addressing their concerns and fully answering their questions
- The role of the church in the spiritual care of the patient and their family members
- The fear that the patient will be in severe pain and that pharmacies in predominately African American neighborhoods will not stock proper pain medications
- Addressing the misconceptions about hospice care

Questions for Discussion

1. Why do you think it was important to have a meeting with Mr. Primm and his daughter? How likely is this scenario to be played out in a real life situation?
2. How were the principals involved in assisting Mr. Primm and his daughter with making decisions regarding his care? What were their individual roles and why was each of them important to this meeting?
3. What were some of the major issues that needed to be addressed?
4. There is an underutilization of hospice care with African Americans. Can you identify some of the reasons Mr. Primm and his daughter were initially reluctant to consider hospice as a viable option for his care?
5. Do you think this situation would have been different if this were not an African American family? If so, how do you think it would have been different?