

Lifelines

from the National Cancer Institute



Palliative and End-of-Life Care in Minority Populations: Questions and Answers

By the National Cancer Institute

African Americans, Hispanics, and other populations of color suffer disproportionately from cancer. Palliative care and hospice care providers offer expert management to alleviate the suffering associated with cancer for the patient and the family. These healthcare professionals can help those affected by cancer deal with physical and spiritual pain and other symptoms, as well as with psychological and social problems. Yet, African Americans and Hispanics utilize hospice and palliative care at a much lower rate than whites. For instance, African Americans comprise less than 8 percent and Hispanics less than 5 percent of patients enrolled in hospice programs.

Studies have identified barriers to hospice and palliative care for minority populations. These barriers include concern about the costs of care and the burden on the family, a mistrust of the healthcare system, a lack of awareness about such services, perceived conflicts of personal or cultural values, and language barriers.

The following questions and answers are based on the APPEAL training curriculum (A Progressive Palliative Care Educational Curriculum for the Care of African Americans at Life's End), offered by the Duke Institute on Care at the End of Life. The APPEAL curriculum was developed by African American experts in palliative care, Richard Payne, M.D., ICEOL Director, and the late Marian Secundy, PhD, and a team of interdisciplinary faculty. Dr. Payne is a renowned expert on this topic and authored relevant information on minority populations for the Institute of Medicine 2001 Report, *Improving Palliative Care for Cancer*.

Isn't hospice a place where people go to die when nothing more can be done for them?

Hospice is an approach to care based on a philosophy that includes a comprehensive set of services for patients and families at the end of life. Care is flexible and provided to a patient at their residence, which may include their home, nursing or residential care facility, hospital, or free-standing hospice facility. Most patients are cared for in their own home.

What makes hospice better than standard care?

Hospice provides better management of pain and other symptoms as well as emotional needs, such as depression and anxiety. The hospice service can reduce caregiver anxiety and improve bereavement adjustment. Families report greater satisfaction with the overall quality of care.

Why hospice for African Americans/ Hispanics?

African Americans and Hispanics are more likely to experience inadequate pain management at the end of life. Caregivers are more likely to report poor communication and less satisfaction with the overall quality of end-of-life care. Hospice expertly addresses all of these issues.

If patients don't have insurance, can they get into hospice?

Hospice care is covered by Medicare and Medicaid as well as by most private insurers. Medicare requires hospice to provide services to those who do not have insurance, regardless of their ability to pay.

What can hospice do for caregivers?

Hospice provides help to family members who are providing homecare, including:

- Instruction on how to provide care
- Nursing visits to monitor the patient's condition
- Home health aides to help with home care
- Volunteer assistance
- Respite care to give the family a break
- Emotional and spiritual support, provided by social work and chaplaincy professionals
- Bereavement services for 13 months after the death of a loved one

How is palliative care different from hospice care?

Palliative care can be offered at any time during the course of a serious illness along with other treatments that are aimed at a cure or controlling the illness. It can also address the physical, emotional, and spiritual needs of a patient and family holistically. There is no requirement that a person be diagnosed or be at the end of life to receive palliative care.

NCI leads the National Cancer Program and the NIH effort to dramatically reduce the burden of cancer and improve the lives of cancer patients and their families, through research into prevention and cancer biology, the development of new interventions, and the training and mentoring of new researchers. For more information about cancer, please visit the NCI Web site at www.cancer.gov or call NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237).

Related resources:

- Coping with Cancer: Supportive and Palliative Care (<http://www.cancer.gov/cancertopics/coping>)
- NCI's Cancer Information Service (CIS) (<http://www.cancer.gov/aboutnci/cis>)