Culturally Appropriate Hospice Care in King County

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According to the National Hospice and Palliative Care Organization (NHPCO), about 1.4 million patients received hospice care in the United States in 2007. Of those who received care, only 9 percent were from the Black community. This is particularly alarming when you consider health care data shows that African Americans have higher mortality rates from cancer, cardiovascular disease, AIDS, and other illnesses. So, what is being done to reach out and improve awareness in communities of color about end-of-life decisions, hospice and palliative care and, most importantly, quality of life at life's end?

From 1995 through 2003, the Robert Wood Johnson Foundation and the Open Society Institute tackled the issue of improving care at the end of life. Their strategy focused on educating the public, training health care providers, and improving access to end-of-life care in medical institutions. Some of their successful projects included:[1]

- *Last Acts*, a campaign that mobilized a coalition of health care and consumer groups to improve end-of-life care
- *On Our Own Terms*, a PBS documentary on dying produced by Bill Moyers that was seen by more than 20 million viewers
- *Five Wishes*, a living will that takes into account a person's medical, personal, emotional and spiritual needs.

Locally, there are several hospice programs, and two that specifically work to improve access for African Americans. Established in 2003, the Seattle African American Comfort Program (SAACP) works to provide education about access, medical, psychosocial, spiritual and legal services to African Americans facing end-of-life issues and considering hospice. In 2005, Providence Hospice of Seattle (PHOS) developed training to increase internal awareness about culturally appropriate end-of-life care, which led to the formation of a Diversity Task Force, and the hiring of a Diversity Coordinator. Monthly Task Force meetings focus on methods to increase cultural awareness of all people of color, while the Diversity Coordinator works to provide hospice information to underserved communities of color throughout King County.

What is hospice?

Hospice is a philosophy rather than a place. Hospice care is an interdisciplinary approach to meeting a person's physical, emotional and spiritual needs at the end of life. When a patient is diagnosed with a life-limiting illness, treatment options turn from cure to comfort, and hospice care can make a profound difference. Providence Hospice of Seattle understands the impact a life-threatening illness can have, and through a customized plan of care, addresses the needs of each patient and their family. The patient, family members, the patient's primary physician and the "Interdisciplinary Hospice Team"—the term used for a patient's circle of caregivers—compose the plan of care. The Team consists of primary physician, medical director, specially trained nurses, medical social workers, hospice aides, physical, occupational and/or speech therapists, volunteers, chaplains, and bereavement counselors.

Hospice services are provided wherever the patient may reside: at home, in a skilled nursing facility, or residential care facility. Providence Hospice of Seattle cares for patients throughout King (including Vashon Island) and south Snohomish County.

What is palliative care?

The final stages of life need not be painful, depressing or frightening. Controlling a patient's physical pain is a key component to hospice care and palliative care. Palliative care means taking care of the whole person—body, mind, spirit, heart and soul. It looks at dying as something natural and personal, and allows each person to have the best quality of life while facing a life-limiting illness.

When should a decision be made about entering hospice?

At any time during a life-threatening illness, it is appropriate to discuss all of a patient's options, including hospice. The decision belongs to the patient and his or her physician. The earlier hospice is involved, the more likely it is that a patient's final days, weeks or months can be comfortable and satisfying.

For more information on no-cost presentations about hospice services and end-of-life issues for your community, private business, or organization; about *Five Wishes*, a legal document that addresses medical, personal, emotional and spiritual needs at end-of-life; or general information about hospice care, contact Reverend Gwendolyn Coates, MA, Diversity and Multicultural Outreach Coordinator at gwendolyn.coates@providence.org or Merlin Rainwater, R.N. M.N, Clinical Educator at merlin.rainwater@providence.org, or call 206-320-4000. For consultation and referral, call 206-749-7701. Visit the PHOS web site at: www.providence.org/hospiceofSeattle.

The authors are members of the Mayor's Council on African American Elders (MCAAE).

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[1] Ethan Bronner, Section Two: "Improving Health Care," The Foundation's End-of-Life Programs: *Changing the American Way of Death, The Robert Wood Johnson Anthology, To Improve Health and Health Care, Volume VI.*