Special Article

Scaling Up Palliative Care Services in Rural Tanzania

Erinn Nanney, MPH, Shelley Smith, MPH, Kristopher Hartwig, MD, FAAFP, and Paul Mmbando, MBChB, DrH
FHSSA, Alexandria, Virginia, USA

Abstract

Access to palliative care in Tanzania, particularly in rural areas, is limited. The Continuum of Care for People Living with HIV/AIDS in Tanzania (CHAT) project began in 2007 with the goal of expanding coverage of palliative care services. This was done by adding home-based palliative care teams to 13 existing hospitals throughout rural Tanzania. By integrating palliative care teams into the existing hospital structure and by using community resources, CHAT rapidly built a network of care. Community involvement and proper training of palliative care professionals and volunteers have allowed for an increasing number of patients to access and accept palliative care services and for CHAT to provide home-based palliative care, with clinical backup, to those in need. J Pain Symptom Manage 2010;40:15–18. *© 2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words

Palliative care, Tanzania, scale-up, FHSSA, ELCT, PEPFAR, OVC, opioid, home-based care, Africa, volunteers

Introduction to the Setting and Problem

The need for palliative care in Tanzania is great. With a population of more than 37 million, there are approximately 1.4 million people living with HIV/AIDS (PLWHAs), and an estimated 20,000 new cases of cancer are diagnosed each year. In 2002, at least one of every 200 Tanzanians needed palliative care and lacked access.[1] Although the lives of many people living with HIV/AIDS are extended by antiretroviral (ARV) treatment, suffering associated with death from this disease remains. The HIV/AIDS epidemic has left an estimated 1.2 million orphans and vulnerable children (OVCs) struggling to survive physically and emotionally, often caring for younger siblings.

To alleviate those families' suffering, a palliative care movement began in Tanzania in the early 1990s.[2] The first palliative care efforts began with four medical providers, all of whom had access to limited allowances of opioids.[3] With no official government policy regarding palliative care, in 2006 the Tanzanian Palliative Care Association was formed to influence a government plan, advocate for professional education, and encourage broader access to oral morphine. Even with these efforts, a significant portion of the population lacks access to palliative care, especially in the rural areas.

Address correspondence to: Erinn Nanney, MPH, FHSSA, 1731 King Street, Suite 300, Alexandria, VA 22314, USA. E-mail: enanney@fhssa.org

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Description of the Intervention

In 2006, the Foundation for Hospices in Sub-Saharan Africa (FHSSA) received a grant to collaborate with the Evangelical Lutheran Church of Tanzania (ELCT), expanding their model hospice/palliative care program at Selian Lutheran Hospital to other Lutheran hospital sites. The goal of the project was to expand coverage of palliative care services at 13 rural sites. The U.S. President's Emergency Plan for AIDS Relief (PEPFAR), through the United States Agency for International Development (USAID), provided resources for the Continuum of Care for People Living with HIV/AIDS in Tanzania (CHAT).

At Selian Lutheran Hospital, CHAT's model for scale-up, a highly trained cohort of home-based care volunteers (HBCV) administers physical, emotional, and spiritual support to community members living with HIV/AIDS or other life-limiting diseases. The use of HBCVs alleviates many concerns related to access to care in the rural, health professional-poor settings found near ELCT hospitals. The Selian model also enlists the local faith-based communities as essential advocates for care of PLWHAs. Through these educational endeavors, the churches serve as a reservoir for volunteer recruitment, identification of OVCs, and referral of patients for care.

Using the pre-existing infrastructure and resources of ELCT hospitals, CHAT began the establishment of care in these facilities by means of a four-step process: 1) educating individual hospitals about palliative care; 2) advocating for palliative care and drug availability with the Tanzanian government; 3) training health care professionals and volunteers to provide quality palliative care; and 4) providing resources and funding for the provision of palliative care.[4] Each hospital provides the basic infrastructure and administrative oversight for their hospital-based palliative care teams, which comprise a full-time coordinator (a nurse), an assistant, a social worker with part-time chaplain support, and oversight from a physician. CHAT also provides medicines and supplies, expanded communication capability, and an outreach vehicle.

The palliative care team works with the community to recruit and train HBCVs. The volunteers receive the three-week Tanzanian National AIDS Control Program HBC training by a government-certified trainer and are supported and supervised by the hospital-based palliative care teams. In cases of severe illness or worsening disease, HBCVs refer individuals/families to the palliative care team, which delivers a full spectrum of services, including medical care, spiritual support, and bereavement counseling. To reinforce these services, palliative care teams collaborate with local congregations to identify OVCs in the communities and provide bedding, nutritional support, health care, psychosocial support, or educational resources, as needed. Through these partnerships, they support the community and families of palliative care patients. In addition, through FHSSA, each of the 13 programs is partnered with a U.S. hospice, so that each organization has access to individualized and continued support, promoting sustainability into the future.

Experience with Implementation

There have been a number of challenges in implementing the CHAT project over the last three years. Because of the decentralized nature of the Lutheran hospital system, the palliative care team from ELCT headquarters negotiated with hospital leadership to work with the project and agree to support it with resources and staff. The lack of knowledge concerning palliative care in Tanzania added to this challenge. Over time, hospital leadership realized the overall acceptance of palliative care in their communities, leading to their support and local ownership of the program.

Although Tanzania has oral morphine, the processes for becoming licensed to administer the drug and gaining access to a supply remain a challenge. Until 2009, Ocean Road Cancer Institute remained the only location in Tanzania with a supply of oral morphine for distribution. Ocean Road now works with consultant hospitals, including the Lutheran-affiliated Kilimanjaro Christian Medical Center (KCMC), to train their staff in the administration of oral morphine. As a result, KCMC receives oral morphine, which may make it possible for the 13 CHAT sites to gain access. All sites are currently applying for a license.

Finally, even though more PLWHAs access ARV drugs and support for their families, the