Implementing a Palliative Care Nurse Leadership Fellowship Program in Uganda

Julia Downing, PhD, RGN, Mhoira Leng, FRCP, and Liz Grant, PhD

Global oncology and palliative care needs are increasing faster than the available capacity to meet these needs. This is particularly marked in sub-Saharan Africa, where healthcare capacity and systems are limited and resources are stretched. Uganda, a country of 35.6 million people in eastern Africa, faces the challenges of a high burden of communicable disease and a rising number of cases of non-communicable disease, including cancer. These dual epidemics are linked with infective etiologies that contribute to many cancers, such as hepatocellular (hepatitis B) and cervical carcinoma (human papillomavirus and HIV). As in many African countries (World Health Organization, 2011), the vast majority of patients in Uganda are diagnosed with cancer too late for curative treatment to be an option because of factors like poor access to healthcare facilities, a lack of health education, poverty, and delays resulting from seeking local herbal or other traditional remedies. Progress is being made with early detection; however, even for patients who present with earlier stage disease, challenges persist in accessing adequate diagnostic and treatment facilities. Although the exact incidence of cancer in Uganda is unknown, estimates suggest that more than 60,000 cases of cancer are diagnosed per year, with about 22,000 cancer-related deaths (Okuku et al., 2013). For example, 2,000 new patients with cancer seek care at the Uganda Cancer Institute in the capital city of Kampala each year; 70% are diagnosed with advanced disease (Okuku et al., 2013). Therefore, the provision of high-quality palliative care services is an essential element of cancer care in Uganda.

This article describes an innovative model of nurse leadership training in Uganda to improve the delivery of palliative care. The authors believe this model can be applicable to other low- and middle-income countries (LMICs), where health resources are constrained and care needs are great.

Palliative Care

The development of palliative care in Uganda is based on a public health approach recommended by the World Health Organization, which emphasizes training and education, availability of opioid pain medications (e.g., morphine), policy reform, research, and the implementation of services (e.g., hospital-based or community palliative care) (Harding et al., 2013; Stjernsward, Foley, & Ferris, 2007). During the past two decades, palliative care provision in Uganda has spread from isolated centers of excellence in Kampala to integrated services throughout much of the country (Worldwide Palliative Care Alliance & World Health Organization, 2014). Seventy-five percent of districts within Uganda now have access to basic palliative