Implementing a Palliative Care Nurse Leadership Fellowship Program in Uganda

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Globally, 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
care services. However, this progress is limited by the reality that palliative care services are often only available at one site within a district, which can cover a vast geographic area, and rely on one trained individual.

Uganda is recognized as a leader in palliative care education and training within Africa (Morris, 2013). For example, Uganda has successfully incorporated palliative care content in undergraduate and postgraduate curricula for doctors and nurses, created a diploma and degree course in palliative care through Hospice Africa Uganda (www.hospiceafrica.or.ug) and Makerere University (www.mak.ac.ug), and developed a diploma in pediatric palliative care through Mildmay Uganda (www.mildmay.or.ug). These courses have trained a wide range of health professionals, including Ugandan nurses, who are now poised to provide palliative care at a higher level.

In Uganda, about 13 nurses exist per 10,000 people (as compared to 1 physician per 10,000 people) (World Health Organization, 2010). Subsequently, nurses play a key role in the provision of palliative care (Downing et al., 2006; Mwangi-Powell, Downing, Powell, Kiyange, & Ddungu, 2015). Many of the palliative care services throughout Uganda are led by nurses. Successful delivery of palliative care requires well-trained nurses with strong leadership skills, but most nurses in LMICs have limited to no opportunities to develop those skills. Nurses in LMICs can struggle to be recognized as specialist practitioners and may not be well prepared to act as change agents and leaders. Lack of opportunity, insufficient skills and technical support, busy schedules without colleagues to share ideas and strategies for research implementation, poor Internet access, and a lack of financial resources contribute to the problem. In addition, existing opportunities for leadership training are targeted to physicians. An urgent need exists for nurses practicing in LMICs to be trained and mentored in leadership skills, so they are equipped not only to provide palliative care services, but also to lead, develop, and manage care delivery services, as well as to have a national and international role as change agents, teachers, and role models.

**Novel Nurse Leadership Program**

The Uganda Palliative Care Nurse Leadership Fellowship program was developed to address the leadership needs of nurses in Uganda and is funded as part of a grant from the Department for International Development in the United Kingdom through the Tropical Health and Education Trust and in partnership with the Global Health Academy at the University of Edinburgh, Makerere University, and the Palliative Care Association of Uganda. The fellowship grew out of a three-year initiative called Integrate: Strengthening Palliative Care (n.d.), which was established by the University of Edinburgh, the African Palliative Care Association, and the Makerere Palliative Care Unit, to develop palliative care through a health systems–strengthening approach across four African countries. The current nurse fellowship program is led by a nurse professor who has lived and practiced in Uganda for the past 15 years and has extensive palliative care clinical experience. This novel two-year program aims to develop nurse leaders by supporting and mentoring them in the implementation of clinical best practices and participation in local and national palliative care–related projects. The belief is that a confident, skilled, resilient, empowered cohort of nurse leaders will not only grow personally, but also be able to contribute to the national development of palliative care in Uganda.

The fellowship recruited palliative care nurse leaders from different regions of Uganda who are currently working in different care settings and organizations; in a variety of clinical, education, and research roles; and with a variety of patient populations. For example, two fellows work with Hospice Africa Uganda, whose population is about 75% patients with cancer. Each fellow applied following an announcement circulated by the Palliative Care Association of Uganda via email, through social media, and on their website. Each fellow was required to obtain formal support, in writing, from his or her supervisor to participate. The fellowship consists of three one-week intensive training modules held in Kampala, in conjunction with mentorship and supervision provided face-to-face in their places of work and remotely using Skype™, email, and WhatsApp. Travel and accommodation are provided for the fellows for the face-to-face modules in Kampala. Mentorship is led and coordinated by the nurse professor and provided by specialist palliative care nurses based in the United Kingdom, some of whom have worked in Uganda or other LMICs and others who are new to international palliative care. Potential mentors responded to an announcement by email and through e-hospice, submitted a curriculum vitae, and were vetted by the nurse professor. Six mentor hubs have been established and provide mentorship to three or four fellows. The mentor hubs consist of individual palliative care organizations, as well as teams of palliative care nurse experts working together to provide mentorship support.

During the fellowship, nurse fellows are engaged in two types of leadership action plans—one local and one national. In between the trainings in Kampala, nurse fellows spend five to six months in their
local work setting, implementing the leadership skills recently learned. Between the first and second modules, nurse fellows are expected to work on their local projects. Between the second and third modules, the nurse fellows are expected to further develop their leadership skills by working on national-level palliative care projects, which have been identified in conjunction with other key stakeholders and the Ugandan Ministry of Health as priority areas.

The first module focuses on the self as a leader and explores self-awareness, learning styles, and conflict management. Several tools are used, including the Leadership Practices Inventory (Kouzes & Posner, 2012), the Learning Style Inventory (Kolb & Kolb, 2013), and the Conflict Style Inventory (Kraybill, 2013). During the first module, fellows identify leadership action plans to implement in their local work setting. The second module focuses on mentorship, self-care, and leadership styles. Different mentorship models, such as the Seven Stage Model (Oasis School of Human Relations, 2011), are discussed, along with different models of organic leadership. The third module focuses on influencing regional and national organizations, engaging others, coaching, media tips, and communication and negotiation skills.

Progress and Challenges

Twenty nurses began the fellowship in August 2015. Eighteen of the fellows completed previous specialist training in palliative care (diploma or degree), and two fellows have bachelor’s degrees in nursing, in addition to basic palliative care training. Examples of local leadership projects that fellows are currently implementing include daily reporting on patients and organizing palliative care training within their hospitals.

National-level fellow projects focus on examining nurse prescription of opioids using a previously developed protocol (Downing, Leng, Kiwanuka, Bakundana, & Powell, 2010). This is a crucial issue because access to opioids remains a significant problem in many African countries (Cleary et al., 2013). Evidence regarding nurse prescription of opioids in LMICs is sought nationally and internationally because Uganda was the first country in the world to amend opioid legislation to allow palliative care–trained nurses to prescribe oral morphine (Jagwe & Merriman, 2007; Morris, 2013; Mwangi-Powell et al., 2015). Five topical subgroups have been formed to support different aspects of the national leadership projects, including (a) a review of the existing curriculum used to train nurse prescribers to ascertain whether it is fit for practice, (b) an evaluation of clinical competence of existing nurse prescribers, (c) a review of the Ugandan health system as it pertains to the delivery of nurse prescription of oral morphine, (d) an evaluation of a nurse training program being implemented by some of the fellows in their local settings, and (e) the use of mobile health in palliative care (Wanlass, 2015). The process that nurse fellows experience in implementing the projects is as important as the projects themselves in the development of leadership skills.

Conclusion

Although the fellowship is still in its early stages, the program is already helping nurses strengthen leadership skills. A formal evaluation of the program’s impact is planned for after the completion of the fellowship. Each of the nurse fellows have successfully implemented their leadership action plans, with strides being made in terms of individual leadership goals and workplace goals. This fellowship program will hopefully be the catalyst for continued leadership training for palliative care nurses who practice in LMICs, enable nurses to develop their skills and lead the development of palliative care in Uganda, and offer a model and framework for nurse leadership training that can be extended to other cadres and countries.

References


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