



The Palliative Care Journey in Kenya and Uganda

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Abstract

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other physical, psychosocial, and spiritual problems. This update is aimed at examining palliative care development/achievements and challenges in Kenya and Uganda and the role of various actors in palliative care establishment in the region. It assesses the policy environment, progress in education, access to essential medicines, palliative care implementation efforts, and legal and human rights work. East African nations have huge disease burdens, both communicable and noncommunicable. HIV and cancer are the major causes of mortality in Kenya and Uganda and put huge demands on the health care system and on the country's economies. All these conditions will require palliative care services as the disease burden increases. Unfortunately, for many African countries, accessing palliative care services, including access to pain relief, remains very limited resulting in serious suffering for patients and their families. The interventions in Kenya and Uganda help palliative care organizations engage with their respective governments to ensure that the social and legal barriers impeding access to palliative care services are removed. J Pain Symptom Manage 2018;55:S46–S54. © 2017 American Academy of Hospice and Palliative Medicine. Published by Elsevier Inc. All rights reserved.

Key Words

Kenya, Uganda, OSIEA, palliative care

Brief Introduction of The Palliative Care Strategy of the Open Society Foundation for East Africa

Open Society Foundation for East Africa (OSIEA) is part of the Open Society Foundation (OSF), a New York-based organization formed in 1993 with a presence in more than 60 countries around the world. OSF is an operating and grant-making foundation that aims to shape public policy to promote democratic governance, public health human rights, and economic, legal, and social reforms. Since 2005, OSF has been represented in East Africa through its Nairobi office, the OSIEA.

The African continent, especially Africa South of the Sahara, is tackling the enormous burden of HIV and AIDS pandemic and looming epidemics of cancer and other noncommunicable diseases (NCDs). Many patients with these conditions experience moderate to severe pain during the diseases trajectory.

Unfortunately, access to life-saving medicine to alleviate pain is still a dream in most African countries, and many die in severe and unnecessary pain.

The palliative care strategy of OSIEA has been to improve the pain and suffering of patients and families through ensuring access to essential medicines for pain relief, building the workforce to deliver palliative care, and including palliative care services in the public health systems in the countries where it works. OSIEA has partnered with International Palliative Care Initiative (IPCI), a public health program (PHP) of OSF since 2007 to support organizations in Kenya, Uganda, and Tanzania to work with their health ministries on the integration of palliative care into the health care system, ensure availability of pain medicines, and palliative care education and training, among other targeted initiatives. In 2010, an advocacy and human rights component was added through the integration of legal support into the

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comprehensive and holistic package of palliative care services in Uganda and Kenya for both the protection of rights of property and family (succession and custodianship). These efforts have been a way to ensure improvements of individual health, well-being, and increased quality of life.

OSIEA is currently working toward strengthening strategic advocacy for palliative care and to connect palliative care, drug policy, and access to controlled medicines.

Introduction

As the world population ages and the prevalence of cancer and other noncommunicable disease continues to rise in low- and middle-income countries, the global, regional, and national needs for palliative care are increasing. It is estimated that about 40 million people around the world need palliative care services each year. Seventy-eight percent of these people live in low- and middle-income countries, with almost half of them living in Africa.¹

In Africa, health systems remain overburdened with an increasing disease burden, great geographical distances, and late presentation of disease, limited financial resources, and a lack of trained health care professionals, inadequate access to essential medicines, and palliative care services at home and in the hospital.

The African Palliative Care Association (APCA) has been a major partner of both IPCI and OSIEA. It was established as the regional palliative care association after a meeting in Cape Town in 2002 of 28 palliative care trainers from across Africa. The group produced the Cape Town Declaration, which holds palliative care and pain and symptom control as a human right for every adult and child with life-limiting illnesses.² In addition, it advocates that such care should be incorporated into national health care strategies, making it accessible and affordable for all in Africa. The mission of APCA is to ensure palliative care is widely understood, integrated into health systems at all levels, and underpinned by evidence to reduce pain and suffering across Africa. There are three key elements to the work of APCA to bring palliative care to all who need it in Africa: increasing knowledge and awareness of palliative care among all stakeholders, strengthening health systems by integrating palliative care at all levels, and building a sound evidence base for palliative care in Africa.

APCA provides a hub for palliative care in Africa, working collaboratively to build effective links between many stakeholders. These include patients, their families and communities, carers (both family and volunteers), health care providers, African governments, policymakers, and decisionmakers, APCA

members (both individuals and organizations), national palliative care associations, organizations and hospices, civil society groups, academic institutions and educators, the media, donors (both within and beyond Africa), and the general public.

The work of APCA with national governments has produced policy change, helped increased access to essential palliative care medications, enhanced education of health care professionals with work to get it integrated into medical and nursing schools, and informed representatives from numerous divisions of government. APCA has produced several publications and informational materials on legal issues and human rights, all of which are available on their Web site (<https://www.africanpalliativecare.org/>).

APCA created the African Palliative Care Research Network (<https://www.africanpalliativecare.org/articles/african-palliative-care-research-network/>) and has contributed significantly to the palliative care literature. The development of the palliative care outcome scale to measure palliative care impact has served as a model around the world.³ APCA also represents all Africa on the regional and global health agenda through its engagement with the African Union, World Health Organization (WHO), Committee of Narcotic Drugs, International Narcotics Control Board (INCB), Human Rights Watch, United Nations Children Fund, and others.

This article describes the current status of palliative care progress in two East African countries, Kenya and Uganda, where OSIEA has funded efforts and describes what needs to be done to address the existing and emerging challenges. The structure of the article follows an adapted WHO public health model for palliative care that emphasizes:

- health policy,
- access to essential medicines,
- education and training,
- implementation and development of services, and
- legal and human rights advocacy.

Kenya

OSIEA and the IPCI of the OSFs' PHP began supporting palliative care in Kenya in 2007 primarily through grants to the Kenya Hospices and Palliative Care Association (KEHPCA) to individual hospices and emerging leaders and later to the Kenyan Legal and Ethical Issues Network in partnership with the Law & Health Initiative of OSF. In 2008, Dr. Zipporah Ali, Executive Director of KEHPCA, was selected as one of the International Pain Policy Fellows of IPCI to review and recommend the changes needed in the laws and regulations governing opioid availability.

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