

Original Article**Progress Update: Palliative Care Development Between 2017 and 2020 in Five African Countries**

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Abstract

Context. This article provides a progress update on the development of palliative care in five countries in Africa—Kenya, Rwanda, South Africa, Tanzania, and Uganda—between 2017 and 2021, and explores the role of palliative care advocates and the Open Society Foundations in this process.

Objectives. To provide a progress update on the development of palliative care in Kenya, Rwanda, South Africa, Tanzania, and Uganda between 2017 and 2021 and to examine the impact of twenty years of Open Society Foundations support for palliative care in the region on the integration of palliative care into publicly funded health systems.

Methods. In the mid-2000s, palliative care pioneers in these five countries, supported by Open Society Foundations, began to train health care providers and engage policy makers to ensure that people with life-limiting illnesses and their families had access to appropriate services and essential medicines. In the late 2010s, it embraced an approach that mixed strategic communications and advocacy for inclusion of palliative care into universal health coverage with technical assistance.

Results. By the mid-2010s, a vibrant palliative care community existed that worked closely with governments to develop palliative care policies, train providers, and ensure access to morphine. By 2021, Kenya and Rwanda had made significant progress scaling up palliative care services as part of the public health care system, and Uganda's government had instructed public hospitals to start providing these services. In South Africa and Tanzania, governments had yet to commit to publicly funded palliative care services.

Conclusion. The experiences in these countries suggest that mixing advocacy, communications, and technical assistance can lead to substantial progress for patient access although full inclusion in universal health coverage remained uncertain in all but Rwanda. *J Pain Symptom Manage* 2022;000:1–8. © 2022 The Authors. Published by Elsevier Inc. on behalf of American Academy of Hospice and Palliative Medicine. This is an open access article under the CC BY-NC-ND license (<http://creativecommons.org/licenses/by-nc-nd/4.0/>).

Key Words

Palliative care, hospice, Africa, Kenya, Rwanda, South Africa, Tanzania, Uganda, health systems, universal health coverage, controlled medicines, morphine

Key Message

This article describes progress in the development of palliative care in Kenya, Rwanda, South Africa, Tanzania, and Uganda between 2017 and 2021 and

examines the impact of twenty years of Open Society Foundations support for palliative care in the region on the integration of palliative care into publicly funded health systems.

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Background

The first hospice in Africa was established in Harare, Zimbabwe, in 1979.¹ In the 1990s, medical missionaries and charitable organizations often led the development of hospice and palliative care.² But without coordinated efforts to advance and finance palliative care as part of health systems, coverage remained poor. A 2008 study found that two-thirds of African countries had no known hospice and palliative care services and only Kenya, Uganda and South Africa boasted significant availability in parts of each country.³

In the 2000s, several funders began supporting palliative care development on the continent. The Diana, Princess of Wales Memorial Fund started funding efforts to integrate palliative care into policies, medical and nursing curricula, and develop children's palliative care services in nine countries.⁴ In 2002, Open Society Foundations' International Palliative Care Initiative (IPCI) made its first foray into Africa with a three-year one million dollar investment in South Africa to advocate for palliative care's full integration into national HIV/AIDS prevention, care, and treatment programs.⁵ The Global Fund to Fight AIDS, TB and Malaria and the US Presidents' Emergency Plan for AIDS Relief both supported palliative care for people living with HIV.⁶

By 2005, Open Society Foundations (OSF) had begun funding palliative care more broadly in Africa, through grants to the African Palliative Care Association and support for national palliative care groups, and collaborations with the Elton John Foundation, the Diana Fund, and Pfizer.⁵ Long-term funding relationships were developed with national palliative care associations in Kenya, Uganda, and South Africa; while civil society organizations and ministries of health in countries including Botswana, Nigeria, Tanzania, and Zimbabwe received short-term support.⁵ IPCI developed funding partnerships with the Open Society Institute for Eastern Africa (OSIEA, 2007) and Open Society Institute for Southern Africa (OSISA, 2006)—both foundations within Open Society network that have their own budgets, boards and staff and operate independently—the staff of which became important champions of palliative care and counterparts of grantees in the region.

Initially, OSF focused on development of professional capacity, networking, leadership development, and technical assistance. Several African palliative care leaders were selected for International Pain and Policy Fellowships⁷ and the Leadership Development Initiative.⁸ The African Palliative Care Association received support for conferences to bring together palliative care advocates and practitioners from across the continent, including for workshops on assessing and addressing gaps in access to pain treatment. In 2010, OSF added support for legal services, such as protection of property and inheritance rights, to grants in South Africa, Uganda and Kenya, and cultivated

dialogue and partnership between palliative care providers and human rights advocates.⁹

In 2014, following the retirement of its directors, the Public Health Program restructured IPCI from a stand-alone initiative to a cross-cutting thematic priority. Funding for palliative care reduced from about US \$3 million to US\$1 million per year, and a new vision formulated that shifted the emphasis of the palliative care work from an “insider” to an “outsider” approach. Funding priorities were shifted from clinical training activities, leadership development, and technical assistance to governments—all hallmarks of the earlier period—to supporting civil society organizations, including organizations of people with lived experience, to publicly advocate and campaign for palliative care, advocate for access to pain treatment as part of a larger effort to mitigate the health effects of punitive drug control, and hold governments accountable when they failed to ensure its availability.¹⁰

Country Progress Updates

Since 2000, palliative care has developed significantly continent-wide. By 2016, eight African countries had developed or were in the process of developing national palliative care policy frameworks others.¹¹ By 2017, 50% of Africa's health departments had a focal person for palliative care.¹² By 2020, hospice and palliative care departments had been established in many hospitals and training institutions in Africa, with a total of 1085 palliative care services, despite economic challenges and the COVID-19 pandemic.⁶

Kenya

By the mid-2010s, Kenya had adopted national palliative care guidelines and integrated palliative care into disease-specific programs and guidance and included palliative care in its cancer control program. The ministry of health was developing a national palliative care policy; had begun procuring morphine powder and building capacity at Kenyatta National Hospital to produce oral morphine solutions for adults and children.⁹ Undergraduate and postgraduate medical and nursing schools had integrated palliative care into their curricula and various other training programs for health workers. About 70 institutions, including more than 30 government hospitals, provided palliative care, including some for children. More than 300 paralegals had been trained to provide legal services to palliative care patients and their families.^{9,13}

In the late 2010s, the Kenya Hospice and Palliative Care Association (KEHPCA) pursued a strategy that combined strategic advocacy and communication with provision of technical assistance to expand access to palliative care and seek palliative care's inclusion in Kenya's universal health coverage program. Its

communications strategy sought to keep palliative care in the media to educate the public. It invested in proactive relationship development with health ministry officials. In the spirit of “nothing about us without us,” KEHPCA made a concerted effort to give a key role to people with lived experience of palliative care in strategy and policy discussions, an innovation for a field that health professionals have dominated.¹⁴

Advocacy resulted in the health ministry issuing circulars instructing 11 provincial hospitals and subsequently 33 district hospitals to work with KEHPCA to set up palliative care units.^{15,16} As the government did not make any financial resources available to support KEHPCA’s work, the organization leveraged donor funding, including from True Colours Trust and the Diana Fund, to allow it to train health workers at these hospitals, organize palliative care teams, provide supervision and mentorship, and work with pharmacists to ensure availability of oral morphine. This collaboration resulted in a significant growth in hospital-based palliative care units, with eventually 60 hospitals integrating palliative care into their services.¹⁷

Kenya also launched its first standalone palliative care policy in 2021.¹⁸ Since 2019, the Kenya Medical Supplies Agency purchases and distributes oral morphine.¹⁹ People with lived experience engaged in advocacy with local governments, resulting in a significant financial commitment for cancer support groups.²⁰⁻²²

Simultaneously, KEHPCA sought to build a coalition of groups to advocate for palliative care as part of universal health coverage. In November 2018, it brought together partners to strengthen advocacy skills and develop a common vision for advocacy and communications for integration of palliative care into Kenya’s universal health coverage program.

KEHPCA and partners successfully advocated for palliative care to be included in a four-county universal health coverage pilot.²³ KEHPCA trained health workers, including volunteer community health workers, and, once service delivery started, mentored providers, and monitored the quality of services. From January to December 2019, patients with palliative care needs in Nyeri, Kisumu, Machakos and Isiolo counties received palliative care, as well as other health services, for free or at highly subsidized rates. The government has not yet indicated whether it will continue the pilots and/or expand them to more counties.

Rwanda

In 2011, Rwanda’s health ministry set the goal of universal access to palliative care by 2020. By the mid-2010s, with support of the Rwanda Palliative Care and Hospice Organization (RPCHO), it had made considerable progress: palliative care policies and a strategic plan had been developed; adequate supplies of opioid analgesics secured and distribution systems set up; and palliative

care training programs had been put in place for healthcare workers. A model for integrating coordinated palliative care into the public health care system at all levels was developed and piloted, and the government had begun training a new cadre of home-based care practitioners to provide palliative care in the home.²⁴

RPCHO supported the government in realizing universal palliative care access. It advocated for additional financing for palliative care services and further institutionalization of training of health providers; engaged in public awareness activities through media outreach, training 40 journalists on palliative care and opioid analgesics; and trained 30 lawyers to provide legal services to people with palliative care needs.

With OSIEA funding, it implemented a project to improve access to palliative care and pain medicines in parts of the country that had fallen behind. The health ministry and RPCHO identified six district hospitals, conducted baseline assessments, helped create and train multi-disciplinary palliative care teams, and subsequently monitored progress.¹ By 2019, these hospitals had made substantial progress, appointing palliative care focal points, increasing patients receiving palliative care, and improving their use of opioid analgesics.^{25,26}

The government amended its drug regulations to improve access to opioid analgesics.²⁶ A list of palliative care medicines is accessible at district pharmacies at no or reduced cost to people with community-based health insurance. The University of Rwanda integrated palliative care into medical and nursing curricula although training of faculty to teach palliative care modules remains a challenge.

Integration into hospital services has advanced but integration of home-based palliative care into the health insurance has lagged as most community-based services are the initiative of palliative care leaders, rather than the result of a uniform effort, and these services are offered only for patients who cannot otherwise reach hospital services. The Rwanda Biomedical Center has developed a model for and hired 232 home-based practitioners; RPCHO helped develop training modules and trainings.²⁶ As of June 2021, these practitioners were providing palliative care in 11 pilot districts, reaching about 6,000 people in 2019/20.^{26,27} These services were not yet covered by Community-Based Health Insurance.

South Africa

In the mid-2010s, South Africa had the most developed network of palliative care providers on the

¹ The hospitals were the district hospitals of Ruhengeri and Byumba in Northern Province, Kibuye in Western Province, Gahini in Eastern Province, Ruhango in Southern Province, and Muhima in Kigali City.

continent, with 150 hospices, mostly in communities, and eight hospital-based palliative care services.²⁸ Services were supported through philanthropy and global health funding as the government's role in palliative care provision was limited. The Hospice and Palliative Care Association of South Africa (HPCA), which was created to represent hospices, had taken the lead in developing palliative care standards, training curricula, and models of care, sometimes in collaboration with government agencies. Following the adoption of the 2014 World Health Assembly resolution on palliative care²⁹ of which South Africa was a co-sponsor, the health minister appointed a national steering committee for palliative care to develop a framework strategic plan that examined public financing of palliative care services and their integration into the public health-care system.²⁹

Since the mid-2010s, HPCA has combined its mandate to support hospices with the role of advocate for greater integration of palliative care into the health-care system. It played an active role in the national steering committee and is advocating for full implementation of government commitments. Simultaneously, it has continued to strengthen palliative care education for health care providers collaborating with universities and provincial health departments; to improve quality of care by refining accreditation standards; and to develop standards for home-based care providers.

Since the mid-2010s, South Africa has launched several initiatives aimed at strengthening the long-term sustainability of palliative care, including:

- In 2017, the National Health Council approved the National Policy Framework and Strategy for Palliative care (NPFSPC) that aims to strengthen palliative care across all levels of the healthcare system and allocate appropriate resources³⁰
- In 2019, a National Health Insurance bill was introduced in parliament that includes a comprehensive package of palliative care services for primary care settings³¹
- In 2020, palliative care was incorporated in the National Referral Policy for South African Health Services, seeking to ensure timely referral of patients to appropriate services³²

Implementation of these commitments, however, has been slow as the health insurance bill remains under review in parliament and the national government has not allocated funds from existing budgets to palliative care. As of this writing, even the health ministry's national palliative care coordinator position was funded from philanthropic contributions.

A 2017 study by South Africa's Medical Research Council found that the public health sector could save significant resources by providing home-based

palliative care rather than inpatient care at the end of life.³³ Since, occupational qualifications and training programs for home-based care assistants and home-based carers have been developed and registered.³⁴ The government, however, was still debating the role of home-based care.

Tanzania

In 2017, OSIEA began supporting the Evangelical Lutheran Church of Tanzania (ELCT) to advance palliative care. ELCT provides palliative care to patients in 23 of its hospitals and five health centers. It also conducts capacity strengthening activities for healthcare and community-based providers to ensure patients can be cared for in their communities.

In 2017, Tanzania counted 16 hospices or hospital-based palliative care services and 26 home-based palliative care services; oral morphine was available; trained nurses were authorized to prescribe morphine; and some medical and nursing schools had mandatory palliative care courses in their curricula.¹² In 2016, the government adopted a national palliative care policy, which provides a framework for scaling up and ensuring quality and affordability of services in the country.³⁵

Since 2017, ELCT has expanded its own provision of palliative care services, aiming to offer them in more lower health facilities and to improve referral systems.³⁵ Simultaneously, it has advocated with the government for scaleup of palliative care services in government facilities, improved access of opioid analgesics, and local resource mobilization for palliative care, using the 2016 policy as an advocacy tool.

One of its main goals was improving access to morphine. At the time, only one institution, Ocean Road Cancer Institute in Dar Es Salaam, reconstituted morphine which led to significant bottlenecks for users due to travel distances and transportation costs. Following a March 2019 meeting with pharmacists and relevant government agencies, regional task forces were established that selected health facilities to develop capacity to reconstitute morphine regionally. During a March 2019 high level advocacy meeting with regional pharmacists in Arusha, ELCT facilitated training of pharmacists, technology transfer, and accreditation for these health facilities. Production of morphine started later that year and by 2020 the number of hospitals with oral morphine had increased from 65 to 114. The government allocated budget for the procurement and distribution of morphine and Tanzania's Medical Devices Agency began training pharmacists on securing, stocking, and dispensing opioid analgesics.³⁶

The Tanzanian government has taken some steps toward inclusion of palliative care into universal health coverage. The National Health Insurance Fund has included palliative care in its package but only for clients with silver and gold insurance policies with high

premiums. ELCT and partners are advocating for inclusion of palliative care into more basic insurance packages.³⁷

The strategic engagement of government officials in Tanzania has resulted in significant progress in a short time. To sustain advances in morphine and palliative care availability, adequate palliative care training for healthcare providers, sufficient oversight over regional reconstitution of morphine, further capacity strengthening in hospitals, and guidance on and support for home-based care are critical, as is inclusion of palliative care in basic health insurance packages.

Uganda

In the mid-2010s, Uganda was among Africa's leaders in availability of palliative care as a result of pioneering palliative care organizations such as Hospice Africa Uganda (HAU),^{6,38} although services were estimated to reach only 10 percent of those in need.⁹ Uganda had made significant progress building a foundation for palliative care, as its Health Sector Development Plan 2015 – 2020 included palliative care; national pain control guidelines and guidelines on the use of narcotic drugs had been developed; nurses and clinical officers were authorized to prescribe morphine; oral morphine was locally reconstituted and distributed; numerous training programs for health providers were established; and paralegals had been trained to provide legal services.⁹

While OSF has supported a variety of palliative care organizations in Uganda, including HAU, the Palliative Care Association of Uganda (PCAU) has been its closest partner. In the mid-2010s, PCAU's sought to combine capacity building, advocacy, research, and resources mobilization. It offered scholarships to health workers to train in palliative care and start up services in their places of deployment; its mentorship program provided support to hundreds of health facilities to provide palliative care and pain management;⁽³⁹⁾ and, together with HAU, it played a critical role in supporting the access to essential medicines for palliative care including the reconstitution, distribution and monitoring of morphine distribution.³⁹ Its advocacy work has focused on promoting palliative care as a human right and pressuring Uganda's government to integrate it into the health system and make resources available.

Uganda has continued to make progress creating a conducive legal and policy environment. Steps were taken to ensure that the 2016 Narcotic Drugs and Psychotropic Substances (Control) Act, which did not initially allow nurses and clinical officers to prescribe morphine, would not interfere with palliative care delivery.^{40,41} The first training course on palliative care for public institutions was developed, as were postgraduate and MSc programs in palliative care.⁴² Palliative care indicators were integrated into the national health information system, strengthening monitoring and

evaluation efforts.⁴³ Local manufacturing of oral liquid morphine was strengthened, and Uganda's essential medicines list amended to include more palliative care medicines.⁴⁴

While Uganda's progress on universal health coverage has been hampered by resource limitations and COVID-19's impact, important steps were taken to integrate palliative care into the public healthcare system.⁴⁵ In March 2021, the health ministry directed all public hospitals to establish palliative care units, stating that UHC "cannot be attained unless palliative care is embraced" and decrying that many hospitals have not allocated space for palliative care despite "the vast number of patients in need of the service."⁴⁶

This directive is particularly timely as the financial position of standalone hospices and the national association for palliative care are precarious due to the COVID-19 pandemic. Indeed, in late 2020 PCAU found that hospices had reduced their operations by more than 50%.⁴⁷ While it is not yet clear how the March 2021 instruction will be implemented, increased government investment in palliative care in public health facilities is essential.

Reflections on Progress and Strategy

Policy and practice change is inherently unpredictable; often attribution of impact difficult and rarely conclusive. The processes by which laws, regulations, policies, and practices change are diverse; policy environments complex; the factors that can influence policies and practices numerous. In this article, a retrospective case study analysis is used to examine impact. The authors acknowledge the methodological limitations of this approach and the fact that, while they seek to be objective, they are not neutral. Likewise, they acknowledge that the effectiveness of specific strategies or interventions may not be generalizable. That said, based on a review of 20 years of work to develop palliative care in these five countries we offer some reflections about the effectiveness and impact of our strategic engagement.

In the mid-2000s, Open Society Foundations supported a wide range of partners across the continent with a wide range of goals: Developing palliative care leaders, creating training programs, advocating for reform of restrictive drug policies, and integrating palliative care into HIV care. After 2015, it focused its approach more narrowly on strategic advocacy and communications, holding governments accountable for ensuring palliative care and pain treatment availability.

The work of palliative care organizations between 2017 and 2021 reflects this shift as a focus on advocacy and communications became more prominent. For example, KEHPCA advocated for palliative care integration into public hospitals services and universal health coverage pilots in Kenya; HPCA advocated for

the implementation of the national policy framework; and ELCT engaged the media to raise public awareness and support for palliative care and access to morphine. These advocacy and communications activities contributed to important advances such as Kenya's health ministry's instruction to integrate palliative care at provincial hospitals; Uganda's health minister's analogous instruction in 2021; and Tanzania's medicines agency's agreement to facilitate regional reconstitution of morphine.

These advocacy and communications victories represent important progress and provide a framework for holding governments accountable for their commitments. But much work remains to be done. For example, the circulars instructing hospitals in Kenya and Uganda to offer palliative care came with little or no budget (Uganda's instruction came after budgets for the year had been passed); South Africa's National Policy Framework and Strategy for Palliative Care has not yet been implemented. Even in Rwanda, which has made the most resources available, implementation has been uneven.

To fill this implementation deficit, palliative care associations have continued to provide technical assistance to governments, which has contributed to significant breakthroughs. In Kenya, KEHPCA's ability to train providers and help organize palliative care teams allowed for a major expansion of services; in Rwanda, RHPCO's technical assistance helped improve equitable access to palliative care services; in Tanzania, ELCT's engagement with hospitals, pharmacists and government medicines agency resulted in local production of morphine; and in Uganda, palliative care indicators have been integrated into national health information management systems.

These experiences suggest a complex and synergistic relationship between advocacy, communications, and technical assistance as the latter can help turn rhetorical governments commitments that result from advocacy into actual services for patients and their families. When the right balance is struck the combination of advocacy and technical assistance can result in greater government commitment. In Tanzania, for example, the government made funds available to purchase morphine after ELCT's helped create capacity to reconstitute it throughout the country. In Kenya, the government increased financing of palliative care after KEHPCA trained providers in provincial hospitals. In Uganda, a commissioner for palliative care will be appointed in 2021 or 2022 who will be responsible for overseeing the implementation of palliative care in public health institutions.

Conclusion

Improving the sustainability of palliative care services in Africa was a major goal of OSF and its partners.

Using strategic advocacy, communications, and technical assistance as tools they sought to advance integration of palliative care into health systems and universal health coverage. While all countries have seen real advances, the universal health coverage process—and palliative care's integration into it—has moved slowly because of complex questions over resources, insurance models, who and what should be covered, and to what extent, and the COVID-19 pandemic. With limited finances, continued advocacy and communications work will be essential to ensuring that when decisions are made on who and what will be covered, palliative care is included. To build on progress to date and ensure that palliative care becomes available to all people who need it in Africa, national governments need to step up and finance palliative care services from national budgets while donors should move from funding specific disease responses to supporting the integration of palliative care.

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