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Research into palliative care in sub-Saharan Africa

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Roughly half a million people die of cancer in sub-Saharan Africa every year. Despite rapid expansion of palliative care for cancer, coverage remains woefully inadequate. The WHO public health strategy for palliative care aims to increase access to palliative care services through its integration into health-care systems. We present the available evidence for the four WHO strategy pillars of policy, education, drug availability, and implementation, and propose a fifth pillar of research activity to stimulate improvement of care. Increased attention to the generation of research evidence is essential to achieve quality and coverage of appropriate palliative care for patients with advanced cancer in sub-Saharan Africa. The use of locally validated, patient-reported outcome measures is an important advance in the measurement and improvement of care and patient wellbeing. Palliative care for patients with cancer in Africa currently receives far less research attention than does palliative care for patients with HIV/AIDS, but in view of projected increasing cancer incidence in the region, generation of local evidence to inform and allow assessment of palliative care for patients with cancer is urgently needed.

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Introduction

An estimated 421 000 people died of cancer in sub-Saharan Africa in 2008.[1] However, poor access to health services and few cancer registries on the continent make this a probable underestimate. Because availability of health services is low and access is poor, about 80% of cancers on the continent are incurable at the time of detection and diagnosis.[2–4] HIV-associated malignant disease is common, and the lifetime risk of a woman in Africa dying of cancer is double that of women in developed countries.[3] In a population-based analysis of cancer survival, outcomes in African countries were poorer than in comparators in Asia and Central America—survival in The Gambia did not exceed 22% for cancer of any site and survival in Uganda did not exceed 13% for cancer of any site apart from breast.[5] A review of childhood cancer treatment in developing countries concluded that the high cure rates seen in developed countries are unlikely to be achieved in Africa because of the scarcity of resources and locally adapted treatment protocols, late presentation, and poor treatment compliance.[6]

WHO guidance states that palliative care is the only realistic public health response for people in Africa with HIV-associated cancers that are responsive to treatment but not curable.[7] Evidence from South Africa and Uganda[8] showed a high prevalence and burden of symptoms in advanced cancer, with a mean of 18 symptoms per patient reported. The five most prevalent symptoms were pain (87·5%), lack of energy (77·7%), sadness (75·9%), drowsiness (72·3%), and worry (69·6%). The five symptoms ranked as most severe were pain (23·2%), sexual problems (21·4%), weight loss (18·8%), "I don't look like myself" (18·8%), and lack of energy (17·9%). The reported prevalence of symptoms in these countries, where a fifth of patients had an underlying HIV diagnosis, was far higher than those reported in other regions of the world.

Investigators of a five-country WHO study in Africa reported multidimensional physical, psychological, social, and spiritual problems in dying patients,[9] which shows the necessity of palliative care.[10] Qualitative investigation has shown that physical pain and financial worries dominate the lives of patients with cancer in Kenya.[11] Analgesia, essential equipment, suitable food, and care are often inaccessible and unaffordable. In an investigation into the quality of life of African patients that received palliative care,[12] patients prioritised their spiritual wellbeing over physical dimensions of quality of life.[13]

Much has been achieved in palliative care in Africa during the past few years.[14] Innovative forms of palliative care, such as roadside care delivered by Hospice Africa Uganda (figure 1),[15] are practised in the continent, together with consultancy to other care settings such as hospital wards,[16] and (more rarely) hospital-based palliative care.[17]


Hospice Africa Uganda

Figure 1: **Hospice Africa Uganda roadside clinic**

However, evidence of the effectiveness of palliative care for patients with cancer has been almost exclusively generated in high-income settings; few publications have covered the innovations and expertise of African palliative care services.[18–22] Investigators of a systematic appraisal of the status of palliative care in sub-Saharan Africa[18] noted that almost no evidence exists for the problems and outcomes of patients, and a comparison of worldwide data on the prevalence of symptoms in advanced progressive diseases[23] identified no data for patients with cancer in Africa.

African cancer palliative care is characterised by innovation in the face of low resources, inadequate investment, and a focus on community rather than inpatient care. Since the first hospice in Africa opened in Zimbabwe in 1979,[24] Uganda, South Africa, Kenya, Zimbabwe, and Tanzania have become so-called beacon countries in the advancement of palliative care in the continent.[25] Although other African countries have developed palliative care services, they have rarely been reported in the scientific literature.

For more on the **African Palliative Care Association** see http://www.africanpalliativecare.org

The African Palliative Care Association (APCA) is a pan-African advocacy body for palliative care across the continent. National associations, such as the Hospice Palliative Care Association of South Africa, the Kenyan Hospice Palliative Care Association, and the Palliative Care Association of Uganda, contribute to clinical mentorship, education, and advocacy towards their respective governments and care providers. Other roles include accreditation and mentorship of palliative care providers, research (in the absence of an adequate number of African academic groups that do such work), and representation of palliative care clinicians (since palliative care is not currently a recognised specialty or subspecialty in any African country). The advocacy role is essential to influence policy makers, educators, funders, and clinicians; although almost no evidence exists that has assessed advocacy strategies for palliative care.[18] Available evidence suggests that sustained effort is needed to maintain improvements in clinical practice, and that palliative care, along with other components of global health development, is under threat because of issues of economic sustainability.[26,27]

Here, we review African cancer palliative care evidence using the framework provided by the WHO public health palliative care strategy, which has been endorsed by relevant organisations in Africa[28] as the most appropriate mechanism for the expansion of palliative care provision in the face of overwhelming need. This strategy[29] is based on four pillars: government policy and national strategy to improve access, education for health workers and the public, drug availability, and implementation throughout health-care systems. We propose and describe a fifth pillar of research activity to inform the four existing pillars with local, high-quality evidence for improvement of patient outcomes, that we believe is necessary to underpin the WHO model. Research into the needs, care, and outcomes of patients with advanced cancer in sub-Saharan Africa is an urgently needed precondition for the provision of equitable, effective, and cost-effective care. The approach of evidence-based health care guides policy, practice, and funding in high-income countries. Where the need for care is greatest and resources most scarce, evidence is even more urgently needed. Additionally, because palliative cancer care was first developed in western countries,[30] evidence is also needed to ensure that appropriate and acceptable care is developed for African settings.

Pillar 1: policy to improve access

Researchers have identifed existing international policies and agreements that regard access to pain relief and palliative care as universal human rights.[31] Palliative care neccesitates detailed assessment of the whole patient and multiprofessional intervention to meet his or her total care needs. Clearly, in a low-income or middle-income setting, health policy must take into consideration the scarcity of resources and the needs of dying cancer patients and their families, which can include problems such as hunger.[8] Patients rely heavily on community and religious resources for support, which compounds the existing poverty of the surrounding communities.[32]

Policy makers also need evidence for the needs of patients and the effectiveness of care; palliative care audits to improve resource allocation are of even greater importance in low-income and middle-income countries than in high-income countries.[33] In a cost analysis study from South Africa, the daily cost of a public hospital palliative care outreach visit was 50% less than the cost of a district hospital inpatient bed;[34] further health economic assessment is urgently needed to guide policy on how best to improve acess to palliative care. The APCA African palliative outcome scale has enabled the measurement of patient outcomes and the effectiveness of care.[35]

Pillar 2: education

People in sub-Saharan Africa with advanced diseases need improved communication and additional information about their diagnoses, outlooks, and the implications of their diseases.[36] Sensitive provision of information about a patient's disease and its implications, and the enablement of patients and families to plan for the future, are core activities of palliative care clinicians. Where palliative care is a novel idea, training for communities is also provided (figure 2). A nursing curriculum on end-of-life care has been successfully delivered in Tanzania, where participants reported that they had received no previous training in palliative or end-of-life care.[37] Assessment of the postgraduate course in palliative medicine at the University of Cape Town, South Africa, showed that it enhanced clinical palliative care skills.[38] Although clinical studies have provided data for the needs and preferences of patients with advanced cancer in Africa,[8,9,11–13] which can be readily applied to clinical curricula, no studies that assess the outcomes of education and training have been done.

Pillar 3: drug availability

Substantial challenges face drug availability for palliative care in sub-Saharan Africa; data for opioid consumption suggest that at least 88% of cancer deaths with moderate to severe pain are untreated.[39] Although the WHO essential medicines list[40] includes the drugs necessary for delivery of palliative care in line with the organisation's pain ladder,[41] drug availability research[42] has shown that even step 1 analgesics (eg, paracetamol) are sometimes unavailable and that supply is unreliable. Uganda has made substantial advances in the past 15 years, such as the empowerment of suitably trained nurses to prescribe opioids for cancer pain, and the explicit inclusion of palliative care in the national health plan.[15,43] According to an assessment of the expansion of opioid availability in health districts in Uganda,[44] concerns that illegal leakage of opioids from palliative care facilities would occur was unfounded, but under-prescription persists even though legislative changes have been implemented and clinicians are educated in opioid use.

In South Africa, because of the focus on primary care, morphine and codeine have been declared essential drugs in primary care settings; a national standard for pain control is also in place, although access is inequitable because of large rural populations and a divided private and public health system.[45] However, a South African model of palliative care has been described[46] that covers patients with HIV/AIDS and patients with cancer, whether public or private, which thereby reduces inequity of access. This novel public–private partnership model of palliative-care provision runs from a ward within a district hospital, is entirely funded by the hospital, and works in partnership with the hospice that provides training and input to patient management. The service has been successfully sustained since its creation in 2006.

For refractory pain and other symptoms, South African hospice clinical practice is in line with international guidance on the practice of sedation for dying patients.[47] Racial disparities in cancer pain intensity persist.[48] In west Africa, evidence of poor opioid availability for cancer pain, together with little focus on assessment of the psychological dimensions of pain, emphasises the need for both drug availability and educational interventions.[49]

Pillar 4: implementation

The fourth pillar, implementation, is exemplified by evidence that shows policy, education, and drug availability are not adequate for sustained change in clinical practice. Continuing mentorship and advocacy are needed to ensure that clinicians are encouraged and supported in the implementation of palliative care.[50] Nationally, a balance of quality and coverage is needed to move palliative care from specialist centres to provision throughout the health system.[18,25] A previous review of palliative care in Africa[18] reported no evidence of effectiveness for the innovative models of cancer palliative care being implemented, although the development and validation of an African patient-reported outcome measure[35,51] has enabled patient outcomes to be measured and improved by use of audit methods designed to optimise allocation of scarce resources and to identify and replicate successful clinical approaches.[33,52]


Hospice Africa Uganda

Figure 2: Training community members to identify and refer patients to Hospice Africa Uganda

Local volunteers can improve community awareness of and access to palliative care services, as has been reported in Uganda.[53] Existing evidence has not adequately addressed the sociocultural aspects of dying from progressive illness in Africa,[54] and such studies will be essential for the development and implementation of appropriate models of care. African national cancer control, treatment, and care programmes must take into account the cultural diversity of populations within countries.[55]

The four pillars of policy, education, drug availability, and implementation cannot achieve integration of palliative care into the public health system without the generation of high-quality, locally relevant evidence for how to achieve each pillar. Without sufficient investment in research activity, how the objectives of each of these pillars can be achieved is unclear, and activities are likely to be less than optimum if decisions are made in the absence of evidence. A fifth pillar of research activity will ensure that practice is evidence-based and replicable, that public health responses reflect the needs and priorities of the populations they serve, and that feasible, acceptable, and effective care is provided.

APCA African palliative outcome scale

A survey to identify the priorities of end-of-life care providers in sub-Saharan Africa suggested a need for local outcome measures and audit methods,[56] which lent support to the belief that the scarcity of outcome data was mainly caused by the absence of appropriate, locally validated outcome instruments.[18] The benefits of

South Coast Hospice Association

Figure 3: **Team members from the South Coast Hospice integrated community-based programme, KwaZulu-Natal, South Africa, visit a cancer patient at home**

patient-reported outcome measures are that they promote quality and equity, and ensure that improvements to care are based on what matters to patients.[57] Subsequent consultation with clinicians led to the identification of the necessary properties of an outcome measure,[58] and a group of experts from across the region developed and completed a pilot study of the APCA African palliative outcome scale in 11 palliative care settings across eight countries.[59] The scale was then fully validated in a further five settings in two of those countries.[51]

For more on **palliative outcome score measures** see http://pos-pal.org/

The scale is based on the set of palliative outcome score measures that have been validated in various settings around the world and are designed to be self-reported and brief, which enables patients and families to score their problems in line with the WHO definition of palliative care. The APCA African palliative outcome scale measures the effect of multidimensional problems on the patient and family during the previous 3 days. A stable three-factor structure has been identified[60] for patient issues: physical and psychological problems (pain, other symptoms, and worry); interpersonal (help and advice for families to plan for the future and the patient's ability to share how they feel); and existential and spiritual (feel that life is worthwhile and feel at peace). This scale is enabling clinicians and researchers to measure care and to build the needed evidence base.

Almost no evidence is available for cancer palliative care for children in Africa, though cancer control programmes for children have to include palliative care provision.[61] Because evidence for paediatric palliative care in sub-Saharan Africa is scarce, we are currently developing and validating a paediatric palliative outcome scale for the region.[62]

Conclusions

We have identified the existing evidence for the WHO public health strategy for palliative care, and have built up the strategy pillars with the development, validation, and use of an African palliative care patient-reported outcome measure. We strongly urge investment in our proposed fifth pillar, generation of evidence, to support the public health strategy for palliative care. To influence policy makers, epidemiological data are needed on the scale and nature of problems faced by patients and their families. Effectiveness data, in terms of patient outcomes and associated costs, are also necessary if national policy is to promote palliative care. Routine data sources, such as cancer registries and place-of-death records, need to be strengthened so that cancer palliative care can be better planned, delivered, and assessed than it is at present.[63,64]

To design and deliver appropriate education, curricula need to convey evidence of patients' problems and effective clinical management protocols in conjunction with in-service training. Educational activities should be assessed to identify effective teaching practices. To ensure the availability of essential drugs, evidence is needed on the prevalence of pain and other symptoms, drug effectiveness, and safety with respect to procurement, storage, and prescription practices. To propose appropriate methods of implementation of palliative care, health services research is needed to identify feasible, acceptable, and effective models of palliative care for the diverse regions of Africa. Research has advanced with the development of African palliative care research methods,[65] and clinical skills and coverage have expanded as a result of the advocacy work of regional and national palliative care associations.

However, people dying of cancer in Africa are still unlikely to receive palliative care because of grossly inadequate coverage. Most African palliative care research has focused on patients with HIV/AIDS rather than patients with cancer.[53] Although the disease course can differ between patients with HIV/AIDS and patients with cancer, opportunities for cancer palliative care to learn from developments in HIV palliative care delivery, such as models of integrated home care (figure 3),[66] development of care standards, and mentorship of emerging services,[67] should not be overlooked. The WHO palliative care public health strategy should be supported by the evidence necessary to promote change, and to achieve the simple and effective management of suffering of patients and their families in sub-Saharan Africa affected by advanced cancer.

Search strategy and selection criteria

We searched PubMed using the term "cancer" in combination with "palliative", "terminal", "end of life", or "hospice", for all countries in Africa. The search covered articles published in English between Jan 1, 1980 and July 1, 2012. Results were supplemented by reference lists and the authors' own publications and files.

Contributors

RH conceived of the report and prepared the first draft; all authors commented on the draft and approved the final version of the report.

Conflicts of interest

We declare that we have no conflicts of interest.

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