Advancing palliative care research in sub-Saharan Africa: from Venice to Nairobi

In sub-Saharan Africa, palliative care funding all goes into treatment. **Richard A Powell, Julia Downing, Faith Mwangi-Powell, Lukas Radbruch** and **Richard Harding** argue that for progress to be made in care provision, this must be complemented by research

Lamenting the ponderous development of palliative care research in Europe over the preceding 25 years, in his plenary address to the European Association for Palliative Care's (EAPC) 4th Research Forum, held in Venice in May 2006, Professor Stein Kaasa identified multiple prerequisites to successful future palliative care research: a critical mass in research groups, dedicated funding, a national strategy for palliative care research and close operational links between academics and clinicians.[1]

In sub-Saharan Africa, despite the need for methodologically robust research to inform the delivery of effective and appropriate palliative care,[2–4] none of these prerequisites exist. It is against this backdrop that this paper presents the palliative care disease burden across the region, before outlining the status quo of African palliative care research, identifying the challenges to that research and highlighting a potential way forward.

Key points

- Just as African palliative care is an emergent discipline, so African palliative care research remains in its embryonic stages.
- There are many obstacles to improving palliative care research in sub-Saharan Africa.
- One of the priorities is to establish a vision and agenda for research development.
- 'Care or research' is a false dichotomy. Ideally, the two should inform each other to their mutual benefit.
- In the absence of a sufficient critical research mass in Africa, there is a need to develop collaborative partnerships.

The disease burden

The palliative care disease burden is significant. By December 2007, an estimated 22.5 million people in sub-Saharan Africa were living with HIV/AIDS, 68% of the global disease burden, with 1.7 million new infections reported in that year alone from this resource-constrained region.[5] Given the decreased mortality rates resulting from increased access to antiretroviral (ARV) therapies, and the continuing high incidence of the disease in the absence of more effective behavioural change programmes, the prevalence of HIV/AIDS across the continent could remain high – or indeed rise.[6]

Moreover, cancer rates in Africa are expected to grow by 400% over the next 50 years.[7] The WHO estimates that there are more than 500,000 annual deaths from cancer in Africa[8] and that, by 2020, 70% of new cancer cases will be in the developing world.[9] The African continent is, however, characterised by resource and infrastructure deficiencies that render governments least able to address the cancer disease burden; survival rates are consequently significantly lower than in developed countries and patients' expectations of disease-modifying oncological treatment are low.[10,11] Indeed, the imperative to address the challenge posed by cancer in Africa recently resulted in the 'London Declaration on Cancer Control in Africa', calling on research institutions, international organisations, the pharmaceutical industry, national governments and the civil society, in developed and developing countries, to unite to deliver comprehensive cancer care to the continent.[10]

Furthermore, there is a growing concern that, as people's lifestyle, nutritional preferences and work patterns change, Africa may experience an

Table 1. Results of a literature search on palliative care

Primary search term	Supplementary search term	Number of references
MeSH: 'Palliative care'	+ Africa	141
	+ Uganda	19
	+ Kenya	8
	+ South Africa	41
MeSH: 'Palliative care'	+ Europe	2,571
	+ Germany	351
	+ UK	1,033
MeSH: 'Palliative care'	+ America	2,504

Key: MeSH = medical subject heading

increase in the incidence of those chronically debilitating, life-limiting diseases characteristic of resource-abundant nations, such as stroke, diabetes, hypertension and heart disease.[12,13] In a region that is already struggling to combat communicable diseases, such non-communicable illnesses will increase the need for palliative care that is effective – in terms of costs and outcomes – and appropriate.

Palliative care in Africa

Provision of palliative care in Africa is inconsistent, often provided from isolated centres of excellence rather than integrated into the mainstream healthcare system. Indeed, for the overwhelming majority of Africans who endure progressive, life-limiting illnesses, access to culturally appropriate, holistic palliative care (that includes effective pain and symptom management) is at best limited, at worst non-existent.[3] A survey of hospice and palliative care services in Africa found that only 21 out of 47 countries had identified hospice or palliative care activity, and only four could be classified as having services approaching some measure of integration with mainstream service providers.[14]

However, the growing awareness of the need to expand palliative care in sub-Saharan Africa, and the increasing availability of funding to meet that need, have resulted in major developments in patient care in recent years, with increasing numbers of care providers demanding to acquire palliative care skills. Despite this progress, critics of palliative care on the continent (what Farmer described as the provision of 'substandard care for poor Africans with AIDS … dressed in fancy-sounding names such as "home-based" or "palliative" care')[15] have implicitly demanded empirical outcome evidence to demonstrate the beneficial impact of allocating what are scarce healthcare resources to this field.

African palliative care research

Despite the reported need for an evidence base among care providers,[16,17] the research that underpins palliative care service provision on the continent is inadequate. The discrepancy between the prevalent disease burden and the extent of health research undertaken is not, of course, peculiar to palliative care in Africa. There is a 10/90 disequilibrium, whereby less than 10% of the total research flow invested annually on global, public and private sector health research is directed towards research into the health problems that account for 90% of the global disease burden (measured in disability-adjusted life-years). This is as relevant today as it was more than a decade ago,[18] and remains high on the global health research agenda.[19]

Indeed, while donor demands (primarily led by the United States President's Emergency Plan for AIDS Relief [PEPFAR]) for the proven impact of funded projects in combination with budgetary transparency have pushed monitoring and evaluation onto the African palliative care agenda, research remains embryonic.

The extent of this developmental research stage is shown in Table 1, based on a basic search of PubMed, conducted on 18 January 2008 and using simple medical subject headings (MeSH) search terms for palliative care research literature.

This marginalisation of palliative care research generally confirms the findings of Harding *et al,*[20] who searched the plenary, oral and poster presentation abstracts from the July 2004 International AIDS Conference in Bangkok and found that only 0.15% of the total 8,629 abstracts included the key palliative care terms 'palliative', 'pain', 'symptom', 'end of life', 'hospice' and 'terminal'.

The relative dearth of published African palliative care evidence is symptomatic of a wider problem; a problem that Volmink and Dare describe as the 'moribund' nature of the continent's health research, a region where 'research capacity – comprising the institutional and regulatory frameworks, infrastructure, investment and sufficiently skilled people to conduct and publish research – varies widely'.[21] This bleak assessment is echoed by the World Bank which, in ranking countries according to their national investments in productivity in science and technology, concluded that only South Africa, Egypt and Mauritius did reasonably well, while other African countries were 'scientifically lagging'.[22]

Impediments to palliative care research in Africa

Just as African palliative care is an emergent discipline – with the first service only established in Zimbabwe in 1979[23] – so African palliative care research remains in its embryonic stages. Some of the obstacles to its development echo those identified in the UK by Richards *et al.*[24] Ten key obstacles are listed below.

Without research, the impact of existing care provision can be validated only by anecdote rather than rigorous evidence

Lack of a research culture

For understandable reasons, palliative care in Africa has concentrated on care provision to address the significant disease burden. This focus has been supplemented by an argument that posits that it is undesirable to reallocate finite scarce resources away from care provision to research.[25] However, 'care or research' is a false dichotomy. Ideally, the two should inform each other to their mutual benefit. Without research, the impact of existing care provision can be validated only by anecdote rather than rigorous evidence; existing practices are followed irrespective of whether they have a positive impact; the cost-effectiveness of interventions remains indeterminate; proven good practice lessons that could be transferred elsewhere on the continent are never learned; and palliative care models coming from resource-abundant countries are transferred to the African context without adaptation through evaluation.

There is also an understandable suspicion regarding the nature of any intended research. If it is not oriented towards addressing local, tangible needs, then it is academic and of minimal import for service providers.

Lack of research skills and knowledge

The second obstacle is the lack of research skills and knowledge among healthcare professionals; that is, the absence of a critical research mass. There are no academic chairs, nor any leading palliative care academic organisation, on the continent. Given the patient-to-doctor ratio in most African countries, especially in rural areas, nurses are pivotal to palliative care provision,[26] but the majority have had no research training.

Isolation

Africa is a vast continent and palliative care services are dispersed. Many professionals work in isolation, individually and organisationally, without a supporting network in which to share experiences, thereby rendering communication and effective research problematic.[27]

Patient accrual and attrition

Due to the inherent nature of palliative care, patient accrual and attrition pose a universal challenge when undertaking research among a population that is sick and dying, and whose ability to engage with the research process can be impaired by the disease progression.[28,29] This can result in missing data, which is problematic for statistical analysis. In Africa, this problem is exacerbated by a traditional culture in which individuals return to their 'village' to die and be buried with their ancestors.[30]

Lack of agreement on outcome measures

Most palliative care research instruments have not been validated in the African context, nor generally in resource-constrained countries.[16,31] Various tools measure outcomes in palliative care,[32] but constructs such as 'quality of life' and 'good death' are culturally specific, rendering it critical that such tools are assessed for validity within different sociocultural settings.

Lack of a common language

Most tools have been developed in the English language. To have linguistic – as well as cultural – relevance in countries with often multiple languages and dialects (in Uganda, there are more than 33 local languages),[33] they have to be translated, adapted and then re-evaluated for their reliability and validity.[34]

Lack of research funding

While there is increased donor funding for palliative care in Africa, this funding primarily goes to care provision and to evaluating the extent of treatment coverage, not to research. Where funding opportunities do exist, most palliative care organisations lack personnel with


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Hospital waiting room in Uganda. For the overwhelming majority of Africans who endure progressive, life-limiting illnesses, access to culturally appropriate, holistic palliative care is at best limited, at worst non-existent

the necessary academic and research qualifications to succeed in obtaining it, or to carry out the funded research.

Dominance of the biomedical model

Given their holistic nature, and unlike standardised medical drugs, palliative care interventions can be difficult to define in a precise and uniform way.[35] Similarly, the notion of allocating to randomised controlled trials, vulnerable patients, whose circumstances are rapidly changing[36] and for whom there is often no second treatment opportunity is, at the very least, contentious.[35] Within the African context, the idea of 'holism' is important, having been evident for centuries in traditional and herbal medicine.[37] While holistic care is intrinsically important to all palliative care, it is especially important in the African context that the discipline incorporates the traditional views of medicine, which in turn must be reflected in palliative care research.

Absence of national research strategies

Another key obstacle is the absence of national strategies for palliative care research embedded into national strategies for palliative care that are aligned to dedicated funding streams that can realise those research strategies.

Absence of a strategic research vision

Research presently conducted on the continent is not underpinned by a strategic rationale centred on the region's palliative care priorities. Not only does this mean that research duplication – a waste of finite resources – is a distinct probability, but also that areas of high importance are potentially being neglected, possibly to meet the research agendas of donor agencies.

The net result is that, currently, there is minimal empirical evidence demonstrating that existing palliative care services meet the needs and expectations of individual patients, provide quality care,[3,38] are cost-effective, offer value for money and are producing lessons that should be replicated elsewhere on the continent.

The drive for a research agenda

Latterly, however, there has been recognition of the need to advance African palliative care research. Importantly, this agenda has not been developed in isolation from mainstream African palliative care experts, who recognise that 'clinical and health service audit and research is desperately needed so that we can establish how best to deliver palliative care in the resource-poor setting, and to establish an information base relevant to the developing world'.[4] This need was echoed by a comprehensive review of the current status of palliative care in sub-Saharan Africa, which uncovered a wealth of clinical and academic experience and yet a dearth of methodologically robust evidence.[3]

While establishing a palliative care research agenda in Africa is not without challenges,[27] the growing interest in establishing an evidence base to underpin palliative care service provision is part of a wider impetus to advance a global palliative care research agenda. Central to this is the Declaration of Venice, produced by the EAPC and the International Association for Hospice and Palliative Care (IAHPC) to develop a global palliative care research initiative with a special focus on non-industrialised countries.[39] More specifically, the Declaration aims to identify palliative care research priorities in developing countries according to the needs of specific patient populations, while taking into consideration the prevailing regional, socioeconomic and cultural contexts; it also recommends the production of a research agenda for palliative care that contributes to the development of a global research strategy by each national or regional association.[39]

To ensure that research remains on the global palliative care agenda, the declaration was supplemented by the Budapest Commitments, which urge national palliative care associations to commit themselves to reaching predefined goals in five areas, including research.[40] It was regionally reaffirmed at the 2nd African

Palliative Care Association Conference held in Kenya in September 2007.[41]

The way forward

To address some of the issues raised above, and to advance the palliative care research agenda on the African continent, a number of key issues need to be addressed.

In the short term, one of the priorities is to establish a vision and agenda for research development. As Chauhan noted, the research topics that comprise this agenda must be 'in tune with the most pressing problems. Topics providing immediate results and solutions for the agonies and problems faced by the common man should be selected and prioritised. Until and unless the indigenous population is convinced of the possible benefits which may accrue to them, probably it may be difficult getting anticipated support for any research for them'.[42]

Establishing and prioritising the most pressing problems requires a systematic methodology to evaluate the most significant disease burden. This methodology is being developed by the African Palliative Care Association (APCA), a Uganda-based organisation with a remit to scale up quality palliative care services across Africa.

In the medium term, and in the absence of a sufficient critical research mass in Africa, there is a need to develop collaborative partnerships (for example, between regional indigenous palliative care experts, university medical schools, hospitals, national palliative care associations, the APCA and international agencies in north–south formations) to ensure that the problems associated with conducting research on the continent are overcome.[24]


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Doctors on an African hospital ward. A comprehensive review of the current status of palliative care in sub-Saharan Africa uncovered a wealth of clinical and academic experience and yet a dearth of methodologically robust evidence

However, there are a number of caveats. While an estimated 56% of literature on palliative care in Africa is written by Africans,[43] a significant proportion of it originates from South Africa alone and is descriptive in nature. Consequently, and to avoid what has been derogatively described as 'annexed site' research undertaken by 'data parachutists', as Costello and Zumla contended,[44] collaborative research should be centred on the following principles: mutual trust and shared decision-making; national ownership; emphasis on translating research into policy and practice; and development of national research capacity. Supplementary to these principles should be the axiom propounded by Edejer, 'Think action. Think local. Think long term',[45] and an ethical dimension that sees researchers from resource-abundant countries adhere to existing guidelines on international research partnerships.[46]

Importantly, there also is a need to institute the organisational architecture necessary to facilitate the development, and ensure the longevity, of such symmetrical research partnerships.[47] This architecture must, inevitably, be underpinned by adequate financial resources, with the success of such partnerships tracked by monitoring and evaluation tools (such as the number of peer- and non-peer reviewed publications, the number of conference presentations and so on).

If the goal of African palliative care research is transparent and grounded in a rationale that can engender a consensus; if the means by which it is to be achieved are seen as equitable and ethically fair (and result in financial investment to improve existing research capacity); and if the findings inform health policy and planning decision-making in African ministries of health, then there is every chance that the negative attitudes that have hampered palliative care research so far will be modified over time, as research is perceived as relevant and an effective means to optimise finite care resources. Indeed, despite the challenges, it is possible to conduct such research. Since 2005, the APCA has been developing collaborative partnerships within Africa and internationally (including with King's College London and the USA-based National Hospice and Palliative Care

Organization) to advance palliative care research on the continent, resulting in several collaborative projects.[38,48]

Conclusions

The argument that gives priority to clinical service delivery over the research necessary to ensure that it is effective has been lost. The debate should now be framed in terms of the potential for equitable complementarity between the two, rather than their antagonistic competition for finite resources.

Nevertheless, expanding the existing financial base to ensure that rigorous research can be conducted is essential; as is the need to forge, in practical terms, the collaborative partnerships needed to implement an African palliative care research agenda, given the existing limitations mentioned above. Without both, the Declaration of Venice would be nothing more than a paper exercise for a continent that desperately needs practical solutions to its substantial challenges.

Expanding the existing financial base to ensure that rigorous research can be conducted is essential

Note

A version of this paper was presented by Richard A Powell at the 4th Research Forum of the European Association for Palliative Care in Venice in May 2006, and, with Lukas Radbruch, at the 2nd APCA Palliative Care Conference in Nairobi in September 2007.

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Richard A Powell, Monitoring, Evaluation and Research Manager; Julia Downing, Deputy Executive Director; Faith Mwangi-Powell, Executive Director, African Palliative Care Association, Kampala, Uganda; Lukas Radbruch, Professor of Palliative Medicine, Department of Palliative Medicine, RWTH Aachen University, Germany, and President of the European Association for Palliative Care (EAPC); Richard Harding, Senior Lecturer, Department of Palliative Care, Policy and Rehabilitation, King's College London, UK