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Generating an African Palliative Care Evidence Base: The Context, Need, Challenges, and Strategies

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Abstract

The enormous burden of progressive, incurable disease in sub-Saharan Africa is reflected in the epidemiology of cancer and HIV. However, there has been little research activity and evidence generated to inform appropriate and effective responses. A collaborative of clinicians, academics and advocates have been active in the design, delivery and reporting of research activites in African palliative care. Here, they report the methodological, ethical, logistic and capacity-based challenges of conducting research in the sub-Saharan context from their experience. A number of strategies and responses are presented. J Pain Symptom Manage 2008;36:304–309.

Key Words

Africa, research, methodology, review

The Context

By December 2007, an estimated 22.5 million people in sub-Saharan Africa were living with the human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS), 62.5% of the global disease burden, with 1.6 million HIV-related deaths and 1.7 million new infections reported in that year alone from this resource-constrained region.[1] Given the decreasing mortality rates resulting from increased access to antiretroviral (ARV) therapies, and the continuing high incidence of the disease in the absence of more effective behavioral change programs, the prevalence of HIV/AIDS across the continent could remain high, or indeed rise.[2]

Additionally, cancer rates across the continent are expected to increase by 400% over

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the next 50 years.[3] The World Health Organization estimates that there are more than 0.5 million annual cancer deaths in Africa[4] and that by 2020, 70% of new cancer cases will be in the developing world.[5]

The African continent is, however, characterized by resource and infrastructure deficiencies that render governments least able to address this disease burden. Survival rates are consequently significantly lower than those in developed countries, and patients' expectations for disease-modifying oncological treatment are low.[6,7] Indeed, the imperative to address the challenge posed by cancer recently resulted in the "London Declaration on Cancer Control in Africa," calling upon research institutions, international organizations, the pharmaceutical industry, national governments, and civil society in developed and developing countries to unite to deliver comprehensive cancer care to the continent.[6]

Moreover, there is a growing concern that, as people's lifestyle, nutritional preferences, and nonsedentary work patterns on the continent change, Africa may experience an increase in the incidence of those chronically debilitating, life-limiting diseases characteristic of resource-abundant nations (e.g., stroke, diabetes, hypertension, and heart disease).[8,9] In a region already struggling to combat communicable diseases, such noncommunicable illnesses will increase the need for effective (in terms of costs and outcomes) and appropriate palliative care.

The Need

The allocation of sufficient resources to undertake methodologically robust research into palliative care in sub-Saharan Africa is required to inform the delivery of such effective and appropriate care.[10–12] Indeed, the growing interest in establishing an evidence base to underpin palliative care service provision in Africa is a component part of a wider impetus to advance a global palliative care research agenda, as embodied in the "Venice Declaration."[13] The Declaration calls for a focus on research and education in the development of palliative care in developing countries through collaboration to address the specific needs of patients within their geographical and socioeconomic and cultural contexts.

Importantly, this agenda has not been developed in isolation from mainstream African palliative care experts, who recognize 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."[12] 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 yet a dearth of methodologically robust evidence[10]— a lamentable fact symptomatic of what has been described as "moribund" African health research generally.[14]

It is hard to imagine how palliative care can be expanded to the levels of coverage and quality needed without robust and persuasive evidence to influence policy, attract funds, and change practice. Systematic reviews demonstrating the effectiveness of cancer palliative care[15,16] and HIV palliative care[17,18] report that the evidence is almost wholly from resource-rich countries and pre-ARV therapy. Clinical practice and national policy should be influenced by current, relevant, and replicable evidence. Currently, this is not possible in the field of palliative care in Africa, and as health service infrastructure improves, palliative care is in competition with other general and specialist care groups for finite resources.

There is, consequently, a general consensus that a need exists to address this deficiency and undertake rigorous palliative care research if we are to ensure that, in the spirit of evidence-based health practice:[19,20] practices and standards of care provision are underpinned by evidence rather than anecdote; lessons learned from service successes are replicated rather than ignored; and limited donor funding is spent optimally, with measurable results, rather than inefficiently with unaccountable outcomes. Moreover, it is imperative that this research is translational in nature, transferring its findings to everyday service provision, thereby ensuring that staff and patients experience its tangible benefits.

However, establishing such a palliative care research agenda in Africa is not without its challenges. The Monitoring and Evaluation Reference Group (MERG), an international multiprofessional body comprised of clinical, academic, and advocacy professionals representing six countries (four of which are African) aligned to the African Palliative Care Association (APCA), has identified the primary methodological challenges confronting such an agenda.

The Challenges

These primary challenges to conducting rigorous palliative care research in Africa are: the dearth of validated outcome measures; multiple sources of potential bias; inadequate research capacity and skills, plus logistical challenges to data collection and transfer; and the absence of formalized mechanisms for ethical research in some countries.

Outcome Measures

The lack of palliative care outcome measures developed and validated in Africa is a fundamental challenge to establishing a rigorous evidence base for the continent. African end-of-life care providers have described the availability of validated tools and methods as a priority for the field.[21] Although the scientific principles underpinning palliative care research are transferable, it is essential that outcome measures used reflect the prevailing diseases[11] (e.g., the unpredictable HIV trajectory), the concept of "total need" in a resource-constrained setting, the family issues (e.g., orphan care) involved, and the basic socioeconomic pressures of income generation and poverty. Measures must also use concepts (especially for quality-of-life research) that have cultural meaning and equivalence among indigenous populations.[22] For example, in the authors' experience, concepts such as "pain" and "anxiety" can lack both intra- and intercultural equivalence among the divergent ethnic groups across and outside Africa. Moreover, compared to resource-abundant settings, a significant proportion of palliative care clients are children (generally defined as a person aged below 15 years). For example, Africa accounts for 25% of the 80,000 annual deaths from cancer among children globally,[23] and 90% of the 2.3 million children worldwide living with HIV.[24] However, beyond the Faces Pain Scale,[25] there is a paucity of validated pediatric measures. Also indicative of their lesser and neglected status, it was only recently that children were included in HIV surveillance statistics.[26]

Sources of Bias

Measurement scoring is particularly problematic when using outcome instruments. Literacy deficiencies preclude the resource-abundant country focus on self-completion questionnaires. Moreover, the overwhelming majority of patients located in African rural communities rarely access a professionally trained health care worker (routine recourse remains to the traditional healer[27]), and effective pain relief is rare. Consequently, data collection risks the introduction of bias through acquiescence due to cultural unwillingness to be critical of the few health care services provided; this jeopardizes the validity of reported data.

The current lack of a cadre of African palliative care researchers due to underinvestment also threatens data validity. Adequate attention needs to be devoted to training researchers in basic research skills (e.g., data collection, cleaning, storage, and analysis), and existing African health researchers must be encouraged and facilitated to engage in the specific challenges of palliative care research.

Further challenges are posed by study attrition rates. Not only do end-stage patients in Africa commonly return to their home village to die,[28] but their inability to pay care costs can result in service discontinuity. The inaccessibility of patients living in rural locales can translate into significant time and financial effort for researchers to carry out data collection on a regular basis. This latter challenge can specifically result in a sampling bias. Further logistical challenges, such as heavy rains, transport limitations, and staff morbidity and mortality due to the HIV epidemic,[29] can reduce sample accrual and retention. Moreover, the lack of accurate population-based epidemiological data, particularly for noncommunicable diseases,[30] prevents probabilistic sampling strategies.

Lastly, chronic financial resource deficits can sometimes "compel" service providers to be uncritical of their outcomes when applying to funding agencies. Only instilling an organizational culture that values the role of project monitoring and evaluation, in conjunction with a questioning funding culture that encourages self-criticism and continuous quality improvement, can address such potential sources of bias and inaccuracy.

Research Capacity and Skills

Inadequate investment in research capacity in Africa, investment that is presently disproportionate to the region's overall burden of disease,[31] has the effect of entrenching health inequalities.[12] Even within the presently lamentable status of health research on the continent, palliative care lags behind other disciplines, despite the fact that up to 52% of African HIV outpatients may be appropriate for palliative care interventions.[32] With few exceptions, funders' relative disinterest in allocating funds to evaluative program activity and in forging a critical mass of African researchers, has resulted in an inability to measure service quality and effectiveness and replicate successes. Building local research capacity is imperative;[33] Africans should not be denied the same right to access evaluated, quality health care as do health service recipients in resource-abundant countries.

Currently, research studies are undertaken in addition to existing work commitments and often are not allocated dedicated funding. This arrangement has often resulted in data collection being perceived as either a burdensome task requiring minimalist involvement, or as an indulgence to be conducted only when convenient, and not as a necessary and critical activity to be integrated into daily routine service delivery. In short, inadequate infrastructure capacity can pose significant problems in data collection, entry, and transfer, issues that are compounded by information and communication technology deficiencies.[34]

Ethical Research

Patients and families affected by poverty, lack of health care provision, and the HIV/AIDS epidemic require particular protection from Research Ethics Committees. The MERG has found that not only do such bodies not always exist locally but, where they do exist, the lack of collaboration between committees may lead to requirements of different protocols and procedures within multi-center studies.

In addition, the oral rather than written tradition evident in Africa has resulted in challenges for research ethics committees in resource-abundant countries requested to review north-south research collaborations conducted in resource-limited countries.[35] The oral tradition often views a patient's word as the most appropriate signifier of permission to participate. However, despite the fact that a request for written permission can offend or confuse a potential respondent, requesting a mark or verbal agreement to participate as a substitute for a signature[36] may not secure ethical approval. At a time when the embryonic African palliative care research agenda is dependent upon north-south collaborative partnerships, this is a potentially significant obstacle.

The Strategies

To address these methodological challenges, and thereby generate both research personnel and robust evidence across Africa, the following strategies are recommended as a way forward.

First, due to the relative absence of research personnel in the field, collaboration between researchers in resource-abundant and the resource-constrained countries of Africa is imperative. This collaboration should not be centered around delivering on predetermined research protocols, but rather on more meaningful sharing of skills aimed at building individual and organizational capacity and thereby ensuring that African research staff are ultimately enabled to undertake the roles of principal investigators (PIs). Research capacity development needs to encompass all phases of the research process, from identification of appropriate questions, to data analysis, to the drafting of internationally recognized peer-reviewed papers.

Second, existing palliative care training courses, which are emerging in greater numbers in Africa, should integrate research methods into their existing curricula for all cadre of staff. Moreover, this research component must be presented as a necessary and critical component of effective service delivery and improvement.

Third, PIs must factor in adequate resources to provide ongoing technical support to African centers engaged in research. This includes research methods, protocol design, data collection, management, cleaning and entry, analysis, and reporting. Moreover, promising new- or mid-level career professionals committed to palliative care research should be supported by formal developmental programs, such as the new African Palliative Scholars Programme.

Fourth, funders should designate resources to evaluate care alongside direct care allocation. This will help ensure the effective and systematic documentation of lessons learned and the replication of successful initiatives and interventions.

Fifth, research and evaluation studies require project-specific staff to ensure that data collection and management are completed in a timely fashion in accordance with the study protocol requirements and are not relegated to second place behind clinical activity.

Sixth, multidimensional outcome measures should be developed and validated that address domains of importance to Africa (e.g., the APCA African Palliative Outcome Scale[37]). Careful cognitive interviewing and revalidation is required if existing measures are to be applied in the African setting.

The responsibility for ensuring that these strategies are applied rests with: *funders* who need to allocate dedicated resources; *educators* who need to teach research methods and the operational value of research as part of palliative care education; *researchers* who need to foster meaningful collaborative partnerships and knowledge transfer; and *practitioners* who need to create a workplace culture that values the role of research in optimizing patient care.

Research is a standard activity in resource-abundant settings; methodologically robust data can, and should, be generated on palliative care in Africa, too.

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