Special Article

How Can We Improve Palliative Care Patient Outcomes in Low- and Middle-Income Countries? Successful Outcomes Research in Sub-Saharan Africa

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Abstract

Palliative care has striven to be evidence-based and to measure and prove its outcomes, although the population we serve offers significant challenges in determining and measuring outcomes. Within low- and middle-income countries, there has been comparatively little outcome evidence in relation to the numbers of patients seen and the magnitude of need for palliative care. Here we report a novel collaborative effort to measure and improve outcomes for patients and families receiving palliative care in two sub-Saharan African countries. J Pain Symptom Manage 2010;40:23–26. *© 2010 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words

Palliative, Africa, research, outcomes measurement

Introduction to the Setting and Problem

Research-based approaches to the design and outcome evaluation of interventions have contributed to changing policy and clinical practice for those affected by progressive and life-limiting disease. However, systematic reviews demonstrating effectiveness of palliative care have identified evidence generated almost exclusively in high-income countries.[1,2] This is despite estimates of 22 million living with HIV infection[3] and nearly 60,000 cancer deaths[4] in sub-Saharan Africa during 2007.

The field of palliative care has been established in sub-Saharan Africa through collaborative efforts by clinicians, advocates, governments, and communities. But still, a major global challenge is to exert influence and deliver palliative care to all those who need

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it. This is particularly a challenge in HIV medicine since the advent of antiretroviral therapy (ART),[5] which has brought new and evolving needs for palliative care. In terms of advocacy (i.e., activities to influence policy, practice, and resource allocation), the palliative care community in sub-Saharan Africa has begun to generate and strategically use robust locally relevant evidence.

Globally, palliative care operates in a context of resource constraints, competing health technologies, new treatment options (especially ART), a complex policy environment, and a demand for evidence-based health care. Therefore, it seems unlikely that we could successfully influence national health plans, funders, and clinicians in the absence of evidence. It seems doubtful that we could exert influence without proving need, appropriateness, feasibility, and effectiveness in terms of outcomes for patients and families. In low-middle-income countries, this is particularly important. The words of Jawaharlal Nehru still hold true today: "It is because we are a poor country that we cannot afford not to do research." Furthermore, there is a strong moral obligation to undertake ethically robust research, as patients everywhere deserve to receive care that has been shown to be effective.

Description of the Intervention

We offer components of a multidisciplinary program of outcome research.

Our initial step was to appraise the state of the science by conducting a systematic review of the evidence for palliative care outcomes. This review highlighted the wealth of experience but dearth of evidence, primarily because of the lack of appropriate locally validated outcome tools.[6] Second, we conducted a survey of end-of-life HIV care providers to determine their priorities, which revealed a wish for local outcome tools and audit methods.[7] Third, we consulted with clinicians to determine the necessary properties of an outcome tool.[8] Fourth, a pan-African group of experts was convened to develop and pilot an African outcome tool across four palliative care settings in three countries[9] (the African Palliative Care Association African Palliative Outcome Scale [APCA POS]). This tool is a brief self-report that enables the patient and family to score their problems across the domains essential to palliative care. Fifth, the tool was subsequently subjected to full validation in five settings in two countries, with 682 patients and 437 family carers, interviewed in eight different languages.[10,11] Sixth, a full clinical audit cycle was designed and implemented using the new tool. This program was funded by the BIGLottery UK Foundation.

The Audit Cycle

Clinical audit cycles aim to embed within care services a clear process for measuring and improving outcomes. In low- and middle-income countries, it is essential to conduct audit to prove the wise allocation of scarce resources and capture and replicate new and emerging clinical success.[12]

With no prior published model of clinical audit in African palliative care, we aimed to design a full audit cycle that allowed local ownership of the process, recognized different levels of activity between facilities, and ensured that local clinical targets were feasible and achievable. In the absence of any prior outcome data, no predetermined outcome targets were in place.

The audit was conducted by four South African and one Ugandan palliative care facility. Within each, a Quality Improvement (Research) Nurse was employed to coordinate the audit. The sequential process was as follows: Step 1, 100 patients (new or with new presenting problems) were recruited at each site and interviewed using the APCA POS weekly for six weeks; Step 2, data were analyzed and presented back to each facility to identify main problems, and how these were managed over time; Step 3, each facility, within a larger meeting of multiprofessional staff, selected target improvements in outcomes; Step 4, teams at each site developed quality improvement strategies to achieve their targets; Step 5, after three months of devising and implementing their strategy, a further 100 patients were recruited at each site and interviewed weekly for six weeks using the APCA POS; and Step 6, data were analyzed and presented back to each facility to determine whether targets had been met.