Special Article

Palliative Care Research in Africa: Consensus Building for a Prioritized Agenda

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Abstract

Context. Palliative care research in Africa is in its relative infancy, with dedicated financial support extremely limited. Therefore, setting research priorities to optimize use of limited resources is imperative.

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Objectives. To develop a prioritized research agenda for palliative care in Africa.

Methods. We used a two-stage process involving palliative care professionals and researchers: 1) generation of an initial topic list at a consultative workshop of experts and 2) prioritization of that list using a consensus development process, the nominal group technique.

Results. Phase 1: 41 topics were generated across five groups, with several topics nominated in more than one group. Phase 2: 16 topics and three broad thematic areas were identified. The two most prioritized topics within each of the three themes were the following: Theme 1: patient, family, and volunteers—1) care outcomes and the impact of palliative care as perceived by patients and caregivers and 2) palliative care needs of children; Theme 2: health providers—1) impact of palliative care training on care and practice and 2) integration of palliative care and antiretroviral therapy services; and Theme 3: health systems—1) palliative care needs assessments at the micro-, meso-, and macro-levels and 2) integration of palliative care into health systems and educational curricula.

Conclusion. Consensus-based palliative care topics determined by the study can assist researchers in optimizing limited research capacities by focusing on these prioritized areas. Subsequent to the identification and publication of the research agenda, concrete steps will be undertaken by the African Palliative Care Research Network and other partners to help implement it. J Pain Symptom Manage 2014;47:315–324. *© 2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

Key Words
Africa, research agenda, participatory, priorities, palliative care

Introduction

Africa is characterized by a significant burden of communicable and non-communicable progressive diseases, especially in sub-Saharan Africa. In 2011, 23.5 million people in the sub-region were living with HIV/AIDS, 69% of the global disease burden, whereas in North Africa and the Middle East, there were only 300,000.[1] Regionally, cancer also is an emerging public health problem.[2] In 2008, there were 715,000 new cancer cases and 542,000 cancer-related deaths in Africa.[3] Of these, 36% were infection related, which is twice the global average.[4] Indeed, as part of the growing non-communicable disease burden, this will contribute to an estimated 3.9 million deaths in Africa by 2020.[5] Additionally, in 2010, Africa accounted for nine of the 22 countries worldwide that comprised 82% of the estimated number of HIV-positive new tuberculosis (TB) cases[6] and 14% of the global burden of new multidrug resistant TB cases.[7]

Despite the reported need among care providers in the region for methodologically robust research to help address this disease burden,[8,9] the evidence base informing the delivery of effective and appropriate funding, policy, and care on the continent is inadequate.[10] Indeed, the relative dearth of published palliative care evidence from Africa is symptomatic of a wider African problem: what Volmink and Dare[11] once described as the "moribund" (p.705) nature of the continent's health research. Moreover, there are unique aspects of health and social care provision on the continent (including the distinct and challenging diagnostic patient profile of those receiving care and the nature and socioeconomic context of the services providing that care) and potential challenges to shared decision making and communication generally by the multitude of languages that characterize some African countries, which require informed exploration.

Some of the critical obstacles to research development have included the lack of a supportive network for mutual experience sharing, the lack of culturally validated patient-reported outcome measures, the absence of palliative care research strategies in national palliative care plans, the lack of a critical research mass among health care professionals, and the absence of a strategic research vision centered on the region's pressing palliative care needs.[12] In the absence of dedicated financial support, it is imperative to set research priorities to optimize the use of the limited available resources.

Additionally, in the absence of a sufficient critical research mass in Africa, there is a need to develop effective international collaboration. In North America, collaborative networks have been formed to advance palliative care research, addressing everyday clinical studies and academic research questions,[13–15] and in Europe, the European Association of Palliative Care Research Network has been established.[16] The benefits of collaboration in research are multiple, including optimizing joint skills and knowledge transfer, building skills capacity, maximizing patient accrual and retention, facilitating successful funding applications, identifying needs and developing effective services that are culturally relevant and appropriate, and establishing networking mechanisms that enable multi-country comparative studies.[17] Additionally, collateral patient-level benefits can include increased personal care attention, greater focus paid to therapeutic dosages and their timings, and increased screening tests to determine eligibility and evaluations to determine outcomes, possibly resulting in improved clinical outcomes.[18] In Africa, examples of network development are found in the fields of cancer and epidemiology[19,20] but less so in palliative care, with notable country-level exceptions in South Africa and Uganda.

To address this weakness, the African Palliative Care Research Network (APCRN) was established at the third triennial conference of the African Palliative Care Association in Windhoek, Namibia, in September 2010, building on our program of work establishing methodological approaches to palliative care that meet the specific African context.[10] Here, we report on the APCRN's development of a prioritized palliative care research agenda for the continent.

Methods

Data Collection

Data collection entailed a sequential, two-stage process, involving palliative care professionals and researchers: Phase 1—generation of an initial topic list at a consultative workshop of experts and Phase 2—prioritization of that list (and any additional identified topics) using a consensus development process.

Phase 1. This workshop was held in Windhoek, Namibia, in September 2010. Following presentations by the workshop facilitators, participants were asked to complete a brief questionnaire requesting basic sociodemographic, occupational, and research experience data, before breaking into group discussions.

The group discussions were facilitated by three palliative care physicians and researchers (L. G., L. R., S. A. M.) and three palliative care researchers (R. A. P., R. H., E. K.). Participants were systematically allocated to five groups, with group numbers (i.e., 1–5) assigned to each individual using a randomly selected starting point. Each group was facilitated to ensure full participation. One of the four questions addressed by the groups was "What topics should we prioritize for palliative care research on the African continent?" Following the group discussions, each of the five groups reported back their discussion points at a plenary session. These points were collated and listed verbatim as they were reported originally, in no prioritized order.

Phase 2. The second workshop was held in Kampala, Uganda, in April 2012, to finalize a prioritized palliative care research agenda for the continent. To develop an agreed research agenda, the workshop used the nominal group technique (NGT) based on the initial thoughts and discussion points expressed at the workshop in Namibia. NGT is a consensus forming methodology that allows for the free exchange of opinions and generation of ideas within a structured, nonhierarchical discussion forum that considers everybody's opinions;[21] it has been used in various settings and subfields to establish health research priorities.[22–25]

NGT lasted approximately 90 minutes and began with an opening statement from the moderator (R. A. P.) that explained the process and purpose of the group's deliberations and that encouraged full and equal participation. Participants were asked to identify the main areas of research that need to be investigated over the next five years. Participants were then provided with an alphabetically ordered (to eliminate any repetition) list of the topics generated at the Phase 1 meeting, adding to that list if they considered it necessary, and were asked to work independently. Ideas were noted individually and subsequently recorded in a round-robin feedback session, without debate, until all ideas were documented. Each recorded idea was then discussed to determine clarity and importance. Lastly, participants were asked to vote to prioritize the expressed ideas according to three criteria: 1) research is urgently needed in that area; 2) there is a gap in the existing evidence in the area or there is no evidence in existence; and 3) research in the area will impact, either directly or indirectly, on the quality of life of patients requiring palliative care and their families. In the prioritizing process, participants were asked to select and record on their sheets the 10 most important items from the group list and then rank the 10 selected ideas, with the most important receiving a rank score of 10 and the least important receiving a rank score of 1. These ranked responses were recorded and the scores of each ranked item computed for the whole group. The ideas that received the highest sum scores in the group were selected as final recommendations for the prioritized APCRN agenda.

Data Management, Analysis, and Ethics

Phase 1 generated basic sociodemographic data regarding participants and an initial list of verbatim-reported research topics. Data were entered into Excel spreadsheets for descriptive analysis. Participants' sociodemographic data were presented as simple frequencies, whereas the list of research topics was arranged by discussion group.

Phase 2 generated participants' basic sociodemographic data and a prioritized list of research topics. Data were entered into Excel spreadsheets for descriptive analysis. Participants' sociodemographic data were again presented as simple frequencies. In view of the nature of the data, the authors decided against formal qualitative analysis, with R. A. P., E. Namisango, R. H. and L. R. categorizing the prioritized research topics into thematic groups. Agreement with the final categories was obtained from all authors.

Because this was a consultation exercise, using health care and research professionals to identify and prioritize research areas, ethical review was not required.

Results

Phase 1

Forty-nine conference participants took part in the first workshop. Among the 37 (75.5%) who completed a brief profiling questionnaire, 25 (67.6%) were female, 20 (54.1%) were from universities, seven (18.9%) from nongovernmental organizations, 10 (27%) from hospices, and 24 (64.9%) were African (Table 1).

The list of identified research topics from the first phase workshop by discussion group are presented in Table 2. When duplicate topics were omitted, 41 topics were nominated across the five groups. Although no one topic was named by all groups, several (e.g., costing/cost-effectiveness or the impact of educational interventions) were nominated by more than one group.

Phase 2

Among the 14 participants at the Phase 2 workshop, 10 were female and six were aged between 40 and 49 years, with seven from universities, one from a hospice, two from a cancer care center, and four from nongovernmental organizations (Table 1). Eleven participants were African, and Africans had less years of experience in palliative care research compared with non-Africans (i.e., Europeans or North Americans).

The prioritized list of research topics, and their thematic areas, prioritized at the second workshop using NGT are listed in Table 3. Three broad thematic areas were identified as follows: 1) patient, family, and volunteers; 2) health providers; and 3) health systems. Within these three areas, 16 priority topics were nominated. The two most prioritized topics within each area were the following:

Theme 1: patient, family, and volunteers—1) care outcomes and the impact of palliative care as perceived by patients and caregivers and 2) palliative care needs of children;

Theme 2: health providers—1) impact of palliative care training on care and practice and 2) integration of palliative care and antiretroviral therapy services; and

Table 1
Characteristics of Workshop Participants

	Phase 1 ($n = 37$)		Phase 2 ($n = 14$)	
Characteristics	Africa (24)	Non-Africa (13)	Africa (11)	Non-Africa (3)
Gender				
Male	6	6	2	3
Female	18	7	9	0
Age group (years)				
20–39	—	—	5	0
40–49	—	—	4	2
50–59	—	—	1	1
60+	—	—	1	0
Current employer				
University	10	10	4	3
Nongovernmental organization	5	2	4	0
Hospice	9	1	1	0
Cancer care center	0	0	2	0
Professional background[a]				
Clinician	5	3	1	0
Researcher	13	5	2	1
Both	4	5	8	2
Experience in palliative care (years)				
≤5	21	6	3	0
6–10	2	2	7	1
>10	1	5	1	2

— Indicates data not collected.
[a] Two missing values.

Theme 3: health systems—1) palliative care needs assessments at the micro-, meso-, and macro-levels and 2) integration of palliative care into health systems and educational curricula.

Discussion

Health research is a fundamental prerequisite to the evolution of solutions to health problems. Specifically, research is essential to identify needs and priorities, demonstrate effectiveness, and reveal an understanding of specific social and cultural issues that should guide health policies and clinical practices. Palliative care research also is needed so that patients with progressive, life-limiting illnesses can receive the best quality palliative care possible. Methodologically rigorous research is required to improve patient and family outcomes and develop palliative care as an evidence-based specialty.[26] This is especially important in resource-poor settings where only limited resources are available for palliative care interventions and their optimal configuration and where efficacy is largely unproven. However, there is also an acknowledgment that this need for rigorous research must be balanced against its feasibility in resource-poor countries, not as a further challenge to adequate palliative care provision in the absence of dedicated research funding, and be implemented in conformity with the World Health Organization's principle of progressive realization that distinguishes the *inability* from the *unwillingness* of a state agency to comply with its "right to health" obligations.[27]

The growing interest in establishing an evidence base to underpin palliative care service provision in Africa is part of a wider impetus to advance a global palliative care research agenda. Central to this is the Declaration of Venice, which aims to identify palliative care research priorities in developing countries according to the needs of specific patient populations, as well as prevailing regional, socioeconomic, and cultural contexts, and recommend the production of a research agenda for palliative care that contributes toward the development of a global research strategy by each national or regional association.[28]

Published palliative care research conducted in resource-poor settings is limited. Pastrana et al.[29] found, from a bibliometric analysis of peer-reviewed publications in two databases to mid-2008, that although 28.9% (245/845) of references originated from lower middle-income

Table 2
Topics for Palliative Care Research in Africa

Group 1	Group 2	Group 3	Group 4	Group 5
• Evidence of effectiveness—service models – On specific outcomes (e.g., coping with poverty) – Cost-effectiveness • Poverty in the context of palliative care—how to provide palliative care with limited transport, staff, wages, etc.? • Dealing with last year days—end-of-life care • How to integrate palliative care in health systems and medical/health care curricula • Carers' experience and support needs (e.g., male carers) • Spiritual and cultural issues—for example, how do beliefs affect patient/carer experience? • What is palliative care in the different conditions (e.g., organ failures and TB) and populations (e.g., children, migrant populations) • Drug availability and accessibility • Mental health in patients/carers	• Bereavement—adults and children • Culture • Models of care and settings • Costing of palliative care in different settings • Specialists vs. generalists • Complementary medicine • Patient outcomes and effectiveness • Training in education • Unmet needs for palliative care • Symptom studies • Best practices and standards of palliative care • Spirituality • Pain management • Sexuality • Palliative care and ART • Poverty and psychosocial issues • Gender • Ethical and legal issues • Comparative research for learning from African innovations • Families, caregivers, and volunteers • Evaluative interventions	• Cost of palliative care in different settings • Best model practices of providing care • Needs assessment—for palliative care - Patient level - Country level - Regional level - International level • Patient perceptions of care outcomes and impact of palliative care • Impact of palliative care training • Status of palliative care in different contexts	• Impact of palliative care • Effectiveness of nurses prescribing morphine • Issues relating to morphine availability • Social support needs of palliative care clients • Education—intervention assessment of health care worker • List effectiveness of models and approaches	• Access to morphine • What is palliative care in Africa? • Palliative care needs for children • Education/teaching/training • Attitudes of service providers (include traditional health system) • Partnerships/collaborations

TB = tuberculosis; ART = antiretroviral therapy.

Table 3
African Palliative Care Research Agenda

Research Themes and Topics
Theme 1: Patient, family, and volunteers
Topics
• Care outcomes and the impact of palliative care as perceived by patients and caregivers
• Palliative care needs of children
• Efficacy of symptom control interventions
• Definition of patient outcomes
• Needs of families, caregivers, and volunteers
• Efficacy of pain management
• Impact of spiritual and cultural issues on the patient/carer experience
Theme 2: Health providers
Topics
• Impact of palliative care training on care and practice
• Integration of palliative care and antiretroviral therapy services
• Assessment of palliative care needs in different conditions (e.g., organ failure and tuberculosis) and populations (e.g., immigrant populations)
• Assessment of drug availability and accessibility
• Effectiveness of nurses prescribing morphine
Theme 3: Health systems
Topics
• Palliative care needs assessments at the micro-, meso-, and macro-levels
• Integration of palliative care into health systems and educational curricula
• Evidence of effectiveness—service models
▪ Cost-effectiveness
▪ Specific outcomes
• Comparative research for learning from African innovations

countries (LMIC), half (46.9%) of the articles were from upper middle-income countries, with only 11% from low-income countries, and 25% of articles with LMIC data were undertaken by lead authors from high-income countries. Only South Africa was a significant contributor to this body of published work from the African continent. This reveals a lack of research capacity in Africa, such that more indigenous trained researchers are needed who can carry a research agenda forward, with full sensibility of the specific challenges and opportunities for palliative care on the continent.

Although palliative care research priorities have been identified in Europe and North America, much of the focus is accorded to physical issues, most often symptom management. Sigurdardottir et al.[30] highlighted three key domains for end-of-life cancer medical research: 1) symptomatology; 2) last days of life and quality of death; and 3) policy and organization of services, with the first, presented as the primary focus, entailing pain (ranked as the top research priority), fatigue, cachexia, delirium, and breathlessness. These findings partly echoed those areas—especially symptomatology—identified as in urgent need of increased research efforts at the Birmingham International Workshop on Supportive, Palliative and End-of-life Care Research in 2006[31] and the domain of improving the quality of hospice and palliative care indicated in North America by the National Hospice and Palliative Care Organization.[32]

Although there is a degree of overlap with the patient-level research priorities found in this study (e.g., efficacy of pain and other symptom control interventions, impact of palliative care), research agendas developed outside Africa may not be applicable to the continent. They do not take into consideration the highly diverse cultural and economic settings within which the priorities are located, as well as the existing limited capacity and resources to conduct palliative care research when resources generally for sometimes competing clinical care provision also are highly constrained. This study also reveals an emphasis on nonclinical areas, including spiritual and cultural issues that can impact on the patient and care experience.

Similar to the findings from the National Hospice and Palliative Care Organization,[32] the needs of special and vulnerable populations, including children, families, other caregivers and service volunteers, diagnostic groups (e.g., TB), and immigrants, also were highlighted. These needs will potentially have implications for the organization and delivery of hospice and palliative care services.

However, some research areas are deeply rooted in the current African palliative care development agenda, including integration with antiretroviral therapy, effectiveness of nurses prescribing morphine, and integration into health and educational systems. Indeed, some similarities are evident in the research agenda for palliative care in a hospital setting developed in Uganda, which comprised three primary strands: patient needs and perspectives (including decision making and choice of place of care), staff needs and perspectives (including palliative care knowledge and skills), and frameworks and care models (including choice of place of care).[33]

The methodology of both phases in this study did not include an evaluation of preferred research methodologies for the identified topics and themes. Pastrana et al.[29] reported that 58% ($n = 142$) of LMIC research articles entailed empirical studies, with 44.9% of them quantitative in nature, half of them cross-sectional in design, and only 2% of them randomized controlled trials. Indeed, a large number of nonempirical studies were reported (16.7%), as well as reviews (14.3%) and position papers (7.3%), reflecting some of the weaknesses in published palliative care research reported elsewhere.[34] In examining European palliative care research, Kassa and Radbruch[35] contended that much has been characterized by small sample sizes and descriptive rather than interventional study designs, without the necessary quality for input into evidence-based medicine. Moreover, study populations often have been described and defined differently between studies, with limited consensus on how to measure important outcomes using standardized definitions.

The relative infancy of palliative care research on the African continent, the need to generate culturally meaningful and operationally significant, hypotheses, as well as the nature of the prioritized topics identified in this study, means that descriptive study designs and qualitative methodologies—and mixed methods for some areas, such as cost-effectiveness studies—will be a partial requirement for African palliative care research in the near future. Additionally, there will be a need to undertake research that focuses on the adaptation and validation of data collection tools that are culturally applicable in highly diverse African settings, such as with the African Palliative Care Association African Palliative Outcome Scale[36] and its pediatric equivalent.[37] For quantitative research, an evaluation of new research methodologies that might be useful for palliative care research, such as the N-of-1 methodology, is needed.[38]

Finally, the workshop participants emphasized that research on palliative care in Africa should not be perceived as a small-scale version of research being pursued in developed regions. Rather, it is contended that the innovative methods used to overcome the dearth of resources on the continent may be well worth investigating in comparative research (e.g., home-based care provision with countries exploring community-based care models).

Limitations

This study had several limitations. First, the research priorities identified were generated by expert opinion rather than from patients themselves experiencing life-limiting conditions (across a range of diagnostic groups, service delivery settings, and sociocultural contexts). It may be important to determine how patients' and caregivers' perspectives differ from those of palliative care professionals and researchers. Second, in the absence of any qualitative enquiry, the rationale underpinning the prioritization process for each participant is unknown. Both limitations merit additional research. Last, although currently peripheral to many palliative care services on the continent, increasing moves to mainstream palliative care provision would necessitate future consultations with government ministries to ensure shared research priorities.

Conclusions and Recommendations

Following a participatory, consultative workshop, NGT was successfully used to reach a consensus on the most important research priorities in the field of African palliative care research. Topics determined by the study can assist researchers in optimizing limited resource capacities by focusing on these prioritized areas. Subsequent to the identification and publication of the research agenda, concrete steps have to be undertaken to implement it. The APCRN will focus its work around this agenda, which at the research prioritization meeting also identified three areas of enquiry that could be pursued for relatively quick delivery and impact.

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