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Current HIV/AIDS end-of-life care in sub-Saharan Africa: a survey of models, services, challenges and priorities

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Abstract

Background: In response to increased global public health funding initiatives to HIV/AIDS care in Africa, this study aimed to describe practice models, strategies and challenges to delivering end-of-life care in sub-Saharan Africa.

Methods: A survey end-of-life care programs was conducted, addressing the domains of service aims and configuration, barriers to pain control, governmental endorsement and strategies, funding, monitoring and evaluation, and research. Both closed and qualitative responses were sought.

Results: Despite great structural challenges, data from 48 programs in 14 countries with a mean annual funding of US \$374,884 demonstrated integrated care delivery across diverse settings. Care was commonly integrated with all advanced disease care (67%) and disease stages (65% offering care from diagnosis). The majority (98%) provided home-based care for a mean of 301 patients. Ninety-four percent reported challenges in pain control (including availability, lack of trained providers, stigma and legal restrictions), and 77% addressed the effects of poverty on disease progression and management. Although 85% of programs reported Government endorsement, end-of-life and palliative care National strategies were largely absent.

Conclusions: The interdependent tasks of expanding pain control, balancing quality and coverage of care, providing technical assistance in monitoring and evaluation, collaborating between donor agencies and governments, and educating policy makers and program directors of end-of-life care are all necessary if resources are to reach their goals.

Background

In 2002 the WHO estimates there were 29.4 million adults and children living with HIV/AIDS in Sub-Saharan Africa, with 2.4 million AIDS-related deaths and 3.5 mil-

lion new infections. Even considering the current global focus on HIV treatment, it must be recognized that the nature of the disease, weak public health infrastructure and other factors [1] make quality palliative and end-of-

life care necessary in Sub-Saharan Africa. The magnitude of AIDS-related deaths, however, is simply too great for existing hospital infrastructures. Community-based palliative and end-of-life care models are needed [2] as is a renewed focus on quality of palliative and end-of-life care.

As national and international funding and policy focus on HIV care for Sub-Saharan African populations, it is imperative to consider existing palliative and end-of-life care models within this region. To develop effective responses, research is needed to identify salient characteristics of HIV end-of-life care programs and their successful strategies. To date, no studies have described the activities and challenges of established end-of-life or palliative care services in this region. This study is the first to gather and synthesize data from Sub-Saharan palliative and end-of-life care programs. It aims to describe and analyse practice, policy and advocacy to inform future developments and research for building HIV palliative and end-of-life care in Sub-Saharan Africa. This is achieved through a cross-sectional survey describing current practice, priorities and challenges in end-of-life HIV/AIDS care.

The World Health Organisation defines palliative care as "active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms, and of psychological, social and spiritual problems, is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families". Palliative care is broader than end-of-life care in that it encompasses physical, emotional, practical, and spiritual aspects of suffering throughout the course illness. The term "hospice care" is often used interchangeably with "palliative care" and "end-of-life" care. This is not entirely correct as "hospice" refers to a particular philosophy of care and to a place where palliative and end-of-life care is practiced.

The fundamental question of whether palliative care is appropriate or possible in developing countries has been posed [3]. The introduction of both home-based and inpatient hospice care in sub-Saharan Africa [4–6] has already provided some answers. These approaches have addressed government funding and support, clinical training, and improved pain control through drug policy advocacy. Additionally, given the magnitude of HIV deaths, programs also have to consider coverage and not simply strive to provide high quality care to a few patients [7].

Consideration of what constitutes quality end-of-life care in non-industrialised countries is worthy of consideration; "total" psychosocial care in resource-poor environments includes additional needs such as orphan care [8], income generation and food security [9]. A comparative

study of terminal cancer patients in Kenya and the UK found that the Africans' main concern was for pain control and analgesia, compared to the UK patients' whose concerns were for emotional pain [10]. Culturally competent end-of-life care should also incorporate alternative belief and care systems, for example training traditional healers in care roles [11–13].

Methods

Sampling and recruitment

This cross-sectional survey generated a convenience sample using a snowball approach. Key non-governmental agencies (NGO's) and bilateral funders of end-of-life and palliative care, as well as HIV care advocates and practitioners within all Sub-Saharan African countries were identified. Following telephone contact with funders, email contact was made with services and local coordinators and they were asked to complete and return the survey. Fifty-four completed surveys were returned, and 48 of the returned surveys met inclusion criteria. Surveys were included in the analysis if they were a service in sub-Saharan Africa providing end-of-life care for (but not necessarily exclusively for) people with HIV/AIDS.

Survey variables and analysis

Twenty-seven questions were included in the survey, which addressed service aims and configuration, including program description and objectives, diseases and stages addressed, multi-professional staffing make-up, patient education, poverty mitigation and primary prevention, barriers to pain control, governmental endorsement and strategies for palliative and end-of-life care, funding, program monitoring and evaluation, and research activity. In addition, respondents were asked to state their current priorities, the types of information most useful to be fed back to them from the survey, and their views on the future of the field. The majority of initial responses for each question were closed multiple-choice responses, with additional space for qualitative comments on each question.

Data analysis

Data were entered into SPSS v11, and recurrent string variables for open-ended questions grouped into themes and/or repeated items.

Results

Settings and funding

Participating countries were: South Africa (n = 27) Zimbabwe (n = 3) Kenya (n = 3) Uganda (n = 2) Benin (n = 1) Ethiopia (n = 2) Gambia (n = 1) Ivory Coast (n = 1) Malawi (n = 1) Nigeria (n = 1) Sierra Leone (n = 1) Swaziland (n = 1) Tanzania (n = 1) Zambia (n = 1) (cross-border projects n = 2). Fourteen described their settings as

rural (30%) 10 as urban (21%) and 23 as mixed (49%) (missing n = 1).

The annual funding for the entire care programs ranged from US \$6,190 to US \$3,300,000 per annum, with a mean of US \$374,884 (median \$100,000 SD \$688,697) (missing n = 10). Funding required monitoring and evaluation in n = 40 (89%) and n = 39 (87%) programs respectively (missing n = 3).

Program aims and configuration

The care systems were grouped into service models. Hospice including each of inpatient, home care, and day care n = 12, including both home care and day care n = 6, only home care n = 7, including both inpatient and home care n = 3; community clinic including each of inpatient care, home care and day care n = 2, including each of primary care, home hospice, and hospice inpatient care n = 1; hospital palliative care project including each of inpatient, home and day care n = 2; home-based care n = 12; inpatient care and home care n = 1; psychosocial care n = 1; paediatric residential care n = 1.

The diseases included were as follows: HIV/AIDS n = 48 (100%), cancer n = 41 (87%), Tuberculosis n = 42 (88%), all advanced disease n = 32 (67%). Further description reported that an estimated 80–95% of patients had HIV/AIDS. Several home-based programs described avoiding HIV discrimination by not including diagnosis in eligibility criteria, but rather using criteria of a "vulnerable household". The disease stages addressed were: point of diagnosis n = 31 (65%), advanced disease n = 42 (88%), and end-of-life care n = 48 (100%) (missing n = 1). The services provided the following types of intervention: direct care n = 48 (100%), advice and information n = 48 (100%), lay education and training n = 43 (90%), professional education and training n = 40 (83%), research and evaluation n = 37 (77%), and policy advocacy n = 31 (65%).

The care elements of the programs constituted a broad mix: information n = 45 (96%), lay carer and family support n = 44 (94%), psychosocial support n = 43 (92%), comfort care n = 42 (91%), pain and symptom control n = 43 (90%), and palliative care n = 42 (89%). The place of care was as follows: home care n = 46 (98%), day care n = 31 (66%), inpatient care n = 24 (51%) (missing n = 1). Of those that provided inpatient care, there was a mean of 15 available beds (range from 3–61, median 8, s.d. 15). Of those that provided home care, a mean of 301 patients were currently seen in a range of 5–1000 (s.d. 247, median = 240).

Thirty-seven programs (77%) addressed poverty effects on disease management and progression. Further description

reported this as achieved through collaboration with multi-sector mitigation programs (n = 15), nutritional assistance and supplementation (n = 16), income generation projects (n = 8), safe house systems/accommodation (n = 4), assistance for food production (n = 5), and crisis admissions (n = 1).

Most services (n = 35, 75%) had a program to educate and diffuse palliative care (missing n = 2), and most also reported an interface with HIV prevention (n = 42, 91%, missing n = 1). Descriptive data reported that prevention was most often directed at the patient (n = 6) and family/lay carer level (n = 14), but also broader community/public health education activity was reported (n = 12). Prevention was described as integrated throughout all care activities (n = 16), and often provided in collaboration with other NGOs (n = 8). Prevention was seen to offer hope and credibility to care programs while avoiding alienation from end-of-life care services (n = 5).

Governmental and cultural contexts

Although government strategy on palliative care was often reported as absent, government endorsement of providers' work was reported by 41 programs (85%). Additional comments reported the importance of investing time in governmental relationships as a key element to a program's success. Governmental endorsement was exemplified by representation of social services and various members of the Ministries of Health on project management committees. Governmental strategy for palliative care was reported by 23 projects (48%), however, no government strategies were reported for Benin, Ethiopia, Gambia, in two-thirds of the Kenyan programs, Sierra Leone, in 14 out of 25 South African programs, Swaziland, and Zambia. Problems reported with government strategies on palliative care included governments not knowing what palliative care is, lack of strategy detail, non-implementation at the local level, strategies being informal, and lack of funding for implementation of strategies.

Forty-seven programs (98%) reported traditional healers playing a role in local health belief and practice. The influence of traditional healers manifested in an estimated 80% of patients seeking their advice, leading to delayed clinic presentation and medical intervention. Traditional healers were often included in care and education programs, with priests, Sangomas, Pandits and Mollanas along with Hindu, Christian and Moslem spiritual care, and were seen as key to gaining community approval and improving service uptake.

Overall, 94% (n = 44) of programs reported having written goals and objectives, and measurement indicators were present in over 90% of these programs. Twenty-nine

programs reported expanded indicator measures which included patients seen and/or activity reports, staff retention and training, quality of life, evaluation of annual business operating/service plan, community capacity and participation, user satisfaction and care standards.

Pain relief

The vast majority of services (n = 45, 94%) reported that they experienced challenges to providing pain relief. These were: drug availability (n = 36, 75%), lack of providers (n = 30, 63%), transportation (n = 29, 60%), stigma (n = 29, 60%), and government restrictions (n = 24, 50%). Other qualitative descriptions of challenges were: drug costs (n = 10), lack of trained personnel to administer (n = 8); lack of clinical expertise/awareness of pain control (n = 7); patient inability to pay (n = 3); fears of misuse of potent narcotics/underprescribing (n = 3); appropriate pain relief drugs absent from essential drugs lists (n = 2); funder restriction on drug procurement (n = 1); clinical disbelief in AIDS-related pain (n = 1); patients not visiting the hospital at late stages of disease (n = 1); and lack of referrals (n = 1).

Quality, monitoring and evaluation

Guidelines for good practice were in place for 34 programs (79%). These were further described as care standard guidelines (including Hospice Association of South Africa/Hospice Palliative Care Association of South Africa/World Health Organisation) (n = 12) and in-house manuals/guidelines (n = 8). Monitoring activity was reported by 37 services (86%) (missing n = 4). The primary monitored activities were described as number of patient visits and carer activity, food security, clinical audit, household survey, training and evaluation. Evaluation activity was reported by 37 services (86%) (missing n = 4), described as audit, patient care and outcomes, patient and carer need, place of death preferences, costs, training and evaluation.

Current priorities and views on the future of the field

Descriptions of program priorities and views for the field were analysed and grouped into 5 categories: epidemiological need and service expansion, access and quality assurance, advocacy, resources and consolidation, and limitations

- *Epidemiological need and service expansion (n = 84)*

Expansion was foreseen to reduce overload on health services and to build health care system capacity, secure provision of palliative care, and expand home-based care. A primary area for expansion was lay and professional education and training, particularly in pain management and palliative care across all advanced disease for the entire health system. Additional areas for service expansion include ARV procurement, expansion into urban and

poor areas with community-managed projects and increased patient coverage. The need for total care elements of emotional support, poverty mitigation, food security, traditional healing, orphan care and nutrition, water, shelter and sanitation through NGO collaboration were noted as areas for expansion. Additionally, tasks of public education and prevention were identified. Community mobilisation and establishment of links between hospices/palliative care and health systems were seen as methods of expansion. There were differing opinions on the success of home-based care, which was viewed as both the only means to provide the necessary care and also as an impractical response due to communities being overwhelmed.

- *Access and quality assurance (n = 30)*

The need for coverage and access without compromising quality was a primary concern among programs, and was seen as achievable through mechanisms of quality assurance, monitoring and evaluation. In addition, the need for clinical training was recognised as necessary in providing a "good death," including training in pain and symptom control and the treatment of opportunistic infections. Further steps included policy and advocacy initiatives and the establishment of centres of excellence.

- *Advocacy, resources and consolidation (n = 23)*

In order to sustain and expand end-of-life services it will be necessary to explore diversified private, bilateral and multi-lateral funding potential in addition to governmental funding. Respondents described the need for education of policy makers and programs managers (advocacy) of end-of-life and palliative care through establishment of academic chairs of palliative medicine, increased national/governmental awareness of and commitment to hospice and palliative care and training, and donor interest in care rather than solely prevention.

- *Limitations (n = 8)*

Limitations to the future field of end-of-life care were identified. These included lack of trained professionals, retention of trained professionals, funding restrictions, excessive stress on lay provision, prohibitive drug costs, increasing patient load, weakness in current health system infrastructure, and lack of communication of effective strategies.

Survey information identified by participants as most useful to be fed back

Respondents were asked what information from this survey would be most useful to them. The most requested information was related to optimising service provision, including drug prescribing, pain relief, palliative care referral criteria, and palliative care training in AIDS. Additional, information was requested on orphan care, nutri-

tion, food security, staff support, and identification of useful journals as well as information on networking and information sharing among other programs and identification of potential partnerships. Eight programs required strategies for palliative care advocacy: demonstration of its feasibility in rural settings, provision of training, education and innovation. A further 8 required information on funding opportunities and sources, and 6 identified informational needs on quality and best practice guidelines, monitoring, evaluation, audit, and the tools and means to their integration.

Discussion

Key issues for consideration

This study found significant limitations in, and pressing need for expansion of, current HIV/AIDS palliative and end-of-life services. Additionally, it highlighted the need for advocacy for palliative and end-of-life care, and a concern for quality measurement. A set of five key inter-related issues should be considered to fund and implement HIV end-of-life and palliative care in sub-Saharan Africa.

1. Pain control is a primary challenge, and must be addressed. This requires development of pain medication regulation, procurement and distribution policies, and education of health professionals, community workers, and affected people in their purpose and use. These activities may be termed advocacy for palliative and end-of-life care, i.e. raising awareness of and promoting the specialism as an achievable and integral element of care. Initiatives intended to expand palliative and end-of-life care must extend beyond direct care programs to include such policy and education efforts.
2. The balance between quality of care and numbers of individuals served must be considered when programs are expanded. Surveyed programs reported strong quality assurance efforts. These efforts, however, must be increased.
3. Programs reported needs for technical assistance in monitoring and evaluation. Such assistance will be required to strengthen measurement of patient outcomes, quality and coverage.
4. Effective palliative care requires collaboration between funders, NGOs, providers, and in-country governmental agencies. Effective networks of these entities will be required to share knowledge, experience and effective strategies.
5. Resources will be required to promote understanding of, and support for palliative care in order to sustain or improve current activities. The rewards of such efforts can be anticipated to be felt in multiple domains of care, better-integrated health policy, and strategy, as well as improved clinical education and training at all levels.

A proposed research agenda

Although hospice and palliative care teams have been shown to improve patient outcomes [14] this study is the

first survey of HIV/AIDS end-of-life care in sub-Saharan Africa. In order to minimize the risk of failure, it is important that new or expanding palliative and end-of-life projects in developing countries understand both the problems and success experienced in existing programs [15]. The implementation of a practical research framework is crucial to measuring the effectiveness of funding efforts and to ensure wise allocation of resources.

The five key issues above delineate an initial set of research topics. Domains to be investigated include availability of pain relieving drugs, pain and symptom control, access to services, extent of coverage programs, education and training (including clinical, administrative and other skills), identification of relevant needs and determination of outcomes for care at the community level, and evaluation of the impact of education of policy makers and program directors about palliative and end-of-life care (sometimes termed advocacy). This presents particular challenges in selecting appropriate measures and methods. Relevant outcomes may include policy, strategy, sustainability, availability and utility of education and training, and integration of end-of-life care into health systems.

Another important area of research is impact of palliative care on prevention. A palliative or end-of-life care setting, be it home or institutional based, offers many opportunities for public health education. Such care may also facilitate the readiness in communities to accept and act on prevention strategies.

Consistent measures will be required in order to systematically evaluate the feasibility and effectiveness of the diverse models and program configurations described in this survey. Despite the fact that HIV disease progression is similar around the world, there is greater symptomatic disease in Africa [16]. Care services, therefore, may need to target those with earlier stages of disease [17]. Hence, the aims and inclusion criteria of programs are relevant variables for outcome evaluation.

The fundamental question of what constitutes a good death has been explored in a single African population with regard to cancer [10]. The HIV/AIDS-specific experience is unknown and merits inquiry.

Of the 42 services (89%) that reported providing palliative care in this survey, 37 (92.5%) reported challenges in pain control. Therefore, while it would be unfair to suggest that palliative care is not understood or achieved, the success with which it is implemented is open to question. Exploring the reasons for this are an important research target, particularly as supportive care is often used interchangeable with palliative care despite the absence of

effective pain (i.e. step 3 of the analgesic ladder) and critical symptom control in supportive care.

Limitations

There are several limitations to this study. It is a convenience sample and therefore does not claim to be representative of all end-of-life care activity in Sub-Saharan Africa. It is not possible to present a response rate as we cannot calculate the number of email recipients or how many of our contacts would have met the inclusion criteria. A response bias may be expected towards those most engaged in research, evaluation and palliative care. South Africa is strongly represented as a country with a network of hospices and comparatively well-developed primary care and a different set of economic and social circumstances in comparison to other Sub-Saharan countries. Therefore, the data may be expected to largely represent those institutions with relatively fewer challenges in end-of-life care. This, therefore, may under represent the challenges across the continent.

Conclusions

This survey indicates that, despite many constraints, integration of end-of-life and palliative care services into the fabric of HIV/AIDS care in sub-Saharan Africa is acceptable and feasible. As international and in-country agencies focus on funding care for those with advanced HIV disease, it is crucial that issues of pain control, quality and coverage, monitoring and evaluation, collaboration between agencies and education of policy makers and program directors are promoted and addressed. These five key areas are inter-related and should be pursued in a coordinated manner.

Competing interests

None declared.

Authors' contributions

RH designed the questionnaire, collected, inputted, and analysed the data and prepared drafts of the manuscript. KS assisted questionnaire design, collected data and commented on the manuscript. KM assisted in questionnaire design and redrafted the manuscript. JoN conceived the project, assisted questionnaire design and commented on the manuscript. IH drafted the questionnaire and commented on the manuscript.

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