

Diana

PALLIATIVE CARE INITIATIVE

Executive Summary

Palliative Care in Sub-Saharan Africa:

An Appraisal

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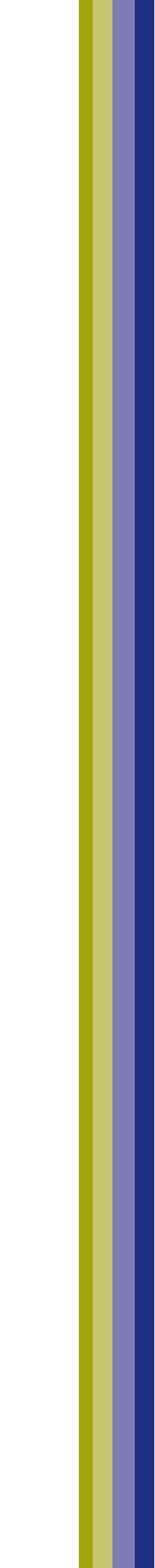
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“HIV/AIDS has made medicine understand that if it is only focused on cure and ignores suffering it is not doing its job. It has made the call for what palliative care is all about imperative, and the role of palliative care in fighting HIV/AIDS inevitable. The amount of suffering is simply too great, and the promise of cure, for many, too distant. Palliative care provides an effective model for integrating many aspects of care that are essential in the fight against HIV/AIDS. Obviously the model will be quite different in Windhoek than Washington.

This report offers an overview of existing palliative care models in Sub-Saharan Africa and provides an excellent foundation for donors, policy makers and practitioners wishing to scale-up palliative care provision in Sub-Saharan Africa.”

Joseph. F. O’Neill MD MS MPH

**Deputy Coordinator and Medical Director,
Office of the Global AIDS Coordinator,
US Department of State**

Foreword

Despite lack of access to effective treatment for people in the developing world affected by HIV/AIDS and other life-limiting illnesses, the availability of palliative care continues to be extremely limited. Millions of people and their families suffer unnecessary pain and distress for want of access to palliative care, a simple and affordable approach which could so readily be incorporated into the work of every doctor, nurse, family member or volunteer. While there is hope that treatment for HIV/AIDS with Highly Active Anti-retroviral Therapy (HAART) will become much more widely distributed, it is not a cure and palliative care is still needed to support people accessing HAART.

Diana, Princess of Wales had an enduring commitment to people facing life-limiting illnesses. With her genius for making human connections, she was intuitively at ease with others' impending death while focusing her attention on life in the present and on how to make it the very best it can be. She understood that the needs of sick people, as well as of their loved ones, are not only medical and physical, but also mental and emotional - the need for relief from physical pain, but also the need for love, resolution and peace of mind. It is therefore appropriate that her Memorial Fund should take up the challenge of promoting palliative care in the developing world through the work of its Palliative Care Initiative, established in 2001.

This programme of grants and advocacy, focusing at present on sub-Saharan Africa, aims to influence policy and raise public awareness in support of palliative care. Our goal is to ensure that palliative care becomes an integral and properly funded part of public health policy in every country in the region. This is being achieved through supporting local 'champions' who provide palliative care, promoting training for doctors, nurses, health workers, carers and volunteers, and advocating for the availability of drugs for pain relief and symptom control.

There is now a wealth of experience in sub-Saharan Africa about the ways in which palliative care can be delivered both affordably and effectively. However, as this excellent report shows, there remains lack of properly documented evidence and research to demonstrate the importance of this work and promote its development. If palliative care is to grow as a widely available specialty delivered to a high standard, then it is vital that the evidence base is increased. We hope that the report, with other mapping work commissioned by The Diana, Princess of Wales Memorial Fund, makes a useful contribution to this effort, as well as providing a source of reference for policy makers, practitioners, donors and researchers interested in this vital issue.



Christopher Spence MBE

Chair

The Diana, Princess of Wales Memorial Fund

1. Executive summary

Rationale

- 1 Palliative care aims to maximise quality of life and relieve the suffering of patients with life-limiting incurable disease, and to support their families and carers.

It is provided through specialist services such as hospices and palliative care teams and in general settings. The HIV/AIDS pandemic and rising cancer rates in Africa have increased the need for well-developed and integrated palliative care services. In sub-Saharan Africa, the concept of palliative care is not well developed and palliative care is largely confined to isolated specialist centres. Services have developed, but in very varied ways. In order to inform future developments, this review aimed to identify and appraise activities, opportunities and evidence of the status of palliative care in Africa.

The World Health Organisation (WHO) defines palliative care as

“an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”

Methods

- 2 Two key sources of information were investigated: firstly, electronic biomedical databases, and secondly prepared reports from funders, non-governmental organisations (NGOs), associations and practitioners. The evidence was analysed according to various headings: context, potential role, current models, and opportunities in relation to sustainability and quality of palliative care.

Main findings

The sub-Saharan African context of palliative care

- 3 In 2003 there were 26.6 million people in sub-Saharan Africa living with HIV, 3.2 million new infections and 2.3 million AIDS-related deaths. In addition, there are more than 0.5 million annual cancer deaths, and cancer rates in Africa are expected to grow by 400% over the next 50 years. 80% of cancer patients present with advanced incurable disease.

- 4 Although the definition of palliative care is globally relevant, what constitutes palliative care needs and services in sub-Saharan Africa is continent-specific, particularly in the light of poverty and HIV disease. Necessary components include practical care, pain and symptom control, counselling/emotional /psychological support, income generation, financial support for food, shelter, funeral costs and school fees, respite, spiritual support and orphan care.
- 5 Within Africa there are diverse attitudes towards death and dying informed by multiple meanings and traditions. This has important implications for the identification of appropriate models and places for end-of-life care. Traditional healers are often the first place where help is sought in both cancer and HIV/AIDS.
- 6 There are significant structural and resource challenges to establishing sustainable palliative care: resource limitations and poor infrastructure, poor access and regulatory limitations on drug procurement (particularly opioids), funding uncertainty and patient inability to pay, high rates of healthcare, staff mortality, and lack of clinical skills training.
- 7 Patients and families need emotional and psychological support, but these are rarely identified. Few such interventions for sub-Saharan African clients have been described.

The role of palliative care in HIV management, including antiretroviral therapy

- 8 Palliative care should be integrated into the management of HIV disease throughout the disease trajectory, from diagnosis to the end of life. The necessity for palliative care throughout the disease course is evidenced by both Western and sub-Saharan African data, with a high prevalence of pain and manageable symptoms from the point of diagnosis. Although the terminal management skills of palliative care are still necessary, patients who access palliative care need not be at the end-of-life.
- 9 Although pain prevalence is high throughout the HIV/AIDS disease trajectory, HIV/AIDS care has historically relied on home-based care without adequate pain and symptom control. Home care providers have recognised this inadequacy, and termed it “home-based neglect”.

- 10** Palliative care is necessary to support current and planned antiretroviral therapy funding initiatives. The clinical data is clear: poor adherence/toxicity/side effects/drug resistance, virologic failure, adverse reactions, and peripheral neuropathy. Some HIV-associated cancers have not reduced greatly in incidence, and the psychological and spiritual needs of people with HIV persist. Even in those countries with universal access to antiretroviral therapy, people with HIV disease continue to die at a higher rate than the uninfected. Palliative care can promote adherence and manage tolerance and also provide end-of-life care for this for whom treatment is unavailable or fails.

Current models of care

- 11** The core steps to service development are advocacy (national policies and guidelines), integration of palliative care into the continuum of care, education and training, drug access and data systems, and the need for opioids is fundamental to palliation. However, it is not yet clear how these steps translate into specific feasible, acceptable accessible and effective models of care at the service level. Although innovation has led to a diversity of models, the need for accessible quality services remains a crucial issue.
- 12** Where available, palliative care appears to be provided by highly trained individuals, but unfortunately does not reach many people who need it.
- 13** Grafting palliative care onto existing networks of home-based care that currently offer inadequate pain and symptom control is feasible. Other systems include referral to specialist services, nurse prescribing of morphine, and lay/professional protocol-led patient management manuals.
- 14** Home-based care is by far the most common model of palliative care provision, a resource-led decision in response to high numbers of patients and modest resources, thereby maximising coverage and sustainability. The home-based care offers flexibility and increased potential for culturally appropriate care, but is limited by the suitability and availability of a home and family care network, and by the geographic area that can be feasibly covered by palliative care providers.
- 15** Innovation has led to specialist and integrated palliative care being delivered by diverse models of care across settings, and in several cases has been developed in the absence of additional resources. Specialist palliative care centres are a focus for interested practitioners, advocacy, policy, resources and education, and have an important role in developing countries.

- 16** Referral networks and coverage maximisation are primary concerns in connecting patients with palliative care needs to quality services. In rural areas where doctors are rare, training at all levels is required. In urban areas, specialist palliative care hospital consultancy as well as the mainstreaming of clinical education are required.
- 17** Although there are many potential models of delivery, the palliative care approach can be employed by every doctor, nurse and volunteer, it can be simple, and protocol driven. The use of simple palliative care manuals is an excellent example of maximising skills at the appropriate levels.
- 18** Community involvement, particularly the use of volunteers to identify those in need, appears to be successful. However, the capacity and methods of volunteer recruitment and retention are still unclear. The diverse and innovative methods of incentives, training and support require further evaluation to ascertain how replicable they are.

Quality assurance

- 19** Community-based TB care has been shown to be more effective than institutionalised care, and palliative care services may benefit from the systems and operational research undertaken in TB care. Integration of HIV care, antiretroviral provision, TB care and palliative care may offer economies of scale as well as access to palliation at those points in time when patients could benefit from the approach.
- 20** Factors for success in community care include: realistic aims in the light of apparent limitations; political will and support; long-term goal setting and adequate time allocation for success; optimal referral systems.
- 21** Palliative care services clearly need to be scaled up in the light of low coverage and high need. Significant resources are needed to ensure that educational and training gains are employed in the workplace and that momentum is retained. Currently, although advocates for palliative care have achieved much, evaluations of advocacy activities are not undertaken.
- 22** Providers report a need for technical support in measuring and auditing quality of care. This is reflected in the general absence of evidence for development, outputs and outcomes, although some services have described measurement and assessment activities in annual reports. The poor recording of data was frequently reported.

Recommendations

For practitioners

- 1** Models and place of care must take into account local understandings of health and illness, and replication of models must consider feasibility and acceptability. Traditional healers form an important element of health services, and should be included in care provision through training and co-management of some symptoms and side effects.
- 2** The Western-originated palliative care model must be adapted to the needs and context of sub-Saharan Africa, and what constitutes a holistic total palliative care service in Africa should be designed at the outset of provision.
- 3** Pain and symptom management, and support, must be provided throughout the disease trajectory from diagnosis to end-of-life. In particular, enormous need and opportunity reside in the many HIV home-based care providers who should be encouraged and enabled to incorporate palliative care.
- 4** Efficient referral systems must be established to connect those in need to palliative care services. These services may be professional or lay, and can operate between various settings, e.g. hospital/specialist consultancy, generic/specialist co-management, community volunteer/specialist. Resources must be anticipated to address the likely increased uptake. Palliative care does not need to be provided in all care settings. If effective referral systems are in place generalist providers who do not wish to meet opioid storage regulations can ensure their patients receive palliation when required.
- 5** Emotional and support needs, particularly of families and carers, should not be overlooked. Further understanding and service responses are needed to meet these poorly explored needs.
- 6** A simple method to increase palliative care skills and coverage is the use of protocol-led care manuals identifying steps for the assessment and management of pain and symptoms. Widespread use of such manuals should be encouraged to disseminate the view that palliative care can be simple, protocol led and employed by all health care staff.

For funders

- 7** Clinical training must be mainstreamed in order to maximise coverage by placing palliation skills in all health settings. However, following training, resources must be allocated to enable continuity and application of skills learned.
- 8** It is not feasible for a single funder or provider to take responsibility for the resources and skills required to meet total need in the sub-Saharan African context. Co-ordination and multisectoral responses must be pursued to meet patient and family needs.
- 9** Antiretroviral programmes require palliative care integration in order to maximise adherence and clinical benefit through the management of toxicities and side effects. Also, funding for ethical health services requires palliation for those whom the treatment fails, who continue to develop life threatening advanced disease, or are unable to access therapy.
- 10** Funders should support advocacy activities to promote and sustain palliative care in sub-Saharan activities. Advocacy programmes must be subjected to evaluation to measure their success in reaching stated objectives.

For policy makers

- 11** Palliative care must be a public health priority in the light of current and projected need particularly in response to the HIV epidemic and increasing cancer incidence. The absence of palliative care is associated with unacceptable levels of poorly managed pain and symptoms.
- 12** The availability of opioids is fundamental to adequate pain relief, and must be guaranteed through legislative efforts and efficient drug supply services where necessary.
- 13** Diversity and innovation are key features of palliative care development in the diverse resource-poor settings of sub-Saharan Africa. However, a strategic approach is necessary to achieve palliative care delivery, incorporating advocacy (national policies and guidelines), integration of palliative care into the continuum of care, education and training, drug access and establishing data systems.

- 14** Explicit strategic approaches are needed to harness the twin approaches of advocacy for palliative care and community-level delivery. With respect to advocacy, the significant gains to date have been largely achieved through the advocacy goals of individuals not strategy. Further investment in developing sub-Saharan African “champions” of palliative care, within national and international strategies, may harness gains to date for longer-term sustainable growth. Advocacy activities should be evaluated.

For researchers

- 15** Systematic attention must be given to feasibility, acceptability, accessibility, effectiveness and designing specific models of care at the service level. The need for innovative, quality, accessible services remains a crucial issue.
- 16** Community-based care projects offer feasibility, optimal coverage, and active referral networks. However, replication of successful demonstration projects would benefit from further process evaluation and description of resources and potential weaknesses, as well as further understanding of the clinical support and community capacity to care.
- 17** In order to generate evidence for effectiveness grounded in the African context, funders must support research and technical assistance for their services across policy, advocacy, development and care objectives. An evaluative programme is required with respect to domains of process, feasibility, acceptability, accessibility and outcomes. To achieve this, technical expertise in measurement design, service goals setting and development, client assessment, quality measurement, audit and outcome research are required.

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