

Palliative care in Africa: an overview

For the majority of Africans with progressive and life-limiting illnesses, access to culturally appropriate holistic palliative care is inadequate.

Faith Mwangi-Powell and Olivia Dix explore the issues

Why palliative care?

Palliative care, has been defined by the World Health Organization (WHO) 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.'¹ It is applicable from the point of diagnosis, through the course of the disease and into bereavement.

In sub-Saharan Africa, the need for palliative care is significant. In 2009, an estimated 22.5 million people were living with the human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) – 67% of the global disease burden – with 1.8 million new infections reported in that year alone.² There were over 700 000 new cancer cases and nearly 600 000 cancer-related deaths in Africa in 2007,³ and cancer rates on the continent are expected to grow by 400% over the next 50 years.⁴ In addition, as people's lifestyles on the continent change, Africa may experience an increase in the incidence of chronic non-communicable diseases (NCDs).⁵ Most Africans, however, have no access to effective screening, early diagnosis, treatment or palliative care; those with cancer and other life-threatening illnesses experience a painful and distressing death. For people with AIDS, antiretrovirals (ARVs), where available, have had a profound impact on patient morbidity and mortality, but they have not negated the need for palliative care. Palliative care has a crucial role in providing effective monitoring of ARV therapy, managing any associated toxicity and side-effects, as well as addressing the new co-morbidities resulting from the prolongation of life.⁶

Barriers to palliative care development

Following WHO's estimation of the need for palliative care as being 1% of a country's total population,⁵ approximately 9.67 million people are in need of palliative care across Africa. Despite this, for the overwhelming majority of Africans with progressive and life-limiting illnesses access to culturally appropriate, holistic palliative care is at best limited, and at worst non-existent.⁷

Several factors exert an adverse influence on the provision of palliative care services for the majority of

people in Africa. Firstly, palliative care is a relatively new discipline in the continent and its development is hampered by the fact that it is not integrated into health systems. Out of 53 African countries, only 4 have palliative care integrated into either their health or their cancer strategic plans (Kenya, South Africa, Tanzania, and Uganda), while two (Rwanda and Swaziland) have developed stand-alone national palliative care policies. Most palliative care is provided by non-governmental, faith, or community-based organisations with no in-built sustainability. Additionally, only five countries have palliative care integrated in the curriculum of health professionals, of which four (Kenya, Malawi, South Africa, and Uganda) have recognised palliative care as an examinable subject, so there is a significant skills training deficit.⁸ These challenges are exacerbated by poor health and social care infrastructures in many African countries and the lack of available health financing. In addition there is a widespread lack of understanding of what palliative care is and its benefits. It is often seen as only valuable at the end of life and yet the benefits of palliative care are vital from the point of diagnosis.

Access to medication is crucial to high-quality and effective pain and symptom management. However, in many African countries, access to even the simplest pain-relieving medication is limited, while strong painkillers, e.g. opioids, are legally restricted.^{8,9} Systemic challenges in the supply chain – from ordering to administering opioids – are compounded by the lack of pharmacists in public health services and the restriction of prescription authority. So, for example, in 2008 the vast majority of morphine was consumed in industrialised countries, while in Africa the regional mean was only 0.33 mg per capita compared with the global mean of 5.98 mg.¹⁰

There is also a lack of methodologically robust evidence-based information on the effectiveness of palliative care; given the wealth of clinical and academic

Patient's quote

'With the medication to help my pain, I can cycle again. I used to cycle 25 km to work every day. I would be in real trouble if the hospice doctor didn't come.' Albert Tembo, 58, HIV patient, Zimbabwe.

Doctor's quote

'As a doctor, sometimes you see a patient with severe pain and you don't know what to do. Palliative care has changed my life and my practice as a doctor. It has made me enjoy my profession once again.' Medical Doctor, Mulago Hospital, Uganda.

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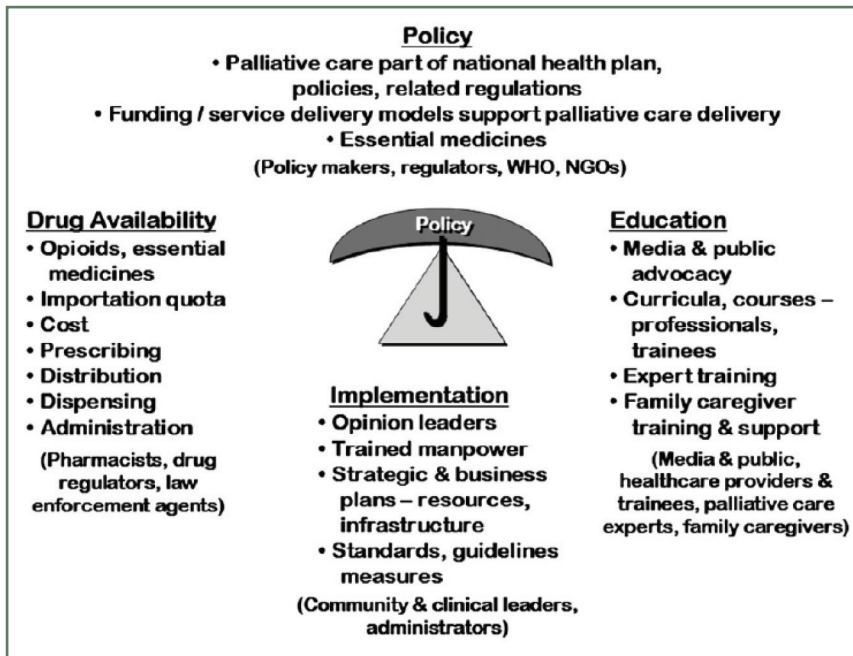


Figure 1 Enhanced WHO public health model.¹³ Reprinted with permission from Elsevier

experience and yet the dearth of methodologically robust evidence,¹¹ research is required to inform the delivery of effective and appropriate care.^{12,13}

Established in 2005, with a mission to ensure palliative care is widely understood, integrated into health systems at all levels, and underpinned by evidence in order to reduce pain and suffering across Africa, the African Palliative Care Association (APCA), encourages governments to use the four-pillar enhanced public health model of palliative care provision (see Figure 1)¹³ to support a population-based approach to palliative care development that focuses on integration into national health systems to increase accessibility.

With regard to health systems strengthening, there is a global recognition that closing the inequitable gaps in global, regional, and national patient outcomes – such as those embodied in the health-related Millennium Development Goals (MDGs) – is dependent on the strategic strengthening of the delivery capacity of health systems. WHO has identified the goals for health systems as good health, responsiveness to the expectations of the population, and fair financial contribution.¹⁴ The six fundamental building blocks of a generic health system include: service delivery; the health workforce; information; medical products, vaccines, and technologies; financing; and leadership and governance.

As well as responding to an urgent and unmet need, the holistic approach to the health needs of the patient, their family and community, and the structures created to deliver palliative care, mean that it has a significant contribution to make to health system strengthening.

For example, in terms of service delivery, palliative

Nobel Peace Prize winner Eli Wiesel noted, 'If I suffer and am silent, it can be a good silence. If I am silent when someone else is suffering, it is a destructive silence. We have had enough silence and destruction.'

care demonstrates important linkages between communities and health services and systems that can benefit health system resource allocation (e.g. care being provided at home rather than in expensive in-patient facilities). More importantly, these linkages ensure that patients receive care where they want it and provide effective referral systems in order that patients receive the right care and treatment from the right place. Palliative care provision also embodies the kind of trained multi-disciplinary team that will be crucial to strengthening the workforce in Africa. Indeed, palliative care in its insistence of an inter-disciplinary model of care provides an effective model for integrating the many aspects of care that are necessary to address HIV/AIDS: medicine, nursing, social care, family members,

religious and spiritual care, and more. Obviously, this model will be quite different from country to country but it is a concept where the focus of care is the patient within the context of their family and the wider community. This offers a point of departure from more traditional and linear means of organising healthcare.

In addition, palliative care is leading the task-shifting agenda on the continent. In Uganda, nurses and clinical officers have been trained through a 9-month specialist palliative care programme and legally allowed to prescribe opioids, thus ensuring that effective pain medication reaches patients wherever they are. This too requires an effective drug procurement, distribution, and quality assurance system that works in conjunction with other essential medicine systems. Palliative care services have demonstrated this is possible, providing valuable lessons for wider medicine distribution. Consequently, strengthening health systems by integrating palliative



Advocacy: the message needs to be broadcast as much in the community as in the hospital

care will have a dual effect; it will ensure that patients have a greater access to care and the systems will benefit from the multiple lessons that can be drawn from the palliative care approaches.

Conclusion

The agenda to address the issues raised here need not be developed by an isolated and limited number of specialists. It requires collaboration and strategic partnerships with the health professionals, especially the clinical experts leading the way in developing and embracing palliative care skills, so that the scale-up of the provision of palliative care in the resource-poor setting can happen. It is worth noting, however, that the provision of palliative care – be it by a hospital in sub-Saharan Africa or a clinic in a high-resource setting – can reflect to the patient, and eventually to the community, that they are worth caring for. It is this reflection of self-worth and dignity that is essential for improving health in low-resource settings. It is only when an individual or a community believes that their life is worth saving that behaviour and social norms can change, for example in the direction of reducing HIV-transmission risk. Palliative care offers this even when curative care remains elusive.

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