

Chapter 33

Effect of Economics on Service Development

Overview

In resource-limited countries, it can be difficult to get governments to support palliative care for cancer. But it has become essential with the HIV/AIDS epidemic to use a holistic approach to control suffering to avoid having all available hospital beds filled with those living with this disease. Palliative care is an affordable and effective form of care when it is supported by governments and donor agencies. This chapter outlines how a country's economic state can affect the initiation and progress of palliative care in the African context. It uses examples of countries with established services and those beginning services to demonstrate the effects of economic constraints on the kind of services provided. The chapter also shows the experience of the authors with donors in the light of the more recent generous approach to funding for HIV/AIDS throughout Africa and the particular needs of NGOs.

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At a Glance

Factors Influencing the Provision of Palliative Care

Integrating and Balancing Palliative Care Services

Barriers to Implementing Palliative Care in Resource-Limited Settings

Economic and Social Restraints on Palliative Care

Donors' Economic Objectives and Policies

References

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Factors Influencing the Provision of Palliative Care

Palliative care has been commenced in several African countries. Many of the patterns of palliative care reflect the inspiration and ideas of the programmes' founders and were commenced with the needs of the local community in mind, although not always with community participation. A programme often reflects the previous experiences of its founder both in Africa and in other countries where the needs may be different but where palliative care is now well developed.

Thus Africa has yielded many patterns of care which now can be assessed in light of the continent's diverse cultural, economic, and other priorities. While this requires the public health approach, the model and approach to care will vary according to the needs of each country and the perceived needs of people living with HIV/AIDS and their carers. Palliative care requires a holistic approach to the psychological, spiritual, cultural, and physical needs of the patient, family, community, and the team. It allows patients to make choices in their lives up to the point of death. Therefore, communities must be involved in choosing their priorities in palliative care and the overall care of those who are dying.

To be effective, the public health approach must consider several country-specific factors. The presence or absence of these factors can guide decision making about how best to introduce palliative care within a public health approach so as to reach as many in the country as possible. The factors also are useful in assessing and monitoring existing palliative care services. For each country they include:

The presence or absence of palliative care and/or support care: Can palliative care be incorporated into existing community support services?

Availability of non-palliative support services on which palliative care could be grafted:

This rapid scale-up approach must ensure that the palliative care team is separate from the support team as the needs of the critically ill and those at end of life require more intense medical and holistic input.

The country's health priorities and indices:

Cancer is rarely included amongst the top 10 causes of death in African countries, and palliative care for cancer alone is not a funding priority. Although HIV/AIDS-related deaths are under-reported, it is accepted that many of the infectious diseases in the top 10 causes of death are HIV-related. Thus the needs of HIV/AIDS patients are a priority for most governments.

Prevailing government policy: Can the health department of a resource-limited government envisage a cost-effective contribution of palliative care/home care for its population in a sustained way (e.g., by decreasing terminal care in hospitals in the medium to long term)? Is there a long term role for a new non-essential service in an already overburdened health services (e.g., will this service relieve other overstretched services, or crowd the others out and increase health service utilisation)?

Education, status of, and cultural approach to

women: Women are typically the main caregivers in the family with a person with HIV/AIDS. In most countries, HIV is more common among women than men (e.g., in Uganda there is a 60:40 female-to-male ratio) and most professional and volunteer carers are women. It is important to address their needs as both infected and affected individuals, particularly as the carers of patients and orphans. In many African countries, women have a secondary place in society and have little say in what happens to them within and outside of marriage, including the practice of female circumcision. Some cultures regard wives as property to be inherited by the husband's family after his death. Some countries are addressing these cultural practices that encourage the spread of the virus and the suffering of women.

The country's economy and poverty indices:

The effects of the epidemic on the population pyramid, family earnings, and the availability of care in the community affect the amount of care and support there will be for people living with HIV/AIDS. Most people in rural areas in Africa depend on the extended family for support when in financial difficulties. To address the ever widening burden of care, it is necessary to increase the skills of caregivers in the community.

The extent of the epidemic and projections:

These figures must be taken into account when budgeting for health services including palliative care and antiretroviral therapy (ART) as part of support care.

Life expectancy: This statistic is an indicator of the effects of the epidemic. It has been observed that life expectancy falls as HIV incidence increases in a country. The availability of affordable ART could reduce this decline because it will extend life.

The availability of ART, and its effect on

palliative care services: ART is becoming more affordable and therefore more widely available. Palliative care programmes are seeing more patients on ART, which affects disease presentation and poses ethical issues such as when it should be discontinued when coming to the end of life. If available to even the poorest in a country, ART could also reduce the number of AIDS patients requiring critical and end-of-life care.

Health services for sexually transmitted infections (STIs), TB, and other opportunistic

and HIV-associated infections: These services are usually more widely developed in theory than in practice, though still not reaching many people at the community level.

The prescriber-to-patient ratio in the country regarding Class-A drugs:

Only doctors and, in a few African countries, medical assistants, can prescribe Class-A drugs, which includes morphine. This limits the number of patients who can be reached with pain and symptom control during critical illness and end-of-life conditions. Expert and approved palliative care training for other health professionals such as nurses, with the support of government, can be a means to increase the number of prescribers (see Chapter 35: Role of Government and Chapter 36: Drug Policy).

The involvement of government and ministry of health in palliative care services and

education: This must be a priority from the initiation of services. Government officials need to be sensitised to the needs and effect of palliative care in reducing the suffering of people living with HIV/AIDS and their families. Models of care should be planned to conform with existing services, terrain, and the ratio of a country's rural to urban populations.

The availability of morphine for use in the

home: If possible, an affordable oral preparation of morphine is a priority before the service commences so that it can be available to rich and poor alike. This also presumes special training of health care workers (HCWs) in its use and advocacy to allay the fears of senior health professionals. The government and national drug authority may need to revise the country's essential drug list to include medications that are affordable for pain and symptom control.

Inclusion of, or opportunities to introduce, palliative medicine in undergraduate and post-graduate training and curricula:

Introducing palliative care in the training of HCWs at all levels ensures the future availability of palliative care throughout the health system.

The people's preferences (wananchi in Swahili) for choosing where to die, and steering services toward meeting the needs of the terminally ill and their carers in the community: It is also important to consider government requirements surrounding death certification and its effects on place of care. For example, in Uganda, as in most African countries, people wish to die at home, close to the ancestral burial grounds and where relatives can be there for them. It is also very expensive to carry a dead body home. In Zambia, on the other hand, people expect to die in hospital because of a law requiring the family to bring the body to the hospital for death certification before burial, which is too expensive. The police also harass a family after a death at home when the deceased has not been seen previously by a recognised health worker.

The integrity of the country for outside funders: In the resource-limited economies of many African countries, palliative care requires the support of international donors. Some countries in Africa have shown by continued corrupt practices that they are unable to handle donations appropriately and have lost the trust of donors. Donors need to see that funding is going to be used for the purpose it is given. Poverty alleviation is very much on donors' agenda today, but if donors see their money only making the rich richer, they will cut or eliminate funding. Integrity at the micro level is an important issue for all those working in palliative care.

Integrating and Balancing Palliative Care Services

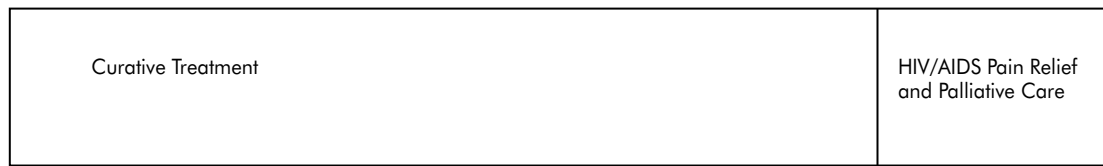
In resource-limited countries, where both cancer and HIV/AIDS are typically diagnosed very late in the course of a person's illness, palliative care services may dominate the available services. In settings where disease-specific therapies are available, palliative care services are balanced with these therapies.

For many people with HIV/AIDS, the unavailability of disease-specific therapies increases their need for symptom control and supportive therapies to improve their quality of life. In settings that offer early diagnosis and disease-specific therapies, palliative care services will support such therapies, increasing as needed along the disease trajectory.

It is important to stress that national HIV/AIDS programs should not view palliative care and disease-specific therapies as either/or phenomena. The more modern and ethically appropriate approach is to view the two as part of a continuum in which care and therapies are prioritised and balanced based on patient needs and available resources. It is also important to fairly distribute available resources to the largest population in a cost-effective and efficient system of health care delivery.

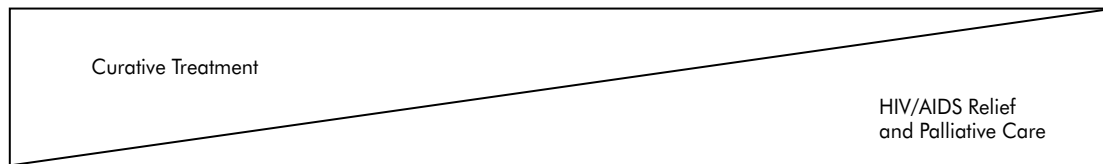
Figure 33.1 illustrates existing and ideal distribution of resources between active disease-specific therapies and palliative care services for people living with HIV/AIDS along the trajectory of their illness.

Figure 33.1: Models for Allocation of Curative and Palliative Care Resources



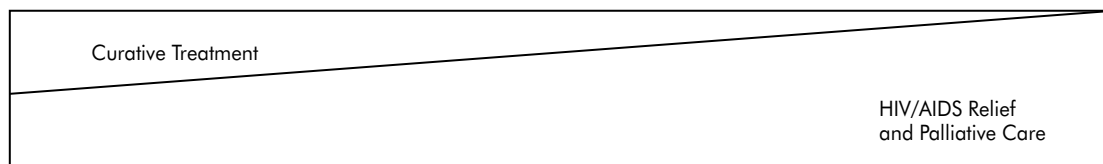
Model 1: Former Allocation of Healthcare Resources

In this model of care, all available resources are used exclusively for active disease-specific treatment, regardless of efficacy or concurrent needs, limiting patients' access to palliative therapy to the last days of life.



Model 2: Proposed Allocation of Healthcare Resources in Developed Countries

In this model, the proportion of resources for palliative care increases as disease progresses and/or as needed.



Model 3: Proposed Allocation of Healthcare Resources in Developing Countries

In this model, in advanced disease, and disease-specific therapies are often not available or appropriate.

Source: Adapted from WHO, 1990.

Barriers to Implementing Palliative Care in Resource-Limited Settings

Major barriers prevent people living in resource-limited settings from accessing the palliative HIV/AIDS care they need. These range from lack of the most basic necessities of food, water, housing, and income to social and cultural barriers — including the stigmatisation of people living with HIV/AIDS and social ostracism (see Table 33.1). Distance from health facilities and inadequate health services are also significant barriers. In Uganda, for instance, 88% of the population lives more than 10 kilometres from any kind of health facility, and many of these facilities lack trained personnel and the most basic medical supplies and medications. Moreover, there are structural and institutional barriers to implementing the key components of HIV/AIDS care and support (WHO/UNAIDS, 2000).

Table 33.1: Barriers and Constraints to Implementing Palliative Care in Resource-Limited Settings

Sector	Barriers
Community	Lack of household resources for essential needs and health care Stigma Gender, religious, social and cultural obstacles Limited access to health services and care resources Difficulties in accessing health facilities (e.g., ill health, poverty, distance) Shortages of relevant HIV information and HIV training opportunities
Governments and Departments of Health	Low priority of financial support to the health sector nationally and internationally Low priority of HIV care within national health budgets Lack of investments in building infrastructure and human resources Limited managerial resources/experience Insufficient remuneration and support for health care workers Insufficient local production of drugs and other commodities, given the weakness of local pharmaceutical manufacturers, markets, and patent protection Lack of essential drug lists and drug procurement not adapted to the needs of people living with HIV/AIDS Poor staff replenishment strategies in place High staff attrition due to HIV-related illness and death as well as migration to countries with better professional opportunities
Local Health Facilities	Irregular and inadequate drug supplies, reagents, and equipment Limited training opportunities Inadequate building infrastructure and human resources
External Partners / Funders	Alternate funding agendas/priorities Historical global policies that did not encourage a strong emphasis on HIV care in practice

Source: Adapted from WHO/UNAIDS, 2000.

Economic and Social Restraints on Palliative Care

In Africa palliative care was first established in the white communities of Zimbabwe and South Africa more than 25 years ago. Economic factors have had a lot to do with the slow inception and progress of palliative care on the continent. Africans who have observed hospice/palliative care in developed countries have considered it too expensive or sophisticated for most countries in Africa. Palliative care and hospice have made inroads in several more African countries, with varying degrees of success and support, including:

Kenya

Kenya was the third country in Africa to offer affordable palliative care with morphine. In 1989 the country did not have affordable morphine for use in the home. Codeine could be bought, but it was too expensive for most families. Powdered morphine was obtained by 1990, and the first palliative care service and teaching programme commenced. Nairobi Hospice, established in 1990, was conceived by whites and designed to reach all in need. From the first, the hospice's inspiration came from the vision of Ruth Woodridge, the wife of a BBC correspondent and a nurse herself, who was upset by seeing patients from poor communities return home in deep suffering. She formed a trust fund which allowed the hospice to open in 2000 with a Kenyan nurse, support staff, and the help of a volunteer nurse from the U.K. Like Hospice Uganda, which commenced in 1993, Nairobi Hospice has faced great difficulties in securing financial support for the many and expanding poor communities in Nairobi, and is now facing a rapidly increasing HIV/AIDS epidemic.

Nigeria

In a 1993 feasibility study, we visited Nigeria where the pioneering Mrs. Fatunmbi was trying to establish Hospice Nigeria in Lagos. She had already visited St Christopher's, in London, three times and had returned to try and raise support for her budding hospice service. She and some volunteer friends were actually visiting terminally ill cancer patients at home to provide supportive services even without financial support. They struggled with many difficulties as they confronted clients' severe pain and symptoms for which they had no medications, and the complete lack of knowledge amongst HCWs of the palliative medicine approach. They had none of the recommended supports required for a new service — affordable medications, government support and training (see Figure 35.1 in Chapter 35: Role of Government).

At the time the political climate and donors' lack of confidence in Nigeria prevented any new humanitarian ventures. Although the Ministry of Health was willing to support palliative care and drug availability if the funds and expertise were available, donors were unwilling to fund projects in Nigeria because of its reputation as 'the most corrupt country in Africa'. More recently, the hospice has obtained beds in the radiotherapy unit at Lagos University Teaching Hospital (LUTH) and Hospice Nigeria has been registered as a charity. But resources are still too low for it to experience the rapid growth of some other initiatives.

South Africa

Palliative care was introduced in South Africa in 1980 as a multicultural and multifaith effort, serving both black and white South Africans. Because of the commitment of its founders to serving all people of South Africa, in defiance of the government's apartheid policy, palliative care programmes never received government funding until apartheid ended. Since the end of apartheid palliative care has been able to expand to respond to the exploding need in South African communities caused by the HIV/AIDS epidemic. The country has developed many innovative services reaching the black communities in particular, where HIV/AIDS and poverty are linked together and rife. Services are adapted to black communities with a very different history and different expectations from the tribes of the rest of Africa, who have not had the tragic history of apartheid. Increasing economic disparities between rich and poor, and the growing epidemic, have produced an expanding population of people requiring palliative care.

Uganda

Following a 1993 feasibility study, Uganda was chosen as the site of the 'model' hospice for Hospice Africa, a charity based in the UK. A model was necessary to prove that palliative care could be delivered in an effective and affordable way in the African cultural context. Uganda was chosen because HIV/AIDS was devastating the country, and death and suffering were widespread. Uganda had the confidence of donors and new, efficient leadership was rebuilding the country after its turmoil between 1971 and 1986. The Minister of Health welcomed palliative care and agreed immediately to the condition that the service required a continuous supply of oral and affordable morphine for use in the home. Hospice Uganda commenced with enough funds for three months and a second-hand Land Rover from the British High Commission.

In 1998 the Ministry of Health began to work with palliative care teams, and Uganda in 2000 became the first African country to include the third requirement, government support, in its five-year strategic plan (see Figure 35.1 in Chapter 35: Role of Government). Palliative care was included as an essential clinical service of HIV/AIDS care and has had support from the ministry ever since. Hospice Uganda has since become a model for countries with limited resources, as was envisioned from the start, demonstrating how to use services already in place and train HCWs at undergraduate and post-graduate levels so the services can be available to all who need them. Palliative care is becoming a realistic, affordable, culturally appropriate service — even at the village level — as the ministry trains its own professionals in outlying districts by having them work with palliative care professionals from Hospice Uganda and the Mildmay Centre in Uganda, which was established in 1998 as a service and training centre.

Zimbabwe

Although created by and for the country's white population, hospice and palliative care was provided to other ethnic groups in the 1980s. When we visited in 1993, we were greatly encouraged to find that the service in Island Hospice in Zimbabwe had a large home care service extending to cancer and HIV/AIDS patients. Approximately 90% of their patients were from the black communities and many from the poorest sector. Still they were spending a large portion of their time providing services within the white communities. Whites expected more concentrated services for their dying and required much time in bereavement support, because they did not have the cultural bereavement supports found in traditional African society. Island Hospice at the time had nine palliative care nurses, nine social workers/counsellors, and no full-time doctor. However, the nurses were empowered to prescribe morphine using the WHO analgesic ladder, and they had the advice of a doctor who attended their case conferences.

These services deteriorated more recently with the economic constraints in Zimbabwe due to political turmoil. Today, many patients are denied pain and symptom control because of the lack of money to buy affordable medicines. The teams, trained to change the end of life into a time of positive living, are dispirited as they struggle not only to support their patients but to keep life and soul together for their own families. In spite of their present woes, they have established their own palliative care association and extensive training programmes, which reach throughout Zimbabwe and into other African countries, by their experienced teams and those they continue to train.

Donors' Economic Objectives and Policies

Most palliative care in sub-Saharan Africa is supported by indispensable donors or charitable contributions. Governments are often moved more by the offer of funds to accompany a service than by the suffering needs on their doorsteps. Donors have high bargaining powers and often dictate what health services should be in a country, although the personnel in the agency may not be aware of the restraints. Many donors come in with preconceived ideas of how palliative care should be, based on their experience in the more well-off countries. Sadly, their approach, which the NGOs they support are forced to accept, is that they know best because they control the funding. However, the trend towards collaboration is an ideal opportunity to develop and implement unique interventions based on evaluations and best practice (see Chapter 37: Partnerships and Collaboration).

Donors' Objectives vs. Actual Need

An important and glaring example is donors' perception of the needs of the patient with HIV/AIDS based on their experience in the developed world. Donors perceived, at least initially, that the greatest need of HIV/AIDS patients in Africa was for counselling. Money flowed in to train counsellors according to a Western model — when Africa already had counsellors trained in their own traditions. They also gave counsellors larger salaries than nurses, leading many nurses, who were traditionally paid very poorly, to move into counselling.

While the staff are now sent to counsel patients, the patients and their families are unable to accept counselling because the smaller pool of nurses in medical care is inadequate to provide the prerequisite management of pain and symptoms. In Uganda there is only one nurse to 4,500 people, and this is decreasing all the time. At the macro level there is a continuous 'brain drain' of health professionals from African countries to Western countries, which offer much higher remuneration, better and safer work environments, and superior opportunities for health professionals and their families. The developed countries, short of nurses, are importing nurses from developing countries, paying them attractive salaries but reducing essential services in places where the epidemic is at its height.

The answer to this problem is not to pay higher salaries to certain sectors only. Some donors are paying much higher salaries than the country could afford to aspire to or maintain when the donors withdraw. This is destabilising the economy, moving essential HCWs away from caring into research and administrative posts with larger salaries. When the period of wealth is over for individuals in these posts, they can only look abroad for posts to give them the funding to continue their children's education or the life styles to which they have become accustomed.

Some struggling hospices do not have enough funding to remunerate their dedicated HCWs. We found one hospice in Zambia where all the workers were listed as volunteers and only received allowances. In Uganda we have had a brain drain from the struggling and poorer hospices into the larger and better funded palliative care and support organisations. Sometimes, the precious pioneer in palliative care, so much needed for the increasing suffering poor, moves into another area altogether after an expensive training from the poorer organisation.

Accountability and Economic Planning of Larger Funds

The availability of more funds for HIV/AIDS care, particularly for ART from the Global Fund to Fight AIDS, Tuberculosis and Malaria (multilateral) and the President's Emergency Plan for AIDS Relief (PEPFAR, a program of the U.S. Government), provides unique opportunities to integrate palliative care services into HIV/AIDS care, allowing for development of infrastructure and staff.

Integrity in planning and transparency in the use of funds, with technical advice from people who give it because they really care for those in need, is needed more than ever. When a society has lived through difficult times in which living from day to day and staying alive make it impossible to save for tomorrow, helping oneself and one's family is a day-to-day necessity. It is essential to closely monitor funds directed to those most in need to assure that the resources actually reach the people they are meant to help.

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