

Quality care at the end of life in Africa

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Each year about 0.5% of the total population in Botswana, Ethiopia, Tanzania, Uganda, and Zimbabwe die from HIV/AIDS or cancer. The members of a WHO project to improve palliative care in these countries discuss their work. The greatest needs of terminally ill patients were for adequate pain relief, accessible and affordable drugs, and financial support to counter the loss of income of both patient and family caregiver. Special emphasis should be given to home based palliative care provided by trained family and community caregivers to counteract the severe shortage of professional healthcare workers

Each year in Africa about 2.5 million people die from HIV/AIDS, and more than 0.5 million die from cancer.^{1,2} Many of these deaths are accompanied by suffering that could be avoided or relieved if adequate palliative care were provided. Quality care at the end of life is a global public health problem.^{3,4}

What is palliative care?

Palliative care, as defined by the World Health Organization (WHO), is 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 careful assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.^{2,4,5} Palliative care regards dying as a normal process and offers support to help the patient and family cope during the patient's illness and in the bereavement period.

What can be done to relieve pain?

WHO has developed a relatively inexpensive yet effective method for relieving cancer pain in about 90% of patients^{6,7} that can be easily extended to patients with HIV/AIDS. Despite this low cost approach, many countries in the developing world provide limited or no palliative care services. A main obstacle is the insufficient availability of opioid drugs because of regulatory and pricing obstacles, ignorance, and false beliefs.

It is clear that not all those in need of drugs in Africa have access to them. WHO estimated that, in 2002, six

million people needed antiretroviral drugs but only about 300 000 (5%) had access to them.⁸ Chronically ill people and many terminally ill people need a great deal of palliative care, which is rarely available from African countries' health services. Palliative care should be seen as complementary to public health initiatives aiming to achieve a better quality of life regardless of the availability or feasibility of curative treatment.

WHO palliative care project in Africa

WHO has initiated a "community health approach to palliative care for HIV/AIDS and cancer patients in Africa project." The goal of this project is to improve the quality of life of patients and their families in African countries by development of palliative care with a public health approach that will provide pain relief and comprehensive care, mainly home based. In resource-poor areas with poor healthcare infrastructure, home based care may be the only feasible means of providing adequate access to palliative care.

Five countries were invited to participate in the project—Botswana, Ethiopia, Uganda, Tanzania, and Zimbabwe. The first phase of this project, in 2001-2, involved identifying palliative care teams at the country level and gaining government endorsement of them. These teams provided leadership, conducted situation analyses to identify the size of the problem and health system capacity, conducted survey assessments to identify the needs of patients and their families, and developed country-level action plans to bridge the identified gaps and improve the performance of existing

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Because of the shortage of healthcare professionals, most terminally ill people in Africa are cared for at home by family members

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palliative care. The second phase of the WHO project began in 2003 and is focused on mobilising resources, problem solving, and project implementation.

In the preliminary surveys to determine the needs of those receiving palliative care and their caregivers, interviews with terminally ill people or their caregivers were held in urban and rural areas and were based on a questionnaire developed by EK and previously used in Kampala and Hoima. The target areas for the surveys were one urban and three rural districts in Botswana, Addis Ababa city in Ethiopia, Tororo district in Uganda (a primarily rural area), Dar es Salaam city in Tanzania, and Goromonzi district in Zimbabwe (a rural area). In each target area the standardised instrument was adapted for local conditions. Local healthcare workers were trained to administer the questionnaire under the supervision of the country palliative care team. Surveys were conducted in all five countries in 2002.

How large is the palliative care burden?

The number of deaths provides a lower limit for the number of people needing palliative care. Each year in Botswana, Ethiopia, Tanzania, Uganda, and Zimbabwe about 610 000 people die from HIV/AIDS and 80 800 die from cancer in a total population of 135.4 million.⁹⁻¹¹ Thus, the number of people needing palliative care would be at least 0.5% of the total population in these countries each year (690 800/135 400 000 or about 1 in 200).

The above estimate, however, is based only on people needing care in the terminal stage of HIV/AIDS or cancer. The number needing palliative care should also include, for example, those dying from diseases other than HIV/AIDS or cancer and those suffering from some serious illness but not dying that same year. A preliminary estimate is that about double the 0.5% figure, or 1% of the population of these countries, needs some level of palliative care each year.

About 80% of cancer patients will have pain in the terminal phase of their disease.³ Dr Merriman from Hospice Uganda has estimated that at least 25% of HIV/AIDS patients have substantial pain during their illness. Thus the number of people dying from HIV/AIDS or cancer in these countries who experience pain is some 217 000 a year (80% of 80 800 plus 25% of 610 000).

End of life experience in Botswana

The project surveyed 92 terminally ill patients. The most acute problems reported were pain (64%), lack of food (59%), lack of social support (41%), cough (39%), headache (38%), body weakness (36%), financial difficulties (36%), and irregular supply of drugs or poor treatment (33%). Twenty two patients stated that their pain persisted despite treatment, apparently because of use of only mild analgesics. Although most of the patients indicated that they received support from relatives (36%) or the government (24%), 27% indicated that they were unable to cope with their situation.

End of life experience in Ethiopia

Eighty six adults from families with a bedridden family member were surveyed. The commonest problems stated for terminally ill patients were pain associated with the illness (76%) and vomiting, diarrhoea, and appetite loss (30%). Other problems included the

cost of and lack of drugs. The major burdens on the family were financial, emotional (anxiety, fear, sadness), and taking care of the patient. In most cases the relief of pain, relief of symptoms, and treatment and drugs were described as needs that were not being met.

End of life experience in Tanzania

Forty patients with terminal disease (19 with cancer and 21 with HIV/AIDS) and their caregivers were surveyed. The commonest problems expressed by the patients were economic (could not earn, 63%), spiritual (missing God's help, 48%), emotional (lost hope, 45%), physical (body pains, 30%; general body weakness or loss of appetite, 28%), and social (felt dependent, 30%; felt isolated, 23%). Common problems identified by the caregivers were financial constraints (45%), lack of time to rest or do other activities (25%), and patients often being short tempered (13%). Both patient and caregiver had to suspend work while the patient was bedridden. Caregivers described their major activities as providing food, drugs, and consolation and helping with washing, feeding, and changing bed linen and clothes.

The patients' greatest fears were that there was no hope for cure (43%) and that they would not be able to support their families (25%). Three quarters of the patients learnt of their diagnosis at a health centre or from a doctor. The rest made their own conclusions based on symptoms, death of a spouse or lover from the same illness, or other non-medical source.

End of life experience in Uganda

The needs of 29 terminally ill patients (died or currently bedridden) as expressed by a family member were the relief of pain (62%), food (52%), relief of other symptoms (48%), provisions for the family (38%), and counselling (34%). Households that have family members with HIV/AIDS suffer a dramatic decrease in income. As infected farmers become increasingly ill, they and the family members looking after them spend less time working on the family crops. The family starts to lose income from unsold crops, has to buy food it would normally grow for itself, and may even have to sell off the farm or household goods to survive.

The problem of nursing bedridden patients included dealing with the patients' changing moods, keeping the patients clean (changing the bedding frequently because of diarrhoea), patients refusing to eat, and patients being completely dependent on carers. The diagnosis of the disease was made at a health facility in 59% of the cases (17 of 29). For the rest, the family either drew their own conclusion based on the signs and symptoms (17%) or never knew the diagnosis (24%).

End of life experience in Zimbabwe

In 44 cases where people had died the greatest needs of the patients, as specified by the caregivers, were drugs for the relief of pain and other symptoms (59%), carers to look after the patient (50%), and food (48%). The most common problems for the family were the scarcity of resources for food and drugs (86%) and pain experienced by the patient (36%).

In 45 cases in which a caregiver was caring for someone terminally ill at the time of the interview, the major problems expressed by the patients were the relief of pain (29%), food (27%), relief of other



CRISPIN HUGHES/SPANOS PICTURES

A woman nurses her father, who has AIDS, in Kampala

How does the current health system deal with terminally ill patients?

Although all five countries have made the development of home based care a priority in order to deal with the HIV/AIDS epidemic, only Botswana has an operational home based care programme integrated into the national health system. In the other four countries home based care is mainly provided by private organisations. However, in Botswana the quality of palliative care services has been reported to be inadequate; 28% of the caregivers interviewed were dissatisfied with the quality of care and treatment received by their patients, primarily because of inadequate treatment or the persistence of pain or other disease symptoms. The main focus of the governmental home based care programmes in Tanzania is to reduce overcrowding in hospitals and to involve the community in providing care for patients.

Nearly all the existing home based care services include supportive care, but only a few include the capacity for providing effective pain relief. The Ministry of Health of Uganda has included the relief of pain and palliative care in its home care package and has made morphine available to those districts that have specialised palliative care nurses. However, this is still insufficient for the provision of morphine at home for most patients in need.

In all five countries the number of medical doctors is low relative to the population size. Nurses provide the bulk of the healthcare workforce; in Zimbabwe 80% of healthcare workers are nurses. Nurses are often the only healthcare provider to come into contact with patients in some hospitals and most rural health centres. Nurses are often also in short supply, however, and care is provided by other healthcare workers with minimal training. These countries are reviewing the potential role that could be played by traditional healers and are considering their possible integration into the healthcare system.

In addition, hospitals are overloaded by the HIV/AIDS epidemic, and some report that more than half of all hospital beds are occupied by HIV/AIDS patients. It is unrealistic to expect the formal health service institutions, such as hospitals and clinics, to be able to provide palliative care at the community or home level. Rather, we anticipate that family members, supported by home and community based organisations, will provide most of the needed palliative care.

Needs of terminally ill patients and their families

Our surveys provided useful, but preliminary, information about the needs of terminally ill patients and their families and caregivers. The patients' main needs seemed to be the relief of pain, accessible and affordable drugs, and financial support. Poverty and sickness combined to put families in a critical financial situation. Other needs included the relief of symptoms other than pain and alleviation of social, emotional, and spiritual problems. Family members and relatives were the main caregivers, but they generally lacked the knowledge and skills to perform their tasks adequately.

symptoms (22%), and lack of drugs (9%). When asked to indicate the main effects of their illness on the family, 58% of the patients said it led to a lack of resources, 44% said it led to a loss of employment, and 29% said it led to a neglect of children's welfare.

Who gives care to the terminally ill?

In the Botswana survey the primary caregiver for all 92 patients interviewed was a family member or a relative. The burden of caring did not fall on any particular age group: 34% were under 40 years old and 28% were 60 or older. In Ethiopia 80% of the patients were looked after by either their spouse or a child, and 20% of these caregivers had no education or only a primary education. Nearly all (95%) of the caregivers in Tanzania were related to the patient by blood or marriage, and 48% of the caregivers had only primary education or no education. People support their sick relations, providing money, food, and clothing as well as direct care. In Uganda 86% of the caregivers were the mother, spouse, or child of the patients. Of these caregivers, 74% had no education or only primary education. The caregivers in Zimbabwe were mainly the patients' spouse, child, or relative (96%).

What part does stigmatisation and discrimination play?

In Botswana, 40% of the cancer patients and 37% of the HIV/AIDS patients had experienced stigma. Most of these patients reported that they relied on family support to help them cope with the stigma. Ethiopian doctors are usually reluctant to pass bad news to patients on any health matter, especially now with AIDS. Fear of discrimination often prevents many Ethiopians from seeking treatment for AIDS. Many people with AIDS have been evicted from their homes by their families and rejected by their friends and colleagues. Infected children are often orphaned or abandoned.

In Tanzania 90% of the patients (80% of those with cancer and all of those with HIV/AIDS) indicated that their illness had caused them to be stigmatised in their community. Experience in antenatal clinics in Tanzania indicated that less than 20% of pregnant women who were infected with HIV disclosed their status to their partners.

Summary points

Each year about 0.5% of the total population in Botswana, Ethiopia, Tanzania, Uganda, and Zimbabwe die from HIV/AIDS or cancer

Stigma, lack of knowledge, limited healthcare infrastructure, scarce human resources, and poor access to pain relief drugs are major barriers to improving palliative care

Terminal illness often causes a family financial crisis because of loss of income from both patient and family caregiver

A WHO project to develop palliative care in these countries found that the greatest needs of terminally ill patients were for relief from pain, accessible and affordable drugs, and financial support

Special emphasis should be given to home based palliative care provided by trained family and community caregivers to counteract the severe shortage of professional healthcare workers

Our results suggest that a palliative care package should include drugs for pain and other symptom relief, food, and family support. Income-generating activities should be promoted to increase family income, and special training packages should be developed for family caregivers. Further investigations in these and other countries are needed to confirm the results of these surveys, to clarify many of the issues raised, and to identify which specific solutions may be the most appropriate.

Need for national policies and community integrated palliative care

National policies and strategies to support palliative care should be established to ensure the availability of analgesics, particularly low cost oral morphine, and other essential drugs. Current restrictive regulations should be revised. These and pricing policy obstacles often limit the accessibility of opioids for pain relief. In most of the five countries only medical doctors, whose numbers are extremely limited, are allowed to prescribe morphine. In many areas a nurse rather than a doctor is the only healthcare provider who comes into contact with patients. Nurses therefore need to be equipped with the skills to provide palliative care when needed, and nurses with specialised training should be given authority for prescribing and dispensing analgesics. However, professional nurses are also scarce and often are not available at the level of community clinics. Training of primary caregivers in prescribing morphine, with adequate supervision by specialised district nurses, may prove to be a valid solution for improving patients' access to morphine. Unrelieved pain in patients is unacceptable because it is generally avoidable.

The public health community should develop palliative care models basing on our findings and further

investigations. Such models should include physical, economic, social, spiritual, and psychological support for chronically and terminally ill individuals and their families. Palliative care should be seen as part of the continuum of health care, and not just for patients in the terminal stage of their disease.² It should be seen as an integral part of a comprehensive care and support framework and should relate to preventive activities as well. In order to ensure accessibility and sustainability, palliative care should be tailored to the cultural and social context, responding to the needs of patients and caregivers and developed within the existing health-care system.

Stigmatisation is fuelling the spread of HIV/AIDS and is creating immense barriers to effective responses to the epidemic as well as the provision of palliative care. Community members should be encouraged to provide love, care, and support to infected people and their caregivers.

The way forward

The goal of this WHO project is to improve the quality of life for patients with cancer or HIV/AIDS in African countries by developing palliative care with a public health approach. It has given special emphasis to team development as an essential strategy for bringing together the people who could eventually take the lead in implementing community based palliative care. WHO has provided funding for the first phase of this project. Additional funds are now being sought to support further applied research and implementation of the action plans. Methods developed will permit other countries to conduct their own situation analyses and for creation of effective palliative care policies and strategies.

The extent of human suffering associated with HIV/AIDS and cancer in Africa today is tragic. The provision of palliative care is an urgent, unavoidable humanitarian responsibility. In many ways palliative care transcends medicine and reflects the values of society, both locally and globally.

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A profile of Anne Merriman (Hospice Africa Uganda) appears in this week's *Career Focus*.

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Patients' voices are needed in debates on euthanasia

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Medically assisted death is legal in a few countries, and discussion about legalisation is ongoing in many others. But legalisation may be premature when we still do not know why patients want euthanasia and whether better end of life care would change their views

Countless debates have been held on euthanasia, but little research has been done into the experiences of patients who request it. Proponents portray an undignified death and opponents fear the potential dangers of legalising euthanasia, but the fundamental question is why patients want euthanasia. Current debates have been based on perspectives of medical professionals, academics, lawyers, politicians, and the public. Qualitative, experiential, and patient based research is needed to help capture the complexity of patients' subjective experiences and elucidate the influences and meanings that underpin their desire for death.

The euthanasia debate

Justifications for legalisation of euthanasia have pivoted on unbearable suffering, respect for autonomy, and dignified death. Proponents argue, from the principles of compassion and self determination, that mentally competent patients with an incurable illness and intolerable suffering should be able to choose the manner and timing of their death. This view is gaining support within an increasingly secular society with an individualistic and utilitarian ethos.

Opponents highlight the potential dangers for patients, healthcare professionals, and society.¹ Doctors should strive to relieve suffering, not end the life of the sufferer; the authority to terminate life would undermine their trustworthiness. Euthanasia is irreversible, yet the will to live often fluctuates widely over the course of a terminal illness.²

Some opponents fear patients might feel obliged to request euthanasia to avoid being a burden, particularly as acts to end life already occur without the patients' explicit requests.³ Regulation of euthanasia cannot be securely enforced, which creates potential for abuse.⁴ Moral disintegration could occur when society views euthanasia as a cheaper and preferable

option to providing care.⁵ Others believe that excellent palliative care obviates the need for euthanasia.⁶

Before ethical debates

A central controversy in euthanasia debates is the difficulty in defining and proving unbearable suffering. What are the dimensions of suffering experienced by patients who desire death? Are we paying adequate attention to diagnosing and relieving suffering, when the customary biomedical model of care has focused more on the disease than the patient? Are we comfortable and competent in communicating with people who are dying? Do we understand the genuine meaning of euthanasia requests? Is the topic of suffering emphasised in medical education and research? In effect, have we overlooked our patients' experience of suffering?

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Euthanasia with Death by John Spooner, 1997