

Executive Summary

Thousands of patients in sub-Saharan Africa suffer from incurable illness, especially HIV/AIDS and advanced cancer. These diseases affect patients and their families in all dimensions of the quality of life - physical, psychological, social and spiritual.

This monograph describes the current status and achievements of the WHO project "A Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients in Sub-Saharan Africa". The goal of this project is to improve the quality of life for HIV/AIDS and cancer patients in sub-Saharan African countries by developing palliative care programmes with a public health approach. A paper that publicized this project and summarized the initial findings has been published in the British Medical Journal (Sepulveda, 2003).

Palliative care, as defined by 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, psychological and spiritual. Palliative care offers a support system to help the patient and family cope during the patient's illness and in the bereavement period.

Five countries are participating in this project - Botswana, Ethiopia, United Republic of Tanzania, Uganda, and Zimbabwe. In these five African countries about 691,000 individuals, or one half of one percent of the total population, will die from HIV/AIDS or cancer each year. These persons need palliative care support to give them a better quality of their remaining life and to permit them to die in dignity. However, the extent of palliative care need is much greater, as it also should include individuals suffering from HIV/AIDS or cancer but not dying that same year and those dying from other diseases. Palliative care must be seen as part of the continuum of care, and not just for patients in the terminal stage of their disease. A preliminary estimate is that about 1.6 million individuals or approximately one percent of the population in these countries need palliative care services annually.

Given the extent of the problem of providing a service to about one percent of the population in countries in which health care resources are already severely limited, a community health approach relying extensively on home-based care and community involvement in the provision of care and support is recommended. The community health approach encompasses team development and networking with community-focused action, a high level of population coverage and periodic evaluations for improving the quality dimensions for better programme performance. It is also vital that these palliative care activities are integrated within the ongoing activities for care and prevention of HIV/AIDS and cancer.

Important governmental as well as nongovernmental initiatives have emerged in recent years to bring palliative care to those in need, but there are still enormous gaps to be bridged. Many initiatives have developed as "islands of excellence", but they are not well integrated into national health systems. One of the major hindrances to the provision of palliative care in this region is the problem of access to medicines, especially opiates for the relief of pain.

The project will be developed in two phases, the first from October 2001 to July 2002 and the second starting in July 2002. In the first phase, technical experts and WHO staff met with teams from the five countries to develop tools and methods to determine the extent of the problem (situation analysis), to identify palliative care gaps (needs assessment), and to develop plans of action to bridge the identified gaps. Team development included identification and participation of

the key stakeholders and endorsement by the government. Two meetings were held, in Uganda and Botswana respectively, to develop the necessary tools and ensure networking among the countries and technical experts. The second phase of this project will be the implementation phase, which includes finalization of the plans of action, mobilization of resources, and monitoring the palliative care projects.

Achievements of this project to date include:

- **Tools and methodology**

The data collection instruments and methodology for undertaking situation analyses and needs assessments in palliative care have been developed and tested in five countries. They have established the baseline palliative care situation and needs for these countries and are now ready for use by others.

- **Situational analyses**

Country-specific data concerning health system performance, the social and health care burden associated with HIV/AIDS and cancer and the capacity to provide palliative care to those in need has been compiled and analysed for the five participating countries.

- **Needs assessments**

Original research was generated to determine the expressed needs and preferences of those receiving palliative care and their caregivers in target areas within the countries.

- **Team development**

Multidisciplinary teams were identified to address palliative care needs at the country level.

These teams included representatives of the key stakeholders and were endorsed by the ministry of health of each respective country.

- **Networking**

A network was established for the sharing of information, collaboration and technical support among partners in the project.

- **Plans of action**

Plans of action that aim to improve access to palliative care and the relief of pain were developed for target areas in each country.

- **Resource mobilization strategy**

Potential sources of resources and project promotional materials were developed to assist in resource mobilization and to describe why this project is worth the investment of resources.

Needs assessments were conducted in selected target areas in each country with the primary goal of identifying the needs of the terminally ill so that appropriate palliative care services can be developed. The greatest needs of terminally ill patients were for adequate pain relief, accessible and affordable drugs, and financial support. When a terminal disease strikes an adult family member, it often provokes a profound financial crisis for the family. The patient is unable to earn any money and the ability of the caretaker (often a family member) to earn money is dramatically reduced. Needed medications such as antiretroviral drugs and chemotherapy are very expensive. The relief of pain was clearly identified as a major concern by both terminally ill patients and those who had experienced an ill family member at home. While opioids for the relief of pain are relatively inexpensive they frequently encounter regulatory restrictions and policy obstacles that limit their accessibility.

Close relatives and family members are key in the provision of palliative care and home-based care. They are the main source of financial support during this crisis period and the caregiver is nearly always a family member or relative. For a terminally ill patient the duration of bed-ridden care at home was typically 3 to 6 months.

Stigmatism stands out as one of the major issues felt by most of the patients with HIV/AIDS and their families. It 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 the sick people and their caregivers.

Further investigation is needed to establish clear programme components and financial requirements for terminally ill patients in an African setting. Nevertheless, it is clear at this time that the recommended palliative care package should include drugs (for pain and other symptom relief), food and family support. A special training package should be developed for family caregivers, to ensure effective use of the individual upon whom the patients rely most. Income generating activities should also be promoted to increase the family income.

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 organizations. 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. In Ethiopia, there is no governmental programme and very few nongovernmental programmes that deal with the provision of palliative care in a home-based setting. The majority of the current services in Dar es Salaam, United Republic of Tanzania are being provided by nongovernmental organizations and voluntary agencies. The main focus of the governmental home-based care programmes in United Republic of Tanzania is to reduce overcrowding of patients 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 the majority of patients in need. In Uganda, home care services are also being provided by a nongovernmental organization, The AIDS Support Organization (TASO), although these services do not yet include the relief of pain.

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. 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, it is anticipated that family members, supported by home and community-based organizations, will provide most of the needed palliative care.

Home-based care may be the only feasible response for adequate access to palliative care in low resource settings. Provision of effective palliative care for patients and families should rely on the development of home-based palliative care integrated within the existing health care system. Countries should plan to bridge current gaps by building on existing strengths within each country and optimizing available resources. Development of low-cost, high coverage approaches and

national policy to promote accessibility and drug availability are key components. An understanding of palliative care needs within the community will help establish broad support of this project by the African people and health authorities in the countries.

Urgent action is necessary to deal with the human suffering associated with HIV/AIDS and cancer in Africa. At least one in every 200 individuals each year in Africa needs palliative care services and there are clear gaps in the ability of existing health services to provide even basic palliative care. Low-cost methods exist that can reduce this suffering. As learned in Botswana, the availability of only mild analgesics is inadequate for the control of pain. The next priority steps in this project are for WHO to assist countries in the revision of legislation to ensure the availability of opioid pain relief medications and to strengthen training programmes on pain medicines. Other important urgent steps include the finalization of palliative care plans of action within each country, endorsement of these plans and their related policies by the governments, and resource mobilization.

In many ways palliative care transcends medicine and is a reflection of the values of the community. It is up to all of us to see that this vital humanitarian need is met.