

COMMUNITY HEALTH APPROACH TO PALLIATIVE CARE FOR HIV/AIDS AND CANCER PATIENTS IN AFRICA

WHO JOINT PROJECT CANCER AND HIV/AIDS PROGRAMMES Botswana/Ethiopia/Tanzania/Uganda/Zimbabwe

Progress Report August, 2002

Executive Summary

This project started in October 2001, and has been conceived as a way to address the crucial palliative care needs of the many thousands of cancer and HIV/AIDS patients and their families in sub-Saharan Africa. The project is a joint initiative between five countries - Botswana, Ethiopia, Tanzania, Uganda, Zimbabwe – and the World Health Organization (country, regional and headquarters offices). Within each country, multidisciplinary teams representing key groups involved in palliative care are responsible for the project, and across the project as a whole there is a steering committee to contribute international expertise in palliative care and public health programme development and implementation. While specifically addressing palliative care, a key concern is to ensure the appropriate integration of these services into the continuum of care for cancer and HIV/AIDS patients, and to ensure sustainability of the initiatives made as part of the project.

The main goal of the project is to contribute to the improvement of the quality of life for cancer and HIV/AIDS patients in southern African countries by facilitating and strengthening the initiation and development of palliative care programmes with a public health approach that will provide pain relief and holistic care to an increasing proportion of terminal patients.

Achievements of this project to date include:

- compilation and analysis of 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 (situational analyses).
- original research to obtain detailed, recent information about the expressed needs and preferences of those receiving palliative care and their caregivers in target areas within the countries (needs assessments).
- development of multidisciplinary teams, representative of key stakeholders and endorsed by Ministry of Health in the majority of cases, to address palliative care needs at country level.
- establishment of a network for the sharing of information, collaboration and technical support between partners in the project (print newsletter and web site).
- drafting of national action plans for improving availability and patient access to opioid analgesics for the relief of pain.
- identification of potential sources of resources.

By the end of 2002, project participants will have published the results of the needs assessments and situational analyses and completed proposals for projects to be undertaken in each country and at the regional level. They will also seek to secure resources to support these projects.

In 2003, the teams will move ahead with the implementation of projects that will address key areas identified for action including:

- advocacy about palliative care
- improved integration of palliative care into existing health systems
- education and training for caregivers and programme managers
- policies and guidelines on palliative care
- improved access to drugs and other supplies
- improved information systems, monitoring and evaluation.

Agencies who could offer technical and financial support are being encouraged to become partners in the project, offering involvement on the basis of location, for example to particular countries or target areas within countries, or according to particular areas of interest, such as training or improved access to drugs. More detail about the project can be found on the web site www.who.int/cancer.

Progress report

Rationale of the project

Thousands of patients in sub-Saharan Africa suffer from incurable illness, mainly HIV-AIDS and advanced cancer that causes them and their families great suffering. The diseases affect patients in all human dimensions: physical, psychological, social and spiritual. Important government as well as nongovernment 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 policies.

Health promotion and prevention, as well as the provision of adequate quality treatment are key strategies to address the burden of HIV/AIDS and cancer. However, preventive strategies will take several years to have the expected population impact and effective treatment requires the development of appropriate and accessible health infrastructure and technology for the good quality provision of care. In the meantime, thousands of terminal patients can be relieved from their pain and suffering by using low cost approaches and mainly community-based strategies that guarantee ownership and seek sustainability.

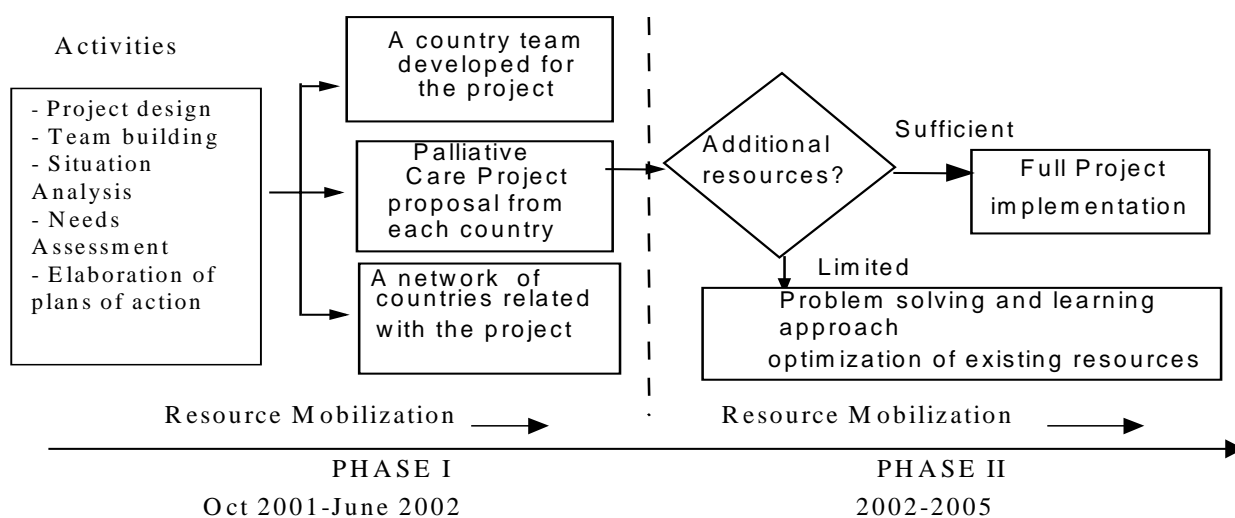
The WHO Programme on Cancer Control is developing this initiative in collaboration with WHO Departments of Care for HIV-AIDS, various relevant governmental and intergovernmental agencies, nongovernmental organizations and the WHO Regional Office for Africa (AFRO). The main goal is to contribute to the improvement of the quality of life for cancer and HIV/AIDS patients in southern African countries by assisting in the development of palliative care programmes with a holistic and community health approach. Initially the governments of five countries, Ethiopia, Botswana, Tanzania, Uganda and Zimbabwe have confirmed participation in this important health initiative.

Report of the Uganda Meeting, 15 to 17 October 2001

Convened by WHO, representatives of the various organizations and the country representatives of the above 5 countries met in Uganda, 15 to 17 October 2001, and agreed to work on a joint project to be developed emphasizing multisectoral and multidisciplinary participation and ownership. A detailed description of the project is available at www.who.int/cancer.

The following components are included in the project and are illustrated in the diagram below:

- a) development of a team approach to palliative care that will guarantee the active participation



- of all the sectors involved from the policy level to the community level
- b) a situation analysis that will identify the magnitude of this health problem and the health system capacity
- c) a needs assessment study to identify the needs of these patients and their families
- d) country palliative care project proposals to bridge the gaps and improve the performance of palliative care programmes
- e) a network of countries for sharing experiences and collaborating
- f) resource mobilization and project implementation in the targeted areas having a holistic and community approach.

WHO provided financial and technical support for Phase I of the project. For moving on to Phase II it is necessary to mobilize resources at the international, regional and country level.

It was agreed to meet in Botswana in July 2002 in order to evaluate Phase I of the project and plan for the implementation phase. The report below summarizes the main objectives, activities, outcomes and recommendations of the Botswana meeting.

Report on the Botswana Meeting, 9 to 12 July 2002

Objectives of the meeting:

1. To evaluate the first phase of the project “Situational analysis and needs assessment” in each country.
2. To develop a joint project proposal WHO-countries, to introduce and/or consolidate a palliative care programme in the government health agenda.
3. Each country team to develop a local project proposal to start and/or continue a palliative care programme in a selected target area.

Participants:

The workshop involved approximately 70 participants, including:

- team members from each of the countries taking part in the project – Botswana (25 participants), Ethiopia, Tanzania, Uganda and Zimbabwe, and delegates from South Africa;
- expert advisors and facilitators;
- WHO staff from countries taking part in the project, the African Regional Office and Headquarters.

Methodology:

The meeting started with a review of the project to date, and an overview of palliative care issues. Country teams then presented their progress during Phase 1, in particular the results of the needs assessments and situational analyses. The following days were divided between short presentations, aimed to give country teams some input on issues relevant to the project (e.g. training, performance indicators, drug availability), and small group discussions during which the country teams each worked on a proposal for a project to be implemented in their country and international delegates worked on a proposal for a regional activity. On the last day of the meeting country teams presented these proposals, participants gave feedback, and the group as a whole decided on recommendations and timelines for proceeding to Phase 2, implementation of the project proposals.

Outcomes:

By the end of the meeting, each country team had received feedback on their activities during Phase 1 of the project (team building, needs assessment and situational analysis) and had developed a draft project proposal for a country level project. The group of international delegates had drafted a proposal for a regional training activity that would complement the country projects. A timeframe for publication of the Phase 1 findings and completion of project proposals was agreed.

Team Building

The project has given special emphasis to team development as an essential strategy for involving all key stakeholders and to bring together people who could eventually take the lead in evaluating and implementing community-based palliative care programmes with the appropriate endorsement of their respective governments. All participating countries have made great efforts in this regard. Tanzania has recognized the need to involve other stakeholders more actively, especially those working in HIV/AIDS. Ethiopia sees the present team as a temporary team that should expand into a task force with much more active involvement of key stakeholders and of the government. Zimbabwe needs to appoint a new team leader as the first one has retired from the Ministry of Health. Uganda has been successful in forming a multidisciplinary team with broad representation of relevant key stakeholders and has obtained support from the Ministry of Health and the WHO country office. The guide provided on team development continues to be a valid framework for guiding and reinforcing team building among the countries.

Situation Analyses and Needs Assessments

All countries except Botswana have finalized the reports on situation analyses for the country and the target area. The needs assessment in the target area has been done by Uganda, Tanzania and Ethiopia. Zimbabwe and Botswana are still finalizing the needs assessments.

A summary of the situation analyses is described in the tables in the annex. These tables give national information on indicators of human development and health systems. Palliative care is addressed in more detail in the consideration of the target areas selected by each country for this project. It is in these target areas that the groups will implement specific programmes with a community health approach.

The analyses of strengths and weaknesses and the assessments of needs for palliative care services and resources for project phase I were provided by the country teams in their Phase 1. When the information was obtained from other sources, the source is specified under each table. Detailed country reports are available upon request.

According to the human development index (UNDP Report 2002), Botswana and Zimbabwe are ranked in the medium category and the other three countries in the low category (Table 1). An estimate of the number of people in need of palliative care has been made on the basis of the numbers of people in the terminal phases of cancer and HIV/AIDS. For the five countries participating in the project it is estimated that the burden of palliative care is over 800,000 cases each year, the great majority being HIV/AIDS patients. Ethiopia has the greatest number of patients in need of palliative care, around 240,000 per year (Table 2).

In all of the countries, the overall health system performance measure, which indicates the achievements in health according to the available resources, is below 0.5 (WHR 2000). Botswana has relatively more resources and better health infrastructure than the other countries involved in this project, but has not reached a health status in accordance with its level of resources (Table 3).

All five countries have health systems which combine modern medicine and traditional medicine. Access to modern medicine is limited and a high percentage of the population will never see a doctor in their lives. The health systems are organized according to different levels of care and great emphasis is placed on primary health care (PHC). In all of the countries, there is serious shortage of human resources and health care providers and hospitals are overloaded by the HIV epidemic. Some of them report greater than 50% of hospital beds occupied by HIV/AIDS patients. Limitations of infrastructure, equipment and supplies are the norm. Home based care is viewed as the key element to respond to the increasing needs in this scenario of very limited health infrastructure and resources. Some countries have already developed strong home based care networks in coordination with the PHC system to respond to the HIV epidemic. Palliative care, as part of the continuum of care of HIV/AIDS, cancer and other chronic conditions can relatively easily be integrated into this existing network.

With respect to palliative care, the countries have a very heterogeneous situation. An analysis of the strengths, weaknesses, opportunities and threats to the projects in each of the countries is summarized in Table 4. In some ways, Uganda is the most developed. In the last ten years, thanks to NGO initiatives, progressive government involvement and the support of the WHO country office, Uganda has been able to include palliative care in the government health agenda which has resulted in the allocation of resources, improved morphine availability, and the provision of training at all levels of care and to undergraduate and post graduate health professionals. It has integrated

palliative care into the existing health system at a district level and is planning to extend the programme to other districts and eventually to the rest of the country.

The rest of the countries have greater gaps in palliative care. In Tanzania the regulating authorities allow the medical use of morphine, and oral morphine is available. In Botswana, Ethiopia and Zimbabwe, however, there are serious limitations on morphine availability due to a combination of factors such as excessively strict regulations, ignorance, stigma and the lack of foreign currency to import drugs.

Zimbabwe has a long tradition in palliative care provided by the hospice movement, however this is still not widely integrated into the health system. There is no exclusive national policy concerning palliative care although palliative care policies are included in the following documents: the Home Based Care Policy, the Discharge Policy and the Ten Year Plan produced by the Committee for Prevention and Control of Cancer in Zimbabwe (PCCZ). Like Hospice Uganda, Island Hospice in Zimbabwe provides training at various levels in palliative care within the community, within the country and to neighbouring countries. In Tanzania, some NGOs are providing palliative care at the district level and the Ocean Road Cancer Institute, with the assistance of Hospice Uganda, has initiated training for health care providers. Botswana and Ethiopia have even greater gaps regarding palliative care however various strengths have been identified, such as PHC, and home based care networks, which will make it possible to integrate palliative care into the continuum of care for HIV/AIDS, cancer and other chronic patients.

Ethiopia, Tanzania and Uganda have already reported on the needs assessment for the target areas. The studies, although not being representative of the whole target areas, provide useful information about the needs of patients, their families and caregivers. Table 5 shows the methodologies used by each country, and the main results. The main problems reported by patients and their families are the need to control pain and other symptoms, financial constraints, lack of food, anxiety, the need for counselling and nursing of bedridden patients. Although stigma was identified as a problem in all three countries, Tanzania and Ethiopia reported a much higher level than Uganda. Family members and relatives are the main caregivers; they acknowledged lack of knowledge and skills to perform their task adequately. In the minority of cases the needs are met, and this is mainly through the work of family caregivers. The preferred site of care is the home, except for Ethiopia, where it was reported as being the health facility. However, this finding may reflect the fact that the Ethiopian needs assessment study was undertaken exclusively with patients attending the Radiotherapy centre, and did not include patients from the general community. Traditional healers seem to have an important role, especially when modern medicine has failed to meet the patients' needs.

Draft project proposals

During the meeting, draft project proposals for a country level project were elaborated and presented by each team. It was agreed that the project proposals for the target area were to be finalized and polished after the meeting.

Countries differed with respect to the amount of detail they provided in these draft project proposals, but common objectives and strategies for addressing them emerged, and these are summarized in Table 6 of the annex. In particular, some key themes that had been identified by the needs assessments and situation analyses, and which had recurred throughout the discussions at the workshop included the importance of advocacy about palliative care, the need to train caregivers and to have this training incorporated into medical and nursing curricula, the need to formulate and

strengthen policies and guidelines on palliative care, the need to improve access to drugs and other supplies and the need to establish or improve systems for monitoring and evaluation.

In addition, all teams listed key activities that would need to be undertaken to achieve these objectives, with accompanying timeframes and identification of responsible bodies, and technical assistance and resources likely to be needed. Two of the five countries, Zimbabwe and Tanzania, were able to identify the amount of funding likely to be needed to support these draft project proposals. The draft proposals from Tanzania and Ethiopia also included indicators to be used to check whether the project is meeting its objectives.

Action plans to improve drug availability

A significant component of the work undertaken by the country teams in developing draft project proposals was the development of action plans to improve drug availability and patient access to opioid analgesics for relief of pain. Background information about the importance of opioid analgesics for the control of pain, morphine consumption in Africa, comparison with the international situation, and a framework for development of action plans was provided by advisors from the WHO Collaborating Center for Policy and Communications. The presence at the Botswana meeting of government representatives from the majority of the countries provided the opportunity for those responsible for palliative care and those working in drug regulation to collaborate. A strong partnership between regulators and health workers has been identified as a crucial prerequisite if improvements in drug availability and access are to be achieved. Key areas for action identified by the country teams included: review, revise national narcotic control laws, regulations; the cost of drugs; the need to source foreign currency to buy imported drugs; restrictions on prescribing and dispensing; expansion of prescribing/dispensing authority to nurses with specialized training; the need for education and training of health workers, policy makers, and the community about appropriate use of pain relief, in particular opioid drugs; the need to address “opiophobia;” and the need to strengthen the monitoring and evaluation of drug use. While each of the countries involved in the project recognized the need for action in the area of drug availability, Ethiopia, the largest country, was identified as having the greatest number of unmet needs and needing the most support to improve its situation. Uganda was seen as being in a strong position and having the potential to offer advice and support to other countries in the region.

Resource mobilization

During the workshop, a number of possible sources of funding were identified including nongovernmental organizations and international organizations such as the World Bank and the Global Fund.

A panel discussion on resource mobilization gave participants some more information about some of these possible sources but, importantly, also drew out certain principles to be kept in mind when drawing up proposals for funding. These included: the increased likelihood of receiving funding for projects that are well integrated into national policy; the need to raise awareness about the importance of palliative care and the potential for low cost, effective service provision; the importance of leadership from model programmes and from groups and individuals who can champion the cause of palliative care; and the need for any group who is applying for funding to be able to demonstrate that they have something that is worth funding and that they can appropriately and efficiently manage the funds that they are requesting. In considering resource mobilization in its broadest sense, including the mobilizing of expertise and people, rather than just funds, attention was also drawn to a number of activities that groups can undertake that “cost” little (in cash terms) but that can have large impacts: such as having the national governments include palliative care into

their policies, and introducing and/or implementing effective policies for access to pain relieving drugs.

Recommendations

The meeting participants agreed to the following actions and timeline for Phase 2 of the project:

Publication of the results of the needs assessments and situational analyses.

Each country team agreed to finalize the presentation of this information and seek publication in a local journal, by end September 2002.

WHO agreed to prepare a consolidated report, incorporating and comparing the results from all five countries, and to seek publication in a scientific journal by end October 2002.

Country project proposals

Each country team agreed to finalize the country project proposals by end September 2002.

The steering committee will then review the proposals and give feedback to each country by end October 2002.

Country teams will seek endorsement from WHO and the relevant Ministry of Health by end November 2002.

Regional project proposal

WHO will further develop, in consultation with the country teams, a proposal for training in palliative care that could be undertaken at regional level, to complement country level activities. The draft proposal will be finalized by end September 2002, and endorsement from WHO and Ministries of Health in each of the countries involved in the project will be sought by end October 2002.

Resource mobilization

Country teams and WHO will pursue resources, with a view to being able to implement the country and regional project proposals as soon as they have been finalized and endorsed.

The WHO network was identified as having a crucial role to play in identifying and helping with the mobilization of resources at all levels: country, regional and international.

Team building and team reinforcement

Although not explicitly pointed out during the Botswana meeting, team building and team reinforcement should continue being a major task in this project. Many countries need to adjust their teams to suit the implementation phase and in order to ensure the proper involvement of all stakeholders and the endorsement of the governments. However it is emphasized that the core project team should not be bigger than 10 to 12 individuals due to the difficulties of managing a large team.

Supervision of Phase II of the project

The project will continue to operate under the leadership of the country teams and the Steering committee. In addition, it has been recognized that the provision of some extra funding to employ an African expert to supervise the Ethiopian project, and another to assist in coordinating the projects in Zimbabwe and Tanzania, would greatly increase the likelihood of these countries being able to implement their proposals in 2003. The suggested time frame is six months, with a possible extension of a further 6 months depending on the outcomes of the consultancy. Uganda does not require this support and Botswana is still working on Phase I of the project.