PART I

A Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients

Extent of the Problem

Development and health system indicators

National information on population characteristics and indicators of human development and health systems are given in Tables 1 and 2 for the five countries participating in this project. According to the human development index (UNDP, 2002), Botswana and Zimbabwe are ranked in the medium category and the other three countries in the low category. The overall health system performance measure is low in these countries. Limitations of infrastructure, equipment and supplies are the norm. 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. All five countries have health systems that combine modern medicine and traditional medicine. Access to modern medicine is very limited. The health systems are organized according to different levels of care and great emphasis is placed on primary health care (PHC). In all the countries, there is a serious shortage of human resources and health care providers and hospitals are overloaded by the HIV/AIDS epidemic. Some of them report greater than 50% of all hospital beds occupied by HIV/AIDS patients (WHO, 2002a).

Table 1. Human development indicators for the year 2000[1]

Country	**Population**		**GDP Per capita (US$)**	**Literacy rate (>15 yrs)**	**Life expectancy at birth (yrs)**	**Health Development Index Rank (out of 173 countries)**
	Total (millions)	**Percent urban**				
Botswana	1.5	44.9	7184	77.2	40.3	126
Ethiopia	62.9	15.5	668	39.1	43.9	168
Uganda	23.3	14.2	1208	67.1	44.0	150
United Republic of Tanzania	35.1	32.3	523	75.1	51.1	151
Zimbabwe	12.6	36.3	2635	88.7	42.9	128

Note:
1. United Nations Development Programme (UNDP, 2002).

Table 2. Health system indicators

Countries	**Percent of population with access to essential drugs, 1999[1]**	**Health expenditure in 1997[2]**		
		Total expenditure on health as % of GDP	**Public expenditure as % of total expenditure**	**Per capita expenditure in US$ at official exchange rate**
Botswana	80–94%	4.2%	61%	132
Ethiopia	50–79%	3.8%	36%	4
Uganda	50–79%	4.1%	35%	14
United Republic of Tanzania	50–79%	4.8%	61%	8
Zimbabwe	50–79%	6.2%	43%	46

Notes:
1. WHO, Department of Essential Drugs and Medicines Policy (<49% very low, 50-79% low, 80-94% medium low, > 95% good access).
2. World Health Report 2000 (WHO, 2000).

Except for Botswana, the proportion of the population with access to essential drugs is low, between 50% and 80%, and the per capita expenditure on health ranges from US $4 to US $46 per year. While the proportion of GDP spent on health is similar in these countries, there is considerable variability with respect to the percentage of this financial burden covered by the government (see Table 2).

Estimating the disease and palliative care burden

The number of deaths provides a lower limit for an estimate of the number of persons needing palliative care. Each year in Botswana, Ethiopia, United Republic of Tanzania, Uganda and Zimbabwe there are approximately 610,000 deaths from HIV/AIDS and 81,000 deaths from cancer (Table 3) (UNAIDS, 2002; Ferlay, 2000). Thus the number of persons needing palliative care would be at least 690,800, or one-half of one percent of the total population in these countries each year (690,800/135,400,000, or 0.51% or 1 in 196).

Table 3. Estimates of annual deaths from HIV/AIDS and cancer and extent of the palliative care burden

Country	**Population (Millions)**[1]	**Number of deaths from HIV/AIDS**[2]	**Number of deaths from cancer**[3]	**Number dying from HIV/AIDS or cancer**	**Proportion of total population needing terminal care**[4] **– lower limit needing palliative care**	**Percent of adults (15-49) living with HIV/AIDS**[2]	**Number dying from HIV/AIDS or cancer and suffering pain**[5]
Botswana	1.5	26,000	800	26,800	1.79% (1 in 56)	39%	7,100
Ethiopia	62.9	160,000	39,900	199,900	0.32% (1 in 315)	6%	71,900
Uganda	23.3	84,000	10,500	94,500	0.41% (1 in 247)	5%	29,400
United Republic of Tanzania	35.1	140,000	21,000	161,000	0.46% (1 in 218)	8%	51,800
Zimbabwe	12.6	200,000	8,600	208,600	1.66% (1 in 60)	34%	56,900
Total	135.4	610,000	80,800	690,800	0.51% (1 in 196)		217,100

Notes:

1. United National Development Programme, Human Development Report 2002 (UNDP, 2002).
2. Joint United Nations Programme on HIV/AIDS, Report on the Global HIV/AIDS Epidemic 2002 (UNAIDS, 2002).
3. GLOBOCAN 2000 (Ferlay, 2000).
4. Proportion of total population (all ages) needing terminal care associated with a death from either HIV/AIDS or cancer each year. This is a conservative lower limit of the proportion of the population that would need palliative care each year.
5. Based on the estimates that at least 25% of HIV/AIDS patients and 80% of cancer patients suffer pain in the terminal phase of their disease.

The above estimate, however, is based only on those persons needing terminal care for HIV/AIDS or cancer. The number actually needing palliative care should also include, for example, those suffering from a serious illness but not dying that same year and those dying from diseases other than HIV/AIDS or cancer. Palliative care should be provided in the context of continuum of care and not only at the end of life. In Uganda it has been estimated that 220,000 HIV/AIDS and cancer patients need palliative care, as compared to an estimated 94,500 patients that will die from either HIV/AIDS or cancer each year. Using this factor of 2.33 (220,000/94,500), it can be estimated that annually about 1.6 million individuals (690,800 x 2.33 = 1,610,000) and their families in these five countries will need palliative care services at some level. Thus a preliminary estimate is that about one percent of the total population of these countries (1.6 million/135.4 million) will need some level of palliative care services each year.

As anticipated, there is a close correlation between the proportion of the population needing palliative care and the proportion of adults living with HIV/AIDS. The highest proportions are found in Botswana and Zimbabwe (Table 3).

Because at least 25% of HIV/AIDS patients and 80% of cancer patients will suffer from pain in the course of the terminal phase of their disease (Merriman, 2000; WHO, 1990), it is estimated that annually at least 217,100 individuals in these five countries will experience great suffering from HIV/AIDS or cancer in the terminal phase of their disease (Table 3). Thus a relatively high level of palliative care support, including both pain relief and terminal care, should be provided to about one-sixth of one percent of the total population (1 in 624) each year. Today, in sub-Saharan Africa, the provision of palliative care is an urgent, unavoidable humanitarian duty (Merriman, 2002).

A needs assessment study recently undertaken in Uganda (Kikule, 2000) showed that the distribution of terminally ill patients was 73% HIV/AIDS, 22% cancer, 3% both and 2% other diseases. The majority of patients preferred to be cared for at home and, in fact, 87% of the caregivers were family members who were very supportive. Among the various needs shared by patients and their caregivers, the major ones were food and welfare. Poverty and sickness combined put the families in a critical situation. Patients experienced pain and other symptoms quite often and 65% declared them a problem. The main fears expressed by the patients were fear of death and abandonment. The study concluded that the home is the best place to care for the terminally ill. However, present home care systems in the Kampala District are not sustainable; they depend heavily on donors and reach a low percentage of the patients. Community participation is minimal with little sense of ownership. Further, the problem of HIV/AIDS is aggravated by a lack of access to the key drugs to control the disease. WHO estimated that in 2002 six million people needed antiretroviral drugs, yet only about 300,000 people (5%) had access to them. However, given the significant antiretroviral drug price reduction and the international community commitment to support developing countries through for instance the Global Fund, the World Bank Multi-country HIV/AIDS Program for Africa and multilateral aid agencies, a target of reaching three million by the year 2005 has been established (WHO, 2002b).

BOX 1

A young Ugandan woman had severe pain because she was in the last stages of a terminal illness. She had been unable to sleep because of severe pain for more than three months before she heard of Hospice Africa Uganda. She was given palliative care including oral morphine to control her pain. As she was reaching the end of her life, she asked her hospice nurse to pass on her message:

"Please thank all. Because of your help I am pain free and able to make provisions for my family after my death."

Although this young women died eight months later, she died in peace and without pain.

Source: Hospice Africa Uganda

The effect of HIV/AIDS and cancer on patients and their families

Patients with HIV/AIDS suffer with problems similar to those commonly encountered in cancer patients. Pain, dyspnoea, wasting, confusional states, psychosocial distress, and other devastating symptoms commonly afflict both HIV/AIDS patients and cancer patients. As symptom aetiology (except for AIDS wasting) is often common across these diseases, the principles of palliative care apply across a broad spectrum of disorders. Regardless of prognosis, the initial diagnosis of these diseases is still perceived by many patients as a life-threatening event, with over one-third of cancer patients experiencing clinical range anxiety and depression. HIV/AIDS and cancer can be equally if not more distressing for the family, profoundly affecting both the family's daily functioning and economic situation.

When cancer or HIV/AIDS is diagnosed, it is a natural human reaction to seek to cure the condition. However, the majority of cancer cases in Africa are incurable by the time they are diagnosed. All too often, the limited government and family resources are used to treat patients with far advanced disease, who really don't benefit from the treatment. This can result in a rapid depletion of resources, restricted access to facilities of those who could really benefit from rapid treatment, and inequitable access to the available treatment facilities. The common reality of a diagnosis of HIV/AIDS or cancer in an adult is a profound economic family crisis. This not only may lead to the loss of income, but the family's remaining income and resources are all too frequently exhausted seeking treatments. But perhaps the saddest of all is the futile frantic search and significant amount of money paid by the family for treatments that are actually unable to prolong the life of a family member with HIV/AIDS or advanced cancer. If families feel abandoned by their formal health care system, they may spend their remaining resources seeking assistance from well-meaning or unscrupulous individuals, who make false promises that they can help.

Efforts should be made to ensure that national cancer control programmes are strengthened to detect cases of cancer at early stages, when the patients can benefit from the treatment. For HIV/AIDS, access to comprehensive care including antiretroviral treatment can reduce HIV-related morbidity and mortality and can reduce hospital costs. The quality of life can be improved and people can return back to work as a productive segment of society. If all people with HIV/AIDS were provided adequate treatment, it would be a chronic and manageable disease, such as hypertension or diabetes. Countries such as Brazil and other western countries who have invested in quality care and antiretroviral treatment of people with HIV/AIDS have seen these benefits. Based on this evidence WHO has declared HIV/AIDS a "Global Health Emergency" and is committed to the target of 3 million people on antiretroviral treatment by 2005.

Programmes and initiatives

Given the very limited health infrastructure and resources and the need to provide a palliative care service to about one percent of the population each year, community and home-based care is viewed as the key to responding to these needs. Some countries have already developed strong home-based care networks in coordination with the PHC system to respond to the HIV/AIDS epidemic. Palliative care, as part of the continuum of care of HIV/AIDS, cancer and other chronic conditions can be integrated into this existing network.

Health promotion and prevention, and the provision of adequate quality treatment are key strategies to reduce the burden of HIV/AIDS and cancer. However, the first two will take many years to have the expected impact on the population and the latter requires the development of appropriate and accessible health infrastructure and technology for the good quality provision of care. In the meantime patients can be relieved from their pain and suffering by using low cost approaches, mainly community-based strategies. Regardless of future trends in the control of HIV/AIDS, the number of deaths from cancer in Africa is anticipated to rise considerably in the next 20 years. The principal factors contributing to this projected increase are the increasing proportion of elderly people, an overall decrease in deaths from communicable diseases other than HIV/AIDS, and the rising incidence of certain forms of cancer, notably lung cancer resulting from tobacco use.

Important palliative care initiatives are already underway in Africa and involve both governmental as well as nongovernmental initiatives, supported in many cases by international organizations. These initiatives have produced a solid knowledge base of how non-costly, good quality palliative care can be provided in low resource settings. They rely mainly on networks of the community members, educated and supervised by a palliative care team. However, there are still important gaps to be bridged in the region. Many countries have not yet considered palliative care a public health problem and therefore it is not included in their health agenda. Several initiatives have developed as “islands of excellence”, yet they are not integrated with the country’s national health policies, and thus have not yet achieved a significant impact on the population of patients. In many countries there are serious impediments to opioid availability, a key element of pain control. Important regional and global health initiatives dealing with related issues have not explicitly considered palliative care among their priorities.

Consequently, there is no doubt that there is a need to advocate for improved policy development regarding palliative care in the region. In order for initiatives to achieve sustainability and adequate coverage it is essential to promote a public health approach in which comprehensive palliative care programmes are integrated with existing health systems and are tailored to the specific cultural and social contexts of the target populations.

The Concept of Palliative Care

Palliative care should be an integral part of the comprehensive care and support for people living with HIV/AIDS (PLWHA) and cancer patients. It should be provided in the framework of a continuum of care from the time the incurable disease is diagnosed until the end of life. In order to ensure adequate population coverage it is also important that it be provided in health institutions as well as in home and community-based organizations (HCBOs).

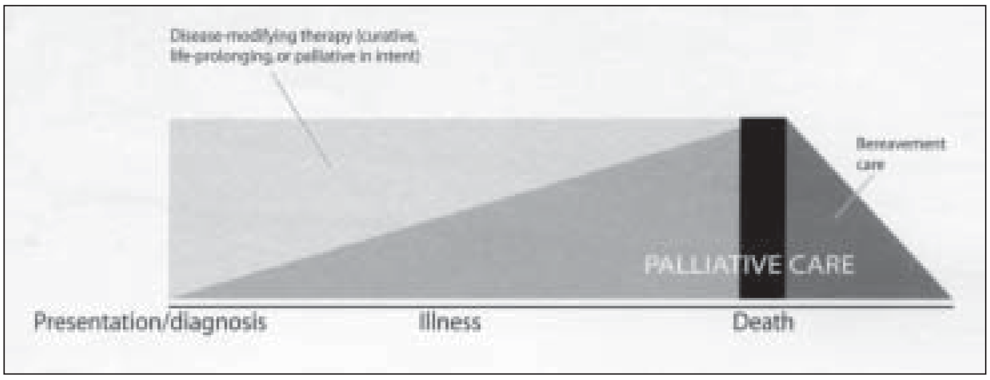
WHO defines palliative care as a holistic approach to improve the quality of life of patients with incurable disease and their families through the prevention and relief of suffering by means of early identification and careful assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2002c). Palliative care:

- affirms life and regards dying as a normal process;
- provides a series of interventions that intend neither to shorten nor to prolong life;
- neither hastens nor postpones death;
- provides relief from pain and other distressing symptoms;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life and includes those investigations needed to better understand and manage distressing clinical complications.

The continuum of care associated with palliative care is described graphically in Figure 2 (AMA, 1999). Therapy intended to modify the disease declines as the illness progresses. Symptom control and supportive care increase as the person nears the end of life. Palliative care provides support for the patient and family during this entire period.

Figure 2. Continuum of Care



Adapted from: American Medical Association. Institute for Medical Ethics (1999) *EPEC: education for physicans on end-of-life care*. Chicago, Ill: American Medial Association: EPEC Project, The Robert Wood Johnson Foundation.

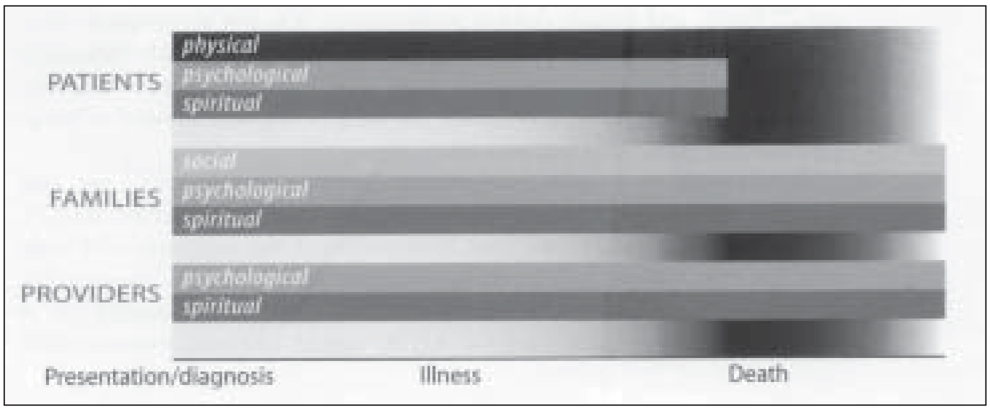
Palliative care, including symptom management, should be applied as early as possible in the course of any chronic illness. Symptoms not treated at onset become very difficult to manage in the last days of life. For example, an individual does not “get used to” pain; rather, chronic unrelieved pain changes the status of the neural transmission of the pain message within the nervous system, with reinforcement of pain transmission, and activation of previously silent pathways. Cachexia, the weakness and wasting of the body due to illness, either directly accounts for the deaths of millions of cancer patients each year, or serves as a major contributory cause (Tisdale, 1997). Control of symptoms throughout the course of illness has an impact not only on quality of life, but also on length of life by influencing the course of disease. In the African context the role of the hospice may extend beyond just the last few months of the patient’s life, to include the concept of long-term care. Bereavement care does not necessarily start at the time of the patient’s death, but actually earlier as the palliative care team prepares the family for the death of their loved one.

The quality of life dimensions of palliative care are illustrated in Figure 3. Palliative care is concerned with not only all aspects of the patient’s needs, but also the needs of the family and of the health care providers (WHO, 2002c). It supports the physical, psychological, social and spiritual needs of these individuals. Therefore it is important to assess these needs and be able to respond with a holistic approach.

Good communication is the key to psychological support. Imparting information must be undertaken with honesty and openness in an atmosphere of sensitivity and compassion with adequate emotional support (Buckman, 1996). The level of information and pace at which it is given should be appropriate for an individual’s ability, needs and culture.

Usually, patients want information on their illness (Simpson, 1991), but in many parts of the world information with ominous portent is withheld from patients. While

Figure 3. Quality of life dimensions of palliative care



this practice is based on compassion and family concern, a "conspiracy of silence" and a "conspiracy of words" may add to a patient's suffering. Progressive acceptance by the patient of what is happening often occurs naturally and slowly in a truly supportive environment. Unless patients are enabled to unburden themselves and share their anxieties and fears, pain and other symptoms may become the intractable avenue through which psychosocial distress is expressed (Twycross, 1994).

Although it may be impossible to offer hope of a cure, it is possible to offer pain relief, psychosocial support, improved quality of life and comfort in dying. However, as with pain management, there is need for specific training in communication skills (Faulkner, 1995).

Pain relief

WHO has developed a relatively inexpensive yet effective method for relieving cancer pain in about 90% of patients. This method is called the WHO ladder for cancer pain relief and is described in Box 2. This method is easily extended to patients with HIV/AIDS because in principle there is no difference between the care of the patient with AIDS and the care of the patient with advanced cancer (WHO, 1990, page 47). The reader is referred to WHO's several publications on policies and guidelines for cancer pain relief and other aspects of palliative care (WHO, 1996; WHO, 1998a; WHO, 1998b) for further information. Published by WHO, "Cancer Pain Relief" (WHO, 1996) sold more than a quarter of a million copies in 20 different languages and was called "the most influential publication in the field" by The Lancet.

An accurate pain assessment is an important first step in dealing with a patient's pain. Care should be taken to not overlook the problem of neuropathic pain that may not respond well to WHO's ladder approach. If the patient's pain is already severe, it is sometimes appropriate to move directly to the third level of the ladder approach, rather than working through the first two steps. While drug therapy is the mainstay of pain management, non-pharmaceutical approaches are also available.

Freedom from pain should be regarded as a human rights issue (WHO, 1998a). Unrelieved pain in patients is unacceptable because it is generally avoidable.

The main obstacles to pain relief are insufficient availability of opioid drugs due to regulatory and policy obstacles, ignorance and false beliefs. In order to overcome these interrelated problems, pain relief activities should always be established within a broader palliative care programme. Policymakers therefore need to:

- identify and acknowledge the problem;
- be aware that the problem can be solved using inexpensive drugs;

BOX 2

WHO Ladder for Cancer Pain Relief

WHO's ladder for cancer pain relief is illustrated in Figure 4

This method can be summarized in five phrases:

"By mouth"

Whenever possible analgesics should be given by mouth in order to permit wide applicability of this method.

"By the clock"

Analgesics should be given by the clock, i.e. at fixed intervals of time. The next dose should be given before the effect of the previous one has fully worn off, to relieve pain continuously.

"By the ladder"

The first step in the ladder is a non-opioid, typified by aspirin. If this does not relieve the pain, an opioid for mild to moderate pain, typified by codeine, should be added as the second step of the ladder. If this fails to relieve the pain, an opioid for moderate to severe pain, typified by morphine, should be used as the third step of the ladder. Additional drugs, called adjuvants, are used under certain conditions. For example, psychotropic drugs are used to calm fears and anxiety.

"For the individual"

There is no standard dose for opioid drugs. The "right" dose is the dose that relieves the patient's pain.

"Attention to detail"

The need for regular administration of pain-relief drugs should be emphasized. Ideally, the patient's drug regimen should be written out in full for the patient and family to work from.

- define policy aims and goals;
- ensure that specific resources are available for pain relief;
- examine resources available at the primary care level, and ensure that doctors and nurses are aware of the resources available and know how to access them.

Availability of medicines for palliative care

A palliative care programme cannot exist unless it is based on a rational national drug policy. This policy should include the following elements:

- acceptance of the WHO essential drugs list;
- regulations which allow ready access of suffering patients to opioids; this may require licensing of specially trained nurses;
- fair pricing by the pharmaceutical industry – this should include access to essential drugs made at low cost in developing countries, and inter-country or regional buying arrangements;
- a logistic plan for equitable in-country distribution;
- emphasis on training within professional schools on the application of the essential drugs.

Involving the family and community

Most patients suffering from a disease without cure prefer to receive care in their homes, which reveals the importance of home-based care within the context of a continuum of care. For this reason, some of the most effective approaches to increase access to care and support including palliative care have been developed and implemented by the affected communities themselves, particularly by people living with or affected by HIV/AIDS. These community actions are based on the direct experiences and initiatives of individuals, families and local groups. Health service planners and providers have come to realize that the involvement of communities and service users in the design, implementation and management of programs and services almost always leads to more appropriate, acceptable and effective outcomes, because:

- households and community groups undertake actions themselves to prevent HIV transmission and to provide care, thus complementing the health sector's efforts;
- communities can promote good health seeking behaviour and appropriate utilization of available health facilities;
- taking into account the expressed needs, opportunities and constraints of a community in developing services will make these more appropriate, acceptable and effective;
- communities can influence social and cultural norms, thus creating a more favourable environment for prevention, care and support of patients with HIV/AIDS or cancer.

Health sector actions should be community-centered, engaging communities and people living with HIV/AIDS or cancer as full and equal partners in the provision of palliative care services and other response to the epidemic. Communities, families and caregivers should be strengthened and supported in order to increase their capacity to participate in that partnership (WHO, 2002d).

A study conducted in Uganda in 2001 showed that the major palliative care needs are control of pain and other distressing symptoms due to opportunistic infections, food, rental and school fees, and counselling targeted toward psychological, spiritual and emotional support. Therefore, palliative care services need to cover not only morphine and other medical pain relief medicines, but rather a holistic approach to palliative care and its integration in other care and support services. Services should cover not only patients but also affected families, caregivers and health workers. Uganda seems to have currently achieved a greater extent of progress in policy development and provision of good quality palliative care; nevertheless it is estimated that the coverage is less than 15%.

The role of families in palliative care is very important. Patients and families may have little knowledge of the disease, its prognosis and its management, including palliative care. They may have low expectations of pain relief or unrealistically high expectations of treatment benefit. Every effort should be made to empower the patient and family and community by:

- involving them in decision-making with regard to treatment;
- explaining treatments in such a way that they can give informed consent (or informed refusal);
- facilitating a continuing sense of being in control by providing appropriate advice and practical support;
- education and training of community and family caregivers.

As noted earlier, palliative care needs may involve the provision of some level of palliative care to one percent of the entire population – those with HIV/AIDS or cancer. In order to provide such a level of palliative care coverage, a community and home-based care approach is necessary. It is unrealistic to expect the formal health service institutions, such as hospitals, clinics, and hospices, to be able to provide such a broad-based extent of care at the community or home level. Rather it is anticipated that family members, supported by HCBOs will provide the majority of the needed palliative care. The formal health services doctors and nurses and the HCBOs will play a fundamental role in the education and training of family members so that they can perform the majority of the daily tasks involved with palliative care.

Home-based care is a programme that through regular visits offers health services to support the care process in the home environment of the person with HIV infection or cancer. Home visits may be the only services provided or they may be part of an integrated programme that offers the patient and their family services in the home. Acceptance of the integral role of palliative care in the management of HIV/AIDS and cancer will enhance its overall understanding and support by the community, political leaders, and health professionals alike.

Project Goal and Objectives

Goal

The main goal of the “Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients in Sub-Saharan Africa Project” is to improve the quality of life of those patients and their families in sub-Saharan African countries by development of palliative care programmes with a public health approach that will provide pain relief and holistic care.

Objectives

The principal objectives are:

1. To develop and reinforce palliative care programmes with a public health approach in response to the needs and gaps identified, considering:
   - a holistic approach to palliative care, providing good quality care to respond to physical, psychosocial, social and spiritual needs, as well as giving special emphasis to pain relief;
   - a systemic approach to programme implementation which considers policy development, provision of care, drug availability, training and education in the context of HIV/AIDS and cancer health problems;
   - integration with the existing health system, involving all levels of care with special emphasis on home-based care, and integration with the ongoing strategies to prevent and control HIV/AIDS and cancer;
   - a team approach at the organizational and care levels;
   - a community health approach that encompasses team development and networking with community-focused action and a high level of population coverage;
   - elements of the quality dimensions for good programme performance: improving access, acceptability, effectiveness and efficiency.
2. To advocate for drug availability and policy development among the governments of the participating countries.
3. To develop a network among the participating countries that will:
   - promote exchange of information and collaboration;
   - advocate for the integration of such programmes into national strategic plans for health and social services.

Project Plan

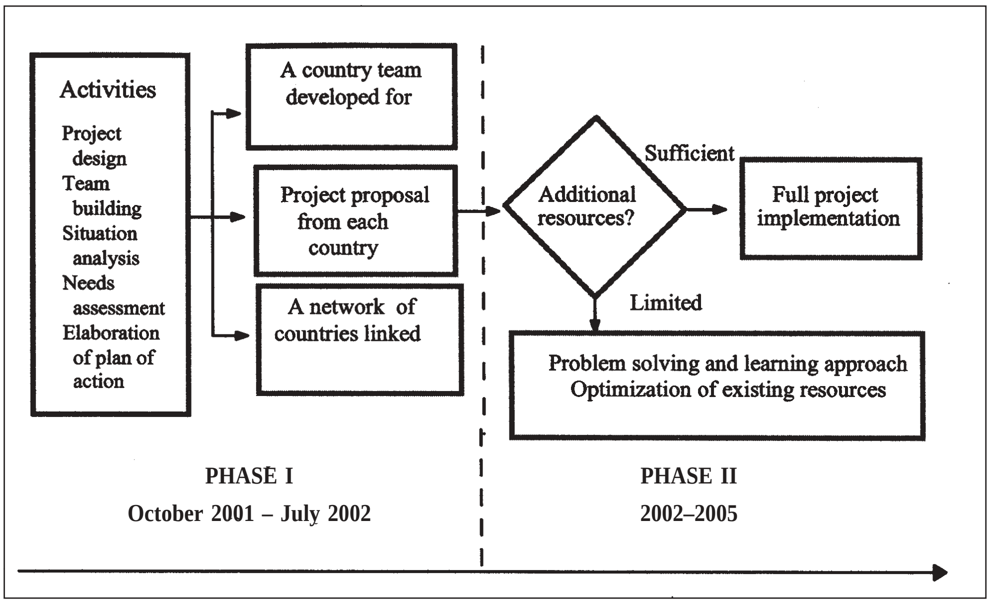
Palliative care is one of the three main priorities of the WHO Programme on Cancer Control (PCC) and is included in the scope of activities of several other WHO programmes. On 4 December 2000 PCC held a Consultation on Treatment and Palliative Care for HIV Patients with Cancer in Africa, mainly supported by funds from UNAIDS. The resulting guidelines serve as a framework for the management of palliative care in Africa (Olweny, 2003).

The "Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients in Sub-Saharan Africa Project" is being conducted by the WHO PCC in collaboration with the WHO Department of HIV/AIDS, a number of governmental and intergovernmental agencies, nongovernmental organizations and the WHO Regional Office for Africa (AFRO). The governments of five countries – Botswana, Ethiopia, United Republic of Tanzania, Uganda and Zimbabwe – have joined this initiative and are actively participating in this important health activity.

Project phases and main activities

The project will be developed in two phases as illustrated in Figure 5. Phase I covered the period from October 2001 to July 2002 and focused on project development, development of tools and methods for situation analyses, needs assessments, and developing plans of action to bridge the gaps. Subsequently Phase II is the implementation phase that consists of finalization of action plans, resource mobilization, implementation, monitoring and evaluation of the palliative care projects.

Figure 5. Advocacy and resource mobilization



Phase I (October 2001–July 2002)

The first phase of the project consisted of developing tools and methods for situation analyses and needs assessments, which were discussed in a workshop in Uganda in October 2001. Subsequently the gaps were assessed in the target areas by comparing the desired outcomes with the existing needs of patients, caregivers, health workers, and status of the health system response to these needs. Based on these gaps, proposals for action and resource mobilization were developed. The following main products were achieved by July 2002: development of country teams for the project; project design; tools and methods for situation analyses and needs assessments; draft project proposals from each of the countries; and a network of countries and individuals linked to the project.

Team building

The first phase of this project involved the identification and government endorsement of country-level palliative care teams. Careful team development was essential because the project intended to contribute to the development of palliative care with a public health approach, integrated with the existing health systems. The team organized for the project gathered individuals with technical and political influence that have the support of government authorities and the community, had motivation and interest to take long term responsibilities in the area of palliative care and were able to convince other key players to be actively involved. These teams took a leadership role in their country, conducted situation analyses to identify the magnitude of this problem and health system capacity, conducted assessments to identify the needs of patients, their families and their caregivers, and developed country-level action plans that aim to bridge the identified gaps and improve the performance of existing palliative care programmes.

Project design and workshops

Workshops were conducted in Uganda in October 2001 and in Botswana in July 2002 to develop consensus project objectives, strategies, activities, timetables and organizational issues. Initially these workshops focused on developing and finalizing methods for conducting situation analyses and needs assessments. Subsequently the situation analyses, needs assessments and draft plans of action were prepared and presented by team members from the participating countries and reviewed by workshop participants. Plans for further refinement of the network, methodology for assisting the implementation phase (Phase II) and development of a consolidated report of Phase I achievements were finalized.

Situation analysis

The situation analysis undertaken in each country aimed:

- To improve the understanding of the HIV/AIDS and cancer health problems in the country and target area;
- To evaluate the capacity of the health systems in relationship to HIV/AIDS and cancer in the country and target area.

A guide for the situation analysis permitted collection of this critical planning information in a standardized fashion. The guide included questions on basic demographic information, overall mortality and morbidity, HIV/AIDS and cancer mortality and morbidity, information on health system capacity (both general and specific for HIV/AIDS and cancer), and the current palliative care programme. The collection of situation analysis information relied entirely on existing information.

Needs assessment

A survey was undertaken to determine the needs and preferences of those receiving palliative care and their caregivers in target areas within each country. Interviews with terminally ill persons or their caregivers were based on a questionnaire developed by Dr Kikule from Hospice Uganda and previously used in Kampala and Hoima. In each target area the standardized instrument was adapted for the local conditions and local health care specialists were trained to administer the questionnaire under the supervision of the country palliative care team. Surveys were conducted in all five countries in 2002. The questionnaire was administered to about 100 persons with a terminal illness or caregivers from a family that had experienced the death of a family member at home. Information was also collected from community members.

Development of plans of action

A framework to assist the project teams in the development of their project proposal was developed based on specific principles. The framework:

- was public health oriented, utililizing a systemic approach to palliative care of HIV/AIDS and cancer patients and tailored to the specific context;
- guaranteed ownership of the project at the local level with wide participation of individuals and organizations involved at the different levels of decision making and implementation;
- focused on managerial aspects and training issues at the local level;
- gave attention to monitoring and measures of evaluation, including indicators of effectiveness (quality of life and others), efficiency, accessibility, acceptability, and caregivers' competence;
- ensured that training was based upon problem solving and team learning at the ground level (workplace, community) using distance learning when appropriate; and
- defined pilot areas and developed a stepwise approach to fill in the gaps so that existing resources and initiatives were optimized in the first stage and resource mobilization projects were developed to allow further reinforcement and expansion.

Network

A network of experts in palliative care aimed to facilitate the exchange of information and the sharing of experiences, as well as identifying and helping with the mobilization of resources at all levels: country, regional and international. WHO and special advisors provided technical assistance and facilitated the process.

Phase II (2002–2005)

If additional funds are raised during 2004–2005 by WHO or the countries themselves, project proposals from each participating country will be implemented. If insufficient additional funds are made available, existing initiatives will be reinforced, improving efficiency and effectiveness using a methodology of problem solving and team learning.

From 2003 onwards, 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 in the existing HIV/AIDS and cancer comprehensive care and support framework as part of the continuum of care;
- education and training for caregivers and programme managers;
- developing national policies and guidelines on palliative care;
- improved access to drugs and other supplies; and
- improved information systems, monitoring and evaluation.

Project management

WHO's Programme on Cancer Control (PCC) in the Department of Management of Non-communicable Diseases manages the activity. A Project Steering Committee, described in the Preface, ensures coordination and scientific orientation.

Country level palliative care teams are responsible for developing the project in each country with the assistance of the Steering Committee. Each team defines the roles among its members according to their skills and competencies to develop the specific tasks the project requires. For example, for Phase I it was highly desirable that the individual heading the process had experience in this kind of study and could dedicate time and efforts to coordinate the initiative.

Due to the collaborative nature of this project a number of other individuals and organizations are partners in this endeavour, mainly the Department of HIV/AIDS, palliative care, health systems and essential drugs sections from the WHO African Regional Office, relevant WHO's country offices, WHO palliative care experts, WHO advisors in managerial aspects and training issues, WHO Headquarters' Long-Term Care Programme, and relevant nongovernmental, governmental and intergovernmental organizations.

Evaluation

The project development was evaluated at the end of Phase I. The initial phase of the project can be considered successful because:

1. The participating countries have:
    - completed team development, conducted situation analyses and needs assessments and developed project proposals according to the needs and gaps identified in their target areas;
    - obtained political support from their governments and some concrete financial support to develop the implementation phase with key activities such as accessibility to drugs and training of health care providers;
    - started networking and enhanced collaboration, especially in the areas of policy development, training, educational material and management issues.
2. Partnership among the international organizations involved in the project has been strengthened and further initiatives are envisaged.
3. By the end of 2003, WHO and the project participants will have published the results of the needs assessments and situational analyses (this project report and a summary paper in a major medical journal (Sepulveda,2003)) and will have completed proposals for projects to be undertaken in each country and at the regional level.

From 2003 onwards the evaluation of the project will consist mainly of a) the analysis of each country evaluation done according to the above-mentioned framework for developing the country project proposals and b) the progress of the network.

By 2003–2004 it is expected that the project will have obtained resources from internal as well as external sources for the implementation phase. It will be considered acceptable if at least "seed money" has been raised. However, the goal will be to obtain sufficient funds for full project implementation in the target areas.

Project meetings

The initial meeting of project participants was held in Kampala, Uganda from 15 to 17 October 2001 (participants are listed in Appendix E). Project strategies and methods were developed by participants from the five countries in order to ensure feasible approaches, an integrated public health approach to palliative care, and a sense of ownership of the project. The meeting resulted in consensus agreement with the overall project proposal and strategies for project team development. Tools and methodologies for the conduct of situation analyses and needs assessment surveys were finalized, as were elements of plans of action for each country.

The second project meeting was held in Gaborone, Botswana from 9 to 12 July 2002 and included more than 70 participants (see Appendix E). The opening ceremonies were honoured by the Minister of Local Government, the Permanent Secretary of the Ministry of Health, the Mayor of Gaborone, the Director of Human Resources in the Ministry of Health, the Deputy Director of Health Services, the WHO Representative and several representatives of UN agencies. Based on the situation analyses and needs assessments, action plans to improve palliative care and address the unavailability of opioid pain medications in each country were developed. Lessons learned from the first phase of the project were summarized, including the strengths and weaknesses of the tools used for the situation analyses and needs assessments. Because of the barriers faced concerning the availability of drugs, each country drafted a plan for improving access to morphine. The importance of integration of each palliative care project proposal into the national health plan was emphasized. A generic training tool in palliative care for training all levels of the palliative care team, including health workers, family caregivers and community volunteers, will be developed. It will be based on existing training materials in Botswana, South Africa, Uganda, and Zimbabwe.

Situation Analysis

Situation analyses were planned in each country to determine the current health status, health system status and to identify the major problem areas. A "situation analysis guide" was developed for this project and is given in Appendix A. The guide not only outlines the information that should be collected, but also describes the phases of conducting the situation analysis and gives an overview "information matrix".

Each situation analysis consists of two components – a situation analysis for the country overall and a situation analysis for the target area. Each country team identified a target area to be the focus of the efforts of this project. Information collected included the current epidemiological status of cancer and HIV/AIDS and the response to control these diseases – with particular emphasis on the palliative care component at the national level and in the target area.

Overview results from the national level situation analyses are summarized in Table 4. The major causes of mortality are either associated with HIV/AIDS or communicable diseases. The prevalence of HIV/AIDS in adults is much higher in Botswana and Zimbabwe, 38.8% and 33.7%, than in the other three countries. Even still, however, the prevalence of HIV/AIDS in Ethiopia, Uganda and United Republic of Tanzania is higher than most other countries in the world, ranging from 5% to 12%.

Kaposi's sarcoma is among the most common cancers in these countries because of its association with AIDS. Head and neck cancer and lymphoma are common in males and, similar to most developing countries, the most common cancers in females are cancers of the cervix and breast.

The situation analysis collected social, economic and cultural context information in order to help develop effective palliative care programmes. Table 5 presents summaries of the statements regarding stigma and discrimination from the national level situation analyses. In general the level of stigmatization associated with HIV/AIDS is very high in these countries. There is clear reluctance for family members to care for a relative with HIV/AIDS at home. This will be a formidable barrier to the development of effective palliative care programmes.

Table 4. Country health status information from the situation analysis

Country	Major causes of mortality	Most common cancers in males (incidence)	Most common cancers in females (incidence)	Prevalence of HIV/AIDS in adult males/females
Botswana	1. HIV/AIDS (18%)[1] 2. Pneumonia (15%) 3. Pulmonary TB (10%)	1. Kaposi's sarcoma (41%)[6] 2. Liver (6%) 3. Lung (6%)	1. Cervix (26%)[6] 2. Kaposi's sarcoma (23%) 3. Breast (20%)	38.8%[11]
Ethiopia	1. Pulmonary TB (10%)[2] 2. Pneumonia (7%) 3. Malaria (5%)	1. Head & neck (43%)[7] 2. Lymphoma (14%) 3. Rectal (13%)	1. Head & neck (25%)[7] 2. Breast (15%) 3. Cervix (12%)	7.3%[12]
Uganda	1. Malaria[3] 2. Respiratory infection 3. HIV/AIDS	1. Kaposi's sarcoma (61%)[8] 2. Prostate (10%) 3. Oesophagus (8%)	1. Kaposi's sarcoma (30%)[8] 2. Cervix (29%) 3. Breast (15%)	5.0%[11]
United Republic of Tanzania	1. HIV/AIDS/TB (38%)[4] 2. Acute febrile (11%) 3. Diarrhoea (9%)	1. Kaposi's sarcoma (21%)[9] 2. Head & neck (13%) 3. Lymphoma (6%)	1. Cervix (32%) 2. Breast (9%) 3. Kaposi's sarcoma (6%)[9]	7.7% 12.2%[10]
Zimbabwe	1. Resp. infect. (22%)[5] 2. Pulmonary TB (20%) 3. Perinatal (13%)	1. Kaposi's sarcoma (33%)[10] 2. Liver (9%) 3. Lymphoma (7%)	1. Kaposi's sarcoma (19%)[10] 2. Cervix (13%) 3. Liver (8%)	33.7%[13]

Notes:

1. Inpatient mortality in Botswana in 1999.
2. Leading causes of death in 2000/2001. Even when AIDS is highly suspected, death certificates routinely cite other causes of death, such as TB.
3. Ministry of Health, Health Policy Statement, 2001/2002.
4. Data are from the AMMP project, covering Dar es Salaam, Kilimanjaro and Morogoro regions, for ages 15-59. "Acute febrile" – acute febrile illness plus malaria.
5. "Respiratory infections" – acute respiratory infections (lower tract).
6. Most common cancers reported in Botswana in 1999 (Cancer Association of Botswana).
7. In 1999.
8. Based on the crude incidence rates from the Kyadondo County cancer registry 1991-1993 as reported in Cancer Incidence in Five Continents, Vol. VII, IARC, Lyon, 1997.
9. National Kaposi's sarcoma percentage estimated based on relative cancer type incidence data from the Ocean Road Cancer Institute.
10. National cancer deaths in 1998.
11. Percent of adults 15-49 years living with HIV/AIDS from UNAIDS Report on the Global HIV/AIDS Epidemic 2002.
12. National data from the Ministry of Health for 2000. The estimated urban prevalence is 13.4% as compared to a rural rate of 5%.
13. Prevalence for ages >15 for 2000.

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.

Characteristics of the target areas selected for this project are given in Table 6. In Botswana the entire country was selected to be the target area. In Ethiopia and United Republic of Tanzania the major urban areas in the country have been selected for the project, each with more than two and a half million people. The other selected target areas are mainly rural areas. In most of these areas education activities in support of home-based palliative care programmes have to take into account the likelihood that the home-based care provider will not be literate.

The major causes of morbidity in these target areas largely reflect the health problems associated with the recent incursion of HIV/AIDS and the long-time established infectious disease problems. While reliable information is generally not available regarding where patients die from HIV/AIDS or cancer, local clinicians state that a clear majority of deaths occur at home. In Ethiopia, for example, it is customary that while a cancer patient may be admitted for establishing the diagnosis,

Table 5. Stigma and discrimination

Country	Stigma and discrimination statement from the country situation analysis
Ethiopia	No prominent Ethiopian is willing to stand up, acknowledge infection and urge others to discuss the issue on a personal and public basis. Health professionals emphasize the unwillingness of Ethiopians to come forward for voluntary testing, even when kits are available. Because HIV/AIDS is correlated with promiscuity, many believe that only immoral people get AIDS. Death certificates, even when AIDS is highly suspected, routinely cite other causes of death, such as TB. When testing proves that AIDS was the cause of death, friends and relatives are usually not told. In fact, Ethiopian doctors are usually reluctant to pass along bad news to patients on any health matter, especially now with AIDS. When donated blood is found to be HIV+, the blood is destroyed and the donor not told. People with or suspected of having HIV are afraid they will be turned away from health care services, employment, or refused entry to a foreign country. Fear of discrimination often prevents many Ethiopians from seeking treatment for AIDS. In numerous cases, those with AIDS have been evicted from their homes by their families and rejected by their friends and colleagues. Infected children, and those who have parents infected by HIV, are often orphaned or abandoned. In Ethiopia, HIV/AIDS-related stigma, characterized by silence, fear, ignorance, intolerance, discrimination and denial are fuelling the spread of HIV/AIDS and are creating immense barriers to effective responses to the epidemic.
Uganda	In 2000-2001 UDHS assessed whether society has accepted people living with HIV/AIDS. Respondents were asked, "If a person learns that he/she is infected with the virus that causes AIDS, should the person be allowed to keep this fact private or should this information be available to the community?" Less than half of the women and three in ten men felt that HIV-positive persons should be allowed to keep this fact confidential. The sentiment did not vary much across subgroups. Only one in ten women and men said that they would be willing to care for a relative with AIDS at their home. Furthermore, half of the women and men believe an HIV-infected female teacher should not be allowed to continue teaching in a school.
United Republic of Tanzania	Stigma and discrimination against people living with HIV/AIDS is quite common in United Republic of Tanzania, and in some areas (e.g. Magu and Mwanza) the level of stigma and denial is very high. Lack of disclosure and partner notification is still a problem. Experience in antenatal clinics suggests that less than 20% of HIV positive pregnant women would disclose their status to their partners. The tendency to link promiscuity to HIV/AIDS is still very strong and contributes to the habit of concealing causes of death for such patients. Gender issues have also been implicated. For example, if a woman is HIV+ she is blamed for infecting the man. But if a man is sick it is seen as an unfortunate stroke of luck – he is given sympathy and not blamed. For cancer the situation is not the same. A patient with cancer will develop fear of death, but there will not be a social stigma. People around the patient will be more sympathetic and caring.
Zimbabwe	The risk of discrimination and stigmatisation is high with respect to HIV/AIDS and is encountered in many spheres of life. Discrimination and stigmatism are experienced from both families and communities.

Note: Botswana stigma and discrimination stated in needs assessment.

they are discharged once the diagnosis of advanced cancer is made. While the number of people per hospital is similar for these target areas, with the exception of Botswana, the number of people per physician is much more variable.

The countries and target areas are very heterogeneous with respect to palliative care. An analysis of the strengths and weaknesses is summarized in Table 7. In a number of ways, Uganda is the most developed. In the last ten years, thanks to nongovernmental 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. This has resulted in the allocation of resources, improved morphine availability, and the provision of training at all levels of care and to undergraduate and postgraduate health professionals. Uganda has also 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.

Zimbabwe has a long tradition of 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

Table 6. Characteristics of the project target areas

Country/ Target area	Target area population	Adult literacy rate[2]	Major causes of morbidity	Deaths that occur at home	Number of hospitals	Number of doctors	Number of nurses and midwives
Botswana Entire country	1,681,000[1] Urban and rural	69%	1. Intest. infections (7%)[4] 2. Pneumonia (7%) 3. Pulmonary TB (5%)	NA	37	475	4,992
Ethiopia/ Addis Ababa city	2,600,000 Urban	23%	1. Resp. infections (19%)[4] 2. Skin infections (14%) 3. Pneumonia (13%)	"Most"[9]	18	169	585[13]
Uganda/ Tororo District	555,600 89% Rural	72%	1. Resp. infections (13%)[5] 2. HIV/AIDS (12%) 3. Trauma (12%)	"Most"[10]	3	19	172
United Republic of Tanzania/Dar es Salaam city	2,800,000 Urban	68%	1. Malaria (55%)[6] 2. Resp. infections (10%) 3. Pneumonia (6%)	"Most"[11]	24	48	359
Zimbabwe/ Goromonzi District	370,000 Rural	85%[3]	1. Pulmonary TB[7] 2. HIV/AIDS 3. Resp. infections[8]	"Most"[12]	3	3	110

Notes:

1. National 2001 census.
2. National figures.
3. World Health Report 1998, WHO Geneva.
4. In patient/health centre morbidity.
5. Percent ranking from a 1995 burden of disease study in the district.
6. Outpatient diagnoses in 2001.
7. Quantitative information is not available.
8. "Respiratory infections" – acute respiratory infections (lower tract).
9. Based on clinical observation. When cancer patients are admitted for establishing the diagnosis, they are discharged once the diagnosis of advanced cancer is made.
10. Nationally only 49% of households are within walking distance to a health facility. Only 43% of rural parishes have any form of health facility.
11. Approximately 60% of HIV/AIDS deaths occur at home (MOH health statistics, 1999).
12. Most people with cancer die at home because they are on home-based care. About 50% of HIV/AIDS patients die in the home and the other 50% in hospital.
13. Registered Nurses, midwives and nurses with specialized training.

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 United Republic of Tanzania, some NGOs are providing home-based pain control at the district level and the Ocean Road Cancer Institute, with the assistance of Hospice Uganda, and have initiated training for health care providers. Botswana and Ethiopia have even greater gaps regarding palliative care, but 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 disease patients.

Education in pain relief and palliative care must be an essential component of training for all who may be expected to treat patients with advanced chronic illness. Implementation of education programmes would have a major impact on the quality

Table 7. Analysis of strengths and weaknesses in palliative care in the target areas

Country	Strengths/opportunities	Weaknesses/threats
Botswana	– Community home-based care programme and guidelines in place – Policy on care and support – Government commitment – ARV programme in place – Counselling programme and guidelines in place – Appropriate structures available - e.g. clinical management committee	– Lack of trained human resources – Lack of understanding of palliative care among health providers – Inadequate capacity to train for palliative care – Inadequate pain relief in the community – Major shortage of health professionals and social workers – Increased burden of care/burnout among caregivers – Inadequate number of hospices, halfway houses and day care centres
Ethiopia	– Strong political commitment for HIV/AIDS prevention and control – Community support and commitment – International organizations, local NGOs and government partnership – Networking with other participating countries in the palliative care project – Availability of national drug policy	– Lack of trained health workers in palliative care – Inadequate capacity to train for palliative care – Social stigma (especially attached to HIV/AIDS) – Poor behavioural change – Cancer not adequately addressed – Shortage of human and material resources
Uganda	– Palliative care included into national health policy, and into planning & budgeting process of health activities – Existing health infrastructure and community-based organizations to provide palliative care – Strong collaboration with other agencies (WHO, TASO, etc.) – Ability to assist other sub-Saharan countries in training and advocacy – Opportunities for special training of health workers – Draft statutory instrument to increase morphine; prescribers await endorsement by MOH	– Inadequate regulatory framework – Few trained health workers – Health units may not have the required standard for handling oral morphine – Other treatment modalities inadequate e.g. simple analgesics – Weak delivery chain may hinder continuous supply – Slow implementation – Difficult coordination of stakeholders – Resistance to change from some health professionals – Inadequate funds for activities – Overwhelming demand
United Republic of Tanzania	– Home-based care is integrated in the health care system – Existing palliative care team at ORCI – Palliative care provided at district level by some NGOs – Support of MOH, district health management and NGOs – Government provides funds for palliative care treatments	– Training of home-based care providers – Availability of manuals on home-based care – Link between hospital-based services and home-based care – Only medical doctors have license to prescribe opioid drugs – Radiotherapy is only available at ORCI
Zimbabwe	– Training is the major strength since the programme started (hospice nurses, community volunteers) – Palliative care is being mainstreamed into the health care system – Community home-based care policy launched in 2001 – Oncology and HIV/AIDS care policy developed as early as 1992 – Guidelines, training manuals and booklet on care of terminally ill have been published	– Lack of health institutional support for home-based care patients – Lack of access to national AIDS levy for AIDS patients – Coordination of home-based care needs improvement – Distribution of narcotic drugs for pain is erratic & inconsistent; the cost is also a problem – Lack of resources and adequate equipment – Shortage of staff – Building and space requirements – Need a cytotoxic drug policy – Procurement of drugs – Implementation of an effective policy on morphine

of life of patients, but will not happen without strong political motivation and leadership (Stjernsward, 1993). An example of a training programme is the Education for Physicians on End-of life Care (EPEC) Project developed by the American Medical Association in the US (AMA, 1999).

The health care system component of the situation analyses for the target areas are given in the country reports given later in this monograph. Current palliative care

Table 8. Results of WHO questionnaire on national narcotic drug policy[1]

Question	**Botswana**	**Ethiopia**	**United Republic of Tanzania**	**Uganda**	**Zimbabwe**
Do the current government policies on drug regulation impede prescribing, dispensing, availability, distribution and access to narcotic drugs of medical value?	No[2]	No	No	Yes[13]	No
Is there any effort to review and revise such policies (see above)?	Yes[3]	Yes	Yes	Yes[13]	Yes
Does the current national drug policy recognize the use of narcotic drugs for pain relief?	Yes	Yes	Yes	Not specific	Yes
Does the current national drug policy stipulate the government's role of ensuring availability of narcotic drugs for medical and scientific use?	Yes	Yes	Yes	Yes	Yes
Is there any government established mechanism or body that licenses, estimates and keeps statistics to ensure adequate availability of narcotic drugs for scientific and medical use?	Yes[4]	Yes[8]	Yes	Yes[14]	Yes[17]
Are there adequate technical and human resources for implementing of these activities (in the previous line above)?	Yes	Inadequate	Yes	No	Inadequate
Does the government have a mechanism of estimating narcotic drug requirement for use as analgesics in palliative care and other conditions?	No	No	No	Yes	Yes
Does the government assess its requirements in narcotic drugs as specified by the International Narcotic Control Board (INCB)?	Yes	Yes	No	Yes	Yes
Has the government established a system to collect information about the medical need in opioid analgesics from health facilities?	NA	Yes	No	Yes	NA
Does the government timely furnish the annual estimates for requirement in narcotic drugs to INCB?	Yes	Yes[9]	No	Yes	Yes
If the medical need for opioid analgesics exceed the estimated amount approved and confirmed by INCB, is it government policy to furnish a request for a supplementary estimate?	Yes	Yes	No	Yes	Yes
Does the government timely submit to INCB the required annual statistical reports in respect to production, manufacture, trade, use and stocks of narcotic drugs?	Yes	Yes	Yes	Yes	Yes
Has the government discussed and informed health professionals about the legal requirements for use of narcotic drugs?	No	Yes[10]	No	Yes[15]	Yes

Has the government identified and addressed concerns of health care professionals about being investigated for prescribing opioids?	NA	Yes[11]	No	Unclear	No
Is there cooperation between the government and health care professionals to ensure availability of opioid analgesics for medical and scientific purposes?	Yes	Yes	Yes	Yes	Yes
Has the government taken steps, in cooperation with licensees, to ensure that there are no shortages of supply of opioid medications caused by inadequate procurement, manufacture and distribution systems?	Yes	Unclear[12]	Yes	Yes	No
Does the national drug policy provide for licensing an adequate number of individuals and entities to support a distribution system?	Yes[5]	Yes	Yes	Yes	Yes
Is there a government established national cancer control programme to which health care resources are allocated?	NA	No	Yes	Yes[16]	No
Has the government adopted the WHO recommendation on use of analgesics for control of pain in palliative care?	No[6]	No	Yes	Yes	Yes
Is palliative care included in: continuing medical education (CME) curriculum, undergraduate and post graduate education curriculum for medicine, pharmacy, nursing and allied health professionals?	NA[7]	No	No	In portions	Yes
Is there terminology in the national drug policy that has the potential to confuse the medical use of opioids for pain with drug dependence?	No	Yes	Yes	No	No
Are there provisions in the national drug policy that restrict the amount of drug prescribed or the duration of treatment?	No	No	No	No	Yes[18]
Are there prescription requirements in the national drug policy that may unduly restrict physicians and patients to access narcotic drugs for pain relief?	No	No	Yes	Yes	Yes[18]

Notes:

1. This questionnaire was adapted by Dr F.M. Sebusubi, Ministry of Health, Uganda from the questionnaire included in “Achieving Balance in National Opioids Control Policy: Guidelines for Assessment” WHO/EDM/QSM/2000.4;
2. Dispensing and prescription guidelines are in place. The Drug Regulating Unit approves orders;
3. Part of the impending review of the National Drug Policy and the hospital guidelines;
4. The Drug Regulating Unit handles this;
5. The provision is not yet implemented;
6. There is a Botswana treatment guide;
7. There is no medical or pharmacy school in Botswana;
8. The Division of Control of Narcotics and Psychotropic Substances is established under the Drug Administration and Control Authority (DACA);
9. The government furnishes annual estimates to the INCB. However, considering the unavailability and irregular supply the annual estimate is felt to be far below the requirement and it is not clear on what kind of information the estimate was based;
10. The government conducts regular training programmes on regulations and guidelines. However, no information is available on level of training, target and frequency;
11. Cooperation is said to be in place. However, information on the type, level and frequency of cooperation is not available;
12. Pethedine and codeine are sometimes available, but not regularly available. Oral morphine is not available; it is only rarely available from abroad;
13. The law requires only medical doctors, dentists, veterinary surgeons or pharmacists to handle narcotic drugs. There are currently not enough in the country. This is being revised to permit nurses and clinical officers trained in palliative care to prescribe certain class A drugs;
14. The National Drug Policy;
15. The role is carried out by the Ministry of Health and the National Drug Authority;
16. A Uganda cancer institute exists;
17. Medicines Control Authority of Zimbabwe;
18. In the regulations.

services and the health care structure are described to facilitate planning for the strengthening and integration of the palliative care programmes.

Drug availability

Governments have a responsibility to establish national policy and programmes in support of palliative care. Policy elements should ensure the availability of opioid, nonopioid, and adjuvant analgesics, particularly morphine for oral administration.

The current status of national narcotic drug policy was assessed by the completion of a WHO questionnaire (see Appendix B). Results of this questionnaire are given in Table 8. In United Republic of Tanzania the regulating authorities allow the medical use of morphine, and oral morphine is available. In other countries, however, there are serious limitations on morphine availability due to a combination of factors such as excessively strict regulations, lack of knowledge, stigma and the lack of foreign currency to import drugs. Different elements of narcotic drug policy need attention in the various countries. WHO and its partners will advocate for drug availability and policy development directly with the concerned governments. The WHO guidelines "Achieving the balance in national opioids control policy" will be used as a reference guide (WHO EDM, 2000). A concrete plan of action will be developed jointly with the country teams and policy advisors.

Needs assessment

A key aspect of the development of this project is the collection of detailed recent information about the expressed needs and preferences of those receiving palliative care and their caregivers in target areas. This information is called the "needs assessment" and was collected by a set of survey instruments developed and adapted for this project. The core of the original research data collected by the needs assessment focused on a small sample of about 100 cases in the target area.

A set of needs assessment tools are given in Appendix C. These were developed by Dr E. Kikule from Hospice Uganda and include:

- Questionnaire for urban patients,
- Questionnaire for family caregivers,
- Questionnaire for heads of households or caretakers of ill rural patients,
- Guide for interviewing programme managers,
- Guide for interviewing hospital medical superintendents,
- Guide for focus group discussions, and
- Guide for interviewing key informants.

Table 9 shows the methodologies used by each country and the main results. These studies, although not covering the entire target areas, provide useful information about the needs of patients, their families and caregivers. 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. Stigma was identified as a problem in all countries. Family members and relatives are the main caregivers; they acknowledged lack of knowledge and skills to perform their task adequately. In a 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 urban 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.

Table 9. Needs assessment for palliative care services in the target area

Country/ study site	Methodology and sample size	Results				
		Health facilities accessibility and utilization	**Caregivers**	**Problems of the family**	**Problems of the terminally ill**	**Patient-preferred site of care/ % consulting traditional healer**
Botswana Entire country	Quantitative collection methods Samples: 92 patients & 96 caregivers in 4 districts	Nearly always a government funded health facility 81% of rural population & 98% of urban population within 8 km of health facility	Relative: 32% Mother: 25% Daughter: 14% Spouse: 12%	NA	Severe pain: 64% Lack of food: 59% Social support: 41% Cough: 39% Headache: 38% Financial: 36%	NA
Ethiopia Addis Ababa city	Qualitative & quantitative collection methods Sample: 100 cancer patients at the radiotherapy center (RT) Focus group discussions at RT centre and NGO	Government owned: 65% Nearest facility: health center: 49% Average distance: 24 minutes walk Attended health facility in course of illness: 89% Majority didn't receive the required care at health center	In order of frequency: spouse, child, close relative	Major problems: Financial Emotional Nursing bed-ridden Stigma and discrimination for HIV/AIDS	Pain and other symptoms: 76% Financial constraints: 50% Anxiety and fear: 20% Stigma Counselling In minority of cases needs are met/mainly by families/relatives	Home: 25% Health facility: 58% Sought traditional healer: 27%
United Republic of Tanzania Dar es Salaam city	Qualitative & quantitative collection methods Random sampling among HIV and cancer patients: Separate interviews held at home for 40 patients and their key caregiver Interviewed 20 from general community and key informants	Government owned: 89% Nearest facility: dispensary: 79% <5 km between home and health facility: 92% Attended health facility in course of illness: 95% Majority didn't receive the required medications	Parent: 30% Spouse: 27% Brother/sister: 10% Relative: 10% Child: 8%	Financial: 45% No time left for themselves: 25% Nursing: 5% Lack of knowledge	Financial: 63% Spiritual: 48% Physical: 30% Emotional: 18% Stigma: 90%	Home: 82% Sought traditional healer: 25%
Uganda Tororo District	Qualitative & quantitative collection methods Samples: 102 households Focus groups Key informants	Government owned: 89% Nearest facility: dispensary: 79% Average distance from home: 3 km Attended health facility in course of illness: 93% Received required treatment all the time: 36%	Parent: 38% Spouse: 24% Child: 24% Other: 14%	Money: 50% Nursing bed-ridden: 17% Health facility too far: 13% Patient's pain: 12% Stigma: 7% Emotional stress: 7%	Pain and other symptoms: 41% Food: 19% Provisions for family: 14% Counselling (patient, family): 13%	Home: 47% Health facility 47% Sought traditional healer: 24%
Zimbabwe Goromonzi District	Quantitative collection methods Sample: 100 caregivers	Nearly always a government funded health facility Rural health centre: 75% District hospital: 24% Average distance from home: 4.9 km	Relative: 46% Spouse: 27% Child: 15%	Resources: 86% Patient's pain: 36% Lack of health care worker support: 32%	Drugs for pain relief: 59% Drugs for other symptoms: 50% Inability to look after self: 50% Food: 48%	Home: 53% Hospital: 31% Nursing home: 9% Sought traditional healer: 16%

Team Development

A guide on team building has been developed for this project by Dr Inés Salas, University of Santiago, Chile (see Appendix D). This guide was sent to all participants prior to the meeting in Uganda in October 2001 to motivate and support team development from the very beginning.

This project has given special emphasis to team development as an essential strategy for involving the key stakeholders and for bringing together people who could eventually take the lead in implementing and evaluating community-based palliative care programmes with the appropriate endorsement of their respective governments. All participating countries have made great efforts in this regard. United Republic of 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.

Plans of Action

The first phase of this project was to determine the palliative care needs of patients and caregivers in the target areas and to develop plans of action from each of the countries to meet these needs. The workshops in Uganda in October 2001 and in Botswana in July 2002 served as forums at which the extent of the problem and strategies for solution were reviewed and consensus objectives and strategies were developed. Draft plans of action were presented by team members from the participating countries at the Botswana workshop and were reviewed by the workshop participants. While there were variations among the countries with respect to the amount of detail provided in the draft plans of action, common objectives and strategies emerged. Goals and objectives for the action plan proposals presented at the Botswana Workshop are summarized and compared in Tables 10 and 11. Key themes identified by the needs assessments and situation analyses, and which recurred throughout the discussions at the workshop included i) the importance of advocacy about palliative care, ii) the need to train caregivers and to have training incorporated into medical and nursing curricula, iii) the need to strengthen policies and guidelines on palliative care, iv) the need to

Table 10. Summary of action plan proposal goals

Country	Goals
Botswana	Total palliative care to patients and their families in life and death Empower family caregivers and reduce burnout of caregivers Patient satisfaction with care provided
Ethiopia	To improve the quality of life for HIV/AIDS, cancer and other chronically ill patients through alleviation of their suffering - thereby reducing the burden for the family and other caregivers
United Republic of Tanzania	To increase the proportion of HIV/AIDS and cancer patients who die with dignity and comfort at home
Uganda	Universal access to quality palliative care for all Ugandans
Zimbabwe	To reach a stage where every terminally ill person and their family have access to comprehensive quality palliative care

Table 11. Plans of action – objectives overview

Objectives	Botswana	Ethiopia	United Republic of Tanzania	Uganda	Zimbabwe
Improve accessibility to palliative care		✓		✓	
Enhance the integration of palliative care services into broader health plans and/or improve integration between different services		✓	✓		✓
Raise awareness about palliative care issues/ advocacy		✓	✓	✓	✓
Improve the level of knowledge and skill among caregivers/provide training	✓		✓	✓	✓
Formulate/strengthen policies and guidelines on palliative care	✓		✓	✓	✓
Formulate/strengthen legislation in support of palliative care			✓	✓	
Improve implementation of existing policies (including referral systems)	✓		✓		✓
Provide support to caregivers	✓				
Improve access to drugs and other supplies	✓	✓	✓		✓
Establish/improve monitoring and evaluation (including cancer registration)	✓	✓	✓	✓	✓
Establish/strengthen supportive structures (halfway houses, hospices, etc.)	✓				
Mobilize resources		✓	✓	✓	
Develop/conduct research		✓		✓	

improve access to drugs, and v) the need to establish or improve systems for monitoring and evaluation. In addition to the goals and objectives described in Tables 10 and 11, country teams also listed key activities that would need to be undertaken to achieve these objectives, with accompanying timeframes and identification of responsible bodies, technical assistance and resources likely to be needed. At the Botswana workshop it was agreed that work on the plans of action would continue back in the home countries after the workshop, until polished versions for the target area were ready for finalization.

A significant component of the work undertaken by the country teams was the development of plans of action 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 in Cancer Care. The presence at the Botswana meeting of government representatives from the majority of the countries provided an opportunity for those responsible for palliative care and those working in drug regulation to collaborate. A strong partnership between regulators and health workers was 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 the review and revision of national narcotic control laws and regulations, the cost of drugs, the need to identify a source of foreign currency to purchase the necessary imported drugs, and revisions of restrictions on prescribing and dispensing palliative care drugs. Further, it is important to consider developing policies and regulations which allow the expansion of prescribing and 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 strengthening the monitoring and evaluation of drug use. While each country 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 requiring 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

WHO provided funding for the first phase of this project. At this time the project is seeking additional financial support to implement the plans of action. Agencies who could offer technical and financial support are being encouraged to become partners in the project. Support could come in a number of different forms, such as involvement with a particular country or target area, or a particular area of interest, such as training or improved access to drugs. Major achievements expected from the projects include access to psychosocial care in the target areas, access to morphine and other pain relief products, training for personnel in the effective delivery of palliative care, training, supervision and support to caregivers, and strengthening of the continuum of care between health institutions and home-based care.

A number of possible sources of funding were identified during the workshops, including nongovernmental organizations and international organizations such as the World Bank and the Global Fund. However, country representatives were reminded that the likelihood of funding is increased when the proposed projects i) are well integrated into national policy and plans of action for comprehensive care and support of HIV/AIDS and cancer patients, ii) raise awareness about the importance of palliative care and the potential for low cost, effective provision of palliative care services, iii) develop local leaders who can champion the cause of palliative care, iv) clearly demonstrate that they have an activity worth funding, and v) show they can appropriately and efficiently manage the funds they are requesting. Resource mobilization should be considered in its broadest sense, as it includes mobilizing the expertise of individuals, in addition to funding. Attention should also be drawn to activities that can be undertaken that have a large impact, but cost little, such as having national governments include palliative care into their policies and implementing effective policies for access to pain relieving drugs.

Recommendations and Next Steps

The provision of effective palliative care for patients suffering from HIV/AIDS or cancer in Africa depends upon the development of effective and low-cost home-based palliative care with broad support of the African people and responsible health authorities in the countries. While the previously described activities are clearly a strong step in this regard, these actions need follow-up and support to carry this important health initiative forward. The following recommendations for future activities in phase 2 of this project are based on discussions of local and international public health leaders and health care providers at the workshops in Uganda in 2001 and Botswana in 2002.

Publication 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 in 2003. WHO agreed to prepare this consolidated report, incorporating and comparing the results from all five countries, including the data collection instruments and methodology. A summary paper promoting this project and reporting the early findings has also been published in a major medical journal (Sepulveda, 2003).

Plans of action

Each country team has finalized a plan of action for their country or target area. These have been submitted to their government through the WHO Representative for implementation and resource mobilisation. The plans are also being reviewed by the members of the overall Project Steering Committee and by advisors with a view to tailoring them to suit the requirements of funding agencies.

Regional training

WHO will further develop, in consultation with the country teams, a proposal for training in palliative care that could be undertaken at the regional level, to complement country level activities. Coordination with the Integrated Management of Adolescent and Adult Illness (IMAI) initiative of WHO and the Ocean Road Cancer Institute project in United Republic of Tanzania is being pursued.

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

Team building and team reinforcement will continue, as many countries will need to adjust their teams in the next few months to better suit the implementation phase and to ensure proper involvement of all stakeholders and endorsement of the governments. However, the project team size should still not be larger than 10 to 12 individuals due to the difficulties of managing a large team.

Leadership of phase 2

The project will continue to operate under the leadership of the country teams and the Steering Committee. Two African experts have been employed to supervise the Ethiopian project and assist in coordinating the projects in Zimbabwe and United Republic of Tanzania. It is anticipated that such support will greatly increase the likelihood that these countries will be able to implement their proposals.

Workshop on training materials and project progress

Subject to availability of funds, a workshop will be organized in Ethiopia to develop palliative care training materials and to review progress made in the implementation of country and joint palliative care projects.

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PART II

Country Reports

Botswana Country Report

The Botswana Project Team is given in Table B-1. The team consists of 17 members from various organizations within the health sector. The main task of the team is to facilitate development and implementation of the comprehensive palliative care programme.

Table B-1. Botswana Project Team

Name	Organization	Relevant skills	Role
Barbara Mudanga	Ministry of Health	National Community Home-Based Care (CHBC) Coordinator, adult health nursing specialist	Team Leader
Stephen Aghayedo	Ministry of Health	Pharmacist	Member
Thonkana Keatweng Gamodimo	Ministry of Local Government (South East District Council)	Community health nursing, palliative care nurse	Member
Elsie Baboni Hulela	Ministry of Health	Clinical nurse specialist, coordinator. of nursing care in anti-retroviral project	Member
Dr William Jimbo	Ministry of Health	Public health specialist, coordinator of clinical management of HIV/AIDS and opportunistic infections	Member
Tebogo Kejelepula	Ministry of Health	Counsellor, social worker, coordinator of HIV/AIDS counselling programme	Member
Josephine Kgolagano	Ministry of Local Government (Serowe/Palapye)	Social worker, counsellor	Member
Nnanaki Mabua	Ministry of Local Government	Social worker, CHBC and orphans policy advisor	Member
Peggy Matome	Holy Cross Hospice	Nurse	Member
Kgoreletso Molosiwa	Ministry of Health	Ministry of Health AIDS Control Programme Manager	Member
Seitepo Motshegwa	Ministry of Health, Princess Marina Hospital	General nurse, clinician	Member
Dr VN Ngcongco	WHO Botswana	Care consultant, HIV/AIDS focal person	Member
David Ngele	Botswana Network for PLWA	PLWA and Director of BONEPWA	Member
Mrs Okaile	Ministry of Health	Principle health nurse, patient care officer	Member
Dr Von Palaski	Princess Marina Hospital	Oncologist and haematologist	Member
George Seleka	Pharma Futura	Pharmacist (private sector)	Member
Theresa Shashane	WHO Botswana	Non-communicable diseases focal officer	Member
Barbara Garland	Botswana Cancer Association	Palliative care nurse counsellor	Team Secretary

Situation Analysis of the Target Area: Country of Botswana

The Republic of Botswana lies at the centre of the Southern Africa Plateau with a mean altitude of 1000 metres above sea level. It is a landlocked country, bordered by the Republic of South Africa to the south, Namibia to the west, Angola and Zambia to the north and Zimbabwe to the northeast.

Demographic Information

A census in 2001 indicated a population of 1,680,900 with 93.8 males per 100 females. Life expectancy at birth is 52.8 years for males and 59.0 years for females. In 2001, 39% of the population was 14 years or younger and 4% was 65 years or older; 54% of the population is rural. Although it has a large land area, Botswana is sparsely populated with a population density of 2.9 per square km. About 89% of the population lives in the eastern part of the country.

Health Status

In 1999 the ten major causes of inpatient mortality were HIV/AIDS (17.9%), pneumonia (14.8%), pulmonary tuberculosis (10.1%), ill-defined intestinal infections (9.5%), ill-defined conditions/signs/symptoms (4.9%), meningitis (3.5%), acute, ill-defined cerebro-vascular disease (2.9%), other diseases of pulmonary circulation and other forms of heart disease (2.6%), nephritis, nephrotic syndrome and nephrosis (2.4%) and anaemia (1.8%). Apart from the fact that HIV/AIDS was the leading cause of inpatient mortality, the HIV/AIDS-related symptoms of pneumonia and pulmonary tuberculosis were the second and third most common types of inpatient mortality. The major causes of inpatient morbidity were ill-defined intestinal infections (7.4%), pneumonia (6.9%), pulmonary tuberculosis (5.2%), obstetric associated conditions (4.9%), HIV/AIDS (3.9%), ill-defined conditions/signs/symptoms (3.7%), malaria (3.6%), acute upper respiratory infections (3.0%), injuries and trauma (2.3%) and hypertensive disease (2.1%).

Botswana is experiencing one of the most severe HIV/AIDS epidemics in sub-Saharan Africa. Although the pandemic began to spread in Botswana during the 1980s, in the 1990s there was a dramatic increase in the spread of the virus. Since the first survey of HIV prevalence among pregnant women attending antenatal clinics was conducted in 1992, prevalence has climbed from 23.7% to 43.9% in Francistown and from 14.9% to 36.2% in Gaborone, the capital. Currently about 35.5% of the sexually active age group (15–49 years) in the country are infected with the virus. Most of those infected with HIV will progress to AIDS and AIDS-related chronic illnesses, such as tuberculosis and cancer. These patients and their families will need palliative care.

In 2000, patients with HIV/AIDS-related illnesses occupied 60%-65% of the hospital beds in the main referral hospitals – Nyangabgwe and the Princess Marina Hospitals. Due to the inability of the health care system to cope with the increased demand for hospitalisation, patients were discharged home when they still needed care. Further, weaknesses in the referral system were also noted during this situation analysis. Palliative care services need to be strengthened and extended to the community and household level.

It has been estimated that in 2000 there were between 36,000 and 57,000 orphans under the age of 15 who had lost their mothers due to AIDS. This number is expected to rise to 139,000 in 2003 and 214,000 in 2010. A proportion of these orphans will develop AIDS and HIV/AIDS-related cancers.

Traditionally in Botswana the family is the greatest resource for persons in need of care and support. However, the dramatic increase in the number of patients with HIV/AIDS adds a heavy burden to the families. Family members suffer from emotional stress as a result of having a member of the family with a terminal illness, especially when the provision of care is prolonged. The situation is made worse when a family member dies leaving orphans, some of which also suffer from HIV/AIDS. The capacity of the extended family to absorb these orphans is stretched to the limit.

National information on cancer is not available. The most common cancers, as reported by the Princess Marina Hospital and Nyangabgwe and Gaborone private hospitals in 1999 were Kaposi's sarcoma (41%), liver cancer (6%) and lung cancer (6%) for males and cervical cancer (26%), Kaposi's sarcoma (23%) and breast cancer (20%) for females. Cancer is not a major cause of morbidity or mortality in Botswana. However, because the burden of HIV/AIDS is heavy and increasing, HIV/AIDS-associated cancers, such as Kaposi's sarcoma, are likely to increase. Health care resource needs for these malignancies are being investigated.

Health System

The Public Health Sector

The Botswana health system is under the authority of the Ministry of Health (MOH) and the Ministry of Local Government (MLG). The MOH provides leadership and guidance in the delivery of health care services, determines overall health policies and strategies, and provides technical support to other stakeholders in the health section to ensure the delivery of quality health care services. The MOH is responsible for setting and communicating the standards of care for all levels in the health system and has direct authority over the referral, district and primary hospitals. The MLG has jurisdiction over basic health services, such as the primary health care (PHC) clinics, health posts and community health services within the districts. It is also responsible for social welfare services. Councils are responsible for health promotion activities, basic curative services, referral where needed, and family health services. The main forum for the MOH, MLG and the Councils is the PHC Coordinating Committee, which meets periodically to coordinate efforts and plan new programmes and training.

Health Facilities and Staff

National health policy in Botswana is implemented through well-established levels of the health care delivery (referral) system. Levels of the referral system and the number of health facilities in 1999 are described in Table B-2. In 1999 there were 2,552 beds in public sector referral and general hospitals, 540 beds in primary hospitals and 412 beds in clinics. However, these facilities were planned for an era in which the health status and intensity of care of patients was expected to improve. These facilities cannot cope with the demand for health services brought about by HIV/AIDS.

Botswana's population is about 54% rural and 46% urban. In 1995 81% of the rural population was within 8 kilometres of a health facility, as compared to 94% of the urban population.

Table B-2. Health facilities

Facility type	**Number**	**Staff**
Specialist hospital	2 Referral, 1 Psychiatric and 3 Private	Specialist professionals (doctors, nurses, midwives and pharmacists)
District/general hospital	16	District medical officers, nurses, midwives and related professionals
Primary hospital	15	Doctors, nurses, midwives and allied health staff
Clinic	227	Nurses, midwives and family welfare educators
Health post	325	Nurses and family welfare educators
Mobile stop	725	Health teams, including nurses and midwives

In 1999 there were 475 medical doctors, 4,992 professional nurses, 775 family welfare educators and 23 pharmacists in Botswana. This is a rate of 3.2 medical doctors and 33.3 professional nurses per 10,000 population. Family welfare educators are elected by the communities, receive basic training in preventive and promotive care, and are expected to perform mainly community-based activities. However, they have often become clinic-based and compensate to some extent for the scarcity of professional nurses and doctors.

Health Programmes

Botswana has a national policy on HIV/AIDS, which was adopted by the government in 1993 and was modified in 1998 to incorporate the strategy of community home-based care. The major provisions of the policy are prevention (creating awareness, promoting positive behavioural changes and condom use), provision of care and support. The overall goals of the policy are to break the cycle of transmission of HIV to reduce the incidence and prevalence of the disease and to support the infected and affected. The policy is cast in a multi-sectoral framework and it mobilizes all governmental, private and non-governmental sectors to collaborate in the national response to the challenges posed by HIV/AIDS. Because the HIV/AIDS epidemic not only affects health but virtually all segments of society, including the socio-cultural, religious, agriculture, education, economic, transport, commerce and industry components, the multi-sectoral response falls under the National AIDS Council (NAC). The NAC is chaired by the President and includes high level representation from the Ministry of Local Government, Ministry of Health, and other key ministries. The following programmes were developed in order to implement the national HIV/AIDS policy: Community Home-Based-Care (CHBC); Information, Education, Communication and Condom Use; Clinical Management of Opportunistic Infections; Counselling and Voluntary Testing, Prevention of Maternal to Children Transmission, Anti-retroviral Drug Therapy; and Sexually Transmitted Infections Control Programme.

Botswana has a national list of essential drugs in accordance with the WHO standard for the management of HIV/AIDS patients. Prescription of the available essential drugs is guided by clinical guidelines. Botswana is the first country in sub-Saharan Africa to undertake to provide antiretroviral drug treatment on a wide scale. Although the antiretroviral drug initiative is still in its infancy, the government plans to make these treatments available in both the urban and rural areas. The guidelines currently include 15 antiretroviral drugs. However, the guidelines do not address the issue of pain treatment for the HIV/AIDS patients, especially with reference to the use of narcotic analgesics.

Botswana has no policy or programme specific for cancer control. Nevertheless there are national protocols for the management of cancer patients. Every patient suffering from cancer has a chance to be referred to one of the two national referral hospitals that have the expertise to treat cancer patients.

Current initiatives aimed at the provision of palliative care services for patients admitted to a health care institution and for patients at home are being provided by both non-governmental organizations and the government. However, these services are acknowledged to be inadequate at all levels and need to be strengthened.

The CHBC Programme was established in 1995 as a way of caring for chronically and terminally ill patients. It was introduced specifically to ensure provision of care and support for the terminally ill and their families in a home environment. The services provided under CHBC include: medical, nursing, counselling, psychosocial support, and social support such as the provision of food and material assistance to both patients and families. The CHBC Programme will provide a good basis for strengthening the quality of palliative care services using a community approach. However, weaknesses have been identified regarding the quality of care in relation to pain and other symptom management and supportive counselling. Current guidelines will have to be reviewed to integrate palliative care principles and procedures.

Although Botswana currently has no national drug policy with respect to narcotic analgesics, since 1992 it has had a Drug and Related Substances Act that provides for control over the regulation of drugs. While the policy does not constitute an impediment with regards to narcotic drug access and availability, currently only medical doctors can prescribe narcotics and only pharmacists can dispense them, thereby limiting access to such drugs by patients on CHBC.

Needs Assessment: Country of Botswana

This study was conducted by Dr H. Akinsola and research assistants. In addition, Elsie Hulela, Barbara Mudanga and Thonkana Gamodimo of the Project Team and Michael Kiwombojjo assisted in the collection and analysis of the information and development of the report.

Study Objectives

The primary objective of this study was to determine the needs and experiences of terminally ill patients and caregivers. Information was obtained directly from CHBC patients and caregivers using an interview survey questionnaire and included the level of effectiveness, possible constraints and recommendations on what could be done to improve the quality of the palliative care services.

Study Design

Four districts were selected for the conduct of the needs assessment: Gaborone, Kanye, Molepolole and Ramotswa. Gaborone was the only urban district surveyed. The sample consisted of 92 patients on CHBC and 96 caregivers. There was a conscious effort to select sub-samples from the four study locations and not to limit the category of CHBC patients and their caregivers to those suffering from HIV/AIDS. Patients with other diseases were included that would have been underrepresented in a purely convenience sample, such as patients with cancer. The survey questionnaire was adapted from the Hospice Uganda questionnaire used previous in Hoima and Kampala. Trained research assistants administered the survey questionnaires under the supervision of the project consultant.

Permission to conduct the surveys was obtained in writing from the Ministry of Health and local authorities before the study commenced. Informed consent was also sought from the individuals and family members who participated in the survey.

Results

Characteristics of the 92 patients on CHBS are summarized in Table B-3. Only 5% of the subjects were less than 20 years of age, while 29% were 60 years or older. Overall, 59% were females and 54% were single. The majority (68%) had no education or only primary education; 76% indicated no current income and 37% reported that they were the breadwinner in the family prior to their illness. One-third of the patients stated that they had been diagnosed as having HIV/AIDS, 16% indicated cancer, and 16% indicated tuberculosis, while 23% indicated other illnesses, such as heart disease, hypertension or diabetes. Twelve percent stated that they had no knowledge of what disease they were suffering from. All the caregivers were identified as being a family member or relative. Within the family, most often the caregivers were the mother (25%), daughter (14%), spouse (12%), sister (10%) or son (5%).

Table B-3. Characteristics of the CHBC patients

Characteristic		Frequency	Percentage
Patient's age[1]	< 30 years	20	23%
	30 to 59 years	42	48%
	60 years and over	25	29%
Gender	Male	38	41%
	Female	54	59%
Marital status	Single	50	54%
	Married or cohabiting	25	27%
	Widowed or divorced	17	18%
Religion	Christianity	72	78%
	Islam	—	—
	Other	20	22%
Level of education	None	32	35%
	Primary	31	34%
	Secondary	22	24%
	Tertiary	7	8%
Occupation	Professional[2]	8	9%
	Housewife or unemployed	60	65%
	Student	5	5%
	Farmer	6	7%
	Other	13	14%

1. Five patients did not indicate their age.
2. Including businessman/woman.

Major Signs, Symptoms and Problems Experienced by the Patients

Major signs and symptoms experienced are reported in Table B-4. Patients identified more than one major sign or symptom. Most patients reported suffering from pain (64%), followed by cough (39%), headache (38%) and body weakness (36%).

The most common types of medication being used by the patients were pain relief (43%) and antibiotics (29%). While 64% reported suffering severe pain, only 43% indicated that they were receiving pain relief medications. Most of the medicines were funded by the government (73%). In addition, medications were also paid for by the individual themselves (21%) or the family (16%).

Table B-5 presents the major problems reported by the patients. The majority of the patients needed food (59%), social support (41%) or financial support (36%). Further, one-third of patients indicated they needed drugs for their ailments. When asked about coping mechanisms, 36% replied that they received support from relatives, 24% indicated they received help from the government (including food baskets), but 27% reported that they are not coping. The government was the major source of supply for the patient's drugs (88%). Some patients received their drug supplies from private stores or pharmacy stores (14%), traditional doctors (10%), CHBC teams during a home visit (9%) or nongovernmental organizations (5%). The

Table B-4. Major signs and symptoms experienced by the patients

Major signs and symptoms	Frequency	Percentage
Severe pain	59	64%
Cough	36	39%
Headache	35	38%
Weakness	33	36%
Psychological stress	26	28%
Anorexia	26	28%
Skin rash	21	23%
Vomiting	18	20%
Oral ulcer	18	20%
Fever	17	18%
Diarrhoea	15	16%
Nausea	15	16%

low involvement of the CHBC team is an area of concern since the majority of these patients were bedridden and were supposed to be continuously supported by health workers with a supply of drugs.

Table B-5. Major problems being experienced by the patients

The problems	Frequency	Percentage
Lack of food	54	59%
Lack of social support	38	41%
Financial difficulties	33	36%
Irregular supply of drugs[1]	30	33%
Shortage of clothing/blankets	25	27%
Social isolation	16	17%
Inadequate shelter	8	9%

1. Irregular supply of drugs or poor treatment pattern

Accessibility of Health Facilities

Patients were surveyed with respect to the accessibility of health facilities. Only one of the 92 patients stated that the nearest health facility was more than 5 miles away. However, of the 84 patients who needed transport to get to a health facility, 46% indicated that it was not easy to get transport.

Patient Satisfaction with Treatment

Patients were asked to describe their level of satisfaction with their treatment regimen. Overall, 64 of the 84 patients (76%) receiving treatment for symptom relief indicated that they were satisfied with their treatment and 61 of the 90 patients (68%) receiving treatment for pain relief were satisfied with their treatment. With respect to pain relief, the major reason for dissatisfaction was persistent pain despite the treatment. This could be explained by the findings reported by the caregivers that the commonly used pain killers for CHBC clients were mild analgesics.

Stigma Experienced by the Patients

Stigma was reported as being experienced by 40% of the 15 cancer patients, 37% of the 30 HIV/AIDS patients and 20% of the 15 tuberculosis patients. The majority of patients (65%) reported that the support of their families was fundamental to their dealing with stigma.

Characteristics of the Caregivers

Information was collected from 96 caregivers. Overall, 89% of the caregivers were females. The age distribution was fairly uniform for the caregivers; between 14% and 20% of the caregivers were in their 20s, 30s, 40s, 50s and 60s. Only 6% of the caregivers were aged 70 or more. The responsibility for caring for the terminally ill did not seem to fall upon any particular age group. These findings contradict the general impression that such care is primarily given by older women. Only 36% of the caregivers were women of 50 years or older. The fact that most of the caregivers were females was not surprising given that a major portion of the patients were single females.

Most often the caregiver was a relative or friend of the patient (30%), mother or grandmother (24%), daughter or granddaughter (14%), spouse (11%) or sister (9%). The caregiver was most often single (46%), married or cohabiting (35%) or widowed (18%). The most common occupation of the caregiver was housewife or unemployed (70%), farmer (10%) or professional (8%).

When asked regarding the length of time the caregiver had provided care, 40% responded less than 1 year, 33% responded 1–2 years, 9% responded 3–4 years, and 14% responded more than 5 years. It appears that some caregivers need to be periodically relieved of their responsibility.

Signs and Symptoms of the Patients Reported by the Caregivers

The caregivers stated that the most common sign or symptom experienced by their patient was pain (22%), coughing (14%), body rash or sores (10%), diarrhoea (9%), headache (9%) or vomiting (8%). These are consistent with the major signs and symptoms reported by the patients. The caregivers reported that most often they used paracetamol, ibuprofen, stopain, massage, promethazine and aspirin to relieve the patient's pain. It should be noted that none of the patients received strong analgesics.

Caregivers Level of Satisfaction and Suggestions

Overall, 28% of the caregivers interviewed felt dissatisfied with the quality of care or treatment being received by their patients. The most common reasons the caregivers felt dissatisfied were "treatment was inadequate" or "treatment needs to be changed" (63%) and that the patient's symptoms or pain persisted (28%).

When the caregivers were asked how they can be assisted with their care-giving roles, they most often responded that the government should supply food for patients and caregivers (40%), give the caregivers a monthly allowance (9%), supply medications to relieve symptoms (9%), and provide the patients with clothing and blankets (8%). Other requests included respite care, health education and regular transport. The above requests for food, financial support, blankets and clothes signify a low level of income among the patients and their caregivers. This suggests an integration of poverty alleviation strategies into palliative care.

Executive Summary and Recommendations

Botswana is experiencing one of the most severe HIV/AIDS epidemics in sub-Saharan Africa. The current HIV/AIDS situation is a substantial drain on the health care delivery system. Ever since the first AIDS case was diagnosed in Botswana in 1986 there has been an increase in the number of new infections and people living with HIV/AIDS. In 2002 an estimated 277,000 people, 17% of the general population, were infected with HIV. In the near future these individuals will progress to AIDS and will require palliative care. The country has also witnessed an increase in the number of patients suffering from non-communicable diseases, such as cancer. More than 900 patients were diagnosed with cancer in 1999.

In order to meet the health needs of its people, the government of Botswana provides a health care delivery system that includes promotive, preventative, curative and rehabilitative services. Services are provided at health facilities, in the community and in the households. However, the health care system is under considerable stress as the sheer magnitude of the HIV/AIDS epidemic threatens to consume the available health resources and facilities.

A needs assessment investigation was conducted to identify the needs of terminally ill patients and their families. Information was collected from 92 terminally ill patients on CHBC and 96 caregivers in one urban district (Gaborone) and three rural districts (Kanye, Molepolole and Ramotswa).

Caregivers and their patients often lack the basic needs necessary to be able to cope with the challenges of community and home-based care. The most acute problems reported by the 92 terminally ill patients 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 due to the common use of only mild analgesics. While 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.

When asked how they can be helped, 40% of the caregivers requested that the government supply food for the patients and caregivers. Other requests including supplying medications to relieve symptoms, providing patients with clothing and blankets, giving the caregivers a monthly allowance, respite care, health education and regular transport. Many of these requests signify a low level of income among the patients and their caregivers, suggesting an integration of poverty alleviation strategies into palliative care.

The demand for palliative care services in Botswana is increasing – primarily due to the expanding HIV/AIDS epidemic and secondarily due to chronic diseases, such as cancer. While current palliative care services have been found to be somewhat inadequate in this investigation, the gaps to be bridged have been identified and the government of Botswana is committed to providing quality health care services to its entire population. The government has already established a suitable base for strengthening palliative care services by its primary health care delivery system, CHBC programme, national HIV/AIDS activities, National Drug Act, cancer management protocols, and strong partnership among the government, civil society and private sector. Additional steps to strengthen the country’s palliative care services are described in the following recommendations, categorized into policies and guidelines, human resources and material resources.

Policies and Guidelines

National policies, political will, programmes and structures exist to implement a national HIV/AIDS programme. While these provide a basis for strengthening palliative care services, current policy however does not place specific emphasis on palliative care. Importantly, the current Drug and Related Substances Act restricts the prescription of narcotics to medical doctors, thereby effectively limiting access to narcotics for the relief of pain for HIV/AIDS and cancer patients in clinics and at home.

The following recommendations are made with respect to policy and guidelines:

a) The need to formulate a cancer management policy;
b) Integration of palliative care into the existing policies and operational guidelines, such as Community Home-Based Care, Clinical guidelines on management of HIV/AIDS, and the National Treatment Guide;
c) Review of the Drug and Regulatory Act, with particular reference to prescription of narcotics by nurses;
d) In the final draft of the National Drug Policy, the government should address the issue of supply and distribution of narcotics, especially in rural areas where the services of pharmacists are not easily available; and
e) Resources in the form of staff supply and training, transport facilities and communications equipment should be increased to strengthen the capacity of the referral system to function as an important support unit for the CHBC programme.

Human Resources

There is an acute shortage of both human and material resources, especially health care professionals, to provide effective palliative care services at all health facilities. Most of the available health care professionals lack the skills to provide palliative care considering the current challenges of caring for terminally ill patients.

The following recommendations are made with respect to human resources:

a) The existing health care providers need to be given in-service training in order to prepare them for the challenges of providing palliative care services;
b) Newly trained staff should also be prepared for the challenges of providing palliative care by the integration of palliative care into the curricula of health care provider training programmes;
c) The technical and financial capacity of community-based and nongovernmental organizations needs to be strengthened in support of efforts to promote their active participation and involvement and to maximize their potential;
d) A programme of care for the caregivers should be established at all levels of the health care continuum, including families and volunteers, in order to reduce the effect of emotional stress associated with caring for terminally ill patients;
e) Other modalities of care, such as the use of hospices and halfway houses, need to be developed and strengthened to complement the efforts being made to improve the quality of Community Home-Based Care services and the quality of life of both the patients and their caregivers; this will also help provide a period of respite for the primary caregivers and help avoid burnout;
f) Considering the acute nature of staff shortages within the CHBC programme and the difficulty of recruiting new staff, a new programme might be established to produce a new category of community care providers for the CHBC, drawing from the pool of unemployed secondary school leavers and the youth.

Material Resources

The community-based organizations and the nongovernmental organizations constitute a valuable resource for providing palliative care services. However, they lack the capacity to perform effectively and therefore need more support from the government to build their capacity.

The following recommendations are made with respect to material resources:

a) The National AIDS Coordinating Agency and other relevant structures should advise the government on the mechanism to share the responsibility for funding palliative care proportionally among the government, nongovernmental organizations, private sector and the public;
b) A mechanism should be developed to ensure the rapid assessment of patients for the CHBC programme and distribution of materials and financial support.

Ethiopia Country Report

The Ethiopia Palliative Care Team is given in Table E-1. This Team consists of eight individuals from different medical disciplines and was established and endorsed by the Federal Ministry of Health. The main tasks of this team were to conduct a situation analysis, prepare a needs assessment on palliative care for cancer and HIV/AIDS patients and to develop a proposal for a palliative care demonstration project. The team, after thorough discussion among the members, selected Addis Ababa as the target area for the palliative care demonstration project.

Table E-1. Ethiopia Palliative Care Team

Name	Organization	Role
Dr Bogale Solomon	Radiotherapy Center, Addis Ababa University	Team Leader
Dr Nardos Wolde Giorgis	Good Samaritan Association	Vice Team Leader
Dr Tesfanesh Belay Adale	Ministry of Health	Member
Dr Mesfin Araya	Psychiatrist, Addis Ababa University	Member
Dr Selamawit Ashagre	Obstetrician and Gynaecologist, Federal Police Hospital	Member
Mr Yehwalashet Bekele	Public Health Specialist, Ministry of Health	Member
Mr Solomon Hagos	Statistician, Ministry of Health	Member
Dr Aseged Woldu	Epidemiologist, Ministry of Health	Member

Situation Analysis of the Target Area: Addis Ababa, Ethiopia

Addis Ababa, the capital city of the Democratic Republic of Ethiopia, is the major urban area and largest city in the country. It extends for 20 km east to west and 25 km north to south and covers an area of 400 sq km. As a center of administration, culture, commerce and industry, its role in the political, social and economic development of the country is significant. The city is sharply divided by class and ethnicity, with informal settlements concentrated near the center and wealthier districts to the southeast and southwest. Rural migrants come from villages all across the nation and dozens of ethnic and linguistic backgrounds. Amhara, Oromo and Gurage are the dominant ethnicities in this diverse city. For the last three decades, Addis Ababa has been the seat of international organizations, such as the Organization of African Unity (OAU) and the United Nations Economic Commission for Africa (UNECA).

Demographic information

Addis Ababa had an estimated population of 2.6 million in 2000, with 48% males and 51% females. Approximately 32% of the population is less than 15 years of age and 9% are 50 years or older. The literacy rate in Addis Ababa is 83% and 82% are Orthodox Christian.

Health Status

The leading causes of hospital morbidity in 2000/2001 were tuberculosis (6%), accidents (6%), homicides and inflicted injuries (6%), acute upper respiratory infection (3%), conditions of the ear (3%), genito-urinary conditions (2%), infective and parasitic diseases (2%), conditions of the eye (2%), fever (2%), and bronchopneumonia (1%). The most common causes of health center morbidity were acute upper respiratory infections (19%), infections of the skin (14%), bronchopneumonia (13%), genito-urinary conditions (10%), intestinal parasites (9%), gastritis and duodenitis (8%), rheumatism (8%), bronchitis (7%), and tonsils/adenoids (6%). It was surprising that HIV/AIDS morbidity was not included in the top 10 leading causes of both health center and hospital morbidity reports. This could be due to various factors, such as the diagnosis was probably lumped under other diseases such as upper respiratory tract infections, bronchopneumonia, or the unavailability of HIV screening services.

No information is available on cancer incidence, prevalence or mortality within Addis Ababa or within Ethiopia overall. However, a health facility morbidity report for 1998 showed that the five most common cancers were cancers of the breast (85 cases), rectum (81), stomach (56), leukaemia (45) and cervical cancer (43). A total of 1341 cancer patients from Addis Ababa were referred to the Radiotherapy Center from 1997 to 2001. Cervical cancer (443) was the most common, followed by breast cancer (309), head and neck cancer (114), thyroid cancer (56), lymphoma (47), sarcoma (41), colorectal cancer (33), bladder cancer (32), Kaposi’s sarcoma (21), and lung cancer (21). The three most common cancers at the Radiotherapy Center were cancers of the cervix (33%), breast (23%) and head and neck (9%), accounting for 65% of all cancer cases. Almost all cases of Kaposi’s sarcoma were attributed to HIV/AIDS. Most of the patients were diagnosed at the late stages of the disease. This can be attributed to a lack of awareness and diagnostic and therapeutic services. Those arriving at the Radiotherapy Center with advanced disease were mostly young women with either cancer of the cervix or breast. There is no cancer control programme or palliative care programme for advanced disease. Both cancer diagnostic and treatment services are far below adequate for the city population and those referred from regions outside Addis Ababa. Establishment of a population or institution-based cancer registry would provide data valuable for health planners and service providers to ensure optimal allocation of scarce resources.

It was estimated that 340,000 people in Addis Ababa were infected with HIV (13% of the population) in 1999. Most infections are found among adults between the ages of 20 and 49. The peak ages for HIV infection are 20-29 for females and 25–39 for males. Almost all of these infected cases will develop AIDS and die within about the next 10 years. Anti-retroviral drugs are neither available nor affordable to the majority of the population. Most patients with HIV/AIDS seek medical care in the late stages of the disease. As the epidemic proceeds, the death rate will increase for almost all ages. However, the impact will be especially severe among adults in the prime working ages, which will have serious consequences for the economic and social development of the nation.

The arrival of HIV/AIDS has caused a secondary tuberculosis epidemic. Many, perhaps half, of all adults in Ethiopia carry a latent TB infection, which is suppressed by a healthy immune system. As HIV disease progresses, it weakens the immune system, which can no longer control the TB infection. The impact of HIV on TB is an especially serious problem because TB is contagious through casual contact. HIV increases the risk of TB for the entire population and treatment of TB is very expensive. Further, because of inadequate treatment of some cases of TB among both

HIV-infected and uninfected people, drug resistant strains of TB are appearing, making it more difficult to treat the disease.

In 1994 about 5% of the hospital beds in Addis Ababa were occupied by patients with AIDS. In 2004 it is projected that about 50% of the beds would be required to meet the needs of AIDS patients, putting considerable strain on the delivery of health services in Addis Ababa. Home-based care is for the most part unavailable. Palliative care is non-existent. There are no opioids available for pain relief.

Health System

The Health Sector

Addis Ababa has eighteen hospitals of which five are administered by the Federal Ministry of Health, five by the Addis Ababa Health Bureau, two by the Ministry of Defence, one by the Police force, two by nongovernmental organizations, and five are private. The hospitals are unevenly distributed. There are also 24 health centers and 8 clinics under the Health Bureau; 153 clinics are owned by private and nongovernmental organizations and 47 health posts are owned by the Health Bureau. A standard health center, with its 5 satellite community health posts, is the first level of health care, providing a package of public health and essential curative services on an ambulatory basis to a population of about 25,000. It is also responsible for the training, monitoring and supervision of community health workers. The health center has a capacity of 10 beds, provides round the clock emergency services and is equipped with relevant diagnostic and therapeutic facilities.

The concept of home-based care is relatively new and has evolved with the emergence of the HIV/AIDS epidemic. This is carried out by three nongovernmental humanitarian organizations: the Medical Missionaries of Mary, Mekdem and Mary Joy.

A new referral system has been put in place and measures are being taken to strengthen the system. In general referrals are made from health centers, health posts and other primary care level clinics and organizations to specialized and general hospitals at a secondary care level, and then to a tertiary care level, which includes the Ghandi Memorial Hospital in Addis Ababa and specialized regional hospitals and centers outside Addis Ababa. The majority of the population gets its health services from primary health care units, despite the existence of a wide range of health facilities in the city. It is perceived that the primary health care units are reasonably accessible and affordable. Government institutions that provide public services are also available in each zone at different levels of capacity.

The Addis Ababa City Administration Health Financing System is the same as that of the National Health Care Financing System. The major reasons for the present poor state of health service in Addis Ababa are under-funding, inefficient utilization and inequitable distribution. The Administration has taken a firm stand to increase public expenditure on health, improve private participation in health care delivery, and improve the rational allocation of the budget and its utilization. The Health Bureau is also making an effort to redirect the available funding from tertiary to primary health care, to not only make it more effective and equitable, but to also make it less costly.

Local health priorities for different population groups have not been clearly defined. However, attention is focused on the under 5 child expanded immunization programmes, safe motherhood, including ante and post natal services, and family planning to increase the contraceptive prevalence rate. With the emergence of the HIV/AIDS epidemic, adults are targeted for the Information Education Communication Programme (IEC), Behavioural Change Campaign (BCC), and condom use, and youth are targeted with other programmes.

Human Resources

Within Addis Ababa, the government supports 138 general physicians, and 31medical doctors of various specialities. It also funds 585 nurse/midwives and 727 other trained health care personnel, including 461 health assistants.

Health Programmes

The target area does not have a specific plan or programme for cancer control. However, screening for cancer with pap smears and mammography is available in both governmental and nongovernmental institutions. Cancer is treated at a number of government and private hospitals. Radiotherapy for palliative care is available at the Radiotherapy Center, Addis Ababa University. Of the narcotic drugs for the control of pain, only codeine is available, although not in regular supply. Morphine is unavailable.

There is a national programme for the control of HIV/AIDS with a hierarchical structure. Similar to the federal level, the Regional AIDS Council (RAC) is composed of members from the regional governments, regional bureaus, religious organizations, nongovernmental organizations, the private sector and patients living with HIV/AIDS. Under the RAC are the Regional AIDS Council Secretariat, the Regional Advisory Board, and the Regional Review Board. Similar mechanisms exist at the wereda and kebele levels.

The priority activities, goals and strategies of the Addis Ababa region for the control of HIV/AIDS are similar to those of the federal level. They include elements of primary prevention (such as the IEC Programme and BCC), diagnosis (voluntary testing for HIV), and treatment (including treatment of opportunistic infections, home-based care, and counselling). There is no current palliative care component within the HIV/AIDS control programme or as a separate programme in Addis Ababa.

Needs Assessment: Addis Ababa, Ethiopia

Executive Summary

The primary goal of this study was to identify the needs of the terminally ill so that appropriate palliative care services can be developed. There does not appear to be any governmental programmes and very few nongovernmental programmes that deal with the provision of palliative care for patients in a home-based setting. According to information collected from co-patients and focus group discussions, most patients prefer to be treated and cared for in health facilities. Major limitations are the costs and the ineffective treatment of some cases, particularly for diseases such as cancer and HIV/AIDS. Medical treatment, according to most of the respondents, is very expensive and drugs are not readily available. Only a few can pay the treatment costs without assistance from relatives. Those who had experienced an ill family member at home identified the relief of pain as a major concern.

The practice of modern medicine, traditional medicine, and holy water treatment run side-by-side in Addis Ababa. Both HIV/AIDS and cancer patients tend to go first to modern health facilities, but these diseases are often not effectively managed at these centers. When there is not a satisfactory solution to the medical problem, patients consider seeking out assistance from traditional medicine or holy water treatment to fill the gap.

Background

In Ethiopia, as in many other sub-Saharan countries, major gaps still prevail and the majority of HIV/AIDS and cancer patients needs regarding palliative care and pain control are not considered a public health priority that can be effectively tackled with relatively low cost measures. Developing a new service requires supporting data to establish the need for and feasibility of the proposed programme. Such information can be used to illustrate the scale of the unmet need and to identify patient populations that can benefit most from a palliative care service. Furthermore, the process of assessing institutional and community need for a palliative care programme will lead to enhanced dialogue, broadened institutional recognition of the importance of palliative care and engagement of a critical mass.

Palliative care exists worldwide and flourishes out of a core respect for the dignity of the dying and for the struggle of the family. Palliative care is the combination of active and compassionate therapy based on spiritual, physical and psychosocial needs intended to comfort and support individuals and families who are living with life threatening illnesses. In many ways it transcends medicine and is a reflection of the values of the community. Today in Ethiopia palliative care is an urgent and unavoidable humanitarian need.

Study Objectives

The main goal of this study was to assess the needs of cancer and HIV/AIDS patients, families, caregivers, and the community at large for palliative care. The initial objective was to produce a working document based on the findings, which can be used in the development and implementation of a palliative care service. The final objective is to improve the quality of life for cancer and HIV/AIDS patients in Ethiopia by facilitating and strengthening the development of palliative care programmes with a public health approach that will provide pain relief and holistic care to an increasing number of terminal patients.

Study Design

The study was of cross-sectional design and collected both quantitative and qualitative information. It consisted of a questionnaire survey of patients, focus group discussions, and a questionnaire survey of key informants.

For the questionnaire survey of patients, the Palliative Care Team adopted a questionnaire tool used at Hoima Village, Uganda, to the Ethiopian setting and translated the survey into the national Ethiopian language, Amharic. Using this study tool, information was collected from 100 consecutive adult cancer patients from Addis Ababa coming to the Radiotherapy Center located at Tikur Anbessa Referral and Teaching Hospital in Addis Ababa.

Focus group discussions involved groups of individuals who were guided by a facilitator and during which group members talked freely and spontaneously about a given topic. The Palliative Care Team prepared a set of questions for the focus group discussions. A total of three focus group discussions were held. One was held in May 2002 at the “Dawn of Hope – Ethiopia” for people living with HIV/AIDS. Three were males and three were females, their ages ranging between 20 and 31 years. All except one came from low socio economic groups and were members of Dawn of Hope – Ethiopia, which by definition means that they have disclosed their HIV/AIDS status to the community. Dawn of Hope – Ethiopia was the first association for people living with HIV/AIDS in the country. Two focus group discussions were held at the Radiotherapy Center for cancer patients receiving radiotherapy. Their ages ranged between 30 and 70 years. The first focus group discussion involved 3 males and 2 females and the second group consisted of 3 females and 2 males.

The focus discussion groups were asked which diseases they thought were incurable, to state them freely and then prioritize the common ones in the area. They were asked to identify what they thought were the health problems in the community they live in, who they thought were most affected by these incurable diseases, and the symptoms associated with these diseases. They were requested to indicate the community's coping mechanisms and strategies with these diseases (e.g. medical, traditional healers, spiritual) and costs for these treatments. They were asked to identify the most common needs among people with incurable diseases, how best to meet the various needs, and how the community can help terminally ill patients and their families. They were asked to describe what they thought were the ideal health services for these patients in the community and how best to maintain and sustain them. They were also inquired about the role of government in providing services for terminally ill patients and their families. A time for other comments and a free discussion followed.

Because of time and bureaucratic constraints, self-administered questionnaires were used to collect information from the key informants, rather than the conduct of in-depth interviews. Fifteen self-administered open-ended questionnaires were distributed to individuals and institutions. The questions included the perceived needs and problems faced by terminally ill patients and how best to meet those needs, local resources available to help the terminally ill and their families and how these resources can be maximized, how the community views these people and how it can support them and their families, and in their opinion what should be the minimum health care package for the terminally ill.

Five medical students, four radiotherapy staff and three Good Samaritan Association staff were recruited and trained to administer the questionnaires and conduct focus group discussions. All three study components – the patient questionnaires, the focus group discussions and the survey of key informants – were conducted between April and June of 2002.

Results

Characteristics of the 100 cancer patients in the questionnaire investigation are summarized in Table E-2. These patients came from all six zones of Addis Ababa and from 26 out of the 28 weredas (administrative zones). Their educational level shows that 51% reached the 9th-12th grade, 14% were diploma graduates from junior colleges, 14% reached the 1st-6th grade, 8% had a first degree and above, and 6% were illiterate. More than half (57%) the respondents were between the ages of 15 and 34. There were 50 males and 50 females, but this was by chance rather than by design. The ethnicity of the respondents closely matches the ethnic distribution of the Addis Ababa population.

Common Health Problems Among Families

Among the major health problems encountered by the family, cough (65%) was the most common, followed by fever (16%), childhood illnesses (8%), diarrhoea (8%), and food shortage (8%). However, 14% said they had no problems. Asked where they would go to seek help if they fall ill, 89% of the respondents said they would seek help at a modern health care facility, 25% at holy water sites, 4% at drug outlets (meaning small drug stores and pharmacies) and only 1% responded that they would seek care from traditional medicine.

Funerals Attended

Most of the respondents (78%) indicated that they had attended one or more funerals during the last 12 months. Table E-3 reports the numbers of funerals attended by respondents. According to tradition, individuals aged 15 to 24 are not expected to attend funerals unless either a close relative or a friend dies. The high funeral attendance rate of the age group 15 to 24 (62%), signifies either they have lost close relatives or friends. Overall, 42% of the respondents reported attending more than 7 funerals. This rate is high even by Ethiopian standards, where many neighbours often attend funerals.

Asked if they knew the cause of death of the deceased whose funerals they attended, 35% responded HIV/AIDS, 27% TB, 9% cancer and 12% due to “berd”. “Berd” is a local expression that can mean a cold, HIV/AIDS, or tuberculosis, but also indicates that someone has died of HIV/AIDS. Of the deceased, 65% were said to be residents of Addis Ababa.

Table E-2. Characteristics of the respondents

Characteristic		Frequency
Respondents	Family members	74
	Household heads	24
	Other	2
Respondent age	15 to 19 years	13
	20 to 59 years	85
	60 years or older	2
Gender	Male	50
	Female	50
Marital status	Married	38
	Single	62
Ethnic group	Amhara	39
	Oromo	21
	Gurage	18
	Tigray	10
	Other	12
Religion	Orthodox	64
	Protestant	17
	Muslim	13
	Other	6
Status on land	Rented house	55
	House privately owned	41
	Other	4
Occupation	Private trade	22
	Government employee	20
	Housewife	12
	Student	15
	Other occupation	17
	Jobless	14
Housing[1]	Mud house	73
	Permanent house	24
Household water	Municipal source	97
	Other	3
Average household size		6.6

1. A permanent house has walls made of brick, stone or blockade.

Table E-3. Funerals attended by respondents

Number of funerals	Percentage
Over seven	42%
Four to seven	18%
One to three	18%
None	22%

Health Facilities

The average distance from the home to the nearest health facility was a 24 minute walk, the longest being a walk of 2 hours. The nearest health facility was a health center (49%), a clinic (32%) or a hospital (19%), of which 65% were government-owned, 27% private, 4% run by a nongovernmental organization and 4% run by a religious organization.

Common Health Problems in the Community

When asked about the HIV/AIDS cases in their community, 61% were aware of HIV/AIDS cases in their community while 39% responded they were not. Of those who were aware of HIV/AIDS cases in their community, close to two-thirds (63%) responded that those affected were in the age range of 24 to 49 years. When asked of the existence of cancer patients in the community, 42% responded yes. Of those who responded in the affirmative, more than half (55%) indicated that females near the age of 45 are the main victims.

Caring for Patients

Forty-one percent of the respondents had taken care of cancer or HIV/AIDS patients. Problems encountered while taking care of these patients included anxiety (22), financial constraints (21), time constraints (8), and not having the skills for caring for such patients (2). When asked where they would prefer the patient to be cared for, 77% answered in a hospital setting, 14% indicated any medical set-up where adequate services are available, and 9% said they would rather care for the patient at home. The reason stated for the choice of a hospital setting is the fact that this kind of facility is better equipped and staffed to deal with the problem. The type of health care facility sought after for the care of such patients was stated as one having facilities for counselling and support, though the nature of the support was not explicitly stated. However, on the kind of health care facility they would like to have in their community, they responded better hospitals (11%), clinics (12%), health centers (9%), accessible (distance and finance) health service (7%), and specialized treatment centers (4%). As far as the administration of such services is concerned, the responses indicated that this should be done by the government (75%), religious organizations (11%), or nongovernmental organizations (9%).

At the time of the study, 86 respondents had a bedridden individual in their family, while 9 indicated that a family member had died within the past 12 months. Problems and needs of these two groups are described in the next two sections.

Families With a Seriously Ill Individual

When asked if the patient had visited a modern health care facility, 98% responded yes. When asked about the diagnosis, 63% indicated cancer and 26% indicated that they did not know. Fifty-five percent indicated that the patient was bedridden for more than 6 months. Fifty-eight percent responded that they feel the patient would have preferred to be looked after in the hospital, 25% indicated the home, and 4% indicated a holy site. The respondents said that 80% are looked after by either their spouse or their children. When asked about the perceived problems of the patient, the common problems were the pain associated with the illness (76%), vomiting, diarrhoea and appetite loss (30%), and other problems, including expense of the medications, lack of medications, bloody discharge, fever and cough, headache, constipation, rheumatic pain, urine retention and suffocation. Of the patients suffering from pain, the pain had been relieved in 41% of the cases. Relief of pain by medical treatment and/or radiotherapy was attributed to support of the family and relatives by 41% of the respondents, whereas only 20% of the patients were self-reliant and 10% received free treatment. Twenty seven percent said that they have sought traditional treatment for the patient. However, 61% said that traditional medicine was not helpful, while 39% said that it relieved the pain. Over 90% responded that they would seek help in a health institution if the illness gets worse. The major burdens on the family while caring for the patient were financial, emotional (anxiety, fear, sadness) and the physical burden of taking care of the patient.

Families With a Recent Death

Of the 100 cancer patients residing in Addis Ababa, nine had a family member who had died in the past 12 months. Six of those deceased were ill for more than one month. The causes of death for these deceased were infections (4), cancer (1), and unknown (4). Of these deceased, 6 were residents of Addis Ababa, one came from abroad, and two came from regions outside Addis Ababa. The reasons for coming to Addis Ababa were for one it was his home, while for the others they were family members. It is interesting to note that one of the nine was stated to be died of cancer, but no cases were identified as being HIV/AIDS. On the other hand, the respondents had earlier stated that the majority of funerals they had attended in their community involved deaths from HIV/AIDS or associated complications.

All respondents said that the deceased would have liked to be taken care of in a health care setting. In 4 cases, the wife was the caregiver, while for the rest the caregivers were children or close relatives. Out of the 9 respondents, 5 indicated that there was not enough money to buy drugs, 2 indicated that drugs were not available, 2 indicated an inability to relieve the pain, and one indicated they had no problems in this regard. Five respondents (56%) said that relief of the pain was the most important need of the deceased. The needs of the deceased not met included pain relief (88%), symptom relief (88%), and treatment and drug needs (100%). In the minority of the cases where the needs were met, it was the families and relatives who assisted.

Eighty nine percent of the deceased had attended modern health facilities during their illness. For 50%, health facility attendance was classified as “regular”. Only 25% indicated that treatment service was free, and of those who paid for their medical expenses, 80% indicated that the cost was more than 800 Birr (US $93). While caring for the deceased, treatment cost was rated as the major expense by 60%. Financial constraints (50%), a lack of required drugs (20%), and anxiety and fear (20%) were the main problems faced. The main support obtained from close family members and relatives was in the form of cash for treatment costs. One of the nine cases was reported as being completely helpless. Seventy percent of the caregivers were not satisfied with the treatment provided to their deceased relatives at health facilities. Relatives of the deceased would have liked the health facility to provide better treatment and care. Five of the 9 respondents used traditional healing practices, including holy water, prayer and traditional medicine. Two stated that the reason for using these services was the ineffectiveness of modern medicine to deal with the illness, and two stated that they preferred traditional healing practices.

Focus Group Discussions: Dawn of Hope – Ethiopia

The most common problems in the community were said to be “Almaz bale chira”, meaning herpes zoster, followed by tuberculosis, HIV/AIDS, child malnutrition, typhoid, uterine infection, shortage of food especially for HIV/AIDS patients, sexually transmitted diseases, and skin diseases. The group focused on the symptoms of HIV/AIDS, including anxiety, nerve problems affecting the extremities, skin problems, eye problems, fatigue, sleeplessness, loss of appetite and neck swelling.

In most cases the community and families are overwhelmed by health problems, such as HIV/AIDS, cancer, hypertension and diabetes, and have difficulty coping particularly with HIV/AIDS. Most seek modern medical care, while others seek both modern medical care and traditional healing. Some seek modern medical care, traditional healing and spiritual healing all at the same time. However, in most cases patients or families sought traditional healing when they felt that modern medicine had not been effective.

It was said that modern medication was expensive and the cost of medications are beyond the reach of most Ethiopians. Furthermore, most government hospitals are said to not admit patients with HIV/AIDS. Anti-viral drugs are said to be available on the black market, but these are also beyond the reach of most residents of Addis Ababa.

The group said that traditional healers prescribe topical and oral medication, the nature of which is not known. Medication prescribed by the traditional healers are said to include modern tablets or capsules that are crushed and mixed with Vaseline or colourful herbs, especially for herpes zoster. The cost of these medications can be high. Many patients elect to go to the holy sites, as there is no cost involved.

The group indicated that there are numerous holy sites, some more famous than others for their miracles of healing, such as Entoto Kidane Mehret in Addis Ababa and Shenkora Yohannes outside Addis Ababa. The group was in agreement that though spiritual healing should not be discredited, it should not be exaggerated. They gave examples of video releases on the healing miracles at the holy water sites "Tebel" which may be misleading. At most of these holy sites, claims were being made of sero-conversion. The group remarked that if real healing and sero-conversion were possible at these sites, the world would have flocked to Ethiopia seeking such miraculous healing. They said that the government should take measures to censor such propaganda, as it would hinder appropriate prevention and control measures. Furthermore, the early bathing in cold water accompanied by long fasting are said to exhaust the already afflicted body and the group agreed that patients end up weaker and sicker than when they arrived at the holy site.

The most common needs among people with incurable disease were said to be love and compassion. Actually, all used an interesting term "fikir yefewes kibat" meaning "love-the balm of healing", which they said is denied to most patients affected by HIV/AIDS and chronically ill bedridden patients who are facing death. All complained of the stigma attached to HIV/AIDS, the inefficient treatment they receive from medical professionals, naming some as non-compassionate and a few as going out of their way to help. Counselling was seen as a major need, along with compassionate care by health professionals and family members. Other needs stated were balanced and good nutrition, and pain and symptom relief.

On the issue of how the community can best meet the various needs of terminally ill patients and their relatives, it was said that families and the community should first accept the patient and respect them, and not judge or ostracize them. Financial support along with moral support and free health services were also emphasized.

Having specialized centers for patients with HIV/AIDS, instead of integrating the services, was considered ideal because neither professionals nor society are sufficiently sensitised to regard them simply as patients, like any other patients, and give them appropriate support and treatment. They said that the hope, care and support environment offered by organizations only catering to patients living with HIV/AIDS was much better than in desegregated institutions.

On how best to sustain the services, it was said that the government should divert money to this effort. As far as cost sharing is concerned, they said that the people are too poor to share costs. The role of "eiders" was also discussed. In Addis Ababa, one is a member of an eider, a community organization with a constitution, membership fee and obligations, which include attending funerals, comforting mourners and preparing food for the wakes. Families in collaboration with eiders arrange funerals. The eider gives out money to the family depending on the relationship of the deceased to the family (spouse, child, mother, etc.). The eider is seen as a potential community organization that could be restructured to support families not only during the funeral and wake, but also during the illness.

It was said that the government could help first by recognizing "the problem of care and support" as a problem and dealing with it as such. It was also said that one of the causes for the spread of AIDS is the hopelessness and unemployment of the youth, which leads to irresponsible behaviour and unsafe sexual practices. The government shouldn't isolate unemployment and poverty from HIV/AIDS and deal with these individually.

Focus Group Discussions: Radiotherapy Center

The group identified HIV/AIDS, cough, unbalanced diet, cancer, malaria, yellow fever, water-borne diseases, and vomiting and diarrhoea in children as the most common problems in the community. Both focal groups felt that the incurable diseases were cancer and HIV/AIDS, which were said to affect many young people, females, children and the elderly. Common symptoms were said to be cough, pain, pallor, bleeding, weight loss, weakness and backache. The frequent coping mechanism by which the community deals with these diseases is that the patients seek help from modern health facilities. However, when these are not effective, they go to traditional healers or use holy water or use all at the same time. Modern treatment is felt to be expensive. Although less effective, traditional healers are less expensive and spiritual/holy water service is free. Most people do not have access to health because they are poor; this issue needs much greater attention.

Information From the Key Informants

Unfortunately, the non-response rate was high for the self-administered questionnaires sent to the key informants; 15 questionnaires were sent and 9 responses were received. The responders included the Radiotherapy Center, four physicians and two nurses from the Police Hospital, and two nongovernmental organizations.

Opinions on the needs and problems of terminally ill patients were varied. For example, the radiotherapy staff who deal exclusively with cancer patients in advanced stages focused on the relief of pain and the lack of strong analgesics, such as oral morphine and codeine, which are not readily available. The physicians who responded also focused on the relief of pain and anxiety. Other perceived problems included financial problems, stigma, hopelessness, the lack of psychological support for the patient and family, and the financial and time constraints associated with caring for a bedridden patient – exhausting the caregivers, especially if they are poor.

It was stressed that the problem of care and support of the terminally ill "must first be recognized" as a priority in health care, after which this unmet need of patients, families and caregivers can be addressed by both governmental and non-governmental organizations. The fact that there are neither governmental nor nongovernmental organizations that have focused on this aspect of illness was also pointed out. The community and local organizations should be sensitised and mobilized to address the issue of care and support of the terminally ill, which includes home-based care and other social services such as counselling and supporting follow up, instituting credit schemes for the family and the paying of school fees. The community working in a cohesive manner was seen as an untapped resource. Specific local resources were not mentioned. Religious organizations such as churches were identified as having the potential for raising and administering funds. These were considered to be the best agencies to undertake such activities. On the issue of mobilizing, enhancing and maximizing local resources, it was stated that an effort should be made to "first assess" the local resources that can be mobilized or enhanced with the help of the community and kebele. Kebele members can play a significant role in identifying local resources that can be mobilized and put to use for terminally ill patients. The community is not devoid of sympathy for these victims, despite the stigma attached. This is a dilemma involving supporting these individuals, not knowing what to do, casting the victims out because of the fear of contamination, and the fear of being face to face with terminal illness and inevitable death. Fingers are pointed at these individuals, especially those with HIV/AIDS. Some sympathize, but do not want to be too close.

The community can play an ideal role in the support of these patients, ranging from not ostracizing them to giving them and their family moral support, financial support and transportation. Churches can give spiritual support. Further, the community can lead in advocacy for obtaining pain relief medications for these patients. The minimal package for the terminally ill should be free access to analgesics, palliative care for pain relief, basic food and shelter.

Reflections on Study Strengths and Weaknesses

Despite the limitations of the survey in both scope and depth, the needs assessment generated important information on palliative care services in the target area. The patient questionnaire generated information on the patient's profile, the caregiver, and perceived needs. Future surveys of this nature should consider restructuring some questions and conducting streamlined versions with clear sampling frames to generate more reliable population-based information. Focus group discussions were inadequate to serve as the basis for general statements concerning palliative care in the target area and conducting a survey at the Radiotherapy Center can introduce a bias. While future investigations in this area are warranted, lessons learned from this current study should be used to improve the survey methodology and thus improve the information generated.

United Republic of Tanzania Country Report

The United Republic of Tanzania Project Team is given in Table T-1. The team is composed of six members with diverse specialities that include oncology, HIV/AIDS, and public health, selected to critically look at the survey and questionnaire tools, modify them to the Tanzanian setting, and conduct and supervise the surveys.

Table T-1. United Republic of Tanzania Project Team

Name	**Organization**	**Relevant skills**	**Role**
Dr Twalib Ngoma	ORCI	Oncologist, management	Team Leader
Dr Florence Temu	ORCI	Public health specialist	Vice Team Leader
Ms Mary Haule	ORCI	Palliative care, home care nurse	Member
Ms Nandera Mhando	UDSM	HIV/AIDS counselling	Member
Dr F.D. Mtango	MUCHS	Community medicine, public health specialist	Member
Dr Angela Ramadhani	Ministry of Health	Public health specialist	Member

Situation Analysis of the Target Area: Dar es Salaam Region, United Republic of Tanzania

The Dar es Salaam Region consists of three municipalities, the Ilala Municipality, the Kinondoni Municipality and the Temeke Municipality. The city of Dar es Salaam is contained within these three primarily urban municipalities, which lie along the east coast of Africa, with Kinondoni in the north, Ilala in the middle and Temeke in the south.

Demographic Information

Extrapolating from the most recent census done in 1988, it is estimated that there are 1,360,000 males and 1,440,000 females, or a total of 2,800,000 individuals currently in the Dar es Salaam Region. Approximately 33% of the population is 14 years or younger and 5% is 65 years or older. Life expectancy at birth is 51.0 years for males and 53.0 years for females.

Health Status

The top 10 causes of outpatient attendances for individuals 5 years of age and above in 2001 were malaria with 54.9% (581,235), acute respiratory infections with 10.3%, pneumonia with 5.7%, diarrhoea with 5.6%, intestinal worms with 5.5%, skin infections with 5.2%, urinary tract infections with 4.8%, minor surgical conditions with 3.5%, pelvic inflammatory diseases and genital discharge with 2.5%, and anaemia with 1.9%. The top 10 causes of admissions for individuals 5 years of age and above in 2001 were malaria with 52.3% (16,609), acute respiratory infections and other respiratory conditions with 8.2%, diarrhoea with 6.5%, urinary tract infections with 6.2%, eye infections with 5.2%, tuberculosis with 4.8%, pneumonia with 3.3%, anaemia with 2.8%, pelvic inflammatory diseases with 2.7% and clinical AIDS with 1.3%.

The Dar es Salaam Region does not have statistics for specific cancers. However the Ocean Road Cancer Institute (ORCI) is in this region and is the only center in the country specialized in cancer treatment. The top 10 causes of attendance for adults at ORCI for 2000 were cervical cancer (34.3%; 586 cancers), Kaposi's sarcoma (12.6%), head and neck cancers (7.4%), oesophageal cancer (6.7%), breast cancer (6.6%), skin cancer (1.8%), bladder cancer (1.6%), cancer of the conjunctiva (1.6%), leukaemia (1.3%), and lymphomas (1.1%). Kaposi's sarcoma was the most common cancer seen among males and was the third most common cancer seen among females at ORCI. The Adult Morbidity and Mortality Project (AMMP) showed that cancer was one of the top five causes of morbidity and mortality among adults in the communities in the Dar es Salaam Region. Most cancer patients die at home. No local information is available concerning the stage of cancer patients at diagnosis. However, clinical observations of cancer patients at Muhimbili National Hospital and ORCI (both in the Dar es Salaam Region) indicate that more than two-thirds of the cancers present initially in advanced stages where cure is not expected and palliative care is indicated.

In 2000, there were 190 deaths from HIV/AIDS in the Dar es Salaam Region, 9 of which were children under 5 years of age (0.5% of all deaths) and 181 in individuals 5 years and older (9.7% of all deaths). Most people with HIV/AIDS in this area die at home. A surveillance study in 2000 showed that the prevalence of HIV/AIDS in Dar es Salaam was 14.9% for female blood donors, 8.3% for male blood donors, and 12.2% for women at antenatal clinics. It is estimated that there are about 16,000 HIV/AIDS patients in this region. The most common secondary infection for HIV/AIDS patients in Dar es Salaam is tuberculosis. Heterosexual transmission remains the main mode of transmission of HIV.

Health System

The Public Health Sector

The Dar es Salaam City/Regional Secretariat is in charge of the health sector in the region. There are health committees or boards at the different levels of health delivery, with oversight of the dispensaries, hospitals and health centers. The referral system principally flows from the home-based care and community-based health care level to the dispensary level to the health center level to the municipality hospital level to the Muhimbili National Hospital or ORCI level. At each level from the municipality down to the dispensary level there are units for promotive, preventive and curative activities. Activities for community-based health care are incorporated under promotive activities.

The three main health priorities within the target area are communicable diseases, non-communicable diseases and reproductive and child health. Activities within communicable diseases focus on HIV/AIDS (including sexually transmitted diseases), epidemics (such as cholera), malaria, tuberculosis, leprosy, and the expanded programme on immunization diseases (measles, tuberculosis, tetanus, diphtheria, pertussis and hepatitis B virus). Within non-communicable diseases, activities focus on diabetes, hypertension and mental health.

Overall, 78% of the population has access to a health facility within 5 km. However, this varies according to the municipality – from 72% in the Ilala and Kinondoni Municipalities to 90% in the Temeke Municipality.

Health Facilities

In-patient and laboratory services are available in 11 hospitals in the Ilala Municipality, in 10 hospitals and 3 health centers in the Kinondoni Municipality and in 3 hospitals and 1 health center in the Temeke Municipality. Outpatient services are available in

7 hospitals, 1 health center, and 110 dispensaries in the Ilala Municipality, in 10 hospitals, 4 health centers and 1 dispensary in the Kinondoni Municipality and in 3 hospitals, 3 health centers and 102 dispensaries in the Temeke Municipality. In this region there are 40 doctors, 8 dental surgeons, 47 assistant medical or dental officers, 205 medical or dental assistants, 85 rural medical aides, 361 nurses, nurse officers, midwives or public health nurses, and 244 maternal and child health aides. There are 10 functioning X-ray machines at hospitals in this region.

Health Programmes

The target area does not have a specific plan or programme for cancer control and no cancer prevention, screening, or palliative care programmes are being delivered. However, the ORCI is a specialized cancer treatment center within this region.

The Dar es Salaam Region does not have a local specific programme for control of HIV/AIDS. Rather, it follows the national AIDS control programme (NACP), that includes primary prevention, screening and early diagnosis, treatment and palliative care activities. Primary prevention activities focus on reducing unsafe sexual behaviours among highly mobile population groups (e.g. long distance truck drivers and taxi drivers), reducing HIV transmission among commercial sex workers, and reducing the vulnerability of youth to HIV/AIDS and STD. Screening and early diagnosis focus on voluntary counselling and testing centres that have been established in the target area. The goal of the treatment component is to provide appropriate STD case management services. In the target area health facilities provide STD treatment, using drugs and other supplies from the national AIDS control programme. Some health staff have been trained on STD control activities by nongovernmental organizations, such as AMREF and GTZ. Syndrome-based treatment guidelines are in place in most clinics and the sexual partner notification effort has shown some success in most of the clinics.

Home-based care services are underway with major contribution from several nongovernmental organizations such as Pastoral Activities and Services for People with AIDS: Dar es Salaam Archdiocese (PASADA), “Walio Katika Mapambano na AIDS Tanzania” (WAMATA; a Swahili acronym for “people in the fight against AIDS”), Comprehensive Community-based Rehabilitation in Tanzania (CCBRT; focusing mainly on eyes and orthopaedics) and, most recently, PATHFINDER. In the target area the palliative care component is part of the HIV/AIDS programmes and is provided through home-based care services. There is a home-based care unit within each of the three municipalities in the target area; Ilala started in 1999, Temeke in 2000 and Kinondoni in 2001. However, home-based care programmes have been run by nongovernmental organizations since 1989 (WAMATA) and 1995 (PASADA). CCBRT also has a home-based care programme with a palliative care component. Within the Dar es Salaam Region efforts are underway to reduce overcrowding of patients in wards, reduce costs to caregivers, alleviate pain, reduce stigma, and sensitize and educate the community.

Nongovernmental organizations have a different way of delivering the palliative care services from the programmes within the municipality administrations, although the Kinondoni Municipality works very closely with CCBRT. Principally, HIV/AIDS patients are being identified in hospitals on discharge or being introduced to the programmes by relatives or by themselves. Palliative care service objectives are achieved through visiting patients at home, educating caregivers, counselling, curative services and spiritual help. Schedules for home visits and follow-ups are set. At the municipality level of home-based care, the administrative and management staff are nursing officers who work under the AIDS coordinators, who are medical doctors with a speciality in public health. At the community level, for each hospital, health center and dispensary, there is a unit for community-based health care, which includes home-based care activities. Most of the other workers are volunteers at the community level. Health facilities at each level provide a room/ office for handling such activities. But most of the programmes in the government setting share offices with other programmes in the health facility. Radiotherapy is only available at ORCI.

Context

There are 7 universities or colleges and 3 health-related universities in the Dar es Salaam Region. The health-related universities provide training in HIV/AIDS and cancer for postgraduate students as part of other major specialities, such as obstetrics and gynaecology and surgery. There is no specific postgraduate training for oncology or HIV/AIDS.

In 1995 the literacy rate in this Region was 95.3% for females and 97.4% for males. The three most common religions are Christianity, Islam and African traditional religion. The major nongovernmental organization for cancer is the Tanzania Cancer Association. There are over 47 nongovernmental organizations dealing with HIV/AIDS in Dar es Salaam.

Needs Assessment: Dar es Salaam Region, United Republic of Tanzania

Members of the team for this investigation include the United Republic of Tanzania Project Team of Dr Twalib Ngoma (Team Leader), Dr Florence Temu (Vice Team Leader), Ms Mary Haule, Ms Nandera Mhando,
Dr F.D. Mtango, and Dr Angela Ramadhani, plus the following research assistants: Dr Irene Kida, Dr Hussein Mtiro, Ms Idda Temba, Dr Zena Mtajuka, Mr Simon Shayo, Mr Frederick Ngusaru, Ms Esther Njau and Dr Salome Mtango.

Executive Summary and Recommendations

A study assessing the palliative care needs of terminally ill patients with HIV/AIDS or advanced cancer was conducted in Dar es Salaam Region in February and March 2002. Both quantitative and qualitative data collection tools were used to gather information. A structured questionnaire was used to obtain information from 19 patients with cancer, 21 patients with HIV/AIDS, 40 caregivers, and 20 members of the general public using a random sampling approach. Qualitative tools were used to gather information from three groups of individuals: (i) those in charge of various home-based care programmes, (ii) those in charge of hospital units for home-based care and (iii) other key informants including a counselor, religious leaders, a traditional healer, those in charge of patient wards or clinics and government leaders.

Various problems and needs for patients with HIV/AIDS and advanced cancer were identified and a number of ways to meet those identified needs were proposed by all groups of interviewees. The primary needs of patients with HIV/AIDS or their families were economic (63%), spiritual (48%), physical (medical) (30%), social (23%) and emotional (18%). Financial incapacity among patients and the caregivers was a major drawback in the general care of such patients. Pain affected the patient not only physically, but also psychologically. Stigma stood out as one of the major issues felt by 90% of these patients and their families. However over 80% expressed different ways they have adapted to overcome the stigma. Family members are a very potent source for de-stigmatization

Close relatives and family members are key in the provision of home-based care. The main reason for a respondent to take on the role of caregiver was the close blood relationship with the patient. Family members and relatives were also the main source of support; 54% of caregivers got support from other family members and relatives. The problems and needs identified by the caregivers in the course of taking care of the patients were primarily financial or a lack of knowledge on how to look after the patients. Lack of protective devices, e.g. gloves and aprons, also demoralized the providers of home care.

Most patients viewed other places for care, including hospitals, as not very favorable for their conditions; 82% of the patients preferred to be nursed at home by their caregivers. However only 58% of the caregivers preferred to look after their patient while at home. Home visiting and home-based services are highly sought after and are perceived as consoling to most patients and their caregivers.

The needs that were identified commonly across the interviewed groups of patients, caregivers and the general community included: financial support, drugs for various conditions, training needs, counseling services, patient's pain and loss of sleep, and food stuffs. Despite the fact that cancer and HIV/AIDS are among the conditions exempted from the cost sharing policy in United Republic of Tanzania, in reality they remain expensive conditions to manage both at home and in hospitals. The key informants proposed to utilize locally available resources to help solve these problems, aiming to provide additional resources and infrastructure to strengthen the existing health system with respect to the support of home-based care.

Information obtained from a wide range of community resource people clearly identified the need for palliative care programmes, dealing with the gaps in the provision of care to the terminally ill. However, financial constraints, a shortage of trained staff, a lack of openness from such patients, and stigma were major constraints to the effective delivery of such services in a home setting. Further investigation is needed to establish clear programme components and financial requirements for terminally ill patients in an African setting. Stigma is a significant problem that the society needs to solve, as most members of the community can't identify with the patient or caregiver and are unfamiliar with the needs of the terminally ill.

It was clear from the palliative care programme descriptions from the Municipalities of Ilala, Kinondoni and Temeke that the government input in palliative care is minimal. The majority of the current services are being provided by nongovernmental organizations and voluntary agencies despite a well-structured health system that includes units supporting community-based health care.

Recommendations given below reflect suggestions made by the various groups of informants and observations based on the questionnaire survey findings. Recommendations are made to the local community, to the governmental and nongovernmental organizations, and to the public health community.

Community members should be involved in the planning and implementation of home-based care, as this will increase openness and cooperation. Various approaches should be undertaken to reduce stigma in the community. Community members should be encouraged to provide love, care and spiritual support to the sick people.

The government should set aside a budget for home care, especially for helping the poor who may not be able to purchase the medicines and supplies needed for home care. The budget allocated to palliative care programmes should be increased, so that it can also satisfy other needs such as food and medicine for patients at home. Programmes should embark upon inter-sectoral collaboration to foster cooperation between the government and non-governmental organizations.

Palliative care workers' motivation should be improved by increasing remunerations and incentives and setting aside funds for compensation in case of accidental infection. Facilities for home-based care including transport should be increased and should have special units for that specific service in hospitals. Governmental and nongovernmental agencies should be encouraged to increase the number of health providers in the communities and increase the number of community-based units. Health care providers should also be encouraged to provide care, love and spiritual support. Community members should be sensitized to recognize their potential in caring for their sick ones through public education and capacity building.

It is recommended that the public health community continue to develop and adopt interventional models basing on these findings. Such models should cover the palliative needs of individuals and their families, including social, physical, economic, spiritual, and psychological/emotional support. A special training package should be developed for family caregivers. Effective use should be made of the caregivers whom the patients rely upon most. Additional strategies for de-stigmatization need to be explored and implemented. Public and private organizations need to jointly explore ways to place home-based programmes especially in areas where the closest health facility is a private facility. Research should be undertaken to determine the most cost-effective provision of palliative care to terminally ill patients with HIV/AIDS or cancer in the target area.

Background

In United Republic of Tanzania there have been various initiatives aimed at the provision of palliative care to patients with incurable diseases, including advanced cancer. HIV/AIDS in particular, has attracted the interest of most organizations with home-based and community-based initiatives. The Ministry of Health in collaboration with the NACP has identified several strategies to support the primary health care providers in the provision of home-based care for HIV/AIDS and chronically ill patients.

Cancer stands as one of chronic conditions that warrant palliative care, and pain is the main symptom experienced by more than 80% of cancer patients in the course of the terminal phase of their illness. Family members are nursing most of these patients at their homes after repeated hospital visits and admissions. In response the specialized cancer institute in United Republic of Tanzania, the OCRI, has adopted the initiative from the WHO Programme on Cancer Control and the WHO Department of Care for HIV/AIDS to strengthen the development of palliative care in African countries.

Study Objective

The objective of this study is to assess the palliative care needs of the terminally ill and their families for the purpose of developing an appropriate palliative care approach for the terminally ill at home.

Study Design

This was a cross-sectional study using both quantitative data and qualitative data. Quantitative data was collected via questionnaires given to 100 individuals (40 patients, 40 caregivers and 20 others). Qualitative data was collected from 6 individuals in charge of home-based care programmes, 6 in charge of hospital home-based care units, and 8 other key informants from the community. This investigation was undertaken within Dar es Salaam city, which is comprised of the 3 municipalities, Ilala, Kinondoni and Temeke. A 3–day training course was conducted for 8 research assistants, which included pre-testing of the questionnaires. Ethical clearance was obtained and permission to conduct the study was obtained from the health authority in Dar es Salaam.

The sample size selected for the questionnaire survey of patients and their caregivers was chosen to be 100 participants to be consistent with the other WHO project participating countries. The plan was to identify 20 patients at random from patients with known HIV/AIDS and 20 at random from patients with known cancer. The 8 interviewers were grouped so that half were to interview patients with cancer and the other half were to interview patients with HIV/AIDS. Depending on the number of clients (N) within the area of responsibility of each interviewer, they selected 5 subjects according to a systematic random sampling scheme in which they selected every nth client using the algorithm, n=N/5. Patients were interviewed in their homes. For each patient a key caregiver was also interviewed in the same home. Thus the 8 interviewers gathered questionnaire information on 40 patients and 40 caregivers. During the implementation phase 21 patients with HIV/AIDS and 19 with cancer were administered the questionnaire. Twenty additional individuals from the general community, not patients or caregivers, were also selected for the questionnaire survey using a similar sampling scheme, to yield a total of 100 completed questionnaires.

The 8 interviewers also conducted a total of 20 qualitative interviews. They interviewed 6 individuals in charge of hospital home-based care units (3 district hospitals and 3 private hospitals), 6 individuals in charge of home-based care programmes (NACP, WAMATA, PASADA, and the 3 municipalities), and 6 other key informants. The key informants were a counsellor, a traditional healer, two religious leaders, an individual in charge of the cancer wards at ORCI, an individual in charge of an STD clinic, one local government leader and one Member of Parliament.

Results

The association between the patient and their respective main caregiver is given in Table T-2.

Table T-2. Relationship between the patient and main caregiver

Main caregiver	Frequency	Percentage
Parent	12	30%
Spouse	11	28%
Brother/sister	4	10%
Close relative[1]	4	10%
Child	3	8%
In-laws	3	8%
Other[2]	3	8%

1. Cousin, uncle or aunt
2. Close friends or grandparents

Relatives and family members were the main providers of home care, and the parent or spouse was the main caregiver in 58% of the cases. Relatives are bound to support their sick ones, volunteering financially, morally and materially. Also the majority of patients were relieved by having relatives around. Despite the fact that only a few patients notified their parents when they first knew about their illnesses, many of them ended up being taken care of by these parents.

Table T-3 presents the characteristics of the caregivers. The pattern of sex distribution in the selected sample of patients can explain the sex distribution of the caregivers because it is customary that patients usually prefer to be nursed by those of similar sex. Overall, 48% of the caregivers had no education or only primary education. A majority of the caregivers (63%) are of the productive age (21–50) and had business or professional employment on top of the caregiver role. This suggests the suspension of production in their respective areas at the time of illness. It is not only the patient who suspends work but also the caregiver. This has also been expressed by the caregivers as one of drawbacks when looking after such patients.

Table T-3. Characteristics of the caregivers

Characteristic		Frequency	Percentage
Caregiver age	15 to 20 years	2	5%
	21 to 60 years	32	80%
	Over 60 years	6	15%
Gender	Male	15	38%
	Female	25	63%
Marital status	Married	25	63%
	Single	11	28%
	Widowed	2	5%
	Divorced	2	5%
Religion	Christian	23	58%
	Muslim	17	43%
Level of education	None	6	15%
	Primary	13	33%
	Secondary (ordinary level)	10	25%
	Secondary (advanced level)	6	15%
	University	5	13%
Occupation	No earning activity	1	3%
	Housewife§§	9	23%
	Business/professional	25	63%
	Peasant	3	8%
	Self employed	1	3%
	Student	1	3%
Disease stated[1]	Cancer	19	48%
	HIV/AIDS	15	38%
	Tuberculosis	3	8%
	Other[2]	2	5%
	Did not know	1	3%

1. Disease the caregiver said the patient was suffering from.
2. Other diseases specified: typhoid – 1, witchcraft –1.

Characteristics of the 40 patients in the home questionnaire investigation are summarized in Table T-4. Half the patients had no education or only primary education. In 9 cases the patients were unaware or unwilling to indicate that they had cancer or HIV/AIDS. Three quarters of the patients learned of their diagnosis at a health center or from a doctor. The remaining one quarter made their own conclusion based on symptoms, loss of a spouse/lover, or other non-medical source. At the time of the interview 33% of the patients stated that they had no earning sources at that time, as compared to only 3% who stated that they had no earning sources before they were ill.

Some patients were not willing to mention their actual underlying health problem, especially those with HIV/AIDS. From the survey methodology employed, all the interviewed patients had an established diagnosis. However, some patients preferred to identify their condition as typhoid or tuberculosis, rather than mentioning HIV/AIDS. On average the majority of patients knew about their illnesses between 1–5 years before the interview. The picture was similar for both diseases.

Table T-4. Characteristics of the patients

Characteristic		Frequency	Percentage
Patient age	15 to 20 years	1	3%
	21 to 60 years	31	78%
	Over 60 years	8	20%
Gender	Male	24	60%
	Female	16	40%
Marital status	Married	21	53%
	Single	10	25%
	Widowed	6	15%
	Divorced	3	8%
Religion	Christian	23	58%
	Muslim	16	40%
	None	1	3%
Level of education	None	6	15%
	Primary	14	35%
	Secondary (ordinary level)	13	33%
	Secondary (advanced level)	5	13%
	University	2	5%
Prev. occupation	No earning activity	1	3%
	Housewife	8	20%
	Business/professional	18	45%
	Peasant	3	8%
	Self employed	8	20%
	Student	2	5%
Known disease	Advanced cancer	19	48%
	HIV/AIDS	21	53%
Disease stated[1]	Cancer	18	45%
	HIV/AIDS	13	33%
	Tuberculosis	6	15%
	Other[2]	3	8%
How they knew	Test at health facility	24	60%
	Told by a doctor	6	15%
	Own conclusions[3]	5	13%
	Suspected when lost partner	3	8%
	Other	2	5%
How long known	Less than 1 year	12	30%
	1 to 5 years	24	60%
	5 to 10 years	3	8%
	Could not recall	1	3%

1. Disease they said they were suffering from.
2. Other diseases specified: typhoid – 1, witchcraft –1, both HIV/AIDS and cancer –1.
3. Made their own conclusions from symptoms

Patient's Perceived Stigma

Ninety percent of the patients (15 with known cancer and 21 with known HIV/AIDS) indicated that their illness had created some sort of stigma toward them. Stigma seems to be a problem these patients can hardly avoid. The patients adopted different ways to handle the stigma. Most commonly they had consoling family members

(40%). However, 26% just kept quiet and did nothing, as they did not know what to do. Other strategies for dealing with the stigma involved meeting with a counsellor or doctor (16%), accepting the diagnosis and being open about it (9%) and having a strong faith in God (9%). Despite the patient's explanations on how the majority of them tried to combat stigma, it should be noted that they still sensed stigmatization.

Patients in this study speculated how others learned about their illnesses. In 58% of the cases the patient themselves told others about their illness, and in one-third of the cases it was believed that the doctors broke the news to others. It was impressive that 58% of the patients decided to open up and tell other people about their illnesses.

Patient's Expressed Problems

Patients were asked to express the different kinds of problems they face in the course of their illness. Problems are grouped in Table T-5 as physical, social, economic, spiritual and emotional.

There was considerable variability among the patients with respect to their expressed physical and social problems. However a frequently mentioned problem was the loss of income. From Table T-3, it is seen that before being ill the majority of the patients were of productive age and were productive members of society. The subsequent falling into dependency can explain the problems expressed in Table T-5 under economic and social problems. Some patients also expressed the fears they

Table T-5. Patient's expressed problems by major type of problem

	Number	Percentage
PHYSICAL PROBLEMS		
Body pains	12	30%
General body weakness and loss of appetite	11	28%
Loss of sleep	9	23%
Low blood level	9	23%
SOCIAL PROBLEMS		
Felt dependent	12	30%
Felt isolated	9	23%
Sexual abstinence	2	5%
ECONOMIC PROBLEMS		
Could not earn	25	63%
Could not purchase what they wanted	6	15%
SPIRITUAL PROBLEMS		
Missing God's help	19	48%
EMOTIONAL PROBLEMS		
Lost hope	18	45%
Felt angry almost all the time	7	18%

had during the course of their illness. Their greatest fears were that there was no hope for cure (43%) and they would not be able to support their families (25%).

Health Care Services

The closest health facilities were government-owned for 75% and private-owned for 20% of the cases. Most of the patients (95%) lived within 5 km of the nearest health facility. This is a success for United Republic of Tanzania; after independence the nation made a major effort to fight against diseases. However, a lack of well-trained personnel and well-equipped facilities remains a problem, particularly in the government owned facilities.

When the patient's condition changed most would take their patient to a nearby clinic or hospital (65%). However, 13% of the caregivers said they would always seek a second opinion from a close relative or friend. Only 3% of the respondents said they would take the patient to a home-based care service. Other options mentioned included taking the patient to a traditional healer and performing first aid at home.

Family members and close relatives remain the key providers of various services, such as covering the costs of treatment, visiting the patient and counselling. Patients were asked to specify the types of medications used. Only hospital drugs were used by 68%, local herbs only by 5%, and both hospital drugs and local herbs by 28%. Costs of the drugs were most often covered by family members or relatives (73%), sometimes by a nongovernmental organization (10%), but infrequently by a hospital (3%).

Also 65% of the caregivers reported obtaining different kinds of assistance from various providers. Such assistance included financial support (45%), food (35%), medications (40%), or someone to relieve the caregiver in looking after the sick (45%). The main provider of such assistance was a family member or relative (54%), nongovernmental organization, such as PASADA, CCBRT or WAMATA (15%), or religious group (15%).

The estimated costs incurred for treatments were primarily between 26,000 and 60,000 Tanzanian Shillings (T Sh.) (US $26 to $60) per month. In 25% of the cases they were less than 26,000 T Sh. per month and in 30% of the cases they were more than 60,000 T Sh. per month.

Patients were asked to specify the type of service they would prefer to receive from a home-based or community-based group. Multiple answers were given. Overall, 60% indicated that they would prefer to get holistic services (including medication, counselling, legal support and spiritual support), 45% specified that they would prefer financial support, 40% indicated that they preferred food, and 23% specified that they would prefer support to the family in counselling, income generating activities and financial aid.

Patients and caregivers expressed their views regarding places of preference for caring terminally ill patients. Overall, 83% of the patients specified that they preferred to be looked after at home. The reasons given for this were that it would be cheaper, hospitals are unkempt with no drugs, there is no love from nurses in hospitals, one cannot eat well while in a hospital, and at home one can easily access other alternative treatments including local herbs. The reasons why 10% of the patients would prefer to be cared for in a hospital were that they are closer to nurses and doctors and that it reduces transport costs to the hospital. The 58% of caregivers that preferred that the patient be cared for at home indicated that it was easier to look after the patient at home and that it was cheaper. The 20% of caregivers that preferred the patient to be cared for at a hospital did so because it was closer to the medical services. Some of the caregivers (18%) indicated that the patient should be cared for at their home village, primarily because hospital medications have failed.

The Caregivers

Many of the caregivers (44%) reported having looked after terminally ill patients previously. Nearly all (90%) of the caregivers had not received any kind of training for caring for a terminally ill patient. Of the four caregivers who had received some training, two obtained the training from a government institution and the other two received training from a course organized by a nongovernmental organization. The duration of their training was between a day and one week. Nearly all of the caregivers (95%) said they were caring for their sick people for free and were not expecting any payment in return.

Caregivers were aware of the patient's problems. The most common problems were the lack of proper medications (43%), a shortage of food and money to meet the patient's needs (28%), and the patient's pain and loss of sleep (13%). Caregivers experienced the following significant problems: financial constraints (45%), a lack of time to rest or do other activities (25%) and patients were short tempered (13%).

Caregivers described their major care activities as providing food, drugs, assisting with washing, feeding and changing (78%) and consoling (23%). While 18% expressed the concern that they had no time to participate in any sort of training, the remainder wanted to learn how to help terminally ill patients. Caregivers were asked to identify the types of assistance they needed. Multiple responses were permitted. The majority of caregivers indicated that they needed financial support (73%). Other common needs of the caregivers included free drug availability (53%), income generating activities (38%), supplies of food (35%), training on the care of terminally ill patients (33%), and having protective devices, such as gloves (25%).

General Community

Twenty members from the general community from different parts of the city were also interviewed regarding the needs of terminally ill people. With an exception of one respondent who was a housekeeper, all others were heads of households. They were from 17 different Tanzanian tribes, 55% were females, 65% were married, and 60% were Christians. The majority (55%) owned houses with title deeds while others were living in hired residences. Their most frequent occupations were business, professional, housewives and watchmen/gardeners. All reported to have a health facility nearby within 5 km, 60% of which were government-owned, 30% privately owned, and 10% owned by various nongovernmental organizations. On average each household had 6.3 members. Of the 20 respondents, 5 had lost someone with a long illness within the last 12 months and 4 of them had someone who was bedridden with a long illness at the time of interview.

The 9 respondents who reported to have had someone with a long illness within the last 12 months or someone who was bedridden with a long illness at the time of interview were asked to describe their experience with the terminally ill. Of the 9 cases, the patient at home had HIV/AIDS (5), cancer (2) or tuberculosis (2). The majority of the patients (5/9, 56%) preferred to be cared for at home; only one patient expressed a preference for a hospital, while the other 3 didn't express a preference. Parents and relatives served the role of caregivers. The patient's main needs and problems were pain (56%), food (33%) and drugs (33%). The most common problems encountered when looking after these terminally ill patients were financial (56%), caregivers that despaired (33%), lack of knowledge about care (17%), and lack of ideal facilities, such as gloves (17%). In two-thirds of the cases, help was sought from a traditional healer. There was strong support of additional services being made available in the community, and the majority of the respondents indicated that the community members should contribute to this effort.

The 20 general community members were surveyed regarding the general health problems facing their families and the community. The most common problems mentioned were malaria (60%), diarrhoea (15%), and recurrent childhood illnesses (15%). Nearly all (95%) indicated that they had attended at least one funeral in the past 12 months; 30% indicated that they attended 4 or more funerals during this period. Respondents indicated that funerals were held most often for the 15 to 49 year age group (55%). These community members were asked to identify which health services should be initiated or strengthened on behalf of the general population in their community. The most common responses were government hospitals with better services (25%), home visits for long-term ill patients (20%) and modern dispensaries with all basic investigations (20%). In this regard, the majority felt that community members should contribute financially and in an advisory capacity.

The view from the general community did not differ very much from what was reflected in patients and caregivers interviews. The primary difference was that among the ways to sustain a home-based programme it was mentioned repeatedly that community members should contribute financially. If this will be pursued then it could be a very promising approach. The challenge would be convincing a healthy, earning community to contribute to a service that they do not individually need at that time.

Interviews of Those in Charge of Home-based Care Programmes

Six programme managers in charge of home-based care programmes were interviewed. Results of these interviews are summarized in Tables T-6 to T-11. The programme managers' understanding of "palliative care" generally considered it to be a service provided to patients to reduce pain. Most programme managers regarded a main aim of palliative care programmes to be the reduction of overcrowding of patients in the hospitals. Home visits, community education, staff education and provision of curative and counselling services at home were the means for achieving these aims.

Most programmes identified those needing home-based care mainly by relying on the data from clinics, health centers, dispensaries and community-based programmes. Some patients however, were introduced into the programmes by their relatives and family members.

Despite the variety of problems encountered during the provision of palliative care, stigma was still a major setback. Nevertheless, associating their illnesses with witchcraft made some not accept services from the home-based programmes.

Despite the lack of clear figures on the number of staff in most programmes, volunteers appear to shoulder most of the responsibilities in the programmes. Volunteers seem to be easily accepted by patients and are readily available to the community. The volunteers are also helpful in the dissemination of information to the patients. However the problem of a lack of incentives was a concern throughout the programmes. Frequent seminars and training helped motivate the staff. However there was no standard training curriculum within the programmes. The guidelines for the provision of home-based care by the Ministry of Health was used by few programmes for their training activities. Some of the problems encountered by the programme's personnel during delivering services at home were related to the poor conditions of the patients' families who could hardly meet their daily basic needs. Some patients were even neglected by their families/relatives.

These programmes have been in existence for a couple of years, the oldest being

13 years old (i.e. started in 1989) and the youngest a year old (started in 2001). A lack of transport and long distances has remained an obstacle in reaching some patients. Problems facing most of the patients as mentioned across the programmes included: physical pain, fear of death and leaving behind helpless dependants, failure to generate income and hence poverty dissoluteness and hopelessness, lack of proper medical services, social stigmatization and discrimination.

In general, the needs of terminally ill persons identified by the programme coordinators/managers were: pain relieving drugs, social and spiritual support and counselling, legal aids (e.g. wills, property inheritance and confidentiality), and daily needs such as food, clothing and money. Most of the programmes had in place a service package for the terminally ill, which covered: medicine and other medical support, counselling services, and education for the families and caregivers.

Services that were provided in special circumstances included: transport to and from health services, food and other essential commodities such as soap, toothpaste and toothbrushes.

Government programmes worked within a specific municipality. Problems noted were: limited numbers of staff and an increasing number of patients, reluctance by relatives to cooperate during the provision of care, reluctance by some terminally ill to use the service offered by the programme, lack of money to buy basics such as food and clothing, and lack of reliable transport, especially for remote patients where public transport is not available.

All the programmes expressed the intention of increasing the number of health care providers and to collaborate with other organizations. The government was seen as an overseer to provide plans of action and resources for delivering home care services. It was impressive to find out that the majority perceived networking positively and as a way to complement rather than to compete with other services in the community.

Despite the fact that most programmes did not provide a statement of their annual budget, the main source of funding was apparently through international organizations, such as the European Union, DANIDA and the UN Development Programme (UNDP) and NGOs such as CBM, AXIUS, and SAT. The National AIDS Control Programs (NACP) of United Republic of Tanzania also provides some funding to some of the programmes.

Patients made no contributions to any of the programmes. On some occasions however, they had to purchase some medicines, though at subsidized prices. Though there were no plans within the programmes for generating funds, empowering the community morally and materially was found to be some of the ways to sustain these programmes. Sharing of some of the resources (offices, vehicles, computers, and staff) was common, especially in hospitals. In general, all programmes recorded a serious inadequacy of equipment for home-based care. In most programmes, patient referrals were effected whenever patients needed special or intensive care. Feedback was possible only upon follow up made by a programme worker from the referring end.

Table T-6. Information on home-based care programme in Temeke Municipality

General programme information	Type	Hospital-based
	Aims	To reduce the number of patients admitted to hospital and to incorporate the community in taking care of the patients. Those at home are identified through testing.
	Problems	Patients are reluctant to be tested. Many patients cannot provide for their own needs and so expect to be given assistance, such as food.
Staffing	Type	Workers are from the hospital, clinic, health center and volunteers.
	Problems	Meeting patients that have been alienated from the community; patients being negative to caregivers; some volunteers expect to be paid for their services, and some withdraw.
	Motivation	Allowances, training and the home-based care kit.
Services provided	Services	Started in 2000, patients are visited twice a week. They can contact staff at home.
	Needs	Glucose and intravenous medicines. Plans are underway to improve these services, hire more staff, and provide money to caregivers and patients.
	Problems	Lack of enough money and transport. Lack of openness, social discrimination and increasing services demand. Furthest patient lives 10 km away.
	Package	Medicine, counselling and resuscitation.
	Evaluation	It has reduced the overcrowding of patients in hospitals. It has also built good relations between the health providers and the families of patients, and facilitated obtaining data.
Networking		Communicating with others enriches the programme and helps educate the community.
Funding		Annual budget is 7 million T Sh. from the government, mainly through the “Sector Wide Approach”. Two-thirds of the budget goes for medicines and home-based kits. One-third goes for salaries and leaflets. No funds are being raised locally and there are no contributions from the patients. Plans are underway for self-generation of funds.
Facilities		Owns one office and shares one vehicle.
Referral system		Patients needing intensive care. Patients are referred from home to clinic to health center to hospital, depending on distance and patient’s condition.
Recommendations		To improve the programme financing to meet the patient’s needs. To increase the number of caregivers in the community. To make vehicle transport available to patients.

Table T-7. Information on home-based care programme in Kinondoni Municipality

General programme information	Type	Hospital-based
	Aims	To reduce the number of patients in wards, reduce spread of infection, and reduce cost to caregivers. Patients are identified at discharge, upon request and by visiting TB staff.
	Problems	Large number of patients compared to staff. Some patients insist upon avoiding hospital.
Staffing	Type	Full-time workers.
	Problems	Some patients refuse to take medicines.
	Motivation	Training and transport allowance.
Services provided	Services	Started in 2001, patients are visited by staff. Patients receive medicine, spiritual counselling, family counselling, and ways to earn money.
	Needs	Patients need counsel, spiritual support, free medicine to reduce pain and help for will.
	Problems	Patient’s aggressiveness and pain. Patients may hurt the caregivers. Patients believe more in traditional medicine. Patients cannot afford some medicines.
	Package	Counselling, medicine at lower cost, and referral to PASADA for spiritual help.
	Evaluation	These services are in great demand. Evaluation at monthly directors meetings.
Networking		Strong network for spiritual support. But there is conflict due to differences in beliefs.
Funding		Budget not available. Main sources are European Union and CBM through CCBRT. No funds are raised locally. The government is corporate with CCBRT in this regard.
Facilities		Shares office with district AIDS coordinator. No vehicle.
Referral system		Referral is done on emergency basis – to hospital, through outpatient departments.
Recommendations		Free medicines to patients; a vehicle, own counselling room, cell phones.

Table T-8. Information on home-based care programme in Ilala Municipality

General programme information	Type	Hospital-based
	Aims	To reduce overcrowding of patients in hospitals and to incorporate society in providing for their patients. Patients are identified through information from health centers.
	Problems	Poor information communication between health centers and care providers at home.
Staffing	Type	Full-time, part-time and volunteers.
	Problems	—
	Motivation	Outreach allowances, bicycles, and training in general patient care and counselling.
Services Provided	Services	Started in 1999, patients are visited. Can contact staff at office.
	Needs	Medicine for reducing pain and money.
	Problems	Alienation, stigma, lack of medicine and distance; furthest patient is 40 km away. Lack of transport, few staff, poor communication with the patients.
	Package	Education to families, counselling, medicine and equipment for treatment of ulcers.
	Evaluation	NGOs (SHIDEFA, WAMATA) and other groups meet the increasing demands.
Networking		—
Funding		Budget not available. Funding from government, cost sharing, NGOs and NACP at district level. No funds raised locally and patients do not contribute.
Facilities		Shares an office. No vehicle.
Referral system		—
Recommendations		To expand HBC services; to educate and sensitize the community to increase participation; to set a definite budget for these programmes.

Table T-9. Information on WAMATA[1] home-based care programme

General programme information	Type	Community-based
	Aims	Betterment of health of the patient at home. To enable families to take care of patients at home through home visits, counselling and curative services.
	Problems	Superstitious beliefs and expenses in hospital.
Staffing	Type	Full-time, part-time and volunteers.
	Problems	Patients cannot afford some medicines.
	Motivation	Volunteers are trained at short courses.
Services Provided	Services	Started in 1989, patients are visited weekly. Furthest patient is 20 km away.
	Needs	Patients need to be near their families; spiritual counselling; assistance in legal matters.
	Problems	Leaving children without care; lack of money leads to poor treatment and physical pain. Relatives refuse to take patients to hospital; loss of hope; and not enough money.
	Package	Treatment, transport, counselling and money for tests; also by CCBRT and PASADA.
	Evaluation	By daily, weekly and monthly reports.
Networking		No official networking with other programmes.
Funding		Budget not available. Costs cover fuel, medicine, salaries, diagnostic tests. Funding externally from DANIDA, AXIUS and SAT and internally from IPP Media. No funds raised locally. Sometimes the government provides medicine and free testing.
Facilities		Shares an office, owns 3 counselling rooms, owns one vehicle.
Referral system		Referral for patients needing intensive care or services not provided by programme.
Recommendations		To improve collaboration with governmental, nongovernmental and private sectors. Community education and sensitisation.

1. WAMATA: Walioi Katika Mapambano na AIDS Tanzania [a Swahili acronym for “people in the fight against AIDS”]

Table T-10. Information on PASADA[1] home-based care programme

General programme information	Type	Hospital and community-based
	Aims	To reduce the stigma and provide spiritual help. Achieved through treatment of pain at home. Patients are identified through home visits or by relatives.
	Problems	Sometimes poor cooperation from some of the patient's relatives.
Staffing	Type	Few staff are full-time. Most are volunteers. Volunteers identify most of the patients.
	Problems	—
	Motivation	—
Services Provided	Services	Started in 1995, patients are visited twice a week. Furthest patient is 30 km away.
	Needs	Patients need to be free from pain; they need love and other important support. More community involvement with terminally ill; churches and mosques can be used.
	Problems	Discrimination; stigmatisation; lack of transport; patients are not open; increased demand for these services; lack of feedback.
	Package	Spiritual counselling, food, soap and other support; also by CCBRT & Temeke Hospital.
	Evaluation	Monthly and regular meetings with staff members.
Networking		Networks with other programmes. Plans to improve collaboration with NGOs.
Funding		Budget not available. Donations from organizations outside the country. No budget is raised locally and patients do not contribute. Government provides some medicines. Programme looking for more donors to hire more caregivers.
Facilities		Owns one office, shares 4 counselling rooms, owns one vehicle.
Referral system		Referral to hospitals, depending on patient's needs.
Recommendations		To expand home-based services. To expand counselling services to society to reduce stigma. To increase the number of staff.

1. PASADA: Pastoral Activities and Services for People with AIDS Dar es Salaam Archdiocese

Table T-11. Information on NACP[1] home-based care programme

General programme Information	Type	Institution-based
	Aims	Palliative care to reduce patient's pain. Achieved by developing projects in the community. Patients identified in health centers, clinics, dispensaries and community.
	Problems	Communication.
Staffing	Type	Full-time staff and volunteers.
	Problems	—
	Motivation	Training, given bicycles, and lunch allowances on working days.
Services Provided	Services	Started in 1995 in 2 regions, now in 6 regions. Patient visits are planned at district level. Contact is through relatives or from health centers.
	Needs	Patients need social support and medicines.
	Problems	No satisfactory medical services and treatment; lack of money; no standard service package; increasing demand of services; community must have a sense of ownership.
	Package	Many groups also provide services.
	Evaluation	Done by special assigned teams at the district level.
Networking		Strong networks with other programmes.
Funding		Budget not available. Funds are obtained from nongovernmental organizations, government, UNDP, community and religious institutions. Government provides staff, office and working facilities. No local funds are raised and patients do not contribute.
Facilities		Shares office. No vehicle.
Referral system		Referrals from home to clinic to health center to hospital, depending on patient's needs.
Recommendations		To emphasize that HBC programmes reduce unnecessary hospital admissions; to build capacity, to improve referral and communications; to develop policy for HBC services; to expand collaboration with other health programmes and mutli-sectoral participation.

1. NACP: National AIDS Control Programme

Interviews of Those in Charge of Hospital Home-based Care Units

Home care services were virtually absent in the three private hospitals interviewed in Dar es Salaam. The only home care service offered in the private hospitals was voluntary HIV screening to those who could afford it. However, home care units were started between 1999 and 2000 in the three government hospitals. All three projects of the city hospitals have the same objectives:

- To reduce the great overcrowding of patients in the hospitals;
- To reduce the travel costs for patient's relatives who have to bring food to their patients and support them during their stay in hospital;
- To continue treatment at home for chronically ill patients who have to be discharged due to lack of room in the hospital or due to patient or relatives' request.

Hospitals offer free registration of patients for home care, providing the home care units with names and addresses of patients who may benefit from home care after hospitalization. Free counselling to the patients for home care service is also offered. There was no regular hospital budget for this particular service. Drugs provided by home care workers include analgesics such as aspirin and panadol, and also wound dressing kits and gloves. At Temeke hospital gumboots are also given to home care workers. The workers also arrange for pastors and sheikhs to deliver spiritual assistance to the terminally ill patients. In all the three districts there was no provision for funding the project by the government or other local institutions, or mentioning of any measures for sustaining the project when donors withdraw.

Hospitals units use the regular employees, equipment, and drugs from the hospital, and compliment them with community volunteers and assistance from mostly religious groups to implement home care. All groups are trained at the hospitals. A range of health workers of different cadres in the government hospitals facilitates the delivery of home-based care.

Although Mwananyamala and Amana hospitals thought there are no problems encountered in giving home care, looking at the recommendations given, one can pick out a number of common problems faced in these hospitals. All three hospitals identified the provision of transport and a field allowance for the home care personnel as major recommendations. In general they also indicated a need for an increase in home care personnel, enlistment of community cooperation, a government budget for a home care unit at the hospital, and funds for assisting those who may be infected through delivery of home care services.

Interviews of Key Informants

The key informants interviewed included a counsellor, a traditional healer, a Christian church leader, a Muslim leader, an individual in charge of a cancer ward, an individual in charge of an STD clinic, a local government leader and a Member of Parliament. These informants described the perceived needs of terminally ill patients by referring to their experiences in dealing with such patients. Most of the needs were commonly mentioned by all the informants. Although the traditional healer also mentioned medication, he did not mean the medications from mainstream medicine, but rather local herbs and some rituals routinely used for terminally ill patients. Among the medications specifically mentioned by other informants were the painkillers.

The first group of needs was "social needs". These included love, closeness to people, counselling, accommodation, cleanliness, legal support (including confidentiality), nutritional support, freedom to decide on their treatment, and education – particularly on their illnesses and the treatments given. Other needs were financial, medical (primarily for medicines) and spiritual.

Problems mentioned included social (lack of confidentiality, dependency, place to stay), psychological (low self esteem, fear of death, loss of hope, short temperedness, denial), financial (loss of job, food scarcity and other constraints), medical (lack of medication and skilled treatment staff) and physical (recurrent illness, pain).

The traditional healer referred to the lack of food for those patients he administers to at his place. This could be linked with the distrust he experienced from most relatives of such patients. It suggests that there is a loss of trust and subsequent abandonment by the patient's relatives.

There were mixed feelings from the respondents indicating the two different ways in which the community views terminally ill people – negatively or positively. In the negative vision, such people are cursed by God or their ancestors, prostitutes (particularly those infected with HIV), bewitched, or a burden. In the positive vision, such people deserve sympathy and empathy. The communities negative feelings were expressed as discrimination, with patients and families getting tired in the process and losing hope; whereas those in the community with a positive view would show love to the end, provide care and become supportive in many ways.

The informants identified locally available resources for the provision of palliative care. This included human resources, such as relatives, society, DHMT and CBHC providers, materials, such as local foodstuffs and local herbs, and infrastructure, such as existing dispensaries and other components of the existing health system in United Republic of Tanzania. The traditional healer had a unique way of looking at these resources, focusing on those used in his rituals and local herbs. A religious leader pointed out that faith is a very important resource. Generally all respondents indicated that some local resources are often available for handling the problems of the terminally ill.

Uganda Country Report

The Uganda Project Team is given in Table U-1. The team consists of 13 members and is representative of all the major institutions participating in palliative care.

Table U-1. Uganda Project Team

Name	Organization	Relevant skills	Role
Dr Jacinto Amandua	Ministry of Health	Commissioner of Clinical Services, consultant physician, health policy formulation and implementation	Team Leader
Dr Betty A.T. Mpeka	Ministry of Health	Public health specialist, Assistant Commissioner in charge of integrated curative services, health policy formulation and implementation.	Vice Team Leader
Dr Esther Aceng	WHO	Public health specialist, WHO desk officer for HIV/AIDS	Member
Dr Banura Cecily	Ministry of Health	Medical doctor, epidemiology, research in cancer, HIV/AIDS	Member
Julia Downing	Mildmay Centre	Nurse, Director Mildmay International Study Centre, palliative care, oncology and HIV/AIDS	Member
Dr A.M. Gakwaya	Ministry of Health	Senior Consultant Surgeon, representing Mulago National Referral Hospital.	Member
Dr J.M. Jagwe	Hospice Africa (Uganda)	Senior advisor in national policy in palliative care	Member (Co-opted)
Dr Ekiria M.N. Kikule	Hospice Africa (Uganda)	Public health specialist, palliative care researcher, Deputy Director Hospice Uganda	Member (Co-opted)
Dr Francis B. Kizito	The AIDS Support Organization (TASO)	HIV/AIDS counsellor	Member
Dr Elizabeth Madraa	ACP/STD/Control Programme, Ministry of Health	Planning, management and implementation, HIV	Member
Dr Anne Merriman	Hospice Uganda	Founder of palliative care, pioneered use of morphine in Uganda	Member
Dr Jospeh Kigula Mugambe	Mulago Hospital	Radiation oncologist, practicing palliative care	Member
Sebisubi Fred Musoke	Ministry of Health	Senior Pharmacist, coordinator of palliative care at MoH, training, drug management and availability	Member

Situation Analysis of the Target Area: Tororo District, Uganda

The Tororo District is located in the eastern part of Uganda approximately 216 km from Kampala. It is bordered on the east by Kenya, on the west by the Iganga District, on the north and northwest by the Mbale and Pallisa Districts, respectively, and on the south by Lake Victoria.

Demographic information

A census in 1991 indicated a population of 306,121 males and 249,453 females. Life expectancy at birth is 44.9 years for males and 49.3 years for females. In 1991, 45% of the population was 14 years or younger and 14.5% was 50 years or older; 88.5% of the population is rural. The most common tribes are the Badama 28%, the Iteso 22% and the Banyole 17%.

Health Status

According to a study on the burden of disease in the district in 1995, the top 10 diseases and conditions are: acute respiratory infections (ARI) with a percentage of total life years lost of 13.4%, AIDS with 12.4%, trauma with 12.4%, measles with 11.6%, tuberculosis with 11.1%, peri-natal deaths with 9.4%, malnutrition with 9%, diarrhoea with 3.6%, malaria with 1.6%, and pregnancy complications with 0.4%.

Information on cancer mortality and incidence is not available in the target area. When a patient is suspected of having cancer, a biopsy is taken, sent to Makerere Medical School for confirmation and classification. Then the results are sent back to the health unit of origin. The time between sending the biopsy and obtaining the results varies, but can take weeks and sometimes months. In the target area, cancer is not yet a public health problem. Since the burden of AIDS is very heavy, AIDS related malignancies are likely to increase in the future.

Most people die of HIV/AIDS at home. Even those who seek health care in health facilities are carried away from health units by relatives to die at home to cut down on the cost of transporting a corpse. Sometimes, this is done against medical advice so the relatives are not properly briefed about palliative care. The HIV/AIDS Surveillance Report indicated 690 cases of AIDS in adults and 20 cases of AIDS in children as of 31 December 2000.

Health System

The Public Health Sector

The District Director of Health Services (DDHS) is in charge of the public health sector in the district. There are health committees at different levels of health delivery, with 9–member committees at the district, sub-county, parish and village levels. The role of these committees is to mobilize communities for health education. In addition to these committees, each health unit has a health unit management committee. A team consisting of district health visitor, health inspector, health educator, and the inspector of drugs supervises the health units.

Health Facilities

According to the Uganda Bureau of Statistics, 2001, the Tororo District has 39 health care facilities excluding drug shops and pharmacies, 3 hospitals, 7 health centres, 11 dispensaries, and 16 sub-dispensaries. The total number of hospital beds both in government and private facilities is 718. In addition, there are 7 private clinics, 52 drug shops and a pharmacy. Most of the private clinics are located in the municipality. According to the Uganda Demographic and Health survey, 49% of the population is within 5 km of a health facility.

In this District there are 15 medical doctors, 1 surgeon, 34 clinical officers, 147 nurse/midwives, 7 dispensers, 7 health inspectors, 25 health assistants, 11 laboratory technologists and 86 nurse aides sponsored by the government. On the nongovernmental side, there is 1 medical doctor, 1 general physician, 1 surgeon, 1 clinical officer, 10 nursing aides, 25 nurse/midwives and 5 other trained health care workers. There are also many traditional healers.

Health Programmes

The target area does not have a specific plan or programme for cancer control. However, health education and improved nutritional habits are on-going activities offered by health workers in both governmental and nongovernmental health facilities. Screening for any cancer is limited to the three large hospitals with specialists. Treatment for cancer is limited to surgery. Otherwise patients are referred to the national referral hospital for radiotherapy or chemotherapy. Palliative care, especially for pain control, is limited. Health workers are not adequately trained in palliative care. In hospitals where health workers have some knowledge about palliative care, drugs for pain control are sometimes out of stock.

The Tororo District has a local specific programme for control of HIV/AIDS. Its goals are to increase awareness and knowledge about HIV/AIDS and other health problems in the community, to create and sustain behaviour change, and to help communities mobilize resources for health. AIDS awareness education, condom promotion and distribution, and prevention counselling are on-going activities at all levels of health care. Screening for HIV is limited to hospitals. In some parts of the district an NGO (AIC) provides the service. The hospitals have no supplies of anti-retroviral drugs although the government is committed to improving access. Treatment for patients with HIV/AIDS is limited to select opportunistic infections based on the availability of drugs. Palliative care services are limited to hospitals. Even then, drugs for pain control are not always available. There are limited services offered by Community Based Organisations CBOs and NGOs but these services do not include the provision of drugs for pain control. Some of the NGOs and CBOs active in the area include:

The AIDS Support Organization (TASO): TASO started in 1990 and is located within Tororo Hospital. On average TASO registers 50 new patients every month. The organization provides treatment, counselling, food, and soft loans to patients to generate income. Patients attend TASO clinics twice a week. In addition, TASO Tororo runs 2 outreach clinics beyond the Tororo District.

AIDS Information Center (AIC), Tororo District: AIC provides HIV counselling and testing services.

Bunyole AIDS Initiative (CBO): The objectives of CBO are to create awareness among people on AIDS, encourage community members to form community AIDS initiatives, and to sensitize community members about the plight of orphans and mobilize resources to take care of orphans.

Needs Assessment: Tororo District, Uganda

Members of the study team for this investigation are: Dr Ekiria Kikule, Principal Investigator and Salim Mabirizi, driver, from Hospice Africa (Uganda); Harriet Mabonga, Branch Manager TASO and field supervisor, Ms Peninah Namisi, facilitator of the focus group discussions, and research assistants, Mr Faustino Angiro, Mr. Vincent Obbo, Ms Tereza Akongo, and Ms Hellen Anyango from the TASO Tororo Branch Team; and the Palliative Care Country Team.

Executive Summary and Recommendations

The main objective of this study was to identify the needs of those dying at home from cancer or AIDS and their families that bear the burden of looking after them, so that appropriate services can be designed. This study was conducted in January and February of 2002 in the Tororo District, which is a rural district in eastern Uganda. It was a descriptive cross-sectional study that used both quantitative and qualitative data collection methods. The district has 4 counties and 21 sub-counties. The two largest counties were purposely selected and sub-counties were selected in the same way. Villages in these sub-counties were selected randomly and so were the households from each of the selected villages. Data were collected from either the household heads or the caregivers at home at the time of the study. Focus group discussions were conducted using already-existing community groups within the District. Key informant interviews were conducted using a church leader, a local council chairman, a traditional healer, and a counsellor.

The quality of health care services in Tororo District is still poor despite the strong presence of government health facilities in the District and utilization of these services by the respondents.

Problems due to terminal illness are prevalent among the respondents in Tororo district, with HIV/AIDS as the most common cause of terminal illness.

The family bears the burden of caring for and supporting the terminally ill. The main needs of the terminally ill at home were identified as pain and other symptom relief, food, provisions for the family, and counselling. Problems of the families nursing the terminally ill at home included money for basic needs in the home such as salt, soap, and antiseptic solutions, nursing a bed-ridden patient, lack of access to health facilities, pain relief for the sick and stigmatization from neighbours. The home and health facility were equally preferred as sites for care of the terminally ill among both the patients and their families.

It was recommended that health services for the terminally ill at home be integrated within the existing health services (curative) and that already existing home-based care programmes in the District, such as TASO, be strengthened to include the control of pain using oral morphine. The recommended palliative care package would include drugs (for pain and other symptom relief, anti-fungals, skin preparations, etc.), food and family support. Income generating activities should also be promoted to increase the family income. A mobilized and sensitized community can play a big part in the sustainability of village health care services.

Background

The Uganda government was the first on the African continent to recognize the danger of HIV to national development and took active steps to fight its spread. The first AIDS cases in Uganda were identified in 1982 in the southern District of Rakai on the shores of Lake Victoria. By 1990, AIDS cases had been reported in almost all the districts of the country. Urban centers along the major road axis were the most affected areas. Infection rates peaked in 1992 with some of the worst hit urban areas registering rates of over 30%. The antenatal prevalence rate was 6.1% in 2000 and was skewed towards the urban areas where the prevalence was 8.7% as compared to 4.2% in rural areas. Heterosexual transmission accounted for 75–80% of the total new infections, mother-to-child transmission including breastfeeding 15–25% and the use of infected blood and blood products and transmission in health care settings 2–4%. The Ministry of Health estimated that 1.44 million people were living with HIV/AIDS in Uganda by the end of 1999. AIDS is currently the leading cause of death among adults and the fourth leading cause of death among the children under five. By itself HIV/AIDS has reduced average life expectancy by about 14 years, to 40 years. It has not only aggravated morbidity and mortality among the population but has affected the work force of families and the country at large.

Uganda’s health status indicators are among the poorest in sub-Saharan Africa. Geographic access to health care is limited to 47% of the population. Only 36% of the staff positions are filled with qualified personnel. Uganda’s current population is estimated to be 22.2 million with over 49% of the population under 15 years of age. The proportion of the population living in absolute poverty (living on less than US $ 1.00 per day) is 44%. In rural areas 34% of the population have no access to health care facilities, compared to only 4% in urban centers.

According to the Ministry of Health’s Annual Health Sector Performance Report for 2000/2001, the Essential Clinical Care Programme aimed at treatment and rehabilitation of patients suffering from communicable and non-communicable illnesses and injuries, includes facilitating access to palliative care for the chronically/terminally ill persons. Oral morphine has arrived in 14 of the 56 districts in Uganda in a pilot project that aims to have morphine available to those who need it throughout Uganda. A statutory instrument is in process, which allows nurses and clinical officers to prescribe morphine. Health sector reforms, including decentralization, have led to administrative and structural changes in the health care delivery system in Uganda. The District Health System is used to deliver a package of health services to the population of Uganda, while the Ministry of Health is responsible for policy formulation, standards and guidelines, overall supervision and monitoring. In addition the Ministry of Health ensures that strategic guidance, technical support and resources are made available to the districts and other health care providers. The referral and other national level health care institutions provide the necessary back up support to the district health care system. However, only 55% of the population in Uganda have access to a health facility within 5 kilometers from the household.

AIDS is an expensive disease. The medicines are costly and patients are unable to work, but still need nutritious foods and medicines. Many Ugandans with AIDS or cancer never get to a health facility because they are too poor or too weak to travel and wait in long queues. Patients who are better off economically tend to live longer and enjoy a better quality of life because they can afford to buy nutritious foods and to pay for medical care and drugs. Conservative estimates are that only 0.5% of the people who need anti-retroviral (ARV) drugs are accessing them from hospitals or clinics because of the cost. The use of ARV drugs is the only treatment strategy currently available worldwide that can control the viral load in these patients and provide a chance for long-term survival. The Ugandan health services on their own cannot possibly cope with the rapidly escalating number of people with AIDS who need medical and nursing care as well as social, psychological and material support. This is why palliative care offers the best alternative for the 99.5% who have no access to ARV drugs as of now. The main objective of this study is to identify the needs of those dying at home from cancer, AIDS or both and the families that bear the burden of looking after them.

Tororo District was chosen for this study because it is relatively undeveloped as far as palliative care services are concerned. In a socio-economic survey done in the District in 2000, it was determined that during their illnesses most people (28%) visited clinics, only 16% managed to visit a hospital (since there are few hospitals within the district), 14% visited dispensaries and 23% did not visit any health institution. For those persons who visited a health institution, in 80% of cases the main reasons cited for this visit were easy accessibility of the health facility from their localities and cost considerations.

The AIDS Support Organization (TASO) provides home care services in the Tororo District for people living with HIV/AIDS. However, these services are only supportive (counselling, patient and family support, orphan care, etc.), as they do not have modern methods of pain management through oral morphine. Hospice Africa (Uganda) working with the government of Uganda and Mildmay International are in the process of introducing these methods through the training of TASO staff in pain management and morphine use.

Study Objectives

The primary objective of this study is to assess the palliative care needs of the terminally ill and their families in rural areas for the purpose of formulating an appropriate palliative care package for the terminally ill at home in rural areas.

Secondary objectives are: i) to determine the size of the problem of the terminally ill and their families in the Tororo District, including the number of patients in need of terminal care, the main problems and needs among them and local resources available to meet these problems and needs, ii) to retrospectively analyze deaths that occurred at home in the 12 months preceding the study to identify the needs of the dying, and iii) to assess the role of traditional healers and traditional medicine as affordable alternatives to orthodox health services and their involvement in palliative care.

Study Design

This was a cross-sectional study using both quantitative and qualitative data. It was conducted in January and February of 2002. This study supplements investigations already completed in other regions of Uganda: the Kampala study (Central Region) and the Hoima Study (Western Region), done in 2000 and 2001 respectively. The target sample size for this study was 100 households. For this study a "household" was the single house and its occupants – sleeping under the same roof, having one head and eating together. The two largest counties, Tororo and Kisoko (West Budama) were selected for this investigation. Similarly, sub-counties were selected within these counties. Villages within the sub-counties were selected randomly. The number of households surveyed from each selected village was proportional to the size of the village (by number of households not geographical area). Data was collected from 102 households.

Preliminary visits to the district were made before the actual study started to sensitize the district authorities about the study and its objectives, and to obtain their cooperation and permission to carry out the study. Recruitment and training of the research field team was also carried out during these preliminary visits. Four research assistants and one supervisor were trained to collect data throughout the selected villages. Another research assistant was trained to conduct the focus group discussions. The questionnaire used for the Tororo District study was a modified version of the one used in the Hoima District. The questionnaire was used to train the research assistants and for field tests before the data collection began.

Focus group discussions involved groups of 6 to 10 individuals who were guided by a facilitator and during which group members talked freely and spontaneously about a given topic. There were 6 separate groups for focus group discussions, three for men and three for women. Participants were selected from groups already existing in the community and included those who either had someone bed-ridden or had lost someone due to a long illness in their family, but had not participated in the questionnaire survey.

The principal researcher carried out the key informant interviews, which included a local council chairman, traditional healer, church leader, opinion leader and counsellor. The data was collected within 7 working days and was analysed by a statistician attached to Makerere University, Kampala, using the EPIINFO 2000 and SPSS computer software programmes.

Results

Characteristics of the 102 respondents in the home questionnaire investigation are summarized in Table U-2. The majority of respondents (77%) were the owners of the homes involved in the study. Over 50% of the population of Tororo District is below the age of 15 years suggesting a high dependence ratio. This places an enormous burden on the productive population of the District to provide for the basic necessities of life. Overall, 4% of the respondents were 20 years of age or less and

16% were over 60 years; 31% were between 31 and 40 years of age. The majority (93%) of the respondents owned the land they lived on, having had the land passed on to them from generation to generation (customary land). Land is the most treasured asset of most of the people, in both rural and urban areas.

About half (52%) of the respondents had a primary education and over a fifth (22%) have never had any education. The status of education in the Tororo District is poor. There are efforts, however, to improve this situation through the Universal Primary Education (UPE) policy. The government of Uganda, through the Ministry

Table U-2. Characteristics of the respondents

Characteristic		Frequency	Percentage
Respondent	Head of household	78	77%
	Caregiver	24	23%
Respondent age[1]	15 to 20 years	4	4%
	21 to 60 years	81	80%
	Over 60 years	16	16%
Gender	Male	49	48%
	Female	53	52%
Marital status	Married[2]	77	75%
	Widowed	19	19%
	Single	6	6%
Tribal group	Atesot	53	52%
	Japadhola	46	45%
	Other	3	3%
Religion	Catholic	63	62%
	Protestant	28	27%
	Other	11	11%
Status on land	Customary land	95	93%
	Own land with title deed	6	6%
	Land leased	1	1%
Level of education	None	22	22%
	Primary	53	52%
	Secondary	22	22%
	Tertiary	4	4%
Occupation	Peasant farmer	75	73%
	Housewife	16	16%
	Formal employment[3]	3	3%
	Other	8	8%
Housing[4]	Semi-permanent house	90	88%
	Permanent house	12	12%
Household water	Bore holes/protected springs	54	53%
	source Other	48	47%
Average household size		7	—

1. One respondent did not indicate their age.
2. Two respondents were separated.
3. Formal employment (e.g. teacher)
4. A semi-permanent house has walls made of mud and wattle with a thatched roof. A permanent house has brick or stone walls and either a tin/iron or tiled roof.

of Education, is working hard to see that this policy succeeds. The respondents were predominantly peasant farmers (73%). In this study, over half the respondents (53%) had access to protected water sources (bore holes and protected springs). The average distance between a household and the nearest water source was one kilometer. The average number of persons in a household in this study was seven.

Common Health Problems Among Families

Whether or not the family had lost someone in the last 12 months or were nursing a bed-ridden person at the time of the study, they were asked to enumerate their health problems as a family. The most common health problems among the families were: malaria (28%), respiratory (chest) infections (23%), family feeding (nutrition) (15%), frequent illness in children (11%), gastrointestinal problems (8%), and, less frequently, skin problems, measles and transport to a health facility. Malaria accounts for 25–40% of all the outpatient visits and 20% of hospital admissions nationwide in Uganda. It is estimated that each malaria attack causes a loss of one working week, and most people suffer from several bouts annually. These results concur with those from focus group discussion where the four most common health problems in the community were identified as malaria, respiratory infections, diarrhoeal diseases and HIV/AIDS. Frequent sickness in the family, crop failure and lack of energy to grow more food were cited as factors contributing to household poverty in the socio-economic survey done in Tororo District in 2000.

Funerals Attended

Even families that had neither lost someone nor were nursing someone with a chronic illness had spent time attending funerals in their villages. Table U-3 reports the numbers of funerals attended by respondents in the 12 months preceding the study. Overall, 69% of the respondents reported attending more than 7 funerals. The main cause of death at these funerals was HIV/AIDS that accounted for 68% of the deaths. In 22% of cases the respondents were not sure of the causes of death. Cancer was cited as a cause of death in 1% of cases. Other causes of death included diarrhoea, measles, malaria and suicide.

Table U-3. Funerals attended by respondents

Number of funerals	Percentage
Over seven	69%
Four to seven	11%
One to three	19%
None	1%

Health Facilities

The health facilities used by the respondents are shown Table U-4. The majority of respondents (79%) lived nearest to a dispensary. Most of the health facilities (89%) used by the respondents in the study were owned by the government. WHO has recommended a minimum level expenditure of US $12.00 per person for health care. In Uganda the total per capita health expenditure ranges between US $7.00 and US $12.00 with only US $3.95 attributed to government and donor spending. The balance comes out of individual pocket payments. The allocation of available resources in the health sector is also inefficient, with more than 63% of the recurrent budget and 54% of trained staff concentrated in hospitals.

Families that had neither lost someone nor were nursing someone with a chronic illness were asked to indicate where they normally went for treatment. Overall, 83% reported going to a nearby government facility and 12% went to a nearby private clinic. One indicated buying drugs from a drug shop and one went first to a nearby

Table U-4. Health facility use by category

Category of Health Facility	Frequency	Percentage
Health Center II – Dispensary	81	79%
Health Center III – Health center with maternity services	10	10%
Health Center IV – Sub-district level health center, serving about 100,000 people	2	2%
Hospital	9	9%

traditional healer. Those buying drugs from drug shops were self-diagnosed and self-treated (no qualified health worker involved). Participants in the focus group discussions felt that by the time the sick go to health facilities for treatment they would have been to traditional healers first.

The distance between the household and a vehicle accessible road varied from less than a kilometer to 16 kilometers, with an average distance of 3 kilometers. The average distance from the household to the nearest health facility was also 3 kilometers. All households within a distance of 5 kilometers from a health facility have been categorized as having access to health care services. Although proximity to a health facility is a good indicator of availability of health services, it does not reveal much about utilization because cost sharing prevents the poor from accessing these health facilities. Also lack of drugs in the health facilities discourages people from attending these facilities. As of 1996, 55% of the Ugandan population had access to a health facility within 5 kilometers.

Respondents who had lost someone after a long illness were asked whether the deceased had attended a health facility during the course of their illness. Although the deceased died at home, 93% of them (14 of 15) had attended a healthy facility during the course of their illness. When these 14 respondents were asked whether the deceased received the treatment they needed at the health facility, 36% indicated yes, 57% indicated sometimes, and 7% indicated no. Of these 14 respondents, one (7%) indicated that the treatment available to the deceased was free, 12 (86%) indicated that they paid for the treatment, and one (7%) was unsure. Sustainable cost sharing is not yet possible because 44% of the population of Uganda live in absolute poverty (earning less than US $7.00 per week) and are therefore unable to meet their basic needs. Hospice Africa (Uganda) estimates that it costs 14,000 Uganda Shillings (USh) per week to care for a patient (approximately US $8.00). The patient is asked to contribute 5,000 USh out of the needed 14,000 USh per week towards the cost of their consultation, transport and medications. Only 40% can afford to pay this subsidized fee. Focus group discussions revealed that even traditional healers could be costly in their services as they charge their fees in cash or kind. This forces the family to sell their property in order to meet the traditional healer’s fees.

The fourteen respondents who had a bed-ridden patient at the time of the study were asked where they went when the patient’s condition worsened. Some respondents indicated more than one place. Of the 33 places where help was sought, 58% were the curative services (a nearby health facility or nurse), 24% tried to cope on their own, and 9% went to a nearby herbalist. While 1% of the respondents sought treatment from traditional healers, 3% turned to them during emergencies when the patients’ condition worsened.

When asked what health services they would want to see introduced in their villages and how they thought these services could be sustained, respondents indicated that they wanted a functioning health facility (48%), sanitation services (19%), access to affordable drugs (15%), and, less frequently, mobile health clinics, access to food, health education and TASO-like services. Respondents in 68% of cases looked to the community for cost sharing, rather than the government, as the primary source of funding to sustain the village health services. They felt that if the communities are adequately sensitized they could contribute money and choose village health committees to run the health services in a sustainable manner. Participants in focus group discussions felt that contributions in the range of 200 to 500 USh per person were affordable by the community. The government was considered the primary source of sustainability by 24% of respondents.

Prevalence of Terminal Illness

Each household head or caregiver was asked whether they had lost someone due to a long illness in the last 12 months prior to the study, or whether there was someone bed-ridden in the house at the time of the study. Their responses are summarized in Table U-5. Overall, 29% of the respondents either lost someone in the last 12 months prior to the time of study or were nursing a bed-ridden person with a terminal illness at the time of the study. In addition 2% had both lost someone and were also nursing a bed-ridden person at the time of the study. Assuming the sample of households was entirely random, the above information can be used to roughly estimate the palliative care need of the community. During a given year about 29% of the households in this District will need at least some level of palliative care services. Using the average household size of 7 individuals, it can be estimated that palliative care services would be needed by about 4% (29%/7) of the population each year, or 1 in every 24 individuals.

Table U-5. Distribution of household illness severity

Household illness severity	Frequency	Percentage
Had lost someone within the last 12 months*	14	14%
Were nursing a bed-ridden patient at time of study*	15	15%
Had neither lost someone nor had a bed-ridden patient	73	74%

* Two households had both lost someone within the last 12 months and were also currently nursing a bed-ridden patient.

Households that have a family member with AIDS suffer a dramatic decrease in income. Decreased income inevitably means fewer purchases and savings. As infected farmers become increasingly ill, they and the family members looking after them spend less and less time working on the family crops. The family begins to lose income from un-marketed or incompletely tended crops, has to buy food it normally grows for itself, and may even have to sell off the farm or household goods to survive.

The distribution of the diagnoses among the patients (deceased or bed-ridden) is shown in Table U-6. The most common cause of morbidity and death among the respondents was HIV/AIDS, (29%, among the deceased and 40% among the bed-ridden). A considerable proportion (28%) of the respondents did not know the diagnosis of the deceased or those they were nursing. The diagnoses shown in Table U-6 are those given by the respondents at the time of data collection. There was no independent verification of the diagnosis since the study was carried out at the household level. It was reported that 59% of these conditions were diagnosed in a health facility and in 17% of the cases the family “saw the signs and symptoms”.

Table U-6. Diagnoses of the patients (bed-ridden and deceased)

Diagnosis	Deceased	Bed-ridden	Total
HIV/AIDS	4 (29%)	6 (40%)	10 (34%)
Cancer	1 (7%)	1 (7%)	2 (7%)
Tuberculosis	2 (14%)	4 (26%)	6 (21%)
Never knew/ We do not know	5 (36%)	3 (20%)	8 (28%)
Other	2 (14%)	1 (7%)	3 (10%)
Total	14	15	29 (100%)

Burden on the family

Respondents were asked how long the deceased were bed-ridden before death or for how long those who had been ill at the time of the study had been bed-ridden. The distribution of the duration of this period is shown in Table U-7. For the majority of bed-ridden patients (60%), the family spent more than 3 months nursing those who were sick.

Table U-7. Duration of illness among the bed-ridden and deceased

Duration	Bed-ridden	Deceased	Total
1 – 4 weeks	3 (20%)	3 (21%)	6 (21%)
5 weeks – 3 months	3 (20%)	4 (27%)	7 (24%)
Over 3 months	9 (60%)	7 (50%)	16 (55%)
Total	15 (52%)	14 (48%)	29 (100%)

Time lost by family members must also be taken into account. A study in the rural Bukoba District of the United Republic of Tanzania found a dramatic change in the allocation of labour time; a woman with a sick husband spent 60% less time on agricultural activities than she would normally do otherwise. In this Tororo District study, 97% of those with a terminal illness (bed-ridden or deceased) were looked after in their own homes. In 3% of the cases the bed-ridden or deceased had been brought to the village for care. When family members in urban areas fall ill they often return to their villages to be cared for by their families, thus adding to the drain of scarce resources and increasing the probability that a spouse or others in the rural community will be infected.

Families make great sacrifices to provide treatment, relief and comfort for another family member who is sick. For the 29 families with a bed-ridden or deceased family member, the caregiver was the mother 38% of the time, the spouse 24% of the time, a child 24% of the time, and other (e.g. sibling, co-wife, or no particular carer) 14% of the time.

Those who were nursing bed-ridden patients at the time of the study and those who had lost someone within 12 months prior to the time of the study were asked to enumerate the problems they were facing or had faced as they nursed the sick/dying. The problems identified were money (to feed the patient/healthcare/drugs) – 50%, nursing a bed-ridden patient – 17%, health facilities (or doctors or nurses) too far away – 13%, not knowing how to ease the pain – 12%, stigma (our neighbours shunned us) – 7%, and other (e.g. emotional stress) – 1%.

In a study done by the AIDS Control Programme (ACP) of the Ministry of Health, The Institute of Public Health of Makerere University and The AIDS Support

Organization (TASO), money also featured prominently among family needs. The money would go into buying bedding and foodstuffs. Caregivers also needed petty cash for buying protective clothing such as gloves, disinfectants, paraffin and soap for both washing and bathing.

The problem of nursing a bed-ridden patient included: dealing with the patient's changing moods, keeping the patient clean (changing the bedding frequently due to diarrhoea), the patient refusing to eat, the patient completely dependent on carer, and persistent diarrhoea. Pain was cited as a problem for the family in 12% of cases. Focus group discussions emphasized that if families had money and access to adequate health care, pain and other symptoms such as persistent diarrhoea would not be a problem. Knowing that the patient had an incurable disease caused emotional stress in some families as they felt they were spending much needed resources to buy drugs for someone who was not going to get well.

The families received help from various sources during the time they nursed the sick. The sources specified were relatives (extended family) – 57%, family (nuclear) – 36%, and TASO – 7%. According to the respondents in this study there were two main areas of expenditure, namely health care (drugs, treatment) and food. It was difficult to verify the cost of looking after the sick person since money came in from many sources and some of the necessities such as drugs and food came in in-kind. A conservative average estimate given by the respondents was between 300,000 USh and 1,000,000 USh (US $167.00 – $550.00).

Respondents were asked if there was anything more they would have wanted to do for the deceased. They specified better health facilities (including adequate treatment and affordable drugs) – 79%, better access to health care (health facilities and drugs) – 14%, and more patient support (including feeding and counselling) – 7%. The majority of respondents (79%) would have wanted to see the deceased receive better health care than what was available at the time of death.

Needs of the terminally ill

The respondents were asked to indicate the needs of their relatives, both the bed-ridden and the deceased in the course their illness. Respondents were permitted to indicate more than one need. These are shown in Table U-8.

Table U-8. Needs of the terminally ill (bed-ridden and deceased)

Identified need	Frequency	Percentage
Pain relief	18	23%
Food	15	19%
Relief of other symptoms	14	18%
Provisions for the family	11	14%
Counselling	10	13%
All of the above needs	8	10%
Other	2	3%
Total	78	100%

The three major needs among the bed-ridden and deceased during the time of their illness were relief of pain and other symptoms (41%), food, (19%) and family provisions (14%). However, pain relief was cited as the fourth most common problem for the families as they looked after the deceased. Pain is subjective and is what the patient says it is, not what others think it should be. Pain is a symptom also commonly experienced by people with HIV infection and its prevalence increases as the disease progress. In HIV disease the common pain syndromes involve the gastrointestinal tract (particularly odynophagia and abdominal pain), the nervous system (both central and peripheral), and those involving the joints and muscle. Merriman estimated that 25% of HIV/AIDS patients suffer from pain during the course their illness. Some studies done in Kampala in 1990 have put this percentage as high as 60%.

The needs of the terminally ill were also identified during the focus group discussions. They were i) food, ii) medical care (treatment), iii) counselling, iv) comfort/care/support, v) bedding and clothing, and vi) shelter.

Some of these needs were being met for the bed-ridden or had been met in the case of the deceased. Overall, 24% indicated that pain was relieved, 20% indicated that food was provided, and 18% indicated that other symptoms were relieved, but not pain. However, 32% indicated that none of the needs were met. The problem of food was indicated as solved only among those who had lost someone. The needs that were met were met by the children (33%), the spouse (24%), an NGO (19%), the parents (14%) and the relatives (10%). The family bore the brunt of looking after the terminally ill. Less than 20% of the needs were met by sources outside the family or the extended family.

The key informants identified some local resources that could be used to help the terminally ill. These included locally grown food that can be shared with the families affected, local herbs that can be identified for treatment, and existing health facilities that can be equipped to handle the terminally ill. During focus group discussions ways were identified in which the community could help in the care of those with incurable diseases. The sick and their families could be encouraged and counselled, including encouraged to seek help, provided with necessary information, social interactions could be initiated to reduce stigma, and community members could pray with the sick. The community could get involved in caring for the sick by assisting to take the patient to and from the health facility, helping the family with food, helping provide the basic needs (e.g. soap, paraffin, salt), and keeping the patient company when the carer is away.

There is evidence to show that community care and support initiatives can relieve health care services from the large patient burdens, while mitigating the impact of HIV illness and death on the people with HIV and their families. The interdisciplinary care offered to patients can be beneficial to both patients and their family caregivers. Even without anti-retroviral treatment, care of an HIV/AIDS patient can improve their quality of life.

Respondents were asked where the bed-ridden persons preferred to be looked after. Overall, 47% indicated they would be preferred to be cared for in their home, 47% preferred care in a health facility and 6% preferred care in Kampala. Reasons for preferring to be cared for at home include that the health services are too expensive, health services are too far to access, and there is a lot of family support for care at home. Reasons for preferring to be cared for in a hospital include access to qualified health workers, access to drugs and other health care, avoiding stigmatisation by the neighbours, and preventing spread of the disease among the family.

How Governments Can Help

Participants in focus group discussions made suggestions as to how the government can assist the terminally ill and their families. They suggested services to those at home, including the rehabilitation and equipping of health facilities in the villages, making drugs available and free (or at least affordable), and facilitating home care programmes to carry out home visits. They proposed assistance to the affected families, including community sensitization and health education to reduce stigma, exempting the sick from graduated tax (because they are no longer working), providing orphan care and support (Universal Primary Education), and providing income generating activities to generate money for basics, such as soap, paraffin and salt.

Traditional Healers

Respondents were asked whether they visited traditional healers during the time they cared for the terminally ill (both the deceased and the bed-ridden). Only 24% (7) had sought traditional healers. Similar studies in urban areas indicated that 35% of the patients used both traditional herbs and western medicines and 1% used only traditional herbs. Participants during group discussions also indicated that consulting traditional healers is one of the community's first coping mechanisms when facing a terminal illness in the family.

Respondents indicated the reasons for seeking help from traditional healers. These included the patient was bewitched (67%), western medicine did not help (11%), traditional herbs were affordable (11%), and recommendations from neighbours (11%). Traditional healers were reported to have helped the sick by the control of pain (13%), the control of other symptoms (25%), and maintenance of appetite (13%). However 50% of the time it was reported that the traditional healers were not helpful.

Zimbabwe Country Report

Table Z-1 gives the Project Team in 2002 for Zimbabwe. The team consists of eight individuals, five from the Ministry of Health and Child Welfare, two from Island Hospice, and one from the University of Zimbabwe.

Table Z-1. Zimbabwe Project Team

Name	Organization	Relevant skills	Role
Mrs Violet Machekano	Ministry of Health and Child Welfare	Community nursing, public health specialist	Team Leader
Ms C M Z Chasokela	Ministry of Health and Child Welfare	Public health specialist	Vice Team Leader
Dr Margaret Borok	University of Zimbabwe	Medical doctor	Member
Mrs Eunice Garanganga	Island Hospice	Palliative care nurse	Member
Ms Cecilia Machena	Ministry of Health and Child Welfare	Community health nurse	Member
Ms Sambulo Mkwananzi	Island Hospice	Training manager	Member
Ms Julieth Musengi	Ministry of Health and Child Welfare	Health promotion officer	Member
Mrs Jane Lilian Muteiwa	Ministry of Health and Child Welfare	Health Promotion officer	Member

Situation Analysis of the Target Area: Goromonzi District

Zimbabwe is a landlocked country in southern Africa, bordered by South Africa to the south, Mozambique to the east, Zambia to the northwest and Botswana to the southwest. It is divided into 10 provinces, including cities for administrative purposes. These are further divided into 58 districts. The Goromonzi District was selected to be the target area for this project. It is a rural area just northeast of Harare, Zimbabwe's capital.

Demographic Information

The population of the Goromonzi District is about 277,900. About 57% of the population are less than 15 years of age and 6.5% are 50 years of age or older. Life expectancy at birth in Zimbabwe was 52.6 years for males and 57.2 years for females in 1995. In 1988 life expectancy was 61 for males and 63 for females. This decrease in life expectancy is probably due to the HIV/AIDS epidemic.

Health Status

The most common causes of morbidity in the Goromonzi District are tuberculosis and immuno-suppressive disease in adults and acute respiratory infections in children. The major causes of death in hospitals in Zimbabwe for all ages according to the National Health Profile of 1999 were pulmonary tuberculosis, HIV/AIDS, acute respiratory infections, malaria and perinatal conditions. The frequency of cancer and HIV/AIDS in Zimbabwe are gradually increasing. It is estimated that there are between 6,000 and 7,000 new cases of cancer each year. Currently about 10% of all deaths in the country are attributed to cancer. It is estimated that 35% of the population of Zimbabwe is HIV positive and there are about 2,100 new cases each week.

In the Goromonzi District most people with cancer die at home because they will be on home-based care. Of those who die from HIV/AIDS, about half die at home and half die in a hospital.

The most common cancers in the Goromonzi District are cancer of the cervix in women and Kaposi's sarcoma and liver cancer in men. Overall in Zimbabwean Black persons the most common cancers in women are cervical cancer (28%), Kaposi's sarcoma (20%) and breast cancer (9%) and in men are Kaposi's sarcoma (41%), prostate cancer (8%) and cancer of the oesophagus (6%). Over 60% of cervical cancer patients treated at the Radiotherapy Centre present with stage 3 or more severe disease. Less than 5% present with stage 1 disease. Late presentation is very common in cancer patients. Some have passed through a lengthy referral system without a definitive diagnosis and some present with late disease because of poor socio-economic background, ethnic beliefs, or lack of awareness of both the patient and primary health care worker. The problem is also compounded by a shortage of trained staff in the rural areas, the source of the majority of cancer patients.

Health System

The Public Health Sector

In Zimbabwe the health services are organized into four graded levels of care, which are the central, provincial, district and rural health centre levels. Each level engages in an appropriate mix of promotive, preventive and curative activities with the higher levels providing support supervision and referral facilities for levels below. In order to ensure political and community input and multi-sectoral collaboration, each of these levels has links with the corresponding structures in the socio-political system.

Health Facilities

In the Goromonzi District the government funds a district hospital, a rural hospital and two rural health centres. Local authorities support thirteen rural health centres. One Roman Catholic Mission, one private clinic and three school clinics provide additional health services. There are 3 medical doctors, 66 nurse/midwives and 44 auxiliary nurses/nurse aides in this District.

Health Programmes

There is no plan for the control of cancer in the Goromonzi District beyond the national programme. The Ministry of Health and Child Welfare has a 10-year national plan for the control of cancer. This plan focuses on cervical cancer, liver cancer, tobacco-related cancers, bladder cancer, skin cancer, and alcohol and diet-related cancers. Programme goals are to reduce the incidence, prevalence and mortality due to cancer, to promote early detection and referral, to provide effective and relevant therapy, and to provide relevant training to health service providers. The strategies for controlling cancer in Zimbabwe include public health screening (e.g. cancer of the cervix or breast), public health education, equipment, palliative care modules for enhancing the quality of life, and the incorporation of cancer control into other existing disease control programmes. Cancer treatment facilities are centralized to Harare and Bulawayo. Long distances, transport costs and insufficient overnight accommodation limit the access of rural Zimbabweans to the two treatment centres. Overcrowding, long waits, and broken down radiotherapy equipment also present a problem. Cancer services are financed by the Government of Zimbabwe and nongovernmental organizations, such as the Cancer Association.

The Ministry of Health and Child Welfare is involved in the provision of palliative care through services provided by Parirenyatwa Hospital, Mpilo Hospital, Harare Hospital, and Zororo Hostel. The Island Hospice and Cancer Center are non-governmental, charity-based private institutions that provide palliative care services. Other private units, such as the Mashambanzou Palliative Care Unit In Waterfalls, Harare also provide palliative care to patients.

The referral pattern for patients with cancer moves from the community (village health worker – providing health education and palliative care), to the primary level (rural health centre – providing health education), to the secondary level (district hospital – providing screening for pre-cancerous lesions) to the tertiary level (provincial hospital – providing referral to the central hospital) to the fourth level (central hospital – providing radiotherapy, chemotherapy and surgery). There is a forty-bed hostel for ambulatory cancer patients at Harare Central Hospital, which is administered by the Cancer Association (Zororo Hostel).

There is no specific plan for HIV/AIDS in the Goromonzi District beyond the national plan. Zimbabwe has a national HIV/AIDS “strategic framework” that focuses mainly on the i) prevention of transmission, control of the spread, care and impact mitigation of HIV/AIDS/STI/TB with voluntary counselling and testing as a strategy, ii) care through the hospital and its referral system to the community home-based care, which is shared by the family and community caregivers, with the help of government and nongovernmental organizations, iii) prevention of parent to child transmission, and iv) information, education and communication strategies to reach specific target groups. Essential drugs for some opportunistic infections are accessible and affordable.

Palliative Care

Palliative care was started in Zimbabwe in 1979 by Island Hospice, a nongovernmental organization, serving patients and families within Harare. In 1990 WHO published the report of an expert meeting on palliative care. Two years later government doctors and other interested groups formed the Prevention and Control of Cancer Committee in Zimbabwe. In 1994 the first post of a Programme Officer for Cancer and Palliative Care was filled. It was funded by WHO. During this period eight provinces and two cities (Harare and Bulawayo) established multidisciplinary palliative care training. A total of 317 professionals, including 19 doctors, were trained in palliative care by Island Hospice in collaboration with the Ministry of Health and Child Welfare. The aim in the Ten-Year Plan (1994–2004) was to have health care personnel trained in palliative care in each provincial hospital. Unfortunately funding ran out.

Nurses in Zimbabwe constitute about 80% of the health care work force. In most hospitals and rural health centres the nurse is the health care provider that comes into contact with the patient. Since the bulk of the patients suffering from cancer or HIV/AIDS are in the rural areas, nurses need to be equipped with the knowledge, skills and attitude to provide palliative care when needed. At present Island Hospice does the only training in palliative care.

Many patients are not receiving palliative care due to a shortage of health care staff. There has been an exodus of health care workers. The major strength of the palliative care activities is the training programme, which has been strong since the programme started. Major weaknesses are a lack of resources and equipment, including drugs and basic materials. Distribution of narcotic drugs for pain relief is erratic and inconsistent. The costs are beyond the income of many patients. All too often staff burn out and a lack of coordination of the programme contributes to poor service delivery.

Needs Assessment: Goromonzi District, Zimbabwe

Executive Summary

A structured questionnaire was used to interview caregivers at home regarding the needs of terminally ill patients. In 44 cases the individual had cared for someone who died within the past 6 months. Nearly all of these caregivers (96%) were related to the patient. The greatest needs of the patients, as specified by the caregivers, were drugs for the relief of pain, drugs for the relief of other symptoms, the inability of the patient to look after themselves, and food. The most common problem for the family was the scarcity of resources for food and drugs. When asked where they sought assistance to meet these needs, most of the caregivers indicated they sought help from the family (68%) or from the church (23%).

In 45 cases the caregiver was caring for someone terminally ill at the time of the interview. The caregiver was most often the patient's relative (49%), spouse (27%) or child (16%). The priority problem expressed by the patient was the relief of pain (29%), relief of other symptoms (22%), food (27%) or drugs (9%). The majority of patients (69%) indicated that their problems centred on money to buy food, drugs, and other home-based care supplies. When asked to indicate the major effects of their illness on the family, 58% specified that it led to a lack of resources, 44% specified it led to a termination of employment and 29% indicated it led to a neglect of children's welfare.

Background

The risk of discrimination and stigmatisation associated with HIV/AIDS is high. This is encountered in many spheres of life and comes from both the family and the community. Often information regarding a partner's HIV status may not be shared for fear of stigmatisation and isolation. Information is given to the public to try to reduce the discrimination against people living with HIV/AIDS.

During 2002, severe economic difficulties were experienced in Zimbabwe for a variety of reasons. Food shortages are one of the results of these problems.

Study Objective

The purpose of this study was to investigate the needs of terminally ill patients, their family and their caregivers to help develop palliative care programmes to meet these needs.

Study Design

A total of 100 caregivers were interviewed at home in the Goromonzi District by trained investigators using the standardized questionnaire. Of these 100 caregivers, 44 had cared for someone who died within the past 6 months and 45 were caring for someone terminally ill at the time of the interview. Some of the terminally ill patients who were able to speak were also interviewed.

Results

The demographic characteristics of all 100 caregivers are given in Table Z-2. The age range of the caregivers was 17 to 80 years. The mean age was 48.5 years. The majority of the caregivers were female (73%), married (65%), Christian (92%) and were either the head of the household (50%) or a family member (31%). The average distance to the nearest health facility was 4.9 kms. Nearly always this was either a district hospital (24%) or rural health centre/clinic (75%) and was a government funded health facility (municipal/local government or national government funded).

Of the 100 caregivers, 59 indicated that they had previously sought out a health service for their terminally ill patient. Of these 59 responses, 88% indicated that they sought out orthodox health services, 7% indicated they sought out a traditional healer, and 5% indicated they sought out a faith healer. However, the figure for

Table Z-2. Characteristics of the caregivers and the residence

Characteristic		Frequency
Gender	Male	27
	Female	73
Marital	Status Single	9
	Married	65
	Widowed	19
	Separated/divorced/unknown	7
Religion	Christian	92
	Muslim	1
	Traditionalist	3
	Other	4
Role within family	Head of household	50
	Family member	31
	Volunteer caregiver	14
	Other	5
Residency status	Home owner	65
	Living with relatives	25
	Tenant/other	10
Rooms occupied	One	10
	Two	19
	Three and above	71
Drinking water	Tap water within house	9
	Communal tap	2
	Borehole/protected well	75
	Unprotected source	14
Toilet facility	Own flush	5
	Blair toilet	51
	Bush	13
	Other	31
Energy source	Electricity	10
	Wood	79
	Paraffin	11
Nearest health facility	District hospital	24
	Rural health centre	75
	Nursing home	1
Sponsor of nearest health facility	Government	43
	Municipal/local government	55
	Private or mission	2
Distance from nearest health facility (mean, in kms)		4.9
Distance from vehicle accessible road (mean, in kms)		5.4

traditional healers may be an underestimate since this information may be withheld at the first interview. The mean length of illness for the terminally ill patients was 11.6 months.

Deaths Within the Past 6 Months

Of the 100 caregivers, 44 had cared for someone who died within the past 6 months. The duration of care was less than a week for 18%, 1 to 4 weeks for 14%, between 4 weeks and one year for 43%, and more than one year for 25%. Of the 44 respondents interviewed, 42 (95%) were related to the patient. Overall, 27 (61%) of the patients were being cared for in their own homes, while 17 (39%) were cared for in other homes. These patients had been moved for a variety of reasons. Some were moved closer to their family burial grounds, some found it cheaper to care for them where they had been moved to, while for others it was more convenient for the caregiver. The patient's preference of place of health care (according to the caregivers) was here at this home (27%), his rural home (27%), in a hospital (32%), does not mind where (7%), or other (7%). Patients were cared for by a husband/wife (27%), relative (43%), child (14%), volunteers (5%) or a combination of the above.

When the caregivers were asked to indicate the disease the patient suffered from, they indicated HIV/AIDS (40%), cancer (5%), bewitched (16%) or other (39%). The caregiver's source of information regarding the nature of illness was a doctor (34%), a nurse (5%), they made their own conclusion (39%), a traditional healer (9%), or other (14%).

The problems faced by the family during the home care, as expressed by the caregiver, are given in table Z-3. Multiple responses were permitted. The table presents the proportion of the caregivers that mentioned each problem. By far the most common problem was a scarcity of funds for food, drugs and other items needed by the family (86%). The next most common problem mentioned was the pain experienced by the patient (36%).

Table Z-3. Problems faced by the family

Problem	Frequency	Percentage
Scarcity of resources for food and drugs	38	86%
Pain experienced by patient	16	36%
Lack of support by health care workers	14	32%
Bed-ridden patient	14	32%
Non-availability of care resources	9	20%
No time for other chores	6	14%

The caregivers were asked to indicate the patient's area of greatest need. Table Z-4 presents the results. Multiple responses were permitted, so this table indicates the proportion of the caregivers that mentioned each need. The most frequently mentioned needs were drugs for the relief of pain, drugs for the relief of other symptoms, an inability of the patient to look after themselves, and food.

When asked where they sought assistance to meet these needs, 68% indicated they sought help from the family, while 23% turned to the church. The health and support institutions mentioned as providing the most help included the public health

Table Z-4. Patient's area of greatest need – expressed by the caregiver

Problem	Frequency	Percentage
Drugs for relief of pain and other symptoms	26	59%
Drugs for relief of other symptoms	22	50%
Inability to look after self	22	50%
Food	21	48%
Counselling	4	9%
Transport	4	9%
Other	5	11%

services (46%), faith healers (14%), church support services (9%), home-based care services (9%), private health services (7%), or traditional healer (5%).

Virtually all (98%) of the patients had attended a health facility at least once before they died. Of these, 83% had received treatment as they required. The rest did not for several reasons. Some failed to raise the money need for the review, x-rays and drugs. One found the drugs out of stock, although they had the money for the purchase. Treatment for 67% of the patients was at the council clinic and was provided free of charge. Of the caregivers who were able to estimate how much they had spent on caring for the sick patient, they indicated their areas of large expenditures were food (61%), medical fees (50%), and children's welfare (41%). When asked which of their patient's needs were met, the caregivers indicated food (84%), drugs (71%), relief of pain (65%), transport (45%) and counselling (27%).

Caregivers were asked whether or not they had sought the services of a traditional healer. Out of 43 who responded, 5 (12%) admitted that they had. The reason they sought the traditional healer was that they had been told their patient was bewitched.

Patients Terminally Ill at the Time of the Interview

Of the 100 caregivers, 45 were caring for someone terminally ill at the time of the interview. When the patient was able to speak, they were interviewed. The majority of the patients were female (60%). Most had a primary education (49%) or a secondary education (33%). Only 11% of the patients had no education. About half of the patients (47%) stated they were unemployed, which probably reflects limitations due to their illness. Of the patients interviewed, 32 (71%) were currently able to do activities of daily living for themselves. The majority (67%) had an income of less than 5,000 Zimbabwean dollars, while 24% had an income of more than 14,000 Zimbabwean dollars. Informal sources of income included gardening and farming (27%) and an adult working child (4%).

When asked to specify their illness, most patients responded tuberculosis (27%) or HIV/AIDS (18%). However, 4% indicated they were bewitched, while 22% did not know their illness. The majority of patients (78%) were being looked after in their usual place of residence. When asked where they would prefer to be looked after during illness, 53% indicated at their present home, 31% indicated in a hospital, 9% indicated in a nursing home, 4% indicated in town and 2% had no preference.

The primary caregiver was most often the patient's relative (49%), spouse (27%) or child (16%). The "priority problem" expressed by the patients was the relief of pain for 30%, relief of other symptoms for 23%, food for 27%, drugs for 9%, an inability to look after self for 7%, counselling for 2% and transport for 2%. Of the 45 patients interviewed, the majority (69%) indicated that their problems centred on money to buy food, drugs and other home-based care supplies. The need that was met for most (96%) was food.

If their condition deteriorated, they would seek help at the rural health centre (78%), at their original rural home (16%), or from a village health worker (4%). One (2%) out of the 45 respondents had sought the services of a traditional healer. Assistance involved the control of pain, management of diarrhoea, and some relief of herpes zoster.

The patients were asked to indicate the effects of their illness on the family. Multiple responses were permitted. Overall, 58% indicated that it led to a lack of resources, 44% indicated it led to a termination of employment, 29% indicated it led to a neglect of children's welfare, and 20% indicated it led to fear.

Homes With No Deaths Within 6 Months and No Terminally Ill Patients

Forty-five individuals were interviewed who had no death at home within the past 6 months and no terminally ill patient at home at the time of the study. They were interviewed to determine their knowledge about long-term and terminal illness, particularly HIV/AIDS and cancer.

The common health problems they observed were coughs and colds (73%), malaria (24%), HIV/AIDS (20%), skin rashes (20%), headaches (11%), sick children (9%), nutritional problems (9%), diarrhoea (7%), tuberculosis (7%), cancer (4%) and other (16%). The sick were most often treated at a nearby clinic (93%). None specified a visit from a home-based caregiver, indicating the lack of such a service in this District.

Funerals Attended

Table Z-5 gives the numbers of funerals attended by respondents in the previous 12 months. More than half have attended more than seven funerals in the previous 12 months. The main perceived causes of death at these funerals were HIV/AIDS (67%), witchcraft (11%), and malaria (7%). The majority of the deceased (93%) were residents of the community.

Table Z-5. Funerals attended by respondents

Number of funerals	Percentage
Over seven	53%
Four to seven	13%
One to three	27%
None	7%

The group felt to be most affected by HIV/AIDS was men and women between 20 and 49 years of age. Eleven of the 45 respondents reported that they had looked after a terminally ill patient before. Seven of them indicated that their major challenge was the relief of pain, and the other four specified that their greatest challenge was the relief of other symptoms. When asked to indicate their knowledge regarding the prevention of cross-infection with HIV during home-based care, 74% indicated the use of gloves, 13% indicated the use of a disinfectant. 13% indicated the use of protective clothing, and 17% indicated the use of separate clothing and utensils for the patients.

PART III

Appendices

APPENDIX A

Situation Analysis Guide*

I. Introduction

Why do a situational analysis?

The situation analysis answers the question: Where are we now? It provides the information required to identify the major problems and gaps that constitute the foundation for the planning, implementation, and evaluation phases of the project. Through the situation analysis, the teams will assess the current epidemiological status of cancer and HIV/AIDS and the country response to control these diseases – with particular emphasis on the palliative care component at the national level and in the districts targeted by the project.

How to do a situation analysis

A situation analysis can be broken down into the following 5 phases.

1. Action plan for the situational analysis

The first step is for the team to review the whole guide during a team meeting and decide which information is needed, if the needed information exists, where it is, and how to collect it. If the requested information is not available in documents and it is very difficult to gather, the project team should try to answer the question with the best estimate possible, combining the professional experiences of the team members. In this case, the idea is to provide the best estimate, assumption, judgement or opinion produced by the group during working meetings. Be balanced and unbiased and identify areas of uncertainty.

2. Gather information from documents, interviews, and field research

There are international sources of information that can be useful, such as WHO, World Bank, and UNAIDS. Also there are probably national and local information sources, governmental as well as non-governmental. Include the date of the information and try to gather the most recent information. Much of the information collected does not change radically over time; if it is kept on file in team project institutions, it can be updated quickly and easily in subsequent review and planning rounds.

3. Apply critical thinking to the collected information and analyse the data collected

If you need more information about critical thinking there are excellent articles about it on the website Center for Critical Thinking. Library articles: Universal Intellectual Standards: The Elements of Critical Thinking; Intellectual Traits http://www.criticalthinking.org/University/univlibdir.html.

Appraise the quality of the collected information by adding a “quality of information” score.

4. Produce the report

Responses to the questions should be consolidated in the report stored on a computer – to facilitate updates. References should be numbered consecutively in the order in which they are first mentioned in the text according to the Uniform Requirements for Manuscripts Submitted to Biomedical Journals, updated October 2001 by the International Committee of Medical Journal Editors. http://www.icmje.org/

5. Circulate the report for comments and produce the final version

* Prepared by Dr Inés Salas, University of Chile, Santiago, Chile

Quality of the Reported Information

For each question a score of the quality of the information (validity and reliability) should be included using a score of 1, 2 or 3, with the following definitions:

1. Good: evidence obtained from well-designed published studies.
2. Middle: evidence obtained from not well-designed published studies, internal unpublished studies, routine surveillance system or database, or expert national or local committee reports or equivalents.
3. Personal experience: opinions and/or clinical or administrative experience of the project team, or colleagues, etc.

Areas of uncertainly should be briefly explained, if pertinent.

Epidemiological Information

The team may find it useful to present information in a table format. In the following guide, specific categories, such as age groups are suggested. However, the team should feel free to use whatever categories and groups are available or appear to be the most relevant for their situation. Nevertheless, it is recommended that detailed distribution by age grouping and gender be used, if possible, to permit response to unforeseen questions in the future. The limits of ages of the children versus adult groups should be specified. Proportions should be calculated, when feasible. If population size is known, rates should be calculated. Teams should feel free to use as many tables as they need to present this key planning information. Sources and year of publication should be indicated on all tables.

Incidence refers to the number of new events that occur in a given period. The event may be the onset of a new disease. Prevalence refers to the number of individuals who have a given disease or other defined attribute at a specific time (point prevalence). For further information on epidemiologic concepts, please consult: http://www.epibiostat.ucsf.edu/epidem/epidem.html#COM.

Decision About the Target Area

The team should identify a target area where it will focus its future efforts and project proposal. Reasons for selection of this area should be given. The criteria for selection could include the burden of advanced cancer and/or HIV/AIDS patients, local amenability to change, resources available in the area, or anticipated community acceptance of the project emphasis and intervention.

II. Country Team Information

1. Date: ____________________

2. Country: _________________

3. Who are the members of the country team? (last name, first name, profession, institution)

4. Who is the country team leader?
   Name:
   Organisation where he/she works:
   Address:

   Phone(s): Fax:
   Email:

Information Matrix

The situation analysis collects information at both the "country" level (Section III) and the "target area" level (Section IV). The following information matrix is a useful concept for summarizing the information collected at these two levels.

Demographic Total population, by gender, age group, rural versus urban areas, and geographic districts. A map with the administrative divisions should be included.

		General	Cancer	HIV/AIDS
Health status	**Mortality**	10 leading causes of death. Life expectancy at birth.	10 leading cancer types and deaths by type of cancer. Total deaths due to cancer by gender and age group.	HIV/AIDS deaths: total, by age group and gender.
	Morbidity: incidence prevalence	Overview assessment: a brief statement.	Annual incidence of the 10 most common cancers: total, by age group and gender. Overview assessment: brief description.	Annual incidence and prevalence: total, by age group and gender. Overview assessment: brief description
Health care system	**Governmental and non-governmental**	Organization at the various levels. Population coverage and access. Health care priorities. Health care facilities and equipment. Human resources. Referral system. Financing.	Cancer control policies, plans and related legislation. National guidelines. Services/ programme activities being delivered by level – including "quality dimensions" (see below). Drug availability. Palliative care component. Structure and finance. Monitoring and evaluation.	HIV/AIDS control policies, plans and related legislation. National guidelines. Services/ programme activities being delivered by level – including "quality dimensions" (see below). Drug availability. Palliative care component. Structure and finance. Monitoring and evaluation.
Context	**Social, economic, and cultural**	Educational facilities. Religion practices. Family attitudes about homecare of the sick and coping with death. Communications channels and leaders.		Existence of stigma and discrimination. Problems associated with suicide, family disruption, school discontinuation, orphan care, etc.

Quality Dimensions of Performance of Health Services

Effectiveness	Do care or service interventions or actions achieve the desired results? Why?
Acceptability	Do care or services provided meet expectations of client, community, providers and paying organizations? Why?
Efficiency	Is the health system achieving the desired results with the most cost-effective use of resources? Why?
Accessibility	Do clients/patients obtain care or service at the right place and right time, based on needs? Why?
Appropriateness	Is care or service provided relevant to client/patient needs and based on established standards? Why?
Health providers competence	Is the health provider's knowledge or skills appropriate to the care/service provided? Why?
Continuity	Does the care or service have the ability to provide uninterrupted, coordinated support across programmes, practitioners, organizations, and levels of care or service, over time? Why?
Safety	Does the care or service avoid or minimize the potential risks of an intervention on people or the environment? Why?

III. Country Information

3.1 Demographic

3.1.1 What is the total population of the country by age group and gender?
3.1.2 Rural versus urban? Other relevant geographic distribution?
3.1.3 Add a country map (one page) with the county or district divisions.

3.2 Health Status

3.2.1 What are the 10 leading causes of deaths (or groups of causes) in your country in the general population and by gender?
3.2.2 What is the life expectancy at birth by gender?
3.2.3 Overview assessment of morbidity. What are the 10 leading causes of morbidity? Summarize with a brief statement.

3.3 Health Status: Cancer

3.3.1 What are the 10 most common cancer deaths in your country in the general population and by gender?
3.3.2 Where do most people with cancer die? (e.g. hospitals, home, etc.)
3.3.3 What is the annual incidence (new cases) of the 10 most common cancers by gender and age group? If you have the population information, please calculate the incidence rates.
3.3.4 Other local or national information about cancer. Examples: disease stage at the moment of patient diagnosis; HIV-associated priority cancers, etc.
3.3.5 Overview assessment of cancer as a public health problem. Summarize with a brief statement.

3.4 Health Status: HIV/AIDS

3.4.1 What are the HIV/AIDS deaths by age group and gender?
3.4.2 Where do most people with HIV/AIDS die? (e.g. hospitals, home, etc.)
3.4.3 What is the prevalence of HIV/AIDS by age group and gender?
3.4.4 Other relevant information about HIV/AIDS. Examples: common opportunistic infections, viral load or CD4 cell count at time of patient diagnosis; distribution of rural versus urban areas, etc.
3.4.5 Overview assessment of the extent of the health problem for HIV/AIDS at the national level. Summarize with a brief statement.

3.5 Health System

The health care system is defined to include all the activities whose primary purpose is to promote, restores or maintain health. Include formal health services, but not informal health services (e.g. traditional healers).

3.5.1 How is the health system organized in your country at the national level, district level and patient-family level? (governmental and non-governmental). Add a flowchart about the country health system.
3.5.2 How is the health system financed? (Government funds, private insurance, out-of-pocket payments, social insurance, others).
3.5.3 What is the population covered by health system, governmental versus nongovernmental?
3.5.4 What is the percentage of population that lives 5 km of health care facilities?
3.5.5 What are the relevant nongovernmental health organizations in your country?

3.6 Health System: Cancer

3.6.1 Does the country have a specific plan or programme for cancer control? If yes, please attach a copy and indicate:
  - Year of formulation.
  - Year of its implementation.
  - Priorities: On which cancer(s) does the plan focus? Sub-group population?
  - Goals and strategies.
  - Palliative care component, with greater detail.

3.6.2 Does the country have a national list of essential drugs for cancer patients? If yes, please attach the list.
  - Are the drugs available (routinely dispensed through the health system)?
  - Are the drugs affordable (accessible and affordable for low-income groups)?

3.6.3 Does the country have legislation on tobacco control? If yes, explain briefly.

3.6.4 Does the country have a cancer surveillance system? If yes, explain briefly.

3.6.5 Does the country have an established cancer registry? If yes, explain briefly for which cancer(s), and if it is population-based or hospital-based.

3.6.6 Is there a unit (or department) for cancer in the ministry of health? If yes, what is the total number of staff?

3.6.7 Is there a budget line for cancer control in the ministry of health's budget document? If yes, explain briefly.

3.6.8 Are there national reference centres for cancer? If yes, explain briefly and are they involved in primary prevention services?

3.6.9 Does the country have treatment and other guidelines for the common cancers? If yes, explain briefly and specify for which types(s) of cancer and/or components of the programme.

3.6.10 What kinds of cancer preventive, early detection, treatment and palliative care services and/or activities are being delivering in the country? And what governmental and non-governmental organizations/units/groups are accountable for the services or activities by different levels of care? Please explain, and give more details particularly about palliative care services.

3.6.11 Are essential equipment and facilities available to offer preventive, early detection, treatment and palliative care cancer services? Explain briefly.

3.6.12 How are the cancer services financed (preventive, early detection, treatment and palliative care)?

3.6.13 Are the cancer control programmes integrated within the primary health care system? Explain briefly.

3.6.14 Have there been efforts to link the different levels of health care delivery structures to facilitate care for cancer patients (integrated care)? If yes, what mechanisms were used to link structures?

3.6.15 If NGOs are involved in cancer control activities in the country, are members of NGOs represented on national committees for cancer control? How is the integration functioning?

3.6.16 What is happening in regard to the existence and the competence of health professionals in the area of cancer control in your country?

3.6.17 If your country does have a cancer control programme, does it includes a monitoring and evaluation component? If yes, what are the indicators used?

3.7 Health System: HIV/AIDS

3.7.1 Does the country have a specific plan or programme for HIV/AIDS control? If yes, please attach a copy and indicate:
  - Year of formulation.
  - Year of its implementation.
  - Priorities: On which area does the plan focus? On which population?
  - Goals and strategies.
  - Palliative care component with more details.

3.7.2 Does the country have a national list of essential drugs for HIV/AIDS patients? If yes, please attach the list.
  - Are the drugs available (routinely dispensed through the health system)? Explain briefly.
  - Are the drugs affordable (accessible and affordable for low-income groups)? Explain briefly.

3.7.3 Does the country have any kind of legislation about HIV/AIDS?

3.7.4 Does the country have an HIV/AIDS surveillance system? Explain briefly.

3.7.5 Is there a unit (or department) for HIV/AIDS in the ministry of health? If yes, explain briefly and indicate what is the total number of staff.

3.7.6 Is there a budget line for HIV/AIDS control in the ministry of health's budget document? If yes, explain briefly.

3.7.7 Are there national reference centres for HIV/AIDS? If yes, explain briefly and indicate if they are involved in primary prevention services?

3.7.8 Does the country have guidelines for the clinical management of HIV/AIDS in hospitals as well as in the community (community/home based care)? If yes, explain briefly.

3.7.9 What kind of HIV/AIDS preventive, early detection, treatment and palliative services and/or activities are being delivering in the country? And what governmental and non-governmental organizations/units/groups are accountable for the services or activities by different levels of care? Please explain and give more details about palliative care services.

3.7.10 Are essential equipment and facilities available to offer preventive, early detection, treatment and palliative care HIV/AIDS services? Please explain briefly.

3.7.11 How are the HIV/AIDS services financed? (preventive, early detection, treatment and palliative care)?

3.7.12 Is the HIV/AIDS control programme integrated within the primary health care system? Please explain briefly.

3.7.13 Have there been efforts to link the different levels of health care delivery structures to facilitate continuum of care for HIV/AIDS patients between hospitals and homes and vice versa (integrated care)? If yes, what mechanisms were used to link structures?

3.7.14 If NGOs are involved in HIV/AIDS control activities in the country, are members of NGOs represented on national committees for HIV/AIDS control? If yes, how is it functioning?

3.7.15 What is happening in regard to the existence and the competence of health professionals in the area of HIV/AIDS control in your country?

3.7.16 If your country has a HIV/AIDS control programme, does it includes a monitoring and evaluation component? If yes, what are the indicators used?

3.8 Context

3.8.1 Educational level indicators. What is the adult literacy rate by gender? What percent of the population completed primary education by gender? What percent of the population competed secondary education by gender? What is the dropout rate for primary and secondary schools?

3.8.2 Cultural. What is the distribution of religions practiced by the population? What are the family views about homecare of the sick and coping with death? What are the communications channels with access to the population?

3.9 Context: Cancer and HIV/AIDS

3.9.1 What is the situation about stigma and discrimination for cancer and/or HIV/AIDS patients?

3.9.2 What are the family views about coping with cancer and/or HIV/AIDS terminal patients?

3.9.3 Please also include other information you consider useful.

IV. Target Area Information

4.1 Demographic

4.1.1 What is the total population of the target area by age group and gender?
4.1.2 Rural versus urban? Other relevant geographic distribution?
4.1.3 Add a target area map (one page).

4.2 Health Status

4.2.1 What are the leading causes of deaths (or groups of causes) in this target area in the general population and by gender?
4.2.2 Overview assessment of morbidity. What are the most common causes of morbidity (incidence and/or prevalence)? Summarize with a brief statement.

4.3 Health Status: Cancer

4.3.1 What are the 10 most common cancers deaths by gender and age group in the target area?
4.3.2 Where do most people with cancer die in this area? (e.g. hospitals, home, etc.)
4.3.3 What is the annual incidence (new cases) of the 10 most common cancers by gender and age group? If you have the population information, please calculate the incidence rates.
4.3.4 Other local information about cancer. Examples: disease stage at the moment of patient diagnosis; HIV-associated priority cancers, etc.
4.3.5 Overview assessment of cancer as a public health problem in the target area. Include expected trends in the near future. Summarize with a brief statement

4.4 Health Status: HIV/AIDS

4.4.1 What are the HIV/AIDS deaths by age group and gender in the target area?
4.4.2 Where do most people with HIV/AIDS die in this area? (e.g. hospitals, home, etc.)
4.4.3 What is the prevalence of HIV/AIDS by age group and gender?
4.4.4 Other relevant information about HIV/AIDS. Examples: common opportunistic infections, viral load or CD4 cell count at time of patient diagnosis; distribution of rural versus urban areas, etc.
4.4.5 Overview assessment of the extent of the health problem for HIV/AIDS in the target area. Include expected trends in the near future. Summarize with a brief statement.

4.5 Health System

4.5.1 How is the health system organized in the target area (public and private, including NGOs, CBOs)?
4.5.2 What are the local health priorities within the proposed target area for different population groups: children, adult, older, women, general population?
4.5.3 What are the hospitals, major health centres and structure of community health clinics/centres, community-based care and home-based care mechanisms within the proposed target area and referral system from the target area?
4.5.4 What is the percentage of population that lives $\leq$ 5 km of health facility? What is the percentage of population that lives $\leq$ 5 km from a vehicle accessible road?
4.5.5 What are the major medical services and medical equipment within the target area and referral system from the target area? If they exist, are they operational? (Include: medical care, clinical lab. services, imaging services, pathology services, emergency services, selected elective and day surgeries, urgent/emergency and elective surgeries, surgery services, oncology services, radiotherapy services, chemotherapy services, specialist palliative care services, critical/

intensive care, telehealth services, hospice services, home care services, day care services, social support services, and others.)

4.5.6 What are the health human resources within the proposed target area and its referral system? What are the numbers of trained health care personnel of all types, overall and broken down by speciality and governmental versus nongovernmental? (Include: medical doctor (all types), general physician, pathologist, radiologist, surgeon, radiotherapist, medical physicist, medical oncologist, paediatrician, gynaecologist, infectious disease specialist, palliative care specialist, physiotherapist, psychiatrist, other medical; non-medical, including nurse, midwife, nutritionist, psychologist, pharmacist, auxiliary nurse, auxiliary midwife, auxiliary sanitarian, family welfare educators, social welfare officers, health care volunteers, other trained health care workers; traditional healers.)

4.6 Health System: Cancer

4.6.1 Does the target area have a local specific plan or programme for cancer control? If yes, please describe the following components, particularly if they are different from the national programme: priorities, goals, strategies, written guidelines, procedures, etc.

4.6.2 What kinds of cancer services and/or activities are being delivering in the target area by level? And what organization/unit/group is accountable for the following specific services or activities?
Primary prevention.
Screening and early diagnosis.
Treatment.
Palliative care.

4.6.3 What is the current quality of health services performance for cancer patients/population within the target area as measured by the “quality dimensions” (see the third page of this appendix)? Include indicators for each dimension for primary prevention, screening and early diagnosis, treatment, and palliative care.

4.7 Health System: HIV/AIDS

4.7.1 Does the target area have a local specific plan or programme for HIV/AIDS control? If yes, please describe the following components, particularly if they are different from the national programme: priorities, goals, strategies, written guidelines, procedures, etc.

4.7.2 What kinds of HIV/AIDS services and/or activities are being delivering in the target area by level? And what organization/unit/group is accountable for the following specific services or activities?
Primary prevention.
Screening and early diagnosis.
Treatment.
Palliative care.

4.7.3 What is the current quality of health services performance for HIV/AIDS patients/population within the target area as measured by the “quality dimensions” (see the third page of this appendix)? Include indicators for each dimension for primary prevention, screening and early diagnosis, treatment, and palliative care.

4.8 Current Palliative Care

Is there a current palliative care component within the cancer and/or HIV/AIDS control programme or as a specific general programme in the target area? If yes, please answer the following questions.

4.8.1 When did the programme begin?

4.8.2 What sick people does the programme intend to serve? Please indicate subgroups and numbers, if possible.

4.8.3 What are the programme goals and objectives? (What the programme must accomplish to be considered successful.)
4.8.4 What is the delivery model of the programme? Please attach a flowchart.
4.8.5 What are the services and activities of the programme? (What the programme does to achieve the objectives.)
4.8.6 How many of each of the following were done last year: general services, specialist services, sub-specialist services?
4.8.7 What are the resources of the programme? (Include: administrative and management staff, interdisciplinary core clinical team, other human resources, space/physical infrastructures (e.g. hospitals, outpatient centres, etc.), medical equipment (e.g. radiotherapy treatment machines), communication technologies and office equipment (computers, fax, phone, etc.), medical supplies: specify drugs, narcotic drugs including oral morphine and others, other supplies, policies and procedures, care protocols or pathways, information system (e.g. health records), financial resources, others.)
4.8.8 What are the distribution, access and cost information for narcotic drugs for pain control, including oral morphine in the target area?
4.8.9 What is the quality assurance system? (Measurement/evaluation, outcomes database, satisfaction surveys, etc.)
4.8.10 What are the methods for evaluating both clinical and financial programme performances?
4.8.11 How many patients with cancer and/or HIV/AIDS did the palliative care programme treat per annum?
4.8.12 Who are the health services partners of the programme?
4.8.13 Who are the community partners of the programme?
4.8.14 How is the programme perceived by patients and providers?
4.8.15 What are the major strengths of the current programme?
4.8.16 What are the major weaknesses of the current programme?
4.8.17 What are the major threats and obstacles (existing and anticipated) in the environment?
4.8.18 What are the major opportunities of the current programme in the environment?
4.8.19 What are the specific problems and needs of the current programme?

4.9 Context

4.9.1 What are the public and private education facilities within the proposed target area? (Include: primary, secondary, all universities and colleges, universities related to health (e.g. medical, nurse), postgraduate health training opportunities, postgraduate training opportunities in cancer, postgraduate training opportunities in HIV/AIDS.)
4.9.2 Educational level indicators in the target area. What is the adult literacy rate by gender? What percent of the population completed primary education by gender? What percent of the population competed secondary education by gender? What is the dropout rate for primary and secondary schools by gender?
4.9.3 What are the religion practices of the population in the target area?
4.9.4 Who are the key people and leaders in the target area?
4.9.5 What are the communication channels that reach the target area population?
4.9.6 List the organizations related to cancer and/or HIV/AIDS that exist in the target area (e.g. name, size and type of services provided)?

APPENDIX B

WHO Questionnaire on National Narcotic Drug Policy*

Governments or other interested groups, including health care professionals, may use the following checklist to guide their analysis of national drug control policies. Please note that some enquiry may be needed prior to answering the questions contained on this checklist.

	Please circle one. If "Yes" please provide a short description.		
1a. Do the current government policies on drug regulation impede;	Yes	No	Information not available
(i) prescribing	Yes	No	Information not available
(ii) dispensing	Yes	No	Information not available
(iii) availability	Yes	No	Information not available
(iv) distribution and	Yes	No	Information not available
(v) access to narcotic drugs of medical value?	Yes	No	Information not available
1b. Is there any effort to review and revise such policies in 1(a)?	Yes	No	Information not available
2. Does the current National Drug Policy recognize the use of narcotic drugs for pain relief?	Yes	No	Information not available
3. Does the current National Drug Policy stipulate the government's role of ensuring availability of narcotic drugs for medical and scientific use?	Yes	No	Information not available
4a. Are there any government established mechanisms or bodies that license, estimate and keep statistics to ensure adequate availability of narcotic drugs for scientific and medical use?	Yes	No	Information not available
4b. Is there adequate technical human resources for implementing the activities in 4(a)?	Yes	No	Information not available
5a. Does the government have a mechanism of estimating narcotic drug requirement for use as analgesics in palliative care and other conditions?	Yes	No	Information not available
5b. Does the government assess its requirements in narcotic drugs as specified by the International Narcotic Control Board (INCB)?	Yes	No	Information not available
5c. Has the government established a system to collect information about the medical need in opioid analgesics from health facilities?	Yes	No	Information not available

	Please circle one. If “Yes” please provide a short description.		
6. Does the government timely furnish the annual estimates for requirement in narcotic drugs to INCB?	Yes	No	Information not available
7. If the medical need for opioid analgesics exceed the estimated amount approved and confirmed by INCB, is it government policy to furnish a request for a supplementary estimate?	Yes	No	Information not available
8. Does the government timely submit to INCB the required annual statistical reports in respect to production, manufacture, trade, use and stocks of narcotic drugs?	Yes	No	Information not available
9a. Has the government discussed and informed health professionals the legal requirements for use of narcotic drugs?	Yes	No	Information not available
9b. Has the government identified and addressed concerns of health care professionals about being investigated for prescribing opioids?	Yes	No	Information not available
10. Is there cooperation between the government and health care professionals to ensure availability of opioid analgesics for medical and scientific purpose?	Yes	No	Information not available
11. Has the government taken steps, in cooperation with licensees, to ensure that there are no shortages of supply of opioid medications caused by inadequate procurement, manufacture and distribution systems?	Yes	No	Information not available
12. Does the National Drug Policy provide for licensing an adequate number of individuals and entities to support a distribution system?	Yes	No	Information not available
13a. Is there a government established national cancer control programme to which health care resources are allocated?	Yes	No	Information not available
13b. Has Government adopted the WHO recommendation on use of analgesics for control of pain in palliative care?	Yes	No	Information not available
13c. Is palliative care included in: (i) continuing medical education (CME) curricula? (ii) undergraduate and postgraduate curricula for medicine, pharmacy, nursing and allied health professionals?	Yes	No	Information not available

	Please circle one. If “Yes” please provide a short description.		
14. Is there a terminology in the National Drug Policy that has the potential to confuse the medical use of opioids for pain with drug dependence?	Yes	No	Information not available
15. Are there provisions in the National Drug Policy that restrict the amount of drug prescribed or the duration of treatment?	Yes	No	Information not available
16. Are there prescription requirements in the National Drug Policy that may unduly restrict physicians and patients to access narcotic drugs for pain relief?	Yes	No	Information not available

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* World Health Organization, EDM (2000) *Achieving Balance in National Opioids Control Policy: Guidelines for Assessment*. WHO Technical Document.

APPENDIX C

Needs Assessment Tools*

Questionnaire for Urban Patients

Date of interview ________________ Interviewer _______________________________

Residence (village/division) ____

1. Patient's age. ________ (years)
2. Patient's gender. Male Female (please circle one)
3. Tribe. ___________________________________
4. Marital Status. Single Married Widowed Separated/divorced (please circle one).
5. Present occupation. Professional# Businessman/woman Housewife Politician/Civic Leader Peasant Farmer Student Unemployed Other (specify)_____________ (please circle one)
   #Professional – Teacher/Doctor/Nurse/Engineer/Accountant/Administrator.
6. Past occupation. Professional# Businessman/woman Housewife Politician/Civic Leader Peasant Farmer Student Unemployed Other (specify)______________ (please circle one)
7. Religion. C.O.U. Roman Catholic Muslim SDA Greek Orthodox Pentecostal Traditionalist Born Again Baha'i Other (specify) ____________ (please circle one)
8. Level of Education. None Primary Secondary Tertiary (please circle one)

9(a) Do you know what you are suffering from? (knowledge of the diagnosis) Yes No (circle one)

9(b) If you do, what diseases are you suffering from? (please circle one)

Cancer	Typhoid
HIV/AIDS	Tuberculosis
Both HIV/AIDS and cancer	Witchcraft

Other (specify) ______________________________

10. When did you first know that you have this illness? (please circle one)
    Less than a year ago
    Over one year ago
    About two years ago
    A long time back
    I really cannot remember
11. How did you get to know about your illness? (please circle one)
    Through a test at a health facility
    I suspected when I lost my spouse/lover
    I made my own conclusions when I saw the symptoms/signs
    My doctor told me
    Other (specify) ______________________________
12. Whom did you first tell about your illness? (please circle one)
    My Parent(s)
    My spouse
    My brother/sister

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* Developed by Dr E. Kikule for "A Study to Assess the Palliative Care Needs of Terminally Ill Persons and their Caregivers in Kampala District, Uganda, May 2001."

My children
My best friend
I haven’t talked about it to anyone
Other (specify) ______________________________

13. How did they get to know about your illness ? (please circle one)
I told them myself when I received the news
My doctor broke the news to them
They made their own conclusions when they saw the symptoms
Other (specify) ______________________________

14. How did your spouse/family react when they learnt of your illness? (please circle one)
They were shocked but stood by me
They were shocked and angry with me
My spouse rejected me and sent me/went away
They rejected me
They were indifferent
They have resigned to the situation
I really do not know
Other (specify) ______________________________

15. Have you felt any stigma because of your illness? Yes No (please circle one)

16. How have you handled the stigma that goes with this disease? (please circle one)
The fact that my family stood by me helped
By accepting the diagnosis and being open about it
I just keep to myself
Talking to a counsellor helped me to cope
By meeting and interacting with others who have the same disease
I have a strong faith in God and this helped
I have refused to accept the diagnosis
Other (specify) ______________________________

17. What is your greatest fear right now?
____

18. Who takes care of you? (Specify your main caregiver) (please circle one)
My spouse
My sister/brother
My grandchildren
My aunt from the village
A friend
My mother
My children
My grandparent(s)
Someone the family hired to do so
Other (specify) ______________________________

19. What are the main problems you are facing as a result of your illness? (circle all that apply)
Physical
Social
Economical
Spiritual
Emotional

20. How is your medical treatment funded? (please circle one)
I meet my own expenses
My employer
Family
Friends
A nongovernmental organization
Other (specify) ______________________________

21. How are your other needs and those of your family funded? (please circle one)
By myself
Family
Friends
A nongovernmental organization
Other (specify) ____________________________

22. Roughly what is your monthly expenditure on treatment? (please circle one)
Less than 5,000 5,000–15,000 16,000–25,000
26,000–35,000 36,000–50,000 Over 50,000
I really do not know

23(a) How far is the nearest health facility from your home? (please circle one)
Right across the road
Less than a half a kilometer
Over a kilometer
About 1–5 kilometers
Over 5 kilometers
I really do not know

23(b) What type of health facility is it? (please circle one)
Government
Private
Nongovernmental

24. Do you have people who visit you regularly? Yes No (please circle one)

25. Where do they come from? (please circle one)
From the home care team
They are my friends from the neighbourhood
They are my relatives
I do not know

26. Where do you get your medical treatment? (please circle one)
From the home care team that visits me regularly
I buy what I need from the nearby drug shops/pharmacy
My doctor supplies what I need
My family buys what I need
Donations from friends
Other (specify) ____________________________

27. How has the home care team helped you? (please circle one)
By providing drugs and counselling
They provide me with foodstuffs
Financially
By providing drugs/foodstuffs/counselling
By providing drugs/foodstuffs/money
Not applicable
Other (specify) ____________________________

28. What more help would you like the home care team to give you? (please circle one)
Services (drugs/medication/legal/spiritual/etc.)
Foodstuffs
Family support (counselling/IGA/ finance, etc.)
Financial support
All the above

Other (specify) ____________________________
Not applicable

29. What type of medication are you using in your treatment? (please circle one)
Western medicines only
Herbal medicines only
Both Western medicines and herbs

30. Where do you prefer to be looked after during your illness? (please circle one)
Here at home
In hospital.
I really do not mind where

31. Give reasons for your answer
____
____

Questionnaire for Family Caregivers

Date of interview _______________ Interviewer ______________________________

Residence (village/division) ____

1. Patient's age. _______ (years)

2. Patient's gender. Male Female (please circle one)

3. Tribe. __________________________________

4. Marital Status (please circle one).

Single	Married
Widowed	Separated/divorced

5. Present occupation. (please circle one)

Professional#	Businessman/woman	Housewife
Politician/Civic	Leader	Peasant Farmer
Student Unemployed	Other (specify)____________	

#Professional – Teacher/Doctor/Nurse/Engineer/Accountant/Administrator.

6. Past occupation. (please circle one)

Professional#	Businessman/woman
Housewife	Politician/Civic Leader
Peasant Farmer	Student
Unemployed	Other (specify)_____________

7. Religion. (please circle one)

C.O.U.	Roman Catholic
Moslem	SDA
Greek Orthodox	Pentecostal
Traditionalist	Born Again
Baha'i	Other (specify) ___________

8. Level of Education. (please circle one)

None	Primary
Secondary	Tertiary

9. Relationship to patient. (please circle one)
Parent Child Brother/sister Grandparent
Spouse Aunt In-law Friend
None – I am hired by the family Other (specify) ____________________

10. What is the patient's diagnosis? (please circle one)
Cancer HIV/AIDS Both HIV/AIDS and cancer
Typhoid Tuberculosis Witchcraft
I do not know Other (specify) ____________________________

11. Have you ever looked after a terminally ill person before? (please circle one)
Yes No

12. How did you come to be looking after this patient? (please circle one)
He/she is my spouse I was the only one available
The person is my brother/sister He/she is my friend
I was asked by the patient I have been hired by the family
The spouse abandoned him/her The person is my child
The person is my parent I volunteered to look after the patient.
Other (specify) ____________________________

13(a) Were you given any kind of training to do what you are doing? (please circle one)
Yes No

13(b) If so, by whom? (please circle one)
By the home care team By Hospice Uganda
By TASO By Mildmay
Other (specify) ________________________ Not applicable

13(c) If so, for how long? (please circle one)
One day For a week For a fortnight
For 1–3 months For 4–6 months For 7–12 months
Not indicated Not applicable
Continuous – whenever the home care team visits

14(a) Do you receive any kind of support to look after this patient? Yes No (please circle one)

14(b) If so, what kind of support was it? (please circle all that apply)
Financial. Protective wear (such as gloves, apron/coat etc.)
Foodstuffs Drugs/medication
There is somebody to take over when I am tired or need to go somewhere.
Transport Other (specify) ____________________________
Not applicable

14(c) If so, who gave you this support? (please circle all that apply)
The family Cancer Institute Hospice Uganda
The home care team Friends Children
My parents My in-laws I support myself from my salary
Other (specify) ____________________________
Not applicable

15. Are you remunerated in any way for looking after this patient? Yes No (please circle one)

16(a) Does the patient tell you about his/her problems? (please circle one)
Yes No Sometimes

16(b) If so, what are the patient's needs?
____
____

17. Does the sick person appreciate what you do for him/her? (please circle one)
Yes No I can’t tell

18. What major problems are you encountering as you look after this patient?
____

19. What exactly do you do in caring for this patient?
____

20. If the patient’s condition change or the patient develops a problem where do you go for help?
To the nearest clinic where a doctor/nurse usually helps(please circle one)
To the herbalist
To the nearest hospital
I do my own first aid using glucose and drugs from the hospice
I go to the home care team that normally looks after him/her
I just wait for the next visit from the home care team
I go to the nearest relative
Other (specify) ______________________________

21. What are your most pressing needs right now?
____

22. Given a chance to be trained in looking after this patient, what things would you like to learn?
____

23. What assistance, if given to you, would make it easier for you to look after this patient? (please circle one)
Financial
Extra bedding
Free drugs
Protective wear such as gloves
Foodstuffs
An income generating project
An assistant
Training in general patient care.

24. Given a choice, where would you prefer to look after this patient? (please circle one)
Here at the patient’s home
I really do not mind either way
In hospital
In my own home in the village

Please give reasons for your answer.
____

____

Questionnaire for Heads of Households or Caregivers of Ill Rural Patients

Date of interview ____________________ Interviewer ______________________________

District ____________________________ County __________________________________

Sub-County _________________________ Parish __________________________________

Location (village, zone) ____

Accessibility: Distance from vehicle accessible road ____________ (kms)

Nearest health facility _______________ Distance from household ______________ (kms)

Category of health facility. (please circle one)
Hospital Health Centre IV Health Centre III Health Centre II

Ownership of Health Facility. (please circle one)
Government Nongovernmental Private Missionary

Section 1. General information

1. Respondent. Head of household Caregiver (please circle one)
2. Respondent's age. _______ (years)
3. Respondent's gender. Male Female (please circle one)
4. Tribe. ________________________________
5. Marital Status (please circle one).
   Single Married Widowed Separated/divorced
6. Occupation (please circle one).
   Professional[#] Businessman/woman Housewife
   Politician/Civic Leader Peasant Farmer
   Student Unemployed Other (specify)________________
   [#] Professional – Teacher/Doctor/Nurse/Engineer/Accountant/Administrator.
7. Religion (please circle one).
   C.O.U. Roman Catholic Moslem
   SDA Greek Orthodox Pentecostal
   Traditionalist Born Again Baha'i
   Other (specify) _______________________
8. Level of Education (please circle one).
   None Primary Secondary Tertiary
9. Status on Land (please circle one).
   Lease Owner with title deed Squatter
   Other (specify) _______________________
10. Number of people in household. _______________
11. Type of House (please circle one).
    Permanent (Brick walls, tinned roof)
    Semi-permanent (Mud and wattle, tinned/grass roof)
    Temporary (Shack, polythene/grass walls)
12. Household Water Source. (please circle one)
    Tap (municipal) Shallow well (protected) Borehole
    Protected spring Lake Other (specify) ________________
13. In this house, have you lost some one within the last 12 months, who had a long illness? (please circle one)
    Yes No
14. Do you have someone right now in this house who is bed-ridden, with a long illness? (please circle one)
    Yes No

Note: If the answer to both questions 13 and 14 are "Yes", then complete the questions in Section 2 and Section 3, then stop.
If the answer to question 13 is "Yes" and the answer to question 14 is "No", then complete the questions in Section 2, then stop.
If the answer to question 13 is "No" and the answer to question 14 is "Yes", then complete the questions in Section 3, then stop.
If the answer to both questions 13 and 14 are "No", then complete the questions in Section 4, then stop.

Section 2. Where someone has died within the last 12 months

1. For how long was the person sick before death? (please circle one)
Less than one week   Between 1 and 4 weeks
Over 4 weeks but less than 3 months   Over three months
Other (specify) ____________________________

2. What did the person die of? (please circle one)
Cancer   HIV/AIDS
The person was bewitched   We never knew what the problem was
Other (specify) ____________________________

3. How was this condition diagnosed? (please circle one)
In hospital   At a certain clinic
We just saw the signs and the symptoms   It was never diagnosed
By the traditional healer/witch doctor

4. How was the deceased related to the household owner? __________________________________

5. Did the deceased use to live here? (please circle one)
Yes   No
(If "Yes" go question 8)

6. If not, where did the deceased come from? (please circle one)
From Kampala   From another village further away from here
From Hoima Town   Not applicable

7. Why was the deceased brought here? (please circle one)
This is his own home   The family burial grounds are near here
It was cheaper for him to be looked after here
I did not know the reason   Other (specify) ____________________________

8. Where did the person prefer to be looked after during his/her illness? (please circle one)
Here at home   In Kampala   In Hoima
In hospital   He was too sick to care   I did not know

9. Who looked after this person during the time he was ill? (please circle one)
I did   His/her spouse
One of the children   Each of us took part
A relative was called in to help out

10. What problems did the family face during this time? (please circle all that apply)
Money for food and drugs
We did not know what was wrong with the person
We did not know how to ease his pain
Generally looking after a bed-ridden patient
Our neighbours shunned us
Getting a doctor/Nurse – health facilities are very far from us
Other (specify) ____________________________

11. What were this person's greatest needs during this time of sickness? (please circle one)
Food   Drugs   Counselling
Relief of pain   Relief of other symptoms such as diarrhoea, vomiting, cough, etc.
Other (specify) ____________________________

12. Did the sick person ever attend a health facility? (please circle one)
Yes   No

13. Did he/she receive the treatment as required? (please circle one)
Yes   No   Sometimes

14. How often did he/she receive this treatment? (please circle one)
Only once   Once a month   Often
Whenever we were told to go back

15. Was this treatment free? (please circle one)
Yes   No
(If “Yes” go to question 17)

16. How much did this treatment cost? (please circle one)
Less than 2,000   2,000–5,000   5,000–10,000
Over 10,000   I cannot remember, but it was a lot

17. Which of the needs of the sick person were met? (please circle one)
Pain was relieved   Other symptoms were relieved but not pain
Food was provided   He/she had the drugs they needed
All were met   None

18. Who met these needs? (please circle one)
Relatives   Friends   Relatives and friends
A nongovernmental organization (specify) ___________________________
Not applicable.

19. What was your greatest problem while looking after this person?
____

20. What/Who did you find to be the most helpful during this time?
____

21. What was your greatest area of expenditure while looking after this person?
____

22. What more would you have wanted to do for this person?
____

23(a) Did you seek the services of traditional healers while looking after your loved one? (please circle one)
Yes, all the time   Yes, sometimes   Not at all
I do not believe in those things

23(b) If so why? (please circle one)
They were the only ones available   They are affordable
We were told that our loved one was bewitched   “Kizungu” medicines were ineffective
Other (specify) _____________________________

24. Where did you go in times of crisis? (please circle one)
There is a nurse in our village, we would go to her
There is a health facility nearby, we would go there for help
To the herbalist nearby
To the neighbours
We had to cope as well as we could, since we had no one to turn to
Other (specify) _____________________________

25. What health services would you want to see introduced in your village?
____

26. How do you think these health services would be maintained?
____

Section 3. Where a terminally ill person is present at the time of the study

1. What is the diagnosis of the ill person? (please circle one)
   Cancer
   HIV/AIDS
   Witchcraft
   TB
   I do not know
   Other (specify) ________________________

2. How long has he/she been bed-ridden? (please circle one)
   One week
   Two weeks
   A month
   For quite sometime now

3. Is this the sick person's home? (please circle one)
   Yes, he/she lives here
   Yes, but he/she normally lives in Kampala
   Yes, but he/she normally lives in Hoima
   No, he/she was only brought here for care

4. Where does this person prefer to be looked after? (please circle one)
   Here at his home
   In hospital
   In his town home where services are available
   He is too sick too mind
   I do not know

5. Who is looking after this person? (please circle one)
   His wife/husband
   The children
   An aunt
   Our grandmother
   Whoever is free gives a hand

6(a) What are this person's main problems/needs? (please circle all that apply)
   Pain
   Inability to look after him/herself
   Expensive drugs/health care
   Diarrhoea
   Nausea/vomiting
   All of the above
   Other (specify) _____________________________

6(b) Which of these have been solved/met? (please circle all that apply)
   Pain has been alleviated/controlled
   Basic needs are being met
   Drugs/health care
   Diarrhoea
   Nausea/vomiting
   None of them
   All of them

6(c) How/by whom?
   ____

7. What has been your greatest problem while looking after this person? (please circle one)
   Finances
   Feeding the patient
   Getting adequate health care/drugs
   The general handling of a bed-ridden person
   The family has been supportive – we have not had many problems
   Facing the fact that our loved one will not get well
   Talking about the coming death and funeral arrangements
   Other (specify) _____________________________

8(a) Have you sought the services of a traditional healer to help this person? (please circle one)
   Yes
   No

8(b) If so, how has the traditional healer been of help? (please circle all that apply)
   He has helped with pain control
   He has managed the diarrhoea very well
   Eliminated nausea and vomiting
   Has helped to maintain the patient's appetite
   All of the above
   His potions have not helped much
   Other (specify) __________________________
   Not applicable

9. What health services would you like to see introduced in your village?
   ____

10. How do you think these services can be maintained?
____

11(a) If the sick person's condition changes for the worse, where do you go for help? (please circle one)
To the neighbours There is a nurse nearby
To the traditional healer There is a dispensary nearby
Other (specify) __________________________

11(b) When you go there are you helped? (please circle one)
Yes, all the time Sometimes, depending on the problem.
Not really Other (specify) __________________________

12. How has this sickness affected the family?
____

Section 4. Where there has been no death in the last 12 months and there is a no terminally ill person present at the time of the study

1. What health problems do you face as a family? (please circle all that apply)
Malaria Coughs and colds
The children are sickly Skin rashes
Family feeding is a problem All the above
Other (specify) __________________________

2. Where do you normally go for treatment when you are sick? (please circle one)
There is a dispensary not far from here
There is a clinic nearby
We treat ourselves with herbs
We buy drugs from a drug shop nearby
There is a traditional healer not far from here
Other (specify) __________________________

3. How many funerals have you attended in the last 12 months in this village? (please circle one)
None (Go to question 6)
1–3 4–7 Over 7 funerals

4. What were the main causes of death among these people? (please circle one)
HIV/AIDS Cancer Witchcraft
Varied causes I am not sure Other (specify) ______________________

5. Were the dead people usually resident in this village? (please circle one)
Yes No, they are brought in from Kampala
No, they are brought in from Hoima No, they are brought in from another village
Other (specify) __________________________

6. Who is most affected by HIV/AIDS in your village? (please circle one)
Young people, both men and women (15–49 years)
Young girls (10–24 years) Young boys (10–24 years)
The older people Generally everybody is affected

7. Have you ever looked after a person with an incurable disease like HIV/AIDS? (please circle one)
Yes No (If "No" go to question 9)

8. What problems did you face during this time?
   ____

9(a) If you had a family member with HIV/AIDS or cancer, where would you prefer to look after this person? (please circle one)
Here at home In hospital
I would not mind where so long as the sick person gets treatment

9(b) Give reasons for your preference.
____

10. What sort of health services would you want people with HIV/AIDS in your village to have?
    ____

11. What health services would you like to see brought to your village?
    ____

12. If such services were brought to your village how do you think they would be sustained?
    ____

Guide for Interviewing Programme Managers

1. General Information
   - (a) Position of interviewee?
   - (b) Base of the programme? (Institution – hospital/clinic or community)
   - (c) Duration of operations?
   - (d) How would you define “palliative care”?
   - (e) What are the aims/objectives of this programme?
   - (f) How are these aims/objectives being achieved?
   - (g) How many clients/patients are there in the programme?
   - (h) How many of these clients/patients need home care at present?
   - (i) What criteria do you use to identify those needing home care?
   - (j) What problems do you encounter in following these criteria?
2. Staffing
   - (a) What is the total number of staff in the programme?
   - (b) What is the breakdown of staff categories? (i.e. part-time/full-time/volunteers)
   - (c) Which category of staff shoulders the most responsibility in the programme?
   - (d) What are the advantages/disadvantages in using volunteer staff? Are there any problems?
   - (e) How is the staff remunerated?
   - (f) What qualifications are required of the staff at the entry point into the programme?
   - (g) What sort of in-service training (if any) do the staff receive to help them do their work?
   - (h) What is the training curriculum for the staff?
   - (i) How adequately does it meet the needs of the clients and their caregivers?
   - (j) What problems do the staff encounter in delivering these services?
   - (k) How do you keep the staff motivated to continue delivering these services?
3. Services Provided
   - (a) When do you start home care services to the client/patient?
   - (b) How often are the clients/patients visited? Is this regular/irregular?
   - (c) How do these patients or their families make contact with you between visits if they need help?
   - (d) How far is the furthest patient from you?
   - (e) Do you have any other contacts with families apart from these home visits?

(f) What do you consider to be the needs of the terminally ill client/patient?
(g) What, in your view, are the problems the terminally ill patient face?
(h) What are the services provided by this programme? (i.e. the service package)
(i) Who else provides these services apart from you?
(j) What problems do you face in providing these services?
(k) Are these problems AIDS-related or due to other factors?
(l) Do you anticipate an increase in the demand for these services? Why? How? When?
(m) How would you attempt to meet these demands?
(n) What plans do you have to improve/develop these services?
(o) What role do you see the government play in the delivery of home care services?
(p) How are you monitoring and evaluating this programme?

4. Networking
   (a) How does your programme link up with other similar services in the community?
   (b) What problems do you encounter in linking with these services?
   (c) How do you think the community can be helped to become aware of:
   the needs of the terminally ill?
   the services available for the terminally ill and their families?
   (d) What role do you see the community play in the home care service delivery?

5. Funding of the Programme
   (a) What has been the total annual budget for this programme, say from 1995 to 2000?
   (b) Can you give a breakdown of this budget into the various cost areas?
   (e.g. drugs/salaries/operations/etc.)
   (c) What is the main source of funds for this programme?
   (d) What percentage of the total annual budget is raised locally?
   (e) Do the clients make any contribution to these services at all?
   (f) What sort of assistance do you receive from the government?
   (g) What plans do you have for the sustainability of this programme?

6. Facilities/Equipment Available For Home Care Activities.
   (a) Do you have your own offices or do you share office space with other services?
   (b) Do you have vehicles set aside for home care? How many?
   (c) Who maintains the vehicles/how are they maintained?
   (d) What other facilities do you have for home service delivery?
   (e) Are these facilities adequate for the home care service demands?

7. Referral Systems.
   (a) Do you have a system of referral in place?
   (b) What sort of clients/patients do you refer?
   (c) Where do you refer the clients?
   (d) How is this referral effected?
   (e) Do you get a feedback after the referral?

8. Recommendations.
   What recommendations would you make concerning the delivery of home care services?

Guide for Interviewing Hospital Medical Superintendents

1. When did the home care department at your hospital start and why?
2. What is the role of the hospital in the home care services?
   (e.g. free lab tests, priority of admission, funds committed to home care)
3. What is the package of services rendered by the hospital home care department?

4. How do the hospital and home care department relate to each other?
5. What problems does the hospital face as it renders the home care services?
6. How is the home care department staffed?
7. Does the hospital provide the staff with any security against contracting diseases such as TB or AIDS?
8. What plans do you have as a hospital to sustain the home care services when the donors pull out?
9. What is your opinion of the home care services you render to clients that come for these services?

Check List For Facilities In Palliative Care Institutions

Facility in the institution		Owned/Shared	Number
Office space			
Counselling rooms			
Transportation:	Vehicles		
	Motorcycles		
	Bicycles		
Protective wear:	Umbrellas/raincoats		
	Gum boots		
	Gloves		
	Other		
Drug containers/carriers			
Computer and printer			
Television & video deck			
Other (specify) ___________________			

Guide for Focus Group Discussions

1. What are the main health problems in your village/community?
(Allow free listing and then prioritize the three most important ones)
2. Which diseases do you think are incurable?
(Allow free listing and then prioritize to four most common ones in the area)
3. Who is the most affected by the four most common incurable diseases?
(Young, old, male, female, children, etc.)
4. What symptoms are associated with these diseases?
5. How does the community here cope with these diseases?
(Treatment/coping strategies – medical, traditional healers, spiritual, etc.)
6. What is the cost for each of these treatment options?
7. What are the most common needs among these people with incurable diseases?
(Identify the disease first and get the needs for each disease)
8. How best do you think these various needs can be met?
9. How can the community help these people who are terminally ill and their families?
10. What sort of health services would you like to see provided for such people in your village?

11. If such services are provided how can they be maintained/sustained?
    (If cost sharing is mentioned what would be the minimum charge per person?)
12. How best do you think the government can help the terminally ill and their families?
13. Any other comment you would like to share with us?
    Thank you very much.

Guide for Interviewing Key Informants

Study participants could include: counsellor, traditional healer, church leader, hospital superintendent, and health worker in charge of HIV/AIDS or cancer ward.

1. What do you think are the (a) needs and (b) problems of the terminally ill?
2. How best can these needs be met?
3. What local resources can you see available to help the terminally ill and their families?
4. How can these resources be maximized/enhanced?
5. How, in your opinion, does the community view these people?
6. How can communities support these people and their families?
7. What do you think the minimum health care package for the terminally ill should be?
   Thank you.

APPENDIX D

Team Development*

Useful Definitions

Key definitions are given below (Wideman, 2001).

- **Team**: Two or more people working interdependently toward a common goal and a shared reward.
- **Team building**: The process of influencing a group of diverse individuals, each with their own goals, needs, and perspectives, to work together effectively for the good of the project such that their team will accomplish more than the sum of their individual efforts could otherwise achieve.
- **Team management**: The direction of a group of individuals that work as a unit. Effective teams are results-oriented and are committed to project objectives, goals and strategies.
- **Teamwork**: Work done by several associates, with each doing a part, but all subordinating personal prominence to the efficiency of the whole.
- **Norms:** Acceptable standards of behaviours within a group that are shared by group members.

How to Select the Right Team

Having the right team can make or break a project. Elements to consider include: team size, overall team composition, team member selection criteria, and the process of recruiting team members.

Team size

The recommended team size is 3–12 members, but the best size is 5–7 members. Smaller teams (3 or 4 members) work faster and tend to produce results more quickly, but they have less diversity. Teams with more than 7 or 8 members require more expert facilitation and often require that sub-teams be formed in order for the team to operate effectively. They have a potential for more ideas and diversity.

Overall team composition

A well-rounded team includes a mix of members of the relevant organizations involved in the project, with a mix of experiences and skills. You need to consider members:

- Belonging to relevant partner organizations of the project.
- With different abilities.
- With technical expertise and skills.
- With administrative skills (e.g. problem solving and decision making skills).
- With interpersonal and communication skills.

The team should include at least one:

- Individual who intimately understands current palliative care services from a public health view.
- Individual who is a technical expert in palliative care and actively participates in the palliative care services and works closely with patients.
- Individual who is completely objective toward the process and outcome of palliative care services (consultant).
- Customer of the services (when possible).
- Supplier (someone who is laterally involved with the palliative care services).
- Individual who is not familiar with the palliative care services (someone who brings a fresh perspective and outlook to the team).

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Team member selection criteria

You need the "best and brightest" on your team, but they must work well together for the project to succeed. When selecting team members, you should prefer persons who:

- Are interested and committed to the common purpose of improving the quality of remaining life for cancer and HIV/AIDS patients.
- Are enthusiastic.
- Are optimistic.
- Are creative, flexible and open-minded.
- Desire self-development and learning.
- Have personal initiative, commitment, and accountability.
- Are well respected among peers and other leaders.
- Are good team players, in that they:
    - Work effectively as a member of a team.
    - Treat others' values, beliefs and opinions with respect.
    - Relate to and interact effectively with individuals and groups.
    - Are willing to cooperate towards common goals.

Recruiting team members

The following steps can be used to recruit individuals for the team. First, review the project goals and the above selection criteria. Second, identify some relevant persons in possible partner organizations and list their potential areas of contribution to the team, including skills and technical knowledge. Third, make informal contact with the selected individuals and/or those who know them in order to determine if they fulfil the criteria. Determine their interest in the project and the time they could commit to the project. Fourth, decide if they are the right person, based on the preliminary information. Fifth, invite them to join the team.

Phases of a team's development

A team is a living entity. It progresses from early to mature phases, independent of the nature of the team or the task it must perform. There are four typical phases in team development (Bateman 1990).

Forming: This is the orientation period. The team is not sure of its task and members are not well acquainted with each other, nor have they learned what sort of a team leader they have. Usually team members want to be told what to do.

Storming: This is the phase when team members feel more comfortable expressing their opinions. They may challenge the team leader's authority and recommendations. Some members may become dissatisfied and challenge not only what the team is to do and how it is doing it, but also the leader's role and style of leadership. This is a sorting out period where each member begins to find his or her place as a team member.

***Norming*:** In this phase, team members begin drawing upon their cumulative experiences for working out their problems and pulling together as a cohesive group. This process should result in the team establishing procedures for handling conflicts, decisions, and methods to accomplish the team projects.

Performing: In this phase, the team has achieved some harmony, defined its tasks, worked out its relationships, and begins to produce results. Leadership is provided by the team members best suited for the task at hand. Members have learned how to work together, manage conflict, and contribute their resources to accomplishing the team's purposes.

Dissolving: When the team has finished the project it is either dissolved or reoriented.

Team building

There are three main components in any team's work: first, the task or content aspect; second, the process aspect, comprising the team's interactions and how its members work together; and third, time and other resources. Teams, especially technical teams, frequently struggle more with process issues than with task issues. In fact, the problems of a team's internal interactions typically inhibit its ability to accomplish its tasks effectively. You can accelerate the norming phase by offering a norm proposal to the team for all to discuss and adapt.

Characteristics of good team building

- The team is clear about goals and established targets.
- Each team member is willing to contribute.
- The team leader has good interpersonal skills and is committed to the team approach.
- A high level of interdependence among team members.
- The team develops a relaxed climate for communication.
- Team members develop a mutual trust.
- Team and individuals are prepared to take risks.
- Team member roles are defined.
- Team norms are defined.
- Team members know how to examine team and individual errors without personal attacks.
- The team has the capacity to create new ideas.
- Each team member knows he can influence the team agenda.

Useful questions for team building

- What are our common vision, goals and established targets?
- What is our agreed-upon strategy?
- What is going to be our common process for working?
- What are the team roles and who will play them?
- What are the responsibilities for these roles?
- What are our team values that will guide how the team will work together?
- What are our norms about: decision making, problem solving process, dealing with conflicts, communication, cooperation, responsibility, meetings, and rewards?
- What is the time frame we have to achieve our goals?

Examples of helpful written norms

- Keeping discussion focused on the objective of the meeting.
- Start and end meetings on time.
- The mediator/facilitator has complete control over the process; the parties can make suggestions, but the mediator controls when and how much people speak.
- Allow only one conversation at a time, no side conversations.
- Don't interrupt.
- Respect the views of all participants.
- Before evaluating a member's contribution, others check their assumptions to ensure they have properly understood.
- Each person speaks on his or her own behalf and lets others speak for themselves.
- Operate from the position of responsibility for our actions and results.
- Speak openly and honestly.
- Say what you mean and mean what you say, but preserve people's self-esteem.
- Seek first to understand before you seek to be understood (from Stephen Covey).
- Keep it constructive; focus on issues and behaviors, not personalities.
- Members can disagree without fear.

- Everyone participates.
- Call a time out if you need one.
- You always have three options: accept it, work to make it better, or leave. You don't have the right to complain if you're not willing to make it better.
- Communicate immediately if you think you may not be able to fulfil an agreement.
- When the group is not working well together it devotes time to finding out why and makes the necessary adjustments.
- Conflict is inevitable but will be managed and dealt with positively.

Team charter: A useful document for team building

A team charter is a written document that defines the team's mission, scope of operation, objectives, time frame, and consequences (Bodwell, 1996). The purpose statement is a one or two line statement explaining why the team is being formed. The purpose statement should align with and support the organization's vision and mission statements. The objectives the team is expected to achieve should be stated in measurable terms. The scope of the team's charter should define organizational or operational boundaries within which the team is expected and allowed to operate and information about the resources available to the team to accomplish its objectives. It might also speak about the time commitment expected of team members and the need to continue to support their day-to-day responsibilities. A section describing top management's support and commitment to the team should also be included.

Team effectiveness

When evaluating how well team members are working together, the following statements can be used as a guide (Yancey, 1998):

- Clearly stated and commonly held vision and goals.
- Team goals are developed through a group process of team interaction and agreement in which each team member is willing to work toward achieving these goals.
- Leadership is distributed and shared among team members and individuals willing to contribute their resources as needed.
- All team members actively participate and roles are shared to facilitate the accomplishment of tasks and feelings of group togetherness.
- Feedback is asked for by members and freely given as a way of evaluating the team's performance and clarifying both feelings and interests of the team members. When feedback is given it is done with a desire to help the other person.
- Team decision-making involves a process that encourages active participation by all members.
- Problem solving, discussing team issues, and assessing team effectiveness are encouraged by all team members.
- Conflict is not suppressed. Team members are allowed to express negative feelings. Confrontation within the team is managed and dealt with by team members. Dealing with and managing conflict is seen as a way to improve team performance.
- Team member resources, talents, skills, knowledge, and experiences are fully identified, recognized, and used whenever appropriate.
- Risk taking and creativity are encouraged. When mistakes are made, they are treated as a source of learning rather than reasons for punishment.
- Clear understanding of the team's relationship to the greater organization.
- The social environment is open and supportive, without authority directed problem solving.
- An underlying feeling that the team will be successful in accomplishing the goals they have set – is an essential part of the social surrounding.
- The environment of the group is supportive, with a focus on learning. A variety of educational tools, including experts in the field, should be readily available to assist the team in problem solving.

- Reward is given in a manner that promotes team cohesiveness. If given in the correct manner, it will likely increase potency, or the belief that the team will perform effectively in the future. Potency can be linked to various other factors including both internal factors (member skills and abilities) and external factors (reputation, resources, leadership).

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APPENDIX E

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APPENDIX F

List of Tables

Part I A community health approach

Part II Country Reports

APPENDIX G

List of Figures

APPENDIX H

List of Abbreviations

AFRO	WHO Regional Office for Africa
AIC	AIDS Information Center
AIDS	Acquired Immune Deficiency Syndrome
AMA	American Medical Association
AMMP	Adult Morbidity and Mortality Project, Tanzania
AMREF	African Medical & Research Foundation, Tanzania
ARV	Anti-retroviral
BCC	Behavioural Change Communication, Ethiopia
BONEPWA	Botswana Network for People Living with HIV/AIDS
CBM	Christian Blind Mission
CBO	Community-based Organizations
CHBC	Community Home Based Care
CCBRT	Comprehensive Community-based Rehabilitation in Tanzania
DANIDA	Danish International Development Agency
DDHS	The District Director of Health Services
EPEC	Education for Physicians on End-of life Care
GTZ	German Agency for Technical Cooperation
HCBOs	Home and Community-Based Oganizations
IEC	Information Education Communication Programme, Ethiopia
IMAI	Integrated Management of Adolescent and Adult Illness
INCB	International Narcotic Control Board
KS	Kaposi's Sarcoma
MoH	Ministry of Health
MUCHS	Muhimbili University College of Health Sciences, Tanzania
NACP	National AIDS Control Programme
NGO	Non-Governmental Organization
ORCI	Ocean Road Cancer Institute, Tanzania
PASADA	Pastoral Activities and Services for People with AIDS: Dar es Salaam Archdiocese
PCC	Programme on Cancer Control
PCCZ	Prevention and Control of Cancer in Zimbabwe
PHC	Primary health care
PLWA, PLWHA	People Living with HIV/AIDS
RAC	Regional AIDS Coodinator, Ethiopia
SAT	Southern Africa AIDS Training Programme
TASO	The AIDS Support Organization
TB	Tuberculosis
UDHS	Uganda Demographic and Health Survey
UDS	University of Dar es Salaam
UNDP	United Nations Development Programme
UPE	Universal Primary Education, Uganda
WAMATA	Walio Katika Mapambano na AIDS Tanzania (People in the fight against AIDS)