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INTRODUCTION

UGANDA IS IN MANY WAYS typical of the African countries whose turbulent postcolonial past has left a legacy of poverty, sickness, and inadequate public services. United Nations statistics reflect this. Life expectancy at birth is approximately 40 years. Infant mortality is at a rate of 114 per thousand live births. The maternal mortality rate is 1,200 per 100,000 live births, and both-gender probability of dying before the age of 5 is 18%. Forty-six percent of the population has access to safe drinking water, and 60% to sanitation facilities. Both figures are lower in rural areas. Total adult literacy is 62%, for females it is 50%. Health expenditures, which are 6% of the gross domestic product (GDP) annually, amount to approximately US $12 dollars per capita, of which public expenditure accounts for only US $3 dollars. Less than half of the population lives within 5 kilometers of a health facility.

Acquired immune deficiency syndrome (AIDS) has drawn most of the attention recently when thought is given to the crisis of health and health care in sub-Saharan Africa. Uganda's efforts to reduce the prevalence of human immunodeficiency virus (HIV) infection have made it something of a public health success story on the continent, although, as reported by Dr. Jack G.M. Jagwe in this International Policy Report, approximately 10% of the population is infected. This translated into more than 800,000 people living with HIV/AIDS by end of 1999, more than 100,000 annual deaths, and 1 million currently living children who are orphans because of the disease.

Yet there are less visible areas of progress as well, including collaborative government and professional efforts to standardize and improve hospice and palliative care. Hospice is just less than a decade old in Uganda. Significant government involvement is even more recent. In this report, Dr. Jagwe describes the evolution of palliative care in Uganda with particular emphasis on the successful campaign to incorporate palliative care in the 5-year Strategic Plan of the Ministry of Health.

Submissions to International Policy Report are welcome. For information, or to submit articles on professional and governmental collaboration for palliative care in the international context, contact the Section Editor, David Barnard, Ph.D., Center for Bioethics and Health Law, University of Pittsburgh, 3708 5th Avenue, Suite 300, Pittsburgh, PA 15213 (e-mail: barnard@pitt.edu).

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The Introduction of Palliative Care in Uganda

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ABSTRACT

Hospice Uganda was established in Kampala, September 27, 1993. Since then the hospice has served over 3,000 patients with cancer, and referrals of patients with HIV/AIDS are increasing steadily. The concepts of hospice and palliative care are well accepted in Uganda, but the delivery of services has been severely constrained by limited resources. Possibilities for growth, both in service provision and education of health professionals, were improved significantly with the incorporation of palliative care objectives into the Ministry of Health 5-year strategic plan.

INTRODUCTION

Hospice Uganda started in Uganda in 1993 by Dr. Anne Merriman, F.R.C.P., a distinguished physician, geriatrician, and palliative care specialist.

The noble objectives of Hospice Uganda in 1993 and now are:

- To provide palliative care services to patients and families living within a 20-kilometer radius of Kampala, the capital of Uganda.
- To carry out education programs in palliative medicine to health professionals at undergraduate and postgraduate levels throughout Uganda so that this form of care can be available to all patients in need.
- To encourage the initiation of hospice in other African countries, by demonstrating a suitable and affordable service for Africa.

HOSPICE IN AFRICA

Dr. Anne Merriman states that the spirit of hospice enables the patients to be in control to the end. Patients are allowed to make choices regarding where they are cared for and their treatment. In giving pain control to patients with cancer, the patients have peace and space to make decisions regarding families and to make peace with themselves and God before they die. The modern hospice as practiced in Uganda has access to the knowledge and use of medication for pain, which allows 95% control of pain and symptoms for 95% of the time. The idea of hospice has been accepted by Ugandans and adopted by medical practitioners. Eighty percent of patients referred to Hospice Uganda are from the national Referral Hospital. The remaining 20% comprise self-referral, relatives referral, and clinics/private hospitals referrals. The referral numbers are increasing steadily.

The first hospice in sub-Saharan Africa started more than 20 years ago in Zimbabwe followed by Nairobi Hospice, Kenya in 1990. These have both multiplied in those two countries. Many countries in Africa need to be introduced to and to adopt the hospice form of management of cancer and human immunodeficiency virus/acquired immune deficiency syndrome (HIV/AIDS) and other incurable diseases. The outdated idea of telling the patient or relative that there is not much we can do for incurable or advanced cancers is gone. Patients want to die at home and it is less expensive to transport a live person home than a dead one. However, to discharge a patient home without palliative care is terrifying and defeatist and a severe sentence for the patient and family.

Hospice at home, through home care team visits, appears to be the most acceptable from the experience of Hospice Uganda. The cultural context of Uganda revolves around the extended family system, which makes caring easier.

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Hospice Uganda believes that training health professionals in this concept and extending it through public health institutions down to the villages may be the solution to all patients with cancer. Fifty-seven percent of our people cannot access health services and many report too late for curative surgery, chemotherapy, or radiotherapy.

UGANDA

Uganda is a small country with a population estimated at 22 million in the year 2000. It has a population growth rate of 2.9% per year, one of the highest in the world. It has a life expectancy of 39 years,[1] a doctor to patient ratio of 1:23,000 average,[1] a cancer prevalence of 0.1%, i.e., 22,000 new cases annually and a prevalence of HIV infection of 10% in adult population.

Uganda is classified among the least developed countries. It is thus a resource-poor country with an annual income per capita of US $300 and where 35% of the population live below the poverty line, i.e., they earn less than US $1 per day. Patients on home care management are asked to contribute to the cost of care. Hospice Uganda estimates that the cost per visit is US $7 but the patient is asked to contribute US $3 towards the cost of their medications. Sixty-five percent of the patients cannot afford this and charities supplement them. This sort of work is precarious; one depends on faith almost daily that God will provide and He does in mysterious ways.

THE WORK OF HOSPICE UGANDA

In Uganda, the first Hospice started on September 27, 1993, in Kampala. In January 1998, Mobile Hospice Mbarara commenced and Little Hospice Hoima followed 6 months later. Hospice Uganda tackled an enormous task. It has treated 3,000 cancer patients so far and also accepts referrals of patients with HIV/AIDS who need pain management.

Hospice Uganda has to date trained more than 600 health professionals in pain management and symptom control using a holistic approach of palliative care. However, these health professionals have not had access to oral morphine, the main analgesic for severe pain. This year the government is correcting this.

INVOLVING GOVERNMENT THROUGH MINISTRY OF HEALTH

In March 1998 at the Botanical Beach Hotel, a historic symposium was held. It was attended by officials of the Ministry of Health, NGO (non-governmental organization) health care givers, leaders of professional organizations in health, e.g., pharmacists, nurses, doctors, etc., and the World Health Organization (WHO), HIV/AIDS home care teams around Kampala and Entebbe.

Dr. Jan Stjernswärd, director of Global Cancer Concern and previous head of Cancer and Palliative Care Unit, WHO Geneva, attended and presented a paper on the subject of "Pain Control Worldwide and Uganda." This symposium interested all the people who attended. A Task Force on Palliative Care and Pain Relief in Cancer and HIV/AIDS at the Ministry of Health was formed.

Through the joint effort of Ministry of Health and WHO Country Representative, the Task Force examined the whole issue of palliative care and Pain Relief for Cancer and HIV/AIDS patients and made recommendations and proposals for a National Policy on Palliative Care. The recommendations were as follows:

- That government adopts a national policy on pain control.
- That the training of all the health professionals at undergraduate and post-graduate level incorporates palliative care into the national curricula.
- That specialist nurses in palliative care are identified after approved training and experience and are empowered to prescribe and supervise the medications.
- That the Ministry of Health works with Hospice Uganda to identify specific needs in a District of Uganda (Hoima) and then plans a strategy to meet the needs at village levels using the existing medical services of the Ministry of Health.

ADOPTION OF PALLIATIVE CARE IN THE NATIONAL HEALTH POLICY PLAN

The symposium and the Task Force recommendations came at the most appropriate moment, when the Ministry of Health was busy dis-

Table 1. Summary of Events Leading to Improved Palliative Care for HIV/AIDS and Cancer in Uganda

Year	*Event*	*Outcome*	*Further*
1993	HU introduces palliative medicine to Uganda and MOH	First oral morphine imported and service and training commenced	
1998	HU calls unifying conference on PC.	Formation of PC Task Force, MOH	Continued meeting up to publication of strategic plan
2000	MOH 5-year strategic plan	PC incorporated as essential clinical service	MOH takes up CME training in PC
2001	1. Publication of guidelines 2. Training of district leaders and health professional trainers 3. Provision of morphine for all districts by MOH 4. Steps taken to change legal statute for midwives prescribing pethidine, to include PC specialist Nurses and Clinical Officers, to prescribe morphine.	1 & 2. Training in progress using HU, Mildmay International. 3. Has been purchased and awaiting training before distribution. 4. In process	Outcome by 2002 should have at least 25% of districts using analgesic ladder appropriately for 20% of those in need.

cussing a national health policy and plan. Hospice Uganda used all the methods of lobbying and advocacy through influential health policy makers to ensure that the recommendations on palliative care were included in the national policy and plan. It was most gratifying to learn later that palliative care as an entity was adopted as part of the Essential Clinical Services in the subsequent 5-year policy and strategic health plan 2000–2005.

THE COLLABORATIVE EFFORTS BETWEEN HOSPICE UGANDA, THE GOVERNMENT OF UGANDA, INCORPORATING OTHER STAKE HOLDERS

The adoption of palliative care as part of Essential Clinical Services opened the floodgates (Table 1). The government has now come to grips with the problem of pain management and symptom control of cancer and HIV/AIDS patients, not only at hospital level but down to the village level where most of the suffering underserved live. This will be done through legislation. By amending the current law, specialist palliative care nurses and clinical officers who have acquired approved and registered training, will be able to deliver palliative care using standard medications including narcotics for pain relief and control of symptoms.

The Ministry of Health has already ordered and received powdered morphine to be reconstituted at the Joint Medical Store, an NGO pharmaceutical organization. In addition, through WHO, the government has secured some funds from the Italian government to strengthen home-based care. Some of these funds have been used for sensitization of district health teams on the introduction and use of oral morphine in the country. This effort is helping to improve credibility in the eyes of professional colleagues on the use of morphine. We hope that as sensitization extends throughout the 56 districts and their public health units palliative care will reach those poor underserved patients in the villages. The government is fully aware that it is overwhelmed by patients with HIV/AIDS who cannot all be admitted in hospitals. As of now, the rate of referrals is on the increase.

CONCLUSION

How palliative care was introduced to Uganda in 1993 has been described. The historic sympo-

sium and subsequent formation of the Task Force, which formulated the contents of a national policy on pain control, has been elaborated. The subsequent adoption by the government of the recommendations saw the incorporation of palliative care into the National Health Policy and the 5-year strategic health plan. This has been followed by recognition of a new cadre of health workers specializing in palliative care empowered to handle, prescribe, and supervise the use of all standard approved medications for palliation in patients with cancer and HIV/AIDS.

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