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Invited review

Going the extra mile with the bare essentials: home care in Uganda

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The development of a home care service from small beginnings in Uganda to becoming a model for African countries is described. This model has proved that palliative care can be adapted to the cultural and economic needs of an African country. The greatest contribution to the success of this programme has been the introduction of affordable oral morphine which can be taken in the home by the patient with the assistance of relatives. With holistic care it is now possible to give the patient the best chance of dying peacefully in the place and with the people they choose. Palliative care has taken root and is included in the current Ugandan 5-Year Health Plan. The integrated education programme ensures that palliative care is embedded in the Ugandan medical curriculum and widens the number of health professionals with knowledge of palliative care. This same programme provides the basis for initiators from other African countries to gain the necessary knowledge and skills.

Keywords: oral morphine, palliative care, sub-Saharan Africa, hospice, education

Introduction

Imagine a world where the only pain relief was paracetamol. This was the situation in most of Sub-Saharan Africa prior to 1993 (which then did not include South Africa) when there were only two countries (Zimbabwe and Kenya) with palliative care and morphine. In 1993, Hospice Africa (HA), a UK-registered charity, was established to support affordable, culturally acceptable palliative care for all in need. In Uganda, a model, home-based, palliative care service was initiated, which would not only provide care but, most importantly, provide education and serve as a teaching model, adaptable to other African countries.

The vision, to bring about affordable and culturally acceptable palliative care to all of Africa, came from my experience at Nairobi Hospice. For the first time, the severe pain of terminally ill patients could be controlled using affordable liquid morphine for self-administration in the home. I had previously worked in Singapore and, through a volunteer initiative to look after seriously ill and dying patients in their own homes, had instigated the first Hospice Care programme in Singapore. There, the formula for oral morphine had been perfected and this was brought to Nairobi in 1989. Professor Kasili, oncologist and the Chair of the Board of Nairobi Hospice, had it approved by the Government of Kenya, and affordable oral morphine was available when I joined them in 1990. Nairobi Hospice was running a very successful local home care service from 1990.

The need for such services for the whole of Africa was dramatically demonstrated when, following the publication of an article written for a special edition of the Christian journal, *Contact*,[1] edited by Dame Cicely Saunders, letters and messages began to arrive from many African countries, requesting my help to bring relief to their dying patients. From this, Hospice Africa was born. Following a feasibility study of several interested countries, Uganda was chosen for the model home care service and Hospice Africa Uganda (HAU) was established as a non-governmental organisation in November 1994.

Background

In the mid-1990s, Uganda was still in the early stages of recovery from the ravages of the Amin/Obote years. More

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Figure 1 **Cancers usually present at an advanced stage as shown by the tumour on the back of this 29-year-old female patient. The nurse, who usually visits, has brought in the doctor to advise, and who is talking to the patient while her sister looks on**

than 80% of the 23 million population made all, or almost all, of their living from agriculture. In addition to widespread poverty, literacy was low and the AIDS epidemic was the major problem, with prevalence estimated at an average of 30%. Since then, prevalence rates have dropped and were estimated to be 6.2% in 2002 (there is some evidence that it is on the increase again). More positively, Uganda's President Museveni, has been the African leader most willing to speak openly about the disease, and the country cited as a model for others to draw from in their fight against AIDS.

Development of Hospice Africa Uganda

With much faith, a team of three, an old Land Rover, donated by the British High Commission in Kampala, and funding for only 3 months, work began in September 1993. At that time, in addition to poverty and illiteracy, there were several other significant barriers. There was a severe shortage of doctors (1993 estimate at about 2–3 per 100,000, almost all in urban centres) and other health professionals. There was almost no understanding of palliative care and doctors were reluctant to prescribe morphine. It was essential for the Government to agree to import morphine powder for reconstitution into the oral liquid drug, for use in the home. This would be controlled by a palliative care team, willing to go the extra mile. Based on this clinical service, training of health professionals could commence.

For the first few months, we worked from the front room of a small house in the compound of a mission hospital in Kampala before moving to another lent to us by a Ugandan business man. Of necessity, we could only provide home-based care, partly on grounds of cost and also because of lack of any existing resource for in-patient care. Later, two pieces of research, by Dr Ekiria Kikule[2] and the World Health Organization (WHO)[3] have confirmed that, in the five African countries studied, home is where the majority of people wish to die.

Memories of our early patients, experiencing the miracle of pain control for the first time, remain vividly fixed in our minds. Instilling the spirit and ethos of palliative care into that small team was relatively easy. We learned from each other and our patients.

For the first few years, the organisation remained small and funding came from individual supporters across the world, from charitable foundations and income from two charity shops set up on Merseyside and run by volunteers from HA. In those early days, with no proven track record, much of our support came from those who had faith in our vision. Quarterly newsletters were a vital source of information for our supporters.

HAU was established to provide palliative care to cancer patients (Fig. 1) but soon it became evident that many patients had HIV/AIDS, with or without cancer. In 1994, HAU carried out research into the need for pain control in AIDS patients. At this time, anti-retrovirals (ARVs) were available only to the wealthy. People were dying in severe pain, without treatment for their opportunistic infections. Having applied the methods of pain control for cancer successfully in patients with AIDS, the team took referrals of patients suffering from this disease.

How it has developed

HAU moved to a permanent home in Makindye, Kampala in 1994. In 1998, two further centres were opened in Uganda. Mobile Hospice Mbarara (MHM) in south-western Uganda was established in order to teach the doctors and health professionals being trained at Mbarara University of Science and Technology, the second medical school in Uganda. In addition to home care and day care, MHM operates out-reach and road-side clinics beyond the usual 20-km radius covered by our

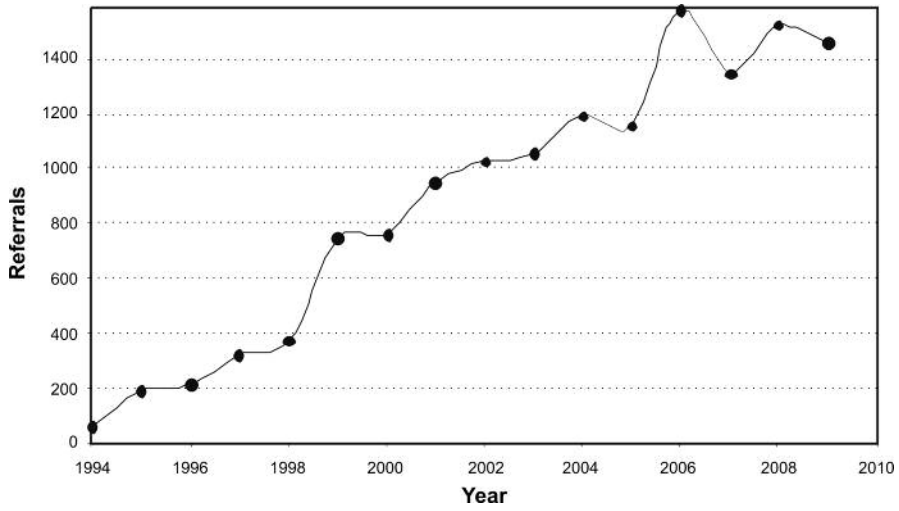

Figure 2 Patients on programme for HAU over the 16 years. Annual referrals for 1994 relate to period from September 1993 to March 1994 only

services, allowing continued care for patients from villages in rural areas. The road-side clinic is an efficient means of delivery in a scattered rural area with low population and could be transferred to other settings. Little Hospice Hoima (LHH) started in the back room of a shop with no water or electricity in a very poor area in the north-west of Uganda. Many patients live in villages deep in the countryside and the model for service delivery is via the community volunteer workers, who identify those in need in their village.

As HAU's reputation grew, donor funding became more diverse and grants became larger. Some major projects, including a purpose-built clinical and education building, were undertaken and this is in the process of being expanded today, with funding from the Irish Government. Headquarters at Makindye is now a very large complex, encompassing both patient care and training facilities for Uganda and other African countries. It has now outgrown its status as an affordable model for African countries and instead the models are now MHM and LHH.

Table 1 Needs for palliative care (PC) in Uganda, 1993 and 2009

	1993	2009
Population in millions	23	33
HIV (%)	30	6.7
HIV (*n* in 000's)	6900	2211
AIDS (*n* in 000's)	986	316
AIDS in need of PC	986	110
Cancer prevalence	0.4	0.4
Cancer patients (*n* in 000's)	92	132
Total in need of PC (*n* in 000's)	1078	242

In 1993, all AIDS patients were in need of requiring palliative care. In 2003, with ARVs we calculate that most are on AVRs and 10% would be in AIDS spectrum of which 50% would be in need of PC. The estimate in 2009 is now the number with HIV divided by 20.
Source: APCA African POS tool <www.apca.co.ug>

Patient numbers have grown dramatically but we expect more patients to receive palliative care from the thousands we have trained from our own service. The outcomes in the country are being measured at present (Fig. 2 and Table 1).

Because of the reduction in the HIV epidemic, the number requiring palliative care is reducing; however, cancer patients are increasing. Another factor to be considered is that the population is ageing and cancer incidence increases with age. Life expectancy in 1993 was 37 years and now is 50 years.

Effective analgesia is absolutely essential. The drug of choice is morphine. Made up in simple liquid format, oral morphine is highly effective and easily understood by the patient and carers making relief of severe pain at home possible. The agreement to allow the import of morphine powder was obtained very early but, in a remarkable process, the law was eventually changed to allow morphine to be prescribed by nurses who had successfully completed the 9-month specialist palliative care and prescribers' course at HAU. A pilot clinical audit is completed and about to be published. This includes measurements of clinical audit for Uganda and South Africa. Preliminary findings indicate satisfactory levels of pain and symptom control using the POS tool for Africa.[4]

Education

The essential strategy for Hospice Africa has been the integration of care and education. The first training course for health professionals began in February 1994. This marked the beginning of an extensive palliative care education programme for Uganda and other African countries. With support from the University and Government, palliative care education has now been integrated into the Ugandan medical curriculum and all medical students spend some time with Hospice.

Education is not restricted to the health professionals and other programmes have involved sensitisation both at governmental and grass-roots level, with all resources including volunteers, traditional healers, spiritual leaders and families being targeted.

A major step forward was the co-operation with Makerere University, which validated the Distance Learning Diploma in Palliative Medicine, the first African Palliative Care qualification. To date, a total of 96 students from Uganda and other African countries have been awarded this qualification. In 2009, this was extended to a Bachelor's degree and it is hoped, eventually, to provide a Master's programme.

Current services

Overseas visitors are surprised by the untreated cancers often seen in Uganda and clinical care for such late-stage patients is often more difficult, but in many parts of Uganda less than 60% of patients ever see a health worker. The others will use the traditional healer. Since the beginning, HAU has involved traditional healers in training programmes, as it gives health professionals insight into their *modus operandi* and is an opportunity to share experiences and encourage referrals. Sometimes, patients come to us as a last resort when all else has failed and their meagre resources are finished.

In Kampala and Mbarara, the patients are mainly referred from the teaching hospitals and in Hoima from the Government District Hospital. However, there are increasing numbers of self-referrals, those who hear about our work from patients and families who have benefited.

Many patients travel from up-country to seek help and are, therefore, outside the catchment radius of 20 km. Originally, the only way to manage this was for the team to relieve the pain, ask the patient to stay nearby until the pain was completely controlled, then give them a month's supply of morphine to take home. Carers were asked to return and report on the patient's progress and collect more medications. This was far from ideal. Now, HAU has trained more people throughout Uganda and morphine is now available in 32 Districts out of 57; patients can be referred on to the nearest centre equipped to deliver their care. This is co-ordinated nationally by the Palliative Care Association of Uganda, established with volunteers in 1999 and with a working office since 2006.

The teams accept anyone who is in pain with a diagnosis or possible diagnosis of cancer or AIDS. Once the diagnosis is confirmed, it may be appropriate for the patient to be referred to one of the networking organisations. We care for cancer patients at any stage of the disease and AIDS patients in pain, who are critically ill or at the end of life. The prognosis these patients has changed significantly since free ARVs became available 3 years ago. ARVs still do not reach patients in the villages but in the urban settings many are receiving them. HAU does not prescribe ARVs but networks with organisations which do. Many patients are referred to HAU with the side effects of ARVs, including neuropathic pain.

In the early years, our service was free. Today, patients are asked to pay UGS5000 (£1.50) per week to cover the cost of medicines and visits from the team but the reality is that less than one-third of our patients can afford this amount. No-one is refused treatment because of inability to pay. Since we began work in 1993, we have cared directly for more than 14,340 patients. The present estimated cost for a week's care for a patient, including home visits and treatment from specialist nurses and doctor if necessary, is UGS22,000 (£7.00).

There are five teams in Kampala, while MHM and LHH each operate with two teams. Each team has their own geographical area. All patients are assessed and a decision is made as to the frequency of home visits. Palliative care is time-intensive and the initial assessments take 1–1.5 h. Follow-up visits are usually shorter, 0.5–1 h. Each team will see 3–7 patients a day and the majority of patients are seen once a week. Home visits may be more frequent initially, when first titrating morphine dose against the pain. Also, more frequent visits occur towards the end of life or during periods of critical illness. Patients and relatives are able to make contact with a member of the team 24 h a day, sometimes talking over problems and receiving advice by phone.

Main achievements

The development of a strong working relationship with the Ugandan Government has been a key step in the development of HAU. The introduction of affordable oral morphine has been the main factor in allowing palliative care to work in the home[5] and this has been achieved without any evidence of diversion or addiction. In 2000, the Ugandan Government included palliative care as 'an essential clinical service for all Ugandans' as part of the 5-Year Health Plan and, in 2003, Ugandan law was changed to allow the prescribing of morphine by nurses, trained by HAU. These landmark decisions by government were a first for the whole of the African continent.

A workable, affordable model of home care culturally adaptable to other African countries, bringing palliative care to those most in need, is now a reality. *Palliative Medicine – Pain and Symptom Control in the Cancer and/or AIDS patient in Uganda and other African Countries* (now in its 4th edition and better known around the world as the 'Blue Book') is the recognised handbook for health professionals in Africa and elsewhere. It has recently been translated into French for use in Francophone countries.[6]

The formation of the Palliative Care Association of

Uganda and the African Palliative Care Association were both initiated by HAU and the early work of both organisations was carried out from the hospice in Kampala. Both of these organisations play a vital part in spreading the message that freedom from pain is a human right and palliative care is possible within the African context.

A total of 6512 people have received training in palliative care from HAU. Palliative medicine is now part of the curricula of the medical school of Makerere and Mbarara Universities and is examinable. In October 2008, the first palliative medicine unit under Internal Medicine at Makerere University, opened for education, clinical service and research. The mobile rounds of home care are the back-bone for teaching clinical skills and show how to work with patients and families while in their own communities.

Challenges

Today, Uganda has a population of 33 million and the population continues to rise. Nearly 50% of the population is under 15 years of age and this brings huge demographic and social challenges, not least in education and HIV prevention. The urban sprawl in Kampala, with a population of over 3 million and Mbarara at 1.5 million, contrasts with rural Hoima District, with a population of 400,000.

The present estimate of AIDS patients requiring palliative care with a prevalence of 6.7%, is 316,000. The cancer prevalence is estimated at 132,000. This means that a total of 242,000 patients with these diseases alone, are now in need of palliative care. Many will receive support care from other organisations but, when they are in severe pain, true palliative care, which includes the modern methods of pain and symptom control, is the only way that those in pain, can be free to make their peace with their God. HAU is still only reaching a fraction of those in need and our challenge is to ensure maximum coverage to all diseases. Today, we are taking our experience to other African countries with support, setting standards and training. Presently, we are supporting initiatives in Malawi, Nigeria, Cameroon, Sierra Leone and Ethiopia.

As with many hospices around the world, HAU faces the challenge of funding and sustainability. For the first few years of operation, HA was the main source of funding. Today, there are registered fund-raising organisations in the UK, Ireland, USA and France and funds are also raised in The Netherlands and Singapore. All of the support organisations around the world are committed to the ideal of affordable and culturally appropriate palliative care in Africa. HAU has an annual budget of £2 million and USAID is a major donor, funding services for those patients with AIDS and cancer with AIDS, but this funding cannot be used for cancer patients without AIDS. Encouraging local fund-raising in Uganda continues to present a challenge and the organisation is almost totally dependent on overseas donors. Even though the economy is growing in Uganda, the rich get richer and the poor get poorer.

Reliance on a few major donors can lead to the agenda of the donor determining the direction of the organisation. The two crucial challenges facing HAU today are:

1. To hold firm to the vision of affordable and culturally appropriate palliative care for cancer and AIDS patients.
2. To maintain that spirit and ethos of palliative care, which motivated the pioneers of the service, in the face of expansion.

HAU has been the model and test-bed for HA.

Conclusions

There have been many difficulties along the way, but with support from friends, both individual and corporate, palliative care in sub-Saharan Africa has become a reality. Those who have worked with Hospice or been trained, are carrying a message of hope to the suffering. Like ripples from a stone thrown into water, this message is travelling further and further. The need for care will always exceed our capacity to provide but at the very least a start has been made. Hopefully, a firm foundation has been laid for those following to build upon.

References

1. Merriman A. Living while dying. *Contact* October 1991; no. 122. Christian Medical Commission, Geneva.
2. Kikule E. A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. *BMJ* 2003; **327**: 192–194.
3. Sepulveda C, Habiyambere V, Amandua J *et al*. Quality care at the end of life in Africa. *BMJ* 2003; **327**: 209–213.
4. Ramsay S. Leading the way in African home-based palliative care. Free oral morphine has allowed expansion of model home-based palliative care in Uganda. *Lancet* 2003; **362**: 1812–1813.
5. Merriman A. *Palliative Medicine: Pain and symptom control in the cancer and/or AIDS patient in Uganda and other African countries*. Hospice Africa Uganda, 2006. French edition 2007. <www.hospiceafrica.or.ug>.
6. Hospice Africa Uganda. Ethos and spirit of hospices in Africa. 2007. <www.hospiceafrica.or.ug>.