FEATURE

Leading the way in African home-based palliative care

Free oral morphine has allowed expansion of model home-based palliative care in Uganda

"We used to have a police escort from the airport—but that is not necessary now." This casual remark by Donna Asiimwe Kusemererwa, assistant manager of Kampala's Joint Medical Store, belies only the slightest hint of the extraordinary work that has been done over the past decade to relieve the pain and suffering of the terminally ill in Uganda. The now-unnecessary police escort was for the importation of cheap powdered morphine, the keystone of Uganda's palliative care movement.

The story of modern palliative care in Uganda starts with a UK physician from Liverpool, Anne Merriman. She originally worked in tropical medicine in Nigeria then trained in geriatric medicine and palliative care in the UK. She was an initiator of hospice care in Singapore and worked as a physician in Nairobi Hospice, Kenya.

Merriman set her sights on developing a modern, affordable, African home-based palliative care service that could be used as a template for other countries on the continent. After feasibility studies in various African countries, Uganda was chosen as the site for the model hospice, mainly because the relatively low rate of corruption meant that the country had support from outside donors.

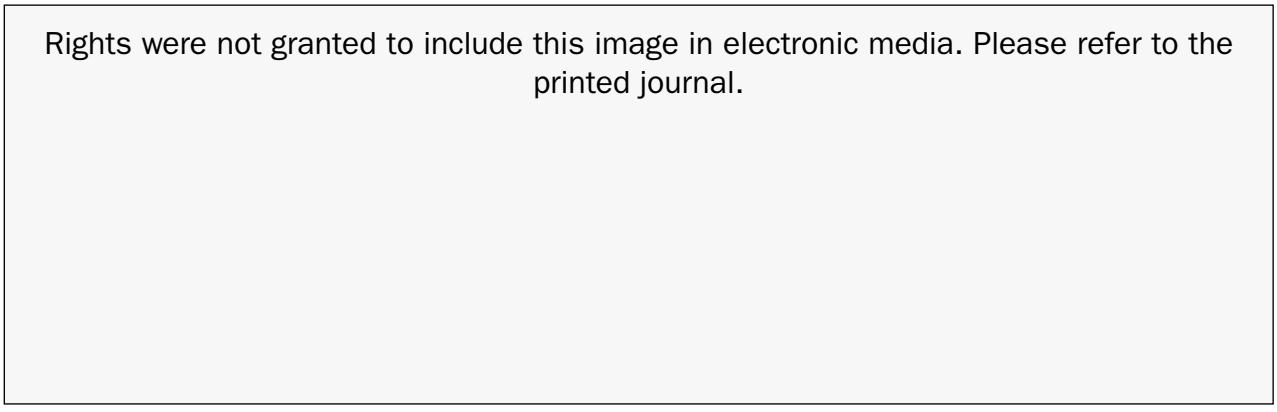
Before Hospice Uganda started work in 1993, however, "I insisted to the government that I would only come if they agreed to import powdered morphine", Merriman emphasises. She was and still is deeply concerned by organisations that claim to provide palliative care, yet are not controlling pain. In 1993, "although many organisations were giving spiritual and practical help, no-one was providing control of severe pain as well", hence the importance of morphine in Hospice Uganda's work and teaching. Although the Ugandan government agreed to make morphine available when the hospice was established, there was still a battle to overcome fear and myths about morphine in the early years.

Great progress has been made since then. Uganda is the first and only African country so far that has made palliative care for people in the terminal stages of AIDS and cancer part of its national health plan, and morphine has been provided free by the government since 2002. The powdered opioid is made up into dilute solutions that the patients can take by mouth. The enlightened government approach has allowed Hospice Uganda to flourish.

The first thing that strikes a visitor to Hospice Uganda, a cluster of low-rise buildings in Makindye, Kampala, is the lack of patients. A small number of patients attend for day care one day a week, but there are no inpatients. The reason is that Hospice Uganda's patients are cared for entirely where they want to be—at home. It costs US$11 per week to care for a patient. The hospice asks for a contribution of $2·50. For the one-third of patients' families that cannot afford $2·50, care is free.

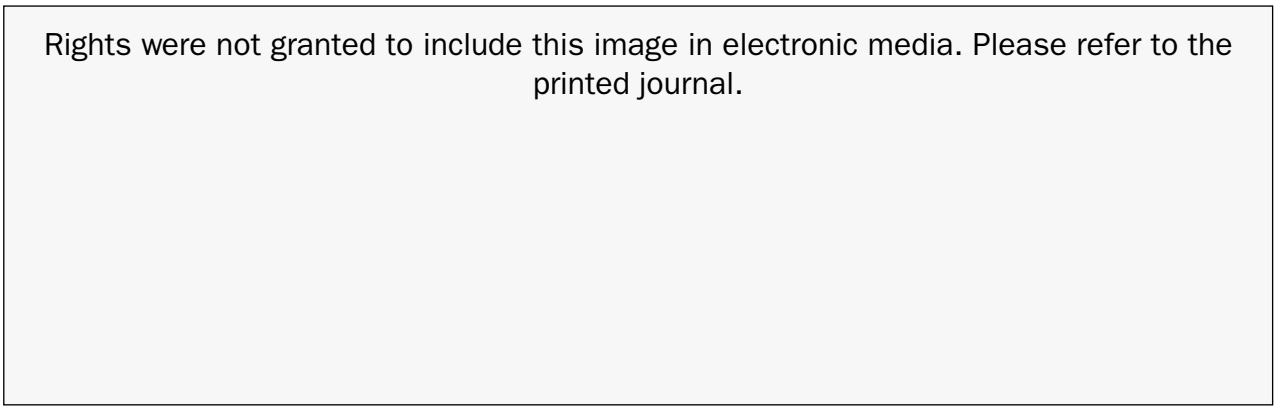
Home care is given to patients within 20 km of Kampala. Hospitals refer patients, but the hospice also has a large group of trained volunteer "vigilantes", who alert the hospice teams to terminally ill people in their communities. After referral, specialist nursing forms the backbone of care for patients almost all of whom have AIDS, cancer, or both. Each day the teams go out to visit patients. A team is usually made up of two nurses and a driver, but where morphine prescription is required, a doctor must be present. A typical patient is Esther, a 36-year-old former schoolteacher with AIDS. Blinded by cytomegalovirus, she has severe recurrent pain as a result of cryptococcal meningitis. Her husband is dead, thus her son and daughter aged 15 and 12 years administer her medicine; about 25% of the terminally ill are cared for by their children. With her pain controlled, Esther is able to make a will to ensure that her children have a home after she dies.

Pain management is key to the wide range of training provided by Hospice Uganda, and education is an integral part of the working week with case conferences and journal clubs. Health professionals and allied workers from within Uganda and other African countries who are attending courses also constantly expand the hospice population. This training ranges from short courses for community workers on caring for the carers of patients to an 18-month distance-learning diploma run in conjunction with Makerere University—the first palliative care diploma accredited by an African university. The 38 students currently enrolled in the diploma course are from Uganda, Ethiopia, Malawi, Cameroon,



Philip Spencer

Patients and carers attend a community clinic near Masaka



Philip Spencer

Preparation of oral morphine solution at Hospice Uganda's pharmacy in Kampala

Zambia, Zimbabwe, and Tanzania. As with all hospice training, this course is specifically designed to teach palliative care that is practically suitable to Africa and easily adapted to the continent's differing cultures.

Last week, for example, 40 Ugandan health professionals were attending a six-day course on management of terminally ill cancer and AIDS patients in the community. Training included lectures on practical and psychological factors in pain management and symptom control, together with lectures on cultural beliefs and use of local remedies, such as frangipani tree sap for herpes zoster pain, ground paw paw seeds for constipation, and passion flower tea for insomnia. Practical advice on legal aspects was also given, such as on handling narcotics and the law on making a will. Group talks covered topics such as traditional methods of preserving the body.

The education team sees training not just as an end in itself but also as an integral part of advocacy. The participants in last week's course, like all those who attend Hospice Uganda's training, are expected to become leaders in palliative care in their home environments and to pass on their skills to colleagues, volunteers, and carers. The hospice team will make follow-up visits to the participants' places of work during the next two months, to ensure that employers are aware that participants who have successfully met the course requirements are capable of dealing with the medication required for palliative care.

"Africa is in an epidemic of death", Ekiria Kikule told the course participants, "but palliative care is suitable and affordable to Africa and allows patients to die in peace and dignity". The numerous roadside coffin makers are a stark reminder of this epidemic of death in Uganda. Less obvious is the epidemic of dying. In a country where life is lived outdoors, the bedridden terminally ill are hidden from view indoors. Thus in rural areas, where few people ever have contact with health professionals, trained volunteers are crucial to referring people in need for hospice care. Such "vigilantes" are a key to the home-based palliative care provided by the Kitovu Mobile Home Care Programme, which runs a palliative care service separate from Hospice Uganda in the largely rural districts of Masaka, Rakai, and Ssembabule.

Carla Simmons, originally from Detroit, USA, is medical adviser to the programme. Palliative care was started in 2000 in the context of the programme's general medical and social care of patients with AIDS and cancer.

"The numerous roadside coffin makers are a stark reminder of this epidemic of death in Uganda"

The availability of free morphine has enabled pain control and control of diarrhoea in the terminal phase of AIDS for patients in their homes, without the cost or disruption of attempting to refer patients to hospital from remote rural locations. Melita, aged 32, is one of the programme's patients in severe pain with end-stage AIDS. Her 9-year-old son is her main carer and times her 4-hourly doses of morphine by listening to the radio. When she dies she will be buried with the rest of her family in the garden. Effective palliative care means that she can spend her last weeks at home, free of pain, with her children.

To increase the accessibility of palliative care in rural areas, the patients who are still mobile or their carers assemble at community clinics once a fortnight. The community volunteers organise the clinics, held in churches, schools, or under trees. Each clinic starts with a discussion about HIV prevention and general AIDS care. The alliance of prevention and palliation may seem unusual, but works, Simmons believes, "because families are more likely to take advice from people they see are actively helping with the problem".

Despite these impressive results, however, only a very small proportion of those in need are receiving palliative care. Hospice Uganda has contributed technical advice and training to a government programme to make oral morphine available in all 56 districts in Uganda. The initiative has included educating not only health professionals but also village chiefs and the local police. Oral morphine has been made available so far in 14 districts. However, with an average ratio of one doctor to 18 700 people, 1:50 000 in some areas, a rethink of prescribing law has been necessary. The government has modified the statute by which midwives may prescribe pethidine to allow nurse specialists to prescribe morphine. The law is expected to come into effect soon, and already 17 nurses have completed the hospice's 9-month specialist prescribers course.

Good practice therefore seems to have laid to rest most of the early fears about morphine. According to Jack Jagwe, senior adviser on national policy, drugs, and advocacy to Hospice Uganda, in the past 10 years, there have been no cases of narcotic abuse or illegal diversion. Moreover, the hospice's advocacy work in other countries is also bearing fruit. Kenya, Tanzania, Malawi, and Ethiopia have taken steps to make oral morphine available. As Jagwe puts it: "They have realised they have been starving their patients of morphine."

Sarah Ramsay

Sarah Ramsay's visit to Uganda was funded by the Diana, Princess of Wales Memorial Fund, which supports Hospice Uganda and the Kitovu Mobile Home Care Programme