Palliative Care in Uganda- as experienced by 2 Irish junior doctors.

Dr.Niamh O'Connor
Dr Caroline Williams

Over the past 20 years added to its long list of problems, this troubled continent of Africa has suffered the added burden of the largest HIV/AIDS epidemic on the planet. Over 20million African deaths have been linked to the disease and in 2003 among the estimated 34-46 million people living with HIV worldwide, 26.6 million were in sub-Saharan Africa.[1] Since the widespread introduction of antiretroviral drugs (ARVs) in 2002 the situation has improved, however ARVs are not a cure. Recent data has shown that commencement of ARVs adds only an average of 4-5 years to the lives of patients living with HIV in Africa[2]. Where patients in developed countries have an array of ARV combination options available to them to ward off the nemesis of viral resistance, HIV patients in Africa usually only have first line drugs, second line at best. Against this backdrop Palliative Care has come to occupy a central role in the care of patients living with HIV and cancer in Africa.

Brief history of Hospice in Africa

The first hospice in Africa was established in Zimbabwe in the late 1970's. Island Hospice was founded in Harare in May 1979 and had developed 17 regional branches by 1997.[3] The visit of Dame Cicely Saunders to South Africa in 1979 added impetus to the development of other hospices there with the establishment of hospices in Johannesburg, Port Elizabeth, Cape Town and Durban.[4] Kenya followed suit, be it almost a decade later, with the opening of Nairobi Hospice in 1990. Palliative care started here in Uganda in 1993 inspired by the vision of the founder, Dr. Anne Merriman.

Palliative Care in Uganda

Dr Merriman, originally from Liverpool trained in University College Dublin. She was working in Nairobi Hospice from 1990-1992. Following her article in 'Contact', an edition edited by Dame Cicely Saunders[5] she was approached by people from several African countries seeking guidance on setting up palliative care services. Thus the suffering witnessed in Nairobi coupled by the cry for help elsewhere in Africa, brought the vision for an affordable and culturally appropriate model for Africa. A feasibility study of the countries requesting Hospice was carried out and Uganda was chosen to be the 'model Hospice'[6]

Hospice Africa Uganda (HAU) opened on the 23rd of September 1993 based in a 2 bedroom house loaned by St Francis Hospital, Nsambya (a Hospital founded by

Franciscan missionaries of Dundalk in Kampala). At the time there were only enough funds to support a team of 3 for 3 months. The team comprised Dr. Merriman, a nurse and a driver. Hospice then relocated to alternative accommodation and then moved one last time to it's current premises at Makindye, Kampala with the help of the Irish Government in 1994. Since then it has expanded to open 2 other centres, one in Hoima and another in Mbarara.

Palliative care in Africa has 2 essential components:
-Control of pain and other symptoms, including the use of powerful analgesics such as morphine for severe pain.
- Supportive care that includes counselling, psychosocial and spiritual support, home based care, treatment for illness, adequate food, water and shelter, legal help and family support, including school fees and other basic living needs.[7]

The latter is of particular importance in the developing world where needs we consider basic in the developed world such as food, transport and education for our children are often a struggle if not an impossibility in sub Saharan Africa, particularly in the setting of terminal illness.

Experiences of 2 Irish Junior Doctors in a Ugandan Hospice

After completing our general professional training in Ireland we came to Uganda to volunteer in Uganda's model hospice here in Kampala. Having met the founder Dr Anne Merriman during one of her trips to Dublin in February we felt assured that it was a lifetime opportunity. Indeed it has proved to be so.

The hospice or just 'hospice' as everyone refers to it as is located in one of Kampala's many hilly suburbs, a place called Makindye. It is the only Palliative care service in the city of 1.2 million people. Hospice structurally consists of a clinical, an administrative and an educational building on very nicely kept green grounds. There are no inpatients and the service operates on home visits and a drop in clinic basis.

Hospice clinical staff is divided into 5 teams, usually each having a covering doctor or medical officer, a nurse and a driver. The city is divided into 5 areas and each team covers that slice of Kampala. You learn quickly to keep your eyes peeled for directional landmarks to patient's homes as on the next visit you are likely to have a different driver and chaos in the maze of the city's slums and countryside often ensues. There are no such luxuries as addresses. Left at the mango tree past the man selling airtime under the yellow umbrella is a far more likely scenario in these parts. More often than not we get to where we are going although, often with a headache and a sore neck from the crevassed roads.

The demand for palliative care services continues to grow. In the annual period from April 1st 2006 and March 31st 2007 Hospice Africa Uganda (comprising the Kampala, Hoima and Mbarara branches) admitted a total of 2291 new patients onto the programme. This represents a 33.8% increase on the previous year when 1711 patients were admitted.[8] Of these 53% (n=1234) were cancer patients, 30% (n=695) were HIV alone, 9 % (207) were HIV and cancer and 8% (155) were classified as 'other'. (Figure 1) 'Other' cases are exceptions to the admission criteria of HIV and/or cancer. They are usually cases where patients have pain that cannot be controlled by simple analgesia and require morphine e.g. severe arthritis.

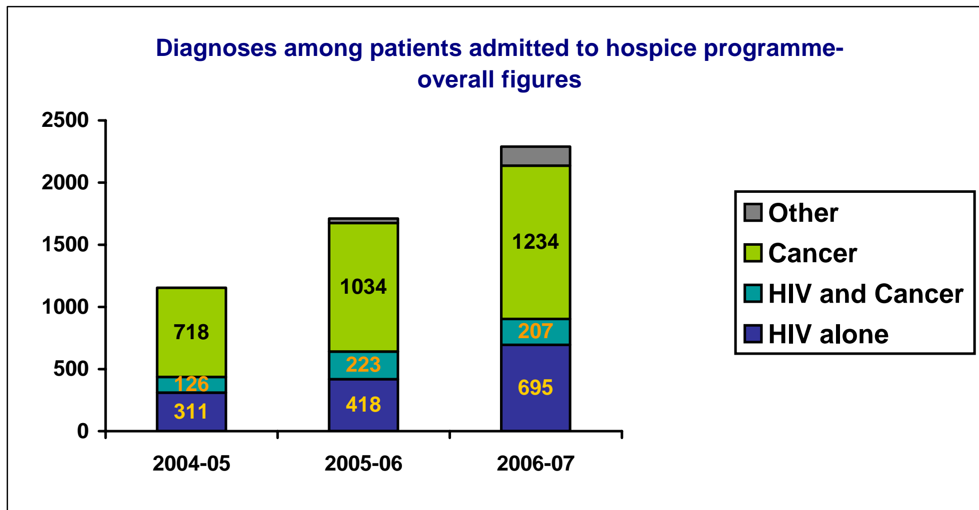

Figure 1: Diagnoses of patients admitted onto Hospice programme

The majority of patients admitted onto the programme are female. In the period 2006/07 60% of admissions were female patients(9), and this predominance of female over male referrals has been a constant trend since 1993.

The age distribution of admissions is shown below. (Figure 2) The largest group being those aged 30-40, typical of current health trends in Africa. This age group is often referred to as the 'lost generation', the age group that has been most affected by the HIV epidemic. They would normally account for the majority of parents and the majority of a country's workforce and so their decline has had a massive impact on both the economy and the family dynamics of Uganda and indeed all African countries. Grandparents and siblings are very often left looking after extended families while industries have lost many of their workers. Life expectancy in Uganda now is 47, but was 38 in 1993 when HIV positivity was at its peak.

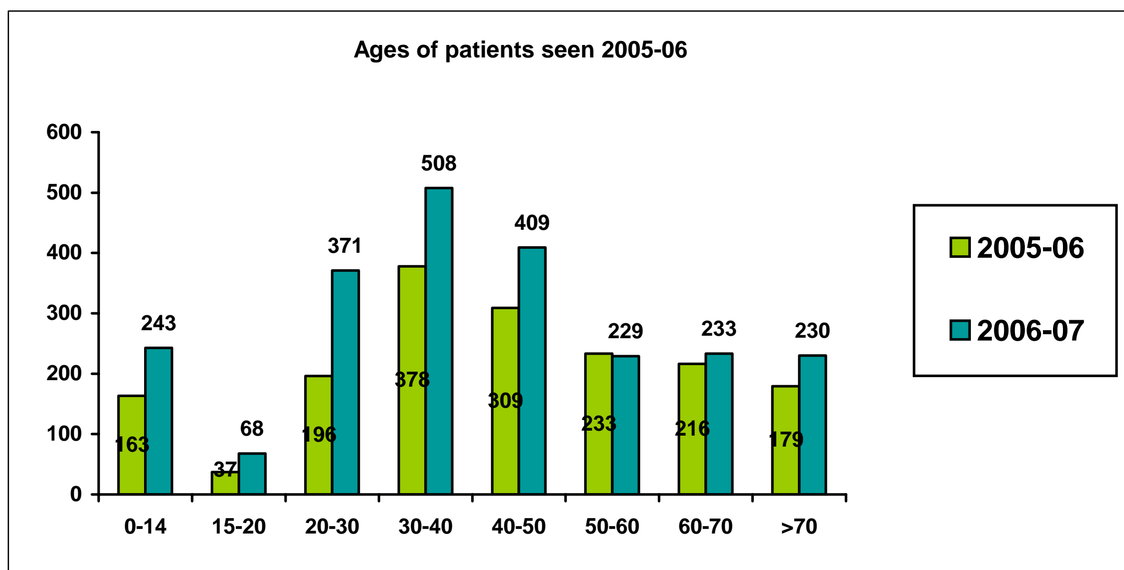

Figure 2: Ages of patients seen 2005-06 and 2006-07

HIV/AIDS in HAU

During the early 1990s HIV prevalence in Uganda peaked at around 15% among all adults, and exceeded 30% among pregnant women in the cities. At the end of 2005 adult prevalence was estimated at 6.7% and an estimated 1 million Ugandan were living with HIV/AIDS.[9] Uganda has been unique in it's approach to the HIV problem. This has a lot to do with the initial handling of the situation by the Uganda President Yoweri Museveni. He has often been applauded for his response which was different to other African nations in that it was both rapid and non-denying. There's a definite openness about HIV in Kampala and a tangible personal pride in the fact that Uganda is one of the few countries in Africa that has witnessed a decline in the rate of HIV. Ugandans feel a personal achievement in this and so they should. It's their problem, their response and their victory.

Care of patients with HIV/AIDS in HAU is both individual and comprehensive. Even with best efforts of ARV treatment programmes, many poor Uganda people fail to access services due to common social constraints such as transport costs, lack of information and lack of carers. There are also the physical constraints that limit access such as pain, weakness and hunger. Through the provision of pain and symptom management as well as offering comfort funds, transport costs, food and psychological support for it's patients HAU has helped many HIV suffers access ARV treatment programmes. It often serves as a halfway house. With a holistic approach HAU offers patients both physical and

psychosocial support before referring them to HIV treatment centres for further or joint care. Despite access to ARVs, symptom burden remains very high among HIV patients with over 40% of those referred to HAU requiring morphine for control of severe pain, and most having multiple symptoms.(8)

Cancer Care in HAU

Overall the five most common cancers we see in HAU are 1) Cervical cancer, 2) Burkitt's lymphoma, 3) Kaposi's Sarcoma 4) Breast Cancer 5) Prostate Cancer. Again the influence of HIV is clearly evident in the high positions of HIV associated malignancies on this list.

There is only one cancer treatment centre in the whole of Uganda. It is located in Kampala's largest teaching hospital, Mulago. The Cancer Institute in Mulago (the National Referral Hospital) employs Uganda's only Oncologist and 2 Radiotherapist/Oncologists. This is the only centre in the country to offer chemotherapy and radiotherapy. Most cancer patients are unable to make the multiple trips because of the financial burden. Inpatient nursing care is not as we know it in the developed world. Patients admitted to hospital must bring their own carer to clean, feed and dispense medications to them. This is almost always a family member. Given that most people are already looking after many children and trying to work to provide for extended families this is often not an option and so patients cannot attend or stay in hospital for treatment. One of the most difficult aspects of working in the palliative care setting for us in Uganda is that we have found ourselves and our teams looking after patients who are now palliative due to lack of funds for curative treatment. This is heartbreaking.

The introduction of affordable morphine to Uganda in 1993 has meant that cancer patients can now live until they die. Dying at home is the wish of almost all Ugandans and by providing home based services this can be achieved in most cases.

HAU patients are provided with bottles of liquid morphine, made up from powder in the Hospice pharmacy and costing the price of a loaf of bread for average patient's needs for 10 days. 500mgs costs 1 US$, 50p or 75 Euro cents. The morphine liquid is coloured either 'green' (1mg/ml), pink (10mg/ml) or rarely and usually for the purpose of buccal absorption blue (100mg/ml). Patients and carers are educated about its administration and potential side effects and they take a dose, measured out with a syringe, every 4 hours and a double dose at night. In our experience here patients are incredibly compliant. There have not been any reported cases of morphine abuse or diversion in Africa to date.

Ugandan people are known to be very friendly amongst African nations. Indeed this is what we have experienced. Patients welcome the team with open arms on home visits and express a level of genuine gratitude that truly is amazing. It's a steep learning curve here, both medically and socially which makes everyday at work a challenge. You really never know what you might be faced with going down the next bumpy path to a patient's home. So far, we've gotten into the boot of a car to make room to transfer a patients, gotten

stuck in mud in the middle of nowhere, filled one of our trucks with payment in the form of jackfruit and sugar cane and battled with a cow for the attention of a patient who continued to feed it grass as we held a consultation. Life and work here is never dull, always different and always worth the journey.

Hospice Uganda through it's advocacy for affordable oral morphine, dedicated staff and practical approach is helping patients who are most in to need access comfort and support in the final stages of their lives.

Picture 1: The end of the road. Our car cannot pass as a furrow has been dug in the road used the previous week to access a patient's home.

Picture 2: Completing our journey to see a patient on foot.

Picture 3: Medicine bag, prescription books & Morphine in the van.

Picture 4: Palliative Care Specialist nurse, Octivia carries out a consultation.

[1] UNAIDS/World Health Organisation : *AIDS Epidemic Update* 2003
[2] Epstein H. The Invisible Cure. Africa, the West and the fight against AIDS. Penguin. ISBN:978-0-670-91356-5
[3] McElvaine D. Zimbabwe: the Island Hospice experience. In Saunders C, Kastenbaum R. *Hospice Care on the International Scene.* Springer, 1997:52
[4] Wright M. and Clarke D. *Hospice and Palliative Care in Africa, a review of developments and challenges*. Oxford University Press. 2006 ISBN 0199206805
[5] Merriman A. Living While Dying, Contact no. 122, October 1991,Christian Medical Commission, Geneva
[6] Hospice Africa Uganda Information leaflet. January 2007. HAU.
[7] www.aidsalliance.org AVFS18 07/05
[8] 14th Annual Report, Hospice Africa Uganda 2006-2007
[9] UNAIDS/WHO 2006 Report on the Global AIDS Epidemic