



SOME FACTS ABOUT HOSPICE AFRICA UGANDA COMPLEX: MAY 2015

Bringing peace to the suffering in Africa, through providing and facilitating affordable and accessible palliative care in Uganda and other African Countries



HOSPICE AFRICA UGANDA (HAU) founded 1993 and registered in Uganda in 1994 (NGO No. 1064), is the model Hospice for HOSPICE AFRICA. Hospice Africa was founded in 1992 and registered in UK in 1993. The founding mission is to bring peace through relief of suffering in Africa through the support of palliative care. Hospice care is a philosophy, not a building, which allows patients to die in the place most appropriate to the patient and family. Thus we do not have inpatient care. Our services are available to Hospitals but the majority of our patients are at home in their communities, where they wish to die with their families and close to their ancestors.

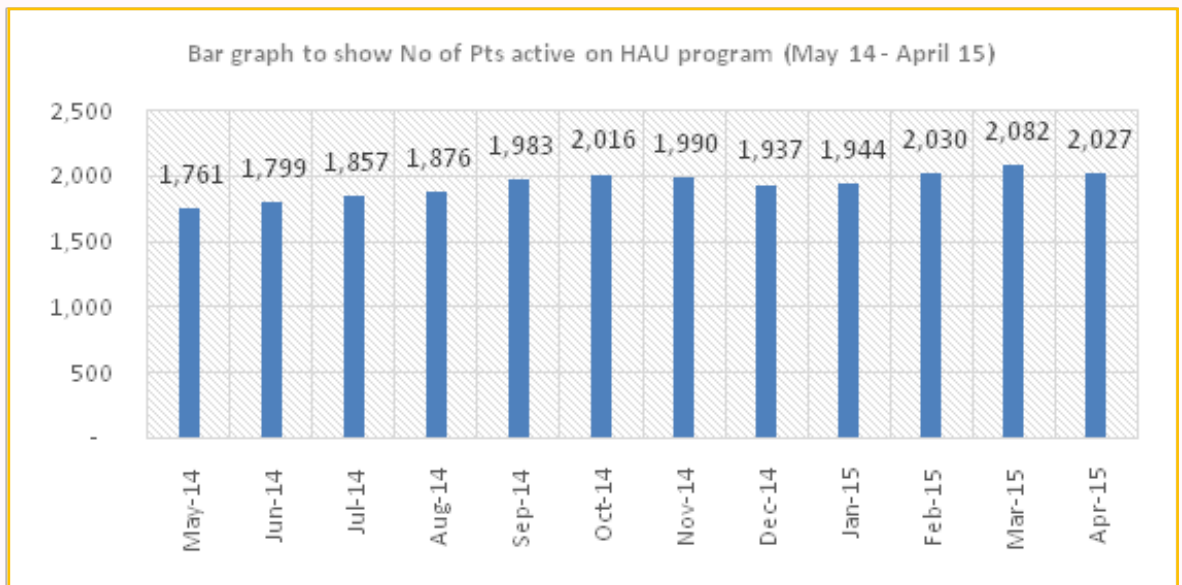
Why palliative care? 1. For cancer: less than 5% of cancer patients in Africa today, reach surgery or oncology services. 2. PC was extended to HIV/AIDS following research into the control of pain and other symptoms in place, in 1994. 3. Other conditions include, NCDs, both as co morbidities within our patients and others, who need specific palliative care because not reaching health services (50% of our people) or palliative care not yet available from their health providers. The Mission, for Africa, was to be achieved through an affordable and culturally acceptable model. Uganda was chosen as the model, and thus became the fourth country to commence palliative care in Sub-Saharan Africa. It was the first to commence with a vision for the whole of Africa. At that time, palliative care was being practiced in Zimbabwe (1979), S Africa (1980) and Kenya, (1990). Mobile Hospice Mbarara and Little Hospice Hoima commenced in 1998. HAU Complex incorporates the Clinical, Education and International Programs aspects of our work, reflected at the three sites. Each section cannot exist without each other.

Our service provides palliative care to cancer patients from diagnosis and to those suffering from HIV/AIDS and other conditions, during critical illness and end of life. We aim to give impeccable care. This is holistic support, but our care is specialised and compassionate, which is time consuming. Thus our numbers may appear low when compared to Support Organisations. However the coverage to all of Uganda is extended through those we train. Education is 50% of our work from training of families in the home, to University under and postgraduate levels. Our advocacy is to Governments, Health Training Institutions; Faith based organisations and the peoples of all countries through the media.

THE SERVICE:

HAU started a service to patients and families on 23 September 1993, with enough funding for 3 team members for 3 months. We have grown but we started as many will start in Africa today, with the first patient. We bring the modern methods of pain and symptom control, counselling and spiritual support to the patient and families. We estimate that up to 50% of our cancer and other patients also have AIDS.

1. Referrals: Most patients in Africa and beyond prefer to be at home when very ill so we encourage discharge home as soon as possible. In latter years community volunteers have been referring patients who are in need from their villages, many of whom have never seen a health worker. From 1993-2003, majority of our



patients were referred from hospitals but most are now from the communities. We have managed the majority of patients at home, breaking through severe pain, using the modern methods of symptom control. 57% of people in Uganda do not access a health worker but now they too can access palliative care through their trained community volunteer and referral systems within their community.



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2. Cost and contributions: Patients are asked to pay 10,000/- per week, towards the total cost of 86,200/-¹ cost for care per week, independent of the no. of visits and medications. About one third of our patients can manage to pay this small contribution. We assist those who cannot afford (60%). Those who are very ill are cared for at home; those who become stronger and are able are encouraged to attend our clinic or day care, at Hospice itself. The total cost includes transport and specially trained staff.

3. Three Hospices: We have three Hospices in Uganda. The three Hospices are part of the umbrella organisation based at Makindye, Kampala. In January 1998, Mobile Hospice Mbarara (MHM) was commenced to provide a model service for the communities in Mbarara and a training facility for the second medical school, Mbarara University of Science and Technology (MUST). In June 1998, Little Hospice Hoima (LHH) was commenced in a shop front in a very poor area of Uganda to demonstrate how Hospice can be commenced with few resources: PC starts with the first patient!

By 30th April 2015	Patients on Programme				Patients cared for to date
	Children (<15)	Adults (15-65)	Elderly (>65)	Total	
HKLA	56	531	147	734	13,064
MHM	62	461	226	749	9,128
LHH	47	463	34	544	3,787
Total	165	1,455	407	2,027	25,979

Patient care: Palliative care is time intensive so our statistics may appear low. Also we estimate that a further 25,000 may have been looked after by those we have trained and are working in health facilities and other Hospices in Uganda, However, although 74% of Districts have a palliative care service, palliative care is still not even reaching 10% of those in need. We have a long way to go!

4. Spreading the care: Those professionals we have trained at HAU and other facilities commenced through HAU, including PC Association of Uganda (PCAU), African PC Association (APCA) and Mulago Palliative Care Unit (PCU), are now working in 90 of our 122 Districts and 133 health facilities are providing palliative care². They are followed up and given further training in conjunction with PCAU. Community volunteers, help care for patients as well as identifying those who need our care when critically ill or at the end of life. They are working with our own teams in Hoima, Kampala, Mbarara, five other free standing Hospices and District teams. We aim to have trained volunteers' country wide. They work closely with those we have trained, in the Districts. Presently all three Hospices are working with MoH.

II TEACHING PROGRAMMES WITH IHPCA:

Without education, palliative care remains within the catchment area. In order to follow the founding Mission to reach all in need in Africa, we are teaching others to fish! The Education Department was recognized by the National Council for Higher Education as a Tertiary Institute in 2009, now renamed "Institute of Hospice and Palliative Care in Africa" (IHPCA). We have a wide spectrum of training programmes ranging from traditional healers and our community volunteers to professional health workers with a degree in palliative care for Africa. Uganda is the only country in Africa recognised to have comprehensive PC service³. It is a model to other African countries. In order for palliative care to be brought to all in need in Uganda, it is essential that palliative care is part of the work of all health professionals as well as the concern of all caring communities. In October 2014, IHPCA was granted the "Other Degree Awarding Institution" status which means it can now award its own Degrees although Affiliation with Makerere will be maintained. In December 2014, HAU's Research and Ethics Committee (HAUREC) was accredited by Uganda National Council for Science and Technology⁴.

Teaching commenced with the clinical service in 1993. The main targets were the undergraduate medical and nursing students and health professionals already in practice. Core short courses were commenced and added to over the years. These include Courses ranging from 3 days to 7 for Health professionals, allied professionals, carers, community volunteers, spiritual leaders, traditional healers, introduction to counseling at the end of life and Training of Trainers (TOT). 2012 brought the "Rapid Prescribers" course as we train Clinical Officers in palliative care and prescribing morphine. These programmes are led and shared across the education departments of each of the three sites.

¹2014 cost equivalent to US\$ 34, Euros 26 or £21 per patient per week.

²PCAU Newsletter May 2014

³WHO & WHPCA: Global Atlas of Palliative Care, 2014

⁴TeHAUREC can now review research protocols submitted by National and International researchers for ethical approval of any research on human participants in Uganda.

Long courses were commenced in 2003. These are the 9 month residential Diploma in Clinical Palliative Care (DCPC), conferred by IHPCA, which equips nurses and clinical officers to deliver specialized palliative care and to prescribe morphine. 131 have successfully completed this course since 2004, and have been awarded their Diplomas. Uganda is the first country to increase prescribers for those in need in this way. Uganda and other African countries are very short of doctors who are the only prescribers in other countries.

Bachelor's degree programme commenced in July 2010. This is a distance learning (e-learning) programme delivered by IHPCA

and presently conferred by Makerere University. The first year can be completed as a Diploma and those with a PC diploma, including DCPC, can enter the degree at year 2. The third BSc in palliative care for Africa was conferred in January 2015. This equips our colleagues in Africa with specialist knowledge, experience and status, enabling them to become advocates, clinical specialists and teachers.



Health workers trained by HAU in Northern Uganda showing a patient how to measure oral liquid morphine before taking it during home visit. The HAU trainer 2nd from right, was assessing their competencies.

Since 2006, we have held a 9 week programme for Tutors in Health Schools throughout Uganda so that training within undergraduate programmes can be extended to all the health professionals of the future.

Training in Palliative Care to date:

1993 up to 30 th April 2015	Short Courses						Long Courses						Medical students	Total	
	HPs and Managers	CVWs	Others	PC Initiators	Health Tutors	Rapid Prescribers	Distance Learning			DCPC					
							Graduates		On training		Graduates	On training			Awaiting grad
							DPC	BSC PC	Yr 1	Yr 2					
3349	838	1981	207	92	80	166	46	32	21	20	131	15	14	3,132	9,643

Hospice Uganda has teaching sessions for undergraduate and postgraduate doctors at Makerere University since 1993, and Mbarara Medical School (MUST), since 1998. These include teaching at the bedside in the home. Also in 1998, palliative medicine became part of the curricula in both medical schools and examinable. In October 2008, the first palliative medicine unit was developed under Internal Medicine at Makerere University (MPCU). The remit is education, clinical service and research.

III INTERNATIONAL PROGRAMMES IN AFRICA:

Since 2000, we have worked with other African countries, following our founding mission. The Model (HAU) is now in place. Thus the founding vision of HA and "third objective" of HAU are promoted through our International Programmes. Commencing with training for Tanzania in 2000, we have been visiting other countries, introducing affordable oral morphine and training new initiatives on the ground. Through advocacy to 20 countries, and later by visiting the services, commencing in these countries, Hospice Africa in UK and France, have supported with training and financially, eleven of these initiatives in eight countries and two in Francophone countries. The Initiators programme is run from International Programmes and to date 147 from Anglophone countries and 60 from Francophone countries have attended this 5 week training. Teams from Uganda have visited, and worked alongside new teams while learning their cultural and economic needs and assisting in setting standards and training on site.



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The countries we are presently working with, include Nigeria, Cameroon, Sierra Leone, Ghana, Congo Kinshasa, Cote d'Ivoire, Tunisia, Senegal, Malawi, Ethiopia, Sudan, Rwanda, Togo, Benin, Guinea Conakry, Burkina-Faso, Mali, Tanzania, Kenya, Zambia and Mauritius. Training programmes have been initiated in some countries and others come to initiators training in Uganda to see how palliative care can work in African countries, within the cultural and economic conditions of today. Other countries send their palliative care leaders for the degree programme and are followed up in country by International Programmes, the Institute of Hospice and Palliative Care in Africa (IHPCA) at HAU and APCA (African Palliative Care Association).

Accommodation in HAU (Makindye)

We have 15 residential rooms for those in training from other African countries. Other health professionals from Uganda and overseas students on electives with hospice also use this facility. However because of limited space, many of our course participants are accommodated in local affordable hotels.

IV FINANCIAL SUPPORT:

Commencing in 1993 with enough funding for 3 team members for 3 months, the annual budget was £24,000 pounds. The budget is now for the three Hospices with 100 in the teams, risen to £1.5M (2M Euros or 2.5M US\$) per year. Meanwhile the patients on the programme have increased from 30 to 2,000+.

Hospice Uganda is entirely dependent on the goodwill of donors. In UK, support comes from two charity shops (Liverpool and Ainsdale) and in France from a Charity Shop in Brittany, all run by volunteers. Major donors have supported us including Irish Aid (18 years) and USAID (10 years) Hospice Africa is registered in UK, Ireland, US and France. We also have financial support currently coming from DFID for the extension of Paediatric PC in Western Uganda; the project commenced on 1st June 2014 and is currently working from MHM. Due to the recession, resulting in donor withdrawal, and recent high inflation, we are now in greater need and are grateful for any support to expand this service to the many still suffering in Africa.

SUPPORT IN UGANDA:

Hospice Uganda is an NGO, registered in Uganda. The Ministry of Health has supported Hospice and Palliative care for the poorest, since we first came in 1993, including paying for oral morphine for use in the home. We have a dedicated Board of Directors who meet quarterly or when necessary. Many volunteers support the work selflessly, particularly improving quality of life for our patients. The Churches, and several companies and organisations in Uganda have assisted us.

If Hospice Uganda is to belong to Uganda, we need to have regular donors and Well-wishers in Uganda. We need businesses and corporate bodies to take on our needs to provide for our patients and families as part of their corporate responsibility. If you live in Uganda, please support our fund raising functions, monthly sales and annual Charity Walk and Fund Raising dinner. Items for sale at the Charity Shop (on site), including your wardrobe contents are gratefully received. Donations of items suitable for sale are gratefully received. If you live elsewhere, donations can be made at <https://mydonate.bt.com/charities/hospiceafrica>

HAU has received several awards for its work in Africa from APCA, KEHPCA and Presidents of Uganda and Ireland. The Founder was nominated for the Nobel Peace Prize, 2014.

V CONTACTING HOSPICE:

To continue this essential work we need your prayers, further financial support and volunteers. Those interested please come and visit us at the Hospice "Nyumba Yemirembe Mu Uganda" situated on Plot 30 Makindye Rd, Kampala or Mobile Hospice Mbarara, on Fort Portal Road, first turn right (see sign), first on right, or Little Hospice Hoima on Kijungu Hill Road in Hoima Town.