



Sustain home-care for 140 cancer-patients @Uganda

Organisation:	HOSPICE AFRICA UGANDA
Budget:	UGX 121,070,615 (\$ 33,170)
Funding request:	UGX 66,588,838 (\$ 18,244)
Beneficiaries:	At least 140 patients seen on home visit
Implementing Agency	Hospice Africa Uganda (HAU) Reg. No.: INDR11821865NB
Main goal for the funding request:	To enhance access to home-based hospice and palliative care services for patients and families in need
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OVERVIEW OF THE PALLIATIVE CARE NEED

Today, the world is faced with an increasing burden of chronic and life-limiting illnesses e.g. cancer, other non-communicable diseases (including heart diseases), HIV/AIDS etc. Thus the need for Palliative Care (PC) for pain, symptom management and management of other socio-economic distresses faced by the family / caregivers is indispensable. Globally, an estimated 56.8 million people need PC annually, 52.8million being adults 18+ years while 3.98million are (children aged 0-17 years)¹. Africa has the largest proportion of adults and children in need of PC¹. Worldwide, only about 14% of people who need PC currently receive it².

Chronic and life-limiting illnesses cause substantial health-related suffering to millions of people and families around the globe. According to the Lancet Commission report on palliative care and pain relief, more than 25.5 million (45%) of the 56.2 million total deaths recorded worldwide in 2015 experienced serious health-related suffering (SHS), and at least 80% of these were from LMICs. Every year, almost 2.5 million children die with SHS, and at least 98% of these are from LMICs with limited resources.

In Uganda, as well, cancer and other NDCs continue to rise and the unmet need for palliative care still remains immense.

According to the Uganda Bureau of Statistics (UBOS) population estimates, of the 42million Ugandans³, 411,593 adults and 86,167 children in Uganda need PC every year and yet only a paltry 6,966 people receive the services². Owing to low/poor socioeconomic status, majority of the Ugandans are poor and cannot afford health services. Their poverty is further deepened when they get incurable illnesses, mainly cancer. A 2017 study found 46 % of cancer patients at one regional referral hospital in Uganda met the World Bank's definition of extreme poverty - \$1.90/person/day⁴.

FUNDING REQUEST: Funding support towards sustenance of home-based hospice and palliative care services for 140 patients at Hospice Africa Uganda (HAU)

HAU delivers home-based care for the extremely vulnerable palliative care patients. These include; those who are bed-ridden / very sick, those who require specialized transportation means to a health facility and yet cannot afford this, those whose condition is worsened by travel such as the elderly and / or very sick, those who are stigmatized by their family / caregivers or

¹ WHPCA & WHO (2020): Global Atlas of Palliative Care 2nd Edition Worldwide Hospice Palliative Care Alliance, Hospice House, 34-44 Britannia Street, London WC1X 9JG. Available at

<http://www.thewhpc.org/resources/global-atlas-on-end-of-life-care>

² WHO (2020): Fact sheet palliative care. Available at <https://www.who.int/news-room/fact-sheets/detail/palliative-care>

³ UBOS (2020): End of month population projections 2015 – 2040. Available at <https://www.ubos.org/explore-statistics/20/>

⁴ Anderson GA, Ilcisin L, Kayima P, Abesiga L, Portal Benitez N, et al. (2017) Out-of-pocket payment for surgery in Uganda: The rate of impoverishing and catastrophic expenditure at a government hospital. PLOS ONE 12(10): e0187293

are living in complex social environments that do not allow them to travel to the health facility, those that are in special camps or living environments such as refugees.

Home-based care is provided by the PC multidisciplinary teams which include nurses, doctors, a spiritual care provider, a social worker, a pharmacist / dispenser and a driver. However due to scarcity of resources, most often visits are done by a nurse who then ensures to include any other support as and when it is necessary.

Expected outputs, outcomes and impact:

Through this support, we expect to continue to deliver home-based PC for at least 140 patients and more. Over a period of 12 months, we expect to visit these patients monthly or even more frequently depending on their disease condition.

The expected outcome is reduced symptom burden and frequency of re-admission for the patients. Their families will further experience reduced health expenditure.

In the longer term, both patients and families will experience an improved quality of life. We have seen that in fact some patients and care takers later resume gainful employment. This improves their welfare impacting positively on the family and community at large. This project will further increase understanding and support for this kind of care.

Rationale for the funding request

For 28 years, HAU has provided home-based hospice and palliative care for all patients regardless of their age, sex, ethnicity, religious affiliation, political inclination and socio-economic status. This work was greatly supported by well-wishers and occasionally grants. The gains made risk being undone by the shortages in donations, a situation exacerbated by the current global Covid-19 pandemic.

BUDGET FOR HOME-BASED HOSPICE AND PALLIATIVE CARE AT HOSPICE AFRICA UGANDA

Activity	Description	Frequency	Amount (UGX)	Amount (USD)	Budget notes
1	Fuel for home visits	Monthly	25,056,000	\$ 6,865	The fuel cost is estimated on the distance from the home to the hospice site either Mobile Hospice Mbarara, Little Hospice Hoima or Hospice Kampala
2	Drugs and medical sundries for home visit	Quarterly	10,520,000	\$ 2,882	We procure medicines for hospice and palliative care every quarter. We provide them free to patients.
3	Comfort fund and basic needs support	Monthly	3,450,000	\$ 945	Basic needs of an emergency nature such as would be met by this budget line include food, clothing, shelter, emergency referral to a higher facility.
4	Salary support for one nurse and a driver	Monthly	82,044,615	\$ 22,478	This includes basic salary only
GRAND TOTAL			121,070,615	\$ 33,170	
AVAILABLE FUNDING			54,481,777	\$ 14,927	
HAU REQUEST FOR SUPPORT			66,588,838	\$ 18,244	

CONCLUSION

Hospice Africa Uganda has been serving the palliative care needs of over 35,000 very sick cancer and / or HIV /AIDS patients, adults and children, meeting their needs in a holistic manner that is physical, emotional, psychological and social. We have managed these achievements because of generous people from all over the world, who are passionate about our vision and mission. We need to be there for our present patients and even new ones especially in this COVID-19 pandemic but as in the words of Helen Keller, *“Alone we can do so little; together we can do so much”*. We really appreciate the work that you do wherever you have touched the needy.

Thank you.

A patient's narrative

I thought it best to write down an article in acknowledgement of the team of Mobile Hospice Mbarara, a branch of Hospice Africa Uganda.... For starters, I am a patient of Hospice who joined them in 2004. I found out that I was sick with HIV in 2001. Life had become very frustrating, threatening and miserable for me due to the intolerable pain that I had due to the sickness and I hope anyone who has had similar experience will agree with me. Believe you me, since I landed on Hospice team, life changed in a miraculous way and I should thank them for the expertise they have. I started getting medications which are one of the biggest relievers of pain, mostly morphine which you take in intervals as prescribed by them for patients with stubborn pain like the one I had. After you have got those doses (**of oral morphine**), it is like you forget almost even that pounding pain that had bedridden you for some time. The encouragement is really superb (**the counselling provided**). Deep in your heart you feel you are a new creation even though you are fully aware that you will never make it. The assurance alone makes you believe that no matter what, you at last have found a home where you belong; even though the days ahead are darker.



SKT in 2004 when she first met hospice (L) and later in 2021 (R)

They assisted me in many ways like; supporting me with most of my basic needs, transport to hospital for check-ups and exercises to mention but a few. So, me generally being in their company fulfills my desires and for once I know I have a future ahead. Once again, thank you so much Hospice team for all your care, love and understanding...Lastly, to the patients out there, I encourage you to join hospice for your pain control and counselling. Do not struggle alone; it is a wonderful team to deal with your pains. You will never regret and you will just get back on your feet and return to your destination full of smiles. So, all you need to know is that Hospice is there and will always be there to handle all your troubles. So, on my own behalf, I will just conclude by giving you the Hospice team the blessing of God and to ask you always to support where you can. I will never forget to give them a handful of thanks for the job excellently done. **Bravo Hospice!"**