



THE UNIVERSITY of EDINBURGH
Global Health Academy



UGANDA PALLIATIVE CARE NURSE LEADERSHIP PROGRAMME

What is the Uganda Palliative Care Nurse Leadership Programme?

The Uganda Palliative Care Nurse leadership programme is an exciting new programme and aims to develop nurse leaders within palliative care in Uganda. Nurses in Uganda have an important role to play in the provision of palliative care, thus by developing nurse leaders it is hoped that we will be able to support the ongoing development and leadership of palliative care within the country, and ultimately improve the quality of life of those needing palliative care. The leadership programme is focused on the development of nurse leaders from different parts of the country, different types of organisations, and working with both adults and children, and in the hospital and community settings. A key component of the project is Clinical and organisational modelling of nurse leadership by palliative care nurses from the UK recognised as leaders in the field

Why nurses and not the multi-disciplinary team?

In the past there have been various programmes aimed at developing leaders in palliative care but they have not been open to nurses, however in Uganda, nurses form the backbone of palliative care, particularly in the rural setting where there is a shortage of doctors. Thus, whilst we believe very much in multi-disciplinary team working in palliative care, this programme is providing an opportunity for nurses to develop as leaders.

Who is running the programme?

It is being run by a partnership between the University of Edinburgh, Makerere University and the Palliative Care Association of Uganda (PCAU), funded through a grant by THET from UK aid. The lead for the project is Prof. Julia Downing who is an Honorary Professor at Makerere University.

What are the aims and objectives of the programme?

The project aims to develop nurse leaders within palliative care in Uganda. By developing nurse leaders it is hoped that we will be able to support the ongoing development and leadership of palliative care within the country, and ultimately improve the quality of life of those needing palliative care. Specifically the project will focus on four main objectives:

- (1) The development of nurse leaders through a nurse leadership development programme, focusing on developing leaders from different parts of the country, different types of organisations, and working with both adults and children, and in the hospital and community settings.
- (2) Clinical and organisational modelling of nurse leadership by specialist nurses from the UK recognised as leaders in the field.
- (3) The expansion of the link-nurse programme, developed at Mulago Hospital, to other hospitals in Uganda in order to develop nurses who can take a lead on palliative care within their wards and hospitals, thus improving the provision of palliative care in their hospitals and surrounding area.
- (4) Working closely with the Ugandan Nurses and Midwives Council in demonstrating the importance of the role of specialist nurse in palliative care, thus laying the foundations for both professional recognition and career progression.

UK Mentorship

Health links and mentorship are important facets of any THET funded partnership programmes. One of the objectives is about clinical and organisational modelling, thus we have set up a mentorship programme for this project, linking mentors in the UK with mentees in Uganda. There are two types of mentors within the programme, those who are able to go to Uganda for an extended period e.g. two-months to a year, and those who can provide regular ongoing mentorship to the nurses remotely from the UK with short visits to Uganda to meet their mentees where possible.

What does 'remote mentoring' involve?

Our model of remote mentoring is currently being developed, however we have several mentor 'hubs' either made up of a team from individual hospices or individuals working together as a 'hub'. Each hub mentors 3-4 of the nurses on the nurse leadership programme. Mentorship takes place via skype, email, WhatsApp and other innovative ways.

In what areas is mentorship provided?

Each of the nurses on the leadership programme has set their leadership goals, and developed an action plan with regards to their own personal leadership skills, along with leadership activities at their work place. During the second part of the programme, the nurses are working together, under supervision, on national level projects including: reviewing training to ensure that it is 'fit for practice'; assessing clinical competency; undertaking a rapid appraisal; and evaluating the new nurse link programmes. The mentors may therefore also have an input into these different projects through their mentorship role.

An induction day was held in December 2015 for the mentors. This day was to set the scene with regards to palliative care in Uganda, introduce them to the nurse leadership programme and discuss the options for mentorship.

What do UK organisation gain from being involved in the project and providing mentorship?

As more and more individuals and organisations are getting involved in international support for palliative care, the evidence is emerging¹ to suggest that volunteering and providing mentorship, whether face-to-face or remotely, can provide real benefits for staff, giving them a fresh perspective, new skills and approaches that can be applied in their own workplaces, developing new knowledge, skills and behaviours learnt from being exposed to different cultures and settings. Alongside this, we are keen to promote the project through our website but also through e-hospice and other social media opportunities. Organisations will be linked to specific nurses who they will mentor, and we will promote the work of the organisation in the project through regular articles in ehospice, blogs and facebook posts. The organisation will also be partners in any reviews as to the role of mentors, papers and publications in this area.

Which partners are involved:

The following organisations have partnered with us on this project to provide mentorship:

- Hospice in the Weald, Kent - <http://www.hospiceintheweald.org.uk>
- St Columba's Hospice, Edinburgh - <http://www.stcolumbushospice.org.uk>
- Palliative Care Works, - <http://www.palliativecareworks.org>
- Dorchester Palliative Care Team
- Princess Alice Hospice - <http://www.pah.org.uk>

¹ <http://www.thet.org/hps/files/innovative-workforce-development-the-case-for-international-health-links>

The Nurse Fellows

The nurse fellows come from across Uganda. Some work with the Ministry of Health in government facilities, some work in NGO's and others in specialist palliative care programmes. The nurse fellows are as follows:

1. Kelet Kalemba – Bwera Hospital, Kasese
2. Biira Yayeri – CARO, Kasese
3. Apollo Arishaba – MJAP Bwizibwera Health Centre IV, Mbarara
4. Mathias Dusabimana – Kabale Hospital, Kabale
5. Jane Mwesige - Kibaale
6. Vicky Opia – Adjumani Hospital and Peace Hospice, Adjumani
7. Viola Ederu – Yumbe Hospital, Yumbe
8. Rose Ngamita - Nebbi General Hospital, Nebbi
9. Ojera Alex Latim – Dr Ambrosoli Memorial Hospital, Kalongo
10. Margaret Kasirye – MSH, Tororo
11. Amoris Jane Okoth – Tororo Hospital, Tororo
12. Nandutu Edith Rita – Bombo Military Hospital, Luwero
13. Margaret Sekyondwa – Mildmay Uganda, Wakiso
14. Charlotte Komunda – Palliative Care Association of Uganda (PCAU), Wakiso
15. Rashidah Nabukalu – Kibuli Hospital, Kampala
16. Rosemary Namwanga – Hospice Africa Uganda, Kampala
17. Roselight Katusabe – Hospice Africa Uganda – Kampala
18. Mwazi Batuli – Makerere/ Mulago Palliative Care Unit – Kampala
19. Liz Nabirye – Makerere/ Mulago Palliative Care Unit – Kampala
20. Florence Nalutaya – Makerere/ Mulago Palliative Care Unit - Kampala

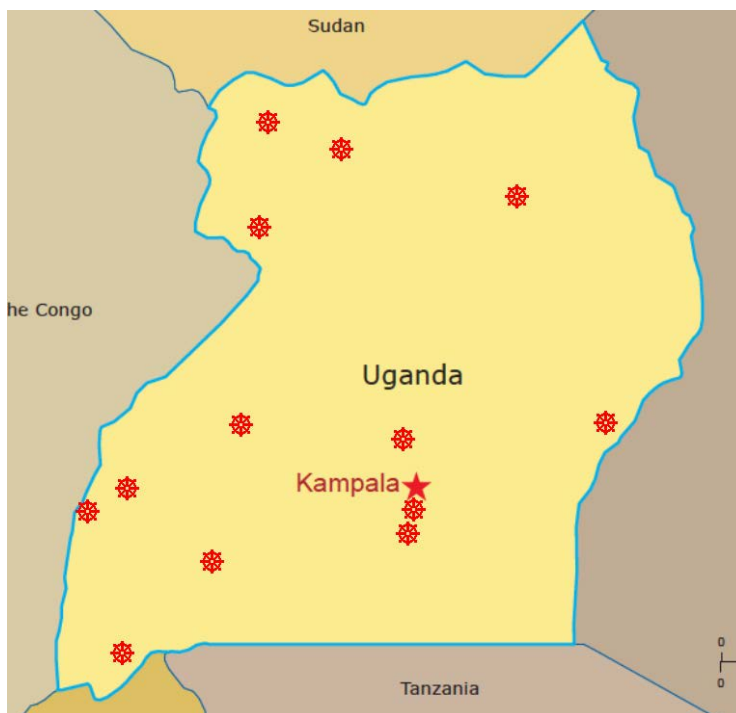


Photo of nurse leaders



Case Studies about some of the nurse fellows

Kelet Kalemba



Kelet is a nurse who works in Bwera General Hospital in Kasese, Western Uganda. He undertook the Diploma in Clinical Palliative Care run at the Institute of Palliative Medicine for Africa, at Hospice Africa Uganda. He developed as a nurse starting as a nursing aide, then an enrolled nurse and then finally qualified as a registered nurse. Since 2011 he has been working as the in-charge for palliative care services for the hospital, providing patient care as well as supporting other staff in the hospital. Prior to that he worked as in-charges for several different wards in the hospital, and is seen by the hospital manager as being a key future leader – their recommendation stated that “*He exemplifies himself as a reliable person, highly motivated and a team player.*”

Kelet was keen to undertake the course due to his “*quest for leadership skills, improving on my team work skills and advocacy for the patients. I am highly hopeful that at the end of this programme, I will be a better leader, team player and an all round professional in terms of handling palliative care cases, and all cases across the nursing profession.*” On describing himself as a leader on commencing the course he noted that Nelson Mandela, John Gerang and Desmond Tutu are role models, people he aspires to – someone who is patriotic, patient, exemplary, self-sacrificing and honest. He finds his work rewarding, is humble, forgiving, determined and focused. On completion of the Leadership Practices Inventory he scored highest in terms of encouraging the heart, enabling others to act, and modelling the way. He needed to work on challenging the process and inspiring a shared vision. At the end of the first module he noted “*the importance of learning about the practices of leadership*” and highlighted in his action plan how he needs to work more with the hospital team and administration to inspire a shared vision, so that the PC services is not seen just as his service, but an integrated part of the hospital, and in order to improve access to palliative care services within the hospital. Although he scored quite well in terms of enabling others to act, he also recognised the

importance of building capacity and mentorship and supporting others to develop. He plans to implement the link nurse training in collaboration with one of the other nurse leaders – Biira, who also works in Kasese. On sharing what he had learnt over the previous six months at the start of the second module, he shared that “when I went back after the module I was in the PNO’s office for a while, acting up as PNO, as the PNO had gone for maternity leave and I initiated a programme to encourage the heart and he helped the hospital administrator to understand the importance of appreciating the work of others and encouraging the heart, and this programme is still ongoing after I left the PNO’s office.” He also realised that “doctors needed to be empowered re knowledge and skills in palliative care so they can lead the way – particularly in terms of prescribing oral morphine, so I initiated some training for the doctors despite the challenges, and also the district drug inspector also attended. When issues come along we are addressing them. I have also been able to link more into the national palliative care association (PCAU) and we have had meetings with the village teams and there is more linkage to us which is good.” He is in a mentorship hub supported by a team of nurses from Dorchester and has been communicating with them, and is working on the project to evaluate nurse prescribing.



How Kelet described himself as a leader



Kelet and his project group working on the work plan for the project to evaluate nurse prescribing supported by Prof Downing – the nurse leaders in the photo are Rashida, Jane, Mwazi, Charlotte, Kelet, Apollo, Matthias and Biira

Vicky Opia



Vicky is a nurse who completed a Diploma in Palliative Care through Makerere University in 2009 and then upgraded this to a degree when the degree became validated – she was one of the first nurses to graduate with the BSc in Palliative Care in 2013. She works in Adjumani, which is in Northern Uganda, an area where there have been many challenges over the years, initially due to the unrest caused by the Lords Resistance Army and more recently they have many refugee camps for refugees from South Sudan. She has been working at the hospital since 2009, and since 2013 has been the Co-ordinator for Palliative Care. She is also the technical director for Peace Hospice in Adjumani District which is a new NGO. She works as a lone palliative care practitioner and chose to develop her palliative care skills as a response to the ever-increasing demand for services for people with life

limiting illnesses and to improve those services. She applied to the nurse leadership programme as she felt it would *“prepare me to have a global outlook on issues of leadership intervention and response, the opportunity to acquire easily transferable knowledge and skills so the community she services will benefit from them, because the university provides uniquely excellent taught and research contentfor Uganda and globally. I believe myself a good candidate for the leadership programme because I am a young, energetic, hardworking, visionary, and motivated person who believes that I can do something for the benefit of my country.”* On commencing the programme she described herself as someone who is able to undertake hard tasks, confident and exemplary, visionary and focused, motivated, innovative and assertive, she also felt that she was a team player and potentially in an influential position in the district. She found the first module of the course very helpful and insightful in looking at her leadership skills, in particular she says *“I learnt about conflict management – at my work place they had conflict with regards to implementing palliative care and realises that she needed to use different conflict styles. In particular I used to avoid the hospital administrator whenever I saw him, pretending to be on the phone, or busy – since understanding more about how I tend to avoid conflict, I went and spoke to the administrator who I had been avoiding, and it went well and now he is supportive of palliative care and palliative care is doing better in the hospital.”* Her action plan focused on enabling others to act through mentorship and she was keen that palliative care would continue when she is not there, challenging the process to ensure that palliative care was included in the district work plans, involving others and having a focus point for palliative care in the hospital. Launching palliative care and the hospice on world hospice and palliative care day and implementing the link nurse programme. She identified 20 nurses to be link-nurses and they were trained in January with support from two of the

other nurses on the leadership programme – Viola (Yumbe) and Liz (MPCU). She also involved local facilitators in order to ensure buy-in to the programme. The course was well evaluated by the students and Vicky is providing ongoing mentorship to the nurses and hopes also to hold quarterly update days to bring them together and share experiences. Vicky is part of the team working on the evaluation of the link nurse programme – she is working with Florence (MPCU), Viola (Yumbe) and Rose (Nebbi) to evaluate the implementation of the programme in several different hospitals around the country and is excited to be able to put into practice some of the skills that she learnt on the degree course. She is receiving remote mentorship from Diana Opio, Michelle McGannon and Jane Appleton (photo attached) and is finding that valuable in exchanging ideas and talking through issues.



Vicky's poster describing herself as a leader



Vicky with her mentor hub, Viola and Rose, with Prof Downing, meeting her mentors on skype

Dissemination

Dissemination of information about the project and its impact is important, To date there have been various routes of dissemination including the following:

ehospice

- Implementing a nurse leadership fellowship in palliative care in Uganda - <http://www.ehospice.com/africa/Default/tabid/10701/ArticleId/18390>
- Mentoring Nurse Leaders in Uganda – my first experience (Janice Logan) http://www.ehospice.com/articleview/tabid/10686/articleid/18393/language/en-gb/mentoring-nurse-leaders-in-uganda-my-first-experience.aspx?utm_campaign=website&utm_source=sendgrid.com&utm_medium=email
- Professor Julia Downing receives an Honorary Fellowship from Cardiff University <http://www.ehospice.com/internationalchildrens/Default/tabid/10670/ArticleId/19987/>

Conferences

- IAPCON (Indian Association for Palliative Care) Conference Feb 2016 (Can we add the pdf http://www.ed.ac.uk/files/atoms/files/nurse_leadership_and_link_nurse_poster.pdf)
- Implementation of a Palliative Care Nurse Leadership Programme in Uganda. APCA/WHPCA Conference August 2016 – link to pdf
- Rapid Appraisal of the Health System in Uganda in the context of palliative care nurse prescribing. APCA/WHPCA Conference August 2016 – link to pdf
- Evaluation of Nurse Opioid prescribers in Uganda. APCA/WHPCA Conference August 2016 – link to pdf
- The Uganda palliative care nurse leadership programme: Partnership with a hospice in the UK. APCA/WHPCA Conference August 2016 – link to pdf
- Implementation and evaluation of the palliative care link nurse programme in Uganda. APCA/WHPCA Conference August 2016 – link to pdf
- A review of the curriculum of nurse opioid prescribers – How competent in prescribing are they after the training. APCA/WHPCA Conference August 2016 – link to pdf

Other articles relevant to the project:

- Recognising Women as change agents in oncology - http://www.roche.com/media/store/roche_stories/women_as_change_agents.htm
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Publications:

- Downing J, Leng M and Grant L. (2016). Implementing a Palliative Care Nurse Leadership Fellowship Program in Uganda. *Oncology Nursing Forum* 43(3) 395-398. DOI: 10.1188/16.ONF.395-398 (<https://onf.ons.org/onf/43/3>)
- Downing J, Batuli M, Kivumbi G, Kabahweza J, Grant L, Murray SA, Namukwaya E, Leng M (2016) Evaluation of a palliative care link nurse programme in Mulago hospital, Uganda: An evaluation using mixed methods. *BMC Palliative Care* 15:40 DOI 10.1186/s12904-016-0115-6 (<http://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-016-0115-6>)



Contact

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