Policy dialogue

Palliative Care for Uganda

Kampala, Uganda
07 August 2012

Report

This report was prepared by the Uganda country node of the Regional East African Community Health (REACH) Policy Initiative.

This policy dialogue was informed by the following policy brief: Nabudere H, Obuku E, Lamorde M. Advancing the Integration of Palliative Care into the National Health System (SURE policy brief). Kampala, Uganda: College of Health Sciences, Makerere University, 2012 www.evipnet.org/sure
Key messages

The following statements represent views, opinions and insights of individual participants in the policy dialogue.

- There is a high burden of cancer, heart disease, accidents and other conditions all contributing to the palliative need.
- Policy recommendations and decisions can be made using the current evidence base despite the lack of high quality, and particularly local evidence.
- Uganda's amendment of related statutes greatly increased access to morphine by allowing non-physician prescribers for the narcotic.
- Alternative, spiritual, and traditional healthcare practitioners should be educated and informed for appropriate patient referrals and to mitigate exploitative practices on the sick and their families.
- Information on palliative care should be translated into the local languages and an accreditation system for providers should be in place so that patients and health workers know where to access these services.
- There is need to include opioids in all relevant policy documents, cross-referencing of related policies, and development of a consolidated national policy on palliative care.
- A comprehensive national umbrella policy should include the options, which need to be integrated into the public health system and made available in the public hospitals and all health facilities.
- Gender empowerment should be articulated as part of the solution and the national policy on palliative care. Gender issues should not exclude men; the public should be educated about involving men as carers.
- Pre-service curriculum integration should be enabled for those who need generic skills and specialty type skills through e-learning and clinical attachments.
- Providers of care, some of whom are not professional health workers, should be protected from risks of tuberculosis, HIV and Hepatitis B.
- The policy development process will continue with the Ministry of Health, including further consultations with stakeholders and support from development partners.
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The views, opinions and insights in this report reflect the understanding (or misunderstanding) of individual participants in the dialogue. These opinions may or may not be consistent with or supported by the policy brief that informed this dialogue or other evidence. It should not be assumed that the opinions and insights in this report represent a consensus of the participants unless this is explicitly stated. Nor should it be assumed that they represent the views of the authors of this report.

Background

The Director General of the Uganda National Health Research Organisation (UNHRO), Dr Sam Okware welcomed participants to the dialogue on Palliative Care for Uganda. He highlighted the high global burden for heart disease, accidents and cancer and commended Uganda’s progress in field of palliative care. The SURE project at Makerere University with stakeholders had produced a policy brief on advancing the integration of palliative care into the health system which was the focus for discussion. The brief describes the problem, highlights three policy options and implementation issues to be considered. He requested the participants to introduce themselves. He introduced the moderator, Mr Delius Asiimwe, the Executive Director of Kabano Research and Development Centre, and requested him to facilitate the proceedings. Mr Asiimwe outlined the objectives, procedures and rules of the dialogue. He invited participants to add value to the policy brief and freely share their views on the subject. Minutes for the meeting would be kept but the identity of the contributors would be kept confidential. He provided a few minutes for participants not familiar with the documents to go over the short report.

The problem

The evidence base in Africa for policy is still quite restricted. However, the lack of high quality evidence does not mean that decisions should not be made and recommendations can still be considered even when the level of evidence is not very high. One user suggested that the definition of palliative care should be made more prominent in the brief. The document mentions limited access to morphine under size of the problem. Government is providing morphine and this is a problem of distribution not availability of the drug. There are challenges with getting this to patients who actually need it. It is mostly stand alone programs providing these services to patients. There are challenges at the grassroots. There are still problems with patients getting morphine from the hospitals. If the community and caregivers knew such a service exists, they would demand for it. If one lives in Mpgi, there is no morphine is available, most patients then try to get to Kampala. There is need to get this information to the community. Uganda was a pioneer in liberalisation of morphine prescription by allowing nurse prescribers through task shifting. We were the first country to amend statutory instruments to allow non-physician prescribers for morphine. WHO took this up as ‘task-shifting’ for expanding prescribing roles to less specialised cadres. However, additional training is needed to help diagnose pain and treat it.
The burden of children is included in the charts and figures providing the total size of the problem, if possible it would be good to desegregate this information. Paediatric palliative care needs should be spelled out very clearly. Non-cancer and non-HIV patients comprise 35-40% of palliative care needs and therefore do need PC. The WHO project in the five African countries did not really move forward to the completion phase as had been hoped. It would be good to include the health systems strengthening framework for WHO. The total burden for palliative care could be higher than reported and most Ugandan families have more than 2 carers per patient, compared to the WHO recommendations therefore increasing the burden from informal caregivers.

There is lack of information among alternative health care providers who promote miracle cures to patients in need of palliative care. The media should be engaged to educate traditional and spiritual alternative providers as this would help to mitigate unnecessary suffering and exploitative costs incurred by the sick and their families.

We have trained people in palliative care and palliative nursing. They would be the focal people to spread the services, but when they return to their postings they are not deployed by their health units to do palliative care work. The Ministry of Health should emphasize that health workers who have received additional training be recognised within the system.

Efforts should be made to translate information on palliative care into the local vernacular languages and an accreditation system for palliative care providers should be in place so that patients and health workers know where to access these services.

**National policy review on palliative care:**
Currently there is high government support but different policy documents have different levels of focus on palliative care. Four documents were reviewed. The Health Sector Strategic and Investment Plan mentions and elaborates on Palliative Care but opioids are not mentioned specifically. The status document on non-communicable diseases does not mention palliative care but brings out high morbidity and mortality statistics on these. The HIV/AIDS strategic plan for 2010/11-2014/15 does not highlight palliative care specifically. The second National Health Policy mentions palliative care but is silent on opioids. There is need for greater integration of palliative care into these documents; with inclusion of opioids in all documents, language translation and advocacy.

One participant mentioned that many policy documents are in draft form and so are not binding; hence greater effort to be made to move draft to final document. Who needs to move drafts to final approval at MOH? All sectors need to be on board in order to support the implementation of policies.

What is the need to mention opioids in all relevant policy documents given that these are component of care already? Opioids need to be specifically mentioned given the myths and this will improve advocacy for their use in other countries. Opioids are only part of the solution given need for spiritual care. 80% of patients present in severe pain with lots of suffering, hence opioids should be prioritised. The dimensions of pain are different including spiritual pain, and opioids are targeting only physical pain. The role of opioids in Uganda has been so prominent that other countries are now learning from it. Morphine consumption per patient should be used an indicator of palliative care access.

There is little cross-referencing in related policies, hence the need for a consolidated national policy that is population based rather than disease focused. There is need to review all policy documents to identify and harmonise issues on palliative care. Human rights issues and more recent statistics from Globocan and UNAIDS should be included in the brief. There is
sufficient data on the current burden to develop a policy. Sensitization is already underway and interest in policy is high among policy makers.

Policy options

**General Discussion of the Options:**

The options are good for service provision; however, these should be framed within the WHO public health model which is made of four pillars. Most of the options focus on implementation of palliative care services. Palliative care should be centred on patients and their families. There is need for evidence to support the integration of palliative care within the national health system, which should also be considered as an option. The sum of options may have a greater impact if implemented together than individually as they are complementary to one another. The evidence base could be expanded to include even lower quality evidence and allow for more options. Some of the local evidence is not documented or ‘peer-reviewed’. The lack of high quality systematic reviews evidence does not mean lack of evidence. Grey literature and local evidence have actually been used in the brief. It is understood that the evidence for the options is from high-income countries, which should not necessarily be ignored just because it is not from low and middle-income settings. We should just be more cautious in adapting it for our settings. Training, education and research have been included in the brief as potential options but these are also very important strategies in addition to the first three. What is the role of hospitals? Radiotherapy and chemotherapy in some cancers, actually lead to prolongation of life, although this is not the aim in palliative care. The options will form part of a comprehensive policy. These should be integrated into the health system and be available in the public hospitals, at the health posts through the referral pathway back and forth. There is need for a national umbrella policy to cover all these.

Home-based care should be adapted to the local setting. Some patients choose to come to hospital for end of life care even though home-based care appears to be preferred generally. Some of the patients who require palliative care may not necessarily be at the end of life. How can we use this evidence for this group of patients? Home-based care helps to reduce demand on hospital care services for patients, which are more expensive and specialized. Palliative care can also be given at the beginning of life-threatening illness as indicated by WHO and not just at the end of life. Income-generating aspects in home-based care are necessary as income is badly needed at this time, mainly because the family provider is affected.

The majority of carers in Uganda are not under stress as would be in the West, as there is sharing of the role between the extended family.

It is important to look at the entire referral pathway which also includes discharge. How patients come into the health system, how they are managed there and then discharged. When there are complications with the patient, the referral links could be reversed. Referral pathways and patient held records can improve on continuity of care for patients.
A strong part of the policy brief was the articulation of gender issues and gender empowerment as a solution. Several dimensions are necessary to address the gender issue. Women provide care for their families, work as volunteers to provide care, and are also sufferers. Uganda has very strong gender empowerment policies, which should be cross-referenced with the relevant national documents and policies. Government will not pass any policy which does not have gender considerations and this will definitely be included in the palliative care policy. Gender issues should not exclude men; the public should be educated about involving men as carers. There is evidence showing change where men have been trained to care.

Palliative care should be provided at all levels of the health system, but a word of caution for having a palliative care unit in every health facility, for example, health centres II. This has extensive financial implications, and these could be established at hospital level as a centre of excellence for that region.

Implementation considerations

The barriers speak to the health systems framework of WHO which has six pillars of health systems strengthening. There is mention of public and private providers, however private-for-profit providers should also be included to reduce on the burden. 95% of healthcare provision is through public-private partnerships and only 5% by the government. The Ministry of Health is already supporting the Private-Not-for-Profit sector in terms of supplies, health commodities, and medications for palliative care.

The strategic plans for Hospice Africa, Mulago Palliative Care Unit, Palliative Care Association of Uganda and the African Palliative Care Association provide a wealth of evidence and strategies that could be used.

There should be pre-service curriculum integration at all levels, for those who need generic skills and specialty type skills. E-learning, computers and clinical attachment do not require someone to leave their workplace in order to acquire skills. Workload is a big issue. Many facilities cannot afford a full-time palliative care health specialist; hence training of nursing officers and clinical officers should be intensified.

Most young doctors do not know how to manage pain because they have not seen morphine. Senior doctors are reluctant to prescribe morphine even when younger doctors and nurses have been trained to accept the use of morphine for control of severe pain. Pethidine has side-effects, is addictive and therefore not desirable. But morphine is appropriate for all severe pain and can be used safely. Hospice Africa Uganda has treated 25,000 patients so far since 1993 and 60% of these have received morphine, but not a single case of addiction has been documented among them. Therefore the myth of addiction should be dispelled.

There are competing priorities in the health sector strategic plan and palliative care is not a priority area, hence the way to go is integration. There is need for collaboration and networking with a multi-sectoral approach with a wider focus on more than just health policies to tackle the problem.
The Church, other traditional providers such as Prometra and spiritual healers should to be brought on board. Journalists and the media have a lot of power in informing the public, how do we get the right information to them for dissemination? There is exploitative behaviour from some faith healers taking money from patients promising cures and sometimes advising patients to shun medical services. How are we going to integrate religious leaders?

Geriatrics is absent from the document, yet contributes to the burden needing care. However, the elderly population of Uganda is only 3%, and palliative care cannot and should not take on geriatric medicine. The two specialties should be respected as such. Most of palliative care is provided as an integrated service together with other specialties, such as geriatrics, cardiovascular disease and renal disease management. Stand-alone PC services are less frequent by comparison.

What is the role of euthanasia in palliative care? The experience with local practitioners in Uganda is that if adequate palliative care is provided, patients die peacefully and do not ask for euthanasia. The training curricula must contain ethical issues, such as euthanasia.

Providers of care, some of whom are not professional health workers, should be protected from risks of tuberculosis, HIV and Hepatitis B.

There is a mentality that patients should die in the hospital. Our culture is supportive of people dying in the home. Taking patients to the hospital to die is culturally disruptive and bewildering for the patient who is terminally ill. In Zambia, they have a policy of people dying in a hospital, so that they could get a death certificate. They have learned from the Uganda experience in palliative care and are now more accepting of home-based care, and allowing patients to die at home. There is a positive aspect of spirituality in Africa. Most people aware of God and this awareness increases as death approaches.

Next steps

The Commissioner for Clinical Services, Ministry of Health:

Dr Jacinto Amandua commented that since we now have the evidence brief, it is urgent to continue with the policy development process at the Ministry of Health. The Ministry has already developed a draft policy on palliative care which was pending input from the research. There are further consultations with stakeholders. There is need for support on this. The WHO country office should be part of these consultations and other development partners such as PEPFAR, EU, DFID, OSI, should also be involved. The African Palliative Care Association announced that they have secured funding from the American Cancer Society committed to the policy development process. After these consultations, the draft policy documents will have to go to the Senior and Top Management at the Ministry, the Cabinet and finally Parliament. Once a cabinet memorandum clears the policy, the rest of the process will become easy.
The Director General, Uganda National Health Research organization (UNHRO)

Dr Sam Okware thanked participants for their passion and commitment to the cause and taking time to contribute extensively to the policy making process on palliative care. Human resources and financial resources are big challenge within the health system.

He thanked Dr. Jacinto Amandua, the Commissioner, Clinical Health Services at the Ministry of Health for his efforts and strong personal interest on the issue of palliative care. Special thanks to the SURE project at the College of Health Sciences for work on the policy brief.

The meeting was adjourned at 2.30 pm.
## Appendix 1: Agenda

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<thead>
<tr>
<th>Time</th>
<th>Session</th>
<th>Organizer/Presenter</th>
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<tr>
<td>8.30 – 9.00 AM</td>
<td>Registration</td>
<td>SURE Secretariat</td>
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<tr>
<td>9.00 - 9.05AM</td>
<td>Welcome by the DG, UNHRO</td>
<td>Dr Sam Okware</td>
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<tr>
<td>9.05 - 9.20 AM</td>
<td>Introduction of participants and Moderator</td>
<td>Dr Sam Okware</td>
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<tr>
<td>9.20 – 9.30 AM</td>
<td>Procedures and Rules of the Dialogue</td>
<td>Mr Delius Asiimwe</td>
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<td>9.30 – 10.30 AM</td>
<td>Problem Section of the Policy Brief</td>
<td>Discussion</td>
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<td>10.30 – 10.45 AM</td>
<td>Uganda Policy Review on Palliative Care</td>
<td>African Palliative Care Association</td>
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<td><strong>10.45 – 11.00 AM</strong></td>
<td><strong>TEA/COFFEE BREAK</strong></td>
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<tr>
<td>11.00 – 12.00 AM</td>
<td>Policy Options Section of the Policy Brief</td>
<td>Discussion</td>
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<tr>
<td>12.00 – 01.00 PM</td>
<td>Implementation Section of the Policy Brief</td>
<td>Discussion</td>
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<td>01.00 – 01.15 PM</td>
<td>Evaluation of the policy dialogue</td>
<td>Dr Harriet Nabudere</td>
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<tr>
<td>01.15 – 01.30 PM</td>
<td>Wrap up and Way Forward</td>
<td>Dr Jacinto Amandua</td>
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<tr>
<td>01.30 – 01.45 PM</td>
<td>Closing Remarks</td>
<td>Dr Sam Okware</td>
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<td><strong>01.45 PM</strong></td>
<td><strong>LUNCH</strong></td>
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<td>Departure</td>
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Appendix 2: Participants

**Dr. Jack Jagwe**  
Senior Advisor  
Hospice Africa Uganda

**Dr. Mhoira Leng**  
Head of palliative Care Unit  
Department of Medicine, Makerere University College of Health Sciences  
New Mulago Hospital Complex

**Dr. Charles Namisi**  
Assistant Coordinator  
Nsambya Home Care

**Dr. Zena Bernacca**  
Chief Executive Director  
Hospice Africa Uganda

**Dr. Katherine Pettus**  
Researcher  
University of California San Diego

**Dr. Jane Nakawesi**  
Academic Program Manager  
Mildmay Uganda

**Sylvia Nakami**  
Program Manager  
Palliative Care Association of Uganda

**Dr. Harriet Namata**  
Senior Research Scientist  
Joint Clinical Research Centre  
Lubowa Kampala Campus

**Prof. Anne Merriman**  
Director of Policy and Interactive Programs  
Hospice Africa Uganda

**Fatia Kiyange**  
Programmes Director  
African Palliative Care Association

**Bernadette Basemera**  
Programme Officer  
African Palliative Care Association

**Christine Rebecca Mubiru**  
Principal Policy Analyst  
Ministry of Health

**Dr. Jacinto Amandua**  
Commissioner, Clinical Services  
Ministry of Health
Dr. Emmanuel Luyirika  
Incoming Executive Director  
African Palliative Care Association

**Rose Kiwanuka**  
Country Director  
Palliative Care Association of Uganda

**Dr. Faith Mwangi-Powell**  
African Palliative Care Association

**Specioza Kabwegyere**  
Chairperson  
Uganda Women’s Cancer Support Organization (UWOCASO)

**Dr. Sam Okware**  
Director General  
Uganda National Health Research Organization (UNHRO)

**David Kavuma**  
Trainer  
Mildmay Uganda

**Dr. Fred Sebisubi**  
Principal Pharmacist  
Ministry of Health

**Dr. Elly Katabira**  
Professor of Medicine  
Department of Medicine, Makerere College of Health Sciences

**Hannington Muyenje**  
IKT Officer  
Makerere College of Health Sciences

**Dr. Mohammed Lamorde**  
Post-doctoral fellow  
Infectious Diseases Institute  
Makerere University

**Delius Asiimwe**  
Executive Director  
Kabano Research and Development Centre

**Robert Apunyo**  
Programs Manager  
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**SURE Secretariat:**  
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Competing interests
None known.

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