Policy dialogue

Palliative Care for Uganda

Kampala, Uganda
09 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

What is a policy dialogue?
A structured discussion focused on an evidence-based policy brief

The agenda from the policy dialogue is attached as Appendix 1

Who participated in the dialogue?
People with relevant expertise and perspectives, including policymakers, civil society and researchers

The complete list of participants is attached as Appendix 2

What was the aim of the policy dialogue?
Thatter discussion and careful consideration should contribute to well-informed health policy decisions

The dialogue did not aim to reach a consensus or make decisions

What is included in this report?
Views, opinions and insights of individual participants reported without attribution

The opinions included 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 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
Key messages

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

- Palliative care should be holistic, including the physical, emotional, social, and spiritual aspects of life. Hospice is now a philosophy for the holistic approach in managing illness.

- The palliative burden is not only high but increasing due to increases in population and life expectancy for Uganda.

- Government should dialogue with and train traditional health practitioners to offer some palliative care and refer where appropriate to specialized health facilities.

- The policy on palliative care by the Ministry of Health should be able to bring all forms of evidence together. Stakeholders should commit to implementing the instituted policy.

- Government should invest in the prevention, early detection, screening, and treatment of conditions requiring palliative care to reduce on the need.

- The model for services introduced by Hospice Africa Uganda is what the industrialized world is seeking because the evidence shows that most patients prefer to die at home.

- The three policy options are complementary and it is necessary to include education and training for palliative care.

- The policy on palliative care should be all embracing and link to other policies in government such as that on non-communicable diseases.
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Background

The Director General of the Uganda National Health Research Organisation (UNHRO), Dr Sam Okware welcomed the Honorable Members of Parliament and other invited guests for the meeting. He invited the participants to introduce themselves. He noted that palliative care is important for terminal illness. The policy brief on advancing palliative care within the health system is the background document for discussion and elaborates three main interventions or options on how to do this including; home-based care; supporting informal carers and planning for discharge.

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 mentioned that research is just one input in the decision making process, and stakeholders views and inputs are also important as a contribution to this process. The evidence brief is not a policy document but contains scientific evidence generated to support the development of policy. MPs engage government on policy and law and can take government to task if falling short according to these regulations. Participants were encouraged to express themselves freely as confidentiality for speakers will be respected. Participants are not required to reach a consensus and can use the information they have received here without attributing contributions to other speakers.

The problem

WHO provides a definition for palliative care and this would be needed when someone has a life-threatening illness, could be cancer, HIV, kidney failure or strokes. If someone could have lived longer without having a particular illness, then palliative care applies. Palliative care should be holistic, including the physical, emotional and the spiritual aspects of life. A holistic approach to managing disease for physical pain and symptoms; Psychological pain - Why did this happen to me? What did I do wrong? Am I bewitched? Social pain: A patient having children is worried about leaving them behind, their property, their relatives disinheriting their dependants, etc. Spiritual pain: where am I going after death?

For most people, it is more than the disease per se, a woman could be abandoned by her partner for suffering from cancer, this could become the bigger problem for her. If you have HIV, does your church reject you? This could be the bigger problem for the patient than just suffering from the disease.
What is the difference between hospice and palliative care? Originally, hospice meant a place for rest for travellers. Hospice is from hospitality (French). The hospices then became hospitals. The idea of palliative care came from Canada, from palliate – to relieve. In Uganda, palliative care and hospice are used interchangeably. In the US, hospice means someone is going to a facility and has only six months to live; this is mainly for purposes of insurance. Hospice first came to Uganda in 1993 by Dr Anne Merriman to offer services and train others in the field. Hospice as an organization and NGO provides training for the community and family, as well as offering palliative care. Palliative care starts from the beginning of the condition or illness, and not necessarily when someone is dying.

There is need for dialogue with traditional health practitioners and if they cannot manage patients’ pain, they should refer them to specialized health facilities. Can we train the traditional practitioners to offer some palliative care? Palliative care, yes, is a specialty, but at the same time can actually be offered by non-specialists. Hospice is now considered as a philosophy for a holistic approach to managing illness. A patient should be able to receive palliative care at any level of the health system provided by different providers with varying levels of specialization.

It is good that there is scientific evidence on this and the policy on this should have been done yesterday. Legislators perhaps know palliative care but in another form, in another language, working with HIV/AIDS committees, through sensitization and screening for cancer in the constituencies. Since we have started let’s continue and have the Ministry turn this into a policy paper, as MPs we shall support this in parliament. What do you want us as MPs to say and how do we say it? If there is a policy in place this would help a lot for the patients who need this care. The PCAU is one association which has been canvassing MPs to promote this cause in Parliament. This is not the first session that MPs are attending on palliative care. The PCAU has done a lot of work in exposing this concept to the members. There is a champions group in parliament as a result of these efforts specifically to advance this cause.

‘I had a personal experience of my own child needing palliative care. Was this the beginning of the end of the life of my child? I took my child home to prepare him for what was coming. The patient needs counselling, yes, but the carers, the family, his mother, also need care. I could not eat, was overwhelmed up to when my child died and I was really affected. Social support was offered in the village and by the extended family. As someone who has a personal experience of suffering, I am committed to championing this cause in Parliament.’

Another recounted a personal experience with a paternal uncle who died from cancer. He had five children in university, could have received this kind of care and lived longer.

There is a lot of work in research that has not been published and a lot of evidence from Uganda that needs organizing and documenting even if it is not reflected in this brief. The policy on palliative care by the Ministry should be able to bring everything together. Instituting the policy is one thing, but commitment to implement it is another. Stakeholders who come to attend these dialogues are actually already committed in some way to the issue.

The key messages indicate a high palliative burden, it is not only high but it is increasing. People are beginning to understand, that if there are progressive symptoms, there is need for care. Increase in population and increase in life expectancy, means there will be more need for palliative care in Uganda. Effective palliative care literally gets patients off their deathbeds and they are able to live productive lives for many more months and even years.
because of this support. This information should be disseminated to all stakeholders. The access is not good, but there has been a definite improvement over time in the health system. If cost-sharing is needed to support these services then that is what we should do.

The main focus of palliative care services is the patient and their caregivers. When a patient is in pain from a long term illness, the family also suffers. When it comes to the community, those who give spiritual help have been left out. Much as the church is caring, the spiritual leaders should also be engaged and informed about this care so they can refer patients who need these services.

Uganda should offer free drugs to cancer patients. Some patients pay up to 1 million shillings per month for treatment. Morphine is not available everywhere. As we develop this policy, is it possible to have radiotherapy machines at the regional hospitals? There is need to train, screen every woman who visits a health facility for cancer of the breast, cancer of the cervix, etc. Most of the conditions in palliative care make people lose hope. If ailments have reached an advanced stage, patients suffer neglect. Staffing issues have always been a problem. Hospitals used to provide meals, transport, and facilitation for patients and social workers but sadly this is no longer the case.

### Policy options

All the policy options are complementary and it is absolutely necessary to include education and training for palliative care. What issues should be considered under home-based care?

Home-based care means a team of specialists visits patients and families in their home to provide services. Outpatient services and inpatient services are also available but only within health facilities and hospitals. In advanced countries, there are specialized hospitals for hospice services exclusively.

The palliative pattern which Dr Anne Merriman introduced to Uganda provides care at home. Patients who have known of the services at Makindye refer themselves to hospice. Home-care should not be restricted to the three or four weeks towards the end of a patients’ life, but can be provided over the course of their illness. The family needs care and support as well. However, emergencies and complications can occur together with the disease while the patient is being cared for at home. This may require management in a hospital and has to be facilitated.

The model being used in Uganda is what the industrialized world is seeking now, because the evidence shows that most patients prefer to die at home. Hospitals can bewilder patients and families prefer to manage the very sick at home, because it is less expensive. Home-based care should also be more affordable to institute for the government.

Some cancers have an offensive smell and it may not be advisable to discharge the patient home as the family would be affected. Actually, the treatments for a bad smell from any external cancers, such as cancer cervix, Kaposi’s sarcoma, are very simple such as crushing of tablets which are then applied to the wound.

The policy should integrate issues of education and awareness of health workers, access to care, and health systems strengthening. Palliative care is included in the degree curricula at Mbarara, Gulu and Makerere Universities.
Everyone at least should know where morphine is available, even if they may not be able to prescribe it. Uganda is a signatory to the international narcotics convention and was a pioneer in Africa, by allowing non-physician prescribers for morphine. The US government by comparison, licensed use of oral morphine solution only last year, so we have been many years ahead since 1993.

WHO recommends 2 carers per patient. Hospice Africa Uganda provides carers with respite days, where patients are brought to the centre to give a break to the relatives at home and this also allows the patients to commune with other patients. The other informal health care givers not mentioned in this discussion are the traditional practitioners.

This dialogue helps to educate stakeholders on this issues, what we need from MPs is support at assembly level. Uganda has garnered a lot of experience in provision of palliative care services from hospice and other providers which could be used to scale up these services in the public system. What we need is secured funding. The Uganda cancer institute has improved a lot since they achieved voter status, as this allows for an independent funding stream.

Implementation considerations

Palliative care is here to improve quality of life; i.e, what you get compared to what you expect. What palliative care does is to change the goal posts, what is the quality of life I can have in the last remaining months, years? This would include goals such as: improved relationships, right guardians for one’s children.

Much as many patients want to die at home, it should be the decision of patients and families together and should not be forced on the patient because the hospital cannot treat and cure the patient. This would be interpreted as rejection by the patient and can be very frightening for them and their families.

Awareness should not stop with the caregivers but should involve village health teams to receive vocational education. Awareness and access to services are an issue. Avail drugs, support, health workers in screening programs for conditions contributing to the palliative burden.

According to the current law, a patient carrying morphine could be charged with handling narcotics. The new policy should enable the safety of patients using morphine.

The policy should include the private-for-profit providers since they are providing services. In Busia district, it is only TASO providing services in the district. I strongly support the issue of integration of services within the public system to increase access.

The African heads of state agreed to raise the budgetary allocation for health to 15%. This is an appeal to the MPs to urge the government to fulfil on this commitment. Most of healthcare is actually funded from out of pocket payments.

Community volunteers are very crucial for the palliative providers such as hospice Africa Uganda. Volunteers providing care should be trained and supported in their role. Self referrals of patients have increased because of the work of community volunteers. Learning from other countries, such as the US, volunteers can be financially compensated, provision of training.
Next steps

The Commissioner for Clinical Services, Ministry of Health:

The policy we are going to develop should be all-embracing and should be linked to other policies in government such as that on non-communicable diseases. We should invest in the prevention, early detection, screening, and treatment of conditions requiring palliative care to reduce on the need. There is need for more research and more evidence regarding models of palliative care which work. Since Hopice Africa Uganda started, it is required that once a student conducts research in the institution, this is documented and archived by the library. This policy brief will be used by the Ministry to brief Senior Management, the Permanent Secretary, the Ministers’ desk and then a Cabinet Memo will be produced. Cabinet now has to pass all policies to prevent policies sitting on the shelf and not being implemented because of lack of funding. Policies should also be informed by the Parliament. Hospice Africa Uganda, the African Palliative Care Association, Palliative Care Association of Uganda, the Mulago Palliative Care Unit will be happy to contribute in development of this policy. The Uganda Women’s Parliamentarians Association is keen to participate. The African Palliative Care Association has secured some funding to support development of a policy on palliative care.

The Director General, Uganda National Health Research organization (UNHRO)

The Uganda National Health Research Organisation will provide grey literature which will contribute to polishing the document. There is scientific consensus on a holistic approach, palliative care is a spectrum of care from the beginning of a condition up to the end of life. Volunteers must be supported and should be included in service provision both at home, community level and in health facilities. We need resources through continued advocacy of all stakeholders at national and district level. I would like to thank the SURE project secretariat, Dr Jack Jagwe and all the various partners and stakeholders who have contributed in developing the document and participating in the dialogues.

The meeting was adjourned at 1.40 pm.
Appendix 1: Agenda

8.30 – 9.00 AM  Registration  SURE Secretariat
9.00 - 9.05 AM  Welcome by the DG, UNHRO  Dr Sam Okware
9.05 - 9.20 AM  Introduction of participants and Moderator  Dr Sam Okware
9.20 – 9.30 AM  Procedures and Rules of the Dialogue  Mr Delius Asiimwe
9.30 – 10.30 AM  Problem Section of the Policy Brief  Discussion

10.30 – 11.00 AM  TEA/COFFEE BREAK

11.00 – 12.00 AM  Policy Options Section of the Policy Brief  Discussion
12.00 – 01.00 PM  Implementation Section of the Policy Brief  Discussion
01.00 – 01.15 PM  Evaluation of the policy dialogue  Dr Harriet Nabudere
01.15 – 01.30 PM  Wrap up and Way Forward  Dr Jacinto Amandua
01.30 – 01.45 PM  Closing Remarks  Dr Sam Okware

01.45 PM  LUNCH

Departure
Appendix 2: Participants

Hon. Nshaija Dorothy Kabaraitysa
Parliament of Uganda

Hon. Muhumuza David
Parliament of Uganda

Hon. Kabasharira Naome
Parliament of Uganda

Hon Twa-Twa M. Jeremiah
Parliament of Uganda

Hon. Khainza Justine
Parliament of Uganda

Hon. Biraaro G. Ephraim
Parliament of Uganda

Hon. Acayo Christine
Parliament of Uganda

Hon. Amongin Jacqualine
Parliament of Uganda

Hon. Mbabazi Betty Ahimbisibwe
Parliament of Uganda

Hon. Akol Rose Okullu
Parliament of Uganda

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Competing interests
None known.

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