Advancing the Integration of Palliative Care in the National Health System

Executive Summary

**Included:**
- Description of a health system problem
- Viable options for addressing this problem
- Strategies for implementing these options

**Not included: recommendations**
This policy brief does not make recommendations regarding which policy option to choose

Who is this evidence brief for?
Policymakers, their support staff, and other stakeholders with an interest in the problem addressed by this evidence brief

Why was this evidence brief prepared?
To inform deliberations about health policies and programmes by summarizing the best available evidence about the problem and viable solutions

What is an evidence brief for policy?
Evidence briefs for policy bring together global research evidence (from systematic reviews*) and local evidence to inform deliberations about health policies and programmes

*Systematic Review: A summary of studies addressing a clearly formulated question that uses systematic and explicit methods to identify, select, and critically appraise the relevant research, and to collect and analyse data from this research

Full Report
The evidence summarised in this Executive Summary is described in more detail in the Full Report

This evidence brief was prepared by the Uganda country node of the Regional East African Community Health (REACH) Policy Initiative
Key messages

The problem:

High Palliative Burden

Cancer and HIV/AIDS account for 80% of the patients in need of palliative care in Uganda. Patients with cardiovascular disease, liver and renal pathology, and neurological and respiratory diseases may also require such care. The current minimum palliative healthcare burden in Uganda is approximately 137,700 patients. Given that an additional two family or voluntary caregivers per patient may also need support, it is therefore likely that the total number of people requiring help is nearer 413,000. Nearly 90% of patients in Uganda who need palliative care do not access such services.

Policy options:

1) Home-based care for end-of-life patients
2) Supporting informal caregivers
3) Planning for discharge in palliative care

1. Home-based care for end-of-life patients increases the likelihood of the terminally ill dying at home, may increase patient satisfaction at one month of follow-up, but may lead to a reduction in the psychological well-being of caregivers who look after patients surviving more than 30 days.
2. Interventions to support informal caregivers may reduce the psychological distress and increase quality of life of carers, but may reduce the ability of carers to cope with their role.
3. Discharge planning probably reduces both the length of hospital stays and unscheduled readmission rates at 3 months, but leads to little or no difference in mortality.
   - Given the limitations of the available evidence, rigorous evaluation and monitoring of resource use and activities are needed for all the selected options within the local context.

Implementation strategies:

A combination of strategies is needed to implement the proposed options effectively

- Strategies to improve the knowledge, competency and care-seeking behaviour of families include: providing home-based care, using Village Health Teams, and providing vocational education and training
- Strategies to improve the knowledge, competency and attitudes of healthcare providers include: educational meetings, information, education, and communications interventions
- Subcontracting and cost sharing for financing
- Use of community volunteers and structured referral sheets to improve referral processes
The problem

The need for palliative care is urgent: globally, an estimated 35 million people experience pain and suffering caused by old age and life-limiting conditions such as cancer, AIDS, and other chronic diseases. (17) Kikule (2003) investigated the state of palliative care for the terminally ill in Uganda, and found that 58% of patients require pain relief and other forms of symptom control. 30% of patients experienced a loss of income, 5% needed counselling support, and 7% required other forms of support such as spiritual guidance. (21)

Current efforts to expand palliative care services nationally include the provision of facility-based and community-based services, as well as training, education and research. (8) Most palliative care in Uganda is provided in isolated centres of excellence which are not comprehensively integrated across the different levels of the health system structure. The use of palliative care teams, which is recommended by the WHO, is also uncommon. (19) Many stakeholders in Uganda have indicated that there is need for a national palliative care policy which can provide a guiding framework for such services. (6) (31)

Size of the problem

Cancer and HIV/AIDS account for eighty percent of the patients needing palliative care in the country. (32) Patients with cardiovascular disease, liver and renal pathology, neurological and respiratory disease may also require palliative care. (32) The current minimum palliative healthcare burden is close to 138,000 patients. (36) An additional 2 family or voluntary caregivers per patient requiring support comes to a total 413,000.

Less than 10% of patients in Uganda who require palliative care access such services. (35) There is a disproportionate effect on women and girls both as sufferers and informal carers in the palliative burden. (38) (40) (41) Currently, there is limited access to oral morphine which is used for pain control and to adjuvants used for the control of side effects to morphine such as nausea, vomiting and constipation. (43)

Cause of the problem

The burden of palliative care is heightened by a number of factors at the community and health systems levels. Most terminally ill patients in Uganda prefer to be cared for at home by their families, as doing so is perceived to offer better security and privacy. Home-based palliative care also helps to minimize the costs involved. (21)

There is widespread lack of awareness among the public, policymakers and health providers about the need for palliative care services. Typically, palliative care is perceived only as end-stage support care for the dying. (49) Key challenges to integrating palliative care within the health sector include the lack of adequate infrastructure, shortages of trained palliative care staff, and insufficient and unstable funding. (52) (35) (49, 52)

There is insufficient local research to inform health decision-makers who need a sound knowledge base to understand the complex burden and best models of care. (48)
Policy options

National stakeholders in Uganda who are involved with the provision of palliative care have attempted to identify potential policy solutions that can aid the scaling up of palliative services within the health system. To this end, attempts have been made to summarize the best available evidence for some of the interventions proposed, but many potential options still require further rigorous investigation. The three policy options presented in this section can potentially be adopted independently, but they also complement one another. Home-based care increases the probability that terminally ill patients will experience a peaceful death surrounded by their loved ones, and improves the quality of life of informal caregivers. Discharge planning also helps to reduce unscheduled admissions and may also free up capacity for acute care services.

Policy Option 1:
Home-based care for end-of-life patients

‘End of life’ refers to the period when death is inevitable and imminent. The primary aim of any treatment at this stage is to improve the patient’s quality of life as opposed to extending length of life or curing the illness. The dying patients’ quality of life takes into account; physical comfort and functioning, psychological and spiritual well-being, cognitive functioning, general meaningfulness of life, as well as, the quality of life of family and loved ones. Home is more than a physical space; it is a ‘normal’ space where one is surrounded by family and friends and the majority of people with progressive illness wish to die at home.

Impact of Home-Based Care for End-of-Life

A good quality systematic review by Shepperd and colleagues (2011) from high income settings investigated the impact of home-care programs for end of life care. The review found that home-based care compared to usual care:

- Increases the likelihood of terminally ill patients dying at home
- May increase patient satisfaction at one month of follow-up
- May lead to a reduction in psychological well-being for caregivers of patients who survive more than 30 days

Policy Option 2:
Supporting Informal Caregivers

Informal or unpaid caregivers in palliative care, (described earlier) include family, friends or volunteers offering support to patients unable to cope on their own. Caregivers of patients with progressive illness suffer from a number of problems; sleeplessness, general deterioration in health, exhaustion, anxiety and depression.
A literature review by Harding et al., 2011 describes groups of interventions to support carers that are currently being developed and tested. (61) These include; Psychological support, Palliative Care/Hospice services, Information and training, Respite Services and Physical Interventions, such as yoga. (61)

**Impact of Supporting Informal Caregivers**

A good quality systematic review by Candy and colleagues (2011) assessed a range of supportive programs for caregivers which included psychological support and practical assistance.(41) The review found that supporting informal caregivers of patients in the terminal phase of disease compared to usual care may:

- Reduce psychological distress in informal caregivers
- Increase quality of life for carers
- Reduce coping with the caring role

**Policy Option 3:**

**Planning for Discharge in Palliative Care**

Most patients suffering from chronic disease are likely to experience frequent acute on chronic episodes requiring care within specialized units. It is desirable to reduce, where possible, demand for in-patient care through provision of acute care services at home or in the community.(62) Non-medical reasons delaying a patient hospital discharge account for approximately 30% of cases and usually result from poor knowledge of the patient’s social circumstances; deficient logistical organization, and inadequate communication between the hospital and community service providers.(63) Discharge planning aims to rectify these avoidable causes through the development of an individualized plan for the patient prior to leaving hospital. (62)

**Impact of Discharge Planning**

A good quality systematic review by Shepperd and colleagues (2010) investigated the effect of discharge planning on unplanned readmissions to hospital, unscheduled readmission within 3 months of discharge from hospital for patients with a medical condition and other outcomes.(62, 65) The review found that discharge planning compared to usual care probably:

- Reduces slightly length of hospital stay
- Reduces unscheduled readmission rates at 3 months
- Leads to little or no difference in mortality
## Implementation considerations

Key barriers to implementing the policy options and implementation strategies to address these are summarised in the table below.

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<tr>
<th>Barriers to implementation</th>
<th>Strategies for implementation</th>
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<tr>
<td><strong>Knowledge, competency and care seeking behavior of families</strong></td>
<td><strong>Home-based care</strong>&lt;br&gt;Home based care facilitates dying with dignity at home and involves family, friends and the neighbors, suitable for a traditional African setting. This increases the probability of patients dying from home, increases patient satisfaction and reduces hospital admissions. (57)</td>
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<td><strong>Village Health Teams</strong></td>
<td>Village Health Team (VHT) is an elaborate strategy implemented by MoH to mobilize individuals and households for better health; such as referral to health facilities. (68)</td>
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<td><strong>Vocational education</strong></td>
<td>Vocational Education for informal care givers during initial hospitalization of patients in need of PC could be considered as part of the package to prepare family members to give care at home. (39) (69)</td>
</tr>
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<td><strong>Knowledge, Competency and Attitudes of Healthcare Providers</strong></td>
<td><strong>Information, Education, Communication</strong>&lt;br&gt;Dissemination of educational materials (IEC) in this case clinical guidelines dissemination improves professional clinical practice. Clinical and other guidelines are available from Hospice Africa Uganda and the African Palliative Care Association. (13, 70) The Mulago Palliative Care Unit has released treatment protocols to be used in hospital settings. (29)</td>
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<td><strong>Educational meetings</strong></td>
<td>Evidence of moderate quality shows that the distribution of educational materials to health professionals improves the process of care and patient outcomes. (71) A synthesis of evidence of low quality shows that educational meetings improve patient care. (71) However, these studies were not specific to PC and done in high and middle income countries.</td>
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<td><strong>Inadequate financial resources</strong></td>
<td><strong>Sub-Contracting</strong>&lt;br&gt;Public Financing with contracting services to suitable private providers, as part of a comprehensive integrated health care programme. This programme would be free to the recipients of PC. A demonstration project in Catalonia, Spain used a beneficial contracting socio-health system based on the combination of payment for structures, daily fees for beds (units), quality assurance, incentives, and structural reconversion assistance. The preliminary</td>
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results showed that more than 80% of the investment was saved, through the radical changes in costs. (72) Low quality evidence suggests that out contracting may improve patient outcomes and reduce household expenditures. (73)

**Cost-Sharing**

Cost-sharing mechanism between providers and recipients of PC to offset a proportion of the financial requirements. Hospice Africa Uganda operates a model that allows PC recipients to pay 10% (UGX: 5,000/-) per week, towards the total cost of UGX: 45,000/- for care per week, independent of the number of visits and medications. About one third of PC patients can manage to pay. Those who cannot afford are then assisted. (25)

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<th>Inadequate facilities and referral processes</th>
<th>Effective Referral Strategies that;</th>
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<td>Diagnostic processes, referring and transferring patients present a bottleneck to effective health services. Long distances to health facilities and concerns that drugs are not available are among the most significant factors reported affecting access to health care. (74, 75)</td>
<td>a) Incorporate community volunteers - Between 2010 and 2011, community volunteers were the third commonest sources of referrals to Hospice Uganda facilities after health units and self-referral. (35)</td>
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<td>b) Use Structured Referral sheets can help improve service delivery for palliative care, particularly in situations of scarcity of clear information on where to seek diagnosis and treatment for cancers. (76, 77)</td>
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<th>Competing priorities</th>
<th>Integration of Services</th>
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<td>Palliative care has not been prioritized for investment as part of the Ugandan Ministry of Health’s 5 year plan. (28) Currently, the four areas of health that form the focus of attention in the third Health Sector Strategic Plan are: 1) sexual and reproductive health, 2) child health, 3) health education, and 4) the control and prevention of communicable diseases (HIV/AIDS, malaria and tuberculosis). The allocation of resources specifically for non-communicable diseases (such as cancers and end-stage organ diseases) will be therefore be challenging, despite the fact that these greatly contribute to the need for palliative care in Uganda. The rise in the burden of palliative care in Uganda is also related to the rise of HIV/AIDS.</td>
<td>Integrated PC at all levels of service delivery with specific roles at each level so as to avoid additional costs (direct and indirect) due to displacement of resources from priority areas by implementing PC as a parallel programme. The World Health Organisation provides guidance on integration of palliative care into the existing health system at all levels. (19)</td>
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The Regional East African Community Health (REACH) Policy Initiative links health researchers with policymakers and other vital research users. It supports, stimulates and harmonizes evidence-informed policymaking processes in East Africa. There are designated Country Nodes within each of the five EAC Partner States. The REACH Country Node in Uganda is hosted by the Uganda National Health Research Organisation (UNHRO). www.eac.int/health

The Evidence-Informed Policy Network (EVIPNet) promotes the use of health research in policymaking. Focusing on low and middle-income countries, EVIPNet promotes partnerships at the country level between policymakers, researchers and civil society in order to facilitate policy development and implementation through the use of the best scientific evidence available. www.evipnet.org