

ADVANCING PALLIATIVE CARE IN THE UGANDA HEALTH SYSTEM: AN EVIDENCE-BASED POLICY BRIEF

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Objectives: This paper describes the development and findings for a policy brief on “Advancing the Integration of Palliative Care into the National Health System” and the subsequent use of this report.

Methods: Key stakeholders involved with palliative care helped identify the problem and potential policy solutions to scale up these services within the health system. A working group of national stakeholder representatives and external reviewers commented on and contributed to successive drafts of the report. Research describing the problem, policy options and implementation considerations was identified by reviewing government documents, routinely collected data, electronic literature searches, contact with key informants, and reviewing the reference lists of relevant documents that were retrieved.

Results: The palliative burden is not only high but increasing due to the rise in population and life expectancy. A few options for holistic, supportive care include: Home-based care increases chances of a peaceful death for the terminally ill surrounded by their loved ones; supporting informal caregivers improves their quality of life and discharge planning reduces unscheduled admissions and has the potential to free up capacity for acute care services. A combination of strategies is needed to effectively implement the proposed options as discussed further in this article.

Conclusions: The policy brief report was used as a background document for two stakeholder dialogues whose main outcome was that a comprehensive national palliative care policy should be instituted to include all the options, which need to be integrated within the public health system. A draft policy is now in process.

Keywords: Palliative, Terminal, End-of-life, Uganda

This paper describes the development, findings, and subsequent use of a policy brief on “Advancing the Integration of Palliative Care into the National Health System” and the subsequent use of this report by policy makers and others from the health sector in Uganda.

The policy brief assesses a health systems problem, potential policy options to address the problem and strategies for implementing those options. The report brings together global

and local research evidence from systematic reviews or single studies to inform deliberations about increasing access to skilled birth care. The evidence report was developed in collaboration with a Working Group of stakeholders in Palliative Care including: policy makers, researchers, health managers, and civil society representatives. The report was used as a background document for meetings (policy dialogues) among policy makers and other stakeholders, either engaged in developing policies for palliative care, or likely to be affected by these policies.

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METHODS

The problem that this evidence brief addresses was identified through survey of key informants identified by the Ministry of Health including policy makers, researchers and other stakeholders. Stakeholders involved with palliative care helped identify the problem and potential policy solutions to scale up these services within the health system. The methods used to prepare the policy brief use the SUPPORT Tools for evidence-informed health policy making (1). Further clarification was sought through review of relevant documents, and discussion with the REACH Uganda Palliative Care Working Group. Research describing the size and causes of the problem was

identified by reviewing government documents, routinely collected data, electronic literature searches, contact with key informants, and reviewing the reference lists of relevant documents that were retrieved.

Strategies used to identify potential options to address the problem included considering interventions described in systematic reviews and other relevant documents, considering ways in which other jurisdictions have addressed the problem, consulting key informants, and brainstorming. Potential barriers to implementing the policy options were identified through brainstorming using a detailed checklist of potential barriers to implementing health policies (1).

We searched electronic databases using index terms or free text in PubMed, OVID, EMBASE, PsychINFO, Health Systems Evidence, Cochrane Library, Campbell Collaboration, DARE, HTA databases, SUPPORT evidence summaries, HINARI for full text articles of citations identified. Grey literature sources searched include: OpenGREY, WHOLIS, Google Scholar, national reports, and government documents. We supplemented these searches by checking reference lists of identified studies and communication with authors to find other relevant published or unpublished studies. The final selection of reviews for inclusion was based on consensus by the authors. For details for the search methodology see the attached Supplementary Table 1, which can be viewed online at <http://dx.doi.org/10.1017/S0266462314000750>.

One of the authors summarized included reviews using an approach developed by the Supporting the Use of Research Evidence (SURE) in African Health Systems project <http://www.who.int/evidence/sure/guides/en/index.html> (1). See Supplementary Table 2. Drafts of each section of the report were discussed with the REACH Uganda Palliative Care Working Group.

RESULTS

The Problem

Palliative care (PC) would benefit an urgent global need for an estimated 35 million people experiencing pain and suffering from life-limiting conditions particularly cancer, AIDS, other chronic diseases and old age (2). Kikule (2003) investigated needs for palliative care for the terminally ill in Uganda and found 58 percent require pain relief and other symptom control, 30 percent suffered loss of income, 5 percent needed counseling support, 7 percent required other support such as spiritual help (3).

There are existing national efforts to expand palliative care services which include; facility-based and community-based services, training, education, and research. In general, the delivery of health services is predominant by the public sector extending from community and primary level care to the tertiary national referral hospitals. However, most provision for

palliation is from isolated centers of excellence without comprehensive integration into the different levels of the health system structure using palliative care teams as recommended by WHO. There are many stakeholders who indicate that there is need to develop a specific policy on palliative care for the country as a guiding framework for these services (4).

Size of the Problem

Cancer and HIV/AIDS account for eighty percent of the patients needing palliative care in the country (5). Patients with cardiovascular disease, liver and renal pathology, neurological, and respiratory disease could also require palliative care (5). The current *minimum* palliative healthcare burden is close to 137,652 patients (6). An additional two family or voluntary caregivers per patient requiring support comes to a total 412,956.

Less than 10 percent of patients in Uganda who need palliation actually access these services (7). There is a disproportionate effect on women and girls both as sufferers and informal carers in the palliative burden (8–10). There is some limited access to oral morphine for pain control and adjuvants to control side effects to morphine such as nausea, vomiting, and constipation.

Cause of the Problem

The burden for palliation is pronounced by several factors; both at community and health systems level. Most terminally ill patients in Uganda prefer to be cared for at home by their families for security, privacy, and cost minimization (3).

There is widespread lack of awareness from the public, policy makers, and even health providers about the need for palliative care services. It is mostly perceived as end-stage support for the dying (11). Challenges in mainstreaming palliative care include; inadequate health infrastructure, shortage of trained palliative care staff, insufficient and unstable funding (7;11;12).

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.

Policy Options

National stakeholders involved with palliative care identified potential policy solutions to scale up services within the health system (4). Attempts have been made to summarize the best available evidence for some of these interventions, but there is still need for more rigorous research on many of the potential options.

The three policy options presented in this section could be adopted independently, but are also complementary to one another. Home-based care increases chances of a peaceful death for the terminally ill surrounded by their loved ones; supporting informal caregivers improves their quality of life and discharge

planning reduces unscheduled admissions and has the potential to 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 moderate quality systematic review by Shepperd and colleagues (13) from high income settings investigated the impact of home-care programs for end of life care.

The review found that home-based care compared with usual care: (i) Increases the likelihood of terminally ill patients dying at home, (ii) May increase patient satisfaction at one month of follow-up, (iii) 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 several 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 (14). These include; psychological support, palliative Care/hospice services, information and training, respite services and physical interventions, such as yoga (14).

Impact of Supporting Informal Caregivers

A good quality systematic review by Candy and colleagues (10) assessed a range of supportive programs for caregivers which included psychological support and practical assistance. The review found that supporting informal caregivers of patients in the terminal phase of disease compared with usual care may: (i) Reduce psychological distress in informal caregivers, (ii)

Increase quality of life for carers, (iii) 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 or 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 (15). Nonmedical reasons delaying a patient hospital discharge account for approximately 30 percent 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 (16). Discharge planning aims to rectify these avoidable causes through the development of an individualized plan for the patient before leaving hospital (15).

Impact of Discharge Planning

A moderate quality systematic review by Shepperd and colleagues (15) 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 (17).

The review found that discharge planning compared with usual care probably: (i) Reduces slightly length of hospital stay, (ii) Reduces unscheduled readmission rates at 3 months, (iii) Leads to little or no difference in mortality.

IMPLEMENTATION CONSIDERATIONS

Key barriers to implementing the policy options and implementation strategies to address these are summarized below:

Barrier to Implementation: Knowledge, competency, and care seeking behavior of families

Most terminally ill patients in Uganda prefer to be cared for at home by their families for security, privacy, and cost minimization. Other factors such as social prejudice, stigma, for HIV/AIDS sufferers isolate patients and their families (3). There is widespread lack of awareness from the public, policy makers, and even health providers about the need for palliative care services.

Strategies for Implementation

Home-Based Care. 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 (13).

Village Health Teams. 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 (18).

Vocational Education. 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 (19).

Barrier to Implementation: Knowledge, Competency, and Attitudes of Healthcare Providers

Many health providers perceive palliative care as end-stage support for the dying taking away precious time and resources from curable conditions (11).

Strategies for Implementation

Information, Education, Communication. 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. The Mulago Palliative Care Unit has released treatment protocols to be used in hospital settings.

Educational Meetings. Evidence of moderate quality shows that the distribution of educational materials to health professionals improves the process of care and patient outcomes (20). A synthesis of evidence of low quality shows that educational meetings improve patient care. However, these studies were not specific to PC and done in high and middle income countries.

Barrier to Implementation: Inadequate Financial Resources

Most of the centers of excellence available rely on external donor funding which makes planning difficult.

Strategies for Implementation

Subcontracting. Public financing with contracting services to suitable private providers, as part of a comprehensive integrated health care program. This program 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 results showed that more than 80 percent of the investment was saved, through the radical changes in costs.

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 percent toward the total cost of care.

Barrier to Implementation: Inadequate Facilities and Referral Processes

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 (21;22).

Strategies for Implementation: Effective Referral Strategies

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 (7).

Use Structured Referral Sheets. These 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.

Barrier to Implementation: Competing Priorities

Palliative Care is not one of the priority areas earmarked for investment by the current Ministry of Health's 5 year plan (23).

Strategies for Implementation: Integration of Services

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 program (24).

CONCLUSION

This policy brief was discussed as a background document for two policy dialogue meetings in Kampala. Participants included people with relevant expertise and perspectives including: members of parliament, policy makers, health managers, researchers, civil society, professional organizations, and the media. The purpose of these dialogues was to conduct a structured discussion of the policy brief on mainstreaming palliative care services within the national health system. These deliberations among health policy makers and other stakeholders can potentially contribute to evidence-informed health policies by adding value to the policy brief through clarification and development of a shared understanding of the problem and its possible solutions.

Stakeholders noted that the palliative burden is not only high but increasing due to the rise in population and life expectancy. Proposed solutions included: a comprehensive national umbrella policy to include all the options, which need to be integrated into the public health system; education of alternative, traditional healthcare practitioners; translation of public health information into local vernacular; an accreditation system for health providers; gender empowerment; relevant preservice and in-service training for health workers.

The policy brief and dialogues were highly evaluated as useful mechanisms to communicate research evidence for

decision making. Following stakeholder recommendations from the policy dialogues; next steps have included further consultations with stakeholders and use of the evidence brief in the policy development process led by the Ministry of Health. A draft government policy is now in progress using research evidence from the policy brief. The findings from this policy brief report are relevant to other low and middle-income countries in expanding palliative care within their public health systems.

SUPPLEMENTARY MATERIAL

Supplementary Tables 1 and 2

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CONFLICTS OF INTEREST

The authors report no conflict of interest.

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