

Advancing the Integration of Palliative Care in the National Health System

Full report

+ 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?

Polymakers, 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

Executive Summary

The evidence presented in this Full Report is summarized in an [Executive Summary](#).

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Competing interests

None known.

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Preface

The purpose of this report

This report is intended to inform the deliberations of those engaged in developing policies on palliative care as well as other stakeholders with an interest in such policy decisions. It summarizes the best available evidence regarding the design and implementation of policies on how to advance palliative care in Uganda's [mainstream] health system.

The purpose of the report is not to prescribe or proscribe specific options or implementation strategies. Instead, the report allows stakeholders to consider the available evidence about the likely impacts of the different options systematically and transparently.

How this report is structured

The report is presented in two parts. The first is an Executive Summary which outlines each section. This Summary may be particularly useful to those who do not have enough time to read the full brief. The second part contains the full report: this details the problem, the available evidence used to address the problem, and the approaches that were used during the preparation of the brief. The Executive Summary and full report each contain a one page summary of the key messages.

How this report was prepared

This report brings together both global and local evidence to inform deliberations about advancing the integration of palliative care services in the health system. We searched for relevant evidence describing the problem, the impacts of options for addressing the problem, barriers to implementing those options, and implementation strategies to address those barriers. The search for evidence focused on relevant systematic reviews regarding the effects of policy options and implementation strategies. We have included information from other relevant studies when systematic reviews were unavailable or insufficient. Other documents, such as government reports and unpublished literature, were also used. (The methods used to prepare this brief are detailed in Appendix 4.)

Why we have focused on systematic reviews

Systematic reviews of research evidence are a more appropriate source of research evidence for decision making than the latest or most heavily-publicized research studies.^(1, 2) The term 'systematic review' refers to a review of the research literature that has an explicit question, an explicit description of the search strategy, an explicit statement about which types of research studies it included and excluded, a critical examination of the quality of the studies included in the review, and a critical and transparent process for interpreting the findings of the studies included in the review.

Systematic reviews have several advantages (1): firstly, they reduce the risk of bias in selecting and interpreting the results of studies. Secondly, they reduce the risk of being misled by the play of chance when identifying studies for inclusion, or the risk of focusing on a limited subset of relevant evidence. Thirdly, systematic reviews provide a critical appraisal of the available research and place individual studies or subgroups of studies in the context of all of the relevant evidence. Finally, they allow others to appraise critically the judgements made in selecting studies and the collection, analysis and interpretation of the results.

Uncertainty does not imply indecisiveness or inaction

Most of the systematic reviews included in this brief concluded that there was “insufficient evidence”. Uncertainty about the potential impacts of policy decisions does not mean that decisions and actions cannot or should not be taken. However, it does suggest the need for carefully planned monitoring and evaluation when policies are implemented.(3)

Limitations of this report

This report is based largely on existing systematic reviews, as well as local and global single studies. Summarizing evidence requires judgements about what evidence to include, the quality of the evidence, how to interpret it, and how to report it. This brief is thus based on the judgements made by the review authors and judgements made by ourselves, but we have attempted to be as transparent as possible about these processes.

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

Introduction and framing of the problem

The Ministry of Health (MoH) in Uganda has initiated a process to develop a national palliative care policy to provide a framework for service delivery and has indicated that there is a need for research evidence to inform the decisions it takes.(4)

This policy brief contributes to the evidence base of policy development for scaling up palliative care services across Uganda, particularly among population groups with ‘special needs’, such as the poor, those living in rural areas, children or parents with life-limiting diseases, the elderly, and the mentally or physically challenged.(5) The Department for Clinical Services (in Uganda’s MoH) has identified a cross-section of twenty-two key stakeholders with relevant expertise in the field of palliative care (including policymakers, researchers, members of civil society, and palliative care practitioners). The information and viewpoints they provided helped to define the problem, identify potential policy solutions, as well as implementation considerations. All of these concerns are addressed in this report.(6)

Background

The modern hospice movement was founded by the nurse, physician and social worker Cicely Saunders. Underpinned by the key principle that holistic care should combine both teaching and clinical research pain and symptom relief. The aim of the hospice movement is to meet the physical, social, psychological and spiritual needs of patients and their families and friends.(7, 8) Palliative care in Uganda began in September 1993 thanks to the efforts of Anne Merriman, a palliative medicine specialist who worked together with the Ugandan government and the World Health Organization. Hospice Africa Uganda, established by Anne Merriman, is now the country’s largest palliative care provider and a regional centre of excellence for training, education and service delivery in the management of patients who suffer from life-threatening illnesses.(8-10)

The World Health Organization (2002) has defined palliative care as “an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care ... affirms life and regards dying as a normal process; intends neither to hasten nor to postpone death; ... uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated...” (11, 12)

The African Palliative Care Association recognizes three levels of service delivery, each determined by patient need. These are: the Primary (basic) Level, the Secondary (intermediary) Level, and the Tertiary (specialist) Level. While the Primary Level provides an essential or minimum package of care, patients receive an advanced range of care components at the Tertiary Level (13). (See **Appendix 3**). Similarly, The European School of Oncology identifies two levels of palliative care, namely basic and specialized care: (14)

Basic palliative care is the level of palliative care which should be provided by all healthcare professionals, in primary or secondary care, within their duties to patients with life-limiting disease.

Specialised palliative care is ... provided at the expert level, by a trained multi-professional team, who must continually update their skills and knowledge, in order to manage persisting and more complex problems and to provide specialised educational and practical resources to other non-specialist members of the primary or secondary care teams.

The palliative clinical skills required should be determined by patient need and provided via clear referral pathways within a health system. Primary, secondary and tertiary services should be provided throughout all levels of the health system hierarchy – from home or community-based care through to formal health facilities; regional or national referral hospitals.

The Cape Town Declaration (2002) declared that pain relief is a human right and outlined key strategies to address suffering related to HIV/AIDS, cancer, and other life-limiting illnesses.(15). And in 2005, the World Health Assembly acknowledged the suffering of cancer patients and their families and urged its Member States to develop and reinforce cancer control programmes.(16)

Globally, 35 million people experience pain and suffering caused by old age or by life-limiting conditions such as cancer, AIDS, and other chronic diseases.(17). The lack of palliative care is therefore an urgent problem. Providing palliative support globally is also likely to benefit the approximately 70 million family or voluntary caregivers who are helping those affected.(18) Developing countries account for two-thirds of the global burden [of 35 million] and a high proportion of patients in these areas are in the advanced stages of illness, with little chance of being cured.(17) Ideally, care should be provided from the moment a life-threatening illness is diagnosed and be adapted to the increasing needs of patients and their families during the progression of a disease, through to the terminal phase and, ultimately, death.(19)

A global body of scientific knowledge on palliative care interventions could be used to improve the quality of life, the process of dying, and the death of sufferers, and their affected families.(17) Within Uganda's already over-stressed health infrastructure, palliative care services have not been adequately scaled up.(20) This is a particularly challenging problem for, as Kikule (2003) has argued, 58% of the terminally ill require pain relief or other symptom control. In addition, 30% suffer a loss of income, 5% need counselling support, and 7% require other support such as spiritual help. (21) Kikule suggests that a good death "occurs at home, in the absence of pain and other distressing symptoms, without stigma or a sense of dependence, and with adequate finances for the basic needs." (Kikule, 2003)

International policy context:

The WHO Cancer programme led by Jan Stjernsward (1980), advocated a worldwide initiative to promote pain relief, opioid availability and palliative care.(22) This project succeeded in increasing global awareness and led to the development of WHO guidelines on cancer pain, opioid availability, symptom control and other aspects of palliative care.(22) (See list, Appendix 1) But despite the progress made thus far in policy development, most countries still do not have palliative care incorporated within their health agendas. And while some countries, like Uganda, have developed 'centres of excellence' (such as Hospice Africa Uganda), these services are not comprehensively integrated within all levels of the health system.(23)

The WHO has also undertaken two key initiatives related to palliative care: one for HIV/AIDS and cancer patients in Africa, and for the improvement of performance of cancer control programmes in Europe.(12, 24) Uganda, together with four other African countries (Ethiopia, Botswana, Tanzania and Zimbabwe) participated in the WHO African project, the purpose of which was to provide a model for palliative care service initiatives in settings with low resource levels.(24) The WHO together with the International Narcotics Control Board harmonized regulatory measures and developed guidelines for national authorities in order to improve opioids access.(23)

The WHO has also developed guidance on the integration of palliative care into existing health system at all levels, especially in community and home-based care provided by networks of palliative care teams. (19) Such care, it has suggested, should be provided:

At community level: By community leaders, village health teams, and family caregivers trained to provide basic home-based care and supervised by primary care level nurses.

At primary care level: By nurses trained in basic palliative care who train and supervise community volunteers and family caregivers. These palliative care nurses are supervised at the district level.

At secondary care level (district hospital): By specialist palliative care teams consisting of: a physician, a nurse to supervise primary health-care clinics, a social worker, and a pharmacist.

At tertiary care level (national or regional hospital): By a specialist palliative care team consisting of: a physician, a nurse, a social worker and a pharmacist. All physicians and nurses who provide basic palliative care should be supervised by the specialist team.

National policy context and achievements:

Uganda was the fourth country in sub-Saharan Africa to institute palliative care, following Zimbabwe (1979), South Africa (1980), and Kenya (1990).(25) Uganda, however, has also managed to realize a broader regional vision than its African counterparts by actively expanding its palliative care services beyond her own borders to include Malawi, Zambia, Ethiopia, Nigeria, Cameroon, Sierra Leone, Sudan and, more recently, Francophone African

countries.(8) Local initiatives, such as Hospice Africa Uganda (HAU), Mildmay Uganda, the African Palliative Care Association,, the AIDS Support Organisation, and the Palliative Care Association of Uganda also provide services, training, education and research at a regional level. (8)

In 1998, the Ministry of Health and national stakeholders, formed a joint task force with the WHO to formulate recommendations on the adoption of palliative care within Uganda's national health policies and plans.(26) As a result, palliative care now forms part of the country's broader national health policy.(27) However, it should be noted that the health sector plan outlines strategies to provide such services within hospitals and health centres providing secondary care only.(28)

The HAU has provided training in palliative care since its inception in 1993 and, in 2010, was recognized as an Institute of Higher Learning by Uganda's National Council of Higher Education (NCHE). Initially the HAU provided training for undergraduate medical, nursing students and health professionals already in practice, but now offers formal certificate, diploma qualifications and degree programmes conferred by Makerere University and Mbarara University. Over 8,000 trained professional and non-professional palliative care practitioners and prescribers have received the training thus far.(8, 25) The Mulago Palliative Care Unit also supports undergraduate and professional curricula, and has developed, implemented, and evaluated a course for a Masters in Internal Medicine degree programme at Makerere University. (29)

To improve access to opioids, the National Drug Authority of Uganda officially registered the use of oral morphine as a palliative treatment (1993) and this treatment has been prepared at HAU ever since. The Ugandan Government has also subsidized Joint Medical Stores (an NGO pharmaceutical organization that supports both public and private health facilities) to reconstitute powdered morphine.(9, 10) A statute to expand the range of providers who can prescribe narcotic analgesics was an important milestone in overcoming problems caused by the shortage of physicians in Uganda. According to this statute, nurses and clinical officers who have a 'certificate in specialist palliative care' are authorized to prescribe and supply morphine for pain and palliative care only.(30)

Clinical guidelines and other forms of guidance used at the national level have also been developed by Hospice Africa Uganda and the African Palliative Care Association in collaboration with multiple stakeholders, including Uganda's Ministry of Health (See Appendix 2). Likewise, the Mulago Palliative Care Unit has recently launched clinical guidelines for use in hospital settings. (29) While Uganda's achievements have been commendable thus far, many stakeholders have indicated that a specific palliative care policy for the country is still needed in order to establish a framework to guide these services. (6)

National policy review on palliative care:

The African Palliative Care Association undertook a comprehensive review of national policy documents in the health sector to identify gaps within the existing system framework.(31) The review highlighted the strong commitment from the Ugandan government to provide gender-sensitive quality care in life-threatening illness such as HIV/AIDS and cancer. The

report advised further integration of palliative care into existing strategies and recommended the prioritization of particular areas for action as part of efforts to scale up palliative services.(31)

Size of the problem

Amandua (2011) found that cancer and HIV/AIDS consist eighty percent of the proportion of 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) Table 1 shows recent morbidity and mortality rate statistics for non-communicable diseases (NCDs) produced by the Ministry of Health. (33)

Table 1: Morbidity and mortality rates for non-communicable diseases

Gender	Mortality from NCDs	Cancer	Chronic respiratory disease	Cardio-vascular disease and diabetes	Others
Males	1094/100,000	12%	15%	51%	22%
Females	685/100,000	20%	8%	56%	16%
Source: MOH, 2011(33)					

Anne Merriman has estimated that 80% of cancer patients experience pain during the terminal phase of their illness. Similarly, 25% of HIV patients also endure pain during the course of their illness, while 50% of those in Stage 4 AIDS experience pain.(34) Table 2 shows the minimum need for palliative care required by people with HIV/AIDS and terminal stages of cancer in both Uganda and the other four African countries which participated in the WHO palliative care project.(24)

Table 2: Cross country comparisons: The extent of the palliative care burden

Country	Number of deaths from HIV/AIDS	Number of deaths from cancer	Total number dying from HIV/AIDS or cancer	Number dying from HIV/AIDS or cancer and suffering pain	Proportion of total population needing terminal care
Uganda	84,000	10,500	94,500	29,400	1 in 247
Botswana	26,000	800	26,800	7,100	1 in 56
Ethiopia	160,000	39,900	199,900	71,900	1 in 315
United Republic of Tanzania	140,000	21,000	161,000	51,800	1 in 218

Zimbabwe	200,000	8,600	208,600	56,900	1 in 60
Source: WHO, 2004 (24)					

Nearly 90% of patients in Uganda who require palliative care do not access such services. (35) Using a ratio of 1:247 to estimate the proportion of those needing terminal care within the total population (see Table 2), the *minimum* palliative healthcare burden in Uganda (assuming a population of 34 million people) will be approximately 137,700 patients.(36) An additional 2 family or voluntary caregivers per patient requiring support comes to a total of 413,000.

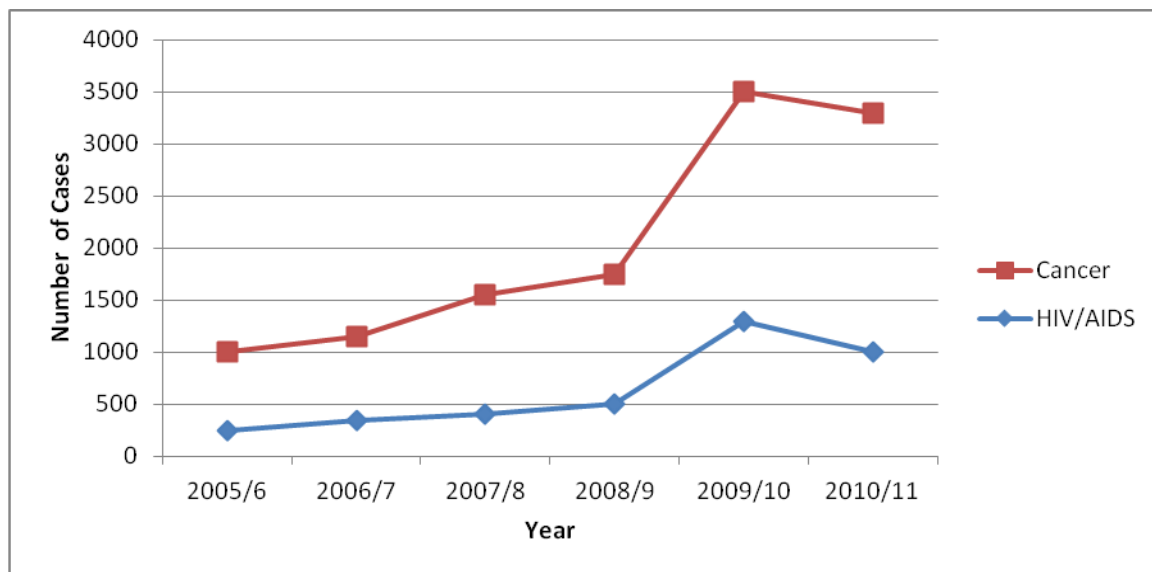
Palliative care is time-intensive and holistic care requires considerable investment in provider-patient relationships.(8) Based on its extensive work in Uganda and the African region, the HAU has estimated that the optimum quality care ratio of health professionals (including doctors, clinical officers, nurses and dispensers) to patients is 1:30.(8) Based on these projections therefore, Uganda's current population level requires at least 13,800 specialist palliative health care professionals. This leaves a gap of 5,800 professional specialists from those trained so far, taking into account that many may not be practicing their skills in their formal employment positions.

Cancer and HIV trends:

HIV infection is largely responsible for the rising trend in incidence and prevalence of cancer over the past decades. HIV-AIDS related cancers include: Kaposi's sarcoma, non-Hodgkin's lymphoma, and cervical cancer. (33)

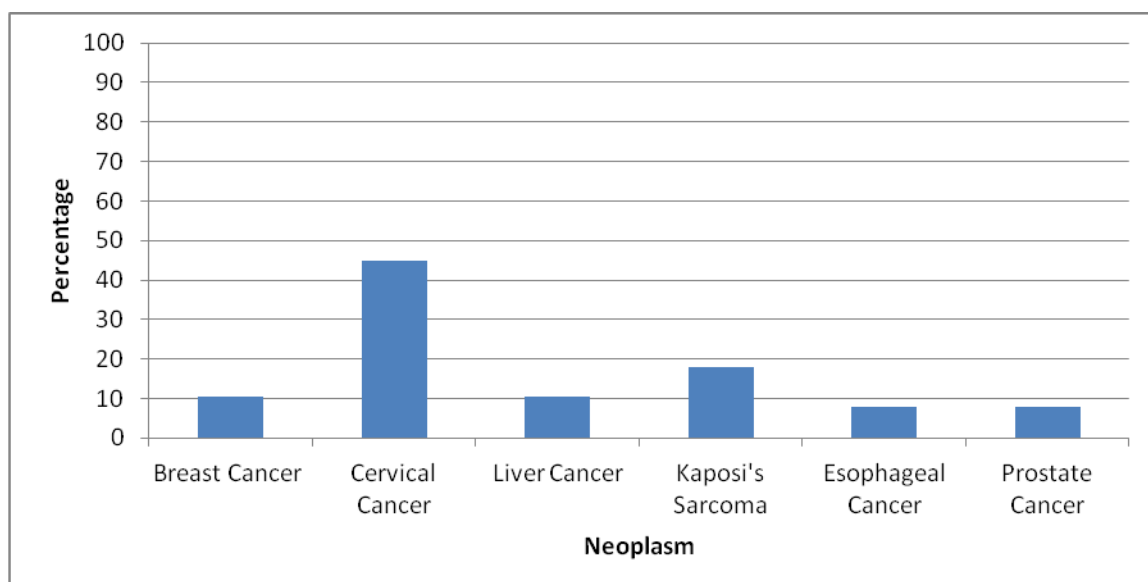
Figure 1 shows the HAU's trend estimates for cancer and HIV in Uganda over the last five years. (See [Figure 1](#)): 57% of palliative care patients had cancer, 30% were HIV-positive, and 10% had both cancer and HIV. Other sources have suggested that HIV/AIDS is the biggest burden of disease in Uganda (73% of patients), followed by cancer (22% of patients), cancer *and* HIV/AIDS (3% of patients), and other conditions (2% of patients).(35)

Figure 1: Cancer and HIV trends over the past five years



The most common forms of cancer in both female and male patients in Uganda are shown in **Figure 2**. (35) The most common forms of cancer in men include Kaposi's sarcoma (33%), liver cancer (29%), prostate cancer (21%), and oesophageal cancer (17%), while the most common forms of cancer in women include cervical cancer (67%), breast cancer (20%), and Kaposi's sarcoma (13%). (35)

Figure 2: The most common forms of cancer in female and male patients



Palliative burden and gender inequity:

In sub-Saharan Africa, 59% of those living with HIV/AIDS are female,(37) while in the age group 15-19 years, for every young man, five to six young women are infected with HIV.(38) A comprehensive review by Gray and Berger (2007) discusses factors influencing high infection rates in women in African and other resource-poor countries including Uganda:(38)

- The socio-economic marginalisation of women has led to greater male control over female sexuality
- Stigma and discrimination in relation to AIDS (and all STDs) is far stronger against infected women, who risk violence, abandonment, destitution, and ostracism from their family and community. Furthermore, women are often blamed for the spread of the disease, even though the majority of them have been infected by their only male partner
- Sexual coercion increases the risk of micro-lesions, therefore increasing the risk of sexually transmitted diseases (STDs) and HIV infection
- Harmful cultural practices such as genital mutilation
- Neglect of women's health needs, nutrition, and medical care as family resources are nearly always devoted to caring for the male partner or children
- Clinical management is based on research done on males, a female focus is imperative to cater for women's' needs
- Civil and military conflicts exacerbate human rights abuses against women and children who are often exposed to sexual violence in crowded, unsafe camps for refugees or the displaced.
- Cultural malpractices, particularly for Uganda, where women and children can be disinherited following loss of the male partner or breadwinner from HIV or other causes

Informal caregivers and the burden of palliative care:

An informal (or unpaid) caregiver is defined as *"a person of any age who provides unpaid help and support to a relative, friend or neighbour who cannot manage [otherwise] to live independently without the carer's help due to frailty, illness, disability or addiction."*(39) Informal caregivers differ from professional (or paid) caregivers (such as doctors, nurses and other health workers) and are often family members or friends who derive social or emotional fulfilment from these relationships.(40) Hudson et al. (2005) found that caregivers associate positive emotions with their roles despite the burden of caring.(40), The caregiver role involves considerable physical, psychological, economic and domestic challenges. These affect the family and friends who need to deal with their own sorrow at the impending loss, many times this results in fatigue, sleeping problems, weight loss, depression, anxiety and an increased risk of death.(41) However, family or friends in an attempt to secure resources for their patient are reluctant to seek support for their own needs.(41) As these issues may influence the quality and duration of home care for the patient and it is important that they are addressed. Harding and colleagues (2003) discuss that the main focus of palliative care services is the patient and caregivers' needs are largely unmet.(42) Much as support for caregivers is a core tenet of palliative care philosophy, this field is less developed compared to other aspects of palliative care services.

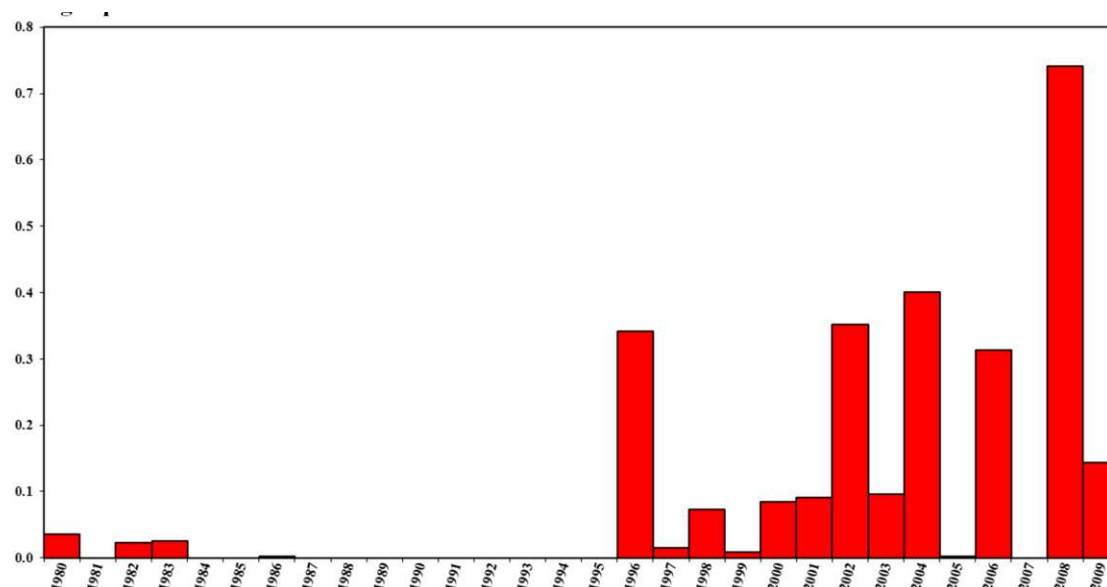
Harding et al (2010) have noted that the availability of opioids for the treatment of neuropathic pain, and the availability of other symptom-controlling drugs, such as anxiolytics (for the treatment of anxiety), are problematic issues in sub-Saharan Africa. (43) In Uganda, for instance, there is still limited access to oral morphine for pain management and adjuvants for the control of morphine side-effects such as nausea, vomiting and constipation.(44)

Figure 3: Districts in Uganda which receive oral morphine (yellow)



Figure 4 shows the consumption patterns for oral morphine in Uganda over the past three decades. (46)

Figure 4: Consumption of oral morphine in Uganda, 1980 to 2009 (milligrams per capita)



Cause of the problem

The burden of palliative care in a country may be influenced by a number of factors, both at the community and the health systems levels.

Social, cultural and family environments:

The wider social and cultural context in which a patient lives will influence when, whether and how care is sought. The specific preferences and needs of a patient's family are also important.(47) Most terminally ill patients in Uganda prefer to be cared for at home by their families as doing so provides better security and privacy, and helps to minimize the costs involved. Social prejudice and the stigma associated particularly with HIV/AIDS, may result in patients and their families being socially isolated. If a family provider is affected, the income available for basic and healthcare needs may be more limited or stop altogether.(48) It is important to engage communities in efforts to change cultural attitudes towards death and dying, and for people to realize that both should be seen as part of a normal cycle of life. Seeking supportive care for patients should be encouraged even when there is no hope of finding a cure.(49) Many families and patients turn to traditional healers to treat terminal illnesses and this may delay obtaining treatment in health facilities.(49)

Inadequate knowledge and awareness of palliative care:

There is a widespread lack of awareness among members of the public, policymakers, and even health providers regarding the need for palliative care services. Typically, these services are perceived as being related to end-stage support for the dying.(50) Under-staffing and high workloads within the health sector may also make personnel less motivated to care for

the terminally ill.(48) Efforts should therefore be made to improve perceptions of palliative care and to highlight the range of potential benefits offered by a holistic form of treatment that helps to restore quality of life.

Availability of hospice and palliative services:

Most facility-based or home-care palliative care programmes and services in Uganda are offered by private providers. Publicly-provided palliative care is also available, and a palliative care unit is in operation at the National Referral Hospital in New Mulago.(25) Other service providers in Uganda include: Hospice Africa Uganda, Association François-Xavier Bagnoud, Mobile Hospice Mbarara, Little Hospice Hoima, Mildmay International (MISC), Joy Hospice Mbale, Kitovu Mobile Home Care, Lira Regional Referral Hospital, and The AIDS Support Organization (TASO).(51) Specialist human resources are scarce. This means that most palliative care is provided in systemically isolated centres of excellence which are not comprehensively integrated across the different levels of the country's health system structure. The use of palliative care teams (as recommended by the WHO) is also uncommon.(19) However, a 2011 global survey by the Worldwide Palliative Care Alliance commended the efforts made by Uganda in developing palliative care services (52), and rated the country's progress towards integrating palliative services within its mainstream health care system as 'advanced'.(52) Further progress needs to be achieved, however, and major challenges will include the inadequacy of the country's health infrastructure, a shortage of trained palliative care staff, and inadequate access to pain and symptom control medicines.(53)

Funding for Palliative Care:

Most of Uganda's centres of palliative care rely on external donor funding.(35) The unpredictable nature of such financing, particularly in the current global economic crisis, makes future palliative care planning challenging. Financial resources such as those offered by the United States President's Emergency Plan for AIDS Relief (PEPFAR) are now more limited, and there are shortfalls too in the funding provided by both the Global Fund and the United Kingdom's (UK's) Department of International Development (DfID). The closure of the Diana, Princess of Wales Memorial Fund, a key funder of palliative care, has also led to service constraints. (50, 53) To achieve financial sustainability, stable government support for palliative care services will therefore be important.

Lack of evidence for Palliative Care:

The 2006 Declaration of Venice committed to developing a Global Palliative Care Research Initiative and noted the paucity of research within Africa.(49)

This forum identified several prerequisites for developing and sustaining palliative care research, including: a critical mass of research groups in the field, dedicated funding, a national strategy for palliative care research, and strong collaboration between academics and clinicians.(54) At present, there is insufficient local research to help health decision-makers understand the complex burden of palliative care and to develop suitable models of palliative care delivery.(49) (Table 3 highlights the lack of palliative care research and knowledge in Africa)

Table 3: Number of research publications on palliative care in Africa

	Where the relevant research journals which contain the individual papers were published		
Period	Total number of research papers cited	Africa	Developed country
<1990	5	1	4
1991–1995	4	0	4
1996–2000	11	0	7
2001–2005	50	4	20
2006–2010	82	4	27
Source: Adapted from Grant, 2011 (49)			

Powell (2008) and colleagues describe reasons underlying this deficiency; protection of finite resources for care provision away from research, a patient population suffering from progressive illness making accrual difficult with high attrition of study participants, most palliative care research tools have not been validated in the African context.(54) Dominance of the biomedical model in research which emphasizes randomized controlled trials as the ‘gold standard’.(54) It may be undesirable and highly inappropriate to assign very sick, vulnerable patients to different treatment arms.

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.(6) 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

‘End of life’ refers to the period when it has become obvious that 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.(13) The quality of a dying patient’s life requires attention to their physical comfort and functioning, their psychological and spiritual well-being, their cognitive functioning, the general meaningfulness of life, as well as the quality of life experienced by their family and loved ones.(47)

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. (55) Patients with terminal illness recognize the practical and emotional challenges of expressing this choice, and worry about being a burden to their carers at home.(56) A number of countries have invested in health services to provide care at home for patients with terminal illness, particularly where public health services are overburdened.(57)

Current Status of Home-Based Care for End-of-Life

A survey by Kikule (2003) on palliative care needs for the terminally ill in Uganda found that a ‘good death’ occurs when the dying person is being cared for at home, is symptom-free and has their holistic needs met.(21) Kikule (2003) found that nearly all terminally ill patients who die at home had been discharged from hospitals.(21) In the survey, all the patients were found to have received home-based care (HBC) as part of programmes run provided by non-governmental organisation (NGOs).

Most home-based care in Uganda is offered through private providers, most of which are located in central or urban regions. Necessarily, the majority of Uganda’s population (i.e. the rural poor) are unable to utilize such services.(51) Although NGOs such as Hospice Africa Uganda, Mobile Hospice Mbarara, Little Hospice Hoima, Mildmay International Uganda,

Joy Hospice Mbale, Kitovu Mobile Home Care and The AIDS Support Organization (TASO) have contributed significantly to addressing this problem,(51) there is still a need for public investment to further integrate home-based care within the mainstream health system and to find ways to overcome such barriers. Some stakeholders have suggested that recognizing home-based palliative carers as a new health worker cadre within the national health human resource framework will also help to address the current problems.

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(58) compared home-based care with usual care. The review found that home-based care for end-of-life: (see **Table 4**)

- ➔ *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 the psychological well-being of caregivers when patients survive more than 30 days*

Table 4: Home-base care for patients who are terminally ill

Outcomes	Impact			Number of studies	Quality of the evidence (GRADE)*
	With standard or usual care	With home based care	Relative change		
Dying at home	444 per 1000	591 per 1,000 (506 to 668)	33% relative increase	3	⊕⊕⊕⊕ High
Patient Satisfaction	Increased satisfaction reported at 1 month, not at 6 months			2	⊕⊕ Low
Follow up: 1 to 6 months					
Carer Burden	One study demonstrated a reduction in psychological well-being for caregivers when patients survived more than 30 days			2	⊕⊕ Low
Follow up 6 months					

*GRADE Working Group grades of evidence

High: We are confident that the true effect lies close to what was found in the research.

Moderate: The true effect is likely to be close to what was found, but there is a possibility that it is substantially different.

Low: The true effect may be substantially different from what was found.

Very low: We are very uncertain about the effect.

Relevance of the research findings to the Ugandan context:

Applicability

The research was conducted in high-income settings (Norway, the United Kingdom and the United States of America (USA)). The applicability of the available evidence to low- and middle-income settings such as Uganda may be uncertain: the infrastructure available for home-based or community care in Uganda, for example, may be substantially different.

Equity considerations

The review did not provide data on the differential effects of home-based care for disadvantaged groups such as those living in rural areas, the poor, the elderly, children, or women with progressive illnesses. Possible harm may be caused through the use of home-based care if it reduces the appropriate use of hospital care and thereby increases complication rates, particularly among disadvantaged populations.

Costs and cost-effectiveness

One trial in the review (Hughes et al., 1992) compared the cost of end-of-life home care with the cost of hospital care, and found no significant cost differences between the two study groups.(59) A second trial (Brumley et al., 2007) reported that the average cost per day incurred by those receiving end-of-life home care was significantly lower than those receiving standard care. (60)

Monitoring and evaluation

The monitoring and evaluation of the effects of home-based care is urgently needed in the Ugandan context. Particular attention should be given to the impact of differential effects on disadvantaged socio-economic groups, as well as the local costs of the intervention, and its cost-effectiveness.

Policy Option 2:

Supporting informal caregivers

Informal or unpaid caregivers in palliative care, (described earlier) include family, friends or volunteers offering support to patients who are unable to cope on their own.(40) People who care for patients with a progressive illness may themselves suffer from a number of problems, including sleeplessness, a general deterioration in health, exhaustion, anxiety and depression.(61)

A literature review undertaken by Harding et al., 2011 identified five key forms of interventions for providing support for carers (62). These are:

- Psychological support: The use of psycho-educational sessions for individuals or for families; telephone interventions; cognitive-behavioural interventions such as stimulus control, relaxation, cognitive therapy, sleep hygiene; music therapy; and home visits
- Palliative care/hospice services: Formal caregivers providing assessments and care to both the patient and family, at home or at health facilities
- Information and training: Training for caregivers in home care and symptom management and use of informational materials
- Respite services: Such as coping skills training programmes, and at-home palliative care respite services
- Physical interventions: Activities such as yoga exercises.

Support for carers potentially protects their health and well-being, and may also help to improve the quality of care provided to the patients who depend on them.

Current status of supporting informal caregivers

The network of mostly private, together with public, providers mentioned earlier take on the dual role of caring for both patients and their families or carers.(51) As noted earlier, the focus of specialist palliative care services is upon the patient, while the needs of caregivers are seldom considered. The needs of carers may vary throughout the period of caregiving and bereavement and many health professionals also feel ill-equipped to provide the necessary support.(42)

Impact of supporting informal caregivers

A good quality systematic review conducted by Candy and colleagues (2011) assessed a range of supportive programmes for caregivers, including psychological support and practical assistance.(41)

The review found that supporting informal caregivers during the terminal phase of a patient's disease compared to usual care may: (see Table 5)

- Reduce psychological distress in informal caregivers
- Increase the quality of life of carers
- Reduce the ability of carers to cope with the caring role

Table 5: Supporting the informal caregivers of patients who are in the terminal phase of their illness

Outcomes	Impact	Number of studies	Quality of the evidence (GRADE)*
	Intervention: Supporting informal caregivers of patients in the terminal phase of illness		
Psychological distress	Measurements for ' <i>psychological distress</i> ' were lower among informal carers who received the support interventions compared to those who did not receive support	8	⊕⊕ Low
Coping with the caring role	Measurements for ' <i>coping with the caring role</i> ' were lower among informal carers who received support compared to those who did not receive support	7	⊕⊕ Low
Quality of life	Measurements for ' <i>quality of life</i> ' were higher for informal carers who received support compared to those who did not receive support	6	⊕⊕ Low
Physical health: sleep quality	There was no difference in <i>sleep quality</i> between the two groups	1	⊕⊕ Low

*GRADE Working Group grades of evidence

High: We are confident that the true effect lies close to what was found in the research.

Moderate: The true effect is likely to be close to what was found, but there is a possibility that it is substantially different.

Low: The true effect may be substantially different from what was found.

Very low: We are very uncertain about the effect.

Overall Assessment: This is a good quality systematic review with only minor limitations.

The relevance of the research findings to the Ugandan context:

Applicability and equity

The evidence is drawn from high-income settings in the United Kingdom, United States and Australia; hence, applicability to the Ugandan context may be uncertain.

The review did not compare findings across different socio-economic groups.

Monitoring and evaluation

There is a need to monitor and evaluate the costs and cost-effectiveness of these mechanisms of support for informal caregivers within the setting of the Ugandan health system. Currently, no such data are available. The differential effects of the interventions upon different disadvantaged social groups will also need to be measured.

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.⁽⁶³⁾ This is a useful cost-containment measure for an under-resourced national health system by increasing acute care capacity in health facilities and hospitals.

A patient's discharge from hospital may be delayed for both medical and non-medical reasons. Non-medical causes account for approximately 30% of delays and usually occur due to poor knowledge about a patient's social circumstances, deficient logistical organisation, and inadequate communication between hospitals and community service providers.⁽⁶⁴⁾ The purpose of discharge planning is to rectify avoidable problems by developing individualized plans for patients prior to their departure from a hospital. Such plans typically include a pre-admission assessment, case findings on admission, individual inpatient assessment, and discharge preparation and implementation. The discharge planning process must be monitored and documented.

Current status of discharge planning

A number of palliative care providers prepare detailed discharge plans for patients. These plans include evaluations of where patients can receive subsequent care closer to their home or community, where patients can procure the necessary medication, and where patients will be able to receive support when sick.⁽⁶⁵⁾ However, system wide and social context issues influence the effectiveness of this process such as poorer patients lacking transport money to go home, lack of 'directories' signaling the relevant health provider per geographical region or area or inadequate patient assessment by health professionals, and consequently poor or no planning for follow-up care.⁽⁶³⁾

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.(63, 66)

The review found that discharge planning compared to usual care probably: (see Table 6)

- *Slightly reduces the length of a hospital stay*
- *Reduces unscheduled readmission rates at 3 months*
- *Leads to little or no difference in mortality*

Table 6: Discharge planning for palliative care

Outcomes	Impact			Number of studies	Quality of the evidence (GRADE)*
	Without discharge planning	With discharge planning	Relative change		
Hospital length of stay Follow-up: 3 to 6 months	The mean length of the hospital stay varied in the control groups, and ranged between 5.7 to 12.4 days	The mean length of the hospital stay of those in the intervention groups was 1.01 days less [than those in the control groups] (1.61 to 0.4 lower)	1 day less on average	10	⊕⊕⊕ Moderate
Unscheduled readmission within 3 months of discharge from hospital For patients with a medical condition	266 per 1,000	226 per 1,000 (199 to 258)	15% fewer unscheduled readmissions	12	⊕⊕⊕ Moderate
Mortality at 6 to 9 months	115 per 1,000	121 per 1,000 (86 to 169)	5% increase in mortality at 6 to 9 months	5	⊕⊕ Low

*GRADE Working Group grades of evidence

High: We are confident that the true effect lies close to what was found in the research.

Moderate: The true effect is likely to be close to what was found, but there is a possibility that it is substantially different.

Low: The true effect may be substantially different from what was found.
Very low: We are very uncertain about the effect.

Overall Assessment: This is a good quality systematic review with only minor limitations.

Relevance of Research Findings to the Ugandan Context:

Applicability

The review assessed studies from the United States, United Kingdom, Canada, Denmark and Australia, all high income contexts therefore applicability is uncertain. The infrastructure for referral, health human resources capacity and community care such as village health teams, first and second level health facilities; II and III may not be comparable to that in industrialized settings.

Equity

There was insufficient data on the differential effects of discharge planning on disadvantaged populations.

Costs and cost-effectiveness

Some studies in the review assessed the effects of the intervention on the costs of health care or the use of medication compared to usual care. The studies showed that discharge planning may slightly reduce hospital care costs.

Monitoring and evaluation

The effects of discharge planning should be rigorously evaluated in the local Ugandan context in terms of its impacts on patient quality of life, on informal care givers, and on resource utilisation prior to scaling up.

Potential alternative policy interventions

Potential interventions identified by the stakeholders concerned with palliative care that have not been explicitly discussed either as policy options or implementation strategies include; gender considerations, patient empowerment, patient registration databases, training, advocacy for palliative care, pharmaceuticals management and governance.⁽⁶⁾ Some of these are discussed further below, but for many of these the research was lacking to advise on policy direction. Advice on how to strengthen research in palliative care is also outlined.

Gender empowerment

The socio-economic empowerment of women and girls would serve to improve the lives of females generally, and not just in health. This is well recognized in the Millennium Development Goal 3 which serves to raise the literacy of women, improve shares of women in wage employment and participation in governance.⁽⁶⁷⁾ Because of the multi-sectoral

nature of gender issues and despite the overwhelming evidence for this, interventions to empower women and girls have not been specifically discussed in this report as they are not exclusive to palliative care alone and hence would not do full justice to this particular problem.

Training and education for palliative care

The European School of Oncology outlines some principles to achieve palliative care education and research below:(14)

- a) Delivery of education through multi-professional programmes which emphasize the integrative approach to supporting patients
- b) Continuing professional education of all specialties and of the primary care team should teach professionals to be aware of their own limitations, to know where to access more information, and how to refer the patient to a local palliative care team
- c) There should be at least one academic centre for palliative care, with a chair of palliative medicine in the country to take the lead on medical education
- d) Information and educational programmes aimed at the public should be available in the relevant languages
- e) available in the relevant languages

Research in palliative care

- a) Research in palliative care should be designed in sympathy with the needs of the patients in mind, and the methods may vary with different research questions and at different stages of the disease
- b) Methodologies for evaluating palliative care interventions and services need to be further developed and tested
- c) Funding for palliative care research could be protected by 'ring-fencing'
- d) Setting up research fellowships in palliative care studies could encourage prospective researchers in this field

Implementation considerations

The public health approach advocated for by the World Health Organisation offers the best opportunity to incorporate the relevant policy strategies at all levels of the healthcare system for palliative care. (68)

The following enablers could enhance the expansion and integration of palliative care within the mainstream health system:

- ➔ *Political support from the national Ministry of Health towards private actors in the sector from inception of hospice services in Uganda till present*
- ➔ *Strong and sustained advocacy efforts by the non-state sector involving the local WHO Country office, AIDS Control program, TASO and others*
- ➔ *Expansion of these services will be made easier by drawing from the wealth of clinical and academic experience gained thus far in-country by the vibrant private sector such as Hospice Africa, APCA and Mildmay International*

Evidence related to barriers to integrating palliative care and ways to overcome them are summarized in **Table 7**.

Recipients of care

Table 7: Barriers to integrating palliative care and proposed strategies to overcome them:

Barrier	Knowledge, competency and care-seeking behaviour of families	
	Most terminally ill patients in Uganda prefer to be cared for at home by their families as this provides security, privacy and helps to minimize costs. But factors such as social prejudice or the stigma of illnesses such as HIV/AIDS, may result in patients and their families being socially isolated.(21) There is a widespread lack of awareness among members of the public, among policymakers, and even among health providers, about the need for palliative care services.(50)	
	Implementation strategies	Evidence
	Home-based care Home based care allows patients to die with dignity at home. Members of a patient's family, as well as their friends and neighbours are usually involved, and home-based care is suitable for traditional African settings. The strategy may help to minimize the costs associated with dying in hospital.	Home-based end-of-life care increases the probability that patients will be able to die at home, increases levels of patient satisfaction, and helps to reduce hospital admissions. (58)

<p>Village health teams</p> <p>The existing Village Health Team structure could be optimized to extend PC services.</p>	<p>Village Health Teams (VHT) were initiated by the Ministry of Health. VHTs are a community's primary point of contact for health issues and refer individuals to health facilities as needed. (69)</p>
<p>Vocational education</p> <p>Vocational education for informal care givers could be provided during the initial hospitalisation of patients in need palliative care. This could form part of a package of health measures to prepare family members for providing palliative care at home.</p>	<p>Indirect evidence from a systematic review of seven studies shows that Community Health Workers are effective in managing acute illnesses in children.(70)</p> <p>Interventions that provide forms of vocational education to caregivers prior to the discharge of stroke survivors from hospital appear promising. However, the results were based on one, small, single-centre study. (39)</p>

Providers of care

Barrier	<p>Knowledge, competency and attitudes of healthcare providers</p> <p>Many health providers regard palliative care as end-stage support for the dying which diverts precious time and resources away from curable conditions. (50).</p>	
	<p><i>Implementation strategies</i></p>	<p><i>Evidence</i></p>
	<p>Information, education, communication</p> <p>The dissemination of educational materials, such as clinical guidelines, improves professional clinical practice.</p>	<p>Clinical and other guidelines are available from Hospice Africa Uganda and the African Palliative Care Association.(13, 71) The Mulago Hospital Palliative Care Unit has released treatment protocols which can be used in hospital settings.(29)</p>
	<p>Educational meetings</p> <p>Continuous medical education can be provided via educational meetings or outreach visits.</p>	<p>Evidence of moderate quality shows that the distribution of educational materials to health professionals improves the process of care and patient outcomes. (72)</p> <p>A synthesis of evidence from low-quality studies shows that educational meetings improve patient care. (72)</p> <p>However, these studies were not specific to palliative care and were conducted in high- and middle-income countries.</p>

Health systems constraints

Barrier	Inadequate financial resources Most palliative care centres of excellence in the country rely on external donor funding and this makes planning difficult.(35, 50)	
	<i>Implementation strategies</i>	<i>Evidence</i>
	Sub-contracting A publicly financed health sector in which services are contracted to private providers as part of a comprehensive integrated health care programme. This programme would be free to recipients of palliative care.	<p>A project in Catalonia, Spain, tested the use of contracting within the health system. The project evaluated a combination of payment structures, daily fees for beds (units), quality assurance, incentives, and structural reconversion assistance. The preliminary results showed that more than 80% of the investment was saved, and radical changes in costs achieved.(73)</p> <p>Three studies provided low-quality evidence that contracting services to non-state not-for-profit providers can increase access to and the utilization of health services. Patient outcomes may be improved and household health expenditures reduced through contracting.. However, these effects may be attributed to factors that are unrelated to contracting. None of the three studies provided evidence to show that contracting is more effective than similar investments in the public sector. (74)</p>
	Cost-sharing Cost-sharing mechanisms between providers and recipients of palliative care 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)

Barrier	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. (75, 76)	
	<i>Implementation strategies</i>	<i>Evidence</i>
	Effective referral strategies that:	
	(a) Incorporate community volunteers and (b) Use of structured referral sheets can help improve service delivery for palliative care, particularly in situations in which information is scarce about where to seek diagnosis and treatment for cancers	Between 2010 and 2011, community volunteers were the third most common sources of referrals to Hospice Africa Uganda facilities after health units and self-referral. (35) In a systematic review of 23 studies, active local educational interventions involving secondary care specialists and structured referral sheets were found to be the only interventions to impact on referral rates. The bulk of this evidence, however, came from developed countries. (77, 78)

Social and political constraints

Barrier	Competing priorities 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.	
	<i>Implementation strategies</i>	<i>Evidence</i>
	Integration of services The integration of palliative care at all levels of service delivery within the health sector. Specific roles at each level will help to avoid additional costs (both direct and indirect) that could be incurred through the displacement of resources from priority areas by implementing palliative care as a parallel programme.	The World Health Organization has provided guidance on the integration of palliative care into all levels of existing health systems. (19)

Appendices:

Appendix 1

WHO guidelines on cancer pain, opioid availability, symptom control and palliative care

Cancer Pain Relief: With a Guide to Opioid Availability was first published in 1986, second edition 1990.

Available in 16 languages.

Cancer Pain Relief and Palliative Care is a report prepared by a WHO Expert Committee. It was released in 1990 and has been translated into 10 languages.

Symptom Relief in Terminal Illness was published in 1998 and has been translated into 8 languages.

Cancer Pain Relief and Palliative Care in Children was published in 1998 and has been translated into 6 languages.

National Cancer Control Programmes: Policies and Managerial Guidelines, 2nd ed. was released in June 2002. Currently it is only available in English, but French and Spanish translations are in progress. Translations into other languages are planned.

Adapted from Sepulveda et al., 2002

Appendix 2

Nationally available guidelines on palliative care

<i>Palliative medicine: Pain and symptom control in the cancer and/or AIDS patient in Uganda and other African countries. Fourth Edition 2006. (Blue Book)</i> Published by Hospice Africa Uganda
<i>Standards for providing quality palliative care across Africa. May 2011.</i> Published by African Palliative Care Association
<i>A clinical guide to supportive and palliative care for HIV/AIDS in sub-Saharan Africa. 2006 Edition.</i> Published by the African Palliative Care Association
<i>Freedom from pain: Pharmacists working with doctors and nurses to secure this human right in Africa</i> Published by Hospice Africa Uganda 2011.

Appendix 3

APCA: Levels of palliative care service

Level(s)	Description	Capability requirements	Resource requirements
Primary/ Basic Level (1)	This package offers a minimum level of palliative care. It includes basic clinical and supportive care services and relies heavily on the referral of patients (and their families) to the more specialized and advanced care offered by Level 2 and Level 3 providers. The standards of the general and basic healthcare services provided at these levels (including the primary care services for palliative care HIV patients, their families, and those with other life threatening conditions), must meet the criteria standards of Level 1.	Uses a holistic approach for the management of basic clinical and non-clinical problems experienced by patients, care givers and families. Provides basic clinical services for the treatment of Opportunistic Infections (OIs), and uses WHO's analgesic ladder guidelines for pain assessment and management. Referral to Level 2 and 3 service providers if management is beyond the capability of patients, caregivers and families. Access to Antiretroviral Therapy (ART) is given through appropriate referrals using a documented process.	Relies mainly on community care providers and a small team of general healthcare providers. In general, relies heavily on community resources to provide these services. Clinical supervision is provided by qualified and experienced professionals.

		Follow-up on drug adherence is done in partnership with the service provider.	
Secondary level/ Intermediary (2)	<p>Intermediary service providers which offer a wide range of services for HIV and AIDS patients and those with other life-threatening conditions. Providers have well-developed collaborations with each other as well as community service providers.</p> <ul style="list-style-type: none"> • All as in Level 1, plus: • At least one team member must have completed a 1-2 week orientation course in palliative care • Ongoing availability of any Step 2 analgesics on-site • Availability of ART • Ols management • Receives referrals from, and makes referrals to Level 1 and Level 3 service providers through formal links • Limited specialized services 	<p>Inter-disciplinary team or at least regular access to on-site medical, nursing and psycho-social and spiritual support via a functional and documented referral network. Care given by both formal and informal providers. Formal care providers give training and support to informal care providers. Access to ART and other medications on-site or through referrals. Well-documented procedures for follow-up on adherence.</p>	<p>An inter-disciplinary or multi-skilled team with some members of the team trained through specialist palliative care programmes. Actors include professional care providers. A professional team works together with trained community care providers using a well-structured and documented process.</p>
Tertiary level/ Specialist Level (3)	<p>Full range of palliative care services, including comprehensive care for the complex needs of patients, care providers, and families. All Level 1 and 2 elements <i>and</i>:</p> <ul style="list-style-type: none"> • Access to ART on-site or through referral • Availability of Step 3 analgesics for use on-site and in the home (e.g. oral morphine, methadone) • Availability of palliative radiation and certain palliative chemotherapies 	<p>Provides specialized palliative care for patients, care providers and families, especially those with complex needs. Physical, social, psychological and spiritual care are all accessed from the same point. Services must meet the most complex needs and occupy a leadership role in palliative care service provision. Receive and manage referrals from Levels 1 and 2 using clear</p>	<p>A multi-disciplinary team with specialist training, skills and experience in palliative care. Actors include doctors, specialist nurses, allied health professionals, spiritual leaders, social care professionals, etc. A professional team working together with trained community care providers through a well-structured and well-</p>

	<p>on-site or else a clear referral procedure for access to such treatments.</p> <ul style="list-style-type: none"> • Certificate- or degree-level training in palliative care represented in the team • Standards of all specialist palliative care services must meet the required criteria for Level 3. 	<p>documentation for the management of such referrals. Can also make referrals back to Levels 1 and 2 as part of ongoing joint care. Formal links with Levels 1 and 2 service providers. Gives consultant support to them, and training and mentorship. Ongoing availability of well-structured professional supervision for community care providers. There is a well-documented procedure for follow-up on adherence to medications.</p>	<p>documented process.</p>
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Appendix 4. How this policy brief was prepared

A detailed description of the methods used to prepare this evidence brief can be found at references. (79, 80)

The problem that this evidence brief addressed was identified through a survey of key informants identified by Uganda's Ministry of Health. These included policymakers, researchers and other stakeholders. Further clarification was sought through a review of the relevant documents, and discussions with the REACH Uganda Palliative Care Working Group. Research describing the size and causes of the problem related to palliative health care was identified through a review of government documents, routinely collected data, electronic literature searches, contact with key informants, and reference lists of the relevant documents retrieved.

Strategies used to identify potential options to address the problem included a consideration of the interventions described in systematic reviews and other relevant documents, ways in which other jurisdictions have addressed the problem, consulting key informants, and brainstorming. Potential barriers to implementing the health policy options were developed using a detailed checklist of potential barriers to implementing health policies.(81)

We searched electronic databases using index terms or free text; PubMed, OVID, EMBASE, PsychINFO, Health Systems Evidence, Cochrane Library, the Campbell Collaboration, DARE, HTA databases, SUPPORT evidence summaries, and HINARI for full text articles of citations identified. Grey literature sources that were searched included; OpenGREY, WHOLIS, Google Scholar, national reports and government documents.

The searches were supplemented by checking the reference lists of identified studies. Document authors were contacted in order to identify further relevant studies, both published and unpublished. The final selection of reviews for inclusion was based on consensus by the authors of this report.

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>.(82)

Drafts of each section of the report were discussed with the Palliative Care Working Group. The external review process of a draft version was managed by the authors. Comments provided by the external reviewers and the authors' responses are available from the authors. A list of the people who contributed to this policy brief or provided comments is provided in the Acknowledgements section.

Glossary, acronyms and abbreviations:

WHO: The World Health Organization

EVIPNet: Evidence-Informed Policy Network (www.evipnet.org)

GRADE: (Grading of Recommendations Assessment, Development and Evaluation) – a system for rating the quality of evidence and the strength of recommendations (www.gradeworkinggroup.org)

REACH: Regional East African Community Health (REACH) Policy Initiative (www.eac.int/health)

SURE: Supporting the Use of Research Evidence (SURE) in African Health Systems (www.evipnet.org/sure)

UN: The United Nations

AIDS: Acquired Immunodeficiency Syndrome

APCA: African Palliative Care Association

HAU: Hospice Africa Uganda

HIV/AIDS: Human Immunodeficiency Virus/Acquired Immunodeficiency Disease Syndrome

MOH: Ministry of Health (Uganda unless otherwise specified)

NCDs: Non-Communicable Diseases

STDs: Sexually Transmitted Diseases

NGOs: Non-Governmental Organizations

HBC: Home-Based Care

MDGs: The Millennium Development Goals

Hospice: A word derived from the Latin word ‘hospitium’ which denoted hospitality and the spirit of care given in a place most suitable to patients and/or their families. In many countries, the word ‘hospice’ is applied to palliative care facilities that specialize in end-of-life care.

Palliative care: The word ‘palliative’ is derived from the Latin word ‘pall’ which originally referred to a blanket or covering which provided comfort. §

Basic palliative care: The level of palliative care which should be provided by all healthcare professionals at a primary or secondary care level, within their duties to patients with life-limiting diseases

Specialized palliative care: Palliative care provided at the expert level, by members of trained multi-professional teams. Members must continually update their skills and knowledge to manage persistent and more complex problems and to provide specialized

educational and practical resources to other non-specialist members of the primary or secondary care teams.

A palliative care unit: A specially configured healthcare unit which provides high quality specialized palliative care. Ideally the unit should provide inpatient beds, ambulatory out-patient or day-care facilities, and home care outreach services,.

End of life: The period when it has become obvious that death is inevitable and imminent. The primary aim of any treatment at this stage is to improve a patient's quality of life rather than extending the length of their life or to cure their illness.

Terminal illness: An active and progressive disease which cannot be cured or adequately treated and will, eventually, cause the patient to die. Curative treatment is no longer appropriate, but palliative care is.

Life-threatening illness: Long-term survival is possible if the disease can be 'interrupted'. The risk of a fatal outcome is otherwise high.

References

1. Mulrow C. Rationale for Systematic Reviews. *BMJ*. 1994;309:597-9.
2. Bero L, Jadad A. How consumers and policymakers can use systematic reviews for decision making. *Ann Intern Med* 1997;127:37-42.
3. Oxman A, Bjørndal A, Becerra-Posada F, Gibson M, Block MG, Haines A. A framework for mandatory impact evaluation to ensure well informed public policy decisions. *The Lancet*. 2010;375:427–31.
4. Amandua J. Palliative Care policy development. 2011.
5. Association APC. APCA Standards for Providing Quality Palliative Care Across Africa. Care for special needs populations. Kampala: APCA; 2010. p. 60.
6. Nabudere H, Lamorde M. "Palliative Care in Uganda" Terms of Reference for the Evidence Brief. Kampala: Makerere University, College of Health Sciences, 2011.
7. Wikipedia. Cicely Saunders 2012. Available from: http://en.wikipedia.org/wiki/Cicely_Saunders.
8. Merriman A. 'Audacity to Love' The Story of Hospice Africa. Dublin, Ireland: Spectrum Print Logistics; 2010.
9. Jagwe JG. The Introduction of Palliative Care in Uganda. *Journal of Palliative Medicine*. 2002;5(1).
10. WHO. WHO Drug Information. Geneva: World Health Organisation; 2007.
11. WHO. WHO Definition of Palliative Care 22 February 2012. Available from: <http://www.who.int/cancer/palliative/definition/en/>.
12. Sepulveda C, Marlin A, Yoshida T, Ullrich A. Palliative Care: The World Health Organisation's global perspective. *J Pain Symptom Manage*. 2002;24:91-6.
13. APCA. APCA Standards for Providing Quality Palliative Care Across Africa. Kampala, Uganda: African Palliative Care Association; 2011.
14. Ahmedzai S, Costa A, Blengini C, Bosch A, Sanz-Ortiz J, Ventafridda V, et al. A new international framework for palliative care. *European Journal of Cancer*. 2004;40:2192–200.
15. Mpanga-Sebuyira L, Mwangi-Powell F, Pereira J, Spence C. The Cape Town Palliative Care Declaration: Home-Grown Solutions for Sub-Saharan Africa. *Journal of Palliative Medicine*. 2003;6(3):341-3.
16. WHO, editor. World Health Assembly. Cancer prevention and control. (9th Plenary Meeting). World Health Assembly; 2005 25 May 2005; Geneva, Switzerland: World Health Organisation
17. Stjernswärd J. Palliative Care: The Public Health Strategy. *Journal of Public Health Policy* 2007;28:42–55.
18. Leng M. Palliative Care Working Group. Kampala: Makerere University; 14 March 2012.
19. WHO. Cancer Control, Knowledge into Action, WHO Guide for Effective Programmes, Palliative Care. Switzerland: World Health Organisation; 2007.
20. MOH. Annual Health Sector Performance Report (2009-2010). Kampala: Ministry of Health; 2010.
21. Kikule E. A good death in Uganda: survey of needs for palliative care for terminally ill people in urban areas. *BMJ*. 2003;327(7408):192-4.
22. Stjernswärd J, Colleau SM, Ventafridda V. The World Health Organisation Cancer Pain and Palliative Care Program: Past, Present and Future. *Journal of Pain and Symptom Management*. 1996;12(2):65-72.

23. Sepúlveda C, Marlin A, Yoshida T, Ullrich A. Palliative Care: The World Health Organization's Global Perspective. *Journal of Pain and Symptom Management*. 2002;24(2):91-6.
24. WHO. A Community Health Approach to Palliative Care for HIV/AIDS and Cancer Patients. 2004.
25. HAU. Some Facts about Hospice Africa Uganda. In: Uganda HA, editor. Kampala, Uganda: Hospice Africa Uganda; 2012.
26. Jagwe JGM, Barnard D. The introduction of palliative care in Uganda. *Journal of Palliative Medicine*. 2002;5(1):159-63.
27. MOH. The Second National Health Policy: Promoting People's Health to Enhance Socio-economic Development
Kampala: Ministry of Health; July 2010.
28. MoH. Health Sector Strategic and Investment Plan. Kampala: Ministry of Health; 2010.
29. MPCU. Annual Report. In: Unit MPC, editor. Kampala, Uganda: National Referral Hospital, Mulago; 2011.
30. The National Drug Authority (Prescription and Supply of Certain Narcotic Analgesic Drugs) Regulations, 2004, (2004).
31. APCA. Review of National Documents for Palliative Care. Country Report: Uganda. Kampala, Uganda: African Palliative Care Association, 2012 July 2012. Report No.
32. Amandua J. The Prevalence of Life-Limiting Illnesses among patients at Mulago National Referral Hospital. London: King's College London; 2011.
33. MOH. A Rapid Assessment of Morbidity and Mortality due to Non-Communicable Diseases in Uganda. In: Program NCD, editor. Kampala, Uganda: Ministry of Health; 2011.
34. Sepulveda C, Habiyambere V, Amandua J, Borok M, Kikule E, Barbara, et al. Quality care at the end of life in Africa. *British Medical Journal*. 2003;327:209-13.
35. HAU. Annual Report 2011. Kampala: Hospice Africa Uganda, 2011.
36. UBOS. 2002 Uganda Population and Housing Census. Kampala, Uganda: Uganda Bureau of Statistics; 2002.
37. UNAIDS. Report on the Global AIDS Epidemic In: AIDS JUNPo, editor. Geneva, Switzerland: UNAIDS; 2006.
38. Gray G, Berger P. Pain in women with HIV/AIDS. *PAIN* 2007;132(S13–S21).
39. Legg Lynn A, Quinn Terry J, Mahmood F, Weir Christopher J, Tierney J, Stott David J, et al. Non-pharmacological interventions for caregivers of stroke survivors. *Cochrane Database of Systematic Reviews* [Internet]. 2011; (10). Available from: <http://www.mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD008179/frame.html>.
40. Hudson PL, Aranda S, Hayman-White K. A Psycho-Educational Intervention for Family Caregivers of Patients Receiving Palliative Care: A Randomized Controlled Trial. *Journal of Pain and Symptom Management*. 2005;30(4):329-40.
41. Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. *Cochrane Database of Systematic Reviews* [Internet]. 2011; (6). Available from: <http://www.mrw.interscience.wiley.com/cochrane/clsysrev/articles/CD007617/frame.html>.
42. R H, J H. What is the best way to help caregivers in cancer and palliative care? A systematic literature review of interventions and their effectiveness. *Palliative Medicine*. 2003;17:63–74.
43. Harding R, Powell RA, Kiyange F, Downing J. Provision of Pain- and Symptom-Relieving Drugs for HIV/AIDS in Sub-Saharan Africa. *Journal of Pain and Symptom Management*. 2010;40(3):405-15.
44. Kiwanuka R. Palliative Care in Uganda. 2011.
45. Kiwanuka R. Morphine distribution in Uganda. 2012.

46. HAU. Morphine Use in Uganda. 2012.
47. Stewart AL, Teno J, Patrick DL, Lynn J. The Concept of Quality of Life of Dying Persons in the Context of Health Care. *Journal of Pain and Symptom Management*. 1999;17(2):93-108.
48. Kikule E. A Good Death In Uganda: Survey Of Needs For Palliative Care For Terminally Ill People In Urban Areas. *British Medical Journal* 2003;327(7408):pp. 192-4.
49. Grant L, Downing J, Namukwaya E, Leng M, Murray SA. Palliative care in Africa since 2005: good progress,. *BMJ Support Palliat Care*. 2011;doi: 10.1136/bmjspcare-2011-000057.
50. Powell RA, Mwangi-Powell, Kiyange F, Radbruch L, Harding R. Palliative care development in Africa: how can we provide enough quality care? *BMJ Supportive & Palliative Care*. 2011;1(2):113-4.
51. Kumar N. Desk Study on Progress in Palliative care. World Health Organisation, 2007 December 2007. Report No.
52. WPCA. Mapping levels of palliative care development: a global update 2011. United Kingdom: Worldwide Palliative Care Alliance, 2011.
53. APCA. Strategic Plan: 2011-2020. Kampala, Uganda: African Palliative Care Association; 2011.
54. Powell RA, Downing J, Radbruch L, Mwangi-Powell F, Harding R. Advancing palliative care research in sub-Saharan Africa: from Venice to Nairobi. *EUROPEAN JOURNAL OF PALLIATIVE CARE*. 2008;15(5):228-33.
55. Gomes B, Higginson Irene J. Factors influencing death at home in terminally ill patients with cancer: systematic review. *BMJ Online*. 2006;BMJ, doi:10.1136/bmj.38740.614954.55.
56. Gott M, Seymour J, Bellamy G, Clark D, Ahmedzai S. Older people's views about home as a place of care at the end of life. *Palliative Medicine*. 2004;18:460–7.
57. Young T, Busgeeth K. Home-based care for reducing morbidity and mortality in people infected with HIV/AIDS. *Cochrane Database of Systematic Reviews* [Internet]. 2010; (1). Available from: <http://www.mrw.interscience.wiley.com/cochrane/clsystrev/articles/CD005417/frame.html>.
58. Shepperd S, Wee B, Straus Sharon E. Hospital at home: home-based end of life care. *Cochrane Database of Systematic Reviews* [Internet]. 2011; (7). Available from: <http://www.mrw.interscience.wiley.com/cochrane/clsystrev/articles/CD009231/frame.html>.
59. Hughes S, Cummings J, Weaver F, Manheim L, Braun B, Conrad K. A randomized trial of the cost effectiveness of VA hospital-based home care for the terminally ill. *Health Services Research*. 1992;26:801–17.
60. Brumley R, Enguidanot S, Jamison P, Seitz R, Morgenstern N, Saito S. Increased satisfaction with care and lower costs: results of a randomized trial of in-home palliative care. *Journal of the American Geriatrics Society*.S5:993–1000.
61. Kinsella G, Cooper B, Picton C, Murtagh D. A review of the measurement of caregiver and family burden in palliative care. *J Palliat Care*. 1998;14:37–45.
62. Harding R, List S, Epiphaniou E, Jones H. How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness. *Palliative Medicine*. 2011;26(1):7–22.
63. Shepperd S, McClaran J, Phillips C, Lannin N, Clemson L, McCluskey A, et al. Discharge planning from hospital to home (Review). *Cochrane Database of Systematic Reviews*. 2010;Issue 1. Art. No.: CD000313. DOI: 10.1002/14651858.CD000313.pub3.
64. Selker H, Beshansky J, Pauker S, Kassirer J. The epidemiology of delays in a teaching hospital. *Medical Care*. 1989;27:112.
65. Mpanga-Sebuyira L. Current situation on discharge planning in Uganda. Kampala: Makerere University; 2012.

66. What are the impacts of discharge planning from hospital to home? A SUPPORT Summary of a systematic review [database on the Internet]. 2011.
67. UN. Investing in Development: A Practical Plan to Achieve the Millenium Development Goals. In: Project TUM, editor.: United Nations; 2005.
68. Stjernswa`rd J, Foley KM, Ferris FD. The Public Health Strategy for Palliative Care. *Journal of Pain and Symptom Management*. 2007;Vol. 33 (No. 5).
69. MOH. Village Health Team: A handbook to improve health in communities. Kampala: Ministry of Health.
70. Christopher J, A. , Le May ea. "Thirty years after Alma-Ata: a systematic review of the impact of community health workers delivering curative interventions against malaria, pneumonia and diarrhoea on child mortality and morbidity in sub-Saharan Africa." *Human Resources for Health* 2011;9(1): 27)
71. HAU. PALLIATIVE MEDICINE: Pain and Symptom Control in the Cancer and/or AIDS Patient in Uganda and other African Countries. Fourth Edition. 2006.
72. Wisyonge C. Which clinical guideline dissemination strategies improve professional practice? A SUPPORT Summary of a systematic review. 2008 August 2008. Report No.
73. WHO. Catalonia WHO Demonstration Project on Palliative Care Implementation *Journal of Pain and Symptom Management*. 1996;Vol 12(No. 2).
74. (IDEAHealth) A. Evidence from systematic reviews to inform decision making regarding financing mechanisms that improve access to health services for poor people. A policy brief prepared for the International Dialogue on Evidence-Informed Action to Achieve Health Goals in Developing Countries Geneva: Alliance for Health Policy and Systems Research; 2006.
75. Mbonye AK, Asimwe JB. Factors associated with skilled attendance at delivery in Uganda: Results from a national health facility survey *Int J Adolesc Med Health* 2010;22(2).
76. UBOS. Uganda Demographic and Health Survey 2006. In: Statistics UBo, editor. Kampala: UBOS; 2006.
77. Akbari A, Mayhew A, Al-Alawi M, Grimshaw J, Winkens R, Glidewell E, et al. Interventions to improve outpatient referrals from primary care to secondary care. *Cochrane Database of Systematic Reviews*. 2005(Issue 4. Art. No.: CD005471.DOI:10.1002/14651858 CD005471.pub2).
78. Pantoja T. Do educational, organizational or financial interventions improve outpatients' referrals from primary to secondary care? . A SUPPORT Summary of a systematic review. 2008.
79. Lavis JN, Wilson MG, Oxman AD, Lewin S, Fretheim A. SUPPORT Tools for evidence-informed health Policymaking (STP) 4: Using research evidence to clarify a problem. *Health Research Policy and Systems*. 2009;7(Suppl 1:S4).
80. SURE. SURE Guides for Preparing and Using Evidence-Based Policy Briefs. Version 2.1. The SURE Collaboration; 2011; Available from: www.evipnet.org/sure. .
81. Supporting the Use of Research Evidence (SURE) in African Health Systems. SURE guides for preparing and using policy briefs: 6. Identifying and addressing barriers to implementing the options. .
82. Supporting the Use of Research Evidence (SURE) in African Health Systems. SURE guides for preparing and using policy briefs: 5. Deciding on and describing options to address the problem. .