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Hospice Africa Uganda: End-of-project evaluation of palliative care services

Annette Bongiovanni

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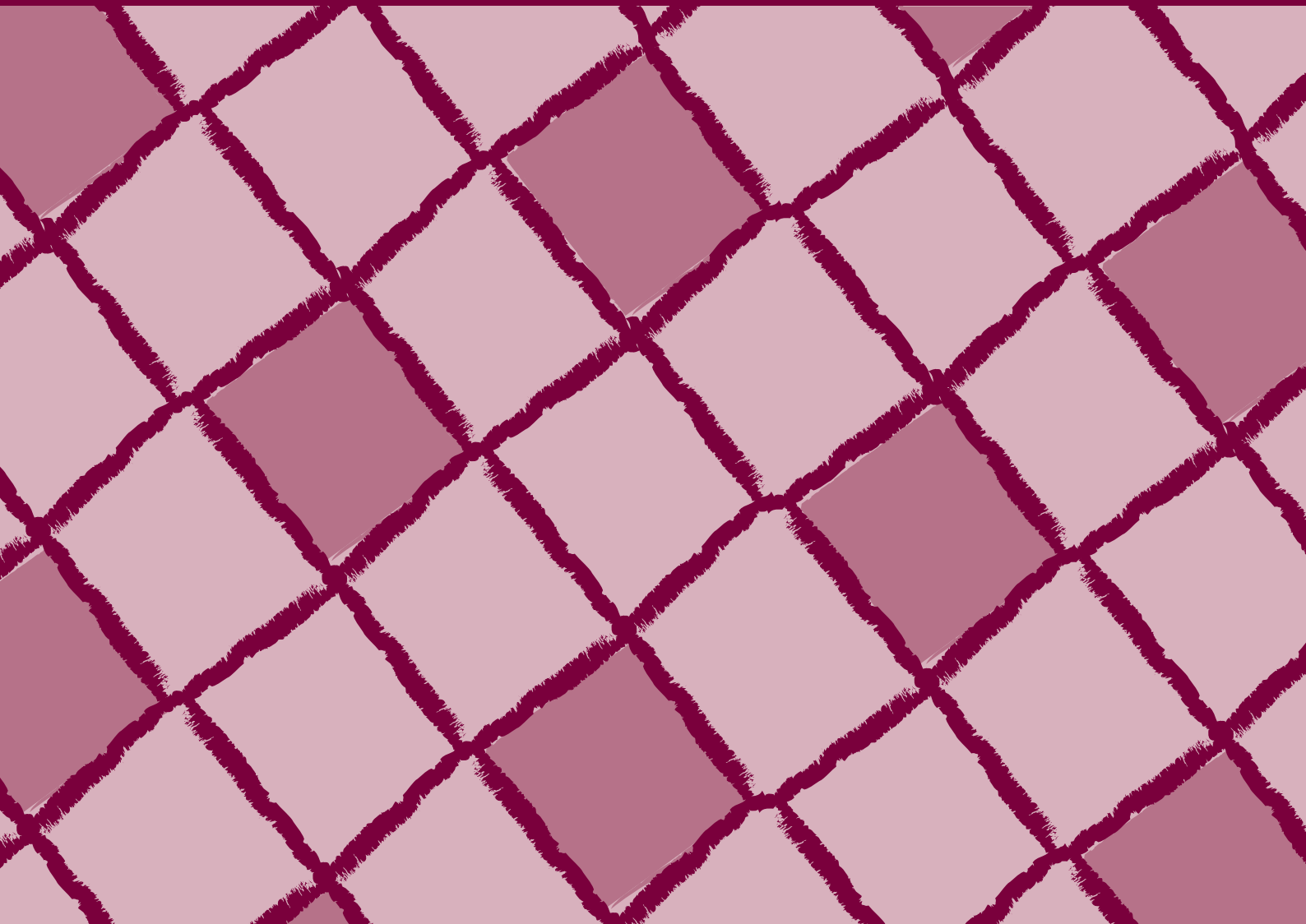
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Hospice Africa Uganda: End-of-Project Evaluation of Palliative Care Services



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**Annette Bongiovanni
Mary Alexis Greenan**

The QED Group, LLC



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Acronyms

APCA	African Palliative Care Association
ART	Antiretroviral Treatment
ARV	Antiretroviral Drugs
CDP	Comprehensive District Training Program
CHW	Community Health Workers (trained by other hospices)
CPCN	Certified Palliative Care Nurse (nine-month HAU training)
CPCO	Certified Palliative Care Medical Officer (nine-month HAU training)
CTP	Cluster Training Program
CVW	Community Volunteer Worker (HAU Trained)
DHO	District Health Officer
DHT	District Health Team
FBO	Faith-Based Organization
FGD	Focus Group Discussion
HAU	Hospice Africa Uganda
LHH	Little Hospice Hoima
M&E	Monitoring and Evaluation
MHM	Mobile Hospice Mbarara
MOH	Uganda Ministry of Health
MS	Medical Superintendent
NGO	Non-Governmental Organization
NASC	National Care Standards Committee
OI	Opportunistic Infection
PC	Palliative Care
PCAU	Palliative Care Association of Uganda
PHA	People Living with HIV/AIDS
QED	The QED Group, LLC.
TASO	The AIDS Support Organization
UK	United Kingdom
USAID	United States Agency for International Development
USD	United States Dollar
VHT	Village Health Teams (trained and supported by MOH)
WHO	World Health Organization

Executive Summary

Introduction

Hospice Africa Uganda (HAU) is a non-governmental organization that provides palliative care services to people living with HIV/AIDS (PHA) and cancer. Based in Kampala with branches in Hoima and Mbarara districts, HAU aims to scale-up palliative care within and beyond the nation's borders. The organization receives a large proportion of its funding from the United States Agency for International Development (USAID)/Uganda, accounting for approximately 60 percent of its revenue (HAU 2007/8). In August 2005, HAU received \$3 million USD through the President's Emergency Plan for AIDS Relief (PEPFAR) funds to expand the scope and access of palliative care services for PHA and their families. Forty-two percent of funds were focused on training and 28 percent went to services provided by HAU's three sites. During the three-year funding period (2005 to 2008), HAU sought to achieve the following objectives:

1. Increase the coverage and scope of palliative care services available to PHA and their families.
2. Train health workers and other HIV/AIDS care providers to integrate pain management, symptom control and end-of-life care into their existing HIV/AIDS care and support programs.
3. Build the capacity of families, communities, and community-based organizations in palliative care provision.
4. Integrate HIV prevention into the palliative care training/education.
5. Build functional networks linking families, communities, health facilities, and civil society organizations in order to enhance easy access to palliative care services.

USAID/Uganda commissioned the QED Group, LLC, via a subcontract from the Population Council, to evaluate its first round of funding to HAU in order to better understand its strategic approaches and the effect it has had on the uptake of palliative care services. In addition, USAID was interested in comparing HAU approaches and strategies to other palliative care service providers, including The AIDS Support Organization (TASO) and Mildmay. The objectives of this evaluation are to:

1. Review HAU approaches and strategies to deliver services and track coverage;
2. Compare HAU approaches to international standards of care;
3. Examine how the HAU education program has contributed to increased availability of palliative care services (pain management, symptom control, end-of-life care) to PHA and their families;
4. Assess HAU approaches and strategies in place to ensure future sustainability of its HIV/AIDS program;

5. Measure the extent to which HAU has succeeded in increasing access to and utilization of quality palliative care services, specifically diagnosis and management of pain, symptom control, as well as spiritual and end-of-life care for PHA and their families.

Methodology

This qualitative study offers a cross-sectional assessment of palliative care in Uganda. It used a multi-method approach including key informant interviews with palliative care leaders and stakeholders in Kampala, in-depth interviews, and focus group discussions (FGDs). Data was collected in eight districts—including Kampala—to account for any regional differences or differences associated with proximity to urban settings where access to resources is greater.

Respondents were categorized into three groups: managers [district health officers (DHO) and medical superintendents (MS) in hospitals], palliative care providers [hospice staff or hospital-based palliative care team (PCT) members, nurses, clinical officers certified in palliative care, and community volunteer workers (CVW)], and patients (representatives of PHA organizations or networks and PHA receiving palliative care). FGDs were conducted with CVWs and PHA receiving palliative care. All other respondents (key informants and in-depth respondents) were interviewed using a semi-structured questionnaire. Data were analyzed using ATLAS.ti software to organize the findings by seven key domains and their associated outcome variables. These domains reflected the evaluation objectives and included: strategies, approaches, standards, availability, access, utilization of services and sustainability.

Results

Specific results for the five evaluation objectives are as follows:

Objective #1: Review HAU approaches and strategies to deliver services and track coverage

HAU service delivery approaches

Respondents indicate that HAU's sites at Makindye in Kampala, Mobile Hospice Mbarara (MHM), and Little Hospice Hoima (LHH) use a number of service delivery approaches:

Institutional approach: The institutional care approach involved seeing patients at the HAU site. New cases are referred by CVWs, health workers in hospitals and health centers, patients that have benefited from HAU palliative care services, and self-referrals. Institutional care allows patients to access services seven days a week. According to some respondents, patients receive better attention and have access to more resources than if they attend a roadside clinic or received home-based care. This approach, however, favors ambulant patients from the nearby community, while those who cannot afford travel or whose symptoms limit their ability to travel may be unable to access services.

Day care: Day care services are provided at all three HAU sites. In the day care center, patients receive care away from their home environment and are provided a meal, entertainment, and emotional support, while caregivers get a break from their duties. The community day care approach allows patients farther from the HAU site to experience a change in the care environment.

Home-based care: Through this approach, a clinical team visits patients living within a 20 kilometer radius of the respective HAU sites. HAU uses a family-centered approach, through which staff interact with family members, educate them about the best care practices such as feeding weak patients, bathing bed-ridden patients, maintaining good sanitary practices, avoiding stigma, and reminding patients to take their medication. The team also inquires about the HIV status of family members and encourages those who have not been tested to seek counseling and testing.

Community outreach: The HAU Makindye site conducts community outreach in the suburbs of Luzira and Mukono at health centers and in Busega at a church. LHH also conducts community outreach, although the magnitude of this approach is not well documented. This approach has helped reach out to the community and scale up services. CVWs organize and mobilize PHA to attend the outreach service delivery points, where they are picked up by HAU vehicles and taken to day care centers. Patients have beds to rest and receive both entertainment and physiotherapy.

MHM operates three mobile outreach programs in Ibanda, Busheyi, and Kamwenge districts, working with CVWs to mobilize patients who would otherwise not be able to access services. Public health facilities are used to replicate services offered at the MHM site. Mobile outreach is combined with roadside and mobile clinics, in which services are provided outside of a typical clinical setting. Roadside clinics serve patients far from the outreach community and the MHM site. Some are set up in people's homes, private clinics, and public health facilities. They support adherence to treatment by engaging defaulters who fail to meet appointments because of transportation difficulties. The MHM palliative care team meets these patients and provides them with care en route to the outreach centers.

Hospital visits: HAU staff visit patients in the Mulago Hospital and the regional referral hospitals. They are expected to visit the respective hospitals three times a week to attend to referred cases and to identify patients in need of palliative care. Recently, MHM started a children's program in the Mbarara hospital, through which pediatric patients receive palliative care and other treatment and care services offered in the hospital.

Tracking coverage

HAU has conducted some monitoring and evaluation (M&E) since 1993, although it was not until 2007 that it began working systematically by applying an M&E framework. Through the AIDS Capacity Enhancement (ACE) Project funded by USAID, HAU received organizational development support to develop its capacity to monitor and evaluate programs. Through this system, HAU has been better able to track its education and clinical outreach programs.

The evaluation team examined the degree to which HAU identifies PHA in need of palliative care services and how it tracks the services provided to those enrolled in its program. Key

informants noted that the proportion of self-referrals by PHA is growing. Many self-referrals are not enrolled in the HAU program because they do not need palliative care. HAU refers these PHA to Mildmay and TASO for other forms of care and treatment, but there is no system to follow them up.

With regard to coverage of services, HAU responds to referrals on a case-by-case basis and tracks only the PHA enrolled in its program. It does not attempt to estimate the landscape of PHA in need of palliative care.

Objective #2: Compare HAU approaches to international standards of care

In 1990, the World Health Organization (WHO) developed the Public Health Strategy approach to integrate palliative care into existing health care systems. This approach focused on translating new knowledge and skills into evidence-based, cost-effective interventions that could reach all individuals in need of services. While the WHO model addresses cancer care, its four main pillars are applicable to HIV/AIDS and include appropriate policies, adequate drug availability, education of health care workers and the public, and implementation of palliative care services at all levels throughout society.

The palliative care standards of Scotland, Australia, and the United Kingdom (UK) provide models of success upon which the African Palliative Care Association (APCA) is building its own guidelines for African governments to use in the development of their own national palliative care standards. Simultaneously, the Palliative Care Association of Uganda (PCAU) is developing national palliative care standards in close collaboration with APCA.

HAU uses a few guidelines and job aides in the delivery of palliative care. One important MOH guideline defines who should prescribe morphine. However, when asked about guidelines, respondents mostly referred to WHO job aides such as the analgesic ladder and pain assessment tools. APCA developed what has come to be called the Palliative Care Outcome Scale (POS), which exists in adult and pediatric formats. The former has been piloted and disseminated widely, while the latter is still under development. HAU staff, the Mulago PCT, and others were familiar with the adult POS and described regular use of this tool.

Despite the fact that the HAU founder developed and published the “Blue Book” (Merriman 1995) guidelines for pain and symptom control, the WHO analgesic ladder and pain assessment tools upon which it has relied are not adequate means for establishing a unified approach to palliative care throughout Uganda. In fact, few HAU respondents were familiar with the Blue Book (HAU 2006). Only one respondent, the APCA representative, mentioned the APCA clinical guide.

Objective #3: Examine HAU’s education program and how it has increased the availability of palliative care services to PHA and their families

HAU has undertaken various efforts to increase the availability of palliative care services with varying degrees of success.

HAU education courses: Currently, HAU conducts short- and long-term palliative care training courses. MHM and LHH conduct short-term courses for health professionals, CVWs, spiritual caregivers, traditional healers, allied professionals, regional medical officers, and ward managers. HAU Kampala conducts two long-term courses: the Clinical Palliative Care Course and the Distance Learning Diploma.

The objectives of the orientation for nurses and doctors are to improve awareness, knowledge, and palliative care skills. Another aim is to prepare health professionals for the introduction of oral morphine. The courses seek to increase the ability to identify and refer patients in need of palliative care to HAU or other centers.

Community volunteer workers: MHM and LHH focus on training CVWs, specifically hospice CVWs and district community health workers (CHWs). District CHWs are identified through community leaders and are part of existing structures, such as the Volunteer Health Teams (VHT) supported by the MOH or drug distributors. Usually these individuals have already been serving in a volunteer role under government programs or in non-profit organizations operating in their respective communities.

Comprehensive district training program versus cluster training program: HAU initially had a Comprehensive District Training Program (CDP), under which it trained health professionals, CVWs, traditional healers, spiritual caregivers, and allied professionals in a targeted district. The CDP has facilitated outreach to District Health Teams (DHTs) and other health providers to promote and mobilize support for palliative care services.

Following USAID's recommendation, HAU eliminated the CDP and adopted a Cluster Training Program (CTP), which focuses on professional health workers in PEPFAR-funded AIDS service organizations from a cluster of districts. CVWs, allied professionals, traditional healers, and spiritual healers are not included in the training. Trainees are expected to register patients during morphine introduction and follow-up with them. However, HAU has struggled to develop a follow-up system because the trained health workers are often from different districts than the patients assigned to them during training.

Objective #4: Assess HAU approaches and strategies in place to ensure future sustainability of its HIV/AIDS program

HAU respondents were unable to offer a sustainability strategy for its HIV/AIDS program beyond USAID funding. When asked about raising local funds to support this work, HAU respondents interpreted this question to refer to user fees. HAU requires patients to contribute 5,000 Uganda Shillings (~\$2.78 USD) on a weekly basis. Yet most patients are unable to afford this contribution, and HAU is unable to deny care as a non-profit organization.

HAU encourages staff members, the general public, and corporations to subscribe as annual members, but respondents noted that this effort has not yielded strong results. With encouragement from donors, HAU has begun focusing on approaches to the private sector. It has also reached out to local embassies for support. Respondents maintain that sustainability

has received serious consideration by HAU's senior management, but has not yet yielded solid plans.

HAU's sustainability may also be undermined by its inability to incorporate services within the government health system. Other than monthly or bimonthly visits to three hospitals by HAU staff for patient follow-up, HAU has no systematic approach to integrate its work into the government health system. The MOH does cooperate with HAU by supporting its nurses and medical officers to attend HAU trainings and with morphine procurement, distribution, and dissemination.

Objective #5: Measure the extent to which HAU has succeeded in increasing access to and utilization of quality palliative care services

In its proposal to USAID for its first round of funding, HAU described its palliative care work as consistent with the WHO holistic approach and inclusive of pain management, control of opportunistic infections, psychosocial and spiritual support, and end-of-life care. According to HAU annual reports, the number of patients accessing palliative care has risen from 1,088 patients in 2004/5 to 2,396 in 2007/8. HAU's greatest achievement has been in pain management, while its efforts to control symptoms are in need of improvement. Psychological and social support are fragile and disparate components in HAU's service delivery mix. Despite the limitations of its services, HAU's work is considered in high regard by many respondents, particularly in terms of its quality of care.

Procurement of morphine: All districts with Certified Palliative Care Nurses (CPCNs) procure morphine except Mpigi. The district hospitals procure it through the DHO, and the referral hospitals procure it directly from the MOH. HAU imports and reconstitutes its own powder, providing it directly to its service delivery sites. According to respondents, morphine is available in the hospitals with CPCNs except Nkozi Hospital in Mpigi. It is also available in organizations with a particular focus on pain management as a component of palliative care.

Treatment of opportunistic infections: HAU has some medication for prophylaxis and treatment of opportunistic infections (OIs). However, its OI management services are weak, and respondents frequently mentioned the need for referrals.

Psychosocial needs: HAU respondents adopted a broad definition of psychosocial needs with more emphasis on the social component. According to respondents, HAU provides inadequate counseling to meet the psychological needs of PHA. Through its comfort fund, HAU has provided some nutritional support, transportation, and coverage of clinical investigation costs. It does not address the need for income generating activities or linking children to sources of support for education.

Spiritual care: Through counseling and training spiritual caregivers, HAU respondents feel it is able to meet the spiritual needs of patients. In hospitals, HAU facilitates fellowship and brings patients together to pray for others.

End-of-life care: HAU does not address the memory book or will writing. It does provide some monetary support to bereaved family members. While succession planning had previously been provided at LHH, will making and memory book writing are no longer in practice.

Conclusions and Recommendations

As a major donor, USAID/Uganda is positioned to help the MOH further develop its palliative care agenda, and more broadly, to share the Uganda experience throughout the region. Based on the findings of this end-of-project evaluation, QED offers the following conclusions and recommendations. Unless otherwise specified, the recommendations pertain to USAID.

Objective #1: Review HAU approaches and strategies to deliver services and track coverage

Conclusions

HAU has a clear mission but lacks strategic vision. HAU comprises a committed group of professionals with a common mission to provide care and comfort. Yet, as an organization, it lacks a common vision and strategic plan to execute its mission.

HAU delivers high quality palliative care services but of a limited scope. HAU concentrates on providing in-depth pain management. It views its palliative care as a model and has received regional and international attention for it. However, its services are narrowly focused on pain management and to a much lesser degree, psychological and spiritual support.

HAU offers limited coverage of PHA. HAU prioritizes delivering high quality services to its existing patient population. It is reluctant to generate demand for its services in light of limited resources and its priority to provide an intense level of care for each patient.

HAU is in a nascent stage of tracking coverage. HAU is on a positive, albeit slow, path to report results on program outputs but does not track outcome variables.

Recommendations

Develop HAU's institutional capacity. USAID should continue to provide capacity building support with a focus on strategic planning, program management, and M&E, with an emphasis on linkages between the three.

Develop and support palliative care teams within the existing USAID/TASO HIV/AIDS program in referral hospitals. USAID should continue to utilize HAU to train health workers and to place them in the 11 referral hospitals in Uganda. USAID could also support an HAU employee based in each of the palliative care teams to serve as a resource and liaison with HAU.

Encourage the MOH to establish a palliative care desk. The MOH should take a stronger leadership and supportive role in palliative care. At a minimum, a palliative care desk could be supported by a couple of HAU-trained nurses and medical officers who could respond to the needs and concerns of palliative care staff in the field.

Conduct an outcome evaluation of HAU's current USAID-funded project. USAID should consider conducting an evaluation of HAU's current project with a focus on outcome indicators. The study should have a strong quantitative component to determine the effectiveness of HAU's interventions.

Objective #2: Compare HAU approaches to international standards of care

Conclusions

The vast majority of respondents were not aware of international standards for palliative care.

Few HAU managers and staff understand the role of standards of care, equating them with guidelines and/or job aides for pain management.

There is no regulation of compliance with palliative care standards. HAU is well respected by the MOH and AIDS organizations for its role as a training institution and in providing pain management services. However, the MOH has not developed a supervisory body for the palliative care programming efforts in Uganda.

HAU is establishing itself as a regional resource for palliative care training. HAU and the provision of palliative care in Uganda as a whole have received considerable attention within the region and from international experts.

Recommendations

Support PCAU to disseminate the Ugandan standards for palliative care. After the Ugandan standards for palliative care are finalized, PCAU will likely need support to develop a communication and dissemination plan. USAID should consider funding PCAU to support its mandate with a specific emphasis on raising awareness of and adherence to palliative care standards.

Advocate for PCAU as the regulatory arm of MOH policies and standards. As an independent, non-implementing body, PCAU is in a neutral position to assess and advise the government on palliative care programming.

Support PCAU in the dissemination of APCA's "Clinical Guide to Supportive and Palliative Care for HIV/AIDS in sub-Saharan Africa" (2006). These guidelines provide the most relevant information for HAU to develop standards that Uganda can use country-wide.

Support PCAU to disseminate Uganda's best practices in palliative care. PCAU's close collaboration with APCA should be supported to share best practices and lessons learned throughout the region. The Uganda experience should reflect the work of HAU, TASO, and Mildmay. The timing for this recommendation might best be in a few years after USAID gains more experience working with HAU and palliative care.

Objective #3: Examine HAU's education program and how it has increased the availability of palliative care services to PHA and their families

Conclusions

The role of the palliative care nurse is not recognized in the formal MOH structure. There is no MOH job category for a palliative care nurse or clinical officer. Trained palliative care providers in public health facilities face a challenging work load, yet their role in palliative care is not recognized or appreciated by medical superintendents.

MOH recruitment for training participants does not consider deployment of CPCN/Certified Palliative Care Medical Officers (CPCOs) and the integration of palliative care into routine patient care. Training needs assessments are not conducted in any systematic fashion, and there are no apparent selection criteria for HAU trainees. The MOH funds many of the participants and therefore decides who shall be trained. HAU does not appear to play a large role in the decision making process.

Mentoring, supportive supervision, and follow-up for trained palliative care health workers are deficient. HAU's involvement stops after training. CPCNs in health centers do not have senior palliative care providers to offer mentorship or supervision. While they look to HAU to provide this support, it is not fulfilling this role.

HAU's training of spiritual caregivers and traditional healers bridge the gap between Western medicine and local practices. Targeting such influential leaders will contribute to the spiritual component of palliative care.

Recommendations

Establish selection criteria for training participants based on needs assessments. HAU, with guidance from PCAU, should develop selection criteria for training participants that consider: a) DHO and MS commitment to palliative care; b) a minimum set of prerequisites; c) the level of demand for palliative care services based on health statistics; d) the availability of a support network to facilitate palliative care services (e.g., for supervision, mentoring, liaising with AIDS organizations, faith-based organizations, legal services); e) the supply of trained palliative care providers in the region.

Establish palliative care champions in MOH health facilities. HAU should prepare a curriculum tailored for experienced CPCNs and CPCOs, preferably HAU staff, who can supervise and support other health providers, and would be based in regional referral hospitals. Their purpose would be to sensitize health facility staff on the integration of palliative care into routine clinical care by: a) mobilizing and supervising other trained health workers; b) providing in-service training on palliative care to reach a larger group of health workers; c) rallying the palliative care team in-house.

HAU should receive support to continue and strengthen its training program for spiritual caregivers and traditional healers. Such training would align well with the international standards of palliative care in terms of ensuring the complete wellbeing of patients.

Objective #4: Assess HAU approaches and strategies in place to ensure future sustainability of its HIV/AIDS program

Conclusions

HAU has no systematic plan for augmenting or expanding its services. There appears to be no HAU national network, but rather, numerous affiliated partners throughout Uganda.

HAU lacks business savvy. HAU does not focus on fundraising in a strategic way. Its approach to new business development consists of small, sporadic efforts without a broad plan of action.

Recommendations

Establish palliative care centers for excellence. HAU should develop a memorandum of understanding with the MOH to establish centers of excellence in all referral hospitals. Such centers should provide mentoring services and be used as a central location for home-based care.

Develop and implement a business plan. HAU must first clearly delineate its vision, organizational goal, and objectives. To facilitate this process, HAU should consider hiring a local business development manager with experience growing international NGOs.

Objective #5: Measure the extent to which HAU has succeeded in increasing access to and utilization of quality palliative care services

Conclusions

End-of-life care is a weak component of HAU palliative care. HAU respondents merge their definition of pain management with end-of-life care. Yet the components of end-of-life care are more far reaching and include psychosocial needs such memory books and succession planning.

Awareness of palliative care services is not widespread. Little has been done by HAU or other organizations to sensitize the general population about the palliative care services. HAU does not prioritize building demand for services, as it feels its resources are stretched.

Trained health workers in public health facilities perceive palliative care as an added burden that lacks institutional support. CPCNs and PCOs are faced with fulfilling their “regular” job first, and lack extra time to provide palliative care. There is an absence of a systematic approach to implement palliative care services in which all stakeholders are made aware of the need for such services. Personnel are supported by the MOH and stakeholders coordinate and collaborate.

Recommendations

Focus HAU’s service delivery agenda on its strengths. HAU’s ability to manage large programs is limited. It cannot provide the full range of palliative care services until it can demonstrate good program management of its existing services. Adding more services might also interfere with HAU’s ability to monitor, use, and report the results of its current work.

These findings support USAID's strategy to fund HAU for training palliative care in AIDS organizations and provide the current range of palliative care services.

Establish strong networks between palliative care providers and support organizations. Such relationships can fill HAU's existing gaps in service delivery that include financial support for PHA's children's education, food, succession planning, will making, and other social and end-of-life services that require specialized skill sets or additional resources. However, given HAU's direct access to PHA in the home, it should make an effort to increase awareness of and facilitate linkages to other programs that can meet these needs for PHA and their families.

Summary

Five key, interrelated issues must be considered to fund and implement HIV end-of-life and palliative care in sub-Saharan Africa. These include: 1) pain control as a primary challenge; 2) the balance between quality of care and numbers of individuals served—especially as programs expand; 3) the need for technical assistance in monitoring and evaluation; 4) effective collaboration between funders, NGOs, providers, and in-country governmental agencies; 5) use of resources to promote understanding of and support for palliative care in order to sustain or improve current activities (Harding 2003). Under this framework, HAU has addressed the first issue of pain control but still needs to grow with regard to the other four. HAU is on a steep learning curve as relatively new recipient of USAID funding. Nonetheless, it is filling an important niche in Uganda.

Uganda has all the pieces to provide comprehensive palliative care, and USAID can help the MOH facilitate the assembly of these pieces into a unified whole. This is a realistic goal and, once achieved, Uganda promises to be a showcase for palliative care in sub-Saharan Africa, and possibly worldwide.

Introduction

Background

Uganda has been successful in decreasing the incidence of HIV/AIDS from nearly 30 percent in the early 1990s to 6 percent by 2002; however the effects of the epidemic are still felt by those infected by the disease as well as those with related cancers. Before the onset of the HIV epidemic in Uganda, 0.1 percent of the population suffered from cancer. With the rise of HIV/AIDS, the Ugandan population has experienced a dramatic increase in cancer. Overall, 40 to 60 percent of all cancer patients attending hospice and registered with the Cancer Registry of Uganda have cancer that is HIV-related. This probably represents a low estimate (Merriman 2002). Among Hospice Africa Uganda's (HAU) patient population, 25 percent of cancers are attributed to Kaposi's sarcoma, and another 25 percent of cancers are estimated to be HIV-associated (Merriman 2002).

There is minimal information available on the number of cancer patients whose illness is solely attributed to their HIV status. World Health Organization (WHO) figures from 2005 show that cancer killed approximately 14,000 people in Uganda, accounting for 3.7 percent of deaths. Among more than 3.5 million clients served by HAU between its Kampala, Mbarara, and Hoima centers, 15 percent are seeking support for their HIV/AIDS-related illnesses (Merriman 2004).

Most terminally ill patients are provided care in their own homes by their families. This is due, in part, to the strain the HIV epidemic has placed on Uganda's already weak healthcare infrastructure—where basic health care reaches only 41 percent of the population, and annual expenditure per capita stands at just \$12 (Kikule 2003). Many cancers associated with AIDS are largely incurable, creating a high demand for palliative care services. Funding is inadequate for palliative care outreach services and where they exist, access is limited, especially in rural areas. WHO defines palliative care as a holistic approach to improve the quality of life of patients with incurable disease and their families through the prevention and relief of suffering by means of early identification and careful assessment and treatment of pain and other problems, physical, psychosocial, and spiritual (WHO 2002). Palliative care is considered a broader term than “end-of-life” care because it addresses the physical, emotional, spiritual, and practical aspects of care, not just the control of pain and other symptoms. Most broadly speaking, such care can also address orphan care, income generation, and food security and end-of-care systems. It should also incorporate alternative belief and care systems, such as traditional healers.

Consideration of what constitutes quality palliative care in developing countries is important in setting international standards. Before palliative care models were implemented in developing countries, questions were raised to its appropriateness. After determining the effectiveness of home-based and inpatient hospice care in sub-Saharan Africa during the 1990s, widespread implementation of internationally supported programs occurred. These approaches have indicated that government funding and support, clinical training, and improved pain control through drug policy advocacy are necessary to create a cohesive approach for palliative-care scale-up. Given the magnitude of HIV, these programs have also considered coverage rather than provision of high quality care to a few patients.

Palliative care was first introduced in Uganda in 1993 by HAU, a non-governmental organization (NGO) that initiated three community-based palliative care programs in rural and urban communities in Kampala, Hoima, and Mbarara (Logie 2005). At that time, HIV/AIDS supportive care for patients living at home was provided by The AIDS Support Organization (TASO), Mildmay, and other programs. These organizations primarily focused on supporting clients and their families with counseling, improving attitudes, and approaches to living with the disease. These organizations provided an excellent means of improving patient care while decreasing the stigma associated with HIV/AIDS in Uganda. Yet, they lacked and still lack modern methods of pain and symptom control crucial to strong palliative care.

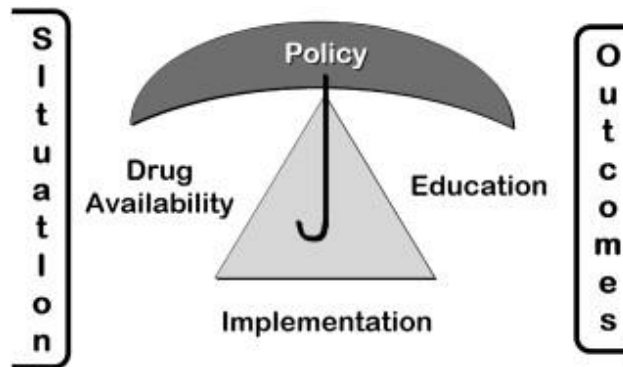
The major donors supporting HAU are Hospice Africa UK, USAID, Friends of Hospice Uganda, the Danish Embassy (DANIDA), Irish AID, the Diana Princess of Wales Memorial Fund, Children's Support, the University College of London, Rose Grant, and Foundation for Hospice in sub-Saharan Africa (FHSSA).

The National Hospice and Palliative Care Organization (NHPCO) is the primary association for hospice and palliative care programs and professionals in the United States. A relatively new organization in the arena of international palliative care, NHPCO formed a partnership with the African Palliative Care Association (APCA), which had an existing relationship with FHSSA. As a result, NHPCO and FHSSA merged (Callaway 2007). In addition to focusing on developing national associations, the NHPCO has concentrated its efforts on the development of standards and systems for measuring the quality and quantity of palliative care. An APCA African Palliative Outcome Scale has been developed and tested through the efforts of NHPCO and these guidelines have been utilized by HAU.

International Standards of Palliative Care

WHO defines palliative care as an approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering. This is done through early identification, careful assessment, and treatment of pain and other problems, whether they are physical, psychological, or spiritual (Callaway 2007). In 1990, WHO developed the Public Health Strategy approach to integrate palliative care into existing health care systems. This approach focused on translating new knowledge and skills into evidence-based, cost-effective interventions that could reach all individuals in a population. WHO targeted national governments, providing advice and guidelines on priorities to implement national palliative care programs and national cancer control programs (Stjernswärd 2007). While the WHO model addressed cancer care, its four main pillars are applicable to HIV/AIDS care and include appropriate policies, adequate drug availability, education of health care workers and the public, and implementation of palliative care services at all levels throughout society (see Figure 1). Despite the recent attention to palliative care on a global scale, developed countries are still in the early stages of establishing standards and guidelines.

Figure 1 WHO Public Health Model (Stjernsward 2007)



The Gold Standard Framework (GSF) is presumably the most progressive approach to enhancing primary palliative care. The GSF was developed through a partnership between the Royal College of General Practitioners, the national charity Macmillan Cancer Support, and the Liverpool Care of the Dying Pathway. In a 2000 pilot program, the GSF was introduced to 12 practices. As of 2007, its associated services reached more than one quarter of the United Kingdom's (UK) population in need of palliative care.

Designed as a locally-based system to optimize the organization and quality of care for patients and their caregivers in the last years of life, the framework includes three processes and five goals. The processes involve the identification of patients in need of palliative or supportive care towards the end of their lives; an assessment of the patient's needs, symptoms, preferences, and any issues important to them; and the planning of care around these needs and preferences with a focus on providing support in the environment in which the patient prefers to live and die. The five goals of the GSF are (Golden Standards Framework 2009):

1. Patients are as symptom-controlled as possible;
2. Patients are enabled to live well and die well in their preferred place of care;
3. Patients receive better advance care planning, information, less fear, fewer crises/admissions to hospital;
4. Caregivers are supported, informed, enabled and empowered;
5. Staff are instilled with improved confidence, communication, and co-working.

The success of the standardized approach to palliative care services was demonstrated in a study that was initiated after 12 months of implementation. It found that approximately 90 percent of practices maintained a palliative care register, and 80 percent had regular primary health care team (PHCT) meetings in which palliative care patients were discussed (Munday 2007).

Scotland offers another example of palliative care standards, which were developed by a National Care Standards Committee (NCSC), with the help of a number of working groups, including people who use the services, their families and caregivers, professional staff, associations, local authorities, health and social care regulators, as well as independent health providers. This collaboration established a set of principles upon which the standards were

based (National Care Standards: Hospice Care 2003). The Scottish Palliative Care Standards (see Annex A) were developed from the perspective of the patient, not the provider. If standards are not met by a registered organization, the organization will be held accountable for the breach in regulation and if severe, the NCSC would move to cancel the registration of the organization's services.

The Australian Government's Department of Health and Aging began to collaborate with Palliative Care Australia (PCA) in March 2004 under the guidance of PCA's Standards & Quality Committee. Ongoing consultation among consumers and stakeholders led to the establishment of new PCA standards (see Annex B) to be used alongside other standards for health services.

Within Africa, South Africa is the only country whose palliative care standards meet WHO standards. These standards represent the minimum service requirements based on WHO's definition of palliative care. During the interviews references were made to South Africa's standards, yet the authors were unable to retrieve a copy of them.

The UK, Scottish, and Australian standards have laid the foundation from which APCA is currently building its guidance for palliative care standards in Africa. They also provide evidence for the Palliative Care Association of Uganda (PCAU) to adapt the APCA guidance to formulate its own national standards.

Rationale

Despite the global focus on HIV treatment, the nature of the disease and a weak public health infrastructure make attaining quality palliative and end-of-life care a challenging goal in sub-Saharan Africa. Given the magnitude of AIDS-related deaths, existing hospital infrastructures have been overwhelmed, making a renewed focus on the quality of palliative and end-of-life care necessary. Great strides have been made to provide care and support in the homes of people suffering from terminal illnesses. In Africa alone, at least a dozen countries have discussed addressing palliative care on a national scale—albeit to varying degrees of implementation.

HAU receives a large proportion of its funding from the United States Agency for International Development (USAID)/Uganda, which as of 2007 accounted for approximately 60 percent of its revenue (HAU 2007/8).

USAID/Uganda is keen to evaluate the hospice experience in Uganda through the HAU lens and in relationship to the other providers of palliative care. The results of this evaluation will elucidate the degree to which HAU and Uganda could become a model for other resource-constrained countries on the continent.

Objectives and Evaluation Questions

In 2005, USAID/Uganda funded HAU's three year project (August 2005 to August 2008): *"Expanding Access and Scope of Palliative Care for People Living with HIV/AIDS and their Families"*. The project objectives were to:

1. Increase the coverage and scope of palliative care services available for PHA and their families;
2. Train health workers and other HIV/AIDS care providers to integrate pain management, symptom control and end-of life care into their existing HIV/AIDS care and support programs;
3. Build the capacity of families, communities and community-based organizations in the provision of palliative care;
4. Integrate HIV prevention into the palliative care training/education;
5. Build functional networks linking families, communities, health facilities and civil society organizations to enhance easy access to palliative care services.

The \$3 million USD of PEPFAR funds were allocated primarily for training (42 percent) and patient care (28 percent). The patient care funds were distributed among HAU's three service delivery sites in Kampala, Mbarara and Hoima. The Kampala Makindye center is located at HAU headquarters and is by far the biggest of the three HAU branches, serving on average about half of the total enrolled HAU patients. Likewise, their staff is far larger than those found in the other branches. In January 1998, Mobile Hospice Mbarara (MHH) was established in the district of the same name. As true with Makindye, MHH provides critical care of illness and end-of-life support to cancer victims and PHA within a 20 kilometer radius of their center through their mobile unit. Services include modern methods of pain and symptom control, counseling and spiritual support to the patient and family. Six months after MHH was started, Little Hospice Hoima (LHH) was founded in a town shop by a volunteer worker. LHH was the first branch to implement HAU's community volunteer worker (CVW) program. Today, LHH's staff of 14 serves a district of 400,000 inhabitants. Similar to MHH, LHH reaches out to a 20 kilometer radius of the town center.

The QED Group, LLC, through a subcontract from the Population Council, conducted an end-of project evaluation of HAU. In the request for task order proposals, USAID requested that the evaluators compare the HAU approaches and strategies to other service providers, specifically including TASO and Mildmay. The objectives of this evaluation are to:

1. Review the approaches and strategies currently used by HAU to deliver services and track coverage achieved;
2. Examine the international standards of care and approaches to palliative care compared to the HAU approaches;
3. Examine how the HAU education program has contributed to increasing availability of palliative care services (pain management, symptom control, end-of-life care) to PHA and their families;
4. Assess the approaches and strategies that HAU has in place now to ensure future sustainability of its HIV/AIDS program; and
5. Measure the extent to which HAU has succeeded in increasing access to, and utilization of, quality palliative care services, specifically diagnosis and management

of pain, symptom control, as well as spiritual and end-of-life care for PHA and their families.

Methodology

Study Design

This qualitative study offers a cross-sectional assessment of palliative care in Uganda. It used a multi-method approach, including key informant interviews with palliative care leaders and stakeholders in Kampala, in-depth interviews, and focus group discussions (FGDs). The latter two took place across eight districts throughout Uganda with various palliative care providers. The evaluation team sought to validate its findings through triangulation and input from key stakeholders, including two advisors: a key policy maker in the Ugandan Ministry of Health's (MOH) HIV/AIDS Program and a representative from the Palliative Care Association of Uganda, who is a leader in the palliative care movement and a former HAU staff member. The data collection instruments delved deeply into an array of variables that directly reflect the five evaluation questions. The team worked closely throughout the process to reach a common understanding of the interpretation of the results thereby minimizing bias. The evaluation team also reviewed HAU program documents and annual reports to the extent they were available. Ethical considerations were vetted with the team to ensure the protection of respondents' views. A methodical approach to data analysis organized the findings according to key domains and outcome variables.

Selection and Description of Sample/Study Participants

Eight district sites were visited to evaluate HAU palliative care program. The rationale was to account for any regional differences, or differences associated with proximity to urban settings, where access to resources is greater. The constellation of sites selected also provided a range of socio-cultural contexts. These eight districts were selected based on the following criteria:

- Districts that will show the full range of services provided by HAU. These services include Independent Hospice; Hospital/Nurse CPCC team; Palliative Care Services with Morphine; and Clinical Palliative Care Nurses/Clinical Officers;
- Comparison districts where no formalized palliative care services are offered by HAU, Mildmay or TASO;
- Districts from the four regions of Uganda: Central, Northern, Western and Eastern Regions;
- Districts representing urban, peri-urban, and rural areas to account for differences in access to resources.

(Refer to Annex C: Site Selection Criteria for Districts, which details the criteria as applied to the eight districts.) The comparison groups provided valuable information on the extent to which alternative approaches, if any, are available for people requiring palliative care in districts where HAU is not operational. This sample includes two districts where no services are provided (Apac and Nakasongola) and three districts where other hospices and hospital-based palliative care teams were likely to be found. Thus, there are three groups where the districts fall as depicted in Table 1 below:

Table 1 Characterization of sampled districts

HAU hospice service sites			Other hospice/palliative care services			Comparison districts	
Kampala	Hoima (LHH)	Mbarara (MHM)	Lira	Jinja	Mpigi	Apac	Nakasongola

The evaluation used three methods of data collection: 1) key informant interviews; 2) in-depth interviews; 3) focus group discussions:

Key informant interviews

Key informants selected at the central (Kampala) level included senior HAU management (e.g., founder, senior policy advisor, directors, evaluation specialist), National Palliative Care Team members, MOH officials involved in palliative and home-based care, and representatives of Mildmay International, TASO, APCA, and PCAU. A “snowball” approach was applied to identify key leadership in the palliative care movement. Several of the informants were also identified through a review of the literature and web-based searches. In addition to the initial informants, a few leaders were identified by advisors from the MOH and PCAU.

In the districts, the team took a comprehensive approach and sought views of respondents ranging from PHA receiving ART and/or palliative care to health providers from each level of service delivery. Eight districts were selected according to three criteria: 1) range of palliative care services; 2) regional (geographic) coverage; 3) access to resources (urban/rural). (See Annex D for the log of interviews.)

District-level¹ respondents were interviewed by one of two methods: in-depth interviews or FGDs:

In-depth interviews

In-depth interviews included District Health Officers (DHOs), medical superintendents (MS)², hospital-based Certified Palliative Care Nurses (CPCN), Certified Palliative Care Clinical Officers (CPCO) managers and nurses in organizations offering palliative care (except in comparison groups) such as HAU, independent faith-based hospice organizations and hospital-based programs, and PHA Network representatives. Before the study team arrived in each district, the MOH and PCAU advisors communicated with the respondents to ascertain their willingness to participate in the interviews.

¹ The eight districts are Kampala, Hoima, Mbarara, Lira, Jinja, Mpigi, Apac, and Nakasongola.

² The team selected the referral hospital (public or private) where patients are sent by the index palliative care organization for that district. In the comparison groups where there are no palliative care services, interviews were conducted with the medical superintendents at the district hospitals.

Focus group discussions

FGDs included two categories of respondents: 1) PHA receiving care (ARVs and/or palliative care); 2) community volunteers, including HAU community village workers, other community volunteers trained by their respective palliative care organizations, or Village Health Teams (MOH-supported volunteers without training in palliative care). The evaluation team was unable to identify PHA who are *not* receiving care because once PHA were identified, they were enrolled into some form of care (monitoring, ART, and/or palliative care). This conclusion was substantiated by key informants. Perspectives of PHA who are not openly seeking care were gleaned during the pilot test through discussions with PHA receiving care and the PHA Network Representative.

Ethical Considerations

The QED Group, LLC fully respects the rights of human subjects who participate in its studies and evaluations.

Ethical principles^{3,4}

During the study, several precautions were taken to ensure the protection of respondents' rights. Ethical principles of respect, beneficence, and justice were applied in the selection of the respondents. In order to apply these principles, the following measures were applied:

Informed consent: No interview began without receipt of informed consent from each respondent (see Annexes E and F). There was one form per interview guide, which had a unique identifier that linked the form to the guide.

Information: In-depth interviews were conducted in a confidential setting, one-on-one, so no one else could hear the respondent's answers. Most often, the interviews occurred in the privacy of the respondent's office. The FGDs took place in a setting where PHA had already gathered to receive care and treatment from a service provider. Both the in-depth interviews and FGDs did not request any information that would personally identify a respondent.

Data collection staff members were in control of their written notes at all times. After the interviews and discussions were completed, they merged their notes into electronic documents that were transmitted by e-mail to QED's network, which is protected by a firewall. In the event the data were transmitted to an incorrect address, all QED emails have a confidentiality statement included as a footer to their e-mails. Each record in the database

³ Department of Health Education and Welfare (1979). *Regulations and Ethical Guidelines: The Belmont Report—Ethical Principles and Guidelines for the Protection of Human Subjects of Research*, Retrieved February 8, 2009, from: The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research Web site: <http://ohsr.od.nih.gov/guidelines/belmont.html>.

⁴ UNAIDS (2007). *Guidelines on Protecting the Confidentiality and Security of HIV Information: Proceedings from a Workshop*.

was identified only by a lettered code indicating the category of the respondent followed by a three letter code for the district, which allowed for disaggregation

Comprehension: The evaluators assessed respondents' ability to make autonomous decisions through a conversation in their own local language and ensured that they had expressed understanding of informed consent. Those respondents judged to be mentally or physically challenged to the extent that they could not make autonomous decisions were not considered for an interview or FGD.

Respondents did not receive any form of inducement or incentive to participate in the study. PHA or volunteers who requested services, care, or treatment were referred to the nurse or other provider responsible for their well-being. The evaluators reiterated their external role to service delivery and employed the cooperation of the local providers to accommodate any requests. Respondent participation was strictly voluntary and questioning only began after informed consent had been secured. Respondents requesting allowances for their participation were offered the option to opt out of the interview.

Data Collection Methods

The evaluation team used a mixed methods approach, which included document reviews, key informant interviews and FGDs in each of these eight sites. The same interview guide was used to elicit information from key informants in Kampala and in-depth interviewees in the districts. A FGD guide was used to stimulate discussion among the PHA and community volunteers (see Annexes E and F for the In-depth Interview Guide and the Focus Group Discussion Guide, respectively). No one interviewee or FGD participant was asked all of the questions in the guide. Through the course of the interview/discussion, the interviewer gauged which questions were best suited to the respondents. He would probe the respondent if he or she did not independently talk about the relevant outcome variables.

The study team visited sites where PHA were already convened to receive support from the hospice. FGD respondents were asked to voluntarily participate by the respective health provider offering care and support. Community volunteers also were present at these monthly sessions and available for FGDs. No criteria for participation were imposed—only those people who independently volunteered joined the FGD. In two districts, Hoima and Apac, the FGDs needed to be conducted within the hospitals where the palliative care teams were based because they might not have outreach components. Home visits were used as a replacement for FGD in situations when the PHA identified were too debilitated to meet publicly. They were also used in situations when FGDs were not logistically feasible because of geographic distances.

Data Management and Analysis

During the interviews and FGDs, information was recorded by the lead in-country evaluator and research assistant. Notes were later discussed and compared before being transcribed into one MS Word document for each interview/FGD. These files were systematically coded and analyzed in ATLAS® a software program for qualitative data analysis. Data were aggregated

at each level of analysis, including: palliative care strategies, approaches, standards, availability, access, sustainability and utilization. There was representation of key leadership at the central level and also for each district.

In order to assess the effectiveness of HAU's strategies and approaches to providing palliative care, a comparative analysis was conducted between HAU and other organizations offering palliative care and between HAU and the two districts where palliative care is currently not offered in any systematic or formal fashion.

The data collected from key informant interviews at the central level were analyzed separately to assess the vision and direction of palliative care on a national level and to provide a larger context within which palliative care resides. Information collected at the district-level was analyzed in the aggregate to provide an illustrative perspective of the palliative care systems throughout Uganda. Thus, there are two units of analysis: the central-level perspective of national leaders and the district-level palliative care networks.

To form the structure of the analysis, seven key domains were defined according to the evaluation questions: strategies, approaches, standards, availability, access, sustainability and utilization of palliative care services. The interview guides were also organized according to these domains and their respective outcome variables of interest. Figure 2 delineates the domains and their corresponding variables.

On May 7, 2009, a data interpretation meeting was convened in Kampala. Preliminary findings were presented to a group of 28 key stakeholders, most of whom were key informants, including the HAU senior management team. The participants represented the nation's key leadership in palliative care. After this meeting, the evaluators revisited the findings and revised their conclusions and recommendations accordingly.

Figure 2 Palliative care domains

Domains	Outcome Variables
Strategies	<ul style="list-style-type: none"> ▪ Definitions ▪ Program planning ▪ Financing ▪ Resource allocation
Approaches	<ul style="list-style-type: none"> ▪ Approaches & models ▪ Methods for reaching patients
Standards	<ul style="list-style-type: none"> ▪ Guidelines ▪ Standards of care
Availability	<ul style="list-style-type: none"> ▪ Deployment ▪ Institutional support ▪ Collaboration ▪ Referral services ▪ Pain management ▪ Treatment for opportunistic infections ▪ Psychosocial needs ▪ Spiritual needs ▪ End-of-life care
Access	<ul style="list-style-type: none"> ▪ Geographic ▪ Socio-cultural ▪ Psychological ▪ Economic ▪ Identification of PHA in need of care ▪ Awareness raising of palliative care services
Utilization	<ul style="list-style-type: none"> ▪ Quality ▪ Pain management ▪ Symptom control ▪ End-of-life care
Sustainability	<ul style="list-style-type: none"> ▪ Strategic plan ▪ Donor funding ▪ Health management information system ▪ Roll-out/Scale-up ▪ Integration into national health system ▪ Indicators of success

Data Quality

The multi-methods study design allows for triangulation of information from a variety of data sources. The team gleaned a range of perspectives from managers, providers, and recipients of palliative care. The technical assistance of the MOH and PCAU advisors not only helped to identify the most appropriate respondents and questions, but also served to validate or refute assumptions of the evaluators.

To test the study's methodology and instruments, a pilot study was conducted in Masaka District. The individuals interviewed included the Director of Kitovu Mobile, a PHA and palliative care organization, the DHO, the MS of Kitovu Hospital, a hospice or palliative care team, and an expert client, also known as peer educator. The team also conducted one FGD

with the PHA and another with CVWs. The methodology proved to be feasible and the data collection instruments were revised and streamlined. The pilot also formed a common understanding of the intent of each question among the evaluation team members.

Limitations of the Study

Interviewer bias was nominal since the same lead-in country evaluator conducted all interviews accompanied by a research assistant. While every effort was made to reach all seven respondents in each district, there was a bias toward more senior level respondents probably because of ease of access. Volunteers were dispersed within districts and not always available for interview. Similarly, unless the evaluators were able to attend a site where PHA were receiving care, it was difficult to form focus groups because of their physical proximity to one another. In some cases, home visits to PHA were conducted in lieu of a FGD. By implication, there is more representation from respondents with formal education and an outside purview of palliative care—volunteers and PHA are underrepresented because they were difficult to physically access once the team arrived in the districts.

This element of selection bias is evident when reviewing the response rates by type of respondent (see Annex D: Interview Log). Senior management and providers are better represented than patients or volunteers. Still, well more than half the PHA representatives and PHA receiving care were interviewed as originally intended. Also, 100 percent of the intended CPCNs were interviewed (none in the comparison groups). Looking at the body of results from the district level, there is under representation in Nakasongola, one of the two comparison districts. This was expected given its remote location. Mpigi, one of the districts in the “other intervention” group, also had a low response rate. Only the DHO, MS, and the CPCNs were interviewed.

Lastly, the patients represented in this study are already open about their HIV/AIDS status and are potentially a less stigmatized group than the general population of PHA. Because of this bias, the study will less likely reveal issues surrounding lack of access to palliative care due to stigma.

Results

Response Rates

There was a fairly good response rate for both the type of respondents and the districts represented (see Tables 2 and 3, a more detailed breakdown of the respondents, is provided in Annex D). Respondents fall roughly into three categories: 1) managers with a system-wide perspective; 2) providers of palliative care; 3) patients. The lowest response rates were among the patients because they were difficult to reach, or, in the case of PHA network representatives, they did not exist in half the districts. The CVWs were also under—represented because even though all districts had volunteers, they were not available for interviews in three of them.

Table 2 Response rates by type of respondent

Managers		Providers			Patients	
DHO	Medical superintendent	Hospice staff or PC team	CPCN/CPCO	CVW CHW VHT	PHA Rep	PHA receiving care
88%	88%	100%	100%	71%	63%	57%

Response rates for the districts are based on the extent to which the team expected all seven types of respondents to be available. The team aimed to interview a minimum of one key informant for each category but often had an opportunity to include one or two other respondents. The FGDs of PHA receiving care and community volunteer workers included about 4 to 6 people per session. The team did not expect to encounter any hospice or palliative care teams, CPCN/CPCOs, or PHA receiving care in the two comparison districts of Apac and Nakasongola. For this reason, the denominator for those specific groups as listed in Table 3 is 6 rather than 8. It is interesting that Apac turned out to have a hospital-based palliative care team and conversely, Mpigi’s Nkozi Hospital was to have had a team but did not. Still, this did not change the organization of the analysis—Mpigi did not fall into the comparison group with Apac and Nakasongola and Apac did not fall into the group of other hospice/palliative care services.

Table 3 Response rates by district

HAU hospice service sites			Other hospice/palliative care services			Comparison districts	
Kampala	Hoima (LHH)	Mbarara (MHM)	Lira	Jinja	Mpigi	Apac	Nakasongola
71%	86%	86%	86%	100%	43%	71%	29%

Results are presented according to the five evaluation objectives.

Objective #1: Review HAU Approaches and Strategies to Deliver Services and Track Coverage

Based on the interview transcripts, it was determined that HAU's three service sites at Kampala, Mobile Hospice Mbarara (MHM) and Little Hospice Hoima (LHH) use a number of service delivery approaches including: 1) institutional and day care; 2) hospital/health center visits; 3) home-based care. MHM also has a unique approach to mobile outreach and roadside clinics. Patients receive clinical assessments, education and information, treatment, and/or referral to another specialist center. Daycare provides the most common source of support for patients in Kampala and Mbarara, and home or hospital visits are other outreach services that strengthen continuity of care. Community-based daycare for HAU patients has also been developed at both the Kampala and LHH sites, improving access for patients, particularly in Hoima's rural setting, where travel is quite difficult. These approaches are further discussed below.

Institutional approach

The institutional care approach involves seeing patients at the HAU site. Through this approach, new palliative care cases are referred by CVWs, health workers in hospitals and health centers, patients that have benefited from HAU palliative care services, and those who are self referred.

Institutional care is an asset to HAU since it allows patients to access services seven days a week. According to some respondents, patients are provided attention and have more resources available relative to the services they would have received if they attended a roadside clinic or received home care. The approach favors ambulant patients from the nearby community while those who either cannot afford the associated travel costs or whose symptoms limit their ability to travel may be unable to access these services.

TASO employs a three-pronged approach to palliative care including outpatient, institutional, and facility based care. Within the institution, counseling services, treatment, and social program activities are available for patients who seek care on a daily basis. There does not appear to be a focus on home-based care; rather, a community-based outreach program utilizes CVWs to organize outreach. A unique feature of TASO is its community distribution drug points (CDDPs) to distribute ARVs within the community. This approach allows the patient to determine where to receive care. The TASO Mulago office further utilizes community ART support agents (CASA), who work with nurses and volunteers to deliver ART to patients at a given location within the community. TASO prioritizes the need to train CVWs and village health workers (VHW), putting more resources into this approach than home based care or institutional care.

The strength of the institutional palliative care approach is that it is cheap on the part of the hospital because it does not involve transportation and other related costs. The approach however turns out to be costly to the patients who may not be able to reach the health facility due to transport challenges, poor health seeking behavior, poverty, etc.

—Medical superintendent

Ray of Hope Hospice, based in Jinja, focuses on home-based care as opposed to institutional and community outreach. Given the economic context of the patients, the approach is best suited for this organization. Kitovu Mobile's dominant approach is institutional care, which is provided at the facility or hospital. Due to financial constraints on the part of the hospital, home-based care is not heavily utilized.

All of these hospice organizations provide a greater context in which palliative care approaches are emphasized. It is clear that each organization has a particular focus and thus different outcomes, the most important difference being whether there is an institutional focus on patient care or capacity building.

Day care

Day care services are provided at all three HAU sites. In the day care center, patients have the opportunity to receive care away from their home environment, where they are provided a meal, entertainment, and emotional support. The community day care approach allows patients far from the HAU site to experience a change in the care environment, just as ambulant patients in the vicinity of HAU are able to attend institutional day care. The challenge is that LHH is only able to organize one community based care, yet several communities have palliative care patients in need. More importantly, patients within easy reach of the day care center are cared for through this approach, while limiting the capacity to reach distant patients.

In Kampala, day care is offered once a week. MHM organizes two on-site day care services per month, which are attended by different patients (patients only attend once a month), whereas LHH organizes one on-site day care service per month. Patients who are unable to physically move on their own are transported by the organization. In addition to the institutional day care, LHH organizes a monthly community day care, which is run by CVWs with the support of LHH staff. HAU hires a local hotel for patients to visit—a replica of the institution-based day care in terms of activities and services.

Home-based care

Home-based care is another approach employed by HAU. A clinical team visits patients living within a 20 kilometer radius of their respective sites. HAU uses a family-centered approach, through which staff interact with family members, educating them about the best care practices such as feeding weak patients, bathing patient in bed, maintaining good sanitary practices, avoiding stigma, and reminding the patient to take his or her medication. The visiting clinical team also inquires about the HIV status of family members. Family members who have not yet been tested are encouraged to seek VCT. If families cannot afford HIV testing services, they are offered the cost of transportation from HAU's "comfort fund."

Some respondents feel that home-based care ensures continuity for discharged patients who in most cases would not be able to continue with the treatment as out-patients. Targeting the family members and involving them in providing care to patients also contributes to patient adherence to treatment.

Despite these benefits, HAU's catchment area limits the patient population reached. The approach is also very costly for the organization. TASO covers a much larger radius (up to 75 kilometers from the district referral hospital) but it has about 20 motorcycles and just as many social workers per hospital to provide coverage. Conversely, the PCT in Jinja hospital covers a half kilometer radius by foot.

Community outreach

The HAU Makindye site in Kampala conducts community outreach in the suburbs of Luzira and Mukono at health centers and in Busega at a church. This has helped in reaching out to the community and also as a means of scaling up. CVWs mobilize and organize PHA to attend the outreach service delivery points. These centers also offer a change of environment, with patients picked up by HAU vehicles and taken to the day care centers. Patients have beds to rest on, and receive entertainment and physiotherapy.

MHM operates three mobile clinic outreach programs in Ibanda, Bushenyi, and Kamwenge districts, working with CVWs who mobilize and organize patients who would otherwise not be able to access palliative care services at the MHM site. The mobile clinic is MHM's unique approach to outreach and is mainly organized in facilities to replicate services offered at the MHM site. MHM's mobile outreach is combined with roadside and mobile clinics, a concept in which services are provided outside of a typical clinical setting. Roadside clinics are organized to serve patients who are far from the outreach community and the MHM site. This helps enhance the adherence to treatment by eliminating defaulters who fail to meet appointments because of transportation difficulties. Some of the roadside clinics are arranged in people's homes, private clinics, and in public health facilities. The MHM palliative care team meets these patients and provides them with care while on its way to the outreach centers.

LHH organizes community outreach efforts as well but does not have a mobile clinic. Like MHM, LHH works with CVWs, who in turn work hand-in-hand with the health centers where the outreach is organized. LHH selects a busy day at the health center to sensitize patients about palliative care. Such outreach brings palliative care services closer to the patients and community members in a manner that is not possible in the clinic or home-based approaches. It is also cost-effective for HAU, since many patients can be attended to at the same time. These services are significantly less expensive than facility based care. This approach fosters disclosure of HIV status in order to receive services. Community outreach services organized at health centers promote sensitization about palliative care, thus increasing awareness among health workers, patients, and other community members.

However, community outreach services provide their own challenge to the MHM and LHH sites because they deplete almost all staff, thus hampering their institutional activities. There is always a trained nurse on-site at any given time. As a result the effectiveness of the

approach is compromised by the volume of patients, precluding the palliative care team from spending adequate time with each patient. As a result, patients might not receive the full spectrum of services, particularly those related to psychological problems. Community outreach and mobile clinics also require a significant number of staff, which poses a challenge to recruitment of CVWs. After they are selected, CVWs need to be trained and retained.

Hospital visits

HAU staff visit patients in Mulago Hospital and the regional referral hospitals. Under this approach, HAU sites are expected to visit the respective hospitals three times a week to attend to referred cases and to identify patients in need of palliative care. However, sometimes the sites do not complete the desired number of visits.

LHH enjoys a good working relationship with Hoima Hospital, affirmed by the DHO, Deputy MS of Hoima hospital, the hospital CPCN, and LHH staff. It works with the CPCN in the Hoima hospital, who is deployed in the ART clinic. This particular nurse has undergone a nine-month course in palliative care. Her training has facilitated the procurement and provision of morphine by Hoima regional referral hospital. All cases of pain are referred to her, and she in turn refers discharged palliative care cases to LHH for follow up and home visits. This CPCN has initiated a palliative care team including other health workers who have attended a palliative care course for health professionals. Furthermore, she is allowed time to attend to palliative care cases identified by other units of the hospital.

Recently, MHM started a children's palliative care program in the Mbarara hospital. The strength of this approach is that pediatric patients receive palliative care plus other treatment and care services offered in the hospital. However, the relationship between MHM and Mbarara hospital is weaker than that of LHH and Hoima hospital. For example, MHM does not make its presence known to management when it visits the hospital, nor does it have a recognized contact person in there.

Tracking coverage

HAU has taken part in monitoring and evaluation (M&E) activities since 1993 although it was not until 2007 that it began working in a more systematic fashion by applying an M&E framework. Through the AIDS Capacity Enhancement (ACE) Project funded by USAID, HAU has been receiving organizational development support. As of April 2007, HAU initiated a rapid assessment of M&E activities using a regional consulting firm hired through ACE. This was accomplished through key informant interviews, FGDs, and self-administered questionnaires. With this newly implemented system, HAU has been better able to track its education and clinical outreach programs.

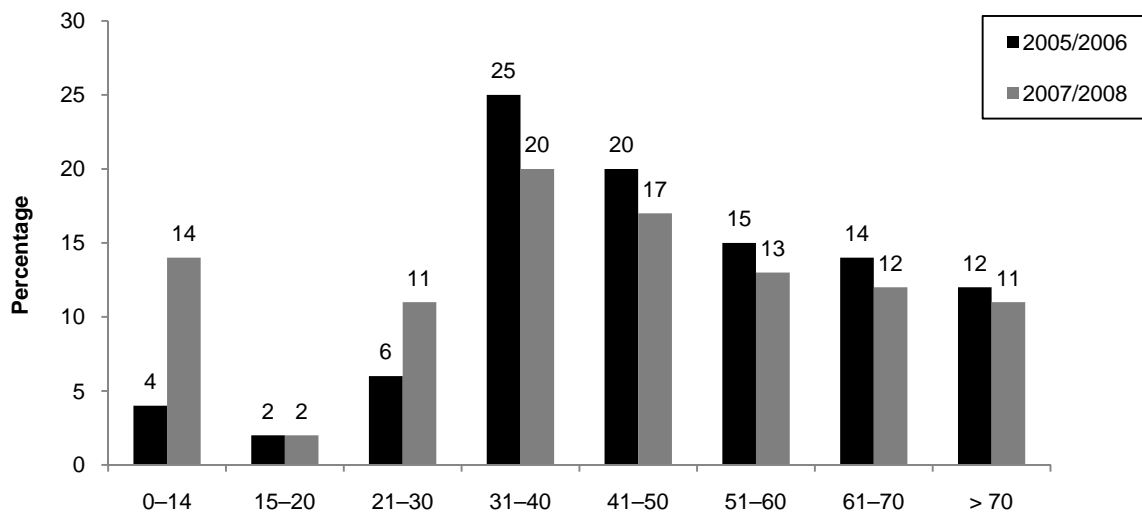
The evaluation team attempted to scrutinize the degree to which HAU identifies PHA in need of palliative care services and how it tracks the service provided to those enrolled in its program. This proved to be difficult because many results from the same data source were conflicting and the team could not reconcile the apparent contradictions even after

discussions with HAU. For example, based on the 2007 annual report, HAU had experienced a 33 percent increase in patients from the previous year, while 2008 saw only a 5 percent increase. Of the 666 patients seen between 2007 and 2008, a majority were self-referred and presented to HAU having heard about the care that it offered. These results confirm reports from key informants who noted that the proportion of self-referrals by PHA is growing. It also indicates that many of these self-referrals are not enrolled in the HAU program because they do not need palliative care. HAU then refers these PHA seeking other forms of care and treatment to Mildmay and TASO but there is no system for following up the status of their referral. There is no record keeping of those PHA not enrolled in its program.

Regarding coverage, HAU is only able to track the PHA enrolled in its program and is not able to offer any indication of the magnitude of unmet need for palliative care. HAU responds to the referrals on a case-by-case basis and is not able to estimate the entire landscape of PHA in need of palliative care.

As noted, M&E data provided by the HAU management team was sparse but included distribution of patients by age group (see Figure 3). Noteworthy is a tripling of the number of pediatric patients registered and nearly doubling of young adults (ages 21 to 30); providing more care to children was an HAU objective.

Figure 3 Age distribution of HAU patients



Other available data included the numbers of patients receiving each type of palliative care service offered by HAU. Annex G was the initial data source provided to the team from the HAU M&E System.

While USAID/ACE developed an M&E system through which HAU could better track coverage of its services, the issue was not well addressed by the HAU respondents. Many of the key informants mentioned the role of CVWs as those who could best determine the patients covered and the services received. They were often cited as the most important resource for identifying new patients in need. Yet this was not supported by data because the

indicators on CVWs are sketchy and for project year three, there are no results reported on them.

Mildmay, TASO, and others provide PHA referrals to HAU, although the degree to which they do so remains unclear. Another point raised was the assessment of patients, in which HAU ascertains patients' eligibility for services. Those patients who do not meet these requirements are informed where they can obtain needed services based on their health status, but these individuals are not recorded and thus no further information is known about the sub-sector of PHA who cannot be served by HAU. In sum, it appears that the CVWs represent the frontline for HAU in terms of tracking services through their interactions with patients, however, this appears to be done on an informal basis and not through an established communication mechanism. And in terms of coverage, HAU's information system is not able to identify the universe of PHA with unmet needs for palliative care services.

Objective #2: Compare HAU Approaches to International Standards of Care

The Uganda National Health Policy and the recently revised National Strategic Framework (NSF) HIV/AIDS (2003/4–2005/6) recognize the need for palliative care, the former as part of the essential clinical care package and the latter specifically mentions palliative care as a sector to be enhanced and given increased attention. The Ministry of Health has incorporated palliative care into the Health Sector Strategic Plans (HSSP). It will be integrated into the health care system, and has improved access to opiates by increasing the prescribers through the changing of the statute in 2004 to include Clinical Palliative Care Nurses/Clinical Officers. The Palliative Care Association Uganda (PCAU) formed in 1999, serves as a forum for palliative care providers with a mandate to support standards, education, and advocacy.

The most applicable document available to HAU is APCA's Clinical Guide to Supportive and Palliative Care for HIV/AIDS in sub-Saharan Africa, published in 2006. This guide was adapted from a collaborative five-day effort of palliative care experts that took place in December 2003 in Cape Town, South Africa. Experts from sub-Saharan Africa, the United States, Canada, and the UK came together to review the United States' Clinical Guide to Supportive and Palliative Care for HIV/AIDS, published in 2003. After extensive review, the content was adapted or rewritten for the African setting.

Based on respondent feedback, only a few members of the HAU staff are aware of recognized international standards for palliative care and even fewer still understand how to apply them in daily practice. Only one respondent indicated she applied international standards—specifically, Liverpool Care of the Dying Pathway and the UK's Gold Standard Framework—in her daily activities. The vast majority of respondents either did not answer the question or gave examples of job aides when queried about international standards. In terms of local standards, only some of the HAU Kampala respondents were familiar with APCA's current effort. Most other health professionals, including the DHOs from Jinja, Mpigi, Nakasongola, were unaware of any international standards. One exception was the PHA representative from Jinja, who was familiar with standards in Ireland, the UK, and the USA and recognized these as operational frameworks for palliative care.

HAU uses a few guidelines and job aides in the delivery of palliative care. One important MOH guideline defines who should prescribe morphine (i.e., doctors, vets, dentists, clinical officers, and nurses trained in clinical palliative care for nine months). Mostly, respondents referred to WHO job aides such as the analgesic ladder for prescribing analgesics and pain assessment tools such as the body charts, numerical rating scale of fingers for adults and smiling faces used for children to assess pain. APCA developed what has come to be called the Palliative Care Outcome Scale (POS), which exists in adult and pediatric formats. The former has been piloted and disseminated widely, including the formal literature, while the latter is still under development and in the pilot phase. HAU staff, the Mulago PCT and others showed familiarity with the adult POS and described regular use of this tool.

The comparison districts were similar to HAU in that they were not fully aware of or adhering to international standards. In the comparison districts, it was noted that Mildmay, Kitovu Mobile, National Palliative Care Team-Mulago, Rays of Hope Hospice Jinja, and the palliative care unit of Jinja were using the WHO analgesic ladder and pain assessment charts but were not using the adult POS. These organizations are waiting for guidelines and standards that are being developed by APCA and PCAU to supplement the existing pain assessment and management tools. In other institutions, health workers had some understanding of pain assessment guidelines and tools but they could not provide specific details. With a couple of exceptions, the DHOs and MSs in the non-HAU districts showed a lack of understanding of palliative care standards and guidelines.

Despite the fact that the HAU founder developed and published the “Blue Book” which contains guidelines for pain and symptom control, the WHO analgesic ladder and pain assessment tools that it has relied on are inadequate for establishing a unified approach to palliative care throughout the country. However, few HAU respondents were familiar with the Blue Book published in 1995 (HAU 2006). Unfortunately, only one respondent made mention of the APCA clinical guide mentioned at the beginning of this section—the APCA representative.

Uganda can establish standards that reflect rigorous approaches of Scotland, Australia, and the UK with appropriate adaptation to its own national context. For example, Scotland’s standards are focused on the perspective of the patient, rather than the provider. This approach is succinctly captured in the first standard:

You can make a positive and informed decision about using the hospice services, helped by the quality and accuracy of the information you receive.

This approach may be unrealistic since it may overwhelm the health care system, but there are positive points that can be applied. Specifically, all patients and their caregivers and families should be confident that their legal and human rights are respected and protected and that the quality of care is the best that can be provided to them, regardless of the setting.

The standards developed in Scotland are based on assumptions that do not necessarily apply to Uganda: that all patients are being cared for in an institution and these institutions are appropriately regulated. As mentioned previously, any hospice in Scotland that does not meet regulations can have its license revoked. While this form of monitoring is ideal, it does not yet occur in Uganda. Given the number of home visits, mobile outreach, and other programs

that take place outside of an institutional setting, regulating the actions of health care providers on a national scale may not be possible. Furthermore, not all providers have received appropriate training, and there is a greater reliance on the community to assist with providing patients end-of-life care.

In contrast to Scotland, Australia's palliative care standards represent "a whole-of-sector approach" to ensure high quality needs-based care, with a focus on the perspective of the provider, rather than the patient. For instance, the first standard states:

Care, decision-making, and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patients, their caregiver/s and families' needs and wishes are acknowledged and guide decision-making and care planning.

This focus on not only is the patient, but also the caregiver or family members, bears relevance in Uganda and resonates with HAU's efforts to care for each and every patient and their family as a unique entity.

Objective #3: Examine HAU's Education Program and How it Has Increased the Availability of Palliative Care Services to PHA and their Families

HAU has undertaken various efforts to increase the availability of palliative care services with varying degrees of success. Indeed, it was somewhat of a challenge to appreciate the depth and breadth of the courses and trainings HAU provides. The following results speak more in terms of the short courses than the long term courses which reflects the information provided to the evaluation team.

HAU education courses

Currently HAU conducts short- and long-term palliative care training courses (see Table 4). While HAU conducts short-term palliative care training courses for health professionals, CVWs, spiritual caregivers, traditional healers, allied professionals, medical officers, and ward managers; evaluation of these courses took place at the LHH and MHM sites. The two long-term courses are the Clinical Palliative Care Course and the Distance Learning Diploma, both of which are conducted by HAU Kampala.

Table 4 HAU education courses

Course	Length	District		
		KAM	MHM	LHH
Long				
Clinical Palliative Care Course	9 months	✓		
Distance Learning Diploma	18 months	✓		
Short				
Health Professionals	6 days		✓	✓
Community Volunteer Workers	5 days		✓	✓
Spiritual Caregivers	3 days		✓	✓
Traditional Healers	5 days		✓	✓
Allied Professionals	5 days		✓	✓
Breaking Bad News	1 day		✓	✓
Introduction to Counseling	5 days		✓	✓
Regional Medical Officers and Ward Managers	2 days		✓	✓

HAU training programs provide an orientation to health workers in palliative care, affording a better understanding and appreciation of palliative care. The objective of this orientation for nurses and doctors is to improve awareness, knowledge and palliative care skills. Another distinct aim is to prepare health professionals for the introduction of the use of oral morphine in the district. This knowledge increases their ability to identify and refer patients in need of palliative care to HAU sites or other centers. Unfortunately, there were several examples cited of health professionals who are unable to practice palliative care because of their workload. In general, palliative care is viewed as a secondary line of care. Some doctors were said to be too busy to start prescribing morphine, while some health care workers were trained before the MS or health center directors—presenting challenges to both patients and management staff. This leaves the CPCNs and CPCOs at odds as they try to introduce palliative services when their superiors are uninformed and perhaps unappreciative of the fact that their subordinates have more information on the topic than they do.

HAU should sensitize hospital administrators and managers in palliative care rather than targeting health workers who directly attend to patients. The hospital administrators and management play a significant role in blessing and supporting palliative care efforts once they appreciate the service.
 —Key informant, Kampala

Some health care workers have successfully overcome the institutional challenges to introducing palliative care. For example, in one district hospital a CPCN was faced with an MS who did not support palliative care.

...we need the health professionals, CVWs, traditional healers, and social workers trained... this is the one weak link [to help] with the CPCNs. These nurses help to mobilize the people to train; they support HAU by training [others]. As well, health professionals go to these nurses for mentorship in terms of clerking patients.
 —Certified palliative care nurse

Through the support of the deputy medical supervisor and the senior principal nursing officer, this nurse was able to continue practicing palliative care and in the end, establish a palliative care team that helped her to administer morphine. In addition, there was some indication of a cascade training effect as exemplified in the text box.

HAU training has provided some health workers with the tools to take an individual initiative to provide palliative care. For example, a physician who had attended a health professionals' course opened a mobile clinic and expanded services by providing lunch and beds for patients to rest. MHM staff noted that an outreach clinic to provide morphine was started by a CPCN who received HAU training. Originally this CPCN used his own time and money to pick up the morphine and was only able to visit a few patients until someone gave him a motorcycle to conduct home visits.

Community volunteer workers: All three HAU sites focus on training CVWs, specifically Hospice CVWs and District community health workers (CHWs), each with distinct roles and relationships with HAU. District CHWs are identified through community leaders and are part of the already existing structures, such as the Volunteer Health Teams (VHT) supported by the MOH or drug distributors. Usually these individuals have already been serving in a volunteer role under government programs or in non-profit organizations operating in their respective communities. HAU then integrates palliative care into their training. Unlike the District CHWs, Hospice CVWs are identified specifically by HAU as individuals who have no previous affiliation to another organization or government program and are trained by LHH to assess pain, identify, and refer patients in need of palliative care to LHH.

Given the preexisting experience and commitment to other organizations of the District CHWs, LHH trains them first—before they select new volunteers to be HAU CVWs who will focus only on palliative care. These CHWs also tend to have expectations in terms of resources such as bicycles, home care kits and cash allowances based on their experiences with their other donor-funded organizations. LHH and MHM could not meet these expectations which warranted selecting new volunteers (CVWs) who are focused only on palliative care and who had no precedent for receiving incentives. The CVW training is a parallel training structure to select volunteers who were independent from all other organization or government activity. These were the hospice-based CVWs that were trained with USAID funding.

MHM and LHH respondents indicate that District CHWs are performing better than the HAU CVWs. This observation was attributed to their years of experience as volunteers, unlike the HAU CVWs who were new to the field of volunteer work. Overall, the HAU CVWs are involved in community mobilization and sensitization for palliative care, mobilizing and organizing patients for community outreach, and community day care. They are instrumental in identifying and referring patients in need of care to HAU sites as well as other palliative care providing centers. In addition, they conduct home visits of patients, thus closing the gap left by the institutional care approach by hospitals and home visits by MHM and LHH.

Spiritual caregivers: Spiritual caregivers are targeted because they are trusted by their followers yet are generally ignorant of their physical symptoms. HAU training enables them to identify patients in pain and to refer them for palliative care. Training spiritual leaders also helps to change their false beliefs that prayer alone is sufficient for healing.

Traditional healers: LHH and MHM target herbalists for training because many patients seek care from traditional healers before (and after) seeking formal health services. Patients are often misled by traditional healers who recommended that they not take drugs. During training, HAU makes an effort to show appreciation to traditional healers for their contribution towards disease management and care. HAU focuses on helping them understand that there are certain conditions that cannot be managed using herbal medicine. It also provides education on recognizing the signs and symptoms of HIV/AIDS and cancer and encourages healers to treat the conditions that can be managed with herbal medicine while referring others for palliative care. LHH and MHM report that training traditional healers and spiritual leaders has improved attitudes toward referring patients to the formal health system. HAU respondents in particular feel that as a result of the training, traditional healers appreciate the limitations of their ability to fully treat all patient illnesses with herbal medicines and have begun to refer patients to HAU.

Comprehensive District Training Program versus Cluster Training Program

HAU initially had a Comprehensive District Training Program (CDP), under which they trained health professionals, CVWs, traditional healers, spiritual caregivers, and allied professionals in a targeted district. The CDP has facilitated outreach to District Health Teams (DHTs) and other health providers to promote and mobilize support for palliative care services. MHM and LHH respondents report that they have greatly appreciated the CDP because it offered a chance to train a large number of agents from different backgrounds. Under the CDP, the CVWs were viewed as an indispensable resource in the identification, referral, and care for palliative care patients. In addition, it was through the CDP that morphine was introduced in the districts.

Following USAID's recommendation, MHM and LHH have been required to drop the CDP and adopt a Cluster Training Program (CTP). It focuses on training professional health workers in PEPFAR-funded AIDS service organizations from a cluster of districts. CVWs, allied professionals, traditional healers, and spiritual healers are not included in the training. In the CTP, health workers are trained for two weeks, one week of which focuses on morphine. According to MHM staff, in a cluster comprising four districts, only 30 health workers from PEPFAR-funded AIDS service organizations would be trained.

Several challenges have arisen under the new system. First, HAU has struggled to develop a follow-up system, since the trained health workers are from different districts. Similar to the CDP, trainees in CTP are expected to register patients during the period of morphine introduction and each to follow-up with the patients served. This assumes that the patients will be from the host district, where the training is held which is not always the case. An unresolved concern is when trainees are matched with patients from a different district which prohibits them from conducting follow-up visits.

The current USAID project funding for HAU eliminated allied personnel and laymen from its training program. Several respondents made the case that nurses need the support of non-health providers to link them with PHA. Allied professionals are viewed as first responders to identify and refer patients before the medical workers. According to many, CVWs in

particular have played a fundamental role in this process, yet this training approach has overlooked them and more generally, their role for referral services. Mildmay sees its core function as improving the quality of life of adults and children living with and affected by HIV through a holistic approach to care. Mildmay's core activities are training and capacity building for care and provision of care, with an emphasis on making courses available for social workers, volunteers, and caregivers. In terms of Mildmay's service delivery, its main approaches are home based and institutional based care.

Objective #4: Assess HAU Approaches and Strategies in Place to Ensure Future Sustainability of its HIV/AIDS Program

HAU respondents were unable to offer a strategy for its HIV/AIDS programs and indicate a dependence on USAID funding. When asked about the prospect of raising local funds to support the HIV/AIDS work, HAU respondents used this to refer to user fees. Both the MHM and LHH require patients to contribute 5,000 Uganda Shillings (about \$2.78 USD) per visit. Yet most patients are unable to afford this contribution, and HAU is unable to deny care as a nonprofit organization. As a result, user fees are unlikely to offer a major source of income for the organization.

In addition, the HAU sites encourage staff members, the general public, and corporations to subscribe as annual members, but according to respondents, this effort has not yielded strong results. Donors are increasingly interested in counter funding from local sources, so HAU has focused on approaching the private sector including Total Uganda (the national gas company), Standard Chartered Bank, Global Trust Bank. HAU has also reached out to local embassies for support. The only outcome to date has been a gift of 24 balls for children from the Dutch Ambassador. HAU's annual report also lists the sale of baked goods as contributing to the funding base. Historically, HAU has enjoyed modest contributions from a variety of donors such as the Diana Fund, Hospice Africa UK, Irish Aid, and others. Certainly having a diversified client base is desirable, yet the total of all the other contributions pale in comparison to the funding levels from USAID. While sustainability has received serious consideration as an issue by HAU's senior management, as yet, it has not yielded any solid plans according to respondents.

There are also concerns about sustainability vis-à-vis HAU's ability to incorporate its services within the government health system. As described above, the relationship between MHM and Mbarara hospital is particularly weak. This is reflected in the training of health professionals in the hospital's palliative care unit and the inconsistent reporting of referrals and visits. MHM's presence in the hospital is barely felt and when visits are made, HAU staff fail to make themselves known to hospital management. It was also observed that MHM staff members viewed its role as one to train health workers while hospital management would be responsible for follow-up. Additionally, both the MHM and LHH have poor working relationships with district health centers, which they use only to organize community outreach. They also do not have palliative care staff coordinating with district health centers. Even when health centers have nurses trained in a health professionals' course, the pace at which palliative care grew was slow, partly because health workers see themselves as performing HAU work and also because they lack institutional support from senior management.

Objective #5: Measure the Extent to which HAU Has Succeeded in Increasing Access to and Utilization of Quality Palliative Care Services

In its proposal to USAID for the first round of funding, HAU described its work in palliative care to be consistent with the WHO holistic approach and to include pain management, control of opportunistic infections, psychosocial and spiritual support and end-of-life care. Specifically, HAU referred to the need to strengthen the affected households and communities through social support interventions. HAU committed to collaborate with income generating agencies, micro-finance, savings and credit and orphans and vulnerable children projects and refer clients and families accordingly. HAU also committed to learn from the other HIV/AIDS organizations such as TASO to improve its capacity to support the bereavement process (e.g., through memory books, support for legal matters) (HAU 2005).

According to HAU annual reports, the number of patients accessing palliative care has steadily risen from 1,088 patients in 2004/5 to 2,396 in 2007/8. As described in further detail below, HAU's greatest achievement has been in pain management, while its progress in the control of symptoms is in need of improvement. Psychological and social support are fragile and disparate components in HAU's service delivery mix.

During the FGDs, many PHA said that people are afraid to receive care from HAU because they did not want to disclose their HIV status. Even when in severe pain, some PHA will not seek palliative care because of the tremendous stigma attached to HIV (see text box). Other barriers to accessing care cited by respondents include a lack of transport and physical abuse from their partners. Yet repeatedly the issue returned to the fear of disclosure.

Procurement of morphine

All districts with CPCNs procure morphine except Mpigi. The district hospitals procure morphine through the DHO, and the referral hospitals procure it directly from the MOH. The HAU imports its own powder, and reconstitutes it, and provides it directly to its service delivery sites. According to respondents, morphine is available in the hospitals with CPCNs except in Nkozi Hospital in Mpigi, and is also available in organizations with particular focus on the pain management as a component of palliative care. There were also reports that at the Nkozi hospital some health workers oriented by the CPCN wrongly administered the medication. There were no reports about abuse of morphine.

In the Jinja referral hospital, morphine is procured directly from the MOH without going through the DHO. The CPCN accounts for the existing supply, which is confirmed by the MS before requesting a re-supply from the MOH. After receipt of MOH clearance, the CPCN picks up the

In response to symptom control:

This is more difficult since we do not have many drugs to substitute for the ones we have [and] once they fail for people vomiting and therefore unable to cope with the available tables, getting a substitute drug combination is not easily possible.

—Palliative care team,
HAU District

new supply from Mulago Hospital in Kampala. There were also no reports of substance abuse due to morphine at this site.

To safeguard against potential abuse of morphine, it is kept under lock and key. Only CPCNs or CPCOs and oriented physicians prescribe morphine; patients are educated about their dosage as determined by the clinician; family caregivers are encouraged to return any unused morphine to HAU or the local CVW.

Apparently, there is a high supply of morphine readily available at the district level most likely due to a lack of demand. Few respondents mentioned ever having a problem obtaining morphine when they needed (see text box).

Treatment of opportunistic infections

HAU has some medication for treating opportunistic infections (OI). However, its OI management services are weak, evidenced by general and vague responses to questions about this service and frequent mentions of the need for referrals. Public health facilities also manage OIs, however there are regular periods when medications are out of stock. Fluconazol, an anti-fungal medicament, is particularly scarce and expensive for patients to procure in the private market.

According to the MS, morphine never runs out, consumption is low, and in common instances, the hospital gives some morphine to Lira regional referral hospital. The MS identified an implication of low consumption of morphine. He noted, 'This indicates that people do not know about the availability of the service and that the institution-based care approach is limiting.'

—HAU representative

Psychosocial needs

According to respondents, a weakness of HAU is inadequate counseling to meet the psychological needs of PHA. HAU respondents adopted a broad definition of psychosocial needs with more emphasis on the social component. Through the comfort fund, HAU has provided some nutritional support, transportation, and coverage of clinical investigation costs. While counseling is provided on an ad hoc basis, it is often done so by staff with minimal training. The comfort fund is 5,000 Uganda Schillings (about \$2.50 USD) and modest food staples offered to the poorest of the poor. There is one trained social worker at HAU headquarters. Overall, HAU's psychosocial component is still weak and there is much that needs to be addressed.

Compared to HAU, TASO was found to have a stronger psychosocial component, including activities and projects for patients. As noted earlier, each hospital where TASO works has approximately 20 social workers on staff. School fees support for children of PHA was also provided. Lastly, TASO was instrumental in succession planning.

Spiritual care

Through counseling and training spiritual caregivers, HAU feels it is able to reach the spiritual needs of patients. In hospitals, HAU facilitates fellowship and brings patients together to pray for others. Some religious leaders of different faiths visit the hospitals to pray with patients in the wards. TASO offers a “morning glory” service during clinic days and it addresses spiritual needs through counseling. Mildmay provides religious services through its church.

End-of-life care

Probably the weakest service provided by HAU is its end-of-life care. HAU does not address the memory book or will writing, income generating activity support to patients, or linking children to sources of support for education. However, HAU does provide monetary support to bereaving family members. Staff sporadically visits bereaved families during the patient’s last days of life, although there is no follow-up with families after the patient’s death, and there is no support available to dependent children such as school fees. PHA

There is stigma. For example, one time we went for a home visit and the patient said the more MHM vehicles seen [near his home] the more likely the [community] would say he has AIDS. With this labeling, there comes the associated treatment people have towards AIDS patients. Cancer is more socially and culturally acceptable than AIDS. Cancer patients are more likely to win sympathy whereas, for AIDS patients, they are judged.

—Palliative care team

respondents underscored the issue of unemployment and expressed a desire for income generating activities to alleviate their financial burden.

Two HAU sites reported having guidelines for will making, but CVWs and patients reported a lack of knowledge about will making and memory book writing.

While respondents noted that succession planning had been instrumental years earlier at LHH, will making and memory book writing activities are no longer in practice. Patients suggested that LHH not only reinstate such activities, but also guide patients to plan for their children’s future. They also underscored the need for LHH to participate in advocacy at the national level to increase both awareness of the children’s future needs and to provide incentives for government programs that provide benefits to PHA. Several respondents mentioned that TASO provides much better end-of life-care especially in terms of succession planning.

Despite the limitations of its services, HAU’s work is considered in high regard by many respondents, particularly in terms of its quality of care. HAU satisfies many groups: patients, CVWs, MSs and DHOs, to name a few. Palliative care in hospitals is also appreciated by patients receiving such care, particularly in terms of pain management. Those benefiting from the HAU comfort fund also expressed satisfaction. In general, PHA were satisfied with the nature of care and support provided. Many receive food support, transportation, and money to meet the basic necessities of life in addition to morphine or other drugs. PHA expressed tremendous gratitude for access to morphine, which alleviates the pain associated with many health problems such as meningitis, herpes zoster, Candida, and Kaposi’s Sarcoma. One

recurring issue that did arise was the need for HAU to assist with children's school fees. In this regard, HAU's role was limited to providing PHA and their families with information on where they could obtain such resources. It was not within HAU's mandate to provide this direct service.

In sum, HAU is stronger in some components of palliative care than others. This may be a matter of priorities and resources. HAU respondents clearly recognized its challenges and shortcomings with some notable exceptions, namely the relevance of a functional M&E system, the importance of making a concerted effort to raise awareness of HAU services, and the significance of a sustainability plan.

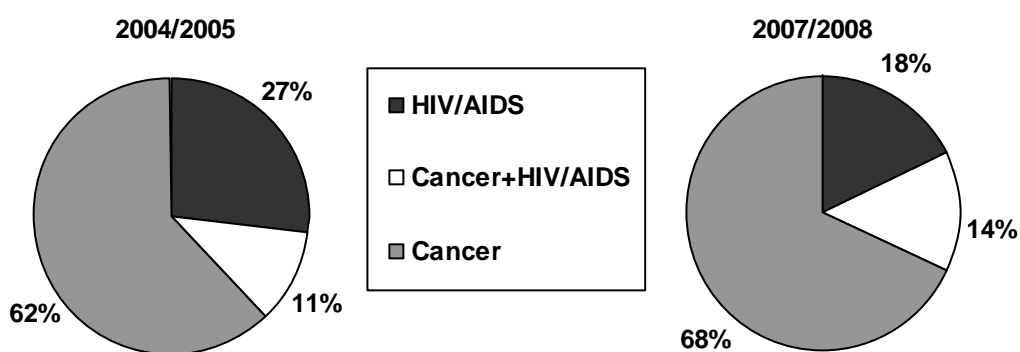
The challenge cited is that many people do not know what HAU is doing and many do not know what palliative care is. They think hospice is a place for dying. The middle and high class people are the most resistant to come to HAU, these [people] suffer a lot of self stigma attributed to late diagnosis and thus delayed seeking of the treatment.

Discussion

An important paradigm shift for HAU brought on by the onset of PEPFAR funding, has been an increased focus on targeting PHA. Unlike TASO and Mildmay, HAU is a palliative care organization and has been less preoccupied with the diagnosis of the patients it serves and more concerned with alleviating pain. In 2004/05, 73 percent of all HAU patients had cancer and among them, 15 percent were HIV-positive. Similarly, in 2007/08, 82 percent of all HAU patients had cancer of which 17 percent had HIV/AIDS. Figure 4 provides the breakdown HAU patients by diagnosis. Noteworthy is that only 38 percent and 32 percent of HAU patients in 2004/5 and 2007/8, respectively, were PHA. The data presented herein show the majority of HAU patients continue to be cancer patients, and in fact the total number of patients with HIV/AIDS is dropping. These results were submitted to the evaluation team after the data interpretation meeting in March 2009 in response to the data presented in Annex G of this report. HAU noted that these are the correct figures, not the data as presented in Annex G originally. After much scrutiny, the evaluators could not reconcile the data presented in Annex G and forewent presenting these figures because they appear to be unreliable.

Assuming that the figures presented in Figure 4 below are correct, a broader question is whether HAU's patient population represents the relative breakdown between these three diagnostic groups in the general population or if HAU has a tendency to serve cancer patients more often than HIV/AIDS patients given their history of working with cancer patients exclusively in the past. Alternatively, cancer patients might be more likely to need palliative care than HIV/AIDS patients on ARVs, for example. The fact that HAU focuses primarily on pain management might also influence its patient population. It is difficult to measure at what point ill patients seek palliative care during the course of their disease, be it HIV/AIDS, cancer, or both.

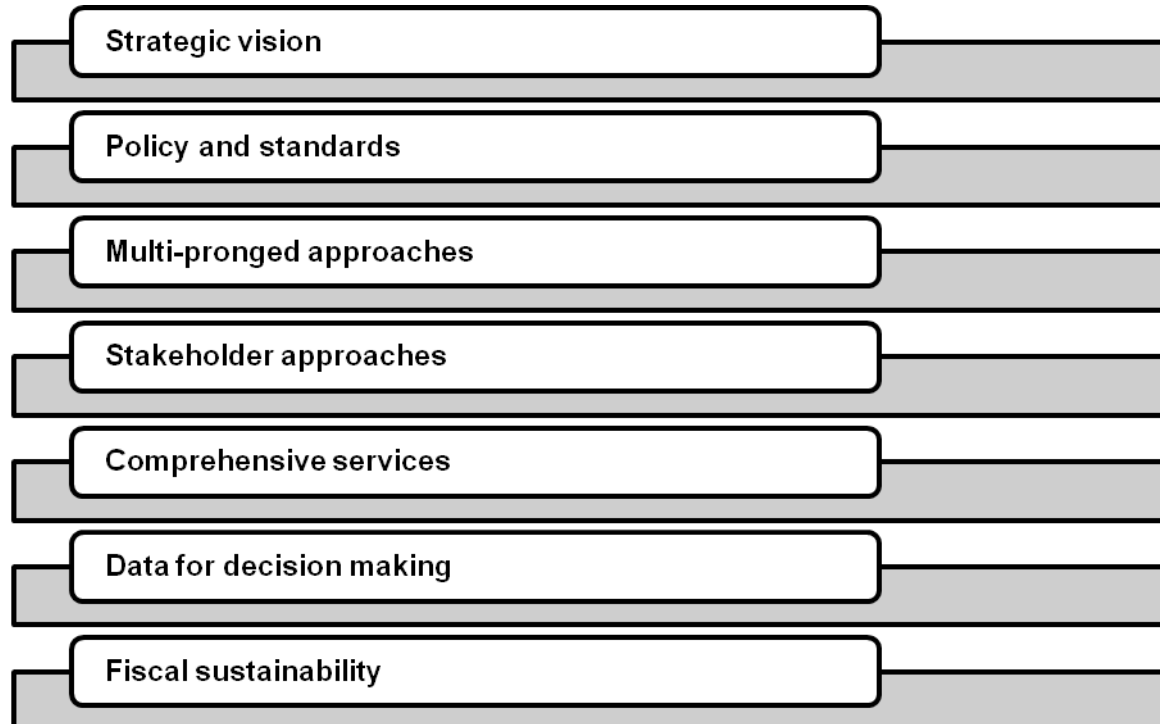
Figure 4 Distribution of HAU patients by diagnosis



To provide palliative care as a sub-component of PHA care and support, several features need to be in place and in balance. Figure 5 delineates the essential elements that, collectively, foster an environment for comprehensive palliative care. To a large extent, it is arguable that these are the same elements needed to provide care and support for PHA. This discussion will

analyze these building blocks of palliative care and comment on to what degree, HAU as an organization is addressing them vis-à-vis the primary AIDS organizations and hospices.

Figure 5 Holistic palliative care



Strategic Vision

HAU is staffed by committed people who have a desire to help each and every one of their patients. In-depth interviews with several of the key leadership figures in HAU reveal a strong sense of commitment to their mission. Less apparent is their collective vision and further, how a common vision could be created. In other words, HAU appears as medley of committed professionals all striving toward the goal of alleviating pain and suffering of their existing patients. But the pathway to reach that goal has been oversimplified and does not cover all that is needed to institutionalize and provide comprehensive palliative care to those who need it. Specifically, HAU's approach is to touch one patient at a time with an emphasis on pain management. In the absence of a clear vision, an action plan to realize the vision, and data to verify its progress, HAU will limit its ability to adequately manage large sums of donor funding. HAU needs to grapple with its view for the future: how prepared is HAU to move toward becoming a standard major NGO with the essential elements illustrated in Figure 5. The following discussion attempts to answer this question.

Policy and Standards

Despite the great many successes, palliative care is still in its infancy and underdeveloped in Uganda. After 16 years of palliative care in Uganda, it is yet to be treated as medical discipline. The demand, however, is far in excess of what is available, while the geographic coverage for palliative care services is limited—an estimated 22 percent sub-country coverage in 40 districts (Uganda AIDS Commission 2005). Rural areas, in particular, tend to be underserved. In these areas, the burden of care falls heavily on households, especially women and girls. HAU has attempted to increase coverage in villages surrounding urban areas through their outreach modalities and the introduction of training of spiritual caregivers in the villages. HAU intends to continue this strategy. However, very few HIV/AIDS clinical or home-based care providers have yet had any training to deliver palliative care.

The MOH has embraced palliative care as evidenced by its incorporation of palliative care into the minimum health care package, passage of a 2004 decree allowing CPCNs and CPCOs to prescribe and dispense morphine in the home, and by providing an adequate supply of morphine to the districts. Also, the MOH frequently pays for its nurses and medical officers to attend HAU's nine month certification program. However, though the MOH requires all hospitals to have palliative care units instituted, MSs do not always support this. Thus, the MOH has laid the groundwork for a supportive policy environment for palliative care services.

The major HIV/AIDS organizations in Uganda respect HAU's expertise in the realm of pain management. There is no doubt that HAU is doing a fine job of training health workers to manage pain in an array of settings ranging from home to hospital. A testament to this is the many referrals to HAU from TASO and Mildmay to assist their patients with pain management. As well, the MOH only entrusts HAU to purchase and reconstitute morphine outside of hospitals. Further, without pain control, the other components of palliative care are difficult to fully address. Thus, HAU has prioritized the most important component.

The bigger question is HAU's role vis-à-vis policy and standards. Evaluation results indicate that few respondents are aware of palliative care standards, and many are using job aids for assessing and controlling pain. HAU service provision does not point to an understanding of comprehensive palliative care as reflected in international standards. This does not imply that HAU's services are inconsistent with international standards but rather that it lacks a theoretical foundation as a point of reference. HAU serves as a technical arm of the MOH. It is primarily a service delivery and training organization and should not be in the position of regulating standards. This would introduce a conflict of interest since HAU, along with the other providers of palliative care, should be accountable to the national standards of palliative care, once released. Notwithstanding, HAU has an important advisory role in the implementation and application of the new Ugandan standards given its historical influence over policy development.

Multi-pronged Approaches

HAU is lauded for its multi-pronged approaches to reach patients. It offers care from hospital to home and in-between, which is particularly remarkable given HAU's limited resources.

TASO, by comparison, offers a range of services but has the resources to maintain a strong institutional presence in all referral hospitals and is fortified with trained social workers with motorbikes to make home visits. An unintentional consequence is awareness building of palliative care. In part, the absence of a concerted effort to raise such awareness has likely contributed to HAU screening more HIV/AIDS patients than necessary, which taxes its limited fiscal resources. Many PHA are seeking care from HAU because they mistakenly believe it to be a comprehensive HIV/AIDS organization offering a range of services from care to treatment. Since HAU does little to promote its services, it does not counter this misinterpretation.

In terms of implementation of palliative care services, there are diverse foci. HAU focuses on pain management and comfort and emotional support. By comparison, TASO and Mildmay operate under a much broader PEPFAR definition of palliative care, although some respondents suggest they are not doing all they could for pain management. TASO and Mildmay have a different approach, focusing on administering ARVs and treating of opportunistic infections at the expense of pain control. These two HIV/AIDS organizations defer to HAU to treat their patients with intractable pain.

Stakeholder Approaches

HAU is a well-known and appreciated entity in Uganda. It represents the gold standard for care and comfort of patients at the end of their lifetime. HAU's focus is squarely on providing high quality comfort and care from the time patients initially are referred or identified until their death. Because it has limited resources, it lacks motivation to stimulate demand, fully knowing that they might not be able to provide their full attention to the patient's needs. All aspects of comprehensive care are catered for, but there is an element of poor documentation. Because HAU views itself as distinct from the other HIV/AIDS organizations, it has trouble seeking collaboration beyond accepting referrals for pain management and making referrals for clinical care and ARTs. This collaboration could go much further. For example, TASO and Mildmay have much to learn from HAU on pain management and the differentiation between symptom control and pain control. Similarly, TASO is reportedly doing more in terms of end-of-life preparation from a psychosocial perspective than HAU is prepared to handle. HAU views end-of-life care in terms of physical comfort and TASO views it more as preparing the family to carry on after the death of their loved one.

Referring back to one of HAU's project objectives—build functional networks linking families, communities, health facilities and civil society organizations to enhance easy access to palliative care services—it appears that PCAU has subsumed this role. PCAU's work with district governments to integrate palliative care as a routine part of service delivery is an important role for them to play, much more so than HAU. Yet, the fact that HAU's work is not fully integrated into the MOH health system needs to be redressed.

Comprehensive Services

HAU and many other respondents argue that one cannot begin to address the other components of palliative care until a patient's pain is under control. TASO and Mildmay on the other hand, offer a broader array of palliative care but refer their patients in pain to HAU for treatment. In other words, none of the hospices or palliative care teams in Uganda are providing comprehensive palliative care. This, however, should not necessarily be construed as a poor practice, as long as these organizations can offer complementary services via one, integrated, MOH system. While the TASO program is integrated into all the MOH referral hospitals and works with MOH staff directly, HAU is working outside of the system. HAU still maintains strong relationship with the government but has much less influence on the system as a whole. HAU has had a policy influence on the Ministry of Health. Statutes have been amended because of HAU's influence, specifically, a 2004 policy that allows CPCNs and CPCOs to prescribe administration of oral morphine.

Data for Decision Making

HAU management has made progress during the past two years in tracking crude numbers of patients, including HIV/AIDS patients versus cancer patients. However, HAU is not tracking outcome indicators such as the percentage of patients who have their symptoms controlled. It is not utilizing the M&E system developed through USAID's ACE project to its optimal potential, nor is it using the results of its M&E system to inform decision making.

One of HAU's institutional strengths is its training programs. In the absence of a functioning M&E system, it is difficult to empirically assess the effectiveness of these training programs. Knowing the types of courses and number of participants is not enough to evaluate whether the courses were of adequate quality or whether the participants used the skills after training. For example, there is some evidence, as described previously, that training participants do not necessarily utilize their training when they return to their respective institutions. There are a host of potential reasons for this, such as inappropriate participant selection criteria, a lack of sensitization and/or involvement of senior management in hospitals or clinics for them to appreciate the role of the trained palliative care health worker, or poor quality of the training. Instituting needs assessments and systematic follow-up and reporting on trainees post-training would provide data to identify problems and strengthen the training program according.

And while HAU views CVWs as one of the essential approaches, monitoring data on CVWs is sketchy and often not collected. Data on patient referrals from CVWs, for example, would have been vital as evidence for the argument to have USAID fund this program component.

Fiscal Sustainability

The area of most concern identified by the evaluation is HAU's future sustainability. HAU senior management is pleased that they are transitioned from being primarily a "membership organization" to a "professional organization," as they put it.

HAU managers did not offer any sense that they were concerned with HAU's strategic vision or future sustainability. Instead, each respondent described a series of interventions and anecdotal results but was unable to formulate the "whole" of the organization. In effect, HAU lacks a systematic approach to control its future direction. A case in point is its lack of a proactive response to USAID's decision not to fund the community volunteers. HAU's perception of local support is limited HAU is not thinking "big" in terms of fiscal management and longevity. In addition, HAU has quite a large staff compared to the number of beneficiaries served and narrow range of services provided.

Conclusions and Recommendations

As a major donor, USAID/Uganda is positioned to help the MOH further develop its palliative care agenda, and more broadly, to share the Uganda experience throughout the region. Based on the findings of this end-of-project evaluation, the QED offers the following conclusions and recommendations. Unless otherwise specified, the recommendations pertain directly to USAID.

Objective #1: Review HAU Approaches and Strategies to Deliver Services and Track Coverage

Conclusions

HAU has a clear mission but lacks strategic vision.

HAU comprises a committed group of professionals with a common mission to provide care and comfort. Yet, as an organization, it lacks a common vision and strategic plan to execute that mission. HAU is not poised to be an HIV/AIDS care and support organization. It is clearly a palliative care organization, which, by virtue of receiving PEPFAR funds, needs to specifically target PHA as beneficiaries.

HAU delivers high quality palliative care services but of a limited scope.

HAU concentrates on providing in-depth pain management. It views its palliative care program as a model and has received regional and international attention for it. However, its services are narrowly focused on pain management and to a much lesser degree, psychological and spiritual support. HAU's end-of-life support is incomplete, especially in terms of preparing the patient's family for life after he/she passes on. Symptom control is also erratic and not a priority. Finally, HAU does not adequately address end-of-life needs such as succession planning, will making, and recording in memory books.

HAU has limited coverage of PHA.

HAU's priority is delivering high quality services to its existing patient population; it is much less interested in expanding coverage. It is reluctant to generate demand for its services in light of limited resources and its priority to provide an intense level of care for each patient.

HAU is in a nascent stage of tracking coverage.

HAU is on a positive, albeit slow, path to report results on program outputs. HAU does not currently track outcome variables. HAU also does not use data for decision making in a formalized way, precluding it from making mid-stream program corrections based on evidence or from reporting on outcomes to USAID.

Recommendations

Develop HAU's institutional capacity.

USAID should continue to provide capacity building support with a focus on strategic planning, program management, and monitoring and evaluation, with an emphasis on linkages between the three. The simplest approach would be to develop HAU's capacity as a training center and a service delivery organization narrowly focused on pain management and end-of-life support. HAU will need technical assistance to develop its end-of-life support services. The team does not recommend encouraging HAU to move beyond this package of services during the life of the current five-year project (e.g., expanding their HIV/AIDS services to include VCT).

Develop and support palliative care teams within the existing USAID/TASO HIV/AIDS program in the referral hospitals.

USAID should continue to utilize HAU to train health workers and to place them in the 11 referral hospitals in Uganda. USAID could also consider supporting an HAU employee to be based in each of the palliative care teams to serve as a resource and liaison with HAU. This would strengthen the collaboration between HAU and TASO and foster a sustainable program that could be eventually assumed by the MOH. The Mulago Hospital PCT could serve as a model to adapt to the district hospital settings. PCAU's work to sensitize district governments to palliative care is an intervention worthy of donor funding because it will support the formation of palliative care teams. USAID should consider funding PCAU to scale up this program which will support the greater palliative care efforts.

Encourage the MOH to establish a palliative care desk.

The MOH should take a stronger leadership and supportive role in palliative care. At a minimum, a palliative care desk could be supported by a couple of HAU-trained nurses and medical officers who could respond to the needs and concerns of palliative care staff in the field.

Conduct a mid-term evaluation of HAU's current project.

USAID should consider conducting a mid-term assessment of HAU's current project with a focus on indicator progress. The study should have a strong quantitative component to determine the effectiveness of HAU's interventions. USAID should not rely on HAU to provide the empirical evidence needed to assess its progress.

Objective #2: Compare HAU Approaches to International Standards of Care

Conclusions

There is general confusion between standards of care and job aides among HAU staff.

Few HAU managers and staff understand the role of standards of care, equating them with guidelines and/or job aides for pain management.

There is a need to regulate compliance with palliative care standards.

HAU has a long history and solid reputation in Uganda. It is well respected by the MOH and HIV/AIDS organizations for its role as a trainer and in providing pain management services. Even so, HAU would not be an appropriate choice for the supervisory body of the MOH's palliative care programming efforts. Aside from an inherent conflict of interest it does not provide comprehensive palliative care. USAID should fund PCAU to disseminate the Ugandan palliative care standards. USAID should work with the MOH to prepare PCAU to become the regulatory body in charge of ensuring compliance with palliative care standards by the respective service delivery organizations.

HAU is establishing itself as a regional resource for palliative care training.

HAU and the provision of palliative care in Uganda as a whole have received considerable attention within the region and from international experts.

Recommendations

Support the dissemination of the Ugandan standards for palliative care.

After the Ugandan standards for palliative care are finalized, PCAU likely will need support to develop a communication and dissemination plan. Funding for PCAU should be considered to support its mandate with a specific emphasis on raising awareness of and adherence to palliative care standards.

Advocate for PCAU as the regulatory arm of MOH policies and standards.

As an independent, non-implementing body, PCAU is in a neutral position to assess and advise the government on palliative care programming.

Support PCAU in the dissemination of APCA's "Clinical Guide to Supportive and Palliative Care for HIV/AIDS in sub-Saharan Africa", published in 2006.

These guidelines provide the most relevant information for HAU to develop standards that Uganda can use country-wide.

Support PCAU to disseminate Uganda's best practices in palliative care throughout the Africa region.

PCAU's close collaboration with APCA should be supported to continue their symbiotic relationship. In this way, Uganda's best practices and lessons learned could be shared throughout the Africa region. The Uganda experience should reflect the work of HAU, TASO, and Mildmay. The timing for this recommendation might best be in a few years—after USAID gleans more experience working with HAU and palliative care.

Objective #3: Examine HAU's Education Program and How it Has Increased the Availability of Palliative Care Services to PHA and their Families

Conclusions

The role of the palliative care nurse is not recognized in the formal MOH structure.

There is no MOH job category for a palliative care nurse or medical officer. Trained palliative care providers in public health facilities face a challenging work load. After palliative care training, CPCNs and CPCOs return to their original jobs to carry out work as they did before. They are expected to fulfill their obligations in their respective health units and to add palliative care as a secondary activity. Yet their role in palliative care is not recognized or appreciated by medical superintendents.

At the time of recruitment for training participants, there is little consideration for deployment and the role of palliative care.

Training needs assessments are not conducted in any systematic fashion, and there are no apparent selection criteria for HAU trainees. The MOH funds many of the participants and therefore decides who shall be trained. HAU does not appear to play a large role in the decision making process. Further, the MOH transfers trained providers irrespective of their capacity to provide palliative care. Oft times, these transfers work against the palliative care efforts initiatives of the trained workers. The end result is that certified nurses and medical officers are neither encouraged nor allowed to practice their newly acquired palliative care skills.

Mentoring, supportive supervision, and follow-up for trained palliative care health workers are non-existent.

HAU's involvement stops after training. CPCNs in health centers do not have senior palliative care providers to offer them mentorship or supervision. Therefore they look to HAU to provide this support, but it is not fulfilling this niche.

HAU's training of spiritual caregivers and traditional healers is an important step to bridge the gap between Western medicine and local practices.

Targeting such influential leaders will contribute to the spiritual component of palliative care.

Recommendations

Establish selection criteria for training participants based on needs assessments.

HAU, with guidance from PCAU, should develop selection criteria for training participants that take into consideration: 1) DHO and MS commitment to palliative care; 2) a minimum set of prerequisite qualifications of the participant; 3) the level of demand for palliative care services based on health statistics; 4) the availability of a support network that would facilitate palliative care services (e.g., for supervision, mentoring, liaisons with AIDS organizations, FBOs, legal services); 5) the supply of trained palliative care providers in the region.

Establish palliative care champions in MOH health facilities.

HAU should prepare a curriculum tailored for experienced CPCNs and CPCOs who can supervise and support other health providers. These change agents should be based in the regional referral hospitals. Their purpose would be to sensitize health facility staff on the integration of palliative care into routine clinical care. This model would work best if the change agents were HAU staff who could: 1) mobilize and supervise other trained health workers; 2) provide in-service training on palliative care to reach a larger group of health workers; 3) rally the palliative care team in-house. More importantly, establishment of palliative care champions in the MOH health facilities can be possible once the ministry recognizes the CPCNs.

HAU should receive support to continue and strengthen its training program for spiritual caregivers and traditional healers.

This would align well with the international standards of palliative care, in terms of ensuring the complete wellbeing of patients. Also, if their input is captured in the project M&E system, it would contribute to HAU's understanding of the population of PHA with an unmet need for palliative care.

Objective #4: Assess HAU Approaches and Strategies in Place to Ensure Future Sustainability of its HIV/AIDS Program

Conclusions

HAU has no systematic plan for either augmenting or spreading its services across the country.

There appears to be no HAU national network, but rather numerous affiliated partners throughout the nation. While there are trained HAU nurses and clinical officers, they are not recognized within the existing health care system, creating difficulty for HAU scale-up. The trained health workers have been re-deployed but left with inadequate support to implement palliative care. HAU realizes that this is not an ideal approach but feels constrained by lack of resources.

HAU lacks business savvy.

HAU does not focus on fundraising in a strategic way. Its approach to new business development is similar to its approach to service delivery: small, sporadic efforts without a broad plan of action. HAU has been reactive rather than proactive in seeking new clients and opportunities, and is not marketing its many strengths. HAU has quickly become dependent upon USAID funding.

Recommendations

Establish palliative care centers for excellence.

HAU should develop a memorandum of understanding with the MOH to establish centers of excellence for palliative care in all referral hospitals. Such centers should provide mentoring services and be used as a central location for home-based care. Given the cost of each home

visit, such centers would allow for better coordination among the organizations providing home-based care.

Support HAU to develop and implement a business plan.

HAU's first task would be to clearly delineate its vision and state its organizational goal and objectives. To help facilitate this process, HAU should consider hiring a local business development manager with experience in growing international NGOs. This expert would help HAU study the donor community and market HAU as a leader in palliative care and related training. This fits with HAU's model to move away from being a "member organization" and towards a "professional organization." Given its plethora of human resources but limited financial resources, HAU should also consider eliminating duplicative positions and/or replacing some positions to allow for new staff with organizational development skills.

Objective #5: Measure the Extent to which HAU Has Succeeded in Increasing Access to and Utilization of Quality Palliative Care Services

Conclusions

End-of-life care is a weak component of palliative care in HAU.

HAU largely downplays the significance of this component. HAU respondents merge their definition of pain management to overlap with end-of-life care. The components of end-of-life care are more far reaching and include psycho-social needs (i.e., memory books) and succession planning as interpreted by TASO.

Awareness of palliative care services is not widespread.

Little has been done by HAU or other organizations to sensitize the general population about the palliative care services. HAU does not prioritize building demand for services because it feels its resources are stretched.

Trained health workers in public health facilities perceive palliative care as an added burden that lacks institutional support.

CPCNs and CPCOs, faced with fulfilling their "regular" job first, find it challenging to carve out extra time to provide palliative care. This results from a lack of a systematic approach to implement palliative care services in a way that all stakeholders are made aware of the need for such services, personnel are supported by the MOH, and coordination and collaboration among stakeholders is facilitated.

Recommendations

Keep the service delivery agenda for HAU focused on its strengths.

The evaluation team agrees with USAID's current strategy to fund HAU for training in palliative care and provision of palliative care services. However, it is not advisable to expect it to provide a wider range of care services until it can demonstrate good program

management of the services it currently provides. Adding more services might interfere with HAU's ability to monitor, use, and report the results of its current work.

Establish strong networks between palliative care providers and support organizations.

Such relationships can fill HAU's existing gaps in service delivery, such as financial support for PHA's children's education, food, and other needs, along with succession planning, will making, and other social and end-of-life services that require specialized skill sets or additional resources. However, given HAU's direct access to PHA in the home, it should make an effort to increase awareness and facilitate linkages of other programs that can meet these needs for PHA and their families.

Decision makers from USAID should visit HAU, meet the patients, and attend a few outreach programs if they are to appreciate HAU's objectives. A closer interaction between HAU and USAID, especially when making decisions, is something that HAU longs for.

—HAU respondent

Summary

Five key, interrelated issues must be considered to fund and implement HIV end-of-life and palliative care in sub-Saharan Africa. These include: 1) pain control as a primary challenge; 2) the balance between quality of care and numbers of individuals served—especially when programs expand; 3) the need for technical assistance in monitoring and evaluation; 4) effective collaboration between funders, NGOs, providers, and in-country governmental agencies; 5) use of resources to promote understanding of and support for palliative care in order to sustain or improve current activities (Harding 2003). When viewing HAU through Harding's lens, it is clear that it has addressed the first issue of pain control but the other four issues are growth opportunities. HAU is on a steep learning curve as a relatively new recipient of USAID funding. Nonetheless, HAU is filling an important niche that no other group fills in Uganda.

Uganda has all the pieces to provide comprehensive palliative care, and USAID can help the MOH facilitate the assembly of these contributions into a unified whole. This is a realistic goal and once achieved, Uganda promises to be a showcase for palliative care in Sub-Saharan Africa, and possibly the worldwide HIV/AIDS community.

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Annexes

Annex A: Scotland's Palliative Care Standards

The following standards were developed by The Clinical Standards Board of Scotland, Council of Palliative Care (2002):

Informing and Deciding

Standard 1 You can make a positive and informed decision about using the hospice services, helped by the quality and accuracy of the information you receive.

Standard 2 You receive services that respond to your needs and preferences. You are involved in decisions about your own care, through effective two-way communication and sharing of information.

Standard 3 You can be confident that your legal and human rights will be protected and that the service is managed in line with all applicable legal requirements.

Standard 4 You feel safe and comfortable in the hospice and can be confident that your right to privacy is protected.

Quality of Care and Treatment

Standard 5 You receive high quality, safe, supportive, and effective care and treatment based on available up-to-date evidence.

Standard 6 You can be confident that your care will be provided by a multi-professional team of staff and volunteers who are suitably qualified and/or skilled for the job.

Infection Control

Standard 7 You are protected from contracting preventable infections while in the hospice. If you are admitted with an infection, you receive appropriate care.

Medicines

Standard 8 Medication forms a significant part of controlling your symptoms. The hospice will manage your medication to maximize the benefit and minimize the harm.

Equipment for Therapeutic and Monitoring Purposes

Standard 9 You can be confident that any equipment needed to support your care will be available. There will be appropriate provision, maintenance, repair, and use of equipment suitable for patients with palliative care needs.

Care of Children

Standard 10 You can be confident that the rights of sick children will be respected and protected.

Living with Illness

Standard 11 You receive support from the hospice in your illness and are helped to continue to get the most out of life.

Well-being

Standard 12 You feel respected as an individual and all your needs are recognized.

Personal Life

Standard 13 You are supported to achieve the right balance for you between privacy and companionship.

Daily Life

Standard 14 You feel comfortable and at ease in your care environment, with the pattern of your daily care routine reflecting your chosen lifestyle.

Play, Education, and Leisure

Standard 15 You can be confident that play, education, and leisure are recognized as being a vital part of children's daily lives.

Keeping in Touch

Standard 16 You receive support to stay involved with the people and organizations which are important to you.

Enjoying Food

Standard 17 You are supported to enjoy your food, and are offered a choice and variety which respects your ethnic, cultural, and dietary requirements.

Caring for those Important to You

Standard 18 You know that the hospice will support your family and carers.

Support and Care for You as a Family

Standard 19 You know that a children's hospice recognizes the special needs of yourselves and the well children in the family.

Planning Your Discharge

Standard 20 Your discharge from the hospice will be a smooth transition to ongoing care. The hospice has comprehensive procedures for planning your discharge in partnership with yourself and others involved.

Advocacy, Comments, Concerns, and Complaints

Standard 21 You can be confident that the hospice will welcome your views on services, so that it can continuously improve the quality of its care. If you feel unable to voice your views, you will receive support from a representative of your choice.

Annex B: Australian Standards for Palliative Care

The following standards were developed by The Council of Palliative Care Australia (PCA) (May 2005):

1. Care, decision-making and care planning are each based on a respect for the uniqueness of the patient, their caregiver/s and family. The patients, their caregiver/s and families' needs and wishes are acknowledged and guide decision-making and care planning.
2. The holistic needs of the patients, their caregiver/s and family, are acknowledged in the assessment and care planning processes, and strategies are developed to address those needs, in line with their wishes.
3. Ongoing and comprehensive assessment and care planning are undertaken to meet the needs and wishes of the patient, their caregiver/s and family.
4. Care is coordinated to minimize the burden on patient, their caregiver/s and family.
5. The primary caregiver/s is provided with information, support, and guidance about their role according to their needs and wishes.
6. The unique needs of dying patients are considered, their comfort maximized and their dignity preserved.
7. The service has an appropriate philosophy, values, culture, structure, and environment for the provision of competent and compassionate palliative care.
8. Formal mechanisms are in place to ensure that the patient, their caregiver/s and family have access to bereavement care, information, and support services.
9. Community capacity to respond to the needs of people who have a life-limiting illness, their caregiver/s and family is built through effective collaboration and partnerships.
10. Access to palliative care is available for all people based on clinical need and is independent of diagnosis, age, cultural background or geography.
11. The service committed to quality improvement and research in clinical and management practices.
12. Staff and volunteers are appropriately qualified for the level of service offered and demonstrate ongoing participation in continuing professional development.

Annex C: Site Selection Criteria for Districts

Selection criteria	District sites							
	Kampala	Hoima	Mbarara	Lira	Mpigi	Jinja	Nakason-Gola	Apac
Range of services								
Independent hospice	HAU Makindye House	HAU Little Hospice	HAU Mobile Hospice Mbarara			Rays of Hope Hospice (FBO)	--	--
Hospital/Nurse CPCC team	Mulago Hospital	Regional Referral Hospital	--	Regional Referral Hospital	Nkozi Hospital (FBO)	Regional Referral Hospital	--	--
Palliative care services with morphine	X	X	X	X		X	--	--
Certified palliative care nurses/Medical officers	X	X	X	X	X	X	--	--
Regional coverage								
Northern				X				X
Central	X				X		X	
Eastern						X		
Western		X	X					
Access to resources: Urban, peri-urban, rural								
Urban	X	X		X				
Peri-urban					X			
Rural			X			X	X	X
Comparison groups								
Other hospice services (Mildmay & TASO)	TASO Mildmay		TASO Mildmay	TASO Mildmay		TASO Mildmay		
No HAU services							X	X

Annex D: Interview Log

Response rates for in-depth interviews and focus group discussions in districts

District Response rate = # interviews completed / # interviews anticipated	In-depth interviews					FGDs	
	DHO 87.5%	Medical Superintendents 87.5%	Hospice Staff or Palliative Care Team (hospital-based) 100%	Certified Palliative Care Nurse/Certified Palliative Care Officer 100%	PHA Rep 57.1%	PHA Receiving Care 62.5%	-CVW (HAU) or -CHW (other hospices) or -VHT (MOH) 71.4%
Kampala 71.4%	Respondent missed interview appointment	Respondent missed interview appointment	yes	yes	yes	yes	yes
Hoima 85.7%	yes	yes	yes	yes	PHA Rep could not be contacted	yes	yes
Mbarara 85.7%	yes	yes	yes	Yes: CPCN interviewed with MHM management	yes	yes	No CVWs available within vicinity
Lira 85.7%	yes	yes	yes	yes	PHA Rep could not be contacted	yes	Yes
Mpigi 42.9%	yes	yes	Nkozi Hospital did not have PCT	yes	PHA Rep Network could not be contacted	Respondents not available	Dates for Jinja fieldwork due
Jinja 100%	yes	yes	yes	yes	yes	yes	Yes
Nakasongola 28.6%	yes	yes	No interview expected	No interview expected	No PHA networks identified	Interviewers did not arrange interview	Interviewers did not arrange interview
Apac 71.4%	yes	yes	yes	No interview expected	yes	Respondents not available	yes

Annex E: In-Depth Interview Guide

Hello, my name is _____. My colleague is _____. We are part of a team from the QED Group that is carrying out an evaluation for Hospice Africa Uganda. The QED Group is a company based in the United States. We are funded by the United States government (USAID) to conduct an evaluation of Hospice Africa Uganda. This study is being conducted in collaboration with other partners including the Ministry of Health and the Palliative Care Association of Uganda.

We are seeking your consent to discuss palliative care. If you agree to participate in this discussion, it will last about one hour. All the information that you will provide to us will be kept confidential and will be used for reporting and planning purposes only. Even then, any other information that can be directly linked to you will not be used. We are not asking for your name or any other personal information that might reveal your identity to others.

The information that you will share with us will help Hospice Africa Uganda and its partners to improve their programs so they can better provide palliative care services in Uganda. Please feel free to share with us any suggestions and recommendations that you may have. The information that you provide to us will not be used against you in any way.

Please let me know if you have any objection to participating in this interview and also if you have any questions before we start. If you don't mind, we will ask you to allow us to tape-record the discussion so that we can be able to remember all your points when we get back. Thank you very much.

Signed by Interviewer: _____

FOR OFFICIAL USE ONLY

Interview date: ____/____/____ Unique

Identifier: _____

Interviewer: _____ Note-taker:

Interview venue: _____ Language used:

Time started: _____ Time ended: _____

Type of Respondent Type (circle one): HAU Program Director Hospice or PC Management

CPCN or CPCO District Health Teams Medical Superintendent

PHA Network Rep Health Provider (doctor, clinical officer, nurse)

IN-DEPTH INTERVIEW GUIDE

IDI.1: Palliative Care Strategy

1. We would like to learn more about your conception of some key terms used when discussing palliative care. Please define the following:
 - i. palliative care:
 - ii. hospice:
 - iii. end-of-life care:
 - iv. home-based care:

2. Describe your institutional (or palliative care)strategy:

3. Do you have a palliative care plan? If so, please describe.

Probes (Use only if needed after respondent answers):

- i. Did you conduct needs assessments before developing this plan? If yes, what does the plan consist of?

4. We are interested in learning more about how you finance palliative care.

- i. Do you have a budget line item for palliative care? If yes, tell me more about this (e.g., How long have you had it? Is it sufficient?)
- ii. Do you have a budget line item for palliative care training? If so, please elaborate (e.g., What type of training is funded? Who makes decisions on how it is used?)
- iii. Does the government support your palliative care program in any way? (e.g., funding, medications, staff, etc.) Describe.

5. Tell us how you allocate resources for palliative care.

- i. What kind of training programs do you have? Who do they target? How long are the programs?
- ii. How do you decide on where you will provide the one week advocacy and sensitization trainings at the district level? What are some considerations you keep in mind?
- iii. How are nurses and clinical officers selected for the nine month training program?
- iv. Do your donors influence how you allocate your resources? If so, how?

IDI.2: Palliative Care Approaches

1. What are your key program approaches/models?
2. What different methods do you use to see patients? (Please describe the strengths and weaknesses of these methods.)
 - i. Which one of these methods do you practice most?
 - ii. Which one of these to you prefer?

IDI.3: Palliative Care Standards

1. Do you have any palliative care guidelines that you follow? If so, please describe.
 - i. Do you use any job aids to help you follow these guidelines (e.g., WHO Analgesic Ladder, pain assessment tools--if yes, ask to see them)?
2. Are you familiar with palliative care standards? If so, please describe.
 - i. In what ways can you relate your program's work with these standards?

IDI.4: Availability of Palliative Care Services

1. After nurses and clinical officers complete their 9 month training, where are they deployed?
2. Do they provide palliative care? Explain.
3. How are the CPCNs supported by hospital management to do palliative care?
4. Do others support these nurses and clinical officers to implement palliative care? How?
5. Do you collaborate with the government or organizations that care for PHA? Describe.
6. Describe your referral system.
 - i. Is there any follow-up or feedback system? Please describe.

Probes (Use only if needed after respondent answers): What issues are addressed?

- ii. HIV testing
- iii. ARV treatment
- iv. Financial support
- v. Legal services

IDI.4: Availability of Palliative Care Services (con't)

7. How do you manage pain of PHA and/or other terminal illnesses?

Ask these questions directly after the respondent completes his answer to "7" above:

- i. Do you use morphine in your palliative care program?
- ii. How do you obtain/procure morphine?
- iii. Are there any issues regarding the availability and use of morphine?
Explain any concerns or issues.
- iv. How does the clinician decide who will receive morphine?
- v. When supplies are limited, how does the clinician prioritize who will receive morphine?
- vi. Has there been any indication that morphine has been administered incorrectly?
- vii. Has there been any indication that morphine has been abused? (e.g., Has morphine ever been used by people other than hospice patients?)
- viii. What measures do you have in place to prevent abuse of morphine by either the clinical staff, the patients or the family caregivers?

8. How do you treat opportunistic infections of PHA?

Ask these questions directly after the respondent completes his answer to "e" above:

- i. Are the medications and supplies needed to treat opportunistic infections available? Explain any concerns or issues.
- ii. How does the clinician decide who will receive treatment of opportunistic infections?
- iii. When time and/or supplies are limited, how does the clinician prioritize who will receive treatment for opportunistic infections?

9. Describe how you address PHA's psychosocial needs.

- i. Bereavement support
- ii. Follow-up counseling with families after death

10. Describe how you address PHA's spiritual needs(e.g., counseling)

IDI.4: Availability of Palliative Care Services (con't)

11. Describe how you provide End-of-life Care.

Probes (Use only if needed after respondent answers):

- i. "Succession Planning"
- ii. food
- iii. family income
- iv. physical comfort (i.e., massage)

IDI.5: Access to Palliative Care Services

a. How do PHA access to palliative care services? Describe any challenges.

Probes (Use only if needed after respondent answers):

- i. Geographic
 - ii. Socio-cultural
 - iii. Psychological
 - iv. Economic
- b. How do you identify PHA who might need your services?
- c. How do make PHA and other terminally ill people aware of your palliative care services?

IDI.6: Utilization of Services

a. How would you rate the quality of your palliative care services? What evidence do you have to support your assessment?

Probes (Use only if needed after respondent answers):

- i. compliance with guidelines or standards of care
 - ii. client satisfaction
 - iii. M&E Indicator reporting
- b. How often are patients reviewed after receiving palliative care? Describe the regularity of the services you provide?

IDI.6: Utilization of Services(con't)

- c. Are you able to provide pain management to all the PHA in need (within your catchment areas)? Explain.
- d. Are you able to provide symptom control to all the PHA in need (within your catchment areas)? Explain.
- e. Are you able to provide end-of-life care to all the PHA in need (within your catchment areas)? Explain.

IDI.7: Sustainability of HAU Program

1. Describe your sustainability plan.

Ask these questions directly after the respondent completes his answer to “1” above:

- i. Do you have a strategic plan? Describe.
- ii. Do you have one master workplan and/or individual project workplans? Describe.
- iii. How do you monitor the progress of your plans? Can you give an example?
- iv. Have you had any specific management training? Describe. (What did you learn?)
- v. How do you make difficult program decisions?

2. Describe your donor funding portfolio.

Probes (Use only if needed after respondent answers):

- i. Do you have an array of donors? Explain
- ii. Do you raise local funds? Please give an example.
- iii. How long can you maintain your current operating level?

3. How does palliative care fit within your health management information system (HMIS)?

Probes (Use only if needed after respondent answers):

- i. Does your HMIS capture palliative care indicators? If so, which indicators do you capture?
- ii. How do you report on palliative care? Do you share your indicators with the MOH?
- iii. What do you do when you find that an indicator isn't progressing in the direction you had hoped?

4. Do you have any plans for scaling up your palliative care services? Please describe.
5. Do you have a mentorship program? Have you been mentored? Please describe.
 - i. Do you have any recommendations for a training-of-trainers mentorship program?
6. Describe your relationship with the National Health System (*for MOH/DHT ask vis-à-vis palliative care programs*)

Probes (Use only if needed after respondent answers):

 - i. How do you collaborate with the public and private sectors at the district level?
 - ii. Have you considered forming integrated palliative care teams that include representatives (e.g., from DHTs, VHTs, local PHA Networks or other CBOs, etc.) What are the opportunities and challenges?
7. How do you rate or measure your success?
8. What would you like to improve upon in your palliative care services if you could? Describe some of the gaps and challenges?
9. How do you think the advent of ARV treatment affected palliative care for PHA?

Annex F: Focus Group Discussion Guide

Hello, my name is _____. My colleague is _____. We are part of a team from the QED Group that is carrying out an evaluation for Hospice Africa Uganda. The QED Group is a company based in the United States. We are funded by the United States government (USAID) to conduct an evaluation of Hospice Africa Uganda. This study is being conducted in collaboration with other partners including the Ministry of Health and the Palliative Care Association of Uganda.

We are seeking your consent to discuss palliative care. If you agree to participate in this discussion, it will last about one hour. All the information that you will provide to us will be kept confidential and will be used for reporting and planning purposes only. Even then, any other information that can be directly linked to you will not be used. We are not asking for your name or any other personal information that might reveal your identity to others.

The information that you will share with us will help Hospice Africa Uganda and its partners to improve their programs so they can better provide palliative care services in Uganda. Please feel free to share with us any suggestions and recommendations that you may have. The information that you provide to us will not be used against you in any way.

Your participation in this discussion is completely voluntary. If you chose not to participate, there will be no negative outcomes. You will not be denied any services, care or treatment if you do not join this group discussion. Your participation will help us to advise Hospice Africa Uganda on how to improve upon their services. While this is an indirect benefit you might one day experience, you will not be receiving any payment or allowances for your participation.

Please let me know if you have any objection to participating in this interview and also if you have any questions before we start. If you don't mind, we will ask you to allow us to tape-record the discussion so that we can be able to remember all your points when we get back. Thank you very much.

Signed by Interviewer: _____

FOR OFFICIAL USE ONLY

Interview date: ____/____/____

Unique

Identifier: _____

Interviewer: _____

Note-taker:

Interview venue: _____

Language used:

Time started: _____

Time ended: _____

Number of participants: _____

Male _____ Female

Type of Respondent Type (circle one):

◇PHA

◇Community Volunteers

FGD.1: General Questions

1. What are the general health problems that people living with HIV/AIDS in this community face? *[If not mentioned, probe for access to treatment and care services, including access to ARVs and palliative care services].*
2. What are the general health problems that people living with terminal illnesses in this community face?
3. If you were to rank the health problems you have mentioned, which of those would you rank among the top 3, and why?

FGD.2: Knowledge of Palliative Care

1. Have you ever heard of the term ‘palliative care’? If yes, what have you heard?
2. Please tell me more about palliative care services that you know of. (Probe for: pain management, symptom control and end-of-life support services)
3. Which people should utilize palliative care services in this community? Why specifically those people?
4. Why is it important for those people you have mentioned in 3 above to utilize palliative care services? Probe: Of what benefit is palliative care to those people? What do you think would happen if these people did not receive palliative care services?

FGD.3 Availability of Services

1. In your opinion, are people aware of where to go for palliative care services? If yes, how do they know? If no, why not?
2. Where, in this community, can one go for palliative care services? Probe for availability of palliative care services in private or government health facilities, and where these facilities are located. Also, probe for number of providers in this community and whether these providers provide palliative care as a specialized service or whether the services are integrated within the general health framework
3. Consider asking about palliative care at home
4. If palliative care services are provided as part of the general government health framework in this community, please ask: At what level (hospital, health center IV, III, II) can one obtain palliative care services in this community?
5. Please tell me more about the palliative care services that the organizations you mentioned in 2 above provide.

FGD.4: Access to Services

1. Let’s talk more about palliative care services in this community. How easy or difficult is it for people to access these services, considering where these services are located? Probe for: distance to the service centers, cost of service, other barriers to accessing services including fear of rejection, stigma and discrimination, blame, etc
2. Assuming I went to a palliative care service center in this community: How soon would I be served?

FGD.5: Utilization and Quality of Services

1. Tell me more about the specific palliative care services (pain management, symptom control, and end-of-life support services) that PHA receive in this community. Why specifically these services?
2. Are you satisfied with the way palliative care services are provided in this community?
3. If you had the authority to advise Hospice Africa Uganda, what specific recommendations would you make to improve the utilization of palliative care services in

this community and the country at large? In general, what advice would you give to the providers of palliative care in Uganda.

THANK YOU FOR YOUR TIME

Annex G: Comparison of HAU Annual Data for USAID Project Years 1–3

Indicator	Year 1				Year 2				Year 3				% Change: Yrs 1 & 3
	K'la	Hoima	MHM	TOTAL	K'la	Hoima	MHM	TOTAL	K'la	Hoima	MHM	TOTAL	
No. of existing HIV/AIDS pts. on program	86	70	41	197	287	197	238	722	239	298	246	783	297.5%
No. of NEW HIV/AIDS pts. put on program	204	168	212	584	137	69	127	333	157	220	144	521	-10.8%
No. of HIV/AIDS pts. seen but not on program	212	361	129	702	141	51	140	332	149	181	56	386	-45.0%
TOTAL no. of new HIV/AIDS pts. seen	416	529	341	1,286	278	120	267	665	306	401	200	907	-29.5%
TOTAL no. all AIDS pts on program#	290	238	253	781	424	266	365	1,055	396	518	390	1,304	67.0%
No. of HIV/AIDS pts. receiving only home care	107	0	63	170	148	62	48	258	133	62	43	238	40.0%
No. of HIV/AIDS pts receiving mix of home, hospital, OPD, outreach care	186	0	190	370	287	197	238	722	239	298	246	783	111.6%
No. of HIV/AIDS pts. who died*	ND	ND	ND	ND	78	37	35	150	47	19	59	125	-16.7%
No. of HIV/AIDS pts. discharged*	ND	ND	ND	ND	29	71	13	113	1	0	6	7	-93.8%
No. of HIV/AIDS pts. re-admitted to program*	ND	ND	ND	ND	1	5	8	14	0	0	0	0	-100.0%
No. of home visits conducted	444	505	258	1,207	444	155	214	813	443	170	130	743	-38.4%
No. of OPD consultations+	693	620	1,011	2,324					195	232	182	609	-73.8%
No. of outreach consultations+	308	171	79	558					33	143	40	216	-61.3%
No. of hospital consultations (Mulago, Mbarara, Hoima)+	264	131	249	644	2,001	655	1,722	4,378	121	51	230	402	-37.6%
No. of other health facility consultations+	75	0	0	75					695	329	624	1,648	2,097.3%
No. of pts. prescribed oral morphine	160	50	94	304	193	39	155	387	178	63	171	412	35.5%
No. of family members/carers trained in PC	0	133	74	207	287	197	238	722	85	15	161	261	26.1%
No. of HIV pts. on ARVs	116	60	40	216	158	75	176	409	178	163	187	528	144.4%
No. of HIV pts. receiving septrin from Hospice	170	173	100	443	165	87	89	341	137	158	81	376	-15.1%
No. of HIV pts. receiving septrin ELSEWHERE	120	173	69	362	49	37	97	183	28	24	221	273	-24.6%
No. of pts. co-managed b/n hospice & others (Q. 4 only in Year 1)	10	123	51	184	158	75	176	409	179	234	234	647	251.6%
No. of HIV/AIDS pts. receiving comfort fund support	120	50	84	254	200	88	106	394	132	109	133	374	47.2%

No. of pts. & family members receiving VCT	24	34	0	58	14	1	3	17	6	7	4	17	-70.7%
No. of pts. receiving nutritional support	80	30	0	110	97	22	6	125	111	73	11	195	77.3%
No of pts. receiving ITMNs	122	22	41	185	123	112	49	284	0	0	0	0	-100.0%
No. of pts. receiving condoms	0	0	0	0	ND*	ND	ND	ND	0	0	0	0	ND
No. of HIV/AIDS pts. enrolled in day care	25	52	26	103	92	71	60	223	38	90	55	183	77.7%
No. of talks held during day-care	4	12	3	19	ND*	ND	ND	ND	5	0	0	5	-73.7%
No. of HIV/AIDS pts. referred by hospice	206	95	0	301	14	1	35	50	160	184	85	429	42.5%
No. of HIV/AIDS pts. referred TO hospice	140	43	188	271	137	69	127	333	0	95	113	208	-23.2%
No. of HIV/AIDS pts. on program referred by CVWs	103	20	119	242	15	12	16	43	19	25	5	49	-79.8%
No. of existing active CVWs	39	45	37	122	40	45	40	125	0	0	0	0	ND
No. of CVWs trained	30	30	29	89	N/A	N/A	N/A	N/A	0	0	0	0	ND
No. of updates held for CVWs	4	2	2	8	4	4	4	12	0	0	0	0	ND
No. of HIV/AIDS pts. co-managed by CVWs & hospice	0	0	0	0	15	12	16	43	0	0	0	0	ND
No. of home visits conducted by CVWs	1,854	1,438	1,632	4,924	2,828	1,142	1,098	5,068	0	0	0	0	ND
No. of supervision visits by hospice	179	30	36	245	12	12	12	36	0	0	0	0	ND

NOTES

ND = No Data

+ After the first year of the program, this data was merged

* Comparison is between Year 2 & Year 3 since no data were available for Year 1.

This row compiled by evaluation team based on HAU figures

LEGEND

Light grey highlights indicate a positive trend

Dark grey highlights indicates a negative trend