

TECHNICAL REPORT

# Integrating palliative care with HIV care in two Ugandan districts using a collaborative quality improvement approach

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**DISCLAIMER**

The views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development or the United States Government.

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### Acronyms

CME	Continuous medical education
DHS	District health system
DQI	District quality improvement
HAU	Hospice Africa Uganda
HC	Health center
HCI	USAID Health Care Improvement Project
HSSP	Health Sector Strategic Plans
INCB	International Narcotics Control Board
JMS	Joint Medical Stores
MHM	Mobile Hospice Mbarara
MoH	Ministry of Health
NDA	National Drug Authority
NGO	Non-governmental organization
NMS	National Medical Stores
PCAU	Palliative Care Association of Uganda
QI	Quality improvement
SR	Sustained release
URC	University Research Co., LLC
USAID	United States Agency for International Development
WHO	World Health Organization

## EXECUTIVE SUMMARY

Pain is a common and debilitating symptom which is gravely underestimated and undertreated in people living with life-threatening illnesses such as AIDS. Uncontrolled pain can have a profoundly negative impact on the quality of life of people living with serious illnesses as well as on their family members.

Palliative care is any care or treatment that aims to reduce the severity of pain and other symptoms, alleviate suffering, and/or improve the quality of life for people facing serious illnesses. Despite widespread efforts, strongly endorsed by the World Health Organization (WHO), to include palliative care as one of the essential services delivered by all health systems, even simple pain management is inaccessible to most people in low- and middle-income countries.

Relative to many of these countries, Uganda has made considerable progress in the field of palliative care, including the establishment of policies and guidelines by the Ministry of Health (MoH) to support implementation of WHO-recommended palliative care treatments. Consequently, many people in need of palliative care in Uganda are now accessing services through hospices and general hospitals, including those run by non-governmental organizations (NGOs). Despite this encouraging development, palliative care services, including pain management, remain largely inaccessible to Uganda's large rural population.

In 2011-2012, the USAID Health Care Improvement Project (HCI) worked with the Uganda MoH to carry out a demonstration improvement project with the aim of integrating quality palliative care services with HIV care in the eastern rural districts of Mayuge and Namatumba. This intervention took place at 13 health facilities and focused on pain management, employing a collaborative improvement approach to engage facility-based teams in developing and implementing best practices for improving palliative care.

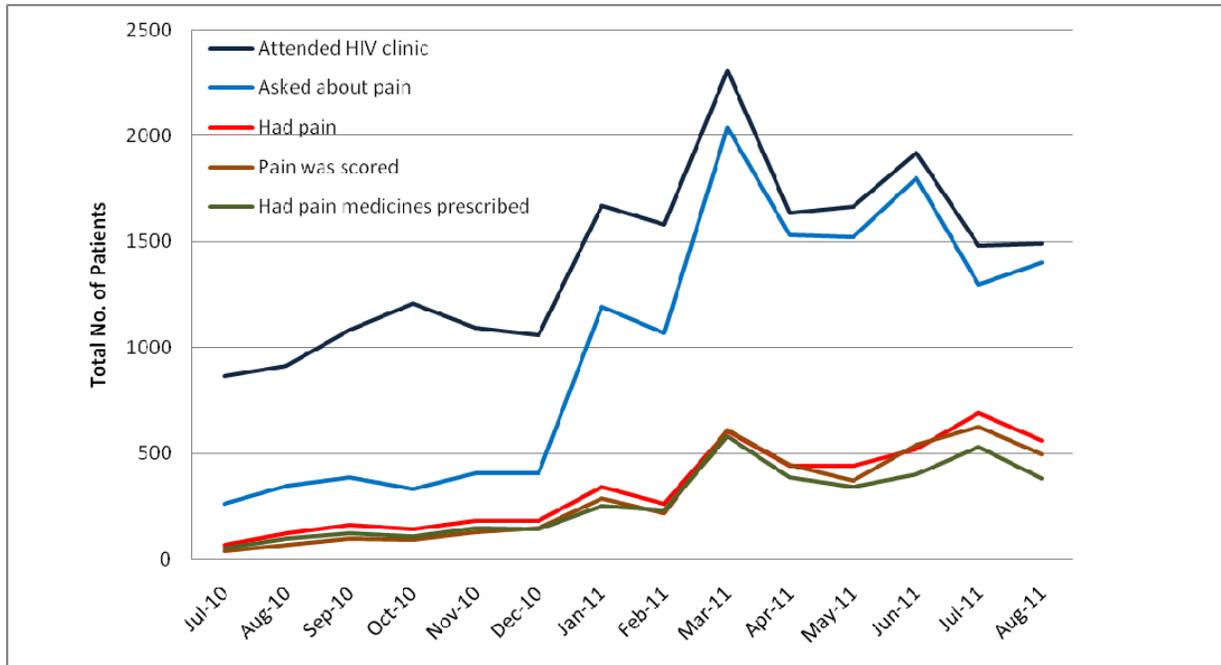
MoH officials at the national level provided advocacy and support for the intervention, and prior to its launch, district health officials were sensitized about palliative care and engaged in facilitating its introduction and ongoing improvement. HCI teamed with the Palliative Care Association of Uganda (PCAU) to provide introductory training in palliative care and improvement methods to health workers and community volunteers, and staff competencies continued to be strengthened over the life of the intervention through regular clinical mentorship and coaching by MoH and HCI staff at all participating sites. Additionally, each district sent one mid-level provider to complete the nine-month course on palliative care required to become a licensed morphine prescriber in Uganda. This was to assure the continued availability of specialized palliative care expertise and morphine prescribing capability in each district.

Facility-based improvement teams focused on implementing the three key steps in pain management: 1) identification of patients in pain, 2) assessment of pain, and 3) management of pain through prescription of medications or referral to other facilities which could provide pain medicines. Teams collected data on indicators established to monitor progress on these three steps and used the data to drive improvement efforts. To ensure that pain and symptoms could be treated appropriately, measures were taken to strengthen the supply chain for essential drugs, including morphine. Results and emerging best practices were shared and spread among the implementing sites during three learning sessions, where representatives from each facility team and district staff would come together with HCI staff.

By the end of the first year of implementation of the intervention, pain management had become a standard practice in the two districts, with oral morphine available for patients with severe pain and health workers able to identify, assess, manage, and refer patients for pain management. Over the course of the intervention, pain assessment and management increased significantly ( $p < 0.001$ ). Across 10 facilities, the proportion of patients asked about pain increased from 30% to 95%. After an initial increase, the percentage of patients who reported pain reached a plateau at around 40%. The proportion of patients with pain whose pain was scored increased from 71% to between 88 -98%.

As community awareness about the availability of pain management grew and pain management practices in the facilities improved, the demand for services increased, and there was up to a nine-fold increase in the number of HIV patients identified as having pain. Despite this dramatic increase and despite struggles with supplies of pain medicines, the percentage of those with pain whose pain was managed ranged from 70-90% (see figure below). A harvest meeting was held after the close of the project to gather and summarize best practices and recommendations for the integration and improvement of pain management in rural areas (Appendix V).

Number of patients: attending HIV clinic, asked about pain, suffering from pain, having pain scored, and prescribed pain medicines in Mayuge and Namutumba districts in Uganda



Given the large investment in HIV programs in many countries, it is clear that best practices and standards established by HIV programs are vital in informing efforts to strengthen health systems in general. The intervention described in this report provides a good example of how, by starting with an emphasis on the key component of pain management, palliative care can be introduced and integrated on a large scale as part of the routine care provided to patients with chronic illnesses in low-resource settings. Serving as models for chronic care in general, HIV care and treatment programs should be continuously encouraged to lead the way in establishing high quality service delivery systems which effectively integrate essential chronic care services like palliative care.

## I. INTRODUCTION

Pain is a common and debilitating symptom which is gravely underestimated and undertreated in people living with life-threatening illnesses.<sup>1</sup> Uncontrolled pain can have a profoundly negative impact on people living with serious illnesses and on their family members. Palliative care is any care or treatment that aims to reduce the severity of pain and other symptoms, alleviate suffering, and/or improve the quality of life for people facing serious illnesses. By alleviating pain and suffering, palliative care improves quality of life, and there is evidence to show that it can even prolong life.<sup>2</sup> Palliative care should therefore be considered a necessary service in the continuum of care for persons living with life-threatening illnesses. This recommendation is strongly supported by the World Health Organization (WHO), which recognizes that palliative care is a critical component of essential health care services.<sup>3</sup>

Thanks to persistent global advocacy for palliative care, many low- and middle-income countries have finally established guidelines and policies regarding pain management. Progress on translating these policies and guidelines into large-scale service delivery has been very limited however, despite the low cost of morphine and other palliative care medications and their presence on the essential drug lists of many countries. Pain management is widely regarded as a human right, and its lack of availability in much of the world has increasingly drawn the attention of the press and of human advocacy groups such as Human Rights Watch, which has released multiple reports and commentaries in recent years on the inaccessibility of morphine and palliative care services in low resource settings.<sup>4,5</sup>

Even in Uganda, considered to be a model for palliative care due to progressive policies, strong advocacy, and active palliative care organizations, pain management remains inaccessible to most people who need it. The WHO estimates that 1% of a country's total population is in need of palliative care at any given time, meaning that approximately 350,000 people in Uganda need palliative care services. Only 10% of these are presently accessing the services however.<sup>6,7</sup>

Reasons for the persistent lack of availability of palliative care are complex, but contributing factors include: 1) scarce resources and/or weak supply chains 2) cultural and psychological barriers to addressing the particular challenges posed by life-threatening illnesses 3) poor engagement of global health leaders, health system officials, and providers in the provision of care that is not clearly curative or life-prolonging, 4) inability or unwillingness of providers to recognize and assess pain and discomfort, 5) fear and inadequate knowledge among health care workers regarding the appropriate use of opioid medications and about pain and symptom management, 6) cumbersome regulatory processes for controlled substances, 7) a severe shortage labor to provide this important aspect of patient care 8) a lack of community and individual awareness about the importance of palliative care and about the availability of medicines which can control pain and symptoms and 9) insufficient advocacy for patients and their families.<sup>8</sup>

In most of Sub-Saharan Africa the HIV/AIDS epidemic has significantly increased the population of people who must chronically cope with life-threatening illnesses. In Uganda, for example, there are over one million people living with HIV/AIDS.<sup>9</sup> HIV/AIDS, along with the growing burden of chronic non-communicable diseases has heightened the need to increase the availability and quality of palliative care services as part of an essential package of care for people with chronic life-threatening illnesses in low-resource settings.<sup>9</sup> The WHO has recommended three steps to guide countries in rolling out palliative care services; 1) adopt a national palliative care policy, 2) train health professionals and educate the public in palliative care, and 3) make available drugs for pain control and symptom management.<sup>10</sup>

With its mission to support affordable, appropriate, and accessible palliative care in Uganda and other African countries, Hospice Africa Uganda (HAU) was founded in 1992. Since then, in collaboration with the Ministry of Health (MoH) and other partners, HAU has championed palliative care through training, provision of palliative care services, and advocacy for policies to facilitate delivery of palliative care to all who need it.<sup>11</sup> The Uganda Ministry of Health has since incorporated palliative care into its Health

Sector Strategic Plans I (2000-2005) and II (2006-2010). It was included as part of the basic care package under “Essential Clinical Services” with the aim of facilitating the provision of palliative care services within the national health system.<sup>12,13</sup> In 2009, however, an audit report of palliative care services in Uganda by the Palliative Care Association of Uganda (PCAU), revealed that services were actually only offered in 32 out of the country’s 80 districts. Furthermore, these services were mainly offered in referral hospitals, mission hospitals, and specialized NGO-supported hospice programs,<sup>14</sup> leaving many people in need of palliative care without access to services. The 85% of Ugandans who live in rural areas have especially poor access to palliative care, even where there are health centers providing general health care services.<sup>15</sup>

In response to the need for effective scale up of palliative care within the government health system, the USAID Health Care Improvement Project (HCI), working in collaboration with the Palliative Care Association of Uganda (PCAU), assisted the Uganda MoH to introduce, improve, and spread palliative care, with a focus on pain management, in two rural districts. This effort, which took place from June 2010 through September 2011, employed a collaborative improvement approach involving 13 public health facilities, including a hospital, three health centers (HC) IV, and nine health centers III.

This report aims to:

- Provide contextual and baseline information on the Uganda health system and on palliative care in Uganda and in Mayuge and Namutumba districts;
- Describe the intervention;
- Depict the results achieved through this intervention; and
- Discuss challenges encountered in implementing the intervention and how they were addressed.

## II. BACKGROUND AND CONTEXT

### A. Uganda Health System

Uganda’s national health system includes: 1) the district health system (DHS), consisting of village health teams (VHTs), HCs II, III, IV and district general hospitals, 2) regional referral hospitals; and 3) national referral hospitals (see Figure 1). According to Health Sector Strategic Plan II, the population estimated to be served at different levels of the DHS is as follows: District General Hospital (District level: 500,000 population), Health Center IV (County level: 100,000 population), Health Center III (Sub-county level: 20,000 population), Health Center II (Parish Level: 5,000 population), and Health Center I (Village Health Team: 1,000 population).

### B. Palliative Care in Uganda

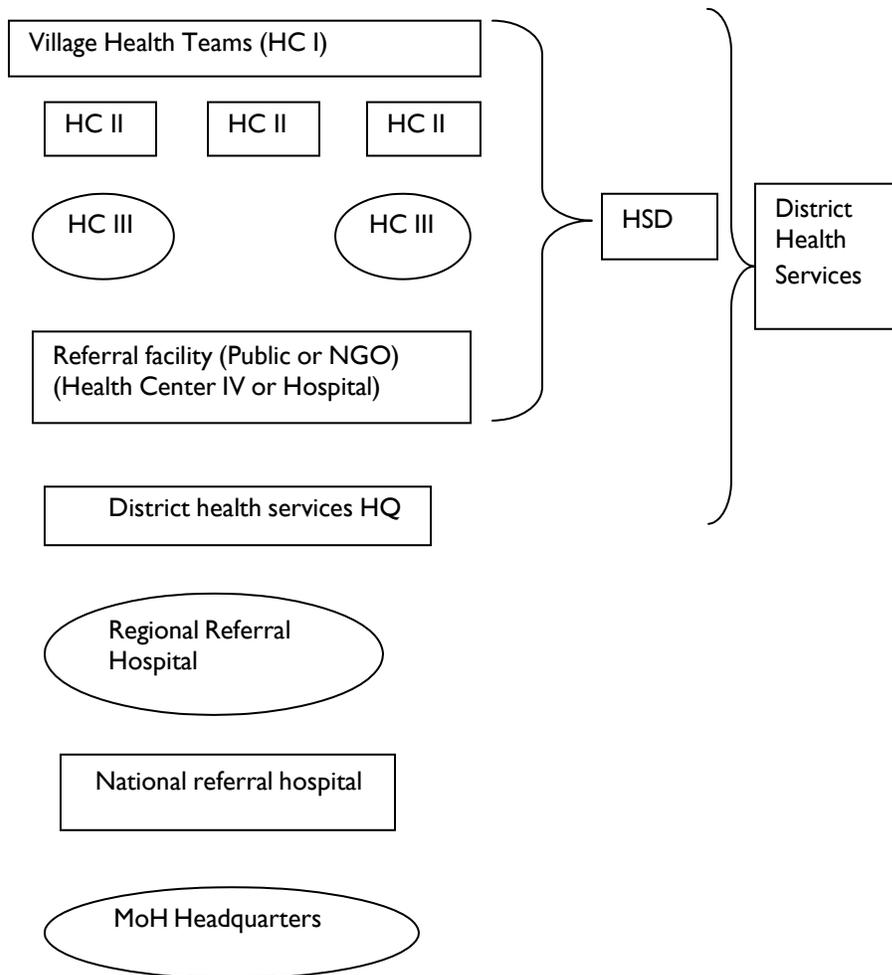
The Uganda MOH has been relatively progressive in the development of policies and guidance to facilitate the delivery of palliative care services. They first established a national policy for palliative care in 1999 and incorporated it into their National Health Strategic Plan and HIV/AIDS policies and guidelines,<sup>12,13</sup> In 2009, 50 facilities in Uganda, including public facilities and private hospices, were providing palliative care services according to a PCAU audit completed that year.<sup>14</sup>

Uganda’s MoH has produced the following documents to facilitate the delivery of palliative care services:

- National Health Policy, 1999: This policy made palliative care for chronically and terminally ill patients’ a priority classified under “Essential Health Care.”
- Guidelines for Handling Class A drugs, March 2001: These guidelines were designed to support procurement, prescription, and dispensing of morphine for pain management.

- Statutory Instrument 2004 No. 24: This instrument authorizes nurses and clinical officers with specialized palliative care training to prescribe morphine for pain relief.

Figure 1: Uganda National Health System



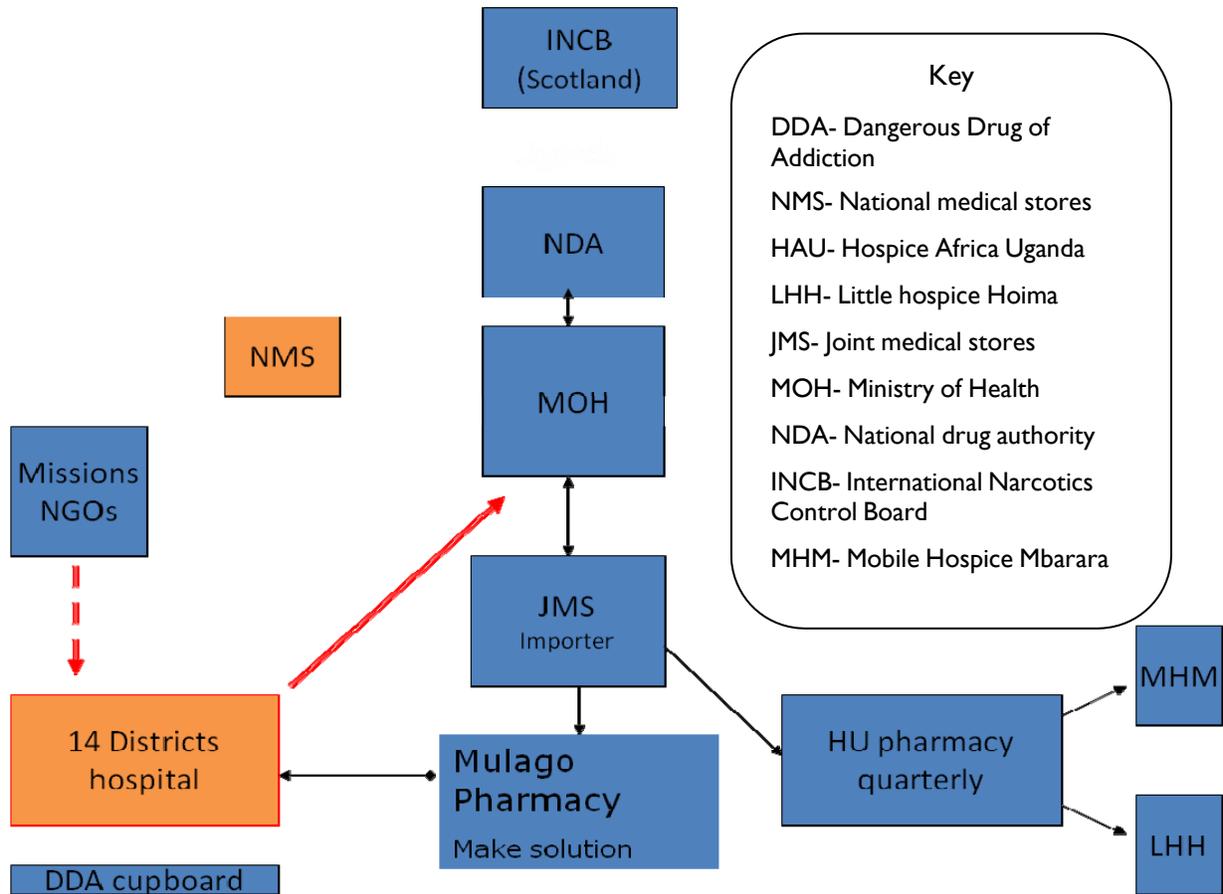
The handling and distribution of opioids and misperceptions around its use can be major barriers to the implementation of good palliative care programs. To alleviate this problem, Uganda's Guidelines for Handling Class A Drugs includes standards for manufacturers, wholesalers, prescribers, dispensers, ward staff and home care teams. The National Drug Authority (NDA), established by the Ministry of Health, is responsible for working with wholesalers and manufacturers to ensure licensing and forecasting of morphine powder needs within international regulations.

The morphine supply chain that existed in Uganda at the start of this intervention is depicted in Figure 2. Under this system morphine powder is imported into the country and reconstituted into oral morphine solution under the supervision of the Ministry of Health. Accredited facilities providing palliative care place orders for their supplies. To be "accredited," facilities must have a doctor or a specially-trained nurse or clinical officer who serves as a clinical palliative care practitioner. Accredited facilities must also have a fixed double lock cupboard for storage of oral morphine.

In the Health Sector Strategic Plan (HSSP) II, under palliative care, the Ministry of Health pledged to ensure adequate stocks of appropriate medicines and supplies at hospitals and HC IVs providing

palliative care services. Table 1 lists the drugs specified in the Essential Drug List and Uganda Clinical Guidelines (2010) for pain management at each facility level. The actual availability of key medicines on the Essential Drug List is low, however. For example, in a 2008 assessment availability was 47.5% and 57.5% in public health facilities and mission facilities, respectively.<sup>17</sup> In the same pharmaceutical situation assessment availability of Paracetamol, Diclofenac and Amitriptyne was found to be 75%, 25% and 25%, respectively, in public health facilities. Inadequate supplies of medicines in the health facilities results in many patients having to purchase them in outside pharmacies.

Figure 2: The morphine supply chain, prior to 2010 changes



Source: Diagram provided by Palliative Care Association of Uganda

A baseline assessment performed in preparation for the intervention described in this report revealed that the availability of these essential medicines was actually very limited at the 13 participating facilities (Table 2) and that there was no morphine available anywhere in either district. The complete absence of morphine, which had historically been somewhat available at the hospital in Mayuge District, was due to a national stock-out that coincided with the start of this intervention.

Table I: Essential drugs for pain management recommended by the Uganda MOH and the health center level at and above which these drugs should be stocked

Medication	Form	Level
<b>NON-STEROIDAL ANTI-INFLAMMATORY DRUGS (NSAIDS)</b>		
Diclofenac	25mg tablet	HC IV
Aspirin	300mg tablet	HC I
Ibuprofen	200mg tablet	HC II
Paracetamol	500mg tablet	HC I
<b>OPIOIDS</b>		
Codeine	30mg tablet	HC IV
Dihydrocodeine	30mg tablet	HC IV
Morphine	Oral solution 1mg/ml	HC III
Morphine	30mg tablet	HC IV
Morphine	10mg tablet sustained release (SR)	HC III
Morphine	30mg tablet SR	HC III
Morphine	60mg tablet SR	HC III
<b>ADJUVANTS (Medications to enhance the effect of other pain medications)</b>		
Phenytoin	50/100 tablet/capsule	HC III
Carbamazepine	200mg tablet	HC IV
Amitriptyline	25mg tablet	HC IV

Source: Adapted from Essential Drug List Uganda (2001) and Uganda Clinical guidelines 2010.

In the 2008 pharmaceutical assessment in Uganda, 64% of health facilities were not usually staffed by physicians. In these facilities only nurses, midwives, and/or clinical officers were present most of the time, and at 56% of the health facilities they served as the senior prescribers.<sup>17</sup> Any efforts to improve access to medicines must of course consider the cadres of health professionals who are actually available to the population and provide them with adequate knowledge and skills to prescribe medicines. To increase access to class A drugs, Uganda expanded prescribing rights for these controlled substances, which were previously limited to doctors, to include nurses and clinical officers with specialist palliative care training. This training for nurses and clinical officers is offered by Hospice Africa Uganda (HAU) and is a full-time, nine-month course. The course teaches clinical officers, nurses, and midwives to practice clinical palliative care with competency to provide effective pain and symptom management, including the appropriate prescription of oral morphine. According to the HAU 2009 annual report, 108 nurses and clinical officers had been trained from the 1993 start of this program to 2010.<sup>18</sup> Considering that most of the health centers (HC) II, III and IV in the country are run by nurses and clinical officers however, this figure is still low.

### C. Intervention Setting

Two districts in the eastern region of the country were selected by the Ministry of Health for participation in the intervention: Mayuge and Namutumba.

#### I. Mayuge District

Mayuge district has an estimated population of 407,000 with an HIV prevalence rate of 7%. The district health system consists of three health sub-districts with one hospital run by an NGO, two HC IV, six HC III (of these, five provide ART), and 31 HC II. According to the 2002 population census, 42% and 32% of households needed to travel 1 - 5km and  $\geq$  5km, respectively, to get to a health facility, and only 25% live within 1km of a health facility.<sup>19</sup>

Table 2: Pain management drugs actually available during the baseline assessment

	Health center	Level	Drugs that were available	Drugs that should have been available but were not
<b>Mayuge District</b>				
1	Buluba	Hospital	Diclofenac, Aspirin, Ibuprofen, Paracetamol, Ibuprofen, Codeine, Dihydrocodeine, Phenytoin, Carbamazepine, Amitriptyline	Morphine
2	Kigandalo	HC IV	Diclofenac, Aspirin, Ibuprofen, Paracetamol, Codeine, Phenytoin, Amitriptyline	Dihydrocodeine, Morphine
3	Kityerera	HC IV	Diclofenac, Ibuprofen, Paracetamol, Phenytoin, Carbamazepine, Amitriptyline	Aspirin, Codeine, Dihydrocodeine, Morphine
4	Baitambogwe	HC III	Paracetamol	Aspirin, Ibuprofen, Morphine, Phenytoin
5	Wabulungu	HC III	Paracetamol	Aspirin, Ibuprofen, Morphine, Phenytoin
6	Mayuge	HC III	Paracetamol, Amitriptyline	Aspirin, Ibuprofen, Morphine, Phenytoin
7	Malongo	HC III	Paracetamol	Aspirin, Ibuprofen, Morphine, Phenytoin
8	Kaluuba	HC III	Diclofenac, Ibuprofen, Paracetamol, Amitriptyline	Aspirin, Morphine, Phenytoin
9	Buwaiswa	HC III	Paracetamol	Aspirin, Ibuprofen, Morphine, Phenytoin
<b>Namutumba District</b>				
10	Namutumba	HC III	Paracetamol	Aspirin, Ibuprofen, Morphine, Phenytoin
11	Bulange	HC III	Paracetamol	Aspirin, Ibuprofen, Morphine, Phenytoin
12	Nsinze	HC IV	Ibuprofen, Paracetamol	Diclofenac, Aspirin, Codeine, Dihydrocodeine, Morphine, Phenytoin, Carbamazepine, Amitriptyline
13	Ivukula	HC III	Paracetamol	Aspirin, Ibuprofen, Morphine, Phenytoin

In Mayuge, only the hospital was able to provide oral morphine due to the presence of a doctor on the staff. According to the Class A drug register, 49 clients with cancer and/or HIV/AIDS had received oral morphine between January and August 2010. At the time of the assessment, there was no morphine available due to the stock-out mentioned above. Even when morphine was available, many of the recipients lived much too far from the hospital to travel there regularly. Most recipients lived closer to lower level facilities, but these were not qualified to provide morphine due to: 1) the lack of certified opioid prescribers and 2) the inability to stock morphine due to the absence of wall-fixed double-lock cupboards required by national policy for morphine storage.

Although WHO Step I and II pain medications were available in lower level health facilities, supplies of these were inadequate, and stock-outs were frequent. Furthermore, there was no proper documentation to ascertain use of medication to relieve pain in HIV/AIDS patients. At baseline health providers did not have adequate skills to assess and manage pain, and the current patient ART cards and registers did not provide for documentation of pain assessment. This situation made it difficult to monitor and evaluate patients with pain.

Rays of Hope Hospice in the nearby city of Jinja was providing palliative care in the district twice a month through outreach services at Mayuge HC III. They reported that during the outreach, between five and 12 patients were being seen at a designated meeting point or in their homes and provided with medicines, counselling, and follow-up.

## 2. Namutumba District

Namutumba District has an approximate population of 249,900 and an estimated HIV prevalence of 5.8%. It is served by one health sub-district, including one HC IV, five HC III (of these, four provide ART), and 28 HC II. At baseline no health facilities were providing palliative care services, and there was no morphine available anywhere in the district. While weaker pain medications were available, there was no documentation to reflect any regular pain assessment or management. The district had only one doctor, a District Health Officer, who functioned mainly in an administrative capacity and did not provide any clinical care. As at the Mayuge health facilities, the analgesic medications available in the Namutumba facilities were mainly WHO Step I medications, but supplies of these were minimal, largely due to regular stock-outs. None of the health facilities had health providers who were certified to prescribe oral morphine, and there were no double lock cupboards for storage of morphine as required by the national guidelines.

## III. OBJECTIVES

Despite Uganda's commendable progress in facilitating the spread of palliative care, access to quality palliative care remains only for patients who are able to go to specialized centers and large health facilities. The intervention described herein aimed to make palliative care services available in two rural districts within the existing government health system, with an emphasis on pain management. The specific objectives of this intervention were:

1. Introduce palliative care, focusing on pain management, at HIV treatment facilities in Mayuge and Namutumba districts in Uganda.
2. Identify and implement accepted clinical practices for establishing and improving palliative care in the context of HIV/AIDS through a collaborative improvement approach whereby quality improvement teams from participating facilities work on shared goals.
3. Engage providers, health officials, and community members in strengthening community support for palliative care and in establishing a system to sustain the continuum of care through referrals between community volunteers and providers of palliative care services at all levels of the health system.
4. Address general health system challenges that are brought to light through the effort to strengthen palliative care.
5. Engage and define the roles of district health leaders in setting up and sustaining quality palliative care programs in the facilities they supervise.
6. Refine and compile "best practices" for establishing quality palliative care services in rural health facilities and for spread to other sites in Uganda and ultimately to treatment

programs for HIV/AIDS and other life-threatening illnesses in other low- and middle-income countries.

## IV. INTERVENTION

Following the baseline assessment conducted in June 2010, a stakeholders meeting was held with local health officials to present the findings and engage them in planning and carrying out this quality improvement initiative. It was decided that the intervention would promote improvement in all aspects of palliative care but would emphasize pain and symptom management for HIV/AIDS patients. Facility-based efforts would be carried out by providers at health centers (and the hospital) providing HIV care and treatment, and community efforts would be undertaken by facility-linked community volunteers. The stakeholders elected to employ a collaborative improvement approach to integrate and improve palliative care for people with HIV and other life-threatening illnesses. Thirteen health facilities were identified as appropriate, primarily due to their delivery of HIV services, to include in this collaborative improvement initiative. These included nine facilities in Mayuge District (one hospital, two HC IV, five HC III, and one HC II) and four facilities in Namutumba District (one HC IV and three HC III).

### A. Collaborative Improvement Approach to Service Integration and Strengthening

Quality improvement principles are based on recognition that health services are delivered through a system made up of multiple processes. Gaps in services are identified, and the processes involved in delivering the services are analyzed to identify ways in which the processes, and consequently the overall system, can be improved. Process changes intended to improve service delivery are employed, and their effectiveness is determined by regularly collecting data to measure the impact of these changes on process or outcome indicators over time. Depending on the results of this assessment, tested changes are abandoned, adapted and retested, or adopted and implemented as established improvements.

Improvement activities are led by facility-based teams made up of the providers in each facility who meet regularly to identify and discuss service gaps, establish goals for addressing these gaps, analyze root causes of barriers to reaching these goals, and identifying changes designed to achieve improvement goals. Changes are then tested and data are monitored on an ongoing basis to determine the effectiveness of tested changes and the need to continue to plan and test changes.

In the collaborative improvement approach applied in this intervention, improvement teams from the participating facilities share common improvement aims and used common indicators to measure progress toward achieving the aims. In this intervention, 13 facility teams and two districts teams worked together on the shared improvement aim of: identifying, evaluating and treating (or referring if necessary) all patients in HIV care who suffer from chronic pain.

In collaborative improvement, each team leads improvement activities at its respective facility, and the teams meet with each other periodically to share and discuss experiences and results, learning from and encouraging each other in the process. These periodic meetings are called learning sessions and often include discussion of clinical topics. During the time between learning sessions, known as action periods, teams work at their facilities to develop and test changes and are coached by district health officials or HCI staff during regular coaching visits.

#### Strengthening the Capacity of the Health Workers to Integrate Pain Management into HIV Care

Two health workers from each of the 13 participating sites, along with health officials from the district palliative care improvement teams participated in a five-day course on palliative care provided by the Palliative Care Association of Uganda in July 2010. The course was delivered using Uganda's national palliative care curriculum for health professionals and also included an orientation to the principles of quality improvement and problem-solving provided by HCI staff. In September 2010, community volunteers linked to each site were also trained by the Palliative Care Association of Uganda, using the

national curriculum for community volunteers. These short courses were intended to build essential skills in palliative care and pain management in order to facilitate the integration of palliative care into existing services for people living with HIV/AIDS and their families. On-site teaching for health providers was performed one month after the initial classroom training to reinforce lessons from the course with a hands-on approach to health worker skill strengthening.

#### Establishing and Supporting the Collaborative Improvement Work

HCI and district officials worked in partnership to facilitate the formation of the multidisciplinary quality improvement teams in the 13 facilities. Some health facilities had existing improvement teams from prior work on HIV care also supported by HCI, and these were re-engaged to address palliative care. The teams led efforts to integrate palliative care at their sites and were responsible for data collection, for identifying reasons for gaps in service delivery, and for planning and testing changes designed to facilitate the integration and strengthening of palliative care services. Ultimately, teams were responsible for assuring the consistent delivery of pain management services to all patients in need of them. A general action plan (see Appendix I) was developed to facilitate the integration of palliative care with HIV/AIDS services.

Sharing workshops – “learning sessions” were held in December 2010, April 2011 and September 2011. At these sessions, teams shared data and experiences and developed facility-specific work plans for the next action period. These learning sessions brought together QI teams from all participating facilities, along with district officials and community volunteers to exchange ideas, share results, encourage one another, and work through challenges in integrating and strengthening palliative care at community, facility and district levels. Site and district teams synthesized information using a tool (see Appendix II) to compile information for sharing their data and changes tested to improve data. The sharing that occurred at the learning sessions helped to spread changes which were effective at one site to other sites. Learning sessions also provided an opportunity for providers from sites that were not doing well to learn from others with similar challenges who were able to successfully overcome these challenges.

Teams were provided with a monthly data compilation form (see Appendix III) so that they could monitor progress against set goals. The teams used documentation journals updated on a regular basis to record changes tested, with detailed descriptions of successful changes which resulted improvement. This information would ultimately be presented and discussed at learning sessions.

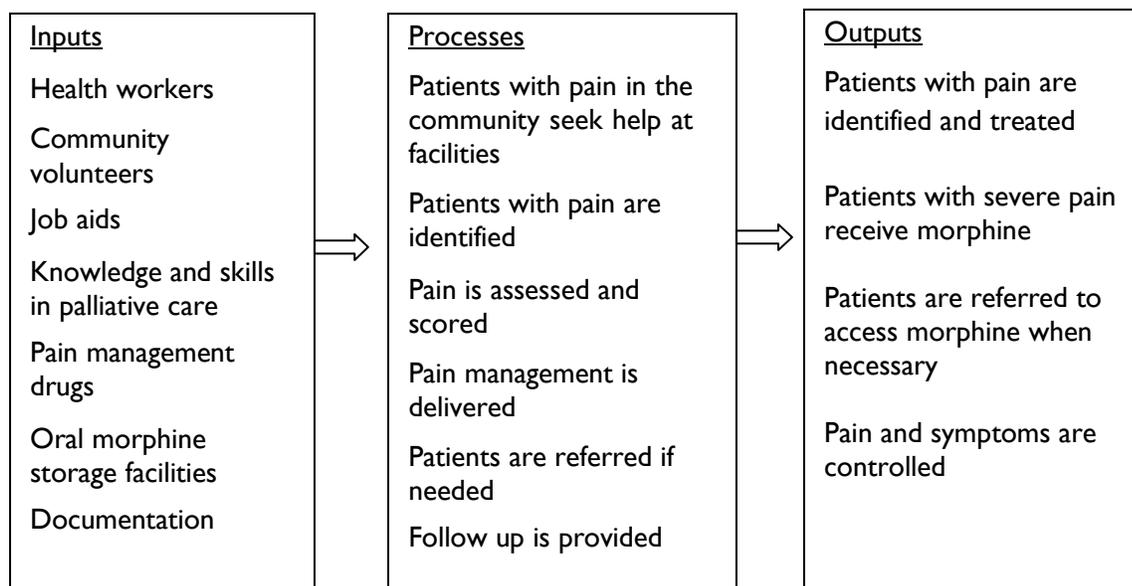
The first learning session, held several months after the initial five-day training in palliative care and improvement, brought together health providers to share their progress in integrating palliative care with other health services. Six sites had made changes in identifying and assessing patients for pain while only three sites had made changes to ensure that pain was scored and documented. These changes were shared with all sites to help them start the integration process. By the second learning session, 12 facilities were identifying, assessing and scoring patients with pain. Health providers shared their progress along with changes that lead to improvement. At this point, teams started to work on ensuring sustainability of the successful changes. The third learning session focused on sustaining palliative care service provision at both the district and the facility levels.

In the action periods between learning sessions, monthly on-site coaching and mentoring was conducted at each site to assist providers in integrating palliative care with HIV care and improve the processes involved in palliative care. This coaching was carried out by HCI staff, the district teams and palliative care specialists from PCAU. Support from the coaches included strengthening the improvement skills of site teams, identifying strategies for sustaining palliative care services, development and provision of documentation tools, and helping to strengthen palliative care practices.

## B. Integration of Pain Management

Integration of pain management required changes at multiple points in the health service delivery system. This system can be described in terms of Donabedian's Systems Model<sup>20</sup> consisting of inputs, processes and outputs (see Figure 3).

Figure 3: A system model for integrating pain management



Teams worked to establish and improve processes to support: 1) identification of patients with pain, 2) assessment and scoring of patients with pain, 3) management of pain and prescription of pain medicine, and 4) appropriate referral of patients. These efforts are described below:

### 1) Identification of patients with pain:

The first major challenge in improving pain management services was to identify patients in need of these services. QI teams agreed to address the challenge of identifying patients with pain as the first step in integrating palliative care services. In order to do this, the QI teams worked on assuring that every patient attending the HIV clinic was asked about pain. In some of the facilities, patients would be asked about pain as part of the triage process. In health facilities without a triage system, clinicians would simply inquire about pain as a standard part of every patient assessment. Patient responses would then be noted on their treatment card.

### 2) Assessing and scoring pain:

All patients who reported having pain would be further assessed. In order to assure that patients were treated appropriately for their level of pain and that the cause of the pain was properly investigated, providers were urged to characterize and score the pain according to the pain assessment method (see Appendix IV) that they had learned at the palliative care training. Providers were also required to explore and document the nature and cause of the pain so as to appropriately manage it.

### 3) Prescription and management of pain:

Once pain was assessed and categorized the provider would prescribe appropriate pain medicine using the WHO pain ladder (see Figure 4), and document this along with any other prescribed treatments on the patient card.

Figure 4: World Health Organization pain relief ladder



Source: <http://lifesciencesnetwork.blogspot.com/2012/11/pain-ladder-by-who.html#!/2012/11/pain-ladder-by-who.html>. Adapted from WHO pain ladder, available at: <http://www.who.int/cancer/palliative/painladder/en/index.html>.

#### 4) Referral:

Patients in the community identified to be in need of pain management, often by community volunteers, were referred to health facilities. Prior to this intervention, community volunteers already had an established role in health, mainly addressing other aspects of HIV care. During this intervention, community volunteers were trained to identify patients with chronic pain in need of treatment by asking their patients about the duration of their pain and about whether they had received any treatment yet. They referred people in need of pain management to health facilities and provided health education in their communities about the availability of pain management services at the local health facility.

Patients who needed a level of care that was not available at the local health facility were referred to other facilities where the needed level of services was available. Patients were commonly referred from lower level to higher level facilities to access oral morphine and other pain medicines, for example, and for diagnostic work-ups unavailable at lower level facilities.

### C. Securing Palliative Care Specialist Knowledge and Leadership

In order to strengthen the capacity of the districts to provide comprehensive palliative care services, including the provision of morphine to patients with severe pain, HCI supported the participation of one clinical officer from Mayuge and one nurse from Namutumba in the nine-month Palliative Care course offered by Hospice Africa Uganda. In addition to creating palliative care specialists for the two districts, this training resulted in each district having a legal prescriber of oral morphine. District officials were engaged to provide ongoing support for the specialists and promote the application of their palliative care skills and morphine prescriber rights. It was agreed that the role of each palliative care specialist would not only be to provide palliative care services but also to build the capacity of other health workers to provide palliative care and to advocate for palliative care throughout the districts.

### D. Logistics and Management of Morphine

As noted previously, there was a national stock-out of morphine at the start of the intervention. Even prior to the stock-out however, only one facility in either district ever had oral morphine available, meaning that very few people with severe pain in these districts ever received morphine. While the MoH worked with palliative care organizations to re-establish a reliable supply of morphine in Uganda,

HCI worked with the districts to prepare to make morphine more widely available to those in need once it became available again at the national level.

In order to meet national standards for accreditation to provide oral morphine, facilities are required to store it in double-lock cupboards fixed to a wall. Only one facility, the district hospital in Mayuge, had such a cupboard prior to the intervention. As part of the intervention, five more facilities selected by the district improvement teams (two in Namutumba and three in Mayuge) were assisted to have the special cupboards constructed and installed. Discussions were held with the district teams focusing on logistics and management of oral morphine. Both districts assigned persons to be responsible for each element of morphine management including: requisition, accountability, and distribution of the drug. Once oral morphine became available, the districts were supported in its procurement through National Medical Store (NMS)/Joint Medical Stores (JMS) with assistance from PCAU.



Wall-fixed double-lock cupboards for storage of oral morphine at a Namutumba HC III. Photo by Suzanne Gaudreault, URC.

### **E. Harvest Meeting**

In June 2012, HCI facilitated a two-day “harvest meeting” in order to gather and share detailed information on the efforts undertaken to integrate pain management into health care services. This meeting informed the development of a change package (Appendix V) to facilitate spread and continuous improvement of palliative care services. The meeting was attended by 18 participants representing the different categories of people who were involved in the implementation of the palliative care improvement collaborative. These included representatives of the MoH and PCAU, health workers (clinical officers, nurses and nursing assistants), palliative care clinical officers, a community volunteer, and a patient.

The first day focused on identifying the different changes tested and adopted over the course of the intervention. The changes were listed and sequenced into seven main focus areas: pain management training, documentation, delivery system designs, availing oral morphine and other pain medicines, community mechanisms, and institutionalization. These areas were identified by meeting participants as

being the main drivers towards achieving the goal of alleviating the pain of patients with life-threatening chronic diseases.

The second day of the meeting focused on evaluating the feasibility and efficacy of tested changes and deciding which changes to endorse, discard, or combine. The different changes were also sequenced according to which changes must occur first in order for others to be effective (see Figure A2 in Appendix V). The participants later discussed and documented in detail how each change was implemented.

## V. RESULTS

### A. Identification and Documentation of Pain

Examination of patient records prior to the intervention revealed that pain was rarely addressed. In order to ensure that providers consistently identified patients needing pain management, site teams decided that all patients must be asked about pain as a symptom. A pain assessment column (see photograph) was added to the longitudinal ART treatment card in order to remind health workers to ask about pain and to provide a place to document pain. At facilities with a formal check-in or triage procedure, patients were asked as part of check-in, either by a clinician or by a lay worker, whether they had pain. The response Y for 'yes' or N for 'no' was recorded in the pain assessment column. The treatment card with this column would then pass to the clinician who would assess and categorize the pain. At sites without a formal triage or check-in process, it was the clinician's responsibility to ask about pain as part of the patient visit.

PROBLEMS	Work/Playing/Atm/Bed	stage	Adhere/Disad/Why/Dispersed	ADH/Why	Regimen/Disad/Why/Dispersed	CD4 HbE word COEs severe	Hgt. RPR CAR, TB spulms, Infant Ab/PCR, other	link/provide (including nutritional support and infantfeeding)	Pain assessment column
Other Cough Joint Pain	W	2	-	ADH/Why	REGIMEN DOSE No. of Days	119			P Y 1/5
	W	2		ADH/Why	ADH/Why 14/14				N 0/5
W	2			ADH/Why	ADH/Why 14/14				Y 1/5
W	2			ADH/Why	ADH/Why 30 days				N 0/5
W	2			ADH/Why	ADH/Why 60 days				Y 2/5
W	2			ADH/Why	ADH/Why 30/30				Y 2/5

HIV patient care card with column added for pain assessment

From the beginning of the intervention until the second learning session, there was a threefold increase in the number of patients who were asked about pain (see Figure 4). The increase was sustained for the remainder of the intervention. After an initial increase in the percentage of patients identified as having pain, the proportion with pain generally stabilized at between 40 – 50% (see Figure 5). For HIV patients, pain assessment and management decisions continued to be documented in the areas of the record where other assessment and management aspects of the patient visit were already being documented.

Figure 4: Percentage of patients who attended the HIV clinic who were asked about pain

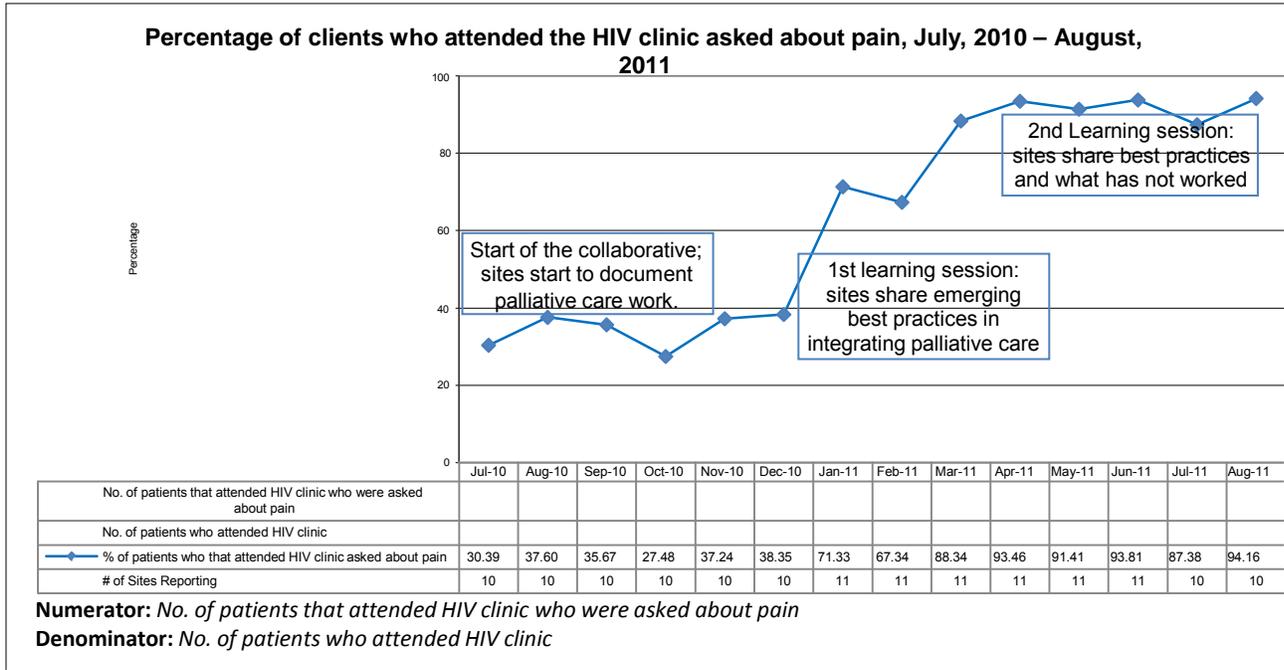
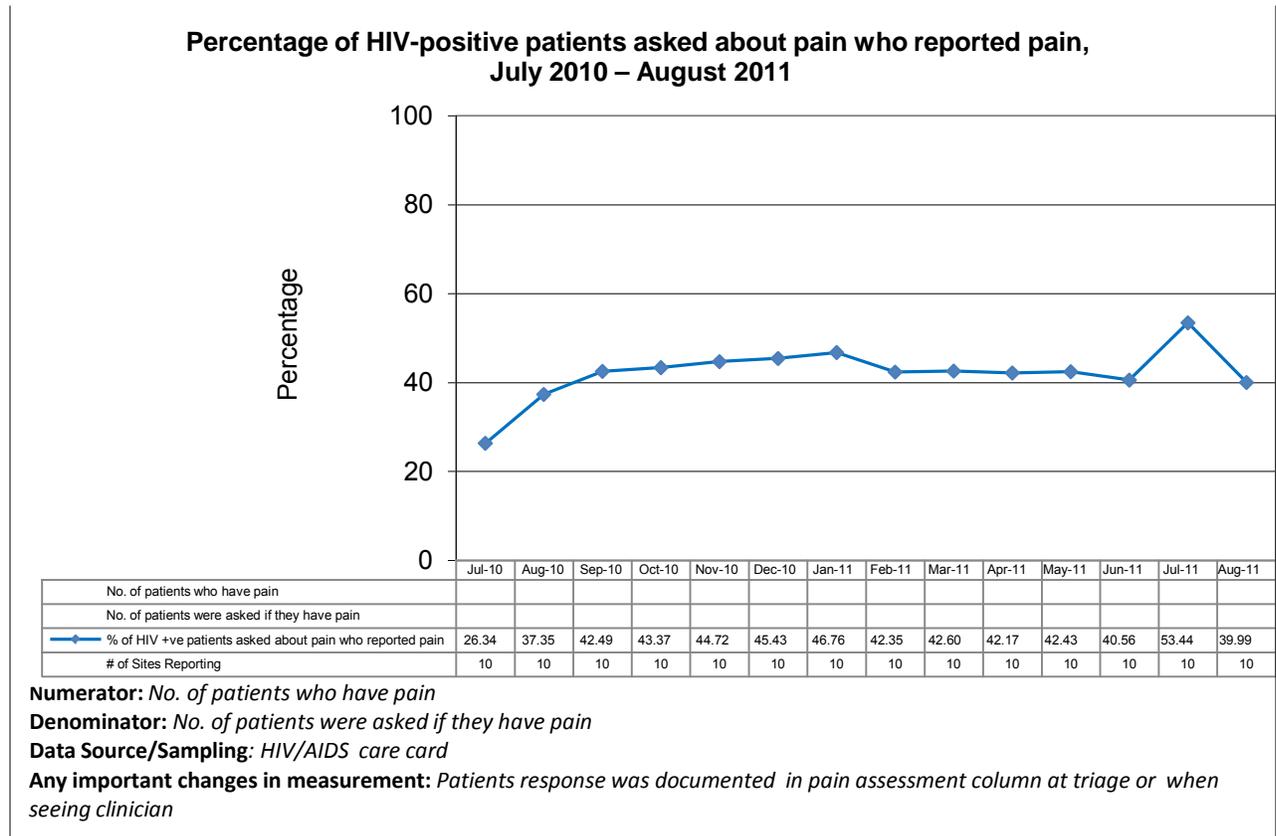


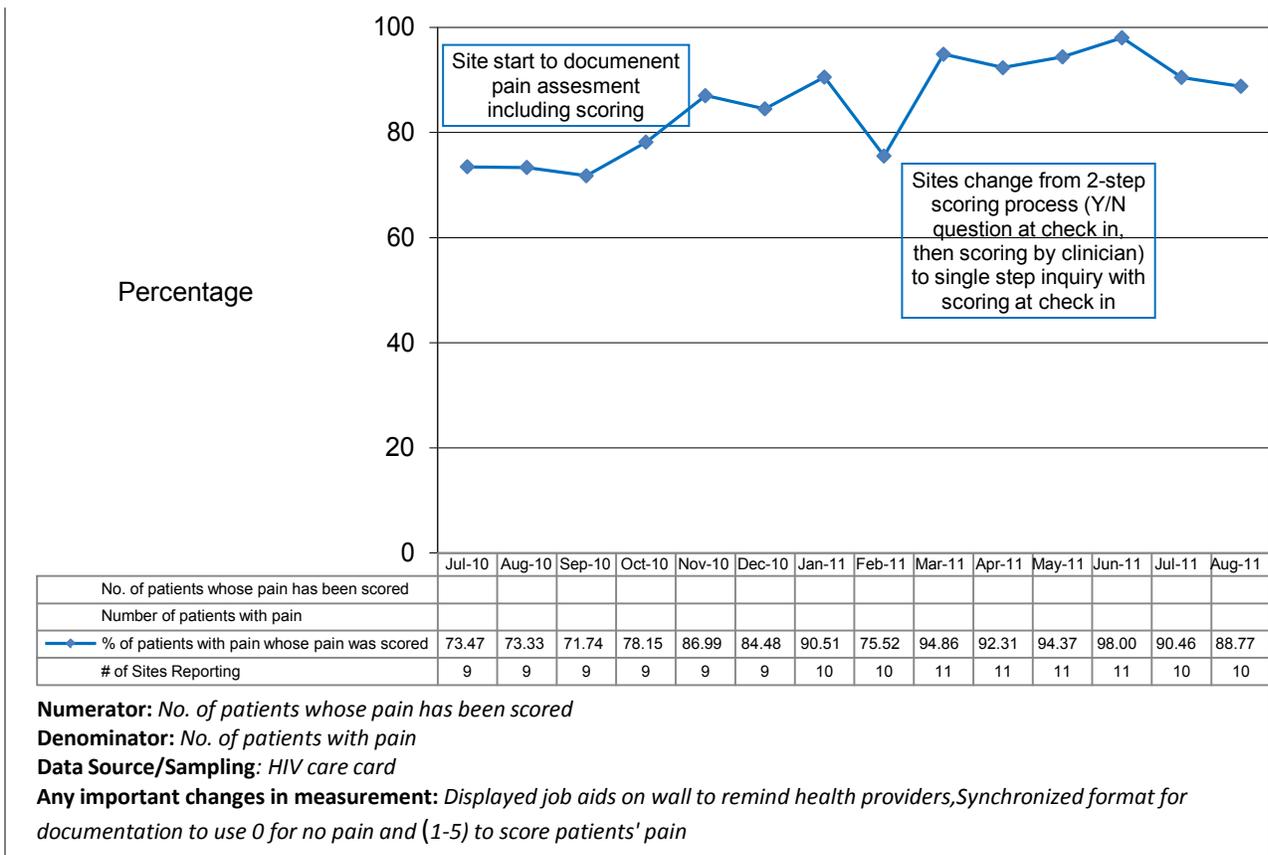
Figure 5: Percentage of HIV-positive patients who reported having pain



At the beginning of the intervention, the improvement teams in four of the sites tested a two-step process of: 1) simple yes/no inquiry about pain at check-in, followed by 2) scoring of pain by a clinician. In other facilities patients, with pain were immediately scored at check-in (often by a lay health worker) using a 0-5 scoring scale with 0 representing no pain and 1-5 indicating the degree of pain as described by patients. Data collected in January 2011 showed that the teams which combined the two steps of asking about and scoring pain then documenting only a pain score (using the 0-5 scoring scale) had many more patients actually scored compared to those which divided the process into two steps, usually carried out by two different people. Upon sharing these results, teams including the Y/N step in the documentation of pain assessment decided to eliminate this step and only document pain already categorized on a scale of 0 - 5. This boosted the percentage of patients identified as having pain whose pain was also scored to 90% (see Figure 6).

Although people with HIV/AIDS were the primary targets of this intervention, there was a “spillover effect” to patients without HIV being cared for in the same facility. Longitudinal documentation only existed for HIV patients, however. Some sites therefore created special registers to include longitudinal documentation of palliative care for non-HIV/AIDS patients (see photo).

Figure 6: Percentage of HIV-positive patients with pain, whose pain was scored, July 2010 –August 2011



Name	Village	Location	Age	Sex	Ref	Pain Assessment Intensity	Diagnosis	Date	Notes
[Redacted]	Bugodi	Bugodi	60	F	70	4/5 Nociceptive	Tramadol Amoxicillin Paracetamol Vib. Abs.	11/1/2011	2nd visit Bwamba HV
[Redacted]	Wazabwa A	Lugalla	55	F	45	4/5 Nociceptive	Amoxicillin 500 mg Cefixime Paracetamol	11/1/2011	
[Redacted]	Buta A	Buta	37y	M	60	Pain P <sub>1</sub> 4/5 P <sub>2</sub> 4/5 P <sub>3</sub> 4/5	Amoxicillin Cefixime Paracetamol Mucolytic / Antitussive	TCA 20/10/10	22
[Redacted]	Bulungu	Wabwa	60y	M		Nociceptive Pain P <sub>1</sub> 2/5	Amoxicillin Paracetamol TCA 20/10/10	TCA 20/10/10	
[Redacted]	Bugodi	Bugodi	60	M	50	P <sub>1</sub> 3/5 P <sub>2</sub> 3/5	Amoxicillin Paracetamol TCA 20/10/10	TCA 20/10/10	

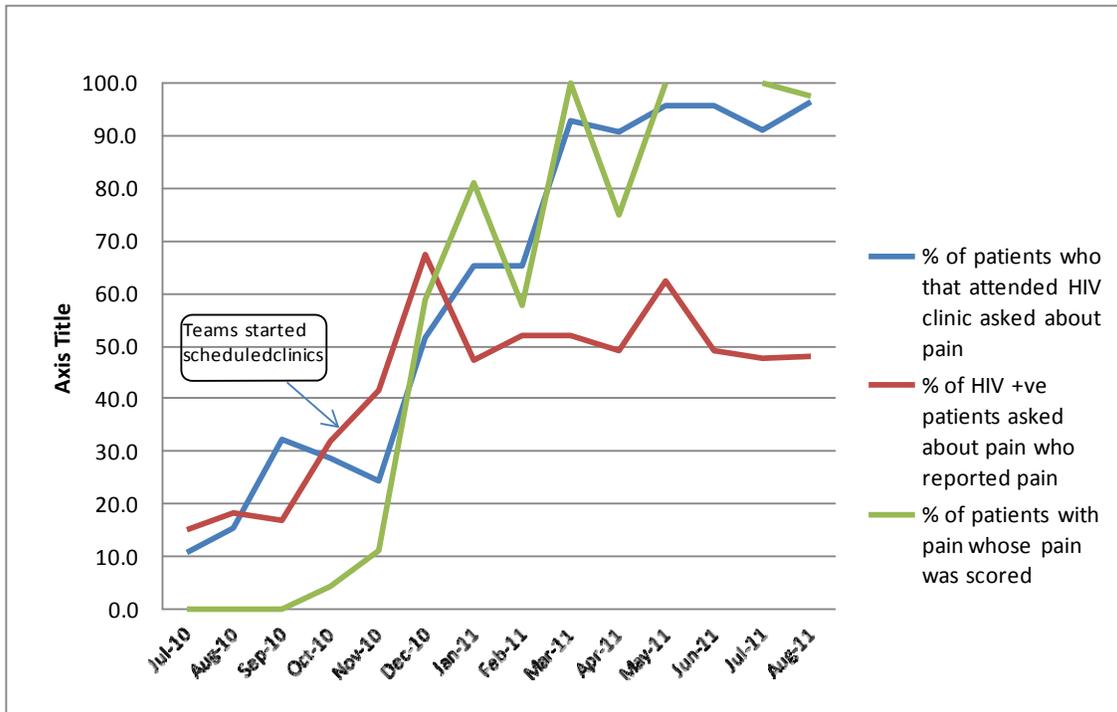
Palliative care register for patients in the general outpatient department. Photo by Juliana Nabwire, URC.

## B. Expansion of Availability of Chronic Care for HIV

At the start of the collaborative improvement project, three health facilities in Mayuge District did not have designated HIV chronic care clinics. Instead, HIV patients would come in for care on any day and without regularity. This resulted in poor documentation and follow-up of patients. HCI and the district quality improvement team worked with the local USAID-funded HIV and TB services support project, STAR-EC, to help these facilities establish scheduled HIV clinic days, supported by experienced staff from elsewhere in the district, in order to improve HIV care and treatment. This led to the establishment of facility-based longitudinal records for HIV patients whose care and treatment information had previously been limited to that entered in patient-held documents. On-the-job training was done during clinic days at these three facilities to strengthen the skills of health workers in providing general HIV and palliative care services.

Clinical mentoring teams, composed of experienced district health workers supported by STAR-EC, scheduled their visits on HIV clinic days in order to provide hands-on training for the health workers. In contract, quality improvement coaching sessions were scheduled on non-clinic days to allow time to meet with the providers, review data, discuss challenges, and agree upon the way forward. Once HIV clinic days were established, the number of HIV patients seen steadily increased from 36/month in July 2010 to 200/month by March 2011. Meanwhile, the percentage of patients with documented pain assessment increased from 10% to over 90%, respectively (see Figure 7).

Figure 7: Percentage of HIV patients asked about pain, reporting pain, and scored for pain at three health facilities in Mayuge District with newly established HIV clinics

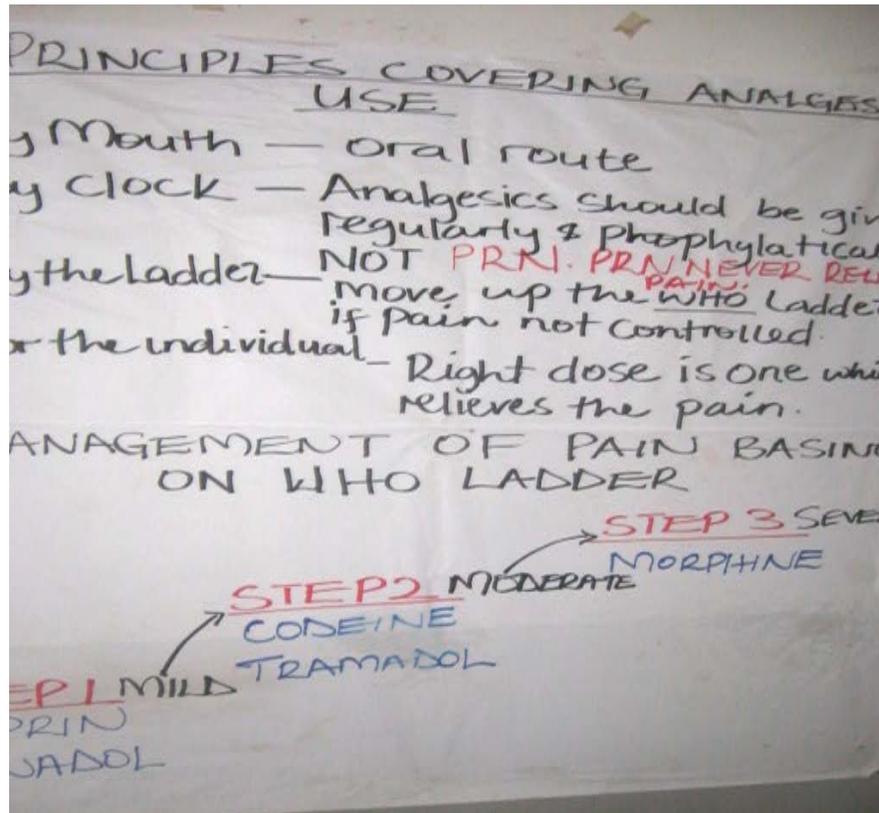


Coaches and health workers reviewing data during a coaching visit. Photo by Juliana Nabwire, URC.

**C. Job Aids**

To support pain assessment, categorization and management, health providers developed their own job aids (see photograph below) or obtained printed job aids from NGOs or other sources. They posted

these job aids on health center walls for easy viewing to facilitate medical decision-making regarding pain management.



Job aid for pain management designed by a facility team and posted on the health center wall. Photo by Juliana Nabwire, URC.

#### D. Strengthening Capacity for Provision of Palliative Care across the Facility Health Care Team

Two providers from each facility were trained during the one-week palliative care course held at the start of the intervention. This capacity-strengthening activity was to intended support the launch of clinic-based palliative care service provision. As time went on, however, coaching and supervisory visits revealed that pain management services were actually not being provided regularly at some of the participating health facilities. Where this was a problem, providers reported that the health workers who were trained in the five-day course on palliative care were seldom available for patient care. The teams were then assisted in building the capacity of all clinical staff to assess and appropriately manage pain. Site teams then organized periodic continuing medical education sessions in their facilities to enable more staff to learn how to assess and manage patients in need of palliative care. Eventually, roles in providing palliative were assigned to specific team members, and the entire team was held accountable for the consistent implementation of pain management services. This resulted in functional site teams which could more effectively overcome periodic challenges like absenteeism among staff members.

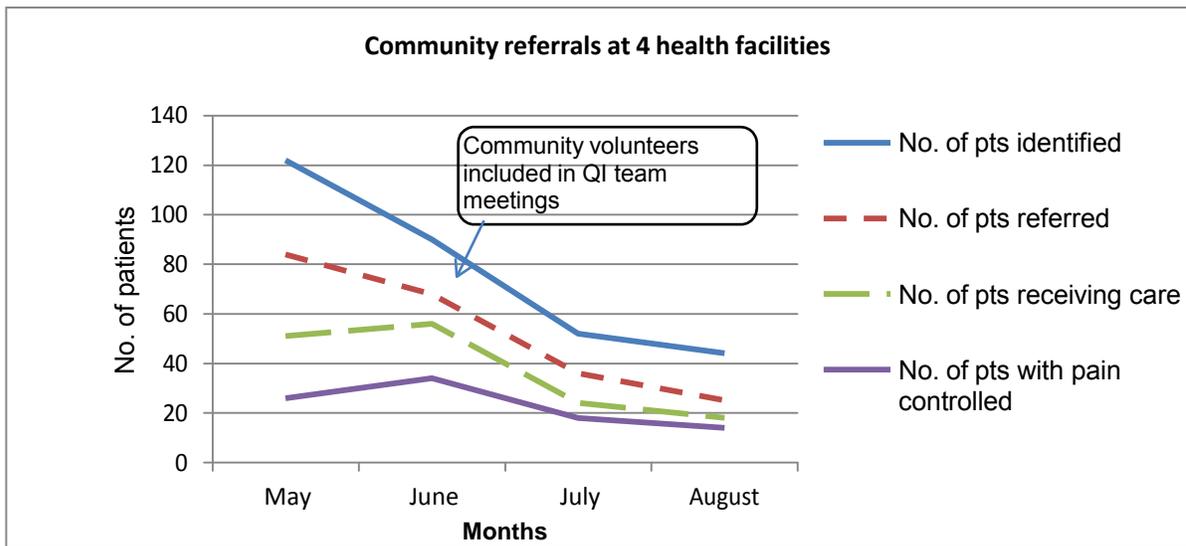
#### E. Community-Health Facility Linkages

At the start of the intervention, health workers at each facility identified community volunteers to serve as links between the community and the health facility for people with palliative care needs. These volunteers were trained using the national curriculum on palliative care for community health workers

and were assigned the tasks of: 1) identifying patients with pain, 2) assessing their pain by asking a few simple questions, 3) assisting patients to take prescribed medicines, and 4) educating patients on general health issues like cleanliness, nutrition and hygiene.

The volunteers were instructed to refer patients with pain to health facilities for proper assessment and management. Data collected in May 2011 showed that community volunteers had identified more than 120 patients in the community needing medical attention for pain, but only about 50 of these were reported to have received care at the facility (see Figure 8). The volunteers explained that many of these patients were too weak to travel to the health facility and were in need of home-based care. Some of these patients were also reported to be very isolated and to not receive adequate care from family members.

Figure 8: Number of patients referred by community volunteers at four health facilities



## F. Improving Access to Pain Medicines through Networking and Referral

Two health facilities liaised with Rays of Hope Hospice in the neighboring town of Jinja, referring patients to be cared for on outreach days, especially to facilitate access to morphine which was very scarce early in the intervention due to a national stock-out.

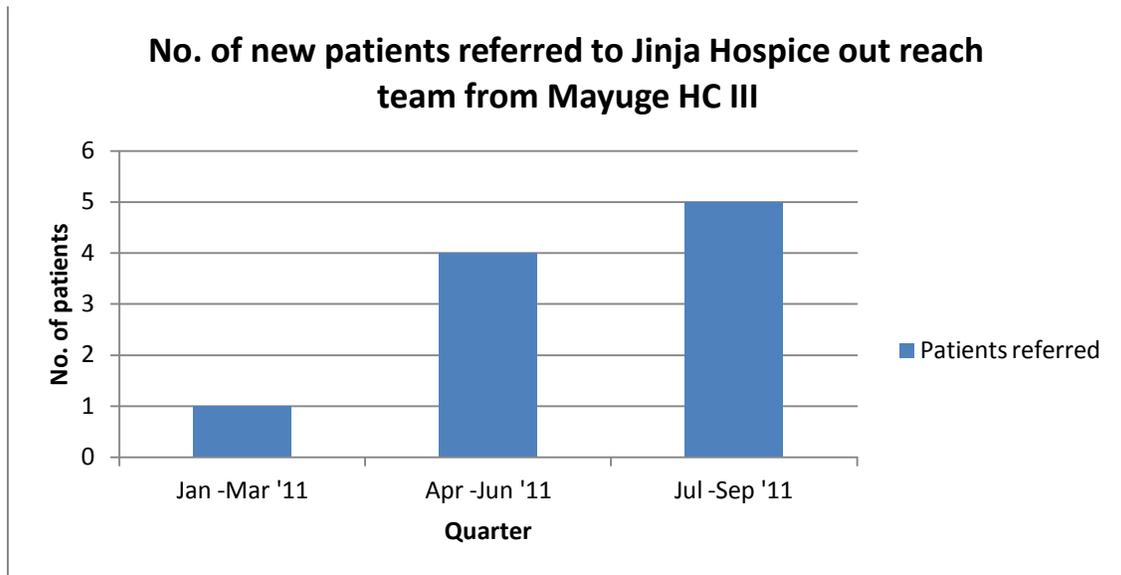
For example, through participation in the improvement project, providers at Wabulungu HC III learned that Rays of Hope provided outreach in their area and arranged for them to stop and provide services at their facility for certain patients in need of specialized care. Patients were given appointments to meet the hospice outreach team on days when they were scheduled to travel to the area.

Rays of Hope hospice team had already been visiting Mayuge HC III twice monthly through their outreach program to provide services to local patients who had enrolled with them elsewhere. Most health workers at this site, however, did not know much about the outreach services and therefore had never considered referring patients to them. Through their participation in the palliative care collaborative improvement project, the providers at the health center learned about hospice care and about which patients could benefit from hospice services. Thereafter, they routinely linked patients who needed specialist care, especially those in need of oral morphine, to the hospice outreach program. Patients were given referral notes and appointment dates for hospice outreach days.

“The hospice team used to come in the district and sees their patients; we did not know much about their work. Now things have changed we send them our patients who need their care and we

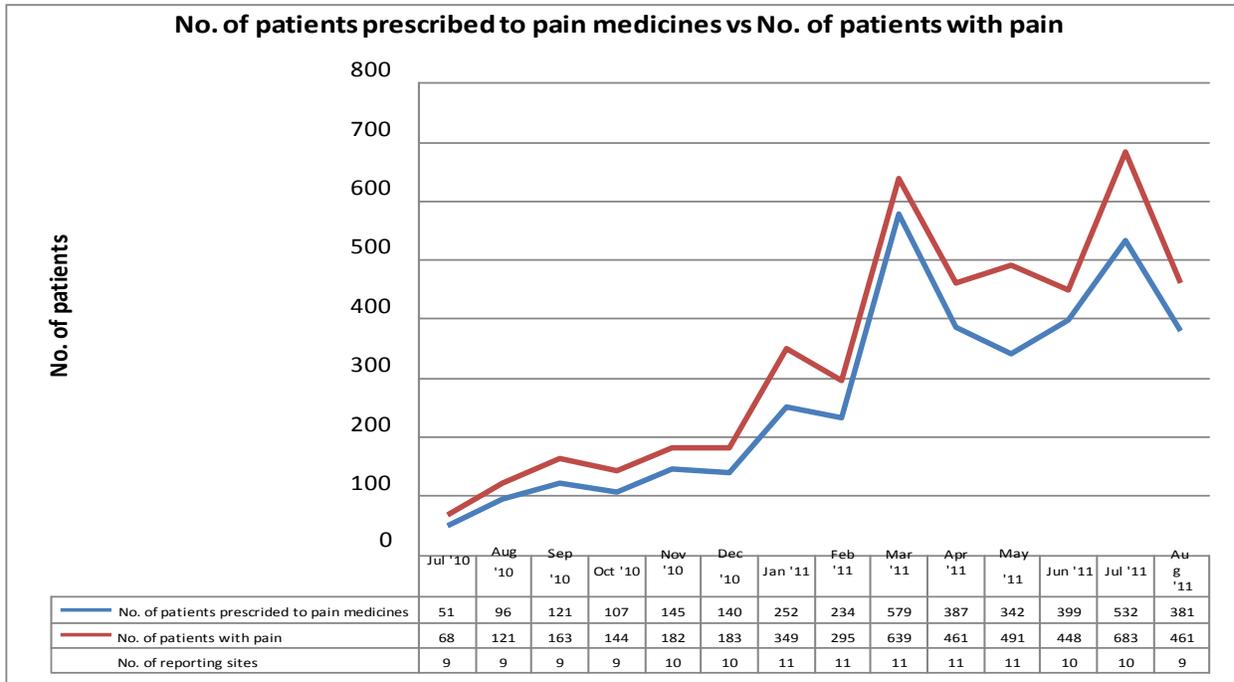
cannot provide it, especially for oral morphine that is used to treat severe pain,” reported a health worker at Mayuge HC III (see Figure 9).

Figure 9: Number of new patients referred to Jinja Hospice outreach team from Mayuge HC III



Despite the rapidly increasing numbers of patients with pain identified and needing management, through these procedures, 70-90% of patients with pain were able to receive appropriate pain medication (see Figure 10). When pain medicines were not available at facilities, providers either gave patients prescriptions to purchase them or referred the patients to other facilities which did have the needed medicines in stock. The national stock-out of morphine posed a particular challenge which was ultimately solved at the national level as described below.

Figure 10: Number of patients with pain and those prescribed pain medicine



## VI. DISCUSSION OF CHALLENGES AND RECOMMENDATIONS

### A. Drugs

Although Uganda is known for its relative progress on establishing policies and systems for making oral morphine available to people with severe pain, the country was facing a national stock-out of oral morphine at the beginning of the intervention. To address this problem and prevent it from happening in the future, PCAU, the MoH and the other national palliative care stakeholders designed a new oral morphine supply chain system (see Figure 11) to ensure its uninterrupted availability in the future. The new system, which was put into place in January 2011, allows accredited health facilities to request and receive oral morphine through the National Medical Stores. With this new system in place, it is expected that health facilities which make orders in a timely manner will receive their supplies promptly.

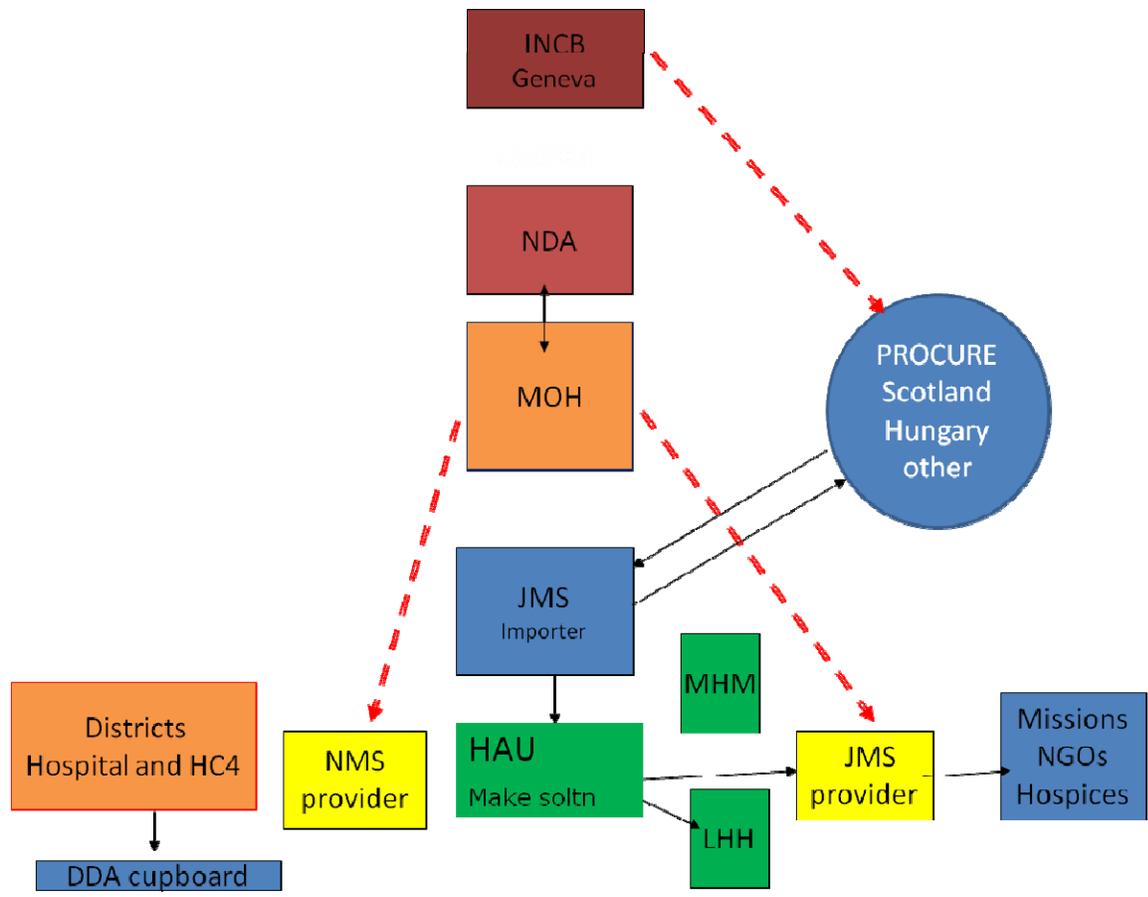
The drug procurement structure for Uganda's health system is described as a "push-pull" system. In this arrangement, health facilities from the level of HC IV and above make bimonthly requests ("pull") for drugs and medical supplies from the National Medical Stores (NMS) through the district health office. Health centers from the HC III level and below do not make their own requisitions for drugs and supplies. Instead the supplies come in kits prepared for them by district health managers. This is referred to as the "push" system.

After the start of the intervention, the health facilities authorized to make requests (the three participating HC IVs and one hospital) added essential palliative care drugs and supplies to their bimonthly orders. Without the ability to make requisitions however, Health Center IIIs were faced with a lack of appropriate medications and/or insufficient quantities of medications to introduce and expand pain management. The drug and medical supply kits sent to the HC IIIs only contained Paracetamol for pain management, even though HC IIIs regularly attend to patients with types of pain which Paracetamol is insufficient or inappropriate to treat. Because HC IIIs are increasingly providing services for chronic illnesses like HIV, they need to be supplied with appropriate analgesics and adjuvants. Advocacy by health workers and implementing partners was undertaken during this intervention, and the Ministry of Health has been informed of the need to improve drug supplies both with respect to quantities of drugs

and also with respect to types of medicines provided. Recently, the MoH informed us that the current list of essential medicines supplied to each type of health center is being reviewed and recommendations by the different stakeholders will be considered.

Another barrier to the scale-up of palliative care in Mayuge and Namutumba Districts was the extremely limited availability of oral morphine even prior to the national stock-out. At the start of the intervention, the only health facility in either district that had ever stocked morphine was Buluba Hospital in Mayuge District, which had received supplies from Jinja Regional Referral Hospital. In order to increase the accessibility of morphine across the two districts, HCI worked with PCAU to support accreditation of the HC IVs to provide oral morphine. This effort included the installation of wall-fixed double lock cupboards and the support of one health worker from each district to become a formally trained licensed prescriber. The District Health Officers were also engaged to help acquire oral morphine. In Namutumba, for example, the district team designated a specific officer to be in charge of managing morphine supplies in the district, working in close collaboration with the District Health Officer.

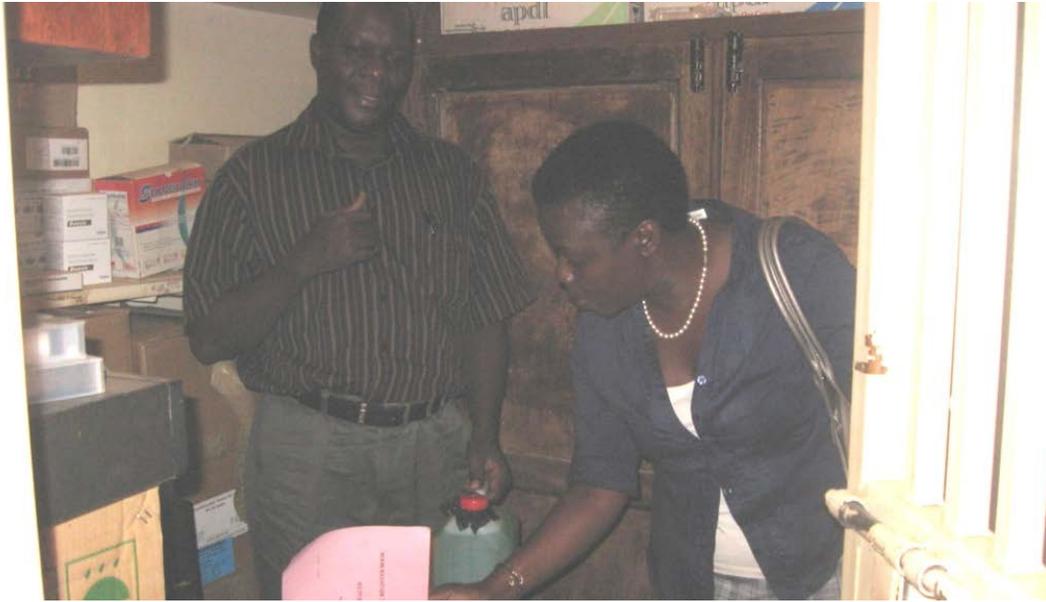
Figure 11: Morphine supply chain system with 2010 changes



**Key**

- DDA- Dangerous Drug of Addiction
- HC4- Health center IV
- NMS- National medical stores
- HAU- Hospice Africa Uganda
- LHH- Little hospice Hoima
- JMS- Joint medical stores
- MOH- Ministry of Health
- NDA- National drug authority
- INCB- International Narcotics Control Board
- MHM- Mobile Hospice Mbarara

Source: Diagram provided by Palliative Care Association of



Ms. Rose Kiwanuka, PCAU Coordinator, handing over oral morphine to the District Health Officer of Namutumba District. Photo by Juliana Nabwire, URC.

## **B. Patient Care**

### Home-based care

The community volunteers identified many patients who needed palliative care services but who were unable to report to health facilities due to weakness and transport costs. Although some home visits were carried out during this intervention, health workers generally cannot travel to communities to provide care because they do not have the means and/or the time to make home visits. Although care and treatment for most patients can be managed in health facilities, there is still a great need for home-based care as a mode of providing services for those who are bedridden or too weak to travel. Home-based care must be built into health service programming with capable staff allocated and supported to provide services to patients and their families. Community volunteers (including Village Health Team members) should play this role in the future so that the need for home visits by clinicians is limited to making an initial assessment. Ongoing care for the patients could then be planned with volunteers, patients, and family members.

### Availability of health workers

Most health facilities in the two rural districts are chronically understaffed, and health care personnel are visibly overburdened as a result. This situation frequently results in compromised quality of patient care, and chronic absenteeism of health workers exacerbates the problem. During the course of the intervention described in this report, facility teams took measures to assure that palliative care was not the responsibility of just one person. This helped ensure its availability even in the absence of particular key staff. To address the widespread problems caused by understaffing and absenteeism and its impact on all health services, leadership at all levels of the health system should comprehensively examine and address root causes for this barrier to quality care.



A team of palliative care providers, health workers and community volunteers visit a patient at home.

Photo by Juliana Nabwire, URC.

#### Inability of referred patients to travel to other health facilities

Patients referred to higher level health facilities for services unavailable at the referring facility frequently do not go because they lack the means to travel. Outreach by palliative care providers to lower level health facilities would help overcome this barrier to care. In this intervention, each district sent a clinician for palliative care specialty training. With support from the district, these specialists should be able to perform ongoing outreach in order to provide palliative care services throughout the district.

#### Strengthening the skills of health workers

Many health workers complained that not enough of the staff were skilled in palliative care because only two staff members received the initial five-day training. Because it is not possible for every health worker to attend training, it is critical that trainees share their knowledge with their colleagues. To assure that those trained share knowledge and skills with other health providers, a standard training package should couple onsite training with regular mentoring and coaching.

Due to the shortage of legal prescribers (i.e., physicians or medical officers) in rural areas of Uganda, gaining access to morphine can be a slow process. The MoH has put into place a system where clinicians who are not physicians can receive specialty training in palliative care which qualifies them to become legal prescribers of morphine. This system has been instrumental in facilitating some scale-up palliative care services in Uganda. The nine-month duration of the course for palliative care, however, which requires participants to be absent from their post, can be a major burden to health facilities which are already chronically understaffed. The expense of the course can also be prohibitive. It would therefore be helpful to revisit the model of training for this course with the goal of shortening it or adapting it so that it does not place such a strain on human resources. This could facilitate the scale-up of palliative care services throughout the country.

#### Team functionality and its impact on patient care

Of patients referred by community volunteers who were able to seek care at health facilities in May 2011, only about half reported that their pain was sufficiently managed through treatment. In June 2011,

the facility-based improvement were asked to include community volunteers at team meetings in order to gain their insights on patients' needs and how best to address these needs. The volunteers provided very valuable input for the improvement teams. For example, at one health facility, the volunteers revealed that some patients who were referred to that facility reported that once they reached the facility, they were refused treatment with an explanation that the palliative care provider was not available. This occurred even though all of the providers had been trained in pain assessment and management by that time. In response to this disturbing feedback, the team resolved that every health provider would be responsible for providing pain assessment and management for any patients needing these services. This resulted in improved provider practices such that by August 2011, over 80% of patients visiting health facilities due to pain reported that their pain was controlled.

Some health workers complained of poor teamwork in general, and it was common for coaches to discover that teams had not met for general staff meetings let alone improvement team meetings, both of which are important for sharing, for team building, and for engaging staff in improving service delivery. Personnel at sites should be required to attend scheduled meetings and continuing medical education sessions in order to contribute to discussions concerning facility operations and quality improvement activities as well as to stay current on evidence-based health care services. This way communication can be constantly facilitated and teamwork strengthened in support of continuous improvement of health services.

### **C. District Leadership**

Direct engagement of local health system leaders is critical both to the successful implementation of quality improvement initiatives in health facilities and to the long-term sustainability of the progress achieved through these initiatives. From the beginning of this intervention, HCI involved the district management personnel directly in the implementation of the palliative care collaborative improvement intervention. The two district improvement teams played an important role in identifying suitable health workers to be trained in palliative care, for example. Furthermore, they participated in all learning sessions and coaching visits where they provided valuable input. Their participation in these activities also made them aware of problems which needed to be addressed at the district management level so that they could follow up appropriately. Their involvement strengthened capacity and engagement at the district level, providing management support to ensure that facility-level achievements could be sustained. Their leadership was further exhibited at various meetings where they regularly gave briefings on the efforts to integrate and strengthen palliative care.

Some districts in Uganda have trained palliative care specialists who are actually unable to provide palliative care services due to lack of support from the district. The newly trained palliative care specialists (who took the nine-month palliative care course) in Mayuge and Namatumba are actually the only active providers of patient care in these two districts who can legally prescribe morphine. They can also cosign for other providers who prescribe morphine but are not authorized to do so. Because their specialized skills and authority are greatly in need, they must be actively encouraged and supported to provide and promote palliative care in their districts. Moving forward, the district managers for Mayuge and Namatumba plan to support their newly trained specialists and facilitate the application of their skills toward the strengthening and spread of palliative care services.

District teams were able to include palliative care activities in their work plan to ensure that there is continued support for these services in the district. District leaders must continue to lobby for health workers, strengthen supply chains for drugs, facilitate training, provide supportive supervision, and work to secure funding. Ongoing leadership at the district level is critical to coordinate health system strengthening activities and create an environment which will sustain the availability of palliative care services.

## D. Community Leadership

In order to reach people suffering from pain and other symptoms in their homes, who would not normally seek help from the health system, community volunteers were engaged to find and link people in need to health facilities.

Although many patients were referred by the volunteers to health facilities, many still did not go for a variety of reasons. As in many rural settings, the most common obstacle to visiting health care providers was probably the large distance between homes and health facilities. This was especially problematic for patients who were the sickest and weakest and often the most in need of medical attention. Some patients elected not to go to health facilities due to frustration with long waiting times and frequent shortages of medicines. Transportation and/or outreach should be facilitated in order to make services accessible to more of the people needing them. The capacity of volunteers and Village Health Teams to provide home-based care should also be strengthened. Furthermore, health facilities must continue to work toward the efficient delivery of quality services and include supply chain strengthening in their improvement efforts, so that people seeking care at these facilities are not turned away or discouraged from returning.

Volunteers involved in this intervention brought to light many other problems in the community. A particularly alarming example was the relatively common abandonment of patients who were very ill by desperate families. Most patient care and daily decisions about care actually take place at home, even for patients who use health facilities. Patients do much better when their family members become engaged and active in their daily lives and care as early as possible in the course of their illness. Communities must therefore be mobilized to educate and provide psychosocial support for their members so that those with sick family members are able to provide ongoing care and support at home.

## VII. CONCLUSIONS

Prior to the era of combination ART, palliative care was the principal clinical service provided to AIDS patients. The birth of the hospice movement in Uganda was in fact focused on AIDS patients and almost all of the early hospice patients in Uganda were infected with HIV.<sup>21</sup> Once combination ART became available, essentially transforming HIV/AIDS from a terminal illness to a chronic manageable condition for many, palliative care was increasingly ignored and even regarded by some in the context of HIV as “giving up”. This was an unfortunate shift in thinking since the impact of palliative care on patient and family health and well-being is well-established. A 2005 review on palliative care for HIV patients in the era of combination ART, covering evidence from high, middle, and low income countries revealed that palliative care improved outcomes for HIV patients in the areas of pain and symptom control, anxiety, insight, and spiritual wellbeing<sup>22</sup>. The continued importance of palliative care for HIV patients is at least as important as it was prior to combination ART for several reasons. First, although combination ART can have a profoundly positive impact on the health of persons suffering from HIV/AIDS, it also increases the complexity of patients’ needs for pain and symptom control, spiritual support, and psychosocial assistance and can greatly lengthen the duration of time over which these needs arise. This is due to the cumulative burden of HIV-related morbidity, including side effects and long term toxicities of anti-retroviral drugs<sup>23</sup>. Second, the need for the kind of support offered by palliative care services is amplified by ongoing stigma, uncertain prognoses, and unpredictable disease courses in the face of evolving therapies, extreme barriers to treatment adherence, and precarious socio-economic conditions. Finally, the need for end of life care, which is encompassed by palliative care, persists among HIV patients. This is due to late presentation of many HIV patients and to failure of combination ART for a variety of other reasons.

With respect to health systems at large, it is also important that providers are empowered to provide services which are palliative in nature to their patients. The failure of health systems to support and facilitate palliative care for HIV patients can have a profoundly negative psychological impact on health

care providers. In the era of combination ART, these providers may come to regard pain, suffering, and death in HIV patients as signs of failure on their part, for example, or they may harshly judge patients for not adhering to treatment - leading to seemingly “unnecessary” suffering and death.<sup>24</sup> This along with feelings of inadequacy and powerlessness to address basic patient needs can result in poor psychological adaptation leading to severe demoralization and disengagement from their job and from their patients. Disengagement of providers often leads to absenteeism, poor health worker retention and poor quality of services provided to patients.

Of course palliative care is important not only for HIV patients but also for patients faced with all life-threatening illnesses. The success of the hospice and palliative care movement in high-income countries has led to the institutionalization of palliative care as a basic service and “standard of care” for suffering patients. In low-income countries, however, palliative care has yet to become accessible to most people, but with growing numbers of people living with and dying of chronic diseases, there has never been a more crucial time for its introduction and scale up. This is because the rapid rise in prevalence of chronic life-threatening conditions means that there are increasing numbers of patients with protracted clinical courses, resulting in prolonged pain and suffering prior to death. The September 2011 UN Summit on non-communicable diseases (NCDs) was a major call to action and step forward in raising global awareness on the growing burden of NCDs and of chronic illnesses in general. As a key component of chronic illness care it is extremely important to develop models and operational standards for delivering palliative care on a large scale in low and middle income countries. The intervention described in this report provides a good example of how, by starting with an emphasis on the key component of pain management, palliative care can be introduced and integrated on a large scale as part of the routine care provided to patients with chronic illnesses in low resource settings.

Global health programming targeting the HIV/AIDS epidemic has been by far the most extensively funded and globally scaled effort to address a single health condition. This unprecedented undertaking has been able to facilitate considerable adaptation of health systems in low- and middle-income countries to meet the special needs of chronic patients. As such, programs implemented to deliver HIV care and treatment are increasingly serving as models for other chronic illnesses, such as cancer and diabetes. In the intervention described in this document, for example, there was a significant “spillover effect” whereby palliative care, especially pain management, was frequently provided to non-HIV patients by facility staff and community volunteers. Serving as models for chronic care in general, HIV care and treatment programs should be continuously encouraged to lead the way in establishing high quality service delivery systems which effectively integrate essential chronic care services like palliative care. In low-resource settings, it is becoming increasingly evident that best practices and standards established by HIV programs are vital in informing efforts to strengthen health systems in general.

## VIII. REFERENCES

1. Larue F, Fontaine A, Colleau SM. Underestimation and under treatment of pain in HIV disease: multicenter study. *BMJ* 1997 Jan 4; 314(7073):23-8.
2. Jennifer S Temel et al, Early palliative care for patients with Metastatic Non-small cell Lung cancer. *N Eng. J Med* 2010; 363:2263-2265
3. WHO National Cancer Control Programmes – Policies and Managerial Guidelines. ed 2. Geneva: WHO; 2002.
4. Human Rights Watch. Needless Pain: Government failure to provide palliative care for children in Kenya. 9 September 2010. By Human Rights Watch
5. Lohman et al. 2010. Access to pain treatment as a human right. *BMC Medicine* 2010; <http://www.biomedcentral.com/1741-7015/8/8>
6. Palliative care in Africa: the need. [http://africanpalliativecare.org/index.php?option=com\\_content&view=article&id=41&Itemid=26](http://africanpalliativecare.org/index.php?option=com_content&view=article&id=41&Itemid=26)
7. Bwambale, T. Nabatanzi, V. 2011. Only 10% Ugandans get palliative care. *New Vision*, 26 August. <http://www.newvision.co.ug/D/8/12/763564>
8. Olaitan A Soyannwo. Obstacles to pain management in low resource settings. A guide to pain management in low resource setting. <http://www.iasppain.org/AM/Template.cfm?Section=Home&Template=/CM/ContentDisplay.cfm&ContentID=12161>
9. UNAIDS, country factsheet 2010. <http://www.unaids.org/GlobalReport/AIDSinfo.htm>.
10. WHO Regional office for Europe 2002, Assuring availability of Opioid Analgesics for palliative care: A report of WHO workshop held in Budapest, Hungary.
11. Stjernswärd J. Uganda: Initiating a Government Public Health Approach to Pain Relief and Palliative Care; *Journal of pain and symptom management*. Volume 24, issue 2 pg 257-264 (August 2002)
12. Ministry of Health, Health Sector Strategic Plan I (2001-2005).
13. Ministry of Health, Health Sector Strategic Plan II (2005/06-2009/10) Volume I.
14. PCAU: Audit report of palliative care services in Uganda, April 2009.
15. Uganda Bureau of Statistics, Statistical abstract 2008. Ministry of Health.
16. Uganda National HIV/AIDS Guidelines 2001 and 2010.
17. Pharmaceutical Situation Assessment -Level II; Health Facility Survey in Uganda, December 2008, Ministry of Health.
18. Hospice Africa Uganda. Factsheet July 2010.
19. Population and Housing Census Analytical Report. Mayuge district (2002).
20. Donabedian, A. 1980. Explorations in Quality Assessment and Monitoring. 3 vols. Ann Arbor, MI: Health Administration Press.
21. Merriman, A. 2010. Audacity to Love: The Story of Hospice Africa, Dublin, Ireland: The Irish Hospice Foundation.
22. Harding R, Karus D, Easterbrook P, et al: Does palliative care improve outcomes for patients with HIV/AIDS? A systematic review of the evidence, *Sex Transm Infect* 81:5 – 14, 2005.
23. Selwyn PA, Forstein M: Overcoming the false dichotomy of curative vs. palliative care for late-stage HIV/AIDS: “Let me live the way I want to live, until I can’t,” *JAMA* 290:806-814, 2003.
24. Karasz A, Dyche L, Selwyn P: Physicians’ experiences of caring for late-stage HIV patients in the post HAART era: challenges and adaptations, *Soc Sci Med* 57:1609-1620, 2003.

## APPENDICES

### Appendix I: General Action Plan for Improvement Teams

	<b>What do we want to do?</b>	<b>How will it be measured?</b>	<b>Where will this be recorded?</b>
1.	Decrease the proportion of clients in pain	Record number of patients who say 'yes' when asked if they are in pain.	Patient record (e.g., hand-drawn column on ART card)
2.	Increase the proportion of clients screened for pain	Count number of clients whose records reflect that they were asked "Are you in pain?"	Patient record (e.g. ART card)
3.	Increase the proportion of clients whose pain is scored	Count number of clients scored whose records reflect that they were scored on a scale of 0-5 where 0 = no pain and 5 = worst pain	To be determined by sites after 1 month of implementation
4.	Increase the proportion of clients whose pain is managed	Count number of clients in pain whose records reflect that they were given any of the drugs in the analgesic ladder	To be determined by sites after 1 month of implementation

## Appendix II: Synthesis Form

### USAID HEALTH CARE IMPROVEMENT PROJECT Palliative Care Collaborative

#### *Synthesis of implemented changes in establishing palliative care in Mayuge and Namutumba districts*

Level name: a) district                      b) Health center                      c) Community

Improvement objective:

Tested Change(s):

Steps, processes or inputs required to introduce change:

Barriers encountered and how did the team overcome them:

What evidence do you have that the change led to an improvement?

What are your next plans?



#### Appendix IV: Pain Assessment Job Aid

	Meaning	Example
<b>P</b>	Precipitating factors	What makes the pain better? What makes the pain worse?
<b>Q</b>	Quality	How would you describe the pain?
<b>R</b>	Radiation	To where does the pain spread or travel?
<b>S</b>	Severity	On scale of 0 to 5 how bad is the pain?
<b>T</b>	Temporal	Is the pain constant, or does it come and go?

#### Pain Assessment Numerical Rating Scale

<b>0</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>
No pain	Mild pain	Moderate pain	Moderately severe pain	severe pain	Overwhelming pain

## **Appendix V: Change Package for Integrating Pain Management in HIV Care**

The USAID Health Care Improvement Project (HCI) worked in collaboration with the Uganda Ministry of Health to demonstrate integration of pain management with HIV care and treatment using a collaborative improvement approach. This intervention took place in the two rural districts of Mayuge and Namutumba at 14 health facilities (1 hospital, 3 HC IV's and 10 HC III's) in 2010-2011. Participants included health officials, health workers and community volunteers. After one year of implementation there was improvement in the different processes of care, namely; identification, assessment and scoring, prescription and management; and referral of patients' pain. The quality improvement teams tested and implemented several changes to improve the above mentioned processes of care so as to integrate pain management with HIV care.

To document and detail the changes which were implemented, a "harvest meeting" – a gathering aimed at systematically collecting, standardizing and documenting strategies and solutions which have been tested and proven to improve care – was held in July 2012 with representatives from the Ministry of Health (MoH), Palliative Care Association of Uganda (PCAU), health facility improvement teams, community volunteers, and a patient who benefitted from pain management.

The two-day harvest meeting's objectives were to: 1) gather and share information on the interventions by QI teams to integrate pain management with HIV care; 2) obtain details of how the interventions were implemented; and 3) develop a how-to -guide for spread and scale up of pain management.

At the harvest meeting, participants were divided into small groups which worked with a facilitator to list change ideas which led to improvement and those which did not lead to improvement along with the sites where these changes were tested and implemented. Participants identified seven drivers necessary to meet the goal of relieving pain among patients with chronic diseases and HIV, namely: pain management training, documentation, delivery system design, availing oral morphine and pain management medicines, community mechanisms and institutionalization. (These drivers of successful pain management are depicted in Figure A1.) Participants used data from their sites to identify and link changes to improvement, and evaluate the changes using available literature, simplicity, scalability and relative importance of the changes. Through this process they generated a list of changes to include in the change package. The changes for each driver were then grouped into concepts and sequenced to show which ones needed to be done before the others (see Figure A2).

By the end of the harvest meeting changes that had been tested and implemented by the QI teams had been developed into a change package that summarizes essential steps that can be used by other health facilities wishing to integrate pain management with HIV care. This list of changes is presented in Table A1.

Figure A1: Driver diagram for pain management integration in HIV care

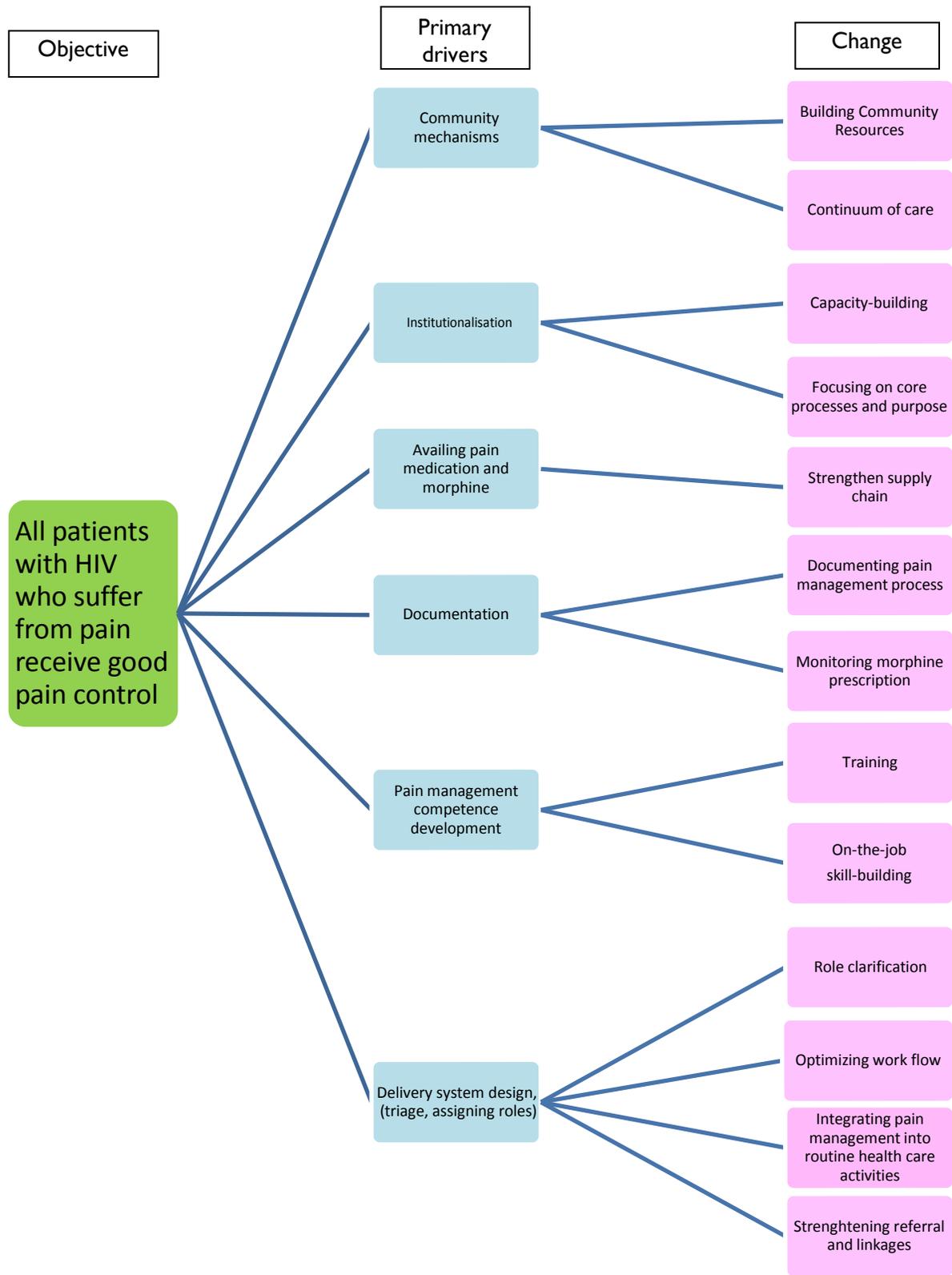


Figure A2: Sequencing of pain management concepts

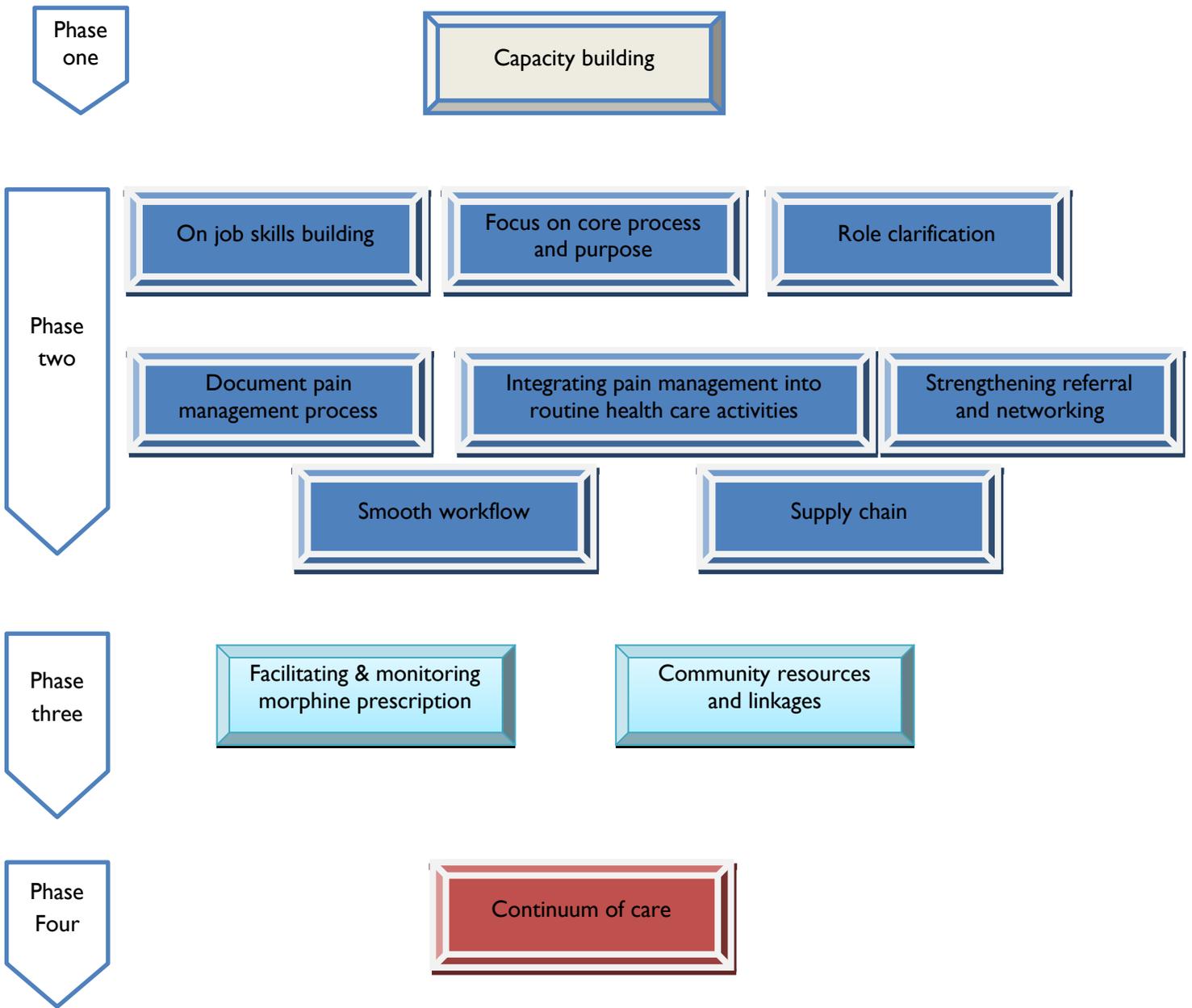


Table A1: Changes developed and tested by teams in Mayuge and Namutumba districts, Uganda

Change concept	Specific challenge to be addressed	Change idea	How to guide
<b>Pain management training</b>			
Capacity building	Inadequate pain management knowledge and skills among health workers	Training of health workers in palliative care	<ul style="list-style-type: none"> <li>• HCI worked with the district to identify health workers to undertake the palliative care training.</li> <li>• Eligibility criteria were agreed on to facilitate the process of identifying the health workers to be trained. Of particular importance was the criterion that persons trained were available and positioned to facilitate implementation at their facility.</li> <li>• Participants included health workers of different cadres including health facility managers and district health management team members.</li> <li>• The training consisted of a 5 day introductory palliative care course for health professionals by PCAU and 2 days of quality improvement training by HCI.</li> </ul>
	No system to identify and track patients in the community	Training of community health workers in identification and referral of patients	<ul style="list-style-type: none"> <li>• The health facility teams were asked to identify community volunteers to serve as a link between the health facilities and the community.</li> <li>• List of nominated community volunteers was shared with the district health management team to decide how many to allocate to each health facility.</li> <li>• Criteria for selection were literacy and willingness to work as volunteers.</li> <li>• Communities were engaged in the selection process, and most of the community volunteers selected already had experience as community volunteers.</li> <li>• The community volunteers received five days of community –oriented palliative care training.</li> <li>• Each participating site had at least one community volunteer attached to it.</li> </ul>
	Inadequate skills to supervise health workers	Training of the district quality improvement team to enable supervision	<ul style="list-style-type: none"> <li>• Core district health team members, who were already members of the district quality improvement team, were trained as coaches to provide supervision of implementing sites.</li> </ul>

Change concept	Specific challenge to be addressed	Change idea	How to guide
	Not all staff at the health facility were able to manage pain	Mentorship of health workers at site level	<ul style="list-style-type: none"> <li>• After the short course in palliative care PCAU provided practical training on site for health workers, including hands on experience in managing pain.</li> <li>• Health workers who participated in the palliative care short course organized continuing medical education sessions in their facilities to train other health workers on pain management.</li> </ul>
	No morphine prescribers	Training of morphine prescribers	<ul style="list-style-type: none"> <li>• Through the district health office, each district was asked to identify an eligible health worker to undertake a 9 month prescribers' course in palliative care.</li> <li>• One role of the trained palliative care clinical officer was to manage the district oral morphine supply by making requisitions and following up on prescription and use of oral morphine.</li> </ul>
On-the-job skill building	Few trained health providers	Cascading transfer of knowledge and skills from district to facility to community teams	<ul style="list-style-type: none"> <li>• Teams were built at the levels of district management, health facility and community volunteers.</li> <li>• Each team was responsible for supporting the transfer of knowledge to ensure human resource capacity building at all levels of care.</li> <li>• At the health facility level, trained health workers ensured transfer of knowledge and skills to colleagues through CMEs and update meetings.</li> <li>• Community volunteers were included in the facility team meetings and they also held community volunteer meetings.</li> <li>• The palliative care clinical officer supervised other sites, in addition to her own site, in implementing pain management.</li> </ul>
	Few trained health providers	Hands-on training at facility and community level	<ul style="list-style-type: none"> <li>• Quarterly mentoring by palliative care experts, including palliative care practitioners recommended by PCAU who sometimes joined regular coaching teams to build health worker skills. This role can be taken on by supervisors or health managers who are knowledgeable on pain management.</li> <li>• The trained palliative care clinical officer</li> </ul>

Change concept	Specific challenge to be addressed	Change idea	How to guide
			took on the role of mentoring other health facilities after HCI stopped directly supporting coaching and mentoring.
Monitoring morphine prescription	Lack of tools to monitor stocks	Use of stock cards to monitor morphine stocks	<ul style="list-style-type: none"> <li>The teams used stock cards and dispensing logs to monitor daily and monthly use and stocks of oral morphine.</li> </ul>
	Lack of tools to monitor stocks	Use of a patient register for clients prescribed morphine, countersigned by a prescriber	<ul style="list-style-type: none"> <li>At health facilities that did not have legal prescribers, patients were provided with oral morphine and registered by the trained clinical officers whose work was supervised by a legal prescriber who would countersign the prescriptions.</li> </ul>
<b>Documentation</b>			
Documenting pain management processes	Lack of tools to document pain management	Created a column on the HIV/ART care card to record pain assessment and scoring	<ul style="list-style-type: none"> <li>Sites assigned a health worker to create a column on every patient care card where pain assessment and scoring would be documented and which would also remind clinicians to assess and manage pain.</li> </ul>
	No documentation tools to record pain management	Introduction of pain management tools	<ul style="list-style-type: none"> <li>Pain management tools were introduced to support the pain assessment and management process.</li> <li>For all patients the pain assessment column on the HIV care card was used while for complicated cases special forms were used to assess, manage and evaluate the patients.</li> <li>Palliative care registers were introduced to register patients who required morphine</li> </ul>
	No consistent method for describing pain severity	Consistently adopted a standard scale for describing pain severity	<ul style="list-style-type: none"> <li>After the first learning session revealed that health providers had different pain scoring systems, teams agreed to consistently use a pain scale of 0 – 5 with 0 – as no pain and 5 representing the most severe pain.</li> </ul>
<b>Delivery system design</b>			
Smooth work flow	Clinic staff too busy to effectively manage patients	Change ART clinic day to a less busy day	<ul style="list-style-type: none"> <li>The teams re-organised the clinics by scheduling HIV clinics on less busy days.</li> <li>Health facilities which did not have established HIV clinics established them on days that were least busy so as to have enough staff to take care of HIV patients.</li> </ul>

Change concept	Specific challenge to be addressed	Change idea	How to guide
		Expert clients were positioned at triage to identify and refer patients with pain to the clinicians	<ul style="list-style-type: none"> <li>• Health facility teams made client flow charts and instituted triaging where patients with pain would be identified and referred for assessment.</li> <li>• Expert patients were mentored on screening and identifying patients with pain.</li> </ul>
Strengthened referral and networking	No mechanism to refer patients from the community	Referral of patients by community health workers using referral notes.	<ul style="list-style-type: none"> <li>• Community volunteers were trained to identify patients in their communities who had chronic pain. They referred patients with pain to the health facilities, using a referral note.</li> </ul>
	Lack of morphine at some health facilities	Inter-facility referrals of patients to access morphine	<ul style="list-style-type: none"> <li>• Health workers used nearest health facility with oral morphine as referral points for patient to access oral morphine.</li> <li>• Patients were provided referral notes to access the oral morphine at palliative care outreach points. (Palliative care providers in the adjacent district were providing services in the district once in two weeks mainly following up patients already started on treatment or the new identified by their community volunteers however this service was not used by the health providers and health facilities).</li> </ul>
Role clarification	No clear roles in pain management	Clinicians were assigned to assess and score patients	<ul style="list-style-type: none"> <li>• Health facility teams assigned clinicians who were responsible for assessing and scoring pain. At some facilities nurses would assess and manage patients with mild pain while those with moderate to severe pain were sent to the clinicians (clinical officers or physicians) for further assessment and management.</li> </ul>
	No clear roles in pain management	Team formation	<ul style="list-style-type: none"> <li>• QI teams consisting of health workers and community volunteers were formed to discuss how to improve palliative care integration at health facilities that did not have them</li> </ul>
Decision support		Use of job aids and wall charts for assessing and scoring pain	<ul style="list-style-type: none"> <li>• Job aids and wall charts were provided by PCAU and HCI.</li> <li>• These were hung on health workers tables and walls and used for reference when attending to patients.</li> </ul>

Change concept	Specific challenge to be addressed	Change idea	How to guide
<b>Availing morphine and other pain medicines</b>			
Supply chain systems	Inadequate amounts of step 1&2 analgesics	Requisition of step 1 & 2 analgesics from National Medical Stores for pain management	<ul style="list-style-type: none"> <li>• District wrote to National Medical Stores to request increased supplies of step 1 &amp; 2 analgesics for HC IIIs while health centers that were authorized to make their own requests (hospital and HC IV) for medicines were asked to quantify needs and include them in their requisitions.</li> <li>• HC IVs were asked to include in their requisitions analgesics for the HC IIIs (which are not authorized to make their own requests) in their health sub-district.</li> </ul>
	Health facilities not able to provide step 3 analgesics due to lack of accreditation	Accreditation of health centers for step 3 analgesics	<ul style="list-style-type: none"> <li>• The district and PCAU worked on accreditation of health centers to provide oral morphine. These health centers were supported by HCI to install double lock cupboards for oral morphine storage and morphine registers.</li> </ul>
	No oral morphine	Procurement of oral liquid morphine	<ul style="list-style-type: none"> <li>• District worked with PCAU and MoH to procure oral morphine. The focal persons were trained on quantifying the needed oral morphine and completing the order forms in triplicate (with copies for the District Health Officer, the National Medical Stores, and the health facility.</li> </ul>
<b>Community mechanisms</b>			
Building community resources	Patients with pain in the community not presenting to health centers for pain management.	Engagement of community volunteers	<ul style="list-style-type: none"> <li>• Community volunteers trained to identify and refer patients with pain to the health facility. (Refer to training of community health workers)</li> </ul>
Continuum of care	Inadequate follow up mechanisms	Involvement of family members in the care of patients	<ul style="list-style-type: none"> <li>• Community volunteers and health workers encouraged and facilitated involvement of family members to support patient care by picking up medicines, caring for patients at home and communicating with health workers</li> </ul>
	Inadequate follow up mechanisms	Home visits and follow up of patients by community volunteers and facility staff	<ul style="list-style-type: none"> <li>• Health workers and community volunteers made home visits for patients who were bedridden. These patients were identified by the community volunteers and/or by family members.</li> </ul>

Change concept	Specific challenge to be addressed	Change idea	How to guide
	Inaccessible patients due to lack of transport	Facilitate community volunteers to reach more patients in the community	<ul style="list-style-type: none"> <li>Community volunteers were provided with bicycles to reach more patients in need of palliative care in the communities</li> </ul>
<b>Institutionalization</b>			
Capacity building	Inadequate or lack of support and funds for palliative care activities	Sensitization of stakeholders	<ul style="list-style-type: none"> <li>PCAU conducted a sensitization meeting with district senior leaders to inform them about palliative care and ask for their support in implementing the activity.</li> </ul>
	Lack of adequate number trained staff in pain management	Training of health workers in palliative care	<ul style="list-style-type: none"> <li>(Refer to capacity building above)</li> </ul>
Focusing on core processes and purposes	Lack of appropriate types and amounts of pain medicines	Supporting availability of pain medicines through requesting National Medical Stores to give adequate amounts of pain medication	<ul style="list-style-type: none"> <li>(Refer to supply chain systems)</li> </ul>
	Palliative care activities are not budgeted for in the district	Integrating palliative care activities in the district work plan	<ul style="list-style-type: none"> <li>The district health team integrated palliative care activities in the district work plan, allowing the allocation of funds for these activities.</li> <li>District quality improvement team participated in the joint (with HCI, PCAU &amp; MOH coaches) and independent coaching and mentorship sessions at health facilities.</li> </ul>