

SUMMARY

PEPFAR Public Health Evaluation – Care and Support –



PHASE I UGANDA

SUMMARY

PEPFAR Public Health Evaluation – Care and Support–



PHASE I UGANDA

Authors: Dr Richard Harding, Victoria Simms, Dr Suzanne Penfold, , Eve Namisango,
Geoffrey Banga Nkurunziza, Claire Nsubuga Kwebiiha, Jacqueline Teera-Ssentongo, Dr Julia Downing,
Richard A. Powell, Dr Faith Mwangi-Powell, Professor Irene J. Higginson
April 2009

This summary was made possible by support from the U.S. Agency for International Development (USAID) under the terms of Cooperative Agreement GPO-A-00-03-00003-00. The opinions expressed are those of the authors and do not necessarily reflect the views of USAID or the United States government. TR-09-69b (4/14/09). Cover photo: Courtesy of MEASURE Evaluation staff.

Acknowledgements

The present study benefited from the participation of a wide range of partners, medical professionals, HIV specialists and palliative care researchers. The authors are grateful for the guidance provided by the United States Government Palliative Care Technical Working Group and to Dr. Rick Berzon (USAID), Dr. Donna Kabatesi (CDC), Dr Dan Wamanya (USAID), Dr Flora Banage (CDC), Dr Premila Bartlett as well as Dr Saul Onyango (MOH), Dr Elizabeth Madraa (MOH). We would like to thank Dr. Julia Henn, Dr Vincent Owarwo and Dr. Mugerwa Margaret Juliana of the Monitoring and Evaluation of Emergency Plan Progress project for their financial and logistical support for conducting data collection. We also thank the technical and administrative staff at MEASURE Evaluation, through which the project is funded, especially Dr. Sian Curtis and Dr. Scott Moreland. Finally we are grateful to the staff and patients at the surveyed facilities without whom the research would not have been possible and for for whom we believe the results will be useful in continuing to provide, and to improve, HIV care and support services.

Table of Contents

1	Acknowledgements
3	Executive summary
3	Rationale
3	Methods
3	Main findings
5	Recommendations
7	Summary Report
7	Introduction & Purpose
7	Methods
9	Findings and Discussion
15	Recommendations
18	References
19	Table 1: Participating facilities
21	Table 2: Components of care available

Executive summary

Rationale

A Public Health Evaluation (PHE) was commissioned to examine PEPFAR-funded HIV care and support. Phase 1 of this PHE aimed to describe the nature and scope of care and support provision according to the five PEPFAR care and support areas (OGAC 2006), including the types of facilities, clients seen, and availability of specific components of care. Phase 2 consisted of a longitudinal study of patients outcomes

Methods

A cross-sectional survey of facility configuration and activity was conducted by collecting quantitative and qualitative descriptive data directly from facilities. Of around 600 PEPFAR-funded HIV care and support facilities in Uganda, 60 (about 10%) were surveyed. At each facility, the following data collection tools were applied: 1) senior staff structured interview, 2) document collection and analysis, 3) pharmacy review, 4) patient focus group discussion.

Main findings

Facility characteristics

Nine facilities were hospitals, 27 were health centres, 13 were health posts and 10 provided mainly home-based care. One facility did not provide health care and was separated from the survey sample for the following analysis. The number of patients seen in the previous three months ranged from 1 to over 16,000 and 65.1% of adult patients were women. On the day of the survey 58% of facilities had electricity and 85% had a safe water supply.

Staff characteristics

Nurses were the most prevalent staff type, working at 86% of facilities. At 75% of facilities there was at least one social worker or CHW. Many staff were volunteers, particularly CHWs. On average there was one nurse per 69 patients, and for all other staff categories, patient load was higher. Psychological, spiritual and social care were often provided at facilities which had no specialist staff in these areas.

Components of care offered

On average facilities provided 36 of 69 surveyed components of care onsite and referred out for a further 11. Most services were provided to patients free of charge. Adherence counselling, nutritional advice, family planning counselling, pre- and post-HIV test counselling, treatment for diarrhoea, and treatment for skin rash were the care components most commonly provided or referred. Outward referrals mainly took place for specialist clinical services such as TB treatment and cancer management. Psychological, clinical and prevention care were provided directly or by referral by all 59 facilities in the main analysis, but spiritual care by 58% and social care by only 41%. These are the five areas of PEPFAR care and support. Forty-six percent of facilities provided antiretrovirals directly, and 32% referred patients outward for ARVs. Toxicity monitoring and treatment failure assessment were available onsite for 89% of the ARV providers.

Management of pain is a cornerstone of palliative care and frequently undervalued. All facilities, with the exception of some HBC facilities, provided or referred for non-opioid analgesics. Opioids were commonly reported but very rarely found in pharmacies. Pre- and post-test counselling was one of the most widely provided components of care, missing at only three facilities (95%). It was the most commonly available type of counselling and support included in the survey. Conversely, psychiatric therapy was one of the rarest components, suggesting that although basic psychological care is available, more complex care is difficult to access.

FGD participants revealed that nutritional care and social care were considered to be closely aligned. The ultimate condition of poverty was lack of food, and food shortage, money worries and problems accessing transport were three aspects of the same problem. Nutritional counselling was one of the most widely available care components, but therapeutic feeding for malnutrition was offered or referred at only 44% of facilities. Social care was the least developed area of care, with many components never offered at hospitals or health posts.

The Basic Care Package (CTX, insecticide-treated net, water treatment, condoms and family counselling and testing advice), the Ugandan version of the PEPFAR preventive care package, was provided in full onsite by 24% of facilities. Condoms were the most readily available item (92%). Treatment for opportunistic infections, malaria and TB was more widely available than preventive care. Malaria treatment was widespread, TB treatment not quite as common (85%), and both were more frequently available than were the respective tests used to diagnose them, suggesting that treatment was taking place based on deduction from symptoms and history.

Prevention with positives was evaluated by five components of care, of which all facilities offered or referred for at least three and 54% offered or referred for all five. However, there may be some differences in understanding as to what constitutes 'PWP' at the facility and public level, as there were differences between the reported availability of the PWP constituent components and the availability of PWP itself.

Pharmacy review

Adult cotrimoxazole was the most widely available drug, stocked in 68% of facilities. Non-opioid analgesics were stocked at 66% and morphine (in date) at 12%. Stockouts were common, with 25% of all reported drug formulations having a reported stockout in the past six months. Eleven facilities reported providing non-opioid analgesics but had none in stock. Similar discrepancies were recorded for codeine (5 facilities), morphine (6) and CTX (8).

Document analysis

First clinical assessment sheets were used at 66% of facilities and 92% kept patient records. Forty-seven percent had care protocols. The content of patient assessment sheets focused only on clinical needs and was not multidimensional.

Staff views

Senior staff saw the key issues for their facility in terms of regular funding, staff training and investment, and care. They reported a need for a separate place for children's care, development of paediatric counselling, and provision of ARVs, drugs to treat infections, school fees for OVCs and food.

Patient focus group discussions (FGDs)

Focus group discussions with patients at 47 facilities revealed that they valued psychological, clinical and social care. The improvements patients wanted were longer opening hours, more training for staff (especially in counselling), a more reliable drug supply, school fees for OVCs, refunds for transport to the facility, and food. To increase uptake of care they suggested outreach activities with drama involving PLWHAs, and provision of visible items of clear benefit such as ITNs and food. Sixty per cent of FGD participants had received condoms and 83% received CTX prophylaxis. Reasons given for not receiving these items or other elements of the BCP were that the facility did not have sufficient supplies and other patients received priority, fear of stigma, unawareness of their existence, allergy to CTX, and stockout.

Recommendations

- Multidimensional HIV care and support requires more space than purely medical assessment and intervention. Facilities should increase their physical space for care services, particularly to allow for counselling sessions in privacy and for children's care.
- Availability of resources to ensure existing services such as transport and electricity are required, as many vehicles are not operational and only half of facilities have working generators. Infection control is also compromised in the absence of infrastructure.
- As staff recommended, the best way to prevent double counting is to improve coordination and strengthen referral. Smaller facilities cannot provide the holistic, complex care required for HIV without the ability to refer patients.
- Comprehensive records should be kept for all patients, detailing the care they receive including inward and outward referrals and needs assessment.
- It was often found that staff were delivering care for which they felt they had not been adequately trained, and patients reported that they were discouraged from attending services where inadequately trained staff were employed. Increasing specialist training and employing staff specifically to deliver non-clinical aspects of care, such as psychological and spiritual care, could widen the availability of specialist care to patients and improve care quality.
- Staff retention is poor because of limited opportunities for development and low pay, and high staff turnover may damage the quality of care provided. Investment in staff is needed which could benefit both staff and patients.
- Volunteers are more likely to remain at facilities if their contribution is seen to be valuable, for example by reimbursing their travel costs.
- In the absence of data on paediatric-only facilities, skills and facilities for care and support of children need to be enhanced for the 20% of facilities that see no children at all.
- As the model most likely to have staff present across all five areas of care, the holistic provision of healthcare model offered by health centres should be replicated.
- HBC facilities should offer basic clinical care, and provide or refer for treatment for anxiety and depression.
- Social care is the least developed aspect of care in the survey. Income-generating activities and home help need to be implemented more widely to help patients overcome the financial barriers to clinical care.
- The BCP should be rolled out to all facilities, with clear and equitable eligibility criteria and adequate provision for all who need it. While the BCP is available at some facilities but not others, 'shopping around' is unavoidable. Treatment of TB, malaria and other infections is

more readily found than prevention care, although prevention is more cost-effective and saves more lives.

- Reliable drug availability is a significant problem which hampers the delivery of care. Supply chains need to be strengthened by improving communication and responsiveness.
- In addition to improvements in morphine supply, training in pain management and opioid use is needed to increase uptake and usage.
- Laboratory services, particularly CD4 testing, should be made more widely available. For smaller facilities, referral networks to larger facilities for such services should be efficient.
- All facilities which provide or refer for ART should provide or refer for CD4 tests and LFT, as essential services for ART.
- Lack of proper records limits the ability of a facility to provide integrated care, monitor stock, manage referrals, plan and budget. Large facilities should have administrative staff specifically employed to handle data management, and train existing staff in record keeping.
- Records forms should be revised and standardised to improve assessment, management and continuity of care and inward/external referral

Summary Report

Introduction & Purpose

This study is part of a larger, two-phase evaluation of PEPFAR-funded HIV/AIDS care and support services in Uganda and Kenya. The aims of this evaluation were to:

- Describe the nature and scope of HIV/AIDS care and support services supported by PEPFAR, including the types of facilities available, clients seen, and availability of specific components of care.
- Evaluate how programme components and costs are related to health outcomes.

The Phase 1 objective was to undertake a cross-sectional survey of facility configuration and activity on a 10% sample of PEPFAR-funded, HIV care and support facilities in Kenya and Uganda (2007). The Phase 2 objective is to collect longitudinal prospective quantitative outcome data on 1200 new patients at 12 facilities in Kenya and Uganda, measuring both quality of life and care outcomes alongside components of care received (2008). Phase 2 methodology also involves a costing analysis to determine cost of care provided. This report presents findings from Phase 1 of the Uganda study only.

Methods

A cross-sectional survey of facility configuration and activity was conducted by collecting quantitative and qualitative data directly from facilities.

Sampling

The approximately 600 PEPFAR-funded HIV care and support facilities in Uganda formed the sampling frame for this study. Exclusion criteria were: (specifically) paediatric HIV/AIDS care and support providers, and difficult to access sites (e.g. insecure, no road access). Of approximately 600 facilities, 60 (around 10%) were selected for inclusion in the study. In order to capture a range of facility sizes within the sampling frame, facilities were stratified by number of patients seen for HIV-related care in FY 06, and divided into three strata (1 to 100, 101 to 500 and >500 patients). This resulted in unequal and calculable sampling fractions. Twenty facilities were randomly sampled within each of the strata.

Data collection tool development

- Senior staff interview — This tool was designed for use across a wide range of care facilities. The researchers interviewed a group of senior staff at each health facility to collect data on patient numbers, infrastructure and staffing. This tool also included a version of the Client Services Receipt Inventory (CSRI) (Beecham and Knapp 2001) adapted for the aims/context of this study. The CSRI assesses service provision / referral for various components of clinical, psychological, social and spiritual care.
- Document collection — A tool was developed on which the existence, format, and language of various patient documents could be recorded. Documents surveyed included: service aims, incoming referral criteria, incoming referral forms, outgoing referral forms, patient charging

forms, ART protocols, care protocols, first clinical assessment sheets, ongoing care assessment sheets, patient records, referral followup forms, stock control sheets, and patient health promotion information.

- Pharmacy review — A tool was developed on which to record the availability of specific drugs commonly used in HIV/AIDS care and support, as well as whether stocks were unexpired/expired, if there had been previous stock-outs of in-date drugs, and storage conditions.
- Patient Focus Group Discussions (FGDs) — FGDs aimed to (1) validate staff interview data relating to components of care offered; and (2) explore aspects of patient care (e.g. most valued components of care, issues in obtaining medicines). The topic guide contained question lines on the following: demographic indicators, (e.g. gender, place of residence (urban, rural or peri-urban), age, household size), and receipt of key components of care including daily cotrimoxazole (CTX), a mosquito bednet and nutritional counselling. All tools were developed by a multidisciplinary team, including medical professionals, HIV specialists and palliative care researchers, in conjunction with the United States Government Care and Support Technical Working Group and the country teams. All tools were piloted in one large and one small Phase 1 facility. Following piloting, the wording and structure of the tools were modified.

Ethical approval

Ethical approval was obtained from the Uganda National Council for Science and Technology and the College Research Ethics Committee at King's College London. All data were anonymised and raw data has been stored separately from consent forms, in a locked filing cabinet in line with ethical guidance and the Data Protection Act.

Data collection procedures

Facilities were informed of the planned survey by the Ministry of Health (MOH). Ugandan researchers attended each site to collect data on a pre-arranged day, between April and August 2007. Data were recorded on two separate sets of identical forms. One set was left with the facility; the other was taken by the researchers and used for data entry. Researchers held interviews with senior facility staff (approximately three per facility). These staff were asked to provide blank patient documents (e.g. referral forms, assessment sheets and patient information sheets), where possible. Researchers visited the pharmacy to review stocks and stock cards, with the assistance of the pharmacist or dispenser. FGDs were held with existing patients (inclusion criteria: adults aware of their positive HIV status, and under HIV/AIDS care and support for at least six weeks, who gave informed consent to participate). Patients were purposively selected by staff with the aim of obtaining a diverse group with respect to gender, age, disease stage and antiretroviral (ARV) use. Approximately five patients in each facility were invited to participate in a researcher-facilitated FGD. Researchers took notes of the discussions; the FGD was taperecorded as a back-up.

Data management and entry

Data were transferred to the APCA offices immediately after collection. Quantitative data were double-entered by two different researchers, and validated, using EpiData v3.1. Data from open-ended questions were entered into pre-formatted templates in MS Word 2003.

Data analysis

Analysis was conducted using Stata v10 (quantitative data) and NVivo v7 (qualitative data).

- Senior staff interview — Frequency tables were generated for key responses, grouped by facility type where appropriate. A Spearman's rank test for correlation was conducted to test the reliability of routine data. The stratified random sampling technique was undertaken to ensure facilities of all sizes were surveyed; however, weighted analysis could not be undertaken due to data inconsistencies. Thematic analysis of content was conducted on qualitative data. Emerging themes were organized into data categories and then agreed between two researchers.
- Document analysis — A matrix was developed through which the number of facilities reporting having pre-specified documents was recorded. In those instances where the percentage of facilities providing examples of documents as a proportion of those who reported having such documents was less than 20%, or where the absolute number of documents was five or fewer, no further analysis was undertaken. In other cases, content analysis was undertaken to determine thematic frequency (type of document, whether a sample was obtained, the specific nature of the information in the document fields).
- Pharmacy review — Frequency tables were generated for each drug, grouped by facility type where appropriate. Data from the pharmacy review was compared with components of care provided, as reported by senior staff.
- FGDs — Information on FGD participants' background and receipt of care items was merged with the Stata database using unique identifying variables. Care reportedly received by FGD participants was compared with the care reportedly provided by facility staff. Thematic content analysis was applied to the remaining FGD data. The principal themes were organised independently into data categories and then agreed between two researchers.

Findings and Discussion

Response rate

Of the 60 facilities selected at random, one was found not to meet the selection criteria, and four were in regions where violence broke out, making the area unsafe for travel. A further three facilities could not be found. All of these facilities were replaced with another randomly selected facility from the same stratum. One facility (a health post) did not provide health care and was excluded from analysis. FGDs were conducted at 47 facilities with a total of 228 patients.

Facility characteristics

Facility staff were asked to indicate which facility type most closely reflected their service from a list of options. Five facilities were referral hospitals, four were district hospitals, 27 were health centres, 13 were health posts and 10 provided mainly home-based care (HBC). The number of patients seen in the previous three months ranged from one to over 16,000; 65% of adult patients were women. On the day of the survey 68% of facilities had electricity and 83% had a safe water supply. Thirty-two facilities had an ambulance, of which five (16%) were not functioning at the time of the survey visit. Of the thirty-eight facilities with a generator, six (16%) were broken down or out of fuel. Three facilities lacked a functioning toilet which patients could use, one of which was a hospital.

Components of care and referrals

On average facilities provided 36 of 69 surveyed components of care onsite and referred out for a further 11, with larger facilities offering more comprehensive care packages. Outward referrals were made particularly for specialist clinical services such as TB treatment and cancer management, al-

though 23 sites had no referral capacity for cancer management.¹ Prevention with positives was evaluated by five components of care, of which all facilities offered or referred for at least three and 54% offered or referred for all five. Most services were provided to patients free of charge.

Provision of holistic care and support

Facilities were analysed according to whether they provided or referred any components of care from each of the PEPFAR domains of care and support: spiritual, psychological, clinical, social or preventive care. Psychological, clinical and prevention care were provided or referred for by all 59 facilities in the main analysis, but spiritual care by 58% and social care by only 41%.

Documents analysed from the reporting sites also demonstrated a focus on clinical care to the detriment of other areas; they were neither multi-dimensional in nature (with a number of key domains omitted) nor multi-professional from a user perspective (i.e. they are primarily to be used by clinicians and nurses). In order to reflect the provision of holistic HIV care, documentation should include its physical, psychological, social, spiritual and cultural aspects for both the patient and their family. Similarly, providers of such diversified care (including counsellors and spiritual care givers) should be accorded a role within the care giving process, with documentation that can capture role and impact.

Focus group discussions revealed high levels of support for psychological, clinical and social care. However, findings indicate that patients accessed a number of services, due to the limited care range available from individual facilities (especially diagnostic testing). Patients stated a preference for facilities that offered some degree of privacy and provided services confidentially – potentially on different premises to the main health centre. Patients outlined a need for more comprehensive care facilities (i.e. one-stop-shops for diagnostic testing, prescription filling) to reduce their health seeking burden.

Antiretroviral therapy (ART)

Forty-six percent of facilities provided anti-retrovirals (ARVs) directly, and 32% referred patients for ARVs. All facility staff who reported supplying ARVs onsite noted that they were given to everyone who needed them. At the same time, some staff reported that they regretted having to ration the number of people who could begin treatment in order to maintain a supply for those already using ARVs. It is possible that when staff reported no restrictions to provision of ARVs, they meant that people were enrolled on a ‘first come, first served’ basis. Toxicity monitoring and treatment failure assessment were available onsite for 89% of the ARV providers. Facility staff saw the ability to provide ARVs as a strength of their service, and patients reported that it was one of the services with which they were most satisfied. Two facilities could not provide data on the number of patients treated in the last three months. Good record-keeping is essential for an ARV programme to maintain adherence and prevent waste.

Pain management

Uganda is a model country for Africa in terms of morphine availability and usage (Logie and Harding 2005); 20% of facilities reportedly provided morphine onsite and 37% referred for it. However, only half of the facilities reporting providing morphine actually had any in stock. The availability of other analgesics was variable. Fifty facilities reported providing non-opioid analge-

sics but only 39 (78%) had any in stock. Sixteen of 21 facilities (76%) had the weak opioid codeine in stock. Additionally, some facilities had very low quantities of these drugs, raising questions about the sustainability of analgesia for patients. Clinical assessment documents frequently did not include assessment of pain.

Most facilities did not record the use of herbal medication, which is widely used among HIV patients in Uganda (Langlois-Klassen et al 2007), and can potentially result in decreased ART bio-availability, treatment interruption, resistance and even failure (Mills et al. 2005). Though currently practised by only a few sites, the integration of traditional and Western medicine is good practice and replication / adaptation to other areas should be pursued.

Psychological health

All facilities provided or referred for at least one component of psychological care, namely adherence counselling. Pre- and post-test HIV counselling was also provided or referred at 56 facilities. FGD participants reported that HIV led to broken relationships and divorce, loss of confidence, internal and external stigma and loneliness, and that counselling helped them tackle these problems. However, 22 facilities provided psychological care but did not employ any counsellors. This is a challenge; a key complaint of FGD participants was the perceived unprofessional behaviour of counsellors, thought by participants to be due to a lack of training. Counsellors reportedly betrayed confidence and lost their patients' trust, deterring patients from accessing healthcare. Psychological assessment was rarely included in documents recording patients' presenting symptoms. It is unlikely that psychological care can be effectively provided without this assessment

Nutrition, social and spiritual care

Social care was the area most frequently lacking among surveyed facilities. One of the services most frequently requested by FGD participants was food, especially for children. Staff also wished to provide food, and felt that their facility was not offering full care without it. Nutritional counselling was widely available at all facility types, but therapeutic feeding for malnutrition was provided or referred at only half of district hospitals and health centres, less than a third of HBC facilities and a quarter of health posts. The most commonly provided spiritual care was staff prayer with patients, offered at 27 facilities (46%) Three facilities employed spiritual care providers but did not provide any of the components of care surveyed; it is possible they provided other types of contextually appropriate spiritual care which were not recorded.

It is notable that in FGDs, patients most commonly cited the need for social intervention, which corresponds to data presented above on the lack of social care provided in surveyed facilities. The need for food and payment of school fees for orphans and vulnerable children were underlined. To increase uptake of care and support patients suggested outreach activities involving drama (led by PLWHAs), and provision of items of clear benefit such as ITNs and food.

Opportunistic infections and preventive care

FGD participants frequently noted that malaria treatment was a highly valued service. Diagnostic and treatment services for malaria and TB were more prevalent than preventative services. ITNs, which demonstrably reduce morbidity and mortality from malaria, were not provided or referred at 42% of facilities despite being part of the BCP. Treatment for other opportunistic infections and

symptoms was widely available at larger health facilities, and at approximately half of HBC facilities. Treatment of some OIs, such as diarrhoea and fungal infections, does not require advanced clinical training, and could potentially be easily scaled up.

Basic Care Package (BCP)

The BCP is Uganda's development of the PEPFAR Preventive Care Package. The purpose of the PCP is to serve as a short list of components of care that every person with HIV should receive as a preventative measure, to protect them from water-borne infections and malaria, and to protect them from transmitting HIV. The Basic Care Package developed for Uganda consists of five items: condoms, CTX prophylaxis, tablets or a filter to improve water cleanliness, an insecticide-treated net (ITN), and information about voluntary counselling and testing (VCT) for the family of the patient (Colindres et al. 2005). At some facilities the first four items were provided together in a boxed kit; others offered individual items as needed. Fourteen facilities (24%) provided all five elements of the BCP onsite. Some patients reported that they had not received ITNs and water treatment because there was a limited supply. Condoms were the most readily available single item (92%).

Laboratory services

Laboratory services are not specified as an element of care and support but they are necessary in order to prevent and manage infections, and monitor HIV progression. Malaria blood film and rapid HIV testing were the most commonly provided or referred lab services, available at almost all hospitals and health centres, around two-thirds of health posts, and 10% of HBC facilities. Nineteen facilities possessed a CD4 machine and 18 referred out for the test. One of the main reasons for FGD participants to visit other facilities was to obtain a CD4 test, and one of the pieces of equipment staff were most likely to want was a CD4 machine. In a resource-limited environment, it is not practical for every health facility to be equipped with expensive laboratory equipment, especially as over 40% of facilities had no electricity at the time of the survey. With some diagnostic tests, such as dried blood spot test for HIV, a sample can be taken at the local clinic and transported to the referral facility, if a strong referral network exists.

Staffing and care provision

Although PEPFAR HIV/AIDS care and support aims to be holistic, employment of staff specialising in all the different components of care was variable, with fewer than 20% of facilities reporting retaining staff of every type. Most facilities (88%) employed a nurse, with a median 69 patients per nurse where available. Half of facilities surveyed had a doctor on staff, two-thirds had a clinical officer, less than half had a pharmacist, one-fifth had a social worker, half had a counsellor, and less than 10% retained paid spiritual staff. These data show that very few facilities offered professional multidisciplinary holistic care on site, and suggest that staff may have had to provide care that exceeded their skill base. For example, 20 facilities were providing counselling services without having any trained counsellors.

Both staff and patients reported a desire for further staff training. In particular, staff acknowledged a need for more counselling training, especially paediatric counselling. Data suggests that the lack of specialist care affected patient experiences. Inappropriate management of confidential information by staff had reportedly led to significant negative life events for some patients. There were

complaints of indiscretion, ill-mannered behaviour and breaking of confidence, leading to a lack of trust between patients and staff. Patients sought out facilities where the counsellors had a reputation for good professional behaviour and confidentiality.

In terms of staff retention and facility sustainability, it is notable that across the entire survey sample volunteers were providing a significant amount of care. Voluntary staff levels were 29% in health posts and 88% in HBC facilities. Designations most commonly staffed by volunteers were spiritual care providers (17% of facilities), community health workers (60%), and counsellors (20%). Volunteering is a positive reflection of commitment to HIV care by a community, and enables facilities to extend their reach with limited resources. However, staff raised concern over the sustainability of facilities with such great reliance on volunteers. Volunteers reportedly had a high turnover, and could leave at short notice. Given the high reliance on voluntary staff found in the smaller facility types, understanding such aspects of care delivery and staff motivation are crucial to care quality and continuity of provision.

Pharmacy stocks

Adult cotrimoxazole was the most widely available drug, stocked in 73% of facilities. Non-opioid analgesics were stocked at 66% and morphine at 12%. Eleven facilities reported providing non-opioid analgesics but had none in stock. Similar discrepancies were recorded for codeine (five facilities), morphine (six facilities) and CTX (eight facilities). Although oral morphine is more widely available in Uganda than in most other developing countries, and nurses are able to prescribe it (Logie and Harding 2005), morphine was only offered directly at 12 facilities and found in the pharmacy at only eight of these facilities. One facility only had an injectable form of morphine, which is not suitable for chronic use.

Fluconazole was stocked by only 24 facilities but other generic antifungals more commonly used, were reported at most facilities. Some facilities had very small quantities of drugs, e.g. 15 morphine tablets or 40 paracetamol tablets. It is possible to provide care with small drug quantities if restocking is frequent and the lead time is short, but FGD participants reported long queues at pharmacies and having to buy drugs at alternative facilities due to stock-outs. Insufficiencies in the drug supply could be due in part to inadequate monitoring at the facility level. For half of drug formulations surveyed, there was no system for stock level tracking, and many facilities used the stock level of 1, i.e. they ordered more of a drug when the last pack was opened. Eleven facilities had no stock control sheets, and of the 49 who reported using them, only 14 provided a copy, many of which were poorly designed and lacked key information. A pharmacist at one hospital reported that they were allowed to order only a certain amount of each drug per month which was not enough to cover the need, making stock-outs inevitable. Of the 55 facilities that stocked any of the drugs reviewed, 47% reported a stockout of at least one of the drugs during the past six months. Out of the 40 facilities offering adult CTX tablets, 38% reported a stockout in the last 6 months, and 33% of non-opioid tablet stocks had been empty in the same time. Patients reported frequent drug stock-outs/ and long queues to obtain drugs in FGDs. Drugs were commonly kept in locked cabinets; however, in a minority of facilities codeine, CTX, fluconazole and non-opioid painkillers were kept in locations accessible to patients.

Documents

First assessment sheets (used to identify and monitor presenting health status and needs) were used at 66% of facilities; ongoing assessment sheets (used to monitor response to care and changes in health status/need) were used at 59% of facilities; outgoing referral forms (used to communicate current health status, specific referral need and existing care provision) were used at 90% of facilities; patient information sheets (designed to monitor care, contact details, prescribing, intervention etc.) were used at all facilities; and patient records were kept at 92% of facilities. Over half of all facilities surveyed lacked any care protocols. Twenty-two facilities provided health promotion materials containing information on living positively, facts about ARV treatment and family planning. Five also had information about alternatives to breastfeeding.

Validation of care components offered (FGDs)

Some discrepancies were noted between services provided (according to providers) and services available, (according to patients) e.g. condoms and water treatment. Reasons offered by patients for lack of provision included insufficient availability, ineligibility, fear of stigma (particularly with respect to condoms), and a lack of awareness of services offered. Patient eligibility for particular services was not addressed in provider interviews.

Study Strengths and Limitations

There are a number of strengths and limitations to this survey. Firstly, the calculation of proportion of patients receiving care could not be conducted as patient numbers were often missing or appeared unreliable. Fourteen facilities were unable to report their patient load over the past three months.

The data collection tool eliciting information on care components was subject to some limitations. The PEPFAR care areas used in the analysis did not contain all the components captured in the questionnaire. Also, the number of components included within each area of care varied greatly, with most areas containing about four components, and clinical care containing over 30. Therefore, the likelihood of facilities providing or referring any element of clinical care is far higher than any element of the other areas of care. This may explain the apparent lower availability of spiritual or social care, although psychological and preventative care were commonly provided/referred for even though these categories also had only small numbers of care components. Also, the non-clinical areas of care and support, defined by PEPFAR, may not include components that facilities offer and that may fall into these areas.

Calculated patient loads are subject to limitations. Firstly, patient contact time was not measured. This may have resulted in over-estimated median patient load values for doctors and clinical officers, for instance, as these staff may in fact undertake only a small amount of clinical work as a proportion of their working day. Secondly, patient load was assessed against job titles, and not job functions. Many staff were found to be undertaking a variety of tasks that would not normally fall under their job title, e.g. nurses who primarily deliver clinical care were also undertaking counseling and dispensing. For these staff, calculated patient loads may be under-estimated.

Furthermore, provider/patient-reported data is subject to bias. For instance, providers may have reported a component of care as “provided/referred for” that was in fact not available, or equally

providers may not have been aware of all care components available to patients. Although provider-reported information could not be accurately validated, patient FGDs allowed for some triangulation of emerging findings. FGD participants may not have been representative of the wider HIV positive patient population.

Participants were patients who were present at the facility on the day of the visit, and asked to participate by facility staff. A purposive sampling frame was developed to maximise diversity; however, it is possible that participants were, for example, more sick than average (as demonstrated by their clinic attendance). Some patients were “peer counsellors” or other clinic volunteers and had received training for these roles, but they did not take part in FGDs. Furthermore, due to the high number of FGDs undertaken over a short timescale, it was not possible to transcribe and translate the discussions. Notes were taken by the facilitator, and these were analysed for content. This method has limitations, in that notes capture less data than transcriptions; some views or opinions may not have been reported here in depth.

With respect to the pharmacy review, it is possible that drugs with another label, or a less common formulation than the one asked about, were in use. The most commonly used drugs were reviewed - identified through wide consultation (although we chose not to include ARVs). Also, despite many documents reportedly being available, a large proportion of facilities could not supply the researchers with an example document. This limited the depth of the content analysis and raises the risk of bias.

Recommendations

Infrastructure

- Multidimensional HIV care and support requires more space than purely medical assessment and intervention. Facilities should increase their physical space for care services, particularly to allow for counselling sessions in privacy and for children’s care.
- Availability of resources to ensure existing services such as transport and electricity are required, as many vehicles are not operational and only half of facilities have working generators. Infection control is also compromised in the absence of infrastructure.

Health management information systems

- As staff recommended, the best way to prevent double counting is to improve coordination and strengthen referral. Smaller facilities cannot provide the holistic, complex care required for HIV without the ability to refer patients.
- Comprehensive records should be kept for all patients, detailing the care they receive including inward and outward referrals and needs assessment.

Staffing

- It was often found that staff were delivering care for which they felt they had not been adequately trained, and patients reported that they were discouraged from attending services where inadequately trained staff were employed. Increasing specialist training and employing staff specifically to deliver non-clinical aspects of care, such as psychological and spiritual care, could widen the availability of specialist care to patients and improve care quality.
- Staff retention is poor because of limited opportunities for development and low pay, and high

staff turnover may damage the quality of care provided. Investment in staff is needed which could benefit both staff and patients.

- Volunteers are more likely to remain at facilities if their contribution is seen to be valuable, for example by reimbursing their travel costs.

Care provision

- In the absence of data on paediatric-only facilities, skills and facilities for care and support of children need to be enhanced for the 20% of facilities that see no children at all.
- As the model most likely to have staff present across all five areas of care, the holistic provision of healthcare model offered by health centres should be replicated.
- HBC facilities should offer basic clinical care, and provide or refer for treatment for anxiety and depression.
- Social care is the least developed aspect of care in the survey. Income-generating activities and home help need to be implemented more widely to help patients overcome the financial barriers to clinical care.
- The BCP should be rolled out to all facilities, with clear and equitable eligibility criteria and adequate provision for all who need it. While the BCP is available at some facilities but not others, 'shopping around' is unavoidable. Treatment of TB, malaria and other infections is more readily found than prevention care, although prevention is more cost-effective and saves more lives.

Drug supplies

- Reliable drug availability is a significant problem which hampers the delivery of care. Supply chains need to be strengthened by improving communication and responsiveness.
- In addition to improvements in morphine supply, training in pain management and opioid use is needed to increase uptake and usage.

Laboratory services

- Laboratory services, particularly CD4 testing, should be made more widely available. For smaller facilities, referral networks to larger facilities for such services should be efficient.
- All facilities which provide or refer for ART should provide or refer for CD4 tests and LFT, as essential services for ART.

Documents

- Lack of proper records limits the ability of a facility to provide integrated care, monitor stock, manage referrals, plan and budget. Large facilities should have administrative staff specifically employed to handle data management, and train existing staff in record keeping.
- Records forms should be revised and standardised to improve assessment, management and continuity of care and inward/external referral

PEPFAR

- The definition of care and support services should be considered, as the survey found a safe water advocacy group currently falls under this heading in terms of funding.
- Method for identifying patient numbers for PEPFAR routine reporting may require revision. There was often a discrepancy with facility-reported numbers.

Further research

- The survey results are mainly self-reported. A real understanding of the extent and quality of care could only be established by further study and measuring patient outcomes. This will be explored in Phase 2.
- A paediatric care and support PHE is required, although there is currently no validated African outcome tool for children.
- Volunteer staff are an important resource. The motivation and retention of volunteers need to be further understood, particularly at HBC facilities which depend heavily on volunteers.
- Spiritual care needs and provision could be further investigated to determine the care provided by spiritual leaders employed at facilities.
- Further study of barriers to care could explore the difference between reported care offered, and care reported to be received.
- Little is known about the strength and effectiveness of referral networks. A study to assess the comprehensiveness and coordination of the system would require a different design. Topics of interest include reasons for referral, the type and distance of facility referred to, patient uptake and follow-up.

References

- Beecham J, Knapp M. (2001) Costing psychiatric interventions, In: G Thornicroft (ed.) Measuring mental health needs. London: Gaskell.
- Colindres R, Mermin J, Ezati E et al. (2008) Utilization of a basic care and prevention package by HIV infected persons in Uganda. *AIDS Care* 20(2): 139-145
- Langlois-Klassen D, Kipp W, Jhangri GS, Rubaale T. (2007) Use of traditional herbal medicine by AIDS patients in Kabarole District, western Uganda. *American Journal of Tropical Medicine and Hygiene* 77(4): 757-63.
- Logie DE, Harding R (2005) "An evaluation of a morphine public health programme for cancer and AIDS pain relief in Sub-Saharan Africa". *BioMed Central Public Health* 5: 82
- Mills E, Foster BC, van Heeswijk R et al. (2005) Impact of African herbal medicines on antiretroviral metabolism. *AIDS* 19(1): 95-97.
- Office of the U.S. Global AIDS Coordinator (2006). "HIV/AIDS Palliative Care Guidance #1 For the United States Government in-Country Staff And Implementing Partners". U.S. Department of State. <http://www.state.gov/documents/organization/64416.pdf> accessed 13.01.08

Table 1: Participating facilities

ID	District	Name	Facility type
202	Kaberamaido	Ocanoyere P/S	Other health centre
203	Bushenyi	Rugarama Health Centre II	health post/dispensary
204	Bushenyi	Swazi Health Centre II	health post/dispensary
205	Bushenyi	Butoha Health Centre II	health post/dispensary
206	Tororo	Nagongera Boys	hospital affiliated health centre
207	Busia	Busamba	health post/dispensary
209	Kyenjojo	Kyenjojo District PHA Forum	home-base care only
210	Kisoro	Kisoro District PHA Forum	home-base care only
211	Bushenyi	Bushenyi District PHA Forum	home-base care only
212	Kampala	Case Medical Centre	other health centre
213	Kumi	Agaria Health Centre II	health post/dispensary
214	Mubende	Mubende District PHA Forum	home-base care only
218	Busia	Buhehe	health post/dispensary
219	Kumi	Nyero Health Centre III	other health centre
220	Rakai	Kifamba	other health centre
221	Kumi	Malera Health Centre III	health post/dispensary
222	Wakiso	Buwambo Health Centre IV	other health centre
223	Rakai	Kasasa	other health centre
226	Mbarara	Kiruhura District	health post/dispensary
227	Bushenyi	Bushenyi TC Health Centre III	other health centre
229	Pallisa	Butesa Community AIDS Initiative	other health centre
230	Rakai	Lyantonde Muslim Health Centre	other health centre
231	Bugiri	UCOBAC	home-base care only
232	Mbarara	Mayanja Memorial Foundation	other health centre
233	Mbarara	Ibanda CDC	other health centre
234	Kampala	Hospice Africa Uganda	other health centre
235	Kampala	Mulago TB-HIV Clinic	training hospital
236	Kumi	Kumi Aids Support Organisation	home-base care only
237	Wakiso	Meeting Point Wakiso Kyamusa Obwongo	home-base care only
238	Kyenjojo	Kyembogo Health Centre-Kyarusenzi	other health centre
239	Kyenjojo	FP Diocese-Kyembogo	home-base care only
240	Mbarara	Bwizibwera ISS Clinic	health post/dispensary
241	Kumi	Kumi DDHS	other health centre
242	Bushenyi	Ishaka Hospital	district hospital
243	Kayunga	Kayunga District Hospital	referral hospital

ID	District	Name	Facility type
244	Lira	Lira - DDHS	referral hospital
245	Mukono	Nile Treatment Centre	health post/dispensary
246	Kabarole	Buhinga Regional Hospital	district hospital
247	Bushenyi	Bushenyi Medical Centre, Katungu	other health centre
248	Kampala	Kawempe Health Centre	hospital affiliated health centre
249	Jinja	Jinja Regional Hospital	referral hospital
250	Mukono	Kawolo Hospital	district hospital
251	Apac	Apac Government Hospital	district hospital
252	Kitgum	St. Joseph's Hospital	other health centre
253	Mbarara	AIC Mbarara	health post/dispensary
254	Kitgum	CHAPS	home-base care only
255	Rukungiri	TASO Rukungiri	other health centre
256	Kampala	AIC Kampala	other health centre
257	Mbarara	TASO Mbarara	other health centre
258	Kampala	Mulago Infectious Diseases Clinic	other health centre
259	Kampala	JCRC - Kampala Clinic	other health centre
260	Mbarara	Mbarara Regional Hospital	training hospital
261	Kumi	Ngora Dispensary	other health centre
263	Mbale	Makhai P/S	hospital affiliated health centre
265	Pallisa	Kadama	other health centre
266	Soroti	Arapai Odudui	health post/dispensary
269	Bushenyi	Rimuri Health Centre II	health post/dispensary
277	Kyenjojo	RWIDE	home-base care only
278	Kyenjojo	Kyenjojo Initiative For Rural Development	home-base care only
279	Rakai	Lwamaggwa	other health centre

Table 2: Components of care available

Area of PEPFAR care and support	Care components included from CSRI	Area of PEPFAR care and support	Care components included from CSRI
Clinical	<ul style="list-style-type: none"> • Pre and post test counselling • Adherence counselling • Nursing care • Adult diagnostic HIV testing • Weighing • Assessment of pain • Strong opioids • Weak opioids • Non-opioid analgesics • Treatment for neuropathic pain • Treatment for nausea/vomiting • Treatment for skin rash/itching • Treatment for diarrhoea • Laxatives • Treatment for thrush • Treatment for oral candidiasis • Treatment for cryptococcus • Treatment for other fungal infections • Treatment for herpes • Treatment for malaria • TB detection and treatment • Therapeutic feeding for malnutrition • Treatment for other opportunistic infections • Management of cancer • Multivitamins • Nutritional advice • Access to safe drinking water at home • Septrin/cotrimoxazole (CTX) • Isoniazid to prevent TB • Mosquito bednets • Wound care • Physiotherapy 	Psychological	<ul style="list-style-type: none"> • Family care-givers support group • Family counselling • Psychiatric therapy • Anxiety/depression treatment
		Spiritual	<ul style="list-style-type: none"> • Visit by pastor • Contact with traditional healer/herbalist • Staff prayer with patients • Memory book work
		Social	<ul style="list-style-type: none"> • Home help • Legal services • Employment training • Loans/microfinance
		Prevention	<ul style="list-style-type: none"> • Family planning counselling • Prevention with positives • Patient HIV support groups • Condoms • Support for family testing

MEASURE Evaluation

Carolina Population Center
The University of North Carolina at Chapel Hill
206 W. Franklin St., CB8120
Chapel Hill, NC 27516 USA
www.cpc.unc.edu/measure

King's College London

Department of Palliative Care, Policy and Rehabilitation
Weston Education Centre
Cutcombe Road
London SE5 9RJ UK
www.kcl.ac.uk/palliative