SUMMARY

PEPFAR Public Health Evaluation
– Care and Support –

PHASE 2 UGANDA

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1 Executive Summary

1.1—Rationale

A Public Health Evaluation (PHE) was commissioned to examine PEPFAR-funded care and support. Phase 2 of this PHE aimed to evaluate how PEPFAR care and support programme components and costs are related to health outcomes.

1.2—Methods

Phase 2 was completed using three methods: a longitudinal quantitative observational study of patient care and self-reported health outcomes over three months; qualitative interviews with patients, informal carers and staff; and a costing study to estimate facility-level costs of providing care and support. Six facilities receiving PEPFAR Care and Support funding were selected to participate in Phase 2 from those which had completed Phase 1. In the longitudinal study, health outcomes were measured using the MOS-HIV and the APCA African POS (Palliative Outcomes Scale), and patient care using a modified Client Services Receipt Inventory (CSRI).

1.3—Main Findings of Longitudinal Quantitative Study

1.3.1—Facility Characteristics

The facilities (numbered 252, 255, 256, 258, 259, and 260, as in Phase 1) all provided outpatient care to people with HIV. They were a mission hospital, two research centres, a testing and care centre, two hospital HIV clinics and a community care organisation.

1.3.2—Participant Characteristics

Six hundred forty-one people were recruited to the study and interviewed at a mean of 32.6 day intervals for four months. During this time, 538 (83.9%) participants completed all four interviews; of those who did not complete all four interviews, seven died, 22 were unable to continue, one refused, one left the study and 72 gave no reason. Participants were aged 18–70

with a mean age of 35, 32% were male, and they had a median of four dependants. Median time from HIV diagnosis to study recruitment was 196 days and 31% had been diagnosed within 14 days of recruitment. For the 63% who had a recent CD4 count, the median count was 297. At the first appointment 25% were accompanied by an informal carer; this proportion later dropped to 17%. The wealth of patients was indicated by their reported living conditions. Over a quarter (26%) of participants used a shared or public latrine, which is considered inadequate sanitation, and 12% sourced drinking water from an unsafe supply. Almost half (46%) used firewood or straw for fuel, which is associated with increased risk of tuberculosis (TB) and respiratory infections.

1.3.3—Care Delivery

Of 52 components of care and support included in the questionnaire, participants received a mean of 13 components per month and 22 during the study. Over 90% of participants received daily cotrimoxazole (CTX), adherence counselling and prevention with positives. Of the five categories of PEPFAR Care and Support (clinical, psychological, spiritual, social and preventive), 100% of participants received clinical care and 98% prevention. Social care was, by some distance, the least commonly received (35%). During the study, 61% of participants received ART at least once, making it the seventh most common component of care. Monthly receipt of CTX increased over time from 70% at baseline to 93% by the end of the study.

Newly diagnosed participants received a mean of eight components of care at baseline, rising to 12 after three months. 19% of this group received all five elements of the Preventive Care Package (CTX, water treatment, an insecticide-treated net (ITN), condoms and voluntary counselling and testing (VCT) information for family members) during the study period and 36% received four. The least commonly received element was family VCT information (49%).

1.3.4—Physical and Mental Health and Multidimensional Problems

At baseline, participants had a mean physical health score of 43.5 and mean mental health score of 44.2 as measured by self-report using the MOS-HIV (with 100 being the best possible health and 0 the worst), indicating substantially impaired quality of life. Their biggest problems as recorded on the APCA African POS multidimensional care scale were not being able to share their feelings with anyone, not having help and advice to help the family to cope, and not feeling at peace.

1.3.5—Differences Between Facilities

Participants at Facility 252 were poorer, with worse physical function and lower CD4 count, compared to participants at other facilities. Facilities 255 and 256 had the highest mean CD4 count and best physical function scores. Care provided was also not the same across facilities. Clinical and preventive care had almost 100% coverage but social care and nursing provision were received by varying proportions of patients at facilities. Participants at Facilities 252, 255, and 259 were more likely to receive additional care components from elsewhere.

1.3.6—Participant Characteristics and Self-Reported Health

Older people had lower physical health at baseline, and relatively wealthier people had better physical and mental health. Participants with a lower CD4 count had worse physical and mental health, although after controlling for physical health, the association between mental health and CD4 disappeared. Participants who received ART or TB treatment in the month before T0 had lower physical and mental health than those who did not. There was no difference in physical or mental health between men and women.

1.3.7—Changes in Health Over Time

Over time, self-reported physical and mental health improved and all multidimensional problems decreased, after accounting for the bias that those with poor health were more likely to drop out of the study. Outcomes also improved for the people with the worst

health at baseline. Age, gender, education and wealth were not associated with change in physical or mental health over time. Participants at Facilities 252 and 259 showed a greater improvement in physical (both) and mental (Facility 259 only) health than the other facilities.

Over three months, participants receiving ART showed less improvement in self-reported physical or mental health than those not taking ART, after accounting for disease stage using CD4 count.

1.4—Main Findings of Qualitative Interviews

Patients reported experiencing pain, physical symptoms, and psychological problems such as anxiety. These were exacerbated by poverty and lack of resources which were recurring themes. Patients valued the services they received, particularly ART and other drugs, and the positive attitude of staff.

Some of the causes of psychological problems were worry over finances, stress due to keeping the diagnosis secret, and being unable to talk about feelings. Stigma and rejection were common problems, as was social isolation to pre-empt and avoid these reactions. Psychological problems had many sequelae including symptoms such as sleeplessness, inhibited access to care, reduced adherence, increased burden for carers, and severe disruption to normal life. Patients derived emotional support from each other and from staff.

Lack of money and lack of food were closely equated. Hunger was a threat to ART adherence, and fatigue, caused by both HIV and hunger, limited patients' ability to work, which reduced income and food availability in a vicious cycle.

There were many burdens to caring including the need to financially support the patient, health costs from the work of caring, and feelings of guilt over not doing enough. Carers found it difficult to access support services, and staff expressed the wish to reach them with home care services.

1.5—Main Findings of Costing Study

There was a very wide variation in costs per patient per year, from $41 at Facility 256 (by far the cheapest, probably because it did not provide ARVs directly) to $719 at Facility 252. The largest cost driver differed

between facilities, and included building rental and utilities at one facility, ARVs at two facilities and other drugs at another. Patient load for clinical staff varied from 1,400:1 at Facility 259 to 165:1 at Facility 258. There were economies of scale, so that facilities with more patients had lower costs per patient.

1.6—Recommendations

» People with HIV have physical and mental health needs throughout the trajectory of illness, and mental health in particular is not related to HIV progression but can be a problem at any stage. Care and support should be available to all patients irrespective of HIV disease severity.

» Care must respond to non-virological dimensions of HIV infection. All patients referred with HIV should be assessed for multidimensional need on a regular basis.

» Participants taking ART experienced self-reported physical and mental health lower than that of pre-ART participants at baseline and they made less improvement over time, even after accounting for CD4 count. Health staff should be aware of the needs of this group, and all patients taking ART should have regular monitoring, to include assessment and management of emotional and physical wellbeing as core clinical activities.

» Counselling services should include the opportunity for patients to raise concerns and discuss problems, rather than focusing solely on educational intervention

» The needs of carers should be included in the patient care encounter. Including carers early in the disease trajectory would improve social care for patients and could help to identify patient needs that are not acknowledged by the patients themselves.

» All patients should be assessed for pain, which should be managed according to the WHO Pain Ladder.

» Home-based care should be encouraged, so that family carers can receive support and services, and to reduce the costs to patients.

» There should be sufficient numbers of non-clinical staff to ensure a manageable patient load for counsellors, nutritionists, social workers and community health workers, and high quality patient care. The areas addressed by these professions were identified as areas of high need for people in this study.

» No problems were reported with the supply of ARVs but supplies of other drugs were frequently unreliable, causing expense to patients and delays to care. Supply chain systems should adopt the best practices of the ART delivery system.

» Chronic hunger is not adequately managed by short-term interventions. Food shortage caused by poverty is a significant problem which inhibits delivery of HIV care. Health facilities should work towards sustainable, adequate food supply for all patients to help maintain health and adherence.

» Patients reported living in an atmosphere of stigma and discrimination which adversely affected their mental health. They recommended increased VCT promotion, in order to change public perceptions of HIV, make it easier for patients to disclose their status, and relieve the stress of secrecy. Increased prevention services would benefit HIV care and support.

» To achieve the best possible physical and mental health outcomes, HIV care and support should include:
  • helping family members care for patients, through training and health care for carers;
  • services to allow families to achieve adequate nutrition, ventilation and sanitation for basic health;
  • a programme of psychological care, including 'talking therapies' and medication, with referral for those with psychiatric problems; and
  • support for patients whose financial situation inhibits their adherence, either directly through inability to pay or indirectly through worry.

» Facility staff who had hosted research projects for years expressed a wish to learn skills and conduct their own research. Future research programmes should include continued building of knowledge and capacity in host settings.

» A study of care and outcomes for children should be undertaken to explore the multidimensional needs of this important population, particularly the expanding group of HIV positive older children for

whom optimal care is still being developed

» Shortage of non-ART drugs delayed patient care and was a common complaint, but the cause of these shortages is unclear. Examination of the barriers to drug delivery and a more detailed investigation of how drugs are supplied would be beneficial in terms of care delivery and patient satisfaction.

» A longer follow-up period would be beneficial to explore whether care and outcomes are maintained over a period greater than three months.

» A study of how different staff working in care and support of HIV patients spend their working hours would enable an examination of how care costs relate to patient outcomes.

» Further study of referral networks from individual facilities would help understand where, as well as why, patients obtain care that is not provided at the principal facility of study.

» The evaluation model used here could be replicated in other countries.

» Interventions to meet these recommendations should be developed, implemented and robustly evaluated in a sample of sites using experimental designs.

2 Summary Report

1.1—Introduction and 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 (a) 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; (b) 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 was to collect longitudinal prospective quantitative outcome data on 1,200 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 also involved a costing analysis to determine cost of care provided. This report presents findings from Phase 2 of the Uganda study only.

2.2—Methods

2.2.1—Study Design

Phase 2 was a mixed methods evaluation consisting of: a longitudinal quantitative study of care received and health outcomes over three months; qualitative interviews with patients, carers and staff; and a survey of key cost drivers.

2.2.2—Tool Selection and Development

For the longitudinal quantitative study the main outcome tools were the MOS-HIV, a 35-item quality of life measure developed in the USA (**1**) and validated in Uganda (**2**), and the ten-item APCA African Palliative Outcomes Scale (POS), to develop in Africa to address the multidimensional concerns of patients and families (**3**). Participants also completed a Client Services Receipt Inventory (CSRI) of care experience and a demography questionnaire. All tools except for demography were completed four times at monthly intervals. Interview schedules with open-ended questions were designed for the qualitative interviews and the costing survey form was designed with input from economists, clinicians and country teams. All tools were piloted prior to use.

2.2.3—Ethical Approval

Ethical approval was obtained from the Uganda National Council for Science and Technology and the College Research Ethics Committee at KCL. 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.

2.2.4—Selection and Recruitment

The largest six facilities from Phase 1 were selected for Phase 2 as they were the most likely to have capacity to undertake the study and be able to recruit 100 participants within the allotted time.

2.2.5—Data Collection

Data collection took place between January and September 2008. Trained health care workers in each facility conducted data collection for the longitudinal quantitative study in the course of their normal work. APCA researchers visited facilities at frequent intervals to monitor progress and to conduct the qualitative interviews. CD4 counts were obtained from patient files; all other data were self-reported. For the costing survey, which was completed last, APCA researchers questioned facility staff including management, clinical staff, accountants and pharmacists.

2.2.6—Data management and Entry

Longitudinal quantitative study data were entered into a purpose-made EpiData 3.1 database by a trained data clerk at each facility. On completion, all forms were transferred to the APCA offices where researchers

re-entered and validated the data. Qualitative interviews were transcribed by APCA researchers, translated forwards and backwards into English, and transferred into an NVivo project file. Costing study data were recorded on paper and entered into an Excel file by the researchers.

2.2.7—Analysis

The longitudinal quantitative study was analysed using Stata 10.0, with the main outcomes being physical health score and mental health score, derived from the MOS-HIV. Cross-sectional techniques including t-tests and linear regression were used to study the association of physical and mental health score with participant and facility characteristics. Multilevel modelling was used to analyse change in health scores over time and whether change was associated with personal characteristics or facility-level care delivery.

Thematic analysis of content was applied to the qualitative interview transcripts, which were coded in NVivo by APCA researchers according to a coding frame developed from the themes found in 18 transcripts. The costing survey data were analysed in Excel by an economist.

2.3—Findings and Discussion

2.3.1—Facility Characteristics

Three of the facilities were located in Kampala and three in other areas of Uganda. Two were branches of large national non-governmental organisations (NGOs) which had been developed in Uganda by and for people with HIV. Facility 256 had the highest loss to follow-up and longest mean time between interviews, probably due to its care model which prioritises confidentiality and ease of access.

2.3.2—Participant Characteristics

Six hundred forty-one patients were recruited at T0, 614 completed the interview at T1, 583 at T2 and 538 at T3, giving a loss to follow-up of 16.1%. The mean age was 35 (range 18–70) and 31.9% were male, with women on average younger than men. This distribution reflects the prevalence of HIV in Uganda (**4**).

At baseline 158 patients (25%) were accompanied by a family member or friend as informal carer; at other timepoints 17% had a carer. Qualitative interviews showed that patients could have multiple identities, caring for other members of the family while themselves receiving care. Some carers reported that they received support from the health facility, such as advice on how to manage emotional stress and encourage the patient, but limited home-based care services and the costs to carers of travelling to the facility made contact difficult.

Median time from HIV diagnosis to study recruitment was 196 days but the median time from facility registration to recruitment was seven days, indicating many participants had either recently changed their care facility or had spent some time unregistered after their diagnosis. Nearly a third of participants (31%) had been diagnosed within 14 days of recruitment, suggesting a high and increasing patient burden for staff.

For the 63% who had a recent CD4 count, the mean count was 331. At the first appointment 25% were accompanied by an informal carer; this proportion later dropped to 17%. The wealth of patients was indicated by their reported living conditions. Over a quarter (26%) of participants used a shared or public latrine, which is considered inadequate sanitation (**5**), and 12% sourced drinking water from a unsafe supply.

2.3.3—Participant Self-Reported Health Outcomes at Baseline

At the beginning of the study, mean physical health score was 43.5 (standard deviation 12.0) and mean mental health score was 44.2 (s.d. 9.5) on a scale from worst possible health at 0 to best possible at 100.

There was no significant difference in health scores between men and women, nor were health scores associated with age or level of education. Participants with higher relative wealth reported better physical and mental health, which was statistically significant using an ANOVA test (physical health F=26.6, $p<0.001$; mental health F=12.0, $p<0.001$).

Using linear regression, a low CD4 count was associated with low physical health score ($p<0.001$), but after accounting for physical health, no association remained between CD4 count and mental health.

Between recruitment and T1 (a month later),

305/615 participants received ART. The ART non-recipients had a higher mean self-reported physical health score than recipients at T1, with 48.5 compared to 42.7 (t=4.7, p<0.001), and a higher mean mental health score, of 48.6 compared to 46.1 (t=2.34, p=0.02). Of the 374 participants with a CD4 count, ART recipients also had a lower mean CD4 count than non-recipients, at 264.5 compared to 424.4 (t=2.95, p=0.02). These findings show that ART non-users were at a less advanced stage of infection than ART users in this observational outpatient cohort.

The most severe problems on the APCA African POS at recruitment were psychological (worry), spiritual (not feeling at peace [6]) and social (lack of help and advice for the family). At recruitment, 36% of participants reported experiencing severe, very severe or overwhelming pain in the previous three days, and 23% reported experiencing symptoms to the same intensity. In addition, 31% had been worried a lot of the time, most of the time or all of the time, 19% had never been able to share their feelings, 22% never, rarely or occasionally found life worthwhile, 16% had not felt at peace at any time, and 32% reported no help or advice for their family to plan for the future.

Few patients were accompanied by a carer at recruitment and they had lower physical health than other patients, suggesting a bias. Patients with carers also had a lower mean mental health score than unaccompanied patients, but this association was lost after adjusting for physical health. It appeared that carers were present to provide physical assistance rather than psychological support.

2.3.4—Care Received

In qualitative interviews, patients frequently reported satisfaction with the care they received, particularly medical treatment, and with improved health thanks to ART. The most commonly received components of care (at any time) were prophylactic cotrimoxazole (CTX) (97%), adherence counselling (93%), prevention with positives (PWP) (91%) and nutritional advice (89%). These are all part of the PEPFAR Care & Support programme, and are all preventive rather than curative. The most rarely provided items were strong opioids (5%), psychiatric therapy, (3%), cancer management (2%) and

treatment for cryptococcal meningitis (1%). Over 98% of participants received some component of PEPFAR clinical care and prevention care during the three months of observation, 78% received spiritual care, 68% psychological care and 35% social care.

The average longitudinal quantitative study participants visited the health centre (a median of an hour's travelling time each way) once a month, took daily medication, and received a mean of 12 other components of care per month. The stress of attempting to adhere to and pay for this regime, while keeping HIV status secret, had psychological consequences described in the qualitative interviews as sleeplessness, worry, isolation and fear. The consequences were also visible in the items with lowest scores on the APCA African POS: being unable to share feelings, lack of help and advice for the family to cope, and not feeling at peace.

CTX, water treatment, an ITN, condoms and voluntary counselling and testing (VCT) information for family members are the five elements of the Uganda Basic Care Package (7). Three months after diagnosis, 87% of the 196 participants diagnosed within two weeks of recruitment were receiving prophylactic CTX and 55% were in a patient HIV support group. Just over half (103, 52.6%) received a safe water source such as a filter or treatment tablets, 131 (66.8%) received an ITN and 143 (73.0%) received condoms.

Symptom control components were more common at the beginning of the study than the end, suggesting symptoms had been effectively controlled. Conversely, social care components were more common at the end of the study period, perhaps indicating a delay on provision of care. Over the three months, almost half the sample (46%) suffered from skin problems and over a quarter (26%) from diarrhoea and from fungal infections, to a severity which required treatment, suggesting a very high symptom burden for an outpatient population.

The most commonly received components of counselling and psychological care were adherence counselling, family planning counselling and nutritional advice. The evidence from focus group discussions in Phase 1 (8) suggests that these components are largely educational in nature, based on informing patients of benefits and risks, and this kind of counselling may not address

psychological issues such as anxiety and lack of peace which were reported as pervasive problems. Very little is known about mental illness in Africa, but the few studies which exist suggest a high burden of depressive and other symptoms (**9, 10**). Depression is associated with reduced adherence, less health-seeking behaviour (**11**) and shorter survival (**12**) for people with HIV.

2.3.5—Unmet Care Needs

In qualitative interviews, patients and carers reported problems including pain, side effects of ART (such as headache and dizziness, itching and pain), cognitive symptoms such as forgetfulness, worry about the future, social problems such as abandonment, shortage of money and food, and isolation. Psychological and social problems were not always addressed in counselling. The problem of staff shortage was a common theme, expressed by patients in terms of long waiting time and by staff in terms of unmanageable patient burden.

Pain is a common symptom in HIV (**13**) and ART may have little effect on its prevalence (**14**), but only 5.3% of participants received morphine during the study while 82.8% received non-opioid analgesics. Given that a third of participants reported severe or moderate pain at T3, it seems likely that the level of morphine provision was insufficient to control all participants' pain. Similarly, 13% of participants received emergency therapeutic feeding and 39% received food, a ratio of one curative treatment to three instances of prevention which suggests more people would have benefited from extra food.

Proportion spent on food is inversely related to income (**15**); in extreme circumstances, poverty and hunger become interchangeable concepts. Lack of food is one of the main barriers to ART adherence (**16**). Financial needs were mentioned more often in qualitative interviews than clinical, emotional, social or psychological needs (which were all prevalent), suggesting that for this group of patients and carers, health concerns were not the greatest source of need. There was virtually no limit to the help which might be asked of a care facility; most commonly food and school fees, but extending to employment, funding for small businesses, construction of a house and even adoption of children. These repeated pleas for assistance suggest a loss of

self-efficacy and the demotivating effects of depression, leading to feelings of disempowerment (**17**). Staff and patients recognised this danger, reporting encouragement to work and remain socially involved; patients often said the care they received had given them courage.

It has been argued that the effects of HIV on society are qualitatively different from other stressors (**18**), and that HIV is associated with social breakdown as the usual strategies for dealing with crisis fail to work (**19**). The combined effect of lost productivity, healthcare costs, reduced social support and increased nutritional needs cause financial stress which is mitigated by short-term measures with negative consequences, such as sale of assets, eating less, and removing children from school. All these strategies were identified in the qualitative interviews.

2.3.6—Facility Comparison

The greatest difference between participant populations at the six facilities was in their relative wealth. When the sample was divided into quintiles based on the DHS model (**20**), over three quarters of participants at Facility 252 were in the poorest quintile, while Facilities 256, 258, and 259 each had over 30% of their participants in the wealthiest quintile.

The number of care components ever received by participants in the course of the study varied considerably by facility, as shown in Table 1. The mean number of components received varied from 13.0 at Facility 256 to 23.9 at Facility 252; indeed, the minimum number of care components received by any participant at Facility 252 was higher than the mean for Facilities 256 and 258. The maximum number of care components a facility delivered would have depended on the resources available to it, but the minimum appears likely to have been a matter of policy, with some facilities (252 and 259) delivering a standard package of care to all their patients.

Care components were allocated into eight themes, and the proportion of participants to receive any care component in a theme between T1 and T3 was calculated per facility, as shown in Table 2. In general, counselling/advice and preventive care were widely received, often by over 90% of participants. The prevalence of other themes was more variable, such as social care,

Table 1: Care Components Ever Received, by Facility					
Facility	Mean	SD	Minimum	Maximum	N
252	23.9	4.2	14.0	34.0	107.0
255	22.0	6.3	6.0	34.0	105.0
256	13.0	6.4	0.0	28.0	113.0
258	13.8	3.9	1.0	22.0	107.0
259	20.1	4.1	11.0	31.0	102.0
260	16.0	4.3	3.0	27.0	107.0

Table 2: Percentage of Participants to Receive Care Theme in T1–T3, by Facility

Care theme	Facility					
	252	255	256	258	259	260
n	107	105	112	107	102	107
Spiritual	99.1	84.8	23.9	69.2	96.1	55.1
Counselling and advice	99.1	94.3	76.1	92.5	98.0	94.4
Preventive	97.2	97.1	69.9	89.7	98.0	94.4
Nursing	88.8	92.4	30.1	12.1	98.0	94.4
Pain	99.1	89.5	46.0	78.5	69.6	91.6
Symptoms	96.3	97.1	53.1	86.0	73.5	90.7
Nutrition	98.1	97.1	69.0	86.9	81.4	95.3
Social	1.9	73.3	1.8	20.6	59.8	1.9

Figure 1: Change in Mean Physical Health Score Over Time
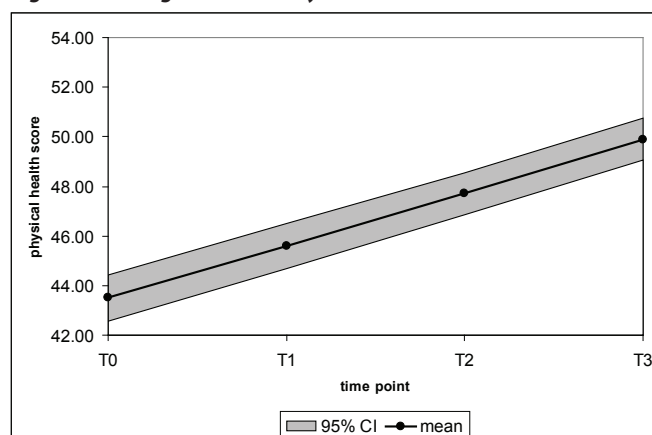
Figure 2: Change in Mean Mental Health Score Over Time

which was widely provided at Facilities 255 and 259, provided to a fifth of participants at Facility 258 and to almost no-one at the remaining three. The allocation of components to themes, and to PEPFAR categories of care, is displayed in Table 5.

2.3.7—Health Outcomes Over Time

Figures 1 and 2 display the mean health scores of participants at each time point, with 95% confidence intervals, showing an increase. Participants who were newly diagnosed with HIV or had developed a new problem, attending PEPFAR-funded HIV care and support clinics, showed statistically and clinically (**2**) significant improvements in their self-reported physical and mental health during the first three months of care.

Table 3 shows the proportion of participants to report severe (scoring 0–1) or moderate (scoring 2–3) problems on each of the seven APCA African POS items over time. All remaining participants reported mild problems (score of 4) or no problems (score of 5). The results show a clinically significant reduction in problems over time for all items.

Change over time was observed for the participants with the most severe problems at baseline, to ensure that the rise in average scores did not mask failure to improve for those with intractable problems. There was no evidence that this was the case, as participants with the worst pain and symptoms scores also improved over time. The association between ART use and outcomes was studied over time using multi-level modelling. Both groups reported improved outcomes over time, but participants taking ART (who had poorer physical

Table 3: Percent of Participants Reporting Severe and Moderate Problems by Multidimensional Item Over Time		T0 n=641	T1 n=614	T2 n=583	T3 n=538
Pain	severe	11.4	2.1	3.6	2.0
	moderate	53.6	46.7	39.1	31.2
Symptoms	severe	5.8	2.1	2.1	1.7
	moderate	44.4	38.4	33.3	26.2
Worry	severe	15.0	8.1	4.6	4.8
	moderate	42.5	37.1	33.6	25.1
Share feelings	severe	31.7	27.3	28.4	24.9
	moderate	36.9	38.7	32.3	25.7
Life worthwhile	severe	11.1	9.1	5.3	5.2
	moderate	35.5	30.6	30.5	24.5
Peace	severe	26.9	15.9	14.2	9.9
	moderate	44.8	44.9	44.3	41.5
Help and advice	severe	52.0	35.9	27.3	21.9
	moderate	30.3	44.7	47.5	39.6

and mental health at baseline) made less improvement in self-reported physical and mental health score from T0 than those who did not receive ART, and participants who received TB treatment also made less improvement in physical health score. The effect was not explained by baseline health, or by most recent CD4 count (which was itself influenced by ART use). ART users on average had more advanced disease which may have limited their capacity to benefit. The fact that health outcomes of ART users improved over time shows that ART alone does not maximise physical and mental health, and complementary multidimensional care and support is also needed.

2.3.8—Health Outcomes, Facility Comparison, and Care

The mean and standard deviation of mental and physical health scores at each facility at the beginning of the study are displayed in Table 4. There was significant variation in participant baseline physical and mental health between facilities (physical health: F=17.36, p<0.001; mental health: F=9.36, p<0.001). Facility 252,

which had the poorest patients, had the lowest mean physical health score, but mean mental health score was higher than expected at Facility 252, given the close association between mental and physical health scores. This may be because Facility 252 provided social and spiritual care to a higher than average proportion of its patients. Facility 256 recruited mainly through VCT, and its participants may have been physically healthier for this reason.

Figures 3 and 4 show the mean change in physical and mental health scores from T0 at each facility. There was no clear tendency for change in physical health score to be associated with physical health score at baseline, but for mental health, Facility 259, which had the highest score at baseline (Table 4), also made the most improvement.

In multilevel modelling, it appeared that the facilities which provided nutritional support to a higher proportion of their patients demonstrated less improvement in physical health over time. Further analysis showed that this association was actually driven by unmet care need. Some facilities had patients with greater physical health needs, and provided them with more nutrition care (and symptom management and pain control). However, this additional care was not enough to compensate for the lower starting point, which prevented patients at these facilities from attaining the health scores of participants at other facilities. Thus, the results showed a negative correlation between care and outcomes.

2.4—Strengths and Limitations

The mixed-methods design was a strength of the evaluation, allowing triangulation between the different elements. The quantitative interviews illuminated what was meant by care and support, the longitudinal quantitative study showed the number of people to receive it, and the costing study showed the various ways in which it could be delivered. Far more data were collected than can be explored here and the dataset will continue to reveal insights into the experience of people receiving HIV care in Uganda.

Use of two well-validated tools, a multidimensional outcome measure as well as the more traditional quality of life questionnaire, allowed more understanding of

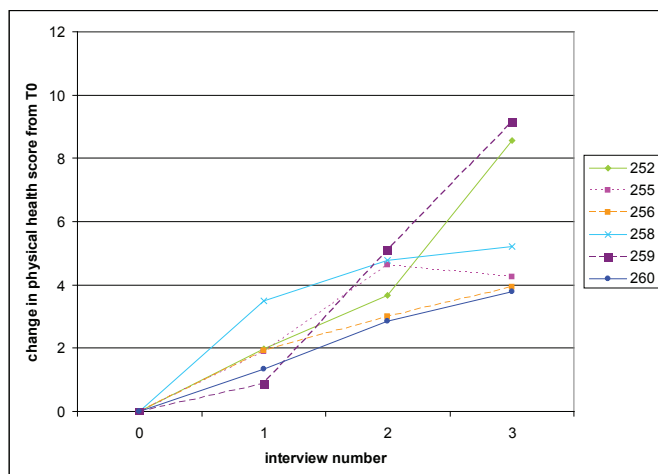**Figure 3: Change in Mean Physical Health Score Over Time, by Facility**

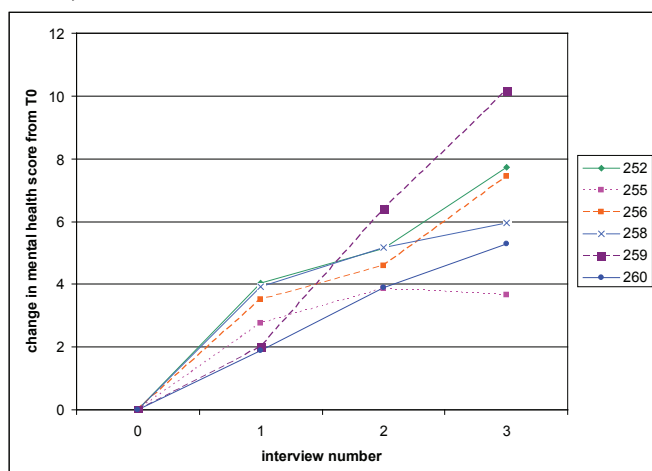**Figure 4: Change in Mean Mental Health Score Over Time, by Facility**

Table 4: Mean Outcome Scores at T0, by Facility				
	Physical Health Score		Mental Health Score	
Facility	Mean	Standard Deviation	Mean	Standard Deviation
252	37.9	9.7	42.6	7.3
255	38.5	12.3	40.3	8.9
256	49.0	11.4	43.9	10.6
258	45.8	10.9	47.0	9.4
259	46.7	12.5	47.7	9.2
260	42.8	10.7	43.9	9.6

the issues causing most concern to patients. Qualitative interviews supported this evidence that psychological problems such as loneliness and anxiety were a cause of distress in the population. The longitudinal study design was appropriate to the study, allowing observation of how quickly problems were managed over time and whether care was sporadic or maintained.

The tightly controlled methods of data collection, management and validation ensured a high quality of data in the longitudinal quantitative study. Completion was very high at all facilities and over time. Qualitative interviews were conducted by external researchers but they often took place on facility property and participants may have felt constrained in speaking negatively about the facility, even though they were assured that the recording would be confidential.

The longitudinal quantitative study was observational, not randomised. It was not a comparison between those in and out of care, nor was it designed to measure the effectiveness of ART, which as a covariate was inextricably associated with disease progression. Given the circumstances of the evaluation, a comparison group was not available and so it is not possible to determine what fraction of the results demonstrated in this study were the result of PEPFAR funding and what would have happened without it. No data exist from before the beginning of the PEPFAR investment which could be used as a baseline.

The facilities were selected purposively from a randomly selected sample, and thus are not representative of all PEPFAR-funded programmes. An evaluation of this kind, which required resources in terms of staff time, space and basic infrastructure from its facilities, could not have been carried out in a truly random sample as the majority of PEPFAR-funded Care and Support facilities are very small.

The study measured care received, not care needed. There is no certainty that all the care components a patient received were necessary, nor that patients received all the care they required. As a result of this and the fact that facilities were different from each other in the care their patients needed, the analysis of the longitudinal quantitative study were driven by the gap between care need and care delivery.

2.5—Recommendations

2.5.1—For Health Professionals

» People with HIV have physical and mental health needs throughout the trajectory of illness, and mental health in particular is not related to HIV progression but can be a problem at any stage. Care and support should be available to all patients irrespective of HIV disease severity.

» Care must respond to non-virological dimensions of HIV infection. All patients referred with HIV should be assessed for multidimensional need on a regular basis.

» Participants taking ART experienced self-reported physical and mental health lower than that of pre-ART participants at baseline and they made less improvement over time, even after accounting for CD4 count. Health staff should be aware of the needs of this group, and all patients taking ART should have regular monitoring, to include assessment and management of emotional and physical wellbeing as core clinical activities.

» Counselling services should include the opportunity for patients to raise concerns and discuss problems, rather than focusing solely on educational intervention

» The needs of carers should be included in the patient care encounter. Including carers early in the disease trajectory would improve social care for patients and could help to identify patient needs that are not acknowledged by the patients themselves.

» All patients should be assessed for pain, which should be managed according to the WHO Pain Ladder.

2.5.2—For Health Facility Managers

» Home-based care should be encouraged, so that family carers can receive support and services, and to reduce the costs to patients.

» There should be sufficient numbers of non-clinical staff to ensure a manageable patient load for counsellors, nutritionists, social workers and community health workers, and high quality patient care. The areas addressed by these professions were identified as areas of high need for people in this study.

2.5.3—For Policymakers

» No problems were reported with the supply of ARVs but supplies of other drugs were frequently unreliable, causing expense to patients and delays to care. Supply chain systems should adopt the best practices of the ART delivery system.

» Chronic hunger is not adequately managed by short-term interventions. Food shortage caused by poverty is a significant problem which inhibits delivery of HIV care. Health facilities should work towards sustainable, adequate food supply for all patients to help maintain health and adherence.

» Patients reported living in an atmosphere of stigma and discrimination which adversely affected their mental health. They recommended increased VCT promotion, in order to change public perceptions of HIV, make it easier for patients to disclose their status, and relieve the stress of secrecy. Increased prevention services would benefit HIV care and support.

» To achieve the best possible physical and mental health outcomes, HIV care and support should include:
  • helping family members care for patients, through training and health care for carers;
  • services to allow families to achieve adequate nutrition, ventilation and sanitation for basic health;
  • a programme of psychological care, including 'talking therapies' and medication, with referral for those with psychiatric problems; and
  • support for patients whose financial situation inhibits their adherence, either directly through inability to pay or indirectly through worry.

2.5.4—For Researchers

» Facility staff who had hosted research projects for years expressed a wish to learn skills and conduct their own research. Future research programmes should include continued building of knowledge and capacity in host settings.

» A study of care and outcomes for children should be undertaken to explore the multidimensional needs of this important population, particularly the expanding group of HIV positive older children for

whom optimal care is still being developed

» Shortage of non-ART drugs delayed patient care and was a common complaint, but the cause of these shortages is unclear. Examination of the barriers to drug delivery and a more detailed investigation of how drugs are supplied would be beneficial in terms of care delivery and patient satisfaction.

» A longer follow-up period would be beneficial to explore whether care and outcomes are maintained over a period greater than three months.

» A study of how different staff working in care and support of HIV patients spend their working hours

would enable an examination of how care costs relate to patient outcomes.

» Further study of referral networks from individual facilities would help understand where, as well as why, patients obtain care that is not provided at the principal facility of study.

» The evaluation model used here could be replicated in other countries.

» Interventions to meet these recommendations should be developed, implemented and robustly evaluated in a sample of sites using experimental designs.

Table 5: Care Components, PEPFAR Categories and Care Themes

Care Components included from CSRI		Care Components included from CSRI	Care Theme
Clinical Support		*Psychological Support*	
Pre and post test counselling	Counselling/advice	Family counselling	Counselling/advice
Adherence counselling	Counselling/advice	Psychiatric therapy	Counselling/advice
Nursing care	Nursing	Anxiety/depression treatment	Symptom management
Wound care	Nursing	*Spiritual Support*	
Assessment of pain	Pain control	Visit by faith leader	Spiritual
Strong opioids	Pain control	Staff prayer with patients	Spiritual
Weak opioids	Pain control	Contact with traditional healer/herbalist	Spiritual
Non-opioid analgesics	Pain control	Memory book work	Social care
Treatment for neuropathic pain	Pain control	*Social Support*	
Treatment for nausea/vomiting	Symptom management	Home help	Social care
Treatment for skin rash/itching	Symptom management	Employment training	Social care
Treatment for diarrhoea	Symptom management	Legal services	Social care
Laxatives	Symptom management	Loans/microfinance	Social care
Treatment for thrush	Symptom management	*Prevention Support*	
Treatment for oral candidiasis	Symptom management	Family planning counselling	Counselling/advice
Treatment for cryptococcal meningitis	Symptom management	Patient HIV support groups	Counselling/advice
Treatment for other fungal infections	Symptom management	Prevention with positives	Prevention
Treatment for herpes	Symptom management	Condoms	Prevention
Treatment for malaria	Symptom management	*Other Support*	
Treatment for other opportunistic infections	Symptom management	Food	Nutrition
Management of cancer	Symptom management	ART	ART
Multivitamins	Nutrition	Assessment of ART	ART
Nutritional advice	Nutrition	Household items	Social care
Access to safe drinking water at home	Nutrition	Infection control training	Prevention
Therapeutic feeding for malnutrition	Nutrition		
TB treatment	TB		
CTX	CTX		
Isoniazid to prevent TB	Prevention		
ITN	Prevention		
Physiotherapy	—		

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