

SUMMARY

PEPFAR Public Health Evaluation – Care and Support –



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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 in Kenya.

1.2—Methods

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

1.3—Main Findings of Longitudinal Quantitative Study

1.3.1—Facility Characteristics

The facilities (numbered 155–160 as in Phase 1) were all HIV outpatient clinics. Four were based in public hospitals, one in an NGO hospital, and one was a health centre.

1.3.2—Participant Characteristics

Six hundred ninety-six people were recruited to the study, and interviewed at a mean of 30.2 day intervals for four months. One hundred four participants did not complete all four interviews; nine died, thirty left the facility, three were unable to continue, and sixty-two did not give a reason. Participants were aged 18–69 (mean 35), 31% were male and 97% had some primary education. Median time from HIV diagnosis to recruitment was 36 days and their median CD4 count was

276 at the beginning of the study. At baseline, 12% were accompanied by an informal carer.

1.3.3—Care Delivery

Of 52 components of care and support included in the questionnaire, participants received a mean of 12 per month and 20 altogether during the study. The most commonly provided were adherence counselling, prevention with positives and CTX, each received by over 90% of participants.

Of the five categories of PEPFAR Care & Support (clinical, psychological, spiritual, social and preventive), 99% of participants received clinical care and 94% prevention. Psychological care was the least commonly delivered (58%). In general participants received clinical care from the facility, social and spiritual care from other sources. Symptom management was obtained both from the facility and from elsewhere.

During the study 76% of participants received ART at least once. Receipt of CTX increased over time, until by the end of the study period 85% were receiving daily CTX and 95% had taken it the previous day.

Forty-one percent of participants were recruited to the study within two weeks of their HIV diagnosis. The care they most commonly received was, in order from the highest prevalence, pre- and post-test counselling, adherence counselling, prevention with positives, CTX, multivitamins, and nutritional advice. During the study 56% received family VCT information, 67% improved drinking water supplies, 47% an ITN, 65% condoms and 92% CTX. These are the components of the preventive care package. Participants who had been diagnosed more than two weeks before recruitment received the preventive care package components with similar frequency.

1.3.4—Physical and Mental Health and Palliative Care Related Problems

At baseline, participants had a mean self-reported physical health score of 46.1 and mean mental health

score of 48.1 as measured using the MOS-HIV (with 100 being the best possible health and 0 the worst), indicating substantially impaired quality of life. Their lowest scores on the multidimensional care scale (APCA African POS) were for not being able to share their feelings with anyone, and not having enough help and advice for the family to cope.

1.3.5—Differences between Facilities

Facilities differed in the relative wealth of their participants and in the proportion who were newly diagnosed (defined as within 14 days of recruitment). Facility 157 had 64% new participants while facility 156 had 13%. The facilities with poorest participants were 155 and 160. Median CD4 count ranged from 332 at facility 156 to 221 at facility 158. Provision of clinical care was high at all facilities, and provision of social care was always low, but the proportion to receive pain management, nursing care or spiritual care varied widely.

1.3.6—Participant Characteristics and Health

Older people, and poorer people, reported lower physical health at baseline, but mental health was not associated with age or relative wealth. There was no difference in mental or physical health between men and women, or between those with different levels of education. Participants with a low CD4 count reported lower physical health and, as a consequence, lower mental health. Whether participants were receiving ART at baseline was not associated with health outcomes. Participants taking ART had similar physical and mental health to those not prescribed ART (and probably with less advanced disease).

1.3.7—Changes in Health Over Time

Over time participants' mean physical and mental health improved and care needs decreased, after accounting for the bias that people with lower health were more likely to drop out of the study. Those with the lowest scores also experienced improvement. Facility 156 showed much less improvement in physical score than average; early gains in physical health then stabilised after the end of the first month. Older participants experienced less gain in health than younger, and wealthier participants experienced more than poorer.

Gender, education, and ART status were not associated with change. Participants receiving TB treatment had the same gains in mental health as those not receiving TB treatment, but less improvement in physical health.

1.4—Main Findings of Qualitative Interviews

Patients reported feeling pain, fatigue and anxiety; invisible, chronic problems. Their main worries and those of carers centred on poverty, realised in difficulty paying for food, transport, drug costs and school fees. They made great efforts to find fruit and vegetables but there was often not enough for the family.

Patients greatly appreciated the quality of care they received and, in most cases, the courteous behaviour of staff. They objected to waiting for a long time to see a health care worker, with opportunity costs and risk of infection in the waiting bay. Staff reported that increasing patient numbers were difficult to manage and that the quality of care was perceived to decline when they were overloaded.

Patients gave each other social and spiritual support, which usually did not come from the facility. There were schemes such as travel reimbursement and provision of soap for home care, sometimes carried out by the facility and sometimes by the individual health worker. Family carers received little support.

Care focused on clinical problems, and standard assessment and monitoring forms included only clinical measures, not emotional wellbeing. Patients were advised not to have too many thoughts, as they reported worry and many thoughts burdening them. They were encouraged to participate in social life and to discipline themselves against feelings of isolation and ostracism.

1.5—Main Findings of Costing Study

There was wide variation in costs per patient per year, ranging from \$77 at Facility 157 to \$1160 at Facility 159. Facility 159 was much more expensive than the others; the next largest cost was \$418. The largest contribution to costs was staff salaries at three facilities, ART at two and lab costs at one. Clinical staff contributed much more to costs than did non-clinical staff. Patient loads were extremely high for non-clinical staff. 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. All patients referred with HIV should be assessed for psychological need on a regular basis. Emotional wellbeing should be a core component of patient assessment in HIV monitoring upon registration and throughout patient care
- » The needs of carers should be included in the patient care encounter. Including carers early on the care trajectory would demonstrate the value of the carer role in the eyes of facilities, improve social care for patients and could help to identify patient needs that are not acknowledged by the patients themselves.
- » Participants established on ART were able to further improve their physical and mental health over three months. Care and support, complementary to ART, can help to optimise health.
- » Health facilities should have a clear policy regarding delivery of social care, food support and financial refunds, so that the burden of decision making and payment does not fall on health delivery staff.
- » Staff need to be supported and protected from risk of burnout to maintain valuable skills in health care and reduce turnover
- » 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 are a severe cause of need for people with HIV.
- » Sufficient space is essential to providing confidential counselling services and meeting patient needs
- » Many participants were initiated onto ART within weeks of their HIV diagnosis, showing that they could have benefited from treatment at an earlier stage. Testing needs further encouragement so that people with HIV are identified as early as possible in the disease trajectory and gain the maximum benefit from care and support services.
- » 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.
- » Policy makers should advocate for increased use of appropriate analgesics, including opioids, to manage chronic pain.
- » The evaluation model used here could be replicated in other countries.
- » 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 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

2.1—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; and (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 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 involved a costing analysis to determine cost of care provided per patient per year. This report presents findings from Phase 2 of the Kenya study only.

2.2—Methods

2.2.1—Study Design

Phase 2 was a mixed methods evaluation consisting of: a longitudinal quantitative observational 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 Kenya Medical Research Institute 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 facilities were secondary or tertiary hospitals, two were district hospitals, and one was a large non-governmental health centre. All facilities had full time doctors, although four facilities did not have any specialist spiritual staff and four facilities did not have any specialist psychological staff. Five facilities had a small number of volunteer staff, and one facility employed 40 of their 99 staff members on a voluntary basis.

2.3.2—Participant Characteristics

Six hundred ninety-six patients were recruited at T0, 634 completed the interview at T1, 613 at T2 and 592 at T3, giving a loss to follow-up of 14.9%. The mean age was 35 (range 18–69) and 31% were male, with women on average younger than men. This distribution reflects the prevalence of HIV in Kenya (4).

At baseline 83 patients (12%) were accompanied by a family member or friend as informal carer, and this proportion was reduced to 3% (n=20) by T3. Qualitative interviews showed that patients could have multiple identities, caring for other members of the family while themselves receiving care. Median time from HIV diagnosis to study recruitment was 36 days, and 267 participants (38%) had been diagnosed within 14 days of recruitment. This high proportion of individuals diagnosed very recently suggests that facilities would have had to increase care provision rapidly to accommodate them, with consequent burden on staff and resources.

For the 90% who had a recent CD4 count at the beginning of the study, the mean count was 322. The wealth of patients was recorded using Demographic and Health Survey methods (5). 42% of participants used a shared or public latrine, which is considered inadequate sanitation (6), and 31% sourced drinking water from a unsafe supply.

2.3.3—Participant Health Outcomes at Baseline

At the beginning of the study, mean physical health score was 46.1 (standard deviation 11.3) and mean mental health score was 48.1 (s.d. 9.5) on a scale from worst possible health at 0 to best possible at 100.

There was no significant difference in self-reported health scores between men and women, nor were health scores associated with age or education. Participants with higher relative wealth reported better physical and mental health, which was statistically significant using an ANOVA test for physical health ($F=3.25$, $p=0.012$) but not for mental health ($F=1.91$, $p=0.108$). The main reason why qualitative interview patients attended for care was because of symptom burden and these findings suggest poorer people bore with symptoms for longer before seeking care.

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), 310 of 694 participants received ART. There was no significant difference in self-reported physical or mental health score between ART recipients and non-recipients at T1. Mean CD4 count was also very similar between the

two groups (323 for ART recipients compared to 322 for non-recipients). Non-recipients in this outpatient cohort would generally have been those not yet eligible for ART and hence with less advanced disease.

The problems scoring most on the APCA African POS at recruitment were lack of help and advice for the family, and inability to share feelings. At recruitment, 22% of participants reported experiencing severe, very severe or overwhelming pain in the previous three days, and 9% reported experiencing symptoms to the same intensity. In addition, 17% had been worried a lot of the time, most of the time or all of the time, 37% had never been able to share their feelings, 20% never, rarely or occasionally found life worthwhile, 16% had never or not very often felt at peace, and 42% 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, the vast majority of respondents reported positive experiences of being under care. The three factors that appeared to constitute a positive experience were good staff attitude, availability of drugs, and short waiting times.

The most commonly received components of care (at any time) were adherence counselling (91%), prevention with positives (90%), prophylactic cotrimoxazole (CTX) (89%), assessment for ART (84%) and multivitamins (84%). The most rarely provided items were prophylactic isoniazid (5%), strong opioids (5%), treatment for cryptococcal meningitis (2%) and cancer management (2%). Ninety-nine percent of participants received some component of PEPFAR clinical care and 94% received prevention care during the three months of observation, 83% received spiritual care, 60% social care and 58% psychological care. Social and spiritual care were the most likely to be received from some other source rather than the research facility. The lowest

level of provision was for psychological care although the APCA African POS showed psychological problems were some of the most burdensome.

Patients were encouraged to remain active, be self-sufficient, attend weddings and celebrations, and be part of community life. By advising patients to discipline their minds not to think of themselves as isolated, staff appeared to be warding off self-imposed stigma.

The average longitudinal quantitative study participant 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 items received by over 75% of participants were all for prevention of infections or of HIV transmission, except for ART and non-opioids.

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, 85% of the 267 participants diagnosed within two weeks of recruitment were receiving prophylactic CTX and 53% of their families had received VCT information. Fifty-nine percent received a safe water source such as a filter or treatment tablets, 45% received an insecticide-treated mosquito net (ITN) and 63% received condoms.

Over the three months, almost a third of the sample (32%) suffered from skin problems and over a quarter (26%) from fungal infections, to a severity which required treatment, suggesting a high symptom burden for an outpatient population. Further, half of participants (50%) were treated for malaria, although most of the data collection took place outside the peak malaria season. Symptom control components were more common at the beginning of the study than the end, suggesting some symptoms had been effectively controlled.

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), psychological turmoil and worry, social problems such as family rejection, shortage of money and food, and difficulty obtaining drugs. Psychological and social problems

were not always addressed in counselling.

Pain is a common symptom in HIV (8) and ART may have little effect on its prevalence (9), but only 5% of participants received morphine during the study while 78% received non-opioid analgesics. Given that mild pain was so common, it seems likely that the level of morphine provision was insufficient to control all cases of severe pain. The most common symptoms in qualitative interviews were pain and lack of energy, which are both invisible and often underdiagnosed or not recognised as a real problem. The multidimensional scores indicated unacceptable levels of pain, and the MOS-HIV results showed that only 23% of participants said they always had enough energy to do the things they wanted to do.

The main problem carers experienced was lack of money to pay for food, transport and school fees. Patients repeated the same three priorities for payment. For at least some patients and carers, poverty was intense. They could not afford to pay the small costs of home-based care such as disposable gloves and soap, which staff ended up providing from their own pocket. Proportion spent on food is inversely related to income (10); in extreme circumstances, poverty and hunger become exchangeable concepts. Lack of food is one of the main barriers to ART adherence (11).

Challenges to care were long waiting times, unaffordable costs (even when treatment was free), and unreliable drug supplies. Staff reported overburden with large numbers of patients and insufficient staff, particularly social workers. Patients and carers stated that high quality care would involve being visited in their homes by someone who knew their situation. In this and other cases, staff said that the patient burden was adversely affecting the quality of care they could offer, due to constraints on time, space, and funds. The discrepancy between needs and resources, exacerbated by overwhelming patient numbers, limits quality of care and also puts staff at risk of burnout (12).

2.3.6—Facility Comparison

There was no marked difference between age, gender and education distributions of study participants at the different facilities, suggesting that the demographic characteristics of the sample are representative of the

wider population and were not skewed by abnormal results from any facility. Probably the greatest difference between participant populations at the six facilities was in their relative wealth; 52% of Facility 155 participants were in the poorest quintile and 48% of Facility 158 participants in the richest, but all quintiles were represented at each facility. The number of care components ever received by participants in the course of the study varied considerably by facility, as shown in Table 1, from a mean of 8.4 at Facility 157 to 15.5 at Facility 155.

Care components were allocated into eight themes, and the proportion of participants to receive any care component in a theme in T1, T2 or T3 was calculated per facility, as shown in Table 2. There were no trends in which facilities had the highest or lowest proportion of participants receiving care. For example, some component of spiritual care was received by 37% of participants at Facility 158 and 65% of participants at Facility 160. Also receipt of counselling and advice was received by over 90% of participants at Facilities 155, 158 and 160, but between 70 and 75% of participants at the other three facilities. The widest variation in receipt of care by facility was for nursing care. 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 improvement in self-reported health over time. 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. Particular increase was noted in the first month.

Table 3 shows the percent of participants who reported 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). In most cases the proportion experiencing either severe or moderate problems decreased, particularly between T0 and T1, when the largest reduction in severe prob-

Table 1: Care Components Ever Received, by Facility

Facility	Mean	SD	N
155	15.5	6.0	109.0
156	11.5	6.2	111.0
157	8.4	4.9	120.0
158	15.8	6.7	120.0
159	10.1	5.8	125.0
160	9.9	5.1	110.0

Figure 1: Change in Mean Physical Health Score Over Time

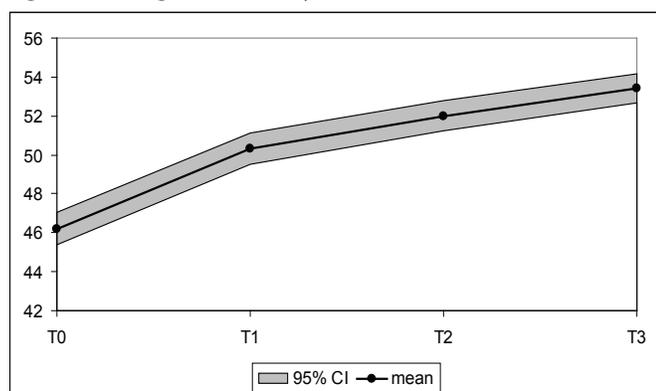


Figure 2: Change in Mean Mental Health Score Over Time

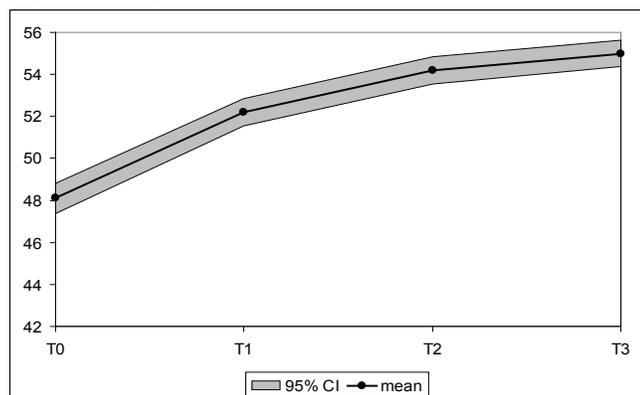


Table 2: Percentage of Participants to Receive Care Theme between T1 and T3, by Facility

Care Theme	Facility					
	155	156	157	158	159	160
<i>n</i>	107	105	106	107	104	105
Spiritual	61.3	51.5	49.1	36.7	52.9	65.0
Counselling/advice	93.6	75.3	75.4	99.1	70.3	95.4
Preventive	94.6	82.2	65.0	97.2	58.8	73.8
Nursing	78.8	26.1	5.2	79.9	33.3	37.9
Pain	70.5	39.7	43.7	69.9	58.5	62.1
Symptoms	53.1	31.8	45.8	66.6	58.5	45.9
Nutrition	95.8	97.6	77.9	96.9	75.4	43.9
Social	23.3	23.3	1.9	9.4	13.8	7.5

Table 3: Percent Reporting Severe and Moderate Problems by Multidimensional Item Over Time

Item		T0	T1	T2	T3
	<i>n</i>	696	634	613	592
Pain	severe	8.1	2.5	2.6	2.0
	moderate	43.3	27.1	22.0	22.8
Symptoms	severe	2.7	1.1	0.7	0.8
	moderate	32.2	16.4	18.3	15.0
Worry	severe	11.2	3.3	2.1	3.2
	moderate	27.7	19.1	16.2	15.2
Share feelings	severe	54.5	49.7	42.4	40.9
	moderate	24.0	28.1	37.7	34.8
Life worthwhile	severe	13.4	8.4	5.6	4.2
	moderate	15.5	10.3	8.5	10.1
Peace	severe	15.8	8.5	7.3	6.3
	moderate	27.0	19.9	17.0	17.1
Help and advice	severe	51.3	39.0	29.9	30.2
	moderate	25.1	35.2	33.6	32.8

lem scores occurred. The exception to this rule was in the two items causing most need at baseline: not being able to share feelings and not having enough help and advice for the family to cope. In these areas, severe problems were apparently reduced only to the status of moderate problems, causing an increase in the proportion to report moderate problems.

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. ART users did not make significantly more or less improvement over time than non-users. The study was observational and ART was prescribed according to need, not randomised. Participants who received TB treatment made less improvement in physical health score than those who did not receive TB treatment. In this case, probably the TB, rather than the treatment, limited their physical health gain.

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. At baseline there was greater variation in physical health score than mental health score by facility, although the variation was statistically significant for both ($p < 0.001$ and $p = 0.018$ respectively using Kruskal Wallis tests).

Figures 3 and 4 show the mean change in physical and mental health scores from T0 at each facility. Facility 156, which had the highest mean health scores at baseline, showed the least improvement over time. Facility 156 also recruited the largest proportion of patients whose reason for attending was to collect medication or a lab test result. It is possible that these participants did not have new presenting problems and thus would have had higher outcomes at baseline, with less potential for improvement over time. Meanwhile, Facility 160, which recorded that the largest fraction of its participants had been referred because of an HIV test result or were newly diagnosed, had the lowest health scores at baseline (Table 4).

Table 4: Mean Outcome Scores at T0, by Facility

Facility	Physical Health Score		Mental Health Score	
	Mean	Standard Deviation	Mean	Standard Deviation
155	43.1	12.8	47.0	10.1
156	49.5	9.2	49.7	8.2
157	47.4	11.6	47.5	10.2
158	46.7	11.8	48.4	9.5
159	47.1	9.6	49.5	9.7
160	42.6	11.2	46.4	8.6

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

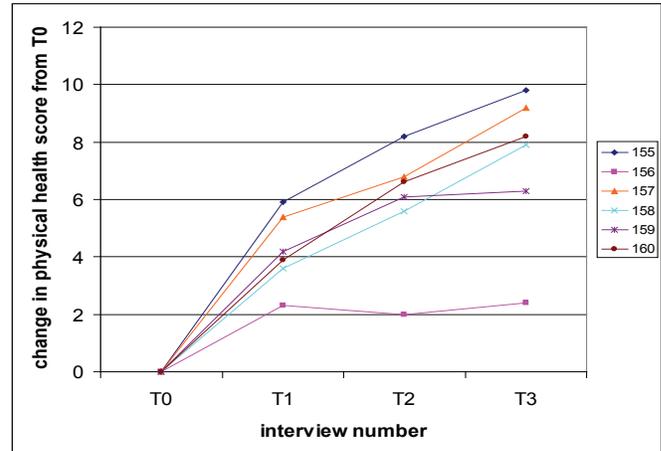
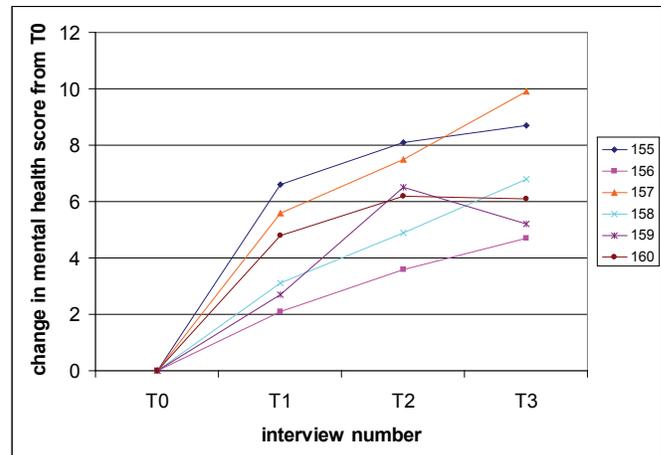


Figure 4: Change in Mean Mental Health Score Over Time, by Facility



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, 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 Kenya.

Use of two well-validated tools, a multidimensional outcome measure as well as the more traditional quality of life questionnaire, allowed more understanding of the issues causing most concern to patients. 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.

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. All patients referred with HIV should be assessed for psychological need on a regular basis. Emotional wellbeing should be a core component of patient assessment in HIV monitoring upon registration and throughout patient care
- » The needs of carers should be included in the patient care encounter. Including carers early on the care trajectory would demonstrate the value of the carer role in the eyes of facilities, improve social care for patients and could help to identify patient needs that are not acknowledged by the patients themselves.
- » Participants established on ART were able to further improve their physical and mental health over three months. Care and support, complementary to ART, can help to optimise health.

2.5.2—For Health Facility Managers

- » Health facilities should have a clear policy regarding delivery of social care, food support and financial refunds, so that the burden of decision making and payment does not fall on health delivery staff.
- » Staff need to be supported and protected from risk of burnout to maintain valuable skills in health care and reduce turnover
- » 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 are a severe cause of need for people with HIV.

- » Sufficient space is essential to providing confidential counselling services and meeting patient needs

2.5.3—For Policymakers

- » Many participants were initiated onto ART within weeks of their HIV diagnosis, showing that they could have benefited from treatment at an earlier stage. Testing needs further encouragement so that people with HIV are identified as early as possible in the disease trajectory and gain the maximum benefit from care and support services including ART.
- » 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.
- » Policy makers should advocate for increased use of appropriate analgesics, including opioids, to manage chronic pain.

2.5.4—For Researchers

- » The evaluation model used here could be replicated in other countries.
- » 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 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.
- » The APCA African POS summary score provided a useful indication of multidimensional care needs in this study population. Further evaluation studies should measure multidimensional outcomes using mixed methods to triangulate the findings.
- » 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.

Table 5: Care Components, PEPFAR Categories, and Care Themes			
Care Components Included from CSRI	Care Theme	Care Components Included from CSRI	Care Theme
<i>Clinical Support</i>		<i>Spiritual Support</i>	
Pre and post test counselling	Counselling/advice	Visit by faith leader	Spiritual
Adherence counselling	Counselling/advice	Staff prayer with patients	Spiritual
Nursing care	Nursing	Contact with traditional healer/herbalist	Spiritual
Wound care	Nursing	Memory book work	Social care
Assessment of pain	Pain control	<i>Social Support</i>	
Strong opioids	Pain control	Home help	Social care
Weak opioids	Pain control	Employment training	Social care
Non-opioid analgesics	Pain control	Legal services	Social care
Treatment for neuropathic pain	Pain control	Loans/microfinance	Social care
Treatment for nausea/vomiting	Symptom management	<i>Prevention Support</i>	
Treatment for skin rash/itching	Symptom management	Family planning counselling	Counselling/advice
Treatment for diarrhoea	Symptom management	Patient HIV support groups	Counselling/advice
Laxatives	Symptom management	Prevention with positives	Prevention
Treatment for thrush	Symptom management	Condoms	Prevention
Treatment for oral candidiasis	Symptom management	<i>Other Support</i>	
Treatment for cryptococcal meningitis	Symptom management	Food	Nutrition
Treatment for other fungal infections	Symptom management	ART	ART
Treatment for herpes	Symptom management	Assessment of ART	ART
Treatment for malaria	Symptom management	Household items	Social care
Treatment for other opportunistic infections	Symptom management	Infection control training	Prevention
Management of cancer	Symptom management		
Multivitamins	Nutrition		
Nutritional advice	Nutrition		
Access to safe drinking water at home	Nutrition		
Therapeutic feeding for malnutrition	Nutrition		
TB treatment	TB		
CTX	CTX		
Isoniazid to prevent TB	Prevention		
ITN	Prevention		
Physiotherapy	-		
TB testing	-		
Psychological	-		
Family counselling	Counselling/advice		
Psychiatric therapy	Counselling/advice		
Anxiety/depression treatment	Symptom management		

References

1. Revicki DA, Sorensen S, Wu AW. Reliability and validity of physical and mental health summary scores from the Medical Outcomes Study HIV Health Survey. *Med Care*. 1998;36(2):126–137.
2. Stangl AL, Wamai N, Mermin J, Awor AC, Bunnell RE. Trends and predictors of quality of life among HIV-infected adults taking highly active antiretroviral therapy in rural Uganda. *AIDS Care*. 2007;19(5):626–636.
3. Harding R, Selman L, Agupio G, Dinat N, Downing J, Gwyther L, et al. Validation of a core outcome measure for palliative care in Africa: the APCA African Palliative Outcome Scale. *J Pain Symptom Manage*. 2008.
4. Central Bureau of Statistics [Kenya], Ministry of Health [Kenya], ORC Macro. *Kenya Demographic and Health Survey 2003*. Calverton, Maryland: CBS, MOH and ORC Macro; 2004.
5. Gwatkin DR, Rustein S, Johnson K, Pande RP, Wagstaff A. *Socioeconomic differences in health, nutrition, and population in Ghana*. World Bank; 2000.
6. WHO/UNICEF Joint Monitoring Programme for Water Supply and Sanitation. *Global Water Supply and Sanitation Assessment 2000 Report*. WHO; 2000.
7. Mermin J, Bunnell R, Lule J, Opio A, Gibbons A, Dybul M, et al. Developing an evidence-based, preventive care package for persons with HIV in Africa. *Trop Med Int Health*. 2005;10(10):961–970.
8. Selwyn PA, Rivard M. Palliative care for AIDS: challenges and opportunities in the era of highly active anti-retroviral therapy. *J Palliat Med*. 2003;6(3):475–487.
9. Harding R, Molloy T, Easterbrook P, Frame K, Higginson IJ. Is antiretroviral therapy associated with symptom prevalence and burden? *Int J STD AIDS*. 2006;17(6):400–405.
10. Engel E. *Die Productions und Consumptionsverhältnisse des Königsreiche Sachsen*. 1877. Berlin.
11. RefType: Generic
12. Agnarson AM, Ericson J, Ekstrom AM, Thorson A. Antiretroviral therapy: what about food? *AIDS*. 2007;21(9):1225–1226.
13. Fournier B, Kipp W, Mill J, Walusimbi M. Nursing care of AIDS patients in Uganda. *Journal of Transcultural Nursing*. 2007;18(3):257–264.