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PEPFAR Public Health Evaluation – Care and Support –

PHASE 2 UGANDA

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Contents

Abbreviations

ABC	Abstain, Be faithful, use a Condom
ANOVA	analysis of variance
APCA	African Palliative Care Association
ART	antiretroviral therapy
ARV	antiretroviral
BCP	Basic Care Package
BMI	body mass index
CHW	community health worker
C&S	care and support
CSRI	client services receipt inventory
CTX	cotrimoxazole
DHS	demographic and health survey
ECOG	Eastern Cooperative Oncology Group
Fac	facility
FBO	faith based organisation
IGA	income generation activity
IQR	inter-quartile range
IRIS	immune reconstitution inflammation syndrome
ITN	Insecticide-treated net
HCW	health care worker
KCL	King's College London
MHSS	mental health summary score
MOH	Ministry of Health
MOS-HIV	Medical Outcomes Scale for HIV
NGO	nongovernmental organisation
OI	opportunistic infection
ORS	oral rehydration solution
PCP	preventive care package
PEPFAR	President's Emergency Plan for AIDS Relief
PHE	public health evaluation
PHSS	physical health summary score
PMTCT	prevention of mother to child transmission
POS	Palliative Outcomes Scale
PCP	Preventive Care Package
PWP	prevention with positives
SD	standard deviation
Se	standard error
Sem	standard error of the mean
STI	sexually transmitted infection
UNC	University of North Carolina
USAID	United States Agency for International Development
USG	United States government
VCT	voluntary counselling and testing
WHO	World Health Organization

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 to 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 a 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 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), 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 care 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 illness severity 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 a recurring theme. 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 inability 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 1400:1 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 per year.

1.6—Recommendations

1.6.1—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 worse self-reported physical and mental health 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.

1.6.2—For Health Facility Managers

- Home-based care should be encouraged, so that family carers can receive support and services such as VCT, 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.

1.6.3—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.

1.6.4—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 problems of this important population, particularly the expanding group of HIV positive older children for whom optimal care is still being developed
- Shortage of 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 Introduction

In 2003 the United States government (USG) funded a five-year, $15 billion initiative to combat the global HIV/AIDS epidemic: the President's Emergency Plan for AIDS Relief (PEPFAR). The funds were allocated approximately as follows: treatment (55%), prevention (20%), assisting orphans and vulnerable children (10%) and palliative care of individuals with HIV/AIDS (15%). PEPFAR has commissioned PHEs in these areas to evaluate funded programmes. Palliative care was subsequently redefined as care and support by OGAC.

2.1—Aim

The aims of the evaluation were (a) to describe the nature and scope of HIV care and support provision supported by PEPFAR in two African countries, including the types of facilities available, clients seen, and availability of specific components of care (Phase 1); and (b) to evaluate how PEPFAR care and support programme components and costs are related to health outcomes (Phase 2).

By meeting these aims, this study was designed to provide detailed descriptions of the care and support services that have been delivered through PEPFAR funding and identify the effective components and costs of the services, to improve the health of people with HIV. Dissemination of the findings is planned, in conjunction with country teams, to inform effective care and support provision within the two PHE target countries and beyond, where lessons can be transferred to other PEPFAR countries.

2.2—Objectives

In order to address these aims the study objectives were (a) to undertake a cross-sectional survey of service configuration and activity by visiting 10% of the facilities being funded by PEPFAR to provide HIV care and support in Kenya and Uganda (Phase 1); (b) to undertake a longitudinal prospective study of 600 patients who were newly diagnosed with HIV or patients with HIV who presented with a new problem attending PEPFAR care and support services. Data collected included self-reported quality of life, core palliative outcomes and components of care received (Phase 2); (c) to conduct qualitative interviews with staff, patients and carers in order to explore and understand service issues and care provision in more depth (Phase 2); and (d) to undertake a cost comparison of care provided, including staff, overhead and laboratory costs (Phase 2).

2.3—Study Overview

The evaluation design was an observational study in Kenya and Uganda using mixed methods. The design comprised two sequential periods of data collection using mixed methodologies.

Phase 1 (2007) was a cross-sectional survey of facility configuration and activity using quantitative and qualitative descriptive data. Phase 1 reports for Kenya (**1**) and Uganda (**2**) have been published separately.

Phase 2 (2008) was a longitudinal evaluation of existing care, focusing on patient outcomes of PEPFAR care and support using validated outcome tools. Supplementary interviews with staff, patients and carers provided in-depth understanding of key issues. An additional cost analysis component in this phase compared patient/family outcomes with their associated costs. Patient data collection took place between January and September 2008, with data collection for the costing component being completed in January 2009. This report focuses on Phase 2 of the evaluation in Uganda.

This evaluation of PEPFAR-funded care and support for HIV was led by King's College London (KCL, Principal Investigator) in collaboration with MEASURE Evaluation at the University of North Carolina (UNC) and the African Palliative Care Association (APCA). The aims, methods and implementation of the evaluation were planned and agreed in consultation with the members of USG Care and Support Technical Working Group, USG Country Teams, and representatives of the Ministries of Health in Kenya and Uganda.

3 Phase 2 Methods

3.1—Study Design

Phase 2 of the care and support PHE was a mixed method prospective evaluation of PEPFAR-funded care and support services. The main component was a longitudinal study of how care components potentially related to HIV patient palliative and general health outcomes over time. In-depth interviews with staff, patients and carers explored in-depth service issues. Descriptive cost data were collected to compare patient outcomes with cost of providing services. There were three parts to Phase 2 of this evaluation, including (a) a quantitative longitudinal study; (b) patient and staff interviews; and (c) a costing survey.

3.2—Rationale for the Study Design

The aim of the study was to evaluate how PEPFAR Care and Support programme components and costs are related to health outcomes. The PEPFAR programme was country-wide and had been implemented for several years before the evaluation was commissioned. Therefore it was not possible to conduct a 'before and after' study. One option was to compare outcomes at facilities receiving PEPFAR funding with those which did not, but this design would have been difficult as there are few large facilities in the target countries which have never received PEPFAR funding, and they would have little motivation to participate. Little information exists regarding the quality of life of Ugandan populations, which could have been used as a comparison sample. Facilities did not have stated targets against which their performance could be compared.

A cross-sectional study would only be able to identify differences between facilities, which might be caused by population factors as well as variations in care and support delivery. A longitudinal cohort study design was selected to allow the effect of care over time to be examined. This design offered the best option for evaluation of outcomes, although it was not possible to remove the effects of previous contact with PEPFAR Care and Support (C&S).

Patient self-reported health was selected as the outcome of interest because care and support aims to improve quality of life, and could not be properly assessed without measuring this outcome. A mixed-methods design incorporating both quantitative and qualitative methods allowed triangulation and greater understanding of the data and its context.

3.3—Protocol development

The protocol was developed by a multidisciplinary team, including medical professionals, HIV specialists and clinical and academic researchers, with review and comment from the USG Care and Support Technical Working Group and the country teams in Kenya and Uganda. All tools were piloted in one facility in Uganda. Following piloting, the wording and structure of the tools were modified and clarified. The tools are presented in Appendices A–D, and described below.

3.3.1—Longitudinal Quantitative Study

The data collection tools for the longitudinal study were four questionnaires, one of them (demography) used only once per person and the others used four times at monthly intervals. The time points, each one month apart, were designated T0 (entry to the study), T1, T2 and T3. A "patient pack" was created for data collection, consisting of all the tools bound in the order they should be used, with the pages colour coded by time point, and preceded by a log page to complete the dates of interviews and a front cover with the patient's ID number. For each facility, questionnaire packs were prepared in two languages; English and a common local language. All the documents were translated into local languages from the English versions twice, independently, by two local researchers. Each of these versions was translated back to English by a third researcher, with any discrepancies discussed amongst the group and an agreed translation decided.

Demographic and medical questionnaire (Appendix A): Basic demographic and medical details were collected using a brief questionnaire administered at T0 (recruitment to study). Four clinical questions were asked at T1: World Health Organization (WHO) stage, date and result of most recent CD4 test, and date of beginning ART. These were moved from T0 to T1 because in piloting, health staff pointed out that the information would not be available to new participants at T0 and the response rate to these questions would be higher at T1.

The African APCA Palliative Outcome Scale (POS) + Eastern Co-operative Global Performance Scale (ECOG) (Appendix B): The APCA African POS is an adapted version of the original POS, which was developed at KCL to address the multidimensional problems of patients with incurable progressive disease and subsequently adapted around the world (**3, 4**). The African APCA POS was validated in ten centres in six Sub-Saharan African countries in 2006 (**5**). Its ten items address the primary physical, emotional and spiritual concerns of patients and families and employs scoring methods appropriate for a range of literacy skills. It was administered at each of the four time points. The validation study demonstrated its properties included sensitivity to change, and it has high levels of patient and clinician acceptability.

The ECOG is a clinician-rated single item measure of performance, with no psychosocial indices of quality of life, also at administered at all four time points (**6**). Scores range from 0 (normal activity) to 4 (unable to get out of bed). The ECOG is the most widely used performance measure (**7**).

Medical Outcome Scale-HIV (MOS-HIV) (Appendix C): The MOS-HIV is a very widely used quality of life measure and has been culturally adapted to the Ugandan HIV setting (**8, 9**). The 35 items, asked at all four time points, address the domains of role function, pain, physical functioning, cognitive functioning, overall health perception, mental health, and vitality. The weighted subscores in these domains are then combined to produce two summary scores measuring physical health and mental health.

Client Service Receipt Inventory (Appendix D): This tool was a version of the Client Services Receipt Inventory (CSRI) (10) adapted for the aims of this study and the HIV setting in Africa in order to collect information about services received by patients in the study. Every month the CSRI recorded receipt of 52 components of physical, psychological, spiritual, social and preventive care, and whether they were received at the facility or from elsewhere.

3.3.2—Qualitative Interviews

Interview schedules (Appendices E, F, and G) were designed to gain greater understanding of service use and provision from the views of the patients, their carers and the staff. The principal themes for patients and carers were experience of facility care, choice of facility, the nature and content of clinical encounters, and principal needs. Interviews addressed medical, psychological, spiritual and social domains. Initial interview transcripts were reviewed and question wording amended where needed to improve clarity of questions and fully explore key issues. The interview schedules, information sheets and consent forms were translated into local languages from the English versions twice, independently, by two local researchers. Each of these versions was translated back to English by a third researcher, with any discrepancies discussed amongst the group and an agreed translation decided.

3.3.3—Costing Study

Because the provision of care is a complex area there are potentially a number of cost components that could be accounted for. Due to the constraints of this multi-methods study, the following key cost elements were examined: (a) labour (by staff type, staff salaries); (b) medicines—ARVs, pain medicines, antibiotics, CTX, other—and their inventories—buffer stock; (c) laboratory items—supplies and equipment; (d) buildings—rent per month or estimated rental value—and utilities; and (e) capital inputs—high end equipment and vehicles.

Because only the major cost drivers were included, the costs in this report are likely to be an underestimate of the real costs of providing care. Cost elements that may be significant, but which were not accounted for include: costs of developing training and HMIS systems, training of health providers, supervision, monitoring and evaluation including HMIS systems, clinic administrative costs, drug and commodities management and maintenance and depreciation on capital assets.

As HIV care and support is provided in a clinical setting in which other non-HIV services are provided, it was necessary to estimate the proportion of some cost elements which are measured for all clincial services and attribute a share for HIV care and support. This is a common issue with the costing of services that are provided in an environment where several medical specialities are simultaneously provided separately at one facility. For labour costs, only staff who were involved in providing care and support services were included so there was no allocation difficulty with staff costs.

To estimate non-ARV drug costs, facilities reported the use of their three most common analgesics, of strong and weak opioids, CTX, the three most commonly prescribed antibiotics for OIs, and TB treatment. The cost of these was divided by the proportion of facility patients who were HIV positive, as a proxy for drug use. Similarly, capital and building costs were allocated to HIV care and support using the proportion of all patients accounted for by HIV patients. Tools were piloted and revised to maximise validity of the data collected and ease of data provision for facilities. Tools were piloted and revised to maximise validity of the data collected, and ease of data provision for facilities.

3.4—Ethical Aapproval and Data Storage

Ethical approval to undertake the study in Uganda was received from the Ugandan National Council for Science and Technology (UNCST, Ref SS 1964) and the College Research Ethics Committee at KCL (Ref CREC/06/07-140). Subsequent tool changes following piloting were also approved.

During longitudinal data collection all questionnaires were stored separately from consent forms, in a locked filing cabinet at the facility. Upon completion of the study, anonymised questionnaires were taken from the facility to the APCA offices for storage in locked filing cabinets. These arrangements were in line with ethical guidance and the UK Data Protection Act 1998.

3.5—Selection and Recruitment

3.5.1—Health Facilities

In Phase 1, the approximately 600 facilities receiving PEPAR Care and Support funding in Uganda were divided into three strata based on the number of patients treated in the past year, and 20 facilities were selected at random from each stratum. From these 60 facilities, the largest six were selected to participate in Phase 2. The inclusion criteria for Phase 2, which applied in addition to those for Phase 1, were that facilities recruited at least 30 new HIV patients a month, had sufficient staff with essential skills to conduct data collection, offered ongoing care and support to enable longitudinal data collection, and had sufficient capacity to engage. The six largest facilities were selected because they were the most likely to meet the inclusion criteria listed above.

3.5.2—Participants

Longitudinal quantitative study: Consecutive patients who met all of the following criteria were approached for participation in the longitudinal study: (a) patients were 18 years of age or over; (b) patients were diagnosed HIV positive; (c) patients knew of their diagnosis; (d) patients had sufficient cognitive ability to answer the questions for the study; and (e) patients were new to service or presenting with a new problem (social, psychological, spiritual or physical). Participants gave informed consent to participate following provision of an information sheet and consent form. These documents were translated into local languages (Swahili, Luo, Runyakitara and Luganda), and were read aloud by the health care worker if the participant was non-literate. Participants were reimbursed travel expenses to the facility of US$5 per visit. Each facility recruited about 100 participants.

Qualitative interviews: Any staff member working at the facility who was involved in the care of patients was eligible to participate in the staff interviews. A purposive sampling strategy was undertaken in order to interview a variety of staff designations. The aim was to complete seven patient interviews, three carer interviews and five staff interviews per facility.

Eligible participants for the patient qualitative interviews were patients of the facility who had already been diagnosed as HIV positive, over 18 years of age, had been under care for at least six weeks, and were not involved in the longitudinal study. These patient participants were asked for consent to approach an identified adult informal carer (i.e., family member or friend who provides assistance/support) in order to undertake a separate qualitative interview. Patient, carer and staff participants gave informed consent to participate following provision of an information sheet and consent form, which was read aloud to the interviewee by the health care worker if the interviewee was nonliterate.

3.6—Data Collection

Facilities were informed of the planned survey through the Ministries of Health in each country.

3.6.1—Longitudinal Quantitative Study

Data collection took place between January and September 2008, with recruitment to the longitudinal quantitative study ending in June to allow all the intervews to be complete. With the exception of CD4 counts, data for the longitudinal quantitative study were self-reported by the participants, and recorded in the questionnaire packs provided by health care workers (HCWs) already employed at each facility.

HCWs recruited patients and completed questionnaires in the course of their regular duties. Funding was provided to the facility directors to support data collection, including purchase of a computer. HCWs were trained by APCA staff in the process of seeking informed consent and the completion of the questionnaires. A researcher maintained contact with each facility through regular visits which would include observing data collection, checking the use of appointment diaries and regular data entry, and delivering additional training as necessary.

Data collection was conducted at recruitment (T0) and at three subsequent interviews a month apart, which coincided with clinical appointments where possible. Once participants had completed the longitudinal study, CD4 counts were extracted from patient records by the HCWs, or by the researchers themselves under the supervision of HCWs.

Early in data collection it became apparent that participants could not always remember the date and result of their last CD4 count. Less than 50% of participants were able to provide a CD4 count and it appeared that these were biased towards people who were more ill or concerned about their health. Accordingly, permission was granted by the ethics board overseeing the study to search patients' records for CD4 counts. Researchers visited each facility after the longitudinal quantitative study data collection had been completed, and copied CD4 counts for the study participants into a specially designed form which preserved anonymity while allowing records to be linked to participants. CD4 count was the only piece of information obtained in this way. The decision to refer to patient records was taken because the researchers knew the information was collected by facilities, and participants had been informed of their result, but simply could not remember the information.

One questionnaire pack contained all the data for one individual. The pages were colour-coded to indicate time points. The front cover of the pack was blank apart from the patient's name. When the final time point was complete, this page was torn out, making the data unidentifiable. The second page included metadata logging the progress of data collection and management at each timepoint.

3.6.2—Qualitative Interviews

The interviews took place between May and September 2008. Single qualitative interviews with staff members, patients and informal carers were conducted by APCA staff and were digitally recorded. Interviews were carried out in several languages including English, Swahili, Luo and Luganda. Interviews were conducted in private, usually in consulting rooms at the care facility.

Most patients were not accompanied by a carer and the few who were accompanied were often very ill, needing the carer's constant presence. As a result, recruitment of sufficient carers for qualitative interviews was difficult. Researchers identified family carers through community outreach teams operating from the care facilities. In this way, a more representative sample of carers of patients at all disease stages could be interviewed.

One facility was in a remote part of the country where the most widely spoken local language was very rare nationally, and spoken by none of the researchers. Rather than exclude an entire ethnic group from this section of the evaluation, the patient and carer interviews were conducted by a member of facility staff who was trained in qualitative interviewing, with the researcher present.

3.6.3—Costing Study

A data collection instrument (Appendix H) was designed and tested to capture the identified cost elements in each of the Phase 2 facilities in which patients were being followed. Facility level data included number of patients seen by staff category in a typical day, hours spent with HIV patients per week and hours worked per week by staff category; number of staff by category involved in HIV care; quantities of medications dispensed in the last three months by kind of drug; numbers of laboratory tests conducted in the last three months; information on physical buildings such as space and an equivalent in rental value of the space; utility costs per month including water, electricity, generator fuel, communications, waste disposal etc.; transport costs, fuel, costs of drivers, maintenance; clinical consumable costs per month, including gloves, syringes, cotton wool swabs, plasters, soap, sterilizing solution etc.; amount spent on volunteer staff including training, travel reimbursements, payment in kind in past three months.

Researchers gathered the information required for the instrument with information provided by key informants at each facility. Key informants varied by facility but generally included the hospital administrator or manager, the accountant, clinicians, nurses and pharmacists. In some cases, more than one site visit was required in order to interview all relevant respondents and to complete the questionnaire.

Unit costs were required for some cost elements. These included staff (i.e., full salaries including allowances), prices of medicines and unit costs of laboratory tests. Salaries were obtained in Uganda from each site and were average levels paid for each staff category. Drug costs were largely obtained from international sources such as the WHO and the International Drug Price Indicator Guide while laboratory test costs were obtained from ATC.

3.7—Data Management and Entry

3.7.1—Longitudinal Quantitative Study

Immediately after collection, data were entered into a pre-designed EpiData v3.1 database with conditional checks for internal consistency. Data entry was conducted at the health care facility by an administrative staff member who had been trained in the use of the tools and the database. When participants had completed the study, the completed data collection tools were transferred to the APCA offices. There research staff conducted a second round of all data entry and validation of the two rounds. Discrepancies identified were corrected by manual checking of questionnaires and results were revalidated until the two datasets were identical. The CD4 information from patient records was entered into a separate EpiData database and merged into the main dataset.

3.7.2—Qualitative Interviews

Interview recordings were transcribed verbatim into MS Word 2003 in the language in which they were conducted. If the interview was not conducted in English, two independent translations into English were then performed, either by the researchers or by experts from the Department of Linguistics at the Institute of Psychology. A team of three then reconciled the two independent translations, referring back to the taped interview if necessary, and agreed upon a final version. For the three interviews conducted by a health worker, a team of three health workers at the facility translated the recordings into English, and a native-speaker linguist later checked the transcript while listening to the tape and made corrections. After the final translation had been agreed, the tapes were destroyed.

A table containing background information on the participant was added to the beginning of each transcript. These data were extracted from interviews and entered into Excel tables.

3.7.3—Costing Study

The data were entered into predesigned Excel spreadsheets. Analysis, including creation of graphs and linear regression, was conducted in Excel workbooks with data drawn together from the different sheets. Clinical staff were defined as doctors, nurses and clinical officers.

4 Analysis Plan

An analysis plan was developed and circulated to all contributors for comment after data collection was completed. The three main sources of data (longitudinal quantitative study, qualitative interviews and costing) were analysed separately. Analysis plans are outlined below, with the research questions in boxed text. Following the implementation of the analysis plans, the results were integrated. The six participating facilities are designated by numbers in this report to preserve anonymity. The same identifying numbers were used in the Phase 1 report so that reference can be made between the two.

4.1—Longitudinal Quantitative Study

Analysis was conducted using Stata v10.

4.1.1—Outcome Measures

The main outcome measures used were the MOS-HIV (health related quality of life) and APCA African POS (palliative care problems). In order to reduce multiple significance testing, for the purposes of this evaluation the MOS-HIV was used as the primary outcome measure, owing to its previous use in longitudinal HIV research in Africa (**11**).

MOS-HIV: The 35 MOS-HIV items contribute to eight multi-item subscales (health perceptions, physical function, role function, cognitive function, pain, mental health, energy/fatigue, and health distress) and two single-item subscales (social function and quality of life). Subscales were computed by summation of individual item scores and conversion to a score out of 100, with 0 indicating the poorest health and 100 indicating the best health. Two summary scores for physical health (PHSS) and mental health (MHSS) were calculated by weighting each subscale score with standard coefficients, then aggregating the weighted scores across subscales, which were also scored out of 100 (**12**). These summary scores were the principal outcomes used from the MOS-HIV.

The PHSS comprises the physical function, pain, role function and social function subscales, with a smaller component from the energy and general health perceptions subscales. The MHSS comprises mostly mental health, health distress, quality of life, cognitive function and energy subscales, with smaller contributions from social function and general health perception subscales. Both scores are standardised so that the mean is 50 and the standard deviation is ten (**12**). Point differences of 3–5 are considered clinically significant (**11**).

APCA African POS: For the APCA African POS, the scores for the first three items (pain, symptoms and worry) were reversed so that for all items, zero represented the worst situation and five the best. Three items are addressed to the main carer of the patient.

The POS is designed to be a multidimensional scale for progressive disease (**13**) and it is unlikely that all the items form a single factor. The APCA African POS items are commonly used separately for clinical audit (**5**). In this study, data from the instrument were used to give more detailed information on the problems of participants attending care facilities, and a total score was created using the seven patient items, but because of its limitations as a single scale it was not used as one of the main outcome variables.

4.1.2—Section A: Cross-Sectional Descriptive Analysis

Facility Characteristics

1. What are the six facilities like in terms of infrastructure and care offered?

Information from the cross-sectional survey in Phase 1 of the evaluation was used to provide a summary of facility characteristic for the six Phase 2 facilities. The location, number of patients per year, type and referral system for inpatients, number and type of fulltime, part-time and volunteer staff at each facility, and the components of care offered were detailed. All this information was self-reported by a small group of senior staff at each facility.

Participants and Interview Numbers

2. How many people were there in the study?
3. How far apart were the interviews?
4. How many people dropped out and why did they leave?

Time points were designated T0 (study entry, or baseline), T1, T2 and T3. Ideally these would each be one month apart but any data collection within two weeks either side of that point was acceptable, in order to minimise the burden of additional travel for participants. Some recoding of timepoints took place. If a participant was recorded to have completed T0, T2 and T3 but missed T1, then T1 was deleted from the record and T2 and T3 were renumbered T1 and T2, to obtain a continuous series of three points. Compressing timepoints in this way made the most efficient use of the data.

An alternative would have been to consider that timepoint was defined by time elapsed since T0, rather than by number of interviews completed. However, as explained above, the time between interviews was not precisely one month and in some cases was considerably more. Using exact time as the definition of a timepoint would have necessitated either renumbering some interviews to T4, T5 and so forth, or dropping them from analysis.

The median, maximum, minimum and inter-quartile range for time between interviews was calculated. A flowchart was produced indicating the loss to follow-up at each data collection point. The number of people recruited, completion rate and mean time between interviews was tabulated by facility.

Participant Characteristics

5. What kind of patients come to these six facilities for PEPFAR Care & Support services?
6. How long have they known they were HIV-positive?
7. Why do they come?
8. How advanced is their HIV disease?

The study group was described in terms of age, gender and number of dependants. The length of time between the date of HIV test result and the beginning of the study was calculated.

The variables from the demography questionnaire which related to socioeconomic status were incorporated into a principal components analysis to generate a single factor. This factor was then split into five quintiles of equal size, to create a categorical variable for relative wealth (**14**). The socioeconomic variables were presented by wealth quintile to portray the characteristics of each level of relative wealth.

The variables included were those used in the DHS surveys: (a) material used to make the walls/roof/floor of the house; (b) type of toilet; (c) main source of drinking water; (d) fuel used for cooking; (e) household ownership of car/bicycle/refrigerator/television/mobile phone/radio.

Reason for attending the facility was a closed question in the demography questionnaire. Individuals whose HIV test date was in the 14-day period prior to joining the study were recoded so that their reason for attending was "new HIV test result." A free text option was provided for those who reported they came because of referral, a new illness or for another reason. The answers in the free text boxes were used to recode some responses. In particular, those who reported that they had been referred from VCT were recoded as having an HIV test result. Reason for joining were tabulated and presented by percentage.

CD4 count is the best measure of the progression of HIV disease commonly in use. CD4 count was used for two purposes: to establish a baseline measure of HIV disease severity at the time of the study, and to observe change in CD4 count over the course of three months of care. During data collection it was discovered that very few participants had two CD4 counts so close together to enable the examination of change over the course of the study. The first purpose of CD4 count (i.e., measure of disease severity) accordingly came to be the main one.

Available CD4 count data was categorised by time. CD4 T1 was fixed within the range from one year prior to the beginning of the study (T0) to the time of the second interview, designated T1. CD4 T3 was in the range from the third interview (T2) to three months after T3. These time ranges were set after consultation with clinicians as to the rate at which CD4 count changed over time and assessment of the data available in patient records. It was important to get a valid count from as many people as possible. If the time period was too short not enough counts would be included, and if it was too long the result would no longer be valid. To balance these competing demands, one year before T1 was agreed as the boundary.

For those individuals who had two CD4 counts to compare, change in CD4 counts from T1 to T3 was analysed using a paired t-test. The two other measures of illness severity, WHO stage and ECOG physical function score, were also analysed. ECOG at the beginning of the study was tabulated and WHO stage at each timepoint was presented by facility.

Care Participants Received

9. What kinds of Care & Support do people receive?
10. What kind of care do they get from the PEPFAR-funded health facility and what do they get from other places?
11. What are the five categories of PEPFAR Care & Support?
12. Which of these five categories are people most likely to get?
13. What care do people get immediately after being diagnosed HIV positive?
14. What is the Preventive Care Package and how many people get it?

The frequency of ever receiving each of the 52 care items listed in the CSRI was calculated. People who responded 'don't know' when asked whether they received a component of care were grouped in the "no" category. Care receipt was reported separately for components received at the study facility and those received at elsewhere. The main figures presented were proportion receiving a care element at a particular time point (as a percentage of those completing the timepoint), and proportion ever receiving the care component (defined as receiving it at least once and up to four times, calculated as a percentage of all study participants).

PEPFAR Care & Support services consist of five categories: clinical, psychological, spiritual, social and preventive care. The 52 components were ordered into these categories based on existing guidelines (**15**) and the percentage of people receiving each category was calculated.

The 196 participants (of 641) whose positive HIV test took place in the two weeks before entering the study were analysed separately in order to explore the care which newly diagnosed people received.

PEPFAR encourages the development of a country-specific Preventive Care Package (PCP) of prophylactic items such as insecticide-treated nets (ITNs), water filters and multivitamins. In Uganda a five-item PCP has been evaluated and is being rolled out across the country. The five elements of the Uganda Preventive Care Package were examined, for newly registered patients (who should be assessed for need of each component) and existing patients.

Care Themes

15. What kind of problems do care components address?
16. What are the themes and patterns of care provision?
17. How many people get antiretroviral therapy and how regularly do they get it?
18. How many people get CTX and do they take it every day?

Care components were grouped into themes according to the issues they addressed and the way in which they were provided. This approach allowed more detailed analysis of the relationships between care components. The care themes were also used in later analysis as an average of the number of people receiving care by facility. For this section, components of care which were very rare (received by fewer than 10% of participants at any time) were removed from the themes, because as outliers they could have unwarranted effects on the results. Each care theme was tabulated. Further analysis is described below by care theme.

Spiritual: involves a visit by a religious leader, prayer with patients, and contact with traditional healer. Spiritual care is a distinct aspect of PEPFAR Care & Support. Staff praying with patients and a visit from a religious leader are the most common types of spiritual care provided through health facilities in Uganda. Many people with HIV visit traditional healers (**16**) and the care delivered by them fits the PEPFAR definition of spiritual care being sensitive to individual and community culture (**15**).

Counselling and advice: involves pre-and post-test counselling, adherence counselling, family planning counselling, patient HIV support groups, family counselling and psychiatric therapy. This theme comprises all "talking therapies." It is sometimes difficult to distinguish counselling as listening and responding to the patient's worries and concerns from counselling as didactic imparting of information. VCT, for example, is a strategy of both prevention and care, assessed for its efficacy in reducing risk behaviour and HIV transmission (**17**). While these are valuable goals, they are a departure from the usual purpose of counselling which is improved health for the individual.

Nursing: involves wound care and other nursing care. Nursing is a specific discipline and its status may vary between facilities.

Pain management: involves assessment of pain and provision of strong and weak opioids or non-opioid analgesics and treatment for neuropathic pain. Pain is a common symptom in HIV (**18**) and all five components in this group are necessary for its relief. The WHO pain ladder (**19**) outlines the need for non-opioid and opioid analgesics until pain has been controlled. Neuropathic pain, which is particularly common in HIV (**20**) is caused by damage to nerves and does not respond to traditional pain medication.

Symptom management: involves treatment for anxiety/depression, nausea/vomiting, skin rash/itching, diarrhoea, laxatives, thrush, oral candidiasis, cryptococcus, other fungal infections, herpes, malaria and other opportunistic infections. The components in this theme were usually defined by the symptom treated, rather than the underlying cause or pathogen, because the cause of a symptom is often not known in HIV disease (**21**). All these physical symptoms and conditions are common in HIV (**21, 22**).

Nutrition: involves food, multivitamins, nutritional advice, safe drinking water, therapeutic feeding for malnutrition. As part of Phase 1 of the evaluation, patient focus group discussions revealed that food was one of the most commonly requested components of care. Poor nutrition comprises two problems: lack of macronutrients (wasting, malnutrition) and lack of micronutrients (vitamins and minerals). Both of these predispose individuals with HIV to infections and ill health. Lack of food is the most fundamental level of poverty.

Social: involves employment training/income generating activities (IGA), home help, household items, legal services, memory book work, loans/microfinance. The social group components were selected after advice from USG country mission teams. Phase 1 qualitative data indicated that the purpose of IGA and microfinance programmes was not only to increase income for families, but to reverse the myth that people with HIV are incapable of acting for themselves. Memory book work was allocated to the social care group because it aims to reduce internalised stigma and improve relations between family members.

Prevention: involves prevention with positives, condoms, ITNs, infection control training, isoniazid for TB prophylaxis. This care group includes both components to protect the person with HIV from other infections, and components to prevent them from infecting others with HIV. Prevention with positives is the general name for a package of care designed to encourage behaviour change (condom use, reduction of partners, and revealing HIV status). Condoms prevent further infection and also protect the individual from other strains of HIV and from other STIs such as herpes. Insecticide-treated nets protect against malaria, which is more common and more aggressive in people with HIV (**23**), and the TB drug isoniazid can be used as a prophylactic for those at high risk of TB.

ART: involves ARVs and assessment of ARV treatment. Antiretroviral therapy consists of more than ARVs. It includes regular assessment to observe signs of developing resistance, toxicity and side effects. Receipt of antiretroviral therapy was tracked over time using a decision tree. Receipt of ARVs and of assessment were compared by facility and timepoint.

CTX: CTX is a broad-spectrum antibiotic proven to reduce morbidity and mortality in people with HIV (**24, 25**). At each interview participants were asked whether they had taken CTX on the previous day and whether they had been given daily prophylactic CTX in the last month. These answers were compared to test adherence.

TB: TB treatment was listed separately from treatment for other symptoms and infection, for two reasons. Firstly, it is the leading cause of death for people with HIV in Africa (**26**). Secondly, the course of treatment lasts for four to six months, long after symptoms have resolved. The full course of treatment must be completed to prevent resistance and recurrence.

Health at the Beginning of the Study

19. What level of physical and mental health do people have at the beginning of the study?
20. What kinds of multidimensional problems do people have?
21. What problems do informal caregivers and family members have?

Physical and mental health summary scores were calculated from the MOS-HIV as described above. The summary scores at the beginning of the study were grouped into blocks of 50 to present as histograms, and analysed for mean, median and standard deviation.

Multidimensional problems were collected in the APCA African POS. Each of the seven patient-completed items was graphed individually and all items were analysed for median and inter-quartile range. These were used rather than the mean and standard deviation because scores were not expected to be parametric. The scores of the seven patient items were added together to create an APCA African POS total score, which was presented as a histogram.

How Participants Differ by Facility

22. Do the six facilities care for different kinds of people?
23. Are the people at some facilities more ill than at others?
24. Do people at different facilities get different kinds of care?
25. Do people at different facilities get all the five categories of PEPFAR Care & Support?
26. Are people at some facilities more likely to get care from elsewhere?
27. How do physical health and mental health vary by facility?

The demographic characteristics of participants were compared according to the facility with which they were registered. Gender split, mean age, median number of dependants and median time to travel to the facility were compared visually. Relative wealth and reason for attending were tabulated by facility. Illness severity was explored by tabulating ECOG scores and mean CD4 count by facility.

The mean, standard deviation, minimum and maximum number of care components received by individuals at each facility was calculated, along with the proportion of participants by facility receiving each of the 52 components of care. The proportion of participants ever to receive each of the five PEPFAR C&S categories was compared between the six facilities. The proportion of participants receiving care from the facility and from elsewhere was also calculated by facility, and a series of stacked bar charts was produced showing the mean number of care components received from each location by facility and time. Finally, mean and standard deviation of physical and mental health scores and total APCA African POS scores were calculated at baseline for each facility, and the extent of the difference was analysed using Kruskal Wallis tests.

Participant Characteristics and Health

28. Do men and women have the same physical and mental health?
29. Do older people have the same physical and mental health as younger people?
30. Does education or wealth make a difference to physical and mental health?
31. Do people whose HIV is more advanced have worse physical or mental health?
32. Do people receiving ART or TB treatment have different physical or mental health?
33. Do patients accompanied by a carer have different physical or mental health?

The association of baseline physical and mental health with demographic characteristics was analysed using appropriate statistical tests, with a significance level of 5% throughout. Mean health scores for men and women were compared using t-tests. The ordinal variables, education, and wealth quintile, were analysed using ANOVA, and the continuous variable age was analysed using linear regression.

CD4 count at T1 was used to represent illness severity. CD4 count was converted into an ordinal variable with four categories which are most commonly referred to for clinical decision-making(27) and epidemiological studies(28). The categories were (a) 0–50: increased mortality risk; (b) 51–200: severe immunosuppression; (c) 201–350: immunosuppression; and (d) above 350. The association of health scores with CD4 category was analysed using ANOVA. In addition, linear regression was used to identify whether mental health was associated with CD4 count after controlling for physical health.

Mean physical and mental health, with standard error, was calculated for people who received antiretroviral therapy at T1 compared to those who did not. CD4 counts for T1 (and the year preceding it) were also compared according to receipt of ART. The hypothesis was that in this observational, non-randomised study of an outpatient population, participants not receiving ART would be those in earlier stages of illness who had not yet been prescribed it. Accordingly, people receiving ART at T1 would have a lower CD4 count (which is one of the criteria for beginning ART), and lower physical and mental health due to their more advanced disease. These hypotheses were tested using t-tests with a 5% significance level. The same analysis was repeated for TB treatment. It was hypothesised that participants with lower physical health would be more likely to be accompanied by a carer, but the same would not be true of mental health. To test this hypothesis, linear regression was used to separate the associations of carer presence with physical and mental summary scores at T0.

4.1.3—Section B: Longitudinal Analysis

Longitudinal multilevel modelling is an approach which makes the most efficient use of data collected over time. Unlike most statistical tests, it includes all timepoints at once, which both reduces the number of tests to be carried out (making false positive results less likely) and allows change to be modelled as a continuous effect. This means that rather than simply finding variables which are associated with any change in outcome, the magnitude of the change can also be considered.

A common problem in longitudinal studies of health outcomes is that patients with the worst health are the most likely to be lost to follow-up, so that a comparison between the beginning and end of the study could find improved outcomes only because a proportion of those with poor health would not contribute to the later timepoint. Longitudinal analysis does not have this bias because all participants can be included whether they complete the study or not. Additionally, longitudinal analysis can reveal patterns over time which would not be identified using traditional methods.

For example, in this population a cross-sectional study at any time would have found that people with greater relative wealth had higher health scores. Longitudinal analysis showed that although this was true, wealth was not associated with change in outcomes over time. Rich and poor gained equally from the care they received, and the difference in health scores was due to poorer participants arriving at the facility with a lower level of health, not to any disparity in care. The technique adopted in this study was multilevel mixed-effects linear regression, selected because it allowed data to be clustered at two levels, by individual and by facility.

34. Were people with worse health at the beginning of the study more likely to drop out?

The question of whether people with lower health scores at the beginning of the study were more likely to be lost to follow-up was a very important one. Many longitudinal studies suffer from the bias caused by the most unwell individuals being most likely to leave the study. To determine whether this bias was present, t-tests were used to compare the mean physical and mental health scores of those who completed all four observations with those who missed at least one. Traditional analysis of longitudinal data involves comparing the earliest observation with the last, so any difference in the scores of completers versus non-completers would bias the findings.

In addition, the same tests were used to compare the mean scores of those who only completed a single observation with those who completed two or more. This was to test the suitability of multi-level modelling, which is explained below. Multi-level modelling uses all data points except the first one, so anyone who only completed one observation would be excluded and it was necessary to test whether this would also cause a bias.

Changes in Health Over Time

35. On average, does health improve, stay the same or get worse during three months of care?
36. On average, do multidimensional problems improve, stay the same or get worse?
37. Do the people with the worst physical and mental health at the beginning of the study get better, stay the same or get worse?
38. Do all six facilities find their patients' physical and mental health changes by the same amount?

Mean, standard deviation and 95% confidence intervals of physical and mental health at each timepoint were calculated and graphed. The change in mean health score from T0 to T3 was calculated, with its standard deviation, and checked for clinical significance.

Comparing mental and physical health score change at different facilities was accomplished using graphs rather than multilevel modelling, because graphs were sufficient for the purpose and provided clarity on exactly how facilities varied. Change in outcomes over time was calculated separately for each participant at each timepoint. Mean change over time was reported as the mean of all individual score changes, rather than mean health score at one time point subtracted from mean health score at another. For example, mean change in mental health score from T0 to T2 was derived by finding the change in health score for each person who had completed both T0 and T2, and then taking the average of these, rather than by subtracting mean mental health at T0 from mean mental health at T2. This method removes the risk of bias due to non-response.

To test whether physical and mental health summary scores changed significantly over time throughout the course of the study, a multilevel modelling method was adopted (**29**). The methods are detailed in Appendix I. This analysis was repeated with the 20% of participants (n=128) who had the lowest physical health score at T0, and with the 20% who had the lowest mental health score at T0, to determine whether the effect of improved outcomes over time extended to those in greatest need. For the APCA African POS, score distribution at each timepoint was tabulated for those who scored 0 (worst possible problem) on the items relating to pain and symptoms. This simple approach was adopted because very few people scored 0 on these items and mean scores could have been biased by a single outlier. The items for pain and symptoms were selected because people with complex, intractable problems in advanced disease may not experience improvement although average scores for the population increase.

Changes in Health Over Time in Detail

39. Do men and women experience the same improvements in physical and mental health?
40. Do people of different ages or with different education or wealth levels show different changes in physical and mental health during the study?
41. Do people taking ART or having TB treatment experience the same change in physical and mental health as people not receiving such treatment?
42. Does being at a facility which offers certain kinds of care have an effect on whether physical and mental health improves?

Differences Between Individuals

To identify whether demographic variables were associated with different changes in physical or mental health over time, the multi-level models developed earlier were now rerun with the addition of each demographic variable (age, gender, education level and wealth quintile), one by one. The models were run exactly as before, except that each contained one demographic covariate. This process of univariate analysis was adopted because it is more careful and the methods were new, to remove the risk of finding unwarranted associations. Education level and wealth quintile were treated as continuous variables for this analysis, because each of them had enough categories of sufficient size to approximate to a continuous distribution.

ART and TB treatment were considered particularly important variables to model over time, for several reasons. Both of them must be maintained over time (for TB treatment, usually for six months; for ART, usually indefinitely), both of them are lifesaving treatments which are associated with side effects, possible drug resistance, and the need for monitoring. Multilevel models were developed to show the association of physical and mental health with ART and with TB treatment over time.

These covariates, unlike any others studied so far, varied over time. Time-invariant characteristics such as age and relative wealth were only measured once and remain constant for each individual. Care availability, discussed below, is constant by facility. By contrast, receipt of ART or TB treatment was elicited at every timepoint and so each of the (maximum of three) observations an individual contributes to the model has its own value.

It was necessary to include CD4 count at T1 in the model as well, because previous analysis had shown that CD4 count was lower in people receiving ART or TB treatment at T1, and it was possible that any effect on health scores could be confounded by lower CD4 count and its consequences.

The intention had been to analyse CTX using the same techniques, but this was not carried out because CTX provision reached almost 100%, meaning that those few individuals who for some reason did not receive it could have been different from the rest in ways which would bias the findings.

Differences Between Facilities

Examining the relationship between health outcomes and care received was complicated by the potential bias that those in the worst health would probably receive the most care, whereas a lack of care could mean either no need of it, or lack of appropriate provision. To avoid this problem, a variable representing available care needed to be developed, which might have a closer association with health outcomes than the level of care individually received. Availability of care was defined as the percentage of individuals at a facility who received care in a particular theme. Care themes were used rather than individual components in order to reduce the number of variables needed in the model and ensure stability. For example, the variable "psychological care," contains information on the percentage of people, per facility, who received at least one component of psychological care at T1, T2 or T3. T0 was excluded because the model analysed change from T0 onwards.

Each of the eight remaining care themes (counselling/advice, nursing care, spiritual care, prevention, nutrition, social care, pain management and symptom management) was included one by one in a univariate multi-level model to identify which ones were associated with mental or physical health over time. As before, multilevel mixed-effects linear regression was used with repeated measures at the individual level and individuals clustered within facilities. The outcomes were mental health score and physical health score. Additional covariates included the baseline value of the other outcome variables (i.e., if mental health score was the outcome of the model, both T0 mental health score and T0 physical health score would be individual-level covariates) and any demographic covariates which had been identified as associated with the outcome. Both T0 outcome scores were included because a separate piece of analysis (Appendix I) showed that the two scores were closely associated and that in some cases an apparent association with mental health score was in fact entirely confounded by physical health score.

All variables had fixed coefficients, with the exception of interview number which was allowed to vary at the individual level. All individual-level and facility-level covariates which were associated with outcome at the 10% level in univariate analysis were taken forward into a multivariate model and eliminated in a downward stepwise procedure if the association was lost. It is usual to use 10% as the acceptance level with stepwise downward regression to avoid dismissing variables too early.

4.2—Qualitative Interviews

The interview transcripts were imported from Word into NVivo 7 for coding and analysis. Information on interviewees' age, gender, household location, family size, profession (for staff), whether they were receiving ART (for patients) and relationship to patient (for carers) was extracted into an Excel table, subsequently imported into NVivo. Identifying information such as names of individuals or care facilities was removed from transcripts. Thematic analysis of content was conducted concurrently on the patient, carer and staff interviews to enable multiple perspectives on each coded theme.

43. How do facilities provide HIV care and what is the nature of the care they provide?
44. What is the experience of patients receiving care and their families?

4.2.1—Development of Coding Frame

Two coding frames were developed and subsequently combined into a single version used for the remainder of the coding. One coding frame was developed in Uganda by the team of APCA researchers at APCA who had conducted the interviews. The other coding frame was developed at KCL in London. The intention was to explore cross-cultural differences and similarities in coding.

In both three-person teams, each researcher coded eight randomly selected interviews (three with a patient, three with a member of staff and two with a carer), creating hierarchical codes. The team members agreed on a coding frame by discussion, comparison and consensus. At a meeting in Kampala, the two coding frames were compared and found to be similar in many respects. A unified coding frame was developed, combining the strengths of both country-level frames. Each code was reviewed for internal consistency and given an agreed definition to ensure it was applied using a standard meaning by each researcher. The Uganda researchers were trained in the use of NVivo 7 and in application of the new coding frame, which was applied to the entire dataset.

Each of the APCA researchers coded three interviews which were checked for consistency at KCL. The APCA researchers then proceeded to code all remaining interviews.

4.3—Costing Study

45. What is the cost of supplying the HIV care received by study participants?
46. What are the main cost drivers of HIV care and support?
47. Are there economies of scale in HIV care and support delivery?

The costing study also allows us to understand what factors influence costs per patient per year. For example we might expect the capital costs of rural facilities to be less than those in urban settings. Similarly if a facility tends to use relatively inexpensive providers it may be less expensive in providing the same service as a facility that has lots of trained physicians. Facilities that do not provide ARVs or do not provide testing may also have lower costs per patient. We might also expect to observe economies of scale with larger facilities (judged by numbers of patients) registering lower per patient costs than smaller ones.

Another possible use of costing data is to guide resource allocation. If two programs have similar outcomes but different costs it may be possible to reallocate program resources to the lower cost program with no loss in health benefits or the less efficient program might change the way it allocates resources so as to emulate the more efficient program. This cost-effectiveness analysis, however, was not part of the present study.

Analysis was carried out using an Excel spreadsheet. Most data were collected in local currency (Ugandan shillings), and converted to US dollars at the current exchange rates. Since only six facilities per country were included and these facilities were not meant to be statistically representative, all results are reported per facility without aggregation across the sample. The average costs per patient for one year of care and support were calculated using aggregated average costs per patient for each of the main components of care for a year. Scatter plots of per-staff member patient load against staff costs, and of per-patient costs against number of patients, were used to investigate economies of scale.

5 Results of Longitudinal Quantitative Study Section A

5.1—Facility Characteristics

The facilities taking part in Phase 2 of this PHE also took part in Phase 1 (the facility survey). Phase 1 data collection took place between April and August 2007. Some of the key results from Phase 1 are presented here to provide context with respect to the nature and scope of HIV care and support provision at the Phase 2 facilities. In Uganda, two of the six largest Phase 1 facilities were located very close to each other and provided complementary services. To remove the risk of recruiting the same people twice, one of these facilities was replaced with the next largest which met the inclusion criteria.

Table 1 presents some information from Phase 1 of the evaluation to describe the six facilities. 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. The usual model of publicly-funded HIV care in Uganda is for patients to be referred to an ISS (Immuno-Suppression Syndrome) clinic in the grounds of a hospital or health centre. The ISS clinic is usually for outpatients. Those patients who need inpatient care are admitted to the main hospital. This model was followed by four of the facilities. The two NGOs lacked inpatient facilities, and referred to hospitals where necessary.

Table 2 shows facilities' self-reports of the care components they provided, either directly or by referral. "Yes" has been abbreviated to "Y," and "referred" to "ref," to make the table more readable with limited space. The majority of clinical and symptom management components were reported by all facilities, whereas spiritual and social care components were often not reported present, particularly at Facilities 258, 259, and 260.

Table 3 shows the number of staff of several key professions working at each facility as reported in Phase 1. Fulltime, part-time and volunteer staff were reported separately. Facility 259 had considerably more nurses and laboratory staff than any of the others.

5.2—Participant and Interview Nnumbers

Six hundred forty-one patients were recruited and 47 people refused to take part in the study. One participant gave consent to take part in the study and then decided to drop out. All data relating to this participant were deleted. Six hundred fourteen participants completed more than one interview. The median number of days between each pair of interviews was 30 (Inter-quartile range 28–32). The shortest time between two interviews for a participant was 13 days and the longest was 203 days. The shortest time to complete all four timepoints was 55 days. Table 4 shows that five of the facilities had a mean time between interviews which approximated

Table 1: Characteristics of Facilities

Facility	Type	Location	Patients in 2007	New Patients in 2007
252	HIV clinic in mission hospital	Rural	2075	79
255	HIV NGO	Urban	4772	401
256	HIV NGO	Kampala	missing	missing
258	HIV clinic/research centre in public hospital	Kampala	9698	828
259	HIV clinic/research centre in public hospital	Kampala	7062	5774
260	HIV clinic in public hospital	Urban	5602	683

Table 2: Facility Self-Reported Care Provision from Phase 1 Survey

Type	**Component of Care**	**Service Provided**					
	Facility	***252***	***255***	***256***	***258***	***259***	***260***
General clinical	Nursing care	Y	Y	Y	Y	Y	Y
	ARVs	Y	Y	ref	Y	Y	Y
	Weighing	Y	Y	Y	Y	Y	Y
	Assess ARV treatment failure	Y	Y	ref	Y	Y	Y
	Monitor ARV toxicity	Y	Y	ref	Y	Y	Y
	Wound care	Y	Y	Y	Y	Y	ref
	Physiotherapy	Y	ref	No	No	Y	ref
Pain management	Assessment of pain	Y	Y	Y	Y	No	Y
	Strong opioids	ref	Y	No	No	Y	Y
	Weak opioids	Y	Y	Y	Y	Y	Y
	Non-opioids	Y	Y	Y	Y	Y	Y
	Treatment for neuropathic pain	ref	Y	Y	Y	Y	Y
Symptoms	Anxiety/depression treatment	Y	Y	Y	Y	Y	ref
	Treatment for nausea/vomiting	Y	Y	Y	Y	Y	Y
	Treatment for skin rash/itching	Y	Y	Y	Y	Y	Y
	Treatment for diarrhoea	Y	Y	Y	Y	Y	Y
	Laxatives	Y	Y	Y	Y	Y	Y
	Treatment for thrush	Y	Y	Y	Y	Y	Y
	Treatment for oral candidiasis	Y	Y	Y	Y	Y	Y
	Treatment for cryptococcus	Y	Y	Y	Y	Y	Y
	Treatment for other fungal infections	Y	Y	Y	Y	Y	Y
	Treatment for herpes	Y	Y	Y	Y	Y	Y
	Treatment for malaria	Y	Y	Y	Y	Y	Y
	TB detection	Y	Y	Y	Y	Y	Y
	TB treatment	Y	Y	Y	Y	Y	Y
	Therapeutic feeding for malnutrition	Y	ref	Y	No	Y	ref
	Treatment for other opportunistic infections	Y	Y	Y	Y	Y	Y
	Management of cancer	ref	ref	ref	ref	Y	ref
Psychological	Pre- and post-test counselling	Y	Y	Y	Y	Y	Y
	Adherence counselling	Y	Y	Y	Y	Y	Y
	Family planning counselling	Y	Y	Y	Y	Y	ref
	Patient HIV support groups	Y	Y	Y	Y	Y	Y
	Family care-givers support group	Y	Y	No	No	Y	No
	Family counselling	Y	Y	Y	Y	Y	Y
	Psychiatric therapy	No	ref	No	Y	ref	ref

Table 2: Facility Self-Reported Care Provision from Phase 1 Survey

Type	Component of Care	Service Provided					
	Facility	*252*	*255*	*256*	*258*	*259*	*260*
Spiritual	Visit by religious leader	Y	ref	Y	ref	No	Y
	Prayer with patients	Y	Y	No	No	No	no
	Contact with traditional healer	No	No	Y	No	No	no
Social	Home help	Y	No	Y	No	No	No
	Transport to care centre	Y	Y	Y	No	No	No
	Employment training	Y	Y	Y	Y	No	Y
	Provide household items	Y	Y	No	No	No	No
	Legal services	No	ref	ref	ref	No	No
	Memory book work	No	Y	Y	No	No	No
Social con't	Family home help	Y	No	No	No	No	No
	Loans/microfinance	Y	No	No	No	No	No
	Infection control training	Y	Y	Y	No	No	Y
Prophylaxis/preventive care	Support for family testing	Y	Y	No	Y	Y	Y
	Prevention with positives	Y	Y	Y	Y	Y	Y
	Multivitamins	Y	Y	No	Y	Y	Y
	Nutritional advice	Y	Y	Y	Y	Y	Y
	Access to safe drinking water at home	No	Y	Y	Y	No	Y
	CTX	Y	Y	Y	Y	Y	Y
	Isoniazid	Y	No	Yes	No	No	Y
	Condoms	Y	Y	Y	Y	Y	Y
	ITNs	No	Y	Y	Y	No	Y
Laboratory	Malaria film	Y	Y	ref	Y	Y	Y
	AFB smear	Y	Y	Y	Y	Y	Y
	CD4 count/test	Y	ref	Y	Y	Y	Y

Table 3: Staff Working at Each Facility *(FT=full-time; PT=part-time; Vol=volunteer)*

Facility	252			255			256			258			259			260		
Staff type	**FT**	**PT**	**Vol**	**FT**	**PT**	**Vol**	**FT**	**PT**	**Vol**	**FT**	**PT**	**Vol**	**FT**	**PT**	**Vol**	**FT**	**PT**	**Vol**
Doctor	2	2	0	2	0	0	1	1	0	11	14	0	8	2	0	6	0	0
Clinical officer	2	0	0	4	2	0	1	0	0	1	0	0	0	0	0	1	0	0
Nurse	2	0	0	6	1	0	3	0	0	6	16	0	32	0	0	5	0	1
Lab staff	2	0	0	2	2	0	6	0	0	4	0	0	32	0	0	4	1	0
CHW	3	0	0	7	0	1	0	9	0	0	0	0	3	0	0	1	0	1
Social worker	1	0	0	0	0	0	0	0	0	0	0	0	2	0	0	0	0	0
Spiritual leader	1	0	0	0	0	0	0	0	0	0	0	1	0	0	0	0	1	5
Nutritionist	1	0	0	0	0	0	0	1	0	0	0	0	1	0	0	0	0	0
Counsellor	3	0	0	12	1	2	3	0	0	9	3	0	5	0	0	4	0	3

Figure 1: Flowchart of Study Participation

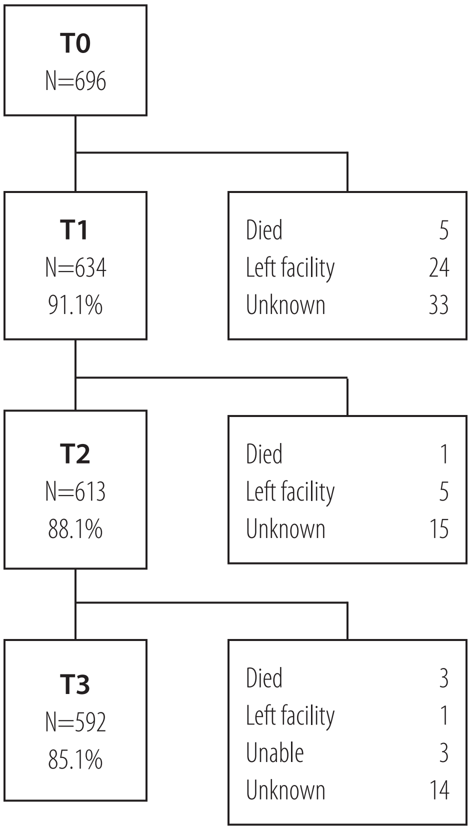


Table 4: Participant Numbers and Interview Details

Facility	252	255	256	258	259	260	Total
N recruited, baseline (T0)	107	105	112	107	102	107	641
N completing two timepoints	106	104	103	100	100	102	614
N completing three timepoints	103	103	85	95	100	97	583
N completing four timepoints	102	97	65	91	100	83	538
N dropouts	5	8	47	16	2	24	103
Mean time between interviews (days)	30.8	30.9	44.2	28.7	28.7	31.4	32.6

one month, as expected, but Facility 256 had a considerably longer time between interviews.

Five hundred thirty-eight participants completed all four interviews, giving a loss to follow-up of 16.1%. The reasons for non-completion are displayed in Figure 1. The proportion lost to follow-up varied greatly by facility (Table 4). The highest level of loss to follow-up was at Facility 256.

5.3—Participant Characteristics

5.3.1—Demography

On average 31.9% of participants were men (n=204), ranging from 21.5% to 39.3% by facility. Participant mean age was 35 years (sd 9 years, range 18–70) and the median number of dependants for participants was 4 (range 0–20). Women were on average slightly younger than men with a mean of 34.2 years compared to 36.7 (t=3.22, p<0.01). Participant age is displayed in Figure 2.

Figure 3 shows the age of participants in five-year categories (scale on the left-hand side of the chart) and the average number of dependants for each age category (scale on the right). Due to the age distribution of the group, represented in Figure 2, the older age groups contained very few participants. The trend was for increasing number of dependants with advancing age, for both men and women. Participants travelled for a median of one hour (IQR 40 minutes to 2 hours, range from 1 minute to 30 hours) to attend the facility.

Nearly half of participants attended school until primary level. Participants most commonly lived in homes with cement or concrete floors and a corrugated roof (Table 5). Most people had a safe water supply, burned firewood or charcoal for fuel, and owned a radio and mobile phone. The majority had a private latrine, often of traditional type (covered or uncovered).

5.3.2—HIV Diagnosis and Reason for Attending the Clinic

At the first interview, participants gave their reason for coming to the facility that day (Table 6). Participants who reported the date of their HIV positive diagnosis within the 14 days prior to beginning the study were coded as coming because of a new HIV test result. Staff

Figure 2: Age of Participants

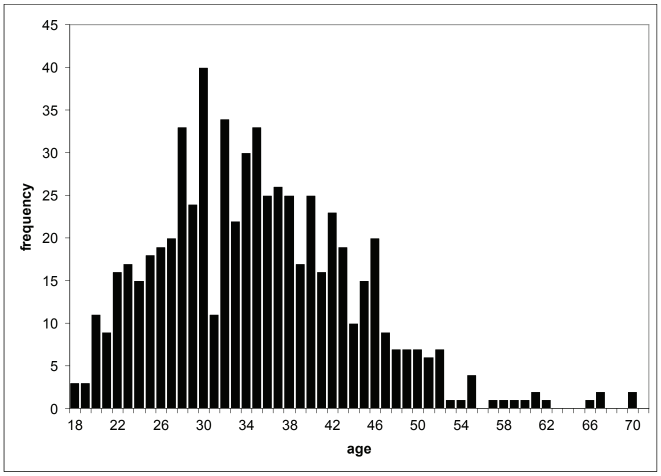


Figure 3: Age, Gender, and Number of Dependants

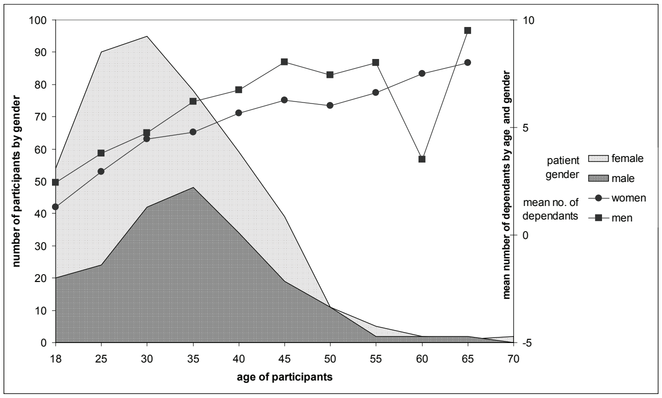


Table 6: Reason for Attending Dacility (One Missing)

Reason	N	%
HIV test result in last 14 days	196	30.6
HIV test result more than 14 days ago	55	8.6
Referred	42	6.6
Obtain medication, lab test or test result	119	18.6
New illness or new presenting problem	223	34.8
Other	5	0.8
Total	640	100.0

Table 5: Population Demographic Characteristics

Population Characteristic	N	%	Population Characteristic	N	%
Highest Level of Schooling Attended			*Source of Drinking Water*		
None	67	10.5	Pipe-borne inside/bottle	113	17.7
Began Primary	314	49.1	Pipe-borne outside	217	33.9
Began secondary	200	31.3	Other safe	234	36.6
Diploma +	59	9.2	Other unsafe	76	11.9
Wall Material			*Type of Toilet*		
Thatch/mud and poles	216	33.8	Private flush	37	5.8
Mud/unburnt bricks	75	11.7	Private VIP latrine	91	14.2
Burnt bricks with mud	142	22.2	Traditional covered pit latrine	167	26.1
Metal sheet/cement block	57	8.9	Traditional uncovered pit latrine	176	27.5
Stone/wood/burnt bricks	150	23.4	Public/shared/outside	169	26.4
Floor Material			*Roof Material*		
Earth	273	42.7	Natural	114	17.9
Cement/concrete	337	52.7	Corrugated iron	511	79.8
Other finished	30	4.7	Finished	15	3.3
Personal Property			*Fuel Source*		
Own Car	59	9.2	Electricity/gas	8	1.3
Own Bicycle	180	28.1	Paraffin/coal	20	3.1
Own Fridge	113	17.7	Charcoal	315	49.2
Own TV	177	27.7	Firewood/straw/grass	291	45.5
Own Mobile Phone	422	65.9			
Own Radio	497	77.7			

reported that after a diagnosis was made, the first appointment slot available might be some weeks ahead. Fifty-five participants recorded that they attended because of a new test result which had taken place more than 14 days ago. Table 6 shows that participants were most commonly attending the clinic for an HIV test result. In a minority of cases the health care worker recorded the condition. Some examples were new infections (malaria, herpes zoster), pain (chest pain, body itching, back pain), symptoms (blisters, diarrhoea, skin rash, swollen legs) and other conditions (stroke paralysis, sight problems, dementia and psychological problems).

At the time the study started the median time since having been diagnosed as HIV positive for a participant was 196 days, or about six and a half months, for the 606 participants with a diagnosis date. The median time from registration at the facility to beginning the study was seven days.

5.3.3—Relative Wealth

The information presented above on home construction, fuel, water and sanitation use, ownership of goods and education was used in a principal components analysis to generate a factor which was then split into equal wealth quintiles. Table 7 presents the percentage of participants reporting assets by quintile. Details of how each component loaded onto the factor are presented in Appendix I.

As an example, 10.1% of people in the poorest 20% of the sample had a mobile phone in the household,

Table 7: Percent of Participants in Each Quintile Reporting the Assets Surveyed

Asset	Wealth Quintile (1=poorest; 5=richest)				
	1	2	3	4	5
Floor Material					
Earth	100.0	80.3	31.3	1.5	0
Cement	0	18.9	64.8	92.5	86.9
Finished	0	0.8	3.9	6.0	13.1
Wall Materials					
Thatch/mud & poles	67.3	68.5	25.8	7.5	0
Bricks – mud or unburnt	33.3	13.6	34.4	41.8	36.1
Metal sheet/cement block	0	0.8	4.7	16.4	22.9
Stone/wood/burnt bricks	0	7.1	35.2	34.3	41.0
Roof Material					
Natural	76.0	8.7	3.9	0	0
Corrugated iron	24.0	91.3	93.8	96.3	94.3
Finished	0	0	2.3	3.7	5.7
Type of Toilet					
Public/shared/outside	19.4	16.5	28.1	41.8	25.4
Latrine	80.6	83.4	71.1	56.0	47.5
Private flush	0	0	0.8	2.2	27.0
Source of Drinking Water					
Bottle/piped inside	0.8	3.1	14.8	24.6	45.9
Piped outside	5.4	7.1	39.1	65.7	51.6
Other, safe	81.4	57.5	32.8	9.0	1.6
Other, unsafe	12.4	32.3	13.3	0.7	0.8
Source of Cooking Fuel					
Electricity/gas	0	0	0.8	3.0	7.4
Paraffin/coal	3.1	0.8	1.6	7.4	2.5
Charcoal	0	12.6	59.4	85.1	89.3
Firewood/straw/grass	96.9	86.6	38.3	4.5	0.8
Personal Property					
Car	2,3	5.5	7.0	4.4	27.9
Bicycle	30.2	41.7	28.9	19.4	20.5
Refrigerator	0	3.1	6.3	14.9	66.4
Television	0	3.9	18.8	25.4	93.4
Mobile phone	10.1	59.8	70.3	90.3	100.0
Radio	46.5	88.2	75.8	81.3	97.5

Table 8: Physical Function at T0

ECOG stage	N	%
0= fully active	321	50.2
1=restricted	232	36.3
2=ambulatory	67	10.5
3=limited self care	19	3.0
4=completely disabled	1	0.2
Total	640	100.0

59.8% of people in the next-lowest quintile owned a mobile phone in the household, and everyone in the wealthiest quintile lived in a household where someone owned a mobile phone.

5.3.4—Illness Severity

ECOG (physical function): The ECOG (Eastern Cooperative Oncology Group) is a measure of physical function, from fully active at 0 to dead at 5 (**6**). In this study, the relevant range was from 0 to 4 (completely disabled, cannot carry on any self-care). Patient physical function at baseline according to the ECOG is shown in Table 8. Just over half of participants in the study were fully active, and most of the remainder were restricted from physically strenuous activity but able to carry out light work.

During the study, the number responding "fully active" increased slightly over time, and all other responses became less common, but the change was minimal and without statistical significance.

WHO staging: Almost all participants at two facilities reported knowing their WHO stage, at two facilities almost no participants knew their stage, and at two facilities about half of participants knew their stage (Table 9). The stages were not reported for the two facilities with few participants recording their WHO stage, as the percentages would be more misleading than useful. The totals in the bottom row include data from all six facilities. WHO stage was not used in further analysis, due to the frequency of missing values and the potential bias caused by the association of WHO staging and facility.

Table 9 shows that Facility 252 had the highest proportion of participants at stage 4, indicating a diag-

Table 9: WHO Stage by Facility

Facility	Participants at T1 with Recorded WHO Stage		WHO stage N (%) participants at T1							
			1		2		3		4	
	N	%	N	%	N	%	N	%	N	%
252	84	79.3	0	0	3	3.6	51	60.7	30	35.7
255	1	1	–	–	–	–	–	–	–	–
256	4	3.9	–	–	–	–	–	–	–	–
258	55	55	0	0	38	69.1	13	23.6	4	7.3
259	99	99	25	25.3	46	46.5	18	18.2	10	10.1
260	93	91.2	11	11.8	54	58.1	54	58.1	3	3.2
Total	336	54.6	39	11.6	113	33.6	137	40.8	47	14

nosis of AIDS.

CD4 counts: Of the 614 participants, 194 had no CD4 count on file within the accepted time period (i.e., between one year prior to T1 and three months after T3), 225 had a measure only at T1, 62 only from T3, and 160 had both. CD4 counts ranged from 1 to 1569 with a mean of 331 and median of 297. The most representative sample is the set of CD4 counts from T1 presented in Table 10, drawn from 385 participants (63% of participants).

In a paired t-test for the 160 individuals who had CD4 counts at both the start and end of the study, there was a significant difference between the two sets of results, with CD4 count higher at T3 (t= -2.54, p=0.01). It is noticeable in Table 10 that the mean CD4 count at T1 of those who had a second count taken at T3 was lower than the overall mean, although this difference was not statistically significant (p=0.2).

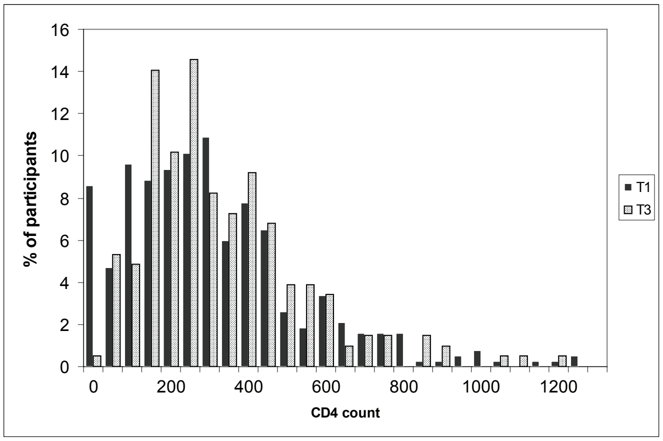
Figure 4 shows the distribution of all CD4 counts at the two timepoints. It should be remembered that the T1 counts do not necessarily date from the time T1. Some were collected up to a year previously. Figure 4, together with the low median, shows that the distribution was positively skewed. More people had a low CD4 count than is reflected by the mean alone.

Change in CD4 count is shown in Figure 5 for the 160 individuals with two counts. Mean CD4 counts increased slightly between T0 and T3, but this change was not statistically significant (Table 10).

Table 10: CD4 Count Statistics

Group	N	Median	Mean	SD	95% CI
All CD4 T1 counts	384	297	331	235	308–355
All CD4 T3 counts	222	301	357	225	328–387
CD4 T1 for those with two counts	160	268	314	240	277–352
CD4 T3 for those with two counts	160	299	348	218	314–383

Figure 4: CD4 Counts at T1 and T3



Validation of CD4 counts: A lowered CD4 count is associated with disease progression and loss of physical function. The T1 CD4 counts were compared by ECOG score to establish whether this expected association was confirmed in the study sample, and validate the use of CD4 in later analysis. As shown in Table 11, there was a clear trend with higher ECOG being associated with lower CD4 count, but the confidence intervals overlapped for most ranges. A t-test was used to compare the distributions for those scoring 0 and 1 on the ECOG scale, and found a highly significant association between ECOG and CD4 count ($t=4.98$, $p<0.001$). Other ECOG values were not used in a test due to low numbers.

CD4 count was grouped into four categories used in clinical decision making and definitions of AIDS (Table 12), showing that in total 32% of participants recorded their most recent CD4 count was below the AIDS threshold of 200 at recruitment.

5.4—Care Participants Received

5.4.1—All Care Components

At each interview participants were asked which components of care from a list they had received in the previous month, from the facility or elsewhere. Out of the 52 components of care examined, a mean of 12.8 (sd=6.6) was received by a participant during one month of the study (Table 13). The highest number of components reported at any one time point was 38 at T0, and the lowest was 0.

The maximum number of care components ever received by an individual was 34 and the minimum was zero, with a mean of 18.1 and median of 18. As shown in Figure 6, the distribution was approximately parametric. Table 14 shows that the most commonly received components of care (at any time) were CTX (97%), adherence counselling (93%), prevention with positives (PWP) (91%) and nutritional advice (89%). These are all part of the PEPFAR Care & Support programme. The most rarely provided items were strong opioids (5%), psychiatric therapy, (3%), cancer management (2%) and treatment for cryptococcal meningitis (1%).

For most symptoms, the percentage of participants receiving treatment was highest for T0 and dropped

Figure 5: Change Between T1 CD4 Count and T3 CD4 Count

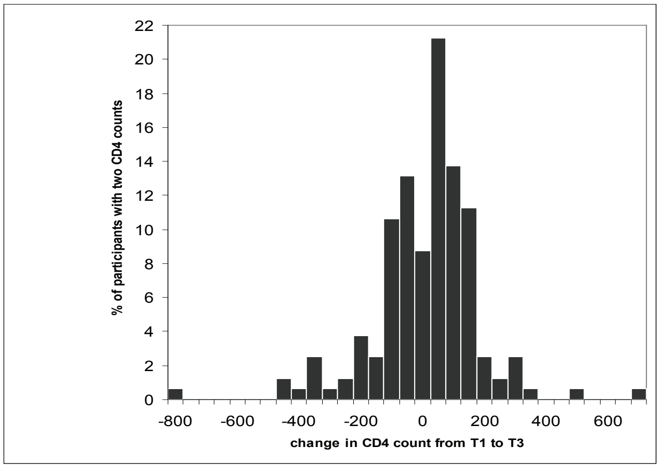


Table 11: T1 CD4 Count Statistics by ECOG Score

ECOG Score	N	Median	Mean	95% CI
0—fully active	170	363	412	372.7–450.3
1—restricted	150	264	281	248.9–313.8
2—ambulatory	52	208	248	200.2–296.6
3—limited self care	12	174	177	102.2–251.0
4—completely disabled	0	–	–	

Table 12: CD4 Count Groupings at Baseline

CD4 Count Group	Description	N (%) with T1 CD4 Count
<50	High risk of mortality	33 (8.6)
51–200	Severe immunosuppression	90 (23.4)
201–350	Immunosuppression	116 (30.2)
>350		145 (37.8)
Total		384 (100.0)

Table 13: Summary of Number of Care Components Received by Timepoint

	T0	T1	T2	T3	Total
Mean	12.5	13.0	12.6	13.0	12.8
SD	8.1	6.3	5.8	5.6	6.6
Maximum	38	35	35	30	38
N	640	615	583	538	2376

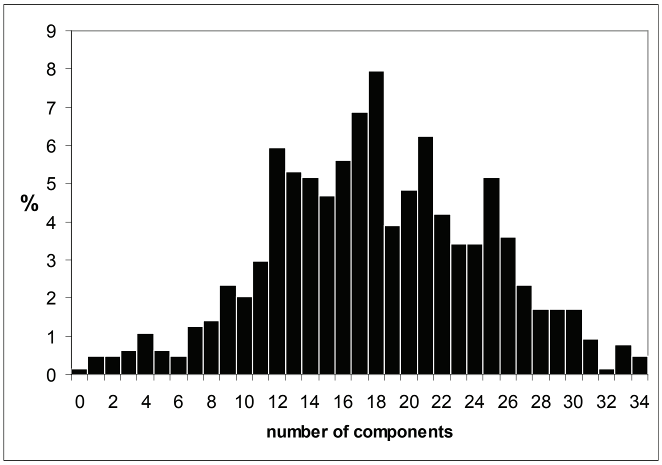
Table 14: Percent of Participants Receiving a Component of Care During the Study

Component of Care	T0	T1	T2	T3	Ever
n	*n=641*	*n=615*	*n=583*	*n=538*	*n=641*
CTX	69.8	88.9	90.6	92.9	96.9
Adherence counselling	70.0	78.5	77.0	85.3	92.7
Prevention with positives	67.3	71.5	71.9	75.3	91.4
Nutritional advice	56.3	67.3	65.2	70.1	88.9
Non-opioid analgesics	56.7	54.5	49.4	43.7	82.8
Patient HIV support groups	38.8	45.7	55.6	63.4	73.3
ART/ARVs	41.4	49.6	55.1	57.3	61.3
Assess ART treatment	40.5	48.1	49.2	53.2	66.3
Family planning counselling	43.8	48.8	46.5	51.1	80.0
Multivitamins	39.2	48.9	46.3	50.6	75.8
Assessment of pain	38.0	50.9	44.8	40.5	76.0
Visit by religious leader	38.4	43.4	44.3	48.0	58.7
Other nursing care	42.5	39.4	43.7	46.1	61.3
Condoms	38.9	43.1	43.7	45.9	71.8
Treatment for other OIs	35.8	45.5	45.6	42.9	67.6
Treatment for malaria	39.1	30.9	29.0	31.0	57.9
Family counselling	30.0	31.4	32.4	36.1	63.0
Access to drinking water	32.5	33.7	34.7	27.7	62.2
Prayer with staff	22.7	27.8	30.9	36.3	57.6
ITNs	33.0	32.5	28.6	21.0	64.1
Wound care	24.5	26.5	29.3	30.3	46.6
Pre and post test counselling	59.2	33.5	11.8	4.5	68.2
Infection control training	25.0	29.3	24.4	29.4	49.3
Food	23.1	22.8	24.5	31.4	38.7
Treatment for skin rash/itching	20.5	24.9	22.3	21.8	46.3
Transport to care centre	4.8	10.4	31.4	34.9	39.6
TB testing	27.2	27.8	14.1	7.1	47.9
Treatment for genital thrush	20.6	18.1	10.8	8.2	32.4
Employment training/IGA	10.8	11.9	14.4	20.5	27.3
Treatment for fungal infections	16.4	10.9	8.2	5.6	25.7
Treatment for nausea/vomiting	13.9	9.6	8.6	8.0	26.1
Treatment for diarrhoea	15.2	9.3	5.3	6.9	26.7
Treatment for anxiety/depression	9.7	7.0	9.8	8.9	20.4
Treatment for oral thrush/candidiasis	14.8	9.9	5.5	4.8	23.2
Loans/microfinance	7.8	6.5	7.9	8.6	17.5

Table 14: Percent of Participants Receiving a Component of Care During the Study

Component of Care	T0	T1	T2	T3	Ever
n	*n=641*	*n=615*	*n=583*	*n=538*	*n=641*
Treatment for neuropathic pain	6.1	8.6	6.4	6.3	17.8
Contact with traditional healer	12.3	5.7	4.1	5.0	17.8
TB treatment	8.3	6.5	5.8	6.5	13.6
Legal services	6.1	5.4	7.4	6.3	13.7
Isoniazid for TB prevention	8.0	6.2	3.4	2.0	12,6
Memory book work	5.3	4.1	4.3	5.4	12.5
Therapeutic feeding for malnutrition	8.6	5.5	2.1	1.9	13.4
Home help	3.6	3.6	2.9	4.7	9.2
Treatment for herpes	5.8	3.3	2.7	1.5	10.5
Household items	3.3	2.4	2.2	3.2	8.4
Treatment for constipation/laxatives	4.8	2.9	1.5	0.7	7.8
Weak opioids	4.4	2.8	1.5	1.3	8.4
Physiotherapy	3.4	1.6	1.5	1.3	6.6
Strong opioids	2.8	1.3	1.5	0.6	5.3
Cancer management	0.8	1.1	0.5	0.7	2.0
Psychiatric therapy	1.3	0.3	0.9	0.6	2.8
Treatment for cryptococcal meningitis	1.1	0.2	0.0	0.2	1.2

Figure 6: Number of Care Components Ever Received by an Individual During the Study



over time. For instance, 16% of participants received treatment for fungal infections at T0, 11% the following month and only 6% by T3. Receipt of CTX also increased steadily over time, reaching over 90% of participants after three months.

5.4.2—Care Received from a Different Facility

Of the mean 12.8 components received in a month, a mean of 9.3 components was received by participants at the facility involved in the study (sd=6.3, maximum=31). The remainder were received elsewhere.

Table 15 shows that the proportion of participants who received care from somewhere other than the facility decreased over time for most components of care. People obtained similar care from other sources as they did from the facility, with some exceptions. Contact with a traditional healer was usually outside the facility, and tailed off rapidly after T0. Loans and microfinance were usually received separately from the facil-

Table 15: Percent of People Receiving a Component of Care at the Facility and Elsewhere

Component of Care	T0 n=640		T1 n=615		T2 n=583		T3 n=538	
	fac	else	fac	else	fac	else	fac	else
CTX	50.8	19.1	81.5	7.5	83.7	6.9	85.5	7.4
Adherence counselling	48.9	21.1	70.2	8.3	67.4	9.6	72.9	12.5
Prevention with positives	53.6	13.8	62.3	9.3	61.4	10.5	65.2	10.0
Nutritional advice	41.1	15.2	58.4	8.9	54.0	11.1	57.2	12.8
Non-opioid analgesics	27.0	29.7	38.4	16.1	35.7	13.7	31.6	12.1
Patient HIV support groups	21.9	16.9	31.7	14.0	38.3	17.3	44.1	19.3
ART/ARVs	35.2	6.3	46.2	3.4	51.3	3.8	53.2	4.1
Assess ART treatment	35.0	5.5	45.5	2.6	47.7	1.5	50.6	2.6
Family planning counselling	28.4	15.3	40.3	8.5	41.0	5.5	46.3	4.8
Multivitamins	30.5	8.8	43.1	5.9	38.8	7.5	42.0	8.6
Assessment of pain	26.3	11.7	42.1	8.8	35.3	9.4	31.0	9.5
Visit by religious leader	4.2	34.2	4.1	39.3	2.2	42.0	3.0	45.0
Other nursing care	25.2	17.3	28.9	10.4	30.9	12.9	33.5	12.6
Condoms	22.5	16.4	33.5	9.6	34.0	9.8	35.7	10.2
Treatment for other OIs	26.1	9.7	36.3	9.3	34.8	10.8	32.2	10.8
Treatment for malaria	19.2	19.8	18.2	12.7	15.1	13.9	15.1	16.0
Family counselling	17.3	12.7	22.1	9.3	22.0	10.5	22.3	13.8
Access to drinking water	17.2	15.3	22.1	11.5	22.6	12.0	16.9	10.8
Prayer with staff	9.7	13.0	13.7	14.1	14.6	16.3	19.3	16.9
ITNs	16.1	16.9	24.9	7.6	24.0	4.6	17.1	3.9
Wound care	16.4	8.1	21.6	4.9	26.1	3.3	26.2	4.1
Pre and post test counselling	38.1	21.1	29.6	3.9	9.6	2.2	3.0	1.5
Infection control training	15.0	10.0	26.0	3.3	23.2	1.2	28.8	0.6
Food	16.3	6.9	17.4	5.4	20.6	3.9	27.3	4.1
Treatment for skin rash/itching	11.3	9.2	19.2	5.7	19.2	3.1	18.0	3.7
Transport to care centre	0.3	4.5	8.8	1.6	30.4	1.0	34.9	0.0
TB testing	21.1	6.1	24.9	2.9	11.5	2.6	5.8	1.3
Treatment for genital thrush	10.3	10.3	13.8	4.2	8.9	1.9	6.3	1.9
Employment training/IGA	4.8	5.9	8.1	3.7	8.4	6.0	11.5	8.7
Treatment for fungal infections	9.4	7.0	7.6	3.3	5.7	2.6	3.7	1.9
Treatment for nausea/vomiting	7.0	6.9	5.5	4.1	4.6	3.9	5.2	2.8
Treatment for diarrhoea	8.6	6.6	6.2	3.1	3.9	1.4	4.1	2.8
Treatment for anxiety/depression	6.1	3.6	5.0	2.0	8.2	1.5	8.4	0.6
Treatment for oral thrush/candidiasis	8.0	6.9	8.5	1.5	4.1	1.4	3.7	1.1

Table 15: Percent of People Receiving a Component of Care at the Facility and Elsewhere

Component of Care	T0 n=640		T1 n=615		T2 n=583		T3 n=538	
	fac	else	fac	else	fac	else	fac	else
Loans/microfinance	1.7	6.1	1.1	5.4	1.2	6.7	0.7	7.8
Treatment for neuropathic pain	4.1	2.0	7.5	1.1	5.0	1.4	5.8	0.6
Contact with traditional healer	0.0	12.3	0.8	4.9	0.2	3.9	1.1	3.9
TB treatment	5.6	2.7	5.0	1.5	5.5	0.3	5.8	0.7
Legal services	2.0	4.1	3.1	2.3	5.7	1.7	4.8	1.5
Isoniazid for TB prevention	6.4	1.6	5.4	0.8	3.1	0.3	1.7	0.4
Memory book work	2.3	3.0	1.3	2.8	3.1	1.2	3.9	1.5
Therapeutic feeding for malnutrition	5.6	3.0	2.8	2.8	1.2	0.9	0.9	0.9
Home help	1.9	1.7	3.1	0.5	2.1	0.9	3.3	1.3
Treatment for herpes	3.3	2.5	3.3	0.0	2.2	0.5	1.5	0.0
Household items	1.4	1.9	2.3	0.2	2.1	0.2	3.2	0.0
Treatment for constipation/laxatives	1.4	3.4	2.0	1.0	1.2	0.3	0.4	0.4
Weak opioids	2.2	2.2	1.6	1.1	0.9	0.7	0.9	0.4
Physiotherapy	2.0	1.4	1.0	0.7	1.0	0.5	0.6	0.7
Strong opioids	0.8	2.0	0.5	0.8	0.3	1.2	0.4	0.2
Cancer management	0.5	0.3	0.8	0.3	0.2	0.3	0.2	0.6
Psychiatric therapy	0.5	0.8	0.0	0.3	0.5	0.3	0.6	0.0
Treatment for cryptococcal meningitis	0.5	0.6	0.2	0.0	0.0	0.0	0.0	0.2

ity, although legal services, after T0, were more often provided by the facility directly. Interventions such as improved access to safe drinking water were provided by another organisation as often as by the facility.

5.4.3—PEPFAR Care and Support Categories

The CSRI components were grouped according to the PEPFAR categories of clinical, spiritual, social, psychological, and prevention (of new HIV infections) as listed in Appendix J. ART, with assessment of ART treatment, was kept as a separate care component.

Table 16 shows that while almost all participants received clinical and preventive care during the four months of data collection, many did not receive psychological, spiritual or social care. Almost 70% of participants received ART at some point and over a third of participants received social care.

Table 16: Percent of Participants Receiving Care

Area of Care	T0 n=641	T1 n=614	T2 n=583	T3 n=538	Ever n=641
Clinical	97.8	98.4	99.0	98.7	99.7
Psychological	34.1	36.1	38.9	42.9	67.7
Spiritual	52.5	56.9	60.4	65.4	77.9
Social	16.3	16.6	19.4	26.0	34.6
Prevention	82.7	88.1	90.7	91.3	97.5
ART	41.4	49.6	55.1	57.3	69.8

Table 17: Percent of Newly-Diagnosed Participants Receiving a Component of Care

Component of Care	T0	T1	T2	T3	Average	Ever
CTX	37.8	80.1	88.0	87.3	71.4	93.4
Adherence counselling	52.0	67.4	66.9	77.5	65.0	87.2
Prevention with positives	51.5	59.4	64.5	66.9	59.9	82.7
Nutritional advice	37.8	49.7	54.2	62.7	50.1	83.2
Family planning counselling	35.2	48.6	55.4	59.9	48.8	78.6
Condoms	31.6	45.9	50.0	57.0	45.1	73.0
Pre and post test counselling	85.7	47.5	18.7	8.5	43.4	94.9
Non-opioids	46.4	41.1	36.1	35.9	40.4	76.0
Multivitamins	16.3	42.8	36.1	42.3	33.5	65.8
Other nursing care	29.1	23.2	36.1	43.7	32.3	51.5
Patient HIV support groups	13.3	26.5	37.2	54.7	31.0	53.6
ITNs	24.0	31.5	31.3	29.6	28.9	66.8
Assessment of pain	17.4	31.7	33.7	34.5	28.7	59.7
Visit by religious leader	21.9	24.9	27.7	38.0	27.5	38.8
TB testing	29.1	41.4	23.5	7.8	26.6	57.1
Wound care	15.8	21.6	30.7	36.6	25.3	42.3
Other OIs	15.8	26.0	31.9	26.1	24.5	53.6
Infection control training	19.4	23.2	23.5	32.4	24.1	43.4
Family counselling	11.7	16.6	30.1	39.4	23.2	48.5
ART/ARVs	11.7	21.7	30.1	30.3	22.7	40.3
Assess ART treatment	12.2	27.8	24.1	26.1	22.1	43.9
Treatment for malaria	26.5	18.2	21.1	19.7	21.6	46.9
Access to drinking water	13.8	23.2	27.1	21.8	21.2	52.6
Prayer with staff	5.6	13.7	25.3	31.7	17.8	39.8
Treatment for skin rash/itching	12.2	21.0	16.3	13.4	15.8	36.2
Transport to care centre	3.1	7.2	24.1	32.4	15.3	29.1
Treatment for genital thrush	16.3	19.3	10.2	9.2	14.2	26.0
IGA	7.1	6.6	9.6	21.8	10.7	20.9
Food	4.6	6.6	6.0	18.3	8.3	18.9
Contact with traditional healer	14.8	5.0	2.4	4.9	7.2	18.4
Treatment for oral thrush	9.2	8.8	2.4	6.3	6.9	16.8
Treatment for nausea/vomiting	7.7	6.1	4.2	8.5	6.6	15.8
Treatment for fungal infections	6.6	6.6	7.2	5.6	6.6	13.3
TB treatment	5.1	6.1	7.8	7.0	6.4	13.8
Isoniazid	5.6	8.8	6.0	4.9	6.4	17.3
Treatment for diarrhoea	7.7	5.5	1.2	5.6	5.1	13.3

Table 17: Percent of Newly-Diagnosed Participants Receiving a Component of Care

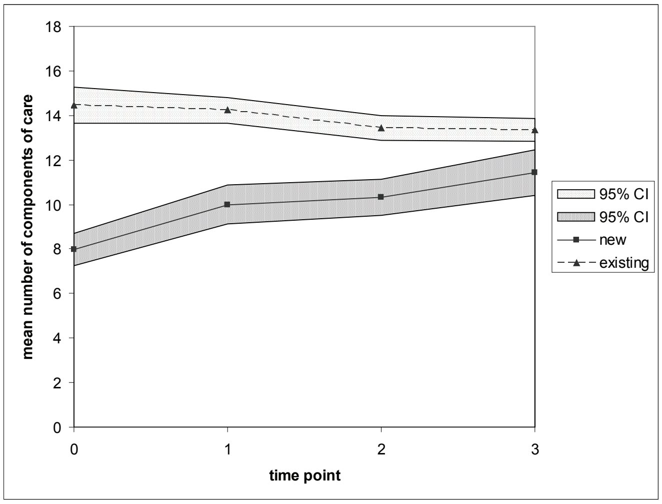
Component of Care	T0	T1	T2	T3	Average	Ever
Treatment for neuropathic pain	1.5	6.1	4.2	6.3	4.4	11.7
Loans	3.1	2.8	6.0	5.6	4.2	11.2
Treatment for anxiety and depression	4.6	3.9	3.0	2.1	3.5	9.7
Legal services	3.1	1.1	2.4	7.8	3.4	10.2
Therapeutic feeding	5.1	5.0	0.6	0.7	3.1	7.7
Memory book work	4.1	5.0	1.8	0.7	3.1	7.1
Treatment for herpes	3.6	2.8	1.8	1.4	2.5	5.6
Treatment for constipation/laxatives	3.1	3.3	1.2	0.7	2.2	7.1
Weak opioids	1.0	2.8	3.0	1.4	2.1	6.6
Strong opioids	1.5	1.7	4.2	0.7	2.1	4.6
Physiotherapy	1.0	1.7	1.2	1.4	1.3	3.1
Household items	1.0	0.6	0.6	2.1	1.0	3.6
Psychiatric therapy	0.5	0.6	1.2	2.1	1.0	2.6
Cancer management	1.5	0.6	0.0	0.7	0.7	2.6
Home help	0.5	1.1	0.6	0.7	0.7	0.0
Treatment for cryptococcal meningitis	0.0	0.0	0.0	0.0	0.0	93.4

5.4.4—Care for People Newly Diagnosed with HIV

The people whose positive HIV test was dated less than two weeks before beginning the study were designated "newly diagnosed." The list of most common components received was similar for the newly diagnosed and the whole group (Table 17), with CTX, adherence counselling, prevention with positives and nutritional advice ranking highest. All these components were provided less frequently on average to the newly diagnosed group.

Three months after diagnosis, 87% of newly diagnosed participants were receiving CTX and 55% were in a patient HIV support group. Food receipt trebled between T2 and T3. Over three quarters of newly diagnosed participants received non-opioid analgesics, considerably more than were assessed for pain. Figure 7 shows that participants newly diagnosed with HIV received on average fewer components of care than those who had been diagnosed previously, and that over time the mean number of care components converged. Previously existing patients received fewer care components over time while those newly diagnosed received more.

Figure 7: Mean Number of Care Components Received Over Time for New and Existing Patients



5.4.5—Basic Care Package

PEPFAR developed the concept of the Preventive Care Package (PCP), a number of specified care components which should be considered essential to prevent opportunistic infections, delay disease progression and prevent HIV transmission (**30**). In Uganda this concept was developed into the Basic Care Package (BCP), which consists of CTX prophylaxis, an ITN, water disinfection, family VCT information and condoms (**31, 32**).

Table 18 shows the elements of the Uganda BCP as they were delivered to participants diagnosed within two weeks of the beginning of the study and diagnosed earlier. The 34 participants had no diagnosis date were not included here. In this sample, of 196 people diagnosed with HIV at T0, 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. CTX was the most widely received component of the five for both groups. A higher proportion of previously diagnosed than newly diagnosed participants received VCT information and water treatment during the course of the study. As with other results, it is important to remember that a particular component of care would not always have been required.

5.5—Care Themes

The components of care were grouped into eight themes as described in the Methods section.

5.5.1—Spiritual Care

Seventy-seven percent of participants received at least one component of spiritual care during the study (Table 19). Contact with a traditional healer most commonly occurred in the month leading up to T0. The two paradigms of health care were more likely to be applied sequentially than concurrently.

5.5.2—Counselling and Advice

The proportion of men and women who received family planning counselling was almost identical; seventy-nine percent compared to eighty percent. The use of HIV support groups increased over time while pre- and post-test counselling reduced (Table 20).

Table 18: Components of the PCP Ever Received by New and Existing Patients, at the Facility or from Anywhere

	Newly Diagnosed n (%) n=196		Previously Diagnosed n(%) n=410	
	fac	**else**	**fac**	**else**
Family VCT information	69 (35.2)	95 (48.5)	218 (53.2)	281 (68.5)
Safe water supply	84 (42.9)	103 (52.6)	176 (42.9)	268 (65.4)
ITN	103 (52.9)	131 (66.8)	170 (41.5)	252 (61.5)
Condoms	133 (67.9)	143 (73.0)	243 (59.3)	290 (70.7)
CTX	165 (84.2)	183 (93.4)	395 (96.3)	404 (98.5)
Two components	35 (17.9)	20 (10.4)	98 (23.9)	60 (14.6)
Three components	40 (20.4)	37 (18.9)	107 (26.1)	87 (21.2)
Four components	54 (27.6)	71 (36.2)	69 (16.8)	118 (28.8)
Five components	24 (12.2)	37 (18.9)	71 (17.3)	113 (27.6)

Table 19: Percent of Participants Receiving Spiritual Care Components Over Time

Component of Care	**T0**	**T1**	**T2**	**T3**	**Ever**
n	***641***	***614***	***583***	***538***	***641***
Visit by religious leader	38.4	43.4	44.3	48.0	58.7
Prayer with staff	22.7	27.8	30.9	36.3	57.6
Contact with traditional healer	12.3	5.7	4.1	5.0	17.8

Table 20: Percent of Participants Receiving Counselling Care Components Over Time

Component of care	**T0**	**T1**	**T2**	**T3**	**Ever**
n	***641***	***615***	***583***	***538***	***641***
Adherence counselling	70.0	78.5	77.0	85.3	92.7
Patient HIV support groups	38.8	45.7	55.6	63.4	73.3
Family planning counselling	43.8	48.8	46.5	51.1	80.0
Family counselling	30.0	31.4	32.4	36.1	63.0
Pre and post test counselling	59.2	33.5	11.8	4.5	68.2
Psychiatric therapy	1.3	0.3	0.9	0.6	2.8

5.5.3—Nursing

Almost half of the study participants required wound care during the course of the study (Table 21). Sixty-nine percent of people who received wound care had infection control training during the study, compared to 31% of people who did not have wound care.

5.5.4—Pain Management

Non-opioid analgesics were a very common component of care, although receipt declined over time (Table 22). Of the 641 study participants, 34 ever received a strong opioid and 54 ever received a weak opioid. Twenty-two people received both. Usually, those who received an opioid had it only in one month. Those who ever received non-opioi d analgesics received a mean of 23 components of care during the study, as compared to 14 for those who did not receive a non-opioid. The difference was highly significant (t= -12.2, p<0.001).

5.5.5—Symptom Management

All symptom treatment components were included in the care theme, whether they were rare or common, because of evidence from Phase 1 that all of them were available at most facilities. The most common symptom management at T0 was treatment for malaria which 39% of participants had received (Table 23). At the other three timepoints the most common symptom management component was treatment for other opportunistic infections, remaining relatively constant between 46% and 43%.

5.5.6—Nutrition

Table 24 shows that nutritional advice was a common component and receipt of this increased over time, while receipt of therapeutic feeding decreased. Seventy-three people (14% of those who completed all timepoints) received food every month, all of them from Facilities 252 and 255. Therapeutic feeding was normally received only once.

5.5.7—Social Care

Only one social component of care was received by more than 10% of participants at any time, which was employment training/income generation assistance (Table 25). Participants at Facilities 255 and 259 most

Table 21: Percent of Participants Receiving Nursing Care Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	***641***	***615***	***583***	***538***	***641***
Other nursing care	42.5	39.4	43.7	46.1	61.3
Wound care	24.5	26.5	29.3	30.3	46.6

Table 22: Percent of Participants Receiving Pain Management Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	***641***	***615***	***583***	***538***	***641***
Non-opioid analgesics	56.7	54.5	49.4	43.7	82.8
Assessment of pain	38.0	50.9	44.8	40.5	76.0
Treatment for neuropathic pain	6.1	8.6	6.4	6.3	17.8
Weak opioids	4.4	2.8	1.5	1.3	8.4
Strong opioids	2.8	1.3	1.5	0.6	5.3

Table 23: Percent of Participants Receiving Symptom Management Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	***641***	***615***	***583***	***538***	***641***
Treatment for other OIs	35.8	45.5	45.6	42.9	67.6
Treatment for malaria	39.1	30.9	29.0	31.0	57.9
Treatment for skin rash/itching	20.5	24.9	22.3	21.8	46.3
Treatment for genital thrush	20.6	18.1	10.8	8.2	32.4
Treatment for fungal infections	16.4	10.9	8.2	5.6	25.7
Treatment for nausea/vomiting	13.9	9.6	8.6	8.0	26.1
Treatment for diarrhoea	15.2	9.3	5.3	6.9	26.7
Treatment for anxiety/depression	9.7	7.0	9.8	8.9	20.4
Treatment for oral thrush/candidiasis	14.8	9.9	5.5	4.8	23.2
Treatment for herpes	5.8	3.3	2.7	1.5	10.5
Treatment for constipation/laxatives	4.8	2.9	1.5	0.7	7.8
Treatment for cryptococcal meningitis	1.1	0.2	0.0	0.2	1.2

Table 24: Percent of Participants Receiving Nutrition Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	*641*	*615*	*583*	*538*	*641*
Nutritional advice	56.3	67.3	65.2	70.1	88.9
Multivitamins	39.2	48.9	46.3	50.6	75.8
Access to drinking water	32.5	33.7	34.7	27.7	62.2
Food	23.1	22.8	24.5	31.4	38.7
Therapeutic feeding for malnutrition	8.6	5.5	2.1	1.9	13.4

Table 25: Percent of Participants Receiving Social Care Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	*641*	*615*	*583*	*538*	*641*
Employment training/IGA	10.8	11.9	14.4	20.5	27.3
Loans/microfinance	7.8	6.5	7.9	8.6	17.5
Legal services	6.1	5.4	7.4	6.3	13.7
Memory book work	5.3	4.1	4.3	5.4	12.5
Home help	3.6	3.6	2.9	4.7	9.2
Household items	3.3	2.4	2.2	3.2	8.4

Table 26: Percent of Participants Receiving Prevention Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	*641*	*615*	*583*	*538*	*641*
Prevention with positives	67.3	71.5	71.9	75.3	91.4
Condoms	38.9	43.1	43.7	45.9	71.8
ITNs	33.0	32.5	28.6	21.0	64.1
Infection control training	25.0	29.3	24.4	29.4	49.3
Isoniazid for TB prevention	8.0	6.2	3.4	2.0	12.6

Table 27: Percent of Participants Receiving ART Components Over Time

Component of Care	T0	T1	T2	T3	Ever
n	*641*	*615*	*583*	*538*	*641*
ARVs	41.4	49.6	55.1	57.3	61.3
Assess ART treatment	40.5	48.1	49.2	53.2	66.3

Table 28: People Who Received ARVs to Receive Support and Monitoring, by Facility and Timepoint

Facility	T0		T1		T2		T3	
	n	%	n	%	n	%	n	%
252	98	100.0	97	97.0	100	100.0	97	99.0
255	28	73.7	14	41.2	12	37.5	11	37.9
256	5	50.0	12	85.7	7	46.7	7	50.0
258	14	93.3	14	93.3	25	78.1	34	94.4
259	33	84.6	52	98.1	56	98.3	61	100.0
260	48	73.9	80	89.9	72	84.7	59	84.3
Total	226	85.3	269	88.2	272	84.7	269	87.3

commonly received IGA, which was received by 28% of women and 25% of men (p=0.36 on a chi squared test).

5.5.8—Prevention

Table 26 shows that 80% of men and 68% of women received condoms during the study (chi=10.7, p=0.001). Prevention with positives was one of the three most common components of care, received by 91% at some point, although its definition was not standardised. Some participants received an ITN more than once during the study.

5.5.9—ART

The percentage of participants receiving ART increased from 41.4% at T0 to 57.3% at T3 (Table 27), which was matched by similar increases in receipt of ART treatment assessment.

Assessment of ARVs, including monitoring toxicity, side effects and suspected resistance, was not always provided with the ARVs. Table 28 shows the percentage of months that support services were provided with ARVs, by facility and time. Facility 255 did not provide sufficient support services to over half its ARV-receiving participants. Only Facility 252 had almost 100% coverage.

5.5.10—CTX

The percentage of participants receiving CTX increased from 69.8% at T0 to 96.8% at T3 (Table 29). The results in Table 30 show that a high proportion of

Table 29: Percent of Participants Receiving CTX Over Time

T0 n=641	T1 n=615	T2 n=583	T3 n=538	Ever n=641
69.8	88.9	90.6	92.9	96.9

Table 30: Adherence to CTX

	T0		T1		T2		T3	
Took CTX yesterday	yes	no	yes	No	yes	no	yes	no
Received daily CTX	399	48	521	26	513	15	494	6
Did not receive daily CTX	35	158	38	30	39	16	28	10

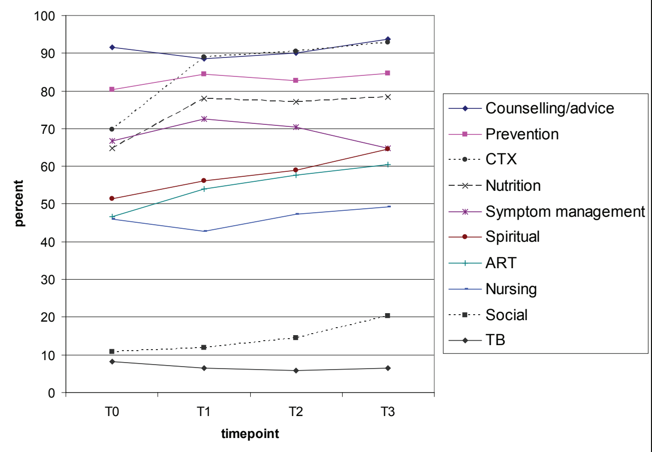
Table 31: Percent of Participants Receiving TB Treatment Over Time

T0 n=641	T1 n=615	T2 n=583	T3 n=538	Ever n=641
8.3	6.5	5.8	6.5	13.6

Table 32: Percent of Participants Receiving Each Care Theme Over Time

Theme	T0	T1	T2	T3	Ever
Counselling/advice	91.6	88.6	90.1	93.7	99.2
Prevention	80.4	84.4	82.8	84.6	97.4
CTX	69.8	88.9	90.6	92.9	96.9
Nutrition	64.8	78.0	77.2	78.3	93.9
Symptom management	66.7	72.5	70.5	64.9	91.0
Pain management	62.7	65.5	59.2	51.9	87.1
Spiritual	51.4	56.1	59.0	64.5	77.0
ART	46.6	54.0	57.6	60.4	69.8
Nursing	45.9	42.8	47.2	49.3	65.4
Social	10.8	11.9	14.4	20.4	27.3
TB	8.3	6.5	5.8	6.5	13.6

Figure 8: Proportion Receiving Each Care Theme Over Time



those who were provided with daily CTX prophylaxis had taken it on the previous day, and that adherence increased over the course of the study (89% at T0, 95% at T1, 97% at T2 and 99% at T3).

5.5.11—TB Treatment

TB testing was dropped from analysis on the grounds that it was not a component of care in itself. The idea had been that all participants should receive TB screening. This does happen, but it emerged that screening consists of checking for signs of TB (including persistent cough, night sweats and weight loss) and only people showing these symptoms are sent for a sputum test which was recorded as a TB test. TB treatment was received by less than 9% of participants at any time point (Table 31).

5.5.12—All Care Themes

Table 32 and Figure 8 show the proportion of individuals receiving any component of care within each theme, by timepoint and overall. Receipt of spiritual care, social care and ART increased steadily over time. Receipt of care in several other themes increased from T0 to T1 and then stabilised, including CTX, nutrition and prevention. Receipt of care in two themes, TB treatment and symptom management, decreased over time. Receipt of nursing and counselling care decreased from T0 to T1 and then increased.

Figure 9: Physical Health Score at Baseline

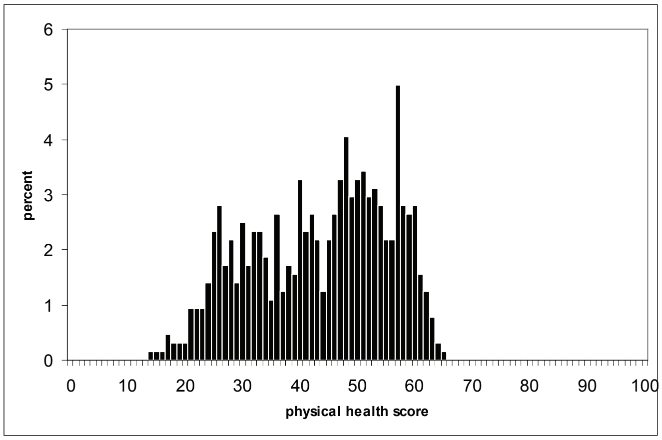
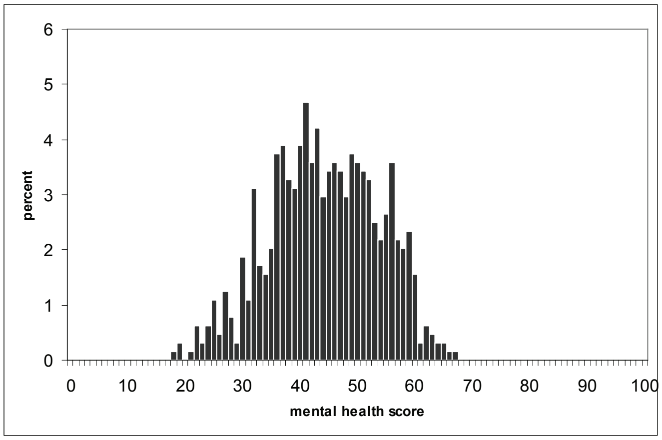


Figure 10: Mental Health Score at Baseline



5.6—Health at the Beginning of the Study

5.6.1—Physical and Mental Health Scores

Figures 9 and 10 present baseline distributions of physical health and mental health summary scores, from 0=worst possible health to 100=best possible health. At baseline the mean physical health score was 43.5 (sd 12.0) and the mean mental health score was 44.2 (sd 9.5). Helath scores could not be calculated for one participants due to an unanswered question.

The physical and mental health summary scores are scaled from worst possible health at 0 to best possible health at 100. Both distributions (Figures 9 and 10) were centred below 50 and there were no outliers towards the extreme values. Mental health scores appeared to be more normally distributed whereas physical health possibly had a bimodal shape.

5.6.2—Multidimensional Care Scores

Each item in the APCA African POS is scored from 0 to 5. The scores were reversed for some items, such that in all cases 0 represented the worst situation and 5 the best. This direction was used because it corresponds to the MOS-HIV, where a higher score corresponds to a better quality of life.

The item scores at baseline are displayed in Figures 11–17 for the first seven items, addressed to the patient. In the figures, the phrases rather than numbers are displayed; in each case, the worst outcome, in the furthest left column, was coded 0, and codes increased by one until the best outcome on the far right, coded 5.

Figure 11: APCA African POS at T0: Please Rate Your Pain During the Last Three Days

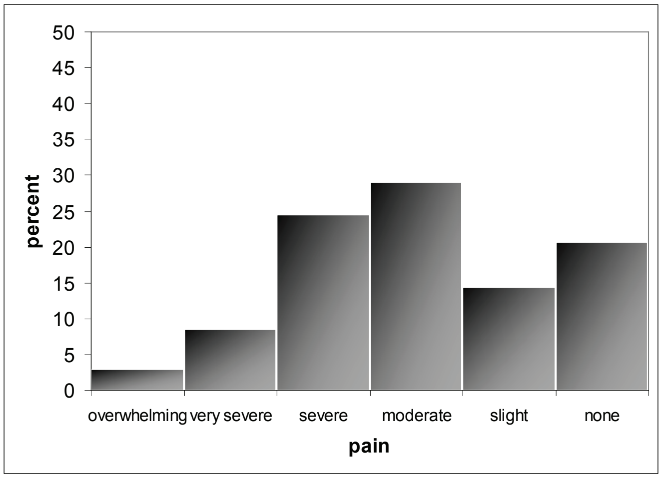


Figure 12: APCA African POS at T0: Have Any Other Symptoms been Affecting How You Feel in the Last Three Days?

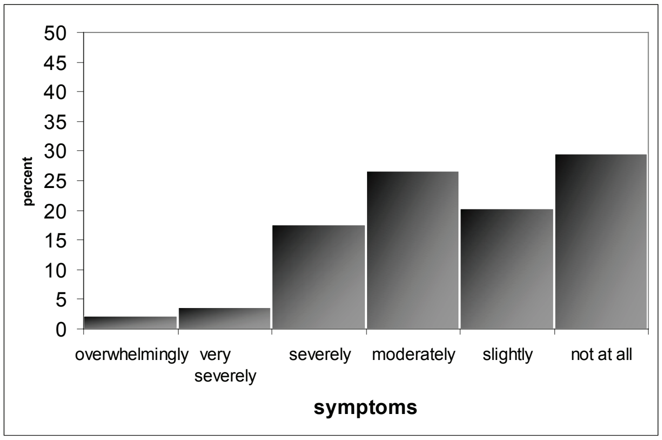


Figure 13: APCA African POS at T0: Over the Past Three Days Have You Been Worried about Your Illness?

Figure 14: APCA African POS at T0: Over the Past Three Days Have You Been Able to Share How You Feel?

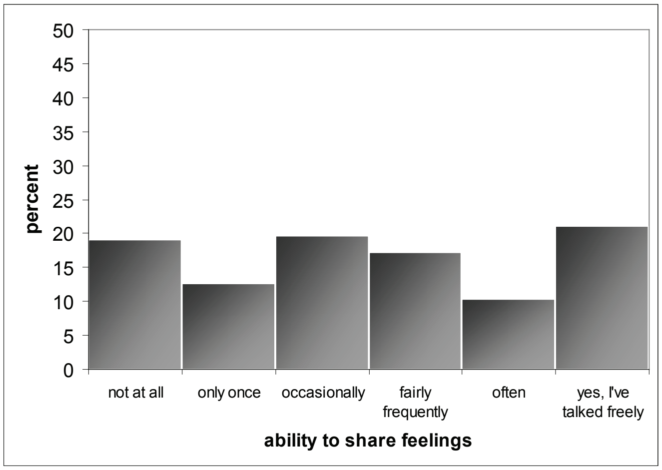


Figure 15: APCA African POS at T0: Over the Past Three Days Have You Felt that Life Was Worthwhile?

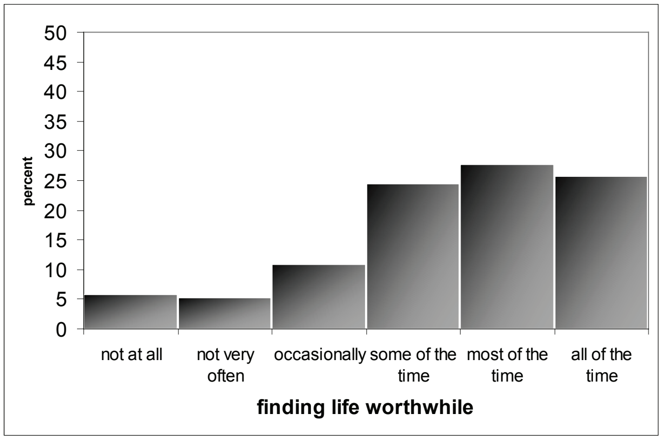


Figure 16: APCA African POS at T0: Over the Past Three Days Have You Felt at Peace?

Figure 17: APCA African POS at T0: In the Past Three Days Have You Had Enough Help and Advice for Your Family to Plan for the Future?

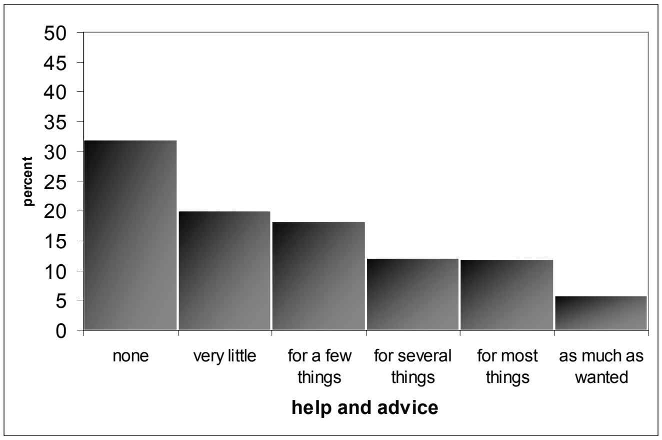
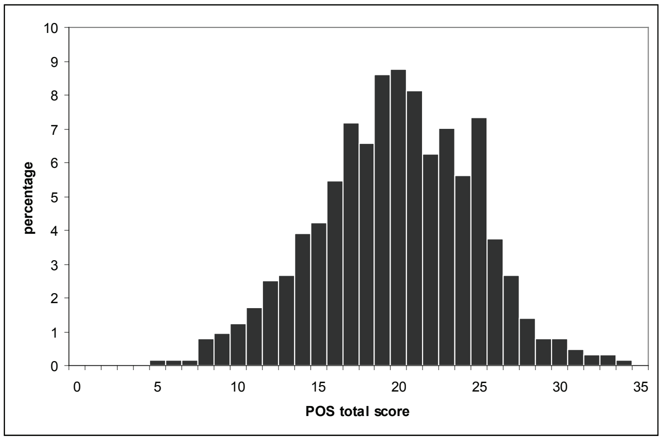


Figure 18: APCA African POS Total Score at T0



Figures 11–17 show that the biggest problems participants reported at baseline were not having enough help and advice, not being able to share feelings, and not being at peace.

The scores of the seven patient APCA African POS items were added together to create an APCA African POS total score. The score has an approximately Normal distribution (Figure 18), with a mean of 19.8 (sd 4.9), and the range is 5–34 out of a possible total of 0–35.

5.6.3—Problems Facing Family Caregivers

The APCA African POS contains three items for informal carers accompanying the patient to answer. APCA African POS domains for carers were frequently not completed, as carers were usually not present at the patient's clinical appointment. Of the number of participants completing each timepoint, a mean of 158 (25%) carers completed all three APCA African POS carer questions at baseline, 107 (17%) at T1, 104 (18%) at T2 and 89 (17%) at T3. Owing to the small proportion of completed carer questions, responses to these items are described here but were not included in the APCA African POS factor calculations.

In Table 33 , the item scales were adjusted as necessary so that in all cases, 0 represents the worst possible problem and 5 no problem. The number of carers completing each question is slightly different from the numbers reported above who completed all three carer questions, as some carers completed fewer than three questions. Carers most commonly reported the central responses to each question, and there was little change in responses over time.

Table 33: Median (IQR) APCA African POS Carer Item Responses

Item	T0	T1	T2	T3
n	*158*	*108*	*104*	*91*
How much information have you and your family been given?	3 (2–4)	3 (2–4)	4 (3–4)	3 (3–5)
How confident does the family feel caring for the patient?	4 (3–5)	4 (3–5)	4 (3–5)	5 (4–5)
Has the family been feeling worried about the patient over the last 3 days?	3 (2–5)	3 (1–4)	4 (2–5)	4 (3–5)

5.7—How Participants Differ by Facility

5.7.1—Participant Characteristics at Different Facilities

The facilities included in the study were from different parts of the country. The characteristics of the facilities themselves have been studied in detail in Phase 1 and summarised in section E1. In addition, the variety of locations of the facilities is likely to mean the characteristics of the participants attending varied also. These are presented in Table 34.

Facilities 255, 256, and 258 had a higher proportion of men than the other three facilities, and people at Facility 252 had more dependants than participants at

Table 34: Demography of Participants by Facility

Facility	Males		Mean		Median		Time to Facility	
	N	%	Age	SD	Dependants	IQR	Median	IQR
252	23	21.5	37.9	9.8	7	6–8	1hr30	40mins–2hr30
255	37	35.2	38.8	8.3	4	3–6	2hrs	1hr–3hrs
256	44	39.3	32.1	8.6	3	1–5	1hr	40mins–1hr30
258	41	38.3	33.7	8.2	4	2–6	1hr	30mins–2hrs
259	29	28.4	34.9	7.3	3	2–5	1hr	30mins–1hr30
260	30	28	33	9.5	3	2–6	1hr	30mins–2hrs
Total	204	31.9	35	9	4	2–7	1hr	40mins–2hrs

Table 35: Education Level by Facility

Facility	None		Began Primary		Began Secondary		Diploma		Degree	
	N	%	N	%	N	%	N	%	N	%
252	27	25.2	57	53.3	22	20.6	1	0.9	0	
255	15	14.3	60	57.1	27	25.7	1	1.0	2	1.9
256	5	4.5	40	35.7	54	48.2	7	6.3	6	5.4
258	4	3.7	62	57.9	28	26.2	11	10.3	2	1.9
259	7	6.9	38	37.3	40	39.2	14	13.7	3	2.9
260	9	8.4	57	53.3	29	27.1	9	8.4	3	2.8
Total	67	10.5	314	49.1	200	31.3	43	6.7	16	2.5

Table 36: People at Facilities within Wealth Quintile *(1=poorest; 5=richest)*

Facility	1		2		3		4		5		Total
	N	%	N	%	N	%	N	%	N	%	
252	82	76.6	11	10.3	12	11.2	1	0.9	1	0.9	107
255	31	29.5	60	57.1	10	9.5	4	3.8	0	0	105
256	2	1.8	3	2.7	25	22.3	45	40.2	37	33	112
258	2	1.9	12	11.2	26	24.3	32	29.9	35	32.7	107
259	3	2.9	9	8.8	18	17.7	32	31.4	40	39.2	102
260	9	8.4	32	29.9	37	34.6	20	18.7	9	8.4	107
Total	129	20.2	127	19.8	128	20	134	20.9	122	19.1	640

other facilities. Table 35 shows that on average participants at Facility 252 had a lower level of education. The facility with the highest proportion of participants at secondary school or above was Facility 256.

The greatest different between facilities was in the relative wealth of participants (Table 36). Over three quarters of participants at Facility 252 were in the poorest overall quintile, making up 64% (82 of 129) of the people in that quintile. The majority of Facility 255 participants were in the second quintile. Facilities 256, 258, and 259, each had less than 3% of their participants in the poorest quintiles and over 30% in the richest.

Figure 19 shows that the poorest quintile was almost all cared for at Facility 252, and Facility 255 cared for most of the participants in the second poorest quintile. The wealthiest quintile was only represented at four of the facilities.

Figure 19: Wealth Quintiles by Facility

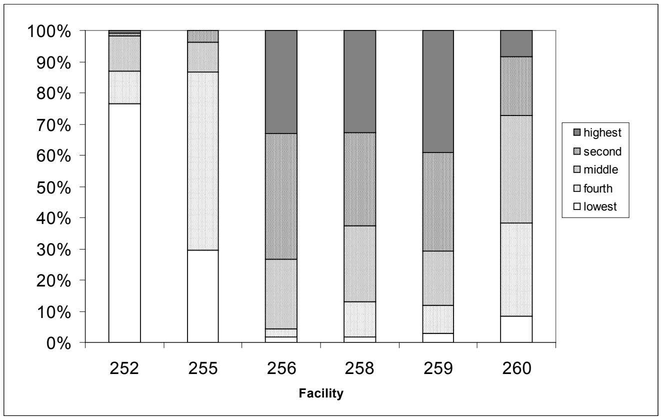


Table 37: Reason for Attending at T0 by Facility

Facility	252		255		256		258		259		260		Total	
	N	%	N	%	N	%	N	%	N	%	N	%	N	%
HIV test result in last 14 days	0	0	20	19.1	82	73.2	27	25.2	36	35.3	31	29	196	30.6
HIV test result more than 14 days ago	0	0	2	1.9	8	7.1	42	39.3	2	2	1	0.9	55	8.6
Referred	0	0	12	11.4	0	0	6	5.6	13	12.8	11	10.3	42	6.6
Obtain medication or lab test	47	43.9	34	32.4	11	9.8	4	3.7	23	22.6	0	0	119	18.6
New illness or new presenting problem	58	54.2	37	35.2	11	9.8	27	25.2	27	26.5	63	58.9	223	34.8
Other	2	1.9	0	0	0	0	1	0.9	1	1	1	0.9	5	0.8

Table 38: ECOG Score at Baseline by Facility

Facility	0 fully active		1 restricted		2–4 ambulatory/limited self care/completely disabled	
	n	%	n	%	n	%
252	22	20.6	40	37.4	45	39.1
255	83	79.1	20	19.1	2	1.9
256	92	82.1	11	9.8	9	8.0
258	55	51.4	47	43.9	5	4.7
259	44	43.1	46	45.1	12	11.8
260	25	23.4	68	63.6	14	9.1
Total	321	50.2	232	36.3	87	13.6

Table 37 shows participants' reasons for attending the facility at T0, analysed by facility. There was considerable variation; for example, 73% of Facility 256 participants were newly diagnosed whereas the next highest proportion (Facility 259) was only 35% and Facility 252 recruited none at all. According to Table 37, two facilities did not accept any patients by referral during the study period. At Facility 258, the most common reason for attending was an HIV test result more than 14 days ago, which was rare at all other facilities.

5.7.2—Illness Severity at Different Facilities

The WHO staging system was rarely used at two facilities, and used about half the time at two others, with the result that WHO scores cannot be compared between the facilities. ECOG scores at baseline are displayed in the table below. All scores of 2 or above were combined, as only 3.1% of participants scored 3 or 4. Table 38 shows that more participants had impaired physical functioning at Facility 252 than at other facilities.

There was great variation in the physical function of participants in the study by facility. The percentage of participants who were fully active at baseline ranged from 20.6% at Facility 252 to 82.1% at Facility 256 (Table 38). The percentage of participants who had limited physical ability (ECOG of 2–4) ranged from 1.9% at Facility 255 to 39.1% at Facility 252. At three facilities, mean CD4 count dropped during the study for those with a measurement at the beginning and the end (Table 39).

5.7.3—Care Received at Different Facilities

All care components: The number of care components received by participants in the course of the study (displayed in Figure 6) varied considerably by facility, as shown in Table 40, from a mean of 13.0 at Facility 256 to 23.9 at Facility 252. The lowest number of components received by a participant was zero (Facility 256), compared to a minimum of 14 components of care being received by participants at Facility 252 and 11 at Facility 259. Some participants at Facilities 252 and 255 received 34 care components out of the 52 examined over the course of the study. Participants at Facilities 255 and 256 reported the greatest variation in number of components (shown by the standard deviation).

The percentage of participants who received each component of care at any time through the study was calculated for each facility (Table 41). Components

Table 39: CD4 Counts at T1 and T3 by Facility

Facility	CD4 Count at T1		CD4 count at T1		CD4 count at T3		CD4 count at T3		CD4 count at T3 and T0		Change in CD4 count	
	N	%	Mean	Sem	N	%	Mean	Sem	N	%	Mean	Sem
252	106	100	267	15	80	74.8	317	16	80	74.8	65	14
255	42	40.4	493	52	14	13.3	674	106	12	11.4	-11	59
256	54	52.4	412	34	5	4.4	349	81	5	4.4	4	28
258	45	45	291	30	61	57	367	30	27	25.2	55	35
259	91	91	299	23	29	28.4	281	32	22	21.6	-28	57
260	36	35.3	341	33	33	30.8	370	38	14	13.1	-32	39
Total	374	60.8	331	12	222	41.3	357	15	160	25	34	13

Table 40: Care Components Ever Received, by Facility

Facility	Mean	SD	Minimum	Maximum	N
252	23.9	4.2	14	34	107
255	22.0	6.3	6	34	105
256	13.0	6.4	0	28	113
258	13.8	3.9	1	22	107
259	20.1	4.1	11	31	102
260	16.0	4.3	3	27	107

are listed in order of the total percentage across all six facilities who received the care, from CTX with the highest coverage to cryptococcal meningitis treatment with the least. It can be seen that three facilities provided CTX to all their participants while the other three provided it to over 90%. The largest differences between facilities were in their provision of social and spiritual care components.

At Facility 252 (a mission hospital), 95% of participants had prayed with a member of staff at least once during the three months of the study, while at Facility 256 only a fifth had done so. Only Facilities 255 and 259 provided a substantial programme of loans and IGA. Facility 260 provided no treatment for anxiety or depression. Two facilities (260 and 258) did not provide strong opioids and Facility 258 did not provide weak opioids either.

Other notable differences between facilities in Table 41 include:

- Facilities 252, 255 and 259 provided pastoral visits more frequently than the others.
- Almost half of Facility 255 participants had contact with a traditional healer.
- Facilities 256 and 260 had fewer than 40% of participants who attended patient HIV support groups.
- Provision of infection control training and nursing care was extremely varied; infection control training varied from 18% to 97% and nursing care from 12% to 98%
- Facility 255 had almost 5% receiving cryptococcal meningitis treatment, as compared to virtually none at all other facilities.
- Almost no-one at Facilities 258 and 260 received food while over 90% at Facility 2525 were given food.
- Facility 255 gave home help and household items to 40% of participants, most other facilities gave none.

Care received away from the facility: Substantial levels of care were received at other locations besides the facilities where the study was based (Table 42). Clinical items such as malaria treatment and treatment for nausea were often sought elsewhere, as well as spiritual care (a visit from a religious leader was very often independent of the facility) and preventive care, for example improved access to water.

Figure 20 shows the mean number of care components per person reported at T0, at each facility. At three of the facilities (255, 258, and 259) the majority

Table 41: Percentage of Participants Ever Receiving Care Components, by Facility

Facility	252	255	256	258	259	260
CTX	100.0	100.0	90.3	96.3	95.1	100.0
Adherence counselling	99.1	81.0	81.4	98.1	98.0	99.1
Prevention with positives	98.1	90.5	71.7	91.6	99.0	99.1
Nutritional advice	99.1	96.2	80.5	77.6	82.4	98.1
Non-opioid analgesic	100.0	94.3	63.7	77.6	80.4	82.2
Family planning counselling	72.0	75.2	73.5	78.5	97.1	85.0
Pain assessment	96.3	85.7	45.1	84.1	56.9	88.8
Multivitamins	83.2	95.2	59.3	47.7	73.5	97.2
Patient HIV support groups	98.1	87.6	37.2	88.8	97.1	34.6
Condoms	61.7	82.9	72.6	61.7	94.1	58.9
Pre- and post-test counselling	64.5	49.5	92.9	83.2	68.6	48.6
Treatment for other OIs	97.2	96.2	54.9	43.9	27.5	85.0
Assess ART treatment	99.1	56.2	39.8	38.3	75.5	90.7
ITNs	66.4	88.6	66.4	59.8	73.5	30.8
Family counselling	85.0	82.9	26.5	39.3	89.2	58.9
Access to drinking water	89.7	87.6	61.1	59.8	35.3	39.3
Other nursing care	97.2	93.3	41.6	29	98	12.1
ART/ARV	99.1	40.0	30.1	38.3	66.7	95.3
Visit by religious leader	99.1	85.7	18.6	40.2	95.1	17.8
Prayer with staff	95.3	38.1	20.4	62.6	72.5	58.9
Treatment for malaria	99.1	78.1	49.6	32.7	46.1	42.1
Infection control training	17.8	69.5	20.4	23.4	97.1	72.0
TB testing	42.1	19.0	82.3	17.8	73.5	51.4
Wound care	63.6	70.5	23.9	10.3	98	17.8
Treatment for skin rash/itching	53.3	66.7	17.7	54.2	43.1	44.9
Transport to care centre	8.4	62.9	4.4	88.8	69.6	7.5
Food	95.3	70.5	11.5	0.9	55.9	0.9
Treatment for genital thrush	34.6	41.0	14.2	23.4	49.0	34.6
IGA	4.7	76.2	6.2	19.6	58.8	1.9
Treatment for diarrhoea	61.7	45.7	14.2	10.3	6.9	21.5
Treatment for nausea/vomiting	45.8	56.2	11.5	6.5	12.7	24.3
Treatment for fungal infections	56.1	38.1	9.7	14	19.6	17.8
Treatment for oral thrush	36.4	34.3	12.4	7.5	26.5	23.4
Treatment for anxiety and depression	63.6	29.5	15.9	4.7	8.8	0
Contact with traditional healer	1.9	48.6	10.6	21.5	20.6	4.7
Loans/microfinance	3.7	58.1	3.5	0	42.2	0

Table 41: Percentage of Participants Ever Receiving Care Components, by Facility

Facility	**252**	**255**	**256**	**258**	**259**	**260**
Treatment for neuropathic pain	18.7	16.2	15	29.9	11.8	15.0
Legal services	0.9	68.6	6.2	0	7.8	0
TB treatment	19.6	9.5	20.4	13.1	12.7	5.6
Therapeutic feeding	20.6	41	11.5	2.8	2.9	1.9
Memory book	26.2	14.3	4.4	0	20.6	10.3
Prophylactic isoniazid	13.1	20	36.3	0	2	2.8
Treatment for herpes	10.3	6.7	6.2	20.6	10.8	8.4
Home help	5.6	45.7	0	0.9	3.9	0
Household items	5.6	40	0.9	0	3.9	0.9
Weak opioids	12.1	9.5	13.3	0	13.7	1.9
Constipation treatment/laxatives	10.3	12.4	2.7	1.9	11.8	8.4
Physiotherapy	15.9	9.5	8.0	0.9	2.9	1.9
Strong opioids	4.7	11.4	13.3	0	2	0
Psychiatric therapy	3.7	2.9	5.3	0.9	3.9	0
Cancer management	0.9	2.9	2.7	0	5.9	0
Treatment for cryptococcal meningitis	0.9	4.8	0.9	0	0	0.9

Table 42: Percentage of People Ever Receiving Care at the Facility and Elsewhere *(fac = facility, else = elsewhere)*

Facility	252		255		256		258		259		260	
	fac	else	fac	else	fac	else	fac	else	fac	else	fac	else
CTX	100	7.5	98.1	50.5	74.3	45.1	91.6	55.1	92.2	30.4	100	7.5
Adherence counselling	97.2	29.9	76.2	44.8	57.5	51.3	91.6	57	96.1	24.5	98.1	8.4
Prevention with positives	93.5	39.3	72.4	59	57.5	28.3	86	20.6	98	29.4	98.1	8.4
Nutritional advice	94.4	35.5	78.1	65.7	63.7	38.9	75.7	21.5	77.5	24.5	98.1	5.6
Non-opioid analgesics	98.1	15	39	89.5	21.2	54	69.2	32.7	47.1	58.8	80.4	15
Patient HIV support groups	79.4	70.1	66.7	56.2	20.4	18.6	83.2	32.7	88.2	49	30.8	7.5
Family planning counselling	53.3	29	62.9	41	52.2	38.1	72	26.2	97.1	22.5	84.1	5.6
Multivitamins	81.3	7.5	80	53.3	49.6	24.8	40.2	14	66.7	25.5	97.2	11.2
Condoms	35.5	32.7	81	27.6	67.3	20.4	59.8	10.3	73.5	82.4	57.9	2.8
Assessment of pain	95.3	14	47.6	63.8	14.2	37.2	73.8	36.4	52	12.7	88.8	3.7
Pre and post test counselling	58.9	11.2	7.6	47.6	88.5	22.1	73.8	51.4	52	22.5	44.9	3.7
Treatment for other OIs	96.3	13.1	68.6	75.2	20.4	44.2	39.3	9.3	21.6	9.8	85	0.9
Family counselling	60.7	49.5	61.9	46.7	9.7	18.6	28	21.5	73.5	33.3	57	10.3
Other nursing care	94.4	27.1	45.7	85.7	15.9	32.7	11.2	18.7	98	19.6	10.3	1.9
Access to drinking water	39.3	84.1	68.6	46.7	51.3	15.9	59.8	0.9	3.9	34.3	36.4	5.6
ITNs	25.2	49.5	86.7	22.9	61.9	9.7	59.8	0.9	10.8	69.6	30.8	0
Assess ART treatment	99.1	1.9	47.6	13.3	23	21.2	35.5	9.3	72.5	6.9	90.7	4.7
Treatment for malaria	99.1	37.4	22.9	73.3	13.3	41.6	13.1	25.2	4.9	42.2	27.1	21.5
ART/ARVs	99.1	0	35.2	16.2	8.8	23.9	36.4	6.5	63.7	10.8	95.3	6.5
Visit by religious leader	38.3	91.6	2.9	84.8	0.9	17.7	0	40.2	2	95.1	10.3	10.3
Prayer with staff	34.6	86.9	28.6	15.2	2.7	18.6	59.8	8.4	2	72.5	57.9	2.8
Infection control training	13.1	7.5	57.1	32.4	15	6.2	15	8.4	97.1	20.6	72	6.5
Wound care	59.8	17.8	58.1	28.6	8	18.6	2.8	8.4	98	15.7	16.8	3.7
Treatment for skin rash/itching	49.5	8.4	48.6	43.8	3.5	15.9	50.5	9.3	30.4	24.5	43	3.7
TB testing	40.2	2.8	4.8	15.2	74.3	21.2	13.1	6.5	67.6	8.8	49.5	2.8
Food	75.7	43.0	66.7	22.9	6.2	6.2	0	0.9	53.9	2.9	0.9	0
Transport to care centre	0	8.4	62.9	2.9	2.7	1.8	88.8	1.9	61.8	20.6	6.5	1.9
Treatment for genital thrush	33.6	3.7	28.6	24.8	6.2	8.8	18.7	8.4	32.4	35.3	32.7	4.7
Employment training/IGA	1.9	2.8	70.5	36.2	1.8	4.4	19.6	0	7.8	55.9	0	1.9
Treatment for nausea/vomiting	41.1	5.6	26.7	43.8	3.5	10.6	2.8	3.7	5.9	12.7	19.6	7.5
Treatment for fungal infections	50.5	10.3	20	29.5	4.4	5.3	10.3	3.7	9.8	16.7	15	4.7
Treatment for diarrhoea	54.2	11.2	19	28.6	2.7	11.5	5.6	5.6	1	5.9	17.8	4.7
Treatment for oral thrush/candidiasis	32.7	4.7	24.8	19	4.4	8	4.7	2.8	16.7	18.6	21.5	3.7
Treatment for anxiety/depression	53.3	12.1	19	13.3	4.4	11.5	2.8	1.9	8.8	1	0	0
Loans/microfinance	0	3.7	24.8	44.8	0	3.5	0	0	0	42.2	0	0

Table 42: Percentage of People Ever Receiving Care at the Facility and Elsewhere *(fac = facility, else = elsewhere)*

Facility	252		255		256		258		259		260	
	fac	else	fac	else	fac	else	fac	else	fac	else	fac	else
Treatment for neuropathic pain	18.7	1.9	10.5	6.7	0.9	14.2	29.9	2.8	9.8	2.9	15	0
Contact with traditional healer	0	1.9	4.8	46.7	0.9	10.6	2.8	18.7	0	20.6	2.8	1.9
Legal services	0	0.9	51.4	31.4	0.9	5.3	0	0	0.0	7.8	0	0
TB treatment	17.8	2.8	3.8	6.7	15.9	5.3	12.1	4.7	11.8	2	5.6	0.9
Therapeutic feeding for malnutrition	16.8	3.7	25.7	22.9	3.5	8	1.9	0.9	2	1	1.9	0
Memory book work	23.4	3.7	11.4	3.8	0.9	3.5	0	0	1	20.6	8.4	1.9
Isoniazid for TB prevention	11.2	1.9	16.2	5.7	32.7	5.3	0	0	1	1	1.9	0.9
Treatment for herpes	7.5	2.8	4.8	2.9	2.7	3.5	17.8	3.7	6.9	4.9	8.4	0
Home help	0	5.6	40	12.4	0	0	0.9	0	0	3.9	0	0
Household items	0	5.6	38.1	3.8	0	0.9	0	0	2	2	0	0.9
Treatment for constipation/laxatives	7.5	2.8	1.9	10.5	0	2.7	1.9	0	6.9	8.8	3.7	4.7
Weak opioids	11.2	0.9	1	8.6	0.9	12.4	0	0	11.8	2	1.9	0
Physiotherapy	12.1	5.6	6.7	2.9	1.8	6.2	0	0.9	1	2	1.9	0
Strong opioids	4.7	0	2.9	8.6	0.9	12.4	0	0	2	0	0	0
Psychiatric therapy	1.9	1.9	0	2.9	1.8	3.5	0.9	0	3.9	0	0	0
Cancer management	0.9	0	1.9	1	1.8	0.9	0	0	2	4.9	0	0
Treatment for cryptococcal meningitis	0.9	0	0	4.8	0.9	0	0	0	0	0	0.9	0

Figure 20: Mean Number of Care Components Received at Each Facility and Elsewhere at T0

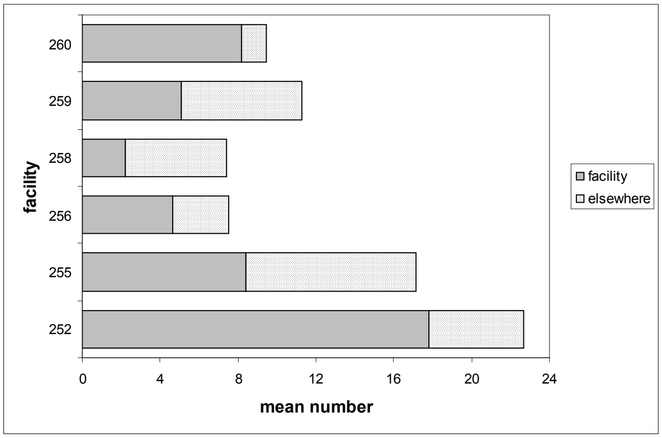


Figure 21: Mean Number of Care Components Received at Each Facility and Elsewhere at T1

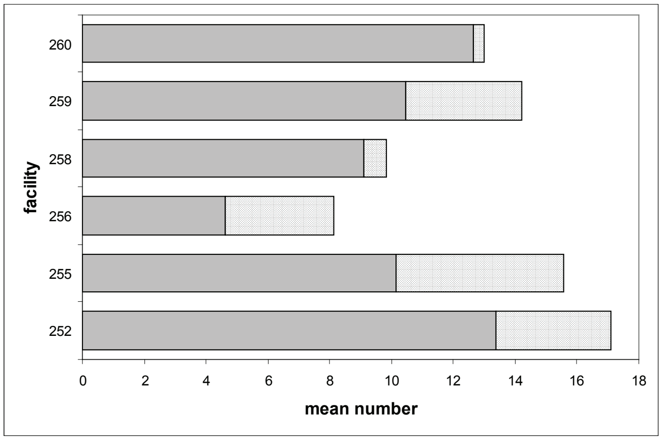


Figure 22: Mean Number of Care Components Received at Each Facility and Elsewhere at T2

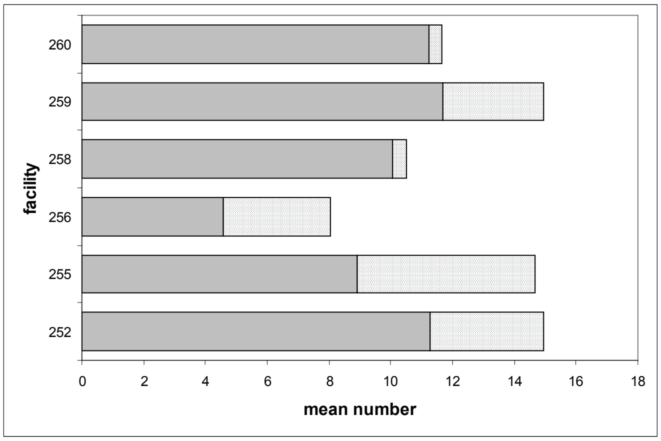
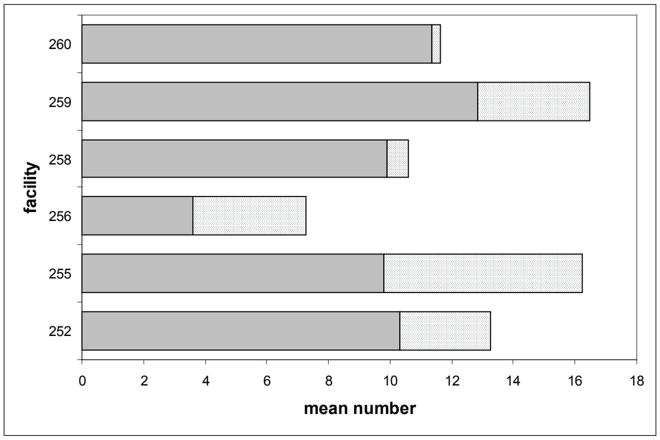


Figure 23: Mean Number of Care cComponents Received at Each Facility and Elsewhere at T3



of care in the month preceding T0 came from outside the facility.

Figures 21–23 show the mean number of components of care received at each facility by timepoint. All three graphs are drawn to the same scale and the facilities are ordered from 252 at the bottom to 260 at the top as in Figure 20. The proportion of components received elsewhere to those received at the facility remained relatively stable over time for each facility. The mean number of care components was also quite stable although participants at Facility 252 received fewer over time and those at Facility 255 received more.

Care Themes: Table 43 shows that Facility 256 had the lowest proportions of participants receiving spiritual care, support/counselling, pain management, symptom control, nutrition, social care and preventive care. The only care group in which Facility 256 did not offer the lowest proportion of care was nursing care. In general, support/counselling and preventive care were widely received, often by over 90% of participants. Other themes were more mixed. Social care 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. Nursing care was also polarised, received by the great majority at Facilities 255, 259 and 260, but by less than a third at Facilities 256 and 258.

PEPFAR Care and Support: Table 44 shows that almost everyone in the study received at least one component of PEPFAR C&S clinical care during the period of observation. The care category least commonly provided

Table 43: Percent of Participants at T1 to Receive Care Theme in T1-T3, by Facility

Care Theme	Facility					
	252	255	256	258	259	260
Spiritual	99.1	84.8	23.9	69.2	96.1	55.1
Counselling/advice	99.1	94.3	76.1	92.5	98	94.4
Preventive	97.2	97.1	69.9	89.7	98	94.4
Nursing	88.8	92.4	30.1	12.1	98	94.4
Pain	99.1	89.5	46	78.5	69.6	91.6
Symptoms	96.3	97.1	53.1	86	73.5	90.7
Nutrition	98.1	97.1	69	86.9	81.4	95.3
Social	1.9	73.3	1.8	20.6	59.8	1.9

Table 44: Percent of Participants Ever to Receive PEPFAR Care Categories, by Facility

Care category	Facility						
	252	255	256	258	259	260	Total
n	*107*	*105*	*112*	*107*	*102*	*107*	*640*
Clinical	100	100	99.1	99.1	100	100	99.7
Psychological	95.3	84.8	38.1	42.1	90.2	58.9	67.7
Spiritual	100	95.2	34.5	78.5	97.1	65.4	77.8
Social	12.1	87.6	14.2	20.6	75.5	1.9	34.6
Prevention	100	100	90.3	97.2	99.0	99.1	97.5

Table 45: Mean Outcome Scores at T0, by Facility

Facility	Physical Health Score		Mental Health Score		APCA African POS Total Score	
	mean	sd	mean	sd	mean	sd
252	37.9	9.7	42.6	7.3	21.3	4.9
255	38.5	12.3	40.3	8.9	19.2	4.4
256	49	11.4	43.9	10.6	19.7	4.3
258	45.8	10.9	47	9.4	20	5.5
259	46.7	12.5	47.7	9.2	19.6	4.5
260	42.8	10.7	43.9	9.6	19.1	5.3

was social care, which varied greatly by facility, with Facilities 255 and 259 providing the most social care.

5.7.4—Health at Baseline at Different Facilities

Mean physical health summary score ranged from 37.9 (sd 9.7) at Facility 252 to 49.0 (sd 11.4) at Facility 256 (Table 45). Mean mental health summary score ranged from 40.3 (sd 8.9) at Facility 255 to 47.7 (sd 9.4) at Facility 259. 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).

The variation in mean baseline APCA African POS total score appeared small, from 19.1 at Facility 260 to a maximum of 21.3 at Facility 252. This range was about half of the smallest standard deviation found within a facility. Nonetheless, APCA African POS total score at T0 was significantly associated with facility on an ANOVA test (F=2.87, p=0.014) demonstrating significant variation in the score between facilities.

5.8—Participant Characteristics and Health

5.8.1—Gender

There was no significant difference between men and women in their MOS-HIV physical or mental health scores at baseline. Mean physical health score at baseline was 42.53 for males and 43.93 for females (t= -1.39, p=0.17). For mental health the mean score was 44.52 for males and 44.08 for females (t=0.55, p=0.58).

5.8.2—Age

At baseline, there was no difference in mental health according to age of the patient. Treating age as a continuous variable, mental health score at the intercept (where age=0) was 44.60. For each increasing year of age mental health score decreased by 0.01, but this change was not significant (t=-0.26. p=0.80). However, there was a significant decrease in physical wellbeing with increasing age. Physical health score was 48.86 at the intercept and decreased by 0.15 for each increasing year of age (95% CI -0.05 to -0.26, t= -2.92, p=0.004).

5.8.3—Education

There was no difference in physical or mental health score between participants who had completed different levels of education, at the 5% confidence level using an ANOVA test (Table 46, p=0.09, p=0.05 respectively). APCA African POS total score was statistically significantly higher for people with more education (p=0.04), although in clinical terms the difference was marginal.

5.8.4—Relative Wealth

At baseline, both mental health score and physical health score were significantly associated with wealth quintile. Participants who had higher relative wealth reported higher outcome scores (Table 47). APCA African POS total score was not associated with wealth quintile.

5.8.5—Illness Severity

Baseline CD4 count was divided into four categories: up to 50, 51–200, 201–350, and above 350 cells/ml. A higher CD4 count was significantly associated with higher physical health score, mental health score and APCA African POS total score (Table 48).

5.8.6—Individual Care Components

Table 49 below shows that the 40 people who received TB treatment in the month preceding T1 had a mean physical health score over eight points lower than those who did not, and a mean mental health score over three points lower. These were both statistically significant on t-tests (physical score t=4.72, p<0.001, mental score t=2.34, p=0.02) and are considered clinically significant. People receiving TB treatment at T1 had a lower mean CD4 count, for the people with a recorded CD4 test in the 13 months before T1 (t=2.95, p=0.02).

Almost half of T1 participants received ART in the month preceding T1. Their mean physical health was almost six points lower than those who did not receive ART (t=6.58, p<0.001) and their mean mental health was 2.5 points lower (t=3.46, p<0.001). People receiving ART had a lower CD4 count than non-recipients (t=6.97, p<0.001).

Table 46: Mean Health Scores at Baseline for Different Education Levels

Education Level	Mean Physical Health Score	Mean Mental Health Score	APCA African POS Mean Total Score
None	41.2	42.7	19.0
Begun primary	42.7	44.1	19.8
Begun secondary	44.8	43.9	19.7
Diploma or higher	45.0	44.7	20.0
F	2.03	2.37	2.49
p	0.088	0.052	0.042

Table 47: Mean Health Scores at Baseline for Different Level of Wealth *(1=poorest; 5=wealthiest)*

Wealth Quintile	Mean Physical Health Score	Mean Mental Health Score	Mean APCA African POS Total Score
1	38.1	41.3	20.4
2	38.6	41.9	19.1
3	44.1	44.1	19.3
4	47.6	46.3	19.7
5	49.2	47.8	20.6
F	26.56	12.02	2.35
p	<0.001	<0.001	0.053

Table 48: Mean Health Scores at Baseline for Different Levels of CD4 Count

CD4 cells/ml	N	Mean Physical Health Score	Mean Mental Health Score	Mean APCA African POS Total Score
<50	33	35.6	41.2	18.0
51-200	90	39.7	42.5	19.5
201-350	116	43.8	45.1	20.8
>350	145	46.5	46.6	20.2
F		11.89	5.60	3.36
p		<0.001	0.001	0.019

Table 49: Comparison of Outcomes Between Participants Receiving and Not Receiving Specific Care Components at T1

	Received	Physical Health			CD4 Count			Mental Heath		
		n	mean	se	n	mean	se	n	mean	se
TB treatment	Yes	40	37.5	1.99	40	44.1	1.33	26	233	43
	No	575	46.2	0.46	575	47.6	0.38	348	341	12
ART	Yes	305	42.7	0.63	305	46.1	0.50	213	265	12
	No	310	48.5	0.62	310	48.6	0.53	161	424	21

6 Results of Longitudinal Study Section B

6.1—Association of Outcomes with Loss to Follow-Up

To determine whether missing data were missing at random with relation to the outcomes, or whether the outcomes were associated with the probability of loss to follow-up, mean physical and mental health scores at T0 for completers and non-completers were compared using t-tests. Table 50 shows that the 26 people who only completed the first observation had a mean physical health score almost four points lower than the mean for the remaining participants, but the difference was not statistically significant (t=1.60, p=0.109). The people who left the study before completion had a lower mean physical health score than those who completed all four observations but again the difference was not statistically significant at the 5% level (t=-1.80, p=0.072).

In Table 51, the 26 people who only completed one observation did not have significantly lower mental health scores than people who completed more than one (t=0.80, p=0.42).However, the 102 people who dropped out at some point during the study had significantly lower mean mental health scores than the 537 who completed all observations (t= -2.95, p=0.003).

The implication of these tests is that any analysis which only included people who had completed all four observations would be biased towards a higher level of mental health than was visible in the whole study population. Conversely, analysis which included all participants except the 26 who only completed an interview at T0 would not necessarily bias the results. Therefore, multilevel modelling, which operates using all observations except the first, is a more appropriate way of exploring change over time in this study than traditional techniques which often exclude non-completers.

Table 50: Mean Physical Health Scores at T0 by Number of Observations Completed

Observations Completed	N	Mean	sd	95% CI
One	26	39.8	14	34.1–45.5
More than one	613	43.6	11.9	42.7–44.6
Less than four	102	41.5	13.4	38.9–44.2
Four	537	43.9	11.7	42.9–44.8

Table 51: Mean Mental Health Scores at T0 by Number of Observations Completed

Observations Completed	N	Mean	SD	95% CI
One	26	42.7	10.5	38.5–47
More than one	613	44.3	9.5	43.5–45
Less than four	102	41.7	10	39.7–43.6
Four	537	44.7	9.4	43.9–45.5

Table 52: MOS Summary Score Changes Over Time

	T0		T1		T2		T3	
	mean	sd	mean	sd	mean	sd	mean	sd
Mental health	44.2	9.5	47.3	9.1	49.3	8.8	51.5	9.1
Physical health	43.5	12	45.6	11.4	47.7	10.6	49.9	10

6.2—Changes in Health Over Time

6.2.1—Physical and Mental Health Scores

Mean summary scores at each timepoint are presented in Table 52 and illustrated in Figures 24 and 25. The increase in mean from baseline to T3 was 6.03 (sd 11.51) for physical health score and 6.74 (sd 9.84) for mental health score, which were both clinically significant (**11**). The figures show that mean physical and mental health scores increased steadily over time.

Multilevel linear regression, with three levels (facility, individual and interview levels), accounting for baseline and including a time variable, showed that mental health and physical health summary scores increased significantly over the three month follow up compared to baseline (Tables 53 and 54).

Figure 24: Change in Average Physical Health Score Over Time

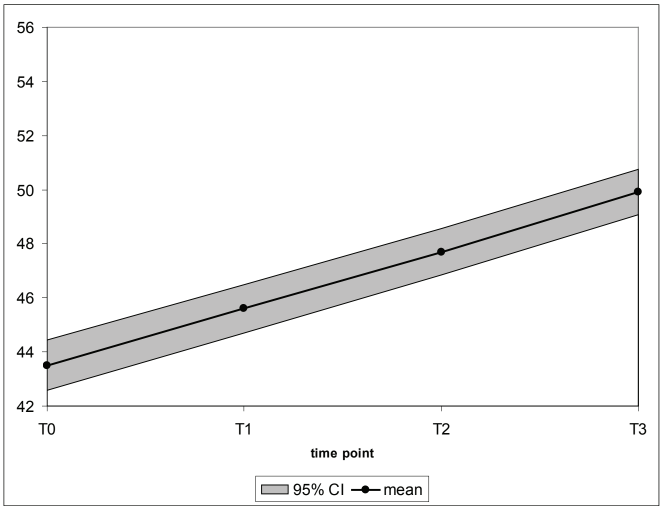


Figure 25: Change in Average Mental Health Score Over Time

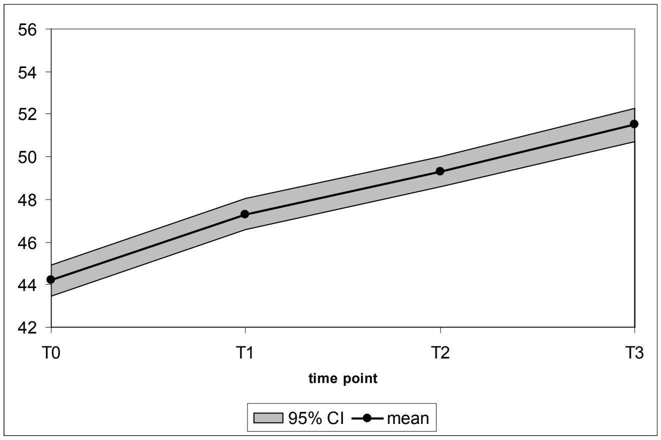


Table 53: Mixed-Effects Model of Physical Health Score Adjusting for Physical Health at T0 and Time

	Coefficient	Standard Error	Z	P	95% CI
Baseline physical health score	0.452	0.025	18.11	<0.001	0.403–0.501
Interview number	2.167	0.200	10.81	<0.001	1.773–2.559
Constant	23.713	1.589	14.92	<0.001	20.598–26.828

Table 54: Mixed-Effects Model of Mental Health Score Adjusting for Mental Health at T0 and Time

	Coefficient	Standard Error	Z	P	95% CI
Baseline mental health score	0.421	0.026	15.92	<0.001	0.370–0.473
Interview number	1.948	0.177	10.98	<0.001	1.600–2.296
Constant	26.710	1.543	17.31	<0.001	23.686–29.734

Tables 53 and 54 contain the fixed effects output only, which can be read as ordinary linear regression. The interpretation of Table 53 is that with each increase in time, from T1 to T2 and from T2 to T3, average physical health score goes up by 2.17. Each additional point in physical health score at T0 means subsequent physical health measures for that person are on average 0.45 points higher.

The 95% confidence intervals represent the range within which the true regression coefficient has a 95% probability of falling, and is calculated by the coefficient plus or minus 1.96 times the standard error.

6.2.2—Multidimensional Care Scores

During the study period all APCA African POS items except feeling that life was worthwhile and feeling at peace showed increases in the median scores, although feeling that life was worthwhile was the most highly scored domain (median = 4) at the beginning of the study (Table 55) and so there was very little potential for improvement.

Table 56 presents a different summary of the same information. The proportion reporting "severe" (the worst two scores) and "moderate" (the middle two scores) problems on each item are reported by time. The

Table 55: APCA African POS Scores for Items (All 0–5)

APCA African POS Item	T0		T1		T2		T3	
	Median	IQR	Median	IQR	Median	IQR	Median	IQR
Pain	3	2–4	4	3–5	4	3–5	4	3–5
Symptoms	3	3–5	4	3–5	4	3–5	4	3–5
Worry	3	2–4	4	3–5	4	3–5	4	3–5
Sharing	2	1–4	3	1–4	3	1–4	3	2–5
Life worthwhile	4	3–5	4	3–5	4	3–5	4	3–5
Peace	3	1–4	3	2–4	3	2–4	3	3–4
Help and advice	1	0–3	2	1–3	3	1–4	3	2–4

Table 56: Percent of Participants Reporting Severe and Moderate Problems by Multidimensional Item Over Time

		T0	T1	T2	T3
	n	*641*	*614*	*583*	*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

results show that the reduction in median scores shown in Table 52 had clinical meaning. In most cases the proportion experiencing severe and moderate problems decreased, particularly between T0 and T1 when the largest reduction in severe problem scores occurred. Lack of help and advice was the only item in which the majority of people had severe problems at T0. The proportion to have moderate problems with feeling at peace did not change much over time, probably caused by moderate problems becoming mild at the same rate that severe problems became moderate. On the help and advice item, moderate problems actually increased substantially between T0 and T1. By T3, just under a quarter of participants still had severe problems with sharing their feelings, while severe pain and symptoms were very rare.

Using multilevel modelling with levels for individual and facility and interview, and controlling for baseline APCA African POS total score and time, the APCA African POS total score significantly increased over the three-month time period compared to baseline ($p<0.001$, Table 56). Figure 26 shows the mean and 95% confidence intervals for APCA African POS total score at each timepoint.

6.3—Participants with the Most Need at Baseline

It is of particular concern that individuals with the most severe problems relating to their HIV status should receive appropriate care. It is possible that the most intractable problems are not dealt with sufficiently, and that an average improvement in scores hides

Figure 26: Change in APCA African POS Total Score Over Time

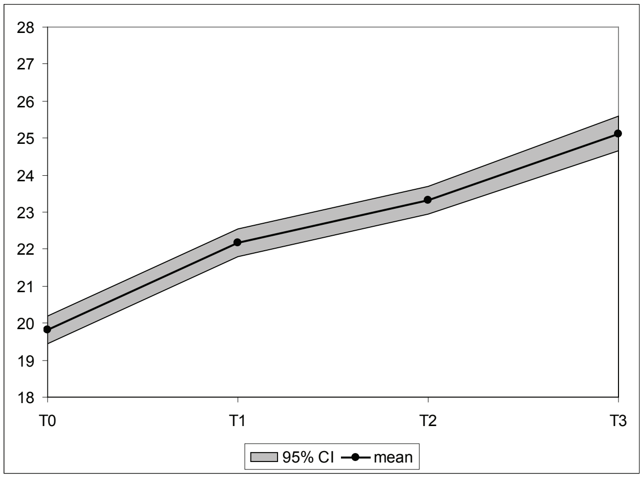
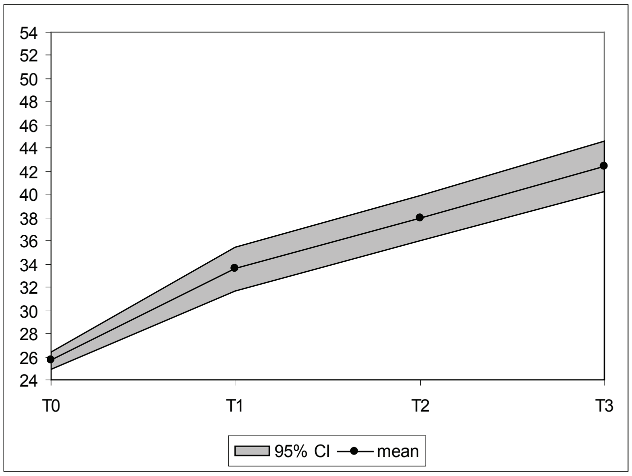


Table 57: Mixed-Effects Model of APCA African POS Total Score Adjusting for Baseline APCA African POS Total Score and Time

	Coefficient	Standard Error	Z	P	95% CI
Baseline APCA African POS total score	0.333	0.027	12.38	<0.001	0.280–0.385
Interview number	1.367	0.113	12.12	<0.001	1.146–1.588
Constant	14.083	0.926	15.21	<0.001	12.268–15.898

Figure 27: Mean Physical Health Score Over Time for the 20% with the Lowest Physical Health Score at T0



this. For this reason the participants with the worst outcomes at baseline were examined to see how their outcomes changed over time.

6.3.1—Physical and Mental Health Scores

The 128 people with the lowest physical health summary score at baseline (20% of the sample of 640) had a mean physical health score at T0 of 25.60 (sd=3.75), increasing at T3 to a mean of 42.45 (sd=10.64). Table 57 shows that physical health increased significantly over time (p<0.001) for this group of people with low physical health at the beginning of the study. This increase is observed in Figure 27 showing the means score at each time. The 95% confidence intervals widen over time, indicating that the sample size was shrinking because of loss to follow-up.

In the 128 people with the lowest mental health score at baseline, mean mental health increased from 31.12 (sd=4.39) at T0 to 45.76 (sd=10.67) at T3. In a multi-level model, the passage of time was associated with an improved mental health outcome, showing that mental health improved for those with the lowest starting value (Table 58). Figure 28 displays the mean mental health score and 95% CIs for the group.

6.3.2—Multidimensional Care Scores

Severe pain and symptoms are sometimes complex and intractable. The scores over time for those who reported overwhelming pain and symptoms at T0 were analysed to determine whether these problems were resolved. Only 19 people reported experiencing the worst category of pain, overwhelming pain, at T0, and 14 reported overwhelming symptoms. Table 60 displays the scores of these groups over time. By T2, the worst score for the group previously in overwhelming pain was severe (**2**), and this was maintained to T3. The group with overwhelming symptoms also generally improved in scores although there were still two people experiencing overwhelming symptoms at T3. Further analysis was not performed on these data because the small numbers involved would make interpretation unreliable.

6.4—Variation by Facility

Table 61 and Figure 29 show that mean physical health score increased at all six facilities over time. Mean

Table 58: Mixed-Effects Model of Physical Health Score Adjusting for Baseline Physical Health Score and Time for the 20% with the Lowest Physical Health Score at Baseline

	Coefficient	Standard Error	Z	P	95% CI
Baseline physical health score	0.364	0.189	1.92	0.054	-0.007–0.735
Interview number	4.350	0.547	7.95	<0.001	3.277–5.422
Constant	20.700	5.140	4.03	<0.001	10.626–30.775

Figure 28: Mean Mental Health Score Over Time for the 20% with the Lowest Mental Health Score at T0

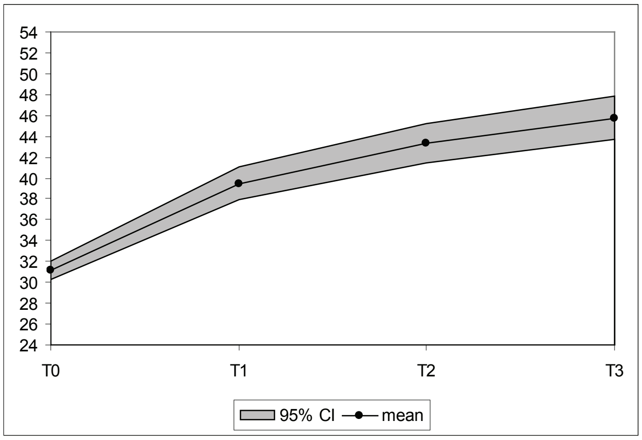


Table 59: Mixed-Effects Model of Mental Health Score Adjusting for Baseline Mental Health Score and Time for the 20% with the Lowest Mental Health Score at Baseline

	Coefficient	Standard Error	Z	P	95% CI
Baseline mental health score	0.317	0.133	2.38	0.017	0.056–0.579
Interview number	3.276	0.472	6.94	<0.001	2.351–4.202
Constant	27.642	4.474	6.18	<0.001	18.873–36.412

Table 60: APCA African POS Pain and Symptom Item Scores Over time for Participants Who Experienced the Worst Score at T0

Item	Number of Participants							
	Pain				Symptoms			
	T0	T1	T2	T3	T0	T1	T2	T3
Overwhelming (0)	19	0	0	0	14	0	1	0
Very severe (1)	0	3	0	0	0	0	0	2
Severe (2)	0	2	3	4	0	4	2	2
Moderate (3)	0	7	6	2	0	4	2	1
Slight (4)	0	2	4	5	0	2	2	4
None (5)	0	2	3	4	0	2	3	1
Total	19	16	16	15	14	12	10	10

Table 61: Mean (SD) Physical Health Score by Timepoint and Facility

Facility	T0	T1	T2	T3
252	37.9 (9.7)	39.8 (10.3)	41.6 (8.5)	46.4 (8.9)
255	38.5 (12.3)	40.6 (11.4)	43.5 (11.0)	43.7 (10.6)
256	49.0 (11.4)	51.0 (10.7)	52.3 (8.8)	54.6 (8.0)
258	45.8 (10.9)	50.1 (8.7)	51.7 (8.7)	52.0 (8.3)
259	46.7 (12.5)	48.0 (10.9)	52.3 (10.2)	56.3 (8.2)
260	42.8 (10.7)	44.4 (10.9)	46.2 (10.5)	47.7 (9.2)

Figure 29: Change in Mean Physical Health Score Over Time for Each Facility

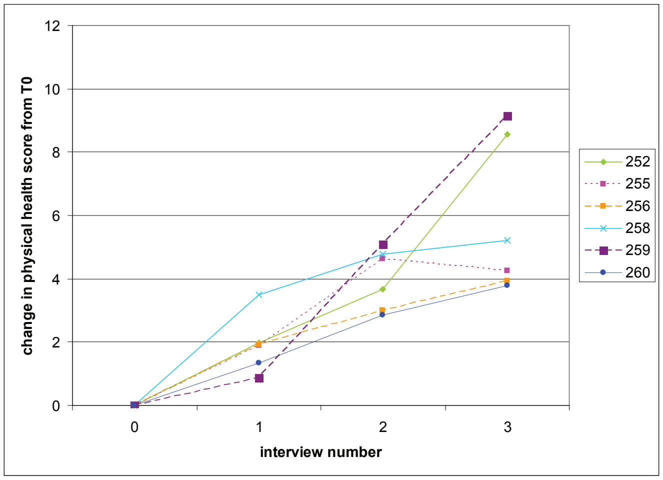


Table 62: Mental Health Score by Timepoint and Facility

Facility	T0		T1		T2		T3	
	mean	sd	mean	sd	mean	sd	mean	sd
252	42.6	7.3	46.5	7.1	47.7	6.8	50.2	7.1
255	40.3	8.9	43.2	8.8	44.4	8.4	44.5	7.7
256	43.9	10.6	47.1	10.9	48.6	9.2	52.1	7.9
258	47	9.4	51.4	8.1	52.9	8.1	53.7	9.3
259	47.7	9.2	49.9	8	54.3	7.4	58.1	7.4
260	43.9	9.6	46.2	9.1	48.3	8.9	50.1	9

improvement was considerably higher at Facilities 252 and 259. There was no clear tendency for change in physical health score to be associated with physical health at T0. For example, the two facilities with the highest and lowest mean physical health score at baseline, Facility 256 and Facility 252 respectively, had very similar trajectories on Figure 22.

6.5—Participant Characteristics

In Tables 63 and 64, each line corresponds to a different univariate model, used to identify variables which might be associated with the outcomes. In each case, baseline summary score and timepoint were also included.

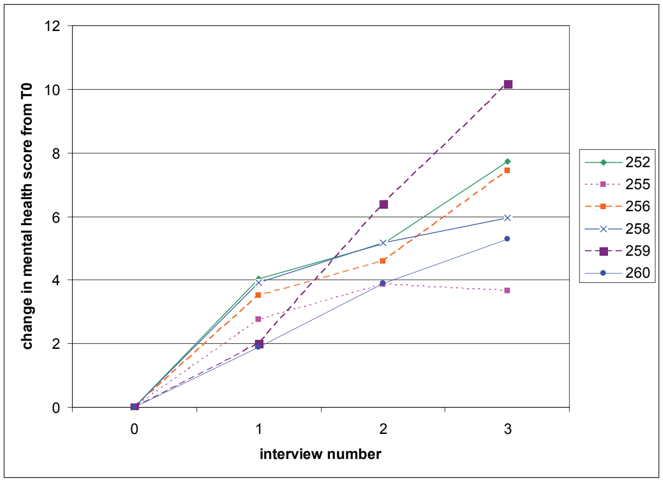
Change in physical health score over time was significantly greater for participants who had attended higher levels of education (p=0.036) and who had greater relative wealth (p=0.077). There was no statistical difference at the 10% level in the change in physical health score between male and female participants, or those of different ages, different levels of wealth or different CD4 levels. Change in mental health score was not associated with any participant characteristics.

6.6—Antiretroviral Therapy and TB Treatment

Having established using t-tests that participants who received ART or TB treatment at T1 had lower physical and mental health than participants not receiving this treatment, multi-level modelling was used to investigate whether the difference was maintained over time.

Table 65 shows the results of three models of physical health over time, all of them including CD4 count and physical health score at the beginning of the study. In addition, one model includes the receipt of TB treatment and another includes ART.

Figure 30: Change in Mean Mental Health Over Time for Each Facility



TB treatment was significantly associated with physical health (coefficient= -3.117, p=0.013). This means that if a participant had received TB treatment in the previous month, their physical health was on average over 3.1 points lower than it would have been for someone who had not received TB treatment. In longitudinal analysis, the coefficient must be interpreted as a combination of effects within individuals and effects between them. Of course, this association does not mean that the TB drugs were actually lowering physical health.

ART was also negatively associated with physical health (coefficient= -1.783, p=0.025). On average, a person on ART had a physical health score 1.8 points

Table 63: Association of Physical Health Score with Demographic Variables (One at a Time), Using Fixed Effects

Variable	Coefficient	Standard Error	Z	P	95% CI
Gender	0.406	0.605	0.67	0.502	-0.780–1.592
Age	-0.007	0.032	-0.21	0.831	-0.070–0.056
Education	0.701	0.334	2.10	0.036	0.047–1.356
Wealth	0.501	0.283	1.77	0.077	-0.054 to 1.056
CD4 count	0.001	0.002	0.74	0.459	-0.002 to 0.005

Table 64: Association of Mental Health Score with Demographic Variables (One at a Time), Using Fixed Effects

Variable	Coefficient	Standard Error	Z	P	95% CI
Gender	0.303	0.528	0.57	0.566	-0.732–1.338
Age	0.036	0.028	1.30	0.195	-0.019–0.091
Education	0.378	0.293	1.29	0.197	-0.196–0.952
Wealth	0.178	0.249	0.71	0.475	-0.311–0.667
CD4 count	-0.000	0.001	-0.07	0.948	-0.003–0.003

Table 65: Multi-level Mixed-Effects Models of Physical Health Over Time Adjusting for Individual Care Received

		No Treatment			TB Treatment			ART		
		coeff	se	p	coeff	se	p	coeff	se	p
Time-invariant	Intercept	22.285	2.089	<0.001	23.433	2.175	<0.001	23.789	2.138	<0.001
	Physical health score at T0	0.458	0.035	<0.001	0.438	0.035	<0.001	0.452	0.035	<0.001
	CD4 at T1	0.001	0.002	0.459	0.001	0.002	0.546	0.000	0.002	0.875
Time-varying	ART	–	–	–	–	–	–	-1.783	0.795	0.025
	TB treatment	–	–	–	-3.117	1.251	0.013	–	–	–
	Time	2.566	0.248	<0.001	2.563	0.249	<0.001	2.606	0.248	<0.001
		var	se		var	se		var	se	
Random	Between facilities	10.755	7.538		12.279	8.501		8.954	6.463	
	Between individuals	1.973	0.902		1.885	0.890		2.014	0.903	
	Time slope	28.744	4.432		27.304	4.359		28.959	4.447	
	Residual	39.110	2.301		39.552	2.330		38.795	2.285	

lower than a person with the same CD4 count who was not on ART would expect. As ART increases CD4 count, a person with the equivalent CD4 count who was pre-ART would be in an earlier stage of disease. CD4 count predicted baseline physical health but was not associated with change over time in any of the models(p=0.459, p=0.546, p=0.875).

Mental health (Table 66) was associated with receipt of ART. A person who had received ART in the previous month scored on average two points lower than someone who had not (coefficient = -2.044, p=0.003). However, there was no association between mental health and TB treatment (p=0.416). As with physical health, CD4 count showed no association with change in mental health over time.

6.7—Care Availability

Each of the eight care themes was included in a multi-level model to identify which ones were associated with mental or physical health over time. These models also included T0 physical health score, T0 medical health score and time. The models for physical health included wealth quintile and education level because these had been found significant in univariate analysis. No demographic covariates were included in the mental health models because none of them had achieved significance at the 10% level in univariate analysis. Mental health was not associated with any care themes at the 10% significance level (Table 68). Physical health was associated with three care themes: pain management, symptom management, and nutrition (Table 67).

Table 66: Multi-level Mixed-Effects Models of Mental Health Over Time Adjusting for Individual Care Received

		No treatment			TB treatment			ART		
		coeff	**se**	**p**	**coeff**	**se**	**p**	**coeff**	**se**	**p**
Time-invariant	Intercept	28.208	2.032	<0.001	28.549	2.078	<0.001	30.514	2.114	<0.001
	Mental health score at T0	0.376	0.037	<0.001	0.370	0.037	<0.001	0.374	0.037	<0.001
	CD4 at T1	-0.000	0.001	0.948	-0.001	0.001	0.903	-0.001	0.001	0.391
Time-varying	ART	–	–	–	–	–	–	-2.044	0.682	0.003
	TB treatment	–	–	–	-0.880	1.083	0.416	–	–	–
	Time	2.245	0.217	<0.001	2.244	0.037	<0.001	2.290	0.218	<0.001
		var	**se**		**var**	**se**		**var**	**se**	
Random	Between facilities	7.243	5.142		7.544	5.342		6.246	4.525	
	Between individuals	1.518	0.680		1.506	0.679		1.643	0.684	
	Time slope	20.226	3.327		19.954	3.332		19.688	3.305	
	Residual	30.087	1.765		30.224	1.779		29.766	1.746	

Table 67: Mixed-Effects Model of Physical Health Score Over Time with Personal and Care Variables

Care group	Coefficient	Standard Error	Z	P
Spiritual	-0.032	0.037	-0.86	0.388
Counselling and advice	-0.137	0.119	-1.16	0.248
Nursing	-0.038	0.023	-1.62	0.105
Pain management	-0.099	0.034	-2.90	0.004
Symptom management	-0.110	0.041	-2.65	0.008
Nutrition	-0.177	0.051	-3.44	0.001
Social	-0.004	0.035	-0.11	0.915
Prevention	-0.119	0.088	-1.36	0.174

Table 68: Mixed-Effects Model of Mental Health Score Over Time with Personal and Care Variables

Care Group	Coefficient	Standard Error	Z	P
Spiritual	0.021	0.037	0.58	0.560
Counselling and advice	0.067	0.127	0.53	0.597
Nursing	-0.013	0.028	-0.46	0.648
Pain management	-0.023	0.056	-0.41	0.684
Symptom management	-0.032	0.063	-0.52	0.606
Nutrition	-0.061	0.092	-0.67	0.504
Social	-0.004	0.034	-0.15	0.883
Prevention	0.023	0.101	0.23	0.817

6.8—Multivariate Modelling

Mental health was not taken further as an outcome variable because it was not found to be associated with any care theme in univariate analysis. The three care themes with which physical health score was associated at the 10% level (pain management, symptom management and nutrition), with the two demographic variables (relative wealth and education) were included in a multivariate model. This is designated Model A in Table 69. The increased number of variables made these models less stable and the Davidon-Fletcher-Powell algorithm was iterated as the default algorithm failed to converge. The change of algorithm would have had no effect on the results and is mentioned only to allow replication of the results.

Pain management, education and relative wealth dropped out of Model A as they were nonsignificant at the 5% level. Nutrition and symptom management remained significant; however, symptom management, which had been negatively associated with physical health when analysed alone, was now positively associated. This change of direction indicates instability of

Table 69: Multi-level Mixed-Effects Models for Physical Health Over Time

	Model A			Model B			Model C		
Fixed effects	**coeff**	**se**	**p**	**coeff**	**se**	**p**	**coeff**	**se**	**p**
Time	2.165	0.201	<0.001	2.167	0.201	<0.001	2.168	0.201	<0.001
Physical health at T0	0.390	0.031	<0.001	0.390	0.031	<0.001	0.390	0.031	<0.001
Mental health at T0	0.118	0.037	0.001	0.125	0.037	0.001	0.125	0.037	0.001
Nutrition	-0.899	0.266	0.001	-0.673	0.267	0.012	-0.212	0.054	<0.001
Symptom control	0.286	0.116	0.014	0.314	0.179	0.080	-	-	-
Pain control	0.182	0.110	0.098	-	-	-	-	-	-
Relative wealth	0.312	0.274	0.256	-	-	-	-	-	-
Education	0.612	0.342	0.073	-	-	-	-	-	-
Random effects	**var**	**se**		**var**	**se**		**var**	**se**	
Facility	0.013	0.466		0.727	0.985		1.343	1.294	
Individual—time slope	1.239	0.671		1.265	0.676		1.219	0.673	
Individual	25.767	3.311		25.846	3.319		25.956	3.323	
Residual	42.467	1.944		42.423	1.943		42.479	1.943	

the coefficient, suggesting that the presence of nutrition in the model drives the symptom management covariate to behave in the opposite direction to that which it normally would.

The next stepwise downward model (Model B) included only symptom management and nutrition. Symptom management was nonsignificant (p=0.08) leaving a final Model C in which increased physical health was apparently associated with passing time, a higher value of physical health at T0, and reduced availability of nutrition care. The three models are shown and interpreted below.

Table 69 shows the final three models of physical health and care. The fixed effects portion of the results can be read as ordinary linear regression results. All fixed effects were time-invariant. The random effects consist of ways to divide the remaining variance in the model into variance between facilities (0.013 for Model A), variance between individuals (25.767), variance in the slope of the time coefficient (1.239), and the remainder which cannot be explained at any level (42.467). The residual was large, meaning that the model did not successfully explain a great deal of variation. Most of the variance was between individuals rather than between facilities. The best way to explain the way physical health changes over time was to allow the effect of time to vary for each individual, with a variance in the slopes of 1.239. When time was modelled as a fixed effect, the mean slope was used to give a coefficient of 2.165.

As the downwards stepwise regression reduced the number of covariates, variance between facilities increased. This variance had previously contributed to the pain and symptom coefficients which required facility-level variation to fit the model. The removal of pain and symptom control reduced the effect of nutrition, as seen by the change in coefficient from -0.899 in Model A to -0.212 in Model C. In the final Model C, all covariates were significantly associated with the outcome. As Table 69 shows, in the final model, physical healthw as predicted to increase by 2.7 at each timepoint, was slightly increased if baseline scores for mental and physical; health were good, but was slightly reduced if the facility-level probability of nutrition care was high.

6.9—Further Exploration of Multivariate Modelling

Two unexpected findings in the multivariate model were addressed through further analysis. The first of these was the fact that higher levels of nutrition care seemed to be associated with a lessened improvement in physical health over time. The second was the way that the coefficients for pain control and symptom management changed sign, from negative to positive.

6.9.1—Negative Association Between Care and Outcome

The apparent association between nutrition and physical health was explored using graphs. The multilevel model appeared to show that participants at facilities which offered nutritional care to the majority of participants experienced less physical health improvement over time.

Figure 31 shows the mean physical health score for each facility at each timepoint, with 95% confidence intervals, plotted against the proportion of facility participants to receive nutrition care between T0 and T3. There is a negative trend associating physical health score and nutrition care. Facilities which offered nutrition care to a higher proportion of their participants tended to have a low mean physical health score at baseline and over time. As a result, the analysis appeared to show that nutrition reduced physical health scores. In reality, low health scores at baseline limited improvement and also made high nutrition care more likely.

Figure 32 shows the increase in mean physical health score (from mean score at T0) for each facility at each timepoint, with 95% confidence intervals. Facilities are positioned along the x axis according to the proportion of their participants receiving nutrition care at any time between T0 and T3. The difference between Figure 31 and Figure 30 is that baseline physical health score has been removed, allowing a direct comparison between gain in health score and nutrition care. There does not appear to be a relationship between receipt of nutrition and improvement in physical health score.

6.9.2—Instability

When analysed alone, symptom management and pain control were negatively associated with physical health score; at facilities where few participants received pain control or symptom management, the improvement in physical health over time was higher (Table 67). When

Figure 31: Mean Facility Physical Health Score Over Time, by Proportion of Participants Receiving Nutrition Care

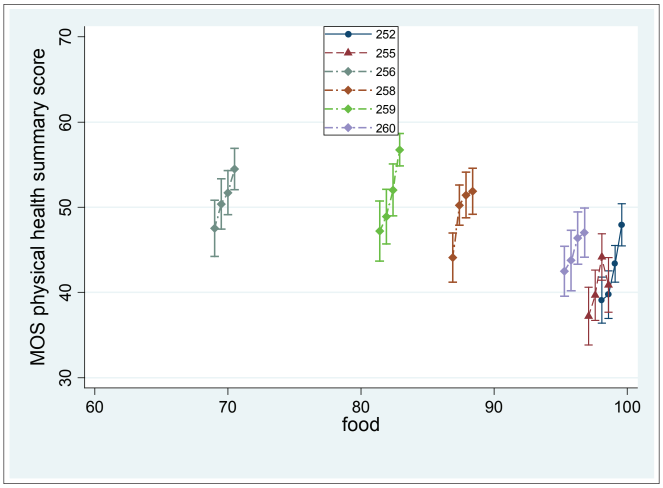


Figure 32: Increase in Mean Facility Physical Health Score Over Time, by Proportion of Participants Receiving Nutrition Care

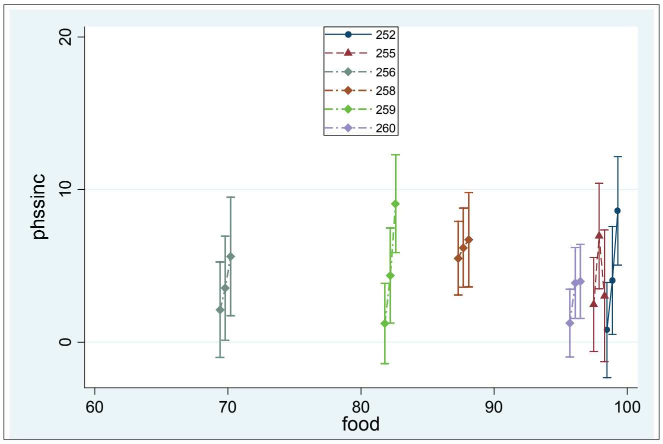


Table 70: Percent of Facility Participants Receiving Nutrition and Symptom Management Care Between T0 and T3 (order)

Facility	Nutrition	Symptom Management
252	98.1 (first)	96.3 (second)
255	97.1 (second)	97.1 (first)
256	69.0 (sixth)	53.1 (sixth)
258	86.9 (fourth)	86.0 (fourth)
259	81.4 (fifth)	73.5 (fifth)
260	95.3 (third)	90.7 (third)

included in a multivariate model with nutrition, these two care themes switched signs and became positively associated with the outcome (Table 69). Both relationships were statistically significant but little importance could be attached to this since they were clearly unstable

The values of nutrition and symptom management were tabulated by facility (Table 70), showing that the two variables were closely associated. The rank order of each was almost identical, except that two of the facilities exchanged first and second place. The effect of nutrition in the model was to drive the symptom management variable to explain this reversal of direction, because any possible negative association between symptom management and health, as suggested by the univariate analysis, would already have been absorbed by the nutrition variable which so closely matched it. The same applied to the pain control care theme.

This high level of collinearity between three care themes also meant that all three were negatively associated with physical health score at baseline, as shown for nutrition in Figure 30. It appears that the facilities where participants had the worst physical health at baseline were the ones most likely to provide nutrition, pain control and symptom management to their patients. As a result, each of these care themes appeared to predict worse outcomes. When they were put together in a model, the three worked against each other and gave rise to unstable results.

7 Results of Qualitative Interviews

The coding frame used to code the qualitative interviews is presented below. Italicised phrases are examples and explanations of the codes. This frame was derived from two independently developed frames, one in Uganda and one in the UK, which are presented in Appendix K. Patient, carer and staff interviews were all coded using the same frame.

7.1—Agreed Coding Frame

- Unmet needs—*not what is provided, but what is self-identified as needed*
  - staff
  - carer
  - patient
    - social/financial
      - food
    - clinical (*e.g., CD4, pain, skin rash, diarrhoea*)
    - emotional/psychological (*e.g., stigma, worry, bereavement, anxiety, desire for child*)
    - preventive (*e.g., ITNs, safe water, condoms*)

- Components of care provided—*what facilities say they actually do and what patients say they got*
  - bereavement/care of dying
  - carers
  - spiritual
  - socio-economic
  - psychological and emotional (*e.g., information, advice*)
  - clinical *(e.g., VCT, RCT,ART, curative, lab services*)
    - adherence counselling
  - preventive (*e.g., ITNs, CTX [Septrin], condoms, water*)

- Experiences of delivering and receiving—*care staff, patient, and carer views*
  - experiences of receiving care—*patient and carer only*
    - positive
    - negative
  - facility strengths and challenges
    - strengths
      - best practice and lessons learned
    - challenges
  - suggestions for improvement

- Multiple identities: patient, staff and carer roles—*description of how patients perform multiple patient, staff and carer roles*

- Access to care—*factors associated with starting care and choice of facility*
  - health seeking behaviour—*reason for initiating care*
  - process of choosing facility—*including being given referral letter*
  - eligibility criteria
  - retention/shopping around
  - costs to patient

- Clinical standards—*care processes and protocols*
  - process of enrollment
  - frequency of contact
  - monitoring and documentation
  - referral mechanisms and reasons
  - education and training of staff
  - supervision of staff

The data are presented by each category in turn as presented in the coding frame, and then the broad themes are reviewed and integrated. Each data theme is illustrated using a direct quote from the transcripts and the anonymous identification for each respondent is given. The inclusion of identification numbers demonstrates the selection of data from across the sample. The number represents the facility ID, and P=patient interview, S=Staff interview and C=family carer interview.

7.2—Description of Sample

The sample consisted of 41 patients, 29 staff members and 21 carers. Each facility hosted seven patient interviews (except for Facility 255 where there were six) and five staff interviews (except for Facility 259 where there were four). Carer interviews ranged from one at Facility 256 to five at Facilities 255 and 258. The sample of patients was 51% male (n=21), aged from 18 to 61 with a median of 37.

The majority (68%, n=28) were receiving ART and the mean household size was 4.7. Two thirds of carers (n=14) were female. Carer self-reported relationship to patients consisted of one mother, one sister, four brothers, four daughters, six wives, one husband, one aunt and three friends. The brothers and sister all specified that they were younger than their patient. Carers were aged 18–52 (median 27) and were more likely than patients to live in rural areas.

Staff represented many disciplines and consisted of seven counsellors, five clinical officers, five nurses, three nurse counsellors, two doctors, two medical officers and five other grades. The median time they had worked at the facility was four years, ranging from two months to 24 years.

7.3—Unmet Needs

The data category of unmet needs demonstrate that patients and families reported having multidimensional needs across domains. Further, the clinical staff identified their own professional needs to enhance care.

7.3.1—Staff Needs

A wide range of professional needs to be able to perform their roles were described. Firstly, staff had a number of training and education needs that were broadly non-clinical and managerial by nature, encompassing administration, management and IT:

> "I have some basic but I think I need more training and skills in computer I would like to go for further training."—S001 259

> "Of course I would like to have, as a project coordinator I would like to know some issues in administration. In fact in management basically like Health Management related course."—S003 252

Second, the clinical management of paediatric HIV patients was identified as a staff need:

> "I would like to get training in Pediatric HIV counseling."—S001 252

> "As we were going through the interview I was just thinking about the children, yes we offer some care for children but I would really want to be something better and I want it to be in the minds of every one that we have children and many are getting affected and infected so a lot should be put towards their care and support. There are many child headed home and we are doing much about all this. They are a quiet but crying group." —S001 260

Third, general clinical updates were identified, including ART and palliative care, to keep clinical skills up to date:

> "I think still trainings towards drug resistance and also on the third and fourth line dugs which are coming. I would like to have that because that is were we are moving because we have had second line and there are patients who are failing on second line and the third line drug is not out open in the market, but soon it might be out there and to us but I would like to have training in that"—S001 259

> "I think it would be good to get oral morphine for pain management because we get certain patients in severe pain and all we have is codeine phosphate."—S001 260

> "I also want to have a course in Palliative care because patients who come here are very sick (terminally ill) and they need to be supported in that area."—S002 259

Fourth, training needs were described in general psychosocial care and in relationship counselling:

> "Then may be an in-depth training in counseling as a health worker you can't keep on referring patients to a counselor. There at times when you need also to counsel them and I have the basic skills like peer counseling of course like before you graduate at University they teach you about peer counseling but that is not enough because I would like to get in-depth training in counseling in HIV."—S003 252

> "Ya mainly in spiritual and social care, I feel we handicapped because they are not institutionalised and you cannot do it as a person. You need the institution to strengthen those components."—S004 260

Fifth, staff were keen to be able to engage meaningfully in research within their facility, to be able to collaborate with overseas research partners and to lead research locally:

> "I would also like to get more training in research methodologies."—S001 259

> "Now that I have spent all these years in a research facility, I think I want very much to continue with research, I have been attached to different studies as a research nurse so I don't want to deviate a way from research but however as a nurse I would like also to do clinical management on the ward, handle patients and I can do counseling."—S002 259

7.3.2—Family/Carer Needs

Family carer needs focused mainly on the socioeconomic problems of feeding and caring for the patient and enabling them to attend clinical care, and on the psychological challenges of being a carer:

> "Since the patient who is my husband has been the bread winner and now he is bed ridden, that is my biggest problem. I don't have money to take care of the patient, I was told to give him a good diet but I cannot afford. At times the food I have potatoes and beans he does not want to take it so I find it a very big problem."—C004 255

Family poverty was compounded by caring for the HIV positive family member, and basic resources to provide home care are limited:

> "The problem I am seeing is that we as care givers some times we don't have any thing when we visit these people and we just move bear handed and when you get there you find the condition of the patient is not good and you can not leave him without giving him anything like money."—C001 252

> "Since he became ill he no longer works although he gets the salary it is not enough. We have many children, mine are two and his are about seven so the challenge I have is school fees and the feeding. Even transport to the facility, because of his condition we need fuel to go the facility because we must use a vehicle. I do not have enough money to feed him so I usually struggle so much, inside my heart I feel he is not feeding properly because I cannot afford the food , I do not have enough money."—C001 255

There could also be health costs to caring, such as the strain of queuing for hours at the health facility:

> "Whenever I go there I over stand waiting for the drugs and end up feeling a headache and some backache pain."—C002 255

The needs of family caregivers were rarely discussed with clinic staff:

> Respondent: "No, we don't normally share with this [emotional and psychological problems] . . . For me as care giver I have never shared such with the health workers here."
> Interviewer: "Yes, tell more, what do you talk about with a health care worker about your finances well being?"
> Respondent: "No we don't discuss this with the health care . . . surely for me, I have never."—C001 259

It is important to note that for ambulatory patients, clinic staff may rarely come into contact with patients' families:

> "We don't see the families. May be if they have come with their families at the very first day of coming for treatment or testing for HIV, that's the only day we can see their families—if that patient has come with a family member but we never see them again. On return they always come back alone."—S004 256

7.3.3—Patient Needs

The multidimensional needs of patients spanned the social/financial (especially food), the clinical/medical, the emotional/psychological and preventive areas.

The ability to attend and benefit from a clinic is challenged by poverty even if the patient is able to pay for transport to attend:

> "I am not okay with the services, we have three clients in the family and we have so many problems including food, money for transport, that is a problem . . . You find a family where all members are infected and they are too poor and they need help. They also need more of home visits because you cannot take all family members to the centre to receive care it is very expensive and such families have unique problems and challenges so it is good for health care workers to come right to the home, assess the situation and help accordingly."—C005 255

> "At times you cannot afford transport costs to come for treatment. And again with these drugs we take, one must feed well and because you cannot really work hard enough because of compromised health at times even getting this food is a big problem. So you may have to stop the drugs because they really raise your appetite. Those are the major challenges."—P001 259

Money spent getting to a care facility means that there was less money available for food once admitted and waiting, and access to ART means that food may be more acutely needed:

> "When we come to hospital, they should help us with food, sometimes patients are badly off in terms of food, you can really feel it if you have starved for two days. If they can give us some posho at least because after spending on transport you cannot again spend on food . . . No I just want to re-affirm that we need food support if possible these drugs are strong and if you take with out food you feel sick and uncomfortable."—P001 260

> "Much as we give our patients the medicine, but having to take the medicine goes beyond having the medicine at home. If I don't have food, I will not take the medicine."—S004 258

The most commonly reported patient physical problems were pain and other symptoms, which can prevent access to healthcare:

> "Sometimes she has this severe pain in her right leg and some times she applies medicines and it stops but it is recurrent. May be after a month or two weeks or even after a week. Like now she is experiencing the pain and that's why she is not able to walk up here with me and that is why I am here to collect her drugs from this clinic."—C001 259

> "Yes, like the ARVs at times cause me stomach pains and pains in the legs and at times severe headache and rotational dizziness and I feel as if I lose balance and focus. Even now I have a problem with my sight and there is away the skin itches particularly in my face and in the chest and not all body parts and I usually report these symptoms and I am prescribed a few tubes and ointments."—P003 259

> "She has been falling sick often, time and again she is down with malaria, fever, diarrhoea and general body pain and these days she gets severe pain in the bones and this pain has limited her from doing any other work. There is a lot of pain in the joints, she feels these are the problems she has being HIV positive client and these never used to have them before."
> —C004 252

Cognitive problems were also reported and could hamper treatment:

> "What is almost disturbing me is my chest pain. This one is always disturbing me and now let us say this month, the last two weeks I have also been forgetful. In fact I am beginning to forget some things a lot like I forgot where I had put my keys and some times I have forgotten the time to take my drugs but the children I have at home they tell me Baba, have you taken your drugs and even that's why I look like this."—P004 252

Patients recognised that while their medical care was highly valued, there are other equally necessary areas of care:

> "Fine they give us the drugs but again there is that other side for instance when your husband gets to know that you are positive he runs away leaving you at home with the children who in turn will need food."—C003 258

Emotional and psychological problems were caused both by the experience of living with the diagnosis of HIV and by the financial worries experienced as a result of it:

> "Any way, my biggest worry is about my future. I have no child and my dreams are shuttered down and it hurts lots. It is an inner most pain which I can't explain to anybody."—P003 259

> "Some of us we are over burden with children at school, nothing to eat and the Umeme people (Electricity bill) are there, so when you go to bed you don't sleep and sometimes I don't sleep at night and that is the problem I have and I know that it is because of what I think about."—P006 259

However, emotional issues were often not addressed, even in counselling:

> "The first day I came here, counsellor told me that I have to always use condoms. That's the only thing I was told . . . I have never gone back to the counsellor. Besides the counsellor knows nothing about my feeling lonely actually no one knows anything of that sort. On my side, I receive every thing that I need but I am not happy."—P001 258

HIV-related stigma from family members, friends and the wider community was often a cause of emotional distress:

> "There is stress and stigma, you find this in the community like our neighbours peep at us to see they say there is no family there they are all going to die so we have that stigma."—C005 255

> "One neighbour commented recently, 'I am surprised this lame woman contracted HIV, do they also engage in sex? It is funny.' Others keep reckoning that one has a danger notice she is a moving grave."—P001 259

> "Some of the people laugh at people who are HIV positive, you can see that they have not tested but they talk about you that you are sick that thing can is something which bring a lot of fear in us, seeing people pointing at you that you are HIV Positive. Some people are not taking us well, not all of them but some do it."—P005 260

> "During those days when they confirmed that I was HIV positive, I lost all my friends and even some of my relatives started ignoring me, even some other friends of mine started abandoned me."—P006 252

This community stigma leads to isolation:

> "So I tend to solve them on my own because one thing I know is that if I over expose my self to people that I have AIDS it will bring me more problems than trying to solve this problem before it gets bad."—P002 259

The burden of knowledge on friends also discouraged patients from disclosing:

> "Yes sir, because the problems I have stem from psychological wellbeing and thoughts because you don't relate well with others because its like If you tell some one that you are positive that persons starts to react in a funny way. Like it has now become difficult now to disclose to some one because even that person you disclose tends to become closed to himself."—P003 259

Psychological problems prevented patients from accessing clinical care:

> "Usually you find that these patients have withdrawn away from the community and their close people. They just stay alone and give up and lose hope in life and also feel that they have already gone to the end of life. They have a thinking that AIDS has marked the end of their life and because of this negative thinking towards life usually they don't come for medication. Some feel that they are useless."—C002 252

In terms of preventive care, patients and families in Uganda described a need for the skills of managing safer sex within relationships (rather than the provision of condoms alone):

> "The health worker had a discussion with me and told me that since my husband and I are positive we should never have sex without using a condom because we may be infected with other sexually transmitted diseases and that won't be good as well. But when I reached home I told my husband what the health worker had told me but my husband refused that I am his wife therefore he cannot use a condom. And because of the husbands set laws, I am in his house and cannot run away so we don't use condoms though we don't regularly meet."—C001 260

7.4—Components of Care Provided

When staff, patients and families were asked about the care they have specifically delivered and received, prompts were given for the multidimensional possible areas of care.

7.4.1—Bereavement Care and Care of the Dying

> "Under bereavement counseling, we tell them that you know every thing has a beginning and every thing has an end. So, one time one day one has to die when things become worse but before things become worse off we have to prepare our selves ready to receive what ever may come our away. So here also spiritual counseling comes in one has to get ready and family members have to know that things will come to an end one day because with HIV it has no cure, so one time one can die, so if one has to die are we ready to accept what will happen? If we have lost one today what have we prepared ready? Are we ready to support the family members, may be the children or if it's the father are we able to support the family or children who will be left or wife? So we have to prepare and be ready to accept what ever case may come We also make if possible if he is still able to make a will such that it will help the family members who are around."—S001 252

The availability of centres locally to refer for provision of specialist palliative care is essential:

> "For the terminally ill patients, say patients who have a difficult condition in stage IV probably Lymphoma we take them to the cancer institute and from the cancer institute some are sent to HOSPICE Africa Uganda for joint management, both cancer therapy, ARVs from [facility] as well Hospice treatment and care."—S001 259

The need for specialist training to provide holistic palliative care within the facility was recognised:

> "We need to be close to them and that's why the hospital discovered that there is need to train some other counselors to have the component of spiritual counseling."—S002 252

For those adequately skilled staff, an appropriate psychological and spiritual care response was described:

> "When we know that the patient has no chances of improving we contact the relatives and prepare them psychologically because some of us have had special training in hospice, they taught us how to handle them and prepare them for eventualities, and by the time the patient reaches the time of dying they are already prepared psychologically they know this patent may have to die and some of them we assist them to write wills or show us their next of kin can be approached and assisted in a special way. In that way I think by the time a patient dies they are prepared enough to handle the situation."—S002 259

It was also suggested that the need for spiritual care at the end of life was culturally evident:

> "We are Africans and we know even from our homes we know someone who is very sick you can do what we call spiritual care assessment, if the person is very sick and people at home are saying ha that one we don't have any hope they have lost hope so we bring in the spiritual care and the usual counselling. The drugs are no longer working and they are saying this one will not even reach tomorrow then that is the time you say at least me go with a reverend because for me I don't know how to pray."—S005 255

However, good terminal care is more than emotional support, and the need for additional components of palliative care was expressed:

> "There is nothing much but when I get to know in time and I have time and I am able at time when we are doing the home visiting I go there and feel sorry for the family but there is nothing much that we offer. Except that psycho social support some bit of counselling being there with the family members."—S003 255

For care of the dying, a significant barrier was the lack of availability of home-based care:

> "We advise the care takers to take them back home and in the past we would provide those home visits- caring for them at home, home based care and palliative care but the funding for home based care was cut so, we no longer have active home based care and when we use the community groups to visit those ill patients we also go."—S003 252

> "Here at [place] if we have a patient dying around here we transport the body, we have ambulances, we help transport the body probably to their homes and of course we console the next of kin and then we end it there. If the patient is at home we cannot do much because we don't have much contact."—S003 259

Bereavement care was rarely mentioned:

> "Bereavement care, it is very important very few provide it, I think I have given it two times since I have been here."—S003 260

In summary, end of life care focused on preparedness and emotional support rather than comprehensive palliative and terminal care.

7.4.2—Family Carers

The focus on carers within clinical time was challenged by lack of contact, although there were good examples of family-based care. The family carer was sometimes treated as part of the unit of care. This was confirmed by family carers:

> "They normally ask me about the problems I am experiencing during provision of care to my patient. And for our problems; also we should come to them and tell them what we are facing/where we are challenged so that they get to know how to assist us."—C001 252

> Respondent: "Basically, what we discuss about with this health worker is about this brother of mine; how he is feeling and how we are caring about him."
> Interviewer: "Do they ever ask you any problems that you have as a carer?"
> Respondent: "They do. . . The problems at home such as; if you have any financial problem, any extended family problem, financial problem etc."
> —C003 259

Carers wanted help to be able to give psychological support to their patients and to manage emotional stress:

> "They should get more counsellors and those counsellors should be capable of talking to the care takers and tell them how to their patients. For

> instance you might be having a patient and you are always barking at her, yet she is sick. You know how people stigmatize others like asking questions like who sent her there. I wasn't with you when you were getting the virus? etc that's bad because a patient will get a bad heart and can do any thing so they should talk to the care takers and tell them what they have to do to support their patients and that's what I really want."—C002 259

The lack of off-site provision was a challenge:

> "Occasionally we get into contact with the patient's family but that is mostly when the family member comes with the patient. We do not have a very well established outreach department where it would involve us going to the patient's home. But mostly when the patient comes with a family member we are able to get in touch. okay, we give the family information about the patient's illness and we also encourage them to test as well and we also counsel them together."—S001 260

As were the financial and opportunity costs to carers of getting to the facility:

> Interviewer: "Do you involve families in your services?"
> Respondent: "We are trying our best it's been such a challenge given the socio economic factors of the patients that come in, like I don't know whether it happens in other HIV clinics."—S004 258

> "Wherever I go there I dont get time to talk to the health worker only who writes for me septrines I get them and then rush back home because I am usually on a hurry and I have left children alone at home, the business so I don't usually talk to the counsellor."—C002 255

Sometimes the facility required a family carer/guardian to be identified by the patient:

> "For the TB people we encourage them to have someone they trust or someone that can help them take their treatment. If like someone is on treatment, the TB treatment, we ask for another contact person in case they are not able to come, in case they have a problem and they are not able to pick the drugs, or someone to remind them take their drugs. So if they are able to come with that person in the clinic we encourage them to do it, if they are not able, we tell them to at least give us the number of that person who is in charge of them."—S005 256

> "At the initial stage we emphasize at least one member of the family or closest member of kin has to be there. Actually that is one of the criteria and if you don't have a close member of the family as a supporter you are not started on treatment so that the person when the patient fails on adherence issues and can give an independent report on the client if the person is responding well or taking the drug properly."—S005 252

7.4.3—Spiritual Care

Spiritual wellbeing and support are important components of the patient disease experience. The awareness of spiritual care needs sometimes formed part of the ongoing contact assessment:

> "Any way they normally ask whether these people (spiritual leaders-priests and pastors) from church ever come to visit me at home to share spiritual needs."—P001 252

As well as providing support and meeting patients needs for spiritual wellbeing, religious observance is also instructed as part of clinical advice, and this was confirmed by staff and patients:

> "Yeah, they talk about it and like me mostly we talk about issues related to God and first we pray and we tell them that they should also pray because any thing in this world can happen but not for his or her need but it's a God given gift and when you are like that first you should know that God exists and secondly the other things also follow."—C001 252

Interestingly, training also incorporated instruction for family carers on how to meet spiritual care needs so that it is not a professional responsibility when patients are not at clinic, and that spiritual care providers would attend patients when they are attending facilities for care:

> "I am busy most of the time and those sessions are usually held during working days. For example she told me that we have to keep him in a clean environment to reduce on infections. The patient needs love, he should sleep under a mosquito bed net, he should take clean and boiled water, he should be given comfort and spiritual guidance. The spiritual leaders come with a message of love, faithfulness in relationship and they encourage us to ask God to give us courage and strength so Tuesdays afternoon they come here and pray with us."—C001 255

A key message is that while religious attendance is essential to wellbeing and should be observed, it should exist alongside adherence to medical intervention:

> "They health workers told us that we should pray to God as well as taking drugs because God cannot work alone but work hand in hand."—C001 260

Sexual fidelity, preventing HIV reinfection or transmission, was a spiritual issue:

> Interviewer: "What do you discuss with the health workers about spiritual care?"
> Respondent: "To be faithful with their partners that's the most important thing and to be faithful means that you know God. A person being faithful that means he loves his God and has the spiritual care."—P004 260

Encouraging fellowship was also seen as a means to facilitate community and social participation and interaction:

> "Yes, it is one the things they talk about. Like how to maintain a personal relationship with God. They tell us that when we are at home we have to love one another and also interact well with neighbours and attend mass at church and be part of fellowship."—P003 252

However, not all patients across facilities had experience of spirituality being a component of their care received:

> Interviewer: "Do the health care workers talk to you about things to do with your spirituality?"
> Respondent: "No I have never heard of it here."—P006 259

> Interviewer: "Tell me frankly do they ask you anything about your spirituality?"
> Respondent: "About spiritual care I have to boldly say no because I have not heard of any spiritual care here. Personally I don't know."—P007 259

7.4.4—Socio-economic Care

There were excellent examples given of social care being an integral component of the multidimensional care given:

> "First of all, he comes for treatment and secondly he comes for counselling in case of something and thirdly when there is food distribution because he is one of the beneficiaries."—C001 252

> "They offer her transport in form of cash to facilitate her when coming back for the next appointment date. They ask her the progress, whether she has improved with her condition or not. You know talking to a sick person is good as they need to find out how the patient is feeling and what is really bothering her. So that is one of the good things they do for her. They talk to her in privacy for confidentiality."—C002 259

> "They normally say that clients should be able to know clearly their financial status because when they don't know their financial status they may be able to demand what they can't afford or what they care taker can't afford."—C003 252

This comprehensive care approach was well described as a complement to ART access:

> "Apart from ARVs, they normally give me transport refund and some assistance like some money, sugar and floor. . . The hospital helps a lot like in a month for instance gives us food stuffs like beans and posho and they also help to monitor the drug toxicity and any other drug side effects that may occur."—P003 252

There were also examples of the absence of integrated care:

> "The challenge I have seen is I think is about nutrition they don't have food someone is the bread winner but he is the one who is sick, the children when they see you riding a motor bicycle they expect may be you have something to give them but we don't give. They see someone coming we just take drugs but on their faces you see something like they are expecting something from you." —S005 255

In addition to social assistance, counselling and guidance on how to generate income, budget, and meet needs was given:

> "They usually come and tell us to budget well for our income so that we can sustain ourselves. We are told not to waste our money in expensive things which do not help us. We are also encouraged to socialise with other people so even if we are positive, this should not stop us from socialising with other people, we should isolate our selves and there are many other people living with this virus of HIV."—C001 255

> "About the social aspect they say that. . . and the financial issues they ask about how I use my salary over the month like how I utilise the 93,000 I earn on a monthly basis."—P001 252

> "There was a seminar where they brought somebody who taught us how to make soap. I think they also bring people who can teach us to some income generating activities."—P005 259

> "They encourage us to raise small amounts of money to rear chicks or pigs or even goats , you may then get some help sometimes."—P007 255

7.4.5—Psychological and Emotional Care

Along with medical treatment and social support, emotional support was seen as an integral component of holistic care:

> "First of all, he comes for treatment and secondly he comes for counselling in case of something and thirdly when there is food distribution because he is one of the beneficiaries."—C001 252

Some very tangible outcomes attributed to emotional support and counselling were described:

> "The problem that I had before sharing with the health worker was that the children used to disturb me a lot and as a result I would beat them saying that after all I am going to die [laughter] but after the health worker educating me on what to do, It's no longer a problem but that was my problem. Whenever I could see them, I would get angry that I would even start thinking that maybe they are also infected and beat them the more but now I am okay. But the only thing that I am told whenever I come is to be strong and have confidence. I was told to leave to relax and leave the children alone basically I am always told constructive things which help me to remain strong."—C003 258

> Interviewer: "You said you had a problem with stigma, how did the facility help you to solve the stigma issue?"
> Respondent: "Through the counsellors I was counselled and I have tried to adhere to what they tell me to do I am now coping. They also say that if I have a problem I should express it to them. And I am fine its ok not to discuss."—P001 252

> "They help us to remain strong in the mind so you think, despite all this I still have a life to protect to live longer. For instance I had despaired lost hope and I even wanted to take poison and commit suicide because I felt were not fitting in society but when I shared it with the counsellor she told me that I am not alone neither the first nor the last to have HIV and that I had no authority to take it away."—P003 258

Significant emotional support was gained through being part of a larger community of HIV-positive people attending the facility:

> "Maybe I will say that they give us a good environment. When you come here you find so many other HIV positive people and this consoles you. You will appreciate that you are not alone, and you gain the courage. We also share experiences, challenges and how to deal with them so I find this very very helpful."—P001 259

This encouragement to access support beyond facility staff included spiritual community, the HIV community, and cognitive strategies:

> "So they health care worker will ask you about your worries, if you appear depressed they will ask you what is depressing you and may be give you counselling. They also ask about your relationship with your family, such things. They encourage us to love each other and they encourage us to disclose to each other. We are also told to join support groups so that we can share our problems with colleagues. We are told that you can live happily if you do that. Well I was worried over loan and after reaching the doctor's room I told him that I am having a problem and you know such problems can even cause your CD4 count to drop and you weaken because of over thinking and worry. So they console you and encourage you to contact a spiritual leader to pray for you. You are also encouraged to talk to friends they can help."—P001 260

Carers were also encouraged to provide emotional support and psychological help to patients:

> Interviewer: "What about on issues concerning how you feel and think, do they ever tell you anything?"
> Respondent: "Yes they do talk to us."
> Interviewer: "How should you handle the patients?"
> Respondent: "We have to take good care of our patients so that they avoid worrying. You comfort her; counsel her so that she doesn't worry about anything."—C004 258

7.4.6—Clinical and Medical Care

CD4 monitoring, receipt of ART and CTX are unsurprisingly the core medical care described. In order to enhance access to medicines, community health workers support patients who are too physically frail to access medicines:

> "If my patient is weak, I just bring form V to collect the drugs and I take the drugs to that patient. I always do it to help the patient."—C002 252

Patients frequently described being able to present problems and complications:

> "Of recent she has been coming here frequently because she has been having complications like dizziness, etc. The drugs she was taking at first were resisting her body and she had to come back and switch to another line. She has been coming here because of these complications like dizziness, diarrhoea."—C002 259

However, in one instance a facility encouraged patients to present minor ailments elsewhere:

> "For minor illnesses we are encouraged to go to near by health centres."
> —P002 260

Advice on how to take (and adhere to) medications was also a commonly described aspect of medical care:

> "Like today, she was not feeling very well and she has malaria, so she came today to get medicines. The health care worker tells her how she is supposed to take the medicine, gives her advice on how to do it and all the necessary information she needs to know about the medicines. She should take the medicines the time they tell her, she should take it in the morning after lunch and then at night."—C004 259

The fact that ART was free was of great importance:

> "That time we used to pay some little money for the drugs but some how I failed to raise the money and gave up. So, I started on herbal medicine-the liquid solution and my health deteriorated and I started shivering and when I came back and the doctor realised that had seen me before and said; you woman I think I know you, aren't you one of my clients on ARVs? I said yes and told him the truth that I had absconded because I failed to pay for the drugs. He told me that there is free treatment and I should begin on medication. And that's my story."—P004 259

7.4.7—Preventive Care

The final component of care described was compromised of preventive care activities. All three elements of the ABC strategy were promoted to patients. Zero grazing originally meant being faithful but for the many widowed patients it was effectively abstinence:

> "Zero grazing is number one-that means you don't go in for sexual intercourse, we are told if you are unable then you have to use condoms, I think I have missed one."—P005 258

> "Ever since I came to know that I have HIV, my sex life changed that I no longer play sex. I believe that when I play sex I use a lot energy and I will become weak. But now I am used to that. They even gave us condoms but ever since we tested with my wife, the appetite is no more."—P003 256

Within discussion about prevention of transmission, the concepts of reinfection and resistance were offered:

> "For example she told me that we have to keep him in a clean environment to reduce on infections. The patient needs love, he should sleep under a mosquito bed net, he should take clean and boiled water, he should be given comfort and spiritual guidance . . . They told both of us that since my husband is on ARVS, we should not have un protected sex we should use a condom or else they talk of re-infections, and since he is on drugs if I have unprotected sex I may acquire a virus strain that is resistant to ARVs so when my time comes to us these drugs, the virus can be stubborn and so the drugs may not help me."—C001 255

Basic universal safety precautions and health promoting daily living were taught to patients:

> "Okay, may be like we are not supposed to share any sharp things with her such as needles, razor blades and if she has used them we dispose them off immediately to a secure place which is out of reach for any other person."—C001 259

> "Well, they normally tell us to maintain hygiene at home and they also tell us that when we are home, our environment must be clean, our house must be clean and we have to eat a balanced diet and hot food. They have been teaching us these things I have mentioned above."—P003 253

> "Ya they told me to use condoms and they taught me how to use them. They asked me if I take alcohol, of which I used to take and they advised me if possible I reduce or I abandon it completely. They also asked me if I smoke, good enough since I was born I have never smoked. Again they advised me about eating well. Eating well needs money so with eating well I have not changed because I don't have money. I only eat as I used to eat."—P006 256

And prophylactic medication was provided alongside the Basic Care Package:

> "I get medicines in particular septrin and I was told that they will help me to fight against opportunistic infections."—P001 258

> "We have to sleep under the nets, to take boiled water-not to take this un boiled water. Ya it is just to take boiled water to sleep under the nets." —P004 256

> "Its courage. They give me courage, they tell me how to live positively, and they gave me a kit containing a jerican, mosquito net, water guard, and condoms."—P006 256

Nutritional counselling was not thought to be sufficient:

> "As people living with HIV, they tell us to have good nutrition or feeding but most of us do not money or even land to cultivate and those who have the land do not have power."—P005 255

7.5—Experience of Delivering and Receiving Care

7.5.1—Patient and Carer Experiences of Receiving Care

Positive experiences: 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 emotional support. Patients' most frequent view on their experience of care received was the tangible change on their health since being provided with ART, and their gratefulness for this (particularly free-of-charge medication access):

> "Because of the patient's improvement which I am now seeing, like in the past he could not even do anything like carrying even water to bath, but now days he even carries a five litre jerrican of water to a bath room. And he can also now move around; from home to the trading centre and to the hospital and back. Because at first I used to carry him, I used to bring him for refill and CD4 count tests and then take him back and then I would bring him back for results."—C001 252

> "The good thing I am receiving here is the drugs. They have given me energy and al least I can do some work because by the time before I was taking this ART drug I was weak, so after taking this ART drugs even now I am just from the garden and at least I am trying to do some thing for myself."—P004 252

However, the emotional support and advice received from staff and other patients that complement ART was also valued:

> "Like the treatment I am getting has now improved the quality of my life and because I get treatment only from here and may be the advise from the counsellors."—P001 252

> "We are like a family because of our status. You get to a time when you meet people in similar situations."—P001 256

> "Maybe I will say that they give us a good environment. When you come here you find so many other HIV positive people and this consoles you. You will appreciate that you are not alone, and you gain the courage. We also share experiences, challenges and how to deal with them so I find this very very helpful."—P001 259

A good staff attitude was associated with being welcoming, and an ability for patients to communicate effectively their needs and experiences to clinicians:

> "They do not shout at patients, they are so gentle and calm. The situation here is different you come just once and receive everything and you away very satisfied. They give me ARVs they gave me the right regimen that does not give me problems. I was battling with lack of appetite but that went away I eat very well these days, I worry less because I am healthy most of the time. I lost my child and my husband but I have peace of mind and when I come here at [facility] and my doctor, my nurse treat so well like I explained I really feel peaceful and happy, and I want to thank them so much and it is only God who can reward them, and grant their greatest desires. that is my prayer." P001 259

> "When I come here the health care workers are friendly."—P001 260

> "Well, doctors and nurses are doing very well here because once you go to them with a problem they counsel you and they don't want you to be worried so much all the time."—P001 252

> "Ah, that one I have to be frank. I have never got a problem with the staffs here because I am even happy that even some when they meet you on the road they are so happy to talk to you and they are so open minded and good."—P002 259

Lastly, the provision of socioeconomic support was mentioned as a positive experience of care:

> "The first one is the drugs I am taking and secondly there is some money they give me like transport and I am a beneficiary of the World Food Programme support like beans and maize floor for posho."—P003 252

Negative experiences: Many more positive than negative experiences were reported. The major problem reported was that of delays due to staff shortages in seeing clinic staff, with implications for hunger, ability to earn money/work crops, and frustration:

> "Basically, what I don't see good here is time, either it is some times we spend here too long here like this morning I arrived here close to 9:30 AM and we are approaching mid day I have not got the service yet and basically that one."—P002 259

> "Oh the major problem is delays. We come here in the morning sit and wait, the process takes too long and there are so many people. The other problem is transportation, we come from very far so it is expensive and also since the journeys are long you may get here late. For example they close at midday sometimes so you cannot take there your documents [prescriptions] to get drugs, this is big challenge."—P002 260

> "They are very many people and the line is very long you come here early in the morning but you leave the clinic in the afternoon or evening because of too many people."—P005 260

This following quote also exemplifies patients not being able to have emotional needs met due to lack of counselling staff:

> "They (hospital) have only few doctors and the patients are very many and that they can not handle them. So, that is why they are delaying here and they take long without taking (feeding) any thing. Besides they come here very early like at 6:00AM in the morning hours and so they delay here up to lunch time without taking anything and that's the problem they are facing. And secondly, they are having few counsellors. And that's the problem and you know a doctor can not give maximum advice to a patient because he needs to see other patients also."—C001 252

A further problem frequently cited was the availability of medicines, and the associated costs to patients and reduction in the likelihood that they will access the drugs that have been prescribed for them:

> "Of course once in a while they say that the drugs or a particular type of drug is not available, go and buy it but this normally happens. . . I said earlier that one of the things that's not so good and presses us is when you come and they tell you that we do not have that drug yet you decided to go come to this centre where you can pay 1,000 shillings and you receive the drugs. Now imagine you get here pay the 1000 shillings you just get some of the drugs and you are told to go and buy the other drugs from a pharmacy. So you have to add more to that 1000 to buy the other drugs from pharmacy else where. So that is pressing it would be good to pay if the 1,000 could cater for everything, that would be more beneficial."—P001 256

> "There are sometimes when you are told to buy a few non essential drugs from the open market or clinics when they don't have them and at times we fail to get them from these clinics and pharmacies."—P003 259

This problem with drug availability was also noted, along with an occasional poor staff attitude:

> "Some times when you come here the health workers are harsh to people, they are rude and some times its like when you come late you have to stay in the line up to 2:00 p.m. and some times you are hungry what, what! So if you want to go the medicines like you want to go back home earlier you have to come also earlier so that you don't get any problems. But people are many so you have to come here by 7:00 a.m."—P005 252

> "We have kids, sometimes we even fail to get what to eat for a balanced diet so when like me a widow you tell me to go and buy the medication because you are busy and you say we are busy and tired. We know and appreciate but that rude tongue is sometimes not good. And In such a situation I am not happy but other nurses and social workers do but not all of them."—P006 259

While the provision of information on prescribed medications was noted earlier as a highly valued received component of care, it was not universally adequately received:

> "We need more information on our medications for me I feel we are not getting enough information, why is it important to take it as prescribed, what may happen later, why they change regimens such things."—P002 260

7.5.2—Facility Strengths and Challenges

Facility strengths: When asked about the particular strengths of a facility, these mirrored the positive experiences of care, particularly staff attitudes towards patients and availability of drugs and services. Staff attitude appears to be key to the patient experience:

> "I have liked the way patients are cared for receiving drugs I feel I want to change and come here."—C001 260

> "Other things are okay, the staff here are friendly, they know how to handle us not like in other hospitals were nurses roughens you up and down. I have never been roughened here!"—P002 259

> "The services here are not bad because we patients are given respect when we come here they make sure they well come us talk to us kindly and give services as we want."—P005 260

The ability to have all needs met appropriately (including medications) onsite and in a timely fashion was seen as essential in defining a positive experience:

> "According to me everything is fine because whenever I come I always get what I want and more so in time."—C004 258

> "Yes it takes a short time here to receive the services."—C005 255

> "These is a book they gave us to help us check for dates, to remind us when to take drugs and then when to return for check up."—C002 255

> "And when you come here there are no complaints like there is no drug in the pharmacy."—P004 252

Lastly, the ability to give hope and spiritual care was described as a positive aspect of care:

> "Words of hope also help on spiritual issues, they encourage us to have faith in God and great hope for the future."—P002 255

<u>Facility challenges</u>: A number of core challenges to participating care facilities were identified. Firstly, challenges were identified by patients in terms of availability of counselling staff and challenges to general access to care due to lack of home care:

> "Counsellors are few and for home visits our family is too big and we have three HIV positive people in the family so they the patients need counselling but when you tell the counsellors they look at the clientele number and it is big yet the counsellors are few. I am not okay with the services, we have three clients in the family and we have so many problems including food, money for transport, that is a problem. Even counsellors do not want to come over for counselling during home visits so that is not fair."—C005 255

The view that expanding patient numbers limited access to care was echoed by staff:

> "Yes this is a big clinic and it is growing day by day yet we have a manpower problem. I said we have quality manpower but it is not adequate. So that is one of the weaknesses that we have as a clinic."—S001 260

This problem of increasing numbers places stress on clinical space in which to deliver care:

> "Our main weakness that probably we have and is about to be solved is space because at the beginning the facility was small, it was designed to handle a limited number of patients bit since ARVs came and now people know we give free ARVs. The numbers are swelling in every time. So the space is very limited although we have well trained health workers we are overwhelmed by number of patients and limited space."—S002 259

The human resource challenge was further exacerbated by difficulties in retaining staff due to the heavy workload and demoralisation:

> "People find it that here there is low payment and yet there is a lot of work so they jump out. So, I must say that the weakness here is only along the line low payment but heavy work load. And demand for life in our local area here is very high but you have to work here even on Sundays, you don't have time to do any other business out side, so it is a big challenge to the staff."—S002 252

> "Lack of motivation, in fact we have lost very many, they have gone saying that they can not withstand and continue with the work we are doing."
> —S002 258

Onsite lab facility expansion was identified as a challenge by staff:

> "We need to do something about the lab so that other tests like liver function tests can be done because in that case we could be in position to scale up and do ART."—S001 256

As mentioned earlier by patients, the ability to secure drug supplies is a challenge to dispensing:

> "In this facility, first of all we get drugs from [supplier], and some times we get it direct from [supplier] to the hospital, some times we get it via partners like [supplier]. And if we get it direct from [supplier], it reaches on time but if some times we get it through partners like [supplier] some times delays on the way and during transportation part of it may get damaged on the way. And these are all challenges but I must say that we have been getting our medicines/drugs on timely basis because we don't wait until the pharmacy is empty. We just look at the stock if it is going down and if it can push the hospital just some few months we immediately make the orders."—S002 252

Lastly, the reliance on donor funds raised concerns about sustainability:

> "Actually, sustainability is a big challenge because our institution is donor dependant. Though we are trying to build and work on IGAs for the hospital we still cannot meet the demand."—S002 252

7.5.3—Suggestions for Improvement

The core areas for improvement reflect the unmet needs, strengths/challenges and experiences of care. The points raised included reduced waiting times, maintaining drug stocks and replacement of ITNs. Additionally home-based care and community visits were suggested, including sensitisation of VCT in order to reduce stigma, and reaching rural areas:

> "They also need more of home visits because you cannot take all family members to the centre to receive care it is very expensive and such families have unique problems and challenges so it is good for health care workers to come right to the home, assess the situation and help accordingly."—C005 255.

> Respondent: "May be if they can put drugs near people mostly those who fear to come to health centres at least they can access them from their homes that can be better."
> Interviewer: "You said these people just fear to come or?"
> Respondent: "There are some people of that kind who may fear coming to health centres because people will see them and say they are sick."—P006 255

One facility provided ARVs by referral and patients would have preferred to receive them directly:

> "On my side I am satisfied but my appeal is about providing us with ARVs from this place. Let them not stop on testing, giving septrin and TB drugs but also give ARVs to those who want to do so from this place. After testing our CD4, they again refer us to other centres yet [facility] is convenient for those around [town]."—P003 256

Many patients and carers asked for economic help, for themselves or for others:

> "I would need support of educating my grandchildren."—P003 255

> "I would suggest that now they became very merciful to help such patients like us at least they should contribute some little funds to help such people who are coming from different areas. If they could be given some transport to take them back."—P002 255

> "So, which means that if possible you should assist us with some things even like these home based care kits, they should give us these gloves because all these are the problems that we have and on the side of family members we see them wash the patient's body and they do it directly using hands and are not protected and because of this the patients can infect other people. If possible those people should be assisted materially."
> —C001 252

7.6—Multiple Identities

In this qualitative component of the study, we aimed to collect information from patients, staff and families to triangulate data and integrate the datasets on experiences and views on care and support. Interestingly, the data demonstrated interrelatedness between these roles, reflecting the fact that staff and carers may also be patients. The presence of openly HIV positive staff/carers is seen to facilitate supportive counselling:

> "I have stayed long taking the drugs and I am now like a counsellor in the home based care programme. So when there is some difficult for patients I come and negotiate with them. I also counsel my fellow HIV patients and at times they tell me what I should communicate to them."—P002 252

> Interviewer: "What brings you to [facility] normally?"
> Respondent: "To get the treatment and care and besides I am working here as a hospital employee."—P001 252

> "I first tested in 2001 at [place] hospital, when they found me positive off course I disclosed first to my family, friends and community. Then when

> [facility] started in 2004 I was number 14 in registration because I had already known what AIDS. Presently, I am a drama member at [place] and I trained as a support agent in [NGO] and now I am a network support agent at health centre three level."—P005 255

Several carers in the study were themselves HIV positive and might be caring for multiple family members:

> "This carer was looking after 3 family members who were [facility] clients and he was HIV positive himself. He had to take on the carer's role because it was just him who was still strong enough though infected. Oral consent was granted by one of his brothers for him to be interviewed as a carer." —C005 255

Patients are encouraged to take roles as community advocates, expert patients and role models:

> "Yes we are encouraged to disclose our sero status and even encourage others to go for testing."—C002 255

> "They also go for outreaches and at times they invite me to talk on their behalf in the community during the out reach days. Actually, out of these outreaches I have gained lots of experiences and I actually replicate the lessons learnt among my family members."—C003 252

> "We are encouraged to offer hope to those living in denial and we encourage them to open up and receive the care. At times I tell people I am HIV positive and some do not believe but what I want them to pick from that is that life can continue normally."—P001 259

> "We are told to encourage friends and relatives who get chronic fevers, sexually transmitted infections, headaches and general weaknesses to go for HIV test and we are told to use persuasive language. In fact the people believe when they see this has been the most powerful tool for communication in my village, I was badly off but now I am health and I can walk so when I talk to other people it is very easy to convince them to come over for testing and enrol into the care system if they are found to be HIV positive."—P001 260

Consistent with this overlap of roles, patients preferred to be employed by the facility where their needs would be understood, and felt the facility should support them in this way if possible.

> "We were in need that if they could give us a chance if there are posts here, they should also include us in [facility] as we come here and they open up our files they also ask us the qualification like me I am diploma holder so I can come under [facility] and get something to do Under [facility] because I think when I come here I will be working with my own people. It is the environment I can fit in well. When I am working with fellow clients and there are clinicians around when I get problem or feel sick they give you the treatment. But when you are working outside there in the community they do not appreciate that you are sick but when we are here as clients, let them see us as clients but clients with qualifications and who can come and help here when there is need."—P002 255

The relationship between long-term patients and the facility could become strained by the uncertainty around the roles of patient, carer and staff member:

> Interviewer: "Is there anything that you see that isn't good whenever you go to AIC?"
> Respondent: "Most of us are trained but again they can never employ us here. In most cases as I told you were are volunteers, we are never considered much for instance if a condition came by, we are the first ones to be shown the exit. When they need you, they will call you like how called me here to be interviewed. I wish they could change and know that we also part of the organisation and explain to us properly what's happening. For example I have spent 20 years in this organisation but they can never employ me as a sweeper they would rather employ someone else yet I can also do that job properly."—P002 256

7.7—Access to Care

7.7.1—Health Seeking Behaviour

Patients described what motivated them to access HIV care, which was usually because they had unexplained symptoms and poor health that were suggestive of HIV infection and advanced disease:

> "Basically, a brother of mine had a problem related to HIV and he was brought here by relatives and after some two weeks he greatly improved and when I developed the same kind of problem my brother had, my relatives and brothers felt wise that I should also give it a try to the same place. By then I didn't know my status but when we came here I had a problem of AIDS and that's how I started."—P002 259

> "By the time I came to [facility] I was weak. So, I decided to come and test my blood for HIV. I found that I was positive and I would like these people to assist me if they can with any thing."—P002 252

> "The first health care worker I met asked me about my history and I told him and by the time I came to this facility I were extremely weak and not feeling well."—P003 259

The other, less common, reason given was routine testing:

> "Okay, I had given birth to a baby. It came to be that this child was born positive, now when I brought her to [place] there at the assessment centre, we were admitted on the children's ward and I spent one and half months on ward 1C. So this child was tested and I was told that she was infected. So from there we went to [place] which is provides care for the children. It is those people that gave a referral letter to this place and then I brought my husband later. But this child passed away after some time."—P003 258

7.7.2—Process of Choosing a Facility

The three principle reasons patients gave for selecting a facility were proximity to home, personal recommendation, and the specific nature of care offered. As transport costs have been identified as a major barrier to care, it is unsurprising that proximity and cost were core reasons for choice of facility:

> "[Place] is near my place and I don't want to incur any transport costs."
> —P003 252

> "At the first time, it was very difficult because I thought they use money and by then I didn't have the money and I had a friend who directed me here and told me care was free. So, that is how I came to find my self at the hospital."—P002 252

The importance of personal recommendation was also key:

> "I first went to a clinic in [place], so as I was there, a friend to my husband whose name is [name] , he actually hails from Masindi. So he advised us to try [place] and recommended that we see [name]."—P001 259

> "Basically, a brother of mine had a problem related to HIV and he was brought here by relatives and after some two weeks he greatly improved and when I developed the same kind of problem my brother had, my relatives and brothers felt wise that I should also give it a try to the same place."—P002 259

Lastly, the nature of the facilities' services also acted as a deciding factor:

> "Now what made me so attached to this centre, when I got to know that there was a post test club for those who have tested positive that gave me the momentum to keep coming here and it made me more of an [place] person. That is why you have managed to find me here."—P001 256

7.7.3—Eligibility Criteria

Staff at all facilities said that they accept any HIV positive patient:

> "No, under [name] Programme supported by PEPFAR we enroll patients as long as they tell us they will be able to come to this facility to pick their ARVs. We don't care about the boundaries. Its other centres which have that criteria of radiuses say they will enroll patients with in 20km radius but for [name] we don't have those barriers as long as they are able to assure as they will have to come in for their refills."—S001 259

> "For all those who are willing and they are able to continue coming to our clinic on a routine basis, we have been able to take care of them with out any big problem."—S002 260

However, caution was exercised in imitating therapy and "patient readiness" was appraised:

> "But if we are talking of the ART we have the clinical criteria what we normally do for some one who is HIV positive should first under go CD4 count and we follow very much guidelines put by the Ministry of Health and when some body goes below 200, the person already qualifies to get the treatment. And we also do carry out some other tests like Liver Function Tests (LFT). And the social aspect there should be there and some body should disclose to the immediate family member and should come with a treatment supporter. This is actually a condition that we have put and some body should be ready to adhere to the medication and should accept to live positively to make the outcome of the treatment to be there. So, if the person is ready to abide by that we get the person ready for treatment."—S002 252

7.7.4—Retention and Shopping Around

The majority of respondents reported that they did not attend multiple care facilities. The exception was when facilities sometimes requested that their patients to attend non-HIV health centres for minor ailments. Feeling that the centre fully meets patient needs was a strong motivator to the patients:

> "Ever since I joined here for treatment I don't go anywhere else because I feel these are the people who know better and if I go to another facility/clinic I have to introduce myself but here they know me well." —P005 259

> "Now what made me so attached to this centre, when I got to know that there was a post test club for those who have tested positive that gave me the momentum to keep coming here and it made me more of an [place] person. That is why you have managed to find me here. This club brought us so close and we became more of children in a home and got a true facility belonging." —P001 256

Even when referral was suggested, the perceived stigma at other centres encouraged patients to stay where they were:

> "Yes, that is why I even refused to be transferred [place]. When you come to receive care here, you are not stigmatised at all, no body cares about who is sick and who is not. We are all the same but its terrible in the villages, when people see you going to the clinic, the entire town will talk about you, have you seen she is infected or that one is a land mine, she can blow you up. Such things." —P001 259

Patients were encouraged to attend health centres for minor ailments, apparently as a way to deal with the large HIV outpatient appointments. However, costs of attending these other facilities proved to be a problem

> "Because I used them even before [place] came. Now [place] gave us appointment dates like every after two months so if you get a headache you go to those health centres. [Place] has done that because clients are very many. So it is negotiation you cannot come to day, tomorrow and the other day you may find that other people are not being served." —P002 255

> "I go there for treatment of minor illnesses but it is all a pain just because it is very expensive to come here. Those people neglect us they tell us to go to our clinics, so I can say their services are very poor in fact now I am not happy to go there." —P002 260

A final reason for attending elsewhere was to determine whether additional advice could be given:

> "Apart from here there is also a government hospital [place], at other times when I have a problem and I go to that hospital and actually they are giving us the same advice like this one. I go there looking for help, mainly because I think they could give me additional help." —P002 252

7.7.5—Costs to Patient

Staff generally reported that all interventions and drugs were free. The availability of free medications was the most commonly reported theme throughout the qualitative study.

> "{Place] has really helped me because they are offering me the drugs. It is very difficult to get money to buy drugs. For example, my husband used to spend shs. 190,000 on my ARVs and that had to be spent on a monthly basis whether you like it or not. So I think you can appreciate that [facility] is helping me so much." —P001 259

The only exception to free care was a minimal registration/attendance fee that covered all services and medications, which was described by staff:

> "We provide services we are donor supported to give the services to the clients. but we wanted this element that when clients come to get the services they don't have a feeling of getting free services, actually our services are for free but they are contributing to the services also by paying five hundred shillings every visit when they come. we think that five hundred when its paid and you are given drugs may be will consider these drugs as very important because you have given in some little money for drugs… we think way of making them contribute there is a way it helps them psychologically it helps them to know that this their service and they are contributing for it." —S001 255

> "However, I would like to note that there is a small user fee (of UG 2,000 shillings) paid only once when clients enroll for care." —S002 252

However, the additional costs of HIV care could be substantial in terms of lost income, sale of assets, difficulty paying school fees, loss of home, dissolution of family ties, and reduced working time:

> "My biggest problem now is the house, I had my produce and sold it that's where I got the money and started constructing but it is at a poor state.

> Most of the time I am caring for the patient so I no longer carry out any casual labour to earn some money."—C004 255

> "Imagine I have also not worked thus no money yet she is there sick! She used to work in a restaurant but she no longer does so due to heat problems yet at least we could afford to cook porridge for her which isn't the case now."—C004 258

> "I only know about one problem and it is about money. Like she is no longer gainfully employed as she was before. Some times she doesn't get the money yet she has to feed us and so on. Like at times she delays to meet our school fees. Ah, such are the ones I know."—C001 259

> "What we need, what I feel we need as HIV patients, it would be good if we could be supported because most of us are widows and we have no houses. We are living in our father's homes and that pains us so much."
> —P007 255

> "Well my other challenge because I am teacher I have to go in the morning and come back in the evening I was even forced to make one of my children a day scholar so that she can come after lunch to help him go to the toilet."—C001 255

> Respondent: "My biggest problem is my education. I am worried about my education whether I will finish or not and the problem I have is between me and my parents. One of them was not willing to pay for me tuition fees . . ."
> Interviewer: "What reasons was he giving?"
> Respondent: "He told my mum that even if they pay for me tuition, I Will not finish, I am going to die soon etc he complained too much."—P004 256

7.8—Clinical Standards

7.8.1—Process of Enrollment

Patients generally reported facilities as being easy to find, and providing a welcome reception:

> "Here, it was very easy because they welcome me, they do not disturb me but give me the comfort and because my place is near the hospital they easily do the follow up and it is easy for the health workers to reach my home."—P003 252

For those with poorer health, enrolment can be made quicker:

> "Yes we accept all patients. All who want to access the service apart from those who are very weak, those who are very sick and can not wait for more than 1hour we will take them to hospital for admission."—S004 256

7.8.2—Frequency of Contact

Community Health Workers may see patients weekly, and ART prescribing was usually monthly. One facility reported dispensing every two months for those responding well to treatment. From the patient perspective, this had obvious advantages:

> "Initially, they used to give and restrict it, giving us for one month but I think to their wisdom they thought it wise that they should increase it like right now I get drugs for a period of two months that keeps my spending a bit better because I don't have to keep coming here every month, like cost of transporting myself, the time you waste here is quite much so if you take it for two months this gives you time to at least relax until when it is finished and then you come for refill."—P002 259

7.8.3—Monitoring and Documentation

The monitoring of patients appeared to be holistic:

> "Well when you get there they will first of all ask you how you feel, your complaints and challenges in daily life. Then if you have a medical problem that requires medication, the medication will be prescribed for you."—P001 260

> "You come and they weigh your kilos, measure your temperature, you go to the doctor and the doctor asks you some questions like how you are feeling and asks you any problem you are having and then after that if you don't have any thing which you are feeling like pain. They tell you to go and get the medicines."—P005 252

However, the documentation procedures described do not always include the assessment of problems beyond basic clinical markers, and therefore a more holistic assessment may depend on the skills and awareness of the clinician:

> "So we do have those standard operating procedures but of course they don't say when a patient has a problem send him to the counsellor. So they are there but they don't involve every thing that comes up."—S002 260

7.8.4—Referral Mechanisms

Facilities described the specific circumstances in which they referred patients out to other facilities. These include medical specialities such as cardiology and for surgery as well as for patients who are ready to initiate ART but for whom there are inadequate drug supplies;

> "Yes, for other conditions apart from HIV, we can refer the clients for some services that we don't have in the hospital. Like may be a heart condition if we hear we don't have enough facilities because our hospital is still under developed and for HIV clients we usually refer them because here we have a sealing in uptake. Like if we are to start on ART there are times when we don't have ART for new ones so we can refer them to other facilities to be enrolled there for ART and those are the kind of referrals we make when there is a sealing like only we are going to may be enrol say only one hundred (100) clients and no more. So, any other clients who come we give them other services but if they want now to be initiated on ART we refer them to other facilities were they can get the services like here we refer them to government hospital."—S001 252

For spiritual care:

> Interviewer: "If a client is in that line, is need of spiritual counselling, what happens?"
> Respondent: "We refer to different places may be to the church. At times you find out which church she is going to, try to probe and see whether there's a counsellor with in that church because they are of different denominations. If he is a Muslim of course there are some sheiks who are within that line. The spiritual counselling actually isn't here. We don't do it."—S001 256

To ensure that patients can access local care:

> "Ok we network with a number of organisations like [place] [place], [place], [place], [place] actually in all, all health centres these days have those units which give care and support. So you ask the clients which places will be convenient for her, which will be near, were he will spend less money and the rest, .and those are the places where the doctors refers the clients to and its mainly for further management, treatments."—S001 256

For malignancies:

> "The only think may be would be the cancer related illnesses like lymphoma which we refer to other centers. Most of the things we can handle them here."—S001 259

And for terminal and palliative care:

> "We refer patients to hospice for terminal care, usually pain management because we do not have oral morphine here, so pain management really." —S001 260

> "For the terminally ill, this facility works with other facilities to make a joint effort to manage the patients. Those for example who come with cancer are referred to Uganda Cancer Institute and those who come with advanced cancer we work with Hospice and are able to be managed at home level because we cannot admit them for the whole year. We usually work with them because for them they are able to visit them in their home and are managed from there."—S002 259

7.8.5—Staff Education and Training

As described under staff needs, further specific training needs were identified in paediatrics, particularly counselling, and ART regimens beyond first line. Other areas of need were as follows:

> "I think I would need skills in marital counselling because apart from clients coming for HIV testing, usually you find that they have marital problems and at times you might find that one is at across word."—S001 256

> "May be a training in special needs. Though they are few but we get them people who are deaf, if I can get a training in sign language. They are few, but at times we get them and we are at a loss so what actually what we do we handle it mechanically if you get a person who can write, you write he reads then he writes you read. So, me may be if we can be equipped may be with those skills, then we would be able to help those because even though they are handicapped but they are also at risk because they also have sex."—S001 256

8 Results of Costing Study

Table 71: Total and Per Patient Cost of Care (US$ Per Year)

Facility		Staff	ARVs	Other Drugs	Lab Cost	Building/Utilities /Rental	Total
252	Total	77,946	585,895	0	140,827	232,372	1,037,040
	Per Patient	22	586	4	40	67	719
255	Total	226,211	173,445	1047476	136,555	785,191	2,368,878
	Per Patient	40	165	184	24	138	550
256	Total	144,351	0	704	33,485	66,012	244,552
	Per Patient	24	0	0	6	11	41
258	Total	753,958	325,226	21050	1,037,060	2,356,364	4,493,658
	Per Patient	85	58	2	116	265	526
259	Total	1,435,636	4,428,324	4454	10,973,039	7,416,247	24,257,700
	Per Patient	21	149	0	160	108	438
260	Total	12,407	979,655	19839	212	275,615	1,287,729
	Per Patient	2	252	3	0	41	297

Table 71 and Figure 33 show that there was a wide variation in costs per patient per year, ranging from $41 at Facility 256 to $719 at Facility 252. Annual costs per patient at Facility 260 were close to the median of $297 per patient.

There was also a wide variation in the components of the costs per patient as seen in Table 71 and Figure 34. Per patient staff costs were similar for Facilities 256, 252 and 259 at between $21 and $24 per patient. Facility 256, which did not provide ARVs directly, had no ARV costs but staff costs comprised nearly 60% of per patient costs. At the other extreme, Facility 260 had very low per patient staff costs ($2) and high per patient ARV costs. At facilities which supplied ARVs, ARV per patient costs ranged from $58 at Facility 258 to $586 at Facility 252. The high overall per patient costs at Facility 252 seems to stem from its high per patient ARV costs. Other drug costs per patient were minimal for most sites except for Facility 255 ($184.) It is notable that Facility 259 had relatively high labora-

Figure 33: Annual Cost Per Patient

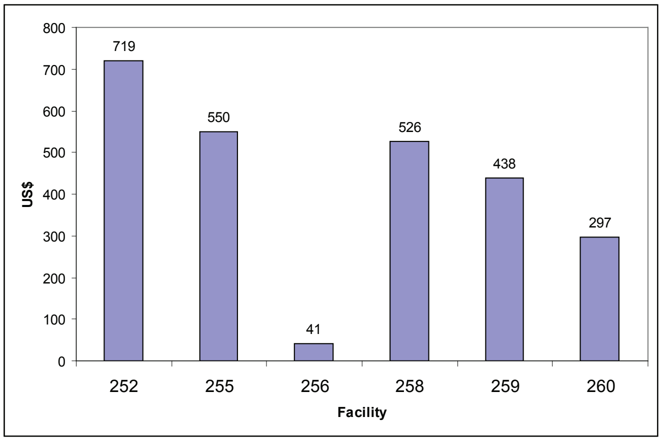


Figure 34: Cost Distribution

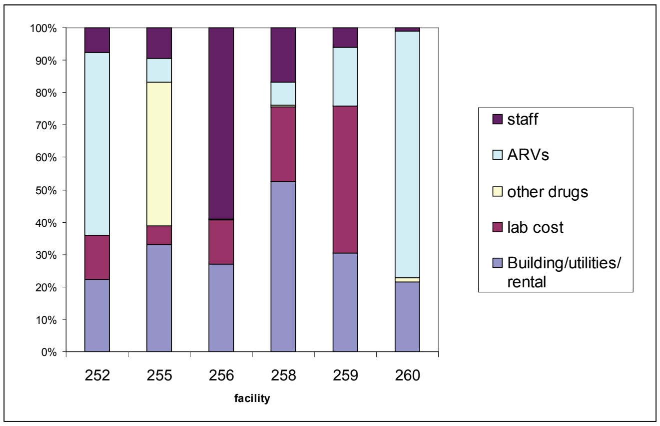


Figure 35: Distribution of Clinical and Non-clinical Staff Costs

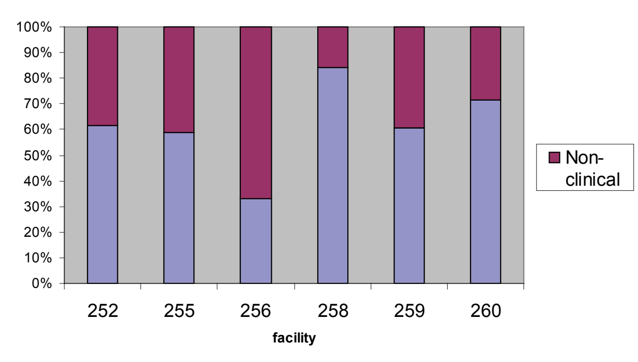


Figure 36: Patient to Staff Ratios

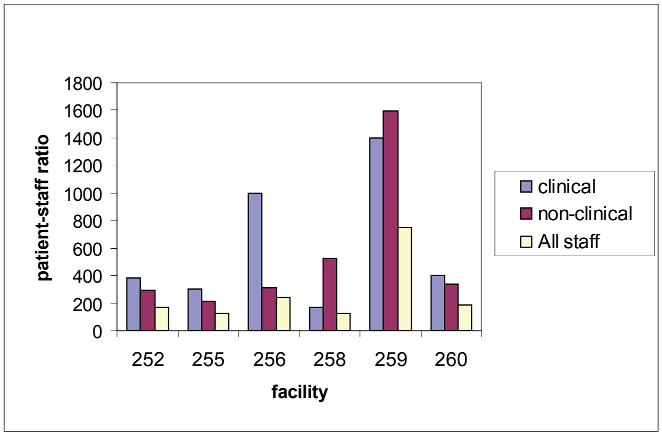
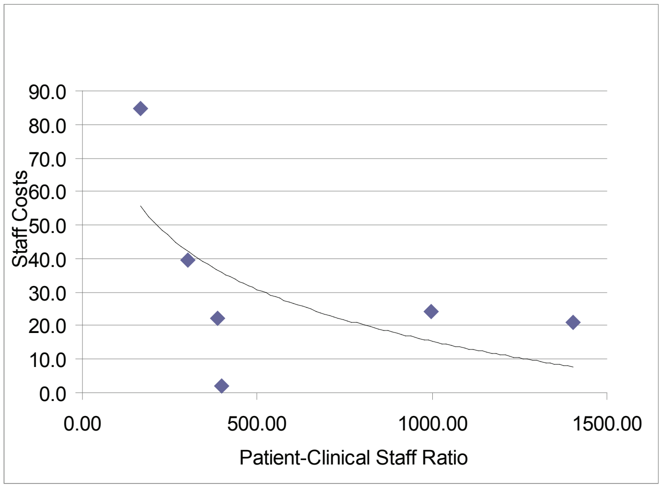


Figure 37: Staff Costs Compared to Patient-Clinical Staff Ratio



tory costs ($160 per patient) and low staff costs ($21.) Building-related costs were lowest for Facility 256 ($11) and highest for Facility 255 ($265.)

The composition of staff costs by clinical staff (defined as doctors, nurses and pharmacists/dispensers) vs. non clinical staff (all other staff types) are shown in Figure 35. For most facilities the proportion of staff costs accounted for by clinical staff was between 60% and 85%. The outlier was Facility 256 where non-clinical staff comprised nearly 70% of staff costs. This may reflect the fact that Facility 256 did not provide any ARV services.

Patient to staff ratios for clinical and non-clinical staff also showed large variation across the facilities (Figure 36). Facility 259 had a very high patient:clinical staff ratio at 1401:1 as compared to Facility 258 with a ratio of 165:1. For non-clinical staff the variations were similar: Facility 259 had the highest number of patients per non-clinical staff member (1597:1) and Facility 255 the lowest (211:1).

It was hypothesised that there would be a relationship between staff costs per patient and patient-staff ratios, i.e, facilities with high patient loads per staff should have lower staff costs. A scatter plot of staff costs versus patient-clincial staff ratios (Figure 36) shows an inverse relationship, supporting the hypothesis.

Figure 38: Relationship Between Unit Cost and Number of Patients

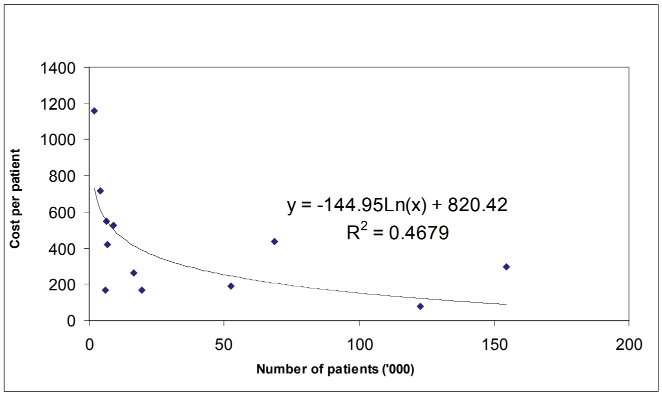
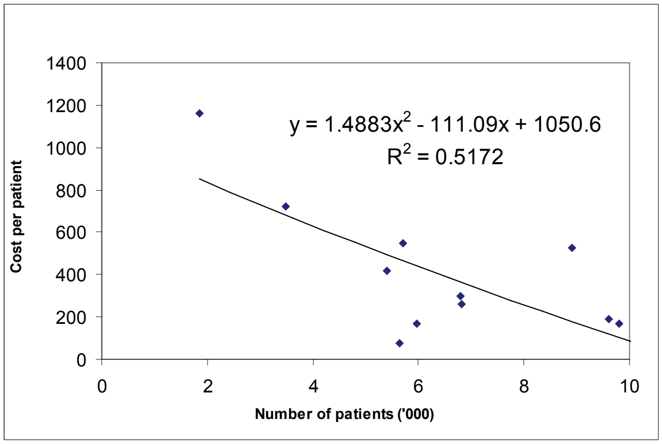


Figure 39: Relationship Between Unit Cost and Number of HIV Patients



8.1—Economies of Scale and Case Loads: Evidence from Uganda and Kenya

The relationship between size of the facilities as measured by number of patients and costs per patient per year was also examined. If there were economies of scale it would be expected that there would be a negative relationship between average costs per patient and patient numbers. This would be similar for staff costs per patient and patient loads for staff. Because there were only six facility per country in this analysis the data for Uganda and Kenya were combined. In Figures 38 and 39 costs per patient were plotted against total number of patients registered at a facility, and again against number of HIV patients. The figures show that for both number of HIV/AIDS patients and total number of patients, the cost per patient is lower in facilities with more patients.

9 Discussion of Longitudinal Quantitative Study

9.1—Facility Characteristics, Participant, and Interview Numbers

In total 641 participants were recruited into the longitudinal quantitative study, between 102 and 112 per facility. The aim was to examine whether and how patient outcomes changed under care.

The overall recruitment and completion rates were very good for a longitudinal study of an outpatient population. The loss to follow-up during the three months of data collection was 16.1%, usually for unknown reasons. The highest loss to follow-up was at Facility 256, where the study manager was seconded to another branch for several months. On her return she followed up participants who had been lost and managed to interview most of them at least once more. Facility 256 was also a specialised VCT centre with an open door policy. One consequence of its accessibility to newcomers was that it was also easy to leave.

Results from Phase 1 showed that clinical and preventive care were reported as being offered at all facilities, while social and spiritual care were most commonly offered at Facility 252, followed by Facilities 255 and 256 (**2**). Very few components were reported to be delivered by referral; care was either provided onsite or not available. All facilities employed nurses and doctors but only three had a nutritionist, three a spiritual leader and two employed social workers. The number of community health workers was very low at most facilities. Three facilities were based in Kampala, two in other towns and one in a mostly rural area.

9.2—Participant Characteristics

9.2.1—Demography

In the sample, women were on average younger than men, and outnumbered them by more than two to one. This reflects the distribution of HIV in Uganda and most African countries, where prevalence is higher among women than men, particularly in younger age groups (**33, 34**). The reason for this disparity may be due to sexual relationships between younger women and older men (**35**).

The maximum age of participants was 70. The most common indicator of HIV in official figures for countries with a generalised epidemic (like Uganda) is the prevalence in the 15–49 age group, termed “adult” (**33**). HIV in older people is a neglected issue (**36**), and although they represent a minority of people with HIV, older people are likely to experience more severe health problems.

The results for distance to travel from home to the facility appear to have a wide range but both extremes are reasonable. One person reported taking one minute to travel from home to Facility 258, which is in central Kampala surrounded by residential areas. The only people to travel more than six hours were two participants at Facility 252, the referral hospital for a very large area with poor transport.

9.2.2—HIV Diagnosis and Reason for Attending

The most common reason for attending the facility was a new presenting problem, followed closely by a new HIV test result. The median time since HIV diagnosis was 196 days but the median time since registration at the facility was seven days, indicating that large numbers of people had been diagnosed some time earlier and had either recently changed their care facility, or had not previously been registered at all. Changing the source of care creates problems because of a lack of patient history and the inadequate referrals framework identified in Phase 1 (**2**).

The fact that almost a third of participants had been diagnosed within the previous two weeks suggests a high and increasing patient burden for staff, although it is important to remember that the inclusion criteria specified participants with a new diagnosis or new problem, thus the results should not be interpreted to mean that every third patient at the facility was newly diagnosed.

The new problems reported by some individuals were not representative of the study population, as the question had a very low response rate. The answers are included in the results because they are indicative of the range of problems that participants experienced, including psychological issues and comorbidities such as stroke, not because they represent the prevalence.

9.2.3—Relative Wealth

The demographic information shows that 26% of the sample used public or shared latrines, or none at all. This represents a substantial risk to health. Access to only shared or public latrines is considered inadequate sanitation by the WHO (**37**) and halving the number of people with inadequate sanitation is one of the Millennium Development Goals. Diarrhoea is a frequent symptom of HIV (and ART), causes high morbidity and mortality (**38**), and can also be deeply distressing if toilet facilities are not appropriate.

In this sample, the wealth quintile in which most people used a public or shared latrine was the second wealthiest, which was unexpected. The finding may be caused by the intersection of wealth with urban living. Participants in the cities, especially Kampala, were more likely to live in brick-built houses with cement floors, which were indicators of relatively greater wealth. In East Africa the number of users per latrine is higher in the city where population density is greater (**39**); thus, although relatively better off, city dwellers can have worse sanitation than people in rural areas.

The vast majority of participants used biomass fuel (charcoal, firewood or straw), which cause indoor air pollution and are a risk factor for respiratory tract infections, cancer, stroke, eye problems, chronic obstructive lung disease and TB in adults, particularly women, as well as a host of other health problems in children (**40, 41**). The main health effects of HIV in Africa are increased susceptibility to pneumonia, TB and bacterial infections, often causing airway obstruction and pulmonary inflammation.

The wealth quintiles were calculated using the standard method developed by the DHS and World Bank (**14**) to give a better representation of relative wealth appropriate to the setting than could be achieved by individual measures. The items having the most effect on wealth factor were having an earth-floored home, using firewood or straw for cooking fuel and having a house with a thatched roof (Appendix I). These traits are associated with rurality as well as poverty. Ownership of a mobile phone loaded positively onto the factor; 10% of the poorest households and 100% of the wealthiest households owned one.

9.2.4—Illness Severity

CD4 counts ranged from 1 to 1569 with a mean of 331 and median of 297, which is below the normal range for a person without HIV. A CD4 count below 50 at admission is a predictor of greatly increased mortality risk (**42**). A CD4 count of 200 is the most widely used level at which to begin ART (27), although ART has also shown benefits between 350 and 200, and current European guidelines suggest 350 as the threshold (**43**).

The people who had two measures of CD4 count had a lower than average mean count at baseline, though the difference was not statistically significant. It is reasonable to think that people with a lower CD4 count might be monitored more closely and tested more frequently. The difference between mean and median demonstrates that the distribution of CD4 count was not parametric, being skewed to the right. However, as the variances of CD4 count at T1 and T3 were similar, and the sample size was large, a paired t-test was robust enough to use.

It is not surprising that although physical and mental health scores increased, ECOG scores did not change over time. The categories of function were large and unlikely to alter from one month to the next. People with more progressed disease had a lower CD4 count and were more likely to have impaired physical function.

The study population consisted only of outpatients, the great majority of whom attended the facility without an accompanying carer. This group is therefore biased towards better health than is experienced by the entire population of people receiving care for HIV, some of whom would have been admitted. It is also possible that some people with HIV were unable to attend due to ill health and lack of carer support. The association between low physical health and loss to follow-up suggests further bias towards better health in the studied population.

9.3—Care Participants Received

A small number of participants reported that they did not know whether they had received a component of care. The only component for which these were particularly prevalent was weak opioids. Health care workers were trained to define components of care if the participant did not understand what they were. The large number of 'don't know responses for a single item (weak opioids) at a single facility (Facility 258) suggests that the staff at Facility 258 may themselves have been unsure what weak opioids were.

Even though certain areas of care, such as social care, were not provided by all facilities, only 7% of care components were obtained by referral. This confirms the Phase 1 finding that referral systems were not well established.

9.3.1—All Care Components

Participants received a mean of 12.8 components per month, which remained stable over time, and a mean of 21.5 different components during the study with a range from none to 43 out of a possible 52. This represents a substantial burden of care, including constant changes in care regimes. That participants received so many different care components within a relatively short time implies they experienced a range of complex multidimensional problems.

The six components received by the largest number of people were all elements of preventive care, and the seventh was ART, which is arguably preventive in that it reduces infectiousness and is a long-term treatment. It is good clinical practice that preventive care should be delivered to the majority of patients and curative care only when this first line has failed. The single most commonly received care component was daily CTX, which increased rapidly over time from 69.8% at T0 to 88.9% at T1 and finally 92.9% at T3. CTX is easy to deliver, is of proven effectiveness and supported by policy guidelines for prescription to everyone with HIV (**24**).

Many symptom control care components became less frequently provided over time. This may indicate that the symptoms had been effectively controlled. For example, provision of antifungals dropped from 16.4% at T0 to 5.6% at T3. The provision of anxiety and depression treatment did not decline over time, perhaps suggesting that these symptoms were more difficult to manage. Social interventions such as IGA and provision of food were more likely to increase over time, indicating a possible delay in provision of these components of care.

9.3.2—Care Received Away from the Facility

In Phase 1 of the PHE, several respondents reported that it was an advantage to receive all their HIV care in one place. Nonetheless, participants in this phase frequently supplemented their care from the research facility. Apart from obvious differences such as visiting a traditional healer, the prevalence of care components at the facility and elsewhere was remarkably similar. HIV-specific care, general clinical care and social care were about twice as likely to be received from the research facility as from somewhere else.

Anthropological studies have shown that when several paradigms of healthcare are available to them, people take advantage of care from all possible sources, even if the underlying philosophies of these healthcare systems are in conflict (**44**). Thus, many people use traditional healers and modern medicine simultaneously.

9.3.3—PEPFAR Care and Support Categories

Over 99% of participants received clinical care, 98% preventive, 78% spiritual, 68% psychological and 35% social. As in Phase 1, social care was the least commonly available service of the five.

9.3.4—Basic Care Package

The elements of the Preventive Care Package should be provided to everyone with HIV who needs them (**32**). They are a minimum level of immediate care for people with HIV. The five elements are evidence-based, focusing on prevention of some of the major causes of morbidity for people with HIV [malaria (**45**), waterborne infections (**46**) and bacterial infections (**25**)], and secondary HIV prevention through two methods; condoms to stop infections and family VCT to provide services to those at higher risk.

In this study, the high burden of treatment for malaria and other infections (including STIs such as herpes) demonstrate the importance of BCP interventions. The fact that 12% of participants had an unsafe drinking water supply is further evidence of their necessity. The BCP does not include interventions to prevent TB, the main cause of mortality in people with HIV, or malnutrition, identified as the major contributory cause of death for people with HIV in a Tanzanian study (**47**).

9.3.5—Care for the Newly Diagnosed

People who have just been diagnosed with HIV in sub-Saharan Africa are known to have a have high prevalence of symptoms including fever and weight loss (**48**), depression (**49**), chest infections, diarrhoea and herpes zoster (**50**). In this study, 76% of participants received painkillers during the first three months after diagnosis, 47% malaria treatment (indicating experience of fever though not necessarily malaria infection), 36% treatment for skin rash, 26% treatment for thrush and 16% treatment for nausea and vomiting. This represents a considerable burden of symptoms.

Treatment for anxiety and depression was received by a small minority of patients (under 10%), even though HIV diagnosis is thought to be a time of high distress (**51**) and the APCA African POS scores indicated psychological need in this group.

Over three months of care, the mean number of care components received by newly diagnosed participants increased from eight to 12 while the mean number for the previously diagnosed decreased slightly. The decrease was largely due to a reduction in receipt of symptom management care such as treatment for diarrhoea and fungal infections, presumably because these symptoms had been controlled. For newly diagnosed participants, on the other hand, there was little reduction in the prevalence of symptom management care, while preventive care such as multivitamins and HIV support groups increased over time. Receipt of food trebled between T2 and T3, suggesting that the process of assessment and allocating food to participants took some time to put in place.

The distribution of care component receipt was approximately Gaussian, i.e., the mean and median were close together, meaning that half of participants received more than ten separate components of health care in the month following HIV diagnosis. This burden of health care indicates a substantial and abrupt change to normal life following diagnosis. Even when care is free at point of delivery, there are associated costs for transport, obtaining drugs from pharmacies, and so on. The burden of transport costs may also cause anxiety to newly diagnosed patients who see themselves having to make sacrifices in future to maintain regular appointments (52). In qualitative studies of HIV diagnosis, uncertainty was one of the defining features (53;54); patients do not know how their disease will progress and what will be demanded of them.

9.4—Care Themes

9.4.1—Spiritual

The number of people visiting a traditional healer reduced rapidly after T0. Possibly it was felt unnecessary or inappropriate after the HIV test result was known. Traditional healers provide more healthcare in Uganda than clinical medicine (55), and are often the first port of call for people who suspect they might have HIV infection. Therefore it is important to build connections between traditional healers and the health system, to encourage referral and increase access to care.

9.4.2—Counselling and Advice

The most commonly received components of counselling were adherence counselling, family planning counselling, and nutritional advice. The evidence from focus group discussions in Phase 1 (**2**) and qualitative interviews in Phase 2 suggests that these three components were largely educational in nature, based on informing patients of benefits and risks. This kind of counselling may not address psychological issues such as anxiety, loneliness or lack of peace, which study outcomes showed to be a burden for participants. These needs may be met through patient support groups, which 73% of participants attended.

Depression is a predictor of reduced survival with HIV, although it is not clear whether this association is due to neurological effects or mediated through behaviour change (56). It is difficult to separate the direct and indirect effects of depression on HIV, as depression reduces health-seeking behaviour and adherence (**57**). Since depression is often a recurring condition, and mild depressive symptoms are a risk factor for HIV infection, separating cause from effect is also complicated. Very little is known about the burden of mental illness in Africa. A study in Uganda found depressive symptoms in 47% of people with HIV (**58**). This and a small number of similar studies (**49, 59**) suggest the possibility of a very high burden of mental illness, suppressing the ability and will to seek healthcare while advancing HIV disease progression.

9.4.3—Nursing

It is interesting to note that 25% of participants received wound care at baseline and this prevalence increased over time. Wounds could have been caused by skin infections, bedsores or other skin breakdown, or injuries. Wounds are a possible route for bacterial or other infection to which a compromised immune system will be vulnerable, and in addition could pose an HIV transmission risk for household carers. Sixty-nine percent of people who received wound care had infection control training during the study, compared to 31% of people who did not have wound care, which suggests that these risks were recognised and dealt with.

9.4.4—Pain Management

Pain is a very common symptom in HIV (**60**), particularly in later stages (**61**), and ART has little effect on the prevalence of pain (**62**). Analgesics should be given by the mouth, by the clock, and by the Pain Ladder (WHO), progressing from non-opioids to weak opioids to morphine until pain is controlled. Apart from the evidence from the APCA African POS and MOS-HIV of lasting pain, the very low use of opioids in this study, with two facilities not providing morphine to any participant and one not providing weak opioids either, would have made adequate pain management impossible.

Uganda has one of the best records in Africa for opioid use (**63**), but nonetheless myths about its addictiveness and danger persist. More people received treatment for neuropathic pain than opioids, although neuropathic treatment is more expensive. At the same time, 83% of participants were given non-opioid analgesics during the study period, indicating a very high prevalence of pain. These 83% received on average eight more components of care during the study than the rest, suggesting that pain was associated with a range of other problems.

The prevalence of pain assessment increased from T0 938%) to T1 (50%). A possible reason is that the use of the study tools, with questions on pain, reminded health care workers to carry out an assessment. During the development of the APCA African POS, health workers reported that using the tool improved their practice (**13**).

9.4.5—Symptom Management

If need can be inferred from treatment, then at the beginning of the study 21% of participants had genital thrush, 21% had skin problems, 15% had diarrhoea, 15% had oral candidiasis and 14% had nausea and vomiting. Over the three months, almost half the sample suffered from skin problems and over a quarter from diarrhoea, at a severity that required treatment. Added to that the level of symptoms which would go unreported or be considered not needing treatment, the symptom burden in daily life is very high. Similarly, a study of HIV outpatients in Tanzania found that 52% were appropriate for palliative care intervention regardless of ART use (**64**).

The receipt of most of these components of care dropped off over time, with treatment for skin rash being an exception. This probably indicates that symptoms were controlled while skin rash was an ongoing complaint. Thirty-nine percent of participants had malaria treatment in the month before T0. In this context, any fever-like symptoms are often treated as malaria until proven otherwise, particularly if participants self-diagnosed and bought their own medicines. However, malaria treatment rate remained high at about a third of participants every timepoint. The majority of data collection took place outside the peak malaria season (January and February), and this level of malarial symptoms in an adult population is much higher than normal and indicates a significant burden of disease.

9.4.6—Nutrition

Lack of food is one of the main barriers to ART adherence, as the drugs are difficult to take on an empty stomach (**47**). In the study, 13% of participants received emergency therapeutic feeding and 39% received food.

Food provision increased at T3, particularly for the newly diagnosed. Water-borne infections are a common cause of morbidity and mortality for people with HIV (**46**). A randomised controlled trial of a safe water system in Uganda found that an intervention of hygiene promotion, simple equipment to purify water, and daily CTX halved the number of work and school days lost due to diarrhoea for people with HIV (**65**). Apart from the health benefits, lost work time (plus the opportunity costs of caring for the sick family member) frequently causes a decrease in income with corresponding difficulty meeting the expenses of adequate food, health care, and other household costs (**66**).

In the Tanzanian study of depression in women with HIV referred to earlier, vitamin supplementation for pregnant women reduced the prevalence of depressive symptoms (**2**). Multivitamins have also been shown to reduce mortality and morbidity (**67**).

9.4.7—Social

Social care was by some distance the care theme with the lowest prevalence, apart from TB treatment which was only applicable to a minority of participants. In the Phase 1 focus group discussions, participants were generally happy with the clinical care they received but when asked about care they would like to have, IGA and microfinance were the most common. The difficulty of paying for the three essential costs of food, transport and school fees was a major theme of the qualitative data. Food and money were scarcely separated; the most common schemes involved providing chicks or seeds so participants could grow their own food and sell the surplus. In addition, IGA was held to have the further benefit of improving self-esteem and self-efficacy, proving that people with HIV were capable of work (**45**).

Home help and provision of household items were rarely received, either from the health facilities or from any other source. That said, some components of preventive care such as water treatment and ITNs could be considered household items as well as preventive items, and these were more commonly received.

9.4.8—Prevention

People with HIV are at increased risk of clinical malaria (**68**). The fact that 21–33% of participants received an ITN at each of four timepoints (usually from the facility) yet 36% never received one at all implies that some participants received more than one. This may not be the most efficient use of resources if the aim is to ensure that everyone with HIV sleeps under an ITN. Prevention with positives (PWP) is a package of interventions aimed at prevention further transmission of HIV and protecting the HIV positive individual from coinfection with other strains. It was one of the most widely received components of care.

9.4.9—ART

Almost 70% of participants received ART during the study period. It is possible that the sample was biased towards those receiving ART, as they may have had more frequent appointments than those not receiving ART and therefore more opportunities to be recruited into the study. Over time, there were some irregularities in reported receipt. Participants might have collected two months' worth of ART and not reported receipt in the second month. An alternative explanation is that some participants could have interrupted their schedule for different reasons, e.g., changing regimen due to toxicity, or taking ART for prevention of mother to child transmission (PMTCT).

Some facilities had inadequate levels of ART monitoring and support. Proper monitoring is essential to control side effects and prevent resistance. One possible consequence of beginning ART is immune reconstitution inflammation syndrome (IRIS), with symptoms such as fever arising from the restored immune system's response to a pre-existing infection (**69**).

9.4.10—CTX

CTX was the most widely accessed component of care, received at least once during the study period by 97% of participants. In Uganda, daily CTX has been shown to reduce morbidity and mortality of people with HIV(70). At every timepoint, about 5% of the sample reported taking CTX on the previous day despite not receiving it for daily use. This occurred with similar frequency at all facilities and so it is unlikely to be an error of understanding. More probably they were receiving a short course of CTX, for example to treat an infection.

9.4.11—TB

Tuberculosis is a very common cause of death for people with HIV (**71**) and HIV is the biggest risk factor for activating latent TB (**5, 72**). In hospital-based studies in Africa, 45–60% of people with HIV were coinfected with TB, and autopsy studies showed that TB was underdiagnosed by 50% even when it was the cause of death (**73**). In Uganda, 7.2% of people about to begin ART were diagnosed with TB (**26**), which is comparable to the point prevalence of TB treatment at each timepoint in this study. Isoniazid was rarely used as a prophylactic in this study, possibly because with a high population prevalence of TB it could be difficult to identify individuals at greater than average risk.

9.5—Health at the Beginning of the Study

The APCA African POS and MOS-HIV used to collect longitudinal data have both been validated for use with HIV positive patients in sub-Saharan Africa (**5, 74**) and have been used longitudinally (**75**), demonstrating their suitability for use in this study. The MOS-HIV and APCA African POS were well completed at all time points, apart from the three carer questions of the APCA African POS which were rarely completed due to the absence of a carer.

The MOS-HIV physical and mental health summary scores of the population at baseline were comparable to those found in other studies of HIV disease in the sub-Saharan African setting (**8, 11**). There is a strange pattern to the distribution of scores. They are designed to be Normally distributed around a mean of 50 with a standard deviation of ten (**12**) but in this population the upper part of the curve drops away very steeply, as though cut off. The reason for this is not known.

The APCA African POS measures multidimensional problems: pain and symptoms (physical); worry and being able to share feelings (psychological); finding life worthwhile and being at peace (spiritual); and having enough help and advice fro the family to cope (social). Each question is representative of clinical need and the items were not designed to be united into domains. APCA African POS scores showed that the psychological, social and spiritual dimensions of HIV infection caused more distress than the physical elements.

9.5.1—Problems Facing Caregivers

Only a minority of patients were accompanied by an informal carer, and they were biased towards worse physical health, so the findings related to carer-reported problems cannot be representative of those informal carers who (presumably) did not attend. The worst multidimensional problems reported by participants were not being able to share how they felt, and not having enough help and advice for the family to plan for the future.

At the same time, very few participants were accompanied by a friend or family carer. Most people felt that they were alone in dealing with their HIV and they came for treatment alone. The costs of getting to the care facility can be substantial in terms of transport fares and lost working time (**76**). An accompanying carer would double these costs. Another possible reason why some participants came alone is that they had not informed their family of their HIV diagnosis.

9.6—How Participants Differ by Facility

9.6.1—Participant Characteristics at Different Facilities

Facility 252 was a mission hospital which offered spiritual care to all its participants and social care to most. Participants there had the lowest wealth quintile average, the highest mean number of dependants, the lowest education level and the highest ratio of women to men. In general Facility 252 was the outlier while the other five facilities were comparable in most participant demographic characteristics. The three Kampala facilities (256, 258, and 259) all had a similar wealth quintile distribution and included the great majority of people in the wealthiest quintile.

Facility 252 was also the exception in that it did not recruit (or register) new patients during the study. This was because a decision was taken by the facility management to suspend recruitment of new patients as they had insufficient funds to deliver ART. Facility 256 specialised in voluntary counselling and testing, and recruited large numbers of patients via that route. Almost three quarters of participants enrolled at this facility had been diagnosed with HIV in the previous 14 days. The high proportion of participants at Facility 258 whose reason was an HIV test more than 14 days ago suggests that this facility often had a delay of several weeks between the positive test result and the first appointment.

9.6.2—Illness Severity at Different Facilities

Participants at Facilities 255 and 256 had the highest physical functioning. These were NGOs which encouraged voluntary counselling and testing.

The individuals with two CD4 counts may not be representative of everyone receiving care. They could have been newly initiated on ART and therefore more closely monitored, or they could have been particularly sick with a lower CD4 count. In addition, the time period between the two counts was different for each participant with a possible range of one month to 21 months. Thus the fact that the change in mean CD4 count was positive at three facilities and negative at the other three should not be taken to represent the level of care or participant health at these facilities.

9.6.3—Care Received at Different Facilities

Provision of spiritual, social and nursing care varied a great deal by facility. Almost everyone received some degree of prevention care, clinical care and pain management.

Facility 256 delivered care to the lowest proportion of its patients in every theme except for nursing care. The main reason for this is probably the higher levels of physical health enjoyed by Facility 256 participants at recruitment. The Phase 1 results do not suggest Facility 256 was greatly different to the others in terms of care offered, apart from providing ART by referral instead of onsite. Also, there was only one component (IGA) which it did not provide to any participant. Facility 259 also lacked one component (treatment for cryptococcal meningitis), Facility 260 did not provide seven of the components examined, including treatment for anxiety and depression, and facility 256 did not provide eight.

The maximum number of care components delivered may have depended on the resources available to the facility. The minimum number appears to have been more a matter of policy. Facilities 259 and 252 provided all their participants with a minimum of 11 and 14 components of care, respectively, suggesting that the facilities had a standard package of care they provided to all patients. Facilities 256 and 258 could not have had a similar policy because their minimum level of care delivery was, respectively, zero components and one.

Strangely, Facilities 252 and 256, which reported offering the most social care in Phase 1, actually delivered social care to less than 2% of participants. Facility 255 had the highest provision of the social care theme (76%), mainly due to the large number of people receiving IGA services.

9.6.4—Health at Baseline at Different Facilities

Participants at the different facilities did not begin with equal health scores. Facility 252, the facility with the poorest patients, unsurprisingly had the lowest mean physical health. The synergy between ill health and poverty is well known. Perhaps unexpectedly, given that physical and mental health were closely associated (Appendix I), Facility 252 did not have the lowest mean mental health score. Facility 256, which had the highest physical health score at 11 points above that of Facility 252, was only 1.3 points above it in mental health. The explanation may be that Facility 252 offered spiritual and social care to a higher proportion of its participants. As explained earlier, Facility 256 mainly recruited through VCT and its participants may have been physically healthier for this reason.

9.7—Participant Characteristics and Health

9.7.1—Gender, Age, Education

Older people experienced worse physical health, which is to be expected in a population aged from 18 to 70. Additionally, there is evidence that older age is associated with more rapid HIV disease progression(**11, 77**). Mental health was not associated with age even though mental and physical health scores were closely linked (Appendix I). Women and men had the same mean physical and mental health scores at baseline, which was also observed in other studies of people with HIV in Uganda (**75**).

9.7.2—Relative Wealth

Greater relative wealth was associated with better physical and mental health at baseline. These results are consistent with the literature on the effects of poverty and health in HIV, and may be caused by the wealthier having better nutritional intake and thus a more robust immune system, health-promoting infrastructure such as a latrine to reduce the risk of infections, more access to transport and medication which are major barriers to care (**78**). Meanwhile, poorer people may tolerate a higher burden of symptoms before spending money and lost work time on visiting a health centre.

It is important to remember that though this study showed the poorest people to have worse health, there is evidence that proportionate wealth is a risk factor for HIV infection (**79**). Poverty may exacerbate the effects of HIV while simultaneously decreasing the probability of infection. The wealth quintiles used in this study were generated from the dataset and can only be used to describe individuals relative to each other, not in absolute terms, thus it is not possible to link wealth to probability of recruitment, as it is with gender.

9.7.3—Illness Severity

All three health outcomes were more severe in the groups with lower CD4 count, agreeing with the evidence for reduced outcomes and quality of life for those with a lower CD4 count (**29**). Physical health score was particularly affected, shown by the high value of F (11.9).

Appendix I shows that when analysed as a continuous variable, mental health was not associated with CD4 count after controlling for physical health. This is not a case of overcontrolling, as physical health was still associated with CD4 after controlling for mental health. It is a real indication that mental health could not be predicted by the progression of disease. Those in the early stages were just as likely to suffer from anxiety, worry or depression as people with AIDS, after accounting for physical health.

The reason that CD4 was analysed categorically in the main body of the report and continuously in the Appendix is that the former was for clinical use and the latter for statistical use. It is the case that people with a CD4 count below 200 are likely, based on these results, to have impaired mental health. The further analysis demonstrates the mechanism, which is that this impairment is probably caused by poor physical health alone.

9.7.4—Individual Care Components

People who received ART or TB treatment in the month between T0 and T1 had worse physical and mental health summary scores than those who had not. In the case of TB it is not known whether the difference is caused by the symptoms of TB or whether TB is a proxy for more advanced HIV. The fact that people receiving TB treatment had a lower CD4 count suggests the latter is partly responsible.

This analysis is not a test of the effectiveness of ART at improving health outcomes. The study was observational and non-random, and ART recipients would have differed systematically from non-recipients.

Those who did not receive it comprised a mixture of people already registered at the facility who did not need ART, newly diagnosed individuals who did not yet need ART, and newly diagnosed individuals who did need it. The first two groups would be likely to have a higher physical score, the last group to have a lower score. The proportions of these groups to each other would determine mean physical score. The findings demonstrate the difficulty of linking care with outcomes.

9.7.5—Association of Outcomes with Loss to Follow-Up

Unlike traditional techniques for analysing longitudinal data, multilevel modelling can make efficient use of data with missing timepoints (**11**). The limitation is that at least two points must be present in order to calculate change. In this study, participants with fewer than four data points showed worse mental health than participants who completed all four. Traditional techniques would have removed these non-responders from analysis and created a bias towards better health.

On the other hand, there were no differences in health outcomes between those who completed only the first interview and those who completed more than one. Therefore, excluding the participants who completed only T0, as is required for longitudinal analysis, does not bias the population.

It is interesting to note that low mental health was significantly associated with loss to follow-up (p=0.003) but low physical health much less so (p=0.072), although both scores at baseline were equally predictive of change over time. In the study, participants were reimbursed their travel expenses, which may have biased follow-up rates away from the normal pattern of attendance. It is possible to speculate that depression, anxiety or discouragement were more likely than physical problems to deter health facility visits, and further analysis using attendance as an outcome variable might be able to explore this.

9.8—Changes in Health Over Time

The results show that participants who were newly diagnosed with HIV or had developed a new problem, attending PEPFAR-funded HIV care and treatment clinics, showed statistically and clinically significant improvements in their self-reported physical and mental health during the first three months of care. It is not possible to determine from these results whether the improvement was caused by the care they received or whether it would have happened in any case. However, improvement in health outcomes over time is contrary to the progressive trend of HIV disease.

The use of the MOS-HIV in longitudinal studies has been demonstrated in Uganda (**74, 80, 81**) and internationally (**1**). Some studies have been analysed using traditional methods and others using longitudinal analysis similar to that presented here. Unusually, this study was multicentred and the analysis included an adjustment for clustering by facility.

Over the three months of the study, five of the seven patient APCA African POS items showed improved mean scores, and the breakdown into more clinically relevant categories showed that there was a reduction in the proportion experiencing severe problems for all items. It appears that the physical problems of pain and symptoms were managed more successfully than the other dimensions of health.

Lack of help and advice, and inability to share feelings, the two items with the highest average scores at baseline, were the only two in which substantial numbers of participants still had severe needs after three months of care. Possibly the problems represented by these items take more time to resolve.

9.8.1—Changes in Health Over Time for Those in Most Need

It was of particular concern that individuals with the most severe problems as recorded on the APCA African POS should receive appropriate care. It was possible that the most intractable problems were not dealt with sufficiently, and that an average improvement in scores hid this. In fact, people with the worst baseline scores showed the most improvement. There is a tendency for outliers to converge to the mean, which increases the probability of improvement for those with low scores. The results should only be interpreted to mean that there is no evidence of unresponsive pain and symptoms, rather than positive evidence that the worst sufferers gained most.

9.8.2—Change in Health Over Time at Different Facilities

Facilities 259 and 252 showed greater change in physical health score than the others, particularly in later timepoints where they showed increasing improvement and the other four facility scores flattened out.. For mental health, Facilities 252, 259 and 256 experienced steady increase in mean scores while the other three levelled off. (It should be remembered that these curves are essentially made up of three points and so a small alteration to any data point is sufficient to change the entire shape of the graph.)

A possible explanation runs as follows. Facilities 252 and 259 provided more spiritual and psychological care than average. The results of the APCA African POS analysis suggest that these dimensions of health take longer to respond to care. Facilities which specialised in physical care generated an improvement in outcomes but the effect was not sustained after pain and symptoms had been controlled (shown by the decline in delivery of symptom management components after T1). Facilities 252 and 259 maintained the effect of increasing improvement in scores because they also delivered long-term psychological and spiritual care. Facility 256 did not demonstrate much improvement in physical health score because mean score was already high at T0 and unlikely to improve, potentially leaving staff the time to concentrate on mental health concerns.

9.9—Changes in Health Over Time in Detail

9.9.1—Participant Characteristics

Mental health score improved over time and was not associated with any demographic characteristics, while participants with more education or relative wealth benefited from increased gains in physical health. Mental health appeared to be more individual and less predictable both in its relationship with disease progression and its responsiveness to care.

9.9.2—ART and TB Treatment

Not only did participants receiving ART at the beginning of the study have lower than average physical and mental health, they also made smaller improvements over time. CD4 count was not sufficient to explain these findings. People on ART had poorer physical and mental health than their CD4 count alone might suggest. In other words, self-reported health did not keep pace with clinical outcomes.

The findings show that ART alone does not create optimal physical and mental health, and complementary multidimensional care and support is important to maximise self-reported health. Outcomes improved for ART recipients over time, showing that there is more opportunity for progress.

Participants receiving TB treatment had lower physical and mental health at the beginning of the study but they gained in mental health at the same rate as the rest of the study population, while physical health improvement was reduced. Indeed, the negative coefficient for TB was larger than the positive coefficient for time, suggesting that participants on TB treatment actually got worse over time in terms of physical health score.

9.9.3—Care Availability

Change in mental health score was not statistically associated with any care themes over time. This finding reflects the evidence from different stages of the analysis that mental health score at baseline and change over time were both individual and unpredictable, either by care receipt, CD4 count, or demographic characteristics. Physical health score was associated with pain management, symptom management and nutrition. Strangely, the associations were negative; receipt of care appeared to lessen improvement in physical health over time. However, the best predictor for health scores at T1, T2 or T3 was health score at baseline; the likely explanation for the results is that facilities with lower mean health scores at baseline were more likely to deliver these care themes to their patients. Multivariate modelling attempted to test this theory.

9.9.4—Multivariate Modelling and Further Exploration

Pain management, symptom management, nutrition, relative wealth and education level were included in a multivariate model of physical health, and after a process of reduction, nutrition was the only time-varying factor to remain. The result showed that at facilities where a larger proportion of participants received nutrition support, there was less improvement in physical health over time. Further analysis was necessary to understand this concerning result.

The graphs of nutrition care against outcome, and the collinearity of the care themes nutrition and symptom management, revealed the reason why nutrition appeared to reduce physical health gain. Essentially, the model was driven by unmet care need. It found an association between the extra care delivered to those in greater need and the gap that still remained between their scores and everyone else's. Therefore the associations were negative.

In the Kenya Phase 2 study, multivariate modelling did not identify care themes associated with health score outcomes, and the primary reason for this was a lack of variability between the facilities in both outcomes and care delivery. All six facilities offered similar care and gained equal improvement in health over time.

In the Uganda study, the problem was different. There was facility-level variation in both the needs of patients and the care they received. Appendix I shows highly significant ANOVA results comparing mean baseline outcome scores by facility. Some facilities had patients with greater mean physical health needs, and they provided them with more symptom management, nutrition and pain control. However, the additional care was still not sufficient to compensate for the lower starting point. Although they were more likely to receive nutrition, symptom management and pain control, their lower physical health scores on recruitment prevented them from attaining the health scores of participants at other facilities. Thus the results showed a negative correlation between care and outcomes. The disadvantages of low physical health at baseline were not outweighed by the greater probability of receiving appropriate care during the study period.

Appendix I also shows that the between-facility variation in physical health scores was twice that for mental health. Physical health was more closely associated with facility, one reason why the models for mental health score failed to show any association with care themes. It is useful to consider why facilities varied in the mean physical health of their recruited patients. The three Kampala facilities had higher scores than the rural ones. The reasons may be to do with access, availability of services, and poverty. Even when services are free, the transport to the facility and loss of work time impose costs on healthcare. HIV disease progression may also have been associated with greater need for symptom management and nutrition care.

10 Discussion of Qualitative Interviews

In this sample, a patient's carer might be their mother, sibling, daughter, spouse, friend or paternal aunt. Apart from married couples, the carer was usually of the same gender as the patient; brothers cared for brothers, daughters for mothers. Six women were caring for their husbands (sometimes sharing this duty with a co-wife), and only one man was caring for his wife. Studies in Africa show that people with HIV are most likely to first disclose their status to a relative or friend of the same gender, and that men are more likely than women to disclose to their sexual partner (**82**), matching the relationships of carers to patients. This suggests that carers could have been the first (or only) person to whom the patient disclosed their status.

The majority of patients, carers and staff reported positive experiences of PEPFAR-funded Care and Support. Patients felt very much part of the facility community, especially at those facilities which aimed for a holistic care approach. One facility has a policy of referring to its patients as 'friends', to encourage this sense.

There was virtually no limit to the help which might be asked of a care facility, including school fees, employment, funding for small businesses, IT training, sponsorship to record an album, construction of a house, adoption of children, and matchmaking. Where the effects of HIV have exhausted the reserves of community and family network resources (**83**), the care facility was expected to step in.

The repeated pleas for assistance also suggest a loss of self-efficacy and the demotivating effects of depression. The periods of illness and dependency in HIV disease damage self-esteem and lead to feelings of disempowerment (**84**). Patients and carers encouraged others to work, not to be discouraged; indeed, very often patients said that the care they received had given them "courage," which in context seems to mean will and spirit, the literal opposite of discouragement, rather than bravery. One of the reasons patients gave for requesting IGA and loans was to prove that with a little initial help they were still capable of earning a living. This finding was also observed in Phase 1.

The fact that financial needs were mentioned more often than clinical, emotional, social or psychological needs (which were all prevalent) indicated that for this group of patients and carers, health concerns were not the greatest source of need. In extreme poverty financial need equates to the need for food, according to Engel's law that proportion spent on food is inversely related to income (**85**).

Discrimination from the community was a problem. Some participants recommended an increase in HIV education and VCT promotion in order to reduce stigmatisation and abuse from the community.

Several patients reported that they had been advised to use condoms but that they now no longer wanted to have sex. Lack of interest in sex is a possible symptom of depression and is associated with impaired physical and mental health in a Ugandan HIV study (**77**).

11 Discussion of Costing Study

The main cost drivers for provision of care at the six facilities were ARVs, other drugs, staff, lab costs, and building rental. There were economies of scale, with larger facilities having lower costs per patient.

Providing care and support for HIV positive patients constitutes a significant part of national HIV/AIDS programs in general, and care and support is a focus of PEPFAR with its commitment to reach 12 million people with care services. In considering scale up and expansion of care and support services it is helpful to know the costs of such services. With almost 40 million people testing positive for HIV and nearly three million people already on ARVs (**77**), the financial sustainability of maintaining and expanding care is a challenge for the public health community.

The cost of providing comprehensive HIV care and support may vary significantly across country settings and program delivery approaches. Calculating care and support costs in a range of settings will provide estimates of annual per-patient care costs that are representative of Emergency Plan-supported programs. Understanding the contextual factors that affect the cost of providing comprehensive HIV care and support is important in interpreting comparative costs analysis across country and program settings.

The overall purpose of the costing component of this study was to estimate the average costs of providing care and support to a patient over a one year period. This could then be used to calculate life time care for patients as a function of their life expectancy, or be used to estimate scale-up requirements of program expansion. However, such modelling was not part of the present study.

12 Integration and Conclusions

Longitudinal quantitative study participants taking ART had lower physical and mental health than other patients, not only because of their CD4 count but because of other problems. Some of these were reported in the qualitative interviews. Issues such as the side effects and toxicity of ART, unmanaged pain, worry over the regular expenditure on transport, health impairment due to reduced spending in other areas such as food, and depression and isolation resulting from stigma, could all have contributed to the lower than expected health and slower improvement experienced by patients taking ART.

It is important to recognise that these findings do not imply patients would have been better off without ART. The analysis compared ART users to non-users, but in reality these groups were very different from each other in more ways than their medication. The non-ART group would largely have been those not yet eligible for ART, with less advanced disease, thus fewer health problems and better physical and mental health. The results show that ART recipients experience diminished self-reported health compared to people with early-stage HIV. They indicate that care and support are needed alongside ART to maximise its potential.

The descriptions of the outcomes of psychological and emotional care demonstrate the importance of this dimension of care. Despair, suicidal ideation and child abuse were all caused by psychological reactions to HIV diagnosis. In these circumstances, treatment such as ART would be of very limited benefit without addressing patients' mental health needs. There is evidence of high levels of depression (**57**) and post traumatic stress disorder (**86**) after HIV diagnosis.

There is some evidence that what was being observed in the qualitative interviews was the consequences of social breakdown due to HIV. It has been argued that the effects of HIV on society are qualitatively different from other stressors (**83**), and that HIV is associated with societal breakdown as the usual strategies for dealing with crisis fail to work (**87**). The person with HIV becomes sick, is less able to work and requires care, leaving the carer less able to earn income or grow food. As a result (**83**) "Given the nature of its impact, households severely affected by AIDS invariably need support in caring for those who are ill, food for the entire household, and assistance to keep children in school" (p. 628). Efforts to mitigate the financial stress include removing children from school, giving children caring responsibility, eating less, and sale of assets, representing short-term saving with long-term negative consequences. All of these responses were identified in the qualitative interviews.

A further problem in HIV is the uncertain trajectory and fluctuating health, coupled with the presence of invisible symptoms such as pain, fatigue, and depression, which were common in the study population. The traditional nature of the sick role, which is a temporary state when work duties are suspended and which depends on the patient making efforts to recover, does not apply in long-term illness (**54**). Patients can be seen as malingering, and denied care, or carers can find themselves dealing with emotional antagonism towards patients (**84**). Both of these effects were reported in qualitative interviews. In the long term, the supportive family network breaks down and patients are neglected (**87**). This is expressed as stigma.

The majority of participants in the longitudinal quantitative study did not receive socioeconomic care components such as food, employment training or microfinance schemes, but these components were very frequent concerns in the qualitative interviews. It was apparent that people hoped, or expected, the care facility would support them and their families in many ways. Staff also felt that financial support was necessary, especially for poorer families, those living in remote areas, and orphans.

The average longitudinal quantitative study participant was taking daily medication, receiving a mean of 12 other care components per month and visiting the health centre (a median of an hour's travel away) every month. The stress of attempting to adhere to this lifestyle, and pay for it, while keeping secret the reason for it had consequences described in the qualitative interviews as sleeplessness, worry, isolation, and fear. The consequences were also visible in participants' most commonly reported problems on the APCA African POS: being unable to share feelings (still a severe problem for 25% after three months of care), lack of help and advice to help the family cope, and not feeling at peace.

Staff in the qualitative interviews reported the difficulty of contacting family members, particularly men, and the problem of patients not disclosing their status to family. Carers found it difficult to take time away from their responsibilities and requested home visits. As a result of these problems, family information on VCT was the least often received component of the Preventive Care Package, at 49%. Patients who have not disclosed their status do not have access to the support of family networks, both emotional and practical (**88**), which improves their quality of life (**77**). Disclosure also has health benefits; maintaining a secret and holding back feelings causes stress which impacts on physical health (**89**). The advantage of non-disclosure is that patients and their families do not face the stigmatisation and rejection experienced by some interview participants and reported in the literature **(90, 91**).

Patients were encouraged to act as role models and they believed that this tactic was the most effective at persuading others to test. There is some evidence that people who have a friend with HIV are more likely to accept VCT (**92**) although the evidence for effect on behaviour change is mixed. For qualitative interview participants, a common reason for taking an HIV test was the experience of symptoms combined with knowing someone else who had tested positive. Rather than laying the responsibility for changing social attitudes on the shoulders of individual patients, community-level interventions are necessary to allow patients to disclose without fear of the consequences, and their families to receive the care they need.

Most people in the longitudinal quantitative study did not have a carer who came with them to the facility. Staff in the qualitative interviews believed the lack of carers was due to non-disclosure by patients, so that nobody was aware the patient needed help.

HIV prevention strategy has shifted since the 1990s from primary prevention (protecting the HIV-negative from infection by increasing knowledge, relying on the Health Belief Model) to secondary prevention (protecting the HIV-positive from transmission by empowerment and engagement) (**89**). As well as being a public health measure, PWP is designed to improve patients' quality of life (**89**) by releasing from stress caused by the burden of secrecy and improving feelings of self-worth and morale. Prevention with positives was one of the most widely received components of care in the longitudinal quantitative study and qualitative interview participants described their receipt of it, centring on encouragement to disclose their status to others and act as role models for VCT, and the ABC strategy. People with HIV show altruistic motives for prevention (**93**) as well as self-preserving motives of avoiding reinfection, and both were observed in the interviews.

Facility 252, which had the highest per-patient costs, had been unable to admit newly diagnosed patients because of lack of resources; specifically, because it would not be able to enrol any more patients onto ARVs. The largest cost driver at Facility 252 was ARVs, but these were donated and the real cost was not borne by the facility. The next highest cost driver is for building costs and utilities, possible due to its remoteness, few suppliers and the necessity of high transport costs.

12.1—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 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 the issues causing most concern to patients. Qualitative interviews supported this evidence that pyschological 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.

12.1.1—Longitudinal Quantitative Study

Strengths: The facilities involved in Phase 1 were selected at random (**29**), thus reducing response bias (facilities confident in the outcomes of their care being more likely to respond to an invitation to participate than others). In phase 2 facilities were selected purposively (by size), and no facilities refused to participate. The longitudinal nature of the study design enabled the change in patient outcomes to be monitored over time, thus overcoming the limitation of a before and after study design (**13**).

Eligible patients were those who were new to the facility or who were presenting with a new problem. These criteria were applied to maximise the potential of detecting any influences of care on patient outcomes in the short follow up time available for this study. Given the chronic illnesses associated with HIV infection, it seemed there was a high possibility of recruiting a great proportion of patients to the study who had had the same illness for a long time, and so were unlikely to change their health outcomes in three months. There was a high response rate and low level of patients leaving the study over the three months.

The difficulty identifying whether patients had received weak opioids at Facility 258 seems to have been the only problem with comprehension. This suggests a gap in knowledge, but its existence adds support to the rest of the data because it suggests social desirability bias did not hinder participants from admitting ignorance. Subsequent patients were asked to participate if they met the inclusion criteria, until the desired number had been recruited. This minimised the possibility of healthcare workers recruiting patients who they thought likely to have favourable outcomes. There were no facilities which struggled to recruit sufficient numbers.

The concise and multi-dimensional nature of the APCA African POS means this study provides valuable data on the multi-dimensional wellbeing of HIV positive patients accessing outpatient clinics in sub-Saharan Africa, and this has potential for future clinical and research uses.

Limitations: The facilities involved in Phase 2 do not necessarily represent the diversity of geography, relative wealth of the facility catchment areas, facility funders, service provision or other aspects that may affect service provision, quality of care, facility attendance or response to treatment. Some of these factors (e.g. relative wealth of the patients, care received at the facility) were measured for individuals and so were accounted for in the analysis. The chance event of selecting three facilities in Kampala, two in other major towns and one very rural, biased the results in (with hindsight) predictable ways.

Facility 256 had a higher dropout rate than others, for reasons discussed above. A high loss to follow-up is a cause of bias. It is unknown which individuals are most likely to remain in the study. Most people left the study for unknown reasons, which means they probably did not return to the facility at all and so the reason could not be ascertained. Thus they did not receive care from the facility. It seems likely that people with greater physical needs might be more likely to attend for care. On the other hand, people with psychological needs might be more likely not to attend, being unable to accept the diagnosis, or concerned about their status being discovered.

One source of bias for the study is the fact that all six facilities cared for outpatients only. People who needed inpatient care were referred to the main hospital and were not referred back to the HIV centre until they were discharged. Thus the people who probably had the most severe symptoms, lowest CD4 count and were most in need of care do not appear in this study. The APCA African POS total score has not previously been calculated and the tool was not designed to be so summarised, although the separate items have been assessed in a validation study of reliability and sensitivity (**33**).

A large number of statistical tests increases the probability of falsely identifying connections. In this study, five demographic covariates plus eight care themes were each modelled separately with two outcome variables, making 26 models. Stepwise downward regression was later used to rule out any covariates which might have been included due to Type II error.

The CSRI recorded the receipt of 52 items of care. It is possible that the tool excluded some items of care, the receipt of which could potentially have been influencing health outcomes. The act of undertaking the study may have influenced the care given, and thus may have affected participant outcomes in a way that normal care would not have shown. Furthermore, even the process of asking a series of questions about how patients feel could be viewed as a form of care in itself, or it might have revealed problems to the health provider that a normal consultation would not have detected.

Analysis of the lowest-scoring individuals to observe change over time is vulnerable to bias caused by regression to the mean. People with a lower score have a greater probability of improved score over time. Therefore, the fact that the people scoring zero on APCA African POS items experienced a greater rise in score than the mean for the entire group should be treated with some caution.

12.1.2—Qualitative Iinterviews

There are several strengths and limitations to the qualitative data. Firstly, although the views of patients, carers and staff were captured in this study, which gave views from the key individuals involved in patient care, respondents were identified by the participating facilities, which may have introduced bias. Second, as the interviews were conducted in a range of languages they had to be analysed in the common language of English.

Although this raised issues of translation and interpretation it allowed respondents to express themselves freely without the constraints of translating their thoughts to a less familiar language. Furthermore, the protocol ensured that interpretation of the local meaning was established. The interviews were coded twice by independent researchers in the UK and Kenya. This process gave rigour to the coding process by reducing individual bias in interpretation. In addition, the cross-country coding allowed the possibility of culturally different interpretations to arise and be discussed.

12.1.3—Costing Study

Care and support is the aggregate of many services, (psychological support, ART, pain management, etc.) The average cost of care for patients will therefore be the aggregate of the costs of providing these individual components. Although this study examined drug, staff, laboratory and facility running costs, the costs per patient for individual components of care could not be calculated. The cost of drugs other than ARVs was a particularly difficult area. A small selection of drugs relevant to HIV care were identified, but the proportion of total drug costs spent on these would depend partly on the extent of the range of drugs offered by the facility.

For other components of care where the cost drivers were higher for staff time than for drugs, such as counseling services, it was not possible to allocate proportional staff time to the specific components of care sufficiently well.

The facilities received funding from the Ministry of Health and in some cases from other donors as well as PEPFAR funding which came through partner organisations. The amount of funding received from PEPFAR and the proportion of its budget that this represented is not known, thus costs at the facility, rather than direct costs to PEPFAR, are the aim of analysis.

Care and support is provided not only at facilities but also in many cases by communities, at the family or household level or by FBOs/NGOs all of which incur costs and contribute to the overall costs of care for a patient. Individual patients may also incur costs in terms of time off of work (lost income) or the opportunity costs of their time in productive work and for transportation. Due to funding limitations, this study only looked at facility-based costs. Other areas of cost which were not represented include those incurred by program managers at the donor level, administration of donor-funded programmes, and training of specialized care and support for HIV positive patients.

Lastly, the study did not take account of cost savings associated with averted illnesses or reduced in-patient costs as a result of effective care and support.

13 Recommendations

13.1—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 worse self-reported physical and mental health 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.

13.2—For Health Facility Managers

- Home-based care should be encouraged, so that family carers can receive support and services such as VCT, 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.

13.3—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.

13.4—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 problems of this important population, particularly the expanding group of HIV positive older children for whom optimal care is still being developed
- Shortage of 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 and 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.

A Demography

P1	Please indicate the patient's gender		**male=1, female=2**	☐

I would like to ask you a few questions about your background:

P2	How old are you (years)?			☐☐
P3	What is the highest level of education you attended?		**none=1**	☐
			attended primary=2	
			attended secondary=3	
			diploma=4	
			degree or higher=5	
P4	What is the main material used to make the floors of your house?	natural	**earth, mud, sand=1**	☐
		finished	**cement=2**	
			linoleum=3	
			parquet/polished wood=4	
			tile=5	
			carpet=6	
			stone=7	
P5	What is the main material used to make the walls of your house?	natural	**thatched/straw=1**	☐
		rudimentary	**mud and poles=2**	
			un-burnt bricks=3	
			burnt bricks with mud=4	
		finished	**cement blocks=5**	
			stone=6	
			Wood timber=7	
			burnt bricks with cement=8	
P6	What is the main material used to make the roof of your house?	natural	**thatched=1**	☐
		finished	**wood/planks=2**	
			corrugated iron sheets=3	
			asbestos=4	
			tiles=5	
			tin=6	
			cement/concrete=7	
P7	What type of toilet do you use at home?		**private flush=1**	☐
			private VIP latrine =2	
			private traditional pit (covered)=3	
			private traditional pit (uncovered)=4	
			public/shared=5	
			bush/field/other=6	
P8	How far from the facility do you live? (kilometres) If not known, ask for means of travel and time taken to estimate distance.		**don't know=888**	☐☐☐ km

P9	What is the main source of drinking water for your house?	safe **bottled=0** **piped inside house=1** **piped outside house (yard, public tap)=2** **protected well=3** **borehole=4** **spring/rain water=5** unsafe **unprotected well=6** **river/stream/pond=7** **tanker truck=8**	☐
P10	What type of fuel does your household mainly use for cooking?	**electricity=01, lpg/natural gas=02** **biogas=03, paraffin/kerosene=04** **coal=05, charcoal from wood=06** **firewood=07, straw/shrubs/grass=08** **dung=10, no food cooked in household=11**	☐☐
P11.1	Does anyone in the household own a …? car	**yes = 1, no = 2**	☐
P11.2	bicycle		☐
P11.3	refrigerator		☐
P11.4	television		☐
P11.5	mobile phone		☐
P11.6	radio		☐

Now I would like to ask you a few questions about your HIV diagnosis:

P12	What date did you enrol into this facility?	**dd/mm/yy** **unknown day= 15, unknown month= 06, unknown year =888888**	☐☐☐☐☐☐
P13	why did you visit this facility today?	**new illness/well-being issue = 1** **referred = 2 (from where)** **obtain medication = 3** **HIV test result = 4** **other = 5 (specify)**	☐ Place from which referred (2), or other reason for attending (5): ____________________
P14	date diagnosed HIV+	**dd/mm/yy** **unknown day= 15, unknown month= 06, unknown year =888888**	☐☐☐☐☐☐
P15	date started on ARV treatment	**dd/mm/yy** **unknown day= 15, unknown month= 06, unknown year =888888** **777777=not on ARV**	☐☐☐☐☐☐
P16	Current WHO clinical stage (1-4)	**8=don't know**	☐
P17	Most recent CD4 count	**don't know=8888**	☐☐☐☐
P18	date of most recent CD4 count	**dd/mm/yy** **unknown day= 15, unknown month= 06, unknown year =888888**	☐☐☐☐☐☐
P19	How many dependants do you have? (family members who are dependent on you including children)		☐☐

B APCA African POS and ECOG

date ☐☐☐☐☐☐

The APCA African POS & ECOG

Question number	ASK THE PATIENT Questions 1-7	POSSIBLE RESPONSES	ANSWER
Q1	Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 days	**0 = No pain at all** **1 = Slight pain** **2 = Moderate pain** **3 = Severe pain (interferes with activities of daily life)** **4 = Very severe pain** **5 = Overwhelming. The worst pain you can imagine**	☝
Q2	Have any other symptoms (e.g. nausea, coughing or constipation) been affecting how you feel in the last 3 days?	**0 = no, not at all** **1 = slightly** **2 = moderately** **3 = severely** **4 = very severely** **5 = overwhelmingly**	☝
Q3	Have you been feeling worried about your illness in the past 3 days?	**0 = Not at all worried** **1 = Worried very occasionally** **2 = Worried some of time** **3 = Worried a lot of the time** **4 = Worried most of the time** **5 = Worried all of the time**	☝
Q4	Over the past 3 days, have you been able to share how you are feeling with your family or friends?	**0 = Not at all** **1 = Only once** **2 = Occasionally** **3 = Fairly frequently** **4 = Often** **5 = Yes, I've talked freely**	☝
Q5	Over the past 3 days have you felt that life was worthwhile?	**0 = Not at all** **1 = Not very often** **2 = Occasionally** **3 = Some of the time** **4 = Most of the time** **5 = Yes, all the time**	☝
Q6	Over the past 3 days, have you felt at peace?	**0 = Not at all** **1 = Not very often** **2 = Occasionally** **3 = Some of the time** **4 = Most of the time** **5 = Yes, all the time**	☝
Q7	Have you had enough help and advice for your family to plan for the future?	**0 = None** **1 = Very little** **2 = For a few things** **3 = For several things** **4 = For most things** **5 = As much as wanted**	☝
	Thank the patient		

date ☐☐☐☐☐☐

	ASK THE CARER Questions 8, 9 and 10 ONLY if consent given by patient and carer		
Q8	How much information have you and your family been given?	**0 = None 1 = Very little 2 = Some 3 = Quite a lot 4 = A great deal 5 = As much as wanted 7 = N/A, no carer/consent not given 8 = carer not present at time of interview**	☝
Q9	How confident does the family feel caring for ____?	**0 = Not at all 1 = Not confident about many things 2 = Confident about a few things 3 = Confident about some things 4 = Confident about most things 5 = Very confident 7 = N/A, no carer/consent not given 8 = carer not present at time of interview**	☝
Q10	Has the family been feeling worried about the patient over the last 3 days?	**0 = Not at all worried 1 = Worried very occasionally 2 = Worried some of time 3 = Worried a lot of the time 4 = Worried most of the time 5 = Worried all of the time 7 = N/A, no carer/consent not given 8 = carer not present at time of interview**	☝
	ECOG (rated by the interviewer)		
Q11	Physical function of patient	**0= fully active, able to carry on all pre-disease performance without restriction 1=Restricted in physically strenuous activity but ambulatory and able to carry out light work, e.g., light house work, office work 2=Ambulatory and capable of all selfcare but unable to carry out any work activities. Up and about more than 50% of waking hours 3=Capable of only limited selfcare, confined to bed or chair more than 50% of waking hours 4=Completely disabled. Cannot carry on any selfcare. Totally confined to bed or chair**	☝

C MOS-HIV

date

The MOS-HIV

Question number	QUESTION	POSSIBLE RESPONSES	ANSWER
I would like to ask you a few questions about your health.			
Q1	In general would you say your health is:	**Excellent=1** **Very good=2** **good=3** **fair=4** **poor=5**	☝
Q2	How much *bodily* pain have you generally had during the past thirty days?	**None=1** **Very mild=2** **Mild=3** **Moderate=4** **Severe=5** **Very severe=6**	☝
Q3	During the past thirty days, how much did pain interfere with your normal work, including both work outside the home and housework?	**Not at all=1** **A little bit=2** **Moderately=3** **Quite a bit=4** **Extremely=5**	☝
The following questions are about activities that a person might do during a typical day. Does your health now limit you in the following activities? And if so, how much?			
		Yes, limited a lot=1 **Yes, limited a little=2** **No, not limited at all=3**	
Q4.1	The kinds or amounts of vigorous activities you can do like digging, fetching water from a well, carrying a load, splitting firewood, running, lifting heavy objects or engaging in strenuous sports		☝
Q4.2	The kinds of moderate activities you can do like washing clothes, moving a jerrican of water or cleaning the house		☝
Q4.3	Walking up hill, climbing stairs		☝
Q4.4	Bending, lifting light objects or kneeling		☝
Q4.5	Walking a moderate distance, like the length of a football pitch or taking a village walk		☝
Q4.6	Feeding, dressing or bathing yourself or ability to use the latrine		☝

date ☐☐☐☐☐☐

The following questions are about work. Does your health now restrict you in doing the following kinds of work?			
Q5	Does your health keep you from working at a job, doing work around the house or attending school?	**Yes=1** **No=2**	☝
Q6	Have you been unable to do certain kinds or amounts of work, housework, schoolwork, because of your health?	**Yes=1** **No=2**	☝
For each of the following questions, please tell me the answer that comes closest to the way you have been feeling.			
	(Interviewer must begin by reading this introductory question to the patient) ***How much of the time during the past 30 days:***	**All of the time=1** **Most of the time=2** **A good bit of the time=3** **Some of the time=4** **A little of the time=5** **None of the time=6**	
Q7	Has your health limited your social activities, like visiting with friends or family?		☝
Q8.1	Have you been a very nervous person?		☝
Q8.2	Have you felt calm and peaceful?		☝
Q8.3	Have you felt depressed?		☝
Q8.4	Have you been a happy person?		☝
Q8.5	Have you felt so depressed that nothing could cheer you up?		☝
Q9.1	Did you feel full of life and energy?		☝
Q9.2	Did you feel totally without energy?		☝
Q9.3	Did you feel tired?		☝
Q9.4	Did you have enough energy to do the things you wanted to do?		☝
Q9.5	Did you feel weighed down by your health problems?		☝
Q9.6	Were you discouraged by your health problems?		☝
Q9.7	Did you feel despair over your health problems?		☝
Q9.8	Were you afraid because of your health?		☝
	(Interviewer must begin by reading this introductory question to the patient) ***How much of the time during the past 30 days:***	**All of the time=1** **Most of the time=2** **A good bit of the time=3** **Some of the time=4** **A little of the time=5** **None of the time=6**	
Q10.1	Did you have difficulty reasoning and making decisions, for example, making plans or learning new things?		☝

date ☐☐☐☐☐☐

Q10.2	Did you forget things that happened recently, for example, where you put things or when you had appointments?		☝
Q10.3	Did you have trouble keeping your attention on any activity for long?		☝
Q10.4	Did you have difficulty doing activities involving concentration and thinking?		☝
	Please tell me the answer that comes closest to describing whether the following statement is true or false for you.	**Definitely true=1** **Mostly true=2** **Don't know=3** **Mostly false=4** **Definitely false=5**	
Q11.1	You are somewhat ill		☝
Q11.2	You are as healthy as any other person you know		☝
Q11.3	Your health is excellent		☝
Q11.4	You have been feeling bad recently		☝
Q12	How has the quality of your life been during the past thirty days? That is, how have things been going for you?	**Very well, could hardly be better=1** **Pretty good=2** **Good and bad parts about equal=3** **Pretty bad=4** **Very bad, could hardly be worse=5**	☝
Q13	How would you rate your physical health and emotional condition now compared to thirty days ago?	**Much better=1** **A little better=2** **About the same=3** **A little worse=4** **Much worse=5**	☝

D CSRI

CSRI date ☐☐☐☐☐☐

Ask the patient if they have received the following care in the last 30 days

	Category of care	Component of care	have you received this care from any facility in the last month? **1=yes, 2=no, 8=don't know**	If yes, where? **this facility=1** **elsewhere=2** **If A=2 or 8, B=7**
Question number		**Question section:**	**A**	**B**
C1	**Spiritual**	visit by pastor etc	☐	☐
C2		prayer with staff	☐	☐
C3		contact with traditional healer	☐	☐
C4	**Psychological**	pre and post test counselling	☐	☐
C5		adherence counselling	☐	☐
C6		family planning counselling	☐	☐
C7		patient HIV support groups	☐	☐
C8		family counselling	☐	☐
C9		psychiatric therapy	☐	☐
	Clinical	**Prevention**		
C10		prevention with positives	☐	☐
		General		
C11		wound care	☐	☐
C12		other nursing care	☐	☐
C13		ART/ARV	☐	☐
C14		assess ART treatment	☐	☐
		Pain		
C15		assessment of pain	☐	☐
C16		strong opioids eg morphine	☐	☐
C17		weak opioids eg codeine	☐	☐
C18		non-opioids eg paracetemol	☐	☐
C19		treatment for neuropathic pain	☐	☐
		Symptom management		
C20		anxiety/depression treatment	☐	☐
C21		treatment for nausea/vomiting	☐	☐
C22		treatment for skin rash/itching	☐	☐
C23		treatment for diarrhoea, including ORS or drip	☐	☐
C24		treatment for constipation/laxatives	☐	☐
C25		treatment for genital thrush	☐	☐
C26		treatment for oral thrush/candidiasis	☐	☐
C27		treatment for cryptococcal meningitis	☐	☐

	Category of care	Component of care	have you received this care from any facility in the last month? **1=yes, 2=no, 8=don't know**	If yes, where? **this facility=1** **elsewhere=2** **If A=2 or 8, B=7**
Question number		**Question section:**	**A**	**B**
C28		treatment for other fungal infections	☐	☐
C29		treatment for herpes (e.g. acyclovir)	☐	☐
C30		treatment for malaria	☐	☐
C31		TB testing	☐	☐
C32		TB treatment	☐	☐
C33		therapeutic feeding for severe malnutrition, i.e. drip	☐	☐
C34		treatment for other opportunistic infections	☐	☐
C35		management of cancer	☐	☐
C36		physiotherapy i.e. excercises to help improve movement	☐	☐
		Prophylaxis		
C37		food	☐	☐
C38		multivitamins	☐	☐
C39		nutritional advice	☐	☐
C40		provided access to safe drinking water at home	☐	☐
C41		septrin/cotrimoxazole to take every day	☐	☐
C42		isoniazid (INH) to prevent TB	☐	☐
C43		condoms	☐	☐
C44		mosquito bednets	☐	☐
C45	**Social**	provide household items	☐	☐
C46		home help e.g. help with bathing, housework, cooking	☐	☐
C47		employment training/IGA	☐	☐
C48		transport/money for bus to care centre	☐	☐
C49		legal services	☐	☐
C50		memory book work	☐	☐
C51		loans/microfinance	☐	☐
C52		infection control training	☐	☐
C53	Did you sleep under a bednet last night?	**1=yes, 2=no**	☐	
C54	Did you take cotrimoxazole yesterday?	**1=yes, 2=no**	☐	
How much have you spent on your care in past month (inclu transport to facility and drugs)				
C55	at this facility?		☐☐☐☐☐☐☐☐	shillings
C56	anywhere else?		☐☐☐☐☐☐☐☐	shillings

Thank patient

E

Patient Qualitative Interview Schedule

- » Introduce self and background
- » Introduce project
- » Explain how patient selected
- » What we will talk about
- » How long it will last
- » Consent and confidentiality
- » Collect consent now
- » Tape recording and destruction
- » What will happen with data
- » Who to speak to if they have any questions
- » Complete basic demographic information about patient

- *Age*

- *Gender*

- *Household size*

- *Household location (urban, peri-urban, rural)*

- *Currently using ART (yes/no)*

- *History*
  - How did you come to find/access the facility?

  - Why did you come to this facility?

  - How easy/difficult was it to become a patient here?

- *Contact*
  - How often do you come to this service?

  - What do you attend the service for?

  - How satisfied are you with the service you receive?
    - * *What is good about it?*
    - * *What is not so good about it?*

  - (If the patient receives medicines) What problems, if any, have you had getting medicines?

- *Need*
  - What would you say are your biggest problems in relation to your HIV diagnosis?
    - * *Suggestions to help patient: These could be anything, such as getting to the facility, pain or other symptoms, childcare, anxiety, etc.*

  - Do you have any other pressing problems that may not be obviously related to HIV?
    - * *Suggestions to help patient: Again, these could be anything such as family relationships, food, etc.*

  - How does the facility help you with these problems, if it does?

  - What help do you currently receive (including medications) from this facility?

  - When you see the health worker, what do you talk about with them?

  - Do they ever talk with you about:
    - * *Spiritual care?—what specifically do they ask/do?*
    - * *Clinical care?—what specifically do they ask/do?*
    - * *Ways to prevent infecting others with HIV?—what specifically do they ask/do?*
    - * *Emotional/psychological well-being?—what specifically do they ask/do?*
    - * *Social or financial issues?—what specifically do they ask/do?*
    - * *General advice and communication skills for you?—what specifically do they ask/do?*

  - Are there ever any things you need or problems you have that you don't talk about?

  - What else does the health worker do for you?

  - Do you feel that staff ever treat you differently from other patients because you have HIV?

  - What would you like an HIV care service to do for you, what things would you need?

  - Which other health services do you go to?
    - * *Why do you go there?*
    - * *What things do you get there?*

  - We are coming to the end of the interview. Is there anything we haven't asked about that is important to you? Do you have any questions?

Thank the patient.

F Carer Qualitative Interview Schedule

- » Introduce self and background
- » Introduce project
- » Explain how patients selected
- » What we will talk about
- » How long it will last
- » Consent and confidentiality
- » Collect consent now
- » Tape recording and destruction
- » What will happen with data
- » Who to speak to if they have any questions
- » Complete basic demographic information about carer

  - *Age*

  - *Gender*

  - *Household size*

  - *Household location* (urban, peri-urban, rural)

  - *Relationship to patient*

  - *Contact*
    - How often does your relative see the service?

    - What do they attend the service for?

    - How satisfied are you with the service they receive?
      - * *What is good about it?*
      - * *What is not so good about it?*

    - Do you collect any medicines from the facility for them?
      - * *If so, what problems, if any, have you had getting medicines for the patient?*

  - Need
    - What would you say are your biggest problems in relation to the patient's HIV diagnosis?
      - * *Are there any other pressing problems you have that may not be obviously related to HIV?*

    - How does the facility help you with these problems, if it does?

- Do you ever see a health worker?
  - * *If you see the health worker, what do you talk about with them?*
  - * *Do they ever ask you about any problems/questions you have as a carer/relative of the patient with HIV (try to use the patient's name)?*

- Does the health worker talk to you or your relative about:
  - * *Spiritual care?*
  - * *Clinical care?*
  - * *How to prevent infecting others with HIV?*
  - * *Emotional/psychological wellbeing?*
  - * *Social or financial issues?*
  - * *General advice and communication skills?*

- What else does the health worker do?

- What would you like an HIV care service to do (i.e., what things would you, the patient, or your family need)?

- We are coming to the end of the interview. Is there anything we haven't asked about that is important to you? Do you have any questions?

Thank the carer.

G Staff Qualitative Interview Schedule

- » Introduce self and background
- » Introduce project
- » Explain how staff member selected
- » What we will talk about
- » How long it will last
- » Consent and confidentiality
- » Collect written consent
- » Tape recording and destruction
- » What will happen with data
- » Who to speak to if they have any questions:

- *About you*
  - What is your job title?

  - How long have you worked at this facility?

- *Access*
  - What criteria, if any, do you have for patients who want to access your service?

  - Are you able to accept all the patients that wish to access your service?
    - * *(If not) How do you choose them?*

  - Are there any costs to patients?

- *Contact*
  - How often/where do you see patients? (i.e. regularity of appointments)

  - Do you ever see their families?
    - * *If so are you expected to offer support to them also?*
    - * *In what ways?*
    - * *Do you?*

  - How do patients get in touch with you?

  - Can you describe the average patient encounter:
    - * *What standard forms/reporting, if any, do you have?*
    - * *What do you ask/record?*

  - What sorts of things do you to talk with the patient about? (For the following areas of care include the following areas of enquiry: do you talk about it? What do you ask? What do you do? Is it part of your job? If not, whose? Do you refer them on in these cases? Are you confident/do you feel able to offer this care?). Prompt:
    * *Spiritual care*
    * *Clinical care*
    * *Ways to prevent HIV transmission*
    * *Emotional/psychological wellbeing*
    * *Social/economic wellbeing*
    * *Bereavement*

  - What do you give them?

- *Care and referrals*
  - What is the difference between caring for early and advanced disease patients with HIV?

  - What happens with dying patients?

  - Do you ever refer HIV patients on to other facilities?
    * *For what?*

- *Multiprofessionalism and training*
  - Do you work with other health care workers in your facility, and if so, how?

  - What sort of problems do you not ask patients about as it someone else's work?

  - What supervision do you receive/give to workers?

  - What training have you had?

  - What extra training would you like?

  - What do you consider to be your own personal skills and strengths in caring for HIV patients?

  - Where do you feel you could do better?

- *Components of care*
  - What problems, if any, do you find with supplying medicines to patients?
    * *Which ones do you use most/least?*
    * *What medicines don't you have that you'd like to have?*

  - If you could add extra services to your facility what would you like to provide?

- Are there any problems relating to HIV that you can't manage in your facility (e.g., severe pain, depression, poverty)?
  * *Is there anything you do for patients in these situations?*

- Do you refer patients to any other services?
  * *What for?*
  * *Please can you describe the process of referring a patient (i.e., details of any written information, patient follow-up, communication with the other facility)*

- *Evaluation*
  - What are the strengths of your facility?

  - What are the weaknesses of your facility?

  - What main challenges do you face in terms of sustainability for your facility?

  - We are coming to the end of the interview. Is there anything else important to you that you would like to say?

H Costing Instrument

facility number **Date**

Completed by : Mackuline Atieno

Names of those interviewed

Accountant:

Pharmacist:

Clinician (drugs, lab tests etc):

(1) Patient numbers

1 total # individuals cared for in past year (2007):

2 # individuals provided with any HIV care in past year (2007), including ART and non-ART:

3 of those, # individuals provided with ART in past year (2007):

NB: all following questions refer to **HIV care only and in the context of patients being HIV positive**

(2) staff

ask a range of staff (doctor, nurse, counsellor, CHW)

	staff type	number of HIV patients you see in a typical day	# hours spent with HIV patients per week	hours worked per week
4.1.1	doctor 1			
4.1.2	doctor 2			
4.2.1	nurse 1			
4.2.2	nurse 2			
4.3.1	counsellor 1			
4.3.2	counsellor 2			
4.4.1	community health worker 1			
4.4.2	community health worker 2			
4.5	*clinical officer*			
4.6	*pharmacist*			
4.7	*lab staff member*			
4.8	*nutritionist*			
4.9	*social worker*			
4.10	*physiotherapist*			

facility number ☐☐☐ **Date** ☐☐☐☐☐☐

	(3) medicines		**ask pharmacist Option A**	**OR ask clinician/pharmacist option B**	
	medicine		**Actual** quantity dispensed in Feb-April 2008(tabs)	**Estimated** quantity used by typical pt in 3 mths (tabs)	
				on ART	pre-ART
5	Abacavir (ABC)				▨
6	Didanosine (ddI)				▨
7	Efavirenz (EFV)	600mg			▨
8	Indinavir (IDV)	400mg			▨
9	Lamivudine (3TC)	150mg			▨
10	Lopinavir (LPV) + Ritonavir (RTV)	200/50mg			▨
11	Nelfinavir (NFV)				▨
12	Nevirapine (NVP)	200mg			▨
13	Stavudine (d4T)	30+40mg			▨
14	Stavudine + Lamivudine				▨
15	Stavudine + Lamivudine + Nevirapine				▨
16	Tenofovir (TDF)	300mg			▨
17	Tenofovir + Emtricitabine (FTC)				▨
18	Zidovudine (ZDV)	300mg			▨
19	Zidovudine + Lamivudine	300/150mg			▨
20	Zidovudine + Lamivudine + Nevirapine				▨
21	strong opioids eg morphine				
22	Septrin/cotrimoxazole				
23	weak opioids eg codeine				
non-opioid painkillers (name 3 most common)					
24.1	1 Paracetamol				
24.2	2 Brufen				
24.3	3 Aspirin				
25	**TB Treatment**				

facility number **Date**

(3) medicines continued **ask pharmacist Option A** **OR ask clinician/pharmacist option B**

		medicine	**Actual** quantity dispensed in Feb-April2008 (tabs)	**Estimated** quantity used by typical pt in 3 mths (tabs)	
				on ART	pre-ART
		other antibiotics for opportunistic infections (name 3 most common)			
26.1	1	Cefzil (500mg)	0		
26.2	2	Amoxil (500mg+250mg)	0		
26.3	3	Doxycycline	0		
		Name 2 most common **first** line ART regimens:		**Estimated** number of patients on this regimen	
27.1	1.___	Stavudine+lamivudine+nevirapine			
27.2	2.___	Zidovudine+lamivudine+nevirapine			
		Name 2 most common **second** line ART regimens:			
28.1	1.___	Zidovudine+lamivudine+lopinavir/ritonavir			
28.2	2.___	Abacavir+didnosine+lopinavir/ritonavir			

(4) lab tests

ask lab staff and doctor **Option A** **or Option B**

	test	**Actual** number of tests this facility conducted in Feb-April 2008	**Estimated** number of tests a typical patient receives in 3 months	
			on ART	pre-ART
29	liver function test (LFT)			
30	AFB smear (TB)			
31	CD4 count			
32	haemotology test (FHG)			
33	viral load			

facility number | | | | **Date** | | | | | | |

(5) building infrastructure and utilities (all, not only HIV) ask accountant/manager

34	Utility costs per month (shillings) Include water, electricity, generator fuel, communications, waste disposal etc	0
35	Transport costs, fuel, drivers, maintenance (shillings)	0
36	Clinical consumable costs per month (shillings) Include gloves, syringes, cotton wool swabs, plasters, soap, sterilising solution etc	0
37	amount spent on volunteer staff (inclu training, travel reimbursements, payment in kind) in past 3 months (shillings)	0

(6) capital costs ask accountant

38	approximate **total** facility space (sq m)	
39	approximate facility space for HIV care (sq m)	
40	rent per month, or estimated rental value	
41	number of four-wheeled vehicles	
42	number of two-wheeled vehicles	

I Further Quantitative Analysis

Loadings onto Wealth Factor

Table 72 shows the contribution of each variable to the single factor, with the exception of six variables which did not contribute at all. The variables loading most heavily onto the factor were having an earth floor, using firewood or straw as cooking fuel and having a thatched roof, loading negatively, and having piped water (either inside or outside the house) and owning a mobile phone or television, loading positively.

Table 72: Loadings onto Wealth Factor

Variable	Loading
Earth floor	-0.266
Firewood, grass or straw for cooking fuel	-0.264
Thatched roof	-0.208
Water piped outside the house	0.182
Water piped inside the house	0.152
Own a mobile phone	0.112
Own a television	0.106
Walls of thatch, mud and poles, or mud and unburnt brick	-0.091
Own a refrigerator	0.087
Private flush toilet	0.084
Public or shared latrine	0.071
Own a radio	0.058
Own a car	0.044
Kerosene, paraffin, lignite or coal for cooking fuel	-0.035
Unsafe water source (river, stream, lake, uprotected well)	0.025
Own a bicycle	0.023
Finished floor (linoleum, tile, carpet, stone)	-0.015
Electricity or gas for cooking fuel	-0.009
Roof of asbestos, tile, tin or cement	-0.008

Association of Mental Health Score with Physical Health Score

Linear regression was used, with CD4 count as a continuous variable, to explore the effect of CD4 on mental health score adjusting for physical health score. The hypothesis was that the observed association of mental health score and CD4 count was explained by the effect of CD4 on physical health score.

It was also hypothesised that participants with lower physical health would be more likely to be accompanied by a carer, but the same would not be true of mental health. To test this hypothesis, linear regression was used to separate the associations of carer presence with physical and mental summary scores at T0.

Table 73 shows that physical health score was associated with CD4 count when analysed alone (Model A) and when mental health score was included (Model B). However, in Table 74, the results show that while mental health score was included with CD4 count in univariate analysis (Model C), the addition of physical health score wiped out the association (Model D). Physical health score was a total cofounder for the apparent relationship between CD4 count and mental health, being related to both.

Table 75 shows that participants with a carer present at T0 had on average a physical health score six points lower than those without a carer (Model A), and if mental health was included in the model (Model B), the difference in physical health remained statistically significant at 4.6 points. Mental health, on the other hand, was two points lower for those with a carer (Table 76, Model C) but there was no significant difference in mental health after adjusting for physical health score (Model D).

Details of Longitudinal Analysis Method

Multilevel modelling was carried out using the Stata xtmixed command function. Outcomes were physical health score and mental health score, measured up to three times at monthly intervals. Baseline score was incorporated as a covariate and not as an outcome. Models included levels for facility and individual. The only random effects was timepoint (interview number, rather

Table 73: Linear regression of physical health score by CD4 count at T0

Model	Covariate	Coefficient	Standard Error	T	P	95% CI
A	CD4 count	0.011	0.003	4.49	<0.001	0.006–0.016
B	mental health score	0.768	0.052	14.89	<0.001	0.666–0.869
B	CD4 count	0.007	0.002	3.60	<0.001	0.003–0.011

Table 74: Linear Regression of Mental Health Score by CD4 Count at T0

Model	Covariate	Coefficient	Standard Error	T	P	95% CI
C	CD4 count	0.005	0.002	2.63	0.009	0.001–0.009
D	Physical health score	0.480	0.032	14.89	<0.001	0.417–0.543
D	CD4 count	-0.001	0.002	-0.11	0.910	-0.003–0.003

Table 75: Linear Regression of Physical Health Score by Carer Presence at T0

Model	Covariate	Coefficient	Standard Error	T	P	95% CI
A	Carer present	-6.066	1.072	-5.66	<0.001	-8.171 to -3.960
B	Carer present	-4.557	0.864	-5.27	<0.001	-6.254 to -2.860
B	mental health score	0.736	0.039	18.80	<0.001	0.659 to 0.813

than actual time interval), which was allowed to have a random coefficient at the individual level. Other covariates were fixed. Demographic and care theme covariates were constant over time, receipt of ART and TB treatment varied. The default independent covariance structure was used. Variance and standard error of variance were reported for random-effects parameter estimates.

Exploring the Variance at Different Levels

Table 77 shows that there was as much variation in summary scores between facilities as within individuals over time. Facility was significantly associated with both outcome scores on an ANOVA test but the F-value was twice as high for physical health score, showing greater variation between facilities for mean physical than mental scores.

Additionally, a multi-level model without covariates was developed to ascertain the contribution of the facility level to change over time (Table 78). There was more variance at the individual level than facility level, showing that participants within facilities were more different to each other than was explained by the difference between facilities.

However, the variance scores were within the same order of magnitude, whereas in the Kenya Phase 2 longitudinal quantitative study, within-facility difference outweighed between-facility difference more than tenfold.

Table 76: Linear Regression of Mental Health Score by Carer Presence at T0

Model	Covariate	Coefficient	Standard Error	T	P	95% CI
C	Carer present	-2.051	0.871	-2.35	0.019	-3.761 to -0.340
D	Carer present	0.893	0.716	1.25	0.213	-0.513 to 2.300
D	physical health score	0.485	0.026	18.80	<0.001	0.435 to 0.536

Table 77: Results of ANOVA Using Facility at T0

	N	R Squared	Adjusted R Squared	F	P
physical health score	639	0.121	0.114	17.36	<0.001
mental health score	639	0.069	0.062	9.36	<0.001

Table 78: Results of Multi-level Model with Random Intercept

	Facility Level		Individual Level	
	Variance	Standard Error	Variance	Standard Error
physical health score	20.739	13.543	56.508	4.224
mental health score	10.006	6.626	35.861	2.796

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PEPFAR Categories of Care

Table 79: PEPFAR Categories of Care

Area of Care and Support	Care Components included from CSRI	Area of Care and Support	Care Components included from CSRI
Clinical	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 CTX Isoniazid to prevent TB ITNs Wound care Physiotherapy	Psychological	Family counselling Psychiatric therapy Anxiety/depression treatment
		Spiritual	Visit by faith leader Staff prayer with patients Contact with traditional healer/herbalist Memory book work
		Social	Home help Employment training Legal services Loans/microfinance
		Prevention	Family planning counselling Patient HIV support groups Support for family testing Prevention with positives Condoms

K Country-Level Coding Frames

Coding Frame Developed by APCA Researchers

- » *Components of care/care provision*
    - Curative, preventive and on going monitoring
    - VCT, RCT and Diagnostic counselling
    - Adherence counselling
    - Spiritual care
    - Bereavement care
    - Socio-economic support
    - Laboratory services
    - Psychological/emotional care
- » *Health seeking behaviour*
    - Associated with self initiation into care
        - Sickly
        - Suggestive symptoms
        - Community advice
    - Reasons for choice of facility
        - Proximity
        - Available services
        - Affordability
- » *Patient and carer's needs*
    - Clinical
    - Preventive
    - Social and financial
    - Emotional/psychological
- » *Structure of HIV/AIDS care services*
    - Criteria for accessing care
    - Enrollment process
    - Frequency of care
    - Documentation in care
    - Differences in care needs for patients at different stages of disease
    - Referrals
    - Costs to patients
    - Education and training
    - Supervision
- » *Strengths, challenges, and service gaps*
    - Services facilities /patients would like to have
    - Challenges faced
    - Patients perceptions of services received

Coding Frame Developed by KCL

- » *Carer roles, relationship to patient and facility*
    - Patient as care provider and educator
- » *Content of service receipt*
    - Advanced and bereavement care
    - Carer
    - Clinical and medicine
    - Monitoring and process
    - Preventive
    - Psychological, counselling and advice
    - Referral
    - Social
    - Spiritual
- » *Experiences of care provision and receipt*
    - Negative experiences
    - Positive experiences
    - Facility self-reported strengths
    - Patient and carer self report
    - Suggested improvements
    - Clinical and facility challenges
- » *Initiating care*
    - Criteria for service entry and care
    - Patient choice of facility
    - Process of enrollment
    - Retention and shopping around
    - Service identification of needs
- » *Needs*
    - Carers
    - Clinical
    - Preventive
    - Psychological
    - Social
    - Staff

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MOS-HIV Responses at T0

Table 80: MOS-HIV Responses at T0

Subscale	No.	Question	Responses					
			poor	**fair**	**good**	**very good**	**excellent**	
Health Perception	Q1	Health is	20.5	50.5	22.0	5.9	1.1	
			true	**mostly true**	**don't know**	**mostly false**	**false**	
	Q11.1	Somewhat ill	28.6	45.9	1.6	18.1	5.8	
	Q11.4	Feeling bad recently	19.7	48.7	1.6	23.6	6.4	
			false	**mostly false**	**don't know**	**mostly true**	**true**	
	Q11.2	As healthy as anyone you know	22.7	42.8	3.1	22.8	8.6	
	Q11.3	Health is excellent	30.6	45.3	3.4	14.2	6.4	
			very severe	**severe**	**moderate**	**mild**	**Very mild**	**None**
Pain	Q2	Bodily pain	4.4	23.0	26.1	14.8	12.3	19.4
			extremely	**quite a bit**	**moderately**	**a little bit**	**not at all**	
	Q3	Pain interfering with daily life	10.0	22.5	18.0	19.4	30.2	
			limited a lot	**limited a little**	**not limited at all**			
Physical Function	Q4.1	Vigorous activities	36.9	34.4	28.8			
	Q4.2	Moderate activities	18.1	30.5	51.4			
	Q4.3	Walking up hill	19.1	41.7	39.2			
	Q4.4	Bending, kneeling	8.6	26.7	64.7			
	Q4.5	Walking	7.0	18.6	74.4			
	Q4.6	Self care	2.3	6.9	90.8			
			Yes	**No**				
Role Function	Q5	Cannot work	38.9	61.1				
	Q6	Cannot do certain kinds of work	42.2	57.8				
			Proportion of Time					
			all	**most**	**a good bit**	**some**	**a little**	**none**
Social Function	Q7	Limited social activities	4.7	11.4	11.1	18.1	15.3	39.4

Table 80: MOS-HIV Responses at T0

Subscale	**No.**	**Question**	**Responses**					
Mental Health	Q8.1	Nervous	1.7	9.4	7.7	34.8	20.3	26.1
	Q8.3	Depressed	2.5	9.7	9.2	35.5	20.6	22.5
	Q8.5	Very depressed	1.9	5.9	6.9	20.2	27.0	38.1
Vitality	Q9.2	Without energy	2.8	10.5	8.0	25.0	28.6	25.2
	Q9.3	Tired	3.3	13.9	9.8	40.2	19.2	13.6
Health Distress	Q9.5	Weighed down	2.3	11.4	8.0	28.9	22.8	26.6
	Q9.6	Discouraged	3.1	8.0	7.0	25.2	18.0	38.8
	Q9.7	Despair	2.8	7.5	6.6	22.7	21.4	39.1
	Q9.8	Afraid	3.6	9.5	6.9	25.0	22.0	33.0
			none	**a little**	**some**	**a good bit**	**most**	**all**
Mental Health	Q8.2	Calm and peaceful	8.6	16.9	33.0	12.8	21.3	7.5
	Q8.4	Happy	5.9	13.8	27.7	13.8	30.0	8.9
Vitality	Q9.1	Full of life	14.5	18.8	27.7	10.2	21.3	7.7
	Q9.4	Enough energy	14.1	15.2	27.7	8.9	25.2	9.1
			all	**most**	**a good bit**	**some**	**a little**	**none**
Cognitive Function	Q10.1	Difficulty reasoning	0.5	5.8	7.3	21.9	17.5	47.0
	Q10.2	Forgetful	0.9	8.3	5.9	22.0	18.9	43.9
	Q10.3	Attention problem	0.6	5.6	6.4	22.8	19.4	45.2
	Q10.4	Concentration problem	0.2	6.3	5.9	20.9	21.1	45.6
			very bad	**pretty bad**	**about equal**	**pretty good**	**very good**	
QoL	Q12	Quality of life	8.3	32.0	35.9	20.0	3.8	
			much worse	**a little worse**	**the same**	**a little better**	**much better**	
Health Transition	Q13	Compared to 30 days ago	5.9	29.4	26.6	31.7	6.4	

M Feedback from Dissemination

Introduction

Part of the objective of this evaluation is, in conjunction with MEASURE Evaluation, to build commitment to utilising the findings and lessons learnt from the study. As a step towards meeting this objective a meeting was held in Kampala in July 2009 with the research team and participating facilities. The purposes of this meeting were (a) to share the results of Phase 2 with participants; (b) to gain insight into the findings from those involved in service delivery to improve the presentation of the findings in the report; and (c) to discuss the recommendations made, with the option of facilities making additional recommendations if desired

Representatives from all six facilities, the country team and the Ministry of Health attended the workshop.

Meeting Outline

Participants were given a summary of the findings. Presentations from the research team explained (a) the parties involved and the aims, objectives, and design of the evaluation; (b) the methods and data collection experiences; and (c) the results.

Participants were then divided into five groups in order to explore key themes that arose from the data in more detail. In addition to the summary report already received, each group was given relevant supplementary data (i.e., report tables and excerpts from qualitative interviews) to aid discussions. Group participants were asked to discuss the main findings relating to the theme allocated.

Prompts to aid discussion included: Were any findings surprising? What are the areas where things are doing well or are on track and why? What areas need improvement and why? Participants were then asked to review and discuss the recommendations contained in the summary report, and finally to draft their own set of recommendations for action in this thematic area using the attached format. Discussion summaries were shared with all.

Meeting Feedback—General

Participants expressed their appreciation at being informed of the findings. In general participants found that the findings were borne out by their own experience. Specifically, they agreed with the conclusions regarding the burden of poverty for patients, staff workload and the importance of motivation, the value of carer involvement, drug supply issues, resource limitations, and the pressure on counsellors.

The Country Team reported that the evaluation showed that ART alone was not sufficient to solve all problems in HIV, with further care and support being necessary. They also agreed that the needs of patients on ART, which are highlighted in the evaluation, are an essential area. The evaluation provided the evidence needed to plan services and distribute funds.

Participants discussed the possible reasons for lower self-reported health among people receiving ART, and speculated that over a period longer than three months, this group might 'catch up' with ART-naïve patients. There was a strong feeling that facilities must offer more than ART management, vital though that was, in the presence of great social, psychological and economic need. Participants were also concerned about over-reliance on donor funds, as reported in Phase 1.

Meeting Feedback—Groups

ART, BCP, Pain Management, Symptom and Infection Management, Prevention

The proportion of participants in the longitudinal quantitative study receiving ART increased from 41.4% to 57.3%, a change which the group found surprising in the relatively short time of three months. The possible reasons for this included increased awareness of HIV, accessibility of services and availability of ART. The group commented on how much the environment of HIV care had changed in the past few years, with the rollout of ART.

The group felt it was important to understand why

CD4 counts were not recorded, especially for those on ART, and pointed out that machines were bought for the facilities yet the tests were not done.

The factors impeding performance for facilities were identified as overwhelming patient numbers, lack of palliative care skills, infrastructure deficiencies, drug supply problems, low staff morale, and the underlying issue of poverty. The group emphasised that research recommendations in themselves were not enough, and action needed to be taken to put them into effect.

Nutrition, Social Care, Psychological Care, Spiritual Care

The group commented that social care was particularly important because social status had a bearing on the mental and physical health of participants, but social support was seen as expensive. The goal was to empower patients, to enable them to improve. Spiritual care was believed to change behaviour, and to be connected with a decline in visits to traditional healers. In Kenya, the relationship between medical services and traditional healers is very poor.

This care required skilled staff. The group commented that the skills and knowledge to provide nutritional counselling, adherence counselling, and family planning counselling were widespread, so these components were well delivered, but social and spiritual care training was less developed.

Facility Strengths and Weaknesses

The group reported that the strengths of the six facilities were (a) a positive staff attitude; good collaboration between clients and counsellors, staff motivation; (b) availability of drugs; (c) holistic patient management, including the ability to give hope and spiritual care; and (d) time management and scheduling.

The areas where improvement was needed were staff training, particularly counselling, development of community home based care, stigma reduction, and staff motivation. Staff motivation was a strength as well as an area of concern because it was such a challenging issue and constantly needed to be addressed. Overwhelming patient numbers, lack of space and shortage of time impeded staff performance and caused disillusion and demotivation, as well as limiting care.

Patient Issues and Perspectives

The group felt that the most important issue was to empower patients to produce their own food and make the family self-sufficient. They had many recommendations to improve patient care (summarised in the table below). These centred around community participation and peer support. The issue of whether to renumerate community volunteers was highlighted, as doing so would make the project non-self-supporting but motivation could be difficult without it.

Carer Issues and Perspectives

The group agreed that the findings of the evaluation reflected their own experiences. They emphasised that carers often had numerous other responsibilities including supporting dependants and caring for other family members, and might also be HIV positive and have health problems. This made long waiting times frustrating as carers had other needs to attend to. Communication was identified as the essential issue for carers. Carers had psychological challenges from feeling left out, having no-one to talk to, and wanting to share the challenges faced in trying to care. They were undervalued, although the group recognised that the work they did was vital. Increasing poverty, as both patients and carers became less able to work and bring in income, added to the burdens of caring.

Each group produced recommendations based on the data. These are presented in the table below, together with the principal supports for them and the main beneficiaries. Some recommendations were made by more than one group and have been merged together.

Table 81				
Recommended Actions	**Data supporting recommendation**			**Beneficiaries**
	Longitudinal	**Qualitative**	**Cost/survey**	
Make staff motivation a priority. Facilities use stress management activities to avoid burnout and reduce turnover		• Facility challenges, staff needs • Staff burden, risk of burnout • Value of positive staff attitude to patients	• High staff: patient ratio	• Staff • Patients
Facilities should have strategy of training staff in palliative care	• Low provision of opioids and palliative care	• Staff training needs, care provided		
Facilities should have a well documented human resources plan to match demand		• Facility challenges, experience of receiving care	• High patient burden for non-clinical staff	
Empower patients to be self-supporting and increase social status—avoid dependency • skills training, e.g. knitting, farm techniques • loan schemes for starting capital • seed projects, e.g. seedlings, chicks • sensitisation towards food security	• Social status as predictor of self-reported health score • High proportion receiving food and therapeutic feeding	• Burden of hunger and food insecurity		• Patients • Carers • Dependants
Enable stable patients to access pharmacy quickly, reduce queuing time	• Range of treatment regimes, some patients receiving complex care and counselling, others only medication	• Waiting time as barrier, carer burden	• Cost of staff time	• Patients • Carers • Staff
Provide components addressing all dimensions of care on one site	• Multidimensional problems, wide range of care components received	• Transport costs, preference for single centre of care	• Economies of scale	• Patients • Carers • Funders
Increase spiritual and psychological care to families. Train staff in spiritual and psychological care to complement the skills and knowledge in counselling	• Multidimensional problems, mental health needs • Low delivery of spiritual care theme	• Psychological needs, anxiety, worry. • Value of spiritual care		• Patients • Carers
Extend VCT to rural areas	• Late presentation, high symptom burden, rapid uptake of ART	• Facility challenges—lack of space, late presentation, difficulty of outreach		• New patients
Provide satellite clinics in rural areas, equipped with drugs and HCWs		• Staff overload, problem of queues, transport difficulties		

Table 81

Recommended Actions	Data supporting recommendation			Beneficiaries
	Longitudinal	Qualitative	Cost/survey	
Expand HBC, give HCWs time to talk to carers and assess family needs. Increase home visits by nurses	• Proportion of patients with carer, proportion not able to share feelings, lack of help and advice for family	• Patient needs • staff interviews		• Patients • Carers
CHWs to provide adequate pain relief in the community and assess regularly when pain is present. Adapt pain management and palliative care skills to their settings	• Proportion receiving pain relief, high prevalence of pain	• Pain reported	• Phase 1: low use of opioids	• Patients
Medicine companions to collect pain medication for patients	• Higher dropout for patients with low physical health • Decreasing pain medication over time	• Some carers report collecting medication for patients		• Patients
Involve religious leaders in the community, encourage patients to visit them	• High proportion not feeling at peace	• Patients reporting no spiritual care at facility		
Regularise appointments	• Complex care regimes	• Queuing and long waiting time	• Phase 1: lack of fixed appointments	• Staff • Patients • Carers
Continuous health education and encouraging hygiene to prevent infections	• Proportion receiving wound care, treatment for OIs			• Patients
Involve carers in planning care. Run workshops in communication skills, information, IGA, and prevention. Encourage disclosure and education.	• Lack of help and advice for carers	• Carers report few services • Burden of poverty, work time lost through caring		• Carers • Patients
Instil a culture of appreciation for carers, give them motivation	• High proportion without a carer	• Carer burden		• Carers • Patients

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