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Guest Editors: Naomi Rutenberg and Waimar Tun
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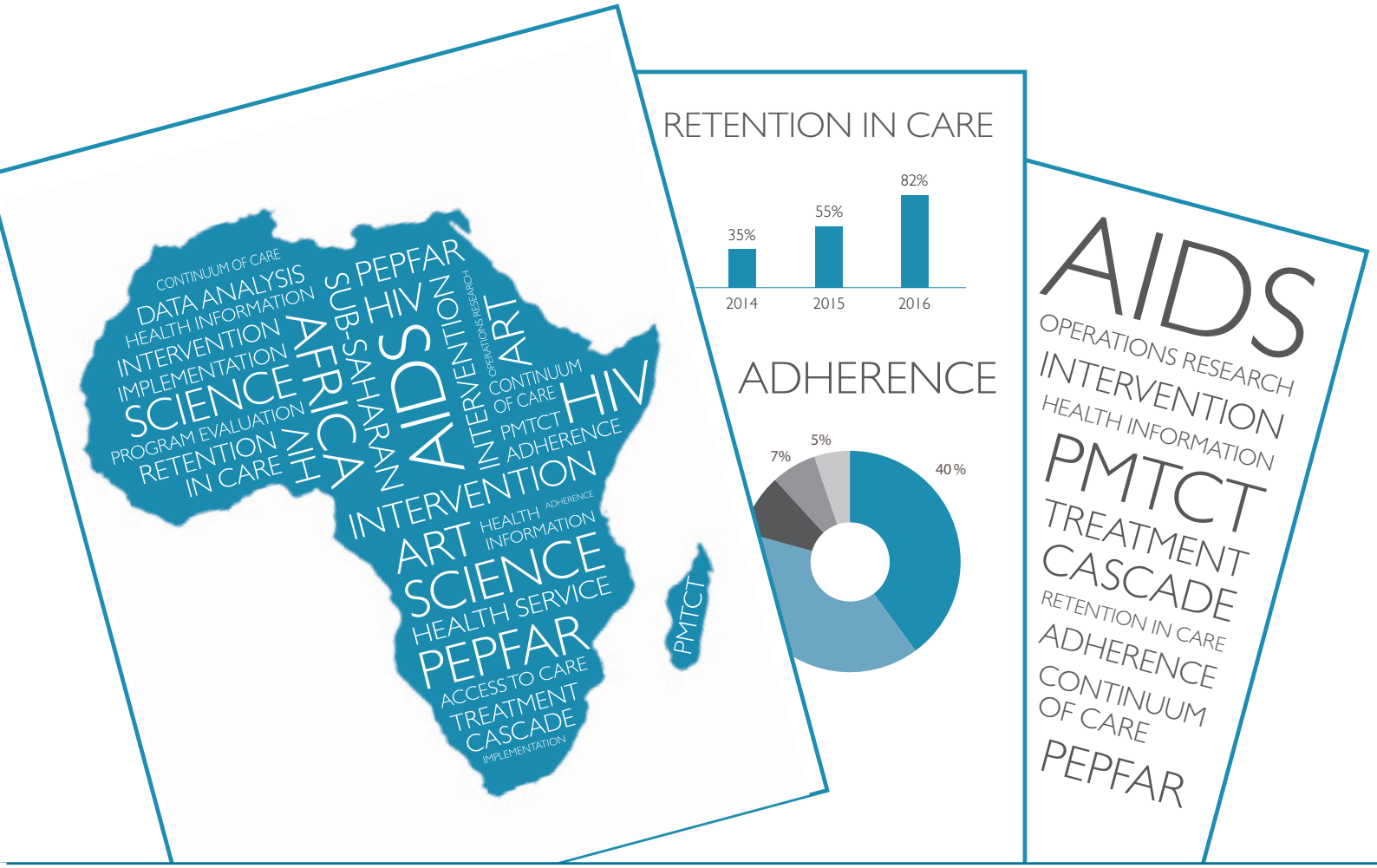

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Editorial

Lessons learned and study results from HIVCore: an HIV implementation science initiative

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The global community has made substantial progress towards halting and beginning to reverse the HIV epidemic. We have seen a 35% decrease in new HIV infections since 2000 and a 42% decrease in AIDS-related deaths since the peak in 2004 [1]. We have effective interventions such as HIV testing and counselling (HTC), prevention of mother-to-child transmission (PMTCT) and voluntary male medical circumcision (VMMC) as part of our tools for curbing the epidemic [2–4]. In addition, scientific results established the effectiveness of antiretrovirals (ARV) to not only treat but also to prevent HIV infections [5–7]. Together these have given us the much needed tools and knowledge to bring the goal of achieving an AIDS-free generation within our reach [8].

Despite great progress, there is a large unfinished agenda in addressing HIV infection and AIDS-related morbidity and mortality [9]. UNAIDS has set forth a goal of 90–90–90 – an ambitious treatment target to help end the AIDS epidemic [10]. By 2020, 90% of all people living with HIV will know their HIV status, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy and 90% of all people receiving antiretroviral therapy will have viral suppression. However, achieving these targets will require unprecedented action to scale up access to the available tools and interventions.

As of June 2015, UNAIDS estimated that globally only 43% of people living with HIV were on antiretroviral treatment (ART), leaving nearly 22 million people living with HIV without treatment [1]. The factors that contribute to the large unmet need for HIV treatment include demand and supply barriers as well as stigma and discrimination against people living with HIV and select sub-populations at high risk of HIV [10,11]. Demand-side barriers include gaps in accessing HIV/healthcare services and getting tested for HIV, in timely initiation of ARV treatment by HIV-positive patients and in adherence to ART and achieving viral suppression. On the supply side, there are major gaps in the provision of HIV testing services, in linkages to HIV treatment and in support to patients to initiate and adhere to ART (Figure 1).

In addition to general supply and demand gaps, contextual factors also create barriers. Rural areas tend to have a smaller number of people living with HIV; however, health facilities in rural areas often face severe health systems constraints in human resources, laboratory equipment, and supply of drugs. Although urban areas tend to have better health systems and less infrastructure challenges, they are challenged by a higher demand for HIV services. Compared with the general population, HIV infection rates are substantially higher among men who have sex with men (3–25 times), sex workers (13.5 times) and people who inject drugs (22–50 times) [12–15]. Although the overall prevalence of HIV is falling, epidemics in these key groups are expanding in many places worldwide. Adolescents and people living with disabilities are two more examples of sub-populations that have specific risks of HIV and needs for tailored services [9,13,16]. Prevention and treatment of HIV in these marginalized groups is difficult to address because of stigma, discrimination and their sequelae.

Addressing these barriers requires knowledge about what strategies are effective for the delivery of HIV testing and treatment for the different settings and sub-populations. We know what to do but not always how to do it. The US President's Emergency Plan for AIDS Relief (PEPFAR) implementation science (IS) framework describes IS as the study of methods to improve the uptake, implementation and translation of research findings into routine and common practices [17]. Since 2005, PEPFAR has been working with implementing partners and national governments in many HIV-affected countries and has contributed to the rapid acceleration of HIV treatment access, availability of care and support services and HIV prevention interventions. IS addresses the gaps in the 90–90–90 coverage and is critical for building upon the progress already achieved with PEPFAR funding.

The Population Council and partners from Elizabeth Glaser Pediatric AIDS Foundation, Palladium, and the University of Washington with funding from the US Agency for International Development (USAID), launched HIVCore, which is a five-year operations research/IS initiative, addressing critical service delivery issues in global HIV and AIDS PMTCT and treatment, care and support programmes.

HIVCore addressed three priorities through IS. First, retention in care, that is, meeting current commitments to patients on treatment and promoting prevention by lowering

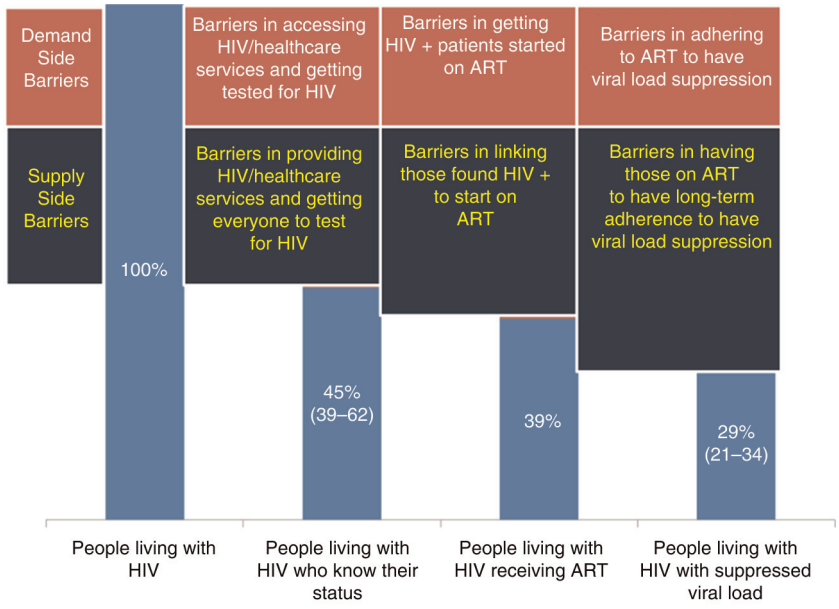

Figure 1. Demand- and supply-side gaps experienced in implementing and accessing HIV treatment among adults in sub-Saharan Africa aged 15 years and more, 2013. Source: UNAIDS 90-90-90 Report, 2014.

population-level viral loads. Second, the integration of HIV and other health and social services, strengthening linkages between community- and facility-based HIV services and the use of innovations in management information systems and information communication technologies to improve linkages to care. Third, continue to roll out and scale up services at existing service sites, add new sites and expand geographic and population coverage.

This journal supplement provides selected results from the HIVCore initiative. The papers are drawn from seven studies in PEPFAR-supported countries in sub-Saharan Africa. The studies address the demand for and/or delivery of treatment for adults and adolescents, PMTCT programmes, enhancing prevention for marginalized young adults by addressing their mental health, and meeting the HIV-related needs of people living with disabilities. One paper provides information on the costs of different service delivery models. One paper and one commentary address important methodological issues in conducting IS.

A number of studies included in this supplement discovered substantial loss to follow-up (LTFU) or attrition from care of HIV-positive clients, anywhere from one-quarter to three-quarters in the first year after HIV diagnosis. The LTFU is generally most severe in the early months after diagnosis. Woelk *et al*.'s study of PMTCT clients in Rwanda found that unmarried, apparently healthy (i.e. ART ineligible), and women with higher CD4 counts at enrolment were at the greatest risk of LTFU in the sites they studied [18]. In Mozambique, men and women who enrolled early in HIV care said that the main reason for obtaining an HIV test – and for enrolling in HIV care – was the presence of signs or symptoms of sickness [19]. Conversely, the main perceived barrier for enrolment was lack of signs or symptoms of sickness. In Uganda, Okoboi *et al*. describe how retention in care was better among younger adolescents (aged 10–14 years) than older adolescents, adolescents who initiated ART in earlier years of the programme when it had a stronger community focus and adolescents who had higher CD4 counts at ART initiation [20].

Certain vulnerable populations have unique needs for HIV services. Tun *et al*. describe how persons with disabilities in Ghana, Uganda and Zambia face many barriers to accessing services that make it very difficult for them to get tested for HIV and, if found positive, many persons with disabilities are unlikely to initiate treatment and be retained in care and treatment due to a myriad of challenges, including stigma related to both HIV and disabilities, physically inaccessible facilities, lack of accessible information, such as in Braille or sign interpreters, lack of trained staff to provide services for persons with disabilities, economic hardships and those who are illiterate [21].

As noted above, IS is about identifying effective ways to improve implementation and address gaps and challenges. The Jani *et al.* study tested a novel intervention among migrant adolescents in Ethiopia based on a formative assessment [22]. The researchers piloted and evaluated the effects of an intervention to reduce mental health problems and improve HIV-related outcomes among migrant adolescents in Addis Ababa. They found that the psychosocial counselling intervention was associated with increased knowledge and uptake of HIV and sexual health services among both male and female vulnerable adolescents, and reduced mental health problems among female adolescents.

Other studies also yielded signposts to what should be done based on the results of formative evaluations. Granato *et al.* found that sites with better retention in care and treatment tended to have more and better trained staff; better physical infrastructure that offer privacy, confidentiality and a better level of comfort for patients; and these

sites actively followed-up HIV-positive patients who missed visits [23]. Activities to promote social support were also associated with higher retention in the Inguane *et al*. study in Mozambique [19]. Other important factors were patients' perceptions that they would get good care, the financial costs of travel and wait time at clinics. Finally, linkage to care and ''re-linkage,'' that is re-connecting patients who have dropped out of care, may require different strategies.

A paper by Vu *et al*. provides a description of the cost per ART visit and annual ART-related costs per patient for three different task-shifting models of ART service delivery in Uganda [24]. Unit costs, the distribution of costs and resource utilization varied widely across the three sites and models, suggesting the potential for efficiency gains in ART service delivery. In particular, HIV programmes in Uganda may save costs by reducing the number of annual ART visits to match the national standard (four ART visits a year on average). Further, non-government organizations providing ART services, similar to these three organizations, Kitovu Mobile, The AIDS Support Organisation (TASO), and Uganda Cares may benefit from collaborating with the government and using government facilities to reduce operational costs.

A major challenge for all these studies was the quality of the national data systems. Many of the studies presented in this supplement encountered significant amounts of missing data in the routinely collected national data sets accessed for these studies. They also encountered a significant amount of variation in the number of services reportedly delivered or patients attended, depending on which data source was consulted. In addition, considerable error was introduced as data were aggregated from the clinic to district or provincial to national level. Gloyd *et al*. detail various types of shortcomings in the data, which is a useful checklist for both evaluating the quality of data and considering investments to improve data quality [25]. Researchers would like to think that secondary data analysis will be the ''low hanging fruit'' and be more efficient and faster given the availability of the data; however, the reality is that the data are often so incomplete and of poor quality that use of these data are highly complex and demanding. While the sheer amount of data that health providers are asked to collect is one source of poor data quality, the silver lining for research is that the volume of data provides the opportunity to compare and triangulate. The authors of the paper describe a variety of approaches, including imputation and sensitivity analysis, for assembling a decent picture of services despite the incomplete data.

The commentary by Kalibala *et al.* highlights the importance of and challenges to paying the same attention to measuring the implementation – that is, the dose, coverage, fidelity and quality – of the interventions as is paid to the outcomes in the target beneficiaries [26]. They remind us that since the purpose of IS is to identify and increase the use of effective service delivery approaches, it is incumbent upon IS studies to evaluate and document these critical elements and publish the processes and materials used in implementation.

Apart from conducting IS to expand the evidence base of effective service delivery approaches at the global, country and programme levels, the HIVCore initiative also focused its efforts on promoting utilization of IS results to enhance decision-making and building local capacity for IS. As an outcome of the engagement of local stakeholders in Ghana in the study on persons with disabilities [21], the Ghana AIDS Commission announced that the new National Strategic Plan (NSP) would be revised to better address the needs of persons with disabilities, as prior to this study Ghana's NSP did not include disability as a challenge in HIV programming, and that disability-accessible educational materials will be developed. Upon completion of the first studies in the initiative, HIVCore convened an international writing workshop to enable sharing of experiences in data analysis and to highlight policy and programmatic implications of study findings. Through the use of experienced investigators and technical advisors, this workshop focused on mentoring less experienced investigators to build their capacity in scientific writing, including writing the first drafts of many of the manuscripts in this supplement.

These IS studies, and others like them, call for attention to the necessary improvements at service delivery points and in sub-national and national systems to expand coverage of HIV care while also strengthening healthcare systems, including data systems, human resources and infrastructure. IS is an iterative process. You ''fix'' one problem, and it is time to examine the next; you expand uptake of HIV care, and you need to do more follow-up; you follow-up and bring more patients back, and you need to expand your adherence support, and so on.

The HIVCore initiative has contributed in many ways to the current HIV implementation agenda as well as sharing of different approaches for research utilization and capacity building for IS. The challenges with the implementation of newer tools and approaches to address the gaps in 90-90-90 coverage are critical for building upon the progress already achieved under the HIVCore initiative.

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Competing interests
The authors declare that they have no competing interests.

Authors' contributions
NR and NNB contributed sections to the first draft of the manuscript. WT contributed to the synopsis of the studies introduced in the manuscript. All authors read and approved the final manuscript.

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Research article

Retention of mothers and infants in the prevention of mother-to-child transmission of HIV programme is associated with individual and facility-level factors in Rwanda

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Abstract

Objectives: Investigate levels of retention at specified time periods along the prevention of mother-to-child transmission (PMTCT) cascade among mother-infant pairs as well as individual- and facility-level factors associated with retention.

Methods: A retrospective cohort of HIV-positive pregnant women and their infants attending five health centres from November 2010 to February 2012 in the Option B programme in Rwanda was established. Data were collected from several health registers and patient follow-up files. Additionally, informant interviews were conducted to ascertain health facility characteristics. Generalized estimating equation methods and modelling were utilized to estimate the number of mothers attending each antenatal care visit and assess factors associated with retention.

Results: Data from 457 pregnant women and 462 infants were collected at five different health centres (three urban and two rural facilities). Retention at 30 days after registration and retention at 6 weeks, 3, 6, 9 and 12 months post-delivery were analyzed. Based on an analytical sample of 348, we found that 58% of women and 81% of infants were retained in care within the same health facility at 12 months post-delivery, respectively. However, for mother-infant paired mothers, retention at 12 months was 74% and 79% for their infants. Loss to facility occurred early, with 26% to 33% being lost within 30 days post-registration. In a multivariable model retention was associated with being married, adjusted relative risk (ARR): 1.26, (95% confidence intervals: 1.11, 1.43); antiretroviral therapy eligible, ARR: 1.39, (1.12, 1.73) and CD4 count per 50 mm^3, ARR: 1.02, (1.01, 1.03).

Conclusions: These findings demonstrate varying retention levels among mother-infant pairs along the PMTCT cascade in addition to potential determinants of retention to such programmes. Unmarried, apparently healthy, HIV-positive pregnant women need additional support for programme retention. With the significantly increased workload resulting from lifelong antiretroviral treatment for all HIV-positive pregnant women, strategies need to be developed to identify, provide support and trace these women at risk of loss to follow-up. This study provides further evidence for the need for such a targeted supportive approach.

Keywords: PMTCT; retention; health facilities; sub-Sahara Africa; Rwanda; mother-infant pairs.

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Introduction

There has been significant progress in the prevention of mother-to-child transmission (PMTCT) of HIV globally. The number of new infections among children decreased by 58% between 2000 and 2014; from 520,000 to 220,000 [1]. The continued success of efforts to combat mother-to-child transmission supports our ultimate goal of being able to eliminate new infections among children globally [2]. This ambitious goal appears feasible if existing resources are used wisely and obstacles are anticipated and overcome. In particular, the PMTCT programme retention of mothers during pregnancy and mothers and infants post-delivery will be vital to achieving this goal. Women and infants who are retained in care have better health outcomes, and women who are retained and adhere to their antiretroviral therapy (ART) are less likely to transmit HIV to others [3,4]. However, HIV-positive pregnant women are less likely to be retained in care than HIV-positive non-pregnant women and men [5–7].

There are several barriers to retention among women and infants in PMTCT programmes. Data suggest that transportation costs, stigma and discrimination and fear of HIV status disclosure, comprise some of the major impediments to an individual continuing in care [8–12]. It is important to understand both individual and facility factors affecting retention along the PMTCT cascade.

Health facility characteristics that may influence retention include both the structural and operational aspects of a facility such as capacity, location, staffing and services provided. One cross-sectional study among HIV-positive post-partum women in Ethiopia found that the likelihood of receiving PMTCT services increased by 7.2 times with every additional nurse per 1500 patients, indicating patient load may be associated with retention [13]. Another study in South Africa

found that patients receiving HIV treatment at local clinics were less likely to be lost to follow-up than patients treated at hospitals [14]. Further, a retrospective cohort study conducted in Malawi among women enrolled in Option B+ programmes found a positive, though weak, association between rural facility location and retention as well as a negative association between attending larger facilities and retention [15].

Overall, these individual- and facility-level barriers result in decreased retention among women and infants throughout the PMTCT cascade [16,17], with only 66% of HIV-positive pregnant women receiving ART and 49% of infants receiving virologic diagnostic testing within the first two months of life in 2014 [18]. Understanding how these barriers impact retention among women and infants at varying time intervals along the PMTCT cascade may contribute to optimizing the performance of PMTCT programmes and identifying innovations to facilitate further improvement in the provision of care.

Rwanda has taken several steps towards reducing the mother-to-child transmission of HIV through the establishment of their comprehensive national HIV programme. Currently, 97% of health facilities offer PMTCT services [19]. As of December 2013, 1.3% of women attending clinics for PMTCT services were HIV-positive, a substantial decrease from 10.8% HIV positivity among pregnant women in 2003 [19]. Further, the number of new infections among children decreased from 6400 in 2001, to less than 1000 in 2012 [18]. Still, levels of retention to the PMTCT cascade in Rwanda as well as individual- and facility-level factors associated with retention are not well understood.

This analysis utilized data collected from five health facilities in Rwanda to assess levels of retention and factors associated with retention to PMTCT programmes among mothers and infants.

Methods

Study design

We undertook a retrospective cohort study among pairs of HIV-positive pregnant women and their HIV-exposed infants (HEI) accessing PMTCT services in Rwanda. Specifically, this study aimed to investigate levels of retention among mother-infant pairs at various stages of the PMTCT cascade and assess individual and health facility characteristics that may influence retention in PMTCT programmes. At the time of the study, Rwanda had implemented Option B PMTCT guidelines (the provision of triple ART for all HIV-positive pregnant women during pregnancy up to the cessation of breastfeeding) for more than two years. Rwanda transitioned to Option B+, the provision of ART for all HIV-positive pregnant women for life, in April 2012, after the data collection period.

Data collection

The retrospective review was conducted among HIV-positive women and infants registered in Option B antenatal and maternity services between November 2010 and February 2012. All PMTCT services were provided within the same unit of a particular facility. Facilities without maternity services referred women for delivery, but the women were expected to return for post-partum services and subsequent follow-up. Data were collected through a review of registers and medical files, as well as interviews performed with in-charges at the study health centres. Registers reviewed include the antenatal care (ANC), PMTCT, labour and delivery, HEI service, postnatal care (PNC), ART and early infant diagnoses registers. Data were extracted by trained data assistants and were directly entered into an MS ACCESS database. One to two informant interviews were conducted with the staff at each of the five study health facilities to collect data on health facility characteristics. Data were collected from March 2013 to May 2013.

In order to collect data on mothers and their infants from multiple registers, the data from these registers were linked. To obtain data on pregnant women, mothers newly diagnosed with HIV or with a known HIV-positive status were identified through the ANC registry by name and then their individual ANC identification numbers were noted. These unique identification numbers were then linked to the pre-ART registry patient numbers. The patient number was used to collect data from the ART, pharmacy and lab registers. To link the mother to the infant, data were also collected from the maternity, PNC and HEI registers. The mothers' unique identification numbers are recorded in the infant's file, enabling the mother/infant pairing. ''Unpaired'' mothers were those for whom there was no linkage or information on infant follow up. To acquire infant characteristics, the HEI registers, HEI card and medical files (the polymerase chain reaction (PCR) and dried blood spot file results) were utilized. Infants with positive PCR results additionally had their details obtained from pre-ART, ART registers and patient files. No attempts were made to trace mothers across facilities.

Women who were referred for any reason were documented in the patient files, together with the dates of referral. These data were captured in the study database and the women subsequently removed from the denominator.

Definition of variables

We defined retention as clinic attendance of the mother in addition to clinic attendance of the mother and infant as a pair. The time intervals along the PMTCT cascade used to assess retention were 30 days after entry into the PMTCT programme, at delivery, 6 weeks and 3, 6, 9 and 12 months post-delivery (postpartum time-points allowed a one-month interval on either side for data collection). Loss to follow-up (LFTU) was defined as missing three consecutive clinic visits.

Facility characteristics included facility location (urban or rural), staffing levels, vacancy rates, the number of ANC clients, volume of deliveries, number of HIV-positive pregnant women, number of doctor visits and onsite availability of CD4 testing.

Site selection and sample size

Sites among those supported by Elizabeth Glaser Pediatric AIDS Foundation (EGPAF) were selected and stratified by type of facility and location for this study. Sites were included if they were an ART initiating site, had at least 40 HIV-positive pregnant women registered in ANC per year, had well-maintained patient records according to programme staff, and experienced minimal test-kit stock-outs. Utilizing this

criterion, five health centres – two urban, three rural – were selected. We estimated a sample size of 474 pregnant women who were either newly diagnosed with HIV or had a known HIV-positive status. The sample size was based on an expectation of 50% (±4%) of the women attending the 12-month post-delivery visit.

Endpoint derivation

To develop the time intervals along the PMTCT cascade, the time period from registration date to the end of the observation period was divided into six segments: 30 days after registration, delivery date, 6 weeks and 3, 6, 9 and 12 months post-delivery (postpartum time-points allowed a one month interval on either side for data collection). A mother/infant was considered retained at each time interval if there was at least one health centre visit or pharmacy pick-up at any time during that time interval. Retention at each time interval was measured dichotomously: a mother/infant received a ''1'' if there was at least one visit, or a ''0'' if there was none. For each mother-infant pair, retention was measured as a count outcome of how many visits out of a possible six visits were accomplished. Thus, the endpoint was the total number of visits (each with a value of one) accomplished out of the six expected.

To estimate retention 30 days after registration, the ART initiation date was utilized. For women who were already on ART, if their initiation date or the first ART refill date since their registration in PMTCT was either within 30 days or within two weeks of the 30 days after registration, respectively, the mother was considered retained. For retention at delivery (health facility or home), all available records were utilized that suggested that the delivery took place including place of delivery, delivery date (if available) and child date of birth (if available). If any one of these records was available, the mother was retained at delivery. With respect to retention post-delivery (6 weeks and 3, 6, 9 and 12 months), if there was any indication of receipt of ART at that time (±1 month), the mother was deemed retained. A similar process was used to estimate infant retention.

Analysis

We estimated the proportion of mothers attending each study health centre visit by comparing the records of those found with the number that should have been seen at that particular visit. For mothers, at 30 days post-registration and at delivery, the denominator was the total number of registered mothers. For mothers at 6 weeks, and 3, 6, 9 and 12 months post-delivery, the denominator was the number of mothers retained at delivery. ''Retention'' was the proportion of the number of visits a mother attended to the total expected visits depending on gestational age at first visit. For infants, the initial denominator was the number of infants born alive, and then the number expected at each assessed time point, excluding known events such as death.

To assess factors associated with retention, we used generalized estimating equations (GEE) Poisson regression to calculate relative risks and the corresponding 95% confidence intervals (CIs) and *p*-values. We used GEE to account for the potential correlation of outcomes between women from the same health facility, assuming an exchangeable correlation structure. We also estimated robust standard errors, adjusting for the clustering within facilities. We included the following demographic, clinical and health facility variables in this analysis: age, parity, marital status, education, employment status, ART eligibility, CD4 count, urban or rural location of facility, facility deliveries, number of HIV-positive pregnant women per facility, HIV-trained nurses and number of doctor visits. Age, defined as a woman's age at registration or delivery, was estimated from the date of birth and the date of registration or delivery, and was scaled into 10 year increments in the analysis. Mother's parity was similarly retained as a continuous variable. Marital status was grouped into married/living as married versus not; education level – primary or less/secondary or more; and employment status – farmer, trader and other, including housewife. CD4 count was grouped into levels of 50 cells/mm^3 and run as this grouped variable; ART eligibility was a dichotomous variable – ART for the mother's own health versus not (e.g. used solely for PMTCT). The health facility variables were based on annual (the preceding year's) data and were included in the analyses as continuous variables, while the total number of HIV-positive pregnant women was scaled into increments of 20 women.

In regression models, we analyzed the demographic, clinical and health facility factors associated with retention, with retention as a variable, the number of visits a mother made out of an expected number of six. This analysis utilized all the available data leading to a more robust estimate of retention. In the univariate (unadjusted) model, we included age in 10-year increments (years at registration), marital status (not married/married), education (primary or less/secondary or more), employment status (farmer, trader, other), parity (0–2, 3 +), CD4 count categorized 50 mm^3, known HIV status, ART eligibility, number of HIV-positive pregnant women (increments of 20 women) per facility, number of deliveries per facility, number of HIV-trained nurses, number of doctor visits and facility location (urban/rural). The number of doctor visits was omitted from the model because of collinearity. In the final multivariate (adjusted) model, we excluded education and the number of deliveries because they were not found to be significant in the univariate analysis.

Statistical analyses were conducted using Stata software (Version 12.1, StataCorp LP, College Station, Texas, USA).

Ethical considerations

We obtained study approval from the Population Council Institutional Review Board and the Rwandan National Ethics Committee. Informed consent was waived, as the study was deemed minimal risk to study participants, the research could not practically be carried out if consent was required and the waiver of consent did not adversely affect the rights and welfare of the participants. All study personnel received training and certification in research ethics. Additionally, data assistants signed confidentiality agreements before interacting with the facility in-charges or working with data. All data were entered on password-protected computers into a password-protected database. When conducting the analyses, all personal identifiers were removed to ensure the confidentiality of the participants.

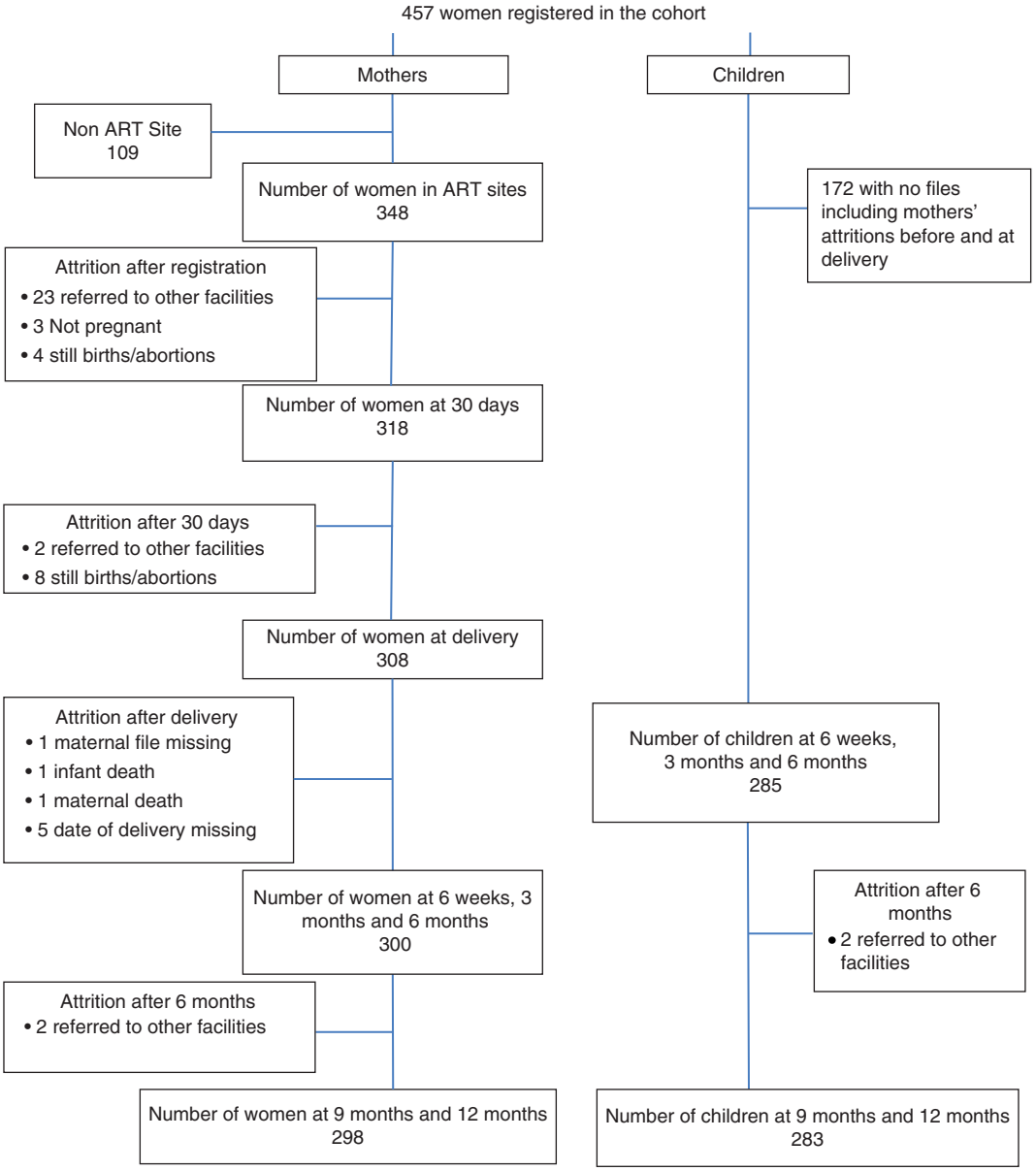

Figure 1. Mother and infant cascade.

Results

Participant and health centre characteristics

A total of 457 women were planned to be followed in the study. Figure 1 presents a cascade of the mothers and infants at the various time intervals. One site with 109 records was excluded from the retention analysis after it was discovered that it was not an ART provision site at the time of the study period, which lowered the number of eligible women to 348. Consequently, although we present the descriptive characteristics of mothers and the health facilities for the original five facilities, only the 348 women, from four facilities, were included for the retention analyses. For the 457 infants born to these women, 172 files were not found, leaving an eligible sample of 285.

Table 1 presents the demographic and clinical characteristics of the paired and unpaired mothers, in addition to the services they received. Paired mothers were the women with located files who were able to be linked to their infants. Unpaired mothers were women who were unable to be linked to their infants. The mean ages and parities of paired and unpaired mothers were similar (mean age: 28.9 vs. 27.9 years, parity: 2.7 vs. 2.5). Although about 80% of women overall were married or living together, a greater proportion of unpaired compared to paired mothers were unmarried/living together, (17.1% vs. 10.2%; $p = 0.035$). Overall, most (74%) women had primary education, but compared to paired mothers, a greater proportion of unpaired mothers recorded secondary education, (16.7% vs. 9.3%, $p = 0.024$).

Table 1. Descriptive characteristics of mothers participating in PMTCT programmes in five health centres in Rwanda

	Paired mothers		Unpaired mothers		Total	
	N	**Mean (SD)**	***N***	**Mean (SD)**	***N***	**Mean (SD)**
Age	283	28.9 (6.2)	172	27.9 (6.5)	455	28.5 (6.3)
Parity	276	2.7 (1.7)	167	2.5 (1.8)	443	2.6 (1.8)
CD4 count[a]	229	511.6 (223.8)	124	520.5 (223.9)	353	514.7 (223.6)
	N	**%**	***N***	**%**	***N***	**%**
Marital status						
Divorced/separated	15	5.4	7	4.2	22	4.9
Living as married	110	38.9	82	48.3	192	42.4
Married	144	50.9	59	34.8	203	44.9
Single	14	5.0	22	13.0	36	8.0
Total	283	100.0	170	100.0	453	100.0
Education						
None	38	14.7	22	13.6	60	14.3
Primary	197	76.1	113	69.8	310	73.7
Secondary	24	9.3	27	16.7	51	12.2
Total	259	100	162	100	421	100.0
Employment status						
Farmer	162	63.3	60	36.6	222	52.9
Housewife	57	22.3	66	40.3	123	29.3
Other	5	2	17	10.4	22	5.3
Trader	32	12.5	21	12.9	53	12.7
Total	256	100	164	100	420	100.0
Known HIV status						
Yes	173	60.7	99	57.6	272	59.5
No	112	39.3	73	42.4	185	40.5
Total	285	100	172	100	457	100
ART eligibility*						
Yes	187	73.6	83	64.3	270	70.5
No	67	26.4	46	35.7	113	29.5
Total	254	100	129	100	383	100
Number of ANC visits						
1	40	14.8	35	35.8	75	20.4
2	77	28.5	24	24.5	101	27.4
3	99	36.6	26	26.6	125	33.9
4+	55	20.3	13	13.3	68	18.5
Total	271	100.0	98	100.0	369	100.0
Type of regimen						
AZT/3TC/NVP	32	13.3	19	15.5	51	14.1
D4T/3TC/NVP	14	5.9	3	2.5	17	4.7
TDF/3TC/EFV	126	52.3	70	57.0	196	53.9
TDF/3TC/NVP	58	24.1	26	21.2	84	23.1
Others	11	4.6	5	4.1	16	4.4
Total	241	100.0	123	100.0	364	100.0

3TC = lamivudine; ABC = abacavir; ANC = antenatal care; ART = antiretroviral therapy; AZT = idovudine; D4T = stavudine; DNA PCR = deoxyribonucleic acid polymerase chain reaction; EFV = efavirenz; HIV = human immunodeficiency virus; NVP = nevirapine; PMTCT = prevention of mother-to-child transmission; SD = standard deviation, [a]CD4 at registration in PMTCT, (first ANC), *$p = 0.059$.

More than half of the women were farmers (52.9%), though this was 63.3% of the paired mothers compared to 36.6% of the unpaired mothers, $p < 0.001$.

Only 18.4% of the women made the recommended four or more ANC visits; proportionately more unpaired (35.8%) compared to paired (14.8%) mothers had only one ANC

visit, $p < 0.001$. The most common treatment regimens among the women were tenofovir combination regimens (77%), while an additional 14% were on AZT combination regimens, with similar proportions among the paired and unpaired mothers.

Description of health facilities

Five health centres were selected (three urban and two rural centres) for sampling. Using data collected in 2011, the average number of ANC clients among the five centres was approximately 1499, ranging from 880 to 2254 patients per centre (Table 2). There were roughly 70 HIV-positive pregnant women at each centre. In addition, an average of 647 deliveries took place at each facility. There was an average of approximately 29 health staffers and 10 HIV-trained nurses at each facility. Doctors visited the health centres approximately seven times each in 2011. Overall, the rural facilities had more staff per patient than the urban facilities.

Programme retention

Table 3 shows the retention among women and infants across the PMTCT cascade with 95% CIs. Among all the women 58% (95% CI: 52%, 64%) were retained 12 months post-delivery, while the infants' 12-month retention was 81% (76%, 86%). Retention for mothers paired with their infant (i.e. infant's file attached to mother's file) was 74% (68%, 80%), similar to the retention for their paired infant of 79% (73%, 85%) at 12 months. Analysis of retention of women without linked infant files shows a lower retention compared to the paired mothers; only 5% of unpaired women delivered at the clinic site, and about 30% were retained over the subsequent time periods. Overall, the majority of loss to retention was observed in the 30 days after antenatal registration. During this period, 33% of mothers overall and 25% of paired mothers were lost-to-follow-up. Losses tended to be minimal at the other time points.

Factors associated with retention

Table 4 presents retention at specified time intervals by selected demographic and clinical factors. Single mothers had the lowest retention at delivery (48%; 95% CI: 30%, 66%), 9 (41%; CI: 23%, 59%) and 12 months (41%; CI: 23%, 59%). Divorced/separated mothers had the lowest retention at six weeks (43%; CI: 17%, 69%), three (36%; CI: 11%, 61%) and six months (36%; CI: 11%, 61%). Retention across the time periods was similar by education levels, while women whose occupation was listed as ''other'' (than farmer, housewife or trader), had the lowest retention across all the time periods from delivery compared to other occupations: 35% at delivery, 53% at 6 weeks and 3, 6 and 9 months, and 47% at 12 months. There was little difference in the proportions retained between mothers with known HIV status and those newly diagnosed across the specified time intervals, with 59% (CI: 52%, 66%) of the mothers of known status retained at 12 months, against 56% (CI: 47%, 65%) of newly diagnosed mothers. Mothers eligible for ART for their own health were better retained across all the time periods, compared with those not eligible and receiving ART solely for PMTCT, 66% (CI: 59%, 73%), were retained at 12 months versus 47% (CI: 37%, 57%), respectively, $p < 0.001$. There was little difference in retention between mothers who attended the recommended four or more ANC visits, versus those who attended three or fewer, 66% (CI: 51%, 80%), versus 65% (CI: 53%, 78%) at 12 months.

In the final model, employment (defined as farmer versus non-farmer) was excluded as it failed to reach significance in an earlier multivariate model. The number of HIV-trained nurses was also dropped as the model did not converge. Table 5 presents the univariate and final multivariate models. In the final model, mothers who were married/living as married were 1.26 (95% CI: 1.11, 1.43) times more likely to be retained than mothers who were single or divorced/separated. Mothers who were eligible for ART for their own health were 1.39 (95% CI: 1.12, 1.73) times more likely to be retained than those who were receiving ART solely for PMTCT. CD4 count was independently and positively associated with retention (ARR: 1.02 per 50 mm^3 increase in CD4; 95% CI: 1.01, 1.03). Mother's parity and age, HIV status at the time of registration, number of HIV-positive pregnant women seen at a facility and facility location (urban/rural) were not significantly associated with retention.

Table 2. Description of the health facilities ($N = 5$)

Variable[a]	Urban (Monthly Min–Max)	Urban (Monthly Min–Max)	Urban (Monthly Min–Max)	Rural (Monthly Min–Max)	Rural (Monthly Min–Max)	Mean (SD)
Number of ANC clients	880 (39–102)	1885 (121–192)	2254 (154–219)	1124 (72–119)	1350 (79–149)	1498.6 (562.4)
Number of HIV+ pregnant women	50 (2–9)	156 (7–19)	81 (3–9)	34 (2–7)	31 (1–5)	70.4 (51.8)
Number of deliveries	403 (19–63)	393 (54–93)	713 (65–130)	640 (38–74)	1086 (54–131)	647.0 (283.4)
Number of health staff	31	35	38	24	18	29.2 (8.2)
Number of HIV- trained nurses	11	10	8	12	10	10.2 (1.5)
Number of doctor visits[b] last quarter	–	9	0	12	8	7.3 (5.1)

[a]Data for 2011; [b]doctors normally visit health facilities for consultation, supervision and support purposes.

Table 3. Mothers'[a] and infants' retention at specified time intervals

Section A

	Mothers' retention[a]			Infants' retention		
Time Intervals	***N* expt.**	***N* (Prop.)**	**95% CI**	***N* expt.**	***N* (Prop.)**	**95% CI**
30 days	318	213 (0.67)	0.62, 0.72	N/A	N/A	N/A
Delivery	308	205 (0.67)	0.62, 0.72	N/A	N/A	N/A
6 weeks	300	203 (0.68)	0.63, 0.73	285	218 (0.77)	0.71, 0.81
2–4 months	300	201 (0.67)	0.62, 0.72	285	243 (0.85)	0.81, 0.89
5–7 months	300	193 (0.64)	0.59, 0.69	285	259 (0.91)	0.88, 0.94
8–10 months	298	185 (0.62)	0.56, 0.68	283	247 (0.87)	0.83, 0.91
11–13 months	298	172 (0.58)	0.52, 0.64	283	228 (0.81)	0.76, 0.86

Section B

	Paired mother's retention[b]			Paired infants' retention		
Time Intervals	***N* expt.**	***N* (Prop.)**	**95% CI**	***N* expt.**	***N* (Prop.)**	**95% CI**
30 days	200	147 (0.74)	0.68, 80.0	N/A	N/A	N/A
Delivery	200	200 (0.100)	N/A	N/A	N/A	N/A
6 weeks	198	166 (0.84)	0.79, 0.89	198	161 (0.82)	0.76, 0.86
2–4 months	198	167 (0.84)	0.79, 0.89	198	173 (0.88)	0.82, 0.92
5–7 months	198	165 (0.83)	0.78, 0.88	198	177 (0.90)	0.85, 0.93
8–10 months	196	155 (0.79)	0.73, 0.85	196	168 (0.86)	0.81, 0.91
11–13 months	196	144 (0.74)	0.68, 0.80	196	154 (0.79)	0.73, 0.85

Section C

	Non-paired mother's retention[a]		
Time intervals	***N* expt.**	***N* (Prop.)**	**95% CI**
30 days	118	66 (0.56)	0.47, 0.65
Delivery	108	5 (0.05)	0.009, 0.09
6 weeks	102	37 (0.37)	0.28, 0.46
2–4 months	102	34 (0.34)	0.25, 0.43
5–7 months	102	28 (0.28)	0.19, 9.37
8–10 months	102	30 (0.30)	0.21, 0.39
11–13 months	102	28 (0.28)	0.19, 0.37

[a]Analysis based on 348 mothers; [b]paired mothers; linked mother-infant records.

Discussion

We found that the majority of loss-to-follow-up for mothers occurred early in the course of the PMTCT programme, with loss of 33% of mothers overall by 30 days after registration into the programme (26% for paired and 44% for unpaired mothers). The high early loss-to-follow-up in our study is similar to that in a Malawi study in which the highest loss of pregnant HIV-positive women occurred soon after diagnosis [15]. After this initial loss, retention decreased by only 10% between 6 weeks and 12 months post-delivery. Retention for mothers was 68% at six weeks post-delivery, decreasing to 58% by 12 months post-delivery.

Overall retention for infants was better than for mothers, with 81% retained at 12 months. For mothers and infants whose records were able to be linked as mother-baby pairs, retention was similar for mothers and infants, 74% at 12 months for mothers and 79% for infants. Factors associated with maternal retention were marital status, parity, CD4 count (per 50 mm^3 increase), whether ART was being received for maternal health, rural health facility location and number of HIV-positive pregnant women seen at the facility.

The proportion of women evaluated as mother-infant pairs retained at 12 months post-delivery found in this study (74%) is similar to data reported by the Rwandan Ministry of Health, which indicated that 70% of women are retained [20]. The 81% infant retention at 12 months is significantly higher than the retention rates for Sub-Saharan Africa reported in systematic review and met-analysis [21]. LFTU among HEI at three months had a pooled estimate of 34% from 11 studies in African countries. A South African study

Table 4. Retention among mothers in PMTCT programmes at specified time intervals by demographic characteristics

	30 days		Delivery		6 weeks		3 months		6 months		9 months		12 months	
	Prop	95% CI	Prop	95% CI	Prop	95% CI	Prop	95% CI	Prop	95% CI	Prop	95% CI	Prop	95% CI
Marital status														
Divorced/separated	0.80	0.60, 0.100	0.80	0.60, 0.100	0.43	0.17, 0 69	0.36	0.11, 0.61	0.36	0.11, 0.61	0.50	0.24, 0.76	0.57	0.31, 0.83
Living as married	0.66	0.59, 0.73	0.64	0.57, 0.71	0.66	0.59, 0.73	0.66	0.59, 0.73	0.64	0.57, 0.71	0.61	0.54, 0.68	0.57	0.49, 0.64
Married	0.67	0.57, 0.77	0.75	0.66, 0.84	0.79	0.70, 0.88	0.78	0.69, 0.87	0.75	0.69, 0.87	0.74	0.65, 0.83	0.66	0.56, 0.76
Single	0.64	0.51, 0.83	0.48	0.30, 0.66	0.52	0.34, 0.70	0.52	0.34, 0.70	0.45	0.34, 0.70	0.41	0.23, 0.59	0.41	0.23, 0.59
Education														
None	0.71	0.57, 0.85	0.71	0.57, 0.85	0.69	0.51, 0.82	0.60	0.44, 0.76	0.60	0.44, 0,76	0.57	0.41, 0.73	0.51	0.34, 0.68
Primary	0.65	0.60, 0.72	0.64	0.58, 0.70	0.66	0.59, 0.72	0.66	0.59, 0.72	0.63	0.56, 0.69	0.62	0.55, 0.69	0.58	0.51, 0.65
Secondary	0.67	0.52, 0.82	0.61	0.45, 0.76	0.61	0.45, 0.77	0.61	0.45, 0.77	0.58	0.42, 0.74	0.53	0.37, 0.69	0.53	0.37, 0.69
Occupation														
Farmer	0.62	0.53, 0.71	0.82	0.75, 0.89	0.72	0.63, 0.81	0.70	0.61, 0.79	0.69	0.60, 0.78	0.66	0.57, 0.75	0.59	0.49, 0.69
Housewife	0.67	0.58, 0.76	0.50	0.41, 0.59	0.61	0.52, 0.70	0.63	0.54, 0.72	0.57	0.48, 0.66	0.56	0.47, 0.65	0.55	0.47, 0.65
Other	0.71	0.49, 0.93	0.35	0.12, 0.58	0.53	0.29, 0.77	0.53	0.29, 0.77	0.53	0.29, 0.77	0.53	0.29, 0.77	0.47	0.23, 0.71
Trader	0.69	0.56, 0.82	0.67	0.54, 0.80	0.65	0.52, 0.78	0.60	0.46, 0.74	0.58	0.42, 0.70	0.56	0.42, 0.70	0.54	0.40, 0.68
Known HIV status														
Yes	0.66	0.60, 0.74	0.70	0.63, 0.77	0.69	0.62, 0.76	0.68	0.61, 0.75	0.67	0.60, 0.74	0.65	0.58, 0.72	0.59	0.52, 0.66
No	0.68	0.59, 0.76	0.61	0.52, 0.70	0.66	0.57, 0.75	0.66	0.57, 0.75	0.60	0.51, 0.69	0.58	0.49, 0.67	0.56	0.47, 0.65
Eligible for ART														
Yes	0.72	0.66, 0.78	0.72	0.66, 0.78	0.76	0.70, 0.82	0.77	0.71, 0.83	0.73	0.69, 0.79	0.71	0.65, 0.77	0.66	0.59, 0.73
No	0.66	0.56, 0.76	0.63	0.53, 0.73	0.60	0.50, 0.70	0.55	0.45, 0.65	0.54	0.44, 0.64	0.52	0.42, 0.63	0.47	0.37, 0.57
Number of ANC visit														
1–3	0.74	0.64, 0.86	0.82	0.73, 0.91	0.74	0.63, 0.85	0.77	0.65, 0.87	0.72	0.61, 0.84	0.70	0.58, 0.82	0.65	0.53, 0.78
4+	0.65	0.50, 0.80	0.80	0.69, 0.93	0.85	0.74, 0.96	0.80	0.68, 0.92	0.80	0.68, 0.92	0.68	0.54, 0.82	0.66	0.51, 0.80

ANC = antenatal care; ART = antiretroviral therapy; CI = confidence interval; HIV = human immunodeficiency virus; PMTCT = prevention of mother-to-child transmission; Prop = proportion retained.

Table 5. Regression model of factors associated with retention among women, unadjusted and adjusted relative risks, ($n = 348$)

	Unadjusted relative risk			Adjusted relative risk[a]		
Variable	**RR**	**95% CI**	***p***	**RR**	**95% CI**	***p***
Married	1.26	1.08, 1.47	0.003	1.26	1.11, 1.43	<0.001
Age/10 years	1.09	1.00, 1.19	0.042	1.01	0.93, 1.03	0.772
Education						
Primary or less	1.02	0.87, 1.21	0.76		Excluded from final model	
Secondary or more		0.78, 1.20	0.75			
Parity	1.12	1.01, 1.24	0.026	1.02	0.89, 1,17	0.752
HIV status: Known	1.07	0.96, 1.18	0.222	0.98	0.92, 1.04	0.455
ART eligible: Yes	1.27	1.14, 1.42	<0.001	1.39	1.12, 1.73	0.003
CD4/50 mm^3	0.99	0.98, 1.01	0.308	1.02	1.01, 1.03	<0.001
Employment						
Farmer	1.19	1.05, 1.33	<0.001		Excluded from final model	
Trader	1.05	0.89, 1.24	0.552			
Other	0.89	0.68, 1.16	0.394			
Facility location: Urban	0.79	0.74, 0.87	<0.001	0.39	0.12, 1.32	0.133
Number of HIV-positive pregnant women/20	0.96	0.95, 0.98	<0.001	1.14	0.91, 1.44	0.251
Number of facility deliveries	0.99	0.99, 1.00	0.406		Excluded from final model	
Number of HIV- trained nurses	1.20	1.14, 1.28	<0.001			

RR = relative risk; [a]adjusted for all covariates listed.

reported a LTFU of 85% at 12 months. This study and most of the other studies were on programmes that offered single-dose nevirapine. These programmes had higher LTFU compared to programmes that offered more intensive regimens such as Option B/B+ [21].

The non-paired mothers appeared to have delivered elsewhere, as only 5% were found in the delivery records. Women may deliver in facilities other than where they have registered, as they may perceive the quality of care to be better in these facilities, or they may deliver at home, where family members can provide support. Many of the unpaired mothers (107/172) were from a single urban facility. During the study period, this facility had begun offering maternity services, so it was observed for a limited time (seven months). Compared to the paired mothers, unpaired mothers tended to be younger, be unmarried, have more secondary education and have occupations other than farming. They also attended ANC less frequently. Literature has found a positive association between levels of education and better retention [11,15]; in our study, this inverse relationship observed in the bivariate analysis could be related to location as more unpaired mothers were found in urban clinics, where retention appeared to be lower.

However, while women attending urban facilities appeared to be less likely to be retained compared to women attending facilities in rural areas, this was not significant in the adjusted model. This finding is at variance with the tendency of higher LFTU of pregnant and postpartum HIV-positive women seen in large urban clinics reported by Tethani in Malawi [15]. Strategies should be developed to better retain single, HIV-positive pregnant women. Such strategies could include peer support groups linked to income-generating or skills-building activities, tracing with active follow-up using mobile phone texting/voice and the use of social media and community health workers. Peer support group approaches have proved to be beneficial in improving retention in some settings [22,23], as has the use of mobile phone texting [24]. In addition, the use of conditional cash transfers could be explored.

ART eligibility was positively associated with retention. This finding is consistent with findings that pregnant women who have needed ART for their own health have better retention compared to women who have not and are receiving ART solely for PMTCT [15]. These women may better understand the need to consistently return to the health facility because they have experienced symptoms. By comparison, women who are not ART eligible may not perceive themselves to be ill. The positive association of CD4 count and retention may be a function of improved CD4 status as a result of medication, but may be also a result of referrals to better care for symptomatic women. Positive associations between CD4 count and retention were reported also among patients on ART in Tanzania, Uganda and Zambia [25]. As an independent predicator of retention, parity may reflect the profile of women attending rural facilities, who tend to be older and married.

The strengths of this analysis include the utilization of numerous registers, the statistical methods used to assess retention and the novel exploration of health facility factors and their impact on retention in Rwanda. A limitation of this study was the limited number of health facilities, though these health facilities were likely to be similar in operation to other health facilities in Rwanda. Another limitation is that retention may have been overestimated, as the availability of good records was a criterion of site selection. The number of participants was smaller than the expected sample size,

which reduced the power to detect differences in retention by the study variables. Finally, the data collection methods were comprehensive, but complicated because of the number of paper-based registers, and the lack of an electronic linkage mechanism among the registers and between mother and infant records.

Conclusions

Our data suggest that unmarried, apparently healthy, HIV-positive pregnant women are at the greatest risk of being lost-to-follow-up and may require additional support for programme retention. With new recommendations that lifelong ART should be started in all HIV-positive individuals, including pregnant women, strategies are needed to identify, provide support and trace those women at highest risk of LFTU. These strategies could include risk profiling and support groups for these women. Our study provides further evidence that a targeted supportive approach, allowing a focus of additional resources to the group of women at the highest risk of being lost, would be appropriate. Areas for further research include closer examination of the factors that could improve retention in urban areas, such as the use of mobile phones/texting and social media, peer groups linked to income generating/skills building activities. Research on facility-level factors could include enhanced counselling, and the optimization of patient tracking, staffing levels and configuration.

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Competing interests
The authors declare that they have no competing interests.

Authors' contributions
GW was responsible for developing the study protocol as well as conducting the analysis and interpretation of data. DN was responsible for data collection, study coordination, analysis and interpretation of the findings. SB was responsible for drafting the manuscript as well as interpretation of the data. EN and HH were responsible for statistical modelling and analyses PM and MR contributed to protocol development and review of the manuscript. AA and RP contributed to protocol and manuscript development. All authors have read and approved the final manuscript.

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Research article

Factors associated with long-term antiretroviral therapy attrition among adolescents in rural Uganda: a retrospective study

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Abstract

Introduction: As access to antiretroviral therapy (ART) increases, the success of treatment programmes depends on ensuring high patient retention in HIV care. We examined retention and attrition among adolescents in ART programmes across clinics operated by The AIDS Support Organization (TASO) in Uganda, which has operated both facility- and community-based distribution models of ART delivery since 2004.

Methods: Using a retrospective cohort analysis of patient-level clinical data, we examined attrition and retention in HIV care and factors associated with attrition among HIV-positive adolescents aged 10–19 years who initiated ART at 10 TASO clinics between January 2006 and December 2011. Retention in care was defined as the proportion of adolescents who had had at least one facility visit within the six months prior to 1 June 2013, and attrition was defined as the proportion of adolescents who died, were lost to follow-up, or stopped treatment. Descriptive statistics and Cox proportional hazards regression models were used to determine the levels of retention in HIV care and the factors associated with attrition following ART initiation.

Results: A total of 1228 adolescents began ART between 2006 and 2011, of whom 57% were female. The median duration in HIV care was four years (IQR = 3–6 years). A total of 792 (65%) adolescents were retained in care over the five-year period; 36 (3%) had died or transferred out and 400 (32%) were classified as loss to follow-up. Factors associated with attrition included being older (adjusted hazard ratio (AHR) = 1.38, 95% confidence interval (CI) 1.02–1.86), having a higher CD4 count (250+ cells/mm^3) at treatment initiation (AHR = 0.49, 95% CI 0.34–0.69) and HIV care site with a higher risk of attrition among adolescents in Gulu (AHR = 2.26; 95% CI 1.27–4.02) and Masindi (AHR = 3.30, 95% CI 1.87–5.84) and a lower risk of attrition in Jinja (AHR = 0.24, 95% CI 0.08–0.70). Having an advanced WHO clinical stage at initiation was not associated with attrition.

Conclusions: We found an overall retention rate of 65%, which is comparable to rates achieved by TASO's adult patients and adolescents in other studies in Africa. Variations in the risk of attrition by TASO treatment site and by clinical and demographic characteristics suggest the need for early diagnosis of HIV infection, use of innovative approaches to reach and retain adolescents living with HIV in treatment and identifying specific groups, such as older adolescents, that are at high risk of dropping out of treatment for targeted care and support.

Keywords: adolescents; HIV treatment; antiretroviral therapy; retention; attrition; community-based delivery; Uganda.

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Introduction

The burden of HIV in Africa is increasingly on adolescents and young adults. Worldwide, adolescents represent 41% of new HIV infections and are the only age group with increasing death rates due to AIDS [1]. Most of the adolescents living with HIV in sub-Saharan Africa (SSA) are girls and young women, who are particularly vulnerable due to such factors as early sexual debut, age disparate sexual partnerships, gender inequality and biological susceptibility [2]. Also of concern are adolescent members of key populations, including adolescents involved in sex work or using drugs, and young males who have sex with males [2].

Despite early successes in the HIV response in Uganda, HIV prevalence among the general population has steadily increased from 6.4% in 2005 to 7.3% in 2011. Risky sexual behaviours, inconsistent condom use, multiple sexual partnerships and low levels of male circumcision contribute to HIV acquisition and transmission in the country [3]. Like elsewhere in SSA, the HIV epidemic in Uganda continues to disproportionately affect young women [3,4]. Among adolescents aged 15 to 19 years, HIV prevalence is estimated at 2.4%, with a higher prevalence among females (3.0%) than males (1.7%) [4].

As antiretroviral therapy (ART) programmes are rolled out, the retention of adolescent patients in HIV care has gained more attention in recent years [5,6]. Yet adolescents face unique barriers to care and treatment, including being unaware of their sero-status due to a lack of disclosure, difficulties in transitioning from paediatric care to self-management, and family structural factors, in addition to the common psychosocial, economic, health systems and medical barriers

faced by adult patients on ART [5,7]. Adolescents and young adults have significantly higher rates of loss to follow-up from HIV care and treatment than adults, which also contribute to their comparatively poorer outcomes [8,9].

Several strategies have been proposed for better engaging this population, including removing age-related barriers to care [10], developing new HIV testing modalities [11,12] and improving management of the transition from paediatric to adult care [13,14]. However, the evidence on retention and reducing loss to follow-up in HIV care programmes is limited for adolescents and targeted research is critical for improving treatment outcomes and reducing morbidity and mortality in this group 18 [6,15–18].

As one of the largest non-governmental ART programmes in Uganda, The AIDS Support Organization (TASO) was founded in 1987 with the aim of providing patient support for people living with HIV. In 2005, TASO started implementing a family-centred testing, treatment and counselling approach if there was a suspicion that any family member was HIV positive, after noticing that patients were sharing drugs with their family members, including parents sharing drugs with their children, and parents sharing drugs among themselves.

TASO's family-centred approach involved conducting home-based HIV counselling and testing to family members of the index patients. Those who tested positive within the family were assessed for ART eligibility using CD4 cell count and World Health Organization (WHO) staging, and if eligible, were linked to TASO's centre for treatment. Those not eligible were linked to TASO for appropriate care and support services and those who tested negative were counselled on risk reduction. TASO used the household-based approach in order to enhance access to testing, counselling and treatment services for all family members including their children and adolescents.

This paper examines the extent of retention in HIV care and the factors associated with attrition of adolescents aged 10 to 19 years in TASO's HIV treatment programmes in Uganda.

Methods

Study design

The study involved a retrospective secondary analysis of clinical data of adolescents aged 10–19 years collected from 10 of the 11 clinics operated by TASO. We excluded TASO Mulago because the site was not providing ART to adolescents during the study period (all adolescents from this site were linked for specialized ART care to Baylor Uganda). Data were extracted on HIV-positive adolescents from a central electronic database at TASO headquarters in Kampala.

Study setting and data collection

As one of the largest non-governmental ART programmes in the country, TASO operates 11 ART service centres across all the regions of Uganda with funding from the United States President's Emergency Plan for AIDS Relief (PEPFAR). These centres are located in mainly rural parts of Uganda and serve a mean catchment area with a 75-km radius. As of 2015, the organization had provided treatment to over 68,020 clients, of whom more than 6% were children and adolescents.

TASO has implemented and revised several service delivery models over the past 10 years, including home-based care, satellite clinics, community drug distribution, as well as more conventional clinic-based approaches. Starting in late 2015, annual routine viral load monitoring is performed as part of TASO's ART programme. Adolescents who have been on ART for more than one year, and are aware of their HIV sero-status, are evaluated by clinicians and counsellors for downward referral to community drug distribution points (CDDPs). Community-drug distribution is a care model for stable patients designed to make ART delivery more efficient for the health system and provide appropriate support to encourage the long-term retention of patients. ART is provided at the community level by trained lay workers who are supervised by a clinical services supervisor. Adherence to drug regimens is evaluated by staff at the time of pill refill by asking patients to self-report the number of pills missed. Adolescents who have difficulty coping with decentralized ART care service at CDDPs are referred back up to the facility-based care delivery model.

Data were extracted from the pre-ART register, ART case evaluation forms, laboratory registry, death registry, ART commencement forms and drug refill forms. Each dataset contains a unique client identification number that merges information pertaining to the same individual from the different datasets. Information was collected on a total of 1228 HIV-positive adolescents aged 10–19 years who enrolled in ART between January 2006 and December 2011 from 10 TASO centres. Data extracted included clients' socio-demographic characteristics, ART start date, treatment regimen, CD4 cell count at enrolment, WHO clinical staging and pharmacy refill data. The datasets also contained information on known deaths and patients who transferred out of the programme. Patient charts were used to supplement the information from the clinical datasets as necessary.

Data analysis

The study outcomes of interest are HIV care retention and attrition. The indicators for retention; mortality, reported as death at TASO and attrition, were generated by identifying adolescents who enrolled in ART between 2006 and 2011 and had at least one clinic visit within the six months before 1 June 2013. Retention was defined as any patient who had at least one clinic visit in the six months before June 2013; was still alive at the end of June 2013, excluding those deaths reported to TASO stopped ART; or was lost to follow-up (LTFU) [19]. Attrition was defined as the number of adolescents whose deaths that were reported to TASO, who were LTFU or who stopped treatment by the end of June 2013. Patients were defined as LTFU if the last contact was more than three months before the end date of the observation period and they were censored at their last contact date with a TASO service. Married was defined as an adolescent who is married or co-habiting with a sexual partner during the review period.

Data were analyzed using descriptive statistics and multivariable regression models in Stata version 12 [20]. Multivariable Cox proportional hazards regression models was used to examine the factors associated with attrition. The results of the analysis are presented as adjusted hazard ratio (AHR) with

95% confidence intervals (CIs) and interpreted as the relative risk of attrition from ART programmes. The models adjusted for socio-demographic and clinical factors, which included age, sex, mode of ART delivery, CD4 at ART initiation and cohort year (i.e. year of initiation). The variables included in the model those found to be associated with retention in ART care in both the literature and TASO's experience, based on factors influencing retention in care among adolescents. A two-tailed statistical test with a *p*-value of <0.05 was considered to be statistically significant for all tests.

Ethical approval

Patients' records were anonymized and de-identified prior to analysis as per TASO's data protection and access policy. The study was approved by the Population Council Institutional Review Board and the Research and Ethics Committee of TASO, as well as registered with the Uganda National Council of Science and Technology (UNCST).

Results

Data were collected on a total of 1228 adolescents who initiated ART between January 2006 and December 2011, with a median time on ART of four years (IQR = 3–6 years). Over half (61%) were young adolescents (aged 10–14 years), 57% were females and 73% had a primary school education. At the time of ART initiation, 19% of patients had a CD4 count of $<100/mm^3$ and 69% had a CD4 count of $<250/mm^3$. Just over three-fifths (61%) obtained their drug refills from a health facility. A total of 792 (65%) adolescents received at least one clinical service in the six months preceding June 2013. For participants not retained in care, 36 (3%) were known to have died or to have transferred out, and 400 (32%) were classified as LTFU (Table 1).

In the bivariate analysis, the factors associated with attrition were TASO site ($p<0.001$), CD4 cell count at initiation ($p<0.001$), age of the adolescent at ART initiation ($p<0.001$), marital status ($p=0.001$) and year of ART initiation ($p<0.001$). TASO Masindi and Gulu facilities reported a higher attrition rate of adolescents than other centres (52 versus 38%, respectively). We also noted variations in the level of retention by site. In particular, the level of retention was lower at TASO Gulu (67%) and Masindi (52%), while TASO Jinja, Soroti and Rukungiri reported better retention as shown in Table 2.

In the multivariate Cox proportional hazards analysis, factors associated with attrition were age (AHR = 1.29, 95% CI 1.01–1.65), CD4 at ART initiation (AHR = 0.51, 95% CI 0.36–0.71) and site of participants: TASO Gulu (AHR = 2.26; 95% CI 1.27–4.02), TASO Jinja (AHR = 0.24, 95% CI 0.08–0.70) and TASO Masindi (AHR = 3.30, 95% CI 1.87–5.84) (Table 3).

Trend in retention analysis showed a higher hazard of attrition among adolescents that initiated ART between 2009 and 2010 (AHR = 2.11, 95% CI: 1.48–3.00) compared to those that initiated ART between 2006 and 2008. Figure 1 shows that retention decreases over time for all cohorts of adolescents who initiated ART between 2006 and 2010; however, retention was consistently higher among the older cohort years (2006–2008) compared to the newer cohort years (2009–2010).

Table 1. Baseline characteristics of adolescents aged 10–19 years in 10 TASO ART centres, 2006–2011 ($n=1228$)

Variable	*n*	Female	Male	Percentage of the totals (%)
Clinical outcome as of June 2013				
Alive and active in care	792	442	350	(65)
Dead	27	13	14	(2)
LTFU	400	236	164	(32)
Transferred	9	6	3	(1)
Site of participant				
Entebbe	103	58	45	(9)
Gulu	97	65	32	(8)
Jinja	99	53	46	(8)
Masaka	170	112	58	(14)
Mbale	163	92	71	(13)
Mbarara	131	71	60	(11)
Masindi	62	34	28	(5)
Rukungiri	131	68	63	(11)
Soroti	128	68	60	(11)
Tororo	144	76	68	(11)
Age (years)				
10–14	750	400	350	(61)
15–19	478	297	181	(39)
Highest level of education				
None	223	119	104	(18)
Primary	894	516	378	(73)
Secondary and above	111	62	49	(9)
Venue of ARV refill				
CDDP	476	278	198	(39)
Health facility	752	419	333	(61)
Marital status				
Single	1170	660	510	(78)
Married	58	37	21	(3)
CD4 at ART initiation				
<250 cells/mm^3	851	486	365	(69)
≥ 250 cells/mm^3	377	211	166	(31)
Year of ART initiation				
2006–2008	453	243	210	(37)
2009–2011	775	454	321	(63)
WHO stage ($n=984$)				
Stage 1&2	725	417	308	(74)
Stage 3	218	133	85	(22)
Stage 4	41	20	21	(4)

LTFU, lost to follow-up; CDDP, community drug distribution point.

Discussion

This study of 1228 adolescents in the TASO ART programme in Uganda demonstrated that nearly two-thirds (65%) of adolescents who initiated ART from January 2006 to December 2011 were retained in care. This finding is comparable to the five-year retention rate of 69% for adults in the same TASO programme [21]. Other studies in SSA have reported

Table 2. Characteristics of active (non-attrition) and non-active (attrition) adolescents aged 10–19 years in 10 TASO centres ($n = 1228$)

	Active ($n = 792$)				Non-active ($n = 436$)				
	n	% of total sample	Male	Female	*n*	% of total sample	Male	Female	*P*
Site of participant									0.000
Entebbe	83	(8)	32	51	20	(10)	13	7	
Gulu	65	(6)	21	44	32	(16)	11	21	
Jinja	95	(9)	44	51	4	(2)	2	2	
Masaka	133	(13)	45	88	37	(18)	13	24	
Mbale	125	(12)	48	77	38	(19)	23	15	
Mbarara	119	(12)	55	64	12	(6)	5	7	
Masindi	32	(3)	18	14	30	(15)	10	20	
Rukungiri	126	(12)	61	65	5	(2)	2	3	
Soroti	127	(12)	60	67	1	(0)	0	1	
Tororo	121	(12)	55	66	23	(11)	13	10	
Age (years)									0.023
10–14	641	(62)	297	344	109	(54)	53	56	
15–19	385	(38)	142	243	93	(46)	39	54	
Highest level of education									0.005
None	193	(19)	86	107	30	(15)	18	12	
Primary	752	(73)	319	433	142	(60)	59	83	
Secondary and above	81	(9)	34	47	30	(15)	15	25	
Venue of ARV refill									0.670
CDDP	631	(65)	277	354	121	(60)	56	65	
Health facility	395	(35)	162	233	81	(40)	36	45	
Marital status									0.007
Single	983	(84)	426	557	165	(82)	8	7	
Married	43	(12)	13	30	10	(6)	84	103	
CD4 at ART initiation									
< 250 cells/mm^3	694	(68)	28	397	157	(78)	68	89	0.005
≥ 250 cells/mm^3	332	(32)	142	190	45	(22)	24	21	
Year of ART initiation									
2006–2008	366	(36)	174	192	87	(43)	36	51	0.046
2009–2011	660	(64)	265	395	115	(57)	56	59	
WHO stage ($n = 984$)	$n = 837$				$n = 167$				
Stage 1&2	626	(64)	259	367	118	(58)	49	50	0.161
Stage 3	177	(18)	69	108	42	(21)	16	25	
Stage 4	34	(3)	20	14	7	(3)	1	6	

retention among adolescents as a major challenge for HIV programmes [3,22,23]. The long-term levels of retention seen in this study could be due to TASO's intensive resources targeting whole families with HIV testing, counselling, treatment and support services, especially in the earlier years of ART.

Retention and attrition rates, however, varied across the country's service centres. Treatment at the Gulu and Masindi centres was significantly associated with a higher risk of attrition. The lower retention rates seen in these centres could be due to their more rural location, the military conflict in the region during the study period, and the increased mobility of patients as part of post-conflict resettlement. The higher retention rates in TASO Soroti, Rukungiri, Jinja and Mbarara centres may be due to the presence of adolescent clinics that offer intensive pre-ART counselling to patients, including a follow-up home-based HIV counselling and testing visit to the family to identify an adherence support buddy. About one-third (32%) of adolescents were classified as LTFU in this study. It is possible that some adolescents may have died and their deaths were unreported, such that they were misclassified as LTFU. However, our finding is comparable to other studies that found LTFU among adolescents ranging from 17 to 30.3% at 24 months of follow up [24,25].

The risk of attrition was significantly lower among adolescents with a higher CD4 count compared to those with a lower CD4 count at the time of ART initiation. This finding is comparable to other research that reported adolescents with

Table 3. Factors associated with attrition among adolescents aged 10–19 years in 10 TASO centres

	Univariate		Multivariate	
List of factors	**HR (95% CI)**	***p***	**HR (95% CI)**	***p***
Gender				
Female	Ref			
Male	1.03 (0.77–1.36)	0.858		
Site of participant				
Entebbe	Ref		Ref	
Gulu	2.02 (1.14–3.59)	0.016	2.17 (1.21–3.89)	0.009
Jinja	0.19 (0.07–0.56)	0.003	0.24 (0.08–0.71)	0.010
Masaka	1.32 (0.77–2.28)	0.314	1.37 (0.79–2.37)	0.266
Mbale	1.37 (0.80–2.36)	0.264	1.69 (0.97–2.98)	0.064
Mbarara	0.48 (0.23–0.98)	0.044	0.43 (0.21–0.91)	0.026
Masindi	2.98 (1.69–5.27)	0.000	3.50 (1.97–6.21)	0.000
Rukungiri	0.19 (0.07–0.51)	0.001	0.18 (0.07–0.49)	0.001
Soroti	0.04 (0.01–0.33)	0.002	0.04 (0.01–0.28)	0.001
Tororo	0.82 (0.45–1.50)	0.528	0.99 (0.54–1.82)	0.969
Age (years)				
10–14	Ref		Ref	
15–19	1.470 (1.11–1.94)	0.008	1.38 (1.02–1.86)	0.038
Highest level of education				
None	Ref		Ref	
Primary	1.21 (0.82–1.79)	0.342	0.91 (0.60–1.37)	0.644
Secondary and above	2.19 (1.31–3.66)	0.003	1.26 (0.72–2.19)	0.418
Venue of ARV refill				
CDDP	Ref			
Health facility	1.00 (0.76–1.34)	0.972		
Marital status				
Single	Ref		Ref	
Married	1.07 (0.70–1.63)	0.750	0.96 (0.62–1.49)	0.858
Minor	2.46 (1.19–5.12)	0.015	1.44 (0.68–3.06)	0.345
CD4 at ART initiation				
< 250 cells/mm^3	Ref		Ref	
≥ 250 cells/mm^3	0.62 (0.44–0.87)	0.005	0.49 (0.34–0.69)	0.000
Year of ART initiation				
2006–2008	Ref		Ref	
2009–2011	1.92 (1.37–2.69)	0.000	2.11 (1.48–3.00)	0.000
WHO stage				
Stage 1 & 2	Ref			
Stage 3	1.25 (0.86–1.82)	0.228		
Stage 4	1.17 (0.54–2.52)	0.691		

lower CD4 cell counts to be more likely to experience attrition compared to those with higher CD4 counts [26]. Additionally, the risk of attrition was not affected by patients' clinical stage, which is not consistent with other studies reporting high rates of attrition among patients in advanced clinical stage disease [27,28]. This could be due to the psychosocial family support the patients received and the TASO home-based chronic care services delivered to patients who were in advanced clinical stages.

We found that the risk of attrition was significantly greater in older (15–19 years) than in younger (10–14 years) adolescents. This finding is comparable to other studies, one carried out in rural Zimbabwe and another in South Africa. The Zimbabwe study followed a cohort of adolescents who initiated ART between 2005 and 2008 [29]. The researchers found that older adolescents experienced greater LTFU than younger adolescents, with a rate per 100 person-years of 10.9 compared to 4.2. Retrospective data from seven South African clinics in urban Gauteng and rural Mpumalanga detected LTFU rates per 100 person years of 23.3 among older adolescents compared to 6.1 among younger adolescents [29,30]. The higher risk of attrition in older adolescents could be due to

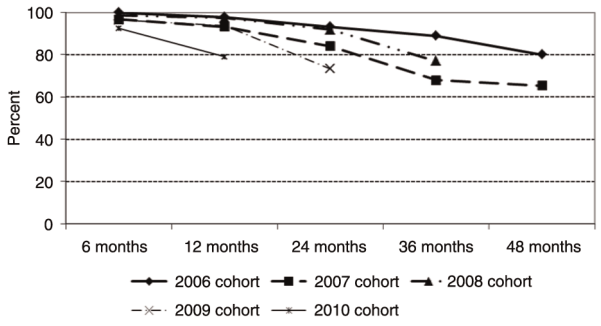

Figure 1. Trends in the level of retention and attrition of adolescents who initiated ART between 2006 and 2010 in 10 TASO centres.

the challenges associated with transitioning from paediatric to adult care, given that the ages 15–19 years also mark an adolescent's transition to adulthood [8].

We also found that retention decreased among adolescents initiating ART in each successive year since 2006 and the gaps widened with longer durations of observation. This could be an indication of a change in TASO's programme from a family-centred approach to a clinic-based approach due to a decline in funding. Given that the 2015 WHO comprehensive ART guidelines removed CD4 and WHO clinical staging requirements for ART eligibility and the promotion of the ''test and treat'' strategy, more adolescents will be placed on ART, which could lead to strains on already resource-constrained health systems in Uganda and elsewhere in SSA. We, therefore, need to develop, pilot and fund innovative approaches for identifying and retaining HIV-positive adolescents in treatment programme if we are to achieve the UNAIDS 90-90-90 targets by 2020.

Limitations

This study has several limitations. First, the type of data recorded in patients' records is limited, preventing us from exploring further certain patterns in the data, such as the unexpected variations in the levels of retention of adolescents by the year of initiating ART or the risk of attrition between female and male adolescents. Second, data used in the analysis are routinely collected and entered by clinicians and might be subject to inaccuracies and incompleteness given the competing priority of ensuring the provision of quality services to clients. For instance, some variables like haemoglobin level, current education level, orphanhood and distance to an ART facility had extensive missing information and were not included in the multivariate analyses to avoid loss of statistical power. This could lead to under-estimation or over-estimation of the outcomes of interest. Third, the proportion of adolescents in TASO ART programmes that had died was based on health facility records; thus deaths that occurred at home might have been misclassified as LTFU.

Conclusions

We found an overall retention rate of 65% among adolescents who initiated ART between 2006 and 2011, with varying durations in the ART programme. Retention was higher amongst adolescents who were younger (10–14 years of age), commenced ART in the early years of the study period and had higher CD4 counts at ART initiation. Advanced disease clinical stage at initiation was not associated with attrition, and retention varied across treatment sites.

The findings of this paper suggest that it is possible to achieve the long-term retention of adolescents in ART programmes. TASO's ART programme provides valuable lessons for improving the long-term uptake of treatment services by adolescents living with HIV. Retention in HIV care was highest when TASO's family HIV counselling approach was operating. This model enabled the TASO staff to conduct home-based HIV testing and counselling of the family members of clients, thus identifying children and adolescents living with HIV who could then be linked to HIV care. It also enhanced sero-status disclosure to the adolescents of their HIV status and of their parents, further facilitating retention in HIV care.

Variations in the risk of attrition from treatment sites and by clinical and socio-demographic characteristics suggest the need for early diagnosis of HIV infection, use of innovative approaches to reach and retain adolescents living with HIV on treatment, like TASO's family-centred approach, and identifying specific groups (such as older adolescents and female patients) that are at higher risk of dropping out of treatment for targeted care and support.

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Competing interests
The authors declare that they have no competing interests.

Authors' contributions
LS and SO designed the study. SO, JB and SK supervised data collection of the study. LS, LJO, CB, DK and SN collected the data. LS, LJO, CB and SO conducted or contributed to the data analysis. LS, LJO, CD, SO and AIY interpreted the data. SO prepared the original manuscript; AY, AS and DMM contributed to subsequent revisions. All authors read and approved the final manuscript

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Research article

Limited accessibility to HIV services for persons with disabilities living with HIV in Ghana, Uganda and Zambia

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Abstract

Introduction: Knowledge about experiences in accessing HIV services among persons with disabilities who are living with HIV in sub-Saharan Africa is limited. Although HIV transmission among persons with disabilities in Africa is increasingly acknowledged, there is a need to bring to life the experiences and voices from persons with disabilities living with HIV to raise awareness of programme implementers and policy makers about their barriers in accessing HIV services. This paper explores how the barriers faced by persons with disabilities living with HIV impede their ability to access HIV-related services and manage their disease.

Methods: We conducted focus group discussions with 76 persons (41 females; 35 males) with physical, visual and/or hearing impairments who were living with HIV in Ghana, Uganda and Zambia (2012–2013). We explored challenges and facilitators at different levels (individual, psychosocial and structural) of access to HIV services. Transcripts were analyzed using a framework analysis approach.

Results: Persons with disabilities living with HIV encountered a wide variety of challenges in accessing HIV services. Delays in testing for HIV were common, with most waiting until they were sick to be tested. Reasons for delayed testing included challenges in getting to the health facilities, lack of information about HIV and testing, and HIV- and disability-related stigma. Barriers to HIV-related services, including care and treatment, at health facilities included lack of disability-friendly educational materials and sign interpreters, stigmatizing treatment by providers and other patients, lack of skills to provide tailored services to persons with disabilities living with HIV and physically inaccessible infrastructure, all of which make it extremely difficult for persons with disabilities to initiate and adhere to HIV treatment. Accessibility challenges were greater for women than men due to gender-related roles. Challenges were similar across the three countries. Favourable experiences in accessing HIV services were reported in Uganda and Zambia, where disability-tailored services were offered by non-governmental organizations and government facilities (Uganda only).

Conclusions: Persons with disabilities living with HIV encounter many challenges in accessing HIV testing and continued care and treatment services. Changes are needed at every level to ensure accessibility of HIV services for persons with disabilities.

Keywords: disability; persons with disabilities; PLHIV; HIV positive; accessibility.

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Introduction

Persons with disabilities represent approximately 15% of the world's population with 80% living in low- and middle-income countries [1]. Further, evidence indicates that persons with disabilities are at the same or elevated risk of HIV because of the many vulnerabilities they face, including poverty, lack of education, lack of sex education, lack of knowledge about HIV and safe sex practices, sexual violence, substance abuse, poor access to health services and stigma and discrimination [2–11]. A systematic review by De Beaudrap *et al*. found that persons with disabilities do not have a lower risk of HIV infection compared with the general population [12].

To address the needs of persons with disabilities living with HIV, HIV services must be inclusive, addressing their specific needs to ensure early diagnosis and timely initiation of HIV treatment, and promote retention and adherence in care and treatment. While research on the challenges encountered by persons with disabilities in accessing health services in sub-Saharan Africa is growing [2,4,9,11,13–18], crucial practical information on their specific challenges and facilitators remains limited, particularly based on data collection directly from persons with disabilities living with HIV [15,18]. Understanding the unique experiences of persons with disabilities living with HIV from their own perspectives and experiences in accessing HIV services will help programmes to address their

specific needs. The objective of this paper is to understand how the barriers faced by persons with disabilities living with HIV impede their ability to access HIV-related services and manage their disease.

Methods

We conducted a three-country study (Ghana, Uganda and Zambia), representing settings of different stages of the HIV epidemic and the degree to which the needs of persons with disabilities are recognized in the National Strategic Plan for HIV and AIDS (Uganda: high; Zambia: moderate; Ghana: low) [19–22]. In order to explore factors affecting access to and use of HIV services, we conducted focus group discussions (FGD) with persons with disabilities living with HIV (2012–2013). Study activities were conducted in the capital city (Accra, Kampala and Lusaka) and one peri-urban or rural site (Amasaman, Jinja and Solwezi) in each country. We established and sought advice from an advisory board in each country, which consisted of leaders from local disabled persons organizations (DPOs) and country AIDS Commissions to provide guidance on study design, implementation and results interpretation. We conducted FGDs to generate richer discussions based on people's potentially differing experiences; feedback from the advisory board indicated it would be acceptable and appropriate.

A total of 17 FGDs were conducted (median: six per group; IQR: 2.5–6). Participants were 18 years or older, HIV positive and had visual, hearing or physical disabilities. Disability and HIV status were self-reported. Participants were recruited as a convenience sample through DPOs and peer referrals. Designated DPO staff recruited candidates in a private and confidential manner providing information about the study including the eligibility criteria. DPO staff instructed interested candidates to attend the FGD at the specified time and place, where the candidates were screened and consented by a study staff. Participants were also asked to invite potentially interested and eligible peers with disabilities to contact the DPO staff. We recruited individuals accessing and those not accessing services at the DPOs. Persons with intellectual or developmental disabilities were not included as it would have required special procedures for appropriate consent, which the ethical review boards were not comfortable with. Participants and their assistants received reimbursement for time and transport. Assistants waited in another room to maintain confidentiality of participants during the FGD. Trained moderators sensitized in working with persons with disabilities conducted the FGD using a semi-structured guide designed to elicit information about barriers and facilitators to access HIV services. Sign interpreters were used for FGDs with hearing-impaired persons. Before each FGD, a researcher (along with a sign interpreter for deaf participants) sought informed consent individually with each potential participant in private and obtained signature or finger/toe print. Interviews were recorded, transcribed and translated.

FGD transcripts were imported into ATLAS.ti v5.2 (ATLAS.ti GmbH, Berlin, Germany). The research team reviewed transcripts and conducted analysis using a framework analysis approach [23–25], which is appropriate for applied research in order to describe and interpret what is happening in a specific setting to provide recommendations as opposed to generating theory to be tested. Codes were developed using key domains outlined *a priori* during research design; during data analysis, three researchers reviewed the transcripts and added codes based on emergent themes. Themes were assessed and compared to determine how often the same concept emerged within and across countries and by disability type. Analysts double coded 30% of the transcripts to ensure quality.

The study was approved by the ethical review boards of the Population Council, University of Zambia, Ghana Health Services, The AIDS Support Organization-Uganda and the Uganda National Council for Science and Technology.

Results

We recruited a total of 76 persons with disabilities living with HIV (41 females; 35 males). Table 1 shows the characteristics of the FGD participants. All but two participants had their disabilities prior to their HIV diagnosis.

Barriers to HIV testing

Most participants indicated that they did not test for HIV until they became sick; hence, late HIV diagnosis was common among this population, regardless of sex, disability type or country. Most participants reported that they were aware of persons with disabilities who delayed HIV testing until they were critically ill.

Table 1. Characteristics of focus group participants

	Ghana (*N* = 14)	Uganda (*N* = 28)	Zambia (*N* = 34)
Type of impairment			
Hearing	4	1	8
Visual	1	14	9
Physical	9	12	17
Physical and visual	0	1	0
Sex			
Female	10	16	15
Male	4	12	19
Median age, years (IQR)	43 (36, 48)	40 (34, 50)	39 (30, 47)
Education			
< Primary or none	2	6	3
Completed primary	2	3	6
Completed secondary	8	5	24
Completed high school	1	13	1
> High school	1	1	0
Marital status			
Single	7	7	14
Married	3	14	10
Divorced/widowed/ separated	4	7	10

IQR: interquartile range.

> . . . if I hadn't gotten sick and been admitted, I wouldn't have been tested. (Female, blind, 39, Ghana)

One of the primary factors impeding access to testing was the lack of information about HIV and HIV testing. In all three countries, the majority of participants reported being disappointed with the limited amount of information in accessible formats (e.g. Braille, large print and sign interpreters) about HIV and the importance of testing. Other major factors impeding access to HIV testing include limited mobility, lack of transportation, social isolation and HIV- and disability-related stigma (discussed in subsequent sections).

Barriers to facility-based HIV services – getting to the clinic

Consistently across all three countries, one of the most significant barriers to accessing facility-based HIV services was related to physical accessibility to and of HIV services facilities. Across all impairment types, many participants mentioned the lack of accessible physical infrastructure (poor roads, lack of sidewalks and ramps, inability to use public transportation) as well as the social and emotional trauma of being taunted by other riders or the driver, or having to pay extra for their crutch or wheelchair on a bus. Particularly in Uganda, many participants frequently spoke about how taxi drivers did not pick them up or they were turned away because of their disability. In all three countries, some spoke of travelling with an assistant to help them but admitted that this brought additional complications due to difficulty of finding someone prepared to give up their time and be publicly seen with a person with HIV, and the additional transport costs required.

> We, the blind, we have challenge – most of our guides do not want to guide us to the areas where the services are offered simply because they fear the community associating them with the HIV/AIDS. (Male, blind, 58, Uganda)

> Another difficulty is that as a result of the long queues at [Clinic X], we as people who are blind are being denied to be escorted by friends and family. They refuse saying when we go, we'll spend the whole day at the clinic just for nothing. (Male, blind, 40, Zambia)

For many, regardless of type of impairment, attending clinic visits with an assistant also presented a challenge to maintaining confidentiality about their HIV status, particularly when picking up medications or attending consultations.

> Sometimes we get to be escorted by family members or friends due to the fact that we can't manage moving alone. So you'll find that the one who escorted you gets to know all your HIV status details and yet information is supposed to be confidential. (Male, physically disabled, 40, Zambia)

Despite the many challenges, a number of participants in Zambia and Uganda reported positive experiences with non-governmental organizations (NGOs) that provided home-based care and outreach services. In particular, participants reported outreach by non-clinical support workers was essential in helping them receive medications, counselling and health education without having to visit a facility.

> We the disabled get services through caregivers like [NGO1], and some come through to our communities and give us information concerning our health. . . . And if found positive, they tell us how to live positively. (Female, physically disabled, 25, Zambia)

> We get these services from [NGO2], and if we are unable to get there, we have peer counselors who carry drugs and come down to the grassroots where we are and provide the services to us. (Female, physically disabled, 50, Uganda)

Facility-level barriers – within the clinic

Once within the health facility, participants reported varying experiences with regard to how services accommodated their impairment-specific needs. In all three countries, many participants indicated that although they had not been directly refused services because of their disability, the challenges they had encountered at the health facilities (most often at government facilities) were so numerous and discouraging that they often ended up forgoing HIV treatment or seeking services elsewhere (e.g. at private facilities or from traditional healers). Disability-specific inaccessibility at health facilities that were mentioned often in all countries included lack of sign language interpreters and Braille or large-print materials, inaccessible toilets and lack of ramps and wide doors for wheelchairs.

In Uganda, a number of participants reported several ways in which healthcare facilities and providers had recognized and addressed their needs; there were no such experiences reported in Ghana and Zambia. Participants indicated that some health facilities were beginning to respond to their needs by improving infrastructure and making accessible information available. Many participants mentioned improved accessibility to some government facilities including construction of ramps and availability of printed HIV-related information resources in large font and pictures.

> After a series of advocacy for provision of HIV/AIDS care and treatment to the blind and physically disabled, the government responded partially to reduce the gap which was affecting the blind and physically disabled. . . . some of these included building of ramps in hospitals for the physically disabled to easily get the service they need. (Male, blind, 49, Uganda)

The lack of skills and sensitivity among healthcare providers emerged strongly from participants in all countries regardless of impairment type. Many participants felt that they were missing out on critical information about how to take care of themselves as a person living with HIV, including taking medications correctly. Deaf participants felt that it was difficult to receive counselling and instructions for taking and adhering to medications. Facilities lacked informational

materials in accessible format, and several participants spoke about their desire for more information on living positively.

> As positive deaf, services are problematic because there are no interpreters, so it makes us miss important information instructions on how to take medication which is a health risk. (Male, deaf, 48, Zambia)

While some deaf persons were able to receive healthcare information through written resources (e.g. leaflets, posters), they acknowledged that this was not possible for illiterate persons, which is common among persons with disabilities due to barriers accessing education.

Participants commonly reported that healthcare providers, anticipating communication challenges, frequently gave priority to people without disabilities, leading to extended wait times and consequently medication stock-outs by the end of the day.

> For us the blind people when we go to those hospitals, they make us sit down and wait and at the end day they don't provide you with any services, eventually they tell you there is no medicine. (Female, blind, 50, Uganda)

> When doctors see a deaf person approaching, there is communication breakdown and therefore do not attend to us. Instead they call hearing people and attend to them. . . . so we are turned down. We feel depressed and demoralized so we just go home and sleep. (Male, deaf, 48, Zambia)

Economic barriers

Many participants pointed out that they face excessive economic challenges due to costs associated with travel to clinics, clinical services and food to support the increased nutritional needs of people on ART.

> We have only one challenge of being poor. . . . the medicine requires us to eat something, so you see that many will become reluctant and not take the medicine simply because they do not have the money to buy the food to accompany the medicine. So they end up not taking the medicine at a regular basis as prescribed by the doctors. (Male, physically disabled, 38, Uganda)

Challenges associated with limited financial resources is especially hard for persons with disabilities; many participants talked about how persons with disabilities are more often unemployed, less educated and live in poverty compared with those without a disability. Many participants, particularly from Ghana, frequently discussed the interconnected linkages between disability and lack of education and illiteracy.

> Lacking education, they are at an extreme disadvantage in comprehending existing HIV prevention messages. I think the main issue is most of us are not mainly educated, so these words [about HIV] when they are mentioned, if you don't get someone to explain it to you, then you are lost. (Female, 30, deaf, HIV positive, Accra, Ghana)

However, there were instances mentioned of economic support, all of which were from Uganda and Zambia. Some participants in Uganda, through local NGOs and community-based organizations (CBOs), reported receiving additional supportive services that help them improve their own livelihoods such as the formation of income-generating activities.

> We as HIV positive and physically disabled people often get groups through which we can access services such as counseling, medicines, and knowledge. For example, here in Jinja, we have [CBO]; . . . we may engage in poultry farming starting from 2 chickens to find means of how to help ourselves. That is why we are thankful to [CBO], and other NGOs which have given us pigs, seedlings for agricultural farming which we rear and gain money and also get food for our personal nutrition in the long run. Hence these groups help us collectively advocate for the services we need. (Male, physically disabled, 58, Uganda)

Stigma related to HIV and disabilities

In all three countries, participants reported experiencing multiple dimensions of stigma from multiple sources, compounding each other to result in social isolation and being cut off from sources of critical information and services. The findings from this study related to the multiple sources of stigma among persons with disabilities, including those living with HIV, have been reported elsewhere [26]. Briefly, the dual stigma of HIV and disability as well as the internalized stigma (i.e. feeling ashamed because of their disability and HIV status) discouraged people from HIV testing due to fear of judgment from others and concern about who will take care of them. This was pervasive in all three countries. These overlapping stigmas are the paramount underlying reason for late HIV diagnosis, sub-optimal attendance at health clinics for ART services and lack of family and community support. Stigmatizing attitudes were rampant in the community as well as at health facilities. Many participants reported that they experienced stigmatizing attitudes from other patients and even healthcare providers when accessing HIV-related services.

> [We] are neglected and segregated by the medical people. Some say we smell. You try very much to seek for his or her attention; the medical person just passes by you so when you go back, you fail to the guts or energy to go back to the hospital because of the way you were treated the day before. . . . [we] lose the morale of getting treatment from the facilities. (Male, physically disabled, 38, Uganda)

To alleviate some of the issues around stigma, some participants in Uganda talked about how instrumental social support from other persons with disabilities living with HIV was in allowing them to deal more effectively with stressors related to living with HIV because there was a sense that

others face similar challenges or will be there to help them if necessary.

> We form our groups as we [people with disabilities] who are HIV positive such that other persons like us cannot think they are alone and this helps to build their spirits and motivate them to living healthy lives. (Female, physically disabled, 50, Uganda)

Access to services by sex

Most female participants felt they had more challenges accessing services compared with males because of their gender roles. Across all three countries, female participants mentioned household and childcare responsibilities and having less money than men as the challenges in seeking healthcare.

> For a man it is easier because we women have a lot to take care of at the home and would not have enough time to go get services. (Female, physically disabled, 25, Zambia)

While there was evidence of differential access to healthcare, most participants felt that men and women with disabilities were not treated differently by providers based on their sex: ''We are treated equally. They don't say you are a man or a woman'' (Female, deaf, 30, Ghana). However, a few female participants in Zambia mentioned longer wait times for women: ''Men are treated first. Women wait in a queue until they are done with them [men], then they start calling names of women'' (Female, deaf, 54, Zambia).

Discussion

Through the voices of persons with disabilities living with HIV, this study highlighted specific challenges and facilitators for persons with disabilities living with HIV in accessing HIV services. They encounter many challenges in accessing HIV testing and continued care and treatment services. These barriers exist at many levels: individual (e.g. lack of accessible HIV information), psychosocial (e.g. stigma), economic (e.g. poverty) and health systems (e.g. provider attitudes and skills, inaccessible physical infrastructure). While some of the barriers are similar to those experienced by HIV-positive persons without disabilities (e.g. HIV-related stigma, long queues at health facilities), these barriers are amplified for persons with disabilities.

The barriers discussed in this paper mirror findings from other studies on persons with disabilities in sub-Saharan Africa [2,4,9,11,13–18]. However, this study emphasizes the struggles faced specifically by persons with disabilities living with HIV in accessing HIV testing and obtaining HIV care and treatment services, which may ultimately have a negative impact on HIV treatment outcomes. We found that the ''double burden'' of being HIV positive and having a disability and the associated stigma lead to delays in accessing essential services such as HIV testing due to fear of results and potential consequences of a positive result. In addition, many delayed HIV diagnosis until they felt sick and upon diagnosis, they did not want to seek care and treatment due to the many challenges they faced getting to the facilities as well as within the facilities. Challenges at point of care highlighted in this study include lack of sensitization and skills among healthcare workers to work with this population and lack of accessible infrastructure which significantly inhibited persons with disabilities living with HIV from obtaining the services they need including information on correct medication usage, adherence and how to live positively. This has major implication for HIV treatment outcomes for persons with disabilities living with HIV as late HIV diagnosis and late initiation (or lack of use) of ART is associated with greater morbidity and mortality.

There is a need to make services accessible to the disabled and sensitize health workers to provide services to persons with disabilities. Further, programmes need to reach out to persons with disabilities for testing and treatment initiation. For example, testing as well as ART can be provided through DPOs or at home through home-based services as shown by some programmes in Zambia and Uganda. Such interventions are part of a compendium of best practices in HIV programming for persons with disabilities [27]. In addition, interventions should not only be targeted at improving services and infrastructure such as provision of sign interpreters and accessible materials or provision of outreach services, programmes must also address stigma reduction and gender equity within the larger community to reduce the stigma associated with HIV and disability and the harmful gender norms that impede the access of women with disabilities to access health services.

Despite the evidence of many challenges in accessing HIV services, this study also found favourable experiences emerging from Uganda and Zambia, resulting from actions initiated by NGOs and DPOs and supportive national policies. Although progress may be relatively slow, Zambia and in particular Uganda serve as examples in supporting and implementing policies and programmes to provide persons with disabilities living with HIV with tailored HIV services. Reports of positive experiences from persons with disabilities living with HIV in Uganda, even within government facilities, are not surprising given that Uganda has one of the most progressive National Strategic Plan for HIV/AIDS with regard to persons with disabilities with specific guidelines for operationalization [19,21]. Supportive policies at the national level as in the case of Uganda and Zambia where there has been systematic inclusion of persons with disabilities in the national HIV planning efforts are likely the reason for the evidence of favourable programming for persons with disabilities in these countries. Such policies pave the way for inclusive services within mainstream health facilities and other efforts by DPOs and NGOs (e.g. home-based care, income generation activities and support groups).

Limitations

Although selection of participants according to different impairments enabled us to capture a range of experiences, the study sample was small and may not be representative of persons with disabilities living with HIV in sub-Saharan Africa. However, the remarkable similarities in the barriers across the three countries despite the different stages of HIV response to persons with disabilities suggest that there are some common challenges across sub-Saharan African settings. Further, the

sample comprised persons with disabilities who were linked in some way to DPOs and many had basic schooling. Thus, the sample may be more resourced and connected than others with disabilities. This may potentially have biased the results to more favourable reports as those not linked to services may likely experience and report negative experience to a greater degree than what is reported here. However, the participants in this study spoke not only about their own experiences as a person with disabilities living with HIV but also about others in similar circumstances. In addition, the use of FGDs, as opposed to in-depth interviews, may have biased the findings as the sample consisted of those who were comfortable with openly discussing their experiences as an HIV-positive person. Those not comfortable being part of a group discussion may represent a subset with greater challenges to accessing services given their discomfort with disclosure. Finally, this study did not include persons with intellectual or developmental disabilities due to ethical concerns. However, this does not indicate that they are free from HIV risk. There is evidence that it is a population at risk for HIV [12,28].

Conclusions

The barriers reported in this study have major implications for the HIV treatment outcomes of persons with disabilities living with HIV and for reaching the UNAIDS 90-90-90 HIV treatment targets [29]. Changes are needed at every level to ensure persons with disabilities have access to HIV services including provision of accessible services, infrastructure and information; formation of support groups for persons with disabilities; changing harmful attitudes around disabilities; HIV and gender norms within the community and in health facilities; and outreach and home-based interventions to mitigate accessibility barriers.

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Competing interests
None.

Authors' contributions
WT was the principal investigator of the study and led the writing of the manuscript. JO was co-investigator, conducted analysis and wrote portions of the manuscript. KS was co-investigator, led the analysis and helped draft the manuscript. SE (Ghana), HA (Ghana) and GM (Zambia) coordinated data collection activities in their respective countries. FM, RK and EN were co-investigators and served on the advisory board. CMN provided technical input in the conception of the study and contributed to interpretation. All authors have read and approved the final version.

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Research article

Reducing HIV-related risk and mental health problems through a client-centred psychosocial intervention for vulnerable adolescents in Addis Ababa, Ethiopia

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Abstract

Introduction: Ethiopia is experiencing an increasingly urban HIV epidemic, alongside a rise in urban adolescent migration. Adolescent migrants are often confronted by unique social challenges, including living in a difficult environment, abuse and mental health problems. These issues can increase adolescents' vulnerability to HIV and compromise their capacity to protect themselves and others from HIV. We piloted and assessed the effects of a targeted psychosocial intervention to reduce mental health problems and improve HIV-related outcomes among migrant adolescents in Addis Ababa.

Methods: A pre- and post-comparison design was used in a cohort of 576 female and 154 male migrant adolescents aged 15 to 18 years in Addis Ababa receiving services from two service delivery organizations, Biruh Tesfa and Retrak. We implemented a three-month client-centred, counsellor-delivered psychosocial intervention, based on findings from formative research among the same target population, to address participants' increased vulnerability to HIV. The intervention package comprised individual, group and creative arts therapy counselling sessions. Key outcome indicators included anxiety, depression, aggressive behaviour, attention problems, social problems, knowledge of HIV, safer sex practices and use of sexual health services. Longitudinal data analysis (McNemar test and random effects regression) was used to assess changes over time in key indicators by gender.

Results: For females, aggressive behaviour decreased by 60% (adjusted odds ratio (AOR): 0.4 (0.25 to 0.65)) and any mental health problem decreased by 50% (AOR: 0.5 (0.36 to 0.81)) from baseline to end line. In addition, knowledge of HIV increased by 60% (AOR: 1.6 (1.08 to 2.47)), knowledge of a place to test for HIV increased by 70% (AOR: 1.7 (1.12 to 2.51)) and HIV testing increased by 80% (AOR: 1.8 (1.13 to 2.97)). For males, HIV knowledge increased by 110% (AOR: 2.1 (1.1 to 3.94)), knowledge of a place to test for HIV increased by 290% (AOR: 3.9 (1.02 to 14.9)), HIV testing increased by 630% (AOR: 7.3 (2.6 to 20.7)) and use of sexual health services increased by 220% (AOR: 3.2 (1.62 to 6.27)). We did not find any significant reduction in mental health problems among male adolescents.

Conclusions: Our findings suggest that a psychosocial intervention was associated with increased knowledge and uptake of HIV and sexual health services among both male and female migrant adolescents and with reduced mental health problems among female adolescents. Mental health problems varied significantly for male and female adolescents, suggesting that future interventions should be tailored to address their different needs and would benefit from intensive follow-up efforts.

Keywords: Ethiopia; mental health; vulnerable adolescents; HIV risk; psychosocial intervention.

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Introduction

In 2011, HIV prevalence in Ethiopia was 1.0% for men and 1.9% for women aged 15 to 49 years in the general population [1]. Although Ethiopia has a relatively low national HIV prevalence of 1% among young adults aged 15 to 24 years [2], it is experiencing an increasingly urban and female-centred HIV epidemic [3]. Risk of infection is higher among young people living in urban settings, especially young women (1.7% female; 0.2% male) [2]. Urban HIV prevalence is also higher at 7.7% compared with 0.9% in rural areas [4]. UNAIDS 2013 data estimated that 74% of new adolescent HIV infections in Ethiopia occur among young women [5].

Additionally, Ethiopia is experiencing a surge in rural-to-urban migration, with an increase in young people migrating to urban areas in search of educational and economic advancement opportunities [6]. Young migrants are often confronted by unique social challenges such as: abuse; lack of education, parental guidance and social networks; inadequate housing and access to health services; and unstable employment conditions [3,7]. However, the experiences of young female and male adolescent migrants differ in important ways.

Female migrants are often at a greater disadvantage than males due to lower educational levels and gender norms that allow for subjugation of females [6]. A 2006 population-based

survey of 1000 adolescents aged 10 to 19 in Addis Ababa found that nearly 25% of migrant females had moved in order to avoid family-mandated early marriages [3]. It has been shown that 77% of working girls in low-income areas of Addis Ababa were domestic helpers, a job associated with low, if any, pay, extreme social isolation and poor working conditions – all factors that can contribute to an elevated HIV risk [8]. Young women are particularly vulnerable to physical and sexual abuse in their homes, places of work or in transit during migration, increasing their susceptibility to HIV [9].

Male migrant adolescents, too, are vulnerable. A 2009 study found that 29% of male street children in the Merkato area of Addis Ababa had been sexually assaulted [10]. A recent study by Habtamu and Adamu [7] found that among male street adolescents and children, nearly all participants reported having heard about cases of sexual exploitation of their male peers. The authors wrote, ''Sexual abuse and exploitation of male migrant adolescents is also one of the emerging social problems affecting the physical, social and psychological wellbeing of children in Addis Ababa'' [7]. Furthermore, highly mobile adolescents are particularly vulnerable to sexually transmitted diseases, such as HIV, and circular migration patterns that can facilitate the spread of HIV between high-prevalence urban centres and low-prevalence rural areas [11]. There is also a widespread belief in Ethiopia that men who have sex with men and male sexual abuse are not ''Ethiopian'' [10], so it can be assumed that male sexual abuse cases go unreported, underreported or misreported.

Resultant negative psychosocial outcomes, such as feelings of guilt, stress, self-blame, anxiety and depression, are common and associated with sexual and HIV-related risks [12,13]. Reasons for increased risk include low self-esteem and self-efficacy, vulnerability to sexual abuse, limited educational opportunities and communication skills, and inability to negotiate safer sex [14]. Nearly 50% of all adult mental health problems begin during adolescence [15], even though they may not be diagnosed until well into adulthood. Research has shown a strong bidirectional link between HIV vulnerability and mental health illnesses [16]. Among adolescents, aggressive discipline, family violence, poor interpersonal relationships and compromised mental health status can increase HIV risk [17], further supporting the need for mental health interventions to halt the spread of the virus.

To date, there is no evidence about the effects of targeted psychosocial interventions on mental health and HIV-related outcomes of young migrant adolescents in Ethiopia. This is the first operations research study aiming to pilot and assess the effects of a targeted psychosocial intervention among this target population in Ethiopia. The intervention was designed to reduce mental health problems, such as anxiety and aggressive behaviour, and to improve HIV-related outcomes, including knowledge of HIV, safer sex practices and use of sexual and reproductive health (SRH) services. The findings will serve as an evidence base for future interventions targeting migrant and vulnerable adolescents in Ethiopia and similar contexts.

Methods

Study design and sample size

The study used a pre- and post-comparison design with the same individuals being followed up over time. Participants included consenting male and female adolescents aged 15 to 18 years in Addis Ababa, Ethiopia, receiving services for the previous three months from two service delivery organizations, Biruh Tesfa and Retrak. Biruh Tesfa works with female migrant adolescents who are predominantly employed as domestic workers, whereas Retrak works with male migrant adolescents who are often engaged in street labour activities, such as petty trade and as bus station porters. Based on client volume at both organizations, we recruited all eligible youth who consented to participate in the study. We recruited a total of 576 eligible females at Biruh Tesfa and 154 eligible males at Retrak in June and July 2013. Following the three-month intervention period, we re-interviewed 315 female participants (56.6%) and 102 male participants (68.5%) at end line.

Description of the intervention

We piloted a client-centred, psychosocial counselling intervention package that was delivered by study counsellors for three months. The intervention package comprised various counselling modalities, including individual, group and creative therapies, such as music, art and drama. All enrolled participants received a minimum of one initial, individual counselling session. Afterwards, each participant was assessed again by his/her counsellor and referred for further group or individual counselling. If after the first session the counsellor deemed that the participant would benefit from further counselling to discuss deeper rooted emotional issues, then he/she was referred for group counselling in the format of art, music or drama therapy.

Counsellors maintained a counselling record book to document issues discussed and enable follow-up in subsequent sessions, as needed. This package of intervention components was modelled on problem-solving therapy, which has been shown to be effective in helping young people deal with a wide range of difficulties and problems that occur in everyday living [19–21].

Counsellors were trained using a standard training curriculum developed by the study team with inputs from both service delivery organizations. Counselling training topics included: adolescent health and development; psychological wellbeing and mental health problems; factors increasing vulnerability of marginalized adolescents; concepts of and ethical issues in counselling; counselling theories, skills and processes; group counselling; and creative therapies and music and drama therapies.

The five-day counsellor training included a practicum day and a one-day refresher training held midway (1.5 months) through the intervention. Counsellors used a client-centred approach, addressing the following: 1) main issues brought forth by the client; 2) possible options and solutions to address the issues and the pros and cons of each option; and 3) plan of action selected by the client to address the problem. Counsellors were also trained to cover topics of sexual health and HIV and AIDS (knowledge, risks and prevention strategies),

alcohol and drug abuse, and previous or current experience with violence.

Measurements

A study expert committee examined four mental-health screening tools and considered the applicability of these tools in Ethiopia based on available guidance and ease of administration, scoring, results interpretation, applicability of the tool for the target age group, and adequate coverage of a range of mental health conditions. The Youth Self-Report (YSR) was chosen as the most appropriate tool for use in this context. This tool went through a systematic process of cultural adaptation and validation. The adapted version, translated into Amharic, was used to measure mental health problems among study participants. Details of the process for adapting the scale, testing for reliability and validity and determining the cutoff points are described elsewhere [22]. The following is a summary of the adaptation and validation process. The YSR identifies eight syndromes approximating the diagnoses from the *Diagnostic and Statistical Manual of Mental Disorders*, *4th Edition* [23]. We chose four syndromes for use in this study based on their prevalence within the sample during the adaptation process (anxious/depressed, social problems, attention problems and aggressive behaviour).

We measured anxiety using a 13-item scale, including such statements as ''I am afraid of certain situations or bad things'' or ''I worry a lot.'' We measured social problems using an 11-item scale, including such statements as ''I don't get along with others'' or ''I am not liked by other kids.'' Attention problems were measured using a nine-item scale, including such statements as ''I have trouble concentrating or paying attention'' and ''I act without thinking.'' Aggressive behaviour was measured using a 17-item scale, including such statements as ''I am mean to others'' and ''I scream a lot.''

Each statement has three answer options: 0 = true, 1 = somewhat true, 2 = very true. During the adaptation, scores from each scale were aggregated and internal validity was assessed (alpha of 0.70 and above). A receiver operating characteristic (ROC) analysis was conducted to determine the area under the curve. The ROC analysis determined the cutoff scores for anxiety problems at 3.5, social problems at 2.5, attention problems at 3.5 and aggressive behaviour at 2.5. The adapted tool was administered verbally to study participants due to low literacy levels.

We measured HIV-related indicators using a validated behavioural survey adapted from the Demographic Health Survey to collect information about key demographic characteristics, experience of abuse, knowledge of HIV, knowledge of a place to test for HIV, perceived risk of HIV infection and use of SRH services. HIV knowledge was measured using the five-item scale from UNAIDS, which has been used and validated in HIV Indicator Surveys and Demographic and Health Surveys [24]. The scale is comprised of five questions about HIV transmission and prevention knowledge: 1) Can people reduce HIV risk by having one sexual partner?; 2) Can people get HIV from mosquito bites?; 3) Can people reduce HIV by using a condom?; 4) Can people get AIDS as a result of witchcraft?; and 5) Is it possible for a healthy-looking person to have HIV?. If participants answered all five questions correctly, they were determined to have ''comprehensive knowledge'' of HIV.

Data analysis

The analysis was stratified by gender. We included data from 315 female participants and 102 male participants, who completed both baseline and end line surveys, to identify changes in key outcome indicators over time. We used analysis techniques applied to longitudinal data (or correlated data). We used the McNemar test at the bivariate level to assess changes in key indicators over time. At the multivariate level we used multiple logistic regression (random effects), adjusting for key socio-economic characteristics. The rationale behind the random effects model is that, unlike the fixed effects model, the variation across individuals is assumed to be random and uncorrelated with the independent variables included in the model. To decide between fixed or random effects, we performed a Hausman test, where the null hypothesis is that the preferred model is random effects *versus* the alternative, fixed effects [25]. Our analyses indicated that random effects regression should be chosen. All analyses were performed in Stata (StataCorp LP, 4905 Lakeway Drive College Station, Texas 77845-4512, USA. version 13).

Ethical considerations

The study was approved by the Population Council Institutional Review Board and the Addis Ababa City Administration Health Bureau. Research activities involving adolescents followed guidance outlined in *Ethical Approaches to Gathering Information from Children and Adolescents in International Settings: Guidelines and Resources* [26]. Young people living outside of parental care are considered *emancipated minors*, defined as living independently of their parents and having the right to make decisions about receiving services without necessitating parental or guardian consent. All participants provided written informed consent.

Results

Sample characteristics at baseline

Table 1 presents the characteristics of the study population at baseline. More than half of the sample (55.7%) had attained one to five years of schooling, and 42% had attained six to eleven years of schooling.

Nearly three-quarters of the male sample (70.6%) could read part or the entirety of a sentence in a local language, whereas 29.4% could not read at all. About 39% of males had temporary employment, 37.9% were self-employed and 15.8% were unemployed. About one-third of males had migrated from a rural village (37.4%) or from a small town (36.1%), and the rest had migrated from another urban town. More than half of the young men (55.7%) were Orthodox Christian, 30.9% were Muslim and 13.4% were Protestant. Very few young men in the sample reported being sexually active (7%). With regard to mental health status at baseline, 49% had social problems, 36.2% had attention problems, 47% had anxiety/depression and 43.2% had aggressive behaviour.

About 54% of the female sample had one to five years of schooling and 46% had six to eleven years of schooling. Approximately 70% of the female sample could read part of

Table 1. Characteristics of the study population at baseline

	Females ($N = 557$) % (n)	Males ($N = 149$) % (n)
Age		
15–16 years old	62.8 (350)	47.3 (70)
17–18 years old	37.2 (227)	52.7 (78)
Education		
1–5 years of schooling	54.0 (301)	57.7 (86)
6–11 years of schooling	46.0 (256)	42.3 (63)
Literacy level		
Unable to read at all	28.8 (156)	29.4 (35)
Read part of the sentence	20.5 (111)	14.3 (17)
Read whole sentence	50.7 (275)	56.3 (67)
Religion		
Orthodox	77.7 (433)	55.7 (83)
Muslim	15.1 (84)	30.9 (46)
Protestant	7.2 (40)	13.4 (20)
Currently living with relative or family		
Yes	70.7 (394)	0.0 (0)
No	29.3 (163)	149.0 (100)
Place lived previously		
Addis Ababa	19.0 (106)	11.6 (17)
Other city	2.7 (15)	14.9 (22)
Small town	10.4 (58)	36.1 (53)
Rural village	67.9 (378)	37.4 (55)
Keep in touch with family		
Yes	87.4 (485)	34.2 (51)
No	12.6 (70)	65.8 (98)
Ever had sex		
Yes	0.6 (3)	6.7 (10)
No	99.4 (496)	93.3 (139)
Mental health outcome		
Had social problem	15.8 (88)	49.0 (73)
Had attention problem	10.0 (56)	36.2 (54)
Had anxiety/depression problem	21.5 (120)	47.0 (70)
Had aggressive behaviour	23.0 (128)	43.2 (45/104)*
Had any mental health problem	37.3 (208)	80.8 (101/125)**

Notes: Values of n in cells may not add up to total population due to missing values. *$N = 104$ and **$N = 125$ due to missing values.

or an entire sentence in a local language. The majority of young women (64.4%) were permanently employed. Only 15.3% were temporarily employed and 11% were unemployed. More than three-quarters of young women (77.7%) were Orthodox Christian, 15.1% were Muslim and 7.2% were Protestant. About two-thirds of the sample reported having migrated to Addis Ababa from a rural area. Only three young women reported being sexually active during the past 12 months (0.6%). With regard to mental health outcomes, 15.8% had social problems, 10% had attention problems, 21.5% had anxiety/depression and 23% had aggressive behaviour.

Characteristics of participants lost to follow-up at end line

Overall, those lost to follow-up (LFU) and those who completed the study were comparable with regard to key characteristics. However, we experienced greater LFU among females in the 17 to 18 age group and who had lower levels of literacy, and among males who had higher literacy levels and fewer anxiety problems (data not shown).

Effects of the intervention on key mental health and HIV-related outcomes

For females, bivariate analyses (Table 2, McNemar test) suggest that the intervention was associated with reduced attention problems and aggressive behaviour and the combined mental health index, ''having any one of the four mental health problems.'' In addition, the intervention was associated with increased knowledge of HIV prevention, knowing a place to test for HIV and having ever tested for HIV. Multivariate logistic regression adjusting for age, education and religion showed that the intervention was associated with a 60% reduction in aggressive behaviour (adjusted odds ratio (AOR): 0.4 (0.25 to 0.65)), a 50% reduction in ''any of the four mental health problems'' (AOR: 0.5 (0.36 to 0.81)), a 60% increase in comprehensive knowledge of HIV (AOR: 1.6 (1.08 to 2.47)), a 70% increase in knowing a place to test for HIV (AOR: 1.7 (1.12 to 2.51)), and a 80% increase in ''ever tested for HIV'' (AOR: 1.8 (1.13 to 2.97)).

For male adolescents, bivariate analyses suggest that the intervention was associated with an increase in HIV knowledge, knowledge of a place to test for HIV, having ever tested for HIV and seeking SRH services. Multivariate analyses, adjusting for age, education and religion, as presented in Table 3, show that the odds of having comprehensive knowledge of HIV increased by 110% (AOR: 2.1 (1.10 to 3.94)) compared with baseline, knowing a place to test for HIV increased by 290% (AOR: 3.9 (1.02 to 14.9)), having tested for HIV increased by 630% (AOR: 7.3 (2.6 to 20.7)) and use of SRH services increased by 220% (AOR: 3.2 (1.62 to 6.27)). The intervention was not associated with any changes in the five key mental health indicators for males.

Discussion

This is the first study to pilot test and assess the effects of a targeted psychosocial intervention among a migrant, adolescent population in Ethiopia. Our study suggests that a psychosocial counselling intervention was associated with increased knowledge and uptake of HIV and sexual health services among both male and female vulnerable adolescents, as well as reduced mental health problems among female adolescents. In particular, the intervention was associated with increased HIV prevention knowledge and HIV testing for both male and female adolescents, as well as increased use of SRH services among males. Although the intervention was associated with reduced aggressive behaviours and overall mental health problems among females, there was no effect on mental health indicators among male participants.

Table 2. Effects of the intervention on mental health and HIV-related outcomes (bivariate analysis)

	Females ($N = 315$)			Males ($N = 102$)		
Variable	**Baseline % (*n*)**	**End line % (*n*)**	***p***	**Baseline % (*n*)**	**End line % (*n*)**	***p***
Mental health outcomes						
Had anxiety problem	20.0 (63)	14.9 (47)	0.07	54.0 (55)	52.0 (53)	0.72
Had social problem	13.3 (42)	8.9 (28)	0.07	51.0 (53)	52.0 (52)	0.87
Had attention problem	8.6 (27)	4.8 (15)	0.05	37.3 (38)	38.2 (39)	0.88
Had aggressive behaviour	24.4 (77)	13.0 (41)	0.0001	53.2 (32)	59.5 (49)	0.47
Had any mental health problem	34.9 (110)	15.1 (79)	0.0035	75.5 (77)	73.5 (75)	0.71
HIV-related outcomes						
Had comprehensive knowledge of HIV	16.8 (53)	24.4 (77)	0.014	20.6 (21)	34.3 (35)	0.04
Perceived HIV risk (low vs. medium + high)	17.1 (54)	14.3 (45)	0.29	23.5 (24)	27.5 (28)	0.51
Knew a place to test for HIV	68.6 (216)	77.2 (243)	0.009	88.2 (90)	95.1 (97)	0.05
Ever tested for HIV	29.8 (86)	36.1 (104)	0.000	45.1 (46)	69.6 (71)	<0.000
Use of SRH service (past 3 months)	48.9 (154)	45.4 (143)	0.31	31.4 (32)	54.9 (56)	0.0004

Notes: p value corresponds to McNemar test; the analyses were performed on those who had complete baseline and end line data.
SRH, sexual and reproductive health.

Available studies conducted in small populations across Ethiopia show a wide-ranging prevalence of mental health problems, varying from 5.5% [28] to 49% of non-at-risk youth reporting mental disorders or mental distress [29]. A key message is that it appears that separation from family is associated with higher levels of mental health problems among young people [30]. Our findings are consistent with findings from the limited available studies in African settings in which psychosocial interventions also resulted in desired behavioural outcomes, but results were mixed for reducing mental health problems [31–33].

A randomized control trial evaluating a school readiness programme with male and female child soldiers in Sierra Leone included many of the same intervention components used in this study, such as addressing mental health stresses and risky behaviours. It found that the youth readiness intervention programme was associated with improved school readiness behaviours but no change in underlying psychological and emotional problems [32]. Other studies among high-risk African-American female adolescents also found that various psychosocial and health promotive group interventions resulted in improved knowledge and behaviour for HIV prevention [31,33].

A related study in South Africa using a community-based art therapy intervention among HIV-affected children and adolescents (ages 8 to 18) found no significant reduction of depression or emotional and behavioural problems, but it did find that the intervention significantly increased participants'

Table 3. Effects on mental health and HIV-related outcomes (multivariate analysis)

	Females	Males
	End line AOR (95% CI)	**End line AOR (95% CI)**
Mental health outcome		
Had anxiety problem	0.7 (0.41–1.06)	0.9 (0.43–1.76)
Had social problem	0.6 (0.36–1.07)	1.1 (0.56–2.1)
Had attention problem	0.6 (0.30–1.24)	1.0 (0.53–1.78)
Had aggressive behaviour	0.4 (0.25–0.65)***	1.4 (0.72–2.89)
Had any mental health problem	0.5 (0.36–0.81)**	0.5 (0.22–1.29)
HIV-related outcome		
Had comprehensive knowledge of HIV	1.6 (1.08–2.47)*	2.1 (1.10–3.94)*
Perceived HIV risk (low *vs.* medium + high)	0.8 (0.47–1.21)	1.2 (0.62–2.30)
Knew a place to test for HIV	1.7 (1.12–2.51)*	3.9 (1.02–14.9)*
Ever tested for HIV	1.8 (1.13–2.97)**	7.3 (2.6–20.7)***
Use of SRH service (past three months)	0.8 (0.55–1.16)	3.2 (1.62–6.27)***

All analyses were adjusted for age, education, religion and types of work. *Significant at $p < 0.05$; **significant at $p < 0.01$; ***significant at $p < 0.001$. AOR, adjusted odds ratio comparing end line to baseline; CI, confidence interval; SRH, sexual and reproductive health.

sense of self-worth and self-efficacy for decision making and dealing with a difficult environment [34]. Furthermore, a trauma-focused cognitive behaviour therapy intervention implemented with female adolescents in the Democratic Republic of Congo, who had been sexually exploited and war affected, found significant reduction in psychological distress and psychosocial difficulties [35].

Taken together, these findings suggest that, although behavioural changes may be detected after a short duration of intervention, changes in psychosocial and mental health problems will likely require an intervention period longer than three months to show any detectable changes.

The differences in use of sexual health services (including seeking counselling for safer sex and HIV-prevention methods) between females and males could be attributed to the accessibility of HIV testing and health education services. Biruh Tesfa mentored females were referred to government-run clinics for health information and services, including HIV testing, whereas males accessed HIV testing and SRH services on site at Retrak with a staff nurse who was known to them. This familiarity of the staff and ease of access may have accounted for an increased use of SRH services among males.

Our findings indicate that a psychosocial intervention addressing underlying mental health issues might foster vulnerable adolescents' capacity to benefit from HIV risk-reduction education and use of HIV-related services. Using a client-centred approach in a targeted psychosocial intervention may improve the psychosocial wellbeing and self-efficacy of participants, ultimately facilitating behaviour change.

The reduction in mental health problems seen only among female adolescents may be explained as follows. First, there were important differences in the groups of male and female adolescents. For example, the prevalence of mental health problems of all four indicators was much higher among males than among females at baseline, suggesting that the intervention might have to be gender specific to see a significant impact.

Second, males were living in more difficult situations – all had previously lived or worked on the street, possibly making their mental health problems more sustained or difficult to change. In addition, they may have required a more intensive, tailored or lengthier psychosocial intervention in order to see a significant change in mental health outcomes.

Finally, Retrak staff reported that when male adolescents first joined the programme, they were quiet and withdrawn, but as they developed trust in Retrak staff and felt safe, they expressed their anger and frustration and became much more demanding and aggressive, which often lasted until they were reintegrated with their families or society. This could partially explain the insignificant mental health findings among male participants.

Limitations

It is possible that sexual activity and/or sexual abuse data were underreported among this population due to social desirability or recall bias, especially in the context of a face-to-face interview.

In addition, the study did not have a control group due to the inability to recruit a larger population for an experimental study design. This limited our ability to tease out the true impact of the intervention on key outcomes. However, this approach is particularly acceptable because the study was designed as operational research with the aim of pilot testing the intervention and measuring changes in outcomes among participants. Resources permitting, a follow-up controlled study would be ideal for examining the impact of the intervention.

Moreover, the study had a high rate of LFU, especially among female participants. LFU could have reduced the statistical power in detecting significant changes in key outcomes. The high LFU rate was due to the mobility of this population and time and financial constraints, which impacted the number of mentors who remained available to assist study counsellors to follow up with study participants for subsequent counselling sessions. Lastly, due to financial and logistical constraints and the high mobility of this migrant population, the intervention could not be delivered for longer than a three-month period.

Conclusions

The findings suggest that a psychosocial intervention is associated with increased knowledge and uptake of HIV and sexual health services among both male and female migrant adolescents, and with reduced mental health problems among female adolescents. The mental health problems of male and female adolescents varied significantly, suggesting that future interventions should be tailored to address their different needs. Furthermore, future operational research using a controlled design among migrant adolescents is needed and would benefit from intensive follow-up efforts to reduce LFU or from a larger sample size.

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Competing interests
The authors declare that they have no conflicts of interest.

Authors' contributions
SK and NJ conceived the study. LK contributed to the intervention design. SK, NJ, LK and KH oversaw the data collection. LV and KH conducted the data analysis. LV and NJ drafted the manuscript. All authors provided critical review and comments and approved the final manuscript.

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Disclaimer

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Research article

Results from a rapid national assessment of services for the prevention of mother-to-child transmission of HIV in Côte d'Ivoire

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Abstract

Introduction: Loss-to-follow-up (LTFU) in the prevention of mother-to-child HIV transmission (PMTCT) programmes can occur at multiple stages of antenatal and follow-up care. This paper presents findings from a national assessment aimed at identifying major bottlenecks in Côte d'Ivoire's PMTCT cascade, and to distinguish characteristics of high- and low-performing health facilities.

Methods: This cross-sectional study, based on a nationally representative sample of 30 health facilities in Côte d'Ivoire used multiple data sources (registries, patient charts, patient booklets, interviews) to determine the magnitude of LTFU in PMTCT services. A composite measure of retention – based on child prophylaxis, maternal treatment and infant testing – was used to identify high- and low-performing sites and determine significant differences using Student's *t*-tests.

Results: Among 1,741 pregnant women newly recorded as HIV-positive between June 2011 and May 2012, 43% had a CD4 count taken, 77% received appropriate prophylaxis and 70% received prophylaxis intended for their infant. During that time, 1,054 first infant HIV tests were recorded. A conservative rate of adherence to antiretroviral therapy was estimated at 50% ($n = 219$ patient charts). Significant differences between high- and low-performing sites included: duration of time elapsed between HIV testing and CD4 results (29.5 versus 56.3 days, $p = 0.001$); and density (number per 100 first antenatal care visits) of full-time physicians (6.7 versus 1.7, $p = 0.04$), laboratory technicians (2.3 versus 0.7, $p = 0.046$), staff trained in PMTCT (10.7 versus 4.7, $p = 0.01$), and staff performing patient follow-up activities (7.9 versus 2.5, $p = 0.02$). Key informants highlighted staff presence and training, the availability of medical supplies and equipment (i.e., on-site CD4 machine), and the adequacy of infrastructure (i.e., space and ventilation) as perceived key factors positively and negatively impacting retention in care.

Conclusions: Patient LTFU occurred throughout the PMTCT cascade from maternal to infant testing, with retention scores ranging from 0.10 to 0.83. Sites that scored higher had more dedicated and trained frontline health workers, and emphasised patient follow-up through outreach and the reduction of delays in care. Strategies to improve patient retention and decrease transmission should emphasise patient tracking systems that utilise critical human resources to both improve data quality and increase direct patient follow-up.

Keywords: PMTCT Cascade; prevention of mother-to-child transmission of HIV; health systems factors; Côte d'Ivoire; health workforce; patient retention.

To access the supplementary material to this article please see Supplementary Files under Article Tools online.

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Introduction

In much of Africa, programmes for the prevention of mother-to-child transmission of HIV (PMTCT) have performed less than optimally [1–4]. Health systems factors cause bottlenecks that impede patient flow through health care services, contribute to inconsistent data quality, and cause patient loss-to-follow-up (LTFU) in various stages of the PMTCT cascade [5,6]. Understanding how pregnant women navigate PMTCT health services and the role of health system factors in disrupting (or facilitating) patient flow helps identify key obstacles to health outcomes and should inform PMTCT programme implementation [7,8]. This approach, at the national scale, is especially pertinent, given that all 21 African priority countries of the Interagency Task Team for PMTCT have adopted one of the World Health Organization's (WHO's) PMTCT Option B/B+ strategies, which include the universal treatment of all HIV-positive pregnant women with combination antiretroviral therapy (cART) [9].

Côte d'Ivoire's *Ministère de la Santé et de l'Hygiène Publique* (MSHP), the Ministry of Health and Public Hygiene, introduced its first nationwide PMTCT programme in 2007, with the goal of lowering the national MTCT rate to 3% by 2015. Despite

nationwide decreases in both HIV prevalence and new infections from 2005 to 2013 [10], UNAIDS and the Côte d'Ivoire National AIDS Council estimated that the MTCT rate remained as high as 25% in 2012 [11]. In response, the Côte d'Ivoire MSHP launched the 2012–2016 National PMTCT Scale-up Plan [12], which outlined a transition of national PMTCT treatment standards from WHO's Option A regimen to the Option B regimen [13].

To help inform the rollout of Option B and better understand the challenges of the existing national programme, the MSHP supported a nationwide operations research project to assess PMTCT programme effectiveness. The primary objectives of this project included:

1) Identify factors associated with bottlenecks in Côte d'Ivoire's PMTCT services.
2) Propose test interventions to reduce LTFU and improve PMTCT outcomes under Option B.
3) Help policy makers select and test such interventions during the nationwide rollout of Option B.

The data presented in this paper highlight the major findings from the rapid nationwide assessment to identify major bottlenecks in Côte d'Ivoire's PMTCT cascade under Option A, and to distinguish characteristics of high- and low-performing health facilities. The assessment was carried out with the support of HIVCore, a United States Agency for International Development (USAID)-funded project under the United States President's Emergency Plan for AIDS Relief (PEPFAR), and was implemented in collaboration with Health Alliance International and the University of Washington.

Methods

Drawing from the 2011 MSHP national PMTCT database of 734 health facilities (public and private) providing PMTCT services in Côte d'Ivoire, 30 sites were selected from among the 320 sites that reported at least 10 HIV-positive pregnant women in 2011. Sites were selected randomly using probability proportional to size sampling, based on the number of women reported HIV-positive in antenatal care (ANC). Seven two-person study teams collected quantitative and qualitative data over the course of two days at each facility in March 2013. Among the 30 randomly selected study sites, 12 (40%) were located in the metropolitan area of Abidjan, 6 (20%) were located in other major urban centres in the country, and the remaining 12 (40%) were located in peri-urban or rural areas distributed throughout the country. At each site, local health facility staff, familiar with on-site registries and patient flow, facilitated data collection.

Quantitative data

Quantitative data from the following sources were abstracted at each site and recorded in a standardised study tool:

1) On-site health facility registries.
2) Individual patient charts of HIV-positive women.
3) Mother-baby booklets (*carnets*), which are issued to all pregnant women at their first ANC visit (ANC1) to record pregnancy and childhood care.

Registry data were collected from all available registries with relevant data for the period of June 2011–May 2012. This time period ensured that all patient data included in the study pertained to mothers who received care under Option A and had given birth by the date of data collection. Patient chart data were abstracted at each facility from up to 20 patient charts belonging to HIV-positive women tested in PMTCT care services prior to June 2012. Charts were selected systematically in reverse chronological order. Carnet data were abstracted from a convenience sample of up to 20 women who were attending infant immunisation services at the study site on the day of data collection. Project team members processed data collection forms to identify and correct inconsistencies. Table 1 lists illustrative quantitative indicators collected and sample sizes for each data source.

Quantitative analysis

For each facility, a composite outcome measure of PMTCT performance (PMTCT score) was calculated using registry data for 29 of the 30 facilities included in the analysis (see discussion of site #30 below). The PMTCT score was defined as the mean of the following three measures of retention identified by key stakeholders:

1) Proportion of HIV-positive pregnant women who received antiretroviral drug (ARV) prophylaxis intended for her infant.
2) Proportion of HIV-positive pregnant women who initiated cart.
3) Proportion of HIV-positive mothers whose infant had an HIV test performed within one year of birth.

Site characteristics from the 10 facilities with the highest PMTCT scores (High Performers) were compared against the 10 facilities with the lowest PMTCT scores (Low Performers) using a two-sample Student's T-test to identify significant differences ($p < 0.05$) between the means of high and low performers. Site characteristics (see Table 2) included quantitative and qualitative measures related to size, location, processes of care and workforce. Workforce characteristics included staff density by cadre, adjusting for patient load at each facility (average ANC1 visits per month) and staff training.

For all site characteristics found to differ substantially between high- and low-performing sites (those with a t-test that resulted in a *p*-value less than 0.10), we used univariate and multivariate logistic regression models with robust standard errors, to determine how those site characteristics were associated with performance, adjusting for available confounders. We determined urban or rural location, catchment and the average number of ANC1 patients per month to be *a priori* potential confounders based on their plausible association with site performance and with each characteristic of interest. These potential confounders were maintained in the model if their inclusion resulted in a change in the effect estimate of approximately 10%. All analyses were performed in Stata 13 IC.

Patient charts were analysed to determine the number of days between the date of the HIV test, CD4 count draw, the

Table 1. Data sources and illustrative indicators collected

Registries	**Sample:** Monthly data from June 2011–May 2012	**Total number of:** • Pregnant women who tested HIV-positive in antenatal care. • HIV-positive pregnant women who had a CD4 count taken. • HIV-positive pregnant women found eligible for cART. • HIV-positive pregnant women newly initiated on cART. • HIV-positive pregnant women who received antiretroviral drugs (ARVs) as prophylaxis intended for herself. • HIV-positive pregnant women who received ARVs as prophylaxis intended for her infant. • First HIV tests administered to HIV-exposed infants
Patient charts	**Sample:** Up to 20 charts per facility of women enrolled in PMTCT care in May 2012 or earlier	**Date of:** • HIV test • Blood draw for initial CD4 count • CD4 count results returned to the patient • Establishment of eligibility for lifetime cART • Initiation of cART • Last recorded visit to the health facility
Carnets	**Sample:** Up to 20 carnets per facility, from a convenience sample of women seeking newborn immunisations on day of data collection	• Type of facility that issued the *carnet* • Proof of administration of HIV test (y/n)

return of CD4 results to patient, and the delivery of ARVs. Suspected outliers were eliminated from the analysis using the interquartile range rule for outliers ($1.5 \times$ IQR). A proxy rate of cART adherence among women on lifelong treatment was calculated as the proportion of charts with a recorded date of patient contact with the health facility within 30 and 90 days of the date of data collection. These cut-offs represent the standard (30 days) and maximum (90 days) number of days of ARVs systematically prescribed in PMTCT care. Carnets do not include an official HIV testing indicator; however, the health facility staff helped identify recognisable codes handwritten into the margins of collected carnets that indicated history of HIV testing.

Qualitative data

Qualitative data were collected at all 30 sites to describe characteristics of the PMTCT cascade and obtain health worker perspectives on perceived facilitators and barriers to the successful completion of PMTCT services. Data collectors conducted semi-structured interviews with one key informant at each site – typically physicians responsible for HIV activities – chosen based on their knowledge of on-site

Table 2. Site characteristics with data source compared between low- and high-performance group by category

Category	Data source	Characteristic
Size	Facility records	Catchment area population
	ANC registry	Total ANC1 visits
Location	Based on location	Abidjan/non-Abidjan
		Urban/rural
Processes of care	Patient charts	Average number of days elapsed, according to patient charts, between HIV test and the return of CD4 results to the patient
	Key informant interviews	Reported number of internal displacements per typical patient
		Reported number of external displacements per typical patient
		Reported timing of patient enrolment (via patient chart)
		Reported average number of days between ANC1 reception and establishment of cART eligibility per patient
Workforce distribution	Key informant interviews and ANC registry	Density of full-time health workers (per 100 ANC1 visits) by cadre
Workforce training	Key informant interviews and ANC registry	Density of staff trained in PMTCT or in cART
		Density of staff who initiate prophylaxis and/or cART
		Density of staff who engage in ART follow-up

PMTCT services. Key informants were asked to describe each step of PMTCT services and create a patient flow map diagramming the number of internal and external displacements required by patients as they navigate PMTCT services at the facility as shown in Figure 1. An internal displacement was defined as any time a patient must move from one room to another within the same visit, while external displacement indicated any time a patient must return to the site for a follow-up visit. Data collectors took written notes and recorded on-site observations using a standardised study tool.

Qualitative analysis

Qualitative data were analysed and compared between sites to assess patient flow within PMTCT services, displacements and delays in PMTCT services, and perceived facilitators and barriers to the successful completion of the PMTCT cascade from ANC1 through infant testing. Informants reported barriers and facilitators separately at each stage of patient flow. Two study team members independently extrapolated recurring themes from interview notes to describe the PMTCT cascade, measure delays and identify system facilitators and barriers to service delivery.

Ethical review

Study procedures, including informed consent, were approved by the National Research Ethics Review Committee of Côte d'Ivoire and the Institutional Review Board (IRB) of Population Council. The University of Washington IRB and the Health Alliance International Ethical Review Committee determined the study to be non-research.

Results

Data collectors noted a total of 18 different official registries, reports and other unofficial data sources related to PMTCT across the 30-site sample. The study team found substantial variation in the availability and completeness of PMTCT-related indicators in on-site registries, and frequent inconsistencies in the data when compared with the same data aggregated and reported at the national level. Only six sites had no missing data in the 12-month study period. One rural site was excluded from the registry and patient chart-based analyses due to the interruption of PMTCT services during the study period. Further discussion of the availability, quality, and use of these and general on-site data has been discussed elsewhere [14–16].

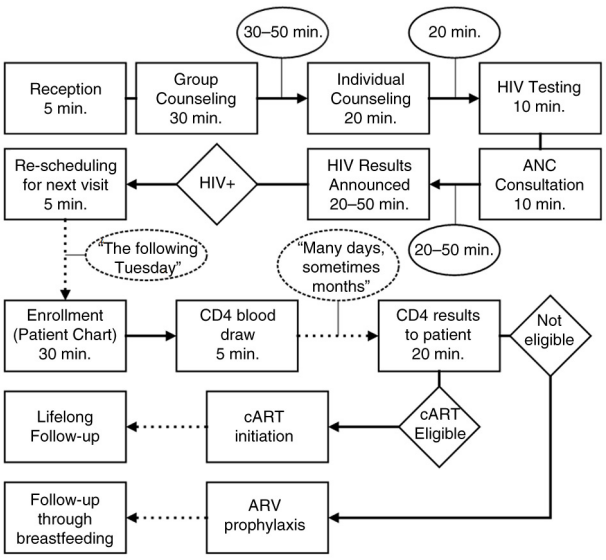

Figure 1. Example of patient flow map.
Flow maps were created at each site to chart patient flow through PMTCT services (rectangles), and identify wait times, and internal (solid arrow) and external (dashed arrow) displacements.

Overall LTFU in the PMTCT cascade

At the 29 sites with registry data during the study period, 38,347 women were registered as having attended ANC1, and 42,162 HIV tests were recorded (110% of ANC1 visits). These may have included tests on non-pregnant women and tests conducted on women attending subsequent ANC visits. Of the registered tests, 1741 (4%) were noted positive. Fifteen sites collected additional information on the number of HIV tests administered only during ANC1. Among 19,173 women who attended an ANC1 at these 15 sites, 17,958 (94%) were reported as having received an HIV test during ANC1, of which 889 (5%) tested positive. At all 30 sites, 590 carnets were available and examined. Of these, 489 (83%) carnets had proof of HIV testing during the mother's most recent pregnancy, and 37 (6%) indicated a positive HIV result. The rate of recorded HIV testing in carnets varied by site of first ANC visit; from 87% ($n = 511$) in carnets belonging to women who attended ANC at a public MSHP site to 59% ($n = 34$) and 55% ($n = 17$) in carnets of women who attended ANC1 at non-governmental health facilities and private clinics, respectively.

Figure 2 shows the PMTCT cascade, based on registry-data alone, from the 12-month study period. During this time, 1741 HIV-positive pregnant women were newly diagnosed and registered at 29 sites. Of these, 744 (43%) were reported as having obtained a CD4 count and received their results, of which 209 were registered as eligible for cART (CD4 <350). During the same time period, 1,333 (77%) HIV-positive pregnant women received ARVs to reduce MTCT, of which 284 were prescribed lifelong cART. The registries recorded 1,224 (70%) mothers who received ARVs for their infants and 1,054 (61%) who returned to have their infant tested for HIV. Five sites did not report performing any HIV tests on exposed infants during the reporting period.

The receipt of appropriate prophylaxis includes both the delivery of ARV prophylaxis and initiation of cart. To estimate the rates of adherence following cART initiation, a total of 330 patient charts of HIV-positive pregnant women enrolled in PMTCT services were abstracted from the 29 sites. Of the selected charts, 219 belonged to women on lifelong cART and included the date of the last contact with the patient. Only 109 (50%) and 61 (28%) of the 219 charts contained evidence of a visit within 90 or 30 days, respectively.

Factors associated with loss to follow-up in the PMTCT cascade

The 10 health facilities in the high-performance group had a mean PMTCT score of 0.65 (range: 0.54–0.83) with a mean PMTCT score among low performers of 0.23 (range: 0.10–0.33).

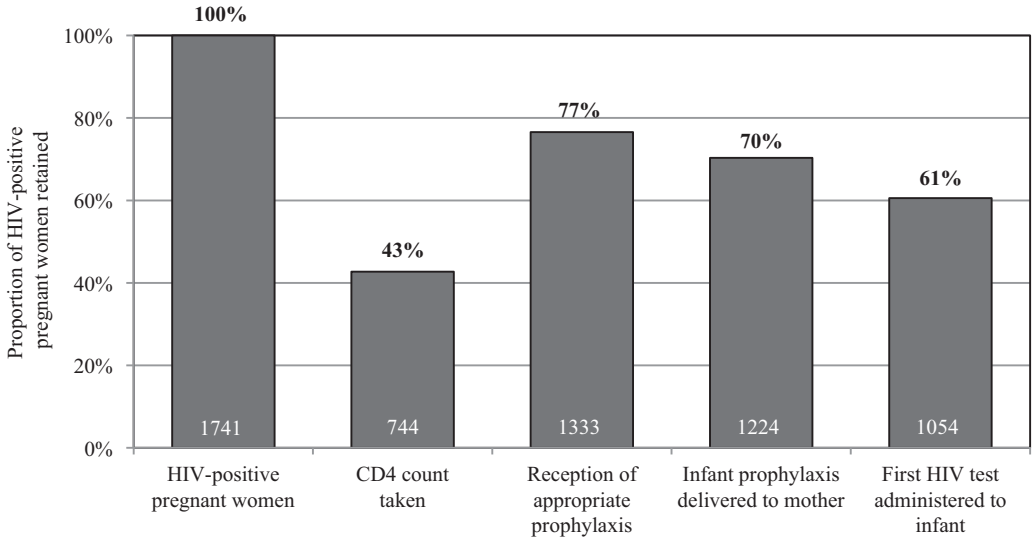

Figure 2. Numbers and percentages of recorded HIV-positive patients reported retained at each step of the PMTCT cascade at 29 health facilities in Côte d'Ivoire.

Size and location

Even though the average catchment area among high performers was twice the size of the average catchment area among low performers, the average number of monthly ANC1 visits was similar between the two groups. Nevertheless, as seen in Table 3, neither size nor location was found to be significantly different between the two groups.

Processes of care

Table 4 summarises site characteristics related to processes of care among high- and low-performing sites. In high-performing sites, the mean number of days between HIV testing and the return of CD4 results to the patient, as reported in patient charts, was nearly half the average time reported at low-performing sites. Similarly, key informant estimates of the time that elapsed from ANC1 to CD4 results, although less overall, were also significantly different between high and low performers. The percentage of sites that followed the MSHP recommendation to open a new PMTCT patient chart immediately following a positive HIV test result was higher among the high-performers; however, the difference was not significant (44% vs. 20%, $p = 0.27$).

Table 3. Comparison of site characteristics between high- and low-performance groups: size and location

Site characteristic	High performers (mean)	Low performers (mean)	*p*
Catchment area	113,853	56,874	0.22
ANC1 attendance (per month)	108.5	101.4	0.79
Ratio – Abidjan: non-Abidjan	3:7	3:7	1.00
Ratio – Urban: Rural	3:7	4:6	0.66

Workforce distribution

Table 5 lists adjusted workforce distribution characteristics (staff density) compared between high- and low-performing sites. Across all technical workforce cadres tested, high-performing sites had more personnel, on average, than low-performing sites. The numbers of health educators and community counsellors were higher on average at low-performing sites. After adjusting for patient load, the density of two health care cadres stood out as significantly different between high- and low-performing sites. These cadres were full-time physicians and laboratory technicians. The magnitude of the difference between the density of nurses at high- and low-performing sites was also noteworthy, although not significant.

Table 4. Comparison of site characteristics between high- and low-performance groups: processes of care

Site characteristic	High performers (mean)	Low performers (mean)	*p*
Days elapsed: HIV test → CD4 results (recorded in patient charts)	29.5 (22.0, 36.9)	56.3 (40.6, 72.0)	0.001
Days elapsed: ANC1 → CD4 results (reported by staff)	5.1 (3.3, 6.9)	11.4 (8.3, 14.6)	0.0009
Patient enrolment time (pre/post CD4)	0.2	0.44	0.27
Internal displacements (typical patient)	5.9	5.5	0.64
External displacements (typical patient)	2.6	2.7	0.66

Confidence intervals (95%) are reported in brackets for characteristics with $p < 0.1$.

Table 5. Comparison of site characteristics between high- and low-performance groups: workforce distribution

Site characteristic	High performers (mean)	Low performers (mean)	*p*
Full-time physicians per 100 ANC1 patients	6.5 (0.02, 0.11)	1.8 (0.01, 0.02)	0.04
Laboratory technicians per 100 ANC1 patients	1.9 (0.9, 3.0)	0.7 (−0.2, 1.5)	0.046
Nurses per 100 ANC1 patients	6.1 (1.1, 11.1)	1.9 (0.8, 3.0)	0.09
Midwives per 100 ANC1 patients	5.7	3.3	0.38
Nurses aids per 100 ANC1 patients	4.2	3.4	0.65
Pharmacy staff per 100 ANC1 patients	1.3	0.7	0.24
Health educators per 100 ANC1 patients	0.2	0.4	0.62
Community counsellors per 100 ANC1 patients	2.7	6.1	0.50

Data are adjusted for patient load based on the mean number of ANC1 visits per month at each health facility. Confidence intervals (95%) are reported in brackets for characteristics with $p < 0.1$.

Table 6. Comparison of site characteristics between high- and low-performance groups: workforce training

Site characteristic	High performers (mean)	Low performers (mean)	*p*
Staff trained in PMTCT per 100 ANC1 patients	10.7 (6.3, 15.1)	4.7 (2.6, 6.7)	0.01
Staff Trained in cART per 100 ANC1 patients	5.8	2.0	0.16
Staff who Initiate cART per 100 ANC1 patients	5.2	2.1	0.18
Staff who conduct follow up per 100 ANC1 patients	7.9 (3.4, 12.4)	2.5 (0.5, 4.4)	0.02
Staff who initiate prophylaxis per 100 ANC1 patients	6.8	4.2	0.22

Data are adjusted for patient load based on the mean number of ANC1 visits per month at each health facility. Confidence intervals (95%) are reported in brackets for characteristics with $p < 0.1$.

Workforce training

As shown in Table 6, on average, more staff had received training or performed specific follow-up tasks in high-performing sites than in low-performing sites. PMTCT training and staff engagement in patient follow-up activities stood out as characteristics differing significantly between high- and low-performing sites.

The inclusion of potential confounders in multivariate logistic regression models did not alter the overall significance of the results observed using the *t*-test for any of the site characteristics evaluated. Although some of the estimated adjusted odds ratios were notably different than unadjusted estimates, these changes were likely due to overfitting models with a small sample size. Therefore adjusted estimates are not presented in this paper, but can be found in the supplementary files.

Perceived facilitators and barriers

Interviews with health workers and observations by the study teams showed varied patterns of PMTCT services with substantial variance in facilitators and barriers to care. When data from interviews and observations were analysed by performance group, three of the top five facilitators cited at high-performing sites also appeared in the top five barriers cited at low-performing sites. These included adequate space (high/facilitator – 8 sites; low/barrier – 8 sites); ventilation (high/facilitator – 8 sites; low/barrier – 6 sites) and the availability of trained staff (high/facilitator – 7 sites; low/barrier – 4 sites). Thus, the presence or absence of these three factors was perceived to have a high impact on overall PMTCT performance. Other perceived factors influencing patient retention included the availability of medicines, tests, supplies, and equipment and conditions for confidentiality.

Although patient flow generally followed MSHP guidelines for PMTCT at all sites, the level of the integration of the HIV services into ANC and timing of enrolment in care varied substantially among sites. Fourteen sites conducted HIV testing in the ANC room (as in Figure 1), while others referred women to another room in a different part of the health facility for the rapid test. Some health workers preferred a separate room for testing for perceived greater confidentiality and efficiency. Other respondents expressed concerns that a separate testing room added to the total time a woman spent receiving overall ANC and PMTCT services.

Patient flow and wait times were frequently cited as both perceived facilitators and barriers to care. Long wait times were often reported in conjunction with insufficient staffing levels and/or appropriate training. For example, a doctor at one urban site noted: ''There is only one antenatal consultation room at this health facility. This means that there is only one health provider who delivers ANC services each day. When there are busy days, wait times can be very long.'' Inversely, some respondents noted low wait times as a result of the availability and training of staff. At one rural site, a key informant noted the impact of having a ''PEPFAR-supported laboratory with qualified personnel'' on reducing wait times and consequently LTFU during the CD4 testing stage.

Discussion

This nationally representative, random sample of antenatal clinics providing PMTCT services in Côte d'Ivoire demonstrated significant losses and delays throughout the PMTCT cascade, from the identification and delivery of appropriate prophylaxis to infant testing and likely adherence to lifelong treatment. These findings are consistent with previous studies that have demonstrated LTFU in the PMTCT cascade in African countries at similar levels [17].

The multiplicity of registries and other data sources likely contributed to inconsistent record keeping and reported data. These inconsistencies – especially with respect to the lower proportion of women tested for HIV reported in the carnets than in registries – raised concerns about the validity of data from standard sources. In the long term, the authors support the improvement of indicator sensitivity and reducing redundancies of data collection. However, in the short term, the use of data from multiple sources can help identify areas for improvement within the existing health information system and note possible undocumented loss – such as the 17% of women lacking documentation of HIV testing in their carnet.

Despite WHO guidelines requiring CD4 testing to determine appropriate prophylaxis under Option A, this study showed that many women received ARVs without undergoing CD4 testing. This suggests that the CD4 test requirement was not the principal barrier to prophylaxis delivery, and that its elimination under Option B/B+ will need to be supplemented with additional strategies to encourage the uptake of ARVs. Further research on specific systems-level interventions will be required following the transition to the option B/B+ regimens to reduce LTFU at this stage in the cascade.

Another finding with implications for Option B/B+ was the low level of adherence to lifelong treatment approximated by using patient chart data. It is likely that actual cART adherence rates may have been higher than the proxy indicator used in this study suggested, as interviewers at several sites noted that many patient visits or transfers were not recorded in patient charts. Patient tracking systems should be highlighted under Option B/B+ to better understand retention following initiation of cART. Such systems would serve to both improve data quality for decision-making, and identify patients at high risk for LTFU [18].

The wide variability of PMTCT scores among sampled clinics suggests that major improvements in PMTCT service effectiveness are possible with attention to the factors noted in this study, such as the training and availability of key human resources and delays in processes of care. Interviews with frontline health workers reinforced these findings and suggested that human resource factors do more to facilitate service delivery, while infrastructural and material deficiencies serve as the most tangible barriers to care. These findings are consistent with previous studies of PMTCT programmes in Sub-Saharan Africa [19,20]. At the policy level, staffing and training should be prioritised. At the facility level, implementable systems-based interventions are needed, such as improvement of physical conditions (space, ventilation, cleanliness) and ensuring the systematic enrolment, documentation and tracking of patients in care.

Limitations

Although this mixed-method assessment was done with a robust national sample of 30 PMTCT sites, the assessment was limited by several factors. Registry analyses were cross-sectional, limiting inferences of causality. When adjusted models were used to attempt to control for confounding in the analysis of correlates of high and low performance, the resulting estimates were imprecise. This was likely due to over-fitting models in a small sample. The continued presence of confounders means that our results must be interpreted cautiously, but this caution should be weighed against the strong scientific plausibility of the likelihood that staffing and training levels influence PMTCT outcomes.

Estimates of LTFU assumed that patients continue to seek PMTCT services at the same health facility. If health facilities had referred out for certain services due to lack of equipment or periodic stock shortages, those patients would not have been accounted for in retention rates. Additionally, key informants were health care facility staff; no patient perspectives were elicited regarding barriers and facilitators to care.

As mentioned above, poor data quality and availability served as both a limitation and opportunity for analysis. Missing data, such as proof of testing in carnets, may have represented non-reporting rather than the failure to provide care. Similarly, the patient chart sample, which likely over-represented HIV-positive women on lifelong cART, may include non-reporting (missing clinical visits; missing charts) or the failure to provide care. This impacted the extent to which carnet and chart-based inferences could be extended to all women in PMTCT care.

Last, though the use of a composite PMTCT score to identify high- and low-performing sites helped to inform areas for intervention, using different measures of retention in the calculation of the PMTCT score would have changed the distribution of sites into low- and high-performance categories. Various combinations of retention indicators and scoring methodologies were tested with the final methodology based on advice from MSHP officials.

Conclusions

This study provided a rapid method to assess national PMTCT programme performance at the health facility level and identify factors associated with high and low performance. In less than two weeks, the study team was able to capture both quantitative and qualitative data from multiple data sources that demonstrated strengths and weaknesses of the PMTCT programme not typically apparent from routine reporting. Despite inconsistencies in both the quality and availability of data across the sample, the combination of multiple existing data sources helped to identify key characteristics of high- and low-performing sites, which should inform interventions to reduce LTFU in the PMTCT cascade.

This study suggests that strategies to improve patient retention and decrease MTCT under Option B/B+ should combine efforts to increase the availability and training of key frontline health workers, improve physical conditions at ANC clinics to enhance patient care and confidentiality and simplify and strengthen data collection systems. A systems focus on patient follow-up with adequate charting and communication with patients is a critical starting point for improving patient retention.

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Competing interests

IA and DA work for the Côte d'Ivoire national HIV/AIDS programme which funds, regulates, and implements PMTCT services in Côte d'Ivoire. SAG, JR, AK, DA, SK and SG work for Health Alliance International, which receives funding to support PMTCT programmes in northern Côte d'Ivoire.

Authors' contributions

SG, JR, SD, SKo, DB, SKa and AK contributed to project conception, protocol development and project implementation planning. IA and DA also contributed to project implementation planning. SD, SKo and DA contributed to data collection. SAG, SG and JR contributed to data analysis. SAG and SG drafted and finalized the article with review from all authors. All authors have read and approved the final manuscript.

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Research article

Assessment of linkages from HIV testing to enrolment and retention in HIV care in Central Mozambique

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Abstract

Introduction: Effectiveness of the rapid expansion of antiretroviral therapy (ART) throughout sub-Saharan Africa is highly dependent on adequate enrolment and retention in HIV care. However, the measurement of both has been challenging in these settings. This study aimed to assess enrolment and retention in HIV care (pre-ART and ART) among HIV-positive adults in Central Mozambique, including identification of barriers and facilitators.

Methods: We assessed linkages to and retention in HIV care using a mixed quantitative and qualitative approach in six districts of Manica and Sofala provinces. We analyzed routine district and health facility monthly reports and HIV care registries from April 2012 to March 2013 and used single imputation and trimmed means to adjust for missing values. In eight health facilities in the same districts and period, we assessed retention in HIV care among 795 randomly selected adult patient charts (15 years and older). We also conducted 25 focus group discussions and 53 in-depth interviews with HIV-positive adults, healthcare providers and community members to identify facilitators and barriers to enrolment and retention in HIV care.

Results: Overall, 46% of the monthly HIV testing reports expected at the district level were missing, compared to 6.4% of the pre-ART registry reports. After adjustment for missing values, we estimated that the aggregate numbers of adults registered in pre-ART was 75% of the number of persons tested HIV-positive in the six districts. In the eight health facilities, 40% of the patient charts for adults enrolled in pre-ART and 44% in ART were missing. Of those on ART for whom charts were found, retention in treatment within 90 and 60 days prior to the study team visit was 34 and 25%, respectively. Combining these multiple data sources, the overall estimated retention was 18% in our sample. Individual-level factors were perceived to be key influences to enrolment in HIV care, while health facility and structural-level factors were perceived to be key influences of retention.

Conclusions: Efforts to increase linkages to and retention in HIV care should address individual, health facility, and structural-level factors in Central Mozambique. However, their outcomes cannot be reliably assessed without improving the quality of routine health information systems.

Keywords: linkages; retention; HIV care; treatment; Mozambique.

To access the supplementary material to this article please see Supplementary Files under Article Tools online.

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Introduction

In the past decade, Mozambique has expanded access to HIV testing services and antiretroviral therapy (ART) and has integrated them into the primary healthcare system [1–4]. Still, the proportion of people with an HIV-positive diagnosis who have been linked to and retained in HIV care has been reported to be low [5,6], similar to much of sub-Saharan Africa [7,8]. The Mozambique Ministry of Health reported in 2015 that ART coverage was only 59% of the estimated treatment needs [9], and, as in other countries in the region, the proportion of those retained in pre-ART care and ART in Mozambique tends to decrease over time [8–10]. This poses challenges to reaching the ambitious 90-90-90 goals of the Joint United Nations Programme on HIV/AIDS' (UNAIDS) [11,12]. The new WHO guidelines on early initiation of ART [13] may contribute to achieving those goals, but only if people who are diagnosed HIV-positive are enrolled and retained in care. Moreover, accurate monitoring of enrolment and retention with reliable information about the HIV cascade [14] is critical for making progress in HIV care. Nevertheless, poor HIV data quality from both routine sources and international implementing partners [9,15] remains a challenge to understanding the cascade.

A study aimed to identify and measure loss to follow-up in the HIV care cascade in Manica and Sofala provinces, Central Mozambique, using adjusted routine health systems data and

patient charts to estimate the proportion of people with an HIV-positive diagnosis who were linked to and retained in pre-ART care and ART. The study also aimed to identify perceived barriers and facilitators of enrolment and retention in pre-ART care and ART.

Methods

Study setting and design

We conducted this mixed methods study in six districts: Beira, Buzi and Dondo in Sofala Province; and Barue, Chimoio and Manica in Manica Province. Beira and Chimoio are the capital cities of Sofala and Manica provinces, respectively. The other four districts are rural. We selected these six districts because of their rural-urban mix, their mix of different levels of health services, and their security. These districts are mostly contiguous and cover most of the major health facilities in Central Mozambique. Self-referral to health facilities inside or outside this six-district region would likely have been infrequent. At the time of the study, HIV testing, pre-ART care and ART were free and widely available throughout the country.

To obtain an overview of HIV testing and HIV care enrolment at the district level, we examined routine monthly reports from all (87) health facilities that provided HIV testing or treatment in those districts. To obtain an in-depth assessment of enrolment, patient flow and retention in pre-ART care and ART at the health facility level, we selected eight of the 87 facilities for further study. The eight facilities were among the 34 facilities that provided ART during the study period; four were the main referral health facilities in rural districts and four were moderate to large patient volume facilities in urban areas.

District overview assessment

We collected and analyzed routine district and health facility monthly reports of HIV testing and HIV testing registries (pre-ART, ART) in each of the six districts from April 2012 to March 2013 (the study period). The study start date corresponds with a major revision of HIV data collection and monitoring registries, including new patient forms, registry books and reporting templates, that had been introduced in Mozambique in early 2012. We also collected data directly from HIV registries at district-level health offices, from pharmacy records of tests distributed and reported positive and from the national electronic health information system, locally known as the *Módulo Básico*.

We conducted descriptive analyses such as frequency for HIV tests, pre-ART and ART registrants, and for missing values in the routine data set. We examined missing value patterns over time and by health facility, and tested several imputation methods to substitute missing values: (1) single imputation using mean, trimmed means (replacing values above 50% of the mean for facilities that had less than five months data) and median, (2) Poisson generalized linear modelling and (3) iterative singular value decomposition (SVD) method (specifically rank-1 SVD approximation). None of these methods yielded consistently higher or lower imputed values than the other methods. We finally used the single imputation method because it gave the most conservative values. We performed the imputations in R (version 3.2) and analysis in Stata 13.1.

Health facility quantitative assessment

At each of the eight health facilities, we abstracted enrolment data from the pre-ART and ART registry books and retention data from patient charts and pharmacy records. Mozambique Ministry of Health policy stipulates that (1) all newly diagnosed HIV-positive patients be first registered in pre-ART registry books (even those who are eligible for ART) and (2) patient charts be created for all pre-ART and ART patients. The pre-ART and ART registry books included dates of HIV-positive and CD4 tests and the dates of ART initiation. We conducted a stratified random sample of registrants from the pre-ART and ART registries separately (using random.org) to obtain 100 charts of patients older than 15 years from each facility, excluding women in prevention of mother-to-child transmission of HIV (PMTCT) programmes. We searched for the selected patient charts in archives, consultation rooms and other parts of the health facilities. Data abstracted from patient charts included demographic characteristics, site of testing, and dates for ordering CD4 tests, receipt of CD4 results, enrolment into care, ART initiation, consultations, ART pickups, and the date of the study team visit. Data were entered into study computers using EPIDATA 3.2 and exported for cleaning and analysis in Stata 13.1.

To construct the overall HIV cascade, we used different data sources for enrolment and retention. Enrolment proportions were measured in two steps: first, by the number of people, district-wide, registered in pre-ART divided by the estimated (adjusted) number of newly diagnosed HIV positive in each district during the study period; and second, by the proportion of charts found among the selected people registered on pre-ART and ART at each of the eight health facilities. Retention rates were measured by the proportion of patient charts with evidence of an ART clinic visit or antiretroviral (ARV) pickup by patient charts or individual pharmacy records within 30, 60 or 90 days prior to the study team visit to the facility. Retention was examined separately for pre-ART and ART patients.

Health facility qualitative assessment

At each of the eight facilities and their surrounding areas, we conducted in-depth interviews (IDIs) with health facility directors and with people living with HIV who (1) enrolled in pre-ART care within 30 days of their HIV-positive test result, (2) enrolled after 30 days from their HIV-positive test result, (3) enrolled but eventually dropped out of pre-ART care and (4) never enrolled in HIV care. In each facility, we had aimed to include at least one person living with HIV from each of the four categories, and adolescents (18–19 years old). Participants were at least 18 years old. Study interviewers contacted and obtained informed consent directly from facility directors before conducting an IDI. During health facility visits, healthcare providers informed people living with HIV eligible for study participation about the study and gave them the option of contacting study interviewers for informed consent if they were interested in participating in the study. In health facility surrounding areas, facility-based outreach workers provided information about the study to people who had dropped out of care or who had never

enrolled in care, and gave them the option of contacting study interviewers for informed consent if they were interested in participating in the study. Study interviewers also conducted focus group discussions (FGDs) with healthcare providers, community outreach workers, and members of patient-support groups at the health facility. They conducted FGDs with community leaders in community meeting rooms. IDIs and FGDs focused on people's experience with HIV testing and HIV care, barriers and facilitators of enrolment and retention in pre-ART care and ART, and on visualizing those experiences, barriers and facilitators through developing patient flow maps in each facility.

Study interviewers took notes and audio-recorded IDIs and FGDs to expand notes and improve reliability. We coded and analyzed notes using ATLAS.ti 7™ (www.atlasti.com/). This paper reports only on the main facilitators and barriers for linkages and retention in pre-ART care and ART, that is, those mentioned by at least three out of the four types of people living with HIV, and in at least four out of the eight study sites. More in-depth analysis of the qualitative data is planned for future publication.

Ethical considerations

The Institutional Review Boards of the Population Council, United States, and the Mozambique National Institute of Health (CIBS-INS) approved the study. All participants provided written informed consent. In the published figures and tables, we replaced actual names of health facilities with anonymous alphabetical codes to avoid adverse events that might result from reporting on low performance.

Results

At the district level, we analyzed all available reports from the 87 facilities providing HIV testing and the 34 facilities providing ART. At the eight health facilities providing ART, we abstracted information from 795 patient charts (430 pre-ART and 365 ART) and we conducted 25 FGDs (comprising 248 participants) and 53 IDIs. We excluded three low-quality IDIs from analysis, leaving 23 IDIs with people who enrolled within 30 days of being diagnosed HIV-positive, seven with people who had enrolled 30 days or more after their HIV-positive test result, 10 with people who had enrolled in care and dropped out and two with HIV-positive people who never enrolled in care. We also conducted eight IDIs with health facility directors.

District-level HIV testing and enrolment in care

Monthly reports submitted at the district level indicated that slightly more people tested HIV-positive than the number of people newly registered in pre-ART care (Table 1). Beira and Manica districts reported fewer people who tested HIV-positive than those registered in pre-ART. Overall, 46% (range 25–65% among districts) of the 1944 monthly reports for HIV testing that were expected from the 87 facilities were missing, compared to 6.4% (range 2–15%) of the 312 expected monthly reports for registry in pre-ART and ART. Missing values were more frequent from the electronic health information system, including three districts without reports for any HIV testing data during the study period. After imputation adjustment, the proportional increase from raw totals was 35% for people tested HIV-positive and only 4.2% for those registered in pre-ART care. With the adjustment, the overall proportion of HIV-positive people who enrolled in pre-ART care in the six districts was 75% (range 46–92%).

Enrolment in HIV care in the eight ART facilities

The overall mean proportion of pre-ART and ART registrants whose charts were located at the health facilities was 60 and 66%, respectively, with a high variation between the facilities (range 31–85% for ART and 7–64% for pre-ART). Patient demographics abstracted from the charts were not significantly different between pre-ART and ART patients (Supplementary Table 1). Pre-ART and ART samples from the eight health facilities had similarly high proportions of women (62% pre-ART and 55% ART). Patients were mostly between 15 and 49 years old (91% pre-ART and 92% ART), and most had primary and secondary level of education (68% pre-ART and 69% ART). The socio-demographic profiles of HIV-positive persons interviewed were similar to those whose charts were reviewed: 95% were between 20 and 49 years of age, 61% were women, 57% reported completing primary and 31% reported completing secondary or higher education level. Thirty-eight percent of interviewees reported being married

Table 1. Monthly reported and adjusted numbers and percentages of people with HIV-positive diagnosis and enrolled in pre-ART between April 2012 and March 2013 in six districts in Manica and Sofala provinces

	Number of people with HIV-positive diagnosis		Number of people with HIV-positive diagnosis enrolled in pre-ART		Proportion of people with HIV-positive diagnosis enrolled in pre-ART	
Districts	**Reported**	**Adjusted**	**Reported**	**Adjusted**	**Reported (%)**	**Adjusted (%)**
Búzi	2104	3363	1549	1658	74	46
Dondo	2898	2757	1681	2681	58	56
Beira	8143	12,040	11,061	11,061	136	92
Manica	2404	3498	2660	2660	111	76
Bárue	2096	2164	1194	1194	57	55
Chimoio	7032	7406	5675	5675	81	77
Total	24,677	33,228	23,820	24,820	97	75

Note: Adjusted numbers combined reported values for reported months and imputed values for missing months.

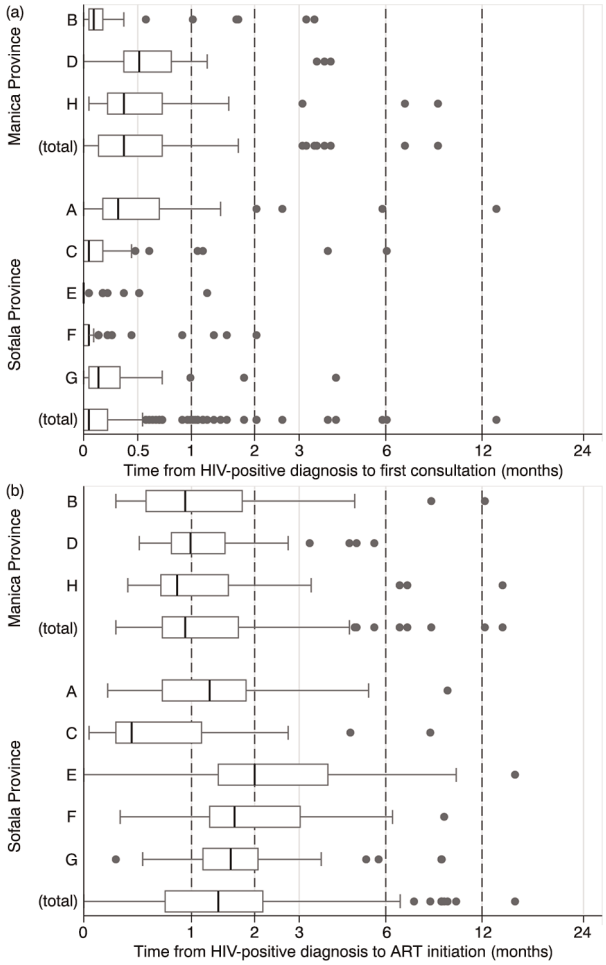

Figure 1. Months from HIV-positive diagnosis to first consultation among pre-ART patients (a), and time from HIV-positive diagnosis to ART initiation among ART patients (b), in eight health facilities in Manica and Sofala provinces.

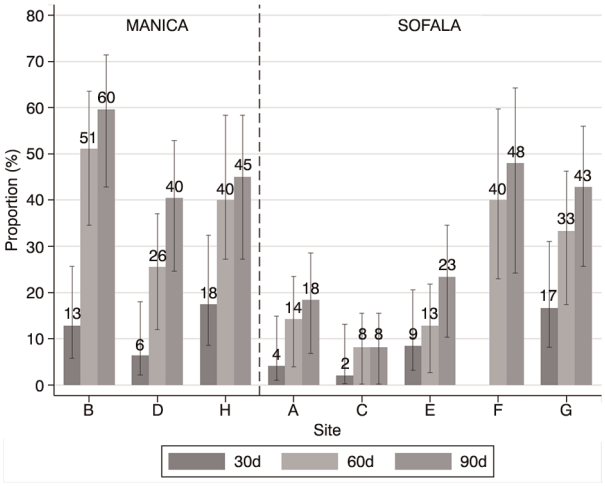

Figure 2. Proportion of ART patient charts with evidence of clinical visit or ARV pickup, 30, 60 and 90 days before study visit in eight health facilities of Manica and Sofala provinces.

or in marital union, 21% widowed and 77% reported having children. Regarding occupations, 33% reported being domestic workers, 24% small business owners and 15% workers in agriculture/fishing.

Patient chart data demonstrated a large variation between the health facilities in time from HIV-positive test to first clinical consultation (overall mean 13.3 days; IQR 0.0–12.0 days; range 0.0–13.3 months) and in time from HIV diagnosis to ART initiation (overall mean 1.8 months; IQR 0.7–2.1 months; range 0.1–12.2 months) (Figure 1).

Retention in ART in the eight ART facilities

Among the 346 ART charts found, the median time from the initiation of treatment until study team visit was 18.6 months. Overall, 34, 27 and 8% of these ART charts had evidence of a clinic visit or ARV pickup within 90, 60 or 30 days of the study team visit, with a wide variation among the eight health facilities (Figure 2). We found that the number of days for which ARVs were dispensed was frequently missing. However, during IDIs and FGDs, health providers consistently reported that ARVs were usually dispensed for 60 days or occasionally for 90 days when patients were clinically stable.

Crude and adjusted logistic regression did not show differences in retention rates between males and females. However, retention (evidence of ARV pickup within 90 days of study visit) in Manica Province was significantly greater than in Sofala Province (Supplementary Table 2).

Overall HIV care cascade

We constructed an overall HIV care cascade (Figure 3) using the following sources of data: (1) district-level proportions of estimated HIV-positive people who were registered in pre-ART, (2) proportions of patients registered in ART in the eight health facilities whose charts were found and (3) proportions of those patient charts with any evidence of clinic visit or ARV pick up within 90 days of our study team review visit. The calculations suggest that, in aggregate, 18% of the HIV-positive patients diagnosed in health facilities during the study period were retained in treatment one to two years later.

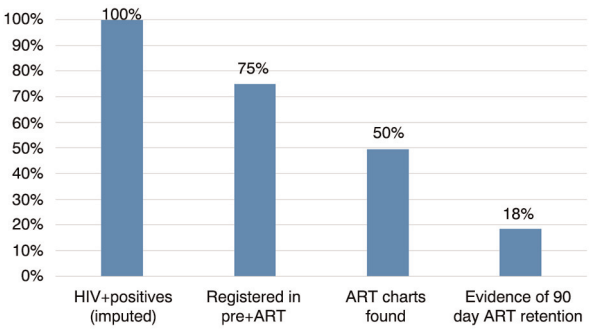

Figure 3. Overall HIV cascade – from HIV testing to enrolment to charts located to retention – aggregate data from eight health facilities in Manica and Sofala provinces. Note: Each bar represents the proportion of the original total of people tested HIV-positive, for example, 50% of HIV-positive charts found = 66% charts found times 75% registered. Adjusted numbers combined reported values with imputed values for missing months.

Perceived facilitators and barriers to HIV testing, enrolment and retention

Most respondents from both the IDIs and FGDs said that they preferred to be tested at sites that provided ART and near their places of residence. Both men and women who enrolled early in HIV care said that the main reason for obtaining an HIV test – and for enrolling in HIV care – was the presence of symptoms of sickness. Conversely, the main perceived barrier for enrolment was lack of symptoms of sickness. Some women who enrolled early mentioned their desire to protect their children from vertical transmission and wishing to live longer to raise their children.

Only early enrollers in HIV care mentioned a facilitator of retention, living near the health facility where one receives HIV care. Perceived barriers for retention included: (1) the perception of poor and disrespectful service at the health facility, especially for people on ART who were late to their ARV pickup appointments and (2) lack of money for food and for transportation.

Table 2 summarizes facilitators and barriers to enrolment and retention in HIV care that were mentioned during IDIs and FGDs.

Healthcare providers described how HIV-positive patients could be lost at different steps along the HIV continuum of care through a variety of delays and loss to follow-up in patient flow that varied by site. For example, losses were especially common in the intervals between patients receiving their HIV-positive result and creating the chart, or between having their blood drawn for laboratory tests and receiving those results. Interviewees also mentioned that, at all eight health facilities, charts were not created in the same room where HIV tests were done and results disclosed. In some health facilities, patients were sent to queue at the health facility reception to have their charts created when frequently charts were not created at all. At other facilities, providers said they took the patient's test results and went to create the chart themselves at the reception. When blood samples were sent to other health facilities to obtain CD4 counts, the results often took several weeks to be returned to patients.

We constructed Figure 4 that shows an idealized flow map for HIV-positive patients in ART, based on the Mozambique 2014 national ART guidelines. The information gathered from our eight FGDs with 74 healthcare providers at the eight study health facilities suggested specific points in the flow map where patients were typically lost to follow-up (LTFU), noted with black downward-pointing arrows with an LTFU label.

Discussion

This study demonstrated substantial losses to follow-up of HIV-positive persons at all points along the HIV care and treatment cascade in Central Mozambique. Moreover, our findings suggest that the routine HIV information, as reported, grossly overestimates both the true enrolment and retention in HIV care. Our findings also suggest that HIV-positive patients experienced major facilitators and barriers for enrolment and retention in HIV care, including individual, health system and structural factors.

Our estimate of the proportion of people diagnosed with HIV who are registered in pre-ART care was slightly higher than other estimates in sub-Saharan Africa [8]. Our overall retention estimates are much lower than nationally reported retention estimates in Mozambique for 2014 (67% at 12 months after ART initiation, and 56% at 24 months) [9,12]. Our low retention estimates are, however, not substantially different than other carefully conducted studies in sub-Saharan Africa [7,11,12]. Our facilitators for enrolment in pre-ART and ART care (e.g. proximity to ART services and severity of illness) were similar to studies elsewhere [16,17]. Yet, in contrast to those studies, facilitators for enrolment and retention in our study seemed to only help those who enrolled early in care (within 30 days of their HIV diagnosis). Our barriers for retention (e.g., lack of symptoms, perceived poor quality of healthcare) were consistent with other studies in sub-Saharan Africa [16–18].

The large variations in patient flow patterns, in observance of national norms, and LTFU found among the eight ART facilities suggest that targeted health systems change, including simplification of patient flow, improved patient information and improving health worker behaviour, might substantially improve performance. The data also suggest that there is an urgent need for strategies to re-link patients into HIV care in Mozambique, using lessons learned from the country and other low-resource settings [19]. Strategies might include having healthcare workers, with whom many patients have developed close relationships, contact patients who have dropped out and understand reasons why they dropped out [19]. Judgemental attitudes or threatening patients is not helpful, as has been reported in other sub-Saharan African

Table 2. Perceived facilitators and barriers to enrolment and retention in HIV care in eight health facilities in Manic and Sofala provinces

	Facilitators	Mentioned by	Barriers	Mentioned by
Enrolment in HIV care	Presence of symptoms	Early enrollers Community leaders	Lack of symptoms	Late enrolment, never enrolled, dropouts, patient-support group and healthcare providers
Retention in HIV care	Proximity to health facility	Early enrollers	Disrespect by health workers, poor quality of healthcare	Early enrolment, late enrolment, dropouts, patient-support group, healthcare providers and outreach workers
			Lack of money for food and transport	Early enrolment, late enrolment and dropouts

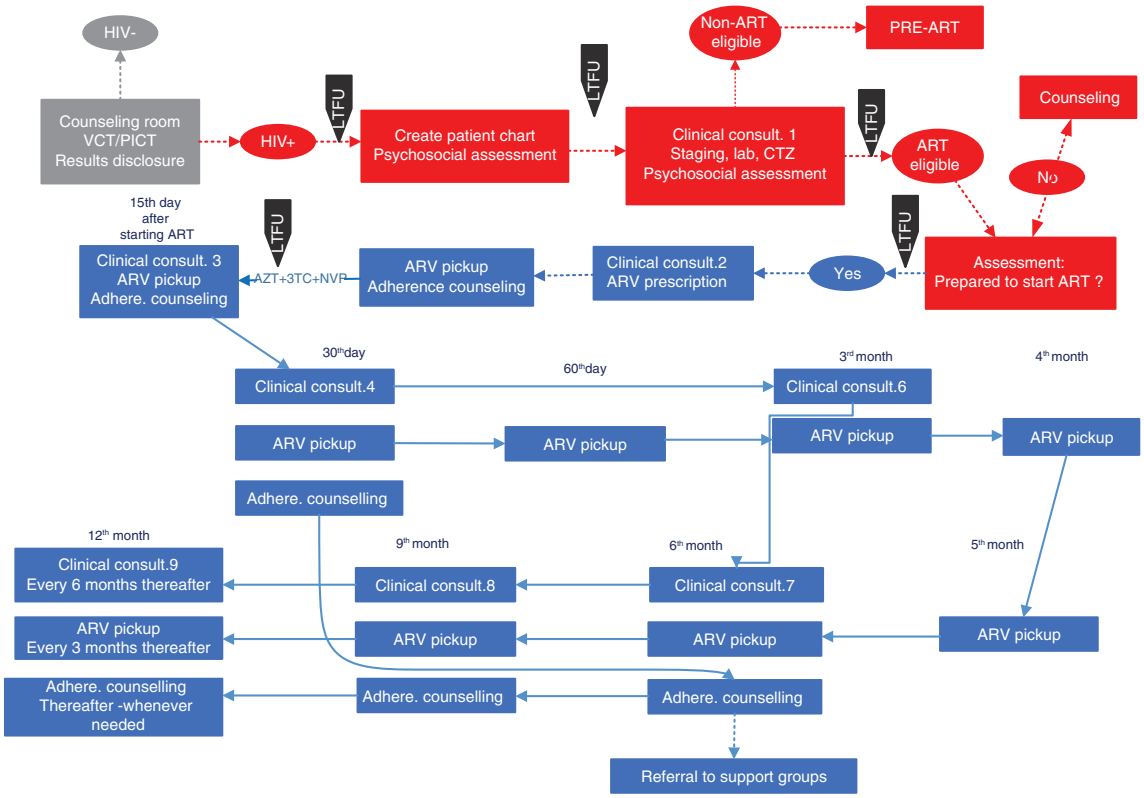

Figure 4. Patient flow map showing loss to follow up along the HIV continuum of care in eight health facilities of Manica and Sofala provinces. ART: antiretroviral therapy; AZT + 3TC + NVP: zidovudine + stavudine + niverapine; CTZ: cotrimoxazole; HIV+: HIV-positive; PICT: provider initiated counselling and testing; LTFU: lost to follow-up; VCT: voluntary counselling and testing.

contexts [20]. However, in Mozambique, many of these healthcare workers battle with work overload [21,22] or lack of motivation because they feel ''exploited and ultimately abandoned'' by the nature of global HIV interventions [23]. Working conditions need to be addressed to complement training. Improving workforce morale, understanding individual patient circumstances (including reasons beyond their control) and bearing in mind that missing visits are inevitable over the lifelong course of HIV care can help in the process of re-linking patients into care [20]. Another strategy, based on our results, would be to simplify algorithms of patient care and confusing patient flow patterns, and to address challenges with patient chart management.

Our finding that a large proportion of those who register in pre-ART (who are thus considered ''linked'' to HIV care) have no evidence of subsequent encounters with the health system is disturbing. The finding raises serious concerns about using registration at ART facilities as an indicator for effective enrolment. Measuring retention is also a challenge. If retention is measured only among those with patient charts or pharmacy records, the results will overestimate the true retention of the people originally tested HIV-positive in the health system. On the other hand, incomplete recording of visits or ARV pickup in patient charts may underestimate true retention of those in care with charts. Follow-up of pharmacy records can complement data on patient retention if the pharmacy records are adequately filled out. All enrolment and retention estimates, however, will be meaningful only when they are based on an accurate denominator of the total numbers of people tested HIV-positive in the health system.

The Mozambique Ministry of Health has acknowledged poor HIV data quality nationally [9,15] and data concerns have been well documented through ethnographic research in Mozambique [21]. Authors concerned about data quality in other countries have called for the use of multiple measures of linkages to HIV care and retention in HIV care and treatment [24–26]. Other lower resolution proxy measures (e.g. viral load) may provide broader generalizability for the measurement of trends in linkage to care over time [27]. We hope that our research will contribute to a deeper understanding of how to use proxy measures of linkage to HIV care and treatment to match the desired programmatic or clinical outcomes.

Limitations

The poor quality of reported data was both a principal finding of the study and a limitation. Although our imputation methods were designed to supplement routine data to obtain more accurate estimates, we cannot be certain that the adjusted estimates reflect the true picture of registry and enrolment in care. Patients may have received effective ART without adequate evidence of their treatment in patient charts. We noted earlier that the data systems in Mozambique did not allow for analysis of individual linkages of people tested HIV-positive to HIV care, since no codes were used

for testing, and as a result testing could not be linked to registries in the ART sites. Thus, it was not possible to ascertain the extent to which people tested HIV-positive might be obtaining care from elsewhere, including outside the study districts. Since transfers of patients were rarely registered, our estimates of retention likely underestimated the true retention of our sample HIV-positive registrants.

The qualitative assessment was limited by the small numbers of HIV-positive people who enrolled late, dropped out or never enrolled in care that we were able to interview. Moreover, the findings related to health systems barriers can only represent the practices at these eight facilities. Other facilities might have presented substantially different qualitative (and quantitative) findings. Nevertheless, our diverse sample that included perspectives of people living with HIV, health providers, and community outreach workers and members provided wide-ranging perceptions.

Conclusions

Our findings suggest that these districts in Central Mozambique face serious challenges to effectively enrol and retain people who are tested HIV-positive in the health system. The poor quality of routine reported data, especially regarding HIV testing, is a major barrier to identifying these bottlenecks. More attention needs to be focused on improving the quality and analysis of routine data regarding all steps of the HIV cascade at each health facility. We think that our careful utilization of routine health system information, which included data quality assessment, triangulation of data from other sources, adjustment by imputation for missing data, and patient chart review, provided a reasonably high-resolution measure of linkage to care. The HIV care cascade model that we constructed provided health facility-specific detail on critical bottlenecks from which tailored interventions can be developed. Our study results also suggest that health system, individual and structural factors were important perceived barriers to enrolment and retention in care. Modifying these factors and assessing their impact with reliable data should substantially improve linkages to enrolment and retention in HIV care and enhance global efforts to address HIV.

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Competing interests
None.

Authors' contributions
CI, SG, JM, CB, JB, SC and JP conceived the study and contributed to the study design. CI, SG, OA, LV and WM analysed the data. CI and SG drafted the manuscript. JM, CB, VW, OA, LV, PA, MJ, WM, JB, JC, SC and JP revised the manuscript. All authors read and approved the final draft.

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Research article

Annual cost of antiretroviral therapy among three service delivery models in Uganda

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Abstract

Introduction: In response to the increasing burden of HIV, the Ugandan government has employed different service delivery models since 2004 that aim to reduce costs and remove barriers to accessing HIV care. These models include community-based approaches to delivering antiretroviral therapy (ART) and delegating tasks to lower-level health workers. This study aimed to provide data on annual ART cost per client among three different service delivery models in Uganda.

Methods: Costing data for the entire year 2012 were retrospectively collected as part of a larger task-shifting study conducted in three organizations in Uganda: Kitovu Mobile (KM), the AIDS Support Organisation (TASO) and Uganda Cares (UC). A standard cost data capture tool was developed and used to retrospectively collect cost information regarding antiretroviral (ARV) drugs and non-ARV drugs, ART-related lab tests, personnel and administrative costs. A random sample of four TASO centres (out of 11), four UC clinics (out of 29) and all KM outreach units were selected for the study.

Results: Cost varied across sites within each organization as well as across the three organizations. In addition, the number of annual ART visits was more frequent in rural areas and through KM (the community distribution model), which played a major part in the overall annual ART cost. The annual cost per client (in USD) was $404 for KM, $332 for TASO and $257 for UC. These estimates were lower than previous analyses in Uganda or the region compared to data from 2001 to 2009, but comparable with recent estimates using data from 2010 to 2013. ARVs accounted for the majority of the total cost, followed by personnel and operational costs.

Conclusions: The study provides updated data on annual cost per ART visit for three service delivery models in Uganda. These data will be vital for in-country budgetary efforts to ensure that universal access to ART, as called for in the 2015 World Health Organization (WHO) guidelines, is achievable. The lower annual ART cost found in this study indicates that we may be able to treat all people with HIV as laid out in the 2015 WHO guidelines. The variation of costs across sites and the three models indicates the potential for efficiency gains.

Keywords: ART; cost; efficiency; task-shifting; community-based ART; Uganda.

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Introduction

Although notable progress has been made in the provision of HIV and AIDS services, the need for HIV and AIDS services continues to expand faster than the available resources in low- and middle-income countries. In the case of Uganda, coverage of the population in need of antiretroviral therapy (ART) was estimated at 331,000 in 2014, representing only half of the total number of people living with HIV (PLHIV) [1]. ART offers PLHIV a chance to live a normal lifespan. Consequently, HIV is increasingly seen as a chronic illness rather than an acute epidemic [2–4]. In addition, new HIV infections continue to occur, contributing to an increased cumulative number of PLHIV [4]. Furthermore, ART has been increasingly seen as an important prevention strategy (treatment as prevention). The World Health Organization (WHO) has recently recommended HIV treatment to all PLHIV regardless of their CD4 count, and many countries are planning on adopting this recommendation [3]. All of these factors are contributing to an increased demand on human and financial resources to deliver ART, thus careful planning and budgeting are needed to ensure universal access to ART [4,5].

The increased demand on human and financial resources to scale up ART presents a problem as many low income countries have historically experienced severe health worker shortages [5]. For example, in Uganda the ratio of doctors to patients is 1:22,000, suggesting an 80% overall health worker deficit compared to the WHO standard [6]. In response to the health workforce shortage and the increased demand for HIV treatment, in 2004 the Ugandan government developed and pilot tested community-based ART delivery and task-shifting models [6,7]. This effort included use of community distribution points and mobile units, or mixed models of community-based and facility-based service provision, to bring HIV care and treatment closer to the community with the delegation of tasks to less specialized health workers and laypersons. With a health worker shortage, these models are critical in

removing barriers to accessing ART care and reducing associated costs.

Although projections of resources needed to deliver ART following the 2015 WHO guidelines have been made at the global level, such projections have not been made frequently in Uganda due to the lack of comprehensive costing data [8,9]. Several initiatives providing ART have been implemented in Uganda; however, there is little information available about the costs of providing ART across these service delivery models [10]. In addition, the available costing studies have had a broader focus on public sector health facilities or were solely based on budgeting data (projected data), without necessarily providing actual costing data [11]. To help fill this gap, we aimed to provide the descriptive annual ART cost per ART client at the three largest non-profit organizations serving PLHIV in Uganda – The AIDS Support Organization (TASO), Kitovu Mobile (KM) and Uganda Cares (UC) – using a retrospective review of routine data. The service delivery models provide free outpatient ART services and serve mainly rural and semi-urban populations [12]. The findings from this study will be valuable for budgetary efforts to ensure universal access to ART in Uganda, following the 2015 WHO guidelines. In addition, costing data is an important input for modelling cost-effectiveness and cost-efficiency analyses to promote long-term sustainability of ART in Uganda and similar contexts [13,14].

Methods

Description of the three service delivery models

Data were collected as part of a larger study assessing the three task-shifting and community-based ART support programmes in Uganda (Table 1) [12]. The three participating organizations serving PLHIV in Uganda included the following: TASO, which comprises 11 centres in four regions and serves nearly 100,000 PLHIV annually; KM, which operates in 10 districts in southwestern Uganda and serves about 2000 PLHIV annually; and UC, which operates 29 clinics in four regions of Uganda and serves nearly 50,000 PLHIV annually.

TASO delivers HIV care through its 11 service delivery centres in four regions across Uganda. Each TASO centre has two types of service delivery models: 1) TASO-Central and 2) TASO outreach clinics, called *community-based drug distribution points* (TASO-CDDPs). TASO-Central clinics provide ART services to clients recently initiated to ART, or complicated cases, as well as CD4 and viral load testing. TASO-CDDPs mainly dispense antiretroviral (ARV) drugs and provide counselling and health exams to stable clients at the community level. At TASO, doctors take on critical and complicated cases and supervise lower-level staff, including nurses and expert clients. Expert clients are PLHIV who have been trained to provide ART adherence counselling, monitor clients lost to follow-up and dispense ARVs. Nurses and expert clients mainly dispense ARVs to stable clients at the community level. In 2012, TASO served a total of 68,584 HIV patients, of whom 33.3% (22,814) were on ART.

HIV care and treatment services at KM are delivered at 111 non-facility-based community locations in 10 districts of the south-western region in Uganda. The organization employs 15 health professionals (doctors and nurses) and 177 expert clients. KM is a task-shifted model where a limited number of doctors undertake the overall management or supervisory roles and provide care to critically ill clients. Expert clients dispense ARVs and provide adherence counselling. In 2012, KM served 2007 clients, of whom 69.1% (1387) were on ART.

Table 1. Characteristics of the three ART delivery models (2012)

Characteristics	Kitovu Mobile	TASO Entebbe	TASO Gulu	TASO Jinja	TASO Rukungiri	UC Balikudembe	UC Nakawa Market	UC Lyantonde	UC Kalisizo
HIV prevalence (adults aged 15 to 49)	10.6%	7.1%	5.8%	5.8%	8.3%	7.1%	7.1%	8.0%	10.6%
Geography	Rural	Semi-urban	Rural	Semi-urban	Rural	Urban	Urban	Rural	Rural
Personnel									
Doctors	1	3	3	3	3	1	1	0	0.5 from MOH
Clinical officers	2	2	2	1	1	1	0	1 from MOH	0.5 from MOH
Nurses	10	5	5	5	5	6	2	1.5 from MOH	1 UC 1.5 from MOH
Lab technicians	1	3	3	2	2	0.5 shared with Nakawa	0.5 shared with St. Balikudembe	1	1
Data managers	1	3	3	3	3	0.8	1	1	1
Total	15	16	16	14	14	9.3	4.5	4.5	5.5
Number of ART clients	1387	6329	6969	5454	4062	2498	530	1250	1669
Number of ART visits	12,510	23,461	28,654	32,233	27,693	12,636	6076	10,345	11,420

Notes: Kitovu Mobile operates in one region, UC operates in four regions and TASO operates in 10 regions. HIV prevalence from Uganda DHS, Demographic and Health Survey, 2012. Personnel and ART client visits are from the organizational structure and records. ART, antiretroviral therapy; MOH, Ministry of Health; TASO, the AIDS Support Organisation; UC, Uganda Cares.

Both CD4 and viral load testing were done at government laboratories.

UC is a collaborative partnership with the Ministry of Health (MOH) and the AIDS Health Care Foundation. The organization has been providing ART at no cost in Uganda since 2001 in 29 clinics across four regions. UC operates two types of service delivery models: 1) UC stand-alone (UC-S) clinics, which are located at UC centres; and 2) UC-MOH, which provides drugs and other supplies to MOH health facilities for HIV care. UC also practises task-shifting as a limited number of doctors take on critical cases or cases referred by nurses, whereas nurses dispense ARVs and conduct routine health assessments for stable clients. In 2012 UC served a total of 3495 HIV clients, of whom 80.3% (2807) were on ART. CD4 count was performed on site whereas viral load tests were sent to government laboratories for analysis.

Site selection

Four TASO centres out of 11 total centres were purposively selected to ensure fair regional representation: Entebbe (Central-1), Jinja (East-Central), Gulu (Mid-North) and Rukungiri (South-West).

KM operates in only one region and all of its 111 outreach mobile units were selected. Currently, UC operates 29 clinics in four regions: North-East, Mid-East, Central-1 and Central-2. Among the four regions of operation, the study team purposively selected the following clinics to ensure a reasonably fair distribution across the regions of Uganda: 1) Soroti, 2) Nakawa, 3) Balikuddembe; 4) Maddu, 5) Rakai, 6) Lyantonde, 7) Kalisizo, 8) Mulanda and 9) Nagongera. Five UC clinics had excessive missing data and they were therefore removed from the analysis.

Costing approach

The costing analysis was undertaken from the provider's perspective. The analysis only included costs that were directly incurred by the provider and excluded costs covered by clients. Ancillary and opportunity costs incurred by patients, such as transportation and time, were not collected.

Data collection period

We chose to collect 2012 data in order to analyze the most recent cost data available (as the study protocol was developed in 2013). Data collection was completed between June and September 2013. The original costing data were recorded in Ugandan shillings (UGX) and converted to US dollars (USD) using 2012 historical exchange rates from OANDA.com. Monthly 2012 data from the sampled facilities were collected and then aggregated for the entire year. The total number of visits for 12 months and the total number of clients at mid-year were used in the analysis.

Data collection methods

The ART drug costs, number of clients, number of visits and operational costs were collected retrospectively using routine monitoring and evaluation (M&E) data from the organizations. In addition, other costs related to service delivery – accounting records, client visit logs, ART distribution logs, equipment inventories and routine reports – were collected. Salaries and benefits of staff directly providing ART services were collected from payroll records. Time spent on ART service delivery was determined based on interviews with staff and their managers, as well as reviews of staff levels of effort in ART services. For staff not working full-time on ART-related services, the time spent on ART was calculated as a ratio of the total number of hours spent on ART divided by the total working hours (eight) per day. The percentage of office rent and operational costs attributed to ART was calculated based on the number of ART clients in relation to the total number of clients for the organization.

Costing data were collected from a programmatic perspective, which included all site-level costs of outpatient ART and supportive care. In addition to direct service provision costs, the study examined site administration, management and operational costs at each site.

A cost data capture tool was developed – according to the US President's Emergency Plan for AIDS Relief (PEPFAR) guidelines on cost elements to be collected for ART programmes – and administered at all three organizations [15]. The tool captured the following: 1) personnel costs, including salaries and allowances of staff who provide ART services as well as administrative staff who manage and support the clinics; 2) ARV costs; 3) other non-ART drugs and supplements, including drugs to prevent opportunistic infections, vitamins, TB drugs and nutrition support; 4) laboratory services related to ART delivery, such as CD4 count and viral load testing, TB testing and basic blood testing; and 5) operational costs, for example equipment, furniture, office rental, car rental, fuel, insurance, travel and office utilities.

Apportionment of shared costs

Apportioning costs for staff not full-time on ART service delivery was estimated based on the number of ART patients *versus* total patients. For TASO, which has a regional structure, personnel costs at the national level were equally shared among the four TASO centres. At UC and KM, headquarter operational costs attributed to ART were equally distributed among all the service delivery points of the organization.

Missing data

Missing data on office space rental and office expenses for UC and KM were replaced with data from the months available. This approach is considered acceptable because office and rental expenses are fairly stable from month to month. Missing data on ARVs and staff time were excessive (30% and above) at five of the nine UC sites; therefore they were excluded from this analysis to ensure accuracy. ARV cost data were complete for all sites. Staff time spent on ART services were calculated for all sites based on accounting records, project records, payroll data and interviews. TASO had complete costing data across all five cost components.

Data analysis

Data from the data capture tool were entered into Microsoft Excel and organized into the five different cost components as described above. Direct costs of ARVs and other ART-specific commodities were captured and analyzed at face value. The total ART-related costs were divided by the total number of annual visits and total number of annual patients to estimate cost per ART visit and annual cost per ART patient.

Table 2. Average cost per visit and annual cost per client across the three models (2012)

Model	Location	Total expenditure (USD)	Total ART clients	Total ART visits	Average annual visits/client	Average cost per ART visit (USD)	Annual cost per ART client (USD)
Kitovu Mobile	Rural (Southwestern Region)	$560,756	1387	12,510	9.0	$45	$404
TASO	Rural (Gulu)	$2,094,695	6969	28,654	4.1	$73	$301
	Rural (Rukungiri)	$1,944,096	4602	27,693	6.0	$70	$422
	Semi-urban (Jinja)	$1,969,940	5454	32,233	5.9	$61	$361
	Semi-urban (Entebbe)	$1,744,231	6329	23,461	3.7	$74	$276
	Overall cost	$7,752,962	22,814	112,041	4.8	$69	$332
Uganda Cares	Urban (St. Balikudembe)	$791,009	2498	12,636	5.1	$63	$317
	Urban (Nakawa Market)	$190,222	530	6076	11.5	$31	$359
	Rural (Lyantonde)	$272,841	1250	10,345	8.3	$26	$218
	Rural (Kalisizo)	$274,717	1669	11,420	6.8	$24	$165
	Overall cost	$1,528,789	5947	40,477	6.8	$38	$257

ART, antiretroviral therapy; TASO, The AIDS Support Organisation; USD, US dollars.

Ethical considerations

The study was reviewed and approved by the Population Council and the Ugandan National Council for Science and Technology IRBs. All of the costing data were extracted from accounting records that did not contain any patient-specific data or personal identifiers. The total number of patient visits in 2012 was collected from clinic records. No personal information of patients was recorded in the data capture tool.

Results

Estimation of ART cost per visit and annual ART cost per client

Table 2 summarizes the 2012 total annual ART-related expenditure, the cost per client visit and annual cost per client in USD. Table 2 also shows the average number of visits per client across the three models. In particular, clients at KM made an average of nine visits to the KM outreach locations for ART care, whereas TASO clients averaged five visits and UC clients averaged seven visits annually. The average cost per visit was $38 for UC, $45 for KM and $74 for TASO clients. The average annual cost per client was $404 for KM, $332 for TASO and $257 for UC clients. The average cost per client for all three organizations was $331 and varied across the four TASO centres and four UC clinics (data not shown).

Cost distribution across the five components of each model

Table 3 summarizes cost distributions across the five cost components at all three organizations.

ARV costs: ARVs accounted for a significant portion of the total ART-related costs. In particular, ARVs comprised 47% of the total cost among KM clients, compared to 44% among TASO and 66% among UC clients. However, the annual ARV cost per client across these three organizations was comparable ($188 among KM, $149 among TASO and $170 among UC clients). It is important to note that in 2012, 95% of TASO clients and 98% of KM and UC clients were on first-line drugs.

Personnel costs: There are significant variations in personnel and other costs across the three organizations. Personnel costs accounted for 25% (KM), 21% (TASO) and 9% (UC) of the total costs. The strikingly lower personnel costs within the UC model were likely due to the fact that some government staff providing services at UC clinics were not captured. This was one limitation regarding personnel costs

Table 3. Cost distribution across five cost components (2012)

Model		Personnel	ARV drugs	Other drugs	Laboratory	Administrative costs	Total USD
Kitovu Mobile	Total	$140,529	$260,641	$59,439	$13,150	$86,996	$560,756
	Distribution	25.1%	46.5%	10.6%	2.3%	15.5%	100%
	Per client	$101.32	$187.92	$42.85	$9.48	$62.72	$404.29
TASO	Total	$1,655,930	$3,399,418	$1,145,544	$477,737	$1,074,333	$7,752,962
	Distribution	21.4%	43.8%	14.8%	6.2%	13.9%	100%
	Per client	$72.58	$149.01	$50.21	$20.94	$47.09	$339.83
Uganda Cares	Total	$135,106	$1,007,376	$65,441	$199,366	$121,500	$1,528,789
	Distribution	8.8%	65.9%	4.3%	13.0%	7.9%	100%
	Per client	$22.72	$169.39	$11.00	$33.52	$20.43	$257.07

ARV, antiretroviral; TASO, The AIDS Support Organisation; USD, US dollars.

within the UC models and thus comparisons should be made with caution.

Other (laboratory, administrative and non-ART drugs) costs: KM spent about 15% of their total expenses on operations and overhead, 11% on non-ARV drugs and 2% on lab services. TASO's distribution of other costs was fairly similar to KM, with 15% attributed to non-ARV drugs, 14% to administrative expenses and 6% spent on lab tests. UC's distribution of other costs was much lower, with 13% of the total expenses spent on labs, 8% on operations and 4% on non-ART drugs. The differences in total ART-related costs per client per year in the three organizations are due to the differences in personnel and these other costs.

Discussion

This study generated data on ART-related costs and resources expended to provide ART to PLHIV in Uganda. We estimated cost per outpatient ART visit and average outpatient annual ART costs using routine health service data from three non-profit AIDS service organizations representing three different ART service delivery models in Uganda. These models are considered decentralized and task-shifted. Doctors or trained clinical nurses are responsible for newly initiated ART clients and critically ill cases; other tasks including drug dispensing and routine health exams are performed by nurses and expert clients. In addition, KM provides services at the community level, TASO provides services at both the facility and community level and UC provides services mainly at the facility level. Consistent with previous costing analyses [8,10,16–20], we found that ARV-related expenses accounted for a significant portion of the total ART-related cost, followed by personnel and administrative costs. In particular, ARVs accounted for nearly 50% of the total expenses for the KM and TASO models and for nearly 70% for the UC model.

Overall, the average annual cost per ART client among the three organizations ($331) was lower than previous analyses conducted in 2008 to 2009 among five PEPFAR countries (Ethiopia, Uganda, Botswana, Nigeria and Vietnam; 2009 data), in which the median annual ART cost was $800 [10]. Another systematic review of studies conducted between 2001 and 2009 found a median ART-related cost of $792 for low-income countries [21]. However, our estimated ART costs were slightly higher than a recent study using 2010 to 2011 data that showed an average cost of $208 per client (Ethiopia, Malawi, Rwanda and Zambia) [20]. Another analysis of 8500 patients from an urban ART centre in Kampala using even more recent data (2012 to 2013) showed a comparable average annual cost per client: $218 among clients on ART for the first year, $284 for clients on ART for more than one year and $431 for patients with TB co-infection [22]. The cost of ARVs has decreased since 2010 [10,13], which is likely the largest contributing factor for the lower annual ART cost in our study and a few other recent studies [13,14]. In addition, these three participating organizations have matured and may be more efficient in serving an increased number of ART clients, as suggested by previous research [13,14]. Lower ART costs suggest that future ART programmes may become even less expensive, especially with the continuing reduction of drug costs.

Another notable finding was the variety in unit costs across sites within each model and across the three models, particularly personnel and operational costs. This finding indicates that there may be potential for cost savings for future ART programmes in Uganda. The variation reflects the differences across the service delivery models as well as the different package of services provided to patients. In particular, the cost per visit was lowest at UC and KM but significantly higher at TASO. However, cost per client was lowest for UC, followed by TASO and then KM. It is important to note that KM was found to be the most expensive model regarding annual ART cost per client. It is surprising that a more decentralized model like KM costs more than less decentralized models like UC and TASO. However, this finding is likely because KM employed a large number of expert clients and had to pay for the ART mobile units to move around rural areas where KM implements its activities. In addition, on average, KM clients made 2 and 1.5 times the total number of visits made by TASO and UC clients, respectively. It is noteworthy that the convenient access and the flexibility of ART visits (even without appointments) might explain the higher number of annual visits per client at KM. In order to achieve efficiency among community-based ART models, such as KM, the number of visits per client per year need to be reduced to four times or fewer.

The distribution of costs was quite comparable between KM and TASO, which is consistent with previous study findings [8,10,13,18,20,23]. KM employed a large number of expert clients (177) for their outreach activities, resulting in personnel costs comparable to that of TASO and higher than UC's personnel costs. However, interpretation of this finding should be made cautiously because UC employs a number of staff from the government and their salary data were not fully captured in this costing data. In addition, UC also used facilities offered by the government free of charge, resulting in a much lower operational cost compared to KM and TASO and contributing to the overall lower ART cost per client for the UC model. This ultimately affects the cost distribution within the UC model. Further, even though ART expenses for UC accounted for nearly 70% of the total cost, the total UC ART cost in terms of absolute dollar value was quite comparable with KM and TASO.

Limitations

First, data for this study were collected retrospectively using routine accounting data, client visit logs, ART dispensing logs, staff payroll data and interviews; thus they were likely to have been subject to recall bias and other types of errors. Second, missing data is likely another threat to the accuracy of our estimate, particularly for the UC model. However, we excluded data from five of the nine UC clinics with excessive missing data. Recall bias and missing data are common limitations of routine programme data, especially data from local and grass-roots-level organizations. Third, although the percentage of clients on second-line ARV drugs was small (2% for KM, 2% for UC and 5% for TASO), we were not able to separate first-line and second-line ARV costs. Fourth, data were collected from only three non-profit HIV service organizations and therefore our cost estimates are likely not

representative of ART costs among patients receiving services from other health sectors or living in other parts of Uganda. Nonetheless, these data are vital for future programming, budgeting and costing analysis and will enrich the pool of available ART costing data, which will likely improve the validity of future systematic analysis.

Although ascertaining clients' ancillary and opportunity costs would have been important to complement the financial data, we were not able to collect information on costs such as time spent waiting at the clinic, transportation and other out-of-pocket payments. Because of data limitations, we did not focus on comparing the annual ART cost per client across the three organizations. Our main goal was to provide estimated ART-related costs per client and to enrich the pool of limited costing data available in Uganda and similar contexts. Nevertheless, these ART costing data yield valuable information for these three organizations and other AIDS organizations in Uganda and other low- and middle-income countries, to assist with future programme planning and budgeting. As we move towards treating everyone with HIV regardless of their CD4 count, careful budgeting is critical to ensure universal access to ART. In addition, despite these limitations, the study has demonstrated the feasibility of using existing routine data to estimate the cost per ART patient visit, while highlighting the need to strengthen the capacities of local organizations to better collect, document and use routine data.

Conclusions

Our study provides the most recent available costing data from the three largest HIV service organizations, representing three different ART service delivery models in Uganda [7]. Unit costs, cost distribution and resource utilization varied widely across the three sites and models, suggesting the potential for efficiency gains in ART service delivery. In particular, HIV programmes in Uganda may save costs by reducing the number of annual ART visits to the national standard (four ART visits a year on average). Further, non-profit organizations providing ART services, similar to these three organizations, may benefit from collaborating with the government and using government facilities to reduce operational costs. Additionally, ART is evolving rapidly with lower ARV costs and the 2015 WHO guidelines recommending treatment for all PLHIV [3]. Our findings of lower annual ART costs compared to previous analyses in Uganda and the region add value to several recent estimated ART costs, suggesting that we may be able to treat more people with the same or even fewer resources. Lastly, the collection of costing data to measure unit costs, cost-effectiveness and cost-efficiency remains critical [2,4]. ART service delivery sites in country would benefit from implementing a standardized cost data-capture tool or M&E system that allows for comparison across sites. In addition, supportive supervision is critical to ensure data quality.

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Competing interests
The authors declare that they have no conflict of interests.

Authors' contributions
LV conceived the study and had overall responsibility for writing the manuscript. SK and NJ led the larger task-shifting study that provided the costing data for this paper. LV and BZ led the data analysis. SW, LB and SO contributed to Table 2; SW and JO contributed to part of the introduction. NB drafted the abstract and provided input for Tables 2 and 3. NJ reviewed the first draft and was responsible for copy-editing. All authors reviewed and approved the final version.

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Review

Opportunities and challenges in conducting secondary analysis of HIV programmes using data from routine health information systems and personal health information

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Abstract

Introduction: HIV programme data from routine health information systems (RHIS) and personal health information (PHI) provide ample opportunities for secondary data analysis. However, these data pose unique opportunities and challenges for use in health system monitoring, along with process and impact evaluations.

Methods: Analyses focused on retrospective case reviews of four of the HIV-related studies published in this JIAS supplement. We identify specific opportunities and challenges with respect to the secondary analysis of RHIS and PHI data.

Results: Challenges working with both HIV-related RHIS and PHI included missing, inconsistent and implausible data; rapidly changing indicators; systematic differences in the utilization of services; and patient linkages over time and different data sources. Specific challenges among RHIS data included numerous registries and indicators, inconsistent data entry, gaps in data transmission, duplicate registry of information, numerator-denominator incompatibility and infrequent use of data for decision-making. Challenges specific to PHI included the time burden for busy providers, the culture of lax charting, overflowing archives for paper charts and infrequent chart review.

Conclusions: Many of the challenges that undermine effective use of RHIS and PHI data for analyses are related to the processes and context of collecting the data, excessive data requirements, lack of knowledge of the purpose of data and the limited use of data among those generating the data. Recommendations include simplifying data sources, analysis and reporting; conducting systematic data quality audits; enhancing the use of data for decision-making; promoting routine chart review linked with simple patient tracking systems; and encouraging open access to RHIS and PHI data for increased use.

Keywords: secondary data analysis; health information systems; personal health information; electronic medical records; data accuracy; missing data; data analysis.

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Introduction

Massive amounts of data have been collected in low- and middle-income countries for HIV programmes over the past several decades. Complex data collection requirements have come from donors, multilateral organizations and ministries of health to monitor their substantial HIV investments [1,2]. To calculate an array of HIV-related tracking indicators, groups have used data from routine health information systems (RHIS), personal health information (PHI), community sample surveys, demographic surveillance sites and special studies.

In this context, RHIS and PHI data provide ample opportunities for secondary data analysis. RHIS data typically come from monthly reports generated at health facilities derived from service-specific registry books. These data are capable of providing accurate, reliable, timely, representative and continuous information on the health system and patients in the system [3–5]. They can be real-time indicators of service coverage and quality, and the numerous repeated observations over extended periods of time can provide robust data for secondary analysis, including quasi-experimental designs, such as controlled interrupted time-series analysis, which provide strong inferences of causality in measuring the impact of programme and policy changes. These facility-level data can also provide knowledge of geographic variation – highlighted as important for focusing on the UNAIDS agenda to ''leave no-one behind'' [6], the World Health Organization (WHO) guidelines for the expansion of antiretroviral therapy (ART) [7] and the PEPFAR 3.0 objectives of doing the ''right thing, right place right time'' [8].

PHI typically includes facility-based patient charts that are either paper-based or electronic medical records (EMR), personal pharmacy pick-up records and/or home-based booklets (e.g. mother-child health booklets). Paper charts remain the mainstay for most patient information; EMR systems are usually managed by international implementing partners and harmonized across countries in which a partner works [9]. EMR data are increasingly used for longitudinal studies that examine enrolment and retention in HIV care [10].

Secondary data represent the low hanging fruit for cost-effective programme evaluation for improving the quality of HIV services. When RHIS and PHI are available and accurate, expensive data collection to assess health system performance can be avoided [11–13]. Furthermore, RHIS and PHI can enable making inferences at the health facility level, in contrast to most intermittent sample surveys, special studies or demographic surveillance sites which most often are not powered to be actionable below the provincial level. RHIS and PHI can be used to guide decision-making at national and sub-national levels, yet problems with accuracy and completeness of the data often undermine their usefulness [14]. Case studies of poor RHIS data are widespread and the use of RHIS is frequently disparaged [15–17]. However, many studies have shown that rapid and relatively low-cost methods of improving data completeness and reliability are highly effective [3,4,18–23].

The aim of this paper is to review the accuracy of RHIS and PHI data collected and used in four studies of the HIVCore project, all published in this JIAS supplement. We believe that these studies, each carried out in a different country, provide a broad spectrum of experiences using RHIS and PHI for secondary data analysis. Our objective is to identify key challenges regarding their use and to identify ways to address those challenges going forward, contextualized in the broader literature [24–28].

Methods

The studies reviewed in this article were conducted across four countries between 2012 and 2015. All of the countries have a substantive PEPFAR presence that includes large international NGO implementing partners and heavy data reporting requirements – a situation that is common in PEFAR-supported countries in sub-Saharan Africa. Each of the studies was conducted with support of the implementing partners. The authors independently reviewed each of the studies and used consensus decision-making to identify themes to achieve a unifying analysis of the studies. Communication was carried out through iterative phone calls, emails and sharing of manuscript drafts.

1) **Prevention of mother-to-child transmission (PMTCT) cascade assessment in Cote d'Ivoire** [24] identified loss to follow-up and associated factors in the Côte d'Ivoire PMTCT programme, using a nationally representative, cross-sectional sample of 30 randomly selected health facilities providing PMTCT. The quantitative aspect of the study assessed 13 indicators from PMTCT-related registries and patient charts to determine the magnitude of loss to follow-up among 1741 HIV-positive women at multiple steps in the PMTCT cascade and compared high- and low-performing sites to identify factors associated with differences in PMTCT performance.
2) **PMTCT retention assessment in Rwanda** [25] investigated levels of retention along the PMTCT cascade among HIV-positive pregnant women and their infants attending EGPAF-supported health facilities using a retrospective cohort analysis among 474 women in 12 health facilities. Data were linked from ANC, PMTCT, labor and delivery, HIV Exposed Infants, postnatal care, ART and Exposed Infant Diagnosis registers.
3) **Task shifting and ART retention in Uganda – cost analyses** [26,27] analyzed annual ART-related costs among the three large AIDS organizations, each representing a task-shifting model. The study team collected cost information regarding ARV drugs, non-ARV drugs, ART-related lab tests, personnel and administrative costs. Data for the analysis came from patient charts and included the client's date of initiation of ART and ARV refill visits to determine attendance and retention.
4) **Assessment of linkages from HIV testing to enrolment and retention in care in central Mozambique** [28] assessed enrolment and retention of HIV-positive individuals through assessment of HIV registries at 87 health facilities in Central Mozambique, and review of 795 patient charts of HIV patients conducted at eight health facilities offering ART. Quantitative data were abstracted from facility monthly reports, HIV registries and patient charts, and adjusted to account for missing and inconsistent values to measure losses to follow-up. ART registries were linked to patient charts via unique patient codes. No unique patient codes were used for HIV testing.

Results

The authors identified several general themes during the analysis of the studies, including missing, inconsistent and implausible data; changing indicators; differential utilization of services; and data linkages.

Incomplete, missing and implausible data

This was by far the most common challenge encountered in all of these studies, both in RHIS and PHI. Incomplete RHIS included missing monthly reports or implausible data in the submitted reports or in the registries on which the monthly reports were based. Incomplete PHI included key information regarding demographics, initiation of treatment, clinic visits, CD4 counts, date of birth and infant information among PMTCT patients. Examples of incomplete, missing and implausible data are described for each study as follows:

The Cote d'Ivoire PMTCT study noted that missing data were widespread in the entire national reported sample. For the 11 registry indicators that were assessed to evaluate the PMTCT cascade, 24 of the 30 study sites had one or more months with no data during the 12-month study period. In addition, PMTCT registries, ART registries and patient charts were incorrectly filled out at 10, 9 and 14 sites, respectively, out of the 30 total sites. The study team found large variability in data completeness from different sites. Moreover, there were major inconsistencies in similar indicators from different sources. For example, the recorded proportion of women tested for HIV was much less in the mother-child vaccination booklets (84%) than in PMTCT testing registries (95%) at the same sites. In addition, at every site, on-site registry indicators were inconsistent with the same indicators in the national database. On average, more than half of all indicators compared had a discrepancy of larger than 5% between on-site data and the same data in the national database. The data

quality and burden of having too many indicators in multiple registries was highlighted as a key finding of the study. In spite of the data weaknesses, authors were able to triangulate data from multiple sources to attain usable estimates for the study analysis.

The Rwanda PMTCT study demonstrated similar challenges with missing key data. The type of regimen was unknown for 20% of the women on ARV. For the infants, 38% of infant files were not found. Among the patient charts, the type of regimen was unknown for nearly half of the women who were reported to be on lifelong ART. In the maternity, postnatal care and HIV-exposed infant registries were used to link the mother-baby pairs. Many of the infant records were missing information, including place of delivery (40% missing), mode of delivery (70% missing) and gender (58% missing).

The Uganda study excluded four of 29 health facilities from one of the three samples because of missing and implausible data. Two additional AIDS service organizations were excluded whose data were inadequate for comparison after data cleaning. Study teams noted frequent duplicate entries of data, dates entered in incorrect formats, including visits falling outside the eligible enrolment period and mismatched site codes. Implausible client histories showed that clients received, in the aggregate, over 125% of ART drugs based on their follow-up period. Many errors necessitated the exclusion of records from the final analysis. In two sites, 78% of all collected client histories failed to meet one of four essential criteria for adherence and only 67 of 304 patient histories were sufficiently complete for analysis for the study. As with other studies, missing data were highly variable among indicators: 64% of all unique client histories were missing drug delivery numbers, regimen information or both; and 92% of all unique client histories were missing one or more scheduled appointment dates. Moreover, large variability in missingness was found between sites.

The Mozambique HIV linkages study demonstrated that missing data and data inconsistencies were common in all stages of the treatment cascade, including testing, enrolment and retention in treatment. Over 46% of the 1944 monthly HIV testing reports expected from the health facilities were missing from the national RHIS. Most HIV testing reports submitted did not report from more than several of the 13 clinical programmes where HIV testing might have occurred. Registration in pre-ART care was more reliably reported; less than 5% of these monthly reports were missing. The much lower missingness among numerators (pre-ART registration) than denominators (HIV testing) caused a large overestimate of the likely true proportion of people tested HIV positive who were enrolled in pre-ART. After the authors imputed data from non-missing months to estimate the missing months, the overall estimated proportion of people tested HIV positive registered in pre-ART dropped from 97 to 75%.

Another challenge from the Mozambique HIV linkages study was that registration in pre-ART care did not necessarily imply enrolment in HIV care. Although patient charts were required for all people that tested HIV positive who registered in care, charts were found in only 66 and 60%, respectively, of patients who had been registered in ART and pre-ART – with a large variation among facilities (41–92% of ART charts found). Patient charts and pharmacy records inconsistently recorded individual patient visits. Only 37% of patient charts that were found demonstrated evidence of active retention. Given the losses in all steps of the ART cascade, the total retention of people tested HIV positive identified in the system was only 18% in a sample whose mean time in treatment was 18 months – when the published national 12-month retention rate over the same period was 67% [29].

Changing measurements and indicators

HIV indicators have frequently evolved to align with changing norms of prevention, diagnosis and treatment. These changing indicators have made conducting time-series analyses difficult. For example, in both the Mozambique and Cote d'Ivoire studies, the proportion of infants who received polymerase chain reaction (PCR) testing had been measured against the number of infants of HIV-positive mothers who had been registered in care. When PEPFAR changed denominators to measure infant PCR testing against all HIV-positive mothers, the proportion of infants PCR tested dropped by nearly half. Different numerator variables for HIV testing in antenatal care gave quite different results when measured against the same denominator (first antenatal visits). When the numerator included all HIV tests in antenatal care, the aggregate reported proportion of women tested exceeded 105%. When the numerator was limited to HIV tests done among women attending first or second antenatal visits, the reported proportion of women tested dropped to 89%.

The proportion of patients retained in ART has been especially difficult to assess due to constantly changing criteria for retention. Different sources of data (patient charts, pharmacy records and/or community outreach registries) change frequently – and different recording systems report different retention rates. Since 2013, PEPFAR partners have measured retention in ART by calculating the percent of adults and children known to be alive and on treatment 12 months after initiation of ART. In both Mozambique and Cote d'Ivoire, the number of people who initiated ART in the 12 months prior to the beginning of the reporting period frequently does not correspond to the reports of the same indicator in the previous year report, usually increasing the reported proportion of people retained in ART.

Differential utilization and patterns of services

The Mozambique linkages study reported two urban districts with a high proportion of patients lost to ART follow-up, some of whom might have simply changed their care to one of the other ART facilities in the same city. Such unrecorded transfers are more likely in urban than in rural areas; thus, the divergence of reported retention from true retention may be greater in urban areas. Transfer rates were reported to be as high as 20% in one urban facility in the Mozambique study, but rare in rural facilities. When transfers are not accounted for in ART retention calculations, reported retention rates may underestimate the true retention.

The Cote d'Ivoire PMTCT study data suggested that proportions of women who were tested for HIV in private health facilities were substantially lower than in government facilities. Although some of the larger private facilities report to the national system, many of the smaller private facilities

do not routinely report. It is possible that pregnant women who elect not to be HIV tested simply attend these private clinics for their first visits to ''opt out.'' If this is true, our reported HIV testing proportions may be substantially overestimated, especially in urban areas where there are higher numbers of private clinics.

Linkage of data

In the Uganda and Rwanda studies, multiple registries across different HIV services or health facilities made it difficult to link individual patient entries among the registries, or to track outcomes of mother-baby pairs. Occasionally, unique patient identification numbers link data sources. In other cases, it has been difficult to link records given the number of patients with similar names. In Mozambique, because patient codes were different among those who tested HIV positive and those who registered in HIV care, no direct linkages regarding HIV patient follow-up, including transfers, could be made. The Rwanda study highlighted the limitation in tracking each mother-baby pair and mothers from ANC to labour and delivery and into postpartum care, as delivery often took place in a different facility. Key information often was not recorded in a patient chart, forcing health workers (or study teams) to search registries for critical information pertaining to that patient.

Other considerations

Time gaps between numerators and denominators were frequently seen in Cote d'Ivoire and Mozambique. Late entries of laboratory tests received after the reporting period when the patient was counted may have underestimated the true proportion of laboratory tests performed in HIV services. Challenges archiving paper-based charts likely contributed to underestimates of patient retention in both Mozambique and Cote d'Ivoire. Storage units were rare, and filing cabinets were overflowing with charts, making it difficult to find charts during the study team visits. Routine review of either paper-based and EMR records was infrequently documented.

Table 1 below summarizes some of the challenges encountered in these analyses of secondary data. Many challenges and their causes are similar for both RHIS and PHI.

Discussion

Many of the challenges that undermine the effective use of both RHIS and PHI were related to the processes and context of data collection. The many duplicative and unlinked registries, multiplicity and changing of indicators and the poor integration of data collection systems across different programmes, all contributed to weak data. Other contributors included the lack of accountability for data quality at facility levels, the substantial burden on health workers to collect and analyze the data, the weak transmission of data upward through health systems and the limited review or use of data for decision-making and policy.

These problems were remarkably consistent among all four countries – countries that represent Anglophone, Francophone and Lusophone cultures and approaches to health care. Their experiences with the burdens and challenges of data collection and analysis are likely generalizable to other countries, especially to those that report on PEPFAR indicators.

Indicators for HIV/AIDS programme tracking, monitoring and evaluation change for numerous, often important, reasons. Multiple stakeholders, with the best of intentions, periodically develop newer and better data collection registers and forms, typically resulting in more indicators added than subtracted. Donors and partners engaged in vertical programmes, operating across many countries, can be relatively blind to other programmes or to the overall RHIS and PHI needs at health facility levels. PEPFAR alone has over 500 indicators for HIV programmes, many of which are supposed to be collected monthly for every health facility. It is no surprise that large numbers of data fields are incomplete in these settings. Over-worked health workers might understandably place less value on accuracy than the recipients of the data, particularly where the use and utility of these data is unclear or unknown by the health care worker who is collecting the data. Reporting is still seen as externally imposed in most places and understanding of the value of data to service delivery is often not clear.

Our review has led to a number of key recommendations for HIV/AIDS data systems going forward. First, data sources, analysis and reporting should be simplified. This will mean fewer indicators, registries and reports – a recommendation

Table 1. Illustrative challenges related to recording and use of secondary data from routine health information systems (RHIS) and personal health information (PHI)

Challenges of recording and using RHIS	Challenges of recording and using PHI (paper charts and EMR)
Excessive registries, indicators, and time burden on health workers	Time burden on providers who fill out (or don't fill out) charts
Inconsistent data entry by multiple people	Culture of lax charting
Limited accountability for quality of registering	Limited accountability for quality of charting
Registry of information in two or more books	Duplicate registry of information by providers
Unlinked information among registries	Unlinked information across registries and charts
Inadequate archives for registry books	Inadequate archives for paper charts
Infrequent data use for decision-making and analysis at facilities and districts	Infrequent chart review for improvement of patient care
Infrequent sharing of data to cross-check	Infrequent EMR maintenance
Infrequent data quality assurance checks	Infrequent data quality assurance checks
Numerator–denominator incompatibility	
Differential patterns of utilization	

that the WHO highlighted in their 2015 *Consolidated Strategic Information Guidelines for HIV in the Health Sector* [30]. The WHO has advocated for only 10 global indicators and a total of 50 targeted indicators at the national level. Achieving this would require stakeholders involved in different programmes to spend substantial time together coordinating indicators, with an eye on the diverse demands of health facility staff, and to work out broad-based RHIS and EMR that can function across programmes and settings. Furthermore, all stakeholders should work to minimize frequent changes to established indicators. When indicators are changed, those enacting changes should clearly describe how these changes might impact the continuity of tracking key indicators over time – or provide guidance on how to maintain optimal indicator continuity.

Second, collaborative RHIS data audits should be built into the overall system to determine the magnitude of data reporting failure, guide site-specific improvements in data management and involve those who generate facility-level data in understanding their own data. Data quality audits and participatory data-use interventions have been carried out across many countries with proven success – not only improving accuracy and completeness of RHIS and PHI, but also enhancing the value and use of data for quality improvement [31,32]. Routine data review meetings, patient chart review and use of data dashboards have been shown to be effective to increase data quality, ownership and use of data for decision-making [33,34]. Major efforts have been carried out in many countries to improve district- and facility-level data, including implanting open source software for district health information systems (DHIS2) [35–39]. However, systems such as DHIS2 have only been effectively nationalized in a few countries [40]. More often, DHIS2 has been implemented at sub-national levels with the support of donors and NGOs, without strong support from the central Ministry level [41]. It is unclear if innovative approaches that are primarily implemented by external entities will solve the fundamental issues we identified, especially the excessive indicators, ability to link data, lack of involvement of health staff in data use and quality assurance data generated at the facility level. Without central Ministry of Health coordination, the issues we highlighted above around linkages of data may only be exacerbated by a patchwork of data systems and indicators across clinics or districts. All stakeholders – national policymakers, facility staff, district and provincial managers, funders and implementing partners – should ensure substantial HIV-related funds are dedicated to ensuring that these data-related activities are seen as an essential element of the overall Primary Health Care system.

Last, RHIS and PHI generated by government, donors and partners should be widely accessible, and where possible, open source, to ensure that the data are consistent, reviewed and appropriately analyzed by all stakeholders to drive data-driven decision-making. As these data are often the only data sources which are actionable at the district and health facility levels, increased investments in these systems are necessary for quality improvement. The current situation, whereby RHIS and PHI are not openly available for secondary analyses, limits their use and continues the status quo whereby most analyses use infrequent community surveys, which fail to provide health facility or district data where action is needed. It has been demonstrated that RHIS data can be paired with community surveys or other HIV-related data sources to estimate who is currently being missed by targeted facility-based ART delivery [30]. Innovative efforts to improve health facility catchment area estimation can also help target investments to areas with high HIV burden and low ART coverage [31]. With increased access, such methods to pair RHIS and PHI data with community sample surveys and/or census data could also help understand which areas of the health system are failing to reach a representative sample of those testing HIV positive.

Conclusions

RHIS and PHI data provide substantial opportunities for investigators, health workers and policymakers to understand health service coverage and use data for real-time health system decision-making. However, the poor and/or variable data quality of RHIS and PHI, along with frequent changes in indicators, difficulties in linking individual-level data over time and data sources, and differential service utilization, all present considerable challenges for analysis and use of these data to improve HIV programmes. Based on our review, we recommend concerted efforts by all stakeholders to simplify indicators, routine reporting and data collection efforts along with focused efforts to maintain key indicators unchanged over time to allow easy monitoring of programme success or failure. These simplified data sources should undergo routine data quality audits and chart reviews, paired with the explicit engagement of health workers and managers in the use of data for analysis and decision-making. With these investments, and the continued expansion of data availability through the open-access movement, RHIS and PHI data will be more widely available and useful for high-quality monitoring and evaluation of HIV-related programmes at the health facility, district, national, and international policymaker levels.

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None

Authors' contributions
SG conceived and wrote the first draft of the manuscript. SG and BHW revised and finalized this manuscript. SK and GW contributed data, reviewed and commented on this manuscript. All authors have read and approved the final version.

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Commentary

Experiences in implementation and publication of operations research interventions: gaps and a way forward

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Abstract

Introduction: According to UNAIDS, the world currently has an adequate collection of proven HIV prevention, treatment and diagnostic tools, which, if scaled up, can lay the foundation for ending the AIDS epidemic. HIV operations research (OR) tests and promotes the use of interventions that can increase the demand for and supply of these tools. However, current publications of OR mainly focus on outcomes, leaving gaps in reporting of intervention characteristics, which are essential to address for the utilization of OR findings. This has prompted WHO and other international public health agencies to issue reporting requirements for OR studies. The objective of this commentary is to review experiences in HIV OR intervention design, implementation, process data collection and publication in order to identify gaps, contribute to the body of knowledge and propose a way forward to improve the focus on ''implementation'' in implementation research.

Discussion: Interventions in OR, like ordinary service delivery programmes, are subject to the programme cycle, which continually uses insights from implementation and the local context to modify service delivery modalities. Given that some of these modifications in the intervention may influence study outcomes, the documentation of process data becomes vital in OR. However, a key challenge is that study resources tend to be skewed towards documentation and the reporting of study outcomes to the detriment of process data, even though process data is vital for understanding factors influencing the outcomes.

Conclusions: Interventions in OR should be viewed using the lens of programme evaluation, which includes formative assessment (to determine concept and design), followed by process evaluation (to monitor inputs and outputs) and effectiveness evaluation (to assess outcomes and effectiveness). Study resources should be equitably used between process evaluation and outcome measurement to facilitate inclusion of data about fidelity and dose in publications in order to enable explanation of the relationship between dosing and study outcomes for purposes of scaling up and further refinement through research.

Keywords: operations research; implementation research; intervention fidelity; process evaluation; intervention publication.

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Introduction

HIV operations research (OR) has been defined as a process of identifying and solving programme problems with the goal of increasing the efficiency, effectiveness, quality, availability, accessibility and acceptability of services [1]. In 2008, The Global Fund to Fight AIDS, Tuberculosis and Malaria, United States Agency for International Development (USAID), World Health Organization (WHO), Joint United Nations Programme on HIV/AIDS (UNAIDS) and the World Bank published a framework for HIV operations and implementation research [2]. That publication states that OR represents implementation research and is defined as any research producing practically usable knowledge that can improve programme implementation regardless of the type of research design, methodology or approach.

Building on this definition, PEPFAR's implementation science (IS) framework describes IS as the study of methods to improve the uptake, implementation and translation of research findings into routine and common practices [3]. Thus, although terminology referring to implementation or OR may vary depending on the context, the main intent is to examine health systems management and sociocultural, economic and behavioural factors that either exist as bottlenecks or that could be tested to improve service delivery and uptake [2].

According to UNAIDS, the world currently has a good collection of proven HIV prevention, treatment and diagnostic tools, which, if scaled up, can lay the foundation for ending the AIDS epidemic [4]. The effectiveness of these tools is often dependent on a number of operational issues on the demand side (e.g., the health care-seeking behaviour of the target audience and sociocultural and contextual barriers) and the supply side (e.g., setting, providers and supplies) [5]. For example, to ensure the efficient use of HIV-testing, operational issues can be addressed by evaluating various HIV-testing approaches, such as routine testing versus voluntary testing, and the outcomes can vary according to purpose and target population [6,7].

Given the need to enhance effectiveness of a broad range of tools in a variety of contexts, OR uses a wide range of methodologies, often making it difficult to have uniform reporting in publications. As a way of addressing this challenge, the *Bulletin of the World Health Organization* established guidelines for reporting on OR, which include intervention frequency, duration and intensity [8]. Similarly, the UK Medical Research Council recently published guidance on conducting and reporting on studies testing public health interventions, recommending that studies provide data on intervention implementation, including provider training, fidelity, dose and adaptation [9].

However, the collection and reporting of process data may sometimes be seen as being in conflict with or a duplication of efforts to measure outcomes [9]. One approach that can ensure that the focus owed to intervention implementation is not lost is to view the study using the lens of programme evaluation, which includes formative assessment (to determine concept and design), followed by process evaluation (to monitor inputs and outputs) and effectiveness evaluation (to assess outcomes and effectiveness) [10]. Indeed, if researchers anticipate analyzing outcome data stratified by intervention exposure, they should pay more attention to how intervention process data is collected and reported [11].

The objective of this commentary is to review experiences in HIV OR intervention design, implementation, process data collection and publication in order to identify gaps, contribute to the body of knowledge and propose a way forward for improving the focus on ''implementation'' in implementation research. The purpose is to emphasize the need to devote as much time and resources to the intervention as are given to outcome measurement.

Discussion

Formative research

Given the diversity of the context in which real-life public health interventions are applied, it is important not to transfer interventions from one setting to another without adaptation based on formative research [12]. Formative research is usually carried out using qualitative methodologies among potential service recipients, potential providers and other stakeholders, as well as a review of retrospective statistics and epidemiological and behavioural data.

Formative research enables understanding of the nature of the problem and the programme responses to address it [1,13,14] and determination of the priority target population [15,16], as well as assessing their needs and perceptions regarding the problem and the proposed intervention. Formative research also fosters an understanding of how the new intervention will be introduced into existing services [6,17,18], the potential role of various actors in delivering the intervention and additional elements required for the intervention [19].

Piloting the intervention

Pilot testing is a key component of intervention design in HIV OR because it enables the determination of the feasibility of the intervention and its acceptability to providers and clients, thus facilitating adaptation.

To start, a cross-section of providers and clients can be asked to comment on the intervention materials. Next, the service should be offered on a small scale to obtain provider and client feedback [14]. There is also a need to be flexible and open-minded to accommodate contextual issues, including resource constraints while, at the same time, ensuring that the core elements of the intervention are retained [17]. Although the retention of core elements is vital to ensure that the intervention can be replicated and scaled up in other settings [20], there is always a tension between the need for standardization of the intervention versus the need to be flexible and adapt the intervention based on findings from pilot testing [17].

Integration and training

When conducting OR, systematic efforts are required to ensure that new interventions are tailored to the realities of local settings [21] and ensure acceptance by existing providers [22]. This process could involve meetings with government authorities, managers, providers and other stakeholders to create awareness and ownership of the planned OR, work out operational issues and clarify roles among the providers [3,23–25].

In addition, the integration of a new intervention must involve training the existing providers in the delivery of the intervention according to procedures and curricula developed or adapted using formative findings [21,26]. After the study is completed, intervention training manuals, as well as videos and other written materials, should be finalized and made accessible to policy makers, programme developers and researchers [27].

In a systematic review of integration of sexual and reproductive health and HIV services, it was reported that integration showed positive effects on HIV incidence, sexually transmitted infections incidence, condom use, the uptake of HIV testing and quality of services. Facilitating factors included stakeholder involvement, capacity building and positive staff attitudes. Inhibiting factors included lack of stakeholder commitment and inadequate staff training, thus highlighting gaps in stakeholder engagement and staff training [28].

Intervention dose

Using inputs from formative research, pilot testing and the process of integration, the ''dose'' of the intervention, such as the number of counselling sessions, may be developed or refined. In addition, standard operating procedures (SOPs) of service delivery are developed to ensure that the intervention is delivered as planned [14,19,29]. Low-intervention exposure has been proposed as one of the reasons for ''flat'' results in intervention trials despite a strong theoretical basis for the potential impact of an intervention [3,29,30]. Thus, it becomes important that studies accurately report intervention exposure. Owing to inconsistency in the reporting of intervention doses, a group of authors have proposed a standardized terminology for intervention dosing, including duration, frequency and amount, that should be used for reporting [27].

In a meta-analytic review of 19 studies of highly active antiretroviral therapy (HAART) adherence interventions, the

number of intervention sessions and their durations varied widely. However, even though overall the interventions were effective in increasing adherence and reducing viral load, there was no difference in outcome by dose [31]. A review of 24 antiretroviral therapy (ART) adherence studies of the interventions also showed an overall positive effect on self-reported adherence, but no variation by duration of exposure. These reviewers were disappointed that the authors did not publish sufficient information about intervention characteristics to enable further exploration of factors beyond duration of exposure [32].

A similar finding was observable in a meta-analysis evaluating the efficacy of HIV behavioural interventions among African-American women, in which it was noted that the efficacy did not differ by the number of sessions. The authors suggested that the success of such interventions may depend more on the intervention components and quality than on the number of sessions [33]. However, in one study among HIV-positive women, it was observed that women who attended eight or more sessions of the intervention reported higher ART adherence [34]. Thus, gaps in reporting of intervention characteristics make it difficult to meaningfully assess the role of the intervention dose and other factors in the outcomes observed. Such an assessment requires detailed process data because the intervention dose may be affected by a multiplicity of aspects. This includes internal factors, such as fidelity, as well as external factors in the target community and beyond, among them an enabling environment and such issues as the weather, politics or population migrations [35].

Uptake and coverage

Though the ultimate purpose of OR may be to determine the outcome of the intervention, it is important that process data is collected to determine the proportion of the targeted population that used the intervention. If the study is measuring outcomes of the intervention among clients receiving a clinic service, the proportion of clients who partook of the intervention among those who attended the clinic could serve as a good measure of intervention uptake and reach [19]. However, if the study is interested in community-level impact, coverage would be a more appropriate measure, and it could be assessed against a denominator of the estimated size of the target population, such as the number of drug users in a city [36] or the number of HIV-positive pregnant women in a district [6].

Fidelity

Fidelity is the extent to which the provider delivers the intervention according to the set SOPs. Fidelity can be measured using client interaction forms[31,32], observation of selected client provider interaction sessions [14], interviews of providers and clients and the use of mystery clients.

In a behavioural programme targeting young people, fidelity was measured using a telephone survey of providers. The results showed varying levels of fidelity. Time constraints were commonly cited as reasons for dropping core elements [37]. In one study of a clinician-delivered HIV risk-reduction intervention, fidelity was measured through clinician self-reports and client exit interviews; it was observed that there was a convergence of opinion between clinicians and patients that only 73% of the intervention was delivered. Other pressing medical priorities are the main explanation for the failure to deliver 100% of the intervention. In spite of the less-than-perfect fidelity, the intervention was effective in reducing high-risk sexual behaviour [22].

In a systematic review of HIV-prevention interventions for young people, most of which were delivered by either teachers, peers or media, no positive effects of the intervention were observed. This was attributed to implementation barriers, including disorganized school schedules and the reluctance of teachers to discuss condoms. The authors recommended devoting more effort to studying implementation difficulties and the determinants of exposure to intervention [11].

Indeed, positive attitudes of providers are important to ensure fidelity. In an evaluation of the factors affecting fidelity in a school HIV education intervention, it was observed that teachers' comfort with the HIV curriculum was the most important predictor of fidelity to the programme [38]. When assessing the rollout of evidence-based HIV prevention interventions, it was observed that the main factors hindering fidelity were a lack of adequate funding, staff and other resources [35,39]. In one study evaluating antenatal care counselling, 203 counselling sessions were observed, and it was reported that counselling sessions were shorter and conveyed fewer messages than required in the SOPs of the intervention [24], emphasizing the need to assess what was delivered versus what was supposed to be delivered [27].

Conclusions

Interventions in OR, like ordinary service delivery programmes, are subject to the programme cycle, which continually uses insights from implementation and from the local context to modify service delivery modalities. Given that some of these modifications in the intervention may influence study outcomes, the documentation of process data becomes vital for understanding factors influencing the outcomes. However, a key issue is that study resources appear to be skewed towards the measurement of baseline and end-line, often relying on the use of routine service delivery statistics for process data [17]. It is also a reality that service delivery in low-resourced settings is plagued by the endemic lack of adequate funding, staff and other resources [5,39,35], resulting in serious gaps in routine data making the data difficult to use in research [40]. OR study protocols should include plans and budgets for process data collection, in addition to baseline and end-line surveys, and not rely only on service delivery statistics [16].

Since the purpose of OR is to test and roll out interventions that enhance the efficient use of proven tools for HIV prevention (e.g., condoms), treatment (e.g., ARVs) and diagnosis (e.g., HIV tests), it is incumbent upon the research team to document and publish the processes and materials used in implementation. This will help answer the questions: ''If it worked, what worked?'' and ''How can it be replicated?'' Intervention materials are an important legacy of a good OR study. Mechanisms for accessing these materials, preferably via the Internet, should be clearly stated in the outcome publication of such a study.

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Competing interests
All the authors are investigators on various operations research and programme evaluation studies under the USAID-funded HIVCore project. All the authors declare interest in ensuring that operations research studies have well-documented intervention development processes.

Authors' contributions
SK wrote the first draft of the paper. The rest of the authors reviewed the various drafts and gave inputs, and SK collated their inputs and produced subsequent drafts of the paper. All authors have read and approved the final version.

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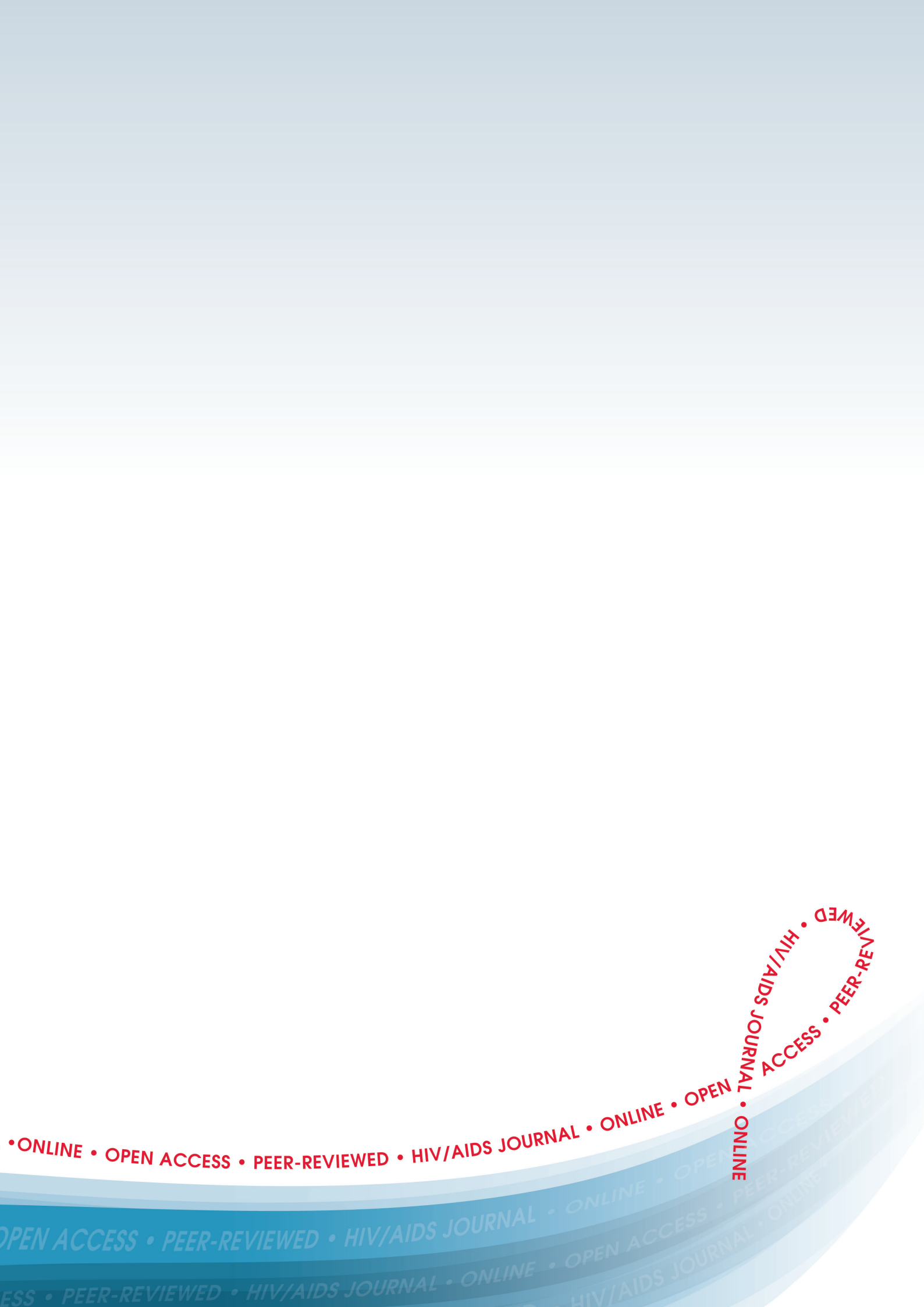
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