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Need for improvements in clinical practice to retain patients in pre-antiretroviral therapy care: data from rural clinics in North West Province

Jennifer Gilvydis, MPH¹, Wayne T. Steward, PhD, MPH², Parya Saberi, PharmD, MAS², John Tumbo, MD³, Jeri Sumitani, MMSc, PA-C⁴, Scott Barnhart, MD, MPH², and Sheri A Lippman, PhD, MPH²

¹University of Washington, Department of Global Health, International Training and Education Center for Health (I-TECH)

²University of California, San Francisco, Center for AIDS Prevention Studies, Department of Medicine

Correspondence concerning this article should be addressed to J. Gilvydis, jay@globalactionconsulting.com.

Name	Contact Details
Jennifer Gilvydis	Box 359932 Seattle, WA 98104 USA Phone: 206.685.8466 jay@globalactionconsulting.com
Wayne T. Steward	UCSF Mail Code 0886 550 16 th Street, 3 rd Floor San Francisco, CA 94158 USA (415) 476-6372 Wayne.Steward@ucsf.edu
Parya Saberi	UCSF Mail Code 0886 550 16 th Street, 3 rd Floor San Francisco, CA 94158 USA Parya.saberi@ucsf.edu
John Tumbo	P.O. Box 222, Medunsa, Republic of South Africa, 0204 27-082-885-8332 tumbo@lantic.net
Jeri Sumitani	232 Bronkhorst Street 203 Optiplan House Nieuw Muckleneuk Pretoria, Republic of South Africa 0181 27-012-433-0100 jsumitani@itech-southafrica.org
Scott Barnhart	Box 359932 Seattle, WA 98104 Phone: 206.685.8466 sbht@uw.edu
Sheri Lippman	UCSF Mail Code 0886 550 16 th Street, 3 rd Floor San Francisco, CA 94158 USA (415) 597-9271 sheri.lippman@ucsf.edu

³University of Limpopo - Medical University of Southern Africa campus, Department of Family Medicine and Primary Health Care

⁴University of Washington, International Training and Education Center for Health, South Africa

Abstract

We examined current challenges with patient engagement in HIV prevention and care in South Africa by assessing the procedures of eight public health clinics in the North West Province. Procedures consisted of (1) an inventory/audit of the HIV Counseling and Testing (HCT), pre-antiretroviral therapy (pre-ART) and antiretroviral therapy (ART) patient registers; (2) extraction of data from a convenience sample of 39 HIV-positive patient files; and (3) thirteen key informant interviews with clinic staff to characterize retention and re-engagement practices for patients. Incomplete registers revealed little evidence of follow-up services, particularly for pre-ART patients. The more detailed examination of patient files indicated substantial disparities in the proportion of pre-ART versus ART patients retained in care. Key informant interviews contextualized the data, with providers describing multiple procedures for tracking and ensuring service delivery for ART patients and fewer procedures to retain pre-ART patients. These findings suggest that enhanced strategies are needed for ensuring continued engagement in HIV care, with a particular emphasis on improving the retention of pre-ART patients. The preventive benefits of ART scale-up may not be achieved if improvements are not made in the proportion of earlier-stage HIV-positive patients who are successfully engaged in care.

Keywords

Retention in care; Lost to follow-up; Pre-ART; ART; South Africa

Introduction

Despite the South African Government's efforts to expand HIV treatment, there remain nationwide challenges along the HIV care continuum, including HIV diagnosis, linkage to care, retention and engagement in care, and viral suppression. Among South Africa's 6.4 million people infected with HIV, only 37.8% of men and 55% of women are estimated to know their status (Shisana et al., 2014). Approximately 35% of the population has never tested (Global Report: UNAIDS report on the global AIDS epidemic 2012, 2012). After screening HIV-positive, a large percentage of patients are lost to follow-up, with only half of those known to be HIV-positive having obtained CD4 testing (Losina et al., 2010). Among HIV-positive clients eligible for the national antiretroviral therapy (ART) program (i.e., CD4 ≥ 350 cells/mm³; pregnant; WHO clinical stage of 3 or 4; or TB co-infected (NDOH, 2010)), 80% are estimated to be receiving care (Global update on HIV treatment 2013: results, impact, and opportunities, 2013). This suggests that a large percentage of those currently out of care are individuals with earlier stages of the disease, not yet eligible for the ART program (pre-ART). Loss to follow-up in this pre-ART population will result in detrimental health and financial consequences associated with late engagement in care (Bakhao et al., 2009), as well as new infections that could be offset if patients were placed on ART and virally suppressed when first ART eligible (Cohen et al., 2011).

As part of longer-term research to develop interventions to improve retention in care in South Africa, we assessed clinic procedures to monitor and ensure continued patient engagement in HIV prevention and care services.

Methods

We visited eight rural, nurse-led primary health clinics to assess clinic procedures for retention in HIV care. Clinics were purposively selected by the Department of Health to provide diversity in numbers of providers, clients served, and population density of the surrounding area. We employed three discrete approaches to understand clinic procedures. First, we conducted an audit of clinic HIV Counseling and Testing (HCT), pre-ART, and ART patient registers. The registers consist of pre-printed tables with column headings (identifiers, dates, results, etc...) for data entry and a row of data for each unique patient to track patient services. The HCT register captures date of service, HIV test result, and referrals made. The pre-ART register records date and result of initial CD4 testing, and documents subsequent CD4 test results until ART-eligible. The ART register tracks medication appointments and routine CD4 and HIV viral load test results.

Second, we extracted data from a convenience sample of up to five HIV-positive patient files per clinic; the sample was drawn from the HCT register at least six months prior to extraction. We sought information on date of positive HIV test result, CD4 and HIV viral load testing (to determine pre-ART or ART status), and, if applicable, ART initiation and receipt of ART. Third, we conducted key informant interviews with 13 facility managers and staff from seven of the clinics; providers at the eighth clinic were not available for interview due to patient load on the visit date. We discussed procedures for retaining and re-engaging pre-ART and ART patients, and storage and distribution practices for ART medications. We received human subjects approvals from the University of California, San Francisco; the University of Washington; and the Human Sciences Research Council in South Africa.

Descriptive statistics for chart extraction data were generated using Stata 13 (StataCorp, College Station, Texas). We calculated the proportion of charts that indicated clients were linked and retained in care. We defined linkage for pre-ART as having a CD4 test conducted after HIV diagnosis and not meeting ART eligibility. Linkage for ART patients was characterized as being ART eligible and initiated on ART. We defined retention for pre-ART patients as having a CD4 test conducted every six months and, for ART patients, as accessing care at least every three months. For qualitative interviews, we documented linkage and retention practices and procedures, and compared and contrasted details across sites.

Results

The median clinic catchment population was 5,000 (range= 1,508–6,300). The median number of patients served per month was 865 (range= 356–3,000) for all services. Clinics' HIV services included rapid testing, polymerase chain reaction testing, CD4 and viral load testing, and ART initiation and distribution.

Register Audit

Data in HCT registers reflected follow-through, with providers denoting that a test happened, its result, and referrals for services made. By contrast, the pre-ART and ART registers reflected a drop-off in either receipt or in recording services provided. Pre-ART registers contained entries for dates and outcomes of initial CD4 screenings, but there were few entries for follow-up CD4 screenings and pre-ART registers had many fewer unique patients than the number of HIV-positive test results documented in the HCT register. Similarly, the ART registers contained information on initial CD4 screening and treatment initiation, including entries for follow-up visits, however, entries for specific patients would drop off after a period of time, with no indication of whether the patient had transitioned to care elsewhere, was deceased, or had fallen out of care. In both pre-ART and ART registers, it was not documented whether patients ever actually received their CD4 results. Very few viral load results were noted in ART registers.

Chart Extraction

Data were extracted from 10 (25.6%) pre-ART, 26 (66.7%) ART and three (7.7%) HIV-positive (unknown pre-ART or ART) patient files. All 39 patients were referred to TB services, 26 (66.7%) for CD4 testing, four (10.3%) to nutritional services, and four to antenatal services. A greater percentage of patients in the ART setting (78.3%) was retained compared to patients in the pre-ART setting (28.6%). (See Table 1)

Adherence counseling and pill counts were documented in five (19.2%) ART patient files, with 19 (73.1%) patients receiving ART on a monthly basis. Three of eight (37.5%) eligible patients had viral load results six months after ART initiation, as per national guidelines.

Key Informant Interviews

The 13 key informants consisted of five facility managers, five counsellors, two nurses, and one peer navigator.

HIV Testing and Linkage

In the seven facilities where interviews were conducted, protocols called for CD4 testing to be conducted immediately following an HIV-positive test result. However, many HIV-positive patients listed in the HCT register were not located in the pre-ART register, suggesting that CD4 tests were not collected or data were not captured in the pre-ART register. Six facility managers reported dispatching caregivers, some from non-governmental organizations (NGO), or staff to follow-up with patients not returning for CD4 results, while one facility called patients to request a return visit. Six clinics were linked with home-based care (HBC) groups; these groups helped trace primarily ART patients who missed appointments or were lost to follow-up.

Pre-ART Services

Follow-up for patients in the pre-ART setting occurred infrequently. In four clinics, pre-ART patients were advised to return in six months, while two facilities reported instructing patients to return monthly, either for vitamins or for co-trimoxazole prophylaxis with six

month CD4 testing. One facility manager reported asking patients to return in three months. Staff in five facilities reported no follow-up for patients who missed appointments, one facility had a counselor tracking pre-ART patients (though tracking methods were not explicit) and one facility dispatched an NGO caregiver to follow-up with patients who missed appointments.

ART Services

All clinics used three-session adherence training prior to ART initiation, with a potential to fast track patients with $CD4 < 100$ cells/mm³ (i.e., 3 sessions in 3 days). Five clinics encouraged treatment supporters to come to the last session. ART was dispensed monthly in all clinics.

Four clinics reported appointment systems for ART patients, either verbal date or card with date, with follow-up of either calling or sending NGO or staff to find patients who missed appointments. Two facilities used the registers to track routine monitoring for patients, with follow-up done either by calling or sending out a HBC caregiver. Across clinics, periodic monitoring of patient files or registers was reported, but there was no definition of loss or systematic approach to determine loss to follow-up.

Discussion

Our findings from rural clinics in North West Province uncovered data demonstrating poor retention of pre-ART patients. Pre-ART registers and chart reviews together demonstrated evidence of initial CD4 screenings, but only a small proportion of pre-ART patients had evidence of being retained in care. Staff in most clinics reported little or no effort to follow-up with pre-ART patients, in contrast to more substantial efforts with ART patients. These findings are consistent with prior research, which found poor retention in the pre-ART setting (Kranzer et al., 2010; Lessells, Mutevedzi, & Cooke, 2011; Mugglin et al., 2012; Rosen & Fox, 2011), and suggest that the problem may arise in part from lack of systematic record-keeping and recommended engagement practices to ensure pre-ART patient retention.

South Africa has prioritized a national, broad-based HCT program to step up rates of early diagnosis; however, systems to retain HIV-positive patients in care have been absent from national guidelines. (New guidelines for ART patients are forthcoming (NDOH, 2014)). This is particularly true for those in the pre-ART stage, resulting in a mosaic of clinical practices with little or no evidence of effectiveness. There is an urgent need to standardize and systematize follow-up and engagement practices in South Africa, particularly in the pre-ART setting and improve data capture to facilitate identification of patients lost to follow-up and to track retention rates.

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Table 1

Linkage and Retention in Care from Patient File Data

Files with documented CD4 values	34/39 (87.2%)*	
CD4 values (cells/mm³)	Mean	226
	Median	156.5
	Range	2 – 772
Proportion initiating ART, among those eligible*	22/24 (91.6%)**	
Days to ART initiation from day CD4 results were received (days)	Mean	36.14
	Median	19
	Range	0 – 151
Pre-ART patients retained	2/7 (28.6%***)	
ART patients retained	18/23 (78.3%****)	
ART patients initiating over 6 months prior to extraction with HIV viral load test results	3/8 (37.5%)	

* Three patient files had no reported CD4 count or any other documentation so we could not determine if they were pre-ART or ART patients. Two files were missing CD4 count values, but these patients had been assigned to pre-ART register in the notes

** We excluded three ART-eligible patients who were documented as transferred to another clinic for ART initiation or who had moved and one patient who had died.

*** We excluded one pre-ART patient who had transferred out of the clinic.

**** We excluded two ART patients who had transferred out of the clinic and one who had died