# Self-disclosure of HIV status, disclosure counseling, and retention in HIV care in Cameroon

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#### ABSTRACT

Poor retention in care is common among HIV-positive adults in sub-Saharan Africa settings and remains a key barrier to HIV management. We quantify the associations of disclosure of HIV status and referral to disclosure counseling with successful retention in care using data from three Cameroon clinics participating in the Phase 1 International epidemiologic Databases to Evaluate AIDS Central Africa cohort. Of 1646 patients newly initiating antiretroviral therapy between January 2008 and January 2011, 43% were retained in care following treatment initiation. Self-disclosure of HIV status to at least one person prior to treatment initiation was associated with a minimal increase in the likelihood of being retained in care (risk ratio [RR] = 1.14; 95% confidence interval (CI): 0.94, 1.38). However, referral to disclosure counseling was associated with a moderate increase in retention (RR = 1.37; 95% CI: 1.21, 1.55) and was not significantly modified by prior disclosure status (p = .3). Our results suggest that while self-disclosure may not significantly improve retention among patients receiving care at these Cameroon sites, counseling services may play an important role regardless of prior disclosure status.

#### **ARTICLE HISTORY**

Received 15 July 2016 Accepted 7 December 2016

#### **KEYWORDS**

HIV care and treatment; disclosure of HIV status; disclosure counseling; retention in HIV care; IeDEA

# Introduction

Retention in care plays a critical role in successful HIV management among people living with HIV. Inadequate retention in care is associated with the progression of HIV disease and worse clinical outcomes, including delayed receipt of antiretroviral therapy (ART) (Giordano et al., 2007), poor immune response (Berg et al., 2005; Brennan, Maskew, Sanne, & Fox, 2010; Lucas, Chaisson, & Moore, 1999; Rastegar, Fingerhood, & Jasinski, 2003; Tripathi, Youmans, Gibson, & Duffus, 2011), increased occurrence of AIDS-defining illness (Park et al., 2007), and an increased rate of all-cause mortality (Brennan et al., 2010; Giordano et al., 2007; Mugavero et al., 2009, 2014; Park et al., 2007; Tripathi et al., 2011). However, ensuring patients' retention in HIV care remains a significant challenge.

Despite the increasing availability of ART programs in sub-Saharan Africa, a systematic review estimated that only 60% of patients were retained in care within two years of ART initiation, with the estimate ranging from 24% to 77% in sensitivity analyses (Rosen, Fox, Gill, & Sepulveda-Amor, 2007). This degree of early attrition is especially concerning in the sub-Saharan Africa region where a large percentage of patients initiate ART at advanced stages of HIV disease (Lahuerta et al., 2014; Lawn, Harries, Anglaret, Myer, & Wood, 2008).

Previous studies have emphasized the importance of social support in HIV care and treatment, suggesting that patients' disclosure of their HIV-positive status to family and friends improves linkage to care and adherence to ART (Bajunirwe et al., 2009; Do et al., 2010; Govindasamy, Ford, & Kranzer, 2012; Katz et al., 2013; Lyimo et al., 2014). However, it less clear whether disclosure or disclosure counseling services similarly improves retention in HIV care. Two studies in the United States (Halperin, Pathmanathan, & Richey, 2013; Wohl et al., 2011) and a study in Uganda (Nakiwogga-Muwanga et al., 2014) reported moderate to strong positive associations between disclosure and retention in care. Yet, the association estimated from a study in Nigeria was weaker and not statistically significant (Charurat et al., 2010). Additionally, while some studies suggest that counseling, supportive healthcare workers, and more time spent talking to clinic staff may facilitate adherence to ART (Nabukeera-Barungi et al., 2015; Sanjobo, Frich, & Fretheim, 2008), no studies to our knowledge have examined the relationship between disclosure counseling and retention in care. It is plausible, however,

that disclosure counseling may increase patients' social support through subsequent disclosure to family or friends or through building a stronger relationship with clinic staff, thereby improving retention in care.

In this paper, we use data from three Cameroon HIV care and treatment clinics participating in the Phase 1 International epidemiologic Databases to Evaluate AIDS (IeDEA) to quantify the association of patients' disclosure of their HIV-positive status with retention in care following ART initiation. We also quantify the association of referral to disclosure counseling with patients' retention in care.

#### **Methods**

# Study population and design

The IeDEA is a global research consortium established in 2005 with funding by the National Institute of Allergy and Infectious Diseases. The consortium's seven regional centers collect and harmonize data from HIV/AIDS care and treatment sites to facilitate cost-effective, epidemiological research of diverse clinical cohorts of HIV-positive patients. The IeDEA network has been described in detail elsewhere (Egger et al., 2012; Gange et al., 2010; Mcgowan et al., 2007).

The Phase 1 IeDEA Central Africa region included HIV care and treatment facilities in Cameroon, Burundi, and the Democratic Republic of the Congo (Divaris et al., 2012; Egger et al., 2012; Freeman et al., 2012; Newman et al., 2012). Participating sites used standardized baseline and follow-up clinical record forms to prospectively collect socio-demographic and medical data from HIVpositive patients. Among Central Africa region countries, the Cameroon sites were unique in having data on a large number of antiretroviral-naïve adults who were initiating ART at their IeDEA enrollment visit (n = 2020); therefore, we restricted our attention to these sites for the present analysis. The three sites in Cameroon were national teaching and referral hospitals, served both urban and rural populations, provided tertiary level of care, and began providing ART between 2000 and 2003.

We used a sample of adults initiating routine HIV clinical care at participating sites in Cameroon between 14 January 2008 and 15 July 2011 (Figure 1). Because factors related to the probability of being retained in care are likely to differ between those newly initiating ART compared to those continuing therapy, we restricted our analyses to new users (n = 2020) to avoid prevalent user bias (Ray, 2003). To be able to ascertain retention in care, defined as at least one follow-up visit occurring within 180 days of the baseline visit, we further restricted

analyses to patients with a baseline visit occurring prior to 16 January 2011 (i.e., with  $\geq 6$  months of possible follow-up before the administrative censoring date). We excluded patients who transferred to care outside of the IeDEA Cameroon sites (n = 10), as well as patients who were scheduled for follow-up visits at atypical intervals of six months or greater (n = 126). Because HIV care differs for pregnant women, we excluded patients who were pregnant or initiating ART for prevention of mother-to-child transmission (n = 50). Thus, the final study sample included 1646 HIV-positive adults initiating ART at Cameroon sites between 14 January 2008 and 15 January 2011.

#### **Ethics statement**

The Phase 1 IeDEA Central Africa region research project was reviewed by the Institutional Review Board (IRB) at the Kinshasa School of Public Health in the Democratic Republic of the Congo, the national ethics committees in Burundi and Cameroon, and the data coordinating center IRB at RTI International. The present analyses were granted an exemption by the University of North Carolina's IRB due to its use of existing, deidentified data.

# **Outcome ascertainment**

Patients were scheduled for routine follow-up visits approximately every three months to monitor HIV progression and treatment. We defined retention in care as attending at least one follow-up visit within 180 days of the baseline visit. Patients who did not attend at least one visit were classified as lost to follow-up while all others were classified as retained in care. The 180-day mark was chosen because it was validated as the best performing indicator of loss to HIV care in a recent study of 1111 facilities contributing data to the IeDEA (Chi et al., 2011). This indicator resulted in the least amount of misclassification of patients' loss to care status (Chi et al., 2011).

#### **Exposures**

The exposures of interest were dichotomous indicators of (1) disclosure of HIV-positive status and (2) referral to disclosure counseling. At baseline visits, providers recorded whether a patient reported having previously disclosed their HIV status to anyone and whether they had given a patient a referral to disclosure counseling. Referrals could be given to patients irrespective of disclosure status. Although completion of counseling was not recorded, all patients referred to counseling were likely to have received it due to the structure of clinic



Figure 1. Adult patients engaging in HIV clinical care at phase 1 leDEA Cameroon sites included in the study sample for analyses of the associations of disclosure and disclosure counseling with retention in care.

appointments. Counseling was available onsite at the time of the regular appointment and was administered by the same healthcare team. Therefore, we used referral as a proxy for receipt of counseling.

### **Covariates**

We used substantive knowledge to identify potential confounders of the associations of disclosure and referral to disclosure counseling with retention in care. The following covariates were recorded at baseline and were chosen as potential confounders in the analysis of HIV status disclosure: age, CD4 cell count, education (i.e., none, primary, secondary, and university), employment status (i.e., employed or unemployed), gender, and HIV clinical stage (i.e., stage I–IV). Providers used

World Health Organization guidelines for HIV stage classification (World Health Organization, 2007). Average alcohol consumption per day (i.e., 0, 1-2, 3-4, 5-6, or  $\geq$ 7 glasses) was also included as a covariate, as alcohol consumption has been associated with non-disclosure and other high-risk behaviors in sub-Saharan Africa settings (Wandera et al., 2015). Because alcohol consumption was also strongly associated with retention in care, it slightly improved the precision of our estimates. Disclosure counseling was not contraindicated for any patients but might have been prioritized for patients in poorer health who might need greater support from both their social network and their HIV care providers. Therefore, CD4 count and HIV clinical stage were selected as potential confounders in the analysis of referral to disclosure counseling.

# **Statistical analyses**

Distributions of baseline characteristics were summarized using medians and interquartile ranges or percentages. We examined the functional form of the association of continuous variables (i.e., age and CD4 count) with the outcome by exploring flexible disjoint indicator and restricted cubic and quadratic spline coding (Greenland, 1995; Harrell, n.d.; Harrell, Lee, & Pollock, 1988; Howe et al., 2011). We chose the coding scheme that resulted in the lowest Akaike Information Criterion statistic while still capturing the biologically plausible covariate-outcome relationship that had been visually assessed with plots. Thus, we chose to model age as disjoint indicators (i.e., 19-24, 25-29, 40-49, 50-59, 60-72, with 30-39 years as the referent) and CD4 count as a restricted cubic spline with knots at the 5th, 35th, 65th, and 95th percentiles.

We used log binomial regression models to estimate crude and multivariable adjusted risk ratios (RRs) for the associations between (1) disclosure of HIV status and retention in care and (2) referral to disclosure counseling and retention in care. Furthermore, in our second analysis, we assessed effect measure modification by disclosure status using a product term and obtained stratum-specific RRs. In all multivariable analyses, we addressed missing values for CD4 cell count (n = 190), age (n = 1), and HIV clinical stage (n = 1) by creating inverse probability weights for being a complete case (Seaman & White, 2011). A priori we identified variables that were theorized to be independent predictors of both the outcome and being a complete case. We retained variables that remained independent predictors of being a complete case as assessed by a likelihood ratio test statistic *p*-value <.1 when comparing the full and reduced logistic regression probability weight models. The final weights were constructed using disclosure, age, alcohol consumption, employment status, HIV clinical stage, and retention in care variables. We applied these weights to all multivariable analyses and used a robust variance to obtain corrected standard errors and 95% confidence intervals (CIs). Statistical analyses were performed using SAS version 9.4 (SAS Institute, Inc., Cary, North Carolina).

# Results

Table 1 describes the baseline characteristics of the 1646 patients at the time of ART initiation. Sixty-seven percent of patients were female, 49% were employed, and 32% were married. The median age was 36 years (IQR: 30–43). The majority of patients did not consume alcohol regularly. A higher percentage of females (78%)

Table 1.	Baseline char	acteristics of 16	546 HIV-pos	itive	patients
initiating	antiretroviral	therapy at thre	e Cameroor	n site	es of the
Phase 1	International	epidemiologic	Databases	to	Evaluate
AIDS Cen	tral Africa (leD	EA-CA) cohort.	2008–2011.		

Characteristic	n	(%)	Median	[IQR]
Sample size	1646			
Age <sup>a</sup>			36	[30–43]
Alcohol consumption <sup>b</sup>				
0 Glasses	871	(53)		
1–2 Glasses	321	(20)		
3–4 Glasses	194	(12)		
5–6 Glasses	140	(9)		
≥7 Glasses	120	(7)		
CD4 cell count <sup>c</sup>			143	[64–231]
Education				
None	92	(6)		
Primary	778	(47)		
Secondary	612	(37)		
University	164	(10)		
Employed	812	(49)		
Female gender	1105	(67)		
Follow-up visit <sup>d</sup>				
0–4 Weeks	104	(6)		
1 Month	167	(10)		
3 Months	1375	(84)		
Married <sup>e</sup>	519	(32)		
WHO clinical HIV stage <sup>a,f</sup>				
Stage I	171	(10)		
Stage II	343	(21)		
Stage III	877	(53)		
Stage IV	254	(15)		

<sup>a</sup>One missing value.

<sup>b</sup>Based on patients' self-report of the average number of alcoholic beverages consumed per day during the last year.

<sup>c</sup>One hundred and ninety missing values.

<sup>d</sup>Timeframe that the provider selected for patients' next regular visit.

<sup>e</sup>Includes monogamous (n = 485) and polygamous marriages (n = 34).

<sup>f</sup>Determined by providers using World Health Organization guidelines for HIV stage classification.

abstained from alcohol consumption than males (23%). Most patients had either a primary (47%) or secondary (37%) level of education. Over half of the patients were determined to be at HIV stage III, and the median CD4 cell count was 143 (IQR: 64–231).

Table 2 provides crude and adjusted RRs for the associations between each of the exposures and retention in care. At the baseline visit, 87% (n = 1429) of patients reported previously having disclosed their HIV status to at least one person. Eighteen percent (n = 295) were referred to disclosure counseling. Overall, 43%

**Table 2.** Associations of disclosure of HIV status and referral to disclosure counseling with retention in care among Cameroon patients initiating antiretroviral therapy.

•	5		
Analysis	Exposure	Crude RR (95% CI)	Adjusted RR (95% CI)
Disclosure <sup>a</sup>	No disclosure	Ref	Ref
	Disclosure	1.08 (0.91, 1.29)	1.14 (0.94, 1.38)
Counseling <sup>b</sup>	No referral	Ref	Ref
	Referral	1.39 (1.23, 1.57)	1.37 (1.21, 1.55)

<sup>a</sup>Adjusted model was weighted to complete cases and adjusted for age, alcohol consumption, CD4 count, education, employment status, gender, and HIV clinical stage.

<sup>b</sup>Adjusted model was weighted to complete cases and adjusted for CD4 count and HIV clinical stage.

**Table 3.** Association of HIV disclosure counseling with retention in care in Cameroon by patients' HIV disclosure status.

Stratum	Counseling referral	Crude RR (95% CI)	Adjusted <sup>a</sup> RR (95% Cl)
No disclosure	No	Ref	Ref
	Yes	1.67 (1.13, 2.46)	1.46 (0.94, 2.27)
Disclosure	No	Ref	Ref
	Yes	1.37 (1.20, 1.55)	1.35 (1.19, 1.54)

<sup>a</sup>Adjusted model was weighted to complete cases and adjusted for CD4 count and HIV clinical stage.

(n = 708) of patients were retained in care. The crude RR comparing retention in care among those who had disclosed their status to those who had not was 1.08 (95% CI: 0.91, 1.28). After using inverse probability weighting to address missing data and adjusting for age, alcohol use, CD4 count, education, employment, gender, and HIV clinical stage, the RR was 1.14 (95%: 0.94, 1.38). This suggested that disclosure of HIV status prior to ART initiation was associated with 1.14 times the likelihood of being retained in care, though the CI included the null value. The crude RR comparing retention in care among those who were referred to disclosure counseling to those who were not was 1.39 (95% CI: 1.23, 1.57) and did not change substantially after application of inverse probability weights and adjustment for confounders (RR = 1.37; 95% CI: 1.21, 1.55). Thus, in the overall study population, those referred to disclosure counseling had a statistically significant increased likelihood of being retained in care.

Referrals to disclosure counseling were provided to 19% (n = 276) of patients who had previously disclosed their HIV status to at least one person compared to 9% (n = 19) of patients who had not disclosed their status to anyone. The adjusted RR for the association of referral to disclosure counseling and retention in care among those who had disclosed their status was 1.35 (95% CI: 1.19, 1.54) (Table 3). Among those who had not disclosed their status, the crude RR was augmented (RR = 1.67; 95% CI: 1.13, 2.46) but less precise after adjustment (RR = 1.46; 95% 0.94, 2.27) due to the small sample size in this stratum. The likelihood ratio test did not provide strong statistical evidence of modification of the association between referral to disclosure counseling and retention in care by prior disclosure status (p = .3).

# Discussion

In this study of HIV-positive adults initiating ART in Cameroon, we found that disclosure of HIV status prior to treatment initiation was associated with a weak but not statistically significant increased likelihood of being retained in care following treatment initiation. However, we found that referral to disclosure counseling at the time of ART initiation was associated with an increased likelihood of being retained in care, regardless of patients' disclosure status.

Few studies have previously examined the association of disclosure with retention in care in non-pregnant adult populations in sub-Saharan Africa, particularly in Central Africa. Though several sub-Saharan Africa studies have reported that disclosure increased linkage to HIV care (Medley et al., 2013) and adherence to ART (Bajunirwe et al., 2009; Birbeck et al., 2009; Charurat et al., 2010; Do et al., 2010; Olowookere, Fatiregun, Akinyemi, Bamgboye, & Osagbemi, 2008), it is possible our weaker association is attributable to differences in the specific mechanisms by which disclosure improves HIV care and treatment outcomes. Some of the potential intermediaries (e.g., emotional support, reminders to take medication, transportation, and financial assistance) might play a stronger role in linkage to care and adherence to ART compared to retention.

While our estimate of association was not statistically significant, it was consistent in direction with results reported from the few previous studies of retention in the United States (Halperin et al., 2013; Wohl et al., 2011) and Uganda (Nakiwogga-Muwanga et al., 2014) and similar to a non-significant, weak positive association reported from a study in Nigeria (Charurat et al., 2010). However, with the exception of the study from Nigeria, studies did not restrict analyses to those newly initiating ART, so participants included patients on ART for varying durations as well as those not on treatment. Thus, our weaker association might be partly due to control for confounding that still remained in previously reported results or other differences in analysis design and study population characteristics.

Prior studies have not used consistent definitions of retention in care which makes it likely that reported results correspond to the association of disclosure with different aspects of healthcare utilization. In sub-Saharan Africa studies, retention was defined as being less than 60 or 90 days late to a follow-up appointment (Charurat et al., 2010; Nakiwogga-Muwanga et al., 2014), while studies in the United States defined retention as a measure of visit constancy (Halperin et al., 2013; Wohl et al., 2011). In our study, we defined retention based on a validated indicator of whether or not a patient in HIV treatment has been lost to follow-up (Chi et al., 2011). However, it is possible that in some settings, disclosure is more strongly associated with decreased appointment delays and increased visit constancy than decreased loss to follow-up. Future research would benefit from assessing the association of disclosure with multiple points of the HIV care continuum using consistent definitions of delays, visit constancy, and loss to follow-up.

It should also be noted that 87% of our study population reported having disclosed their status. This was much higher than the approximate 50-75% disclosure prevalence from the Uganda and New Orleans studies which also reported the strongest measures of association. Thus, our contrast of those who had disclosed their status to at least one person versus those who had not disclosed their status to anyone might have obscured heterogeneity in the effect of disclosure. It is possible that those who had disclosed their status to more people experienced a stronger likelihood of being retained in care than those who had disclosed their status to few people. A study in the United States found that among those who had disclosed their HIV status to at least one social network member, there was a stronger association with retention in care among those who disclosed to more network members (Wohl et al., 2011). Therefore, it is possible that we would have found a stronger association by categorizing disclosure as a continuous or categorical variable if data had been available. This would have likely also improved our ability to detect a statistically significant association by increasing the variability in our exposure. Additionally, disclosure to certain people (e.g., spouse, friend, etc.) might have varying effects on retention in care. Future studies, particularly those conducted in populations with a high prevalence of disclosure, might benefit from collecting more detailed data on disclosure as we have described.

To our knowledge, our analysis is the first study to quantify the association of referral to disclosure counseling at ART initiation with retention in care in a sub-Saharan Africa country. Interestingly, we found that referrals substantially increased the likelihood of retention in care among all patients, regardless of whether they had previously disclosed their status to anyone. It is possible that the increase in retention in care was more pronounced among those who had not previously disclosed their status, but the small percentage of patients in this category limited our ability to detect this.

It is unknown whether referral to disclosure counseling led patients to subsequently disclose their HIV status to members of their social network. It is possible that this was the case and patients were able to access further social support and resources through this process, thereby increasing the likelihood of retention in care. Another possibility is that the process of disclosure counseling is important in its own right. The additional contact and counseling with HIV care staff might increase patients' perceived support from, and improve their relationships with, their HIV care providers. As only 18% of patients were referred to disclosure counseling, scaling up this existing healthcare service might be a simple intervention that has the potential to increase retention in care and improve overall clinical outcomes.

Potential limitations of our analyses are social desirability bias, missing data on CD4 count, and measurement error related to disclosure counseling and retention in care. Social desirability bias might have led patients to over report having disclosed their HIV status. However, the disclosure prevalence estimated in our study population was similar to that reported by another study in Cameroon (Suzan-Monti et al., 2011). Data on CD4 count were missing for 12% of our study sample due to limited access to laboratory testing services. We addressed these missing data using inverse probability weighting. We used documentation of a referral to disclosure counseling as a proxy for receipt of disclosure counseling. Our results may be subject to exposure misclassification bias if some patients referred to disclosure counseling did not receive it. However, we believe measurement error is minimal, as counseling was available onsite at the time of the regular appointment. Finally, our definition of retention in care as at least one follow-up visit within 180 days is an imperfect measure. Because this definition was previously validated using data from 111 IeDEA study sites across six regions, we believe it was the best indicator of initial retention in regard to resulting in the least amount of outcome misclassification (Chi et al., 2011).

There are several strengths of our analyses. These include a longitudinal design, the restriction of analyses to those newly initiating ART to avoid prevalent user bias, and the use of a measure of retention that has been validated in international HIV populations. Additionally, the use of data from a clinical cohort of patients in Cameroon provides a large sample of patients in routine HIV care. Our analyses contribute to the limited literature quantifying the associations of disclosure and disclosure counseling with retention in care.

# Conclusion

Adequate retention in care is essential to slow the progression of HIV disease and reduce HIV/AIDS-related morbidity and mortality. Our analyses demonstrate that in these clinics in Cameroon, patients' disclosure of their HIV status prior to ART initiation only minimally improved initial retention in care. Regardless of patients' disclosure status at the time of ART initiation, however, referral to disclosure counseling significantly increased retention in HIV care. Our results emphasize the importance of support services in maintaining HIV care and present a potential mode of improving retention using existing counseling services.

# **Acknowledgements**

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. We are grateful to the patients and local staff at Hôpital Général of Yaoundé, Limbé Provincial Hospital, and Hôpital Militaire for their contributions to this study. We also thank Nadya Belenky for her assistance in the formulation of this research, Ms Kristen Stolka and Ms Jeniffer Iriondo-Perez at RTI International, as well as staff at the IeDEA regional office (Kinshasa, DRC): Dr John Ditekemena, Mr Christian Konde, and Mr. Kashamuka Mwandagalirwa.

## **Disclosure statement**

No potential conflict of interest was reported by the authors.

#### Funding

The Phase 1 IeDEA-CA network was funded by the National Institute of Allergy and Infectious Diseases, National Institutes of Health [NIH/NIAID 1 U01 AI069927].

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