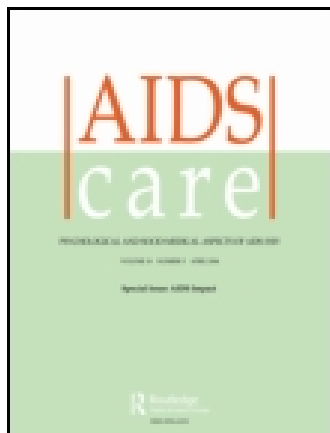


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Non-enrollment for free community HIV care: findings from a population-based study in Rakai, Uganda

Gertrude Nakigozi^{a*}, Fredrick Makumbi^b, Steven Reynolds^c, Ronald Galiwango^a, Joseph Kagaayi^a, Fred Nalugoda^a, Absalom Ssettuba^a, Joseph Sekasanvu^a, Jackson Musuuza^a, David Serwada^b, Ron Gray^d and Maria Wawer^d

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Improved understanding of HIV-related health-seeking behavior at a population level is important in informing the design of more effective HIV prevention and care strategies. We assessed the frequency and determinants of failure to seek free HIV care in Rakai, Uganda. HIV-positive participants in a community cohort who accepted VCT were referred for free HIV care (cotrimoxazole prophylaxis, CD4 monitoring, treatment of opportunistic infections, and, when indicated, antiretroviral therapy). We estimated proportion and adjusted Prevalence Risk Ratios (adj. PRR) of non-enrollment into care six months after receipt of VCT using log-binomial regression. About 1145 HIV-positive participants in the Rakai Community Cohort Study accepted VCT and were referred for care. However, 31.5% (361/1145) did not enroll into HIV care six months after referral. Non-enrollment was significantly higher among men (38%) compared to women (29%, $p = 0.005$). Other factors associated with non-enrollment included: younger age (15–24 years, adj. PRR = 2.22; 95% CI: 1.64, 3.00), living alone (adj. PRR = 2.22; 95% CI: 1.57, 3.15); or in households with 1–2 co-residents (adj. PRR = 1.63; 95% CI: 1.31, 2.03) compared to three or more co-residents, or a CD4 count >250 cells/ul (adj. PRR = 1.81; 95% CI: 1.38, 2.46). Median (IQR) CD4 count was lower among enrolled 388 cells/ul (IQR: 211,589) compared to those not enrolled 509 cells/ul (IQR: 321,754).

About one-third of HIV-positive persons failed to utilize community-based free services. Non-use of services was greatest among men, the young, persons with higher CD4 counts and the more socially isolated, suggesting a need for targeted strategies to enhance service uptake.

Keywords: HIV; HIV care; enrollment

Introduction

The HIV/AIDS epidemic remains a serious public health problem in sub-Saharan Africa. In addition to the ongoing need for better prevention programs, there is an urgent need to optimize utilization of HIV care and treatment services, since it is estimated that only 48% of persons currently in need of antiretroviral therapy (ART) were receiving treatment in southern Africa in 2008 (World Health Organization & UNAIDS, 2009). Improved understanding of factors affecting HIV-related health-seeking behavior is a crucial component of this effort. Factors associated with lower use of general health care include male gender, lower education, economic status, cultural beliefs, limited access to quality care, distance to health facilities, larger family size, and higher parity (Babar, Shaikh, Juanita, & Syed, 2007; Babar & Juanita, 2004; Katung, 2001; Nyamongo, 2002; Thorson, Hoa, & Long, 2000; Yamasaki-Nakagawa

et al., 2001; Yip, Wang, & Liu, 1998). However, data on factors associated with non-enrollment for free of cost HIV/AIDS care services in a community-based program in a mature and generalized HIV epidemic setting are limited. Rakai is a population-based setting in contrast to most ART programs that are clinic-based and thus limited in determining the proportion of eligible persons and factors associated with non-enrollment into appropriate care and treatment at a population level.

Since 1994, the Rakai Health Sciences Program (RHSP) has conducted annual HIV surveillance (via the Rakai Community Cohort Study – RCCS) among all consenting adults residing in 50 rural Rakai District communities. The RHSP is a collaboration between researchers at the Johns Hopkins University, Baltimore, USA, and Makerere University, Kampala Uganda and Uganda Virus Research Institute, Uganda. The RCCS is an open cohort initiated in 1989 that enrolls and follows up all

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resident consenting adults aged 15–49 in their homes to provide survey information and biological samples for detection of HIV, STDs, and other infections, in addition to provision of health education and, care and treatment for HIV/AIDS. The majority of participants request and receive their HIV results and HIV-positive persons are referred to community HIV care services which are offered free of charge through community resident counselors and mobile clinics. Since 2005, through the community surveys, RCCS has performed CD4 cell counts annually to determine eligibility for ART. Therefore, RCCS provides a unique opportunity to assess acceptance of HIV results and uptake of HIV care, and to examine factors associated with non-use of services with the aim of having an improved understanding of factors affecting HIV-related health-seeking behavior at population level in an effort to inform the design of more effective HIV prevention and care strategies. We therefore set out to assess such factors in Rakai, using data drawn from the RCCS surveys conducted from February 2005 to August 2006.

Methods

Study setting and population

The RCCS maintains annual surveillance of consenting adults aged 15–49 years in 50 villages in rural Rakai district, South Western Uganda. Over 90% of residents agree to the annual survey participation, and provide written informed consent, sociodemographic, behavioral, health and care-seeking information, and a venous blood sample for HIV testing. Participants receive counseling on HIV prevention and are strongly urged to learn their serostatus. However, participants have the option of declining their result even if they provide a blood sample. HIV results are provided free of charge, by trained Rakai Program counselors in the participant's home or at RHSP community counseling facilities.

HIV-positive individuals who accept their HIV results receive post-test counseling, including the need to enroll into HIV care and are referred to the closest Rakai Program HIV/AIDS (Suubi or "hope") mobile clinics which visit each community at bimonthly intervals. There are 17 mobile clinics staffed by physicians, clinical officers, nurses, and counselors. HIV care has been provided since June 2004 through funding from the President's Emergency Plan for AIDS Relief (PEPFAR). A Basic Care Package (BCP) provided includes health and nutritional education, counseling on living with HIV, prophylaxis of opportunistic infections with cotrimoxazole (Mermin et al., 2004), insecticide-impregnated bed nets, and

clean water vessels with hypochlorite disinfectant. CD4 testing is conducted annually or as clinically indicated, and ART is provided for persons with a CD4 cell count ≤ 250 and/or WHO clinical stage IV disease. All HIV-related services are provided free of charge.

Interview/surveys

In this analysis, we assessed determinants of non-enrollment into HIV care services among HIV-positive persons at a population level, using data drawn from the RCCS surveys conducted from February 2005 to August 2006. In these Surveys, structured Luganda language interviews were conducted confidentially by trained same-sex interviewers, collecting information on sociodemographic characteristics, health, and behaviors including health-care seeking where data on use of care and ART from the HIV (SUUBI) clinics were obtained. We also obtained detailed information on household composition structure and possession of modern objects already collected in the RCCS censuses in the same time period.

Sample collection, testing, and enrollment into care

All HIV and CD4 testing were conducted in the RHSP laboratory located in Rakai District; HIV-1 serostatus was determined by two HIV-1 enzyme immunoassays (EIAs) and confirmed by Western blot according to standard operation procedure, while CD4 counts were assessed using a BD Facscalibur. All HIV-positive patients who had received their HIV-test results and post-test counseling were referred into care. Enrollment into HIV care was therefore defined as HIV-positive participant reporting to the SUUBI (Hope) HIV clinic for care as asked in the referral availed post-receipt of HIV-test results within six months of referral but before the end of April 2008 as the data analysis cut-off date, or entry into HIV care with any other provider.

Statistical analysis

Non-enrollment into care was defined as failure of HIV-positive persons who had received their HIV-test results, post-test counseling, and referral more than six months prior to April 2008, to make at least one contact with the RHSP HIV clinics or other HIV care providers.

The six-month cut-off was selected as a marker of programmatically significant delay in care seeking because a prior study indicated that 34.1% of ART-eligible patients who did not initiate ART died within six months (Bassett et al., 2009). We determined the

Table 1. Baseline characteristics of study participants.

Characteristics	Not in care, <i>n/N</i> (%)	In care, <i>n/N</i> (%)	<i>p</i> -Value
Overall	361/1145 (31.5)	784/1145 (68.5)	
Sex			
Female	238/361 (65.9)	580/784 (74.0)	0.005
Male	123/361 (34.1)	204/784 (26.0)	
Age (years)			
Mean (SD)	30.0 (7.05)	33.6 (7.05)	
Median (IQR)	29 (25–35)	33 (29–39)	
Age group (years)			
15–24	86/361 (23.8)	77/784 (9.8)	< 0.0001
25–34	184/361 (51.0)	375/784 (47.8)	0.324
35–49	91/361 (25.2)	332/784 (42.4)	< 0.0001
Marital status			
Not married	148/361 (41.0)	366/781 (46.9)	0.064
Married	213/361 (59.0)	415/781 (53.1)	
Main occupation			
Agriculture/housework	195/361 (54.0)	485/781 (62.1)	0.01
Other occupation	166/361 (46.0)	296/781 (37.9)	
Education level			
Primary or lower	259/361 (71.8)	605/780 (77.6)	0.033
Secondary or higher	102/361 (28.2)	175/780 (22.4)	
Alcohol use			
No	140/361 (38.8)	347/781 (44.4)	0.073
Yes	221/361 (61.2)	434/781 (55.6)	
Socio-economic status			
Upper tertile	63/361 (17.5)	160/784 (20.4)	0.241
Middle tertile	170/361 (47.1)	341/784 (43.5)	0.255
Lower tertile	128/361 (35.5)	283/784 (36.1)	0.834
Currently pregnant			
No	195/224 (87.1)	521/565 (92.2)	0.024
Yes	29/224 (12.9)	44/565 (7.8)	
CD4 count (cells/ul)			
Mean (SD)	544 (307)	421 (277)	< 0.0001
Median (IQR)	509 (321–754)	388 (211–589)	
CD4 Category			
≤250	43/270 (15.9)	238/772 (30.8)	< 0.0001
251+	227/270 (84.1)	534/772 (69.2)	
Bedridden in past 30 days			
Yes	47/361 (13.0)	103/781 (13.2)	0.937
No	314/361 (87.0)	678/781 (86.8)	

Note: Bold values are significant at $p = 0.05$.

proportion of non-users of care by participant characteristics, and estimated unadjusted and adjusted prevalence risk ratios (adj. PRR) of non-use (non-enrollment) of care using log-binomial regression or generalized linear models (GLM) with a Poisson family and log link with robust standard errors (Guangyong, 2004), when the log-binomial

regression model failed to converge). Covariates associated with non-enrollment for care in the bivariate analyses with p values ≤ 0.15 and potential confounders were included in the multivariable models. Statistical analyses were performed using StataTM Release 9.2 (Stata Corporation, 4905 Lakeway Drive, College Station, TX 77845, USA).

Table 2. Proportion not enrolled in care, and adjusted PRR for non-enrollment into care.

Characteristic	Not in care/total received results >6 months, <i>n/N</i>	Proportion not in care (%)	Adjusted PRR, ^a 95% CI	<i>p</i> -Value
Total	361/1145	31.5		
Sex				
Female	238/818	29.0	1.0	
Male	123/327	38.0	1.40 (1.10, 1.78)	0.006
Age group (years)				
15–24	86/163	52.8	2.22 (1.64, 3.00)	<0.0001
25–34	184/559	32.9	1.47 (1.15, 1.89)	0.002
35–49	91/423	21.5	1.0	
Marital status				
Not married	148/514	28.8	1.0	
Married	213/628	33.9	1.21 (0.94, 1.56)	0.141
Main occupation				
Agriculture/ housework	195/680	28.7	1.0	
Other occupation	166/462	35.9	1.02 (0.82, 1.25)	0.876
Level of education				
Primary or lower	259/864	30.0	1.0	
Secondary or higher	102/277	36.8	1.23 (0.99, 1.54)	0.067
Household size (index person inclusive)				
1	44/89	49.4	2.22 (1.57, 3.15)	<0.0001
2–3	136/319	42.6	1.63 (1.31, 2.03)	<0.0001
4 +	181/737	24.6	1.0	
CD4 category				
< = 250	43/281	15.3	1.0	
251 +	227/761	29.8	1.84 (1.38, 2.46)	<0.0001

^aAdjusted for variables that were statistically significant in the bivariate analysis and those that were potential confounders (age, sex, occupation, education level, household size, and CD4 count).

Note: Variables (bedridden in past 30 days, socio-economic status, education level, alcohol use) are not used in the adjusted model, as described in the statistical methods are NOT shown in the table. Bold values are significant at $p=0.05$.

A socioeconomic index was constructed from the household possession of modern objects, dwelling structure, number of rooms, and availability of electricity. The socioeconomic index scores were classified into higher, middle, and lower, based on the 33rd, 66th, and 99th tertiles. Occupation was divided into home-based non-cash employment – “agriculture/housework” and “other occupations” for those working for cash wages.

Results

HIV result receipt and enrollment into care

A total of 12,216 RCCS participants accrued between February 2005 and August 2006, where 1451 (11.9%)

were found to be HIV positive. Of the HIV-positive participants, 45 refused to learn their HIV results (3.1%) and 261 had not received their HIV results more than six months before data closure (not shown in table). Therefore, a total of 306 HIV positive were excluded from further analysis. The remaining 1145 (78.9%) HIV-positive persons had received their HIV results and were referred for HIV care more than six months prior to closure of the data-set. At time of data closure, 361 of the 1145 eligible persons (31.5%) had not yet enrolled into HIV care.

Baseline characteristics

Table 1 shows the baseline characteristics of the study participants. Those “enrolled in care” and the non-

enrollees (not in care) were similar in characteristics with respect to marital status, alcohol use, socio-economic status, and being bedridden in the past 30 days. Non-enrollees were more likely to be younger, to have a formal education of secondary school or higher, have a higher CD4 count and more likely to be involved in an occupation earning cash. Among females, clients who failed to enroll into HIV care were more likely to be pregnant compared to their enrolled counterparts.

Predictors of non-enrollment into care

Table 2 shows the proportions of participants not enrolled in HIV care and the adj. PRR of non-enrollment into care.

Non-enrollment into care was significantly higher among men compared to women (adj PRR: 1.40; 95% CI: 1.10, 1.78, $p=0.006$). Other factors significantly associated with non-enrollment into care included: younger age (15–24 years, adj. PRR = 2.22, 95% CI: 1.64, 3.00; or age 25–34 years, adj. PRR = 1.47; 95% CI: 1.15, 1.89) compared to persons 35 years or older; living alone (adj. PRR = 2.22; 95% CI: 1.57, 3.15); or in households with 1–2 co-residents (adj. PRR = 1.63 95% CI: 1.31, 2.03) compared to three or more co-residents; a CD4 count >250 cells/ul (adj. PRR = 1.81; 95% CI: 1.38, 2.46). Median (IQR) CD4 count was lower among participants in care (388 cells/ul; IQR: 211,589) compared to those not enrolled (509 cells/ul; IQR: 321,754).

Discussion

In this program which provides free access to community-based HIV care, 31.5% (361/1145) of persons who knew their HIV-test results did not utilize HIV care. Thus, underutilization of HIV services remains a substantial problem in this rural setting.

The determinants of health-care utilization have been assessed for several conditions (Babar & Juanita, 2004; Katung, 2001; Nyamongo, 2002; Thorson et al., 2000; Yamasaki-Nakagawa et al., 2001) but not specifically for HIV in community-based and free of cost services in generalized and mature HIV epidemic resource-limited settings. In part, this is because most HIV care programs are clinic-based and do not have population-based data with which to determine the proportion of the eligible general population who do not access care. In this regard, the Rakai Program is unique, and provides information on the drivers of health seeking among HIV-positive patients. Those studies that assessed health-care utilization for malaria and tuberculosis or chronic cough treatment (Hoa,

Thorson, Long, & Diwan, 2003) highlighted socio-demographic factors like gender, with women taking longer to report for modern care; low level of education; cultural beliefs and practices; gender discrimination; status of women; knowledge and duration of sickness; the anticipated cost of treatment; and a patient's judgment of the intensity of sickness as important factors in utilization of care services. In this study, we found that men, persons with a high CD4 count and younger persons were less likely to enroll into care. A study in Burkina Faso (Sauerborn, Berman, & Nougara, 1996) had similar conclusion on age but the above-mentioned studies differ on the gender conclusion. The reversal in gender-related utilization of free HIV care compared to "paid for" services as shown in other studies could point to cost as a probable factor limiting women's ability to seek care early, especially since women in sub-Saharan Africa are often less economically empowered. In this study, women's ability to seek care therefore improved once services were availed free of cost.

Other studies found that large family size was associated with poor health-care utilization (Babar & Juanita, 2004) but in contrast, we found that persons living alone or in households of three or fewer members were less likely to use care (Table 2). Provision of social support is a means through which social networks influence health behaviors (Lisa, Thomas, Ian, & Teresa, 2000), and our findings suggest that persons living in isolation or with fewer contacts may be vulnerable to poor health-care utilization due to the lack of support. Persons with higher CD4 counts who were not yet eligible for ART were also more likely not to enroll for care, possibly because they were asymptomatic and had no felt need for care. Perception that an illness is not serious is a major reason given for failure to utilize health care (Negussie & Chepngeno, 2005). Our findings are consistent with US health service utilization studies among HIV-infected adults in which patients with lower CD4 counts were more likely to visit outpatient facilities for care (Fleishman et al., 2005). Factors such as occupation, educational status, alcohol use, SES, and parity in women were not associated with utilization of free HIV-care services. Education status often reflects level of knowledge and may also influence one's occupation and hence income; woman's parity may reflect the extent of care burden a family experiences and this affects resource allocation to care services; SES reflects one's ability to pay for a service while alcohol may be an avenue for resource wastage. In this study, all these factors were not statistically significant for care utilization probably because these services were offered free of cost to all

and also, level of knowledge about HIV care availability were similar for all study participants due to the continuous community HIV health education offered in Rakai district communities. WHO/UNAIDS estimates that only 48% of the sub-Saharan African population in need of ART are actually receiving this service (World Health Organization & UNAIDS, 2009). In this analysis, of the 1042 HIV-positive persons with a known CD4 count, 281 (27%) individuals had CD4 \leq 250 and were eligible for ART (Table 1). A total of 238/281 (84.7%) of these ART-eligible persons had enrolled for HIV care and treatment, suggesting that good access to treatment and community outreach can result in high (albeit still not optimal) treatment utilization. However, of the 761 individuals with CD4 counts $>$ 250 (not yet eligible for ART initiation), 227 (29.8%) failed to enroll for care and thus did not benefit from the BCP, an intervention that has been shown to delay disease progression and to reduce morbidity and mortality (Mermin et al., 2004). Basic care is much less costly than ART; so increased efforts to encourage utilization of such care would benefit patient's health and potentially defer the more expensive ART. It is also worth highlighting that 39.7% of HIV-infected pregnant women did not return for care. This finding strongly suggests a need to have targeted efforts to bring pregnant women into care in order to reduce mother-to-child transmission of HIV.

Findings from this study will inform policy on the design of interventions to limit non-enrollment of HIV-positive persons into HIV care.

In the Rakai program, HIV-positive persons who fail to enroll into HIV care program are actively followed up through community resident counselors.

Study strength and limitation

The strength of this study lies in the use of data derived from population-based cohort surveys in a mature and generalized HIV epidemic resource-limited setting. This makes the findings more generalizable to other settings. The use of secondary data, however, poses a limitation since the initial data collection tools were designed to address different research questions. We were therefore unable to explore some factors such as health beliefs, distance to health unit, etc. which have been identified as important for health-care utilization.

In conclusion, even with a free community-based program with intensive outreach we found that 31.5% of HIV-infected persons failed to utilize services even after learning their HIV results and being counseled to seek care. Non-enrollment for care was more common among men, the young, persons in

small households, suggesting a need for targeted strategies to enhance service uptake.

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