Socioeconomic Support Reduces Nonretention in a Comprehensive, Community-Based Antiretroviral Therapy Program in Uganda

Stella Talisuna-Alamo, MD, MDC, Robert Colebunders, MD, PhD,†‡ Joseph Ouma, BStat, MStat,§ Pamela Sunday, BScQE,* Kenneth Ekoru, BStat, MStat,|| Marie Laga, MD, PhD,¶ Glenn Wagner, PhD,# and Fred Wabwire-Mangen, MD, PhD***

Objectives: We evaluated the benefit of socioeconomic support (S-E support), comprising various financial and nonfinancial services that are available based on assessment of need, in reducing mortality and lost to follow-up (LTFU) at Reach Out Mbuya, a community-based, antiretroviral therapy program in Uganda.

Design: Retrospective observational cohort data from adult patients enrolled between May 31, 2001, and May 31, 2010, were examined.

Methods: Patients were categorized into none, 1, and 2 or more S-E support based on the number of different S-E support services they received. Using Cox proportional hazards regression, we modeled the association between S-E support and mortality or LTFU. Kaplan–Meier curves were fitted to examine retention functions stratified by S-E support.

Results: In total, 6654 patients were evaluated. After 10 years, 2700 (41%) were retained. Of the 3954 not retained, 2933 (74%) were LTFU and 1021 (26%) had died. After 1, 2, 5, and 10 years, the risks of LTFU or mortality in patients who received no S-E support were significantly higher than those who received some S-E support. In adjusted hazards ratios, patients who received no S-E support were 1.5-fold (1.39–1.64) and 6.7-fold (5.56–7.69) more likely to get LTFU compared with those who received 1 or ≥2 S-E support, respectively. Likewise, patients who received no S-E support were 1.5-fold (confidence interval: 1.16 to 1.89) and 4.3-fold (confidence interval: 2.94 to 6.25) more likely to die compared with those who received 1 or 2+ S-E support, respectively.

Conclusions: Provision of S-E support reduced LTFU and mortality, suggesting the value of incorporating such strategies for promoting continuity of care.

Key Words: HIV, socioeconomic support, loss to follow-up, mortality, retained antiretroviral therapy, community-based care

(*J Acquir Immune Defic Syndr* 2012;59:e52–e59)

INTRODUCTION

Antiretroviral therapy (ART) scale-up has transformed HIV/AIDS into a chronic, manageable disease.[1–4] However, life-long medication adherence and frequent clinic visits for clinical monitoring, laboratory tests, and counseling are intensive and demand patient commitment. For many poor patients, the indirect costs for these frequent visits including transport, missed employment days, and out-of-pocket expenses pose major barriers,[5–7] and are a primary reason for loss to follow-up (LTFU).[4,8–10] "I am sorry I missed my last clinic appointment. I had to look for money to buy food. In addition, none of my 5 school-age children attend school and the landlord wants rent. How can I spend the day at the clinic instead of looking for money to solve these problems?" This quote highlights the fact that the poor adapt their health care use to avoid costs they cannot meet at the risk of compromising their health.[8] Reestablishing the livelihoods of households of people living with HIV through socioeconomic (S-E) support (includes financial and nonfinancial benefits that are given to poor patients to improve adherence to medication and retention) may therefore be required to ensure retention in ART programs. However, with the urgency of initiating as many people as fast as possible on ART, little attention has been paid to S-E needs of the poor. Indeed, the initial 5 years of excellent patient outcomes[10–14] reported by rapidly scaled-up ART programs have dwindled, and presently, many programs are reporting substantial patient attrition.[15] In a review of 33 African cohorts, Rosen et al[16] reported overall retention rates of about 60% at the end of 2 years, which was largely attributed to LTFU. LTFU rates are influenced by S-E factors,[16–18] including characteristics

Received for publication July 12, 2011; accepted December 15, 2011.

From the *Medical Department, Reach Out Mbuya HIV/AIDS Initiative, Kampala, Uganda; †Department of Clinical Sciences, Institute of Tropical Medicine, Antwerp, Belgium; ‡Epidemiology and Social Medicine, University of Antwerp, Antwerp, Belgium; §Department of Strategic Planning, Management Sciences for Health, Kampala, Uganda; ||Clinical Epidemiology Unit, Makerere University; ¶HIV Epidemiology and Control Unit, Institute of Tropical Medicine, Antwerp, Belgium; #Health Unit, RAND Corporation, Santa Monica, CA; and **Department of Epidemiology and Biostatistics, Makerere University School of Public Health, Kampala, Uganda.

The authors have no funding or conflicts of interest to disclose.

S. Talisuna-Alamo, F. Wabwire-Mangen, R. Colebunders, and M. Laga conceived the study. S. Talisuna-Alamo and P. Sunday were involved in the data extraction. S. Talisuna-Alamo, J. Ouma, and K. Ekoru were responsible for all the statistical analyses and the initial manuscript draft. All authors contributed to the writing of the manuscript and approved the final version.

Correspondence to: Stella Talisuna-Alamo, MD, Reach Out Mbuya HIV/AIDS Initiative, P.O. Box 7303 Kampala, Uganda (e-mail: stellaalamo@gmail.com).

like provision of free services and comprehensive care, which have been shown to contribute to higher retention.[19,20] However, data are lacking on the long-term benefits of S-E support on retention in ART programs in resource-limited settings.

This retrospective observational cohort evaluation was undertaken to understand the contribution that S-E support plays in enabling patient retention. It is based on the 10-year experience of Reach Out Mbuya (ROM), a comprehensive, community-based ART program in Uganda.

METHODS

Study Site and Population

ROM was established in 2001 as a community, faith-based organization. It serves primarily the HIV care needs of the "poorest of the poor" from a defined catchment area, which includes 5 villages (Banda, Kinawataka, Giza Giza, Nakawa, and Acholi Quarters) that are within a 5-km radius of Kampala (the capital city). These villages are characterized by lack of basic social services including health care. The clients served are highly mobile, with many having migrated in search of work or health care. Kinawataka is a central point for long-distance truck drivers and is in close proximity to military barracks, potentially exacerbating prostitution and HIV transmission. Acholi Quarters is predominantly inhabited by persons displaced by the war in Northern Uganda; poverty and unemployment are potential drivers of the HIV epidemic in this area. To improve access, ROM provides services at 3 clinics (Mbuya, Kinawataka, and Banda) located within the vicinity of the 5 villages. The ROM model of care, fully described elsewhere,[21,22] offers comprehensive ART including concurrent S-E support interventions, designed to respond to the patients' basic needs. S-E support in the context of ROM means financial and nonfinancial benefits given to the poor and vulnerable as a strategy to improve medical outcomes. The types of S-E supports available to ROMs patients include school fees, rent payment or provision of shelter, employment at ROM, interest-free loans, adult literacy instruction, income-generating activities, transport, skills-building activities, and food assistance. Community health workers (CHWs) carry out a household assessment of every patient using standard questionnaires before enrollment to determine their S-E needs. Patients found eligible for S-E support at enrollment are referred to social workers, who carry out additional assessments using standard questionnaires, semistructured interviews, or validated tools[23–26] to confirm eligibility. S-E support is provided on a "needs-most gets-first" basis. Reassessments for continued support are done annually using the same standard questionnaires, and patients whose S-E situations have stabilized are phased-out using a predetermined phase-out plan.

Measurements, Definition of Outcomes, and Outcome Ascertainment

Demographic characteristics (age, sex, marital status, religion, village, and clinic), clinical characteristics (baseline CD4 counts, ART status, and occurrence of tuberculosis), and S-E support types (school fees, house rent, interest-free loans, adult literacy, income-generating activities, employment at ROM, skills building, and food assistance) were obtained from the clinics electronic records.

Patients were categorized as follows. (1) They were classified as "dead" if they appeared on ROM's lists of dead patients. If a patient dies in a health facility, a death certificate is provided and serves as proof of death. However, if the patient dies out of a health facility and death notification is availed by a CHW, family member, or any community member, the availability of a verbal autopsy (method of obtaining information about a deceased person by asking questions of family and others who can describe the mode of death or circumstances preceding death where post-mortem pathologic examination is not feasible) in the patient files serves as notification of death. If neither a verbal autopsy nor death certificated is available in the patient's records, the patient is classified as LTFU.

(2) Patients were categorized as "lost to follow-up" if they were enrolled with ROM but had a last contact with the facility 90 days or more before the end of the follow-up period and were not known to have died or to have been transferred out to another facility. (3) Patients were categorized as "retained" if they were still continuing care at ROM and had at least 1 contact with the facility during the 90 days before the end of the follow-up period. Transfer out is a desirable outcome and were excluded from the definition of attrition. Additionally, it was excluded from our category of retained patients because there are no statistics from Uganda on the estimated proportion of patients who "transfer-out" and in fact "transfer in-to" another treatment site and what their outcomes are within the new treatment site.

S-E support was categorized as (1) "no S-E support" if the patient received none of the S-E support types provided by ROM, (2) "1 S-E support" if the patient received only 1 S-E support type, or (3) "2 or more S-E support" if 2 or more S-E support types were received.

Deaths and LTFU were reported to the clinic by CHWs, who are responsible for defaulter (patients who fail to show up for appointments) tracing. Defaulter tracing is done on the same day that a patient misses a clinic appointment such that mortality among those LTFU is documented within a week of the missed appointment. In addition, a randomly selected representative sample of patients who were classified as LTFU was traced by a research team to ascertain their true outcomes during the follow-up period. Previous studies[16] have found a mortality of 20–60% among those classified as LTFU. We estimate that mortality among our LTFU group will be about 10%, given ROM's several interventions that are in place to ensure retention of patients and to identify those who are dead early. With a power of 95% and a significance level of 0.05, a total of 579 patients would be required to get our predicated estimates.

Data Analysis

Baseline characteristics of cohort were described using counts and percentages. Patients who died or were LTFU and those alive at the end of the study period were censored at the date of their last clinic visit. Multivariable Cox proportional

hazard models were constructed to estimate hazard ratios of mortality and LTFU, comparing those who received no S-E support, 1 S-E support, and 2 or more S-E support, while adjusting for relevant baseline covariates. Patients were analyzed by the highest number of S-E support they received. However, a patient who received a particular form of S-E support more than once was classified as having received that S-E support only once.

Village of residence was dropped from the analysis because it was strongly correlated with clinic (clinics are located within the villages). We tested the proportional hazards assumptions for potential interaction between each variable and time in a given model using the likelihood ratio test. We fitted Kaplan–Meier curves using annual intervals as the step-down points to describe the cumulative probability of progression to death or LTFU stratified by the number of S-E support types. We used the log rank test to examine statistical difference between groups. Results for death and LTFU were presented as probability estimates, rates, and hazard ratios with 95% confidence intervals (CIs). All reported P values are exact and 2-tailed, and P less than 0.05 was considered significant.

Ethical approval was obtained from Makerere University School of Public Health Institutional Review Board and the Uganda National Council of Science and Technology.

RESULTS

Sample Characteristics

Between May 31, 2001, and May 31, 2010, 7801 patients had been enrolled at ROM. Two hundred six patients were excluded from the study because they were followed up for less than 90 days (did not meet the definition of LTFU). Four hundred ninety patients who were formally referred to another facility and 451 who were aged <18 years were also excluded from the study. Children were excluded because their determinants of access to health including S-E support and treatment outcomes (adherence and retention) are determined by their parents or guardians. In addition, there is additional support provided to only children, which requires that their outcomes be analyzed separately.

Six thousand six hundred fifty-four (85%) of the patients were eligible for the study. After 10 years of follow-up, 2700 (40.5%) of them were still retained in care at ROM, 2933 (74%) of those not retained were LTFU, and 1021 (26%) had died (Fig. 1).

Table 1 shows the baseline characteristics of the study patients. The cohort was predominantly middle-aged, female, Catholic, married, and receiving services from the Kinawataka clinic. In total, 2669 (40%) of the patients evaluated received at least 1 S-E support type, the most common of which were food (1667, 59.6%), loans (2072, 31.2%), and school fees support for the patient's children (716, 25.6%). Others included training in entrepreneurship skills (236, 8.4%), rent payment (126, 4.5%), employment at ROM (114, 4.1%), and material support (88, 3.2%). Seven hundred sixty patients received 2+ forms of S-E support with a median 2 (interquartile range: 2–7).

Lost to Follow-up

The median time from enrollment to LTFU was 5.2 years (interquartile range: 2.3–7.7 years). Figure 2 shows the Kaplan–Meier estimates for LTFU for patients who received no S-E support, 1 S-E support, or 2 or more S-E support types. We observed a significant difference between the S-E support categories over time (log rank test, $P < 0.001$). At 1, 2, 5, and 10 years, the probability of being LTFU in those who received no S-E support was 17.3% (95% CI: 18.7 to 16.1), 27.7% (CI: 29.4–26.2), 58% (CI: 60.0 to 56.0), and 91.3% (CI: 92.8 to 89.8), respectively. The probability of being LTFU for those who received 1 S-E support was 11.8% (CI: 13.5 to 10.4), 19.6% (CI: 21.6 to 17.7), 44.2% (CI: 41.5 to 77.7), and 74.6% (CI: 77.7 to 71.4), respectively, whereas the probability of being LTFU for those who received 2 or more S-E support was 1.9% (CI: 3.3 to 3.8), 3.8% (CI: 5.6 to 2.6), 13% (CI: 15.9 to 10.6), and 33.6% (CI: 38.7 to 28.7), respectively.

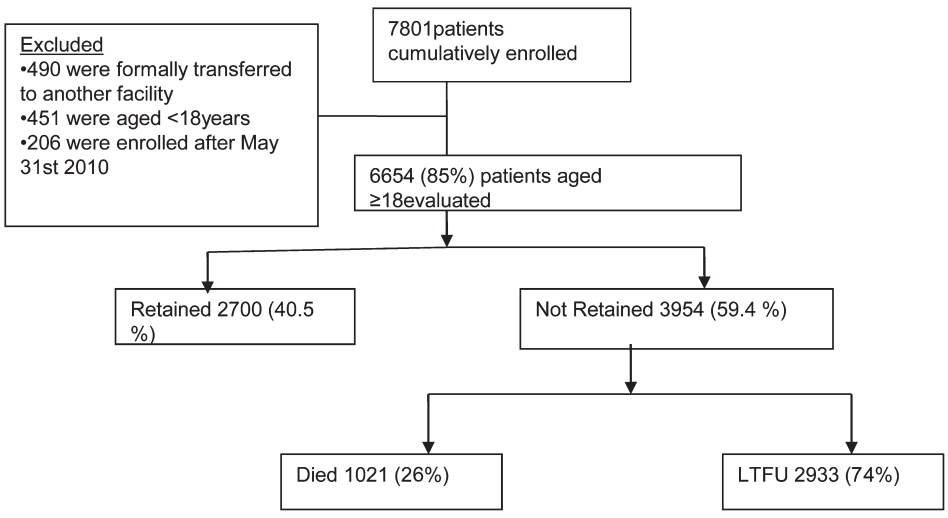

FIGURE 1. Flow chart of patients enrolled at the ROM HIV/AIDS Initiative clinics between May 31, 2001, and May 31, 2010.

TABLE 1. Patient Characteristics at Enrollment at ROM HIV/AIDS Initiative

Variable	All Patients, n (%)	LTFU, n (%)	Died, n (%)
Total	6654	2933	1021
Age (years)			
18–25	428 (6.4)	194 (6.6)	56 (5.5)
25–34	2,668 (40.1)	1130 (38.5)	367 (36.0)
35–44	2529 (38.0)	1149 (39.2)	405 (39.7)
45+	1029 (15.5)	460 (15.7)	193 (18.9)
Sex			
Male	2,416 (36.3)	1088 (37.1)	400 (39.2)
Female	4238 (63.7)	1845 (62.9)	621 (60.8)
Religion			
Catholic	4172 (62.7)	1772 (60.4)	625 (61.2)
Protestant	1903 (28.6)	887 (30.2)	291 (28.5)
Muslim	579 (8.7)	274 (9.3)	105 (10.3)
Marital status			
Single	291 (4.4)	127 (4.3)	11 (1.1)
Married	4661 (70.1)	2154 (73.4)	743 (72.8)
Widowed	895 (13.5)	355 (12.1)	136 (13.3)
Divorced	807 (12.1)	297 (10.1)	131 (12.8)
Clinic			
Mbuya	2570 (38.6)	1206 (41.1)	465 (45.5)
Banda	925 (13.9)	368 (12.6)	129 (15.9)
Kinawataka	3159 (47.5)	1359 (46.3)	427 (50.9)
CD4 count*			
<100	1286 (23.5)	518 (24.1)	278 (39.2)
100–250	1723 (31.5)	785 (36.4)	289 (41.1)
>250	2457 (45.0)	849 (39.5)	139 (19.7)
ART status			
Pre-ART	3941 (59.2)	1431 (48.8)	452 (44.3)
ART	2713 (40.8)	1502 (51.2)	569 (55.7)
S-E support			
None	3985 (59.9)	1973 (67.3)	653 (64.0)
One	1971 (29.6)	818 (27.9)	310 (30.4)
Two+	698 (10.5)	142 (4.8)	58 (5.7)

*Of 5546 who had CD4 count at enrollment.

In bivariate analysis, all forms of support except food support were independently significantly associated with LTFU. In Table 2, we show the results of the unadjusted and adjusted Cox proportional hazard models of time to LTFU. The overall LTFU rate was 15.10 per 100 person-years (PY). However, the LTFU rate for patients who received no S-E support was 20.48 per 100 PY compared with 13.50 per 100 PY for those who received 1 S-E support and 3.84 per 100 PY for those who received 2 or more S-E support. The adjusted model showed that risk of LTFU increased significantly with decreasing number of forms of S-E support received after adjusting for sex, religion, marital status, clinic, baseline CD4 count, and CD4 count at last clinic visit. Relative to patients who received 1 S-E support, patients who received no S-E support were 1.5 times (CI: 1.39 to 1.64) more likely to get LTFU compared with those who received 1 form of S-E support and 6.7 (CI: 5.56 to 7.69) times more likely to get LTFU compared with those who received 2 or more forms of S-E support.

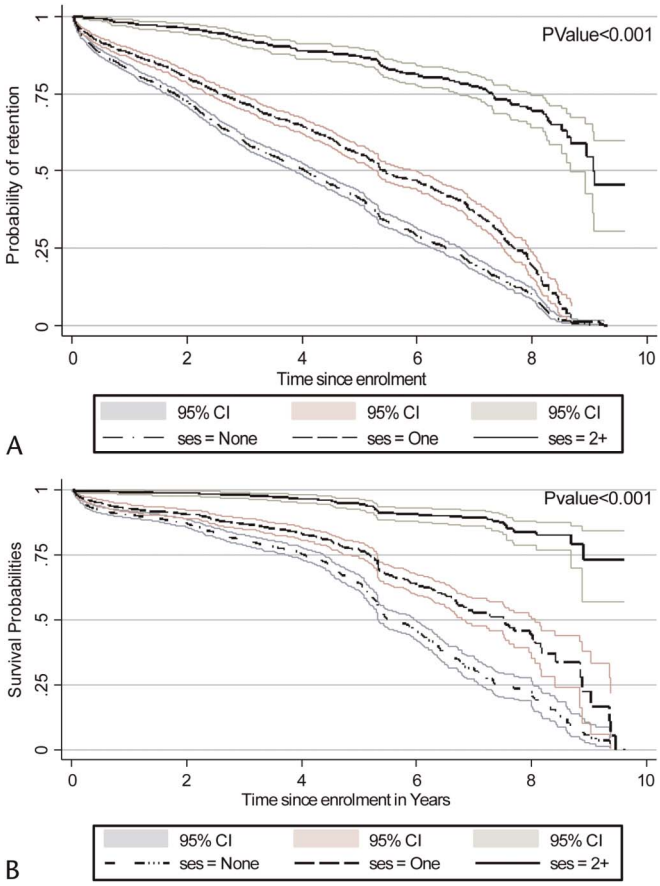

FIGURE 2. Retention benefits of S-E support on survival in ROM (A) Kaplan–Meier plot showing probability of not getting LTFU stratified by S-E support (n = 2933). B, Kaplan–Meier plot showing probability of survival stratified by S-E support (n = 1021).

Mortality

The median survival time was 7.5 years (interquartile range: 5.0–9.0). Figure 2b shows the Kaplan–Meier plots for survival over a 10-year period. Cumulative mortality showed an increasing trend with a decrease in number of S-E support received and was highest for patients who received no S-E support (log rank test, $P < 0.001$). At 1, 2, 5, and 10 years, the probability of death in those who received no S-E support was 10.0% (CI: 11.5% to 8.7%), 13.2% (CI: 14.9% to 11.7%), 33.8% (CI: 36.5% to 31.2%), and 28.9% (CI: 79.1% to 71.5%), respectively. The probability of death for those who received 1 S-E support was 7.2% (CI: 8.9% to 5.8%), 9.5% (CI: 11.4% to 7.9%), 22.5% (CI: 25.5% to 19.9%), and 51.9% (CI: 56.9% to 47.2%), respectively, whereas the probability of death for those who received 2 or more S-E support was 0.7% (CI: 1.9% to 0.3%), 1.1% (CI: 2.4% to 0.5%), 5.1% (CI: 7.4% to 3.5%), and 18.5% (CI: 23.2% to 14.1%), respectively.

In bivariate analysis, all forms of support except food support were independently significantly associated with mortality. In Table 3, we show the unadjusted and adjusted mortality outcomes for all patients who received no, 1, and

TABLE 2. Demographic, S-E, and Clinical Characteristics Associated With LTFU in Multivariable Cox Proportional Hazard Models (N = 2933)

Variable	Time at Risk	Incidence Rate/100 PY	Unadjusted Hazard Ratio (95% CI)	*P*	Adjusted Hazard Ratio (95% CI)	*P*
Age (years)						
18–24	10.6212	17.6	1		Dropped	
25–34	78.1144	14.2	0.83 (0.71 to 0.97)	0.018		
35–44	73.4096	15.3	0.89 (0.77 to 1.04)	0.165		
45+	28.5256	15.8	0.951 (0.77 to 1.08)	0.281		
Sex						
Male	62.86	16.9	1		1	
Female	127.988	14.1	0.80 (0.74 to 0.86)	<0.001	0.89 (0.82 to 0.96)	0.003
Religion						
Catholic	128.12	13.6	1		1	
Protestant	48.33	17.9	1.41 (1.30 to 1.53)	<0.001	1.52 (1.40 to 1.65)	<0.001
Muslim	14.21	18.7	1.49 (1.30 to 1.69)	<0.001	1.69 (1.48 to 1.92)	<0.001
Marital status						
Single	6.899	17.6	1		1	
Married	131.164	16.1	0.86 (0.72 to 1.04)	0.122	0.89 (0.74 to 1.07)	0.201
Widowed	31.021	11.3	0.58 (0.47 to 0.71)	<0.001	0.73 (0.60 to 0.90)	0.003
Divorced	21.584	11.9	0.76 (0.61 to 0.94)	0.010	0.76 (0.62 to 0.94)	0.012
Clinic						
Mbuya	67.9324	17.4	1		1	
Banda	34.0527	10.7	0.61 (0.54 to 0.69)	<0.001	0.70 (0.63 to 0.79)	<0.001
Kinawataka	88.6857	14.9	0.92 (0.84 to 0.99)	0.038	0.92 (0.85 to 0.99)	0.045
Medication status						
ART	95.020	15.08	1		1	
Pre-ART	95.650	14.35	0.98 (0.91 to 1.05)	0.560	0.96 (0.89 to 1.03)	0.281
Tuberculosis						
Yes	33.68	2.82	1		1	
No	156.98	17.708	1.02 (0.84 to 1.25)	0.787	1.24 (0.93 to 1.63)	0.134
Baseline CD4 count						
<100	37.5494	13.555	1			
100–250	54.5686	14.037	1.04 (0.93 to 1.16)	0.449	1.26 (1.07 to 1.49)	0.006
>250	74.7254	11.241	0.91 (0.81 to 1.01)	0.083	1.35 (1.17 to 1.57)	<0.001
CD4 count at last clinic visit						
<100	8.7211	30.1568	1		1	
100–250	31.4285	16.3864	0.54 (0.47 to 0.63)	<0.001	0.59 (0.51 to 0.69)	<0.001
>250	93.9504	5.5135	0.18 (0.15 to 0.21)	<0.001	0.22 (0.19 to 0.26)	0.001
S-E support						
None	94.099	20.48	1		1	
One	59.614	13.50	0.65 (0.60 to 0.71)	<0.001	0.66 (0.61 to 0.72)	<0.001
Two+	36.957	3.84	0.15 (0.12 to 0.18)	<0.001	0.15 (0.13 to 0.18)	<0.001

2 or more S-E support. The overall mortality rate was 7.8 per 100 PY. However, those who received no S-E support had a mortality rate of 10.91 per 100 PY compared with 6.91 per 100 PY and 1.73 per 100 PY for those who received 1 and 2 or more forms of S-E support, respectively. After adjusting for age, sex, marital status, medication status, presence of tuberculosis, and baseline and last CD4 counts, patients who received no S-E support were 1.5 times (CI: 1.16 to 1.89 times) more likely to die compared with those who received 1 form of S-E support, and 4.3 times (CI: 2.94 to 6.25 times) more likely to die compared with those who received 2 or more forms of S-E support.

Outcome Ascertainment

Of the 2933 patients who were LTFU, 579 (20%) were randomly sampled and traced for outcome ascertainment. Only 66 (11.4%) were confirmed dead, 232 (40%) had stopped care but available within the communities, and 249 (43%) had self-transferred to another facility. Only 32 (5.5%) patients could not be traced.

DISCUSSION

A key outcome of ART programs is the combined attrition due to death and LTFU. In ROM, a comprehensive, community-based ART program, only 40% of the patients

TABLE 3. Demographic, S-E, and Clinical Characteristics Associated With Mortality in Multivariable Cox Proportional Hazard Models (N = 1021)

Variable	Time at Risk	Incidence Rate/100 PY	Unadjusted Hazard Ratio (95% CI)	*P*	Adjusted Hazard Ratio (95% CI)	*P*
Age (years)						
18–24	6.744	8.3032	1		1	
25–34	56.268	6.4868	0.72 (0.55 to 0.96)	0.024	0.58 (0.41 to 0.84)	0.004
35–44	53.249	7.5682	0.83 (0.62 to 1.09)	0.193	0.60 (0.42 to 0.87)	0.008
45+	21.274	8.9778	0.96 (0.71 to 1.29)	0.806	0.77 (0.52 to 1.14)	0.198
Sex						
Male	45.088	8.7828	1		1	
Female	92.448	6.6956	0.72 (0.64 to 0.20)	<0.001	0.88 (0.75 to 1.04)	0.133
Religion						
Catholic	90.874	6.8446	1		—	
Protestant	35.592	8.1196	1.22 (1.06 to 1.41)	0.005	—	
Muslim	11.069	9.3949	1.42 (1.16 to 1.76)	0.001	—	
Marital status						
Single	4.688	2.1327	1		1	
Married	90.317	8.1823	3.77 (2.02 to 7.05)	<0.001	4.72 (1.94 to 11.5)	0.001
Widowed	24.7308	5.4992	2.32 (1.22 to 4.43)	0.010	3.71 (1.49 to 9.22)	0.005
Divorced	17.800	7.3032	3.48 (1.83 to 6.62)	<0.001	4.08 (1.64 to 10.12)	0.002
Clinic						
Mbuya	45.420	10.1717	1			
Banda	26.144	4.8577	0.45 (0.36 to 0.54)	<0.001	Dropped	
Kinawataka	65.972	6.4572	0.70 (0.62 to 0.80)	<0.001		
Medication status						
ART	59.201	9.6112	1		1	
Pre-ART	78.335	5.6935	1.5 (1.34 to 1.74)	<0.001	1.37 (1.17 to 1.61)	<0.001
Tuberculosis						
Yes	7.056	8.644	1		1	
No	130.480	7.311	0.72 (0.56 to 0.94)	0.015	0.56 (0.42 to 0.75)	<0.001
Baseline CD4 count						
<100	29.030	9.438	1		1	
100–250	38.654	7.476	0.83 (0.69 to 0.96)	0.015	0.64 (0.48 to 0.84)	0.001
>250	57.958	2.398	0.27 (0.22 to 0.33)	<0.001	0.45 (0.34 to 0.58)	<0.001
CD4 count at last clinic visit						
<100	5.316	17.493	1		1	
100–250	22.913	6.197	0.35 (0.27 to 0.46)	<0.001	0.36 (0.28 to 0.48)	<0.001
>250	81.758	1.076	0.06 (0.04 to 0.08)	<0.001	0.78 (0.06 to 0.11)	<0.001
S-E support						
None	59.34	10.9184	1		1	
One	44.69	6.9141	0.59 (0.51 to 0.67)	<0.001	0.67 (0.53 to 0.86)	0.002
Two+	33.49	1.7316	0.11 (0.08 to 0.14)	<0.001	0.23 (0.16 to 0.34)	<0.001

were retained in care after 10 years. However, outcomes ascertainment confirmed that about 50% of those who were classified as LTFU had actually self-transferred to another facility (a more favorable outcome).

An earlier evaluation of ROM[21] found a retention rate of 89% at 12 months and 82% at 24 months. Rosen et al[16] found retention rates in Uganda of only 49% at 12 months and 46% at 24 months, with a trajectory toward even lower retention rates at the latter time points. Additionally, in a study of 13 African cohorts, Braitstein et al[15] noted an average of 15% LTFU at 12 months after ART initiation with variability ranging from 0% to 44% across programs. We have not come across similar studies that document 10 years of follow-up with which to compare our findings with. However, contrary to its early comparably excellent retention rates, ROM is now experiencing increasing LTFU and mortality.

The increasing LTFU at ROM may have several explanations. First, ROM serves a poor, mobile population with rural–urban migration patterns. Earlier ART scale-up efforts in Uganda targeted the urban population.[27] Expansion in availability of ART in rural communities has increased providing opportunities for patients who had migrated in search of health care to be treated closer to their homes. This confirms the importance of decentralizing ART scale-up with strengthened referral between rural and urban facilities. The increasing LTFU rates may also reflect the decreasing

capacity to adequately follow-up and support patients to remain in care given the escalating caseload and adversely affected health worker:patient ratios.[22] At the time of this evaluation, ROM had 2700 active patients cared for by 9 nurses and 34 CHWs giving a clinician:patient ratio of 1:300 and CHWs:patient ratio of 1:80. Moreover, the CHWs who are responsible for tracing defaulting patients have several other assignments including home-based care and adherence monitoring, confirming residency of new patients, referring clients for HIV testing, follow-up of orphans and vulnerable children, assessment of patients eligibility for S-E support, managing referrals between the community and facility, community sensitization on health matters, record keeping, and report writing. Unlike other studies,[28,29] we found an insignificantly higher LTFU among ART compared with pre-ART patients. This difference could be a result of intensive follow-up and defaulter tracing of both pre-ART and ART patients by CHWs at ROM. Retention was better among females, which is consistent with findings from similar studies[30] and calls for innovative male-friendly strategies that can link and retain men in care. A high proportion of patients classified as LTFU had in fact self-transferred to other centers, highlighting the challenge that programs in resource-limited settings face in ascertaining the vital status of patients, which poses an obstacle in understanding the effectiveness of ART programs. Linked countrywide data using unique patient identifiers, shared across facilities may address this challenge. Tracing patients at home is labor intensive and may not be cost effective for facility-based programs. However, about 80% of the patients deemed LTFU at ROM had either stopped care (but available in the communities) or self-transferred to other facilities. It is therefore apparent that even in community-based programs, the number of patients who get LTFU exceeds the number that can be traced by the CHWs. Additionally, patients who stopped care or self-transferred from ROM are likely to be dissatisfied with the service or have barriers that the current model of care does not address. Although this article does not explore this issue further, the findings warrant further investigations, which are under way.

Although better than that found in several other studies,[13,31] the substantial mortality among ROM's patients can be explained by provision of care to patients presenting with late-stage disease. Lower baseline CD4 counts have been shown to predict nonretention mainly associated with mortality.[13] In our study, pre-ART patients were almost 1.4 times ($P < 0.001$) more likely to die than the ART patients, a possible reflection of late initiation of ART among those who are eligible. Several studies have documented substantial mortality among those LTFU.[15,16] In contrast, our study found only 5.5% mortality among those deemed LTFU, which may reflect stronger notification, death ascertainment, and reporting of deaths by CHWs at ROM. Patients who miss an appointment are traced at home on the same day. In addition, patients who are newly enrolled or have lower CD4 counts are followed up more intensively than the more stable patients such that mortality is documented within a week of a missed appointment.

Delivery of care through satellite clinics or home-based care has previously been shown to ensure continuity of care.[32] There was considerable variation in LTFU and mortality across ROMs clinics. Although Kinawataka has the highest number of patients, it was more likely to retain more patients than Mbuya, which is less proximal to the communities it serves. Banda, which is most proximal to the communities, had the best retention, confirming that distance and transportation barriers can easily be overcome by the use of satellite clinics located close to the population served.

Our findings confirm that providing S-E support addresses several poverty-related barriers associated with poor retention in ART programs in resource-limited settings. It was not possible in this analysis to separate individual benefits of the different types of S-E support because of the small numbers of beneficiaries receiving some types of S-E support. Our findings, however, illustrate that the combined effects of S-E support are beneficial in reducing both mortality and LTFU. There was high drop out of patients in the last 2 years of follow-up, and there are several plausible explanations for this. ROM beneficiaries of S-E support are the poorest and are more likely to have lower CD4 counts due to delayed access to care. Benefits of S-E support may therefore be more significant if strategies for early testing and linkage into care are scaled-up. It is also possible that as people regain their strength and return to work, the motivation to remain in care for basic needs support declines. Additionally, the increasing availability of ART in the rural settings may be a motivation for people who had migrated to the ROM catchment area in search of health care and S-E support to return back home to their families.

These findings have a number of implications for the delivery of ART in resource-limited settings. Foremost, our experience shows that over 10 years, there is a high patient attrition from ROM, a program that addresses many socio-structural barriers including strong systems for monitoring patients. However, given available data on earlier retention rates in resource-limited settings, it is possible that the current rates we observe at ROM may still be considerably better. These findings come amidst recommendations for community-based, comprehensive programs as a strategy to improve patient retention in ART programs in resource-limited settings.[13,32] As mentioned earlier, important questions remain unanswered and additional studies are under way to understand the reasons for LTFU from ROM. Second, the high mortality rates highlight the urgent need for innovative strategies to enhance the uptake of testing for mobile populations and to ensure that those who test positive are quickly linked into care through a decentralized ART delivery model. Third, although we found benefits of S-E support in reducing both mortality and LTFU, the pathways and effects of S-E support on mortality (eg, via food security) and LTFU (eg, via ability to pay for transport) are different. It may therefore be necessary to unpack which aspects of S-E support have greater retention benefits for different target groups or populations. Ultimately, the efficiency and effectiveness of the model of care can be improved. Last, the labor-intensive, comprehensive design of ROM raises questions about the cost-effectiveness of the model, which needs to be examined including broader benefits to the families and communities.

This analysis is not without limitations including its retrospective nature and the use of data, which were collected for purposes of clinical care and not research. Additionally, reported mortality estimates could have been underestimated as some predictors of death also predict LTFU, and LTFU most likely represents a heterogeneous group including those with as of yet undetermined deaths.[33–36]

CONCLUSIONS

Our study demonstrates an association between lower patient attrition/mortality and LTFU and S-E support in a community-based ART program in sub-Saharan Africa. Other programs in resource-limited settings should incorporate strategies to integrate or link patients into S-E support initiatives. However, better understanding of contextual factors for LTFU and the cost-effectiveness of this model are required before conclusions can be drawn about its scalability.

ACKNOWLEDGMENTS

The authors would like to thank all the patients and staff for all their contributions toward the data used for this evaluation.

REFERENCES

1. Egger M, May M, Chene G, et al. Prognosis of HIV-1-infected patients starting highly active antiretroviral therapy: a collaborative analysis of prospective studies. *Lancet*. 2002;360:119–129.
2. Hogg RS, Yip B, Kully C, et al. Improved survival among HIV-infected patients after initiation of triple-drug antiretroviral regimens. *CMAJ*. 1999;160:659–665.
3. Mocroft A, Vella S, Benfield TL, et al. Changing patterns of mortality across Europe in patients infected with HIV-1. EuroSIDA Study Group. *Lancet*. 1998;352:1725–1730.
4. Sterne JA, Hernan MA, Ledergerber B, et al. Long-term effectiveness of potent antiretroviral therapy in preventing AIDS and death: a prospective cohort study. *Lancet*. 2005;366:378–384.
5. Weidle PJ, Wamai N, Solberg P, et al. Adherence to antiretroviral therapy in a home-based AIDS care programme in rural Uganda. *Lancet*. 2006;368:1587–1594.
6. Colebunders R, Kamya M, Semitala F, et al. Free antiretrovirals must not be restricted only to treatment-naive patients: experience in Uganda suggests that restricting access is not the way forward. *PLoS Med*. 2005;2: e276.
7. Chesney MA, Morin M, Sherr L. Adherence to HIV combination therapy. *Soc Sci Med*. 2000;50:1599–1605.
8. Wallman S, Baker M. Which resources pay for treatment? A model for estimating the informal economy of health. *Soc Sci Med*. 1996;42: 671–679.
9. Coetzee D, Hildebrand K, Boulle A, et al. Outcomes after two years of providing antiretroviral treatment in Khayelitsha, South Africa. *AIDS*. 2004;18:887–895.
10. Goudge J, Govender V. *A Review of Experience Concerning Household Ability to Cope With the Resource Demands of Ill-health and Health Care Utilization. Regional Network for Equity in Health in Southern Africa (Equinet) Policy Series No. 3*. Harare, Zimbabwe: Training and Resource Centre; 2000.
11. Mills EJ, Nachega JB, Buchan I, et al. Adherence to antiretroviral therapy in sub-Saharan Africa and North America: a meta-analysis. *JAMA*. 2006; 296:679–690.
12. Bekker LG, Orrell C, Reader L, et al. Antiretroviral therapy in a community clinic: early lessons from a pilot project. *S Afr Med J*. 2003;93:458–462.
13. Stringer JS, Zulu I, Levy J, et al. Rapid scale-up of antiretroviral therapy at primary care sites in Zambia: feasibility and early outcomes. *JAMA*. 2006;296:782–793.
14. Boulle A, Bock P, Osler M, et al. Antiretroviral therapy and early mortality in South Africa. *Bull World Health Organ*. 2008;86:678–687.
15. Braitstein P, Brinkhof MW, Dabis F, et al. Mortality of HIV-1 infected patients in the first year of antiretroviral therapy: comparison between low-income and high-income countries. *Lancet*. 2006;367:817–824.
16. Rosen S, Fox MP, Gill CJ. Patient retention in antiretroviral therapy programs in sub-Saharan Africa: a systematic review. *PLoS Med*. 2007;4:e298.
17. Mills EJ, Nachega JB, Bangsberg DR, et al. Adherence to HAART: a systematic review of developed and developing nation patient-reported barriers and facilitators. *PLoS Med*. 2006;3:e438.
18. Weiser S, Wolfe W, Bangsberg D, et al. Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana. *J Acquir Immune Defic Syndr*. 2003;34:281–288.
19. Nash D, Korves C, Saito S, et al. Characteristics of facilities and programs delivering HIV care and treatment services are associated with loss to follow-up rates in programs from 7 Sub-Saharan African countries. Fifteenth Conference on Retroviruses and Opportunistic Infections, Boston, MA, February 2008. [abstract 838]. Available at: http://www.retroconference.org/2008/Abstracts/33224.htm Accessed October 15, 2009.
20. Lawn SD, Kaplan R, Wood R, et al. Promoting retention in care: an effective model in an antiretroviral treatment service in South Africa. *Clin Infect Dis*. 2007;45:803.3.
21. Larry WC, Alamo S, Guma S, et al. Two year virologic outcomes of an alternative AIDS care model: evaluation of a peer health worker and nurse-staffed community-based programme in Uganda. *J Acquir Immune Defic Syndr*. 2009;50:276–282.
22. Amanyire G, Wanyenze R, Alamo S, et al. Client and provider perspectives of the efficiency and quality of care in the context of rapid scale-up of antiretroviral therapy. *AIDS Patient Care STDS*. 2010;24:441–446.
23. WFP/UNHCR. UN/Inter-agency Guidelines WFP/UNHCR Joint Assessment Guidelines (JAMs), March 2009.
24. FAO/WFP. Joint Guidelines for Crop & Food Security Assessment Missions (CFSAMs), January 2009.
25. IASC. Initial Rapid Assessment (IRA): Guidance Notes & Field Assessment Form.
26. UNAIDS, UNICEF, USAID, WFP and FAO. *An Update on the National Plans of Action for Orphans and Children Made Vulnerable by HIV/AIDS and the Second Phase of the Rapid Assessment, Analysis and Action Planning Process*. New York, NY: UNICEF; 2005.
27. WHO/UNAIDS. *Access to HIV Treatment Continues to Accelerate in Developing Countries, but Bottlenecks Persist*. Geneva, Switzerland: World Health Organization; 2005.
28. Bassett IV, Wang B, Chetty S, et al. Loss to care and death before antiretroviral therapy in Durban, South Africa. *J Acquir Immune Defic Syndr*. 2009;51:135–139.
29. Losina E, Bassett IV, Giddy J, et al. The "ART" of linkage: early loss to follow-up (LTFU) after HIV diagnosis at two PEPFAR sites in Durban, South Africa. Presented at: XVIIth International AIDS Society Meeting; August 3–8, 2008; Mexico City, Mexico. Poster TUPE0345.
30. Wools-Kaloustian K, Kimaiyo S, Diero L, et al. Viability and effectiveness of large-scale HIV treatment initiatives in sub-Saharan Africa: experience from Western Kenya. *AIDS*. 2006;20:41–48.
31. Mills EJ, Bakandab C, Birungi J. Mortality by baseline CD4 cell count among HIV patients initiating antiretroviral therapy: evidence from a large cohort in Uganda. *AIDS*. 2011;25:851–855.
32. Zachariah R, Teck R, Buhendwa L, et al. Community support is associated with better antiretroviral treatment outcomes in a resource-limited rural district in Malawi. *Trans R Soc Trop Med Hyg*. 2007;101:79–84.
33. Maskew M, Mac Phail P, Menezes C, et al. Lost to follow up: contributing factors and challenges in South African patients on antiretroviral therapy. *S Afr Med J*. 2007;97:853–857.
34. Yu JK, Chen SC, Wang KY, et al. True outcomes of patients on antiretroviral therapy who are "lost to follow up" in Malawi. *Bull World Health Organ*. 2007;85:550–554.
35. Bisson GP, Gaolathe T, Gross R, et al. Overestimates of survival after HAART: implications for global scale-up efforts. *PLoS One*. 2008;3:e175.
36. Lawn SD, Myer L, Harling G, et al. Determinants of mortality and nondeath losses from an antiretroviral treatment service in South Africa: implications from program evaluations. *Clin Infect Dis*. 2006;43: 770–776.