Community-based contact tracing for patients enrolled in a district-wide program for antiretroviral therapy

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Background

Adherence to combination antiretroviral therapy (ART) is considered a major challenge to the long-term survival of AIDS patients.[1, 2] Many studies have shown that non-adherence to treatment results in poor viral suppression, increased disease progression and heightened mortality.[3-5]

Although most have focused on adherence in the context of medication (i.e., percentage of prescribed pills ingested), several recent studies have shown that timeliness for clinic appointments also correlates highly with virologic outcomes.[6-8] The primary advantage of this approach is the ease with which data may be collected, particularly given the difficulties inherent to obtaining accurate pill counts in a large programmatic setting.

We studied why people miss clinic appointments in the setting of a large African program for HIV care and treatment. We also investigated the effectiveness of a district-wide initiative for contact tracing through: (1) success rate of follow-up home visits and (2) rate of return visits following patient contact.

Methods

The Lusaka district program for HIV care and treatment has been described elsewhere.[9, 10] Briefly, services have scaled up rapidly since May 2004 and are now fully implemented in 12 of the district's primary health care facilities. As of June 2006, an estimated 39,000 had enrolled into long-term care, with more than 27,000 initiating antiretroviral therapy (ART). All care is provided free of charge.

Care is provided according to the Zambian National Guidelines, which closely follow guidelines set forth by the World Health Organization.[11] Specific patient indicators are routinely entered into a centralized database, including date of next appointment.[12] At enrollment, all patients provide locator information such as address, telephone number, and hand-drawn maps; these are updated as needed at later visits.

On a regular basis, lists of patients with missed visits are generated and provided to a home-based care coordinator at each facility. This coordinator then divides the list according to geographic location for further follow-up by home-based caregivers.

Overall, 272 caregivers have been trained specifically for patient follow-up in the context of HIV care and treatment. This includes emphases surrounding patient confidentiality and privacy, recognition of basic drug side effects, and basic counseling on treatment adherence. Because they are part of a larger district initiative, these volunteers are not paid directly for these home visits. Instead, they receive access to exclusive income generating activities, such as micro-credit schemes and second-hand clothing sales. At the completion of home visits, each caregiver provides an open-ended, written synopsis of the encounter.

For this analysis, we collected follow-up information from a cohort of patients from May 2005 to September 2005. We reviewed and classified these forms according to the outcome of the visit (patients successfully traced, patient untraceable, and patient reported to have died). Any reasons the patient cited for missing an appointment were categorized and tabulated.

We then linked these patient forms to their clinical history. Individual-level patient information was derived from our programmatic database. We thus compared the various groups (e.g. traceable, untraceable, dead) based on demographic and medical characteristics. We also were able to determine rates of return to the clinic, following the home visit.

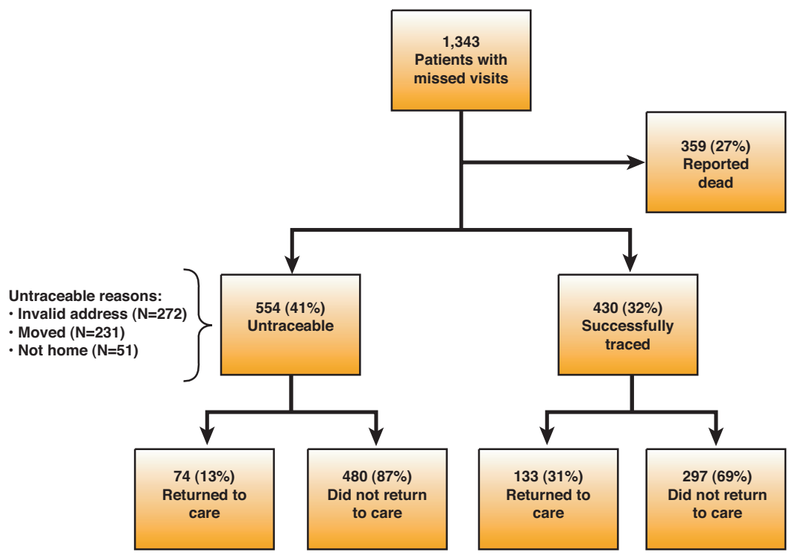
We compared continuous variables across patient classifications using t tests and evaluated the normality assumption for each using the Kolmogorov-Smirnov test. We compared dichotomous and categorical variables with the Chi-square test statistic or Fisher's exact test statistic. A p-value of ≤ 0.05 was considered significant. Data were analyzed between January and June 2006 using SAS® version 9.1.3 (SAS Institute, Cary, NC, USA).

Results

Between May 2005 and September 2005, home-based caregivers were dispatched to trace 1,343 patients with missed appointments. Of the 1,343 patients who we attempted to trace, 654 (49%) were on ART and 301 (22%) did not yet qualify for HIV treatment. An additional 388 (29%) failed to return after only one visit and did not receive their CD4+ lymphocyte or WHO staging result. The median age of the patients was 32 years (IQR=27-39). 38% of patients were male.

Of these 1,343 late patients, 554 (41%) were untraceable because the provided address was invalid; the patient had moved; or the patient was not at home. Of the remaining 789, 359 (46%) were reported to have died. Only the remaining 430 (54% of those traced, 32% overall) were contacted directly and reminded about their missed appointment (FIGURE 1).

FIGURE 1: Outcomes of home-based care follow-up of late patients



Patients were then categorized as: (1) traceable, (2) untraceable, and (3) known dead. Full comparisons of demographic and medical characteristics are shown in (TABLE 1). Although untraceable patients resembled those who were known to be alive (i.e., traceable), we believe the group likely represents a mixture of individuals alive and dead.

TABLE 1: Comparison of patients followed-up after a missed appointment

	Untraceable (N = 554)	Traceable (N = 359)	P*	Reported dead (N = 430)	P*
Biographic characteristics					
Age, mean (sd)	31.3 (11.3)	31.6 (11.4)	0.60	33.5 (11.0)	0.003
Male, n (%)	215 (39%)	138 (32%)	0.03	154 (43%)	0.21
Enrollment health indicators					
Entry WHO stage			0.69		<.0001
1	119 (22%)	80 (19%)		19 (5%)	
2	126 (23%)	100 (24%)		44 (12%)	
3	251 (46%)	201 (49%)		223 (63%)	
4	48 (9%)	32 (8%)		223 (63%)	
Entry WHO stage 3 or 4, n (%)	299 (55%)	233 (56%)	0.65	290 (82%)	<.0001
CD4+ count, n (%)			0.11		<.0001
< 50	94 (19%)	50 (13%)		126 (38%)	
51 – 200	183 (36%)	147 (37%)		137 (42%)	
201 – 350	119 (24%)	104 (26%)		44 (13%)	
> 350	108 (21%)	93 (24%)		22 (7%)	
Entry CD4+ count ≤ 200	277 (55%)	197 (50%)	0.14	263 (80%)	<.0001
Entry body mass index, mean (sd)	20.4 (3.5)	21.1 (3.8)	0.01	18.6 (3.7)	<.0001
Tuberculosis co-infection at enrollment	37 (7%)	32 (7%)	0.64	35 (10%)	0.09
ART history/eligibility			0.01		0.001
On ARVs before coming to our clinic site	17 (3%)	20 (5%)		11 (3%)	
Started ARVs at our clinic site	220 (40%)	205 (48%)		181 (50%)	
On ARVs	237 (43%)	225 (52%)		192 (53%)	
Did not return after enrollment visit	177 (32%)	99 (23%)		112 (31%)	
Not eligible for ARVs	140 (25%)	106 (25%)		55 (15%)	
Drug regimen, n (%)			0.84		0.04
ZDV + 3TC + NVP	129 (23%)	124 (29%)		75 (21%)	
ZDV + 3TC + EFV	4 (1%)	7 (2%)		3 (1%)	
D4T + 3TC + NVP	87 (16%)	84 (20%)		95 (26%)	
D4T + 3TC + EFV	8 (1%)	4 (1%)		8 (2%)	
Subsequently returned to clinic for continued care, n (%)	**74 (13%)**	**133 (31%)**	**<.0001**	**N/A**	**N/A**

* Both traceable patients and patients reported to have died were compared with untraceable patients.

Reasons for missed visits were recorded in 271 of 430 (63%) of the patients who were successfully traced. Common reasons for missed visits are shown in TABLE 2. Other reasons included: confusion about the date of the appointment; patient's employer not allowing time off; and hospitalization at time of clinic appointment. Some patients also cited religious beliefs, side effects, and a lack of support as reasons for missing their clinic appointment.

TABLE 2: Most commonly cited reasons for missing an appointment

Reason	N	% of patients who gave reason
Too sick to come to the clinic	61	23%
Away from home	43	16%
Too busy with work or personal business	36	13%
Unsure about starting antiretroviral treatment	19	7%
Negatively influenced by other people	18	7%
Surplus of medication at home	17	6%
No money for transportation to and from clinic	14	5%
Dissatisfied with clinical experience	14	5%
Confused or misinformed about drug regimen	14	5%
Lost patient ID card	14	5%
Forgot about appointment	13	5%
Feels better	10	4%

Lastly, we compared the proportion of individuals that returned to clinical care following an attempted home visit among the traceable and untraceable groups. Patients successfully contacted by home-based caregivers were more likely to return to the clinic compared with those who were untraceable (31% vs. 13%, $p < 0.0001$). For patients who were successfully contacted, median time from home-based caregiver interaction to return clinic visit was 14 days (IQR=5-30).

Conclusions

- Despite the availability of free ART in Lusaka, patients face significant barriers to attending their clinic appointments. Our review serves as a reminder that patients need assistance in balancing the demands of daily life with the challenge of adhering to treatment.[13]
- While this program modestly improved the rate of late patients returning to the clinic, it is inefficient: the data suggest that 18 attempted home visits are required for one late patient to return to care. Possible ways of improving this program include paying caregivers an incentive fee for each successful follow-up visit; ensuring that clinical staff routinely review locator information with patients; and expanding available clinic space and counseling staff for further adherence support.
- Although imperfect, our model of community-based contact tracing provides tangible benefits to late patients. Our experiences here provide a useful framework for programs in similar settings. Novel strategies are clearly needed to improve the number of traceable patients and bolster the rate of return visits.

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