Tracing patients lost-to-follow-up on antiretroviral treatment in an urban slum: Experience from a partnership between an HIV-Clinic and a Non-Governmental Organization Network in Mumbai, India
Tracing patients lost-to-follow-up on antiretroviral treatment in an urban slum: Experience from a partnership between an HIV-Clinic and a Non-Governmental-Organization Network in Mumbai, India

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We declare that we have no conflict of interest.

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ABSTRACT

Aim
This paper describes a cooperative initiative between an HIV-clinic and non-government organization network providing lost-to-follow-up tracing and delayed appointment follow-up of patients on antiretroviral treatment.

Background
Loss-to-follow-up among patients on antiretroviral treatment is a major challenge in resource-constrained settings. A model of cooperation between a Médecins Sans Frontières HIV-clinic and a non-governmental-organisation network was piloted in a Mumbai slum. A steady decline in delayed appointments and loss-to-follow-up was observed over a four years period.

Methods
A mixed-method study conducted in January 2011 explored potential reasons for declining loss-to-follow-up-rates. A retrospective, quantitative analysis of patient data was undertaken complemented by 22 semi-structured interviews, four focus-group discussions to explore patients’ and providers’ perceptions of tracing activities.

Results/Findings
The clinic loss-to-follow-up-rate has steadily declined from mid 2008 to 2011. Thirty-eight (4.6%) of 819 patients registered during the period were lost-to-follow-up with most lost during the first year. Rates of loss-to-follow-up between 0.3-2.4% were observed over the last two years. Phoning the day before an appointment was perceived as the most useful intervention to avoid missing appointments. The analysis revealed a widespread fear of forced disclosure by patients during home visits.
Conclusions

The low loss-to-follow-up-rate cannot be attributed to the network tracing activities alone. Phoning before appointments may result in fewer delayed appointments and prevent loss-to-follow-up. Home visits should be a last resort method of patient tracing because of the risk of HIV-status disclosure and the possibility of discrimination from family and neighbours.

Key Words: HIV/AIDS, Loss-to-Follow-Up, Nursing, HIV Disclosure, Patient tracing, Discrimination, Resource-limited settings
SUMMARY STATEMENT

What is already known about this topic

- Loss-to-follow-up among patients on antiretroviral treatment is a major programmatic challenge in both rich and resource-constrained settings.
- There is a dearth of proven models and interventions for improving HIV patient retention in care, even less from resource-limited settings, especially urban slums.

What this paper adds

- Low loss-to-follow-up rates can be achieved and maintained in small and medium scale HIV-programs in an urban slum setting.
- A cooperative initiative between an HIV Clinic and a Non Governmental Organisation network to provide loss-to-follow-up tracing of patients on antiretroviral treatment is a promising model; however it may only be a contributing factor to keeping patients in care, rather than the main reason.
- Home visits should be kept at a minimum in a slum setting to avoid the high risk of HIV status exposure and lasting discrimination.

Implications for practice and/or policy

- A model using community peer support for HIV patients appeared to result in a low loss-to-follow-up rate among urban slum dwellers in Mumbai and should be considered in similar settings.
- Alternative interventions to improve retention in care such as phoning the day before an appointment should be explored and tested in similar and different contexts.
INTRODUCTION

Reducing loss-to-follow-up (LTFU) rates among ambulatory patients on antiretroviral treatment (ART) remains a major challenge in both rich and resource-limited settings (Weigel 2011, Narchega et al 2010, Brinhoff et al 2009, Chi-Chen et al 2008, Tweya 2010, Kwong-Leng Yu 2007). Using an existing community based Non Government Organization (NGO) network to trace patients LTFU in a slum setting is an innovative approach not widely described. One example of using community based organizations (CBOs) to connect high risk inner city populations in New York to health services is described by Indyk and Rier (2006). Whilst this does not refer specifically to tracing patients LTFU and is linked to the provision of specialist medical services to hard to reach populations, it does promote the idea of using CBO members and their capacity of ‘intimate primary attachment in cases where family ties are weakened to satisfy unmet needs, providing a doorway to life saving treatment’ (Indyk 2006) for people living with HIV/AIDS (PLWHA). A similar usage of CBOs to provide peer-based patient follow up in the community is also being trialled by the National Aids Control Organization (NACO) in some ART centres in India.

Avoiding delays in scheduled appointments is vital in maintaining consistent drug supplies for patients to avoid ART interruption and subsequent viral rebound. The possibility that both delayed appointment and LTFU rates may be reduced in PLWHA living in low resource settings by the utilization of similar community based networks was the primary motivation for the following study. The study describes how a loosely organized community-based NGO network currently provides tracing for patients late for appointments and those LTFU for a Médecins Sans Frontières (MSF) HIV clinic in Mumbai, India.
Background

India has the third largest number of people living with HIV in the world (UNAIDS 2009, UNGASS 2010). An estimated 80% of HIV infections in Mumbai is considered to be heterosexually transmitted (AVERT HIV/AIDS website; UNAIDS 2009). The prevalence of HIV in the city is estimated to be 0.5% (AVERT HIV/AIDS website; UNAIDS 2009). Access to affordable health care is limited for all except the most wealthy. Whilst the private sector has the capacity to provide an advanced standard of health care, the public sector functions as a low resource option most of the time (Patil 2002, World Bank 2001).

The HIV-Clinic was initiated in 2006 to provide access to Antiretroviral Therapy (ART) for ambulatory patients unable to obtain care from the public ART centres. Retrospective examination of clinic records indicated that by the end of 2009 the LTFU rate at the Clinic was less than 1% which was considered unusually low given the setting and target population. Patients late for scheduled appointments in the clinic had also declined from 15% to 5%. This is potentially important from the point of view of the patient and programme outcomes. The period between scheduled appointments is directly related to patient ART supplies. Delayed appointments mean that patients are more likely to run out of ART contributing to viral resistance and viral rebound. Patients returning after a gap in care or treatment often require the provision more acute medical and nursing interventions in order to be re-stabilized. Such delays may compromise long term program outcomes and adversely affect survival rates.

Ensuring patients keep scheduled appointments is vital for treatment success and general wellbeing. Information on approaches to limit delays in low resource settings is scarce.

Data collected by the World Health Organization from various ART programs in low resource settings suggest an average of 21% of patients are lost to follow up six months after starting
ART (Weigel 2011, Kwong-Leng 2007). By two years, in parts of sub Saharan Africa, as many as 40% of patients are LTFU. Patient tracing is labour-intensive and time-consuming often taking up valuable nursing resources; with around 34% of traced patients never being found (Weigel 2011, Narchega 2010, Binkoff 2009 Kwong-Leng Yu 2007).

THE STUDY

Aim

The aim of the study is to describe the patient tracing activities performed by a NGO network for the MSF HIV clinic in Mumbai. The clinic’s low LTFU rate and the trend in delayed appointments were investigated retrospectively to examine possible reasons, exploring a widely held belief among the network that the low rates were somehow related to the community network’s tracing activities. Information was gathered to explore the acceptability of the approaches used in the clinic to reduce delayed appointments.

Design

The study design chosen was a mixed method, descriptive study involving quantitative documentation of the trends in delayed scheduled appointments and LTFU and a qualitative component to describe patient and staff experiences of tracing activities and to explore the patient acceptance of the approaches currently used in the clinic to minimize delayed appointments.

Participants

The population of interest were ambulatory ART-users attending the Clinic and HIV/AIDS NGOs providing patient tracing activities for MSF. Key Informants also included five clinic
staff directly involved in tracing at the clinic level as well as NGO representatives who were purposely selected to ensure experience of outreach work.

Current clinic patients were purposively selected to try to obtain a sample that reflected both the typical social and demographic characteristics of the cohort and the not so typical. The sample included patients ranging in age from twenty-eight to fifty-five and a mixture of male and female patients and transgender in proportions reflective of the current cohort mix. Both patients with experience of missed appointments and those who had never missed an appointment were included. Patients on ART were selected from the clinic register each morning for four weeks until qualitative data saturation was reached at thirteen patients. The inclusion criteria included current patients aged 18 years or more who agreed to participate and all NGOs that worked regularly with the clinic to trace patients. Patients recently transferred from MSF to government ART centres, were also included, as were key clinic staff involved in tracing activities. Patients less than 18 years were excluded for ethical reasons and because they made up so few of the cohort. Patients communicating principally in a language unable to be translated by the locally recruited translator were also excluded. NGO exclusion criteria included any HIV/AIDS NGO not working with MSF and those not working with people living with HIV/AIDS or any Organization in the tracing network that did not agree to participate in the study.

Data collection

Quantitative
Monthly project monitoring data was obtained from the existing monitoring tools used in the clinic [FUCHIA (Follow Up and Care of HIV Infection and AIDS, Epicentre, Paris France)] and Excel data bases retrospectively from 2006 to the end of 2010. This was collected and analyzed in January 2011.

**Qualitative**

Qualitative data collection took place over a one month period from mid January to Mid February 2011. Semi-structured interviews were conducted the afternoon following recruitment in the morning. A total of thirteen patient interviews and nine key informant interviews were conducted. Members of the NGO network were formally invited to attend focus group discussions, or a personal interview. Written information explaining the study was made available at all NGO meetings. Information sheets were posted around the clinic. Two focus group discussions were performed with NGO representatives. All nine groups actively involved in patient tracing activities were represented, with discussion group sizes ranging from seven to ten participants.

Face to face semi structured interviews were conducted by the first co-author to elicit the patients’ knowledge of the NGO network and any experience of patient tracing activities in the presence of the translator. Questions probed the knowledge of the NGO network, use of other NGOs and their experience of missed and delayed appointments, the clinic, and NGO patient tracing (home visits). Interviews ranged from 40 to 60 minutes in duration and were taped recorded for later transcription. Responses were also interpreted into English during the interview to enable the interviewer to understand responses and adapt the line of questioning where necessary to try to elicit more information about a new idea.

Interviews were also conducted with four NGO outreach workers and five clinic staff by the same interviewer probing their knowledge of the NGO network and their experiences of
tracing patients. In addition, two focus groups were conducted by the first co-author following
scheduled patient support group meetings at the clinic to triangulate the findings from the
semi structured patient and key informant interviews. The discussion groups lasted an average
of 1½-2 hours. Two focus groups were also conducted with NGO outreach workers. All
sessions were interpreted into English and tape recorded for later transcription.

Interview notes written by the interviewer during interviews (using the direct verbal
interpretations into English by the translator of the respondent’s responses to the questions)
were also included in the data for analysis.

Ethical considerations

A number of ethical issues were considered by the researchers in the formation of the study
protocol. These included informed consent, patient vulnerability, the influence of caste, the
maintenance of confidentiality and data protection. The protocol was approved by the Curtin
University Ethics Committee and the MSF Ethics Review Board. The NGO community was
also involved in the consultation process.

Data analysis

Quantitative

Description of the data and simple statistical analyses was performed using Excel and SPSS
(version 16.0, Chicago, IL). Chi-square test for trend was used; p-value was set at 0.05. Data
on late appointments and patients LTFU were used to calculate rates of attrition and retention
of all patients. For the purposes of clarity, lost-to-follow-up was defined as patients who had
defaulted on treatment for 3 months (Chalker 2008). A delayed appointment category was
included and describes patients who are late for their scheduled appointment, this being the
primary tracing activity occurring from within clinic. The assumption made here is that a
patient who is persistently late for appointments is more likely to become a defaulter.

Delayed appointments therefore have been used as a proxy indicator of potential LTFU.

**Qualitative**

The two principal co-authors coded each interview transcription independently and the final categories were compared and negotiated until consensus was reached (Garrison 2006). The content of the focus group transcriptions were analysed in the same way.

Coding categories were developed using mixed coding methods. Where specific answers to closed ended questions were required, closed coding was used. For the majority of the open questions, the data was coded directly from the participant responses to questions using open and axial coding methods to determine categories and form sub categories. The thematic analysis was done manually by the first co-author and then again by the second co-author as a way of cross checking the data, using content analysis to firstly discover repeated words, ideas and themes, then comparing the categories and themes with those of the first co-author. Saturation was deemed to have occurred when no new themes or sub categories or ideas were revealed from the data. Descriptive quotes were chosen to demonstrate the main ideas and the range of participant responses.

**RESULTS - QUANTITATIVE**

Delayed visits and loss-to-follow-up rates over time

A total of 827 HIV-infected patients were registered in the HIV-clinic between January 1\textsuperscript{st} 2006 and December 31\textsuperscript{st} 2010. Out of these, 613 patients have been started on ART. By the end of December 2010, among patients on ART, 65 had died (11%), 38 were LTFU (6%), 199 were transferred to public ART centres, once their clinical condition was stabilised.
(32%), and 311 patients were alive and in treatment (50%), followed up in the clinic. The LTFU rate dropped from 9.2% at the end of 2008 to 0.3% by 2009 (p<0.001). (Figure 2) The clinic has recorded an average of 3,900 consultations per year. Delayed appointments have also reduced over time from 15.4% in 2006 to just 5% in 2010 (p<0.01). The decline in the proportion of late appointments can be seen from mid 2008 with a much sharper decline occurring in 2010 (Figure 1).

FINDINGS - QUALITATIVE

Sample Characteristics

Thirteen patient interviews were conducted. Patients ranged in age from twenty-eight to fifty-five years, eight were male, three female and two transgender. This was generally reflective of the overall gender proportion in the current cohort where ⅔ of the cohort were male. Of the sample, three were currently unemployed with one other engaged in irregular seasonal work. Both Hijra (transgender) relied on daily donations to survive. Of the four employed participants, three were self employed. Eight of the group reported having some family support whilst five had no family contact.

Main Themes

There were four major themes identified from the data.

Knowledge of the NGO network

Of the thirteen patients interviewed none were aware of an NGO network. In contrast, all key informants and NGO outreach workers were aware of the NGO network attributing to it a high level of importance. This finding was not unexpected and is perhaps more a reflection of the patients’ position at the periphery of the network (Newman 2007, Harvey 2002, Krishna
Knowledge and experience of other NGOs and their activities was limited apart from the point of initial contact for referral.

**Patient Tracing**

None of patients interviewed were aware of patient tracing activities and none had knowingly experienced them. The idea of patient tracing was viewed as life saving and “something that should be done.”

“It would provide an opportunity to know what the situation was, why the person wasn’t coming, the person if they were sick could be brought for treatment.”

The reasons given for late or delayed appointments were usually work, family or illness related.

“When I miss an appointment its like depending on the climate [at work]. Now at that time, say its monsoon or I have a school bus [to drive] even if I tell them I need a holiday it depends if there is a substitute bus driver available. If there is, then they will allow. If there isn’t, then I usually have extra medicine for two to four days. If I alone stop a bus [by going for my appointment] then 400 students will be stranded...and 800 parents inconvenienced. I am serving 400 students and from there I also get food....so every time a compromise and an arrangement must be reached.”

Others who had never missed appointments commented that their strategy for avoiding missed appointments included keeping appointments marked in a diary, setting the alarm on their mobile phone and receiving a reminder call from the clinic the day before the appointment was due.

Among patients there was significant conflict around the idea of home visits, reflecting the level of social isolation experienced by PLWHA in the community (Donley 2009, Smith 2008...
Pachankis 2007, Slade 2007). There was a strong appreciation that someone was willing to care by visiting them, but most feared home visits because of the associated risk to privacy and confidentiality in the slum setting. Such visits may inadvertently have revealed their HIV status and precipitated lasting discrimination from the family and close-living neighbours (Dahab 2011, Donely 2009, Greef 2008, Smith 2008, Pachankis 2007, Slade 2007).

“To discuss something especially if you have to use the words...those words we cannot speak. Confidentiality cannot be maintained in a chawl system (refers to tenement building with shared walls, water supply and toilet) because, lets say they explain about what medicines have to be taken, then information regarding us will become known to others. That type of discussion cannot be held in a chawl. If you go to a house and have this interview there then people will not be able to speak so freely because the atmosphere around will not be so conducive.”

Patient focus group discussions confirmed similar views to those expressed above.

“It would feel good but then our neighbour would ask for what they have come, what were they asking, which medicine were they talking about.”

“Actually, it [home visit] is usually okay for the NGO people like the peer educators but for those people who are defaulters and who are the persons we are trying to find, there is some hesitation. Who is coming here, why is he asking about myself and my treatment? He is scared in the sense that since he has come people will ask who is he and why has he come here. There is a fear about it so they say don’t make the effort to reach our houses. Some NGOs love going to their [the client] places but there is a fear [because] neighbours will try to get information.”

**Stigma and Discrimination**

This theme was revealed repeatedly in patient interviews and focus group discussions (Dahab 2011, Golab 2009, Donely 2009). There was a persistent expression of fear and concern
around the social consequences of being found positive and discrimination was reported in varying forms by ten out of thirteen patient respondents.

“Nurses and doctors write “seropositive” in the patient’s file. It means the entire staff at the hospital come to know. First, if they are a good doctor he(reacts) normally [to the person]. There are some doctors who are very bad in the way they speak”

“Depending whether the patient is male or female, they are kept in a remote corner [of the ward]. We get many experiences like that”

All patients described well developed strategies to reduce exposure to discrimination and avoid the possibility of forced disclosure of HIV status.

“We don’t speak in front of neighbours. We go behind closed doors”

“They don’t go to the nearest[health] centre. They go somewhere far because they feel someone might see them and all.”

“Theyir phone is normally switched off. Sometimes they give another number or an incomplete number. They give someone else’s name and address at times”

**Treatment**

Barriers to treatment access was a persistent theme throughout NGO and patient interviews.

NGO staff felt awareness about HIV had increased at the community level but there were still many misconceptions. Patients often remained unaware of the benefits of ART. Patients and NGO respondents voiced concern over restrictions around access to second line therapy.

“Some patients don’t know about ART, first line or second line. To ensure there is no misunderstanding about the medicines in his mind, follow up is necessary.”

Only three patients interviewed reported missing ART for reasons of sickness or family responsibilities. Patients felt that this was related to the fact that the clinic gave several days extra medication beyond the date of the next scheduled appointment.
“I do make a point to reach on the date of the appointment. If I am not able to come I send my daughter to get the medicines”

Peer support was pivotal in getting the ‘right [correct] information’ to the patient regarding ART and connecting them to [similar] others to return the LTFU to treatment (Kabore 2010, Khan 2009, Koen 2008, Smith 2008, Nachega 2006, Finn, Merzel 2003).

“Because we are positive we feel like he is our brother, it’s a kind of relation between us. Maybe he is getting a salary but he is visiting us to give a good service. On his visit he asks about the problems. He brings balm and other medicines for us from his NGO.”

Breaches of confidentiality were reportedly common among medical and nursing staff in public hospitals and ART centres. This exposed the patient to the consequences of unplanned disclosure and discrimination, contributing to a failure to seek early treatment and to potential LTFU (Donley 2009, Greef 2008, Smith 2008).

“In the case a nurse comes to know that a person has HIV then she will go and tell the entire village”

Table 1 summarizes the main qualitative findings of the study.

**DISCUSSION**

The study demonstrated it is possible to reduce delays in scheduled appointments and have low LTFU rates in urban slum settings. However there are a number of limitations to this study that make it difficult to show a direct association between the LTFU rate and NGO patient tracing activities. The size of the patient sample was small at thirteen participants, which while sufficient for data saturation and reflective of the overall patient cohort characteristics, was not adequate enough to generalise the findings to larger settings.
The caste system remains a strong social influence in India and there may have been unintended bias due to caste variation in group discussions that may have unintentionally influenced individual participation and the qualitative findings.

Of particular concern during the research planning was the clinic ‘Staff-Patient-NGO’ relationship. The researchers, who were mostly MSF staff members, were concerned how existing hierarchical relationships might influence the study participant recruitment, the study implementation and the study findings (Benoit 2006, Liamputtong 2007). Using staff unknown to the NGO members and patients significantly reduced the risks of unintended (and intended) influence, but may have negatively affected the trust level of some participants, affecting the overall rate of participant recruitment (Benoit 2006, Liamputtong 2007) and potentially excluding some particularly vulnerable patients.

It is possible the network of NGOs may have had unique characteristics that favoured this setting rather than another. Each patient received regular adherence counselling at every clinic visit and many patients now had the accumulated benefits of both counselling (and peer support (Nachega 2006). This may have influenced the overall late appointment and LTFU rates.

Patients may have been more highly motivated to seek care and continue treatment because of the difficulties in accessing reliable care in Mumbai. Less motivated, more vulnerable patients may have given up seeking care after ‘negative’ experiences in the public system. The patients may, therefore, be particularly loyal to the clinic.
The investigators had hoped to avoid the pitfalls of native speakers by employing a professional translator but the impediments to providing a well trained, experienced translator were both contextual and structural.

Despite these limitations, the study has provided some very interesting findings that are particularly important at the programmatic level. The initiative described shows promise in its potential to reduce LTFU but it is likely this is not the only reason for the low LTFU. Other factors relating to delayed appointments may also have been just as important here. The late appointment follow-up system may have been being done more systematically than when the clinic first began (Carre 2008, Tulsky 1999, Gregory 1992). Patients who had been attending the clinic regularly for some time may have developed a strong bond with the staff whom they saw regularly (Indyk 2006). Many had also been exposed to a significant amount of regular adherence counselling and ongoing peer support. The clinic had a small cohort compared to some other HIV projects which provides an opportunity for continuity of medical and nursing care not always possible in larger projects. Whilst this may have also led to a selected cohort who were particularly loyal to the clinic and may have also facilitated the formation of primary attachment relationships with some staff over time, especially for those patients lack family support (Indyk 2006).

Some of decline in delayed appointment rates may have also been related to beginning a scheduled appointment system late in 2009, organized by the clinic nurses to reduce patient waiting times (Hardon 2007). The importance of early appointment follow up was then re-emphasised with all patients and staff at this time with the receptionist receiving additional training about the importance of phoning the patient promptly to reschedule delayed and missed appointments. For those patients not contactable the same day, the receptionist refers
them to a counsellor to follow up. If no contact is made here it is only at this point NGO tracking is instigated.

The existence of a well structured delayed appointment follow up system in the clinic may have significantly influenced the delayed appointment decline and subsequent LTFU rates, supporting recent similar findings by Tweya in Malawi (2010). It is likely the consistent early follow up of delayed appointments may also prevent some patients from becoming LTFU.

The qualitative data identified patients’ overall experience of the clinic, the comprehensive approach to care, and the continuity of staff relationships with the patient as important factors, coming through strongly in patient focus groups as being important for patient retention. The experience at the MSF clinic was compared regularly throughout the discussion with the more ‘negative’ experience of the government centres. The MSF clinic was described as being ‘like our own family members’. All of these factors are widely known to influence adherence to treatment and patient retention. Perhaps it was these aspects as well as the systematic approach to patient follow up that accounted for the clinics decline in delayed appointments and low LTFU.

The strong decline in delayed appointments and the description of the methods of appointment follow up used in the clinic were important in demonstrating a successful approach to reduce delayed appointments that is acceptable to patients, avoiding disruption to ART supply and the resulting viral rebound so contributing to long term survival. A structured approach and early follow up of delayed appointments can be successfully performed by trained non-nursing staff, avoiding the unnecessary burden of using scarce nursing resources on patient follow-up. Simple measures such as a telephone call reminder regarding appointments was appreciated by patients and could be easily implemented in small
to medium sized projects. The qualitative data clearly demonstrated the patient acceptability of such approaches to avoid delayed appointments in the clinic.

Other findings pointed to a lack of knowledge about the function of and availability of antiretrovirals in the public sector and a perception of limited access to second line treatment. Given that the peer relationship appeared to be highly valued by most patient participants in this study it is perhaps appropriate for important health messages for patients to be channelled through a peer-based network such as the model described. Regular opportunities for peer training are provided in the clinic and the trainings could be regularly facilitated by nurses in other programmes to ensure the accuracy of the health information. A shift in the focus of patient education from HIV transmission to treatment literacy may also be appropriate in this context.

A lack of privacy and confidentiality at home and in the public hospital setting was a persistent theme throughout the qualitative data and is known to be a significant factor in cases lost-to-follow-up (Greef et al 2008). Nurses and Doctors were identified as the main culprits for failing to maintain confidentiality regarding a persons HIV status in the hospital setting and family and neighbours, at home. Given the significant psychological and social consequences of forced disclosure it is imperative that systems are put in place to protect patient identity and maintain confidentiality in all clinic settings and that home visits by health workers are discouraged in settings such as a slum where privacy and confidentiality cannot be guaranteed. Clinic-centered care may be more appropriate here.

CONCLUSION

The analysis of the monitoring data at the MSF clinic revealed a low LTFU rate and a declining trend in the numbers of delayed over time. This is unusual given the setting and target population (Weigel 2011 Tweya 2010, Jose 2008, Kebede 2006 Erstad 2005). The
collaboration between the clinic and the existing local community based NGOs to formulate an effective LFTU tracing network model was shown to be feasible and has implications for other HIV clinics with limited staff resources or barriers of distance and time. Whilst the clinics low LFTU rate cannot be clearly attributed to the networks tracing activities in this study, its role in reducing LTFU rates and improving adherence by providing peer to peer counselling cannot be ruled out.

Lost-to-follow-up tracing was perceived as a useful way to bring patients back to treatment by patients and providers but home visits should be avoided in a slum setting because of the high risk of HIV status exposure and lasting discrimination. Other methods of tracing need to be explored. Patients reported that a telephone reminder the day before a scheduled was the single most useful intervention to assist them in avoiding missed appointments. The reported lack of confidentiality among staff in some treatment centres is concerning and remains a significant barrier for the successful return of patients lost- to-follow-up everywhere.

Other programmes should consider using community-based peer networks for patient tracing where nursing resources are limited or there are barriers of transport or distance. The programs may undertake the systematic and early follow up of delayed appointments using designated trained staff, to ensure confidentiality, reduce risks associated with antiretroviral treatment interruption and reduce the potential for loss-to-follow-up. Programs may provide a telephone reminder or text to patients the day before an appointment to assist in avoiding delayed or missed appointments. Programs should consider providing several days of antiretrovirals beyond scheduled appointment date to enable patient to contend with unplanned delays and avoid the risk of treatment interruption. Finally, programs may consider avoiding home visits in settings where privacy is limited and HIV stigma and risk of discrimination is high.
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Table 1. Summary of Qualitative Findings

<table>
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<tr>
<th>Responses</th>
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| Patients: 13/13  
NGO staff: 4/4  
Clinic staff: 5/5  
FGD: 2/2 |
| Patients: 10/13  
NGO staff: 2/4  
Clinic staff: 5/5  
FGD: 2/2 |
| Patients: 10/13  
Clinic staff: 5/5  
FGD: 2/2 |
| Patients: 10/13  
Clinic staff: 5/5  
FGD: 2/2 |
| Patients: 10/13  
Clinic staff: 5/5  
FGD: 2/2 |
| Patients: 10/13  
Clinic staff: 5/5  
FGD: 2/2 |
| Patients: 7/13  
NGO staff: 4/4 |
| Patients: 8/13  
NGO staff: 4/4  
Clinic staff: 3/5  
FGD: 2/2 |
| Patients: 11/13  
FGD: 2/2 |
| Patients: 13/13  
NGO staff: 4/4 |
| Patients: 10/13  
NGO staff: 4/4  
Clinic staff: 3/5  
FGD: 2/2 |

- Most NGO workers and patients felt the tracing activities and peer counselling would assist LTFU patients return more quickly to treatment.

- Telephoning the day before a scheduled appointment was perceived the most important intervention to avoid missed appointments by patients and staff.

- Extra ART supply several days beyond scheduled appointments was helpful in contending with unplanned delays.

- Many patients expressed a desire not to have visits at home, preferring to meet outside their immediate community to avoid being recognized or overheard. The risks related to HIV exposure and forced disclosure of HIV status from inquisitive, close-living neighbours at home was for most, too grave a consequence.

- Innovative strategies were adopted by some patients to avoid the risk of HIV disclosure, and by NGO workers to establish contact with LTFU patients.

- Peer support was considered pivotal to getting right information to the LTFU patients.

- Patients reported a lack of information regarding other NGO activities and assistance available.

- Patients and NGO workers felt there was a lack of information about the availability of ART.

- Concern was expressed over the restricted access to second line therapy and delays in starting new treatment.
Captions

**Figure 1.** Delayed clinic consultations over time, Médecins Sans Frontières HIV-Clinic, Mumbai, India.

**Figure 2.** Loss-to-follow-up over time, Médecins Sans Frontières HIV-Clinic, Mumbai, India.
Figure 1.
Figure 2.