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Lost to follow up from tuberculosis treatment in an urban informal settlement (Kibera), Nairobi, Kenya: what are the rates and determinants?

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ABSTRACT

Patients lost to follow up (LTFU) from treatment are a major concern for tuberculosis (TB) programmes. It is even more challenging in programmes in urban informal settlements (slums) with large, highly mobile, impoverished populations. Kibera, on the outskirts of Nairobi, Kenya is such a community with an estimated population of 500 000 to 700 000. Médecins Sans Frontières (MSF), in collaboration with the Kenyan Ministry of Public Health and Sanitation (MPHS), operate three clinics providing integrated TB, HIV and primary health care. We undertook a retrospective study between July 2006 and December 2008 to determine the rate of LTFU from the TB programme in Kibera and to assess associated clinical and socio-demographic factors. Thanks to an innovative 'Defaulter Tracing Programme', patients who missed their appointments were routinely traced and encouraged to return for treatment. Where possible, reasons for missed appointments were recorded. LTFU occurred in 146 (13%) of the 1094 patients registered, with male gender, no salaried employment, lack of family support and positive TB smear at diagnosis found to be significant associations (P value ≤ 0.05). The most commonly cited reasons for LTFU were relocation from Kibera to 'up-country' rural homes and work commitments.

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1. Introduction

The rise in tuberculosis (TB) in Kenya has been largely attributed to the Human Immunodeficiency Virus (HIV) epidemic, as well as high levels of poverty and the growth of urban informal settlements (slums). In 2005 over 35% of all notified TB cases in Kenya were from the five largest urban areas.¹

In resource-limited settings, where the health care services are poorly developed, lost to follow up (LTFU) from

treatment is a major challenge to TB programmes.^{2,3} A number of reasons why patients are LTFU are described in the literature: studies conducted in urban settings in Nepal, Madagascar and in Ethiopia showed that distance, traveling costs incurred by patients to reach treatment centres, and insufficient knowledge about the need to take daily treatment were the major factors associated with poor adherence to TB treatment.^{2,4–6} Additional contributory factors included work commitments, stigma associated with TB and lack of family support.

However, these studies did not provide information on the rates or factors associated with LTFU in the context of an informal settlement. Kibera, outside Nairobi, Kenya, is such a settlement, with a highly mobile, impoverished

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population. Médecins Sans Frontières (MSF) in collaboration with the Kenyan Ministry of Public Health and Sanitation (MPHS) operates three health centres providing TB, HIV and primary health care in this environment. The programme provides free care and is located within the informal settlement, thereby minimising the factors of traveling cost and distance which have been associated with LTFU in other contexts. In addition, the programme has the unique feature of a routine follow up mechanism for all patients who do not attend their regular TB appointment: the Defaulter Tracing Programme. Given the differences in setting and organisation of this programme compared to the literature, we wished to assess the rate and reasons for LTFU among patients started on TB treatment in the three clinics. These factors have not been well studied in the environment of an informal settlement. Also, the information available on patients not attending their appointments from the Defaulter Tracing Programme provided a unique opportunity to learn more about factors of LTFU.

The objectives of this study were to determine: (1) the rate of LTFU from the TB programme amongst patients registered in the three MSF/MPHS clinics in Kibera, (2) whether routinely documented socio-demographic factors (age, sex, HIV status, economic status) were associated with LTFU and (3) the reasons why patients are LTFU from the TB programme in Kibera.

2. Methods

2.1. Study design

The study was a retrospective, un-matched case-control analysis of routinely-collected data, comparing the records of TB patients who were LTFU from their treatment (cases) with a group of patients who successfully completed treatment (controls).

2.2. Study setting

The study was conducted in the three MSF/MPHS clinics within the Kibera informal settlement, Nairobi, Kenya. Kibera is located approximately 5 km southwest of Nairobi city centre and is referred to as the largest informal settlement in East Africa. Population estimates range from 500 000 to 700 000.⁷ The informal settlement is geographically divided into 12 villages that are ethnically heterogeneous but similar in terms of social and environmental conditions, characterized by poverty, poor quality and over-crowded housing, inadequate water supply, poor sanitation, environmental degradation, and limited access to health care and other services.⁷ Due to a lack of comprehensive data, the incidence of TB and prevalence of HIV in Kibera are unknown.

2.3. Patient education and the Defaulter Tracing Programme

Minimising the LTFU patient rate is widely recognised as one of the main challenges in providing effective TB treatment. From July 2006, MSF adopted the rifampicin-

based, six-month treatment regime for newly diagnosed TB patients. Recognising the particular importance of adherence to this new treatment, MSF put in place measures to reduce the number of patients LTFU and to facilitate tracing of those patients. Lessons learned from tracing HIV patients LTFU in Kibera were applied when developing TB tracing protocols. Patients diagnosed with any form of TB were registered in the standard national TB register and the patients' clinical and appointment cards were completed. Every effort was then made to inform the patients about their disease and the necessary treatment regime through patient education sessions provided to every patient upon diagnosis. Education sessions included information about possible side effects from TB treatment and drug interactions with antiretroviral drugs for those patients co-infected with HIV.

The Defaulter Tracing Programme began on the same day of diagnosis, when a social needs assessment was performed by a social worker. This included an assessment of the patient's economic status and explored issues that could potentially have interfered with treatment adherence. Where possible, the social worker offered assistance to address any issues identified. For example, patients with psychological or psychosocial problems were referred to the clinic counsellors or psychiatrists for support; patients suffering from food insecurity were linked with local partner organisations offering nutritional support. At this stage, patients were also asked for their consent to be traced at home in the event of a missed appointment. If they agreed, full contact details were recorded on the social needs assessment form for tracing purposes. The patients were also requested to give the name and contact details of a trusted relative or friend who could be contacted in the event of a missed appointment should the patients themselves be unreachable.

Patients who failed to turn up for their scheduled appointments were identified by the clinician or nurse working in the TB clinic. Their files were handed to a social worker for tracing, who attempted to contact the patients to establish why they had not attended the clinic for treatment. The social worker contacted the patients by telephone where possible, otherwise they visited their last recorded physical address. Once traced, the patients were encouraged to return to the clinic to continue treatment. If the patients were not found at home, their trusted friends or relatives were contacted and asked to inform the patients to report to the clinic. No details of the patients' condition were disclosed to the friends or relatives. If patients subsequently failed to attend another clinic appointment, a second telephone call or home-visit was made. Any reasons for missing the appointment identified by the social workers were recorded in the 'Defaulter Tracing Form'. These were transferred to the 'Defaulter Tracing Database' for monitoring and evaluation. Patients returning to the clinic were counselled on the importance of completing treatment, and the course of treatment was extended to cover the period they had missed their pills.

2.4. Sample

Cases and controls were identified using TB treatment registers kept in the three clinics, which comprised

of patient's demographic data, clinical information and unique TB treatment numbers assigned at registration. Eligible patients were those started on TB treatment between 1 July 2006 and 31 December 2008. Cases of LTFU were defined as those patients started on anti-tuberculosis treatment in the three MSF clinics who missed TB clinic appointments for two consecutive months. Controls were defined as TB patients from the same period who were considered to have successfully completed a full course of treatment (cured or treatment completed).

A sample size calculation was made assuming a worst-case scenario of 50% LTFU (actual number not known) with a precision of 5%, an alpha error of 0.05 and an assumed Odds Ratio of 2.0. Epi Info, stat Calc, CDC, Atlanta, Georgia, USA. Since it was an unmatched case control study, double the number of controls over cases was chosen to reduce potential bias. This resulted in a sample of 111 cases and 222 controls, which were selected at random from the TB register sorting patients by their unique identifier.

2.5. Data collection

Retrospective data extraction for cases and controls was by review of clinic cards, social needs assessment forms and the Defaulter Tracing Database, transcribing information onto a standardised data collection form.

2.6. Analysis

All study data were entered in to a Microsoft Excel® spreadsheet and analysed in SPSS 12.0 statistical software (SPSS Inc., Chicago, IL, USA).

Descriptive statistics were used to determine the rate of LTFU and distribution of patients' characteristics. Univariate and multivariate logistic regression were used to

determine the factors associated with LTFU. A *P* value of ≤ 0.05 was considered statistically significant and a 95% confidence interval (CI) was used throughout.

2.7. Outcome measures

The outcomes included (1) the proportion of patients who were described as LTFU, as compared to the total number of patients registered and started on treatment during the study period and (2) the reasons for LTFU as listed on the Defaulter Tracing Forms including: patient went up country, confirmed dead, admitted to hospital, traced and came back, refused to come back, unable to come back, and not possible to trace. These reasons were categorised as such based on the earlier experience of the social workers who had begun tracing in an informal manner.

3. Results

3.1. Overall rate of LTFU and distribution

Out of 1094 patients started on TB treatment between July 2006 and December 2008, 146/1094 (13.3%) were LTFU. From the 146 LTFU, 111 were randomly selected as cases. Amongst these cases, 36/111 (32.4%) were LTFU in the first two months of treatment (described as early), 34/111 (30.6%) between the second and the fourth month, and 41/111 (36.9%) after the fourth month (late). Some of the patients had missed their clinic appointments on several occasions before eventually becoming LTFU.

3.2. Associations with LTFU

Table 1 summarises the factors associated with LTFU. Compared to controls, LTFU patients were significantly

Table 1
Factors associated with lost to follow up (LTFU)

Variable	LTFU <i>n</i> (%)	OR	Adjusted OR (95% CI)	Multivariate <i>P</i> -Value
Sex				
Female	37/140 (26.4)	0.58	0.51 (0.31–0.85)	0.01
Male	74/193 (38.3)	1.0	1.0	
Age (years)				
≤ 34	69/205 (33.7)	1.04	1.01 (0.60–1.69)	0.97
≥ 35	42/128 (32.8)	1.0	1.0	
Type of TB				
PTB	94/265 (35.5)	1.65	1.28 (0.64–2.54)	0.49
EPTB	17/68 (25.0)	1.0	1.0	
Smear at diagnosis				
Pos	57/137 (41.6)	1.87	1.72 (0.10–2.96)	0.05
Neg/NS	54/196 (27.6)	1.0	1.0	
HIV Status				
Pos	55/191 (28.8)	0.62	0.81 (0.48–1.36)	0.43
Neg/NS	56/142 (39.4)	1.0	1.0	
Treatment assistant				
Yes	63/217 (39.4)	0.58	0.56 (0.34–0.92)	0.02
No/NS	48/116 (41.4)	1.0	1.0	
Employed				
Yes	28/111 (25.2)	0.57	0.49 (0.29–0.85)	0.01
No/NS	83/222 (37.4)	1.0	1.0	

OR: odds ratio; CI: confidence interval; PTB: pulmonary tuberculosis; EPTB: extrapulmonary tuberculosis; Pos: positive; Neg: negative; NS: not specified.

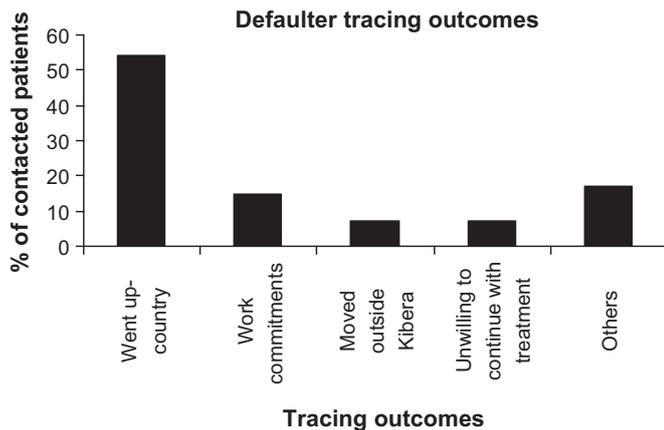


Figure 1. Defaulter tracing outcomes for patients lost to follow up (LTFU).

more likely to have been male than female, and were more likely to have had a positive sputum smear at the time of TB diagnosis. Patients with salaried employment and those with a treatment assistant (family support) were significantly less likely to be LTFU. Although not statistically significant, patients testing positive for HIV were less likely to be LTFU.

3.3. Outcomes of the Defaulter Tracing Programme

Out of the 111 patients LTFU, 86/111 (77.5%) were contacted. Direct contact was made for 27/111 (24.3%), while for 59/111 (53.2%) contact was made through either a friend or relative. It was not possible to contact the remaining 25/111 (22.5%) patients. Out of the 222 controls, 27/222 (12%) had missed at least one clinic appointment; they were contacted and encouraged to return to the clinic to continue with treatment until successful completion.

The most common reason given for LTFU among the 46/86 (54%) patients contacted, was relocation from Kibera to their 'up-country' rural homes. Thirteen out of 86 (15%) cited work commitments and lack of time off to attend TB clinic, six out of 86 (7%) had moved from their last known address to locations outside Kibera and were unable to attend their appointments, and six out of 86 (7%) were unwilling to continue with their TB treatment. The remainder, 15/86 (17%), cited various other reasons (see Figure 1). Amongst the 25 patients that were not contacted, the primary reason in 15/25 (60%) was that incorrect contact information had been given by the patient at the time of registration.

The study period encompassed the time of post-election violence suffered by Kenya following the disputed presidential election of December 2007. However MSF managed to keep TB/HIV services going during the post-election violence.⁸ One out of the 86 (1%) cases contacted reported being unable to continue treatment due to the violence. Seven out of 27 (26%) controls that missed an appointment and were traced cited the violence as the reason for missing their appointment; all 27 subsequently returned to the clinic and completed their treatment.

4. Discussion

This study looked into factors associated with LTFU in the understudied context of an urban informal settlement in Africa, having minimised the factors associated with LTFU identified by studies in other contexts. The study found a LTFU rate of 13% compared to the Kenyan national average of 9% in 2007.⁹ Patients were found to be LTFU throughout the course of treatment. One third were LTFU in the first two months of treatment and one third after the fourth month of treatment. Males and those with a positive TB smear at diagnosis were more likely to be LTFU, while those with a salaried employment or with family support were less likely to do so. By far the predominant reason for LTFU was relocation of the patients from Kibera to their 'up-country' rural homes.

The strengths of this study were the comprehensive data collection that involved routinely collected outcomes in the three clinics, verbal consent requested from patients at registration to be traced in the event of missed appointment and a strong Defaulter Tracing Programme which was able to follow up patients when they missed their clinic appointments. Tracing of patients who miss their appointments is important to encourage and remind patients to attend the clinic and complete their treatment as scheduled, and also to check that their condition has not worsened. The programme managed to contact 77% of the patients that were LTFU. Mobile telephone technology was a convenient and effective means of doing this, especially for a transient population for whom home visits may prove fruitless.

Despite the existence of the Defaulter Tracing Programme, there was a higher rate of LTFU (13%) in Kibera as compared to the Kenyan national average. This was likely due to the mobile nature of the population, often returning to their villages 'up-country'. The rate of LTFU could have been higher had the Defaulter Tracing Programme not managed to contact patients who had missed an appointment and encouraged them to continue with treatment.

Males were more likely to be LTFU than females; this may be due to the challenges of finding work. Anecdotal reports indicate that most of the males in Kibera work as daily labourers, employed on a casual basis. They meet at a central point every day to compete to be hired for the day in homes and industries within Nairobi city. Patients who work mainly as daily workers are unable to obtain sick leave for treatment. These patients are forced to choose between working for the day and attending the clinic for treatment; most prioritise work as soon as they start feeling better. Studies conducted in other urban environments in Madagascar⁵ and Ghana¹⁰ also showed that males were more likely to be LTFU than females. Practical changes should be made to the TB programme in Kibera to encourage more male patients to complete their treatment. These measures could include extensive or flexible hours of operations to ensure that those patients who have to go to work are seen outside the 'normal' working hours or during the weekends. Time and effort should also be invested in education, particularly for male patients, and in building a good rapport between male patients and health care workers. This would encourage patients to seek support

from the staff whenever their work situation conflicts with their clinic visits, thus enabling them to fulfill their obligations to their employers and at the same time continue with treatment.

The study showed that family support was protective against LTFU, a finding supported by other research.¹¹ Family support could include financial assistance, collecting medication, supervising taking of medication, reminding of appointments and providing emotional support. The clinics should find innovative ways of engaging and encouraging the families of TB patients, as partners or co-service providers of TB services.

The reason why patients with positive smears (SM+) at the start of TB treatment were more likely to be LTFU compared to those whose smears were either negative or not specified is unclear. Similar findings were observed in a study in Ghana,¹⁰ where SM+ patients received a more efficacious regimen compared to the other patients. This led to a faster improvement in their condition and patients often stopped treatment early when they were feeling better. In Kibera, patients with all forms of TB are treated with the same drug regimen. Further studies are required to clarify the observation in this study.

There was a trend (not statistically significant) that those patients testing HIV positive were less likely to be LTFU. This contradicts other studies which have reported that HIV positive patients tended to have a higher rate of LTFU compared to HIV negative patients.^{6,12} In the MSF-supported clinics in Kibera, once a patient is diagnosed with HIV, he or she is strongly encouraged to undergo 'HIV treatment literacy'. Treatment literacy consists of purposefully designed information and education sessions to help people living with HIV understand their illness and its treatment. Evidence has shown a positive correlation between improved treatment adherence and a patient's understanding of their disease and its treatment.^{11,13} We therefore recommend the development of a specific treatment literacy for all TB patients not currently benefiting from an HIV Treatment Literacy programme.

The role of stigma associated with TB within Kibera may have contributed to the LTFU. Several studies have indicated that community members or peers have a strong influence on TB patients' treatment taking behaviour.¹¹ This underscores the importance not only of building a trusting relationship between the health care workers and the patients, but also of addressing TB related stigma in the Kibera community.

4.1. Limitations

The type and quality of data retrieved from the retrospective record review somewhat limited the study. The reasons for LTFU were limited to the pre-defined operational variables that were not designed to provide in-depth details.

5. Conclusion

This study described a higher LTFU rate in Kibera as compared with the Kenyan average. We believe that the LTFU rate in Kibera might have been even higher, had the

Defaulter Tracing Programme not been in place. Some factors associated with LTFU among patients living in difficult socioeconomic conditions were identified. Male gender, unemployment and lack of family support should alert clinicians to a higher risk of LTFU and prompt them to offer closer supervision. TB treatment literacy sessions for patients not currently benefiting from the HIV treatment literacy programme may improve LTFU rates.

Authors' contributions: KWK: conception and design of the study, analysis and interpretation of data. SD, MK and TR: design of the study, technical support, revision and critical review of manuscript. All authors read and approved the final manuscript. KWK is guarantor of the paper.

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Conflicts of interest: None declared.

Ethical approval: Approval to undertake the study was obtained from the Division of Leprosy, Tuberculosis and Lung Diseases (DLTLD) in Kenya. Ethical approval was obtained from the MSF Ethics Review Board and the International Union against TB and Lung Diseases' Ethics Advisory Group prior to data collection and analysis.

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