

Improving TB patient follow-up of a large urban setting in a low-income country

A case study in Kampala, Uganda

Introduction

Tuberculosis (TB) control in large urban settings poses a unique challenge for many national TB programmes, including those in low-income countries. This is attributed to a number of factors including social, operational, economic, and managerial constraints.¹⁻⁷ There is a need for intensified efforts to address TB in urban settings if global TB control targets as well as those of the Millennium Development Goals (MDGs) are to be attained. Indeed, increasing case detection and treatment success rates remain a priority area of action for TB control in the World Health Organization (WHO) Africa Region.⁸ Non-governmental organizations (NGOs) have been called upon to contribute to TB control by collaborating and developing partnerships with NTPs.⁹ This case study is a description of the improvement attained in patients' TB treatment outcomes in Kampala, Uganda's largest urban area, following interventions implemented with support of the United States Agency for International Development (USAID) Tuberculosis Control Assistance Program (TB CAP). In Uganda, TB CAP is implemented by the International Union Against TB and Lung Disease (The Union), which provides technical and financial assistance to Kampala to improve its performance.

Setting

Kampala is home to 5% of Uganda's total population, estimated to be over 30 million.¹⁰ The city is divided into five administrative units (divisions that are equivalent to districts in the rest of the country), with each having a TB focal person who supervises TB and TB/HIV activities. Unlike other districts in Uganda, which is divided into eight zones, a Zonal, rather than a District TB and leprosy supervisor oversees the implementation of TB activities and supervises the five division's TB focal persons. Kampala accounts for 20–25% of the total TB cases notified annually in the country. About 40–50% of all TB patients in Kampala are notified by the national referral hospital in Mulago.¹¹ The other patients are notified by 38 other health facilities, all of which are registered with Kampala City Council (KCC), the city's administrative authority.

Over the period 2005–2008, Kampala notified more than the expected number of TB patients but the cure rate and consequently the treatment success rate remained low. This has been attributed to: poor acceptance of community-based TB care in the urban setting, despite being national policy; inadequate follow-up mechanisms for tracking of patients; incomplete records; and weak coordination mechanisms between the various divisions in the city. In addition, information on collaborative TB/HIV services such as HIV testing for all TB patients, cotrimoxazole preventive therapy (CPT) and antiretroviral therapy (ART) for HIV-positive TB patients was not routinely collected or recorded in the health unit TB register.

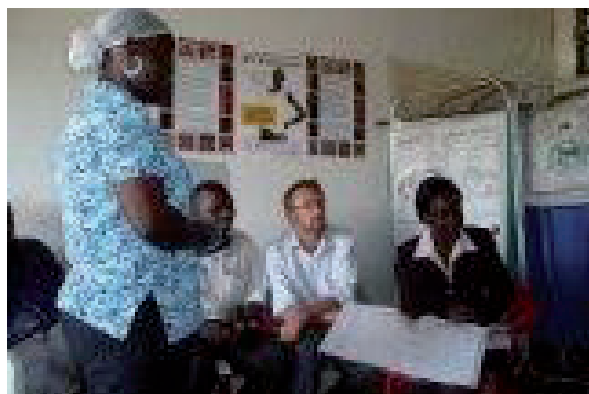
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Methods and procedures

At the beginning of the district implementation of TB CAP in the second quarter of 2008, Kampala's TB and HIV management teams held a joint planning meeting. The teams identified their problems in relation to TB and HIV service provision and devised ways of addressing them. Technical and financial support to implement the planned activities was subsequently provided by TB CAP. The following interventions were implemented to improve performance.

Training of health workers in TB/HIV, including records management

Facility-based health workers were taken through refresher training in TB/HIV at their places of work. This involved training a team of trainers that went on to conduct facility level trainings in TB/HIV with aspects of recording and reporting for TB and HIV. A total of 64 male and 84 female health workers were trained by a team of 10 trainers.



A community volunteer (standing) explains the implementation of directly observed therapy (DOT) at the supported site in Kawempe Division



A member of the hospital staff explains the process of patient follow-up during a TB CAP monitoring visit



A training session in progress

Enhancing patient follow-up through telephone calls and home visits

Telephone lines were set up at each of the five Kampala division headquarters, where the division TB focal person has an office. Health workers providing TB services at health facilities were sensitised about the telephone follow-up system. They were asked to offer this system of follow-up to those patients that accepted it. Health workers were also asked to record patients' telephone contacts or those of close relatives or friends in the TB register. During routine supervision visits to health facilities, the division TB focal person developed and continuously updated a line listing of patients who missed their appointment (called treatment interrupters, TIs) to collect drugs or follow-up medical review. The creation of a line listing of TIs started in June 2008 and the listing initially comprised patients registered in 2007 and 2008; this practice continued into 2009 for TIs identified in 2009.

The division TB focal person made telephone calls to the TIs to find out why they had failed to return to the health facility, and to agree on the next steps. Some TIs were found to have transferred themselves to other health units but were still on treatment; for such patients, all the division TB focal person did was to update his/her records to reflect this. Some patients were found to have stopped taking drugs and were supported to resume treatment (before they arrived at the point of defaulting).

Those patients who could not be traced using telephone calls were followed up through home visits. However, when the home visits were found to be time consuming and costly, with only limited success, they were dropped as an intervention of patient follow-up.

Conducting meetings to harmonise records of TB patients

Inter-division meetings for division TB focal persons in Kampala

These meetings took place quarterly and were mainly aimed at exchanging information about patients who crossed from one facility or division to another. The line listing of TIs created by the division TB focal person was the key tool used to exchange information during these meetings. In addition, each division TB focal person made sure she/he reviewed Mulago Hospital records on a monthly basis so as to identify patients who had been transferred to health facilities in his/her division.

Inter-district meetings between division TB focal persons in Kampala and district TB and leprosy supervisors in neighbouring districts

The objective of these meetings was to discuss data for patients who had been formally transferred or self-transferred out of, or into, Kampala's healthcare system and whose records were found to be incomplete.

Supporting community-based organisation (CBO) to follow up patients in communities and provide DOT

One CBO was funded to follow up TB patients diagnosed at Mulago Hospital who resided in Kawempe Division in Kampala (the division where Mulago Hospital is located) and provide DOT to them. Of the 100 patients enrolled in 2008, 97% completed treatment (56% had a confirmation of cure).

Results

Magnitude of patient records updated following the interventions

A total of 8405 TB patient records were updated over the period July 2008–Dec 2009. These included records of patients registered in 2007, 2008, and 2009. The largest proportion (90%) of patient records updated occurred during meetings at division level. Table 1 gives a summary of the numbers of patient records updated following the interventions listed. Because of the limited success noted in the first quarter of implementation of home visits, the intervention was subsequently discontinued.

Improvements in TB patient treatment outcomes following the interventions

Following the enhanced patient follow-up by telephone, division and inter-district meetings, provision of DOT in Kawempe Division as well as improved recording and reporting, the proportion of patients evaluated in Kampala increased from 28% in 2006 to 96% in 2007. As a result the treatment success rate (TSR) increased from 17.2% to 73.1% for patients registered in 2006 and 2007 respectively. Although the improvements continued into 2008, there were shortages of TB drugs in Kampala that affected the treatment outcomes for patients registered in that year. Table 2 gives a summary

Table 1 Patient records updated following implementation of interventions

Intervention	2008		2009		Total
	July–Sept	Oct–Dec	Jan–March	April–Jun	
Meetings*					
Division level	1506	2113	1992	1965	7576
District level	100	86	79	74	339
Telephone calls	143	74	68	54	339
Home visits	8	–	–	–	8
Total	1757	2273	2139	2093	8405

* The figures given reflect the patient records updated during the meetings in the quarter indicated irrespective of the year the patients were registered.

of the improvement in patient outcomes over the period 2006 to 2008.

Improvement in TB/HIV indicators

Dissemination of TB health unit registers that had a provision for TB/HIV indicators in Kampala was completed during the second half of 2007; therefore data on TB/HIV indicators were not being routinely recorded in health unit registers before that time. However a number of health facilities had identified innovative ways to accommodate this data in the health unit register by drawing extra columns. Table 3 provides a summary of the performance of Kampala with regard to TB/HIV collaborative activities.

Table 2 Improvement in TB treatment outcomes following the interventions

Treatment outcome	2006 (n=2983)	2007 (n=3430)	*2008 (n=3548)
Cure rate (%)	6.4	40.0	46.9
Treatment success rate (%)	17.2	73.1	59.8
Default + transfer out (%)	9.8	19.5	17.0
Died (%)	0.8	2.0	2.1
Failure (%)	0.2	0.6	0.1
% of records evaluated	28.0	95.2	79.0

*At the time of writing, the article the Kampala Zonal office was compiling reports for 21% of records that had not yet been evaluated. The final treatment success rate is expected to change when this exercise is completed.

Table 3 Improvement in TB/HIV indicators

Indicator	2006	*2007 (n=3430)	2008 (n=7815)	2009 (n=7467)
% tested for HIV	n/a	56.0	78.1	80.0
Of those tested % HIV+	n/a	56.7	64.0	72.0
Of those testing HIV+, % placed on CPT	n/a	66.6	72.0	95.0
Of those testing HIV+, % placed on ART %	n/a	22.4	32.0	24.8

*Only TB/HIV data for smear-positive patients as opposed to all TB patients registered were indicated because this category of patients were followed up during the interventions described earlier.

Discussion

Experience during the implementation of these interventions has shown that improving follow-up of TB patients in large urban centres such as Kampala is possible. When programmes employ simple and cost-effective interventions, such as supporting coordination meetings and telephone calls to treatment interrupters, it is possible to follow up patients in large urban centres and maintain complete and up-to-date records.

In this case study, the TSR for Kampala rose from 16% in 2006 to 73% in 2007, just 1 year following

implementation of simple and inexpensive interventions that served to strengthen the health system. Some have questioned the sustainability of such improvements given that the bulk of the finances that supported such interventions originated from donors.¹² It should be noted that Uganda's total healthcare expenditure of US\$18 per capita is far below that recommended as the minimum healthcare expenditure required to deliver a basic package of health services.^{13–15} Moreover, over 50% of this healthcare expenditure occurs at household level, implying that government contribution to healthcare expenditure is less than desirable, leaving a significant financing gap.¹⁶ Donor funds in this case only serve to reduce, but cannot close, this gap, which ideally and eventually should be filled by the government. Intensification of advocacy efforts should continue to push the government to commit more funds towards health. In addition, sustainability of improvements in TB control, could be achieved when the practical, cost-effective interventions that build health systems continue to receive funding through other global health financing initiatives even when one donor stops funding them, or ideally when the government itself takes responsibility.

The majority of the missing or incomplete patient records were updated through coordination meetings among division TB focal persons. Holding such a meeting every quarter provided them with an opportunity to reconcile records of their patients with missing or incomplete information. Although this was a simple, inexpensive intervention the returns were enormous. Before each meeting, the division focal persons did their own follow-up and developed an updated health unit register, together with the list of missing patients or patients with incomplete information based on which information could be exchanged during the actual meeting.

Most of the incomplete records were due to failure of health workers to update the health unit register or due to self-transfer by patients to other health facilities. This contradicted the generally held belief that

the problem of TB control in Kampala was due to patients defaulting on treatment after improving during the initial phase. During the interventions described above, it was realised that many patients whose records in the health unit registers appeared incomplete had actually been taking their treatment as required or had completed treatment, but the health workers had not taken the time to update the health unit register accordingly.

Ensuring that health workers update health unit registers at the appropriate occasion (during refill of drugs, HIV testing, follow-up smears, etc.) plays a key role in addressing the low TSR in Kampala. Such a function may be carried out by any health worker who works in the TB clinic.

It is also interesting to note that most of the patients whose records in the health unit registers were incomplete or missing were found living in the city, again contrary to the belief that these patients had gone back to their districts of residence (origin). This was discovered during both the enhanced follow-up of patients through telephone calls and coordination meetings. This implies that interventions that seek to improve follow-up of TB patients within the city or maintain the improved follow-up so far attained should prioritise supporting enhanced information exchange within the city divisions themselves.

Conducting home visits did not significantly contribute to the tracing of patients lost to follow-up. Since it was quite time-consuming and costly, it was eventually dropped from the list of interventions. In our experience in Kampala, home visiting as an intervention to improve treatment outcomes of TB patients can only be useful if there are adequate resources in terms of personnel, facilitation to travel, and time.

Although the TSR for Kampala improved, the cure rate has still remained low and the implementation of DOT is still limited. This low cure rate is partly attributed to inadequate transfer of information from the lab register to the health unit register. In a number of instances TB patients are sent by clinicians to the lab for follow-up smears but their results are not recorded in the health unit register. At present, The Union through TB CAP is supporting the harmonisation of information between the lab and health unit register.

Although The Union has supported provision of DOT in Kampala through partnership with one CBO, the proportion of TB patients on DOT has still remained low. To address this challenge, The Union is undertaking efforts to identify other CBOs whose capacity can be strengthened to provide DOT.

Conclusions and recommendations

In this case study, we have shown that improving follow-up of TB patients in Kampala, the largest urban centre in Uganda, is possible, especially when programmes employ simple and cost-effective interventions such as coordination meetings and telephone calls to enhance patient follow-up. Coordination meetings, during which division TB focal persons had an opportunity to share/exchange information about patients contributed most significantly to the improvement in the treatment outcome of patients. Incomplete patient records in health

unit registers were noted as one of the key gaps that led to reporting a low TSR. Supporting the process that led to improvement in record-keeping played a key role in improving treatment outcomes in Kampala. TB patients in Kampala that had been described as 'lost' had not necessarily left the city, as became evident during the division focal persons' meetings. Interventions to improve follow-up of TB patients in the city should therefore prioritise information exchange at division level among division TB focal persons, as opposed to trying to find patients outside the city.

Home visiting as an intervention aimed at following up patients in a situation of limited resources did not result in a significant improvement in treatment outcomes in Kampala.

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