Community-based active case-finding to reach the most vulnerable: tuberculosis in tribal areas of India

A. Vyas,* J. Creswell,† A. J. Codlin,‡ V. G. Rao,§ B. Kumar,¶ S. Khaparde,# S. Sahu†
*Asha Kalp, Gwalior, India; †Stop TB Partnership, Geneva, Switzerland; ‡Independent Consultant, Manchester, UK; §National Institute for Research in Tribal Health, Jabalpur, †Global Coalition of TB Activists, New Delhi, #Central TB Division, Government of India, New Delhi, India

SUMMARY

BACKGROUND: India has the world’s largest indigenous/tribal population. Many areas with large tribal populations suffer from weak infrastructure and services. Surveys have shown a high prevalence of TB among Saharia communities, who rarely access public services. We evaluated a community-based active TB case-finding intervention.

METHODS: Community health workers screened people for TB symptoms in Saharia communities, made referrals, collected sputum for transport to laboratories, and initiated and supported anti-tuberculosis treatment. Microscopy testing was performed at government laboratories. The intervention tracked the people screened, referrals, the people tested, laboratory results, treatment initiation and outcomes.

RESULTS: Community health workers verbally screened 65,230 people, 8,723 (13%) of whom had symptoms. Of these, 5,600 were tested, 964 (17%) of whom were smear-positive. During the intervention, we observed a +52% increase in people tested at laboratories and an +84% increase in TB case notifications. Pre-treatment loss to follow-up decreased and treatment success increased slightly.

CONCLUSIONS: In India, particularly among tribal populations, many people with TB are missed by current approaches due to poor access. Community-based active case-finding can help identify more people with TB in tribal and remote rural areas by addressing barriers to health seeking as well as help reach ambitious country and global notification targets.

KEY WORDS: key populations; active case-finding; detection; sputum transport; indigenous population

THE STOP TB PARTNERSHIP’S Global Plan to End TB 2016–2020 and the World Health Organization’s (WHO’s) End TB Strategy lay out ambitious targets to reach people with TB who have been missed by health services. In 2017, 3.6 million people were not diagnosed, treated or reported to National TB Programmes (NTPs). India alone accounts for 1 million of those missed people with TB. These individuals are often poor, marginalised and vulnerable, and they are frequently part of key populations for TB, which include people with increased exposure to TB, limited access to TB services and greater risk of TB due to biological or behavioural factors. A substantial proportion of people with TB who are missed by NTPs are likely treated by private providers and not reported, particularly in South Asia. Improvements in India’s electronic recording and reporting system have facilitated the inclusion of private sector treatment in notifications, resulting in substantial increases. However, many people with TB who are missed suffer from severe physical, economic, legal or other access barriers and truly remain untreated.

This is one reason TB kills more than 430,000 people in India every year. India has the largest indigenous (the word ‘tribal’ is used in India) population worldwide—more than 100 million people across the country. Tribal communities often suffer from high rates of poverty, stigma, disease burden and poor access to health services due to geographic and infrastructure barriers. The TB burden among the different tribal groups in India taken together, measured using small prevalence surveys, is >1%, whereas TB burden is >3% among the Saharia tribe living in Madhya Pradesh, which is more than 10 times the national estimate. Despite the high TB rates, little has been done to address the needs of this key population.

For TB services to reach more people, community outreach efforts must be expanded. Active case-finding (ACF) interventions have been evaluated in urban slums, rural populations and migrant/mobile populations. These activities can often identify people with TB earlier in their disease progression, and can increase the number of people treated after
controlling for secular notification trends and changes in control areas.22

Through Stop TB Partnership’s TB REACH initiative, a community-based organization, Asha Kalp, developed an ACF intervention to provide ‘last mile’ TB screening, testing and treatment support to Saharia communities in collaboration with India’s Revised National Tuberculosis Control Programme (RNTCP). The cultural practices and sensitivities of the Saharia people were included to ensure the acceptability and success of the intervention, including fluency in the local language of lay workers used as outreach staff. These ACF activities were evaluated to determine their impact on TB case notifications and treatment outcomes reported by the RNTCP at a district level.

METHODS

This ACF intervention was implemented between 1 July 2014 and 30 June 2015 by Asha Kalp, which linked RNTCP services and the local population in Gwalior District (2013 population: ~2 million people; area: 4560 km²). Large parts of Gwalior are rural, with no public transport options and long distances to health facilities. Gwalior comprised four TB reporting units (TUs, Figure 1). The intervention area comprised two TUs (Dabra and District TB Centre Gwalior) and contained 130 government-run health facilities, of which 12 were diagnostic microscopy centres (DMCs), where TB diagnosis and treatment were offered. An estimated 116 000 Saharia lived in the intervention area (~11% of its population). The remaining two TUs, containing 114 health facilities and including nine DMCs, served as the control area and were not provided with additional services beyond the RNTCP routine care.

Twelve individuals were recruited as community health workers (CHWs) from nearby villages to ensure they spoke the local language, understood the local culture and had access to community members. The CHWs received a monthly base stipend (INR2000 = USD31). They were required to own or have access to a motorbike and were also paid a monthly travel and communication allowance (INR2300 = USD35) to assist with outreach efforts. Additional performance-based payments were provided for each person with smear-positive TB started on treatment (INR225 = USD4), and for sustaining quarterly treatment success rates ≥ 80% for patients supported by each CHW (INR1000–1500 = USD15–24). Control measures for monitoring CHW incentives were conducted through data audits, register checks and interviews with identified patients.

CHWs were assigned a defined catchment area for screening consisting of 7–8 villages. Saharia homes were identified and mapped to facilitate the ACF activities, and CHWs visited each village every other day for screening and eventually, treatment support. They visited homes and verbally screened all consenting individuals (adults and children) for the presence of the following symptoms: cough, fever,
using 2012 data as the baseline because a pilot study (for smear-positive and all forms TB) were calculated TB notifications in the intervention and control areas. Pre/post changes in to the end of the intervention (June 2015) from from the baseline period beginning 1 January 2009 up to the second half of the project. In the first 6 months of the intervention, CHWs referred 913 individuals to laboratories for testing. However, none of those referred could be traced in laboratory registers and this strategy was abandoned in favour of community-based sputum collection. CHWs collected samples from 5600 people in the community (64% of those with symptoms). A large proportion of people with TB symptoms could not produce a proper sample. They were advised that, if the symptoms persisted, they could provide the CHW with another sample during the next visit, or visit the DMC for care. Microscopy testing resulted in the identification of 964 people with smear-positive TB (17% of those tested). All but eight people detected through ACF (99%) were initiated on treatment and notified to the RNTCP.

## RESULTS

Between 1 July 2014 and 30 June 2015, CHWs verbally screened 65,230 individuals in the intervention area (Table 1). Data monitoring and continuous processes for programme improvement resulted in a +54% growth in screening numbers in the second half of the intervention. Of those screened, 8723 (13%) individuals with symptoms were identified. The proportion of screened individuals with symptoms declined from 18% in the first half to 10% in the second half of the project. In the first 6 months of the intervention, CHWs referred 913 individuals to laboratories for testing. However, none of those referred could be traced in laboratory registers and this strategy was abandoned in favour of community-based sputum collection. CHWs collected samples from 5600 people in the community (64% of those with symptoms). A large proportion of people with TB symptoms could not produce a proper sample. They were advised that, if the symptoms persisted, they could provide the CHW with another sample during the next visit, or visit the DMC for care. Microscopy testing resulted in the identification of 964 people with smear-positive TB (17% of those tested). All but eight people detected through ACF (99%) were initiated on treatment and notified to the RNTCP.

### Table 1: Yields from community ACF activities in Gwalior, Madhya Pradesh, India

<table>
<thead>
<tr>
<th>Activity</th>
<th>2014 Q3 n (%)</th>
<th>2014 Q4 n (%)</th>
<th>2015 Q1 n (%)</th>
<th>2015 Q2 n (%)</th>
<th>All quarters</th>
</tr>
</thead>
<tbody>
<tr>
<td>People screened verbally</td>
<td>13,085</td>
<td>12,594</td>
<td>19,497</td>
<td>20,054</td>
<td>65,230</td>
</tr>
<tr>
<td>People with TB symptoms</td>
<td>2,360 (18)</td>
<td>2,384 (19)</td>
<td>2,131 (11)</td>
<td>1,848 (9)</td>
<td>8,723 (13)</td>
</tr>
<tr>
<td>Referrals to laboratory</td>
<td>524 (22)</td>
<td>389 (16)</td>
<td>Strategy abandoned</td>
<td>913 (11)</td>
<td></td>
</tr>
<tr>
<td>Arrived at laboratory and tested</td>
<td>0</td>
<td>0</td>
<td>1,669 (78)</td>
<td>1,357 (73)</td>
<td>5,600 (64)</td>
</tr>
<tr>
<td>Community sputum collection</td>
<td>1,030 (44)</td>
<td>1,554 (65)</td>
<td>1,699 (78)</td>
<td>1,357 (73)</td>
<td>5,600 (64)</td>
</tr>
<tr>
<td>Smear-positive TB detected</td>
<td>206 (20)</td>
<td>248 (16)</td>
<td>286 (17)</td>
<td>224 (17)</td>
<td>964 (17)</td>
</tr>
<tr>
<td>Started on treatment</td>
<td>203 (99)</td>
<td>244 (98)</td>
<td>285 (100)</td>
<td>224 (100)</td>
<td>956 (99)</td>
</tr>
</tbody>
</table>

ACF = active case-finding; Q = quarter; TB = tuberculosis.
Table 2 Laboratory testing and smear-positive TB results in Gwalior, Madhya Pradesh, India

<table>
<thead>
<tr>
<th>People who underwent smear microscopy*</th>
<th>People with smear-positive TB*</th>
</tr>
</thead>
<tbody>
<tr>
<td>2012 baseline laboratory data</td>
<td>11 359</td>
</tr>
<tr>
<td>Intervention period laboratory data</td>
<td>17 266</td>
</tr>
<tr>
<td>Additional people tested/diagnosed</td>
<td>5 907</td>
</tr>
<tr>
<td>Change from baseline, %</td>
<td>+52.0</td>
</tr>
</tbody>
</table>

*Includes only people who underwent diagnostic testing using smear microscopy (no treatment follow-up or controls included). TB = tuberculosis.

Microscopy testing results for the intervention area are given in Table 2. In the 2012 baseline period, 11 359 people were tested using smear microscopy for diagnosis while, during the intervention, 17 266 people were tested. The increase in testing of 5907 (+52%) people correlated with the number of samples transported from communities by CHWs (5600). Similarly, 1447 smear-positive cases were detected during the 2012 baseline period, while 2459 people were detected during the intervention period (an increase of 102 people [+70%]). Pre-treatment loss to follow-up between laboratory detection and treatment initiation decreased from 38% during the 2012 baseline period to 32% in the intervention period.

Table 3 shows the TB case notification data in the intervention and control areas. During the 2012 baseline period, 907 smear-positive and 1440 all forms TB patients were treated and notified in the intervention area while, during the intervention period, 1667 smear-positive and 2650 all forms patients were treated (i.e., increases of respectively +83.8% and +84%).

As the TB notification trend in the intervention area from 2009 to 2012 was slightly negative, the regression analysis showed even greater increases based on trend-expected notifications (+89.4% for smear-positive and +90.8% for all forms). In the control area, smear-positive notifications decreased slightly from 839 to 793 (−5.5%) between 2009 and 2012, while there was a +17.3% increase in all forms notifications (1524 to 1787). The regression analysis showed similar results.

Table 4 shows that treatment outcomes were slightly improved between the 2012 baseline and intervention periods despite a large increase in notifications. Treatment success rates increased from 82.6% to 84.8%, while the proportion of people lost to follow-up decreased from 8.0% to 6.9%.

**DISCUSSION**

Our results document an extremely high TB burden in central India among pockets of tribal populations, much of which remains undetected. ACF efforts focused on community outreach can effectively reach people with TB who are missed by existing services. Ensuring local community involvement and participation in these approaches is critical. While substantial efforts have been made to link private providers to the RNTCP, many people in remote rural communities who suffer from TB are not accessing health care and do not benefit from private sector engagement strategies.

The WHO recommends screening for active TB in geographically defined populations with high levels of undetected TB, and for subpopulations with poor access to health services. We found that the point estimate of undiagnosed smear-positive TB among those screened (1.5%) was higher than the point estimate in a recent systematic review of bacteriologically proven TB among household contacts (1.2%). Such high levels are alarming and suggest that Saharia and similar populations located throughout India should be urgent candidates for larger scale ACF efforts, preventive therapy and interventions to improve other social determinants.

We observed large increases in TB case notifications at a district level by targeting a relatively small population (11% of the district’s population) at very high risk. These data suggested that the standard passive approach to case-finding is insufficient, and that tailored approaches are needed to reach all those in need. Our findings can help design and target ACF activities planned under the new national strategic plan.

Table 3 Changes in TB notification, Gwalior, Madhya Pradesh, India

<table>
<thead>
<tr>
<th>Evaluation area</th>
<th>Control area</th>
</tr>
</thead>
<tbody>
<tr>
<td>Smear-positive</td>
<td>All forms</td>
</tr>
<tr>
<td>2012 baseline notifications</td>
<td>907</td>
</tr>
<tr>
<td>Intervention period notifications</td>
<td>1667</td>
</tr>
<tr>
<td>Additional notifications</td>
<td>760</td>
</tr>
<tr>
<td>Change from baseline, %</td>
<td>+83.8</td>
</tr>
<tr>
<td>Expected notifications during intervention period*</td>
<td>880</td>
</tr>
<tr>
<td>Additional notifications</td>
<td>787</td>
</tr>
<tr>
<td>Change from expected notifications, %</td>
<td>+89.4</td>
</tr>
</tbody>
</table>

* Trend-adjusted with a linear regression of TB case notification data from 2009 Q1 to 2012 Q4 (16 quarters). TB = tuberculosis; Q = quarter.
ACF approaches often lead to many symptomatic individuals who are unable or unwilling to produce sputum for testing. Individuals with symptoms are often referred for testing as a minimal effort approach. In this setting, referring individuals with symptoms to a laboratory without providing transport support elicited very poor results. People screened through outreach may be less likely to follow referral advice due to geographical barriers, economic and time burdens and competing interests. Highly marginalised populations such as the Saharia are unlikely to seek care at public facilities due to stigma and access barriers, including high costs, long travel times and poor transportation options, leaving large pockets of the population with poor access to care. Actively tracking referrals testing during the intervention allowed evidence-based decisions to be made for specimen transport and highlighted the usefulness of appropriate monitoring of ACF.

The cohort of people treated during the intervention had improved outcomes, including a reduction in pre-treatment loss to follow-up rates, although these remained high. A systematic review of TB treatment outcomes in people detected using ACF did not find differences in treatment outcomes compared with passive case-finding, while a review on pre-treatment loss to follow-up documented a range of 4–28% in Asia. Even in a resource-limited setting and even when the number of TB treatment initiations are almost doubled, stable and high treatment outcomes can be maintained by providing additional informational, transport and treatment support by community-based workers.

Our evaluation had some limitations. The intervention was programmatic, not a controlled trial, and changes in notification cannot be definitively linked to our intervention. However, use of a control population strengthens the evidence that the additional TB cases found were linked to the intervention. Moreover, in districts supported by Asha Kalp, increases in the number of samples submitted for testing and TB cases diagnosed who were identified directly by CHWs were in line with overall TB testing and case notification gains at a district level whether by a simple pre/post or by regression analysis. Another limitation was the lack of more sensitive diagnostic tests; we had access to only smear microscopy at DMCs. Radiography and molecular testing likely would have identified many more people with TB.

While some ACF interventions have documented very low yields among those people tested, the yields from our ACF intervention were quite high (17% of those tested and 1.5% of people screened), which is similar to passive care-finding in India. TB case-finding interventions that work outside health facilities will involve higher costs than standard passive approaches. We did not measure costs or the cost-effectiveness of the interventions in this analysis because these have been evaluated elsewhere.

Approaches focusing on detection and treatment from a biomedical perspective alone will not be sufficient. As key populations often suffer from extreme poverty, other social interventions will likely be needed for maximum impact. These social support interventions were not included in our study and could be considered in future research.

**CONCLUSIONS**

The TB burden among the Saharia tribe in Madhya Pradesh is very high and many people with TB are being missed by the current passive approaches run by government services. To better serve key populations such as tribal groups, community-based and community-led interventions are required. By involving community-based organisations, conducting outreach activities, collecting and transporting sputum for testing, and supporting treatment to promote adherence, we were able to substantially increase TB notifications while maintaining good treatment outcomes. To meet ambitious national and global TB targets, such interventions should be considered in rural areas of India, where limited access to services have been documented.

**Acknowledgements**

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JC, AJC and SS are members of the Stop TB Partnership. The views expressed here are their own and do not necessarily represent the Stop TB Partnership’s official position. BK was a member of the Wave 4 TB REACH Proposal Review Committee but did not review proposals from India.
References


CONTEXTE : L’Inde a la plus grande population indigène/tribale au monde et de nombreuses régions ayant une vaste population tribale souffrent de la faiblesse des infrastructures et des services. Les enquêtes de prévalence ont mis en évidence une prévalence élevée de tuberculose (TB) parmi les communautés Saharia qui ont rarement accès aux services publics. Nous avons évalué une intervention de recherche active des cas de TB en communauté.

MÉTHODE : Les travailleurs de santé communautaire ont dépisté la population à la recherche de symptômes de TB dans les communautés Saharia, ont fait les réferences, recueilli les crachats pour les transporter aux laboratoires, et mis en route et soutenu le traitement de la TB. Les examens microscopiques ont été réalisés dans des laboratoires de l’état. L’intervention a suivi les personnes dépistées, les références, les personnes testées, les résultats du laboratoire, la mise en route du traitement et ses résultats.

RÉSULTATS : Les travailleurs de santé communautaire ont dépisté verbalement 65 230 personnes dont 8723 (13%) avaient des symptômes ; 5600 personnes ont été testées, dont 964 (17%) ont eu un frottis positif. Au cours de l’intervention, nous avons observé une augmentation de +52% des personnes testées dans les laboratoires et une augmentation de +84% des notifications de cas de TB. Le nombre de perdus de vue avant le traitement a diminué et le taux de succès du traitement a légèrement augmenté.

CONCLUSION : En Inde, particulièrement parmi les populations tribales, de nombreuses personnes atteintes de TB sont manquées par les approches actuelles en raison de leurs problèmes d’accès. La recherche active des cas en communauté peut permettre d’identifier davantage de personnes atteintes de TB dans les communautés tribales et les zones rurales isolées en éliminant les obstacles à la recherche des cas et contribuer à atteindre les cibles ambitieuses de notification nationale et mondiale.

RESUMEN

MARCO DE REFERENCIA: La India cuenta con la mayor población indígena o tribal del mundo y muchas zonas con altas poblaciones tribales sufren de deficiencias de las infraestructuras y los servicios. Las encuestas han puesto de manifiesto una alta prevalencia de tuberculosis (TB) en las comunidades Saharia, cuyos integrantes acuden muy rara vez a los servicios públicos de salud. En el presente estudio se evaluó una intervención comunitaria de búsqueda activa de casos de TB.

MÉTODOS: Agentes sanitarios de la comunidad realizaron un tamizaje de síntomas de TB en comunidades Saharia, practicaron remisiones y recogieron muestras de esputo que transportaban a los laboratorios, iniciaron el tratamiento antituberculoso y prestaron apoyo durante el mismo. La baciloscopía se realizó en laboratorios del sistema público. Como parte de la intervención se dio seguimiento al número de personas examinadas, las remisiones, las personas con exámenes de esputo, los resultados de laboratorio, la iniciación del tratamiento y a los desenlaces.

RESULTADOS: Los agentes de salud comunitarios practicaron el tamizaje verbal de 65 230 personas y 8723 eran sintomáticas (13%). Se practicaron baciloscopias a 5600 personas, de las cuales 964 obtuvieron un resultado positivo (17%). Durante intervención se observó un aumento de 52% de las personas examinadas en los laboratorios y un aumento de 84% de la notificación de casos de TB. Ocurrió una disminución de la pérdida durante el seguimiento antes de iniciar el tratamiento y hubo un leve aumento del éxito terapéutico.

CONCLUSIONES: En la India, sobre todo en las poblaciones tribales, los mecanismos vigentes pasan por alto muchas personas con TB debido a un deficiente acceso a los servicios de salud. Las intervenciones comunitarias de búsqueda activa de casos podrían mejorar la detección de personas con TB en las zonas rurales tribales y remotas, al superar los obstáculos a la búsqueda de atención de salud y contribuirían a alcanzar las ambiciosas metas de notificación nacionales y mundiales.