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ORIGINAL PAPER

# Infection of the Invisible: Impressions of a Tuberculosis Intervention Program for Migrants in Istanbul

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**Abstract** This paper reviews the experience of the Istanbul Tuberculosis Aid Program, which targeted tuberculosis (TB) disease in the growing irregular migrant populations of Istanbul. This experience illustrated the importance of community-based public health interventions when dealing with an infectious disease like TB among vulnerable groups. Our data is derived primarily from a qualitative study carried out with program stakeholders. We summarize lessons for success of ITAP as: (1) Strengthening impact and outreach of TB intervention among irregular migrant communities through involvement of multiple stakeholders (2) Increasing TB awareness through a community targeted approach (3) Increasing TB contact tracing and treatment success among infected irregular migrants, and, (4) Improving overall health seeking behavior of irregular migrants through empowerment and trust. Given these particularities we list our policy suggestions for revision of regulations regarding TB control and healthcare needs of irregular migrant populations.

**Keywords** Tuberculosis · Infectious diseases · Migration · Community-based healthcare · Turkey

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## Introduction

Tuberculosis (TB) has been at the forefront of public health crises around the world, and there have been many attempts to fight its spread and control its effects on populations [1–3]. Community health care programs have proven to be effective in many different settings of the world to deal with communicable diseases like TB [4–6]. In such programs the main aim is to reach vulnerable groups who do not normally have access to basic health services and a wide range of activities are covered that contribute to prevention, diagnosis, improved care and treatment adherence that have positive influence on the outcomes of all types of TB [7]. In this article we would like to present the experiences from such a program, the Istanbul Tuberculosis Aid Program (ITAP), which was a short-lived[1] albeit successful community-based program targeting TB contagion among irregular migrant[2] populations in Istanbul.

[1] The main reason for ITAP's discontinuation was an inability to institutionalize the program despite several efforts made in this direction. Under Turkish legislation the condition for a civil society initiative to receive foreign funding is that it must be implemented through an existing Turkish institution. Program coordinators did approach three different organizations on this matter, however each of them remained reserved about taking up such a program because it involved working with irregular migrants, which was seen as a "tricky" issue that could upset state authorities. Consequently, a formal bank account could not be obtained for ITAP, funding resources obtained from abroad could not be transferred to Turkey and efforts to raise additional funds had to remain limited to the charitable contributions of immediate social circles in Turkey.

[2] The International Organization for Migration defines an irregular migrant as "A person who, owing to unauthorized entry, breach of a condition of entry, or the expiry of his or her visa, lacks legal status in a transit or host country. The definition covers inter alia those persons who have entered a transit or host country lawfully but have stayed for a longer period than authorized or subsequently taken up unauthorized employment (also called clandestine/undocumented migrant or migrant in an irregular situation). The term 'irregular' is preferable to 'illegal' because the latter carries a criminal connotation and is seen as denying migrants' humanity [8]."

Over the last two decades Turkey has been subject to the large-scale and ever-increasing movement of migrants arriving from abroad for purposes of employment, settlement, seeking refuge or transiting onwards to a third country [9]. While the national background, demographic profile and migration motives of these populations are highly diverse, they have the shared attribute of many of their members having irregular status in Turkey in terms of residency and employment rights [10, 11]. Despite their growing presence, Turkey has been slow in responding to the needs of these communities, particularly with respect to accessing healthcare. As a consequence, irregular migrants with health needs find themselves in a perilous situation, where the effects of limited access are amplified by undocumented status and restricted rights, poor living and working conditions, financial and linguistic constraints, and cultural differences [12]. Under these conditions, irregular migrant populations in Turkey become especially vulnerable to contagious diseases, such as TB, which can be life threatening for the individual and poses serious risks to overall public health [13].

In view of this background, ITAP was founded in July 2005 and ran until April 2008, creating the first community-based TB program for irregular migrants in Istanbul. It was developed as a collaborative effort between two social entrepreneurs and the Istanbul anti-TB association (IVSD), a quasi-governmental association with 11 clinics running across the city. ITAP's first goal was to raise awareness about the causes and consequences of TB and encourage irregular migrants to be screened without fear of reprisal. If one tested TB positive, that person was then able to receive free treatment in a clinic regardless of his/her legal or economic status. As this population is highly transient and mobile, ITAP utilized also specific strategies like house visits and constant contact with the patient in order to encourage him/her to remain in Istanbul until the end of treatment. Despite the absence of any funding, all services and facilities were offered voluntarily and free of charge.

In this paper, we argue that the experience of ITAP teaches us the importance of community-based public health interventions targeting vulnerable populations when dealing with an infectious disease like TB. While ITAP is a local example, these strategies can also be extrapolated for the healthcare needs of other vulnerable populations in Turkey and elsewhere.

## Methods

### Study Design

The paper presents results from a retrospective qualitative study of ITAP through field notes and semi-structured interviews conducted face-to-face and over email, carried out between February and July 2014 with leading stakeholders who took active part in running the program between 2005 and 2008 (See Appendix). We used a procedure of convenient and snowball sampling in selecting the interviewees. All names used throughout the paper are pseudonyms to protect the privacy of participants.

### Research Questions

Our main goal was finding out about the impact of ITAP on irregular migrant populations. With this goal in mind, interviews centered on the following four questions: Do you think, TB is a significant health problem among irregular migrant populations in Istanbul? Are there any particular difficulties you face in treating irregular migrants, as compared to natives? Were there any notable differences when ITAP was being implemented? Were there any notable differences when ITAP was discontinued? The four community health workers (CHW) and the program co-coordinator were further asked to recount some of the most memorable encounters they experienced as part of their work for ITAP.

### Thematic Analysis

We performed a qualitative textual analysis of the interviews to come up with the themes presented in the Results section. After interviews were complete, interview transcripts were coded for prevalent themes independently by three authors, and commonly agreed themes were reached after a process of discussions and a second round of coding.

### Limitations

Qualitative interviews could be carried out only with ITAP stakeholders. Despite attempts made to locate a number of TB-infected migrants that had benefitted from ITAP through two of the community leaders that remained in Istanbul, none could be reached as they had all migrated further, being scattered to numerous other parts of the world.

Measuring the success of ITAP retrospectively in quantitative detail has not been possible since anti-TB clinics keep records of screened patients only if they are TB-positive. While keeping of such records independently by ITAP could have been possible, given the voluntary nature of the program, which was run by two coordinators already employed full time elsewhere and five community volunteers, this was not given priority. Rather, in view of the legal precariousness and consequent fears of the concerned population, ITAP made every effort to assure that documentation and registration would not be requested in

the absence of a serious health risk being found. Even in TB-positive cases, formal identification was very often not demanded, with ITAP community mediators serving as person of contact and follow-up.

## Results

The successes and failures of ITAP experience taught us several lessons that could be translated into community-based health services throughout.

### Strengthening Impact and Outreach of TB Intervention Through Involvement of Multiple Stakeholders

ITAP was a joint program involving IVSD clinics and migrant community representatives. Given its historical and ongoing success, the participation of IVSD in the ITAP program was crucial in enabling TB outreach, education and observation activities among the populations of concern. When ITAP was being established, IVSD agreed to provide screening and treatment to irregular migrants at four clinics in Istanbul (Taksim, Kumkapı, Zeytinburnu and Kadıköy), which are areas where these communities are known to reside, thus both facilitating broader local access and diminishing transportation costs for these communities.

ITAP also actively worked on collaborating with non-governmental aid and support organizations working with irregular migrants in Istanbul, including some faith-based organizations, which were at the time highly successful in reaching out to the most vulnerable communities in Istanbul. The words of Bernard, a social worker for a faith-based organization, confirm this outcome: “We already had many contacts in irregular migrant communities. But ITAP offered a program on screening and treating TB for them. Because we were concerned about TB in irregular migrant communities, we wanted to take part. We organized educational activities, went to TB centers, met doctors and gained experience. The experience of the people in the field really helped”.

Secondly, these collaborations proved to be crucial for procuring non-medical supplementary support (food, clothing, blankets, nutrients, heaters, etc. and in some case housing) that is also an indispensable part of full and effective TB treatment. Most of the interviewees, such as Bahar, a medical doctor who worked with ITAP, mentioned the importance of livelihood support in this case, saying access to food, shelter and clothing “was not a problem” during ITAP. Lisa, who was then a director of a faith-based organization, was another one who commented on the importance of this connection:

> TB was a growing concern for irregular migrants in Istanbul. (…) When the project [ITAP] was implemented we had a means to help detect TB. We (…) provide[d] services to help them with medication and housing and nutrition. This was so encouraging to all who were working with the irregular migrant population.

Nese, one of the program co-coordinators for ITAP, illustrated the importance of engaging multiple stakeholders to provide a meaningful environment for recovery with her story about a patient they visited at his house:

> We found him living in one of the poorest neighborhoods in the city (…) We wrote down our site visit notes and shared them with the director of a charitable organization specializing in the rights of migrant/refugee populations. They raised a fund to move him to a proper place. In the meantime, we asked IVSD to provide him with monthly food packages. A colleague volunteered to take care of him during his treatment and moved in with him to his new apartment. In a couple of months, we all witnessed how much he held on life with a great deal of progress.

### Increasing TB Awareness Through a Community Targeted Approach

After the program started being fully operational in September 2005, ITAP volunteers began conducting house visits where they encouraged irregular migrants to get screened and presented educational materials on TB and nutrition, made available in seven different languages (Arabic, English, Farsi, French, Lingala, Russian, Swahili). During the 3 years the program was implemented, seven different national communities (Congo, Ethiopia, Nigeria, Somalia, Sudan, Russia and Rwanda) assisted in the development of the initiative by appointing CHWs/interpreters and DOT observers who received the necessary training and supervision. The program put special emphasis on people from African countries, as many studies have shown that Africans in Turkey suffer more from discrimination than any other group [14–17].

The importance of using the migrant populations’ language is demonstrated in the anecdotes of some interviewees such as Bahar who mentions the language barrier between dispenser staff and the migrants, or Jamal, who started to work as an Arabic interpreter mostly for Sudanese and Somali people and over time became a trusted consultant for all these people who started calling him for issues outside of healthcare. Another example was Nese who told the story of meeting an African patient in vivid detail:

> In May 2006, I was asked to come down to see 'an African patient' in the clinic located in our university. The healthcare specialists there were desperate because…[t]he only language he knew was French..(…) I walked over and saw a male African patient, not older than 25 years of age, very tall and extremely thin. I greeted him, introduced myself, tried to explain his diagnosis in detail and why he should come to clinic everyday to take his medications. I also mentioned the duration of treatment with possible side effects of drugs and assured him that ITAP would be of help in case he needed anything and his treatment would be free of charge. (…) He thanked me with all his heart for the information and instructions and said that it was for the first time in months he was able to communicate with someone regarding his malady and got answers for his questions. Then he burst into tears.

After this story, Nese went on to describe the importance of community involvement aside from the language barrier, stressing the difference of priorities of irregular migrant populations as vulnerable groups, saying "if a healthcare intervention is planned, involvement of their own communities provide them a sense of security and makes things easier (…) particularly in a long and arduous treatment like TB that necessitates patient adherence". Along the same lines, Ziya, another medical doctor working with ITAP, told about a specific case, where after meeting the community leader of Senegal "[H]e referred not only TB patients but also people with other health problems", to other doctors and hospitals, including a Senegalese man with a liver abscess that required surgery. Ziya helped this man using his own social network, free of charge. Bahar also made a similar point about compliance regarding DOT treatment, repeating how during ITAP they were able to "implement DOT in a perfect way and followed up each and every patient".

Similarly, Bernard described how difficult it became to reach irregular migrants (potentially) infected with TB after ITAP:

> We only accepted the ones that came to us but we could not reach them by ourselves. Educational activities were stopped. We all know that we have many cases that we are not able to reach. We still and even more need help, a kind of structure to increase awareness among newcomers in particular. Because, you know, immigrant communities are mobile, moving. We no longer go to communities to search for new patients.

The same difficulty in reaching new populations after ITAP is also repeated in relation to trust issues below, in section Discussion.

### Increasing TB Contact Tracing and Treatment Success as Well as Decreasing Defaults Among Infected Irregular migrants

Migration in general poses new public health risk [18, 19], increasing in particular transmission of contagious diseases such as TB. Among migrant populations, active TB infection occurs mainly due to reactivation of latent infection. Reactivation rates are higher especially within the first 2–5 years after migration [20]. Therefore availability and accessibility of TB programs is crucial particularly in the first years of entry. Furthermore, considering that migrants are highly transient, when they leave to another country it is almost impossible to follow up and monitor the ongoing treatment, which poses major problems related to ongoing transmission in other countries, and development and transmission of new and/or drug-resistant strains. As put by Mahmoud, the medical program advisor, "The importance of such a program is that migrants (regular or irregular) are at increased risk of reactivation of TB. … In order to ensure that these patients get the care they need, and to stop the spread of the disease in the community, it is essential to find these patients, put them on treatment and follow closely".

ITAP also ensured follow-up at every stage of treatment. When a patient diagnosed with TB fell out of contact for any reason, the CHWs often reached them in a short time by using community networks. Both Nese, who stressed the importance of following up with the patient at every stage of treatment in TB, and Bahar, who pointed out to frequent address and phone number change of irregular migrants, confirmed the accomplishment of ITAP in reaching the patients and ensuring the continuity of treatment. Ziya also described the difference between ITAP period when "thanks to the community leaders and home visits, irregular migrants' awareness of TB was enhanced significantly", and afterwards when they lost access to the crowded households that irregular migrants shared (which increased the possibility of 10-15 people sharing the same house coming to screening together), losing the ability to do contact screenings along with it. As put by Bahar, after the discontinuation of ITAP they were "only able to test and treat people who can come and seek help by themselves. We are neither able to reach them by community networks nor can trace their close contacts. So, chemoprophylaxis or other preventive measures are out of question actually".

### Improving Overall Health Seeking Behavior of Irregular Migrants Through Empowerment and Trust

As part of its agreement, IVSD suspended two policies in relation to ITAP patients: the obligation to present a valid ID and pay a fee for screening. These two steps were crucial in ensuring the success of the program, because among this population besides financial limitations, fear of detention and/or deportation in the event of being identified continues to form a major impediment against seeking help when in medical need.

Most of the comments from our interviewees noted the positive effects of these policies. For example, Bernard, contrasted the times before and after ITAP as such;

> [Before ITAP], a lot of people were deported as well because hospitals submitted information about people without proper documentation to the Foreigners Police. ITAP made a big difference. It created a big difference on both irregular migrants side and Turkish TB control side. Awareness has been raised extremely.

The same view that confidentiality led to increased trust and better TB control was repeated by Nese, Ziya, and Ali, who also pointed out how this had a somewhat permanent effect on how much irregular migrants started to trust the IVSD clinics and people who used to work for ITAP and still live in Istanbul. On a similar vein, Jamal commented on the continued effects of ITAP on trust and healthcare seeking behavior of irregular migrants as such:

> After the program, even until now, people continued to approach me. They always asked: "why are you not taking care of us any longer?". I tried to explain if I could have the means to do so, I definitely would.

In turn, following the discontinuation of the program, a perceived decrease in the number of migrants coming to TB clinics was noted. Bahar mentioned how "nowadays [irregular migrant patients] do not come as easily, they seem to be coming here only at an advanced stage of sickness, which makes the treatment much more difficult". Or as in Bernard's words; "… after ITAP, irregular migrants wait until they are almost bed-ridden". Ali and Nese made the same point and underlined the important role played by ITAP training activities and house visits which encouraged people to seek help immediately when they have symptoms like persistent cough, weight-loss, night sweats, etc.

## Discussion

These four themes outlined in the Results sections provide a roadmap for what we believed to have been a successful community-based TB program for irregular migrant communities. Involving non-healthcare based stakeholders working with irregular migrants and ensuring their cooperation to provide them with their food and shelter needs is an important result, as well as involving the national/ethnic communities in the processes of detection, treatment and follow-up. Ensuring trust of the irregular migrant populations stand out as a very important lesson, particularly considering their vulnerability with regards to law enforcement. Most importantly, all these efforts need to be long-term and sustained in order to make a real difference. Below, we make some concrete suggestions to ensure such a difference.

## Conclusion

In view of the context and ITAP experiences presented above, the following conclusions can be reached.

- Turkey's NTP needs to be revised in view of the particular conditions, needs and concerns of vulnerable irregular migrant populations, including for example language barriers, requirements for presenting a valid ID, fear of deportation, financial restrictions, poor living and working conditions, lack of familial support and/or social networks in which patient feels secure, and regular contact to ensure finalization of treatment.
- Community-based programs are complementary and do not replace NTPs. Therefore Turkish NTP should encourage such programs and move towards combining official health units and community-based healthcare initiatives, which is known in many countries as leading to successful outcomes in targeting TB [20–24] and is also a growing demand (recognized) among migrant community leaders themselves.
- As portrayed through the experiences of ITAP, community-based public health interventions can be highly effective and successful in both identifying and overcoming such needs, and is an approach that must be integrated into public health initiatives for irregular migrants in Turkey. This approach enables to focus on preventive measures and at-risk groups and also helps to increase overall performance of NTPs.
- Considering the importance of long-term treatment in overcoming TB, it is also important to ensure the sustainability of such programs, such as in easing the legal barriers ahead of international collaborations.

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**Ethical Standard** This study was originally presented at the Mobility and Health Panel of the Annual Meeting of Reproductive Health Working Group (Oman on 27–29 January 2014). Following the high interest and encouraging comments of panel participants, authors were convinced by the relevance and timeliness to more thoroughly analyze and internationally publish on these experiences. As this idea developed after research and writing of the original paper had already been completed, review and approval by an Ethics Committee was not sought.

## Appendix

List of interviewees with pseudonyms:

1. Ziya, male, 57, medical doctor.
2. Bahar, female, 46, medical doctor.
3. Bernard, male, 52, CHW/interpreter.
4. Jamal male, 41, CHW/interpreter.
5. Samuel, male, 42, CHW/interpreter.
6. Lisa female, 63, director of a faith-based organization.
7. Ali, male, 45, medical doctor.
8. Nese, female, 45, program co-coordinator.
9. Mahmoud, male, 44, Dr./program advisor.
10. Rob, male, 38, CHW/interpreter.

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