

Knowledge, attitudes, beliefs, and stigma related to latent tuberculosis infection: a qualitative study among Eritreans in the Netherlands

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Abstract

Background Tailored and culturally appropriate latent tuberculosis (TB) infection screening and treatment programs, including interventions against TB stigma, are needed to reduce TB incidence in low TB incidence countries. However, we lack insights in stigma related to latent TB infection (LTBI) among target groups, such as asylum seekers and refugees. We therefore studied knowledge, attitudes, beliefs and stigma associated with LTBI among Eritrean asylum seekers and refugees in the Netherlands.

Methods We interviewed adult Eritrean asylum seekers and refugees: 26 semi-structured group interviews following TB and LTBI related health education and LTBI screening, and 31 semi-structured individual interviews with Eritreans during or after completion of LTBI treatment. We used a thematic analysis to identify, analyse and report patterns in the data.

Results Despite TB/LTBI education, misconceptions embedded in cultural beliefs about TB transmission and prevention persisted. Fear of getting infected with TB was the cause of reported enacted (isolation and gossip) and anticipated (concealment of treatment and self-isolation) stigma by participants on LTBI treatment.

Conclusion The inability to differentiate LTBI from TB disease and consequent fear of getting infected by persons with LTBI led to enacted and anticipated stigma comparable to stigma related to TB disease among Eritreans. Additional to continuous culturally sensitive education activities, TB prevention programs should implement evidence-based interventions reducing stigma at all phases in the LTBI screening and treatment cascade.

Introduction

To reduce tuberculosis (TB) incidence, low TB incidence countries focus on TB prevention through tailored latent TB infection (LTBI) screening and treatment programs.(1–3) Stigma can hamper the effectiveness of such programs as it may impede the uptake of LTBI testing and treatment because of people’s concern about reputational loss and stigma by participating in a “TB project”.(4) It is therefore important to address LTBI related stigma.(5, 6) There is abundant evidence showing that insufficient knowledge about TB and negative social attitudes towards TB causes stigmatization. Consequently, patients conceal their disease, do not comply with treatment and isolate themselves. We lack insights in the burden of LTBI related stigma among target groups for TB prevention activities in low TB incidence countries.(7, 8)

Scambler (2009) defined stigma as “a social process, experienced or anticipated, characterized by exclusion, rejection, blame or devaluation that results from experience, perception or reasonable anticipation of an adverse social judgement about a person or a group.”(9) Stigma can be classified in three categories (7, 10): (1) enacted stigma, in which a person experiences exclusion and/or discrimination. For example, TB patients are regularly rejected by family, friends or communities, resulting from fear of TB.(11); (2) felt stigma, in which a person has feelings of shame, fear, and guilt regarding

their (potentially) stigmatized disease. For example, labelling immigrants as high-TB-risk groups can induce feelings of discrimination.(11) (3) anticipated stigma, in which a person perceives, fears and/or expects stigmatization because of their disease. For example, Chinese immigrants in Canada believed that society would exclude those with an LTBI diagnosis.(8) Out of fear of exclusion, they would conceal their LTBI diagnosis and treatment to people in their social network. Besides suffering of the individual, stigma can also negatively affect public health: fear of TB and related stigma can cause diagnostic and treatment delays, as persons would rather hide their symptoms than seek care, leading to a continuous risk of TB transmission, more severe morbidity, and poorer treatment outcomes.(10–12) Furthermore, concealment can lead to continuous risk behaviour and failure to embrace preventive measures.(10)

Despite worldwide increasing efforts to rapidly implement TB prevention activities among target groups such as high-TB-risk migrants, very few studies have focused on LTBI knowledge, attitudes, beliefs and stigma. We therefore studied LTBI related knowledge, attitudes, beliefs, and stigma among Eritrean asylum seekers and refugees -currently the largest group of people with TB disease (13, 14) in the Netherlands.

Methods

This qualitative study is part of the TB-ENDPoint project, which studied the implementation, national impact and cost effectiveness of LTBI screening and treatment among high-TB-risk migrant groups in the Netherlands. It incorporated three mixed method studies (qualitative and quantitative research methods), which evaluated the implementation among 1) immigrants (15), 2) asylum seekers -predominantly Eritreans- living in asylum seeker centres (16), and 3) Eritrean refugees living in communities for maximum of ten years.(17) For this paper we used data from semi-structured interviews with Eritrean asylum seekers living in asylum seeker centres(15) and Eritrean refugees living in communities(17) in the Netherlands. Eritreans from both studies were predominantly from the same cohort (arrival in The Netherlands 2013-2017) of Eritrean asylum seekers characterized by a great proportion of male young Christian adults, literate but mostly without higher education, from a rural background, from the ethnic group Tigrinya.(16-19) As part of LTBI screening, participants received TB and LTBI group education before LTBI testing. The education session was designed in an interactive manner and consisted of a presentation using posters or PowerPoint slides. The education was taught in the participants' mother tongue, using professional interpreters. Furthermore, participants with an LTBI diagnosis received further education by the TB physicians and nurses throughout the care cascade, also with use of professional interpreters.

Data collection

All interviews primarily focused on identifying facilitators and barriers for LTBI screening and treatment. The interview topic guide contained additional sections focused on TB background knowledge, TB and LTBI knowledge acquired during pre-LTBI screening education, attitudes and beliefs about TB, and experienced or perceived TB and LTBI related stigma. Those interview sections were the source of the

data used in this study. Interviews with Eritrean asylum seekers and Eritrean refugees were conducted in November 2016-December 2017 and January 2017-May 2017, respectively.

In total, we conducted 26 semi-structured group interviews (21 with Eritrean asylum seekers and 5 with Eritrean refugees) with 2-12 participants (duration 30-60 minutes) directly after the LTBI education and screening, in a separate room to ensure privacy. Additionally, we conducted 31 individual interviews (21 with Eritrean asylum seekers and 10 with Eritrean refugees) (duration 15-60 minutes) with participants who were on, or recently completed, LTBI treatment. All interviewees gave written a-priori informed consent for audio-taping and analysis of interviews. Author DTH verbally transcribed and translated all interviews into English. We chronologically numbered audio-recording and interview transcripts and stored them on an encrypted server. We did not save any identifiable information, such as names, on any of the files. We did not register participants' gender or age. Table 1 provides a detailed overview of qualitative data collection.(16, 17)

Analysis

After familiarization with the transcripts, we used an applied thematic approach(20) to analyse our data, which allows for identification of codes and themes in an inductive manner. We identified themes and subthemes from which we developed a coding scheme to guide the coding of transcripts, which we refined along the coding process (by author IS). In regular meetings authors IS, DTH and JS discussed coding, (sub)themes and interpretation of the data.(21) We used MAXQDA (Version 11, VERBI GmbH, Berlin, Germany) to assist in qualitative data analyses.

Results

We identified five themes: 1) Knowledge and beliefs about TB and LTBI, 2) Attitudes to TB and LTBI, 3) Felt stigma of persons on LTBI treatment, 4) Enacted stigma of persons on LTBI treatment, 5) Anticipated stigma.

Knowledge and beliefs about TB and LTBI

Background knowledge of TB disease

Most participants had basic knowledge of TB. Some participants, often age 30 or older, explained that they gained initial knowledge about TB through campaigns organized by the local governments in the nineties/early 2000s in Eritrea. They described TB as a serious disease called “the Big Cough”, representing its most common symptom: prolonged persistent cough. Furthermore, most participants said TB could be fatal without treatment.

TB transmission and prevention

Despite the education provided in the TB-ENDPoint project, misconceptions about TB transmission and prevention persisted. Both appeared to be embedded in old cultural beliefs about disease transmission

and prevention, perceived to be true for diseases in general. Participants described non-relevant TB transmission routes: sharing drinking cups, sharing cigarettes, eating together, cutting with sharp materials and hereditary (parent to child transmission) contaminated water, cold weather, lack of personal hygiene, and mosquito bites. Furthermore, they described the following corresponding prevention measures: use own drinking cup and eating utensils, get a separate sleeping place and ventilate the house (the latter two relevant for contagious TB).

Understanding LTBI

Participants shared that they had no knowledge on LTBI prior to the TB-ENDPoint education session. Following the education, most participants described LTBI as a condition without symptoms, in which the sleeping, or hidden, bacteria can cause TB disease later in life. However, some described LTBI as an early stage of TB disease, which was characterized by the absence of symptoms. A few participants described LTBI as “closed” and TB as “open” disease.

LTBI and TB versus HIV and AIDS

To differentiate LTBI from TB, many participants compared it to the difference between HIV and AIDS: a person with LTBI or HIV is infected with the bacteria, whereas a person with TB or AIDS is sick. Additionally, some other participants compared the symptoms of TB to those of HIV/AIDS: in both situations the patient would lose weight and would become very weak. Also, when asked to explain the appearance of stigma in the Eritrean society, participants used examples about HIV/AIDS.

Participant after LTBI screening: “Yes there is of course some fear of isolation. For example, if I have HIV, I would be isolated from the society. There could be people who would try to support you but there are also people who don’t want to come close to you. (...) When one wise person tells you, the disease is nothing serious and you can get treated, then you will get some hope. You can focus on the fight for your health. Otherwise, if I am sick with AIDS and if you and other people isolate me then it means I have no support. In that case you can even get ready to end your life. If I have a disease, I don’t want others to know that I am sick, because they are going to isolate me. (...) This is also common for TB disease” [Group interview (GI) 21]

Attitudes towards TB and LTBI

Almost all participants said stigma against TB patients occurs within the Eritrean community. Some said that isolating a TB patient would be wrong and they should rather provide support. Most, however, would likely avoid a person with TB disease because of fear of getting infected. Some explained that isolation was not to intentionally hurt or stigmatize the person, but rather to take care and protect oneself.

Participant after LTBI screening: “In Eritrea if you hear stories that someone has TB, you would be scared to meet him.” [GI 24]

Participants linked isolation in different ways to knowledge about TB and LTBI. Some said that isolation emerged because of insufficient knowledge about TB and LTBI, and that the projects' education prior to the LTBI screening had led to understanding and support from community members. On the other hand, few participants said that health education created more awareness and consciousness about severity of TB disease among people who previously had limited knowledge and were more indifferent. This in combination with persistent misconceptions about TB transmission, could lead to other attitudes.

Participant on LTBI treatment: "A friend of mine in Eritrea had TB, and I used to go with him everywhere. (...) We were together most of the time, he would cough around me, but I never cared much. Maybe because I didn't know much about the disease. (...) I mean, I did not know how someone can get the disease. Now [after receiving education in the Netherlands] I understand much better." [Individual interview (II) 29]

Felt stigma of persons on LTBI treatment

None of the participants on LTBI treatment described feelings of shame or guilt regarding their LTBI diagnosis. Some persons experienced felt stigma after receiving a letter stating they had a positive test result. They described feelings of shock and disbelief when they found out they tested positive for LTBI. However, the felt stigma was taken away by the extensive explanation about LTBI and treatment possibilities by the TB physician. Participants felt calm and said they were happy "it was only the TB bacteria and not TB disease". Some participants wondered where they could have been infected with TB.

Participant on LTBI treatment: "I remember something in the military. There was a friend, he was a good barber. He was very thin, and he would keep coughing on top of my head while he was cutting my hair. (...) I always think of TB if people cough around me, no other disease scares me than TB. (...) So, for me, I think it was that friend who transmitted it to me. I am happy that it is not TB disease. (...) Some people decided to stop going to him because they were scared..." [II 24]

Enacted stigma of persons on LTBI treatment

Participants who intentionally/unintentionally disclosed their LTBI treatment to relatives and friends received different reactions. Some said they received good support because their friends were also educated on TB and LTBI, which contributed to treatment adherence and completion. Some participants received demotivating reactions: a few community-members told stories about poisonous medication given in the Netherlands. Some participants with LTBI experienced isolation and stigmatization. For example, one participant on LTBI treatment experienced gossip by other Eritreans in the asylum seeker centre.

Participant on LTBI treatment: "There is two of us taking the treatment and all the people have been whispering and talking about us. They isolate you. I don't tell them the details of what I am doing, but they know that I have the infection. (...) They make you feel as if you bought the disease from the market. It feels as if you have HIV." [II 31]

Other participants on TB and LTBI treatment, living in a group house, experienced similar stigmatization. They explained that, despite the education about TB and LTBI their roommates avoided socializing with them, covered their mouth and nose when interacting, and stressed them to use separate drinking cups and a different toilet. The participants felt hurt, and some isolated themselves. Some participants had addressed the issue with the TB nurse (Ethiopian origin), who organized an additional education session at the group house they were living in. However, cultural beliefs and fear for disease transmission persisted over new information from TB professionals and the stigmatization continued. Some wished they never were screened. Despite the experience, participants showed strength and commitment to complete their treatment.

Participant on LTBI treatment: "When the TB nurse came to give us the education, she told us all that our case cannot be transmitted. But they wouldn't believe that, they still think that it can be transmitted." [II 22]

Participant on TB treatment: 'Before, we used to share [spoons], and I would give her a bite she would do the same. We were like sisters but that time she said: "I will not use your spoon because you have TB". I felt really bad. (...) The TB nurse told me that I cannot infect other people, even if I tell that they [roommates] don't believe it. They would say: "What else do you think they would tell you, maybe they don't want you to be stressed".' [II23]

Participant on LTBI treatment: "Despite their reaction, I wouldn't want to stop my treatment. It might affect my feelings when they say things in front of me for the moment, but I don't think of stopping my treatment. I am hoping to move to my own house, just to be away from their presence. But for now, until I finish my medicine, I just have to sit in my room." [II 22]

Anticipated stigma

In most interviews, participants said that they would not mind talking about being screened for LTBI. However, out of fear for gossiping and isolation by the community, one would rather conceal a positive test result (see quote GI 21 above). Indeed, some participants on LTBI treatment explained that because of this fear they concealed their LTBI treatment as it would be too difficult to explain the difference between the treatment for infection and disease to others, fearing gossip and isolation.

Participant on LTBI treatment: "Most of the time people ask you why you are taking the medicine and I cannot say it is for TB because they wouldn't understand the difference. There are also some people if you tell them that you are taking medicine for TB, they wouldn't want to come close to you." [II 19]

Some participants said it was nearly impossible to hide their treatment from friends. For example, during social events they had to explain to friends that they could not drink alcoholic beverages because it was not allowed in combination with the medication.

Participant on LTBI treatment: "When some friends offer you a drink and you would say no, they keep asking why and sometimes they get shocked if you tell them that you are taking medicine for TB. Then

you would try to explain to them, but they wouldn't understand it. So, it is always difficult to explain to people. When you try to explain what happened, some would say: "Oh you are becoming like a mouse for an experiment of some medicine". [II 18]

Most participants wished for a change in the Eritrean community. They wished people would start to focus on one's own health, rather than what others say. Some participants used the following expression: "One who hides his wounds, hides his remedy", indicating that not going for TB testing because of fear of gossip and isolation could only harm oneself as one will not find out about being infected with TB and therefore will not receive treatment.

Participant: "I think you should just think about yourself, for example, if I come to do the test and worry about what others may say about me, then it is hiding your own wound." (...) [GI 23]

Discussion

We used data from semi-structured interviews with Eritrean asylum seekers and refugees screened and/or treated for LTBI to gain insights in knowledge, attitudes, beliefs, and stigma related to TB and LTBI. Despite education, which all study participants received as part of the LTBI screening, felt and enacted stigma among Eritreans on LTBI treatment emerged because of fear of infection and persisting misconceptions about transmission of TB and LTBI. Our study results show that enacted and anticipated stigma related to LTBI occurred, such as (fear of) isolation by community-members and concealment of LTBI treatment, because of the inability of persons to differentiate LTBI from TB. Consequently, people fear to get infected with TB, which is the most common cause of TB stigma.(22–25) Our study showed that LTBI related stigma is, to a great extent, comparable to TB related stigma. This is in line with a previous study among Chinese immigrants in Canada, which linked LTBI related stigma to limited knowledge about LTBI and confusion with TB disease.(8) Although interviewees experienced felt and enacted stigma, which could impede treatment start and completion(25, 26), strong motivation resulted in high uptake and completion rates.(16, 17)

To successfully implement TB prevention programs and to overcome persisting stigmatizing community norms about TB, interventions focused on knowledge-shaping and attitude changing are needed.(25, 27) Educators -such as TB care staff and community-workers- should appropriately portray messages: emphasizing the contagiousness of TB rather than effective prevention measures may fail to subvert stigmatizing behaviours and could create even more fear.(23, 28)

Although TB treatment support interventions reducing stigma have been described (24–27), there is a lack of evidence on effective interventions for persons on LTBI treatment. Moreover, if LTBI treatment support is in place at all, very few countries provide education and psycho-emotional support to those on LTBI treatment.(29) There is thus a need for an overview of evidence-based interventions effectively addressing stigma in LTBI screening and treatment programs, which can be adopted in policies and practice.

We interviewed Eritrean asylum seekers and refugees, a relatively unknown group of interest for TB prevention in the Netherlands, who were screened for LTBI. We were unable to interview Eritreans who refused the LTBI screening or treatment. Our results suggest that non-participation might be partially stigma related. It would therefore be important to study reasons for non-participation in LTBI screening and refusal of LTBI treatment. Furthermore, participants may have withheld relevant information, as topics such as TB and stigma are sensitive. However, this study was able to induce discussion among interviewees and generate valuable information about the TB and LTBI knowledge, attitudes, beliefs and stigma among Eritreans tested and/or treated for LTBI.

Conclusion

Both anticipated and enacted stigma were reported by Eritrean asylum seekers and refugees who were screened or treated for LTBI. Due to the difficulty to differentiate LTBI from TB and the persistent fear of TB infection and disease, embedded in beliefs, LTBI related stigma was comparable to TB related stigma. There is a need for evidence-based interventions addressing TB and LTBI stigma, which – in addition to culturally appropriate education throughout the care cascade- future TB prevention programs should implement.

Abbreviations

LTBI latent tuberculosis infection

TB tuberculosis

Declarations

Ethics approval and consent to participate

The Medical Ethical Committee (METC) of the Academic Medical Centre Amsterdam (AMC) waived the need for full ethical approval of the protocol of the TB-ENDPoint project as Dutch public health services responsible for TB prevention, care and control, are licensed to conduct LTBI screening, which was conducted as part of the existing screening policy. All interviewees gave written a-priori informed consent for audio-taping and analysis of interviews. We followed the ethical principles of the Declaration of Helsinki, adopted by the World Medical Association (WMA Declaration of Helsinki 2000).

Consent for publication

Not applicable

Availability of data and materials

This study's data are not publicly available due to the sensitivity of the data and the privacy of our participants, but are available from the corresponding author (ineke.spruijt@kncvtbc.org) upon

reasonable request.

Competing interests

The authors declare that they have no competing interests

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Authors' contributions

IS wrote the study protocol, supervised data collection, performed data analyses and wrote the manuscript. DTH recruited and interviewed participants, transcribed and translated interviews with Eritrean participants and supported in data interpretation. JS supervised the qualitative research of this study. All authors read, commented and approved the final manuscript.

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Tables

Table 1. Qualitative research methods

Source of data	TB-ENDPoint interviews with Eritrean asylum seekers living in asylum seeker centres in the Netherlands (16) TB-ENDPoint interviews with Eritrean refugees living in communities with a maximum duration of stay in the Netherlands of 10 years (17)
Informed consent	Written a-priori informed consent
Communication	Tigrinya (written and verbal)
Transcript	Verbatim translated from Tigrinya in English (by author DTH ¹)
Group interviews with Eritreans screened for LTBI (total of 26)	
Type of interview	Semi-structured group interview
Source of data	Eritrean asylum seekers: n= 21, between 2-12 participants per interview Eritrean refugees: n= 5, between 4-6 participants per interview
Participant selection	Participants were invited to participate in group interviews after they had been educated and screened for LTBI
Timing of interview	Directly after LTBI education session and screening
Location	On site of the LTBI screening in a separate room to ensure privacy <ul style="list-style-type: none"> - at one of the asylum seeker centres - at one of the Public Health Services
Duration of interviews	Between 30-60 minutes
Incentive	None (drinks and snacks were provided during the interview)
Individual interviews with Eritrean clients on LTBI treatment (total of 31)	
Type of interview	Semi structured individual interviews
Source of data	Eritrean asylum seekers: n= 21 Eritrean refugees: n= 10
Participant selection	TB nurses asked Eritrean clients on LTBI treatment for their consent to be approached by phone by author DTH for an invitation to participate in an individual interview and to set an appointment if willing to participate.
Time	Between 15 and 60 minutes
Location	Location to the client's convenience
Incentive	10-euro voucher

LTBI Latent tuberculosis infection, *TB* Tuberculosis

¹ All communication, including interviews, with participants were in Tigrinya conducted by the study's trained research assistant (author DTH), born in Eritrea, with similar background characteristics as the participants, holding a bachelor's degree in Anthropology.