Why test for tuberculosis? A qualitative study from South Africa

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Setting: Early testing and treatment initiation are crucial for controlling the tuberculosis (TB) epidemic, especially in high-burden countries such as South Africa.

Objective: To explore reasons why patients opted to test for TB and the context in which they were tested.

Design: This qualitative study was nested in a larger study evaluating patients who did not initiate anti-tuberculosis treatment after diagnosis. In-depth interviews were conducted with 41 patients across five provinces of South Africa.

Results: While most patients presented for testing because of their symptoms, unfortunately many waited until their symptoms were severe and thus remained infectious for longer. Outreach campaigns and TB screening at primary health care facilities were perceived favourably, although some respondents were unclear as to the nature of the tests being performed and had concerns about the implications. Positive health care worker attitudes towards presumptive TB patients contributed towards prompt testing and treatment initiation.

Conclusion: As patients often delayed presenting for testing, strategies to engage early with presumptive TB patients so that testing and treatment can commence without delay should be a priority for TB programmes.

A key challenge that needs to be addressed to curb the continuing high incidence of tuberculosis (TB) in South Africa¹ is early disease detection and treatment before transmission can occur.² The growing threats of drug resistance³ and TB and human immunodeficiency virus (HIV) co-infection⁴ have created a particular emphasis on active case finding. Studies have shown that patients do not access health care for TB testing and treatment due to misinterpretation of their symptoms and financial constraints (Kenya);⁵ fears of what others might say or of receiving a simultaneous diagnosis of HIV (Eastern Cape of South Africa);⁶ and limited access to facilities and poor communication between health care workers (HCWs) and patients (Senegal).⁷

Although community and household TB screening methods to actively find cases are employed worldwide,⁸ according to a systematic review these methods are based on scanty evidence, especially in terms of their impact on TB epidemiology.⁹ The Zambia South Africa Tuberculosis and HIV/AIDS Reduction (ZAM-STAR) trial, for example, the only study included in the review that directly evaluated impact on TB epidemiology, had inconclusive findings.¹⁰ The same review did, however, find moderate evidence that screening

increases the number of cases found in the short term, for example in South Africa,¹¹ Cambodia¹² and the Netherlands,¹³ and that these cases were found earlier, and with less severe disease, in Cuba¹⁴ and Mexico, for example.¹⁵

A World Health Organization (WHO) review¹⁶ found that screening methods could be perceived as beneficial in high-burden communities, whether conducted on the basis of symptoms, chest X-ray or sputum investigation. Further research was suggested to explore the needs of specific communities and the potential relationship between individuals' willingness to be screened and their acceptance of treatment, if necessary.

In South Africa, there was no formal active case-finding policy at the time of this study, as is the case in various countries, probably because the evidence of individual and community-level benefits is limited⁹ and not cost-effective, depending on the screening algorithm.¹⁷ Outreach campaigns to test for TB, especially around events such as World TB Day and community education efforts at health care facilities, schools and worksites, have nevertheless been carried out country-wide. In addition to these approaches, the motivation for individuals from the specific selected communities to undergo testing and the context in which they were tested would provide valuable insights to develop other case-finding strategies. This is particularly important when TB programmes use active case finding to identify individuals to be tested, an approach that is now advocated by the WHO in certain settings¹⁸ to ensure that 'missed cases', estimated in 2012 to be 3 million globally, are found.

Our aim was therefore to explore the patients' perceptions about testing for TB and their subsequent initiation on treatment.

METHODOLOGY

Study design, data collection and respondents

This study was nested within a larger study examining the extent of initial loss to follow-up (LTFU) among TB patients.¹⁹ The study was conducted at primary health care facilities (PHC) in five provinces of South Africa from October 2010 to October 2011, including the Eastern Cape, North West province, Limpopo, Mpumalanga and KwaZulu-Natal, all of which have endemic TB and high HIV co-infection rates. The WHO 2012 global tuberculosis report estimated the number of HIV-positive incident TB cases in South Africa at 330 000.²⁰ The facilities included urban, peri-ur-

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ban and rural settings, but none in city centres. The communities were mostly of poor socio-economic status. Most individuals from these communities, particularly in urban or peri-urban settings, lived within accessible distance from a PHC, while the dispersal of communities in rural settings increased the need to travel.

For the larger study, 16 PHCs were visited in each province. At each PHC, the research team selected up to 10 patients diagnosed with TB who had not started treatment (initial LTFU) and 10 patients who had initiated treatment from the facility registers. The team attempted to trace these patients to their homes. Many patients could not be traced, however, due to distances between the PHCs and households, and language and time limitations, as each facility was visited only for a day and at some of the facilities none of the selected patients who were initial LTFU could be found. Only 19 of the initial LTFU patients could be traced for the qualitative study. As we wanted to interview more or less the same number of respondents who had initiated treatment, 22 were interviewed in this group, giving a final sample of 41. A pure purposive sample was thus not obtained; however, we tried to keep the sample balanced by including a similar number of initial LTFU patients and patients initiated on treatment. Given the case-finding approach, there is no reason to believe that those interviewed were different from other potential participants. There was no variation in age between those included and those who were not, but slightly more women were interviewed. No participants refused to be interviewed.

The in-depth interviews were recorded by two field workers who had experience and training in qualitative interviewing and who were given additional training in the research subject matter and the discussion schedule, which was similar for both those initiated on treatment and LTFU patients. The interviews took approximately 35 min on average. The key question for those initiated on treatment was 'What enabled you to attend the facility to be tested for TB, receive your results and begin treatment?'; while for initial LTFU patients the key question was, 'Why did you not come back to the facility to receive your test results and potentially begin treatment for TB?'. In both cases, the probes covered the accessibility of the facility, the experience at the facility, the use of alternative health services, concerns about being diagnosed with and getting treatment for TB, difficulties generated by poverty and external events that may have affected their presenting for treatment. The field workers were aware of the individuals listed as being on treatment and initial LTFU, and focused on those issues in the interviews.

Data analysis

The interviews were recorded and then transcribed and translated into English. The two authors read 10 interviews each to draw out a set of themes. These were discussed and a common list was drawn up that formed the basis of the analysis. The themes drew on the aim of the study and the interview transcripts. Each theme was defined so that a common understanding could be referred to during the coding process. Once the theme list was complete, the two authors divided the interviews and coded them using the theme list. All interviews were read by both authors to ensure a common understanding around the meanings attached to each theme. The first author led the analysis using an interpretive approach that worked directly with the contextual issues faced by the respondents,²¹ with strong contribution from the second author. The validity of the final analysis was tested by the authors re-reading the interviews while checking for contradictory findings. Where contradictory findings occurred, new insights were

added to the text and the analysis was edited where necessary. The text includes quotes from the interviews to illustrate the arguments.

Ethics, consent and permissions

The proposal was approved by the Human Research Ethics Committee of Stellenbosch University, Cape Town, South Africa (N10/06/187). Consent to record was obtained prior to starting the interviews. The study was explained in the respondent's native language. No incentives were provided.

RESULTS

The sample of 41 interviews was divided between patients initiated on anti-tuberculosis treatment ($n = 22$) and initial LTFU patients ($n = 19$), and was distributed across the provinces: eight respondents from the Eastern Cape (six adherent, two initial LTFU), five from KwaZulu-Natal (three adherent; two initial LTFU), nine from Limpopo (four adherent, five initial LTFU), 15 from Mpumalanga (six adherent, nine initial LTFU) and four from Northwest province (three adherent, one initial LTFU).

The themes generated during the interviews included motivations for and barriers to testing, community outreach campaigns, being tested while visiting the PHC for another purpose and concerns about being tested without permission.

Motivations for and barriers to testing

The principal motivation for testing was the presence of symptoms. Based on education in the community and the awareness of people they knew who had TB, respondents claimed there was generally good awareness for how to identify TB in themselves and others (Participant 20 [P20]). Of concern was that many respondents waited before presenting for testing, sometimes until the pain, which was noted as a symptom of advanced TB, became unbearable, or until the intrusion of the disease in their lives left them dysfunctional. This was particularly true for male respondents who were working and did not want to risk losing income or potentially even their jobs (P6). When respondents were unwilling to be tested on their own account, their family often encouraged them to go. Respondents spoke about the importance of protecting their family and therefore being tested and, if necessary, treated. A number of respondents, both male and female, who were already undergoing treatment and had begun to feel better, spoke of encouraging others to be tested for TB. They wanted others to be treated and cured also, and used themselves as examples (P39).

Respondents raised a number of concerns around presenting to the PHC for testing. There were fears about testing positive for drug-resistant TB (DR-TB), as treatment was described as being painful and possibly requiring hospitalisation. There were also fears about being tested for HIV and being found to be positive (P17). Part of these concerns included stigmatisation due to the diagnosis, especially if they were suspected of having multi-drug-resistant TB or HIV (P3). There also appeared to be a wish to simply deny the possibility of having TB.

Concerns were raised by a limited group of respondents that they were scared of going to the PHC to be tested, as they were previously lost to follow-up during treatment and were afraid the nurses would berate them. Respondents also complained about PHC system problems, stating, for example, that they had not received their results. Some had been to the PHC but their results were not ready and they were told to return, while others expected to have their results delivered to them at home and were

not visited. A small number of respondents reported that their TB was not diagnosed at the first visit or that they were not properly tested and that they had to return to be tested again (P12).

Statements of respondents regarding motivations for and barriers to testing included the following:

I learned it a long time ago from school and also from reading the pamphlets ... that is how I came to know of this disease and the reality of all those things that says if a person is infected with TB these are the symptoms (P20).

I was sick and could not even work so I was forced to go to the clinic and get help (P6).

... You know how I was, so I would like each and every one of you to know too their status and get treatment (P39).

They are afraid that they will be tested also for HIV and they will be found that they are HIV positive but you are not there for that (P17).

When you were diagnosed that you have TB, you have that thing called stigma, maybe you are afraid of being looked at by people or what the community will say about you when they found out that you are taking the treatment (P3).

They told me that I just had fever that is why I felt so weak. The next morning I decided to go to the clinic again because I never got sick like that (P12).

Community outreach campaigns

There was a consistent theme across many of the interviews that the respondents had been approached by outreach teams to be tested. Nurses came to the households during community campaigns, or families or individuals were asked to go to the PHC for testing. One woman reported that she had symptoms but did not want to go to the PHC. The community HCW came to her house because her sister had TB and took her sputum as well. Two weeks later they returned to inform her that she needed to start treatment. She decided to do so although she lived a 45 min walk from the PHC in a semi-rural area. As she and her sister were on treatment simultaneously, they could support each other, and seeing her sister with the disease motivated her. She elected to go to a different PHC for treatment, however, even though it was further away, as her sister had consistently complained about her treatment at the PHC she attended (P27).

Positive staff attitudes contributed to a willingness to test for TB and HIV. This was important, as the respondents then felt ready and happy to go to the PHC to start treatment. One man who reported serious symptoms was treated very well by the staff and therefore started treatment easily. He was taken to the PHC near his home and tested for both TB and HIV. The rapid treatment and positive attitudes gave him a feeling of confidence in the services. He also understood, based on the explanations of the staff, why the treatment was necessary (P21).

I felt free when I went to the clinic (P21).

Respondents tested when visiting the PHC for another purpose

There were consistent reports of respondents stating that when they presented at the PHC for another purpose, the HCW suggested testing their sputum for TB.

Depending on the province, the initial reasons for going to the PHC varied. In Mpumalanga people went to be tested for malaria, while in other areas respondents spoke of going to be treated for 'flu'. Some reported having a range of examinations, including HIV, blood pressure and diabetes, and others spoke of going for

mental health or trauma-related reasons. While in many cases the HCW diagnosed active TB, in other cases, where there was no active disease, sputum smear microscopy was performed as a screening method. Many of these respondents reported being shocked by the result, as they had not expected to be diagnosed with TB. One woman reported that she had presented for a cough that she thought was connected to passive smoking. She was startled when staff in a PHC vehicle informed her she needed to start anti-tuberculosis treatment, which she subsequently continued (P12).

Even at the clinic they did ask me if I was smoking and I told them it was my boyfriend.

Concerns about testing without permission

Concern and anger were expressed by respondents who felt that they were tested without consent or under duress. Some respondents appeared to have been tested without permission, as they were not aware that the test was for TB. One respondent described that he only became aware of the possibility of having TB when the nurses arrived at his house to tell him that he had TB, as he claimed not to have realised that he was being tested. The nurses had to explain the procedure to him when he received his test result. There was also a recurring theme among respondents who did not feel ill but were tested, indicating a lack of understanding as to why they were tested, as they felt healthy and therefore did not believe the positive test result.

DISCUSSION AND CONCLUSIONS

Patients presented for TB testing based on their symptom knowledge and their desire to be well and to protect those close to them. While this is not particularly new or significant, it should be acknowledged as part of efforts to get patients to test for TB and, if positive, to accept that they have the disease. This passive approach does not, however, take into account the reasons shown in our study for resisting testing, including avoiding sick leave, fear of being seen on treatment, fear of being diagnosed with DR-TB or HIV, and denial about having TB. It should also be kept in mind that as early TB disease may be asymptomatic,²² presumed TB patients who test positive might not experience symptoms and may therefore not be easy to convince to initiate treatment. Many adult patients wait for advanced symptoms to appear, and are very ill or even dysfunctional when they finally present at health care facilities, often with smear-positive disease,²³ and with a greater risk of exposure for other community members. Relying on symptom recognition alone is therefore inadequate, as many patients with TB will remain infectious in their communities for an extended period of time before presenting for diagnosis and treatment. This forms part of the motivation for outreach campaigns. It is important, however, to maintain an ethical balance between testing individuals in the community, which may be experienced as paternalistic depending on the method used, as has been argued with directly observed therapy,²⁴ versus securing patients' autonomy and agency to decide for themselves whether and when to test. The concern about active TB disease remains that it is infectious; not only are the patients with the disease affected, so are the community members to whom it could be transmitted. The rights of the individuals must therefore be balanced against those of the community, especially when taking into account the threat of drug resistance.²⁵

We could not find other studies that specifically addressed the fears of patients to be tested for TB because of the possibility of receiving a diagnosis of DR-TB, as was shown in our study.

This should be further investigated, especially in the South African context, where DR-TB is a major concern, with 1.8% of newly diagnosed cases and 6.7% of retreatment cases being multidrug-resistant.²⁶

Family or community members can either be supportive²⁷ or have a negative attitude^{5,28} towards TB patients. It is important to understand these social pressures to engage families and communities to become partners in the fight against TB, by assuming a moral responsibility to share patients' needs and to recognise individual dignity.²⁹ HCWs should therefore engage not only with patients but also with their families and community members. HCW training should include focus areas on how to successfully engage and educate patients, family and community members. It is imperative that HCWs acknowledge that their attitudes towards patients can make a major contribution to patients' willingness to initiate treatment and adhere to treatment once initiated.³⁰ Strategies to encourage positive HCW-patient relationships could include developing transformational nursing leadership³¹ in order to improve patient outcomes, and increasing the number of staff members appointed, which has been shown to reduce adverse patient events in hospital settings³² and discourage nurse absenteeism.³³

The outreach campaigns appear to have had a positive response from most respondents, especially when the context of the testing was explained and the health care staff were friendly and respectful. Of concern was that the nature of the tests was not always explained to respondents, a practice that could undermine trust in the health services and reduce willingness to receive treatment. Ethical issues arise when individuals are tested without their knowledge: the autonomy and right to decision-making of the individual are not respected.³⁴ The impact of hidden testing on treatment initiation and subsequent adherence must therefore be evaluated. Consideration must also be given to the fears around testing positive for DR-TB, due to the specific treatment programmes, and for HIV.

The limitations of the study were that the larger study was not primarily directed at identifying reasons for TB testing, but rather at reasons for initial LTFU. This different focus meant that some aspects of the question may have been missed. Furthermore, as this was a qualitative study, the selected sample means that the results cannot be easily generalised.

In summary, our results provide valuable insights into why patients tested for TB and how they perceived the testing approach. Qualitative studies from other high burden TB-HIV settings could confirm our findings. Strategies to engage with presumptive TB patients early so that testing and treatment can commence without delay should be a priority for TB programmes.

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Contexte : La précocité des tests à la recherche de tuberculose (TB) et de l'initiation du traitement est cruciale dans la lutte contre l'épidémie, surtout dans les pays durement touchés comme l'Afrique du Sud.

Objectif : Explorer les raisons pour lesquelles les patients ont décidé de faire un test de TB et le contexte dans lequel ce test a été réalisé.

Schéma : Cette étude qualitative a été réalisée au sein d'une étude plus vaste évaluant les patients qui n'ont pas débuté leur traitement de TB après le diagnostic. Des entretiens approfondis ont été réalisés avec 41 patients dans cinq provinces d'Afrique du Sud.

Résultats : Les patients se sont présentés pour un test en raison de leurs symptômes, mais malheureusement beaucoup ont attendu que

leurs symptômes soient graves et ils sont donc restés contagieux plus longtemps. Les campagnes de stratégies avancées et le dépistage de TB dans des structures de soins de santé primaires ont été perçus favorablement, même si certains répondants n'étaient pas sûrs de la nature des tests à faire et étaient préoccupés par leurs implications. Une attitude positive des prestataires de soins vis-à-vis de patients présumés tuberculeux a contribué à la rapidité du dépistage et de la mise en route du traitement.

Conclusion : Les patients ont souvent retardé le moment de réaliser un test ; c'est pourquoi des stratégies visant à intervenir auprès de patients présumés atteints de TB précocement de façon que le test et le traitement soient réalisés sans délai devraient être une priorité pour les programmes TB.

Marco de referencia: La práctica de las pruebas diagnósticas de la tuberculosis (TB) y el comienzo del tratamiento en forma oportuna son fundamentales en el control de la epidemia, sobre todo en los países con una alta carga de morbilidad como Suráfrica.

Objetivo: Examinar las razones por las cuales los pacientes acuden en busca de pruebas diagnósticas de la TB y el contexto en el cual se practican estas pruebas.

Método: Un estudio cualitativo anidado en un estudio más amplio, en el cual se evaluaron los pacientes que no iniciaron el tratamiento tras recibir el diagnóstico de TB. Se practicaron entrevistas exhaustivas a 41 pacientes en cinco provincias de Suráfrica.

Resultados: Los pacientes acudieron en busca de pruebas diagnósticas debido a los síntomas que presentaban, pero desafortunadamente muchos esperaron hasta que las manifestaciones eran más graves y permanecieron contagiosos durante un período

más prolongado. Las campañas de sensibilización y detección de la TB en los centros de atención primaria de salud se percibían de manera favorable, aunque algunos de los participantes no comprendían claramente el tipo de exámenes que se practicaban y se preocupaban por sus consecuencias. Las actitudes positivas de los profesionales de salud frente a los pacientes con presunción clínica de TB favorecieron una práctica temprana de las pruebas y una pronta iniciación del tratamiento.

Conclusión: Con frecuencia los pacientes retrasan el momento de acudir en busca de pruebas diagnósticas; por esta razón en los programas contra la TB debe ser prioritaria la introducción de estrategias que fomenten un contacto temprano con los pacientes que pueden padecer TB, a fin de practicar sin demora las pruebas diagnósticas e iniciar oportunamente el tratamiento.