

BMJ Open Impact of prolonged isolation on adolescents with drug-susceptible tuberculosis in Lima, Peru: a qualitative study

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ABSTRACT

Objectives Patients with tuberculosis (TB) generally are instructed to isolate at the beginning of treatment in order to prevent disease transmission. The duration of isolation varies and may be prolonged (ie, lasting 1 month or more). Few studies have examined the impact of isolation during TB treatment on adolescents, who may be more vulnerable to its negative effects.

Methods This study took place from 2018 through 2019 in Lima, Peru, where the Ministry of Health mandates the exclusion of patients with TB from educational institutions for at least 2 months. Using semi-structured guides, we conducted individual in-depth interviews with adolescents who received treatment for drug-susceptible TB, their primary caregivers and health providers. We performed thematic analysis of the transcribed interviews.

Results We interviewed 85 participants: 34 adolescents, 36 caregivers and 15 healthcare workers. At the time of their TB diagnoses, 28 adolescents were in secondary, postsecondary, vocational or military school. Adolescents with drug-susceptible TB were prescribed home isolation usually for 2 (and occasionally for 1) months. Consequently, they could neither attend school nor socialise with family members or friends. Two primary themes emerged from the interviews. First, as a result of their exclusion from school, most adolescents fell behind academically and had to repeat a semester or academic year. Second, absence from school, separation from friends and loved ones, and reinforcement of TB-related stigma (arising from fear of TB transmission) harmed adolescents' mental health.

Conclusion Prolonged isolation led to educational setbacks and emotional trauma among adolescents with TB. Prolonged isolation is not supported by current evidence on TB transmission and is problematic from a human rights perspective, as it violates adolescents' rights to education and freedom of movement. Isolation recommendations should be re-evaluated to align with data on TB transmission and the principles of patient-centred care.

BACKGROUND

Globally, an estimated 850 000 adolescents, defined by the WHO as individuals

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This qualitative study had a robust sample size (n=85) and included perspectives from adolescents, their primary caregivers and health providers.
- ⇒ The analysis incorporated both data and investigator triangulation.
- ⇒ A Community Advisory Committee provided input on the interview guides.
- ⇒ Because this is a secondary analysis, we may not have captured all impacts of prolonged isolation and may not have reached data saturation with respect to this topic.
- ⇒ There may have been selection bias, as adolescents who were not enrolled may have had different experiences than those who participated in the study.

10–19 years old, become ill with tuberculosis (TB) each year.¹ In general, patients being treated for pulmonary TB are instructed to isolate to prevent airborne transmission of *Mycobacterium tuberculosis*. Guidelines for the discontinuation of isolation vary across settings.² Some Ministries of Health (MOHs) allow discontinuation of isolation after 2 weeks as long as the patient is adherent to and tolerating appropriate treatment. Other MOHs require longer isolation periods and/or multiple sputum smears that are negative for acid-fast bacilli (AFB).² In most settings, isolation occurs at home, while in former Soviet republics, patients with TB disease are isolated in TB hospitals.^{3–5}

Few reports have described the impact of prolonged isolation, which we define as lasting 1 month or more, on adolescents with TB.⁶ Adolescents may be particularly vulnerable to the negative effects of prolonged isolation. During adolescence, increased social interaction, particularly with peers, contributes to psychological and social development.⁷ During the COVID-19 pandemic,

school closures, isolation and quarantine were associated with depression and anxiety in adolescents.⁸ Absence from secondary, postsecondary or vocational school may lead to worse educational outcomes and lower future earnings.⁹

The TB guidelines of the Peruvian MOH lack detailed recommendations for isolation, stating only that patients should be informed about the potential need for isolation.¹⁰ However, according to national policy, patients with TB cannot attend school for at least the first 2 months of treatment; they can return to school only if they have AFB-negative sputum samples at the end of the first and second months of treatment, even if their pretreatment sputum was smear-negative.¹¹

We conducted a qualitative study in Lima, Peru to better understand barriers to treatment adherence among adolescents treated for drug-susceptible pulmonary TB, as well as other challenges faced by adolescents with TB. In this paper, we report on a critical theme that emerged from the data: prolonged isolation during TB treatment and its impact on adolescent well-being.

METHODS

Setting

Peru has a population of 33 million people and an estimated TB incidence of 116 per 100 000 per year.¹² Lima, the densely populated capital, accounts for 54% of the country's TB cases.¹³ In 2015, the largest proportion of new TB cases in Peru was among young people aged 15–24 years, accounting for 29% of all new cases.¹³ In Peru, over 70% of patients with TB receive care at public health facilities run by the MOH.¹⁴ Patients receive in-person directly observed therapy (DOT) for TB at the health centre closest to their home. Nurses and nurse technicians (licensed vocational nurses) supervise DOT. Treatment of drug-susceptible TB typically consists of a 2-month intensive phase with four medications given daily, followed by a 4-month continuation phase with two medications given three times per week. All study participants received TB treatment before the COVID-19 pandemic.

Inclusion and exclusion criteria

We recruited three groups of study participants: adolescents, their primary caregivers and health providers. We included adolescents who (1) were diagnosed with drug-susceptible pulmonary TB; (2) were between the ages of 10–19 years at treatment initiation; (3) received DOT at a health centre run by the MOH; and (4) in the preceding 12 months, either completed TB therapy or were lost to follow-up from TB treatment. We excluded adolescents who had extrapulmonary TB or who received any second-line TB drugs. Each adolescent identified the adult whom they considered their primary caregiver during their TB illness; we excluded adolescents whose primary caregivers did not agree to participate in a separate interview. Caregivers without legal guardianship of minors could participate as long as informed consent was obtained from

the adolescent's legal guardian. For the health provider group, we included nurses and nurse technicians who had supervised DOT at an MOH facility for at least 6 months.

Sample size and recruitment

We estimated a priori that a sample size of 30–45 adolescent-caregiver dyads and 10–15 healthcare providers would be sufficient to reach thematic saturation for our primary objective of identifying barriers to treatment adherence. We aimed to include adolescents from three age strata: 10–13 years old, 14–16 years old and 17–19 years old. We further aimed to achieve gender balance among the adolescents, but expected caregivers and health providers to be predominantly women.^{15 16}

Study personnel identified eligible adolescents from TB treatment rosters at health centres in Lima. Health centre staff called consecutive eligible adolescents—or their parent/guardian if they were a minor—to obtain permission for study personnel to contact them directly. Study personnel then called, or visited, potential participants to describe the study and invite them to participate. We enrolled a purposeful sample of 15 nurses and nurse technicians who worked in health centres with high volumes of patients with TB.

Data collection

We developed and piloted semi-structured individual interview guides with open-ended questions (see online supplemental material). Because the primary objective of the study was to identify barriers to treatment adherence, the interview guides did not include direct questions about isolation. They did, however, include questions about missing school and other activities, and, in line with standard semi-structured interview methodology, probed for details about patients' isolation experiences, when appropriate.

Three Peruvian investigators (MW, EA, LS), who had prior training and/or experience conducting interviews and were employed by Partners In Health-Peru (PIH-Peru), conducted interviews in Spanish from August 2018 to May 2019. The interviewers had no prior relationships with adolescent and caregiver participants, but had professional relationships with some of the health providers who participated in the study. Interviews with adolescents and caregivers took place privately in the participants' home. Health worker interviews took place in a closed room at their workplace. Two interviewers were present whenever possible to allow the second interviewer to take notes and ask clarifying questions as needed. Interviews lasted 45–60 min and were audio-recorded and transcribed verbatim. Participants were reimbursed with grocery gift cards valued at 45 Peruvian *soles* (approximately US\$13).

Patient and public involvement

The Community Advisory Committee (CAC) of PIH-Peru is an independent group of nine volunteers who ensure that research studies respond to the needs of the community. The CAC approved this study and provided input on

the interview guides. Additionally, we piloted and refined the interview guides in response to feedback from the first several participants in each participant group. The results of our study will be shared with the CAC and the Peruvian MOH.

Data analysis

We performed thematic analysis, which summarises textual data by identifying themes that extend across interviews.¹⁷ First, three authors (SDR, JC, SC) listened to 10 interviews to immerse themselves in the data. Then, they created two initial codebooks: one corresponding to the adolescent and caregiver interviews, and the other to the health provider interviews. The analysis was not informed by any theoretical frameworks; rather, we used an inductive approach, in which our codebook was informed by repeated readings of the transcripts and contained only themes that emerged from the data. The three authors individually coded a subset of the interviews, compared their coding, resolved discrepancies through group discussion, and refined the codebooks accordingly. They repeated this process until they agreed on codebooks that captured all interview content. Next, five authors (VEOR, CBB, SDR, JC, SC) applied the final codebooks to all interviews using NVivo V.12 (QSR International, Cambridge, USA). Eight (9.6%) interviews were independently coded by two authors; inter-rater agreement was >90%. Remaining interviews were coded by one author.

We performed data triangulation by comparing general findings between all three groups and participant-specific details between adolescent-caregiver pairs. VEOR and SC independently reviewed the codes to identify emergent themes related to isolation practices and their impacts, developed a conceptual framework, and identified and

translated illustrative quotes. All reported findings were verified by multiple sources.

This study has been reported in accordance with the Consolidated Criteria for Reporting Qualitative Research checklist (online supplemental material).¹⁸

RESULTS

This analysis includes 85 interviews: 34 adolescent-caregiver dyads (68 interviews), 15 healthcare workers and 2 additional caregiver interviews without accompanying adolescent interviews. [Figure 1](#) shows the number of individuals who were invited to participate, enrolled and interviewed. [Table 1](#) describes the characteristics of the study participants.

At the time of their TB diagnoses, all but six adolescents in this study were in secondary, postsecondary, vocational or military school. Two adolescents had full-time jobs at the time of treatment initiation.

Isolation practices

All participants reported having been instructed to isolate and refrain from activities outside the home, other than medical appointments. Most adolescents and health providers reported the duration of isolation to be a minimum of 2 months, consistent with the previously mentioned policy, while a few reported 1 month. When asked why they were instructed to isolate, participants most commonly reported it was to prevent disease transmission.

... they told me that [in] the first phase [of treatment] I was contagious and that I had to be in my house ... And so, for two months I had to be [in my

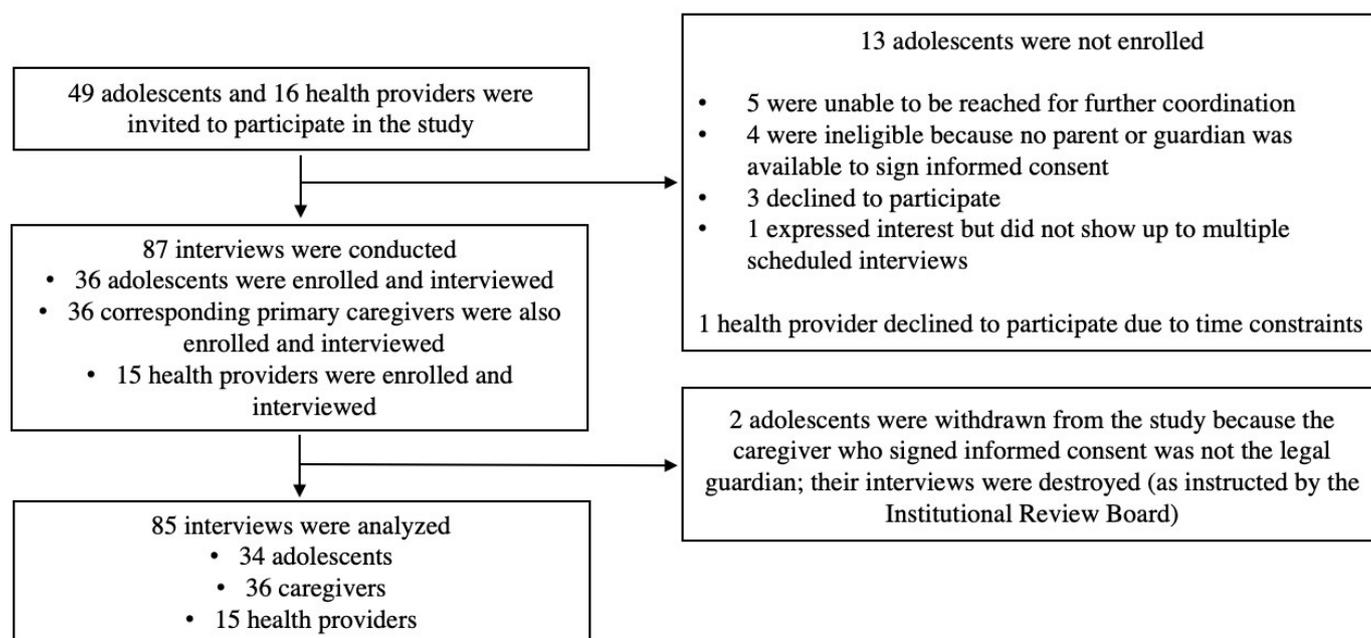


Figure 1 Flowchart of participant recruitment and enrolment.

**Table 1** Characteristics of study participants

	Adolescents (n=34)	Caregivers (n=36)	Health providers (n=15)*
Age in years, median (IQR)	17 (14–19)	41 (35–48)	41 (32–49)
Females, n (%)	13 (38)	35 (97)	13 (87)
Relationship to adolescent, n (%)			
Mother	NA	27 (75)	NA
Aunt	NA	3 (8)	NA
Older sister	NA	5 (14)	NA
Father	NA	1 (3)	NA
Number of health centres represented	27	27	14†
Studying full-time, n (%)	29 (85)	NA	NA

*Ten (67%) were nurses, while five (33%) were nurse technicians.
†5 of 14 health centres were not represented among adolescents and caregivers; a total of 32 health centres were represented among all study participants.

house], until after the AFB [smear] found me not to be contagious. (Participant #79, 17 years old male)

... until [the patient's] sputum sample is negative, [which] it would be in a month [after starting treatment] ... they leave their other activities ... that is, school, friendships, because we help them see how many [others] it is that they will infect if they're smear-positive. They are going to infect their best friends, people who are closest to them—right?—and at school, all the people who surround them. (Participant #16, nurse technician, 52 years old female)

A few healthcare providers cited the need for physical rest, as well as time to adapt to treatment side effects as another reason for prolonged isolation and exclusion from regular activities:

No, you have to rest ... for at least two months, because you are in treatment. Plus ... you have a [lung] lesion ... if you exert yourself, well, it will hurt. There may be bleeding, and you are going to harm yourself. (Participant #63, nurse, 52 years old female)

... the doctor recommended to us that [my sister] miss a month [of school] to get used to the adverse reactions that the medications might have—she wanted to be able to continue going to school because she was smear-negative so she wasn't transmitting to anyone—but more than anything, I told my mother that sometimes isoniazid has strong side effects, ethambutol has very strong side effects, it's better that she rest at home a month ... not the two months that the doctor at the health center recommended, but the month that the pulmonologist at [the hospital]

recommended ... (Participant #34, sister of a 15 years old female)

Lived experiences

Isolation meant that adolescents could not attend school, gather with friends or participate in other social events; some even isolated from other household members. The few participants who were employed had to quit their jobs or take a leave of absence. Participants' descriptions of how they experienced isolation were similar:

I literally lived shut in. (Participant #81, 19 years old female)

I did nothing, right? I did not like to be like that: lying, sitting, sleeping. (Participant #60, 19 years old male)

... [The health providers] told me, "You are not going to skate, you are not going to play matches, you are not going to go outside, you are not going to be with your friends. You cannot do anything. You are going to be in your room, in your bed with open windows and open doors. (Participant #66, 16 years old male)

Adolescents complied with home isolation with few exceptions. One adolescent stopped going to school, but continued to spend time with friends (Participant #84, 19 years old male). Two adolescent participants ignored doctors' orders to take a leave of absence from school because they wanted to avoid falling behind in their studies. Another chose to enrol in fewer courses rather than miss the semester:

It is not that I completely missed [the semester], but I did take fewer courses at my university ... I thought about not attending that semester, but I was going to fall very behind. (Participant #47, 19-year-old male)

Impact on education and training

Several participants referred to a national policy that directs educational institutions to facilitate medical leave for students with TB and to provide support so the students do not have to repeat the semester or academic year¹⁹:

[T]hey cannot be discriminated against, they cannot be kicked out, they cannot let them fail the school year, and the educational institution has an obligation to support that tuberculosis patient. How? ... By not making him miss the school year, and through other means, they have to see how to support him so he doesn't miss the school year [such as] through tutoring (Participant #13, nurse, 36 years old female)

Despite this policy, most adolescent participants fell behind in school and had to repeat a semester or academic year.

Participant: Yes, halfway through the year they told me that I was sick ... my mother took me out of school ... there were 3 months left to finish [the school year].

Interviewer: And did [the school] support you with your grades or did you lose the year?

Participant: No, I lost the year. (Participant #65, 11 years old male)

I was just a month away from finishing university. So, it was shocking to me because a single month, getting sick and no longer going [to school], shakes you quite a bit ... I missed the semester and had to retake it again this year. (Participant #3, 20 years old male)

The educational setbacks experienced by adolescent participants may alter their prospects for higher education, career trajectory and/or employability. One adolescent, who missed a month of school, risked no longer being competitive for a prestigious government-funded scholarship, Beca 18, which covers university tuition and related expenses for students with high academic achievement and limited financial resources. As the adolescent's sister recounts:

... her grades dropped due to the month that she missed [of school] while on medical leave ... Now she wants to apply for the Beca 18, [but] her final grade is lowered, so she has been put at a disadvantage from that month that she missed ... Supposedly, when one has a medical leave, supposedly, they explained to me that they have to carry over her grades from [the previous term] ... but they didn't do it ... (Participant #34, sister of a 15 years old female)

Participant #45 was training to become a pharmacy technician, but at the time of the interview, conducted 7 months after he began treatment, he had not resumed his programme.

... I felt bad because I was doing fine in everything, grades [and] all that, and to leave all that ... Yes, I lost the [school] year ... I had to leave my vocational [school] and then dedicate myself to the health center. (Participant #45, 17 years old male)

Five other participants (one other vocational school student, two secondary school students and two military trainees) also had not resumed their classes or training at the time of their interviews, which were conducted more than 6 months after their isolation period ended.

While most participants who were studying at the time of their TB diagnosis experienced educational setbacks, there were a few exceptions. As previously mentioned, two adolescents continued to attend school despite instructions to stay home. Additionally, for several adolescents, the first phase of TB treatment coincided with summer break; thus, they missed fewer days of school and did not need to repeat the semester. However, even these participants found themselves struggling academically when they returned:

I stopped going [to school] for a week, and that may have complicated my studies because there were subjects that I was studying, and well, when I returned to

my classes, I did not know where I was, and I tried to catch up, to ask my friends. (Participant #38, 19 years old male)

Many participants commented that even after the home isolation period, the requirement of in-person DOT made going to school challenging, as clinic and school schedules often conflicted.

... when I started studying [again] ... I had to ask permission ... to be late [to school] so that I could, um, go to the [health] center in the morning to be able to take my pills. (Participant #1, 18-year-old female)

Impact on mental health

Home isolation led to emotional distress among adolescents for multiple reasons. First, extended absence from school led to despair, which was related to both missing regular interactions with peers and teachers and anxiety over academic performance.

... He was sad because he doesn't like to miss school, he doesn't like it ... He felt sad, a little depressed because he wanted to go to school, but they forbade him to go to school. (Participant #82, mother of a 14 years old male)

At the beginning [I felt] a little, a little down, like sad ... because all of your progress in your studies stops. You were moving forward, and from one moment to another everything ends. You have to stay away from people because you are infectious to others. (Participant #6, 19 years old male)

Physical separation from family members and friends also affected adolescents' moods:

For the first few months I did feel a bit, like, forgotten, closed off ... from my friends ... I was separated [from them]. (Participant #52, 18 years old male)

The most difficult thing for me is to leave my family and feel alone ... and live alone for a while until I recover ... during those days I felt alone, without even a single family member. (Participant #32, 18 years old male)

[She was] different, depressed. My daughter is [usually] very happy ... She was sad, down ... [for] three months she was like this here at home. (Participant #8, mother of a 12 years old female)

Separation from loved ones exacerbated the difficult emotions that some adolescents experienced in reaction to their TB illness. One participant tearfully recounted how being separated from her daughter for months worsened her depression:

I got more depressed ... I lay in bed ... I wanted to tune everything out ... they told me that [TB] could lead to death. Plus, I was not with my daughter. That time was the worst. (Participant #54, 20-year-old female)



Another adolescent wanted to spend time with her friends to feel better. However, her mother enforced home isolation:

She was too sad, too worried. Basically, after taking her pills, she felt down. She wanted to go out to parties ... I didn't let her because she's sick. [I told her,] "You can't go out at night" ... Well, she would tell me, "Mom, but I feel sad". (Participant #76, mother of a 17-year-old female)

Many adolescent boys identified sports as their primary social activity and described feeling at a loss when they had to stop participating in sports during treatment. The combination of home isolation and beliefs about the dangers of exercise during TB treatment led to adolescents' exclusion from sports. One adolescent, who was told by his doctor to stop skateboarding because his lung could rupture if he fell, explained:

I felt bad because [skateboarding] was what I did ... I have been skateboarding for nine years ... my friend also bought himself [a skateboard] and most of us were [skateboarding] from a young age ... Anyway, in other words, that was my life, skateboarding [and] being with my friends ... until I got sick, and I still do not do it [despite having finished treatment]. I have stopped doing so many things ... (Participant #66, 16 years old male)

Finally, prolonged isolation practices stemmed from and reinforced stigma, which is driven in large part by fear of TB transmission. Because of their TB illness, adolescents and their caregivers experienced anticipated stigma (the belief that others will devalue them), enacted stigma (the experience of being devalued by others) and internalised stigma (the absorption of negative messages about oneself). These stigma experiences led to depression and shame and contributed to the emotional trauma of having TB.

Interviewer: Can you describe Miguel's [pseudonym] emotional state when they told him that he had TB?

Participant: Oh, bad, as if he were going to die. He felt horrible because his friends stayed away, my dad and my mom stayed away, my sister-in-law also kept her baby away ... My mom was weak, she had diabetes, and she had gotten sick, and my older brother told Miguel not to get close to my mom because he might give TB to her ... But Miguel, he felt bad, bad, bad. The whole month at the beginning that he found out, he locked himself in his room, he didn't want to go out, he didn't want to take the pill, he said that he wanted to die. (Participant #67, sister of a 16 years old male)

Adolescents received several forms of emotional support during the home isolation period. Many adolescents were consistently encouraged and reassured by family members, and sometimes health providers. Some

adolescents used social media platforms to stay connected with friends, as well as video and phone calls with family members.

Most adolescents reported improvement in their mood when they were released from home isolation, returned to school and began spending time with family and friends.

Interviewer: [How did you feel] when you isolated yourself from your friends?

Participant: Actually, it did shock me a lot, because that's when I went into depression, I felt a little sadder ...

Interviewer: And how would you describe yourself now?

Participant: Like before, before everything happened, I've gone back to being as cheerful as I was before. (Participant #38, 19 years old male)

DISCUSSION

In this study, we observed that adolescents with drug-susceptible TB were routinely instructed to isolate at home for 1–2 months at the start of treatment. The only policy that explicitly defines the isolation period is limited to school attendance; yet, in practice, health providers extended this restriction to all activities outside the home (other than attending medical appointments). As a result of prolonged isolation, adolescents suffered detrimental effects to their education and mental health.

During adolescence, interactions with the social environment shape the development of cognitive, social and emotional capabilities that serve as the foundation for well-being in adulthood.^{7 20} Our findings suggest several pathways by which prolonged isolation undermines adolescents' ability to thrive and reach their full potential (figure 2).

First, prolonged isolation disrupts education. Of 28 adolescents in our study who were in school or vocational/military training at the time of TB treatment initiation, six still had not resumed their programme more than 6 months after isolation ended. The adolescents in our study experienced educational setbacks despite a national policy that directs schools to support students on TB treatment so that these students do not have to repeat the semester or academic year.¹⁹ The reasons underlying this disconnect between policy and reality were not explored in our interviews; however, schools may lack the resources to help students make up 1–2 months' worth of lessons. Our findings are similar to observations from other settings. According to cost surveys administered by the WHO to families affected by TB in 10 countries, 18.7% (95% CI 8.8% to 28.7%) of households with an adolescent with TB reported educational disruptions.²¹ In South Africa, China, Ukraine and India, adolescents whose schooling was disrupted because of TB reported learning difficulties on resuming classes, anxiety about their academic and professional futures, and altered

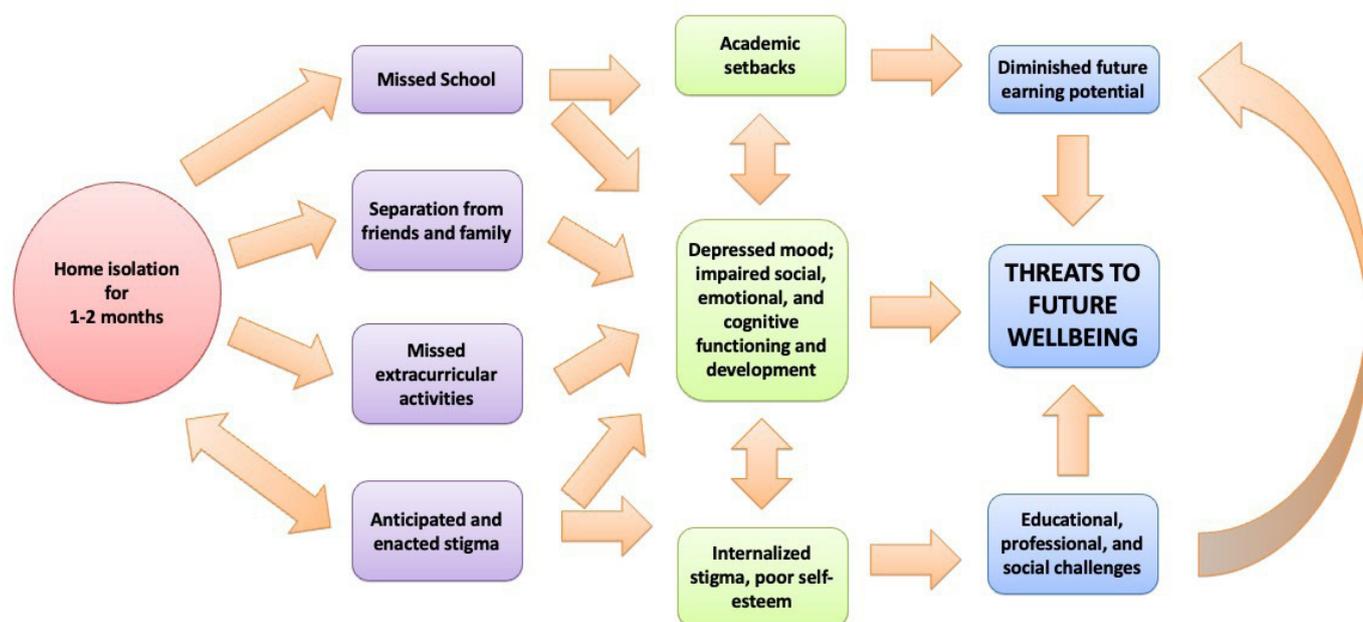


Figure 2 Pathways between prolonged home isolation and threats to adolescents' future well-being.

career trajectories.^{5 22–24} Educational setbacks impede adolescents' ability to transition into the workforce. Because adolescents with TB tend to come from families with fewer socioeconomic resources, educational attainment may be even more crucial for securing future earning potential.

Second, prolonged isolation may interfere with adolescents' social and cognitive development. Adolescents' frequent peer interactions, which are often facilitated through school, support the development of self-identity, empathy and the skills to understand and navigate social situations.^{4 7 25} Moreover, social deprivation during adolescence may result in increased aggression and diminished performance on tasks that require learning and attention.^{7 26}

Third, poor mental health in adolescence may extend to adulthood, impairing physical and psychosocial well-being and limiting professional and personal opportunities.²⁷ Positive interpersonal relationships and participation in school and other group activities are associated with improved adolescent mental health.^{27 28} In contrast, in our study, adolescents who were physically isolated because they had TB—and thus excluded from school and other activities—experienced loneliness and depression. These findings are similar to those of other qualitative studies of children and adolescents with TB in South Africa, Russia, Ukraine, and India.^{4 5 22 24}

Fourth, stigma arising from fear of TB transmission underlies prolonged isolation practices, which, in turn, reinforce stigma against patients with TB. Among our participants, being subjected to TB-related discrimination exacerbated the emotional trauma of the illness. As shown in other qualitative studies of children and adolescents with TB, adolescents are particularly vulnerable to internalised stigma, which may lead to low self-esteem

and its sequelae, including psychological, educational, professional, and social challenges.^{22 24 29}

Although quantitative studies would be helpful to further characterise the short-term and long-term sequelae of prolonged isolation on adolescents with TB, the data from this and other studies—which have been conducted in diverse settings—consistently demonstrate the harms of this practice. Furthermore, prolonged isolation in this context is problematic from a human rights perspective, as it violates adolescents' rights to education and to freedom of movement.^{30–32} While governments may limit certain rights for the benefit of public health, these limitations must be based on objective grounds and must not be arbitrary.³³ Yet, the prolonged isolation imposed on adolescents in Peru and other settings do not align with scientific evidence on TB transmission. The US Centers for Disease Control and Prevention, Infectious Diseases Society of America and American Thoracic Society all have adopted the 'two week rule', which considers transmission risk to be eliminated once patients have received adequate treatment for 2 weeks, have demonstrated clinical improvement, and have a negligible risk of MDR-TB.³⁴ The 'two week rule' was derived from expert consensus, though some experts, citing multiple human-to-guinea pig transmission studies, believe that just a few days of effective treatment are sufficient for minimising transmission risk in most cases.³⁵ Moreover, once patients are on effective treatment, sputum smear positivity no longer predicts infectivity.³⁴

To optimise the well-being of adolescents with TB, MOHs must ensure that their TB isolation guidelines are clear, non-arbitrary and in alignment with both existing evidence on disease transmission and the principles of patient-centred care, the latter of which is central to the WHO's End TB Strategy and 'involves systematically

assessing and addressing the needs of patients'.³⁶ In most cases, the isolation period can be safely shortened to 2 weeks, as long as the aforementioned conditions are met.³⁴ While some providers cite the need to rest or adapt to adverse treatment events as rationalisations for prolonged isolation, these reasons are not evidence-based, and providers should evaluate the needs and preferences of adolescents and their caregivers before using these arguments to justify prolonged isolation.

In parallel, adolescents should receive other forms of social support to minimise the harms of isolation. In Russia, adolescents who were hospitalised for TB developed friendships with each other, and this mutual acceptance and understanding helped them feel better about themselves and feel part of a community, despite being separated from their friends and family. Positive relationships with caregivers, and healthcare providers also mitigated the negative impacts of TB-related isolation on adolescent well-being.⁴ Similarly, when asked for recommendations for developing patient-centred care, adolescents with TB in India and their caregivers recommended peer support platforms and outreach to reduce stigma and discrimination within families and communities.²⁴

This study has limitations. Because the primary objective of this study was to identify barriers to treatment adherence, the interview guide did not focus specifically on isolation, so we may not have captured all impacts of prolonged isolation and may not have reached data saturation with respect to this topic. Most adolescent participants were male and older. Although this distribution reflects the higher incidence of TB in this subgroup, the experiences of younger and/or female adolescents may not be fully represented in our dataset. There may have been selection bias, as adolescents who declined to participate or were otherwise unable to be enrolled may have had different experiences than those who participated in the study. Like all qualitative studies that use non-probabilistic sampling, our findings may have limited generalisability to other populations and settings. Nevertheless, the overarching themes that emerged in our study—about the negative impacts of prolonged isolation on adolescents' academic progress and mental health during the treatment and immediate post-treatment periods—align with those of studies from several other diverse settings.^{4 5 21–24} Finally, our study did not include adolescents with drug-resistant TB, who may experience longer isolation periods and, thus, more disruptions to their education and mental health.

CONCLUSIONS

In this study, we observed that adolescents with TB who isolated at home for 1–2 months suffered detrimental educational and mental health consequences. To support the well-being of adolescents with TB, MOHs need to re-evaluate their isolation recommendations and align them with data supporting rapid cessation of

transmissibility after initiation of adequate treatment, as well as the principles of patient-centred care.

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Contributors SSC, LL and JTG designed the study. EA, LS and MW collected the data. SSC, VEOR, CBB, JC and SDR conducted the analyses. All authors interpreted the data and critically reviewed the manuscript. All authors approved the final draft for submission. SSC accepts full responsibility for the work and the conduct of the study; had access to the data; and controlled the decision to publish.

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REFERENCES

- 1 Snow KJ, Cruz AT, Seddon JA, *et al*. Adolescent tuberculosis. *Lancet Child Adolesc Health* 2020;4:68–79.
- 2 Petersen E, Khamis F, Migliori GB, *et al*. De-isolation of patients with pulmonary tuberculosis after start of treatment - clear, unequivocal guidelines are missing. *Int J Infect Dis* 2017;56:34–8.
- 3 Chiang SS, Sheremeta Y, Padilla RS, *et al*. Pediatric multidrug-resistant tuberculosis in Kyiv City, Ukraine. *J Epidemiol Glob Health* 2019;9:56–61.
- 4 Zvonareva O, Witte S, Kabanets N, *et al*. Adolescents in a tuberculosis Hospital: qualitative study of how relationships with doctors, caregivers, and Peers mediate their mental wellbeing. *PLoS One* 2021;16:e0257379.
- 5 Karayeva E. *The impact of hospitalization on Ukrainian adolescents who have completed tuberculosis treatment in Kyiv City, Ukraine [master's thesis]*. Brown University, 2020.
- 6 Moscibrodzki P, Enane LA, Hoddinott G. The impact of tuberculosis on the well-being of adolescents and young adults. *Pathogens* (Published Online First: 8 December 2021).
- 7 Orben A, Tomova L, Blakemore S-J. The effects of social deprivation on adolescent development and mental health. *Lancet Child Adolesc Health* 2020;4:634–40.
- 8 Meherali S, Punjani N, Louie-Poon S. Mental health of children and adolescents amidst COVID-19 and past pandemics: A rapid systematic review. *Int J Environ Res Public Health* (Published Online First: 4 April 2021).
- 9 Allen CW, Diamond-Myrsten S, Rollins LK. School absenteeism in children and adolescents. *Am Fam Physician* 2018;98:738–44.
- 10 Ministerio de Salud (Perú). *Norma técnica de salud para La atención integral de las personas afectadas POR tuberculosis*. Lima, Peru: MINSa, 2013. cdn.www.gob.pe/uploads/document/file/382664/Norma_t%C3%A9cnica_de_salud_para_la_atenci%C3%B3n_integral_de_las_personas_afectadas_por_tuberculosis20191011-25586-i65fww.pdf
- 11 Ministerio de Salud (Perú). *Directiva administrativa No. 080-MINSA/2017/DGIESP: Directiva sanitaria para La intervencioen ante La presencia de un caso de tuberculosis en Una institución educativa*. Lima, Peru: MINSa, 2017. docs.bvsalud.org/biblioref/2019/02/963670/rm-1098-2017-minsa.pdf
- 12 World Health Organization. *Global tuberculosis report 2021*. Geneva, Switzerland: WHO, 2021. www.who.int/publications/i/item/9789240037021
- 13 Alarcón V, Alarcón E, Figueroa C, *et al*. Tuberculosis en El Perú: Situación epidemiológica, avances Y desafíos para SU control. *Rev Peru Med Exp Salud Publica* 2017;34:299–310.
- 14 Ministerio de Salud (Perú). *Dirección de Prevención Y control de la tuberculosis. Sala situacional: Dashboard*. Lima, Peru: MINSa, 2021. www.tuberculosis.minsa.gob.pe/DashboardDPC/TB/Dashboard.aspx
- 15 Chiang SS, Roche S, Contreras C, *et al*. Barriers to the diagnosis of childhood tuberculosis: a qualitative study. *Int J Tuberc Lung Dis* 2015;19:1144–52.
- 16 Chiang SS, Roche S, Contreras C, *et al*. Barriers to the treatment of childhood tuberculosis infection and tuberculosis disease: a qualitative study. *Int J Tuberc Lung Dis* 2017;21:154–60.
- 17 Hsieh H-F, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res* 2005;15:1277–88.
- 18 Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19:349–57.
- 19 Ministerio de Salud (Perú). *Aprueban El reglamento de la Ley No. 30287, Ley de prevención Y control de la tuberculosis en El Perú*. Lima, Peru: MINSa, 2016. busquedas.elperuano.pe/normaslegales/aprueban-modificacion-del-reglamento-de-la-ley-n-30287-ley-decreto-supremo-n-035-2016-sa-1410176-10/
- 20 Patton GC, Sawyer SM, Santelli JS, *et al*. Our future: a Lancet Commission on adolescent health and wellbeing. *Lancet* 2016;387:2423–78.
- 21 Nishikiori NV K. The socio-economic impact of TB on children, adolescents and their families: findings from national TB patient cost surveys. annual meeting of the child and adolescent TB Working group of the world Health organization. *Virtual* 2021.
- 22 Franck C. *Assessing the Importance of Stigma in Children's Experience of MDR-TB Treatment in the Western Cape Province, South Africa [thesis]*. London School of Hygiene & Tropical Medicine 2012.
- 23 Zhang S, Li X, Zhang T, *et al*. The experiences of high school students with pulmonary tuberculosis in China: a qualitative study. *BMC Infect Dis* 2016;16:758.
- 24 Das M, Mathur T, Ravi S, *et al*. Challenging drug-resistant TB treatment journey for children, adolescents and their care-givers: a qualitative study. *PLoS One* 2021;16:e0248408.
- 25 Ellis WE, Zabatany L. Understanding processes of peer clique influence in late childhood and early adolescence. *Child Dev Perspect* 2017;11:227–32.
- 26 Almeida ILdeL, Rego JF, Teixeira ACG, *et al*. Social isolation and its impact on child and adolescent development: a systematic review. *Rev Paul Pediatr* 2021;40:e2020385.
- 27 World Health Organization. *Guidelines on mental health promotive and preventive interventions for adolescents: helping adolescents thrive*. Geneva, Switzerland: WHO, 2020. www.who.int/publications/i/item/guidelines-on-mental-health-promotive-and-preventive-interventions-for-adolescents
- 28 La Greca AM, Harrison HM, relations Apeer. Friendships. and romantic relationships: do they predict social anxiety and depression? *J Clin Child Adolesc Psychol* 2005;34:49–61.
- 29 Health and Behaviour Unit, Department of Sustainable Development and Healthy Environments. *Adolescent Mental Health Promotion: Trainers' Guide on Enhancement of Self-Confidence*. New Delhi, India: WHO Regional Office for South-East Asia, 2003. apps.who.int/iris/bitstream/handle/10665/204759/B4898.pdf?sequence=1&isAllowed=y
- 30 UN General Assembly. Universal Declaration of human rights. United nations, 1948. Available: <https://www.un.org/en/about-us/universal-declaration-of-human-rights> [Accessed Available from Jun. 14, 2022].
- 31 UN General Assembly. International covenant on civil and political rights. United nations, 1966. Available: <https://www.ohchr.org/en/instruments-mechanisms/instruments/international-covenant-civil-and-political-rights> [Accessed Jun. 14, 2022].
- 32 UN General Assembly. Convention on the rights of the child. United nations, 1989. Available: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child> [Accessed Jun. 14, 2022].
- 33 UN Commission on Human Rights. The Siracusa principles on the limitation and Derogation provisions in the International covenant on civil and political rights, United nations, 1984. Available: <https://www.icj.org/wp-content/uploads/1984/07/Siracusa-principles-ICCPR-legal-submission-1985-eng.pdf> [Accessed Jun. 18, 2022].
- 34 Migliori GB, Nardell E, Yedilbayev A, *et al*. Reducing tuberculosis transmission: a consensus document from the World Health Organization Regional Office for Europe. *Eur Respir J* 2019;53:1900391.
- 35 Dharmadhikari AS, Mphahlele M, Venter K, *et al*. Rapid impact of effective treatment on transmission of multidrug-resistant tuberculosis. *Int J Tuberc Lung Dis* 2014;18:1019–25.
- 36 World Health Organization. *The end TB strategy*. Geneva, Switzerland: WHO, 2015. https://www.who.int/tb/End_TB_brochure.pdf?ua=1

SUPPLEMENTAL MATERIAL for “The impact of prolonged isolation on adolescents with drug-susceptible tuberculosis in Lima, Peru: A qualitative study” by Oliva Rapoport, et al.

Contents:

1. Semi-structured interview guides, page 2
2. Codebooks, page 10
3. COREQ Checklist, page 14

SEMI-STRUCTURED INTERVIEW GUIDES

Groups 1, 3 and 5: Adolescents Treated for Drug-Susceptible Pulmonary TB

- Group 1: Finished the treatment with good adherence
- Group 3: Quit therapy
- Group 5: Finished the treatment with poor adherence

Introduction

This introduction aims to:

1. Explain the purpose of the interview.
2. Emphasize that the interviewees are the experts and therefore we would like to learn about their experiences and perspectives.
3. Ensure confidentiality. We will not share what you tell us with anyone, including parents/guardians, the health center, etc.
4. Explain the recording and the importance of speaking loudly.

Good morning, my name is, I belong to the NGO Partners In Health, this is an institution that works on projects focused on different health problems that affect the community. In this case, I have come to talk with you as you are an adolescent who has received care for TB and I want to understand the experience you have had in this role. The purpose of this interview is to learn from what you share with me, in order to understand how to improve care for adolescents who may have TB in the future. It is important that you understand that this is a conversation, it is not a questionnaire, and therefore there are no incorrect answers, everything related to the illness you have faced is important to me. To be able to remember everything we talk about, I'm going to record our audio conversation with a small recorder that will capture only our voices, this is because I cannot take note of everything we are going to talk about, this audio will later be transcribed for reading and analysis along with other interviews, if at any time your name is mentioned at the time of transcribing we will change your name to another, so there is no way to identify you, after that we will delete the audio file. If there is a question that you do not want to answer, you can tell me and we can move on to the next question, do not feel obligated to answer me if you do not want to. Feel free to share your experiences whether they are pleasant or not. I will not discuss what we talk about with your parents or the health center.

So if you agree to do the interview, we can begin (start recording)

Today is, and we are going to start the interview by asking you

- What area/zone is your home in?
- Who do you live with?
- Do you currently attend school?

Questions

Beliefs / Knowledge

1. Before getting sick with TB, what did you know about the disease?
2. And now that you have had TB, how has your knowledge of TB changed?

3. Do you have a relative or friend who has had TB? What do you know about his/her illness?

Start of the Disease / Diagnosis

4. Could you tell me how you found out you had TB? How was it that you got to the health center? Who did you go with? Why did you go?
5. How do you think you got TB? (i.e. Did you have any contact with a family member or friend with TB?)
- (If applicable) When you learned that person had TB, how did you react?
 - (If applicable) Did you go to a healthcare facility to get tested?
6. Tell me about your experience of falling ill and going to the health center.
- How long did you have symptoms before you went for a medical evaluation?
 - Why did you decide to go to the Health Center?

The Treatment

7. Tell me about the process of going to the health center to receive medication for TB. Could you tell me or describe a typical day when you were going to take your treatment at the health center? (What time did you go, before or after school? How long did you take, with whom did you go? What did you take your pills with? Did you go by motorcycle, car or on foot?)
- How long did it take you?
 - Did you miss school because you went to take your medications?
 - Did you miss other activities because you went to take your medications?
 - How many days of treatment did you miss? Why?
 - What other factors made it difficult to take your TB medications (e.g.: transportation costs)?
 - Who was responsible for making sure you went to the health center every day to take your medications? You or someone else? Who?
 - Who supported you in taking your treatment? (someone to remind you to go or accompany you, or to provide you with transportation or breakfast)
 - Only Groups 1 and 5:** What things helped you to finish your treatment?
8. How did the TB pills affect you (for better or worse)?
- How did you do with the treatment medications, did you have any difficulty taking the medications?
 - What problems did you have taking the TB pills?
 - Could you swallow the pills?
 - What discomfort did the TB medications cause you?
 - If you have had discomfort:** What did the doctors and nurses do at the health center to help you with these discomforts?
 - Did you consider stopping your medication when you no longer had symptoms of TB?
 - Group 3 only:** How have you felt since you stopped taking your TB medications?

Emotional State

9. How would you describe your state of mind before getting sick?
10. After you got sick, was there a change in your mood?

- a. How did you feel when you found out you had TB?
 - b. During treatment, how did your mood change?
 - c. Who gave you emotional and psychological support during your TB illness?
11. How did TB alter your life?
 12. In general, how is your relationship with your family? How is the relationship with your parents before and after having TB?
 13. Who did you tell you had TB? Tell me why you decided to tell that person or persons that you had TB?
 14. Have you ever felt discriminated against because you had TB?

Medical Care

15. How satisfied are you with the TB care you received at the health center?
16. How have you been treated by the health personnel at the health centers or hospitals? . . . Did you experience a situation that caused you discomfort or have you been treated poorly?
 - a. What information did the health personnel give you about TB and TB treatment?
17. If you could improve care for adolescents with TB, what changes would you make?
 - a. Regarding the diagnostic process
 - b. Regarding the treatment process
18. What do you think could help teens learn about the importance of being evaluated if they have been in contact with someone with TB, and the importance of taking all their medications as they should be taken?

Conclusion:

19. What do you think can happen if you do not take your TB medications as you should?
20. **(Groups 1 and 2):** Can you tell me what led you to complete your treatment for TB?
21. **(Only Group 3):** Can you tell me what led you to stop taking your TB medications? What else would have helped you finish the TB treatment?
22. What part of this experience of getting sick with TB has been the most difficult?
23. Is there anything else about TB treatment that is important for me to know?
24. Is there anything else related to your TB experience that you would like to tell me about?

Notes:

Groups 2, 4 and 6: Parents / Guardians of Adolescents

- Group 2: Children finished their treatment with good adherence
- Group 4: Children abandoned therapy
- Group 6: Children finished their treatment with poor adherence

Introduction

This introduction aims to:

1. Explain the purpose of the interview
2. Emphasize that the interviewees are the experts and therefore we would like to learn about their experiences and perspectives
3. Ensure confidentiality. We will not share what you tell us with anyone, including the children, the health center, etc.
4. Explain the recording and the importance of speaking loudly

Good morning, my name is, I belong to the NGO Partners In Health, this is an institution that works on projects focused on different health problems that affect the community. In this case, I have come to talk with you since you were in charge of a teenager who has received TB care and I want to understand the experience you have had in this role. The purpose of this interview is to learn from what you share with me, in order to understand how to improve care for adolescents who may have TB in the future. It is important that you understand that this is a conversation, it is not a questionnaire, and therefore there are no incorrect answers, everything you tell me about the illness that the adolescent in your care has faced is important. To be able to remember everything we talk about, I'm going to record our audio conversation with a small recorder that will capture only our voices, this is because I cannot take note of everything we are going to talk about, this audio will later be transcribed for reading and analysis along with other interviews, if at any time your name is mentioned at the time of transcribing we will change your name to another, so there is no way to identify it, after that we will delete the audio file. If there is a question that you do not want to answer, you can tell me and we can move on to the next question, do not feel obliged to answer me if you do not want to. Feel free to share your experiences, whether they are pleasant or not. I will not discuss what we talk about with your family or with the health center.

So if you agree to do the interview, we can begin (start recording)

Today is, and we are going to start the interview by asking you

- What area/zone is your home in?
- Who do you live with?
- What is your occupation? (referring to whether you work or not and in what)

Questions

Beliefs / Knowledge

1. Before your child got sick with TB, what did you know about the disease?
2. And now that your child has had TB, how has your knowledge of TB changed?

3. Do you have a family member or friend who has had TB? What do you know about their illness?

Start of the Disease / Diagnosis

4. How do you think your child was infected with TB? (i.e. Did he/she have contact with a family member or friend with TB?)
- (If applicable) When you learned that this person had TB, how did you and your family react?
 - (If applicable) Did your child go to a healthcare facility to be evaluated?
5. Tell me about your child's experience of falling ill and going to the health center.
- How long did your child have symptoms before going for a medical evaluation?
 - Why did you decide to go to the Health Center?

The Treatment

6. Tell me about the process of going to the health center to receive TB medicine.
- How much time did it take?
 - Did your child have to miss school?
 - Did you have to miss work?
 - How many days of treatment did your child miss? Why?
 - What other factors made it difficult to take the TB medications (e.g. transportation costs)?
 - Who was responsible for making sure your child went to the health center every day to take his/her medications?
 - What did you do to help your child take his/her TB treatment?
 - Only Groups 1 and 5:** What things helped your child finish his/her treatment?
7. How did the TB pills affect your child (for better or worse)?
- What problems did your child have with taking the TB pills?
 - Could your child swallow the pills?
 - What discomfort did the TB medications cause?
 - If your child had any discomfort:** What did the doctors and nurses at the health center do to help with these discomforts?
 - Did your child consider stopping his/her medicine when he/she no longer had TB symptoms?
 - Group 3 only:** How has your child felt since he/she stopped taking his/her TB medicine?

Emotional State

8. How would you describe your child's mood during TB treatment?
- How did your child feel when he/she found out he/she had TB?
 - Who provided your child with psychological or emotional support during TB treatment?
9. How would you describe the relationship you have with your child?
10. Who did you tell that your child had TB and why?

11. Can you tell me about situations in which your family has felt discriminated against because of your child's illness?
12. What type of financial problems has your family had due to your child's TB disease?
 - a. **If you received help:** What type of financial support did you receive during your child's TB treatment?

Medical Care

13. How satisfied are you with the TB care your child received at the health center?
 - a. How were you and your child treated by the health center staff?
 - b. What information did the health personnel give you and your child about TB and TB treatment?
14. If you could improve care for adolescents with TB, what changes would you make?
 - a. Regarding the diagnostic process
 - b. Regarding the treatment process

Conclusion:

15. Do you think your child is rebellious? Does he/she follow the rules and advice of adults?
16. What do you think can happen to an adolescent with TB if he/she does not take his/her TB medications?
17. **(Only Group 3)** Can you tell me what led your child to stop taking his/her TB medications? What else would have helped your child finish his/her TB treatment?
18. For you, what was the most difficult aspect of your child's illness?
19. Is there anything else about TB treatment that is important for me to know?
20. Is there anything else about your TB experience that you would like to tell me about?

Notes:

Group 7: Health Personnel

Introduction

This introduction aims to:

1. Explain the purpose of the interview
2. Emphasize that the interviewees are the experts and therefore we would like to learn about their experiences and perspectives
3. Ensure confidentiality.
4. Explain the recording and the importance of speaking loudly

Good morning, my name is, I belong to the NGO Partners In Health, this is an institution that works on projects focused on different health problems that affect the community. In this case, I have come to talk with you because you work in a health center where you provide TB care to adolescents, and I want to understand the experience you have had in this role. The purpose of this interview is to learn from what you share with me, in order to understand how to improve care for adolescents who may have TB in the future. It is important that you understand that this is a conversation, it is not a questionnaire, and therefore there are no incorrect answers, everything related to the care of adolescents affected by TB is important to me. To be able to remember everything we talk about, I'm going to record our audio conversation with a small recorder that will capture only our voices, this is because I cannot take note of everything we are going to talk about, this audio will later be transcribed for reading and analysis along with other interviews, if at any time your name is mentioned at the time of transcribing we will change your name to another, so there is no way to identify it, after that we will delete the audio file. If there is a question that you do not want to answer, you can tell me and we can move on to the next question, do not feel obliged to answer me if you do not want to. Feel free to share your experiences, whether they are pleasant or not. I will not discuss what we talk about with your boss or colleagues at the health center or with the patients you care for.

So if you agree to do the interview, we can begin (start recording)

Today is, and we are going to start the interview by asking you

- What is your position at the health center?
- How many people do you work with?
- How long have you been working there?

Questions:

1. Who transmits TB to adolescents? Family members? Friends?
2. What information do you give to teens and their parents or guardians about TB and TB treatment?
3. Tell me about the process of arriving to the health center to distribute anti-TB drugs.
 - a. How much time does each adolescent need?
 - b. Do you know what activities adolescents tend to miss when they go for treatment? (classes, work, etc.)
 - c. Do you know what activities parents tend to miss when they go with their teenagers for treatment? (classes, work, etc.)

- d. What other barriers are there?
4. What kind of psychological or emotional support do teenagers receive during their TB treatment?
5. If adolescents suffer any side effects from anti-TB drugs, what does the health center staff do to treat them?
6. Have you noticed any association between the improvement of symptoms and the abandonment of treatment in adolescents with TB?
7. What differences have you noticed between adolescents with good adherence and adolescents with poor adherence to TB treatment?
 - a. Regarding the socioeconomic situations and levels of education of their families
 - b. Regarding the support that their parents / guardians give them
 - c. Regarding the beliefs that the adolescent and his/her family have regarding TB
 - d. Regarding the severity of TB disease
 - e. Regarding the side effects of the medications
 - f. Regarding the psychological state of the adolescent
8. What challenges do you face in identifying, diagnosing, and treating adolescents with TB?

Conclusion:

9. If you could make treatment for TB easier for teenagers, what changes would you make?
10. Do you have any other thoughts on adolescent adherence to TB treatment that you would like to share?

Notes:

CODEBOOKS

Adolescent/Caregiver Interviews

1. Beliefs/knowledge: any beliefs or knowledge that the interviewee had or has about TB, can be general or pertain to the adolescent's own illness, include any comments about how the beliefs/knowledge have changed.
 - 1.1. Transmission: pertaining to how one gets TB (include any possible source cases)
 - 1.2. Nutrition: pertaining to role of nutrition in TB pathogenesis
 - 1.3. Temperature: e.g., I stood in front of the fridge, and that's why I became sick with TB
 - 1.4. Curability: pertaining to whether TB can be cured
 - 1.5. Bad consequences: what happens when you don't take your pills as prescribed
 - 1.6. Other: other beliefs/knowledge not covered in 1.1-1.5, include here any comments about general changes in beliefs/knowledge or specific changes that do not fit under any of the other categories
2. Symptoms: symptoms experienced prior to treatment initiation or during treatment (try to differentiate from medication side effects), duration of symptoms, effect of treatment on symptoms.
3. Diagnosis: any data relating to the process of getting diagnosed with TB.
4. Reaction to diagnosis: reaction on the part of the adolescent or relative, may include sadness, fear, depression, disbelief; including confiding/disclosing diagnosis to others
5. Transportation: how the adolescent actually commuted to the health center for DOT and how long it took.
6. DOT: data related to the actual process of taking the medications at the health center, or in rare cases, at a different location (whether it was actually supervised, how long it took, who accompanied the patient to DOT, etc.).
7. School: any effect of having TB on the adolescent's education, including obligatory leave of absence from school, experience of stigma upon return to school, difficulty with schoolwork, etc.
8. Isolation: any physical (e.g., had to stay in my room for the first month) or social (e.g., I missed my friends' parties because I didn't want to transmit TB) isolation and especially the adolescent's emotional reaction to the isolation.
9. Family: any description of how the adolescent relates to his/her family.
 - 9.1. Family support: pertaining to any support that a parent/guardian or another relative gave the adolescent during treatment, including reminders to take medications, accompaniment to the health center, etc.
 - 9.2. Family challenges: may include lack of parental involvement in the adolescent's life, blame for adolescent's illness, include TB-related discrimination by other family members, which will be double-coded under 'stigma' as well
 - 9.3. Relationship changes: any description of how relationships within the family changed during or after the adolescent's TB illness
 - 9.4. Household: description of who lives in the household with the patient, including activities related to household contact investigation
10. Motivation: what the adolescent explicitly identifies as the reason(s) that s/he adhered to treatment, either in response to the interviewer's question "what motivated you to finish

- treatment” or by stating this elsewhere in the interview (e.g., “I finished my therapy because I didn’t want my TB to become resistant”).
11. Missed doses: number of doses missed and why, health impact of missing doses/quitting treatment.
 12. Side effects: any symptoms attributed by the interviewee to anti-TB medications, the impact of these side effects on the adolescent’s wellbeing.
 13. Desire to quit: any reference to feeling tempted to stop taking medications at any point during therapy.
 14. Mental health: any reference to how having TB impacted the adolescent’s mental health.
 15. Stigma: experiences of discrimination because of having TB from any source, including family members.
 16. Substance use: any data related to the use of alcohol, tobacco, or other drugs by the adolescent.
 17. Other patients: comments about interactions with other TB patients, may include advice/support received from other TB patients, seeing MDR patients needing to get daily injections.
 18. Medical care: any comments about interactions with health center staff.
 - 18.1. Support: strategies used by health center staff to help adolescents take and/or finish treatment; may include encouragement, strategies such as text message reminders, use of video DOT, informing parents/guardians of poor adherence
 - 18.2. Side effect help: how doctors and nurses either helped or did not help adolescents deal with side effects
 - 18.3. Poor treatment: any feelings of being disrespected or otherwise treated poorly by health center staff
 - 18.4. Patient education: information that health center staff gave to adolescents and their families about TB
 - 18.5. Other: other comments about medical care not covered in 18.1-18.4
 19. Economics: comments pertaining to family’s financial situation.
 20. Suggestions: any suggestions about how to improve care for adolescents with TB and their families.
 21. Biggest challenge: what the adolescent or parent/guardian explicitly identifies as the most difficult aspect of the TB illness experience.

Healthcare Provider Interviews

1. Transmission: any beliefs/knowledge about how adolescents get TB (i.e., from family members, from riding on the bus, etc.).
2. Nutrition: any beliefs/knowledge about the impact of nutrition on TB pathogenesis or treatment. Be especially on the lookout for comments relating beliefs about poor nutrition causing TB to feelings of guilt.
3. Patient education: what kind of information the health providers explicitly give to patients and family members about TB.
4. Quality of care: comments about the quality of medical care received by TB patients and their families, including things that health providers perceive to be good or bad care (e.g., you can’t tell the patient right away that s/he has TB for fear that s/he develops psychological

trauma from the news). Also include comments about building rapport, which seems to be a frequent comment from providers.

- 4.1. Strategies to prevent quitting therapy: examples include video DOT, calling parents to check on adolescents who aren't showing up to health center, etc.
5. DOT: description of the process of DOT, including the amount of time it takes. Do not code sentences relating to barriers or facilitators to DOT that could fit under another category. For instance, a statement of the health center's limited hours for DOT would be coded here, but a statement about the challenges of getting to the health center due to expensive transportation, then that would be coded under "transportation." Strategies that health providers develop to promote adherence, such as coordinating with other health facilities to provide DOT, video DOT using cell phones, etc., would go under 4.1.
6. Pills: any information about patients' inability or ability to swallow pills. Commentary about how health providers teach patients to swallow pills should be double-coded under "patient education" and "swallowing pills." Also, any comments about pill fatigue. Side effects from pills should not be coded here.
7. Mental/emotional health: comments related to mental/emotional health of adolescents that do not fit under one of the following subcodes
 - 7.1. Reactions: any emotional or psychological reaction on the part of the adolescent to diagnosis or treatment
 - 7.2. Psych care: provision of or need for psychological care for adolescents with TB
8. Stigma: any comments pertaining to the stigma that adolescents and their families face as the result of having TB. If a comment about stigma includes a description of how an adolescent became depressed (or had some other mental/emotional consequence) due to TB-related discrimination, then that comment should be double-coded under "stigma" and "mental/emotional health."
9. Substance use: any information about TB patients' or their family members' use of alcohol and/or drugs.
10. Family
 - 10.1. Job/finances: any information about how family finances impact or are impacted by TB treatment. Include commentary about adolescents' or family members' jobs, and how those jobs impact or are impacted by TB treatment. Comments about how parents' jobs preclude ability to accompany kids should be double-coded under 10.1 and 10.2.
 - 10.2. Accompaniment/support (or lack of): comments pertaining to any support that the family provides (e.g., going with adolescent to health center for DOT, encouragement to finish treatment, etc.). Could also include lack of support.
 - 10.3. Relationships: any changes in family relationships due to TB. Different from 10.2. This code is more about whether, for instance, the adolescent became closer with his/her parents because they went through this terrible illness together, or whether the TB experience drove a wedge between the kid and his/her relative who discriminated against him/her due to TB.
 - 10.4. Emotional reactions: family members' emotional reactions to diagnosis and treatment, etc., including any provision of psychological care for them
 - 10.5. Perceptions/beliefs: Any family perceptions/beliefs that don't fit under any other node (e.g., toad extract and other alternative medicines will cure TB). Comments about parents' disbelief that child has TB due to good nutrition should be coded under nutrition.

- 10.6. Knowledge: Include here any comments about general knowledge or ignorance with respect to TB on the part of patients and their families.
11. Side effects: any information about side effects to TB medications, including how the health center staff responds to adolescents who report side effects to meds.
12. Housing status: any information about TB patients' or their family members' housing status, particularly how housing status may relate to treatment adherence.
13. Transportation: any comments about transportation to/from the DOT site(s), including cost and time spent.
14. School: any effect of having TB on the adolescent's education, including obligatory leave of absence from school, difficulty with schoolwork, etc. Any information about experiencing discrimination at school should be double-coded under "school" and "stigma."
15. Activities: comments about how TB illness and treatment impacts participation in sports, hobbies, social events.
16. DOT attendance: quotes related to when adolescents tend to stop showing up for meds, any patterns in attendance, etc.
17. Suggestions: suggestions that the interviewee has about how to improve care for adolescents with TB.
18. Interesting NOS: any interesting comments that do not fit under any of the other nodes.

CONSOLIDATED CRITERIA FOR REPORTING QUALITATIVE RESEARCH (COREQ)

Adapted from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19(6): 349-357.

Item	Item number	Guide question	Answer (page on which answer may be found)
Domain 1: Research team and reflexivity			
<i>Personal Characteristics</i>			
Interviewer/Facilitator	1	Which author/s conducted the interview or focus group?	Elmer Altamirano, Liz Senador, Milagros Wong (page 9).
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	Victoria E. Oliva Rapoport, BA Elmer Altamirano, BA (Psychology) Liz Senador, LVN Milagros Wong, RN Catherine Beckhorn, BA Julia Coit, MPH Stephanie Roche, MPH PhD Leonid Lecca, MD, MSc Jerome T. Galea, PhD, MSW Silvia S. Chiang, MD, ScM
Occupation	3	What was their occupation at the time of the study?	Victoria E. Oliva Rapoport: MD-ScM Candidate Elmer Altamirano: Research study personnel Liz Senador: Research study personnel Milagros Wong: Research coordinator Catherine Beckhorn: Research intern Julia Coit: Research associate Stephanie Roche: PhD candidate in global health metrics and implementation science Leonid Lecca: Executive Director of Socios En Salud – Sucursal Peru and Lecturer at the Department of Global

			Health and Social Medicine at Harvard Medical School Jerome T. Galea: Assistant Professor at the School of Social Work at the University of South Florida Silvia S. Chiang: Assistant Professor of Pediatrics at Alpert Medical School of Brown University and Attending Physician in Pediatric Infectious Diseases at Hasbro Children's Hospital
Gender	4	Was the researcher male or female?	There were two primary study interviewers, one male and one female. A third study interviewer was female.
Experience and training	5	What experience or training did the researcher have?	Individual interviews were conducted from August 2018 to May 2019 in Spanish by three Peruvian study personnel (MW, EA, LS) with prior training and/or experience conducting interviews (page 9).
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	The interviewers had no prior relationships with adolescent and caregiver participants; however, they did have prior collaborations with some healthcare worker participants (pages 9-10).
Participant knowledge of the interviewer	7	What did the participants know about the researcher?	Details described in the interview guides (Supplemental Material pages 2, 5, 8).
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator?	Details described in the interview guides (Supplemental Material pages 2, 5, 8).
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and theory	9	What methodological orientation was stated to underpin the study?	Thematic analysis (pages 10-11)

<i>Participant selection</i>			
Sampling	10	How were participants selected?	Adolescents and caregivers: invited consecutive eligible individuals Healthcare workers: convenience sample (page 9)
Method of approach	11	How were participants approached?	Face-to-face or telephone
Sample size	12	How many participants were in the study?	85 (page 12, Figure 1)
Non-participation	13	How many people refused to participate or dropped out? Reasons?	Adolescents refused: 4 Healthcare worker refused: 1 (Figure 1)
<i>Setting</i>			
Setting of data collection	14	Where was the data collected?	Adolescents and caregivers: Participant's home Healthcare workers: workplace (page 10)
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	No (Page 10)
Description of sample	16	What are the important characteristics of the sample?	Please see Table 1.
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	See interview guides (Supplemental Material pages 2–9). Guides were pilot tested (page 10).
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	No
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	Audio recording (page 10)
Field notes	20	Were field notes made during and/or after the interview or focus group?	Yes (page 10)
Duration	21	What was the duration of the interviews or focus group?	45-60 minutes (page 10)
Data saturation	22	Was data saturation discussed?	Yes (pages 8 and 26)
Transcripts returned	23	Were transcripts returned to participants for	No

		comment and/or correction?	
Domain 3: Analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	Five (page 11)
Description of coding tree	25	Did authors provide a description of the coding tree?	Yes, see codebooks (Supplemental Material pages 10–13)
Derivation of themes	26	Were themes identified in advance or derived from the data?	Derived from the data (pages 10-11)
Software	27	What software, if applicable, was used to manage the data?	NVivo version 12 (page 11)
Participant checking	28	Did participants provide feedback on the findings?	No
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified?	Yes (pages 12–22)
Data and findings consistent	30	Was there consistency between the data presented and the findings?	Yes
Clarity of major themes	31	Were major themes clearly presented in the findings?	Yes (pages 12–22)
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	Yes (pages 15 and 17)