Analyzing Adolescent-friendly Tuberculosis Services in Lima, Peru: A Qualitative Study

By

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INTRODUCTION

Every year, an estimated 800,000 adolescents (ages 10-19 years) develop tuberculosis (TB) disease [1, 2]. Unfortunately, most surveillance systems fail to disaggregate adolescent data, grouping those <15 years old with children and those ≥15 years old with adults [1, 2].

Adolescents have specific healthcare needs due to their unique life stage as they undergo rapid physical and emotional developmental changes [3]. In addition, adolescents are transitioning from dependence on caregivers to autonomy [3]. A needs assessment and review of national healthcare services for adolescents from 25 countries revealed that adolescents face multiple healthcare barriers due to restrictive laws, limited health services, and treatment protocols that are not tailored to their age group [4, 5, 6]. To improve healthcare services for adolescents, the World Health Organization (WHO) has published guidelines for the provision of quality adolescent-friendly services (AFS) [4]. The fundamental framework of AFS consists of equity, accessibility, acceptability, appropriateness, and effectiveness as dimensions of care [4, 6]. More specifically, the guidelines include promoting adolescents' health literacy, providing community support, training healthcare workers to provide adolescent-friendly care, designing health facilities to appeal to adolescents, collecting disaggregated data on adolescent health for research and quality improvement, and involving adolescents in their own healthcare decisions [4, 6].

Most national TB programs (NTPs) have not defined specific standards to address the needs of adolescents in TB care [7]. Several NTPs have not recognized the need for specific guidelines for providing adolescent-friendly care [8]. However, there is growing

recognition of importance of considering adolescents' specific needs when providing TB care. Acknowledging this need, the WHO commissioned an international expert consensus panel to propose interventions to optimize care for adolescents with TB or at risk of TB [3]. The findings of this expert panel are included in the most recent WHO Operational Handbook on pediatric TB [3, 9]. Assessment of critical gaps in TB services for adolescents with respect to the WHO's AFS framework is vital to improve TB treatment outcomes for this vulnerable group [2, 4].

To address this gap in the literature, we conducted a secondary analysis of data from a qualitative study in Lima, Peru, that focused on investigating factors that impact TB treatment adherence among adolescents. The purpose of this analysis is to identify the barriers and facilitators relating to adolescent-friendly TB services, as defined by the WHO's AFS framework.

METHODS

Setting

Peru has a population of 34 million people and an estimated TB incidence of 130 per 100,000 per year [10]. About 59.3% of TB cases are diagnosed and treated in the Lima metropolitan area, which includes Lima, the nation's capital, and Callao, the neighboring port city [11]. Patients receive TB treatment through directly observed therapy (DOT) at a health center near their homes. DOT is supervised by a trained healthcare provider who watches the patient take medications to ensure they are receiving the prescribed dosage and to monitor their response to treatment. These health centers are operated by the Ministry of Health (MINSA) [10]. For the treatment of drug-susceptible TB, Peru's NTP endorses a regimen consisting of a two-month intensive phase with four

medications given daily, followed by a four-month continuation phase with two medications given three times per week.

Study Population

Three groups of study participants were recruited: adolescents, their primary caregiver, and healthcare providers. Inclusion criteria for the adolescents were as follows: diagnosed with drug-susceptible pulmonary TB, between the ages of 10–19 years at treatment initiation, received DOT at a health center run by MINSA, and either completed TB therapy or were lost to follow-up from TB treatment in the previous 12 months. Adolescents who had extrapulmonary TB or received any second-line TB drugs were excluded. To recruit caregivers, each adolescent identified the adult whom they considered their primary caregiver throughout their TB treatment. Adolescents whose primary caregivers did not agree to participate in a separate interview were excluded. Healthcare providers consisted of nurses and nurse technicians, the equivalent of licensed vocational nurses (LVNs), who supervised DOT at a MINSA facility for at least six months.

Ethics

This study was approved by the institutional review boards of the Peruvian National Institute of Health and Rhode Island Hospital. All participants ≥18 years old and parents/legal guardians of participants <18 years old provided written consent. Participants <18 years old provided written assent.

Data Collection

Local staff from Socios En Salud, the Peruvian sister organization of the international non-governmental organization [NGO] Partners in Health, conducted the in-depth interviews (IDIs). The interviewers received extensive training and have had previous experience conducting IDIs. All IDIs were conducted in Spanish from August 2018 to May 2019. The interviewers had no prior relationships with the adolescents and their caregivers but had professional relationships with some of the healthcare staff who participated in the study. IDIs lasted for 45-60 minutes, were audio-recorded, and were later transcribed verbatim. The IDIs with adolescents and their caregivers took place in their homes, while the healthcare providers were interviewed at their workplace in a private setting.

Data Analysis

Data were analyzed using a qualitative framework method approach, which enables multi-disciplinary teams to work together to select the most appropriate framework [12]. This approach has seven stages, including transcription, familiarization with the interview, coding, developing a working analytical framework, applying the analytical framework, charting data into the framework matrix, and interpreting the data [12]. The IDIs were transcribed and uploaded to NVivo Version 20.7.0.1533 (QSR International, Cambridge, U.S.A.). All researchers involved in the analysis familiarized themselves with the interview guide. One investigator (DA) coded all transcripts, using both inductive codes from the interview data and deductive codes from the interview guides and AFS framework [6, 13]. Together, the research team selected the WHO AFS guidelines as the analytical framework. Themes were mapped onto a matrix of the

barriers and facilitators related to each AFS dimension of care [4]. The matrix examined how adolescent TB services were and were not meeting the WHO guidelines for adolescent health services in Lima [6].

RESULTS

This analysis utilizes a total of 85 interviews: 34 adolescents, 36 caregivers, and 15 healthcare providers. Fourteen of 34 (41.2%) adolescents had optimal adherence to TB treatment, 11 (32.4%) had suboptimal adherence, and 9 (26.4%) were lost to follow-up. During their TB treatment, 28 (82.4%) adolescents in this study were in secondary, postsecondary, vocational, or military school. Only 2 (6%) adolescents had full-time jobs during treatment. Ten nurses and five nurse technicians were interviewed. Participants were able to share their experiences across 32 health centers in Lima. In Table 1, we summarize the facilitators and barriers of adolescent-friendly TB services within the framework of the WHO AFS five dimensions of care: accessibility, equity, acceptability, appropriateness, and effectiveness. Below, we elaborate on the most important findings.

Accessible

The WHO defines AFS accessibility as "adolescents *are able to* obtain the health services that are available" [6]. Participants shared their experiences on insurance/expenses, care location, and hours of operation.

Insurance/expenses

TB diagnosis and treatment in Peru are supposed to be free of charge for anyone enrolled in the public health insurance program, *Sistema Integral de Salud* (SIS) [14]. This program allows low-income people access to healthcare services [14]. However,

obtaining SIS was complicated for a few participants; they shared that the process was complex due to paperwork, long waiting periods, and complications when switching from different insurance programs. With that in mind, it could be challenging for patients to commence treatment when they need SIS. Even when patients had access to SIS, they often had to pay for a portion of their TB treatment because many public health centers that accepted SIS did not have adequate equipment for X-rays and other diagnostic tests. This lack of diagnostic resources caused adolescents and caregivers to visit private health centers to pay for these exams, which are required to start treatment and transition from the intensive phase to the continuation phase. Therefore, a family with economic barriers may have limited access to TB care.

> *When I quit treatment, I tried to come back [to receive treatment], but I was told to bring an X-ray so that I can continue the treatment. At the time, I had stopped working, and I could not afford to pay for an X-ray. My mother did not have money, and I did not know where to find the money. This was the reason why I quit treatment entirely.*
>
> - Adolescent female, 19 years old

> *I was struggling economically, but I still had to pay for the X-rays that they were asking for. I had a small amount of money because I have four children and currently my partner is the only person that works in my household. I had difficulties accessing SIS because previously I worked with a company that provided another insurance, which was blocking the access to apply for SIS. Eventually, I was able to obtain SIS for my daughter, but it was difficult because there was a lot of paperwork.*

- Mother of 10-year-old adolescent

Care location

Under SIS, participants could receive TB care only at their assigned public health center nearest to their primary residence. This requirement was particularly challenging for adolescents who lived between multiple households – for instance, if their parents were separated or if they worked or studied in other parts of the city. An adolescent participant who alternated living with his mother and his father shared:

Interviewer: After the first week you were living with your father you didn't go to the health center because there was no money [for bus fare]?

Participant: I would go, but not every day, one day yes, one day no, or one day yes, two days no.

Interviewer: Okay, and the days you didn't go [to the health center] was because there was no money?

Participant: Correct… But I would ask the [health center] lady if she could give my mom the medication so I can take it [at my mother's] home… The lady said no that it wasn't possible because it is against the health center's protocol, they cannot give anyone the medications to take at home.

- Adolescent male, 14 years old

Another participant shared that her family member was diagnosed with TB and started living in her household, but SIS prevented them from accessing treatment at the neighborhood center.

I tried to bring my nephew who also has TB but was living with my family, and he was denied services because his SIS was assigned to another location.

- Adolescent female, 19 years old

Hours of operation

Adolescents, caregivers, and healthcare providers explained that the TB treatment hours started in the early morning and ended in the early afternoon. These limited hours are a barrier for some patients, as they conflict with their other responsibilities. During the first two months of treatment, adolescents have more flexibility to attend DOT appointments, as they are required to be isolated at home and are prohibited from attending school [15]. After they are allowed to return to school, schedule conflicts make it challenging to attend appointments. One participant shared that he missed appointments during the morning because he prioritized taking exams. The health center did not allow him to pick up the medications or offer different appointment hours.

> *Interviewer: Was there any occasion in which you could not go to take the medication?*
>
> *Participant: Actually, yes, I was studying in the mornings and sometimes I had exams so it was not easy to go there personally to take my medication. There were even times when my mother also spoke with the healthcare staff, but she was not allowed to bring me the medication so that I could take it at home because they have to supervise each patient taking their medication at the health center.*

- Adolescent female, 19 years old

Some adolescents have job obligations that they must prioritize to support their family economically, but treatment appointments can create conflicts with work. In addition, caregivers often want to or are requested by healthcare providers to accompany

adolescents to treatment. The attendance of caregivers can further complicate scheduling appointments because caregivers would need to adjust their work schedules.

Interviewer: Did you ever have to miss work to accompany your child?

Participant: Yes, I did have to miss work or arrived late, so I had to explain to my coworkers that my daughter was undergoing treatment.

- Mother of 15-year-old adolescent

Some, but not all, health centers accommodated adolescents' schedules by allowing adolescents to take or pick up medications in the afternoon.

We explain to each patient that there are two schedules. The main schedule is in the morning from 8 am to 1 pm, but when we treat adolescent patients that are still in school, we offer an evening schedule. During the beginning stage of treatment when they can't go to school, they usually come in the morning.

- Female nurse, 48 years old

A few healthcare providers created the option of video-recording medication intake for adolescent patients who could not go to the health center regularly. This approach was only used in a few locations at the time of the study, but healthcare providers thought it can be a promising tool to address accessibility.

Sometimes there are these moments or times that adolescents have that make it impossible for them to go to the health center. We could help with the use of technology. We are also doing it in cases in which it is difficult for them to go [to the health center] for any reason. They send us a video.

- Female nurse, 48 years old

Equitable

In the AFS framework, equity is defined as "all adolescents, *not just some groups of adolescents*, are able to obtain the health services available" [6]. We were only able to obtain limited information on noncitizen access to TB services.

Noncitizens access

In Peru, citizens and noncitizens – including undocumented immigrants and refugees – can receive TB treatment free of charge through the NTP (Law 30287) [16]. However, to access TB treatment in Peru, most individuals, independent of citizenship status, sign up for SIS and undergo a diagnostic evaluation, which typically includes a chest X-ray and a sputum test, to determine whether the individual has active TB. If TB is detected, the individual will be referred to a healthcare facility for treatment.

> *The [diagnostic] sample is free. People or patients can go to any health facility, regardless of the area where you live, they can take their [sputum] sample. . . There is no problem. They can live in any zone [of the city], they can even be from another city, or from another country…*
>
> - Female nurse, 28 years old

As previously mentioned in the accessibility section, the ability to utilize SIS to obtain free TB care is good in theory. Still, in practice, some barriers can hinder treatment equity for adolescents. In our study, we were only able to recruit participants who were Peruvian citizens so there was limited information about the TB diagnosis and treatment experiences of adolescents who were undocumented immigrants or refugees.

Acceptable

In their AFS framework, the WHO defines acceptability as "adolescents *are willing* to obtain the health services that are available" [6]. The related topics that were emphasized by study participants were privacy, cleanliness, ventilation, and respect.

Privacy

Adolescents, caregivers, and healthcare providers all stated that some facilities did not provide private spaces for patients to wait or take their medications. As a result, some adolescents feared being stigmatized by friends and neighbors if they were seen receiving TB treatment.

> *Participant: I would prefer to go pick up medication and take them at home.*
>
> *Interviewer: Why does it make you uncomfortable to take them at the health center?*
>
> *Participant: Because I feel embarrassed, and there are also other people watching me.*
>
> *Interviewer: Were you afraid that someone recognized you?*
>
> *Participant: Yes.*
>
> - Adolescent male, 17 years old

> *I believe that there should be more private spaces when they [the adolescents] take their medication since someone they may know, such as neighbors or friends, can see them take their medications. Adolescents can be concerned about who is watching them.*
>
> - Mother of 16-year-old adolescent

At some health centers, adolescents had to walk through a specific door for TB patients, which caused strangers to become instantly aware of a patient's TB diagnosis. This layout meant that the adolescents did not have the privacy to withhold their TB diagnosis from others at the health center when attending their appointments.

> *There are two doors. They won't let you go through the main door because you can't go through there. And it's like they look down on you: if you have a mask, they don't let you pass through. When I got off the motorcycle with a mask, it's like everyone was looking at you and you feel the pressure. It feels like a distaste in your mouth, like being thrown out just because you have TB.*
>
> - Adolescent male, 14 years old

A healthcare provider also commented on the lack of privacy for patients in their facility:

> *You see my office. There is no privacy… they all enter through that one door. As it is small, everyone here can find out their TB diagnosis. Adolescents are sometimes scared that a classmate or someone they know is there and sees them.*
>
> - Female nurse, 38 years old

Cleanliness and ventilation

Participants mentioned that some health centers were unclean and/or lacked adequate ventilation. These environments can be discomforting and uninviting, especially since patients are visiting on a regular basis for their DOT appointments. Participants shared:

Interviewer: If you could improve care for adolescents, what changes would you make, what would you like to do?

Participant: The first thing I would do create a larger space, so there is more airflow and for it be cleaner at the health center.

- Adolescent male, 19 years old

I think that spaces for patients should be cleaner. The room was very dirty, and it did not appear to be an adequate atmosphere for the patients.

- Mother of 15-year-old adolescent

Respect

Adolescents do not want to feel like people are judging them when they are receiving care. They fear that healthcare providers may scold them or ask them uncomfortable questions [6]. They also feel nervous that healthcare providers and staff do not maintain confidentiality about their health issues [6]. For the most part, adolescents and caregivers in the study reported being appreciative of being treated with respect when attending treatment appointments.

Interviewer: What do you think of the TB care you received at the health center?

Participant: Oh, they seemed very friendly, very trustworthy. They are very kind. I really liked the care. I still remain in contact with the nurses even though I no longer I go as often.

- Adolescent female, 16 years old

Interviewer: How satisfied are you with the care your child received at the center?

Participant: Very happy because they knew how to work with my little girl.

Interviewer: How were you and your child treated by the health center?

Participant: Well, kindly. They were all respectful.

- Mother of 11-year-old adolescent

However, there were some exceptions in which health center staff disrespected adolescents, and this type of treatment could discourage adolescents from continuing their treatment. A caregiver shared that her daughter experienced discomfort when a healthcare provider was harassing her into going on a romantic date.

He says to her, 'When are we going out?' He wanted to ask her out, and then my daughter tells me, 'Oh, mom, he makes me nervous, he's bothering me, so I don't go to take my medication. I'm not going there anymore.'

- Mother of 13-year-old adolescent

In addition, when attending their appointments, some adolescents are being ignored in favor of older adults when they are waiting in line for their medications.

They [the health center personnel] are assisting older adults first even though some adolescents were waiting in line before them. Several adolescents are in a hurry to go to school. It is not fair for them to wait longer just because they are younger.

- Mother of 14-year-old adolescent

Appropriate

In the AFS framework, the WHO defines appropriateness as "the *right health services* (i.e., the ones they need) are provided to them" [6]. Participants emphasized the importance of psychological care, nutritional counseling, and treatment of substance abuse disorders for adolescents with TB.

Psychological care

As TB is associated with depression, psychological support for patients is important [9, 17]. Healthcare providers mentioned that adolescents diagnosed with TB are provided with an appointment with a psychologist.

> *All patients go through formal [psychological] evaluation as a requirement for admission [to the TB treatment program]. Everyone must have their psychological report, and, in summary, there are at least three evaluations during treatment: admission, at the end of the intensive phase, and discharge.*
>
> - Female nurse, 48 years old

Psychologists can help adolescents to manage and cope with the stress and anxiety associated with TB treatment.

> *Adolescents can benefit from having a psychologist to talk with them while they are continuing their treatment. This way, adolescent can also communicate with their parents if they are struggling. The psychologist can serve as an additional support for patients when they are doing through difficult times.*
>
> - Mother of 14-year-old adolescent

These psychologists can even help motivate adolescents to finish treatment.

The psychologist made my son feel better. [She told him], 'When you heal, you will have strength and you won't feel ill,' she told him […] That's when he understood [the importance of treatment]. He then started taking his medications until he finished the treatment.

- Mother of 10-year-old adolescent

Unfortunately, not every health center had psychological care available for adolescent TB patients.

Interviewer: What [health] services did you receive?

Participant: Nutrition. I did not receive psychological services. The psychology lady was never there, and they never told me a day or time to come.

Interviewer: Would you have liked to seen in [the] psychology [service]?

Participant: Yes.

- Adolescent female, 16 years old

There should be psychologists who can help them cope with this disease, so they know they are not going to die [as long as they] follow an adequate treatment, nutrition. With this help, they can have the strength within themselves.

- Mother of 18-year-old adolescent

Nutritional counseling

In Peru, there is a strong emphasis placed on nutrition and its role in TB pathogenesis and treatment [18, 19]. Some adolescent participants mentioned that having nutritional deficiency is the reason people fall ill with TB.

Interviewer: What do you think could help prevent adolescents from getting TB?

Participant: A good diet, eating at the right times, not neglecting themselves, not overloading themselves with emotions… oh and also to stop eating fast food.

- Adolescent female, 16 years old

Interviewer: How could this type of disease be prevented?

Participant: Having a good diet because honestly, I didn't eat, I ate very little, but I drank soda, I loved soda, to this day I drink soda… my defenses have been low and that is why I got TB, for not having a good diet

- Adolescent female, 19 years old

A portion of caregivers in the study also attribute adolescents' TB illness to poor nutritional status.

Interviewer: Why do you think you son fell with TB?

Participant: Because he did not want to eat. He did not eat well. That is why I would say he got this disease.

- Mother of 19-year-old adolescent

In Peru, because of the strong emphasis placed on the role of nutrition in TB pathogenesis, the nutritionist is perceived as a fundamental member of the TB treatment team. Nutritionists can help adolescents maintain a healthy diet, ensuring that they receive the necessary nutrients to support their physical health. An adolescent, who was overweight and at risk for diabetes, shared that he had nutritional challenges that were properly addressed with the help of a nutritionist during TB treatment.

They gave me a glucose test when I was weighing 86 kilos, and that's where they helped me. They took me to a nutritionist so they could teach me how to eat and all that. It was very helpful.

- Adolescent male, 19 years old

However, nutritional care was inconsistently provided to participants, as the availability of this service varied depending on the health center where the adolescent received care.

Interviewer: Did your son spend time with the nutritionist at the health center?

Participant: We never got to talk to one. Even now I still hope that (name of the adolescent) will talk to one.

- Mother of 18-year-old adolescent

Treatment of substance use disorders

Adolescents with TB and substance use disorders should receive care for this comorbidity since they may be at higher risk of loss to follow-up from TB treatment [9].

Most of those who quit treatment are influenced by addictions. When there is an adolescent patient with a history of addictions such as drug use and alcohol use, we know that they are going to become poorly adherent [to treatment]. In the first one or two weeks, they are adherent [to treatment] because we are working with them, but with time, and as they see that their health is improving, and the symptoms are going away, they start again with their addictions.

- Female nurse, 36 years old

A participant who was lost to follow-up shared his difficulties with substance use and TB treatment:

> *I thought a lot about drugs. I wanted to smoke, nothing else… I no longer wanted to take my medication, but now I feel very bad. I thought I was a big boss and now thanks to the lady from the health center, they are helping me. Now I will try to comply with my treatment so I can recover from this illness.*
>
> - Male adolescent, 17 years old

Some health centers psychologists provide support to adolescent patients with substance use disorders, but as previously discussed, access to these services is limited.

> *We have a psychologist sent by the Ministry of Health. He is the one who goes speaks with all the patients for the first time at the start of their treatment. And for the patients who have problems at home, [problems] with drugs, with alcohol, they go twice or three times a week, or once or twice a week.*
>
> - Female nurse, 41 years old

Healthcare providers have also tried to address challenges with these adolescents by going to their homes to check on their status and find ways to help them continue their treatment. However, visiting their homes is not enough to ensure that these types of patients receive proper care.

> *Remember when I told you about the beginning about a boy who passed away last year? We would go to his house when he was still 16 or 17 years old, and one day he was so under the influence that he threatened the doctor and me with a knife […] He would constantly quit his [TB] treatment.*
>
> - Male nurse technician, 42 years old

We are fighting, achieving, crying, but unfortunately, these patients are in the world of drugs, dysfunctional families, so there is no support. There is only the staff who went, who try to go to their homes to check on them.

- Female nurse, 31 years old

Effective

In the AFS framework, the WHO defines effectiveness as "the *right health services are provided in the right way and* make a positive contribution to their health*"* [6]. Components of effective care include emotional support and education about TB.

Emotional support

Adolescent TB patients benefit from having adequate emotional support throughout TB treatment, which is long and difficult [3, 20]. When a caregiver is engaged in the treatment journey, they can encourage adolescents during difficult periods. Healthcare providers play a key role by communicating with the caregivers about the importance of support at all stages of the adolescent's TB treatment.

We work with the parents because they are the ones that can influence the adolescent to continue their treatment by making sure that the adolescent feels well, and doesn't feel lonely, or upset about having TB

- Female nurse, 28 years old

Caregivers were appreciative of the healthcare providers' support as they felt more prepared and informed about the treatment.

Well, until now it went very well because they [healthcare providers] helped me, they supported me by telling me that my daughter should come to the health

center to take her medication […] I never had knowledge about the disease since none my family ever had it. They even helped me with my son and keeping track of how he was also feeling. I would sometimes even forget about the treatment, but they will continue to kindly remind me.

- Mother of 15-year-old adolescent

Healthcare providers can play a critical role in providing emotional when adolescents lack support from caregivers and other family members.

The adolescent patients with good adherence are the ones who have the support of their family. Because they are looking out for them, they bring them to take their medication, and the non-adherent adolescent patients do not have the support of their family. I had a patient who did not have the support of her mother. She yelled at her, hit her, did not give her support, demoralized her, said ugly things to her even in front of me, so how would she feel? Obviously, she would feel bad, so sometimes she came to cry, and sometimes she didn't want to continue taking her medication.

- Female nurse, 32 years old

They can also assess mental health and provide necessary emotional support or referrals to additional services at various timepoints throughout their treatment:

In the nursing department, when we do the initial treatment interview, we give our support when discussing their psychological needs. We do the follow-up because we usually see each patient every day so when we see certain traits of depression or anxiety, we try to schedule an appointment with a psychologist

- Female nurse, 36 years old

Adolescents in our study reported being more likely to adhere to their treatment regimen when they felt supported by their healthcare providers [9]. One innovative way providers supported adolescents was creating WhatsApp groups to engage with patients. An adolescent shared:

> *I always had nurses who were very supportive. They are looking out for you. They even created a WhatsApp group so that we can be in contact to remind me to take my medication or letting me know when the health center is about to close so I can go to my appointment on time. They also had meetings to inform us about specific things like discussing mental health among patients with TB. They were planning on developing a way to create more of these meetings, so patients do not feel alone. I truly feel very satisfied with the support, and I am thankful for them.*

- Adolescent male, 19 years old

Education about TB

Participants emphasized the importance of improving public awareness about TB. Increasing public awareness could encourage people with TB symptoms to seek testing and diagnosis in a timely manner. In relation to adolescents specifically, participants recommended holding workshops at schools or in at-risk communities to discuss TB symptoms, prevention, and testing.

> *I think they should give talks at the schools, but there should also have assembly for parents so they can properly explain to them about the disease.*

- Mother of 10-year-old adolescent

I think that there should be workshops at schools so they would be more informed about TB. They could learn that it can happen to them or a family member but that it is curable.

- Adolescent female, 15 years old

A caregiver shared that the schools were already have workshops to discuss sexual education so introducing information about TB would be an effective way to address this knowledge gap, but the workshops need to be dynamic.

Workshops need to be dynamic to comprehend TB effectively. Schools are already having workshops for adolescents regarding sexual education by bringing experts in the topic. They could do similar things to educate them about TB.

- Mother of 18-year-old adolescent

Educational workshops on TB not only could help increase awareness about TB symptoms and diagnosis but also help people become more understanding and less judgmental of people with TB, potentially leading to less stigma. School staff and teachers could also benefit from these workshops to learn to provide appropriate social and educational support for adolescents in TB treatment. Some adolescents have faced discrimination at school due to their TB diagnosis, and such training, particularly education about the rapid cessation of transmissibility after effective treatment initiation, may reduce TB-related stigma. An adolescent shared:

My dad went to tell my teacher that I had tuberculosis, and the teacher didn't take it well. She said, 'No, he has to be apart from everyone. He doesn't need to be in my classroom, and if he has that [TB], then he needs come back fully healed.' The

teacher also said, '... He has to be apart in another room or at home, because he can't be here there are several students who have poor health.' And I was like, 'Ah, okay.' I grabbed my backpack and left. I just left. I didn't say anything. The director also told me we're going to send me messages or something like that, they were supposed to send me my homework, but I never received anything. They never sent me anything

- Adolescent male, 16 years old

Overall, it is important that schools are aware that adolescents with TB have rights and that they should not be discriminated against.

When there are new cases in national schools, everyone is surprised, they think that the patient with tuberculosis should be excluded, that they should be taken out for that school year, they don't offer much help. I personally go to try to talk to the director or the head director and explain that there is a TB law that includes patient's rights

- Female Nurse, 36 years old

In summary, collaboration between health centers and schools is crucial to enhance community awareness about TB, reduce TB-related stigma, and optimize adolescent engagement in TB care while continuing classes.

Table 1: Barriers and facilitators of adolescent-friendly TB services according to the World Health Organization's framework on adolescent-friendly care

Dimension of care	Definition	Facilitators	Barriers	Suggestions for improvement from adolescents, caregivers, healthcare providers
Accessible	"Adolescents *are able to* obtain the health services that are available"	-Health centers are close to patients' homes -Treatment is free of charge for patients with SIS	-Limited service hours -Difficult to receive TB treatment in any other location, which is challenging when patients travel, move, or study/work in a different part of the city -Chest radiographs are not always free of charge -Acquiring SIS, the public health insurance, can be challenging	-Utilizing technology for medication intake such as video DOT -More flexible service hours available -Provide health centers with functioning X-ray machines
Equitable	"All adolescents, *not just some groups of adolescents*, are able to obtain the health services available"	-Treatment available for any patient regardless of citizenship or other legal status	-Challenging process to obtain SIS, the public health insurance, which is needed to access free treatment -Restriction of health centers based on location of residence	-No relevant suggestions provided by participants
Acceptable	"Adolescents *are willing* to obtain the health services that are available"	-Most healthcare providers show respect towards adolescent patients	-Lack of privacy at health centers, leading to inadvertent disclosure of adolescents' TB status -Poor ventilation at health centers -Unclean treatment spaces	-Making sure that health centers have adequate spaces for adolescent patients that are clean, well ventilated, and private
Appropriate	"The *right health services* (i.e., the ones they need) are provided to them"	-Psychology and nutritional services are, in theory, part of the package of care for all TB patients	-Due to staffing shortage, not all adolescents are evaluated by psychologists and/or nutritionists	-Investing in providing psychological and nutritional support for all adolescent patients -Detecting and treating substance use disorders
Effective	"The *right health services are provided in the right way and* make a positive contribution to their health"	-Most healthcare providers are able to establish trust with adolescents and thus support them through treatment	-There is a lack of public understanding about TB leading to TB-related stigma and discrimination	-Implementing innovative workshops at schools for teacher, staff, and students to expand knowledge of TB and reduce TB-related stigma and discrimination

Abbreviations: DOT, directly observed therapy; SIS, *Sistema Integral de Salud* (Integrated Health System, the public health insurance for low-income people); TB, tuberculosis; WHO, World Health Organization.

DISCUSSION

In this study, we examined adolescent TB services in Lima, Peru using the AFS dimensions of care framework. Significant barriers to adolescent TB care included limited TB treatment hours, lack of functioning X-ray machines, staffing shortage of psychologists and nutritionists, and inadequate social or educational support at school for adolescents on TB treatment. On the other hand, key facilitators included that most of the TB care is free of charge, health centers are near patients' homes, and the majority of adolescents receive strong emotional support from healthcare providers.

Creating more patient-centered care options is crucial to delivering adolescent-friendly TB services [21]. Patient-centered care consist of providing care that is responsive, respectful, and inclusive of a patient's preferences or needs to guide them through clinical decisions [21]. This approach is also one of the pillars for the End TB Strategy developed by the WHO to treat TB globally [21]. Currently, in-person DOT is the standard of care in Peru. In-person DOT requires adolescents to attend their appointments at their designated health center to receive their medications. While a systematic review and meta-analysis on TB treatment adherence shoed that DOT results in significantly better outcomes than self-administered therapy (SAT) [22], alternatives such as video directly observed therapy (VDOT) were also appropriate approaches for treatment delivery [22]. In our study, one healthcare provider mentioned using VDOT to assist patients with difficulty attending in-person appointments. However, VDOT is still not formally implemented in the country. This treatment alternative can address various barriers adolescents have accessing TB services, including limited service hours and scheduling conflicts. A pilot study using VDOT for TB in Uganda found that it was a feasible tool that resulted in high levels of adherence [23]. Another study in Cambodia found that the use of VDOT is

promising and effective [24]. These treatment options can appeal to adolescents as they are more likely to be technologically literate than other age groups and promote privacy when accessing TB care, as they can sometimes fear judgement from others when seeking care at health establishments.

In addition, nutritional and psychological assistance are essential components of a patient-centered approach to TB care [21]. Psychological support for adolescents with TB is particularly important given that mental illness is a leading cause of morbidity and mortality among this age group [9, 20]. Moreover, a study in Ethiopia with a psychological counseling intervention for patients with TB showcased a significant impact on treatment adherence [25]. A study on nutritional education for patients with TB found that nutritional awareness had a fundamental role in the diagnosis, management, and recovery from TB [26]. This nutritional assistance can benefit patients with TB as it can promote healthy diets and address malnutrition during treatment. Participants in our study who had access to nutritionists and psychologists expressed their gratification for having these resources during treatment. Unfortunately, this was not the case for many participants, as there is a shortage of these services for patients with TB in Lima. Giving adolescents several patient-centered options can result in positive treatment outcomes and satisfaction during their TB treatment [21].

Integrating TB education into schools could improve adolescent-friendly TB services in Peru by limiting the barriers to care. Schools play a critical role in adolescents' ability to complete TB treatment while continuing their education. When adolescents are diagnosed with TB, they are at risk of experiencing discrimination and stigma, which may negatively impact treatment adherence and lead to academic difficulties [20]. This negative impact is due to

adolescents experiencing judgment from individuals at their schools, causing them to skip school and/or avoid continuing their treatment [20]. In Peru, a large portion of the discrimination and stigma stems from the lack of understanding of TB from other students and staff. Education about TB through schools can potentially address knowledge gaps and decrease TB-related stigma. Multiple studies have found that school-based educational initiatives have been effective in reducing stigma and discrimination and increasing knowledge about TB. A study in South Africa about engaging adolescents in TB through drama provided an innovative way to educate adolescents about TB in school settings to address TB-related stigma [27]. The study reported that the theatrical educational production motivated awareness about TB among adolescents [27]. Similarly, another TB education program for adolescents in Malaysia found that a school-based program was an effective intervention to increase knowledge and decrease TB-related stigma [28]. Utilizing similar methods to educate both students and staff could serve as a useful approach to increase knowledge about TB in Lima. This idea aligns with the suggestions where participants shared the benefit of creating TB workshops at school, ultimately raising awareness and dispelling misconceptions about TB.

LIMITATIONS

The limitations of this study include that the interview guide was not developed to inquire solely about adolescent-friendly treatment but rather focused on facilitators and barriers to treatment adherence. This interview guide did not specifically query the impact of identity (e.g., sexual orientation, citizenship status) on TB care; thus, the study produced limited data in relation to equity.

CONCLUSION

The WHO AFS framework can be a useful tool to examine TB services for adolescents as it addresses their specific needs. NTPs may consider conducting this type of analysis in their setting to ensure suitable and inclusive services for adolescents with TB and to improve treatment outcomes.

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