“we need to fight for them”

Determinants of TPT uptake and completion amongst caregivers of child contacts across three high TB burden countries: A qualitative sub-study

Jeniffer Nagudi, Lonze Ndelwa, Lindiwe Tsope, Samson Wilson, Resignation Pelusa, Fezeka Mboniswa, Thobani Ntshiqa, Manthomeng Matete, Juli Switala, Kavindhran Velen, Salome Charalambous, Rachel Mukora

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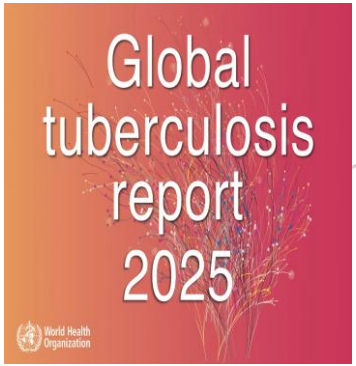
Background

Global TB disease burden among children and young adults in 2024

- 1.2 million TB incident cases
- 172,000 TB-caused deaths



TB preventive treatment among children and young adults contacts of TB patients

- Child contacts at higher risk of developing TB compared to adult contacts
- TPT uptake at 25% in 2024 among all contacts; far from the 90% target by 2027
- TPT uptake and completion is dependent on adult caregivers

CUT-TB Trial

- We assessed caregivers' perspectives on TPT as part of a large cluster randomised pragmatic CUT-TB trial
- CUT-TB Trial: Community and Universal Testing for TB among contacts of TB patients
- Trial Objective: Measure the effectiveness of universal testing compared to standard TB screening for TB detection in Lesotho and Tanzania and for TPT initiation for South Africa

CUTTB

Study Aim & methods

- **Aim**: To understand the caregivers' (parents and legal guardians) experiences of caring for children on TPT

Study design: Cross-sectional descriptive qualitative study nested within the CUT-TB study.

Study Period: November 2023 - November 2024.

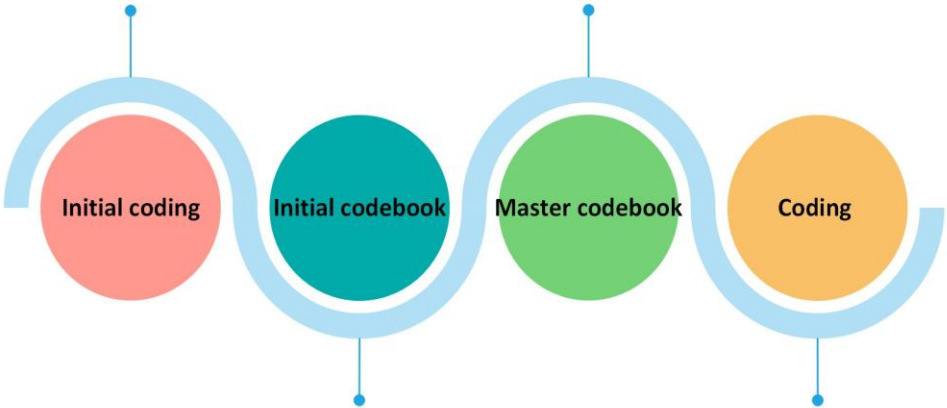
Study Population: Purposively sampled caregivers (parents and legal guardians) of children referred for TPT enrolled in the CUT-TB trial.
Total of 45 caregivers, i.e. 15 caregivers from each of the 3 countries

Mode: Face to face semi-structured in-depth interviews (IDIs).
IDIs guides were informed by the Consolidated Framework for Implementation Research(CFIR) and Health Stigma and Discrimination Framework.

Data Analysis

❖ Analysis plan

- One indepedent coder from each of the countries coded 10% of the transcripts
- All the 3 coders developed a single master codebook



- Each of the 3 coders compiled an initial codebook from coded transcripts
- Remaining transcripts were coded using the master codebook

❖ Analysis framework

Consolidated Framework for Implementation Research(CFIR)

❖ Analysis approach

Deductive and inductive thematic analysis

❖ Themes

1. Outcomes of TB testing
2. Barriers and motivators of TPT initiation and completion
3. Stigma marking
4. Drivers and facilitators of stigma
5. Impact of TB at individual, interpersonal and community level

Findings - Demographics

Variable	Overall N (%)	South Africa (n= 15)	Lesotho (n= 15)	Tanzania (n= 15)
Gender				
Male	7 (16%)	1 (7%)	3 (20%)	3 (20%)
Female	38 (84%)	14 (93%)	12 (80%)	12 (80%)
Age				
Median (IQR)	39 (31 – 53)	48 (31 – 56)	49 (33 – 57)	35 (30 – 45)
18 – 24	2 (4%)	1 (7%)	0 (0%)	1 (7%)
25 – 44	21 (47%)	6 (40%)	5 (33%)	10 (67%)
45 – 64	16 (36%)	7 (47%)	7 (47%)	4 (27%)
≥ 65	4 (9%)	1 (7%)	3 (20%)	0 (0%)

*IQR: Interquartile range

Findings

- Understanding the importance of TPT encouraged caregivers to start their children on TPT

"…I started hearing about it at the clinic that there's TPT. I didn't even know that there is something that we can take to be **protected** but when they said there is a pill that we'll take to be **protected from TB** and then I was happy …at the end maybe if my husband gets better it'll come to me or to the kid but when they said there's a treatment to **prevent** that and then I was happy about that".

South Africa, Female, 32 years

"I know that my son is given those medicines so that he cannot be **infected** with TB(….) I felt better just so that we could give him tuberculosis preventive treatment".

Tanzania, Female

Findings

- High value placed on children's health, encouragement from facility staff and absence of side effects were motivators to TPT initiation and completion

"Take the treatment yes, because the sad part about it is that there are small children, and life is on these young children and those who are still growing. So, **we need to fight for them**, so that they can live".

South Africa, Female, 54 years

"The way the **clinic encourages** and encourage us the way they treated us the way you walked with us this journey… Thank you that you made us to have **power**, you made us to have **strength**, you made us to have **knowledge**"

South Africa, Female, 48 years

I am really happy because it prevented him from being sick with TB. Also, since he **never experienced any side effects**, he remained **normal**, like any other child, that means TB preventive treatment is beneficial.

Lesotho, Female, 34 years

Findings

- The method of sample collection was identified as a challenge to TB testing

"I wasn't aware that she would feel the **pain**. I thought maybe they will do the way they have checked me through coughing, but for her they took 30 minutes while the child was crying, I didn't know that".

South Africa, Female, 48 years

"I find TB testing procedure for children very **difficult** and **uncomfortable** for them".

Lesotho, Female, 52 years

Findings

- Distance to and long hours at the facility and treatment formulation were identified as barriers to TPT

"…xxx facility is too **far** and I have to travel by foot to get there. I have to travel past the plateau and through the valley. By the time I have to travel back home, it is late and I have to sleep over in another village before I can complete my journey back home. I wish they could bring the pills **closer** to us.

Lesotho, Female, 33years

"Because of these **pills** that make us not to be in good terms with my child…If there is syrup the syrup is better".

South Africa, Female, 31years

Findings

- TB testing and being on TPT led to caregivers and their children being discriminated against

"People who knew assumed that this child… [clears throat] I don't know but it was like they assumed she was **sick**…whenever they felt like there was something… they would just come and **fetch their children**. There were those who did not like when their children are with mine.

Lesotho, Female, 57 years

" …even the child in the next room was **afraid** to sit next to my son …When he was sitting next to them and they told him "you have TB, you will infect us, just leave" (in a harsh tone)

Tanzania, Female

Conclusion

- Communities need to be educated on TB and TPT. Knowledge of TB and TPT and lack thereof were pivotal on whether the child was started on TPT and whether caregivers and their children experienced stigma.
- Clear explanations and motivation from health care workers on TPT and its importance were vital in caregivers' decisions to start and keep their children on TPT.
- Non-invasive sample collection for TB testing among children needs to be explored.
- Further research on child-friendly TPT regimens is necessitated.

Programmatic/ Policy implications

- Providing comprehensive information on TPT to caregivers of child contacts prior to TPT initiation should be provided.
- Briefing caregivers on the TB testing procedures, before sample collection, should be a priority.
- Countries should prioritise the introduction and scale-up of child-friendly TPT formulations.

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