

Conflict of Interest

The author has declared no conflict of interest.

Understanding the challenges faced by children, adolescents and their care-givers during the treatment journey for drug-resistant tuberculosis: Qualitative study, Mumbai, India



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Background

Children with drug-resistant TB (DR-TB): Global estimates (annual)
~25,000-32,000, of whom **21% probably die.**

Mumbai, India = High proportion DR-TB; >50% population live in urban slums

MSF in Mumbai provides free of charge treatment and care to patients with DR-TB in MSF clinic and government hospital (in collaboration with National TB Programme).



Rationale

Treatment outcomes of children and adolescents are known, but **gap in knowledge persists for children and adolescents' needs and experiences during DR-TB treatment.**

AIM

To better understand patient, guardian and healthcare provider perspectives on the DR-TB treatment journey of patients and caregivers.

Methods

Study design

A qualitative study involving **in-depth-interviews of purposively selected participants**

Study setting: MSF Clinic, Mumbai

- Outpatient, free treatment and care by multidisciplinary team
- **‘Care buddy’**: One family member (mother or father) provides support and monitors adherence
- Directly-observed-treatment at home initially for three months by outreach nurses, later by care buddy
- Training for dose modification (or drug compounding)
- Tailor-made counselling tools
- A self-administered checklist (daily doses) for monitoring adherence



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Methods

Study population and participants:

- Adolescents (n=6; >1yr DR-TB treatment or cured)
- Guardians of children and adolescents; n=5
- Healthcare providers including programme managers; n=8



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Data management

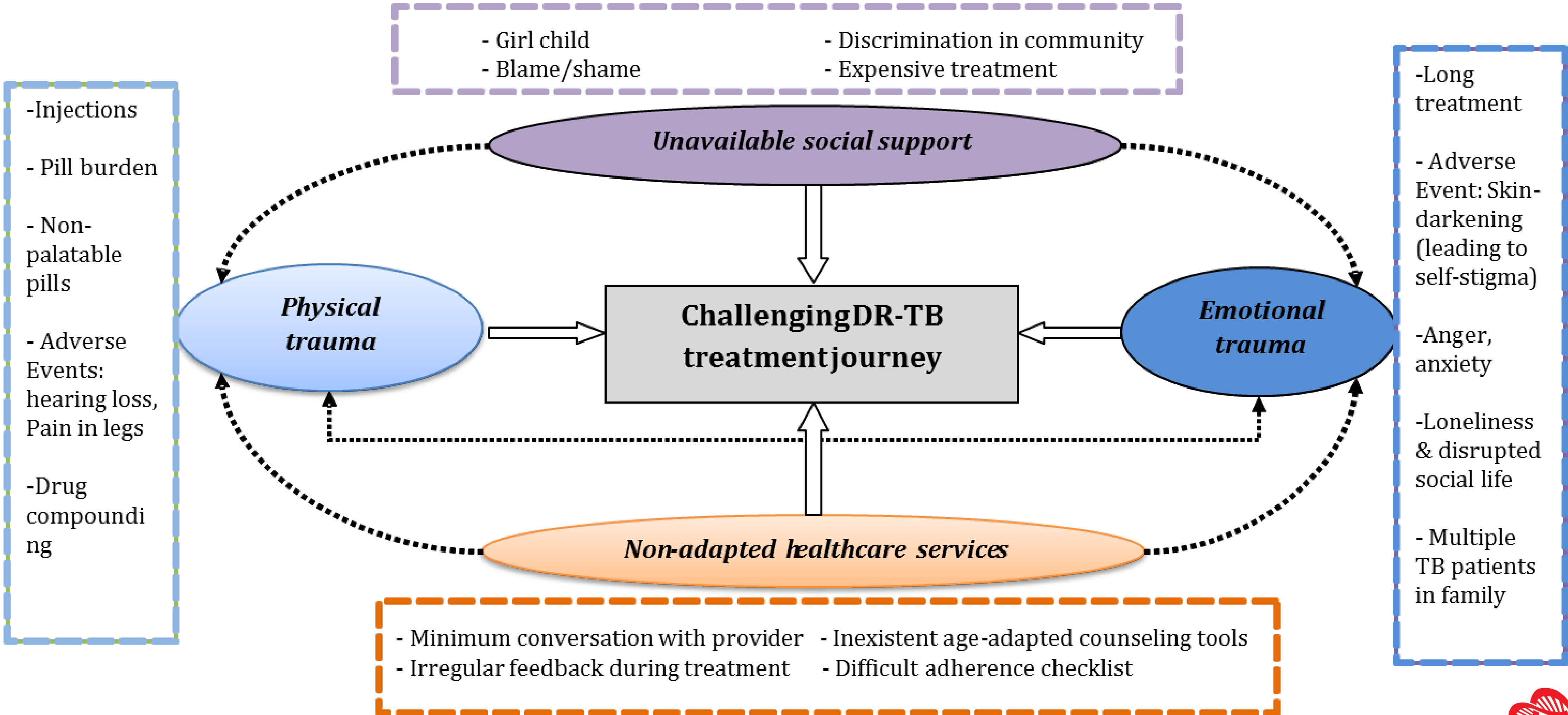
Open-ended interview guides, in English or Hindi (local language); September-November 2019

Thematic network analysis

We obtained **ethics approval** from the MSF ERB and IRB of Tata Institute of Social Sciences, Mumbai, India

Results

Overarching theme and sub-themes:



Affect on LIFE due to illness:



2

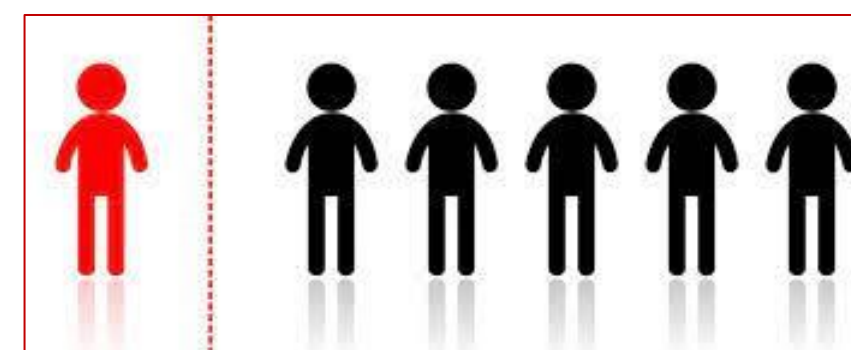
Home isolation



Missed meeting with peers

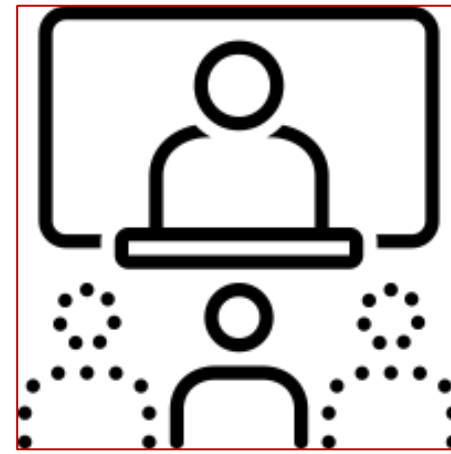


Sports/physical activity are difficult



Stigma

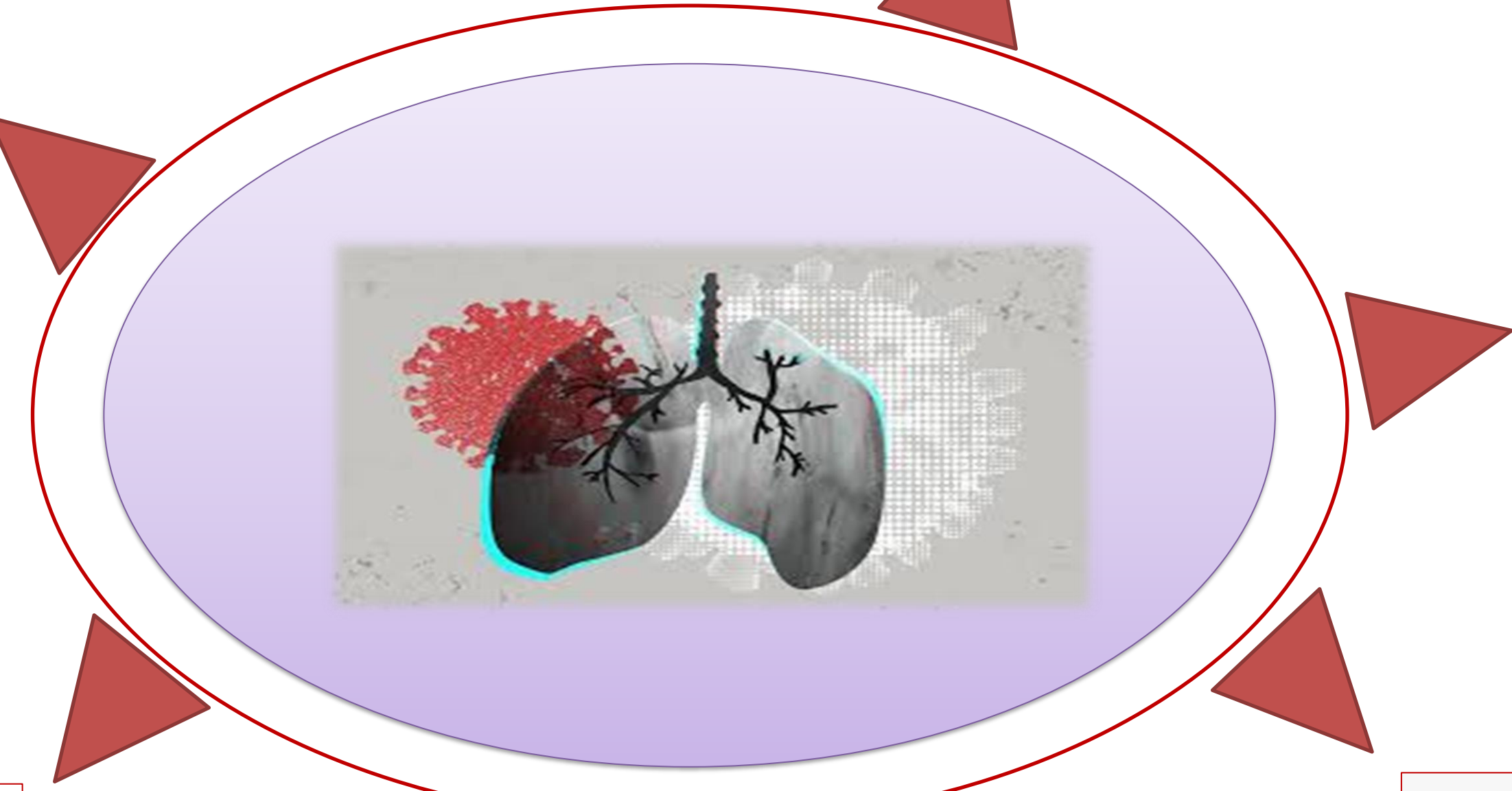
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School/college absence



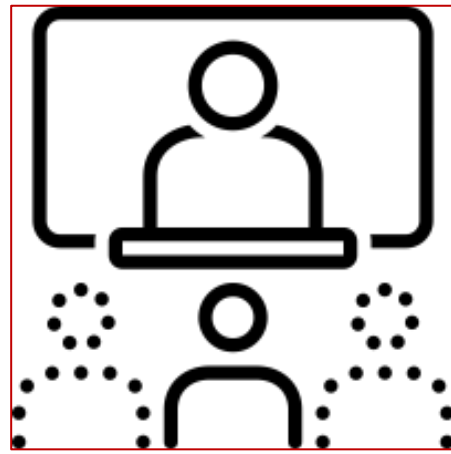
Plans for future?



Affect on LIFE due to illness:



Home isolation



School/college absence



3

Missed meeting with peers

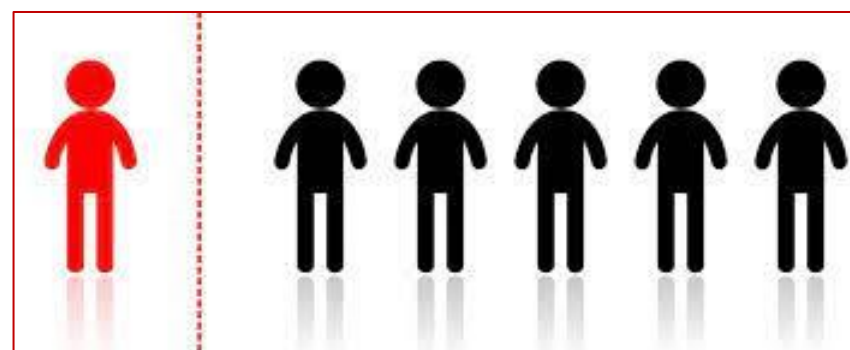


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Sports/physical activity are difficult



Plans for future?

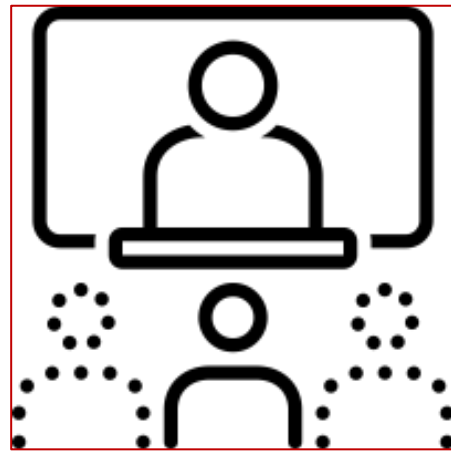


Stigma

Affect on LIFE due to illness:



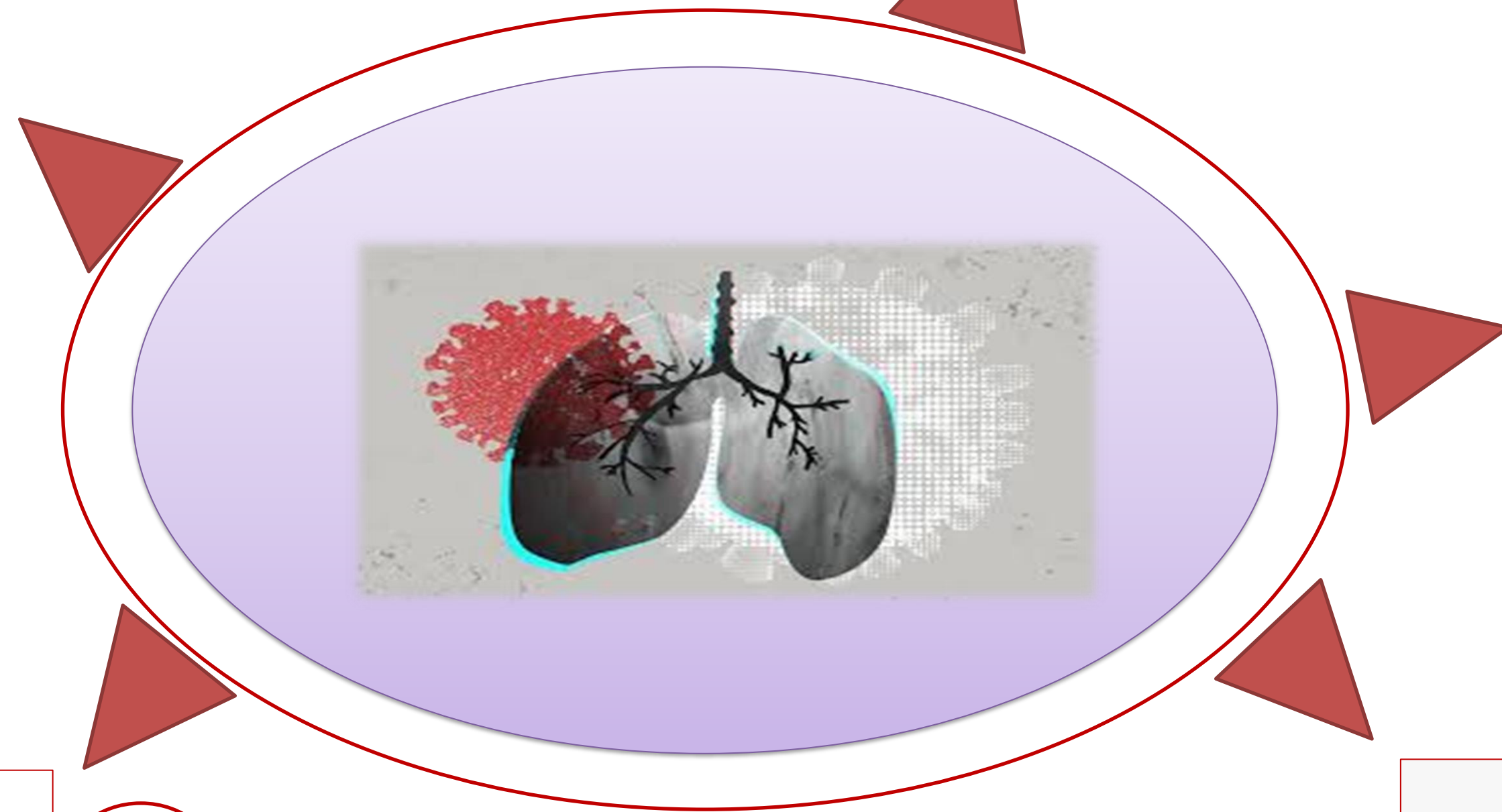
Home isolation



School/college absence



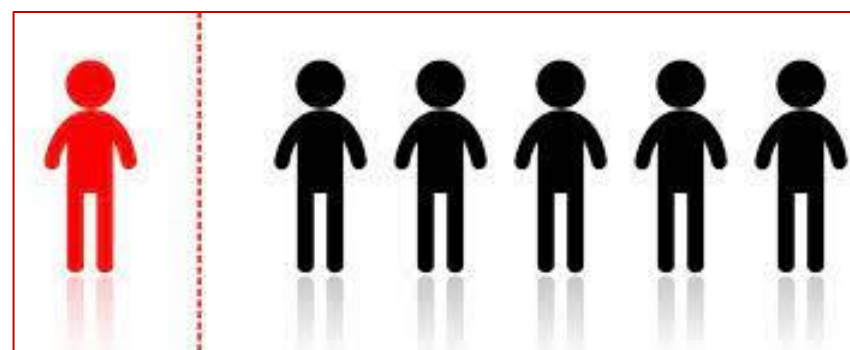
Missed meeting with peers



Sports/physical activity are difficult

5

Stigma



6

Plans for future?



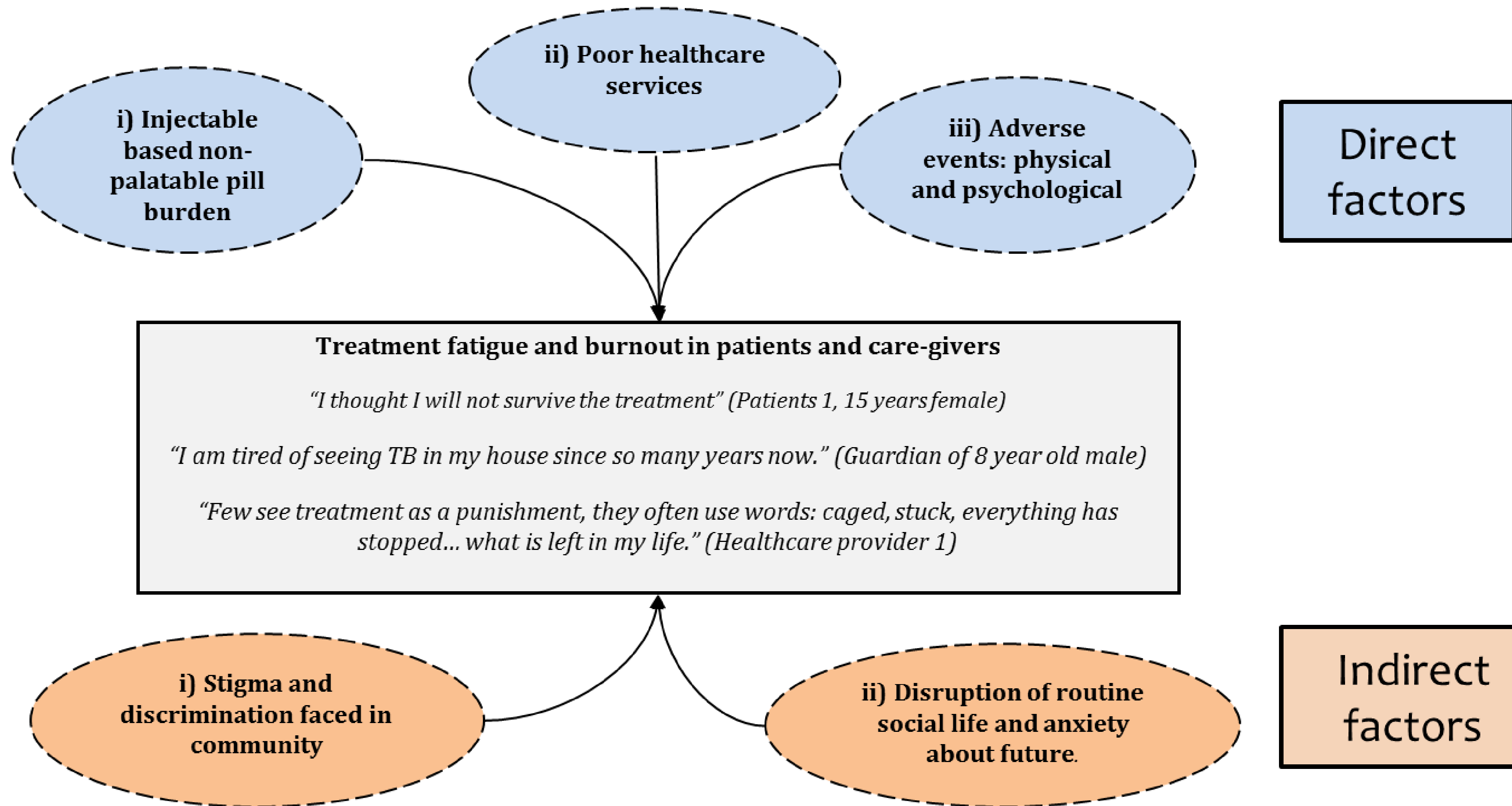
Patient and Family: One unit

- Family and peer support: Cornerstone of treatment continuation.
- Decision regarding treatment (regimen or provider) depends heavily on the family/caregiver of the patient.
- Adherence issues/treatment interruptions common in adolescents.

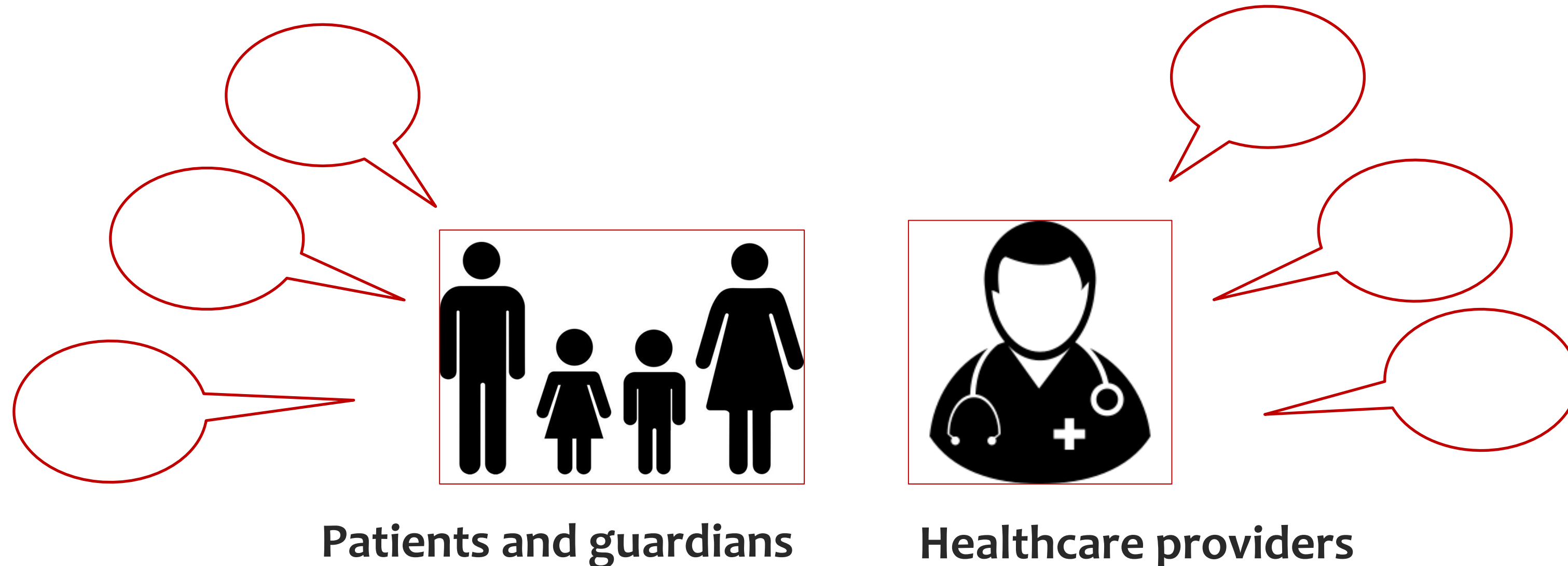


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Treatment fatigue and Burnout



Recommendations by participants



Recommendations for developing child/adolescent-friendly care

- Injectable-free regimen; palatable medications
- Interaction with providers
- peer-support platforms (separate for children and adolescents)
- Patient-friendly counselling and adherence tools
- Improved TB awareness in families, schools and communities

Limitations

Sampling was not wide enough to explore in-depth differences between groups that could impact the overall TB experience (single parent vs joint family households; single or married; HIV co-infection; access to newer vs older drug regimens)

Conclusions

DR-TB Treatment is challenging for patients and caregivers.

Therefore,

- Consider 'Patient and family as one unit' for packages of care
- Tailored socio-psychological approach along with medical care
- Develop patient friendly services – diagnosis, treatment & care



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Current initiatives in our project

Paediatric DR-TB package

- Dedicated paediatric day
- Age-appropriate counselling tools
- Child-friendly space
- Cartoon-based treatment calendars



Photo © MSF



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For adolescents

- Adolescent peer-support group meetings
- One-to-one interactions for motivation/adherence

Beyond our capacity...

1. Injectable free, paediatric formulations for DR-TB drugs (in guidelines but lacks implementation on ground)
2. Child-friendly packaging of paediatric TB drugs (cartoon blister pack)
3. Inter-department collaborations of National TB programmes with maternal and child health, adolescent, and nutritional programmes
4. Refresher trainings (clinical and soft-skills) for healthcare workers



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Acknowledgements



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