



"I WOULD CRY ALL THE TIME": THE INDIRECT YET COMPLEX IMPACT OF LIVING IN A HOUSEHOLD AFFECTED BY TB ON CHILDREN IN CAPE TOWN

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BACKGROUND

- TB is well-known social disease, inextricable linked with poverty
- TB affects the poorest in society but can also cause further poverty due to loss of income and illness related expenses
- WHO End TB Strategy and UN High Level Meeting on TB stressed the need to address the social determinants of TB
- TB impacts households and children beyond the diagnosed individual.
- Our previous study found that TB places a significant burden on the household.

BACKGROUND

- Caring for people with TB was reported to affect physical and mental health, increase financial stress and conflict in the household, and affect children. (Vanleeuw et al., 2024)
- Few studies have investigated the indirect impact of TB in the household on children, and none by listening to the children themselves.
- Our study aimed to address this gap by exploring children's experiences of living in a TB-affected household.

METHODOLOGY

Study Design: Exploratory qualitative study

Participants:

- 17 Children from 9 households in Langa, Cape Town, South Africa.
- Age: 8-17 years during TB episode, 10-20 years during interview.
- Household members with TB: Mother (7), Aunt (6), Grandfather (1), Uncle (3)
- Jan – March 2023

DATA COLLECTION TECHNIQUES

River of Life drawing

- Children illustrated their life experience, including the TB episode

Qualitative interviews

- In-depth interviews with all 17 children, guided by the River of Life drawing

RIVER OF LIFE EXERCISE

- Children received a blank sheet of paper and colouring pencils.
- They were prompted to envision their life as a river.
- “If your life was a river, what shape would it take, and what significant events mark its different turns and bends?”
- Children drew significant life events and their emotions along the River of Life, and labeled them with the corresponding years or age



DATA ANALYSIS



All data was analyzed using Graneheim et al's (2004) content analysis methods.



Transcripts translated into English and cross-checked for accuracy.



Field notes captured contextual details and emerging themes.



Validation of coding:
Initial coding conducted by 2 researchers, followed by comparison and consensus-building.



Ongoing iterative process: Analysis still underway for remaining data

RESULTS

TB as a traumatic event:

- While the impact varied, having a household member with TB was a significant traumatic event for most children.

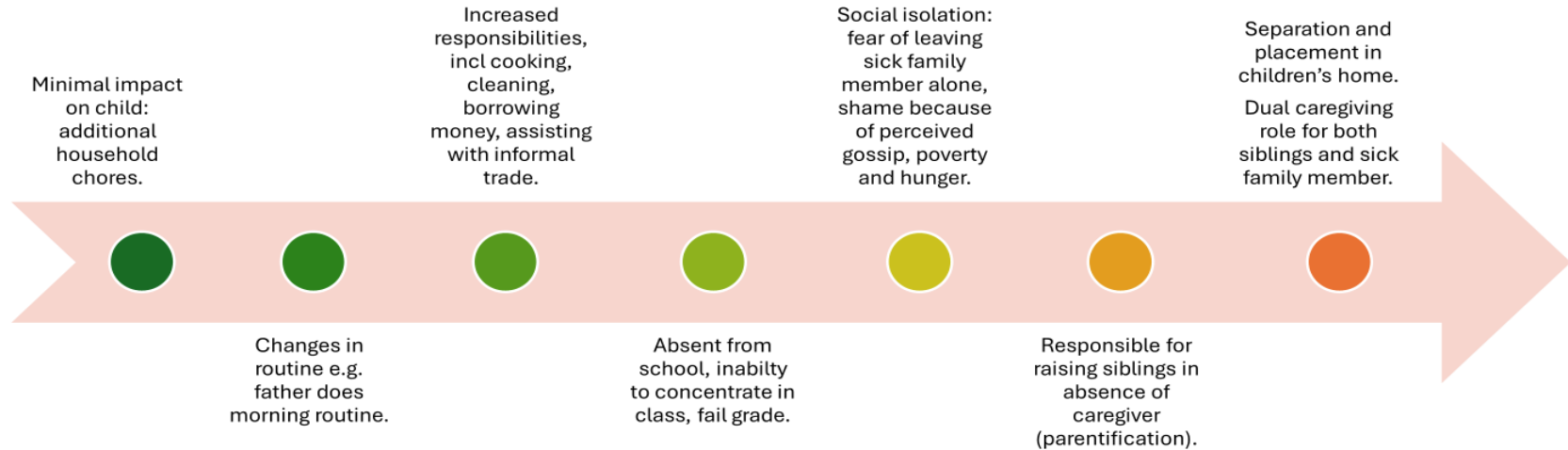
Pre-existing challenges:

- The impact of TB was compounded by pre-existing household challenges, leading to increased vulnerability.
- e.g., absence or neglect by a caregiver, parentification, trauma, substance abuse, poverty, food insecurity.

Children experienced:

- Separation from primary caregivers; relocation and displacement; increased household responsibilities and parentification; disruptions in schooling.

Wide range of impact on the child



RESULTS

Psychological effects:

- Children exhibited significant signs of psychological impact, including anxiety, depression, and trauma responses.

Identified risk/protective factors:

- Household stability
- severity of the illness
- presence of a caregiver
- prior or simultaneous non-TB-related trauma
- level of food insecurity
- level of support

Main protective factor:

- The presence of a surrogate caregiver, such as a grandparent or older sibling, provided a strong protective effect.

IDENTIFIED RISK/PROTECTIVE FACTORS



PROTECTIVE FACTORS

- Less severe illness: sick but still up and about
- Sick household member is e.g. aunt, uncle
- **Presence of caregiver e.g. mother or surrogate caregiver e.g. older sibling, grandparent**
- Child remains in the family home
- Stable home (consistent presence of caregiver, no major conflict)
- Levels of support from family, neighbours, friends, school, social workers
- Food security and coverage of basic resources (clothing)



RISK FACTORS

- Severe illness e.g. bedridden
- Caregiver illness e.g. mother
- **Absence of caregiver or surrogate caregiver**
- Separation and/or placement of children
- Prior or simultaneous traumatic experiences such as neglect, hunger, parentification, conflict and/or dysfunction in the home
- Lack of support from family, neighbours, social workers
- Food insecurity & poverty



IMPLICATIONS OF THE STUDY

Psychosocial impact:

- The presence of TB in households significantly affects children's emotional health and family dynamics, even if they themselves have not been infected with the disease, resulting from heightened financial and social stress.

Stress reduction measures:

- To mitigate this impact and reduce stress levels, we emphasize the importance of maintaining household systems, providing additional support at all levels, and offering emotional care.

Integration of support services:

- Integrating psychosocial support services directed at the whole household, not just the PWTB, into TB programs is crucial. This integration can alleviate stress and enhance coping mechanisms among affected children and families.

Research gap:

- Further investigation is needed to explore the long-term effects of living in a household with TB for children, including their emotional well-being and social development.

CONCLUSION

- The diagnosis of TB in a household member is profoundly traumatic for children.
- TB exacerbates pre-existing household challenges and amplifies children's vulnerability.
- Household stability, the presence of (surrogate) caregivers, and robust support systems mitigate the impact of TB on children.
- Ongoing research is needed to explore the diverse factors influencing the indirect impact of TB on children.
- Addressing the impact of TB on children requires a multifaceted approach, including stress reduction measures and integrated support services at both individual and household levels.

ACKNOWLEDGEMENTS

Thank you for your attention to our study on the psychosocial impact of TB on children and families.

For any inquiries or further information, please feel free to reach out to Lieve Vanleeuw at lieve.Vanleeuw@gmail.com

We extend our sincere gratitude to the children and parents that participated in the study, the SAMRC and Tampere University, and Tampere TB Foundation for their invaluable support throughout this research endeavor.

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