

“I don’t trust anybody else”-The lived experiences of primary caregivers of children with pediatric TB in a Cape Town Hospital

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Introduction

- Primary caregivers facilitate Tuberculosis (TB) care after the child has been discharged from the health facility
- Early TB diagnosis in children at a primary health facility improves the TB prognosis
- The treatment that they experience in the health facility by frontline health care workers will illicit more trust between the community and clinical staff
- There is less research on the day-to-day experience of primary caregivers of pediatric TB compared to the child’s biomedical progress

Aims and objectives

Our specific objectives are:

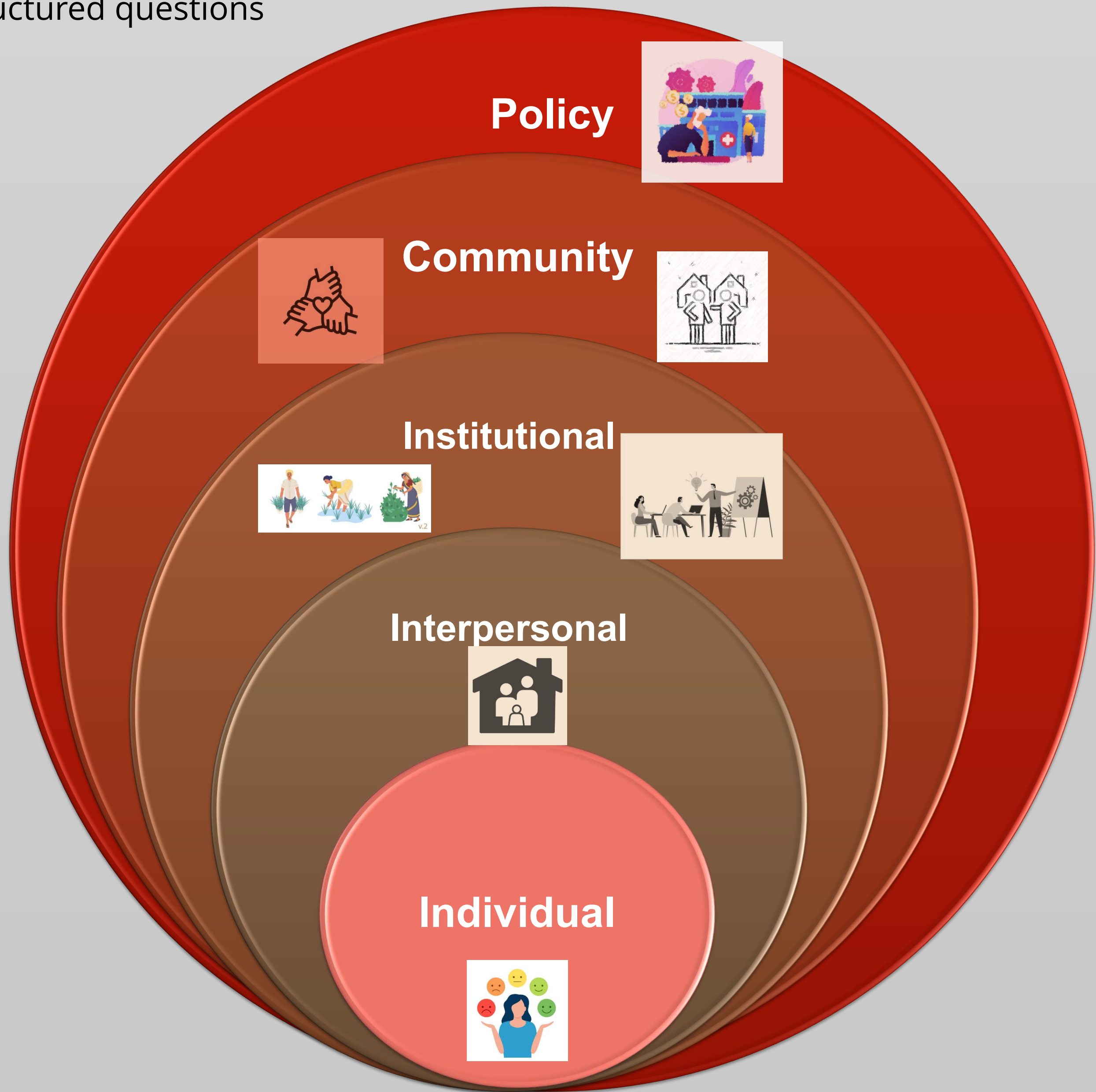
- To describe the daily lived experiences of primary caregivers of children with TB
- To explore interpersonal interactions between caregivers and the healthcare workers at the health facilities that they visit including the research unit.

Demographics of Participants

Participant #	Age of Caregiver	Marital status	# of children	Employment status	Education level	Number of visits to the research unit	Treatment duration of the child at interview date
1	27	Domestic partnership	2	Unemployed	Grade 10	5 th	6-month post treatment visit
2	29	Single	3	Employed full time	Grade 10	2 nd	1 month of medication
3	33	Partnered but living apart	1	Part time	Grade 12 (matriculated)	3 rd	6-months of medication
4	32	Domestic partnership	4	Unemployed	Grade 7	3 rd	3 months of medication - end of treatment
5	28	Married	3	Unemployed	Grade 12	3 rd	3 months of medication - end of treatment
6	44	Married	3	Employed	Grade 11	3 rd	3 months of medication - end of treatment
7	55	Single (partner abandoned home)	3	Part time work	Grade 6	2 nd	1 month of medication
8	47	Single	2	Employed	Grade 12 (matriculated)	4 th	6-month of medication
9	33	Domestic partnership	3	Employed	Grade 12 (Matriculated)	2 ND	1 month of medication
10	31	Partnered living apart	3	Employed	Grade 11	2 nd	1 month of medication
11	36	Married	3	Employed	Grade 9	2 nd	1 month of medication
12	34	Partnered living apart	3	Unemployed	Grade 12	5 th	6-month post treatment

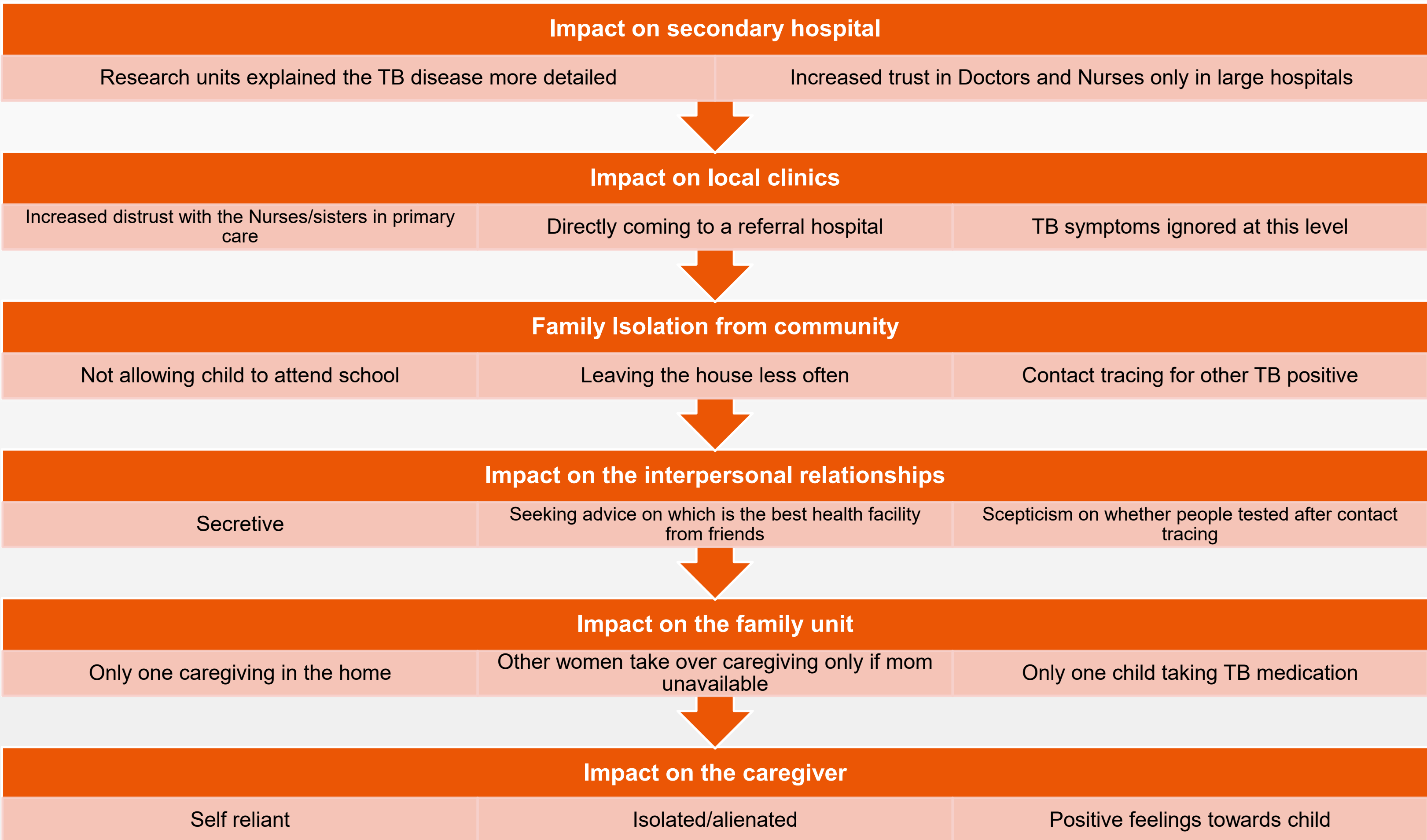
Methodology

- Qualitative study was conducted at Red Cross Children’s Memorial Hospital where mothers were interviewed right after an appointment with a research doctor
- By using inductive thematic analysis, I created the predominant themes and subthemes to understand the lived experienced of these caregivers
- Participant were de-identified by assigning each interview a number
- The 12 participants participated in in-depth face-to-face interviews that had semi structured questions



Results

- I) Self inflicted social alienation
- II) High stress induced by sickly child
- III) Absenteeism from work and school
- IV) High levels of trust in Red Cross Hospital
- V) Low trust in Primary Care facility



Subthemes and Quotes

Internal turmoil

I was asking myself, like, what did I do? What did, what did my child do? –P.1

Sole Burden of care

‘I don’t have help from no family, not even his father, no one helps me. So, I need to stand man alone for my kids.’ P.2

“Because my child is my responsibility” P.8

Job insecurity

‘So they couldn’t, justify firing me, because of the sickness, well they know it’s wrong. So they always, like stretching for something. So I said, no, no, no, don’t do this. It’s fine, I can quit.’ P.3

Varied healthcare worker interactions

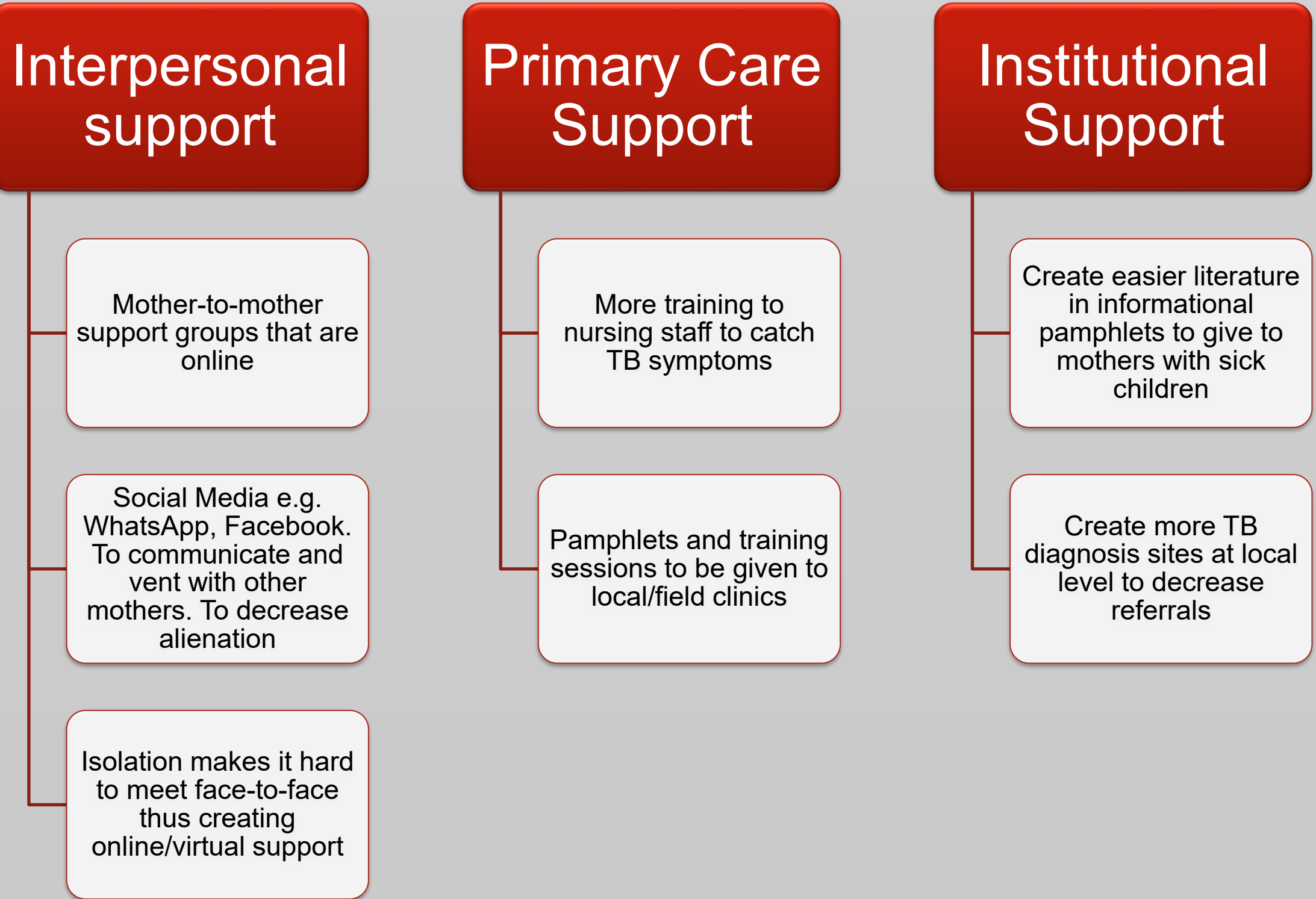
It’s not perfect, but it’s like, I’m okay doing this. P5

He [Dr] shouted at me on me P3

Conclusions

- Mothers fear ask for Hospital referral letter to go to a secondary health facility, or they bypass this letter and go themselves in desperation. They experience aggression with healthcare workers when they do not have a referral letter even when the child needs to be admitted
- Mothers become secretive and private about their lives whilst their child is on medication
- Absenteeism for mom at work can lead to job loss or workplace strife similarly the child misses school due to extended illness
- The mother Isolates herself and family from peers and family while child is taking medication

Implications



Acknowledgements

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