



## Accelerating progress to end TB

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INSIGHT STUDY - Uncovering insights into the lived experiences of caregivers of children suffering from drug-resistant tuberculosis

**R Gaida**, M Williams, S Nyathie, N Mshweshwe, L Ramangoaela, R Matji and A Williams

[raziagaida@gmail.com](mailto:raziagaida@gmail.com)

**For more information, please contact:**

**T:** +27 (0) 87 821 1109, **E:** [info@tbconference.co.za](mailto:info@tbconference.co.za) / [registration@tbconference.co.za](mailto:registration@tbconference.co.za)

## BACKGROUND AND OBJECTIVES

- With paediatric drug-resistant tuberculosis (DR-TB), children and caregivers take the journey together.
- The emotional response to diagnosis, hospital admission and adverse effects of medication may impact the wellbeing of the caregiver, thus affecting the outcome of the child.
- South African policy favours decentralised care, meaning that most children are treated at home with the caregiver as the daily carer.
- The study aimed to explore the experiences of caregivers of children being treated for DR-TB at a high-burden facility in Nelson Mandela Bay, Eastern Cape.

## METHOD

- Qualitative design – one on one in depth interviews with caregivers.
- Purposively selected participants from the cohort of children who were being treated at the selected facility at the time of the study – caregivers who attended clinic visits were asked to participate.
- Written consent was obtained from all participants.
- Interviews were transcribed for analysis
- Ethics approval was obtained from Nelson Mandela University (H21-ENG-CCT-001) and the Eastern Cape Department of Health (EC\_202110\_014).

# RESULTS

27 interviews  
were  
conducted

| Theme                                                                                                                                            | Sub-themes                                                                                                                                                                                                                                                                              |
|--------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Participants describe their experiences with their child and the healthcare system and their experiences of caring for a child with DR-TB</b> | <ul style="list-style-type: none"><li>- Reactions when child is diagnosed with DR-TB and continual clinic visits</li><li>- Emotions due to child being hospitalised</li><li>- Challenges with side effects of DR-TB medication and nutritional deficits</li><li>- Social care</li></ul> |
| <b>Participants' suggestions for improvement in systemic assistance during the DR-TB journey with a child</b>                                    | <ul style="list-style-type: none"><li>- More information about TB and children is needed</li><li>- Financial challenges and effects on treatment, care and support for child and family</li><li>- Support systems</li></ul>                                                             |

# RESULTS

| Participants describe their experiences with their child and the healthcare system and their experiences of caring for a child with DR-TB                         | Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                           |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Reaction when the child was diagnosed with DR-TB – varying reactions (sadness, stress, anger, guilt, fear)                                                        | <p>P15: <i>'I was angry with my sisters because both of them are stubborn and neither one of them wanted to go for treatment.'</i></p> <p>P9: <i>'So, we also blame ourselves, the signs had been there, but we did not take serious...'</i></p> <p>P12: <i>'It's sad when a child is sick.'</i></p> <p>P4: <i>'I was stressed about – yhuuu! – how is my baby going to be treated here...'</i></p>                                                                                                                                                                              |
| Emotions due to the child being hospitalised – feelings of guilt, separation anxiety, physical impact, inability to visit due to cost                             | <p>P4: <i>'yho it was really painful...I was crying in the bus until I arrived home...the worst thing is that he was breastfeeding at the time...'</i></p> <p>P6: <i>'And then I come in then one day I asked the doctor if I can take my child home I will do everything in my powers...because I can't sleep...'</i></p> <p>P9: <i>'it is far, we informed her that we won't be able to visit her regularly.'</i></p> <p>P11: <i>'It was difficult [to leave], I have to lie and say I'm coming back. Then call the hospital and speak to her and she would be upset.'</i></p> |
| Challenges with nutritional deficit and side effects of DR-TB medication – food insecurity, getting the child to take the medication and managing adverse effects | <p>P2: <i>'sometime there is, somethings to eat, sometimes there's not something to eat...'</i></p> <p>P6: <i>'At the beginning he reacted and vomited the pills...later he developed a rash on the face and complained of an itchy body.'</i></p>                                                                                                                                                                                                                                                                                                                               |
| Social care – big need for social grants and financial support, interactions with social workers, unavailable legal documents for children                        | <p>P1: <i>'The other children are my daughter's kids and <b>does not even have an ID.</b>'</i></p> <p>P4: <i>'But sometimes we receive milk and pap from the social workers...'</i></p> <p>P7: <i>'<b>No there are no food parcels that we are receiving, we are try our best to survive</b>'.</i></p> <p>P5: <i>'I haven't seen the social worker...I tried...but she was busy...'</i></p>                                                                                                                                                                                      |

# RESULTS

| Participants' suggestions for improvement in systemic assistance during the DR-TB journey with a child                                                                                                                              | Quotes                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                          |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| More information about TB and children is needed – limited knowledge of caregivers about the disease, expressed a desire for more information                                                                                       | <p>P4: <i>'I can hear that my child has XDR however I do not know what type and do not have much information about it.'</i></p> <p>P8: <i>'The doctor informed me that it is RR...I am not knowledgeable on which one is RR...'</i></p> <p>P9: <i>'Not that much [information], they emphasised that it can be treated...'</i></p>                                                                                                                                                                                                                                                                                                                              |
| Diverse challenges and its effect on treatment, care and support for child and family –experiences with stigma, transport to the clinic for follow up appointments, waiting time at the clinic, preparation to attend clinic visits | <p>P1: <i>'there are a lot of people taking TB treatment...really the judgement and gossip around TB has become less',</i></p> <p>P15: <i>'There was some people in our street that wanted to kept their children away from him although they knew he was on treatment.'</i></p> <p>P1: <i>'It is better to endure and wait for the transport that we are given by the government...we really can't afford it [to travel at own expense].'</i></p> <p>P1: <i>'it works on your mind, because you need to have lunch, sweets and drinks for the children...[for a day at the clinic]'</i></p> <p>P7: <i>'I don't manage every time, I don't have money.'</i></p> |
| Support systems – varying levels of emotional and financial support from family and communities, many were isolated                                                                                                                 | <p>P2: <i>'Some of them are far [relatives], and those in the same street don't support.'</i></p> <p>P3: <i>'It was said to be MDR, I had to sit alone...[family would not come near her].'</i></p> <p>P8: <i>'I am alone...no support.'</i></p> <p>P14: <i>'she [sister] helped me, even the time I got sick, she was the one taking care of me...'</i></p> <p>P16: <i>'it's just this child support grant I receive so, what must I do at the end of the day then its finished here...sometimes I don't have anything to eat even...'</i></p>                                                                                                                 |

# CONCLUSIONS

- Separation during hospitalisation was emotionally challenging – resulting in physical manifestations.
- Caregivers were not necessarily aware of how long their child would be admitted – recommend establishing in-person or virtual support groups.
- **Social challenges** such as the lack of finances, food insecurity, little support from family and communities and stigma towards ill children – recommend community-based programmes to educate the public about DR-TB to reduce stigma and improve access to social workers for social grants.
- Social grants are available but sometimes inaccessible – recommend reconsidering the value of child grants, provision of food packs based on the child's nutritional requirements, and decentralised provision of Home Affairs and Social Development services to make grants more accessible.
- **Information** needed about transmission, types of TB and treatment – recommend developing caregiver-specific literature to provide more information about DR-TB and the journey.