Clinical paediatric tuberculosis research: Field experiences from Cape Town, South Africa

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Implementing research in low- and middle-income countries (LMICs) involves multiple operational and socioeconomic challenges. In order to make global health research equitable, it is essential to overcome these challenges and implement research where the burden lies. We describe cultural, socioeconomic, recruitment and retention challenges experienced in our paediatric research in South Africa. We found that additional strategies and resources were required to address the specific cultural and socioeconomic aspects in order to conduct high-quality research in our facility.

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In 2021, tuberculosis (TB) was the second leading infectious disease after COVID-19[1] with an estimated 1.2 million children and young adolescents developing TB and 14% of TB-related deaths occurring in children.

The COVID-19 pandemic negatively affected milestones to end TB and urgent action is needed to undo the impact of the pandemic.[1] The pandemic has also led to increased awareness about the decolonisation of global health research.[1,2] Socioeconomic challenges, including community safety, poverty and cultural factors make implementing research in low- and middle-income countries (LMICs) challenging, further exacerbated by the disparities caused by the COVID-19 pandemic.[2] Despite the high disease burden, paediatric TB research has received low priority and inadequate funding. The World Health Organization (WHO) has reported a funding gap of USD15 billion.[1]

Understanding the complexities of research in LMICs is important to make global health research more equitable. We aimed to describe challenges experienced in paediatric TB research in Cape Town, South Africa (SA). Specifically, we describe (*i*) the socioeconomic contexts from which many potential participants are recruited, and (*ii*) study staff's attempts to operationalise recruitment/retention strategies, including challenges experienced.

Methods

Overview of the prospective observational cohort

The *Umoya* study is a prospective observational cohort study focused on TB diagnostics, following children with presumptive TB from diagnosis through to their long-term outcomes.[3] Through informal discussions with the study team, led by a socio-behavioural scientist, several themes relating to the challenges experienced were identified, including socioeconomic, cultural and COVID-19 pandemic-related challenges.

Socioeconomic context

SA is a country of contrast, with the highest GINI coefficient indicating extreme inequalities within the population. An estimated 90% of the population is dependent on the public healthcare system. Approximately 18 million (47%) South Africans receive a social grant and 20% depend on social grants as their main source of income.[4] Despite the availability of social grants, ~28% of South Africans live below the poverty line.[4,5]

The present study was conducted at Tygerberg Hospital located in the Cape Metropolitan District (CMD), Western Cape Province, SA. Many communities in CMD exhibit high levels of poverty, unemployment, overcrowding and drug abuse.[5]

Household structure and TB transmission risks

Households in SA are generally more fluid, meaning they consist not only of biological relatives but also of friends and extended families.[6] Grandmothers are often seen as the caregivers of children in low-income, multigenerational households. In many households, only one family member works to support the whole family. Most families live in informal settlements without access to safe water, proper sanitation and formal housing. These households are almost always overcrowded, which is strongly associated with the risk of transmission of infectious diseases, such as TB and COVID-19 .[7]

Cultural context

Communities in SA follow varying religions and cultural belief systems. The use of rituals is a common phenomenon in most communities. Cultural beliefs play a role in how a child or adult will gain entry to health services as well as adhere to treatment. Sometimes, more value is found in the cultural explanation of illness rather than in the perspective offered by health professionals.[8] An example from our study was a child who presented with kwashiorkor at the hospital and the mother believed his distended abdomen was because the child was visited by a 'snake' and that was why the child looked so fat (oedematous).

COVID-19 pandemic

SA initially had one of the most stringent lockdowns and all non-essential research was paused. Research resumed towards the end of 2020, with additional challenges of staff being anxious about getting infected, significant delays in vaccine availability and the need to procure additional personal protective equipment, which was more expensive owing to high demands. Furthermore, COVID-19 and TB have overlapping symptoms and a positive COVID-19 test, especially in the early phase of the pandemic, often resulted in deferring of TB work-up.[1] The COVID-19 pandemic and lockdown further exacerbated financial challenges owing to loss of work, reduced working hours and salary cuts.[9]

Aspects of interest

The process of recruitment and retention of participants can be challenging for research teams owing to the underlying socioeconomic challenges, household dynamics and cultural beliefs.

Recruitment

Recruitment is challenging because of issues around cultural beliefs, explanation of illness, language barriers and the necessity of legal guardianship for the consent process, which is essential to protect the safety and rights of individuals. Consent for a study involving children needs to be obtained from the legal guardian (assent). In our setting, grandmothers are often primary caregivers; however, they do not hold legal guardianship owing to the challenges of obtaining documentation. Consenting is a long process which entails a verbal explanation of the study, partially because of illiteracy.[10] Furthermore, because SA has 11 official languages and in Cape Town, with three main languages (Afrikaans, English and isiXhosa), multiple counsellors are required to ensure assent in the guardian's home language.[10]

Retention/follow-up

Retention and follow-up in our study face challenges owing to financial instability, competing priorities and safety concerns. In certain areas of Cape Town, transporting participants can be dangerous, especially during community or taxi strikes, which impede access to study visits. Further, identifying homes is difficult in informal settlements with no formal street names and a lack of visible house numbers.[10] Also, migration of caregivers to other provinces to care for children or attend family events leads to extended absences, resulting in missed study visits and disruptions to TB care.[10] Lastly, participant reimbursement for time and travel is a sensitive balance,[6,8] especially in LMICs where payment may mean another meal on the table.

Conclusion

To conduct research in LMICs, understanding and adapting to cultural and socioeconomic aspects is crucial. Additional resources, such as multiple counsellors for language support and drivers for home visits to improve retention and follow-up, are needed. Fig. 1 describes the challenges specific to our setting and suggested solutions.

Ending TB requires investment in research and innovative approaches. The high burden of TB in LMICs underscores the need for relevant research in order to create a sustainable research environment and improve the health of the most vulnerable populations.

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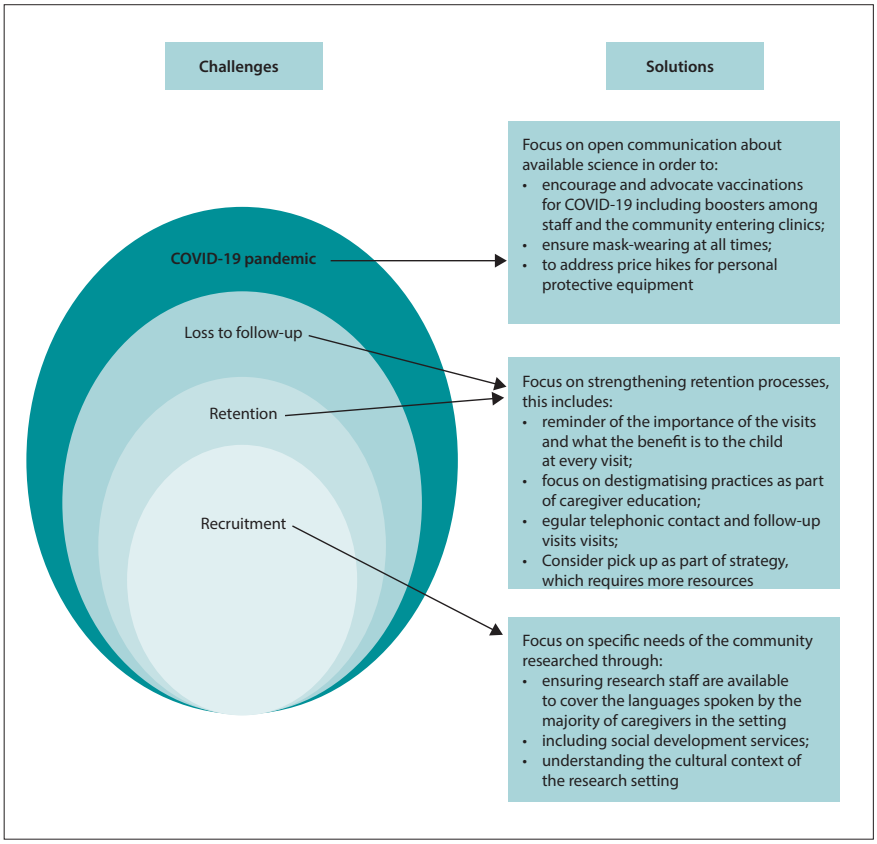

Fig. 1 Summary of the research challenges experienced when conducting clinical research

and supervised the writing process. All authors participated in the *Umoya* study, contributed to the content of the article and approved the final version.

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Conflicts of interest. None.

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