Reviewer's report

Title: Assessing the impact of multidrug-resistant tuberculosis in children: An exploratory qualitative study

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Reviewer: Jennifer Furin

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Major compulsory revisions:

This is an interesting and informative paper on a very important topic about which there is no other information in the published academic literature. Drug-resistant forms of TB are a growing problem throughout the world, and recent estimates suggest that as many as 33,000 children become sick with the disease annually. While there has been a large body of data published about the experiences of adults with DR-TB, and a few publications about the experiences of adolescents, this will be the first paper on the topic of treatment experiences among children with DR-TB. As such, it is a seminal piece of work and would clearly add to the growing literature on DR-TB in children. The paper, however, needs multiple modifications and significant editing in order to maximize its impact and ensure that the data and conclusions are presented in a way that is clear to others working in the field.

On a whole, the paper is far too long and is in need of significant editing. Furthermore, the categories of results presented in the manuscript are confusing and the structure of the results section has them reading like a seemingly random list, with no linkages or ties to one another. Thus, it is easy for the reader to get “lost” in all the information that is presented, both in the results and in the conclusions sections. In addition, there are some statements made in the results and conclusion section that are not back up with the quotes and stories presented by the authors. A significant amount of editing is needed to make this paper ready for publication. Furthermore, the lack of organization in the results section seems to overlook trends and linkages in some of the categories presented. Although I have not seen the primary data myself and hesitate to comment on how the authors should interpret their rich and textured volume of research, it seems that there are three overarching themes that unify the data presented in this paper, with multiple sub-categories within these three major themes. Recognizing that the data presented may not give me the full picture, I would suggest the results be organized in the following larger categories and subthemes:

1) Experiences with the actual treatment itself. The subthemes here could be a) problems with pills and medications; 2) the academic impact of the length of the regimen and hospitalization requiring the child to miss school; and 3) the financial impact of the long and difficult treatment process of the child. The way I interpret the data here is that the current therapy for DR-TB in children has too many pills
and injections with difficult side effects. In addition is prolonged and often requires hospitalization, thus impacting the child’s academic and the family’s financial potential.

2) Relationship with self. The subthemes here could be a) self-perceptions; b) shame/stigma; and c) disclosure. Disclosure could also serve as a bridging theme, with the third category listed below, which is:

3) Relationships with others. The subthemes could include: a) relationship with family; b) psychological impact of the family; and c) the mitigating effect of social support.

The authors do not have to adopt this framework if they do not feel it reflects the data they collected. However, they need to provide some sort of framework in which their results can be presented, as the way it reads now there appears to be no discernible pattern to the “laundry list” of findings.

There are also major problems with the conclusions, and this section is also too long. The discussion and conclusion need to be presented in a cleaner and more concise fashion. Overall, I think the conclusions are trying to say three things. First, that the current treatment regimen in terms of its length and complexity makes it difficult for children to complete treatment and affects them academically and financially. Although there appear to be no long lasting effects in the younger children, they, like adults would benefit from a shorter, more manageable treatment regimen. I would be curious to hear how the authors think children would fare in the setting of the new drugs and regimens being developed for DR-TB, especially since they are left out of most of the clinical trials. Second, the data seems to suggest there is a real need for psychosocial support of the children in order to mitigate the potential negative effects of stigma/shame and help them manage disclosure. Finally, the need for improved psychosocial support to families/caregivers is also apparent from the data, especially give the data on the importance of social support. Again, the authors may wish to come to their own more pointed conclusions. As it stands now, however, the section does little to leave the reader with a sense of what the implications of the data presented are.

There are other sections in the paper in need of sharp editing. The introduction could really be cut down to 3 paragraphs, with a presentation on MDR-TB, the problems with the regimen, and the experiences of adults; a section on the psychosocial impact of TB and other chronic disease in children, and a final paragraph noting that this is the first paper to describe the experiences of the children and the potential implications of such data. The paragraph under “Background” needs to be moved to the introduction and incorporated into the paragraphs mentioned above.

The section on settings should mention the rise of MDRTB in South Africa and describe the situation for children there. South Africa is actually one of the few places where there is a good description of DR-TB in children, and some information on this should be presented in the setting section. The data collection, data analysis, and ethical considerations could all be edited to 1 paragraph each. Given the breadth of all the suggested edits, I have not made
more specific comments on the paper.

I am recommending extensive edits to this paper prior to it being suitable for consideration. This review, however, should not discourage the paper’s authors. There is a wealth of information here on an extremely important topic, which has not yet been reported in the medical literature. If the authors are able to address some of the issues described above, I have no doubt that this work will set a precedent and make a valuable contribution to the literature describing the hardships of children with DR-TB and making recommendations on how such children and their families can be better served.

**Level of interest:** An article of importance in its field

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**

I declare that I have no competing interests.