

Author's response to reviews

Title: Success with antiretroviral treatment for children in Kigali, Rwanda:
Experience with health center/nurse-based care

Authors:

Johan van Griensven (jvgrie@yahoo.com)
Ludwig De Naeyer (interact-ta@terramail.rw)
Jeanine Uwera (jnine06@yahoo.fr)
Anita Asimwe (anitaa@tracrwanda.org)
Claire Gazille (clairugema@yahoo.fr)
Tony Reid (tony.reid@brussels.msf.org)

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Author's response to reviews: see over

Dr Melissa Norton, MD
Editor-in-Chief
BMC Pediatrics

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Dear Editor,

RE: MS: 1121892766193108 - Success with antiretroviral treatment for children in Kigali, Rwanda: Experience with health center/nurse-based care

Thank you very much indeed for your letter and the comments of the reviewers on the above mentioned manuscript.

We have now revised the paper in line with the reviewers' comments. Please find following for your kind consideration:

- 1) A "point by point" response to the comments and suggestions of the reviewers (Editor letter **MS: 1121892766193108coverR1.doc**)
- 2) A new revised version of the manuscript marked R1 (**MS: 1121892766193108R1.doc**)

While hoping that these changes would be satisfactory, we remain open to further suggestions and comments.

Yours Sincerely,

Johan van Griensven
Médecins sans Frontières (MSF)
6089, Kigali, Rwanda

Tel: (250)08597623
Fax: (250) 510993
E-mail: jvgrie@yahoo.com

POINT BY POINT RESPONSE TO THE EDITORS AND REVIEWERS COMMENTS AND

SUGGESTIONS

Manuscript Ref. MS: 1121892766193108

RE: Success with antiretroviral treatment for children in Kigali, Rwanda: Experience with health center/nurse-based care

RESPONSE TO THE EDITORS COMMENTS

Thank you very much for your comments. In light of the same, we have made the following amendments to the paper.

RESPONSE TO REVIEWER 1

Thank you very much for reviewing this paper and for your detailed comments and suggestions.

We have tried to revise the manuscript in line with your suggestions and comments. The specific changes and response to the different points raised include:

1. "using nurses"

We agree this word choice was indeed unfortunate and have rephrased this throughout the manuscript with "nurse-centered" or nurse-based".

2. "Disclosure"

The confusion probably relates to the specific context of HIV and children. Testing is usually done in the presence of a/the parent(s). A positive result can thus result in the parent "disclosing" his/her status. In addition, at the beginning of the program, there was a tendency not to inform the child of the "positive" result after testing. Thus, at a later stage, the status had to be disclosed or revealed. We verified literature on the use of the word "disclosure" in this context, which is in line with the use in this manuscript.

3. Nurse staffing in the health center

For most part, the physician was permanently available and as such could be consulted at any time. We also think this has been an important factor and have emphasized the need of a careful skill mix of nurses and physicians (Discussion, page 20).

We have added some information on the type nurse training in Rwanda and the type of nurses mostly employed in the program (Methods, page 7).

4. "scored"

The reason we wanted to specify this is that the FDC used in the program were originally produced for adult use; scored tablets can

easily be split for pediatric use, and allow more exact dosing for children.

5. "Transportation costs"

- This has been phrased more clearly (Methods, page 14)

6. Kaplan-Meier curve

- This has been added (Figure 3)

7. This has been corrected (Methods, page 16).

8. "grade 2 and 3 with grade 3"

- This has been rephrased (Results, page 18).

9. The legend of Table 2 has been corrected. We have also simplified the table. Some of the data can be found in Figure 3. Those already provided in the text have been removed.

RESPONSE TO REVIEWER 2

Thank you very much for reviewing this paper and for your detailed comments and suggestions.

We have tried to revise the manuscript in line with your suggestions and comments. The specific changes and response to the different points raised include:

Major comment

We agree that this experience of nurse-based, decentralized ART pediatric care is currently very relevant given the ongoing debate and have tried to emphasize this more strongly following your recommendations. In the Introduction and Methods section the following topics have been added: 1) health worker distribution in Rwanda 2) traditional roles of doctors and nurses 3) how the roles were adjusted in this program. We have added a Table, summarizing the tasks for physicians and nurses in the physician-centered and nurse-centered model. The acceptability among health workers and patients and the sustainability of the model has been addressed in more detail in the Discussion.

You rightly point out that psychosocial care has been better described and that we could improve on our referencing.

We have added some relevant references and have removed descriptions of certain aspects of the program that are well covered in literature. Still, we would like to propose to keep an additional focus in this paper on the psychosocial aspects of the program for the following reasons:

1) although detailed information exists on disclosure and support groups for children, this remains a neglected aspect in many pediatric ART programs in resource-constrained settings, in particular outside the specialized-care setting. We think that our experience emphasizes the need and feasibility of organizing this at health centers and provides at least some data on how this can be organized at the primary health center level.

2) we had previously linked with other MSF programs to receive additional feed-back to focus our manuscript. The focus on psychosocial care was one of the aspects of our program that they found particularly interesting and important to make widely available.

3) the poor implication of psychosocial care within pediatric ART programs and the need to emphasize this has been confirmed by several experts within MSF with extensive operational experience.

Minor comments

1. 'virtually no studies'
 - This has been rephrased: "No published studies"
2. 'Sample'

- This has been changed into 'Study population'
3. 'facilitated'
 - This sentence has been rephrased. Given the new focus of the paper, the sentence has been moved to the discussion (Discussion, page 20).
 4. 'Financial incentives'
 - Issues related to sustainability and how these incentives have been integrated within the national program are now described in the Discussion (Discussion, page 24).
 5. The indications for treatment changes have been clarified (Methods, page 9).
 6. Adequate has been replaced by 'Timely and careful' (Methods, page 11).
 7. Separate has been replaced by 'dedicated' (Methods, page 12).
 8. Children support groups
 - Given the new focus of the paper, we have removed some details about the support groups but referenced to relevant documents instead (Methods, page 12).
 9. The syrup formulation
 - As suggested, this has now been added in the limitations (Discussion, page 26).
 - However, since this only involved 9 children, we think the implications on the program outcomes to be minor.
 10. Adherence measurement
 - This was indeed phrased in a confusing way
 - The measure of adherence we actually used is 'pharmacy refills' which is a more standard measure of adherence
 - The confusion related to the fact that pharmacy refills go with a consultation (clinical attendance) within our program and are thus closely related, but the measure used for adherence monitoring in this report was based on pharmacy refill data.
 11. 'The need for nurse-managed and decentralized care'
 - Given the new focus of the paper, this has been elaborated in the Methods and Discussion (see also major revision above).
 12. Accessibility and Acceptability
 - We have added additional issues supporting the suggested higher accessibility and acceptability of decentralized ART (Discussion, page 20-21).
 - However, given the fact that this was not specifically monitored during the program, it has been phrased more carefully.
 - The relevance of gauging caregiver's and children's feelings and perceptions is highlighted in the discussion (Discussion, page 27).
 13. "never achieved in hospital setting"
 - This has been phrased more carefully and in more in more detail (Discussion, page 19-22).

14. "sensitive approach"
 - This has been phrased more carefully and references relating to this subject have been added (Discussion, page 22).
15. As suggested, "treatment-changing" side-effects has been changed in "severe" side-effects (Discussion, page 23).
16. Validation of nurse-decisions
 - This has not been formally validated
17. side effects... nurses
 - Additional evidence supporting the accuracy of the nurses' diagnosis of side-effects have been added (Discussion, page 23).
18. External support by MSF directed at capacity building
 - This is indeed the case and has been put more clearly in the Discussion (page 24).
19. handing over 2007
 - This has been updated (Discussion, page 24).
20. "elements required..."
 - Given the new focus of the paper, several of this issues are now addressed throughout the paper (lack of doctors, context of Rwanda...)
 - As such, we feel that this summary does not add anything particular anymore and have removed it.
21. "Moving target"
 - We agree this phrasing was not entirely correct and have rephrased in line with your comments (Discussion, page 25).
22. Adopted children
 - This is indeed a complex issue. Since this is not the main issue of the paper, we preferred to remove it.
23. Limitations
 - The limitation related to the drug formulation has been added (Discussion, page 26).
 - The confusion regarding the adherence measures has been addressed (see point 10)
24. Damage repair
 - This is an idea we received through feed-back from another pediatric program
 - Since this is indeed poorly documented in literature, it is indeed difficult to provide evidence in support of this statement, and the phrase has been removed.
25. Importance of "Patients' perceptions and satisfaction"
 - We have added a phrase clarifying this statement (Discussion, page 27).
26. Future research
 - The replicability of nurse-driven pediatric ART has been added.
27. We admit the phrasing 'using nurses' was indeed not appropriate and have rephrased it throughout the text.

28. The role of the physician in the program has been detailed now in the Methods and Discussion section and in Table 1.

While hoping that these amendments would be in line with your suggestions, we meanwhile remain open to any further suggestions.

Yours sincerely,

Johan van Griensven
Author for correspondence