

PEER REVIEW HISTORY

BMJ Paediatrics Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Risk factors for mortality in culture-negative neonatal sepsis in Malawi: a propensity score-matched analysis Caregiver perspectives on the long-lasting impact of the COVID-19 pandemic on children with cerebral palsy in Johannesburg, South Africa
AUTHORS	Adams, Skye Nandi Bhorat, Razina Moosa, Aneesah

VERSION 1 – REVIEW

REVIEWER	Tamara Morris United Kingdom of Great Britain and Northern Ireland
REVIEW RETURNED	17-Mar-2024

GENERAL COMMENTS	<p>The authors highlight the impact that the COVID-19 pandemic has had on populations of children with disabilities such as those with CP, and their families even beyond the period of the lockdown. How this has affected and continues to affect children and families in countries with limited resources in the post-covid era, is of particular concern, worthy of investigation to inform policy towards developing a targeted response.</p> <p>While an enormous amount of work has gone into interviewing and analysing the data, with some interesting findings, the manuscript in its current form is not ready for publication.</p> <p>My main reason for this decision is that the findings do not provide sufficient evidence to substantiate the claim that caregivers continue to face significant challenges post-COVID. This is a small sample of interviewees, most were employed caregivers and some had private health insurance, whether the circumstances differ for children living with unemployed caregivers and/or receiving healthcare through the public health system is not discussed.</p> <p>There is insufficient evidence presented here to advocate for policy change - if there are more clear data from the interviews that could be used these should be included. Ongoing difficulties with mobility/struggles with daily living in the post COVID time needs to be strongly highlighted and if this can be related to those with socioeconomic disadvantage this would make the argument to address inequities in services for children with CP even stronger.</p> <p>I have several comments which the authors might wish to consider:</p> <p>Title and Abstract</p> <ul style="list-style-type: none">- In the title and in the abstract – mention early on where in South Africa the study takes place, and which populations the children come from, the country is large, and diverse and this could provide some context- The word 'long-term' is used for a period of about 1 year post pandemic, 'long lasting' may be a better option- Use the generic term 'caregivers' consistently since not all were parents <p>Methodology</p>
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	<ul style="list-style-type: none"> - Explain how families were recruited to participate in this study, include whether some families did not consent to participate - Mention in the methods why more than 1 caregiver in some families was included - was there an interview guide, what were the questions asked and were any standardized anxiety/depression/stress surveys used? <p>Results</p> <ul style="list-style-type: none"> - Table 2 does not add much new to information already presented in Table 1, perhaps any information not in Table 1 can be merged into this table from table 2 - It is notable that for 2 families each with 2 children, and different caregivers interviewed, I imagine the experience would be similar for caregivers in the same family, and would rather see interviews with more families from diverse circumstances, to obtain wider perspectives - Noted that the type of CP was not available for all, however it would be helpful to have more details if possible about the severity of CP eg what proportion were wheelchair bound or ambulatory? The experience of families could differ widely depending on this - The proportion of caregivers employed and children accessing private healthcare indicates that most participants are from better resourced circumstances, it would be interesting to compare experience of better resourced caregivers to those unemployed and receiving public health care <p>Themes</p> <ul style="list-style-type: none"> -lines 18-21 page 7 keep the same order of the themes as presented from the next paragraph. - Under the long-term regression – the quotes mostly relate to the time during the pandemic, and motor skill regression. What is reported under this heading does not sufficiently make the case for ongoing difficulties with access to services, - The themes should be separated, concerns about being exposed to infection post- lockdown is a different issue to 'long term regression' <p>Discussion</p> <ul style="list-style-type: none"> - Figure 1 this belongs within the results section - The authors do not convincingly make the case in results or discussion that in a resource limited setting like South Africa, following the reversals in gains that COVID precipitated, it will be very challenging to address the needs of disabled children, especially from disadvantaged circumstances - Results are repeated extensively in the discussion, discussion mostly repeats results and does not robustly - Limitations should come before conclusion remarks. - The lack of generalisability is a limitation, and expand this to discuss why the results are not generalisable
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VERSION 1 – AUTHOR RESPONSE

Dear Reviewers,

Thank you for your feedback and constructive comments on the manuscript to BMJ Paediatrics Open. Your comments were all very helpful and clear. We appreciate the time you have taken to review this paper. Each reviewer's comments have been addressed in the table below (point by point basis). We have also provided a line reference as to where the changes can be found in the paper as well as highlighted any changes made so that these can be easily identified.

Please let us know if you have any further queries or comments,

Kind regards,

Adams, S.N., Bhorat, R., Moosa, A.
Article authors

No. Reviewers Comments Address Reference

General/ Editor Feedback

1. Please check on the Author's names on the main document and in the system below. The names indicated in the main document must match the name registered in the ScholarOne submission system. Please also provide full author names, rather than only initials Edited Title page

2. References must be numbered sequentially as they appear in text. References numbers in the text must be inserted immediately after punctuation (with no word spacing)- for example,[6] not [6].

Where more than one reference is cited, separated by a comma- for example, [1, 4, 39].

For sequences of consecutive numbers, give the first and last number of the sequence separated by a hyphen- for example, [22-25]. • Removed spacing in the in-text references.

- Added comma where more than one reference has been cited.
- Provided hyphen for sequence of consecutive numbers. References

Throughout document

3. Please remove all your figures in your main document and upload each of them separately under file designation 'Image' (except tables and please ensure that figures are in better quality or not pixelated when zoomed in). Removed figures from main document and provided as .JPG Figures

4. Please include figure legends at the end of your main manuscript. The figure legend or figure caption is a title or brief explanation appended to your figure Added Figure legend

5. Please respond to the reviewer's comments. There is certainly merit in this submission, but there are several limitations that need to be addressed, as highlighted. Discussion should synthesise the results and contextualise them- especially with respect to low resource settings, elsewhere in Africa. Thank you for your comments. I have addressed the reviewers comments below and reworked the discussion to ensure better synthesis and contextualisation of the results, especially in low resource settings.

Reviewer 1

1. Title and Abstract: In the title and in the abstract – mention early on where in South Africa the study takes place, and which populations the children come from, the country is large, and diverse and this could provide some context Added detail: Participants were recruited from various CP-specific schools and organisations in Johannesburg, South Africa. Abstract

Title

2. Title and Abstract: The word 'long-term' is used for a period of about 1 year post pandemic, 'long lasting' may be a better option Edited and changed to long-lasting Throughout document

4. Title and Abstract: Use the generic term 'caregivers' consistently since not all were parents Edited and changed to caregivers Throughout document

5. Methodology: Explain how families were recruited to participate in this study, include whether some families did not consent to participate Additional information on recruitment has been added: The researchers compiled a list of special education schools and organizations catering to children with CP across Johannesburg to facilitate participant recruitment. Although ten sites were initially approached, only six responded and were included in the study. Subsequently, participant information were distributed by the schools/organizations to all eligible individuals within their networks, inviting them to contact the researchers if interested in participating.

As the schools/organisations sent out the letters, it is not clear the of the exact number that were sent.

However, only fourteen participants responded to the call. Participants

6. Methodology: Mention in the methods why more than 1 caregiver in some families was included. Added detail: To ensure a comprehensive understanding of children with CP, from caregiver perspectives, multiple caregivers were included in some families. This decision was informed by the recognition of the diverse roles caregivers play in supporting children with CP, including grandparents and fathers, whose perspectives are often underrepresented in disability research particularly in the South African context. Additionally, the different roles and experiences of the children many of these caregivers may have. By intentionally including multiple caregivers, such as grandmothers and fathers, the study aimed to address this limitation and capture a more diverse range of experiences of children with CP. Procedure

7. Methodology: was there an interview guide, what were the questions asked and were any standardized anxiety/depression/stress surveys used? Added detail under online supplementary material 1.

No standardized surveys or measures were used. Supplementary material 1.

8. Results: Table 2 does not add much new to information already presented in Table 1, perhaps any information not in Table 1 can be merged into this table from table 2 Table 1 and Table 2 have been amended. Demographic information is now being reported on a group level and not an individual level to comply with ethical standards of reporting participant data. Table 1

9. Results: It is notable that for 2 families each with 2 children, and different caregivers interviewed, I imagine

the experience would be similar for caregivers in the same family, and would rather see interviews with more families from diverse circumstances, to obtain wider perspectives In the current study, mothers were the ones who predominantly responded to the research call. In order to diversify our participants, we asked if other family members would also like to be interviewed and we got additional responses from a grandmother and a father.

Procedure

10. Results: Noted that the type of CP was not available for all, however it would be helpful to have more details if possible about the severity of CP eg what proportion were wheelchair bound or ambulatory? The experience of families could differ widely depending on this Additional information has been provided on the GMFCS rating to speak to the severity and ambulatory status of the children. Table 1

11. Results: The proportion of caregivers employed and children accessing private healthcare indicates that most participants are from better resourced circumstances, it would be interesting to compare experience of better resourced caregivers to those unemployed and receiving public health care Comparisons have been made and included in the results. I have also highlighted the studies participants and those that speak to the majority of South Africa who do access public healthcare services. Results

12. Themes: lines 18-21 page 7 keep the same order of the themes as presented from the next paragraph.

Edited Themes

13. Themes: Under the long-term regression – the quotes mostly relate to the time during the pandemic, and motor skill regression. What is reported under this heading does not sufficiently make the case for ongoing difficulties with access to services. Edited and added detail to highlight how long term regressions have continued to have an impact post lockdown and made reference to continued challenges with regressions, muscle stiffness and the continued inability to access schools or rehabilitative services. Results

14. Themes: The themes should be separated, concerns about being exposed to infection post- lockdown is a different issue to 'long term regression' Separated theme to main and sub-theme Themes

15. Discussion: Figure 1 this belongs within the results section Moved Figure 1 to results Figure 1

Results

16. Discussion: The authors do not convincingly make the case in results or discussion that in a resource limited setting like South Africa, following the reversals in gains that COVID precipitated, it will be very challenging to address the needs of disabled children, especially from disadvantaged circumstances Discussion has been reworked to remove repetition and ensure better synthesis and contextualisation of results.

Discussion

17. Discussion: Results are repeated extensively in the discussion, discussion mostly repeats results and does not robustly Discussion has been reworked to remove repetition and ensure better synthesis and contextualisation of results. Discussion

18. Discussion: Limitations should come before conclusion remarks. Edited Discussion

19. Discussion: The lack of generalisability is a limitation, and expand this to discuss why the results are not generalisable Added detail on why the results are not generalisable. Discussion

REVIEWER	Tamara Morris United Kingdom of Great Britain and Northern Ireland
REVIEW RETURNED	19-May-2024

GENERAL COMMENTS	<p>I am pleased with the way the authors have addressed the concerns and the paper is now much improved.</p> <p>There are a few minor edits and grammatical errors noted including the following:</p> <p>Page 3 line 53 - should be 'catering to the needs of ...'</p> <p>Page 4 line 3 'it is not clear the of the exact - should be something like 'we were unable to determine the exact number... because...'</p> <p>Page 5 line 35 should read 'A comprehensive review of the data.was undertaken and themes identified'</p> <p>Page 6 line 15/16 - percentages quoted for GMFCS do not match what is in the table</p> <p>Page 7 line 43 should be "older children experience a gap'</p> <p>Page 8 line 7 - write physiotherapist in full</p> <p>Page 10 line 10 - - remove - 'and this is not the case for many of the other caregivers in the study and in South Africa - this should be only in the discussion'</p> <p>Page 11 Line 17 - please provide reference</p> <p>Page 12 Line 40 should read 'Notably, families of children with CP, an already vulnerable population continue to...'</p>
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	<p>Page 13 line 9 - remove the phrase ' highlightingting to the generalisability '</p> <p>Line 33 should start 'In conclusion the findings of this study underscore ...' and exclude sentence 'while the findings of this study may not be universally applicable'</p> <p>Line 38 - I am not sure I saw evidence to substantiate the claim that 'challenges related to' cultural perceptions surrounding disability'</p>
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VERSION 2 – AUTHOR RESPONSE

Thank you we appreciate your feedback and constructive comments to improve the quality of the paper.