PEER REVIEW HISTORY

ARTICLE DETAILS

TITLE (PROVISIONAL)	Family caregivers experience of care with a child with cerebral palsy: the lived experiences and challenges of caregivers in a resource-limited setting in northern Ghana
AUTHORS	Mwinbam, Mavis Mallory Suglo, Joseph Nyarko Agyeman, Yaa Kukeba, Margaret Wekem

VERSION 1 - REVIEW

REVIEWER	Dr. Melissa Gladstone University of Liverpool, Department of Women and Children's Health
REVIEW RETURNED	05-Jan-2023

GENERAL COMMENTS	This article describes the views of 13 caregivers of children with cerebral palsy who were recruited and who had in depth interviews conducted through a referral hospital in Ghana. It aims to look at the challenges of managing a child with cerebral palsy in the Ghanaian setting. It is important to gain views of caregivers and particularly those from this marginalised group and there are fewer articles regarding this within the African setting – although some from settings in Africa already – including Ghana, Kenya, Malawi. It is great, however, to see that the team who wrote this article are all from Ghana (as far as I can tell from the institutions listed) and this comes very much from the perspective of those living in Ghana not from outside. The article needs quite a bit of work with regards to grammar and writing style and the abstract and title would benefit from a review from one of the senior authors. It does not represent the rest of the paper as well as it could do. Abstract The methods need to more specifically provide as much info as is possible as outlined in the COREQ guidelines – it can not provide all as it has to be short – but some more specificity would be good e.g. whether a topic guide was used, where families were recruited, whether they were audiorecorded and transcribed and translated or not (this info is in the main text). Results – what does "sociocultural" mean as a challenge in the abstract – this might need a bit of clarifying in the abstract so it is clearer to the reader. Results are interesting but it might be worthwhile thinking about whether they could be provided in any kind of framework or theory which might bring them together in a way that enables those reading it to make sense of it more and which also considers how to move some of this information forwards.

The conclusions are a little non-specific – even though they are important – it would be good to consider how the results could be used by those in policy in a more specific way e.g. if economic challenges were highlighted – could this be considered or advocated for more by policy makers and those who are creating programmes or if physical burden is high = could ways to support families with this physical burden be considered in the future e.g. through the use of devices or mechanisms that might help families. Some of this could come from the “How this study might affect research, policy and practice” section.

Main paper:
Methods:
Line 99 - What demographic information was requested – could this be clearer or more specific? It looks like it is in the results table. And were there reasons for gaining this information and did this affect purposive sampling in any way? Was there choice about who was interviewed due to any of their characteristics?
Line 101 – why in depth interviews chosen rather than focus groups? A short sentence outlining why in depth interviews were considered the best methodology would be helpful.
Line 101 – is there a topic guide to add to the supplementary files? How was this created? Was it open ended in terms of the questions? Did this influence the results found?
Line 107/108 – could the authors be more specific about how they ensured accuracy – what process did they use exactly for transcribing and translating to ensure this (actually explained more in lines 114 – 119 – so maybe make reference to this earlier)? Is there anything else they did to ensure validity and quality data?
Data analysis – do not need to repeat that was transcribed – said in paragraph above
Table 1 – might be possible to group the caregivers aged >40 into one group rather than 3?
Figure 1 – needs some formatting work – I also wonder if any theory could be considered to bring the different main themes together within the figure? Or at least to be discussed within the discussion? Are there other papers who have come up with similar groupings of issues? It would be really helpful if there was a way to bring these results together to think about how they could be addressed/who/how they might be addressed – thinking about a framework might help with this – e.g. how can these barriers be supported – does it need to be thought about at different levels – if support was given where are the different levels that it is required? This would add to the discussion.
The discussion could be more linked to a framework and thoughts that have been put into the “How this study might affect research, policy and practice” section.
Some specific grammatical issues are:
Lots of different words used for resource poor/resource limited/resource constrained – might be good to just use one terminology throughout.
Title
“resource constrained”
Abstract
Limited resource – might be better as “resource limited”
Hospital -= hospital – check all capitols
Line 91 – participant recruitment
Line 97 – thumb not thump
101 – in depth interview topic guide

	102 – probing not Probing Line 119 – Severally? What does this mean? Line 120 – audio files Line 127 – confidentiality Line 138 – were women, with 12 being biological parents… Line 140 – “detailed demographic information” There are many more grammatical errors that should be checked. Maybe using a programme such as word grammar checker might help.

REVIEWER	Dr. Jerry Ninnoni University of Cape Coast College of Health and Allied Sciences, Mental Health
REVIEW RETURNED	06-Feb-2023

GENERAL COMMENTS	The philosophical standpoint needs to be clarified. The background needs to be more focused and sufficiently demonstrate the study's relevance. Phenomenology as a design is inappropriate and consistent with the analysis and findings.

VERSION 1 – AUTHOR RESPONSE

Reviewer 1

This article describes the views of 13 caregivers of children with cerebral palsy who were recruited and who had in depth interviews conducted through a referral hospital in Ghana. It aims to look at the challenges of managing a child with cerebral palsy in the Ghanaian setting.

It is important to gain views of caregivers and particularly those from this marginalised group and there are fewer articles regarding this within the African setting – although some from settings in Africa already – including Ghana, Kenya, Malawi. It is great, however, to see that the team who wrote this article are all from Ghana (as far as I can tell from the institutions listed) and this comes very much from the perspective of those living in Ghana not from outside.

Response: Thank you for the review

The article needs quite a bit of work with regards to grammar and writing style and the abstract and title would benefit from a review from one of the senior authors. It does not represent the rest of the paper as well as it could do.

Response: Review of the title and sections of the abstract have been carried out to make them more representative of the paper.

Abstract

The methods need to more specifically provide as much info as is possible as outlined in the COREQ guidelines – it can not provide all as it has to be short – but some more specificity would be good e.g. whether a topic guide was used, where families were recruited, whether they were audiorecorded and transcribed and translated or not (this info is in the main text).

Response: More information has been provided in the methods sections according to the COREQ guidelines

Results – what does “sociocultural” mean as a challenge in the abstract – this might need a bit of clarifying in the abstract so it is clearer to the reader.

Response: This has been made clearer in the abstract section

Results are interesting but it might be worthwhile thinking about whether they could be provided in any kind of framework or theory which might bring them together in a way that enables those reading it to make sense of it more and which also considers how to move some of this information forwards.

Response: Thank you for the review suggestion to use a framework. We have done a scoping of the existing literature if we could find a framework that best relates to our findings. However, we used an inductive process of enquiry and analysis of the data, and the findings as they stand currently seems challenging to be provided using an existing framework.

The conclusions are a little non-specific – even though they are important – it would be good to consider how the results could be used by those in policy in a more specific way e.g. if economic challenges were highlighted – could this be considered or advocated for more by policy makers and those who are creating programmes or if physical burden is high = could ways to support families with this physical burden be considered in the future e.g. through the use of devices or mechanisms that might help families. Some of this could come from the “How this study might affect research, policy and practice” section.

Response: Thank you for the review comment. We have reviewed our conclusion section and made more clearer and specific conclusion in relation to policy and social interventions.

Main paper:

Methods:

Line 99 - What demographic information was requested – could this be clearer or more specific? It looks like it is in the results table. And were there reasons for gaining this information and did this affect purposive sampling in any way? Was there choice about who was interviewed due to any of their characteristics?

Response: The demographic characteristics that were collected from participants and why we sought that information has now been indicated in the manuscript text and table.

Line 101 – why in depth interviews chosen rather than focus groups? A short sentence outlining why in depth interviews were considered the best methodology would be helpful.

Response: It would have been practically difficult to bring participants with different medical appointment dates together for a group meeting at a single venue. Getting a convenient meeting room to accommodate all participants would have also been challenging. Based on these and other ragmatic reasons, individual interviews were conducted.

Line 101 – is there a topic guide to add to the supplementary files? How was this created? Was it open ended in terms of the questions? Did this influence the results found?

Response: Topic guide has been added as supplementary material and other details requested indicated in the manuscript.

Line 107/108 – could the authors be more specific about how they ensured accuracy – what process did they use exactly for transcribing and translating to ensure this (actually explained more in lines 114 – 119 – so maybe make reference to this earlier)? Is there anything else they did to ensure validity and quality data?

Response: Thank you for the review. This information has been provided and brought forward than before.

Data analysis – do not need to repeat that was transcribed – said in paragraph above

Response: This sentence has been deleted.

Table 1 – might be possible to group the caregivers aged >40 into one group rather than 3?

Response: The three rows have been merged now as recommended.

Figure 1 – needs some formatting work

Response: This has been done

I also wonder if any theory could be considered to bring the different main themes together within the figure? Or at least to be discussed within the discussion? Are there other papers who have come up with similar groupings of issues? It would be really helpful if there was a way to bring these results together to think about how they could be addressed/who/how they might be addressed – thinking about a framework might help with this – e.g. how can these barriers be supported – does it need to be thought about at different levels – if support was given where are the different levels that it is required? This would add to the discussion.

The discussion could be more linked to a framework and thoughts that have been put into the “How this study might affect research, policy and practice” section.

Response: Throughout the results and discussion sections of our revised script, we have tried to think about how the findings could be addressed. Other studies have not come out with similar groupings of issues as indicated in figure 1. But this might because the categories of issues we highlighted were generated inductively, and no framework was use to guide our line of interviewing or analysis as it would have been if we had used a deductive approach.

Some specific grammatical issues are:

Lots of different words used for resource poor/resource limited/resource constrained – might be good to just use one terminology throughout.

Title: “resource constrained”

Response: We have reviewed the paper to ensure consistency with regards to the use of words

Abstract

Limited resource – might be better as “resource limited”

Hospital -= hospital – check all capitols

Line 91 – participant recruitment

Line 97 – thumb not thump

101 – in depth interview topic guide

102 – probing not Probing

Line 119 – Severally? What does this mean?

Line 120 – audio files

Line 127 – confidentiality

Line 138 – were women, with 12 being biological parents…

Line 140 – “detailed demographic information”

There are many more grammatical errors that should be checked. Maybe using a programme such as word grammar checker might help.

Response: Proofreading of paper has been carried out to correct mistakes.

Reviewer 2

The philosophical standpoint needs to be clarified.

Response: We have added some more text under the study design to make this clearer. However, to prevent the paper from being too lengthy, we did not go deeper into the different philosophical discussions.

The background needs to be more focused and sufficiently demonstrate the study's relevance.

Response: We have made the background section succinct and the relevance of the study presented within the last quarter of the background. We tried to avoid extensive literature review in the background that will make it overly long.

Phenomenology as a design is inappropriate and consistent with the analysis and findings.

Response: Other qualitative approaches could have also been used in this study. Nevertheless, phenomenological principles acknowledge people's ties with their physical, social, and emotional world. Thus, reality of a phenomenon is tied to peoples’ experiences. In this study, we unearthed caregivers’ experiences/Challenges from their own perspective. The method of data analysis used was to allow the issues emerge from the data (Inductive process) using the content analysis approach. This analysis approach appears acceptable from the qualitative studies literature.

VERSION 2 – REVIEW

REVIEWER	Dr. Melissa Gladstone University of Liverpool, Department of Women and Children's Health
REVIEW RETURNED	09-Apr-2023

GENERAL COMMENTS	This paper reads better and I am glad that the authors have made an effort to provide more extensive information on methodology which helps put the article in context and ensures the quality of the piece of research. The paper is still hard to read in places and it is a shame that there is not more of a framework to underpin the results in relation to other studies. I think this might help frame it. Please check the terminology of LMIC (low and middle income) vs low resource or resource limited or resource-poor – it seems to vary throughout the article. Abstract: Line 18: (Intro) I would not say “could be” but I would say "may be" more emotionally and physically exhausting as it is not necessarily always the case that all parents find looking after children with CP emotionally and physically exhausting. Methods: Could you say instead? "We conducted a qualitative study underpinned by phenomenological principles where it is believed that the

reality of a phenomenon is tied to caregivers experiences. In this study, we unearthed caregivers' experiences/Challenges from their own perspective. The method of data analysis used was to allow the issues emerge from the data (Inductive process) using the content analysis approach. This analysis approach appears acceptable from the qualitative studies literature."
And then… "We recruited 13 caregivers of children with CP from the physiotherapy unit at Tamale teaching hospital, Ghana and conducted individual in depth interviews supported by an open ended topic guide. Interviews were audiorecorded, transcribed and translated and were then coded inductively prior to conducting a content analysis of the data when grouped into themes"

The writing style is difficult to read in places and I feel that the whole paper could do with a review by a copy editor.

Results – similarly hard to read – could you try – "Barriers that emerged from the data, to managing a child with cerebral palsy included those at the level of socio-cultural barriers (values attitudes and belief systems within society), economic challenges with looking after a child aw well as the immediate physical care burdens. Societal barriers included; discrimination and isolation, lack of family and societal support with poor access to health information, education. Financial constraints included…

What is already known:
This whole section needs to be more specific with that known with clarity of what the gaps are which this paper is filling.
For one of these bullet points, I would change to: * Caring for a child with cerebral palsy may impact on caregiver physical and psychological health.

What this study adds:
I have provided some other examples which might be helpful as it feels that the present statements are not very specific to the article written.
- Parents of children with CP in Ghana describe experiences of social isolation and stigma within their communities.
- Caregivers of children with CP in Tamale Hospital in Ghana perceive that they have limited information on the cause and course of the condition.
- Caregivers describe high levels of spending on health care as well as the loss of businesses and jobs.
- There is a need to tackle how to prevent stigma and social isolation for caregivers of children with CP.
- Provision of better information for caregivers on the health related issues, cause and prognosis for children with CP may enable parents to feel more empowered to help their children in the future.

Introduction:
Line 66 – sentence does not seem complete
Line 69-73 – could this be one sentence rather than two?
Line 74 – could be rewritten to "with more living in low resource settings" rather than "with a more significant number living in LMIC settings".
Line 88 – could it be rewritten more clearly? "For some caregivers, provision of care can be a burdensome, daunting task that can impact on their physical and psychological well-being (REF NEEDED). This is often worse in resource-limited settings where........"
Line 92 - Remove "Therefore" and start with "This study was designed to evaluate..."
Line 99 – "phenomenological research methods have been employed in

underpinning this study as it aims to describe the lived experience of individuals caring for children with CP."
Line 98 and 102 = this sentence and line 98 could somehow be better linked.

Line 106 - It is important to remain balanced. What is the point of doing this research if the assumption is already made that it is difficult. What about the families that are resilient and manage children well - it is good to have positive examples and positive info as well as just the negative. otherwise we don't know what might work well and what enables families to manage. Please could the authors consider this and ensure that the text does not come with the assumption that it is always difficult and distressing for parents as it is not clear there is research to say that this is the case. See article https://dsq-sds.org/article/view/3209/3291

Lines 109-111 – needs a reference.

Lines 111- 114 – could it be rewritten as "To ensure that we understand the lived experience for families of children with CP with regards to caregiving, it is important that we collect qualitative in depth data which provides detailed information as to the barriers and facilitators that families may experience to support them in caregiving".

Sampling and recruitment:
Could this be rewritten as: "We undertook a purposive non-probability sampling technique where we concluded once we met data saturation (23,24)"

Line 138-140 - What does it mean by the last line in this paragraph and why does this matter? Can this be clearer? Is there any info on MMM's age/sex/experience/reflective practice?

Line 142 – maybe "We gathered…."

Line 144-146; could part of this sentence be changed to… "experience, however were not used to select participants purposively"

Line 149 – suggest – "Our topic guide provided open ended questions which were then probed based on the participant's response."

Findings –
First sentence probably not needed as it is in the methods

Could "thirty-nine" be written as 39?

Table 1 – clarity on what SHS means?

The results still might be better in some kind of framework - Could the results be at least framed as Societal/macro economic issues vs internal abilities and individual issues of the caregiver and child – as these would be tackled at very different levels if considering interventions –
Or could the results be framed within the ICF framework re environment - society, financial, - it might be helpful for the authors to consider what some frameworks and models there are for interventions or what might be created and how – which could be linked a bit more to the paper. See articles such as; Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S.D., Wood, E., 2004. Caregiving process and caregiver burden: Conceptual models to guide research and practice. BMC Pediatrics 4.. https://doi.org/10.1186/1471-2431-4-1 or other papers from India using a

	biopsychosocial model https://www.medrxiv.org/content/10.1101/2022.07.08.22277266v1.full.pdf Significant “theme from the data rather than “significant category” (line 195) Line 203 – please consider removing; “according to pp 11” – this does not make sense to a reader. Or pp 211 “like the pp 211 account”… please remove and consider "Furthermore, one mother described her feeling like she was the subject of ridicule with the belief that some members of the community might even intentionally push…” Line 204 – could this be rewritten as “For example, one caregiver of a 2 year old child with CP explained how attending social gatherings was a challenge due to the negative language used to describe her child as not human but animal (like a snake).” Line 384 – I would not talk about “ the majority” in a qualitative piece of research. Discussion: This really needs framing more within a framework to make sense of how to address the issues raised. I wonder if a figure trying to pull the results together might help?

VERSION 2 – AUTHOR RESPONSE

Reviewer 1

This paper reads better and I am glad that the authors have made an effort to provide more extensive information on methodology which helps put the article in context and ensures the quality of the piece of research.

Response: Thanks so much for the review.

The paper is still hard to read in places and it is a shame that there is not more of a framework to underpin the results in relation to other studies. I think this might help frame it.

Response: We have done proof reading of the manuscript to ensure it reads better. Thanks so much for the suggested articles and framework which we have used to structure our results.

Please check the terminology of LMIC (low and middle income) vs low resource or resource limited or resource-poor – it seems to vary throughout the article.

Response: We have corrected this and used resource-limited throughout the article.

Abstract:

Line 18: (Intro)

I would not say “could be” but I would say "may be" more emotionally and physically exhausting as it is not necessarily always the case that all parents find looking after children with CP emotionally and physically exhausting.

Response: Thank you. This has been corrected.

Methods: Could you say instead? "We conducted a qualitative study underpinned by phenomenological principles where it is believed that the reality of a phenomenon is tied to caregivers experiences. In this study, we unearthed caregivers' experiences/Challenges from their own perspective. The method of data analysis used was to allow the issues emerge from the data (Inductive process) using the content analysis approach. This analysis approach appears acceptable from the qualitative studies literature."

Response: Thank you for the suggested edits. Changes has been made.

And then… "We recruited 13 caregivers of children with CP from the physiotherapy unit at Tamale teaching hospital, Ghana and conducted individual in depth interviews supported by an open ended topic guide. Interviews were audiorecorded, transcribed and translated and were then coded inductively prior to conducting a content analysis of the data when grouped into themes"

Response: Suggested edits have been made.

The writing style is difficult to read in places and I feel that the whole paper could do with a review by a copy editor.

Response: We have done proof reading and editing of the paper.

Results – similarly hard to read – could you try – "Barriers that emerged from the data, to managing a child with cerebral palsy included those at the level of socio-cultural barriers (values attitudes and belief systems within society), economic challenges with looking after a child aw well as the immediate physical care burdens. Societal barriers included; discrimination and isolation, lack of family and societal support with poor access to health information, education. Financial constraints included…

Response: Suggested edits have been done. Thank you

What is already known:

This whole section needs to be more specific with that known with clarity of what the gaps are which this paper is filling.

For one of these bullet points, I would change to: * Caring for a child with cerebral palsy may impact on caregiver physical and psychological health.

Response: We have reworded this section to be more specific and clearer.

What this study adds:

I have provided some other examples which might be helpful as it feels that the present statements are not very specific to the article written.

Response: Thanks for the comments and suggestions. The changes have been made.

Line 66 – sentence does not seem complete

Line 69-73 – could this be one sentence rather than two?

Response: Changes have been made.

Line 74 – could be rewritten to "with more living in low resource settings" rather than "with a more significant number living in LMIC settings".

Response: Corrections made

Line 88 – could it be rewritten more clearly? “For some caregivers, provision of care can be a burdensome, daunting task that can impact on their physical and psychological well-being (REF NEEDED). This is often worse in resource-limited settings where........”

Response: Parts of this section has been edited and some sentences deleted.

Line 92 - Remove "Therefore" and start with “This study was designed to evaluate...”

Response: Suggested changes done.

Line 99 – “phenomenological research methods have been employed in underpinning this study as it aims to describe the lived experience of individuals caring for children with CP.”

Response: Thank you. This insertion has been made.

Line 98 and 102 = this sentence and line 98 could somehow be better linked.

Response: The two has been linked.

Line 106 - It is important to remain balanced. What is the point of doing this research if the assumption is already made that it is difficult. What about the families that are resilient and manage children well - it is good to have positive examples and positive info as well as just the negative. otherwise we don’t know what might work well and what enables families to manage. Please could the authors consider this and ensure that the text does not come with the assumption that it is always difficult and distressing for parents as it is not clear there is research to say that this is the case. See article https://dsq-sds.org/article/view/3209/3291

Response: This section has been edited and some sentences removed.

Lines 109-111 – needs a reference.

Lines 111- 114 – could it be rewritten as “To ensure that we understand the lived experience for families of children with CP with regards to caregiving, it is important that we collect qualitative in depth data which provides detailed information as to the barriers and facilitators that families may experience to support them in caregiving”.

Response: This section has been edited and parts deleted as part of the response to the preceding comment.

Sampling and recruitment:

Could this be rewritten as: “We undertook a purposive non-probability sampling technique where we concluded once we met data saturation (23,24)”

Response: Thank you for the suggested wording. This has been accepted

Line 138-140 - What does it mean by the last line in this paragraph and why does this matter? Can this be clearer? Is there any info on MMM's age/sex/experience/reflective practice?

Response: This last sentence has been deleted. It was initially written to make known the researcher who conducted the interviews. The role of the various authors has been indicated towards the end of the paper.

Line 142 – maybe “We gathered….”

Response: Correction done

Line 144-146; could part of this sentence be changed to… “experience, however were not used to select participants purposively”

Line 149 – suggest – “Our topic guide provided open ended questions which were then probed based on the participant's response.”

Response: Changes done as suggested

Findings – First sentence probably not needed as it is in the methods

Could “thirty-nine” be written as 39?

Response: Corrections done

Table 1 – clarity on what SHS means?

Response: Full meaning of SHS indicated in table 1

The results still might be better in some kind of framework - Could the results be at least framed as Societal/macro economic issues vs internal abilities and individual issues of the caregiver and child – as these would be tackled at very different levels if considering interventions –

Or could the results be framed within the ICF framework re environment - society, financial, - it might be helpful for the authors to consider what some frameworks and models there are for interventions or what might be created and how – which could be linked a bit more to the paper. See articles such as; Raina, P., O'Donnell, M., Schwellnus, H., Rosenbaum, P., King, G., Brehaut, J., Russell, D., Swinton, M., King, S., Wong, M., Walter, S.D., Wood, E., 2004. Caregiving process and caregiver burden: Conceptual models to guide research and practice. BMC Pediatrics 4.. https://doi.org/10.1186/1471-2431-4-1 or other papers from India using a biopsychosocial model https://www.medrxiv.org/content/10.1101/2022.07.08.22277266v1.full.pdf

Response: Thanks very much for the suggested resources. Very helpful. Our findings have now been presented within a framework. See figure 1

Significant “theme from the data rather than “significant category” (line 195)

Response: Correction has been made at this section

Line 203 – please consider removing; “according to pp 11” – this does not make sense to a reader. Or pp 211 “like the pp 211 account”… please remove and consider "Furthermore, one mother described her feeling like she was the subject of ridicule with the belief that some members of the community might even intentionally push…”

Response: This has been removed.

Line 204 – could this be rewritten as “For example, one caregiver of a 2 year old child with CP explained how attending social gatherings was a challenge due to the negative language used to describe her child as not human but animal (like a snake).”

Response: Changes and edits made in manuscript.

Line 384 – I would not talk about “ the majority” in a qualitative piece of research.

Response: Thank you. This has been deleted.

Discussion:

This really needs framing more within a framework to make sense of how to address the issues raised. I wonder if a figure trying to pull the results together might help?

Response: The discussion section has now been presented within a framework. See figure 2. Thanks so much for all the ideas and suggestions offered.

VERSION 2 – REVIEW

REVIEWER	Dr. Melissa Gladstone University of Liverpool, Department of Women and Children's Health
REVIEW RETURNED	29-May-2023

GENERAL COMMENTS	This paper is looking much better and generally just needs some support for grammar prior to publication. I have provided a few suggestions.. Introduction Maybe… “The family caregivers' perspective of this phenomenon needs exploring to facilitate the development of innovative services” and… “Our study explored the challenges family caregivers face with children with cerebral palsy in a resource-limited context in northern Ghana”. Methods We conducted a qualitative study underpinned by phenomenological principles where it is believed that the reality of a phenomenon is tied to the perspectives that caregivers’ have of their own experiences. In this study, doing so, we unearthed caregivers’ experiences/challenges from their own perspective. The method of data analysis used was to allow the issues emerge from the data (Inductive process) using the content analysis approach. We used inductive coding within our content analysis to enable us to ensure that issues were emerging from the data rather than pre-conceived. This analysis approach appears acceptable from the qualitative studies literature. We recruited 13 caregivers of children with cerebral palsy from the physiotherapy unit at Tamale teaching hospital, Ghana and conducted individual in-depth interviews supported by an open-ended topic guide. Interviews were audio recorded, transcribed, and translated, were then coded inductively prior to conducting a content analysis of the data when grouped into themes. We then used thematic content analysis to place themes in groupings relating to challenges and facilitators to care. Results We have identified barriers to managing a child with cerebral palsy including; socio-cultural barriers (values, attitudes and belief systems within society), economic challenges and immediate physical care burdens. Societal barriers included; discrimination and isolation, lack of family and societal support with poor access to health information and formal education. I have adjusted some of this abstract but it might be good to add a little more detail in the results and something more specific on

	economic challenges and immediate physical care burdens. You also mention lack of information on course and cause in your longer paper (and as one of the results themes) – could you add this to the results in the abstract? You could also provide one sentence on the demographics of the population that you interviewed in the results. In the actual results you talk about multidimensional model of caregiving process and caregiver burden proposed by Raina and colleagues – should this be mentioned in the abstract results? Introduction Line 80-81 – “The effects of CP on the growing child range from permanent disorders in movement to posture and activity limitation”. This line is a bit clunky. Could it read; “Cerebral palsy causes permanent damage to the brain which then limits the child’s ability to have full postural control, mobility and complete activities of daily living.” Note that font is different in places in the paper! Methods Line 123 – “We undertook a purposive non-probability sampling technique where we concluded once we met data saturation”. Again – this sentence is a little hard to read. How about; “We utilised a purposive (non probability) sampling technique to identify and recruit participants. Once we met data saturation, we did not recruit further participants”. Also last sentence line 132 –“We guided participants who consented to participate in the research to sign/thumb print the consent form before commencing data collection.” Could it be written “Participants who consented then signed or printed their thumb print on the consent from prior to data collection”. Guided sounds a little like you are pressurising them.. Line 139 – 140 “However, experiences were not used to select participants…..” I would delete this line – it seems confusing. Data analysis – I wonder if you should put in brackets () for each section the initials of whoever was involved in each part e.g. interviewing, translation, analysis etc e.g. “We further grouped into subcategories….. (MM,…….) – it makes it more transparent as to who did what. Table 1 – check with editorial team about table – not sure if N and % should be in same column – also formatting probably needs checking Results Line 200 “Caregivers reported how the sociocultural viewpoint make society hostile towards them, and challenging living with a child with CP. Salient challenges narrated by caregivers included stigma and misconceptions about CP.” - this is quite a confusing sentence to read… Could you say “Caregivers reported how they perceived that

	individuals within society were often hostile to them challenging their ability to live with their children with CP. In particular, caregivers mentioned how other members within their community often stigmatised them and had misconceptions about CP including how it might have been caused”. Line 209 “Furthermore, one mother described her feeling like she was the subject of ridicule with the belief that some members of the community might even intentionally push her why her child is not walking”. Could you say; “One mother enunciated how she felt the subject of ridicule - describing how she believed that some members of the community intentionally questioned her on things they knew her child could not do.” Furthermore, this same mother recounted how she and her child were even seen as having something that might be “caught” or infectious with others purposely not sitting near her on public transport.” Line 216 – “Other caregivers felt discrimination against their children was obvious which scare them from associating with others.” – Could you say; “Similarly, some caregivers mentioned how they felt discriminated against even by their relatives who would not allow their own children to interact with a child with a disability in case it might be ………. – could expand a little? Line 222 – “A caregiver added that the challenges in caring for a child with CP in the community are compounded by community members believing that CP results from punishment from the gods, and others say children with CP are spirits. According to them, such claims provoke emotional pain. It also appears such perceptions compel caregivers to seek a cure and on whether the children were spirits. Could you say “It was shocking to hear that one caregiver even described how much community members stigmatised children with CP – believing that CP results as a punishment from “the Gods” and furthermore, that children with CP are “spirits”…. Again – could expand this a little?? And then say… “This emerged in caregiver’s verbatim as emotionally very painful leading some caregivers to seek cures through traditional healers in order to better understand whether their children were “spirits” or “possessed” ….again – could expand further… Line 233 – “demonstrated in their submission”… Do you mean “described through their interviews…”? Line 240 “See the submission of some participants”. I would rewrite this as “An example of experiences that were enunciated by caregivers include;” Line 284 “Caregivers also expressed experiencing body pains and having to depend on pain medications to relieve themselves due to strenuous nature of the care they provide for their child with CP. Caregivers also commented that the care became more challenging as their child grew older. As seen in the verbatim quotations below, the

complains of body pains is associated with having to lift and move the…..

Could you say; “Caregivers expressed how they often experienced body pains - depending on medications to relieve the pain from the strenuous nature of the care they provide for their child with CP. Caregivers also commented that care became more challenging as their children grew older and particularly mentioned how body pains were related to having to lift and move….”

Line 305
“Even though participants report show that the internet has helped them to understand their
child's condition better,…”

Could you say “Even though participants reported that the internet helped them to understand…”

Line 313 – Could you say “Social support…” rather than “The Social support…”

Line 321 – Maybe you don’t need “as represented in the following statement…”

Line 326 – “Although caregiving role is traditionally a woman's role, and thus consistent with the findings of this study, considering the additional care needs of the child with CP, it would be expected the caregivers received support, at least from their spouses. However, the statement below captures the experiences of most of the caregivers in terms of support from their spouses.

Could you give a bit more of your own perspective on what this means to you? E.g. “Although caregiving roles in Ghana are traditionally female, considering the additional care needs of a child with CP, many mothers might benefit from support from spouses.” It was clear however in the statements of most of the caregivers that we interviewed, that spouses were unsupportive and unhelpful most of the time – almost in rejecting the child with CP and their caregiver” (or something along those lines??)

The figure I think helps but I wonder if it could be linked a little more e.g. like Brofennbrenner’s model? Or something similar – with the caregiver and child in the centre and then economic issues and health information outside that and then stigma and contextual measures outside that? It might link it better.

VERSION 3 – AUTHOR RESPONSE

Reviewer 1

This paper is looking much better and generally just needs some support for grammar prior to publication.

I have provided a few suggestions..

Response: Thanks so much for the review and suggested edits

Introduction

Maybe… “The family caregivers' perspective of this phenomenon needs exploring to

facilitate the development of innovative services” and… “Our study explored the challenges family caregivers face with children with cerebral palsy in a resource-limited context in northern Ghana”.

Response: Suggested edits accepted.

Methods

We conducted a qualitative study underpinned by phenomenological principles where it is believed that the reality of a phenomenon is tied to the perspectives that caregivers’ have of their own experiences. In this study, doing so, we unearthed caregivers’ experiences/challenges from their own perspective. The method of data analysis used was to allow the issues emerge from the data (Inductive process) using the content analysis approach. We used inductive coding within our content analysis to enable us to ensure that issues were emerging from the data rather than pre-conceived. This analysis approach appears acceptable from the qualitative studies literature. We recruited 13 caregivers of children with cerebral palsy from the physiotherapy unit at Tamale teaching hospital, Ghana and conducted individual in-depth interviews supported by an open-ended topic guide. Interviews were audio recorded, transcribed, and translated, were then coded inductively prior to conducting a content analysis of the data when grouped into themes. We then used thematic content analysis to place themes in groupings relating to challenges and facilitators to care.

Response: Majority of this suggested edits have been accepted. To keep within the abstract word count requirement of 300 words, we have not included some of the details. This however may not affect the standard of the work.

Results

We have identified barriers to managing a child with cerebral palsy including; socio-cultural barriers (values, attitudes and belief systems within society), economic challenges and immediate physical care burdens. Societal barriers included; discrimination and isolation, lack of family and societal support with poor access to health information and formal education.

Response: Suggested edits accepted with some few rewording to reduce word count.

I have adjusted some of this abstract but it might be good to add a little more detail in the results and something more specific on economic challenges and immediate physical care burdens.

Response: Specifics on economic challenges and immediate physical care burdens now included in abstract.

You also mention lack of information on course and cause in your longer paper (and as one of the results themes) – could you add this to the results in the abstract? You could also provide one sentence on the demographics of the population that you interviewed in the results.

Response: Information on cause and course provided in abstract.

Information on the demographics and population could not be included in the abstract because of word count limitations. However, details of these are provided in the main manuscript.

In the actual results you talk about multidimensional model of caregiving process and caregiver burden proposed by Raina and colleagues – should this be mentioned in the abstract results?

Response: This has now been mentioned in the results section of abstract

Introduction

Line 80-81 – "The effects of CP on the growing child range from permanent disorders in movement to posture and activity limitation". This line is a bit clunky. Could it read; "Cerebral palsy causes permanent damage to the brain which then limits the child's ability to have full postural control, mobility and complete activities of daily living."

Response: Suggested edits accepted

Note that font is different in places in the paper!

Response: Thank you. Proof reading has been done and same font type and size used.

Methods

Line 123 – "We undertook a purposive non-probability sampling technique where we concluded once we met data saturation". Again – this sentence is a little hard to read.

How about; "We utilised a purposive (non probability) sampling technique to identify and recruit participants. Once we met data saturation, we did not recruit further participants".

Response: Suggested edits accepted

Also last sentence line 132 –"We guided participants who consented to participate in the research to sign/thumb print the consent form before commencing data collection." Could it be written "Participants who consented then signed or printed their thumb print on the consent from prior to data collection". Guided sounds a little like you are pressurising them..

Response: Suggested edits accepted

Line 139 – 140 "However, experiences were not used to select participants….." I would delete this line – it seems confusing.

Response: This line has been deleted.

Data analysis – I wonder if you should put in brackets () for each section the initials of whoever was involved in each part e.g. interviewing, translation, analysis etc e.g. "We further grouped into subcategories….. (MM,…….) – it makes it more transparent as to who did what.

Response: The initials and roles of each of the authors has been indicated under the author contribution section of the paper.

Table 1 – check with editorial team about table – not sure if N and % should be in same column – also formatting probably needs checking

Response: This has now been put in same column

Line 200 "Caregivers reported how the sociocultural viewpoint make society hostile towards them, and challenging living with a child with CP. Salient challenges narrated by caregivers included stigma and misconceptions about CP." - this is quite a confusing sentence to read…

Could you say "Caregivers reported how they perceived that individuals within society were often hostile to them challenging their ability to live with their children with CP. In particular, caregivers mentioned how other members within their community often stigmatised them and had misconceptions about CP including how it might have been caused".

Response: Suggested edits accepted

Line 209 “Furthermore, one mother described her feeling like she was the subject of ridicule with the belief that some members of the community might even intentionally push her why her child is not walking”.

Could you say; “One mother enunciated how she felt the subject of ridicule - describing how she believed that some members of the community intentionally questioned her on things they knew her child could not do.” Furthermore, this same mother recounted how she and her child were even seen as having something that might be “caught” or infectious with others purposely not sitting near her on public transport.”

Response: Suggested edits accepted

Line 216 – “Other caregivers felt discrimination against their children was obvious which scare them from associating with others.” –

Could you say; “Similarly, some caregivers mentioned how they felt discriminated against even by their relatives who would not allow their own children to interact with a child with a disability in case it might be ………. – could expand a little?

Response: Suggested edits accepted

Line 222 – “A caregiver added that the challenges in caring for a child with CP in the community are compounded by community members believing that CP results from punishment from the gods, and others say children with CP are spirits. According to them, such claims provoke emotional pain. It also appears such perceptions compel caregivers to seek a cure and on whether the children were spirits.

Response: Suggested edits accepted

Could you say “It was shocking to hear that one caregiver even described how much community members stigmatised children with CP – believing that CP results as a punishment from “the Gods” and furthermore, that children with CP are “spirits”…. Again – could expand this a little??

And then say… “This emerged in caregiver’s verbatim as emotionally very painful leading some caregivers to seek cures through traditional healers in order to better understand whether their children were “spirits” or “possessed” ….again – could expand further…

Response: Suggested edits accepted

Line 233 – “demonstrated in their submission”… Do you mean “described through their interviews…”?

Response: Thanks for this. Corrections made.

Line 240 “See the submission of some participants”. I would rewrite this as “An example of experiences that were enunciated by caregivers include;”

Line 284 “Caregivers also expressed experiencing body pains and having to depend on pain medications to relieve themselves due to strenuous nature of the care they provide for their child with CP. Caregivers also commented that the care became more challenging as their child grew older. As seen in the verbatim quotations below, the complains of body pains is associated with having to lift and move the…..

Could you say; “Caregivers expressed how they often experienced body pains - depending on medications to relieve the pain from the strenuous nature of the care they provide for their child with CP. Caregivers also commented that care became more challenging as their children grew older and particularly mentioned how body pains were related to having to lift and move….”

Response: Suggested edits accepted

Line 305 “Even though participants report show that the internet has helped them to understand their child's condition better,…”

Could you say “Even though participants reported that the internet helped them to understand…”

Line 313 – Could you say “Social support…” rather than “The Social support…”

Line 321 – Maybe you don’t need “as represented in the following statement…”

Response: Suggested edits accepted. Thank you.

Line 326 – “Although caregiving role is traditionally a woman's role, and thus consistent with the findings of this study, considering the additional care needs of the child with CP, it would be expected the caregivers received support, at least from their spouses. However, the statement below captures the experiences of most of the caregivers in terms of support from their spouses.

Could you give a bit more of your own perspective on what this means to you? E.g. “Although caregiving roles in Ghana are traditionally female, considering the additional care needs of a child with CP, many mothers might benefit from support from spouses.” It was clear however in the statements of most of the caregivers that we interviewed, that spouses were unsupportive and unhelpful most of the time – almost in rejecting the child with CP and their caregiver” (or something along those lines??)

Response: Suggested edits accepted

The figure I think helps but I wonder if it could be linked a little more e.g. like Brofennbrenner’s model? Or something similar – with the caregiver and child in the centre and then economic issues and health information outside that and then stigma and contextual measures outside that? It might link it better.

Response: Thanks so much. We have restructure this figure, taking into consideration Brofennbrenner’s model as suggested.