

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)	Experiences of children with disabilities during the COVID-19 pandemic in Sweden: A qualitative interview study
AUTHORS	Fäldt, Anna Klint, Filippa Warner, Georgina Sarkadi, Anna

VERSION 1 – REVIEW

REVIEWER	Reviewer name: Ms. Erin Beneteau Institution and Country: University of Washington, United States Competing interests: none
REVIEW RETURNED	16-Jan-2022

GENERAL COMMENTS	<p>General comments to the authors of "Experiences of children with disabilities during the COVID-19 pandemic in Sweden: A qualitative interview study"</p> <p>I commend the authors for conducting this study and for highlighting the importance of including children's perspectives on the pandemic, including children with disabilities. The majority of my questions for the authors relate to the methods used. Additional details regarding the methods would provide increased understanding on how the authors' arrived at their conclusions.</p> <p>Abstract: I immediately wondered how the data was analyzed based on the descriptions in the methods and results sections. Also, based on the statement in the conclusion, I was unsure if the parents were interviewed as well as the children.</p> <p>Introduction: The authors present the case well, although I believe that there might be some additional, relevant research that has taken place since the pandemic (2020 and 2021) which could also be cited to strengthen the authors' case for this particular research study.</p> <p>Methods: The introductory sentence states "a qualitative methodology" but does not provide citations for the type of methodology used. There are many qualitative methods and it is unclear which method is used at this point as the theoretical underpinning for this study. Table 2 (description) refers to "hand signs." It is unclear if this term refers to individualized signs unique to a child or if they are signs from an established sign language.</p> <p>Data Collection: It is unclear if the children attended the same school, different schools, and if they were all located in the same geographic area. More details in this area would be helpful in understanding the sample population and how generalizable the findings might be. The authors provided a wonderful explanation of why the phrase "corona" was used in the study. This is important to include since this is not a universal term.</p>
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	<p>It would be very helpful to understand the types of information that were collected from the parents prior to the interviews- this could be provided as supplementary information, along with the interview guide.</p> <p>Providing an average length of time of interviews or a range of time for interviews would be helpful in understanding more about the methods and procedures of this study.</p> <p>Data analysis: I am personally unfamiliar with the citation provided (22) for the analysis. Are there additional references the authors can provide to increase clarity as to the analysis approach used? Similarly, the authors cite Patton's textbook (23) and if the BMJ Open citation system allows it, it would be helpful to have a page number. Alternatively, the authors could add a brief sentence explaining how the field notes were used to validate- did all authors review them independently after initial coding of the transcripts? Did they review them together? Did it result in any changes to the coding or the findings?</p> <p>Ethical statement: I appreciated the ethical statement. However, I would like more details on how the information was presented, particularly given that some of the participants have intellectual/cognitive disabilities. Was all consent information provided verbally? How did the interviewer check for understanding from the child participant? Were parents also consented since their reactions were included in the analysis?</p> <p>Table 2 (Results)- Just a note that the table numbering does not seem consistent. The first description of "Kim" uses language which can be considered objectifying such as "moves the tongue" instead of "moves their tongue." I'm certain the authors do not intend to objectify the participants, given the care they've taken in providing rationale for including participants with complex communication needs in research. So this is a small edit that can be made and checked throughout the quotes and examples.</p> <p>Results: In this section the authors conclude that children were not worried about their own health but were concerned about their grandparents. In the supplemental materials, the visual prompt regarding concern is for grandparents. It would be helpful to see the prompts for children about their concern for themselves or others- or have additional details in the methods about how these types of questions were asked. As the manuscript is presented now, it appears that the children were prompted about their grandparents with the visual prompt but not other family members or themselves. If the only visual prompt was for grandparents, more details regarding the methodological choice for that prompt vs others would be helpful for other researchers wanting to do similar work. Conclusions about the parents' reactions to their children's responses are also made in the results, however, there is no data presented to support those for the reader to follow as there is for the child participants. Adding in a table of data (quotes and behaviors) would be helpful- however, it is unclear if parents were consented as part of the research study or if their data was adjunct to the study. Clarification in this area is needed if the parents' reactions are presented as part of the findings.</p> <p>In the first sentence regarding loneliness, the statement "the children" implies that all participants felt lonely. If that is the case, it is clearer for the reader to state that all participants indicated that they were 10 out of 10 on the scale.</p> <p>Discussion: It might be helpful for the authors to tie in the conclusion of using adequate pictorial support to engage in interviews with prior work which has also highlighted this need and the effectiveness of using</p>
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	<p>these techniques.</p> <p>Similarly, there are a number of studies which have discussed loneliness and limited social networks for children, teens, and adults with complex communication needs and it would strengthen the discussion to include these works in addition to citation 26.</p> <p>Methodological considerations: A definition of "relevant background" would be helpful here- do the authors mean diagnosis, communication abilities, or something else?</p> <p>Conclusion: Earlier in the results, it appeared that children were worried about their grandparents but in the conclusion it is stated that the children missed their grandparents. It would be helpful to have consistency across both sections.</p>
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REVIEWER	<p>Reviewer name: Dr. Benita Powrie</p> <p>Institution and Country: University of Huddersfield, United Kingdom of Great Britain and Northern Ireland</p> <p>Competing interests: None</p>
REVIEW RETURNED	21-Jan-2022

GENERAL COMMENTS	<p>Thank you for asking me to review this worthwhile and interesting paper that gathers the views of children and young people who were heavily affected by the pandemic, but who are often neglected in research. The authors are to be commended for ensuring these voices are heard. I enjoyed reading this paper and feel it offers important insights on child views and experiences during the pandemic. For example, the amplified impact on school disruption for young people with additional needs owing to loss of opportunities due to absence of key people from the school day is an important consideration and easily overlooked without papers like this drawing it to attention.</p> <p>I have a few recommendations to consider to make the paper stronger and clearer, particularly around the methods.</p> <ol style="list-style-type: none"> 1. Separate the research aim from the methods so it is clearly visible. 2. Ethical considerations: I can see that approval has been given, but I would like to have more information on the organisation providing scrutiny, ie was it a university, national health board, etc to provide assurance on the level of scrutiny the study has had. Please clarify how information on the study purpose was provided for families and children, and what was done to ensure children could provide informed assent. 3. Participants: Please clarify the scope of the study and whether this was national or regional in nature. Please clarify whether all respondents were included in the study. Inclusion and exclusion criteria should also be stated. 4. Data collection: It would support credibility and confidence in this section to include reference to literature on interviewing this population and experience of interviewers in being an effective communication partner for people with communication differences. The experience of the interviewer is referenced in the methodological considerations – but this meant this reader wondered about this all the way through which distracts from the message. Please also state whether the children were known to interviewer or not. <p>Use of field notes should be discussed in data collection, including how these were used to support trustworthiness.</p> <p>The interview guide appears sound and well-constructed for the topic and population, and description of communication strategies appear appropriate.</p> <p>Figure 2 – how did you address the risk of acquiescent answering or responding based on the moment they were asked the question</p>
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	<p>rather than giving a previously held view? Additional questions asking for similar grading on something not likely to happen due to corona would reduce this risk – if you did this, then give an example. If not – then consider whether this was a limitation. It would be helpful to know the time period of the interviews, to situate the experiences of the children and young people within the pandemic overall.</p> <p>5. Data analysis: Steps taken to support trustworthiness such as multiple coders should be discussed in methods section rather than at the end of the paper. This includes how the researchers ensured the children with potential echolalic responses had their views considered.</p> <p>A few typographic errors are noted for correction (line numbers refer to numbers printed on the left hand side of page): Page 6, line 39 – “Recruitment efforts intended to reach children and young people with a variety of disabilities, child gender and parent country of origin” Page 6, line 39-50 move this section to “participants” Page 30, line 50 – typo: “talking and signing” Page 16, line 3 – “we analysed the intonation and engagement” – suggest maintaining third person throughout</p>
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VERSION 1 – AUTHOR RESPONSE

23-Feb-2022

bmjpo-2021-001398 - "Experiences of children with disabilities during the COVID-19 pandemic in Sweden: A qualitative interview study."

Thank you for the opportunity to revise our manuscript entitled "Experiences of children with disabilities during the COVID-19 pandemic in Sweden: A qualitative interview study"

The reviewers' recommendations were constructive, and we believe the revisions have improved the manuscript. We answer the reviewers' comments point-by-point below. A version with the changes marked (in yellow highlight) is submitted alongside the resubmitted manuscript. The given page numbers refer to the PDF document produced by the online system.
The alternations exceeded the words limit by 55 words.

Abstract:

I immediately wondered how the data was analyzed based on the descriptions in the methods and results sections. Also, based on the statement in the conclusion, I was unsure if the parents were interviewed as well as the children.

Answer: Thank you for this comment, we have restructured the abstract and added information regarding the field notes (page 3).

Introduction:

The authors present the case well, although I believe that there might be some additional, relevant research that has taken place since the pandemic (2020 and 2021) which could also be cited to strengthen the authors' case for this particular research study.

Answer: Some additional citations regarding the negative impacts of the pandemic on health behaviours and the mental health of children with disabilities have been added to the Introduction section (page 5).

Methods:

The introductory sentence states "a qualitative methodology" but does not provide citations for the type of methodology used. There are many qualitative methods and it is unclear which method is used at this point as the theoretical underpinning for this study.

Answer: We have added some clarification here, as well as a reference to qualitative content analysis (pages 7-8).

Table 2 (description) refers to “hand signs.” It is unclear if this term refers to individualized signs unique to a child or if they are signs from an established sign language.

Answer: We have clarified that the hand signs referred to are based on Swedish sign language. This clarification is made in Table 1, in the column ‘Mode of primary communication during the interview’(page 6).

Data Collection:

It is unclear if the children attended the same school, different schools, and if they were all located in the same geographic area. More details in this area would be helpful in understanding the sample population and how generalizable the findings might be. Answer: More detail has been added on how the participants were recruited, including clarification that the children varied in place of residence (page 6). The authors provided a wonderful explanation of why the phrase “corona” was used in the study. This is important to include since this is not a universal term.

It would be very helpful to understand the types of information that were collected from the parents prior to the interviews- this could be provided as supplementary information, along with the interview guide.

Answer: The collection of facilitating methods were performed in an unstructured manner. There are now examples of collected information described (page 7).

Providing an average length of time of interviews or a range of time for interviews would be helpful in understanding more about the methods and procedures of this study.

Answer: The range and mean time of the interviews are now described in the methodology section of the paper (page 8).

Data analysis:

I am personally unfamiliar with the citation provided (22) for the analysis. Are there additional references the authors can provide to increase clarity as to the analysis approach used?

Answer: We have added the reference of Elo and Kygnäs, which is a common reference for the chosen methodology (page 8).

Similarly, the authors cite Patton’s textbook (23) and if the BMJ Open citation system allows it, it would be helpful to have a page number. Alternatively, the authors could add a brief sentence explaining how the field notes were used to validate- did all authors review them independently after initial coding of the transcripts? Did they review them together? Did it result in any changes to the coding or the findings?

Answer: We have altered the description of the method to clarify how the field notes were used (page 8).

Ethical statement:

I appreciated the ethical statement. However, I would like more details on how the information was presented, particularly given that some of the participants have intellectual/cognitive disabilities. Was all consent information provided verbally? How did the interviewer check for understanding from the child participant? Were parents also consented since their reactions were included in the analysis?

Answer: Thank you for pointing out this important need for information. Written consent was collected from all custodians of the children. The process for this has been added to the manuscript (page 8-9). Consent was not collected directly from the children, as per Swedish ethical law. However, as described in the manuscript, the interviewer performed an assent process with all children and supported them to identify a ‘stop’ signal if they decided to end their participation at any point.

Table 2 (Results)- Just a note that the table numbering does not seem consistent.

Answer: The table numbering and order has been checked

The first description of “Kim” uses language which can be considered objectifying such as “moves the tongue” instead of “moves their tongue.” I’m certain the authors do not intend to objectify the participants, given the care they’ve taken in providing rationale for including participants with complex communication needs in research. So this is a small edit that can be made and checked throughout the quotes and examples.

Answer: Thank you for highlighting the risk of objectifying the participating children, which we certainly did not intend. We have reviewed the quotes and amended this issue. We have opted to use “their” instead of “he” or “she” to conceal the gender of the child, to protect their identity (page 9-10 and 13).

Results:

In this section the authors conclude that children were not worried about their own health but were concerned about their grandparents. In the supplemental materials, the visual prompt regarding concern is for grandparents. It would be helpful to see the prompts for children about their concern for themselves or others- or have additional details in the methods about how these types of questions were asked. As the manuscript is presented now, it appears that the children were prompted about their grandparents with the visual prompt but not other family members or themselves. If the only visual prompt was for grandparents, more details regarding the methodological choice for that prompt vs others would be helpful for other researchers wanting to do similar work.

Answer: Visual prompts were used throughout the interview. Figure 2 represents only an example, which has been clarified in the manuscript when referencing the figure (page 7).

Conclusions about the parents' reactions to their children's responses are also made in the results, however, there is no data presented to support those for the reader to follow as there is for the child participants. Adding in a table of data (quotes and behaviors) would be helpful- however, it is unclear if parents were consented as part of the research study or if their data was adjunct to the study.

Clarification in this area is needed if the parents' reactions are presented as part of the findings.

Answer: The parents' reactions to their children's response were based on the reflective field notes. We have added examples and quotes to clarify what was included in the field notes (page 9-11).

In the first sentence regarding loneliness, the statement "the children" implies that all participants felt lonely. If that is the case, it is clearer for the reader to state that all participants indicated that they were 10 out of 10 on the scale.

Answer: We have read through the transcripts and found that not all children express their loneliness, therefore we have changed the first sentence regarding Loneliness to "Several children" (page 14).

Discussion:

It might be helpful for the authors to tie in the conclusion of using adequate pictorial support to engage in interviews with prior work which has also highlighted this need and the effectiveness of using these techniques.

Answer: Thank you for this suggestion. We have added a reference mentioning the benefits with pictorial support (page 15).

Similarly, there are a number of studies which have discussed loneliness and limited social networks for children, teens, and adults with complex communication needs and it would strengthen the discussion to include these works in addition to citation 26.

Answer: Thank you for this suggestion. We have added a further citation to the point regarding social networks in the Discussion (page 15).

Methodological considerations:

A definition of "relevant background" would be helpful here- do the authors mean diagnosis, communication abilities, or something else?

Answer: We have added examples of relevant backgrounds (page 16).

Conclusion:

Earlier in the results, it appeared that children were worried about their grandparents but in the conclusion it is stated that the children missed their grandparents. It would be helpful to have consistency across both sections.

Answer: Both aspects, i.e. worrying for and missing grandparents, are mentioned in the Conclusion section as grandparents featured two analysis categories: 'Very worried someone will get sick, especially the elderly' and 'Loneliness and Longing for Granny and Grandpa'.

Reviewer: 2

Dr. Benita Powrie, University of Huddersfield

Thank you for asking me to review this worthwhile and interesting paper that gathers the views of children and young people who were heavily affected by the pandemic, but who are often neglected in research. The authors are to be commended for ensuring these voices are heard. I enjoyed reading this paper and feel it offers important insights on child views and experiences during the pandemic. For example, the amplified impact on school disruption for young people with additional needs owing to loss of opportunities due to absence of key people from the school day is an important consideration and easily overlooked without papers like this drawing it to attention.

I have a few recommendations to consider to make the paper stronger and clearer, particularly around the methods.

1. Separate the research aim from the methods so it is clearly visible.

Answer: We have separated the aim from the methods as suggested (page 5 -6).

2. Ethical considerations: I can see that approval has been given, but I would like to have more information on the organisation providing scrutiny, ie was it a university, national health board, etc to provide assurance on the level of scrutiny the study has had.

Answer: The Swedish Ethical Review Authority approved the study. This information has been added to the manuscript (page 11).

Please clarify how information on the study purpose was provided for families and children, and what was done to ensure children could provide informed assent.

Answer: We have added information about the provision of study information and that the legal custodians of the children gave written consent for the child's participation (page 8-9). As described in the manuscript, the interviewer performed an assent process with all children and supported them to identify a 'stop' signal if they decided to end their participation at any point.

3. Participants: Please clarify the scope of the study and whether this was national or regional in nature. Please clarify whether all respondents were included in the study. Inclusion and exclusion criteria should also be stated.

Answer: We have added inclusion criteria and information that no child was excluded (page 6).

4. Data collection: It would support credibility and confidence in this section to include reference to literature on interviewing this population and experience of interviewers in being an effective communication partner for people with communication differences.

Answer: A reference has been added to the section, alongside information regarding the interviewer's prior experiences (page 7).

The experience of the interviewer is referenced in the methodological considerations – but this meant this reader wondered about this all the way through which distracts from the message. Please also state whether the children were known to interviewer or not.

Answer: We have added this information to the Methodology section of the paper (page 7).

Use of field notes should be discussed in data collection, including how these were used to support trustworthiness.

Answer: The use of field notes has been added to the Data collection section of the manuscript (page 8)

The interview guide appears sound and well-constructed for the topic and population, and description of communication strategies appear appropriate.

Figure 2 – how did you address the risk of acquiescent answering or responding based on the moment they were asked the question rather than giving a previously held view? Additional questions asking for similar grading on something not likely to happen due to corona would reduce this risk – if you did this, then give an example. If not – then consider whether this was a limitation.

Answer: We did not perform grading questions on issues unrelated to the pandemic, which could be considered a limitation. We have added this to the manuscript (page 17).

It would be helpful to know the time period of the interviews, to situate the experiences of the children and young people within the pandemic overall.

Answer: The time period of the interviews has been added to the Data collection section of the manuscript (page 8).

5. Data analysis: Steps taken to support trustworthiness such as multiple coders should be discussed in methods section rather than at the end of the paper. This includes how the researchers ensured the children with potential echolalic responses had their views considered.

Answer: Whilst we have decided to keep these aspects in the Methodological considerations section of the manuscript, the strategy for utterances considered to be echolalia and the collaborative effort of the analysis process are both mentioned in the Data analysis section too (page 8).

A few typographic errors are noted for correction (line numbers refer to numbers printed on the left hand side of page):

Page 6, line 39 – "Recruitment efforts intended to reach children and young people with a variety of disabilities, child gender and parent country of origin"

Page 6, line 39-50 move this section to "participants"

Page 30, line 50 – typo: "talking and signing"

Page 16, line 3 – "we analysed the intonation and engagement" – suggest maintaining third person throughout

Answer: Thank you for pointing out these errors. We have altered the sections as suggested.

VERSION 2 – REVIEW

REVIEWER	Reviewer name: Dr. Benita Powrie Institution and Country: University of Huddersfield, United Kingdom of Great Britain and Northern Ireland Competing interests: None
REVIEW RETURNED	15-Mar-2022

GENERAL COMMENTS	All my suggested changes have been answered satisfactorily. I recommend this interesting and worthwhile paper be published.
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VERSION 2 – AUTHOR RESPONSE

VERSION 3 – REVIEW

REVIEWER	Reviewer name: Institution and Country: Competing interests:
REVIEW RETURNED	

GENERAL COMMENTS	
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REVIEWER	Reviewer name: Institution and Country: Competing interests:
REVIEW RETURNED	

GENERAL COMMENTS	
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REVIEWER	Reviewer name: Institution and Country: Competing interests:
REVIEW RETURNED	

GENERAL COMMENTS	
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VERSION 3 – AUTHOR RESPONSE