

PEER REVIEW HISTORY

BMJ Open publishes all reviews undertaken for accepted manuscripts. Reviewers are asked to complete a checklist review form (<http://bmjopen.bmj.com/site/about/resources/checklist.pdf>) and are provided with free text boxes to elaborate on their assessment. These free text comments are reproduced below.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Understanding parents' experiences of disease course and influencing factors: A three-year follow-up qualitative study among parents of children with functional abdominal pain
AUTHORS	Brekke, Mette; Brodwall, Anne

VERSION 1 – REVIEW

REVIEWER	Rubén Nieto Universitat Oberta de Catalunya Faculty of Health Sciences Spain
REVIEW RETURNED	02-Apr-2020

GENERAL COMMENTS	<p>Thanks for the opportunity to review such an interesting manuscript. I think it has a great potential but I have the following concerns:</p> <p>Introduction:</p> <ul style="list-style-type: none">- A more extensive review of qualitative research in the field of pediatric pain and functional abdominal pain is needed- A better justification of why this study is needed will be useful. What is already available in the literature? <p>Methods:</p> <p>Much more details are needed in relation to important aspects such as children's age (it seems they included a wide range from 5 to 15, can it affect results?), informed consent and ethics committee, procedure for selecting the original sample and for contacting them again three years later, interviewer attitude during interviews, and much other details related to the interviews and procedure...</p> <p>Analysis: Do interviewers agree in relation to the code system developed? Did they use any index for computing agreement? How do they develop their system of codes?</p> <p>Results:</p> <ul style="list-style-type: none">- It is not clear which is the criteria to ascertain that a child is recovered. How should parents express that?- Probably themes and sub-themes would benefit from a more extensive explanation.- I am not a native english speaker, but I feel that the paper would benefit from a professional review of english. <p>Discussion:</p> <p>I think that authors need to review extensively qualitative literature in pediatric abdominal pain and connect their results, discussing agreements and disagreements. Also a more in depth discussion about important limitations such as age (they consider a wide range) or sample should be discussed.</p>
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REVIEWER	Maria Lalouni Karolinska Institutet, Sweden
REVIEW RETURNED	07-Apr-2020

GENERAL COMMENTS	<p>I read the article with great interest and believe this follow-up qualitative study gives important information about the long-term experiences of having a child with a functional abdominal pain disorder. Here are my comments:</p> <ol style="list-style-type: none"> 1. I'm not an expert of qualitative studies I have some concerns about the thematic analysis: The themes identified seem to represent the questions asked rather than themes emerging from the text. For example, the first theme was: 1) How has the child's abdominal pain affected the family during the last three years? I believe a theme would be more like " Family burden and frustration". This goes for all themes and in fact in the conclusion at the end of the discussion "issues about school" and "the importance of a diagnosis" are highlighted. These seem more like themes than the ones described in the Results. 2. The discussion needs more work. The results are not discussed in relation to previous research and quotes are hanging loose. There are many sentences starting "Walker wrote..." or "Sjögård wrote..." Please discuss how your result relates to the findings of other researchers work. 3. Strengths and Limitations page 15. Please describe how does the interviewer describing herself as a scientist improve the interview quality and interpretation? 4. Conclusion page 15. I think it would be a good idea to shorten your intro - and get more directly to your conclusions. 5. Introduction page 4. Could you please describe the main results of your prior study which you are now doing a follow-up on? 6. Introduction page 4, line 8: Please describe what the differences are for functional constipation and provide a reference.
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VERSION 1 – AUTHOR RESPONSE

Reviewer(s)' Comments to Author:

Reviewer: 1

Reviewer Name: Rubén Nieto
 Institution and Country:
 Universitat Oberta de Catalunya
 Faculty of Health Sciences
 Spain

Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below Thanks for the opportunity to review such an interesting manuscript. I think it has a great potential but I have the following concerns:

Response: Thank you for your valuable comments, which we address below.

Introduction:

- A more extensive review of qualitative research in the field of pediatric pain and functional abdominal pain is needed

Response: We conducted a new literature search with the help of a librarian, not only of qualitative research. There is not much done in the field recently, but we included two more references (ref. number 22 and 27).

- A better justification of why this study is needed will be useful. What is already available in the literature?

Response: As far as we have been able to find out through literature searches, this is the first study where the same researcher interviews a complete cohort of parents of children with functional abdominal pain again three years after a first interview. The focus in the first interviews as well as now has been broad – comprising the situation of the whole family, not only that of the child. The parents were able to reveal what had facilitated improvement or also what had not – and we think such information will be valuable for clinicians who treat these patients. We have now pointed this out at the end of the Introduction section.

Methods:

Much more details are needed in relation to important aspects such as children's age (it seems they included a wide range from 5 to 15, can it affect results?),

Response: Actually, for the first interview study in 2016, we deliberately chose to include children over a wide age span, in order to capture various experiences among the parents. We thus did not limit our focus to children of a specific age, but could include children between 5 and 15 years of age. Those who were included, were between 6 and 13.5 years old in 2016. This indeed can affect the results, but in a way that we aimed for. We have now specified this in the Methods section, under the heading Participants and have added the exact age of the included children.

...informed consent and ethics committee,

Response: We obtained written informed consent from all participants, as well as approval from the Ethics committee. According to BMJ Open's Instructions for authors, this is stated at the end of the article under the heading Ethics approval.

.... procedure for selecting the original sample and for contacting them again three years later,

Response: This was the procedure for selecting the original sample, as stated in the article published in 2018 (Parents' experience when their child has chronic abdominal pain: a qualitative study in Norway. Brodwall A, et al. *BMJ Open* 2018;8:e021066. doi:10.1136/bmjopen-2017-021066):
 "We recruited participants referred to a hospital located in a mid-sized Norwegian town that covers 440 000 inhabitants within the town and the surrounding area. Inclusion criteria: Children/adolescents 5–15 years old with abdominal pain, referred to hospital from a GP who had not found a diagnosis to the pain. Exclusion criteria: Inability to communicate in the Norwegian language. A dedicated nurse at the outpatient department recruited parents of children aged 5–15 years recently presenting with RAP. She informed the parents about the study, handed out written information and obtained the phone numbers from those who wished to participate. The first author contacted the parents to arrange an interview. Fourteen parents were interviewed, and saturation was achieved. We did not identify new information by adding more participants. The recruitment was therefore stopped."
 The parents who agreed to participate in 2016, were asked if the researcher could contact them again after 3 years for a second interview, and all parents gave their consent. So, after 3 years, the first author contacted the parents on telephone and asked for a second interview.

We have now added some more information on recruitment, and have also specified that detailed information regarding the original recruitment process can be seen in the former paper – see the Method section under the heading Participants.

.....interviewer attitude during interviews, and much other details related to the interviews and procedure...

Response: We have added information about the interviewer presenting herself as a researcher, to emphasize that she – although being an experience therapist – had no such responsibilities in this setting (also the second reviewer requested this). See the Methods section under the heading Interviews. Otherwise, the interviewer was empathetic, though neutral, and encouraged the parents to speak freely. This has also been added to the article (Methods, Interviews).

Analysis: Do interviewers agree in relation to the code system developed? Did they use any index for computing agreement? How do they develop their system of codes?

Response: As the first author carried out all interviews, there was only one interviewer. Both authors participated to code the data obtained. They did not use computer software in the analyzing process. They discussed the analyzes until they reached agreement. This information has been added to the article – (Methods section, Data analysis).

Results:

- It is not clear which is the criteria to ascertain that a child is recovered. How should parents express that?

Response: Thank you for this remark. We have now added information on the definition of “recovered”: Recovered was defined as no subjective complaints and return to school and other activities (see Results under the heading Current status of abdominal pain).

- Probably themes and sub-themes would benefit from a more extensive explanation.

Response: Also the second reviewer has requested a different presentation of the themes. We agree to your remarks on this matter. We have now carried out an extensive revision of the Results section and have chosen different labels for the themes.

- I am not a native english speaker, but I feel that the paper would benefit from a professional review of english.

Response: Actually, the article has undergone professional language editing already, by one of the firms our department uses for this purpose.

Discussion:

I think that authors need to review extensively qualitative literature in pediatric abdominal pain and connect their results, discussing agreements and disagreements. Also a more in depth discussion about important limitations such as age (they consider a wide range) or sample should be discussed.

Response: As stated above, we have carried out a new literature search on pediatric functional abdominal pain as such, and have also focused on qualitative research in the field. Also according to requests from Reviewer 2, we have re-written the Discussion section to better connect our results to previous research.

Regarding the age span – see above under the heading Methods.

Reviewer: 2

Reviewer Name: Maria Lalouni

Institution and Country: Karolinska Institutet, Sweden Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below I read the article with great interest and believe this follow-up qualitative study gives important information about the long-term experiences of having a child with a functional abdominal pain disorder. Here are my comments:

Response: Thank you for reviewing this manuscript and for your valuable comments, which we address below.

1. I'm not an expert of qualitative studies I have some concerns about the thematic analysis:

The themes identified seem to represent the questions asked rather than themes emerging from the text. For example, the first theme was: 1) How has the child's abdominal pain affected the family during the last three years? I believe a theme would be more like " Family burden and frustration". This goes for all themes and in fact in the conclusion at the end of the discussion "issues about school" and "the importance of a diagnosis" are highlighted. These seem more like themes than the ones described in the Results.

Response: Thank you for pointing this out. We realize that the choice to use the questions in the interview guide as subheadings also in the Results section was not a good one. We have no selected subtitles which relate directly to the themes identified. See "Results" section. We also chose to present fewer citations and instead more of the information drawn from the transcripts.

2. The discussion needs more work. The results are not discussed in relation to previous research and quotes are hanging loose. There are many sentences starting "Walker wrote..." or "Sjögård wrote..." Please discuss how your result relates to the findings of other researchers work.

Response: We agree and have now revised the whole Discussion section – both to omit the direct citations and to more directly link our results to previous studies. We also include two new references (ref. 22 and 27) after doing a new literature search.

3. Strengths and Limitations page 15. Please describe how does the interviewer describing herself as a scientist improve the interview quality and interpretation?

Response: We have added a brief explanation of this. Reviewer 1 requested information on this matter in the Methods section, so we also provide an explanation here (Methods, Interviews).

4. Conclusion page 15. I think it would be a good idea to shorten your intro - and get more directly to your conclusions.

Response: We have followed your advice and have shortened the Conclusion section.

5. Introduction page 4. Could you please describe the main results of your prior study which you are now doing a follow-up on?

Response: We have now briefly added the main results of our former study to the Introduction section.

6. Introduction page 4, line 8: Please describe what the differences are for functional constipation and provide a reference.

Response: We have now pointed out the gender difference in functional constipation, and have added the reference (ref 7).

VERSION 2 – REVIEW

REVIEWER	Maria Lalouni
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	Karolinska Institutet, Sweden
REVIEW RETURNED	21-Jun-2020

GENERAL COMMENTS	<p>I have reviewed the manuscript and am happy with most of the changes made. I believe it ads valuable information about paediatric FAPDs and how these diagnoses are perceived by parents and the impact it may have on the families' lives. I have only a few minor comments:</p> <p>Discussion, page 12 - Please summarize your main results (your themes) before discussing them.</p> <p>Discussion, page 12 - You write: The parents should be advised to reduce concerned responses to their child's pain, focusing on distraction instead. The parents' role and mindset need to be changed from protecting the child from possible harm to being a coach to encourage and support the child to engage in normal activities.</p> <p>This is giving advice in the beginning of the Discussion. In the rest of the Discussion you discuss the results, please change this part too so that your findings are discussed. You have references for the statements above, rephrase them so that it is clear that other studies have found this.</p> <p>If you want to look at an exemple of discussion findings in a qualitative study:</p> <p>https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0164311</p> <p>Conclusion, page 15</p> <p>You state: "This undermines the importance of psychoeducation about the symptoms and pain treatment strategies".</p> <p>Instead of "undermines" I believe you mean "emphasizes" or a similar wording?</p>
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VERSION 2 – AUTHOR RESPONSE

Responses to reviewer

I have only a few minor comments:

Discussion, page 12 - Please summarize your main results (your themes) before discussing them.

Response: We intended to keep the summary of results as brief as possible, but we have now expanded it a little – see page 12.

Discussion, page 12 - You write: The parents should be advised to reduce concerned responses to their child's pain, focusing on distraction instead. The parents' role and mindset need to be changed from protecting the child from possible harm to being a coach to encourage and support the child to engage in normal activities.

This is giving advice in the beginning of the Discussion. In the rest of the Discussion you discuss the results, please change this part too so that your findings are discussed. You have references for the statements above, rephrase them so that it is clear that other studies have found this.

Response: We agree this looks like advice on our behalf, though our intention was to relate our findings to those of other studies. We have now changes this and hope it has become clearer.

Conclusion, page 15

You state: "This undermines the importance of psychoeducation about the symptoms and pain treatment strategies".

Instead of "undermines" I believe you mean "emphasizes" or a similar wording?

Response: Thank you for pointing this out. We actually mean to say "underlines" – and not "undermines". This has now been corrected.