# 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)	Parents' experience when their child has chronic abdominal pain—a
	qualitative study in Norway
AUTHORS	Brodwall, Anne; Glavin, Kari; Lagerløv, Per

# **VERSION 1 – REVIEW**

REVIEWER	Mark Tighe
	Poole hospital,
	Longfleet Rd,
	Poole
	Bh15 2JB
REVIEW RETURNED	14-Dec-2017

This qualitative study is well-written, addresses a useful and important area of paediatrics, that is difficult for many clinicians and tests their communication skills and bond with the families. However I couldn't see a statement regarding informed, written consent, which would be important to include. Establishing a broader base in terms of number of patients and their range of backgrounds would be useful e.g. single parent families (only 2 in this study), and different levels of understanding and healthcare expectations; and looking at those children with other diseases and functional symptoms. Some of the findings are well-known in the literature, but the feelings of siblings, and the parental desire for a quick fix. This study talks about parents saying: 'The doctors were good at informing us that these symptoms are not dangerous, but we know no more about the reasons for the pain, without then suggesting ho to explain+manage the pain and evaluating the acceptability of these techniques (e.g. distraction/CBT) to parents. If we can understand how better to market our formulation of FGID and get better 'buy-in' our ability to support parents' frustrations with our focus on functional rehabilitation. More details are needed on the selection of the cohort: e.g. co-existing diseases and what investigations they had. Parents can feel upset depending on their expectations, which haven't been asked about. Some could feel rightly aggrieved if e.g. coeliac screen hadn't been checked.  Also the authors state in their conclusion: 'However, the parents and the child are often left without any guidance about how to manage the recurrent pain'. This wasn't a specific question/outcome, and so should be amended.

REVIEWER	Amanda Feinstein Stanford University
	US
REVIEW RETURNED	27-Jan-2018

### **GENERAL COMMENTS**

**BMJ Review** 

Abstract

P2 Line 36- It is unclear what is meant by "complained about too much alertness" in this context.

P3. Review wording/phrasing "parent of children" rather than "parents to children." Edit this throughout the paper.

"needle in the haystack" is too colloquial

"general practice in common"- please reword as this is unclear Intro

P5 line 1 "The treatment of paediatric abdominal pain should attempt to focus on the influence of the parents." This sentence is unclear. Be more specific about what you mean by "the influence of the parents."

P5. Are there any specific hypotheses? Please state these after the aims.

Please be consistent in language regarding children, adolescents, youngsters, school-age children etc.

In general, the intro is in need of further development to lead the reader toward the aim of the study. The literature and statistics cited are great, but please build upon this to tell a cohesive and compelling story as to why the current study is being conducted. Methods

In terms of the methodology, can the authors please include a more technical description of their qualitative interview method. Also, were any potential patients (i.e., other stakeholders) included in the development of the questions to be asked in the interviews? Recruitment

What were the inclusion and exclusion criteria? Please state. Please say more about the decision to stop recruitment after 14 interviews (i.e., theoretically or based on literature).

Interviews

Location of the interviews may be a confounding variable. Did authors consider how it may impact families to be interviewed at work and home compared to in a clinical setting? Also, what confidentiality practices were put in place regarding interviews at the parents work place?

Data Analysis

Typically more than one person must transcribe in order to provide reliability of the transcription/data.

Results

The first few sentences of this section describing the participants is very confusing. Please rework this section so that it flows better. Table 2. Replace "boy and girl" with male and female. It may be better to state in the text the N and % for male and female, rather than having this in the table as it takes up so much room. Same recommendation for the parent interviewed. Also, please consider an alternate table format, perhaps an APA style format. "pain as a family project" does not seem to be a title that well captures the section discussed on p9. Consider an alternate title. What is the "index child?"

I would avoid including details about which case # said which comments as this may compromise confidentiality, given that you list ages, birth order and sex of the child for each case. If families were to read the research, they may be able to discern which case they are.

P10 line 3. "Humiliating"- may consider a different word choice as this was not directly stated by families and may be an overexaggeration

Discussion

P11. Consider replacing the term "common project" P 11 paragraph 2- NICE!

#### Conclusions

"These families need a competent doctor to discuss handling the pain in daily life and strategies for its management." Is this sentence implying that the doctors who treat families who refuse to buy-into a functional diagnosis are incompetent? There are many competent and wonderful physicians who treat kids with abdominal pain, who have patients (and families) who refuse to believe or accept a diagnosis. There are also many families who are treated in interdisciplinary clinics with multiple providers- MD, psychologists, physical therapists, nutritionists etc- who also still refuse to believe their diagnoses.

Authors may wish to delve further into the work of Lynn Walker and Rona Levy, both of whom have conducted great research on CBT for chronic pain and include parents in their CBT work with families. I would greatly caution the authors against concluding their paper by suggesting that most families are left with inadequate care. I do not know the medical system in Norway and can only speak to my experiences in the U.S. and based on much literature from North America. Functional pain is a delicate subject that certainly takes a caring physician, time spent ruling out other diagnosis, and finesse in providing psycho-education. I think the conclusion could have focused more on the kinds of topics to be addressed in CBT interventions or medical interventions that can be utilized in primary care.

I think one of the overarching issues that may need to be addressed is that this paper seems to be discussing how patients are treated in primary care, and not necessarily how they are managed in a specialty clinic such as GI or a pediatric pain clinic. Authors may consider focusing more in the intro and in the discussion section on types of interventions utilized by GI's and psychologists, and then compare that to how FGID's are managed by primary care doctors, leading to an important argument that more PCP's must be equipped with the tools needed to support those with FGID's.

# **VERSION 1 – AUTHOR RESPONSE**

We have done changes in the Strengths and Limitations section according to your recommendation. Table 2 is removed, some of the information is now written in the text.

We have included a Patient and Public Involvement statement in the main manuscript.

Dear Reviewer 1
Mark Tighe
Poole hospital, Longfleet Rd, Poole, Bh15 2JB

Thank you for your comments to our article.

The statement regarding informed, written consent is in the Declaration page 14 according to BMJ Open's instructions for authors.

In this study we did not focus on the backgrounds of the parents using a convenient sampling.

The number of patient in the study is commented on in Recruitment page 7, obtaining saturation of information.

It would have been interesting to find out more about how better to market our formulation of FGID and get better "buy-in" our ability to support parents' frustration but in this study we have focused on the parents experience with having a child with FGID in the family.

We have now in page 7, Recruitment, written inclusion and exclusion criteria.

All the children had a physical examination in the paediatric department in the hospital as written in the article. We have not focused on the somatic examination of the children but on parents' experience when their child was discharged without a somatic explanation.

The statement: 'However, the parents and the child are often left without any guidance about how to manage the recurrent pain' was a response to specific questions and appeared through communication with the parents. This was mentioned by the parents in the interview as a response to question 9 and 10 in the interview guide.

Dear Reviewer 2 Amanda Feinstein Stanford University, US

Thank you for your comments to our article.

We have done changes according to your recommendations.

P2: We have changed the word in the sentence.

P3: We corrected "parents to children " also throughout the paper.

Intro.

P5: We have changed the sentences here to: "The parent's response to the paediatric abdominal pain should be in focus as an important part of the treatment".

As this is a qualitative study we have chosen not to have specific hypotheses because we wanted to explore the experience of the parents.

We have used the expression that is mentioned in the original articles (school-age children etc.). The word Youngsters is replaced.

The intro: We have made changes according to your suggestions to why the current study has been conducted.

#### Methods.

The technical description of the qualitative interview: Please see changes in Recruitment; data analysis and interviews.

In the development of the questions no patients were included, but medical students made comments.

### Recruitment.

Inclusion and exclusion criteria are now stated.

We have written more about saturation after 14 interviews.

### Interviews.

We have given more information on location of the interviews in the paper.

## Data analysis.

All three authors read the transcript individually while listening to the audiotape and worked together on their interpretation to achieve a common understanding. Thus inaccuracies in the transcript could be corrected.

## Results.

We have reworked the first sentences of the section and removed Table 2. Some of this information is now written in the text.

"Pain as a family project" is changed to "How the pain rules the family"

We wanted to show that most of the interviews were used in the article by applying a number of the informant to the statements, but accept that the numbers are removed because of confidentiality. P10 "Humiliating" is replaced with "hurting".

P11. The term "Common project" is rewritten.

#### Conclusion.

In Norway there are no interdisciplinary clinics with multiple providers for these children. The GPs must handle these patients themselves.

In this article we have focused on the parent's experiences and not on types of interventions utilized by GP's and psychologists etc. This indeed is very interesting and could be an idea for another article.

#### **VERSION 2 - REVIEW**

REVIEWER	Mark Tighe
	Poole Hospital, UK
REVIEW RETURNED	05-Mar-2018

GENERAL COMMENTS	This reads much better: and the improvements are clear. Couple of minor suggestions:
	'There is not always a multidisciplinary level of care between the GP and the specialist services.' needs clarifying.
	Change to 'A dedicated nurse at the outpatient department recruited parents OF children aged 5-15 years old recently PRESENTING WITH recurrent abdominal pain.'
	Change 'When fourteen interviews were completed, saturation was achieved.' recommend rephrasing this.
	Change: 'quite room' Rephrase: To change THE parent's responses to this pain, even a brief phone-call applying social learning and cognitive behavioural
	therapy instead of an impersonal contact could be effective' Otherwise this is a valuable addition to the literature. I'd recommend someone with an expertise in qualitative studies reviews the
	methodology if not already performed.

### **VERSION 2 – AUTHOR RESPONSE**

### **Editorial Requirements:**

- Please work to improve the quality of English throughout the manuscript, either with the help of a native speaking colleague or with the assistance of a professional copyediting agency.

The English is edited by a native speaking colleague.

- Please revise the Strengths and Limitations section (after the abstract) to focus on the methodological strengths and limitations of your study rather than summarizing the results.

We have done changes in the Strengths and Limitations section according to your recommendation.

Reviewer: 1

Reviewer Name: Mark Tighe

<sup>&</sup>quot;Index" child is changed to "the affected child".

Institution and Country: Poole Hospital, UK Please state any competing interests: None

Please leave your comments for the authors below

This reads much better: and the improvements are clear. Couple of minor suggestions:

'There is not always a multidisciplinary level of care between the GP and the specialist services.' needs clarifying.

This is now clarified in the text.

Change to 'A dedicated nurse at the outpatient department recruited parents OF children aged 5-15 years old recently PRESENTING WITH recurrent abdominal pain.'

Changes are done.

Change 'When fourteen interviews were completed, saturation was achieved.' recommend rephrasing this

We have rephrased the sentence.

Change: 'quite room'

Changes are done.

Rephrase: To change THE parent's responses to this pain, even a brief phone-call applying social learning and cognitive behavioural therapy instead of an impersonal contact could be effective'

Changes are done.

Otherwise this is a valuable addition to the literature. I'd recommend someone with an expertise in qualitative studies reviews the methodology if not already performed.

Thank you.