

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)	Perception of first respiratory infection with <i>Pseudomonas aeruginosa</i> by people with cystic fibrosis and those close to them: an online qualitative study.
AUTHORS	Palser, Sally; Rayner, Oliver; Leighton, Paul; Smyth, Alan

VERSION 1 - REVIEW

REVIEWER	Janice Abbott Professor of Health Psychology University of Central Lancashire UK
REVIEW RETURNED	22-Jun-2016

GENERAL COMMENTS	<p>The authors have undertaken a novel piece of work in which parents and people with CF are given 'a voice', so that their perspective of first infection with <i>Pseudomonas aeruginosa</i> may be incorporated into future patient management, delivering better care to patients and families. The work will add to the existing literature.</p> <p>Introduction and rationale The introduction is succinctly written with a clear rationale and aim of the work.</p> <p>Methods The choice of methodology is appropriate in cystic fibrosis and the authors have presented their justification for this.</p> <p>The manuscript requires a short statement concerning ethics / consent.</p> <p>How were the items developed for the survey? (Clinician / patient experience, from the literature?).</p> <p>Data analyses and interpretation The information available as to the characteristics of the sample is limited: there are approximately 68% parents and 25% people with CF. Typically, this would be a problem, but it likely that clinical status, age, gender, country of residence etc. is of little importance as the message is generic and global. A useful variable would have been whether or not parents/patients have actually experienced first PA acquisition. Many have, as the quotes illustrate, and this could be made explicit when reporting the data.</p> <p>The analyses of the data have been undertaken with considerable</p>
-------------------------	---

	<p>meticulousness and integrity. The validity checks demonstrate scientific rigor, although it would be helpful to know how much initial agreement there was between authors and how disagreements were resolved.</p> <p>The lengthy, textual way in which qualitative information is presented can be off-putting to readers who want to glean information easily from a paper. The authors could consider:</p> <p>a. Tabulating thematic data so that it is more easily accessible to the reader.</p> <p>b. It may also be useful to separate the responses from parents and people with CF as clinicians may need to communicate different information to these groups (unless there is evidence from the data that this would be futile).</p> <p>Figure 2 is difficult to interpret and requires clarification. How were the 'words in context' used to generate the three themes? Does each questions and their 'words in context' generate an associated theme or was all the data used to generate the themes, which happened to be 3 in number?</p>
--	---

REVIEWER	Donald R VanDevanter, PhD Case Western Reserve University School of Medicine United States
REVIEW RETURNED	06-Jul-2016

GENERAL COMMENTS	<p>This is a carefully described and concise analysis that describes psycho-social aspects of a sentinel event in the progression of cystic fibrosis.</p> <p>A few minor suggestions:</p> <p>Unless a reader is intimately familiar with CF, it may not be obvious that the article is dealing with AIRWAY infection with Pseudomonas aeruginosa (never really clearly stated in the introduction or Discussion). This is particularly relevant as there is discussion of patient perception of infection avoidance techniques and a feeling of infection inevitability. If this were bacteremia or a soft tissue infection, then precautions would be relatively straightforward (as they are for hepatitis or hemorrhagic E. coli) and these patient reactions would seem somewhat irrational. As we know, they are unfortunately not irrational at all, as we all have to breath. (Also, without this clarification, it would not be clear why the term 'lung' was excluded from algorithms).</p> <p>The authors might consider a bit of consolidation in the Discussion, including trimming the amount of Method recapitulation.</p> <p>Title: shouldn't it be "an" online survey?</p> <p>Page 11, Line 17: I think there may be a "PA" missing here</p>
-------------------------	--

VERSION 1 – AUTHOR RESPONSE

REVIEWER(S)' COMMENTS TO AUTHOR

Reviewer: 1

Reviewer Name: Janice Abbott

Institution and Country: Professor of Health Psychology, University of Central Lancashire, UK

The authors have undertaken a novel piece of work in which parents and people with CF are given 'a voice', so that their perspective of first infection with *Pseudomonas aeruginosa* may be incorporated into future patient management, delivering better care to patients and families. The work will add to the existing literature.

Response: We thank the reviewer for these positive comments.

INTRODUCTION AND RATIONALE

The introduction is succinctly written with a clear rationale and aim of the work.

Response: Thank you.

METHODS

The choice of methodology is appropriate in cystic fibrosis and the authors have presented their justification for this.

The manuscript requires a short statement concerning ethics / consent.

Response: A statement has been added to the methods section. "The Research Ethics Committee of the Faculty of Medicine & Health Sciences, University of Nottingham, indicated that the research did not require formal ethical approval."

How were the items developed for the survey? (Clinician / patient experience, from the literature?).

Response: Our survey was designed, based on the experiences of people with CF. We have added an explanation of this.

DATA ANALYSES AND INTERPRETATION

The information available as to the characteristics of the sample is limited: there are approximately 68% parents and 25% people with CF. Typically, this would be a problem, but it likely that clinical status, age, gender, country of residence etc. is of little importance as the message is generic and global. A useful variable would have been whether or not parents/patients have actually experienced first PA acquisition. Many have, as the quotes illustrate, and this could be made explicit when reporting the data.

Response: Space was limited in the online questionnaire and we did not ask specifically if each respondent had direct experience of first infection with *P. aeruginosa*. In retrospect, we believe it would have been useful to ask this question. However, from review of the free text responses, 164 of 393 (42%) respondents made direct reference to their experience of first infection with *P. aeruginosa*. We have added this information in the results section.

The analyses of the data have been undertaken with considerable meticulousness and integrity. The validity checks demonstrate scientific rigor, although it would be helpful to know how much initial agreement there was between authors and how disagreements were resolved.

Response: Thank you for these positive comments. We have added a clarification of how keywords-in-context were selected and how disagreements were resolved. "Keywords-in-context were selected independently by two authors (SP and PL) with disagreements adjudicated by a third author (AS)."

The lengthy, textual way in which qualitative information is presented can be off-putting to readers who want to glean information easily from a paper. The authors could consider:

- a. Tabulating thematic data so that it is more easily accessible to the reader.
- b. It may also be useful to separate the responses from parents and people with CF as clinicians may need to communicate different information to these groups (unless there is evidence from the data that this would be futile).

Response: We thank the reviewer for these comments. We have added table 1 which gives examples of the codes contributing to each theme, together with example quotations corresponding to each code. We believe this will provide a summary of our qualitative data and an illustration of how they have been derived. This should help the reader with little time. The narrative results section will give a more nuanced interpretation. We have documented which quotations are from parents and which are from people with CF, in the narrative results section and the new table.

Figure 2 is difficult to interpret and requires clarification. How were the 'words in context' used to generate the three themes? Does each questions and their 'words in context' generate an associated theme or was all the data used to generate the themes, which happened to be 3 in number?

Response: We apologise that this was not clear. We have added an explanation to the paragraph entitled "Key words, words in context and themes". "The words in context (from questions 2 to 4) contributed to all of the three themes identified and these themes are shown in the grey boxes on the right."

Reviewer: 2
Reviewer Name

Donald R VanDevanter, PhD

Institution and Country

Case Western Reserve University School of Medicine
United States

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

Please leave your comments for the authors below

This is a carefully described and concise analysis that describes psycho-social aspects of a sentinel event in the progression of cystic fibrosis.

Response: We thank the reviewer for these positive comments.

A few minor suggestions:

Unless a reader is intimately familiar with CF, it may not be obvious that the article is dealing with

AIRWAY infection with *Pseudomonas aeruginosa* (never really clearly stated in the introduction or Discussion). This is particularly relevant as there is discussion of patient perception of infection avoidance techniques and a feeling of infection inevitability. If this were bacteremia or a soft tissue infection, then precautions would be relatively straightforward (as they are for hepatitis or hemorrhagic *E. coli*) and these patient reactions would seem somewhat irrational. As we know, they are unfortunately not irrational at all, as we all have to breath. (Also, without this clarification, it would not be clear why the term 'lung' was excluded from algorithms).

Response: We thank the reviewer for this point and we have clarified that our qualitative research deals with respiratory infection with *P. aeruginosa* in people with CF. We have changed the title of the paper to: "Perception of first respiratory infection with *Pseudomonas aeruginosa* by people with cystic fibrosis and those close to them: an online qualitative study." We have also made it clear that we are referring to respiratory infection with *P. aeruginosa* at key points throughout the text.

The authors might consider a bit of consolidation in the Discussion, including trimming the amount of Method recapitulation.

Response: The recap of the methodology in the "Discussion" section has been trimmed as requested.

Title: shouldn't it be "an" online survey?

Response: Thank you. This has been corrected – see above.

Page 11, Line 17: I think there may be a "PA" missing here

Response: Thank you, this has been added.

VERSION 2 – REVIEW

REVIEWER	Donald R VanDevanter, PhD Case Western Reserve University School of Medicine USA
REVIEW RETURNED	23-Aug-2016

GENERAL COMMENTS	Thank you for carefully addressing my comments. This is a useful addition to the literature
-------------------------	---