

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.

This paper was submitted to a another journal from Archives of Disease in Childhood but declined for publication following peer review. The authors addressed the reviewers' comments and submitted the revised paper to BMJ Paediatrics Open. The paper was subsequently accepted for publication at BMJ Paediatrics Open.

ARTICLE DETAILS

TITLE (PROVISIONAL)	Using the Internet to cope with Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis in adolescence: a qualitative study
AUTHORS	Brigden, Amberly; Barnett, Julie; Parslow, Roxanne; Beasant, Lucy; Crawley, Esther

VERSION 1 - REVIEW

REVIEWER	Reviewer name: van de Putte, Elise Reviewer Affiliation: Wilhelmina Children's Hospital, General Pediatrics No competing interests
REVIEW RETURNED	27-Oct-2017

GENERAL COMMENTS	<p>This is a well conducted qualitative study on an interesting and controversial topic.</p> <p>Abstract OK Introduction Clinicians are reluctant in accepting internet as a resource for their patients (this week in the English newspapers: GP's block patients who google). It's important to mention this reluctance of clinicians. This article may diminish this reluctance and bridge the gap between clinicians and their patients.</p> <p>The authors elaborate on the advantages of the internet but they could elaborate more on the possible disadvantages by giving examples of misleading or inaccurate medical information and their possible deteriorate effect. Could it be a disadvantage that CFS/ME adolescents won't give up their diagnosis and want to continue being a patient with CFS/ME, identifying themselves with their (internet) peers?</p> <p>Methods</p> <ul style="list-style-type: none"> • Selection of participants, it seems important to select participants who are in different stages of disease: start, middle, end, cured. • How were the interviewers trained? • Procedure: please refer to the (online) interview topic guide <p>Results</p> <ul style="list-style-type: none"> • Mean disease duration? • Duration of interview? <p>Themes s 30: 2x 'this'</p> <p>Implications</p>
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	<ul style="list-style-type: none"> • Could you encourage patients to write their narrative and share this with other patients? • Training of clinicians: please elaborate on this important remark. How would you train clinicians? Give examples.
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REVIEWER	Reviewer name: Andrew, Kennedy Reviewer Affiliation: Central Paediatrics I have no conflict of interest.
REVIEW RETURNED	27-Oct-2017

GENERAL COMMENTS	<p>I enjoyed reading the paper but I feel the very small non randomised sample size severely restricts any broad implications from this sample being seen as representative for adolescents with CFS/ME. I believe the paper needed a larger sample size, inclusive of severely affected individuals as well as those from non english speaking background and those that don't attend a specialist service. I believe the views of those who didn't self identify as using the internet would have been useful in potentially helping to find out why they didn't and what they would be looking for in such sites.</p> <p>I was quite surprised by the lack of any respondents describing any negative or unhelpful sites, apart from the odd 'dark' patient story, as this had been raised an potential concern in the introduction. Either they did and it was not reported or they didn't and found almost all sites helpful but this seems unlikely to be the case for all patients accessing health data on CFS/ME so agin suggests the sample size was too restrictive.</p> <p>I believe this study could and should be a basis for more expansive research in this area.</p>
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VERSION 1 – AUTHOR RESPONSE

Comments from reviewer 1

This is a well conducted qualitative study on an interesting and controversial topic.

Abstract: OK

Comment: Introduction Clinicians are reluctant in accepting the internet as a resource for their patients (this week in the English newspapers: GP's block patients who google). It's important to mention this reluctance of clinicians. This article may diminish this reluctance and bridge the gap between clinicians and their patients.

Response: This is a useful comment and highlights the timely nature of the paper. We agree that this is an interesting point to make in our introduction, and we now state the following:

“These conflicting findings, and the associated uncertainty about the potential impact of accessing online resources on patient’s responses to their condition, may underpin clinicians’ reluctance in accepting the internet as a resource for their patients [references]”.

References:

<https://www.independent.ie/irish-news/health/patients-told-to-stop-using-dr-google-and-go-to-gp-35995590.html>

Ahluwalia S, Murray E, Stevenson F, Kerr C, Burns J. 'A heartbeat moment': qualitative study of GP views of patients bringing health information from the internet to a consultation. *Br J Gen Pract*. 2010;60(571):88-94.

Comment: The authors elaborate on the advantages of the internet but they could elaborate more on the possible disadvantages by giving examples of misleading or inaccurate medical information and their possible deleterious effect. Could it be a disadvantage that adolescents with CFS/ME won't give up their diagnosis and want to continue being a patient with CFS/ME, identifying themselves with their (internet) peers?

Response: Theme development was driven by the data. The disadvantage of internet was not one of the major themes developed from the data. We specifically highlight this in the results as we state:

"The majority of participants did not highlight the potential negatives, such as reading personal stories of suffering. This tended to be a marginal part of the experience and participants employed strategies to manage negatives."

We also address this issue in the discussion, highlighting some of the reasons being this finding:

"The power-balance and age-dynamic could have meant that the adolescents may have felt discouraged from sharing certain behaviours and experiences with an adult, for fear of disapproval, shame or embarrassment."

We feel that it would be over-interpreting the data if we stated that internet use could mean that they would not want to give up their identity, as this is not something that participants discussed.

Comment: Methods Selection of participants, it seems important to select participants who are in different stages of disease: start, middle, end, cured.

Response: We have added a table which shows the number of months from initial assessment to the date of interview in order to provide a sense of where the participants were in the stage of their condition. There is a range of newly diagnosed (4 months), to those that have been experienced the condition more chronically (25 months). We also now state in the results:

"Participants were at different stages of the condition; the mean number of months from initial assessment to interview was 12.89 months (SD 7.98) with a range of 4 months to 25 months. See table 1 for the participant demographic and clinical characteristics.

Comment: How were the interviewers trained?

Response: We have added the following to the methods section:

"The interviewer was completing an MSc in Health Psychology which covered qualitative methods. Practical training and guidance was provided through supervision and guidance around development of the topic guide as well as interviewing style."

Comment: Procedure - please refer to the (online) interview topic guide

Response: We now refer to the topic guide in the methods section under the new sub-heading "Topic guide".

Comment: Results Mean disease duration?

Response: We now present a results table which shows the number of months from initial assessment to the date of interview (see above). Comment: Themes s 30: 2x 'this' deleted

Response: Thank you for spotting this. We have now corrected this typo.

Comment: Implications Could you encourage patients to write their narrative and share this with other patients?

Response: We have slightly expanded the implications section of the discussion to provide more detail about improvements that could be made to the current information provision, including the use of patient narratives or vignettes.

We now state: "Content could be improved by providing information that is important to young people: symptoms, treatments and ways to explain the condition to peers. Content could also be improved by: providing a greater depth of information; using storytelling and patient vignettes; and ensuring language is age-appropriate. Incorporating technological affordances for example videos and interactive interfaces, may also be beneficial."

Comment: Training of clinicians: please elaborate on this important remark. How would you train clinicians? Give examples.

Response: We now state:

"... training could be useful to address this. This could include training clinicians about the type of sites young people visit; exploring clinician's views and balancing any negative attitudes with the potential benefits that young people report; and exploring ways clinicians can open-up conversation about internet use."

Comments from reviewer 2 Comments to the Author I enjoyed reading the paper but I feel the very small non-randomised sample size severely restricts any broad implications from this sample being seen as representative for adolescents with CFS/ME. I believe the paper needed a larger sample size, inclusive of severely affected individuals as well as those from non-english speaking background and those that don't attend a specialist service. I believe the views of those who didn't self-identify as using the internet would have been useful in potentially helping to find out why they didn't and what they would be looking for in such sites.

Response: Thank you. We are not clear why the reviewer wanted a randomized sample as this is a qualitative study. Whilst we agree that the sample size is small, we believe that this study still adds value. We discuss the limitations of the sample size in the results. We state:

"The sample size is small, and a larger sample may have added richer data to themes and may have also allowed for greater exploration of deviant cases. ... Participants classified themselves as White British and therefore the findings may not apply to other Ethnic backgrounds. Participants were recruited from a specialist CFS/ME service, those who chose not to or who are unable to access specialist treatment may use the internet differently"

We agree that an interesting area for future research could be to explore the acquisition of information and support for those who do not use the internet. However, the research question of this current study was how young people with CFS/ME use the internet. Therefore, the research question could not be addressed with participants who did not use the internet.

The decision not to include severely affect patients, was a decision based on ethical grounds. We did not include severely affected participants as we felt that in these cases, there was too great a potential for the interviews to exacerbate symptoms.

We have clarified this in the methods section, we now state:

"Adolescence were excluded if they ... were severely affected5 (as we felt there was a risk that the interview might make symptoms worse)."

Comment: I was quite surprised by the lack of any respondents describing any negative or unhelpful sites, apart from the odd 'dark' patient story, as this had been raised as a potential concern in the introduction. Either they did and it was not reported or they didn't and found almost all sites helpful but this seems unlikely to be the case for all patients accessing health data on CFS/ME so again suggests the sample size was too restrictive

Response: As discussed above, theme development was driven by the data. The disadvantage of internet was not one of the major themes developed from the data. Comment: I believe this study could and should be a basis for more expansive research in this area.

VERSION 2 – REVIEW

REVIEWER	Reviewer name: Andrew Kennedy Institution and Country: Paediatrician and Adolescent and Adult Medicine Physician (private practice) Sydney, Australia. Competing interests: Nil
REVIEW RETURNED	29-Apr-2018

GENERAL COMMENTS	<p>I reviewed an earlier iteration of this paper and am delighted to review this version which is much improved. The paper now better explains methodology, expands upon the information obtained in the interviews and better explains the power of the study despite a relatively small sample size. I think the strengths and limitations are also better discussed and the discussion and conclusions drawn are much more clearly described.</p> <p>I am recommending this paper be accepted and I do not think further revision is required.</p>
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REVIEWER	Reviewer name: david Vickers Institution and Country: CCS NHS Trust UK Competing interests: none
REVIEW RETURNED	21-May-2018

GENERAL COMMENTS	I think this is a useful study, and gives insight into how young people seek out information and support.
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