Author's response to reviews

Title: Patient experiences, attitudes and expectations towards receiving information about anti-TNF medication: A qualitative study

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Author's response to reviews: see over
Dear Editor,

Thank you for consideration of our paper entitled “Patient experiences, attitudes and expectations towards receiving information about anti-TNF medication” for publication in BMC Musculoskeletal Disorders.

Although the third reviewer’s feedback was submitted late, we have responded to all comments and made changes to the manuscript accordingly. Please see our responses below.

Yours Faithfully,

Dr Paul Arkell
Reviewer 1 comments:

My one major comment is on the limitation of the sample set selected. In particular, this was a cohort of patients who all appear to have responded to anti-TNF therapy, were currently doing well, and had experienced only minor infections while on therapy. The authors should discuss that this experience might be different from a patient who did not respond to therapy or had experienced a more common but serious adverse event, such as infection, as their feelings around information provided may be substantially different. The authors do mention recall bias in their discussion but I think this should be brought out further.

The following amendments have been made to paragraphs 7 and 8 of the discussion:

- Following passage added: “While this sample size would routinely be seen as adequate for this type of qualitative research, incorporating the opinions from a wider spectrum of people may have generated more themes. All participants were under the care of a single rheumatology centre, and experience of information received at other sites may be different. All participants were successfully established on anti-TNF therapy and the experience of individuals who have discontinued the medication may be different, potentially with less willingness to trade risk of adverse reaction for potential symptomatic relief, and a desire for more information about new medications.”

- Following passage added: “It is possible they did not accurately recall the information they received or what form it was in. Importantly there was also potential for participants to confuse information relating to anti-TNF with information from previous counselling sessions for other rheumatoid arthritis medications over the years.”
Reviewer 2 comments:

Major compulsory revisions:

1) Abstract: The final line of the results section does not present the results on the experience of anti-TNF. Please could this be expanded.
   
   - Following sentence added: “Most were positive, describing effects on quality of life as well as symptoms.”

2) Methods: The authors state that they use Colaizzi’s procedural steps for content analysis. The term content analysis is often used more to describe a quantitative approach (e.g. X number of patients thought...). How does Colaizzi’s steps differ from traditional content analysis to produce thematic results? It would help to have more clarity in this section.
   
   - Following passage added: “Data analysis used content analysis combined with Colaizzi’s procedural steps.[13] Whereas content analysis involved identifying recurring words and themes from the focus group data. The addition of Colaizzi’s procedural steps provided a framework which enabled the researchers to move beyond the stage of solely identifying the themes to exploring the meaning (and its significance) relating to the themes. This approach increased the researchers understanding of the experience and information needs of patients taking anti-TNF therapy”

3) My understanding of this is that it uses a Phenomenological approach.
   
   - See response to 2 above.

4) Results: Theme 1 – final sentence. Please add a quote to evidence the statement that participants expressed their trust in the rheumatology team, as the finding that participants will deliberately hide symptoms of infection indicates they do not trust their medical team enough to be fully open with them.
   
   - Following quotations added: “[Named rheumatology nurse and doctor], they’re like God to me. What they say goes! You know, I feel, I’ve got a lot of confidence in them. I feel like I trust them with my life.” – Val. “What I like is that she’s at the end of the phone ... you know, if we were worried we could always get hold of her.” – Helen

5) Discussion: Could the authors comment on the small number of participants in the limitations of this study and the fact that all participants had received their information from one centre.
   
   - Following passage added: “While this sample size would routinely be seen as adequate for this type of qualitative research, incorporating the opinions from a wider spectrum of people may have generated more themes. All participants were under the care of a single rheumatology centre, and experience of information received at other sites may be different. All participants were successfully established on anti-TNF therapy and the experience of individuals who have discontinued the medication may be different, potentially with less willingness to trade risk of adverse reaction for potential symptomatic relief, and a desire for more information about new medications.”

Minor essential revisions:

1) Throughout: The word data is plural, i.e. data are not data is
2) Throughout: The repeated use of the word compliance implies that patients are passive in their care, adherence is a more usual word

- **Amendment made**

3) Introduction: Para 1 – could the authors provide a reference for the European Medicines Agency 1999

- **Amendment made**

4) Methods: Para 3 – 1st line – could the authors state one male and one female focus group - I appreciate that it is later stated that 2 groups were used (and this is indicated by the 2 different durations) but it would be useful to have this information explicitly at this point.

   - Passage changed to: In May 2011 two facilitated focus groups (one male and one female) took place in a conference room at HRC. These lasted 108 and 94 minutes duration respectively.

5) Methods: Final para – the practice of asking participants to validate the analysis is more recently thought to be unnecessary in qualitative research. However, I appreciate that this is one of Colaizzi’s procedural steps. Please add the Colaizzi reference again here (perhaps after ‘To validate the analysis’) to clarify that this is why this was done for a reader who is not familiar with these steps.

   - **Amendment made.**

6) Results: Para 1 – Could the authors rephrase the first line in order to clarify the numbers. At the moment this sentence reads as though there were 10 participants in each focus group, but my understanding from the rest of the manuscript is that 10 participants took part in total (5 in each group).

   - Passage changed to: Out of the 10 men and 10 women who were invited, five of each agreed to take part.

**Discretionary revisions:**

1) Title: The quote from Helen in Theme 1: “It could give me two heads and I’d still try it” would make a nice addition to the beginning of the title – describing the findings and may capture the attention of a potential reader.

   - **Amendment made. Thanks for this suggestion.**

2) Abstract: In the results section, last sentence of 1st para, the authors may consider altering the word ‘admitted’ to ‘reported’. The word ‘admitted’ feels judgemental.

   - **Amendment made.**

3) Abstract: In the conclusion, the authors may consider mentioning the issue of concealing illness as this is an important finding

   - **Amendment not made as this is already outlined in the results section of the abstract.**
4) Results: Theme 1: Line 10 – as in point 1, the word ‘admitted’ feels judgemental, would the authors consider changing this.

- Amendment made.

5) Discussion: 3rd Para discusses active and passive decision making. Would the authors consider commenting on whether this might relate to Leventhal’s active and passive coping strategies and whether this might point to a future area of research?

- A discussion on the use of different theoretical constructs for active/passive strategies was felt to be outside the intended scope of this paper.
Reviewer 3

1) The sample size is too small (5 in each focus group) for the study to be conclusive.

   - We are unable to agree with this reviewers comment, we feel that 10 participants would routinely be seen as adequate numbers for qualitative research - the numbers needed for qualitative research are commonly much lower than those in quantitative studies.

2) The time allocated for each focus group (94 and 108 minutes) was very short, regarding the introductory talk delivered by group facilitator and multiple subjects considered in the topic guide. I wonder if there was enough time for each patient to speak freely or even speak about the subjects proposed in topic guide.

   - The length of the focus groups was dictated by the group not the facilitator, with adequate opportunity for participants to discuss the topic areas. These comments could be inserted into the paper, but the team feel that these comments simply reflect normal practice and would not add to the paper by inclusion.

3) The patients selected were not in different ages (at least in female group) or disease activity. They had all severe disease regarding pre-treatment DAS levels.

   - In the UK, RA patients have to be above a level of severity (DAS > 5.1) to be eligible for treatment with anti-TNF. Assuming that all units comply with NICE guidance, this study reflects disease severity that would be encountered in normal clinical practice across the UK.

4) The major concern is that the authors did not present any model how they had identified their 4 themes. According to streamlined code-to-theory models for qualitative inquiries, we need at least to know the codes and how these codes were categorized to reach those themes.

   - Please see the response to reviewer 2, who requested more information on how Colazzi's steps are used for content analysis. This gives a clear description of how the themes were identified.

5) In discussion: There were no analysis on the findings, and the authors have not presented any theory based on their themes and results. They had no discussion regarding different factors influencing patients' attitude and expectations in various communities (such as cultural background, disease severity, insurance and providers, etc).

   - The authors do not feel that it would be accurate or practical to try to reflect in a qualitative study of 10 patients, on the impact of patients being in different communities, cultural groups or insurance levels (not relevant for a UK population as 95% of health care is provided by the NHS). This area has been recognised as requiring evaluation, and a quantitative follow on questionnaire project of a much larger group to explore these issues is planned.

6) The authors had no new message for the readers.

   - The team do not agree with this statement. There are no pre-existing qualitative studies of patients' needs for information about anti-TNF. Although many of the themes are those that health care providers MIGHT expect from their patients, this cannot and should not be assumed.
- There are also areas which are truly unexpected, such as the recurring theme of patients reporting a tendency to underreport other illnesses in order to continue their anti-TNF - surely a finding of real potential clinical importance.