Author’s response to reviews

Title: The impact of gout as described by patients, using the lens of the International Classification of Functioning, Disability and Health (ICF): A qualitative study.

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18th March 2020

Dr Ciaran Martin Fitzpatrick
The Editor
BMC Rheumatology

Re: BRHM-D-19-0084
The impact of gout as described by patients, using the lens of the International Classification of Functioning, Disability and health (ICF): a qualitative study
Thank you for the opportunity of a revised submission. We have tried to address each of the reviewer comments as explained below. All page and line references refer to the revised manuscript and are highlighted in the manuscript text. We hope that the revised manuscript will be acceptable.
Reviewer 1

1. Can the final paragraph in the background more explicitly clarify the need for this study and what the results are supposed to add to the field?

Response: We have added additional text to this paragraph, which clarifies these points. Text added (page 5, lines 6-9):

A core-set of ICF categories relevant to people with gout is highly useful to ensure adequate content coverage of tools and instruments to evaluate outcomes, including patient-reported outcomes, in clinical care, intervention studies and other outcomes research.

2. Final paragraph in the conclusions to be followed by some short text about future research?

Response: We have added additional text that explains the research now required for a core set of ICF categories. Text added (page 13, lines 15-21)

According to the development process recommended by the ICF Research Branch, further research necessary to identify a core-set of ICF categories for gout are: (1) application of the generic ICF Checklist (https://www.who.int/classifications/icf/icfchecklist.pdf?ua=1) list of categories to patients with gout and (2) a consensus workshop of relevant stakeholders to consider all the data from preceding empirical research and to formulate the final core-set.

Reviewer 2

1. More details about the data collection procedures for each study.

Response: We have added more text about the data collection, including purpose and an overview of the interview questions, and the duration of interviews/focus groups. The sentences about transcript length have been deleted in favour of interview or focus group duration.

Additional text in relation to the Auckland study (page 6, lines 5-8):
Questions were motivated an overall question of “Why is gout so severe in Counties Manukau?” These included questions about the history of the patients’ lifetime experience of gout and pre-disease-onset knowledge of gout.

Additional text in relation to the duration of the focus groups:
Each focus group lasted about 2 hours and 30 minutes. (page 7, lines 5-6).

Additional text about the US study:
The main motivation for this study was to understand the patient experience of gout in order to better measure clinical study endpoints or to guide development of a gout-specific outcome measure for clinical trial use. (page 6, lines 14-17).
... with a main focus on symptoms and burden,... (page 6, lines 14-17)
Additional text about the Spanish study:
Each focus group lasted about 2 hours and 30 minutes. Discussion prompts included: what causes gout, how gout was diagnosed, symptoms of gout, effects in daily life, experience of treatments, relationships with health professionals, and societal concepts of gout. (page 7, lines 5-9)

2. Single researcher coding

We agree that this is a limitation. We do not have information on the percentage of disagreements in the 10% of data that was dual-coded. Unfortunately, we cannot address this problem satisfactorily except to acknowledge it as a limitation.

Additional text:
Nearly all the data coding was done by a single observer. This is acknowledged as a significant limitation, as the coding reliability cannot be calculated. However, it did mean that coding was consistent across the 3 data sources. (page 12, lines 21-23)

3. Presentation of data in Table 2

Response: We have re-presented the number of participants as percentages as suggested. We have not removed the final column since that was the basis of displaying the most frequent 20 ICF categories; we agree that aggregates disguise differences between studies but the results from the individual studies are also displayed so the Table is fully informative.
The request for average number of references per participant appears to be motivated by a better description of the distribution of the number of references across participants. We don’t think a mean value would help illustrate the reviewers point, but a median value might help to a limited extent.
The data was coded per transcript so that it was difficult to determine the number of references per participant for the 2 focus group transcripts. We have chosen to describe the median number of references per participant for the US and NZ interviews only, for these reasons.

Changes made to Table 2.