Author’s response to reviews

Title: The impact of the illness label ‘gout’ on illness and treatment perceptions in Māori (Indigenous New Zealanders)

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Author’s response to reviews:

Dear Dr Fitzpatrick,

Re: The impact of the illness label ‘gout’ on illness and treatment perceptions in Māori (Indigenous New Zealanders)

Thank you for your positive response. We have addressed all the comments raised by the reviewers. Page and paragraph references refer to the clean copy of the revised manuscript.

Reviewer 1
One wonders whether one or two sentences could be added in the Introduction about the theory/theoretical model underlying the study. I am aware of how medical journals want Introductions to be written but it is important, in my view, for the rheumatology scientific and clinical community to be able to read just a bit about the solid theoretical underpinning of the current work.
Response: We have added the following sentences (page 3, para 3 onwards): “Illness labels are an important starting point for the formation of illness perceptions and can have an important impact on people’s beliefs about illness and decisions about management strategies [18]. Research shows patients construct organised cognitive representations of their illness that share a common structure and guide behaviour aimed at managing the illness [19, 20]. We have recently reported a study of supermarket shoppers in Aotearoa/New Zealand to examine the influence of the illness label ‘gout’ on the perceptions of the illness and its management [21]……..”

I’m not a native speaker of English but one wonders whether 'urate crystal arthritis' isn't an extremely difficult set of words (crystal ~crystal meth? etc.). This issue might need some explanation, I feel.
Response: We believe it is unlikely that the ‘crystal meth’ issue is relevant in this population, as this is not a term used to describe methamphetamine in New Zealand. However, we agree that this is a
complicated term, and we have amended the discussion to address this point (page 10, para 1): “This study also showed large differences in perceptions of illness understanding between the labels, with understanding about ‘gout’ significantly higher than understanding about ‘urate crystal arthritis’. Reducing familiarity with an illness label may provide health professionals with the opportunity to introduce new concepts about illness causation and management strategies to patients. There is also a risk that a more complex label might also increase uncertainty about the disease and its treatment”.

Any information on selection bias in the respondents? If 'gout' has such a high prevalence especially in Maori samples, those Maori that actually suffer from gout might not go to the shopping center?
Response: It is likely that those who are experiencing a gout flare would not be visiting a supermarket, due to the severe pain associated with a flare. However, this study aimed to understand community perceptions, not just perceptions for those with the disease. We did observe that more women were recruited, and that the average age was relatively young, so the views of older men may not be fully represented.
This point has been addressed with additional text in the discussion (page, para): “A potential limitation is the use of a community sample, rather than a group of people with a diagnosis of gout. Specifically, those experiencing a gout flare were unlikely to be recruited into the study, as the severe pain of a gout flare often limits ambulation which would be required for supermarket shopping. The study population of supermarket shoppers was also relatively young and predominately female, and the views of older men may not be fully represented. Although the demographics of the study population may not reflect those of people with gout, we consider the recruitment strategy appropriate, as influencing community attitudes about the illness is likely to have substantial benefits for affected individuals, who frequently experience blame and negative comments from partners and employers at the time of a gout flare [15, 16]………”

'Gout' does figure in a couple of novels (in English): any suggestions about how novels (and films), and Maori 'folk beliefs' (and white NZ -ers') might be studied in order to examine and shape illness perceptions re gout?
Response: Our group has previously published on the lay depictions of gout in contemporary news media (ref 12) and we are currently undertaking an analysis of contemporary film and television depictions of gout. We have added a paragraph that summarises prior studies of the experience of gout in Māori and made some new suggestions about future work. This includes looking at the acceptability of the label in the wider patient group with gout and more work in Maori on illness perceptions, including the use of patient drawings of their illness (page 10, para 2).

One wonders whether in the Discussion some attention could be given to intervention studies (in other medical conditions than gout) that aim at changing illness perceptions, and associated changes in various categories of outcome.

Response: We have added the following paragraph to the discussion to address this point (page 10, para 3 onwards): “Previous clinical trials in other diseases have demonstrated that changing illness perceptions can have positive effects on health outcomes. For example, in young adults with asthma, a targeted text message programme that changed illness perceptions led to improved medication adherence [32]. Furthermore, a brief in-hospital illness perception intervention following myocardial infarction leads to earlier return to work and lower reports of angina symptoms post-discharge [33]. Future studies will examine the effects of an alternative illness label on the perceptions and outcomes in people with gout.”
A minor issue: in the manuscript the authors tend to use 'disease' and 'illness' as if they are synonymous. They are not, as the authors are very well aware.
Response: We thank the reviewer for this insightful observation. We have reviewed and amended this terminology throughout the manuscript to ensure consistency with accepted concepts of illness and disease (see tracked version).

Reviewer 2
No changes were suggested

We hope that these changes and comments are acceptable to you and the reviewers. A tracked copy of the manuscript has been submitted with the revised manuscript.

Yours sincerely

Nicola Dalbeth