Author's response to reviews

Title: Understanding the information needs of women with rheumatoid arthritis concerning pregnancy, post-natal care and early parenting: A mixed-methods study

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Author's response to reviews: see over
Dear Dr Singh,

**RE MS: 1507269497161496 - Understanding the information needs of women with rheumatoid arthritis concerning pregnancy, post-natal care and early parenting: A mixed-methods study.**

Thank you for providing us with the opportunity to revise this manuscript. Our responses to the reviewers’ comments are described on the following pages and we have submitted marked and clean copies of the revised manuscript.

We thank the reviewers for their positive feedback and consider that their helpful suggestions have led to an improved manuscript.

Yours sincerely,

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Response to Editor’s and Reviewers’ comments

We thank the reviewers for their positive feedback and insightful comments and consider that these have led to an improved manuscript. Please note that all page numbers listed below relate to the tracked changes version of the revised manuscript.

Editorial request

- Please state whether the map depicted in Figure 2 is your own or taken from another source.

The map depicted in Figure 2 was constructed using the online Google Maps software; however, the permissions and copyright information on the Google website is difficult to interpret for online open access publications (it relates to either printed materials or websites). In view of this, we have decided to remove Figure 2 and present the participant location data under the subheading ‘Participant characteristics’ (page 8):

“The geographic distribution of the sample was broad, with representation from 7 Australian states and territories (Australian Capital Territory: \(n=1\); New South Wales: \(n=3\); Queensland: \(n=5\); South Australia: \(n=2\); Tasmania: \(n=1\); Victoria: \(n=13\); Western Australia: \(n=2\)). As shown in Table 1, participants lived in major cities (\(n=13\, 48\%\)), regional areas (\(n=12\, 44\%\)) and remote areas (\(n=2\, 7\%\))."

Reviewer 1

Minor essential revisions

- Authors may want to discuss the applicability of EULAR recommendations of patient education in inflammatory arthritis in this group of patients.

We thank Dr Ndosi for this helpful suggestion and we have now added the following sentences to the Discussion:

“This fits well with recent European League Against Rheumatism (EULAR) recommendations about the importance of needs-based patient education that can be accessed over the disease course and at different life stages [24].” (page 16)

“It is also in line with recent EULAR recommendations that highlight the need for providers of patient education in inflammatory arthritis to have access to specific training in order to develop and maintain their knowledge and skills [24].” (page 17)

Discretionary revisions

- The authors may want to add a recent survey on patient and practitioner’s attitudes towards treatments during pregnancy as this may help enrich the discussion section.

We agree this will be useful information to add to the Discussion and have now included the following statement regarding the survey findings:

“A recent multi-national survey of women with RA also found that 91% of participants believed their rheumatologist was capable of helping with treatment decision-making during pregnancy [22].” (page 15)
• Figure 3 is a ‘boxed’ text and appears more like a table to me

Thank you for this comment; we have now re-labelled Figure 3 as ‘Table 4’ (page 28) and have updated the citation to this table in the manuscript (page 16).
Reviewer 2

1. The results of the individual telephone interviews and the focus groups are not unexpected considering previous work in this area (Østensen M, Rugelsjøen A. Problem areas of the rheumatic mother. Am J Repr Immunol 1992; 28: 254-5.). However, the study reveals a large gap in the knowledge on reproduction issues in the region of patient recruitment. The knowledge available on the internet and in publications is obviously not disseminated sufficiently to health professionals, so patients are left with a huge number of unanswered questions.

We thank Dr Ostensen for these comments and we now have incorporated her observations into the Discussion:

“A number of countries have already developed information portals for women with rheumatic diseases, although it is evident that these resources are not being sufficiently disseminated to women with RA in Australia (or their healthcare providers), leaving women with unmet information needs.” (page 16)

2. Several countries have taken care of pregnancy issues in regard to patients with rheumatic disease. The authors should perhaps add some information on services available for patients with rheumatic disease in other countries. When reading the narratives one cannot but feel frustrated that so much of the information that is “out there” has not reached the region in spite of being available in English language. By just using the search terms “arthritis in pregnancy” numerous articles pop up, several of them of very good quality, for example provided by the Arthritis Foundation.

We have now included information on services available for patients with rheumatic disease in other countries, highlighting the United Kingdom and United States as specific examples:

“A number of countries have already developed information portals for women with rheumatic diseases, although it is evident that these resources are not being sufficiently disseminated to women with RA in Australia (or their healthcare providers), leaving women with unmet information needs. For example, the Arthritis Foundation in the US offers several webpages relating to rheumatic diseases and pregnancy [27], as does Arthritis Research UK [28] and the National Rheumatoid Arthritis Society in the UK [29].” (page 16)

3. The National Service for Pregnancy and Rheumatic disease in Trondheim, Norway has focused on the practical needs that arise after a baby is born to a parent suffering from arthritis. Early experience showed that the patients themselves have to be asked which problems they experience in caring for a baby and how they solved their problems. The booklet “Being a rheumatic mother” was based on solutions the patients themselves had found; it was published in 1994 in an English translation. Today it is distributed to patients in an updated version.

Thank you for this information, which we have now added to the Discussion:

“Booklets containing practical information for women with RA are distributed to patients in countries such as Norway [32], and a version tailored to meet the needs of Australian women would be a valuable resource.” (page 16)
4. Information on pregnancy and child caring cannot just be copied from a foreign source; it has to be developed in a country or region on the background of the ruling health system, the resources available in the region and the life style of the population.

We agree completely with Dr Ostensen’s views and our team is now embarking on a program of further work to a) develop consensus among health professionals (rheumatologists, obstetricians and pharmacists) regarding appropriate messages to convey to Australian women with rheumatoid arthritis; and b) develop and evaluate context-relevant educational materials and resources for this patient group.

5. I agree with the key message of the paper that arthritis organizations and health care professionals should actively involve in the task to create patient accessible information on reproduction issues. The points presented on page 16, line 397-406 are particularly important. Arthritis organizations could arrange contact to peers by organizing groups – we got very positive feedback from groups of mothers and expecting mothers with rheumatic disease.

We have now added the following sentence to the Discussion:

“Arthritis organisations also have an important role to play, from acting as ‘resource hubs’ to facilitating peer support (for example, by organising or initiating groups that enable women with RA to share their personal experiences of pregnancy).” (page 17)

6. A final point is that awareness of pregnancy and post-partum issues is needed throughout the range of health care providers. International conferences on Pregnancy and Rheumatic Disease have been arranged since 1992, and an increasing number of publications have appeared throughout the last decade. The key to improve the patient situation is to communicate the knowledge, to disseminate it and to make it accessible in every-day language to the patient. The present paper gives a voice to the patients telling health professionals what they really need to know.

We greatly appreciate this positive feedback and hope that this paper will improve understanding among healthcare providers of the information needs of women with RA concerning the pregnancy and post-natal periods. We agree with the importance of raising awareness of pregnancy and post-partum issues among healthcare providers and have now added the following sentence to the Discussion:

“Increasing awareness of pregnancy and post-natal issues across the range of healthcare providers is also essential.” (page 16)