Using qualitative research to help mothers with rheumatoid arthritis

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Rheumatoid arthritis

Acknowledgement: Virginia and Alex
Chronic disease management framework
- Multidisciplinary clinical input
  - Difficult for rural and remote and private settings
- Active engagement by patients for “self-management”
  - Knowledge / understanding
  - Skills
  - Practical strategies
- Additional support
  - Peer support
  - Resources
Program objectives

Phase 1
• What is the reality for Australian women/mothers with RA?
  • Needs assessment, especially regarding information/resources to support care
  • Mixed methods approach

Phases 2-4
• Develop evidence-informed solutions based on findings from phase 1
Methods (Phase 1)

Sampling frame

Survey (n=27)

Interviews (n=15)

Focus groups (n=12)

Virtual (rural/remote/interstate)

Face-to-face (metropolitan Melbourne)
<table>
<thead>
<tr>
<th>Category</th>
<th>Count (n)</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years), median (IQR)</td>
<td>32 (31-36)</td>
<td></td>
</tr>
<tr>
<td>Australian-born, n (%)</td>
<td>24 (89)</td>
<td></td>
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<tr>
<td>University education, n (%)</td>
<td>19 (74)</td>
<td></td>
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<tr>
<td>Years since diagnosis, median (IQR)</td>
<td>5 (2-13)</td>
<td></td>
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<tr>
<td>Residential location, n (%)</td>
<td>57 (24)</td>
<td></td>
</tr>
<tr>
<td>Major city</td>
<td>13 (48)</td>
<td></td>
</tr>
<tr>
<td>Regional area</td>
<td>12 (44)</td>
<td></td>
</tr>
<tr>
<td>Remote area</td>
<td>2 (7)</td>
<td></td>
</tr>
<tr>
<td>Pregnancy status</td>
<td>57 (24)</td>
<td></td>
</tr>
<tr>
<td>Pregnant within last 5 years</td>
<td>18 (67)</td>
<td></td>
</tr>
<tr>
<td>Currently pregnant</td>
<td>5 (19)</td>
<td></td>
</tr>
<tr>
<td>Considering pregnancy in next 5 years</td>
<td>18 (67)</td>
<td></td>
</tr>
</tbody>
</table>

![Australia map with markers indicating major cities and regions](attachment:image.png)
Results

1. Lack of specific information regarding pregnancy and the post-natal period

2. Information needs are dependent on the individual situation

3. Rheumatologist as the primary information source

4. Information gaps:
   - Drug toxicity
   - Access to support services
   - Practical strategies
   - Information for carers and workplaces

5. Accessible information via electronic formats

6. Arthritis consumer organisations as a resource hub
Online, multi-format, multi-media resource hub for women with RA and their families, administered by arthritis consumer organisations

1. Lack of specific information regarding pregnancy and the post-natal period

4. Information gaps:
   - Drug toxicity
   - Support services
   - Practical strategies
   - Information for carers and workplaces

5. Accessible information via electronic formats

6. Arthritis consumer organisations as a resource hub

“I'd say the first five years of having RA because I’ve had no idea, information was scarce, I had done millions of Google searches and there was nothing. Nothing about pregnancy, breastfeeding and RA.... I thought am I the first person in the entire world to have RA and be pregnant, you know... “ (Focus group participant)

“...just like a website where you can go, where there’s PDF documents with lots of information and lots of research to say all of the entire world has done all this research and this is what the majority sort of says” (Focus group participant)
Recommendation #2

Online peer support and portal for sharing lived experiences with a focus on disseminating practical strategies

1. Lack of specific information regarding pregnancy and the postnatal period

2. Information needs are dependent on the individual situation

4. Information gaps:
   - Access to support services
   - Practical strategies

5. Accessible information via electronic formats

"...I can remember going to the maternal health centre and telling them that... you know, with the pain was just getting too bad and I was going to have to go onto these drugs again and I’d have to stop breastfeeding, and we had a very young maternal health nurse at the time and she said well you just have to decide whether you’re going to be selfish and choose yourself over your child...you know that's a hard decision, and yeah, if you had a support person that you could sort of lean on I think that would be really helpful”

(Focus Group participant)
Training for midwives & maternal child health nurses

Recommendation #3

1. Lack of specific information regarding pregnancy and the post-natal period
2. Information needs are dependent on the individual situation
4. Information gaps:
   - Drug toxicity
   - Access to support services
   - Practical strategies
   - Information for carers and workplaces

“What I would have liked was to have my community health nurse...to have them educated, and it doesn’t necessarily have to be just women with RA, but a mother who’s got chronic health issues to actually have someone come to the house and say “Right” and spend the day with you or come on a regular basis and say “Look, this is how we can help you”. Because you get, you feel a bit hopeless actually”

(Interview participant)
Promote the role of arthritis consumer organisations to healthcare professionals

Recommendation #4

...but when you initially first, say, get pregnant and you go to your regular GP, you know, they won’t... they don’t have anything, so even... I don’t know, even if it’s something that they can say well ring your local arthritis group in your capital city and they’ll have everything for you there...

(Focus Group participant)
Recommendation #5

Raise community awareness that RA affects young people

“... picked up a brochure for my mother which was about... a brochure for carers of people with arthritis, and just so she could get some understanding, but the picture on the front really, old wrinkly hand and it was all kind of twisted, and I thought oh, that’s not a good perception. People don’t... and when you tell them you have arthritis, they really don’t understand because they think it’s still, it’s still an old people’s thing.” (Focus Group participant)

2. Information needs are dependent on the individual situation

4. Information gaps:
   - Drug toxicity
   - Access to support services
   - Practical strategies
   - Information for carers and workplaces

6. Arthritis consumer organisations as a resource hub
Translation of evidence (Phase 2)

Meta-review of safety and toxicity of medications used in Australia to treat RA in pre-, peri-, and post-natal periods
**Phase IIA**

Audit of adequacy of contraception among female patients with RA taking DMARDs
**Phase IIB**

Systematic review of interventions to improve knowledge/skills in women with RA
**Phase IIC**

E-Delphi study to develop cross-discipline consensus on messages concerning RA medications and contraception
**Phase III**

Develop resources for consumers and health professionals
**Phase IV**
Acknowledgements

• Funding – *phase I*
  – Angior Family Foundation via NAB Trustees
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• Funding – *phases II – III*
  – Pharmaceutical companies

• Recruitment
  – State-based arthritis organisations and Arthritis Australia
Thank you

www.arthritisvic.org.au/research

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