

Closing the pregnancy-related information gap for women with rheumatoid arthritis

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Editorial

Although rheumatoid arthritis (RA) affects women across the lifespan, it has particular implications for women who are planning a family given the physical and psychosocial impacts of the disease and the potential adverse effects of RA medications. Conception (and contraception), pregnancy and breastfeeding must all be carefully planned and managed with appropriate clinical guidance [1]. There is a clear need for accurate, evidence-based and freely accessible information to support shared decision-making between women with RA, their families and treating healthcare professionals during this important life stage. For families living in rural and remote areas or low and middle-income countries where access to rheumatology care is limited, this is especially important [2]. Considering recent evidence around unmet educational needs and limited evidence for the effectiveness of educational interventions, it is evident that more can be done to better support women with RA across the pregnancy and post-natal continuum.

Several qualitative studies from Australia and the Netherlands have highlighted key pregnancy-related educational needs and concerns among this patient group. Our recent study investigated the specific educational needs of women with RA who were pregnant, planning a pregnancy, or who had been pregnant in the last five years [3]. Participants cited a lack of accessible and relevant information (particularly around the safety and toxicity of RA medications) and expressed a strong desire for practical strategies from peers to assist them in meeting the daily challenges of caring for a young baby. Another study found that women with RA contemplating pregnancy experienced considerable uncertainty around the impact of RA medications on their unborn child and the effect of ceasing medications on their disease status [4]. In their study of men and women with inflammatory arthritis (88% had RA), Nota et al reported that younger patients worried about the effect of disease-modifying anti-rheumatic drugs (DMARDs) on fertility and pregnancy when deciding whether to commence therapy [5]. These perspectives and others [6] suggest that contemporary arthritis education should incorporate pregnancy-related information for people with RA during their reproductive years, and include a focus on both knowledge and practical skills.

Patient education that is targeted to an individual's information needs and life stage should form a fundamental component of routine care for people with inflammatory arthritis, as emphasised by recent EULAR recommendations [7]. In relation to the provision of pregnancy and post-natal education in the context of RA, however, the evidence base regarding effective interventions is extremely limited. We recently completed a systematic literature review to determine the effectiveness of interventions designed to improve knowledge or self-management skills concerning contraception, pregnancy and breastfeeding in people with RA [8]. Of the 68 studies eligible for inclusion in our review, only one specifically evaluated pregnancy-focused education or self-management support for people with RA [9]. That particular randomised controlled trial evaluated a 'motherhood choices decision aid' for RA, which was developed to assist women with RA in making informed choices about having children (or having additional children). The 45-page decision aid resource is publicly available (<http://arthritisnsw.org.au/wp-content/uploads/2014/03/RA+and+motherhood+decision+tool.pdf>) and includes information on RA, pregnancy and the post-natal period, personal narratives, decision-making tasks, and links to online resources and telephone helplines in several countries. The study found that participants who were given the motherhood decision aid had a greater increase in knowledge around RA and pregnancy-related topics and a greater reduction in decisional conflict, compared to a no-intervention control group; however, the study did have some methodological limitations. A further eight studies identified in our systematic review described interventions containing only minor components that could be considered relevant to conception, contraception, pregnancy or breastfeeding, within broader RA educational or self-management programs. Despite RA being prevalent among women of childbearing age, it is clear that published models of disease education do not adequately cater to this important life stage.

In the proceedings of the 2014 American College of Rheumatology Reproductive Health Summit [10], Kavanaugh et al acknowledged the need for improved interdisciplinary communication among medical specialists who care for people with inflammatory and autoimmune conditions during pregnancy and we agree this is an important path to pursue. Conflicting advice from health professionals in relation to pregnancy issues can be a significant source of frustration and

confusion for women with RA [3]. To address this issue, our research group is currently undertaking a national e-Delphi study involving experienced rheumatologists, obstetricians and clinical pharmacists. The study is designed to establish cross-discipline consensus on key messages that should be delivered to women with RA by health professionals, in relation to contraception, pregnancy, breastfeeding and early parenting. Outside the clinical setting, arthritis consumer organisations also have an important leadership role to play, in acting as resource hubs that collate and disseminate pregnancy-related information to health professionals and to women with RA and their families [3]. This is particularly relevant given new developments in RA therapy over the past decade and the delay in evidence-informed recommendations filtering down to clinical practice. Some arthritis organisations (including those in Australia, the United Kingdom and the United States) already offer pertinent online resources to inform patient education in the clinical setting but awareness of these portals among health professionals may be limited.

In conclusion, there is currently little evidence regarding effective educational resources to inform and support women with RA and their families during their reproductive years. On a positive note, this represents an exciting opportunity to develop and evaluate targeted resources encompassing the medication-focused information *and* pragmatic peer knowledge and skills that are clearly sought by this patient group. There is also scope to expand the content of existing arthritis education programs to include a 'path to parenthood' component that spans the contraception to post-natal spectrum.

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