

Editorial

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

More can be done to support women and their families

Although RA affects women across their lifespan, it has particular implications for women who are planning a family, given the physical and psychosocial impacts of this disease and the potential adverse effects of RA drugs. Conception (and contraception), pregnancy and breastfeeding must all be planned and managed carefully, 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 the treating health-care professionals during this key stage of life. For families living in rural and remote areas or low- and middle-income countries where access to rheumatology care is limited, this is particularly important [2]. Given the recent evidence around unmet educational needs and limited evidence for the effectiveness of educational interventions, it is clear that more needs to be done to 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 past 5 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 experienced considerable uncertainty about the impact of RA medications on their unborn child and the effect of ceasing medications on their disease status [4]. In a study involving men and women with inflammatory arthritis (88% had RA), *Nota et al.* [5] reported that younger patients worried about the effect of DMARDs on fertility and pregnancy when deciding whether to commence therapy. 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 emphasized by recent EULAR recommendations [7]. However, with regard to the provision of pregnancy and post-natal education in the context of RA, the

evidence about 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 randomized 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 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 with a no-intervention control group; however, the study did have some methodological limitations (e.g. participant follow-up beyond the immediate post-intervention period was not undertaken, and an intention-to-treat analysis was not reported). 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 programmes. Despite the prevalence of RA among women of childbearing age, it is clear that published models of disease education do not adequately cater to this important stage of life.

In the proceedings of the 2014 ACR 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 that this is an important path to pursue. Conflicting advice from health professionals regarding pregnancy issues can be frustrating and confusing 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 on contraception, pregnancy,

breastfeeding and early parenting. Outside the clinical setting, arthritis consumer organizations 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 potential delay in evidence-based recommendations filtering down to clinical practice. Some arthritis organizations (including those in Australia, the UK and the USA) already offer relevant 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 about effective educational resources to inform and support women with RA and their families during their reproductive years. On a positive note, this is an exciting opportunity to develop and evaluate targeted resources encompassing 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 programmes to include a path to parenthood component that spans the contraception to post-natal spectrum.

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