

Editorial

Optimizing Care for Pregnancy in Rheumatic Diseases: Barriers and Potential Solutions



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With improved disease control, an increasing number of women with rheumatic diseases (RDs) are considering pregnancies. Though there are many international guidelines available for managing pregnancies in RD, the execution of a plan for such care is generally limited by several factors, leaving gaps between evidence and practice.¹⁻⁴ In this issue of *The Journal of Rheumatology*, a multicenter survey by Tani et al on patient care pathways in pregnant women with rare and complex connective tissue disease is an important step in attempting to map existing care pathways.⁵ Data were collected from 69 centers across 21 countries. Ninety-one percent of centers provided services to pregnant women with RD by a multidisciplinary team (MDT) that included gynecologists/obstetricians (though formalized inclusion of other disciplines was present only in 30% of centers). Pre-pregnancy care was provided in a majority (96%) of these centers, and in 64%, this care was provided by community-based general practitioners. However, a formalized care pathway for these pregnant women was established only in 49% of centers, and there was lack of adequate use of appropriate checklists or predefined protocols during the pregnancy (20%) and postpartum (19%) phases. Likewise, the frequency of monitoring during the pregnancy and postpartum phases was also variable between centers. Heterogeneity between these centers was further evident in their ability to prescribe drugs compatible with pregnancy.

Notwithstanding a lack of generalizability arising mainly out of the involvement of far more centers based in Europe (54 out of 69 centers, with 27 from Italy) and a sampling bias due to survey respondents mostly being specialists in reproductive rheumatology, the present study does hold up a mirror in front of us with regard to providing optimum care for pregnancy in RDs.⁵

Clinical care pathway (CCP) is defined as a “complex intervention for the mutual decision making and organization of care processes for a well-defined group of patients during a well-defined period.”⁶ A customized CCP is a potential tool to minimize errors and promote standard evidence-based practices in the context of pregnancy and RDs.^{7,8} The development of a well-designed CCP with widespread implementation in reproductive rheumatology will require coordination with obstetricians/gynecologists, identification of common goals, clear definition of roles and responsibilities, and integration into the existing healthcare system.⁷ The RarERN Path is a methodology created within the European Reference Networks, specifically designed to develop an organizational reference model of CCP in rare rheumatologic conditions that can be adapted to various contexts.⁹ The study by Tani et al has attempted to map existing CCPs in reproductive rheumatology, achieving partial fulfillment of the first step of the RarERN path.⁵ Further steps would be mapping existing patient stories, designing an optimized common CCP, reaching a consensus on an optimized CCP, defining the key performance indicators and instructions for application in specific healthcare contexts, refining the CCP, and launching a pilot phase to assess the applicability and adaptability of the CCP.⁹ In this editorial, we have discussed major barriers and solutions to optimize care for pregnant patients with RDs.

Several studies have underscored the unmet needs in reproductive rheumatology from the patient’s perspective. In a survey on the reproductive health needs of young and adolescent women suffering from pediatric RDs, both patients and

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parents expressed anxiety and fears about sexual life, pregnancy, contraception, and teratogenic medications.¹⁰ They felt dissatisfaction in discussing these issues with rheumatologists and most often were referred to gynecologists to address them. Participants also reported differences of opinion and communication gaps between gynecologists and rheumatologists.¹⁰ In another survey of women with RDs conducted across 6 developed nations (USA, UK, France, Germany, Italy, and Spain), between 30% and 55% of patients felt that their family planning and pregnancy-related concerns were not adequately addressed, and the majority (38%) of them felt that their gynecologist was the right care provider compared to rheumatologists (12%) to discuss these issues.¹¹ In another survey carried out in a single center in the United States, women with RDs preferred rheumatologists to initiate and rediscuss relevant aspects of sexual and reproductive health.¹² Further, patients felt they were acting as intermediaries between the gynecologists and rheumatologists, and preferred that these providers communicate directly with each other. In this same study, their desire for clear information regarding the effects of drugs and of their disease on fetal and maternal health was underscored.¹²

From the rheumatologist's point of view, key challenges identified by a focus group exercise included medically ill-timed pregnancies, poor adherence to medications, limited communication and coordination between rheumatologists and obstetricians/gynecologists, and discomfort in initiating conversation about pregnancy and contraception.¹³ Common reasons put forth were busy clinic schedules, lack of appropriate knowledge to cover all issues, and resultant lack of confidence in discussing them. In this context, it is worth noting that most women, regardless of education level or socioeconomic status, reported feeling intimidated by their rheumatologist and were therefore hesitant to speak up about their true pregnancy desires.¹³

A lack of consistent advice and/or information across multiple healthcare professionals has also been noted, including that about prescribing drugs during the pregnancy and

postpartum phases.¹¹ Differences in recommendations between rheumatology- and gynecology/obstetrics-specific guidelines about the usage of certain drugs in pregnancy, such as biological agents and cyclophosphamide, do not help the situation.^{2,14-16} Such difference of opinion regarding drug safety during pregnancy may lead to anxiety regarding medication use and nonadherence. Acknowledgment of the patient's desire for pregnancy, frank discussion of available data emphasizing improved fetal and maternal outcomes with proper use of medications, and enhanced collaboration with obstetricians are important measures to gain the patient's confidence and improve adherence. Patient support groups, specific educational material for patients, and helplines are other helpful measures.

Developing nations have several unique challenges with regard to managing reproductive issues in patients with RDs.^{17,18} Due to diverse healthcare delivery systems, access to rheumatology services is not uniform, with variation not only between the countries but also within a country with concentration in urban areas. As the primary care physician may be the healthcare provider in such nonurban settings, there is a need for educating them using customized continued medical education events.

Availability of all therapeutic options and resources for regular monitoring of drugs may not be equal across all the nations. To improve the applicability of relevant international guidelines, patient representation, consideration of the potential resource implications of the recommendation, and inclusion of monitoring or audit have been identified as key areas.¹⁹ There is a need for countries to develop their own guidelines that are suited to their population. This may include modifying the available recommendations in view of specific clinical, cultural, financial, and logistical needs. Prospective comprehensive registries for pregnancy and RDs are required for gathering relevant data and developing country-specific recommendations.²⁰

One of the potential ways to facilitate access to pregnancy-related rheumatology services is to use digital health technologies.²¹ In addition to providing real-world data, its additional benefits for

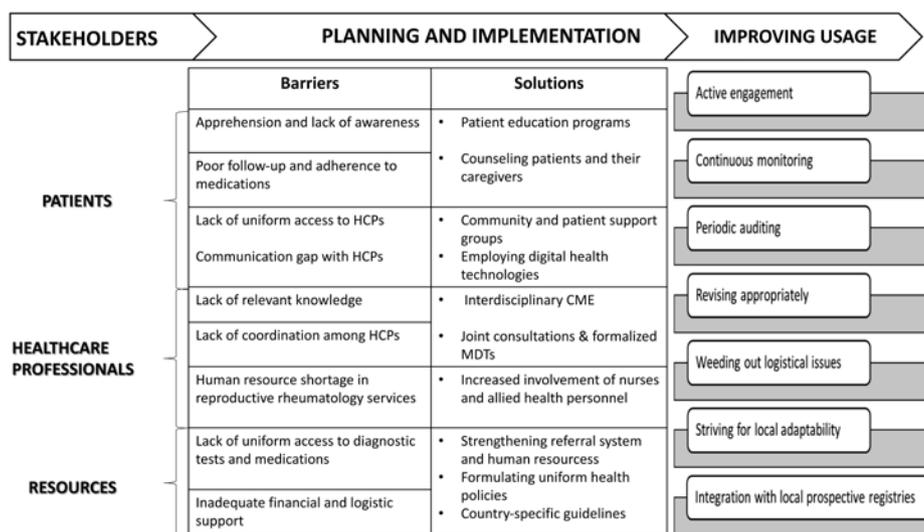


Figure. Barriers and their potential solutions for optimizing care for pregnancy in rheumatic diseases. CME: continued medical education; HCP: healthcare professional; MDT: multidisciplinary team.

a pregnant woman with RD include improved accessibility in remote areas, avoidance of travel, and potential savings on costs and time. However, in this context, the challenges include selection of the right patient, language barriers, access and comfort with internet usage, requirement of a facilitator, and potential medico-legal problems.²²

Addressing human resource shortages in rheumatology by involving nurses, midwives, and physician assistants is a potential solution. The role of rheumatology nurses has now expanded and includes involvement in shared decision making. Some studies have reported greater satisfaction with nurse-led clinical care as they promoted a holistic approach, better patient self-management, and emotional support.²³ Involvement of rheumatology nurses in rheumatology-led pregnancy clinics could be an empowering solution for emotional and physical health requirements of pregnant women with RDs.²⁴

There is a need to promote the use of pregnancy-specific assessment tools and outcome measures (such as the British Isles Lupus Assessment Group [BILAG] 2004-Pregnancy Index, Lupus Activity Index in Pregnancy, Systemic Lupus Erythematosus Pregnancy Disease Activity Index [SLEPDAI], and modified Systemic Lupus Activity Measurement [m-SLAM]) in routine practice to enable experts to guide management and pave the way for uniform standard of care.²⁵

In conclusion, efforts to optimize care pathways for pregnancy in RDs are a work in progress. As the area is complex with multiple stakeholders, there are several issues that require attention (Figure). The recent developments in this field, particularly in the last decade, have offered hope with several potential solutions.

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