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Delivering Care for Pregnant Women with Rheumatic and Musculoskeletal Diseases

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Abstract

Aim

To establish current practices regarding the management and monitoring of women with RMDS in Ireland and to identify current challenges.

Methods

An anonymous electronic survey was distributed amongst Rheumatology consultants, trainees, nurses and allied health professionals across Ireland in 2023. Data collected related to current structures in place for pregnancy care of women with RMD.

Results

Participants: 29% (n=19) Consultant Rheumatologists, 18% (n=12) Registrars, 27% (n=18) Clinical Nurse Specialists, 20% (n=13) ANP. Significant variability existed across clinical sites for pregnancy care delivery in RMD, with combined rheumatology/obstetric clinics occurring in only 18% of units. In 41 % (n=27) of centres, women with RMD are reviewed once per trimester and 27 % (n=18) of centres reported no change to pre-pregnancy care (Figure 1). In most hospitals, 56 % (n=37) there is no named Obstetrician for managing complex RMD

patients during pregnancy. Challenges identified in delivering desired care included suboptimal communication between Rheumatologists and Obstetricians (23 %, n=15), complex care needs of patients (17 %, n=11), suboptimal infrastructure (17 %, n=11) (Figure 2).

Discussion

Significant variation exists regarding management of pregnancy in women with RMD in Ireland. The development of a national pathway for management and monitoring of women with RMD during pregnancy would streamline care, facilitating the optimisation of maternal health, control of disease activity and neonatal outcomes.

Introduction

Rheumatic and Musculoskeletal diseases (RMD) frequently affect women of childbearing age, covering a wide spectrum of conditions. Women with pre-existing RMD who are planning a pregnancy or who develop these conditions during pregnancy often require specialist input from a maternal-foetal medicine specialist and a Rheumatologist.

Rheumatologists and Obstetricians are increasingly involved in the care of women with RMD in Ireland.[1] The management of RMD patients during pregnancy has undergone significant changes in recent decades, with unique reproductive health challenges for both Rheumatologists and Obstetricians.[2] Major challenges associated with the clinical management of pregnant women with RMD include incomplete information related to medication safety, especially for new medicines.[3] Additionally, the signs and symptoms of active RMD may mimic those of normal pregnancy and standard disease activity scores may not be clinically accurate during pregnancy.[4]

Systemic RMDs often affect women in their reproductive years and may complicate the course of pregnancy in the postpartum and antenatal period, with both risks for the mother and foetus.[5] With planning and regular surveillance throughout pregnancy, most women with RMDs can have successful and safe pregnancies.[6] Combined care between Rheumatologists and Obstetricians has been shown to improve foetal and maternal outcomes in RMD patients during pregnancy.[7]

Due to the variable severity of RMD, their comorbidities and specific treatments, optimal disease management is essential prior to, during and following pregnancy.[6] RMDs should be ideally quiescent for 6 months on non-teratogenic drugs before conceiving. The need for

effective pre-counselling is essential to gather details pertinent to disease activity, pre-existing comorbidities and serological profile.[8]

The mother and foetus should be monitored regularly throughout pregnancy so that potential complications are identified early and managed appropriately. Medications should be regularly reviewed at each stage of pregnancy in keeping with the current American College of Rheumatology (ACR) guidelines.[9] The European League against Rheumatism (EULAR) task force defines overarching principles and considerations for use of anti-rheumatic drugs during pregnancy, lactation and surveillance.[3] Similarly, The American College of Rheumatology (ACR) emphasizes the importance of an integrated patient management system that includes Rheumatologists, Obstetricians and other specialists.[9]

Management of RMD and pregnancy should be tailored to the individual patient's history and disease activity.[2] The aim of this study is to establish current practices regarding the management and monitoring of women with RMD in Ireland and to identify current challenges to implementing dedicated clinical pathways.

Methods

A national working group composed of physicians and nursing representatives in the Republic of Ireland and Northern Ireland in the field of rheumatology co-designed a survey focused on organisational aspects of care delivery in patients with RMD during pregnancy. In March 2023, a 17-question anonymised online survey was distributed using a well-recognised electronic survey tool. Rheumatology consultants, Registrars, Clinical Nurse Specialists (CNS), Advanced Nurse Practitioners (ANP) and Allied Health Professionals currently working in rheumatology units in Ireland were invited to participate. The survey collected demographics and data focusing on current delivery of care in place for pregnant women with RMD in Irish Rheumatology units.

The survey contained a total of 17 open and closed end responses, divided into three primary areas of inquiry:

1. Epidemiology, daily clinical practice and demographics of respondents (n= 4).

2. Current management of patients with RMD during pregnancy and interactions between Obstetrics and Rheumatologists (n= 8)

3. Preferences, challenges and barriers to implementing a dedicated clinical pathway for managing women with RMD in Ireland (n= 5).

The respondents were provided with a list of possible options to survey questions, with the opportunity to expand answers with unmentioned variants. Respondents were free to respond spontaneously in their own words, if the questionnaire options did not sufficiently describe local practice in their Rheumatology centre. All participant data were anonymised prior to statistical analysis. Questionnaire data were transferred from survey Monkey to an Excel database and checked for fidelity. Frequencies and percentages were calculated for categorical data. IBM SPSS version 29.0.1.0 was used for statistical analysis using descriptive statistics.

Results

Epidemiology and demographics

In total, there were 65 respondents. This was composed of 82% (n=54) female, 17% (n=11) male. Respondents represented a range of healthcare professionals who care for women with RMDs including 29% (n=19) Consultant Rheumatologists, 18% (n=12) Registrars, 27% (n=18) CNS, 20% (n=13) ANP.

Current Management of patients with RMD in Ireland

Respondents indicated that significant variability exists across Rheumatology clinical sites for pregnancy care delivery. Preconception counselling was conducted in 61% (n=40) of General Rheumatology clinics overall for women of childbearing age.

Notably, in over half of hospitals 56% (n=37), there is no named Obstetrician for managing complex RMD patients during pregnancy. Pregnant women with RMD are managed in separate Rheumatology and Obstetric clinics with no formal shared care in 61 % (n=40) of centres. Combined Rheumatology and Obstetric clinics are operating in 18% (n=12) of centres. A further 14% (n=9) reported management in separate Rheumatology and Obstetric clinics with combined MDT meetings/discussion between the specialities. A dedicated RMD pregnancy clinic led by Rheumatology with a separate Obstetric clinic was reported by 2% of participants (n=1).

Monitoring throughout pregnancy differed vastly across centres. In 41% (n=27) of centres, women with RMD are reviewed once per trimester and 27% (n=18) of centres reported no change to pre-pregnancy care. Less than 5% (n=3) of clinical centres arranged monthly reviews during pregnancy. Alternative arbitrary monitoring arrangements existed in 41% (n=27) of centres based on local clinical practice.

Results demonstrate significant variability exists between clinicians and time to review post-partum in Ireland. (See Figure 1.) The majority 49% (n=32) of respondents desired to review

patients between six weeks and three months post-delivery and 46% (n=30) of centres reported offering clinical reviews in this period at present. There was no statistically significant difference (p>0.05) between healthcare groups and the typical time to review post-delivery.

Preferences, challenges and barriers to implementing a dedicated clinical pathway for managing women with RMD in Ireland

Almost two-thirds (65%, n=42) of respondents support the development of a dedicated clinical pathway for management of all RMD cases during pregnancy, while a lesser (31%, n=20) feel a dedicated pathway is only required for complex RMD cases.

Results demonstrate 47% (n=31) of respondents feel a dedicated outpatient clinic for managing all women with RMD is needed during pregnancy and a further 40% (n=26) would support a dedicated clinic for complex cases.

The main perceived challenges to providing optimal care to patients with RMD during pregnancy according to respondents included complex care needs (17%, n=11), suboptimal communication between rheumatologists and obstetrics (23%, n=15), and lack of infrastructure to support the appropriate management of patients (17%, n=11) (See Figure 2.). Lesser perceived challenges included medication safety (15%, n=10) and management of active disease occurring during pregnancy in (12%, n=8) (See Figure 2).

The key barriers to establishing specialised clinics identified in this study included a lack of clinical space (62%, n=41), insufficient staffing (46%, n=30) and maternity hospital not co-located with the main hospital (50%, n=33). A lack of expert knowledge was reported in 29% (n=19) of respondents as a barrier to implementing dedicated clinics.

Discussion

The results of this survey demonstrate a wide variation in care delivery for women with RMD in Ireland during the prenatal, antenatal and post-partum period. Pregnant women with RMD are managed in various settings. Combined Obstetric and Rheumatology clinics existed in only 18 % (n=12) of centres, separate Rheumatology and Obstetric clinics with no formal shared care existed in the majority (61 %, n=40) of centres. In over half of hospitals 56% (n=37), there is no named Obstetrician for managing complex RMD patients during pregnancy.

Monitoring throughout pregnancy and times to review post-partum differed vastly across centres. Almost one third (28%) of respondents reported offering no change to pre-pregnancy

care. Suboptimal communication between Obstetrics and Rheumatology (23%), lack of appropriate infrastructure (17%) and complex care needs (17%) were the most significant challenges identified.

At present there are no national guidelines for managing patients with RMD during pregnancy in Ireland. The results of this survey suggest the need for the development of a national pathway in Ireland for managing patients with RMD during pregnancy. According to the British Society of Rheumatology (BSR) guidelines, patients with RMD should receive tailored pre-pregnancy counselling. The BSR guidelines recommend reviewing patients during pregnancy and at the four month mark postpartum by practitioners with expertise.

At present significant variability exists between clinicians and time to review post-partum in Ireland. In the postpartum setting, disease activity is often seen to worsen when measured by different parameters, including joint counts, pain measures, and Disease Activity Score (DAS).[11]

The results of this study suggest suboptimal cross-collaboration between specialities. Less than one fifth of centres are operating as combined Rheumatology and Obstetric clinics. In over half of centres, there is no named Obstetrician for managing complex RMD patients during pregnancy. Current guidelines recommend consultation and information sharing across specialities, with cross collaboration regarding drug therapy decisions during pregnancy and lactation to optimise disease control, obstetric outcomes and ultimately maternal and foetal health.[12]

Additionally, current best practice guidelines recommend that patients with RMD who are planning a pregnancy or currently pregnant should be managed in a multidisciplinary setting with close Obstetric and Rheumatology input.[2] Less than one fifth of respondents reported delivering care in combined Rheumatology and Obstetric clinics in current Irish practice. The majority of centres reported delivering care in separate Rheumatology and Obstetrics clinics, with no formal shared care arrangements. Interestingly, in the literature, there are studies in which multidisciplinary care is provided during pregnancy planning and pregnancy in Europe and the United Kingdom (UK).

In the UK favourable maternal and foetal pregnancy outcomes are reported from service models providing joint Obstetric and Rheumatology clinics, including high live birth rates and low miscarriage/stillbirth rates.[13] In Italy, a recent publication presented promising outcomes of a multidisciplinary model for patients with systemic lupus erythematosus and nephritis, including care from Obstetrics, Rheumatologists and Nephrologists who adhered to a pre-defined treatment protocol.[14] Similarly, a recent multidisciplinary obstetric unit in Spain demonstrated improved pregnancy outcomes for women with RMD and hereditary

thrombophilia.[15] Other similar multidisciplinary collaborations during pregnancy have been reported across Europe and published with favourable results for patients with inflammatory rheumatic diseases.[16,17]

Although multidisciplinary care is provided in reality across Europe, there is a lack of publications focused on multidisciplinary care models in the literature to guide objectives and procedures going forward. In the Irish context, there is no integrated health system at present. There are resource limitations due to demographic changes, insufficient staffing and continuing economic escalations of infrastructure hampering reform and the development of integrated care models for RMD patients during pregnancy.[18]

Significant heterogeneity in the delivery of care for pregnant women with RMD is identified in this survey. The delivery of care to patients with RMD may be limited by deficiencies in our current healthcare setting. Management of the pregnant RMD patient should be tailored to the individual patient's history and disease activity. Women may struggle to find sufficient information to guide them on pregnancy and planning in the absence of dedicated clinical pathways and resources for reproductive health.

The authors acknowledge an element of bias may exist from respondents, as those with a vested interest or involvement in RMD pregnancy management may have been more inclined to complete the survey. This may have impacted the representativeness of the results, and indicates that services may be even worse than reported. Additionally the authors acknowledge the possibility that respondents may have been from the same institution, especially across different healthcare professional roles. This may have created an element of bias in terms of replication of data and affected internal validity if members of the same organisation gave different answers regarding their Pregnancy care delivery.

The majority of respondents indicated that the development of dedicated clinical pathways and specialised clinics are needed in Irish clinical practice for managing RMD patients during pregnancy. The development of a national framework could substantially support women of reproductive age with RMD to plan pregnancy effectively, unify care and promote optimisation of maternal health, control of disease and neonatal outcomes.

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Figure 1:

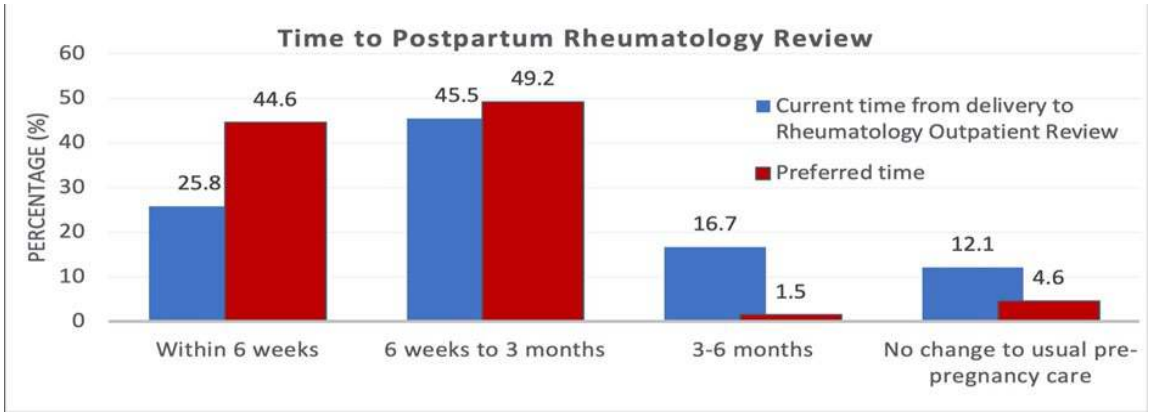
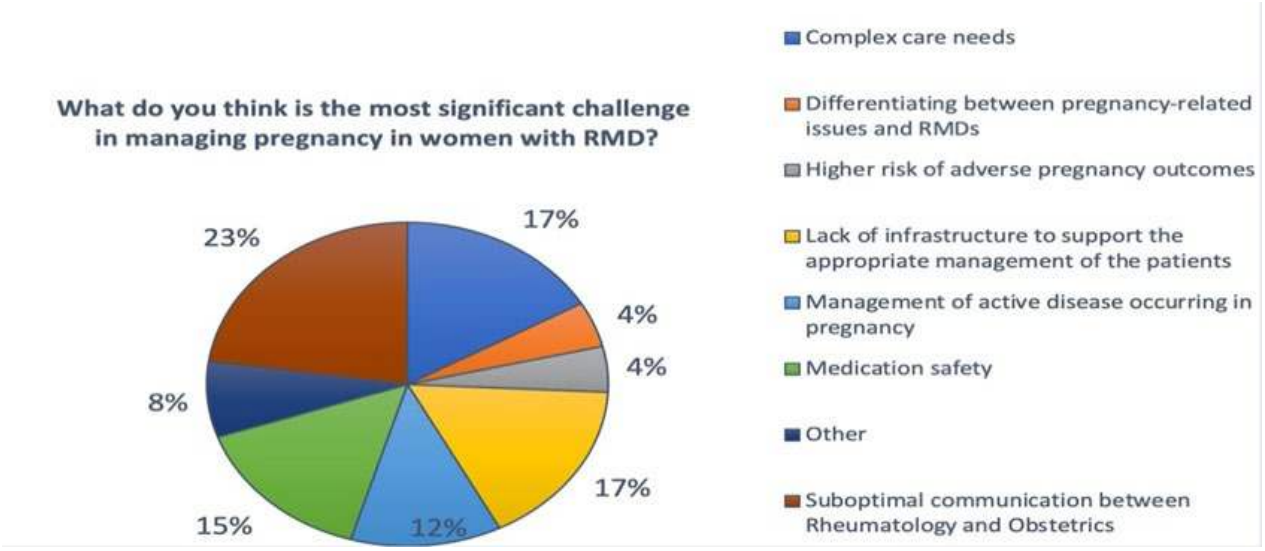


Figure 2:



Declarations of Conflicts of Interest:

None declared.

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