

direction for future investigations to improve the care and outcomes of patients with AAV.

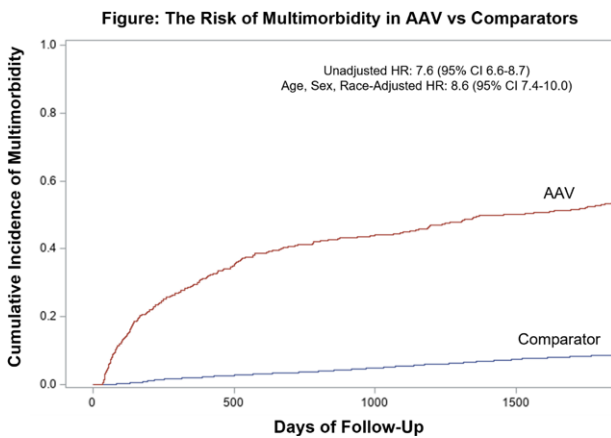
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Table 1. The Burden of Multimorbidity in AAV

	AAV Cases	Comparators
N	547	5259
Age (mean, SD)	59 (17)	59 (17)
Female (%)	39%	39%
Race		
White	88%	92%
Black/African American	2%	2%
Asian	1%	1%
Other	2%	2%
Unknown	3%	1%
BMI (mean, SD)	28.3 (6.9)	28.5 (7.3)
Proportion with Multimorbidity		
Year 1	37.8%	5.7%
Year 2	50.7%	8.7%
Year 3	54.4%	11.8%
Year 4	61.4%	14.9%
Year 5	66.2%	19.1%
Days Free from Multimorbidity*		
Year 1	282	353
Year 2	489	696
Year 3	666	1028
Year 4	823	1353
Year 5	963	1671

*Adjusted for age, sex, race



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Supporting patients in taking active part in their care

OP0306-HPR POINTS TO CONSIDER FOR PATIENT EDUCATION PROVIDED BY NURSES ON METHOTREXATE USE. A EUROPEAN CONSENSUS INITIATIVE

Keywords: Self-management, Nursing, Patient information and education

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Background: Methotrexate (MTX) is the anchor and most prescribed disease-modifying anti-rheumatic drug (DMARD) for inflammatory rheumatic diseases (IRDs). This treatment can be very efficacious but can also have serious, life-threatening side effects. Adequate education and follow-up of patients/carers are therefore essential and dedicated rheumatology nurse consultations are an important part of this. However, many patients across European countries do not have access to these nurse consultations and there are no agreed and clearly defined standards of care on this topic[1].

Objectives: To develop points-to-consider (PtC), based on the best available evidence and experts' opinion, on the nursing education of patients (or carers) with IRDs taking MTX.

Methods: A nominal group of adult and pediatric nurses (n=19) from 16 European countries, one rheumatologist, one pharmacist, and two patients, was established by the Portuguese Association of Health Professionals in Rheumatology (APPSReuma). The group convened virtually to agree on the protocol for developing the PtC, including the research questions for a scoping review and for a European survey to collect patients', nurses' and rheumatologists' experiences and perceptions about MTX education. The results from the scoping review and the surveys (presented elsewhere) were then used to devise and refine overarching principles and specific PtC statements through two virtual meetings and one online Delphi questionnaire. European Standard Operating Procedures for the development of recommendations/PtC were used.[2]

Results: The group reached consensus on three overarching statements and five PtC (Table 1). Almost all PtC were based on available scientific evidence, and all obtained high levels of agreement (>8/10).

Table 1. Points-to-consider for the nursing education of patients/carers taking methotrexate.

#	Overarching Principles	Level of Evidence of rec-	Strength comen-da-	Agreement Mean %
			tion (SD)	≥8
1	All patients prescribed MTX and their carers should receive treatment-specific education.	--	--	9.4 (1.5) 94
2	Education for patients prescribed MTX needs to be ongoing and requires continuous review by the rheumatology team.	--	--	9.5 (1.1) 94
3	Nurses should have access to training regarding methotrexate treatment and stay up to date through continuous education	--	--	9.5 (0.9) 94
PtC				
1	Patients prescribed MTX and their carers should be offered education by a nurse when starting treatment, changing the route and when required by the patient.	3	C-D	9.7 (0.6) 100
2	Patients prescribed MTX should have access to a nurse for needs-based education to improve treatment knowledge#, enhance satisfaction with care and quality of life*	#C	*D	9.8 (0.5) 100
3	Nurses should support patients and carers with relevant self-management skills related to MTX treatment, to ensure safety and improve self-efficacy.	3	C	9.8 (0.4) 100
4	Education about MTX should be tailored to the individual patient/carer needs.	3	C	9.7 (0.7) 100
5	Education on MTX for patients and carers can be delivered through face-to-face or online interactions, supplemented where necessary by telephone consultations, written or online resources.	3	C	9.4 (1.7) 94
6	Nurses should promote and support adherence to MTX by identifying and discussing potential barriers and facilitators.	3	C	9.7 (0.6) 100

Conclusion: A set of PtC to improve the quality of care provided to patients with IRDs and their carers regarding the education and support that should be provided by nurses specifically on MTX use, has been developed. The ultimate goal is to optimize MTX intake, improve efficacy, reduce side effects and ensure adherence to treatment. A plan is currently underway for the uptake and implementation of these PtC, recognizing the crucial role that the multi-professional rheumatology team plays in this.

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"So what now?" - living and planning life while co-existing with an RMD

OP0307-PARE

WHAT ARE THE UNMET NEEDS OF PREGNANT PATIENTS DIAGNOSED WITH INFLAMMATORY RHEUMATIC DISEASES RECEIVING CARE IN A HIGHLY SPECIALIZED REPRODUCTIVE RHEUMATOLOGY CENTER? THE RESULTS OF THE CAPRI STUDY

Keywords: Pregnancy and reproduction, Patient information and education

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Background: Inflammatory rheumatic diseases (RD) often affects women in their childbearing years. Despite extensive counselling, we noticed that in RD patients there is an increasing need of more information concerning pregnancy and parenting. This suggests that there are still unexplored information needs regarding pregnancy and parenting in women with RD. To our knowledge, there are no studies exploring these unidentified information needs.

Objectives: The aim of this study was to evaluate the unmet needs of women diagnosed with RD that received highly specialized care in a tertiary Reproductive Rheumatology center.

Methods: Women (≥18 years) diagnosed with RD (such as rheumatoid arthritis, spondyloarthritis, psoriatic arthritis or juvenile idiopathic arthritis), who were followed-up by the Reproductive Rheumatology team from the Department of Rheumatology of the Erasmus University Medical Center were invited to complete an online questionnaire. The questionnaire was divided into different sections: pre-conception, pregnancy, post-partum, parenthood and support received/needed by informal caregivers such as family, friends, neighbors etc. The questions were related to the support and information provided by the team, problems experienced, unmet needs and the patient's general characteristics.

The patients were offered the possibility to give additional remarks (free text). Descriptive statistics were used to represent the outcomes.

Results: From a total of 181 women who were invited to fill out the online questionnaire, 95 women (52%) completed the questionnaire. It concerns women in the age between 22 and 45 (mean of 33yrs), with a RD, who received their first (n=56), second, or third baby between 2019 and 2021. Overall, the care of the rheumatology team was highly rated by the women (satisfaction score of 88 (scale 0-100) for the rheumatologist and 92 (scale 0-100) for the rheumatology nurses (Table 1). 18 Women (19%) experienced any problem during the period around their delivery and/or post-partum. Six women indicated that their problems persisted. A lack of mental health support regarding disease coping (4 out of 6) was the most frequently mentioned persisting problem. In addition 2 out of 6 women indicated a need for additional communication with the rheumatology team regarding information, indication and adjustment of their medication between the regular outpatient clinic visits.

Conclusion: The care provided by the Reproductive Rheumatology team was highly rated by the majority of the women. Nevertheless, the following unmet needs were identified: a) mental health support regarding disease coping and, b) the opportunity to communicate about medication beyond the regular outpatient visits. Despite a very high satisfaction rate of patients treated by the Reproductive Rheumatology team some of them experience health problems that remain unsolved. This will help us to improve our patient-centered care as we aim at matching our care as appropriately as possible to patient needs. In the future, we want to identify the characteristics of the women who need more information, more mental support and, more contact between the regular consults, so we can help them solve their problems and fill their needs.

Table 1

	N=103
Age years mean, (range)	32.5 (22-45)
Diagnosis, n (%)	
• Rheumatoid arthritis	43 (41.7%)
• Psoriatic arthritis	17 (16.5%)
• Spondyloarthritis	16 (15.5%)
• Juvenile Idiopathic arthritis	15 (14.5%)
• Other immunological disease	3 (2.9%)
• Other forms of arthritis	1 (0.9%)
Number of children, mean (%)	1.4 (1-3)
Age of youngest months, mean	13.9 (1-30)
Age at diagnosis mean, (range)	
• Rheumatoid arthritis	25 (0-39)
• Psoriatic arthritis	26.5 (18-33)
• Spondyloarthritis	28.8 (19-39)
• Juvenile Idiopathic arthritis	7.9 (2-16)
Counselling received n (%)	96 (96.97)
Higher professional education and university educated, n (%)	57 (64.77)
Working hours weekly, n (range)	27.5 (8-40)
Support, n (%)	
• Partner	96 (93.20)
• Family	41 (39.81)
• Others	7 (6.8)
Information received in the Department of Rheumatology, n (%)	
• Rheumatology nurse	13 (13.54)
• Rheumatologists	3 (3.13)
• Both	80 (83.33)
Problems experienced during pre-conception, pregnancy, after birth n, (%)	
• Yes	18 (19.15)
• No	76 (80.85)
Did you solve the problems? n (%)	
• Yes	6 (33.3)
• Partially	6 (33.3)
• No	6 (33.3)
Are you satisfied with the counseling received from the rheumatology nurse? (0-100) mean, range	92.74 (45-100)
Are you satisfied with the counseling received from the rheumatologist? (0-100) mean, range	88.47 (36-100)

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