Patient Experiences of Rheumatoid Arthritis Models of Care: An International Survey

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INTRODUCTION

- Key model of care elements for rheumatoid arthritis (RA)
- Key element 1: Recognize symptoms/seek care
- Patients must understand that their RA is not "just arthritis"
- Key element 2: Access to specialist care
- Early identification, assessment, and referral to appropriate specialists are essential steps in proper RA management - Key element 3: Medical management
- The management of RA is complex and requires constant monitoring with a specialist to ensure its effectiveness - Key element 4: Shared care
- Treatment decisions must be made through agreement between the patient and the health care team, and there must be adherence to the treatment regimen, including appropriate lifestyle changes
- Key element 5: Self-care
- Patients must be fully educated about their medical conditions and the importance of adherence to the treatment
- Despite the global prevalence of RA, a single model of care has not yet been established,¹ and little is known about the RA patient journey at the population level across countries
- A global survey of RA patients was conducted to better understand patients' experiences of the RA model of care and to identify common challenges and gaps

OBJECTIVES

• To gain insights into RA model of care experiences from the RA patient perspective and to gain understanding of patients' knowledge about RA

METHODS

- A global survey of RA (self-reported) patients was conducted by 18 RA patient organizations from 25 countries across Europe, the Middle East, and North and South America (March 15 to June 9, 2017)
- The survey consisted of a short online questionnaire available in 16 languages, which included questions about the patient's disease journey through the 5 key RA model of care elements
- Data were pooled across countries and analyzed using STAR ODEC version 2.9.13 for those countries with >30 respondents

RESULTS

Geographic Representation

• 2690 respondents from 14 countries were included in the analysis (**Figure 1**) Most respondents were from Brazil (40.0%) and France (27.4%); however, there were no significant differences in responses except for reported remission

Figure 1. Respondents by country.



Sociodemographics



Key Element 1: RA Patients Recognize Symptoms and Seek Care

- Delay in RA diagnosis was evident (**Figure 3**) first symptoms
- and 17% of respondents classified it as mild

Key Element 2: Access to Specialist Care

- 20 months (median, 3 months)



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Respondents reported an average of 22 months (median, 5 months) for diagnosis of RA after they experienced their

Most respondents in the patient survey classified their current degree of RA severity as moderate (59%) or severe (24%)

• The average time from patients experiencing their first symptoms to visiting a rheumatologist for the first time was

• The waiting time until a first appointment with a rheumatologist was >3 months in 33% of patients (**Figure 3**)

Most respondents (66%) were informed of their RA diagnosis by a rheumatologist (Figure 4) Approximately one-fifth of respondents were informed of their RA diagnosis by their family doctor or general practitioner



Key Element 3: Medical Management

Frequency of Rheumatologist Visits

Most respondents (60%) visited their rheumatologist for disease management every 1-3 months, highlighting that a substantial proportion (40%) do not visit their rheumatologist often enough

Once a month 11% Once every 3 months 49% Once every 6 months 27% - Once a year I see them when I need to 8% Never

Treatment for RA

• Although patients usually started methotrexate, hydroxychloroquine, or sulfasalazine at diagnosis (56%), 23% reported not starting for \geq 4 months (**Figure 5**)

Figure 5. Time interval between diagnosis and initiation of methotrexate, hydroxychloroguine, or sulfasalazine.

Data are percentages based on 93% of the total number of respondents (N = 2690).



- Rheumatologis Family doctor/GI HCP other than family docto Other HCP Respondent provided information about RA they found independently (7%)
- Guidelines recommend the use of biologic response modifiers or targeted synthetic small molecules if conventional synthetic DMARDs fail²⁻⁵
- Although 83% of respondents said their current disease activity was moderate or severe, only 37% indicated they were receiving a biologic response modifier or targeted small molecule (Figure 6)



Data are percentages of total number of respondents (N = 2690.)

Key Elements 4 and 5: Shared Care and RA Patient Self-Care

• Survey respondents felt confident when talking about RA (Figure 7)



Sources of information used to learn about RA







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- Online survey with the potential for respondent misinterpretation and for variations in the interpretation of questions and response options
- Respondents might have had difficulty knowing whether a thorough physical examination was performed • The respondent population might not have been fully representative of a heterogeneous RA population because most patients were recruited through patient advocacy groups and were likely to be highly motivated
- Furthermore, 90% of the respondents were women, which differs from the 3:1 women-to-men distribution expected of patients with RA diagnoses

CONCLUSIONS

- The findings of this large international patient survey highlight self-reported gaps and delays in all 5 key elements of a standardized RA model of care
- Delays in time to diagnosis were reported by respondents
- Delays in time to a rheumatologist consultation were also reported by respondents
- Initiation of DMARD therapy was delayed for many respondents, and a substantial proportion did not undergo assessment of disease management often enough
- Use of combination DMARD therapy was also rare, with only 1% of respondents receiving the combination of methotrexate + hydroxychloroquine + sulfasalazine
- Additional education and information are needed to increase patients' level of confidence to describe their RA experience and to improve the effectiveness of their self-care
- These survey findings offer an opportunity for patient advocacy groups to overcome barriers to an optimal RA model of care by providing evidence-based education, information, and advocacy leadership to people living with RA

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DISCLOSURES

C.L. Koehn is employed by Arthritis Consumer Experts.

- K. Lendvoy is employed by Arthritis Consumer Experts and consulted on this project to F. Hoffmann La Roche Ltd.
- M. Souveton is an employee of F. Hoffmann La Roche Ltd.
- Y. Ma, L. Li, A.M. Hoens, and J.M. Esdaile have nothing to disclose.

Patient Organizations

Platform of Organizations of People With Rheumatic Diseases in Southern Europe (AGORA)

- Asociación Mexicana de Familiares y Pacientes con Artritis Reumatoide (AMEPAR)
- Associazione Nazionale Malati Reumatici (ANMAR) Asociatia Pacientilor cu Afectiuni Autoimune (APAA)

Associazione Nazionale Persone con Malattie Reumatologiche e Rare (APMAR)

- Arthritis Consumer Experts
- Danish Association of Young People With Rheumatism (DAYR)
- Grupo de Apoio aos Pacientes Reumáticos do Ceará (GARCE)
- Grupo de Pacientes Artríticos de Porto Alegre (GRUPAI)

Association of Patients With Rheumatoid Arthritis (ORS), Serbia

Fundacion Red de Apoyo Social de Antioquia (RASA) Rheumatic Diseases Organization in Crete (RDOC)

- Remisija
- RheumaNET
- RP EncontrAR Brazil Slovenian Rheumatism Association
- Snaga

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