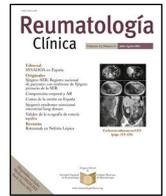




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Original Article

Evaluation of the educational needs in Argentine patients with rheumatoid arthritis using the SpENAT questionnaire[☆]



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ABSTRACT

Background: The SpENAT, a Spanish version of the Educational Needs Assessment Tool, is a self-completed questionnaire that assesses educational needs (ENs) with the purpose of providing tailored and patient-centred information. It consists of 39 questions grouped into the 7 following domains: *Pain management, Movement, Feelings, Arthritic process, Treatments, Self-help measures and Support system.*

Objectives: The objective of the study was to describe the ENs of rheumatoid arthritis (RA) patients using the SpENAT and to determine the main sources of information consulted by these patients.

Material and methods: Multicenter, observational, cross-sectional study. We included consecutive patients ≥ 18 years with diagnosis of RA (ACR 87/ACR-EULAR 2010). Sociodemographic data, disease characteristics and clinimetric properties were recorded. All patients completed the SpENAT and were asked about the sources employed to obtain information about their disease.

Statistical analysis: Population characteristics were described. ENs were determined as percentages of the highest possible score for each domain. Needs for each domain according to sex, years of

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education, disease duration, use of biologicals and functional capacity were analysed by means of ANOVA, and bivariate comparisons were made with Student's *t*-test and the Bonferroni correction. Correlation between domains was determined with the Spearman correlation coefficient. We compared patients' age by source of information with Student's *t*-test.

Results: We included 496 patients from 20 centres in Spain. More ENs were observed in the domains of *Movement, Feelings* and the *Arthritic process*. Patients with higher educational level (>7 years) reported more ENs in the *Arthritic process* and *Self-help measure domains*. A higher functional impairment (HAQ-A ≥ 0.87) was associated with more ENs in every domain. Patients with high activity showed more ENs than those in remission in the domains of *Pain management, Movement, Feelings, Treatments* and *Support system*, as well as those with low activity in *Self-help measures* and *Support system* domains. All SpENAT domains showed positive correlations among each other ($P < .0001$), the most important being *Pain management/Movement* and *Treatments/Arthritic process* ($r \geq 0.7$). The source of information most frequently consulted was the rheumatologist (93.95%); those who made use of Internet were on average younger ($P = .0004$).

Conclusion: RA patients were very interested about knowing more about their disease. High functional impairment was associated with more ENs. Patients with high disease activity had higher EN levels in almost every domain. The rheumatologist was the main source of information for the patient with RA.

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Evaluación de las necesidades educacionales de los pacientes con artritis reumatoide mediante el cuestionario SpENAT

R E S U M E N

Introducción: El Educational Needs Assessment Tool-versión española (SpENAT) es un cuestionario autor-reportado que evalúa las necesidades educacionales (NEd) con el fin de dar información adaptada y centrada en el paciente con artritis reumatoide (AR). Comprende 39 preguntas agrupadas en 7 dominios: *Manejo del dolor, Movimiento, Sentimientos, Proceso de artritis, Tratamientos, Medidas de autoayuda y Sistemas de apoyo*.

Objetivos: Evaluar las NEd en pacientes con AR mediante el SpENAT y determinar cuáles son las principales fuentes de información a las que consultan.

Material y métodos: Estudio multicéntrico, observacional, analítico, de corte transversal. Se incluyeron pacientes consecutivos ≥ 18 años con diagnóstico de AR (ACR 87 y/o ACR-EULAR 2010). Se consignaron datos demográficos, nivel educativo, características de la enfermedad y medidas clinimétricas. Todos los pacientes completaron el SpENAT y fueron interrogados acerca de las fuentes a las que acuden para obtener información de su enfermedad.

Análisis estadístico: Se describieron las características poblacionales. Se determinaron las NEd como porcentajes del puntaje máximo posible de cada dominio. Se compararon las necesidades por dominio según sexo, años de educación, tiempo de evolución, uso de biológico y capacidad funcional mediante test de Anova y las comparaciones de a pares con prueba *t* de Student y corrección de Bonferroni. Se determinó correlación entre los dominios con test de Spearman. Se comparó la edad según la fuente de información con la prueba *t* de Student.

Resultados: Se incluyeron 496 pacientes de 20 centros de todo el país. Se observaron mayores NEd en los dominios *Movimiento, Sentimientos* y *Proceso de artritis*. Los pacientes de mayor nivel educacional (>7 años) refirieron mayores NEd en los dominios *Proceso de artritis* y *Medidas de autoayuda*. Un mayor deterioro funcional (HAQ $\geq 0,87$) se asoció con unas mayores NEd en todos los dominios. Los pacientes con alta actividad mostraron mayores NEd que los pacientes en remisión en los dominios *Manejo del dolor, Movimiento, Sentimientos, Tratamientos* y *Sistemas de apoyo*, y que los pacientes con baja actividad en los dominios *Medidas de autoayuda* y *Sistemas de apoyo*. Todos los dominios del SpENAT mostraron correlaciones positivas entre sí ($p < 0,0001$), siendo las más importantes *Manejo del dolor/Movimiento* y *Tratamientos/Proceso de artritis* ($r \geq 0,7$). La fuente de información más consultada fue el reumatólogo (93,95%); quienes recurrían a Internet tenían una menor edad en promedio ($p = 0,0004$).

Conclusión: Los pacientes con AR manifestaron un gran interés por conocer más sobre su enfermedad. Un elevado deterioro funcional se asocia con mayores NEd. Los pacientes con alta actividad de la enfermedad presentan mayores NEd en casi todos los dominios. El médico reumatólogo es la principal fuente de información del paciente con AR.

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Introduction

Rheumatoid arthritis (RA) is a chronic systemic inflammatory disease characterised by the presence of a destructive polyarthritis with major impact on several areas of the patient's life. Despite the huge variety of effective pharmacological treatments currently available, any improvement in the health and quality of life of the

patient may depend on their ability and willingness to meet with all treatments prescribed and to carry out self-care activities.^{1,2} As a result, education is an essential element of treatment, which allows patients to care for themselves, complete everyday activities and take essential decisions from a health-wise viewpoint. If the patient does not receive this information from qualified staff they will try to find it from other sources, with the consequent

possibility of it being erroneous and/or incomplete. This in turn can lead to negative reactions, making the treatment process more complex. Education provides many advantages both in clinical terms and socially, and helps the patient to face up to their health problems. It also has a positive influence on the recovery process. For this reason, it is considered an integral part of high quality medical care.^{3,4}

It has been recommended that education focuses on the patient and is adapted to satisfy the need for individual knowledge,⁵ because it has been proven that non directed education does not provide long-term effects in patients with RA.^{1,6,7} For this, it would be useful for doctors to have a tool to assess patients' perception of educational needs. The Educational Needs Assessment Tool (ENAT)⁸ is a self-completion questionnaire which was originally designed in United Kingdom and subsequently validated in several European countries (Spain, Portugal, Germany, Poland, the Low Countries, Finland, Norway and Sweden), leading to the Spanish SpENAT version. It consists of 39 questions grouped into 7 domains: *Pain management* (6 questions), *Movement* (5 questions), *Feelings* (4 questions), *Arthritic process* (7 questions), *Treatments* (7 questions), *Self-help measures* (6 questions) and *Support systems* (4 questions). Response are based on a Likert type 5-point scale of: "not important at all", "slightly important", "quite important", "very important" and "extremely important".¹

Up until now educational needs (ENs) in Argentina of patients with RA have not been systematically assessed. For this reason, the purpose of this study was to assess the ENs on the disease in patients with RU using the SpENAT questionnaire, and to determine what the main sources of information consulted by these patients are.

Material and methods

A multicentre, observational, analytical, cross-sectional study was conducted. We included consecutive patients ≥ 18 years with a diagnosis of RA (ACR 87 and/or ACR-EULAR 2010^{9,10}). Other associated collagenopathies (except Sjögren's syndrome) were excluded, as was any difficulty by the patient in reading and understanding the questionnaire. Demographic data, educational level (quantified by years of education), disease characteristics and clinimetric properties (number of painful and swollen joints, visual analogue scale for pain, overall disease assessment by the patient and the physician, disease activity measured by the DAS28 and functional capacity measured through the HAQ-A) were recorded. All patients completed the SpENAT (we obtained the authors' authorisation for its use) and were asked about the sources they had used to obtain information on their disease.

Statistical analysis

Population traits were described. ENs were determined as percentages of the highest possible score for each domain. Needs for each domain were compared according to sex, age, years of education, disease duration, use of biologics and functional capacity using the ANOVA test and bivariate comparisons were made with the Student's *t*-test and Bonferroni correction. Correlation between the domains was determined with the Spearman correlation coefficient. We compared patient's age by source of information using the Student's *t*-test.

The study was undertaken in compliance with the regulations stipulated by Law 3301/09 of the Ministry for Health of the Government of the City of Buenos Aires and the Declaration of Helsinki, and was approved by the ethics and educational committees. All patients agreed to participate in the study and gave their informed consent.

Table 1
Population characteristics (N = 496).

Characteristics	
Age in years, mean (SD)	52.2 (4)
Age < 40 years, n (%)	86 (17.3)
Age ≥ 40 years, n (%)	410 (82.7)
Women, n (%)	444 (89.5)
Years of study, n (%)	
≤ 7 years	168 (33.9)
> 7 years	328 (66.1)
Evolution of RA in months, median (IQR)	108 (48–180)
Early RA, n (%)	53 (10.7)
RF, n (%)	445 (89.7)
ACPA, n (%)	308 (64.4)
Nodular, n (%)	97 (19.7)
Erosive, n (%)	318 (64.4)
Treatment, n (%)	
NSAIDs	258 (52)
Glucocorticoids	229 (46.2)
DMARDs	462 (93.2)
Biologics	146 (29.4)
Functional capacity	
HAQ, median (IQR)	.875 (.25–1.5)
HAQ $\leq .87$, n (%)	238 (48)
HAQ $> .87$, n (%)	258 (52)
Disease activity	
DAS28, median (IQR)	3.44 (2.46–4.66)
Remission, n (%)	149 (30)
Low activity, n (%)	68 (13.7)
Moderate activity, n (%)	190 (38.4)
High activity, n (%)	89 (17.9)

ACPA: anti-protein antibodies/citrullinated peptide antibodies; NSAIDs: non-steroidal anti-inflammatory drugs; RA: rheumatoid arthritis; SD: standard deviation; DAS28: Disease Activity Score 28; DMARDs: disease-modifying anti-rheumatic drugs; RF: rheumatoid factor; HAQ: Health Assessment Questionnaire; IQR: interquartile range.

Results

We included 496 patients from 20 centres in Spain. The percentage of women was 89.5% and mean age was 52.2 years (SD 12.7). Clinical characteristics, laboratory data and treatment data are contained in [Table 1](#).

Analysis of the responses obtained in the SpENAT questionnaire revealed that there were higher ENs in domains *Movement*, *Feelings* and *Arthritic process* ([Table 2](#)). The women had higher ENs than the men in these same domains ($P = .0023$, $P = .0041$ and $P = .0437$, respectively). Patients who were aged ≥ 40 had higher ENs in the *Treatments* domain ($P = .0345$), and in those with over 7 years of education the highest ENs were in the domains *Arthritic process* ($P = .0407$) and *Self-help measures* ($P = .0176$). Greater functional impairment ($HAQ \geq .87$) was associated with higher ENs in all domains in a statistically significant manner.

Patients with high levels of disease activity ($DAS28 > 5.1$) showed higher ENs than those in remission in the domains *Pain management* ($P = .0115$), *Movement* ($P = .0448$), *Feelings* ($p = .0355$), *Treatments* ($P = .0360$) and *Support systems* ($P = .0230$), and those patients with low disease activity on domains *Self-help measures* ($P = .0175$) and *Support systems* ($P = .0075$). Patients with moderate activity showed higher ENs in the *Pain management* domain compared with patients in remission ($P = .0036$).

No differences were observed in the ENs between early RA (defined by time of evolution under 2 years) and established RA, between patients with or without biologics treatment.

All the SpENAT domains showed positive correlations to one another ($P < .0001$), with the most important being *Pain management/Movement* and *Treatments/Arthritic process* ($r \geq .7$).

Regarding information sources which patients regularly consult ([Fig. 1](#)), the most frequently consulted was the rheumatologist

Table 2
Educational needs in patients with rheumatoid arthritis according to SpENAT domains (N=496).

	Pain	Movement	Feelings	Arthritis	Treatments	Self-help	Support
Mean (IQE)	79.17 (70.83–91.67)	90 (75–95)	81.25 (75–100)	89.29 (75–100)	78.57 (71.43–100)	75 (70.83–93.75)	75 (62.5–93.75)

IQE: interquartile range.

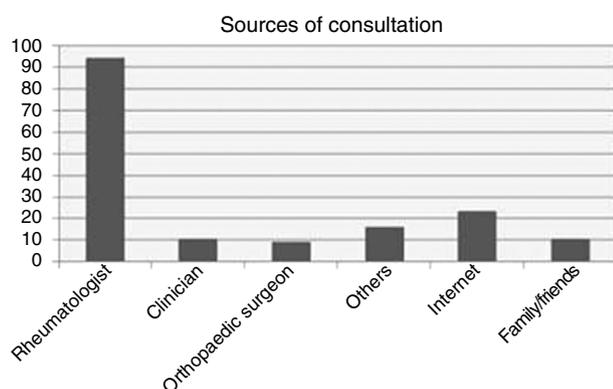


Fig. 1. Sources consulted by patient with rheumatoid arthritis (n = 488).

(93.95%), and those who used Internet were on average younger ($P=.0004$).

Discussion

RA affects .2%–1% of the Caucasian population and it has been estimated that in Argentina there are approximately 400,000 people who suffer from the disease.¹¹

RA is therefore a major problem in Argentina and must be dealt with by both medical teams and by patients. This is a disease which without proper treatment leads to physical, emotional and social limitations. Diagnosis of RA may arouse different feelings, such as impotence, negation, fear and depression, affecting the quality of life of these patients. As with all chronic disease, education is an essential element of treatment since it improves comprehension, increases adherence to treatment and helps to put self-help strategies into practice. Knowledge is a tool that allows the patient to confront their health problems, heighten self-care, boost decision making and help them cope with the consequences of their disease.¹²

In several studies standardised education was observed to have limited long-term effects, and the concept of an education focused on the ENs of the patient was introduced, which was also called “effective education”. For a tailored education it is essential to determine which aspects of RA are of interest to each individual in particular. Although up until recently no tools were available to systematically assess the ENs in patients with RA, in 2011 the cross-cultural validation of the ENAT was performed in 7 European countries, leading to the SpENAT and providing the only objective and valid tool in Spanish to date.¹

Recently Ndosi et al. studied the effects of education based on patient needs. This was a multicentre, single blind study which compared self-efficacy, knowledge and health status in 2 groups of patients with RA who were educated with and without ENAT application. Although no significant differences were found between the groups regarding knowledge, they did observe that the patients who were informed according to their interests improved in self-sufficiency and health aspects, such as pain, stiffness, sleep, social interaction and psychological status. Moreover, the ENAT domain scores were lower at the end of the study, demonstrating a reduction in ENs.¹³

Our study was the first to use SpENAT in Argentina and therefore the first to assess the ENs of patients with RA in our country. According to the results obtained, the patients with RA have a greater interest in receiving information about *Movement*, *Feelings and Arthritic process*. The *Movement* domain refers to joint protection measures, such as the use of objects which make daily life activities easier, the administration of strength, periods of joint activity and rest, and ways of preventing deformity. Also, in the *Feelings* section emphasis was placed on stress, mood changes, asthenia and the causes of the feelings of sadness or depression which may accompany disease evolution. Lastly, the *Arthritic process* encompasses: cause, type of arthritis, genetic transmission, forms of treatment, quality of life, functional limitation and evolution. That stated above proves that the patient with RA requires a holistic approach, with participation from the rheumatologist being essential, together with that of other health specialists such occupational therapists, kinesiology and mental health.

Consistent with findings from European studies,^{1,12} our study found there were significant differences in the ENs depending on the sex and level of education, with them being higher for women and for people with a higher educational level.

It is outstanding that patients with a higher functional impairment and high level of disease activity had greater ENs, but no significant differences were found between early and established RA, demonstrating that it is not duration but level of disability and disease activity which determines interest in finding out more about the disease.

Although it was observed that the rheumatologist was the primary source of information for patients with RA, report bias cannot be ignored, since administration of the questionnaire was made in the rheumatology unit.

Another possible limitation to the study was the fact that patients' knowledge prior to the administration of the SpENAT was not measured, since this knowledge could alter individual ENs.

One strength of this study was that several centres throughout Argentina, including regions with major social, economic and cultural differences were able to participate in it. This inter-regional diversity afforded the study a highly representative study population for Argentina.

Conclusion

RA patients were greatly interested in knowing more about their disease. The ENs were highest in the domains *Movement*, *Arthritic process* and *Feelings*. Major functional impairment was associated with greater ENs. Patients with high disease activity presented higher ENs in almost all domains. Those with a higher educational level have more ENs in the domains of *Arthritic process* and *Self-help measures*. The rheumatologist was the principal source of information for the RA patient.

This was the first study to assess ENs of RA patients in Argentina. We believe that the results obtained emphasise the need for effective education from multidisciplinary teams to offer optimal treatment and increase adherence to treatment in patients suffering from RA, thereby improving their long-term prognosis.

Conflict of interests

The authors have no conflict of interests to declare.

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