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Original

## Information Needs of Patients With Spondyloarthritis About Their Disease<sup>☆</sup>



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### ABSTRACT

**Objective:** 1. To describe the information provided to, or inquired about, by patients with axial spondyloarthritis and psoriatic arthritis. 2. To analyse improvements.

**Methods:** Analysis of the discourse of focus groups (with patients, some of them from patient associations, and rheumatologists). The discussion included the identification of elements that shape the reality being studied, describing the relationship among them and summarising the results by: (1) thematic segmentation; (2) categorization according to situations, relationships, opinions, feelings or others; (3) coding of the various categories, and (4) interpretation of results. Representativeness was ensured by using a typological framework.

**Results:** Rheumatologists are the main source of information. Patient associations have a fundamental role and are well-regarded. Internet is used with caution due to its limited reliability. Patients are interested in: disease characteristics and treatments, the course and prognosis, and social, administrative and other kinds of support. More information is needed (objective and constructive, avoiding a catastrophic tone); it should be provided progressively, adjusted to patients features and needs. There are areas for improvement including: the standardisation and updating of contents (based on scientific evidence), the optimisation of informative materials (written, electronic), and other resources such as nursing and primary care.

**Conclusions:** Rheumatologists are the main and most reliable source of information for patients with spondyloarthritis and psoriatic arthritis. Patient associations have an important role and are well regarded. Changes in the content, format and sources of information are required.

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## Necesidades informativas de los pacientes con espondiloartritis sobre su enfermedad

### RESUMEN

**Objetivo:** 1. Describir la información que reciben o buscan los pacientes con espondiloartritis axial y artritis psoriásica. 2. Analizar fórmulas para mejorar la misma.

**Métodos:** Análisis cualitativo del discurso en grupos focales (con pacientes asociados y no asociados y reumatólogos) para identificar los elementos que configuran la realidad estudiada, describir las relaciones entre ellos y sintetizar el resultado mediante: 1) segmentación según criterios temáticos; 2) categorización en función de situaciones, relaciones, opiniones, sentimientos u otras; 3) codificación de las diversas categorías, y 4) interpretación de los resultados. Se diseñaron casilleros tipológicos para asegurar la máxima representatividad de la muestra.

**Resultados:** El reumatólogo es la principal fuente de información. Las asociaciones de pacientes juegan un papel fundamental y son muy bien valoradas. Internet se consulta con mucha cautela por falta

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de filtro. Son temas de interés las características de la enfermedad y sus tratamientos, pero también la evolución, el pronóstico y las ayudas sociales, administrativas y de otra índole. Se necesita más información (objetiva y constructiva, no catastrofista), que debe darse de forma progresiva y adaptada a las características y necesidades del paciente. Existen áreas de mejora y de oportunidad que incluyen: la estandarización y actualización de contenidos (basados en la evidencia) y la optimización de materiales (escritos, electrónicos) y de otros recursos, como enfermería o atención primaria.

**Conclusiones:** El reumatólogo es la fuente de referencia y de veracidad en relación con la información proporcionada a pacientes con espondiloartritis axial y artritis psoriásica. Se precisan cambios en cuanto al contenido, el formato y las fuentes de información.

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## Introduction

Information provision to patients with chronic musculoskeletal diseases is considered good practice and is recommended in national and international guidelines.<sup>1–5</sup>

However, different studies have revealed possible defects (in quantity, quality, time, format and content) in the information which patients with axial spondyloarthritis (SpA) and psoriatic arthritis (PA) receive in standard clinical practice.<sup>6–8</sup> Furthermore, there is currently a lot of information outside of the system, for example, on the internet, which is accessible to the majority of patients and which often offers contents without scientific bases. All of this has a very great impact on the performance of these patients.<sup>9</sup>

In a survey conducted with patients with ankylosing spondylitis (AS), only 50% had access to written information, many did not like what they had read because of its negative tone, and others considered the information received confusing or even contradictory.<sup>7</sup> In one observational study which included patients with axial SpA and PA, almost 100% of them complained that their doctors used language which was very difficult to understand.<sup>6</sup> In one group of over 1000 patients with rheumatoid arthritis and AS, over half commented that they had received no or scarce information on the diagnosis and medication, exercises and everyday life activities.<sup>8</sup>

The objective of this study was to assess the informational traits and needs of patients with axial SpA and PA, in addition to the considerations of the rheumatologists in this regard.

## Method

### Study Design

A qualitative study with two focus groups of patients and rheumatologists was conducted. Typologies were used to identify the participating patient profiles in order to guarantee their representation (those associated and those not, different age groups, gender, with short and long disease progression). Similarly, another specific typology was designed for the rheumatologists (different ages, gender, with new technology and communication channel skills).

The focus groups took place within a month, in viewing facilities in possession of the standard requirements for this type of group, with a structurally and symbolically neutral ambience. The discussion was transcribed in literal format and analysis was semiological.

The group moderators were experts in qualitative techniques.

### Patient and Rheumatologist Selection

We contacted the Spanish coordinator of the Spondylitis Associations (CEDE) and Action Psoriasis to invite them to participate in the project. They were sent the typologies for selection of associated patients. Nonassociated patients were selected from a hospital centre with equal compliance of typologies. Finally, we contacted the rheumatologist participants directly coming from hospitals with different characteristics, from different cities and with different levels of experience in axial SpA and PA patient management.

### Discussion Guide

Information on the following aspects was collected: (a) current knowledge of patients about the disease; (b) Information sources and channels (healthcare professionals, patient associations, internet, social networks, etc.); (c) confidence level, satisfaction and usefulness of the information received/requested/sought; (d) search chain/request for information (depending on the subject, the situation of the patient, their disease status, etc.); (e) information provision barriers and facilitators and (f) information which could be given to patients (type, form, format, time etc.).

### Statistical Analysis

A description of the focus group discussion was carried out.

## Results

### Associated and Non-associated Patients

In one focus group nine patients belonging to an association participated, five with axial SpA and four with PA. Six non-associated patients attended the other focus group, three with axial SpA, three with PA. The age range of the 15 patients varied from 19 to almost 80, 68% of whom were male and 20% with a disease of recent onset. All participants resided in the autonomous community of Madrid. Since the main findings were similar, we will describe them jointly below. All patients agreed that information on their disease is essential and that in general a high level of information is currently available to them.

The first source of information is the rheumatologist (both for associated and non-associated patients), but due to the amount and quality of it, the associated patients consider patient associations as a highly relevant alternative source. "I really discovered the disease and a whole lot of day to day living things when I went to one of the groups in the association". Information they gain from family members/friends is not relevant. The use of other sources (internet, written press, television,

social networks, forums, blogs, etc.) depends enormously on the patient profile but they are clearly less important information sources.

In general, the level of satisfaction with the information received is acceptable, but could be greatly optimised, particularly that provided by healthcare professionals. Regarding its veracity, for the majority this depends on the source: if it comes from a doctor or an association it is taken for granted that it is true. However, they are more critical opinions which defend that, regardless of the source, one has to search for systems to analyse veracity and particularly in written information (reference it, etc.). The veracity of internet information is doubtful (except the association and scientific society webs, etc.).

Great variability exists on the usefulness of the information received/sought. In general, patients find useful what the doctor or nurse tells them but the information obtained from the patient associations is particularly useful, since it is much more in keeping with what they are looking for/need.

The issues on which they demand more information (out of importance) for the patients are: disease progression, disease prognosis (the most important, particularly at the beginning), causal and trigger factors, pharmacological and non-pharmacological treatments, psychological aspects to the disease. As this advances, other concerns or needs appear such as issues relating to the world of employment, adaptations, administrative-legal issues and in the case of pregnancy, the mother-child impact, etc.

Regarding timing and when best to gain information, all patients say always, even if it is only to recap. One of the principal barriers to this that they mention is the lack of time in the doctor's surgery.

Patients unanimously agree too, that all information offered must be objective, updated and adapted to the patient (traits, time: it is not the same at diagnosis as long-term) in a positive and constructive tone.

Finally, to improve this situation, the patients proposed a series of actions which are summarised in [Table 1](#).

**Table 1**  
Proposals From Patients With Spondyloarthritis (SpA) and Psoriatic Arthritis (PA) for Improving the Information They Receive.

#	Proposal
1	Development of general information on paper (a brief guide to the most important aspects of the disease and its treatments), based on evidence, which was distributed in the doctor's surgery (and which may also be available elsewhere, such as websites of interest). This would serve as a reminder of all the medical information given in the surgery.
2	Development of written materials and other formats, such as videos, on more specific aspects of the diseases (exercise and sport, diet and nutrition, skin care, self-care, how to improve self-esteem, etc.)
3	Systematically provide information on the existence of patient associations.
4	Generate expert patient groups to more specifically attend to information needs on medical aspects of the disease
5	Foster the spread of information through social networks such as Facebook, etc. Improve the level of knowledge on AS and PA of all healthcare professionals involved (including rheumatologists)
6	Improve communication and empathy between doctors and patients
7	Increase the motivation of healthcare professionals
8	Increase (or focus in one specific consultation) time spent to inform or resolve doubts patients may have.
9	Inform family members/carers
10	Inform society in general

### Rheumatologists

A total of 11 rheumatologists participated, with favourable gender and age distribution.

Participants consider that the rheumatologist should be the main source of information. Nurses and other healthcare professionals, together with patient associations, from an informative viewpoint, would be complementary/reinforcements to the rheumatologist.

They consider that the patients with axial SpA and PA demand information on different aspects of their disease, and particularly on evolution, prognosis and treatments. They also demand information on alternative medicine, although it is believed that they later made little use of it. They do not usually demand information on additional tests. This usually increases over time and in some way demonstrates that patients actively seek information. They do not perceive of many differences with regard to information demands between patients with axial SpA and those with PA.

The demand for information is greater from younger people and varies if it is the first visit or successive visits. On disease diagnosis, patients are asked about genetic issues and fertility, treatments and disease prognosis to a greater extent. As time passes, information on sport and nutrition become more important. It also depends on other factors such as gender (more for women who also ask about specific issues such as fertility, or diet and nutrition) or educational level.

In the opinion of the rheumatologists, apart from the characteristics, cause and treatments, patients should be aware of other aspects which are presented in [Table 2](#), where other proposals which arose in this group are listed.

They also believe it is pertinent to measure out the information, adapting it to the patient characteristics and needs and always avoiding catastrophic messages. Several special patient profiles were identified, where provision of information was more sensitive: patients of child-bearing age, older people, those with poor

**Table 2**  
Proposals From Rheumatologists for Improving the Information Provided to Patients With Spondyloarthritis (SpA) and Psoriatic Arthritis (PA).

#	Proposal
1	Ask before informing on what the patients know about their disease and its treatments
2	In addition to providing information on the characteristics, causes, evolution and treatment of the disease, provide information on: <ul style="list-style-type: none"> <li>• Psychological and emotional aspects</li> <li>• Appearance of possible complications which have to monitored, such uveitis.</li> <li>• Comorbidities and impact on the disease</li> <li>• Benefits of adhering to treatment and importance of this</li> <li>• Reasons why treatment is proposed and objectives and treatment strategy</li> <li>• Follow-up (pattern of visits, analytical controls, serological controls, Mantoux, nurses, etc.)</li> <li>• Alternative therapies (characteristics and evidence)</li> <li>• Toxic habits (tobacco, alcohol, others), vaccines, pregnancy</li> <li>• Nonpharmacological treatment/s patients may adhere to alone: exercise, lifestyle habits. Medicine is evolving towards the patient managing their disease, i.e. self-control</li> <li>• Involvement and levels of responsibility of healthcare professionals</li> </ul>
3	Measuring out and adjusting information depending on the patient and the moment
4	Increasing skills for communicating with rheumatologists and nurses directly involved in caring for these patients
5	Increasing knowledge of other specialists, primary care attention and society in general on axial SpA and PA
6	Standardising information contents (always based on the best available evidence) and formats and channels

prognosis markers or with comorbidity or certain personalities traits (avoidance tactics, hypochondriacs, etc.). Verbal information continues to be key for the rheumatologists although other avenues should be explored, such as written information (leaflets), videos and technological applications.

Another series of proposals for improving patient information is suggested (Table 2).

## Discussion

In these focus groups we explored what the information the patients received or looked for was like and discussed a series of proposals (from both patients and rheumatologists) to improve both the content and format and channel.

The main conclusion of this study is that there are areas of improvement and new possibilities in the information which are given to the patients with axial SpA and PA, as we have seen in other countries in our environment.<sup>6–9</sup>

The rheumatologist continues to be the main source of information, as well as being a figure in whom the patients confide. This figure should therefore be the driving force, together with the patients and their associations, for the changes that appear to be needed to improve information on these diseases.

Our results highlight that we are currently living within a context where, on the one hand, there is very limited time spent in the doctor's surgery, an essential place for correct provision of information, but on the other, other resources are available that we can provide which aid and complement this task enormously. Patient associations, nurses, primary care, new information technology (social networks, etc.) can deliver much in this regard.

However, bearing in mind that it is essential to focus on patient care, we must adapt the message (clear, objective, constructive, and positive) and communication to patient characteristics.<sup>8</sup> Furthermore, thanks to the globalisation of healthcare issues, we must be highly rigorous with information that is communicated regardless of the format or channel. This forces us to standardise the messages, to base them on the best available evidence and keep them updated.

We found similar results in the literature. In our study we verified that the amount and quality of the information received is not always optimum. It has been published that in patients with EA, only 50% had access to written information, and for many of them this was confusing.<sup>7</sup> In another observational study, almost 100% of patients did not understand a great part of the language used by the doctors.<sup>6</sup> In our patients it was also obvious that the information they needed was diverse, not just for their disease and drugs but also the indications for their daily life, exercise, labour issues, etc. Similar needs were published.<sup>8</sup>

In the case of rheumatologists, and in line with that expressed by the patients, there is a clear need for improvement regarding information given to patients. In this regard, several documents were published which also reflected this need and how important it is to work on this matter.<sup>5,10</sup>

This study has several limitations regarding the interpretation and generalisation of the results. Firstly, the results refer to the opinion of 15 patients and 11 rheumatologists. However, in order to guarantee the representativeness of the sample, in the case of the patients, for example, typologies were generated to include different patient profiles. When the rheumatologists were selected factors such as the type of hospital, city or experience were also determined so that different profiles could be represented. Notwithstanding, although focus groups have the advantage that

group interaction can take place, stimulating ideas individually and enabling the study of group interaction processes, they may also inhibit the expression of thoughts of some participants due to timidity, lack of privacy, fear or intimidation by other participants. To minimise this impact, the methodology actively focused on asking those people who were less participative. Lastly, we should also mention the limitation regarding information summaries. We have to take into account the possible bias of the researcher, who may analyse findings in favour of his or her hypothesis. The moderators' experience of conducting focus groups reduced this drawback, with techniques being appropriate for information analysis.

To conclude, the major challenge we face in increasing the level of knowledge and satisfaction of our patients with axial SpA and PA is to improve the information we provide.

## Ethical Liabilities

**Protection of people and animals.** The authors declare that no experiments using human beings or animals have been carried out for this research study.

**Data confidentiality.** The authors declare they have followed the protocols of their centre of work on patient data publication.

**Right to privacy and informed consent.** The authors declare that no patient data appear in this article.

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## Conflict of Interests

The authors have no conflict of interests to declare.

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