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# **Original Article**

# Proposals for the incorporation of the nursing role in the certification of axial spondyloarthritis units. Literature review and expert consensus\*



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#### ABSTRACT

*Objective:* To analyse the role of nursing in the approach to axial spondyloarthritis (axSpA) and to make proposals to include the role of rheumatology nursing consultations (RECs) in the quality certification of these specialized units.

*Methods*: A systematic review of the nursing role in quality certification systems in the management of axSpA was conducted. Subsequently a consensus conference was held with the participation of three rheumatology nurses to determine elements that should be considered in future revisions of certification standards.

Results: The systematic review yielded five papers as relevant. None of the publications reviewed explicitly proposed standards applicable to nursing care in the management of patients with axSpA, although they contemplated the activities of this professional group. The proposals agreed upon to incorporate the role of RECs in the certification standards for axSpA monographic units included the following: basic equipment and resources, organization, administration of pharmacological treatments and promotion of adherence, standardized programmes for axSpA, telematic consultation for monitoring the stable patient, registry of patient-reported outcome measures and e-consultation.

Conclusions: The literature on quality standards and certification standards for axSpA monographic units is scarce and hardly reflects the role of RECs in providing quality care. The consensus proposals in this study would incorporate RECs into quality certification standards. In the future, the increased presence of RECs in Spain should be accompanied by a review of the indicators regarding their role.

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# Propuestas para la incorporación del rol de enfermería en la certificación de unidades de espondiloartritis axial. Revisión bibliográfica y consenso entre expertas

RESUMEN

Palabras clave:
Espondiloartritis axial
Enfermería
Revisión sistemática
Conferencia de consenso
Calidad de la atención de salud
Certificación

Objetivo: Analizar el papel de enfermería en el abordaje de la espondiloartritis axial (EspAax) y plantear propuestas que permitan incluir el rol de las consultas de enfermería en reumatología (CER) en la certificación de calidad de las unidades especializadas.

Métodos: Revisión sistemática del rol de enfermería en los sistemas de certificación de calidad en el abordaje de la EspAax, seguida de conferencia de consenso con participación de tres enfermeras especializadas en reumatología para determinar elementos a considerar en futuras revisiones de las normas de certificación.

Resultados: La revisión sistemática arrojó cinco documentos relevantes. Ninguna de las publicaciones revisadas proponía estándares aplicables a la labor asistencial de enfermería en el manejo de pacientes con EspAax, aunque contemplaban actividades propias de este colectivo. Las propuestas consensuadas para incorporar el rol de las CER en las normas de certificación de las unidades monográficas de EspAax incluyeron: equipamientos y recursos básicos, organización, administración de tratamientos farmacológicos y promoción de la adherencia, programas estandarizados para EspAax, consulta telemática para control del paciente estable, registro de medidas de resultados informados por los pacientes y e-consulta. Conclusiones: La literatura sobre estándares de calidad y normas de certificación de las unidades monográficas de EspAax es escasa y apenas refleja el papel de las CER en la provisión de una atención de calidad. Las propuestas consensuadas en este trabajo incorporarían las CER en las normas de certificación de calidad. En el futuro, la mayor presencia de CER en España debiera ir acompañada de la actualización de los estándares.

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#### Introduction

The care model in hospitals is evolving towards increasingly specialised and monographic multidisciplinary clinical units that are integrated into the overall care pathway for their intended patient profile. Monographic care has proven cost-effective in the management of various chronic health conditions. It has been specifically associated with a reduction in admissions, exacerbations, symptom intensity, emergency department visits and, in specific cases, lower hospital mortality<sup>1,2</sup>. Monographic units also help optimise treatment and follow-up (monitoring)<sup>1,3</sup>. Specialised consultations have been observed to produce better clinical results at a similar cost to general consultations<sup>4</sup>.

Regardless of the health condition being treated, nurses play a key role in these monographic units<sup>5</sup>. The benefits of their work from a healthcare, economic and research perspective include savings in face-to-face medical consultations and visits to the emergency department<sup>6</sup>.

Certifying these units is a way of ensuring their efficient management and the provision of quality patient care, and thereby reduce unnecessary variability. Hospitals consider it appropriate for professional societies and associations to promote the accreditation of monographic units<sup>7</sup>. Accreditation standards should reflect the role of nursing.

Rheumatology nurse consultations (RECs) specific to axial spondyloarthritis (axSpA), are not yet widespread in Spain and their scope is unknown. It has also not been studied whether the quality criteria and standards proposed for monographic axSpA units extend to the work of RECs.

Accreditation in the healthcare sector is defined as externally evaluating the performance of an organisation, system, or programme according to a predefined set of standards that take a quality improvement approach to the whole service, covering both the operational and clinical aspects of healthcare provision<sup>8</sup>. The main objective of this external assessment is to improve the quality of care and patient safety by standardising clinical practice and reducing variability<sup>9–11</sup>.

Accreditation (or quality certification) has been shown to have a positive impact on performance, organisational policies and struc-

tures (e.g. reduction of hospital stay, human resource management, integration of services, etc.), care quality, safety culture and clinical processes and outcomes (reduction in complications, readmissions, mortality, etc.) $^{12-14}$ . However, there are also some studies that have found that certification has not resulted in the improvement expected $^{11,15,16}$ .

Despite the need for further research into the key elements that ensure the effectiveness of quality certification, it is considered an appropriate mechanism for promoting continuous improvement in healthcare organisations, in addition to meeting minimum performance levels<sup>11</sup> and facilitating and shortening the time taken to translate evidence into practice in healthcare organisations<sup>10</sup>. In the case of axSpA, although there is broad consensus on the role of nurses, little progress has been made in incorporating their care responsibilities into the certification standards.

AxSpA is a chronic inflammatory disease that primarily affects the spine and sacroiliac joints and has a significant impact on these patients' functional capacity and quality of life. Its most common symptoms include limited mobility, morning stiffness and inflammatory spinal pain, which manifest insidiously and gradually<sup>17</sup>.

The prevalence of axSpA ranges between .1% and 1.4% worldwide<sup>18</sup> and between .3% and 1.3% in Europe<sup>10</sup>. In Spain, the annual incidence of this health condition is estimated at 7.2 cases per 100,000 inhabitants<sup>19</sup>. Figures vary according to ethnicity, geographical location, and the presence of the HLA-B27 antigen<sup>20,21</sup>.

AxSpA is a highly disabling disease, with a permanent sick leave rate of 9.3%. The total annual cost per patient has been estimated at euro11,462.3<sup>10</sup>. Delay in diagnosis makes it difficult to prevent this situation, which, in the case of axSpA, is an average of 7 years<sup>22,23</sup>. One of the barriers that has been found to limit the quality of care in the management of axSpA is the variability between healthcare organisations in covering these patients' care needs.

SpACE is the first Spanish standard to establish the basis of a certification model for the quality of monographic axSpA treatment units dependent on rheumatology services<sup>24</sup>. This standard consists of 14 standards grouped into 3 dimensions: assessment and treatment, coordination, person-centred care, and patient safety. Its application combines the processes of self-assessment by the

unit seeking certification and external assessment (audit) by a third party, external to the health institution<sup>25</sup>.

Although the assignment of nurses to specialised rheumatology units is recent, their role is widely recognised. In 2012, 10 recommendations were made on the role of nurses in the management of chronic inflammatory arthritis, including axSpA<sup>26</sup>. The basic tool in the nursing approach to these diseases is education to increase the patient's knowledge and autonomy in managing their disease and to encourage their involvement in self-care<sup>27</sup>.

The main objective of this study was to explore proposals for indicators and standards for quality nursing care for people with axSpA. As a secondary objective, proposals were made to include RECs in the quality certification of monographic axSpA units.

#### Methods

A mixed methodology study combining a literature review and qualitative techniques (consensus conference) in 2 consecutive phases. The first phase consisted of a literature review of studies on standards for quality nursing care for axSpA and the subsequent comparative analysis between the national standard (SpACE) and international proposals, with a specific review of the role of nursing. In the second phase of the study, a consensus conference was held with the participation of REC nurses to draft proposals to include their professional activity in the quality certification of monographic axSpA units.

Phase 1. Literature review and comparative analysis of proposed standards for quality care in axial spondyloarthritis

# Eligibility criteria

For the literature review, the research question was formulated following the PICO model as follows: In monographic care units for patients with axSpA (P), do the certification rules and quality standards (I) proposed at national and international level (C) incorporate the role of the rheumatology specialist nurse (R)? And if so, with what content? (R).

The initial inclusion criterion for this review was any publication that included standards for quality nursing care for patients with axSpA. However, as we noted that none of them focused on the role of nursing, all publications including standards for quality care for axSpA patients were selected.

# Information sources and search strategy

A search of the national and international literature on standards for quality nursing care for patients with axSpA was conducted in January 2021. The databases MEDLINE (PubMed), EMBASE and Cochrane Library were used for the search. The following MeSH (medical subject heading) descriptors and keywords were combined as controlled vocabulary and free text: "spondylarthritis", "axial spondylarthritis", "spondylitis", "ankylosing spondylitis", "quality improvement", "quality of health care/standards", "rheumatology/standards", "standard of care/standards", "quality indicators, health care", "delivery of health care/standards" and "nursing". For a broader search, no restrictions as to language, date or document type were applied. Detailed search strategies are shown in the supplementary material.

# Selection process

The identified articles were exported to the RefWorks reference manager to delete duplicates. The identified papers were then first screened by title and abstract to eliminate those that did not meet the inclusion criteria. Following this screening, 2 reviewers independently read the full text of the remaining papers and assessed their eligibility.

Data collection process and risk of bias assessment

Two reviewers extracted data from the studies that were finally selected, and discrepancies were resolved with the help of a third reviewer. The following information was collected: authors, year of publication and nursing-related indicators of quality of care for patients with axSpA. The data were collected in an ad hoc spreadsheet.

Two independent researchers then analysed the degree of agreement between the 14 standards of the SpACE standard and those of the documents selected in the review. In the event of disagreement, a third researcher's opinion was used to determine correspondence between standards.

Regarding analysis of the role of nursing in the provision of quality care for people with axSpA, we checked whether the selected articles made specific mention of this group and, if not, we analysed which of the proposed standards could contribute to standardising their work.

Phase 2. Consensus conference to define proposals aimed at incorporating rheumatology nursing consultations in the certification of monographic axial spondyloarthritis units

Between February and April 2021, an online consensus conference was held with the participation of 3 specialist rheumatology nurses, with experience in the approach to axSpA and a track record of more than 10 years in this field. The limited presence of RECs in Spain and the lack of nurses specialising in rheumatology made it difficult to recruit a larger number of professionals who met the criteria to participate in the study. Three rounds were held until consensus was reached on the proposals to be included in a future revision of the quality certification standards for monographic axSpA units. The final proposal was shared with the research group who reviewed it and then gave their approval.

# Result

Phase 1. Literature review and comparative analysis of proposed standards for quality care in axial spondyloarthritis

# Selection of studies

An initial 114 papers were identified from the database search, of which 8 were deleted as duplicates. The title and abstract of 106 papers were examined and 92 papers were excluded as they did not meet the inclusion criteria for this review. Fourteen publications were selected for eligibility assessment through full-text reading and, finally, 5 were included in the present review as they included quality standards for quality care for patients with axSpA (Fig. 1).

# Results of the synthesis and comparative analysis

Table 1 specifies which standards of the SpACE standard were also included in the international proposals described in each of the 5 publications selected in the literature review. All the standards of the national standard appeared in at least one of the publications reviewed. The most frequently collected measures were: clinimetry and patient assessment (Bath Ankylosing Spondylitis Disease Activity Index [BASDAI], Visual Analogue Pain Scale [VAS], Ankylosing Spondylitis Disease Activity Score [ASDAS], Bath Ankylosing Spondylitis Functional Index [BASFI], Health Assessment Questionnaire [HAQ], and ASAS Health Index), delays in care, health education plans, and assessment of pain, spinal mobility, and functional capacity.

Regarding the role of nurses, none of the reviewed publications explicitly proposed standards applicable to their care role in the management of patients with axSpA. However, standards that could apply to RECs would include application of the adult functional capacity rating scale, patient information and education

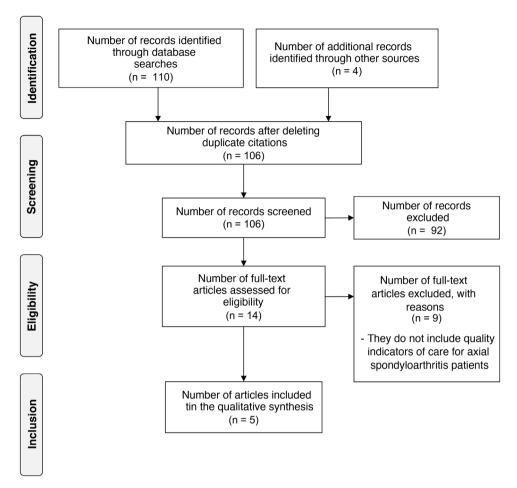


Fig. 1. PRISMA Flow chart. Graphical representation of the search and study selection process, from the number of records identified in the search to the number of studies finally included in the review.

activities to improve patient knowledge of the disease and self-care practices, and collection and recording of self-report and clinical assessment measures (e.g., VAS), assessment of patient experience, and risk management for safe care, including reporting of safety incidents.

Risk of bias

Other unpublished studies in English or Spanish with experiences of rheumatology nurses from other countries were not included.

Phase 2. Consensus proposals for incorporating rheumatology nursing consultations in the certification of monographic axial spondyloarthritis units

The inclusion of nurses in axSpA or other quality certification standards should cover the following REC activities:

Equipment and basic resources. Nursing staff in the practice should have, apart from the physical space where patients can be seen, their own telephone line, educational material, blood pressure monitor, and scales. There should be appointments in the nursing diary at least 3 days a week, so that a record can be kept of the patients seen, applying the protocols for the management of rheumatic patients, such as monitoring disease modulating drugs, both biological and synthetic, and their correct self-administration and adherence, and setting up communication channels between other professionals (physiotherapist, psychologist, dietician, etc.).

*Organisation.* The organisational models of RECs have in common that they focus on the care of the rheumatology patient<sup>33</sup>. The

available evidence is that these consultations improve the patient's quality of life and satisfaction and the effectiveness and efficiency of the health system (efficient use of resources, improved clinical outcomes and reduced waiting times and costs). Patient assessments using the VAS, HAQ, BASDAI and BASFI, as well as metrology and physical examination, usually take place in this consultation.

*Nursing and pharmacological treatments.* The nurse's role in the management of pharmacological treatments includes training in self-administration techniques, correct dosage, the recognition of potential safety incidents and promoting treatment adherence.

Structured and standardised nurse-led programmes (e.g., expert axSpA patient programme). Education programmes<sup>33</sup> can encourage patients with axSpA to self-manage their health condition correctly and to adhere to pharmacological and non-pharmacological treatment (diet, physical exercise, and healthy habits), thus increasing their satisfaction and quality of life and being cost-effective for the healthcare system (cost reduction associated with fewer individual visits and visits to other specialists). Therefore, structured, evaluated, and standardised nursing programmes for people with axSpA are recommended that can be used in any rheumatology unit/service nationwide. The format of these programmes could be based on previous experience of expert patient programmes<sup>34</sup> in other diseases, such as rheumatoid arthritis or fibromyalgia, as these have proven their usefulness in promoting the self-care, coresponsibility, and autonomy of people with a chronic disease.

Telematic consultation (e-consultation) for monitoring stable patients. It is proposed to monitor patients with axSpA using a checklist that combines objective (analytical) and subjective parameters and patient assessment of their symptoms (morning

Correspondence between the standards of the SpACE standard and those of international proposals.

SpACE standard	Coto et al. (2020) <sup>28</sup>	Abad et al. $(2014)^{29}$	Zochling et al. $(2007)^{30}$	$NICE(2018)^{31}$	Kiltz et al. (2019) <sup>32</sup>
01. Assessment of pain scale		Yes	Yes	Yes	
02. Assessment of spinal mobility		Yes	Yes	Yes	
03. Assessment of remission or low disease activity		Yes	Yes		
04. Assessment of extra-articular manifestations		Yes	Yes		
05. Assessment of functional capacity		Yes	Yes	Yes	
06. Radiographic follow-up of the axSpA		Yes			
07. Clinimetry and assessment of the patient	Yes	Yes		Yes	Yes
08. Delays in care		Yes	Yes	Yes	Yes
09. Multidisciplinary care	Yes	Yes			
10. Consultation with Primary Care	Yes	Yes			
11. Access to MRI				Yes	
12. Health education plans		Yes	Yes	Yes	Yes
13. Patient satisfaction		Yes			
14. Adverse event reporting system		Yes			

stiffness, axial or peripheral involvement, and VAS score). Pretrained patients can submit their PROM (patient reported outcomes measures, such as BASFI, BASDAI or HAQ) assessments by email or mobile application. From the acute phase reactants (C-reactive protein [CRP] and erythrocyte sedimentation rate [ESR]) and patient relevant domains, disease activity scores (ASDAS) would be calculated. If the disease is active or in flare up, an appointment with rheumatology would be made, whereas if in remission, the checklist would be maintained. Treatment, tolerance and adherence and possible adverse effects would be assessed. Health education on aspects of the disease and lifestyle habits (exercise and nutrition) would then be reinforced. The next follow-up appointment (faceto-face or telematic) would be scheduled according to the patient's condition and test results.

Telematic consultation (e-consultation) with nurses to facilitate communication and coordination between different health areas and deliver comprehensive care to the patient. This type of consultation is implemented in some rheumatology units in Spain. Patients with axSpA require multidisciplinary and coordinated care that enables continuity of care in and out of hospital. This type of consultation allows direct and effective communication between specialised care and primary care<sup>35,36</sup> through digital health information systems, which promotes person-centred care and contributes to quality of care and patient safety<sup>21,35</sup>. It also facilitates the speedy resolution of queries, within a maximum 72 h by e-mail<sup>35</sup>. This type of consultation, together with specialist nurses, plays a key role in the coordination between care levels to speed up the early diagnosis of axSpA.

# Discussion

This study confirms that there are opportunities to improve the quality certification standards by considering the role of the REC in ensuring comprehensive care for patients with axSpA. The activities covered under the quality standards do not require substantial changes, other than mentioning the professional profile and activities for which nurses are responsible. This decision would encourage incorporating nurses with a specific profile in the care of these patients, which, given the consensus on its advisability<sup>26</sup>, would be of benefit to patients.

The role of nurses in the management of axSpA has not been explicitly described in the literature, nor routinely covered under standards for quality care. The literature review has identified the need to improve the quality certification standards of specialised axSpA units by incorporating the work of RECs in the framework of integrated care. This incorporation should go hand in hand with a greater offer and promotion of specialist rheumatology nurses. In Spain, the experience of RECs with patients with axSpA in specialised monographic units is limited, and therefore the validity of the standards to be defined should be reviewed in the medium term. In this regard, some initiatives, such as the one promoted by the Valencian Society of Rheumatology Nursing Group (GESVR), seek to lay the foundations for incorporating rheumatology nursing agendas according to the needs, resources, and agreements with the management of each rheumatology unit or department<sup>37</sup>.

The experience of RECs with patients with axSpA in specialised monographic units is not widespread in our country. This, together with the lack of visibility of the role of nursing in general and in terms of quality certification in particular, made it impossible to include the term nursing in the definition of search equations in the literature review. This result, undesirable in methodological terms, only confirms the lack of literature on this subject and the need to address it. As for the consensus conference, the main limitation was the small number of participants involved in drafting the proposals. This calls for future broader consensus studies, using this or

another qualitative research technique such as the Delphi study, to strengthen the proposals to incorporate RECs into the certification standards of units specialising in axSpA and other rheumatological diseases. The development and validation of instruments to specifically evaluate the work of nurses in quality certification processes would also be useful.

Finally, this study was undertaken taking the Spanish healthcare model and the SpACE standard as a reference, and therefore caution should be exercised in generalising it to other contexts.

#### **Conclusions**

This study is a first approach to recognising the role of the specialist rheumatology nurse in monographic axSpA units, and in the quality certification standards of these units. The scarce implementation, documentation, and coding of RECs in Spain greatly limited the scope of the study, designed as a first step to place a line of work yet to be explored and implemented on the agenda of how to approach axSpA. The proposals presented here seek to make the role of nursing in providing quality care for axSpA patients more visible, while helping to incorporate it into certification standards. As the experience of RECs grows in Spain, it may be necessary to include new elements in the certification standards that reflect the role of nursing in the care of these patients. Future studies will need to further analyse the adequacy of quality criteria and standards in monographic axSpA units, taking nursing activity into account.

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# **Conflict of interests**

The authors have no conflict of interests to declare.

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