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Reflexion Article

Design and implementation of clinical care centres for spondyloarthritis. A benchmark care and disease model in chronic pathologies

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ABSTRACT

Introduction: Spondyloarthritis (SpA) is a musculoskeletal disease presenting with phenotypic clinical manifestations, integrating a set of interrelated inflammatory conditions, which share immunogenetic, epidemiological, and therapeutic characteristics.
Objective: to do a reflection exercise through the experience of designing and implementing a clinical care center for spondyloarthropathies, from the administrative and clinical perspective to the implications in decision making and impact on the different indicators related to efficiencies and safety of the services included in the model.
Results: In clinical practice, the reality of the care process in patients diagnosed with SpA represents an area of opportunity in multiple aspects. The fragmentation of clinical care and the heterogeneous flow of the patient in the care pathway, are associated with suboptimal and undesired clinical outcomes. Several aspects highlight the reality of patients with SpA in the national scenario, which -to a certain extent- could reflect what is observed in other Latin American countries. SpA represents a very significant burden for society and for individuals affected by this condition. Comprehensive assessment of the burden of disease from the perspective of the clinician and the patient is important, in order to support decisions related to treatment and comprehensive management of this condition. The improvement in health outcomes and the reduction in the cost of chronic inflammatory diseases, such as SpA, are the main advantages of implementing a care model in specialized centres integrating a multidisciplinary team.
Conclusion: This is an opportunity to include the perspective of individuals affected by this condition, seeking integration between an informed patient and a highly qualified multidisciplinary care team in the comprehensive management of patients with SpA.

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Diseño e implementación de centros de cuidado clínico en espondiloartritis. Un modelo de atención y de enfermedad referente en patologías crónicas

Palabras clave:
Espondiloartritis
Modelo de atención
Enfermedades crónicas

RESUMEN

Introducción: La espondiloartritis (EspA), enfermedad musculoesquelética que se presenta con diferentes y variadas manifestaciones clínicas, integra un conjunto de condiciones infamatorias interrelacionadas, las cuales comparten características fenotípicas, inmunogenéticas, epidemiológicas y terapéuticas.
Objetivo: hacer un ejercicio de reflexión a través de la experiencia de diseñar e implementar un centro de cuidado clínico en espondiloartropatías, desde la perspectiva administrativa y clínica hasta las implicaciones en la toma de decisiones e impacto en los diferentes indicadores relacionados con eficiencias y seguridad de los servicios incluidos en el modelo.
Resultados: En la práctica clínica habitual, la realidad del proceso de atención en pacientes con diagnóstico de EspA representa un área de oportunidad en múltiples aspectos. La fragmentación del cuidado clínico y el flujo heterogéneo del paciente en la vía de atención tienen como consecuencia que los desenlaces clínicos obtenidos no sean los óptimos y deseables. Varios aspectos destacan la realidad de los pacientes con esta enfermedad en el ámbito nacional, que hasta cierto punto podría reflejar lo observado en otros países de América Latina. Las EspA conllevan una carga muy importante para la sociedad y para los individuos afectados por esta condición. La evaluación integral de la carga de la enfermedad desde la perspectiva del clínico y del paciente es importante para ayudar a tomar decisiones sobre el tratamiento y el manejo integral de la enfermedad. La mejora en los desenlaces en salud y la reducción del gasto de las enfermedades crónicas inflamatorias, como es el caso de EspA, constituyen las principales ventajas de la implementación de un modelo de atención en centros especializados que involucre un equipo multidisciplinario.
Conclusión: Lo anterior se constituye en un escenario de oportunidad para incluir la perspectiva de los individuos afectados por esta condición, buscando el encuentro entre un paciente informado y motivado y un equipo de atención multidisciplinaria altamente calificado y entrenado en el manejo integral de pacientes con EspA.

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Overview of the disease

Spondyloarthritis (SpA) is a musculoskeletal disease that presents with different and varied clinical manifestations and integrates a set of interrelated inflammatory conditions, which share phenotypic, immunogenetic, epidemiological and therapeutic characteristics. The age of onset of symptoms corresponds to young individuals, under 45 years of age. These patients report chronic back pain (more than 3 months of evolution) associated with morning stiffness, most of the time located in the lumbar region. Likewise, it can affect peripheral joints (oligoarthritis of the lower limbs) and entheses (regions where a tendon, a ligament or the joint capsule inserts into the bone). Concomitantly with the initial symptoms or during the course of the disease, extra-articular manifestations such as psoriasis or uveitis may occur.[1] Recently, the Colombian Association of Rheumatology published a set of treatment recommendations for patients with predominantly axial[2] and predominantly peripheral[3] SpA, aimed at health professionals, payers of health expenses, decision makers and government entities that generate health policies.

In the case of SpA, there are studies on the epidemiology of the disease that have reported different results, related to the classification criteria used, the population distribution of the risk factors and, finally, the methodology used to detect the cases. The global prevalence of SpA is highly variable; a range of 0.20% (95% confidence interval [CI]: 0.00–0.66) to 1.61% (95% CI: 1.27–2.00) is estimated.[4] An estimated prevalence range between 0.28 and 0.90% has been reported in Latin America.[5] A prevalence of 0.11% (95% CI: 0.03–0.36) for ankylosing spondylitis and 0.28% (95% CI: 0.02–0.27) for undifferentiated SpA has been determined in Colombia using the Community Oriented Program for Control of Rheumatic Diseases (COPCORD) methodology.[6] Similarly, it has been estimated an overall incidence of SpA in the range between 0.5 and 8.2 cases per 100,000 inhabitants. These data are influenced by the frequency of the HLA-B27 allele in the studied population, which in the case of Colombia has been estimated at 12.1% in individuals with clinical signs suggestive of SpA[7] and at 1.8% in healthy individuals.[8]

Spondyloarthritis in the scenario of clinical practice

In the usual clinical practice, the reality of the care process in patients diagnosed with SpA represents an area of opportunity in multiple aspects. The fragmentation of clinical care and the heterogeneous flow of the patient in the care pathway result in clinical outcomes that are not optimal nor desirable. The following aspects highlight the reality of the patients with SpA in the national scenario, which to a certain extent could reflect what has been observed in other Latin American countries.

Diagnostic delay in SpA continues to be a challenge in clinical practice, along with the active search for strategies to reduce the delay in the early identification of this clinical condition. According to what was reported in the European Map of Axial Spondyloarthritis (EMAS) study,[9] the estimated diagnostic delay is 7.4 years. This diagnostic delay affects to a greater extent women, younger individuals at the time of onset of symptoms, and those patients who are evaluated by a greater number of healthcare professionals. Likewise, the lack of knowledge of the disease among health professionals who are not rheumatologists has a negative impact on early diagnosis and timely suspicion of the disease in this type of patients. This is reflected in a longer time interval between the onset of the symptoms and the diagnostic confirmation. This situation not only affects the physical, psychological and social well-being of patients, but also has an economic impact on society in relation to the associated costs derived from the frequent use of health services and the difficulties to join or stay in the labor market.

The access to diagnostic tests and specialized centers that offer a comprehensive approach and follow-up is an aspect that must be considered in the control of the disease, as well as to avoid functional deterioration. Imaging techniques such as magnetic resonance imaging of sacroiliac joints, ultrasound, acute phase reactants and liver, kidney and hematological function laboratory tests constitute useful paraclinical tools for the identification of these patients and, in some cases, for their clinical follow-up.[10] In this sense, clinical care centers allow the interaction of a large number of health professionals (dermatologists, ophthalmologists, gastroenterologists, physiatrists, orthopedists, radiologists, nutritionists, psychologists, pharmaceutical chemists, internists, family and general physicians) focused on offering comprehensive care for patients with SpA, in terms of early diagnosis, treatment and rehabilitation under the leadership of the rheumatologist.[11] The foregoing aimed at achieving the best health-related results, through the optimization of available resources, the obtention of a clinical remission or a low level of activity, as well as the prevention of joint destruction, disability and associated complications, so that the quality of life of the patients is favorably impacted. Similar experiences on a national scale in rheumatoid arthritis (RA) have been satisfactory.[12]

To have a broad impact on the health status of patients, it is necessary to include the development of community strategies for diagnosis, through awareness raising and education of primary care physicians and specialists involved in the follow-up of patients with SpA. Intervention models aimed at patients with chronic low back pain or psoriasis with clinical suspicion or diagnosis of SpA, together with education strategies for early detection and referral by primary care providers, constitute a felt need in the national context.

In routine clinical practice, it had been described a wide variability and insufficient capture of the variables necessary to follow up patients with axial SpA (axSpA) and psoriatic arthritis.[13] Several studies have reported that 87% of medical histories do not record an assessment of disease activity, 84% do not include a functional assessment, and 60% do not contain an assessment of joint involvement.[14] With the aim of standardizing routine clinical practice and improving both the management and the prognosis of axSpA, guidelines for patient follow-up have been published on a national and international scale.[15] Their adequate implementation in the context of clinical practice is developed in the setting of clinical care centers that include homogenized medical records, which capture the important variables for follow-up and traceability over time. Technological platforms that allow the integration of clinical, paraclinical, imaging variables and outcomes reported by the patients constitute a priority need. The integration of patient information in the big data scenario will allow the design of computational analyses and predictive models that optimize early diagnosis, therapeutic decision making, patient follow-up and adherence to treatment.[16]

Reflection on the burden of disease

SpA represents a very important burden for society and for individuals affected by this condition. Comprehensive assessment of the disease burden from the perspective of the clinician and the patient is important to help make decisions about treatment and comprehensive management of the disease. Real-world studies have reported that patients with axSpA and psoriatic arthritis have a longer time from the onset of symptoms to diagnosis (seven and three years, respectively), compared to those with RA (less than two years). Likewise, this group of patients has a burden of disease comparable to or greater than that of patients with RA, assessed using patient-reported outcome measures and disease activity outcome measures.[17] The foregoing reflects the impact of the disease and reveals that this condition is not adequately recognized in the clinical (health professionals) or administrative (insurers, auditors, health providing institutions, government entities) scenarios. In this sense, the importance and usefulness of strategies aimed at offering better control of the disease in patients with SpA stands out.

Regarding the spectrum of the disease, individuals with radiographic AxSpA (traditionally defined as ankylosing spondylitis) typically represent a more severe clinical, functional, and imaging form,[18] measured in terms of acute phase reactants, patient-reported outcomes, and clinimetry, compared with the non-radiographic axSpA subtype.[19] However, what is striking is related to the use of medications, including biological therapy, since there are no differences observed, which reflects that the burden of the disease is similar, regardless of the radiological severity of the involvement. At this point, the radiographic and non-radiographic forms share a similar clinical presentation, with comparable disease burden,

therapeutic modality, and treatment effect.[20] What was mentioned above becomes more relevant considering that patients with access, and therefore early diagnostic and therapeutic approaches, represent significant savings for the health system, less disability (functionality), better productive capacity and better quality of life.[21]

This disease model represents a high health, economic and social burden that must be taken into account in the management of the disease, not only by the rheumatologist and health professionals, but also by all the actors in the system. SpA is a chronic progressive inflammatory disease that leads to functional limitations, which affects not only physical health, but also mental health. Its impact on labor productivity is an issue of great concern for the society, since this condition begins early in life (around the third decade), and the subsequent loss of productivity contributes to the significant socioeconomic burden. Furthermore, for the patients themselves, work is a key aspect of the impact of the disease, since it alters important aspects linked to quality of life, such as financial stability, work ability, memory or concentration and other daily living activities.[22]

It should be taken into account that the available resources are a key factor for the optimal follow-up of patients with SpA and can be a limiting factor. The heterogeneous presentation of the condition, the coexistence of different clinical manifestations, the impact of comorbidities, the diagnostic delay and the essential role of imaging modalities in the diagnostic process support the need to integrate multidisciplinary teams to improve clinical, social and productive outcomes of patients with SpA.

Risk management models. What is their impact on decision-making?

Understanding how the health system is financed and how resources flow, including mechanisms of contracting between actors, is essential for any process of service provision. Every quality care process must be based on risk management, since knowledge of the population, the clear definition of strategies and the search for intervention alternatives consistent with the level of risk are the pillars for the best results with the best cost-effectiveness.

Contracting is the point that articulates the actions of the provider and the payer, where, in an ideal model, the rate is only a point of reference. This means that the best contracting model is the one that best fits the conditions of the pathology (SpA), the supply and demand of services, including the needs and expectations of the parties, regardless of whether it is the cheapest or the most expensive that can be contracted. There is no perfect contracting model, but knowing the implicit and explicit incentives of each one, as well as having a clear attention route and the flow of information to guarantee follow-up, allows us to build processes that benefit all parties in the long term, especially the patients.

Payment modalities can fluctuate between contracting per capita and contracting per event, with a wide variety of options between these two points, which include different levels of risk sharing between actors. The technical risk and the risk of the provision must be evaluated in each of the scenarios, where the supply and demand of services must lead a consensual evaluation that yields the best contracting model for the conditions exposed.

If the foregoing is taken into account, hand in hand with the defined contracting, the clinical management model, in which the systematization of processes and the reduction of variability must seek the best decision making, in line with the technical expertise and rational use of resources must be articulated. Management, at any of its levels (macro, meso or micro), must lead to improving patient health outcomes, patient satisfaction with the care process, and levels of safety and efficiency that allow for cost optimization without sacrificing at no point the quality provided and perceived.

Towards a center for clinical care in spondyloarthritis. Strategies for its implementation

The improvement in health outcomes and the reduction in expenditure for chronic inflammatory diseases, such as SpA, are the main advantage of implementing a care model in specialized centers that involve a multidisciplinary team. It is dangerous that saving lead to a reduction in access to health services, so the best way to achieve significant savings, from an economic point of view, is to improve the health status of the patients.[23] The above, based on other similar disease models.

In this sense, among the main challenges, the optimization of the care model, which often does not meet the needs of effective clinical management, is characterized by the absence of administrative support for clinical leaders and lacks a robust technological system of integration, analysis and interpretation of information stands out. The main reason for this may be the misalignment between the needs and the care provider systems, designed to a great extent for acute illnesses.[24] The specialty care models are becoming more relevant, and the sectoral challenge is to build them, taking into account the operational scope and their definitions.[25] The foregoing includes, among others, provision based on available scientific evidence with cost-effective interventions, opportunity of access and the evaluation of health outcomes and results.

Finally, the care models for chronic diseases[26] make emphasis on patient participation, through a more active role in the context of healthcare services. The concept of ëmpowermentïn the training of the patients to take responsibility for their health situation is the great challenge in the successful implementation of this type of care models in SpA. The latter becomes important if the philosophy of p̈atient-centered careïs considered as the central axis around which the rest of the dimensions related to intervention based on scientific evidence, the organization of the service, the team and interdisciplinarity and the environment revolve. All of the above constitutes a scenario of opportunity to include the perspective of the individuals affected by this condition, seeking the encounter between an informed and motivated patient and a multidisciplinary care team highly qualified and trained in the comprehensive management of patients with SpA.

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Authors' contribution

Conception of the idea: WB. Search and compilation of evidence: WB, HA, PM and GQ. Writing of the manuscript: WB, HA, PM and GQ. Review of the manuscript: WB, HA, PM and GQ. All authors read and approved the final text.

Conflict of interest

The authors declare that they have no conflict of interest.

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