Reumatología Clínica

Original Article

Motivations and Objections to Implement a Spondyloarthritis Integrated Care Pathway. A Qualitative Study With Primary Care Physicians☆

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A R T I C L E   I N F O

A B S T R A C T

Background and objectives: Previous to the development of a clinical pathway (CP) for early spondyloarthritis (SpA), a qualitative study was performed to know the attitude of primary care physicians (PCP) with respect to CP implementation.
Methods: 5 discussion groups (2 in Madrid, 2 in Barcelona and 1 in Sevilla) and 3 interviews in Bilbao, were performed. PCP with different profiles were included. Groups and interviews were carried out by experts on qualitative methodology.
Results: PCP know little about CP. Motivations of professionals to work on a SpA CP were: to improve patients care, availability of a specialist consultant, possibility of learning and doing research, remuneration, and professional recognition. Objections to CP implementation were: extra work, excessive bureaucracy, absence of a specialist consultant, computer difficulties, and no remuneration. SpA knowledge by PCP was defective. PCP associated the term "spondylitis" with osteoarthritis, low-back pain, ankylosing spondylitis and psoriatic arthritis. They only referred patients to the rheumatologist to confirm the diagnosis, when patients complained and when treatment was ineffective.
Conclusions: For an optimal CP implementation, the following is deemed necessary: (1) a practical, simple program that eases the interaction with the rheumatologist without an increase on the PCP work load; (2) to provide continuous feedback by the specialist and (3) to provide knowledge on SpA to PCP.

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Factores motivadores y barreras para implantar una vía clínica de atención precoz de espondiloartritis: estudio cualitativo con médicos de atención primaria

R E S U M E N

Fundamento y objetivo: Previo al desarrollo de una vía clínica (VC) para espondiloartritis (EspA) precoz, se realizó un estudio cualitativo para conocer la actitud de los médicos de atención primaria (MAP) respecto de su implantación, para aumentar sus posibilidades de éxito.
Métodos: Se realizaron 5 grupos de discusión (2 en Madrid, 2 en Barcelona y 1 en Sevilla) y 3 entrevistas en Bilbao. Se incluyeron MAP con perfiles que garantizaran la diversidad de puntos de vista. Tanto grupos como entrevistas fueron realizados por expertos en metodología cualitativa.
Resultados: En general, los MAP no conocen las VC. Se consideraron motivaciones para su implantación: mejorar la atención de los pacientes, disponibilidad de un consultor especialista, posibilidad de formación e investigación, remuneración y reconocimiento profesional. Se consideraron dificultades para su implantación: trabajo adicional, burocratización excesiva, falta de respuesta del especialista,

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desconocimiento informático y la no remuneración. El conocimiento de las EspA por los MAP fue deficiente: se asociaba simultáneamente «espondilitis» con artrosis, lumbalgia, espondilitis anquilosante y artritis psoriásica. Solo derivaban al especialista para confirmar el diagnóstico, lo demandaba el paciente o el tratamiento era ineficaz.

Conclusiones: Para implantar una VC de EspA, con colaboración óptima de primaria es necesario: *a)* formalizar los procesos a través de un programa sencillo, práctico y aprobado por gerencia, que facilite la interacción con el especialista sin aumentar la carga de trabajo; *b)* permitir una retroalimentación de seguimiento del paciente a lo largo de todo el proceso, además de un consultor permanente, y *c)* proporcionar formación en EspA a los MAP.

Introduction

Spondyloarthritis (SPA) is a group of rheumatic diseases that share many clinical, radiological, and genetic and epidemiology characteristics, which clearly distinguishes them from other inflammatory diseases of the musculoskeletal system, especially rheumatoid arthritis (RA), which has a pattern that differs by having distinct joint and extraarticular manifestations, absence (seronegative) of serum rheumatoid factor and a strong association with the major histocompatibility antigen class I, HLA-B27, in most cases. Furthermore, there is evidence from studies in humans and in animal models that suggest the involvement of bacteria or bacterial products in its ethiopathogenesis.[1]

Currently, the group includes ankylosing spondylitis (AS), reactive arthritis, psoriatic arthritis subgroups, arthritis associated with inflammatory bowel disease, a subgroup of juvenile idiopathic arthritis and undifferentiated spondyloarthritis. Its clinical spectrum is broad and heterogeneous, expressed with varying intensity in each of the diseases that make up the group.

The prevalence of ESPA is not low, affecting 1.9% of the general population.[2] In Spain, the National Spondyloarthropathy Validation Study[3] showed an average prevalence of 13% in patients consulting rheumatology services, ranging from 8% to 16% among the different Spanish regions. It is estimated that the SPA, a young persons disease, involves an average annual loss of 62 working days per patient. In 20% of patients with these diseases, it leads to a career change, another 20% retires from any professional activity, and 27% attains permanent[4] disability status. It is therefore a relatively high prevalence diseases and an important social load. However, so far they have not been given the same attention as other rheumatic diseases such as RA and osteoporosis.

Although today there are new classification criteria for an earlier SPA diagnosis,[5,6] it is true that until recently diagnostic criteria required the presence of signs which, by their nature, are late, such as radiological sacroiliitis or decreased mobility,[7] which could induce delays in diagnosis and limit their use for early diagnosis, among others problems.[8] The average delay in diagnosis of SPA in Spain is known from the REGISPONSER project and averages over six years,[9] a phenomenon that is similar to other countries.[10] This delay is due to both the insidious onset of the disease and the application of criteria which require the presence of "advanced changes" and the fact that SPA are not well-known to the non-specialist, both due to problems of academic training and because sometimes they lack adequate support in rheumatology. Until recent years, early diagnosis may have had less value, given the absence of effective treatment measures. Currently, treatment response in autoimmune diseases has greatly improved and is spreading to SPA. In addition, there are more effective treatments that could alter the progression of structural lesions and progression to ankylosing disease.[11]

The Spanish Foundation of Rheumatology (FER) in 2009 designed the Esperanza (Hope) Program, a clinical pathway (CP) for early SPA that integrates primary and specialty care, which aims to reduce the variability in clinical practice, facilitating early diagnosis, improved training of general practitioners and specialists, optimizing health resources and stimulating research. Prior to the development of the CP, and after the problems was identified with the launch of a similar program in 2004 for RA (SERAP[12] Program), the Spanish Foundation for Rheumatology (FER) conducted a qualitative study to explore the level of knowledge of the CP between primary care physicians (PCP), assessing difficulties in its inception, the motivations and obstacles to the acceptance of a CP, with assessment of knowledge in SPA and evaluating the needs and expectations of primary care in these diseases, in order to incorporate this information in planning programs for management and increasing their chances of success.

Materials and Methods

The main objective of qualitative research techniques is not to empirically prove the facts, but to analyze and interpret the meanings, motivations and behaviors related to such events. For the purpose of this study, given its exploratory nature, it was considered that the most appropriate technique was conducting focus groups. We developed a typological box to identify the profiles of participating physicians to ensure the diversity of views and the number of groups that would be necessary. A profile of the participants was established that would allow applying surveys to PCP of the national health system, which included different age groups, different number of years in practice, different sexes and diverse population areas (rural and urban). It was also considered necessary to allow groups to know the different situation in terms of geographical area, as there are differences in this respect after the transfer of the management of the health system to autonomous regions. Specifically, it was considered important to understand the systems differing aspects in Basque, Catalan and Andalusian regions. Were conducted 5 focus groups (two in Madrid, two in Barcelona and one in Seville).

The focus groups were composed of between 6 and 8 PCP and held within a week, consecutively, in rooms that were eligible for this type of groups, with a neutral environment in the structurally and symbolically. The speech was recorded entirely in audio and video, transcribed verbatim and analyzed semiologically. In Bilbao, given the difficulty of organizing focus groups with audiovisual recording, three key informants were selected to allow the box to complete the typological profile in terms of age, years of experience, participation and collaboration with the rheumatology CP. Interviewers were experts and followed an index map that reproduced the terms of discussion. Both groups and the interviewers completed the collection of the information when it was confirmed that the recording had been saturated, i.e. when new comments were redundant and added nothing new. The moderation of groups and the interviews were conducted by sociologists and experts outside the project with qualitative techniques, both for data collection and analysis. Semiological analysis was performed with the help of the Nudist Live program identifying categories and codes, using the inductive method.[13]

Index Map

Information was collected on the following aspects: (a) current PCP knowledge of SPA, (b) interest and general knowledge in CP programs, (c) potential resistance to the program: potential difficulties in implementing a proper chain of command to ensure feasibility, saturation of primary care centers (PCC), availability of resources (time, computers, etc.); (d) aspects of the program motivators: extrinsic (remuneration, professional recognition, awards, curriculum, etc.). intrinsic (increased knowledge, satisfaction of a job well done, research ability, etc.), transcendence (improved patient care, improved relationships between primary and specialist care, etc.), (e) expectations for the program: deficiencies, potential improvements in care and on clinical pathways, etc.

Results

Knowledge of Clinical Pathways

In general, PCP do not know the CP except in Andalusia, where there are programs associated with the Andalusian Health Service. Difficulties were considered for implementation: the lack of cooperation of specialized care, insufficient computerization of specialized care consultations, possible problems with the protection of patient data and software compatibility with that already in use in primary care.

"In primary care, we do not use that nomenclature" (Madrid), "Never heard of it" (Bilbao).

"The CP is a group of tools that help you work through protocols" (Sevilla), "This is intended to unify criteria" (Sevilla), "It is more than an outpatient hospital" (Sevilla), "There is a "reference" with which one can check working in this field and also available to the PCP to facilitate communication between primary and secondary care" (Sevilla),"Are they going to want specialists for these plans? Insurance would refuse" (Madrid/Barcelona/Bilbao), "We are not computer specialists" (Madrid/Barcelona/Seville/Bilbao),"Each area has different software. If there was a single program, I see this as feasible" (Madrid), "In theory, everything is very nice, but there are many difficulties in practice" (Barcelona).

Motivations to Accept the Clinical Pathway

There are different motivations for receiving CP plans related to the age and experience of the PCP, which determine two distinct profiles of professionals: (a) young: proactive, entrepreneurial, interested in training and in the activities to improve their resume, interested in new proposals to improve health care and selfless attitude towards financial rewards, (b) Veterans: passive, disillusioned with new health reform proposals, uninterested in training and only incentivized by financial rewards. The "youth" and "seniority" are identified more by the motivations that move the PCP and their degree of "burn out" than biological age.

The motivations for the benefit of those plans were of different types, related with transcendent, intrinsic, extrinsic and/or management aspects.

Transcendent Motives

Transcendent aspects were assessed in a similar manner in both PCP profiles: (a) improvement of patient care, reducing waiting times, number of visits, diagnostic tests and drugs, (b) increased patient contact and greater involvement in monitoring, and (c) having a specialist consultant with which to exchange information and to develop a workable feedback relationship.

"It improves patient care, is faster and saves resources" (Barcelona), "it would save waiting time for patients" (Madrid), "There would be feed-back to the specialist" (Barcelona/Sevilla/Madrid); "Having a consultant at the clinic visit who coordinates and with whom to exchange opinions" (Barcelona), "diagnostic tests would be economized" (Madrid).

Intrinsic Motives

The intrinsic aspects were of particular value in the profile of the "young" PCP and posed the possibility of training and research, the ability to rotate one month a year in a hospital service and self-satisfaction of a job well done; "It would be very interesting to do training" (Barcelona/Madrid).

"The self-satisfaction of doing a good job as a doctor and thinking about the good of the patient" (Barcelona/Madrid): "It would be nice to rotate one month a year in a hospital service, if you looking for an answer for your query" (Barcelona).

Extrinsic Motives

Regarding the extrinsic aspects, differences were again seen in the PCP profile. The 'veterans' assessed compensation for participation in the program, while the "young" were interested in professional recognition and curriculum. The only aspect that was agreed on by both profiles was the lack of interest in the prizes that the center could give.

"The career recognition is important" (Madrid/'young'), "For me, the resume is very important" (Madrid/'young'), "The curriculum is of no concern to me" (Madrid/'veterans').

Management Reasons

Management issues were of particular interest to both profiles of PCP, because they related to daily work. The CP would be a tool to facilitate work, as long as the program design ensured its implementation at reasonable times without cost to the health system. In addition, the application should be easily accessible, intuitive in operation, and ideally with direct access to relevant information on the network. Finally, the support of a scientific society to seriously ensure the program and scientific content was considered important.

"That could facilitate work" (Barcelona), "It is very important for it to be well made, well designed. This is to facilitate work" (Madrid/Sevilla), "Having all patient information is important" (Madrid/Barcelona).

"The support of a scientific society would give seriousness to the content" (Madrid), "It has to be easy to use and not crash every 2 to 3 hours" (Sevilla).

Obstacles in Accepting the Clinical Pathway

Although the obstacles commented by accepting PCP for the CP were less numerous than the motivations, they still were very important: time requirement or additional work, excessive bureaucracy, lack of awareness of actual practical use, lack of response from the specialist or computer ignorance and lack of remuneration. Of these, the most important, and it would be limiting to qualify for the CP plans, was the time requirement or additional work.

"If it takes longer and requires more work but helps the patient. . ." (Madrid/Barcelona/Seville/Bilbao), "If it has no real use and takes time. . ." (Madrid/Barcelona), "I am alone and I have 4–5 minutes per patient. If it takes time, it would be impossible" (Bilbao), "There are many programs that have been started and completed within 2–3 years" (Barcelona): "If a specialist suddenly became interested

in diseases that previously did not matter, you think: what's behind their interest?" (Madrid/Barcelona),"Is there a political or economic interests? Probably. . ." (Madrid).

"The top (managers) give you more work. Coming from the SEMFyC/another society, we must see who implanted this and why" (Madrid/Barcelona/Sevilla), "Who benefits from this?" (Madrid), "Will treatments be penalized in primary care?" (Madrid/Barcelona/Sevilla).

Knowledge of Spondyloarthritis in Primary Care

PCP simultaneously associated "spondylitis" as: SA, psoriatic arthritis and so on with other very frequent musculoskeletal conditions such as osteoarthritis and low back pain, in fact, the term "spondylitis" proved too nonspecific for PCP. PCP referred single patients to specialists when they needed diagnostic tests that cannot be requested from primary care, when the patient demanded it or when treatment was ineffective. Finally, the PCP questioned the usefulness of a CP in a disease considered rare, not life-threatening and which has a thankless treatment, so they rarely recognized the need to referr this type of patient to the specialist.

"What is AS?, because spondyloarthropathies in general lump all osteoarthritis and any spinal condition" (Madrid), "Fortunately, we do not have many, they are rare" (Sevilla/Madrid); "spondylitis and fibromyalgia are diseases that have little or no interest to the specialist" (Barcelona), "No problem for referral to a rheumatologist, he sees them fast. The problem is that they have no therapeutic weapons" (Madrid).

"What sense does it make for diseases in which there is a case in 2 million?" (Madrid), "This is not to save lives" (Barcelona), "This little bone pathology we would refer to the specialist" (Barcelona), "It is a very rare disease, and nobody wants to see them: neither trauma nor rheumatology or us" (Barcelona/Madrid).

Discussion

This qualitative study highlights very important aspects for the implementation of a CP for the collaboration of primary care and, specifically, a CP dedicated to patients with SPA. On the one hand, it highlights the lack of knowledge, but above all expectations of the PCP in SPA; indeed we suspected this as the cause of delayed diagnosis in autoimmune diseases, but that is offset very positively by training and collaboration thereon. On the other hand, there is an ambivalent disposition towards the CP, providing data on the motivations and barriers to its implementation. Specifically, we understood that the PCP would find it difficult to accept a CP that increased workload and not be fast and intuitive, yet collaborate in case their participation would be a real benefit and was approved by the patient.

A remarkable result of this study showed that a key aspect that we had previously identified as crucial for the establishment of an efficient CP is feedback. The SERAP program, through which 34 early arthritis units (UAP) were established, identified this factor as the most important association with good referral from primary care, even over the efforts of the rheumatology units in the formation of PCP.[12] Maintaining contact between physicians responsible for these units and primary care physicians, especially physicians who derived patients was no good for them; it was essential to improve the efficiency of the referral to the UAP. Again, in this qualitative study we reveal discontent by the PCP in the absence of information from the specialist regarding patients referred to these units.[12,14]

It also highlights the importance of ease of use and operation of any CP with computer systems at local or autonomous community levels.[15–18]

The results of this study were used to design a CP in Spain in 25 health areas, as a pilot for implementation nationwide. Each of the barriers was analyzed and several solutions proposed, finally adopting the more practical.[19]

In short, if the goal is to implement a CP for SPA with optimal primary care collaboration it is necessary: (a) formalize processes through a simple program and approved by management, to provide the maximum interaction with the specialist without increasing workload and to ensure confidentiality; (b) allow monitoring of patient feedback throughout the entire process, including reports and recommendations for treatment as well as the presence of a permanent consultant, and c) provide training to PCP on SPA, preferably accredited and with curricular value.

Ethical disclosures

Protection of human and animal subjects. The authors declare that no experiments were performed on humans or animals for this investigation.

Confidentiality of Data. The authors declare that they have followed the protocols of their work centre on the publication of patient data and that all the patients included in the study have received sufficient information and have given their informed consent in writing to participate in that study.

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

Conflict of Interest

Annex 1. Esperanza Study Group

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