A bibliometric study of the scientific publications on patient-reported outcomes in rheumatology

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Marta Redondo, MS, PhD[a], Leticia Leon, MS, PhD[a,b],*, Francisco Javier Povedano, MS, PhD[a],
Lydia Abasolo, MD, PhD[b], Miguel Angel Perez-Nieto, MS, PhD[a],
Francisco López-Muñoz, MD, PhD[a,c]

[a] Health Sciences Faculty, Camilo José Cela University, Madrid, Spain
[b] Department of Rheumatology, Instituto de Investigación Sanitaria del Hospital Clínico San Carlos (IDISSC), Hospital Clinico San Carlos, Madrid, Spain
[c] Neuropsychopharmacology Unit, Hospital 12 de Octubre Research Institute (i+12), Madrid, Spain

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ABSTRACT

Introduction: We have conducted a bibliometric study of the scientific publications on patient-reported outcomes in the field of rheumatology.

Methods: SCOPUS was the database used in this bibliometric study. We performed two searches. The main search involved selecting the documents published between 2000 and 2014 limited to top-tier journals addressing rheumatic and musculoskeletal diseases, using specific descriptors together with the operator and main descriptor "patient-reported outcomes" (PROs), and we performed a secondary search, with the following specific descriptors: "pain," "functional capacity," and "fatigue." We used bibliometric indicators for articles distribution (Price's law for the increase of scientific literature and Bradford's law for dispersion of articles). We also calculated the participation index of the different countries.

Results: A total of 983 original articles were published between 2000 and 2014. Our results confirmed the fulfilment of Price's law (correlation coefficient $r = 0.9385$ after linear adjustment). The average number of articles per Bradford Zone was 327.6. A total of 30 different journals were published. The type of growth for the descriptors "pain" ($r^2 = 0.5417$ compared to $r^2 = 0.4839$) and "fatigue" ($r^2 = 06276$ compared to $r^2 = 0.5544$) is exponential, whereas it is linear for the descriptor "functional capacity" ($r^2 = 0.6769$ compared to $r^2 = 0.3779$).

Discussion: This study revealed significant linear growth of patient-related outcomes in global terms, as well as upward trends for most of the citation-based bibliometric indices, especially significant from 2010 to 2014. Pain and fatigue have greater growth as PRO concepts.

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Introduction

The management of rheumatic and musculoskeletal diseases (RMDs) has undergone major changes in recent decades due to increasingly earlier diagnosis and, above all, to their more appropriate treatment [1–5]. All these developments have led to a significant clinical and functional improvement in patients, as well as in the expected outcomes of their treatment. With a view to achieving this, rheumatologists need to refine their therapeutic decisions, whereby it is essential to identify the key variables related to the development of rheumatic disorders, and design assessment instruments that are valid and reliable for their measurement.

Accordingly, there is a broad array of instruments, from classical objective measures (painful joints, inflamed joints, and sedimentation rate-ESR), which are supplemented by others based on imaging techniques, such as radiographic progression and ultrasound scans, through to other more subjective ones, generally self-reported by patients [2]. These measures are called patient-reported outcomes (PROs) [3], which are reports provided directly by patients about how they feel or function in relation to a health condition and its therapy, but, the point of view of the patient traditionally has not been considered by the professionals or policymakers to establish health care decisions. PROs may relate to symptoms, perceptions, or other aspects perceived by patients. PROs have been increasingly gaining in importance in recent years

in the field of rheumatology. Their growing impact has coincided also with the ever more widespread notion of giving patients more say and greater involvement, according to the popular "Treat to Target" strategy, focusing on the identification of therapeutic targets (with remission being the first of these), and dealing with patients in a way that helps to achieve them, which therefore calls for great effort and care in the assessment [4,5].

These measures appear to have complemented and enriched the assessment of patients with an RMD, and as such have been acknowledged in the recommendations of the OMERACT initiative, which endorses their validity both in clinical trials and in clinical practice [6]. In fact, several research studies have reported that one of the most commonly used PROs, the Routine Assessment of Patient Index Data 3 (RAPID3), which combines data on another three aspects (pain, disability, and overall assessment of the patients) have proven to be as effective as other traditional measures such as DAS28 and CDAI with a view to identifying control and clinical groups in clinical trials with MTX or with biological pharmaceuticals [7–13]. Furthermore, a recent review concludes that all clinical trials confirm the use of PROs and RAPID3 for identifying therapeutic remission and guiding a "Treat to Target" strategy in the normal clinical care for a patient with an RMD [14].

Moreover, the patient can be able to complete all PRO's questionnaires in all its appointments, while they are waiting in the waiting room to be seen by the physician. All this information can be very useful to complete the clinical visit and to have a broader view of the health problem of patient [15,16]. But furthermore, this self-assessment prepares the patient before visit, thus improving their communication with the physician [17].

Nevertheless, despite the growing recognition of PROs as major assessment instruments, and their proven success at determining the effectiveness of treatments, their use is very heterogeneous. In order to overcome this limitation, as well as the one arising from the need to use solely those that have been endorsed, the European League Against Rheumatism (EULAR) has compiled an Outcomes Measures Library (OML), which includes 236 instruments (106 generic and 130 specific). It has permitted achieving the objectives of reducing the variability in the use of PROs, increasing rheumatologists' understanding of them and their endorsement, highlighting the importance of using the right assessment tool in the proper way and, finally, detecting errors in transcultural adaptations [15].

When delving further into the study of PROs, and in spite of their heterogeneity—they are numerous and very varied—the literature has shown that they are grouped into only a few domains, with just three of them accounting for the highest percentage of instruments and research studies. Accordingly, a systematic review identifies a total of 63 measures of PROs in 109 articles, which are distributed as follows: the most frequently evaluated domain is functional capacity, basically using the HAQ (83.4%); followed by patient global assessment (PGA), for which use is made above all of a visual analog scale (VAS) (63.3%); and thirdly, pain, which in most cases is also assessed with a VAS (55.9%). The review covers other domains also used for the evaluation of RMDs, such as quality of life (22%), coping (10%), psychological distress (4%), and sleep (2%) [16]. The review also refers to fatigue (4%), a common symptom of many RMDs, which is also one of the ACR-EULAR remission criteria, although it appears that only 5% of patients with rheumatoid arthritis (RA) in remission stop suffering from it, which is of growing concern to medical practitioners [17].

Considering the above, this article seeks to conduct a bibliometric analysis, hitherto unavailable, of the tendency and weight of PROs in RMDs that will enable us to gauge the performance of scientific outputs in this field. The use of bibliometric indicators for studying research activity in a specific field such as rheumatology is a new design based on the premise that scientific publication is the basic outcome of that activity [18]. This can make bibliometric studies a useful tool for evaluating the social and scientific importance of a discipline, a specific field, or what this case would be like as a construct, that of PROs, within a particular field [19]. In order to explore this study in greater depth, a series of more specific goals have been established: assess the temporal evolution of the concept of PROs in relation to their scientific output, explore their distribution in the different scientific journals in the field, and conduct a sub-analysis of some of the more relevant aspects of RMDs (pain, disability, and fatigue).

Methods

The database used in this bibliometric study, SCOPUS [20], is the largest abstract and citation database of peer-reviewed literature: scientific journals, books, and conference proceedings. It covers nearly 22,000 titles from over 5000 publishers, of which 21,500 are peer-reviewed journals in the scientific, technical, medical, and social sciences (including arts and humanities).

This work involved two searches. The main search, using remote download techniques, led to the selection of documents published between 2000 and 2014, limited to top-tier journals addressing RMDs, and using the specific descriptors "*pain*," "*patient global assessment*," "*functional capacity*," "*fatigue*," "*health-related quality of life*," "*psychological distress*," "*ability to cope*," "*wellbeing*," "*sleep*," "*work*," "*social life*," "*productivity loss*," together with the operator and main descriptor "*patient-reported outcomes*." The secondary search involved three sub-analyses; in this case, the specific descriptors were replaced in each case by the following: "*pain*," "*functional capacity*," and "*fatigue*." For the purposes of this study, we considered all original articles, brief articles, reviews, editorials, letters to the editor, etc., and all duplicated articles were omitted.

In this study, we applied the following bibliometric indicators: Price's index, doubling time and annual growth rate, Price's transience index, and Bradford Zones.

Among the bibliometric indicators of production, we applied Price's law [21]. This law is the most widely used indicator for analyzing the productivity of a specific discipline or a particular country, as well as for reflecting the fundamental aspect of scientific production, namely, its exponential growth. To assess whether the scientific production in optometry follows Price's law of exponential growth, we made a linear fit of the data obtained, according to the equation $y = 4.8738x - 25.476$, and another adjustment to an exponential curve, according to the equation $y = 6.9378e^{0.0905x}$.

Other quantities related to growth are doubling time and annual growth rate. The former is the amount of time required for the subject matter to double its production; the annual growth rate represents the magnitude's growth over the previous year, expressed as a percentage. The equation that calculates the doubling time (D) is represented by the following expression

$$D = \frac{Ln2}{b}$$

where b represents the constant that relates growth rate to the amount of science acquired.

It is also interesting to determine the number of authors with a single publication. This is known as the transience index, or Price's law. Its calculation is given as the percentage ratio of authors with one publication to the total. Mathematically, it would be expressed as

$$TI = \frac{\text{Authors with a single publication}}{\text{Total number of authors}} * 100$$

The last indicator to be used here is the scattering index, known as the Bradford Zone. With the aim of revealing the distribution of the scientific literature in a particular discipline, Bradford proposed a model of concentric zones of productivity (Bradford Zones). Bradford explained that the highest percentage of bibliographical output in a particular subject tends to concentrate in a small number of journals. This observation implies a sharp decrease in the usefulness of expanding the reference search away from its core [22]. The most common way to represent this law is through a semi-logarithmic plot, which represents the calculated number of articles, $R(r)$, versus the cumulative number of journals, r. Thus, once the data have been plotted, the sorting of articles is distributed into approximately three equal parts. One is the nucleus or core, and the other two are the peripheral zones (linear zone). In the core, the number of articles increases slowly, giving rise to a curve, defined as the Groos droop [23]. This model allows identifying the journals most widely used or with the greatest weight in a given field of scientific output.

As an indicator of the publications' influence, we used the impact factor (IF). This indicator, developed by the Institute for Scientific Information (Philadelphia, PA), is published annually in the *Journal Citation Reports* (JCR) section of the *Science Citation Index* (SCI). A journal's IF is calculated according to the number of times the journal has been cited in SCI source journals over the previous 2 years and the total number of articles published by that journal in those same 2 years. The JCR lists scientific journals by specific areas, ascribing to each one of them its corresponding IF, and establishing a ranking of "prestige" [24].

Results

Based on the search criteria used, during the period of 2000–2014, a total of 983 original articles dealing with different aspects of PROs in Rheumatology field were retrieved (articles, reviews, letters to the editor, etc.). Of these, 746 articles included "pain," 172 included "fatigue," and 53 included "functional capacity. Figure 1 shows their chronological distribution.

As the figure shows, the mathematical fit to a curve gives us the correlation coefficient $r = 0.9385$, indicating that 6.15% of the variability is not explained by this fit. On the other hand, the exponential fit of the values measured gives $r = 0.7862$, and therefore a percentage of residual variability of 21.38%. These data
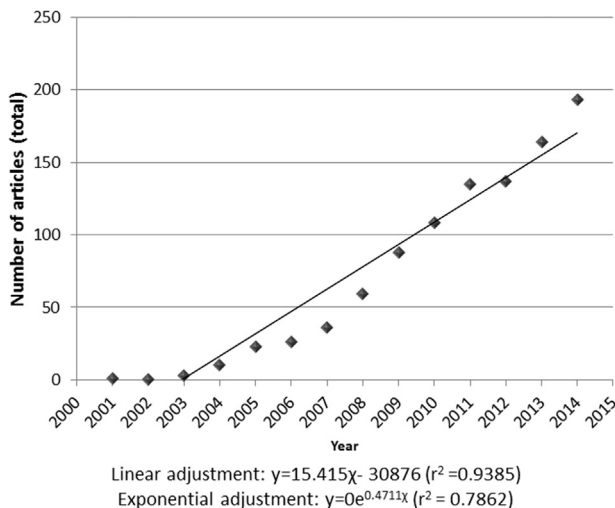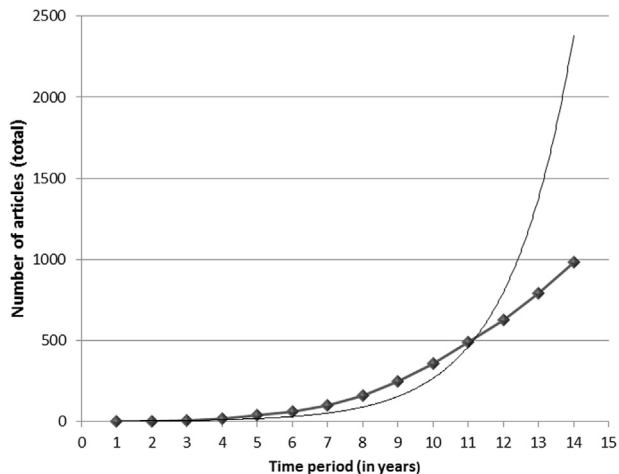
Fig. 2. Temporal evolution (in years).

allow us to conclude that the database analyzed is better suited to a linear fit, and that the postulates of Price's law are fulfilled.

The 5-year distribution reveals a sharp increase in the period 2010–2014, with a 74.97% increase over the prior period.

To calculate doubling time, the scatter plot in Figure 2 shows the temporal production of publications along the trend line, which was fitted to the equation $y = 1.1136e^{0.5476x}$, with a correlation coefficient of 0.9256. This production corresponds to 15 years and a doubling time of 1.26 years.

If we consider output by countries, United States, United Kingdom, and Canada are the most productive, and by institutions, we have the University of Toronto, VU University Medical Center, and Stanford University School of Medicine (Fig. 3).

The 983 documents are signed by 3977 authors, which means a co-authorship rate of 4.04. There are 3060 authors with just a single document, which means a transience rate of 76.94%.

As regards the scientific journals publishing the articles on PROs, the Bradford model was applied. Each Bradford Zone would contain a similar number of articles, but the number of journals in which these articles were published would increase on passing from one zone to the next followed. This model permits identification of the journals most widely chosen for literature publication, or the journals with the greatest weight in a given field publishing scientific literature. The average number of articles per Bradford Zone was 327.6. Table 1 shows the division into Bradford Zones of the articles considered here.

As regards the sub-analysis conducted with the descriptors "*pain*," *functional capacity*," and "*fatigue*," the number of documents retrieved is 746, 53, and 172, respectively. The co-

Fig. 1. Chronological distribution. Growth of scientific production on PROs. A linear adjustment of the data was carried out, and a fitting to an exponential curve was found, to follow Price's law of exponential growth for PROs publication production.
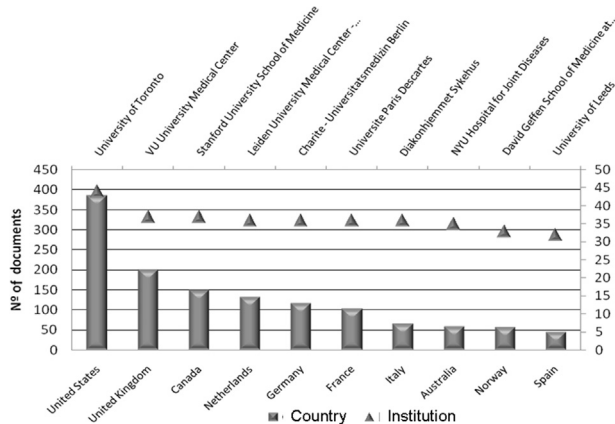
Fig. 3. Contributions of the most productive countries and institutions.

Table 1
Distribution of journals according to Bradford Zones

	No. of journals	% Journals	No. of articles	% Articles	Bradford multiplier
Core	2	4.44	287	29.20	
1st Zone	4	8.89	342	34.79	2
2nd Zone	39	86.67	354	36.01	9.75
Total	45	100	983	100	5.87

Table 2
Authorship for the three descriptors

	No. of documents	Total no. of authors	No. of authors with one article	Co-authorship index	Transience rate
Pain	746	3206	2549	4.3	79.51
Functional capacity	53	310	287	5.8	92.58
Fatigue	172	808	708	4.7	87.62

authorship rate for these three descriptors is similar, standing at between four and five authors per document, with a high transience rate (occasional authors), as shown in Table 2.

The rate of growth for the descriptors "pain" ($r^2 = 0.5417$ compared to $r^2 = 0.4839$) and "fatigue" ($r^2 = 0.6276$ compared to $r^2 = 0.5544$) is exponential, whereas it is linear for "functional capacity" ($r^2 = 0.6769$ compared to $r^2 = 0.3779$) (Fig. 4).

The doubling time in the scientific literature is 2.43 years for pain, 1.92 for functional capacity, and 2.37 for fatigue.

Discussion

The results of this bibliometric analysis provide a comprehensive overview of the development of the scientific literature in the PROs field over the past 15 years; an output that according to the results appears to have increased linearly, with an especially sharp rise in recent years, specifically over the period 2010–2014, with a growth figure of 74.97% over the previous period.

This increase in output has been recorded especially in pain and fatigue. Surprisingly, the functional capacity associated with the concept of PRO does not record such a significant increase, even though the literature reviews single it out as the most widely assessed variable in the field of rheumatology [16]. As HAQ is the most commonly used instrument for its assessment and in view of its characteristics, many professionals do not consider it a pure PRO, so conducting a joint search for both terms produces low returns. Functional capacity is probably one of the favorite PROs among rheumatologists because they consider it to be a much more objective measure, and one that is less subject to the patient's impressions, views, or emotions. By contrast, pain and PGA are almost always understood as PROs because they are more subjective concepts for patients.

In RMD trials, heterogeneity is noted [16], in particular in PGA, which can basically be measured using two different wordings: one related to a general health VAS and the other to the patient's assessment of disease activity [25,26]. The results may differ,
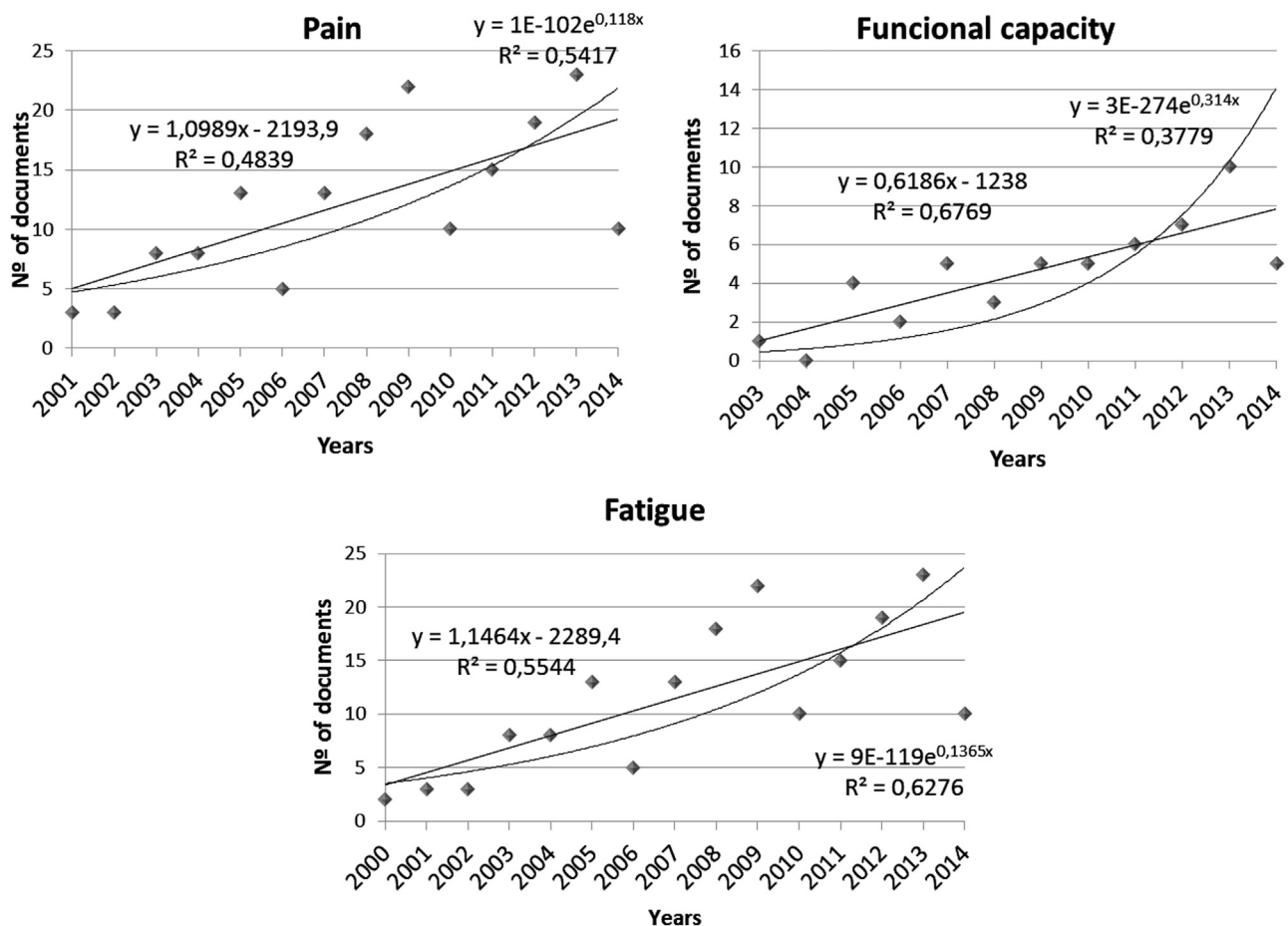

Fig. 4. Growth comparison (exponential and lineal) for the descriptors *"pain," "functional capacity,"* and *"fatigue."*

which is particularly important since PGA is the only PRO included in the usual composite measures of disease activity, such as the Disease Activity Score (DAS).

These results point in the direction proposed by many rheumatologists, who call for the need for better measures to avoid pain and fatigue, with a view to making them more "objective" and sensitive to change. A further aspect to be considered is the importance of showing patients how to answer these PROs in contexts of routine medical appointments, not just in clinical trials or specific protocols. For as some scholars stress, the patients themselves are obviously the ones best placed to describe and report on their pain and their overall state of health [27,28]. This self-assessment prepares them for their visit to the rheumatologist, thereby improving their communication with the physician and effectively complementing the rest of the assessment [29]. Moreover, the patient's point of view gives additional important information to the physician that allows evaluating the longitudinal evolution of the patient, helping in the clinical decision. In addition to these advantages, PROs have high feasibility: they are often free (unless copyrighted), non-invasive, and painless, and do not require costly equipment [30].

It is remarkable that the journals in the first two quartiles are the ones accounting for the most publications on PROs, which clearly shows that ever greater importance is being given in rheumatology to working with measures that include the patient's point of view.

This study's main strength is its breadth both in the scope of the search and in the content analyses of the articles in question. Our search was not limited to one journal, which contributes to the richness of the data gathered, and the results confirm the broad distribution of the available evidence (across 45 different journals). In addition, bibliometric analyses are often limited to providing quantitative indicators on the development of a field in terms of the number of publications, citation scores, and geographical spread. The current review went beyond relying solely on these indicators, and conducted a rigorous analysis with new indicators to reveal in more depth the qualitative trends in the content of the published research. Owing to the vast amount of data gathered, it is beyond the scope of this review to provide a comprehensive discussion of all the trends.

Notwithstanding the rigorous approach, certain limitations need to be carefully considered. The review covered only those articles for which an English abstract was available through an online database. Although most journals use English as the main language, and provide an abstract free of charge, this restriction might have induced a language and publication bias. For example, the need for an abstract to be eligible for the coding process led to a moderate number of exclusions, and so some key articles were not included in the final selection. We might then have excluded those articles on PROs if the authors had not used our descriptors in the titles or as key words. Moreover, local journals not indexed in databases during the study period, and those contributions from researchers at scientific conferences and meetings were also excluded from this study [30].

Nevertheless, in spite of the major limitations listed above that generally affect bibliometric studies, they are still considered useful in assessing the social and scientific relevance of a given discipline or field [19]. Bibliometric studies continue to be important as an effective complement for the opinions and judgements of experts in each field, by providing a useful and objective measure for evaluating the results of scientific activity. They provide a more realistic view of the bigger picture, and reveal the research trends in a specific discipline, as well as predict how the research activity might evolve for a given scientific speciality [31].

In summary, this study provides an opportunity to reveal the recent changes in the representativeness and evolution of publications involving research into the literature on PROs in recent years. The findings confirm the considerable growth in this literature in the RMD field, which is particularly noticeable for the topic of pain and, fortunately, fatigue, as both fields are extremely significant from a patient's point of view.

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