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Laure Gossec, Francis Berenbaum, Pierre Chauvin, Karine Lamiraud, Francoise Russo-Marie, et al.. Reporting of patient-perceived impact of rheumatoid arthritis and axial spondyloarthritis over 10 years: a systematic literature review.. *Rheumatology*, 2014, 53 (7), pp.1274-81. 10.1093/rheumatology/ket480 . hal-01011805

HAL Id: hal-01011805

<https://hal.univ-brest.fr/hal-01011805v1>

Submitted on 30 Apr 2024

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Original article

Reporting of patient-perceived impact of rheumatoid arthritis and axial spondyloarthritis over 10 years: a systematic literature review

Laure Gossec^{1,2}, Francis Berenbaum^{3,4}, Pierre Chauvin⁵, Karine Lamiraud^{6,7}, Françoise Russo-Marie⁸, Jean-Michel Joubert⁹ and Alain Saraux¹⁰

Abstract

Objective. RA and axial SpA have an important impact on patients' lives. The objective of this study was to explore the reporting of different aspects of that impact in publications, with a focus on differences between diseases and over time.

Methods. A systematic literature review retrieved all articles reporting on the life impact of RA or axial radiographic SpA in adults published within the last 10 years and issued from European research. The data were classified into physical impact (including pain, functional assessment and fatigue), psychological impact (including psychological distress and coping) and social impact (including relationships, family and social life). The number of articles published over time was analysed by linear regression.

Results. In all, 1352 abstracts were screened and 149 publications (40 056 patients) were analysed: 129 articles (86.5%) concerned RA and 16 (10.7%) concerned axial SpA. The mean number of articles reporting on the physical aspects of impact was 11.4 (s.d. 4.8) per 2-year period, but increased more than 2-fold (from 7 articles in 2001–3 to 15 in 2010–11), in particular due to recent publications on fatigue, whereas the number of articles on psychological aspects [mean 12.4 (s.d. 4.0)] decreased markedly after 2006. Publications reporting on social aspects [mean 8.2 (s.d. 4.1)] remained globally stable.

Conclusion. In the era of biologics, there is an interest in the patient-perceived life impact of RA and axial SpA in the European literature, but the impact of RA has been the subject of greater exploration. There are clearly trends over time in the reporting of impact.

Key words: rheumatoid arthritis, spondyloarthritis, impact, quality of life, pain, fatigue, social, coping.

Introduction

The two most frequent chronic inflammatory diseases are RA and axial SpA, with prevalence around 0.3% for each [1, 2]. Both of these diseases have an impact on patients' lives [3–5]. Due to the nature of these diseases, there is an

important impact on physical aspects such as pain and functional capacity, however, in recent years there has been growing interest in other aspects of personal life impact, such as fatigue [6]. Psychological impact of chronic inflammatory rheumatism is also certainly important, with increased prevalences of anxiety and depression [7], while coping mechanisms are often used by people with rheumatism to minimize their impact [8]. Finally, these chronic diseases have effects on social lives, including personal relationships within the family as well as outside of the family, e.g. with friends [9].

Although there is a large body of literature on quality of life and disease impact in RA and axial SpA, our clinical impression was that impact has not been explored similarly in RA and in axial SpA. Furthermore, we were interested in exploring differences over time (trends) in publications regarding disease impact.

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Submitted 5 July 2013; revised version accepted 9 December 2013.

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Many of the studies published on quality of life and disease impact in RA and axial SpA have used qualitative methods such as focus groups or individual interviews to explore the patient's experience in depth. However, qualitative studies are, by their nature, small in size [10]. On the other hand, surveys and/or quantitative studies harvest information from large sample sizes, but cannot explore situations in depth. Therefore we thought it would be interesting to pull together information from these two sources.

About 12 years ago, innovative treatments were introduced in the field of rheumatology: i.e. biologic therapies. Biologics have been a major breakthrough in terms of RA and SpA management and have profoundly modified the disease course. Short-term and long-term studies also report modifications in terms of disease impact. It therefore appears that studies focusing on disease impact should distinguish the biologic era from the previous era.

Disease impact is probably culture dependent, at least in terms of its expression (e.g. pain is not expressed similarly in all cultures) [11]. Furthermore, there are many differences between health insurance and/or welfare systems, particularly between the USA and Europe, that may lead to differences in expressions of impact and also to different interests in medical and public health research. In the present study, we chose to focus on European results and publications to obtain more homogeneity.

Thus the objectives of this work were to explore the reporting of personal life impacts in RA and axial SpA, with a focus on differences between the two diseases across Europe over the last 10 years. To this end, we performed a systematic literature review.

Materials and methods

A systematic literature review was performed in January 2012 with the help of a librarian. The search aimed to retrieve all articles published within the past 10 years and reporting results of European research on the personal life impacts of RA or axial SpA (i.e. including AS) in adults. Only original articles published in English or French were retained. The aspects of disease considered here as personal impacts were pain, functional assessment, sleep, fatigue, psychological distress, anxiety, depression, fears and beliefs, coping, locus of control, optimism, relationship with a significant other, family, social life and friends and general quality of life. Exclusions included studies not reporting results for RA or axial SpA (e.g. studies in PsA), studies published before 2001 (using the limit published in the last 10 years) and studies not reporting on personal impact (e.g. articles reporting on genetic studies, imaging or the prevalence of disease were excluded, as well as articles reporting only on the impact on work and professional life). Articles reporting on quality of life, but specifically in the context of a treatment (e.g. in a randomized controlled trial), were excluded, as the objective was not to assess treatment effects and their impact on patient quality of life, often

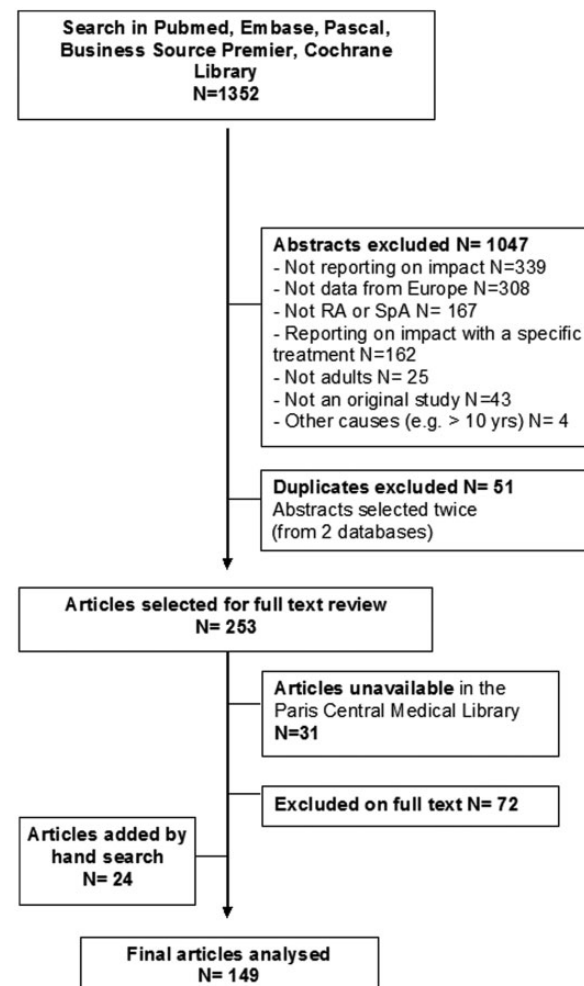
assessed by quantitative criteria, but rather the magnitude of reporting in real-life conditions.

Article selection process

The following databases were searched: Medline, Embase, Pascal, Business Source Premier and the Cochrane library. The lists of references were also hand searched. The keywords and limits used are detailed in supplementary Table S1, available at *Rheumatology* Online. A flow chart (Fig. 1) summarizes the selection process.

In all, 1352 abstracts were retrieved: 253 articles were selected as full texts, 24 articles were added by hand search, 31 articles were unavailable in the Paris Central Medical Library and 72 articles were excluded on full text. The final selection comprised 149 articles (supplementary Table S2, available at *Rheumatology* Online). Given the qualitative nature of most articles, the quality of the selected articles scored by the Jadad score was uninformative and is not presented.

Fig. 1 Flow chart of the article selection process



Data collection

The abstracts were screened and the relevant articles (Fig. 1) were obtained in full text. They were then analysed and the data extracted were entered into an Excel table. Each abstract and full-text article was analysed by one reviewer (L.G.). General elements were collected in each article, including the year of publication, country of origin of the data, study design, number of centres and demographic variables for the patients (mean age, gender and disease duration where available).

The personal life impact of RA/SpA was collected and was classified by the authors into different aspects of impact, namely general aspects, physical impact (considered here to include pain, functional assessment sleep and fatigue), psychological impact (including psychological distress, anxiety and depression, fears and beliefs, coping, locus of control and optimism) and social impact (including relationship with a significant other, family, social life and friends). A given article could be classified into several aspects of impact if it gave relevant information on these different aspects (supplementary Table S2, available at *Rheumatology* Online). In most cases the data regarding the description of impact itself were strictly qualitative.

Data interpretation

The aim was specifically to find trends in reporting of life impact across diseases and over time: the data extracted from each article were presented to the co-authors by the aspect of impact as defined above. Group discussions led to the selection of the most relevant information. The number of articles published over time in the two diseases studied and according to the aspect of impact is reported. One reviewer (L.G.) classified articles referring to RA and axial SpA according to the aspect of impact and the year of indexation in PubMed. A second reviewer proceeded similarly for a random 10% of the articles; the results were very concordant with an agreement of 98%.

Data analysis

It was not possible to pool the data regarding results of impact (e.g. through meta-analysis), thus these results are presented qualitatively only (supplementary Table S3, available at *Rheumatology* Online). The number of articles published over time was analysed by univariate linear regression.

Results

Description of the articles and the population and differences between RA and axial SpA

In all, 149 articles were analysed (Fig. 1 and supplementary Table S2, available at *Rheumatology* Online). Of these, 129 (86.5%) articles concerned RA [of which, 15 (11.6% of RA articles) concerned early RA/early arthritis], 16 (10.7%) concerned axial SpA and 4 (2.7%) concerned both of these diseases. The total number of patients with RA or axial SpA was 40 056: 33 047 (82.5%) and 5257 (13.1%), respectively; 1752 (4.4%)

were in studies assessing both diseases ($n=1082$ RA and $n=670$ axial SpA). Furthermore, 1404 patients were used as controls—usually not age- or sex-matched however.

The distribution of the publications across countries was unequal, with many publications from the United Kingdom ($n=44$) and the Netherlands ($n=35$), then Sweden ($n=13$) and Norway ($n=11$). The other countries had fewer than 10 publications each (in decreasing order, Finland, France, Ireland, Germany, Turkey, Greece, Italy, Austria, Denmark, Spain, Estonia, Belgium, Lithuania, Portugal and Slovakia). Fourteen publications were issued from international studies (thus several countries). All the retained articles were in English.

Most of the studies ($n=135$, 90.6%) had a qualitative component: of these, 33 articles (24.4%) reported on individual interviews (total patients 1668) and 11 articles (7.3%) on focus group exercises (total patients 532), the others comprised surveys or questionnaires, or used several of these methods. The studies were monocentric ($n=77$), bicentric ($n=16$), multicentric ($n=29$) or the number of centres was not clearly reported ($n=27$). Five studies reported results issued from >1000 patients [5, 12–15].

Reporting of life impact over time

Globally, if we consider periods of 2 years, the number of articles about the physical, psychological and social impact of RA and SpA on patient life remained almost stable in 2001–11 (28–33 articles, depending on the period; Fig. 2). The number of articles reporting the impact of SpA remained low throughout the period. In the past 10 years there was a linear increase in the number of articles reporting the impact of RA from 2001 to 2006 (β coefficient 3.1, $P=0.01$). After 2006–07, the number of articles dropped slightly in 2008–09 (28 articles), but increased again in 2010–11, with 31 published articles.

Reporting of different aspects of impact

The physical impact of disease was widely assessed, in particular for pain, function and fatigue (Table 1). Pain was specifically explored in 15 articles, whereas functional

Fig. 2 Reporting of life impacts in RA and SpA over time in 149 publications

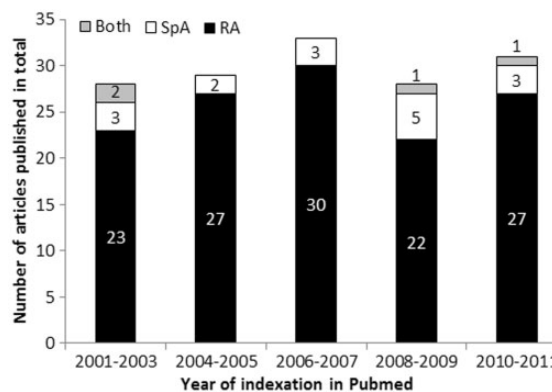


TABLE 1 Distribution of publications across the different aspects of impact

Aspect of impact	Domain	Articles, <i>n</i>	Cumulative patients, <i>n</i>	Articles on RA, <i>n</i>	Articles on SpA, <i>n</i>	Articles on both diseases, <i>n</i>
Physical	General	12	3670	11	0	1
	Pain	15	5659	12	3	0
	Functional capacity	27	11 580	24	3	0
	Fatigue	19	4174	16	3	0
Psychological	Psychological distress and depression	32	6189	30	2	0
	Anxiety	11	8876	10	1	0
	Coping, helplessness and perception of control	20	2934	18	1	1
	Fears and beliefs	6	463	6	0	0
Social	Other psychological aspects	16	9831	14	2	0
	Partner, couple, marriage, family	17	9969	16	1	0
	Social support	10	1591	9	1	0
	Social life	9	8538	8	1	0
General aspects	Leisure activities	8	1366	8	0	0
	General quality of life	11	8020	7	3	1
	Patients' priorities and expectations	15	3238	14	1	0
	Relationship with health care professionals and satisfaction with care	19	9028	16	2	1
	Flares	3	293	1	2	0

Some articles may be counted several times if they reported on several aspects of impact.

capacity was explored qualitatively in 27 articles, again with a vast majority of articles focusing on RA ($n=24$, 88.9%). Fatigue was explored in 19 articles, particularly in RA (16 articles, 84.2%). Twelve articles reported on the general physical impact and on patient priorities regarding physical impact or on aspects other than pain, function and fatigue, i.e. morning stiffness and sleep [16–20].

Psychological impact was also well explored. In particular, 32 articles reported on psychological distress and depression, and 11 articles focused specifically on anxiety [7, 12, 21, 22]. However, the publications were unbalanced between RA and SpA. Coping, helplessness and perception of control were investigated in 20 articles, 18 of which dealt with RA [23]. Fears and beliefs were little explored (six articles).

Articles on social impact were published less often. Social impact was analysed as family impact, couple/partner impact, sexuality and parenting (17 articles); social support (10 articles); impact on social life and friends (9 articles) and leisure activities (8 articles) [9, 12, 24–25].

Some aspects of impact could not be classified specifically into physical, psychological or social aspects, either because they concerned several of these domains or because they were very general (e.g. patient priorities) (Table 1). An overview of the data on the impact is summarized in Supplementary Table S3, available at *Rheumatology* Online.

Reporting of different aspects of the impact of RA and axial SpA over time

The analysis of reporting the different aspects of impact over time indicated some differences and trends (Fig. 3).

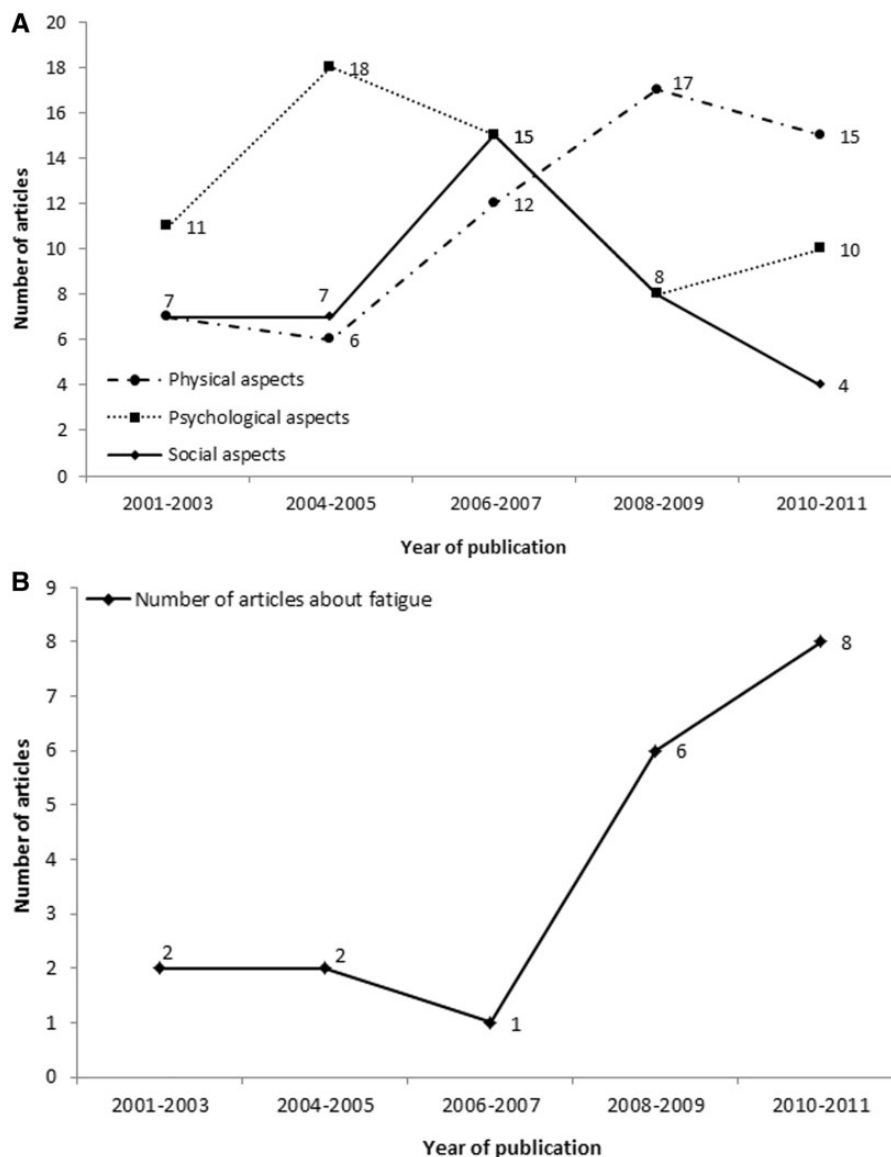
The total number of articles reporting on physical impact was 57 [the mean number of articles per 2-year period was 11.4 (s.d. 4.8)]. Fig. 3 shows an important increase in these publications: the number of articles reporting on the physical aspects of impact increased more than 2-fold (from 7 articles in 2001–03 to 15 in 2010–11).

The total number of articles reporting on psychological impact was 62 [the mean number of articles per 2-year period was 12.4 (s.d. 4.0)]. However, here the trend was reversed; the number of articles on psychological aspects showed a peak in 2004–5 (18 articles) and decreased afterwards with only 10 articles in 2010–11. The number of articles on social aspects remained globally low in 2001–11 (4–7 articles), with a peak in publications in 2006 (15 articles). Thus the total number of articles reporting on social impacts was 41 [the mean number of articles per 2-year period was 8.2 (s.d. 4.1)]. When checking the components of physical impact (Fig. 3B), it was found that the increase was largely driven by the exploration of fatigue, mainly in RA patients, with the number of publications going from 5 before 2006–7 to 14 after that date (a 3-fold increase).

Discussion

This study has shed light on some important trends in publications over the past 10 years in Europe concerning the life impact of chronic inflammatory rheumatism. First, publications on the patient perspective are numerous: the literature search found 1352 articles and 149 articles were

Fig. 3 Reporting of life impacts in RA and axial SpA: trends over time



(A) The number of articles reporting on different aspects of impact in RA and SpA and reported by year of indexation. Of note, some articles are counted several times if they reported on several aspects of impact. **(B)** The number of articles reporting specifically about fatigue in RA and SpA and reported by year of indexation.

fully analysed. Second, it was very apparent that there was disequilibrium between the reporting of life impacts in RA and in axial SpA, with 129 articles (86.6%) concentrating solely on RA. Finally, it seemed that there were some trends over time during the 10-year study period: considering periods of 2 years, the number of articles in the period 2001–11 on psychological, physical and social aspects remained globally stable over time (28–33 articles; Fig. 2), but with different distributions across aspects of impact, with more emphasis in recent years on the physical aspects of impact, particularly fatigue.

This study has some limitations. The literature research turned out to be difficult due to the large scope of the

objective. It was a challenge to find appropriate key words, leading to a large number of rejected abstracts, and some articles were found only by hand searching. Furthermore, some articles were not available for analysis in our large medical library. However, the working group verified manually some of the search against alternative searches or articles they had knowledge of, leading us to suppose the results are exhaustive. We limited the search to articles published in Europe over the last 10 years. This leads to a review that does not take into account data issued from other continents, which is a limitation; in fact, >300 publications were not analysed because they were from non-European countries. However, our aim was

to obtain a snapshot of the publications in this field over a homogeneous region, i.e. Europe [11, 26], even though Europe is large, multicultural and with subsidiary and nationally based (or even regionally based) health and welfare policies. We chose to analyse only data not issued from trials, which is also a potential limitation. Initially we hoped to be able to obtain pooled numbers, e.g. through meta-analyses, but given the qualitative nature of the data, it was not possible to perform quantitative data pooling [27, 28]. Thus we chose to analyse the distribution of publications across disease aspects and over time. Some articles were counted several times if they reported several aspects of impact [e.g., 12, 23], and in some cases the classification into physical or psychological aspects of impact was not easy. However, a rigorous and predefined grid was used to classify the aspects of impact, and the expert committee discussed at length this classification.

There were much more data available on the life impacts of RA than axial SpA. There are several possible explanations for this, the prevalence of the two diseases being very close [1, 2]. First, there are nomenclature discrepancies in the field of SpA: terminologies vary and subgroup definitions may differ, e.g. the inclusion or not of PsA in SpA and the terms used to define axial vs peripheral SpA [29]. This leads to potential difficulties when screening the literature. The Assessment in Spondyloarthritis group has recently defined a new nomenclature that may clarify these issues. In this study we concentrated on axial SpA, but in fact all the articles we found related to radiographic axial SpA (or AS). Second, there are differences in populations and also potentially in quality of life between RA and axial SpA, which may explain why there are fewer publications in the field of SpA—although this remains to be proven [30]. Third, axial SpA has been less studied (in some countries, low back pain is mainly dealt with by orthopaedists) and new treatments such as biologics were introduced later in axial SpA (the first biologics were approved in 2003 in axial SpA vs in 2000 in RA by the European Medicines Agency).

This systematic review indicates some trends over time in reporting of life impacts. Over the first years and until 2004–5, psychological impact was highly published, particularly psychological distress (32 articles on psychological distress and depression), but over the following years that aspect of disease was reported on less often. Over the same period, reporting of the physical aspects of impact increased >2-fold. When looking in detail, we found publications on pain and functional disability remained almost globally stable, but publications on fatigue were the driver of this increase, with 19 publications on fatigue, of which 14 were after 2008. It can be debated whether fatigue is physical or psychological, but in any case, publications concerning fatigue have increased. Certainly there are trends in medicine as elsewhere, and an interesting study may give rise to ideas for further research. Furthermore, the publication of a new patient-reported measure may lead to several publications regarding that measure [23, 31, 32]. Another element to take into account is the recent emergence of several competing drugs and biologics in the field of rheumatology,

which has led pharmaceutical companies to publish on life impacts of particular diseases with perhaps the objective of increasing the patient-perceived acceptability of their drugs. Taking this into account may somewhat explain the decrease in publications related to psychological impacts and the increase in publications related to physical impacts, since it had to be proven that biologics were effective at reducing the physical aspects of the disease.

The impact of RA was explored in 129 articles. However, and similar to other authors [28], we found that a limitation of the qualitative literature in rheumatology is that few studies report findings from non-white populations [26]. Future research should address these gaps. Both RA and axial SpA impact the physical, psychological and social aspects of life. Patient priorities include pain and function (both in RA and SpA), well-being, fatigue and energy and leading a normal life. Fatigue is known to be a symptom of SpA and is in fact assessed in the BASDADI [33], the widely used score of disease activity in SpA. However, this systematic review only found one article pertaining directly to fatigue in SpA [34]. Psychological well-being and psychological distress, i.e. depression and anxiety, were frequently reported on, particularly in RA. On the other hand, the impact of both diseases on family life, social life, friends and socializing and leisure activities was less explored.

Fears and beliefs have been little reported on in the articles included in the present systematic review. Although beliefs and illness perceptions are certainly important both for treatment adherence and for global disease impact, there was little interpretable data.

In conclusion, although there is clearly interest in patient-perceived life impacts of RA and axial SpA, there are important discrepancies across diseases and between aspects of impact. Further work on the life impacts of axial SpA and on the social impacts of RA and SpA is warranted.

Rheumatology key messages

- Patient-perceived impact of chronic inflammatory rheumatism is more frequently described for RA than for axial SpA.
- The psychological impact of RA was published on more often before 2005.
- There has been more emphasis in recent years on physical impact and fatigue in RA.

Acknowledgements

We wish to thank the other members of the working group for their input: Christophe Hudry, Caroline Dreuillet, Florence Mathoret-Philibert, Maud Poussière, Gabrielle Cukierman and Thibault de Chalus. We also wish to thank Mme G. Utard from the Paris Library of Medicine for expert help in the literature search.

Funding: This project was funded by an unrestricted grant from the Arthritis Fondation Courtin, a French charitable

organization dedicated to the promotion and support of biomedical research in severe joint diseases, and UCB Pharma.

Disclosure statement: L.G. received honoraria from Fondation Arthritis for the present work. L.G. and A.S. have also received honoraria from Abbott, BMS, Chugai, Pfizer, Roche, Schering-Plough and UCB, but these honoraria were unrelated to the present study. J.-M.J. is a UCB company collaborator and owns stock options from UCB. All other authors have declared no conflicts of interest.

Supplementary data

Supplementary data are available at *Rheumatology* Online.

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