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Original article

Essential knowledge for patients with rheumatoid arthritis or spondyloarthritis: Results of a multicentric survey in France among health professionals and patients

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ABSTRACT

Objective: Information and education are recommended for patients with inflammatory arthritis including rheumatoid arthritis (RA) and spondyloarthritis (SpA). However, there is no consensus on which knowledge is essential to enhance patients' self-management. The aim of this study was to determine such knowledge.
Methods: Based on published knowledge questionnaires (KQs) collected by a systematic literature review, a list of items was elaborated, classified in domains and sub domains. A Delphi process was performed with rheumatologists, healthcare professionals and patients in 2014–2015, selecting the items considered useful.
Results: Three published KQs were analysed: 2 for RA; 1 for SpA and 5 unpublished KQs were collected. In the KQs, 90 knowledge items were mentioned for RA and 67 for SpA. The 1st Delphi round enlarged the list to 322 items for RA and 265 items for SpA. The second round selected 69 and 59 knowledge items for RA and SpA respectively, of which 36 (52%) and 34 (57%) were not present or modified from the published KQs. Key domains included treatment strategies, managing

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cDMARDs and bDMARDs, managing symptomatic medications. Knowledge on non-pharmacological treatment concerned pain and fatigue, physical activity, adaptative skills to personal and professional environment, patient-HP communication and shared decision-making.

Conclusion: The present study provides a corpus of knowledge considered essential for patients in the self-management of their arthritis. The selection of many items reflects recent emphasis on professional recommendations and the patients' perspective. Future work should lead to the development of new updated KQs for patients with inflammatory arthritis.

1. Introduction

Patient education is recommended in the management inflammatory arthritis (IA): rheumatoid arthritis (RA) and spondyloarthritis (SpA) [1–4]. Specific recommendations on patient education have been published by The European League Against Rheumatism (EULAR) [5], reinforcing that patient education is an integral part of standard care. The aim of patient education is to allow patients to participate in their own care and manage their disease in order to improve or maintain their quality of life [5–9]. Education includes a wide range of educational activities based on a planned interactive process to help patients to acquire personal skills [5,7]. Several educational needs have been identified such as knowledge and management of the disease, side effects of treatments and corresponding risk factors, non-pharmacological treatment, pain control, physical exercises and behavior change [5,10–13]. Although patient education is not merely transmission of knowledge, this phase is required. Moreover, assessing the patient's knowledge is part of the educational process and also part of the evaluation of the effectiveness of educational interventions [6,7]. However, to date, there is no consensus on which knowledge is essential for patients with IA.

Previous studies have led to the development of knowledge questionnaires (KQs) for patients with RA [14–16] and SpA [17–19]. Moreover, more specific questionnaires address medications such as methotrexate [20,21] or biologics [22,23]. Most of these KQs, particularly the general KQs [14–17], were constructed before the biologics era or before new issues such as comorbidities [24] or physical activity [25] had become prominent.

In this context, the aim of this study was to determine which knowledge is considered essential for patients to manage their arthritis, as the acquisition of this knowledge would be recommended as part of educational interventions in IA.

2. Methods

A steering committee consisting of 2 rheumatologists and 1 rheumatology nurse launched a multicentric survey through a 2-step process. In the first step, the steering committee collected existing KQs through a systematic literature review of published KQs and a non-systematic collection of unpublished KQs commonly used in France. From these KQs, we elaborated a first list of items (list 1), classified in domains and sub domains, for instance domain: disease knowledge, sub domain: causes, symptoms, evolution course, diagnosis. . .

The second step consisted in a Delphi process with the participation of rheumatologists, healthcare professionals (HPs) and patients. HPs were selected through the Patient Education Section of the French Society of Rheumatology (http://sfr.larhumatologie.fr/) on a voluntary basis. Patients were recruited by the rheumatologists and HPs with the following conditions: a diagnosis of RA or SpA including psoriatic arthritis and non-radiographic spondyloarthritis, ability to read French and agreement to participate in the survey. No personal or medical data was collected at any point and ethical approval was not necessary.

In the first Delphi round, participants were asked to enlarge on list 1 with as many items as they considered important for self-management. The instructions were to add items according to the recommendations of RA/SpA management [1–4] and their own experience. The enlarged list (list2) passed through the 2nd Delphi round which selected the items considered useful by more than 50% of participants. The items with similar meaning were then grouped by the steering committee to obtain list 3. Then, we compared the relative importance of the domains obtained in list 3 to the domains in list 1 issued from the former KQs. We also compared the domains considered essential by participants for patients with RA versus patients with SpA.

2.1. Statistical analysis

The analyses were computed using Stata (version 12, StataCorp, College Station, USA). Study sample was described by frequencies and associated percentages for categorical data and by median and range [minimum–maximum] for continuous data. Comparisons were performed using Chi2 or *t* tests as appropriate.

3. Results

3.1. Phase 1- literature review

Two patient KQs were found in the literature for RA patients, the Patient Knowledge Questionnaire (PKQ) developed in 1991 [14] and the ACREU Rheumatoid Arthritis Knowledge Questionnaire (questionnaire developed in 1997 [16]. A more recent version of the PKQ was published in 2004 and validated in patients with early RA [15]. One patient KQ was found in the literature for SpA patients, developed in 1998 [17]. A French survey using this questionnaire had been performed in France in 2004 [18]. Furthermore, 5 unpublished KQ were collected (3 for RA, 2 for SpA) among multidisciplinary education teams in France, one of which has been used in a randomized trial [26]. In total, 90 knowledge items were mentioned for RA and 67 for SA in the questionnaires, which mainly included knowledge on the disease and treatments (Fig. 1).

3.2. Phase 2–Delphi process

In all, 207 participants responded in the 2 Delphi rounds, 103 for RA and 104 for SpA from 13 multidisciplinary teams dealing with IA across France, in 2014–2015. The second round was performed in 2 parts due to the large number of items to be selected. The number of participants in each round ranged from 33 to 36. One third of the participants were rheumatologists, one third were HPs and the other third included patients (Table S1; See the supplementary material associated with this article online). HPs were mostly nurses and a few physiotherapists and occupational therapists.

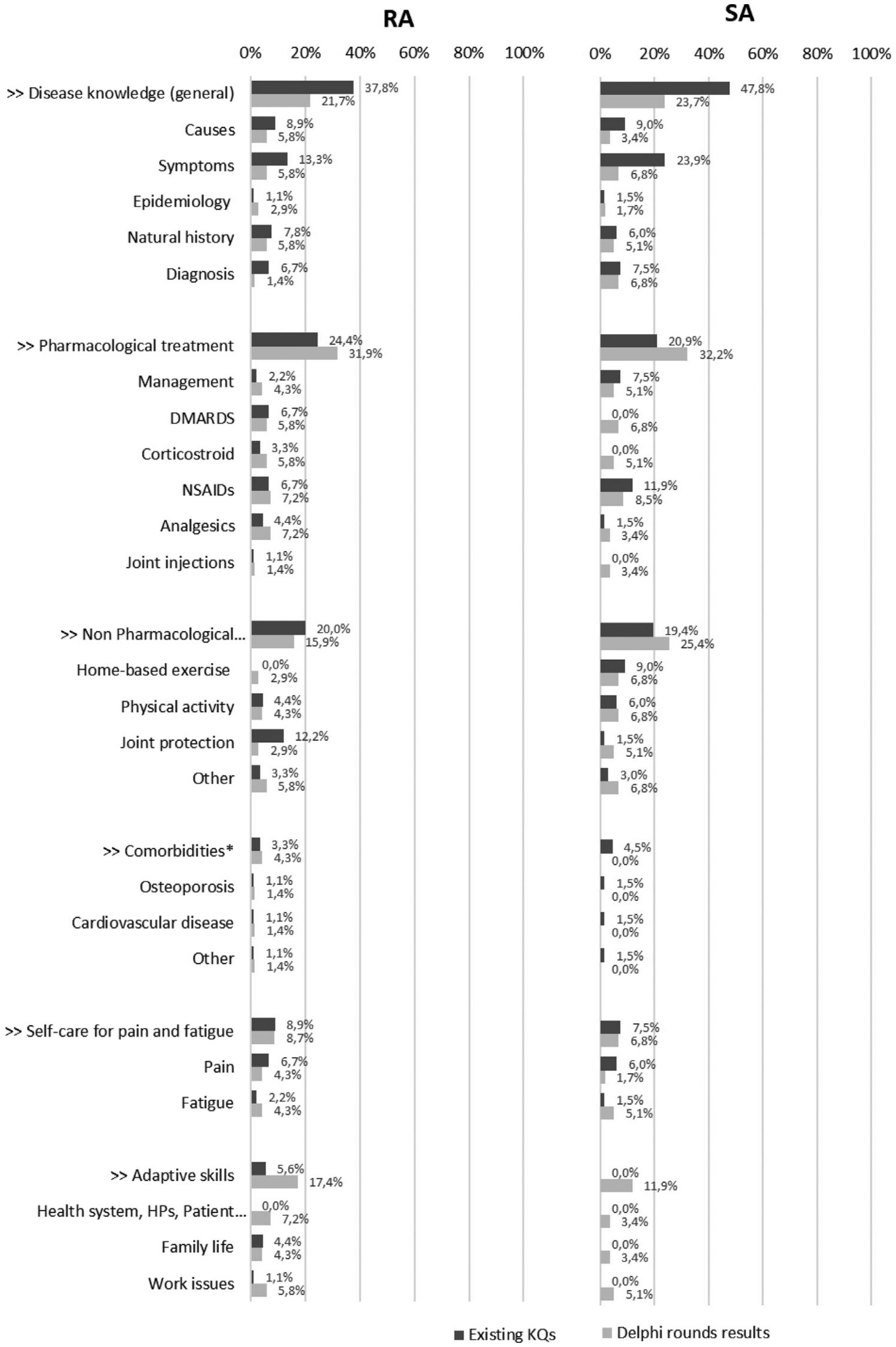

Fig. 1. Domains of knowledge in existing KQs and those obtained through Delphi rounds: results are number of items per domain.

Among the patients, one associative patient and 2 peer-patient educators participated in each round. Participants could be different from one round to another to enlarge the representativeness of the sample.

The 1st Delphi round enlarged the list to 322 items for RA and 265 items SpA (i.e., a 2.5 to 3-fold increase). The second round selected 135 and 92 knowledge items for RA and SpA respectively. After the items with similar meaning had been grouped, the final list of key knowledge (list 3) contained 69 items for RA and 59 items for SpA (Table 1, Fig. 1).

The essential knowledge on disease and pharmacological treatment included knowledge on symptoms and disease course, treatment strategies, managing conventional disease-modifying drugs (cDMARDs) and biological disease-modifying drugs (bDMARDs), managing symptomatic medications: glucocorticoids, NSAIDs, painkillers and joint injections. The importance of co-morbidities were also mentioned (Tables S2–S3).

Knowledge on non-pharmacological treatment concerns pain and fatigue, home exercise, physical activity, dealing with personal and professional environment, e.g. family and intimate life, social

Table 1
Comparison between domains of knowledge in existing KQs (list 1) and domains obtained through Delphi rounds (list 3).

	RA			SpA		
Domains of knowledge	List 1 N/%	List 3 N/%	% adjusted change *P* value	List 1 N/%	List 3 N/%	% adjusted change *P* value
Disease knowledge	34/38.8	15/21.7	– 44% 0.03	32/47.7	14/23.7	−50% 0.005
Pharmacological treatment	22/24.4	22/31.9	+ 31% NS*	14/20.9	19/32.2	+54% NS*
Non-pharmacological treatment	18/20	11/15.9	– 20% NS*	13/19.4	15/25.4	+31% NS*
Comorbidities	3/3.3	3/4.3	+ 30% NS*	3/4.5	0	NS*
Self-care for pain and fatigue	8/8.9	6/8.7	−0.2% NS*	5/7.5	4/6.8	−9% NS*
Adaptive skills: psychosocial, professional issues, health care system	5/5,6	12/17,4	+ 310% 0.02	0	7/11.9	New occurrence 0.004
Total	90/100	69/100	0%	67/100	59/100	0%

NS*: non-significant.

relationship, work issues, participating in self-management education programs. Dealing with HPs were considered important by participants (Tables S4–S5).

In the knowledge corpus, some items were not present in the published KQs or were modified, 36 for RA and 34 for SpA. Although differences were found between the knowledge domains for RA and SpA in list 1 and in list 3, these differences were not statistically significant ($P = 0.42$ and $P = 0.50$ respectively).

3.3. *Comparison of previous knowledge domains versus Delphi results*

The knowledge domains were compared between list 1 and list 3 (Table 1). One of the main significant results for both RA and SpA was a decrease of key domains concerning the disease presentation: the participants showed a lessened interest for causes and symptoms (Tables S2–S3). The overall number of items concerning pharmacological treatments did not change for RA but biological disease-modifying drugs (bDMARDs) were now included. The items concerning pharmacological treatments increased for SpA, due to the appearance in the list of bDMARDs. The content of pharmacological strategy also changed for both RA and SpA (Tables S2–S3).

The number of items in relation with non-pharmacological treatment and self-care did not change. However, sub domains of non-pharmacological treatment varied: less joint protection for RA, new occurrence of other treatments for SpA such as spa, sophrology or yoga. Within SpA self-care, the items concerning pain self-management were replaced by fatigue self-management (Tables S4–S5).

Another significant change was the considerable increase of adaptative skills for RA: patients' pathway, relation with HPs, shared decision-making, the interest of patient education and professional issues (Tables S3–S4). These skills had not been mentioned in former KQs for SpA and made an appearance in List 3 (Fig. 1).

4. Discussion

The present study brings important information regarding what knowledge is essential to patients in managing their IA. These issues had not been addressed in the recent years particularly since the biologic era, which makes the novelty of the study as well as the participation of patients in the Delphi process. We identified 59 (for SpA) to 69 (for RA) knowledge items, which should be included in patient education processes. Key knowledge includes disease knowledge, treatment strategies, DMARDs and symptomatic medications. Managing pain and fatigue, physical activity were considered important as well as adaptative skills to personal and professional environment.

The proposed updated list is in agreement with the currently-recommended management of IA [1–4], particularly in regard to the new pharmacological strategies and bDMARD treatment. This list will be helpful when assessing patient knowledge, and when setting up or evaluating patient education processes. Furthermore, we found that 36 items for RA and 34 items were not addressed in the published KQs or needed to be modified. This indicates that these published KQs were no more adapted in IA, which reflects changes in knowledge but also in healthcare providers' strategies and priorities in the field of IA.

Moreover, if knowledge is considered as part in the acquisition of new skills, the former KQs mostly included cognitive knowledge centered on the disease and the symptoms i.e., on biomedical domains that would be more useful to HPs than to patients. Patient competences in chronic disease include cognitive knowledge, know how (practical skills) and adaptative skills [6,7,27,28]. By involving patients and a large panel of HPs interested in patient education, we intended to cover a large scale of competencies. Our study showed that patients knowledge should not only be focused on the disease and treatment but should also include a range of adaptive skills: these include generic issues such as how to deal with the health system, the patients' pathway, shared decision-making, the possibility of being helped by a multidisciplinary team or the interest of patient education. Work issues were also put forward because of the improvement in the patients' health status since the biologics era [29,30]. In our study, physical activity was recommended and not limited to home exercise but included sports, and exercise in general especially for SpA patients in concordance with the recommendations [25]. Other non-pharmacological treatments were also mentioned such as foot problems for RA patients [31]. Self-care management included the management of fatigue that has become an essential problem for SpA patients [32].

The strength of our study is to have involved a large number of HPs and patients from different French regions. Some patients were associative patients or peer-patients participating in patient education programs, who had more knowledge of the management of IA and a good perception of what were the other patients' needs. As a result, the type of knowledge we found was closer to the general of concept of health competencies and may better answer to the patients' educational needs [12,13]. Some randomized trials have shown that educational programs based on the patients' educational needs are efficient [33] and have better results on self-efficacy and health outcomes than current patient education programs [34–36]. By providing a consensus-based knowledge corpus, our study will be susceptible to improve the content of educational interventions in IA and patient counselling [37].

Another strength of the study was to put forward knowledge for SpA patients, which had seldom been done in the literature before [38]. The survey addressed patients with spondylitis ankylosing but also patients with non-radiographic spondyloarthritis and psoriatic arthritis. This is why glucocorticoid treatment and joint injections were mentioned by the participants.

Our study has some limitations. It has been conducted only in France, consequently its validity should be tested in other countries. However, since patient education's main objective is to answer patients needs on self-management, cross-cultural differences need to be taken into account. The main limitation was that all participants were not perfectly aware of the current recommendations of IA management e.g. non-selected patients and also some of the nurses who may have been prone to propose items according to their own experience only. Some domains were therefore put aside by the Delphi process, such as comorbidities in SpA (although these were retained in RA [24,28,39]). In SpA, patients and HPs were not sufficiently aware of comorbidities [38,40] nor of the role of tobacco consumption [41]. Another gap between results of the present study and professional recommendations relates to painkillers. Patients and HPs mentioned the opportunity of using level 2 analgesics in case of high intensity pain. This should not be retained as a chronic prescription in IA since strong opioids for noncancer pain due to musculoskeletal diseases are not more effective than acetaminophen or NSAIDs [42,43]. However, the input of patients helped the emerging of knowledge that was of importance to patients though not represented in recommendations, based on management strategies.

Finally, it would be interesting to validate these knowledge items by additional studies. The development of new updated KQs for patients with RA and SpA, using our results are in current development. Including these essential knowledge in patient education programs would also be a way of validation.

In conclusion, the present study provides a consensual corpus of essential knowledge for patients with RA and SpA in the self-management of their IA. The corpus has been updated since existing KQs appeared obsolete. Key knowledge includes a large range of domains not only focused on disease and treatment but also on other aspects of disease management such as self-care of fatigue and adaptive skills. Domains have changed over time, correlated to the recent emphasis on the professional recommendations and the patients' perspective.

The corresponding author certifies that all authors approved the entirety of the submitted material and contributed actively to the study.

Disclosure of interest

The authors declare that they have no competing interest.

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Appendix A. Supplementary data

Supplementary data (Tables S1–S5) associated with this article can be found, in the online version, at https://doi.org/10.1016/j.plantsci.2004.08.011.

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