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

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## **Abstract 250**

**Background:** 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 by >50% of participants.

**Results:** 3 published KQs were analysed: 2 for RA; 1 for SpA and 5 unpublished KQs were also collected. In the KQs, 90 knowledge items were mentioned for RA and 67 for SpA. The Delphi process involved 18 to 32 participants in each round.. The 1<sup>st</sup> 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%) not present in the published KQs or were modified. Key domains included pharmacological treatment, coping with fatigue, adaptive skills to professional issues, 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. Many items were not present in published KQs, reflecting 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.

Total 1990

## 1. Introduction

Patient education is recommended in the management inflammatory arthritis (IA): rheumatoid arthritis (RA) and spondyloarthritis (SpA) [1,2,3,4]. 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. Material and 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.

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

#### 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. (**Table 1**).

#### Phase 2 – Delphi process

In all, 218 participants responded in the Delphi rounds, 107 for RA and 111 for SpA from 13 multidisciplinary teams dealing with IA across France, in 2014-2015. The number of participants in each round ranged from 18 to 32: 11-14 rheumatologists in each RA and SpA round, 8-12 and 12 patients respectively and 6-7 and 7-10 HPs respectively. HPs included mostly nurses. Other HPs were physiotherapists and occupational therapists. 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**), 36 and 34 respectively not present in the published KQs or were modified. There was no significant difference between the domains for RA and SpA in list 1 ( $p = 0.42$ ) nor in list 3 ( $p = 0.50$ ).

## Comparison of previous knowledge domains versus Delphi results

The knowledge domains were compared between list 1 and list 3 (**table 2**). 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 (supplementary tables 1 and 2). 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 (supplementary tables 1 and 2).

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 (supplementary tables 3 and 4).

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 (supplementary tables 3 and 4). These skills had not been mentioned in former KQs for SpA and made an appearance in List 3 (**Table 2**).

## 4. Discussion

The present study brings important information regarding what knowledge is essential to patients in managing their IA. Through a methodical, formal process involving both a literature review and physician, HP and patient input, we identified 59 (for SpA) to 69 (for RA) knowledge items which should be included in patient education processes. 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 may be unadapted 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]. 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.

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. This study opens the way to the development of new updated KQs for patients with RA and SpA.

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

Domains of knowledge	RA		SpA	
	Existing KQs	Delphi rounds results	Existing KQs	Delphi rounds results
<b>Disease knowledge (general)</b>	<b>34</b>	<b>15</b>	<b>32</b>	<b>14</b>
Cause of IA	8	4	6	2
Symptoms	12	4	16	4
Epidemiology	1	2	1	1
Natural history	7	4	4	3
Diagnosis	6	1	5	4
<b>Pharmacological treatment</b>	<b>22</b>	<b>22</b>	<b>14</b>	<b>19</b>
Management strategy	2	3	5	3
DMARDs	6	4	0	4
Glucocorticoids	3	4	0	3
NSAIDs	6	5	8	5
Analgesics	4	5	1	2
Joint injections	1	1	0	2
<b>Non pharmacological treatment, general</b>	<b>18</b>	<b>11</b>	<b>13</b>	<b>15</b>
Home-based exercise	0	2	6	4
Physical activity	4	3	4	4
Joint protection	11	2	1	3

Other	3	4	2	4
<b>Comorbidities, general</b>	<b>3</b>	<b>3</b>	<b>3</b>	<b>0</b>
Osteoporosis	1*	1	1*	0
Cardiovascular disease	1*	1	1*	0
Other comorbidities	1	1	1*	0
<b>Self-care for pain and fatigue</b>	<b>8</b>	<b>6</b>	<b>5</b>	<b>4</b>
Pain	6	3	4	1
Fatigue	2	3	1	3
<b>Adaptive skills: psychosocial, professional issues, health care system</b>	<b>5</b>	<b>12</b>	<b>0</b>	<b>7</b>
Healthcare system, communication with HPs, interest of patient education	0	5	0	2
Family life	4	3	0	2
Work issues	1	4	0	3
<b>TOTAL</b>	<b>90</b>	<b>69</b>	<b>67</b>	<b>59</b>

DMARDs: disease modifying drugs; NSAIDs: non steroidal anti inflammatory drugs

Table 2 Comparison between domains of knowledge in existing KQs (list 1) and domains obtained through Delphi rounds (list 3)

Domains of knowledge	RA			SpA		
	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

Supplementary table 1 Rheumatoid arthritis. Essential knowledge on disease and pharmacological treatment

Domains (nb items )	
Disease knowledge (15)	
Etiology and risk factors (4)	Genetic predisposition (1), autoimmunity (1) smoking as risk factor (2) Triggering factors often reported : psychological trauma, stress, life events (2)
Symptoms (4)	Inflammatory symptoms : swelling (1), night awakenings, morning stiffness (1) Fatigue (1) Topography : hands, feet, symmetrical (2)
RA distribution in the population (2)	Women are more affected (2) RA occurs at any age, children may be affected (2)
Disease course (4)	The risk of structural impairment is higher in case of high disease activity. (1) RA course includes periods of flares and remission (2) RA is a chronic disease (2) The risk of disability is nowadays lower due to new pharmacological strategies. (2)
Diagnosis (1)	Difficulty of diagnosis (1)
Pharmacological treatment (22)	
Strategy (3)	The aim of RA management is remission or low disease activity(1) RA management is based DMARDs and symptomatic treatments(1) DMARDs prescription within the first months after the first symptoms improves the disease course (2)
DMARDs (4)	Clinical and biological monitoring DMARDs is essential (1) DMARDs must be personalized with a shared decision with the rheumatologist (1) Infections are the main adverse effects (AE) of biologics (1) Patients should be aware of side effects of biologics(2)
Glucocorticoids (4)	Do not abruptly stop corticosteroids (1) Fast effect, not DMARDs. (1) Diet measures are needed in case of corticosteroids treatment (reducing salt and sugar, more calcium and protein intakes). (2) Corticosteroids may be prescribed for short period to help passing a flare or wait until a new DMARDs becomes effective. (2)
NSAIDs (4)	NSAIDs have gastrointestinal (GI) AE: ulcer, gastritis.

	<p>Black stools may be a symptoms of GI bleeding. Medications may be needed to prevent GI AE. (1)</p> <p>NSAIDs mechanisms of action are different from those of Corticosteroids. (2)</p> <p>NSAIDs are preferably used during flares. They can be stopped when flares are over. (2)</p> <p>NSAIDs dose may be managed by the patient himself. However, patients should not use self-medication without the doctor's advice. (2)</p>
Analgesics (5)	<p>Level 2 painkillers that are stronger than level 1, such paracetamol-codeine or tramadol-paracetamol. (1)</p> <p>Association of analgesics and anti-inflammatory is permitted. (1)</p> <p>Painkillers may be used before a potentially painful exercise(1)</p> <p>Daily paracetamol consumption should not exceed 3 grams/ day (2)</p>
Intraarticular injections (2)	<p>Rheumatologist may suggest an intra articular (IA) corticosteroid injections that may be preceded by a joint puncture. (2)</p> <p>IA injections is useful when a limited number of joints are involved. Otherwise the change of DMARDs strategy should be considered. (2)</p>

(1) Items selected by > 2/3 participants

(2) Items selected by > 50 % participants and < 2/3 participants

Supplementary table 2. Spondyloarthritis. Essential knowledge on disease and pharmacological treatment

Disease knowledge	
Etiology and risk factors (2)	Genetic predisposition, HLA B27 is an important genetic factor (1) Triggering factor often reported: psychological trauma, stress (2)
Symptoms (4)	Uveitis is associated with SpA. Uveitis treatment is urgent. (1)  Topography : spine, heels, hips, anterior chest(2)  Inflammatory symptoms : night awakenings, morning stiffness(2) Fatigue(2)
SpA distribution in the population (1)	First symptoms usually occur before 30 years old (2)
Disease course (3)	SpA is a chronic disease (2) SpA course includes periods of flares and remission (2) Risk of spine permanent stiffness(2)
Diagnosis (4)	Diagnosis is sometimes difficult. (1)  X-rays may be normal. In this case, MRI and/ or ultrasound are useful for diagnosis(1)  Different features: axial /peripheral/enthesopathic (2)  HLA B27 antigen presence versus diagnosis (2)
Pharmacological treatment	
Strategy (3)	SpA management includes pharmacological and non-pharmacological treatments. (2) Several NSAIDs should be tried (2) In case NSAIDs are not effective, biologics may be used. (2)
DMARDs, biologics (4)	Biologics increase the risk of infections (1)  Biologics require precautions in case of surgery, dental care, vaccinations, child conception) and should be kept in the refrigerator (1)  DMARDs are not symptomatic treatments, delayed but long term action (2)  DMARDs clinical and biological monitoring (2)
NSAIDs (4)	There is an individual susceptibility to NSAIDs and the minimum effective dose should be sought (1)



	<p>NSAIDs have gastrointestinal (GI) AE, which varies according to NSAIDs. Black stools may be a symptoms of GI bleeding. (1)</p> <p>NSAIDs should not associated with aspirin, oral anticoagulants, over-the-counter ibuprofen or another NSAIDs. (1)</p> <p>NSAIDs are at risk of cardiovascular diseases e.g hypertension and of renal impairment. Some NSAIDs have greater cardiovascular risks than others (1) NSAIDs are used to improve pain due to inflammation (2)</p>
Glucocorticoids (3)	<p>Avoiding prolonged use of corticosteroids is recommended. (2)</p> <p>Do not abruptly stop corticosteroids(2)</p> <p>There are adverse effects of corticosteroids : weight gain, salt retention, facial swelling, hypertension, diabetes, delay in wound healing (2)</p>
Analgesics (2)	<p>Painkillers may be used during flares if NSAIDs are not effective. Different level of painkillers may be used according to the level of pain intensity. (1)</p> <p>Painkillers may be taken any time of the day e.g before a potentially painful exercise or physical activity(2)</p>
Glucocorticoids injections (2)	<p>Joint injections may be useful(2)</p> <p>Rest is recommended after a joint injection(2)</p>

(1) Items selected by > 2/3 participants

(2) Items selected by > 50 % participants and < 2/3 participants

Supplementary table 3. Rheumatoid arthritis. Essential knowledge on non-pharmacological treatment, comorbidities, self-care and adaptative skills

non-pharmacological treatment	
Home exercise (2)	Home exercise include simple and easy gestures (1)

	Home exercise may reduce morning stiffness. (1)
Physical activity (3)	<p>Physical activity has many benefits, e.g fatigue reduction, improvement of psychological well-being and self-confidence, osteoporosis prevention...(1)</p> <p>Physical activity is a key element in the management of RA. (1)</p> <p>Physical activity must be tailored according to the patient's condition. (2)</p>
Joint protection (2)	<p>Rest is recommended when flares are too painful. (2)</p> <p>Joints should not be overstrained, e.g small finger joints. (2)</p>
Other non-pharmacological treatments (4)	Rest orthotics are useful, particularly during flares. (1)
	<p>Good footwear is beneficial. (1)</p> <p>Hot or cold application can help reducing morning stiffness(2)</p> <p>Healthy and diversified diet is recommended: not too much meat or dairy products, avoid dietary deficiencies. (2)</p>
Comorbidities	
Comorbidities (3)	<p>RA is a risk factor for cardiovascular diseases. (1)</p> <p>Active RA is a risk factor for infections. Glucocorticoids increase the risk of infections. (2)</p> <p>RA is a risk factor of osteoporosis (2)</p>
self-care	
Pain management (3)	<p>Pain self- management means a good knowledge of RA by the patient and a good knowledge of oneself. (1)</p> <p>For pain self- management, it is useful to know the difference between pain due to inflammation and pain due to overuse. (2)</p> <p>One should not wait for a high pain level before taking a painkiller. (2)</p>
Fatigue management (3)	Communication on fatigue is difficult. One should not feel ashamed to allow fatigue and accept help from

	<p>other people. (1)</p> <p>Fatigue is a complex symptom, with many determinants (1)</p> <p>One should know how to split activities(2)</p>
Adaptative skills	
Relationship with health professionals (5)	<p>Cooperation and communication between the rheumatologist and the physician are needed to improve the patient pathway. (1)</p> <p>Trustful relationship between the patient and doctors and health professionals is essential, enlightening the importance of an equal to equal dialogue, openness and listening in order to promote a shared decision making. . Patients should be allowed to acknowledge they do not understand the medical discourse. (1)</p> <p>Patient associations can provide aid and resources. (2)</p> <p>Patient education is useful. (2)</p> <p>Patients should be told that they can ask help from health professionals: rheumatologist, GP, nurse, physiotherapist psychologist, dietician, occupational therapist, pharmacist, podiatrist, social worker, psychiatrist... (2)</p>
Family life, social relationships, intimate life (3)	<p>Communication and understanding may be difficult with close ones (family, friends) partly due to the fact that RA is no longer an obvious disease. (1)</p> <p>Patient education is useful to share with other patients. (2)</p> <p>RA has an impact on libido, sexuality, intimate life, and self-image. Dialogue within in the couple is essential. (2)</p>
Work issues (4)	<p>Importance of maintaining professional life (1)</p> <p>Having a tailored position in work may help to pursue an active professionally life. (2)</p> <p>Opportunities for professional rehabilitation. (2)</p> <p>Disclosing RA within one's workplace is not compulsory. (2)</p>

(1) Items selected by  $> 2/3$  participants

(2) Items selected by  $> 50\%$  participants and  $< 2/3$  participants

Supplementary table 4. Spondyloarthritis. Essential knowledge on non-pharmacological treatment, comorbidities, self-care and adaptive skills

Home exercises (4)	<p>Home exercises are part of SpA treatment (1)</p> <p>Exercises and stretching are beneficial for spine stiffness, as well as extension exercise for spine. (1)</p> <p>Rehabilitation programs may be useful as well as patient education favouring home exercise. (2)</p> <p>Home exercise should be practiced regularly. (2)</p>
Physical activity (4)	<p>Physical activity should be tailored. (1)</p> <p>Physical activity is beneficial for health and psychological well-being. (1)</p> <p>Mild pain allows physical activity. In this case, physical activity is not at risk of flares. (2)</p> <p>Many sports are permitted, not only swimming and walking. (2)</p>
Joint and spine protection (3)	<p>Daily postures are beneficial (2)</p> <p>Good bedding is useful. (2)</p> <p>Occupational therapists give advice: for instance they propose ergonomic tools. (2)</p>
Other non-pharmacological treatments (4)	<p>Hot or cold application can help reduce pain. (2)</p> <p>Relaxation, sophrology, acupuncture, yoga are of interest (2)</p> <p>Physiotherapy and massages may help (2)</p> <p>Balneotherapy may be useful (2)</p>
Comorbidities 0	
self-care	
Pain management (1)	<p>Patient education should include pain self-management (1)</p>
Fatigue management (3)	<p>Fatigue has many determinants: inflammation and flares, medications, lifestyle, mood, sleep disorders. (1)</p> <p>Tailoring activities helps to improve fatigue such as alternating moments of rest and exercise. (1)</p> <p>Physical activity and training improve fatigue (2)</p>
adaptive skills	
Relationship with health professionals (3)	<p>Follow-up should be regularly performed by the rheumatologist with a communication between the rheumatologist and the GP (1)</p>

	<p>It is of interest for patients to be aware all the potential health professionals of the patients' pathway: rheumatologist, GP, pharmacist, physiotherapist, dietician, occupational therapist, social worker, psychologist. (2)</p> <p>The patient should not hesitate to get in touch with health professionals and ask questions, e. by preparing the medical consultation (2)</p>
Family life, social relationships, intimate life (2)	<p>Patients should not hesitate to explain and talk about their illness to their close ones. Communication is essential (1)</p> <p>SpA has an impact on family and social life (2)</p>
Work issues (3)	<p>Occupational therapy is useful in the workplace. For some patients professional rehabilitation may be important. (1)</p> <p>Physicians at the work place may play a role for professional rehabilitation. (2)</p> <p>Opportunities for professional rehabilitation. (2)</p>

(1) Items selected by > 2/3 participants

(2) Items selected by > 50 % participants and < 2/3 participants

## REFERENCES

1. Daien C, Hua C, Gaujoux-Viala C, et al. Update of French Society for Rheumatology Recommendations for Managing Rheumatoid Arthritis. *Joint Bone Spine* 2018. doi: 10.1016/j.jbspin.2018.10.002. [Epub ahead of print]
2. Wendling D, Lukas C, Prati C et al, 2018 update of French Society for Rheumatology (SFR) recommendations about the everyday management of patients with spondyloarthritis. *Joint Bone Spine* 2018;85:275-284.
3. Smolen JS, Landewé R, [Bijlsma J](#), et al. EULAR recommendations for the management of rheumatoid arthritis with synthetic and biological disease-modifying antirheumatic drugs: 2016 update. *Ann Rheum Dis*. 2017;76:960-977.
4. van der Heijde D, Ramiro S, Landewé R, et al. 2016 update of the ASAS-EULAR management recommendations for axial spondyloarthritis. *Ann Rheum Dis*. 2017;76:978-991.
5. Zangi HA, Ndosi M, Adams J et al, EULAR recommendations for patient education for people with inflammatory arthritis. *Ann Rheum Dis*. 2015;74:954-62.
6. World Health Organization. Therapeutic Patient Education. Continuing Education Programmes for Health Care Providers in the Field of Prevention of Chronic Diseases. World Health Organization 1998. [http://www.euro.who.int/\\_\\_data/assets/pdf\\_file/0007/145294/E63674.pdf](http://www.euro.who.int/__data/assets/pdf_file/0007/145294/E63674.pdf) (07/01/2019)
7. Guide Méthodologique Structuration d'un programme d'éducation thérapeutique du patient dans le champ des maladies chroniques HAS-INPES juin 2007. [https://www.has-sante.fr/portail/jcms/c\\_1241714/fr/education-therapeutique-du-patient-etp](https://www.has-sante.fr/portail/jcms/c_1241714/fr/education-therapeutique-du-patient-etp) (07/01/2019)
8. Algrante JP, Wells MT, Peterson JC. Interventions to Support Behavioral Self-Management of Chronic Diseases. *Annu. Rev. Public Health* 2019. 40:9.1–9.20
9. Hoving C, Visser A, Mullen PD, van den Borne B. A history of patient education by health professionals in Europe and North America: from authority to shared decision making education. *Patient Educ Couns* 2010;78:275-81.
10. Kristiansen TM, Primdahl J, Antoft R, Hørslev-Petersen K. Everyday life with rheumatoid arthritis and implications for patient education and clinical practice: a Focus Group Study. *Musculoskeletal care* 2012;10:29-38.

11. Ndosi M, Tennant A, Bergsten U, et al. Cross-cultural validation of the Educational Needs Assessment Tool in RA in 7 European countries. *BMC Musculoskelet Disord*. 2011;12:110.
12. Meesters JJ, Vliet Vlieland TP, Hill J, Ndosi ME. Measuring educational needs among patients with rheumatoid arthritis using the Dutch version of the Educational Needs Assessment Tool (DENAT). *Clin Rheumatol*. 2009;28:1073-7.
13. Beauvais. C., Rahal A. , Hassani. K, Pouplin S. Detection of educational needs of patients with inflammatory arthritis : feasibility and results in routine care. *Educ Ther Patient/Ther Patient Educ* 2014; 6: 20107
14. Hill J, Bird HA, Hopkins R, Lawton C, Wright V. The development and use of Patient Knowledge Questionnaire in rheumatoid arthritis. *Br J Rheumatol*. 1991;30:45-9.
15. Hennell SL, Brownsell C, Dawson JK. Development, validation and use of a patient knowledge questionnaire (PKQ) for patients with early rheumatoid arthritis. *Rheumatology (Oxford)* 2004;43:467-71.
16. Lineker SC, Badley EM, Hughes EA, Bell MJ. Development of an instrument to measure knowledge in individuals with rheumatoid arthritis: the ACREU rheumatoid arthritis knowledge questionnaire. *J Rheumatol*. 1997;24:647-53.
17. Lubrano E, Helliwell P, Moreno P, Griffiths B, Emery P, Veale D. The assessment of knowledge in ankylosing spondylitis patients by a self-administered questionnaire. *Br J Rheumatol*. 1998;37:437-41.
18. Claudepierre P, Flipo RM, Sibilía J et al. Patient knowledge of their disease: a French multicenter study in ankylosing spondylitis. *Joint Bone Spine* 2004;71:550-6.
19. da Rocha Lopes SM, Duarte JA, Mesquita CT. Cross-cultural adaptation and validation of the Portuguese version of "The assessment of knowledge in ankylosing spondylitis patients by a self-administered questionnaire". *Rheumatol Int*. 2016;36:515-9.
20. Ciciriello S, Buchbinder R, Osborne RH, Wicks IP. Improving treatment with methotrexate in rheumatoid arthritis-development of a multimedia patient education program and the MiRAK, a new instrument to evaluate methotrexate-related knowledge. *Semin Arthritis Rheum*. 2014;43:437-46.



21. Fayet F, Savel C, Rodere M, et al. The development of a questionnaire to evaluate rheumatoid arthritis patient's knowledge about methotrexate. *J Clin Nurs*. 2016;25:682-9.
22. Gossec L, Fautrel B, Flipon E, et al. Safety of biologics: elaboration and validation of a questionnaire assessing patients' self-care safety skills: the BioSecure questionnaire. An initiative of the French Rheumatology Society Therapeutic Education section. *Joint Bone Spine* 2013;80:471-6.
23. Rat AC, Fautrel B, Flipon E, et al. Factors associated with knowledge and safety skills of arthritis patients receiving biologics: A survey of 677 patients. *Joint Bone Spine*. 2017 ;84:163-168.
24. Dougados M, Soubrier M, Perrodeau E, et al. Impact of a nurse-led programme on comorbidity management and impact of a patient self-assessment of disease activity on the management of rheumatoid arthritis: results of a prospective, multicentre, randomised, controlled trial (COMEDRA). *Ann Rheum Dis*. 2015;74:1725-33.
25. Rausch Osthoff AK, Niedermann K, Braun J, et al. 2018 EULAR recommendations for physical activity in people with inflammatory arthritis and osteoarthritis. *Ann Rheum Dis*. 2018;77:1251-1260.
26. Giraudet-Le Quintrec JS, Mayoux-Benhamou A, Ravaud P, et al. Effect of a collective educational program for patients with rheumatoid arthritis: a prospective 12-month randomized controlled trial. *J Rheumatol*. 2007;34:1684-91.
27. D'Ivernois JF, Gagnayre R. Apprendre à éduquer le patient : approche pédagogique. 4e éd. Collection Éducation du patient, Paris:Maloine;2011.p. 88-98.
28. Fabre S. Evaluating therapeutic patient education: Objectives and criteria. *Joint Bone Spine*. 2017;84:121-123.
29. Verstappen SM. Rheumatoid arthritis and work: The impact of rheumatoid arthritis on absenteeism and presenteeism. *Best Pract Res Clin Rheumatol*. 2015 ;29:495-511.
30. Bertin P, Fagnani F, Duburcq A et al. Impact of rheumatoid arthritis on career progression, productivity, and employability: The PRET Study. *Joint Bone Spine*. 2016 Jan;83:47-52.

31. Graham AS, Stephenson J, Williams AE. A survey of people with foot problems related to rheumatoid arthritis and their educational needs. *J Foot Ankle Res.* 2017;10:12.
32. Dures E, Kitchen K, Almeida C, et al. "They didn't tell us, they made us work it out ourselves": Patient perspectives of a cognitive-behavioral program for rheumatoid arthritis fatigue. *Arthritis Care Res* 2012;64:494-501.
33. Pot-Vaucel M, Aubert MP, Guillot P, et al. Randomised study versus control group of customised therapeutic education for patients in follow-up for rheumatoid arthritis. *Joint Bone Spine* 2016;83:199-206.
34. Drăgoi RG, Ndosu M, Sadlonova M, et al. Patient education, disease activity and physical function: can we be more targeted? A cross sectional study among people with rheumatoid arthritis, psoriatic arthritis and hand osteoarthritis. *Arthritis Res Ther.* 2013;15:R156.
35. Ndosu M, Johnson D, Young T, et al. Effects of needs-based patient education on self-efficacy and health outcomes in people with rheumatoid arthritis: a multicentre, single blind, randomised controlled trial. *Ann Rheum Dis.* 2016;75:1126-32.
36. Gossec L, Molto A, Romand X, et al. Recommendations for the assessment and optimization of adherence to disease-modifying drugs in chronic inflammatory rheumatic diseases: A process based on literature reviews and expert consensus. *Joint Bone Spine.* 2018 . doi: 10.1016/j.jbspin.2018.08.006. [Epub ahead of print]
37. Packham J, Arkell P, Sheeran T, Brownfield A, Cadwgan A, Ryan S. Patient experiences, attitudes and expectations towards receiving information about anti-TNF medication: a quantitative study. *Clin Rheumatol.* 2017;36:2595-2600.
38. Dzubur E, Khalil C, Almaro CV, et al. Patients' Concerns and Perceptions Regarding Biologic Therapies in Ankylosing Spondylitis: Insights from a Large-Scale Survey of Social Media Platforms. *Arthritis Care Res (Hoboken).* 2018. doi: 10.1002/acr.23600. [Epub ahead of print]
39. Boo S, Oh H, Froelicher ES, Suh CH. Knowledge and perception of cardiovascular disease risk among patients with rheumatoid arthritis. *PLoS One.* 2017;12:e0176291.

40. Ljung L, Sundström B, Smeds J, Ketonen M, Forsblad-d'Elia H. Patterns of comorbidity and disease characteristics among patients with ankylosing spondylitis-a cross-sectional study. *Clin Rheumatol*. 2018 ;37:647-653.

41. Naranjo A, Bilbao A, Erausquin C, et al. Results of a specific smoking cessation program for patients with arthritis in a rheumatology clinic. *Rheumatol Int*. 2014 ;34:93-9.

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