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## Development and application of a questionnaire to assess patient beliefs in rheumatoid arthritis and axial spondyloarthritis

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1 **Development and Application of a Questionnaire to Assess Patient**  
2 **Beliefs in Rheumatoid Arthritis and Axial Spondyloarthritis**

3

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18 *Thibault de Chalus was an employee of UCB Pharma at the time of the study*

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#### 9 **CONFLICT OF INTEREST**

10 LG, PC, CH, CD, ST and AS report non-financial support from UCB Pharma and  
11 Fondation Arthritis during the conduct of the study; FB reports non-financial support  
12 from UCB Pharma during the conduct of the study; GC and J-MJ are employees of  
13 UCB Pharma; TdC was an employee of UCB Pharma at the time of the study; VS and  
14 FR-M declare that they have no competing interest. The authors have full control of  
15 all primary data and agree to allow the journal to review these data if requested.

1 **ABSTRACT**

2 ***Introduction/Objectives***

3 Misinterpretation of patient beliefs may complicate shared decision-making in  
4 rheumatoid arthritis (RA) or axial spondyloarthritis (axSpA). The objective of this  
5 study was to develop a questionnaire to assess patients' beliefs about their disease  
6 and its treatment, and to identify patient characteristics associated with these beliefs.

7 ***Method***

8 All beliefs reported by >5% of 50 patients in a previous study were reformulated  
9 with a partnering patient organization into statements with which participants could  
10 rate their agreement on a scale of 0–10 (totally disagree to totally agree). The  
11 resulting Questionnaire for Arthritis Dialogue (QuAD) was made available to patients  
12 with RA or axSpA. A score  $\geq 7$  was considered a strongly-held belief. Associations  
13 between patient characteristics and individual lifestyle beliefs were assessed using  
14 multiple logistic regression.

15 ***Results***

16 The 21-item QuAD was completed by 672 patients (432 RA, 240 axSpA; mean [ $\pm$ SD]  
17 age: 54.2 [ $\pm$ 14.2]; 63.7% female). The most widely held beliefs were related to  
18 uncertainty about progression (n=354, 54.0%), heredity (n=309, 47.8%) and flare  
19 triggers (n=283, 42.7%). The unwarranted belief that physical activity is deleterious  
20 to disease activity was associated with markers of psychological distress and lower  
21 educational levels.

22 ***Conclusions***

1 The beliefs of patients with RA or axSpA about their disease are wide-ranging. Since  
2 these may be unwarranted and may lead to inappropriate behaviors, physicians  
3 should discuss these beliefs with their patients. The QuAD may facilitate this  
4 dialogue, and may also be useful in population studies to standardize the assessment  
5 and evolution of beliefs over time.

6 **Key words**

7 Rheumatoid arthritis, outcome measures, spondyloarthritis, behavior, patient attitude  
8 to health

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1 **INTRODUCTION**

2 Chronic inflammatory rheumatic diseases (CIRDs), of which rheumatoid arthritis (RA)  
3 and axial spondyloarthritis (axSpA) are the most frequent, are progressive diseases  
4 that evolve with an unpredictable and fluctuating course over the patient's lifetime.  
5 The chronic nature of these diseases, the heterogeneity of physical manifestations  
6 between patients, and the difficulty in foreseeing disease flares and long-term  
7 progression create uncertainty and stress for the patient. In addition, they make it  
8 difficult for patients to develop a valid internal representation of their disease [1].

9 This may in turn lead to misplaced disease perceptions and treatment expectations  
10 [2, 3], and the development of inappropriate behaviors for managing disease  
11 manifestations and coping with their consequences [4, 5]. For example, patients who  
12 believe that disease flares are triggered by physical activity may actively pursue a  
13 sedentary lifestyle, with detrimental consequences for their CIRD and their general  
14 health [6]. The erroneous assumption that diet has an impact on disease may also  
15 lead the patient to make poor nutritional choices [7]. In addition, expectations about  
16 the benefits and risks of treatment with disease-modifying antirheumatic drugs  
17 (DMARDs) may influence treatment adherence [8] or perceptions of tolerability [9].

18 Therefore, it is important for physicians to understand their patients' beliefs about  
19 their disease, and to initiate a dialogue with the patient about unwarranted beliefs,  
20 with the goal of modifying behavior and thereby improving overall health. However,  
21 very little research has been published relating to the beliefs and apprehensions of  
22 patients with CIRDs [10].

23 In order to gain more information about disease perceptions in patients with CIRDs,  
24 a research program was initiated, with the aim of developing a questionnaire to  
25 evaluate these beliefs. The specific objectives of this study were to develop a

- 1 questionnaire to assess beliefs in patients with RA or axSpA regarding their disease
- 2 and its treatment, and to identify patient characteristics associated with these beliefs.
- 3

## 1 **MATERIALS AND METHODS**

### 2 **Development of the Questionnaire for Arthritis Dialogue**

3 A previous qualitative study of disease perception in patients with RA or axSpA was  
4 performed in 50 patients (25 with RA and 25 with axSpA) [11]. Based on data from  
5 this study [11], all items reported by >5% of patients were rephrased as assertions,  
6 with help from a partnering patient organization. This questionnaire covered the  
7 most widely-held perceptions about disease and treatment. Other questions related  
8 to patient fears and beliefs are reported elsewhere [12]. Each item was scored on a  
9 10-point numerical rating scale (NRS) ranging from 0 (totally disagree) to 10 (totally  
10 agree).

11 The questions were tested in a sample of 10 patients for linguistic validation and  
12 cognitive debriefing. The original French questionnaire was translated into English  
13 through two independent forward translations (French to English) followed by two  
14 independent back translations (English to French), with reconciliation of the  
15 translated texts [13]. The questionnaire took around 25 minutes to complete.

### 16 **Application of the Questionnaire for Arthritis Dialogue to a wide sample**

17 This cross-sectional, prospective study included patients with RA or axSpA in  
18 everyday practice in France, and was implemented by hospital and community  
19 rheumatologists between July 2014 and October 2015. The study was performed in  
20 accordance with Good Epidemiological Practice [14] and relevant French guidelines  
21 for patient surveys. Verbal informed consent was obtained from all participating  
22 patients. The study protocol was considered by the Ethics Committee of the St  
23 Antoine Hospital, Paris, to be both ethical and outside the scope of French legislation  
24 restricting biomedical research (session of 7<sup>th</sup> October 2014). The study was also



1 declared to the National Advisory Committee on Medical Research Information  
2 (CCTIRS) and the French national data protection agency (CNIL).

3 All rheumatologists currently practicing in France were invited to participate in the  
4 study though post and email. Each participating rheumatologist was expected to  
5 invite all consecutive patients with RA or axSpA during routine outpatient visits who  
6 fulfilled the eligibility criteria (up to 20 patients per investigator). Adult patients  
7 (aged >18 years) with a diagnosis of RA according to the American College of  
8 Rheumatology/European League Against Rheumatism (ACR/EULAR) classification  
9 criteria [15], or of axSpA according to the Assessment in Spondyloarthritis  
10 International Society (ASAS) classification criteria [16], were eligible and were  
11 enrolled if they agreed to participate. Patients who were unable to complete a  
12 questionnaire in French were excluded.

### 13 **Data collection**

14 Patients were asked to complete both the beliefs questionnaire and other questions  
15 relating to fears (44 items in total) [12], the Hospital Anxiety and Depression Scale  
16 (HADS) [17], the Arthritis Helplessness Index (AHI) [18], the Patient Global  
17 Assessment (PGA) of overall disease activity (scored between 0–10), and for patients  
18 with axSpA, the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) [19]. All  
19 questionnaires were in French. Patients also provided information on  
20 sociodemographic indicators, health insurance coverage and disease duration.

21 In parallel, rheumatologists provided information on their own age, gender, type of  
22 practice (hospital, community or mixed) and geographical region, in addition to  
23 information about the patient on current treatment, disease activity measured with  
24 the 28-item Disease Activity Score calculated with erythrocyte sedimentation rate

1 (DAS28[ESR]) [20] for RA, and an overall assessment of disease activity scored from  
2 0–10.

### 3 **Statistical analysis**

4 Data were analyzed for all patients for whom both patient and physician  
5 questionnaires were available. For each item of the questionnaire, mean value  $\pm$   
6 standard deviation (SD) and the percentage of patients with scores  $\geq 7$  were  
7 determined both for the total population, and for the RA and axSpA subgroups.  
8 Comparisons were performed with the  $\chi^2$  test (corrected for continuity) or Fisher's  
9 exact test, as appropriate. A score of  $\geq 7$  was taken to indicate strong agreement  
10 with the opinion presented. This cut-off was chosen on an empirical basis; in the  
11 absence of any known disease characteristic with which these beliefs are correlated,  
12 we did not feel that it was realistic to attempt psychometric calibration of the VAS.

13 In order to identify variables associated with a score  $\geq 7$  for a given item, we  
14 performed a univariate regression analysis for all patient and physician variables  
15 documented in the study. Variables with an association at a probability threshold of  
16 0.20 ( $\chi^2$  test) were entered into a backwards stepwise multiple logistic regression  
17 analysis. A threshold of 0.05 was used for retention of variables in the model.

18 Multiple imputation methods (Markov chains using Monte Carlo simulations) were  
19 used for missing data when this concerned  $>5\%$  of all patients. When this proportion  
20 was  $\leq 5\%$ , missing data were replaced with the median value of the full study  
21 sample. All statistical analyses were performed using SAS® Version 9.2 (SAS  
22 Institute, Cary, NC, USA).

### 23 **Role of the funding source**

1 UCB Pharma sponsored the study and the development of the manuscript and  
2 reviewed the text to ensure that from a UCB Pharma perspective, the data presented  
3 in the publication are scientifically, technically and medically supportable, that they  
4 do not contain any information that has the potential to damage the intellectual  
5 property of UCB Pharma, and that the publication complies with applicable laws,  
6 regulations, guidelines and good industry practice. The authors approved the final  
7 version to be published after critically revising the manuscript for important  
8 intellectual content.

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## 1 **RESULTS**

### 2 **Characteristics of the Questionnaire for Arthritis Dialogue**

3 The Questionnaire for Arthritis Dialogue (QuAD) includes 44 items in total, 21 of  
4 which cover beliefs on the cause of disease, disease flares and treatments. The  
5 remaining 23 items concern fears that are described in detail elsewhere. [21]

### 6 **Participants in the validation study**

7 Of the 1618 rheumatologists in France who were contacted, 134 agreed to  
8 participate in the study (including 20 who were exclusively community-based, 51  
9 exclusively hospital-based and 29 with a mixed practice), and 100 enrolled at least  
10 one patient.

11 A total of 796 patients were enrolled, of whom 672 (84.4%) were available for  
12 analysis (**Table 1**). The remaining patients were excluded, due to either missing  
13 physician (n=98) or patient (n=12) questionnaires, or because the diagnostic criteria  
14 for RA/axSpA were either not fulfilled (n=5) or not documented (n=10). The median  
15 number of patients enrolled by each center was six. Patients with RA were more  
16 frequently female, and older on average than those with axSpA. Both physician and  
17 patient global assessments were higher for patients with axSpA than for those with  
18 RA. In both groups, around three-quarters of patients were undergoing treatment  
19 with biological DMARDs.

### 20 **Beliefs of patients with rheumatoid arthritis and axial spondyloarthritis**

21 The 21 relevant items in the QuAD (**Table 2**) included beliefs about psychological  
22 factors (2 items), genetic factors (2 items), physical activity (4 items), diet (4 items),  
23 and other lifestyle factors (3 items). The remaining items were categorized as  
24 miscellaneous beliefs (6 items).

1 Mean ( $\pm$ SD) scores for each item of the QuAD ranged from 0.7 ( $\pm$ 1.6) for “I think  
2 that drinking alcohol (even moderately) triggered my disease” to 6.3 ( $\pm$  3.2) for “I  
3 don't know how my disease will progress (and that worries me)”. The proportion of  
4 patients rating each item of the QuAD with a score  $\geq$ 7 is presented in **Figure 1**.  
5 Overall, beliefs appeared to be more strongly held in patients with axSpA than in  
6 those with RA. The three most widely held beliefs were: “I don't know how my  
7 disease will progress (and that worries me)” (n=354, 54.0%), “I am afraid of passing  
8 my disease on to my children” (n=309, 47.8%), and “I think that my flare-ups are  
9 triggered by fatigue” (n=283, 42.7%).

#### 10 **Characteristics of patients with specific lifestyle beliefs**

11 A comprehensive listing of patient characteristics associated with individual lifestyle  
12 beliefs, identified from the univariate and multivariate analyses, is provided in  
13 **Online Resource 1** (physical activity items), **Online Resource 2** (food and diet  
14 items) and **Online Resource 3** (other lifestyle items).

15 Findings from the multivariate analysis are presented in **Table 3**. The belief that  
16 ‘eating certain foods could reduce disease flares’ had more acceptance in women  
17 than in men. The belief that ‘physical activity could reduce disease flares’ had more  
18 acceptance in patients with higher education, while fewer patients in this subgroup  
19 believed that their disease may have been caused by physical overload. In contrast,  
20 more patients with high HADS scores for anxiety or depression (or both) believed  
21 that ‘their disease was caused by physical overload’ and that ‘flares were triggered  
22 by physical effort’, whereas fewer held the opposite belief that ‘physical activity could  
23 reduce flares’. Similarly, more patients with high AHI scores believed that disease  
24 flares could be triggered by physical activity, or that their disease may have been  
25 caused by environmental factors such as pollution. The belief that ‘drinking alcohol

1 or smoking caused the disease' was more widely accepted among financially  
2 deprived patients (those eligible for an income subsidy from the state).

3 Some differences were observed between patients with RA and those with axSpA.  
4 Compared to patients with RA, those with axSpA were more likely to believe that  
5 taking physical exercise could reduce disease flares, and less likely to believe that  
6 their disease was caused by smoking.

7 These multiple logistic regression analyses were reiterated twice: firstly, by  
8 introducing age and gender as forced variables in the models, and then with patient-  
9 reported disease activity (visual analogue scale, VAS) and disease duration as forced  
10 variables. Although these adjustments altered the odds ratios minimally, the  
11 variables retained in the models were not changed (data not shown).

## 1 **DISCUSSION**

2 The aim of this study was to develop a questionnaire to evaluate the beliefs of  
3 patients with RA and axSpA, and to identify patient characteristics associated with  
4 these beliefs. In a large sample of patients with RA or axSpA, our study identified a  
5 wide range of patient opinions on their disease and its treatment, and a number of  
6 demographic, socioeconomic and psychological factors associated with these  
7 opinions.

8 No individual belief was strongly held by more than half of patients overall. However,  
9 more than one-third of patients attributed their disease to psychological or genetic  
10 causes, whereas less than ten percent attributed it to causes that have little support  
11 from medical opinion, such as diet, pollution, smoking, infection, vaccination or  
12 alcohol consumption. In contrast, beliefs about lifestyle and CIRDS were often  
13 erroneous, perhaps due to inadequate patient education, or because of psychological  
14 distress. These beliefs need to be explored by physicians and discussed with the  
15 patient to ensure that the patient maintains as healthy a lifestyle as possible.

16 The diversity of beliefs identified include those that are consistent with current  
17 medical opinion, such as the belief that axSpA may have a genetic cause; those that  
18 are inconsistent with medical opinion, such as the belief that CIRDS may be caused  
19 by vaccination, and those for which there is limited medical consensus or where  
20 medical opinion is evolving. In general, the beliefs held were similar between  
21 patients with RA and those with axSpA, which may be explained by the similarly  
22 unpredictable course of the two diseases, the common core symptoms, and the fact  
23 that these patients will usually be cared for in the same healthcare facilities and thus  
24 be exposed to the same sources of information. However, patients with axSpA were  
25 around twice as likely as those with RA to attribute their disease to a genetic origin,

1 likely reflecting awareness of a strong association between SpA and HLA-B27 [22].  
2 In contrast, when asked to suggest possible causes for their disease, patients with  
3 RA were more likely to cite emotional factors. Moreover, patients with axSpA, who  
4 were on average younger and had a higher level of education than those with RA,  
5 were more likely to believe that physical activity could be beneficial to their disease  
6 (in agreement with current medical thinking) and less likely to believe that their  
7 disease was caused by smoking.

8 In this study, we focused on beliefs relating to lifestyle. This choice reflects the fact  
9 that these beliefs may be modifiable, potentially leading to changes in lifestyle.

10 Investigation of a patient's beliefs about lifestyle, and a dialogue about unwarranted  
11 beliefs, may help modify behavior and improve health. For example, patients who  
12 are convinced of the benefits of physical activity might adopt a regular exercise  
13 routine. In addition, dispelling unwarranted fears about the risks of vaccination may  
14 encourage patients to be vaccinated against infectious diseases.

15 In some cases, different groups of patients held opposing beliefs, such as those  
16 relating to the impact of physical activity or diet on disease flares. For example, the  
17 proportion of patients who believed that physical activity triggered their disease  
18 flares (35.5%) was comparable to the proportion of those who held the opposite  
19 opinion, that physical activity reduced their flares (36.5%). It should be noted,  
20 however, that the two items are not wholly comparable, since they are phrased  
21 somewhat differently: the deleterious belief referring to 'physical effort' (passive) and  
22 the beneficial belief referring to 'doing sport or physical activity' (active).

23 Nevertheless, the characteristics of these two groups of patients were different:  
24 those who considered physical activity to be detrimental were more frequently  
25 anxious or depressed and expressed a high helplessness score, possibly indicating



1 that this belief was associated with psychological distress. In contrast, patients who  
2 believed that physical activity was beneficial tended to be better educated, less  
3 depressed, and to rate their disease activity as low. With respect to this particular  
4 belief, it is noteworthy that medical opinion has evolved over recent years – whereas  
5 in the 20<sup>th</sup> century many physicians had a conservative approach to exercise in  
6 patients with CIRDs, a consensus has now emerged that exercise and sports  
7 activities are helpful in the short- and long-term management of disease, which is  
8 reflected in current practice guidelines [23, 24].

9 The study has a number of limitations that should be considered when interpreting  
10 the results. Firstly, participation of rheumatologists was voluntary and not  
11 remunerated, and physicians with a hospital practice were over-represented. This  
12 may have influenced the representativeness of the patient sample included.  
13 However, the age and gender distributions of enrolled patients were similar to those  
14 of the overall RA [25] or axSpA [26] populations. Nevertheless, the proportion of  
15 patients in this study who were undergoing treatment with biological DMARDs was  
16 much higher than national figures (75%, versus 14% of all French RA patients [25]  
17 and 26% of all axSpA patients [26]). Another factor to be considered in  
18 interpretation of these data relates to the choice of the cut-off value for the  
19 identification of 'strongly held' beliefs ( $\geq 7$  on the VAS). This choice was purely  
20 empirical and, in the absence of any known disease characteristic with which these  
21 beliefs are correlated, we do not believe that it is realistic to attempt any  
22 psychometric calibration of the VAS. Use of a threshold lower than 7 would clearly  
23 generate higher percentages of 'believers'. Finally, it is important to note that the  
24 items of the QuAD were derived from a qualitative survey of French patients [11]. It  
25 is possible that patients in other countries or cultures would have different concerns  
26 [27, 28], which would be interesting to evaluate in future studies.

1 We believe that exploring patient beliefs about disease and treatment with a  
2 questionnaire such as the QuAD is useful for the physician in several ways; for  
3 example, to facilitate dialogue with the patient and to help patients understand their  
4 disease and form realistic treatment expectations. In particular, we believe that  
5 physicians should discuss lifestyle beliefs with their patients in order to dissipate  
6 unwarranted concerns and unfounded beliefs, and to encourage the adoption of  
7 healthy lifestyles. Facilitating physician-patient dialogue in this way would be  
8 expected to improve the overall quality of care, and to encourage the patient to  
9 become an active partner in setting and achieving treatment goals. In addition, the  
10 questionnaire may be a useful component of therapeutic education programs for  
11 structuring debate about disease perceptions. Finally, patients may feel that their  
12 perceptions and concerns about their disease are not considered important or  
13 discussed by their physician, and the availability of the QuAD might help to address  
14 this need. At a population level, the questionnaire could also describe shifts in beliefs  
15 over time (following awareness campaigns, for example).

16 In conclusion, it is important to understand and discuss patients' beliefs about  
17 inflammatory rheumatic diseases in order to optimize the quality of care. The QuAD  
18 provides a simple tool to help achieve this, and merits further assessment.

## 19 **ETHICAL STATEMENT**

20 The study was performed in accordance with Good Epidemiological Practice [14] and  
21 relevant French guidelines for patient surveys. Verbal informed consent was obtained  
22 from all participating patients. The study protocol was considered by the Ethics  
23 Committee of the St Antoine Hospital, Paris, to be both ethical and outside the scope  
24 of French legislation restricting biomedical research (session of 7<sup>th</sup> October 2014).

25 The study was also declared to the National Advisory Committee on Medical

1 Research Information (CCTIRS) and the French national data protection agency  
2 (CNIL).

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- 13

1 **TABLES**

2

3 **Table 1** Patient characteristics

	RA [n= 432]	axSpA [n= 240]	TOTAL [N=672]
Age (years)	58.3 (13.1)	47.0 (13.2)	54.2 (14.2)
Gender (Women, %)	276 (74.0%)	94 (45.2%)	370 (63.7%)
Professional activity			
In employment	162 (38.2%)	167 (70.5%)	329 (49.8%)
Retired	201 (47.4%)	30 (12.7%)	231 (34.9%)
Other	61 (14.4%)	40 (16.8%)	101 (15.3%)
Education level			
Primary	77 (18.0%)	11 (4.6%)	88 (13.3%)
Secondary	219 (51.3%)	134 (56.3%)	353 (53.1%)
Tertiary (post-high school)	131 (30.7%)	93 (39.1%)	224 (33.7%)
Disease duration (years)	13.1 (11.4)	13.8 (10.6)	13.4 (11.1)
Disease activity			
DAS28(ESR)	2.6 (1.2)	-	-
BASDAI	-	3.3 (2.2)	-
Physician global assessment (0–10)	2.75 (2.12)	3.44 (2.41)	3.00 (2.25)
Patient global assessment (0–10)	3.03 (2.45)	4.27 (2.61)	3.48 (2.58)
Treatments			
Corticosteroids alone	6 (1.8%)	-	6 (1.1%)
NSAIDs alone	-	36 (15.1%)	36 (6.4%)
Synthetic DMARDs ± corticosteroids/ NSAIDs	61 (18.7%)	15 (6.3%)	76 (13.5%)
Biological DMARDs (alone or in combination)	252 (77.3%)	173 (72.7%)	425 (75.4%)
Other	2 (0.6%)	7 (2.9%)	9 (0.7%)

4 Data are presented as mean values (standard deviation) for continuous variables, and as  
5 frequency counts (%) for categorical variables. Data were missing for some patients for all  
6 variables. axSpA: axial spondyloarthritis; BASDAI: Bath Ankylosing Spondylitis Disease Activity  
7 Index; DAS28(ESR): 28-item disease activity score measured with erythrocyte sedimentation  
8 rate; DMARD: disease-modifying anti-rheumatic drug; NSAID: non-steroidal anti-  
9 inflammatory drug; RA: rheumatoid arthritis.

10



1 **Table 2** The QuAD questionnaire and mean scores for each item in patients with RA  
 2 or axSpA

QuAD Item		RA n=432	axSpA n=240	TOTAL N=672
	<b>Psychological factors</b>			
P1	I think that my disease was triggered by an emotional shock. (A difficult or stressful period in my life).	5.1 (3.9)	3.6 (3.8)	4.6 (3.9)
P2	I think that flare-ups of my disease are triggered by psychological factors (stress, upset, low morale, etc.).	4.6 (3.5)	4.7 (3.3)	4.7 (3.4)
	<b>Genetic factors</b>			
G1	I think that my disease has a genetic cause.	4.0 (3.6)	6.6 (3.5)	5.0 (3.8)
G2	I am afraid of passing my disease on to my children.	4.7 (4.1)	6.8 (3.7)	5.5 (4.1)
	<b>Physical activity</b>			
F1	I think that my disease was triggered by physical overload.	2.9 (3.3)	3.1 (3.3)	3.0 (3.3)
F2	I think that flare-ups of my disease are triggered by physical effort.	4.2 (3.5)	5.4 (3.2)	4.6 (3.4)
F3	I think that my flare-ups are triggered by bad posture or staying in the same position for too long.	3.2 (3.3)	5.7 (3.3)	4.1 (3.5)
F4	I think that doing sport or a physical activity reduces my flare-ups.	4.5 (3.3)	5.9 (3.0)	5.0 (3.3)
	<b>Diet</b>			
D1	I think that my disease may have been triggered by what I ate.	1.3 (2.3)	1.3 (2.3)	1.3 (2.3)
D2	I think that drinking alcohol (even moderately) triggered my disease.	0.7 (1.7)	0.5 (1.4)	0.7 (1.6)
D3	I think that eating certain foods triggers my flare-ups.	2.1 (2.9)	2.0 (2.7)	2.0 (2.8)
D4	I think that eating certain foods reduces my flare-ups.	2.2 (3.0)	1.9 (2.7)	2.1 (2.9)
	<b>Other lifestyle factors</b>			
O1	I think that my flare-ups are triggered by fatigue.	4.9 (3.4)	5.8 (3.1)	5.2 (3.3)
O2	I think that smoking (even moderately) or being exposed to passive smoking triggered my disease.	1.5 (2.5)	1.0 (1.8)	1.3 (2.3)
O3	I think that my disease was triggered by something in the environment, like pollution.	1.6 (2.5)	1.3 (2.4)	1.5 (2.5)
	<b>Miscellaneous</b>			
M1	I think that my flare-ups are triggered by a change in the weather.	4.3 (3.4)	5.1 (3.4)	4.6 (3.4)
M2	I think that my disease was triggered by a vaccination.	1.4 (2.7)	1.3 (2.7)	1.3 (2.7)
M3	I think that my disease was triggered by an infection.	1.7 (2.7)	1.7 (2.7)	1.7 (2.7)
M4	I think that some types of alternative medicine (osteopathy, acupuncture, sophrology, homeopathy, etc.) reduce my flare-ups.	3.5 (3.4)	3.8 (3.3)	3.6 (3.3)
M5	I think that all treatments have negative effects in the long term.	4.9 (3.5)	5.4 (3.1)	5.1 (3.4)
M6	I don't know how my disease will progress (and that worries me).	5.9 (3.2)	7.0 (3.1)	6.3 (3.2)

3 Scores are presented as mean scores (standard deviation) on a scale from 0–10, where 10  
 4 indicates full agreement. axSpA: axial spondyloarthritis; QuAD: Questionnaire for Arthritis  
 5 Dialogue; RA: rheumatoid arthritis.

- 1 **Table 3** Principal associations between patient variables and strongly held beliefs
- 2 (QuAD score  $\geq 7$ )

	QuAD Item	Patient variable	Reference		OR [95% CI]
F4	Physical activity reduces flares	Diagnosis	RA	axSpA	2.15 [1.50–3.08]
O2	Disease caused by smoking	Diagnosis	RA	axSpA	0.60 [0.36–0.96]
D4	Certain foods reduce flares	Gender	Men	Women	2.22 [1.18–4.20]
F1	Disease caused by physical overload	Education	Higher	High school	2.14 [1.30–3.53]
F4	Physical activity reduces flares	Education	Higher	High school	0.42 [0.29–0.60]
O2	Disease caused by smoking	Social deprivation	Not deprived	Deprived	2.04 [1.15–3.62]
D2	Disease caused by alcohol	Social deprivation	Not deprived	Deprived	4.18 [1.19–14.6]
F1	Disease caused by physical overload	Anxiety	HADS-A $\leq 8$	HADS-A $> 10$	2.87 [1.67–4.92]
F2	Flares triggered by physical effort	Anxiety	HADS-A $\leq 8$	HADS-A $> 10$	1.59 [1.03–2.45]
F4	Physical activity reduces flares	Depression	HADS-D $\leq 8$	HADS-D $> 18$	0.58 [0.38–0.88]
F2	Flares triggered by physical effort	Depression	HADS-D $\leq 8$	HADS-D $> 8$	1.49 [1.00–2.23]
F2	Flares triggered by physical effort	Helplessness	AHI $< 20$	AHI $\geq 20$	1.77 [1.23–2.54]
O3	Disease caused by environmental factor	Helplessness	AHI $< 20$	AHI $\geq 20$	2.93 [1.38–6.18]

- 3 The codes for the questionnaire items correspond to those listed in **Table 2**. Data are
- 4 presented as odds ratios (OR) with 95% confidence intervals (CI). AHI: Arthritis Helplessness
- 5 Index; axSpA: axial spondyloarthritis; HADS: Hospital Anxiety and Depression Scale; QuAD:
- 6 Questionnaire for Arthritis Dialogue; RA: rheumatoid arthritis.

7

1 **FIGURE LEGENDS**

2 **Fig. 1** Proportion of patients with strongly held beliefs (QuAD score  $\geq 7$ )

3 The codes for the questionnaire items correspond to those listed in **Table 2**.

4 □: patients with RA (n=432); ■: patients with axSpA (n=240).

5 QuAD: Questionnaire for Arthritis Dialogue.