The Journal of Rheumatology 2020;47:xxxx
doi:10.3899/jrheum.191353
First Release October 1 2020

The Journal of Rheumatology

Do Illness Perceptions and Coping Strategies Change Over Time in Patients Recently Diagnosed With Axial Spondyloarthritis?

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ABSTRACT. ***Objective.*** It is unknown if in axial spondyloarthritis (axSpA) patients' illness perceptions and coping strategies change when disease activity changes.

Methods. Patients diagnosed with axSpA and with 1 or more follow-up visits (1 and/or 2 yrs in the SPACE cohort) were included. Mixed linear models were used for illness perceptions (range 1–5), coping (range 1–4), back pain (numeric rating scale range 0–10), health-related quality of life (range 0–100), physical and mental component summary (PCS and MCS; range 0–100), work productivity loss (WPL; range 0–100), and activity impairment (AI; range 0–100%), separately, to test if they changed over time.

Results. At baseline, 150 axSpA patients (mean age 30.4 yrs, 51% female, 65% HLA-B27+) had a mean (SD) numeric rating scale back pain of 4.0 (2.5), PCS of 28.8 (14.0), MCS of 47.8 (12.4), WPL of 34.1% (29.8), and AI of 38.7% (27.9). Over 2 years, clinically and statistically significant improvements were seen in the proportion of patients with an Ankylosing Spondylitis Disease Activity Score (ASDAS) of low disease activity (from 39% at baseline to 68% at 2 years), back pain (−1.5, SD 2.2), AI (−14.4%, SD 27.2), PCS (11.1, SD 13.3), and WPL (−15.3%, SD 28.7), but MCS did not change (0.7, SD 13.9; $P = 0.201$). In contrast, illness perceptions and coping strategies did not change over a period of 2 years. For example, at 2 years patients believed that their illness had severe "consequences" (2.8, SD 0.9) and they had negative emotions (e.g., feeling upset or fear) towards their illness ["emotional representation", 2.5 (0.8)]. Patients most often coped with their pain by putting pain into perspective ["comforting cognitions", 2.8 (0.6)] and tended to cope with limitations by being optimistic ["optimism", 2.9 (0.7)].

Conclusion. While back pain, disease activity, and health outcomes clearly improved over 2 years, illness perceptions and coping strategies remained remarkably stable.

Key Indexing Terms: back pain, illness behavior, quality of life, spondyloarthritis, work performance

We have previously shown that in patients with chronic back pain, including that caused by axial spondyloarthritis (axSpA), negative illness perceptions had a substantial effect on the relationship between reported back pain intensity and more generic health outcomes[1]. Illness perceptions are patient-formulated beliefs about their illness, and may help them better understand their illness, but they also reflect the patient's emotional state[2]. In this study, a similar intensity of back pain was associated with more impairment in health-related quality of life (HRQOL) and more work productivity loss (WPL) when patients had negative illness perceptions such as a belief in severe "consequences" of their illness, beliefs in "chance" (or bad luck) as the cause of their back pain, and negative emotions around their back pain ("emotional representation")[1]. We further found that certain coping strategies (i.e., decreasing physical activities and adapting the level of activities following back pain) had a negative influence on the effect of back pain on HRQOL[1]. Coping strategies include cognitive and behavioral strategies that help patients to better manage the stress associated with having to live with an illness. Choices for coping strategies are determined by illness perceptions. Coping strategies could, for example, help in reducing, mastering, minimizing, or tolerating pain[2].

Therefore, the results of our previous study demonstrated that health outcomes are also determined by illness perceptions and not only by biomedical factors such as inflammation. This leaves open the option that health outcomes in patients with axSpA can be improved by influencing illness perceptions in a positive manner and possibly by interfering with coping strategy

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Accepted for publication April 24, 2020.

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choices. In this regard, it is unknown if illness perceptions and coping strategies remain stable over time, especially if disease activity improves, as literature reports conflicting results among patients with other rheumatic diseases[3,4,5]. Moreover, it is not well investigated if a decrease in disease activity is associated with an adjustment of illness perceptions and a change in the use of certain coping strategies.

One longitudinal study has investigated coping strategies over time in patients with radiographic axSpA (r-axSpA) and only slight changes in coping strategies were found over a 4-year time period; these changes were not related to changes in pain or physical functioning[6]. While this particular study investigated patients with longstanding disease and r-axSpA only, it is possible that patients' illness perceptions and coping strategies are more susceptible to change in an early phase of a disease, as over time patients receive more information about their disease, gain more experience with their disease, and understand their disease better[7].

A first step in investigating this hypothesis is to assess if illness perceptions and usage of particular coping strategies in patients with axSpA are susceptible to change when disease activity changes. We have explored this question in patients with axSpA in the SPondyloArthritis Caught Early (SPACE) cohort, during the first 2 years after the diagnosis was received[8].

MATERIALS AND METHODS

Patients included in the SPACE cohort with data at baseline and at 1- and/or 2-year follow-up visits between January 2009 and August 2018 were included. An extensive description of the SPACE cohort is available elsewhere[8]. In brief, the SPACE cohort is an ongoing multicenter inception cohort of patients with chronic back pain ≥ 3 months and ≤ 2 years, and an onset before 45 years of age. Patients from the Netherlands, Norway, and Italy were included. Local medical ethics committees provided approval for the study (Medical Ethical Committee Leiden University Medical Center: P08.105; Regional Committee for Medical and Health Research Ethics in South-East Norway: 2014/426; and Azienda Ospedaliera di Padova: 2438P) and informed consent was obtained from all study participants before inclusion. The study was performed in accordance with the Declaration of Helsinki.

A fixed diagnostic investigation according to protocol was performed for all patients at baseline, 1 year, and 2 years. This investigation consisted of medical history, physical examination, laboratory assessments, imaging, and questionnaires. The clinical diagnosis was provided by treating rheumatologists based on clinical findings and local reading of imaging. Only patients who received an axSpA diagnosis with a level of confidence regarding the diagnosis of ≥ 7 from the treating rheumatologist at baseline were included in the analysis. We did not invite patients to comment on study design or interpretation of the results. Patients were not invited to contribute to the writing or editing of this manuscript for readability or accuracy.

Patients were asked to report their back pain intensity in the past 7 days on a numeric rating scale (NRS) ranging from 0 (no pain) to 10 (unbearable pain). Illness perceptions were assessed with the Revised Illness Perception Questionnaire (IPQ-R), which covers 8 dimensions (Table 1)[9,10]. Likert scales were used to score all items of each dimension ranging from 1 (strongly disagree) to 5 (strongly agree), except "identity", which ranges from 0–15. Higher scores in the "consequences" dimension indicate stronger beliefs in the negative effect of the illness by the patient on their life. Higher scores in the "acute/chronic timeline" or "cyclical timeline" dimensions indicate stronger beliefs that the illness is chronic or cyclical, respectively. When patients have high scores in the "personal control" or "treatment control" dimensions, they feel that they have more personal control over the illness or they think that the prescribed treatment of their illness is effective. Patients with high scores on "illness coherence" feel that they understand their illness, whereas patients with high scores in the "emotional representation" dimension have more negative emotions such as fear, anger, or depressive feelings towards their illness. Higher scores on the dimensions representing possible causes ("psychological attributions," "risk factors," "immunity," "accident," and "chance") indicate that a patient has strong beliefs that a certain factor such as genes or an accident is the cause of their illness[10].

A particular illness perception may have a negative, positive, or mixed effect on health outcomes depending on the coping strategies that were used[7]. The combination of illness perceptions and coping strategies are numerous, which makes the interpretation of a single illness perception or coping strategy difficult. However, in general, it is assumed that strong beliefs in severe "consequences," attributing many symptoms to an illness ("illness identity"), strong beliefs that the disease is chronic ("timeline acute/chronic"), and having negative emotions towards an illness ("emotional representation") are associated with a worse health outcome. A feeling of control over the illness ("personal control" and "treatment control") and having a better understanding of the illness ("illness coherence") are associated with better health outcomes[11]. The mean scores of each subscale of the IPQ-R were analyzed as no aggregated score of the IPQ-R is available.

The Coping with Rheumatic Stressors (CORS) questionnaire measures coping strategies used by patients and addresses the most important stressors of rheumatic diseases, namely pain, limitations, and dependence (Table 1)[12,13]. Coping with pain is addressed by "comforting cognitions," "decreasing activities," and "diverting attention". "Optimism," "pacing," and "creative solution seeking" are covered by coping with limitations. Coping strategies that reflect coping with dependence are "accepting" and "showing consideration." All items of each coping strategy were scored on Likert scales ranging from 1 (never/seldom used) to 4 (very often used). Frequent use of a particular coping strategy is indicated by higher scores. Interpretation of a single coping strategy is difficult and rarely investigated but frequent use of "decreasing activities" for coping with pain or adapting the level of activity ("pacing") for coping with limitations seem to be associated with worse health outcomes in rheumatic diseases[1,14,15,16]. Other coping strategies described by the CORS were thus far not found to be associated with health outcomes in the literature. For each subscale of the CORS, mean scores were analyzed, as no aggregated score is available for the CORS questionnaire.

It was assumed that measuring the effect of axSpA on generic QOL, on work productivity, and on the participation in daily activities provides insight into the total burden of axSpA. The Medical Outcomes Study 36-item Short Form survey (SF-36) was used to assess HRQOL[17]. The 8 subscale scores were recoded, recalibrated, and transformed into scale scores ranging from 0 (worst health) to 100 (best health). Age- and sex-matched scores of each country were used to weight the scores. No Italian age- and sex-matched scores were available, therefore Dutch weighted scores were used for these patients[18,19]. The SF-36 physical component summary (PCS) and mental component summary (MCS) scores were calculated, converted, and compared to the general population mean score of 50. Better HRQOL is indicated by higher PCS and MCS[20].

The Work Productivity and Activity Impairment questionnaire (WPAI) was used to assess work productivity. As the SPACE cohort contains both patients with and without a diagnosis of axSpA, WPAI general health version 1.0 was used and not the SpA disease-specific version. Patients were asked to fill out questions about the number of hours actually worked, number of missed working hours due to axSpA, number of missed working hours due to other reasons (e.g., holidays), and the effect of axSpA on work productivity and daily activities, on an NRS from 0 (health problems had

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Table 1. Overview of illness perceptions and coping strategies measured by the IPQ-R and CORS questionnaires[9,10,12,13].

Label/Dimension	Explanation	Example
Illness perceptions		
Identity	The totality of experienced symptoms that the patient attributes to his/her illness	Symptoms as "pain" or "fatigue"
Consequences	Perceived effect of the illness on the patient's life	"My illness has major consequences on my life"
Acute/chronic timeline	Perceived likeliness of chronicity of the illness	"My illness is likely to be permanent/chronic rather than temporary"
Personal control	Perceived personal control over the illness	"There is a lot which I can do to control my symptoms"
Treatment control	Perceived efficacy of treatment	"My treatment will be effective in curing my illness"
Illness coherence	Extent to which the patient feels he/she understands the illness	"My illness is a mystery to me"
Cyclical timeline	Patient's perceptions of variability of the illness	"My symptoms come and go in cycles"
Emotional representation	Experienced negative emotions due to the illness	"When I think about my illness I get upset/angry/afraid"
Illness perceptions (causative)		
Psychological attributions	Believing that psychological attributions are a possible cause for the illness	"Stress/worry or my mental attitude (e.g., thinking about life negatively)"
Risk factors	Believing that risk factors are a possible cause for the illness	"Hereditary–it runs in my family"
Immunity	Believing that immunity is a possible cause for the illness	"A germ or virus"
Accident	Believing that accident is a possible cause for the illness	"Accident or injury"
Chance	Believing that chance is a possible cause for the illness	"Chance or bad luck"
Coping with pain		
Comforting cognitions	Coping with pain by putting pain in perspective	"I think the pain will decrease in time"
Decreasing activities	Coping with pain by decreasing activities	"I stop my activities"
Diverting attention	Coping with pain by thinking about/focusing on something else	"I think of pleasant things"
Coping with limitations		
Optimism	Coping with limitations by being optimistic	"I try to be optimistic"
Pacing	Coping with limitations by adapting/lowering the level of activity	"I take more time for my activities"
Creative solution seeking	Coping with limitations by searching for creative solutions to cope with limitations in daily life	"I try to find new ways of getting things done"
Coping with dependency		
Accepting	Coping with dependence by making efforts to accept the level of dependence	"I accept my dependence on other people"
Showing consideration	Coping with dependence by considering other people's feelings	"I try not to ask too much from any one person"

CORS: Coping with Rheumatic Stressors; IPQ-R: Revised Illness Perception Questionnaire.

no effect on work) to 10 (health problems completely prevented working) in the past 7 days. WPL (i.e., total work impairment due to axSpA) and activity impairment (i.e., total effect of axSpA on daily activities) summary scores were calculated on a scale from 0% (no work productivity loss/activity impairment) to 100% (total work productivity loss/activity impairment). Higher percentages indicate greater impairment[21].

Statistical analysis. Continuous variables were presented as mean (SD) and categorical variables as number (frequencies). Mixed linear models with a random intercept and including time as a single continuous variable were run to investigate if each illness perception and coping strategy changed over 2 years, taking into account the correlation between visits within patients and to handle possible missing timepoints. Median age and sex were tested for effect modification in order to assess if illness perceptions and coping strategies differ between age subgroups and between women and men. Results were stratified for sex and age (median) when the interaction term was statistically significant ($P < 0.10$). $P < 0.10$ is a frequently used P value to test the effect of interactions so as to not miss a relevant effect modification. $P < 0.002$ ($P < 0.05/21$), corrected for multiple testing (i.e., 21 effects: 13 illness perceptions + 8 coping strategies) of illness perceptions and coping strategies were considered to be statistically significant. Back pain, HRQOL, WPL, and activity impairment were also assessed for change over time by mixed linear models. Stata SE V.14 (Statacorp.) was used for data analysis.

RESULTS

Data at baseline and at least 1 follow-up visit at 1 year or 2 years were available for 193 axSpA patients. Forty-three patients were excluded from the analyses as they did not complete all questionnaires (IPQ-R n = 16, CORS n = 27). Of the 150 remaining patients, 94 had data on all visits, 36 had data at baseline and 1 year, and 20 had data at baseline and 2 years.

At baseline, patients had a mean (SD) age of 30.4 years (7.9), a mean symptom duration of 13.2 (6.9) months, approximately half of patients were female (51%), 65% of the patients were HLA-B27–positive, 27% had radiographic sacroiliitis, and

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Table 2. Baseline characteristics of axSpA patients in the SPACE cohort.

	All Patients n = 150	Patients With 2 Follow-Up Visits n = 94	Patients With 1 Follow-Up Visit n = 56
Age, yrs, mean (SD)	30.4 (7.9)	30.0 (7.9)	31.2 (7.7)
Female	77 (51)	48 (51)	29 (52)
Symptom duration, mos, mean (SD)	13.2 (6.9)	13.7 (6.7)	12.4 (7.0)
IBP	107 (71)	65 (69)	42 (75)
Good response to NSAID[a]	73 (49)	47 (51)	26 (46)
Uveitis	23 (15)	14 (15)	1 (16)
Psoriasis	35 (23)	22 (23)	13 (23)
IBD	14 (9)	8 (9)	6 (11)
Positive family history	71 (47)	41 (44)	30 (54)
Enthesitis (heel)	62 (41)	49 (52)	13 (23)
Dactylitis	23 (15)	18 (15)	5 (9)
Peripheral arthritis	43 (29)	30 (32)	13 (23)
HLA-B27 positivity	97 (65)	56 (60)	41 (75)
Elevated ESR/CRP	65 (43)	45 (48)	20 (36)
Sacroiliitis on radiographs (local)	40/148 (27)	25/93 (27)	15/55 (27)
Sacroiliitis on MRI (local)	94/147 (64)	62/92 (67)	32/55 (58)
Use of NSAID	119 (79)	76 (81)	43 (78)
Use of bDMARD	5 (3)	5 (3)	0 (0)
No. SpA features[b], mean (SD)	3.4 (1.7)	3.6 (1.8)	3.2 (1.6)

Values are presented as n (%) unless stated otherwise. [a] Back pain not present anymore or is much better 24–48 h after a full dose of NSAID. [b] Excluding imaging and HLA-B27 positivity. axSpA: axial spondyloarthritis; bDMARD: biologic disease-modifying antirheumatic drug; CRP: C-reactive protein; ESR: erythrocyte sedimentation rate; IBD: inflammatory bowel disease; IBP: inflammatory back pain; MRI: magnetic resonance imaging; NSAID: nonsteroidal antiinflammatory drug; SpA: spondyloarthritis; SPACE: SPondyloArthritis Caught Early.

Table 3. Health outcomes over time in axSpA patients in the SPACE cohort.

	Range	Baseline n = 150	Year 1 n = 130	Year 2 n = 114	Change per Year B (95% CI)
Back pain	0–10	4.0 (2.5)	3.1 (2.4)	2.5 (2.2)	**–0.8 (–1.0 to –0.5)**
PCS	0–100	28.8 (14.0)	36.4 (14.3)	39.4 (12.4)	**5.4 (4.2 to 6.6)**
MCS	0–100	46.6 (13.6)	47.9 (12.0)	47.8 (12.3)	0.7 (–0.4 to 1.7)
WPL[a]	0–100	34.1 (29.8)	23.5 (27.1)	19.7 (24.1)	**–7.5 (–10.5 to –4.5)**
Activity impairment	0–100	38.7 (27.9)	27.6 (25.9)	24.0 (23.1)	**–7.4 (–9.7 to –5.2)**

Values are presented as mean (SD). Statistically significant results are printed in bold ($P < 0.05$). [a] Only patients who were employed at a timepoint are described (baseline n = 111; 1 year n = 103; 2 years n = 94). axSpA: axial spondyloarthritis; MCS: mental component summary; PCS: physical component summary; SPACE: SPondyloArthritis Caught Early; WPL: work productivity loss.

64% had sacroiliitis on magnetic resonance imaging (Table 2). Baseline characteristics were similar for patients with 1 or 2 follow-up visits.

Baseline mean back pain (SD) was 4.0 (2.5), PCS was 28.8 (14.0), MCS was 46.6 (13.6), WPL was 34.1% (29.8), and activity impairment was 38.7% (27.9; Table 3). Over 2 years, back pain [mean change –1.5 (2.2)] and activity impairment [–14.4% (27.2)] decreased clinically and statistically significantly, PCS [11.1 (13.3)] and WPL (–15.3% (28.7)] improved clinically and statistically significantly, while MCS did not change [0.7 (13.9)]. At baseline, 39% of the patients had an Ankylosing Spondylitis Disease Activity Score (ASDAS) of < 2.1 and at 2 years, 68% of the patients had an ASDAS of < 2.1, reflecting a state of low disease activity.

Sex was found to be an effect modifier for the illness perception "accident" (interaction term $P = 0.015$), for coping strategies "pacing" ($P = 0.004$) and "creative solution seeking" ($P = 0.004$), and median age was an effect modifier for illness perceptions "identity" ($P = 0.090$) and "acute/chronic timeline" ($P = 0.077$), indicating that these illness perceptions and coping strategies differ between sex and age subgroups. Therefore, results were stratified for these factors (Table 4) and only small changes were found between these subgroups.

In contrast to disease activity variables, illness perceptions,

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Table 4. Illness perceptions and coping over time in axSpA patients with baseline and/or 1- or 2-year data (n = 150).

		Baseline	Year 1	Year 2	Change per Year
Illness perceptions	Range	n =150	n = 130	n = 114	B (95%CI)
Identity	0–15				
Age < 29 yrs		4.6 (2.3)	4.6 (2.5)	4.1 (2.0)	−0.3 (−0.5 to 0.02)
Age ≥ 29 yrs		4.9 (2.6)	5.3 (2.8)	5.1 (2.7)	0.09 (−0.2 to 0.4)
Consequences	1–5	2.9 (0.7)	2.8 (0.8)	2.8 (0.9)	−0.09 (−0.2 to −0.03)
Timeline (acute/chronic)	1–5				
Age < 29 yrs		3.7 (0.8)	3.7 (0.8)	3.7 (0.8)	0.05 (−0.06 to 0.2)
Age ≥ 29 yrs		3.6 (0.8)	3.8 (0.8)	4.0 (0.7)	**0.2 (0.08 to 0.3)**
Personal control	1–5	3.3 (0.6)	3.3 (0.6)	3.4 (0.6)	0.06 (0.008 to 0.1)
Treatment control	1–5	3.5 (0.5)	3.4 (0.6)	3.5 (0.6)	0.01 (−0.04 to 0.07)
Illness coherence	1–5	3.3 (0.8)	3.5 (0.8)	3.6 (0.7)	**0.2 (0.1 to 0.2)**
Timeline (cyclical)	1–5	3.6 (0.8)	3.6 (0.8)	3.6 (0.8)	−0.04 (−0.1 to 0.04)
Emotional representation	1–5	2.7 (0.8)	2.6 (0.8)	2.5 (0.8)	**−0.1 (−0.2 to −0.08)**
Possible causes for illness					
Psychological attributions	1–5	2.1 (0.9)	2.1 (0.9)	2.1 (0.9)	−0.005 (−0.06 to 0.05)
Risk factors	1–5	2.2 (0.6)	2.2 (0.6)	2.1 (0.6)	−0.01 (−0.06 to 0.03)
Immunity	1–5	2.3 (0.8)	2.4 (0.9)	2.3 (0.9)	−0.03 (−0.1 to 0.04)
Accident	1–5				
Male		2.3 (1.2)	2.1 (1.1)	2.0 (1.1)	−0.2 (−0.3 to −0.04)
Female		1.8 (1.0)	2.1 (1.2)	1.9 (1.1)	0.07 (−0.07 to 0.2)
Chance	1–5	3.3 (1.2)	3.2 (1.2)	3.3 (1.2)	−0.02 (−0.1 to 0.08)
Coping strategies					
Coping with pain					
Comforting cognitions	1–4	2.8 (0.6)	2.9 (0.6)	2.8 (0.6)	0.01 (−0.04 to 0.06)
Decreasing activities	1–4	2.1 (0.6)	2.1 (0.6)	2.0 (0.6)	−0.05 (−0.1 to −0.008)
Diverting attention	1–4	2.3 (0.6)	2.4 (0.6)	2.4 (0.6)	0.03 (−0.02 to 0.07)
Coping with limitations					
Optimism	1–4	2.8 (0.7)	2.9 (0.7)	2.9 (0.7)	0.08 (0.02 to 0.1)
Pacing	1–4				
Male		2.1 (0.6)	2.1 (0.6)	2.0 (0.6)	−0.05 (−0.1 to 0.006)
Female		2.2 (0.6)	2.3 (0.6)	2.4 (0.6)	0.08 (0.007 to 0.2)
Creative solution seeking	1–4				
Male		2.3 (0.6)	2.4 (0.6)	2.3 (0.07)	0.01 (−0.05 to 0.07)
Female		2.3 (0.6)	2.4 (0.6)	2.6 (0.06)	**0.1 (0.07 to 0.2)**
Coping with dependency					
Accepting	1–4	1.8 (0.6)	1.8 (0.6)	1.7 (0.6)	−0.03 (−0.09 to 0.02)
Consideration	1–4	2.7 (0.6)	2.7 (0.6)	2.7 (0.6)	0.004 (−0.05 to 0.06)

Values are presented as mean (SD) unless stated otherwise. Changes in illness perceptions and coping strategies were considered to be statistically significant and printed in bold when $P < 0.002$ ($P < 0.05/21$, correction for multiple testing). axSpA: axial spondyloarthritis.

and coping strategies showed minimal changes over time (Table 4). For example, after 2 years patients still had strong beliefs in severe consequences ["consequences", mean (SD) 2.8 (0.9)], still had strongly negative emotions towards their illness ["emotional representation", 2.5 (0.8)], and still had strong beliefs in chance/bad luck ["chance", 3.3 (1.2)] as being the cause for axSpA.

Patients most often coped with pain by putting pain into perspective ["comforting cognitions", mean 2.8 (0.6)], most often coped with limitations by trying to be optimistic ["optimism", mean 2.9, (0.7)], and most often coped with dependence on other people by considering the feelings of these people ["consideration", mean 2.7, (0.6)] after 2 years. Similar results were found for patients with 1 or 2 follow-up visits (data not shown).

DISCUSSION

Over 2 years, back pain intensity decreased over time, HRQOL improved, and WPL and activity impairment decreased. However, patients' illness perceptions and coping strategies proved to be remarkably stable. Female and male patients, and younger and older patients did not differ markedly in this regard. As illness perceptions did not change over time, patients continued to have illness perceptions that had a negative effect on the association between back pain and health outcomes, as shown in the previous study[1].

It is often assumed that in the first period after a diagnosis changes, illness perceptions may take place and during a late phase of the disease, it might be more difficult to change illness perceptions[22,23]. Hagger, *et al*[7] also hypothesized that illness

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perceptions and coping strategies change between an early and late disease phase. It is thought that patients in an early disease phase perceive an illness as a health threat. Patients therefore form illness perceptions that are reflecting a negative emotional state (e.g., having strong beliefs in "consequences" and having strong negative emotions toward their illness "emotional representation"), which may lead to more passive coping strategies. Over time, through patients' experience with their disease and with treatment, they form other illness perceptions such as more "illness coherence" (understanding their illness better), which may lead to more active coping strategies[7].

Others believe that illness perceptions are already formed before patients are seen by a physician. In fact, one of the consequences of forming these illness perceptions is seeking care. The medical information that patients receive from their physicians will be assessed in the context of previously gathered information and integrated in such a way that it fits into a patient's view of life[24]. This in turn suggests that once formed, illness perceptions and chosen coping strategies are less susceptible to change when patients are seeking care from their physician.

These theories are contradicting and unfortunately data on illness perceptions and coping strategies in axSpA are scarce. The only longitudinal study among patients with longstanding r-axSpA suggested that coping strategies did change over 4 years' time[6]. However, this study only showed numerically small changes in coping strategies. For example, the mean (SD) increase in score for coping with pain by using decreasing activities was only 0.77 (4.6) on a scale from 8 to 32. Moreover, the changes in coping strategies were not related to changes in pain or physical functioning, and are compatible with the hypothesis that coping strategies are not susceptible to changes in disease status, as well as in line with our findings in a much earlier phase of the disease. Other observational studies also reported that illness perceptions and coping strategies remained relatively stable over time among patients with various diseases, including other rheumatic diseases and chronic low back pain[4,5,25,26,27,28,29,30].

In contrast, randomized controlled trials seem to suggest that illness perceptions can actually be changed. These trials showed that illness perceptions changed after being specifically targeted by an intervention such as a group education program or cognitive behavioral therapy among patients with other diseases (e.g., asthma, diabetes)[31–39]. One study in patients with myocardial infarction even claimed that by changing illness perceptions, patients could return to work sooner than the patients who did not receive the intervention[32]. Another study in chronic back pain patients also reported that patients who received an intervention (i.e., providing information based on patients' illness perceptions) changed their illness perceptions to a greater extent than patients who received usual care[40].

At this moment it remains unclear if illness perceptions and coping strategies change spontaneously or can be targeted by an intentional intervention. Further, no data are available on clinically important changes in illness perceptions or coping strategies, making it difficult to assess whether these changes are truly relevant changes.

In our current study, no clinically relevant differences in illness perceptions and coping strategies were found by sex or age, while in literature differences were found in illness perceptions and coping strategies between males and females in other diseases[41,42]. In patients with r-axSpA, older age was associated with more frequent use of "pacing" in order to cope with limitations[6]. This could not be confirmed in the current study.

In theory, contracting a disease with significant complaints and uncertain prospects may lead to a change in formerly established beliefs about that disease (reference shift). This study does not preclude that reference shift has taken place before inception, but the fact that this study included patients with very early disease, at least in the field of axSpA, makes it less likely. We have shown here that such a reference shift did not occur during the period of more intense to less intense symptoms. In the literature, contradicting theories have been described regarding when or in which phase a change in illness perceptions and coping strategies will take place.

A limitation of this study is that we were not able to investigate why illness perceptions and coping strategies remained relatively stable while back pain and health outcomes showed substantial improvements. We do not expect that the effect of illness perceptions and coping strategies differ over time, as health outcomes are still substantially affected and not comparable to the general population after 2 years, even though they have improved. This suggests that health outcomes are still under the influence of illness perceptions and coping strategies, and that health outcomes can be further improved by targeting unfavorable illness perceptions and coping strategies. A randomized controlled trial might be conducted comparing usual care with usual care plus an additional intervention targeting negative illness perceptions in order to investigate whether illness perceptions change if they are targeted, and if a change in illness perceptions is related to a change in health outcomes. It is important not only to target negative illness perceptions but also to target coping strategies, as illness perceptions are known to influence the usage of coping strategies[7].

In summary, our results suggest that illness perceptions and coping strategies are rather independent of variation (decrease) in disease status. When managing patients with axSpA, one should not only take into consideration the intensity or severity of the disease but also external traits, like illness perceptions and coping strategies, that may modify the relationships between signs and symptoms on the one hand, and long-term outcomes on the other hand. It is unclear if illness perceptions and coping strategies could be improved by specific therapeutic interventions in patients with axSpA and if an improvement in illness perceptions is associated with an improvement in health outcomes.

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