The burden of early axial spondyloarthritis

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Chapter 7

Do illness perceptions and coping strategies change over time in patients recently diagnosed with axial spondyloarthritis? A two-year follow-up study in the SPACE cohort

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Submitted

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 ≥1 follow-up visit (1 and/or 2 year(s)) in the SPACE-cohort were included. Mixed linear models were used for illness perceptions (range: 1-5), coping (range: 1-4), back pain (NRS: 0-10), health-related quality of life (HRQoL range: 0-100; (physical (PCS) and mental component summary (MCS)), work productivity loss (WPL), 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 years, 51% female, 65% HLA-B27+) had a mean (SD) VAS 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 two years, clinically and statistically significant improvements were seen in the proportion of patients with ASDAS low disease activity (from 39% to 68%), back pain (-1.5 (2.2)), AI (14.4% (27.2)), PCS (11.1 (13.3)) and WPL (-15.3% (28.7)), but MCS did not change (0.7 (13.9), p=0.201).

In contrast, illness perceptions and coping strategies did not change over a period of two years. For example, at two years patients believed that their illness had severe '*consequences*' (2.8 (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

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

INTRODUCTION

We have previously shown that in patients with chronic back pain, including chronic back pain caused by axial spondyloarthritis (axSpA), negative illness perceptions had a substantial impact on the relationship between reported back pain intensity and more generic health outcomes.[1] Illness perceptions are patient-formulated beliefs about their illness, which may help them to better understand their illness but they also reflect the emotional state of the patient.[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 when patients had negative illness perceptions such as a belief in severe '*consequences*' of their illness, beliefs in (bad) '*chance*' 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 impact of back pain on HRQoL.[1] Coping strategies are cognitive and behavioral strategies helping patients to better manage 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]

So, the results of the previous study demonstrated that health outcomes are also determined by illness perceptions and not only by biomedical factors such as inflammation. It leaves open the option that health outcomes in axSpA patients can be improved by influencing illness perceptions in a positive manner and possibly by interfering with coping strategy 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.[3-5] Moreover, it is also 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, while 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 illness perceptions and coping strategies are more susceptible to change in patients in an early phase of a disease, as over time patients receive more information about their disease, gain more experience 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 changes in disease activity. We have explored this question in patients with axSpA in the SPondyloArthritis Caught Early (SPACE)-cohort, the first two years after receiving the diagnosis.

METHODS

Patients included in the SPACE-cohort with data at baseline, one, and/or two year(s) 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 a multicentre ongoing inception cohort of patients with chronic back pain ≥3 months and ≤2 years and an onset before <45 years from the Netherlands, Norway, and Italy. 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, Azienda Ospedaliera di Padova: 2438P) and informed consent was obtained from all study participants before inclusion.

A fixed diagnostic work-up according to protocol was performed for all patients at baseline, one year, and two years. This work-up 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 involve 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 seven 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 eight dimensions, see **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 on '*consequences*' dimension indicate stronger beliefs in the negative impact of the illness by the patient on his life. Higher scores on '*acute/chronic timeline*' or '*cyclical timeline*' dimension indicate stronger beliefs that the illness is chronic or cyclical, respectively. When patients have high scores on '*personal control*' or '*treatment control*' dimension, they feel that they have (a lot) 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, while patients with high scores on '*emotional representation*' dimension have more negative emotions such as fear, angriness 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 impact on health outcomes depending on the coping strategies that were used.[7] 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; feeling a lot of control over the illness ('*personal control*' and '*treatment control*') and 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.

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 (see **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 hardly 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, 14-16] Other coping strategies described by the CORS were thus far not found to be associated with health outcomes in literature. For each subscale of the CORS mean scores were analyzed.

It was assumed that measuring the impact of axSpA on generic quality of life, on work productivity, and on the participation in daily activities provides insight in the total burden of axSpA. The 36-item Short-Form Health Survey (SF-36) was used to assess HRQoL.[17] The eight subscale scores were recoded, recalibrated and transformed into scale scores ranging from 0 (worst health) to 100 (best health). Age- and gender-matched scores of each country were used to weight the scores. No Italian age- and gender-matched scores were available, therefore Dutch weighted scores were used for these patients.[18, 19] 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), general health version 1.0, was used to assess work productivity. Patients were asked to fill out questions about the amount of actually worked hours, amount of missed working hours due to axSpA, amount of missed working hours due to other reasons (e.g. holidays), and the impact of axSpA on work productivity and daily activities on an NRS from 0 (health problems had no effect on work) to 10 (health problems completely prevented working) in the past seven days. Work productivity loss (WPL, i.e. total work impairment due to axSpA) and activity impairment (i.e. total impact 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]

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 impact 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 understand 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"*

Table 1. Continued

Label/Dimension	Explanation	Example
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.

Statistical analysis

Continuous variables were presented as mean (standard deviation (SD)) and categorical variables as number (frequencies). Mixed linear models were run to investigate if each illness perception and coping strategy changed over 2 years taking into account the correlation between visits within patients. Median age and gender were tested for effect modification. Results were stratified for gender and age (median) when the interaction term was statistically significant (p<0.10). P-values of <0.002 (p<0.05/21, corrected for multiple testing) 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, Texas, USA) was used for data analysis.

RESULTS

A baseline and at least one follow-up visit at one year or two years was 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 one year, and 20 had data at baseline and two 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, about half of patients was female (51%), 65% of the patients was HLA-B27 positive, 27% had radiographic sacroiliitis, and 64% had sacroiliitis on MRI (**Table 2**). Baseline characteristics were similar for patients with one or two 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 two years, back pain (mean change (SD) -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 ASDAS of <2.1 and at 2 years 68% of the patients had an ASDAS of <2.1, reflecting a situation of low disease activity.

Gender 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), which indicates that these illness perceptions and coping strategies differ between gender 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 parameters, illness perceptions 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)), had still strongly negative emotions towards their illness ('*emotional representation*', 2.5 (0.8)) and had still strong beliefs in (bad) chance (‘*chance*’, 3.3 (1.2)) being the cause for axSpA.

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

	All patients	**Patients with 2 follow-up visits**	**Patients with 1 follow-up visit**
Baseline characteristics	**n=150**	**n=94**	**n=56**
Age in years, mean ± SD	30.4 ± 7.9	30.0 ± 7.9	31.2 ± 7.7
Female	77 (51)	48 (51)	29 (52)
Symptom duration in months, mean ± SD	13.2 ± 6.9	13.7 ± 6.7	12.4 ± 7.0
IBP	107 (71)	65 (69)	42 (75)
Good response to NSAIDs [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 (mm)/CRP (mg/L)	65 (43)	45 (48)	20 (36)
Sacroiliitis on X-rays (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 NSAIDs	119 (79)	76 (81)	43 (78)
Use of bDMARDs	5 (3)	5 (3)	0 (0)
Number of SpA features [b]**, mean ± SD**	3.4 ± 1.7	3.6 ± 1.8	3.2 ± 1.6

Results are presented as number (%) unless stated otherwise. [a] Back pain not present anymore or is much better 24–48 hours after a full dose of NSAID. [b] Excluding imaging and HLA-B27 positivity. CRP, C-reactive protein; DMARDs, disease modifying anti-rheumatic drugs; ESR, erythrocyte sedimentation rate; HLA-B27, Human Leucocyte Antigen B27; IBD, inflammatory bowel disease; IBP, inflammatory back pain; MRI, magnetic resonance imaging; NSAIDs, Non-Steroidal Anti-inflammatory Drugs; SpA, Spondyloarthritis; X-rays, radiography.

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

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; -0.5)**
PCS	0-100	28.8 (14.0)	36.4 (14.3)	39.4 (12.4)	**5.4 (4.2; 6.6)**
MCS	0-100	46.6 (13.6)	47.9 (12.0)	47.8 (12.3)	0.7 (-0.4; 1.7)
WPL[a]	0-100	34.1 (29.8)	23.5 (27.1)	19.7 (24.1)	**-7.5 (-10.5; -4.5)**
Activity impairment	0-100	38.7 (27.9)	27.6 (25.9)	24.0 (23.1)	**-7.4 (-9.7; -5.2)**

Results are presented as mean (SD). Statistically significant results are printed in bold (p<0.05).
[a] Only patients who were employed at a time point are described; baseline n=111, 1 year n=103, 2 years n=94. PCS, Physical Component Summary; MCS, Mental Component Summary; WPL, Work Productivity Loss.

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

Illness perceptions	Range	Baseline n=150	Year 1 n=130	Year 2 n=114	Change per year B (95%CI)
Identity	0-15				
Age <29 years		4.6 (2.3)	4.6 (2.5)	4.1 (2.0)	-0.3 (-0.5; 0.02)
Age ≥29 years		4.9 (2.6)	5.3 (2.8)	5.1 (2.7)	0.09 (-0.2; 0.4)
Consequences	1-5	2.9 (0.7)	2.8 (0.8)	2.8 (0.9)	-0.09 (-0.2; -0.03)
Timeline (acute/chronic)	1-5				
Age <29 years		3.7 (0.8)	3.7 (0.8)	3.7 (0.8)	0.05 (-0.06; 0.2)
*Age ≥29 years**		3.6 (0.8)	3.8 (0.8)	4.0 (0.7)	0.2 (0.08; 0.3)
Personal control	1-5	3.3 (0.6)	3.3 (0.6)	3.4 (0.6)	0.06 (0.008; 0.1)
Treatment control	1-5	3.5 (0.5)	3.4 (0.6)	3.5 (0.6)	0.01 (-0.04; 0.07)
Illness coherence*	1-5	3.3 (0.8)	3.5 (0.8)	3.6 (0.7)	0.2 (0.1; 0.2)
Timeline (cyclical)	1-5	3.6 (0.8)	3.6 (0.8)	3.6 (0.8)	-0.04 (-0.1; 0.04)
Emotional representation*	1-5	2.7 (0.8)	2.6 (0.8)	2.5 (0.8)	-0.1 (-0.2; -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; 0.05)
Risk factors	1-5	2.2 (0.6)	2.2 (0.6)	2.1 (0.6)	-0.01 (-0.06; 0.03)
Immunity	1-5	2.3 (0.8)	2.4 (0.9)	2.3 (0.9)	-0.03 (-0.1; 0.04)
Accident	1-5				
Male		2.3 (1.2)	2.1 (1.1)	2.0 (1.1)	-0.2 (-0.3; -0.04)
Female		1.8 (1.0)	2.1 (1.2)	1.9 (1.1)	0.07 (-0.07; 0.2)
Chance	1-5	3.3 (1.2)	3.2 (1.2)	3.3 (1.2)	-0.02 (-0.1; 0.08)

Table 4. Continued

Coping strategies	Range	Baseline n=150	Year 1 n=130	Year 2 n=114	Change per year B (95%CI)
Coping with pain					
Comforting cognitions	1-4	2.8 (0.6)	2.9 (0.6)	2.8 (0.6)	0.01 (-0.04; 0.06)
Decreasing activities	1-4	2.1 (0.6)	2.1 (0.6)	2.0 (0.6)	-0.05 (-0.1; -0.008)
Diverting attention	1-4	2.3 (0.6)	2.4 (0.6)	2.4 (0.6)	0.03 (-0.02; 0.07)
Coping with limitations					
Optimism	1-4	2.8 (0.7)	2.9 (0.7)	2.9 (0.7)	0.08 (0.02; 0.1)
Pacing	1-4				
Male		2.1 (0.6)	2.1 (0.6)	2.0 (0.6)	-0.05 (-0.1; 0.006)
Female		2.2 (0.6)	2.3 (0.6)	2.4 (0.6)	0.08 (0.007; 0.2)
Creative solution seeking	1-4				
Male		2.3 (0.6)	2.4 (0.6)	2.3 (0.07)	0.01 (-0.05; 0.07)
*Female**		2.3 (0.6)	2.4 (0.6)	2.6 (0.06)	0.1 (0.07; 0.2)
Coping with dependency					
Accepting	1-4	1.8 (0.6)	1.8 (0.6)	1.7 (0.6)	-0.03 (-0.09; 0.02)
Consideration	1-4	2.7 (0.6)	2.7 (0.6)	2.7 (0.6)	0.004 (-0.05; 0.06)

Results are presented as mean (SD) unless stated otherwise. *Changes in illness perceptions and coping strategies were considered to be statistically significant when $p<0.002$ ($p<0.05/21$, correction for multiple testing).

DISCUSSION

Over two years, back pain intensity decreased over time, HRQoL improved, and WPL and activity impairment decreased. Thus, a general conclusion of improved disease activity is more than justified. However, patients' illness perceptions and coping strategies proved to be remarkably stable. Female and male patients and younger and older patients did not markedly differ in this regard. As illness perceptions did not change over time, patients remained having illness perceptions that had a negative impact 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 in 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 (2017) also hypothesized that illness 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 which are reflecting a negative emotional state (e.g. having strong beliefs in '*consequences*', and having strong negative emotions towards their illness, '*emotional representation*', which may lead to more passive coping strategies. Over time, patients gain more experience with their disease and treatment and 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 of their physician.

These theories are contradicting theories and unfortunately data on illness perceptions and coping strategies in axSpA is 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 nor in physical functioning, which is compatible with the vision that coping strategies are not susceptible for changes in disease status, and are 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, 25-30]

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. Furthermore, no data are available on clinically important changes in illness perceptions or coping strategies which makes it difficult to assess whether changes are truly relevant changes.

In the current study no clinically relevant differences in illness perceptions and coping strategies were found by gender 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, higher 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.

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 impact of illness perceptions and coping strategies differ over time, as health outcomes are still substantially impacted and not comparable to the general population after two 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 if 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 to not only target negative illness perceptions but to target also 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. 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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