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Abstract

Objective

To investigate the association between illness perceptions and disability both cross-sectionally and over two years in patients with hand osteoarthritis (OA).

Methods

Illness perceptions and self-reported disability were assessed at baseline and after two years in 384 patients with primary hand OA (mean age 61 years, 84% women, n = 312 with follow-up) with the Illness Perception Questionnaire – Revised (IPQ-R), Functional Index for Hand OA (FIHOA), Australian/Canadian Hand OA Index (AUSCAN) and Health Assessment Questionnaire (HAQ). Risk ratios for high disability (highest quartile) at both time points were estimated for tertiles of IPQ-R dimensions, using Poisson regression. The mean IPQ dimension change difference between patients with and without disability progression (change FIHOA ⩾1, AUSCAN >1.4, HAQ >0.22) was estimated with linear regression. Analyses were adjusted for age, Doyle index and baseline score.

Results

At baseline, stronger negative illness perceptions were associated with high disability. Baseline illness perceptions were also associated with high disability after two years, although adjustment made apparent that these associations were confounded by baseline disability status. Most illness perceptions changed over two years; understanding increased, OA was regarded as more chronic and fewer emotions and consequences, and less personal and treatment control, were experienced. Two-year change in disability was different between patients with and without progression for the illness perceptions of more perceived consequences, symptoms, treatment control and emotions.

Conclusion

Illness perceptions seemed to be implicated in disability and its progression. Our results suggest that interventions could focus on improving baseline disability, potentially using illness perceptions to accomplish this goal.

Introduction

Hand osteoarthritis (OA) is a common musculoskeletal disease leading to disability[1–3]. Disability has a heterogeneous course[4] and is poorly associated with structural (radiographic) measures[5–7]. This might be explained by the contribution of psychosocial factors to self-reported disability. Examples of such factors are depression, illness perceptions, coping styles and anxiety[8–10].

Knowledge about these factors aids understanding why some patients report more disability than others and how their disability will develop over time, which in turn could lead to patient-tailored interventions[11]. In the present study, we will focus on one of these factors: illness perceptions.

When patients are confronted with an illness, they build a mental model to make sense of, and manage, their health problem[12]. The 'Common Sense' Model describes this mental model by suggesting how cognitive and emotional representations and beliefs, so-called illness perceptions, influence a patient's coping, health behaviour and health outcomes (e.g., disability)[13]. In other words, illness perceptions are the thoughts and feelings of a patient about his/her illness.

Illness perceptions have been associated with disability in cross-sectional studies in patients with generalized OA, lower extremity OA and hand OA[8,10,14–16]. In short-term follow-up studies, more negative illness perceptions (e.g., more perceived consequences or more emotional representations) were associated with unfavourable clinical outcomes in patients with knee or hip OA[17,18] and in patients with other musculoskeletal conditions[19–21]. A long-term observational study in patients with generalized OA showed that increasing negative illness perceptions over time were accompanied by progression of disability[10]. Trials intervening on negative illness perceptions in patients with diabetes, heart disease and back pain (i.e., chronic conditions) showed that perceptions can change to more positive and that this has positive effects on health outcomes[22–24]. All this also suggests that in patients with hand OA, illness perceptions could be of importance as potential modifiable factors that could serve as a treatment target. However, longitudinal studies on illness perceptions in relation to (change in) functional status in patients with hand OA are unavailable[25], leaving it unclear whether illness perceptions are relevant as targets. To be a relevant target, change over time should be possible and this change should be relevant (i.e., associated with change in outcomes).

Therefore, in the present study, we investigated whether illness perceptions changed after two years and whether this change was associated with a change in functional status (progression of disability) in patients with hand OA. To further evaluate the relevance of

illness perceptions, we studied the association of baseline illness perceptions with disability status both at baseline and after two years. This is important knowledge in the light of informing patients about disease prognosis, but also to identify patients that are most at risk for worse outcomes. The latter is the patient group that could benefit most from treatment. We hypothesize, in a secondary care cohort of patients with hand OA, that negative illness perceptions are associated with poor clinical outcome and that a change in illness perceptions is associated with a change in disability.

Materials and methods

Study design

The present study is part of the Hand OSTeoArthritis in Secondary care (HOSTAS) study, an ongoing observational cohort study in hand OA[26]. For this report, patients included from January 2011 onwards and who completed relevant questionnaires were considered.

Patients

Consecutive patients with primary hand OA from the outpatient clinic of the Leiden University Medical Center (LUMC) were included between January 2011 and October 2015. Primary hand OA was defined according to the diagnosis of the treating rheumatologist. Patients with secondary hand OA (e.g., due to trauma) and patients with hand symptoms explained by another diagnosis were excluded[26]. Patients were followed annually with postal questionnaires and biennially with an additional research visit. Written informed consent was obtained from all participants. The study was approved by the LUMC medical ethical committee.

Illness perceptions

Illness perceptions were studied using the Illness Perception Questionnaire – Revised (IPQ-R)[12,27], which was assessed biennially, together with a research visit. The IPQ-R measures both cognitive and emotional representations of illness in three sections with nine subscales (Figure 1). The questionnaire has been shown to be valid and consistent in a population with musculoskeletal hand problems[8].

The first section is the identity subscale, concerning symptoms that patients attribute to OA. For fourteen commonly occurring symptoms, patients indicated whether they think these symptoms have to do with their OA always, often, sometimes or never. All always, often or sometimes indicated symptoms were summed (range 0-14).

The second section consists of 38 questions (0-4, Likert scale) spread over seven subscales. The consequence subscale (n = 6 questions) is about the impact of OA on daily life. The timeline acute/chronic (n = 6) represents beliefs about the perceived chronicity of the disease, whereas the timeline cyclical (n = 4) is about the variability in course of symptoms and the disease process. Illness coherence (n = 5) represents the patient's understanding of OA. The emotional representations subscale (n = 6) reflects negative emotions due to OA. The personal (n = 6) and treatment (n = 5) control subscales represent beliefs about possibilities for influencing the symptoms and disease course on a personal level and with treatment. Items were summed per subscale, accepting a maximum of one missing item.

For both the first and second section, a higher score means stronger illness perceptions in that particular subscale. For personal control, treatment control and illness coherence, a higher score/stronger perception is considered more positive, whereas for identity and for the other representations subscales, a higher score/stronger perception is considered more negative.

The third section comprises the causes subscale, with 18 possible causes of OA subdivided into four dimensions: psychological attributions (n = 6), immunity (n = 3), risk factors (n = 7) and chance (n = 2). Items were rated on a 5-point Likert scale: totally disagree (1) to totally agree (5). Answers were dichotomized to disagree/no opinion and agree. To provide insight in which causes are associated with disability, we analysed per cause.

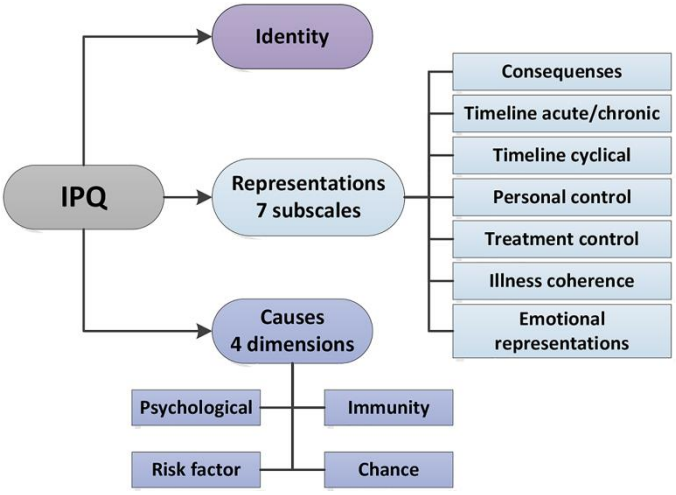

Figure 1. Three sections of the Illness Perception Questionnaire – Revised.

Self-reported disability

Self-reported disability was assessed annually with the Functional Index for Hand OA (FIHOA), with the Australian/Canadian Hand OA index (AUSCAN) and with the Health Assessment Questionnaire (HAQ)[28–30]. The FIHOA is a hand-specific questionnaire concerning physical functioning. The ten questions (each scored from 0 to 3) were summed (total score 0-30). A maximum of two missing items was accepted. The AUSCAN is also a hand-specific questionnaire, of which we used the nine questions concerning hand function (0-4, Likert scale), summed to a total score (range 0-36). A maximum of two missing items was accepted. The HAQ measures overall disability and consists of 24 questions (each scored 0-3) in eight categories. The highest scores per category were summed and divided by eight, resulting in a total score ranging from 0 to 3. A maximum of two missing categories was accepted. For all questionnaires, a higher score means worse function, hence more disability.

Clinical assessment

During physical examination at baseline, performed by trained research nurses, all distal interphalangeal (DIP), proximal interphalangeal (PIP), interphalangeal (IP), metacarpophalangeal (MCP) and first carpometacarpal (CMC) joints were assessed for the number of joints with bony swelling (total range 0-30), with limited range of motion, and with deformity (both ranges 0-22; MCP 2-5 excluded). Furthermore, tenderness on palpation (range 0-3 per joint) was assessed in 24 joint units: all DIP, PIP, first IP, first MCP and first CMC joints individually and second through fifth MCP joints as one joint group. In each patient, the Doyle index for the hands was the summed score of the 24 joint units (range 0-72)[31]. Joints outside the hands were also assessed for tenderness upon palpation or movement (range 0-3), as specified in the Doyle index[31]. Scores of 48 units were summed into a total score ranging from 0 to 144. Patient-reported hand symptoms and physical examination were used to determine fulfilment of the American College of Rheumatology criteria for hand OA[32]. In addition, a research nurse recorded the number of comorbid diseases (range 0-17)[26].

Radiographic assessment

Joints of both hands (n = 30) were scored on a scale of 0-4 on conventional dorsal-volar radiographs, according to Kellgren-Lawrence (KL) system[33]. Scoring was blinded for demographic and clinical data (WD). Intra-observer reliability, based on randomly selected radiographs (10%), was good (intraclass correlation coefficient >0.9). Scores were summed per patient into a total KL score for the hands (range 0-120).

Statistical analysis

When questionnaires had missing items (not exceeding the maximum number of allowed missing items), values were replaced with the (sub)scale mean value. Questionnaires with too many missing items were regarded as missing. The change in score after two years was calculated as the follow-up score minus the baseline score. Change equal to or above the minimal clinically important difference (MCID) was used for HAQ (0.22) to classify patients as progressed; changes below this value were regarded as not progressed[34]. For AUSCAN function, the retrograde of the minimal clinically important improvement (MCII) was used, i.e., 1.4[35]. Since, for FIHOA, no MCII or MCID is known, progression was defined as the minimal change potentially detectable, which is 1 unit (or 3.3%)[36].

Associations between illness perceptions at baseline (determinant) and disability at baseline and at follow-up (outcome), presented as risk ratios (RRs) with 95% confidence intervals (CIs), were studied using a Poisson regression model with log link function and robust standard errors[37]. For these analyses, scores for each subscale of illness perceptions were categorized into tertiles to show a trend between groups, while providing the best power and best possible balance of number of patients per group. Disability scores were categorized into quartiles, in order to provide contrast (high vs low). A score in the highest quartile was considered high disability and a score in the other quartiles was considered low disability. Hence, RRs represent the incremental risk of high disability per tertile of illness perception score, with the lowest tertile as a reference. In the causes section, analyses were not performed per tertile, but for each individual cause. Mean differences of change in illness perceptions after two years between groups with and without progression of disability were estimated using linear regression.

Analyses were adjusted for age and Doyle index. For FIHOA and AUSCAN analyses, the hand Doyle index was used, whereas for the HAQ analysis the total Doyle index was used. Additional adjustments were made for baseline score of the outcome (i.e., baseline FIHOA, AUSCAN or HAQ) in longitudinal analyses with the Poisson model (baseline illness perceptions and two-year disability status) and for both baseline score of the outcome and baseline illness perception score in the linear regression model (change in illness perceptions and progression of disability over two years). In addition, for sensitivity analysis, adjustments for sex, BMI, total hand KL-score, and number of comorbidities were made.

All cross-sectional analyses were done on cases with complete baseline data for IPQ-R, whereas all longitudinal analyses were performed in patients with available follow-up

data. SPSS software for Windows, versions 20.0 and 23.0 (IBM, Armonk, NY, USA), was used.

Results

Study population

Of 388 eligible patients, 384 (99%) had baseline IPQ-R questionnaires available (Table 1). Both baseline and two-year follow-up was completed by 312, 311, 314 and 311 patients for IPQ-R, FIHOA, AUSCAN and HAQ, respectively. Reasons for no available follow-up were: too many missing items to calculate total scores, dropout or skipped two-year visit. Patients with and without follow-up did not differ in age, sex, BMI or baseline function scores (data not shown).

Associations of illness perceptions and disability at baseline

Table 2 shows cross-sectional associations between illness perceptions and disability at baseline, both for hand-specific (FIHOA, AUSCAN) and overall (HAQ) functional status. The

Table 1. Baseline characteristics of 384 primary hand osteoarthritis (OA) patients.

Variable	
Age, years, mean (SD)	60.9 (8.4)
Sex, women, n (%)	322 (84)
Body mass index, mean (SD)*	27.6 (4.9)
Fulfilling ACR criteria for hand OA, n (%)	346 (90)
Number of comorbid diseases (0-17), median (range)*	0 (0-5)
Patient-reported disability, median (range)	
FIHOA (0-30)	9.0 (0-26.7)
AUSCAN (0-36)*	16.0 (0-36)
HAQ (0-3)	0.9 (0-2.3)
Physical exam hands, median (range)	
Bony swelling joint count (0-30)	11 (0-24)
Deformity joint count (0-22)	3 (0-16)
Doyle index of the hands (0-72)	4 (0-70)
Joints with limited ROM count (0-22)	4 (0-22)
Physical exam overall, median (range)	
Doyle index (including the hands) (0-144)	7 (0-88)
Radiographic scoring hands, median (range)*	
KL summed score (0-120)	16 (0-89)

*Number of patients represented in data if not 384: BMI 378, comorbidities 374, AUSCAN 382, KL score 381. ACR: American College of Rheumatology; FIHOA: Functional Index for Hand OA; AUSCAN: Australian/Canadian hand OA index; HAQ: Health Assessment Questionnaire; ROM: range of motion; KL: Kellgren-Lawrence.

Table 2. Associations between baseline illness perceptions and baseline self-reported disability in 384 patients with hand osteoarthritis (OA).

		FIHOA	AUSCAN	HAQ
		RR (95% CI)	function	RR (95% CI)
	Mean (SD)	Q4: score≥13	RR (95% CI) Q4: score≥22	Q4: score≥1.25
Identity (0-14)	4.9 (2.2)			
0-3		1	1	1
4-5		1.9 (1.04-3.4)	2.2 (1.1-4.1)	1.7 (0.9-3.1)
6-13		3.0 (1.6-5.3)	3.3 (1.7-6.2)	3.0 (1.7-5.6)
Timeline acute/chronic (6-30)	26.2 (3.6)			
12-24		1	1	1
25-28		1.4 (0.9-2.0)	1.1 (0.7-1.7)	1.0 (0.7-1.5)
29-30		1.1 (0.7-1.6)	1.0 (0.7-1.6)	1.0 (0.6-1.4)
Consequences (6-30)	16.5 (4.3)			
6-14		1	1	1
15-18		2.1 (1.2-3.5)	1.4 (0.8-2.3)	1.2 (0.7-2.1)
19-30		3.2 (2.0-5.2)	2.7 (1.7-4.2)	3.6 (2.3-5.6)
Personal control (6-30)	18.6 (3.6)			
6-17		1	1	1
18-20		1.1 (0.7-1.6)	1.1 (0.7-1.6)	1.1 (0.7-1.6)
20.4-29		1.0 (0.7-1.6)	1.3 (0.9-2.0)	1.3 (0.8-2.0)
Treatment control (5-25)	13.9 (2.7)			
5-12.5		1	1	1
13-15		0.7 (0.5-1.03)	0.8 (0.5-1.1)	0.9 (0.6-1.3)
16-20		0.8 (0.5-1.2)	1.1 (0.7-1.6)	0.8 (0.5-1.3)
Illness coherence (5-25)	18.6 (3.8)			
6-17		1	1	1
17.5-20		0.5 (0.4-0.8)	0.9 (0.6-1.3)	0.8 (0.5-1.1)
21-25		0.6 (0.4-0.9)	0.6 (0.4-1.01)	0.5 (0.3-0.8)
Timeline cyclical (4-20)	13.2 (3.2)			
4-11		1	1	1
12-14		0.7 (0.5-0.997)	0.8 (0.5-1.2)	0.8 (0.5-1.2)
15-20		0.7 (0.5-1.01)	0.8 (0.5-1.2)	0.9 (0.6-1.1)
Emotional representations (6-30)	14.4 (4.9)			
6-12		1	1	1
13-15		1.5 (0.9-2.5)	1.5 (0.9-2.4)	1.2 (0.7-1.9)
16-30		2.3 (1.5-3.5)	1.9 (1.3-2.9)	1.9 (1.3-2.9)

Results are risk ratios (RR, 95% CIs) for having a disability score in the highest quartile (Q4) vs a score in the other quartiles per tertile of illness perception scores; 1 = reference. Adjusted for age and Doyle index. FIHOA: Functional Index for Hand OA; AUSCAN: Australian/Canadian Hand OA Index; HAQ: Health Assessment Questionnaire.

illness perception subscales of identity, consequences and emotional representations were associated with high disability on all three outcomes and in a dose-response way. This means, that stronger negative perceptions (higher tertiles) had a higher risk for high disability compared with the lowest tertiles. In other words, patients who experienced more symptoms (identity), consequences or emotions had an increased risk for high disability at baseline. In contrast, a stronger positive perception, i.e., more understanding of the illness (illness coherence), was associated with a lower risk for high disability on the FIHOA and HAQ. Stronger beliefs about a cyclical disease course were associated with a lower risk of disability on the FIHOA only. Additional adjustment for sex, BMI, radiographic damage (hand KL-score) and number of comorbidities did not essentially change the estimates.

Change in disability and illness perceptions over two years

After two years, 50% (157/311) of patients worsened in the FIHOA score, with a mean score-increase of 3.7 (SD 2.6), while 37% (117/314) and 36% (112/311) of patients worsened more than the MCII/MCID in AUSCAN function and HAQ scores, with a mean increase of 5.6 (SD 3.6) and 0.4 (0.2). Illness perceptions also changed in the time frame of two years (Table 3). The illness perceptions that changed in the whole group were: timeline acute/chronic, consequences, personal control, treatment control, illness coherence and emotional representations. This means that patients were, over time, understanding more of their illness, regarding their OA as more chronic (timeline), but experiencing less personal and treatment control. Furthermore, they perceived fewer emotions and fewer consequences of their OA.

Association of baseline illness perceptions with high disability after two years

We explored the association of illness perceptions at baseline and high disability (a score in the highest quartile) after two years (Table 4). We found longitudinal associations for several illness perceptions: the more baseline symptoms a person attributed to their OA (identity), the stronger the perceived consequences and the more emotions, the higher the risk of disability at follow-up for all outcomes. Similarly, more baseline illness coherence was associated with less disability at follow-up on the FIHOA and HAQ. Baseline perceived chronicity (timeline acute/chronic), personal control, treatment control and beliefs about a cyclical timeline did not show an association with disability after two years (Table 4). Additional analyses showed that baseline disability scores were associated with disability scores after two years. Adjustment for baseline disability scores resulted in the

Table 3. Mean change in illness perceptions after two years for the whole group and between groups with and without progression in disability in 312 patients with hand osteoarthritis (OA).

	Whole group		FIHOA^		AUSCAN function^		HAQ^	
	Baseline, mean (SD)	Change, mean (95% CI)	Progression (yes/no) n = 155/154	Change difference, mean (95% CI)*	Progression (yes/no) n = 115/195	Change difference, mean (95% CI)*	Progression (yes/no) n = 112/198	Change difference mean (95% CI)*
Identity (0-14)	4.8 (2.3)	0.0 (-0.2; 0.3)	0.3/-0.3	0.6 (0.2; 1.0)	0.2/-0.1	0.3 (-0.2; 0.7)	0.4/-0.2	0.6 (0.2; 1.1)
Timeline acute/chronic (6-30)	26.3 (3.6)	0.6 (0.2; 1.0)	0.7/0.6	0.6 (-0.1; 1.3)	0.9/0.5	0.7 (-0.1; 1.4)	0.4/0.7	0.2 (-0.6; 0.9)
Consequences (6-30)	16.5 (4.3)	-0.5 (-1.0; -0.1)	0.4/-1.4	2.1 (1.3; 2.9)	0.3/-1.0	1.6 (0.7; 2.5)	0.4/-1.1	1.7 (0.9; 2.5)
Personal control (6-30)	18.4 (3.7)	-0.5 (-0.9; -0.1)	-0.5/-0.5	0.1 (-0.7; 0.8)	-1.0/-0.2	-0.6 (-1.4; 0.2)	-0.7/-0.4	-0.1 (-0.9; 0.7)
Treatment control (5-25)	13.8 (2.7)	-0.8 (-1.2; -0.5)	-1.1/-0.5	-0.8 (-1.4; -0.2)	-1.5/-0.4	-1.0 (-1.6; -0.3)	-0.8/-0.8	-0.1 (-0.7; 0.6)
Illness coherence (5-25)	18.6 (3.8)	0.6 (0.2; 1.0)	0.4/0.8	-0.2 (-0.9; 0.5)	0.3/0.7	-0.3 (-1.1; 0.4)	0.4/0.7	-0.3 (-1.0; 0.5)
Timeline cyclical (4-20)	13.3 (3.2)	-0.0 (-0.4; 0.4)	-0.2/0.2	-0.3 (-0.9; 0.4)	-0.1/0.1	-0.3 (-1.0; 0.4)	0.0/0.0	0.2 (-0.5; 0.9)
Emotional representations (6-30)	14.3 (4.8)	-0.8 (-1.3; -0.4)	-0.6/-1.1	0.9 (0.02; 1.7)	-0.3/-1.2	1.1 (0.2; 2.0)	-0.5/-1.1	0.8 (-0.1; 1.7)

^For FIHOA, AUSCAN and HAQ there were 3, 2 and 2 patients, respectively, of whom a delta could not be calculated due to missing data. *Adjusted for age, Doyle index, baseline score of outcome (i.e., FIHOA, AUSCAN, and HAQ) and baseline score of illness perception. FIHOA: Functional Index for Hand OA; AUSCAN: Australian/Canadian Hand OA Index; HAQ: Health Assessment Questionnaire.

Table 4. Associations between baseline illness perceptions and self-reported function scores at two years follow-up in 312 patients with hand osteoarthritis.

	FIHOA RR (95% CI), Q4: score ≥15		**AUSCAN function** RR (95% CI), Q4: score ≥22		**HAQ** RR (95% CI), Q4: score ≥1.38	
	Adjusted*	Adjusted**	Adjusted*	Adjusted**	Adjusted*	Adjusted**
Identity (0-14)						
0-3	1	1	1	1	1	1
4-5	3.1 (1.4-7.1)	2.3 (1.0-5.1)	2.5 (1.3-4.8)	1.4 (0.7-2.6)	2.9 (1.3-6.7)	2.1 (0.9-4.5)
6-13	4.7 (2.1-10.7)	2.5 (1.1-5.7)	2.8 (1.4-5.6)	1.0 (0.5-2.0)	5.4 (2.3-12.3)	2.2 (0.9-5.1)
Timeline acute/chronic (6-30)						
16-24	1	1	1	1	1	1
25-28	1.0 (0.6-1.6)	0.8 (0.5-1.3)	1.2 (0.7-2.0)	1.1 (0.7-1.7)	1.1 (0.7-1.9)	1.1 (0.7-1.7)
29-30	1.0 (0.6-1.6)	1.0 (0.7-1.5)	1.1 (0.7-1.8)	0.9 (0.7-1.4)	1.0 (0.6-1.6)	1.2 (0.8-1.7)
Consequences (6-30)						
6-14	1	1	1	1	1	1
15-18	1.6 (0.9-3.0)	1.1 (0.6-1.9)	1.0 (0.6-1.8)	0.9 (0.5-1.4)	1.0 (0.6-1.7)	1.0 (0.6-1.6)
19-30	3.0 (1.7-5.0)	1.5 (0.8-2.6)	2.0 (1.3-3.3)	1.0 (0.7-1.6)	2.1 (1.3-3.4)	0.9 (0.6-1.4)
Personal control (6-30)						
6-17	1	1	1	1	1	1
18-20	1.1 (0.7-1.8)	1.0 (0.7-1.6)	0.8 (0.6-1.3)	1.0 (0.7-1.4)	1.2 (0.8-1.9)	1.2 (0.8-1.7)
20.4-28	1.3 (0.8-2.2)	1.4 (0.9-2.1)	1.0 (0.6-1.6)	1.1 (0.8-1.7)	1.3 (0.8-2.1)	1.1 (0.8-1.6)
Treatment control (5-25)						
5-12.5	1	1	1	1	1	1
13-14	0.7 (0.4-1.3)	0.8 (0.5-1.4)	0.7 (0.4-1.2)	0.9 (0.6-1.5)	1.1 (0.6-1.8)	1.3 (0.8-2.0)
15-20	1.0 (0.7-1.6)	1.2 (0.8-1.7)	1.1 (0.7-1.6)	1.1 (0.8-1.6)	1.2 (0.7-1.8)	1.3 (0.9-1.8)
Illness coherence (5-25)						
6-17	1	1	1	1	1	1
17.5-20	0.6 (0.3-0.9)	0.7 (0.4-1.0)	0.8 (0.5-1.3)	1.0 (0.7-1.4)	0.6 (0.4-0.9)	0.8 (0.6-1.2)
21-25	0.5 (0.3-0.8)	0.5 (0.3-0.8)	0.6 (0.4-1.0)	0.8 (0.5-1.3)	0.4 (0.3-0.7)	0.8 (0.5-1.2)
Timeline cyclical (4-20)						
5-11	1	1	1	1	1	1
12-14	1.4 (0.8-2.3)	1.7 (1.1-2.6)	1.1 (0.7-1.6)	1.4 (1.0-2.0)	1.1 (0.7-1.8)	1.1 (0.7-1.6)
15-20	1.3 (0.8-2.2)	1.5 (1.0-2.4)	0.8 (0.5-1.3)	1.1 (0.7-1.6)	1.3 (0.8-2.0)	1.2 (0.8-1.8)
Emotional representations (6-30)						
6-12	1	1	1	1	1	1
13-15	1.3 (0.8-2.3)	1.0 (0.6-1.8)	1.0 (0.6-1.8)	0.8 (0.5-1.3)	1.1 (0.6-1.9)	0.9 (0.5-1.4)
16-30	2.1 (1.3-3.3)	1.5 (0.9-2.3)	1.8 (1.1-2.8)	1.2 (0.8-1.9)	2.2 (1.4-3.4)	1.2 (0.8-1.9)

Results are risk ratios (RR, with 95% CIs) for having a disability score at follow-up in the highest quartile (Q4) vs a score in the other quartiles per tertile of baseline illness perception scores; 1 = reference. *Adjusted for age and Doyle index. **Adjusted for age, Doyle index, and baseline score of the outcome (i.e., FIHOA, AUSCAN, and HAQ). FIHOA: Functional Index for Hand OsteoArthritis; AUSCAN: Australian/Canadian Hand OA Index; HAQ: Health Assessment Questionnaire.

disappearance or in a large decrease (identity with FIHOA) of the associations between baseline illness perceptions and two-year disability status (Table 4).

Change in illness perceptions between patients with and without progression of disability

In Table 3 the mean change in illness perceptions after two years is shown for two groups: with and without progression of disability. The adjusted mean difference in the change of the illness perceptions between these groups is also presented. The illness perceptions timeline acute/chronic, personal control and illness coherence changed at the group level, but this change did not differ between patients with and without progression. However, in other illness perceptions there was a difference between the groups. For the consequences subscale, patients with progression in disability on all outcomes had increased in perceived consequences after two years, where patients who did not progress decreased. Similar results were seen for perceptions about identity (FIHOA and HAQ), treatment control (FIHOA and AUSCAN) and emotions (FIHOA and AUSCAN), i.e., patients with disability progression on the FIHOA, AUSCAN and/or HAQ were experiencing more symptoms, less treatment control or fewer decreased emotional representations after two years than patients without progression.

Causes of OA and high disability

Patients indicated for 18 possible causes whether they thought (agreed) these factors could have caused their OA (Table 5). The most indicated causes were heredity (66%), ageing (74%) and chance or bad luck (55%). Causes that were associated with high disability at baseline were mostly psychological causes: stress or worry, family problems or worries, overwork, own personality and poor medical care in the past. These causes were only indicated as a cause by <15% of the patients, except for overwork (33%).

Discussion

In our large secondary care cohort with two-year follow-up of patients with primary hand OA, we found that the perceptions that patients have of their illness were associated with self-reported disability due to hand OA at the same moment. The baseline perceptions patients had about their illness were also associated with high disability after two years. However, these associations were confounded by the baseline disability score. The perceptions patients have about their illness showed small changes over the two-year time frame. Progression in self-reported disability was associated with a change in

Table 5. Associations between perceptions about individual causes of osteoarthritis (OA) and disability at baseline in 384 patients with hand OA.

	Disagree or no opinion/agree (% agree)	FIHOA RR (95% CI) Q4: score ≥13	AUSCAN RR (95% CI) Q4: score ≥22	HAQ RR (95% CI) Q4:score≥1.25
Psychological				
Stress or worry	334/48 (13)	1.5 (1.0-2.3)	1.7 (1.1-2.5)	1.7 (1.1-2.5)
Own mental attitude e.g., thinking about life negatively	376/6 (2)	1.9 (0.8-4.3)	2.0 (0.9-4.5)	2.0 (0.9-4.5)
Family problems or worries	352/30 (8)	1.1 (0.6-2.0)	1.7 (1.1-2.7)	1.5 (0.9-2.5)
Overwork	259/125 (33)	1.5 (1.04-2.0)	1.4 (0.97-1.9)	1.6 (1.1-2.2)
Own emotional state, e.g., feeling down	361/22 (6)	1.4 (0.8-2.5)	1.5 (0.8-2.7)	1.7 (0.97-2.8)
Own personality	366/17 (4)	1.4 (0.7-2.6)	2.4 (1.6-3.7)	2.7 (1.8-4.0)
Risk factor				
Hereditary	130/253 (66)	1.2 (0.8-1.7)	1.3 (0.9-1.9)	0.9 (0.7-1.3)
Diet or eating habits	349/31 (8)	1.5 (0.9-2.4)	1.3 (0.7-2.2)	1.4 (0.9-2.4)
Poor medical care in the past	363/17 (5)	2.1 (1.3-3.4)	1.7 (0.9-3.0)	1.9 (1.1-3.3)
Own behaviour	327/53 (14)	1.4 (0.95-2.1)	1.1 (0.6-1.7)	1.2 (0.8-1.9)
Ageing	100/283 (74)	0.8 (0.5-1.1)	1.1 (0.7-1.6)	0.9 (0.6-1.3)
Alcohol	379/5 (1)	1.5 (0.5-4.5)	Not possible	0.8 (0.1-4.5)
Smoking	374/9 (2)	0.8 (0.2-2.9)	0.9 (0.2-2.9)	1.8 (0.8-3.7)
Immunity				
Germ or virus	375/8 (2)	Not possible	0.5 (0.1-3.0)	Not possible
Environmental pollution	372/9 (2)	1.3 (0.5-3.2)	1.3 (0.5-3.3)	1.2 (0.5-3.3)
Altered immunity	334/49 (13)	1.1 (0.7-1.8)	1.3 (0.9-2.1)	1.3 (0.9-2.1)
Chance				
Chance or bad luck	172/209 (55)	0.7 (0.6-1.1)	0.7 (0.5-1.0)	0.9 (0.7-1.3)
Accident or injury	358/25 (7)	1.2 (0.7-2.2)	0.9 (0.4-1.9)	0.9 (0.5-1.9)

Results are risk ratios (RR, with 95% CIs) for having a disability score at baseline in the highest quartile vs a score in the other quartiles per individual cause of OA (dichotomised to disagree/no opinion vs agree); 1 = reference. All results are unadjusted. FIHOA: Functional Index for Hand OA; AUSCAN: Australian/Canadian Hand OA Index; HAQ: Health Assessment Questionnaire.

perceived consequences, symptoms a person attributed to their OA, treatment control and emotions.

In line with our results, a cross-sectional population-based study also found associations between symptoms and consequences and hand/finger function. However, that study did not find associations between other illness perceptions and disability[8]. Differences between studies could be explained by differences in the study population and in the methods of assessing disability. Unfortunately, that study had no longitudinal data available. Compared with a six-year longitudinal study in patients with OA in multiple sites, we found similar results in illness perception subscales that changed in the follow-up period and in subscales where changes were associated with progression in disability[10]. These studies, as well as a study comparing patients with diabetes and OA, support our findings that identity and consequences are important subscales in patients with OA[8,10,38].

Similar to the six-year study[10], in our study, the magnitude of changes and strength of found associations was limited. Since there is no known cut-off for clinically relevant changes in illness perceptions, we do not know whether small changes are relevant. Therefore we related them to progression in disability to provide clinical meaning. We showed that after two years, which could be the term of a clinical trial, change is possible and that this change is relevant (i.e., associated with change in outcomes). Since illness perceptions are possible modifiable factors, this suggests they could serve as a treatment target.

After two years, patients perceived their disease as more chronic (higher score for timeline) and experienced less treatment and personal control. The changes in these illness perceptions are considered more negative. However, within the context of OA, which is a progressive disease with very limited treatment modalities and no available disease-modifying treatment, a perception of less treatment and personal control could also be regarded as realistic and could reflect increasing insight into the nature of the disease. The latter is in line with increasing illness coherence (less negative over two years). Therefore it is questionable whether, in the context of OA, perceiving less treatment and personal control and a chronic timeline is more negative. This is also reflected in perceiving fewer emotions and consequences, both reflecting that patients perceive their disease as less negative over two years.

We studied the association of underlying beliefs of patients about the causes of their OA with disability. The most often mentioned causes (ageing, heredity and chance/bad luck) are widely recognized as causes for OA and were not associated with disability[1]. Several other causes, that are not generally linked to OA pathophysiology were associated with disability; these were mostly psychological (e.g., stress or worries). This illustrates that

perceptions about causes of OA, which are likely incorrect from a pathophysiological point of view, are related to higher disease burden. Changing these perceptions, for example by education, could be a treatment target. It should be noted, however, that most causes that were associated with disability in our cohort were only mentioned by a minority of patients. Nevertheless, this is a proportion that is similar to a study where ~10% of the patients blamed themselves for their OA[38]. Other studies did not find associations for psychological attributions as a cause dimension with disability[8,10,19]. This could be explained by not investigating separate causes, but instead by aggregating all psychological causes into one item.

Although we showed that baseline illness perceptions showed strong associations with baseline disability, their association with two-year disability status virtually disappeared when the baseline disability score was taken into account. This could be explained by confounding by baseline disability. Hence, based solely on baseline illness perceptions, it is not possible to give a prognosis about two-year disability status. In contrast, the six-year follow-up study in generalized OA found a predictive ability for baseline illness perceptions and disability status at follow-up. This difference could be due to differences in follow-up time (six vs two years), in location of OA (multiple sites vs hand) and in severity of OA (we found a higher baseline HAQ and AUSCAN function compared with their population)[7,10]. In our study, baseline illness perceptions and baseline disability were strongly related, which suggests that by improving baseline illness perceptions, disability could also improve. Studies in patients with hand OA had not yet been performed, but a case report in a knee OA patient supports this hypothesis[39].

A strength of our study is that we used different validated self-reported questionnaires to evaluate disability. However, the measured constructs of disability are different; HAQ measures overall disability, including hand disability, while AUSCAN and FIHOA are hand-specific. Several studies showed that FIHOA and AUSCAN are strongly correlated but not 100%[40]. This means that FIHOA and AUSCAN may measure somewhat different aspects of the construct of hand disability. In our current study, AUSCAN performed worse than FIHOA in the association with illness perceptions, supporting FIHOA as the preferred measure for hand disability[41]. However, in general, it is still to be determined, and beyond the scope of this article, which outcome measure is recommended to study hand disability and whether there are other suitable outcome measures besides FIHOA and AUSCAN[40].

Studying three outcomes enabled us to identify perceptions that are most relevant. The most relevant perception seemed to be perceived consequences, as this perception was associated with three outcomes in almost all analyses. Nevertheless, there were quite a few differences between the sections of the IPQ-R and the subscales within a section in

relation to functional status. Therefore illness perceptions, as in this questionnaire, remain rather heterogeneous and can reflect several items within the topic. It should be noted that studying several determinants and outcomes raises the issue of multiple testing. Since our study is observational/empirical, we chose not to adjust for multiple testing[42]. Consequently, it is possible that our results are due to chance. However, that other studies are in line with our study supports the validity of our results[8,10,19].

There are several limitations we need to address. The first is that both determinant and outcome in our study were self-reported, and inherently subjective. It could be that patients with more negative perceptions tend to report more disability, while the same patients would not score as disabled on more objective performance tests, such as hand mobility or grip strength. However, we deliberately have not taken such tests into account as outcomes for several reasons. It is possible that performance tests too are influenced by negative illness perceptions and therefore their objectivity could be questioned[43]. Furthermore, and in our opinion more important, disability is a patient-reported outcome, thus reflecting the patient's perspective. It is the subjective (experienced) disability that medical care should focus on, regardless of the objective performance. Therefore, it is important to know which factors are associated with subjective disability in order to design patient-tailored treatment strategies. As a second limitation, the choice for our method of analysis, i.e., working with tertiles and quartiles, means that data are lost when categorizing. However, categorizing provides more contrast and makes results easier to interpret. Furthermore, we chose this method to enable comparison with earlier studies[10]. Finally, patients included in our cohort all sought medical care in a secondary care center, whereas we can assume that many patients with hand OA stay in primary care or do not consult a doctor[8]. This could have biased our results. Probably, secondary care patients are a selection of patients with hand OA with more negative illness perceptions and more disability than patients in primary care. When selecting on already negative perceptions and high disability, change could be a regression-to-the-mean effect. Therefore, we adjusted our analysis of change for the baseline score of illness perceptions and baseline disability. Selection of patients with negative illness perceptions and high disability could also lead to too little variability. This could explain why we found that illness perceptions were not associated with two-year disability after adjustment for baseline disability.

In conclusion, we found that illness perceptions show an association with disability at baseline and can change over two years. For several illness perception subscales, change was associated with progression of disability over two years, implying that these could be relevant treatment targets. However, the association between baseline illness perceptions and two-year disability status is confounded by baseline disability status. This suggests

that interventions could focus on improving baseline disability score, potentially using illness perceptions to accomplish this goal.

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