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Arthropathies in inflammatory bowel disease : Characteristics and impact on daily functioning

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CHAPTER 6

The impact of arthropathies on illness perceptions, coping strategies, outcomes and their changes over time in IBD patients: a 12-month follow-up study

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ABSTRACT

Background: Arthropathies are a common extra-intestinal manifestation (EIM) in inflammatory bowel disease (IBD). This study evaluated the differences in illness perceptions, coping strategies and illness outcomes between IBD patients with and without arthropathies at baseline, and examined changes at 12 months in these variables in patients with arthropathies.

Methods: In total, 204 patients with (n=123) and without (n=81) arthropathies completed questionnaires at baseline and after 1 year assessing illness perceptions, coping, quality of life (QoL) and work and activity impairment. A linear regression analysis assessed the impact of arthropathies on these factors compared to patients without arthropathies. A mixed model analysis evaluated changes in illness perceptions, coping and outcomes in patients with arthropathies over time.

Results: Patients with arthropathies had more persistent thoughts on symptomatology and the variability of symptoms, held more negative views on the effects of illness, had heightened emotions that impacted daily functioning and had a poorer understanding of IBD than patients without arthropathies. Patients with arthropathies could more efficiently divert attention, felt more useful to others and perceived a reduced physical and mental health and an increased activity impairment compared with patients without arthropathies. At follow-up, patients with arthropathies were more sceptical about the effectiveness of medical treatment, but were better able to adapt their activities to their complaints compared with baseline.

Conclusion: Patients with arthropathies in IBD adopt different illness perceptions, coping strategies and outcomes compared with patients without arthropathies, which is important to know when designing behavioural and physical interventions to improve functioning.

INTRODUCTION

Inflammatory bowel diseases (IBD), comprising Crohn's disease (CD) and ulcerative colitis (UC) are immune-mediated chronic inflammatory diseases of the gastrointestinal tract characterized by periods of inflammation and remission. Receiving a diagnosis of IBD can be stressful, and can impact illness outcomes such as quality of life (QoL), activity impairment and work productivity in a variety of ways.¹⁻⁴ IBD is associated with a range of extra-intestinal manifestations (EIMs) of which arthropathies, with a prevalence of approximately 30%, are the most common.⁵⁻⁷ Arthropathies can be subdivided into inflammatory (spondyloarthritis; SpA) and non-inflammatory (arthralgia) musculoskeletal symptoms. Recent studies have shown the significant impact of arthritis and IBD separately on different illness outcomes. It is well recognized that disability in patients with arthritis and in patients with IBD is not only associated with clinical variables of the disease process itself, but also with behavioural factors including illness perceptions and coping strategies.⁸⁻¹⁰ Illness perceptions are individual cognitions and emotions about a disease.¹¹ Coping refers to cognitive and behavioural efforts and strategies to deal with stressful stimuli, such as a chronic illness. Different coping styles may be required to deal with the various aspects of a disease.¹² Understanding and targeting the illness perceptions and coping strategies of IBD patients with and without arthropathies by medical or psychological interventions may improve treatment in this patient population and may thereby improve illness outcomes including QoL, and activity and work impairment.

We have shown that arthropathies in IBD patients have a strong negative impact on QoL and work impairment.¹³ However, it is unknown whether this is caused by differences in illness perceptions, coping strategies and illness outcomes in IBD patients with and without arthropathies. Therefore, our goal in the present study was to examine the differences in illness perceptions, coping strategies and illness outcomes between IBD patients with and without arthropathies. A secondary aim of our study was to evaluate changes in illness perceptions, coping strategies and outcomes at 12 months follow-up in IBD patients with arthropathies. This line of research might be instrumental in identifying targets for intervention via addressing and changing maladaptive illness perceptions and coping styles.

METHODS

Our cohort was based on the JOINT cohort⁵, which includes 255 IBD patients (155 with and 100 without self-reported arthropathies), all with a long IBD disease duration.¹⁴ Of these 255 patients, 204 were included in the present study based on completion of all questionnaires at study inclusion and after 1-year follow-up. Of the 204 participants, 178 patients completed the questionnaires based on their IBD, of which 109 had self-reported joint complaints. Subsequently, 8 patients fulfilled the questionnaires based on having arthropathies and 18 patients completed the questionnaires regarding other diseases. IBD patients were classified with self-reported arthropathies when they had chronic back pain (CBP) and/or peripheral joint complaints currently or during the previous year. A rheumatologic examination was performed in all 204 patients (123 patients with and 81 without self-reported joint complaints) at baseline and after 12-months follow-up. At both study time points patients were asked to complete questionnaires about disease activity, illness perceptions, coping strategies, quality of life, as well as activity and work impairment.^{11,15-19} Illness perceptions were measured with the Revised Illness Perception Questionnaire (IPQ-R). This questionnaire covers 8 subscales including 'Identity' (thoughts about the illness and the symptoms associated with it), 'Timeline chronic' (cognitions about the duration), 'Timeline cyclical' (perceived variability of symptoms), 'Consequences' (ideas about the severity of the illness and the impact on daily functioning), 'Personal control' (cognitions about the manageability of the illness through personal efforts), 'Treatment control' (perceptions about the effectiveness of medical treatment), 'Emotional representations' (the emotional impact) and 'Illness coherence' (personal understanding of the illness).¹³ Coping strategies were evaluated with the Coping with Rheumatic Stressors Questionnaire (CORS), which assesses eight coping strategies covering the different consequences of coping with pain, limitations and dependence.¹⁷ Coping strategies covering pain included 'Comforting cognitions' (self-encouragement), 'Decreasing activity' (taking more rest) and 'Diverting attention' (thinking about nice things). Strategies covering limitations encompassed 'Optimism' (thinking positively), 'Pacing' (adapting the level of activities) and 'Creative solution seeking' (creative things to achieve a goal). Strategies related to dependence included 'Acceptance' (making an effort to accept one's dependence) and 'Consideration' (being useful to others). Illness outcomes included QoL, activity and work impairment. QoL was measured with the Short Form (SF)-36 and was subdivided into physical health via the physical component score (PCS) and mental

health by the mental component score (MCS).¹⁸ Activity and work impairment was measured with the Work Productivity Activity Index (WPAI).¹⁹ The study was approved by the institutional medical ethical committee of the LUMC and patients signed a written informed consent prior to study enrolment.

Statistics

All analyses were performed in SPSS, version 23.0. Descriptive statistics were used for patients' characteristics, and comparisons of the baseline characteristics of patients with and without arthropathies were analysed with an independent t-test and a chi-square test. Linear regression models were used to assess potential associations of arthropathies as a predictor of illness perceptions, coping strategies and outcomes in IBD patients. Variables with a statistical level of $p \leq 0.05$ in the univariate analysis were included in the multivariate analysis. The multivariate analysis included 'arthropathies' as the independent variable, adjusted for age, gender, IBD disease activity, smoking, employment status and 5-ASA treatment, since these variables were significantly different at baseline between study groups. For the follow-up analysis, a linear mixed model was used. IBD patients with arthropathies at baseline were included in this analysis and compared with the follow-up sample consisting of the same IBD patients with arthropathies except for the patients who reported a cessation of their joint complaints after 1-year. A p-value ≤ 0.05 was considered statistically significant.

RESULTS

Demographic data

Of the 204 IBD patients included in the present study, 123 (60.3%) had self-reported arthropathies and 81 (39.7%) had no arthropathies. IBD patients with arthropathies had a mean IBD disease duration of 15.3 (SD=12.0) years at study inclusion, a mean age of 44.1 (SD=13.8) years, and were representative of the JOINT cohort.⁵ IBD patients with arthropathies were more often diagnosed with Crohn's Disease (CD) ($p=0.03$), an active disease course ($p < 0.001$), with a mean Harvey Bradshaw Index (HBI) of 6.0 ($p < 0.001$) and were more often smokers ($p=0.009$) compared with IBD patients without arthropathies. Of the 123 patients with arthropathies, 63 patients (51.2%) reported peripheral joint complaints only, 12 patients (9.8%) reported back pain and 48 (39%) reported both axial and peripheral joint complaints. In total, 13 (10.6%) patients were formally

diagnosed with arthritis by a rheumatologist based on physical examination and radiographs. Sixteen patients (13%) met the ASAS criteria for axial and peripheral SpA. IBD patients without arthropathies (n=81) were more likely to be male (p=0.003), employed (p=0.007) and were more often treated with 5-ASA (including sulfasalazine or mesalazine) for their IBD (p=0.02) compared with the patients with arthropathies (Table 1). Of the 123 IBD patients with self-reported arthropathies at baseline, 12 reported a cessation of joint complaints at 1-year follow-up, leaving a total of 111 (90.2%) patients with joint complaints. In the group without arthropathies (n=81), 4 of 81 patients developed self-reported arthropathies during the 12-months follow-up.

Differences in illness perceptions, coping strategies and outcomes between IBD patients with and without arthropathies at baseline

Univariate analyses showed that arthropathies in IBD patients were associated with the illness perceptions 'identity' β (95% CI): 1.05 (0.73 to 2.28), p<0.001; 'cyclical timeline' 1.63 (0.70 to 2.55), p=0.001; 'consequences' 2.52 (1.17 to 3.86), p=0.001, 'personal control' -1.22 (-2.34 to -0.11), p=0.032, 'emotional representations' 1.69 (0.31 to 3.06), p=0.017, 'illness coherence' -1.36 (-2.42 to -0.31), p=0.011 and 'treatment control' -0.83 (-1.58 to -0.07), p=0.031. In addition, arthropathies were associated with the coping strategies 'decreasing activity' 1.33 (0.15 to 2.51), p=0.027, 'diverting attention' 1.61 (0.39 to 2.82), p=0.010, 'pacing' 1.72 (0.16 to 3.29), p=0.031 and 'consideration' 1.11 (0.11 to 2.11), p=0.030). Significant associations between arthropathies and the following illness outcomes were found: 'physical health' -3.61 (-6.25 to -0.97), p=0.008, 'mental health' -9.00 (-11.40 to -6.12), p<0.001, 'activity' 0.21 (0.14 to 0.29), p<0.001 and 'work impairment' 0.11 (0.01 to 0.20), p=0.030.

In the multivariate model, arthropathies remained associated with a strong 'identity' 1.15 (0.31 to 1.98), p=0.007, more 'cyclical timeline' 1.33 (0.33 to 2.34), p=0.010, increased 'consequences' 2.00 (0.60 to 3.42), p=0.006, more 'emotional representations' 1.58 (0.08 to 3.08), p=0.039 and less 'illness coherence' -1.29 (-2.45 to -0.14), p=0.029 compared with patients without arthropathies. These results indicate that IBD patients with arthropathies had more persistent thoughts about symptoms and the perceived variability of these symptoms associated with illness, they had more negative beliefs about the effect of IBD, they experienced an increased emotional burden of the illness on daily life and had a reduced coherence of IBD compared with patients without arthropathies (Table 2). Furthermore, arthropathies in IBD were related to increased 'diverting

attention' 1.34 (0.02 to 2.66), $p=0.047$, more 'consideration' 1.18 (0.10 to 2.27), $p=0.033$. The illness outcomes including a poorer 'mental health' -3.10 (-5.99 to -0.23), $p=0.035$ and 'physical health' -7.22 (-9.68 to -4.77), $p<0.001$, and elevated levels of 'activity impairment' 0.15 (0.07 to 0.23), $p<0.001$ were found in IBD patients with arthropathies. More specifically, IBD patients with arthropathies were better able to alter the focus of their attention, were more helpful to others, but experienced poor physical and mental health, and greater activity impairment compared to IBD patients without arthropathies.

Follow-up

The secondary aim of the present study was to examine changes of illness perceptions and coping strategies in IBD patients with arthropathies at 1-year follow-up. After 12 months, IBD patients with arthropathies had lower scores on the illness perception dimension 'treatment control' ($p=0.001$), but had an increased score on the coping strategy 'pacing' ($p=0.030$) (Table 3). These results indicate that IBD patients with arthropathies perceived the use of medical interventions having little efficacy, but they were more able to adapt the level and intensity of their activities in daily life over time.

DISCUSSION

In this longitudinal follow-up study, we explored the effect of IBD-related arthropathies on illness perceptions, coping strategies and outcomes, and evaluated the changes in these factors at 1-year follow-up in IBD patients with arthropathies. The findings of this study indicate that persistent thoughts on symptomatology, perceived variability of symptoms, increased negative ideas regarding illness, increased emotional impact on daily functioning and less personal understanding of IBD, were all illness perceptions more commonly perceived by patients with arthropathies compared to patients without arthropathies.

In the present study, we found a different coping pattern in patients with arthropathies compared to patients without arthropathies. IBD patients with arthropathies were more able to divert attention and were trying to be more useful to others. Parekh et al. have reported that patients who use optimistic, adaptive coping styles have an increased QoL compared to IBD patients who use evasive coping styles.²⁰ In contrast to the report by Parekh et al., patients

with arthropathies in the present study applied these optimistic coping strategies ('diverting attention' and 'consideration') more frequently, but still reported a reduced mental and physical health and elevated levels of activity impairment compared with patients without arthropathies. This impaired QoL in IBD patients with arthropathies, subdivided into mental and physical health, has also been found in a study with patients with psoriatic arthritis (PsA) compared with patients with psoriasis only (PsO). Patients with PsA experienced greater physical disability than those with PsO, reflecting the functional disability due to the musculoskeletal disease. As a contrast with our results, no differences were found regarding mental health between the PsA and PsO patients.²¹

In the present study, IBD patients with arthropathies had less faith in the effectiveness of medical treatment at 1-year follow-up. This may be attributed to the fact that patients still reported arthropathies after one year, despite regular medical IBD treatment, indicating that this medical intervention was ineffective in alleviating their joint complaints. Furthermore, we have previously reported that active IBD is associated with arthropathies.⁵ In this study, the mean HBI and Simple Clinical Colitis Activity Index (SCCAI) showed a score above 4, signifying active IBD.

Bijsterbosch et al. studied changes in illness perceptions over a period of 6 years in patients with osteoarthritis (OA). Over this period, understanding of the illness (i.e., 'illness coherence') increased, patients perceived their illness as less manageable and more chronic, but associated fewer negative emotions with the OA. Patients who displayed increased symptoms, a negative impact on daily life and had stronger beliefs regarding chronicity after 6 years follow-up experienced a progression of disability.⁹ IBD patients with arthropathies were better able to adapt the number and intensity of activities to their complaints after 1 year follow-up, indicating that they adjusted to IBD-related symptoms compared to baseline. In patients with RA and diabetes mellitus (DM), Gåfvels et al. described a change in coping strategies during 24 months follow-up. In both patient groups, less perceived effort was required to reduce the problems associated with disability and less support was obtained from family and friends. In addition, RA patients perceived a reduced ability to adapt to disease-related disability.²²

Some limitations need to be acknowledged. A first limitation of our study was cohort selection. We included IBD patients with a mean disease duration of

15.3 years and a mean arthropathy duration of 11.6 years after IBD diagnosis. Broadbent et al. reported that most illness perceptions are created in the first months after the patient is diagnosed with a disease.²³ In addition, once an illness perception has been developed, this perception will hardly change over time.²⁴ Future studies should include newly diagnosed IBD patients ideally with concurrent or future onset of arthropathies. The second limitation that needs to be mentioned is that 178 of the 204 IBD patients completed the questionnaires regarding their IBD, of which 109 patients had self-reported joint complaints. Only 8 completed the questionnaires based on arthropathies. Nevertheless, the apparent differences in illness perceptions, coping and outcomes between the groups with and without arthropathies found in the present study probably indicate that IBD patients with arthropathies consider IBD and arthropathies to be one disease and thus attribute subconsciously one illness perception, coping strategy or outcome to both diseases. A third limitation is that the CORS questionnaire used in the present study was originally designed to measure coping in RA patients and has not been validated in IBD patients. Though, this questionnaire was considered appropriate in the present study since the CORS has been validated in patients with RA, an inflammatory joint disease. Future research could use the recently developed IBD-Cope to evaluate the coping strategies in IBD patients and this could be compared with results obtained by the CORS.²⁵

Despite these limitations, the present study provides a better understanding of the impact of arthropathies on illness perceptions, coping and outcomes in IBD patients. However, although arthropathies in IBD were associated with different illness perceptions, coping strategies and outcomes compared to patients without arthropathies, for the health professional it is important that these issues are addressed for all IBD patients visiting the outpatient clinic. It is also important that the gastroenterologist actively listens to a patient's complaints and additionally explores the impact of the disease on daily functioning. This may modify the maladaptive illness perceptions; the perceived diversity of symptoms related to IBD, strong (negative) views concerning severity, the increased emotional impact and the lower coherence of the illness in IBD patients. Furthermore, the gastroenterologist should be aware of the impact of IBD-associated arthropathies on mental and physical health and activity impairment. Effects that might possibly be reduced by physical exercise and psychosocial interventions.²⁶⁻²⁷ Cognitive behavioural therapy (CBT) or mindfulness-based therapies appear to be effective in IBD patients, resulting in

improved QoL, medical therapy adherence and coping, and should therefore be considered in the health management of these patients.²⁸

Although, over the long-term, IBD patients with arthropathies became more sceptical about the efficacy of medical interventions, they were better able to adapt physical activity to their complaints compared to patients without arthropathies. Knowledge and understanding of these progressive changes in patients' illness perceptions and coping strategies should help stimulate the promotion, for recently diagnosed patients with IBD and arthropathies, of CBT and face-to-face consultations with a psychologist aimed at disease self-management. Furthermore, it is important that gastroenterologists provide a clear explanation of the intended effects of medication on arthropathies and the importance of achieving IBD remission, since disease activity is associated with arthropathy.⁵

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TABLES

Table 1. Baseline characteristics.

	IBD patients with arthro- pathies (n=123)	IBD patients without arthropathies (n=81)	P-value
Type of IBD, n (%)			0.03
Crohn's disease	95 (77.2)	51 (63.0)	
Ulcerative colitis	28 (22.8)	30 (37.0)	
Male, n (%)	40 (32.5)	43 (53.1)	0.003
Age at inclusion (years), mean (SD)	44.1 (13.8)	44.5 (13.7)	
Age of IBD onset (years), mean (SD)	28.4 (11.9)	26.6 (10.4)	
IBD disease duration (years), mean (SD)	15.3 (12.0)	17.4 (11.6)	
HBI, mean (SD)	6.0 (4.9) (n=95)	2.3 (2.5) (n=51)	<0.001
SCCAI, mean (SD)	4.1 (1.6) (n=28)	3.6 (2.0) (n=30)	0.49
Smoker, n (%)	36 (29.3)	11 (13.6)	0.009
Employed, n (%)	68 (55.3)	60 (74.1)	0.007
Current medication use, n (%)			
5-ASA (mesa, sulfa)	20 (16.3)	24 (29.6)	0.02
Steroids	8 (6.5)	2 (2.5)	0.19
Immunosuppressive drugs (Aza/6MP/MTX)	28 (22.8)	17 (21.0)	0.78
Anti-TNF	33 (26.8)	23 (28.4)	0.81
None	34 (27.6)	15 (18.5)	0.14
Type of joint complaints, n (%)			
Peripheral joint complaints	63 (51.2)	-	
Back pain	12 (9.8)	-	
Both	48 (39.0)	-	
Diagnosed with arthritis and fulfilled the ASAS criteria*, n (%)	13 (10.6%)	-	

*ASAS criteria for SpA

HBI = Harvey Bradshaw Index, SCCAI = Simple Clinical Colitis Activity Index, SD = Standard Deviation.

Table 2. Univariate and multivariate linear regression models showing potential associations for arthropathies as a predictor for illness perceptions, coping strategies and illness outcomes in IBD (n=204; 123 patients with self-reported arthropathies).

Variable	Univariate		Multivariate*	
	Beta (95% CI)	P-value	Beta (95% CI)	P-value
Demographic characteristics				
<i>Type of IBD</i>				
CD (ref)	0.14 (0.02 to 0.27)	0.027		
UC				
<i>Gender</i>				
Male (ref)	0.21 (0.07 to 0.34)	0.003		
Female				
<i>Active IBD</i>				
Yes (ref)	0.26 (0.13 to 0.40)	<0.001		
No				
<i>Smoking</i>				
Yes (ref)	0.16 (0.04 to 0.27)	0.009		
No				
<i>Employed</i>				
Yes (ref)	-0.18 (-0.32 to -0.05)	0.006		
No				
<i>5-ASA treatment</i>				
Yes (ref)	-0.13 (-0.25 to -0.02)	0.023		
No				
Illness perceptions				
Identity	1.05 (0.73 to 2.28)	<0.001	1.15 (0.31 to 1.98)	0.007
Timeline chronic	0.17 (-0.78 to 1.12)	0.729	-	-
Timeline cyclical	1.63 (0.70 to 2.55)	0.001	1.33 (0.33 to 2.34)	0.010
Consequences	2.52 (1.17 to 3.86)	0.001	2.00 (0.60 to 3.42)	0.006
Personal control	-1.22 (-2.34 to -0.11)	0.032	-0.83 (-2.03 to 0.37)	0.176
Emotional representations	1.69 (0.31 to 3.06)	0.017	1.58 (0.08 to 3.08)	0.039
Illness coherence	-1.36 (-2.42 to -0.31)	0.011	-1.29 (-2.45 to -0.14)	0.029
Treatment control	-0.83 (-1.58 to -0.07)	0.031	-0.48 (-1.28 to 0.31)	0.230
Coping strategies				
Comforting cognitions	1.36 (-0.04 to 2.76)	0.057	-	-
Decreasing activity	1.33 (0.15 to 2.51)	0.027	0.64 (-0.61 to 1.88)	0.316
Diverting attention	1.61 (0.39 to 2.82)	0.010	1.34 (0.02 to 2.66)	0.047
Optimism	0.58 (-0.29 to 1.44)	0.190	-	-
Pacing	1.72 (0.16 to 3.29)	0.031	0.87 (-0.73 to 2.46)	0.286
Creative solution seeking	1.0 (-0.14 to 2.14)	0.086	-	-
Acceptation	0.24 (-0.86 to 1.33)	0.670	-	-
Consideration	1.11 (0.11 to 2.11)	0.030	1.18 (0.10 to 2.27)	0.033
Illness outcomes				
Mental health	-3.61 (-6.25 to -0.97)	0.008	-3.10 (-5.99 to -0.23)	0.035
Physical health	-9.00 (-11.40 to -6.12)	<0.001	-7.22 (-9.68 to -4.77)	<0.001
Activity impairment	0.21 (0.14 to 0.29)	<0.001	0.15 (0.07 to 0.23)	<0.001
Work impairment	0.11 (0.01 to 0.20)	0.030	0.09 (-0.02 to 0.20)	0.094

*Beta's shown in the multivariate model represent the value for the variable 'arthropathies' adjusted for demographic characteristics (type of IBD, gender, active IBD, smoking, employment status and 5-ASA).

Table 3. Changes in illness perceptions, coping strategies and illness outcomes in IBD patients with arthropathies in 1-year follow-up.

	IBD patients with arthropathies t = 0 (n=123)	IBD patients with arthropathies t = 12 (n=111)	P-value*
Illness perceptions, mean (SD)			
Identity	4.95 (2.83)	4.97 (2.87)	0.95
Timeline chronic	26.08 (3.39)	26.12 (2.73)	0.92
Timeline cyclical	14.68 (2.91)	14.79 (2.66)	0.67
Consequences	19.50 (4.40)	19.79 (4.64)	0.34
Personal control	17.00 (3.77)	17.11 (3.96)	0.72
Emotional representations	16.08 (5.02)	15.58 (5.36)	0.18
Illness coherence	18.15 (3.97)	18.43 (3.89)	0.45
Treatment control	15.53 (2.83)	14.56 (3.05)	0.001
Coping, mean (SD)			
Comforting cognitions	26.63 (4.49)	26.45 (4.37)	0.64
Decreasing activity	18.41 (3.77)	18.70 (4.26)	0.35
Diverting attention	19.36 (3.99)	19.30 (4.10)	0.89
Optimism	14.94 (3.09)	14.86 (3.13)	0.78
Pacing	24.13 (5.37)	25.16 (5.49)	0.03
Creative solution	20.31 (3.96)	20.66 (4.46)	0.42
Accepting	12.82 (3.86)	13.15 (3.65)	0.35
Consideration	19.38 (3.48)	19.54 (3.11)	0.61
Illness outcomes, mean (SD)			
PCS	43.42 (9.00)	43.76 (9.28)	0.63
MCS	45.33 (10.16)	45.36 (10.16)	0.98
Work impairment (n)	0.29 (0.29) (n=68)	0.27 (0.27) (n=62)	0.78
Activity impairment	0.43 (0.27)	0.40 (0.28)	0.26

SD = Standard Deviation. *Mixed model analysis.

