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RESEARCH PAPER

Social participation in early and established rheumatoid arthritis patients

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ABSTRACT

Purpose: The aim of the study was to examine whether rheumatoid arthritis (RA) patients with different levels of restriction in social participation differ in disease related as well as psychosocial variables and whether a similar pattern can be found among early and established RA patients. *Method*: Two samples of RA patients with early ($n = 97$; age $= 53 \pm 12.3$ years; disease duration $= 2.8 \pm 1.2$ years; 76% women) and established ($n = 143$; age $= 58 \pm 10.3$ years; disease duration $= 16.1 \pm 3.6$ years; 86% women) were collected. The pattern of differences for the patients with different level of participation restriction (no restriction, mild, moderate or high restriction) was explored by the Jonckheere–Terpstra test. *Results*: Significant differences were found between patients with different levels of social participation restrictions in both samples in pain, fatigue, functional disability, anxiety, depression and mastery. Generally, it was found that patients with higher restrictions experienced more pain and fatigue, more anxiety and depression and reported lower mastery. Similar pattern of differences concerning disease activity and self-esteem was found mainly in the established group. *Conclusions*: The study shows that the level of perceived restrictions in social participation are highly relevant regarding the disease related variables such as pain, fatigue and functional disability as well as psychological status and personal resources in both early and established RA.

➤ IMPLICATIONS FOR REHABILITATION

- Supporting involvement and participation of individuals with rheumatoid arthritis is important for decreasing the impact of RA symptoms on everyday life.
- Recognition and empowerment of individual resources such a mastery and self-esteem of RA patients could be beneficial for overcoming restrictions in participation.

KEYWORDS
Anxiety, depression, functional disability, participation, rheumatoid arthritis

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Introduction

Social participation has been defined in the International Classification of Functioning, Disability and Health (ICF) as an involvement in life situations [1]. Life situations are represented by a spectrum of different domains such as social, economic, civic, interpersonal, domestic or educational. Health-related factors as well as environmental factors and personal factors are understood to be interactively related to and affect social participation [1,2]. Recent literature on variables associated with decreased social participation in the general population includes mainly variables such as older age, lower basic mobility, worse balance confidence and worse activity level [3,4]. However, this is understood to not be a straightforward relationship and studies show that a broad range of variables affect social participation [3,5]. This is especially relevant for chronic diseases, which are incurable and may cause irreversible and lifelong changes in performing various activities and this way impose significant restrictions in participating in life situations [6,7].

We focus on social participation among a very specific chronic disease rheumatoid arthritis (RA). The current inability to cure RA highlights the importance of social participation in the broadest sense. Like other chronic diseases RA affects performance in life activities; for example it significantly affects the ability to work, pursue hobbies or perform other valued activities [8]. In addition, in RA social roles might also become

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threatened as a consequence of decreased function and erratic pattern of the disease [9–11]. Regarding psychological functioning, persons with RA have been found to be at risk for increased levels of anxiety and depression [12,13]. Current studies show that especially valued activities involving participation in social activities are significantly associated with anxiety and depression and psychological distress was found to be the most important variable associated with social participation [8,14]. Thus, restrictions in participation in different life activities might be significantly associated with RA and its symptoms and furthermore this might be substantially influenced by the social environment [2,6].

The impact that RA imposes on an individual patient can be more or less obvious to the social environment and due to the erratic pattern of disease activity in RA fluctuations in functional disability exist [9]. As a result of this inconsistency social expectations may vary according to the present status of the patient. For example, patients with RA may often be misinterpreted to be lazy by their social environment. On the other hand, when the symptoms are visible the other propensity of seeing the disease rather than the person might result in social exclusion. This is especially important when considering the possibilities for social participation of RA patients and stresses the importance of social environment and personal resources when trying to stay socially active when living with RA [8].

According to the ICF, restrictions or limitations in participation should be assessed against a generally accepted standard such as comparing an individual's capability and performance to an individual without a similar health condition [1]. This concept of comparisons with others from the patient's social environment and especially with healthy peers as employed by the ICF might be relevant in the RA, especially regarding the understanding of how RA negatively affects one's self-worth and especially self-esteem. While participation in RA has been up to present addressed mostly with respect to the decreased functional level there is a need to apply broader measures which take into consideration patient's perspective and acknowledge the role of social and personal resources [15–18].

Well recognized constructs such as self-esteem and mastery constitute important personal resources that have been shown to be related to various aspects of RA [19,20]. These resources might be highly relevant for social participation [5,8]. When the disease progresses the inability to keep up with one's peers might negatively affect one's self-worth and especially self-esteem [20,21]. Furthermore, mastery understood as the extent to which people believe that they have control over their physical and interpersonal environments is also highly relevant for remaining active [22–24].

The aim of the study was to examine whether RA patients with different levels of restriction in social participation differ in disease-related variables such as pain, fatigue, functional disability as well as psychosocial variables such as self-esteem and mastery and whether a similar pattern can be found among early and established RA patients.

Methods

Samples

The study samples were recruited at rheumatology outpatient clinics in Eastern Slovakia. Two separate samples consisted of early RA patients with the disease duration of 4 years or less according to the protocol of the original EURIDISS project [25] and established RA patients with disease duration of 12 years or more as it has been defined for the purposes of the Slovak continuation of the EURIDISS project. Essential inclusion criteria were the fulfillment of at least four criteria of the American College Rheumatology Criteria [26], diagnosis within the above specified range of time and absence of other serious chronic diseases. The study was approved by the local Ethics Committee and the patients provided informed consent prior to participation in the study.

In the established group, 222 patients were approached and 157 (71%) agreed to participate. Fourteen patients were excluded from the current study due to missing data on social participation restrictions leaving the response rate of 143 (age = 58 ± 10.3 years; disease duration = 16.1 ± 3.6 years; 86% women) patients. In the early patient group, 143 patients were approached and 112 (78%) agreed to participate. Fifteen patients were excluded due to missing data on social participation leaving 97 patients for analysis (age = 53 ± 12.3 years; disease duration = 2.8 ± 1.2 years; 76% women).

Participating patients underwent routine examination by a rheumatologist. Next, patients participated in a structured interview with a trained interviewer lasting about 90 min and completed self-report and interview based questionnaires regarding pain, fatigue, functional disability, social participation, anxiety, depression, self-esteem and mastery.

Measures

Sociodemopraphic data

Sociodemographic data such as age, gender and data concerning education and employment status were obtained via a self-report questionnaire. Age was treated

as continual variable. Patients indicated their highest level of achieved education which was categorized into elementary, secondary and university education and similarly provided information on the current employment status (working/unemployed, retired, disabled – officially recognized significantly reduced work ability with entitlement to government benefits).

Clinical data

Disease activity was assessed via the Erythrocyte Sedimentation Rate during the first hour and tender as well as the swollen joint count. Patients assessed their disease activity on a visual analog scale and a comprehensive Disease Activity Score (DAS 28) [27] was calculated for each patient.

Functional disability

Functional disability was measured using the 20-item Health Assessment Questionnaire (HAQ) [28]. HAQ is a standard and reliable measure frequently used in rheumatologic practice and research to assess the level of functional disability meaning functional difficulty in performing specific tasks of self-care. Respective items of the measure reflect activities of daily life and respondents indicated how much difficulty they have in performing these activities on a four-point scale ranging from ''without difficulty'' (0) to ''unable to do'' (3) with higher score indicating more functional difficulty. In addition, within the measure the respondents provided information about using of assisting devices, which is included in the total final score ranging from minimum 0 to maximum 3 with higher score indicating higher disability. Chronbach's alpha in the samples was found to be 0.96 for both samples.

Pain

Pain was measured using a subscale of the Nottingham Health Profile (NHP), a generic self-report measure [29]. The pain subscale contains eight items referring to the experience of pain. Each item can be answered either yes or no. The sum of all answers creates the total score, a higher score indicating more pain [29]. Cronbach's alpha for this subscale was 0.81 and 0.84 in the samples.

Fatigue

Fatigue was similarly addressed using a subscale of the NHP [29]. The fatigue subscale contains three items referring to the experience of pain. Each item can be answered either yes or no. The sum of all answers creates the total score [29,30], a higher score indicating more fatigue. Cronbach's alpha for this subscale was 0.75 and 0.80.

Anxiety and depression

The Hospital Anxiety and Depression Scale (HADS) has been frequently used among the RA population for assessing the levels of anxiety and depression [30]. In this instrument, patients were asked to answer each question assessing the level of recent symptoms on a four-point Likert type scale. The entire scale consists of two subscales of seven items addressing anxiety and seven items addressing depression. The score of each scale ranged from 0 to 21 and a higher score indicated more anxiety or more depression [30]. The scale was found to be sufficiently reliable with Cronbach's alpha of 0.79 and 0.80 for anxiety and 0.82 and 0.64 for depression in the studied samples.

Self-esteem

Self-esteem was measured by the Rosenberger Self-Esteem Scale [31]. This scale consists of five positively and five negatively formulated items evaluating one self. Each item is evaluated on a four-point Likert type scale, where respondents indicate the level of agreement with each statement. A higher score indicates higher self-esteem. This scale has shown good psychometric properties and has been frequently applied in samples of RA patients. Cronbach's alpha in the study samples was found to be 0.85 and 0.82 for the whole scale.

Mastery

Mastery was measured by the Pearlin–Schooler Mastery Scale which measures the sense of global personal control [32]. The scale consists of seven items of which two apply reverse scoring. Each item is evaluated on a five-point Likert type scale on which respondents indicate agreement or disagreement with each statement. The score ranges form 7 to 35 with higher score indicating higher sense of mastery. The scale has shown acceptable psychometric properties in general population as well as on samples of patients with chronic disease. Cronbach's alpha for the scale was 0.65 and 0.75.

Social participation

Social participation was measured by the Participation Scale developed for patients with chronic conditions [33]. The scale is based on the ICF. In this instrument respondents indicate whether they perceive to have the

same opportunities to take part in different life situations when they compare themselves with their healthy peers. Such comparisons have been shown to be important for patients' goals in everyday functioning and overall well-being [33,34]. Then, they indicate the extent of the participation restriction ranging from no problem to large problem. The whole scale consists of 18 items. However, item 16 referring to ''keeping utensils with others'' was not applied in this study as it is more relevant for infectious disease. Cut-off scores distinguishing the level of participation restrictions have been created and were applied in the current study as follows 0–12 ''no restriction'', 13–22 ''mild restriction'', 23–32 ''moderate restriction'', 33–52 ''severe restriction'' and above 52 ''extreme restriction''. The scale showed very good psychometric properties in both studied samples. Cronbach's alpha for the scale in the studied samples was 0.85 and 0.89.

Statistical analysis

Means, standard deviations, frequencies and percentages were calculated for the studied samples and compared by *t*-tests and chi-square tests for differences. Further due to smaller sample size, of groups with different participation restrictions, non-parametric statistical procedures were applied in order to address the research question. Medians and inter-quartile range were computed for each variable. The overall pattern of differences in disease related variables and psychosocial variables for patients with different level of participation restrictions (''no restriction'', ''mild restriction'', moderate restriction'' or ''high restriction'') was explored by the Jonckheere–Terpstra test. This was followed by the Mann–Whitney *U* test to specify differences between individual groups. The effect size of the detected differences was assessed by the *r*-effect size coefficient with the suggested level of the effect size by Cohen as follows: small effect size, $r = 0.1–0.20$; medium, $r = 0.20–0.50$; large, $r = 0.50$ or higher [35].The analyses were performed for both studied samples separately. All data were analyzed using SPSS-16 (Released 2007. SPSS for Windows, Version 16.0, SPSS Inc., Chicago, IL).

Results

The early and established samples were found to differ in age, disease duration and the established group was found to be more female. Regarding the employment status and working abilities significantly more patients still worked in the early RA sample and significantly more patients were disabled among the established group. Furthermore, the established patients showed worse functional status when assessed by the HAQ but further differences regarding psychosocial variables or social participation were not detected as seen in Table 1.

As displayed in Table 2, a gradual increasing tendency of the median was found in all measured variables across groups except for disease activity, where the median

Table 1. Summary statistics and descriptive statistics of the early and the established RA samples.

	Early RA	Established RA	
	Mean (SD)/%	Mean (SD)/%	*p* Value
Age	53.3 (12.3)	57.8 (10.3)	0.000
Gender (female)	76%	86%	0.054
Married	71%	70%	NS
Living alone	10%	13%	NS
Disease duration	2.8 (1.2)	16.1 (3.6)	0.000
Working	38%	21%	0.000
Retired	32%	34%	NS
Disabled	21%	44%	0.000
University education	16%	11%	NS
SP no restriction	47%	46%	NS
SP mild restriction	29%	25%	NS
SP moderate	14%	16%	NS
SP high	10%	14%	NS
Disease activity (DAS28)	4.09 (1.28)	4.09 (1.40)	NS
Pain	4.59 (2.50)	4.75 (2.59)	NS
Fatigue	1.64 (1.26)	1.69 (1.22)	NS
Functional disability	1.15 (0.73)	1.38 (0.72)	0.022
Depression	5.44 (3.77)	4.92 (2.98)	NS
Anxiety	7.07 (3.81)	6.27 (3.77)	NS
Self-esteem	29.45 (3.92)	29.68 (4.34)	NS
Mastery	21.65 (4.21)	21.83 (4.82)	NS

Independent *t*-test or chi-square test were applied to test for mean or frequency differences. SP, social participation restriction; ns, non-significant. Pain and fatigue were measured by NHP, functional disability was measured by HAQ, depression and anxiety were addressed by HADS, Self-esteem was measured by Rosenberger Self-Esteem Scale, mastery was measures by Perceived Mastery Scale.

Table 2. Comparison of disease activity, pain, fatigue, functional disability, depression, anxiety, self-esteem and mastery in the RA samples according to the level of participation restrictions separately for the studied groups.

	No restriction		Mild restriction		Moderate restriction		High restriction			
	$N = 46$		$N = 28$		$N =$v13		$N = 10$			
Early RA	Median	(IQR)	Median	(IQR)	Median	(IQR)	Median	(IQR)	*p*	*r*
Disease activity (DAS 28)	3.8	(3.1–4.8)	4.3	(3.0–5.1)	4.3	(3.3–5.4)	4.9	(3.4–5.7)	0.370	0.09
Pain	4	(2–6)	6	(3–7.75)	6	(5–7.5)	5.5	(3.75–7.25)	0.002	0.31
Fatigue	1	(0–2.5)	2	(0–3)	3	(1.25–3)	3	(1.75–3)	0.005	0.21
Functional disability	1	(0.5–1.38)	1	(0.25–1.63)	1.38	(1.31–2)	2.06	(1.21–2.28)	0.002	0.31
Anxiety	6	(3.5–7.5)	6	(4.25–8.75)	8	(4.5–12)	9.5	(6.75–13.25)	0.004	0.28
Depression	4	(2–6)	5	(3–7)	8	(4–11.5)	8	(5.25–10.25)	0.000	0.37
Self-esteem	29.5	(28–32)	29	(27–32)	29	(27.25–30.5)	27	(24–30)	0.024	0.23
Mastery	24	(21–26)	21	(19–23)	20	(18–23.5)	18.5	(16.75–21.25)	0.000	0.45
Established RA	$N = 65$		$N = 35$		$N = 23$		$N = 20$			
Disease activity (DAS 28)	3.6	(2.7–4.4)	4.9	(3.9–5.5)	4.8	(3.6–5.2)	4.9	(3.4–5.7)	0.000	0.29
Pain	4	(2–6)	6	(3–7)	7	(3–8)	6	(4–8)	0.000	0.34
Fatigue	1	(0–2.5)	2.5	(1–3)	3	(1–3)	2	(2–3)	0.000	0.30
Functional disability	1	(0.44–1.5)	1.5	(1.28–2)	1.88	(1.13–2.25)	1.75	(1.25–2.38)	0.000	0.43
Anxiety	4	(2–7)	7	(4.75–9)	8	(4–11)	9	(5.25–11)	0.000	0.42
Depression	3	(2–5)	5.5	(3–7)	5	(3–8)	7	(5.25–9)	0.000	0.40
Self-esteem	31	(29–35)	29	(26.5–31.5)	29	(28–31)	27	(23–28)	0.000	0.37
Mastery	24	(21–26.25)	20	(18–23)	19	(16–21.75)	20	(17-22)	0.000	0.39

IQR, inter quartile range. Differences between groups were analyzed by Jonckheere–Terpstra test. *r* – overall effect size of the test.

differences were not found to be significant in the early RA group. In the early RA sample, small to medium overall effect sizes were observed regarding most differences. Furthermore, the largest effect size was observed in mastery. In the established sample differences were observed in disease activity, functional disability, anxiety and depression, self-esteem and mastery with medium effect sizes. Generally, a gradual tendency in the pattern of differences according to participation restrictions was shown in both samples. Overall, patients with higher restrictions in social participation reported more pain, more fatigue, worse functional disability, more anxiety and depression as well as lower levels of mastery. Regarding self-esteem the results were less clear, especially in the early RA sample where a pattern was not found to be the same as in other variables.

As shown in Table 3 in the early sample most significant differences were observed between the group with ''no restriction'' and the groups with ''moderate restriction'' and ''high restriction'' in social participation. A medium effect size in statistically significant differences was observed in mastery between the group ''no restriction'' and the group with ''high restriction'' in social participation. While in the established sample a similar pattern was observed, more significant differences were found when the ''no restriction'' and the ''mild restriction'' groups were compared. These analyses produced small to medium effect sizes in statistically significant differences. Nevertheless, the highest significant differences were similar to early RA sample observed when the group with ''no restriction'' was compared with the ''high restriction'' group. Medium effect sizes in differences were also observed in functional disability, anxiety and depression. Differences were also detected in self-esteem but the pattern was less clear and when compared with group of moderate restriction only a borderline level of significance was reached. Finally, differences in mastery were observed when the group with ''no restriction'' was compared with all other groups. This was similar to the early RA sample and produced a medium effect size.

Discussion

The study explored differences in disease-related variables such as disease activity, pain, fatigue, functional disability, psychological functioning and personal resources in RA patients with different levels of perceived restriction regarding social participation. The analysis was carried out among the early and the established RA samples separately with the further aim to examine the pattern of differences in the explored groups.

We have found that patients who reported more restrictions in social participation tended to report more pain, more fatigue and worse functioning disability regardless of whether they belonged to the early or the established RA sample. The findings showed a clear pattern and the level of perceived restrictions in social participation reflected different symptoms of RA quite accurately. However, the fact that the two investigated

Table 3. Effect sizes of significant differences between groups with different level of social participation restriction in measured variables in the early and established RA samples.

	SP1–SP2	SP1–SP3	SP1–SP4	SP2–SP3	SP3–SP4
Early RA					
Disease activity	NS	NS	NS	NS	NS
Pain	0.24*	0.36**	NS	NS	NS
Fatigue	NS	0.27*	0.30*	NS	NS
Functional disability	NS	0.32*	0.36**	NS	NS
Anxiety	NS	0.37**	0.36***	0.38**	NS
Depression	NS	NS	0.33*	0.41**	NS
Self-esteem	NS	NS	0.33*	NS	NS
Mastery	0.35**	0.35**	0.48***	NS	NS
Established RA					
Disease activity	0.37***	0.24**	0.23*	NS	NS
Pain	0.26**	0.31**	0.33**	NS	NS
Fatigue	0.35***	0.28**	0.29**	NS	NS
Functional disability	0.34***	0.42***	0.41***	NS	NS
Anxiety	0.36***	0.35***	0.41***	NS	NS
Depression	0.29**	0.29*	0.48***	0.28*	NS
Self-esteem	0.26**	NS	0.47***	0.33*	0.39*
Mastery	0.35***	0.41***	0.36***	NS	NS

Displayed values are effect sizes (r); differences were tested for significance applying Mann–Whitney U test. SP1, "no restriction" in social participation; SP2, "mild restriction" in social participation; SP3, "moderate restriction" in social participation; SP4, "high restriction" in social participation.
*$p < 0.05$,
**$p < 0.01$,
***$p < 0.001$; NS, not significant.

groups of patients did not differ significantly in most of the assessed variables limits the interpretation regarding the second part of the study aim. Since the criteria for early RA included patients with disease duration up to 4 years might have caused that they were already adjusted and thus did not significantly differ from the established group with a much longer disease duration.

Generally, the results suggest that applied concept of peer comparisons could be suitable in the RA context. Specifically, within this approach patients' view is acknowledged and such assessment seems to be sensitive enough to the specificity of the environmental needs of an individual. This is highly relevant to current concepts of social participation and in line with the recent influential study of Hammel et al. [36]. However, it must be also mentioned that disease activity was found to follow the same pattern only in the established group and differences were not found in the early RA sample. Relating the findings to the current research more generally, it can be said that studies applying other assessment methods of social participation or addressing other chronic diseases showed similar results [15,33].

Furthermore, patients with higher restrictions in social participation reported more feelings of anxiety and depression which was confirmed in both studied samples. This is an important finding as it shows the far reaching importance of psychological functioning in RA [19]. Provided that participation restrictions were assessed using the concept of peer comparisons a bi-directional relationship between anxiety, depression and the perceptions of restriction in social participation must be considered [19,21,37].

Next, the personal resources of self-esteem and mastery were explored. The role of self-esteem has been shown to be associated with general adjustment to the RA especially among the established patients where significant differences were found between all groups with different levels of social participation except for one while in the recent RA only the patients with the highest and the lowest social participation differed in personal mastery consistently according to the level of participation restrictions in both groups. Significant differences were found even between groups without restriction and mild restriction. Mastery has been found to be related to various aspects of adaptation in chronic diseases including RA [24,37]. From the results that are shown in this study it seems to be strongly related to social participation.

Overall the study has found a clear pattern of associations between the level of restriction in social participation and symptoms of RA, anxiety and depression as well as mastery in both studied samples. Self-esteem showed such a clear pattern only in the established sample, similarly to disease activity. Generally, the demonstrated close associations of social participation with disease-related variables emphasize the importance of social participation in RA patients and also provide certain support for the utility of the peer comparison concept when assessing social participation within the RA context.

Strengths and limitations

The current study has a number of strengths. In particular, the research design allowed the research question to be investigated twice in two samples consisting of patients with different disease duration. Within this design the repeated investigation produced more substantial support for the findings. Furthermore, the concept of peer comparisons regarding social participation is relatively new and produced significant results when examined against relevant disease related and psychosocial variables for RA patients.

However, the limitations of the study must be discussed. The early RA group used in this study consisted of patients with disease duration long enough to adjust and this way when compared with the patients with substantially longer period of RA only few differences were found. It must be critically admitted that in order to address the changes in social participation it is necessary to focus on the period immediately following the diagnosis. It has to be mentioned that similar issue could be significant in relation to the established RA patients. While various lengths of disease duration have been used in different studies this study used the period of twelve years which is to certain extent arbitrary. It is important that the future research focuses on the dynamics of the changes and studies them longitudinally.

Furthermore, the statistical results are based on non-parametric tests, which impose limitations for the statistical power of the findings regarding their statistical inference. It would be useful in the future research to employ larger samples to verify the findings and especially apply multivariate approach. Lastly, it must be also mentioned that cross-sectional data on which the analyses were based do not allow drawing causal conclusions about the associations.

Implications

Data regarding social participation are needed for monitoring, program planning and conducting interventions among RA patients. These data are crucial for targeting-specific aspects of the disease in an individual patient in relation to his/her unique restrictions in social participation. As the current study shows the level of perceived restrictions in participation, based on comparisons with peers, reflects the levels of pain, fatigue, functional disability, anxiety and depression but also self-esteem, mastery and disease activity in established RA. In order to improve patient's quality of life it might be beneficial to consider the interactive relationship between the aspects of RA, personal resources and social participation.

Declaration of interest

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