Social participation in early and established rheumatoid arthritis patients

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(pending revision)

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±12.3years; disease duration=2.8±1.2years; 76%women) and established (n=143; age= 58±10.3years; disease duration= 16.1±3.6 years; 86%women) RA 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 only 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.

Keywords: social participation restrictions, rheumatoid arthritis, functional disability, personal resources, anxiety, depression

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. In this way they impose significant restrictions in participating in life situations [4,6,7].

It social participation among a very specific chronic disease rheumatoid arthritis (RA) that will be the focus. The current inability to cure RA highlights the importance of social participation in the broadest sense [4,8]. 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. In addition, in RA social roles might also become threatened as a consequence of decreased function and erratic pattern of the disease [9,13]. Regarding psychological functioning, persons with RA have been found to be at risk for increased levels of anxiety and depression [14,15]. Current studies show that especially valued activities involving participation in social activities are significantly associated with anxiety and depression and psychological distress was the most important variable associated with social participation [7,8,13,16,17]. Thus restrictions in participation in different life activities might be significantly associated with RA and its symptoms. 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 ofte be misinterpreted to be lazy by those in 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 the importance of the social environment and personal resources when trying to stay socially active when living with RA [8,13].

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 RA. By this, the understanding of how RA interferes with personal and social lives from the point of view of the patients themselves. Participation in RA recently addressed with respect to the decreased functional level shows that there is a need to apply broader measures which take into consideration the patient´s perspective and

acknowledge the role of social and personal resources [18,19-22].

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 [23-24]. These resources might be highly relevant for social participation [5,16]. When the disease progresses the inability to keep up with one's peers might negatively affect one's self worth and especially self-esteem [24-26]. Further, 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 in social life [27-29].

Based on the aforementioned the aim of the study is to explore whether statistically significant differences can be found in disease related variables such as pain, fatigue, functional disability and personal resources such as self-esteem and mastery between patients who report different levels of restriction regarding social participation. A further aim is to examine the pattern of differences in early and established forms of RA.

Methods

Sample

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 four years or less and established RA patients with disease duration of 12 years or more. Essential inclusion criteria were the fulfillment of at least 4 criteria of the American College Rheumatology Criteria (ACR) [30], 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. An additional 14 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. An additional 15 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 ninety minutes 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 a continual variable. Patients indicated their highest level of educational achievement which was categorized into elementary, secondary and university education and similarly provided information on the current employment status (working/ unemployed, retired, disabled,).

Clinical data

Disease activity was assessed via the Erythrocyte Sedimentation Rate (ESR) during the first hour and tender as well as the swollen joint count. Patients assessed their disease activity on a visual analogue scale and a comprehensive Disease Activity Score (DAS 28) [31] was calculated for each patient.

Functional disability

Functional disability was measured using the 20-item Health Assessment Questionnaire (HAQ) [32]. HAQ is a standard and reliable measure frequently used in rheumatologic practice and research to assess the level of functional disability. 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 [33]. The pain subscale contains 8 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 [33]. 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 Nottingham NHP [33]. The fatigue subscale contains 3 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 [33], 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 [34]. 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 7 items addressing anxiety and 7 items addressing depression. The score of each scale ranged from 0-21 and a higher score indicated more anxiety or more depression [34]. 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 [35]. This scale consists of 5 positively and 5 negatively formulated items evaluating one self. All responses were calculated separately forming positive and negative evaluation of oneself and also a combined single score was applied. Current studies support this approach and it was applied by this study [35]. Each item is evaluated on a four point Likert type scale where respondents indicate the level of agreement with each statement. Higher score indicates higher positive and negative self-esteem. Next the overall score indicates the overall level of 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 [36]. The scale consists of 7 items of which two apply reverse scoring. Each item is evaluated on a 5 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 (SP) was measured by the Participation Scale developed for patients with chronic conditions [37]. The scale is based on the International Classification of Functioning, Disability and Health (ICF) [1]. In this instrument respondents indicate whether they perceive themselves to have the same opportunities as their healthy peers or not to take part in life situations. These situations are related to mobility, self care, communication, learning and applying knowledge, domestic life, community life, interpersonal relationships, social life and major life areas. After identifying the areas of perceived restriction the respondents are asked to indicate the

extent to which they see each restriction as a problem in their life with possible answers 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 [37] and were applied in the current study as follows 0-12 "no restriction" (SP1) , 13-22 "mild restriction" (SP2), 23-32 "moderate restriction"(SP3), above 33 "high restriction"(SP4). 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. Furthermore due to smaller sample size of groups with different participation restrictions, non parametric statistical procedures were applied in order to address the research question. The median and inter-quartile range was 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: trivial effect size $r<0.1$; small effect size, $r= 0.1 - 0.23$; medium, $r= 0.24 - 0.36$; large, $r = 0.37$ or higher [38].The analyses were performed for both studied samples separately. All data were analyzed using SPSS-16.

Results

The early and established samples were found to differ in age and disease duration. 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. Further, the established patients showed worse functional status when assessed by the Health Assessment Questionnaire (HAQ) but further differences regarding psychosocial variables or social participation were not detected as seen in Table 6.1.

Table 6.1 Summary statistics and descriptive statistics of the early and the established RA samples

	Early RA Mean (SD)/%	Established RA 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%	0.004
Retired	32%	34%	Ns
Disabled	21%	44%	0.000
Unemployed	6%	1%	0.000
University education	16%	11%	Ns
SP1* no restriction	47%	46%	Ns
SP2 mild restriction	29%	25%	Ns
SP3 moderate	14%	16%	Ns
SP 4high	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 (global)	29.45 (3.92)	29.68 (4.34)	Ns
Positive self-esteem	15.17 (2.00)	15.35(2.05)	Ns
Negative self-esteem	10.73 (2.51)	10.70 (2.72)	Ns
Mastery	21.65 (4.21)	21.83(4.82)	Ns

Note 1 Independent t-test or chi square test were applied to test for mean or frequency differences
*Note 2 *abbreviation SP - social participation restriction; Ns – non significant*
Note 3 Pain and Fatigue were measured by Nottingham Health Profile, Functional disability was measured by Health Assessment Questionnaire, Depression and Anxiety were addressed by Hospital Anxiety and Depression scale, Self-esteem was measured by Rosenberger Self-esteem Scale, Mastery was measures by Perceived Mastery Scale
Note 4 SP1 "no restriction" in social participation, SP2 "mild restriction" in social participation, SP3 "moderate restriction" in social participation, SP4 "high restriction" in social participation

As displayed in Table 6.2 a gradual increasing tendency of the median was found in all measured variables across groups except for disease activity and negative self-esteem where the median 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 while differences regarding depression produced a large effect. Moreover, the highest 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 a large effect and other significant differences produced a medium effect. 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.

Table 6.2 Comparison of 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		p	r
	Median	(IQR)	Median	(IQR)	Median	(IQR)	Median	(IQR)		
Early RA	N=46		N=28		N=13		N=10			
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 (total)	29.5	(28-32)	29	(27-32)	29	(27.25-30.5)	27	(24-30)	0.024	0.23
Self-esteem (positive)	15	(15-16.75)	15	(14-15)	14.05.12	(14-15)	14	(12.75-16)	0.002	0.32
Self-esteem (negative)	11	(9-12)	11	(9-11.5)	11	(9.25-12)	12.5	(10.5-14)	0.153	0.15
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 (total)	31	(29-35)	29	(26.5-31.5)	29	(28-31)	27	(23-29)	0.000	0.37
Self-esteem (positive)	15	(15-17)	15	(14-16.5)	15	(14-16.5)	14	(13-15)	0.000	0.34
Self-esteem (negative)	10	(8-11)	12	(9.5-13)	11	(9-12)	12	(11-14.75)	0.000	0.32
Mastery	24	(21-26.25)	20	(18-23)	19	(16-21.75)	20	(17-22)	0.000	0.39

Note 1 IQR – inter quartile range
Note 2 differences between groups were analyzed by Jonckheere-Terpstra test
Note 3 r – overall effect size of the test
Note 4 SP1 "no restriction" in social participation, SP2 "mild restriction" in social participation, SP3 "moderate restriction" in social participation, SP4 "high restriction" in social participation

As shown in Table 6.3 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 large effect in statistically significant differences was observed in mastery between the group "without any 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 a small to medium effect in statistically significant differences. Nevertheless, the highest significant differences were similar to the early RA sample observed when the group with "no restriction" was compared with the "high restriction" group. Large effects in differences were observed in functional disability, anxiety and depression. Differences were also detected in self-esteem but the pattern was less clear and when compared with the 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.

Table 6.3 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 (total)	Ns	Ns	0.33*	Ns	Ns
Self-esteem (positive)	Ns	0.31*	0.33*	Ns	Ns
Self-esteem (negative)	Ns	Ns	0.28*	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 (total)	0.26**	Ns	0.47***	0.33*	0.39*
Self-esteem (positive)	0.20*	Ns	0.43**	0.32*	Ns
Self-esteem (negative)	0.27*	Ns	0.42***	Ns	Ns
Mastery	0.35***	0.41***	0.36***	Ns	Ns

*Note 1 *p< 0.05, **p<0.01,***p<0.001, Ns- not significant*
Note 2 displayed values are effect sizes (r); differences were tested for significance applying Mann-Whitney U test
Note 3 SP1 "no restriction" in social participation, SP2 "mild restriction" in social participation, SP3 "moderate restriction" in social participation, SP4 "high restriction" in social participation

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.

It was 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. These results suggest that the applied concept of peer comparisons was relevant in the RA context. Within this approach the 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 [38]. 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 [18, 37].

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 [23]. 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 [23,25,40].

Next, the personal resources of self-esteem and mastery were explored. Self-esteem was assessed by the positively and the negatively worded items separately. Among the early RA patients no differences were observed in negative self-esteem while in the established group both positive and negative self-esteem significantly differed. The role of self-esteem has been shown to be associated with general adjustment to RA especially later in the disease [24]. Findings of this study show an interesting pattern of associations because positive and negative evaluations of oneself might differ especially in the early phase of the disease when the disease has not become fully part of a patient's life.

Lastly, personal mastery consistently differed 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 [29,41]. 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, similar 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. Firstly, 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, certain limitations of the study must be also acknowledged such as combining objective and subjective measures of participation. In addition, 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 don't 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 this relationship between aspects of RA, personal resources and participation restrictions in various life situations.

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