Living with Rheumatoid Arthritis

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CHAPTER 7

Social participation and health related quality of life in early and established rheumatoid arthritis patients

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(submitted)

Abstract

Purpose: The aim of the study is to explore the associations between restrictions in social participation and health related quality of life (HRQoL) in early and established group of rheumatoid arthritis (RA) patients.

Methods: Two samples with early (n=97; age=53 ±12.3 years; disease duration=2.8 ±1.2 years; 76% women) and established (n=143; age=58±10.3 years; disease duration=16.1±3.6 years; 86% women) RA patients were collected. Social participation restrictions in different life situations were measured by the Participation Scale; HRQoL was addressed by the physical and mental health components of the SF-36 (PCS&MCS). Data were analyzed using hierarchical regression models controlling for the relevant variables.

Results: Perceived social participation restrictions in the group of early and established RA patients were found to be negatively associated with both PCS (β=-0.40; $p \leq 0.01$, β=-0.45; $p \leq 0.01$) and MCS (β=-0.47; $p \leq 0.01$, β=-0.36; $p \leq 0.01$). Further PCS and MCS were associated with pain and fatigue. However in the established RA group pain was found to be associated only with PCS and fatigue only with MCS.

Conclusions: Restrictions in social participation seem to be negatively related to both PCS and MCS. This was relevant in both the early and the established group of RA patients and suggests the importance of participation in the community for HRQoL in RA patients.

Introduction

Health related quality of life (HRQoL) has become a very frequent and relevant study topic in various chronic diseases. Increasing interest has been seen especially in incurable chronic diseases such as Rheumatoid Arthritis (RA) [1-3]. RA is an autoimmune disease characterized by joint

inflammation, pain, fatigue, and physical impairment, which often leads to considerable functional and social disability. Many of its symptoms significantly affect the HRQoL of the patients, which has been shown in many studies [4-6]. Furthermore RA is accompanied by frequent flare-ups and remissions which form an unpredictable course of the disease activity and which elicit feelings of uncertainty especially early in the disease [7].

RA symptoms have been shown to cause problems in different areas of life, for example by reducing or restricting a patient's ability to work, leading to the loss of valued activities and causing problems in taking social roles [5-8]. These symptoms further affect the ability of the patients to take part in different social activities and may impose significant restrictions on social participation [8]. While HRQoL has received a lot of attention and is a well established concept, the concept of social participation has not been sufficiently explored within the context of RA.

Aspects of social participation have often been only partially addressed in RA patients and almost exclusively in relation to functioning in the social environment or in employment [6, 9-11]. RA often restricts patients´ ability to perform different tasks in everyday life especially as a result of the increased functional disability. However, patient's own perception should also be taken into consideration in order to address social participation. For example Groarke et al. [12] demonstrated that the nature of disability and especially how an individual evaluates the impact of her/his disability on everyday life is very important regarding the changes it brings. This is in line with the International Classification of Functioning, Disability and Health (ICF) model which emphasizes that disability should be addressed within the concept of participation which involves personal and social resources [13].

Recently studied factors related to decreased social participation have included older age, lower mobility, worse functional status, and decreased activity levels [14-15]. However, such associations with social participation depend on how social participation is addressed as well as how the specifics of a chronic disease are conceptualized. While functional disability creates activity limitations, social participation should be approached with respect to its specificity as well as a broader individual and social perspective [11-13].

A recent study showed that social participation was closely related to HRQoL and it has been suggested that quality of life and social participation might be somewhat overlapping constructs [15]. It can be argued that these concepts should be clearly distinguished with the application of the ICF framework [13]. While HRQoL in RA has been shown to be closely associated with different aspects of RA such as the levels of experienced pain, fatigue, the level of disease activity and psychological status especially depression, studie are needed to explore how social participation is related to HRQoL itself [16-22]. At this point it is important to emphasize that the crucial issue is what kind of measure is actually used to conceptually measure social participation. In this study we propose that the subjective perception and evaluation of an individual plays the most important role in this process. We adopt the approach of a recently developed measure based on the concept of peer comparisons, which has been suggested as a suitable approach by ICF [14]. Furthermore this concept is in line with the WHO definition of health

and allows distinguishing conceptually HRQoL and social participation in RA context.

The aim of the study is to explore the associations between social participation and health related quality of life in an early and established group of RA patients while controlling for the effect of relevant variables such as sociodemographic variables, pain, fatigue, functional disability, disease activity and depression.

Methods

Sample

The study samples were recruited at rheumatology outpatient clinics in Eastern Slovakia. Two separate samples consisted of early RA patients with a disease duration of four years or less and established RA patients with a 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) [22], diagnosis within the above specified range of time and absence of other serious chronic diseases. The study was approved by the local Ethics Committee (no. 57/2007) 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 restriction leaving 143 participants (age=58±10.3 years; disease duration=16.1±3.6 years; 86% women). 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 participants (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 and completed self-report and interview based questionnaires regarding pain, fatigue, functional disability, social participation, depression and HRQoL.

Measures

Sociodemographic variables

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

Clinical data

Disease activity was assessed via the Erythrocyte Sedimentation Rate (ESR) during the first hour and tender as well as swollen joint count. Patients assessed their functional status on a visual analogue scale and Disease Activity Score (DAS 28) was calculated for each patient [21].

Functional disability

Functional disability was measured using the 20-item Health Assessment Questionnaire (HAQ) [23]. 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 provide information about using of assisting devices, which is included in the total final score ranging from 0-3 with the higher score indicating more disability. Chronbach´s alpha was 0.96 for both groups.

Pain

Pain was measured using the subscale of the Nottingham Health Profile (NHP), a generic self-report measure. 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 [24-25]. Cronbach's alpha at baseline for this scale was 0.81 and 0.84 in the samples.

Fatigue

Fatigue was measured on a 100 mm visual analogue scale with 0 indicating no fatigue and 100 indicating the highest possible fatigue.

Depression

Depression was addressed applying the depression subscale of the Hospital Anxiety and Depression Scale (HADS). The HADS has been frequently used among the RA population. In this instrument patients were asked to answer each question assessing the level of recent symptoms on a four-point Likert type scale. The scale consists of 7 items addressing different symptoms of depression. The score of the scale ranged from 0-21 and a higher score indicated more depressive symptoms [26]. The scale was found to be sufficiently reliable with Cronbach's alpha of 0.82 and 0.64.

Health related quality of life

The Short form health survey (SF-36) is a generic instrument for measuring perceived health and especially health related quality of life across different populations. The SF-36 has been widely applied among different populations with a chronic disease including rheumatic disease and rheumatoid arthritis.

The scale consists of eight subscales, which can be combined into two parts focusing separately on mental health component (MCS) and physical health component (PCS) with a higher score indicating better HRQoL [3,27]. Cronbach's alpha for MCS 0.90 and 0.87 and for PCS was 0.93 and 0.91 in the study samples.

Social participation

Restrictions in social participation were measured by the Participation Scale constructed for patients with chronic conditions. The scale is based on the International Classification of Functioning, Disability and Health (ICF).In this instrument respondents indicate whether they perceive to have the same opportunities or not to take part in life situations related to mobility, self care, communication, learning and applying knowledge, domestic life, community life, interpersonal relationships, social life and major life areas when they compare them selves with their healthy peers. After identifying the areas of perceived restriction the respondents are asked to indicate the extent to which they see each restriction as a problem with possible answers ranging from no problem to large problem. The total score is caltucated to indicate the level of perceived restrictions in social participation. 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 [28]. The scale showed very good psychometric properties in both studied samples with Chronbach´s alpha 0.85 and 0.89.

Statistical analyses

First, zero order correlations were conducted to reveal significant associations between the studied variables. Next, hierarchical multiple linear regressions were conducted in order to explore the associations between the social participation restrictions and two compound measures of HRQoL, the MCS and the PCS. Five steps were applied in each regression model allowing to successively control sociodemographic variables and other independent variables of pain, fatigue, functional disability, disease activity and depression. All analyses were conducted in SPSS 18.

Results

Descriptive statistics

Firstly, frequencies means and standard deviation of the applied measures were calculated and are displayed in Table 7.1. Studied samples of the early and established patients were checked for differences. The established sample was older, had longer disease duration, more disabled and showed worse functional status.

Table 7.1 Characteristics of the early and the established RA patient groups in measured variables

	Early RA (Disease duration ≤ 4 years)		Established RA (Disease duration ≥ 12 years)		
	Mean/N	SD/%	Mean/N	SD/%	p-value
Gender	74	76%	123	86%	0.054
Age	53.3	12.31	57.82	10.34	0.001
Disease duration	2.80	1.17	16.11	3.61	0.050
Living alone		10%		13%	Ns
Working		38%		21%	0.000
Retired		32%		34%	Ns
Disabled		21%		44%	0.000
Unemployed		6%		1%	0.000
Pain	4.59	2.50	4.75	2.59	Ns
Fatigue	5.65	2.30	5.38	2.30	Ns
Functional disability	1.15	0.73	1.37	0.72	0.022
Disease activity	4.08	1.27	4.08	1.39	Ns
Depression	5.43	3.77	4.92	2.97	Ns
Mental health component	50.65	21.77	55.24	19.51	Ns
Physical health component	35.02	20.09	34.40	18.97	Ns
Social participation restrictions	14.86	11.64	16.54	14.30	Ns

Note 1: differences in means and frequencies were checked by independent t-tests and chi-square tests

Correlation analyses

Correlation analyses were conducted between all studied variables. In the early RA sample PCS and MCS showed high correlations with pain, fatigue and functional disability and depression. The correlation of MCP with disease activity was low but significant. Further MCS and PCS were found to be associated with restrictions in social participation. Additionally, restrictions in social participation manifested significant correlations with pain, functional disability and depression.

Generally a similar pattern of correlations was observed in the established sample, however, contrary to the early RA sample disease activity showed significant correlations with both PCS and MCS and was further related to depression and restrictions in social participation. In addition social participation restrictions were found to be related to fatigue, which was not observed in the early RA sample.

Regression analyses

Hierarchical regression models were applied in both samples exploring the associations of restrictions in social participation on PCS and MCS. Regarding the early RA group in the regression model on the MCS restrictions in social participation showed significant associations in the first step and remained significant until the last step. Furthermore pain and fatigue were found to consistently contribute to the model accounting for 27% of the variance. In the last step depression significantly contributed to the model. The model accounted for 58% of variance in MCS.

Table 7.2 Correlations of the studied variables in the early and established RA groups

											Established RA group	
		1.	**2.**	**3.**	**4.**	**5.**	**6.**	**7.**	**8.**	**9.**	**10.**	**11.**
1.	**Gender**	1	**-0.12**	**-0.06**	**-0.05**	**-0.09**	**-0.15**	**-0.26****	**-0.10**	**0.16**	**0.09**	**-0.07**
2.	**Age**	*0.04*	1	**0.11**	**0.13**	**0.12**	**0.20***	**0.08**	**0.09**	**-0.12**	**-0.02**	**0.09**
3.	**Disease duration**	*-0.19*	*0.15*	1	**0.15**	**0.19**	**0.22**	**0.17**	**0.14**	**-0.19***	**0.05**	**0.11**
4.	**Pain**	*-0.12*	*0.12*	*-0.15*	1	**0.48****	**0.60****	**0.33****	**0.30****	**-0.67****	**-0.37****	**0.34****
5.	**Fatigue**	*-0.26***	*-0.10*	*-0.06*	*0.38***	1	**0.43****	**0.16**	**0.27****	**-0.51****	**-0.45****	**0.30****
6.	**Functional disability**	*-0.21**	*0.07*	*-0.03*	*0.53***	*0.41***	1	**0.37****	**0.32****	**-0.70****	**-0.38****	**0.44****
7.	**Disease activity**	*-0.34***	*0.02*	*-0.22**	*0.32**	*0.20**	*0.40***	1	**0.25****	**-0.35****	**-0.30****	**0.20***
8.	**Depression**	*.0.20*	*0.00*	*-0.07*	*0.27***	*0.49***	*0.36***	*0.11*	1	**-0.37**	**-0.51****	**0.41****
9.	**PCM**	*0.24**	*-0.10*	*0.02*	*-0.67***	*-0.56***	*-0.64***	*-0.20*	*-0.43***	1	**0,57****	**-0.46****
10.	**MCP**	*0.23**	*-0.14*	*-0.01*	*-0.55***	*-0.58***	*-0.54***	*-0.21**	*-0.55***	*0.79***	1	**-0.37****
11.	**SPR**	*0.04*	*-0.03*	*0.01*	*0.30***	*0.18*	*0.36***	*0.08*	*0.37***	*-0.40***	*-0.46***	1
		Early RA group										

Note 1: Early in italics and established in bold
Note 2: PCM – physical component, MCP – mental component, SPR- social participation restrictions
*Note 3: * $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.01$*

In the established RA group the model was found to be less powerful. While restrictions in social participation were still found to be significantly associated with MCS as among the early RA patients, it ceased to be significant after depression was added to the model in the last step. Further only fatigue but not pain were found to be significantly contributing to the model. Overall the model accounted for 35% of the total variance in MCS.

The same model was applied to explore the associations with PCS. In the early RA group restrictions in social participation remained significantly related to PCS throughout the model, where its associations were mostly reduced by adding pain and fatigue in the model, which together accounted for 36% of the variance. Adding depression in the last step did not significantly increase the explained variance. The total explained variance was 62%.

In the established RA group a similar pattern of associations was observed with restrictions in social participation significantly related to PCS throughout all the steps. However, only pain and not fatigue were found to significantly contribute to the model. Similarly adding depression in the last step did not significantly improve the model. The total explained variance was 59%.

Overall an additional interesting pattern was observed. While in the early RA sample there was no distinction between pain and fatigue, and both were significantly related to both aspects of HRQoL. However, in the established group fatigue was associated only with MCS and pain only with PCS.

Discussion

The aim of this study was to explore associations between perceived restrictions in social participation and health related quality of life in an early and established group of rheumatoid arthritis patients while successively controlling for relevant variables.

Firstly, the restrictions in social participation were generally found to be significantly and negatively associated with both the mental health component and the physical component of HRQoL. This trend was confirmed in both groups of early and established RA patients. Hierarchical regression models which allowed controlling for the influence of other variables showed that the strength of the association was reduced by adding other variables into the model; however, this association remained significant and contributed to the models showing that it was uniquely related to HRQoL. It is especially interesting that the pattern of associations observed between social participation and two aspects of HRQoL was found to be of a similar pattern and strength in both studied groups. While an overlap between social participation and HRQoL has been discussed, this study shows that perceived restrictions and peer comparison might be a useful way to conceptually differentiate between these constructs and avoid artificial overlap in the measurement [15,28,30].

Table 7.3 Association of social participation with Mental component of HRQoL in the early and the established RA groups

		Early RA patients					Established RA patients				
		Step1	**Step2**	**Step3**	**Step4**	**Step 5**	**Step1**	**Step2**	**Step3**	**Step4**	**Step 5**
1.	**SPR**	-0.47**	-0.49**	-0.30**	-0.25**	-0.19*	-0.36**	-0.39**	-0.25**	-0.22*	-0.12
2.	**Gender**		0.20*	0.06	0.07	0.06		0.13	0.08	0.04	0.02
	Age		-0.18	-0.14	-0.13	-0.12		-0.08	0.03	-0.02	0.05
	Disease duration		0.08	-0.03	0.00	0.00		0.07	0.10	0.11	0.12
3.	**Pain**			-0.32**	-0.29**	-0.30**			-0.17	0.11	0.06
	Fatigue			-0.37**	-0.34**	-0.25**			-0.30**	-0.29**	-0.27**
4.	**Functional disability**				0.16	0.13				-0.07	-0.07
	Disease activity				0.08	0.07				-0.12	-0.08
5.	**Depression**					-0.23**					-0.33**
R^2 change %		22	7	27	2	3	12	3	14	2	9
Total R^2 %			29	56	58	61		15	18	32	40
Adj.Δ R^2 %						58					35

Note 1: displayed values are betas (β)
Note 2: SPR- social participation restrictions, HAQ – Health Assessment Questionnaire (disability)
*Note 3: * $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.01$*

Table 7.4 Association of social participation with Physical component of HRQoL in the early and the established RA groups

		Early RA patients					Established RA patients				
		Step1	**Step2**	**Step3**	**Step4**	**Step 5**	**Step1**	**Step2**	**Step3**	**Step4**	**Step 5**
.	**SPR**	-0.40**	-0.42**	-0.23**	-0.17*	-0.16*	-0.45**	-0.46**	-0.25**	-0.15*	-0.14*
2.	**Gender**		0.27**	0.09	0.12	0.12		0.12	0.06	0.02	0.02
	Age		-0.12	-0.07	-0.06	-0.06		-0.16*	-0.10	-0.05	-0.06
	Disease duration		0.08	-0.02	0.02	0.02		-0.12	-0.08	-0.04	-0.04
3.	**Pain**			-0.47**	-0.40**	-0.40**			-0.51**	-0.36**	-0.35**
	Fatigue			-0.30**	-0.23**	-0.21*			-0.14	-0.13	-0.13
4.	**Functional disability**				-0.31**	-0.30**				-0.30**	-0.30**
	DAS 28				0.17*	0.17*				-0.07	-0.05
5.	**Depression**					-0.04					0.04
R^2 change %		16	8	36	6	0	20	7	29	5	0
Total R^2 %			24	60	66	66		27	58	63	62
Adj.Δ R^2 %						62					59

Note 1: displayed values are betas (β)
Note 2: SPR- social participation restrictions, HAQ – Health Assessment Questionnaire (disability)
*Note 3: * $p \leq 0.05$; ** $p \leq 0.01$; *** $p \leq 0.01$*

Furthermore, the highest amount of explained variance in all models was attributed to pain and fatigue, which is in line with other studies [16,31,32]. However, in this study a different pattern was observed in the early and the established group. Fatigue was related to the MCS and pain was related to the PCS in the established group. Such a distinction was not shown in the early RA group where both associations were equally strong. It seems that the physical and mental component in the established form of RA is associated with different symptoms and especially the role of fatigue deserves much more attention.

A number of studies have shown that the conceptualization of HRQoL requires at least two dimensions where one is defined as psychological or psychosocial and the second related the physical status [17,33,34]. This distinction was supported in the established RA group. From the point of view of the current findings it is interesting to note that restrictions in social participation were related to both aspects of HRQoL with a similar strength.

The adapted approach to assessing restriction in social participation by peer comparison rather than measures which are directed on frequency of certain behaviors related to participation or number of social activities were found to be relevant to aspects of RA. This approach has been successfully adopted in self-management programs previously but not to assess social participation [35]. Even though there is still much controversy about how social participation should be measured our study shows that in the context of HRQoL the chosen approach seems to constitute a viable route.

Strengths and limitations

The study aim was addressed on two samples consisting of patients with different disease duration. This contributes to the validity of the findings. The distinction of early and established RA groups was defined somewhat arbitrarily. The applied approach to social participation would benefit from a closer look at the changes in participation at the very onset of RA. The concept of the peer comparisons regarding social participation was in this study shown to be significant when addressed in the broader context of HRQoL research. Lastly, the findings of our study are based on cross-sectional data and do not allow drawing causal conclusions about the associations between social participation and HRQoL.

Implications

Based on the present findings it would be beneficial for future research to address the perception of restrictions on social participation very early after the onset of the disease within longitudinal designs. This way it would be possible to detect the contribution of changes in specific aspects of social participation and explore further how these changes are related to HRQoL. Furthermore, taking into consideration restrictions in participation imposed by RA along with changes in functional status as a part of regular treatment might improve targeting psychosocial intervention for individual patients and help to improve or at least maintain their HRQoL.

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