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ORIGINAL ARTICLE

Social Participation and Health Related Quality of Life in Early and Established Rheumatoid Arthritis Patients

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Abstract Social participation has been recognized as one of the key variables to be addressed in disability research yet few studies addressed the association between restriction in participation and quality of life in the context of rheumatoid arthritis. The aim of this study was 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. 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. Respondents completed questionnaires on pain (NHP), fatigue (VAS), functional disability (HAQ), depression (HADS), social participation restrictions (Participation scale) and health related quality of life (SF-36). Data were analyzed using stepwise regression models controlling for the relevant variables. Perceived social participation restrictions in the group of early patients were found to be negatively

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associated with the mental health component of the HRQoL ($\beta = -0.192$; $p \leq 0.05$) and in the established RA group with the physical health component of the HRQoL ($\beta = -0.271$; $p \leq 0.001$). These results generally suggest the importance of social participation with regard to HRQoL in RA.

Keywords Rheumatoid arthritis · Social participation · Health related quality of life

Introduction

Health related quality of life (HRQoL) is a well-established and frequently studied topic in health research and especially in the context of disability. Increasing interest in this concept over the last decades can be seen especially in the research of chronic diseases. More recently, another similarly broad and yet very specific concept of participation has attracted attention of many researchers. The relevance of this concept has been supported by the ICF where participation stands as one of the key constructs (WHO 2002).

While various approaches exist to studying HRQoL, it has been standardized to a large extent in various populations. Participation has been operationalized differently and generally accepted standardized measures are waiting to be developed. The potential overlap between HRQoL and participation is currently a very frequently discussed topic. However, one distinction can be pointed out. HRQoL is usually based on the evaluation of one's state in various health domains or with regard to an overall health status. Participation can be understood more as one's evaluation of involvement in social roles and subjective importance of such involvement (especially in the context of health problems and decreased functioning). Taking advantage of both, the existing standardized measures of HRQoL, as well as more explorative methods for addressing participation, this study will focus on the association between social participation and HRQoL, and this research aim will be limited to and specific for the context of Rheumatoid Arthritis (RA) (Bazzichi et al. 2005; Hill et al. 2007; Wolfe et al. 2010).

RA is an autoimmune disease characterized by joint inflammation, pain, fatigue, and physical impairment, which often lead to considerable functional disability. It has been shown that many of its symptoms significantly affect HRQoL (Doeglas et al. 2004; Nagyova 2005). Furthermore, RA is accompanied by frequent flare-ups and remissions which form an unpredictable course of the disease activity and elicit feelings of uncertainty especially early in the disease (Suurmeijer et al. 2001). RA symptoms have been generally shown to cause problems in different areas of life, for example by reducing or restricting patients' ability to work, leading to the loss of valued activities and causing problems in performing social roles (Krol et al. 1998; Neugebauer et al. 2003). These symptoms further affect the ability of the patients to take part in different social activities and may impose significant restrictions on their social participation (Katz et al. 2006). While the 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 addressed in RA only partially and almost exclusively in relation to functioning or employment (Doeglas et al. 1995; Suurmeijer et al. 1995). It is well known that RA often restricts patients' ability to perform different tasks of everyday life, especially as a result of an increased functional disability. However, patient's own perception should be also taken into consideration in order to address social participation. For example, Groarke (2004) has demonstrated that the nature of disability, and especially how an individual evaluates the impact of her/his disability on everyday life, is very important with regard to 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 includes personal and social resources (WHO 2002).

Recently studied factors related to decreased social participation included older age, lower mobility, worse functional status, and decreased activity levels (Arnadottir et al. 2011; Kuhlow et al. 2010). 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 poses activity limitations, social participation should be approached with respect to context specificity as well as include particular social perspective (Groarke 2004; WHO 2002).

The 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 (Brown 1990; Suurmeijer et al. 2001). However, further research is needed to explore how is social participation related to HRQoL. 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 by an individual plays the most important role in this process. We adopt the approach of a relatively recently developed measure based on the concept of peer comparisons, which has been suggested as a suitable approach guided by ICF (van Brakel et al. 2006; WHO 2002). Furthermore, this concept is in line with 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 among early and established group of RA patients while taking into account other relevant variables such as sociodemographic variables, pain, fatigue, functional disability, disease activity and depression which have been shown to be strongly associated with HRQoL in RA.

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 4 years or less and established RA patients with a disease duration of 12 years or more. Participants were consecutive patients who fulfilled the essential inclusion criteria which consisted of the fulfillment of at least 4 criteria of the American College Rheumatology Criteria (ACR) (Arnett et al. 1988), 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 written informed consent prior to participation in the study.

In the established group 222 patients were approached and 157 (71 %) agreed to participate. 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. 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 made a general health assessment on a visual analogue scale and the Disease Activity Score (DAS 28) was calculated for each patient (Makinen et al. 2005).

Functional Disability

Functional disability was measured using the 20-item Health Assessment Questionnaire (HAQ) (Fries 1991). 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 to 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 with assigned weights

from which a total score is calculated and ranges from 0 to 100. A higher score indicates more pain (Hunt et al. 1981; Macejova et al. 1999). 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 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 to 21 and a higher score indicated more depressive symptoms (Zigmond and Snaith 1983). 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 (Linde et al. 2009; Wolfe et al. 2010). Cronbach's alpha for MCS was 0.90 and 0.87 and for PCS it 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 to take part in different life situations when they compare themselves with their healthy peers. Then they indicate the extent of the participation restriction ranging from no problem to a large problem. The whole scale consists from 18 items with higher score indicating more perceived restriction in social participation (van Brakel et al. 2006). The scale showed very good psychometric properties in both studied samples with Chronbach's alpha 0.85 and 0.89.

Statistical Analyses

Firstly, descriptive statistics was calculated and comparisons between the early and the established samples were explored using t-tests and chi-square tests. Then, zero order

correlations were conducted to explore the associations between the studied variables. Next, stepwise regression models were built in order to explore the associations between the social participation restrictions and two compound measures of the HRQoL, the MCS and the PCS. In these models sociodemographic variables, disease related variables consisting of disease duration, disease activity, pain, fatigue, functional disability, depression and finally social participation restriction were entered in all tested models. These analyses were conducted to explore whether social participation restrictions explain additional variance in the models. All analyses were conducted in SPSS 21.

Results

Descriptive Statistics

Descriptive statistics and sample comparisons are displayed in Table 1. The differences were observed between the studied samples with regard to gender and age where quite naturally the established sample was found to be older and with a longer disease duration. In addition, differences were observed with regard to employment and work status. The established RA patients showed also a significantly higher disability as measured by the HAQ than the early RA patients. Other

Table 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)		*p*-value
	Mean/N	SD/%	Mean/N	SD/%	
Gender (female)	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
Work disabled		21 %		44 %	0.000
Unemployed		6 %		1 %	0.000
Pain	53.15	31.60	54.83	33.46	ns
Fatigue	5.65	2.30	5.38	2.30	ns
HAQ	1.15	0.73	1.37	0.72	0.022
DAS 28	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

Differences in means and frequencies were checked by independent t-tests and chi-square tests

significant differences with regard to health and disease related variables were not found.

Correlation Analyses

The correlation analysis revealed that restrictions in social participation were negatively associated with both the PCS and the MCS with a medium sized correlation (Table 2). This was found in both the early RA and the established RA sample. In the early RA group the PCS and the MCS showed further significant correlations with pain, fatigue, functional disability and depression. The correlation between the MCP and disease activity was low but significant. With regard to the restrictions in social participation, this variable showed, similarly to HRQoL indicators, 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 the PCS and the MCS and was further related to depression and was also related to 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

Stepwise regression models revealed that restrictions of social participation were related to the MCS only in the early RA (Table 3). Restrictions in Social participation were significant and explained unique variance in the MCS. However, this variance was very small and most of the variance was explained by pain and depression. The whole model explained 56 % of variance. In the established RA sample, the restrictions in social participation were not found to be related to the MCS and most of the explained variance was attributed to depression. In contrast to the early RA sample, pain was not significant and additional variance was explained by disease duration and disease activity. Finally, fatigue was found to be significant in both models. Overall, the model in the established RA group was found to be less powerful and explained 35 % of the total variance in the MCS.

The same model was applied to explore the associations with the PCS (Table 4). In the early RA sample, restrictions in social participation were not found to be associated with the PCS in this model. Most of the variance was explained by pain and functional disability and the model explained 58 % of variance. In the established RA group, restrictions in social participation were found to be related to the PCS and contributed to the explained variance although with a very low percentage. This model was very similar to the model of early RA but most of the variance was explained by functional disability and not pain. The total explained variance in this model was 54 %.

Discussion

The aim of this study was to explore the associations between perceived restrictions in social participation and health related quality of life in early and established rheumatoid arthritis patients. Firstly, restrictions in social participation were generally found to be

Table 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**	**−0.04**	**−0.09**	**−0.15**	**−0.26****	**−0.10**	**0.16**	**0.09**	**−0.07**
2.	Age	*0.04*	*1*	**0.11**	**0.12**	**0.12**	**0.20***	**0.08**	**0.09**	**−0.12**	**−0.02**	**0.09**
3.	Disease duration	***−0.19***	***0.15***	1	**0.17***	**0.19**	**0.22**	**0.17**	**0.14**	**−0.19***	**0.05**	**0.11**
4.	Pain	*−0.11*	**0.07**	*−0.06*	1	**0.48****	**0.60****	**0.34****	**0.28****	**−0.65****	**−0.36****	**0.34****
5.	Fatigue	*−0.26***	***−0.10***	*−0.06*	*0.41***	1	**0.43****	**0.16**	**0.27****	**−0.51****	**−0.45****	**0.30****
6.	Functional disability	*−0.21**	*0.07*	*−0.03*	*0.50***	*0.41***	1	**0.37****	**0.32****	**−0.70****	**−0.38****	**0.44****
7.	Disease activity	*−0.34***	*0.02*	*−0.22**	*0.29**	*0.20**	*0.40***	1	**0.25****	**−0.35****	**−0.30****	**0.20***
8.	Depression	*.0.20*	*0.00*	*−0.07*	*0.29***	*0.49***	*0.36***	*0.11*	1	**−0.37**	**−0.51****	**0.41****
9.	PCM	*0.24**	*−0.10*	*0.02*	*−0.68***	*−0.56***	*−0.64***	*−0.20*	*−0.43***	1	**0,57****	**−0.46****
10.	MCP	*0.23**	*−0.14*	*−0.01*	*−0.56***	*−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										

Early in *italics* and established in **bold**

PCM physical component, *MCP* mental component, *SPR* social participation restrictions

*$p \leq 0.05$; **$p \leq 0.01$; ***$p \leq 0.01$

Table 3 Stepwise linear regression model of the mental health component of HRQoL in early and established RA

	Early RA						Established RA				
		β	t	p	R^2 change			β	t	p	R^2 change
1.	Pain	−.307	−3.691	.000	.350	1.	Depression	−.384	−5.330	.000	.236
2.	Depression	−.229	−2.753	.007	.152	2.	Fatigue	−.315	−4.413	.000	.087
3.	Fatigue	−.216	−2.541	.013	.033	3.	Dis. duration	.174	2.496	.014	.022
4.	HAQ	−.135	−1.597	.114	.021	4.	DAS 28	−.170	−2.403	.018	.026
5.	SPR	−.192	−2.491	.015	.029						
	Total R^2	0.585					Total R^2	0.372			
	Adj. R^2	0.562					Adj. R^2	0.353			

SPR social participation restrictions, *HAQ* Health Assessment Questionnaire (functional disability)

significantly and negatively associated with both the mental health component and the physical component of the HRQoL. This trend was found in both samples among the early and the established RA patients, respectively. However, further exploration using stepwise regression models, which allowed controlling for the influence of other variables, showed that the strength of the association was significantly reduced by other variables in the model. Nevertheless, this association remained significant in two models and contributed to these models by showing that restrictions in social participation were uniquely related to HRQoL. This was found with regard to the MCP among the early RA and PCS in the established sample. This points to an interesting trend suggesting that there is a different role of social participation in the early and established phase of RA. 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 an overlap in the measurement (Ackerley et al. 2009; Kuhlow et al. 2010; van Brakel et al. 2006).

Next, the highest amount of explained variance in all models was attributed to pain, functional disability and fatigue, which is in line with other studies (Strand and Khanna

Table 4 Stepwise linear regression models for the physical health component of HRQoL in early and established RA

	Early RA						Established RA				
		β	t	p	R^2 change			β	t	p	R^2 change
1.	Pain	−.430	−5.318	.000	.457	1.	HAQ	−.271	−3.630	.000	.442
2.	HAQ	−.318	−3.980	.000	.103	2.	Pain	−.150	−2.257	.026	.073
3.	Fatigue	−.200	−2.606	.011	.031	3.	Fatigue	−.146	−2.261	.025	.021
						4.	SPR	−.271	−3.630	.000	.017
	Total R^2	0.590					Total R^2	0.553			
	Adj. R^2	0.576					Adj. R^2	0.540			

SPR social participation restrictions, *HAQ* Health Assessment Questionnaire (functional disability)

2010; Treharne et al. 2008; Zautra et al. 2007). However, in this study a different pattern was observed in the early and the established group, while pain was most strongly associated with HRQoL in the early RA, depression and functional disability seemed to explain most of the variance in HRQoL in the established sample of RA.

A number of studies have shown that the conceptualization of HRQoL requires at least two dimensions from which one is defined as psychological or psychosocial and the second is related physical status (Arnold et al. 2004; Kojima et al. 2009; Suurmeijer et al. 2001). 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, however, the observed trend was different with respect to disease duration.

The adapted approach for assessing restrictions in social participation by peer comparison rather than by measures which are directed on the frequency of certain behaviors related to participation or the number of social activities, were found to be relevant to aspects of RA. This kind of approach has been successfully adopted in self-management programs previously but not to assess social participation (Cardol et al. 2002). 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. However, it must be said that the distinction of early and established RA 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. Furthermore, the concept of the peer comparisons regarding social participation was in this study shown to be relevant when addressed within a broader context of HRQoL research. Lastly, the findings of our study are based on cross-sectional data do not allow drawing causal conclusions about the associations between social participation and HRQoL.

Implications

Based on the present findings, it would be beneficial that future research addresses the perception of restrictions in social participation very early after the onset of the disease within longitudinal designs. This way it would be possible to detect the contribution of the 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 disability as a part of regular treatment, might improve targeting psychosocial interventions for individual patients and help to improve or at least maintain their HRQoL.

Compliance with Ethical Standards

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Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all participants.

Conflict of Interest The authors declare no conflict of interests.

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