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Social Role Participation in Patients With Ankylosing Spondylitis: A Cross-Sectional Comparison With Population Controls

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Objective. Participation in social roles for persons with chronic disease is important for their quality of life, but interpretation of the data on participation is difficult in the absence of a benchmark. This study aimed to compare social role participation in patients with ankylosing spondylitis (AS) to population controls using the Social Role Participation Questionnaire (SRPQ).

Methods. There were 246 AS patients and 510 population controls who completed the SRPQ, which assesses participation in 11 roles (with scores ranging 1–5) across 4 dimensions (importance, satisfaction with performance, satisfaction with time, and physical difficulty), and additionally ranked their 3 most important roles. The ranking of role importance, the SRPQ dimension scores, and the gap between importance and satisfaction with performance of roles were compared between patients and controls.

Results. Patients (62% male; mean ± SD age 51 ± 12 years) and controls (70% male; mean ± SD 42 ± 15 years) ranked intimate relationships, relationships with children/stepchildren/grandchildren, and employment as the most important roles. Compared to controls, patients gave higher scores on the SRPQ to importance (3.75 versus 3.43), but reported lower satisfaction with performance (3.19 versus 3.58) and greater physical difficulty (3.87 versus 4.67) ($P \leq 0.05$ for all). The largest differences in gaps between importance and satisfaction with performance for patients compared to controls were seen in the physical leisure, hobbies, and traveling and vacation categories, in which patients assigned higher importance but reported especially low satisfaction.

Conclusion. As society places increasing emphasis on individual responsibility to participate fully in social roles, the current data suggest that health care providers should pay more attention to participation restrictions experienced by patients with AS.

Introduction

Participation in social roles is essential for individuals in all stages of their lives. As a result, social role participation is increasingly considered a relevant outcome in observational studies and in intervention programs that

intend to improve the overall functioning and health of patients with chronic diseases (1–3). Available literature on patients with ankylosing spondylitis (AS) and the impact of the disease on the participation in several social roles provides substantial evidence that patients

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Significance & Innovations

- Patients with ankylosing spondylitis ranked, similar to population controls, intimate relationships, relationships with children/stepchildren/grandchildren, and employment as their most important social roles.
- Patients assigned somewhat higher importance to social roles than controls, but were substantially less satisfied with their performance and experienced more physical difficulty.
- The greatest difference in the gaps between importance and satisfaction with performance between patients compared to controls were observed for the roles physical leisure, hobbies, and traveling and vacationing.

experience restrictions in work (1), as well as more limited evidence of restrictions in intimate relationships, hobbies, leisure, and community life (3–5). However, research examining the impact of AS on a broad range of roles at the same time, and addressing the relative value or importance of different roles in relation to experienced difficulties, is missing. Part of the challenge in participation research is figuring out how to conceive of social role participation and how to measure it. Participation covers multiple roles, and each role can be assessed across several dimensions, such as satisfaction, difficulty, time spent, and role performance, which makes it a complex construct to measure and to report (2,6).

The Social Role Participation Questionnaire (SRPQ) is a promising instrument, as it assesses participation in 11 roles across multiple dimensions: importance, satisfaction with time, and satisfaction with performance (5,7). In a subsequent study, it was suggested that “satisfaction with time” be removed, because alongside “satisfaction with performance,” it was redundant (6). Finally, including “physical difficulty” as an additional and relevant dimension was proposed (8). In Canadian patients with AS ($n = 44$), the original SRPQ was found to be valid and reliable and showed that patients highly valued participation in diverse social roles, but were not satisfied with their performance, nor with the time they spent in roles (5). To provide a better understanding of the interpretation of participation by patients with AS, comparison with the general population is needed. Without such a reference, it is difficult to conclude whether problems in participation are attributable to AS, or are similarly experienced by population controls. The aim of the present study was to examine and compare the level of social role participation in AS patients with population controls. We hypothesized that patients and controls would rate “importance” and “satisfaction with time” similarly, but that patients would rate “physical difficulty” and “dissatisfaction with performance” higher, resulting in a greater importance–satisfaction gap than control subjects.

Subjects and methods

Subjects. Patients were recruited as part of a multicenter cross-sectional study, the Social Participation in Ankylosing Spondylitis Study. Patients from 6 hospitals in The Netherlands, who were at least 18 years old, had registered with AS according to Dutch diagnosis-related groups or similar patient lists, and in whom the modified New York criteria was confirmed by the treating rheumatologist, were invited by letter (9). Control subjects were recruited from an open national online panel of the research institute Ipsos. Based on knowledge of cross-sectional samples in AS, with recruitment we aimed to achieve a control sample of adults with an average age of 42 years and a male:female distribution of 3:1 (10). Control subjects were excluded if they were indicated to have any musculoskeletal disorders or were not familiar with the Dutch language (11). The study was approved by the ethics committee of Maastricht University Medical Center, and patients provided written informed consent.

Assessments. All subjects were asked to complete the online survey. Sociodemographic background questions addressed age, sex, and education level, and general health was assessed by the 36-item Medical Outcomes Study Short Form 36 (SF-36), which has Physical Component Summary (PCS) and Mental Component Summary (MCS) scores (range 0–100, with higher scores reflecting better health) (12).

Social role participation was assessed using the validated Dutch version of the SRPQ, which assesses the influence of health on 11 roles and a “general participation” role for each of the 3 initial participation dimensions (importance and satisfaction dimensions, as well as the physical difficulty dimension, which was added later by the developers) (8,13). Each role was rated on a 5-point Likert scale: the dimension importance ranged from 1 (not at all important) to 5 (extremely important), and for both satisfaction dimensions from 1 (not at all satisfied) to 5 (extremely satisfied), and for the physical difficulty dimension from 1 (unable to do) to 5 (no difficulty) (8). Five roles could be rated as not applicable (having a partner/intimate relationship, having children/stepchildren/grandchildren, other family, employment, and current schooling or education), and in such cases, only the dimension importance was rated. Ratings on the individual roles can be averaged into dimension scores. To deal with nonapplicable roles, for the physical difficulty dimension, it was assumed that there were no restrictions experienced if the role was not applicable, while for the satisfaction dimensions, scores were averaged over the number of applicable roles, when subjects participated in at least 9 of 11 roles (8). Finally, the SRPQ allows for calculation of a participation gap score, which is the difference between importance and satisfaction with role performance, in those for whom the role was applicable. After completion of the SRPQ, patients were asked to rank which role was most, second, and third most important to them.

Table 1. Frequency of a social role as the most important or in a patient's top 3 most important social roles*

Roles	Ankylosing spondylitis, %		Controls, %	
	Most important	In top 3	Most important	In top 3
Intimate relationships†	45.3	63.8	42.7	67.3
Relationships with children/step-/grandchildren†	21.0	54.5	20.8	43.1
Employment††	11.1	38.6	16.6	43.1
Social events	8.2	32.9	10.9	37.5
Physical leisure activities	5.3	36.6	3.1	26.5
Travel or vacation	3.3	30.1	1.8	26.7
Hobbies	3.7	18.3	2.8	21.2
Relationships, other family†	0	8.9	0	13.3
Community, religious, cultural	1.2	9.8	0.7	11.6
Casual contact with others	0	4.9	0	4.3
Education†	0.4	1.6	0.2	4.7

* Ranks for controls are standardized for age and sex difference compared to patients.
† Intimate relationships: 79.9% of patients and 75.4% of controls have a partner; relationships with children: 74.8% of patients and 55.3% of controls have grand-/stepchildren; employment: 56.9% of patients and 77.7% of controls are employed; relationships with other family: 97.6% of patients and 97.5% of controls have other family; education: 16.3% of patients and 22.9% of controls follow an educational track.

Statistical analysis. Statistical analysis was performed using PASW Statistics 20 (SPSS) and Stata, version 12. After we checked for normality of the data, comparisons between patients and controls were performed with independent *t*-tests (age, SF-36 PCS), Mann-Whitney U test (SF-36 MCS), or chi-square test (sex, applicability of role). Before making comparisons regarding the SRPQ and ranks, data of controls were first standardized. Based on the age (in 10-year increments) and sex distribution of patients, indirect standardization (for ranks) was performed with age and sex strata, and direct standardization as well, by using a standardized weight (for the SRPQ). Subsequently, 95% confidence intervals around the difference of means were calculated. *P* values less than or equal to 0.05 were considered statistically significant.

Results

Of 740 invited patients with AS, 296 (40%) agreed to participate, of which 246 (83%) completed the questionnaire. Of 2,767 invited controls, 784 (28%) agreed to participate, of which 510 (65%) completed the questionnaire. Controls were more often male (70% versus 62%) and younger (mean \pm SD age 42 \pm 15 years versus 51 \pm 12 years) (see Supplementary Table 1, available on the *Arthritis Care & Research* web site at <http://onlinelibrary.wiley.com/doi/10.1002/acr.22907/abstract>). Further, controls more often had a higher professional education or university degree (49% versus 33%), were more often employed (78% versus 57%), had children/stepchildren/grandchildren less often (55% versus 75%), and were more often following an educational track (23% versus 16%) (*P* \leq 0.05 for all). Finally, controls scored better on the PCS (53.5 \pm 8.7 versus 38.7 \pm 10.1), but similar to patients on the MCS (49.6 \pm 11.8 versus 49.2 \pm 12.8).

Most important roles. When ranking roles according to importance, the first, second, and third most important roles for both patients and controls were intimate relationships,

relationships with children/stepchildren/grandchildren, and employment (Table 1). Patients more frequently reported physical leisure and travel/vacation among their 3 most important roles, whereas controls more often ranked social events in their top 3.

Social role participation in patients with AS versus population controls. Table 2 shows the scores of each role as well as of the average of all 11 specific roles of the SRPQ, across the different dimensions, between patients and controls. Based on the averages of 11 roles, patients reported a higher importance, were less satisfied with their performance, and experienced more physical difficulties, but did not differ from controls in satisfaction with time. The largest difference between patients and controls was seen in the dimension physical difficulty, where patients indicated more physical difficulties. When investigating individual roles instead of averages of all roles, the similar patterns of higher importance but more physical difficulty and less satisfaction with performance among patients compared to controls were observed. The role "physical leisure" was much more important for patients than for controls. Exceptions for a significantly higher importance for patients were observed in the roles intimate relationships and employment. However, when limiting the analyses of importance to those for whom the role was applicable, the mean \pm SD employment score became much higher in patients (4.32 \pm 0.69) and significantly different from controls (3.93 \pm 1.95) (see Supplementary Table 2, available on the *Arthritis Care & Research* web site at <http://onlinelibrary.wiley.com/doi/10.1002/acr.22907/abstract>). The largest differences in the dimension "physical difficulty" between patients and controls were observed for physical leisure, employment, and travel and vacation. The general participation item of the SRPQ showed the same patterns of differences between patients and controls for each dimension, as the scores were based on the average of 11 roles.

Table 2. Mean \pm SD SRPQ scores for dimensions (11 roles) and individual social roles for patients (n = 246) and population controls (n = 510)*

SRPQ role	Role importance†		Satisfaction with time		Satisfaction with performance		Physical difficulty	
	Patients	Controls	Patients	Controls	Patients	Controls	Patients	Controls
	Average 11 roles	3.75 \pm 0.52	3.43 \pm 0.61†	3.22 \pm 0.71	3.32 \pm 0.78	3.19 \pm 0.75	3.58 \pm 0.85†	3.87 \pm 0.66
General item	4.26 \pm 0.73	3.98 \pm 1.01†	3.26 \pm 0.91	3.51 \pm 1.03†	3.01 \pm 0.99	3.53 \pm 1.19†	3.50 \pm 0.86	4.56 \pm 0.86†
Intimate relationships	4.11 \pm 0.96	3.97 \pm 1.41	3.68 \pm 0.96	3.76 \pm 1.20	3.64 \pm 1.03	3.87 \pm 1.15†	3.96 \pm 0.86	4.68 \pm 0.73†
Relationships with children	3.97 \pm 1.37	3.76 \pm 1.74†	3.46 \pm 0.98	3.54 \pm 1.08	3.55 \pm 1.04	3.87 \pm 1.06†	3.68 \pm 0.86	4.43 \pm 1.20†
Employment	3.48 \pm 1.31	3.42 \pm 1.62	3.19 \pm 1.04	3.70 \pm 1.46†	3.24 \pm 0.91	3.85 \pm 1.41†	3.50 \pm 0.81	4.68 \pm 1.02†
Social events	4.11 \pm 0.84	3.71 \pm 1.08†	3.16 \pm 0.97	3.22 \pm 1.19	3.15 \pm 1.04	3.57 \pm 1.14†	3.99 \pm 0.86	4.75 \pm 0.69†
Physical leisure	3.78 \pm 0.98	3.20 \pm 1.37†	2.89 \pm 1.02	2.85 \pm 1.23	2.71 \pm 1.03	3.14 \pm 1.34†	3.29 \pm 0.89	4.33 \pm 0.98†
Hobbies	3.87 \pm 0.92	3.43 \pm 1.21†	3.01 \pm 0.95	3.21 \pm 1.08†	2.95 \pm 1.00	3.55 \pm 1.21†	3.92 \pm 0.81	4.81 \pm 0.56†
Other family relationships	3.90 \pm 0.96	3.59 \pm 1.19†	3.42 \pm 0.86	3.37 \pm 1.05	3.41 \pm 0.81	3.56 \pm 1.09†	4.05 \pm 0.83	4.80 \pm 0.69†
Travel or vacation	4.13 \pm 0.93	3.86 \pm 1.13†	2.94 \pm 1.10	3.18 \pm 1.19†	2.91 \pm 1.09	3.45 \pm 1.32†	3.55 \pm 0.98	4.69 \pm 0.87†
Community	3.00 \pm 1.23	2.74 \pm 1.64†	3.06 \pm 1.03	3.32 \pm 1.23†	3.02 \pm 1.04	3.62 \pm 1.23†	3.94 \pm 0.90	4.70 \pm 0.89†
Casual contact	3.80 \pm 0.90	3.44 \pm 1.16†	3.41 \pm 0.88	3.38 \pm 1.03	3.45 \pm 0.92	3.69 \pm 1.10†	4.59 \pm 0.66	4.88 \pm 0.57†
Education	2.36 \pm 1.20	1.93 \pm 1.33†	3.08 \pm 0.95	3.24 \pm 1.33	3.08 \pm 0.91	3.67 \pm 1.69†	4.02 \pm 0.67	4.94 \pm 0.26†

* Scores range from 1 (not at all important/not at all satisfied/unable to do) to 5 (extremely important/extremely satisfied/extremely satisfied/no difficulty). Scores of controls adjusted for differences in age and sex distribution compared to patients. SRPQ = Social Role Participation Questionnaire.

† Scores for this dimension are provided for all subjects, regardless of whether the role was applicable.

‡ Significantly different compared with patients ($P \leq 0.05$).

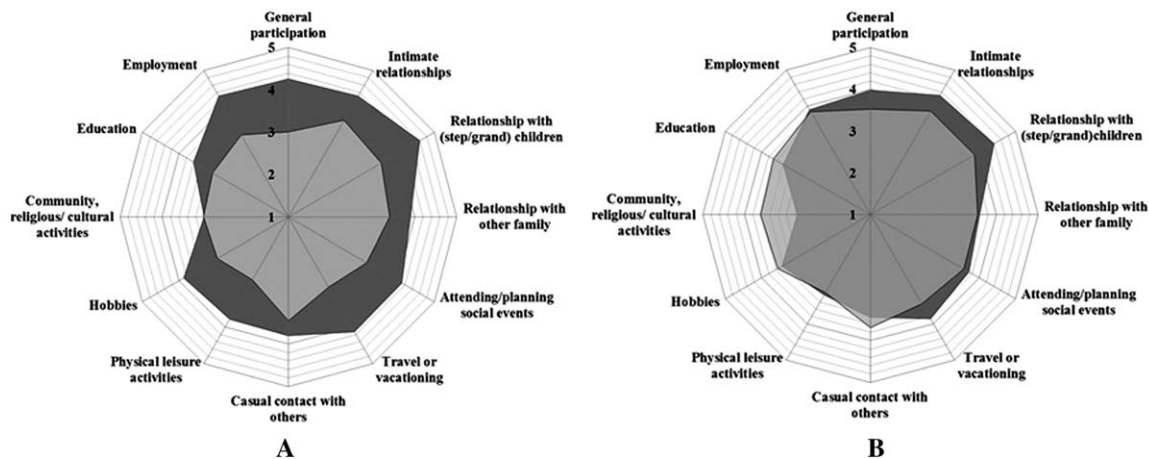


Figure 1. **A**, Importance of role domain (darkly shaded) in patients with ankylosing spondylitis (AS), where 1 = not at all important and 5 = extremely important, and satisfaction with role performance (lightly shaded) in patients with AS, where 1 = not at all satisfied and 5 = extremely satisfied. **B**, Importance of role domain (darkly shaded) in controls, where 1 = not at all important and 5 = extremely important, and satisfaction with role performance (lightly shaded) in controls, where 1 = not at all satisfied and 5 = extremely satisfied.

The gaps between importance and satisfaction with performance in all roles are represented graphically for patients and for controls separately (Figure 1). Within patients, the 5 largest importance–satisfaction gaps were found in the roles traveling or vacationing, physical leisure, work, relationships with children/stepchildren/grandchildren, and in planning/attending social events. Compared to controls, patients had significantly greater gaps for all roles. The 5 largest differences in the importance–satisfaction gaps between patients and controls were observed in the roles physical leisure, hobbies, traveling or vacationing, planning/attending social events, and casual contacts.

Discussion

This study is the first that directly compared participation in a broad range of social roles in patients with AS and controls. Patients and controls ranked the same roles as most important. Yet patients provided higher importance scores in almost all roles while reporting more physical difficulties and a lower satisfaction with performance, resulting in larger gaps between importance and satisfaction with performance in several social roles when compared to population controls.

Intimate relationships, relationships with children/stepchildren/grandchildren, and employment were identified as the most important social roles by patients as well as controls, indicating that regarding the current selection of measured roles, patients and healthy subjects value the same types of roles as most important in their lives. Moreover, while patients ranked physical leisure more often in their top 3 of most important roles, controls valued participation in social events more. In contrast to what we hypothesized, patients reported higher importance for almost all roles, compared to controls. Response shift is a likely explanation for this observation. Confrontation with health problems and resulting restrictions in social roles apparently cause patients to reevaluate the importance of

social role participation in life (14). While this was in general a positive valuation, patients may also devalue or minimize roles in which they no longer participate, as could be seen for the employment category, when this was no longer applicable. The largest difference in importance between patients and controls was seen in the role physical leisure. This is less surprising, as patients likely experience the benefits of physical activity and exercise on pain and stiffness in the affected joints, explaining the shift toward higher importance for physical leisure. Our findings in AS are different from those of a previous study of 177 middle- and older-aged patients (≥ 40 years) with osteoarthritis (OA), who rated their roles at a similar level of importance as healthy controls (8). While this could be an effect due to age, the majority of the 197 patients in the present study (80.1%) were also ≥ 40 years old. Explaining the differences in observation in AS and OA is complex and likely the result of an interplay between disease burden, contextual factors in the environment, and the personalities of the patients, including reevaluation. Future research on patterns for differential evolution of the importance of roles in life between healthy persons and persons with different chronic diseases might be interesting.

More in line with our expectations and the literature (8), patients were less satisfied with performance and experienced more physical difficulty than controls. Patients experienced the most physical difficulty in the roles physical leisure, employment, and traveling and vacationing, where the SRPQ scores were lowest. Interestingly, for the satisfaction with time dimension, differences with controls were less apparent, and equal satisfaction (or dissatisfaction) was observed in various social roles. Although population controls are also less satisfied with the time spent in several roles, the dissatisfaction is likely caused by different reasons than those in patients. The lower ability of satisfaction with time to discriminate between patients and controls adds to the validity of the previous decision (5,13) to remove “satisfaction with

time” from the SRPQ, as it does not provide additional information.

The higher importance and lower satisfaction with the performance of roles in patients resulted in a greater participation gap for the former group compared to healthy individuals. Within patients, these gaps were largest for roles that were most important to them (relationships with children/grandchildren/stepchildren and employment), but also for traveling and vacationing, physical leisure, and planning/attending social events. Compared to controls, overall the type of roles with gaps observed between patients and controls were largely the same as those observed within the patients-only group. However, the gap difference in the roles that were most important, compared to controls, had a slightly different order, with the largest gap difference seen for physical leisure and hobbies, followed by travel/vacation, planning/attending social events, and in casual contacts. Studying participation gaps is a novel approach to examining participation and provides insight into what patients miss or desire in their lives. This might be particularly helpful to clinicians in treating patients, as well as in designing interventions that target individual patient needs. While society puts increasing emphasis on the individual’s responsibility to participate fully in social roles, the current data suggest that health care providers should pay more attention to participation restrictions experienced by patients with AS.

Some limitations of the study need to be considered. Participants were required to have internet access. An informal survey in our department already some years ago found that almost 90% of AS patients had internet access, and the percentage is likely similar in the same age group in the general population. Also, response rates were low, but likely not different from those of many other survey studies. Further, the sample of patients unexpectedly included more females and was older than we expected based on our knowledge of other cross-sectional samples (10). Some research suggests that AS is increasingly being diagnosed among women, but the possibility that a subgroup of patients had nonradiologic axial spondyloarthritis cannot be excluded (15). This might influence external validity. However, as we adjusted for the small differences in age and sex, it will not have affected the internal validity of this study. While in patients the importance–satisfaction gap was quite large for several roles, no formal data are available as yet about interpretability and clinical relevance. Future research on important difference and acceptable state could allow research on participation to move forward. While some mechanisms to explain differences in participation between patients and controls have been proposed earlier in the discussion, the cross-sectional design of the study warrants caution with regard to drawing conclusions on causality.

In summary, patients with AS and controls rank the same roles as most important. However, patients value the importance of almost all roles higher while experiencing more physical difficulties and less satisfaction with their performance. These findings suggest that clinicians and researchers should pay more attention to social role

participation in patients with AS, as it was obvious that social roles had a lot of meaning for them.

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AUTHOR CONTRIBUTIONS

All authors were involved in drafting the article or revising it critically for important intellectual content, and all authors approved the final version to be submitted for publication. Mr. van Genderen had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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Acquisition of data. Arends, van Gaalen, van der Heijde, Heuft, Luime, Spoorenberg.

Analysis and interpretation of data. van Genderen, Plasqui, Landewé, Laccaille, Gignac, Boonen.

ROLE OF THE STUDY SPONSOR

AbbVie had no role in the study design or in the collection, analysis, or interpretation of the data, the writing of the manuscript, or the decision to submit the manuscript for publication. Publication of this article was not contingent upon approval by AbbVie.

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