

Consequences of Rheumatoid Arthritis for Performance of Social Roles — A Literature Review

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ABSTRACT. *Objective.* To obtain quantitative estimates of restrictions in participation, i.e., the performance of social roles, in patients with rheumatoid arthritis (RA).

Methods. Participation categories were selected from the International Classification of Functioning, Disability and Health (ICF) (preliminary) Comprehensive Core Set for RA. A literature search was performed utilizing PubMed and PsychInfo. Articles were included if: (1) performance in at least one of the participation categories was described; (2) patients with RA were compared to a healthy reference population or their performance over time was described; (3) published between 1995 and 2005; and (4) written in English.

Results. Seven participation categories were selected from the Comprehensive Core Set for RA, resulting in 50 articles included in the review. Almost all studies focused on remunerative employment ($n = 30$), recreation and leisure ($n = 17$), or both ($n = 3$). RA patients had an increased risk of being without a paid job compared to well adjusted reference groups (absolute difference 4% to 28%, odds ratios 1.2 to 3.4). Restrictions in employment occurred already within the early phase of RA and varied greatly among studies. Two years after diagnosis, disability benefits increased up to roughly 30% in some European cohorts. In the category of recreation and leisure most studies focused on socializing ($n = 16$). Patients with longstanding RA experienced a decrease in socializing (range, Cohen's d , -0.46 to -1.0), but changes over time were minor.

Conclusion. RA patients experience restrictions in the performance of remunerative employment and in recreation and leisure (socializing). Due to the lack of studies, no conclusions on other ICF categories describing social roles could be made. (First Release April 1 2007; J Rheumatol 2007;34:1248–60)

Key Indexing Terms:

RHEUMATOID ARTHRITIS PARTICIPATION SOCIAL ROLES EMPLOYMENT
INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

An important consequence of rheumatoid arthritis (RA) is disability, ranging from limitations in executing a simple task to restrictions in societal roles¹⁻³. Within the framework of the International Classification of Functioning, Disability and Health (ICF), disability can be described as limitations in “activities” (execution of a task or action) and restrictions in “participation” (involvement in a life situation)^{4,5}. Measurement and knowledge of the functional consequences of RA have traditionally focused on activities⁶, e.g., dressing and grooming, as assessed by the Health Assessment Questionnaire (HAQ). However, there is growing interest in the influence of RA on the performance of social roles, i.e., participation, such as in employment⁷. In this review, partici-

pation refers to the social roles that individuals have in their current environment. The performance of social roles as an outcome measure in RA may drive rehabilitation and treatment, in addition to outcomes in the domain of “activities.”

Participation comprises a broad array of societal functions, and it is not evident which areas are (most) important to assess in patients with RA. An important proposition was recently introduced with the preliminary RA Comprehensive ICF Core Set of Activities and Participation⁸. This denotes 32 categories of the ICF with which the prototypical spectrum of problems in function of RA patients can be described. This preliminary version was constructed on the basis of an extensive consensus process among 17 experts from 12 countries — 7 physicians specializing in physical and rehabilitation medicine, 7 rheumatologists, one nurse, one occupational therapist, and one physical therapist. The consensus process integrated evidence on relevant ICF categories according to patients, a Delphi exercise among experts, and a systematic review on the type of outcome assessments in clinical trials⁹⁻¹¹.

The preliminary Comprehensive ICF Core Set offers a good starting point to assess and describe participation in patients with RA, but its application is complicated by several factors. First, in the proposed set no distinction is made between “activities” and “participation.” In the ICF it is argued that this distinction depends on the needs and purposes

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of a study, and guidelines are provided⁴. A second factor concerns insight into participation restrictions. Although the content of the comprehensive set is currently being tested worldwide, no review of the literature with respect to the influence of RA on the participation categories included in the set and their sensitivity to treatment and prevention has been published yet. Such a review may be very helpful in the process of identifying relevant participation categories in particular studies. Third, participation categories can be selected from the preliminary set, but little is known about the best method to measure these social roles¹².

In order to improve insight into the consequences of RA on participation, the RA Comprehensive ICF Core Set was taken as a starting point to select social roles. Interest was focused, not on the occurrence of restrictions in social roles, but on quantification of the effect of RA. Thus, the aim of this review is to obtain quantitative estimates of restrictions in participation, i.e., the performance of social roles, in patients with RA.

MATERIALS AND METHODS

Selection of participation categories from the RA Comprehensive ICF Core Set. The RA Comprehensive ICF Core Set of Activities and Participation was used as a starting point⁸. As the set comprises both activities and participation, a classification method proposed by the World Health Organization was applied to select only those categories referring to participation, i.e., social roles.

The classification method applies at the level of the chapters by which activities and/or participation are described in the ICF. The 9 ICF chapters include: (1) learning and applying knowledge, (2) general tasks and demands, (3) communication, (4) mobility, (5) self-care, (6) domestic life, (7) interpersonal interactions and relationships, (8) major life areas, and (9) community, social and civic life⁴. According to the classification, chapters refer to activities, to participation, or to both. The relevant chapters describing participation

were selected, reflecting the personal view of the authors. From all 9 ICF chapters one or more categories were included in the RA Comprehensive ICF Core Set. Through the classification method at chapter level, participation categories could be identified.

Table 1 shows the ICF chapters dealing with participation according to the authors. All categories on participation in the RA Comprehensive ICF Core Set were included. Categories in the Comprehensive ICF Core Set that the authors considered to represent “activities” were excluded, such as activities of daily living comprising writing (Chapter 1), carrying out daily routine (Chapter 2), using communication devices and techniques (Chapter 3), fine hand use, walking, using transportation (Chapter 4), and dressing and eating (Chapter 5). The ICF chapter “Domestic life” was thought to represent both activities and participation. The category “assisting others” was considered to refer to participation, while “acquisition of goods and services,” “doing housework,” and “preparing meals” were thought to refer to activities. In total, 7 ICF categories representing social roles were selected to guide the extraction of data on social roles.

Literature study. A literature search for the 7 ICF participation categories was performed in Pubmed and PsychInfo. The search terms were “rheumatoid arthritis” in combination with “disability,” “handicap,” “participation,” and one of the selected ICF categories or subcategories (Table 1). Articles were included if: (1) performance in at least one of the selected participation categories was described^{4,12-14}; (2) performance of RA patients in social roles was compared with a healthy reference population (cross-sectional studies, longitudinal studies), or performance among RA patients was described over time (longitudinal studies); (3) the articles were published between 1995 and 2005; and (4) articles were written in English.

Longitudinal studies without a reference population were included in this review to provide evidence for changes in the performance of social roles over time. Intervention studies could also be included, since almost all patients currently receive treatment and treatment may affect the impact of RA on social roles. Only studies published between 1995 and 2005 were included, because treatment and intervention in RA have changed considerably in the past decade.

The literature search identified 350 abstracts, from which 143 articles were retrieved for further review. Of these articles, 35 were excluded as they

Table 1. Number of studies included in this review that describe the selected participation categories.

ICF Chapters Containing Participation	Categories Included in the RA Comprehensive ICF Core Set Describing Participation	Articles Describing Participation Category (n = 50) [#] (studies containing longitudinal data)
(6) Domestic life	• Assisting others (assisting others and being concerned about others' well-being)	1 (1)*
(7) Interpersonal interactions and relationships	• Family relationships (creating and maintaining kinship relationships) • Intimate relationships (creating and maintaining close or romantic relationships)	1 (1)* 4 (2)
(8) Major life areas	• Remunerative employment (engaging in all aspects of work for payment) • Work and employment, other specified and unspecified (e.g., illegal employment, not unpaid employment)	33 (22) 0 (0)
(9) Community, social and civic life	• Community life (engaging in all aspects of community social life) • Recreation and leisure (engaging in any form of play, recreational, or leisure activity)	2 (1) 20 (11)

* This study contains one measure addressing both categories. [#] In 6 studies 2 participation categories were described and in 2 studies 3 categories were described.

did not assess participation categories or provided only summary scores from which participation could not exclusively be studied. Due to the lack of a reference population or a description of social roles over time, 43 articles were excluded. Other studies were excluded if they reported findings for RA patients and non-RA patients ($n = 9$) or overlapped with studies already included ($n = 6$). In total, 50 articles were included for study.

In the data extraction procedure, information from all articles was collected for: RA population (number, age, sex, diagnostic criteria, disease duration, treatment, type of population, selection on work participation/disability, country); reference population (number, selection, adjustment to RA population); study design (cross-sectional/longitudinal, followup period, intervention); and measurement of the performance of social roles, and performance of social roles by RA patients and reference populations. Data extracted on the performance of social roles included the number or percentage of persons experiencing (no) restrictions and continuous variables derived from questionnaires. Data extraction was performed by one author (GG) according to a standardized format, and extracted data were reviewed by a second author (AB) for consistency and completeness. In cases of doubt, data were discussed until agreement was reached (GG, AB).

A distinction was made between studies on early RA (disease duration ≤ 2 years) and established RA (disease duration > 2 years). In addition, medical treatment was recorded to allow for a treatment effect on the performance of social roles, since the recent introduction of disease modifying antirheumatic drug (DMARD) combination therapy and biologicals has had a profound effect on disease prognosis¹⁵. Treatment was considered to be conservative when a pyramid approach had been used. Treatment was considered intensive when a prompt start with DMARD therapy, combination treatment, and/or biological therapy was reported¹⁶. Studies were judged by 2 authors (GG, JH); in cases of doubt, conservative treatment was chosen.

Findings are expressed primarily as (1) odds ratios (OR), (2) Cohen's d statistic, and (3) percentages. OR as a measure of association was calculated by means of a 2×2 table with approximate 95% confidence intervals (CI). If the number of subjects in the reference population was not described, the reference population was assumed to contain as many subjects as the RA population in order to calculate the 95% CI. Cohen's d , reflecting the standardized difference between 2 means, was calculated with $d = (M_1 - M_2)/(SD_{\text{pooled}})$. The 95% CI of Cohen's d was calculated with $d \pm 1.96 \cdot (SD_{\text{pooled}}/\sqrt{n-1})$. If only the standard deviation of the RA population was available, this value was taken as the SD_{pooled} . In order to interpret the relevance of the effect, a Cohen's d value of 0.2 was thought to represent a small difference ($-$), 0.5 a medium difference (\pm), and 0.8 a large difference ($+$). In this review a negative Cohen's d reflects a decreased performance in a social role. A similar overview of the relevance of results was done for odds ratios, with values ≥ 2.0 considered a large effect ($+$), values between 1.5 and 2.0 a medium effect (\pm), and odds ratios < 1.5 a small effect ($-$).

For all trials, data from different treatment groups within the study population were pooled if no significant differences in restrictions in social roles between groups were reported.

RESULTS

In total, 50 articles were included¹⁷⁻⁶⁶. Almost all studies focused on remunerative employment ($n = 30$) or recreation and leisure ($n = 17$) or both ($n = 3$) (Table 1). In 38 out of 50 studies patients satisfied the 1958/1987 American College of Rheumatology criteria^{17,18,21-27,29,30,32,35,38,40-47,49-51,53-58,60-66} and in the remaining studies patients were clinically diagnosed ($n = 10$)^{20,28,31,33,34,36,37,39,48,59} or satisfied the ICD-9 code ($n = 2$)^{19,52}. In only 3 studies did patients receive intensive DMARD treatment^{34,35,43}.

Studies on paid employment are presented in Table 2 and Table 3, respectively, showing the cross-sectional studies

comparing RA patients to reference populations and the longitudinal studies on RA patients. Findings with respect to recreation and leisure are given in Table 4 and Table 5.

Remunerative employment. Performance of paid employment or lack thereof was defined in different ways: (1) (not) having paid employment, abbreviated as "(no) work"; (2) number of days on work disability/sick leave; (3) work productivity; (4) (no) work disability (partial/permanent, official/self-reported, with or without social benefits); (5) (early) retirement; and (6) work loss without benefits. Twenty-three out of 33 studies used a self-constructed questionnaire/interview to obtain employment data, while others used disability registries^{17,19,32,42,43,47,50}, diaries³⁵, the Work Limitation Questionnaire³⁷, or the Activity Enumeration Index³³.

In 12 cross-sectional studies the prevalence of not having a paid job was higher in patients with established RA compared to general population samples^{17,18,21-23,27,39,54,55,57,65,66} (Table 2). The absolute difference ranged from 4% to 28%, and overall odds ratios ranged from 1.2 to at most 3.4, when RA patients were compared to adjusted subgroups from the general population ($n = 8$)^{17,18,21,22,55,57,65,66}. Odds ratios were somewhat higher and more variable when RA patients were compared to less comparable reference groups (absolute differences between 13% and 43%, range of OR 1.9–8.4), such as reference groups selected on being healthy^{27,39,54} or patients' caregivers²³.

Decreased employment (OR 2.0–2.7) was mirrored by (partial) work disability in 5 studies (absolute difference 11% to 52%, OR 2.5–33.1)^{17,18,22,55,57}. The risk of unemployment seemed to be higher among RA patients in older age groups ($n = 4$)^{22,44,55,66}, although one study⁶⁵ did not support this observation. Chorus, *et al*²¹ described an increased risk of unemployment with increasing disease duration, which achieved significance from 6 years of RA onwards.

In 2 out of 7 studies a difference in not having a paid job was found between women and men^{22,55}. In a country with a high labor force participation (LFP) of women, female patients with RA more often had no paid job compared to the female population than male patients compared to the male population (women: absolute difference 37%, OR 5.6; men: absolute difference 16%, OR 2.0)²², whereas in a country with traditionally low LFP of women the opposite pattern was observed (women: absolute difference 7.7%, OR 1.5; men: absolute difference 24%, OR 3.4)⁵⁵. In a country with traditionally low LFP of women, 2 studies described a higher risk of (partial) work disability in women than in men^{17,57}.

Nine longitudinal studies described that work participation was already restricted in the early phase of RA (Table 3)^{17,18,29,30,32,35,41,50,63}. The proportion of patients with early RA who were employed was reduced by about one-third during the first 2 years of followup in 3 studies^{29,30,35}, and another study found that the highest decline in work participation took place during the first years of RA¹⁸. After 2.5 to 6 years, 40% to 53% of the employed patients had stopped work-

Table 2. Cross-sectional studies on work participation in RA patients compared to reference populations.

RA Population					(Calculated) Restrictions in Work Participation Compared to Reference Population					
Author, Country	Selection	Disease Duration (yr) [§]	No. (%) [§]	Age (SD) [§]	Measure ment	Reference Population	% No work in RA patients	OR No Work Relevance	OR (partial) Work Disability [% WD in RA patients]	Sick Leave [No. of days/% in RA patients]
(55) Nether lands	Hospital based	2.8 (1.6)	211	25-64	Q	GP*	2.55 [61%] M: 3.44 [47%] F: 1.46 [67%]	+	5.94 [37%]	+
(17) Nether lands	Hospital based	2.8 (1.8)	132 (62)	<65	R	GP*	M: 1.98 [49%] F: 1.44 [77%]	±	M: 5.13 [25%] F: 18.8 [23%]	+
(18) UK	Population based, work before and at RA onset	4.2 (1.1)	110 (65)	—	Q	N = 110*	2.44 [42%]	+	32.0 [33%] (=Full WD)	+
(57) Nether lands	Hospital based	4.3 (2.6)	293 (73)	50 (10)	Q	GP*	2.03 [44%] M: 2.09 [29%] F: 1.90 [55%]	+	2.45 [21%] M: 1.78 [19%] F: 2.89 [21%]	+
(23) Brazil	Hospital based	8.3 (5.4)	62 (89)	46	Q	N = 62*	5.52 [87%]	+		
(54) UK	Hospital based	9.8 (14)	13 (100)	42 (8)	Q	N = 24*	1.87 [38%]	±		
(22) Lith	Hospital based	10.4 (8.6)	238 (86)	52 (10)	Q	GP*	2.70 [59%] M: 1.95 [68%] F: 5.54 [54%]	+	33.1 [55%]	d: 1.53 [46 d/yr] +
(21) Nether lands	Hospital based	11.9	1056 (72)	49	Q	GP*	1.20 [39%] M: 1.47 [26%] F: 1.11 [52%]	—	RR WD: 6-10 yr: 1.1 11-15 yr: 1.3 16-20 yr: 1.6 ≥21yr: 1.8	±
(27) Norway	Hospital based	20 (10)	264 (100)	57 (11)	Q	N = 61**	6.8 [60%]	+		
(39) Canada	Hospital based	≥ 1	143	50 (12)	Q	N = 142**	8.35 [57%]	+		
(19) UK	Population based, work	—	469 (28)	50	R	N = 469*				OR sick leave claim: 3.81 [70%] +

Table 2. Continued.

(33) USA	Hospital based	—	381	≥50	AEI	N = 147*	No valued work performed: 1.62 [53%]	±
(65) Ger	Hospital based	—	± 25000	41-60	Q	GP*	M: 2.88 [37%] (west) M: 3.43 [53%] (east) F: 2.03 [59%] (west) F: 3.22 [66%] (east)	+
(66) Ger	Hospital based	—	6996	18-60	Q	GP*	M: 2.29 [42%] F: 2.07 [58%]	+

§Disease duration, no. of subjects, sex, and age of the population correspond to the study (sub)population for which restrictions in social roles are shown in this table. R: registry, Q: self-constructed questionnaire/interview, GP: general population, *: adjustments made for age and sex, ♦: reference population selected on being healthy, ▼: reference population are caregivers of RA patients, d: Cohen's d, RR: rate ratio, + : large difference/effect, ± : medium difference/effect, — : small difference/effect, WD: work disability, AEI: Activity Enumeration Index, NL: the Netherlands, Ger: Germany, Lith: Lithuania.

ing^{18,40,41,63}. A study on patients with longstanding RA found that employment decreased at a constant rate⁴⁴. Four out of 6 studies with detailed data on work disability over time described that the increase in work disability was highest during the early phase of RA^{18,32,50}, or that work disability was already remarkably high at study onset²⁶. The prevalence of officially registered work disability was 31% after one year according to one study³², and was 23% and 29% after 2 years in 2 other European studies^{17,50}. In the established phase of RA, official disability benefit prevalences ranged from 30% to 72% after 5 years^{17,32,50}. In contrast, a study by Wolfe, *et al*⁶² in the USA reported a much lower registered work disability, as only 25% of the RA patients received benefits after 11 years of RA.

In addition to employment status, more refined measures of work participation have been used. A large proportion of RA patients experienced sick leave during the early phase of RA, and sick leave prevalences of 53% and 82% were reported after one year of followup^{30,41}. In addition, patients with established RA reported more days of sick leave than the general population (46 days vs 11 days, respectively)²². One study found a decrease in work productivity and an increase in days missed from work in patients with established RA over a 6-month period, but this was not accompanied by an increased loss of employment³⁷.

Early intensive medical treatment for 2 years resulted in significantly fewer days lost due to sick leave and work disability compared to conservative treatment after 5 years in the FIN-RACo study⁴³. The COBRA study (short-term intensive treatment), however, did not report a significant effect on absenteeism during the first year of followup of patients with early RA³⁵. One observational study on patients with established RA receiving biological therapy for more than one year showed that work capacity and sick leave days did not deteriorate over a one-year period³⁴.

In summary, the performance of paid employment was restricted in RA patients compared with reference populations. Paid employment decreased and work disability increased from the early phase of RA onward. Intensive treatment may positively affect work participation.

Recreation and leisure. In the ICF category "recreation and leisure," performance in "socializing" was studied most frequently (16 out of 20 studies; Tables 4 and 5)^{20,23-25,27,28,31,36,42,46,49,51,53,59,60,64}. Socializing consisted of engaging in informal or casual gatherings with others, such as visiting friends or relatives or meeting informally in public places⁴. Instruments used to measure socializing were: (1) the Medical Outcomes Study Short-Form General Health Survey (SF-36) — social function^{20,23,36,51,53,59,60,64}; (2) Arthritis Impact Measurement Scales 2 (AIMS2) — social activities^{25,46,49}; (3) Social Network Delineation Questionnaire (SNDQ) — total network size^{27,28}; (4) Impact of Rheumatic Diseases on Health and Lifestyle questionnaire (IRGL) — social network²⁴; (5) Disease Repercussion Scale (DRP) —

Table 3. Longitudinal studies of work participation in RA patients.

RA Population					(Calculated) Changes in Work Participation Between Baseline and Followup			
Author and Country	Selection	Disease Duration (yr) [§]	No. (% F) [§]	Age (SD) [§]	Measure ment	Followup (yr)	Work	Other
(32) Finland	Hospital based, work at disease onset	< 6 mo	103 (78)	45	R	20		
							1 yr: 31%, 3 yr: 33%, 8 yr: 50%, 15 yr: 72%, 20 yr: 80%	
(50) Finland	Hospital based, work at diagnosis	6.4 mo	82 (73)	40	R	9.9		
							1 yr: 5%, 2 yr: 23%, 3 yr: 26%, 5 yr: 30%, 8 yr: 38%	
(41) Germany	Hospital based, work at RA onset, no benefits except for RA	7 (3.5) mo	133 (63)	47 (9)	Q	2.5 (2.3)	-41%	Sick leave: 1 yr: 82% (113 (11)d) 2 yr: 35% (26 (6)d) Work loss, no benefits: 9%
							17%	
(29) Finland	Hospital based	9 (11) mo	62 (61)	49 (11)	Q	2	-29% [baseline 84%]	+25% [baseline 13%]
(26) Sweden	Hospital based	11.4 (6.6) mo	106 (67)	53 (13)	Q	6-7	baseline: 47%, 1 yr: 52%, 2 yr: 52%, 5 yr: 41%	Retirement: baseline: 17%, 1 yr: 19%, 2 yr: 19%, 5 yr: 28%
(30) Sweden	Hospital based	< 1	211 (69)	55 (15)	Q	1	-15% [baseline 50%]	Sick leave: +9% [baseline 44%] Early retirement: +6% [baseline 6%]
(40) Germany	Hospital based, work at study onset	≤ 1	73 (73)	49 ⁺ (39-55)	Q	6 (2)	-53%	Work loss without benefits: 8% Normal retirement: 8%
(35) # Nether lands	Hospital based	< 2	65	—	Q, diary	1	-13% [baseline 42%]	Retired: +6% [baseline 16%]
(43) # Finland	Hospital based	< 2	138	18-65	R	5		
(63) UK	Hospital based, work at study onset	< 2	353 (60)	< 60: 93%	Q	5	-40%	d (work disability days: IT vs.CT): 0.75 [IT: 29 days; CT: 15 days]
(17) Nether lands	Hospital based, work at baseline	2.8 (1.8)	76	< 65	R	0-6		baseline: 14%, 1 yr: 18%, 2 yr: 29%, 3 yr: 42%, 4 yr: 44%, 5 yr: 72%

Table 3. Continued.

RA Population										(Calculated) Changes in Work Participation Between Baseline and Followup			
Author and Country	Selection	Disease Duration (yr) [§]	No. (% F) [§]	Age (SD) [§]	Measure ment	Followup (yr)	Work	Permanent Work Disability/ Disability Benefits	Other				
(18) UK	Population based, work at RA onset	First examination shortly after disease onset	CH1: 160 (71) CH2: 134 (61)	49 (11)	Q	8.6	CH1: 4.2 yr: -47%, 8.6 yr: -63% CH2: 4.2 yr: -40%	CH1: 4.2 yr: 33%, 8.6 yr: 42% CH2: 1 yr:23%, 2yr: 33%, 4.2 yr: 37%	CH1: Retirement: 4.2 yr: 10% 8.6 yr: 18% CH2: Retirement: 4.2 yr: 1.5%				
(62) USA	Hospital based	Shortly after disease onset	509	51 (13)	R	18		11 yr: 25%, 24.8 yr:50%					
(58) Croatia	Hospital based	6.6	95 (81)	50	Q	3.6	-22% [baseline 44%]	+20% [baseline 6%]	Old age pension: +2% [baseline 12%]				
(47) Germany	Hospital based	7.4 (8.4)	338 (76)	57 (12)	R	1		+ 0.4% [baseline: 29%]					
(44) USA	Hospital based, work at study onset	8.5 ⁶⁷	472 (71)	< 64: 89%	Q	9	1 yr: -15%, 2 yr: -22%, 3 yr: -31%, 4 yr: -35%, 5 yr: -44%, 6 yr: -50%, 7 yr: -57%, 8 yr: -62%, 9 yr: -68%						
(37) USA	Population based, work, no plan to retire within 2 yr	10.6 (9)	87 (87)	48 (9)	Q, WLQ	6 mo Ref: N= 173 (41 (10) yr, 73% F)	RA: -3% Ref: -2%		d (productivity RA): -0.17 [baseline: -3.7% productivity lost] d(productivity ref): +0.75 [baseline: -2.3% productivity lost] d (absence RA): -0.33 [baseline 0.7] d(absence ref):+1.18 [baseline 0.8] Difficulties at work: +19% [baseline 27]				
(38) Sweden	Hospital based	12 (10)	96 (88)	55 (12)	Q	1							
(34) # Sweden	Hospital based	—	93	< 65	Q	1			Work capacity: +2% [baseline: 31%] d (sick leave): +0.13 [baseline: 1.6 dl]				
(33) USA	Hospital based	—	381	≥ 50	AEI	5 Ref: N = 147*			Difference in valued work of RA and reference: -1% [change RA: -26%] [†]				
(42) Finland	Hospital based, work at study onset	—	26	—	R	2		23%					
(52) USA	Population based, no work	—	23 (87)	18-55	Q	1	9% [baseline: 0%]						

See Table 2 for abbreviations. # (part) of the patient population received intensive treatment. [†] Score in brackets is the difference between baseline and followup in RA patients. Ref: reference population, IT: intensive treatment, CT: conservative treatment, CH1: cohort 1, CH2: cohort 2. [‡] Median (interquartile range).

Table 4. Cross-sectional studies of recreation and leisure in RA patients compared to reference populations

(Calculated) Restrictions in Recreation and Leisure Compared to Reference Population								
Author, Country	Selection	Disease Duration (yr) [§]	No. (%F) [§]	Age (SD) [§]	Measure ment	Reference Population	[score RA patients]	Relevance
(60) UK	Population based	5.5 (IQR 5.2-5.9)	302 (67)	60	SF-36	GP*	Social functioning in RA = 75% reference score [75]	NA
(20) UK	Hospital based	6 (IQR 1.5- 12)	83 (56)	58 [†]	SF-36	GP*	d (social functioning) = -1 [52]	+
(53) USA	Hospital based	6.8 (8.3)	438 (73)	54 (12)	SF-36	GP	Social functioning in RA = 71% reference score [60]	NA
(23) Brazil	Hospital based	8.3 (5.4)	62 (89)	46	SF-36	N = 62 [▼]	d (social functioning) = -0.92 [59]	+
(51) Norway	Hospital based	12.9	944 (79)	62	SF-36	GP*	d (social functioning) = -0.63 [67] [#]	±
(59) USA	Hospital based	14.2 (9.5)	43 (63)	57 (12)	SF-36	GP, patients' partners	d (social function vs. GP): -0.46 [71] d (social function vs. partners): M: -0.51, F: -0.33	—
(36) Australia	Hospital based	15.6 (9.9)	81 (80)	58 (11)	SF-36	GP*	d (social function): -0.48 [71]	—
(46) Nether lands	Hospital based	19.0 (11)	231 (62)	64 (12)	AIMS2	N = 131*	d (social activities): -0.75 [5.6]	±
(27) Norway	Hospital based	20 (10)	264 (100)	57 (11)	SNDQ	N = 61**	d (total network size): -0.37 [15]	—
(39) Canada	Hospital based	≥ 1	128	50 (12)	Diary	N = 124**	d (time spent with leisure): 0.03 [38 hr/wk] d (time spent with valued+ competent leisure): -0.42 [9.4 hr/wk]	—
(33) USA	Hospital based	—	381	≥ 50	AEI	N = 147*	OR parties, trips, vacation: 0.94 [80%] OR cultural leisure outside home: 0.60 [72%] OR sedentary leisure in home: 1 [99%]	— + —

See Tables 2–3 for abbreviations. * Adjustment made for age, *: adjustments made for age and sex, † median age, [#] data reflect Cohen's d after adjusting RA population to reference population of age 60 years (57% F), ♦: reference population selected on being healthy, ▼: reference population are caregivers of RA patients, IQR: interquartile range, SNDQ: Social Network Delineation Questionnaire, AEI: Activity Enumeration Index, NA: not applicable.

social activities³¹; (6) Pain Disability Index — social activity⁴²; and (7) the Support Questionnaire for Transactions (SSQT) — social companionship²⁸.

Nine cross-sectional studies found that patients with established RA reported reduced socializing compared to reference populations^{20,23,27,36,46,51,53,59,60} (Table 4). In 6 studies Cohen's d ranged from -0.46 to -1 when participation was assessed by the SF-36 (difference 11 to 27 points) or AIMS2 (difference 0.94 points), generally indicating medium to large restrictions^{20,23,36,46,51,59}.

Six longitudinal studies indicated that socializing did not change remarkably in patients with established RA during a followup period of 3 months to 5 years^{24,25,28,31,36,42,49} (Table 5). In 5 out of 6 studies Cohen's d ranged from -0.18 to 0.02, indicating only small changes in socializing. Two studies suggested that restrictions in socializing might be reduced using conservative treatment⁵³ and nonsteroidal antiinflammatory drugs⁶⁴ in patients with established RA.

In summary, performance in the subcategory "socializing" was restricted when compared with reference populations in

cross-sectional studies. In studies describing socializing in patients with established RA over time, however, socializing remained relatively stable.

Four out of 20 studies described recreation and leisure in more general terms in established RA. Recreation and leisure was measured by the Pain Disability Index — recreation⁴², the Activity Enumeration Index³³, a diary³⁹, and a self-constructed questionnaire³⁸. Two longitudinal studies suggested that changes in recreation and leisure of patients with established disease were small^{38,42}. However, one study observed that active recreational activities outside the house were restricted and decreased more in RA patients over a 5-year period, but sedentary leisure activities in the house were not restricted, compared to the reference group³³. Further, a cross-sectional study found that RA patients spent less time with satisfactory leisure (d = -0.42)³⁹.

DISCUSSION

This study clearly showed that patients with RA experience restrictions in participation, i.e., the performance of social

Table 5. Longitudinal studies of recreation and leisure in RA patients.

RA Population					(Calculated) Changes in Recreation and Leisure Between Baseline and Followup [Baseline score of RA patients]			Relevance
Author Country	Selection	Disease Duration (yr) [§]	No. (% F) [§]	Age (SD) [§]	Measure ment	Followup (yr)		
(25) Australia	Hospital based	2.8 (2.5)	81 (100)	42 (11)	AIMS	1	Social activity: +7% [4.1]	NA
(24) Nether lands	Hospital based	3.5 (2.1)	59 (71)	54 (12)	IRGL	1	d (social network size): 0.10 [1.7]	—
(53) USA	Hospital based	6.8 (8.3)	438 (73)	54 (12)	SF-36	1	Change in score of SF-36 social functioning: Placebo: 0 ⁶⁸ Leflunomide group: +9.8 ⁶⁸ MTX group: +7.7 ⁶⁸	NA
(48) China	Hospital based	7.1 (9.8)	45 (87)	51 (13)	Weinberger Question- naire	9 mo	d (exercise in intervention group): 0.89 [5.4] d (exercise in control group): -0.39 [5.3]	+ —
(64) USA, Canada	Hospital based	11 (10)	691 (73)	55 (20- 90)	SF-36	3 mo	d (social function placebo): -0.11 [57] ♦ d (social functioning 2xday 500 mg naproxen): 0.15 [60] ♦ d (social functioning 2xday 200 celecoxib): 0.36[55] ♦	— — —
(31) UK	Hospital based	11	96	22-84	DRP	3 mo	d (social activities) : -0.16 [4.8]	—
(38) Sweden	Hospital based	12 (10)	96 (88)	55 (12)	Q	1	No decrease in problems with hobbies Frequency exercise (times/wk): +7% [1.4]	NA
(28) Norway	Hospital based	20 (10)	161 (100)	57 (11)	SNDQ SSQT	18 (4) mo	d (total network size): 0.02 [15.4] ♦ d (social companionship): no change ♦	— —
(49) Sweden	Population based	69% >10	66 (74)	—	AIMS	5	d (social activities): -0.11 [3.7]	—
(42) Finland	Hospital based, work at study onset	—	26 (-)	—	PDI	6 mo	d (social activity): -0.18 [32] d (recreation): 0.20 [48]	— —
(33) USA	Hospital based	—	381 (-)	≥ 50	AEI	5 Reference: N= 147*	Difference RA and reference Recreation (parties/trips/vacation): -7% [-14%] [†] Cultural leisure outside home: -4% [-16%] [†] Sedentary leisure in home: -1% [-2%] [†]	NA

See Tables 2–3 for abbreviations. ♦: data of other treatment group(s) not shown, [†] score in brackets reflects the difference between score at baseline and followup in RA patients. IRGL: Impact of Rheumatic Diseases on Health and Lifestyle questionnaire, DRP: Disease Repercussion Scale, Q: self-constructed questionnaire/interview, SNDQ: Social Network Delineation Questionnaire, SSQT: Support Questionnaire for Transactions, PDI: Pain Disability Index, AEI: Activity Enumeration Index.

roles, in daily life. Most notably, the performance of remunerative employment was restricted in patients with early RA and established RA. Evidence for restrictions in socializing, a subcategory of recreation and leisure, was found for patients with established RA. Indications exist that restrictions in paid employment can be reduced by intensive treatment. Due to the lack of studies on other participation categories selected from the preliminary RA Comprehensive ICF Core Set, we could make no conclusions on the occurrence and full extent of restrictions.

It should be stressed that the RA Comprehensive ICF Core Set was used in this study as a starting point for identification of relevant categories of participation and subsequent search for articles to be included in the review. Our findings therefore depend on the authors' opinion of what may represent participation. A small difference in interpretation of the concept of participation would have resulted in slightly different results. In addition, the overview of quantitative estimates of restric-

tions in social roles we present cannot be interpreted as a validation study of the Comprehensive Core Set. Some limitations should be considered with respect to this review. Key words, titles, and abstracts of useful articles may not always suggest that the consequences of RA in the domain of participation were measured. Although it is possible that we therefore missed some useful studies, we believe this will not substantially affect the essence of our findings. In addition, studies containing useful information may not be described in this review as a result of the restrictions we imposed with respect to the design of the study, and because findings had to reflect the participation categories of interest and no other participation categories or activities. We are confident that these relatively strict measures provided the best insight in the selected social roles. It must be acknowledged that considerable heterogeneity in measurement methods was present. For example, social function as assessed by the SF-36 differs from questions on the number of persons in the social network

(IRGL). Similarly, officially recognized work disability may underestimate the effect of RA on employment and is often not reciprocal to paid employment. The quality of the reference groups differed between studies and the choice of the reference group influenced the observed differences in participation. Given the differences in definition and measurement of social roles, we did not attempt a formal metaanalysis on the overall effect of RA on social roles. This review focused on describing observed differences and not on their statistical significance. The reason is that some confidence intervals may have been very wide due to lack of information on the number of subjects in the reference group. Moreover, only 2 out of 30 longitudinal studies included a reference group. In all other longitudinal studies, it therefore remained unclear which part of the changes in the performance of social roles could be ascribed to RA and which part would also appear among aging healthy subjects. Further, longitudinal studies including only patients employed at study onset might have underestimated the overall influence of RA on employment, as these studies only focused on patients that succeeded in remaining employed until study onset. Finally, the amount of information that was equally and systematically described in studies was limited. Therefore, it was not possible, for example, to summarize time trends.

We found that paid employment was the most frequently studied social role in outcome and intervention studies of RA. From a patient's perspective, employment is valued as an important outcome⁶⁹. A considerable proportion of RA patients experienced sick leave, quit their employment, or became work disabled during the first few years of RA. Thus, from the very early phase of RA onward, there is a need for preventive measures and intervention to maintain participation in this social role. Measures should include medical treatment, but also interventions at work, such as adaptations in the workplace or adjustments of job activities⁷⁰.

In accord with findings of our review, paid employment has been integrated in the brief RA ICF Core Set⁸. OMERACT 7 has recognized employment as the main outcome measure in the domain of participation, but did not recommend that it be routinely included in clinical trials yet. Our findings strongly support that if consequences of RA are assessed for the ICF domain of "participation" in outcome and intervention studies, work participation is one of the first outcomes of choice. Several measures are available to assess remunerative employment. Employment can best be assessed with refined measures such as work disability days and work productivity (e.g., the Work Limitation Questionnaire)⁷¹. These measures provide more insight into participation and are more sensitive to change than the crude employment status^{35,43}. In addition to insight into the performance of a social role, assessment of paid employment provides the possibility of determining the indirect costs of illness to society, and can be used in cost-effectiveness analyses of treatment strategies.

The proportion of RA patients experiencing work restric-

tions over time differed across countries. The higher proportion of RA patients experiencing work restrictions in The Netherlands and Finland compared to the USA may be partly explained by differences in the social benefits system (which is considered an environmental factor in the ICF). A recent study by Chung and colleagues confirmed the influence of the accessibility of disability benefits on work disability⁷². In ankylosing spondylitis, it has also been described that more favorable disability benefits probably result in greater work disability⁷³. As well, the traditional labor force participation may be influenced by cultural patterns. This could be illustrated by the fact that women in The Netherlands experienced a lower risk of work restrictions than men, but fewer women are at risk due to the traditionally low female LFP. The influence of environmental factors on employment status complicates comparisons among RA patients in different countries and in different time periods. However, work productivity may be more comparable among studies than employment status.

After paid employment, socializing, a subcategory of recreation and leisure, was most frequently studied in RA patients. RA patients value the performance of recreation and leisure in general as important^{69,74,75}. Neither this category nor its subcategory, socializing, has been included in the brief ICF Core Set and the OMERACT core set. However, a large proportion of the RA patients is either above employable age, chooses not to have a paid job, or is permanently work disabled. Additional measurement of socializing may therefore be of interest in all outcome and intervention studies assessing the consequences of RA in the domain of participation. Socializing can be assessed by the well known generic SF-36 (social functioning) instrument or the disease-specific AIMS2 (social activities), both of which are often used in patient research. However, these outcome measures were not designed to assess the performance of social roles within the framework of the ICF. More appropriate questionnaires can probably be expected in the near future.

The restrictions in the subcategory socializing and in recreation and leisure in general did not show a dramatic deterioration over time. This could be due to the long disease duration of subjects in the selected studies or the relatively short followup periods. However, it also seems likely that RA patients may adapt their needs to their capacities, and hence present a relatively stable situation. This was supported by the fact that the performance of sedentary recreation remained stable, while the performance of specific types of active recreation, requiring more adaptation, decreased. Socializing may be influenced by medical treatment. A recent study described in abstract format found that social functioning improved in patients receiving intensive treatment as measured by the SF-36⁷⁶. Unfortunately, none of the reports included in this review studied recreation and leisure in patients with early RA.

Five out of 7 participation categories that we selected from

the preliminary RA Comprehensive ICF Core Set were seldom studied, and therefore no conclusions on the occurrence of restrictions can be made. Findings were not described in detail since they cannot easily be combined^{15,33,42,45,56,59,61}. Generally, it is not feasible to routinely assess all 7 ICF categories in the domain of participation among patients with RA. To date, only evidence of restrictions in the performance of employment and of socializing exists. Future studies are needed for more insight into which selection of social roles is of the most interest during different stages of life of patients of RA, and in how these social roles can best be measured.

Intensive medical treatment aiming at remission has been shown to influence the consequences of RA in the ICF domains of "body function and structure" and "activities"^{15,77}. There are indications that early intensive treatment may also positively affect work participation (FIN-RACo⁴³). However, this effect may not be achieved with short-term intensive treatment (e.g., 6 months) (COBRA) and/or short followup³⁵. When intensive treatment enhances work participation, this would add to the cost-effectiveness, and hence would support the availability of the treatment. It is to be expected that more studies on the effect of intensive treatment on participation will be performed in the near future.

In summary, patients with RA experience restrictions in the performance of social roles, i.e., in remunerative employment and in recreation and leisure (socializing). Intensive treatment may reduce restrictions in employment. Our findings in this review support the inclusion of at least work characteristics and a measure of socializing (e.g., the generic SF-36) in outcome and intervention studies examining the consequences of RA in the ICF domain of participation.

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