

Problems in Work Participation and Resource Use Should Not Be Underestimated in Patients with Early Spondyloarthritis

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ABSTRACT. Objective. To explore the effect of early spondyloarthritis (SpA) on worker participation and to investigate variables associated with work outcomes as well as the effect on resource use.

Methods. Patients included in an early SpA cohort completed a questionnaire comprising items on employment status, sick leave, presenteeism, and resource use. Logistic regressions were used to investigate the associations between work status and clinical characteristics, and linear regressions were used to investigate the association between at-work productivity loss and clinical characteristics. Resource use across patient groups with different employment status was investigated with linear regression analyses.

Results. One hundred forty patients participated in our study. Of the patients, 69% were male, the mean age was 41 years, and the disease duration was 4.8 years. Twenty-six patients (19%) were not employed because of SpA. Among 114 employed patients, sick leave was reported in 28% in the previous year. Forty-one percent of the patients reported reduced productivity at work. Multivariable regression analyses showed that high Bath Ankylosing Spondylitis Metrology Index and Ankylosing Spondylitis Quality of Life score were associated with not being employed and with reduced productivity at work. Annual costs of productivity loss attributable to sick leave and presenteeism amounted to €2000 per patient. Patients who reported sick leave show a higher (health-related) resource use.

Conclusion. After only 5 years of diagnosis, a considerable proportion of patients with SpA is not employed, and those working have substantial sick leave and productivity loss. Among patients reporting sick leave, resource use is higher. Alertness to work participation even in patients with a short disease duration is urgently needed. (First Release Oct 15 2014; J Rheumatol 2014;41:2413–2; doi:10.3899/jrheum.140396)

Key Indexing Terms:

SPONDYLOARTHRITIS
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Spondyloarthropathies — or now commonly known as spondyloarthritis (SpA) — are a group of related chronic inflammatory rheumatic diseases characterized by pain and inflammation of the spine and sacroiliac joints and/or peripheral joints. While ankylosing spondylitis (AS) is the prototype of the disease, also psoriatic arthritis (PsA), SpA associated with inflammatory bowel diseases (IBD), reactive arthritis, juvenile-onset SpA, and undifferentiated SpA belong to the spectrum. SpA can have predominantly

axial or peripheral symptoms, but in addition to these articular manifestations, extraarticular manifestations such as uveitis, IBD, and psoriasis also contribute to the burden of the disease.

SpA onset happens early in life (depending on the type of SpA, ranging from the second until the fourth decade), so the effect of the disease on labor force participation can be long-lasting. Restrictions in labor force participation are not only important for the individual patient and his or her family, but also for society because it results in loss of productivity and societal productivity costs.

The majority of research on worker participation among people with SpA is concentrated on AS. It is well known that patients with AS have restrictions in work participation, ranging from reduced levels of productivity at work (presenteeism) to absence from work because of sick leave, and eventual withdrawal from the workforce because of disability^{1,2,3}. However, these studies are mainly performed in patients with long disease duration^{1,2,4,5,6,7}. Limited data are available on worker participation early in the disease process of AS and studies regarding other types of SpA. This seems odd because work participation is important for

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patients' quality of life, and the effect of the disease lasts most of their lives.

Therefore, we studied employment status, sick leave, and presenteeism in patients with a recently diagnosed SpA (the majority had axial complaints), and we investigated the association between work participation and clinical disease-related factors and resource use.

MATERIALS AND METHODS

Study population. Patients with a recent diagnosis of SpA according to the European Spondylarthropathy Study Group criteria⁸ and inflammatory back pain⁹ were consecutively enrolled in the prospective early SpA cohort in the Jan van Breemen Research Institute/Reade, a large outpatient rheumatology clinic in Amsterdam. The diagnosis of SpA consisted of AS (if patients also fulfilled the modified New York criteria)¹⁰, undifferentiated SpA, patients with inflammatory back pain, PsA, IBD or reactive arthritis, and juvenile SpA. For our study, all consecutive patients of the early SpA cohort with a disease duration < 5 years and aged ≥ 18 and ≤ 65 years were included. The study protocol and consent forms were approved by the local medical ethics committee. All patients provided written informed consent.

Assessments and definitions: early SpA cohort assessments. Patients participating in the early SpA cohort completed questionnaires and underwent physical, laboratory, and radiographic assessments at regular intervals. Every year, data were collected on self-reported questionnaires [Bath Ankylosing Spondylitis Disease Activity Index (BASDAI), Bath Ankylosing Spondylitis Functional Index (BASFI), and Bath Ankylosing Spondylitis Patient Global Assessment (BASG)], disease manifestations [Bath Ankylosing Spondylitis Metrology Index (BASMI) 3-point scale, 0–10¹¹, Maastricht Ankylosing Spondylitis Enthesitis Score (MASES)], extraarticular manifestations, laboratory tests (erythrocyte sedimentation rate, C-reactive protein), and radiology measurements (radiographs of the pelvis and spine).

Work participation questionnaire. In addition to the early SpA cohort assessments, a work participation questionnaire was developed and sent to all included patients in 2010. This questionnaire contained items on work participation, absenteeism (withdrawal from work because of sick leave or work disability), presenteeism (level of productivity while at work), quality of life, and resource use in the previous year.

Questions on work participation contained items on educational level, work status (employed or not employed), reasons for not being employed, and questions on work disability (work-disabled or not work-disabled, meaning officially disapproved for work by insurance company doctors). The number of working days and working hours per week were recorded. Patients were asked whether they experienced problems at work because of SpA (difficulties in finding a job, dismissal, unemployment for longer than a month, rejection for positions at work, rejection for positions at work after medical examination, change in employer or function, rejection for promotion, ineligibility for education or insurance), whether they needed to make changes at work because of their disease, and about the importance of work for their well-being [on a numerical rating scale (NRS) 0–10, 10 being very important]. Sick leave was assessed by the number of times employed patients had been absent during the last year and the number of work days they were absent. At-work productivity (presenteeism) was assessed by the Quantity and Quality method (QQ method)¹². The QQ method consists of 2 numeric rating scales, 1 asking about the quantity and 1 about the quality (of the last working day, both on an NRS 0–10, 10 is normal, which means no reduction in productivity). Overall, presenteeism is the product of quantity and quality divided by 10 ($Q \times Q \div 10$).

Assessments and definitions: quality of life questionnaire. Disease-specific, health-related quality of life was studied by using the Ankylosing Spondylitis Quality of Life questionnaire (ASQoL)¹³. ASQoL consists of 18 items (yes = 1 or no = 0) that measure different areas of life, including mood and emotions, social life, hobbies, everyday tasks, personal and

social relationships, and physical activity. The sum of the scores ranges from 0–18, whereby lower scores indicate a better quality of life.

Questions on health resource use. Additional questions were included about SpA-related visits to the rheumatologist (number), visits to other specialists or therapists (yes/no, which types of specialists/therapists, which complaints), the need for help in daily chores at home (yes/no, help from whom), and adjustments at home (yes/no, what kind of adjustments) in the past year. Finally, a question was included on whether the rheumatologist pays attention to the patient's work (yes/no). The outcome variables concerning health resource use consist of number of visits to a rheumatologist and other practitioners, proportion of patients requiring help in daily activities, and proportion requiring adjustments at home.

Statistical analyses. Demographics and disease characteristics were summarized by descriptive statistics. Data were expressed as means (SD) or medians [interquartile range (IQR)] as appropriate. From the Centraal Bureau voor de Statistiek/Statistics Netherlands, we received numbers of unemployment and sick leave days of the general population (in the Amsterdam area) that were used to perform a "goodness-of-fit test" to compare our numbers with the numbers of the general population. To calculate the costs of sick leave and at-work productivity loss per year, the sick leave days were converted into working hours absent. Next, the remaining working hours per year were multiplied by $1 - (Q \times Q \div 10)$ to estimate the hours lost because of at-work productivity loss. Finally, the total number of hours of productivity loss was multiplied by the hourly wage for paid employment by age and sex as derived from the Statistics Netherlands. Univariate and multivariate logistic regression methods were used to investigate the associations between the work status and disease characteristics. Univariate and multivariate linear regression methods were used to investigate variables associated with productivity loss, therefore, we first normalized the QQ scores. Presence of at-work productivity loss (presenteeism) was defined as having a $Q \times Q$ score < 10. In the multivariate analyses, covariates with a univariate association with a p value < 0.05 were included (if no collinearity was present). To understand resource use across patient groups with different employment status, univariate and multivariate linear regression analyses were performed.

For all analyses, SPSS version 15.0 (SPSS Inc.) was used and a p value < 0.05 was considered statistically significant.

RESULTS

Main clinical characteristics of patients with early SpA. Of the 180 patients who were enrolled for our study, 140 returned the questionnaire (response rate 78%) and were included. Nonparticipants did not differ in age and sex from the participants. Patients were predominantly male (97/140, 69%) and white (118/140, 84%; Table 1). Seventy-four percent of the patient group consisted of patients with AS. The precise SpA diagnoses were specified (Table 1), of which most patients had axial disease. According to the new Assessment of Spondyloarthritis International Society criteria, 91.4% had axial SpA disease and 8.6% had peripheral SpA (counted with data available)¹⁴. The mean disease duration ("time since diagnosis") was 4.8 years (2.7 yrs) and the median symptom duration ("time since first symptoms") was 10 years (0.6–16.0 yrs). Almost all patients (89%) received nonsteroidal antiinflammatory drugs, 6% were treated with a disease-modifying antirheumatic drug, and 10% with a biological.

Work status in patients with early SpA. One hundred fourteen patients (81.4%) worked for pay while 26 patients (18.6%) had no paid work (Table 2). Of those not employed,

Table 1. Main clinical characteristics of patients with early spondyloarthritis (SpA). All values are n (%) unless otherwise specified.

Clinical Characteristics	n = 140
Demographics	
Men	97 (69)
Age, yrs, mean (SD)	41 (10)
Race, white	118 (84)
Educational level, high/low	82 (59)/58 (41)
Types of SpA	
Ankylosing spondylitis	103 (74)
Undifferentiated SpA	21 (15)
SpA and inflammatory bowel disease	4 (3)
Reactive arthritis	2 (1)
Psoriatic arthritis	10 (7)
Disease characteristics	
Disease duration, yrs, mean (SD)	4.8 (2.7)
HLA-B27 positivity	110 (80)
CRP, mg/l, < 10, median (IQR)	4.0 (2.0–12.0)
ESR, mm/h, < 20, median (IQR)	10.0 (5.0–20.3)
BASDAI, 0–10, median (IQR)	3.0 (1.7–4.8)
BASFI, 0–10, median (IQR)	2.2 (0.8–3.8)
BASMI, 0–10, median (IQR)	1.0 (0.0–2.0)
MASES, 0–39, median (IQR)	3.0 (0.0–5.0)
mSASSS, 0–72, median (IQR)	3.0 (1.0–6.3)
Uveitis history	38 (27.1)
Psoriasis history	14 (10.0)
Inflammatory bowel disease history	5 (3.6)
Peripheral arthritis history	45 (32.1)
Current medication	
NSAID	124 (88.6)
DMARD	8 (5.7)
TNF- α blockers	14 (10.0)

Educational level high: high school, preuniversity education, higher vocational education, and university. Educational level low: elementary education, lower vocational education, and intermediate vocational education. CRP: C-reactive protein; ESR: erythrocyte sedimentation rate; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; BASFI: Bath Ankylosing Spondylitis Functional Index; BASMI: Bath Ankylosing Spondylitis Metrology Index; MASES: Maastricht Ankylosing Spondylitis Enthesitis Score; mSASSS: modified Stoke Ankylosing Spondylitis Spinal Score; NSAID: nonsteroidal antiinflammatory drug; DMARD: disease-modifying antirheumatic drug; TNF- α : tumor necrosis factor- α .

3 patients never had a paid job and 23 (16.4%) stopped working after a median disease duration of 10 months (–2.3–3.3 yrs). The IQR indicates that some patients (8/23, 35%) stopped working before the official diagnosis was made. Twenty-one of 23 patients (91%) who stopped working indicated that this was partly or fully because of their SpA-related symptoms and that therefore they were receiving an official disability allowance.

In the general population of the Amsterdam area, the unemployment rate is 5.4%, which means that the unemployment rate among the SpA population is at least 3 times higher (goodness-of-fit $p < 0.001$). The 114 patients with a paid job worked for 4.5 (1.0) days a week and 33.8 h (9.2) a week. Thirty-seven percent (42/114) worked part time (< 5 days/week) with a mean working week of 3.5 (0.9)

Table 2. Work status in patients with early spondyloarthritis (SpA). All values are n (%) unless otherwise specified.

Work Characteristics	n = 140
Work status	
Paid job	114 (81.4)
No paid job	26 (18.6)
Ever paid job	23 (16.4)
Never paid job	3 (2.1)
Disease duration until stopping work, yrs, median (IQR)	0.9 (–2.3–3.3)
Working hours	
Working days, per week, mean (SD)	4.5 (1.0)
Working hours, per week, mean (SD)	33.8 (9.2)
Full time	72 (63.2)
Part time	42 (36.8)
Working days, per week, mean (SD)	3.5 (0.9)
Number men/women working part time	21 (50)/21 (50)
Importance of work for general well-being	
Importance of work in employed patients, median (IQR)	8.0 (7.0–9.0)
Work disability	
Not on work disability	117 (83.6)
On work disability	23 (16.4)
Because of SpA	21 (15.0)
Because of other reason	2 (1.4)

IQR: interquartile range.

days and mean working hours of 25.2 (9.1) a week. The distribution of men and women who worked part time was equally divided. Employed patients rated the importance of their work for their general well-being at 8.0 (7.0–9.0).

Association between disease-related characteristics and work status. In univariate analyses, being employed was significantly associated with lower age, higher education, and lower ASQoL (better overall quality of life), and lower BASDAI, BASFI, MASES, and BASMI scores (lower disease activity and less impairment of physical function, tender enthesitis, and spinal mobility; Table 3). Extraarticular manifestations or radiological damage were not associated with working status [Bath AS Radiological Index (BASRI), sacroiliac joint scores, modified Stoke Ankylosing Spondylitis Spinal Score (mSASSS); not all data shown]. In multivariable logistic regression, only BASMI and ASQoL remained the significant associated variables for being employed.

Work-related problems. Almost a third (42/136, 31%) of all patients employed or ever employed experienced on 1 or more occasions career problems because of their disease, such as difficulties in finding a job (19/136, 14%), dismissal (12/136, 9%), unemployment for longer than a month (13/136, 10%), rejection for positions at work (9/136, 7%), rejection after health assessment (3/136, 2%), change from employer or function (27/136, 20%), rejection for promotion (3/136, 2%), no admission to education (4/136, 3%), or refusal for insurance (5/136, 4%).

One-fifth (23/114, 21%) of the employed patients

Table 3. Association between clinical characteristics of patients with early spondyloarthritis and working status.

Variables	Univariable		Multivariable	
	OR (CI)	p	OR (CI)	p
Age	0.96 (0.92–0.99)	0.028	0.98 (0.94–1.03)	0.428
Male sex	1.88 (0.78–4.53)	0.159	—	NS
Symptom duration	0.97 (0.91–1.03)	0.340	—	NS
Education	1.52 (1.03–2.25)	0.035	1.30 (0.78–2.14)	0.312
BASFI, 0–10	0.61 (0.49–0.76)	< 0.001	0.92 (0.56–1.50)	0.738
BASDAI, 0–10	0.69 (0.56–0.84)	< 0.001	1.25 (0.83–1.89)	0.284
ASQoL, 0–18	0.78 (0.70–0.87)	< 0.001	0.76 (0.68–0.86)	< 0.001
BASMI, 0–10	0.65 (0.51–0.82)	< 0.001	0.63 (0.47–0.84)	0.002
MASES, 0–39	0.80 (0.71–0.90)	< 0.001	0.91 (0.79–1.05)	0.186
mSASSS, 0–72	0.97 (0.93–1.01)	0.142	—	NS
ESR, mm/h, < 20	0.97 (0.94–1.00)	0.064	—	NS

Significant data are in bold face. BASFI: Bath Ankylosing Spondylitis Functional Index; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; ASQoL: Ankylosing Spondylitis Quality of Life; BASMI: Bath Ankylosing Spondylitis Metrology Index; MASES: Maastricht Ankylosing Spondylitis Enthesitis Score; mSASSS: modified Stoke Ankylosing Spondylitis Spinal Score; ESR: erythrocyte sedimentation rate; NS: not significant.

declared that they would like to make changes in their work situation because of their disease, varying from having the opportunity to work fewer hours per day to adaptations of their chairs/desks. A few patients mentioned the wish to have more possibilities to move around during the working day.

Another third (37/114, 32%) of the employed patients already had made changes at work such as changing jobs (4/114, 4%), reducing working hours (10/114, 9%), adjustments of their work environment (14/114, 12%), and negotiating the number of tasks (9/114, 8%).

Sick leave and presenteeism in working patients with early SpA. Among working patients, sick leave because of SpA was reported in 32/114 patients (28%) with a median number of 2 (IQR 1.0–2.8) sick leave episodes and a median number of 4.0 (IQR 3.0–12.8) days of sick leave per patient with sick leave per year (Table 4). This resulted in 288 days of sick leave per year for the total group. The productivity costs because of sick leave were €59,131 per year for all 140

patients, resulting in median costs of €0.0 (0.0–263.0) per patient per year. In the general population of the Amsterdam area, the sick leave rate is 4.2%, which means that sick leave in the SpA population is reported about 7 times more frequently (goodness-of-fit $p < 0.001$).

Presenteeism measured by the QQ method showed that 47/114 of working patients (41%) reported a reduction in either quantity or quality of their work performance. On average, the quantity of work patients with SpA performed compared with normal was 9.0 (1.8) and the quality of the work was 9.3 (1.4). This resulted in an overall at-work productivity of 84.7% compared to normal, indicating at-work productivity loss of 15.3%.

The costs for at-work productivity loss based on the QQ method for the total group of 140 patients was calculated to be €843,457 and a median cost of €991 (€0–10,591) per patient per year. The total costs of productivity loss (presenteeism and absenteeism) in the last year were €902,588, with a median of €1983 (€0–10,591) per patient per year.

Association between disease-related characteristics and at-work productivity loss. In univariate linear analyses, at-work productivity loss (measured by the QQ method) was significantly associated with older age, longer symptom duration, lower education, higher ASQoL (lower quality of life), higher BASDAI, BASFI, and BASMI (higher disease activity and more impairment of movement), and higher enthesitis score (MASES; Table 5). Extraarticular manifestations or radiological progression variables (BASRI, sacroiliac joint scores, mSASSS) were not associated with at-work productivity loss (not all data shown). In multivariable linear regressions, education, ASQoL, and BASMI remained significantly associated with at-work productivity loss (presenteeism).

Resource use by patients with early SpA and relation to

Table 4. Sick leave and presenteeism in working patients with early spondyloarthritis. Values are median (IQR) unless specified otherwise.

Characteristics	n = 114
Sick leave	
Sick leave, past yr, n (%)	32 (28)
Number of days of sick leave, per yr	4.0 (3.0–12.8)
Cost of sick leave, €/patient/yr*	0.0 (0.0–263.0)
Quantity and Quality method	
Quantity × Quality, 0–100%, mean (SD)	84.7 (23.7)
Productivity loss, hrs/yr	30.4 (0.0–347.8)
Costs of productivity loss, €/patient/yr*	991.0 (0.0–10,591.0)
Costs of productivity loss and sick leave, €/patient/yr*	1983.0 (0.0–10,591.0)

*Measured over n = 140. IQR: interquartile range.

Table 5. Association between clinical characteristics of patients with early spondyloarthritis and at-work productivity.

Variables	Univariable		Multivariable	
	β	p	β	p
Age	-0.022	0.008	-0.016	0.113
Male sex	0.144	0.423		NS
Symptom duration	-0.028	0.027	0.006	0.654
Education	-0.513	0.001	-0.398	0.010
BASFI, 0–10	-0.192	< 0.001	0.072	0.351
BASDAI, 0–10	-0.156	< 0.001	-0.053	0.479
ASQoL, 0–18	-0.109	< 0.001	-0.103	0.003
BASMI, 0–10	-0.149	0.004	-0.113	0.044
MASES, 0–39	-0.059	0.027	-0.030	0.214
mSASSS, 0–72	-0.002	0.831		NS
ESR, mm/h, < 20	-0.002	0.821		NS

Significant data are in bold face. BASFI: Bath Ankylosing Spondylitis Functional Index; BASDAI: Bath Ankylosing Spondylitis Disease Activity Index; ASQoL: Ankylosing Spondylitis Quality of Life; BASMI: Bath Ankylosing Spondylitis Metrology Index; MASES: Maastricht Ankylosing Spondylitis Enthesitis Score; mSASSS: modified Stoke Ankylosing Spondylitis Spinal Score; ESR: erythrocyte sedimentation rate; NS: not significant.

work status. Thirty-four percent of patients visit the rheumatologist because of their disease once per year, 41% of patients visit 2–3 times a year, and 16% visit ≥ 4 times a year, with an average of 2 visits a year (Table 6). Forty-seven percent of the patients (66/140) also visit other healthcare providers for their SpA. This means visits to the physiotherapist (38/140, 27%), manual/cesar/mensendieck therapists (23/140, 16%), rehabilitation specialists (4/140, 3%), general practitioners (13/140, 9%), or other specialists/therapists such as orthopedists, podiatrists, ophthalmologists, and dermatologists (21/140, 15%). An additional 13 patients (9%) made use of alternative medicine.

In total, 40% of patients (56/139) needed assistance in their daily activities from family members (35%), relatives (4%), or paid professionals (4%). Other resources or adjustments in the house were needed for daily activities in 21% of the patients (29/140) and included orthopedic devices, adjusted chairs or beds, and bath or toilet adjustments.

Univariate linear analyses showed differences in resource use between employed patients, patients who reported sick leave in the previous year, patients who experienced problems at work, and patients who were officially work-disabled (Table 6). Patients who reported sick leave in

the past year (compared to those who worked without sick leave) paid more visits to the rheumatologist (2.3 vs 1.8, $p = 0.04$) or other healthcare providers (62% vs 38%, $p = 0.020$), and needed more help in daily activities (62% vs 29%, $p = 0.001$). Employed patients with problems at work more often reported needing help in daily activities (59% vs 31%, $p = 0.002$) compared to employed patients without problems at work. Patients who were officially work-disabled more frequently reported the use of help in daily activities (75% vs 35%, $p = 0.001$) and making adjustments at home (45% vs 17%, $p = 0.004$) compared to those who were not work-disabled.

Multivariate linear analysis showed that patients who reported sick leave paid significantly more visits to the rheumatologist ($p = 0.039$), made more use of other healthcare providers ($p = 0.011$), and needed more help in daily activities ($p = 0.008$) than did those who did not take sick leave. Patients reported that their rheumatologist paid attention to problems concerning employment in 45% of the cases, while 42% reported that the rheumatologist paid no attention to work-related problems. The patients without a paying job, especially, reported that there was not enough attention paid to their problems (76%).

Table 6. Healthcare resource use in patients with early spondyloarthritis and relation to work status. Values are n (%) unless otherwise specified.

Variables	All Patients n = 140	Employed Patients n = 114	Sick Leave n = 34		Problems at Work n = 42		Work-disabled n = 21		
			p	p		p		p	
Visits rheumatologist, mean (SD)	2.0 (1.5)	1.9 (1.3)	0.129	2.3 (1.4)	0.040	2.0 (1.4)	0.530	2.5 (2.4)	0.103
Use of other medical care	66 (47)	51 (45)	0.235	21 (62)	0.020	21 (33)	0.649	10 (48)	0.963
Help in daily activities	56 (40)	42 (37)	0.078	21 (62)	0.001	24 (59)	0.002	15 (75)	0.001
Adjustments at home	29 (21)	22 (19)	0.336	9 (27)	0.269	12 (30)	0.108	9 (45)	0.004

Significant data are in bold face.

DISCUSSION

Our study showed that 19% of patients with early SpA had withdrawn from the labor force because of their complaints within 5 years after diagnosis. In addition, a substantial portion of the patients with SpA already experienced work-related (21%) and career-related problems (31%) as a result of SpA. Sick leave was reported in 28% of the working population during the past year and 41% reported reduced productivity while at work. This resulted in substantial costs for productivity loss in AS, which are estimated at almost €2000/patient/year, as well as higher healthcare resource use. Multivariable regressions showed that high BASMI (less spinal mobility) and ASQoL (lower quality of life) were significantly associated with not being employed and with reduced at-work productivity.

Previous studies of worker participation were mainly done in patients with longstanding AS (≥ 12 yrs) and show employment rates between 34% and 96%^{7,15,16,17}. Boonen, *et al* compared a Dutch AS population with longstanding disease (12 yrs) with the general population and showed that labor participation was decreased by 11%⁴, and estimated in another study that withdrawal from the labor force after diagnosis was 3 times higher than expected from the general population¹⁸. In general, with increasing age and disease duration, more chronically ill patients withdraw from work¹⁹, but Boonen, *et al* showed that the risk was more pronounced in younger patients with AS^{1,18}. Our present study indicated that work participation is already reduced early in the course of disease, sometimes even before the official diagnosis is made, at young age and with relatively mild disease. We reported a rate of 18.6% unemployment compared with 5.4% in the general population of Amsterdam (at least 3 times higher). This is in concordance with Chorus, *et al*¹⁵, who found that 27% of the patients with AS had already withdrawn from the labor force after a mean disease duration of 6.3 years and showed no influence of disease duration on labor force participation in the Netherlands. These data make clear that young patients should receive special attention with regard to work restrictions early in the disease.

For patients with SpA, not being employed was associated with more restrictions in spinal mobility (BASMI) and reduced health-related QoL (ASQoL). ASQoL includes not only aspects of disease activity and physical function, which are also partly represented in BASDAI and BASFI, but also includes emotional aspects and is likely, therefore, strongly associated with work problems. BASMI provides additional objective information on restrictions in mobility. Both BASMI and ASQoL seem to influence labor force participation in early stage disease, which makes them important for monitoring because having paid employment contributes to better physical and mental quality of life^{15,18,20,21}. Other studies in longstanding AS underscore the importance of these factors,

in addition to high disease activity measures in the BASDAI, BASFI, BASG, and spinal restriction measurements^{7,15,22}. Chorus, *et al* also showed the importance of behavioral coping styles and work-related factors like ergonomic and climatic conditions for patients with AS¹⁵. They found that early adjustments at the workplace prevent patients from early withdrawal from work. This is in line with our findings that 21% of patients reported the need for changes at work, and 31% had already arranged changes to remain in labor force.

Sick leave in the previous year was reported in our study in almost 30% of the patients with a paid job, while Boonen and ter Wee reported 50% sick leave over a period of 2 years in patients with longstanding AS^{2,23}. The limited literature available shows comparable numbers of days of sick leave in AS^{2,23,24}. Sick leave in the general population of the Netherlands was 4.2%, which means that the young patients with AS reported a 7 times higher sick leave percentage.

Importantly, at-work productivity (presenteeism) showed that quantity and quality of work was nearly normal (9.0 vs 9.3), notwithstanding that 41% of the patients reported some reduced at-work productivity. BASMI and ASQoL were again also associated with reduced at-work productivity, as well as education. SpA seemed to have an important effect on health in a broad range of aspects expressed by a high ASQoL, which could likely lead to restrictions in labor participation by early withdrawal from work and also reduced at-work productivity. Also, Braakman-Janssen, *et al* showed significant productivity loss (by QQ) in patients with rheumatoid arthritis compared to controls, although even the controls reported some presenteeism²⁵. It should be emphasized that there is discussion on whether self-reported productivity on a visual analog scale is a valid proxy for productivity loss in reality²⁶ because there might be a discrepancy between subjective and objective measurements, although this also applies for other subjective measurements such as pain, function, and QoL. Therefore, we made use of experienced-based measures to calculate productivity (costs) that should be interpreted with some caution. Research indicates that the relationship between reported and observed productivity is not linear, and is dependent on job and workplace characteristics, including the possibility to compensate for at-work productivity loss^{27,28}.

To the best of our knowledge, our study is one of the first to show that healthcare resource use is associated with work status in SpA. Patients who reported sick leave needed more medical care and assistance in daily activities compared to those who did not report sick leave. Patients with SpA experience serious problems in the workplace; one might expect rheumatologists to be interested in these problems because of the possible consequences for patient health and socioeconomic productivity²³. However, at least 42% of patients report that their rheumatologist did not ask about

work or work-related problems. Rheumatologists' awareness of work-related problems should be improved and preventive measures taken. It is important to realize that in SpA, problems arise at an early stage and can be recognized when an occupational history is performed, for instance by the rheumatologist asking about sick leave, problems at work, and the need for help in daily activities. Good cooperation and communication between different specialists, such as occupational physicians and occupational therapists, can make important differences for the patient, even if only small adjustments are made^{23,29}.

It is important to note that the majority of the patients with early SpA in our study did not receive treatment with tumor necrosis factor (TNF)-blockers, because of the relatively low disease activity (mean BASDAI score 3.0). Studies of treatment with anti-TNF in longstanding AS not only show important improvement in disease activity, but also in work-related issues such as sick leave, productivity, and keeping or reintegrating patients into the workplace^{24,26,30,31}. The group in our study that received TNF blockers was too small to compare their work participation rates with those of the non-TNF-treated patients.

Some limitations of our study must be mentioned. Data were obtained from self-administered questionnaires voluntarily completed at home, and therefore it was not possible to validate the data using objective measures. Thus, these "subjective" outcomes can be different from "objective" measures. However, the questionnaire included well-validated instruments^{13,32,33,34,35,36}. Further, it is important to emphasize that this early SpA cohort mainly included "mild cases" because patients with high disease activity usually participated in a biologics register. Given that fact, the numbers we present in our study are probably even somewhat underestimated. Since some questions cover the past period, recall bias possibly influenced some of the outcomes³⁷. Lastly, it has to be mentioned that our study does not contain a control group to make good comparisons with the general population. To the best of our knowledge, our study is the first to report on work participation in a group of patients with early SpA, making our study unique.

Withdrawal from the labor force in early SpA is substantial. It has become clear from our study that in relatively young patients with SpA with mild disease activity and short disease duration, 20% had withdrawn from work, 30% were on sick leave, and 40% had reduced productivity (rounded figures). Moreover, a substantial portion already experienced work-related and career-related problems. These problems can be recognized earlier by performing a proper occupational history. Therefore, more attention to work-related aspects of this disease is urgently needed at an earlier stage.

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