Chapter 7

Problems in work participation and resource utilisation should not be underestimated in patients with an early SpA

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Abstract

Objective: To explore the impact of early SpA on worker participation and to investigate variables associated with work outcomes as well as the impact on resource utilisation.

Methods: Patients included in an Early SpA cohort completed a questionnaire comprising questions on employment status, sick leave, presenteeism and resource utilisation. 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 utilisation across patient groups with different employment status was investigated with linear regression analyses.

Results: 140 patients participated in this study of which 69% was male, mean age of 41 years and disease duration of 4.8 years. Twenty-six patients (19%) were not employed due to 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 BASMI and ASQoL were associated with not being employed and with reduced productivity at work. Annual costs of productivity loss due to sick leave and presenteeism mounted to €2,000 per patient. Patients who report sick leave show a higher (health related) resource utilisation.

Conclusion: After only 5 years of diagnosis, a considerable proportion of SpA patients is not employed and those working have substantial sick leave and productivity loss. Among patients reporting sick leave, resource utilisation is higher. Alertness to work participation even in patients with a short disease duration is urgently needed.

Introduction

Spondylarthropathies - or now commonly called Spondyloarthritis (SpA) - comprises 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, 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 besides these articular manifestations also extra-articular manifestations like uveitis, IBD and psoriasis contribute to the burden of the disease.

Because of the onset of SpA is early in life, depending on the type of SpA ranging from the second till fourth decade of life, the impact of the disease on labour force participation is important as it would have consequences for the entire adult life. Restrictions in labour force participation are not only important for the individual patient and his family but also for society as it results in loss of productivity and societal productivity costs.

Among persons with SpA, the majority of research on worker participation 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 due to sick leave and eventually withdrawal from workforce due to work disability [1-3]. However, these studies are mainly performed in patients with long disease duration [1, 2, 4-7]. Limited data are available on worker participation early in the disease process of AS and studies regarding other types of SpA. This seems odd, since work participation is important for the quality of life patients experience and the impact of the disease lasts most of their lives.

Therefore we studied work participation comprising employment status, sick leave and presenteeism in patients with a recently diagnosed Spondyloarthritis of which the majority had axial complaints and we investigated the association between work participation with clinical disease related factors and resource utilisation.

Patients and methods

Study population

Patients with a recent diagnosis of Spondylarthropathy according to the ESSG criteria [8] and inflammatory back pain [9] were consecutively enrolled in the prospective Early Spondyloarthritis cohort in the Jan van Breemen Research Institute/Reade, a large outpatient rheumatology clinic in Amsterdam. The diagnosis Spondyloarthritis consisted of AS (if patients also fulfilled the modified New York criteria) [10], undifferentiated SpA, patients with inflammatory back pain and, psoriatic arthritis, inflammatory bowel diseases or reactive arthritis and juvenile SpA. For this 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 complete with regular intervals questionnaires and undergo physical, laboratory and radiographic assessments. Every year data were collected on self reported questionnaires (BASDAI, BASFI and BASG), disease manifestations (BASMI (3 point scale (0-10)) [11], MASES), extra-articular manifestations, laboratory tests (ESR, CRP) and radiology measurements (X-rays 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 due to sick leave or work disability), presenteeism (level of productivity while at work), quality of life and resource utilisation in the previous year.

Questions on work participation contained items of 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 doctors). In case of employment details on the number of working days and

working hours per week were asked. Questions about whether patients experienced problems at work due to SpA (difficulties in finding a job, dismissal, unemployed for longer than a month, rejected for positions at work, rejected for positions at work after medical examination, changed from employer or function, rejected of promotion, not admitted for education or insurance), the need to make changes in work because of their disease and the importance of work for their well being (on a NRS 0-10, 10 is very important). Sick leave was assessed by the number of times employed patients had been absent during the last year and the number of working days being absent. At-work productivity (presenteeism) was assessed by the Quantity and Quality method (QQ method) [12]. The QQ method consists of two numeric rating scales, one asking about the quantity and one about the quality (of the last working day, both on a 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*Q/10).

Quality of life questionnaire

Disease specific health-related quality of life (HR-Qol) was studied by using the Ankylosing Spondylitis Quality of Life questionnaire (ASQol) [13]. ASQoL consists of 18 items (yes=1 or no=0) which measures 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 resource utilisation

Additional questions were included about SpA related visits to the rheumatologist in the past year (number), visits to other specialists or therapists (yes/no, which types of specialists/therapists, which complaints) and 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 or not the rheumatologist pays attention to work (yes/no). The outcome variables concerning resource utilisation were number of visits to rheumatologist and other practitioners, proportion 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 (and standard deviations) or medians (and interquartile ranges) as appropriate. From the 'Centraal Bureau voor de Statistiek/Statistics Netherlands' we received numbers of unemployment and sick leave of the general population (in the Amsterdam area), which we 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, first the days sick leave were converted into working hours absent. Next, the remaining working hours per year were multiplied by 1-(Q*Q/10) to estimate the hours lost due to at-work productivity loss. Finally, the total number of hours productivity loss was multiplied by the hourly wage for paid employment by age and gender as derived from the 'Centraal Bureau voor de Statistiek/Statistics Netherlands' of the 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 normalised the QQ-scores. Presence of at-work productivity loss (presenteeism) was defined as having a Q*Q score <10. In the multivariate analyses, covariates with a univariate association with a p-value <0.05 were included (if no colinearity was present). To understand resource utilisation across patient groups with different employment status, univariate and multivariate linear regression analyses was performed.

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

Results

Main clinical characteristics of early SpA patients

Of the 180 patients who were enrolled for this study, 140 patients returned the questionnaire (response rate of 78%) and were included. Non-participants did not differ in age and sex from the participants. Patients were predominantly male (97/140, 69%) and Caucasian (118/140, 84%) (Table 1). The patient group consisted for 74% of AS patients. The precise SpA diagnoses were specified (Table 1), of which most patients had axial disease.

Table 1. Main clinical characteristics of early SpA patients

	N=140
Demographics	
Men[a]	97 (69)
Age[b], (years)	41 (10)
Race[a], (caucasian)	118 (84)
Educational level[a], (high/low)	82 (59)/58 (41)
Types of Spondylarthropathies	
Ankylosing spondylitis[a]	103 (74)
Undifferentiated spondylarthropathy[a]	21 (15)
SpA and inflammatory bowel disease[a]	4 (3)
Reactive arthritis[a]	2 (1)
Psoriatic arthritis[a]	10 (7)
Disease characteristics	
Disease duration[b], (years)	4.8 (2.7)
HLA-B27[a], (positivity)	110 (80)
CRP[c], (mg/l) [<10]	4.0 (2.0-12.0)
ESR[c], (mm/hr) [<20]	10.0 (5.0-20.3)
BASDAI[c], (0-10)	3.0 (1.7-4.8)
BASFI[c], (0-10)	2.2 (0.8-3.8)
BASMI[c], (0-10)	1.0 (0.0-2.0)
MASES[c], (0-39)	3.0 (0.0-5.0)
mSASSS[c], (0-72)	3.0 (1.0-6.3)
Uveitis[a], (history of)	38 (27.1)
Psoriasis[a], (history of)	14 (10.0)
Inflammatory bowel disease[a], (history of)	5 (3.6)
Peripheral arthritis[a], (history of)	45 (32.1)
Medication	
NSAIDs[a], (current)	124 (88.6)
DMARDs[a], (current)	8 (5.7)
TNF-α blockers[a], (current)	14 (10.0)

Educational level high=high school+pre-university education+higher vocational education+university; Educational level low=elementary education+ lower vocational education+indermediate 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; NSAIDs=Non Steroidal Anti-Inflammatory Drugs; DMARDs=Disease Modifying Anti-Rheumatic drugs; TNF-α=Tumor Necrosis Factor-α. [a]Number (%), [b]Mean (SD), [c]Median (IQR).

According to the new ASAS criteria, 91.4% had axial SpA disease and 8.6% peripheral SpA (counted with data available) [14]. The mean disease duration ('time since diagnosis') was 4.8 (2.7) years and the median symptom duration ('time since first symptoms') was 10

years (IQR= 0.6-16.0 years). Almost all patients (89%) used NSAIDs, 6% was treated with a DMARD and 10% with a biological.

Work status in early SpA patients

One-hundred-fourteen patients (81.4%) worked for pay while twenty-six patients (18.6%) had no paid work (Table 2). Of those not employed, 3 patients never had a paid job and 23 (16.4%) stopped working after a median disease duration of 10 months (IQR= -2.3-3.3 years). The interquartile range indicates some patients (8/23=35%) stopped working before the official diagnosis has been made. Twenty one of twenty-three (91%) patients who stopped working indicated this was partly or fully due to their SpA related symptoms and therefore they were receiving an official disability allowance.

In the general population of Amsterdam area the unemployment rate is 5.4%, which means that the rate of not being employed of the SpA population is at least three 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 (9.2) hours a week. Thirty-seven percent (42/114) worked part time (<5 days/week), with a mean working week of 3.5 (0.9) 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 importance of their work for their general wellbeing at 8.0 (7.0-9.0).

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Association between disease related characteristics and work status

In univariate analyses, being employed was significantly associated with lower age, higher education but also with lower ASQoL (better overall quality of life), lower BASDAI, BASFI, MASES and BASMI scores (lower disease activity and less impairment of physical function, tender enthesis and spinal mobility) (Table 3).

Table 2. Work status in early SpA patients

	N=140
Work status	
Paid job[a]	114 (81.4)
No paid job[a]	26 (18.6)
Ever paid job[a]	23 (16.4)
Never paid job[a]	3 (2.1)
Disease duration till stopping work[c], (years)	0.9 (-2.3-3.3)
Working hours	
Working days[b], (per week)	4.5 (1.0)
Working hours[b], (per week)	33.8 (9.2)
Full time[a]	72 (63.2)
Part time[a]	42 (36.8)
Working days[b], (per week)	3.5 (0.9)
Number men[a]/women working partime[a]	21 (50)/21 (50)
Importance of work for general well being	
Importance of work in employed patients[c]	8.0 (7.0-9.0)
Work disability	
Not on work disability[a]	117 (83.6)
On work disability[a]	23 (16.4)
Due to SpA[a]	21 (15.0)
Due to other reason[a]	2 (1.4)

[a]Number (%), [b]Mean (SD), [c]Median (IQR).

Extra-articular manifestations or radiological damage (BASRI, SI-joint scores, mSASSS) were not associated with working status (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 in one or more occasions career problems due to their disease comprising difficulties in finding a job (19/136,14%), dismissal (12/136, 9%), unemployed for longer than a month (13/136, 10%), rejection for positions at work (9/136, 7%), rejection after health assessment (3/136, 2%), changed from employer or function (27/136, 20%), rejection for promotion (3/136, 2%), no admission for education (4/136, 3%) or refusal for insurance (5/136, 4%).

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

Variables	Univariable		Multivariable	
	Odds Ratio (CI)	P-value	Odds Ratio (CI)	P-value
Age	0.96 (0.92 - 0.99)	**0.028**	0.98 (0.94 - 1.03)	0.428
Gender (male)	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/hr) [<20]	0.97 (0.94 -1.00)	0.064		NS

BASFI= Bath Ankylosing Spondylitis Functional Index; BASDAI= Bath Ankylosing Spondylitis Disease Activity Index; BASMI= Bath Ankylosing Spondylitis Metrology Index; MASES= Maastricht Ankylosing Spondylitis Enthesitis Score; mSASSS= modified Stoke Ankylosing Spondylitis Spinal Score; ASQoL= Ankylosing Spondylitis Quality of Life; ESR= Erythrocyte Sedimentation Rate.

One fifth (23/114, 21%) of the employed patients 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 during the working day.

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

Sick leave and presenteeism in working early SpA patients

Among working patients sick leave due to 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 due to 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 Amsterdam area the sick leave rate is 4.2%, which means that sick leave in the SpA population is reported about 7 times more frequent (goodness of fit: p<0.001).

Presenteeism measured by the QQ method showed that 47/114 (41%) of working patients reported a reduction in either quality or quantity of their work performance. On average the quantity of work SpA patients 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 €843,457 and a median costs 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 €1,983 (0-10,591) per patient per year.

Table 4. Sick leave and presenteeism in working early SpA patients

Sick leave	N=114
Sick leave, (past year)[a]	32 (28)
Number of days of sick leave, (per year)[c]	4.0 (3.0-12.8)
Cost of sick leave, (€/patient/year)[c*]	0.0 (0.0-263.0)
Quantity and Quality method	
Quantity*Quality, (0-100%)[b]	84.7 (23.7)
Productivity loss, (hours/year)[c]	30.4 (0.0-347.8)
Costs of productivity loss, (€/patient/year)[c*]	991.0 (0.0 - 10,591.0)
Costs of productivity loss and sick leave, (€/patient/year)[c*]	1,983.0 (0.0 - 10,591.0)

[a]Number (%), [b]Mean (SD), [c]Median (IQR), *measured over N=140.

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 higher age, longer symptom duration, lower education but also with 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). Extra-articular manifestations or radiological progression parameters (BASRI, SI-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 utilisation in early SpA patients and relation to work status

Thirty-four percent of the patients visits the rheumatologist because of their disease once per year, 41% 2-3 times a year and 16% ≥4 times a year, with an average visits to the

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

Variables	Univariable		Multivariable	
	B	P-value	B	P-value
Age	-0.022	**0.008**	-0.016	0.113
Gender (male)	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/hr) [<20]	-0.002	0.821		NS

BASFI= Bath Ankylosing Spondylitis Functional Index; BASDAI= Bath Ankylosing Spondylitis Disease Activity Index; BASMI= Bath Ankylosing Spondylitis Metrology Index; MASES= Maastricht Ankylosing Spondylitis Enthesitis Score; mSASSS= modified Stoke Ankylosing Spondylitis Spinal Score; ASQoL= Ankylosing Spondylitis Quality of Life; ESR= Erythrocyte Sedimentation Rate.

rheumatologist of 2 times a year (Table 6). Forty-seven percent of the patients (66/140) also visit other health care providers for their SpA. This comprised visits to the physiotherapist (38/140, 27%), manual/cesar/mensendieck therapist (23/140, 16%), rehabilitation specialist (4/140, 3%), general practitioner (13/140, 9%) or other specialists/therapists (21/140, 15%) like orthopaedists, podiatrists, ophthalmologists and dermatologists, further 13 (9%) declared to make use of alternative medicine. In total 40% (56/139) needed assistance in their daily activities, by 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), varying from orthopaedic devices, adjusted chairs or beds, and bath or toilet adjustments.

Univariate linear analyses showed differences in resource utilisation 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). Especially patients who reported sick leave in the past year, paid more visits to the rheumatologist (2.3 vs 1.8, p=0.04), other healthcare providers (62% vs 38%, p=0.020) and needed more help in daily activities (62% vs 29%, p=0.001) compared with those who worked without sick leave. Working patients with problems at work reported more often help in daily activities (59% vs 31%, p=0.002) compared with employed patients without problems at work.

Patients who were officially work disabled reported more frequently to make use of help in daily activities (75% vs 35%, p=0.001) and reported more frequently adjustments at home (45% vs 17%, p=0.004) compared with those who were not work disabled. Multivariate linear analysis shows that especially 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). Patients reported that their rheumatologist had attention for problems concerning employment in 45% of the cases, while 42% reported that the rheumatologist had no attention for work related problems. Mainly the non-employed patients reported that there was not enough attention for their problems (76%).

Table 6. Resource utilisation in early SpA patients and relation to work status

	All patients N=140	Employed patients N=114	Sick leave N=34	Problems at work N=42	Work disabled N=21
Visits Rheumatologist[b]	2.0 (1.5)	1.9 (1.3) p=0.129	**2.3 (1.4) p=0.040**	2.0 (1.4) p=0.530	2.5 (2.4) p=0.103
Use of other medical care[a]	66 (47%)	51 (45%) p=0.235	**21 (62%) p=0.020**	21 (33%) p=0.649	10 (48%) p=0.963
Help in daily activities[a]	56 (40%)	42 (37%) p=0.078	**21 (62%) p=0.001**	**24 (59%) p=0.002**	**15 (75%) p=0.001**
Adjustments at home[a]	29 (21%)	22 (19%) p=0.336	9 (27%) p=0.269	12 (30%) p=0.108	**9 (45%) p=0.004**

[a] Number (%), [b] Mean (SD).

Discussion

This study shows that 19% of patients with early SpA had withdrawn from labour force because of their complaints within 5 years after diagnosis. In addition, a substantial portion of the SpA patients 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 €2,000/patient/year, as well as higher resource utilisation. Multivariable regressions showed that high BASMI and ASQoL were significantly associated with not being employed and reduced at-work productivity.

Previous studies on worker participation were mainly performed in AS patients with longstanding disease (≥12 years) and show employment rates between 34% and 96% [7,

15-17]. Boonen et al. compared a Dutch AS population with longstanding disease (12 years) with the general population and showed that labour participation was decreased by 11% [4] and estimated in another study that withdrawal of labour force after diagnosis was three times higher than expected from the general population [18]. In general with increasing age and disease duration, more chronically ill patients withdraw from work [19], but Boonen et al. showed that the risk was more pronounced in younger AS patients [1, 18]. The present study indicates that work participation is already reduced early in the course of disease, sometimes even before the official diagnosis was made, at young age and with relatively mild disease. We reported an rate of not being employed of 18.6% compared with 5.4% unemployment in the general population of Amsterdam which is at least 3 times higher. This is in concordance with Chorus et al, who found that 27% of the AS patients already had withdrawn from labour force after a mean disease duration of 6.3 years and showed no influence of disease duration on labour force participation in The Netherlands [15]. These data make clear that young patients should receive special attention with regard to work-restrictions early in the disease.

Not being employed in SpA 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 stronger associated with work problems. BASMI provides additional objective information on restrictions in mobility. Both BASMI and ASQoL seem to influence labour force participation in early stage disease which makes them important for monitoring since 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 BASDAI, BASFI, BASG and spinal restriction measurements [7, 15, 22]. Chorus et al. also showed the importance of behavioural coping styles and work related factors like ergonomic and climatic conditions in AS patients [15]. They described that early adjustments at the workplace prevent patients from early withdrawal of work. This is in line with our findings that patients reported the need for changes at work in 21% and 31% had already arranged changes to remain in labour force.

Sick leave in the previous year was reported in this study in almost 30% of the patients with a paid job, while Boonen et al. reported 50% sick leave over a period of two years in longstanding AS [2, 23]. The scarce 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 AS patients reported a 7 times higher sick leave percentage.

Importantly, at-work productivity (presenteeism) of those employed showed that quantity and quality of work was nearby 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 seem to have an important impact on health in a broad range of aspects expressed by a high ASQoL, which could likely lead to restrictions in labour participation by early withdrawal from work and also reduced at-work productivity. Also Braakman-Janssen et al. showed significant productivity loss (by QQ) in RA patients compared to controls, although even the controls reported some presenteeism [25]. It should be emphasised that there is discussion whether self-reported productivity on a visual analogue scale is a valid proxy for productivity loss in reality [26], as there might be a discrepancy between subjective and objective measurements, although this also applies for other subjective measurements like pain, function and QoL. Therefore we made use of experienced based measures to calculate productivity (costs), which should be interpreted with some caution. Scarce research indicates that the relation between reported and observed productivity is not linear and dependent on job and workplace characteristics including the possibility to compensate for at-work productivity loss [27, 28].

Our study is one of the first that shows that resource utilisation is associated with work status in SpA. Especially patients who reported sick leave needed more medical care and assistance in daily activities, compared with those who did not report sick leave. Because patients experience serious problems in working life due to their SpA, one might expect interest of the rheumatologist for their problems because of the possible consequences on their health and socioeconomic productivity [23]. However, at least 42% of all the patients report that their rheumatologist did not ask for work or work related problems. Awareness of rheumatologists for work related problems should be improved and preventive measures should be 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 asking for sick leave, problems at work and need for help in daily activities. Good cooperation and communication between different specialists like occupational physicians, insurance

physicians or occupational therapists can make important differences for the patient by possibly only small adjustments [23, 29].

It is important to note that the majority of the early SpA patients in this study did not receive treatment with TNF-blockers, because of the relative 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 reintegrate patients in the work participation [24, 26, 30, 31]. The group in our study that received TNF-blockers was too small to compare the results of work participation with the non-TNF-treated patients.

Some limitations of this study must be mentioned. Data were obtained by self administered questionnaires voluntarily completed at home and therefore it was not possible to validate these data using objective measures, so these 'subjective' outcomes can be different than 'objective' measures. However, the questionnaire included well validated instruments [13, 32-36]. Further, it is important to stress that this Early SpA cohort mainly included 'mild cases', since patients with high disease activity usually participated in a biologics register. Given that fact, the numbers we present in this study are probably even somewhat underestimated. Since some questions cover the past period, recall bias possibly influenced some of the outcomes [37]. At last, it has to be mentioned that this study does not contain a control group to make good comparisons with the general population. To the best of our knowledge this study is the first study that reports about the work participation in a group of early Spondyloarthritis, which makes this study unique.

In conclusion, withdrawal from labour force in early SpA is substantial. It has become clear from this study that in relatively young SpA patients with mild disease activity and short disease duration, there is already 19% withdrawal from work, 30% sick leave and presenteeism in 40%. Moreover, a substantial portion already experiences work-related and career-related problems. These problems can be recognized earlier by performing a proper occupational history. Therefore more attention for work related aspects of this disease is urgently needed in an earlier stage of the disease.

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