

Employment, work disability, and work days lost in patients with ankylosing spondylitis: a cross sectional study of Dutch patients

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Abstract

Objective—To evaluate employment status, work disability, and work days lost in patients with ankylosing spondylitis (AS).

Methods—A questionnaire was sent to 709 patients with AS aged 16–60. The results of 658 of the patients could be analysed.

Results—After adjustment for age, labour force participation was decreased by 15.4% in male patients and 5.2% in female patients compared with the general Dutch population. Work disability (all causes) was 15.7% and 16.9% higher than expected in the general population for male and female patients respectively. In particular, the proportion of those with a partial work disability pension was increased. Patients with a paid job lost 5.0% of work days as the result of having AS, accounting for a mean of 10.1 days of sick leave due to AS per patient per year in addition to the national average of 12.3 unspecified days of sick leave.

Conclusion—This study on work status in AS provides data adjusted for age and sex, and the differences from the reference population were significant. The impact of AS on employment and work disability is considerable. Work status in patients with AS needs more attention as an outcome measure in future research.

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In a broader concept of patient outcomes in chronic diseases, psychosocial and economic end points need to be considered in addition to traditionally defined outcome measures. Important economic end points are health resource utilisation and labour force participation. Labour force participation is important from a societal point of view because it is a major determinant of the economic burden of illness. From the patient's point of view, it is also relevant because of its influence on social contacts and self esteem and therefore on quality of life.¹ It is known that musculoskeletal disease is the leading cause of work disability in the United States.²⁻⁶ The same is true in the Netherlands, where musculoskeletal diseases and neuropsychiatric disorders are the most important causes of sick leave and work disability, each accounting for 29% of all causes of prolonged sick leave and permanent work disability at the time of the study.⁷ Much less is known about the relative contributions of the different subgroups of musculoskeletal disease to total work disability. For rheumatoid

arthritis, several studies on labour force participation and its determinants have been published.⁸⁻²¹ For ankylosing spondylitis (AS), however, few and inconsistent data on labour force participation exist,²²⁻³⁶ and no data are available for the Netherlands. The prevalence of AS in the Netherlands is estimated to be 0.08–0.1%, accounting for about 11 700 patients with AS.³⁷ The disease is about three times more common in men than women and usually starts in the third decade of life.³⁷ It may lead to major functional limitations not only because of spinal disease but also because of extraspinal disease manifestations such as peripheral arthritis, inflammatory bowel disease, and uveitis. In this study, we investigated cross sectionally prevalent employment, work disability, and sick leave in patients aged 16–60 years with AS who regularly visit a rheumatologist.

Methods

PATIENTS

Patients were selected from the nationwide Dutch Standard Diagnosis Register of Rheumatic Diseases (SDR) in which more than 37 (66%) of all Dutch rheumatology practices (80% of rheumatologists) participate.³⁸ Rheumatologists register all outpatients once a year. On the basis of the proportion of rheumatologists participating in the SDR, the number of patients in the SDR with the diagnosis AS, and an estimated number of patients with AS in the Netherlands of 11 700, probably 40–50% of patients with AS are under the care of a rheumatologist. A geographically representative sample of 15 practices were invited to participate in this study and all agreed. Two of the eight Dutch academic practices were included. This number of practices was chosen in order to obtain a large enough sample of patients. Selected patients had consulted their rheumatologist in 1995 or 1996, had to be between 16 and 60 years of age, and had to have a diagnosis of AS.

QUESTIONNAIRE

In September 1997 patients received a postal questionnaire on sociodemographic, disease related, and work related variables. Sociodemographic factors comprised sex, age, race, marital status, family situation, education, profession, income, and work status. Disease related questions assessed age at diagnosis, comorbidity, medication, extra-articular manifestations of AS, the BAS-FI measuring functional status,³⁹ the BAS-DAI measuring disease

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activity,⁴⁰ the BAS-G measuring patient global assessment,⁴¹ and the Self Assessment Joint Score.⁴² Questions about career history and characteristics of the present job were also asked. Jobs were classified by the system used by Statistics Netherlands into agricultural, industrial, transportation, administrative, servicing, and specialist or managerial.³⁹ For statistical purposes, jobs were classified as manual or non-manual. Jobs in the agricultural, industrial, and transport sectors were considered to be manual. Finally, module I of the Health and Labour Questionnaire was included. This questionnaire assesses at one point in time the absence from paid work during the preceding two weeks. Construct validity and feasibility of module I of the questionnaire were tested in the general Dutch population and in patients with various chronic diseases.⁴³

DEFINITION OF END POINTS ON WORK STATUS

Employment or labour force participation refers to the ability to perform paid work. This study does not look at the ability to perform unpaid work or the quality of the paid work. Full time work was defined as working 32 hours a week or more. Work disability was defined as official disability under the Dutch social security system. Six categories of work disability exist, and work disability of 80–100% is regarded as full work disability, while the other categories are considered as partial work disability. The reported work disability is from “all causes” and not exclusively attributable to AS. Unemployment is defined as receiving official unemployment benefit. Sick leave for those with a paid job was assessed by the Health and Labour Questionnaire at one point in time and was defined as absence for at least half a day from paid work because of AS.

DESCRIPTION OF THE SOCIAL SECURITY SYSTEM IN THE NETHERLANDS

The Dutch social security benefit programme applies to all people below 65 years of age who are in employment. In the Netherlands, as in many other European countries, but in contrast with the situation in the United States, a distinction is made between sick leave (work incapacity but the patient has an employment contract) and work disability (employment contract stops). The Dutch social security benefit programme is administered by the employer in collaboration with occupational health and safety organisations for the first 52 weeks of sick leave and by public social security associations for the work disability. For the entire first year of sick leave, the employer is responsible for provision of the sickness benefit, which may vary by 70–100% of the former gross wage. Medical certification is not required to claim sickness benefit. After three months of continuous sick leave, the occupational health and safety organisation of the employer is legally obliged to evaluate whether a rehabilitation programme is possible. Part time work can be part of the rehabilitation plan.

After one year of continuous sick leave, the social security association must decide on

eligibility for a permanent work disability pension, which can be full or partial and ranges from 0% to 100%. In August 1993, the eligibility criteria changed. A work disability pension is allowed if the patient has objective medical restrictions in performing any type of work, independent of age and profession. If the percentage of the disability exceeds 15%, a benefit will be allowed ranging from 25% to 70% of the former gross wage. Benefits are financed through social contributions from employees and employers. Persons who do not have an income through employment from the social security system may receive a social benefit allowance.

COMPARISON WITH THE GENERAL DUTCH POPULATION

Data on sociodemographic characteristics, labour force participation, and unemployment of the Dutch population were retrieved from Statistics Netherlands (CBS).⁷ Data on work disability in the Dutch population were retrieved from the National Organisation of Social Security Associations (LISV).⁴⁴ Because in our study the upper age limit for inclusion was 60 years, whereas in the general population the age of retirement is 65 years, we recalculated the CBS and LISV data for ages up to 60. Data on sick leave in the study population were compared with the results of a cross sectional study with the same instrument in the general Dutch population.⁴³ Reference data for the Dutch population were from 1997 for labour force participation and work disability and from 1996 for data on sick leave.

STATISTICAL METHODS

We aimed to show a difference in employment of at least 10% and in work disability of at least 5% in comparison with the Dutch population. By using formulae for comparison of proportions,⁴⁵ the required sample size was 247 and 338 patients for employment and work disability respectively. With an assumed response rate of at least 50%, we decided to invite 1000 patients with AS to participate. Data were analysed using SPSS 8.0 or Excel software. Proportions were calculated for fully completed questions. Job classification was adjusted for age and sex. The data on employment and disability were adjusted by indirect standardisation and presented as adjusted ratios and as adjusted rates.⁴⁵ For the adjusted ratios, 95% confidence intervals were calculated.

Results

RESPONSE RATE

The correct address of 152 of the 1092 patients could not be retrieved. Of the remaining 940 patients, 709 agreed to participate and received the questionnaire, which was completed by 658 patients. This accounts for a total response rate of 70%. Participants did not differ in age and sex from non-participants. Mean age was 43.5 years and 42.3 years and proportions of male patients 70% and 69% for participants and non-participants respectively.

Table 1 Patient characteristics for the total group and by sex compared with the Dutch population

Patient characteristics	Dutch population 15–60 years	Total group (n=658)	Men (n=461)	Women (n=197)
Male (%)	50.9	70.0		
Age, years (SD) [range]	—	43.5 (9.4) [18–60]	44.0 (9.3) [18–60]	42.5 (9.4) [19–60]
Disease duration, years (SD)	—	12.2 (8.0)	12.4 (8.4)	10.0 (7.5)
Living with a partner (%)	79.8	83.1	81.8	86.3
Peripheral arthritis (%)*	—	25.8	34.0	22.2
Total hip replacements (%)	—	3.6	2.8	5.6
IBD (%)†	—	4.3	5.2	3.5
BAS-FI‡	—	34.4 (24.6)	35.3 (24.8)	38.7 (24.2)
BAS-DAI§	—	38.8 (24.0)	36.6 (23.7)	43.8 (23.9)
BAS-G¶	—	41.2 (26.4)	40.2 (26.4)	43.3 (26.3)
>12 years formal education (%)	25.5	19.3	22.6	11.8
Manual workers (%)	18.2	22.4	35.6	9.3

Where appropriate, values are mean (SD).

*At least one joint on the Self Assessment Joint Score (swollen joints).

†Active inflammatory bowel disease (IBD) for preceding three months for which drug treatment was needed.

‡BAS-FI: Bath Ankylosing Spondylitis Functional Index; range 0–100; higher values indicate worse function.

§BAS-DAI: Bath Ankylosing Spondylitis Disease Activity Index; range 0–100; higher values indicate higher disease activity.

¶BAS-G: Bath Ankylosing Spondylitis Global Assessment; range 0–100; higher values indicate worse global assessment.

DESCRIPTION OF THE PATIENT POPULATION

Table 1 shows the sociodemographic and disease characteristics of the study group. In a subgroup of patients (n=137) belonging to two of the participating centres, the diagnosis AS as stated in the SDR was confirmed according to the radiological New York criteria for sacroiliitis by an independent reader in 99.3% of these patients.⁴⁶ The sex ratio of the study population compares well with other existing data.⁴⁷ The prevalence of inflammatory bowel disease and peripheral arthritis is more difficult to compare with results in the literature because different definitions are used and different populations studied. Our results fall within the reported figures.^{25 26 47–49} On the basis of Statistics Netherlands job classification, the age adjusted proportion of patients with AS who had a manual job was higher than in the general Dutch population.

WORK STATUS

Altogether, 4.1% of patients (3.0% of male patients and 6.6% of female patients) had never had a job. The unemployment rate was 4.4%, for both male and female patients, and 2.5% received a social benefit allowance (2.8% of male patients and 2.5% of female patients). In the Dutch population, the unemployment rate for those of working age was 4.1% (3.8% of male patients and 5.2% of female patients), and 5.4% received a social benefit allowance at the time of the study.⁷ In table 2 employment and full employment are presented as proportions of the total group for each age and sex category together with the reference data for the Dutch population. In table 3, these figures are shown for work disability and full work disability. Both tables also provide the adjusted ratios with the 95% confidence intervals and the adjusted rates for patients with AS. Clearly

Table 2 Percentage employment (and full employment) in patients with ankylosing spondylitis (AS) by sex and age category in comparison with the Dutch population

	AS total	AS men	AS women	Dutch total	Dutch men	Dutch women
<20 years	0 (0)	0 (0)	0 (0)	19.8 (7.6)	21.7 (9.2)	17.7 (5.7)
20–24 years	50.0 (42.9)	44.4 (33.3)	60.0 (60.0)	57.4 (39.7)	58.6 (46.1)	56.2 (33.1)
25–29 years	70.4 (55.8)	70.4 (65.4)	70.6 (41.2)	79.6 (61.4)	85.9 (79.4)	73.0 (42.7)
30–34 years	74.2 (57.8)	80.6 (77.8)	57.9 (10.5)	78.5 (55.8)	91.4 (84.6)	62.5 (25.5)
35–39 years	73.1 (53.9)	83.9 (72.6)	57.1 (25.0)	75.6 (52.4)	93.3 (86.1)	57.6 (17.5)
40–44 years	70.2 (51.5)	76.1 (63.0)	53.6 (21.4)	75.3 (50.2)	92.3 (83.4)	57.8 (16.2)
45–49 years	64.5 (43.9)	68.9 (52.8)	52.9 (20.6)	70.3 (48.8)	87.7 (80.4)	52.2 (15.9)
50–54 years	58.6 (48.5)	71.4 (56.0)	18.5 (7.4)	70.6 (50.1)	92.9 (83.6)	47.4 (15.1)
55–60 years	38.0 (29.7)	43.3 (34.8)	24.0 (16.0)	45.2 (31.8)	65.0 (55.2)	25.1 (7.9)
Total*	62.9 (46.7)	69.5 (57.8)	47.5 (20.9)	65.7 (47.1)	78.8 (70.1)	52.2 (21.0)
Adjusted ratio [95% CI]	0.82 [0.78 to 0.87] (0.77 [0.71 to 0.84])	0.80 [0.76 to 0.85] (0.74 [0.68 to 0.80])	0.90 [0.77 to 1.03] (1.12 [0.81 to 1.42])			
Adjusted rate†	54.2 (35.5)	63.4 (51.8)	46.9 (23.4)			

Values in parentheses are percentages of each category that are fully employed.

*Raw rates for the whole group.

†Adjusted rates for the study group after indirect standardisation.

Table 3 Percentage work disability (and full work disability) in patients with ankylosing spondylitis (AS) by sex and age category in comparison with the Dutch population

	AS total	AS men	AS women	Dutch total	Dutch men	Dutch women
15–25 years	0 (0)	0 (0)	0 (0)	1.5 (1.2)	1.8 (1.3)	1.3 (1.2)
22–34 years	15.3 (6.3)	12.2 (4.1)	22.2 (1.1)	3.3 (2.7)	2.9 (2.4)	3.7 (3.0)
35–44 years	27.0 (18.1)	28.1 (14.1)	24.6 (10.1)	6.0 (4.2)	6.5 (4.1)	5.6 (4.3)
45–54 years	41.7 (23.0)	44.3 (24.1)	34.4 (19.7)	12.4 (8.5)	15.4 (9.5)	9.2 (7.4)
55–60 years	57.6 (39.1)	62.7 (43.3)	44.0 (28.0)	21.7 (17.4)	29.7 (21.7)	13.6 (11.7)
Total group*	33.8 (18.7)	36.1 (20.2)	28.7 (15.2)	7.0 (5.1)	8.4 (5.6)	5.6 (4.6)
Adjusted ratio [95% CI]	3.10 [2.77 to 3.42] (2.76 [2.32 to 3.20])	2.88 [2.53 to 3.22] (2.41 [1.97 to 2.85])	4.00 [3.12 to 4.87] (2.60 [1.74 to 3.46])			
Adjusted† rate	21.8 (12.6)	24.1 (13.7)	22.6 (11.9)			

Values in parentheses are percentages of patients in each category who have full work disability pension.

*Raw rates for the whole group.

†Adjusted rates for the study group after indirect standardisation.

Table 4 Percentage employment and work disability as raw rates, adjusted rates after indirect standardisation for age (and sex), and as the difference in percentage between the patients and the Dutch population

	Total	Difference	Men	Difference	Women	Difference
Employment						
Population	65.2		78.8		52.2	
Patients; raw data	62.9	-2.3	69.5	-9.3	47.5	-4.7
Patients; indirect standardisation	54.2	-11.0	63.4	-15.4	46.9	-5.2
Work disability						
Population	7.0		8.4		5.6	
Patients; raw data	33.8	+26.8	36.1	+27.7	28.7	+23.1
Patients; indirect standardisation	21.8	+14.8	24.1	+15.7	22.6	+16.9

employment is decreased in both male and female patients, but this is only statistically significant in male patients. The decrease in full time employment is greater for men, whereas for female patients with AS the decrease in employment can be attributed to a decrease in part time employment. For both sexes, a significant increase in work disability rates was observed. This increase was more pronounced for partial than for full work disability.

WORK DAYS LOST

Module I of the Health and Labour Questionnaire was completed by 389 (92.5%) patients with a paid job. Five questionnaires could not be interpreted, resulting in a total of 385 (90.9%) questionnaires that could be analysed. Twenty five (6.5%) patients (5.2% of male patients and 11.4% of female patients) reported taking sick leave during the preceding two weeks. Of all the work days, 5.0% (4.1% for male patients and 9.1% for female patients) were lost due to sick leave because of AS. Extrapolating these data to days of sick leave per year results in 10.1 (8.8 days for male patients and 15.3 days for female patients) days of sick leave due to AS per patient per year. For the general Dutch population, the mean number of non-specific days of sick leave per person per year is 12.3 (12.2 days for men and 14.1 days for women). In the Netherlands, employees on continuous sick leave for more than three months are likely to be waiting for a disability assessment, but are still officially registered as employees. When these patients (three men and four women) are eliminated from the analysis, 4.3% of men and 6.7% of women reported an episode of sick leave, and 3.3% of possible work days were lost due to AS. Extrapolating these data to the number of days of sick leave would result in 6.5 extra days of sick leave per patient per year (6.9 for male patients and 5.7 for female patients).

Discussion

Among Dutch patients with AS, labour force participation is reduced, work disability increased, and extra sick leave substantial. We feel that an 11% decrease in employment and 15% increase in work disability is relevant from the clinical and societal point of view. The reduction in labour force participation is more pronounced for men than women. Sick leave for those with a paid job, however, is more consequential for female patients.

Our findings on employment and work disability were obtained after adjustment for age and sex, which was apparently not

performed in other studies. In table 4, we compare the raw and adjusted rates of labour force participation and work disability and present the difference from the general population for each method. Clearly, total labour force participation fell from 62.9% to 54.2% after adjustment for age and sex.

Data from the literature on work status in patients with AS are conflicting. Figures on labour force participation vary from 34% to 96%^{22-26 28 31 33 34 36 50} and for work disability from 3% to 36%.^{22 25-29 31 32 34 35 51} The results in the literature, however, are difficult to interpret. Disease characteristics are not always provided and sample sizes are usually small. Moreover, data were never adjusted for age, and sex, and clear reference data on employment for the general population were only provided in one study.⁵⁰

We may have introduced bias to some degree by examining patients with AS who were under the specialised outpatient care of a rheumatologist. This is supported by results in the literature, where employment in patients with AS from a hospital setting^{26 35} is in general lower than in populations obtained from patient associations or community studies.^{28 29 50} Also, a study from Norway that compares work status and disease severity between hospital and community patients with AS²⁴ showed that hospital patients with AS had lower employment and more severe disease. It should also be noted that, compared with the Dutch population, our patients were more likely to have manual professions and to be of lower social class based on educational level and job classification. As it has been shown that withdrawal from work as a result of AS is associated with jobs characterised by prolonged standing,²⁷ this may have influenced our results. We do not know whether the overrepresentation of manual workers in our group is a true reflection of Dutch patients with AS or is due to the method of sampling. Usually, those who do not respond to questionnaire studies have on average a lower educational level and more manual jobs.⁵²⁻⁵⁶ If this is applied to our findings, it suggests underrepresentation of manual workers and therefore underestimation of the impact of AS on work status. Alternatively, it is possible that the usual underrepresentation of the lower social class did not occur in our sample, which would result in overestimation of the impact of AS on work status.

It should be noted that reported work disability in this study is for all causes and not solely attributable to AS. Most studies did not mention whether they recorded disease specific

work disability, which contributes to the difficulties in comparing different studies. The Dutch social security system allows a combined (partial) disability pension and a (part time) job. It seems that patients with AS in the Netherlands often receive a partial disability pension. For female patients, this was not associated with a corresponding increase in part time jobs.

Although the number of AS related days of sick leave for those with a paid job is substantial, our data are not as bad as in other studies. We report 8.8 and 15.3 days of sick leave per patient per year for male and female patients respectively, in addition to the non-specific absence of 12 days per year for men and 14 days per year for women reported for the general population.⁴³ However, a Slovak study³⁵ reports 39.5 days of disease specific sick leave per patient per year, and a Mexican study 45.8 days per year (for all causes) in the cross sectional part of the study²² but only one day per patient per month in the prospective study.²³ Some comments need to be made. Firstly, there is no reason to believe that AS attributable sick leave shows seasonal variation. The questionnaire was sent in September. Continuing studies in our group on weekly variation in disease activity or on sick leave in another cohort show no seasonal influence (unpublished data). Therefore we think the results of the Health and Labour Questionnaire can reliably be extrapolated to one year. Secondly, it is known that sick leave varies with age and is influenced by professional class. As the number of patients taking sick leave in the study group was quite small and as the Health and Labour Questionnaire has no reference data for sick leave by age or profession, we could not adjust for these variables. Because our study population is somewhat older and has an overrepresentation of manual professions, sick leave may be somewhat overestimated. Finally, we instructed patients to provide data on disease specific sick leave. However, one may question whether patients can really distinguish between illness due to AS and other causes. Also, it has not been investigated whether patients with a chronic disease take the same disease non-specific sick leave as people without chronic disease. Although we are somewhat reluctant to accept relative proportions of disease specific and non-specific sick leave as presented here, it is clear that absence from work in patients with AS is greater than normal. For comparison, sick leave attributable to migraine is four days a year for women and one day for men.⁴³

In contrast with AS, work status in patients with rheumatoid arthritis has received considerable attention over the past two decades. Various studies have reported a reduction in labour force participation of 40–50% after a disease duration of up to 10 years.^{11 13 17 19–21 57} Also in the Netherlands, labour force participation of patients with rheumatoid arthritis was reduced after a mean disease duration of 12 years in comparison with the general population.¹⁸ However, figures on work status in

patients with rheumatoid arthritis and AS are difficult to compare. There are major differences in age and sex between the two types of patients, and published results are not adjusted for age and sex.

In the past, work status in patients with AS has received insufficient attention. Our study shows that the impact on this outcome measure is considerable, at least in patients treated by rheumatologists. It is important to assess differences from reference populations. Clearly, prospective studies on work status need to be carried out as well as research into factors influencing this end point.

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