

EXTENDED REPORT

Employment perspectives of patients with ankylosing spondylitis

A M J Chorus, A Boonen, H S Miedema, Sj van der Linden

Ann Rheum Dis 2002;**61**:693–699

See end of article for authors' affiliations

Correspondence to:
AMJ Chorus, TNO
Prevention and Health, PO
Box 2215, 2301 CE
Leiden, The Netherlands;
AMJ.Chorus@pg.tno.nlAccepted
27 February 2002**Objectives:** To assess the labour market position of patients with ankylosing spondylitis (AS) in relation to disease duration and to identify potential factors in relation to withdrawal from the labour force.**Methods:** A cross sectional mail survey was conducted among 658 patients with AS. Participation in the labour force was defined as having a paid job. The independent effect of duration of disease was examined by an indirect method of standardisation. A broad variety of risk factors were examined separately and in a combined analysis, including sociodemographic factors, disease related variables, coping styles, and work related factors. Attributable and preventable fractions were calculated from the combined analyses to assess the relative importance of the contributing factors.**Results:** Probability of participation in the labour force was similarly reduced in patients with AS with different durations of disease. Pacing to cope with limitations was the most relevant factor in increasing the risk of withdrawal from the labour force, accounting for 73% of withdrawals. Coping with limitations by often seeking creative solutions, high disease activity, increased age, and insufficient support from colleagues or management were also positively associated with withdrawal from the labour force. Technical or ergonomic adjustments of the workplace, working in large companies, and coping with dependency style through frequent acceptance were negatively associated. Of these factors, technical or ergonomic adjustment was the most relevant in terms of reducing the risk.**Conclusion:** Sociodemographic factors, disease related factors, coping styles, and work related factors contribute simultaneously to withdrawal from the labour force.

Ankylosing spondylitis (AS) is a chronic systemic inflammatory rheumatic disorder that primarily affects the axial skeleton, with sacroiliitis as its hallmark. Involvement of the limb joints other than the hips and shoulders is present in 30% of patients. Clinical manifestations of the disease usually begin in late adolescence or early adulthood. Onset after the age of 40 is rare. The disease has both skeletal and extraskelatal manifestations and is clinically three times more common in men than in women. Pain, stiffness, and fatigue are the most often reported symptoms of patients with AS.^{1,2} As in most rheumatic diseases, the severity of symptoms varies greatly among patients and varies over time in individual patients.

After rheumatoid arthritis (RA), ankylosing spondylitis is the major type of inflammatory rheumatic disease. By contrast with RA, knowledge about the burden of illness in AS is less well established. Generally, AS is considered to be a disease in which relatively good functional capacity and working ability are maintained. Previous studies of working ability among patients with AS reported employment rates of between 34% and 96% after mean duration of disease of 12 years or more.^{1,3,4} Despite this, none of the studies investigated the independent effect of duration of disease on participation in the labour force. As age, sex, education, and demand in the labour market may influence the likelihood of people stopping work, it is important to consider these factors when studying work disability. In patients with AS educational level may be influenced by the onset of the disease at a relatively young age. So in a previous study we controlled for age and sex and found that participation in the labour force was decreased by 11% compared with reference data for the general population of working age. The comparison with reference data of the same time period for the general population allowed for an indirect control for demand in the labour market.⁴

Most studies of risk factors for work disability in patients with AS have considered a limited range of possible risk

factors. Factors found to be associated with continued employment include younger age, higher socioeconomic status, prolonged standing, vocational counselling, and indicators of less disease activity.^{1,3} Only two studies are known which used multivariate statistical techniques to determine the independent effect of different sociodemographic and work factors on the risk of work disability.^{6,7} One study, by Barlow *et al*, found that anxious and depressed mood and lower self esteem were associated with work disability in patients with AS.⁸ In a previous study, behavioural coping was identified as a relatively new potential risk factor in relation to work.⁷

The purpose of this study was to explore the employment prospects for patients diagnosed with AS by exploring modifiable factors, which could be used to construct vocational interventions to prevent or postpone early withdrawal from the labour force. We therefore examined the influence of disease duration on participation in the labour force compared with the general Dutch population. We also studied a broad range of work related variables in relation to withdrawal from the labour force and we assessed the relative importance of work related factors in combination with sociodemographics, disease related factors, and coping styles.

METHODS

Sample selection

The present study was conducted in a Dutch nationwide study group of 658 patients aged 18–59 years diagnosed by a rheumatologist. Eligible patients were identified using the national

Abbreviations: AS, ankylosing spondylitis; BASDAI, Bath ankylosing spondylitis disease activity index; BASFI, Bath ankylosing spondylitis functional index; BASG, Bath ankylosing spondylitis global health index; CORS, coping with rheumatic stressors; SDR, Standardised Diagnosis Register of Rheumatic diseases; VHQ, vocational handicap questionnaire

Standardised Diagnosis Register of Rheumatic diseases (SDR), a representative database with information on diagnoses of the patient population of 80% of all rheumatologists in the Netherlands.⁹ From this database a random sample of patients with AS aged 16–59 years was selected from a geographically representative sample of 34 rheumatologists (34% of all rheumatologists participating in the SDR, 27% of all rheumatologists in the Netherlands), working in 15 practices (42% of all SDR practices) throughout the Netherlands. All patients were contacted by mail by their own rheumatologist, and 658 (60.3% of the initial cohort, 70.0% of the patients traceable) agreed to participate in the study. All patients filled out a self administered questionnaire adjusted to their current employment status (having a paid job, having no paid job but had a paid job in the past, and never had a paid job) and containing several standardised instruments. Data were obtained on sociodemographics, disease characteristics, functional abilities, health related quality of life, present and past working conditions, and coping with the disease. We limit our description of variables to those which were assessed to address our present study purpose. The design of the present study has been described in detail elsewhere.^{4,7}

Sociodemographic variables

Year of birth, sex, and highest attained level of education were identified as sociodemographic variables. Attained educational level was separated into three categories based on the Dutch educational system (primary education (0–8 years), secondary education (9–16 years), and higher vocational education/university (17 years and more)).

Disease characteristics

Disease activity was assessed using a Dutch version of the Bath ankylosing spondylitis disease activity index (BASDAI)¹⁰ containing six questions focusing on fatigue (one item), axial pain (one item), peripheral pain (one item), enthesopathy (one item), and morning stiffness (two items). Each question was scored on a visual analogue scale (VAS). The BASDAI score (0–10) was calculated as the mean value of the mean of the first four items and the mean of the last two items referring to morning stiffness. A higher score indicates more disease activity.

Patients were asked about the year in which AS was diagnosed. Furthermore, patients reported their current use of medication, whether they had total hip replacement, and whether they had AS related comorbidity and other chronic disorders.

Activities in daily life

To assess functional abilities in daily life, a Dutch version of the Bath ankylosing spondylitis functional index (BASFI) was used. This contains eight questions on function in AS and two questions reflecting the patients' ability to cope with everyday life.¹¹ Each question was scored on a VAS, the mean of which gave the BASFI score (0–10). A higher score indicates worse outcome.

Employment situation

All patients reported on their employment history using a Dutch generic structured instrument, the vocational handicap questionnaire (VHQ), which had been validated in previous studies among Dutch chronically ill people.^{12–14} This instrument assesses present occupational situation, vocational handicaps, employment history, and income compensation by work disability pensions. Data were also collected on the year of the first real paid job and job changes. To describe the present or last job, data were collected on field of work, job demands, size of company, accessibility of the workplace and transportation mobility, job adjustments, social support from colleagues, and management in the workplace. Patients who

had withdrawn from the labour force were asked to indicate in which year they stopped working and whether they had left for work related reasons, disease related reasons, or other personal reasons. For patients who left the labour force after being diagnosed, the duration of employment after diagnosis was calculated.

Coping

Behavioural coping styles were assessed using the disease specific coping with rheumatic stressors (CORS) instrument.^{15,16} The CORS measures eight coping styles directed at the most important chronic stressors of inflammatory rheumatic diseases—that is, pain, limitations, and dependence. Three scales refer to pain: comforting cognition (nine items), decreasing activities (eight items), and diverting attention (eight items). Three scales measure styles of coping with limitations: optimism (five items), pacing—that is, adapting one's level of activity (10 items)—and creative solution seeking (eight items). Two scales refer to dependence: making efforts to accept one's level of dependency (six items), and showing consideration (seven items). For each item, patients reported how often they made use of that particular coping strategy (seldom or never, sometimes, often, very often).

Global wellbeing

The instrument used to assess global wellbeing was the disease specific Dutch version of the Bath ankylosing spondylitis global health index (BASG), containing two questions on the impact of AS on global wellbeing in the past week and in the past six months.¹⁷ Each question was scored on a VAS, the mean of which gave the BASG score (0–10). A higher score indicates more impact of the disease on the global wellbeing of the patient.

Data analysis

The influence of disease duration on the participation in the labour force of patients with AS was studied by comparing age and sex specific levels of employment in our AS population with those in the general population using an indirect standardisation method. We therefore calculated, for our study group, ratios of the observed (O) and expected (E) number of working people for evenly spaced five year categories of disease duration. Our study design meant that the first category ranged from one to five years of disease duration. Expected levels of participation in the labour force were computed using reference data for the general Dutch population relating to age and sex specific levels of employment.¹⁸ The O/E ratio can be interpreted as the relative chance of patients with AS having a paid job compared with the general population, adjusted for age and sex. A rate ratio of 1.0 indicates an equal chance, a rate ratio of less than 1.0 a decreased chance, and a rate ratio of more than 1.0 an increased chance. To examine statistically significant differences between the AS group and the general population, we obtained the variances of the O/E ratios, and estimated their 95% confidence intervals ($O/E \pm 1.96 \times \sqrt{\text{var}(O/E)}$). If a rate ratio of 1.0 is included in the interval, then the estimate is not statistically significant at the α level of 0.05.¹⁹

In evaluating sociodemographics, disease related variables, coping styles, and various work related factors in relation to withdrawal from the labour force, we compared characteristics of patients who had withdrawn from the labour force any time after being diagnosed with AS and patients still employed at the time of the study. For employment factors, we examined the characteristics of the last job position of the patients who had withdrawn and the characteristics of the present job of the employed patients. Firstly, all variables were subjected to univariate analysis using χ^2 tests to determine proportional variance between groups and *t* tests were

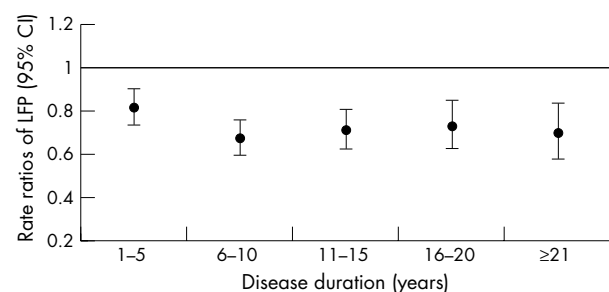


Figure 1 Relation between disease duration and labour force participation (LFP) among patients with ankylosing spondylitis (AS), standardised for age and sex and expressed as rate ratios.

conducted to analyse differences between group means. In addition, we assessed the relative importance of socio-demographic and disease related factors and work related factors in the relationship with withdrawal from the labour force in a multivariate context. A multiple logistic regression analysis with a forward stepwise procedure was therefore performed to assess the simultaneous associations of those socio-demographic, disease related, and work related factors that were found to be significant at the $p \leq 0.05$ level, when tested by univariate analysis. A variable was entered into the equation when the α level for rejecting the null hypothesis was 0.20. This level was chosen to ensure adequate power for the selection of variables to have acceptable performance for statistical testing.¹⁹ For implementation of the results in practice, each continuous variable was dichotomised at the median score of the total group of patients who performed a job at any time after diagnosis.

On the basis of the final logistic regression model of the stepwise procedure, attributable fractions and preventable fractions were subsequently calculated to estimate the overall

proportion of withdrawals from the labour force that could be either attributed to, or prevented by, sociodemographic, disease related, or work related factors. The adjusted attributable fraction is the proportion of withdrawals from the labour force, which is attributed to exposure by that factor. It was calculated as the exposed proportion of patients withdrawn from the labour force multiplied by $(aOR-1)/aOR$ where aOR is the odds ratio for that risk factor, adjusted for all other factors in the final model.

The adjusted preventable fraction was the proportion of withdrawals in a situation of non-exposure that could be prevented by exposure to that factor. It was calculated as the unexposed proportion of patients withdrawn multiplied by $(1-aOR)$.

To examine possible recall bias, we performed the same stepwise forward multiple regression analysis with a subsample of patients who had withdrawn from the labour force during the five years before the study and a subsample of patients with five or fewer years of disease. The cut off point of five years was chosen to ensure adequate statistical power for the logistic regression.¹⁹ All statistical analyses were performed using SPSS for Windows, version 10.0.7.

RESULTS

Overall participation in the labour force in this cohort of patients with AS with a mean disease duration of 12.4 years, standardised for age and sex, was 54.2% (63.4% in males and 46.9% in females), which was a significant reduction of 11.0% (15.4% in males and 5.2% in females) compared with the Dutch general population of working age. Data about overall participation in the labour force has been presented extensively in a previous paper.⁴ In further exploring the labour market position of these patients, we studied whether disease duration had an effect on the chance of having a paid job among patients with AS compared with the chance of having

Table 1 Patient characteristics and disease status and outcome of patients with a paid job at assessment compared with patients withdrawn from the labour force any time after diagnosis

	AS patients withdrawn from the labour force after diagnosis (n=156)	AS patients with a paid job at assessment (n=421)	p Value*
Age (years), mean (SE)	46.6 (0.7)	42.3 (0.4)	<0.001
Sex (men, %)	66.7	77.4	0.008
High vocational colleges/University (%)	9.6	25.2	<0.001
Age at time of diagnosis (years), mean (SE)	31.8 (0.8)	30.6 (0.4)	0.163
Disease duration (years), mean (SE)	14.8 (0.7)	11.8 (0.4)	<0.001
Disease activity (BASDAI 0-10), mean (SE)	5.1 (0.2)	3.3 (0.1)	<0.001
Disability score (BASFI 0-10), mean (SE)	5.3 (0.2)	2.9 (0.1)	<0.001
Total hip replacement (%)	7.7	2.9	0.010
Medication use at time of assessment (%):			
Pain medication other than NSAID	32.1	20.0	0.002
NSAID	73.7	70.8	0.488
DMARD	12.2	7.8	0.106
Other non-specified	7.7	4.5	0.133
Coping with pain, mean (SE):			
Comforting cognition (9-36)	26.3 (0.4)	27.1 (0.2)	0.049
Decreasing activity (8-31)	21.4 (0.3)	16.8 (0.2)	<0.001
Diverting attention (8-30)	18.4 (0.4)	17.4 (0.2)	0.012
Coping with limitations, mean (SE):			
Optimism (5-20)	14.7 (0.2)	14.9 (0.2)	0.432
Pacing (10-40)	29.6 (0.4)	23.5 (0.3)	<0.001
Creative solutions (8-32)	21.4 (0.4)	19.1 (0.2)	<0.001
Coping with dependency:			
Accepting (6-24)	13.8 (0.3)	12.7 (0.2)	0.002
Consideration (7-28)	19.5 (0.3)	18.6 (0.2)	0.015
Global wellbeing (BASG, 0-10), mean (SE)	5.8 (0.2)	3.6 (0.1)	<0.001
Work disablement pension (officially recognised, %):			
80-100	63.5	NA	
15-80	13.5	18.3	0.170

*Differences in proportions tested by χ^2 test; group means tested by Student's *t* test.

BASDAI, Bath ankylosing spondylitis disease activity index; BASFI, Bath ankylosing spondylitis functional index; NSAID, non-specific anti-inflammatory drugs; DMARD, disease modifying antirheumatic drugs; BASG, Bath ankylosing spondylitis global index; NA, not applicable.

Table 2 Work related factors of AS patients withdrawn from the labour force after diagnosis compared with AS patients with a paid job at assessment

	% of AS patients withdrawn from the labour force after diagnosis (n=156)	% of AS patients still holding a paid job at assessment (n=421)	p Value*
Job characteristics:			
Field of activity:			
Administrative	17.3	18.5	0.736
Transport	7.1	5.2	0.402
Marketing and sales	12.8	12.6	0.941
Service	14.7	14.3	0.881
Industrial	35.2	25.2	0.006
Professionals	12.2	24.0	0.022
Part time job	21.6	27.6	0.154
Special training for the present/last job position	46.2	55.6	0.044
Additional job training after diagnosis	50.0	67.0	<0.001
Changed field of activity after diagnosis	49.4	55.5	0.189
AS influenced choice on last/present job position	25.6	30.6	0.241
Executive job position	30.1	34.9	0.279
Ever performed a physically demanding job	69.2	55.1	0.002
Ever performed a mentally demanding job	51.9	57.7	0.213
Size of company (<100 employees)	68.2	48.9	<0.001
Work adjustments:			
Adjusted working hours	17.9	20.4	0.507
Adjusted job demands	13.5	14.3	0.808
Technical/ergonomic adjustments	8.3	17.6	0.006
Physical and social environmental factors:			
Difficult access to work place	13.7	3.3	<0.001
Reduced transportation mobility at the workplace	14.1	2.4	<0.001
Colleagues informed on AS	69.2	76.0	0.098
Dependent on colleagues	49.4	23.5	<0.001
Negative attitude of colleagues towards patient	24.4	7.6	<0.001
Negative attitude of management towards patient	17.3	3.6	<0.001
Insufficient support colleagues or management	41.0	12.8	<0.001

*Differences in proportions tested by χ^2 test.

a paid job given a patient's age and sex according to reference data from the general population in the working age range. Figure 1 shows rate ratios and their 95% confidence intervals for the relative chance of labour force participation in patients with AS for five year categories of duration of disease. It was found that all of the rate ratios were significantly reduced, which implies that the probability of participating in the labour market was reduced in patients with a relatively short disease duration as well as in patients with long disease duration. Moreover, rate ratios of patients with longer disease duration did not differ significantly from patients with short disease duration—that is, having the disease influences the probability of holding a paid job, but the duration of the disease has no additional influence.

Of the total study group of 658 patients, 81 (12.3%) had either stopped working before diagnosis (n=41 patients (6.2%)), or had no work history at all (n=27 patients (4.1%)) or had an unknown work history (n=13 patients (2.0%)), whereas 577 patients (87.7%) held a paid job, at least temporarily, at some time after being diagnosed with AS. Work history of the total study group has previously been described in more detail.⁷

For studying determinants of withdrawal from the labour force, we restricted our study group to those 577 patients with a paid job sometime after diagnosis. Of these patients, 156 (27.0%) had withdrawn from the labour force after a mean disease duration of 6.3 years; 94.9% of these patients indicated that they stopped working for medical reasons. Most cited AS related reasons for withdrawal were physical limitations (86.1% of the patients withdrawn due to AS) and being fatigued at work (77.4% of the patients withdrawn due to AS). Only 3.2% of the withdrawals had stopped working because of retirement. Table 1 presents patient characteristics, disease status, and outcome of the group of patients that stopped working at any time after being diagnosed with AS compared with the group that was working at the time of assessment.

On the basis of univariate comparisons, it was found that, on average, patients with AS who were younger, male, or more highly educated were more likely to be employed at the time of assessment, a trend similar to that in the general population in the same working age range. Patients who had withdrawn from the labour force had significantly longer disease duration, showed higher disease activity, experienced more disabilities in daily life and used more medication, and more often had total hip replacement. In general, the group of patients who had withdrawn had different coping strategies and experienced less favourable global wellbeing compared with patients who were still in employment.

More than three quarters of the patients who had withdrawn from the labour force had been officially recognised as work disabled to some extent, as they received income compensation in the form of a work disablement benefit. In the Dutch social security system, employees who are on full or partial sick leave for more than a year are entitled to a work disablement benefit after work disability has been officially recognised on the basis of a medical and ergonomic examination. This pension provides income compensation up to a maximum of 70% of the last income earned, for a maximum period of five years. At the end of that period, the person's ability to work has to be reassessed. The level of compensation is dependent on age, number of years worked, and levels of work disablement. People whose ability to work is impaired by 80%–100% are entitled to full work disablement benefit. People whose ability to work is impaired by 15%–80% are entitled to partial work disablement benefit. In the Netherlands, it is therefore possible to receive work disablement benefit and to remain in employment, usually on a part time basis. In our study population, 18.3% of the patients with a paid job had been officially recognised as having a work disablement.

The associations between various employment factors and withdrawal from the labour force are presented in table 2.

Patients with AS who had withdrawn from the labour force were more often active in the industrial sector and less active

Table 3 Importance of risk factors for early withdrawal from the labour force among patients with AS: attributable and preventable fractions*

Factor (exposed/non-exposed)*	aOR	Proportion of AS patients withdrawn from the labour force exposed to the factor	Attributable fraction (%)	Proportion of AS withdrawn from the labour force not exposed to the factor	Preventable fraction (%)
Coping with limitations: pacing ((very) often v sometimes/never)	6.3	0.87	73		
Support of colleagues or management (insufficient v sufficient)	3.4	0.41	29		
Transportation mobility at the workplace (reduced v not reduced)	4.1	0.14	11		
Technical/ergonomic adjustments (yes v no)	0.2			0.92	73
Disease activity (BASDAI ≥ 3.7 v < 3.7)	1.8	0.71	32		
Attitude management (negative v normal/positive)	5.3	0.17	14		
Additional training after diagnosis (yes v no)	0.5			0.50	25
Coping with limitations: creative solutions ((very) often v sometimes/never)	2.1	0.68	36		
Size of company (≥ 100 employees v < 100 employees)	0.5			0.68	34
Age (≥ 45 years v < 45 years)	2.0	0.63	32		
Coping with dependency: accepting ((very) often v sometimes/never)	0.5			0.64	32
Access to workplace (difficult v not difficult)	2.7	0.14	9		
Coping with pain: decreasing activity ((very) often v sometimes/never)	1.6	0.65	24		
Disease duration (≥ 11.5 years v < 11.5 years)	1.5	0.55	18		
Coping with pain: comforting cognition ((very) often v sometimes/never)	0.6			0.19	8

* If factor is positively associated with withdrawal from the labour force the proportion of AS patients withdrawn from the labour force exposed to that factor and the attributable fraction is presented, if a factor is negatively associated then the proportion of AS patients withdrawn from the labour force not exposed to that factor and the preventable fraction is presented. Variables are listed in order of their entry into the regression; BASDAI, Bath ankylosing spondylitis disease activity index; aOR, adjusted odds ratio (controlled for all variables in the table presented).

as professionals (for example, physicians, teachers, and policy makers) than currently employed patients. Fewer patients who had withdrawn were specially trained for their last job position, fewer of them had followed any job training at all, and more of them had performed a physically demanding job at some time during their working career.

Patients who were still in employment worked more often in larger companies and more often had technical or ergonomic work adjustments.

Patients who had withdrawn from the labour force reported difficult access to the workplace and reduced transport mobility at the workplace more often than currently employed patients. With respect to the social environmental factors at the workplace, patients who had withdrawn were much more dependent on their colleagues. Compared with patients still in employment, they also thought more often that attitudes of colleagues and management were negative and that there was insufficient support from both colleagues and management.

Table 3 lists the results of the stepwise forward logistic regression for the combined effect of sociodemographic and disease related factors and work related factors. Because functional ability, use of medication, and global wellbeing were highly correlated with disease activity and field of activity correlated highly with educational level ($r > 0.6$), we chose to enter only the variables for disease activity and educational level into the models to prevent colinearity.

Variables listed in table 3 were entered into the final regression model in sequence as presented. The following variables, which were significant by univariate analysis, were excluded during the forward stepwise procedure: sex, educational level, diverting attention to cope with pain, special training for the last job position, and performed a physically highly demanding job at some time during working career. Overall, the model showed that coping styles and disease related, sociodemographic, and work related factors contributed substantially to withdrawal from the labour force.

When the proportion of patients who had withdrawn from the labour force was calculated in terms of each factor, it

emerged that pacing to cope with limitations accounted for 73% of the withdrawals from the labour force. On the other hand, it was found that 73% of the withdrawals could still have been employed if technical or ergonomic adjustments of the workplace had been arranged. Other important factors increasing the risk were often/very often seeking creative solutions to cope with limitations (36%), a high disease activity (32%), older age (32%), and insufficient support from colleagues or management (29%). Other important factors, which reduced the risk, were working in a large company (34%) and frequent/very frequent acceptance to cope with dependency (32%).

In subsample analyses of patients who had withdrawn from the labour force within five years before the study and of patients with five or fewer years of disease, the same factors were identified. The following variables were stronger in the subsample of patients with five or fewer years of disease compared with patients in the full sample or in the subsample of patients withdrawn within five years before the study: pacing to cope with limitations, disease activity, attitude of the management, and access to the workplace.

DISCUSSION

Despite the fact that the overall participation in the labour force of the patients with AS under study was lower compared with the general population,⁴ the present study indicates that the probability of participating in the Dutch labour force is already reduced in patients with AS of relatively short disease duration, and participation in the labour force is not additionally influenced by duration of disease. By contrast with our study, most other reports on participation in the labour force and disease duration among patients with AS deal with groups with a work history, and found employment rates which still ranged from 79% to 85% after 20 years of AS, and from 53% to 81% after 30 years of AS.²⁰⁻²² Our study also considered patients without a work history and controlled for the

common risk factors of participation in the labour force: age and sex. Therefore, our results give a deeper understanding of the position in the labour market of patients with AS among the general working population in relation to their duration of disease.

We report that sociodemographic factors, coping styles, disease related factors, and various work related factors substantially contribute to withdrawal from the labour force in patients with AS. In a previous study we already identified coping as an important factor related to work among patients with AS.⁷ In this study, we further explored behavioural coping simultaneously with other factors. Pacing to cope with limitations—that is, adapting the level of activity indicated by “I take more time for my activities”, “I stop doing my activities in time”, or “I take full account of my limitations”—was the major positively correlated factor. This implies that a passive way of coping with the limitations is associated with withdrawing from the labour force. Moreover, we found that five of the eight different coping styles assessed in this study significantly contributed to withdrawal from the labour force. With the exception of our previous study, we know of no earlier study that has covered the effect of behavioural coping in relation to employment in patients with AS. A recent study by Barlow *et al* investigated cognitive coping in relation to work in patients with AS.⁸ In fact, for patients with rheumatic diseases in general, only a few studies have examined the independent effect of behavioural coping on outcome of illness, and only two studies in rheumatoid arthritis found that patients use behavioural coping strategies when dealing with problems at work.^{23–26} Earlier studies indicated that patients with AS used adaptive coping mechanisms to cope with stressful situations and that these patients were comparable with patients with other rheumatic diseases in the use of active or passive coping mechanisms.^{27,28} Therefore, our findings in patients with AS stresses the importance of behavioural coping in relation to employment in patients with rheumatic diseases in general and in patients with AS in particular.

The major employment factor negatively associated with withdrawal from the labour force was technical or ergonomic adjustment of the workplace. One earlier study by Fellman *et al* found that 62% of patients with AS had pain when working which was induced by a wrong or monotonous posture, long working times, and unfavourable climatic factors at work.²⁹ Guillemin *et al* found that exposure to cold conditions and prolonged standing increased the risk of long term work disability.⁶ Yelin *et al*, on the other hand, found no relation between getting equipment and the improvement of employment status of persons with musculoskeletal conditions. Compared with our study, Yelin *et al* found a relatively low frequency of people getting special equipment (5.3%) in a relatively old population with various musculoskeletal conditions.³⁰ On the basis of those earlier studies and our study, we conclude that the ergonomic and climatic conditions at the workplaces of patients with AS specifically should be analysed at an early stage and adjusted to the needs of these patients to prevent problems at work.

Other major work related factors with negative correlations were working in a large company and additional job training after diagnosis, whereas insufficient support from colleagues or management, reduced transportation mobility at the workplace, difficult access to the workplace, and negative attitude of the management were positively correlated. Only a few of these factors have been previously investigated in a multivariate context among patients with AS.⁵ In line with our finding, vocational counselling and job training had already been identified as a protective factor against long term disability by Guillemin *et al*.⁶

It should be pointed out that our study has some methodological limitations. Data were collected by a self administered questionnaire and we did not validate these data using objective measures. However, the questionnaire included several

well validated instruments for assessing disease activity and outcome independently of employment status.^{10–17} So it is not likely that our results were substantially and systematically affected in any direction by differential misclassification; in other words there was no systematic difference in rating of disease activity and outcome between patients who had withdrawn and patients who still had a paid job.

Although data about employment were collected retrospectively, we think that considerable recall bias is less likely, because we found that work related factors were equally important in a subsample of patients who had recently withdrawn from the labour force.

With respect to coping, the cross sectional design of our study does not allow us to state that the explanatory variables have a causal relationship with withdrawal from the labour force. Our study does not rule out the competing explanation that withdrawal from the labour force invokes passive coping styles such as “pacing” as a way of coping with limitations or that behavioural coping and withdrawal from the labour force are reciprocally interrelated. On the other hand, research on coping in AS found that the coping mechanisms used did not vary with the duration of AS,¹ meaning that patients with AS may develop a coping style early in the illness and use their favourite strategies to deal with stressful situations. A more longitudinal approach is needed to assess whether the association between coping and withdrawal from the labour force in AS is one of effect rather than cause.

To provide information on the extent to which withdrawal from the labour force is due to a specific factor, and to estimate potential maximum effect of intervention programmes in the light of these factors, we calculated attributable and preventable fractions. Application of this technique is relatively new in this field of research. It is only found in two other studies in patients with RA.^{24,31} Considering our results with respect to, for instance, pacing to cope with limitations (accounting for 73% of the withdrawals) and disease activity (accounting for 32% of the withdrawals), it can be calculated that the sum of the fractions exceeds 100%. Despite being aware that any withdrawal from the labour force could be caused or prevented by various factors, there might be a tendency to think that the sum of these fractions should be 100%. In fact, separate components of the underlying mechanism are not mutually exclusive. Therefore, the upper limit of the total of all fractions of all the components is not 100% but infinity. Only a fraction of withdrawal from the labour force attributable to or preventable from a single component cannot exceed 100%.¹⁹ This is also the case in our study.

In summary, our findings show that it is important to consider sociodemographic factors, disease related factors, behavioural coping styles, and work related factors in both research and vocational management of patients with AS. Research on the subject should give more attention to the study of behavioural coping and attitudes towards work depending on the nature and conditions of the work and on the social work environment and their effects on employment. Therefore, we emphasise that developers of intervention programmes dealing with work problems in patients with AS should consider and evaluate the involvement of a multidisciplinary team of professionals with medical, paramedical, psychosocial, and occupational health expertise. Furthermore, we think that cooperation from employers and from colleagues is important to achieve maximum reduction in early withdrawal from the labour force among these patients. In practice, patients should be encouraged to remain active despite the stressors of their disease. Moreover, patients should be encouraged and guided to recognise and develop their talents, and if possible, they should extend their education. In general, companies should be encouraged to promote positive attitudes towards people with disabilities.

ACKNOWLEDGEMENTS

For helping to recruit patients we gratefully thank all rheumatologists and their assistants at the following rheumatology centres: Sint Antoniusziekenhuis Nieuwegein, Rode Kruisziekenhuis Den Haag, Bosch Medicentrum Den Bosch, Sint Laurentiusziekenhuis Roermond, Sint Jansgasthuis Weert, Groene Hartziekenhuis Gouda, Albert Schweitzerziekenhuis Dordrecht, Kennemer Gasthuis locatie Deo Haarlem, Lievensberg Ziekenhuis Bergen op Zoom, Tweesteden Ziekenhuis Tilburg, Rijnstate Ziekenhuis Arnhem, St. Maartenskliniek Nijmegen, Medisch Spectrum Twente Enschede and Academisch Ziekenhuis Maastricht. We also thank Mr. Cees J Wevers, occupational physician, TNO Work and Employment Hoofddorp, for allowing us to use the VHQ.

Authors' affiliations

A M J Chorus, Division of Public Health, TNO Prevention and Health, Leiden, The Netherlands

A Boonen, Sj van der Linden Department of Internal Medicine, Division of Rheumatology, University Hospital Maastricht, The Netherlands

H S Miedema, Netherlands Expert Centre for Work-Related Musculoskeletal Disorders, University Hospital Rotterdam, The Netherlands

REFERENCES

- 1 **Ward MM**. Quality of life in patients with ankylosing spondylitis. *Rheum Dis Clin North Am* 1998;24:815–27.
- 2 **Ward MM**. Health-related quality of life in ankylosing spondylitis: a survey of 175 patients. *Arthritis Care Res* 1999;12:247–55.
- 3 **Zink A**, Braun J, Listing J, Wollenhaupt J. Disability and handicap in rheumatoid arthritis and ankylosing spondylitis: results from the German rheumatological database. *German Collaborative Arthritis Centers*. *J Rheumatol* 2000;27:613–22.
- 4 **Boonen A**, Chorus A, Miedema H, van der Heijde D, van der Tempel H, van der Linden S. Employment, work disability, and work days lost in patients with ankylosing spondylitis: a cross sectional study of Dutch patients. *Ann Rheum Dis* 2001;60:353–8.
- 5 **Boonen A**, de Vet H, van Der HD, van Der LS. Work status and its determinants among patients with ankylosing spondylitis. A systematic literature review. *J Rheumatol* 2001;28:1056–62.
- 6 **Guillemin F**, Briancon S, Pourel J, Gaucher A. Long-term disability and prolonged sick leaves as outcome measurements in ankylosing spondylitis. Possible predictive factors. *Arthritis Rheum* 1990;33:1001–6.
- 7 **Boonen A**, Chorus A, Miedema H, van Der HD, Landewe R, Schouten H, et al. Withdrawal from the labour force due to work disability in patients with ankylosing spondylitis. *Ann Rheum Dis* 2001;60:1033–9.
- 8 **Barlow JH**, Wright CC, Williams B, Keat A. Work disability among people with ankylosing spondylitis. *Arthritis Rheum* 2001;45:424–9.
- 9 **Miedema HS**, Linden SM vd, Rasker JJ, Valkenburg HA. A national database of patients visiting rheumatologists in the Netherlands: The Standard Diagnosis Register of Rheumatic Diseases. A report and preliminary analysis. *Br J Rheumatol* 1998;37:555–61.
- 10 **Calin A**, Nakache JP, Gueguen A, Zeidler H, Mielants H, Dougados M. Defining disease activity in ankylosing spondylitis: is a combination of variables (Bath ankylosing spondylitis disease activity index) an appropriate instrument? *Rheumatology (Oxford)* 1999;38:878–82.
- 11 **Calin A**, Garrett S, Whitelock H, Kennedy LG, O'Hea J, Mallorie P, et al. A new approach to defining functional ability in ankylosing spondylitis: the development of the Bath ankylosing spondylitis functional index. *J Rheumatol* 1994;21:2281–5.
- 12 **Andries F**, Wevers CW, Wintzen AR, Busch HF, Howeler CJ, de Jager AE, et al. Vocational perspectives and neuromuscular disorders. *Int J Rehabil Res* 1997;20:255–73.
- 13 **Wevers CW**, Brouwer OF, Padberg GW, Nijboer ID. Job perspectives in facioscapulohumeral muscular dystrophy. *Disabil Rehabil* 1993;15:24–8.
- 14 **Nijboer ID**, Wevers CJ. Vocational rehabilitation of young adults with a disability of one arm or hand. *Int J Rehabil Res* 1993;16:45–7.
- 15 **van Lankveld W**, van't Pad Bosch, van de Putte L, Naring G, van der Staak C. Disease-specific stressors in rheumatoid arthritis: coping and well-being. *Br J Rheumatol* 1994;33:1067–73.
- 16 **van Lankveld W**, Naring G, van der Staak C, van 't Pad Bosch, van de Putte L. Stress caused by rheumatoid arthritis: relation among subjective stressors of the disease, disease status, and well-being. *J Behav Med* 1993;16:309–21.
- 17 **Jones SD**, Steiner A, Garrett SL, Calin A. The Bath ankylosing spondylitis patient global score (BASG). *Br J Rheumatol* 1996;35:66–71.
- 18 **Statistics Netherlands (CBS)**. *Survey of general population in the working age 1997*. The Hague: Statistics Netherlands, 1998.
- 19 **Rothman KJ**, Greenland S. *Modern epidemiology*. 2nd ed. Philadelphia: Lippincott-Raven, 2000.
- 20 **Ringsdal VS**, Helin P. Ankylosing spondylitis: education, employment and invalidity. *Dan Med Bull* 1991;38:282–4.
- 21 **Lehtinen K**. Working ability of 76 patients with ankylosing spondylitis. *Scand J Rheumatol* 1981;10:263–5.
- 22 **McGuigan LE**, Hart HH, Gow PJ, Kidd BL, Grigor RR, Moore TE. Employment in ankylosing spondylitis. *Ann Rheum Dis* 1984;43:604–6.
- 23 **Blalock SJ**, DeVellis BM, Holt K, Hahn PM. Coping with rheumatoid arthritis: is one problem the same as another? *Health Education Quarterly* 1993;20:119–32.
- 24 **Chorus AM**, Miedema HS, Wevers CW, van Der LS. Work factors and behavioural coping in relation to withdrawal from the labour force in patients with rheumatoid arthritis. *Ann Rheum Dis* 2001;60:1025–32.
- 25 **Harter M**. Psychosomatic aspects of rheumatic diseases. *Psychother Psychosom Med Psychol* 1993;43:100–9.
- 26 **Basler HD**, Rehfisch HP. Cognitive-behavioral therapy in patients with ankylosing spondylitis in a German self-help organization. *J Psychosom Res* 1991;35:345–54.
- 27 **Gunther V**, Mur E, Traweger C, Hawel R. Stress coping of patients with ankylosing spondylitis. *J Psychosom Res* 1994;38:419–27.
- 28 **Mengshoel AM**, Forre O. Pain and fatigue in patients with rheumatic disorders. *Clin Rheumatol* 1993;12:515–21.
- 29 **Fellmann J**, Kissling R, Baumberger H. (Socio-professional aspects of ankylosing spondylitis in Switzerland.) *Sozio-professionelle Aspekte der Spondylitis ankylosans in der Schweiz*. *Z Rheumatol* 1996;55:105–13.
- 30 **Yelin E**, Sonneborn D, Trupin L. The prevalence and impact of accommodations on the employment of persons 51–61 years of age with musculoskeletal conditions. *Arthritis Care Res* 2000;13:168–76.
- 31 **Allaire SH**, Anderson JJ, Meenan RF. Reducing work disability associated with rheumatoid arthritis: identification of additional risk factors and persons likely to benefit from intervention. *Arthritis Care Res* 1996;9:349–57.



Employment perspectives of patients with ankylosing spondylitis

A M J Chorus, A Boonen, H S Miedema and Sj van der Linden

Ann Rheum Dis 2002 61: 693-699
doi: 10.1136/ard.61.8.693

Updated information and services can be found at:
<http://ard.bmj.com/content/61/8/693>

	<i>These include:</i>
References	This article cites 28 articles, 9 of which you can access for free at: http://ard.bmj.com/content/61/8/693#BIBL
Email alerting service	Receive free email alerts when new articles cite this article. Sign up in the box at the top right corner of the online article.

Topic Collections

Articles on similar topics can be found in the following collections

[Ankylosing spondylitis](#) (412)
[Calcium and bone](#) (719)
[Connective tissue disease](#) (4208)
[Degenerative joint disease](#) (4600)
[Immunology \(including allergy\)](#) (5089)
[Musculoskeletal syndromes](#) (4907)
[Rheumatoid arthritis](#) (3228)

Notes

To request permissions go to:
<http://group.bmj.com/group/rights-licensing/permissions>

To order reprints go to:
<http://journals.bmj.com/cgi/reprintform>

To subscribe to BMJ go to:
<http://group.bmj.com/subscribe/>