Impact of Functional Impairment in Ankylosing Spondylitis: Impairment, Activity Limitation, and Participation Restrictions

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ABSTRACT. *Objective.* To describe difficulties in everyday activities related to impaired function in patients with ankylosing spondylitis (AS), and to examine possible sex differences in the impact of the disease. In addition, to examine the relationships between measures of personal characteristics, impairment, and activity/participation levels within the framework of the International Classification of Functioning (ICF).

Methods. A total of 152 patients with AS took part in a clinical examination including anthropometric measures, blood samples, and self-reported disease related measures. The Canadian Occupational Performance Measure (COPM) interviews were performed to describe and measure activity limitations and participation restrictions perceived by the patient during the last year. The study variables were categorized and analyzed according to the levels of the ICF model using bivariate and multivariate statistical approaches.

Results. The mean age of patients was 47 (SD 13) years, 58% were men, and the mean disease duration was 15 (SD 12) years. The problems most frequently reported in COPM interviews were "interrupted sleeping," "turn head when driving," "carry groceries," and "having energy for social activities." Women reported higher level of disease activity and more physical limitations than men. Disease activity and reduced mobility (impairment variables) seemed to result in more activity/participation restrictions in female than in male patients. The impairment variables explained only one-third of the activity and participation restrictions perceived by patients.

Conclusion. Activity limitations and participation restrictions reported by patients were only partly explained by the impairment variables. Further research should identify social, structural, and attitudinal barriers influencing activity and participation in patients with AS. (J Rheumatol 2005; 32:516–23)

Key Indexing Terms:
ANKYLOSING SPONDYLITIS   FUNCTIONAL IMPAIRMENT
INTERNATIONAL CLASSIFICATION OF FUNCTIONING
CANADIAN OCCUPATIONAL PERFORMANCE MEASURE

During the last 2 decades, the field of rehabilitation has undergone major conceptual advances. The patient perspective and the individuals' potential to participate in society have currently become central questions[1-3]. A biopsychosocial model, describing health and health conditions as a result of biological, psychological, and social factors, has replaced the medical model of disability considered as an individual problem[4]. As a consequence, the term "functioning" has been broadened from a former meaning mainly related to the organ level, to include personal and societal dimensions. Further, the influence of personal and environmental factors has been recognized as crucial in how an individual experiences the consequences of a trauma or a chronic disease[4].

The World Health Organization (WHO) has played an important role in this process by developing the framework for the International Classification of Functioning, Disability and Health (ICF)[5]. The ICF classifies health and health related components in 2 dimensions, one comprising body functions and structures and the other activity and participation (Figure 1), with impairment, activity limitations, and participation restrictions as the negative terms or consequences. The model also classifies contextual facilitators or barriers that include either personal or environmental factors (Figure 1).

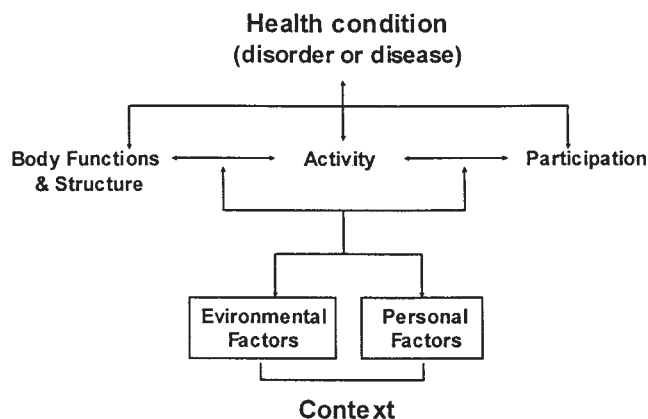The ways that consequences of chronic diseases are

Figure 1. The International Classification of Functioning, Disability and Health (ICF).

described and evaluated are influenced by the perspective of the evaluators[6]. From a purely medical perspective, patients' functioning, disability, and health are seen as consequences of a disease process, whereas a rehabilitation perspective also focuses on personal and environmental factors that potentially may influence the functional consequences[7]. Discordance between medical disease manifestations and functional impairment and sex differences in the effects of disease are reported in several studies of chronic diseases[8–12].

Ankylosing spondylitis (AS) is a chronic, inflammatory and progressive disease[13], and the medical consequences, in terms of pain, reduced mobility, and deformity of the spine, are well known[14-16]. However, less is known about the influence of the functional impairments due to AS, including how these may differ between men and women.

Several disease-specific instruments for AS have been developed, but availability of instruments assessing activity limitation and participation restrictions is limited in AS as well as in other diseases. The patient perspective is currently given increasing attention in the field of rehabilitation and management of patients with chronic diseases[17,18]. Patient-centered outcome measures are designed to address the problem areas specific for each individual and acknowledge the experience and perspective of the patient[19]. The Canadian Occupational Performance Measure (COPM) is an individualized instrument, developed to describe and measure both the qualitative and quantitative aspects of problems, limitations, and restrictions as perceived by the individual[20]. The semistructured COPM interview may therefore serve as an appropriate instrument to identify, on an individual level, the activity limitations and participation restrictions most relevant for patients with AS.

Our objectives were to describe the impact of functional impairments due to AS, as perceived by patients. We also wanted to examine possible sex differences in the effect of the disease, and to examine the relationships between measures on personal, impairment, and activity/participation levels within the framework of the ICF.

MATERIALS AND METHODS

Patients. Patients were recruited from an AS register at Diakonhjemmet Hospital, Oslo. The register was established by identifying patients through the medical records of the Department of Rheumatology, Diakonhjemmet Hospital, and includes 465 patients fulfilling the New York classification criteria[21]. These patients received a postal questionnaire in 2002, and 314 (67%) completed questionnaires were returned. In 2003, those still living in Oslo were invited to undergo a clinical examination including filling in questionnaires (n = 283). One hundred fifty-two patients accepted the invitation to participate by completing the questionnaires and the physical examination.

The study was approved by the Ethical Committee for Medical Research.

Study variables. A comprehensive questionnaire package including sociodemographic data, disease related factors and medical history, self-reported disease activity, and physical function and health status was administered to the patients. A clinical examination of all patients was carried out by a physical therapist, including anthropometric measures of the spinal column, hip, and shoulder joints. An occupational therapist performed a COPM interview addressing activity limitations and participation restrictions as perceived by the patients during the last year. Blood samples were collected. The study variables were categorized according to the dimensions of the ICF model (Figure 1) as follows.

Personal variables. Personal variables included age, sex, disease related factors, education level (low: ≤ 12 years, high: > 12 years), and occupational status (yes/no).

Impairment variables. Impairments are according to the ICF defined as problems in body structures or functions in terms of significant deviation or loss (e.g., deformity) of structures (e.g., joints) and/or functions (e.g., reduced range of motion, pain, fatigue)[7].

The most important clinical characteristics of AS are inflammation, reduced spinal mobility, pain, and fatigue. The following measures were chosen to reflect the impairment level.

The Bath AS Metrology Index (BASMI) was used to measure spinal and hip mobility. The BASMI includes 5 clinical examinations of spinal column and hip joints, i.e., the distance from tragus to wall, lumbar flexion and lateral flexion, cervical rotation, and intermalleolar distance[22]. The ratings are classified in categories from 0 to 2, where 0 is normal mobility. The BASMI score is the sum of the scores given for each test (0 to 10).

The Bath AS Disease Activity Index (BASDAI) is a self-administered instrument developed to assess disease activity in AS. BASDAI consists of 6 visual analog scales (VAS) relating to major symptoms relevant to AS: fatigue, spinal pain, joint pain, localized tenderness, and morning stiffness (measured in terms of both degree and length of time stiffness persists). The BASDAI items range from none (0) to very severe (100) symptoms. The mean score of 5 items (mean of the 2 morning stiffness items plus the 4 remaining items) is applied as an estimate of disease activity. The BASDAI has been shown to be user-friendly and reliable and to reflect the entire spectrum of disease[23].

The erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) were measured and applied as biological signs of inflammation.

Activity and participation variables. According to the ICF, activity limitations are described as the individual's difficulties in performing tasks or activities, and participation restrictions as problems the individual may experience in involvement in life situations[5].

The COPM is a generic and individualized instrument designed to describe and measure patients' perception of activity performance and satisfaction with performance over time[24]. The administration of the COPM is a stepwise procedure, starting with a semistructured interview where the

patients define their occupational performance problems within 3 areas of self-care, productivity, and leisure. When the item list is completed, patients are asked how important it is to be able to do the activities, by rating each problem for importance on a scale from 1 (not important at all) to 10 (extremely important). Finally, patients rate the most important activities (up to 5) for Performance and Satisfaction on scales of 1 (not able to do it, not satisfied at all with the performance) to 10 (able to do extremely well, extremely satisfied with the performance). Total Performance score and Satisfaction score are calculated by dividing the sum of the scores by the number of reported important activities[24]. In this study, participants reporting no problems were assigned values 10 for both Performance and Satisfaction.

The Bath AS Functional Index (BASFI) is a self-assessment instrument consisting of 8 specific questions regarding function and 2 questions reflecting the patient's ability to cope with everyday life. The ability to perform 8 specific physical activities (e.g., put on socks or stockings, pick up a pen from the floor, rise from a supine lying position on the floor) and 2 items about the ability to perform physical work and fulfil working obligations at home or at work. The responses are given on VAS scales. The mean score of the 10 items gives the final BASFI score ranging from 0 (easy) to 100 (impossible)[25].

The Medical Outcome Study Short Form-36 (SF-36) is a generic instrument providing information about 8 different aspects of subjective health. The SF-36 is widely used in health surveys in the general population as well as in various populations with different diseases[26]. The items of the SF-36 are grouped into 8 subscales, including a 10-item physical functioning scale that was used as a measure of activity limitation in this study. The raw scores of the scale were coded and recalibrated following the standard guidelines (0 = worst health, 100 = best health)[27].

Data analysis and statistics. The data were analyzed using SPSS for Windows, v. 11 (SPSS Inc., Chicago, IL, USA).

For categorical variables, proportion and frequency counts were calculated. The problems described and prioritized during the COPM interviews were grouped and categorized, and the prevalence and prioritization of the problems were visually displayed in a bar graph.

Mean and standard deviation were computed for continuous variables. Independent samples t tests were performed to calculate sex differences. Associations were examined by bivariate (Pearson correlation coefficient or linear regression) or multivariate (block-regression analysis) statistical approaches.

The COPM Performance score was chosen as the key measure of patients' perception of the activity limitations and participation restrictions in the regression analyses (dependent variable). A block-regression analysis[28] was used to calculate the explanatory power of the independent variables on the COPM score. For this purpose, the independent variables were classified and entered into the model in 2 blocks:

Block 1, personal factors: age, sex, disease duration, comorbidity, education level, and occupational status;

Block 2, impairment variables: BASDAI, BASMI, ESR, and CRP.

The regression analysis was repeated after replacement of the COPM Performance score with the COPM Satisfaction score, and with the disease-specific and the generic activity/participation measures (BASFI and SF-36 physical functioning). Scatterplots of the residuals for the models were analyzed, and the distribution of the residuals was found acceptable. The level of statistical significance was chosen as 5%.

RESULTS

According to data from the survey in 2002, the participants in this study (n = 152) did not differ from the nonparticipants (n = 131) in terms of the BASDAI scores [mean 52 (SD 24) and 47 (SD 21), respectively; p = 0.08] and BASFI scores [mean 33 (SD 26) and 30 (SD 23), respectively; p = 0.30]. The study participants were on average 5 years older than the nonparticipants [mean age 42 (SD 11) and 47 (SD 13] years, respectively; p < 0.001].

Descriptive statistics of the study participants are presented in 3 variable groups (personal, impairment, and activity/participation variables) in Tables 1 to 3. No significant difference was found between male and female patients in personal characteristics (Table 1).

Women reported higher disease activity than men (impairment level, Table 2) as well as more severe physical limitations and a greater negative impact on occupational performance and satisfaction with performance on the COPM scales (activity/participation level, Table 3).

The most frequently reported problems in the COPM interviews were "interrupted sleeping" (n = 83), "turn head when driving" (57), "carry groceries" (54), and "energy for social activities" (53) (Figure 2). Of these, sleeping problems reached the highest priority for improvement.

Generally, there were no significant sex differences in the number of described or prioritized problems (data not shown).

Significant correlations were found between the COPM Performance and BASDAI and BASMI, and between BASFI and all impairment variables (Table 4).

The associations between the COPM Performance score and the impairment variables (BASDAI, BASMI) were explored in separate sex analyses (Figure 3). The BASMI score explained 3% of the variation on the COPM Performance score for male patients (ß –0.16, confidence interval –0.3, 0.02, p = 0.09), and 19% for female patients (ß –0.6, CI –0.8, –0.3, p < 0.001; p value for interaction = 0.001) (Figure 3A). For the BASDAI score, the explanatory power was 28% (ß –0.06, CI –0.9, –0.04, p < 0.001) and 41% (ß –0.07, CI –0.09, –0.05, p < 0.001), respectively (p value for interaction = 0.81) (Figure 3B).

The multiple regression model is illustrated in Table 5. The personal variables (age and sex, disease duration, comorbidity, educational and occupational status) were entered as block 1 and accounted for 11% of the variation in the COPM Performance score (p = 0.02). The impairment variables constituted the most significant contribution to the

Table 1. Personal factors. Values are mean (SD) for continuous variables, and counts (%) for categorical variables.

	Total Sample, n = 152	Male, n = 88	Female, n = 64	p*
Age, yrs	47 (13)	47 (13)	47 (13)	0.97
Disease duration, yrs	15 (12)	16 (12)	14 (12)	0.34
Comorbidity present, n (%)	61 (40)	33 (38)	28 (44)	0.47
Living with partner, n (%)	81 (54)	46 (53)	35 (57)	0.67
Education > 12 years, n (%)	91 (60)	57 (65)	34 (54)	0.18
Employed, n (%)	108 (72)	68 (77)	40 (65)	0.09

* Sex comparison: independent sample t test (continuous variables) or chi-square (counts).

Table 2. Impairment variables. Values are mean (SD).

Measure	Total Sample, n = 152	Male, n = 88	Female, n = 64	95% Confidence Interval of Difference	p
BASDAI	44.3 (23.2)	38.0 (21.0)	53.1 (23.6)	–22.3, –8.0	< 0.001
BASMI	2.7 (2.6)	3.0 (3.0)	2.2 (1.9)	–0.2, 1.7	0.06
ESR	17.7 (16.5)	16.9 (16.8)	18.8 (16.2)	–7.4, 3.6	0.49
CRP	9.2 (11.7)	10.8 (16.8)	8.9 (11.7)	–3.0, 6.9	0.44

Sex comparisons: independent sample t test.

Table 3. Variables of activity limitation and participation restrictions. Values are mean (SD).

Measure	Total Sample, n = 152	Male, n = 88	Female, n = 64	95% Confidence Interval of Difference	p
BASFI*	32.4 (24.3)	27.7 (23.4)	39.0 (24.2)	–19.0, –3.6	0.004
SF-36 physical function**	71.8 (21.4)	77.2 (20.0)	64.3 (21.2)	6.1, 19.5	< 0.001
COPM performance***	5.9 (2.5)	6.3 (2.5)	5.4 (2.4)	0.2, 1.8	0.02
COPM satisfaction***	5.2 (3.0)	5.6 (3.0)	4.5 (2.9)	0.2, 2.1	0.02

* 0–100, 100 = worst score, ** 0–100, 100 = best score, *** 0–10, 10 = no problems. Sex differences: independent sample t test. BASFI: Bath Ankylosing Spondylitis Functional Index, COPM: Canadian Occupational Performance Measure.
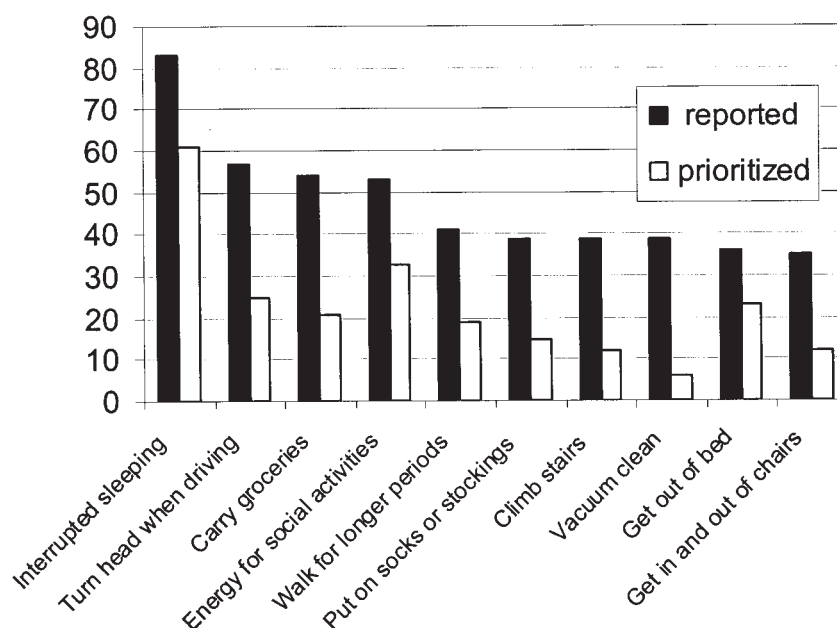

Figure 2. The 10 most frequently described and prioritized problems reported by patients with AS in COPM interviews (n = 152).

explanation of the dependent variable, with an additional 28% (block 2, p < 0.001). The most important variables were the BASDAI (p < 0.001) and the BASMI (p = 0.03). The inflammation markers showed no significant contribution (p > 0.1). The final model explained a total of 39% of the variation in the COPM Performance scores (patients' perceived problems regarding activity and participation).

Repeating the procedure with the COPM Satisfaction score as dependent variable showed similar results. However, with the disease-specific functional index (the BASFI) or the generic physical function measure (the SF-36 physical function) as dependent variables, the total explanatory power was 66% (p < 0.001) and 55% (p < 0.001), respectively (additional data not shown).

Table 4. Pearson correlation coefficients between measures of impairment and activity/participation level.

Impairment Variables	COPM Performance		BASFI	
	Pearson Correlation	p	Pearson Correlation	p
BASDAI	–0.60	< 0.001	0.68	< 0.001
BASMI	–0.22	0.01	0.51	< 0.001
ESR	–0.09	0.29	0.21	0.01
CRP	–0.07	0.40	0.25	0.003

COPM: Canadian Occupational Performance Measure, BASFI: Bath Ankylosing Spondylitis Functional Index.

DISCUSSION

The problem areas most frequently experienced by patients with AS in this study were related to crucial activities of their daily functioning. The most frequently reported difficulties were driving a car, interrupted sleeping, shopping, and having energy for social activities, problem areas that severely influenced the individuals' life and functioning. To address these problems, an interdisciplinary and multidimensional approach is needed, including traditional medication and physical and occupational therapy, as well as an enhanced focus on possible environmental structural, social, and attitudinal barriers.

Women reported more disease activity and physical limitations than men, and restrictions in spinal mobility (BASMI) explained nearly 20% of the variations in the COPM Performance scores for women, but only 3% for men. The sex differences in strength of associations remained after adjustment for other disease variables in a multivariate regression analysis (data not shown). This is in accord with results of other studies, suggesting that the sex differences in levels of reported function are only partly explained by biological or anatomical changes[29]. The mechanisms for the commonly observed skewed sex ratio regarding disease consequences are unknown[30], but have been discussed in several reports[10,31-35]. In a study of patients with osteoarthritis, women reported significantly higher levels of pain and physical disability than men. However, analyses revealed that catastrophizing mediated the relationship between sex and measures of pain[12], indicating that psychological factors may explain some of these differences. Further, different disease manifestations in men and women with AS have been reported, with more peripheral joint involvement in women[36,37], which may contribute to sex differences in disease impact. Additional important factors for understanding sex variations may be related to underlying biological mechanisms of pain and to expectations regarding social roles[11]. The sex variation in disease experience seems to be unsettled and complex, and should be carefully considered in research as well as in clinical practice.

The development of the ICF model may be regarded among the greatest advances in rehabilitation in the last decades, and implementation of the ICF in clinical research and practice has given rise to both a more systematic analysis of patients' problems and a more consistent communication among health professionals[3]. However, understanding and measuring the participation dimension may be compli-
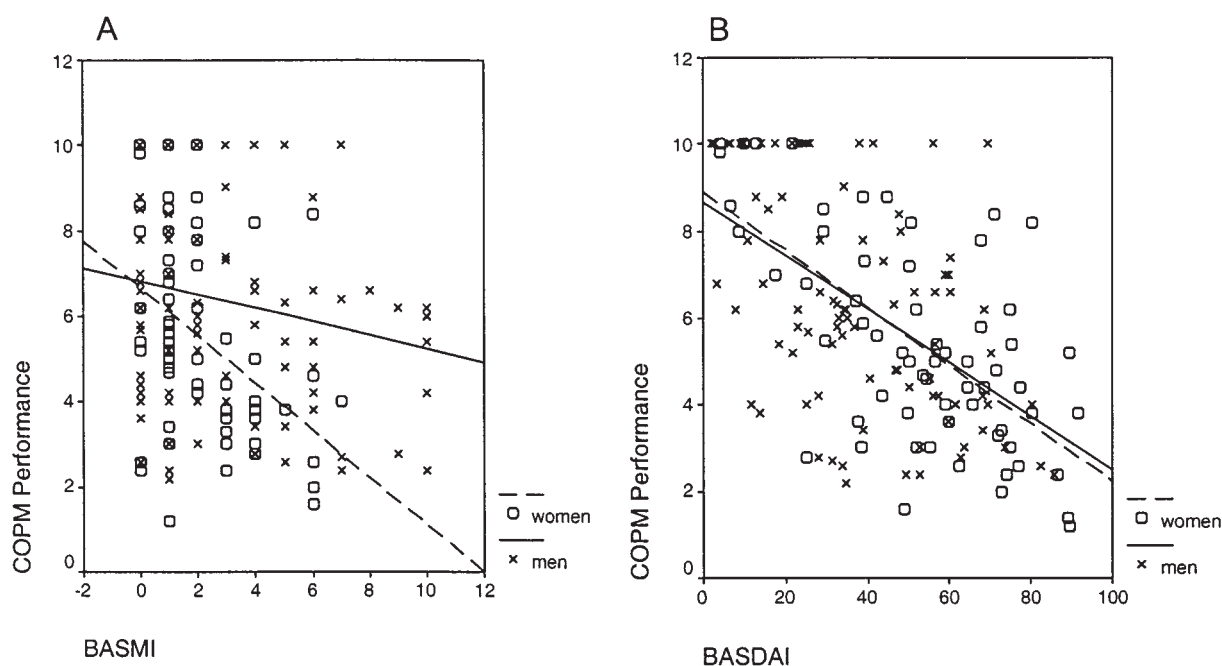

Figure 3. Scatterplots show the correlations between COPM Performance and BASMI (A) and BASDAI (B). BASMI: R^2 men = 0.03, R^2 women = 0.19 (p = 0.001). BASDAI: R^2 men = 0.28, R^2 women = 0.41 (p = 0.81).

Table 5. Associations between the dependent variable COPM Performance and the independent variables entered in blocks according to the ICF dimensions. ß (confidence interval) and p value are given for the final model.

Variables	Regression Coefficients ß (CI)	p	R^2 Change	Change p	Total R^2 Change
Block 1: personal variables			0.11	0.02	0.11
Age	0.002 (–0.04, 0.04)	0.92			
Sex (men = 0)	–0.19 (–1.0, 0.6)	0.63			
Disease duration	–0.002 (–0.04, 0.04)	0.94			
Comorbidity (yes = 0)	–0.19 (–0.9, 0.5)	0.61			
Education (low = 0)	–0.21 (–1.0, 0.5)	0.58			
Occupation (yes = 0)	–0.63 (–1.5, 0.2)	0.15			
Block 2: impairment variables			0.28	< 0.001	0.39
BASDAI	–0.6 (–0.08, –0.04)	< 0.001			
BASMI	–0.21 (–0.4, –0.02)	0.03			
ESR	–0.007 (–0.04, 0.03)	0.68			
CRP	0.03 (–0.01, 0.06)	0.19			

cated[38,39]. According to Wade, *et al*[3], instruments assessing participation tend to take an "outsider's view" and may thus not attend to the patients' perspective[38,40-42]. In rehabilitation, self-reported measures of functional status are frequently used. These instruments may be classified in 3 groups: generic instruments that may be applied across different conditions and diseases (e.g., SF-36); condition-specific instruments to assess disability within a specific group (e.g., BASFI); and individualized patient-specific measures, such as the COPM[19]. The different types of outcome measures serve different purposes for research, assessment, clinical reasoning, and intervention planning. In this study, the semistructured COPM interview was used. The psychometric properties of this instrument have been established in many groups of patients, among them patients with fibromyalgia and chronic pain[43,44], rheumatoid arthritis (RA)[45], and osteoarthritis[46]. The COPM interviews identified the problem areas specific for each individual, and acknowledged the experience, perspectives, and concerns of the patient, thereby enhancing understanding of how AS affects the life and functioning of the individual.

To our knowledge, this is the first study to explore the associations within the framework of the ICF in AS. In a cross-sectional study of patients with RA, the relationships between measures of impairment, activity limitations, and participation restrictions were investigated[39]. As in our study, significant associations between impairments and activity limitations were found, as well as between activity limitations and participation restrictions[39]. Using multivariate statistical approaches in this study, we found that less than 40% of variation in the patient-reported activity limitations and participation restrictions in the COPM Performance scores was explained by the independent variables, mostly by variables on the impairment level. As the COPM interview has a personal and individual focus, factors that create structural, social, or attitudinal barriers in the patient's environment may not be recorded. The remaining explanatory factors influencing the COPM scores may thus be related to environmental conditions. This may be illustrated by the most frequently cited problem areas in this study. In addition to relevant pain-management to improve sleeping problems, environmental factors should also be addressed, such as appropriate bedroom and mattress/pillows, and routines and habits facilitating good sleeping. Similarly, the difficulties turning one's head when driving a car may be addressed by placement of mirrors and installation of parking distance control.

In accord with the traditional understanding of AS as an individual medical condition, patients with AS are routinely offered appropriate medication and physical therapy. According to Imrie[4], this individual perspective may be insufficient, and the understanding of disability as an individual condition may underestimate the wider social and environmental influence on the disease consequences. Other perspectives are suggested, such as social and attitudinal barriers and structural environmental limitations. In the effort to reveal how chronic diseases affect the individual's life and functioning, these are important perspectives that should be emphasized in the research agenda for the field of rehabilitation and chronic diseases. This also indicates that successful rehabilitation implies societal changes.

A strength of this study was the use of the COPM interviews. This instrument revealed patient-reported activity and participation problems without predefined response alternatives, and the responses should therefore reflect the activity and participation problems valid for this group of patients appropriately. Another strength was the comprehensive data collection, which allowed us to cross-validate the findings in the block-regression analysis with the replacement of the primary dependent variable with other related variables (COPM Satisfaction, SF-36 Physical Function, BASFI). The analyses with the BASFI and the SF-36 Physical Function as the dependent variables gave stronger associations than using the COPM Performance as depend-

ent variable. This may be due to the COPM interviews, which enable patients to select problems in any aspect of life, in contrast to the predefined problem areas in the other measures. According to the most frequently reported problems in the COPM interviews (Figure 2), this instrument recorded problem areas not addressed in the disease-specific or generic measures, like interrupted sleeping and having energy for social activities.

We used a hospital register for identifying patients with AS for this study. It may be questioned whether a sample based on a hospital register is representative for the patient group or if it includes those most afflicted by disease. However, the clinical routine in Norway is that patients should have the diagnosis of AS confirmed by a rheumatologist. Thus, this patient cohort comprises patients being seen by both specialists and primary care physicians as their regular medical professional, indicating that the sample is representative.

Limitations of this study are related to the cross-sectional design not allowing conclusions about cause and effect relationships. Further, selection bias cannot be excluded. However, the relatively large group of patients was aged between 25 and 82 years, and the whole range of disease activity, physical functioning, and joint mobility scores was represented, indicating a representative group of AS patients.

This study showed that the impact of functional impairment due to AS influences crucial activities of patients' daily functioning. Measures of disease activity and reduced spinal mobility (impairment level) resulted in more activity and participation problems in women than in men. The impairment variables explained a third of the variation in the patients' perceived problems on the activity/participation level. Further research should aim at identifying possible social, structural, and attitudinal barriers influencing patients' activity and participation.

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