Identification of the Most Common Problems by Patients with Ankylosing Spondylitis Using the International Classification of Functioning, Disability and Health

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ABSTRACT. ***Objective.*** The International Classification of Functioning, Disability and Health (ICF) aims to classify functioning and health by a number of categories divided over 3 components: body functions and body structures, participation and activities, and environmental factors. We identified the common health problems of patients with ankylosing spondylitis (AS) based on the ICF from the perspective of the patient.

Methods. During structured interviews with the extended ICF checklist, trained assessors collected data from 111 patients with AS. ICF categories identified by more than 5% of the patients as at least mildly impaired or restricted were selected. Categories identified by less than 5% were removed. Additional impairments/restrictions reported by more than 5% of the patients, after the structured interviews and not yet included in the checklist, were added.

Results. One hundred nineteen (72%) out of 165 categories of the extended ICF checklist were identified to be at least mildly impaired or restricted. Within each of the 4 components of the ICF, at least one-third of the categories were impaired or restricted for more than 50% of the patients. Thirty-nine (33%) categories were related to movement and mobility. Within the component "environmental factors" the categories "support of immediate family" and "health professionals" were the most important facilitators, "climate" was the most important barrier. Eight impairments were additionally mentioned as relevant. These were hierarchically lower levels of ICF categories previously included and they were added.

Conclusion. One hundred twenty-seven ICF categories represent the comprehensive classification of functioning in AS from the patients' perspective. The results underscore the need to address the 4 ICF components when classifying functioning and to emphasize that functioning implies more than physical functioning. (First Release Oct 1 2006; J Rheumatol 2006;33:2475–83)

Key Indexing Terms:
ANKYLOSING SPONDYLITIS FUNCTIONING PATIENT PERSPECTIVE
INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH

Ankylosing spondylitis (AS) is a chronic rheumatic disorder that primarily affects the sacroiliac (SI) joints and the spine[1]. In addition to the spinal manifestations, extraspinal comorbidities, comprising peripheral arthritis and enthesitis (in 25% of patients), uveitis (in 40% of patients), psoriasis (in 8% of patients), and inflammatory bowel disease (in 8% of patients), add to the burden of the disease[2]. The effects of pain, reduced mobility, and AS-related comorbidity on functioning are well recognized[3-6].

Current recommendations by the ASessment in Ankylosing Spondylitis (ASAS) working group regarding outcome assessments in AS include functioning as a domain

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Accepted for publication July 27, 2006.

of outcome for clinical trials, as well as clinical record-keeping[7]. Several disease-specific instruments to assess physical functioning are described in the literature — the Bath Ankylosing Spondylitis Functional Index (BASFI), the Dougados Functional Index (DFI), the Health Assessment Questionnaire modified for the spondyloarthropathies (HAQ-S), and the Revised Leeds Disability Questionnaire (RLDQ)[8-15]. However, the patients' perspective was not included in the development of all questionnaires and these condition-specific measures typically cover only selected aspects of the whole patient experience associated with AS. Moreover, the measures vary quite considerably regarding the concepts included and the precision with which these concepts are defined[16]. In addition, the instruments were developed to measure disease consequences, but not to assess functioning and health in relation to the disease process, nor to assess the importance of environmental and personal factors[17]. Therefore, they may not be ideal for a global evaluation of health, since functioning and health are not primarily an outcome, but also the starting point in the assessment of a patient.

Based on the new International Classification of Functioning, Disability and Health (ICF), it is now possible to define the specific and full spectrum of problems in functioning of patients with any type of disease in a more systematic way by using a globally agreed-upon language of functioning and health[18]. The ICF is composed of 1454 categories relevant to functioning and health, divided over 3 of 4 components — "body functions and structures," "activities and participation," "environmental factors" (Figure 1[19]). The fourth component "personal factors" has not yet been classified. To apply the ICF in medicine, the ICF needs to be tailored to the needs of medicine. To achieve this goal, condition-specific ICF Core Sets, comprising the categories relevant for the particular condition, are being developed. In the development of condition-specific Core Sets, a standardized approach is applied. The ICF checklist version 2.1a is the generic starting point for the development of the condition-specific Core Sets[20]. In the first step, the checklist is extended with categories identified from the classic disease-specific instruments that assess functioning[21]. Second, structured interviews with patients are performed using the ICF to identify the most common health problems from the patient's perspective. Next, the inclusion of expert opinion is guaranteed by a Delphi exercise. Finally, a consensus conference confirms the final condition-specific Core Sets by vote. The main advantages of Core Sets can be found in clinical medicine, research, and healthcare decisions[22]. Briefly, in clinical medicine, the ICF provides a common language among health professionals from different disciplines and helps to provide tailor-made clinical care by assessing the specific needs of the patient. In research, the ICF can be considered an (new) objective standard to describe functioning comprehensively. For healthcare authorities, the

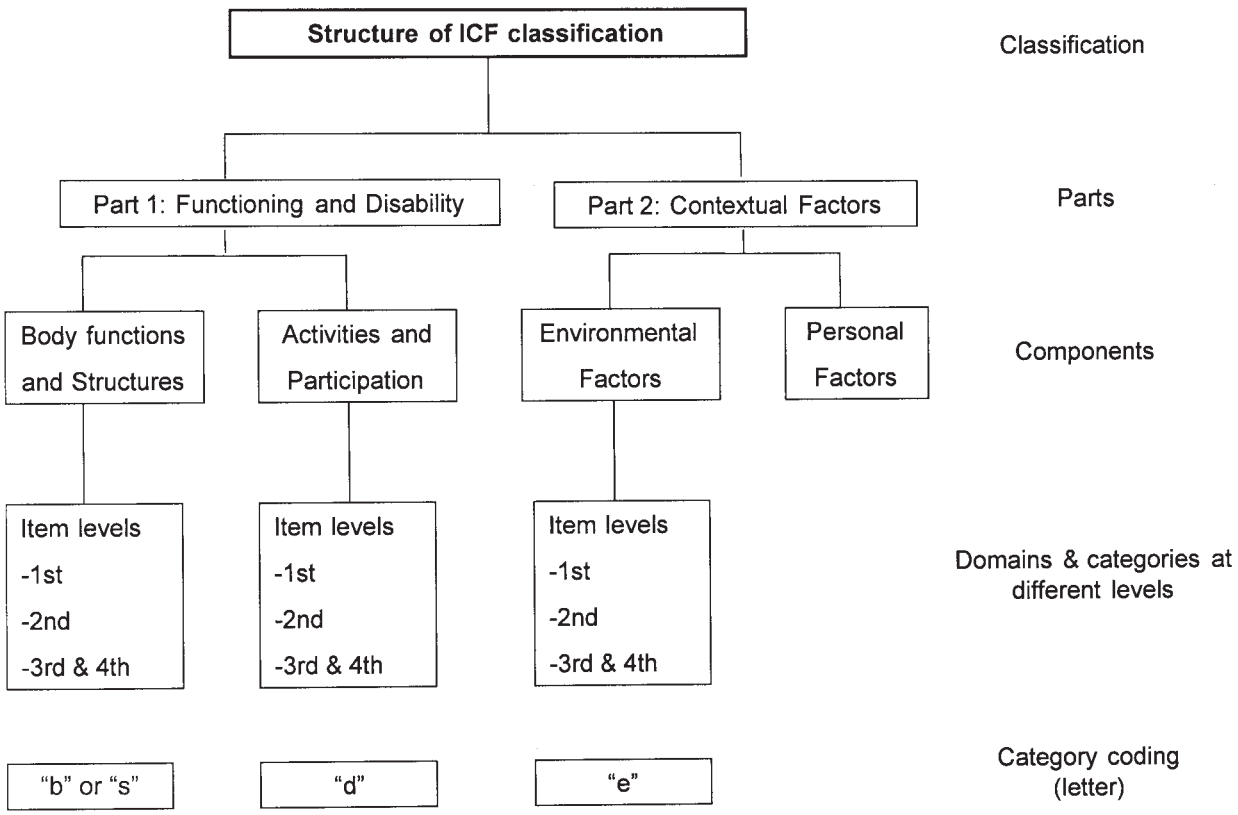

Figure 1. The International Classification of Functioning, Disability and Health.

ICF is a unique tool to compare burden of illness among diseases world-wide[23].

We describe the results of these structured ICF interviews in patients with AS, with the ultimate goal of assuring the perspective of patients in the development process of the ICF Core Sets for AS. Both the global perspective on functioning and the inclusion of the patients' perspective are rarely addressed in the literature[8-10].

MATERIALS AND METHODS

A cross-sectional study with a convenience sample of patients with AS was conducted in 2 study centers, University Hospital Maastricht in The Netherlands and the Rheumazentrum Ruhrgebiet in Herne, Germany. The study protocol and consent forms were approved by the Ethics Committee of the University Hospital in Maastricht and by the Ethics Committee of Westfalen-Lippe of the University of Münster. Inclusion criteria for patients were: a diagnosis of AS according to the modified New York criteria[24], age at least 18 years, with sufficient knowledge of the Dutch or German language, comprehension of the purpose of the study, and giving signed informed consent.

Measures. Sociodemographic data included sex, year of birth, and current working status; disease characteristics included duration of disease and general comorbidities. Non-AS-related comorbidities were assessed by the Self-administered Comorbidity Questionnaire[25]. AS-related comorbidities included inflammatory bowel disease, uveitis, and psoriasis, and were considered if they were clinically symptomatic during the past 5 years. Patients also completed the BASFI, a widely used condition-specific instrument to measure functioning, designed by a multiprofessional expert team with major input of patients[9]. Eight of the 10 items concern activities of functioning in everyday life and 2 additional questions concern the ability to cope with everyday life.

The ICF checklist version 2.1a represents a selection of 126 ICF categories at the first and second levels of the ICF hierarchy from the whole ICF classification system[20]. The structure of the ICF checklist (Figure 1) is similar to the structure of the ICF and comprises categories of 3 out of the 4 components of the ICF: body functions (*b*) and structures (*s*), activities and participation (*d*), and environmental factors (*e*). Each component is further divided into a number of chapters that consist of a number of ICF categories in 4 different hierarchical levels. A category represents the unit of the ICF classification. Within the hierarchical code system of the ICF classification, they are designated by the letters *b*, *s*, *d*, or *e*, referring to the component (or domain within the component) of the classification. The letter is followed by a numeric code starting with the chapter number (1 digit), followed by the second level (2 digits) and the third and fourth levels (1 digit each). For example, in the category b28013, the letter *b* refers to body functions, the first-level number "2" refers to chapter 2, "sensory function," the second-level number "80" refers to "sensation of pain," and the number "13" refers to the third and fourth level, specifying "pain in the back." Of the 126 categories of the checklist, 31 (25%) belong to body functions, 16 (13%) to body structures, 48 (38%) to activities and participation, and 31 (25%) to environmental factors (Table 1).

The ICF checklist is the starting point to develop the extended checklist, which has additional categories that are specific for functioning in patients with the disease of interest. For AS, these additional categories were identified after the content comparison between the ICF and the AS-specific instruments for assessment of physical functioning: the BASFI, DFI, HAQ-S, and the RLDQ[26]. The method of the content comparison of the specific instruments with the ICF is a specific validated process called linking. The precise process and result of linking the AS-specific instruments of physical functioning is described elsewhere[21]. Overall, 51 ICF categories were identified. Thirty-nine of these were not yet included in the ICF checklist and were therefore added. The total of 165 categories (126 of the original ICF checklist and 39 based on the linking) is referred to as the extended ICF checklist for AS. Thirty-six of these categories belong to the body functions component, 16 to the body structures component, 78 to the activities and participation component, and 35 to the environmental factors component (Table 1).

The level of impairment or restriction due to AS for each category is qualified on a 4-point scale (0, no impairment/restriction; 1, mild impairment/restriction; 2, moderate impairment/restriction; 3, severe impairment/restriction; and 4, complete impairment/restriction). For the environmental factors component, the category can be either a facilitator or a barrier. A comparable 0 to 4 scale is applied, but to denote that a category is a facilitator, a positive sign is added (e.g., +2), and to denote the category as a barrier, a negative sign is added (e.g., –2). The option "not specified" (ns) is applied when the available information is not sufficient to quantify the severity of the problem, and the option "not applicable" (na) when the category is not applicable to the patient. For impairments not caused by AS or AS-related comorbidity, the option C (comorbidity) is filled in, without further quantification of the level of impairment.

It is important to note that ICF categories have different hierarchical levels that are part of the extended checklist for AS. For example, the second-level category b440, respiration functions, but also the third-level category b4402, depth of respiration (which is a specification of the former), are included in the body functions component. However, the categories at a higher level (b4402, depth of respiration) cannot be quantified as worse than the corresponding lower-level category (b440, respiration functions) from which it is a specification.

Table 1. Distribution of ICF categories over the 3 components (body functions and body structures are separated) of the ICF checklist version 2a, the ICF checklist extended with categories after linking the BASFI, DFI, HAQ-S and RLDQ to the ICF, and the final ICF checklist for AS after the interviews.

	Body Functions (b)	Body Structures (s)	Activities and Participation (d)	Environmental Factors (e)	Total
ICF checklist, Version 2.1a	31	16	48	31	126
Additional ICF categories for AS after linking*	5		30	4	
Extended ICF checklist for AS	36	16	78	35	165
Categories impaired reported by > 5% of patients	22	10	55	32	
Additional categories reported by > 5% of patients		1	7		
Final ICF checklist for AS	22	11	62	32	127

* AS-specific instruments that measure physical functioning and that are linked to the checklist are the BASFI, the DFI, the HAQ-S, and the RLDQ.

Data collection procedures. Patient recruitment and data collection including the ICF interviews were performed by a medical student (IvE) in The Netherlands and a rheumatologist (JZ) in Germany. Both were trained to perform ICF interviews in a structured one-day workshop by researchers of the WHO ICF Collaborating Center from the University of Munich and had an additional training session with AS patients at University Hospital Maastricht. The training involved familiarization with the World Health Organization model of functioning and disability and with the ICF. Detailed and precise guidelines to perform these structured interviews were provided. In addition, training interviews were held with the individual patients. Data were collected using the extended ICF checklist for AS. The qualifier scale was explained to the patients. After the interview, patients were asked whether there were any other relevant health subjects that should have been discussed during the interview, and additional subjects were documented.

Analysis. Descriptive statistics were used to characterize the study population and to examine the frequency of problems recorded by the extended ICF checklist. Depending on the distribution of the variables according to the Kolmogorov-Smirnov test[27] with $\alpha < 0.05$ either means or medians are reported. The ICF categories of the components "body functions and body structures" and "activity and participation" that were at least mildly impaired (qualified as 1 up to 4) in more than 5% of the patients were retained and reported. In the "environmental factors" component, only the ICF categories that represent a facilitator or a barrier for more than 5% of the patients were reported. Similarly, additional health areas considered as relevant by at least 5% of the patients were linked to the ICF categories and were reported here. The 5% cutoff was applied as a standard for the development of all condition-specific core sets and was chosen in order not to miss categories that might be relevant for patients.

Data entry and analyses were performed with SPSS 12.0 for Windows.

RESULTS

Between June and August 2004, 111 patients were interviewed. Interviews took between 40 and 50 minutes. Table 2 shows the sample is representative of a cross-sectional group of patients under care of a rheumatologist. One hundred nineteen (72%) out of a total of 165 ICF categories of the extended checklist were quantified as at least mildly impaired/restricted by more than 5% of patients (Table 1). These categories and the proportional distribution of patients' scores over all the qualifiers are presented in Tables 3 to 6.

Table 2. Demographic and disease characteristics of 111 patients with AS.

Patient Characteristics	n = 111
Sociodemographic data	
Male patients; n (%)	81 (73)
Age, yrs; mean (SD)	48 (13)
Current working status, %	
Paid employment	37
Unemployed (due to AS)	22
Paid employment (20–80%) and (partial) unemployed due to AS	13
Unemployed (due to another reason)	1
Keeping house/homemaker	5
Retired	19
Student	3
Disease characteristics	
Duration of disease, yrs; mean (SD)	15 (11)
AS related comorbidities, %	
Peripheral arthritis	39
Inflammatory bowel disease	16
Uveitis	32
Psoriasis	7
HLA-positive, n (%)	77 (83)
No. of comorbidities*, mean (SD), median	0.9 (1.2) 0
BASFI (0–10), mean (SD)	5.2 (2.5)

* Only non-AS-related comorbidities resulting in impairment in functioning are included.

For categories referring to body functions (component body functions and structures), 22 of the 36 (61%) categories of the extended checklist were reported as at least mildly impaired by more than 5% of patients (Table 1). "Mobility of joints" and "sensation of pain" were impaired in more than 95% of patients (Table 3). Seven further ICF categories were impaired in more than 50% of patients and were related to "energy," "sleep," "respiration," and "muscle and movement functions" (Table 3).

For categories referring to body structures (component body functions and structures), 10 of the 16 (63%) categories were impaired in more than 5% of the patients (Table 1). "Structure of trunk" and "structure of pelvic region" were the 2 categories impaired in more than 95% of patients (Table 4). Three further ICF categories that were impaired in more than 50% of patients related to "structure of the neck, shoulder and lower extremity."

For the component "activities and participation," 55 of the 78 (71%) categories were identified as restricted in more than 5% of patients (Table 1). "Changing basic body position" and "lying down" were the 2 categories identified as restricted in more than 95% of the patients (Table 5). Twenty-five further categories, the majority belonging to "mobility" and "self-care," were identified as restricted by more than 50% of patients.

In the component "environmental factors," 32 of the 35 (91%) categories were identified as a barrier or a facilitator in more than 5% of the patients (Table 1). None of the categories were a barrier or a facilitator for more than 95% of patients (Table 6). Eleven categories were identified as a facilitator for more than 50% of patients, whereas only one was identified as a barrier. The most frequent facilitators were "immediate family" and "health professional," with frequencies of 89 and 88, respectively. The most frequent barrier was climate, which represented a barrier for 60% of the patients.

Eight additional health areas were reported by at least 5% of the patients to be relevant to describe their functioning and health (Table 1). Linking these health areas to the ICF showed that they were all specifications, that is, more specific fourth-level categories, of existing third-level categories of the extended checklist. Within the "body structures," hip joint was reported as impaired; and in the component "activities and participations," turning the neck sidewards and upwards, activities with the arms above shoulder level, walking more than 1 kilometer, swimming, cycling, walking on different surfaces, and washing one's own hair were reported as restricted.

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Table 3. Categories of the extended ICF checklist referring to "body functions" in the component "body functions and structures" reported as at least mildly impaired by more than 5% of patients, ordered by frequency. Figures present the proportional distribution (%) of patients' answers over the qualifiers (explained below) and the overall proportion of patients identifying the category as at least mildly impaired (last column).

Body Functions	C	NS	NA	0	1	2	3	4	Sum of 1–4
b710 Mobility of joint				2	22	44	21	12	98
b280 Sensation of pain		1		2	19	44	33	1	97
b130 Energy and drive				19	25	30	26		81
b134 Sleep				23	25	31	21		77
b780 Sensations related to muscles and movement*				24	30	36	10	1	76
b7800 Sensation of muscle stiffness*				30	28	33	9	1	70
b730 Muscle power				41	39	17	3	1	59
b440 Respiration	4			38	28	25	6		58
b4402 Depth of respiration*	2			40	29	25	5		58
b152 Emotional				51	28	15	5		49
b735 Muscle tone				52	33	12	2	1	48
b640 Sexual	2	3		66	14	14	1		30
b515 Digestive	3			69	17	11	1		29
b525 Defecation	3			72	17	8			25
b530 Weight maintenance	3			76	17	5			22
b140 Attention				89	7	4			11
b435 Immunological	1			91	5	3			8
b430 Haematological	3			90	4	3	1		7
b765 Involuntary movements				94	5	1			6
b760 Control of voluntary movement*				94	2	2	1	1	6
b7603 Supportive functions of arm or leg*		1		94	2	2	2		6
b144 Memory				95	4	2			5

* Additional categories based on linking of the BASFI, DFI, HAQ-S, and RLDQ to the ICF categories. Sum of percentages does not equal 100 due to rounding. C: impairment due to a comorbidity; NS: not specified; NA: not applicable. 0: no impairment, 1: mild impairment, 2: moderate impairment, 3: severe impairment, 4: complete impairment. Indented categories represent sub-specifications.

Table 4. Categories of the extended ICF checklist referring to "structures" in the component "body functions and structures" reported as at least mildly impaired by more than 5% of patients, ordered by frequency. Figures present the proportional distribution (%) of patients' answers over the qualifiers (explained below) and the overall proportion of patients identifying the category as at least mildly impaired (last column).

Body Structures	C	NS	NA	0	1	2	3	4	Sum of 1–4
s760 Trunk				2	11	46	36	5	98
s740 Pelvis				3	17	41	35	5	97
s710 Head and neck region	2			10	21	25	30	13	88
s750 Lower extremity	2			30	24	26	16	2	68
s720 Shoulder	1			42	25	17	13	2	57
s430 Respiratory system	3			61	19	15	2		36
s730 Upper extremity	2			65	14	13	7		33
s5 Structures related to the digestive, metabolism and endocrine systems	4			73	12	9	3		23
s2 Eye, ear and related structures	5			76	13	6			19
s8 Skin and related structures	5			89	4	2			5
Hip joint*									

* Additional category, not included in the extended ICF checklist, mentioned by > 5% of the patients. Sum of percentages does not equal 100 due to rounding. C: impairment due to a comorbidity; NS: not specified; NA: not applicable. 0: no impairment, 1: mild impairment, 2: moderate impairment, 3: severe impairment, 4: complete impairment.

Table 5. Categories of the extended ICF checklist in component "activities and participation" reported as at least mildly restricted by more than 5% of patients, ordered by frequency. Figures present the proportional distribution (%) of patients' answers over the qualifiers (explained below) and the overall proportion of patients identifying the category as at least mildly restricted (last column).

Activities and Participation	C	NS	NA	0	1	2	3	4	Sum of 1–4
d410 Changing basic body position*				3	10	25	45	17	97
d4100 Lying down*				5	18	33	40	5	95
d455 Moving around*				5	10	14	27	44	95
d415 Maintaining a body position*				6	12	33	41	8	94
d4552 Running*				7	11	13	25	44	93
d4105 Bending*				7	27	33	26	7	93
d4154 Maintaining a standing position*				10	21	30	34	6	90
d640 Doing housework			2	12	24	41	20	1	86
d4153 Maintaining a sitting position*				14	26	42	18		86
d920 Recreation and leisure				18	25	38	16	3	82
d4150 Maintaining a lying position*				18	36	35	10	2	82
d430 Lifting and carrying objects	1			18	31	31	18	2	81
d420 Transferring oneself*				21	33	24	20	2	79
d4551 Climbing*		1		21	25	35	14	5	78
d4201 Transferring oneself while lying*				23	32	24	20	1	77
d4300 Lifting*	1			23	34	27	14	1	77
d4101 Squatting*	2			23	24	8	29	14	75
d475 Driving			1	25	38	28	6	3	74
d4103 Sitting*				30	30	25	15	1	70
d520 Caring for body parts				30	25	18	19	7	70
d5204 Caring for toenails*			1	29	25	18	19	7	70
d4751 Driving motorized vehicles*			6	24	39	25	5	2	70
d450 Walking				37	24	25	13	1	63
d540 Dressing				38	37	19	6		62
d5403 Taking off footwear*				39	38	18	5		61
d910 Community life		1	1	40	19	32	8		59
d850 Remunerative employment	2		26	14	21	16	4	17	58
d5402 Putting on footwear*				38	38	18	6		62
d620 Acquisition of goods and services				51	30	16	3		49
d4104 Standing*				51	23	19	6	1	49
d6200 Shopping*				51	30	16	3		49
d530 Toileting	1			63	23	13			36
d445 Hand and arm use*	1			65	22	9	4		35
d510 Washing oneself				68	20	5	6	1	32
d630 Preparing meals	1		4	65	23	5	3		31
d5100 Washing body parts*				72	17	6	5	1	28
d5102 Drying oneself*				72	19	5	5		28
d465 Moving around using equipment			62	10	8	6	9	5	28
d5400 Putting on clothes*				73	19	5	4		27
d470 Using transportation*			5	68	16	8	2	1	27
d4452 Reaching*				74	18	6	3		26
d5101 Washing whole body*				76	17	3	4		24
d4453 Turning or twisting the hands or arms*				82	11	4	3		18
d440 Fine hand use	2			83	10	3	2	1	16
d560 Drinking				85	8	5	2		15
d770 Intimate relationships			1	87	7	3	3		13
d4402 Manipulating*	2			88	6	2	1	1	10
d4400 Picking up*	1			92	4	3		1	7

Table 5. Continued.

Activities and Participation	C	NS	NA	0	1	2	3	4	Sum of 1–4
d750 Informal social relationships			1	92	5	1	1		7
d710 Basic interpersonal interactions				93	5	2	1		7
d760 Family relationships				93	5	1	2		7
d830 Higher education			90	3	4	4			7
d720 Complex interpersonal interactions				94	1	5	1		6
d740 Formal relationships			1	93	5	1	1		6
d660 Assisting others				95	3	2	1		5
Neck side-wards and upwards**									
Activities with the arms above shoulder level**									
Walking more than 1 km**									
Swimming**									
Cycling**									
Walking on different surfaces**									
Washing one's own hair**									

** Additional categories based on linking of the BASFI, DFI, HAQ-S, and RLDQ to the ICF categories. * Additional categories, not included in the extended ICF checklist, mentioned by > 5% of the patients. Sum of percentages does not equal 100 due to rounding. C: restriction due to a comorbidity; NS: not specified; NA: not applicable. 0: no impairment, 1: mild restriction, 2: moderate restriction, 3: severe restriction, 4: complete restriction. Indented categories represent sub-specifications.

(76%) of the 165 categories were reported to be relevant by the patients.

Consistent with the spinal and articular manifestations of AS, 42 categories (35%) were related to movement and mobility, represented in the components "body functions and structures" and "activities and participation." Twenty-eight of these categories (66%) were identified as a problem by more than 50% of the patients.

Problems due to extraarticular organ involvement related to AS such as uveitis, inflammatory bowel disease, and psoriasis were described within the components "body functions" and "body structures" and contributed to another 5 categories. These categories were reported as impaired by less than 50% of the patients, in line with the prevalence of these comorbidities in AS[2].

Concordant with the recognized impact of the disease on vitality[6,28,29], the categories "emotional functions," "sleep functions," and "energy and drive functions" were reported by 49%, 77%, and 81% of patients, respectively, as impaired. Social functioning was infrequently reported to be restricted. The ICF categories for "interpersonal interactions" were reported as restricted by only 7% of patients, and "intimate relationships" by 13%[6,30,31]. On the other hand, participation in social activities (d920: recreation and leisure) was frequently reported as impaired (82%).

Eight health areas were additionally mentioned by patients after the interview, and these could all be linked to specifications of ICF categories already included in the extended checklist. The most notable examples were "turning the head sidewards and upwards" and "activities with the arms above shoulder level."

The linked categories of the existing measures for physical functioning in AS (BASFI, DFI, HAQ-S, LRDQ) were all identified as relevant for patients[25]. However, it must be emphasized that not all these relevant items were included in each of the questionnaires and that several categories identified as important in the study were not addressed in any of these questionnaires.

On this point, it is notable that 32 out of 35 categories (91%) of the "environmental factors" component were reported by the patients to be a barrier or a facilitator. Remarkably, patients quantified them more often as a facilitator than as a barrier. Most frequently reported as a barrier was "climate," specified by the patients as cold and dampness[32,33]. The most frequently mentioned facilitators were "immediate family," "health professionals," and "healthcare services, systems and policies"[34]. Although there are some reports confirming the importance of social support for functional ability[6] or revealing the positive influence of adaptations in the workplace and support of management for labor force participation[35], the full influence of environmental variables on outcome is insufficiently explored. Our study offers an indication of which type of environmental variables could be considered candidates for future evaluation.

When interpreting these results some issues should be considered. First, most of the patients were recruited from a university hospital and represent a sample with somewhat more severe disease. However, at this stage of the development of an ICF Core Set for AS, overestimation of the burden of disease is acceptable. A low cutoff of 5% for identification of a relevant category was chosen for the same reason. Although only 2 interviewers were involved in this study, who were trained together, the way the interviews were conducted might have influenced the results. The study represents the Dutch and German perspective, and especially within the component of "environmental factors" cultural differ-

Table 6. Categories of the extended ICF checklist in the component "environmental" reported to be a facilitator or barrier by more than 5% of the patients, ordered by frequency. Figures present the proportional distribution (%) of patients' answers over the qualifiers (explained below) and the overall proportion of patients identifying the category as at least mildly impaired (Σ 1–4).

Environmental Factors	C	NS	NA	0	Facilitator Σ 1–4	Barrier Σ 1–4
e310 Immediate family				8	89	3
e355 Health professionals				12	88	0
e410 Individual attitudes of immediate family members				18	78	4
e320 Friends				18	77	5
e110 Products and substances for personal consumption				14	76	11
e450 Individual attitudes of health professionals			1	23	73	3
e115 Products and technology for personal use in daily living	1			28	71	1
e1150 General products and technology for personal use in daily living*	1	1	1	31	64	2
e420 Individual attitudes of friends			1	29	62	8
e225 Climate				31	9	60
e580 Health services, systems and policies				23	55	23
e325 Acquaintances, peers, colleagues, neighbors and community members				43	50	6
e155 Design, construction, and building products and technology of buildings for private use		2		51	44	3
e120 Products and technology for personal indoor and outdoor mobility and transportation			6	48	43	3
e150 Design, construction, and building products and technology of buildings for public use		2	1	54	4	40
e460 Societal attitudes			1	57	8	34
e1151 Assistive products and technology for personal use in daily living*			64	2	33	1
e330 People in position of authority		1	38	22	32	7
e590 Labour and employment services, systems and policies			6	57	31	6
e570 Social security, services, systems and policies		1	3	45	29	23
e585 Education and training services, systems and policies			13	60	25	3
e135 Products and technology for employment*			29	41	24	5
e1201 Assistive products and technology for personal indoor and outdoor mobility and transportation*		1	78	3	17	1
e550 Legal services, systems and policies		1	3	79	14	3
e540 Transportation services, systems and policies			1	86	12	2
e525 Housing services, systems and policies			5	84	11	0
e340 Personal care providers and personal assistants			89		10	1
e535 Communication services, systems and policies		1	1	88	10	0
e125 Products and technology for communication		1		89	9	1
e465 Social norms, practices and ideologies			1	88	6	5
e360 Other professionals		1	78	14	6	2
e455 Individual attitudes of other professionals			78	15	6	0

* Additional categories based on linking of the BASFI, DFI, HAQ-S, and RLDQ to the ICF categories. Sum of percentages does not equal 100 due to rounding. C: impairment due to a comorbidity; NS: not specified; NA: not applicable. 0: no barrier/facilitator, 1: mild barrier/facilitator, 2: moderate barrier/facilitator, 3: severe barrier/facilitator, 4: complete barrier/facilitator. Indented categories represent sub-specifications.

ences might influence the findings. This is more likely to appear in the grading as a facilitator or a barrier than in identification of the particular relevant category. Finally, it must be taken into account that personal factors have not yet been classified, and thus were not included in the study. Therefore, the complete health experience of a person can only be comprehensively described when these factors are taken into account.

A total of 127 ICF categories represent a comprehensive classification of functioning in AS from the patients' perspective, and the result is an important step toward development of the ICF Core Set for AS. The classic instruments to assess physical functioning all contain items that are relevant but do not cover the full spectrum of variables that explain functioning in AS, especially environmental factors. Identification of patients' problems on the level of categories will allow study of the relevance of individual or groups of categories for different types of outcomes.

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