

# Body image in patients with ankylosing spondylitis

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## Abstract

### Objective

Physical disabilities generally cause disturbances in a patient's body image. The aim of the present study is to assess the prevalence of different aspects of body image disturbances (attractiveness/self-confidence, negative body judgement, accentuation of external appearance, worry about possible physical deficits, sexual problems and physical vitality) in patients with ankylosing spondylitis (AS) in the context of the severity of impairment, mood and pain intensity.

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### Methods

Fifty-six patients with AS and 48 healthy controls were investigated using a questionnaire for assessing one's body (1) and the body image questionnaire (2). Furthermore, in the AS patients' medical parameters including BASMI and BASFI, pain intensity and state of well-being were assessed.

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### Results

In comparison to the controls, the AS patients reported significantly more worries about possible physical deficits. The mildly impaired patients (including significantly more women) were even more insecure than the severely impaired patients. Furthermore, the patients considered themselves as being less attractive. The AS patients reported better physical vitality than the controls. This result might be due to patients carrying out regular physical activity and performing exercises with therapeutic value. There were no differences between the groups concerning sexual problems. The total group of AS patients showed normal scores in the state of well-being and did not report pain intensity as being higher than what is expected in chronic pain patients in general.

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### Conclusion

Rheumatologists should address problems in body image in patients with AS and in severe cases psychological therapy should be initiated.

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### Key words

Ankylosing spondylitis, body image, attractiveness, vitality, sexuality

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## Introduction

Body image and experience of one's body includes, among other conscious experiences and inner representation of the body, also the individual's appraisal of and feelings about the body and its function (1, 3). Gillies (4) defines body image as "...the mental picture one has of his physical being, together with a heavy overlay of feelings about that structure. In other words, one's body image is an emotional view of one's physical self as seen in the mind's eye. Ordinarily, an individual's body image exists on the fringe of awareness". Chronic diseases, in particular those accompanied by deformities and disabilities, are generally associated with severe disturbances of the body image (5).

The available literature on this subject under the rubric of chronic rheumatism contains just a few studies on patients with chronic polyarthritis (RA) that focus on body image (5-7). These studies report on worries about the body in RA patients in general and pronounced sexual problems in women with RA who subjectively suffered a higher degree of morning stiffness than those who suffered to a lower degree. In the few studies conducted on patients with ankylosing spondylitis (AS), body image is defined primarily by "external appearance and physical attractiveness" as well as "body functioning" or "fitness". Ward (8) reported that about 50% of patients suffering from AS had "concerns about their appearance". Hider *et al.* (9) who investigated the effects of regular physical exercises on body appearance, body function and body awareness failed to find any influence of physical exercises on body image.

The mean scores on the body scheme variables of the AS patients investigated in this study show, however, that these patients did not consider themselves as being severely impaired in their body scheme. In most of the studies so far, sexuality, which is most closely associated with body image, was not closely investigated. If the subject of sexuality is at all addressed in AS patients, it is done in a peripheral manner, as a part of investigations on quality of life. In this context, Cakar *et al.* (10) reported that about 50% of AS patients suffer

from sexual problems, usually associated with joint involvement, decreased functionality, increased disease activity, decreased health quality and depression. Ozgül *et al.* (11) reported a significant association between sexual problems and anxiety in AS patients.

The aim of the present study is to gather more precise data on body image in AS patients (compared to healthy controls) taking into consideration factors such as severity of handicaps, pain experience and state of well-being.

## Materials and methods

About 50% of patients with AS for this study were recruited from those undergoing treatment at the Spa Sanatorium in Gasteiner Radon Galleries and the rest through the Austrian Association of Morbus Bechterew. The control group of healthy individuals, matched for gender and age, were recruited from the circle of friends of the hospital staff. All subjects were informed by a psychologist about the goal and objectives of the investigation as well as the processing of the questionnaires.

After obtaining informed consent and gathering demographic data, all the subjects were requested to complete the questionnaire on the assessment of their body (1) and the questionnaire on body image (2). In patients, additional illness-related aspects such as BASMI (12) and BASFI (13) were assessed. Furthermore, patients also filled in the pain experience scale (14) and a scale for assessing their state of well-being (15). The investigated parameters are described below in greater detail.

### BASMI (12)

In addition to sex, age and occupation, data are gathered on time elapsed since the first appearance of complaints and time since diagnosis. Furthermore, tragus to wall, lumbar flexion, cervical rotation, lumbar side flexion and intermalleolar distance are assessed. The severity of functional impairment can be estimated from the sum of scores lying between 0 and 10.

### BASFI (13)

The BASFI score (made up of the average of 10 single question scores) is

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employed for the subjective assessment of a person's disability during various activities of daily living. Mean scores of  $\leq 2$  cm are characterised as very mild or mild disability, values between 2.1 and 4.9 as moderate, and higher values (up to 10 cm) as severe or very severe disability.

#### *Pain experience scale (14)*

The development of the pain experience scale is based on pain descriptors of the expanded McGill Pain Questionnaire (16) and comprises a total of 24 items, 14 for capturing affective pain experience (e.g. I experience my pain as torturing), and 10 for assessing sensory pain experience (e.g. I experience my pain as a hammering). In the German language countries, this questionnaire is considered to be a well-validated and reliable instrument for assessing the sensory and affective components of pain.

#### *Adjective mood scale (AMS, 15)*

This scale consists of 28 items for the assessment of fluctuations in well-being. For example: at the moment, I am feeling more "worn-out", more "alert" or "neither-nor". The highest possible score is 56; people scoring 18 or higher are considered as suffering from either somatic or general complaints indicating a poor subjective state of well-being. High AMS scores correlate highly with clinically relevant depression ( $r=0.85-0.90$ ). The mean value for depressive patients is 37.6 (SD $\pm$ 12.65), and for healthy individuals, it is 11.86 (SD $\pm$ 9.75).

This test is also used for the reason that, in addition to the total score, a subscore (based on 8 items) reflecting the degree of fatigue can be plotted, an aspect that is of particular interest in AS patients (15).

#### *Questionnaire for assessing one's body (1)*

This questionnaire was designed primarily to investigate the body concepts of psychosomatic patients. The questionnaire consists of 52 items which are to be answered with 'true' or 'not true'. By means of factor analysis, it is possible to extract 4 factors.

*Factor 1: Attractiveness/self-confidence.* This scale is defined by 15 items and

describes in the first instance satisfaction and joy with one's own body or their opposites – for instance, 'I am happy with my figure' or 'I wish I had a different body'.

*Factor 2: Accentuation of external appearance.* This factor defines 17 items which are related, in particular, to the emphasis on external appearance. 'I often look at myself in the mirror' or 'I enjoy looking at myself' are some of the typical items.

*Factor 3: Worry about possible physical deficits.* This scale consists of 13 items and focuses primarily on one aspect, namely, a marked attention directed to one's own body and uncertainty about or lack of faith in physical functioning, such as 'I cannot rely on my body'.

*Factor 4: Sexual problems.* There are 7 items in this scale, concerned with sexual dissatisfaction, sense of shame regarding sexuality and unhappy sexual feelings. For example, 'I am often blocked in my sexuality' or 'I don't like to be touched'.

#### *Questionnaire on body image (2)*

This questionnaire for gathering data on disturbances of body image and of body concept comprises 20 items with a 5-level rating scale (is not at all true to completely true). Two scales can be derived by factor analysis as follows:

*Factor 1: Negative body judgement.* This scale comprises, on the one hand, the judgement on the external appearance of the body, and on the other, an evaluative description of the mood about and the feeling of well-being in one's own body. For instance, "I sometimes wish to have quite a different appearance" or "I feel myself at home in my own body".

*Factor 2: Vitality.* This scale focuses attention on the energetic and movement-associated aspect of body image, for instance, "I trust my body to a large extent" or "I feel full of power."

#### *Statistics*

For description, quantitative variables were characterised by medians and 25<sup>th</sup> and 75<sup>th</sup> percentiles, and categorical variables by absolute and relative frequencies. Since patient responses deviated

from normal distribution the evaluation of group differences was performed using Mann-Whitney U-tests. Correlations between single variables were calculated with the help of Spearman's rank correlation coefficient. We considered  $p \leq 0.001$  to be statistically highly significant,  $p < 0.05$  to be statistically significant, and values between  $p \geq 0.05$  and  $p \leq 0.1$  were interpreted as tendency or trend.

#### **Results**

A total of 56 AS patients and 48 healthy controls were included in the study. Besides comparing the whole group of patients with the control group, patients with severely restricted spinal movement were compared with those with mild movement limitations in their spine. The classification of patients into the two groups (those with mild vs severe functional limitations) was based on the sum of BASMI scores. Individuals with a total score of 0-4 were classified as mildly impaired ( $n=34$ ), those with a score of 5-10 as severely impaired ( $n=22$ ).

#### *Sociodemographic parameters*

The most important demographic data of the two groups of patients and control subjects are shown in Table I. Patients and healthy controls are comparable in sex, age and profession. Within the patient group there were significantly more women than men in the group of patients with mild impairment.

#### *Medical parameters, pain and subjective state of well-being in AS patients*

Table II shows the medical parameters, the pain experience and the state of well-being of all patients and also a comparison of patients with mild and severe impairments.

There were highly significant differences between the two groups in the BASMI-score, but they did not differ in the BASFI-score.

Significant differences were found between the two groups also in the duration of illness, operationalised at the time point of diagnosis. A longer period of time since diagnosis had elapsed in severely impaired patients compared to

**Table I.** Sociodemographic parameters.

Sociodemographic parameters	BASMI-score									
	AS-patients		Healthy controls		p	Mildly impaired (0-4)		Severely impaired (5-10)		p
	Median	Pct. 25 <sup>th</sup> - 75 <sup>th</sup>	Median	Pct. 25 <sup>th</sup> - 75 <sup>th</sup>		Median	Pct. 25 <sup>th</sup> - 75 <sup>th</sup>	Median	Pct. 25 <sup>th</sup> - 75 <sup>th</sup>	
Age	52.50	41.25 - 60.00	57.00	34.25 - 66.00	0.632	49.50	40.50 - 61.25	54.00	43.75 - 60.00	0.369
Gender	n	%	n	%	0.238	n	%	n	%	0.001***
Female	25	48.1	27	51.9		21	84	4	16	
Male	31	59.6	21	40.4		13	41.9	18	58.1	
Profession	n	%	n	%	0.476	n	%	n	%	0.702
Employed	31	49.2	32	50.8		19	61.3	12	38.7	
Retired/housewife, -man	24	61.5	15	38.5		14	58.3	10	41.7	
Others/in training	1	50	1	50		1	100	0	0	

\* $p \leq 0.05$ , \*\* $p \leq 0.01$ , \*\*\* $p \leq 0.001$ .

**Table II.** Medical parameters, pain and state of well-being of AS-patients.

Medical parameters, pain and state of well-being		BASMI-score						
		AS-patients		Mildly impaired (0-4)		Severely impaired (5-10)		p
		Median	Pct. 25 <sup>th</sup> - 75 <sup>th</sup>	Median	Pct. 25 <sup>th</sup> - 75 <sup>th</sup>	Median	Pct. 25 <sup>th</sup> - 75 <sup>th</sup>	
BASMI		4.00	2.00 - 5.75	3.00	2.00 - 3.25	6.00	5.00 - 6.00	<0.001***
BASFI		1.80	1.30 - 2.30	1.80	1.20 - 2.20	1.95	1.50 - 2.45	0.126
Time since diagnosis (years)		13.50	6.00 - 20.75	9.00	5.00 - 20.00	17.00	13.00 - 26.50	0.012*
Time since first complaints (years)		25.00	17.00 - 32.75	20.00	13.50 - 33.25	28.00	19.75 - 32.75	0.135
Pain (SES)	Affective pain component	25.00	18.25 - 31.75	25.50	20.75 - 31.25	23.00	16.75 - 34.00	0.382
	Sensory pain component	16.00	13.00 - 21.00	16.00	12.75 - 22.25	15.00	13.00 - 18.25	0.263
Adjective Mood	Total score	10.00	4.00 - 16.75	10.00	4.75 - 18.50	6.00	2.75 - 16.25	0.294
Scale (AMS)	Fatigue score (8 items)	3.00	1.00 - 6.75	3.50	1.00 - 7.25	2.50	0.00 - 5.00	0.323

\* $p \leq 0.05$ , \*\* $p \leq 0.01$ , \*\*\* $p \leq 0.001$

those with mild impairments. However, there were no differences between the two groups as far as the time when their complaints started is concerned.

AS patients described their sensory as well as affective pain components as being average, that is, the T value, in comparison with reference values of patients with “multifocal pains” was between 40 and 50. There were no differences between the two groups of patients in their sensory or affective pain components.

AS patients did not describe their subjective state of well-being as being negative. Their mean scores were responding to the norm values of the healthy controls (mean: 11.86, SD: 9.75). There were also no differences between the mildly and severely impaired patients either in their subjective well-being or in the extent of their fatigue symptoms

which can be specifically calculated from 8 out of the total number of given items.

*Body image and body scheme - comparison of patients with healthy controls*

AS patients showed significantly higher “negative body judgement”, significantly less “attractiveness and self-confidence” and significantly more “insecurity and worries” about their bodies. Mildly impaired patients expressed significantly more worries than even the severely impaired.

Both groups of patients described significantly higher “vital body dynamics” than the healthy controls. There were no differences between the groups in “sexual problems” and “accentuation of body appearance”, although severely impaired patients took significantly

less care of their external appearance than mildly impaired patients.

*Correlations between body image parameters*

In the group of AS patients taken as a whole, there were some expected significant correlations between the 6 investigated parameters of body image. In brief, the more the patients reject their bodies, the less they feel attractive; they also suffer more with worries about their bodies and also suffer physical sexual discomfort. On the other hand, there was a significantly positive correlation between “insecurity and worry about the body” and “accentuation of physical appearance”.

The factor of “vitality” appeared to have conspicuously little relation to other factors of body image, so that it possibly represents a relatively independent

**Table III.** Body image and body scheme.

Body Image	BASMI-score									
	AS-patients		Healthy controls		<i>p</i>	Mildly impaired (0-4)		Severely impaired (5-10)		<i>p</i>
	Median	Pct. 25 <sup>th</sup> - 75 <sup>th</sup>	Median	Pct. 25 <sup>th</sup> - 75 <sup>th</sup>		Median	Pct. 25 <sup>th</sup> - 75 <sup>th</sup>	Median	Pct. 25 <sup>th</sup> - 75 <sup>th</sup>	
Questionnaire for assessing one's body										
Attractiveness/self confidence	12.00	7.00 - 13.00	14.00	11.25 - 15.00	0.001***	12.00	7.00 - 13.00	11.00	6.75 - 13.00	0.560
Accentuation of external appearance	7.00	5.00 - 9.00	7.00	5.25 - 8.75	0.869	8.00	5.75 - 9.00	6.00	4.75 - 8.00	0.044
Worry about possible physical deficits	6.00	3.00 - 7.75	3.00	1.25 - 4.00	0.003**	6.50	3.00 - 8.00	4.00	1.00 - 6.25	0.010*
Sexual problems	1.00	0.25 - 2.75	1.00	1.00 - 2.75	0.952	1.00	0.00 - 2.25	1.00	0.75 - 3.00	0.972
Questionnaire on body image										
Negative body judgement	31.50	27.25 - 36.00	19.00	15.00 - 22.75	<0.001***	31.00	27.75 - 36.00	33.00	26.75 - 36.25	0.517
Vitality	41.00	38.00 - 44.00	35.00	31.25 - 41.50	<0.001***	41.00	37.75 - 44.00	41.50	37.75 - 44.75	0.737

\* $p \leq 0.05$ , \*\* $p \leq 0.01$ , \*\*\* $p \leq 0.001$ 

parameter that is correlated only with "accentuation of physical appearance" (Spearman=3.53;  $p=0.008$ ).

#### Correlations between medical parameters, pain and state of well-being

As expected, there was a significant correlation between BASMI and BASFI (Spearman = 0.294;  $p=0.001$ ). Also sensory and affective pain components showed significant correlation (Spearman = 0.6;  $p<0.001$ ). There were no correlations between pain experience and the subjective state of well-being. At least, the two questionnaires used in this study measured parameters which are independent of each other. The BASFI-score correlated significantly with the affective pain component (Spearman = 0.405;  $p=0.002$ ) as well as with the state of well-being (Spearman = 0.41;  $p=0.002$ ), the sensory pain component correlated negatively with the BASMI-score (Spearman = -0.266;  $p=0.0047$ ).

#### Discussion

Physical disabilities generally are associated with disturbances of the body image (5). Among patients suffering from chronic rheumatic diseases it is the rheumatoid arthritis patient, in whom worries about the body and sexual discomfort have been already described (7). The present study focused on disturbances of the body image of AS-patients, taking into consideration the severity of handicaps, pain experience and state of well-being.

The group of AS patients we investi-

gated reported enjoying a good state of well-being and unremarkable fatigue symptoms. This finding is in contrast to other studies like Ward (8) or Zochling and Braun (17). Ward reported that more than 60% of his study population suffered from fatigue and nearly 30% from depression. Zochling and Braun (17) conclude in their review on mortality in AS patients that they are expected to have a higher risk for developing mental problems. In agreement with the findings of Gerecz-Simon *et al.* (18) and Incel *et al.* (19), according to which AS patients do not have above average pain experience, also our patients described their sensory and affective pain components as not being more intense than those expected in patients having to live with chronic pain.

In this context, we would like to draw attention to the high correlation between the affective pain component as well as the subjective state of well-being (AMS) and the BASFI-scores. Thus the BASFI-scores not only correlate with scores on functional impairment (20) it might possibly indirectly hint at the presence of a depressive mood too, an aspect that needs to be more closely investigated.

Concerning body image, there is something unexpectedly remarkable about the results. AS-patients described themselves as being significantly more vital, energetic and oriented to physical activity than healthy controls. Physically they felt stronger, fitter and healthier. A possible explanation for this finding might be the fact that gymnastics and

movement therapy, which are highly important for the outcome of the disease, is incorporated into the daily lives of these patients and the subject of physical fitness is ever present in their minds. Generally, almost all AS patients have some experience with special gymnastic programs and more than 90% want to continue with them in the future (21, 22). Another possible explanation is "justification of effort" according to the motto "what costs much effort should also have good effects".

Furthermore, "vitality" was independent of other factors of the body scheme and was correlated only with the "accentuation of physical appearance". Patients were as attentive to their "physical appearance" as the healthy controls. There were also no differences between patients and controls concerning sexual mis-feelings or sexual problems, a result that is contrary not only to reports in chronic inflammatory rheumatic diseases, such as rheumatoid arthritis (7, 23), but also in other chronic diseases such as multiple sclerosis (24, 25, 26) or Parkinson's disease (27, 28). It cannot be excluded that a certain amount of dissimulation played a role here despite assessment being anonymous. It is also likely that the investigated subjects were at an age when the importance and value of sexuality was possibly lower than in younger persons.

As expected, "insecurity and worries about the body" in AS patients was present to a significantly higher extent than in the healthy controls, the mildly impaired patients were even more inse-

cure and doubtful about their physical functions than those more severely ill and ill for a longer period of time. They felt that they were less able to control their bodily functions. It is possible that these patients with mild symptoms are not taken seriously and that doctors do not find it necessary to give them adequate information. It was also notable that there were significantly more women than men among the mildly impaired patients. In this context, attention is drawn to the controversial issue of diagnosis of AS. Although the group of mildly impaired patients the majority of whom were women claimed to have had an equally long duration of physical complaints as the severely impaired male-dominated group of patients, the time elapsed since diagnosis was shorter in the former group.

This finding is in agreement with data on diagnosis delay in women. Women suffer hardly or only very little from calcification, so that no massive disease progression can be seen on x-ray, and they also suffer for years under persistent inflammatory pain and pain-dependent loss of function. Pain and degree of disability are as intense as in men (29, 30). Thus, in contrast to men, women are at a higher risk of being classified as suffering from psychosomatic illnesses. Our result once again highlights the need for modified diagnostic criteria (31), in order to prevent possible diagnostic delay in women (30).

Furthermore, AS patients considered their bodies as a whole unattractive and were full of self-doubts, they had a disapproving attitude towards their bodies compared to the healthy controls. Between the patients with mild or severe impairments (and thus also between women and men) there were no differences.

To sum up, patients with AS who often seem to be “pulling themselves together” (32), have to deal with some problems concerning body image. Therefore, two key points must be kept in mind as part of the care protocol of AS patients: It is likely that these patients make a negative body judgement (patients do not judge themselves as being as attractive as healthy controls); women, in particular, even with mild impairments,

may suffer from body-related anxiety and worries. These problems should be addressed in patient interviews and if found necessary, psychological help should be offered and initiated. Therapy programs including body centered exercises showed encouraging results in the body image of other chronic diseases like MS (33). The aim of subsequent studies could be to evaluate the effectiveness of such body-related interventions alone or in combination with established therapeutic methods in patients with AS.

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