

Body image of women with rheumatoid arthritis

S. Gutweniger¹, M. Kopp¹, E. Mur², V. Günther¹

¹Unit of Clinical Psychology, Department of Psychiatry;

²Unit of Rheumatology, Department of Internal Medicine,
University Hospital of Innsbruck, Innsbruck, Austria.

Abstract

Objective

Physical disabilities generally cause severe disturbances in a patient's body image perception. The aim of the present study was to investigate different aspects of body image, including sexual dissatisfaction, in women with rheumatoid arthritis (RA) in relation to their subjective impression of handicap.

Methods

Forty women with RA were investigated using a series of instruments: Strauss and Appelt's questionnaire for assessing one's body (1), the body perception scale of Paulus (2), and an interview focusing on appearance, worries about health and sickness, and sexual dissatisfaction. In addition, clinical parameters and the subjective extent of morning stiffness were documented, and patients with a high degree of morning stiffness were compared to patients with a low degree of morning stiffness.

Results

In contrast to patients with a low degree of morning stiffness, patients with a high degree of morning stiffness worried significantly more about their bodies ($p \leq 0.05$) and reported significantly more problems in sexuality ($p \leq 0.05$).

Conclusion

Our results suggest that morning stiffness plays a very important role in how severely a woman feels herself to be handicapped. Severely handicapped women have to deal with anxieties about health and have sexual problems. Physicians should not shy away from addressing these issues and in severe cases psychological therapy should be initiated.

Key words

Body image, sexuality, rheumatoid arthritis.

S. Gutweniger, MA; M. Kopp, PhD; Erich Mur, MD; Verena Günther, PhD, Associate Professor.

Please address correspondence and reprint requests to: Prof. Verena Günther, Unit of Clinical Psychology, Department of Psychiatry, University Hospital, A-6020 Innsbruck, Austria.

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Introduction

According to Gillies (3), the concept of body image includes the inner picture one has of one's 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. Chronic diseases, in particular those accompanied by deformities and disabilities, are generally associated with severe disturbances of body image (4, 5). The number of investigations which address the problem of body image in patients with RA is relatively small, and such studies as there are on this subject have reported conflicting results.

Cornwell and Schmitt (6), as well as Ben-Tovim and Walker (5), claim that as far as body image is concerned, RA patients differ hardly at all from healthy controls and, in comparison with other patient groups (for example, patients with lupus erythematosus), do not feel ashamed of themselves. In contrast, Vámos (7) suggests that, although often hidden, a disturbed body image and the desire for cosmetic changes is often responsible for an RA patient's decision to undergo surgical procedures. Furthermore, in his study it becomes clear that the perception of disfigurement of the hands is very subjective and plays a significantly more important role than perhaps objective medical opinion about the hand deformity.

Our own clinical experience suggests that often the extent of morning stiffness is used by patients as a criterion for estimating the severity of their handicap. This does not necessarily agree with the objective clinical findings of laboratory tests and radiographs.

What is common to all the studies conducted so far is that they define body image in the first instance by 'external appearance and physical attractiveness' (8) and neglect other important aspects such as faith in the body's functions and satisfaction in sexuality. Furthermore, in most of the investigations the degree of disability was not considered, and in particular patients with subjectively milder disability were not distinguished from those with more severe handicaps.

Against the background of these considerations, it was the aim of this study to

gather data on different aspects of body image (physical appearance, anxieties about health and sexual dissatisfaction) in a group of women with RA, taking into consideration the subjectively estimated extent of morning stiffness (as a measure of subjective handicap). In order to avoid confounding factors, in a study of this kind the age of the subjects must be within a certain range so that changes in body image are not the result of the aging process. For this reason, only patients in the age group 30 - 55 years with a confirmed diagnosis of RA were included in the study and, since our focus included sexual problems, the participants had to be living in a partnership situation.

Patients and methods

Subjects

Out of a group of 45 women who were invited to enroll in this study, 3 refused and 2 had no time for the subsequent interview. Thus we had a group of 40 women who participated in the study and gave their informed consent after the objectives and purpose of the study had been explained to them.

Sociodemographic variables and common measures of disease activity were assessed. We used the Steinbrocker functional stage and radiographic stage (9), joint swelling, the erythrocyte sedimentation rate (ESR) and quantitative latex tests. Further joint tenderness was evaluated. In addition to these data, the subjective impression of morning stiffness was documented using a visual analogue scale 10 cm long with the poles 'no morning stiffness' and 'extremely severe morning stiffness'.

Psychological instruments

1. Strauß and Appelt (1) Questionnaire for assessing one's own body.

This questionnaire was designed primarily to investigate the body concepts of psychosomatic patients. At the same time, this questionnaire has also proved to be useful for evaluating psychotherapeutic and physical therapeutic effects. 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 the satisfaction and joy with one's own body or its opposite - 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 an uncertainty about or lack of faith in physical functioning, such as 'I know that my body is like something dead' or 'I can rely on my body'.

Factor 4: Problems regarding sexuality. There are 7 items in this scale, which is 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'.

The internal consistency of the scales, expressed as Cronbach's alpha 0.85, 0.72 and 0.69, 0.72, can be considered satisfactory. As far as the re-test reliability is concerned, a three-factor solution with the following values 0.67, 0.84, and 0.69 can also be regarded as satisfactory.

2. Subscale 'Emphasis on attractiveness' of the Body Perception Questionnaire of Paulus (2).

This is the second of four scales included in the Body Perception Questionnaire of Paulus. Physical attractiveness plays a decisive role at a time when interpersonal contacts are being established and bodily stigmatisation, especially in women, can have a truly catastrophic effect. The 22 items in this scale assess the extent to which appearance is adjusted to meet social norms. 'I try to conceal as well as I can the unattractive aspects of my body' or 'I try to meet the ideals of beauty as envisaged by our society' are characteristic items of this scale.

The internal consistency of the scale, expressed as Cronbach's alpha 0.87, is to be considered quite satisfactory.

After they had completed the questionnaires, patients were interviewed by the female psychologist who conducted the investigations. They were asked as to their feelings or problems when filling in the questionnaires. In addition, they were requested to draw our attention to other problems, if any, relating to body image and sexuality which, in their opinion, were not captured by the questionnaire. This interview was further used to check the questionnaires for completeness; unanswered items were explained once again and answers obtained. Thus it was possible for us to record complete data on all 40 of our patients.

Statistical procedure

In order to determine whether the two groups were comparable with regard to clinical and sociodemographic variables, Mann-Whitney U tests or chi-square tests were performed. For comparison of the mean values of the questionnaire variables between the groups, an analysis of covariance (with the covariates Steinbrocker's functional stage and duration of illness) was used. Following Rothman (10), no alpha adjustment was made.

To assess the relationships between the subjective degree of morning stiffness and clinical parameters (functional measures, laboratory measures), the Spearman correlation coefficients were calculated.

Results

On the basis of the VAS scale, 20 patients considered themselves as suffering from a low degree of morning stiffness ($\bar{x} = 1.41$ cm), while 20 patients considered themselves as suffering from a high degree of morning stiffness ($\bar{x} = 6.46$ cm). The two groups did not differ significantly in terms of either socio-demographic or clinical parameters (Tables I and II).

Furthermore, there was no significant correlation between the extent of morning stiffness and different clinical measurements (Steinbrocker functional and radiographic stage, ERS, joint swelling). A comparison of the two groups (high vs. low morning stiffness) showed that worries about the body, as well as problems with regard to sexuality, were more pronounced in patients with high morning stiffness (lower values on the scales imply the presence of a highly pronounced problem in the corresponding area). The differences did not disappear even when the functional Steinbrocker stage and the duration of illness were taken into consideration as covariates. The two groups did not differ in terms of their estimate of their own attractiveness, or in their beauty-promoting activities (Table III).

Discussion

Investigations of patients with RA usually employ clinical data and data from

Table I. Socio-demographic parameters.

Groups	Low degree of morning stiffness (n = 20)	High degree of morning stiffness (n = 20)	p-value
Parameters	mean \pm SD	mean \pm SD	
Age	43.5 \pm 8.7	46.6 \pm 5.5	0.371
Duration of partnership	18.5 \pm 10.3	18.1 \pm 10.7	0.935
Number of children	1.7 \pm 0.9	1.9 \pm 1.1	0.723
Marital status	Frequency/ %	Frequency/ %	0.788
Married	15/ 75%	15/ 75%	
Single, but with a steady partner	2/ 10%	1/ 5%	
Divorced, but with a steady partner	3/ 15%	4/ 20%	
Education	Frequency/ %	Frequency/ %	0.896
Elementary school	8/ 40%	7/ 35%	
Secondary modern school	10/ 50%	12/ 60%	
Grammar school	2/ 10%	1/ 5%	

Table II. Clinical parameters.

Groups Parameters	Low degree of morning stiffness (n = 20) mean \pm SD				High degree of morning stiffness (n = 20) mean \pm SD				p-value
Duration of illness (mos.)	82.9 \pm 67.3				130.7 \pm 100.3				0.123
Erythrocyte sediment. rate (ESR/1st hr)	25.9 \pm 20.0				19.3 \pm 13.3				0.279
Rheumatoid factor (U/ml)	34.9 \pm 58.2				34.4 \pm 51.3				0.967
Number of tender joints	5.2 \pm 6.5				9.5 \pm 9.1				0.123
Number of swollen joints	7.2 \pm 6.1				7.8 \pm 6.0				0.724
Ritchie articular index (RAI)	2.6 \pm 3.1				4.8 \pm 4.4				0.112
	Value				Value				
	1	2	3	4	1	2	3	4	
Steinbrocker stage/ X-ray (no. of pts.)	2	11	5	2	4	6	9	1	0.387
Steinbrocker stage/ Function (no. of pts.)	11	6	3	0	7	8	3	2	0.487

Table III. Comparison of patients with high and low degrees of morning stiffness (analysis of covariance with Steinbrocker function and duration of illness as covariates).

Groups	Low degree of morning stiffness (n = 20)	High degree of morning stiffness (n = 20)	p-value
Variables	mean \pm SD	mean \pm SD	
Attractiveness/self confidence	18.7 \pm 3.9	19.0 \pm 3.8	0.871
Accentuation of the external appearance	23.1 \pm 2.9	23.4 \pm 2.8	0.465
Worry about possible physical deficits *	20.9 \pm 2.2	18.9 \pm 2.8	0.029
Problems about sexuality*	12.2 \pm 1.2	11.1 \pm 2.1	0.010
Emphasis on attractiveness	57.0 \pm 8.2	56.4 \pm 8.4	0.550

* p 0.05

arthritis patient questionnaires. While these are very useful for assessing functional disabilities in daily activities, they give relatively little information about the subjective extent of the overall handicap. In extensive interviews with our patients, it became clear that patients employ morning stiffness as a criterion of their overall handicap; problems in specific daily activities are less important for them.

Important components of the body image, especially worries about one's body, are more pronounced in patients experiencing a high degree of morning stiffness than in those with a low degree of morning stiffness. Thus, patients who thought of themselves as being severely handicapped have a greater mistrust regarding their own bodily processes, are made unsure of themselves by their bodies and develop a tendency to pay overmuch attention to their own bodies. Fur-

thermore, a feeling of having inadequate control over one's own body and a lack of faith in its functional ability characterize these patients.

The impression of being severely handicapped goes hand in hand with severe problems in the area of sexuality. Patients with RA feel blocked in their sexuality and have to fight against a sense of shame and dissatisfaction in their sexuality. These results do not appear at first glance to be surprising. Earlier studies have already described sexual problems in patients with RA. However, this was attributed to limitations in mobility of the knee and hip joints (11-13).

Given the results of our questionnaires and interviews, however, this interpretation appears too simplistic. Underlying psychological mechanisms must also be taken into consideration in an analysis of intimate interpersonal problems, as in the case of sexuality. Thus, from

the point of view of social psychology it may be the 'aesthetic barrier' that is the primary cause of sexual problems in the handicapped (14). Individuals whose external appearance is different from that of others appear strange. What the people around us notice is any deviation from the aesthetic norm. Handicapped people feel this implied rejection and attempt, even within their partnership, to appear as normal as possible. The comment by one of our patients is characteristic. She told us that she gets up at 5 o'clock in the morning because she does not want her husband to see her struggling with cutting the bread for breakfast with her crippled, awkward hands. She wants to be important to him, she wants him to look at her as an attractive woman, not as a crippled old person. However, precisely this attempt to conceal one's deficits might hinder the maintenance of a close relationship and this inevitably leads to sexual problems.

In spite of the increased uncertainty and worry about the body and the even greater problem of sexuality associated with such feelings, the two groups did not differ in their feelings regarding their own attractiveness and in their efforts to maintain an attractive appearance. Thus, even severely handicapped persons have some degree of satisfaction with their own bodies and enjoy activities of body care that improve their external appearance.

From these results, what conclusions can be drawn regarding the psychological care of RA patients? Attending rheumatologists should ask patients about their

subjective impression of handicaps in addition to assessing clinical parameters. In our experience, morning stiffness plays a very important role in whether and how severely a patient feels herself to be handicapped, and this parameter does not correlate significantly with clinical parameters such as the Steinbrocker functional stage, the radiographic stage, the ESR, or joint swelling. Our global approach to the evaluation of handicap might capture a different aspect than the arthritis patient questionnaires, where a high correlation was found to clinical parameters (15-17).

Women with a high degree of subjective morning stiffness often have problems concerning their body image and sexuality, but are reluctant to talk about such intimate problems unless encouraged to do so. In a relaxed atmosphere, however, our patients not only talked with unexpected openness about these problems, but did so with an obvious sense of relief.

Attending physicians therefore should not shy away from discussing problems of sexuality and perceptions of one's body, and in the case of severe problems the initiation of psychological therapy should not be delayed. In this case, an integrative psychotherapeutic approach with the following central content appears suitable: patients must be made conscious of their deep-seated fears regarding rejection by their partners, and as a consequence must be encouraged to be open about it with their partners and even to seek their help. A sense of security and the realisation that the handicap will not endanger the partnership can be achieved only when the patient puts her fears to the test and finds them in the fi-

nal analysis to be unfounded. In certain cases, it may be helpful to involve the partner in the therapy process.

Above and beyond this, with the help of techniques of imagination (e.g. 'travels through the body'), patients should be helped to experience their bodies as a source not only of pain but also of pleasant feelings. These mental exercises, however, should be performed during pain-free periods.

The therapeutic approach, it goes without saying, needs to be individually tailored to the patient's needs, within the context of her personal and social deficits as well as resources. This means that the underlying personality structure or possible personality disorder (18), coping abilities (especially with interpersonal stressors) (19), and effective functioning in professional life and leisure time are all factors that must be taken into consideration.

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