## University of Groningen

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Published in:
Clinical Rheumatology

DOI:
10.1007/s10067-006-0216-3

IMPORTANT NOTE: You are advised to consult the publisher's version (publisher's PDF) if you wish to cite from it. Please check the document version below.

Document Version
Publisher's PDF, also known as Version of record

Publication date:
2007

Link to publication in University of Groningen/UMCG research database

Citation for published version (APA):
van Berlo, W. T. M., van de Wiel, H. B. M., Taal, E., Rasker, J. J., Schultz, W. C. M. W., \& van Rijswijk, M. H. (2007). Sexual functioning of people with rheumatoid arthritis: a multicenter study. Clinical Rheumatology, 26(1), 30-38. https://doi.org/10.1007/s10067-006-0216-3

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# Sexual functioning of people with rheumatoid arthritis: a multicenter study 

Received: 23 November 2005 / Revised: 12 January 2006 / Accepted: 12 January 2006 / Published online: 1 March 2006
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#### Abstract

The objective of this study is to compare men and women with rheumatoid arthritis (RA) to controls regarding sexual motivation, activity, satisfaction, and specific sexual problems, and to determine the correlation of physical aspects of the disease with sexual functioning. Questionnaire for screening sexual dysfunctions (QSD), self-constructed questionnaire on experienced distress with joints during sexual activities, arthritis impact measurements scales 2 (AIMS2), and the modified disease activity score 28 (DAS 28) were the methods used. RA patients were recruited from a registration base in three Dutch hospitals. Controls were age and sex matched healthy volunteers. A completed questionnaire was sent back by 271 patients (response $23 \%$ ). Forty-seven men and 93 women were clinically examined to obtain the DAS 28. Male patients felt less sexual desire, and female patients masturbated and fantasized less than controls. Differences in satisfaction were not found. Male and female patients


[^0]did not experience more sexual problems than controls. Among the women, correlations were predominantly found between age and sexual motivation and activities, among the men between physical health and sexual problems. Up to $41 \%$ of the men ( $4-41$ depending on the joints), and up to $51 \%$ of the women (10-51 depending on the joints) have troubles with several joints during sexual activities. Medications influencing ejaculation in men correlated with distress with orgasm. Conclusions are that patients are less sexually active than controls and a considerable number of both male and female patients have trouble with their joints during sexual activities. However, patients do not differ from controls regarding sexual satisfaction. Physiological changes due to RA are apparently independent from those on psychological level. It is argued that sexual satisfaction also depends on personal and social factors. In men, physical health and disease activity are more related with sexual problems than in women.

Keywords Rheumatoid arthritis • Sexual functioning • Sexual problems • Sexual satisfaction

## Introduction

For a variety of reasons, it may be assumed that rheumatoid arthritis (RA) influences sexual functioning. People with RA suffer from pain, restricted joint movements, and fatigue, and they can have problems with self-esteem and body image. It is also possible that medication causes sexual problems. Research on the subject is limited, and shows a divergent picture (see Van Berlo et al. [1] for a literature review.) The percentage of arthritic patients who experience sexual problems ranged in these studies from 31 to $76 \%$ [2-8]. Sexual problems, however, were defined in different ways: from not specified "sexual difficulties" [2] to specific forms of sexual dysfunction. These are therefore made operational in different ways. In most studies, (structured) interviews or self-constructed self-report questionnaires have been used. Moreover, studies differed considerably in method, with only a few using healthy
controls [3, 9-13]. In many studies, the rheumatic diseases were not specified.
In this study, the influence of rheumatoid arthritis on sexual functioning has been investigated. A standardized, validated instrument to measure sexual functioning (see also Quaresma et al. [14]) and a healthy control group were included. Heterosexual and homosexual patients were distinguished.
The aims of the study were:

1) To evaluate sexual motivation, sexual activity, and sexual satisfaction among men and women with rheumatoid arthritis.
2) To establish problems in sexual contact with the partner.
3) To compare sexual functioning of people with RA to the sexual functioning of healthy controls.
4) To determine the influence of the disease on sexual functioning.

## Materials and methods

## Subjects

Patients with RA were recruited from the standard diagnosis registration [15] of the departments of rheumatology in three hospitals: the Medisch Spectrum Twente Hospital in Enschede (a large regional hospital), the university hospital in Groningen, and the Wilhelmina Hospital in Assen (a small hospital serving mainly a rural area). Inclusion criteria for participating were: (1) RA according to the American College of Rheumatology criteria [16] and/or Sjögren's Syndrome [17], (2) age 18 years and older, and (3) sufficient knowledge of the Dutch language to complete a self-report questionnaire. All patients who met the criteria received a form on which they could indicate their willingness to participate. If so, they received a package including all questionnaires by mail. No reminders were sent. All patients were also invited to come to the hospital for a clinical examination by a research nurse.

The control group consisted of a convenience sample of 107 healthy volunteers. They were a subgroup of a larger sample of volunteers, who were recruited using the snowball method among acquaintances of the author of the questionnaire for screening sexual dysfunctions (QSD) (see below) and some other researchers in the Netherlands. The subgroup was selected on the basis of age and sex. Controls were only invited to participate if they did not have a severe disease.

Measures

## Sexual functioning

The short versions of the QSD [18] were used to measure sexual functioning. The QSD is a multidimensional selfreport questionnaire with subscales addressing the fre-
quency of sexual problems and the experienced distress with these problems. Formats for different kinds of sexual relationships are available (i.e., for men and women with a female partner, a male partner, and without a partner). In this study, individual items of the QSD were used to measure the frequency of desire for sexual contact, sexual contact, masturbation, and sexual contact against the will of the respondent. These frequencies are rated on sevenpoint scales ( $1=$ less than once per month, $7=$ several times a day). Subscales were used addressing both frequency and experienced distress of several sexual problems and sexual satisfaction [19]. Responses were rated on five-point scales ( $1=$ almost never, $5=$ always; $1=$ no distress, $5=$ very much distress; $1=$ very dissatisfied, $5=$ very satisfied). The subscale "sexual satisfaction" consists of two items: "How satisfied are you with your current sexual life?" and "How satisfied are you with the sexual contact you have with your partner?" The QSD is widely applied in research and clinical practice in the Netherlands, but not yet in studies on RA [20-24]. Research on the validity of this instrument is available [25].

## Sociodemographics

The QSD also contains information on sociodemographics, i.e., age, marital status, length of relationship, and educational level ( $1=$ primary school, $7=$ university $)$.

## Physical function and pain

Physical function and pain were assessed with the DutchAIMS2 (Arthritis Impact Measurement Scales), a selfreport questionnaire [26, 27]. The AIMS2 includes scales to measure physical function (scales for mobility, walking and bending, hand and finger function, arm function, self-care, and household tasks), and one scale to measure pain. The scores per scale range from 0 (good health) to 10 (poor health). The physical dimension score was computed by averaging the scores of the contributing scales. A selfconstructed questionnaire was used to measure experienced distress with seven joints during sexual activities. The scores range from 1 (very much distress) to 5 (no distress).

## Comorbidity

Comorbidity was also assessed with the AIMS2. Ten comorbidities were listed explicitly to be checked where applicable. Respondents could also check "other comorbidities" and describe these themselves.

## Disease activity

Patients were clinically examined by two research nurses in the hospitals of Groningen and Enschede to assess disease activity. The modified disease activity score (DAS 28) is an
index of disease activity [28, 29]. It includes (1) a joint index of 28 joints evaluated for tenderness and swelling, (2) erythrocyte sedimentation rate (ESR), and (3) general health assessment scored on a visual analogue scale (VAS). The higher the score, the more active the disease.

## Use of medication

In the AIMS2 Questionnaire an extra question was included regarding medication intake. Medications were divided in (1) drugs specifically prescribed for RA or often taken together with RA medication such as H2 blockers, protonpump inhibitors, and antihypertensive drugs, (2) drugs for other indications, and (3) psychopharmaceuta. The effect of these medications on sexual functioning-as far as known from literature-were scored, i.e., the effect on libido, erection, and orgasm/ejaculation with regard to men, and on libido, lubrication and orgasm with regard to women [30, 31].

## Statistical analysis

Data analysis was performed using SPSS-PC software (version 11.0). Analyses included descriptive statistics, chisquare tests, $t$ tests, analysis of variance (ANOVA) with Bonferroni post hoc test, and analysis of covariance (ANCOVA) with educational level as a covariate because controls were significantly higher educated than patients. When variables were not normally distributed, the nonparametric Mann-Whitney $U$ test was performed, as well as Spearman correlations. $p$ values $<0.05$ were considered significant.

Ethics
The ethical committees of the three participating hospitals approved of the study.

## Results

## Response

A total of 1,196 people with RA and/or Sjögren's syndrome were invited to participate in the study by means of a reply form. A completed questionnaire was sent back by 271 patients, 243 with RA and 28 with either Sjögren's syndrome ( $n=3$ ) or Sjögren's syndrome and RA. The response was $23 \%$. The reply form was returned by 261 people with RA who refused to participate in the study, this is $22 \%$ of those invited. Although one needs to be careful in making generalizations, we compared the refusers and nonresponders with those who agreed to participate (Table 1).

There were no differences in sex between the three groups, nor between the participants and those who either refused or did not respond ( $n=925$ ). Among the men, no differences in age were found between the three groups and between the participants and all refusers. Among the women, those who refused were significantly older than the participating women and the nonresponding women, and also, refusing and nonresponding women were significantly older than the participating women. The percentage of patients without a partner was also higher among those who refused.

Twenty-seven women and three men reported not having a partner. Because the number of single men was too small,

Table 1 Response percentages and demographic characteristics of participants, refusers, and nonresponders

|  | Participants ( $n=271$ ) |  | Refusers ${ }^{\text {a }}$ ( $n=261$ ) |  | Nonresponders ${ }^{\text {b }}$ ( $n=664$ ) |  | Refusers and nonresponders ( $n=925$ ) |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | Men $(n=81)$ | $\begin{aligned} & \text { Women } \\ & (n=190) \end{aligned}$ | $\begin{aligned} & \text { Men } \\ & (n=56) \end{aligned}$ | Women $(n=189)$ | $\begin{aligned} & \text { Men } \\ & (n=187) \end{aligned}$ | Women $(n=424)$ | $\begin{aligned} & \text { Men } \\ & (n=243) \end{aligned}$ | $\begin{aligned} & \text { Women } \\ & (n=613) \end{aligned}$ |
| Sex ${ }^{\text {c }}$ (\%) | 30 | 70 | 23 | 77 | 31 | 69 | 28 | 72 |
| $\begin{aligned} & \text { Age } \\ & {[\operatorname{mean}(\mathrm{SD})]^{\mathrm{d}}} \end{aligned}$ | 57.4 (11.3) | 53.6 (12.7) | 59.5 (12.6) | 59.1 (13.3) | 55.9 (12.8) | 55.8 (14.2) | 56.7 (12.8) | 56.8 (14.0) |
| Partner |  |  |  |  |  |  |  |  |
| Male (\%) | - | 84 | - | 78 | unknown | unknown | unknown | unknown |
| Female (\%) | 96 | (1) ${ }^{\text {e }}$ | 74 | - |  |  |  |  |
| No (\%) | 4 | 16 | 26 | 22 |  |  |  |  |

[^1]the data on patients without a partner were omitted. Only one patient, a woman, was homosexual.

Forty-seven men and 93 women agreed to undergo a clinical examination to obtain the DAS28.

In this article we are only reporting on people with RA who have a partner of the opposite sex ( $n=213$ ).

## Sociodemographic and clinical characteristics

There is no statistical difference in age between male patients and controls or between female patients and controls. (Table 2) Male and female controls are significantly higher educated than the male and female patients, respectively.

Although patients with severe comorbidity were not invited to participate, it appeared that $51 \%$ of the patients had some kind of other health problem (as measured with the AIMS2): Twenty-five percent had hypertension, $9 \%$ heart problems, $5 \%$ diabetes, $4 \%$ cancer, $13 \%$ lung disease, $1 \%$ kidney disease, $1 \%$ liver disease, $8 \%$ stomach problems, $1 \%$ blood disease, and $14 \%$ had other health problems.

Patients from the three different hospitals did not differ from each other regarding health status (as measured with the AIMS2) and sexual problems (as measured with the QSD).

## Sexual functioning

## Sexual desire, sexual activity, and satisfaction with sexual life

Male and female patients, more often than controls, did not feel any desire for sexual contact with their partner, did not have sexual contact with their partner, did not masturbate, and did not have sexual daydreams or fantasies. However, female patients and controls did not differ significantly regarding sexual contact with the partner. Both male and female patients also differed significantly from controls
regarding the frequency of sexual activities, desire, and fantasies.

Differences between male patients and controls regarding frequency of sexual fantasies, sexual contact, and masturbation were not significant after correction for education. Among the women, differences between patients and controls were no longer significant regarding frequency of sexual desire and sexual contact. Results are summarized in Table 3.

## Sexual problems

It appeared that patients, both men and women, did not have more sexual problems than controls, and did not experience more distress from these problems (Table 4). On the contrary, when differences were found, controls more often had problems and suffered more from these problems, especially the women. However, both male and female patients had significantly more often pain, and suffered more from this pain, than controls.

## Physical determinants of sexual functioning

Age, duration of disease, disease activity (DAS28), physical function, and pain were considered as physical determinants. It appeared that physical functioning and, to a lesser extent, disease activity and duration of the disease correlated with various sexual problems in men but not in women (Tables 5 and 6). In women, correlations were predominantly found between age and sexual motivation, activity, and fantasies; the older the women, the less motivation and activity.

To explore further on the influence of specific aspects of the disease on sexuality, we asked the patients to what extent they experienced distress with their joints during several sexual activities (Table 7). A considerable number of the patients, especially the women, experienced much to very much distress with their joints during sexual activities.

Table 2 Sociodemographic and clinical characteristics of men and women with RA and healthy controls

|  | Men |  |  | Women |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | $\frac{\text { Patients }(n=76)}{\text { mean (SD) }}$ | $\frac{\text { Controls }(n=54)}{\text { mean (SD) }}$ | $t$ test | $\frac{\text { Patients }(n=136)}{\text { mean (SD) }}$ | $\frac{\text { Controls }(n=53)}{\text { mean (SD) }}$ | $t$ test |
| Age | 57.6 (10.6) | 54.9 (9.4) | n.s. | 52.7 (11.8) | 49.4 (10.8) | n.s. |
| Age partner | 54.6 (11.2) | 50.9 (11.4) | n.s. | 55.2 (11.9) | 50.2 (12.4) | $p<0.05$ |
| Length relationship (in years) | 31.0 (12.2) | 25.8 (14.2) | $p<0.05$ | 28.6 (13.9) | 25.1 (12.5) | n.s. |
| Education (1-7) ${ }^{\text {a }}$ | 3.4 (1.7) | 5.4 (1.9) | $p=0.000$ | 3.3 (1.7) | 5.0 (1.7) | $p=0.000$ |
| Disease duration (in years) | 13.1 (9.8) |  |  | 13.8 (11.1) |  | n.s. |
| Disease activity (DAS28) | 3.50 (1.45) |  |  | 4.25 (1.42) |  | $p<0.01$ |
| Physical function (0-10) ${ }^{\text {b }}$ | 2.08 (1.85) |  |  | 2.39 (1.70) |  | n.s. |
| Pain (0-10) ${ }^{\text {b }}$ | 4.36 (2.21) |  |  | 4.92 (1.99) |  | n.s. |

[^2]Table 3 Sexual motivation, sexual activity, and sexual satisfaction of men and women with RA and healthy controls

|  | Men |  |  | Women |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | $\begin{aligned} & \text { Patients } \\ & \frac{(n=76)}{\%} \end{aligned}$ | $\begin{aligned} & \begin{array}{l} \text { Controls } \\ (n=54) \end{array} \\ & \hline \% \end{aligned}$ | Chi ${ }^{2}$ test | $\begin{aligned} & \text { Patients } \\ & \frac{(n=137)}{\%} \end{aligned}$ | $\begin{aligned} & \text { Controls } \\ & \frac{(n=53)}{\%} \end{aligned}$ | Chi ${ }^{2}$ test |
| Sexual daydreams/fantasies (yes) | 65 | 89 | $p<0.01$ | 37 | 68 | $p=0.000$ |
| Desire for sexual contact with partner (yes) | 85 | 96 | $p<0.05$ | 86 | 96 | $p<0.05$ |
| Sexual contact (yes) | 82 | 94 | $p<0.05$ | 90 | 98 | n.s. |
| Masturbation (yes) | 52 | 79 | $p<0.01$ | 29 | 70 | $p=0.000$ |
| Sexual contact against will (yes) | 1 | 4 | n.s. | 22 | 30 | n.s. |
|  | Mean (SD) | Mean (SD) | $t$ test | Mean (SD) | Mean (SD) | $t$ test |
| Frequency sexual daydreams/fantasies (1-7) | 2.41 (1.51) | 3.06 (1.50) | $p<0.05^{\text {a }}$ | 1.42 (.94) | 1.94 (1.27) | $p<0.01{ }^{\text {b }}$ |
| Frequency desire for sexual contact with partner $(1-7)$ | 3.21 (1.55) | 4.10 (1.40) | $p<0.01$ | 2.89 (1.44) | 3.44 (1.34) | $p<0.05^{\text {a }}$ |
| Frequency sexual contact (1-7) | 2.83 (1.52) | 3.51 (1.26) | $p<0.01^{\text {a }}$ | 3.22 (1.47) | 3.74 (1.38) | $p<0.05^{\text {a }}$ |
| Frequency masturbation (1-7) | 1.84 (1.30) | 2.43 (1.45) | $p<0.05^{\text {a }}$ | 1.24 (0.81) | 1.77 (0.94) | $p=0.000^{\text {b }}$ |
| Frequency sexual contact against will (1-7) | 1.00 (0.00) | 1.00 (0.00) | - | 1.15 (0.62) | 1.08 (0.39) | n.s. ${ }^{\text {b }}$ |
| Sexual satisfaction (1-5) | 3.56 (0.90) | 3.58 (0.81) | n.s. | 3.69 (0.80) | 3.73 (0.93) | n.s. |

${ }^{\text {a }}$ n.s. after correction for education with ANCOVA
${ }^{\mathrm{b}}$ Non-parametrically tested with Mann-Whitney $U$ test, correction for education not possible

Table 4 Differences in sexual problems between patients and healthy controls

|  | Men |  |  | Women |  |  |
| :---: | :---: | :---: | :---: | :---: | :---: | :---: |
|  | Patients $\frac{(n=76)}{\text { Mean (SD) }}$ | Controls $\frac{(n=54)}{\text { Mean (SD) }}$ | Mann-Whitney $U$ test | $\begin{aligned} & \hline \begin{array}{l} \text { Patients } \\ (n=137) \\ \hline \text { Mean (SD) } \end{array} \end{aligned}$ | Controls $\frac{(n=53)}{\text { Mean (SD) }}$ | Mann-Whitney $U$ test |
| Frequency sexual problems ${ }^{\text {a }}$ |  |  |  |  |  |  |
| Erectile problems | 1.50 (0.78) | 1.49 (0.64) | n.s. |  |  |  |
| Lubrication problems |  |  |  | 1.44 (0.80) | 1.67 (0.88) | $p<0.05$ |
| Sexual excitement problems | 1.24 (0.37) | 1.28 (0.37) | n.s. | 1.48 (0.73) | 1.71 (0.78) | $p=0.01$ |
| Orgasm problems | 1.24 (0.48) | 1.29 (0.34) | n.s. | 1.72 (1.01) | 2.03 (1.04) | $p<0.01$ |
| Ejaculation problems | 1.29 (0.62) | 1.26 (0.66) | n.s. |  |  |  |
| Premature orgasm | 1.33 (0.55) | 1.53 (0.50) | $p<0.01$ | 1.17 (0.33) | 1.14 (0.35) | n.s. |
| Genital pain | 1.04 (0.26) | 1.10 (0.36) | n.s. | 1.30 (0.64) | 1.41 (0.64) | n.s. |
| Genital insensitivity | 1.03 (0.14) | 1.12 (0.33) | n.s. | 1.14 (0.46) | 1.25 (0.57) | n.s. |
| Pain elsewhere | 1.61 (0.99) | 1.08 (0.39) | $p=0.000$ | 1.56 (0.95) | 1.09 (0.41) | $p=0.000$ |
| Negative emotions | 1.02 (0.10) | 1.07 (0.17) | n.s. | 1.05 (0.19) | 1.11 (0.26) | $p<0.05$ |
| Experienced distress with sexual problems ${ }^{\text {b }}$ |  |  |  |  |  |  |
| Erectile problems | 1.48 (0.74) | 1.35 (0.58) | n.s. |  |  |  |
| Lubrication problems |  |  |  | 1.41 (0.72) | 1.63 (0.80) | $p<0.05$ |
| Sexual excitement problems | 1.35 (0.58) | 1.26 (0.38) | n.s. | 1.39 (0.62) | 1.66 (0.74) | $p<0.01$ |
| Orgasm problems | 1.29 (0.53) | 1.20 (0.40) | n.s. | 1.50 (0.74) | 1.61 (0.61) | $p<0.05$ |
| Ejaculation problems | 1.29 (0.63) | 1.12 (0.28) | n.s. |  |  |  |
| Premature orgasm | 1.30 (0.59) | 1.41 (0.50) | $p<0.05$ | 1.10 (0.25) | 1.05 (0.18) | n.s. |
| Genital pain | 1.06 (0.29) | 1.15 (0.54) | n.s. | 1.39 (0.74) | 1.47 (0.72) | n.s. |
| Genital insensitivity | 1.03 (0.17) | 1.14 (0.39) | $p<0.05$ | 1.11 (0.32) | 1.20 (0.41) | n.s. |
| Pain elsewhere | 1.58 (0.97) | 1.12 (0.48) | $p=0.000$ | 1.60 (1.02) | 1.09 (0.35) | $p=0.000$ |
| Negative emotions | 1.05 (0.16) | 1.11 (0.23) | $p<0.05$ | 1.09 (0.34) | 1.20 (0.47) | n.s. |

[^3]Table 5 Significant Spearman correlations between physical aspects of the disease, pain and age, and sexual motivation, sexual activity, sexual satisfaction, and sexual problems among men with RA

|  | Age | Duration of disease | Disease activity (DAS28) $(n=47)$ | Physical function (AIMS2) | Pain <br> (AIMS2) |
| :---: | :---: | :---: | :---: | :---: | :---: |
| Sexual motivation, sexual activity, and sexual satisfaction |  |  |  |  |  |
| Frequency desire for sexual contact with partner | -0.30 |  |  |  |  |
| Frequency sexual contact | -0.35 |  |  |  |  |
| Frequency sexual problems |  |  |  |  |  |
| Erectile problems |  |  |  | 0.25* |  |
| Sexual excitement problems |  |  |  | 0.26* |  |
| Orgasm problems |  |  |  | 0.35** |  |
| Ejaculation problems |  | 0.29* | 0.30* | 0.31** |  |
| Pain elsewhere |  |  | 0.30* | 0.47** |  |
| Negative emotions |  |  |  | 0.29* | 0.26* |
| Experienced distress with sexual problems |  |  |  |  |  |
| Erectile problems |  |  |  | 0.36** |  |
| Sexual excitement problems |  |  | 0.38* | 0.35** |  |
| Orgasm problems |  |  | 0.39** | 0.32** |  |
| Ejaculation problems |  | 0.25* |  | 0.34** |  |
| Pain elsewhere |  |  | 0.35* | 0.44** |  |
| Negative emotions |  | 0.28* | 0.33* | 0.36** | 0.27* |

Variables with no significant correlations and nonsignificant correlations are not reported

* $p<0.05$
${ }^{* *} p<0.01$


## Use of medication

Almost all patients (men $97 \%$ and women $96 \%$ ) were taking medication (for RA, other diseases or psychopharmaceuticals), irrespective of possible side effects for sexual
functioning. With regard to the control group, this is unknown.

Of the male patients, $63 \%$ took medication for RA (or medications prescribed for side effects) with a known effect on the libido (e.g., indometacine, cimetidine, diclofenac-

Table 6 Significant Spearman correlations between physical aspects of the disease, pain and age, and sexual motivation, sexual activity, sexual satisfaction, and sexual problems among women with RA
$\left.\begin{array}{lllll}\hline & \text { Age } & \begin{array}{l}\text { Duration of } \\ \text { disease }\end{array} & \begin{array}{l}\text { Disease activity (DAS28) } \\ (n=79)\end{array} & \begin{array}{l}\text { Physical function } \\ \text { (AIMS2) }\end{array}\end{array} \begin{array}{l}\text { Pain } \\ \text { (AIMS2) }\end{array}\right]$

[^4]Table 7 Rather much to very much distress with several joints during sexual activities among men and women with RA

|  | Men <br> $(n=76)(\%)$ | Women <br> $(n=134)(\%)$ |
| :--- | :--- | :--- |
| Caressing the partner |  |  |
| Shoulder | 22 | 31 |
| Elbow | 21 | 16 |
| Wrist/fingers | 29 | 51 |
| Masturbation |  |  |
| Shoulder | 6 | 17 |
| Elbow | 4 | 19 |
| Wrist/fingers | 16 | 44 |
| Intercourse, patient under partner |  |  |
| Shoulder | 15 | 23 |
| Elbow | 7 | 10 |
| Wrist/fingers | 16 | 25 |
| Hip | 14 | 35 |
| Knee | 12 | 28 |
| Ankle/foot | 5 | 18 |
| Neck | 15 | 18 |
| Intercourse, patient on top of partner |  |  |
| Shoulder | 30 | 34 |
| Elbow | 31 | 27 |
| Wrist/fingers | 41 | 44 |
| Hip | 15 | 33 |
| Knee | 32 | 49 |
| Ankle/foot | 20 | 32 |
| Neck | 21 | 24 |
|  |  |  |

misoprostol, naprosyne), $87 \%$ with a known effect on erection (e.g., methotrexate, indometacine, sulphasalazine, hydroxychloroquin), and $54 \%$ with a known effect on ejaculation (e.g., methotrexate, naprosyne).
Among the women with RA, these percentages are quite different. $1.5 \%$ used medication for RA with a known effect on the libido (e.g., cimetidine, medroxyprogesteron), $1.5 \%$ with a known effect on lubrication (e.g., cimetidine), and none of the women used RA medication with a known effect on orgasm. It is important to mention that the influence of medication on the sexual functioning of women has hardly been investigated. Because the number of women who used medication with a known effect is negligible, the data of the women were not explored. With regard to the men, a comparison was made between men who used RA medication with a known effect and those who did not. Differences concerning sexual activities (sexual fantasies, masturbation, desire, and sexual contact) were not found. With regard to frequency of and experienced distress with sexual problems, men who used medication with a known effect on ejaculation experienced indeed more distress with orgasm than men who did not use this medication [means (SD) resp. 1.39 ( 0.58 ) and 1.17 (.44), $p<0.05$ (non-parametrically tested).

## Discussion

People with RA felt less desire for sexual contact with their partner, had less sexual contact, masturbated less frequently, and fantasized less frequently than healthy controls. After correction for education, male patients still felt less sexual desire than controls, and female patients masturbated and fantasized less than female controls. Differences in sexual dysfunctions were hardly found. Regarding frequency of and experienced distress with sexual problems, men and women with RA had even lesser problems than controls. The fact that RA patients do not differ from controls regarding sexual dysfunction may indicate that a high percentage of a healthy population of this age has sexual problems anyway. This, however, does not mean that RA patients do not have problems during sexual activities. A considerable percentage of the patients indicated that they have trouble with their joints during sexual activities.

We noticed a remarkable difference between men and women with RA. Considering the correlations between sexual problems and physical aspects, we see that physical function and disease activity, and to a lesser extent duration of the disease, played a far more conclusive role among the men than among the women. For the women, physical function, disease activity, and duration of the disease did not have an influence on sexual problems whatsoever. However, more women than men had trouble with their joints during several sexual activities. This result may confirm the idea that women generally place a different value on sexuality than men, focusing more on social, cultural, and emotional factors, while men are more focused on their bodies [32, 33]. Another explanation may be that men are supposed to have an active role in sexual activities, and therefore have more physical problems during sex.

Patients and controls did not differ regarding sexual satisfaction, despite the fact that patients appeared to have less sexual desire, were less sexually active, and had considerable distress in the joints during sexual activities.

Physiological changes due to RA are apparently independent from those on a psychological level. This has also been found in other studies regarding the consequences of disease on sexuality [19, 34, 35]. It seems that patients adapt their conceptions when confronted with illness or handicap, and other factors play a role regarding (the satisfaction of) sexual life. Therefore, although direct sequelae of the disease such as pain, fatigue, and stiffness may interfere with sexual functioning (see also Hill et al. [36]), an improved communication within the relationship, better mutual understanding, and other priorities like enjoyment of what is still possible, may compensate the negative effects. In an earlier study, Rasker et al. [37] for example found that a substantial number of people with RA experience an improved relationship. Healthy people weigh such negative and positive factors in their lives as well. Healthy women, for example, attributed negative influences on sexuality to busy jobs, young children, less time in general, and conflicting sexual desire [19]. Thus,
changes in sexual functioning after the onset of a chronic disease do not automatically lead to sexual problems. Whether sexual dissatisfaction occurs will also depend on personal factors, social factors, and the context in which these (negative) changes occur [35, 38, 39].

A few comments on this study must be made. The first concerns the low response. An explanation may be that people with RA are relatively ill and rather old. They may have other priorities than sexuality. The focus of the study on sexuality may have made patients apprehensive. In such cases the questions on sexuality were considered to be too intimate, too detailed, and not relevant for their current situation (see also Klee et al. [40]). They may also have been reluctant to cooperate as they were also invited to participate in a clinical investigation in the hospital. Due to the low response, the results should be regarded with some caution, as one could doubt the representativeness of the sample. However, the results sustain current theoretical notions on the topic of sex and disease [35], and are in line with other studies in this field [19, 41]. Moreover, age and sex of the participating patients did not differ much from nonresponding patients, and are conform to what one would expect (mean age between 55-60 years, proportion male patients about $30 \%$ ). The percentage of patients without a partner was higher among those who refused. This may explain why some did not want to cooperate, as was in fact mentioned on several forms. They judged themselves as inappropriate respondents as they did not have a partner.

The second comment concerns the comparability of the patients and the controls. The two groups differed significantly on the level of education and after correction for education some of the differences between patients and controls regarding frequencies of sexual activities disappeared.

Finally, except motivation, sexual activities and satisfaction, the QSD measures specific sexual dysfunctions, such as problems with arousal and orgasm. It may be questioned whether a standard questionnaire regarding sexual functioning is sufficient to study this aspect in RA patients. A more specific questionnaire aiming at the specific aspects of the disease may give a clearer picture.

Acknowledgements This study is part of a comprehensive study on the influence of RA and Sjögren's Syndrome on sexual functioning. The research is funded by the Dutch League Against Rheumatism (Nationaal Reumafonds). The authors thank all the patients for participating in the study. We are grateful to the participating hospitals for their permission to conduct the study and the rheumatologists for their cooperation, especially Dr. H. Bernelot Moens, Dr. J. Mertens, and Dr. F. Speerstra. We also thank Dr. P. Vennix, J. Vroege, C. van der Put, S. Massaut, and the research nurses and rheumatology nurse practitioners, A. ter Avest, A. Alberda, and W. Lolkema for their contribution.

## References

1. Van Berlo WTM, Vennix P, Rasker JJ, et al (1999) Rheumatic diseases and sexuality: a review of the literature. Rheumatol Eur 28/3:113-117
2. Baldursson H, Brattstrom H (1979) Sexual difficulties and total hip replacement in rheumatoid arthritis. Scand J Rheumatol 8:214
3. Blake DJ, Maisiak R, Koplan A, Alarcon GS, Brown S (1988) Sexual dysfunction among patients with arthritis. Clin Rheumatol 7:50-60
4. Brown GMM, Dare CM, Smith PR, Meyers OL (1987) Important problems identified by patients with chronic arthritis. S Afr Med J 72:126-128
5. Ferguson K, Figley B (1979) Sexuality and rheumatic disease: a prospective study. Sex Disabil 2:130-138
6. Gordon D, Beastall GH, Thomson JA, Sturrock RD (1986) Androgenic status and sexual function in males with rheumatoid arthritis and ankylosing spondylitis. QJM 60:671-679 (New Series)
7. Hill RH, Herstein A, Walters K (1977) Juvenile rheumatoid arthritis: follow-up into adulthood-medical, sexual and social status. Can Med Assoc J 114:790-794
8. Kraaimaat FW, Bakker AH, Janssen E, Bijlsma JW (1996) Intrusiveness of rheumatoid arthritis on sexuality in male and female patients living with a spouse. Arthritis Care Res 9:120-125
9. Blake DJ, Maisiak RS, Brown S, Koplan A (1986) Acceptance by arthritis patients of clinical inquiry into their sexual adjustment. Psychosomatics 27:576-579
10. Blake DJ, Maisiak R, Alarcon GS, Holley HL, Brown S (1987) Sexual quality of life of patients with arthritis compared to arthritis-free controls. J Rheumatol 14:570-576
11. Curry SL, Levine SB, Corty E, Jones PK, Kurit DM (1994) The impact of systemic lupus erythematosus on women's sexual functioning. J Rheumatol 21:2254-2260
12. Elst P, Sybesma T et al (1984) Sexual problems in rheumatoid arthritis and ankylosing spondylitis. Arthritis Rheum 27:217-220
13. Majerovitz SD, Revenson TA (1994) Sexuality and rheumatic disease: the significance of gender. Arthritis Care Res 7:29-34
14. Quaresma MR, Goldsmith CH, Lamont J, Ferraz MB (1997) Assessment of sexual function in patients with rheumatic disorders: a critical appraisal. J Rheumatol 24:1673-1976
15. Miedema HS, Van der Linden SM, Rasker JJ, Valkenburg HA (1998) National database of patients visiting rheumatologists in The Netherlands: the standard diagnosis register of rheumatic diseases. A report and preliminary analysis. Br J Rheumatol 37:555-561
16. Arnett FC, Edworthy SM, Bloch DA et al (1988) The American Rheumatism Association 1987 revised criteria for the classification of rheumatoid arthritis. Arthritis Rheum 31:315-324
17. Vitali C, Bombardieri S, Moutsopoulos HM et al (1993) Preliminary criteria for the classification of Sjoegren's syndrome: results of a prospective concerted action supported by the European Community. Arthritis Rheum 36:340-347
18. Vroege JA (1994) Vragenlijst voor het signaleren van Seksuele Dysfuncties (VSD), 5e versie [Questionnaire for screening Sexual Dysfunctions (QSD), 5th version]. AZU/NISSO, Utrecht, The Netherlands
19. Vroege JA (1995) Vragenlijst voor het signaleren van seksuele dysfuncties (VSD). Codeboek 5de versie. [Questionnaire for screening sexual dysfunctions (QSD). Codebook 5th version]. AZU/NISSO, Utrecht, The Netherlands
20. Kylstra WA, Leenhouts GHMW, Everaerd W et al (1999) Sexual outcomes following treatment for early stage gynecological cancer: a prospective multicenter study. Int J Gynecol Cancer 9:387-395
21. Van Lankveld JJ, Weijenborg Pt, Ter Kuile MM (1996) Psychologic profiles of and sexual function in women with vulvar vestibulitis and their partners. Obstet Gynecol 88:65-70
22. Lottman PEM, Jongen PJH, Rosier PFWM et al (1998) Sexual dysfunction in men with multiple sclerosis-a comprehensive pilot study into etiology. Int J Impot Res 10:233-237
23. Vroege JA, Zeijlemaker BYM, Scheers MM (1998) Sexual functioning of adult patients born with meningomyelocele. Eur Urol 34: 25-29
24. Van Minnen A, Kampman M (2000) The interaction between anxiety and sexual functioning: a controlled study of sexual functioning in women with anxiety disorders. Sex Relationship Ther 15:47-57
25. Vroege JA (1996) Vragenlijst voor het signaleren van Seksuele Dysfuncties (VSD). $4^{\text {de }}$ versie: Validatiestudies. [Questionnaire for screening Sexual Dysfunctions (QSD). 4th version: validation studies]. Leiden: Rijks Universiteit/Utrecht: AZU
26. Riemsma RP, Taal E, Rasker JJ, Houtman PM, Van Paassen HC, Wiegman O (1996) Evaluation of a dutch version of the AIMS2 for patients with rheumatoid arthritis. Br J Rheumatol 35:755-760
27. Evers AWM, Taal E, Kraaimaat FW et al A comparison of two recently developed health status instruments for patients with arthritis: Dutch AIMS2 and IRGL. Br J Rheumatol 37:157-164
28. Prevoo MLL, Van 't Hof MA, Kuper HH, Van Leeuwen MA, Van de Putte LBA, Van Riel PLCM (1995) Modified disease activity scores that include twenty-eight-joint counts. Development and validation in a prospective longitudinal study of patients with rheumatoid arthritis. Arthritis Rheum 38:44-48
29. Fuchs HA, Brooks RH, Callahan LF, Pincus T (1989) A simplified twenty-eight-joint quantitative articular index in rheumatoid arthritis. Arthritis Rheum 32:531-537
30. Maurice WL (1999) Sexual medicine in primary care. Mosby, St. Louis, MO
31. Van de Wiel H, Weijmar Schultz WCM, W Houvast (1993) Over seksualiteit en handicap [To hold on to. On sexuality and handicap]. Boom, Meppel, The Netherlands
32. Vennix P (1989) Seks en sekse. Verschillen in betekenisgeving tussen vrouwen en mannen (Sex and gender. Differences in sexual values between men and women). Eburon, Delft, The Netherlands
33. Baumeister RF (2000) Gender differences in erotic plasticity: the female sex drive as socially flexible and responsive. Psychol Bull 126:347-374
34. Van Basten JPA, Jonker-Pool G, Van Driel MF, Sleijfer D Th, Van de Wiel HBM, Hoekstra HJ (1995) The sexual sequelae of testicular cancer. Cancer Treat Rev 21:479-495
35. Weijmar Schultz WCM, Van de Wiel HBM (2003) Sexuality, intimacy and gynecological cancer. J Sex Marital Ther 29: 121-128
36. Hill J, Bird H, Thorpe R (2003) Effects of rheumatoid arthritis on sexual activity and relationships. Rheumatology 42:280-286
37. Rasker JJ, Bronner AE, Verzijden D (1984) Reuma hebben. Wat het betekent reumatoïde arthritis patiënt te zijn [To have rheuma. What it means to be a rheumatoid arthritis patient]. Lederle Nederland (the Netherlands), Etten Leur, The Netherlands
38. Simon W, Gagnon JH (1986) Sexual scripts: permanence and change. Arch Sex Behav 15:97-120
39. Cornelissen PGJ, Rasker JJ, Valkenburg HA (1988) The arthritis sufferer and the community: a comparison of arthritis sufferers in rural and urban areas. Ann Rheum Dis 47:150-156
40. Klee M, Groenevold M, Machin D (1997) Quality of life of Danish women: population based norms for the EORT QLQC30. Qual Life Res 6:27-34
41. Weijmar Schultz WCM, Van de Wiel HBM, Bouma J, Janssens J (1990) Evolvement of psychosexual functioning after treatment for cancer of the vulva: a prospective study. Cancer 66:402-407

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[^1]:    ${ }^{\text {a }}$ Sixteen refusers did not indicate their gender
    ${ }^{\mathrm{b}}$ We do not know how many of the nonresponders had RA and how many Sjögren's syndrome, and also how many of them had a partner. From 53 individuals we did not know the gender. No data are available about the mean age of the patients from Assen who did not respond; the mean age mentioned is from patients from the other two hospitals
    ${ }^{\text {c }}$ Differences in sex between the groups were tested with chi ${ }^{2}$ tests, and were not significant
    ${ }^{\mathrm{d}}$ Differences in age were tested with ANOVA and the Bonferroni post hoc test. Differences between the men in the three groups were not significant. Women in the refusing group were significantly older than the women in the response group ( $p=0.000$ ) and the women in the nonresponse group ( $p<0.05$ ). When refusers and nonresponders were taken together and compared with the participants, differences in sex were also not found. Differences in age among the men were also not found; nonresponding and refusing women were significantly older than the participating women ( $p<0.01$ )
    ${ }^{\text {e }}$ Only one female patient reported to have a homosexual relationship

[^2]:    ${ }^{\mathrm{a}} 1=$ elementary school, $7=$ university
    ${ }^{\mathrm{b}} 0=$ good health, $10=$ poor health

[^3]:    ${ }^{\text {a }} 1=$ almost never; 5 = always
    ${ }^{\mathrm{b}} 1=$ no distress; $5=$ very much distress

[^4]:    Variables with no significant correlations and nonsignificant correlations are not reported

    * $p<0.05$
    ${ }^{* *} p<0.01$

