

Effects of rheumatoid arthritis on sexual activity and relationships

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Objectives. The primary aim of this research was to assess patients' perceptions of the effects of rheumatoid arthritis (RA) on their sexual relationship and sexual activity, the causes of any difficulties and who they would turn to for help.

Methods. A self-report questionnaire was distributed to 74 patients attending a regional rheumatology clinic and returned by prepaid post. Fifty-nine questionnaires were returned (response rate 80%) and 57 of them were usable.

Results. Thirty-five per cent of the cohort thought that their disease strained their relationship with their partner, and reasons for this included curtailment of daily and social activities, changes in the balance of the relationship, emotional changes and changed financial circumstances. Over half (56%) of the patients found that their arthritis placed limitations on sexual intercourse and the principal reasons cited were fatigue and pain. Sexual ability was important to 58% of the sample and ageing had a negative impact on its importance ($P < 0.005$). Poor communication was a major problem, patients being reluctant to approach health professionals and vice versa. The topic of sexual relationships was broached with patients attending one nurse practitioner's clinic, but only one other patient had ever been offered any discussion. Thirty-nine per cent of the cohort would consider talking to someone if they had a problem and the nurse and the doctor were the professionals most often chosen.

Conclusion. RA impacts on the sexual lives of a large minority of patients and this is a problem that patients and health professionals are reluctant to discuss face to face. However, patients do appear to be willing to complete questionnaires and this may be an acceptable format for assessment. Further training and support is needed by nurses and other health professionals in this sadly neglected area.

The reality of living with illness impacts on the sexuality of many patients [1]. This is particularly so with a disease such as rheumatoid arthritis (RA) as it is a chronic, systemic, inflammatory condition that is both painful and potentially physically disabling. RA can affect almost every domain of life, including relationships and sexual function. Nurses often play a central role in the care of rheumatology patients, providing holistic care, but sexuality remains an area that many feel unable to discuss [2, 3]. This is unfortunate, as sexuality is an important aspect of the lives of the majority of people.

Sexuality has been described as an essential part of the whole person, an integral part of being human, including one's total sense of self [4], and is linked to the quality of life of the individual [5]. Sexuality is a complex aspect of human life, comprising much more than the act of sexual intercourse [4]. In 1936 Freud described the distinction between sex and sexuality thus: 'sex is something we do, sexuality is something we are' [6]. Sexual expression has been cited as a crucial part of an individual's self-identity, and so is important in all stages of health and illness [7]. It is therefore imperative that nurses raise the

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subject of sexuality with their patients and it has been suggested that all practising nurses should reflect on whether they are addressing this topic adequately [1, 8].

There is an abundance of research into the effects on sexuality of chronic diseases such as diabetes and renal disease [9], but there is relatively little pertaining to sexuality and RA. This is surprising, as RA affects 1–2% of the UK population, all races and social classes, and the most common age of onset is between 30 and 50 yr [10], when humans are sexually active.

The research to date suggests that some patients experience problems within relationships and this occurs more frequently if the disease presents within an established relationship [11, 12]. Some studies have focused on the frequency of sexual intercourse and satisfaction with it. One early study demonstrated a lower frequency of sexual intercourse, orgasm and decreased sexual desire in females following the onset of RA [13]. These results were not entirely substantiated by two later controlled studies that found no difference in the frequency of intercourse between patients with RA and healthy controls [14, 15]. The study by Elst *et al.* [14] showed similar experiences in both cohorts in the intensity of orgasm, whilst Blake *et al.* [15] reported equal levels of satisfaction with sexual activity in both their experimental and their control group. Other authors have reported similar findings [16].

There has been some research into the effects of the symptoms of RA on patients' sexual lives. Loss of physical function, fatigue and pain have been shown to interfere with sexual pleasure [14, 17]. The former study [14] reported that patients with RA preferred shortened foreplay and time to reach orgasm because of increased pain. The higher the level of pain, physical disability and depression, the greater the effect on sexuality, regardless of gender [9].

Anecdotal evidence from patients and partners attending a nurse-led rheumatology clinic, from patients on a rheumatology ward and discussion with nurses at national meetings suggests that RA impacts on sexual relationships and activity and that this topic warrants further investigation. The aims of this study were to investigate the patients' perceptions of (i) the effects of RA on their sexual relationship; (ii) the effects of RA on sexual activity; (iii) the causes of any difficulties; and (iv) which health professionals patients consider to be appropriate confidant(s).

Patients and method

Patients

Pilot study. A modified version of an existing questionnaire was piloted on 10 randomly selected patients with RA attending two consecutive rheumatology out-patient clinics at the large northern teaching hospital where the major study was to take place.

Main study. The final questionnaire was distributed via a rheumatology nurse practitioner or junior hospital doctors' clinic to 74 patients with RA who were participating in a study of outcome. The inclusion criteria admitted any

patient over 18 yr of age with a positive diagnosis of RA. Patients were enrolled consecutively into the study and then allocated randomly to the nursing or medical clinic by a computer-generated code.

Method

A self-administered questionnaire was used as such questionnaires allow patients the option of anonymity, a large sample can be obtained relatively quickly, analysis is quick and interviewer bias is eliminated.

The literature search revealed a questionnaire specifically developed for use with patients who have arthritis [17]. It consists of 11 closed-ended questions with yes/no replies, and four of these had additional space for comment. Scrutiny of the tool by researchers and patients revealed that additional questions and alterations to the language were required and so permission for these changes was obtained. The revised questionnaire was a mixture of open- and closed-ended questions and a Likert scale, and comprised five domains: patient-partner relationship; sexual relationship and sexual activity; impact of disease symptoms; impact of drug therapy; and communication.

An independent assessor distributed the questionnaire in the out-patient clinic. Patients were informed about the content and asked to complete it at home and return it in a prepaid envelope; none refused. Patients were assured of anonymity and advised not to include their name if they did not wish to be identified. Thirteen (22%) chose this option.

Analysis

The questionnaire was a combination of closed- and open-ended items and results were interpreted using both descriptive statistics and content analysis, as described by Polit and Hungler [18]. Two independent analysts scrutinized the handwritten replies several times and each constructed a list of words and themes. The lists were then compared for words and themes common to both, and these were then categorized. The themes that emerged from the data were illustrated with patient quotations.

Results

Pilot study

Demographic data from the pilot study are shown in Table 1. Patients were asked to complete the questionnaire and then interviewed by a researcher, who asked about its readability, face validity, comprehensiveness and ease of completion. None thought the questionnaire was too embarrassing to complete or suggested that any additional items should be included. All 10 patients found it easy to read and physically easy to complete and so this was considered to be a suitable version for use (Appendix 1).

Main study

Questionnaires were returned by 59 (80%) patients; two were left blank, leaving 57 usable. Some patients had not answered all questions.

Forty seven individuals (82%) of the cohort were female (Table 1), so that females were slightly over-represented compared with the expectation for an RA population.

TABLE 1. Demographic data

Sex	<i>n</i>	Age: median (range) (yr)	Disease duration: median (range) (yr)	Single	Married	Divorced	Widowed
Pilot study							
Female	7	61 (50–74)	20 (5–40)	0	4	1	2
Male	3	60 (41–64)	17 (9–25)	0	3	0	0
Main study							
Female	47	58 (36–75)	18 (3–40)	5	33	3	6
Male	10	60 (38–76)	17 (5–35)	0	8	1	1

Patient-partner relationship. Eleven of the 57 (19%) patients who answered the question ‘Do you think your arthritis has put a strain on your relationship with your partner?’ stated that this question was not applicable. Of the remaining 46 patients, 30 (65%) did not believe that their disease exerted any undue strain on their relationship but 16 (35%) did. A number of patients blamed themselves for any problems. A typical reply came from a 40-yr-old man who had been married for 17 yr and had had RA for 12 yr. He wrote:

‘To some extent. The problem is on my side really. Feel guilty about not being able to pull my weight etc.’

The comments by patients about causes of strain fell broadly into four categories: curtailment of activities; changes in the balance of the relationship; emotional change; and financial changes.

Curtailments of activities were generally caused by the symptoms of the disease and many patients highlighted the symptoms as being the underlying stressor. One 58-yr-old female wrote:

‘Unable to share in walking—something we always like to do. Fatigue a problem.’

A comment from a 36-yr-old female who has been married for 10 yr and has had RA for 3 yr:

‘I don’t think he ever really understands the fatigue, pain and probably depression that I was suffering. Although he was supportive.’

Changes in the balance of the relationship tended to be implied. For instance, a 48-yr-old male wrote:

‘My partner has to care for me when I have a flare up. She probably feels more for me than I do.’

Many patients mentioned that they or their partner had become ‘short tempered’ and ‘lacked patience’ and this strained the relationship. Again, this was caused by the symptoms of the disease. This is summed up by a 58-yr-old female in the following way:

‘Yes (it causes strain), if the pain is awful and you take it out not intentionally on the one you love and then regret your outburst.’

A 62-yr-old divorced man and a 58-yr-old female alluded to the strain produced by reduced earnings. She wrote:

‘My husband gave up a good business to look after me. Also I am not as cheerful as I was. Sometimes get very depressed, get fed up with pain.’

Only one woman remained singularly positive about the strain on her relationship with her partner. She was a 45-yr-old, married for over 20 yr, and had been diagnosed 16 yr ago. She wrote:

‘He always has to look after me or consider my ability to do certain things. I don’t think this has a significant effect but probably strengthened our relationship.’

Sexual relationship and activity. Alterations to sexual relationships were not applicable to 14/56 (25%) who answered this question and one patient did not know. Twenty three (56%) of the 41 remaining did not believe that RA had changed their relationship with their partner in any way, and 18 (44%) did. Reasons cited were pain, fatigue, dry vagina, difficulty with comfortable positioning, reduced interest and lack of spontaneity. One patient stated that age makes the sexual relationship unimportant, one thought it the least of her problems, and one patient had a partner who also had arthritis which made the physical relationship impossible. One 55-yr-old female believed that her RA was the underlying reason for her divorce.

Patients were asked ‘Does your arthritis limit sexual intercourse in any way?’ This question was inapplicable to 15 (27%) of the cohort. Of the remainder, 23/41 (56%) did not think that their RA had an impact, but 18/41 (44%) thought that it had. The symptom-related reasons for this were pain ($n=11$), difficulty with positioning ($n=7$), fatigue ($n=5$), flares ($n=1$), and one patient simply felt too ill.

The importance of sexual ability was assessed by a single question, and responses were graded as ‘not important’, ‘of little importance’, ‘important’ and ‘very

important'. Fifty patients completed this question. The majority considered sexual ability to be important or very important, 23 (46%) classing it as important and six (12%) as very important. One 36-yr-old female who had been married for 10 yr wrote:

'As a young woman sex plays a big part in my relationship with my husband. I think it is an important part of my general good feeling/well being.'

A 49-yr-old female who had been diagnosed 20 yr ago stated:

'My husband and I have been married for 30 yr and we have always had a loving sexual relationship. He is not over demanding which is most probably a good thing but I do believe it is important, with all my problems to still have a normal sex life.'

Another 63-yr-old female who rated sexual ability as being important stated:

'Sometimes I am so tired and in pain that sex is the last thing I think about. A cuddle is just as nice.'

Conversely, sexual ability was of little importance to five (10%) patients, and of no importance to 16 (32%). A 53-yr-old female married for 30 yr and who had had RA for over 20 yr wrote:

'My husband and I have never had a relationship that relied solely on the sexual side. Over the years we made love when we wanted to. He is a sensitive person and always seemed to know when an appropriate time was. Neither of us has ever had a strong sexual desire and it is not something we miss.'

The median age of the patients to whom sexual ability had no importance was 68.5 yr (range 53–76). This was considerably older than those to whom it was of little importance (median 49 yr; range 42–67), important (median 51 yr; range 38–63) or very important (median 50 yr; range 36–66). The Mann–Whitney *U*-test showed these differences to be significant ($P < 0.005$).

Impact of disease symptoms. The majority of patients experienced the physical symptoms of RA (Fig. 1). Forty-five patients answered the question that asked if specific symptoms affected their ability to make love. Of these, six ticked 'not applicable'. Of the remaining 39, 23 (59%) thought it did and 16 (41%) answered 'no'. Fatigue was the most frequently cited problem, followed by pain and reduced function (Fig. 2).

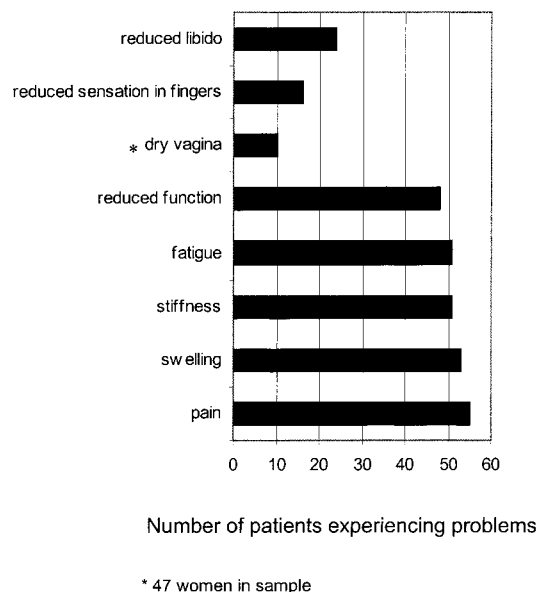


FIG. 1. Demographic data.

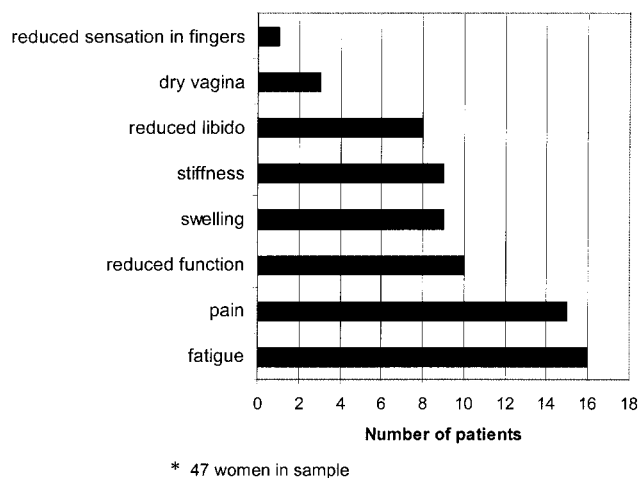


FIG. 2. Symptoms affecting the ability to make love.

One female who had reduced libido wrote:

'Not sure if this is the arthritis or just being 47!!'

The problems encountered were summed up poignantly by a 49-yr-old married female in the following way:

'I have no interest in physical satisfaction because my body is a source of pain, discomfort and limitation rather than pleasure.'

Impact of drug therapy. Patients with RA may be prescribed a number of different categories of drugs for their disease. Some disease-modifying drugs are known to affect fertility, for instance sulphasalazine, and a study has also indicated that non-steroidal

anti-inflammatory drugs may sometimes be associated with infertility, but this requires further long-term research [19]. A number of other commonly prescribed drugs, such as methotrexate, azathioprine and cyclophosphamide, are known to be teratogenic [20]. However, few of the drugs used in the treatment of RA are known to affect libido and patients in this study were well informed of this. Of the three (1%) patients who cited drugs as causing sexual problems, one thought that all her drugs were implicated, one cited methotrexate and one dothiepin. One patient stated that her husband was taking a hypotensive drug and she rightly believed that this impaired his sexual ability.

Communication. Twenty couples (35%) discussed the effect that arthritis had on their sexual relationship and 19 (33%) did not. This question was not thought applicable by 18 (32%). A question regarding the partner's comprehension of any sexual difficulties caused by RA showed that only four patients thought that their partner lacked understanding.

Research in other specialities shows professional-patient communication about sexuality to be a taboo topic. As expected, the majority of patients, 37 (66%), had never been asked by any health professional about the impact of RA on their sexual lives. Of the 19 (34%) who said the topic had been raised, 18 (95%) had been asked by the same rheumatology nurse practitioner. Eight (14%) patients who were experiencing problems had previously raised their concerns with at least one other person, in five instances with friends or relatives. Only three patients had consulted a health professional (a doctor, a nurse and an occupational therapist).

Of the 49 patients who answered the question about talking to someone if they had a problem, 19 (39%) said they would do so, but the majority, 29 (59%), said they would not. One patient was not sure. When asked to say who they would approach with their concerns, many gave multiple answers, and the nurse and the doctor was the person chosen most often (Table 2). Two patients stated that if they had a problem they would choose to see any trained professional and two said they would consult anyone. This was summed up by a 36-yr-old female who had been married for 10 yr:

'Probably a friend. I think it would be very useful to have the opportunity to discuss things with a trained professional.'

Discussion

This research produced an 80% response rate, much higher than the 40–60% normally expected from postal questionnaires [21]. This may be due to the patients' goodwill and their wish to please the department that manages their disease. Whatever the reason, such a large response demonstrates that the majority of patients are willing to complete and return questionnaires concerning their sexuality. In this study only two patients who returned the questionnaire found it embarrassing. One 48-yr-old male patient wanted more of the same and wrote on the back of his questionnaire:

'As my partner has diabetes I would welcome a similar survey directed at people who suffer from it.'

Additionally, the majority of patients, 44 (77%), did not choose to remain anonymous, giving added weight to the acceptability of sexual questionnaires.

This study has highlighted the problems with communication. Many patients are reluctant to raise sexual issues themselves; only 39% of this cohort believed they could do this. Unfortunately, health professionals also appear reluctant to raise the topic. The majority of patients in this study had had RA for many years and had consulted many members of the multidisciplinary team but prior to seeing a nurse practitioner only one had ever been asked if their disease had caused them any sexual problems. Although the literature indicates that nurses are not proactive in discussing sexuality [22], in this research the rheumatology nurse practitioner had asked 18 patients if they had problems. Had she not been in post, it is probable that only one of the cohort would have had the opportunity for discussion. There are many possible reasons for this void in care and some of these are set out in a Royal College of Nursing publication discussion and guidance document [23]. They include poor training or education in sexuality and sexual health; lack of relevant experience; religious or personal views; the belief that the topic is not important or appropriate; and embarrassment.

The results from this research broadly support the findings of other authors [9, 13, 14, 17], that RA does affect patient-partner relationships and sexual activity in a large minority of patients. An additional finding in this cohort is that ageing does appear to have an impact on the importance the patient places on sexual ability. The study also demonstrates that a large minority (35%) of patients believed that RA is an additional stressor in relationships and all but one viewed this negatively. Just over half (56%) of the respondents found that their arthritis limited sexual intercourse and this limitation was in general symptom-related, fatigue, pain and reduced joint function being the primary culprits.

TABLE 2. Patients' preferred confidant(e)

Confidant(e)	
Doctor	12
Nurse	13
Physiotherapist	1
Occupational therapist	3
Relative	4
Friend	7
Agency such as SPOD ^a	0
Other	4

^aSPOD, Sexual Problems of the Disabled.

Many of the patients' problems were related to symptoms, and if the symptoms were better controlled this could lead to an improvement in the patients' sexual relationships and activity.

In summary, RA does impact on the relationships and sexual activities of a large minority of patients, and if nurses are to provide truly holistic care it is a topic that they need to address. This coincides with the discussion and guidance document produced by the Royal College of Nursing [23], which states 'Nurses need to recognise that sexuality and sexual health is an appropriate and legitimate area of nursing activity, and that they have a professional and clinical responsibility to address it'. However, before nurses undertake this responsibility they must be competent. This means that further training and support need to be available to ensure that nurses are able to develop their professional competence. Guidance for nursing staff in this important area has recently been published [8].

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Appendix 1 Sexuality Questionnaire

Self-completed questionnaire used in the study

-
- Do you think your arthritis has put a strain on your relationship with your partner?
If yes can you say how? Not applicable/Yes/No
 - Do you think your arthritis has altered your sexual relationship in any way?
If yes can you say how? Not applicable/Yes/No
 - Does your arthritis limit sexual intercourse in any way?
If yes can you say how? Not applicable/Yes/No
 - How important to you is your sexual ability?
Can you explain a little more? Not important/of little importance/important/very important
 - Do you have any of these problems?
a) Pain in your joints or muscles Yes/No
b) Swollen joints Yes/No

- | | |
|--------------------------------------|-----------------------|
| c) Joint stiffness | Yes/No |
| d) Fatigue | Yes/No |
| e) Reduced joint function | Yes/No |
| f) Dryness of the vagina | Not applicable/Yes/No |
| g) Loss of sensation in your fingers | Yes/No |
| h) Reduced sexual drive | Yes/No |
6. Do any of the above problems affect your ability to make love?
 If yes please state which by writing the appropriate letter, for example a, g
7. Do you and your partner ever discuss the effect your arthritis has on your sexual relationship?
 Not applicable/Yes/No
8. Does your partner understand any difficulties your arthritis causes with your sexual relationship?
 Not applicable/Yes/No
9. Do you think that any of the drugs you take for your arthritis affect your sexual ability?
 If yes say which:
 Not applicable/Yes/No
10. Has any health professional ever asked if your arthritis has affected your sexual life?
 If yes, please state who:
 Yes/No
11. Have you ever approached anyone to discuss any problems that you have experienced with your sexual life?
 If yes was it a:
 Doctor Yes/No
 Nurse Yes/No
 Physiotherapist Yes/No
 Occupational therapist Yes/No
 Relative Yes/No
 Friend Yes/No
 Agency such as SPOD Yes/No
 Other Yes/No
 If other please say who:
12. If you had any problems would you consider talking to any of the above people for help?
 If yes please state who:
 Yes/No

THANK YOU FOR TAKING THE TIME TO COMPLETE THIS QUESTIONNAIRE
