Sexuality and Rheumatic Disease: A Prospective Study

Kristi Ferguson, A.C.S.W.
Barbara Figley, R.P.T., M.A.

ABSTRACT: A prospective study of 70 women and 30 men admitted to the University of Michigan Arthritis Center Adult Inpatient Unit was undertaken to document the incidence of specific sexual problems and to learn from individuals who were not having difficulty. Pain secondary to disease was the most significant factor for both women and men. Interventions were attempted, and long term follow up is planned.

INTRODUCTION

In recent years the recognition that sexuality is a legitimate health concern has gained widespread acceptance. Studies have documented the need for sex education and counseling in a wide variety of disabilities, including for example, spinal cord injury,[1] diabetes,[2] breast cancer,[3] and renal disease.[4] In the field of rheumatology, however, there is little information available other than isolated case examples or general surveys. In 1973 Lachniet and Onder[5] studied four women with arthritis and documented common problems as well as potential solutions. Two textbooks in rheumatology, one by Ehrlich[6] and the other by Katz[7] have devoted specific chapters to sexuality, and both authors reiterate that the available information is largely anecdotal.

Kristi Ferguson is the Program Leader for Social Work, and Barbara Figley is the Program Leader for Physical Therapy, at the University of Michigan Arthritis Center. Reprint requests should be directed to Ms. Ferguson, University Hospital, Room F4337, 1405 East Ann Street, Ann Arbor, Michigan 48109. This study was supported by a grant from the National Institutes of Health (AM 20557). The authors would like to thank Drs. Giles Bole and Donald R. Kay of the Arthritis Center, and Dr. Theodore M. Cole of the Department of Physical Medicine and Rehabilitation, for their suggestions and support.

0146-1044/79/1400-0130 $00.95 © 1979 Human Sciences Press

Objectives:

In response to the need for further information regarding the sexual problems of individuals with rheumatic disease, a prospective study of 100 patients was initiated with the following objectives: a) to document the incidence of specific sexual problems in rheumatic diseases; b) to learn from individuals who were able to maintain intimate relationships even though they had physical limitations; c) to develop and test interventions, and d) to use the information obtained to educate physicians and health professionals about sexual concerns of individuals with rheumatic diseases.

Rheumatoid arthritis, the most common disease in this study, affects women more than men in a ratio of 3:1, and the age of onset is most often between 20 and 40 years of age. It is an inflammatory systemic disease which can cause pain in many joints of the body. Persons affected by RA can have mood changes associated with changes in the activity of the disease (called a "flare" when the disease is active, a "remission" when it is inactive) with resultant changes in the level of pain and functional capacity. Some individuals with RA have significant joint deformity.

The next most common disease in this study is systemic lupus erythematosus. SLE is a multisystem disease, and one of its symptoms is arthritis, although the arthritis is generally not deforming. Lupus is commonly treated with corticosteroid drugs which often cause changes in physical appearance, especially in the face and trunk, as well as emotional lability. Lupus also is characterized by flares and remissions. Adjusting to changes in physical appearance from steroids is added to adjustments in disease activity for many individuals with lupus and some with RA.

Scleroderma or progressive systemic sclerosis is a connective tissue disease which often results in tightening of the skin in many parts of the body and decreased vaginal lubrication. Facial skin changes can alter an individual's appearance, and skin tightening over the extremities often leads to decreased joint mobility.

METHODS

One hundred individuals admitted to the University of Michigan Arthritis Center Adult Inpatient Unit (see Table 1 for description of sample) were screened for current sexual problems at admission as part of a comprehensive allied health assessment. This assessment is a 20 minute interview by either a nurse, occupational therapist, or social worker. The specific questions relative to sexuality were: "Has illness caused a change in your sexual functioning?" and "Is that a concern for you?"

A protocol for the study of sexuality in rheumatic disease patients was established based on review of available literature and clinical experience (Table 2). Included

TABLE 1

Patient Sample

	Women N=70	Men N=30
Rheumatoid arthritis	25	11
Systemic Lupus erythematosus	12	3
Scleroderma	7	0
Other connective tissue diseases	16	14
Other diseases	8	2
Juvenile rheumatoid arthritis	2	0

was a list of ten potential problems, the information necessary to assess each problem, and possible interventions. For the purpose of this project, detailed sex histories were not believed to be necessary.

RESULTS

Of the 70 women interviewed, 39 percent reported no change in sexual functioning as a result of rheumatic disease. Seven per cent reported a change in function but did not identify it as a concern, while 54 percent reported concerns which were addressed during hospitalization. Of the 30 men interviewed, 33 percent reported no change in sexual functioning, 10 percent reported a change but were not concerned, and 56 percent reported concerns which were addressed during hospitalization.

Table 3 summarizes the relative incidence of problems listed in the protocol. The percentages described represent the percent incidence of those reporting problems, not the total sample. Since 38 out of 70 women reported problems, the 13 who reported pain as an interfering factor in sexual activity, for example, represent 34 percent of those women reporting problems and 18 percent of all of the women in the study.

As expected, pain was the most prevalent problem for both men and women. Lack of interest was the second most significant problem for men, while problems with a partner was second for women. Even though the literature suggests that limited range of motion is a major impediment to sexual activity,[2,3] in this study other factors were more important.

In order to examine the relationship of age to reporting of sexual problems, a percentage was calculated by dividing the number of women or men reporting problems by the total number of women or men in a given age group. Totals were calculated by combining the women and men into one group (see Table 4). In the younger age group (18-25), six of the seven women with problems were single and were either interested in new ways of

TABLE 2

Sexual Counseling Protocol

	Problem	Assessment	Intervention
1.	Pain or weakness	Specify cause, location and nature	Recommend measures to relieve or minimize, i.e., position, warm bath, medication
2.	Fatigue	Time of day, cause, nature	Pacing, scheduling, establishing priorities
3.	Lack of interest	Determine influencing factors, i.e. medication, disease activity, depression	Educate to promote understanding of the effect of pain, fatigue, and disease activity on interest
4.	Limited range of motion	Define functional limitations	Suggestions on positioning alternate forms of expression
5.	Lack of lubrication	Determine cause	Suggest psychological or physical measures as indicated
6.	Erectile difficulties	Determine contributing factors, i.e. medical or psychological	Considering altering medications if possible, appropriate counseling measures
7.	Fear of pregnancy, interfering medical problems (e.g. vaginal or penile ulcers, urinary tract infection)	Refer to physician or nurse to determine appropriate medical intervention, assess implications for individual and/or partner	Recommend appropriate medical measures; provide counseling regarding impact of decisions
8.	Feelings of unattractiveness	Determine if perception by self, partner and/or others	Promote positive body image and acceptance of body, enhance feelings of self worth
9.	Problems with partner	Assess cause, e.g. fear of causing pain, partner's disinterest, responsibility for satisfaction, sexual roles, general relationship problems	Education and counseling as appropriate
10.	Lack of partner	Evaluate possibilities for meeting other people, individual's own response	Discuss self-pleasuring affirmation of self, encourage social contacts

TABLE 3

Incidence of Specific Problems in the Intervention Group

Problem	Women N=38	Men N=17	Total N=55
1. Pain or weakness	13 (34%)	10 (59%)	23 (42%)
2. Fatigue	7 (18%)	5 (29%)	12 (22%)
3. Lack of interest	4 (10%)	6 (35%)	10 (18%)
4. Limited range of motion	2 (5%)	3 (18%)	5 (9%)
5. Lack of lubrication	5 (13%)	———	5 (9%)
6. Erectile difficulties	———	3 (18%)	3 (5%)
7. Fear of pregnancy, other medical problems	6 (16%)	2 (12%)	8 (15%)
8. Feelings of unattractiveness	6 (16%)	1 (6%)	7 (13%)
9. Problems with partner	11 (29%)	3 (18%)	14 (25%)
10. Lack of partner	8 (21%)	1 (6%)	9 (16%)

TABLE 4

Age and Sex Distribution of Sexual Problems

Age	Women	Men	Total
18-25 years	7/10 (70%)	1/2 (50%)	8/12 (67%)
26-35 years	8/16 (50%)	5/7 (71%)	13/23 (57%)
36-45 years	7/7 (100%)	5/7 (71%)	12/14 (86%)
46-55 years	6/17 (35%)	1/3 (33%)	7/20 (35%)
Over 55 years	10/20 (50%)	5/11 (46%)	15/31 (48%)

meeting people and establishing relationships, or required advice regarding pregnancy and birth control. The age group reporting most problems for both women and men was 36-45 years.

CASE EXAMPLES

Five case examples illustrate the interrelationships of physical and psychosocial factors in sexual problems of individuals with rheumatic disease.

CASE 1

Mrs. A is a 49 year-old housewife with rheumatoid arthritis. She expressed concern about her relationship with her husband, and said that he was upset because of her steady downhill course. A joint interview with a member of the medical staff and social worker revealed that her husband was quite concerned about causing pain during sexual activity as well as in other expressions of intimacy. Discussion centered around their communication and understanding of RA. At follow up they had resumed their previous level of sexual activity.

CASE 2

Ms. B is a 32 year-old woman with scleroderma, joint swelling, and vaginal dryness. She was a very attractive woman whose appearance had been changed by her disease. She was unable to get out of the house often for social activities, and her former partners had all moved to other cities. Medically her joint problems improved with aspirin, and the professional interventions dealt with her own beliefs about herself, recommendations about artificial lubrication, and self pleasuring.

CASE 3

Mr. V is a 48 year-old truck driver with rheumatoid arthritis which was poorly controlled. He had not had intercourse for six months and suffered from severe joint pain, a loss of self esteem because he had to give up his job, and depression. The medical intervention brought his disease under better control, and the professional interventions consisted of discussing his concerns about his masculinity as well as affirming sexuality as part of his overall health. The night before discharge he was reading "Truck-toons", an X-rated comic for truckers, which indicated that at least his interest in sexuality had returned. Follow up revealed that his depression was much improved, and he had resumed sexual activity.

CASE 4

Mr. H is a 58 year-old salesman with rheumatoid arthritis and degenerative hip disease which was extremely painful. He had not had intercourse for one year. Assessment revealed that he had pain and limited motion in many joints as well as decreased self esteem secondary to loss of ability to perform tasks which in the past had been routine. The medical intervention brought his disease under better control, and he has since had a total hip replacement. The professional intervention involved encouraging him to express his feelings of worthlessness, helping him to recognize the impact of his disease on sexuality, and affirming that his sexual concerns were an important part of his total health. Follow up revealed that he and his wife were beginning to be intimate again, but were doing so gradually because the second hip replacement had not been completed, and he still had severe pain in the unoperated hip.

CASE 5

Mrs. B is a 35 year-old registered nurse with systemic lupus erythematosus. She reported that she and her husband were able to continue an active sexual relationship even though her appearance had changed dramatically from steroids. She still felt positive about herself and commented that candlelight and a pretty nightgown easily covered any flaws in her appearance.

Discharge Status.

In terms of discharge status of the 54 individuals in the intervention group, 47 percent of women and 53 percent of men expressed an expectation that they would be able to return to previous levels of activity or were willing to try suggested alternatives (see Table 5). Most of the individuals in the group in which no change was expected at discharge either had unresolved medical problems or were involved in relationships in which either they or their partners were unable or unwilling to change. In 18 percent of the 54 cases in the intervention group, the goal was not necessarily to change the level of functioning but rather to provide information, such as making recommendations about dealing with problems in future flares of the disease or discussing the need for birth control.

The high incidence of problems in the 36-45 age group could indicate

TABLE 5

Outcome of Interventions at Discharge

	Women N=38	Men N=17	Total N=55
1. Expects to be able to resume former level of activity or to try alternatives	18 (47%)	9 (53%)	27 (49%)
2. Does not expect a change in pre-admission level of functioning	10 (26%)	2 (12%)	12 (22%)
3. Further intervention necessary	4 (10%)	3 (18%)	7 (13%)
4. Intervention not expected to change level of functioning, i.e. primarily medical or preventive in nature	6 (16%)	3 (18%)	9 (16%)

general life cycle problems, that is, children leaving home and adults reexamining their relationships as well as personal goals. It could also reflect either an increased willingness to express concerns or incidentally greater disease-related problems of the individuals in that age group.

As a result of this study, several educational programs have been initiated. An inservice training program for nursing staff described the purposes of the study, and future programs are planned to train nurses to do the initial screening. A presentation to the arthritis service medical staff has resulted in increased awareness of sexual problems and additional referrals regarding sexual concerns of patients. A local group of health professionals interested in arthritis sponsored a discussion of the protocol and sexuality in rheumatic disease. Documentation of interventions is in the patient's chart, and a letter from the allied health team to the local physician includes a brief description of the interventions, including those involving sexual problems. Long term follow up of the 100 individuals studies is planned, utilizing either questionnaires or interviews, or both.

DISCUSSION

Gathering information about sexual concerns as part of a total assessment provides a more comfortable avenue for discussion for both health professionals and individuals with rheumatic disease. A few individuals were not assessed for sexual concerns at admission because the format had not been established, and it is interesting to note that none of them independently introduced the topic. As health professionals we have also found it difficult later to find the "right time" to introduce the topic of sexuality if it has not been introduced at the time of admission.

Since disease-related pain has not been described as a major long range contributor to sexual problems of individuals with other diagnoses such as spinal cord injury,[1] breast cancer,[3] or renal disease,[4] it is important to keep in mind that control of the disease can often resolve problems of individuals with rheumatic disease. Helping people recognize the relationship of arthritis pain to sexual problems can provide encouragement.

The fact that lack of interest was reported more often by men may indicate that they have higher performance expectations for themselves, while the partner problems reported more by women may indicate a greater emphasis on caring and intimacy. Although limited range of motion is a significant problem for some individuals, adjustments in positioning or type of activity can resolve some problems.

SUMMARY

This study of 100 patients demonstrated that many individuals with rheumatic disease have sexual concerns and are interested in discussing them, but in most cases will not initiate discussion themselves. It is helpful to include questions regarding sexual functioning as part of an overall assessment. Another important finding was that although there are problems, some individuals are able to maintain intimate sexual and personal relationships even though they have a disease. These individuals can provide information and experiences which can be shared with other patients who are having problems. A final important outcome was the demonstration that, just as medical problems are amenable to specific treatment, many sexual concerns are amenable to intervention.

REFERENCES

1. Cole TM: Sexuality and the Spinal Cord Injured. In Green R (ed): *Human Sexuality: A Health Practitioner's Text.* Baltimore: Williams and Wilkins, 1975.
2. Renshaw DC: Impotence in diabetics. *Dis Nerv Sys* 36:369-371, 1975.
3. Frank D, Dornbush RL, Webster SK, Kolodny RC: Mastectomy and sexual behavior: A pilot study. *Sex Disab* 1:16-26, 1978.
4. Abram HS, Hester LR, Sheridan WF, Epstein GM: Sexual Functioning in Patients with Chronic Renal Failure. In LoPiccolo J, LoPiccolo L (eds): *Handbook of Sex Therapy.* New York: Plenum Press, 1978.
5. Lachniet D, Onder J, Becker M: Sexual counseling, arthritis, and women. Paper presented at the Annual Meeting of the Arthritis Foundation, 1973.
6. Ehrlich GE: *Total Management of the Arthritic Patient.* Philadelphia: JB Lippincott Company, 1973.
7. Katz WA: *Rheumatic Diseases: Diagnosis and Management.* Philadelphia: JB Lippincott Company, 1977.