

“Sexuality is an integral part of human life. It carries the awesome potential to create new life. It can foster intimacy and bonding as well as shared pleasure in our relationships. It fulfills a number of personal and social needs, and we value the sexual part of our being for the pleasures and benefits it affords us....Sexuality encompasses more than sexual behavior...not only the physical, but the mental and spiritual as well.”

*David Satcher, MD, PhD
Surgeon General (1)*

The fatigue and pain from arthritis, the limitations put on movement, and the damage or disfigurement caused to joints often create difficulties in a sexual relationship. Without prompting from the health professional, it is unlikely that clinicians will be aware of their patients' sexual issues. This chapter begins with an overview of why these important discussions may not be taking place. Next, the prevalence and potential causes of sexual dysfunction among rheumatic disease patients are discussed. Finally, strategies to encourage open discussion between health care providers and their patients, as well as suggestions to address sexual difficulties are also included.

THE ELEPHANT IN THE CLOSET

There is general agreement that patients' sexual interests should be addressed when providing health services (2). Nevertheless, discussions of sex and sexuality are frequently neglected in the health care system. A recent poll of 500 US adults age 25 and older found that 71% felt their doctor would dismiss any concerns about sexual problems they might bring up (3). And 68% expressed concern that discussing sexual problems would embarrass their physicians. Three-quarters believed there would be no medical treatment for their problems.

Health professionals are equally reticent to discuss sexual issues with their patients. Among rehabilitation specialists in the UK, 80% agreed that sexual adjustment was important for patients, yet only 9% felt comfortable discussing these issues with patients (2). The majority had never been asked by patients, and had not initiated discussion about sexual issues. Most (86%) said they were poorly trained in this area and nearly all (94%) said they were unlikely to discuss sexual issues with their patients. Clearly, training in human sexuality and sexual counseling needs to be integrated into the training of health care professionals.

Concerns about sexual relationships and activity are common among adolescents with rheumatic diseases as well. Like adults, pain and physical limitations account for much of the problem (4). However, adolescents may have additional concerns. The development of a healthy body image, which is important to all adolescents, may be hindered by problems with growth, use of corticosteroids (which alters fat deposition and can cause acne and hirsutism), or scars from orthopedic surgeries (4). In a study of 246 adults with juvenile idiopathic arthritis, Packham and Hall noted that about 7% reported being sexually active before age 16, and 38% were sexually active before the transfer to adult rheumatology care at age 18 (4). This suggests that discussion about

sexuality needs to begin in adolescent rheumatology clinics. Because of concerns about teratogenicity associated with use of antirheumatic drugs, there is a need to address contraception with adolescents.

PREVALENCE OF SEXUAL DYSFUNCTION

Sexual problems are common among patients with rheumatic diseases. For example, a recent study of rheumatoid arthritis (RA) patients reported more than half (56%) of the patients found that their arthritis placed limitations on sexual intercourse; the principal reasons cited were fatigue and pain (5). Sexual dysfunction appears to be equal among male and female patients with RA (5,6), though it may cause more overall distress among men. Overall, sexual ability is important to the majority of patients with rheumatic diseases, although up to half may lose interest during the course of their disease (5,6). About 60% of RA patients reported being dissatisfied with the quality of their sex lives (5). Men with RA often have reduced levels of testosterone (7). However, in younger patients with inactive or less active disease, sexual activity and frequency does not appear to differ from healthy age-matched controls (6,8).

In primary Sjögren's syndrome, dyspareunia (difficult or painful intercourse) occurs in up to 50% of women (9). Gynecologic problems including endometriosis occurs more frequently (10). Vaginal dryness and dyspareunia are also frequent among women with systemic lupus erythematosus. Up to one-third of men with ankylosing spondylitis report decreased libido, erectile dysfunction, and difficulty ejaculating (11). Systemic sclerosis can result in a range of sexual problems in women; in men, erectile dysfunction is often the result of small vessel disease, which affects the quality of erections (12).

Although the majority of sexual problems appear to be related to pain and disability, psychological issues also may play an important role (4,6,8,13). Many patients report that their disease has had a negative effect on their body image and self-confidence (4,13). Functional limitations may limit opportunities for socializing to form relationships, especially in adolescence. Relationships may be complicated by the fact that one's partner also becomes the caregiver at times. Depression and anxiety disorders are more common among rheumatic patients than the general population (13–19).

MEDICATIONS

Fortunately, most of the drugs used in the treatment of RA do not appear to affect libido or sexual functioning. However, Ostensen notes that there are reports of impotence in patients treated with methotrexate (6). Many RA drugs, however, are not compatible with pregnancy or are known teratogens (e.g., methotrexate, cyclophosphamide, chlorambucil, leflunomide), making the use of effective contraceptives mandatory. Cyclophosphamide may cause long-term ovarian failure such that consideration of egg harvest is sometimes indicated prior to the use of this medication. Additional administration of cholestyramine is needed to wash out leflunomide and its long-lived metabolites before considering conception.

The safety of other medications, including biological therapies, in pregnancy is less clear. Hydroxychloroquine is often continued during pregnancy and corticosteroids are also used.

Several drugs used for RA or medication side effects can be especially problematic in men, and sometimes interfere with libido (e.g., citrmetidine, diclofenac, misoprostol, naproxen), erection (e.g., methotrexate, sulfasalazine, hydroxychloroquine), and ejaculation (e.g., methotrexate, naproxen) (13). Of some consideration as well is reversible azoospermia that may occur with sulfasalazine.

Up to 40% of persons with RA have clinically significant levels of depression (14,20–22). Clinical depression is frequently associated with loss of interest in sex (23). However, sexual dysfunction is also a common side effect of antidepressant medications. Loss of desire and difficulty with orgasm occur in up to 30–60% of individuals who use a selective serotonin reuptake inhibitor or a serotonin-norepinephrine reuptake inhibitor (24).

In summary, sexual problems are common among patients with rheumatic diseases. Reasons for this are multifactorial and include disease-related issues, psychosocial concerns, and medications. Nevertheless, Ostensen (6) notes that most problems related to sexual functioning do respond to treatment and, as a result, should be addressed as part of routine rheumatic care. A review of factors that can facilitate discussion about problems with sexual function is offered below.

COMMUNICATION

The comfort level of the professional in addressing sexual functioning can enhance the comfort with which the patient or couple can express concerns. Obtaining a sexual history may be an easy way to broach the subject. Opening this door gives the patient “professional permission” to discuss sexual functioning and intimacy (25).

Human sexuality has many more dimensions to it than mere physiological functioning. Sex involves 2 people whose feelings must be recognized. However, when chronic illness is involved and one’s sex life changes, it can be even more difficult to raise concerns with a health care provider. There are a variety of reasons for this, including embarrassment or frustration, even fear. When sexual activity diminishes or stops completely, emotional estrangement can quickly occur. Encouraging patients to confront the issue of sex, in all its complexity, is the first step to ensuring that the problem is addressed to the mutual satisfaction of both partners (26).

Clinicians can help couples to navigate the difficulties of dealing with the persistent and invisible nature of chronic pain and the relationship patterns that emerge. Open communication can dispel myths and allay fears. Communication also will help to lessen the need to guess what others feel and need, and it will help to clarify boundaries (27). Questions regarding a patient’s sexual relationship should be direct and general, and integrated into the routine care of all patients (see Table 1). It is often helpful to reassure patients that this is not an uncommon issue. Statements like “Many people with arthritis mention changes in their intimate physical relationship. Have you had any

Table 1. Strategies for opening the lines of communication with patients

Try the following prompts:

- Has arthritis put a strain on your relationship?
- Has arthritis put a strain on your sexual relationship?
- Does your arthritis interfere with sexual intercourse?
- Do you and your partner ever discuss the effects arthritis has on your relationship sexual or otherwise?

Table 2. Selected patient education materials

- The Arthritis Foundation offers “Guide to Intimacy with Arthritis,” available through local chapters, on the Web at www.arthritis.org, or by calling 800-568-4045.
- The Scleroderma Foundation offers a brochure on sexuality in scleroderma through their Web site (www.scleroderma.org) or by calling 800-722-4673.
- The National Institutes of Health (NIAMS) offers a patient information sheet and patient care guide for health professional entitled “Sexuality and Lupus” at <http://www.niams.nih.gov/hi/topics/lupus/lupusguide/chppis10.htm>.
- The Center for Research on Women with Disabilities has made available the National Study of Women with Physical Disabilities—Executive Summary at <http://www.bcm.edu/crowd/?pmid=1407>.

difficulty with pain affecting your sexual relationship?” can help to normalize the patient’s experience and decrease self-consciousness and embarrassment (25). Once the lines of communication have been established, strategies to improve or renew physical intimacy can take place. Before beginning any discussion about sexual intimacy, it is important to first examine your own beliefs and potential biases about the topic. Personal views on homosexuality, sex in the elderly population, between unmarried couples, the use of sexual aids, etc., should never be imposed (27).

Sex re-education is a critically important yet missing component in the arthritis education that is offered for the patient (Table 2). It is important to convey to patients that an active and satisfying sex life is possible, and indeed important to the overall health and well being. Most importantly, patients need to be aware that help is available by identifying and addressing problems directly and creatively.

PAIN MANAGEMENT

Pain management goes hand in hand with time management in the setting of sexual intimacy. In order to maximize comfort, planning will be key (Table 3).

- Pain medications should be taken 30 to 60 minutes before engaging in sexual activity.
- Pillows and/or rolled sheets should be on hand to support joints.
- Avoid cold temperatures.
- Vaginal dryness is often a major issue. Petroleum-based products should never be used. Popular water-based lubricants include Astroglide, K-Y jelly, Replens, and Wet Original. These lubricants work well for partner sex, manual masturbation, and sex-toy play.

ALTERNATIVE POSITIONS

The sex positions people typically used before arthritis may no longer be possible because of the stress that is now placed on affected joints. Modification of these positions or trying completely new positions may help rejuvenate the patient’s sex life.

Before going on, remember that if excessive movement triggers arthritis pain, encourage the patient’s partner be the one who provides the movement during sex. Also, if arousal is now more difficult because of arthritis, consider the use of a water-based lubricant and a vibrator to enhance arousal.

Although there are many sex positions, most are variants of a few basic positions. Everyone’s needs are different, so when reviewing

Table 3. A patient's guide to improving sexual function

<p>1. Open communication between partners</p> <ul style="list-style-type: none"> • Be honest with your partner about feelings, desires, and sexual needs. • Address each other's fears of physical harm. • Discuss each other's willingness to redefine intimacy through new positions, sexual aids, different techniques. <p>2. Use tactile communication</p> <ul style="list-style-type: none"> • Kissing, caressing, petting, or massage may help restore lost intimacy and assist in helping both partners relax. • Some couples may want to try using the hands or mouth to help achieve orgasm. <p>3. Environmental factors</p> <ul style="list-style-type: none"> • Plan blocks of time, within your regular schedule, when both of you are relaxed and comfortable. • Make sure that you get rest ahead of time. • Avoid cold temperatures by taking a warm bath or shower before sex. • Warm the bed by replacing cotton sheets with flannel sheets or turn on an electric blanket for a few minutes before getting into bed. <p>4. Medications</p> <ul style="list-style-type: none"> • Take pain medication at least 30 minutes before sexual activity. • Discuss any possible sexual side effects of medications with your pharmacist. • Water-based lubricants may be helpful in the presence of vaginal dryness. Some common brands are Astroglide, K-Y jelly, Replens, and Wet Original. Never use petroleum-based products. <p>5. Sexual Positions</p> <ul style="list-style-type: none"> • <i>The modified missionary position.</i> The woman—who is unable to move her legs apart, has stiff knees, or has had a hip replacement—is to lie on her back with a pillow supporting her hips and thighs. The man can then lie on top of her, supporting his own weight on his elbows, hands, and knees. • <i>Spoon position.</i> When the woman has painful hips or has had a hip replacement, she can lie on her side with her partner lying closely behind her. Imagine spoons stacked side by side in your silverware drawer. With a pillow between her knees, the man can enter her vagina from behind. • <i>Standing.</i> This position is a good one, especially when both partners are bothered by stiff or aching hips and knees. Both partners stand, with the woman using a tabletop or other piece of furniture for support. The man stands behind the woman and can enter her vagina from behind. • <i>Kneeling.</i> When the woman has hip stiffness or has had a hip replacement, she can kneel on a pillow, supporting her arms and chest on a low piece of furniture. The man kneels behind the woman and can enter her vagina from behind. • <i>Sitting.</i> For women with back or hip stiffness and pain, this is a good position that will offer support without any weight on top. With the man sitting in a comfortable chair, the woman sits in his lap. Many find this position to be more comfortable than sitting in bed. • <i>Lying down.</i> When a man has painful hips, back, or knees, or when he has had a knee or hip replacement, he can lie on his back, using a pillow under his neck for support. The woman straddles him, supporting herself on her knees or leaning forward and supporting herself on her elbows.

sexual positions with a patient, let him or her decide which will work best. Patients should take the following into consideration:

- comfort level
- personal inhibitions
- overall sexual satisfaction

The missionary position, with the man on top, offers problems for many people with arthritis, especially if the person has pain in his or her hips or knees. Having the woman sitting on top of the man may not work well if her hips and other large joints are affected.

There are pleasurable ways to achieve sexual satisfaction other than through intercourse. Many couples may be unfamiliar with oral sex but may want to explore this possibility. A comfortable position may be easier to find than with intercourse. Foreplay may become of greater importance.

Encourage creativity: For example, if hands are painful use the backs of the hands to caress the partner's breasts or genitals. Sexual aids from massage oils to vibrators may be suggested.

SUMMARY

A healthy active sexual life is important to overall wellbeing, self-confidence, self-esteem and general wellbeing. Unfortunately, sexual problems are common among persons with rheumatic illnesses. Discussions about sex and sexuality continue to be absent from most health care relationships. A major barrier has been lack of training of health care professionals about sex and sexuality. Though pain, fatigue, and limited mobility may interfere with sexual functioning, improved communication with the health care provider and partner can enhance understanding, identify new options for intimacy, and even improve the relationship through increased closeness.

REFERENCES

1. Satcher D. The Surgeon General's call to action to promote sexual health and responsible sexual behavior. Accessed June 8, 2006. URL: <http://www.surgeongeneral.gov/library/sexualhealth/call.htm>.
2. Haboubi NHJ, Lincoln N. Views of health professionals on discussing sexual issues with patients. *Disabil Rehabil* 2003;25:291-6.
3. Marwick C. Survey says patients expect little physician help on sex. *JAMA* 1999;281:2173-4.
4. Packham JC, Hail MA. Long-term follow-up of 246 adults with juvenile idiopathic arthritis: social function, relationships and sexual activity. *Rheumatology (Oxford)* 2002;41:1440-3.
5. Hill J, Bird H, Thorpe R. Effects of rheumatoid arthritis on sexual activity and relationships. *Rheumatology (Oxford)* 2003;42:280-6.
6. Ostensen M. New insights into sexual functioning and fertility in rheumatic diseases. *Best Pract Res Clin Rheumatol* 2004;18:219-32.
7. Tengstrand B, Carlstrom K, Hafstrom I. Bioavailable testosterone in men with rheumatoid arthritis-high frequency of hypogonadism. *Rheumatology (Oxford)* 2002;41:285-9.
8. Ostensen M, Almqvist K, Koksvisk HS. Sex, reproduction, and gynecological disease in young adults with a history of juvenile chronic arthritis. *J Rheumatol* 2000;27:1783-7.
9. Skopouli FN, Papanikolaou S, Malamou-Mitsi V, Papanikolaou N, Moutsopoulos HM. Obstetric and gynaecological profile in patients with primary Sjogren's syndrome. *Ann Rheum Dis* 1994;53:569-73.
10. Haga HJ, Gjesdal CG, Irgens LM, Ostensen M. Reproduction and gynaecological manifestations in women with primary Sjogren's syndrome: a case-control study. *Scand J Rheumatol* 2005;34:45-8.
11. Sant SM, O'Connell D. Cauda equina syndrome in ankylosing spondylitis: a case report and review of the literature. *Clin Rheumatol* 1995;14:224-6.
12. Nowlin NS, Brick JE, Weaver DJ, Wilson DA, Judd HL, Lu JK, et al. Impotence in scleroderma. *Ann Intern Med* 1986;104:794-8.
13. van Berlo WT, van de Wiel HB, Taal E, Rasker JJ, Weijmar Schultz WC, van Rijswijk MH. Sexual functioning of people with rheumatoid arthritis: a multicenter study. *Clin Rheumatol*. In press.
14. Covic T, Tyson G, Spencer D, Howe G. Depression in rheumatoid arthritis patients: demographic, clinical, and psychological predictors. *J Psychosom Res* 2006;60:469-76.
15. Brown GK, Nicassio PM, Wallston KA. Pain coping strategies and depression in rheumatoid arthritis. *J Consult Clin Psychol* 1989;57:652-7.