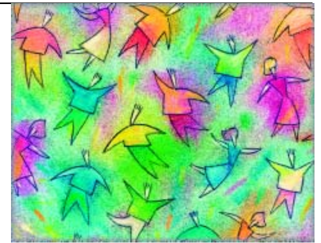
Chronic illness and sexuality



Rosemary A McInnes*

RELATIONSHIP AND SEXUAL satisfaction are important boosters of quality of life,[1] a crucial concern for patients who live with chronic illness. In a life restricted by illness, sex can be a powerful source of comfort, pleasure and intimacy, and an affirmation of gender when other gender roles have been stripped away. For patients with chronic illness and their partners, a satisfying sex life is one way of feeling "normal" when so much else about their lives has changed.

ABSTRACT

- Sex remains an important contributor to quality of life in many patients with chronic illness and their partners.
- The effects of chronic illness on sexuality are multifactorial and can impact on all phases of sexual response.
- Sexual dysfunction and dissatisfaction in chronically ill patients are underdetected and undertreated because of barriers to doctor–patient discussion about sex and lack of medical training in human sexuality.
- For doctors to become more motivated to broach the topic of sex, they need to recognise that people may be sexually interested even though they are old, ill or disabled.
- The PLISSIT model provides a graded counselling approach that allows doctors to deal with sexual issues at their own level of expertise and comfort.

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Effects of chronic illness

Chronic illness can have profound negative effects on relationship and sexual satisfaction of both patients and partners. The effects of chronic illness on sexuality are multifactorial and can impact on all phases of sexual response (Box 1). Effects can also be classified into biopsychosocial categories.[3]

Biological effects

- Sexual desire, capacity and activity may be altered by illness through interference with the hormonal, vascular and neural integrity of the genitalia, as well as the effects and side effects of medications. Commonly used medications that may impair sexual function are shown in Box 2.

> ***Case history:*** A 50-year-old man was referred with erectile dysfunction of 12 months' duration. History-taking revealed that he had painful arthritis, particularly affecting his left knee, and had been taking methotrexate for 12 months. Methotrexate was replaced with an anti-inflammatory agent, with great improvement in his sexual function.

- Reduced cardiovascular and pulmonary function, fatigue or pain[5] may limit or halt sexual activity.
- Surgical procedures and medical treatments may result in altered appearance and bodily function (eg, scarring, amputation, tracheostomy, mastectomy, colostomy and hair loss). The psychological distress that often accompanies altered body image can limit patients' sexual satisfaction.

Psychological effects

- Anxiety, loss of self-esteem, grief and depression associated with chronic illness can impair sexual fulfilment. While some couples easily accept limitation or cessation of sexual activity caused by chronic illness, for others alteration of sexual function or unsatisfactory sexual relations can precipitate a significant emotional crisis.

> ***Case history:*** A 35-year-old woman suffered from severe erosive lichen planus of the vagina with repeated haemorrhages necessitating vaginectomy and urinary diversion. She was married with two children. As sex was very important to this woman, a neo-vagina was surgically fashioned, but was rendered useless by adhesions and scarring. It was some years before the patient was able to accept that she could never have penetrative sex with her husband again. She felt unfeminine and inadequate and reacted with depression, anger and emotional withdrawal. At times, she expressed suicidal ideation. With counselling and support, the couple gradually adapted to non-intercourse techniques of lovemaking.

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Social effects

■ Society is generally uncomfortable with the notion that people who are ill or disabled might still want, or have, sex. While sexual activity may be placed on hold as other aspects of living with chronic illness intervene,[7] sex remains a vital part of day-to-day living, even for men and women who are seriously disabled by illness. For example, of 383 patients who began non-invasive mechanical ventilation for chronic respiratory failure, 46% did not change their level of sexual activity, 36% were less active sexually, and 13% were more active. The average frequency of intercourse was about five times per month. The study concluded that even when a significant degree of disability is present, the desire for and experience of sexual activity persists.[8]

■ Many doctors and patients wrongly regard decline of sexual function as an inevitable consequence of ageing. Chronic illness becomes more common as men and women age. In fact, sexual dysfunction is often related more to comorbid illness than to ageing alone.[9]

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■ The sexual concerns of single, separated and divorced men and women with chronic illness are often disregarded. Sadly, it is assumed that, because of chronic illness or disfigurement, a discussion about sex is irrelevant because this person is “unlikely to form a relationship”. In reality, disabled people do become romantically involved. In addition, sexual activity does not require a partner. Doctors also need to be sensitive to patients’ sexual orientation. As chronic illness affects both heterosexuals and homosexuals, talking about sex with a doctor may necessitate “coming out” as a gay man or lesbian. Overcoming sexual stereotypes is crucial when dealing with sexual issues.

1: Sexual dysfunction associated with chronic illness[2]

Reduced sexual desire

Impaired sexual arousal
- Erectile dysfunction in men
- Lack of lubrication or dryness and coital discomfort in women
- Lack of subjective pleasure

Orgasmic dysfunction
- Delayed ejaculation or anorgasmia in men
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Painful intercourse, including vaginismus

Sexual aversion

2: Commonly used medications that may impair sexual function[4]

Benzodiazepines	Neurotoxic cancer chemotherapies
β-Blockers	Oestrogens
Calcium-channel blockers	Opiates, including synthetic opiates
Cimetidine	Phenytoin
Digoxin	Progesterones
Lipid-lowering agents	Thiazide diuretics
Lithium	Tricyclic antidepressants
Monoamine oxidase inhibitors	Selective serotonin reuptake inhibitors

Barriers to sexual discussion

Despite the obvious biopsychosocial impacts of chronic illness on sex and relationships, only a minority of patients receive help for sexual concerns. For example, although the effects of diabetes on erectile function are widely known, a Danish study found that only 10% of diabetic men attending a specialist diabetic clinic had discussed sexuality with a doctor.[11]

Reasons for lack of doctor–patient communication about sex include:

■ Minimal training of doctors on relationship and sexual health issues compared with physical and mental health issues. As a result, doctors tend to dismiss sexual aspects of health as being less important than the diagnosis and treatment of illness. Additionally, many doctors lack the comfort, expertise and willingness to discuss intimate aspects of patients’ lives.

■ Reluctance on the part of patients to bring up their sexual concerns with doctors.[12] Patients may feel embarrassed, ignorant, anxious and inadequate and fear being ridiculed for wanting sex when they are ill, old, or both. Patients are often unaware that their sexual dysfunction is related to their medical condition or treatment. Many patients still believe

that sexual problems are "all in the mind" or that no remedies are available.

What can doctors do?

To broach the subject of sex comfortably with patients, doctors need to tackle three areas:

Attitudinal change. To promote enquiry and discussion about sex and relationships with chronically ill patients, entrenched negative attitudes must change, and myths and stereotypes must be rejected. The following beliefs provide a foundation for a more constructive perspective:

- Sex and relationships are important aspects of health.
- It is the doctor's role to address quality of life issues including sexual health.[13]
- People may be sexually interested and active even though they are sick, old, disfigured or disabled.
- There is more to sex than just penis-in-vagina intercourse.

Acquiring knowledge. Doctors need to acquire basic knowledge about sexual function and dysfunction[14] and the impact of illness and medications on sexual relations.[13]

Acquiring skills. Doctors need to know how to open up the topic of sex for discussion and provide help to patients and their partners using a simple plan.

PLISSIT model of sexual counselling

The PLISSIT model of sexual counselling presents four levels of intervention, ranging from the simplest to the more complex (Box 3).[15] This graded model allows doctors to manage difficulties according to their own level of comfort and expertise. While some doctors may wish to provide all four levels of intervention, those who choose to raise the subject of sex, answer simple questions and, if necessary, refer to an expert are providing adequate intervention to their patients. Initial attempts at sexual discussion may feel clumsy and embarrassing, but levels of comfort increase every time such discussions take place.

As doctors are most likely to be involved at Level 1 ("permission", or broaching the subject of sex), I will discuss this in more detail. Active screening for sexual concerns must be considered an essential part of the routine work up for any patient who suffers from a chronic illness, regardless of his or her age. This level not only gives the patient permission to talk about sex, but also seeks the patient's consent to explore this intimate topic. Doctors need to be respectful if patients decline this opportunity, or limit information gathering, because of cultural or other taboos. Seeing the partner as well as the patient can be very helpful.

Questions about sexual issues are more comfortable for both doctor and patient when the patient understands the relevance of such questions to his or her situation. Relevance can be demonstrated, and discussion encouraged, in two simple steps:

- Embed questions about sexual function in an appropriate context by making a statement that links the patient, his or her medical history (the diagnosed illness or treatment) and sexual difficulties.
- Ask an open ended question. These questions begin with "how" or "what" and invite a more discursive answer than just "yes" or "no". Some examples are shown in Box 4.

Once the subject of sex has been broached, a sexual history can be taken, focusing on the areas of patient concern. Keep language simple and begin with less confronting issues before moving on to more explicit and possibly embarrassing ones.[18] The doctor can proceed with sexual counselling following the PLISSIT model or refer to a specialist for further treatment as needed.

3: PLISSIT model of sexual counselling[15]

The four levels of this model are:

P (permission)

The doctor introduces the subject of sex and encourages the patient to discuss sexual concerns and ask questions. Often the doctor's continuing support and interest is enough to mitigate a patient's suffering.[16]

LI (limited information)

At this level, information can be provided about the impact of illness on sexuality and the effects of treatments on sexual function.

SS (specific suggestions)

Suggestions might include reading printed material about sexuality and illness, taking pain relief before sexual activity, or advice about alternative sexual techniques or coital positions.[17] Treatment may involve counselling, medication, or both. Some couples may require relationship counselling in addition to sexual counselling.

IT (intensive therapy)

This level requires further training and is usually given by an expert counsellor, psychologist, social worker or psychiatrist.

4: Examples of questions broaching the subject of sex (the "permission" level in the PLISSIT[15] model)

Routine questioning

"I always ask whether patients are having any relationship or sexual problems. Your sexual health is an important part of your life. Sometimes an illness or medication can affect your sexuality. How has your relationship been going lately?"

Generalising

"People with chronic renal failure often experience sexual difficulties, such as loss of desire or problems with enjoyment. How have you been affected?"

Normalising

"When a woman receives a diagnosis of breast cancer it's normal for her to be concerned about how treatment might affect her sex life. What worries have you had?"

Using statistics

"Over 80% of men with peripheral vascular disease report problems with sex, such as difficulty gaining and keeping an erection. What changes have you noticed?"

Other open ended questions

"What kinds of sexual problems have you had?"
"What happens when you and your partner try to make love?"
"How is your health affecting your relationship?"

Conclusion

Chronic illness can be frustrating for both doctor and patient. While it may be difficult to slow or limit the damaging effects of chronic illness, doctors can make a real and very positive difference to their patients by providing advice and support in the important areas of sexuality and relationships.

Competing interests

None identified.

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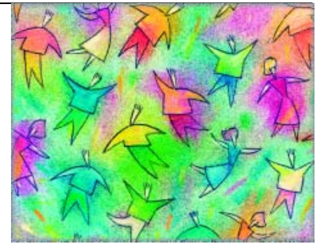
Chronic illness and sexuality



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This level requires further training and is usually given by an expert counsellor, psychologist, social worker or psychiatrist.

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"I always ask whether patients are having any relationship or sexual problems. Your sexual health is an important part of your life. Sometimes an illness or medication can affect your sexuality. How has your relationship been going lately?"

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