

Discussing sex with disabled patients

A conspiracy of silence is harmful and unnecessary

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Health is not only the absence of illness but also overall psychological and physical well-being. An important aspect of this well-being is sexual health. Unfortunately, though, in caring for the chronically ill or disabled, physicians often overlook sexuality. There is no question that physical illness can affect social functioning. The medical literature is full of references to the social impact of illnesses such as cancer or spina bifida. Patients with chronic conditions often list sexuality as a primary concern.^{1,2} Physicians may discuss social behaviors, such as tobacco and alcohol use, but all too often neglect to discuss sexual concerns.

Both patients and physicians may be uncomfortable bringing up sexuality. Patients often prefer that their physicians broach the subject, but for this to happen, physicians must be comfortable discussing sexuality, a topic fraught with controversy and embarrassment. Many studies show that physicians are apprehensive about discussing sexual issues with patients.³⁻⁵ Identified causes of this apprehension include lack of training, fear of intrusion, and fear of inadequate knowledge. Physician discomfort with patient sexuality results in inadequate sexual histories and subsequent gaps in patient care.

Common errors stem from assumptions made about patients' sexual behaviors and concerns. Doostan and Wilkes outline the scope of sexual dysfunction from differing chronic conditions.³ In patients with invisible conditions, we might assume normal function and provide routine guidance regarding sexuality and family planning or, too often, forego any discussion of sexual concerns at all.

Society often views patients with more visible disabilities as sexually innocent. Outsiders and family alike may assume that they are unlikely to find sexual partners. Physicians can be guilty of these same assumptions and fail to address sexual concerns or provide education. We must consider the desire of families and caretakers to "protect" developmentally disabled patients from sexual predators by withholding sex education. At the same time, we must acknowledge that this decision can result in inappropriate sexual behaviors because sexuality is inherent in all people, regardless of disability.

Studies on adolescents with chronic conditions show the need to take sexual histories and provide sex education. Teens with obvious physical disabilities are undoubtedly sexually active.^{6,7} In a large survey of high school students by Suris et al., there were no differences between adolescents with and without chronic conditions on a

number of factors including self-report of previous sexual intercourse, previous pregnancy, or contraceptive use.⁷ This study also reported no difference between adolescents with visible versus invisible conditions; obvious disabilities might affect self-esteem and body image, however, and thereby influence relationships.

There is evidence that patients with physical disabilities receive inadequate education regarding marriage, family planning, sexually transmitted infections, and sexual abuse.^{7,8} These patients must, therefore, be at risk for adverse sexual consequences. Physicians must be careful to tailor education to patients' specific conditions, because "routine" courtship and sexual relationships are not necessarily the norm and inappropriate information might be harmful.

Medical education in human sexuality and sexual history-taking is often missing in both residency and medical school curricula.

It is our role to safeguard the health and well-being of our patients, however hard it is to overcome our biases regarding their illnesses and their sexuality. Physicians are comfortable addressing sexuality from the fact-based biomedical model, but when there is less science, we grow insecure in our roles as healer and teacher. If we are confident with our knowledge and expertise, we can more willingly and competently provide sexuality counseling.⁸

Medical education in human sexuality and sexual history-taking is often missing in both residency and medical school curricula. In a recent unpublished survey of primary care residents at our institution, most residents indicated that their training in patient sexuality was fair to poor in both residency and medical school. This is supported by the Maheux and Temple-Smith studies, in which physicians cited lack of appropriate training as a reason for inadequate sexual history-taking.⁹ Physicians who received residency training in human sexuality provided better histories than those who did not.

Didactic discussion of human sexuality in the contexts of health promotion and specific illnesses is important, but actual practice and application of sexual history-taking and counseling play the larger role in

improving physicians' confidence. The use of standardized role-playing will allow trainees to apply techniques and information in a safe setting prior to confronting these issues with actual patients.

As primary care providers, we are not expected to conduct intensive interventions when sexual concerns arise. Often brief interventions make significant impacts on our patients. A commonly used brief intervention is the PLISSIT model developed by Annon,¹⁰ with four progressive levels—(1) permission, (2) limited information, (3) specific suggestions, and (4) intensive therapy—that can guide assessments and interventions to improve sexuality in healthy and chronically ill patients. Broaching the topic of sexuality often gives patients permission to discuss their concerns and can be all that is needed to overcome barriers to healthy sexuality.

The conspiracy of silence around sexuality in the chronically ill and disabled is harmful and unnecessary. Increasing our comfort in discussing sexuality and routinely including sexual histories in our assessments will allow our patients to have more fulfilling lives.¹¹

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