

Sexual health of women with disabilities

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A long-term disability can have a profound impact on a woman's innate sense of sexuality, sexual function and, occasionally, fertility. Research findings suggest that some 14% to 20% of women over 15 years of age have a long-term disability;¹ this means that most physicians will be involved in the care of physically or mentally challenged women. Nevertheless, there is little in the medical literature about sexuality and disability, and many medical school curricula have only recently begun to address the issue in any detail. Various myths about sexuality and disability prevail in our society, with the result that the sexual well-being of disabled women is often neglected.

These myths include the following:

- disabled women are asexual
- only independently functioning women can handle sexual relationships
- disabled women who are single are celibate
- disabled women cannot be mothers
- all disabled women are heterosexual
- disabled women should be grateful for sexual relationships
- disabled women are different
- youth and beauty are essential to sexuality.

Physicians can reject these myths and attempt to understand the possible impact of disability on their patients' sexuality.

Sexual self-image

The sexual self-image of women who have grown up with disability may be influenced by societal attitudes. Becoming disabled may alter a woman's self-image, and fears of losing independence and of being viewed as "sick" can erode sexual confidence. Women with spinal cord injuries interviewed by Kettl and Zarefoss² reported that the biggest change after injury was in their perceived attractiveness; they found themselves less attractive by some 50% on average. In some instances the women's overall physical appearance had not changed markedly; clearly, one's sense of "attractiveness" goes a lot deeper.

Sadly, sexual abuse and sexual harassment are more commonly experienced by disabled women than by nondisabled women³ and can be particularly devastating in view of the already vulnerable self-esteem of women with disabilities. Moreover, some men who do credit disabled women as sexual make inappropriate, unwanted and exploitative advances.

The importance of validating a disabled patient's sexual identity must be stressed. The physician can provide this validation by initiating discussion of the woman's sexual function and of safer sexual practices. Unfortunately, many physicians fail to initiate such discussion and respond to concerns voiced by the patient herself by suggesting that she consult another health professional (e.g., a psychologist). This implies that it is not a straightforward matter for a disabled woman to be a sexual person. The few sexual self-help books that do address physical disability use illustrations of fully able, attractive bodies. The sexuality of women with cognitive disabilities tends to be disregarded even more. Inappropriate or misguided sexual remarks made by women with cognitive disabilities may provoke anxiety in her caregivers, but are often ignored rather than being met with a helpful response.



Education

Éducation

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Relationships

Forming new relationships can be especially challenging for women with disabilities. Many are afraid of rejection and do not even try. Some disabilities (such as lower spinal cord or conus lesions causing bladder and sexual difficulties but sparing the limbs) are “hidden,” which poses the extremely difficult question of when to disclose the problem to a potential partner. The woman must weigh the need to establish sufficient trust and closeness before disclosure against her unwillingness to mislead anyone. Living conditions may restrict opportunities for meeting potential partners. Some women want a care-giving partner, whereas others prefer to be independent. This may not be clear to the potential partner, male or female. Issues affecting lesbian women with disabilities — a minority within a minority — are explored by Duffy⁴ and Califa.⁵

Data on the stability of relationships of women with and without disabilities are scant. Investigators in the US have found that overall divorce rates for women with spinal cord injuries are a little lower than those for the general female population and that divorce rates are lower for those married after as opposed to before the injury.⁶ Follow-up studies have indicated that marriages that begin after the injury seem happier both generally and sexually.⁷

Some women speak of relationships becoming even closer after the disability occurred. As one woman reported, “if circumstances hadn’t forced us to develop our sexual relationship, we might never have discovered the depth and variety of feelings and experiences that are now part of our entire life, not just our sex life.”⁸

For women with cognitive disabilities the challenge is enormous, particularly if insight and self-awareness are impaired. An awareness of social subtleties such as eye contact and a sense of personal space may be inadequate, and behaviours that promote acceptance by other people may have to be learned. This can be difficult for women with attention deficits that prevent them from screening out distractions. Physicians referring a patient with a cognitive disability to other health care providers can point out that the patient may well have sexual needs and may need help in establishing appropriate relationships.

Sexual desire

The most common sexual concern for women with or without disabilities is that of low desire. To distinguish between low motivation to be sexual and a truly low biological drive, the physician needs to ask about sexual fantasies, dreams and sexual arousal from erotica. The wish to self-stimulate also indicates ongoing biological drive. As often as not, women with a disability other than brain damage have intact biological sexual drive. It may well be that lack

of privacy, misinformation, concerns about birth control, lack of sexual skills in the partner or interruption of the physiological sexual response are the underlying reasons for a poor outcome and lost motivation.

Some medications, especially codeine, tranquilizers and some antidepressants, lessen sexual desire. Occasionally, heightened desire associated with dopaminergic agents for the treatment of parkinsonism causes the partner to feel insecure: “It’s not me she desires, she’s just feeling the effect of those drugs.”

Explaining the “normality” of low desire in the presence of fatigue can facilitate discussion of timing sexual activity to coincide with a period of the day when the woman has more energy. It can be helpful to explain that sexual desire is not an automatic drive similar to the drive to breathe or to eat, but a complex entity that can be shut down if all is not well both physically and psychologically. Thus, problematic low desire could invite relationship counselling, antidepressant medication, psychological help to address past negative experiences, or investigation of actual sexual dysfunction. When motivation to be sexual is lost because intercourse is frustratingly difficult, helping the couple explore nonpenetrative sex can be helpful.

For patients who need antidepressant therapy, medications should be chosen carefully to prevent a lessening of sexual desire. Currently, nefazodone rather than a pure selective serotonin reuptake inhibitor (SSRI) is often tried with a view to avoiding decreased libido; in the near future, mirtazapine will also be available. Bupropion has recently been introduced in Canada; likely because of its dopaminergic action, it may not only be less likely to inhibit sexual desire but it may actually increase sexual desire and response.⁹

Physical limitations

Muscle weakness, spasticity, spasms, tremor, contractures and other conditions that limit mobility can take their toll on sexual enjoyment. To caress, stroke, stimulate, self-stimulate, move one’s body or enjoy simple physical closeness are all treasured aspects of the sexual relationship that may be difficult or impossible for the disabled woman.

It may be helpful for the physician to explain that in some cultures the norm is to explore the sexual potential of the whole body, mind and spirit as the couple touches, talks, caresses, kisses and only sometimes purposefully stimulates to actual orgasm. Creative bodily positioning, minimizing the focus on penile–vaginal contact and fostering eroticism can lead to greater pleasure and intimacy. To achieve this it is very helpful to involve both partners in counselling.

Encouragement to explore nonpenetrative and non-genital stimulation may need to be explicit. When a woman’s partner has a disability that precludes manual stimulation, then self-stimulation in the partner’s presence



can add to the couple's mutual enjoyment. Some women with quadriplegia report the ability to be sexual using shared fantasies, prolonged eye contact or sexual talking.

Many disabling conditions are associated with chronic pain, which can in itself be a potent distraction from sexual awareness, desire and arousal. Even more common is the inhibiting effect of long-term use of narcotic agents on the sensorium.

Recent research on chronic pain physiology and management can guide our prescription of pharmacologic agents that interrupt pain circuits, including low-dose tricyclic antidepressants and anticonvulsants, and of nonpharmacologic approaches, including transcutaneous electrical nerve stimulation, acupuncture and, in some cases, nerve blocks or neurotomies.

The stress on the body of sexual arousal, orgasm and physical sexual activity may exacerbate dyspnea, angina and arthritic pain. Even the rigidity and tremor of Parkinson's disease can be increased by sexual arousal and orgasm.¹⁰ For some disabled women, insecurity about urinary or fecal continence can strongly inhibit sexual motivation. Altered sensation can cause sexual stimulation to feel more like urgency of micturition. Incontinence is a definite risk for some, particularly at the time of orgasm.

In addition to seeking the help of rehabilitation nurses in establishing optimal continence, the physician might consider the judicious restriction of fluids, anticholinergic medication or desmopressin acetate before a sexual experience.

Changes in sexual response

Physical arousal may be impaired in some women with neurological conditions. In a Swedish study involving 47 women with advanced multiple sclerosis,¹¹ most participants were premenopausal and 36% reported decreased lubrication. Congestion of the clitoris and bulb of the vestibule is often similarly reduced such that stimulation is less pleasurable and less intense. Lubrication is usually said to be adequate in women with spinal cord injuries.

There is very little information specifically directed to physiological arousal in postmenopausal women with disabilities that limit mobility. Estrogen is often withheld in view of the increased risk of thromboembolic events in immobile patients. Thus, genital arousal may be limited and associated with dyspareunia from lack of estrogen-dependent lubrication and vaginal elasticity. In the long term, estrogen lack may be associated with painful osteoporotic fractures and angina from ischemic heart disease, further interfering with mental and physiological arousal.

Topical estrogen in the form of a ring that releases estradiol over 12 weeks will provide adequate vaginal estrogen with minimal systemic absorption.¹² Systemic absorption of topical vaginal estrogen cream can be minimized by using

just a quarter of an applicator full once a week. Polycarboxophil, an inert polymer that restores vaginal elasticity, lubrication and correct pH balance can also be used. Until 1996, transdermal estradiol was thought not to promote thromboembolic events. However, 3 studies published in that year¹³⁻¹⁵ showed little difference in risk of thromboembolic risk between the oral and transdermal routes.

Neurological disease can interfere with the orgasmic reflex. Of the 47 women with multiple sclerosis who participated in the Swedish study, 40% reported diminished orgasmic capacity.¹¹ Sixty-two percent had reduced genital sensation, some with allodynia, some with hyperesthesia. Weakness of the pelvic muscles was reported by 77%. Of 54 women observed after spinal cord injury,² almost 50% were unable to reach orgasm; of those who could, half felt that orgasm was altered. It is interesting that some women without genital sensation and with complete lesions occasionally report orgasmic experiences.¹⁶ We should also bear in mind that women with spinal cord injury can still experience dysmenorrhea. Branches of the vagus nerve reaching the pelvis could account for some of these unexpected occurrences.¹⁷ SSRIs have roughly a 50% to 70% chance of delaying orgasm even if neurological disease is absent.⁹ As discussed earlier, other antidepressants may be tried to avoid this side effect.

Occasionally, women with multiple sclerosis or stroke with supranuclear damage to the pyramidal tract report uncontrollable laughter followed by uncontrollable weeping just as they approach orgasm. This may be alleviated by an SSRI (possibly on an as-needed basis). Women with Parkinson's disease often report changed orgasms in that the sexual tension no longer reaches a definite peak but rather a number of high points and then is rather abruptly lost.¹⁰

Conveyed in the anterior spinothalamic and pyramidal tracts, the orgasmic pathway can easily be tested in an office setting. A normally appreciated cold stimulus to the clitoris and the ability to voluntarily contract the external anal sphincter indicates intact orgasmic pathways. Given these findings, the woman then knows that she may again experience orgasm, given the right mental and physical stimuli. Women who would normally decline the use of a vibrator can be informed that an extremely fast stimulus is often needed when there is neurological damage. When there is no genital sensation at all, nongenital areas are sometimes able to "take over" as stimulation sites for orgasm.

Clearly, the same spectrum of causes of dyspareunia exists in women with and without disabilities; these include vestibulitis, vaginitis, vulvitis, endometriosis, previous radiotherapy and interstitial cystitis. If new ways to become aroused have not been learned, the lack of arousal-associated vaginal expansion and congestion will cause penetration to be painful.

Estrogen lack is obviously a common concern after



menopause. Vaginismus — an involuntary heightened tone of the lower third of the vaginal musculature with associated overcontraction of superficial and deep pelvic muscles when vaginal entry is attempted — is a syndrome whose cause is unclear. Theoretically, it might be expected in conditions with associated muscle spasticity, but this has not consistently been reported. Data are also lacking to support the hypothesis that the syndrome is more common in women who have been sexually abused.¹⁸ Figures for the prevalence of vaginismus in the nondisabled community are lacking, but the clinical experience of sexual medicine consultants and sexologists is that it is certainly not uncommon and may well be present in women with disabilities.

Full assessment of dyspareunia in disabled patients takes time. It is particularly important that the woman know in advance exactly what will be done and why. Her full understanding and implicit consent are extremely important given the probability of previous sexual abuse. An examination table that lowers adequately and a nurse in attendance are desirable. The careful examination of the introitus for women with entry dyspareunia and histories suggestive of vaginismus may well prove challenging but will be necessary to exclude introital pathology such as vestibulitis (exquisite tenderness of the margin between the hymen and the inner edge of the inner surface of the labia minora, particularly over the posterior lateral aspects), which is present in about a third of women whose histories suggest lifelong vaginismus.¹⁶ This must be excluded before traditional treatment for vaginismus with inserts can possibly be useful. Dyspareunia associated with estrogen lack can be addressed with local estrogen applications, as described earlier.

Fertility and birth control

Although most disabilities do not directly interfere with fertility, many women with disabilities have difficulty becoming pregnant. Infertility workups may be especially stressful (especially if the examination table does not lower sufficiently, stirrups do not support thighs, or there is a lack of respect during examination of the genitalia, given that the patient “can’t feel”). Women tell of difficulties finding a specialist who is willing to help them achieve a pregnancy.

Although the infertility workup is basically similar to that for nondisabled women, some adjustments may be needed, such as the use of laparoscopy instead of hysterosalpingogram in women with severe leg and pelvic contractures, and monitoring for autonomic dysreflexia in women with spinal cord injuries who are undergoing endometrial biopsies or egg retrieval.

With respect to contraception, sponges, diaphragms, female condoms and estrogen-containing oral contraceptives may all be inappropriate when mobility is limited. If oral contraceptives containing estrogen must be avoided,

a progesterone-only pill, depot-medroxyprogesterone acetate, an intrauterine device, tubal ligation, or partner use of a condom or vasectomy may be considered.

Conclusion

Disability has an impact on a woman’s sexual identity and confidence, her sexual desire and function and her ability to find a partner. She remains a sexual person with the potential to have sexual experiences and to build relationships that include sexual aspects with their associated sense of bonding, commitment and fulfilment — but she will need help. Recognition of her sexuality, provision of information to enable her to safely express that sexuality, and accurate assessment and management of any sexual concerns are integral components of care and fall within the province of the “generalist.” Declared sexual medicine consultants are scarce. Sex therapists are similarly in short supply in Canada and do not usually have medical training. Given the prevalence of disabilities, family physicians, gynecologists, internists and urologists all have a responsibility to ensure that our practice is responsive to the needs of women with disabilities. Such responsiveness ranges from the awareness of possible past or ongoing abuse to the equipping of offices so that women can be adequately examined and assessed.

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