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Gathering a Sex History from a Physically Disabled Adult

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Sexuality is a health issue and should be integrated into clinical settings that focus on the rehabilitation needs of people with disabilities. It is as critical as any other activity of daily living and should be given an equal priority by the health care team. Finally, it is important for health professionals to have a good understanding of their own sexual issues if they are to be effective with their patients. Based on these assumptions, this article provides an overview and definition of basic sexual questions and concerns for people with disabilities. It provides an overview of the interview process with appropriate questions for both men and women as well as their partners.

KEY WORDS: history; interview; sexuality.

ASSUMPTIONS

My work in sexuality and physical disability is predicated on three basic assumptions. The first is that sexuality is a health issue. In many clinical settings, sexuality is not acknowledged frankly and, therefore, may not be readily accepted as a health issue. A second assumption is that the person working with sexuality must have a good understanding of his or her own sexuality. It is inappropriate for the practitioner to impose upon the client a personal view of sexuality. My third assumption is that sexuality should be dealt with in the same way as other important issues in the health care setting. Since the author is a physician, I offer the medical model. It is the process of taking a history, performing a physical examination, and making a diagnosis followed by specific recommendations. The medical model lends itself to the topic of sexuality

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when the individual also has a physical disability. Some examples from our Sexuality and Physical Disability Clinic may help to illustrate the model.

EXAMPLE 1

A young woman with muscular dystrophy presents with severe hip flexion contractures and a compensatory lumbar lordosis. Her concern is how she can use and position her body for genital sexual activity.

EXAMPLE 2

A 62-year-old married man attends clinic with his wife. He is referred for evaluation of erectile dysfunction. He has a very satisfactory forty-year relationship with his wife. His problem began after an acute myocardial infarction six years earlier. Before then, he experienced only minimal difficulty with erectile function. Their customary sexual pattern was to have sexual intercourse once a week and they have used the same female dominant position. Since his heart attack, his erectile dysfunction is somewhat improved by changing to a male dominant position. He and his wife rate sexual intercourse and their own orgasms as relatively unimportant to themselves but very important to each other. His examination was normal including his genital, vascular, and neurologic examinations.

EXAMPLE 3

A 37-year-old married woman comes to clinic alone. She complains of pain on intercourse. This is her third and her husband's second marriage. She was well until a motor vehicle accident about fifteen months earlier. Since then, she has had incapacitating back pain. Physicians have told her she must "learn to live with it." She received six months of physical therapy and many medications for pain and relaxation which did not help. She does not use alcohol and she gives guarded reference to impending litigation. Prior to her accident, she was ambivalent about sex, because intercourse often led to pain due to difficulty with vaginal lubrication. She now dreads sexual intercourse because of the back pain which it produces. She also worries about lack of vaginal lubrication leading to frequent breaking of the condom which is their preferred choice of contraception. She is seeking help to "rescue the marriage." Their social life had deteriorated because of his concern for her pain. Her gynecologic examination six months ago was normal.

EXAMPLE 4

A 46-year-old man attends clinic because of erectile dysfunction and a spinal cord injury. His wife attended with him and remained in the room throughout the interview. He has been married for seventeen years and the couple have adopted two children. He worked as a laborer, had been physically active all of his life, and greatly valued outdoor sports. Two and a half years ago he became a C/6 incomplete quadriplegic in a motor vehicle accident. His neurologic function has improved over the last several months, and there is now hope that he will be able to walk again. Financial matters are secure since he has no-fault and other insurance programs. His initial request was for a penile implant. He wanted a sufficiently large and stiff penis to resume intercourse and he would like his penis to securely retain a condom-like external catheter. He has two attendants who are in their home all of the time. He brings with him detailed records, on which he and his wife have documented numerous aspects of his physical condition. Prior to his accident, he weighed 400 pounds but he has lost 100 pounds since then. His wife is also obese and they had adapted their postures in order to have penile-vaginal intercourse. Following his accident, they could not assume the same physical postures for intercourse nor would his flaccid penis allow penetration. He and his wife sleep in the same room but in different beds. She is very upset about the invasiveness of the constantly present attendants. On one occasion, they had been interrupted by an attendant coming into the room while they were attempting sexual activity.

These four examples illustrate problems for which the medical model can be helpful. However, information about common sexual dysfunctions and sexual behavior is not helpful by itself. I ask that you reflect on how you would manage these cases.

DEFINITIONS OF COMMON SEXUAL DYSFUNCTIONS

Conventional information about sexuality divides problems into male and female sexual dysfunctions. The most common male prolem is erectile dysfunction, improperly and pejoratively called impotence. (A term equally unfortunate is frigidity when applied to women.) Other male problems are delayed ejaculation and premature ejaculation. A fourth common problem is sexual aversiveness.

Women have another set of commonly seen problems. One is called dyspareunia or pain on intercourse. A second problem, pre-orgasmia, describes a situation in which a woman has not yet experienced her first orgasm. A third problem is secondary orgasmic dysfunction in which she no longer has the

orgasms she wants when she wants them. Like men, women can also experience sexual aversiveness. A last, and uniquely female, problem is vaginismis or tightening and spasm of the perivaginal muscles preventing penetration.

Does information about common sexual problems help the clinician with the examples cited above? By itself, I believe not. However, the medical model of an interview coupled with a physical examination can lead to the creation and offering of specific interventions which are both helpful and educational.

THE INTERVIEW

This discussion assumes that the person being interviewed is an adult. The interviewer should ask about previous sexual experience. How one approaches the patient or client depends upon whether there have been previous experiences. A fundamental issue is to determine whether or not the problem is primarily or only secondarily related to the disability. The presence of a physical disability does not ensure that the sexual dysfunction and the disability are causally linked.

The medical model starts with a history, progresses to an examination, and concludes with recommendations. The examiner begins with the chief complaint, obtains a history of the illness, queries about past medical events, obtains a social history, and then reviews the body's organ systems. Unlike the traditional medical model, however, when obtaining a sexual history, one must provide information and education at the same time. Not to do so can produce fright. Whereas one may ask a person about diarrhea or headaches without evoking fear and anxiety, it is not wise to ask a person about sexual practices and feelings and then remain silent. Raising the question might be frightening. Patient education is a mandatory accompaniment to the history taking process.

Questions About Genital Function to Ask Men

One should ask about erections—when they occur and their character (firmness, duration). Also ask about ejaculation. The sensation of ejaculation is very important to many men. If the sensation has decreased or changed in quality, men may view it as a sexual dysfunction. Visible evidence of ejaculation is also important to some men who draw conclusions about their male sexuality from the volume of their ejaculate.

Questions About Genital Function to Ask Women

Vaginal lubrication is important for comfort. One should ask if it is sufficient to facilitate vaginal stimulation. Ask also about vaginal pain. The impor-

tance of this was pointed out earlier in one of the examples. Another issue is arousal. Is the woman sexually aroused when participating in sexual activities? A unique issue for women is menstrual periods. Does menstrual pain interfere with her willingness or her ability to be intimate? Does she engage in or avoid sex during menses? Orgasm is also an important topic to ask about. Ask about the sensation as well as its importance to her. While some people are not greatly concerned about their own orgasm, it may be important to the partner.

Questions for Men and Women

Masturbation is an important area of discussion for both men and women. Is it a solitary act or is it done with one's partner? If masturbation is done privately, does the person feel shame or embarrassment? Masturbatory habits are varied. For some people masturbation must include orgasm and for others it may be simply touching or caressing. Questions should be asked about erection or lubrication during masturbation as well as the character of orgasm with masturbation. Some people believe it is wrong or sinful to give or receive pleasure through masturbation. Information about moral or religious beliefs may provide insight about masturbation as well as about the choices of sexual options. What people do or experience when they masturbate by themselves compared to what they do when having sexual activity with another person can give clues to diagnosis.

What is the sexual orientation of the person? One cannot assume a heterosexual orientation for everyone. For some, orientation is bisexual and for others it is homosexual or same sex. One cannot assume that all married people are heterosexually oriented.

It is critical to know each person's expectations for sex. A male patient said he was dissatisfied with his sex life because the world did not "shake underneath me" when he had his orgasm. His expectation was important to understand in the context of medical assessment.

Associated medical issues also need to be explored. In today's society, it is necessary to learn how much the patient knows about sexually transmitted diseases and safe sex practices.

Knowledge about medications is important because some affect arousal, concentration, erectile function, or ejaculation. Alcohol or drug abuse are frequently the cause of sexual dysfunctions.

Questions for the Partners

Ask the patient to estimate the importance which his or her partner attaches to the problem under discussion. What are the partner's opinions, expec-

tations, and satisfactions? It is most useful to confirm the replies with the partner directly. Sometimes one partner does not fully understand the other's opinions. Ask also about the couple's relationship, its status, how long it has been in effect, its strengths and weaknesses, and how effectively the partners communicate with each other. Ask the couple jointly about their sexual activities, frequency, who initiates, and about the variety of their activities. Variety is not necessarily the spice of life to some people. Some want the comfort of sameness and repetition. Ask about desires and fears that the person might have. Concerns about self image, fertility, and pregnancy can all profoundly influence the sexual experience. And don't forget to ask about physical and mental abuse which is increasingly recognized as an epidemic in our country today.

A sexual history includes a social history. Because of the great amount of diversity in the Western world, it is important to touch upon religious, moral, and cultural influences on sexuality. Living arrangements may be part of a sexual dysfunction if privacy and comfort are absent. How much privacy can be obtained and how much dependence or independence exists within the partnership? Conclude with a review of systems just as one does in the traditional medical model. Throughout the interview, one needs to provide education in order to remove fear from the process.

The Environment

One should create an appropriate environment for the interview in order to promote information exchange. Simply sitting down with someone and talking about intimacy is not likely to succeed unless you can make the interview room a comfortable place. Ambience may be more important in this situation than when taking a traditional medical history. Comfort is essential. There are many ways to achieve it and it must be done because you will be talking about some of the most intimate, interesting, or fearful aspects of a person's life.

How does one enter another person's personal space quickly when there is so little time? One does so by asking for and receiving permission to do so. Explain that, in the process of gaining information and helping, you must ask questions about the patient's personal and private life. Point out that the best way to help is to ask questions and request answers. Ask if you may proceed and you will almost always be told, "Yes." You now have permission in your hand and you have taken the worry out of being emotionally close to the interviewee. You have permission to proceed. Doors are open.

There are ground rules for the interview. In the process of asking direct and specific questions that might be considered prying under other circumstances, explain that if a person wishes not to answer a question, there will be no urging to do so. In these ways try to establish comfort.

It is also important to observe body language which can say much. Facial expressions, body tension, relaxation, disapproval—they all can be indications of unspoken thoughts. The examiner must be equally aware of his or her own body language. Sit forward, smile, be friendly, look interested. Watch for these unconscious communications.

"The elephant in the room" is a term I have borrowed over and over again. Simply put, it is this. If an elephant appeared in a room where two people are talking, it would be unthinkable not to acknowledge its presence. In an interview session, elephants sometime appear, e.g., scarcely hidden hostility, an obvious contradiction of fact with opinion, chemical dependency, etc. Ignoring the obvious is dysfunctional. One should acknowledge it. One should also be forthright, honest, and supportive.

Think about the language being used. A person may be more comfortable with such words as "hard on," "come," and "screw" instead of erection, orgasm, and intercourse. For purposes of communication, the examiner should choose language that is meaningful to the patient. Doing so doesn't mean bringing oneself to another level. It means communication. If it is uncomfortable to use such language, you may wish to practice in order to become more comfortable. In this way, words do not become handicaps to communication.

One needs to clarify, constantly clarify. Earlier I stated that one cannot assume that a patient is heterosexual simply because most people are. In another context, one cannot assume that the patient or client is attempting "sexual intercourse" unless one is clear about the activity that is being called sexual intercourse. One cannot assume that a person talking about masturbation is describing masturbation as you understand it. You cannot assume. You must ask. Therefore, I recommend that you clarify, clarify, clarify.

Through the entire process, be affirming both of the patient and of sexuality. It is harmful not to affirm the person in distress as a valuable person and it may be damaging not to affirm sexuality. Lastly, bestow ownership of both the problem and the solution upon the person or couple. In this way, the attention and commitment of the person or couple is focused upon problem identification and solution. Contrariwise, it is tempting for some people to deflect their problems or transfer them to the examiner. Make it understood that the issue presented to you is not yours. It belongs to the patient/client and he/she owns the solutions that might be found.

CONCLUSIONS

I will conclude with a last case example using the specific disability of head injury. It provides an excellent context in which to apply some of the concepts discussed above.

Behavioral Issues

Appropriateness, language, grooming, and mannerisms are some aspects of behavior which are affected by head injury. They have clear correlates in terms of sexual initiatives as well. The appropriateness, grooming, and mannerisms of a head injured person can be thought of in sexual terms. They frame the questions to be asked and the things to look for. Executive functions are often affected in people with head injury. Abstract thought, initiative, focusing, planning, organization, follow through, and self monitoring are examples of executive functions which correlate directly with sexual activity. Brain injury can affect sexuality simply by affecting cognitive function.

Emotional issues can be affected by brain injury—affect, impulsivity, irritability, or rage. These emotions can be recast in sexual terms and take on special and poignant meanings. Misapplied they can completely inhibit intimacy.

General Sexual Issues

Several other general issues apply to all physically disabled people as sexual human beings. Does the disabled person still feel in charge of self, still feel like an adult? Has the disability produced feelings of dependency and infantilization? The person may still keep memories of former experiences and grief and anger may arise from the disability. Role boundaries between the disabled person and care-providing family members may be crossed and lead to confusion and anxiety. These issues must be recognized by the treating professional and steps taken or referral made for their management.

SUMMARY

I believe that the familiar medical model can serve the health practitioner very well in working with a person who is disabled. It can assist in gathering information and in making recommendations within the sexual arena. In considering sexuality and disability at the same time, one cannot be limited to dealing with customary sexual dysfunctions. Specific guidelines for gathering information are developed through several case examples which bring together the factors of sexuality and physical disability.

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