

ADOLESCENT SEXUAL DEVELOPMENT AND SEXUALITY

Assessment and Interventions

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Chapter 16

Sexuality Issues for Adolescents With Physical and/or Developmental Disabilities

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INTRODUCTION

It is important to address issues of puberty, sexuality, and reproduction with adolescents with disabilities and their families. More and more youth and young adults with disabilities are presently cared for at home or in small group environments, rather than in large institutional settings. Many receive specialized education and services for the handicapped, with the aim of integrating them into society. Sexuality and reproductive decision making have become issues many have had to confront. Preparing such youth in a sensitive, developmentally appropriate manner for the physical and psychosocial changes that accompany adolescence has become an important task for medical and mental health providers (Blum, 1997). In addition to educating youth with disabilities and their caretakers about puberty and sexuality, it is often necessary to discuss prevention of unwanted pregnancy and victimization and offer contraception when appropriate.

BARRIERS TO OBTAINING REPRODUCTIVE HEALTH CARE

Similar impediments to accessing reproductive health care exist for teens with physical and developmental disabilities as exist for adolescents who are chronically ill. For most teens with disabilities, fewer opportunities exist to acquire information about sexuality, fertility, and contraception. Schools for the

handicapped do not routinely teach sexuality and reproduction. Parental over-protection of adolescents with handicaps may also hinder acquisition of sexuality information and may make teens with questions too self-conscious to ask. The medical provider should assume a poor knowledge base when counseling such adolescents (Stevens et al., 1996).

In addition, adolescents with physical disabilities may receive their health care primarily from subspecialty medical providers, such as orthopedists, cardiologists, or neurologists. An unfamiliarity and discomfort with reproductive health care issues may discourage subspecialty providers from discussing sexuality with their patients. Also, it may be difficult for youth with both physical and development disabilities to access reproductive health care confidentially, on their own, as they may be dependent on others for mobility.

SEXUALITY COUNSELING ISSUES

The goal of sexuality counseling depends on both the cognitive level and maturity of the adolescent. If cognition is appropriate for age and development, counseling should be geared toward teaching an adolescent about sexuality, possible physical impairments that might interfere with its expression, and negotiating relationships. If associated developmental disabilities are present, the medical provider must educate and counsel according to the level of the patient's understanding, often working with the parent/caretaker to ensure that sexuality is expressed in a safe and appropriate manner. For teens who are cognitively impaired, counseling should include discussions of privacy with respect to sexual body parts and appropriate public behavior (Quint, 1999).

Adolescents with more visible disabilities face different challenges than those whose primary impairment may be cognitive. Opportunities for social interaction and sexual exploration may be limited for those teens who depend on others for mobility or who require constant assistance in most activities of daily living. Achieving a sense of independence and privacy is necessary in order for such adolescents to develop romantic relationships and to explore their sexuality. In addition, as body image becomes an important concern during adolescence, teens with visible disabilities and intact cognition may feel frustrated, self-conscious, and, at times, depressed. Speaking confidentially with such adolescents, not in the presence of caretakers or aides, may be a first step in allowing them some autonomy in their sexual lives.

For those whose disability is primarily cognitive, different issues must be addressed (Elkins & Haefner, 1992). Adolescents with cognitive disabilities may look like their peers and attempt to engage in relationships without the social awareness that can protect them from victimization. They may have little understanding of puberty and reproduction. These teens must be prepared for the body changes associated with puberty in a concrete, reassuring manner, appro-

appropriate to their level of comprehension. Caretakers as well should be counseled about puberty, and the potential for sexual activity and abuse. Contraception may need to be discussed early, depending on the opportunities for social interaction and the level of risk assessed (Philips & Shulman, 2000; Quint, 1999).

Adolescents with physical and/or developmental disabilities may experience social isolation, with restriction of peer groups, depending on their living and educational situations. Social immaturity may impair their judgment and allow teens with handicaps to make poor social choices. Prior to any discussions of sexuality, the medical provider needs to assess the teen's level of functioning with respect to independence, social awareness, ability for abstract thought, and understanding of future consequences. An adolescent's ability to enter into a consensual relationship is of major import. The provider should gently try to identify any possible history of sexual exploitation or abuse. Of note, for teens with both physical and mental disabilities, issues of menstrual hygiene may be of more immediate concern to families and caretakers and may offer an entree into discussions of sexuality and contraception (Quint, 1992).

The Gynecological Examination

The provider should first explore with the patient (and often, with the family) the impact of the physical disability on sexual anatomy and physiology (Elkins & Haefner, 1992). A comprehensive examination can be undertaken, if the patient understands and can cooperate, and when she is ready, to determine the level of sexual functioning that is present and the degree of physical sensation the teen is capable of feeling. For adolescents who are already sexually active, a pelvic exam is recommended but may be difficult to perform. The patient may not be cognitively capable of understanding the examination and may not allow it. Visual aids that clearly show the female anatomy, as well as anatomically correct dolls, may be helpful in preparing the teen with mental disabilities for the pelvic examination. Patients with physical disabilities and spasticity may have difficulty using stirrups and positioning themselves in order to allow a speculum exam. Accommodations may need to be made, such as foregoing the use of stirrups or examining a patient on her side, and partial or incomplete examinations may have to suffice ("Reproductive health care . . ." 1997).

Fertility and Contraceptive Counseling

Fertility Issues

When counseling youth with disabilities, reproductive potential must be explored, with attention to genetic factors and the risk to the fetus from med-

ications or primary maternal conditions. Many young women with physical disabilities are fertile. Women with paraplegia are generally capable of conception and carrying a pregnancy to term. Women with Down's syndrome have an increased risk of having children with Trisomy 21 and a secondary increased risk of miscarriages and stillborn pregnancies, but they can have normal pregnancies. It is advisable to consult with a geneticist when counseling young women with possible genetic conditions, in order to assess fetal risks (Philips & Shulman, 2000, p. 7).

Contraceptives

The patient's disability will certainly have an impact on the contraceptive methods available to the teen and her ultimate choice. The medical provider must assess the adolescent's manual dexterity (Can the girl take pills out of container? Can she insert a diaphragm or a vaginal ring?) and whether the parent/caretaker is available to help. The patient's mobility and risk for thromboembolic disease, especially if she has circulatory problems, also will influence her contraceptive choice. In addition, the provider must assess how the patient's physical/mental impairment will affect her ability to adhere to a contraceptive regimen. Often legal guardians and/or caretakers will need to be involved in the decision to choose a contraceptive method, especially for those adolescents with significant cognitive impairment, and if so, they should be informed of the risks and benefits of the chosen method (Kjos, 1999).

With all adolescents who are capable of understanding, condom use should be stressed, even if another method of contraception is also dispensed. It may be helpful to actually demonstrate what a condom looks like and how it is used. The need for protection against sexually transmitted infections should be emphasized, and it should be reiterated concretely that infected persons may be asymptomatic.

Combined oral contraceptives or the transdermal patch (Ortho-Evra®) can be prescribed for many adolescents with disabilities. Advantages include regulation of menses with the potential for less dysmenorrhea and decreased menstrual flow as well as a reduction in premenstrual symptoms. An adolescent with disabilities may need a caretaker's help with pill dispensation and patch application and removal, or with supervision and reminding. Teens with immobility, who may be at risk for blood clots, those with uncontrolled hypertension, and those with a history of a cerebrovascular accident, however, should not be offered estrogen-containing pills and should be counseled to use progestin-only methods of contraception.

Injectable progestin-only contraception, Depo-medroxy-progesterone-acetate (DMPA), is a good choice for teens who may not adhere to a daily pill regimen or who have contraindications to estrogen. Although there may be

irregular menstrual bleeding after the first injection, this usually subsides with time, and amenorrhea is eventually common. Not only is DMPA an excellent method of contraception, it may have the added benefit of aiding with menstrual hygiene by temporarily ablating menses. Of concern, however, is the long-term risk of osteoporosis associated with DMPA; this may be particularly worrisome for teens with immobility who have an independent risk of osteoporosis during their lifetime. Some experts encourage supplemental oral calcium for at-risk patients on DMPA. In addition, some patients on this method experience weight gain, which can be problematic for adolescents with disabilities who depend on others for transfers and mobility.

The diaphragm is a method rarely recommended in adolescence and may be particularly challenging for teens with disabilities to use, as it requires forethought, manual dexterity, and a maturity usually achieved only in young adulthood. The intrauterine device (IUD) may be an acceptable method for certain adolescents with disabilities, as it is long lasting and metabolically neutral. However, concerns about the risk for pelvic infection and the need to monitor for side effects and check the string may make its use somewhat limited in teens with disabilities. Another progestin-only method of contraception, the subdermal implant (currently unavailable, although several newer systems may be released in the future), may again become an option for adolescents with disabilities; however, this method requires patient cooperation for insertion and removal, and for patients on certain anticonvulsants, there is significantly reduced efficacy. The progestin-only pill (mini-pill) may also be an option for teens with estrogen contraindications or for those who may not desire an injectable method. However, consistent daily use for this pill in particular must be emphasized, as efficacy decreases significantly if it is not taken at the same time daily.

Sterilization formerly was considered the contraceptive method of choice for women with severe mental disabilities; however, as awareness of the civil rights of the mentally handicapped has increased, involuntary sterilization is no longer considered an acceptable option for most women with disabilities ("Reproductive health care . . .," 1997). Many providers are now uncomfortable recommending a nonreversible contraceptive method for women who cannot clearly give consent. Currently, health care providers tend to favor other effective reversible methods of contraception over sterilization. Often parents of young women with severe disabilities request sterilization because they fear unintended pregnancy; usually they can be convinced to try another effective reversible contraceptive. In the rare circumstances when sterilization is seriously being considered, state regulations need to be clarified, and consultation with an ethics committee, other health care providers, family members and caretakers, and mental health services is necessary prior to proceeding.

The availability of emergency contraception (either the progestin-only or

the estrogen/progestin combination method) should be stressed to both adolescent patients and their caretakers. In cases of unprotected sexual activity, the teen should be counseled to present to a medical provider as soon as possible, but within seventy-two hours, for dispensation of emergency contraception. There are few contraindications to emergency contraception, and it can be reassuring to both adolescents and their families to have such a "just-in-case" medication available.

CONCLUSION

With mainstreaming of adolescents and adults with physical and developmental disabilities into general society, and with increased opportunities for educational and social integration, it has become important to counsel such youth about sexuality and reproduction. Medical and mental health providers need to be particularly sensitive to the patient's cognitive status, as well as to the level of emotional and social maturity. Often families and caretakers need to be involved in this process. There are many contraceptive options available to youth with disabilities; as always, risks and benefits must be weighed against the possibility of unintended pregnancy. If in doubt, expert consultation should be sought.

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