Reproductive Management Strategies

Women in the United States with intellectual and/or developmental disabilities who lack either the cognitive or physical ability to manage reproductive care issues have historically had these issues managed for them, both by caregivers and medical providers, at the discretion of their legal guardian. Reproductive healthcare decisions related to menstruation, hormone administration, contraception, pregnancy/parenting, and surgical sterilization have been made with little regard for the individual's preferences or legal rights.

The last two decades have brought considerable change in attitudes concerning persons with disabilities in general. The advent of the American with Disabilities Act of 1990 helped bring focus to the issues facing individuals living with disabilities in the U.S. People with intellectual or developmental disabilities are no longer maintained primarily in institutional settings, but are residing in supported living settings within their communities. As people with intellectual and developmental disabilities become more independent, access to appropriate reproductive healthcare services becomes increasingly important.

Primary care providers should be informed concerning reproductive healthcare issues specific to the care of women with significant intellectual and/or developmental disabilities. These issues include: maintaining adequate hygiene during menstruation, access to sex education and the expression of sexuality, behavioral issues related to hormonal cycling, appropriate methods of contraception, risk for sexual abuse and reporting procedures, and legal implications of guardianship status on provision of care.

Menstrual hygiene - Studies have shown that the majority of women with intellectual disabilities can manage menstrual hygiene with appropriate education and repetitive coaching. Menstrual management using hormonal therapy to induce amenorrhea or reduced menstrual cycling is frequently used for individuals whose level of intellectual disability absolutely precludes adequate menstrual hygiene. In extreme cases, endometrial ablation or hysterectomy may be considered.

Endometrial ablation - refers to the removal or destruction of the endometrium, or lining of the uterus. Endometrial ablation may be performed as a treatment for heavy uterine bleeding. In approximately 60% of cases amenorrhea is produced. Endometrial ablation typically produces sterilization; however, there is not 100% certainty of this. Areas of the uterine lining are difficult to reach and may thus remain viable. Pregnancy conceived subsequent to ablation is considered very high risk. This procedure may be performed in an outpatient setting.

Hysterectomy - hysterectomy refers to surgical removal of the uterus. The rationale for this procedure in women without disabilities is typically related to malignancy or other disease conditions. Hysterectomy in women with severe intellectual or developmental disabilities may be performed to stop menstruation or insure sterility. This intervention should only be considered after all other measures have been exhausted.

Sex education - Individuals with intellectual and/or developmental disabilities should be educated concerning their bodies, appropriate expressions of sexuality, gender differences, reproductive healthcare, prevention of sexually transmitted diseases, masturbation, definition of sexual abuse, etc. Care providers should not assume that a patient with an intellectual or developmental disability is not sexually active.

Sexual expression -Women with developmental and/or intellectual disabilities possess the same human right to sexual expression as other women. Women with intellectual disabilities should receive sex education - including instruction in appropriate outlets for sexual drives. Where indicated, individuals should be encouraged to use discretion during masturbation, in a non-judgmental manner.

Behavioral issues and hormonal cycling - fluctuations in hormone levels during a woman's monthly cycle may result in fairly significant mood swings as well as concomitant changes in behavioral patterns. As frequently occurs in cycling women without disability, emotional lability may be present. Some women with intellectual disability may become aggressive during the premenstrual and menstrual phase of their cycle (see resource document on Biological Setting Events). This may be related to an inability to verbally express feelings of pain. Women experiencing significant symptoms frequently respond to medical intervention, such as hormonal regulation or treatment with an antidepressant such as an SSRI.

Contraception for women with significant intellectual and/or developmental disabilities is a controversial subject among caregivers, guardians, healthcare providers, and lawmakers alike. Women with intellectual disability may or may not be capable of consenting to sexual relations. However, primary care providers caring for women with

intellectual or developmental disabilities should not assume that the woman is not at risk for pregnancy. An individual with a legal guardian in some situations may still be capable of consensual sexual activity. Furthermore, women with intellectual or developmental disabilities are at increased risk for sexual abuse - which may result in pregnancy. Some frequently employed methods of contraception are briefly outlined below.

Non-surgical contraceptive methods

Condoms/Spermicides - require fairly high level of cognitive functioning to be effective; may be an effective option for those with mild degree of intellectual impairment. Condom use offers the added benefit of STD prevention.

Oral contraceptives - Oral contraceptives, when taken as prescribed, are a very efficient means of birth control, with efficacy approaching 100%. Oral contraceptives consist of hormones, thus may also be used to regulate the menstrual cycle and reduce menstrual flow. Many parent/caregivers report difficulties with daily administration. The risk of potential side effects (e.g., breast cancer and cardiovascular disease) from lifetime administration, as well as viable alternatives, should be seriously considered before prescribing oral contraceptives.

*It is important to note that some anti-seizure medications may alter hormonal enzyme metabolism and thus potentially decrease the effectiveness of both oral and transdermal hormone-based contraceptives. Additionally, women with mobility limitations may experience an increased risk of thrombosis; thus potential cardiovascular effects of oral contraceptives should be carefully considered before prescribing these agents to women in this population.

Injections of the drug Depot-medroxyprogesterone Acetate (DMPA) are generally well tolerated by patients and typically receive high overall satisfaction ratings by parents/caregivers of women with significant intellectual/developmental disabilities. DMPA induces amenorrhea, reduces hormonal cycling, and is a highly effective contraceptive. One of the benefits of DMPA is that it need only be administered four times per year. Primary care providers should be aware that the drug does cause significant weight gain. Furthermore, hormone therapy has been linked to unfavorable cardiovascular effects and breast cancer. All factors should be considered before prescribing DMPA.

Transdermal contraceptive patch - transdermal estradiol delivery systems such as the norelgestomin/ethinyl (Ortho Evra) patch offer an attractive alternative to oral hormonal contraception for some women. The patch is easy to apply and need only be applied once weekly. Hormone levels typically fluctuate less with this system of delivery - thus the 'patch' has the potential to alleviate some of the behavioral symptoms of estrogen withdrawal.

Contraceptive surgical interventions

Endometrial ablation - refers to the removal or destruction of the endometrium, or lining of the uterus. Endometrial ablation results in amenorrhea in 60% of cases, and typically produces sterilization; however, there is not 100% certainty of this. Areas of the uterine lining are difficult to reach and may thus remain viable. Pregnancy conceived subsequent to ablation is considered very high risk. This procedure may be performed in an outpatient setting.

Tubal ligation - involves surgically severing or blocking the fallopian tubes in order to prevent pregnancy. Tubal ligation represents 72% of all sterilization in the United States. Major complications from the procedure are rare, with an estimated incidence of 0.5%. Tubal ligation is nearly 100% effective in preventing pregnancy. Tubal ligation does not require an abdominal incision or general anesthesia and may be performed in an outpatient setting under conscious sedation. Tubal ligation alone does not affect hormonal cycling or menstruation; however, the procedure offers a much less invasive and safer alternative to hysterectomy for those wishing to produce sterilization.

Hysterectomy refers to the surgical excision (removal) of the uterus. This procedure is either performed through an incision in the suprapubic area or through the vagina. Hysterectomy eliminates menstrual bleeding and prevents pregnancy. Hysterectomies may include the removal of the ovaries and fallopian tubes. In this case, the procedure results in hormone withdrawal and sudden onset of menopause. The opinion (1999) of the American College of Obstetrics and Gynecology is that "hysterectomy performed solely for the purposes of sterilization is inappropriate."

Kirschner, K.L., Gill, C.J., Reis, J.P., & Hammond, C. (2005). Health issues for women with disabilities in J.A. Delisa (Ed.), *Physical medicine and rehabilitation: Principles and practice*, 4th ed., (Vol. 2). New York: Lippincott, Williams, and Wilkins.

Long, L., & Montouris, G. (2004). Knowledge of women's issues and epilepsy (KNOWIE-II): A survey of health care professionals. *Epilepsy & Behavior, 6*, 90-93.

Paransky, O.I., & Zurawin, R.K. (2003). Management of menstrual problems and contraception in adolescents with mental retardation: A medical, legal, and ethical review with new suggested guidelines. *Journal of Pediatric and Adolescent Gynecology, 16*, 223-235.

Servais, L. (2006). Sexual health care in persons with intellectual disabilities. *Mental Retardation and Developmental Disabilities, 12*, 48-56.

Zupanc, M.L. (2006). Antiepileptic drugs and hormonal contraceptives in adolescent women with epilepsy. *Neurology, 66*, S37-S45.