Women with Disabilities: Reproductive Care and Women’s Health

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Women with disabilities: Reproductive care and women’s health

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Abstract

Children, adolescents, and women with disabilities experience the same sexual development, pubertal changes, concerns, and desire to reproduce as their typically developing counterparts. However, society has tended to stigmatize women with disabilities as “asexual” and ignore this aspect of their health care. These women are less likely to receive gynecological exams, contraception, and evaluation of sexual dysfunction. Unfortunately, having a disability places women at risk for sexual exploitation and abuse as well as sexually transmitted infections. Therefore, reproductive health care for these women is imperative. A number of barriers to receiving reproductive care exist. However, with proper education and knowledge on the part of women with disabilities, schools, caregivers, and health care providers, these barriers can be overcome.

Keywords: Disability, women with disabilities, reproductive care, women’s health, sexuality, contraception, barriers to care

Introduction

All women have a right to reproductive care regardless of intellectual or developmental disability. Unfortunately, this right has traditionally been overlooked or neglected by many health care providers. Often, women with disabilities are considered to be ‘asexual.’ We have found, however, that women with disabilities are just as likely to be sexually active as women without disabilities. Sex is an innate human desire regardless of mental or physical capabilities. It is a basic human need involving feeling valued and attractive. Giving and receiving affection and sharing are needs that are met through sexual behavior (1). All people have a desire to love and to be loved. The initial coital act is called sexarche. In most cultures of the world sexarche occurs sometime during adolescence (2). A number of
factors influence sexual behavior. These factors include society, one’s physical body, one’s cognitive functioning, and one’s emotions.

### Physical barriers to care
- Lack of transportation
- Small doorway, difficult for wheelchair
- Non-electric doors
- Lack of ramps or stairs-only
- Lack of scale that accommodates wheelchair
- Small hallways, difficult for wheelchair, cane, crutches, etc. to navigate
- Small exam rooms, door may not close with wheelchair inside

### Access to care

All women, especially those with an intellectual or developmental disability should have access to reproductive health care. A disability may be physical, developmental, or due to mental illness. The World Health Organization (WHO) breaks down the term “disability” into three domains. The first is impairments or deviations from the “norm” in the population. This includes losses of body structure or function. The second is activity. This is a person’s ability to perform a task. The third domain is participation or involvement in life situations. Whether someone is disabled is partially caused by contextual factors. Contextual factors include the roles that society imposes as opposed to looking at an individual and their own strengths (3). Approximately 27 million women in the United States have a disability and the number is growing. Of women over 65 years of age, 50% report living with a disability (4). Women with disabilities need the same general medical care that all women require but may additionally require specialty care.

### Patient barriers to care
- Perceived lack of money
- Lack of comfort
- Lack of education
- Physical barriers
- Communication difficulty

There are a number of barriers to providing women with disabilities access to care. However, all humans deserve optimal quality of life and those with disabilities should not be excluded. Women with disabilities need reproductive healthcare and deserve to have aspects of sexuality, contraception, childbearing, and menopause discussed and evaluated by healthcare professionals. Barriers to care may include lack of time by the health care professional as there may be other medical, physical, and functional needs that need to be addressed during the office visit (1). Other barriers include difficulty navigating wheelchairs or special equipment through tight office hallways, waiting rooms or small exam rooms. There may be a lack of knowledge in the health care provider or lack of the patient being able to communicate a concern. In addition, there may be poor reimbursement for a health care provider’s services. There are also myths and misinformation among health care providers regarding the sexuality of women with disabilities (5).

### Provider barriers
- Lack of knowledge
- Lack of appropriate reimbursement
- Multiple medical problems
- Time constraints
- Lack of comfort

Studies have shown that adolescents with physical disabilities are as sexually experienced as their peers without physical disabilities (1). A study of adult women with chronic physical disabilities in the United States found that across all women, 3.5% report being currently pregnant. Of these currently pregnant women, 3.8% did not have chronic physical disability whereas 2.0% of women did report a chronic physical disability. The study concluded that women with chronic physical disability do become pregnant and that the numbers will likely continue to increase (6).

### Historical background

Since the 1970s the professional approach to care for women with disabilities has undergone significant changes. Women who were previously residents in chronic care institutions and hospitals are now integrated into the community setting. Instead of
having care provided within the institution or hospital, individuals and their caregivers must now seek care on their own (7). Also during the 1970s, up to 80% of parents and service workers favored sterilization as a form of birth control in people with intellectual disabilities (8). A study in 1984 found that 46% of parents reported having considered sterilization for their daughters with intellectual disability and 26% were actively seeking the operation. The interest in the operation was correlated with increased severity of disability and difficulty teaching menstrual hygiene (8). A study in 2002 found that parents and teachers of individuals with intellectual disability still supported sterilization as a form of contraception in persons with severe intellectual disability (8).

Historically, women with physical disabilities have been stigmatized regarding their reproductive and sexual health. Even some clinicians have viewed women with disabilities as asexual and unfit potential parents (6). Women with intellectual disabilities have also been stigmatized and not provided the opportunity to become mothers (9). In a society in which the terms motherhood and womenhood have often been used synonymously, women with physical and intellectual disabilities were often denied the opportunity to become mothers. This has been especially unfortunate as a women’s life throughout history has often been determined by her ability to reproduce, bear, and raise children (9). There is a history involuntary sterilization, coerced abortions, pressure to undergo tubal-ligations, overuse of long acting contraceptives, hysterectomies, and the loss of custody of children among women with disabilities (9).

The desire for sterilization of women with disabilities by parents and caregivers stems from concerns about vulnerability to abuse, ability to parent, and sexual hygiene (menstrual hygiene). There have been high profile legal cases regarding sterilization that was non-consensual (10). There has also been a suspicion of massive eugenic sterilization programs in different Western countries in order to “improve the gene pool.” These led to case reports, ethical and legal discussions, editorials, and retrospective review on the subject of whether “to sterilize or not to sterilize” persons with intellectual disability (10). Fortunately, as a result of increased public and healthcare professional research and awareness, there are now a number of options to effectively manage menstrual hygiene and contraception concerns without resorting to permanent sterilization.

Another extremely disturbing historical fact is that of “virginal cleansing.” For centuries, it was believed that sexually transmitted infections could be cured by having sexual intercourse with a virgin. Women with intellectual disabilities were often targeted as they were labeled as “virgins” and were reportedly placed in brothels in Victorian England. There is no documentation about the role of this practice in the spreading of sexually transmitted diseases among people with intellectual disabilities (10).

**Sexuality is a normal human desire**

All humans have a desire for sexual intimacy. Sexuality is a complex process involving one’s biologic sex, core gender identity, and gender role behavior (11). Health care professionals, parents, and educators may assume that because a woman has a disability she does not have sexual feelings or behaviors. However, there are normal stages of sexuality that all humans experience beginning in infancy. According to Erikson, psychosexual development proceeds through a series of stages. The stages are as follows: basic trust (ages 0 to 1 year), autonomy (ages 1 to 3 years), initiative (ages 3 to 6 years), industry (6 to 11 years), identity (ages 11 to 17 years, and finally, intimacy (ages 16 to 25 years) (12).

During adolescence, sexual development similarly follows predictable stages. Preadolescence is the first stage. During this stage, one’s body has not yet started to develop pubertal changes. Children are gathering information about sexuality. During early adolescence, the next stage (ages 11-14 years), pubertal changes have begun to appear. These adolescents are very concerned about their body and are curious about the changes that are occurring (13). They may have sexual fantasies or masturbate in response to sexual feelings (14). Sexual activities are most often nonphysical (14). They develop “crushes” and may transition from obedient to rebellious (13). At this age, adolescents have little ability to understand later consequences (14). Next is middle
adolescence (ages 15-17 years). Adolescents this age are very self-absorbed and introspective (13). They may withdrawal or rebel and test limits. These adolescents are becoming able to think abstractly as opposed to concretely (13). Pubertal changes are at their peak at this stage as well as risky behaviors (13,14). They can think of later consequences but do not always (14). The third stage is late adolescence (ages 18-25 years). These adolescents are able to think abstractly, they have mostly finished pubertal changes (13). They are able to establish more intimate sharing relationships which may include sexual relationships (13, 14).

Research has shown that adolescents with physical disabilities are as sexually experienced as their peers (1). However, these teens are more at risk of adverse consequences. Adolescents and women with disabilities are more likely to be victims of sexual abuse. They are also at risk of unwanted pregnancy and sexually transmitted infection, often due to a lack of education or lack of discussion about reproductive health at health care provider visits.

Puberty

Puberty is a difficult time for all adolescents, but especially for females with a disability. For a teen with a disability life itself is challenging. Puberty or the onset of menses can upset the delicate balance in a teen with a disability’s life (16). Puberty typically occurs in predictable, sequenced stages. In general, puberty and menarche (the first menstrual period) as well as monthly menstrual cycles are the same in adolescents with a disability as those without a disability (16). The typical progression of puberty in females is the onset of breast development (also called thelarche) which occurs on average at age 10 for Caucasian females and age 8.9 for African American females (17), followed by pubic hair development, growth spurt, and finally menarche. On physical exam, breast development and pubic hair development can be staged according to the Sexual Maturity Rating.

<table>
<thead>
<tr>
<th>Adolescent sexual development (13,14)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Preadolescence:</strong></td>
</tr>
<tr>
<td>- information gathering about sexuality</td>
</tr>
<tr>
<td>- lack of pubertal changes in the body</td>
</tr>
<tr>
<td>- masturbation which is a normal behavior</td>
</tr>
<tr>
<td>- concrete thinking</td>
</tr>
<tr>
<td><strong>Early adolescence (ages 11-14 years):</strong></td>
</tr>
<tr>
<td>- pubertal changes have begun</td>
</tr>
<tr>
<td>- body concern and curiosity</td>
</tr>
<tr>
<td>- sexual fantasies</td>
</tr>
<tr>
<td>- may masturbate in response to sexual feelings</td>
</tr>
<tr>
<td>- &quot;crushes&quot;</td>
</tr>
<tr>
<td>- previously obedient, may become rebellious</td>
</tr>
<tr>
<td>- little understanding of later consequences</td>
</tr>
<tr>
<td>- concrete thinking</td>
</tr>
<tr>
<td><strong>Middle adolescence (ages 15-17 years):</strong></td>
</tr>
<tr>
<td>- self-absorbed</td>
</tr>
<tr>
<td>- may test limits</td>
</tr>
<tr>
<td>- able to think more abstractly</td>
</tr>
<tr>
<td>- increased understanding of later consequences, but may be impulsive</td>
</tr>
<tr>
<td>- peak of risky behaviors</td>
</tr>
<tr>
<td><strong>Late adolescence (ages 18-25 years):</strong></td>
</tr>
<tr>
<td>- able to think abstractly</td>
</tr>
<tr>
<td>- rejoin with parents</td>
</tr>
<tr>
<td>- assumption of adult roles, commitment</td>
</tr>
<tr>
<td>- may have intimate sharing relationships</td>
</tr>
<tr>
<td>- sexual behavior more expressive</td>
</tr>
</tbody>
</table>

During adolescence, the goal is to be normal. Healthy adolescents do not need to prove they are normal. However, chronically ill or adolescents with disabilities do. For this reason, adolescents with disabilities may emulate risky behaviors as part of a normal process of maturation (15).
Sexual maturity rating – Breast development

<table>
<thead>
<tr>
<th>Rating</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>4.</td>
<td>Enlargement of the breast and projection of the areola as a secondary mound</td>
</tr>
<tr>
<td>5.</td>
<td>Adult configuration of breast, areola no longer projects as secondary mound</td>
</tr>
</tbody>
</table>

There are some conditions which are associated with early puberty. Overall, children with neurodevelopmental disabilities are 20 times more likely to experience pubertal changes earlier than their typically developing peers (1). The exact reason for this is poorly understood but may have to do with neurological changes involving the pathways that lead to pubertal development (1). Patients with spina bifida have also been demonstrated to have earlier sexual maturation. Most studies attribute this to a history of hydrocephalus, although data examining early puberty in females with spina bifida without hydrocephalus are lacking (12,18). The average age of menarche for females with spina bifida ranges from 10.9 to 11.4 years where the average age in females without spina bifida is 12.7 years (19). Other disorders associated with early puberty include obesity, intellectual disability, Williams syndrome, meningomyelocele, and neurofibromatosis (2).

Patients with cerebral palsy tend to start puberty earlier and end puberty later than their typically developing peers. The median age of menarche for Caucasian females with cerebral palsy is 14 years (12). One hypothesis about why children with developmental disabilities may go through, or finish, puberty later is that patients often have difficulty swallowing and gastrointestinal motility disorders that can affect their nutritional status (12). There is a known link between decreased nutritional status and delayed puberty.

<table>
<thead>
<tr>
<th>Disorders associated with early puberty (2, 18)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cerebral palsy</td>
</tr>
<tr>
<td>Hydrocephalus</td>
</tr>
<tr>
<td>Obesity</td>
</tr>
<tr>
<td>Mental retardation</td>
</tr>
<tr>
<td>Spina bifida</td>
</tr>
<tr>
<td>Williams syndrome</td>
</tr>
<tr>
<td>Neurofibromatosis</td>
</tr>
</tbody>
</table>

Societal factors as barriers for women with disabilities

There are entrenched social and cultural beliefs that create barriers for women with disabilities and prevent them from being able to explore their sexuality (19). This is a global phenomenon. Generally, this stems from a lack of knowledge and education. Parents of children with disabilities may be guilty of furthering this phenomenon. Parents may “infantize” their children with disabilities, especially those children and adolescents who need help with basic self-care (1). It is often easier to develop a set routine in caring for a child or adolescent with a disability than letting them practice and exercise independence. Especially for children and adolescents with difficulty communicating, it is not uncommon for a parent to forget that all adolescents have a desire to become more independent, and adolescents with disabilities are no exception (1). Parents are encouraged to optimize the child or adolescent’s independence in the areas of self-care and social skills (1).

An adolescent’s sexual development is influenced by many factors that can be classified as either internal or external (20). Internal factors include physical growth, mental development, neurological, and biological changes. External factors include exposure to violence, trauma, chemicals, and the family, peer, school, and neighborhood environment (20). Any of these factors may have a negative influence on an adolescent and impede the development of healthy sexuality. In particular, the adolescent may have poor self-esteem, a negative body image, or poor intimate peer relationships (20). Physical factors that may impede the development of healthy sexuality in adolescents include delayed physical or mental development, being overweight, and being physically different from peers (20). Exposure to violence negatively affects healthy development of sexuality includes sexual molestation, sexual assault, rape, being harassed or bullied, and dating violence. Adolescents with disabilities may have fewer opportunities to interact with peers and experience making social mistakes. They may engage in fewer socially reinforcing activities. They are often not prepared for dating relationships and have not developed the skills to avoid or prevent
nonconsensual sex or dating violence (20). The media also has a large influence on all of our children and adolescents and provides increased exposure to casual sex and dating violence with little concern about negative consequences.

**Sex education**

Sexuality education provided by parents, teachers, and health care professionals can help overcome barriers to healthy sexual development. All children, adolescents, and adults have the right to know about their body and understand how it works. Developmentally appropriate discussions that are introduced early and continued through adulthood increase comfort and awareness of important topics such as healthy sexuality, contraception, and sexual abuse. One study by McCabe et al found that 50% of people living with a disability had not received any form of sex education (19).

Children with disabilities have the same rights to sex education as their typically developing peers. Individual Education Plans (IEPs) in schools can include sex education for children with disabilities. Specifically, body parts, personal care and hygiene, pubertal changes, medical exams, social skills, contraception strategies, sexual expression, and rights and responsibilities of sexual behavior can be included in IEPs (1). The use of anatomically correct dolls, role playing, and frequently reviewing and reinforcing learned material are often beneficial strategies (1).

Parents actually have the biggest influence over their child’s behavior (21). Having open and close relationships between parents and children positively influences communication behavior. Parents can be active healthy role models for their children in addition to actively discussing how to have healthy relationships (21). Parents can teach children about appropriate ways to show affection (21). They can teach anatomically correct names of body parts and that certain parts are private (21). Parents can help children develop a healthy body image and be comfortable with who they are (21). They can discuss when and where it is appropriate to display sexual behaviors, including masturbation (21). They can teach the difference between love and sex and how to make responsible decisions about being sexually active (21).

Healthcare providers should also play a major role in sex education for children, adolescents, and women with disabilities. Discussing sexuality in a developmentally appropriate manner at every visit helps the woman to feel comfortable. Reassurance about the normalcy of sexual feelings and desires is important. Also, educating parents of adolescents with disabilities that sexuality is a part of all adolescent’s development and should not be ignored. Remembering that adult women with disabilities are not ‘asexual’ but actually at higher risk for not using contraception, having poor prenatal, pregnancy, and postnatal care, and at risk for sexual abuse and addressing these issues frequency is especially important.

**Sexual abuse**

Sexual abuse is a devastating, and unfortunately common, phenomenon. It is estimated that there are 3 million cases of abuse in those with and without disabilities under age 18. The cases are categorized as sexual abuse (14%), physical abuse (26%), neglect (53%), and emotional abuse (5%) (2). The Youth Risk Behavior Surveillance Survey from 2007 revealed that 9.9% of adolescents ages 15-19 had been slapped, hit, or otherwise physically hurt by their boyfriends or girlfriends (2). Research has shown that the prevalence of sexual abuse is higher in children, adolescents, and women with disabilities. According to the National Center on Child Abuse and Neglect, children with disabilities are sexually abused at a rate that is 2.2 times higher than that of their typically developing peers (1). The US Department of Justice reports that 68% to 83% of women with developmental disabilities will be sexually assaulted sometime during their lifetime. Also, less then half of them will seek legal assistance or treatment services (1). It is estimated that 4.8 million women experience intimate partner related physical assaults and rapes. Women with a disability are much more likely to report experiencing some form of intimate partner violence (37.3%) during their lifetime versus women without a disability (20.6%) (4).
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Adverse consequences of sexual abuse are numerous. There are psychological effects which include depression, sexual dysfunction, sleep disturbance, runaway behavior, youth violence, delinquency, school failure, and school dropout (2). Individuals with a history of abuse also are at risk for suicidal ideations, attempts, and completions (2). Physical effects may include enuresis (urinary accidents), sexually transmitted infections, and pregnancy (2). Additional consequences of sexual abuse may include excessive masturbation, juvenile prostitution, severe parent-youth conflicts, chronic drug abuse, and eating disorders (2).

Barriers to gynecological care

Worldwide, women with disabilities are confronted with barriers to receiving appropriate reproductive care. Studies of women with disabilities have shown that they are less likely to receive pelvic exams, Pap smears, mammograms, and sexual health information (18). McRee et al. used data from the National Longitudinal Study of Adolescent Health and examined associations between physical disability and multiple reproductive health indicators. It was found that females with physical disabilities had lower odds of having a pap smear in the past 12 months than females without disabilities. The study found similar odds for sexually transmitted infection (STI) screening (22). A study by Parish and Saville showed that women with cognitive disabilities had worse rates of receiving cervical cancer and breast cancer screenings but had better rates of receipt of influenza shots (23). Lin et al completed a study of 521 women in Taiwan with physical disabilities. They found that of women over 15 years, 71.5% had ever had a pap smear. In addition, the mean age of the first pap smear was 39.21 years (24).

The lack of care for people with disabilities is, unfortunately, a global phenomenon. For example, a study by Trani et al compared health status and access to care services between disabled and non-disabled men and women in urban and peri-urban areas of Sierra Leone (25). It was found that people with severe disabilities had less access to public health care services than non-disabled people after adjustment for other socioeconomic characteristics (25). It was also found that disabled women were as likely as non-disabled women to report having children and desiring another child (25). This showed that disabled women are not only sexually active but need access to reproductive health services (25).

Another study by Smith et al. evaluated how well health services in Lusaka, Zambia currently met the safe motherhood and reproductive health care needs of women who have physical impairments leading to disability (26). This study found that women with disabilities encounter various social, attitudinal, and physical barriers to accessing safe motherhood and reproductive health services. They found a general assumption among reproductive health care service providers that women with disabilities will not be sexually active. Women with disabilities may have a strong desire for children and affection which may leave them vulnerable to sexual exploitation. This in combination with the attitudes of health providers leaves these women more vulnerable to sexually transmitted infections such as HIV. The study also found that nurse-midwives had a fear of delivery complications in women with disabilities which may result in routine over-referral to tertiary maternity facilities. These facilities are outside the woman’s local community and may be difficult for her to get to due to mobility limitations (26).

In Taiwan, Lin et al found that caregivers did not have adequate supportive behaviors towards reproductive health care for women with intellectual disabilities, particular in arranging preventive reproductive health care. Again, caregivers often assume women with disabilities are not engaged in sexual activity and do not have the same reproductive health needs as the general population (27). A lack of education, as well as common societal beliefs, combine to result in decreased reproductive care for women with disabilities.

Women with physical disabilities in the United States have traditionally been referred to specialists, mainly physical medicine and rehabilitation specialists to coordinate and manage care. These specialists are not primary care providers and thus do not provide routine reproductive health care. This has led to gaps in women with physical disabilities routine health maintenance (including Pap smears, mammograms) (28). Adolescents and women with disabilities have the same reproductive health needs.
as their peers. They may, however, have medical problems that are more complex than the general population. They may have multiple medications to manage, require coordination with multiple specialists, have joint contractures that can make traditional gynecologic exams difficult, may have special nutritional needs, and may also have difficulty communicating (7).

A National Study on Women with Physical Disabilities, completed in the United States, reported that 31% of women with disabilities surveyed had been refused to be seen for medical care by a physician (29). Discrimination in healthcare may take many forms and involve a range of people. Discrimination could come from health care providers (physicians and nurse practitioners), support staff such as nurses, technicians, and schedulers, policy makers in government and industry, and even facility and equipment designers (29). Unfortunately, multiple studies have shown this discrimination is a global phenomenon that results in sub-par reproductive care for women with disabilities. Education, societal awareness, and government policies are all imperative for bridging this expansive gap of care.

**The office visit**

During an office visit for reproductive care, all efforts should be made to overcome barriers to care. As with all patients, care should be taken to ensure comfort during the visit. An ideal office setting has electric doors, an uncluttered waiting room, wide hallways, and large exam rooms to accommodate wheelchairs and special equipment. Office staff should be friendly and welcoming. The office should be equipped with a scale that accommodates wheelchairs. Primary care offices which provide medical care, mental health care, a nutrition specialist, and social work are comprehensive in their approach and can provide “one stop shopping” for women with special needs.

**Medical history**

A routine and thorough history should be completed including current concerns, medications, past medical history, hospitalizations, surgeries, immunizations, family history, and diet. A social history should be assessed at a developmentally appropriate level including who patient lives with, the patient’s educational level and career goals, social activities, and substance use. Violence or abuse that the patient has been exposed to should be assessed, and any abuse reported to appropriate authorities. A detailed and confidential sexual history is very important including total number of partners, gender of partners, type of sex (oral, anal, or vaginal), condom use, contraceptive use, exposure to sexually transmitted infections, menstrual history, and whether the patient has been coerced into participating in sexual activity. Assessing the patient’s attitudes and concerns about sexual activity and pregnancy is also enlightening and important for providing comprehensive care. The patient and caregivers can also be asked about concerns regarding the patient’s menstrual hygiene. Goals, especially in relation to menses, sexual activity, contraception, and pregnancy are important to assess.

### Factors complicating gynecologic care for women with disabilities (2,11)

<table>
<thead>
<tr>
<th>Factor</th>
</tr>
</thead>
<tbody>
<tr>
<td>Increased prevalence of orthopedic disorders (e.g., kyphoscoliosis)</td>
</tr>
<tr>
<td>Increased prevalence of joint complications (e.g., contractures, spasticity)</td>
</tr>
<tr>
<td>Possible difficulty with communication (with patient, caregiver, or clinician)</td>
</tr>
<tr>
<td>Lack of knowledge of caregiver</td>
</tr>
<tr>
<td>Lack of knowledge of healthcare provider</td>
</tr>
<tr>
<td>Caregiver or Provider refusal to provide care</td>
</tr>
<tr>
<td>Refusal of patients to accept care</td>
</tr>
<tr>
<td>Increased prevalence of autonomic dysreflexia</td>
</tr>
<tr>
<td>Possible coexistence of neurological problems (e.g., tic disorders, epilepsy)</td>
</tr>
<tr>
<td>Increased prevalence of nutritional problems (e.g., gastroesophageal reflux, feeding tube complications)</td>
</tr>
<tr>
<td>Possible skin problems such as decubitus ulcers that may limit positioning</td>
</tr>
</tbody>
</table>

**Preparation for exam**

Females of all ages are often apprehensive about gynecological exams. A warm and reassuring professional atmosphere may help to ease patient
discomfort. Women should be asked who they would like to be present for the exam and whether they would like a caregiver to be present. Women should be informed in a developmentally appropriate manner about the exam and any instruments to be used. If needed, assistance should be offered in transferring to the exam table or changing into a gown. Adequate time should be allotted for these activities. Personal privacy should be respected.

Pap smear guidelines

Adolescents who are not sexually active, do not have a history of sexual assault or abuse, and have no gynecologic symptoms do not require a pelvic exam. As of March 2012, the U. Preventive Services Task Force and the American College of Gynecology changed recommendations for pap smears (30). Pap smears are no longer recommended annually unless a woman has a history of high grade cervical lesions, cervical cancer, or has an immunocompromising illness, like HIV, which may increase her risk of cervical cancer (30). Routine pap smears are currently recommended every three years after age 21 years regardless of age of initiation of sexual activity or sexual history. Pap smear screening prior to age 21 is not recommended. For women ages 30-65 years, screening may occur every 3 years with cytology or every 5 years with cytology and HPV testing. It is no longer recommended that women over 65 years be screened regardless of new sex partners. Also, women who have had a hysterectomy, including removal of the cervix do not need to be screened (30).

United States Preventive Services Task Force Pap Smear Screening Guidelines as of March 2012 (30)

<table>
<thead>
<tr>
<th>Women &lt; 21 years</th>
<th>Women 21-65 years</th>
<th>Women 30-65 years</th>
<th>Women &gt; 65 years</th>
<th>Women with hysterectomy including removal of cervix</th>
</tr>
</thead>
<tbody>
<tr>
<td>Screening not recommended</td>
<td>Screen every 3 years</td>
<td>Screen every 3 years with cytology or every 5 years with cytology and HPV screening</td>
<td>Screening not recommended</td>
<td>Screening not recommended</td>
</tr>
</tbody>
</table>

Exam

Exam positions may need to be altered in order to complete a pelvic exam based on the woman’s disability. For example, females with spina bifida may have kyphoscoliosis, hip dislocation or subluxation, and lower extremity contractures which would make a traditional gynecologic exam difficult (18). Latex allergy is common in patients with spina bifida (23% of women with spina bifida have latex allergy) (18). Other conditions in which a person has been exposed to a number of medical and surgical interventions may also put the patient at risk for latex allergy. Therefore, latex-free gloves and equipment should be readily available for all exams.

If a child needs a gynecologic exam, they may be placed in the mother’s lap. Toys may aide in distracting and calming the child. A child may also be placed in the frog-leg position (lying face-up with knees bent and relaxed to the side) or knee-chest position (child is on exam table lying face-down with knees tucked under chest) (2). For adolescents or adults, traditional stirrups may be used depending on the woman’s level of physical disability. If alternate positions are needed for the exam, the frog-leg position, V position, M position, or elevation of the legs without hip abduction may increase comfort (1, 11).

An alternative position is the woman lying on her side with an assistant elevating the upper leg. The rectoabdominal examination may be an acceptable alternative to pelvic examination (provided a pap smear is not required) (1). This is best performed after the bowel has been evacuated by an enema (1). The bimanual exam may be performed with one finger (11). Sometimes sedation is necessary to provide a thorough exam with the least discomfort to the patient (2).
Gynecological exam positions (1, 2)

<table>
<thead>
<tr>
<th>Position</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Frog-leg</td>
<td>Knees bent and relaxed to the side</td>
</tr>
<tr>
<td>Traditional</td>
<td>Legs up in stirrups, knees bent</td>
</tr>
<tr>
<td>stirrups</td>
<td></td>
</tr>
<tr>
<td>Knee-chest</td>
<td>Patient face-down with knees brought up to chest</td>
</tr>
<tr>
<td>M position</td>
<td>Knees bent but upright legs</td>
</tr>
<tr>
<td>V position</td>
<td>Legs straight and out to the side</td>
</tr>
<tr>
<td>Side-lying position</td>
<td>Patient lying on side, assistant to lift up leg</td>
</tr>
</tbody>
</table>

Testing and specimen collection (2)

<table>
<thead>
<tr>
<th>Specimen Collection</th>
<th>Details</th>
</tr>
</thead>
<tbody>
<tr>
<td>Direct discharge</td>
<td>Collection if prepubertal, may be tested for N. gonorrhoeae and C. trachomatis since in prepubertal females vaginal cells are columnar epithelium</td>
</tr>
<tr>
<td>Pap Smear</td>
<td>According to guidelines</td>
</tr>
<tr>
<td>Endocervical swab</td>
<td>(in patients who are post-pubertal) for N. gonorrhoeae and C. trachomatis</td>
</tr>
<tr>
<td>Urine collection</td>
<td>for N. gonorrhoeae and C. trachomatis, testing via polymerase chain reaction (PCR)</td>
</tr>
<tr>
<td>pH of vaginal fluid</td>
<td></td>
</tr>
<tr>
<td>Wet mount</td>
<td>Vaginal fluid with normal saline looking for clue cells (diagnosis of bacterial vaginosis) and trichomonads (diagnosis of trichomoniasis)</td>
</tr>
<tr>
<td></td>
<td>Vaginal fluid with potassium hydroxide (KOH) looking for Candida</td>
</tr>
</tbody>
</table>

Autonomic dysreflexia

Health care providers should be aware of autonomic dysreflexia. Autonomic dysreflexia may occur in women with spinal cord lesions (11). The condition may be triggered by sexual stimulation, constipation, or a genital examination (11). Various effects may occur with stimulation and range from a tingling sensation to respiratory arrest (11). Health care providers should plan appropriately and be prepared for possible life saving measures when completing a genital exam on a woman with a spinal cord lesion.

During the gynecological examination, it is important to note any abnormalities. The exam should carefully evaluate the presence of any discharge or rash. If the patient has a history of bloody foul-smelling discharge, the presence of a foreign body within the vagina should be taken into consideration. Prepubertal females should be evaluated for labial adhesions. In an adolescent, the sexual maturity rating should be noted. If there is concern for sexual abuse, it is important that a provider trained in sexual abuse evaluations performs the exam.

Anatomic abnormalities

Females with conditions like spina bifida may have associated reproductive tract anomalies. For example, women with spina bifida may have bicornuate uterus although the exact prevalence is unknown (18). If there is decreased pelvic floor strength and tone, these women are more likely to develop a prolapsed uterus at a younger age (18). In women with other congenital syndromes, reproductive anomalies should always be considered.

Vulvar rash

Vulvar rashes may be caused by irritation, poor hygiene, urine leakage with subsequent vulvar irritation, candida infection, bacteria, psoriasis, drug-induced, lichen sclerosus, genital warts, molluscum contagiosum, or herpes simplex virus. Vulvovaginitis is a nonspecific condition that occurs due to irritation to the skin. Irritation may be caused by poor hygiene, reaction to undergarments (especially synthetic undergarments), bubble baths, or reaction to another caustic substance. Treatment is removal of the offending agent and improved hygiene. Barrier creams are helpful to prevent or repair skin breakdown. If a bacterial or fungal superinfection is suspected, cultures may be obtained and treatment with either an antibiotic or antifungal should be initiated (2).

If there is concern about pain with urination or foul-smelling urine a urinalysis and urine culture should be obtained. If a urinary tract infection is diagnosed, it should be treated with appropriate antibiotics. An anatomic defect of the urinary system such as urethral cyst or urethral prolapse may cause leakage of urine with a secondary rash. If urinary tract infections are recurrent, referral to urologist or nephrologist is appropriate along with imaging studies (2).

A painful rash, vulvar erythema, and vaginal discharge are concerning for bacterial vulvovaginitis. A variety of bacteria may cause this infection including Streptococcus (Groups A and B), Escherichia coli, and Shigella. Vulvovaginitis caused
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by Streptococcus is a common infection in girls. It is caused by autoinoculation due to a pharyngeal streptococcal infection or pharyngeal colonization. In this case, the rash is bright red, maculopapuler, and sometimes “sandpaper like.” Vulvovaginitis caused by a bacterial infection should be treated with an appropriate antibiotic (2).

A fungal rash (often caused by Candida albicans) is erythematous and typically has “satellite lesions.” There may be a white appearance to some of the rash. Fungal rashes are common in skin folds that have a tendency to stay moist. Treatment of a fungal rash includes cleaning with mild soap and warm water as opposed to commercial wipes, avoiding prolonged moisture in the area, and using an antifungal cream or ointment. A barrier cream is helpful to prevent or repair skin breakdown. A low potency steroid such as 1% hydrocortisone may also be used (2).

A chronic condition that causes vulvar skin thinning in an “hourglass” pattern is lichen sclerosus. This condition often presents along with vulvar pruritis, excoriation, bleeding, burning, and secondary infection. The etiology of this condition is unknown. It may be misdiagnosed as sexual abuse in a child due to the loss of vulvar architecture. Treatment includes use of topical steroids (clobetasol) tapered over several weeks. Barrier creams may also be used (2).

A rash in the genital area may be due to a drug-induced eruption, especially if other mucus membranes are involved. The offending agent should be stopped immediately. Depending on the severity, the patient may require hospitalization. A rash caused by psoriasis is scaly and chronic. Psoriasis may improve with a steroid cream but a referral to a pediatric dermatologist or pediatric gynecologist may be necessary. Molluscum contagiosum causes umbilicated raised lesions. These lesions may occur anywhere on the body in addition to the genital area. Treatment may vary from a “watch and wait” approach if few lesions are present to curettage, cryotherapy, and use of medications such as imiquimod. A pediatric dermatologist is recommended for molluscum infections which are persistent or extensive (2).

Herpes simplex virus (HSV) is transmitted via sexual contact, although there have been rare cases of autoinoculation or transmission via fomites. Once the virus is obtained there is no definitive treatment, although symptoms can be managed. Symptoms during a primary (first) outbreak are sometimes severe. Acyclovir taken at first onset of symptoms may shorten the duration of the outbreak. If symptoms are severe, including multiple lesions, swelling, and pain the woman may have difficulty with urination due to pain. Topical pain relievers along with urinating and defecating in a tub of warm water are useful to prevent adverse consequences. Consequences of a severe HSV infection may include urinary tract infection (due to pain with urination), constipation (due to pain with defecation), and labial agglutination.

Mites, including scabies and pubic lice may present with pruritis and an excoriated rash. Pubic lice are evident on examination of pubic hair. Nits (eggs) may also be found on the axillary hair or eyelashes (2). The lice create crusted papules on the skin at sites of feeding. Pubic lice may be spread through sexual contact or contact with infected fomites. Lice need to be treated and nits removed. Treatment needs to be repeated in 7-10 days (2). Clothing and bedding need to be laundered. Scabies, Sarcoptes scabiei, infestation causes intense itching, typically at night. Skin lesions may be papules, vesicles, pustules, and burrows where the female mites burrow into the skin to deposit eggs (2). Skin lesions are most commonly seen on finger webs, wrists, axillae, and belt line. Scabies are best treated with 5% permethrin cream applied from neck down for 8-14 hours and repeated in 7-10 days. All members of the family need to be treated. Infested clothes and bedding need to be laundered or stored in a plastic bag for 72 hours (2).

Vaginal discharge

Vaginal discharge may be caused by bacterial vaginosis, fungal infection (typically C. albicans), physiologic leucorrhea, vaginal foreign body, or sexually transmitted infection. Bacterial vaginosis is a common infection and is not sexually transmitted. It is caused by a number of anaerobic microbes, with Gardnerella vaginalis present in all cases. The microbes flourish due to a change in the vaginal pH which may be due to soaps that disrupt the natural pH. Semen may also cause a change in the vaginal pH. Therefore, women that are sexually active may be
more at risk of getting bacterial vaginosis, especially when there is a new partner. Vaginal douching also increases risk of developing bacterial vaginosis due to alternation of the normal vaginal pH. Symptoms include a thin white or grey vaginal discharge and often a fishy smell. A diagnosis of bacterial vaginosis is made by seeing clue cells on microscopy with normal saline and an elevated vaginal pH. Bacterial vaginosis is treated with Metronidazole 500 mg twice daily for 7 days.

A fungal infection (typically C. albicans) causes a thick cottage-cheese like discharge and often, pruritis. This infection is also not sexually transmitted. Diabetes, immunosuppression, and recent antibiotic use are all risk factors for yeast infections. To diagnose fungal infections a vaginal swab is obtained. Hyphae are visualized on microscopy when a drop of potassium hydroxide (KOH) is added. The infection is typically treated with an oral antifungal medication. Topical medications are available but may be less effective.

Physiologic leucorrhea is a normal discharge that may be confused with a sexually transmitted infection. The discharge is typically clear to white, may be watery or mucoid, and varies in amount from minimal to moderate (2). Usually the discharge is odorless and no irritation should be present (2). Physiologic leucorrhea is due to estrogen stimulation that occurs well before the onset of menses (2).

Bloody discharge with a foul odor should raise suspicion for a vaginal foreign body. In prepubertal females, or women unable to tolerate a pelvic exam, the vaginal canal can be irrigated with normal saline with a pediatric feeding tube. Toilet paper, beads, retained tampon, or virtually any object may be found. If a secondary infection is present, antibiotics may be necessary. A retained foreign body may cause toxic shock syndrome which requires treatment for shock as well as infection or sepsis in addition to removal of the foreign body (2).

Vaginal discharge along with vaginal or perianal pruritis may be seen in children or women with pinworm (Enterobius vermicularis) infestations. Pinworm transmission is via the fecal-oral route. A swab may reveal lemon-shaped pinworm eggs under microscopy. Treatment is with oral mebendazole or albendazole (2).

Sexually transmitted infections such as chlamydia, gonorrhea, and trichomoniasis may also cause vaginal discharge. In prepubertal females or women unable to consent to sexual activity, sexually transmitted infections such as these are highly suspicious for sexual abuse. Any female with an STI or concern for abuse should also be screened for syphilis and HIV. In adolescents, Epstein-Barr virus (infectious mononucleosis) can be transmitted through intimate contact with a sex partner (2). Hepatitis A and hepatitis B can be transmitted through sexual contact. Vaccines are available and strongly recommended for both hepatitis A and hepatitis B (2). Group A Streptococcus may cause genital rash and vaginal discharge and may be obtained through auto-inoculation or genital-pharyngeal contact with an infected partner (2).

**Vaginal bleeding**

Vaginal bleeding in a prepubertal female may be due to accidental injury, labial agglutination, or sexual abuse. Irregular vaginal bleeding after menarche may be due to an immature hypothalamic-pituitary-ovarian axis, a menstrual disorder, or be medication-related. Prepubertal females should be evaluated for any genital, anal, or perianal bruising due to trauma. Accidental injury from falls, for example, may also cause bruising or injury. A vaginal hematoma may appear after an accidental straddle injury. Suspicion for abuse requires an evaluation by a trained clinician, social worker, and mental health counselor. The clinician should be aware that other conditions may be confused with sexual abuse including vaginal ridges, imperforate hymen, clitoral or labial hypertrophy, or ambiguous genitalia (2). Labial agglutination is a common condition that may be mistaken for sexual abuse. It is caused by the absence of estrogen in a prepubertal child. Treatment consists of topical conjugated estrogen twice daily for two weeks then daily for one to two weeks. Mechanical separation should be used as a last resort or as an emergency treatment if urinary retention occurs.

Other causes of vaginal bleeding in a prepubertal child include vaginal infections (Group A Streptococcus), lichen sclerosis, precocious puberty, urethral prolapse, vaginal foreign body, and
genitourinary neoplasms (e.g., rhabdomyoscarcoma and granulosa cell tumor of the ovary) (2). There may also be congenital vulvar hematomas which typically self-resolve between 2 and 10 years of age. Other vascular defects may need to be ruled out with imaging studies (2).

Human papillomavirus vaccine

The human papillomavirus (HPV) vaccine is recommended for all females and males ages 9-26 years. There are two different vaccines. Cervarix is a bivalent vaccine and Gardasil is a quadrivalent vaccine. Gardasil has the added benefit of preventing HPV types that cause most genital warts. The vaccine has been shown to prevent cancers of the anus, vulva, and vagina caused by HPV. Human papillomavirus is transmitted through sexual activity so obtaining the vaccine prior to the initiation of sexual activity is ideal. However, the vaccine is still recommended if sexual activity has already been initiated. Most sexually active people will have the virus at some time in their lives and may not have any symptoms. It is estimated that 12,000 women are diagnosed with cervical cancer in the United States and 4,000 women die from the disease (31). Genital warts are present in about 1% of sexually active adults in the United States at any one point in time (31). Both HPV vaccines are given as a series of three shots over six months. Women who have received the vaccine still need routine pap smears.

Menstrual problems

Menstrual hygiene and menstrual disorders are issues of particular concern to females with disabilities and their caregivers. Females with physical disabilities may have physical limitations in their ability to use menstrual hygiene products. Females with cognitive disabilities may have difficulty understanding how to take care of their menstrual hygiene. Explaining the normalcy of periods and that this is not “bad blood” may ease a woman’s discomfort (16). In general, adolescents who are toilet-trained can learn how to take care of menstrual pads (16).

Dysmenorrhea

Dysmenorrhea is painful menstruation and is very common in adolescents (10-45%) (16). Adolescents or women with disabilities may not be able to express the discomfort they are feeling. Instead, they may have cyclic behavior changes. Behavior changes may include seizures, crying spells, temper tantrums, autistic behavior or self-abusive behavior (16). It can be helpful to keep a menstrual and behavior calendar to document issues surrounding menstruation. The calendar is especially helpful if there is concern for Premenstrual Tension Syndrome (PMS) or Premenstrual Dysphoric Disorder (PMDD) (16). Non-steroidal anti-inflammatory drugs (NSAID) often improve dysmenorrhea and may decrease menstrual flow by up to 20% due to their prostaglandin inhibitory effects (16). Medical management of menstruation may also improve symptoms. If there is concern for PMS or PMDD an oral contraceptive pill with drospirenone may be helpful (16).

Amenorrhea

Secondary amenorrhea may be a relief for a patient and her caregivers, but can lead to osteopenia or osteoporosis. If amenorrhea is due to anovulation, there is a potential for endometrial hyperplasia if left untreated. Low weight and hyperprolactinemia can both cause low estrogen levels which may result in amenorrhea (16). Hyperprolactinemia may be caused by antipsychotics or metoclopramide (16). A cause should be sought for the amenorrhea and appropriate treatment initiated.

Irregular menstruation

There are several factors that contribute to menstrual irregularities in women with disabilities. Irregular menstrual bleeding is common in adolescents in the first two years after menarche due to an immature hypothalamic pituitary ovarian axis (anovulatory cycles). Women with disabilities may have abnormal uterine bleeding associated with thyroid disease, anticonvulsant therapy, or neuroleptic medications (1). It is known that women with epilepsy have an
increased incidence of reproductive endocrine disorders. Disorders these women may have include amenorrhea, anovulatory cycles, and oligomenorrhea. The presence of polycystic ovarian syndrome in women with epilepsy is 10-20% while in the general population the prevalence is 5-6% (16). Women with polycystic ovarian syndrome have irregular periods along with acne or hirsutism due to increased circulating androgens. A number of anticonvulsants including carbamazepine, phenytoin, and phenobarbital increase the activity of the cytochrome P450 hepatic enzyme. Due to increased enzyme activity, steroid hormones are cleared more rapidly and menstrual irregularities occur (16). Women with Down syndrome (Trisomy 21) may have coexisting thyroid disease with often leads to menstrual irregularities (16). Nutrition problems such as gastroesophageal reflux or feeding tubes may cause hypothalamic oligomenorrhea or amenorrhea (16). This is due to hypothalamic suppression of GnRH pulses as a result of stress placed on the body due to inadequate nutrition (16). Medications causing hyperprolactinemia (e.g., antipsychotics and metoclopramide) may cause hyperprolactinemia which may lead to irregular bleeding and eventually amenorrhea (16).

Contraception

<table>
<thead>
<tr>
<th>Menstrual in Females with a Disability (32)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Menstrual periods add a significant amount of stress to patients, families, schools, and other caregivers.</td>
</tr>
<tr>
<td>2. Menstrual Management may significantly improve quality of life for the patient and caregivers.</td>
</tr>
<tr>
<td>3. Medical problems like cyclic seizures may improve with hormonal menstrual management.</td>
</tr>
</tbody>
</table>

The best time to start talking about managing menstruation in females with disabilities is before it starts (32). For the health care provider, initial onset of secondary sex characteristics is an ideal time to talk about puberty, menstruation, and sexuality. It is, however, not appropriate to medically intervene with menstruation prior to menarche even though families may request this. It is difficult, if not impossible, to predict how heavy or painful periods will be or even when the first one will occur (32). Menstrual management should not occur until menses has started. It is important to discuss menstruation and contraception with all women, regardless of whether she has a disability or not. There are a number of options available for menstrual management and contraception. Depending on the woman, each has benefits and possible side effects. The women’s medications, medical problems, and family history must always be taken into consideration when weighing risks and benefits of contraceptive methods. Anticonvulsants may decrease the effectiveness of certain methods. The United States Medical Eligibility Criteria for Contraceptive Use, published in 2010 outlines the use of contraceptives in a number of specific conditions as well as medications (33).

**Oral contraceptive pills**

Oral contraceptive pills (OCPs) contain a combination of estrogen and progesterone and have evolved over the last 50 years (20). OCPs have the benefit of decreasing menstrual flow and cramping over time. They have also been found to decrease the incidence of ovarian and uterine cancers. They regulate periods and decrease acne. For the pill to work effectively, it must be taken at approximately the same time every day. Missed pills result in contraceptive failure and irregular menstrual bleeding. Chewable pills are available. Contraindications to taking the combined OCP include hepatic disease and breast disease that is sensitive to estrogen. In addition, hypercoagulability, venous stasis, or endothelial damage should be evaluated which are all risk factors for deep venous thrombosis (DVT). Women with disabilities who have limited mobility with prolonged sitting or lying are at increased risk of venous stasis and therefore, a theoretical increased risk of DVT (16). Prior to initiation of OCPs, a careful family history should be completed to evaluate possible inherited prothrombotic disorders (16). In addition, the United States Medical Eligibility Criteria should be reviewed to ensure the pills are compatible with the patient’s conditions or risk factors (33). Other possible side effects include nausea, emesis, headaches, breast congestion, and mood changes. OCPs are taken daily for three weeks. The fourth week in the pack is a placebo week where menstruation should occur. On the following week, a new pill pack should be started.
Several brands of OCPs now offer continuous pills for three months (as a result, the woman would have only 4 periods a year). Risks and benefits of these pills are the same as above although there is a greater risk of breakthrough bleeding. If breakthrough bleeding occurs, discontinuing pills for 4-5 days in order to have a mini-period usually resolves the problem.

**Progesterone-only pills (minipills)**

Progesterone only pills (POPs) or minipills are available for women who have a contraindication to taking estrogen or who are breastfeeding. The disadvantage of these pills is that they must be taken within a narrow window of time each day. If the pill is greater than 3 hours late, a backup method must be used for at least two days. This pill is taken continuously, without a placebo week. A side effect is breakthrough bleeding as with other progesterone-only methods.

**Patch**

A transdermal patch is available which contains estrogen and progesterone similar to OCPs. The patch is useful for women who have difficulty remembering to take daily pills or have difficulty swallowing. However, compared to OCPs which contain norgestimate, higher estrogen levels in the patch have been reported to be associated with a twofold increase in DVT (16). In addition, women may find the patch irritating and try to remove it. If the patch is placed on the lower back the problem may be resolved (16).

**Vaginal ring**

The vaginal ring is a soft, flexible, transparent ring (20). The ring contains both estrogen and progesterone, similar to OCPs. The ring is placed intravaginally by the patient. The ring stays in place for three weeks and is then removed for one week when menstruation occurs. The following week, a new ring is inserted. Women must be comfortable with their bodies and the insertion and removal process in order to use this method. Benefits include that once it is in place, it can be “forgotten” for three weeks as opposed to taking a pill daily. Potential side effects include vaginal discomfort, foreign body sensation, and vaginitis (20). Additional side effects are similar to those of OCPs (20).

**Barrier methods**

Barrier methods include condoms, diaphragms, and cervical caps. These methods require physical dexterity and motivation for use. Women who are allergic to latex, as is common in women with spina bifida, are unable to use standard latex condoms. Latex-free condoms are available but provide less protection against pregnancy and STIs. They are also more likely to break during sexual intercourse (1). The typical use failure rate of male condoms is 18% (34). Diaphragms and cervical caps are inserted into the vagina prior to sexual intercourse. They fit over the cervix and function to block sperm. Before they are inserted they must be filled with spermicide. They must be properly fitted by a trained health care professional (34). Diaphragms and cervical caps are used less commonly than other methods.

**Depot medroxyprogesterone acetate (DMPA)**

DMPA or “Depo” is given as an injection of 150 mg every 12 weeks. It can be given to patients who have a contraindication to receiving estrogen. Benefits of DMPA include effective contraception, decreased dysmenorrhea, lower premenstrual tension syndrome, and possible reduction in seizures (20). Side effects of DMPA include weight gain, acne, irregular menstrual bleeding often leading to amenorrhea (which may be a benefit to some patients), loss of hair, depression, and anxiety (20). In 2004, the United States Federal Drug Administration placed a black box warning on DMPA that warned of significant bone loss and advised against using it for greater than two years (20). In patients with disabilities limiting mobility, the side effects of weight gain and decreased bone density are of particular concern.
Implanon/Nexplanon

Nexplanon (previously Implanon) is a form of long-acting reversible contraception (LARC) that is placed subdermally in the bicipital groove (upper arm) (20). It is a 40-mm long, 2-mm diameter rod that releases etonogestrel (a progesterone) and provides three years of contraception (20). It may be inserted in a gynecologist’s or primary care physician’s office with local anesthetics. Women with disabilities, particularly cognitive disabilities, may not tolerate the procedure and sedation may be necessary (16). Nexplanon does not have effects on bone density and does not contain estrogen which is contraindicated in patients with prothrombotic disorders. The most common side effect is irregular menstrual bleeding although 33% of women are amenorrheic. Irregular menstrual bleeding may be undesirable (16). The bleeding can be managed with NSAIDs, doxycycline (100 mg twice daily for 5 days), or OCPs (20, 35). Efficacy may be decreased in patients with liver disease, patients taking anticonvulsants, St. John’s wart, and rifampin (20).

Intrauterine devices (IUDs)

The IUD is also a long-acting reversible contraceptive method. The T-shaped device is placed in the uterus by a trained professional. An off-label use is decreased menstrual flow in women with heavy periods (16). The Mirena IUD lasts for 5 years and releases 20 micrograms of levonorgestrel per 24 hours (20). Copper IUDs (ParaGard) last for 10 years and prevent pregnancy by interfering with sperm motility. The copper IUD is a nonhormonal method and does not affect menstruation. Here are high rates of amenorrhea and limited side effects with IUDs. Insertion for women with disabilities may need to be done under anesthesia due to unpredictable cooperation and a potentially small uterus. A possible side effect is perforation of the uterus during insertion.

Emergency contraception

Emergency contraception is most effective if used between 72 and 120 hours after sexual intercourse (20). Emergency contraception prevents implantation but is not teratogenic if pregnancy has already occurred (20). Emergency contraception is available over the counter in many parts of the world including the United States (20). IUDs may also be used as emergency contraception.

Sterilization

Caregivers and family members of women with disabilities may request surgical sterilization. Reasons for such a request include desire for menstrual management and avoiding consequences of sexual maturation (36). There is also a mistaken belief that surgical sterilization will diminish the chances of sexual abuse or acquiring STIs (36). However, sterilization does not prevent abuse and STIs may still be acquired. Families and caregivers may be unaware of advances in the area of menstrual management. In addition, most individuals with disabilities respond well to education about socially appropriate displays of affection (36). Surgical sterilization has ethical and legal ramifications (16). An ethics consult and knowledge of state laws are highly recommended prior to such a procedure (16).

Sexual dysfunction

Sexual dysfunction in females may manifest as a lack of sexual desire, decreased sexual desire, pain with sexual activity, or orgasmic dysfunction (2). It is important for health care providers to be sensitive and ask about such topics as sexual expression is a normal part of the lives of all human beings. Cognitive limitations, physical limitations, mental disorders (such as depression), medications, and certain medical problems may contribute to sexual dysfunction (11). Physical limitations such as arthritis, amputations, ostomies, or abnormal genitalia may interfere with sexual expression (2). Women with ostomies may be
afraid or embarrassed about an odor whereas women with arthritis may be in physical pain (2). Medications such as certain antidepressants (selective serotonin reuptake inhibitors [SSRIs] or selective norepinephrine reuptake inhibitors [SNRIs]), anticonvulsants, and antipsychotics may induce sexual dysfunction (2). Medical conditions such as diabetes mellitus, hypertension, and obesity may begin in adolescence and persist into adulthood and are also associated with sexual dysfunction (2). The earlier these conditions are managed, the better the prognosis for the improvement or correction of the dysfunction. Women with spinal cord lesions are at risk for autonomic dysreflexia (11). This is a condition that is triggered by sexual stimulation, constipation, genital examination or other actions (11). It may lead to a variety of effects ranging from a tingling sensation to respiratory arrest (11). Women with spinal cord lesions may also have painful bed sores (11). When evaluating sexual dysfunction, it is important to remember the range of cognitive as well as physical influences on sexual expression.

Pregnancy

Historically, women with disabilities have been discouraged from pregnancy. This was based on the beliefs that pregnancy may pose a threat to life, pregnancy may worsen disability, or that the disability status was incompatible with motherhood (37). Studies have found that women with disabilities naturally commonly desire pregnancy. Information about in vitro fertilization and surrogate motherhood should be available to them (28). Studies in the United States have shown that women with disabilities report difficulty finding health care providers and hospitals that were experienced in managing pregnancy and childbirth for women with disabilities (28). The women may “settle” for less experienced providers (28).

Women with disabilities may experience problems with bladder function including bladder spasms, infections, leakage, and increased difficulties surrounding catheter use (28). Constipation and back strain (which may worsen kyphoscoliosis) are common problems seen in pregnancy (18, 38). They may have increased skin problems during pregnancy due to possible decreased mobility (28). Reduced lung volume due to an expanding uterus may result in breathing difficulties and an increased risk of pneumonia (28). The risk of autonomic dysreflexia also increases during pregnancy as does the risk of blood clots (28).

Morton et al., found that women with physical disabilities experience higher rates of preterm deliveries, low birthweight infants, and pregnancy complications (37). These increased complications illustrate the need for women with disabilities to have access to comprehensive reproductive health care services including preconception, prenatal, and postnatal care. The care of women with disabilities is best managed with an interdisciplinary team of primary care providers, obstetricians, anesthesiologists, neurologists, psychiatrists, occupational therapists, and physical therapists (28).

Menopause

Menopause is the natural end of menstruation and fertility. It typically occurs when women are in their forties or fifties. Complications of menopause arise from decreased estrogen levels and include increased risk of cardiovascular disease, osteoporosis, urinary incontinence, decreased skin integrity, decreased sexual function, and weight gain. As women with disabilities are living longer, healthier lives they are at increased risk of complications during and after menopause. For example, women with poor mobility may be at increased risk of osteoporosis and weight gain. If sexual dysfunction is already occurring, vaginal dryness or decreased sensation may further worsen sexual dysfunction. Decreased skin integrity may increase the risk of decubitus ulcers. Health care providers need to carefully and thoughtfully monitor for these consequences of menopause and treat appropriately.

Conclusion

A number of studies have shown that education is the key to improving reproductive health care for women with disabilities (9, 39, 40, 41). Proper and comprehensive education about reproductive issues is
necessary for women with disabilities as well as their schools, caregivers, and health care providers. The attitudes of future professionals will determine the quality and support for these women (9). Specifically, women with disabilities should receive comprehensive and ongoing sexuality education in schools. Caregivers should be trained in the normalcy of sexual expression, menstrual management, contraception, pregnancy care, and the menopausal transition. Caregivers may attend special classes, learn through internet modules, or receive specific training in their workplace for reproductive issues. Health care professionals may learn through focused classes, virtual patient training modules, listening to women with disabilities as special speakers, and overall increased exposure to reproductive care for women with disabilities (41). Continuing education modules, as well as practice consultants can provide invaluable in increasing awareness to the specific needs of women with disabilities (42). Better billing for comprehensive health care services would also provide more incentive for health care providers as currently more complicated visits are commonly not adequately covered by insurance providers (42).

In general, moving towards a model of a disability being not “an individual possessive trait but rather a socially mediated phenomenon which can be challenged and changed” (19) emphasizes that women with disabilities have the same needs for sexual expression and reproductive care as women without disabilities. However, society and cultures around the globe have typically labeled women with disabilities as “asexual” and ignored this very important aspect of care. It is important to remember that children, adolescents, and women with disabilities go through the same stages of sexuality development and puberty as those without disabilities. Comprehensive and thoughtful education and care must be provided to all women throughout the lifespan as well as their caregivers and health care providers.

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