# **Chapter 55**

Sexual Aspects of Physical Disability

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Medical interest in sexuality and sex therapy has its roots in the pioneering work of Masters and Johnson, which was originally published in the 1960s (1). Their work in human sexual response marked a new era in which sexuality became a legitimate area of clinical work and scientific investigation. Clinical observations from their laboratory were widely reported in the media of that era and ultimately served as an important component of the sexual revolution of the 1960s. In addition, the treatment techniques developed by Masters and Johnson served as a foundation for clinical sex therapy and have been extensively utilized in the treatment of male and female sexual dysfunctions. Since that time, the field of sex therapy has undergone tremendous growth as new advances in medicine and psychology have expanded our understanding of human sexuality and behavior (2). Moreover, interest in sexuality and sex therapy has become an interdisciplinary activity that spans a broad scope of theoretical approaches and medical treatments.

For people with disabilities, the acceptance of sexuality as a justifiable and sanctioned area of rehabilitation has been much more controversial (3). Historically, people with disabilities received little information on sexuality and were often regarded as nonsexual and incapable of an intimate relationship. This misperception not only has persisted in the general population but has been equally prevalent in the medical community as well. In spite of the similarities in sexual functioning for people with and those without disabilities, the tendency has been to emphasize the differences between the two groups and to view people with disablility as being sexually impaired (4). Obviously, this tendency goes much deeper than issues of sexuality and is a reflection of society's general discomfort of people with disabilities. In reality, the sexual rights and responsibilities of people with disabilities are identical to those of all other people. Everyone, regardless of disability, has the right to sexual information and expression and the right to develop the fullest potential in all aspects of life.

The history of addressing sexual issues during the rehabilitation process dates back only to the 1970s when Theodore and Sandra Cole developed the "Sexual Attitude Reassessment" (SAR) program to train rehabilitation professionals (5). These early workshops quickly gained in popularity throughout the rehabilitation community and for many years were offered at major medical facilities in the United States and Canada. The focus of these programs was on values clarification and communication. Their purpose was to increase the practitioner's level of comfort with and awareness of sexual issues among people with disabilities. In these ways, the SAR programs were very successful, but they tended not to provide the counseling skills necessary to assist individuals in their sexual adjustments after disability. To some extent during the 1970s, the idea of sexual education for people with disabilities was academic. People in rehabilitation were beginning to recognize the need for sexuality services, but there was little agreement as to how and when these services should be provided. There was also little agreement as to who

should provide sexual education services, and often patients left rehabilitation with no information because various members of the rehabilitation team assumed that other disciplines had addressed sexual concerns (6). Such lack of coordination for sexuality services and the failure to address these concerns in various team meetings simply perpetuated the notion that information on sexuality was of little importance to people with disabilities. Ultimately, people with disabilities themselves began to demand further information regarding their sexual functioning and their capacity to have children.

To clarify issues discussed in this chapter, it is important first to define *sexuality*. Sexuality is the integration of the physical, emotional, intellectual, and social aspects of an individual's personality that express maleness or femaleness. Sexuality is an expression of the total personality evident in everything done by a person (7). Interactions with others, personal hygiene, speech, dress, and expressions of affection are all an important part of sexuality. Given this broad definition, sexuality may be regarded as an avenue toward intimacy and may be directly or indirectly affected by the presence of a disability. Disabilities such as blindness, burns, and cancer, for example, may not directly impair genital functioning but can affect communication, body image, and self-esteem. Ultimately, disruptions in these areas may compound physical and psychological well-being and result in various secondary conditions requiring medical treatment (8).

## ANATOMY AND PHYSIOLOGY OF HUMAN SEXUALITY

Throughout the health care professions, it is recognized that an understanding of sexual anatomy and physiology is a prerequisite to further consideration of sexual diagnostic and treatment issues. Although the interaction of psychological and physical factors is nowhere more obvious than in sexual behaviors, a basic review of physiologic factors provides a framework for further discussion.

#### Male Sexual Anatomy

The sexual organs of the male consist of a complex combination of tubes, glands, valves, and muscles that work together to produce sperm, store it, and deliver it outside of the body (Fig. 55-1). The penis consists of three cylindrical bodies of erectile tissue. The paired corpora cavernosa lie parallel to each other and just above the corpus spongiosum, which contains the urethra. The male urethra, which acts as the conduit for both urinary and genital systems, extends from the internal meatus in the urinary bladder to the external meatus at the tip of the penis. It is divided into three regional segments: prostatic, membranous, and penile. The penile segment of the urethra is the longest and extends about 15 cm in the adult male. It has a ventral concave curve in its proximal



Figure 55-1. Male sexual anatomy.

segment, which is continuous with the membranous urethra until it reaches the lowest level of the symphysis pubis, where it continues into the free part of the penis as the pendulous urethra (9).

The erectile tissues of the penis consist of irregular sponge-like networks of vascular spaces interspersed with arteries and veins. The distal portion of the corpus spongiosum expands to form the glans penis. Each cylindrical body is covered by a fibrous coat of tissue, the tunica albuginea, and all three corpora are enclosed in a covering of dense fascia. At the base of the penis, the corpora cavernosa diverge to form the crura, which attach firmly to the pubis and ischium. The blood supply to the penis derives from terminal branches of the internal pudendal arteries.

Erection occurs as a result of vasocongestion within the spongy tissue of the penis. When the penis is flaccid, the vascular spaces in the erectile tissue are relatively empty; with arteriolar dilation, blood flows into the network of sinuses in the spongy tissue, and increased hydraulic pressure results in enlargement and hardening of the penis. When the rate of arterial inflow of blood is matched by the rate of venous return, a state of equilibrium is reached and the erection is maintained. The role of venous blockade in the process of erection is uncertain, but detumescence occurs as a result of venous outflow exceeding arterial input.

The scrotum is a thin sac of skin containing the testes. Involuntary muscle fibers are an integral part of the scrotal skin; these muscle fibers contract as a result of exercise or exposure to cold, causing the testes to be drawn upward against the perineum. These alterations in the scrotum are important thermoregulators for this reason: Since spermatogenesis is temperature sensitive, elevation of the testes in response to cold provides a warmer environment by virtue of body heat, whereas loosening of the scrotum permits the testes to move away from the body and provides a larger skin surface area for the dissipation of intrascrotal heat (10). The scrotum is divided into two compartments by a septum.

The testes are the male reproductive organs and function as the site of spermatogenesis and also play an important role in the production of sex steroid hormones. The testes lie within the scrotal sac, suspended by the spermatic cords. Spermatozoa are produced in the seminiferous tubules of the testes while steroid hormone production occurs in the Leydig cells located in the interstitial tissue. Although architecturally these tissues are admixed within the testes, the two functions are under separate control from the pituitary gland (11). The glandular structure of the testes is about 4 to 5 cm long and 2 to 3 cm thick. The blood supply to the testes is closely associated with that to the kidney because of their common embryologic origin.

#### Female Sexual Anatomy

The external genitalia of a woman are called the *vulva* and consist of the labia majora, the labia minora, the clitoris, and the perineum. Bartholin glands, which open on the inner surfaces of the labia minora, may be considered functionally within the context of the external genitals, although their anatomic position is not in fact external. The appearance of the female genitalia varies considerably from one woman to another, including variations in size, pigmentations, shape of the labia, location of the clitoris, and location of the urethral meatus and the vaginal outlet.

The female urethra is about 4 cm long and about 6 mm in diameter. It begins at the internal meatus and runs anteroinferiorly behind the symphysis with a gentle ventral curvature firmly adherent to the anterior wall of the vagina. Except during the passage of urine, the urethral lumen is stellate in shape and completely occluded. The entire urethra is rich in elastic and collagen fibers. The female urethra is much more readily dilatable than the male urethra (11).

The clitoris itself contains very sensitive nerves that react when stimulated by either psychological or physiologic factors. It is located at the point where the labia majora meet anteriorly and is made up of two small erectile cavernous bodies enclosed in a fibrous membrane surface and ending in a glans or head. The clitoris is richly endowed with free nerve endings, which are extremely sparse within the vagina. The clitoris is not known to have any function other than serving as a receptor and transducer for erotic sensation. The tip of the clitoris is covered by a small area of tissue usually referred to as the *clitoral hood*. This hood tends to protect the sensitive nerves located in the clitoris. The size and shape of this hood varies among women and is not related to the amount of sexual



Figure 55-2. Female sexual anatomy.

pleasure that a woman can receive when she is sexually stimulated (10).

The internal genitalia of the female include the vagina, cervix, uterus, fallopian tubes, and ovaries (Fig. 55-2). These structures may show considerable variation in size, spatial relationship, and appearance as a result of individual differences as well as reproductive history, age, and presence or absence of disease.

The mouth of the cervix provides a point of entry for spermatozoa into the upper female genital tract and also serves as an exiting point for menstrual flow. The endocervical canal contains numerous secretory crypts that produce mucus. The consistency of cervical secretions varies during various phases of hormonal stimulation throughout the menstrual cycle. At the time of ovulation, for example, cervical secretions become thin and watery; at other times of the cycle, these secretions are thick and viscous, forming a mucous plug that blocks the cervical os (12).

The vagina is a soft tube that is several inches long and can extend during sexual intercourse. It exists more as a potential space than as a balloon-like opening. In the unstimulated state, the walls of the vagina are collapsed together. The walls of the vagina are completely lined with a mucosal surface that is now known to be a major source of vaginal lubrication; there are no secretory glands within the vaginal walls, although there is a rich vascular bed.

The uterus is a muscular organ that is situated in close proximity to the vagina. The lining of the uterus and the muscular component of the uterus function quite separately. The myometrium is important in the onset and completion of labor and delivery, with hormonal factors thought to be the primary regulatory mechanism. The endometrium changes in structure and function depending on the hormonal environment. Under increasing estrogenic activity, the endometrium thickens and becomes more vascular in preparation for the possible implantation of a fertilized egg.

The fallopian tubes or oviducts originate at the uterus and open near the ovaries, terminating in fingerlike extensions called *fimbriae*. The fallopian tube is the usual site of fertilization; the motion of cilia within the tube combined with peristalsis in the muscular wall results in the transport of the fertilized ovum to the uterine cavity.

#### The Sexual Response Cycle

The sexual response cycle, originally proposed by Masters and Johnson, is regarded as the most accepted description of the physiologic and behavioral aspects of sexuality (13). These phases have been defined as excitement, plateau, orgasm, and resolution and were originally determined by extensive laboratory studies. The phases are observed in both men and women, although the demarcation between stages is somewhat arbitrary for both sexes and is dependent on such factors as age and general health.

#### **Excitement Phase**

Excitement occurs in response to sexual stimulation because of either touch (i.e., reflexogenic) or imagination (i.e., psychogenic) in both men and women. This stage is governed mainly by the parasympathetic nervous system through the S2, S3, and S4 levels via the cauda equina. The sympathetic nervous system (T11–L1) is also involved, but to a lesser extent (14). Psychogenic stimuli can be both facilitatory and inhibitory, and the degree of stimulation necessary to achieve physiologic arousal is affected by psychological stimulation. Libido is also affected by general health, neurotransmitters, serotonin, dopamine, depression, anxiety, relationship issues, and medication. Both men and women show increases in muscle tension, breathing rate, heart rate, and blood pressure.

In men, the excitement stage is characterized by penile erection as a result of vasocongestion in the spongy tissue. The scrotum contracts and the testes are brought close to the body. In some men, nipple erection occurs as well.

In women, the excitement stage is characterized by vaginal lubrication, with vasocongestion leading to a transudate of fluid (10). Other changes include expansion of the inner two-thirds of the vagina and elevation of the uterine body, cervix, and labia majora. The clitoris enlarges as well. The nipples become erect, and the breasts may swell.

#### Plateau Phase

The plateau stage consists of the high level of sexual arousal that precedes the threshold levels required to trigger orgasm. The duration of the plateau phase varies considerably, depending on the length of time necessary to reach orgasm. If stimulation is ineffective during this phase, the body will show a gradual reduction of the physiologic phenomena that are characteristic of this phase.

In men, vasocongestion continues in the following way: The penis enlarges further and can deepen in color. The testes elevate and rotate anteriorly, coming to rest against the perineum.

In women, the process of vaginal expansion, clitoral engorgement, and nipple erection continues. A redness known as a *sex flush* may spread over parts of the abdomen, breasts, and chest wall.

Extragenital features of this stage seen in men and women include further changes in tachypnea, tachycardia, elevated blood pressure, and generalized myotonia. With continued stimulation, the individual will enter the third phase of sexual response.

#### Orgasm Phase

Masters and Johnson (1) theorized that orgasm is triggered by a neural reflex arc once the orgasmic threshold is reached. For both men and women, this stage is under control of the sympathetic nervous system. If no major psychological issues emerge, the individual will progress through one or more orgasms. Intensity and duration of the orgasm vary from individual to individual and depend on arousal, psychological, and physiologic features.

In the male, accessory sex organ contraction concentrates seminal fluid, which consists of live sperm and prostatic seminal vesicle and vas deferens secretions. The man first experiences a felling of ejaculatory inevitability. The internal sphincter of the bladder closes to ensure the forward propulsion of seminal fluid. Orgasm is experienced as rhythmic contractions of the pelvic muscles, prostate, and penile shaft.

In the female, orgasm is also experienced as rhythmic muscular contractions of the uterus, anal sphincter, and the outer one-third of the vagina. In many women, more diffuse experiences are noted as well, including peripheral muscular contractions and changes in electroencephalographic (EEG) activity (15).

#### **Resolution Phase**

Males undergo a refractory period immediately after ejaculation. Further ejaculation cannot occur although an erection is possible. The length of this refractory period varies and tends to be affected by factors such as arousal, age, and general physical health. The refractory period for young men may be as short as 10 minutes compared to over 1 hour for an elderly man. Women do not experience a refractory period after the initial orgasm and have the potential to experience several successive orgasms if stimulation continues. During the resolution stage, vasocongestion and the changes that have occurred during the previous phases tend to reverse. The process is generally more rapid for men than for women.

# PHYSICAL AND PSYCHOLOGICAL ASSESSMENT

A comprehensive physical assessment is an important part of the patient's work-up. The assessment of the patient's sexual functioning has several objectives: 1) to legitimize the patient's concerns about sexuality and to provide an opportunity for discussion of this topic; 2) to involve the patient (and couple) fully in the decision and treatment process; and 3) to identify the physical, psychological, and social correlates of the sexual functioning (16). An understanding and empathic evaluation can serve as both a challenge and a reward for the patient and the health care provider. Specifying the details of specific sexual functioning-how it occurs-is necessary but not sufficient. Fundamental to long-term positive outcome is assessing (and treating if indicated) the relevant physical features, psychological issues, and relationship concerns brought about by the person's sexual functioning. Developing a solid therapeutic alliance and enlisting the patient's participation comprise the bedrock on which a positive assessment can be completed (17).

## Attitude of the Examiner

A gentle, organized, and empathetic approach is the most useful. In order to be successful, the physician or rehabilitation professional must form an alliance with the patient and the couple. It is crucial that the atmosphere be safe, open, and nonjudgmental. The professional must speak in a language that is understandable to the patient and be flexible to the patient's needs, without having a rigid agenda. The clinician must be able to follow subtle leads so that difficult and sensitive material can be expressed. A sensitivity to nonverbal expressions of anxiety and conflict is highly valued and will lead to a more positive outcome (18). Comfort with the topic and one's own sexuality is essential to conveying acceptance and safety to the patient (19). The absence of self-understanding about sexuality may lead the physician to do harm to the patient and a disservice to the medical profession. Regardless of personal style on the part of the professional, validating the patient's experience, supporting any feelings of loss, and being empathetic to the degree of difficulty involved in the disclosure are "basic skills" for clinical inquiry (20).

The examiner must realize that the person with a disability may require more time in pre-examination preparation because of issues such as transfers to the examination table, emptying of the urinary bag, undressing or dressing, history taking, and speech and cognitive impairments. Professional and ancillary staff that may be assisting should be knowledgeable in both attitude and skills most helpful to the patient. The examiner should be clear as to the goals of the assessment and the problems that may occur, such as bladder and bowel accidents.

The examiner should use the opportunity of the examination to discuss issues of sexually transmitted diseases (STDs), especially if the patient is sexually active

in nonexclusive relationships (21). Open-ended questions can often be extremely valuable and provide additional information that may be especially sensitive for the patient to discuss. An example of one such question is, "Is there anything else that I have not asked that would be helpful for us to discuss?" This is also the time in which education about symptoms, condom use, and safe sex techniques should be provided to the patient. Most patients, female and male, are not aware of the signs or symptoms of STDs, nor are they aware of the fact that a significant portion of the infected population is without symptoms. Depending on the sexual history, some patients should be screened for infection.

## **Physical Examination**

### Female Patient

The female patient should be positioned on the examining table to ensure a sense of stability. This may require safety belts, extra pillows, as well as ancillary staff members to assist the patient and the examiner. Having an ancillary person on each side and the examiner at the foot of the table during the genital-rectal examination allows the examiner to conduct the examination with good control over safety and to maximize this opportunity for evaluation. As a matter of practice, bladder and bowel care should be completed before the examination. Just prior to the examination, the bladder should be emptied. Necessary steps should also be taken to empty the lower bowel, as assessment can be inaccurate if the lower bowel is distended because of a stool. For example, a determination of diaphragm size, for the female, can be incorrect if the stool distends the vagina and alters the examiner's perception of distance from the symphysis to the posterior fornix (22).

Breast examination is essential. Breast selfexamination should be taught, or arrangements should be made for the patient to have her breast examined every 3 months. If the patient is at high risk for breast cancer, the examination should be completed on a monthly basis. If the patient is unable to conduct the examination, a relative, visiting nurse, or personal care attendant should perform the examination. Breast palpation should include the neck, supraclavicular and ancillary nodes, and the nipples to check for discharge.

Women with disabilities can have special concerns about their breasts. Concerns from women with congenital disability may reflect feelings of inadequacy and lack of sexuality. For a woman with a traumatic injury, the sense of loss may include the breast. This may reflect a sense of loss of one's femininity and the ability for childbearing. Other women have reported that their breasts, along with their neck and shoulders, were the most arousable (23). The patient must be given ample time to discuss these concerns if the examiner believes that issues such as these are a concern for the woman. Before the pelvic examination, placement of a pad on the examining table may be helpful in case of a bladder accident. Flaccid buttocks may need extra cushioning on the examining table as well. This provision is especially important if there are any signs of redness indicating skin breakdown. Feet can be secured in stirrups with elastic wraps or other bandages. It is important to note that the labia minora and majora of women who use wheelchairs may appear more atrophic than age would suggest. This appearance is usually due to muscular atrophy from injury (24). Speculum insertion must be conducted gently and carefully. Care should be taken to test the temperature of the instrument prior to insertion, as it is possible to trigger autonomic dysreflexia with a speculum that is too cold.

Several more points should be noted. A mirror should be available to demonstrate findings to the patient. This form of education to the patient should be an ongoing part of the entire physical examination. Observation and inspection of the skin of the lower back, the buttocks, and the genitals should be conducted at the time of the examination. Inspection of the clitoris, by retraction of the clitoral hood, should be performed by employing gentle contact. Bimanual examination of the vagina and rectum, including occult blood testing, should be performed on each patient. Finally, in obtaining Papanicolaou smears, samples from the endocervix and the exocervix should be gathered before any STD samples are obtained. This ensures that any abnormal cells are retrieved for cytologic evaluation and not lost to the microbiology laboratory analysis.

#### Male Patient

The classic male genital examination should be conducted. Special care and attention should be paid to the skin of the penis and foreskin. As with all patients, concerns about body image will be important and merit special attention. Routine blood chemistry tests, hormonal assays, determination of the sensory threshold of the genital area, vascular assessment, neurologic evaluation of male sexual dysfunction, and nocturnal penile tumescence monitoring with sleep EEG should be included in a comprehensive work-up (25). In addition to the sexual history taking, obtaining knowledge of all medications used, prescription and nonprescription, should be part of the assessment.

When the examination has been completed, skin around the genital and rectal areas should be gently washed. Plain tap water will dissolve water-soluble jelly. Cornstarch or talc should be used to avoid moisture and all fabric edges should be checked to avoid skin breakdown. Assistance with dressing and transfers should be provided as needed.

#### **Psychological Assessment**

A number of authors have emphasized physicians' increasing awareness of the importance of including a sexual history as part of the standard database (25–27). One reason the sexual history is relevant is the high incidence of sexual dysfunction in a medical patient population, including people with physical disabilities. Another reason is the high incidence of STDs that often go undiagnosed. Regardless, the sexual history provides the physician with a valuable perspective in understanding the patient's values, relationships, overall adjustment, and health-maintaining behaviors. The sexual history also provides the patient with the opportunity to ask questions about sexual adjustment as well as his or her own unique physical abilities.

A simplified sexual history often includes such areas as the patient's past and current sexual functioning, partner satisfaction, relationship history, medications used, behavioral repertoire, traumatic events such as abuse, and specific difficulties brought on by the illness or disability (28). A nonjudgmental stance that respects the values and preferences of the patient is necessary to maintain rapport, to foster the patient's autonomy, and to promote candor. Most training programs include specific opportunities for the practitioner to understand and evaluate his or her own values so that he or she does not impose them on the patient (29). Open-ended questions tend to promote this nonevaluative atmosphere. Naturally, this nonjudgmental attitude must stop short of sanctioning attitudes or practices that are psychologically or physically harmful to the patient and his or her sexual partner.

The language of the interview should be neither too casual nor too technical. In reality, many patients have some anxiety about sexual topics and the language of the interviewer will set the tone for the patient to discuss the topic and to ask questions of a sensitive nature. The interviewer models a sensitive and matter-of-fact attitude while listening carefully to the attitudes expressed by the patient's verbal and nonverbal behavior. More difficult topics are generally reserved for later in the interview, when greater rapport and trust have already been established. As a general rule, it is a good idea to ask if the patient or partner would find it helpful to speak with someone knowledgeable about sexuality and disability in order to gain more information or to discuss the topic in more depth. Referral may then be made to physicians such as urologists and physiatrists or other professionals such as nurses, psychologists, or social workers.

## SEXUALITY AS A DEVELOPMENTAL ISSUE

The theory of developmental tasks was originally discussed by the psychologist Eric Erikson (30). These stages represent the critical periods of development from birth to death. The first three stages of development represent infancy and childhood. They reflect the achievement of trust, autonomy through mobility, and the ability to explore the environment. Even at these early stages in life, sexual behaviors and curiosity are quite typical and expected. This is true for children with and without disabilities.

As individuals move through life, they encounter a number of tasks set by their cultural milieu and by themselves as biologic entities. These developmental tasks are particularly critical as they must be mastered if children are to develop more mature social and interpersonal skills. When disability occurs, not only are the current developmental tasks threatened, but the persons, at least temporarily, regress to an earlier stage of development. This regression has broad implications for an individual's psychological and sexual adjustment. Because the person's sense of masculinity or femininity is an integral part of these developmental milestones, disability can create confusion and conflict in both gender identity and gender role, identity and role being different aspects of the same process. For people with disabilities, confusion regarding both gender identity and gender role can make the adjustment process more difficult, especially without adequate role models and sources of emotional support.

*Gender identity* is the inner experience of one's self as male or female; *role* is the outward expression of that identity (31). Without resolution of these conflicts, more complex tasks such as the formation of relationships and the achievement of a positive self-esteem may never occur. Thus, for a person with a disability, a healthy sexual adjustment and the ability to achieve intimacy depend on successful resolution of the developmental tasks at the time of injury or onset of illness.

The developmental process can be further complicated for young people with gay and lesbian orientations. More than simply a matter of having a same-sex partner, gay and lesbian identity is similar in scope to ethnic or racial identity, involving identification with the values of a discrete subculture (32). The process of forming a gay or lesbian identity evolves in stages from confusion and conflict around the emerging awareness of the same-sex urges to acceptance. For the person with a disability, the presence of homosexual issues can further complicate an already difficult sexual adjustment.

Congenital disabilities often prevent the child from gaining essential information about the body. Overprotection by parents, discouragement of sexual exploration, and a lack of adequate socialization often add confusion to male and female roles. Since identity is formulated before the age of 3 years, confusion regarding sexuality lends itself to later feelings of inferiority and difficulty relating to members of the opposite sex. Children with a disability are often isolated from peers and may regard themselves as "not equal" to their playmates (33). These deficits in the early sexual education of a child can easily become more difficult to manage later in life.

During puberty and adolescence, the achievement of sexual identity and acceptance in peer group relationships are the goals to be accomplished. As the adolescent grows and enters young adulthood, one of the primary developmental tasks is the development of intimacy and the concurrent strivings toward independence. Traumatic injury at this time threatens these important peer relationships and fosters dependency on the family unit. Adolescents with a disability often feel unattractive and ashamed of their bodies. Subsequently, they feel unwanted by the opposite sex and incapable of establishing a meaningful relationship. Without a sense of sexual identity, even late adolescents can lack the ability to make vocational and educational decisions or to assume responsibility for their own behavior. Thus, future emotional growth is threatened.

Aging is also an often overlooked developmental stage (34,35). Although the reality is that elders can continue to be sexually active throughout the life span, internalized negative attitudes can inhibit sexual expression in later years. The stigma against aging is even greater in the disabled community than in the culture at large and is experienced with fear at earlier ages than for individuals without disability.

## SEXUAL ADJUSTMENT

Adjustment to a physical disability or illness is a gradual process that occurs over an extended period of time. The individual must mourn the losses and ultimately develop coping strategies that will validate the meaningfulness of the new postinjury life. Successful adjustment depends on the recognition that choice is still available and is influenced by many factors such as age at onset, quality of social supports, physical health, gender, and type of illness or injury.

Successful sexual adjustment also requires the same gradual, and sometimes painful, emotional process. Losses need to be grieved so that the remaining strengths can be developed and nurtured. Because of different personality styles, however, not everyone completes this difficult adjustment. Some individuals, for example, may have experienced more profound earlier periods of grief and trauma because of early emotional, physical, or sexual abuse (36). Perhaps there were few emotional supports during childhood, and the grieving may have extended for prolonged periods of time. The resolution of predisability psychological issues may be necessary for the individual to master the demands and responsibilities of living with a disability.

After onset of a traumatic disability, individuals frequently go through a period of reduced sexual drive or performance. Others go through a period of sexual acting out, presumably to validate their survival and sexual identity. However, substantial numbers of people fail to resume an active sex life after injury because of misinformation, problems of adjustment, or shame regarding body image and function (7). Those who do assume an active sex life after injury are often advised by rehabilitation staff members to keep separate the roles of sexual partner and care provider (37,38). Having one's sexual partner provide intimate medical care can be destructive to the relationship. Mixing these roles often places one member in a needy, helpless position while the other member is perceived as powerful and giving. Such an unequal balance of power in a relationship tends to dilute feelings of intimacy and to be the source of feelings of resentment and anger.

To the extent that a person with a disability can learn to value his or her new sexual abilities, as opposed to trying to regain the same sexual expressions that existed before the injury, and to establish a positive level of communication, the person will achieve a satisfying sexual adjustment. These adjustments, however, often come slowly after a period of intense grieving and sadness. Many individuals find that emotional relationships and physical intimacy do not occur for many months following discharge from the rehabilitation center. Even then, the process can be slow and painful. Sexual experimentation may or may not be a part of this adjustment process, depending on the individual's ability to take risks and tolerate feelings of vulnerability.

People with disabilities who achieve success in their sexual functioning often do so because of increased communication and a willingness to experiment with developing romance and intimacy as well as technique. They are secure enough to realize that not every experiment will work and they value nongenital erogenous zones. They are typically more comfortable with their own bodies and continue to feel a sense of self-worth and self-respect (39,40). As a result, partners also feel validated and perceive the sexual relationship to be warm, caring, and mutually enjoyable.

The importance of communication cannot be overstated. The development of skills in communication about sexual topics and of methods of pleasure is the single most critical aspect of successful sexual adjustment. Specific and immediate communication between partners can relieve intense feelings of anxiety, fears of rejection, and concerns about physical safety. For this reason, psychological counseling and education about sexuality while the patient is in rehabilitation must emphasize these areas and provide the individual with the opportunity to develop and strengthen these skills.

Although psychological considerations need to be addressed in all discussions regarding sexuality, physical functioning is equally important. Often in rehabilitation, it can be extremely supportive and helpful to the patient if a sensitive discussion regarding physical capabilities is provided as soon as the individual is ready. Usually, the patient will indicate his or her readiness by asking questions regarding attractiveness, dating, relationships, and intimacy. Even if the individual does not raise these concerns during hospitalization, it is usually appropriate for staff members to offer information if the patient seems interested and curious. Such topics as libido, erections, orgasms, lubrication, fertility, mobility, sensation, and bladder functioning are all relevant to the sexual functioning of people with disabilities (29,41).

# SEXUAL DESIRE

Inhibited sexual desire is a highly prevalent dysfunction, affecting possibly up to 50% of sex cases seen in clinical settings (42–44). Although no data currently exist, this figure is probably higher for people with disabilities. Now known as hypoactive sexual desire disorder, it is characterized by persistently low or absent sexual fantasies and desire for sexual activity not caused by substance abuse or a primary psychiatric disorder. It is not uncommon for individuals with desire disorders to present themselves to the rehabilitation clinic with a variety of other sexual difficulties in addition to the primary problem of low desire. Couples may also present without a desire disorder but with desire discrepancy (where the partner's levels of desire are at variance with one another). Attempts are underway to clarify the diagnosis and the concept of normal desire and to standardize treatment. In patients with a psychiatric disturbance or severe reactive depression, the treatment is generally longer and outcomes less certain. Considerable research is still needed in this area of sexual dysfunction.

The sudden onset of disability or the more chronic issues of malaise, pain, fatigue, or stress can contribute to decreased libido (45). Low desire after onset of a traumatic disability is, for the most part, of limited duration. As adjustment proceeds, sexual desire often returns slowly and on a steady basis. The level of depression after disability occurs may in fact be the single greatest factor in determining the level of desire for sexual activities. If depression is more severe, or if there are substantial relationship issues that emerge after the onset of disability (or that were present before the onset of disability), the return of sexual desire may be more protracted and may require counseling or medications for it to resolve. Depressions associated with disability are complex medical problems that require an indepth evaluation and treatment plan. Often a psychiatric or psychological consultation may be warranted. In other instances, the precipitating factors responsible for the loss of sexual desire may be less apparent. Additional effort will be required to unravel the chain of events responsible for diminishing the libido. Changes in sexual desire may also be somewhat variable over time, depending on the emotional well-being of the person with the disability and his or her partner.

In addition to traumatic disability, many chronic illnesses and medications can result in inhibited sexual desire, either temporarily or permanently (42,46). Neuroendocrine disorders, cancer, heart disease, renal failure, liver disease, chronic lung disease, drug or alcohol addiction, and multiple sclerosis are among the conditions that can have a physical effect on sexual desire. Also, numerous medications may inhibit desire. Included are antihypertensives (propranolol, methy1dopa), neuroleptics and sedatives (diazepam, phenobarbital), mood active drugs (phenelzine sulfate, alprazolam), cancer chemotherapy, glaucoma medications, and anticonvulsives (44,47). Even serotonin reuptake inhibitors, which are used to treat depression, which itself reduces desire, can result in loss of desire and other sexual dysfunctions.

## MALE SEXUAL FUNCTIONING

The capacity to achieve erections is often altered in most men who sustain damage to the central nervous system. This typically includes injuries such as spinal cord injury and stroke as well as progressive disabilities such as multiple sclerosis and diabetes. Men with congenital disabilities such as cerebral palsy and muscular dystrophy typically retain the ability to achieve erections but more often report difficulties in mobility, positioning, and communication. If erections are altered, such as with spinal cord injury, the man may still be capable of reflexogenic erections. This is especially true with men who have sustained upper motor neuron lesions. Although these erections may not be suitable for penetration, they can usually be achieved and sustained by ongoing manual stimulation of the genital area. Some authors suggested that techniques such as stuffing can be mutually satisfying to the couple, while others discussed the importance of medical interventions to improve erection quality (37,48,49).

Sensory disturbances are also a prominent symptom in many of the patients with disabilities that affect central nervous system functioning. Many individuals report a complete loss of sensation below the level of the lesion. Other men who have partial sensation may experience some sparing of sensation in the genital area, although these areas may not be as sensitive as prior to the onset of disability. For example, the man may be able to differentiate hard touch but be unable to experience soft touch or stroking. Areas of intact sensation, usually above the level of injury, are often considered hypersensitive and can be another source of erotic pleasure. For other men, these areas can be a source of pain and are to be avoided during times of sexual behavior. Intensely erotic areas that are often used in sexual activity may be at the nipple line or in the vicinity of the ears, scalp, and neck. Because of the wide variations among different individuals, it is important to encourage patients and their partners to experiment with sexual functioning in order to gain a better understanding of their own unique situations.

In recent years, procedures such as penile injections, implants, vacuum constrictive devices (that fit over the penis), as well as various surgical procedures have gained increased popularity for men with neurogenic erectile difficulties (Figs. 55-3 and 55-4). Despite problems associated



Figure 55-3. Response battery-powered vacuum erection system. (Courtesy of Mentor Urology.)



Figure 55-4. Inflatable and bendable penile implants. (Courtesy of Mentor Urology.)

with these various devices such as corporal scarring, infection, and mechanical failure, patient satisfaction has generally been positive (50). Dissatisfaction has usually been caused by size of the penis, firmness of the erection, temperature of the penis, or difficulty in manipulating the device. Other couples have reported a loss of spontaneity with love making and a feeling that use of a mechanical device seems unnatural and a deterrent to their sexual expression.

Alternative methods of delivering drugs to the erectile bodies have also been widely discussed and evaluated. Originally, it appeared that one of the most promising forms of treatment was the application of nitroglycerin plasters directly to the penile shaft (51). In pilot studies, however, transdermal nitroglycerin, minoxidil, and prostaglandin E failed to induce rigid erections, apparently because of insufficient transfer of the drug through the skin (52).

Recently, the use of injections of alprostadil (Caverjet) has resulted in a major breakthrough in the treatment of erection problems for men with and without disabilities. Developed by the UpJohn Company, alprostadil was the first drug approved by the FDA for the treatment of erection problems. The drug received clearance by the FDA in July 1996, and was quickly made available in over 30 countries including the United States, France, Spain, Italy, and the United Kingdom.

As with other injection therapies, alprostadil is administered by a small needle into the corpus cavernosum. It relaxes the smooth muscle, which in turn enhances blood flow into the penis, creating an erection. Men receive the initial treatments by a medically trained professional, in order to determine the dosage and to learn the injection technique. For men with limited hand functioning, the injections are performed by their sexual partners. After these initial injections, the man and his partner take the medication home and use it whenever they desire. Usually injection therapies can be used once a day and up to three times per week.

Pain in using various injection medications does seem to be a common feature, although to date no data on this side effect exist for men with or without disabilities. Naturally, the amount of pain perceived depends on the amount of intact sensation after the onset of disability. Other side effects from the various injection therapies may include scarring, bleeding, and prolonged erections, known as *priapism* (53,54). Other medications commonly used for injections include papaverine and phentolamine as well as prostaglandin E. These medications, although experimental in nature, have been used for several years and the side effects may be less pronounced, especially with good training as to the technique. Because their erection problems are usually not vascular in nature, men with disabilities often find that small doses of these medications have a very significant positive impact on erection quality.

Other methods of drug delivery to the erectile bodies are currently under investigation. For example, the administration of alprostadil to the urethra mucosa for transfer to the erectile bodies has recently gained attention and is now available with prescription. Transurethral alprostadil appears to be effective with men of various age groups who demonstrate erectile dysfunction from a variety of organic causes. Side effects from this method of administration seem to be minor and were limited to penile pain in a minority of men in the initial studies (55).

Oral medications to improve erections are clearly the cutting edge in erection research around the world. There will be a tremendous market for oral medications once FDA approval has been obtained. Currently medications such as Viagra (Sildenafil) from Pfizer Pharmaceutical Company have great potential for men with erection problems. Other centers are doing clinical testing on various hormone therapies to improve male sexual functioning. The results of these studies seem very promising and breakthroughs are happening on a regular basis.

The ability to diagnose and treat infertility in men is another area that continues to improve. For men with disabilities of the central nervous system, fertility rates have generally ranged anywhere from 1% to 10% (56). Reports of pregnancies initiated were typically undocumented and anecdotal. Problems were due to either difficulties of sperm retrieval or poor sperm quality. Newer methods of retrieving sperm through electroejaculation and vibratory stimulation are demonstrating very positive results (57). In other cases, surgical sperm aspiration coupled with in vitro fertilization is offering new hope for couples wishing to have children. In other men, techniques to reduce testicular temperatures are having positive results on spermatogenesis and sperm production.

Of the advanced procedures, intracytoplasmic sperm injection (ICSI) has offered hope to many couples for whom poor sperm quality has been an issue (58). With ICSI, sperm is collected from the man through an assisted ejaculatory procedure if necessary. A single sperm is then injected directly into the egg, which was retrieved through a surgical procedure. Once the egg has been fertilized, it is then placed back in the uterus. Because of the effectiveness of the ICSI procedure, a growing number of reproductive clinics are adopting the procedure and using it for men with poor sperm motility and quantity.

As a result of these new procedures, the possibility of parenthood for people with disabilities has changed greatly. Ten years ago, men were often told that fatherhood was not possible after onset of a disability and were discouraged in their hopes of having a child. Currently, if the man with a disability has sperm, there is the potential for fatherhood. Rehabilitation professionals who provide education to their patients need to realize that these new procedures are available and that parenthood is possible.

## FEMALE SEXUAL FUNCTIONING

The literature on sexuality for women with disabilities has historically lagged behind the research being conducted for men with disabilities. One author suggested that age-old myths regarding female sexuality, cultural stereotypes, and the low incidence of traumatic disability in women are to blame (59). This situation seems to be changing, however, as women's sexuality and wellness have become an increasing priority for funding sources such as the National Institute on Disability and Rehabilitation Research and the National Institutes for Health. In spite of the growing attention to this area, there are still many unanswered questions that have far-reaching implications for the woman with a disability.

For the most part, changes in the female genital tract are most common after neurologic trauma or disease. These changes include vaginal lubrication, labial swelling, clitoral swelling and regression, and changes in the perception of orgasm. Most of the reports on female sexual changes following disability, however, tend to be anecdotal with little scientific basis. Since many of the findings tend to be self-reports, some researchers (59) suggested that the existing data are inaccurate and that this method is insufficient to obtain objective, quantifiable data on sexual arousal (Table 55-1).

One of the few scientific studies that examined sexual relationships following spinal cord injury was conducted by Sipski and Alexander (66). They questioned 25 female spinal cord-injured patients about sexual activities and frequency of sex before and after spinal cord injury. Ten subjects (40%) resumed sexual activities within 6 months of injury and an additional 6 (24%) resumed

sexual activity within 2 years after injury. Frequency of activity also decreased after the onset of disability. Whereas 16 (64%) of the women had engaged in sexual activity at least weekly before the injury, only 12 (48%) were as active after the injury. The number of sexual partners was also evaluated and no significant difference was noted for the number of partners before injury versus after injury for the group as a whole or based on neurologic injury. Finally, whereas sexual intercourse was the woman's favorite sexual activity before the injury occurred, kissing, hugging, and touching were preferred after the injury.

Many aspects of a woman's sexuality, including libido or desire, arousal, response, and specific sexual behaviors, may be altered after a traumatic injury. Complications encountered by women with traumatic disabilities include management of autonomic hyperreflexia (drastic changes in blood pressure), management of bowel and bladder continence, and management of spasticity. In some women with multiple sclerosis or spinal injury, lubrication may become reflexogenic, facilitating penetration of the vagina. Changes in desire and arousal may result from the impact of changes in her physical status on her perception of herself, from role changes that may occur as a result of injury, or from the anger and depression that often accompany the onset of a disability (22).

Current research on female sexuality now appears to be exploring issues related to vaginal contractions, intensifying perception of the orgasm, and stimulating vasodilation of the pelvic region. All require further investigation but seem to indicate a renewed interest in the field and a commitment to understanding female sexuality and disability. Most importantly, newer research is providing a renewed sense of hope for women with

Level of Injury	Sexual Response
C1-C3	Reflex lubrication. Altered sexual sensations during excitement and plateau phases. Severe respiratory difficulties may impair sexual activity. No change in sexual desire. Fertility remains unchanged.
C4-C5	Reflex lubrication likely. Psychogenic lubrication unlikely. Oral sex possible. Erotic zones above clavicle likely.
C6	Most common level of injury. Sensation same as for injury at C4–C5. Holding and caressing possible.
C7-C8	Increased potential for use of hands.
T1	Same as for injury at C7–C8 but with increased manual dexterity.
T2-T5	Sensation from level of diaphragm. Reflex clitoral erection and lubrication. Possible orgasm from nipple and breast stimulation.
T6-T10	Reflex erection of clitoris, labial swelling, and reflex lubrication with stimulation. Vaginal tone generally intact. No genital sensation at rest. Genital sensation altered during excitement phase.
T10-T12	Water-soluble lubricant needed for intercourse due to absence of reflex and psychogenic lubrication. No genital sensation during excitement and plateau phases.
Below T12-S1	Response to direct stimulation present but much less than lesions above T11. Lubrication is psychogenic. At rest, internal genitals sensate, external genitals insensate.
L1-L2	Psychogenic erection of clitoris, lubrication, labial swelling, and skin flush possible but unlikely.
L3–L4	Psychogenic reactions unlikely.
L5-S1	Clitoral erection and lubrication unlikely.
S2-S4	No reflex clitoral erection. No genital sensation at rest. Vagina remains well lubricated.

Table 55-1: Sexual Response in Women with Complete Spinal Cord Lesions

Source: Data from Weinberg (60), Zasler (61), Berard (62), Glass (63), Sipski and Alexander (64), and Whipple (65).

disabilities, offering important applications for clinical practice (65).

Of special note in the current research on women are new data regarding orgasms in women with spinal cord injury. Sipski and Alexander (67) demonstrated that a large percentage of women with spinal cord injury achieved orgasm regardless of the pattern or degree of neurologic injury. Furthermore, they ascertained that no consistent characteristics have been identified to predict which women with spinal cord injury would be able to achieve orgasm. These new data seem to indicate that education of women regarding their sexuality plays an important role in their overall sexual adjustment and is a determining factor in their general sexual satisfaction. These studies have had vast implications on previous assumptions regarding women with disabilities and have sparked renewed interest in the physiologic sexual responses in women following the onset of disability.

An area that has been particularly neglected is the issue of menstruation in women who have sustained traumatic injury. Yet, the role of motherhood and the emotional issues connected with this cannot be overestimated. Menses is important to a woman; it reinforces her belief in herself as a woman, which in turn affects her selfesteem (68).

Cessation in the menstrual cycle may occur for a number of reasons other than menopause or pregnancy. These reasons may include changes in hormone secretion, severe psychological disturbances, or significant trauma such as spinal cord injury. Concerns about menstruation are typical early in the rehabilitation program.

Menstrual periods generally continue after onset of a traumatic disability, with a temporary post injury interruption of menses occurring for at least 6 months. In women with spinal cord injury, rates of temporary amenorrhea range from 44% to 58% in research samples (64,68,69). The nature of the disability tends not to be associated with an interruption of menses. In some studies, there were changes in cycle length, duration of flow, amount of flow, and changes in amount of menstrual pain after the onset of disability. Ovulation in most disabilities tends to be unaffected because the location of the ovaries makes them less susceptible to changes in body temperature (70). Menstrual self-care should include frequent changing of tampons and absorbent pads to guard against the risk of infection, toxic shock, and pressure sores. Concerns about reduced fertility, with most disabilities, are unfounded, and conception should not be a problem for most disabled women (71).

The issue of birth control is somewhat problematic for women with disabilities. However, Zasler (61) suggested that in the age of acquired immunodeficiency syndrome (AIDS), the choice is no longer so controversial: Unless the relationship is monogamous and long-standing, the safest method is a thick latex condom with a spermicidal foam or jelly containing nonoxynol-9. This method is believed to protect against AIDS and other STDs. Limiting the number of sexual partners is also recommended for AIDS prevention. The combination of a diaphragm and foam is also thought to reduce risk, but the limited dexterity of many women with disabilities makes it difficult to insert and remove; reduced sensation also prevents detection of an incorrectly placed diaphragm, which might cause irritation and subsequent bladder infection. The partner or personal care attendant might assist in placing the device (72).

Birth control pills are known to increase the risk of blood clots, signified by leg pain, in the general population. Women with mobility impairments are already at higher risk for developing blood clots because of reduced circulation in the lower extremities and may not be able to sense the warning pain. For this reason, some health experts consider their use contraindicated; however, no empirical studies have been conducted to document the increased risk (64). Those people who do recommend the pill for women with reduced mobility argue that the new low-dose pill minimizes the risk. Blood clots are more common in the first 6 months following traumatic injury, so delay in prescribing birth control pills until that time and provision of frequent follow-up checks—usually twice per year should minimize the risk (72).

Patients who have a disability and become pregnant often face a wide variety of medical issues that are not as common among the general population. These include an increased risk of urinary tract infection, anemia, sepsis, pressure sores, unattended births, and autonomic hyperreflexia, and difficulty with transfers toward the end of pregnancy. Therefore, proper follow-up by an obstetrician knowledgeable about disability is essential. In reality, however, finding such a medical professional may be difficult and the obstetrician may need ongoing consultation with the physiatrist in order to address disability specific issues.

It follows that to improve the sexual satisfaction of women with disabilities, new treatments must be developed and documented. New data on reproduction and wellness must be communicated to women who have disabilities. These may include medical treatments such as the use of biofeedback and vibratory stimulation or psychological approaches such as patient education or new forms of sexual counseling (23). Only then will women begin to have the information that they deserve regarding their bodily processes and sexuality.

# STAFF TRAINING AND INSTITUTIONAL ISSUES

Staff training in sexuality is a critical feature of any comprehensive rehabilitation program. This training must include programs aimed at values clarification as well as those that provide specific information on disability and sexuality. In addition to the training curriculum, administrative support of the sexuality program must be evident to staff members, families, and patients alike. This administrative approval establishes a positive therapeutic environment where openness, empowerment, and caring are the foundations of the rehabilitation process.

Although not all staff members need be sex counselors, all should feel comfortable with the topic of sexuality and communicate a sense of openness about the topic. This necessitates an awareness of one's own values and reactions to sexually related issues. Generally, anxiety, shame, and discomfort about sexuality are common (29,73). Putting this anxiety aside and becoming aware of our personal reactions to sexual issues is a long process that requires sensitization, education, and practice. Often a first step in reducing this tension is acknowledging one's feelings to another person. In a work setting, a peer support group or discussion with a colleague can be especially helpful in overcoming personal barriers about sexuality.

In addition to processing personal feelings about sexuality, specific information on sexuality and disability must also be taught to staff members. Without correct up-todate information about sexuality, staff members will only add confusion to an already difficult topic. Even worse, the patient and partner could be given incorrect information that will have a negative effect on their overall adjustment and relationship. An ongoing lecture series is often helpful in this regard. Typical issues addressed in such a program include sexual anatomy and physiology, effects of medications, physical functioning, treatment options such as penile injections and implants, counseling techniques, professional roles, and gay and lesbian issues.

Staff members should be able to facilitate positive sexual identity for all rehabilitation patients, including exposure to healthy role models. Patients require specific information on medications, sexual techniques, communication styles, as well as complications such as dysreflexia that may be experienced when using a vibrator or during childbearing.

The development of a sexuality committee within a facility is often the method of choice in addressing ongoing sexual issues and problems (73). Ideally, a member of the administration should serve on the committee. His or her presence validates the committee's function and provides a sense of security, safety, and recognition to its members. The development of institutional guidelines and procedures is usually the first task of the committee and often its most important function. It is essential that the committee

establish guidelines on some of the most sensitive interactions that occur in the day-to-day functioning of the institution. Typically issues to be addressed include such matters as whether to establish a privacy room, public versus private masturbation, sexual activity with a partner, dissemination of birth control information and supplies, prevention of sexual assault, prevention of STDs, and policies concerning the relationships between patients and staff members.

Most often in-service education programs will raise concerns about staff-patient interactions. This interaction is usually the primary area of staff anxiety, and sensitive discussion is most often welcomed and appreciated. In addition, an overview of behavior modification techniques can be helpful. This overview should be especially geared to sexual issues and should be combined with theoretical discussions of reinforcement schedules and behavioral contingencies. Finally, the importance of limit setting and professional boundaries should be discussed and emphasized.

## CONCLUSIONS

For people with disabilities, there are multiple restrictions on the expression of sexuality. These stem from cultural biases, social ignorance, and unfounded fears regarding the person with a disability. For homosexual men and women, these fears and biases are significantly intensified, and there is a serious lack of information and resources available in the area of sexual health. The responsibility of medical professionals is to achieve a balance between protecting the rights and privacy of hospitalized patients and providing a safe and enriching environment. As staff attitudes are retrained away from control and from imposing restrictive values, a therapeutic environment that fosters self-esteem and sexual growth will unfold in the rehabilitation setting.

In the last decade, we have witnessed tremendous progress in the areas of sexuality and disability. However, there is much left to be done so that men and women from all sexual orientations are included in this revolution. What once began as a passing fad outside of mainstream rehabilitation has now become an accepted standard of practice for the rehabilitation team. Education about sexuality is a critical component of the rehabilitation process. More importantly, people with disabilities are now recognized as having the same rights, needs, and desires as all people.

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