

Women with Spinal Cord Injury

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INTRODUCTION

Demographics

Each year in the United States alone 11,000 people sustain spinal cord injuries (SCI). It is estimated that the annual incidence of SCI, not including those who die at the scene of the accident, is approximately 40 cases per million populations in the U. S. (Stover, DeLisa & Whiteneck, 1995; UAB, 2001). The number of people in the United States who are alive today and who have SCI has been estimated to be between 183,000 and 230,000 persons. SCI primarily affects young adults in what would be the prime of their lives. Fifty-five percent of SCI's occur among persons in the 16 to 30 year age groups, and the average age at injury is 32.1 years.

Overall, four out of five individuals in the national spinal cord injury database are male. Although this four-to-one male to female ratio has varied little since 1990, the percentage of males has decreased to 80.5% (from 81.8% in the 1970's). Specific statistics about women with SCI are more difficult to obtain, although a few studies have focused on aspects of issues related to women with SCI or women with disabilities in general (Nosek, Howland, Rintala, Young & Chanpong, 1997; Jans & Stoddard, 1999). Considering the youthful age of most persons with SCI, it is not surprising that most (53.4%) are single when injured. Among those who were married at the time of injury, as well as those who marry after injury, the likelihood of their marriage remaining intact is slightly lower when compared to the uninjured population.

The etiology of SCI varies, with motor vehicle crashes accounting for 38.5% of the SCI cases reported. The next largest contributor is acts of violence (primarily gunshot wounds), followed by falls and recreational sporting activities. Interesting trends in the spinal cord injury database show that the proportions of injuries due to motor vehicle crashes and sporting activities have declined while the proportion of injuries from acts of violence and falls has increased steadily since 1973. The etiology of SCI for women are : motor vehicle accidents (58%), falls (18%), violence (14%), sports (6%) and other causes (4%) (UAB, 2001). The economic impact of SCI (both new injuries and ongoing care) in the US is estimated to be \$4 billion per year. Although less than 10% of patients with SCI die as a direct result of their injury, most are disabled to some degree, and their lives are dramatically changed by these disabilities and the accompanying financial burden.

Classification of Spinal Cord Injury

Spinal cord injury has been classified in a variety of ways over the years. The simplest classification is quadriplegic/ tetraplegic or paraplegic and complete or incomplete injury. However, by utilizing the Standard Neurological Classification of Spinal Cord Injury (American Spinal Injury Association [ASIA], 1996) and systematically examining the dermatomes and myotomes, one can determine the cord segments affected by the SCI. From such an examination, several measures of neurological damage are generated, e.g., neurological level, sensory level, motor level, sensory scores (pin prick and light touch), motor score and zone of partial preservation. Assessment of the physical impact of the injury must also be accompanied with measurement of impairment and disability by using the Functional Independence Measure (FIM) (ASIA, 1996).

Functional Outcomes

Expected outcomes and their measurement for individuals with SCI are divided into four domains: motor recovery, functional independence, social integration and quality of life. Outcome based practice guidelines can provide estimates of the effect of rehabilitation on functional status or activity restrictions. An excellent resource is available to all health care providers to give detailed descriptions of the expected outcomes of people with a motor complete spinal cord injury at 1 year after injury. The Outcomes Following Traumatic Spinal Cord Injury: Clinical Practice Guidelines for Health-Care Professionals (PVA, 1999) are presented with the full recognition that outcomes are not fully under the influence or control of health-care providers. Differences in patient characteristics; the course of medical events; psychological, social and environmental supports; cognitive abilities all have strong influences on outcomes.

PRIMARY HEALTH ISSUES OF SPINAL CORD INJURY

Just 50 years ago someone injured with a SCI was not expected to live very long if at all, after injury (Whiteneck, Charlifue, Gerhart, Lammertse, Manley, Menter & Seedroff, 1993). Advances in medicine, nursing and rehabilitation techniques as well as improved equipment have aided in extending the life span of people with SCI to near-normal lengths. Healthcare professionals have a need to be acutely aware of the severity and extent of physiologic changes that result from spinal cord injury (SCI) involving knowledge of all women's health issues and all aspects of her disability (Jackson, 1995). From the moment of injury, there are permanent changes in sensory and motor function. Bowel, bladder and sexual function are generally impaired as well. Clinical practice guidelines to aid the health care practitioner in current trends and excellent medical management of the persons with SCI are currently available (Paralyzed Veteran's of America [PVA], 1997, 1998, 2000) . Depending on the level and extent of injury, the person maybe using assistive devices for mobility and daily functional activities. With less severe injuries and appropriate devices, ambulating may be possible for some. If the injury involves the upper cervical region of the spinal cord, the person may be completely paralyzed and in the most severe cases may require a ventilator for respiration.

DeJong (1997) points out six ways in which the ongoing health care needs of persons with a disability are different from those of the general population:

- The narrow margin of health, which necessitates careful monitoring to avoid medical problems. While also true of certain health conditions shared by people without disability (i.e., upper respiratory tract infections, pneumonia), the impairments and functional limitations result associated with spinal cord injury result in a thinner margin of health, leading to increased medical problems.
- Limited availability of “insurance” coverage for health care and preventive medicine.
- The risk of acquiring a chronic health condition at an earlier age than is usual in the general population (e.g., coronary artery disease in the individual whose mobility is limited; or in whom lack of aerobic exercise leads to increased weight gain and an earlier onset of type II diabetes).
- Onset of a new health condition, which leads to a secondary functional loss, with resulting significant physical limitations and increased dependence.
- A more complicated and prolonged course of treatment before restoration of their previous functional status.
- The need for durable medical equipment devices and other assistive technologies which require detailed knowledge by both the prescriber and the patient.

ASSOCIATED CONDITIONS LEADING TO SECONDARY DISABILITY

The longer someone lives, the more likely it becomes they will experience some medical conditions which are secondary to the original injury. Pope and Tarlov (1991) report that a secondary condition is any additional physical or mental health condition that is causally related to a primary disabling condition. Any secondary condition has the potential to adversely affect a person's quality of life, independence and may even become life threatening if not treated in a timely manner. Marge (1988) states that it behooves those who serve the disabled to study and understand the factors which result in additional disabilities and to take effective steps to reduce the risk of secondary problems in people with disabilities.

Because of the profound physiologic changes that result from SCI, these people will have increased lifelong susceptibility to a number of secondary conditions. Secondary conditions as defined earlier are an indirect consequence of the limitations imposed by the injury. For instance, pressure sores often occur in people with SCI due to the loss of sensation that would normally alert a person to impending harm, a painful stimulation or trauma to the skin. The loss of the ability to move or shift body weight could also contribute to the breakdown of skin on the ischials and tailbone areas. Yet skin sores are not a necessary consequence of SCI and can be prevented with attention to regular weight shifts and skin inspections, proper hygiene, appropriate padding and equipment. Overall health promotion practices including attention to nutrition, fluid intake, exercise and smoking cessation also contribute to good skin health. Other secondary conditions including urinary tract infections, spasticity, pneumonia and deep vein thrombosis, pose

serious health threats because they can greatly increase the morbidity of the person with SCI, and may result in early mortality.

Engaging in appropriate health maintenance and health promoting behaviors, such as avoiding alcohol and drug use, proper nutrition, exercise and stress management techniques can minimize the risk of developing secondary conditions. Psychological and educational prevention strategies may potentially be very effective in minimizing the number of secondary conditions for women with SCI.

Women with physical disabilities and SCI specifically are at risk for a variety of secondary conditions, including preventable medical, psychological, social, and physical complications as well as environmental obstacles and barriers. Few epidemiological studies have specifically focused on the incidence, prevalence, and severity of secondary conditions or the underlying causative factors for women with SCI. However, clinical experience and research efforts have begun to generate a listing of secondary conditions that are thought to occur frequently in the general population of women with disabilities (Coyle, Santiago, Shank, Ma & Boyd, 2000; Seekins, Clay & Ravensloot, 1994).

Summary of Secondary Conditions Among People with SCI

1. Pulmonary complications are the most common cause of death in the acute and chronic phases after SCI
2. Cardiovascular conditions such as deep vein thrombosis, pulmonary embolism, and autonomic dysreflexia are also major causes of morbidity and mortality
3. Metabolic dysfunction associated with altered endocrine function, sedentary lifestyle, and impaired neurogenic influence, including heterotopic ossification, osteoporosis, pathologic bone fracture and immobilization hypercalcemia.
4. Pressure ulcers due to loss of sensory input, immobilization, poor diet, lack of self-care, improper seating and bedding equipment
5. Urinary tract infections are the most common secondary complication with upper tract urological complications higher risk to long-term health and survival.
6. Secondary musculoskeletal problems including spasticity, contractures, pain, post-traumatic syringomyelia, osteoporosis with limb fracture, and heterotopic ossification
7. Psychosocial secondary disabilities reported include increased depression, drug and alcohol use, prescription drug overuse and social isolation.

(Charlifue et al, 1999; Coyle et al, 2000; Dunn et al, 2000; Johnson et al, 1998; Krause, 2000; Krause et al, 2000; Krause et al, 2001; Marge, 1988; Phillips et al, 1998; Pruitt et al, 1998; Shackelford et al, 1998)

The Health Practices and Secondary Conditions Project has been developed to study the many demographic, general and disability-related health maintenance, and contextual factors that appear associated with the presence of secondary conditions among persons with disabilities. However, the relative influence of these factors requires clearer understanding if appropriate health prevention and promotion strategies are to be identified. The purpose of this study is to investigate the relationship of key disability-related health maintenance practices and contextual factors to the presence of secondary conditions. The Rehabilitation Research and Training Center (RRTC) on Health and Wellness is funded by the National Institute on Disability and Rehabilitation Research (NIDRR) to conduct research and training to support the health and wellness of persons with long term disabilities. Intended to specifically address the conditions of cerebral palsy, multiple sclerosis, post-polio syndrome, amputation and spinal cord injury, the web site (www.healthwellness.org) will be of interest and value to all persons with disabilities, and in fact, all persons without disabilities as well. For more information about this study and related activities contact: Rehabilitation Research and Training Center, Oregon Health & Science University, PO Box 574, Portland, OR 97207, 503-494-3534.

HEALTH PROMOTION

Health promotion is the science and art of helping people change their lifestyle to move toward a state of optimal health. Optimal health is defined as a balance of physical, emotional, social, spiritual and intellectual health. Attention to health promotion and wellness for people with SCI has been noted in the literature much more extensively in recent years (Lanig, Chase, Butt, Hulse & Johnson, 1996; Laskin, James & Cantwell, 1997; Marge, 1988; Rimmer, 1999; Thierry, 1998; Thomas, 1999, Warms, 1987). This emphasis on promoting good health practices reflects a shift in thinking in health care providers who are more attuned to prevention of secondary disabilities and the promotion of overall good health. For women with SCI this is an important aspect of her primary health care plan.

In a book titled "Talking About Health and Wellness with Patients: Integrating Health Promotion and Disease Prevention into Your Practice", (2000) Dr. Steven Jonas proposes a framework for all health care providers to utilize for presenting health promotion information to any patient. These factors along with some modification can be utilized as a framework when working with a woman with SCI:

- **Engaging in a suitable regular exercise program** — Exercise for a woman with SCI will have to be modified depending on level of injury, muscle mass available, personal taste and availability of equipment, programs and motivation. The challenge lies in developing an exercise program that maximizes functional capacity, within limitations created by the level of injury and physiological changes that influence cardiovascular response to exercise. Physiologic impairment may include extensive muscular paralysis and sympathetic nervous system impairment. These frequently result in two major exercise-related problems: 1) reduced ability to voluntarily perform large muscle group aerobic exercise; and 2) inability to stimulate the cardiovascular system to support higher rates of aerobic metabolism (Figoni, 1997; Washburn & Figoni, 1998). Physical fitness for the person with SCI often cannot be

defined in terms of the traditional conceptions of physical fitness of the general population. Rather physical fitness must be defined in a broader sense that encompasses appropriately modified descriptions of endurance, strength, flexibility and cardiovascular performance (Chase, 1996).

The National Center on Physical Activity and Disability (NCPAD) promotes healthy lifestyles for people with disabilities by disseminating the latest information, providing up-to-date resources, and conducting research on physical activity and disability. NCPAD can be accessed through the world wide web at <http://www.ncpad.org> or by phone 800-900-8086.

- **Having a body weight and fat proportion that reasonably correspond to normal for one's age, sex, and height** – Although there are no published weight standards for individuals with paraplegia or quadriplegia, in studies by Peiffer and Cox (as cited in Lanig, 1996b) it is recommended that levels of ideal body weight should be set lower for SCI individuals than for non-disabled persons. It is suggested for those with paraplegia, body weight be maintained at 10-15 pounds (4.5-6.8 kg) below the Metropolitan Life Weight and Height Table recommendations for height and body frame. For individuals with tetraplegia, the recommended guideline is 15-20 pounds (6.8-9.0 kg) below that of standard weight recommendations. On a more practical note, however, will be the availability of an appropriate scale for weighing the person with a spinal cord injury. The usual stand up model of a height-weight scale is impractical for someone using a wheelchair. Alternative weighing mechanisms, such as floor-model produce scale at the local grocer, a scale located in a local hospital, or an overhead, bed scale may have to utilized.
- **Eating a reasonably balanced diet containing a moderate level of fat** – Healthy eating is good for all people but especially important for a woman who is unable to maintain or lose weight due to the SCI. Encouraging women to take control of this area of their life can be empowering. Support by way of dietary counseling and education may be of help. Attention to the financial status of the client may be a factor in the quality and quantity of food she is able to obtain. Socioeconomic, environmental, and disability-related functional issues that may affect nutritional habits must often be assessed and addressed during the nutritional assessment in a manner not necessary in the general non-disabled population (Lanig, 1996b).
- **Using neither tobacco products nor prescription mood-altering drugs on a non-prescription basis. Using alcohol or any other recreational mood-altering drugs in moderation, if at all** – Observation of behavior and periodic assessment of the client's use of mood-altering substances should be a part of any health care encounter. Use of the quick and easy measurement tool CAGE may useful in any health care assessment. The CAGE was designed as a quick and easy measurement instrument to evaluate a patient's alcohol usage and to determine if further assessment is necessary. CAGE stands for cutting down, annoyance by criticism, guilty feeling, and eye openers as described in Ewing's work (as cited in Lanig, 1996a). The CAGE has been found to be a valid measure of alcohol usage among the SCI population as stated in Tate's study (as cited in Lanig, 1996a).

- **Handling stress productively** – An individual with SCI may master all the requisite skills of physical self-care, transfers, and medication needs, yet be quite ill prepared for “living” in the real world upon completion of a rehabilitation experience. It is postulated that after the onset of a SCI, the psychological challenges of accommodation are equal to or greater than the physical challenges (Butt & Lanig, 1996). SCI is not solely a biological event, it is most certainly a biographical event that dramatically occurs within the context of one’s personality and life. How a person is handling the stress of the injury in the context of their own life will be a most important assessment to consider.
- **Practicing safe sex** – Sexually transmitted diseases (STD) are a significant health risk in society as a whole and must be addressed for the woman with SCI as well. Topics to be addressed as part of a sexual health assessment include: an overview of STD’s, signs and symptoms of STD’s, education regarding safer sex practices, and treatment of STD’s (Johnson & Lanig, 1996).
- **Preventing abuse** – Physical and sexual abuse is an area that must be addressed in a comprehensive sexual health program. Sadly, it has been reported in Rines and Breen, that individuals with disabilities are at greater risk for physical and sexual abuse than those without disabilities (as cited in Johnson & Lanig, 1996). Abuse frequently occurs by caregivers. Women with SCI who are abused by their personal care providers may be afraid to report the abuse due to concerns about abandonment or retaliation. Education and awareness on how to recognize situations that might be conducive to abuse or abusive relationships, such as social isolation and stressed caregivers, should be provided as well as general safety issues related to security and meeting new dates (Johnson & Lanig, 1996)
- **Protecting personal safety (without becoming obsessive about it)** – Personal safety for a woman who uses a wheelchair takes on a wider dimension encompassing physical safety of the person, safety in mobilization and equipment, safety in the home as well as emotional and mental safety. The health care provider while not able to provide all safety information or precautions will want to at least be aware and sensitive to those areas and encourage the woman to seek support as needed.
- **Maintaining an up-to-date, age-appropriate immune status** – Vaccine-preventable diseases occur among adults because vaccines recommended for adults are not optimally used; for example; more than 40,000 persons die annually in the United States from influenza and pneumococcal pneumonia (DeCastro et al, 1999). Routine vaccine schedules for the general adult population with special consideration for at-risk individuals, including influenza and tetanus boosters should be followed according to the latest recommendations as published in the Morbidity & Mortality Weekly Reports (Centers for Disease Control [CDC], 1994).

HEALTH ASSESSMENT

An essential task of the health care team is to ensure that the non-disability related, general health care needs of the woman with SCI are addressed as well as a thorough assessment of specific SCI-related issues. There is a fair amount of consensus in the medical rehabilitation literature on the core of concepts that should be incorporated into

evaluations of the disability-related health status of individuals with SCI (Lanig, 1996). Additionally, empiric incorporation of certain general health risk assessments related to smoking, obesity, diet, cancer, and family history risk factors for disease seem appropriate for the SCI population. In addition to SCI-specific issues, health care practitioners must be sensitized to a variety of general preventative health care screening activities and the essential components of core health practices.

Components of the basic SCI-related health assessment conducted every one to three years after completion of an acute medical rehabilitation program should include:

1. Medical evaluation: screening assessment appropriate to age, gender, SCI level, and general health-related risk factor status, comprehensive history and physical examination (including motor and sensory neurologic evaluation)
2. Assessment of health-protecting and health-promoting behaviors as recommended by national health organizations, lifestyle behaviors, tobacco and alcohol use review
3. Body weight, blood pressure & pulse, forced vital capacity
4. Hematologic and biochemical studies including cholesterol/ HDL/triglycerides)
5. Urologic evaluation consisting of upper tract evaluation (renogram, ultrasound, or intravenous pyelogram); as well as lower tract evaluation (cystogram, post-void residuals and cystoscopic examinations)
6. SCI self-care routines
7. Stress management and coping techniques
8. Leisure activity assessment

(Shackelford et al, 1998; Lanig, 1996a)

Additionally, specific assessment of organ systems in regards to secondary conditions is recommended. Detailed screening and early detection activities are listed below.

Organ System	Primary & Secondary Prevention Assessment Areas
Respiratory	<ul style="list-style-type: none"> • Smoking/exposure to second-hand smoke • Influenza and pneumococcal vaccine status, especially for high levels of paraplegia/tetraplegia • Knowledge regarding respiratory complications and management of such • Posture/ kyphoscoliosis/ trunk spasticity/ abdominal distention/ obesity problems for potential impact on chest expansion and respiratory function
Cardiovascular	<ul style="list-style-type: none"> • Risk factors: family history, physical activity, decreased exercise capacity, abnormal lipid-lipoprotein profile, abnormal carbohydrate metabolism, obesity, smoking, impaired peripheral circulation • Knowledge regarding diet, smoking, weight control, activity options, smoking cessation resources • Age-related changes
Skin	<ul style="list-style-type: none"> • Knowledge regarding prevention of skin breakdown and risk factors • Age and condition of wheelchair and cushion • Posture/ pelvic obliquity/ spasticity-induced shearing and pressure issues • Body weight and nutritional status impact on skin vulnerability • Transfer skills • Pedal edema/ footwear condition • Smoking cessation, sunscreen use on insensate areas • Age-related changes
Neuromusculoskeletal	<ul style="list-style-type: none"> • Upper extremity pain issues related to functional impact • Lower extremity/ lower back degenerative changes with impact on ambulating skills • Spasticity issues and impact on transfer safety, posture, or shearing/ pressure on skin • Stability of sensory/ motor profile • Charcot joint arthropathy with impact on trunk stability/ dysreflexia patterns/ pain issues • Neuropathic pain phenomena (new onset pain vs. stable pattern), functional impact

Organ System	Primary & Secondary Prevention Assessment Areas
Genitourinary	<ul style="list-style-type: none"> • Bladder hygiene/ bladder management techniques • Infection, incontinence rates • Urinary tract stone formation (upper & lower tracts) • Genitourinary system surveillance history to date • Gynecologic history – breast, pelvic exams, post-injury amenorrhea, BSE performance, postmenopausal hormone replacement • Sexual health and fertility concerns
Gastrointestinal	<ul style="list-style-type: none"> • Bowel elimination program-technique/ duration/ regularity • Early identification of hypomobility problems • Nutrition and hydration • Anticholinergic use and impact on elimination • Gallstone disease • Symptomatic hemorrhoids (bleeding, dysreflexia inducing) • Age-related changes
Functional Status	<ul style="list-style-type: none"> • Changes in function secondary to changes in strength, endurance, fatigue, pain • Changes in personal care assistance, transportation, health care resources, personal stressors
Nutritional Assessment	<ul style="list-style-type: none"> • History & physical exam • Body weight • HDL-C/LDL-C; fasting serum glucose • Swallowing difficulties • Functional, economic, or environmental influences on dietary habits/ adequacy of nutrient intake • Medication effect on appetite/ bowels • Diet intake and meal composition
Breast Cancer	<ul style="list-style-type: none"> • Evaluate risk factors carefully • Inquire about monthly self or caregiver-conducted BSE • Initiate training and education if needed • Physician breast examination annually • Mammography – annually or biannually for ages 40-49 (varying opinions); annually after age 50

Organ System	Primary & Secondary Prevention Assessment Areas
Cervical Cancer	<ul style="list-style-type: none"> • Evaluate risk factors carefully • Annual Papanicolaou (Pap) smear (biannual examination acceptable in absence of risk factors)
Tobacco, Alcohol and Substance Use Evaluation	<ul style="list-style-type: none"> • Smoking/ second hand smoke exposure • Alcohol/substance utilization and functional consequences • CAGE screening questionnaire/ brief MAST screening tool

(Lanig, 1996a)

Only in the last 10-15 years has there been a ground swell of sensitivity and research interest in the areas of women's health; most often this activity has been directed toward reproduction and depression. For practitioners, obtaining information regarding secondary conditions of women with SCI has been a demanding task. Concerns often are about issues of physical and economic access to general health and gynecologic healthcare delivery systems, sexuality and sexual health behavior, relationships, menstrual management, pregnancy and parenting. In addition many women with SCI experience frustration in locating information about themselves.

SEXUAL FUNCTION AFTER SCI

The changes in physiologic sexual response in both males and females with SCI are dependant on the level of injury, the completeness of the injury, and the type of neurological injury to the sacral nerve roots (Comarr, 1966; Jackson, 1995; Johnson & Lanig, 1996; Sipski, Alexander & Rosen, 2001; Westgren, Hulting, Levi, Seiger & Westgren, 1997). Though the changes in females have been less extensively studied than those in males, trends are changing in that arena and there is more information available now than ever (Linsenmayr, 2000; Sipski, 1991). Increased attention recently has been directed toward better understanding the physiology of reflex lubrication, psychogenic lubrication, and the nature of orgasm in women. Orgasm – or the mind's pleasurable interpretation of physical or physiological events – has been reported to occur in both males and females with SCI, but the physiology of these genital and extragenital experiences has not been documented. Orgasms, whether they are extragenital or genital in origin, have been reported in individuals with complete and incomplete injuries. Most of the literature on alterations in sexual function after SCI has been through self-report surveys. Limited data has been gathered in laboratory settings by actual observation techniques. However, based on a recent study by Sipski et al., 2001, preservation of the ability to perceive sensation in the T12-L2 dermatomes should predict the ability for psychogenically based genital vasocongestion. Proper examination and counseling for women with SCI should include sensory testing in the T11-L2 region and determination of the degree and type of injury affecting S2-S5. Women with preservation of T11-L2 sensation should be encouraged to maximize their psychogenic sexual experiences. All women should be educated that a longer and possibly more intense degree of genital stimulation may be necessary to achieve orgasm

It is important to note the emphasis that human sexuality and activity is never purely a physiologic event. Individuals with SCI must be encouraged to explore their own bodies, physical capabilities, and physiologic sexual response (Johnson & Lanig, 1996). It should be noted that the cited possible changes in female sexual response after SCI have been based on the assumption that female sexual function is analogous to that of males. On the basis of this premise, it is currently thought that reflex lubrication, psychogenic lubrication, and perceptions of orgasms will be closely related in some degree to those changes observed in male erection, emission, and ejaculation.

FERTILITY ISSUES

Fertility is essentially unchanged in females after SCI. Alterations in the menstrual cycle may occur in the form of amenorrhea and have generally been reported to be a temporary situation with loss of menstruation occurring anywhere from 6-18 months. Immediately following injury, amenorrhea occurs in 85% of women with cervical or high thoracic injuries, and 50% to 60% of women overall. By 1 year post-injury, 90% of women have returned to regular menstrual cycles. The level and completeness of the injury do not seem to influence the cycle (Comarr, 1966; Linsenmayar, 2000; Sipski & Alexander, 1992). Other studies have indicated similar reports with a median time of five months post-injury before the return of menses (Axel, 1982; Charlifue, Gerhart, Menter, Whiteneck & Manley, 1992). Once menses returns, a woman does have the ability to have children.

Contraception

Contraception is a very important piece of health education for all women with SCI. And by all means contraception should be utilized if pregnancy is not a desired outcome. An outline of contraceptive options should be provided for all women. However, the optimum contraceptive option for women with SCI has not been firmly established. Oral contraceptives are typically considered to be contraindicated in women with SCI because of the increased risk of deep vein thrombosis (DVT). Nonetheless, a survey of 70 women who had been using birth control pills for an undetermined amount of time after onset of SCI yielded only four reports of a blood clot episode (McClure, 1990). The relative contraindication of birth control pill use among women with SCI is therefore an area in need of further investigation (Sipski & Alexander, 1992). Investigation is needed, for example, to determine if the newer low-dose estrogen birth control pills may be safer than earlier pills. Progesterone pills and the sub-dermal progestin implants (Norplant implant), which do not contain estrogen, and are not contraindicated in women with preexisting DVT, may be safer for women with SCI.

Diaphragms and cervical caps have variable success rates. For women with limited hand function or limited mobility, placement of these devices can be difficult and even impossible in some cases. Additionally, lack of sensation can hinder the proper placement of these devices that would then compromise their effectiveness. The *intrauterine device (IUD)* is relatively contraindicated in women with no sensation because of their inability to perceive abdominal or uterine pains associated with misplacement or dislodging, sign of infection, or ectopic pregnancy. *Condoms or spermicidal jelly or foams* provide for the safest and most reliable form of contraception for

women with SCI. Partners of women with limited mobility and hand function will have to assist with use and application of the condom and spermicide. As in all cases, for those individuals not involved in monogamous relationships, condoms should be worn for the prevention of sexually transmitted diseases. Tubal ligation or abstinence has also been reported in small numbers as a means of birth control (Charlifue, et al., 1992).

Pregnancy, Labor and Delivery

Women with SCI can conceive, carry to term and deliver normal healthy babies, most often through vaginal delivery (Drench, 1992) but pregnancy and delivery can present challenges to both the patient and her physician (Baker & Cardenas, 1996). Proper prenatal care and adequate planning for the later stages of the pregnancy will reduce the risk of complications. Women who do choose to become pregnant need to be aware of the number of potential prenatal, perinatal, and postnatal issues associated with the spinal cord injury. In some cases these issues might also occur in the able-bodied population but due to the nature of the SCI, women and their health care providers need to be especially vigilant. The issues of pregnancy for women with SCI are as follows:

- Prenatal — constipation, urinary tract infections, decreased vital capacity, deep vein thrombosis, pressure ulcers, increased spasticity, autonomic dysreflexia
- Perinatal — premature delivery, autonomic dysreflexia, deep vein thrombosis, pressure ulcers
- Postnatal — episiotomy skin breakdown, deep vein thrombosis (Linsenmayar, 2000)

Additionally, all medications must be reviewed carefully by the physician or other health care provider to determine the safety of these agents during the pregnancy and breast-feeding. Several resources on the safety of medications in pregnancy are available and should be consulted for each medication prescribed if the health care provider is unfamiliar with its impact on pregnancy (Baker & Cardenas, 1996). Neonatal diazepam withdrawal, for example, can be an adverse effect of maternal diazepam use during pregnancy. A thorough evaluation of all medications including over-the-counter and herbal supplements should be conducted as part of the health care encounter.

Gastric motility normally decreases during pregnancy. This can be especially difficult for a woman with a neurogenic bowel. It is recommended that people with SCI establish a regular bowel evacuation program sometimes requiring the use of suppositories and manual removal of stool. Constipation and hemorrhoids are frequent in women during pregnancy and may be problematic in women with SCI. Special attention to diet and fluid intake during pregnancy may help in the management of both these complications. Stool softeners, laxatives, fiber additives and suppositories may become necessary, but with careful guidance of a health care professional. Prune juice is a natural, gentle laxative that may prove more acceptable to both the woman and her health care team.

Another important issue is the possibility of increased urinary tract infections (UTI). Close consultation with an obstetrician needs to occur to decide the best and safest antibiotic regimen if a woman does develop a UTI. Preventive measures include abundant fluid intake, especially water, special attention to hygiene and handwashing, catheter care, including daily cleaning around the catheter and regular catheter changes.

If the woman uses the intermittent catheterization program (ICP) and is normally restricting fluids to prevent bladder overfilling, she may have to increase the frequency of catheterizations or consider using an indwelling urethral catheter temporarily for the time of pregnancy to insure adequate fluid intake.

There is a viable concern for the risk of deep vein thrombosis in pregnant women with SCI given the hypercoagulable state during pregnancy, relative immobility of the woman and restricted venous return from the growing uterus. Despite these concerns, few cases of deep vein thrombosis or pulmonary embolism have been reported (Baker & Cardenas, 1996). Prophylactic anticoagulation cannot be recommended, therefore, without other risk factors such as prior thromboembolic disease associated with pregnancy or oral contraceptive use. Lower extremity edema is a common problem of pregnant women and has been reported as a significant problem for women with SCI (). Any significant change in edema requires prompt evaluation for thrombosis. Heparin is reported as the anticoagulant of choice for both therapy and prophylaxis as it does not cross the placenta (Charlifue, et al., 1992).

The single most significant medical complication pregnant women with SCI levels at or above the T6 level is undoubtedly autonomic dysreflexia (AD) (Pope, Markenson, Bayer-Zwillero, & Maissel, 2001). AD has occurred in up to 85% of patients with SCI lesions above the T5-6 level (Desmond, 1970). Unmodified sympathetic spinal reflexes cause autonomic dysreflexia. With an intact spinal cord and its associated neural tracts, supraspinal centers modulate sympathetic responses. However, in cases in which the spinal cord is disrupted, noxious input (pleasurable or painful) can cause intense sympathetic outflow which progresses without modulation (Crosby, St. Jean, Reed & Elliot, 1992; Hughes, Short, Underwood & Tebbutt, 1991) resulting in extremely high blood pressures. Noxious sensory input from irritation or distension of skin, bladder, bowel, and pelvic viscera can cause this severe hypertension. Removal of the noxious stimulus and use of parenteral antihypertensives, regional anesthesia and general anesthesia can treat AD (Nygaard, Bartscht & Cole, 1990; Wanner, Ragoth & Zach, 1986). Although advances have been made in the health of patients with SCI, these women are still have high-risk pregnancies and the risk is exclusively maternal. Appropriate care and monitoring must be provided for those women at risk for AD throughout the entire pregnancy, labor and delivery.

Transfers, weight shifts, and bed mobility may become more difficult and predispose the woman with SCI to pressure sores as weight increases. A woman who is pregnant may need some additional help with transfers and the bowel program, as weight gain becomes an issue into the pregnancy. Spasticity has been noted to increase and can become problematic during all phases of pregnancy. In the antenatal period there is high incidence of skin breakdown at the episiotomy site (Verduyn, 1986).

Wheelchairs, cushions, bath equipment and, bedding may need to be temporarily modified to protect the skin against the added weight and pressure. The use of a transfer board or lift system may be considered for those who don't usually use them. Pregnant women are encouraged to seek advice from a physical or occupational therapist that will be able to help them with these adaptations in mobility and equipment. Many health care providers may not realize the benefits of referring a patient to a Physical Therapist or Occupational Therapist to assist with equipment modifications, mobility adaptations, and design of other assistive aides for baby and child care (Lipson & Rogers, 2000).

Breast and Cervical Cancer Screenings

Women with disabilities are among the most disadvantaged groups in our society and are just as likely to be at risk for breast and cervical cancer as women in general. Women with SCI may be at even greater risk due to reproductive cancers as they are more likely to be nulliparis, less likely to exercise, less control over diet, and may have a tendency toward obesity after injury.

Welner (1998) suggests that physical barriers and lack of information that affect women with disabilities and the health care provider delay screening and diagnosis of certain types of gynecologic cancers and sexually transmitted diseases. Nosek & Howland (1997) demonstrated that women with disabilities were less likely to receive regular pelvic examinations than women without disabilities. The most notable finding in a study by Iezzoni, McCarthy, Davis & Siebens (2000) found persistently lower rates of Papanicolaou test and mammography use among women with major mobility impairments, even when controlled for demographic characteristics and health care access.

Decreased compliance with screening guidelines has been associated with a variety of factors including, low income, low education levels, lack of regular health care, and fear of cancer and treatments. Several unique physical and attitudinal barriers have been shown to reduce the likelihood that women will receive recommended preventive services. These include: inaccessible equipment, difficulty transferring onto standard exam tables, difficulty with positioning, and lack of provider knowledge (Theiry, 2000). More attention should be paid to screening and preventive services for people with mobility difficulties, shortened appointments times, physically inaccessible care sites and inadequate equipment which could further preventive care for this population (Iezzoni, et al., 2000).

Provider attitudes may be the most difficult barriers to overcome. If a health care provider views a woman with a disability as asexual, there may be the misconception that these women do not need regular gynecological care or that it is impossible to perform a comprehensive examination because of the physical challenges. An excellent resource for provider education is the "Reproductive Health for Women with Spinal Cord Injury: The Gynecological Examination" is a training video and study guide for health care providers developed and available through the University of Alabama at Birmingham. To obtain a copy of the video and study guide, please contact the Training Office, University of Alabama at Birmingham Medical Rehabilitation Research and Training Center, UAB Department of Physical Medicine & Rehabilitation, 1717 6th Ave, South, Room 506, Birmingham, Alabama 35233-7330, 205-934-3283.

The woman with SCI may be limited in her own ability to perform breast self-exams (BSE) due to upper extremity sensory and motor impairments. A care attendant or family member may have to be trained to assist with a monthly exam as part of overall personal care training. All women with SCI need to be educated about regular BSE and other signs and symptoms of breast cancer regardless of the level of SCI. A woman with a high level of SCI can be taught how to direct a regular BSE as part of her personal care and be responsible for monthly self exams as part of her own health promotion routines.

Interventions and programs aimed at women with disabilities are developed around the country. One such program is the Breast Health Access for Women with Disabilities in Oakland, California. This a community-based program that provides a free clinical breast exam, BSE education, and referrals to accessible mammography sites for women over age 20 and who have barriers due to physical disability.

The Alta Bates Comprehensive Breast Center is an active sponsor of Breast Health Access for Women with Disabilities, an innovative program designed to help women, who are unable to perform breast self-examinations or for whom standard mammography equipment is inadequate, receive breast cancer screening and detection services. The frustration expressed by women with disabilities, over lack of access to breast health care and education, was the catalyst behind the development of Breast Health Access for Women with Disabilities.

Breast Health Access for Women with Disabilities Offers:

- Individualized breast self-exam training, a clinical breast exam and breast health education provided by the project's specially trained breast health nurse in a specially equipped exam room.
- A mammography machine which is easily accessible for most women who use wheelchairs.
- Referrals to other community resources available to women with disabilities.
- Educational workshops in the community for women with disabilities and for social service and health care providers.

Services are provided at the Herrick Campus of Alta Bates Medical Center on Dwight Way in Berkeley, and at the imaging facility at 5730 Telegraph Avenue. Call the Intake Facilitator at (510) 204-4866 for more information.

Mammography can also present challenges to the mobility-impaired woman who is unable to stand up for a mammography exam. LORAD, a division of Hologic Technologies manufactures an wheelchair-accessible mammography machine, the M-IV. The Lorad M-IV Mammography System has a tilt arm that conforms to the position of the woman in a seated position. To locate an accessible mammography unit in your area contact: LORAD Medical, 36 Apple Ridge Road, Danbury, CT 06810, 203-207-4500, www.loradmedical.com or by sending an e-mail message to info@loradmedical.com.

All sexually active women need regular pelvic examinations. Women with severe functional impairments are less likely to have regular pelvic exams (Iezzoni, et al., 2000; Nosek & Howland, 1997). The most common reason for not having regular exam--"inability to get onto exam table", as well as health care providers not knowing techniques for doing a complete pelvic exam on women with a disability. Many women with SCI cannot comfortably assume the traditional (lithotomy) pelvic exam position which requires the woman to be on her back, knees bent, legs spread apart with the feet

placed in metal stirrups at the foot of the exam table. This traditional position for many women with SCI is virtually impossible due to lack of lower extremity motor control, poor balance, spasticity and contractures, inability to slide down to the end of the table to stirrups and inability to keep feet placed in the stirrups. Alternative positions such as side-lying, knee-chest position which does not require the use of the stirrups and is good for the woman who feels comfortable and balanced lying on her side. An assistant may provide support for the woman while she is on the exam table and assist with the exam if necessary. *Table Manners – A Guide to the Pelvic Examination for Disabled Women and Health Care Providers* (Ferreyra & Hughes, 1984) is an excellent illustrated booklet that gives practical suggestions for exam preparation, undressing and transfers techniques and alternative positions for the pelvic exam. This booklet may be ordered from Planned Parenthood, Golden Gate, 815 Eddy Street, Suite 300, San Francisco, CA, 94109, 415-441-7858 or through their website, www.ppgg.org.

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