Women with spinal cord injury (SCI) have unique health care needs related to the physical and psychological changes that occur after injury. As women account for only about 20% of all spinal cord injuries, research examining their health issues has been somewhat limited. This is a review of some of the general and gynecological health concerns of women with SCI and recent research findings in these areas.

### Menstruation

It is normal after a spinal cord injury for a woman's menstrual cycle to stop for a time. As early as 1966, Comar reported that half of his patients stopped menstruating after injury; however, most resumed within the first 6 months. In a recent study involving the Model SCI System Centers by Jackson (1999), the average time reported by participants for resuming menses (bleeding) after injury was 4.3 months with a range from 1 week to 24 months.

There was little difference in the average length of the menstrual cycle or in the number of days of menstrual menses before and after injury. In this study, some women (7.9%) did report a permanent end to their menses at the time of injury, while another 9.7% experienced menopause within one year post-injury.

Dr. Jackson has treated women at the Reproductive Health Clinic for Women with Disabilities at Spain Rehabilitation Center at the University of Alabama at Birmingham since 1988. She observed in an earlier study that women with SCI have a significant increase in muscle and bladder spasticity either just before or with the onset of menses (Jackson, 1995). This observation held true in her recent study (Jackson, 1999).

Menstrual cramping was more common prior to injury (42%) than afterwards (27%). Although not as significant, premenstrual syndrome (irritability & emotional instability) and excessive gain of water weight were symptoms that continued after SCI. Almost one-fourth of all women with SCI had increased bladder or muscle spasticity or autonomic symptoms such as sweating, headache, or flushing during their menstrual cycle.

### Fertility / Birth Control

Once a woman with SCI resumes her menses, there is no evidence that her ability to have children is affected (Jackson, 1995). Therefore, it is important for a woman to use a method of birth control following her injury if she does not want to become pregnant. While there are many choices available, there are risks for women with SCI associated with each method.

Birth control pills that contain estrogen increase the risk of deep venous thrombosis (DVT) in some non-injured women. There is no evidence that DVT risk is greater in women have chronic stable SCI. Caution should be considered, however, before starting birth control pills after acute injury due to the newly acquired immobility. The risk of DVT is even greater for all women who smoke (Jackson, 1995).

In the survey by Jackson (1999), 70% of women who were sexually active used birth control. The most commonly used methods prior to injury were birth control pill (57%), condom (35%) and sterilization (19%). After injury, the most popular forms of birth control used were condoms (39%), sterilization (26%) and birth control pills (22%).
Menopause

A recent study (Jackson, 1999) showed that the age at which women with spinal cord injury went through menopause (43.3 yrs) is not statistically different from women who underwent menopause prior to their injury (45.5 yrs). However the study did show that 14.6% of the women reported going through menopause within one year after their injury.

The same study showed there was little difference in the average age of women who reached menopause pre-injury to those who reached menopause post-injury. Reported symptoms common to menopause were similar in both groups. Women who experienced menopause post-injury did report more mood disorders, as well as symptoms related specifically to their injury, such as spasticity, autonomic dysreflexia and bladder spasms.

Hysterectomy

The incidence of hysterectomy reported in Jackson’s study (1999) is similar in women both pre and post injury. Some of the reasons for post-injury hysterectomy were related to concerns such as birth control, menstrual management, etc.

Osteoporosis

There is a loss of bone density below the level of injury after spinal cord injury. This is due, in part, to the individual’s immobility and inability to bear weight on some bones. Women with SCI need to be aware that after menopause there can be a further decrease in their bone density. This may lead to osteoporosis.

Jackson’s study (1999) shows that only 19% of women with SCI reported being placed on hormone replacement therapy (HRT) after menopause. Yet almost one third of women who experienced menopause after injury reported new long bone fractures. The use of hormone replacement therapy and its possible risks and benefits to women after SCI still is uncertain and needs further study.

Sexually Transmitted Diseases

Recent data reported by Jackson (1999) showed that gynecological infections (STDs) occurred more frequently in women pre-SCI than post-injury. This could be the result of a decline in sexual intercourse after injury. However, any woman who is sexually active is at risk for sexually transmitted diseases (STD), so safe sex needs to be practiced.

Cancers

A study by Nosek (1997) reported that women with disabilities were less likely to obtain pelvic exams than able-bodied women. Both groups did regularly get mammograms.

Women who participated in a more recent study by Jackson (1999) were more conscientious about having an annual Pap smear. Only 14% reported having no Pap smears post-injury compared to 19% pre-injury. However, these women did not get Pap smears as regularly after injury. There was no significant difference in the results of the Pap smears reported pre- and post-injury.

The report was not as positive with regard to women post-injury getting a mammogram. 63% did not get a mammogram post-injury. Approximately the same number of women reported doing breast self-examinations after injury as before. However, there were only one-third of the women who reported doing self-examinations regularly each month.

A spinal cord injury does not make a woman immune to cancers (breast, cervical, colon). All women should continue annual gynecological exams that include a Pap smear, mammogram and hemocult test as well as taking preventive measures such as breast self-exams.

Sexual Activity / Functioning

Many changes that a woman experiences as a result of her spinal cord injury may affect her sexuality and sexual function. Earlier it was thought that women with SCI could not enjoy intercourse or reach orgasm; they should only be passive and satisfy their mate (Billings, 1982). Recent research
indicates that women can resume active, enjoyable sex lives after their injury (Whipple, 1998).

In recent years, researchers began looking at both the psychogenic (mental) and reflex (physical) response to sexual arousal in women with complete and incomplete spinal cord injuries. The studies by Sipski (1999) show that women with complete or incomplete SCIs, who have upper motor neuron injuries, had the capacity for reflex vaginal lubrication. Women with incomplete injury may have psychogenic vaginal lubrication, but this is usually related to the type of injury (more specifically the degree to which one has the ability to perceive pinprick sensation in the T11-L2 dermatomes). Women post-injury may be less likely than women without SCI to achieve orgasm. However, there is no significant difference among women with different levels of SCI.

Surveys and research indicate that women with spinal cord injury are often able to have orgasms and/or pleasurable feelings. How this occurs when there is damage to spinal nerves is still not clearly understood. One study by Komisaruk & Whipple (1997) suggests that vagus nerves send genital sensory activity directly to the brain, bypassing the spinal cord. Sipski (1999) suggests that orgasm may be part of a reflex response of the autonomic nervous system. This is similar to a reflex response of a neurogenic bladder in voiding. In the self-reported study done through the Model Systems (Jackson, 1999), of the women who were sexually active following their injury, a little over half (54%) reported experiencing orgasm and another 30% reported extragenital pleasure. Only 16% reported neither.

More research is beginning to focus on the treatment of sexual dysfunction in women with SCI with a goal of improving their sexual satisfaction. One project (Sipski, 2000) is examining the effect of sildenafil (Viagra) in women with SCI. Early studies suggest that sildenafil may partially reverse the sexual dysfunction experienced by some women with SCI.

In the recent Model SCI System study of women with SCI (Jackson, 1999), 87% reported participating in sexual activity before injury and 67% reported participating after injury. The likelihood of participating in intercourse after injury did increase with time. 49% of women 1-year post injury were sexually active; 65% at 2-10 years post-injury and 76% of women at 11+ years post injury. Another predictor of sexual activity was level of injury: cervical level, 62%, thoracic level, 70% and lumbar/sacral level, 82%. The type of injury (complete or incomplete) was not a predictor.

Some problems the women reported that limited sexual activity after injury included difficulty with positioning (42%), increased spasticity (27%), bladder incontinence (17%), autonomic dysreflexia (11%) and problems with Foley catheters (7%).

**Summary**

The research on women’s health issues in the spinal cord injury population is limited. The recent Model Spinal Cord Injury System’s study (Jackson, 1999) was the largest cross sectional survey to date on reproductive health in women with spinal cord injury. While it was a self-reported survey with no age-matched, able-bodied control group, it provides a large amount of data on the concerns and behaviors of women with SCI related to their reproductive health and issues such as osteoporosis and hormone replacement therapy.

The need continues for a better understanding of the physical and neurological sexual responses in women post-injury to improve sexual functioning and satisfaction. As the life expectancy increases for all individuals with SCI, there is a greater need to understand the aging factors that influence the health and quality of life for women with SCI.

Information on **Pregnancy and Women with SCI** is discussed in two SCI InfoSheets written by this Center. One InfoSheet is for individuals with SCI and discusses the issues of planning for one’s pregnancy, care during pregnancy, labor and delivery. The second InfoSheet reviews the same issues as they relate to the health care professional working with these women. Both are available on the Spinalcord Injury Information Network web site - www.spinalcord.uab.edu/show.asp?durki=21479 or from the Fax Info System at 205-975-8376.
References


Resource Centers

Breast Health Access for Women with Disabilities
www.bhawd.org/
2001 Dwight Way, Berkeley, CA 94704
510-204-4866

Center for Research on Women with Disabilities
www.bcm.tmc.edu/crowd/
3440 Richmond Ave, Ste B, Houston, TX 77046
800-44-CROWD or Email: crowd@bcm.tmc.edu

Health Resource Center for Women with Disabilities
www.rehabchicago.org/community/hrcwd.htm
Rehabilitation Institute of Chicago
345 E. Superior St, Rm 106, Chicago, IL, 60635
312-908-7997

Reproductive Health Clinic for Women with Disabilities
http://main.uab.edu/show.asp?durki=8970
Spain Rehabilitation Center - 1st Floor Outpatient Clinic
1717 6th Ave So, Birmingham, AL 35233
205-934-5858 or 205-934-4131

Resource Materials

The Enemy Within, the Battle Without
http://newmobility.com/
review_article.cfm?id=136&action=browse
From New Mobility magazine [Nov, 1998] by Rachel Ross. Discusses fighting for accessible services to beat breast cancer. Includes information on how to do a breast self-exam if your hands do not work, accessible mammography, risk factors for cancer, and treatment/recovery from cancer.

Osteoporosis, Menopause and Disability
www.newmobility.com/
review_article.cfm?id=197&action=browse
From New Mobility magazine [October, 1999] by June Price. How osteoporosis is a concern for individuals with SCI (both men and women) and recommended treatments.