

Women with traumatic spinal cord injury : sexuality, pregnancy, motherhood, quality of life

Author: Westgren, Ninni

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Department: Institutionen för klinisk neurovetenskap, arbetsterapi och äldrevårdsforskning (NEUROTEC) / Department of Clinical Neuroscience, Occupational Therapy and Elderly Care Research (NEUROTEC)

Abstract

The aim of this thesis was to focus on females with traumatic spinal cord injury (SCI) regarding sexuality, pregnancy, motherhood and quality of life (QL) by assessing: 1. Pregnancy and delivery II. Parental ability and quality of family life III. SCI-related sexual dysfunction IV. Sexual experiences after injury V. Associations between QL and major outcome variables. Study I and II comprised all women in Sweden with SCI who became pregnant and delivered babies during 1980-1991. Medical records and personal interviews were used for retrieval of data. Study III comprised 62 females out of 65 in a near total prevalence population of 353 individuals with traumatic SCI (Stockholm Spinal Cord Injury Study, SSCIS). Personal interviews and medical records were used for retrieval of data. Study IV comprised 8 women from the SSCIS population. Data was collected from personal in depth interviews and was analyzed using a qualitative approach. Study V comprised 320 men and women from the SSCIS population. Health-related QL was assessed by Short Form 36 (SF 36). The number of women who become pregnant and start families after SCI is increasing. The delivery rate by cesarean section was six times higher than in the general population and the indication for this procedure was in half of the cases no other than the SCI per se. The 49 deliveries (of 52 babies) occurred in 23 different hospitals, thus contributing to insufficient experience and thereby probably to an unnecessarily high sectio rate. The most common pregnancy-related complication in this study was urinary tract infection. The specific SCI-related issue that needed particular consideration was autonomic dysreflexia. The general outcome was favourable. However, especially women with higher-level lesions (above T6) benefit

from specialist care. Families with a mother confined to wheelchair due to SCI perceived themselves as leading a family life similar to their peers, in every important aspect. They preferred to live an independent family life, with very little external assistance. They were well integrated as families in the society, with work, schools and recreation. The medical consequences of SCI in women that interfere most with sexual activity are urinary incontinence, or fear thereof, spasticity and positioning problems. The sexual aspects of medical problems are seldom addressed, neither by the women, nor by the doctor. The loss of functions important for sexuality needs to be recognized and the psychological aspects of mourning met with empathy and respect before introducing alternative or compensatory ways of expressing sexuality. The best predictor of sexual rehabilitation outcome is the pre-injury experiences and attitudes. Quality of life is lower in a SCI population than in a normative population. However, a comparison between SCI subgroups revealed no impact on overall QL by the extent of injury. Among medical complications, the presence of neurogenic pain had the strongest negative impact on QL.

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