

INTERNATIONAL SPINAL CORD INJURY DATA SETS

MALE SEXUAL FUNCTION BASIC DATA SET – COMMENTS

(Version 1.0)

The working-group consists of:

Marcalee Sipski Alexander representing The Executive Committee of the International Spinal Cord Injury Standards and Data Sets.

Fin Biering-Sørensen representing The Executive Committee of the International Spinal Cord Injury Standards and Data Sets.

Graham Creasey, representing the American Spinal Injury Association (ASIA)

Stacy Elliott, representing the American Spinal Injury Association (ASIA)

Margaretha Kreuter, representing the International Spinal Cord Society (ISCoS)

Jens Sønksen, representing the International Spinal Cord Society (ISCoS)

Collection of data on male sexual function should routinely be performed when male individuals with spinal cord lesions consult doctors with knowledge regarding spinal cord lesions. In addition data on male sexual function should routinely be reported in scientific documents related to male sexual function and related areas. The purpose of the Male Sexual Function Basic Data Set for Spinal Cord Injury (SCI) is to standardize the collection and reporting of a minimal amount of information on the male sexual function in daily practice in accordance with the purpose and vision of the International Spinal Cord Injury Data Sets (Biering-Sørensen et al. 2006). This will also make it possible to evaluate and compare results from various published studies.

For clinical purposes, it is acknowledged that not all individuals may have an interest in discussing sexual concerns. Therefore, in this data set an option is provided for individuals to decline to speak about their sexual function. It is recommended, however, that before this option is chosen, the individual is asked to provide information solely for documentation of the impact of their injury upon responses. This will allow appropriate documentation of the impact of injury upon sexual responses for future comparison in the medical record and will ensure data is present if retrospective research is considered in the future.

The data in this Male Sexual Function Basic SCI Data Set will generally be used in connection with data in the International SCI Core Data Set (DeVivo et al. 2006), which includes information on date of birth and injury, gender, the cause of spinal cord lesion, and neurologic status. In addition, the Core Data Set contains information on whether a vertebral injury was present, whether spinal surgery was performed, whether associated injuries were present, whether the patient with spinal cord lesion was ventilator-dependent at the time of discharge from initial inpatient care, and the place of discharge from initial inpatient care.

A spinal cord lesion may be traumatic or non-traumatic in aetiology. All lesions to the spinal cord, conus medullaris, and cauda equina are included in the present context.

It is extremely important that data be collected in a uniform manner. For this reason, each variable and each response category within each variable has specifically been defined in a way that is designed to promote the collection and reporting of comparable minimal data.

Use of a standard format is essential for combining data from multiple investigators and locations. Various formats and coding schemes may be equally effective and could be used in individual studies or by agreement of the collaborating investigators.

Acknowledgement:

We are thankful for comments and suggestions received from Michael DeVivo, Susan Charlifue and Lawrence Vogel.

Endorsed by:

References:

Biering-Sørensen F, Charlifue S, DeVivo M, Noonan V, Post M, Stripling T, Wing P. International spinal cord injury data sets. *Spinal Cord* 2006 Sep;44(9):530-4.

Courtois FJ, Charvier KF, Leriche A, Raymond DP. Sexual function in spinal cord injured men. I. Assessing sexual capacity. *Paraplegia*. 1993;31:771-784.

Courtois FJ, Charvier KF, Leriche A, Raymond DP, Eyssette M. Clinical approach to erectile dysfunction in spinal cord injured men. A review of clinical and experimental data. *Paraplegia*. 1995;33:628-635.

DeVivo M, Biering-Sørensen F, Charlifue S, Noonan V, Post M, Stripling T, Wing P. International Spinal Cord Injury Core Data Set. *Spinal Cord* 2006 Sep;44(9):535-40.

Giuliano FA, Rampin O, Benoit G, Jardin A. Neural control of penile erection. *Uro Clin North Am*. 1995;22(4):747-66.

Schmid DM, Hauri D, Schurch B. Nocturnal penile tumescence and rigidity (NPTR) findings in spinal cord injured men with erectile dysfunction. *Int J Impot Res* 2004;16:433-40.

Sipski ML, Alexander CJ, Gomez O, Spalding J. The Effects of Spinal Cord Injury on Psychogenic Sexual Arousal in Males: *Journal of Urology*, 2007 177(1) 247-51.

VARIABLE NAME: Date of data collection

DESCRIPTION: This variable documents the date of data collection

CODES: YYYYMMDD
Unknown

COMMENTS: This collection of data on male sexual function may be carried out at any time after the spinal cord lesion.
Therefore the date of data collection is important to be able to identify the data collected in relation to other data collected on the same individual at various time points. In addition, the date is likewise important to calculate the time interval from date of birth (age), and time interval from date of lesion (time since lesion).

VARIABLE NAME: Interest in discussing sexual issues

DESCRIPTION: This variable documents whether the individual expressed interest in discussing sexual issues with the clinician or researcher.

CODES: Yes
No, but willing to provide limited information for chart documentation
No, prefers the discussion is stopped

COMMENTS: Used in combination with the date, this variable allows one to document a man's desire to discuss sexual issues at a specific point in time.

VARIABLE NAME: Sexual issues unrelated to spinal cord lesion:

DESCRIPTION: This variable documents whether the person complained of sexual issues prior to or after their spinal cord lesion that are unrelated to the spinal cord lesion.

CODES: No
Yes, specify _____
Unknown

COMMENTS: Sexual issues are prevalent in the general population. In addition there are many issues that a man with a spinal cord lesion can have with respect to sexuality after the lesion that are not directly related to the spinal cord lesion. If a preexisting or concomitant sexual problem is present it is not possible to

determine the exact impact of the spinal cord lesion on sexual function and the data should be appropriately identified.

Unknown refers to individuals who were not sexually active prior to their lesion, thus it would be unknown if sexual dysfunction was present.

VARIABLE NAME: Sexual dysfunction related to the spinal cord lesion.

DESCRIPTION: This variable is based on history and presence of personal distress. Sexual dysfunction may be regarding desire, erectile dysfunction, ejaculatory or orgasmic dysfunction.

CODES: Yes
No
Unknown

COMMENTS: Spinal cord injuries result in predictable alterations in genital sexual arousal and can result in changes in the ability to achieve orgasm. In addition, sexual desire is often diminished after spinal cord lesion and related neuropathic changes can cause pain associated with sexual activity. If a man complains of personal distress as result of any of these concerns the change is considered a sexual dysfunction.
Unknown refers to reports by individuals that have not been sexually active after the spinal cord lesion thus they do not know if they have a sexual dysfunction

VARIABLE NAME: Psychogenic Erection

DESCRIPTION: Psychogenic erection is erection that occurs solely based on arousal in the brain e.g. through hearing, seeing, feeling or fantasy (erotic thoughts). Psychogenic erection is penile tumescence with resulting increase in size and firmness of the penis that occurs without physical stimulation, which in usual circumstances should be adequate to allow penetration.

CODES: Normal
Reduced/altered
Absent
Unknown

COMMENTS: In able-bodied men erections are usually a combination of psychogenic and reflex; however, in men with spinal cord lesions, varying types of erectile function may be preserved (Courtois, 1993, 1995; Giuliano 1995). Psychogenic erection potential may be based on degree of preservation of sensory function in T11-L2 dermatomes.

Normal refers to presence of an ability to achieve and maintain erections in response to psychologic stimulation after spinal cord lesion that is equivalent in quality and duration as prior to spinal cord lesion.

Reduced/altered, refers to presence of an ability to achieve erections in response to psychologic stimulation that is partially impaired or altered in quality and/or duration as compared to prior to the spinal cord lesion.

Absent refers to a complete inability to achieve penile tumescence and firmness to psychologic stimulation after the spinal cord lesion

Unknown refers to reports by individuals that have not been sexually active after the spinal cord lesion thus they do not know if they have changes in psychogenic erection

VARIABLE NAME: Reflex erection.

DESCRIPTION: A reflex erection is penile tumescence with resulting increase in size and firmness of the penis that occurs with genital stimulation, which in usual circumstances should be adequate to allow vaginal penetration.

CODES: Normal
Reduced/altered
Absent
Unknown

COMMENTS: In able-bodied men erections are usually a combination of psychogenic and reflex; however, in men with spinal cord lesion, varying types of erectile function may occur. Reflex erection potential is based on presence of reflex function in S2-5 spinal segments.

Normal refers to the presence of a reflex erection to genital stimulation that is equivalent in quality and duration as prior to spinal cord lesion.

Reduced/altered, refers to presence of an ability to achieve erections in response to genital stimulation that is partially impaired or altered in quality and/or duration as compared to prior to the spinal cord lesion.

Absent refers to a complete inability to achieve penile tumescence and firmness to genital stimulation after the spinal cord lesion.

Unknown refers to reports by individuals that have not been sexually active after the spinal cord lesion thus they do not know if they have changes in reflex erection

VARIABLE NAME: Ejaculation

DESCRIPTION: The forceful propulsion of semen externally from the urethral meatus.

CODES: Normal
Reduced/altered
Absent

Unknown

COMMENTS: *Normal* refers to normal antegrade ejaculation occurring after a similar amount of sexual stimulation as prior to spinal cord lesion.
Reduced/altered, refers to ejaculation that is possible after sexual stimulation, but is changed after the spinal cord lesion in either time required to ejaculate, or changes in semen volume, color, or quality.
Absent refers to an absence of external semen propulsion to sexual stimulation following the spinal cord lesion despite attempts to ejaculate.
Unknown refers to reports by individuals that they have not been sexually active thus they do not know if they are able to achieve ejaculation after the spinal cord lesion

VARIABLE NAME: **Orgasmic function**

DESCRIPTION: Orgasm is the perception of sensation of a peak feeling of sexual release, or climax, after which the man with spinal cord lesion feels gratified. It may be accompanied by an overall increase and then decrease in muscle tone and may or may not be accompanied by ejaculation. The potential is based on history.

CODES: Normal
 Reduced/altered
 Absent
 Unknown

COMMENTS: *Normal* refers to reports by individuals that there is no change in their ability to achieve orgasmic sensations subsequent to their spinal cord lesion.
Reduced/altered, orgasm occurs after spinal cord lesion even if it reported that it takes longer to occur and/or the feelings associated with orgasm are different. i.e. may be possible, though partially impaired.
Absent refers to inability to achieve orgasm after spinal cord lesion despite trying to achieve orgasm on multiple occasions.
Unknown refers to reports by individuals that they have not been sexually active thus they do not know if they are able to achieve orgasm after spinal cord lesion.

INTERNATIONAL SPINAL CORD INJURY MALE SEXUAL FUNCTION BASIC DATA SET – FORM (Version 1.0)

Date of data collection: YYYYMMDD

Interest in discussing sexual issues

- Yes
- No, but willing to provide information for the medical record
- No, prefers the discussion is stopped

Sexual issues unrelated to spinal cord lesion:

- No
- Yes, specify _____
- Unknown

Sexual dysfunction related to the spinal cord lesion:

- Yes
- No
- Unknown

Psychogenic Erection

- Normal
- Reduced/altered
- Absent
- Unknown

Reflex Erection

- Normal
- Reduced/altered
- Absent
- Unknown

Ejaculation

- Normal
- Reduced/altered
- Absent
- Unknown

Orgasmic Function

- Normal
- Reduced/altered
- Absent
- Unknown