

INTERNATIONAL SPINAL CORD INJURY DATA SETS FEMALE SEXUAL FUNCTION BASIC DATA SET (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 female sexual function is universal when female individuals with spinal cord lesions consult doctors with knowledge regarding spinal cord lesions. The purpose of the Female Sexual Function Basic Data Set for Spinal Cord Injury (SCI) is to standardize the collection and reporting of a minimal amount of information on female 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 Female 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, 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 de Vivo, 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.

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.

Sipski ML, Alexander CJ, Rosen RC. The Neurologic Basis of Sexual Arousal and Orgasm in Women: Effects of Spinal Cord Injury. *Ann Neurol* 2001;49:35-44.

VARIABLE NAME: Date of data collection

DESCRIPTION: This variable documents the date of data collection

CODES: YYYYMMDD
Unknown

COMMENTS: This collection of data on female sexual function may be carried out at any time after the spinal cord lesion.
Therefore the date of data collection is imperative 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 interested 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 should be stopped

COMMENTS: Used in combination with the date, this variable allows one to document a women'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 the 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 woman 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, arousal, pain or orgasmic dysfunction.

CODES: Yes
No
Unknown

COMMENTS: Spinal cord lesions result in predictable alterations in genital sexual arousal and can result in changes in the ability to achieve orgasm (Sipski et al, 2001) In addition, sexual desire is often diminished after spinal cord lesion and related neuropathic changes can cause pain associated with sexual activity. If a woman complains of personal distress as result of any of these concerns the change is considered a sexual dysfunction.
Unknown refers to reports by individuals who have not been sexually active after the spinal cord lesion thus they do not know if they have a sexual dysfunction

VARIABLE NAME: **Psychogenic genital arousal**

DESCRIPTION: Psychogenic genital arousal is increased genital vasocongestion that usually manifests itself as the presence of clitoral engorgement and vaginal lubrication, amongst other signs, and occurs from arousal generated from the brain e.g. through hearing, seeing, feeling or fantasy (erotic thoughts)

CODES: Normal
Reduced/altered
Absent
Unknown

COMMENTS: Psychogenic genital arousal potential may be based on degree of preservation of sensory function in T11-L2 dermatomes. When querying individuals about psychogenic arousal it is recommended that the interviewer focus on the woman's awareness of vaginal lubrication as opposed to clitoral engorgement.
Normal includes reports of no change in time to achieve lubrication, amount of lubrication or duration of lubrication subsequent to the spinal cord lesion.

Reduced/altered includes reports of either altered time (longer or shorter) to achieve, amount of lubrication, or duration of lubrication. It would also include reports of excessive psychogenic lubrication.

Absent refers to women having no lubrication despite being psychologically aroused.

Unknown refers to reports by individuals that they have not been sexually active thus do not know if they are able to achieve psychogenic genital arousal after the spinal cord lesion.

VARIABLE NAME: Reflex genital arousal.

DESCRIPTION: Reflex genital arousal is that which increases genital vasocongestion, manifested by the presence of clitoral engorgement and vaginal lubrication amongst other signs, based solely on genital stimulation (activation of the sacral reflex).

CODES: Normal
Reduced/altered
Absent
Unknown

COMMENTS: Reflex genital arousal potential is thought to be based on presence of reflex function in S 2-5 spinal segments. When querying individuals about reflex arousal it is recommended that the interviewer focus on the woman's awareness of vaginal lubrication as opposed to clitoral engorgement.

Normal no change in time to achieve lubrication, amount of lubrication or duration of lubrication with genital stimulation subsequent to the spinal cord lesion.

Reduced/altered, includes reports of either altered time (longer or shorter) to achieve, amount of lubrication, or duration of lubrication. It would also include reports of excessive reflex lubrication.

Absent refers to individuals having no awareness of lubrication despite being genitally stimulated. Absent reflex arousal is thought to only happen in the presence of complete cauda equina or conus lesion.

Unknown refers to reports by individuals that they have not been sexually active thus they do not know if they are able to achieve reflex arousal after the spinal cord lesion.

VARIABLE NAME: Orgasmic function

DESCRIPTION: Orgasm is the perception of sensation of feeling good through sexual stimulation, of reaching a climax after which the woman with spinal cord

lesion feels gratified. May be accompanied by an overall increase and then decrease in muscle tone. 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 orgasm or sensations or orgasm subsequent to their spinal cord lesion.
Reduced/altered, orgasm occurs after spinal cord lesion even if it is reported to take 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.

VARIABLE NAME: **Menstruation**

DESCRIPTION: Menstruation is the process of cyclical blood loss through the vagina of the endometrium of the uterus.

CODES: Normal
Reduced/altered
Absent
Unknown
Not applicable

COMMENTS: *Normal* refers to no change in duration, frequency or quantity of menstrual flow and no change in subjective experience or symptoms of menstruation after the spinal cord lesion.
Reduced/altered, i.e. menstruation has been initiated, though partially impaired or changed. This refers to a change in the duration, frequency or amount of menstrual blood flow after spinal cord lesion. It can also refer to a change in the quality of sensations or other autonomic phenomena associated with menses.
Unknown means the impact of the spinal cord lesion on menstruation is unknown.
Not applicable means the woman was not menstruating at the time of spinal cord lesion, thus there is not an impact on menstruation.

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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 problems unrelated to spinal cord lesion:

- No
- Yes, specify _____
- Unknown

Sexual dysfunction related to the spinal cord lesion:

- Yes
- No
- Unknown

Psychogenic genital arousal

- Normal
- Reduced/altered
- Absent
- Unknown

Reflex genital arousal

- Normal
- Reduced/altered
- Absent
- Unknown

Orgasmic function

- Normal
- Reduced/altered
- Absent
- Unknown

Menstruation

- Normal
- Reduced/altered
- Absent
- Unknown
- Not applicable