

INTERNATIONAL SPINAL CORD INJURY FEMALE SEXUAL AND REPRODUCTIVE FUNCTION BASIC DATA SET VERSION 2.0

The International Spinal Cord Injury Female Sexual and Reproductive Function Basic Data Set (Version 2.0) was developed by Marcalee Alexander, Peter New, Fin Biering-Sørensen, Frederique Courtois, Giulio Del Popolo, Stacy Elliott, Carlotte Kiekens, Jean Gabriel Previnaire and Lawrence Vogel. The present International Spinal Cord Injury Female Sexual and Reproductive Function Basic Data Set (Version 2.0) is a revision of the previous Version 1.0 (Alexander et al. 2011).

The International Spinal Cord Injury Female Sexual and Reproductive Function Basic Data Set Version 1.0 has been endorsed by the American Spinal Cord Injury Association and the International Spinal Cord Society.

The International Spinal Cord Injury (SCI) Female Sexual and Reproductive Function Basic Data Set is designed as a tool to record data on female sexual function when female individuals with spinal cord lesions consult doctors with knowledge regarding spinal cord lesions. It is different from the International Standards to Document Remaining Autonomic Function after SCI (Alexander et al. 2009) as these are designed solely to report the neurologic impact of injury on sexual responses and not whether there are any concerns with sexual dysfunctions. The purpose of the Female Sexual and Reproductive Function Basic Data Set for SCI individuals 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 SCI 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 being sexual or discussing sexual concerns (Lombardi et al. 2015). Therefore, this data set provides an assessment of the individual's interest in speaking about her sexual function and in obtaining further information. It is recommended that individuals answer all of the questions in the data set during their assessment. This will allow appropriate documentation of the impact of spinal cord lesions regarding sexual responses in the medical record and will ensure data is present if retrospective research is considered in the future.

The data in this 2nd version of the International SCI Female Sexual and Reproductive Function Basic Data Set is different from other data sets because the information is self-reported and does not rely on the physical examination or specific testing. The changes were based on the self-report questions developed by New and Currie in 2016. It is recommended that the clinician use the attached standard questions when assessing female sexual function for the data set.

The data in this International SCI Female Sexual and Reproductive Function Basic 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 individual 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. The revised International SCI Core Data Set 2.0 has a modification to the question regarding gender. In addition to male and female, there is also a response option for 'Transgender or other related' gender orientations.

The International SCI Female Sexual and Reproductive Function Basic SCI Data Set may be appropriate for youth as young as 12 years of age and is appropriate for those 15 years and older; however, social, cultural, religious and legal issues must be taken into account when applying this Data Set to individuals prior to 18 years of age.

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.

Changes from Version 1.0 to Version 2.0

References to the Autonomic Standards

Changes to the data sets include the reference in the data sets to the International Standards to Document Remaining Autonomic Function after SCI (Alexander et al. 2009) and their differences. The data set is meant as a tool to record data in the medical record or to use during research whereas the autonomic standards are meant as a tool to describe the neurologic impact of the SCI on autonomic responses.

Change to self-report format

The data set has been modified to include specific questions to ask individuals based upon the work of New and Currie (2016). This basic sexual function data set is thus different from most others in that it is meant to be recorded based upon self-report.

Clarification of the use in the Pediatric Population

This data set has also been updated to describe its usefulness in the pediatric population. Recommendations are that this data set may be applicable for children as young as 12 but is generally applicable for children 15 years of age and above. Of course social, legal and religious issues must be taken into account in the pediatric population.

Interest in discussing sexual issues

The variable “No, but willing to provide information for the medical record” has been changed to “Yes, but only willing to provide limited information for chart documentation”. This is felt to be a more positive portrayal of the discussion.

Sexual Orientation

The variable “sexual orientation” has been added to the data set along with appropriate values including “heterosexual”, “bisexual”, “homosexual (lesbian)”, “asexual”, “prefer not to say”, and “do not know” (Sell, 2007).

Sexual problems unrelated to the spinal cord lesion

This variable has been expanded to also include the details “sexual problems or issues that were present before your spinal cord lesion or that occurred after your injury but are unrelated to the spinal cord lesion.” With the transition to self-report questions this terminology seemed a better way to ensure proper information is collected from individuals with SCI.

Multiple self-report variables

The values have been updated to include the option of “not applicable” in conjunction with the option of “unknown” in appropriate variables.

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Questions and suggestions regarding the International Spinal Cord Injury Female Sexual Function Basic Data Set should be directed to Marcalee Alexander:
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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. 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

QUESTION: Are you interested in discussing sexual issues?

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

CODES: Yes
Yes, but only interested in providing 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 woman's desire to discuss sexual issues at a specific point in time.

VARIABLE NAME: Sexual Orientation

QUESTION: How would you best describe your current sexual orientation?

DESCRIPTION: This variable documents the individual's current primary sexual orientation.

CODES: Heterosexual
Bisexual
Homosexual (lesbian)
Asexual
Prefer not to say

Do not know

COMMENTS: Used in combination with the date, this variable allows one to document a woman's current sexual preferences.
Heterosexual: Only sexually interested in men
Bisexual: Sexually interested in both women and men
Homosexual (lesbian): Only sexually interested in women
Asexual: Has no sexual interest
Prefer not to say: The individual does not wish to answer this question
Do not know: The individual does not know the answer to this question

VARIABLE NAME: Sexual issues unrelated to spinal cord lesion

QUESTION: Do you have any sexual problems or issues that were present before your spinal cord damage, or that occurred afterwards but are unrelated to the spinal cord damage?

DESCRIPTION: This variable documents whether the person reports sexual issues or problems prior to or post their injury that are unrelated to the spinal cord lesion.

CODES: No
 Yes, specify _____
 Unknown/Not applicable

COMMENTS: Sexual issues are prevalent in the general population and can predate the spinal cord lesion. In addition, there are many concomitant 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 (Basson et al. 2000). If a preexisting or concomitant sexual problem is present it might not be possible to determine the exact impact of the SCI on sexual function and the data should be appropriately identified.
Unknown/Not applicable 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.

QUESTION: Do you have any sexual problems or issues related to your spinal cord damage?

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

CODES: Yes
No
Unknown/Not applicable

COMMENTS: Spinal cord lesions result in predictable alterations in genital sexual arousal and can result in changes in the ability to achieve arousal and orgasm. In addition, sexual desire may be diminished after spinal cord lesion and related neuropathic changes can cause pain, incontinence or other issues associated with sexual activity. If a woman complains of regular persistent sexual distress as result of any of these changes it is considered a sexual dysfunction.

Unknown/not applicable 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

QUESTION: How would you rate your ability to have psychogenic genital arousal? (This is when genital changes and lubrication occur without any physical touching of the genitals. This may occur if a woman thinks, sees or hears something sexual or just through kissing)

DESCRIPTION: Psychogenic genital arousal is increased genital vasocongestion that usually manifests itself with the presence of clitoral engorgement and vaginal lubrication, amongst other signs and occurs based on arousal in 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 (Sipski et al. 2001).
Normal includes reports of no change in time to achieve lubrication, amount of lubrication or length of time of lubrication subsequent to the spinal cord lesion.
Reduced/altered includes taking more or less time than prior to injury to achieve lubrication, decreased amount of lubrication, and change in length of time of lubrication that lubrication is maintained. It would also include reports of excessive psychogenic lubrication.
Unknown/Not applicable refers to reports by patients who have not been sexually active or experienced any psychogenic stimulation after the spinal

cord lesion thus they do not know if they have any changes in psychogenic lubrication.

VARIABLE NAME: Reflex genital arousal.

QUESTION: How would you rate your ability to have reflex genital arousal?
(This is when genital changes and lubrication occur because of physical stimulation or touch.)

DESCRIPTION: Reflex genital arousal is general arousal that increases genital vasocongestion that usually manifests itself with the presence of clitoral engorgement and vaginal lubrication, amongst other signs and occurs solely based on genital or sacral stimulation.

CODES: Normal
Reduced/altered
Absent
Unknown/Not applicable

COMMENTS: Reflex genital arousal potential is thought to be based on presence of reflex function in S2-5 spinal segments (Sipski et al. 2005).
Normal refers to the presence of vaginal lubrication to genital stimulation occurring in the same intensity and timing as prior to the spinal cord lesion.
Reduced/altered, vaginal lubrication that occurs as a result of genital stimulation may be decreased or increased in volume or may take more or less time to occur than prior to injury.
Absent reflex arousal is thought to happen only in the presence of complete cauda equina syndrome or complete sacral lesion.
Unknown/Not applicable refers to reports by individuals that they have not been sexually active either alone or with a partner thus they do not know if they are able to achieve reflex arousal after the spinal cord lesion.

VARIABLE NAME: Orgasmic function

QUESTION: How would you rate your ability to have an orgasm?

DESCRIPTION: Orgasm is the perception of sensation of a peak feeling of sexual release, or climax, after which the person with spinal cord lesion feels satisfied. Orgasm may be accompanied by an overall increase and then decrease in muscle tone, and changes to blood pressure, heart rate and respiratory rate. The potential is based on self-report.

CODES: Normal
Reduced/altered
Absent
Unknown/Not applicable

COMMENTS: *Normal* refers to reports by women that there is no change in their ability to achieve orgasm or experience orgasmic sensations subsequent to their spinal cord lesion.

Reduced/altered refers to orgasm that occurs after spinal cord lesion but may occur inconsistently or takes longer or less time to occur and/or the feelings associated with orgasm are different. i.e. may be possible, though different or partially impaired. Orgasm may also be considered altered if the woman has a change in her ability to achieve multiple orgasms.

Absent refers to inability to achieve orgasm after spinal cord lesion despite trying to achieve orgasm on multiple occasions.

Unknown/Not applicable refers to reports by individuals that they have not been sexually active either alone or with a partner thus they do not know if they are able to achieve orgasm after spinal cord lesion.

VARIABLE NAME: Menstruation

QUESTION: How would you rate your current menstruation pattern?

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 blood flow after spinal cord lesion.

Reduced/altered, i.e. may be possible, though partially impaired. 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 SCI on menstruation is unknown

Not applicable means the person was not menstruating at the time of spinal cord lesion, thus there is not an impact on menstruation.

INTERNATIONAL SPINAL CORD INJURY FEMALE SEXUAL AND REPROGUTIVE FUNCTION BASIC DATA SET – DATA COLLECTION FORM

Date of data collection: YYYYMMDD

Interest in discussing sexual issues

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

Sexual orientation

- Heterosexual
- Bisexual
- Homosexual (lesbian)
- Asexual
- Prefer not to say
- Do not know

Sexual problems prior or unrelated to the spinal cord lesion:

- No
- Yes, specify _____
- Unknown/Not applicable

Sexual dysfunction related to the spinal cord lesion:

- Yes
- No
- Unknown/Not applicable

Psychogenic genital arousal

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

Reflex genital arousal

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

Orgasmic function

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

Menstruation

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