

ORIGINAL ARTICLE

International Spinal Cord Injury Female Sexual and Reproductive Function Basic Data Set

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Objective: To create the International Spinal Cord Injury (SCI) Female Sexual and Reproductive Function Basic Data Set within the International SCI Data Sets.

Setting: An international working group.

Methods: The draft of the data set was developed by an international working group consisting of members appointed by the International Spinal Cord Society (ISCoS), the American Spinal Injury Association (ASIA), and a representative from the Executive Committee of the International SCI Standards and Data Sets. The data set was developed in an iterative process with review and comments by members of the Executive Committee of the International SCI Standards and Data Sets, ISCoS Scientific Committee, ASIA Board and the ISCoS Council, as well as all interested organizations and individuals. In addition, the data set was posted for 2 months at the ISCoS and ASIA websites for comments. ISCoS and ASIA approved the final version of the data set. To make the data set uniform, each variable and each response category within each variable have been specifically designed to promote the collection and reporting of comparable minimal data.

Results: Variables included in the International SCI Female Sexual and Reproductive Function Basic Data Set are as follows: date of data collection, interest in discussing sexual issues, sexual issues unrelated to spinal cord lesion, sexual dysfunction related to spinal cord lesion, psychogenic genital arousal, reflex genital arousal, orgasmic function and menstruation. Complete instruction for data collection, data sheet and training cases are available at the websites of ISCoS (<http://www.iscos.org.uk>) and ASIA (<http://www.asia-spinalinjury.org>).

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Introduction

The ability of people with spinal cord injuries to live productive lives has increased greatly with the development of technology. In conjunction with this potential change in lifestyle, there has been an increase in information available regarding the sexual potential^{1,2} and possibilities for sexual expression for women with spinal cord injury (SCI).^{3,4} International Standards for the Documentation of Autonomic Function post SCI have recently been described,⁵ and recommendations regarding education and counseling for sexual concerns in women with SCI have recently been published.^{6,7} With the increase in information available to educate women with SCIs, there is also an increased need for data pertaining to outcomes and treatments in use in

different centers and countries. These data are most easily compared if there are common international data sets collected on individuals with SCIs.

To ascertain that sexual issues are adequately addressed in persons with SCIs, it is recommended that collection of data related to female sexual and reproductive function is a routine part of follow-up care in persons with SCI lesions.

The purpose of this manuscript is to present a standardized format for collection and reporting of a minimal amount of information on female sexual and reproductive function in daily practice in accordance with the purpose and vision of the International SCI Data Sets.⁸

Materials and methods

The first draft of the International SCI Female Sexual and Reproductive Function Basic Data Set was prepared by a working group consisting of members appointed by the

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American Spinal Injury Association (ASIA), the International Spinal Cord Society (ISCoS), and a representative of the Executive Committee of the International SCI Standards and Data Sets.

The developmental process for the International SCI Female Sexual and Reproductive Function Basic Data Set followed the steps given below:

1. The working group of the SCI Female Sexual and Reproductive Function developed the first draft data set during a 1-day meeting in Reykjavik, following the meeting of the ISCoS in Iceland in June 2006. This draft was further developed through e-mail communication between the group members.
2. The data set was reviewed by the members of the Executive Committee of the International SCI Standards and Data Sets.
3. Comments from Committee members were incorporated into the data set.
4. Members of the ISCoS Scientific Committee and ASIA Board were also asked to review the data set.
5. Comments from the Committee/Board members were addressed and further adjustments of the data set were performed.
6. Relevant and interested organizations including ASIA and ISCoS, and individuals were invited to review the data set online as the proposed data set was posted on the ISCoS and ASIA websites for 2 months to allow comments and suggestions.
7. Comments were discussed, and when appropriate, minor adjustments were made to the data set.
8. To finalize the data set, members of the ISCoS Council, Scientific Committee and ASIA Board received the data set for final review and approval.
9. Relevant International Organizations and Societies will be invited to endorse the data set.

The data in the International SCI Female Sexual and Reproductive Function Basic Data Set shall be seen in conjunction with data in the International SCI Core Data Set,⁹ which includes information on date of birth and injury, the cause of the spinal cord lesion, and neurological status. In addition, the International SCI Core Data Set contains information on whether a vertebral injury was present, spinal surgery was performed, associated injuries were present, the patient with spinal cord lesion was ventilator-dependent at the time of discharge from initial in-patient care, and the place of discharge from initial in-patient care. Information from other International SCI Data Sets may also be relevant depending on the particular topic under evaluation, for example, the International SCI Lower Urinary Tract Function Basic Data Set¹⁰ or the International SCI Bowel Function Basic Data Set.¹¹

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

It is very important that data to be used be collected in a uniform manner. For this reason, each variable and each

response category within each variable have been specifically defined in a way to promote the collection and reporting of 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.

Results

The complete data set is included in the Appendix. The complete data syllabus, data sheet and training cases are available at the respective websites of ISCoS (<http://www.iscos.org.uk>) and ASIA (<http://www.asia-spinalinjury.org>).

Date of data collection

This collection of data on female sexual function may be carried out at any time after the spinal cord lesion. 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 important to be able to calculate the time intervals from date of birth (age) and date of lesion (time since lesion).

Interest in discussing sexual issues

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.⁶

Sexual problems unrelated to spinal cord lesion

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 pre-existing 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 before their lesion, thus, it would be unknown if sexual dysfunction was present.

Sexual dysfunction related to spinal cord lesion

Spinal cord lesions result in predictable alterations in genital sexual arousal and can also result in neuropathic changes that can cause pain associated with sexual activity.¹²

If a woman complains of personal distress as a 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 whether they have a sexual dysfunction.

Psychogenic genital arousal

Psychogenic genital arousal is increased genital vasocongestion that usually manifests itself as the presence of clitoral engorgement, vulvar swelling and vaginal

lubrication, amongst other signs, and occurs from arousal generated by the brain, for example, through hearing, seeing, feeling or fantasy (erotic thoughts). Psychogenic genital arousal potential may be on the basis of degree of preservation of sensory function in T11-L2 dermatomes.^{1,5} 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 genital swelling and lubrication, amount of lubrication, or duration of swelling and lubrication subsequent to the spinal cord lesion.

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

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

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

Reflex genital arousal

Reflex genital arousal potential is thought to be on the basis of presence of reflex function in S2-5 spinal segments.^{1,5} 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 includes reports of no change in time to achieve genital swelling and lubrication, amount of lubrication, or duration of swelling and lubrication subsequent to the spinal cord lesion.

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

Absent refers to women having no genital swelling or lubrication, despite being genitally stimulated. It is thought only to happen in the presence of complete cauda equine or conus lesion.

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

Orgasmic function

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. It may be accompanied by an overall increase and then decrease in muscle tone. Documentation of the potential of women to achieve orgasm is based upon self-report.

Normal refers to reports by individuals that there is no change in their ability to achieve orgasm or sensations of 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, that is, 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 whether they are able to achieve orgasm after spinal cord lesion.

Menstruation

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, that is, 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 the spinal cord lesion. It can also refer to a change in the quality of sensations or other autonomic phenomena associated with menses.¹³

Unknown means the impact of the spinal cord lesion on menstruation is unknown.

Not applicable means that the woman was not menstruating at the time of the spinal cord lesion, thus, there is no impact on menstruation.

Discussion

The International SCI Female Sexual and Reproductive Function Basic Data Set has been developed in an iterative process, with a first draft developed by specialists representing major societies and associations working within the fields of sexual function and SCI. Following this initial development, the data set was opened for review internationally. The working group reviewed all responses and made adjustments to the data set where appropriate.

Ideally the International SCI Female Sexual and Reproductive Function Basic Data Set will be frequently reviewed and where necessary updated by the working group and ASIA/ISCoS. In addition, the working group welcomes approaches from individuals or groups with ideas for improvement. It is recommended though that individuals realize this presentation is that of a Basic SCI Data Set, thus, any additions or changes must be simple so as to provide the most easily assimilated information for follow-up consultations of people with spinal cord lesions.

Conflict of interest

The authors declare no conflict of interest.

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Appendix

International SCI female sexual and reproductive 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 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