

ORIGINAL ARTICLE

International Spinal Cord Injury Male Sexual Function Basic Data Set

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Objective: To create the International Spinal Cord Injury (SCI) Male Sexual 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 the 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 the interested organizations and individuals. Next, the data set was posted for 2 months at the ISCoS and ASIA's 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 defined in a way that is designed to promote the collection and reporting of comparable minimal data.

Results: Variables included in the International SCI Male Sexual 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 erection, reflex erection, ejaculation and orgasmic function. Complete instructions for data collection, data sheet and training cases are available at the website of ISCoS (<http://www.iscos.org.uk>) and ASIA (<http://www.asia-spinalinjury.org>).

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Introduction

Men comprise the majority of persons with spinal cord injury (SCI). With the advent of phosphodiesterase type 5 inhibitors and new options to promote fertility there has been a great increase in the ability of men with SCIs to participate in a complete reproductive relationship. The International Standards for the Documentation of Autonomic Function post-SCI have recently been described¹ and recommendations regarding education and counseling for sexual concerns in men with SCI have recently been published.^{2,3} With the increase in therapies available to remediate sexual dysfunctions in men with SCIs, there is also an increased need for the 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 men with SCIs.

Sexuality is a broad term encompassing both emotional and physical aspects of a person's sexual makeup whereas the term sexual function generally refers to the physical aspects of a person's sexual responses. For purposes of this data set the focus is on the physical impacts of SCI on sexual function, rather than emotional or relationship issues. Consequently, in order to ascertain that sexual issues are adequately addressed in men with SCIs it is recommended that collection of data related to sexual function is a routine part of follow-up care in men 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 male sexual function in daily practice in accordance with the purpose and vision of the International SCI Data Sets.⁴

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Materials and methods

The first draft of the International SCI Male Sexual Function Basic Data Set was prepared by a working group consisting of members appointed by the 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 Male Sexual Function Basic Data Set followed the steps as given below:

1. The working group of the International SCI Male Sexual Function Basic Data Set developed the first draft data set during a 1-day meeting in Reykjavik following the ISCoS meeting 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 and individuals were invited to review the data set, and the proposed data set was further posted on the ISCoS and ASIA websites for 2 months to allow comments and suggestions.
7. Comments were discussed and when appropriate, 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 of the data set.

The data in the International SCI Male Sexual Function Basic Data Set shall be seen in conjunction with data in the International SCI Core Data Set,⁵ 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 inpatient care and the place of discharge from initial inpatient 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 Set⁶ or the International SCI Bowel Function Basic Data Set.⁷

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 should 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 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 male sexual function may be carried out at anytime after the spinal cord lesion.

Therefore, the date of data collection is imperative to be able to identify the data collected in relation to the other data collected on the same individual at various time points. In addition, the date is likewise important to be able to calculate the time interval from date of birth (age) and time interval from date of lesion (time since the lesion).

Interest in discussing sexual issues

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.

Sexual problems unrelated to spinal cord lesion

Sexual issues are prevalent in the general population. In addition, there might be some 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 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 result in changes in the ability to achieve orgasm.⁸ If a man 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 if they have a sexual dysfunction.

Psychogenic erection

Psychogenic erection is erection that occurs solely based on arousal in the brain, for example, through hearing, seeing,

feeling or fantasy (erotic thoughts). 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 can be preserved.^{9–12}

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 the 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 with before 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.

Reflex erection

Reflex erection is penile tumescence with resulting in increase in size and firmness of the penis that occurs with genital stimulation, which are usual circumstances that should be adequate to allow vaginal penetration. 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 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 before the spinal cord lesion.

Reduced/altered includes reports of an ability to achieve erections in response to genital stimulation that is partially impaired or altered in quality and/or duration as compared with before 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 they have not been sexually active thus, they do not know if they have changes in reflex erection.

Ejaculation

Ejaculation comprises the forceful propulsion of semen externally from the urethral meatus.

Normal refers to normal antegrade ejaculation occurring after a similar amount of sexual stimulation before spinal cord lesion.

Reduced/altered refers to ejaculation that is possible after sexual stimulation, but is changed after the spinal cord lesion either in 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 the 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.

Orgasmic function

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.¹³ The potential is based on history.

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 is reported that it takes longer to occur and/or the feelings associated with orgasm are different, that is, may be possible, though partially impaired.¹³

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.

Discussion

The International Male Sexual Function Basic SCI 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 spinal cord injury. 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 Male Sexual and Reproductive Function Basic SCI Data Set will be frequently reviewed, and when 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 Spinal Cord Injury Male Sexual Function Basic Data Set—Form (Version 1.0)

Date of data collection: YYYY/MM/DD

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