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ORIGINAL ARTICLE

International lower urinary tract function basic spinal cord injury data set

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Objective: To create the International Lower Urinary Tract Function Basic Spinal Cord Injury (SCI) Data Set within the framework of the International SCI Data Sets.
Setting: International working group.
Methods: The draft of the Data Set was developed by a working group consisting of the members appointed by the International Continence Society, the European Association of Urology, 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 final version of the Data Set was developed after review and comments by the members of the Executive Committee of the International SCI Standards and Data Sets, the ISCoS Scientific Committee, ASIA Board, relevant and interested (international) organizations and societies (around 40) and persons, and the ISCoS Council. Endorsement of the Data Set by relevant organizations and societies will be obtained. 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 Lower Urinary Tract Function Basic SCI Data Set are as follows: date of data collection, urinary tract impairment unrelated to spinal cord lesion, awareness of the need to empty the bladder, bladder emptying, average number of voluntary bladder emptyings per day during the last week, incontinence within the last 3 months, collecting appliances for urinary incontinence, any drugs for the urinary tract within the last year, surgical procedures on the urinary tract and any change in urinary symptoms within the last year. Complete instruction for data collection, data sheet and training cases available at the website of ISCoS (www.iscos.org.uk) and ASIA (www.asia-spinalinjury.org).
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Keywords: spinal cord injury; international data set; urology; bladder emptying; incontinence

Introduction

Causes of death after spinal cord injury (SCI) have changed from being primarily due to urinary tract diseases increasingly to being caused by cardiovascular diseases and respiratory complications,[1–4] thus becoming more similar to the causes of death in the general population. This is at least true in centres providing centralized care for individuals with SCI. Over the past 60–70 years, life expectancy after SCI has simultaneously increased dramatically,[5] although within the last three decades research has shown the absence of a substantial decline in mortality after the first 2 years after injury.[6] The longevity in persons with SCI still remains below the life expectancies in the general population.[1–3,7,8] Because of the increasing prevalence of individuals living with SCI, both traumatic and nontraumatic lesions, there is an increasing need for data pertaining to SCI. To facilitate comparisons regarding injuries/lesions, treatments and outcomes between patients, centres and countries, such data should be in the form of common international data sets collected on individuals with SCI. Many countries have established SCI databases.[9] These and many other countries are finding it increasingly important to have comparable data so that the services

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affecting outcome of SCI can be assessed and compared worldwide.[9]

Collection of data on lower urinary tract function is universal when individuals with spinal cord lesions consult their SCI physician for follow-up.

The purpose of this manuscript of the International Lower Urinary Tract Function Basic Data Set for SCI individuals is to present a standardized format for collection and reporting of a minimal amount of information on the lower urinary tract in daily practice in accordance with the purpose and vision of the International Spinal Cord Injury Data Sets.[9] This will also make it possible to evaluate and compare results from various published studies.

Materials and methods

The first draft of the International Lower Urinary Tract Function Basic SCI Data Set was prepared by a working group consisting of the members appointed by the International Continence Society (ICS), the European Association of Urology (EAU), the American Spinal Injury Association (ASIA), the International Spinal Cord Society (ISCoS), together with a representative of the Executive Committee of the International Spinal Cord Injury Standards and Data Sets.

The developmental process for the Lower Urinary Tract Function International Basic SCI Data Set followed the steps given below:

(1) The working group of the International Lower Urinary Tract Function Basic SCI Data Set finalized the first draft data set during a 3-day meeting in Copenhagen in November 2005. This was further elaborated by frequent e-mail communication between the group members, including development of a syllabus for the data set. In developing and harmonizing the data set the working group has used internationally recognized definitions, in particular those of the ICS.[10] The data set has been tried in clinical practice to test its usability.
(2) The data set was reviewed by the members of the Executive Committee of the International SCI Standards and Data Sets.
(3) Comments from the Committee members were discussed in the working group and appropriate changes made to 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 discussed in the working group and a response was made and further adjustments of the data set performed.
(6) Relevant and interested (international) organizations and societies (around 40) and individuals with an interest were also invited to review the data set. In addition, the data set was posted on the ISCoS and ASIA websites for 2 months to allow comments and suggestions.
(7) Comments were discussed by the working group and, where appropriate, minor adjustments to the data set were made.
(8) To conclude this part of the consultation, members of the ISCoS Scientific Committee, Council and ASIA Board received the data set for final review and approval.
(9) Endorsement of the data set will be obtained by the relevant (International) Organisations and Societies.

The data in this International Lower Urinary Tract Function Basic SCI Data Set shall be seen in conjunction with data in the International SCI Core Data Set,[11] which includes information on date of birth and injury, gender, the cause of spinal cord lesion and neurological 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 of nontraumatic 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 have been specifically 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.

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 (www.iscos.org.uk) and ASIA (www.asia-spinalinjury.org).

Date of data collection

This collection of data on lower urinary tract 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 (that is, in the International SCI Core Data Set[11]). In addition, the date is likewise important to have the time interval from date of birth (age), and the time interval from date of lesion (time since lesion).

Urinary tract impairment unrelated to spinal cord lesion

To evaluate the lower urinary tract function in an individual with spinal cord lesion, it is necessary to know if there are any other urinary tract impairments unrelated to the spinal cord lesion.

Awareness of the need to empty the bladder

Awareness of the need to empty the bladder is described as any kind of bladder sensation as defined by ICS,[10] that is,

normal (the individual is aware of bladder filling and increasing sensation up to a strong desire to void), increased (the individual feels an early and persistent desire to void), reduced (the individual is aware of bladder filling, but does not feel a definite desire to void) or nonspecific bladder sensation (the individual reports no specific bladder sensation, but may perceive bladder filling as abdominal fullness, vegetative symptoms like sweating or spasticity). No awareness of the need to empty the bladder should be noted as 'no'. Absent bladder sensation, according to the definition of bladder sensation by ICS (the individual reports no sensation of bladder filling or desire to void),[10] is not exactly the same as filling sensation and desire to void can be absent while temperature sensation or electrosensation can be present.

Bladder emptying

For each method of bladder emptying, it should be stated whether this is a main or a supplementary method. Two main and more supplementary methods may be indicated (adopted from Levi and Ertzgaard[12]).

Normal voiding Voluntary initiation of micturition without reflex stimulation or compression of the bladder. This does not presume entirely normal function.[12]

Bladder reflex triggering comprises various manoeuvres performed by the individual with spinal cord lesion or an attendant in order to elicit reflex detrusor contraction by exteroceptive stimuli. The most commonly used manoeuvres are suprapubic tapping, thigh scratching and anal/rectal manipulation.[10]

Voluntary bladder reflex triggering indicates that the spinal cord-lesioned individual him-/herself or the attendant triggers the bladder reflex.

Involuntary bladder reflex triggering implies that there is no voluntary triggering of the voiding, but the individual with spinal cord lesion just lets the urine run by itself when the reflex detrusor contraction occurs by itself.

Bladder expression comprises various manoeuvres aimed at increasing intravesical pressure in order to facilitate bladder emptying. The most commonly used manoeuvres are abdominal straining, Valsalva's manoeuvre and Credé manoeuvre.[10]

Catheterization is a technique for bladder emptying using a catheter to drain the bladder or a urinary reservoir.[10]

Intermittent catheterization is defined as drainage or aspiration of the bladder or urinary reservoir/continent urinary diversion, with subsequent removal of the catheter.

The following types of intermittent catheterization are defined by ICS:[10]

Intermittent self-catheterization is performed by the individual with spinal cord lesion him-/herself.

Intermittent catheterization can also be performed by an *attendant* (for example, family member or personal aid).

Indwelling catheterization An indwelling catheter remains in the bladder, urinary reservoir or urinary conduit for a period of time longer than one emptying.[10]

Transurethral indwelling catheterization indicates that the urine is drained through a catheter placed in the urethra.

Suprapubic indwelling catheterization indicates that the urine is drained through a catheter via the abdominal wall.

Sacral Anterior Root Stimulator (SARS): Emptying the bladder by electrical stimulation of the anterior sacral nerve roots via implanted electrodes.

Noncontinent urinary diversion/ostomy: This includes ureterooileocutaneostomy (Bricker conduit), ileovesicostomy and vesicostomy.

Average number of voluntary bladder emptying per day during the last week

The average number of voluntary bladder emptyings per day during the last week is given separately. This number refers to the number of voluntary bladder emptyings irrespective of the method.

Any involuntary urine leakage (incontinence) within the last 3 months

Urinary incontinence is defined by ICS[10] as the complaint of any involuntary leakage of urine. In the Basic Data Set, a simple indication of severity and collection of urine is given only.

Bladder reflex triggering that including into a collection system, for example, condom catheter may be voluntary and thus not considered as incontinence. But if the condom or ostomy bag falls off and the individual complains of incontinence, then it should be recorded as 'yes'.

No involuntary urine leakage (incontinence) within the last 3 months implies no leakage of urine outside the urinary tract or a closed urinary collection system. Instances of leakage less than monthly is considered as 'no' unless the individual with spinal cord lesion does consider it a problem, and then it is to be coded as 'monthly'.

Collecting appliances for urinary incontinence

Collecting appliances are any externally applied aids to avoid urinary leakage, or devices for collection of urine. Regular use of one or more collecting appliances is to be recorded. Individuals with spinal cord lesions who use such appliances less than once a month, for the sake of safety, and have no more than occasional episodes of leakage during a year should be excluded.[12]

Any drugs for the urinary tract within the last year

This includes bladder-relaxant drugs, that is, drugs causing relaxation of the detrusor, like anticholinergics, tricyclic antidepressants, and so on. These drugs may also be delivered intravesically. This does not include treatment with injections into the detrusor.

Sphincter and bladder neck-relaxant drugs, such as α-adrenergic blockers and so on. This does not include treatment with injections into the sphincter.

Antibiotics and antiseptics used for treatment or prophylaxis of urinary tract infections are coded separately. For prevention of urinary tract infections, drugs such as methenamine are included.

Surgical procedures on the urinary tract
Bladder stone or upper urinary tract stone removal includes any type of removal, including via endoscopy, extracorporal shock wave lithotripsy (ESWL) or open lithotomy. Ileoureterostomy is corresponding to the former ileal loop or ureteroileocutaneostomy (Bricker conduit). The continent catheterisable valves include Monte and Mitrofanoff procedures.

Any change in urinary symptoms within the last year
Lower urinary tract symptoms are, according to the ICS, the subjective indicator of a disease or change in conditions as perceived by the individual with spinal cord lesion, attendant or partner, and may lead him/her to seek help from health care professionals.[10] Symptoms may either be volunteered or described during the interview with the individual with spinal cord lesion. They may be qualitative as well as quantitative, for example, change in frequency, urgency, nocturia, incontinence, hesitancy, slow stream and so on. Many individuals with spinal cord lesion and bacteriuria have no associated signs or symptoms. Chills and fever are often considered to be signs of acute pyelonephritis; however, these signs do not confirm an infection in the upper urinary tract.[13] Still, chills and fever may be the only symptoms in persons with spinal cord lesion and pyelonephritis, bacteremia, upper tract obstruction by calculi, renal abscesses and periphrenic abscess. Other suspicious signs and symptoms may include increased sweating, abdominal discomfort, costovertebral angle pain or tenderness and increased muscle spasticity.[13] Cloudy and malodorous urine and changes in urine pH may be signs of urinary tract infection, but can also occur with colonization, changes of bacterial organisms and various food intakes. Increased spontaneous voiding or larger residual urines including acute urinary retention may be seen with acute infection.[13]

Discussion

The International Lower Urinary Tract Function Basic SCI Data Set has been developed in an iterative process, with a first draft developed by specialists representing major societies or associations working within the fields of urology and spinal cord injury. Following this initial development, the data set was opened for review by around 40 organizations working with people suffering spinal cord lesions, together with other interested parties and individuals who were invited to provide comments and suggestions. The working group reviewed all responses and made adjustments to the Data Set where appropriate.

Ideally this International Lower Urinary Tract Function Basic SCI Data Set will be frequently reviewed and where necessary updated by the working group and ASIA/ISCoS. In addition, the working group, through the corresponding author, will welcome approaches by groups and individuals with ideas for improvement. However, it should be recognized that what has been presented in this paper is a Basic SCI Data Set, and as such it should be kept simple so as to provide the most easily assimilated information for follow-up consultations of people with spinal cord lesions.

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Appendix
International Spinal Cord Injury Data Sets

LOWER URINARY TRACT FUNCTION BASIC DATA SET - FORM

Date of data collection: YYYYMMDD

Urinary tract impairment unrelated to spinal cord lesion:
☐ No ☐ Yes, specify_____ ☐ Unknown

Awareness of the need to empty the bladder:
☐ No ☐ Yes ☐ Not applicable ☐ Not known

Bladder emptying:	Main	Supplementary
Normal voiding	☐	☐
Bladder reflex triggering		
Voluntary (tapping, scratching, anal stretch, etc.)	☐	☐
Involuntary	☐	☐
Bladder expression		
Straining (abdominal straining, Valsalva's manoeuvre)	☐	☐
External compression (Credé manoeuvre)	☐	☐
Intermittent catheterization		
Self-catheterization	☐	☐
Catheterisation by attendant	☐	☐
Indwelling catheter		
Transurethral	☐	☐
Suprapubic	☐	☐
Sacral anterior root stimulation	☐	☐
Non-continent urinary diversion/ostomy	☐	
Other method, specify_____	☐	☐
☐ Unknown		

Average number of voluntary bladder emptyings per day during the last week __

Any involuntary urine leakage (incontinence) within the last three months:
☐ No ☐ Yes, average daily ☐ Yes, average weekly ☐ Yes, average monthly
☐ Not applicable ☐ Unknown

Collecting appliances for urinary incontinence:
☐ No ☐ Yes, condom catheter/sheath
☐ Yes, diaper/pad
☐ Yes, ostomy bag
☐ Yes, other, specify_____
☐ Unknown

Any drugs for the urinary tract within the last year:

□ No □ Yes, bladder relaxant drugs (anticholinergics, tricyclic antidepressants, etc.)
□ Yes, sphincter/bladder neck relaxant drugs (alpha adrenergic blockers etc.)
□ Yes, antibiotics/antiseptics: □ For treatment of urinary tract infection
□ For prophylactic reasons
□ Yes, other, specify_____
□ Unknown

Surgical procedures on the urinary tract:

□ No □ Yes, supra-pubic catheter insertion, date last performed YYYYMMDD
□ Yes, bladder stone removal, date last performed YYYYMMDD
□ Yes, upper urinary tract stone removal, date last performed YYYYMMDD
□ Yes, bladder augmentation, date last performed YYYYMMDD
□ Yes, sphincterotomy/urethral stent, date last performed YYYYMMDD
□ Yes, botulinum toxin injection, date last performed YYYYMMDD
□ Yes, artificial sphincter, date last performed YYYYMMDD
□ Yes, ileovesicostomy, date last performed YYYYMMDD
□ Yes, ileoureterostomy, date last performed YYYYMMDD
□ Yes, continent catheterizable valves, date last performed YYYYMMDD
□ Yes, sacral anterior root stimulator, date performed YYYYMMDD
□ Yes, other, specify_____ , date performed YYYYMMDD
□ Unknown

Any change in urinary symptoms within the last year:

□ No □ Yes □ Not applicable □ Unknown