Spinal Cord (2012) 50, 797–802

www.nature.com/sc

REVIEW

International spinal cord injury musculoskeletal basic data set

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Objectives: To develop an International Spinal Cord Injury (SCI) Musculoskeletal Basic Data Set as part of the International SCI Data Sets to facilitate consistent collection and reporting of basic musculoskeletal findings in the SCI population.
Setting: International.
Methods: A first draft of an SCI Musculoskeletal Basic Data Set was developed by an international working group. This was reviewed by many different organizations, societies and individuals over 9 months. Revised versions were created successively.
Results: The final version of the International SCI Musculoskeletal Basic Data Set contains questions on neuro-musculoskeletal history before spinal cord lesion; presence of spasticity/spasms; treatment for spasticity within the last 4 weeks; fracture(s) since the spinal cord lesion; heterotopic ossification; contracture; the location of degenerative neuromuscular and skeletal changes due to overuse after SCI; SCI-related neuromuscular scoliosis; the method(s) used to determine the presence of neuromuscular scoliosis; surgical treatment of the scoliosis; other musculoskeletal problems; if any of the musculoskeletal challenges above interfere with activities of daily living. Instructions for data collection and the data collection form are freely available on the International Spinal Cord Society (ISCoS) website (www.iscos.org.uk).
Conclusion: The International SCI Musculoskeletal Basic Data Set will facilitate consistent collection and reporting of basic musculoskeletal findings in the SCI population.
Spinal Cord (2012) **50,** 797–802; doi:10.1038/sc.2012.102; published online 4 September 2012

Keywords: spinal cord injury; International Data Set; spasticity; contracture; fracture; scoliosis

INTRODUCTION

Individuals with spinal cord injury (SCI) are highly susceptible to premature musculoskeletal complications.[1] An SCI potentially accelerates age-related declines in the function of body structures compared with able bodied individuals. In addition, individuals sustaining an SCI at older age may have other pre-existing co-morbidities that affect their functional capability. Therefore, individuals with SCI are at increased risk of upper limb extremity pain,[2,3] rapid bone loss in the lower extremities,[4,5] and fractures.[6] SCI also results in spasticity and contractures in approximately two-thirds of individuals.[7] There is the additional risk of progressive scoliosis for those injured at a young age. Information on these and other musculoskeletal complications are important because they help guide management and provide accurate estimates of the magnitude of the problem.

A spinal cord lesion may be traumatic or non-traumatic in etiology. Lesions to the spinal cord, conus medullaris and cauda equina are included in the term.

The purpose of the International Spinal Cord Injury (SCI) Musculoskeletal Basic Data Set for individuals with spinal cord lesions is to standardize the collection and reporting of a minimal amount of information on musculoskeletal status in accordance with the purpose and vision of the International SCI Data Sets.[8] This will also enable evaluation and comparison of results from various published studies, and help guide future research.

The data in this International SCI Musculoskeletal Basic SCI Data Set will be used in connection with data in the International SCI Core Data Set,[9] which includes information on date of birth and injury, gender, cause of spinal cord lesion and neurologic status. In addition, the Core Data Set contains information on the history of the injury and initial management including presence of vertebral injury, need for spinal surgery, associated injuries and place of residence upon discharge after initial inpatient care.

It is important that data can be collected in a uniform manner from a scientific perspective as well as for improved patient care. For this reason, each variable and its accompanying response category has been defined to promote the collection and reporting of comparable minimal data. In addition, a standardized format has been specified to enable the compilation of 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

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Received 1 June 2012; revised 31 July 2012; accepted 3 August 2012; published online 4 September 2012

the collaborating investigators. However, recommendations for variable names and database structure are available at the websites of the International Spinal Cord Society (ISCoS) (www.iscos.org.uk), and the National Institute of Neurological Disorders and Stroke (NINDS) the Common Data Elements Project website (www.CommonData Elements.ninds.nih.gov).[10,11] The International SCI Musculoskeletal Basic Data Set was produced under the auspices of ISCoS and the American Spinal Injury Association (ASIA).

MATERIALS AND METHODS

An initial version of the International SCI Musculoskeletal Basic Data Set was prepared by a working group consisting of the authors. All members of this group have clinical and research experience related to the topic of the data set. Attention was directed at ensuring the Data Set was basic and could be used by clinicians in various settings and countries at minimal cost or need of advanced technical equipment. The data collected would provide the minimal amount of standardized information necessary for a basic musculoskeletal evaluation of a person with SCI. To ensure consistency in the data collection and to facilitate interpretation, detailed information is provided in a syllabus for each specific variable and each response category.

The process for developing this version of the International SCI Musculoskeletal Basic Data Set followed the steps given below:

1. The working group of the International SCI Musculoskeletal Basic Data Set initially met over a 2-day workshop on 10–11th May 2010 in Copenhagen, Denmark.
2. Afterwards, the first draft of the data set was finalized during extensive E-mail contact among group members.
3. The data set was reviewed by members of the Executive Committee of the International SCI Standards and Data Sets.
4. Comments from the Committee members were discussed in the working group and appropriate adjustments made to the Data Set.
5. Members of the ISCoS Executive and Scientific Committees and ASIA Board were also asked to review the Data Set.
6. Comments from the Committee/Board members were discussed in the working group and a response was made and further adjustments of the Data Set were performed.
7. Relevant and interested scientific and professional (International) organizations and societies (around 40) and individuals were also invited to review the Data Set. In addition the Data Set was posted on the ISCoS and ASIA websites for over 2 months to allow comments and suggestions.
8. Comments were discussed and responded to by the working group. Where appropriate, adjustments to the Data Set were made.
9. To conclude this part of the consultation, members of the ISCoS Executive and Scientific Committees and ASIA Board members received the Data Set for final review and approval.
10. The International SCI Musculoskeletal Basic Data Set was then further scrutinized by the team working on the NINDS, Common Data Elements Project, in cooperation with the Executive Committee of the International SCI Standards and Data Sets committees.[10,11]
11. Finally, the data set was used to collect information on several cases to confirm its function in the clinical setting.

RESULTS

The data sheet is included in the Appendix and the data sheet and syllabus are available on the ISCoS website (www.iscos.org.uk). Listed below are the variables included in the International SCI Musculoskeletal Basic Data Set:

Date of data collection

Collection of data on musculoskeletal conditions may be performed at any time following the spinal cord lesion. It is therefore imperative to collect the date of data collection to compute the time lapse since the initial spinal cord lesion. This will permit the information obtained to be related to other data collected on the same individual at various time points.

Neuro-musculoskeletal history before spinal cord lesion

This variable consists of three parts, documenting: pre-existing congenital deformities of the spine and spinal cord, pre-existing degenerative spine disorders and pre-existing systemic neurodegenerative disorders. The diagnosis and location of any disorders, and the date and type of any previous surgery for congenital deformities or disorder shall be specified. It is important that any neuro-musculoskeletal disorders preceding the onset of the spinal cord lesion are documented, because relevant pre-existing neuromuscular disorders may influence management.

Congenital disorders include malformations or other pathologies of bones, such as infantile idiopathic scoliosis,[12,13] congenital spinal canal stenosis,[14] achondroplasia,[15,16] muscles (muscular dystrophy) or neural tissues (syringo-hydromyelia). These also include combined multi system/organ disorders such as myelomenigocele,[17,18] malformations of the craniocervical junction (that is, Arnold Chiari type, congenital stenosis, Klippel-Feil anomalies)[13,19,20] or tethered cord.[21,22] Sometimes, these conditions are present in early childhood but only become symptomatic during adolescence or advancing age. This may be due to progression or unmasking of the condition.

Degenerative spine disorders are more prevalent with aging. The most common disorders are lumbar[23,24] and cervical[25,26] spinal canal stenosis, spondylosis and degenerative systemic disorders (like diffuse idiopathic skeletal hyperostosis and rheumatoid arthritis). These disorders typically develop slowly with the spinal cord often adapting to extensive morphological changes before notable impairment. The onset of impairments is usually slow and insidious and therefore not noticed by individuals for a considerable time. However, the degenerative changes can increase susceptibility to spinal cord lesions from relatively minor insults, for example, minor falls with mild extension/flexion trauma inducing a central cord syndrome.[27]

Systemic neurodegenerative disorders comprise conditions like multiple sclerosis, amyotrophic lateral sclerosis and others. They typically occur in adults and are characterized by an acute or chronic progressive course which can eventually present as tetra/paraplegia.

Presence of spasticity/spasms

The presence of spasticity/spasms in the upper and lower extremities is captured using the modified Ashworth scale,[28] that is, at or above one on the modified Ashworth scale, or observation of spasms. A spinal cord lesion leaves about half of all individuals with involuntary spasms (muscle jerks), altered motor control and/or spasticity.[29] This altered control can be expressed in a variety of ways.[30] The common definition of spasticity is based on the finding of increased resistance to passive stretch. Although modified Ashworth scale captures only a few aspects of a rather multidimensional and phenomenologically diverse symptomatology, the clinically important key elements are measured.[31]

Abnormal motor control is manifested as negative signs (paresis or paralysis) or positive signs, often termed as 'spasticity'. This is a broader definition than focusing on exaggerated responses to passive movement, specifically velocity-dependent responses, which are present only about a third of the time in individuals with 'spastic' SCI.[32] More commonly, the positive signs frequently and prominently include loss of coordination of voluntary movement and spasms, or involuntary movement. One way of characterizing the multidimensional nature of 'spasticity' is with a battery of

tests, but additional validation of these tests is required before advocating their widespread use.[33] (Modified) Ashworth[28,34] and Tardieu scales[35] have proven useful to some extent, but rely on subjective evaluation of specific characteristics of spasticity and thus are limited in their applicability and are population dependent. They are commonly used for research purposes.[36] It is noted that there may be mechanical changes in muscle fiber, collagen tissue and tendon properties secondary to 'spasticity',[37] which may confound the assessment.[38]

Treatment for spasticity within the last 4 weeks

This variable documents if the person with SCI has received any kind of treatment for spasticity within the last 4 weeks. A 'yes' is indicated if any kind of treatment has been used for spasticity over the last 4 weeks regardless of whether it was prescribed or not. This may include physical, pharmacological, surgical or other. Four weeks has been chosen to give recent status.

Fracture(s) since the spinal cord lesion

This variable documents whether the person with SCI has had any type of fracture since the spinal cord lesion, the date the fracture occurred, and whether or not the fracture was a fragility fracture. The detailed location is specified as seen in the Appendix. The date of the fracture should be recorded, but if the precise date is unavailable, the month and/or year should be recorded and the date left blank. Only fractures not previously documented need to be recorded. Therefore, if information for the data set is being collected for the first time after SCI, all previous fractures since SCI should be recorded. Thereafter, only fractures that have occurred since the last recording of information for the data set should be recorded.

It is important to distinguish between incident and fragility fractures. Fragility fractures result from low force injuries insufficient to fracture normal bone.[39,40] Common etiologies of fragility fractures after SCI include leg torsion during transfers or rolling in bed, or falling to the floor from a wheelchair or commode on a flexed knee. Compression fractures of vertebral bodies should be considered as fragility fractures, in the absence of reported trauma. In comparison, incident fractures are caused by injuries sufficient to fracture normal bone (that is, motor vehicle accident).

Heterotopic Ossification

This variable documents the diagnosis and location of Heterotopic Ossification (HO) (see Appendix). It is a diagnosis based on signs and symptoms and confirmed with positive imaging. Method used to document HO is specified as X-ray, CT scan, triple phase bone scan, or other specified method.

HO refers to the abnormal formation of bone in soft tissues typically around joints such as the hips, knees, shoulders and elbows. The initial signs and symptoms are often related to inflammation with swelling, restricted range of motion, hyperemia, and, if perceived, pain. HO is associated with elevated serum alkaline phosphatase and confirmed with plain X-ray or CT indicating detectable calcified bone formation or triple phase bone scan before calcification. These are reliable and sensitive indicators of the formation process. HO can also be confirmed with MRI and ultrasound although these are less commonly used.

The incidence of HO varies in SCI populations from 10 to 53%.[41] It commonly develops within the first 2–3 weeks after SCI and is most common at the hip (70–97%) and knee.[42,43] Ultrasound can be used as a screening tool if there is a high index of suspicion, but should then be confirmed by one of the tests listed above.[44]

Contracture

This variable documents the presence of joint contracture(s) at various locations (see Appendix). Contractures are a common complication of SCI[45–48] and are characterized by a loss in passive joint range of motion.[49,50] It is important to identify contractures to implement appropriate treatments and monitor change.[51] Passive joint range of motion can be measured quantitatively with a goniometer[52] however, for the purposes of this data set the committee recommends the use of visual and physical assessment to determine the loss in joint range of motion. Only obvious loss in joint range of motion that can be readily seen or easily felt should be recorded as a contracture. More subtle loss in joint range of motion should only be recorded as a contracture if it warrants intervention or has clear and marked deleterious implications on function, hygiene, skin management or any other aspect of quality of life.[53] For example, subtle loss of passive elbow extension in a person with C6 tetraplegia would be recorded as a contracture if it clearly prevents the person from transferring. An equivalent subtle loss of passive elbow extension would not be recorded as a contracture in a person with C4 tetraplegia if it had no obvious and marked deleterious implications.

The location of degenerative neuromuscular and skeletal changes due to overuse after SCI

The location is to be given as indicated in the Appendix. This variable requires the assessor to distinguish musculoskeletal changes induced by overuse from independently occurring neuropathic and visceral pain. The most common symptoms of overuse are pain and discomfort. Overuse injuries commonly occur at the musculotendinous junction but can also occur at the cartilage, bone and bursa.[54] Shoulder pain is present in approximately 30–70% of persons with SCI. Its severity and presence is influenced by age, duration of injury, neurological level (more in people with tetraplegics), severity of injury, wheelchair use, sitting posture, flexibility, stability of the shoulder joint and overall body mass index. Shoulder pain is more common in people with SCI of older age, and for women.[55–57] Manual wheelchair users often experience pain that limits activities of daily living (ADL) such as transfers, propulsion and overhead reaching. Shoulder pain may be due to propelling a wheelchair over many years.[58] It is however also seen in individuals heavily reliant on crutches or canes to ambulate.[59] Overuse injuries of the elbow tend to result in muscle/tendon strains or nerve entrapments.[60] Wrist overuse injuries often lead to carpal tunnel syndrome. Lower extremities may also be affected in individuals with SCI. Knee problems have been described, due to, for example, trauma, and tears of ligaments.[61] In case, the degenerative neuromuscular or skeletal changes due to overuse in the neck, upper or lower back is located in the midline without lateralization both right and left is to be marked.

SCI-related neuromuscular scoliosis

This variable documents any appreciable observable lateral deviation in the normally straight vertical line of the spine due to the sequelae of SCI, that is, if there is an observable deviation of the head over the trunk and pelvis during unsupported sitting or standing due to scoliosis as a co-morbidity of SCI. If the head is aligned over the pelvis during unsupported sitting (not balanced with arms/hands; lateral supports; chest straps; and so on) or while standing erect then there is no scoliosis. This variable does not include problems with the alignment of the spine due to problems other than SCI, such as idiopathic scoliosis, pre-injury neuromuscular scoliosis, as in Marfan's Syndrome, Larson's Syndrome, Down's Syndrome, Klippel Feil Syndrome, degenerative disk disease, osteoporosis in the aging spine, and so on.

There is a wide range of normal variation in sagittal profiles and it is possible that each individual has specific requirements for cervical/lumbar lordosis and thoracic kyphosis as a result of pelvic orientation. Scoliosis is defined as a 10 degree curvature of the spine.[62] Scoliosis is a known musculoskeletal complication of SCI, particularly when SCI occurs at a younger age.[63–69]

Method of assessment, when a scoliosis is present

This variable indicates the method(s) used to determine the presence of neuromuscular scoliosis, for example, observation in sitting; observation in standing; plain radiographs in sitting; or plain radiographs in standing.

The clinical and physical examination is pivotal to the diagnosis of scoliosis and is evidenced by the observed lateral deviation of the head, trunk and pelvis over the spine and shoulder asymmetry. For the evaluation of neuromuscular scoliosis, it is important to temporarily remove any modification to a wheelchair or seating system that is providing external support to maintain head and spine alignment (for example, lateral supports, chest harness).[69–71] Likewise, any type of support to the trunk in the form of a brace or binder needs to be removed to determine if scoliosis is present.

A diagnosis of scoliosis requires a plain radiograph that shows a Cobb Angle of at least 10 degrees.[62,72] While the Cobb Angle of 10 degrees is used as the definitive diagnoses for idiopathic scoliosis, there is evidence that strong inter-rater reliability of the Cobb Angle in SCI also falls within 10 degrees and hence has been adopted as the radiographic diagnosis of neuromuscular scoliosis.[73]

Surgical treatment of scoliosis

This variable documents if and when scoliosis has been surgically treated. Nearly, all children injured with SCI before reaching skeletal maturity will develop scoliosis and 75% will require some type of surgical intervention to stop the progression of the curve.[63,64] When the SCI occurs in adolescence, 78% of children injured at 14 years, 57% of children injured at 15 years, and 50% of children injured at 16 years develop scoliosis that requires either conservative treatment (modifications to wheelchair, bracing) or surgical intervention (spinal fusion).[63,68]

Other musculoskeletal problems

This variable documents the presence of any other specified musculoskeletal problems not described above. This variable requires the assessor to specify any other type of musculoskeletal problem not captured in the other variables. This could among other issues include gibbus formation in relation to Pott's paraplegia.[74,75]

Do any of the musculoskeletal challenges above interfere with your activities of daily living?

This variable documents if any of the musculoskeletal challenges above interfere with daily activities, such as transfers, walking, dressing, showers, and so on. and is recorded as No, not at all; Yes, a little; Yes, a lot. This variable requires the assessor to directly ask the individual with a spinal cord lesion the following question 'Do any of the musculoskeletal challenges above interfere with your activities of daily living (transfers, walking, dressing, showers, and so on)?' This variable captures the individual's perceptions about the deleterious implications of any of the musculoskeletal challenges above on daily life. The perspective of the individual is important and this variable enables individuals to focus on the impact of musculoskeletal changes on activities relevant to them, whether it is due to spasticity,[76] heterotopic ossification, contracture(s), neuromuscular or skeletal overuse, scoliosis[68,69] or other musculoskeletal problems.

DISCUSSION

The data collected in the International SCI Musculoskeletal Basic Data Set will be available in conjunction with the data in the International SCI Core Data Set, which among other items, includes information on date of birth and injury, gender, the cause of SCI and neurological status.[9] To make this basic data set as useful as possible in a clinical setting, we have kept the number of items to a minimum. The working group believes that the items included cover the most clinically relevant information about possible musculoskeletal conditions in individuals with a spinal cord lesion. The working group recognizes that information in the International SCI Musculoskeletal Basic Data Set could be extended by other clinically important information, whenever appropriate.

To facilitate the use of the International SCI Data Sets, this International SCI Musculoskeletal Basic Data Set and its data collection (form included in the Appendix) have been developed in a similar format to the previous International SCI Basic Data Sets. Additional work and research is now required to validate and translate this data set into use. In this respect, it is additionally advised to adhere to the recommendations given by the Executive Committee for the International SCI Standards and Data Sets.[77] The authors invite all those who are interested to participate in this open and ongoing process.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

ACKNOWLEDGEMENTS

Medtronic A/S, Denmark has supported the development of this Data Set with an unconditional grant. We are thankful for comments and suggestions received from Lawrence Vogel, Susan Charlifue, Vanessa Noonan, Volker Dietz, Marcel Post, Govert J Snoek, Inge Eriks Hoogland, Giorgio Scivoletto, Douglas J Brown, Vivien Jørgensen, Anne Lannem, Brooke Wadsworth, Martha Somers, Michael G Fehlings, Jon Hassler, and the National Institute of Neurological Disorders and Stroke (NINDS) the Common Data Elements (CDE) Project Team.

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APPENDIX

International spinal cord injury musculoskeletal basic data set form (Version 1.0)

Date performed: YYYY/MM/DD

Neuro-Musculoskeletal history before spinal cord lesion (collected once):

☐ Pre-existing congenital deformities of the spine and spinal cord
If yes, specify Diagnosis and Location_____
If previous surgery due to this, description_____
Date of surgery YYYYMMDD ☐ Unknown

☐ Pre-existing degenerative spine disorders
If yes, specify Diagnosis and Location_____
If previous surgery due to this, description_____
Date of surgery YYYYMMDD ☐ Unknown

☐ Pre -existing systemic neuro-degenerative disorders
If yes, specify Diagnosis and Location_____
If previous surgery due to this, description_____
Date of surgery YYYYMMDD ☐ Unknown

Presence of spasticity / spasms
☐ No ☐ Yes
Treatment for spasticity / spasms within the last four weeks?
☐ No ☐ Yes

Fractures, heterotopic ossifications, contractures, or degenerative changes/overuse:

	Fractures since spinal cord lesion (only those not documented previously)				Heterotopic ossification		Contracture		Degenerative changes / Overuse	
	Right	Left	Date of fracture YYYY/ MM/DD	Fragility fracture	Right	Left	Right	Left	Right	Left
Neck / Cervical spine										
Shoulder/ Humerus										
Elbow										
Forearm										
Wrist										
Hand										
Upper back / Thoracic spine										
Lower back / Lumbar spine										
Pelvis										
Hip / Femur										
Knee										
Tibia / fibula										
Ankle										
Foot										

Method used to document heterotopic ossification, if present:
☐ X-ray ☐ CT-scan ☐ Triple phase bone scan ☐ Other method, specify_____

Scoliosis
☐ No ☐ Yes
If scoliosis is present, method of assessment (check all that apply)
☐ Observation in sitting ☐ Observation in standing
☐ Plain radiographs in sitting ☐ Plain radiographs in standing
If scoliosis is present,
Surgically treated? ☐ If Yes: Date of surgery YYYYMMDD ☐ Unknown

☐ **Other musculoskeletal problems; specify**_____

Do any of the above musculoskeletal challenges interfere with your activities of daily living (transfers, walking, dressing, showers, etc.)?
☐ No – not at all ☐ Yes, a little ☐ Yes, a lot