INTERNATIONAL SPINAL CORD INJURY DATA SETS

PULMONARY BASIC DATA SET – COMMENTS

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Pulmonary complications, in particular pneumonia, are a leading cause of death in individuals with spinal cord lesions (Hartkopp et al. 1997; DeVivo et al. 1999; Lidal et al. 2007), and therefore it is important to record basic information on bronchopulmonary function in daily practice when following individuals with spinal cord lesions. 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.

The purpose of the International Pulmonary Basic Data Set for Spinal Cord Injury (SCI) individuals is to standardize the collection and reporting of a minimal amount of information on bronchopulmonary function in daily practice in accordance with the purpose and vision of the International Spinal Cord Injury Data Sets (Biering-Sørensen et al. 2006). This will also make it possible to evaluate and compare results from various published studies.

The data in this Pulmonary Basic SCI Data Set generally will 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 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.

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.

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VARIABLE NAME: Date of data collection

DESCRIPTION: This variable documents the date of data collection.

CODES: YYYY/MM/DD
Unknown

COMMENTS: As the collection of data on bronchopulmonary function may be carried out at any time following the spinal cord lesion, the date of data collection is imperative for computing time since the initial spinal cord lesion and to relate the information to other data collected on the same individual at various time points.

VARIABLE NAME: Pulmonary conditions present before spinal cord lesion (collected once):

DESCRIPTION: This variable documents the history of pulmonary diseases that predated the spinal cord lesion.

CODES: None
Asthma
Chronic obstructive pulmonary disease (COPD), including chronic bronchitis (CB), and emphysema
Sleep apnea
Other, specify
Unknown

COMMENTS: These codes include pulmonary conditions diagnosed prior to the spinal cord lesion that may negatively impact pulmonary function. Asthma and COPD are relatively common conditions associated with airflow obstruction. If the information has been documented once it is not necessary fill in this variable again, to avoid redundant data.

VARIABLE NAME: Smoking history

DESCRIPTION: This variable documents the smoking history, and quantifies smoking by average daily use and by the number of pack-years smoked.

CODES: Never smoked
Former smoker
Current smoker
Unknown
If a former smoker, which year did you quit smoking: _____
If a former or current smoker, for how many years did (have) you smoke(d)?

If a former or current smoker, on average how many (cigarettes/cigars/pipes) do (did) you smoke on a daily basis (answer all that apply):

Number of cigarettes
Number of cigars
Number of pipe bowls
Unknown

For former or current cigarette smokers only, the number of pack-years of smoking [(average number smoked daily)/20] x (number of years smoked) = pack-years

COMMENTS: When judging bronchopulmonary issues in individuals with spinal cord lesions, the influence of smoking is an important factor (Linn et al. 2003; Jain et al. 2006; Stolzmann et al. 2008).

VARIABLE NAME: Pulmonary complications and conditions **after** the spinal cord lesion within the last year:

DESCRIPTION: This variable documents pulmonary complications or conditions occurring after the spinal cord lesion and within the last year.

CODES:
None
Pneumonia:
Number of episodes of pneumonia treated with antibiotics.
Number of episodes of pneumonia requiring hospitalization.

Asthma
Chronic obstructive pulmonary disease (COPD), including chronic bronchitis (CB), and emphysema
Sleep apnea
Other respiratory conditions, specify
Unknown

COMMENTS: Pneumonia is one of the leading causes of mortality in individuals with spinal cord lesions (Hartkopp et al. 1997; DeVivo et al. 1999; Lidal et al. 2007), therefore it is important to record this information in detail and whenever possible. Other respiratory complications and conditions may develop after sustaining a spinal cord lesion, including atelectasis (lung collapse), and other disorders with high disease prevalence in the general population (i.e. asthma, COPD).
Sleep apnea, either obstructive or central in etiology, is a relatively common yet frequently unrecognized condition among individuals with spinal cord lesions (Leduc et al. 2007; Berlowitz et al. 2005). Sleep apnea may adversely affect sleep quality and daytime functioning, and studies in the general population suggest that obstructive sleep apnea is a risk factor for the development of hypertension, stroke, and myocardial infarction.

VARIABLE NAME: Current utilization of ventilatory assistance:

DESCRIPTION: This variable documents any assistance device utilized at the time of evaluation to augment ventilation.

CODES: None
Mechanical ventilation: Yes, less than 24 hours per day
Yes, 24 hours per day
Yes, unknown number of hours per day
Diaphragmatic pacing device: Date inserted: YYYY/MM/DD
Phrenic Nerve Stimulation: Date inserted: YYYY/MM/DD
Bi-level Positive Airway Pressure (BiPAP): Date started use: YYYY/MM/DD
Other, specify
Unknown

COMMENTS: Respiratory insufficiency is common following spinal cord lesions. Ventilatory assistance devices include, but are not limited to: mechanical ventilators, phrenic nerve stimulators, diaphragmatic pacers, external negative pressure devices, and bi-level positive airway pressure (BiPAP). These devices do not include routine administration of oxygen, intermittent positive pressure breathing (IPPB), or continuous positive airway pressure (CPAP). Wording of this variable reflects the International Spinal Cord Injury Core Data Set for the type of ventilatory assistance used to sustain respiration at discharge after the initial rehabilitation period following the spinal lesion (DeVivo et al. 2006). As the situation may have changed since discharge from the initial inpatient period the question is asked.

INTERNATIONAL SPINAL CORD INJURY PULMONARY BASIC DATA SET FORM (Version 1.0)

Date performed: YYYY/MM/DD ☐ Unknown

Pulmonary conditions present <u>before</u> spinal cord lesion (collected once):
☐ None
☐ Asthma
☐ Chronic obstructive pulmonary disease (includes emphysema and chronic bronchitis)
☐ Sleep apnea
☐ Other, specify_____
☐ Unknown

Smoking history:
☐ Never smoked ☐ Former smoker ☐ Current smoker ☐ Unknown
If a former smoker, which year did you quit smoking? _____
If a former or current smoker, for how many years did (have) you smoked? _____ years
If a former or current smoker, on average how many (cigarettes/cigars/pipes) do (did) you smoke on a daily basis (answer all that apply):
_____ cigarettes
_____ cigars
_____ pipe bowls
☐ unknown
For former or current cigarette smokers only, the number of pack-years of smoking [(average number smoked daily)/20] x (number of years smoked): _____ pack-years

Pulmonary complications and conditions <u>after</u> the spinal cord lesion within the last year:
☐ None
☐ Pneumonia: Number of episodes of pneumonia treated with antibiotics: ___
Number of episodes of pneumonia requiring hospitalization: ____
☐ Asthma
☐ Chronic obstructive pulmonary disease (includes emphysema and chronic bronchitis)
☐ Sleep apnea
☐ Other respiratory conditions, specify_____
☐ Unknown

Current Utilization of Ventilatory Assistance:
☐ None
☐ Mechanical Ventilation: ☐ Yes, less than 24 hours per day
☐ Yes, 24 hours per day
☐ Yes, unknown number of hours per day
☐ Diaphragmatic pacing: Date inserted: YYYY/MM/DD
☐ Phrenic nerve stimulation: Date inserted: YYYY/MM/DD
☐ Bi-level Positive Airway Pressure (BiPAP) Date started use: YYYY/MM/DD

☐ Other, specify_____
☐ Unknown