INTERNATIONAL SPINAL CORD INJURY DATA SETS

QUALITY OF LIFE BASIC DATA SET (Version 1.0)

The working-group consists of:
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Conceptual issues on Defining Quality of Life (QoL)

Different approaches have been used to investigate QOL of individuals. Unfortunately, no single definition of quality of life that everyone agrees upon exists (and may never exist), given the breadth of literature that addresses this topic and the varying definitions used in studies. The evaluative or subjective approach defines QOL as the congruence between aspirations (wishes, desires, goals, plans, etc.) and accomplishments (possessions, statuses, roles, etc.) as perceived by the person involved. Subjective definitions of QOL include the concepts of life satisfaction, feelings of well being, morale and happiness. In the social sciences, subjective quality of life (or well-being) is generally thought to consist of a cognitive and an affective part. The cognitive part is the evaluation of one's life, mostly measured as the satisfaction with one's life as a whole or in particular domains. The affective part consists of both positive (joy, positive mood) and negative emotions (depressive feelings, anxiety, etc) (Argyle 2001). Following this approach, subjective quality of life can be defined as "reflecting an individual's overall perception of and satisfaction with how things are in their life." (Wood-Dauphinée et al 2002).

The literature also defines quality of life as a multi-faceted concept; studies suggest a relationship between perceived physical health and psychological health with quality of life. In one study (Ludwig 1991 as reported by Bullinger 2002), the dimensions of physical, psychological, social and functional health all seemed relevant for the quality of life concept from the point of view of the study respondents. Therefore, assessing these components may be useful in order to capture a general picture of an individual's perceived quality of life. It is important to recognize the effect of cultural factors in assessing quality of life. The World Health Organization addressed this issue in their WHOQOL project, defining QoL as "an individual's perception of his/her position in life in the context of the culture and value systems in which he/she lives, and in relation to his/her goals, expectations, standards and concerns (WHO 1995).

The purpose of this basic dataset is to standardize the collection and reporting of a minimal amount of information necessary to evaluate and compare results of published studies. It should include the minimal number of data elements which together can be collected in routine clinical practice. For the purposes of this data set, and to ensure its international applicability and comparability, we use the definition provided by Wood-Dauphinée et al (2002). The QoL basic dataset therefore reflects subjective quality of life and not other definitions of quality of life. Therefore, each person will assess his or her own quality of life from a personal perspective and utilize his or her own internal standards and assessment to do so. In this assessment, people may consider all factors that they feel contribute to their quality of life, whether these are related to health, finances, family or other factors.

Measurement issues
By definition, a rating of subjective quality of life can only be provided by the person him or herself. Such self-ratings are often mistrusted as being inherently unreliable and invalid. Although there certainly are problems, things are not as bad as they might look at first sight. The danger of reflecting only momentary moods that might change quickly may be reduced by asking people to describe how they have felt 'during the past few weeks', instead of how they feel 'now'.

The selection of appropriate QoL measures needs to take into account the psychometric properties of these measures as well as their content and purpose. There are many ways of ensuring that selected measures are appropriate and have strong psychometric properties. For example, response bias can be reduced by using self-report measures and by using a series of indirect questions instead of one question with an obvious target. Measurement error can be reduced by using multi-item questionnaires, although single items perform quite satisfactorily (Veenhoven 1996). Research has shown that responses to measures of happiness, mood, and well-being usually correlate strongly with each other, indicating substantial concurrent validity. Non-response and 'don't know' responses tend to be low. Variability of life satisfaction ratings is much lower than variability in mood (Eid et al 2004). Most people claim to be satisfied, and perceive themselves as happier than average, and it is quite possible that most people truly are satisfied with life, and that we underestimate satisfaction of others because misery is more salient than prosperity (Veenhoven 1996).

The basic SCI Data Set for Qualify of Life consists of three questions, as described below. Steps are being taken to develop one or more Extended Data Sets to address greater details regarding various aspects of Quality of Life.

References
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INTERNATIONAL SPINAL CORD INJURY DATA SETS - QUALITY OF LIFE BASIC DATA SET - COMMENTS

Each variable and each response category within each variable have been specifically defined in a way that is designed to facilitate the collection of a uniform basic data set.

VARIABLE NAME: **Date of data collection**

DESCRIPTION: This variable documents the date of data collection

CODES: YYYY/MM/DD

COMMENTS: The collection of data on Quality of Life (QoL) may be carried out at any time after the spinal cord lesion; however, the working group suggests administering these questions after an individual has left the acute setting and is in rehabilitation or has been discharged to a community setting. The *Date of data collection* variable is necessary in order to identify when the data were collected. This variable provides a way to relate the collected data to other data collected on the same individual at various time points.

VARIABLE NAME: **General quality of life** (overall well-being)

QUESTION: **Thinking about your own life and personal circumstances in the past four weeks, how satisfied are you with your life as a whole? Please use a scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied). You can use 0 or 10 or any number in between.**

DESCRIPTION: This variable documents how the individual with spinal cord lesion subjectively rates his or her general quality of life on a 0-10 scale, with 0 = completely dissatisfied and 10 = completely satisfied.

CODES: Numeric self-rating

COMMENTS: To be able to evaluate the subjective assessment of general QoL, a consistent definition is necessary. While numerous definitions exist, no single definition fits all individuals in all settings. Therefore, each individual will have to consider what factors contribute to his or her own quality of life and answer within that context.

VARIABLE NAME: **Rating of physical health**

QUESTION: **How satisfied are you with your physical health in the past four weeks? Please use a scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied). You can use 0 or 10 or any number in between.**

DESCRIPTION: This variable documents how the individual with spinal cord lesion subjectively rates his or her satisfaction with physical health on a 0-10 scale, with 0 = completely dissatisfied and 10 = completely satisfied.

CODES: Numeric self-rating

VARIABLE NAME: **Satisfaction with psychological health**

QUESTION: **How satisfied are you with your psychological health, emotions and mood in the past four weeks? Please use a scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied). You can use 0 or 10 or any number in between.**

DESCRIPTION: This variable documents how the individual with spinal cord lesion subjectively rates his or her satisfaction with psychological general mood on a 0-10 scale, with 0 = completely dissatisfied and 10 = completely satisfied.

CODES: Numeric self-rating

INTERNATIONAL SPINAL CORD INJURY DATA SETS
QUALITY OF LIFE BASIC DATA SET– DATA FORM (Version 1.0)

Date performed: (YYYYMMDD) _____ / _____ / _____ Unknown

1. **Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole in the past four weeks? Please use a scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied). You can use 0 or 10 or any number in between.**

    Completely dissatisfied   Completely satisfied

    ☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

2. **How satisfied are you with your physical health in the past four weeks? Please use a scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied). You can use 0 or 10 or any number in between.**

    Completely dissatisfied   Completely satisfied

    ☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

3. **How satisfied are you with your psychological health, emotions and mood in the past four weeks? Please use a scale ranging from 0 (completely dissatisfied) to 10 (completely satisfied). You can use 0 or 10 or any number in between.**

    Completely dissatisfied   Completely satisfied

    ☐0 ☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10