

## Original Article

# Measuring quality of life of persons with spinal cord injury: external and structural validity

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**Study design:** Measurement evaluation of the external and structural components of validity.

**Objectives:** To examine the relationships between quality of life (QOL) as measured by the spinal cord injury (SCI) version of the Ferrans and Powers Quality of Life Index (QLI) and other constructs represented within the model of disablement; and to examine the domains and scoring model of the QLI by exploring item and overall score/section score relationships.

**Setting:** Community, Alberta, Canada.

**Methods:** A convenience sample of 98 individuals with SCI living in the community completed the QLI and measures representing the model of disablement including the ASIA motor index, Functional Independence Measure, Reintegration to Normal Living index, Rosenberg's Self-Esteem Scale and Rotter's Internal–External Locus of Control scale.

**Results:** Four of the five *a priori* hypotheses were supported. Locus of control was not significantly related to QOL as expected. Factor analysis resulted in a five-factor structure that differed from the four-domain model of the original QLI. Scoring relationships indicated that both the satisfaction and importance ratings contribute to the overall score, although not equally.

**Conclusion:** There is support for the external component of validity although further examination regarding locus of control for persons with SCI is warranted. The structural component of validity requires further investigation to elucidate the domains of the SCI version of the QLI and the contribution of the importance scores.

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**Keywords:** spinal cord injury; quality of life; measurement; validity

## Introduction

Quality of life (QOL) is an important aspect of a complete outcome evaluation to document the effects of rehabilitation for persons with disabilities, including those with spinal cord injury (SCI).<sup>1,2</sup> The key issue is the method with which to do this. QOL instruments include characteristics that are objective, subjective or a combination of both.<sup>3</sup> Multiple approaches have been used in studies evaluating quality of life in the SCI population and the number of different instruments nearly equals the number of studies conducted.<sup>4</sup> Recent meta-analyses<sup>5,6</sup> note that the variety of measurements, designs, analyses and interventions create difficulty when drawing conclusions from study comparisons.

Quality of life is widely accepted as multi-dimensional, however there is no universal agreement on the

definition, which may contribute to the wide variety of generic and disease-specific measures. Within research of QOL involving persons with SCI, many of the instruments demonstrate low psychometric standards.<sup>4</sup> Psychometric properties should be re-evaluated whenever an instrument is used in a new setting or with a different group of people than that for which it was originally intended.<sup>3,7</sup> With respect to SCI specific instruments, many are study-specific without evidence of psychometric evaluation. Published information of instrument reliability and validity is available for only two of the SCI specific measures.<sup>8,9</sup> However, for these two measures, there is limited documentation of the guiding framework or conceptualization, process of item selection and content validation.

Two conceptual frameworks inform the design and evaluation of this study. Loevinger<sup>10</sup> provides a framework of three components of validity, useful for instrument evaluation when the measure is a non-

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observable construct such as QOL. The substantive component expands on the traditional view of content as an empirical evaluation of item relevance involving the analysis of response processes, possibly using 'think aloud' protocols. Reflection of QOL for persons with a disability should consider satisfaction and importance of life aspects and the impact of disability. The structural component refers to the structural relations of items through evaluation of item or subscale interrelationships and scoring models and their consistency with what is known about the construct, possibly using free sort tasks or factor analysis. This evaluation should support the multi-dimensional conceptualization of QOL as well as the use of weighted scores to represent the contribution of both satisfaction and importance. The external component focuses on the patterns of relationships between similar and dissimilar measures of the construct evaluated in a manner consistent with the traditional view of construct validity. External validity would be evident when the *a priori* hypotheses regarding the relationships are supported.

The model of disablement is the second framework used in this study. Within rehabilitation science, the International Classification of Functioning, Disability and Health (ICF) recently revised by the World Health Organization<sup>11</sup> has become the widely accepted model of disablement on which to evaluate rehabilitation outcome measures.<sup>1</sup> Within the model, information is organized in two parts: (1) functioning and disability and (2) contextual factors. The components of functioning and disability include: (a) *body functions and structures* where body functions are 'the physiological functions of the body systems' and body structures are 'anatomical parts of the body such as organs, limbs and their components'; (b) *activity* which is 'the execution of a task or action by an individual'; and (c) *participation* which is 'the involvement in a life situation'. The complete background of an individual's life is represented by contextual factors, which may be (a) *environmental* and/or (b) *personal* factors. Environmental factors include the physical, social and attitudinal environment external to the individual. Personal factors include features of the individual that are not part of the health condition, such as age, gender, educational background, experiences, personality, lifestyle, fitness and coping styles, to name a few.

The purpose of this study was to evaluate the external and structural components of validity of the SCI version of the Ferrans and Powers Quality of Life Index<sup>12</sup> (QLI). The substantive component was addressed in a previous study.<sup>13</sup> Conceptual development and psychometric testing of the generic version of the QLI has been well documented.<sup>12,14</sup> The external component of validity was evaluated by examining five *a priori* hypotheses about the relationship between QOL, and the components of the disablement model. It was hypothesized that there would be no significant relationship between QOL and (1) motor function, representing *body functions and*

*structures* or (2) functional independence representing *activity*. It was also hypothesized that significant correlations would be found between QOL and (3) community integration, (4) self-esteem and (5) locus of control representing *participation* and *personal contextual factors*. The structural component of validity (domains and scoring model) was evaluated by exploring item interrelationships of the QLI using factor analysis and the relationships between the weighted total score and non-weighted section scores. It was hypothesized that the factor structure would be similar to the original four factor structure,<sup>14</sup> and that there would be significant relationships of equal magnitude between the total score and section scores confirming the contribution of the satisfaction and importance ratings.

## Methods

### Participants

A convenience sample of 98 individuals (76 men, 22 women), all current members of the Canadian Paraplegic Association – Alberta, were enrolled in the study. To reduce the possibility of distress associated with the evaluation quality of life, ineligible participants were individuals with concomitant head injury or less than 1 year post injury. The participants ranged in age from 21 to 81 years with the average age being 45.2 years. The average time since injury was 15.5 years with a range of 1.1 to 77.7 years. Just over half (56.1%) of the participants had a cervical injury. Forty-nine per cent of the participants were married. Most participants were unemployed (43.9%) and 17.3% were retired. Of those that were employed, the majority worked full-time. Ten individuals were attending school either full time or part time. The participants in this study had relatively high levels of education, with almost 60% having some level of post-secondary training. All were living in the community except for four individuals who were in long-term care facilities. Many characteristics of this sample are similar to the characteristics of other studies of quality of life for individuals with SCI<sup>15,16</sup> with the exception of age and duration of injury; the participants of this study were older and had been injured for a longer time.

### Instruments

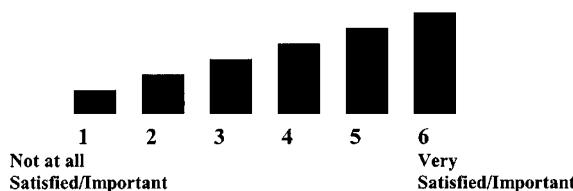
Quality of life was measured with the SCI version of the QLI, which included item modification based on the results of previous work.<sup>13</sup> The revised SCI version included 37 items in each of two sections: one measuring satisfaction with various life aspects and the other measures the importance of those aspects. The multi-dimensional nature of QOL is reflected in four domains, including health & functioning, family, social & economic and psychological & spiritual.<sup>14</sup> All items in each section are scored on a 6-point bar graph

scale (Figure 1) and scores are then calculated by weighting the satisfaction item with its corresponding importance item. A total score can be calculated as well as domain subscores with a possible range from 0 to 30. The rationale for the scoring scheme is based on an individualistic ideology that quality of life would be better for those who are satisfied with aspects of life they value and lower for those who are dissatisfied with valued aspects of life.<sup>12</sup> Psychometric analysis indicates very good results for one month test-retest reliability, internal consistency, criterion and construct validity.<sup>12,14</sup>

The following measures were used as part of the evaluation of the external component of validity.

The standard neurological classification of spinal cord injury by the American Spinal Injury Association (ASIA) was used in this study as an indicator of *body functions and structures*.<sup>17</sup> These standards allow the determination of the motor and sensory levels through the evaluation of key muscle and sensory levels. This study used the motor index score in which key muscles in 10 paired myotomes are tested. The strength of each muscle, right and left side, is graded on a 6-point scale ranked from 0 (total paralysis) to 5 (normal active movement) for a total score ranging from 0–100. The ASIA total motor index score has been used in research examining the relationship of life satisfaction and social support within the context of the ICF model of disablement.<sup>16</sup>

The Functional Independence Measure<sup>19</sup> (FIM) is a comprehensive measure of *activity* frequently used in research and practice with various patient groups. A client's degree of functional independence for 18 activities in the areas of self care, sphincter control, mobility, locomotion, communication and social cognition are rated on a 7-point Likert scale with one indicating 'total assistance' and seven representing 'complete independence'. Possible scores range from 18 to 126, the higher score indicating greater independence. Within this study the 13 items of the motor subscale were used such that the score ranged from 13 to 91. The psychometric properties of the FIM have been extensively evaluated and excellent results have been demonstrated for reliability, validity and responsiveness.<sup>19–22</sup>



**Figure 1** Six point bar graph scale used by participants to indicate responses for each section (satisfaction and importance) of the QLI

The Reintegration to Normal Living index (RNL), a self-report questionnaire designed to assess global function within the community was used to assess participation.<sup>23</sup> This measure considers the client's perceptions of their own capabilities in terms of physical, social and psychological performance. Eleven statements are scored using a visual analogue scale anchored by phrases that require the client to determine whether or not the statement describes their situation.<sup>24</sup> The total score ranges from 0 to 110, but is proportionally adjusted so the maximum score is 100. The evaluation of reliability, responsiveness, content, criterion and construct validity indicates very good results.<sup>24</sup>

Two personal contextual factors were also measured. Firstly, self-esteem was measured with Rosenberg's Self-Esteem Scale (RSES).<sup>25</sup> Self-esteem, refers to the beliefs one has about oneself in terms of respect and worth, involving both positive and negative attitudes. Internal factors such as self-worth and outside sources such as social factors, achievements and physical appearance contribute to self-esteem. The RSES is composed of 10 statements with four choices of agreement; the scores range between 10 and 40 with a higher score indicating higher self-esteem. Reproducibility and scalability have been reported as good to excellent. Good internal consistency of the RSES was demonstrated in a more recent study involving spinal cord injured participants.<sup>26</sup>

The second personal contextual factor was locus of control as measured by Rotter's Internal–External (IE) scale.<sup>27</sup> Persons believing they have high degree of control over life events have an internal locus of control, and those believing they have little personal control have an external locus of control. This is a forced-choice 29-item scale, which includes six distracter items, with scores ranging from 0 to 23 as determined by totaling the number of externally oriented responses checked. The higher the score the more externally oriented the individual. Reports for reliability were acceptable and discriminant validity was indicated by low relationships with variables of intelligence and social desirability.

There were no additional instruments required to address the structural component of validity, since the evaluation of this component is inherent in the QLI itself.

### Procedures

The participants were required to undergo a physical examination and complete a number of questionnaires as set out in the hypotheses. To enhance compliance, accuracy and improve comfort level, the questionnaires were administered during face-to-face evaluations in the participant's location of choice. All participants were required to sign a consent form prior to commencement of data collection. At the meeting with each participant, demographic information was collected first and then a physical examination was

conducted to determine the ASIA total motor score followed by the administration of the remaining questionnaires. If any of the participants could not read or write proficiently, assistance was given by the investigator.

#### *Analyses*

Descriptive statistics were used to summarize the sociodemographic information of the sample and the data collected with each of the instruments used in the study. To examine the external component of validity, Pearson's correlation coefficients were calculated between the QLI and each of the measures representing the model of disablement. Each of the calculated correlation coefficients was compared with the *a priori* hypotheses to determine if the theoretically expected associations existed. Considering that multiple comparisons were made, the acceptable level of significance was  $P < 0.01$ . To analyze the structural component of validity with respect to the domain structure, an exploratory factor analysis was applied to the QLI data. Principal axis factor analysis with oblimin rotation was used to identify the underlying dimensions of the QLI. Five criteria were used to determine how many factors to extract: simple structure, kaiser's criterion, scree plot, loading factor (0.4 or greater), and the factorial complexity (the number of items that loaded on more than one factor). In addition, the resulting factors were compared descriptively to the model of disablement to determine conceptual fit. To analyze the structural component of validity with respect to the scoring model, non-weighted scores were tabulated for the satisfaction section and the importance section of the QLI. Pearson's correlation coefficients were then calculated between the weighted QLI total score and the non-weighted section scores.

## Results

#### *External component*

The descriptive results for the scores on all measurements are presented in Table 1. The relationships among all of the measurements are presented in Table 2. Four of the five *a priori* hypotheses regarding associations between QOL and measures representing the model of disablement were supported. The QLI was not significantly related to the level of *body functions and structures* or the level of *activity*. As expected the QLI was significantly related to community integration, an indicator of *participation*, and the magnitude of the correlation was as predicted. The QLI was also significantly related to self-esteem, a *personal contextual factor* that can mediate the disablement process, and again the magnitude of the correlation was as predicted. The hypothesis concerning the relationship between QOL and locus of control, was not supported by the data. It was hypothesized that there would be a significant moderate correlation

**Table 1** Descriptive results for participants' scores on the six measurements ( $n=98$ )

| Instrument                | Mean  | Standard deviation | Range*   |
|---------------------------|-------|--------------------|----------|
| QLI                       |       |                    |          |
| Overall                   | 21.01 | 4.27               | 11–30    |
| Health & Functioning      | 19.92 | 4.83               | 6.38–30  |
| Social & Economic         | 21.56 | 4.26               | 11.75–30 |
| Psychological & Spiritual | 21.74 | 5.49               | 5.64–30  |
| Family                    | 22.94 | 5.58               | 8–30     |
| ASIA                      | 43.38 | 26.09              | 0–98     |
| FIM                       | 62.58 | 25.57              | 18–91    |
| RNL                       | 23.05 | 13.54              | 3–78.36  |
| RSES                      | 31.29 | 5.42               | 19–40    |
| LOC                       | 9.1   | 3.75               | 0–17     |

\*Ranges of possible scores for the QLI: 0 to 30; ASIA: 0–100; FIM: 13 to 91; RNL: 0 to 100; RSES: 10 to 40; LOC: 0 to 23. QLI, Quality of Life Index; ASIA, American Spinal Injury Association (motor score); FIM, Functional Independence Measure; RNL, Reintegration to Normal Living (Index); RSES, Rosenberg Self-esteem Scale; LOC, Locus of Control

with this construct, which is also a *personal contextual factor* that could mediate the disablement process.

#### *Structural component*

**Domains** There was incomplete data for the factor analysis in order to evaluate the QLI domains as part of the structural component of validity. Four items of the QLI are complementary (have/do not have a spouse; have/do not have a job) and another item only applied to those with children resulting in missing data points for these five items. It was determined that it did not make sense conceptually to apply the mean score to the missing data points in order to include them in the analysis. Therefore, 32 items were subjected to the factor analysis. Given the small sample size and the deletion of five items from the analysis, these results should be considered preliminary and interpreted with caution. Although the hypothesis was not supported, the results give some indication of potential structure differences for the domains of QOL for individuals with SCI.

Only a five, six or seven factor solution met all the five criteria used to determine the number of factors to extract. The five factor solution best fit all criteria. Problems with the six and seven factor structure included: factors that only contained two items, non-loading of items, factorial complexity and bipolarity.<sup>28</sup> With the five factor pattern matrix there were fewer problems with item loadings and each factor was comprised of five to seven items. The five factor structure accounted for 54.7% of the variance with the first factor accounting for 34.5% and remaining variances ranged from 2.9 to 7.4%. Using the 0.4 loading criterion, there were four items that did not

**Table 2** Correlation matrix of all measured variables ( $n=98$ )

| Variable | QLI   | ASIA  | FIM     | RNL      | RSES     | LOC    |
|----------|-------|-------|---------|----------|----------|--------|
| QLI      | 1.000 | 0.058 | 0.202   | -0.654** | 0.609**  | -0.024 |
| ASIA     |       | 1.000 | 0.847** | -0.196   | 0.054    | -0.12  |
| FIM      |       |       | 1.000   | -0.348** | 0.171    | -0.175 |
| RNL      |       |       |         | 1.000    | -0.483** | -0.042 |
| RSES     |       |       |         |          | 1.000    | -0.242 |
| LOC      |       |       |         |          |          | 1.000  |

\*\*Correlation is significant at the 0.01 level (two-tailed). QLI, Quality of Life Index; ASIA, American Spinal Injury Association (motor score); FIM, Functional Independence Measure; RNL, Reintegration to Normal Living (Index); RSES, Rosenberg Self-esteem Scale; LOC, Locus of Control

load onto any factor and two items that showed factorial complexity. All four items loaded on a factor using the 0.3 loading criterion. In the cases of factorial complexity, when one loading was substantially higher on one factor as compared to the other four factors, the highest loading was considered salient.<sup>28</sup> The loadings of the weighted items on the factor structure for the five factors are shown in Table 3. The fit of the loadings on each factor was further corroborated by conceptual fit.

Six items loaded saliently on *Factor 1* and appear to be closely related to happiness/self-fulfillment. Although loading of the item pertaining to 'sex life' was low, it would fit conceptually within this grouping when considering the emotional and attitudinal aspects of a sexual relationship. *Factor 2* contained eight items reflecting a theme of social relationships. These social relationships include friends, family and the greater community, which would include 'neighbourhood' although the item did not have a high loading on this factor. Six items loaded saliently on *Factor 3* representing life functions. All of the items appeared to be concerned with functional task performance or involvement in life situations. Three items within this factor showed factorial complexity although all could be viewed with respect to task and situation components. *Factor 4* contained five items that appeared to represent circumstances or experiences that could affect an individual's involvement in life situations. Most of the seven items that loaded on to *Factor 5* seemed to reflect the issue of self-perceived wellness of mind, body and spirit. The diversity of the items seems to reflect integration or balance necessary for complete wellness. The two items with low loading would fit conceptually, with an obvious connection for the item referring to 'faith' and the consideration of the physical and psychological impact regarding the item 'ability to have children'.

**Scoring** Correlations between the non-weighted section scores (satisfaction and importance) and the weighted total QLI score were calculated to evaluate the scoring model as part of the structural component of validity. The weighted total QLI score was highly correlated with the mean satisfaction score ( $r=0.99$ )

and moderately correlated with the mean importance section score (0.43), contrary to the hypothesis. Although the range of the scale responses from one to six was used for both the satisfaction and importance sections, the satisfaction scores approximated a normal distribution, whereas the distribution of the importance scores was skewed with 85% of the rating being either five or six indicating high importance.

## Discussion

Generally, the results of this study support the external validity of the QLI within the applied theoretical framework. Considering that the results are preliminary, there are some concerns about the structural validity of the QLI with respect to the domains and the scoring model indicating areas of future study.

### External component

Within this study the relationships between the QLI scores and other measures were studied within the context of the ICF.<sup>11</sup> With respect to the relationship between quality of life and impairment of *body functions and structures* as represented by level of injury, the literature is fairly consistent. Most studies have found no significant difference in the QOL scores between groups based on level of injury<sup>29,30</sup> although contradictory results of one study<sup>15</sup> may be related to differences in the sample and methods. Using the ASIA total motor index score, as used in this study, other research has found little or no association between body functions and structures and QOL.<sup>16,31,32</sup> These results are further supported by a meta-analysis of the effects of disablement in which the relationship between impairment and QOL was weak.<sup>5</sup> Despite results of this study and others, items representing body functions and structures should not be excluded from QOL measures. For example, pain has been shown to significantly influence QOL for persons with SCI.<sup>33</sup>

Documented research has not demonstrated consistent results with respect to the magnitude of the relationship between QOL and *activity*. Significant correlations have been documented between QOL and function in daily activities,<sup>26,29</sup> however other studies

**Table 3** Loadings of items on factors from the pattern matrix for the five factor model<sup>a</sup>

| Item                                 | I            | II           | III          | IV    | V     |
|--------------------------------------|--------------|--------------|--------------|-------|-------|
| Chances for a happy future           | 0.781        |              |              |       |       |
| Happiness in general                 | 0.736        |              |              |       |       |
| Life in general                      | 0.659        |              |              |       |       |
| Peace of mind                        | <u>0.586</u> |              |              |       | 0.310 |
| Yourself in general                  | <u>0.433</u> |              |              |       | 0.390 |
| Your sex life                        | 0.326        |              |              |       |       |
| Emotional support from family        |              | 0.769        |              |       |       |
| Health care                          |              | 0.696        |              |       |       |
| Family's happiness                   | 0.326        | <u>0.686</u> |              |       |       |
| Home, Place where you live           |              | 0.675        |              |       |       |
| Family's health                      |              | 0.654        |              |       |       |
| Your friends                         | 0.304        | <u>0.496</u> |              |       |       |
| Emotional support from others        |              | <u>0.459</u> |              |       | 0.344 |
| Neighbourhood                        |              | 0.309        |              |       |       |
| Ability to take care of yourself     |              |              | 0.751        |       |       |
| Ability to go places                 |              |              | <u>0.634</u> | 0.361 |       |
| Usefulness to others                 |              |              | 0.618        |       |       |
| Ability to clear your lungs          |              |              | 0.535        |       |       |
| Control your life                    | 0.432        |              | <u>0.529</u> |       |       |
| Take care of family responsibilities |              |              | <u>0.455</u> | 0.423 |       |
| Take care of financial needs         |              |              |              | 0.717 |       |
| Amount of worries in your life       |              |              |              | 0.586 |       |
| Your education                       |              |              |              | 0.538 |       |
| Things you do for fun                |              |              |              | 0.487 |       |
| Amount of pain you have              |              |              |              | 0.423 |       |
| Your personal appearance             |              |              |              |       | 0.642 |
| Health                               |              |              |              |       | 0.529 |
| Chances of living a long life        |              |              |              |       | 0.480 |
| Achievement of personal goals        |              |              |              |       | 0.445 |
| Energy for everyday activity         |              |              |              |       | 0.406 |
| Your faith                           |              |              |              |       | 0.391 |
| Ability to have children             |              |              |              |       | 0.312 |

<sup>a</sup>The salient loading for the items that loaded on two factors is underlined

contradict these findings.<sup>16,32</sup> Differences in the measures used to evaluate functional independence and QOL could explain the varied results. In addition, none of the QOL measures used were validated for persons with spinal cord injury. As with this study, the FIM score has been used in other studies to represent activity and results indicate a weak relationship between QOL and activity.<sup>16,32</sup> In addition, meta-analysis has shown that the association between QOL and activity is weak to moderately strong and not found consistently.<sup>5</sup>

The results of this study indicated a strong relationship between QOL and participation represented by measurement of community integration. Although most studies have evaluated specific aspects of participation separately, conclusions consistently show that enhanced participation is associated with greater quality of life.<sup>5,15,16,29,34</sup> Community integration of rehabilitation clients, as measured by the RNL,

was related to QOL and the magnitude of the correlation was similar to this study.<sup>24</sup> Multiple components of participation are associated with quality of life demonstrating the importance of rehabilitation efforts toward community reintegration and successful participation in society. The need to consider the influence of the attitudinal barriers of society as an environmental factor that impacts participation is also important.

It was expected that *personal contextual factors* of self-esteem and locus of control would be significantly related to QOL. In this study the participants demonstrated a relatively high level of self-esteem and this was related to the perception of a better QOL, thus supporting the hypothesis. The average score for self-esteem in this study is similar to the scores of other studies of individuals with SCI that also used Rosenberg's Self-Esteem Scale.<sup>26,35</sup> In addition, self-esteem was found to be a significant predictor of life

satisfaction and the correlation was almost identical to the present study.<sup>30</sup> During rehabilitation, developing self-esteem through exploration and redefinition of identity within a peer-support program may benefit QOL.<sup>36</sup>

Participants in this study demonstrated an internal locus of control, they perceived themselves as being in charge of their lives. However, this *personal contextual factor* was not shown to be associated with QOL as hypothesized. Some studies report low perceived or external locus of control<sup>16,35</sup> while others have found a more internally oriented or higher perception of control.<sup>29,37</sup> It is difficult to compare results when different measures were used. Perceived control has been shown to be significantly associated with QOL in three separate studies of individuals with spinal cord injury.<sup>16,29,38</sup> These results are contradictory to the present study and it is possibly related to either differences between the sample of this study or measures used. The results and implications are unclear. Individuals with spinal cord injury may view control differently or perhaps the instrument used to measure locus of control did not tap the issues of concern for persons with SCI. 'Control over life' has been identified by quadriplegic adults as influencing QOL.<sup>39</sup> For persons with SCI, locus of control may not be stable as suggested by Rotter,<sup>27</sup> but may be reflected by a model recognizing variability over time.<sup>40</sup> Only longitudinal study can elucidate this issue and determine validity of the QLI with respect to the relationships of personal contextual factors and QOL.

### *Structural component*

**Domains** The preliminary evidence from this study indicates that the domains of the QLI as originally conceptualized may not represent the situation of individuals with SCI. The interpretation requires caution and the evidence should be viewed as mainly hypothesis generating since the analysis was incomplete and the variance accounted for was low. However, the domains represented in the factor structure of this study are similar to the conceptualization of QOL by other authors.<sup>41,42</sup> Structure differences could indicate the use of domain subscores from the original QLI may not be applicable to other patient populations. The pattern of items within the factors identified do give insight to the relationships among different life aspects and how these may be conceptualized as dimensions of QOL for persons with SCI. In addition, the evaluation contributes to the understanding of the integration of QOL with respect to the model of disablement although further research to substantiate the authors' interpretation is required.

**Factor 1** labeled happiness/self-fulfillment appears to reflect the *personal contextual factors* from the model of disablement. Individuals with SCI have identified that a positive 'attitude toward life' to facilitate coping and acceptance, significantly influ-

ences QOL.<sup>43</sup> Many items within this factor were part of the psychological and spiritual domain of the original QLI. Sex life was originally an item within the health and functioning domain of the QLI, and appears conceptually out of place. However previous research of persons with SCI has documented a strong emphasis on the emotional and intimate experiences related to a satisfying sexual relationship.<sup>13,44</sup>

Social relationships, the label applied to *Factor 2* appears to best relate to *participation* within the disablement model. Five of the eight items in this factor come from the social and economic domain of the original QLI. Two of the items referring to family were originally part of the family domain although they represent social relationships. The issue of relationships with family and others is not new to the conceptualization of QOL and has been identified by persons with SCI as significantly affecting their QOL.<sup>36,39,45</sup> Inclusion of the item referring to health care, originally part of the health and functioning domain, seems questionable. However, the nature of health 'care' implies a participatory relationship with respect to government programs and health care resources or attendant/residential care.

The items represented within *Factor 3* labeled life functions appear to span the *activity* and *participation* levels of the model of disablement. All of these items were included in the original health and functioning domain of the QLI. Individuals with SCI have identified the concept of functional independence/maximizing potential as an important category of QOL.<sup>39,45</sup> This factor seemed to include items that represented situations of participation with others. With respect to 'family responsibilities', participation is represented by fulfillment of family role responsibilities. This would confirm the importance of integrating individual and family activities within rehabilitation.

Most of the items within *Factor 4* labeled life situations appear to represent a theme of positive or negative effects on *participation*. The items of this factor were originally part of either the social and economic domain or the health and functioning domain. It appears that any of the items individually or in combination could affect the life situation for the individual. Although pain most often represents the level of *body functions and structures*, it may reflect a barrier to participation. The ability to cope with pain has been shown to affect adjustment to spinal cord injury and QOL.<sup>33</sup> The item referring to 'doing things for fun' has been discussed with respect to the limitations of financial resources affecting participation.<sup>13</sup> The notion of life situations presented here is somewhat distinct and may reflect issues and life challenges more specific to persons with SCI.

**Factor 5**, which has been labeled wellness of mind, body, and spirit, indicates a necessity of balance between *body functions and structures*, *activity* and *participation*. With respect to the 'ability to have children', QOL includes a balance of biological

function as well as family life and psychosocial functioning. In a qualitative study of persons with disabilities, including SCI, participants that reported a good QOL expressed a balance of body, mind, and spirit through task and role performance, finding purpose or meaning in life, having a spiritual foundation and feeling satisfied when comparing oneself with others.<sup>46</sup> Many of the integrative aspects described by the participants are reflected in the items of this factor, including faith. In fact, spirituality has been recognized as an important contributing factor to QOL.<sup>42</sup>

These results should be considered preliminary. Factor analysis can produce unstable results when the sample size is small relative to the number of items or if factors are identified that do not account for much of the variance as is the case in this study. Within the QLI, it may not be necessary to have complementary items, such as 'having/not having a job' when perhaps one item referring to 'employment situation' would suffice. Including an item referring to children implies that the normative situation is to have offspring and one item referring to 'family relationships' may be adequate. These changes may result in less missing or non-applicable item responses. Although the first factor accounted for the greatest proportion of the total variance, similar results in a study of QOL for persons with SCI have been reported.<sup>8</sup> These results generate hypotheses related to unique issues of QOL for persons with SCI. There are also theoretical implications in recognizing the interdependence of specific life aspects and how the model of disablement may be used to guide intervention and outcome evaluation. The use of domain subscores may facilitate the planning and evaluation of interventions aimed at improving QOL and this remains to be resolved within the context of future clinical trials.

**Scoring** The conceptualization of the scoring model of the QLI adheres to the individualistic ideology by incorporating ratings of satisfaction and importance in the final score. Results for this study did not support the hypothesis of equal contribution of the satisfaction and importance sections. The primary influence of weighting items by importance is reflected in the inferences made from the QOL scores. Decisions regarding appropriate client-centered interventions to enhance QOL should be made on the basis of the individual's perception of their QOL with respect to the importance of specific life aspects. It has been argued that 'quality of life may not be properly characterized unless patients are also invited to rate the importance of the problems'.<sup>47</sup> Research has shown that the degree of importance of specific life domains contributing to QOL is unique to individuals.<sup>43,45</sup> Whether a treatment or research context, the consideration of the scaling of the importance section is necessary. Within this study the importance scores mostly reflected high importance. Perhaps the dis-

mination of the levels of importance would be facilitated with a less negative anchor phrase at the one end of the scale. At this time, prematurely eliminating the importance scores from the QLI would risk the possibility of losing valuable information. Possibly the information from the two sections could be used separately. The satisfaction scores may give an accurate picture of QOL, whereas the importance scores may indicate areas for intervention, resource allocation or further study.

### Conclusions

Although there is a need for further psychometric evaluation of the SCI version of the QLI, this study represents an important step in the refinement of an instrument that shows promise for rehabilitation research and practice. The QLI is based on an ideology that reflects the subjective nature of the construct. Also, this is one of few measures to incorporate the individual's perspective relating to importance of life aspects, although further work of the scale is required. Considering that both generic and other disease-specific versions exist, with common core items, cross study comparisons are possible. However, comparisons should be made only to total scores of core items at this time, since it is possible that the domains of QOL may differ for other patient populations. The emphasis of restoring independent physical function may not completely address the factors that influence successful rehabilitation in the long term. The interpretation of QOL within a model of disablement may elucidate the personal contextual factors that could mediate the impact of limitations of body functions and structures, activity and participation. Within the clinical setting QOL assessment with the QLI may identify aspects that are of greatest concern to individuals with SCI and assessments over time can elucidate the changes in criteria used to determine QOL. This could better facilitate long-term rehabilitation intervention strategies particularly those aimed at community reintegration. Through the use of QOL ratings the client could become a partner in rehabilitation helping to identify their own problems and plan possible solutions.

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