Understanding Quality of Life in Adults with Spinal Cord Injury Via SCI-Related Needs and Secondary Complications

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Background: Understanding the factors that can predict greater quality of life (QoL) is important for adults with spinal cord injury (SCI), given that they report lower levels of QoL than the general population. **Objectives:** To build a conceptual model linking SCI-related needs, secondary complications, and QoL in adults with SCI. Prior to testing the conceptual model, we aimed to develop and evaluate the factor structure for both SCI-related needs and secondary complications. **Methods:** Individuals with a traumatic SCI ($N = 1,137$) responded to an online survey measuring 13 SCI-related needs, 13 secondary complications, and the Life Satisfaction Questionnaire to assess QoL. The SCI-related needs and secondary complications were conceptualized into factors, tested with a confirmatory factor analysis, and subsequently evaluated in a structural equation model to predict QoL. **Results:** The confirmatory factor analysis supported a 2-factor model for SCI related needs, $\chi^2(61, N = 1,137) = 250.40, P < .001$, comparative fit index (CFI) = .93, root mean square error of approximation (RMSEA) = .05, standardized root mean square residual (SRMR) = .04, and for 11 of the 13 secondary complications, $\chi^2(44, N = 1,137) = 305.67, P < .001$, CFI = .91, RMSEA = .060, SRMR = .033. The final 2 secondary complications were kept as observed constructs. In the structural model, both vital and personal development unmet SCI-related needs ($\beta = -.22$ and $-.20, P < .05$, respectively) and the neuro-physiological systems factor ($\beta = -.45, P < .05$) were negatively related with QoL. **Conclusions:** Identifying unmet SCI-related needs of individuals with SCI and preventing or managing secondary complications are essential to their QoL. **Key words:** life satisfaction, needs, quality of life, secondary complications, spinal cord injury

Life expectancy of adults with spinal cord injury (SCI) has generally increased since 1973 such that, in 2006, the odds of dying within the first year of a spinal cord injury (SCI) were 2.2 times lower and adults with SCI were living approximately 3.5 years longer.¹ Given this increase in life expectancy, understanding how to improve the quality of life (QoL) of this population has become imperative. Recent evidence further points to the importance of QoL, as adults with SCI were found to report significantly lower levels of QoL than adults without SCI (effect size = .77).² For the purpose of this study, QoL is defined as life satisfaction. This definition is consistent with Dijkers³ definition of QoL as subjective well-being.

In a seminal article, Post and colleagues⁴ demonstrated that greater QoL was associated with lower social functioning problems, psychological

function problems, age, and being married. The main conclusion drawn from this study was that functioning health variables (eg, social and psychological functioning) were better predictors of QoL than injury-related variables (eg, SCI severity). This article has paved the way for future studies to investigate a broad range of social and psychological functioning health variables. van Leeuwen and colleagues⁵ conducted a systematic review looking at the relationship between psychological factors and QoL. Across 48 studies, the authors concluded that locus of control (ie, belief a person can direct his or her life), coherence (ie, experience life as comprehensible, manageable), self-worth, hope, purpose in life, and positive affect were consistently related with QoL. In another study conducted during the rehabilitation process, van Koppenhagen and

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colleagues⁶ revealed that less pain, fewer secondary impairments, and functional status were related to higher QoL. Participation in physical activity has also been linked with greater QoL, as highlighted by 2 reviews.^{7,8}

Despite the growing evidence of the predictors of QoL, a social functional variable that has rarely been considered in QoL for adults with SCI is SCI-related needs. SCI-related needs are defined as services that are necessary to support a person's community living (eg, housing, transportation, peer support). SCI-related needs have been a focus of the Spinal Cord Injury Community Survey of Adults with SCI.⁹ In one article stemming from this project, we have demonstrated that vital needs such as housing and transportation are typically more often reported as being met than personal development needs such as emotional support and peer support.¹⁰ Despite these findings, there is a limited amount of research on SCI-related needs. It is now imperative to look further at these needs and their relationship with other important variables for adults with SCI such as QoL.

A study with 895 adults with traumatic brain injury investigated injury-specific needs and their association with a variety of outcomes, including QoL. The authors revealed a negative relationship between the extent to which the needs were unmet and QoL, which was, in fact, the third strongest associated variable among 14 variables in the model.¹¹ Similar findings were found in a recent study with 3,439 cancer patients. The authors concluded that when individuals' specific needs are left unmet, there is a reduction in QoL.¹² These studies provide evidence that condition-specific needs and QoL are related, and further investigation in adults with SCI is warranted.

In addition to investigating the association between SCI-related needs and QoL, we sought to determine the role of secondary complications. Secondary complications have been identified by the SCI community as a priority area.¹³ Secondary complications have consistently been found to have a negative impact on the QoL of adults with SCI.¹³ For instance, van Koppenhagen and colleagues demonstrated a positive relationship between higher QoL and fewer secondary complications.⁶ Barker et al¹⁴ also revealed that the

overall average severity of 40 different secondary complications was most strongly associated with QoL when they were entered in a regression with 6 other SCI-related variables (eg, time since injury, age, community integration). A review by Whalley Hammel¹⁵ further highlighted the multitude of studies linking secondary complications to QoL. Despite this evidence, she argues that there needs to be more research on secondary complications, especially regarding the complexities of secondary conditions and their interrelationships with other variables such as QoL.¹³

Given this call for research, the purpose of this study was to build a conceptual model linking SCI-related needs, secondary complications, and QoL in adults with SCI. To our knowledge, no studies have investigated the relationship of such needs with secondary complications and QoL in a conceptual model.

Methods

Participants

Participants ($N = 1,137$) were aged 18 years or older, had a traumatic SCI diagnosis, lived in the community for at least 1 year, understood English or French, and lived in Canada. All study participants who complete the survey were offered a \$25 gift certificate as well as a complimentary subscription to the *Solutions* magazine. Participant characteristics are presented in the traumatic lesion column of Table 1 in the first article of this issue.⁹

Measures

Demographics measure

Demographic information included the following questions: date of SCI, age, relational status, gender, ethnic origin, language, postal code, education level, living setting, living arrangement, personal income, source of income, and annual household income.

SCI Health Questionnaire: Secondary Complications

The Spinal Cord Injury Health Questionnaire: Secondary Complications was used to assess

secondary complications.¹⁶ This questionnaire focuses on the 21 most frequent secondary complications that can occur after an SCI (eg, sexual dysfunction, autonomic dysreflexia, urinary tract infection). For this study, we used 13 of the 21 secondary complications, because a number were not frequently reported (eg, respiratory infections, deep vein thrombosis) and resulted in too many counts of zeros, rendering the variable too skewed and kurtotic for transformation. For 12 of these 13 variables, participants indicated whether they had experienced the complication on a 0 (*never*) to 5 (*every day*) Likert scale. For pressure ulcers, the 13th secondary complication, participants reported the number of new pressure ulcers in the last 12 months (1, 2, 3, 4, or 5+). In a follow-up question, participants rated the extent to which the complication limited their activities on a 1 (*not at all*) to 5 (*completely*) scale. For this study, we used a metric to assess the secondary complications by multiplying the rating of the occurrence of the complication with the degree the complication limited daily activities. This multiplication gave a range of scores between 0 and 25. A lower score represented lower prevalence and lower limitation of the secondary complication.

SCI-Related Needs Measure

Information on 13 SCI-related needs for people with SCI was collected with the SCI-Related Needs Measure.⁹ The SCI-Related Needs Measure consists of 8 sections, and only 3 of the sections were used in this study. (The first and second articles in this issue provide a detailed description of this measure.^{9,10}) The first section identified the presence of the need. If the need was not required, the participant was given a score of 0. If the need was required, the participant answered the second section by indicating to which level their SCI-related needs were met (1 = *completely* to 5 = *not at all*). In the eighth section, participants rated the importance of the need to enable them to live a full life (1 = *not at all* to 5 = *extremely*). Data from all 3 sections were multiplied to create a need importance index, in which a higher score represented an unmet need that was extremely important for full life functioning (range, 0-25).

Life Satisfaction Questionnaire-11

The Life Satisfaction Questionnaire-11 (LiSAT-11) is a standardized and validated QoL measure that asks 11 questions about satisfaction in various areas of life, including life in general, vocation, financial situation, leisure, social/friends/family, sexual life, family life, and physical and mental health (1 = *very dissatisfying* to 6 = *very satisfying*).¹⁷ For the structural equation modeling, we aggregated common themes of this measure. For instance, physical and mental health items were combined to create a health construct, the family life items made up a family construct, and other life domains were scaled together. Life satisfaction as a whole and self-care management items were included as individual items on the QoL factor.

Procedures

For a more detail description of the procedures and methods for the SCI Needs Survey Project, see the first article within this issue.⁹ Briefly, the primary recruitment strategies were through awareness campaigns (ie, media advertisements) and publicity with community groups and partners. Interested participants had the option to complete the survey online (87%) or over the telephone. The data were collected by a market research organization (Mustel Group; <http://www.mustelgroup.com>). Prior to answering the survey, participants read an information sheet and completed a consent form. The project was approved by the Université Laval Research Ethics Board.

Data analysis

Normality of data was inspected prior to conducting a structural equation model. No data were missing and, therefore, missing data patterns did not need to be verified. Prior to testing the conceptual model, a confirmatory factor analysis was tested for the concepts of SCI-related needs and secondary complications to validate the structure. Once the structure of these latent constructs was validated, the conceptual model was tested.

Amos v. 21 was used to build and evaluate the confirmatory factor analyses for the latent variables of SCI-related needs and secondary complications factors and the structural equation model to test the conceptual model. For all latent variables, one indicator variable was set as the reference variable and had a unit loading identification constraint of 1.0. The factor loadings and model fit of both the confirmatory factor analyses and the structural equation model were used to determine whether the model was acceptable. Model fit was considered acceptable with a nonsignificant chi-square, comparative fit index (CFI) $\geq .90$, root mean square error of approximation (RMSEA) $\leq .08$, and the standardized root mean square residual (SRMR) $\leq .10$.¹⁸ Any modification fit changes were evaluated with the Akaike Information Criteria (AIC) and the chi-square difference test. A reduction in the AIC and a significant chi-square indicates a favorable modification.

Results

SCI-related needs: Confirmatory factor analysis

Ten of the 13 SCI-related needs were considered to be normally distributed. The last 3 SCI-related needs were slightly skewed and kurtotic (range skewness, 1.78-2.36; range kurtosis, 2.29-4.92). The reason for this distribution was for the higher presence of zeros in these variables, meaning that a number of individuals reported not requiring the need in question. Given only the slight violation of the skewness and kurtosis, we used bootstrap estimates with 1,000 iterations when running the confirmatory factor analysis to reduce the influence of nonnormality. In addition, we tested a confirmatory factor analysis with a correlation matrix that only included the associations of the variables when all zeros were removed to determine whether the model fit still had acceptable fit and whether the zero inflated scores impacted the models. Prior to testing the confirmatory factor analysis, the 13 SCI-related needs were conceptualized by the authors. The 13 SCI-related needs were hypothesized to result in a 2-factor model. The first factor consisted of vital needs such as housing, equipment, and

transportation needs, whereas the second factor included personal development needs (eg, peer support, job training). The 2-factor needs model was supported as indicated by the model fit indices: $\chi^2(62, N=1,137) = 276.22, P < .001$, CFI = .92, RMSEA = .055 (90% CI, .049-.062), SRMR = .043, AIC = 360.22. Due to the exploratory nature of this model, we also looked at the modification fit indices. The only modification fit index that made conceptual sense was to add a cross-loading to the case management need, as this need was deemed as important for vital and personal development needs. This modification resulted in a better fitting model, $\chi^2(61, N=1,137) = 250.40, P < .001$, CFI = .93, RMSEA = .052 (90% CI, .046-.059), SRMR = .042, AIC = 336.40, and was supported by the reduction in AIC ($360.22-336.40 = 23.82$) and a significant chi-square difference test [$\Delta\chi^2(1) = 25.82, P < .001$]. In addition, the correlation between the vital and personal development need factor in this confirmatory factor analysis was .62, indicating a strong relationship without collinearity. This 2-factor SCI-related needs model will be used in the structural model. The model was also tested with the aforementioned zero-removed correlation matrix, which revealed a minimally acceptable fit of the model: $\chi^2(61, N=393) = 282.78, P < .001$, CFI = .87, RMSEA = .096 (90% CI, .085-.11), SRMR = .053. This supplemental analysis confirms the model tested with all data.

Secondary complications: Confirmatory factor analysis

Of the 21 secondary complications assessed in this study, only 13 were entered into the conceptual model and they all had acceptable skewness and kurtosis values. Because of the presence of zeros, we also tested the confirmatory factor analysis with a correlation matrix that excluded the zeros. The same panel conceptualized 2 factors for 11 secondary complications. Sexual dysfunction and pressure ulcers were entered as separate variables. The first factor relates to bladder and bowel functions (eg, urinary tract infections and constipation) and the second to neuro-physiological systems (eg, neuropathic pain, spasticity, and fatigue). The confirmatory

factor analysis confirmed good model fit: $\chi^2(44, N=1,137) = 305.67, P < .001, CFI = .91, RMSEA = .060$ (90% CI, .053-.067), SRMR = .033, AIC = 393.87. Factor loadings ranged from .43 to .75. The correlation between the neuro-physiological systems and bowel-bladder factors was .63. No modification indices were considered to be conceptually valid. The zero-removed correlation matrix confirmatory factor analysis had minimally accepted fit, thus confirming the model: $\chi^2(49, N=646) = 245.11, P < .001, CFI = .88, RMSEA = .079$ (90% CI, .069-.089), SRMR = .049.

Conceptual model

The initial structural model included paths from unmet vital needs and unmet personal development needs to each of the secondary complications variables (ie, bowel-bladder complications, pressure ulcers, sexual dysfunction, neuro-physiological systems) and to QoL. Then each secondary complication variable was linked to QoL. This initial model had adequate fit, $\chi^2(116, N=1,137) = 1661.32, P < .001, CFI = .86, RMSEA = .052$ (90% CI, .049-.054), AIC = 1893.32. Given the exploratory nature of this conceptual model, the model was trimmed by removing all paths that were nonsignificant and nonmeaningful (standardized coefficient of $<.10$). This model trimming resulted in the removal of 6 paths to QoL: (1) unmet vital needs – sexual difficulties; (2) unmet personal development needs – bowel-bladder; (3) unmet personal development needs – pressure ulcers; secondary complications of (4) bowel-bladder, (5) pressure ulcers, and (6) sexual difficulties. The trimmed model had acceptable fit, $\chi^2(110, N=1,137) = 1672.66, P < .001, CFI = .86, RMSEA = .051$ (90% CI, .049-.054), SRMR = .049, AIC = 1892.66. This trimmed model was used because it was the most parsimonious without negatively affecting the fit as demonstrated by the AIC difference ($1893.32 - 1892.66 = 0.66$) and the chi-square difference test [$\Delta\chi^2(6) = 11.34, P > .05$]. The final conceptual model is illustrated in **Figure 1**. Unmet vital needs had a significant and positive relationship with bowel-bladder complications, pressure ulcers, and neuro-physiological systems with QoL. Unmet personal development needs

was significantly related to sexual dysfunctions and neuro-physiological systems. Both unmet needs and the neuro-physiological systems factor had a significant association with QoL, accounting for 53% of the variance in QoL.

Discussion

The purpose of this study was to build a conceptual model linking SCI-related needs, secondary complications, and QoL. The results demonstrated that both the vital and personal development SCI-related unmet needs and the neuro-physiological systems factor had a direct and negative relationship with QoL. These results illustrated the importance of SCI-related needs on QoL in adults with SCI, given that they remained significant in the presence of multiple secondary complications variables. This study is therefore the first to test a conceptual model that examines the relationship between SCI-related needs, secondary complications, and QoL.

Pertaining to the relationship between the unmet SCI-related needs and QoL, the significant relationship is consistent with previous research in adults with traumatic brain injury¹¹ and patients diagnosed with cancer.¹² Furthermore, it is important to highlight that unmet vital SCI-related needs had a significant relationship with a number secondary complications factors (ie, neuro-physiological systems, pressure ulcers, and bowel and bladder), whereas unmet personal development SCI-related needs were associated with neuro-physiological systems and sexual dysfunction. These results highlight that vital needs such as housing, attendant care, and transport and personal development needs (eg, emotional support, peer support) are equally important in predicting secondary complications and QoL. The importance of personal development needs has also been argued by Hess and Hough.¹⁹ The authors stated that we need to increase the opportunity for personal development through avenues such as emotional support and peer support in adults with SCI to inform and educate these adults on issues such as their sexuality and sexual function.¹⁹ The results of this study support such statements, as personal development needs were linked with

Figure 1. Final conceptual structural equation model. All paths are significant. Standardized regression coefficients are presented on the directional arrows and a correlation coefficient is on the bidirectional arrow.

sexual dysfunction. Rehabilitation centers and community organizations should focus on both types of needs, as they are essential to help reduce the burden of secondary complications and enhance the QoL of adults with SCI.

Only the neuro-physiological systems factor was associated with QoL. We had expected to see a stronger relationship between sexual dysfunction and bowel-bladder factors with QoL, given that these have been identified as key priorities areas by adults with SCI.²⁰ However, the multivariate relationship showed that only the neuro-physiological systems factor predicted QoL alongside the SCI-related needs. Although this result may seem surprising, the 2 secondary complications of fatigue and sleep problems stood out, as they had the strongest correlation with QoL ($r = -.51$ and $-.47$, respectively)

when we dissected the QoL relationship of each of the components of the neuro-physiological systems factor. This finding is noteworthy because fatigue (and, by association, sleep problems) is rarely mentioned as a key SCI priority,²⁰ despite evidence showing its relationship with QoL in adults with SCI.²¹ In addition, sleep problems and fatigue are often included as items of depression scales.²² Therefore, the relationship between these secondary complications and QoL may be explained by the established relationship between depression/mental health and QoL.^{22,23} More research on this topic is necessary and, as a result, we support Simpson and colleagues' claim that fatigue and sleep problems need greater attention in the SCI literature as they may play an important role in understanding QoL in this population.

Strengths, limitations, and future research

As previously mentioned, this study was the first to use a conceptual model to investigate the relationship among SCI-related needs, secondary complications, and QoL in adults with SCI. The large sample of this study allowed us to test the model with structural equation modeling. This study investigated a number of priority areas in the SCI domain, including bowel, bladder, and sexual dysfunctions,²⁰ and examined the interconnections between secondary complications and other outcomes such as QoL.¹³ Aligning research with the priorities of adults with SCI is important in order to build evidence to better address their main areas of concern. Despite these strengths, there are several limitations in this survey that must be acknowledged. For example, the recruitment process did not allow the randomized selection of participants and the level of participation is uneven across Canada, creating a potential selection bias and a nonresponse bias. Also, the high number of sections and questions may have induced fatigue or boredom in participants, leading to an under- or overestimation of behaviors, beliefs, and knowledge and, consequently, to a potential information bias. (Refer to the first article of this issue for more details about general study limitations.⁹) This study includes a cross-sectional design. Therefore, no causation can be inferred from these results. In addition, QoL was solely

assessed through life satisfaction and represents only one category of QoL. Future research could then attempt to replicate this model using a longitudinal design and multifaceted evaluation of QoL. Future studies could also examine whether this model would be the same in a sample of adults with nontraumatic SCI.

Conclusion

SCI-related needs should not be overlooked, as they appear to be important predictors of secondary complications and QoL in adults with SCI. Rehabilitation and other community programs could consider assessing individuals' vital and personal development needs. This assessment could help tailor programs to meet specific SCI-related needs and subsequently reduce the burden of secondary complications and improve the QoL of adults with SCI.

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