

## THE THOUGHT OF LIVING WITH SPINAL CORD INJURY: HOW AN IMAGINED DISABILITY AFFECTS LIFE SATISFACTION

Derek J. Gaudet<sup>1</sup>, Lisa A. Best<sup>2</sup>, & Najmedden Attabib<sup>3</sup>

<sup>1</sup>M.A., Department of Psychology, University of New Brunswick Saint John (Canada)

<sup>2</sup>Ph.D., Department of Psychology, University of New Brunswick Saint John (Canada)

<sup>3</sup>M.D., Department of Neurosurgery, Saint John Regional Hospital (Canada)

### Abstract

Paralysis resulting from a spinal cord injury is a traumatic, life changing event having both acute and prolonged effects on an individual's life satisfaction (LS). Ethical and methodological considerations make research on the initial impact of paralysis on LS using a patient population difficult. As spinal cord injury and other debilitating injuries can affect anyone, understanding how the average person thinks about living with paralysis caused by spinal cord injury offers important insight to how individuals might the injury during the initial days. Using an online-survey methodology we examined how the average person believes two levels of paralysis, paraplegia and quadriplegia, could affect their overall LS. Four-hundred and eighteen participants completed a demographics questionnaire, the Life Satisfaction Questionnaire-11, and the Big Five Inventory-2. Additionally, the participants indicated the degree to which they thought that their life was worth living. After completing these measures, they were asked to imagine themselves living with paraplegia. While doing this, they re-completed the LiSAT-11 and rated the degree to which they thought life would be worth living. They completed these measures one additional time, after imagining themselves living with quadriplegia. Analyses revealed a significant main effect of tSCI scenario on LiSAT-11 scores. LiSAT-11 scores were considerably lower than the participant's actual LS in both imagined paralysis conditions, being lowest in the quadriplegia condition. The degree to which they believed that their life would be worth living followed the same trend. Although participants believed that their lives were currently worth living, they believed life would be substantially less worth living if they were either paraplegic or quadriplegic. Several personality domains were also found to be associated with these factors. *Discussion:* The results of the present study provide insight into how traumatic spinal cord injury might affect LS and self-worth in, at least, the initial days of injury. The findings could also have implications for early psychological intervention.

**Keywords:** *Life satisfaction, spinal cord injury, disability, paralysis.*

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### 1. Introduction

Life satisfaction refers to an important component of subjective well-being and consist of a global evaluation of one's life as a whole (Diener et al.,1985). Traumatic spinal cord injuries (tSCI) are life changing events that can have a huge impact on life satisfaction. Depending on the severity and location of the injury, the effects of a tSCI can range from minor numbness to complete paralysis of the limbs. In Canada, there are an estimated 43,974 individuals living with a tSCI, with 43% classified as having some level of paraplegia (disability in the lower limbs) and 56% with some degree of quadriplegia (reduced function and sensation from the neck down). Traumatic spinal cord injury most commonly occurs between 15 to 29 years of age (Noonan et al., 2012). This is of particular importance as this age range also corresponds to the years for which an individual is striving to establish their independence and autonomy. These factors are associated with life satisfaction (Cavazos Arroyo, 2013). As severe tSCI removes some degree of a sense of autonomy and independence, at least initially, it is likely that tSCI will have a considerable impact on an individual's life satisfaction when it occurs during those years.

For obvious methodological constraints, most studies examine life satisfaction recovery of individuals living with severe tSCI injuries after discharge. That research has demonstrated that some recovery of life satisfaction occurs following the first two years after discharge (van Leeuwen et al., 2012), but little is understood about the effect that tSCI has on an individual's pre-injury life satisfaction. Obtaining a reliable measure of pre-injury satisfaction is almost impossible, as it would be certainly be influences by their present circumstances. One way to examine the potential effects of tSCI on life satisfaction is to ask a healthy population to compare current aspects of their lives to imagined scenarios in which they are living with a severe tSCI and then compared those results with a sample of individuals living with the condition.

Gerhart et al. (1993) reported that many people strongly believe that their lives would change for the worse and that a satisfactory life would be impossible after a spinal injury. Further, it is interesting to note that the participants in this study were emergency care professionals who deal with traumatic situations on a regular basis. In spite of their personal experience with injury, participants still held negative beliefs about the realities of living with severe disability. When asked to imagine themselves living with a severe tSCI, only 18% of participants could imagine that they would be glad to be alive. In fact, 92% of those actually living with a severe tSCI reported that they were happy to be alive. These results suggest that people hold largely negative and inaccurate beliefs about the well-being and life satisfaction of those living with severe disability. This is important to consider, as these inaccurate beliefs likely affect how individuals process a tSCI event immediately after injury.

Regardless of what we think we “know” about living with severe tSCI, there are numerous famous cases that seemingly contradict our largely negative beliefs. Rick Hansen, Christopher Reeves, and Stephen Hawking are all famous cases of individuals who appear(ed) perfectly satisfied with their lives, even after acquiring a severe disability. In addition to examining the extent to which individuals believe that their overall life satisfaction would decrease as a result of severe tSCI, we were also interested in the possibility that certain personality traits might act as “protective factors” that might allow an individual to imagine a life with severe tSCI, while also maintaining a certain degree of life satisfaction. Here, we consider how basic personality domains (i.e., Extraversion, Agreeableness, Conscientiousness, Neuroticism, and Openness to Experience) are related to how individuals think about living with paraplegia and quadriplegia.

In the present study, we asked people to imagine how satisfied they be with different aspects of their lives if they were living with 1) paraplegia and 2) Quadriplegia. We compared measures of their actual life satisfaction to measures of life satisfaction in each of these scenarios. We hypothesized that a decrease in life satisfaction would occur, and that people would believe that their lives would be less worth living. We also suspected that personality, specifically negative emotionality, would be negatively correlated with perceived life satisfaction, whereas agreeableness, extraversion, conscientiousness, and open-mindedness would be positively correlated with perceived life satisfaction.

## 2. Method

### 2.1. Measures

Participants were required to complete a series of survey's and questionnaires including a demographics section, the Big Five Inventory-2 (BFI-2), the Life Satisfaction Questionnaire-11 (Li-SAT-11). In addition to this, participants were asked to respond on a seven-point Likert scale, ranging from not at all (1) to completely (7), the extent to which they believed life is worth living. The demographics questionnaire asked participants for their age, gender, as well as for information on several other aspects of their life, such as education and vocation, not considered in the present analysis. The BFI-2 measures five domains of personality (Extraversion, Agreeableness, Conscientiousness, Negative Emotionality, and Open Mindedness), as well as three facets of each domain. The BFI-2 has been demonstrated to have excellent psychometric properties (Soto & John, 2017). The Life Satisfaction Questionnaire – 11, asks individuals to indicate the extent to which they are satisfied with 11 areas of their lives on a six-point Likert scale ranging from very dissatisfying (1) to very satisfying (6). The LiSAT-11 has been shown to have good psychometric properties (Post et al. 2012). Participants also responded to a single Likert scale item asking them to rate the degree from not at all (1) to completely (7) that they believed that their life was worth living.

### 2.2. Procedure

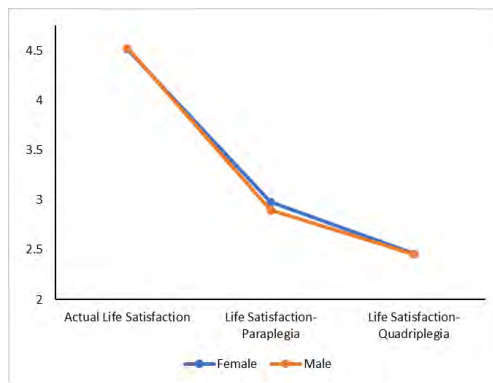
Study participants were directed to the study by one of two methods. In the first method, the study was circulated via social media relying on a snowball sampling approach. In the second method, participants were recruited from psychology courses at the University of New Brunswick. Responses remained entirely anonymous in both situations. All participants were provided with an internet link that they could follow to the study. University students followed a link through a campus research participant recruitment site which automatically granted them a bonus point upon completion of the study. All participants provided informed consent. The study was a repeated measures design divided into 3 phases. In the first phase, they responded to a series of demographics questions which were followed by the BFI-2, LiSAT-11, and a single Likert scale item asking them to rate the extent to which they felt that their life was worth living. This phase acted as a means to collect “baseline information” and always came first. Personality and life satisfaction measures were presented in a randomized order. After completion of the first phase, the experimental manipulation phase took place. Participants were told to imagine a scenario that they were living with a tSCI that resulted in paraplegia. While imagining this, they were then asked to complete the LiSAT-11 in a way that reflected how they would feel about their life satisfaction. After completing the LiSAT-11, they were also asked to rate the extent to which they believed that their life would be worth living. They followed this procedure one final time, while imagining that they were living with Quadriplegia. The order of Paraplegia and Quadriplegia tSCI scenarios was counterbalanced to control for order effects.

### 3. Results

Four hundred and fifty-six respondents provided informed consent and completed the online study. The final sample was 81% female, with a mean age of 20.41 years ( $SD = 4.73$ ). The online study took approximately 30 minutes to complete.

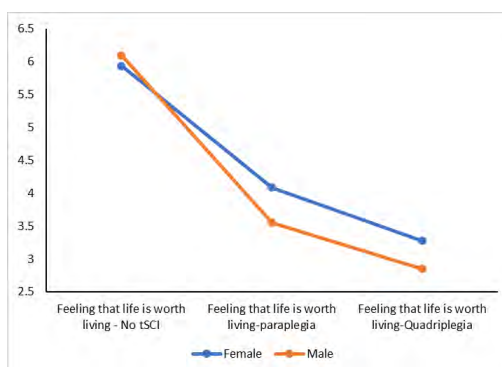
A mixed design 3x2 (tSCI scenario by gender) two-way repeated measures ANOVA was conducted to determine whether people believed that their life satisfaction would decrease following tSCI, as measured by LiSAT-11 scores. The results of this analysis indicate that the assumption of sphericity was not met, therefore the Greenhouse-Geisser correction was used. The Analysis revealed a statistically significant main effect of tSCI scenario on LiSAT scores,  $F(1.83, 759.42) = 628.71, p < .001, \eta^2 = .602$ . Gender was not found to have had an effect on LiSAT-11 scores, nor was the interaction effect between tSCI scenario and gender found to be statistically significant. Pairwise comparisons indicate that life satisfaction decreased with severity of imagined impairment. LiSAT-11 scores were found to decrease as a result of imagining themselves living with tSCI resulting in paraplegia ( $p < .001$ ), and then again when imagining themselves living with quadriplegia ( $p < .001$ ). The decrease from the paraplegia scenario to the quadriplegia scenario was also found to be statistically significant ( $p < .001$ ). Results of the analysis are displayed in figure 1.

Figure 1. Life satisfaction scores by tSCI scenario.



A mixed design 3x2 (tSCI scenario by gender) two-way repeated measures ANOVA was conducted to determine whether people believed that their life would be worth living following tSCI, as measured by responses to a single Likert scale question. Again, the assumption of sphericity was found to be violated, so a Greenhouse-Geisser correction was used. The analysis revealed a statistically significant effect of tSCI scenario on whether participants believed that their life would be worth living,  $F(1.61, 710.40) = 522.43, p < .001, \eta^2 = .542$ . The main effect of gender was not found to be statistically significant. The interaction effect between gender and tSCI scenario was found to be statistically significant,  $F(1.61, 710.40) = 7.639, p = .001, \eta^2 = .017$ . Specifically, feeling that life would be worth living dropped when participants imagined themselves having to live with a tSCI resulting in paraplegia ( $p < .001$ ) or Quadriplegia ( $p < .001$ ). This decrease was also statistically significant between tSCI paraplegia and tSCI Quadriplegia scenarios. Post hoc analysis of the interaction effect revealed a statistically significant difference between genders in feeling that life would be worth living for paraplegia, but no difference in ratings for the No tSCI or tSCI quadriplegia conditions. The results of this analysis are displayed below (figure 2).

Figure 2. Feeling that life is worth living Likert responses by tSCI scenario.



To determine the relationship between personality domains and LiSAT-11 scores, as well as with the life worth living variable, we examined the correlations between each of the BFI domain scale factors and LiSAT-11 scores in each of the tSCI scenarios. Life Satisfaction in the tSCI condition was found to be positively correlated with Agreeableness, suggesting that when imagining oneself living with paraplegia, higher levels of agreeableness are associated with higher levels of predicted life satisfaction. Correlations are presented in the table below. Negative emotionality was the only other personality trait associated with LiSAT scores in the tSCI scenarios. It was found to be negatively correlated with LiSAT scores in both paraplegia and quadriplegia scenarios. Next, we examined the correlations between LiSAT scores in the tSCI scenarios and each personality trait. Many more of the correlations emerged as statistically significant in this analysis, although some of the effect sizes are quite small.

Table 1. Correlations between LiSAT scores / life worth living scores and BFI-2 personality domains.

	Extraversion	Agreeableness	Conscientiousness	Negative Emotionality	Open-Mindedness
LiSAT No tSCI	<b>.327***</b>	<b>.377***</b>	<b>.297***</b>	<b>-.479***</b>	.003
LiSAT tSCI Paraplegia	.043	<b>.118*</b>	.077	<b>-.138**</b>	.043
LiSAT tSCI Quadriplegia	.048	.057	.032	<b>-.130**</b>	.037
Life Worth Living - No tSCI	<b>.291***</b>	<b>.321***</b>	<b>.297***</b>	<b>-.493***</b>	.051
Life worth living - Paraplegia	<b>.093*</b>	<b>.200***</b>	<b>.099*</b>	<b>-.132**</b>	<b>.119*</b>
Life worth living - Quadriplegia	.014	<b>.145**</b>	<b>.107*</b>	<b>-.142**</b>	.086

Note: \*\*\*  $p < .001$ , \*\*  $p < .01$ , \*  $p < .05$

As we can see, in some cases personality variables are related to LiSAT-11 scores and feeling that life is worth living across all three conditions in a similar way. To determine whether there is a statistically significant difference in the effect size of these correlations, Fisher's  $r$ -to- $z$  transformation was used. The results indicated statistically significant differences between some of the correlation effect sizes. In all cases except openness, the effect size of the correlation between personality domains and LiSAT-11 scores was larger for the No tSCI condition, then in the other two scenarios. The difference between the effect size of the correlation between LiSAT-11 scores and personality domains in the No tSCI condition and the same variables in the two tSCI scenarios (where both correlations are statistically significant) were found to be statistically significant. The same pattern was found for the life worth living variable.

#### 4. Conclusions

The present study examined the extent to which individuals believed that their life satisfaction would be impacted by severe disability caused by tSCI. Here, we found that when participants imagined themselves living with paraplegia or quadriplegia, they believed that their overall life satisfaction would decrease. In addition to this, it was shown that the more severe the disability, the greater the decrease in life satisfaction. The drops in life satisfaction were not only statistically significant, but also substantial enough to be quite meaningful. Overall, present life satisfaction ( $M = 4.52$ ,  $SD = .741$ ) dropped from "rather satisfying" to "dissatisfying", when participants were imagining themselves living with paraplegia ( $M = 2.95$ ,  $SD = .985$ ), and almost to "very dissatisfying" when imagining themselves living with quadriplegia ( $M = 2.457$ ,  $SD = .998$ ). Participants also indicated that feeling as though their lives were worth living also depended on whether they were living with a severe disability. On a seven-point Likert scale, from not at all (1) to completely (7), participants indicated a strong belief that their life, at present, was worth living ( $M = 5.97$ ,  $SD = 1.344$ ). When asked to imagine themselves living with paraplegia, there was a considerable drop to just below the theoretical neutral point of "4" ( $M = 3.96$ ,  $SD = 1.786$ ). There was another considerable decrease when imagining themselves living with quadriplegia ( $M = 3.18$ ,  $SD = 1.828$ ). The interesting finding here is not necessarily that people believe that life satisfaction and feeling that life is worth living would decrease under these conditions, but rather, the degree to which they believe that these aspects of their lives would decrease. In feeling that life was worth living, there was also an interesting interaction effect for gender and tSCI scenario. Males and females both felt to the same degree that their lives were worth living without tSCI, but when imagining themselves living with paraplegia, they differed in the extent to which they believed they would still feel that way. Females fell above the theoretical neutral point ( $M = 4.09$ ,  $SD = 1.756$ ), but males fell below it by a considerable amount ( $M = 3.55$ ,  $SD = 1.776$ ), this difference was statistically significant. This difference between genders disappeared when males and female imagined themselves living with quadriplegia, suggesting that such a disability is perceived as

simply too much to handle. This suggests that females believe that they would still be able to manage their lives with paraplegia, but males would be more heavily burdened by the disability. The reason for such a difference might be understood when considering traditional gender roles that could play a role in subconscious processing. Traditional gender stereotypes suggest that males need to be perceived as strong and powerful to first to attract a mate, and then be able to protect and provide for their families. Any form of paralysis would hurt that perception. Although the social climate on traditional gender roles has been changing for some time, there is still evidence of their persistence in society. It's likely that multiple factors play a role in this particular interaction effect, but it will require additional research to determine the cause.

We also examined whether or not there was evidence that how participants perceived that their life satisfaction in tSCI scenarios. When examining the correlations between these variables and the personality domains of the BFI-2, Extraversion, Agreeableness, Conscientiousness, were positively correlated with life satisfaction and Negative Emotionality was negatively correlated with Life satisfaction. Openness was not significantly correlated with life satisfaction. This exact pattern has commonly been found in the literature (Steel et al., 2008). When participants imagined themselves living with either paraplegia or quadriplegia, most of these relationships, except Negative Emotionality and Agreeableness in the paraplegia scenario, disappeared. In terms of agreeableness, this suggests that the more Agreeable and individual is, the better their life satisfaction. This relationship carries over to some extent, although with a statistically significant reduction in effect size, when asked to imagine what their life satisfaction would be if they were living with paraplegia. The relationship, however, disappears in the quadriplegia scenario. In terms of Negative Emotionality, the higher levels of Negative Emotionality are associated with lower life satisfaction in all three scenarios. Although Negative Emotionality maintains a negative correlation with perceived life satisfaction in the two tSCI scenarios, the correlations again show a statistically significant decrease in effect size. This again suggests that personality plays less of a role in perceiving your life satisfaction in the two tSCI scenarios than it does in determining your actual life satisfaction.

In the present study, we examined the extent to which healthy people believed that a tSCI resulting in paraplegia and then quadriplegia would affect their life satisfaction, as well as whether they still believed that their lives would be worth living in those scenarios. This was done as a means to examine the potential effect that a real tSCI injury has on an individual's life satisfaction. A limitation to this method is that none of these participants actually had a tSCI, and many never will. Although this may be true, it is possible for anyone to sustain a tSCI. It is likely safe to assume that the individuals in this sample are not much different from those who actually sustain a tSCI. A better understanding of how the general population thinks about living with tSCI informs us of how those same individuals might process a tSCI injury during the initial days of recovery. This study is a smaller part of a much larger project. The next step will involve comparing these perceptions of life satisfaction to the life satisfaction of individuals who are actually living with paraplegia and quadriplegia caused by a tSCI. In addition to this, the LiSAT-11 also focuses on 11 specific areas of life satisfaction. A closer examination of these areas should reveal which areas people believe will be most impacted by paraplegia and quadriplegia and could inform early intervention strategies to address those concerns.

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