

Development and validation of a quality of life questionnaire for individuals with spinal cord injury

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ABSTRACT

Objective: Create and test the psychometric proprieties of the specific instrument for the quantification of the quality of life in subjects with spinal cord injuries. **Methods:** From the existing consensus methods was chosen the Delphi technique for the creation of the questionnaire and the SF-36 for criteria method. **Results:** The internal consistence was $\alpha=0,827$. The intra and inter evaluators confidence shows itself high by the intra class correlation coefficient and the Brand and Altman test by the difference of average. Can be observed strong correlations between the QVLM and SF-36 in the functional capacity and physical aspects domains and moderate correlation in the health state and emotional aspects domains. There was a significant difference between the four applications of QVLM, demonstrating that the questionnaire is sensible to change. **Conclusion:** The QVLM was created with a suitable methodology and the evaluation of the psychometrics proprieties turn out to be on a valid, reliable, consisting and sensible to changes instrument.

Keywords: Quality of Life, Spinal Cord Injuries, Surveys and Questionnaires

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INTRODUCTION

The World Health Organization Quality of Life (WHOQOL GROUP) of the WHO has defined that Quality of Life (QoL) is *"The individual's perception of his position in life in the context of the culture and value system in which he lives and in relation to his goals, expectations, standards and concerns"*.¹ The interest and applicability of the QoL expression in health sciences derive mainly from the definition of Health assumed by the Constitution of the World Health Organization (WHO) (1948) as *a state of complete physical, mental and social well-being and not simply as absence of disease*. This definition implies that health promotion initiatives are not only aimed at controlling symptoms, reducing mortality or increasing life expectancy, but also at valuing aspects such as well-being and quality of life.

Inactivity after spinal cord injury causes a decrease in muscle mass and aerobic capacity, osteoporotic propensity, renal dysfunction, and also increases the individual at risk for heart disease what consequently reduces these patients' life expectancy.² Functional impairments due to spinal cord injury vary from one individual to another, and performance in the abilities of the activities of daily living are strongly jeopardized, causing the individual to have functional incapacity predisposition and, therefore, several degrees of dependence, especially regarding mobilization, self care, feeding, household activities, among others,³ significantly reducing their quality of life.

The use of questionnaires as assessments is useful, once it standardizes the reproducibility of the proposed measures⁴ and it allows an objective evaluation of subjective symptoms such as pain, anxiety, depression and others. It is a low-cost approach and its use in clinical practice identifies the patients' needs and evaluates the effectiveness of an intervention. In clinical trials, they serve as an instrument for measuring outcomes and are also important as a component of cost-benefit analysis of a treatment.⁶

Choosing the most appropriate instrument for a study is not always straightforward because there is a vast number of these questionnaires and the study results can be influenced by that choice. Regarding patients with spinal cord injury, generic instruments have been used to evaluate their quality of life, however, most of them have been developed for the evaluation of the health of the general population or for specific groups such as the WhoQol^{7,8} and SF36.^{9,10} Considering the particularities of the patient with spinal cord

injury in their new life condition, the need for assessment instruments designed specifically for this group becomes imminent. The understanding of the concepts such as reliability and validity, and the most adequate methods to evaluate the assessment instruments can aid the choice of the best instrument for each investigation.¹¹

OBJECTIVE

The objective of this study was to create and test the psychometric properties of a specific instrument to quantify the quality of life of individuals with spinal cord injury by using an appropriate creation and validation methodology.

METHODS

From the existing consensus methods, the Delphi^{12,13} technique was chosen to create the questionnaire due to the number of participants that were involved, the procedure to be written, the anonymity of the comments, and the available time (about two years) to carry out the study.

Participants

Individuals with spinal cord injury between the C5 and L2 segments according to the American Spinal Injury Association (ASIA)¹⁴ classification participated in this study. Individuals with reading difficulties and patients with other associated neurological diseases were excluded from the study. All participants signed an informed consent form and this study was approved by the local Ethics Committee (nº. 012/2010). This study was developed in a University Hospital from 2010 to 2012. The estimated sample was 72 participants considering the prevalence of 0.18% of spinal cord injury (census 2010)¹⁵ and standard error of 1%.¹⁶

Questionnaire development

A team of epidemiologists (with training in nursing, medicine, psychology, physical education and occupational therapy) and clinical physiotherapists was organized, one of them trained in statistics, who was responsible for selecting the questionnaire, the participants, as well as the construction of the questionnaire, analysis of responses and feedback formulation. All professionals involved had more than eight years of experience in treating patients with spinal cord injury.

For the development of the initial questions, we gathered information from the literature and from a structured interview with 30 individuals with spinal cord injury. Therefore, the questionnaire Quality of life in spinal cord injury 1 (QLSCI1) was developed. All the response options were a 5-point Likert scale (I totally agree – I totally disagree).

After that, a list of specialists in the areas of neurology, neurological physiotherapy, social work, physical education, occupational therapy, nursing and psychology was established, for whom questions regarding the best way to assess quality of life after the spinal cord injury was sent. The questions included:

- which aspects should be approached in the evaluation of an individual with spinal cord injury [for recent events, consider the moment of diagnosis and hospitalization], during rehabilitation (after hospital discharge), after rehabilitation (more than 1 year of injury)]?
- what criteria do you consider important to evaluate the quality of life of an individual with spinal cord injury?
- for a specific questionnaire for individuals with SCI, which domain do you consider indispensable?
- is there any question/matter that, in your professional opinion, cannot be miss in a questionnaire specific to individuals with spinal cord injury?

As the questions and respective answers returned, the team added the specialists' significant considerations to the QLSCI1. The specialists were given feedback and the opportunity to discuss the results of the decisions made by the team.

The QLSCI1 was sent to a group of specialists in neurofunctional physiotherapy for suggestions. There was absolute secrecy of the identifications of these professionals, to assure no change of information between them. They were requested to give suggestions concerning the questionnaire and to make considerations for each question.

Based on the QVLM1 and the changes accepted by the team, the quality of life in spinal cord injury questionnaire 2 (QLSCI2) was developed based on the QLSCI1 and the specialist' suggestions and considerations. This new questionnaire returned to the specialists with a feedback so that they could discuss the results and decisions made by the work team.

After the QLSCI2 return and its adjustments, the work team considered three of the four Delphi stages for consensus defined as "general agreement of the majority" to be sufficient and the final result was the quality of life in spinal cord injury (QLSCIQ) questionnaire.

This questionnaire was tested in the target population for cultural equivalence evaluation (pre-test). Participants in this process reported doubts and suggestions regarding the instrument. All reports were analyzed by the team and, when necessary, adjustments were made. Only then a definitive version of the instrument was obtained. Therefore, the final version is composed of 74 items, divided into five domains: General Health Status (28 items), Social Relationships (11 items), Functional Independence (14 items), Accessibility (4 items), and Emotional Aspects (17 items). The options for answers are: (1) I totally disagree, (2) I partially disagree, (3) I neither agree nor disagree, (4) I partially agree, and (5) I strongly agree. The total score ranges from 74 to 370 points and the higher the score, the worse the individual's quality of life.

Psychometric properties evaluation

Reliability

The QLSCIQ was applied to eligible participants for this phase of the study. For the reliability analysis, three applications of QLSCIQ were necessary: On the first day two evaluators (A and B) applied the questionnaire with a maximum interval of one hour (inter-rater evaluation). Between 24 and 72 hours after the initial application the evaluator A applied the questionnaire again (intra-rater evaluation).

Validity

The generic quality of life questionnaire (SF-36) was used as a validity reference criteria. The validity was accepted if:

- The QLSCIQ and SF-36 scores of the physical and functionality domains reached a Strong correlation ($r \geq 0.7$);

- The QLSCIQ and SF-36 score of the mental health and social aspects domains of the SF-36 reached a weak to moderate correlation ($0 > r < 0.7$).

Responsiveness

The QLSCIQ was applied to individuals with spinal cord injury at four times: initial, after three months, after six months and after nine months of the beginning of the interviews.

Statistical analysis

The Shapiro-Wilk test was used to test the normality distribution. The variables that satisfied the assumptions were presented in mean and standard deviation, whereas the other

variables were presented in median and their respective quartiles (1st and 3rd). The inter-rater consistency was estimated by Cronbach's alpha coefficient. For the intra and inter-rater reliability, the following tests were used: Correlation coefficient - ICC (single random effect) and their respective 95% confidence intervals for each ICC value and the Bland and Altman concordance test were used. In the Bland and Altman concordance test the following tests were included: the mean difference between the measurements (\bar{d}) and their respective 95% confidence intervals (95% CI for \bar{d}), the standard deviation of the mean difference (SD of \bar{d}) and the limits of agreement.

To evaluate the construct validity, the Spearman Correlation Coefficient and its respective 95% confidence intervals were used to correlate the QLSCIQ score and the following domains of the SF-36: physical component, functionality, mental health and social aspects. To obtain the change sensitivity when comparing the different QLSCIQ scores, the Analysis of Variance (ANOVA) for repeated measu-

res was used. The Mauchly sphericity test was applied and, as its assumptions were violated, technical corrections were performed by the Greenhouse-Geisser test. As the F-test was significant, the Bonferroni multiple-comparison test was applied. The floor and ceiling effects were presented descriptively through the percentiles 5 and 95 in the four weeks of application of the instrument. Statistical significance was set at 5% ($P \leq 0.05$). The analyzes were performed by the SPSS® programs (Statistical Package for Social Sciences version 20.0) and MedCalc® (version 11.3.3.0).

RESULTS

The QLSCIQ questionnaire was applied to 72 individuals with spinal cord injury between C5 and T12 segments; 15 (20.8%) were tetraplegic and 57 (79.2%) were paraplegic and the questionnaire application mean time was 3 (SD = 1) minutes. Table 1 shows the characterization data of the studied sample.

Table 1. Sample characteristics (n=72)

Characteristics	
Age (years)	
Mean	40.79
SD	10.99
Gender (n,(%))	
Female	35 (48.6)
Male	37 (51.4)
Time after stroke (years)	
Median	7
1 st quartile	3
3 rd quartile	14
Diagnosis (n,(%))	
C5	4(5.6)
C6	2(2.8)
C7	4(5.6)
C8	5(6.9)
T1	4(5.6)
T2	5(6.9)
T3	3(4.2)
T4	4(5.6)
T5	6(8.3)
T6	4(5.6)
T7	6(8.3)
T8	5(6.9)
T9	5(6.9)
T10	10(13.9)
T11	4(5.6)
T12	1(1.4)

The internal consistency was $\alpha = 0.827$. The intra and inter-rater reliability values were shown to be high by the intraclass correlation coefficient (Table 2), and the Bland and Altman test by the mean difference (Figures 1 and 2).

Strong QLSCIQ correlations with SF36 can be observed in the domains of functional capacity and physical aspects and moderate correlations in the domains of health and emotional aspects. The correlations found between QVLM and SF-36 in the domains of functional capacity, physical aspects, health status and emotional aspects are described in Table 3.

There was a significant difference between the four QLSCIQ applications, demonstrating that the questionnaire is sensitive to change. The values of the variance in the four evaluations (initial, three, six, and nine months) are described in Table 4. The floor and ceiling effects were presented descriptively (Table 5) and no substantial presence of these effects was observed.

DISCUSSION

The aim of this study was to create and test the psychometric properties of a specific instrument for quantifying the quality of life of individuals with spinal cord injury. In the creation stage, adaptations regarding vocabulary were made based on the reports of individuals with spinal cord injury and on the clinical experience of the professionals involved, minimizing possible dualities of interpretation, allowing the questionnaire to be applied as an interview by the evaluator or to be completed by the interviewee himself, without relevant changes in the results, as observed in Jelsness-Jørgensen et al.¹⁷ in the validation of the questionnaire on the quality of life of patients with inflammatory bowel disease (Norwegian version of the short health scale), that also used the SF-36 as a reference criteria.

In the validation of the QLSCIQ questionnaire, the results indicate high intra and inter-rater reliability, and the internal consistency reached $\alpha = 0.827$. This ensures that the QLSCIQ is a valid and responsive instrument for clinical practice and research. Paiva et al.¹⁸ in the validation of the BSIqol questionnaire, obtained an internal consistency of $\alpha = 0.79$.

For the validation, two statistical tests are required: the ICC and the Bland and Altman,¹⁹ once the ICC alone does not provide enough information about the reliability of the measurements due to the variation magnitude influence between subjects and the

Table 2. ICC reliability test and Bland and Altman (n = 72)

	ICC (Single random effect)			Bland and Altman		
	CCI	[CI 95%]	d	CI 95% da d	SD da d	CL 95%
Intra-rater	0.994	[0.990;0.995]	-0.35	-0.67; -.002	1.39	-3.06; 2.37
Inter-rater	0.994	[0.991;0.996]	-0.11	-0.43; 0.21	1.37	-2.79; 2.57

ICC = Intraclass correlation coefficient; CI 95% = 95% Confidence interval; d = mean difference; SD, standard deviation of d; CL = Concordance limits.

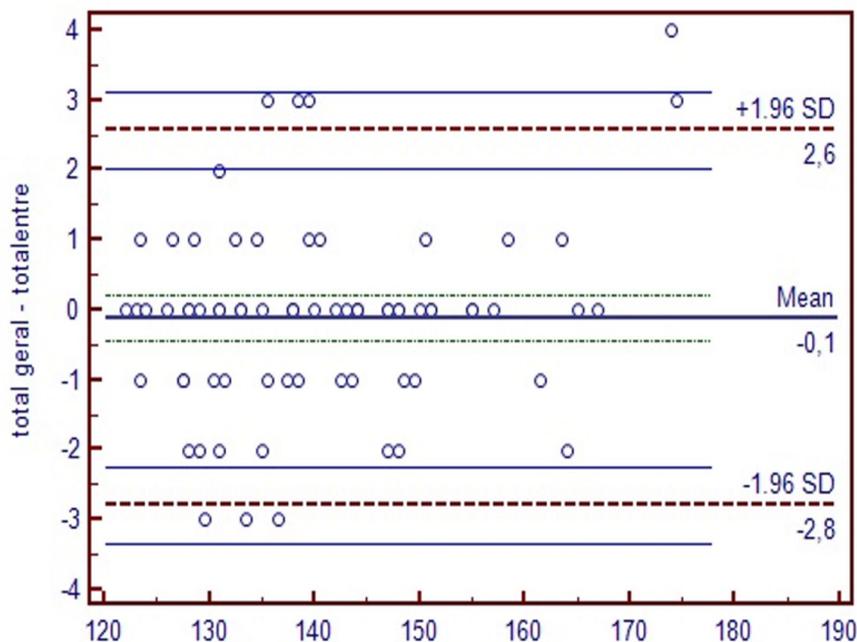


Figure 1. Bland and Altman inter-rater

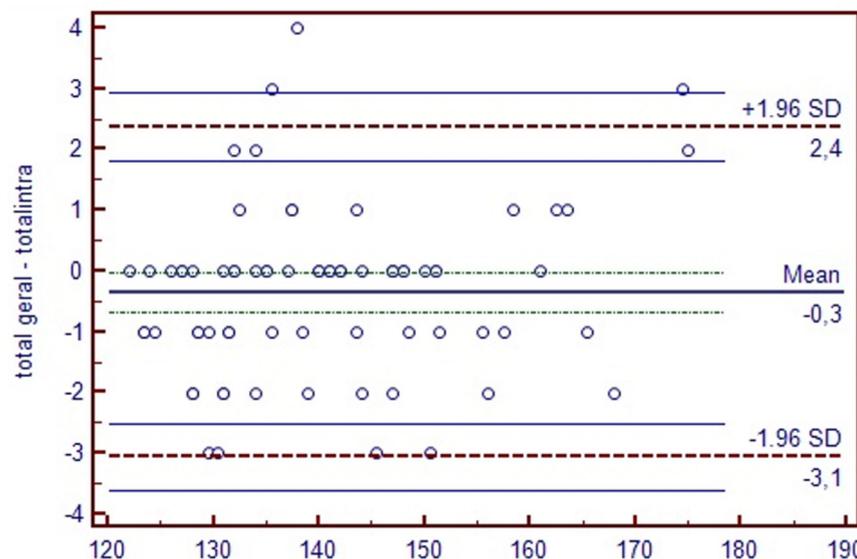


Figure 2. Bland and Altman intra-rater

Table 3. Correlation between QLSCIQ and SF-36 (n = 72)

	Initial	Month 3	Month 6	Month 9
QLSCIQ x SF-36 _{Functionality}	-0.76	-0.72	-0.70	-0.71
QLSCIQ x SF-36 _{Physical aspects}	-0.74	-0.70	-0.70	-0.71
QLSCIQ x SF-36 _{Health status}	-0.39	-0.42	-0.41	-0.41
QLSCIQ x SF-36 _{Emotional aspects}	-0.52	-0.48	-0.56	-0.49

Table 4. QLSCIQ values along the four applications

	Median
QLSCIQ _{initial}	138**
QLSCIQ _{month 3}	140*
QLSCIQ _{month 6}	136#
QLSCIQ _{month 9}	142#**
P	0.023

*, **, # = statistically significant difference P < 0,05.

Table 5. Floor and ceiling effects

	Floor effect (5%)		Ceiling effect (95%)		Total	
	n	%	n	%	n	%
QLSCIQ _{initial}	3	4.2	3	4.2	6	8.3
QLSCIQ _{month 3}	4	5.6	3	4.2	7	9.7
QLSCIQ _{month 6}	4	5.6	3	4.2	7	9.7
QLSCIQ _{month 9}	5	6.9	3	4.2	8	11.1

measurement error. Also, the ICC alone does not show the indication of the measured value or its variations, and it is impossible of being clinically interpreted. On the other hand, the Bland and Altman²⁰ test provides a figure in which the size and amplitude of differences, and the errors or outliers in measurements can be easily interpreted. Moreover, this method presents the values of the confidence interval for the mean difference and the limits of agreement. These data, respectively, will indicate the errors in the measurements and may indicate a clinical interpretation.²¹

For validating the Multidimensional Fatigue Inventory (MFI), Elbers²² used both statistical tests, ICC and Bland and Altman.

Strong correlations ($r > 0.7$) were found between the QLSCIQ and SF-36²³ in the physical component and functionality domains, as well as moderate correlation ($r < 0.7$) in health and emotional domains. Pereira,²⁴ in the validation of the LEFS instrument in Portuguese language, found strong correlations between the LEFS and SF-36 in the physical component domain and moderate to the functional capacity domain. As for the areas of mental health and social aspects, they found weak correlations.

Differences were found between the scores of the first application of the QLSCIQ

when compared to the other three following and between the second and the fourth application. In this study, responsiveness was assessed through analysis of variance of repeated measures since the same people answered the questionnaire along four different times. Cacchio²⁵ in the validation of the Italian version of the LEFS, assessed the effect size responsiveness to the standardized mean response and found values of 1.26 ($P < 0.001$) and 1.38 ($P < 0.001$) respectively.

Terwee et al.²⁶ found 24 definitions for responsiveness and divided them into three groups: The first group defines it as the ability to detect changes in general, the second is the ability to detect important clinical changes, and the third defines it as the ability to detect real changes in the measured domain. The authors also reviewed the different statistical tests used to determine it and found 31 different statistical calculations (including the tests used in this study). The authors concluded that all tests revealed a longitudinal validity or a measure of the treatment effect. Also, there is no standard method for this purpose.

The use of the SF-36 as a reference criteria for questionnaire validation is a limitation of this study. It is known that this instrument was designed to evaluate quality of life in patients

with rheumatoid arthritis and later translated and adapted to Brazil.²³ And because there is no specific instrument to evaluate the quality of life of individuals with spinal cord injury, this instrument was used. Several limitations are found in adopting generic scales for specific conditions, since scale management is made difficult by participants' lack of understanding of the reason for answering such questions.²⁷

Specifically, for questions regarding patients with spinal cord injury, generic expressions such as "climb stairs", "run", or "walk" raise questions about the alternative to be chosen. And the failure to approach specific events of the routine of these patients generates results that do not fit the reality.

For future researches, it is observed that the development and validation of instruments to assess the quality of life or its specific components has become an important gap. However, in order to evidence their measurement properties, these instruments should be repeatedly evaluated in different situations, that is, in different rehabilitation and research centers, and by several researchers.

Concerning clinical practice, the application of this questionnaire will provide a clearer patients evaluation on clinical, surgical and rehabilitation procedures or other forms of intervention due to the revealing demonstration of the quality of life status of these individuals, once it is of a specific tool to evaluate their new condition. The repeated applications of this instrument over time can define the improvement or worsening of the patient with spinal cord injury in different aspects, facilitating to the professional to prescribe the treatment according to the evolution of the patient, in an individualized care, specific to the real needs of the individual.

With the specific evaluation of the quality of life of patients with spinal cord injury, rehabilitation projects as well as other areas of Health Sciences, may focus their efforts to fulfill the quality of life of these individuals, making their social inclusion easier, favoring their employment and improvement of their family economic conditions as well as reducing health system expenditures with diseases due to both physical inactivity and psychological disorders.

CONCLUSION

The QLSCIQ was created with adequate methodology and the evaluation of psychometric properties rated the questionnaire as a valid, reliable, consistent and sensitive tool.

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QVLM - Questionário de Avaliação da Qualidade de Vida de Indivíduos com Lesão da Medula Espinal

Este questionário é sobre como você se sente a respeito de sua qualidade de vida dentro da sua condição de indivíduo com Lesão da Medula Espinal. POR FAVOR, responda a todas as questões. Se você não tem certeza sobre que resposta assinalar, escolha entre as alternativas, aquela que julgar ser mais apropriada.

Estas questões são sobre como você avalia seu ESTADO GERAL DE SAÚDE. Assinale a que mais se enquadra na sua condição hoje.		Discordo totalmente (1)	Discordo parcialmente (2)	Nem concordo e nem discordo (3)	Concordo parcialmente (4)	Concordo totalmente (5)
1	Sinto ou senti dores no último mês.					
2	Sinto dor a maior parte do dia.					
3	Sinto ou senti calafrios, febre no último mês.					
4	A qualidade do meu sono é ruim.					
5	Tive algum tipo de infecção nos últimos 30 dias.					
6	Não tenho ou não posso ter relações sexuais.					
7	Tenho úlcera de decúbito (escaras, feridas...).					
8	Estou acima do peso adequado.					
9	Me sinto doente, independente da minha lesão.					
10	No último mês precisei ser hospitalizado.					
11	Minha pele é desidratada, descamativa.					
12	Uso outra sonda além da de alívio (bolsa coletora, uripen...).					
13	Necessito de ajuda de outra pessoa para esvaziar minha bexiga.					
14	Perco urina na roupa ficando com odor desagradável.					
15	Minha pressão arterial está alterada.					
16	Não evacuo regularmente.					
17	Minha alimentação é inadequada.					
18	Não consigo ingerir pelo menos 1 litro de líquido por dia.					
19	Me sinto doente frequentemente.					
20	Meu tônus muscular (musculatura endurecida) e/ou movimentos involuntários (que ocorrem sem minha vontade) interferem no meu dia-a-dia.					
21	Tenho outros problemas de saúde não resolvidos (luxação, deformidades, ossificações).					
22	As mudanças de decúbito não acontecem a cada 2 horas (por mim ou cuidador).					
23	Nunca recebi orientações de uma enfermeira.					
24	Nunca recebi orientações de uma nutricionista.					
25	Nunca recebi orientações de um fisioterapeuta.					
26	Nunca recebi orientações de um assistente social.					
27	Nunca recebi orientações de um médico.					
28	Não pratico atividade física regular.					
Aqui falaremos um pouco sobre suas RELAÇÕES SOCIAIS. Assinale apenas 1 alternativa para cada questão.		Discordo totalmente (1)	Discordo parcialmente (2)	Nem concordo e nem discordo (3)	Concordo parcialmente (4)	Concordo totalmente (5)
29	Nunca estou rodeado de pessoas queridas.					
30	Não posso e não consigo sair sozinho de casa.					
31	Não me sinto bem com minha família.					
32	Não me sinto bem em lugares públicos.					
33	Não tenho apoio de amigos.					
34	Não tenho apoio de familiares.					
35	Não tenho vida social.					
36	Não participo de grupos (igreja, esportes, escola, clubes).					
37	Não trabalho ou não conseguiria trabalhar mais se quisesse.					
38	Não estudo ou não conseguiria estudar mais se quisesse.					
39	Teria dificuldade em ser readmitido no trabalho para um cargo adaptado às minhas condições.					

Sobre sua INDEPENDENCIA FUNCIONAL, assinale a alternativa que mais se aproxima de como você está hoje, dentro das suas capacidades no dia-a-dia.		Discordo totalmente (1)	Discordo parcialmente (2)	Nem concordo e nem discordo (3)	Concordo parcialmente (4)	Concordo totalmente (5)
40	Não sou capaz de me alimentar sozinho.					
41	Não sou independente com cadeira de rodas.					
42	Não consigo tocar cadeira de rodas.					
43	Eu não consigo dirigir.					
44	Sou totalmente dependente de cuidados de outras pessoas.					
45	Não consigo realizar transferências sozinho					
46	Não sou capaz de me vestir sozinho.					
47	Não sou capaz de cuidar da minha casa sozinho.					
48	Não alcanço os eletrodomésticos, roupas e objetos de minha casa.					
49	Não tomo banho sem necessitar de ajuda.					
50	Tenho dificuldades de transportar objetos.					
51	Minha casa não é adaptada à minha condição.					
52	Não posso me locomover em pé.					
53	Não posso ou não consigo utilizar computador e acessar internet.					
Nesta etapa, avalie quais são as suas dificuldades em se tratando de ACESSIBILIDADE. Assinale 1 alternativa para cada questão.		Discordo totalmente (1)	Discordo parcialmente (2)	Nem concordo e nem discordo (3)	Concordo parcialmente (4)	Concordo totalmente (5)
54	Não consigo entrar na maioria dos lugares em que vou.					
55	Tenho dificuldades de acesso a bares, restaurantes, cinema, festas...					
56	Tenho problemas com transporte.					
57	Tenho dificuldades de me locomover sozinho na cidade.					
Agora precisamos saber a respeito dos seus ASPECTOS EMOCIONAIS. Seja o mais verdadeiro que conseguir, e assinale 1 alternativa para cada questão.		Discordo totalmente (1)	Discordo parcialmente (2)	Nem concordo e nem discordo (3)	Concordo parcialmente (4)	Concordo totalmente (5)
58	Fico triste a maior parte do dia.					
59	Sou infeliz.					
60	Tenho muitos pensamentos ruins quanto ao meu futuro.					
61	Sinto falta do que fazia antes da lesão.					
62	Tenho dificuldades em aceitar minha nova condição.					
63	As pessoas são melhores do que eu.					
64	Sou incapaz.					
65	Vivo constantemente com medo.					
66	Sinto-me prisioneiro.					
67	Sou muito nervoso na maior parte do tempo.					
68	Estou insatisfeito com minha vida.					
69	Tenho vergonha da minha condição.					
70	Sinto-me mal quando as pessoas me olham na rua.					
71	Sinto-me rejeitado.					
72	Brigo bastante em casa.					
73	Tenho dificuldade financeira devido a minha nova condição de vida.					
74	Sinto-me um peso para minha família.					
Pontuação:						
Pontuação máxima do questionário = 370 (considerando todas as alternativas 5)						
Pontuação mínima do questionário=74 (considerando todas as alternativas 1)						
Avaliando qualidade de vida:						
Quanto maior a pontuação PIOR a qualidade de vida						
Quanto menor a pontuação MELHOR a qualidade de vida						