







## Satisfaction and meaning in life for individuals with traumatic spinal cord injury

### *Satisfação e o sentido da vida para pessoas com lesão medular traumática*

 Fabiana Faleiros Santana Castro<sup>1</sup>,  Karina de Fátima Bimbatti<sup>2</sup>,  Adriane Aparecida Gonçalves de Carvalho<sup>2</sup>,  Mariele Lenhari Gonçalves<sup>2</sup>,  Filipe Gustavo Lopes<sup>3</sup>,  William Schutt<sup>4</sup>

#### ABSTRACT

**Objective:** To analyze meaning in life, satisfaction with life, and the influence of sociodemographic variables in Brazilians with Spinal Cord Injury (SCI). This was a quantitative, cross-sectional, and descriptive study. Participants: Adults with traumatic SCI. **Methods:** The data were collected through the Survey Monkey platform using the Meaning in Life Questionnaire and the Satisfaction With Life Scale; the sample was composed of adults 18 years old or older with Traumatic SCI. **Results:** Most of the participants were male (75.5%), with a mean age of 36.22. The average score on the Satisfaction With Life Scale was 21.26, which corresponds to the Slightly satisfied category. The mean scores, respectively, for search and presence of meaning in life were 22.61 and 25.32, indicating that most participants find life meaningful even though they don't explicitly search for meaning. There were significant associations between satisfaction with life and the meaning in life. **Conclusion:** In the rehabilitation process for people with Traumatic SCI, the assessment of satisfaction and the meaning of life must be managed together along with other psychological variables. Considering the complex life context of people suffering from a Traumatic SCI, there is a need for both holistic and individualized understanding during the rehabilitation process.

**Keywords:** Spinal Cord Injuries, Personal Satisfaction, Brazil

#### RESUMO

**Objetivo:** Analisar o sentido da vida, a satisfação com a vida e a influência de variáveis sociodemográficas em brasileiros com Lesão Medular Traumática. Trata-se de um estudo quantitativo, transversal e descritivo com participantes adultos com LM traumática. **Método:** Os dados foram coletados por meio da plataforma Survey Monkey, utilizando o Questionário de Sentido da Vida e a Escala de Satisfação com a Vida; a amostra foi composta por adultos de 18 anos ou mais com LM traumática. **Resultados:** A maioria dos participantes era do sexo masculino (75,5%), com média de idade de 36,22 anos. A pontuação média na Escala de Satisfação com a Vida foi de 21,26, o que corresponde à categoria pouco satisfeito. As pontuações médias, respectivamente, para busca e presença de sentido na vida foram 22,61 e 25,32, indicando que a maioria dos participantes acha a vida com sentido, embora não busque esse sentido explicitamente. Houve associações significativas entre satisfação com a vida e o sentido da vida. **Conclusão:** O processo de reabilitação de pessoas com LM traumática deve conter a avaliação da satisfação e do sentido de vida em conjunto com outras variáveis psicológicas. O contexto de vida das pessoas que sofrem de uma LM traumática é complexo e há uma necessidade de compreensão holística e individualizada durante o processo de reabilitação.

**Palavras-chave:** Traumatismos da Medula Espinal, Satisfação Pessoal, Brasil

<sup>1</sup> Professora, Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo - EERP-USP

<sup>2</sup> Acadêmica, Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo - EERP-USP

<sup>3</sup> Enfermeiro, Rede Sarah de Hospitais de Reabilitação / Belo Horizonte

<sup>4</sup> PhD Student in Clinical Psychology, Case Western Reserve University

#### Corresponding

Fabiana Faleiros Santana Castro  
E-mail: [fabifaleiros@eerp.usp.br](mailto:fabifaleiros@eerp.usp.br)

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## INTRODUCTION

Traumatic SCI is characterized by a sudden impairment of the structures of the spinal canal, resulting in motor, autonomic, and sensory alterations. It has psychological and social repercussions, and SCI is often considered among the worst conditions that can affect a human being. When acquiring a traumatic SCI, individuals develop coping strategies in accordance with their life experiences and the relationship(s) they establish with their environment. They usually pass through several phases, including shock, negation, recognition, and adaptation.<sup>1,2</sup> The implications and impacts of traumatic SCI on the lives of young people can change the degree of meaning they find in life and their overall satisfaction with life. SCI can also interfere directly with their coping capacity and success in rehabilitation.<sup>3</sup>

Satisfaction with life depends on judgments made by the individual himself/herself, according to the criteria of the person; it is a cognitive and critical process that involves a comparison of one's own life with the standard that one considers appropriate.<sup>4</sup> Meaning in life is described as a positive variable indicative of well-being, which facilitates coping and adaptation and always considers the point of view of the individual. Therefore, there is no universal meaning for life, just as there is no formula for finding that meaning.<sup>5</sup> While satisfaction with life reflects, in part, individual well-being subjectively and considers aspects such as happiness, positive affect, and state of mind,<sup>6</sup> meaning in life can be understood within positive psychology as the main motivational factor for human beings, as it is directly related to self-determination, positive perception of life, the future and oneself, and the integrative acceptance of adversity.<sup>7</sup>

Despite the relevance and implications of emotion in the process of rehabilitation for people with Traumatic SCI, few Brazilian studies analyze meaning and satisfaction with life in this population. This gap in the literature is noteworthy considering the unique social and demographic characteristics of Brazil.

## OBJECTIVE

The objective of the present study is to analyze meaning in life, satisfaction with life, and the influence of sociodemographic variables for Brazilians with SCI. This project is essential to support future policies and interventions, promote the valuation of life, and improve rehabilitation for young people with SCI. Ultimately, this research could have far-reaching effects not only for the individuals suffering from SCI and their families but for Brazilian society at large.

## METHOD

This is a quantitative, cross-sectional, and descriptive study. It was approved by the Ethics and Research Committee (ERC) at the University of São Paulo (USP) according to Resolution 466/12 of the National Council of Ethics in Research of the Health Department, which deals with ethics in research with human beings under the protocol No. CAAE: 89766518.6.0000.5393.

For data collection, the Ed Diener Satisfaction With Life Scale (SWLS) was used. This scale was validated for the Brazilian

Portuguese and consists of five statements, answered on a Likert scale from one to seven (ranging from "totally disagree" to "strongly agree").<sup>4,8</sup> To evaluate meaning in life, Michael F. Steger's Meaning in Life Questionnaire (MLQ) was used, which is composed of 10 statements also on a Likert scale from one to seven (ranging from "absolutely false" to "absolutely true").<sup>5</sup>

For the characterization of the study participants, a form developed from the Core Dataset and by the International Spinal Cord Society (ISCOS) was used<sup>9</sup> in addition to sociodemographic data, such as name, date of birth, rehabilitation service attended, level of the SCI, city and state, schooling, profession, and family income. No information about the severity of the injury nor the support of the ventilator at hospital discharge according to ISCOS was provided, as the questionnaire was self-administered and Brazilian participants were not able to answer in-depth questions about SCI. The instruments selected for data collection were transferred to the Survey Monkey platform, generating a virtual version. This virtual version was previously approved in a pre-test with four people.

Participants were contacted through a voluntary Neurorehabilitation research group register for participation in SCI studies. To disseminate the study, specific links were created for each data collection medium (e-mail and message sending application), which were sent to the 700 registered volunteers.

Links to the virtual questionnaire were available for three months, from March to May 2018, until the minimum sample of 200 participants was reached. Participants who did not complete the questionnaire were excluded (15 participants) as were those outside the inclusion criteria (two participants) due to the cause of their injury. Thus, the present study obtained a sample of 200 adult participants with traumatic SCI.

To analyze descriptive statistics, absolute and relative frequency calculations were performed for qualitative variables, and calculations of central tendency (mean, median) and variability (minimum, maximum, and standard deviation) were performed for quantitative variables. The values of means (m) and medians (md) were presented with the respective standard deviations (sd). The average time to complete the online form was generated by the SurveyMonkey® platform and the categorization of SWLS and MLQ data was suggested by the authors.<sup>4,5</sup>

Level of satisfaction with life was rated as "extremely dissatisfied" for participants who scored between five and nine, "dissatisfied" for those between 10 and 14, "Slightly dissatisfied" for those between 15 and 19, "neutral" for those at 20, "Slightly satisfied" for those between 21 and 25, "satisfied" for those between 26 and 30, and "extremely satisfied" for participants between 31 and 35.<sup>4</sup>

The MQL is composed of two subscales, Presence of Meaning and Search for Meaning, and four possible classifications: a) Score above 24 in both subscales (participant has a presence of meaning and searches for meaning in life); b) Score above 24 in the Presence subscale and below 24 on the Search scale (participant has a presence of meaning, but does not search for meaning in life); c) Score below 24 in the Presence subscale and above 24 in the Search subscale (participant has no presence of meaning, but searches for meaning in life); d) Score below 24 in both subscales

(participant has no presence of meaning and does not search for meaning in life).<sup>5</sup>

Statistically, authors used bilateral tests for categorical variables and Fisher's exact test. For comparisons of numerical variables, the Kruskal-Wallis non-parametric test was conducted. A p-value of 0.05 was the threshold for statistical significance.

## RESULTS

The sample was composed of 200 traumatic SCI participants, aged between 18 and 60 years, with a mean age of 36.22 years old (SD 9.17) and mean age at the time of injury of 26.30 years (SD 8.89). The mean time of injury was 10.66 years (SD 98.99), with a median of 8.12 (n= 199). 74.5% of the sample were male and 25.5% female. Table 1 shows the sociodemographic data of participants.

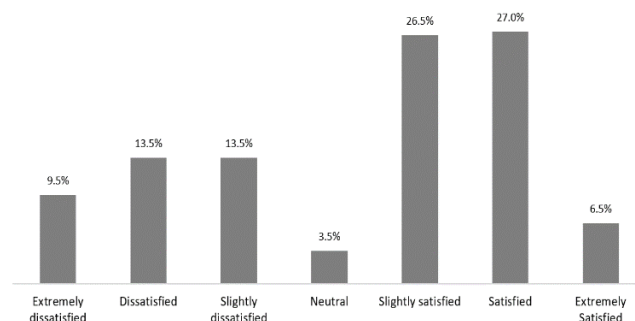
**Table 1.** Distribution of participants according to bio-sociodemographic data, (n= 200), Brazil, 2019

	Frequency	%
<b>Schooling</b>		
Elementary school (1 <sup>st</sup> to 4 <sup>th</sup> grade, complete or incomplete)	3	1.5
Elementary school (5 <sup>th</sup> to 8 <sup>th</sup> grade, complete or incomplete)	17	8.5
High school, complete or incomplete	78	39.0
Higher education, complete or incomplete	83	41.5
Specialization/Master's Degree and PhD	19	9.5
<b>Occupation</b>		
Retired or Beneficiary (medical leave, pensioner)	132	66.0
Employed or freelance	34	17.0
Student	17	8.5
Unemployed	12	6.0
Others	5	2.5
<b>Family income</b>		
Up to \$258.92 (1 MW*)	23	11.5
More than \$258.92 up to \$776.773 (More than 1 up to 3 MW*)	66	33.0
More than \$776.773 up to \$1294.62 (More than 3 up to 5 MW*)	45	22.5
More than \$1294.62 up to \$1812.47 (More than 5 a up to 7 MW*)	17	8.5
More than \$1812.47 up to \$2589.24 (More than 7 up to 10 MW*)	15	7.5
More than \$2589.24 (More than 10 MW*)	12	6.0
Not informed and "I don't know"	22	11.0
<b>Cause of Injury</b>		
Traffic accident	102	51.0
Firearm	41	20.5
Diving	24	12.0
Other (Riding, fall of objects, surgery, etc.)	16	8.0
Fall	16	8.0
Melee weapon	1	0.5
<b>Type of injury</b>		
Paraplegic	104	52.0
Tetraplegic	94	47.0
Did not know how to inform	2	1.0

\*MW = Minimum Wage in Brazil. Reference value: R\$ 954.00 = \$258.92 USD

Regarding the level of SCI, 47% had cervical involvement (tetraplegia), 46.5% thoracic, 5% sacral (paraplegia) and 1.5% did not know. Besides that 13% of participants did not claim to have attended any rehabilitation service and another 13% claimed to have performed only physiotherapy or occupational therapy. The majority of the participants (60%) were satisfied with their lives, although only 33.5% of them were extremely satisfied or satisfied (Fig. 1).

Mean life satisfaction was 21.26 (SD7.6 2), which corresponds to the classification of "Slightly satisfied." The average satisfaction with life was 21.26 (SD 7.62), a score that represents the classification "Slightly satisfied." The minimum and maximum scores obtained were five and 35, respectively.



**Figure 1.** Distribution of participants according to life satisfaction (n= 200), Brazil, 2019

No associations were found between satisfaction with life and other sociodemographic variables such as gender (p= 1.000, Fisher's exact test), income (p= 0.891, Fisher's exact test), and type of injury (p= 0.696, Fisher's exact test).

Table 2 shows associations between the time of traumatic SCI and Satisfaction with life, together with the mean, median, and standard deviation of the time of injury in months. There was a statistically significant difference between the time of injury and satisfaction with life (p= 0.026).

**Table 2.** Mean, median, standard deviation, of the injury time according to the level of satisfaction with life (n= 199)

Satisfaction with life	M	SD	MD	min	max	P-value*
Extremely dissatisfied	89.79	83.66	61.87	10.13	372.33	
Dissatisfied	90.30	43.19	84.20	17.20	207.97	
Slightly dissatisfied	142.32	119.87	68.93	18.20	359.10	
Neutral	99.68	39.10	115.60	28.37	150.10	0.026
Slightly satisfied	143.71	92.37	111.60	18.20	345.93	
Satisfied	125.83	111.30	84.20	17.20	602.60	
Extremely satisfied	191.25	112.78	145.07	63.83	435.23	

\* Kruskal-Wallis

Table 3 shows the distribution of participants according to meaning in life through the two MLQ subscales. The mean of the Search subscale was 22.61 (SD 7.81) and the mean of the Presence subscale was 25.32 (SD 7.31). Also, there was no evidence of associations between sociodemographic variables as gender (p= 0.866, Fisher's exact test), income (p= 0.497, Fisher's exact test), and type of injury (p= 0.996, Fisher's exact test) and meaning in life.

**Table 3.** Distribution of participants according to meaning in life (n= 200), Brazil, 2019

Meaning in life	Frequency	%
Has search and presence of meaning in life	43	21.5
Has presence but no search for meaning in life	74	37.0
Has no presence but searches for meaning in life	51	25.5
Has no search nor presence of meaning in life	32	16.0



Table 4 indicates the associations between time of injury and meaning in life, together with the mean, median, and standard deviation of the time of injury in months. No statistically significant difference was found between the time of injury and meaning in life. There was, however, an association between the SWLS and MQL, shown in Table 5. An association was found between the SWLS and MQL ( $p$ -value = 0.0005); thus, satisfaction with life is associated with meaning in life.

**Table 4.** Mean, median, and standard deviation of the injury time according to the level of meaning in life ( $n=199$ ), Brazil, 2019

Meaning for life	M	DP	SD	min	max	P-value*
Has search and presence of meaning in life	127.99	91.72	92.30	17.20	359.10	0.083
Has presence but no search for meaning in life	150.15	114.01	115.60	19.23	602.60	
Has no presence but searches for meaning in life	105.45	81.17	85.23	17.20	327.70	
Has no search nor presence of meaning in life	112.94	90.27	80.13	10.13	372.33	

\* Kruskal-Wallis

**Table 5.** Associations between the participants' classifications according to meaning in life and satisfaction with life ( $n=200$ ), Brazil, 2019

Meaning for life / Satisfaction with life	Has search and presence of meaning in life	Has presence but no search for meaning in life	Has no presence but searches for meaning in life	Has no search nor presence of meaning in life	P-value **
Extremely dissatisfied	1	0	10	8	0.0005
Dissatisfied	5	4	11	7	
Slightly dissatisfied	7	3	12	5	
Neutral	0	4	2	1	
Slightly satisfied	10	20	13	10	
Satisfied	17	33	3	1	
Extremely satisfied	3	10	0	0	

\*\* Fisher's exact test

## DISCUSSION

With some exceptions, this study replicates previous sociodemographic findings for individuals with SCI. Most people with SCI have paraplegia, which corresponds to thoracic, lumbar, and sacral level injuries, and the current data confirm results from previous studies.<sup>10,11</sup> However, these findings are not homogeneous, as some research has indicated a greater prevalence of tetraplegia (cervical level).<sup>12,13</sup> In addition, the majority of participants were male and young.

Like previous national and international studies, current data show that SCI most commonly affects men about 30 years old.<sup>14,15</sup> Some authors attribute this profile to the fact that young and masculine individuals are more likely to engage in reckless behaviors.

The primary causes of traumatic SCI are traffic accidents, followed by violence (firearms) and sports (diving). This applies to Brazil, and Brazilian authors highlight accidents with

motorcycles or cars and violence such as firearm injuries as main causes of SCI.<sup>10,14</sup> In the current study, only 8% of causes were attributed to falls, while national and international literature suggests there is a higher incidence of falls resulting in SCI due to the aging of populations; older age is associated with a reduction of causes related to violence as well.<sup>11,14</sup>

This result may be related to the age of the participants in this research, which was between 18 and 60 years old. Our findings suggest that SCI prevention campaigns in Brazil should consider educational measures for the prevention of violence in and out of traffic. SCI can have tremendous financial implications at both an individual and societal level. The majority of participants received an annual income of less than \$776.773 (three Brazilian minimum wages, considered in most of Brazil to be lower middle class), which parallels other research, in which around 60% of participants made less than three minimum wages (MW).<sup>16</sup>

According to the latest Brazilian demographic census, 75% of the families with a disabled family member live on less than three MW.<sup>17</sup> This reality is likely a consequence of acquired disabilities since most of the people affected by SCI stop contributing to their family income after their accident.<sup>2,18</sup> Also, it is common in Brazil for at least one family member to assume the role of a caregiver after a loved one is significantly injured. This caregiving family member often must stop working, which has consequences not only for the family but for the country.

In these cases, Brazil loses taxpayers and important members of its labor force, highlighting the need for improved rehabilitation services. By adopting as an objective the development of maximum autonomy and the inclusion of people with disabilities in the labor market, both individuals and society at large will benefit.

The majority of participants attained complete or incomplete higher education, making the current sample distinct from other studies. In previous research, the average level of schooling has been lower, with the most subjects failing to complete elementary education.<sup>17,19</sup> Our findings also contrast with data from the Brazilian Institute of Geography and Statistics, which reports that the average educational level of people with disabilities is lower than that of the typical Brazilian population.<sup>20</sup>

Previous studies have already pointed to the possibility of greater access to online research, by people with higher education,<sup>21-23</sup> which may be because individuals with higher levels of education generally have better access to health information and research and, consequently, register more often for voluntary participation in medical research. Although 69.3% of households have Internet access in Brazil, there are still 21,247 thousand households without such access.<sup>16</sup>

While the majority of this study's participants had incomplete or complete higher education and were of an economically active age, 66% of individuals with SCI are retired or receive some type of benefit. In the typical Brazilian population, according to the IBGE, men aged 35 to 39 represent the highest level of occupation.

Around 86.5% of the total number of men working are in this age group. This is significant because individuals of this age who acquire a SCI typically stop working and stop making social security contributions. The importance of investing in rehabilitation policies is evident, as such policies will facilitate

disabled people's return to the labor market, rather than keeping them on social security; as a bonus, work plays an important role in personal achievement.<sup>18</sup>

The average life satisfaction in this study was 21.26, which corresponds to "slightly satisfied." In another Brazilian study, in which the same scale was used on a sample of doctors, average life satisfaction was 23.5, which fits the same Likert classification and underscores the adverse working conditions of this professional class.<sup>8</sup> In addition, the average SWLS score was 21.1 in a survey of patients with Parkinson's disease from several European countries.<sup>24</sup>

This similarity may be due to the dimensions assessed by the SWLS, which broadly conceptualize satisfaction with life, including past, future, profession, family life, and religious experiences. Thus, SCI does not represent less satisfaction with life compared to other populations that also experience stressors (but that do not have health problems) and populations that present significant loss of autonomy such as Parkinson's.

When analyzing SWLS responses, most participants were slightly satisfied or satisfied with life. However, since satisfaction with life is directly related to health, work, social relationships, and autonomy,<sup>25</sup> the frequencies of participants who were extremely dissatisfied and dissatisfied with life are also notable. Thus, future research should assess the variables associated with these emotional aspects in addition to investments in rehabilitation centers that provide more comprehensive care.

In a Swedish study, the SWLS was applied to elderly people with SCI. This sample's mean score was 20.7, and no associations were found between satisfaction with life and demographic variables such as gender and the type of injury.<sup>26</sup>

Despite the higher rate of Swedish development relative to Brazil, both countries showed no associations between satisfaction with life and sociodemographic variables. This may be related to aspects of personal coping such as resilience, defined as an adaptation process involving behaviors, thoughts, and actions that can be learned and developed over time in response to traumatic events.<sup>27</sup> Since acquiring a SCI can be traumatic, resilience has the potential to favor the individual's overcoming, preserving, and adapting to this new condition.

Unlike these studies, SCI research in the United States associated life satisfaction with several demographic, social, functional, and clinical characteristics, such as gender, number of readmissions in the last year, years since the injury, disability, mobility, occupation, and social integration.<sup>28</sup> Some of these variables were related to the rehabilitation service attended, as about 13% of participants did not attend any rehabilitation service and another 13% only attended physiotherapy. Much of these individuals, in other words, were not receiving the full benefits of rehabilitation services, and their life satisfaction was suffering as a result.

By better analyzing, reporting, and structuring the support networks of people with SCI (which could involve utilizing a multidisciplinary mental health team and supporting social/work relations, for example), rehabilitation services could provide many additional benefits for SCI patients. No associations were found between the level of SCI injury (i.e. paraplegia and quadriplegia) and satisfaction with life. Another

study that assessed quality of life in this population similarly found no association between these variables, suggesting that life satisfaction is complex and that variables such as race, culture, and resilience also need to be investigated.<sup>29</sup> On the other hand, a Norwegian study of individuals with incomplete SCI identified significantly greater life satisfaction among the participants who were exercising regularly.<sup>30</sup>

Another study with Americans with SCI suggested that impairment (level of injury) contributed indirectly to life satisfaction, through its impact on motor disability.<sup>28</sup> In this sense, the literature shows that the severity of the injury is not related to psychological well-being, but to the perceived loss of physical skills and the generation of meaning and purpose in life, which are variables directly related to positive adaptation after SCI.<sup>31</sup> It is therefore imperative that the rehabilitation process is thorough and not prematurely discontinued, and that it incorporates the expertise of multiple professionals.

An association was found between injury time and life satisfaction. This finding replicates previous studies, in which the same association was found with other satisfaction scales and may be related to the ability to adapt to new conditions over time.<sup>17</sup> Rehabilitation plays an important role in the coping process, since the establishment of goals and the resumption of lost activities, as well as the reduction of dependence, leads to a consequent improvement in quality of life.<sup>32,33</sup> These factors are directly related to life satisfaction as perceived by the individual. Considering the self-criterion of this variable, results confirm that individuals with SCI can rebuild and redefine their lives.

Most participants experienced meaning in their lives, but most did not actively search for meaning. One interpretation of this finding, according to the MQL, is that participants generally experienced meaning in their life, but did not explore such meaning.<sup>34</sup> This finding is important for people with SCI, since having a well-defined life purpose is considered a component of psychological well-being.<sup>35</sup> However, not searching for meaning in life, when analyzed in isolation, can be problematic; some studies indicate that searching is related to the perception of a future goal and can motivate the finding of strategies to achieve their goal,<sup>36</sup> and can represent a protective factor that promotes resilience.<sup>37</sup> In addition, 16% of the participants did not search for or have meaning present in their lives. Even though they did not represent the majority, this is a notable portion of the sample since having a defined meaning protects against suicide. Therefore, the rehabilitation process must find ways to help these people find meaning.

Most of the sample felt their lives were meaningful but did not search for meaning: search and presence scores were 22.61 and 25.32, respectively. These scores are lower than those found in adolescents without SCI in another Brazilian survey, in which averages were 25.88 and 27.00, respectively.<sup>38</sup> In another international study, the MQL was administered to undergraduate psychology students and a correlational analysis between search and presence was conducted.

The authors concluded that, for some people, more searching may decrease presence, but at the same time, searching was correlated with extensive cognitive measures.<sup>39</sup>

These studies all indicate the importance of considering sample populations, as the presence of SCI probably influences how presence and search for meaning relate. Experiencing

meaning in life and searching for a satisfactory life are needs important during adulthood. Even in the face of changing roles such as a decline in physical capacity and an accumulation of interpersonal losses, people can understand their experiences and their purposes.<sup>40</sup> In this sense, measures are necessary both for the prevention of SCI, which mainly affects young people, and for the establishment of rehabilitation programs that consider psychological variables. This study shows that further research is needed to investigate variables that make up the complex context of rehabilitation for people with SCI.

There were several notable limitations to this study. Aside from typical cross-sectional constraints, collecting data through a virtual platform may have limited the participation of a portion of the Brazilian population without access to the Internet. As such, future studies should include data from people without Internet access. Future studies should also attempt to include more in-depth information about the severity and nature of the participants' SCI.

## CONCLUSION

This study shows that variables related to mental health for those who have suffered traumatic SCI, such as life satisfaction and meaning in life, are associated. The rehabilitation process for people with SCI should incorporate an evaluation of overall satisfaction and meaning in life, in addition to other important psychological variables.

The environmental and broader life context for those with traumatic SCI is complex and more research is needed to understand this debilitating condition. Future studies should aim towards developing more individualized and holistic treatment, focusing on improving the autonomy and the integrated participation of people with SCI in society.

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