# Central neuropathic pain: implications on quality of life of spinal cord injury patients

Dor neuropática central: implicações na qualidade de vida de pacientes com lesão medular

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#### **ABSTRACT**

BACKGROUND AND OBJECTIVES: Pain is one consequence of spinal cord injury, added to micturition and intestinal disorders, changes in sexuality and reproduction, and social and family issues. Understanding pain and its interference with quality of life may help professionals assisting patients to find the most adequate way to control neuropathic pain. Investigators of the International Association for the Study of Pain have evaluated articles from 1975 to 2007 and have observed that the least studied subject was spinal cord pain. This study aimed at evaluating quality of life of patients with neuropathic pain induced by traumatic spinal cord injury.

**METHODS**: This is a quantitative, transversal, exploratory and descriptive research.

**RESULTS:** Seventy percent of patients with neuropathic pain classify it as severe to intense, with scores above five in the visual analog scale. Males, aged between 30 and 39 years, married, with injury by fall, paraplegic, with incomplete injury and injury time between one and five years are those most suffering with pain. Quality of life is better for patients with complete spinal cord injury and who were wounded by firearm. Patients with fecal incontinence have referred worse quality of life and also stated that pain impaired their lives.

**CONCLUSION:** It was observed that patients referring more severe pain have worse quality of life and social relations, which address personal relations, sexual life and support from friends. **Keywords:**Pain, Quality of life, Rehabilitation, Spinal cord injury.

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#### **RESUMO**

JUSTIFICATIVA E OBJETIVOS: A dor é uma das consequências da lesão medular, somada às disfunções miccional e intestinal, alterações na sexualidade e reprodução, às questões sociais e familiares. Conhecer a dor e sua interferência na qualidade de vida pode fazer com que o profissional que assiste o pacienteconsiga seguir o caminho mais adequado para o controle da dor neuropática. Estudiosos da Associação Internacional para Estudo da Dor, pesquisaram artigos de 1975 até 2007, e observaram que o tema menos estudado é sobre dor em lesão medular. O objetivo deste estudo foi avaliar a qualidade de vida de pacientes com dor neuropática decorrente de lesão medular traumática.

**MÉTODOS**: Trata-se de uma pesquisa quantitativa, transversal, exploratória e descritiva.

RESULTADOS: Setenta por cento dos pacientes com dor neuropática a caracterizam como forte a intensa, com valor superior a cinco na escala analógica visual. Homens, com idade entre 30 e 39 anos, casados, lesão por queda, paraplégicos, com lesão incompleta e tempo de lesão entre um e cinco anos são os que mais sofrem com dor. A qualidade de vida é melhor em pacientes com diagnóstico de lesão medular completa e que tiveram o ferimento por arma de fogo como causa da lesão. Pacientes com incontinência fecal referiram pior qualidade de vida e também afirmam que a dor atrapalha sua vida.

**CONCLUSÃO:** Observou-se que pacientes que referiram maior intensidade de dortêm pior relação em qualidade de vida e no fator social, que aborda relações pessoais, vida sexual e apoio que recebem dos amigos.

Descritores: Dor, Lesão medular, Qualidade de vida, Reabilitação.

# INTRODUCTION

Traumatic spinal cord injury (TSCI) is a major public health problem in Brazil, where a high number of patients have spinal cord injury (SCI). Spinal cord trauma is frequent and diversified in gender, age, causes, injury level and trauma severity, affecting younger people, predominantly males in the peak of productivity<sup>1-4</sup>.

TSCI is spinal cord aggression which may cause partial or total volunteer mobility and/or sensitivity (tactile, painful, deep) loss, in addition to impairment of urinary, intestinal, respiratory, circulatory, sexual and reproductive systems<sup>5</sup>.

TSCI is consequence of death of spinal cord neurons and interruption of communication between axons originating in the brain and their connections. This rupture of communica-

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tion between brain and all other body parts below the injury determines different changes observed in TSCI patients<sup>6</sup>.

These patients, in addition to motor and sensory impairment, to different complications such as neurogenic bladder and bowels, sexual dysfunction, spasticity, pressure ulcer and central neuropathic pain, also suffer with social and environmental issues, because many of them are prevented from working, enjoying life and studying. Among such complications, neuropathic pain is the one impairing the most patients' quality of life (QL)<sup>7</sup>.

Pain management, from evaluation to intervention, joint and interdisciplinary work to develop knowledge in different therapeutic modalities looking for effective early and late treatment of pain and attempts to better understand and manage pain, especially with the use of drugs and/or non-pharmacological alternatives, such as physiotherapy, psychotherapy, thermotherapy and/or acupuncture have been suggested as specialized, multiprofessional and interdisciplinary care.

Pain is a consequence of SCI, added to urinary and intestinal disorders, to skin integrity maintenance, changes in sexuality and reproduction, to social and family issues. Everything is related to the need for dynamic and specialized care.

Chronic pain, especially chronic neuropathic pain patients, often experience dramatic changes in their lifestyle, which result in persistent distress caused by pain, with repercussions on the way they perceive QL. In addition to distress caused by pain, there are frustrations of ineffective therapies, of the wide variety of poorly enlightening tests and unsatisfactory answers of the health team with regard to the nonexistence of a precise diagnosis or that little can be done to relieve them<sup>1</sup>. Understanding pain and its interference with QL may lead professionals assisting patients to find a more adequate way and to associate modalities to control neuropathic pain.

Researchers of the International Association for the Study of Pain (IASP), have searched articles published from 1975 to 2007, with 4525 articles on pain, and have observed that the least studied subject is SCI pain, with just 1% of articles throughout the period¹. It is described that pain is one of the most common problems experienced by individuals who suffered TSCI. Although loss of functionality is considered the most significant consequence of this injury, pain may determine the ability or not of individuals to fully return to their activities⁴.

QL studies have shown that pain may negatively interfere with SCI individuals, changing their mood, self-perception of the difficulty of coping with injury-related problems and may also cooperate for the appearance of incapacities<sup>8</sup>. In Brazil, QL has been studied, especially in chronic health-disease conditions and as adjuvant in the analysis of therapeutic interventions<sup>9</sup>.

There are virtually no specific studies with people suffering SCI and, in Brazil, there are still few studies relating QL and SCI. However, consequences of this trauma, as well as social difficulties, are realities in the lives of these people and may interfere with their QL<sup>10-12</sup>.

Patients with pain have daily life losses higher than those that,

although with SCI, do not have associated chronic pain. Early identification and adequate treatment of these injuries contribute for better QL of such people<sup>13</sup>.

Pain evaluation and management, as well as performing daily activities with the highest possible level of independence and recovery of functionality are critical for SCI patients. Relieving them from this distress is one of the goals of the interdisciplinary team involved with the complex process of reestablishing biopsychosocial balance and reintegration to society of people with spinal cord injury<sup>9,14</sup>.

Understanding QL perception of people with TSCI-related pain may subsidize interventions during the rehabilitation process to maintain or improve QL of those people.

In light of the above, this study aimed at evaluating QL of patients with TSCI-related central neuropathic pain.

#### **METHODS**

This is an exploratory and descriptive, cross-sectional study, with quantitative approach, developed in two institutions, being one a government teaching hospital with specialized institute to assist people with locomotor system disorders, located in the city of São Paulo. The other is a large private charitable institution also located in the city of São Paulo. Sample of this study was made up of the selection of patients of both institutions, which are reference in the treatment of SCI.

Inclusion criteria were people with TSCI, of both genders, with minimum age of 18 years, with complete or incomplete injury for at least one year, without treatment for pain and having concluded the Rehabilitation Program, in conditions to verbally answer questions, being assisted by the institutions where the study was carried out.

Exclusion criteria were people with TSCI for less than one year, with associated brain injury, such as brain trauma and other diseases affecting cognitive and speaking functions, and patients referring no painful sensation or that had never felt pain. We have contacted 62 patients with TSCI assisted in the institutions. From these, nine had no pain and were excluded, totaling a sample of 53 individuals.

Data collection has included interviews with patients by applying McGill Pain Evaluation scale to measure subjective characteristics of pain referred by patients, a visual analog scale (VAS) for pain intensity evaluation, where zero meant totally without pain and 10 with extreme pain, and the QL tool World Health Organization Quality of Life Assessment Instrument (WHOQOL-BREF) short version of WHOQOL-100, which basically evaluates what is important for people and what interferes with their QL<sup>14</sup>.

WHOQOL-BREF QL tool provides a profile based on scores of the four domains of the tool: physical, psychological, social and environmental relations, where the higher the scores, the better the QL. Data were associated and correlated according to relevant variables and were analyzed according to injury level and extension, duration and external cause. The relationship between McGill and WHOQOL was measured with Pearson correlation coefficient; Student *t* test was used

for categorical variables when there were two categories, and ANOVA or Kruskal-Wallis tests were used for more than two categories. Significance level was 5%.

This study was approved by the Institutional Research Committee under protocol 123.195/2012.

# **RESULTS**

Participants were, in their majority, males aged between 30 and 49 years, married, retired, with high school education, SCI caused by falls, paraplegic with incomplete injury, with between one and five years after injury (Table 1).

**Table 1.** Socio-demographic and clinical characteristics of traumatic spinal cord injury patients. São Paulo, 2013

Categories	n	%
Gender		
Male	40	75.0
Female	13	25.0
Age (years)		
18 to 29	6	12.0
30 to 39	15	28.0
40 to 49	15	28.0
50 to 59	9	17.0
60 or above	8	15.0
Marital status		
Single	17	32.0
Married	32	60.0
Other	4	8.0
Education		
Illiterate	1	2.0
Able only to sign the name	2	4.0
Basic	17	32.0
High school	18	34.0
Graduation	11	21.0
Post-graduation	4	7.0
Occupation		
Retired	29	55.0
Employed	16	31.0
Autonomous	5	9.0
Unemployed	3	5.0
Etiology		
Fall	24	45.0
Traffic accident	16	31.0
Firearm wound	8	15.0
Other (trauma)	5	9.0
Neurological level		
Paraplegic	32	60.0
Tetraplegic	21	40.0
Type of injury		
Incomplete	31	58.0
Complete	22	42.0
Time of spinal cord injury (years)		
1 to 5	16	31.0
6 to 10	15	28.0
11 to 15	5	9.0
16 to 20	9	17.0
Above 20	8	15.0

With regard to pain intensity, 70% of neuropathic pain patients have characterized it as severe to intense, with VAS scores above five. Male patients with SCI, aged between 30 and 39 years, married, retired, with basic education, injury etiology by fall, with incomplete injury and injury time between one and five years are those most suffering with pain, scoring it above five in VAS, characterizing severe to intense pain (Table 2).

QL evaluation was p≥0.05, that is, there has been no statistically significant difference between variables and QL.

Patients referring higher pain intensity had worse QL in the social domain, which addresses personal relations, sexual life

**Table 2.** Neuropathic pain intensity in variables related to spinal cord injury. São Paulo, 2013

Categories	VAS≤5 Total %	Pain>5	
Gender	10(a) 70	Total %	
Male	15 (94)	25 (67.5)	
Female	1 (6.0)	12 (32.5)	
Age (years)	1 (0.0)	12 (02.0)	
18 to 29	2 (12.5)	4 (11.0)	
30 to 39	4 (25.0)	11 (30.0)	
40 to 49	5 (31)	10 (27.0)	
50 to 59	2 (12.5)	7 (19.0)	
60 or above	3 (19.0)	5 (13.0)	
Marital status	0 (10.0)	0 (10.0)	
Single	4 (25)	13 (35)	
Married	12 (75)	20 (54)	
Other	0 (0)	4 (11)	
Education	S (S)	. ()	
Illiterate/able only to sign name	2 (12.5)	1 (3)	
Basic	5 (31.25)	12 (32)	
High-school	8 (50)	10 (27)	
Graduation/post-graduation	1 (6.25)	14 (38)	
Occupation	(= = 7	()	
Unemployed	1 (6.25)	2 (5.5)	
Retired	10 (62.5)	19 (51)	
Autonomous/employed	5 (31.25)	16 (43.5)	
Etiology			
Firearm wound	2 (12.5)	6 (16)	
Fall	8 (50)	16 (44)	
Traffic accident	6 (37.5)	10 (27)	
Other(trauma)	0 (0)	5 (13)	
Neurological level			
Paraplegic	13 (81.25)	28 (75)	
Tetraplegic	3 (18.75)	9 (25)	
Type of injury			
Incomplete	8 (50)	23 (62)	
Complete	8 (50)	14 (38)	
Time of spinal cord injury (years)			
1 to 5	4 (25)	12 (32)	
6 to 16	6 (37.5)	9 (25)	
11 to 15	1 (6.25)	4 (11)	
16 to 20	4 (25)	5 (13)	
Above 20	1 (6.25)	7 (19)	

VAS = visual analog scale.

and support of friends.

In our study, when comparing McGill scale scores and WHO-QOL descriptors, it was observed that QL is better for patients with complete SCI as compared to patients with incomplete SCI, as well as it is better in patients wounded by firearm (Table 3).

Patients with fecal incontinence have reported worse QL in

**Table 3.** Relationship between studied variables and McGill Scale. São Paulo, 2013

	McGill n descriptors		McGill index pain	
	Mean	p value	Mean	p value
Visual analog scale		<0.01		<0.01
<=5	9.06		17.12	
>5	14.54		32.05	
Gender		0.08		0.28
Male	12.20		26.30	
Female	15.00		31.38	
Reason for accident		0.49		0.35
Firearm wound	15.37		36.50	
Fall	12.08		23.60	
Traffic accident	12.72		28.00	
Other	13.25		30.25	
Fecal incontinence		0.88		0.88
No	12.94		27.35	
Yes	12.71		28.07	
Urinary incontinence		0.60		0.09
No	12.53		24.35	
Yes	13.28		31.12	
Spasticity		0.51		0.38
No	13.23		28.88	
Yes	12.263		25.15	
Pressure ulcer		0.25		0.45
No	13.62		28.96	
Yes	12.00		25.83	
Type of injury		0.31		0.22
Complete	12.04		24.59	
Incomplete	13.48		29.64	
Occupation		0.53		0.50
Unemployed	14.00		26.66	
Retired	12.33		26.63	
Employed	14.07		30.07	
School education		0.31		0.26
Basic	12.70		26.45	
College	14.46		32.73	
High school	11.77		24.44	
Marital status		0.57		0.21
Married	12.56		25.50	
Single	13.38		30.66	
Injury level		0.42		0.47
Tetraplegic	12.19		25.71	
Paraplegic	13.34		28.75	

the physical aspect, as well as with regard to the issue that states that pain negatively impacts their lives as compared to McGill scale scores and WHOQOL descriptors.

With regard to gender, age, marital status, type of injury, school education, time of injury, spasticity, urinary incontinence and pressure ulcer, results show that these variables neither increase or decrease the effect of pain on OL.

After statistical analysis of QL data of these patients, it was observed that scores are better for patients with complete SCI as compared to patients with incomplete SCI, as well as they are better for patients with SCI caused by firearm wound.

#### DISCUSSION

Data from different countries show that 85% of TSCI patients with pain, especially neuropathic pain (found in 57.6% of studied patients), are males, with mean age of 33.2 years and major trauma etiology is FAW and traffic accidents<sup>15</sup>.

A Swiss study specifically with neuropathic pain patients has shown prevalence of 26% in a group of 402 TSCI patients<sup>15</sup>. This study has not found correlation between pain and age, level and type of injury (complete or incomplete), only that 13% of patients had pain at injury level and 27% below injury. A different study carried out in the United States (USA) with SCI patients, has not found statistically significant correlation between pain prevalence and demographic aspects and medical variables, including injury level <sup>16-18</sup>.

Significantly larger differences were found in individuals with chest injury, who had higher prevalence of musculoskeletal pain (92%) as compared to the general group (72%). There were no differences in neuropathic pain prevalence between different injury levels<sup>19</sup>.

In the follow-up of individuals of previous study along five years, there has been report of association of neuropathic pain below injury level and tetraplegia, and this pain was present in 50% of tetraplegic patients as compared to 18% of paraplegic patients<sup>4</sup>. However, data presented by other authors do not confirm such result.

Turner et al.<sup>19</sup> have described lower prevalence of neuropathic pain at injury level in those with injuries between C1 and C4 as compared to those with injuries between L1 and S4 or S5, but have not found statistic correlation between both parameters. A study in the United Kingdom has not confirmed any association between injury level and prevalence of pain.

In England, a study on chronic pain in general after spinal cord injury, where a questionnaire was applied, had as result that 79% of patients have reported pain, with 39% describing it as severe. The comparison of groups referring pain and those not referring pain, using Chi-square test, has shown that complete injury causes more chronic pain (p<0.05) and increases pain severity (p<0.05). Chronic pain had significant impact on daily activities and was a major factor for unemployment (18%) and depression (39%)<sup>4</sup>.

In the USA, other study on general pain after SCI has indicated prevalence of approximately 80% of this pain. The study states that it is not more common in males or females, as

well as that there are no differences in pain intensity between genders<sup>20</sup>. Differences in age groups were also not found. However, the study observes that pain prevalence is higher in individuals who were working when suffered SCI, in those with higher school education and paraplegia, incomplete injury and caused by violent acts, confirming our study data, where falls had the highest prevalence of pain<sup>18</sup>.

Two different studies on the subject state that 30% of painful patients after spinal cord injury classify this pain as severe/intense<sup>5</sup>.

A longitudinal 5-year study had surprising results when relating pain to psychological factors and physical incapacity. Pain was the third most frequently mentioned difficulty associated to SCI, second only to motor incapacity and sexual dysfunction, respectively<sup>4</sup>. Painful patients have also shown further mood changes, according to Kessler and Mroczek Mood Inventory, as compared to painless patients<sup>4</sup>.

Using Hammell Chronic Pain Classification<sup>8</sup>, a study has evaluated the relation between pain intensity and interference with daily life activities, including work and social activities, and results have shown that chronic pain has originated incapacity in 28.7%, with 12.3% of patients classified as level III (high incapacity – moderately limiting pain) and 16.4% with level IV (high incapacity – severely limiting pain).

According to authors, post-SCI pain should be adequately managed since it interferes with the rehabilitation process, affecting the development of daily life activities and QL. In addition, it significantly interferes with mood, leading to depression and even to suicide<sup>9,17</sup>.

After SCI, QL is affected and the search for a new balance, according to new limitations, is the goal. However, when the injury is followed by complications, especially neuropathic pain, this balance is difficult to be reached. Major complications decreasing QL scores were neuropathic pain, spasticity, neurogenic bladder and bowels. These complications have further negative effects on QL<sup>9</sup>.

Other researchers also state that painful patients have the lowest scores in all QL domains. However, an American study shows that social aspects, in that country, are not so affected. A justification might be characteristics of social support networks, especially with regard to health, which are more appreciated in that country.

In this context, it is important to evaluate these aspects involved in pain of SCI patients so that management and interventions for its relief are based on patients' cognitive behavior. Added to this, the best treatment is based on the understanding of pain mechanisms<sup>4</sup>.

# CONCLUSION

Our results have shown that TSCI patients referring higher pain intensity had worse relation with QL, especially in the social aspect. It was observed that QL is better in patients with complete SCI and is also better in patients who had FAW as cause of SCI. Patients with fecal incontinence have referred worse QL in the physical aspect and have stated that pain impairs their lives.

Our results should be analyzed considering study limitation, which was small sample size, which may limit generalization of findings. In addition, one cannot neglect the difficulty of discussing this study data due to the inability of comparing data with previous results, because the literature is very limited with regard to pain and QL after SCI.

So, our results point to the need of other investigations on the subject, which may support initiatives aiming at the implementation of intervention and support programs which are effective to manage neuropathic pain in TSCI patients, aiming at improving their QL.

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