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Long-term psychosocial outcomes in the population with spinal cord injury living in the community

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Tesi Doctoral dirigida pels doctors:

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*"When we are no longer able to change a situation
- we are challenged to change ourselves."*

*"Quan no podem canviar la situació a la què ens enfrontem,
- Ens trobem davant el repte de canviar-nos a nosaltres mateixos".*

*"Cuando no podemos cambiar la situación a la que nos enfrentamos,
- nos encontramos ante el reto de cambiarnos a nosotros mismos".*

Viktor E. Frankl

1. Abstract

Joan Saurí Ruiz.

Long-term psychosocial outcomes in the population with spinal cord injury living in the community. Doctoral thesis 2017. Department of Neuropsychology, Institut Guttmann, Badalona (Barcelona), Spain.

The main aim of this thesis was to determine to what extent injury-related variables, sociodemographic characteristics or psychosocial aspects are predictive of the adjustment process among community-residing individuals with spinal cord injury (SCI). A secondary objective of this thesis was to adapt and validate into Spanish language two specific questionnaires for spinal cord injury individuals to assess pain and coping strategies respectively. This thesis is divided into three separate studies:

- I. Psychometric evaluation of the Spanish version of the MPI-SCI.
- II. Adaptation and validation of the Spanish version of the Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL CSQ-S).
- III. Depression in individuals with traumatic and non-traumatic spinal cord injury living in the community.

Participants of paper I, II and III were individuals with SCI living in the community and attended an annual comprehensive hospital check-up. Paper I encompassed 126 individuals with an SCI and chronic pain (CP) and proved that the Spanish version of the West Haven-Yale Multidimensional Pain Inventory for Spinal Cord Injury (MPI-SCI-S) is a reliable and valid measure. Its subscales have a prediction capacity over the person's perception of well-being. In paper II 511 subjects with SCI were included in the study and the results verified the robustness of the structure of the Spanish version of the Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL CSQ) and coping strategies contributed to the prediction of outcomes related to disability adaptation such as quality of life or social participation between others. In paper III a total of 831 individuals with traumatic or non-traumatic SCI were enrolled in the study and a higher prevalence of probable major

depressive disorder (PMDD) was noted for individuals with a non-traumatic SCI. The results demonstrated that risk factors between the two etiologies did not differ greatly. Female sex, chronic pain, and lower levels of/difficulties in participation were associated with the presence of PMDD.

This thesis concludes that chronic pain is related to psychological distress and may be a risk factor to adaptation to disability in the population of SCI individuals. Also, provided further support for the positive effect of psychological factors such as coping strategies during adaptation to physical disabilities. Several demographic and injury-related aspects that may coexist at a greater frequency among individuals with NT-SCI seem to indicate a greater emotional vulnerability and a bigger difficulty in adapting to disability. Female sex, chronic pain, environmental barriers to participation, low mobility, low occupation score, and difficulty integrating socially should alert clinicians to an increased risk for a negative long-term outcome such as depression. Finally, the results of this thesis highlights the need for greater awareness and implementation of treatment aims to empower individuals with SCI and facilitate their smooth reintegration into the community.

Keywords: spinal cord injury, rehabilitation, adjustment, quality of life, community integration, coping, depression, anxiety and pain.

2. Resumen

Joan Saurí Ruiz.

Resultados psicosociales a largo plazo en la población de personas con lesión medular que viven en la comunidad. Tesis doctoral 2017. Departamento de Neuropsicología, Institut Guttmann, Badalona (Barcelona), España.

El objetivo principal de esta tesis fue determinar en qué medida las variables relacionadas con la lesión, las características sociodemográficas o los aspectos psicosociales tienen capacidad predictiva del proceso de adaptación en los individuos con lesión medular que viven en la comunidad. Un objetivo secundario de esta tesis fue adaptar y validar al Español dos cuestionarios específicos para individuos con lesión medular para evaluar el dolor y las estrategias de afrontamiento respectivamente. Esta tesis se divide en tres estudios separados:

- I. Evaluación psicométrica de la versión española del Inventario Multidimensional del Dolor para la Lesión Medular (MPI-SCI).
- II. Adaptación y validación de la versión en Español del Cuestionario de Estrategias de Afrontamiento Relacionadas con la Lesión Medular (SCL CSQ-S).
- III. Depresión en individuos con lesión medular traumática y no traumática que viven en la comunidad.

Los participantes de los estudios I, II y III fueron individuos con lesión medular (LM) que viven en la comunidad y asistieron a la valoración integral periódica en el hospital. El estudio I comprendió a 126 individuos con LM y dolor crónico y demostró que la versión en español del Inventario Multidimensional del Dolor para la LM (MPI-SCI-S) es una medida fiable y válida. Sus subescalas tienen una capacidad de predicción sobre la percepción subjetiva de bienestar. En el estudio II se incluyeron 511 sujetos con LM y los resultados verificaron la robustez de la estructura de la versión española del Cuestionario de Estrategias de Afrontamiento relacionadas con la LM y las estrategias de afrontamiento contribuyeron a la predicción de resultados relacionados con la adaptación a la

discapacidad como la calidad de vida o la participación social entre otros. En el estudio III se incluyó un total de 831 individuos con LM traumática o LM no traumática y se observó una mayor prevalencia de probable trastorno depresivo mayor en individuos con LM no traumática. Los resultados demostraron que los factores de riesgo entre las dos etiologías no difirieron mucho. El sexo femenino, el dolor crónico, y los niveles más bajos de/dificultades en la participación se asociaron con la presencia de probable trastorno depresivo mayor.

Esta tesis concluye que el dolor crónico está relacionado con el malestar psicológico y puede ser un factor de riesgo para la adaptación a la discapacidad en la población de individuos con LM. Además, aporta mayor reconocimiento del efecto positivo de factores psicológicos como las estrategias de afrontamiento durante la adaptación a las discapacidades físicas. Varios aspectos demográficos y relacionados con la lesión que pueden coexistir con mayor frecuencia entre los individuos con LM no traumática parecen indicar una mayor vulnerabilidad emocional y una mayor dificultad para adaptarse a la discapacidad. El sexo femenino, el dolor crónico, las barreras ambientales a la participación, la baja movilidad, la baja ocupación y la dificultad para integrarse socialmente deberían alertar a los clínicos sobre un mayor riesgo de resultados negativos a largo plazo como puede ser la depresión. Finalmente, los resultados de esta tesis remarcan la necesidad de una mayor concienciación e implementación de los objetivos de tratamiento dirigidos a capacitar a las personas con LM y facilitar su reinserción en la comunidad.

Palabras clave: lesión medular, rehabilitación, ajuste, calidad de vida, integración comunitaria, afrontamiento, depresión, ansiedad y dolor.

3. Resum

Joan Saurí Ruiz.

Resultats psicosocials a llarg termini en la població de persones amb lesió medul·lar que viuen a la comunitat. Tesis doctoral 2017. Departament de Neuropsicologia, Institut Guttmann, Badalona (Barcelona), Espanya.

L'objectiu principal d'aquesta tesi va ser determinar en quina mesura les variables relacionades amb la lesió, les característiques sociodemogràfiques o els aspectes psicosocials tenen capacitat predictiva del procés d'adaptació en els individus amb lesió medul·lar que viuen a la comunitat. Un objectiu secundari d'aquesta tesi va ser adaptar i validar a l'Espanyol dos qüestionaris específics per a individus amb lesió medul·lar per avaluar el dolor i les estratègies d'afrontament respectivament. Aquesta tesi es divideix en tres estudis separats:

- I. Avaluació psicomètrica de la versió Espanyola de l'Inventari Multidimensional del Dolor per la Lesió Medul·lar (MPI-SCI).
- II. Adaptació i validació de la versió en Espanyol del Qüestionari d'Estratègies d'Afrontament relacionades amb la Lesió Medul·lar (SCL CSQ-S).
- III. Depressió en individus amb lesió medul·lar traumàtica i no traumàtica que viuen a la comunitat.

Els participants dels estudis I, II i III van ser individus amb lesió medul·lar (LM) que viuen a la comunitat i van assistir a la valoració integral periòdica a l'hospital. L'estudi I va comprendre a 126 individus amb LM i dolor crònic i va demostrar que la versió en espanyol de l'Inventari Multidimensional del Dolor per a la LM (MPI-SCI-S) és una mesura fiable i vàlida. Les seves subescales van mostrar una capacitat de predicció sobre la percepció subjectiva de benestar. En l'estudi II es van incloure 511 subjectes amb LM i els resultats van verificar la robustesa de l'estructura de la versió espanyola del Qüestionari d'Estratègies d'Afrontament relacionades amb la LM i les estratègies d'afrontament van contribuir a la predicció de resultats relacionats amb l'adaptació a la discapacitat com la qualitat de vida o la participació social entre d'altres. En l'estudi III es va incloure un total de 831 individus amb

LM traumàtica o LM no traumàtica i es va observar una major prevalença de probable trastorn depressiu major en individus amb LM no traumàtica. Els resultats van demostrar que els factors de risc entre les dues etiologies no van diferir molt. El sexe femení, el dolor crònic, i els nivells més baixos de / dificultats en la participació es van associar amb la presència de probable trastorn depressiu major.

Aquesta tesi conclou que el dolor crònic està relacionat amb el malestar psicològic i pot ser un factor de risc per a l'adaptació a la discapacitat en la població d'individus amb LM. A més, aporta major reconeixement de l'efecte positiu de factors psicològics com les estratègies d'afrontament durant l'adaptació a les discapacitats físiques. Diversos aspectes demogràfics i relacionats amb la lesió que poden coexistir amb més freqüència entre els individus amb LM no traumàtica semblen indicar una major vulnerabilitat emocional i una major dificultat per adaptar-se a la discapacitat. El sexe femení, el dolor crònic, les barreres ambientals a la participació, la baixa mobilitat, la baixa ocupació i la dificultat per integrar-se socialment haurien d'alertar als clínics sobre un major risc de resultats negatius a llarg termini com pot ser la depressió. Finalment, els resultats d'aquesta tesi remarquen la necessitat d'una major conscienciació i implementació dels objectius de tractament dirigits a capacitar les persones amb LM i facilitar la seva reinserció a la comunitat.

Paraules clau: lesió medul·lar, rehabilitació, ajustament, qualitat de vida, integració comunitària, afrontament, depressió, ansietat i dolor.

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In Memoriam

Professor Paul Kennedy, a British Clinical Psychologist of international renown, and distinguished academic and productive researcher, unexpectedly passed away on 13 September 2016.

5. List of publications

This thesis is based on the following papers, which are referred to in the text by corresponding Roman numerals.

- I. Soler MD, Cruz-Almeida Y, **Saurí J**, Widerström-Noga EG. Psychometric evaluation of the Spanish version of the MPI-SCL. *Spinal Cord*. 2013 Jul;51(7):538-52. doi:10.1038/sc.2013.21. Epub 2013 Apr 23. PubMed PMID: 23608807; PubMed CentralPMCID: PMC3803149.
- II. **Saurí J**, Umaña MC, Chamarro A, Soler MD, Gilabert A, Elfström ML. Adaptation and validation of the Spanish version of the Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL CSQ-S). *Spinal Cord*. 2014 Nov;52(11):842-9. doi:10.1038/sc.2014.44. Epub 2014 Apr 29. PubMed PMID:24777162.
- III. **Saurí J**, Chamarro A, Gilabert A, Gifre M, Rodriguez N, Lopez-Blazquez R, Curcoll L, Benito-Penalva J, Soler D. Depression in Individuals With Traumatic and Nontraumatic Spinal Cord Injury Living in the Community. *Arch Phys Med Rehabil*. 2017 Jun;98(6):1165-1173. doi:10.1016/j.apmr.2016.11.011. Epub 2016 Dec 16. PubMed PMID: 27993583.

6. List of abbreviations

SCI	Spinal Cord Injury
ASIA	American Spinal Injury Association
ISNCSCI	International Standards for Neurological Classification of Spinal Cord Injury
CNS	Central Nervous System
AIS	ASIA Impairment Scale
T-SCI	Traumatic Spinal Cord Injury
NT-SCI	Non Traumatic Spinal Cord Injury
AD	Autonomic Dysreflexia
UTI	Urinary Tract Infections
NBD	Neurogenic bowel Dysfunction
QOL	Quality Of Life
DVT	Deep Vein Thrombosis
PE	Pulmonary Embolism
HO	Heterotopic ossification
UTI	Urinary Tract Infections
SAC	Stress Appraisals and Coping
ICF	International Classification of Functioning, Disability and Health
PMDD	Probable Major Depressive Disorder
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders
MPI-SCI	Multidimensional Pain Inventory for Spinal Cord Injury
SCL CSQ	Spinal Cord Lesion-related Coping Strategies Questionnaire
WHOQOL	World Health Organization Quality of Life
CIQ	Community Integration Questionnaire
PHQ-9	Patient Health Questionnaire 9

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8. Introduction

8.1 Background

Even though spinal cord injuries are documented as far back as 3000 to 2500 years B.C.¹ it was not until after the Second World War that the majority of persons sustaining a spinal cord injury (SCI) came to survive long-term. This was partly thanks to Sir Ludwig Guttman, who established a spinal unit at Stoke-Mandeville, the United Kingdom, and introduced multidisciplinary staffing². Care and treatment rapidly progressed thereafter, as did knowledge about complications. Sustaining an SCI is, of course, always devastating for the person and his family, but research has made it possible for such patients to live a life of nearly normal length today. Although an SCI is most often associated with loss of motor and sensory functions, it is often complicated by secondary complications such as pain, spasticity, incontinence, pressure sores, urinary tract infections, neurogenic bowel dysfunction and sexual difficulties.

Spinal cord injuries are classified worldwide according to the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI)³. The international consensus to use this classification has facilitated comparisons between centers and studies.

8.2 Institut Guttmann

Fundació Institut Guttmann (non-profit organization) is a leading hospital in the medical treatment, surgery and full rehabilitation of patients with SCI, Acquired Brain Damage or any other serious neurological disability. Its goal is to provide the most comprehensive, customized and specialized medical and rehabilitation care at the highest human, scientific and technical level. Its modern facilities, a team of nearly 400 practitioners and a record of 20.000 treated patients make Institut Guttmann one of the most advanced, world-class hospitals of its kind. As a research Institute, affiliated to the Universitat Autònoma de Barcelona, its mission is the development of education, scientific

and research aspects in the area of neuroscience in general, and neurorehabilitation and technologies applied to personal independence in particular. Collaboration between the hospital -Excellence Centre- and the higher education institute -Knowledge Centre- allows for the optimization, generation and transfer of new expertise in this specialized scientific area.

The Institute Guttmann has established three research lines (Neurorehabilitation of Spinal Cord Injury, Neurorehabilitation of Acquired Brain Damage, and Pediatric Neurorehabilitation) and six transverse strategic programs on translational research (Bioengineering applied to the person's functional independence; Neurostimulation, Neuromodulation and non-invasive stimulation; ICT applied to neuropsychological rehabilitation and cognitive stimulation; Neurorehabilitation of digestive function; Regenerative medicine applied to SCI and ABD; and Analysis of results applied to knowledge generation).

During the period 2002-2016, Institut Guttmann has worked in 223 research studies, has produced a total of 266 scientific indexed articles (with an accumulated impact factor of 778'26), there have been 754 submissions in various national and international congresses of the specialty, and has worked in the development of 32 doctoral theses.

The Institut Guttmann has among its objectives to promote specialized training of health professionals linked to the world of Neurorehabilitation, while increasing knowledge of the techniques and experiences that promote health and quality of life of people affected by a severe physical disability, including two master's degrees, in the European higher Education Area: Master in Neurorehabilitation, and Master of Neuropsychological Rehabilitation and Cognitive Stimulation.

The Institut Guttmann is integrated as associated partner to the Catalonia Health Ecosystem Reference Site (4 stars) to the 2016 Call for EIP AHA (Specific Actions: B3, A1, A3, C2 and D4) in collaboration with the Government of Catalonia (Ministry of Health, Ministry of Presidential Department, Ministry of Business and Knowledge, Ministry of Governance, Public Administrations and Housing, Ministry of Labour, Social Affairs and Families); other public health entities (Servei Català de la Salut, Institut Català de la Salut),

the Agency for Health Quality and Assessment of Catalonia (AQuAS), the TICSALUT Foundation and the Health Universitat de Barcelona Campus (HUBc).

8.2.1 Institut Guttmann Spinal Cord Injury Unit

The characteristic care model of the Institut Guttmann is based on the intervention of an expert multidisciplinary team, the compassion and specialization of its professionals, and the scientific rigor with which it operates; together with modern facilities and the continuous incorporation of the latest technology, these make the Institut Guttmann one of the world's leading hospitals in its field today. The care and neurorehabilitation activity of the Institut Guttmann is organized by functional units and clinical programs for the rehabilitation of patients, as well as a number of specific clinical procedures able to bring significant qualitative improvements in the health field and in the improvement of the quality of life of those affected by a neurological disability.

The Institut Guttmann SCI Unit is an inpatient and outpatient clinic at the Institut Guttmann Hospital of Neurorehabilitation. The hospital has been accredited as a National Reference Centre -CSUR- for the treatment of complex spinal cord injury, by the Ministerio de Sanidad, Servicios Sociales e Igualdad (Ministry of Health, Social Services and Equality of Spain).

The Institut Guttmann SCI Unit is responsible for lifetime care and follow-up after a traumatic or non-traumatic SCI. After initial rehabilitation at the clinic, patients usually move to an independent living situation and continue their rehabilitation at the Institut Guttmann day-care program. After completing rehabilitation, the individuals with SCI are offered health examinations on a regular basis. These examinations take about 3-4 hours during which individuals are assessed by each member of the clinical team (physician, nurse, physiotherapist, psychologist, social worker). The Institut Guttmann SCI Unit offers outpatient care for SCI-related complications and has developed specialized clinics for treating complications after SCI such as psychological difficulties associated to the adaptation process to disability.

8.3 Spinal Cord

The spinal cord is the major conduit through which motor and sensory information travels between the brain and body. It is a part of the central nervous system (CNS) and is a continuation of the neuronal tissue of the brain. It occupies the upper two thirds of the spinal canal and ends below the first lumbar vertebra. At the level the cord broadens to form the conus medullaris. Neural tissue identified as nerve roots constitutes the cauda equina and occupies the remainder of the lumbar canal. The average length of the spinal cord is 43-45 cm. The cord, conus and cauda equina are surrounded by the meninges. The spinal cord consists of 8 cervical nerve roots C (1-8), 12 thoracic nerve roots Th (1-12), 5 lumbar nerve roots L (1-5) and five sacral nerve roots S (1-5). Each nerve root receives sensory information from skin areas called dermatomes. Similarly each root innervates a group of muscles called a myotome. While a dermatome usually represents a discrete and contiguous skin area, most roots innervate more than one muscle, and most muscles are innervated by more than one root. The cervical nerve roots C (1-8) control signals to the back of the head, the neck and shoulders, the arms and hands, and the diaphragm. The thoracic nerve roots Th (1-12) control signals to the chest muscle, some muscles of the back, and parts of the abdomen and the lumbar spinal nerves. L (1-5) control signals to the lower parts of the abdomen and the back, the buttocks, some parts of the external genital organs and parts of the leg. Finally the sacral spine nerve roots S (1-5) control signals to the thighs and lower parts of the legs, the feet, most of the external genital organs, and the area around the anus. The vertebral column is composed of 33 vertebrae: 7 cervical, 12 thoracic, 5 lumbar, 5 sacral, which are fused and 3 to 5 fused coccygeal vertebrae. The typical vertebra consists of body and arch and the spinal cord lying within the arch³.

The blood supply of the spinal cord derives mainly from the anterior spinal artery. The grey matter of the spinal cord is surrounded by white matter consisting of ascending and descending fibers. Fibers carrying similar sensory information or motor functions travel together in tracts.

8.4 Spinal Cord Injury

Spinal cord injury (SCI) is a serious lesion in the CNS that may cause lifelong disability. SCI affects conduction of sensory and motor signals across the site(s) of lesion(s), as well as the autonomic nervous system. Interruption of the spinal cord causes paralysis of voluntary mobility and absence of any sensation below the affected area; it also involves the lack of control over the urethral and anal sphincters, sexual and fertility disorders, autonomic nervous system disorders and risk of other complications (pressure sores, spasticity, kidney processes etc.).

SCI is a devastating physical, emotional, and socioeconomic event for an individual. It occurs in people of all ages and is one of the most complex and challenging areas of neurosciences in terms of medical-surgical and multidisciplinary rehabilitative management. The incidence of the spinal cord injury (SCI) varies depending on both the countries and the used methodology. Globally, it could range between 9 and 53 SCI per million inhabitants per year. Approximately, 20% die during pre-hospital and transport period⁴. In Spain, the incidence of the SCI is estimated on 12-20 new cases per million per year, being the incidence of traumatic SCI almost 12 cases per million inhabitants per year. The estimated prevalence of SCI in Spain is approximately 350 individuals per million inhabitants per year, with a progressive and increasing evolution in time due to the higher life expectancies as a consequence of specialized treatments. SCI predominantly affects men, with a relation 4:1 with respect to women. They are mainly young patients, with a mean age of 35 years. The most common etiology is traumatic (81,5%). Of all traumatic spinal cord injuries, traffic accidents, 52,4% of these, are the most frequent cause, followed by chance accidents (22,8%), work accidents (13,6%), sport accidents (5,3%), suicide (2,3%) and others (3,6%). The level of impairment varies depending on the study, and it is approximately 60% (45%-75%) paraplegia and 40% (35%-53%) tetraplegia⁵⁻⁶.

In high-income countries, SCI can be viewed less as the end of a worthwhile or productive life and more as a personal and social challenge that can be successfully overcome. This change reflects better medical provision, which means that people are able to survive, live and flourish after injury. For instance, people who develop SCI can now usually benefit from

improved emergency response, effective health and rehabilitation interventions, and technologies such as respirators and appropriate wheelchairs, together with more extensive social services and more accessible environments. As a result, lives can be saved and functioning can be maximized. Many people with SCI can now anticipate not just a longer life, but also a fuller and more productive life, than they would have had in previous generations.

8.5 Neurological classification of the SCI

Spinal cord injuries are classified into five types by the American Spinal Cord Injury Association (ASIA) and the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI). By systematically examining the dermatomes and myotomes, clinicians can determine the cord segments affected by the SCI³. The ASIA has defined an international classification as shown in table 1 based on the neurological levels, touch and pinprick sensations tested in each dermatome (table 2) and strength of ten key muscles on each side of the body (table 3), i.e. shoulder shrug (C4), elbow flexion (C5), wrist extension (C6), elbow extension (C7), hip flexion (L2), knee extension (L3), ankle dorsiflexion (L4), long toe extension (L5), and ankle plantar flexion (S1).

The following definitions are important in order to understand SCI³:

Tetraplegia: This term refers to impairment or loss of motor and/or sensory function in the cervical segments of the spinal cord due to damage of neural elements within the spinal canal. Tetraplegia results in impairment of function in the arms as well as typically in the trunk, legs and pelvic organs, i.e. including the four extremities. It does not include brachial plexus lesions or injury to peripheral nerves outside the neural canal.

Paraplegia: This term refers to impairment or loss of motor and/or sensory function in the thoracic, lumbar or sacral (but not cervical) segments of the spinal cord, secondary to damage of neural elements within the spinal canal. With paraplegia, arm functioning is spared, but, depending on the level of injury, the trunk, legs and pelvic organs may be involved. The term is used in referring to cauda equina and conus medullaris injuries, but not to lumbosacral plexus lesions or injury to peripheral nerves outside the neural canal.

Neurological level of injury (NLI): The NLI refers to the most caudal segment of the spinal cord with normal sensory and antigravity motor function on both sides of the body, provided that there is normal (intact) sensory and motor function rostrally. The segments at which normal function is found often differ by side of the body and in terms of sensory and motor testing. Thus, up to four different segments may be identified in determining the neurological level, i.e., R(ight)-sensory, L(eft)-sensory, R-motor, L-motor. The single NLI is the most rostral of these levels.

Incomplete SCI: This term is used when there is preservation of any sensory and/or motor function below the neurological level that includes the lowest sacral segments S4-S5 (i.e. presence of "sacral sparing"). Sensory sacral sparing includes sensation preservation (intact or impaired) at the anal mucocutaneous junction (S4-5 dermatome) on one or both sides for light touch or pin prick, or deep anal pressure (DAP). Motor sacral sparing includes the presence of voluntary contraction of the external anal sphincter upon digital rectal examination.

Complete SCI: This term is used when there is an absence of sensory and motor function in the lowest sacral segments (S4-S5) (i.e. no sacral sparing)⁷.

Table 1. Descriptions of Categories from ASIA Impairment Scale (AIS)

ASIA grade	SCI	Description
A	Complete.	No sensory or motor function is preserved in the sacral segments S4-S5
B	Incomplete	Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-S5, AND no motor function is preserved more than three levels below the motor level on either side of the body
C	Incomplete	Motor function is preserved below the neurological level, and more than half of key muscle functions below the single neurological level of injury have a muscle grade less than 3 (Grades 0–2)
D	Incomplete	Motor function is preserved below the neurological level, and at least half (half or more) of key muscle functions below the NLI have a muscle grade >3
E	Incomplete	If sensation and motor function as tested with the ISNCSCI are graded as normal in all segments, and the patient had prior deficits, then the AIS grade is E. Someone without a SCI does not receive an AIS grade

Table 2. Motor index 0-5*

Grade	Description
0	Total paralysis
1	1 palpable or visible contraction
2	Active movement, full range of motion, gravity eliminated
3	Active movement, full range of motion, against gravity
4	Active movement, full range of motion, against gravity and provides some resistance
5	Active movement, full range of motion, against gravity and provides normal resistance
5*	Muscle able to exert, in examiner's judgment, sufficiently, pain on effort or contracture
NT	

Table 3. Sensory functions

Grade	Description
0	Absent
1	Impaired
2	Normal

8.6 Aetiology of the SCI

The cause of SCI can be either traumatic or non-traumatic.

8.6.1 Traumatic SCI

Within traumatic spinal cord injury (T-SCI) transportation-related accidents (are the most frequent cause of injury (57%), followed by falls (24.6%) and to a lesser extent by violence (3.9%) and sports (1.9%)⁸. The incidence of T-SCI is highest among young persons with an average age of injury is 42.6 years⁹. Most individuals have their injury when they are between 20 and 40 years of age. About 80% of the T-SCI individuals are males⁸⁻¹⁰. According to the National Spinal Cord Injury Statistical Center⁹ since 2010 the most frequent discharge of persons registered in their databases neurologic category is incomplete tetraplegia (40.6%), followed by incomplete paraplegia (18.7%), complete paraplegia (18%) and complete tetraplegia (11.6%).

8.6.2 Non-traumatic SCI

Non-traumatic SCI (NT-SCI) appears to represent a significant proportion of individuals with SCI admitted to rehabilitation settings. Guttmann and colleagues² in a study of 3,000 SCI admissions reported that nearly one third were the result of non-traumatic etiology. NT-SCI is a growing problem as we currently live longer¹¹.

The individuals with NT-SCI are in most cases older at the time of injury than in persons with a T-SCI. Most subjects are over 40 years of age at the onset of the disorder. NT-SCI presents a more balanced relationship between genders with approximately 40% being females^{12,13}. Individuals with NT-SCI more often have an incomplete SCI and more likely to result in paraplegia. Persons affected with a NT-SCI frequently have other medical problems like hypertension, cardiac diseases, degenerative disorders, arthritis and diabetes mellitus^{14,15}. Their rehabilitation is therefore complicated and they have more medical needs than the T-SCI patients¹⁶. The major causes of NT-SCI's are tumors, degenerative diseases or vascular problems¹⁷. In some cases the patients get their SCI during or after surgical treatment.

8.7 Prognosis after SCI

Neurological recovery and functional improvement occur after T-SCI and NT-SCI during standard treatment and rehabilitation, as part of the natural recovery process. Walking recovery is one of the main goals of patients after SCI: walking is rated at first place (together with bladder and bowel function) at least by patients with incomplete lesions^{18,19}. The degree of recovery depends on the type, level and the severity of injury²⁰. Studies show that ASIA classification on admission to hospital after the injury is of utmost importance for the prognosis²¹. If the SCI is complete the prognosis is poor and a majority of the patients will remain complete on discharge from hospital²²⁻²⁶. However, if the injury is incomplete the prognosis is much better^{27,28}. About half of the patients that are ASIA B (motor complete) on admission will improve at least one ASIA grade on discharge. For patients that are ASIA C and D the prognosis is even better as shown in table 4²⁹. In summary, predicting the final neurological and functional outcome is of great importance in planning the treatment, rehabilitation and discharge of patients with SCI.

Table 4. Prediction of recovery according to AIS impairment scale

AIS grade at admission	AIS grade at discharge				
	A	B	C	D	E
A	92%	4%	4%	0%	0%
B	2%	48%	49%	1%	0%
C	0%	2%	30%	60%	8%
D	0%	0%	2%	68%	30%
E	0%				

8.8 Secondary medical complications after SCI

SCI frequently, but not inevitably, leads to complications in many organ systems. The most frequent and/or important complications will be reviewed briefly:

Autonomic dysreflexia (AD)

SCI and specially cervical SCI imply serious disturbances in autonomic nervous system function³⁰. Autonomic dysreflexia (AD) is triggered by a noxious stimulus below the level of the lesion, which then activates unopposed sympathetic activity³¹. The symptoms are episodes of high blood pressure, headache, sweating and bradycardia. The rise in blood pressure can cause sudden death due to brain hemorrhage. Common causes of AD are an over extended bladder, severe constipation, sexual activity or urinary tract infections (UTI)³².

Neurogenic bowel dysfunction (NBD)

Neurogenic bowel dysfunction (NBD) is colon dysfunction due to the absence of nervous control, resulting in constipation, incontinence and discoordination of defecation.

Neurogenic bowel dysfunction constitutes a problem both in the acute and chronic stages after SCI and may lead to a severely disabling condition. Constipation and/or fecal incontinence cause stress, insecurity and has a marked impact in quality of life (QOL)^{33,34}.

Decubit/Pressure ulcers

Lack of sensation, skin collagen degradation, immobilization and incontinence are major risks factors contributing to occurrence of pressure ulcers after SCI. Pressure sores are more common in complete SCI individuals and occur over bony prominences³⁵. They have many deleterious consequences, including permanent scarring, osteomyelitis, amputation and sepsis. When pressure ulcers occur, healing takes long time, and treatment is costly and may include hospitalization and surgery. In addition, they affect a person's family and social life. Pressure ulcers can also lead to death. It is estimated that pressure ulcers are responsible for approximately 8% of deaths in people with SCI in high-income countries³⁶.

Pressure ulcers are most common around the sacrum, ischial tuberosity and greater trochanter of the femur. They progress through different stages of severity if left untreated. They are scored from stage 1 to stage 4. Stage 4 pressure ulcers are severe and invariably require hospitalisation and surgery. Stage 1–stage 3 pressure ulcers vary from superficial red areas to full skin thickness injuries³⁷. In high-income countries, pressure ulcers are either managed with hospitalisation or regular home nursing, and pressure relieving devices such as alternating pressure air mattresses.

Deep vein thrombosis (DVT)

DVT and subsequent pulmonary embolism (PE) occurs frequently following SCI, particularly in the acute phase. Peripheral vasodilatation, absent or reduced lower extremity muscular function and immobility leads to venous stasis and are important factors for the DVT development. Thrombi in the deep veins are potentially life threatening and can lead to PE³⁸. DVT remains the third leading cause of death after SCI and the incidence of PE has been estimated as 4.6%. Prevention is the key to decreasing morbidity and mortality.

Heterotopic ossification

Heterotopic ossification (HO) is the formation of the lamellar bone within the tissues where normally osseous tissue does not exist. Neurogenic HO is a frequent complication after SCI. It normally appears from 1 month to 4 months after injury and leads to impaired functional status and contractures³⁹.

Osteoporosis

Following SCI both calcium and collagen are lost from the bones. The resulting osteoporosis increases the likelihood of fractures. Osteoporosis progresses gradually for five years after injury, at which time it reaches a plateau. Osteoporosis can cause fractures after light traumas⁴⁰.

Pain

Chronic pain has been recognized as a significant and frequent consequence of either traumatic or non-traumatic SCI⁴¹⁻⁴⁵. Chronic pain has often been mentioned as an important factor of loss in quality of life and psychological well-being after a physical disability^{43,45}, significantly affecting the ability to cope and adapt to the SCI^{46,47}.

Longstanding pain is a common problem after SCI in both traumatic and non-traumatic etiology. The pain may be nociceptive or neuropathic. A pain is diagnosed nociceptive when aching in an area with signs of inflammation or/and with painful joint movements. In the other hand, a pain is diagnosed neuropathic when burning or shooting in an area with sensory disturbances to pinprick and touch and without relation to movements or signs of inflammation. The incidence of chronic pain was found in earlier studies to vary between 18% and 94%. More recent research has found that nearly all patients with SCI during the in-hospital rehabilitation experience pain and that neuropathic pain is one of the most common types of pain. Furthermore that 61% of patients with SCI suffered from pain with severe to moderate intensity.

Nevertheless neuropathic pain is one of the most challenging problems after SCI and affects psychological well-being and overall QOL⁴⁸. SCI pain management is further complicated by a multitude of cognitive, emotional, behavioural and social factors that can adversely affect, or buffer, the pain experience⁴⁹⁻⁵¹.

Pneumonia/respiratory insufficiency

Respiratory complications are the most common cause of death following SCI⁵². These complications occur as a result of a reduction in inspiratory and expiratory ability. Inadequate inspiration results in reduced ventilation of the lungs leading to atelectasis. Ineffective coughing allows secretions to build up in the lungs with subsequent atelectasis, pneumonia, and respiratory insufficiency resulting⁵³.

Spasticity

Spasticity is a disorder of the motor system that occurs after injury to CNS, which may

increase the disability of individuals with SCI. In SCI individuals symptoms of spasticity are often present after a period of spinal shock and in many cases, the QOL is negatively affected. Spasticity is more prevalent in higher lesions and incomplete lesions and the presence of problematic spasticity has been significantly correlated with cervical incomplete (ASIA B-D) injury⁵⁴. There is a significant association between spasticity and contractures (reduced range of movements). Quick stretching of muscles excite exaggerated reflex responses, cutaneous stimuli also evoke abnormal reflex response. Treatment includes rehabilitation techniques and modalities, physiotherapy pharmacological options, injection techniques, intrathecal baclofen, and surgery⁵⁵. A SCI individual can benefit from spasticity in daily living, when dressing, walking and transfers.

Urological problems

Most spinal cord injuries affect bladder functions because the nerves that control the functions of those organs originate in the segments near the lower termination of the spinal cord and are cut off from the brain input. Without coordination from the brain, the muscles of the bladder can empty suddenly without warning, or become over-full without releasing. In some cases the bladder releases, but urine backs into the kidneys because it is not able to get past urethral sphincter. The great risk that urologic dysfunction poses is possible damage to the kidney function. It is therefore essential that the bladder is emptied completely to avoid urinary tract infections (UTI), which is a common complication after SCI⁵⁶⁻⁵⁸.

Most people with spinal cord injuries use intermittent catheterization to empty their bladders^{59,60}.

Sexual problems

Problems with sexual dysfunction are commonly experienced following SCI due to the neurological changes incurred as a result of the injury. Such difficulties can lead to emotional distress for the individual with SCI and have a negative impact on QOL and social relationships. Most SCI women remain fertile and can conceive and bear children.

Depending on the level of injury, man may have problems with erection and ejaculation, and most will have compromised fertility due to decreased motility of their sperm^{61,62}. Treatments for men include vibratory or electrical stimulation and drugs such as sildenafil. Many couples may also need assisted fertility treatments to aid spinal cord injured men to father children. As SCI individuals often are young at the time of injury sexuality and fertility are of utmost importance for living a full-worthy life^{63,64}.

8.9 Psychosocial aspects after SCI

Due to advances in medical technology and techniques, individuals who have incurred a SCI can now expect to live an almost normal life span⁶⁵⁻⁶⁷.

Consequently, individuals now have to deal with the impact of their SCI for a far greater period of time, which will require continuous adjustments across the life span. With the average postinjury life expectancy of a person with a SCI now measured in decades rather than days, sequelae of the injury and secondary medical complications intensify the experience of disability by negatively impacting on long-term health, quality of life, mobility and independence and having an adverse impact on long-term adjustment. This issue merit considerable attention^{68,69}. Although medical science has made major advances in life expectancy, it is crucial to focus on psychosocial aspects in a life in which patients have been injured and/or experience motor impairment. SCI is associated with abnormal levels of psychological morbidity⁷⁰, substance abuse and risk of suicide⁷¹. SCI both traumatic and non-traumatic causes lifelong disability and may lead to difficulties in psychosocial adaptation either in the acute phase or in the chronic phase. SCI individuals are forced to continuously adapt to their condition by making adjustments within several specific domains, including mobility, self-care, lifestyle and social relations^{72,73}. SCI is a common phenomenon that generates needs not only to individuals who live with but also to their families. This must be addressed from the field of neurorehabilitation taking into account not only the medical and physical factors directly related to the disability but also their impact on

its consequences on a psychological, social and environmental level of the persons affected and their relatives. Therefore, it requires great efforts of coping and adaptation leading to the person and his family to live a high emotional distress⁷⁴.

Consequently, psychosocial issues have become more prominent in SCI research in the last few decades. It is fundamental to increase our understanding of how individuals and their relatives cope effectively, and what factors lead to effective adjustment, so as to more effectively support those who are in vulnerable position against psychological morbidity and the risk to social isolation.

The International Classification of Functioning, Disability and Health (ICF)⁷⁵ provides a comprehensive and universally accepted framework to classify and describe functioning, disability and health in people with all kinds of diseases or conditions, including SCI. The dynamic influence of psychological and social factors in SCI is best depicted by the ICF, which outline the dynamic interaction between body functions (i.e. secondary medical complications, such as pain), an individual's personal or psychological functioning, the level of participation (i.e. work, family and social interactions) and its relation with environmental factors⁷⁶⁻⁷⁸.

8.9.1 Stress, Appraisals and Coping (SAC)

A person with a disability such as SCI must cope with a variety of potential stressors such profound and long-term changes, chronic pain, spasticity, inability to feel and move body parts, inability to control internal organ functions, sexual dysfunction and, in severe cases, inability to breathe independently. Individuals also need to develop and maintain relationships with caregivers and other professional staff as well as with treatment procedures and hospital environments. Furthermore, disability frequently challenges people's emotional balance, self-image, relationships with family and friends, and often involve preparing for an uncertain future. Due perhaps in part to the diversity of stressful situations associated with SCI and individuals' diverging life situations, the literature on coping has become voluminous.

As psychological adjustment to SCI may be a challenging process, it is helpful to understand how patients perceive their health situations and how they navigate difficult circumstances within the context of their perceptions. Much research has derived from the Lazarus and Folkman theoretical framework of stress and coping⁷⁹⁻⁸³, which is considered the most authoritative theoretical framework in the field. Beginning in the 1960s and 1970s, stress was considered to be a transactional phenomenon dependent on the meaning of the stimulus to the perceiver^{84,85}. Stressors are demands made by the internal or external environment that upset balance, thus affecting physical and psychological well-being and requiring action to restore balance⁸⁶.

The Transactional Model of Stress Appraisals and Coping (SAC) is a framework for evaluating the processes of coping with stressful events. Stressful experiences are construed as person-environment transactions. These transactions depend on the impact of the external stressor. This is mediated by firstly the person's appraisal of the stressor and secondly on the social and cultural resources at his or her disposal. Appraisal is defined as the cognitive process of categorising an encounter with respect to its significance for well-being, while coping is defined as behavioural efforts to manage specific demands that are appraised as exceeding personal resources⁸⁶⁻⁸⁸. When faced with a stressor, a person evaluates the potential threat (primary appraisal). Primary appraisal is a person's judgment about the significance of an event as stressful, positive, controllable, challenging or irrelevant. Facing a stressor, the second appraisal follows, which is an assessment of people's coping resources and options⁸⁸. Secondary appraisals address what one can do about the situation. Actual coping efforts aimed at regulation of the problem give rise to outcomes of the coping process. In the table below the key constructs of the Transaction Model of Stress, Appraisals and Coping are summarized (table 5).

It is important to note that stress does not affect all people equally⁸⁹, but stress can lead to illness and negative experiences. Coping with stress is therefore an important factor, it affects whether and how people search for medical care and social support and how they believe the advice of the professionals⁹⁰.

The Stress, Appraisal and Coping model proposed by Lazarus and Folkman⁸³ has been successfully employed to explain how persons with SCI adjust to chronic disability⁷².

Table 5. Key constructs of the Transaction Model of Stress and Coping

Concept	Definition
Primary Appraisal	Evaluation of the significance of a stressor or threatening event.
Secondary Appraisal	Evaluation of the controllability of the stressor and a person's coping resources.
Coping Strategies	Actual strategies used to mediate primary and secondary appraisals.
Problem management	Strategies directed at changing a stressful situation.
Emotional Regulation	Strategies aimed at changing the way one thinks or feels about a stressful situation.
Outcomes of coping	Emotional well-being, functional status, health behaviors.

Adapted from Glanz, K. et al.⁹¹

Coping with, and adapting to, SCI should not be viewed as a single event, but rather as a dynamic process that unfolds over time, as the individual's circumstances and interactions with the environment change. Some authors⁹² have suggested that different phases of the rehabilitation process tend to pose different psychological and physical demands on the person with SCI and, accordingly, different coping challenges for the individual. In the acute phase of SCI, the focus is on physical stabilization. The person may be highly dependent on clinical care, and might be in a state of shock or acute stress. At this point of greater vulnerability, the person is likely to be focused on issues of stabilization and safety, and care providers, including psychologists, can assist with this process. During rehabilitation, the focus turns to improving functioning and maximizing independence. Psychologically, the person is challenged to stay motivated and maintain a sense of self-efficacy, even as they may be facing enduring functional limitations. Toward the end of rehabilitation, when many

of the activities of daily living have been addressed, the focus shifts to community living, with its concomitant challenges related to housing, relationships, and employment.

In this adaptation process, the coping strategies used by the individual can impact both positively and negatively on physical and mental health outcomes. Coping can be defined as the use of cognitive, behavioral, and emotional strategies for managing stressful situations⁹². This includes any effort a person makes to preserve mental and physical health, even if the strategy is ultimately maladaptive. Folkman and Lazarus⁸⁸ have identified several categories of coping behavior. Active coping strategies utilizing problem-solving and positive reappraisal (e.g., reframing of events and negative thinking) appear to be more effective and adaptive when individuals are faced with potentially chronic stressors such as SCI. Conversely, excessive focus on emotional experience (e.g., venting) as a coping strategy tends to be associated with more negative outcomes, as does the prolonged use of avoidance or disengagement strategies⁹³. Folkman and Lazarus allow that most coping strategies are not inherently positive or negative, and the usefulness of any one strategy will depend on the context of its use and the ability to flexibly shift from one strategy to another. For example, a problem-solving approach might eventually become maladaptive in a situation that cannot be changed. Moreover, a moderate amount of denial or distancing might be helpful, especially early on, allowing the person to gradually transition to more active strategies to manage a chronic stressor.

Different studies have concluded that the relation between psychological strategies people employ to deal with difficulties and the adaptation is stronger than the relation between physical disability factors and adjustment^{72,94}. Likewise, coping strategies have been found to explain more of the variance of psychological impact than socio-demographic and lesion related variables⁹⁵⁻⁹⁷.

Originally, studies about coping after SCI were of a largely cross-sectional design nature. These studies were useful in helping to discover the importance of coping strategies, which people used within the construct of psychological adaptation⁹⁸ as well as emphasizing how coping appeared as the single most important predictor of psychological outcome^{98,99}.

Specific coping strategies were identified, which accounted for significant proportions of variance within psychological outcomes, which can be both adaptive and maladaptive. Overall, adaptive strategies were found to be used more so than maladaptive ones with acceptance found as the most commonly used strategy^{96,100}. A shift toward the use of longitudinal studies has increased the clinical relevance of studies within coping, as well as helping to provide a more detailed picture of the nature of coping over an extended period of time postinjury. Previous longitudinal studies within the literature have reflected an overall consistency and stability in which coping strategies are most and least commonly used, as well as identifying the nature of coping strategies used¹⁰¹. Nevertheless, methodological limitations, like the use of generic coping measurement instruments⁷² have restricted the possibility to establish the relationship between coping and adaptation to disability after an SCI. These instruments are very long, cannot reflect all the particularities of SCI and make studies difficult to compare^{94,102}.

Recent reviews have called for more research of a longitudinal nature to better understand the predictive values of the initial psychological response to long-term coping and adjustment, as well as helping to develop a better understanding of the changes associated with SCI across the life span¹⁰³⁻¹⁰⁵. In a 21-Year longitudinal, multiple-wave panel study, Kennedy and colleagues⁹⁵, concluded that coping strategies in the early stages of rehabilitation are an important predictor of long-term psychological outcomes, and this finding has clinical implications for psychological aspects of rehabilitation.

8.9.2 Depression, anxiety and difficulties in the adjustment process to disability

Psychiatric disorders are not an inevitable consequence of SCI and most individuals never experience sufficient distress that it interferes with rehabilitation. Nevertheless, SCI brings change to all levels of the person's life, and can lead to psychological distress, at least temporarily, even in the most resilient individuals¹⁰⁶.

Indeed, the psychological impact of SCI is evidenced by the fact that there is a higher

incidence of anxiety and depression in affected individuals when compared with the general population^{10,71}. Although it is common and understandable that individuals will experience a certain amount of negative emotion towards disability, the percentage for which these emotions develop into clinically significant psychological problems is relatively low (around 25-30%), and the majority of people sustaining a SCI go on to lead satisfying and rewarding lives.

Conceptual and methodological problems hamper research to mental health of people with SCI¹⁰⁷. In the early phase of SCI, it is difficult to distinguish between temporary depressed mood and a persistent adjustment disorder. Questionnaires used to measure mental health disorders have not been developed for use in people with SCI, so that some of the items might reflect physical consequences of SCI instead of mental problems. Further, these questionnaires have been developed to screen for mental health disorders, and a score above a certain cutoff point only indicates a possible or probable mental health disorder¹⁰⁵.

The most studied emotional disturbance in SCI is depression. There is wide variability in prevalence estimates (10–60%). It is important to distinguish between a normal grief reaction to SCI and true clinical depression¹⁰⁷. Depression is not a single entity, but a spectrum of disorders that vary by length of time symptoms are experienced and degree of severity.

A recent prospective study found major depression to be amongst the most prevalent psychological conditions experienced post-SCI¹⁰⁸. However, estimated rates of depression within the SCI population vary widely from study to study. In a review by Bombardier et al., the point prevalence of probable major depressive disorder (PMDD) in studies using diagnostic interviews was found to range from 9.8% to 37.5%¹⁰⁹. In a more recent meta-analysis of studies using a diagnostic criterion based on the Diagnostic and Statistical Manual of Mental Disorders, 4th edition¹¹⁰ (DSM-IV) this was estimated at 22.2%¹¹¹. Furthermore, for individuals living in the community, rates reportedly range from 11% to 60%⁷¹. Of the various depressive disorders, adjustment disorders are generally encountered after SCI. An adjustment disorder with depressed mood is diagnosed when

the constellation of symptoms does not meet the criteria for a depressive disorder or bereavement¹⁰⁷.

In general population, risk factor for depression can be genetic, psychological, social, and environmental. They include prior episodes of depression, family history of depressive or bipolar disorder, family history of suicide attempts, current suicidal ideation, age of on-set under 40, chronic pain, female gender, lack of social support, postpartum, life stressors, concurrent medical illness, and concurrent substance abuse. Specific risk factors for individuals with SCI include complete neurologic injury and medical comorbidity with traumatic brain injury¹⁰⁷. Social and environmental risk factors include a poor social network, few financial resources, vocational difficulties, inferior living arrangements, the need for personal and transportation assistance, and family disruption before injury. Biologic factors that contribute to depression include somatic effects of SCI such as fatigue and sleep disturbances, personal or family history of depressive illness, pain or presence of a general medical condition or medication that may cause or contribute to depression. Some medications that may cause or contribute to depression that are frequently used in SCI population include metoclopramide, glucocorticoids, anabolic steroids, cimetidine, ranitidine, and clonidine¹⁰⁷. However, medication-induced depression is not very common. Because physiological symptoms of depression are often somatic effects of SCI, it is important to ascertain the presence of other symptoms of depression, such as dysphoria and distractibility. Psychological risk factors for depression and maladjustment after SCI include psychological structure (i.e., narcissistic and antisocial personality features and behaviors), and preinjury history of psychological or psychiatric impairment including: substance abuse, coping style, a poor social support system, poor problem-solving abilities, unresolved conflicts from previous losses or trauma, shame, hopelessness, bereavement, and having the opinion that death is better than living with SCI¹¹². Post-SCI predictors of depression are despondency, alcohol abuse, apathy, expressions of shame, stress, weight loss, anger, and destructive behavior¹¹³. In the SCI population, indirect forms of self-harm, such as self-neglect or alcohol and substance abuse, are more prevalent than actual suicide attempts, which themselves can lead to potentially fatal medical

complications, such as bladder infections and pressure ulcers.

Although depression has been the factor most frequently studied in terms of adjustment to SCI, more attention must be given to other reactions such as anxiety and its related disorders. There are few studies that have focused specifically in evaluating anxiety disorders or symptoms of anxiety. Al-Owesie et al¹¹⁴, in a study with traumatic SCI individuals during the rehabilitation phase found that 18.62% showed symptoms of anxiety. However, Scivoletto and colleagues⁴⁷ found a 13% prevalence of anxiety disorders in a sample of 100 people with SCI assessed at 12 months post-SCI. Thirty percent of individuals with SCI have been found to have higher levels of anxiety and depression up to 2 years post-injury¹¹⁵. Examination of psychological impact has previously found a high level of consistency over time when looking at measures of depression longitudinally from 2 weeks to 10 years postdischarge¹⁰¹, as well as across a number of other SCI samples¹¹⁶⁻¹¹⁸. Stability shown within rates of depression suggests that, in those individuals with elevated risk for depression, this risk is likely to continue with higher resulting probability for future repeated episodes than those with lower risk¹¹⁹. Conversely, the course of anxiety over time has been found to be less stable^{118,120}.

In a recent study, Bonanno and colleagues¹²¹ proposed that the pattern of psychological impact over time is more complex than previous studies have suggested. The trajectory of depression following SCI was studied across a 2 year period from point of injury. Four different patterns were found: a highly prevalent pattern of stable low symptoms (suggesting a resilient outcome), a pattern of high symptoms followed by recovery (decreasing over time, leading to stabilization in the second year), a delayed symptom elevation pattern (characterized by an initial moderate level of symptoms, which elevated dramatically up to the 1-year mark), and finally a pattern of chronically high symptoms. The majority of individuals were found to exhibit psychological resilience (indicated by stable low symptoms), but the existence of three other patterns illustrates the highly diverse nature of psychological impact within SCI. Similar findings were reported by van Leeuwen et al.¹²², whose SCI rehabilitation study found five distinct mental health trajectories between the start of active rehabilitation and 5-years post discharge, comparable to those of Bonanno et

al.¹²¹. In another recent study, Bombardier and colleagues¹²³ found three distinct, clinically meaningful depression trajectory classes during the first year after SCI. Results highlighted the prominence of low depression as the modal response. The authors reported that depression scores and other data obtained during inpatient rehabilitation, such as psychiatric history, grief symptoms, pain and poor quality of life predicted membership in persistently depressed trajectory groups. They concluded that trajectory groups and predictors can inform patient education as well as depression monitoring, treatment, and targeted research efforts.

As a consequence of the psychological morbidity after a SCI, there are also a number of associated psychosocial risks such as increased hospitalization periods and increased medical complications in SCI when compared with the general population¹¹⁷. It is fundamental to increase our understanding of how individuals cope effectively, and what factors lead to effective adjustment, so as to more effectively support the one third of individuals who report elevated levels of anxiety and/or depression¹²⁴.

Because mental health problems affect rehabilitation and long-term outcomes in general, psychological services need to be provided as part of SCI treatment. Although psychopharmacologic agents are helpful in treating neurovegetative and mood disturbance symptoms, they cannot address the cognitive aspects of emotional disorders or the social environmental, and interpersonal concerns associated with depression, anxiety or maladjustment related disorders. These are best addressed through psychotherapy. The choice should be individually tailored. For example, cognitive behavioural therapy (CBT) incorporates a variety of techniques to facilitate emotional and behavioural change on the part of the person. CBT can include addressing 'irrational' or negative thoughts, increasing opportunities for participating in rewarding activities and instruction in relaxation. Individuals with SCI who had high levels of anxiety or depression in the acute phase of hospitalization and who received group cognitive therapy had reduced symptoms with maintenance of up to 2 years. Psychological interventions (such as cognitive CBT or coping

effectiveness training) are efficacious for reducing psychological morbidity either as stand-alone strategies or in combination with antidepressant medication, with some being effective for improving overall quality of life and psychosocial functioning following SCI¹²⁵⁻¹²⁷. Emotional disorders such as depression or the risk of suicide can occur at any time and therefore should be addressed in outpatient, medical follow-up visits.

8.9.3 Longterm outcomes and Quality of life after Spinal Cord Injury

In past studies, adjustment was described as the absence of anxiety and depression. In the current doctoral thesis, we rely on a model that focuses on a broader definition of psychosocial adaptation, taking into account not only the absence of disorders, but also positive indicators (e.g., QOL, participation and community integration)⁹³.

In a broad sense, the principal aim of physical medicine and rehabilitation is to maximize the quality of life (QOL) of persons with SCI¹²⁸. Although there are many definitions of QOL, elements include life satisfaction, physical integrity, material/success comfort, spiritual satisfaction, a sense of meaning or purpose, and relationship satisfaction. QOL as a concept has received considerable attention in health care settings and clinical research, and has been widely used as a clinical outcome of persons with disabilities in general, and persons with SCI specifically^{69,128-130}.

Despite the considerable challenges faced by people with SCI, research suggests that most individuals do adapt and report a favorable QOL^{131,132}. Ratings of QOL are lower in SCI individuals when compared with nondisabled individuals and persons with SCI report a lower rate of feelings of wellbeing^{68,133}. However, as many as 75% have rated their quality of life to be either good or excellent¹³⁴, and this has demonstrated stability over time¹³⁵.

Research has identified a variety of factors associated with a higher quality of life and greater wellbeing for people with SCI, including: perceived health status and safety, emotional support and stronger relationships with family and friends, self-esteem, physical and social activity and opportunity for meaningful work, involvement in leisure activities, and a strong

sense of spirituality^{68,132,136}.

As people with SCI age, they are likely to experience new difficulties in coping, as they face loss of strength and endurance, functional decline, and concomitantly a greater need for assistance¹³⁷⁻¹³⁸.

Previous research has revealed a link between secondary complications and QOL, and a recent study by Hammell¹³⁹ reported how individuals with SCI identify issues such as pain, fatigue, and pressure sores as areas in which they consider more research would be beneficial in improving their lives. Hammell also argued that further research is necessary to elucidate the link between secondary complications and QOL and the impact of environmental barriers on community and vocational participation. Interestingly, however, research has suggested that severity of disability and level of injury in SCI are not related to psychological health or quality of life^{131,138}. A study of Pierce and colleagues¹⁴⁰ concluded that the level of participation (particularly mobility and social integration), age, and the perceived health status were predictive of QOL, in comparison with activity level and degree of disability. The model suggested that individual's perceived health status is more important to his or her adjustment to SCI and perceived QOL than injury related deficits.

The literature underlines the relationships between psychosocial factors and long-term adjustment outcomes such as QOL. For example, as said before, it is known that severity of injury is not the best predictor of most long-term outcomes. Researchers have found that while the level and extent of neurologic preservation does predict independence in activities of daily living certain medical complications^{35,141} and mortality¹⁴², they do not strongly predict such postinjury outcomes as perceived stress^{138,143,144} emotional distress marital stability¹⁴⁵⁻¹⁴⁸ long-term job and employment stability¹⁴⁹, productivity¹⁵⁰⁻¹⁵¹ life satisfaction, perceived well-being, or overall quality of life (QOL)^{134,152-156}. Instead, these outcomes are influenced by such diverse factors as mobility, family support, coping, productivity, self-esteem, financial stability, education, participation and the physical and social environment^{35,134,138,141-149,151-157}. Thus, psychosocial factors must be taken into account to explain differences in long-term adjustment outcomes. Notwithstanding, despite there's a voluminous body of

literature and the advance of the relevance of non-injury related factors in this field, the associations between variables are not clear and sometimes contradictory. This fact highlights the need for further investigation.

9. Purpose of the thesis

The main aim of this thesis was to determine to what extent injury-related variables, socio-demographic characteristics or psychosocial aspects are predictive of the adaptation process among community-residing individuals with SCI. A secondary objective of this thesis was to adapt and validate into Spanish language two specific questionnaires for spinal cord injury individuals to assess pain and coping strategies respectively.

The specific aims of the three papers included in this thesis were as follows:

Paper I.

The primary purposes of the study were to confirm the factor structure of the Spanish version of the Multidimensional Pain Inventory for SCI (MPI-SCI-S) and to test its internal consistency, and construct validity.

Was expected that pain would be predictive of subjective QOL.

Paper II.

The purposes of the study were to adapt the Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL-CSQ-S) into the Spanish Language and to examine the relationship between coping strategies, global quality of life and psychological adaptation.

Was expected that coping strategies related to Acceptance and Fighting spirit would positively predict psychological adaptation, whereas Social reliance was expected to demonstrate both negative (QOL and social participation) and positive (anxiety and depression) relationships.

Paper III.

The aims of the study were: (1) to determine the prevalence of probable major depressive disorder (PMDD) among independent samples of NT-SCI and T-SCI individuals; (2) to describe the different aspects of depression between the etiologies; and (3) to examine the risk of depression through socio-demographic, injury-related, and psychosocial variables. It was hypothesized that NT-SCI individuals may have an increased risk of psychological complications such as depression.

10. Methods

10.1. Participants

10.1.1 Paper I. A cross-sectional study on persons with SCI and chronic pain, based on a postal survey.

Individuals registered at the Institut Guttmann SCI unit were offered periodic check-up examinations. Between April of 2005 and July 2007 all subjects who performed the periodic follow-up assessment at the outpatient SCI clinic were informed about the study. In all, 558 individuals agreed to participate and were given a questionnaire package including the MPI-SCI-S. Only 126 subjects sent back by mail the questionnaire package (response rate 22.6%). Of the 126, 43 (34.1%) had a traumatic injury and 83 (65.9%) a non-traumatic injury; 78 (61.9%) were male and 48 (38.1%) were female. The mean age was 49 years. No significant differences were found between responders and non-responders with the exception of educational level.

10.1.2 Paper II. A cross-sectional validation study on persons with SCI based on an individual assessment.

Individuals with SCI living in the community attended their comprehensive follow-up evaluation at the outpatient SCI clinic of the Institut Guttmann between March 2010 and July 2011. A total of 511 subjects with SCI were included in the study. The mean age was 50.6 years, range 17.5-87.2 years. The mean time since injury was 15.44 years, range 1.40-62.47 years. Of the 511 participants, 349 (68.3%) had a traumatic injury and 162 (31.7%) had a non-traumatic injury; 375 (73.4%) were male and 136 (26.6%) were female; 191 (37.4%) had a complete paraplegia, 158 (30.9%) had an incomplete paraplegia, 54 (10.6%) had a complete tetraplegia and 108 (21.1%) had an incomplete tetraplegia.

10.1.3 Paper III. A cross-sectional study on persons with SCI based on an individual assessment.

Data were collected on individuals with SCI now living in the community, who completed a comprehensive follow-up assessment at the Institute Guttmann in Barcelona, Spain. A total of 1036 individuals with SCI attended an annual comprehensive hospital checkup between April 2, 2007 and October 8, 2008. Only those who completed the Patient Health Questionnaire 9 (PHQ-9) were included, giving a total of 831 individuals. Of the 831, 556 (66.9%) had a traumatic injury and 275 (33.1%) had a non-traumatic injury; 597 (71.8%) were male and 234 (28.2%) were female; 294 (35.4%) had a complete paraplegia, 265 (31.9%) had an incomplete paraplegia, 106 (12.8%) had a complete tetraplegia and 166 (20%) had an incomplete tetraplegia. The mean age was 49.84 years, range 18-89 years.

10.2. Instruments and main outcome measures

The following questionnaires were chosen as they are frequently used to measure the concepts addressed in this thesis, they have good psychometric properties and have previously been used with individuals with SCI.

10.2.1. *The West Haven-Yale Multidimensional Pain Inventory*

The West Haven-Yale Multidimensional Pain Inventory (MPI) was developed to gain the subjective experiences of many aspects of chronic pain¹⁵⁸. It is a 52-item, 12-subscales inventory divided into three sections: 1) pain experiences; 2) responses of significant others to communications of pain; and 3) participation in daily activities. The MPI is theoretically linked to the cognitive-behavioral conceptualization of chronic pain, where emphasis is placed on the assessment of subjective distress and the impact of pain on patient's lives¹⁵⁸. Widerström-Noga et al performed factor analyses on the MPI to determine its appropriateness for use after SCI¹⁵⁹. A slightly revised version of the MPI consisting of 50-

items and 10 subscales divided into 3 sections was determined to be appropriate for use in SCI. The SCI sections include: Section 1 subscales: life interference (8-items), support (3-items), life control (3-items), pain severity (3-items); Section 2 subscales: distracting responses (4-items), negative responses (3-items), solicitous responses (5-items); Section 3 subscales: household activities (5-items), activities away from home (5-items), social activities (5-items), outdoor work (3-items)¹⁵⁹⁻¹⁶¹.

10.2.2. *The Psychological Global Well-being Index*

The Psychological Global Well-being Index (PGWBI) was developed to measure subjective psychological well-being or distress in the general population¹⁶². It explains how the individuals feel about their own health status rather than how they feel about external conditions. The questionnaire contains 22 items grouped into the following six dimensions: "Anxiety", "Depression", "Positive well-being", "Vitality", "Selfcontrol", and "General health". In the original questionnaire, scores are calculated according to the 6-point response options (6 representing the most positive response and 1 the most negative). The overall score ranges from 22-132. Scores for each of the six dimensions of the PGWBI are also obtained. For the purpose of this thesis we only used the "Positive well-being" dimension as an outcome measure of adaptation. The Spanish version of the PGWBI has shown satisfactory psychometric properties¹⁶³.

10.2.3. *Spinal Cord Lesion-related Coping Strategies Questionnaire*

The Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL CSQ)^{99,164} was developed specifically for use with individuals with SCI to explore coping processes. It contains 12 items measuring 3 coping strategies: Acceptance (degree of revaluation of life values), Fighting spirit (extent of independent behaviour in spite of the lesion), and Social reliance (tendency to display negative psychological or social dependency). Higher scores indicate that the individual tends to use that coping strategy in the given situation. The scale has good psychometric properties, with acceptable internal validity correlations and internal reliability coefficients for the three strategies. The questionnaire used in the present thesis

contained amended wording of some questionnaire items, based on the findings of previous research¹⁶⁴.

10.2.4. *Short version of the World Health Organization Quality of Life assessment*

The brief version of the World Health Organization Quality of Life assessment (WHOQOL-BREF) is an international, cross-culturally comparable QOL assessment instrument. It is being developed as a short version of the WHOQOL-100 for use in situations where time is restricted, where respondent burden must be minimised and where facet-level detail is unnecessary. The WHOQOL-BREF assessment is a self-reported questionnaire that contains 26 items, and each item represents 1 facet. The facets are defined as those aspects of life that are considered to have contributed to a person's QOL. Among those 26 items, 24 of them make up the 4 domains of physical health (7 items), psychological health (6 items), social relationships (3 items), and environment (8 items), whereas the other 2 items measure overall QOL and general health^{165,166}. Respondents rated the intensity, frequency, or evaluation of the selected attributes of QOL during the previous 2 weeks on a 5-point Likert-response scale. Higher scores on each subscale indicate a greater perceived QOL in that area. The translation process used by the WHOQOL Spanish group to develop a linguistically and culturally appropriate version for use in Spain has been revised and is reported elsewhere^{167,168}. This measure has previously been used in the SCI population¹⁶⁹. For the purpose of this thesis we only used the scores of the overall QOL.

10.2.5. *Community Integration Questionnaire*

The Community Integration Questionnaire (CIQ) was originally designed as a measurement of community integration for individuals with traumatic brain injury¹⁷⁰. The 15-item measure yields three subscales which examine Home Integration (e.g. Who does the grocery shopping at home? Who does the normal everyday housework?); Social Integration (e.g. Who looks after your personal finances?); and Productive Activities (e.g. Do you work/volunteer? How often?). Scores for these domains are generated based on the frequency of engaging in roles and activities, and responses are weighted according to

level of independence in performing roles and activities. Three items relating to employment, school and volunteer activities are scored on a 6-point scale, and the other 12-items are scored on a 3-point scale. The response scales inquire about frequency and level of independence for each activity, with higher responses indicative of higher frequency or independence. Subscales scores maybe summed together to generate a total score between 0-29; higher scores indicate higher levels of community integration. Individual domain scores of the CIQ allow the clinician to determine where individuals are succeeding or struggling in re-integration after injury. The CIQ has been validated for use with SCI populations¹⁷¹.

10.2.6. *Hospital Anxiety and Depression Scale*

The Hospital Anxiety and Depression Scale (HADS)¹⁷² was developed to assess anxiety and depression in a non-psychiatric population. Is a valid, self-rating, screening test that consists of 14 items: 7 on anxiety and 7 on depression. Responses are based on the relative frequency of symptoms over the past week, using a four point Likert scale ranging from 0 (not at all) to 3 (very often indeed). Responses are summed to provide separate scores for anxiety and depression symptomology; each of anxiety or depression scale have a score range of 0-21. Higher scores indicating greater likelihood of depression or anxiety. A cut-off point of 8/21 for the Anxiety subscale gave a specificity of 0.78 and sensitivity of 0.9; a cut-off point of 8/21 for the Depression subscale gave a specificity of 0.79 and a sensitivity of 0.83.

10.2.7. *Patient Health Questionnaire 9*

The Patient Health Questionnaire 9 (PHQ-9) is a 9 item screening measure devised to identify probable major depressive disorder (MDD) among adult primary care patients^{173,174}. The items parallel the diagnostic criteria of major depression, according to the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) . It was developed for use with medical patients to establish validity in populations with high rates of nonspecific physical symptoms that can confound a diagnosis of major depression. To be consistent with MDD diagnostic

criteria, each of the 9 depression items [(1) little pleasure or interest in doing things; (2) feeling down, depressed, or hopeless; (3) sleeping too little or too much; (4) feeling tired or having little energy; (5) poor appetite or overeating; (6) feelings of worthlessness or guilt; (7) concentration problems; (8) psychomotor retardation or agitation; and (9) thoughts of suicide] is rated according to how persistent the symptom has been in the past 2 weeks: 0 (not at all), 1 (several days), 2 (more than half the days), or 3 (nearly every day). We followed several scoring methods by which the PHQ-9 can be used as an indicator of major depression. The PHQ-9 may be used as a continuous measure of depression severity. The values for each of the 9 item scores can be summed, resulting in a total score ranging from 0 to 27. We used the cutoff value of 10 or higher to define "probable MDD", which is the optimal cutoff for identifying independently diagnosed MDD (sensitivity, .88; specificity, .88) in primary care patients¹⁷⁵. Alternatively, the PHQ-9 can be scored in a manner parallel to the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) diagnosis of MDD. With the use of the DSM-IV approach to scoring the PHQ-9, a positive screen is one where at least 5 symptoms are endorsed "more than half the days" (suicidal ideation is considered endorsed at the level of "several days"), with at least 1 being a cardinal symptom, either (1) anhedonia or (2) depressed mood. The sensitivity and specificity of these criteria are .73 and .98 respectively¹⁹. In the present study, we considered "depressed" those who met these categorical criteria. The PHQ-9 has shown to have good internal consistency and construct validity in SCI and other samples¹⁷⁴⁻¹⁷⁷.

10.3. Statistical analysis

10.3.1. Paper I

Groups and subgroups are presented as absolute numbers and percentages.

Age, age at injury, and time since injury were calculated as mean values \pm standard deviations. Continuous variables were tested with the *t*-test. Categorical data were compared using chi-square test.

Correlation between variables were analyzed with a univariate analysis, the Pearson correlation test. Data are presented with the correlation coefficient.

All tests were two-tailed and a P-value less than 0.05 was considered statistically significant.

Stepwise multiple regression analyses were used to determine which variables had the ability to predict positive well-being.

Cronbach's alpha correlations were used to assess internal reliability.

Confirmatory factor analysis (CFA) was performed for each subsection of the questionnaire in order to confirm the factor structure of the MPI-SCI-S. The CFA was conducted using analysis of moment structures (AMOS)¹⁷⁸.

10.3.2. Paper II

Groups and subgroups are presented as absolute numbers and percentages.

Age, age at injury, and time since injury were calculated as mean values \pm standard deviations. Continuous variables were tested with the *t*-test. Categorical data were compared using chi-square test. Successive one-way ANOVA tests were employed to examine the effect of socio-demographic and lesion-associated variables on coping strategies. Confirmatory factor analysis (CFA) was also conducted using robust methods and reliability coefficients.

In addition, hierarchical regression analysis was performed. In this regard, socio-demographic factors, lesion-related variables, and functional independence were entered into the sequential equations, respectively, followed by coping strategies. Furthermore, psychosocial adaptation measures were considered to be dependent variables (i.e., anxiety, depression, QOL, and social participation).

Data were analysed using the Statistical Package for Social Sciences (version 16.0) and Estructural Equation Modeling Software EQS 6.1.^{179,180}

10.3.3. Paper III

Groups and subgroups are presented as absolute numbers and percentages.

Age, age at injury, and time since injury were calculated as mean values \pm standard

deviations.

A normality test was performed (Kolmogorov-Smirnov test) as normality was not assumed for the variables included in the analyses (all p-values <0.05).

Chi-squared analysis was used to detect any significant differences in categorical variables between groups (T-SCI vs. NT-SCI), while a Mann-Whitney U test was used for continuous variables.

An alpha level of 0.05 was used to determine statistical significance, excepting the multiple comparisons with the PHQ-9 items, where the Bonferroni correction was applied (alpha level of 0.005).

A set of logistic regression analyses were performed to determine the variables associated with depression.

11. Summary of the results

11.1. Paper I

One-hundred-and-twenty-six individuals (15% response rate) returned the packages with the questionnaires filled out. Of the 126 participants, 79 were men and 47 were women. In relation to the cause of injury, 43 (34.1%) were traumatic and 83 (65.9%) were non-traumatic.

The Spanish version of the MPI-SCI is a reliable and valid measure for evaluating chronic pain impact following SCI in a Spanish-speaking population.

The internal consistency of the MPI-SCI-S subscales ranged from acceptable ($r=0.66$, Life Control) to excellent ($r=0.94$, Life Interference). The validation instruments also displayed adequate internal consistencies, i.e., Cronbach's alpha ranging from 0.61 for the Internal Health Locus of Control (IHLC) to 0.92 for the Brief Pain Inventory Interference Scale (BPI).

All MPI-SCI-S subscales showed adequate construct validity, with the exception of the Negative and Solicitous Responses subscales.

Social support from "one person" vs. Perceived social support network (possible socio-demographic differences between Spanish and American people). The frequency of marriage was 62% vs. the original study only 31%. (High levels of social support not necessarily imply support from spouses – High support from "significant others" not imply high levels of social support).

The correlation coefficients obtained suggested that the MPI-SCI-S subscales had minimal to no relationship with the MHLC, confirming the discriminant validity of the scales.

Confirmatory factor analysis suggested that 4 items had to be removed to improve factor structure. These items may reflect cultural differences between Spanish and Americans. Afterwards, confirmatory factor analysis suggested an adequate factor structure for the MPI-SCI-S.

Three MPI-SCI-S subscales significantly predicted overall perception of well-being. A combination of high levels of support, low levels of affective distress, and a high degree of general activities was significantly associated with higher scores on the well-being subscale of the PGWB.

Overall perception of well-being was significantly predicted by a combination of 2 measures assessing the same constructs as the MPI-SCI-S. Specifically, high scores on the well-being subscale of the PGWB were associated with low scores on depression (Beck Depression Inventory¹⁸¹), and higher perceived levels of support as measured by the Duke-UNC¹⁸².

11.2. Paper II

Of the 511 individuals with SCI living in the community that participated in the study, 375 (73.4%) were male and 136 (26.6%) were female. In relation to etiology, 349 (68.3%) had a traumatic cause of injury and 162 (31.7%) a non-traumatic.

Anxiety levels: non clinical 378 (74%) - possible cases 70 (13.7%) - clinical levels 63 (12.3%).

Depressive levels: non clinical 415 (81.2%) - possible cases 65 (12.7%) - clinical levels 31 (6.1%).

No gender-based differences were observed in relation to coping strategies.

Higher scores in the Acceptance coping strategy were reported for those who were single, graduate individuals, with a traumatic etiology and younger at the onset.

Individuals who have higher educational levels (secondary or graduate) reported higher in scores on Fighting spirit.

Married individuals, with lower educational levels, who had a tetraplegia, with a non-traumatic etiology at an older age at injury onset, reported higher scores on Social reliance.

Confirmatory Factor Analysis indicated that the original correlated, three-factor model sufficiently fit the data obtained in this study.

Anxiety ($r=-0.35$), depression ($r=-0.49$), Acceptance ($r=0.48$), and Fighting spirit ($r=0.37$) correlated moderately with QOL.

Traumatic etiology and higher acceptance scores were related to increased QOL.

Being male, younger and scoring high in positive coping skills (Acceptance and Fighting spirit) was associated with better results in social participation (community integration).

Female gender, low educational level, being single, and scoring high in Social reliance were found to be predictors of increased anxiety scores. In this regard, Acceptance appeared as a protective coping skill.

High positive coping scores (Acceptance and Fighting spirit) were found to predict lower depression scores, and Social reliance appeared represent a negative coping strategy.

Acceptance and fighting spirit were positively related to adaptation outcomes (i.e: QOL, CIQ).

Acceptance was negatively related with Anxiety and Depression.

Fighting Spirit was negatively related with Depression.

Social reliance was negatively related with social participation (CIQ) and positively with anxiety and depression.

Our findings suggest that these three distinct coping strategies have differential effects over adaptation outcomes.

11.3. Paper III

A total of 831 community residing individuals with SCI were part of the sample. In relation to gender, 597 (71.8%) were male and 234 (28.2%) were female. Traumatic injury was the most frequent cause of SCI (66.9%) and was most commonly caused by motor vehicle accidents. The most frequent cause of NT-SCI was degenerative disorders, followed by neoplastic processes.

The results showed clear differences in most of the socio-demographic and injury-related variables between T-SCI and NT-SCI individuals.

T-SCI individuals were significantly younger at the time of injury compared to NT-SCI individuals.

NT-SCI individuals were significantly more likely to be female, have a lower level of education, be less engaged in currently productive activities (work, study, homemaking), less likely to be single, and have lower level incomplete injuries.

A rather large proportion of NT-SCI individuals suffered from chronic pain (55.3%), whereas a lower proportion of T-SCI individuals suffered from this condition (42.2%).

Overall, 16.2% of participants met the criteria for PMDD, though a higher prevalence was noted for NT-SCI individuals (21.1%) than for T-SCI individuals (13.8%).

Suicidal ideation was reported for 19% of the total sample. No statistically significant differences were observed between NT-SCI (22.5%) and T-SCI (17.3%).

Risk factors for PMDD between T-SCI and NT-SCI did not differ greatly.

Female gender, chronic pain and lower levels of difficulties in participation were associated with the presence of PMDD.

12. Discussion

In Catalonia, as well as internationally individuals with SCI increase their demands for holistic approach to rehabilitative interventions. Such interventions should focus on increasing possibilities for empowerment, social participation and QOL. Empowerment may be a social, cultural, psychological or political process through which individuals and social groups are able to express their needs, present their concerns, devise strategies for involvement in decision-making, and achieve political, social and cultural action to meet those needs. Health promotion not only encompasses actions directed at strengthening the basic life skills and capacities of individuals, but also at influencing underlying social and economic conditions and physical environments which impact upon health. In health promotion, empowerment is a process through which people gain greater control over decisions and actions affecting their health. Thus, rehabilitation after an SCI does not end with the hospitalization period or discharge from the ambulatory treatment, it is a process that continues over time until the person acquires the skills and strategies to cope with adversities in an adaptive way and is able to give a meaning to his or her life. For this reason it is essential for the rehabilitation system to monitor and assess injury-related and psychosocial aspects that could be involved in adjustment outcomes at a short, middle or long-term period.

12.1 Methodological issues

The compendium of studies that take part of this thesis were cross-sectional designs in nature and do not have a direct relation to each other. The main outcome measures used in each study are different in each paper and it makes difficult to compare the results or to obtain global conclusions. The most common aspect between the three papers is that are community-based studies of individuals with SCI that assisted the Institute Guttmann for the follow-up assessment at the outpatient clinic.

12.2 Socio-demographic and Injury-related variables

Our descriptive analysis revealed that the samples included in the different studies of the present thesis were similar to other previously examined cohorts as well as to the general SCI population. However, the participants of the several studies compiled in the current thesis displayed an increased mean age in comparison to other investigations⁹⁴. This might be explained by the fact that most SCI studies have focused on traumatic injuries, which tend to occur at younger ages, whereas in the samples of the present thesis we have included non-traumatic injuries, which tend to occur at older ages. However, a recent study has described a trend toward increased traumatic aetiologies among the elderly in the Spanish population⁸.

Traumatic injury was the most frequent cause of SCI in paper II and III while in paper I results showed the opposite. The findings of the current thesis confirm previous data suggesting that injury characteristics do not constitute the main predictors of psychosocial adaptation^{72,97}. However, results of paper II showed that traumatic injuries tended to yield better results when considering global QOL. This might be explained by the fact that non-traumatic lesions, which possibly result from medical processes (e.g., tumours, degenerative conditions, and vascular problems), could be associated with a longer adjustment process than traumatic injuries (i.e., individuals with SCI may be able to accept the prognosis more quickly in the case of an accident).

In paper III, depression was found to be significantly higher for NT-SCI individuals (21.1%) compared to those with T-SCI (13.8%). These results are comparable to those reported by Scivoletto et al.⁴⁷ (NT-SCI 21%; T-SCI 15%), though small sample sizes (NT-SCI: n=19) appeared to limit the significance in their case. Conversely, Migliorini et al.¹⁸³ found the prevalence of depression to be 33.9% for NT-SCI, with even higher rates reported for T-SCI (37%).

12.3 Emotional distress

Positive finding of the current thesis is that most of the participants were not depressed neither anxious. Normal levels of anxiety and depression were observed, and were similar

to those described by previous studies¹⁸⁴. Therefore, our samples appeared to be psychologically well adjusted, with a low proportion of individuals showing clinical levels of anxiety and depression (Paper II: approximately 12% and 6%, respectively; Paper III: PMDD 16.2% and no depressed 83.8%).

The results of the current thesis were consistent with previous research in relation that symptoms of depression in SCI have been related to older age, more secondary complications^{185,186}, female gender¹⁸⁶, pain¹⁸⁷, lower levels of physical and leisure activities¹⁸⁸, and less community and social participation^{108,189}; many of which are known to apply to NT-SCI individuals^{11-13,17,190}.

12.4 Predictors of adaptation outcomes

Paper I confirmed the hypothesis that having a combination of lower levels of affective distress, higher levels of general activity and lower levels of negative support predicted positive well-being. In this regard, a systematic literature review in SCI shows that social support is related to better physical (e.g., lower frequency of urinary tract infections or pressure ulcers) and mental health (e.g., lower symptoms of depression or anxiety), lower pain, effective coping, better adjustment to disability and higher life satisfaction and QOL¹⁹¹. In paper II, coping strategies as measured by SCL-CSQ-S appeared as predictors of several psychosocial adaptation outcomes. Coping mechanisms appeared to be related to adaptation, especially the strategy of Acceptance. According to Lazarus and Folkman⁸³, individuals are more likely to engage in Acceptance and active coping strategies when they perceive a stressful situation as treatable/manageable and estimate the degree to which they have the skills and/or resources to cope with their situation. Thus, those who accept the situation might be more likely to gain psychological well-being, thereby facilitating social integration into the community. As in previous reports¹⁹²⁻¹⁹⁴ Acceptance in paper II seemed to be beneficial with regard to psychosocial factors and promoted adaptive changes. In accordance with previous studies^{184,192-194} Acceptance and Fighting spirit coping strategies appeared to predict adaptation to disability in the second study of the current thesis, ultimately protecting the individual from anxiety and depression. Also in line with our

hypothesis, the Social reliance coping mechanism was negatively related to community integration, but positively associated with anxiety and depression. As shown in previous investigations, Social reliance was significantly related to lower functional outcomes and difficulties during social interactions^{120,194}.

QOL scores obtained in the present thesis were similar to those described by previous studies¹⁸⁴.

12.5 Pain and SCI

In paper I pain appeared as a predictor of perception of well-being while in paper III chronic pain resulted as a risk factor for depression. A previous study involving Spanish SCI individuals with and without chronic pain, showed statistically significant differences between the pain prevalence and the perception of psychological well-being; those who suffered chronic pain were the ones with more psychological distress⁴⁸.

Paper I was developed in a sample exclusively composed by individuals with chronic pain. Interestingly, two thirds of the total had a non-traumatic injury. Suggesting a bigger prevalence of pain among NT-SCI individuals. In the same direction, results of paper II showed a rather large proportion of NT-SCI individuals suffered from chronic pain (55.3%), whereas a lower proportion of T-SCI individuals suffered from this condition (42.2%). Regardless of aetiology, in paper III chronic pain was common among patients with SCI (45.8%) but NT-SCI reported a significant higher prevalence of this secondary complication. Most studies comparing pain prevalence between the two aetiologies have been performed during the first stages after the injury acquisition and some of them have reported a higher prevalence in T-SCI¹⁹⁵. However, Cosar et al.¹⁹⁶, found a bigger prevalence of neuropathic pain in NT-SCI (26.3%) than in T-SCI (19.6%). Notwithstanding, differences found in Paper III were not unexpected. As Werhagen et al suggested¹⁹⁷, we believe, especially in long-term, there are some characteristics associated to aetiologic profile (injury-related and demographic) that could determine that NT-SCI individuals would be more vulnerable towards chronic pain. But there is no empirical support for this hypothesis and further research is needed to test it.

Results of paper III in relation to the possible association between pain and depression were consistent with research by Hoffmann et al.¹¹⁷, who reported that higher pain scores were associated with increased odds of depression at 5 years post-SCI¹⁹³. In addition, it has been noted that females with SCI tend to suffer more from pain¹⁹⁹ and depression¹⁸⁵. There may be a relationship between all these variables and the etiology itself, given that in non-traumatic lesions there are a higher percentage of women than in traumatic injuries.

12.6. Adaptation and validation studies

Findings of Paper I and Paper II of the current doctoral thesis supported the good psychometric properties of the Spanish versions of the Multidimensional Pain Inventory for Spinal Cord Injury (MPI-SCI-S) and the Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL CSQ-S) respectively. Paper II showed evidence that cultural and linguistic equivalence was obtained in SCL CSQ-S. MPI-SCI-S subscales with the exception of the "Negative Responses" and "Solicitous Responses" subscales (perhaps due to the wording of the items and probable cultural and/or socio-demographic differences between Spanish and American people) showed satisfactory criterion-related validity and internal consistency confirming its usefulness as measure for assessing pain in individuals with SCI. In paper II, low internal consistency could be attributed to the short length of its subscales. Nevertheless, the structure of the SCL CSQ-S was robust and the results supported its use as a tool to measure the use of coping strategies in Spanish SCI individuals. Although the SCL CSQ previously demonstrated acceptable psychometric properties, only a few studies have analyzed its sensitivity to change^{120,194}.

Knowledge obtained from the validated measurement instruments in this thesis can be utilized for both research and clinical work. Paper I and II has contributed to the secondary goal of the current thesis of adapting measurement instruments to local language and culture in order to facilitate the use of these important tools in diverse clinical settings.

13. General conclusions

Most individuals with SCI living in the community appeared to be well adjusted in terms of psychosocial outcomes. Optimal levels of QOL, social participation, anxiety and depression were observed.

The importance of non injury-related factors, especially psychosocial factors, increases our understanding of long-term SCI outcomes.

It is possible that SCI individuals accept the consequences of their disability (Acceptance) through achieving goals (Fighting spirit).

Our findings have suggested the existence of two well-differenced patterns of coping:

1. Well-educated individuals, who suffered a traumatic injury when they were young, were able to effectively utilize Acceptance as a coping strategy.
2. Social reliance represented the main coping mechanism used by married individuals with a low education level, who displayed a non-traumatic aetiology.

Chronic pain is related to psychological distress and may be a risk factor to adaptation to disability in the population of SCI individuals.

Knowledge obtained from the validated measurement instruments (MPI SCI-S; SCL-CSQ-S) in this thesis can be utilized for both research and clinical work.

Individuals with NT-SCI may be more vulnerable to depression and to report lower levels of QOL than those with T-SCI. This brings a new hypothesis about a possible longer adjustment process among non-traumatic individuals.

Depression in individuals living with SCI in the community is related to the difficulties of everyday life, which may result from factors such as barriers to participation and lack of social support. It seems that these obstacles maintain depression over time.

The results presented in the current thesis reflect the importance of access to the environment and participation as an important mechanism associated with QOL and the adaptation process to disability.

The results of the current thesis highlight the need for greater awareness and implementation of treatment aims to empower individuals with SCI and facilitate their smooth reintegration into the community.

Treatment and prevention of depression and other psychological disorders, promotion of social participation and reduction of environmental barriers are targets of intervention programs.

Scheduling periodic follow-up assessments is essential to monitor, maintain, and improve the health of individuals with SCI, and to maximize opportunities for community integration, avocational and vocational achievement, and psychosocial adjustment.

Demographics of the SCI population are changing, highlighting the need for rehabilitation systems and health care providers to make appropriate adjustments in order to adapt to the requirements of the individuals with different outcomes and trajectories.

Understanding the components that are important to psychosocial adjustment and QOL of persons with a SCI is the first step in making it a reality.

14. Future research and closing remarks

The current doctoral thesis provided sound evidence for the significance of psychosocial outcomes in persons with SCI in the long-term context. It is the hope that the collected evidence can serve as basis for the targeted support of persons with SCI. In the other hand it brings new hypothesis and considerations that should be addressed in futures studies:

Prospective studies are needed to analyze the possible role of etiology in emotional responses and adaptation to the SCI.

More multivariate investigations with prospective designs of SCI outcomes including dispositional variables are needed.

Clinical trials of psychological interventions are needed in order to improve the quality of assistance and cover the needs of SCI individuals.

Longitudinal studies starting in the early-acute phase are needed to clearly infer causality and to depict the role of psychological variables in the short, mild, and the long-term context.

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Appendix I

ORIGINAL ARTICLE

Psychometric evaluation of the Spanish version of the MPI-SCI

MD Soler^{1,2}, Y Cruz-Almeida³, J Saurí^{1,2} and EG Widerström-Noga^{4,5,6,7}**Study design:** Postal surveys.**Objectives:** To confirm the factor structure of the Spanish version of the MPI-SCI (MPI-SCI-S, Multidimensional Pain Inventory in the SCI population) and to test its internal consistency and construct validity in a Spanish population.**Setting:** Guttmann Institute, Barcelona, Spain.**Methods:** The MPI-SCI-S along with Spanish measures of pain intensity (Numerical Rating Scale), pain interference (Brief Pain Inventory), functional independence (Functional Independence Measure), depression (Beck Depression Inventory), locus of control (Multidimensional health Locus of Control), support (Functional Social Support Questionnaire (Duke-UNC)), psychological well-being (Psychological Global Well-Being Index) and demographic/injury characteristics were assessed in persons with spinal cord injury (SCI) and chronic pain ($n=126$).**Results:** Confirmatory factor analysis suggested an adequate factor structure for the MPI-SCI-S. The internal consistency of the MPI-SCI-S subscales ranged from acceptable ($r=0.66$, Life Control) to excellent ($r=0.94$, Life Interference). All MPI-SCI-S subscales showed adequate construct validity, with the exception of the Negative and Solicitous Responses subscales.**Conclusions:** The Spanish version of the MPI-SCI is adequate for evaluating chronic pain impact following SCI in a Spanish-speaking population. Future studies should include additional measures of pain-related support in the Spanish-speaking SCI population.*Spinal Cord* (2013) **51**, 538–552; doi:10.1038/sc.2013.21; published online 23 April 2013**Keywords:** psychometric properties; spinal cord injuries; chronic pain; Multidimensional Pain Inventory; validity

INTRODUCTION

Longstanding pain is a major complication after spinal cord injury (SCI) affecting approximately 80% of patients,¹ which is associated with lower levels of psychological well-being^{2,3} and decreased daily function.⁴ Therefore, a reduction in pain's effects on functioning is an important goal of all pain interventions. Consequently, a comprehensive pain assessment taking multiple aspects of the psychosocial impact into account is integral to designing optimal treatments.

The West Haven-Yale Multidimensional Pain Inventory is a self-report questionnaire measuring the impact of pain on an individual's life, how others respond to that person's pain and frequency at which the individual engages in specific daily activities.⁵ The MPI has been used in numerous pain populations and has been found to have good psychometric properties including sensitivity to a variety of treatments. The IMMPACT group⁶ has recommended this instrument for the assessment of individuals suffering from chronic pain and as an outcome measure in clinical trials.

In the original Spanish validation of the West Haven-Yale Multidimensional Pain Inventory,⁷ the authors also concluded that the Spanish MPI was acceptable to measure important domains related to chronic pain such as perceptions of impact of pain on daily life, social

support, self-control and activity levels. However, that version⁷ was developed for Spanish chronic pain patients in general, and not for individuals with chronic pain and physical impairments such as SCI. Thus, it is inappropriate to assume that measures developed to be used with other chronic pain populations can be readily used in people with SCI.

Based on exploratory and confirmatory factor analyses, Widerström-Noga and colleagues revised the MPI for use in the SCI chronic pain population.⁴ The reliability and validity of the MPI-SCI for most subscales were later demonstrated in a sample of individuals with SCI and chronic pain.^{2,8} Despite the widespread use of the MPI in clinical pain practice in Spain to assess pain impact,⁷ the psychometric properties of a Spanish version of the MPI-SCI (MPI-SCI-S) have not yet been evaluated. The primary purposes of the present investigation were to: (1) confirm the factor structure of the MPI-SCI-S; (2) test its internal consistency, and (3) construct validity.

MATERIALS AND METHODS

Individuals who received an annual assessment at the outpatient SCI clinic (April 2005–July 2007) were informed about the study. Those who agreed to participate were given a questionnaire package including the MPI-SCI-S (Appendix) that was sent back by mail. Demographic and injury information

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was collected from patient's medical records. Participants were: (1) over 18 years old, (2) had chronic pain (>1 year), (3) chronic SCI (>2 years) and (4) average pain intensity of three or more on a Numerical Rating Scale (NRS). The Ethics Committee of the Hospital of Neurorehabilitation Institut Guttmann approved the study.

MPI-SCI

The MPI is a 60-item questionnaire⁵ based on the cognitive-behavioral perspective on chronic pain answered on a 7-point Likert scale. It comprises Section 1 (pain impact), Section 2 (responses by significant others) and Section 3 (common activities) with subscales assessing pain severity, pain interference, affective distress, control over life, support from significant others, responses by significant others (negative, distracting and solicitous responses) and the performance of common, general activities (Table 1). The MPI-SCI^{2,8} is a modified version of the MPI developed to be used in persons with SCI where Section 3 asks about pain-specific interference.

Translation of the MPI-SCI

The development of the MPI-SCI-S and evaluation of its psychometric properties were performed according to recommendations for adaptation and validity of health questionnaires and diagnostic tests.⁹ The original English version of the MPI-SCI was translated by a co-author (Yenisel Cruz-Almeida). The translation was reviewed by three experts including two specialists in pain management and a clinical pain researcher. As the original version of the questionnaire was well defined and structured, the expert panel did not consider it necessary to redefine its sections or reformulate any of the original questions. No cultural bias that could be equivocal or non-translatable was detected in the original instrument. This intermediate version was then tested in a sample of seven patients to assess initial feasibility and other potential comprehension problems. The final version was back-translated into English by two other professional translators (different from the first translator and English natives) and again reviewed and approved by the panel experts. The MPI-SCI-S is presented in the Appendix.

NRS

Participants rated their average pain intensity during the past week on a 0–10 NRS, with anchors 0 (no pain) and 10 (pain as bad as could be). The NRS¹⁰ was recommended by the IMMPACT group for use in pain clinical trials⁶ and by the 2006 NIDRR SCI Pain outcome measures group.¹¹

Table 1 Scales, subscales used in the present study and their abbreviations

<i>Scales and subscales</i>	<i>Abbreviations</i>
MPI-SCI pain severity	PS
MPI-SCI life interference	LI
MPI-SCI life control	LC
MPI-SCI affective distress	AD
MPI-SCI support	S
MPI-SCI negative responses	NR
MPI-SCI solicitous responses	SR
MPI-SCI distracting responses	DR
MPI-SCI general activity	GA
MPI-SCI pain interference with activities	PA
Numerical rating scale	NRS
Brief pain inventory	BPI
Beck depression inventory	BDI
Duke-UNC functional social support questionnaire	Duke-UNC
Internal health locus of control	IHLC
Powerful others health locus of control	PHLC
Chance health locus of control	CHLC
Functional independence measure	FIM

Brief Pain Inventory (BPI) interference

The 12-item subscale measures the interference with general activity, sleep, mood and enjoyment of life, walking ability, ability to work and perform daily tasks, and relationship with other people. The BPI was adapted for people with physical impairments and SCI, and it has shown excellent psychometric properties in this population.¹²

Beck Depression Inventory (BDI)

The BDI is a 21-item scale measuring symptoms indicative of clinical depression. The measure is considered to be reliable in the SCI population.^{8,13}

Multidimensional Health Locus of Control (MHLC)

The MHLC¹⁴ consists of three subscales: (1) the internal health locus of control subscale that assesses the extent to which one believes that internal factors are responsible for health and illness; (2) the chance health locus of control (CHLC) subscale that assesses the extent to which one believes that health and illness are a matter of fate, luck or chance; and (3) the powerful other health locus of control subscale assessing the belief that one's health is determined by powerful others. Previous research has supported its use in SCI.¹⁴

Functional Independence Measure (FIM)

The FIM¹⁵ quantifies severity of activity limitation by assessing performance in six areas: self-care, locomotion, mobility, sphincter control, communication and cognition. In the current study, only FIM scores related to motor independence were analyzed. This subscale has shown excellent internal consistency⁸ and can be administered in-person or via telephone format.¹⁶

Duke-UNC

The Duke-UNC Functional Social Support Questionnaire¹⁷ is a self-administered instrument designed for use in primary care settings. It measures two components of perceived emotional support: confidant and affective support. Moderate-to-excellent reliability and validity of the scale are supported by a previous study in Spain.¹⁷

Psychological Global Well-being Index (PGWBI)

The PGWBI was developed to measure subjective psychological well-being or distress in the general population. The Spanish version of the PGWBI has shown satisfactory psychometric properties.¹⁸ The questionnaire contains 22 items grouped into six dimensions, but for the present study the 'positive well-being' dimension was used for analyses.

Statistical analysis

Using SPSS 20.0, Pearson correlations and paired *t*-tests were used for continuous variables and χ^2 tests were used for dichotomous variables. All tests were two-tailed and a *P*-value less than 0.05 was considered statistically significant. Cronbach's alpha correlations were used to assess internal reliability. To assess the ability of the MPI-SCI-S to predict positive well-being, two separate stepwise multiple regression analyses were performed with positive well-being as the dependent variable. In order to confirm the factor structure of the MPI-SCI-S, a confirmatory factor analysis (CFA) was performed for each subsection of the MPI-SCI-S (that is, pain impact, interpersonal support and activities). The CFA was conducted using analysis of moment structures (AMOS)¹⁹ as previously described.⁸

RESULTS

Participants

The study postal packages containing consent forms and questionnaires were given to a total of 558 subjects with a 22.6% response rate (*n* = 126). Detailed demographic and injury-related characteristics are presented in Table 2. No significant differences were found between responders and non-responders with the exception of educational level.

Table 2 Demographic and injury characteristics of participants with chronic pain duration greater than 6 months who were invited to participate in the study (n = 558)

	Respondents (n = 126)	Non-respondents (n = 432)	P-value
Age (years), mean ± s.d.	49.0 ± 13.8	49.6 ± 17.5	0.714
Time since injury (years), mean ± s.d.	11.8 ± 10.8	11.8 ± 9.9	0.989
Gender, n (%)			
Men	78 (61.9)	298 (69.0)	0.136
Women	48 (38.1)	134 (31.0)	
Neurological level of injury, n (%)			
ASIA A complete	78 (61.9)	241 (64.8)	0.379
ASIA B incomplete	20 (15.9)	42 (11.3)	
ASIA C incomplete	28 (22.2)	85 (22.8)	
ASIA D incomplete	0 (0)	4 (1.1)	
SCI etiology, n (%)			
Traumatic	43 (34.1)	172 (39.8)	0.248
Non-traumatic	83 (65.9)	260 (60.2)	
Marital status, n (%)			
Married	79 (62.7)	244 (58.4)	0.074
Single	36 (28.6)	138 (33.0)	
Separated	6 (4.8)	7 (1.7)	
Divorced	3 (2.4)	6 (1.4)	
Widowed	2 (1.6)	23 (5.5)	
Education level, n (%)			
Elementary school or less	59 (46.8)	261 (60.4)	0.005
High school completion	45 (35.7)	95 (22.0)	
At least college	22 (17.5)	63 (14.6)	

Abbreviation: ASIA, American Spinal Injury Association (ASIA) impairment scale; SCI, spinal cord injury.

Reliability internal consistency

The Cronbach's alpha of the MPI subscales averaged 0.81 and ranged from 0.66 (LC) to 0.94 (LI). The validation instruments displayed coefficients ranging from 0.61 (internal health locus of control) to 0.92 (BPI; Table 3).

Convergent validity

All subscales, except the NR and the SR, were strongly correlated with the hypothesized-related construct (Table 4). The PS subscale was highly ($r=0.67$) correlated with the NRS, whereas LI was strongly ($r=0.75$) correlated with the BPI. Although the S ($r=0.36$) and DR subscales ($r=0.35$, $P<0.001$) were significantly correlated with the Duke-UNC, the NR and the SR subscales were not significantly correlated with the Duke-UNC.

Discriminant validity

To examine discriminant validity, the LC, S, DR, NR and the SR subscales were compared with the MHLC chance orientation, whereas all other MPI subscales were compared with the powerful other orientation of the MHLC, a construct hypothesized to correlate only moderately or minimally with the MPI subscales. There were trivial correlations between the MPI subscales and the MHLC (Table 4).

Table 3 Internal consistencies of the MPI-SCI subscales and validation instruments

MPI-SCI scales	Cronbach's alpha MPI-SCI	Cronbach's alpha Validation instruments
Pain severity	0.79 (3)	NRS, NA
Life interference	0.94 (8)	BPI, 0.92 (7)
Life control	0.66 (3)	IHLHC, 0.61 (6)
Affective distress	0.80 (3)	BDI, 0.85 (18)
Support	0.88 (3)	Duke-UNC, 0.87 (11)
Negative responses	0.77 (3)	Duke-UNC, 0.87 (11)
Solicitous responses	0.69 (5)	Duke-UNC, 0.87 (11)
Distracting responses	0.74 (4)	Duke-UNC, 0.87 (11)
General activity	0.88 (18)	FIM, 0.88 (13)
Pain interference with activities	0.93 (18)	BPI, 0.92 (7)

Abbreviations: BDI, Beck Depression Inventory; BPI, Brief Pain Inventory; Duke-UNC, Functional Social Support Questionnaire; FIM, Functional Independence Measure; IHLHC, internal health locus of control; NRS, Numerical Rating Scale.

Table 4 Construct validity of the MPI-SCI subscales and validation instruments

Spanish MPI-SCI scales	Convergent validity Instrument, r, probability	Discriminant validity Instrument, r, probability
Pain severity	NRS, 0.67, $P<0.000$	PHLC, 0.18, $P=0.054$
Life interference	BPI, 0.75, $P<0.000$	PHLC, 0.14, $P=0.119$
Life control	Self-control, 0.35, $P<0.000$	CHLC, -0.09, $P=0.312$
Affective distress	BDI, 0.48, $P<0.000$	PHLC, -0.05, $P=0.556$
Support	Duke-UNC, 0.36, $P<0.000$	CHLC, 0.12, $P=0.214$
Negative responses	Duke-UNC, -0.19, $P=0.056$	CHLC, 0.13, $P=0.161$
Solicitous responses	Duke-UNC, 0.17, $P=0.076$	CHLC, 0.10, $P=0.289$
Distracting responses	Duke-UNC, 0.35, $P<0.000$	CHLC, 0.11, $P=0.254$
General activity	FIM, 0.35, $P<0.05$	PHLC, -0.06, $P=0.517$
Pain interference with activities	BPI, 0.50, $P<0.000$	PHLC, 0.02, $P=0.979$

Abbreviations: BDI, Beck Depression Inventory; BPI, Brief Pain Inventory; CHLC, Chance health Locus of Control; Duke-UNC, Functional Social Support Questionnaire; FIM, Functional Independence Measure; NRS, Numerical Rating Scale; PHLC, Powerful Other Health Locus of Control.

Predictive validity

To examine the ability of the MPI-SCI-S to predict a person's perception of positive well-being, all MPI-SCI-S subscales were entered as independent variables in a stepwise multiple regression analysis with the well-being subscale of the PGWB score as the dependent variable (Table 5). High levels of S ($P<0.01$), low levels of AD ($P<0.001$) and a high degree of GA ($P<0.01$) were significantly ($P<0.001$) associated with higher scores on the well-being subscale of the PGWB. Similarly, when all the validation measures were entered in a second regression, overall perception of well-being was significantly ($P<0.001$) predicted by low scores on the BDI ($P<0.01$), and higher scores on the Duke-UNC ($P<0.01$) (Table 5).

CFA

In order to assess the fit of the hypothesized model in each section of the MPI, fit indices greater than 0.75 were deemed appropriate similar to criteria used in previous studies using the MPI-SCI.^{6,8} All indexes supported adequate fit of the hypothesized models in Section 1

Table 5 Stepwise regression analysis predicting a person's perception of well-being

Variables ^a	Standardized coefficient	t-value	Probability
Affective distress	-0.308	-3.68	0.000
General activities	0.264	3.16	0.002
Negative support	-0.263	-3.15	0.002
BDI	-0.293	-2.92	0.004
Duke-UNC	0.272	2.71	0.008

Abbreviations: BDI, Beck Depression Inventory; Duke-UNC, Functional Social Support Questionnaire; PGWB, Psychological Global Well-Being.

^aDependent variable: well-being subscale of the PGWB ($n=126$); multiple $R^2=0.30$; adjusted multiple $R^2=0.28$; F-ratio=14.7; $P<0.000$.

^bDependent variable: well-being subscale of the PGWB ($n=126$); multiple $R^2=0.24$; adjusted multiple $R^2=0.24$; F-ratio=15.7; $P<0.000$.

(NFI = 0.81, CFI = 0.89) and Section 2 (NFI = 0.77, CFI = 0.86). However, fit indices of the 18 items in Section 3 suggested that the model could be significantly improved (NFI = 0.72, CFI = 0.73). After re-inspecting the data, four items did not apply to many participants. These were: 'How often do you mow the lawn?' (17.4%); 'How often do you work in the garden?' (31.4%), 'How often do you wash the car?' (60%) and 'How often do you work on the car?' (60%). Therefore, these items were removed to reassess model fit within Section 3 and the new model indices supported an improved and adequate fit (NFI = 0.88, CFI = 0.89).

DISCUSSION

The results of the present study suggest that the MPI-SCI-S is a reliable and valid measure for use in the Spanish SCI chronic pain population with the exception of the Negative and Solicitous responses subscales. The subscales of the MPI-SCI-S demonstrated acceptable reliability coefficients (0.66 to 0.94). High Cronbach's alpha coefficients indicate that the items of the MPI-SCI-S are consistent in the domains they measure. Coefficients below 0.60 indicate inadequate reliability, and coefficients greater than 0.90 indicate excellent reliability useful for making individual treatment decisions. Our results are also similar to those obtained for the original MPI-SCI, which were reported to be consistently greater than 0.60.⁸

The present study also demonstrated that the MPI-SCI-S has acceptable construct validity across the pain intensity, pain interference, locus of control, social support and functional independence domains with the exception of the negative responses and solicitous responses. Unlike reliability, it is uncommon for a correlation (that is, validity) coefficient to be greater than 0.50, and rarely exceeding 0.50. Moreover, a recent review of depression and anxiety measures in the SCI population,¹³ used the following criteria for validity coefficients: (1) excellent (≥ 0.60); (2) adequate (0.30–0.59); and (3) 'poor' (≤ 0.29). According to these criteria the PS and LI subscales had excellent validity, the LC, AD, S, DR, GA and PA had adequate validity, whereas the NR and SR subscales had poor validity. The poor validity coefficients for the NR and SR subscales using the Duke-UNC scale might be related to the wording of the items. Although the MPI-SCI-S significant other subscales ask specifically about the perceptions of the person who suffers from pain regarding social support from one person identified as the 'significant other', the Duke-UNC items are concerned with the perceived social support network. It is also possible that this result indicates cultural and socio-demographic differences between Spanish and American people. For example, in

the original version developed by Widerström-Noga,⁸ only 31% of the subjects were married, whereas the marriage frequency was doubled (62%) in our sample. Having high levels of social support does not necessarily imply high levels of support from spouses or significant others or conversely having high levels of support from significant others does not guarantee high levels of social support.

The present results also support the discriminant validity of the MPI-SCI-S subscales. It was hypothesized that the internal health locus of control (IHLOC) would correlate more highly with a similar construct, namely, life control, and lower with the less related subscales of the MPI-SCI. Consistent with previous research we found only minimal to no relationships between MPI-SCI-S subscales and the MHLC.⁸

The CFA of the activity subscales of the MPI-SCI-S suggested that several items had to be removed to improve the factor structure. In particular, items infrequently endorsed, such as, activities involving work in the garden or on the car were removed. This may reflect cultural differences relating to different ways of life.

In the original MPI-SCI, the authors hypothesized that the subscales of the MPI-SCI and the set of measures used for testing the convergent validity should be able to predict satisfaction with life in a person with SCI. In the present study, we used a person's perception of well-being, which is a dimension of the PGWB and another measure of quality of life. Similar to the study by Widerström-Noga *et al.*,⁸ we confirmed the hypothesis that having a combination of lower levels of affective distress, higher levels of general activity and lower levels of negative support predicted positive well-being. A previous study involving SCI patients with and without chronic pain, showed statistically significant differences between the pain prevalence and the perception of psychological well-being; those who suffered chronic pain were the ones with more psychological distress.³

Several limitations to this study should be noted. At the time of study design, we did not include measures to analyze test-retest stability of the MPI-SCI-S. Future research is needed to test the stability of the MPI-SCI-S over time in the Spanish population. However, the MPI-SCI-S showed excellent internal consistency indicating adequate reliability. Another potential limitation is that the instruments used in this study were administered via postal surveys and the return rate was very low 22.6%. A possible explanation for this low response rate could be the lack of motivation of the participants to complete the questionnaires. Unlike many other studies, subjects did not receive any kind of financial reward to answer the questions. In addition, the set of questionnaires was quite long and required a relatively long time to be completed. Another possible explanation could be that the educational level was a limitation to understand the content of the questions. Many participants who never returned the questionnaires (60.4%) reported an educational level of elementary school or less compared with our participants (46.8%). Finally, future psychometric studies in different Spanish speaking populations with SCI should be performed to assess transcultural validation.

In conclusion, the MPI-SCI-S subscales with the exception of the NR and SR subscales were found to have satisfactory criterion-related validity and internal consistency confirming its usefulness as a measure for assessing multidimensional pain in individuals with SCI. Future studies should include additional measures of social support to adequately assess this domain.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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APPENDIX

INVENTARIO MULTIDIMENSIONAL DE DOLOR (Para personas con lesión medular)

Fecha: _____

¿Cuándo le comenzó el dolor? Mes: _____ Año: _____

Instrucciones

Uno de los factores más importantes de nuestra evaluación incluye el examen de su dolor desde su punto de vista porque obviamente usted es la persona que mejor puede identificar su dolor. Las siguientes preguntas están diseñadas para detallar aspectos de su dolor y la manera en que este le afecta en su vida. **El cuestionario tiene tres secciones.** Debajo de cada pregunta hay una escala donde usted puede marcar su respuesta. Lea cada pregunta con atención y *haga un círculo alrededor del número* que correctamente se adapte a su condición en la escala. Si encuentra que la pregunta no le implica a usted, por favor *haga un círculo alrededor del número que está delante de la pregunta*. Cuando haya completado el cuestionario, revise sus respuestas para verificar que haya respondido a todas las preguntas. Use la última página para añadir información o comentarios adicionales que nos puedan ayudar a entender mejor su problema con el dolor.

Antes de comenzar, conteste las dos siguientes preguntas de pre-evaluación.

1. Algunas preguntas del cuestionario se refieren a la persona a quien usted se siente más apegada. Esta persona puede ser su esposo o esposa, o puede estar relacionada con usted de otra manera. Es muy importante que usted identifique a alguien en esta capacidad. Indique con cual de las siguientes personas usted considera que tiene dicha relación (por favor, escoja solamente una):

- | | | |
|--|--|---|
| <input type="checkbox"/> Esposo / Esposa | <input type="checkbox"/> Compañero / Compañera | <input type="checkbox"/> Compañero de casa o de cuarto |
| <input type="checkbox"/> Amigo / Amiga | <input type="checkbox"/> Vecino | <input type="checkbox"/> Padre, Madre, Hijo, Hija u otro familiar |
| <input type="checkbox"/> Otra persona: _____ | | |

2. ¿Vive usted actualmente con esta persona?

- Sí
 No

Cuando conteste las preguntas que refieren a su esposo o esposa, siempre responda en referencia a esta persona que usted acaba de indicar.

Sección I

Esta parte le hace preguntas para ayudarnos a conocer más acerca de su dolor y como este le afecta en su vida. Debajo de cada pregunta hay una escala para que usted pueda contestar. Lea cada pregunta con atención y *haga un círculo alrededor del número* que correctamente se adapte a su condición en la escala. El siguiente ejemplo puede ayudarle a comprender mejor como debería contestar estas preguntas.

Ejemplo

¿ En que medida se siente nervioso cuando va en coche y el tráfico es abundante ?

0	1	2	3	4	5	6
<i>nada nervioso</i>						<i>extremadamente nervioso</i>

Si usted no se siente nervioso cuando viaja en coche con tráfico abundante, pondría un círculo alrededor del número 0. Si usted se siente extremadamente nervioso cuando viaja en coche con tráfico abundante, pondría un círculo alrededor del número 6. El número 0, sería usado para indicar que usted no se pone nada nervioso y el número 6, sería usado para indicar que usted se pone extremadamente nervioso.

1. Indique el nivel de su dolor en este momento.

0	1	2	3	4	5	6
<i>ningún dolor</i>						<i>dolor muy intenso</i>

2. Por lo general, ¿En que medida interfiere el dolor en sus actividades diarias?

0	1	2	3	4	5	6
<i>no interfiere</i>						<i>interfiere extremadamente</i>

3. Desde que le comenzó el dolor, ¿En que medida este ha cambiado su habilidad para trabajar?

0	1	2	3	4	5	6
<i>no ha cambiado</i>						<i>ha cambiado mucho</i>

4. ¿En que medida ha cambiado el dolor la satisfacción o el placer que recibe de sus actividades sociales o de recreo?

0	1	2	3	4	5	6
<i>ningún cambio</i>						<i>ha cambiado extremadamente</i>

5. ¿Recibe apoyo o ayuda de su esposo(a) en relación a su dolor?

0	1	2	3	4	5	6
<i>no me ayuda en nada</i>						<i>me ayuda en todo lo posible</i>

6. Indique su estado emocional durante esta última semana.

0	1	2	3	4	5	6
<i>extremadamente bajo o deprimido</i>						<i>extremadamente alto</i>

7. ¿En que medida ha interferido el dolor en su capacidad para descansar de forma suficiente?

0	1	2	3	4	5	6
<i>no ha interferido</i>						<i>ha interferido extremadamente</i>

8. Más o menos, ¿qué intensidad ha tenido su dolor durante la última semana?

0	1	2	3	4	5	6
<i>nada intenso</i>						<i>extremadamente intenso</i>

9. ¿En que medida puede usted anticipar cuando su dolor comenzará, mejorará, o aumentará?

0	1	2	3	4	5	6
<i>nunca puedo anticipar</i>						<i>frecuentemente puedo anticipar</i>

10. ¿En que medida ha cambiado el dolor su habilidad para participar en actividades sociales o de recreo?

0	1	2	3	4	5	6
<i>ningún cambio</i>						<i>ha cambiado extremadamente</i>

11. ¿ En que medida limita usted sus actividades para prevenir un aumento en su dolor?

0	1	2	3	4	5	6
<i>nada</i>						<i>mucho</i>

12. ¿ En que medida el dolor ha cambiado la satisfacción o el placer que recibe de sus actividades familiares?

0	1	2	3	4	5	6
<i>ningún cambio</i>						<i>ha cambiado extremadamente</i>

13. ¿ En que medida su esposo(a) se preocupa por usted a causa de su dolor?

0	1	2	3	4	5	6
<i>no está preocupado</i>						<i>está extremadamente preocupado</i>

14. Durante *la última semana*, ¿ siente que ha tenido el control sobre su vida?

0	1	2	3	4	5	6
<i>ningún control</i>						<i>mucho control</i>

15. En un día típico, ¿ En que medida cambia su dolor (aumenta o mejora)?

0	1	2	3	4	5	6
<i>no cambia</i>						<i>cambia bastante</i>

16. ¿ En que medida sufre a causa de su dolor?

0	1	2	3	4	5	6
<i>no sufro</i>						<i>sufro extremadamente</i>

17. ¿Con qué frecuencia puede hacer algo que reduzca su dolor?

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

18. ¿ En que medida ha cambiado el dolor sus relaciones con su esposo(a), familia u otra gente?

0	1	2	3	4	5	6
<i>no ha cambiado</i>						<i>ha cambiado extremadamente</i>

19. ¿ En que medida ha cambiado el dolor la satisfacción que recibe de su trabajo (___ marque aquí si usted actualmente no trabaja)

0	1	2	3	4	5	6
<i>no ha cambiado</i>						<i>ha cambiado extremadamente</i>

20. ¿ En que medida le presta atención su esposo(a) a causa de su dolor?

0	1	2	3	4	5	6
<i>no me presta atención</i>						<i>me presta mucha atención</i>

21. Durante *la última semana*, ¿ En que medida siente que se ha podido enfrentar a sus problemas?

0	1	2	3	4	5	6
<i>no he podido</i>						<i>he podido muy bien</i>

22. ¿ En que medida siente que tiene control sobre su dolor?

0	1	2	3	4	5	6
<i>no tengo ningún control</i>						<i>tengo mucho control</i>

23. ¿ En que medida ha cambiado el dolor su habilidad para hacer las tareas de la casa?

0	1	2	3	4	5	6
<i>no ha cambiado</i>						<i>ha cambiado mucho</i>

24. Durante *la última semana*, ¿ En que medida ha tenido éxito al enfrentarse con situaciones problemáticas en su vida?

0	1	2	3	4	5	6
<i>ningún éxito</i>						<i>mucho éxito</i>

25. ¿ En que medida ha interferido el dolor en su habilidad para planear actividades?

0	1	2	3	4	5	6
<i>no ha interferido</i>						<i>ha interferido extremadamente</i>

26. Durante *la última semana*, ¿ En que medida se ha sentido irritable?

0	1	2	3	4	5	6
<i>nada irritable</i>						<i>extremadamente irritable</i>

27. ¿ En que medida el dolor ha cambiado o interferido en sus amistades con personas fuera de su familia?

0	1	2	3	4	5	6
<i>ningún cambio</i>						<i>ha cambiado extremadamente</i>

28. Durante *la última semana*, ¿ En que medida se ha sentido tenso o ansioso?

0	1	2	3	4	5	6
<i>nada tenso o ansioso</i>						<i>Extremadamente tenso o ansioso</i>

Sección II

En esta sección estamos interesados en saber como su esposo(a) (u otra persona con la que usted vive o pasa la mayoría de su tiempo) responde cuando sabe que usted tiene mucho dolor. En la escala debajo de cada pregunta, haga un círculo alrededor del número que indique con que frecuencia su esposo(a), u otra persona, le responde de este modo cuando su dolor es muy fuerte.

1. Me ignora.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

2. Me pregunta si me puede ayudar y como.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

3. Me lee.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

4. Se irrita conmigo.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

5. Hace el trabajo o las tareas que yo debería hacer.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

6. Me habla de otras cosas para distraerme del dolor.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

7. Se frustra conmigo.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

8. Trata de que yo descanse.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

9. Trata de que yo participe en una actividad.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

10. Se enfada conmigo.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

11. Me da medicamentos para el dolor.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

12. Me anima para que yo trabaje en un pasatiempo.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

13. Me proporciona algo de comer o beber.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

14. Enciende la televisión para distraerme del dolor.

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

Sección III

Abajo hay una lista de 18 actividades diarias. Por favor indique **con qué frecuencia** usted participa en estas. En la escala debajo de cada pregunta haga un círculo alrededor del número que indique mejor **cómo el dolor** afecta su participación en dichas actividades.

1. Lavar los platos:

a. ¿Con qué frecuencia realiza esta actividad?

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

b. El dolor reduce mi participación en esta actividad:

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

2. Cortar el césped (___ marque aquí, si usted no tiene césped):

a. ¿Con qué frecuencia realiza esta actividad?

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

b. El dolor reduce mi participación en esta actividad:

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

3. Comer fuera de casa:

a. ¿Con qué frecuencia realiza esta actividad?

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

b. El dolor reduce mi participación en esta actividad:

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

4. Jugar a las cartas u otros juegos:

a. ¿Con qué frecuencia realiza esta actividad?

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

b. El dolor reduce mi participación en esta actividad:

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

5. Ir de compras al supermercado:

a. ¿Con qué frecuencia realiza esta actividad?

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

b. El dolor reduce mi participación en esta actividad:

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

6. Trabajar en el jardín (___ marque aquí si usted no tiene jardín):

a. ¿Con qué frecuencia realiza esta actividad?

0 1 2 3 4 5 6
nunca muy frecuentemente

b. El dolor reduce mi participación en esta actividad:

0 1 2 3 4 5 6
nunca muy frecuentemente

7. Ir al cine:

a. ¿Con qué frecuencia realiza esta actividad?

0 1 2 3 4 5 6
nunca muy frecuentemente

b. El dolor reduce mi participación en esta actividad:

0 1 2 3 4 5 6
nunca muy frecuentemente

8. Visitar amigos:

a. ¿Con qué frecuencia realiza esta actividad?

0 1 2 3 4 5 6
nunca muy frecuentemente

b. El dolor reduce mi participación en esta actividad:

0 1 2 3 4 5 6
nunca muy frecuentemente

9. Ayudar con la limpieza de la casa:

a. ¿Con qué frecuencia realiza esta actividad?

0 1 2 3 4 5 6
nunca muy frecuentemente

b. El dolor reduce mi participación en esta actividad:

0 1 2 3 4 5 6
nunca muy frecuentemente

10. Reparar el coche (___ marque aquí si usted no tiene coche):

a. ¿Con qué frecuencia realiza esta actividad?

0 1 2 3 4 5 6
nunca muy frecuentemente

b. El dolor reduce mi participación en esta actividad:

0 1 2 3 4 5 6
nunca muy frecuentemente

11. Viajar en coche o en autobús:

a. ¿Con qué frecuencia realiza esta actividad?

0 1 2 3 4 5 6
nunca muy frecuentemente

b. El dolor reduce mi participación en esta actividad:

0 1 2 3 4 5 6
nunca muy frecuentemente

12. Visitar familia (____ marque aquí si usted no tiene familia más cerca que 150 Km):

a. ¿Con qué frecuencia realiza esta actividad?

0 1 2 3 4 5 6
nunca muy frecuentemente

b. El dolor reduce mi participación en esta actividad:

0 1 2 3 4 5 6
nunca muy frecuentemente

13. Hacer la comida:

a. ¿Con qué frecuencia realiza esta actividad?

0 1 2 3 4 5 6
nunca muy frecuentemente

b. El dolor reduce mi participación en esta actividad:

0 1 2 3 4 5 6
nunca muy frecuentemente

14. Lavar el coche (____ marque aquí si usted no tiene coche):

a. ¿Con qué frecuencia realiza esta actividad?

0 1 2 3 4 5 6
nunca muy frecuentemente

b. El dolor reduce mi participación en esta actividad:

0 1 2 3 4 5 6
nunca muy frecuentemente

15. Ir de viaje:

a. ¿Con qué frecuencia realiza esta actividad?

0 1 2 3 4 5 6
nunca muy frecuentemente

b. El dolor reduce mi participación en esta actividad:

0 1 2 3 4 5 6
nunca muy frecuentemente

16. Ir a un parque o a una playa:

a. ¿Con qué frecuencia realiza esta actividad?

0 1 2 3 4 5 6
nunca muy frecuentemente

b. El dolor reduce mi participación en esta actividad:

0 1 2 3 4 5 6
nunca muy frecuentemente

17. Lavar la ropa:

a. ¿Con qué frecuencia realiza esta actividad?

0 1 2 3 4 5 6
nunca muy frecuentemente

b. El dolor reduce mi participación en esta actividad:

0 1 2 3 4 5 6
nunca muy frecuentemente

Hacer reparos necesarios en el hogar:

a. ¿Con qué frecuencia realiza esta actividad?

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

b. El dolor reduce mi participación en esta actividad:

0	1	2	3	4	5	6
<i>nunca</i>						<i>muy frecuentemente</i>

Appendix II

ORIGINAL ARTICLE

Adaptation and validation of the spanish version of the Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL CSQ-S)

J Sauri^{1,2,3}, MC Umaña^{2,4}, A Chamarro^{2,5}, MD Soler^{1,2,3}, A Gilabert^{1,2,3} and ML Elfström⁶**Study design:** Cross-sectional validation study.**Objectives:** To adapt the Spinal Cord Lesion-related Coping Strategies Questionnaire into the Spanish language (SCL CSQ-S) and to examine the relationship between coping strategies, global quality of life and psychological adaptation.**Setting:** Data were collected through individuals with spinal cord injury (SCI) now living in the community who completed their routine follow-up assessment at the Institute Guttmann in Barcelona, Spain.**Methods:** Forward and backward translation into Spanish of the English version of the questionnaire. Questionnaires of global Quality of Life, Community Integration, Coping, Depression, Anxiety and Functional Independence were administered to 349 adults with paraplegia and 162 adults with tetraplegia. Statistical analysis included confirmatory factor analysis and regression analysis.**Results:** The factorial structure of the questionnaire was partly verified. The original correlated, three-factor model sufficiently fit the data obtained in this study: $\chi^2(48) = 109.46$; $P < 0.001$; Comparative Fit Index = 0.96; Tucker–Lewis Index = 0.96; Root Mean Square Error of Approximation = 0.050 (0.038–0.062); Akaike information criterion = 13.46. Items were found to be good indicators of their respective latent factors, showing adequate factorial charge ranges (between 0.41 and 0.75). The reliability coefficient (Cronbach's α) for the Acceptance subscale was 0.74, for Social reliance 0.76 and for Fighting spirit 0.69. Coping strategies as measured by SCL-CSQ-S contributed to the prediction of outcomes related to adaptation to disability.**Conclusion:** The results of the study show some evidence for the robustness of the structure of SCL CSQ-S and show that the Spanish version of the questionnaire largely replicate previous results. Coping strategies, especially Acceptance, are related to adaptation to injury.*Spinal Cord* (2014) **52**, 842–849; doi:10.1038/sc.2014.44; published online 29 April 2014

INTRODUCTION

Spinal cord injury (SCI) is one of the primary causes of neurological disability in Spain. In fact, it is estimated that there are 12–20 new cases of SCI per million inhabitants per year. Thus the overall prevalence of SCI in Spain is approximately 350 individuals per million inhabitants.¹ SCI represents a long-term medical condition that produces irreversible physical, psychological and social consequences. Therefore, SCI individuals are forced to continuously adapt to their condition by making adjustments within several specific domains, including mobility, self-care, lifestyle and social relations.^{2,3} Indeed, the psychological impact of SCI is evidenced by the fact that there is a higher incidence of anxiety and depression in affected individuals when compared with the general population.⁴

The use of coping strategies has been identified as an important mechanism by which SCI individuals adjust to their state of chronic disability.^{5,6} Notably, SCI-related coping strategies were found to impact psychological variability more than socio-demographic or lesion-related factors.⁶ Nevertheless, methodological limitations, such

as the use of generic coping instruments,² have made it difficult to establish the relationship between coping and SCI adaptation. Indeed, commonly used coping assessments are very long, do not adequately reflect the complexity of SCI and are difficult to compare.⁵

For these reasons, the Spinal Cord Lesion-related Coping Strategies Questionnaire (SCL CSQ)^{7,8} was developed. The SCL CSQ assesses coping based on three distinct subscales: Acceptance (degree of reevaluation of life values), Fighting spirit (extent of independent behaviour in spite of the lesion), and Social reliance (tendency to display negative psychological or social dependency). The original SCL CSQ, which was previously described (that is, item generation, factor identification and scale reliability), was found to meet a basic level of reliability and validity.⁸ In addition, it showed improved performance when compared with a general coping measure.⁹

Notably, socio-demographic and injury-related characteristics (for example, age, time since lesion and gender) were considered during development of the SCL CSQ.⁸ Although there was relatively low variability associated with these background characteristics, the

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Acceptance subscale was found to increase with time since injury in the short term (6–12 weeks post injury)¹⁰ and over several years (persons injured 1–4 years vs ≥ 5 years).^{7,8} In addition, the Social reliance subscale was reduced over time when considering both the short (6–12 weeks post injury)¹⁰ and long (1–4 years vs ≥ 5 years) perspectives.⁸

Differences with regard to neurological status were less consistent than those observed when considering time since injury. In the developmental study, individuals with functionally complete tetraplegia, who used a wheelchair and displayed impaired function in their upper extremities (tetraplegia: ASIA A, B, C), reported higher levels of Social reliance than those with less neurological deficit.⁸ In the first European cross-national validation study, subjects with complete paraplegia scored significantly higher in the Fighting spirit subscale when compared with individuals with complete tetraplegia.⁷ In addition, subjects with thoracic injuries produced higher scores related to Fighting spirit than those with cervical injuries.⁷ Although the SCL CSQ was developed to assess individuals with traumatic lesions, it also appears to be applicable to cases involving non-traumatic lesions.^{7,10,11}

The SCL CSQ has been used to study the relationship between coping and psychological outcomes.^{5,10,12–14} In fact, higher scores in the Acceptance and Fighting spirit subscales indicated better psychological functioning and quality of life (QoL), whereas high scores in Social reliance were linked with psychological distress. These results have highlighted the fact that appropriate psychological support may promote improved long-term QoL and independence in SCI individuals.¹⁴ In accordance with this notion, Kennedy *et al.*¹¹ suggested that initial stages after injury were associated with the use of strategies that were not typically required for everyday life.

Our clinical experience has suggested that prolonged Social reliance may produce greater feelings of dependency and psychological discomfort, leading individuals with SCI to drift toward poor adaptation. In contrast, Fighting for the best possible conditions and Acceptance can lead to improved adaptation.

Moreover, we believe that a broader concept of disability adaptation should consider social participation,³ absence of psychological problems (for example, anxiety and depression) and a good QoL.¹⁵

Purpose

There exists a growing need to develop effective functional measures in the field of neurorehabilitation. In the present study, we have produced a Spanish language version of the SCL CSQ and analysed its factorial structure and validity during the measurement of psychosocial adaptation outcomes. According to previous research, we expected that coping strategies related to Acceptance and Fighting spirit would positively predict psychological adaptation, whereas Social reliance would demonstrate both negative (QoL and social participation) and positive (anxiety and depression) relationships.

MATERIALS AND METHODS

Participants

A total of 511 subjects with SCI were included in the study. These individuals were living in the community and attended their annual comprehensive follow-up evaluation at the hospital between March 2010 and July 2011. They were between the ages of 17.5 and 87.2 years (mean: 50.6 years (s.d. = 14.3)), were fluent in Spanish and had completed the rehabilitation process. Notably, subjects with concomitant brain injury, communication issues or previous psychiatric disorders were excluded. Socio-demographic and lesion-related data are presented in Tables 1 and 2.

Table 1 Descriptive statistics of lesion-related variables, functional independence, anxiety, depression, quality of life, social integration and coping strategies

Variables	n	Range		Median	Mean	s.d.
		Min.	Max.			
Age (years)	511	17.50	87.26	49.36	50.66	14.37
Age at injury (years)	511	3.22	79.42	32.94	35.21	15.16
Time since injury (years)	511	1.40	62.47	13.87	15.44	10.00
SCIM II	511	13	100	73.00	67.18	22.97
Anxiety	511	0	20	5.00	5.76	3.72
Depression	511	0	20	3.00	4.15	3.74
Global QoL	511	4	20	16.00	14.00	3.70
CIQ total	511	1	25	16.00	15.54	5.28
Acceptance	511	1	4	3.00	3.00	0.61
Social reliance	511	1	4	2.66	2.62	0.74
Fighting spirit	511	1	4	3.20	3.18	0.47

Abbreviations: CIQ, Community Integration Questionnaire scores; Global QoL, quality-of-life scores as measured by the WHOQOL-BREF; SCIM II, Spinal Cord Independence Measure II scores.

Design

A cross-sectional validation study was used.

Materials

Data regarding socio-demographic and lesion-related variables were collected from the database at Institut Guttmann, a neurorehabilitation hospital located in Barcelona, Spain.

The instruments selected for use in this study represent commonly used tools, which have previously been applied to the SCI population.

Measures

Spinal Cord Independence Measure (SCIM II). We assessed functional independence using the second version of the SCIM. The SCIM II consists of three main categories: (1) self-care; (2) respiration and sphincter management; and (3) mobility. Each of these areas is subdivided into 18 subitems, which collectively yield a score ranging between 0 and 100. Higher scores indicate greater functional independence. The psychometric properties of this assessment have been reported elsewhere.¹⁶

Hospital Anxiety and Depression Scale (HADS). The HADS self-assessment questionnaire contains subscales related to anxiety and depression. Each of these subscales is composed of seven items. Answers are given on a four-step Likert scale (0–3), and the individual response values are summed to yield overall scores for anxiety and depression. The psychometric properties of the Spanish version were previously reported.¹⁷

Global QoL rating. We utilized the short version of the World Health Organization Quality of Life Questionnaire (WHOQoL-BREF)¹⁸ to obtain a single rating of overall QoL. This item reads ‘How would you rate your quality of life?’ and is reported based on a five-point response format that ranges from 1 (very poor) to 5 (very good).

Community Integration Questionnaire (CIQ). Social participation was measured using the revised version of the CIQ, which assesses three domains: home competency, social interactions, and productive activities. Both domain-specific and cumulative (ranging from 0 to 25) scores can be calculated, with higher punctuations indicating better community integration. Notably, this measure has been used previously to assess an SCI population.¹⁹

SCL CSQ. The SCL CSQ was developed for use with individuals with SCI and is comprised of three subscales: (1) Acceptance, which focuses on the lesion and its ramifications as integrated parts of the individual’s life (for example, I have been able to see my injury in relation to other things in life); (2) Fighting spirit, which assesses the subject’s ability to make the best of life despite the lesion (for example, I always try to manage on my own as much as possible); and (3) Social reliance, which examines the patient’s perception of

Table 2 Coping strategies and comparisons between socio-demographic and lesion-related variables of the sample

Characteristic	<i>n</i>	%	Acceptance, mean (s.d.)	P-value	Fighting spirit, mean (s.d.)	P-value	Social reliance, mean (s.d.)	P-value
Sex				0.44		0.68		0.19
Male	375	73.4	3.01 (0.60)		3.18 (0.47)		2.59 (0.73)	
Female	136	26.6	2.96 (0.62)		3.17 (0.45)		2.69 (0.75)	
Marital status				0.004*		0.24		0.000**
Married	263	51.5	2.92 (0.63)		3.15 (0.47)		2.76 (0.70)	
Divorced/separated	18	3.4	2.76 (0.66)		3.05 (0.57)		2.77 (0.70)	
Single	222	43.4	3.10 (0.56)		3.22 (0.45)		2.43 (0.75)	
Widow/widower	8	1.5	3.21 (0.28)		3.12 (0.28)		2.87 (0.43)	
Education level				0.04*		0.001**		0.000**
Illiterate	8	1.5	2.87 (0.48)		2.85 (0.20)		2.91 (0.55)	
Read/write	44	8.6	2.77 (0.62)		2.95 (0.64)		2.98 (0.67)	
Primary	205	40.1	2.98 (0.62)		3.18 (0.47)		2.76 (0.72)	
Secondary	140	27.4	3.02 (0.56)		3.24 (0.39)		2.48 (0.71)	
Graduate	114	22.3	3.10 (0.61)		3.22 (0.45)		2.37 (0.74)	
Type of lesion				0.32		0.68		0.000**
Complete paraplegia	191	37.4	3.06 (0.61)		3.21 (0.50)		2.47 (0.78)	
Incomplete paraplegia	158	30.9	2.94 (0.62)		3.15 (0.45)		2.58 (0.70)	
Complete tetraplegia	54	10.6	3.01 (0.57)		3.17 (0.42)		3.04 (0.57)	
Incomplete tetraplegia	108	21.1	2.98 (0.59)		3.19 (0.45)		2.72 (0.71)	
Cause of lesion				0.007*		0.17		0.003*
Traumatic	349	68.3	3.05 (0.59)		3.20 (0.47)		2.55 (0.74)	
Non-traumatic	162	31.7	2.89 (0.63)		3.14 (0.46)		2.76 (0.70)	
Age at injury, years				0.000**		0.16		0.000**
0–15	25	4.9	3.21 (0.62)		3.35 (0.40)		2.61 (0.75)	
16–30	212	41.5	3.10 (0.59)		3.22 (0.46)		2.43 (0.69)	
31–45	149	29.2	2.96 (0.61)		3.15 (0.48)		2.65 (0.77)	
46–60	92	18	2.87 (0.54)		3.13 (0.49)		2.83 (0.66)	
61–75	28	5.5	2.66 (0.68)		3.07 (0.37)		3.10 (0.72)	
76+	5	1.0	3.20 (0.48)		3.08 (0.22)		3.20 (0.18)	
Time since injury, years				0.01*		0.67		0.6
1–5	82	16.0	2.89 (0.61)		3.21 (0.45)		2.60 (0.71)	
6–10	120	23.5	2.95 (0.65)		3.12 (0.49)		2.65 (0.80)	
11–15	96	18.8	3.00 (0.55)		3.18 (0.42)		2.62 (0.76)	
16–20	83	18.2	3.05 (0.56)		3.20 (0.43)		2.42 (0.70)	
21–25	60	11.7	3.14 (0.59)		3.21 (0.46)		2.62 (0.66)	
>26	70	13.7	3.11 (0.60)		3.21 (0.54)		2.80 (0.71)	

* $P < 0.05$.** $P < 0.001$.

dependence upon others (for example, my injury has taught me that I am now dependent upon others). Items are rated on a four-step Likert scale (1–4). Scores represent the mean of the rating for each subscale, with higher scores indicating greater use of the specific strategy.⁸ Notably, the revised version of the English questionnaire was used for the translation process in this study,¹⁰ and a protocolled process was followed for obtaining linguistic, conceptual and metric equivalencies. Specifically, items were translated from both English and Swedish into Spanish, which resulted in five versions that were assessed by five expert psychologists. A unified version was produced and evaluated during individual interviews of 10 subjects. These 10 participants indicated that they had difficulties understanding some of the items within the forward-translated questionnaire. Following correction of these discrepancies, two Spanish–English bilinguals performed backward translation for comparison to the original version and observed equivalence. Subsequently, individual interviews were conducted on five participants, who indicated good comprehension.

Finally, the SCL CSQ-S was tested in a pilot study in order to confirm that there was a high level of item acceptability and comprehension. Items resulting from the backward translation process to Spanish are shown in the Appendix.

Procedure

For data collection, a psychologist personally delivered a folder containing the questionnaires and respective instructions to each study participant during his/her annual examination at the hospital. Notably, the Institut Guttmann Ethics Committee approved the study, and all participants gave written informed consent.

Data analysis

Several statistical techniques were used in the present study, and we conducted both descriptive and correlational analyses. Indeed, *t*-tests were performed to

examine possible gender or lesion-related differences, whereas successive one-way analysis of variance tests were used to examine the effect of socio-demographic and lesion-associated variables on coping strategies. Confirmatory factor analysis was also conducted using robust methods and reliability coefficients. In addition, hierarchical regression analysis was performed. In this regard, socio-demographic factors, lesion-related variables and functional independence were entered into the sequential equations, respectively, followed by coping strategies. Furthermore, psychosocial adaptation measures were considered to be dependent variables (that is, anxiety, depression, QoL and social participation). Data were analysed using the Statistical Package for Social Sciences (version 16.0) and EQS 6.1. Moreover, model fit was assumed in accordance with Kline:²⁰ a Root Mean Square Error of Approximation <0.08 along with Tucker–Lewis Index and Comparative Fit Index values of approximately 0.95. In order to compare models, the Akaike information criterion was applied, with lower values indicating better fit.

Although there were 10 missing values in the single Global QoL rating, they were replaced using the scale mean and had no impact on our analysis. Notably, there were no other missing data associated with the variables included in the present study.

Statement of ethics

All applicable institutional and governmental regulations concerning the ethical use of human volunteers were followed throughout the course of this investigation.

RESULTS

Descriptive statistics

The study variables are presented in Table 1. Considering the cutoffs from the anxiety scale, we observed that 378 (74.0%) participants showed non-clinical levels, whereas 70 (13.7%) subjects could be considered as possible cases. However, we found that 63 (12.3%) individuals displayed clinical levels of anxiety. With regard to depression, 415 (81.2%) cases could be classified as non-clinical, 65 (12.7%) participants represented possible cases and 31(6.1%) subjects showed clinical levels.

In Table 2, we present the means and s.ds. associated with the different socio-demographic and injury-related variables of the SCL CSQ-S subscales. We found no gender-based differences. Nevertheless, significant differences were observed in the Acceptance subscale with relation to marital status, education level, cause of lesion, age at injury and time since injury. In fact, pairwise comparisons revealed that single, graduate individuals, who suffered a traumatic injury when younger, displayed significantly higher scores for Acceptance. With regard to Fighting spirit, greater scores were associated with individuals having secondary or graduate educational levels. For the Social reliance subscale, pairwise comparisons indicated that higher scores were associated with married individuals having lower educational levels, who had suffered tetraplegia caused by non-traumatic aetiology at a late age.

Confirmatory factor analysis

Our findings indicated that the original correlated, three-factor model sufficiently fit the data obtained in this study (Table 3). Indeed, items were found to be good indicators of their respective latent factors, showing adequate factorial charge ranges: Acceptance (0.57–0.73), Fighting spirit (0.41–0.72), and Social reliance (0.68–0.75) (see Figure 1). In addition, the following correlations were calculated among the latent factors: Acceptance with Fighting spirit (0.89; $P<0.05$), Acceptance with Social reliance (-0.26 ; $P<0.05$), and Fighting spirit with Social reliance (-0.17 ; $P<0.05$). Considering the high correlation observed between Acceptance and Fighting spirit, alternative models were tested, involving items from the two factors that pertained to a unique factor or two factors combined into a second-order factor. We found that the original three-factor model, which displayed better performance within all fit indices, was the most plausible option (see Table 3).

Furthermore, we calculated the reliability coefficient (Cronbach’s α) for each subscale: Acceptance (0.74), Social reliance (0.76), and Fighting spirit (0.69). Indeed, these coefficients approximated the value for acceptable internal consistency (0.70).

Correlation analysis

Bivariate Pearson’s correlation coefficients were calculated. Although age and age at time of injury correlated moderately with other socio-demographic and lesion-related variables, they showed lower correlation with adaptation and coping measures. Moreover, our data indicated that anxiety ($r = -0.35$), depression ($r = -0.49$), Acceptance ($r = 0.48$) and Fighting spirit ($r = 0.37$) correlated moderately with QoL. The correlation matrix for all study variables is presented in Table 4. We observed that the correlation between Acceptance and Fighting spirit was considerably lower in bivariate analyses compared with confirmatory factor analysis. This finding may result from the fact that confirmatory factor analysis correlation terms are obtained between measures without measurement error.

Regression analysis

Results obtained from the multiple hierarchical regression analysis are shown in Table 5. When global QoL rating was considered as the dependent variable, lesion-related and socio-demographic factors did not significantly contribute to the variance. Our analysis revealed that cause of injury and Acceptance accounted for 29.2% of the variance. Also, traumatic injury and higher Acceptance scores were related to increased QoL.

When CIQ was the dependent variable, actual age, marital status, gender, education, SCIM, Acceptance, Fighting spirit and Social reliance accounted for 58.1% of the variance. In addition, we found that male gender, younger age and scoring high in positive coping skills were associated with greater CIQ scores.

Table 3 Fit of CFA models

	$\chi^2(df)$	χ^2/df	CFI	TLI	RMSEA (90% CI)	AIC
M1: original three factors intercorrelated	109.46 (48)**	2.80	0.96	0.96	0.50 (0.38–0.62)	13.46
M2: alternative model	176.03 (53)**	3.32	0.92	0.92	0.67 (0.56–0.78)	70.03
M3: model with second-order factor	137.96 (47)**	2.97	0.94	0.94	0.62 (0.50–0.73)	43.96

Abbreviations: AKI, Akaike information criterion; CFA, confirmatory factor analysis; CFI, Comparative Fit Index; CI, confidence interval; RMSEA, Root Mean Square Error of Approximation; TLI, Tucker–Lewis Index.

Note: M1: the three original factors are intercorrelated; M2: the items of the two correlated factors, Acceptance and Fighting spirit, are tested as pertaining to an unique factor; M3: the two correlated factors, Acceptance and Fighting spirit, are tested as conforming a second-order factor.

** $P<0.001$.

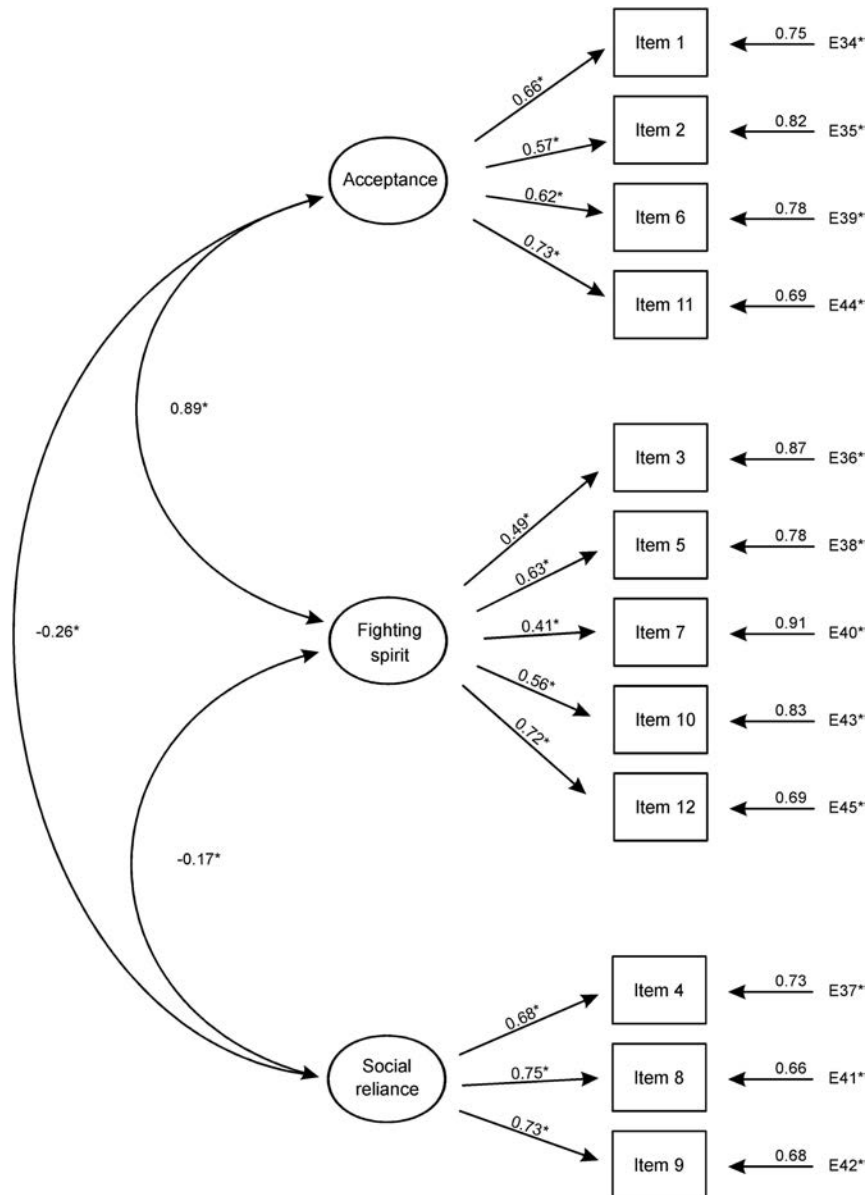


Figure 1 Parameter estimations for structural equation model of the SCL-CSQ-S. * $P < 0.05$.

In the case of anxiety as the dependent variable, gender, education, marital status, Acceptance and Social reliance accounted for a 21.9% of the variance. Furthermore, female gender, low educational level, single relationship status and scoring high in Social reliance were found to be predictors of increased anxiety scores. In this regard, Acceptance was demonstrated to be a protective coping skill.

Our analysis of depression indicated that Acceptance, Fighting spirit and Social reliance could account for 35.4% of the variance. High positive coping scores were found to predict lower depression scores, and Social reliance appeared to represent a negative coping strategy.

Standardized regression coefficients from the three models indicated that Acceptance and Fighting spirit were positively related to adaptation outcomes. In addition, Acceptance was negatively related to anxiety and depression, whereas Fighting spirit was only negatively associated with depression. In contrast, Social reliance was negatively related with CIQ and positively associated with anxiety and

depression. Taken together, our findings suggest that these three distinct coping strategies have differential effects over adaptation outcomes, supporting the notion that Acceptance and Fighting spirit represent independent factors.

DISCUSSION

In the present study, we present evidence that cultural and linguistic equivalence was obtained following translation of the original SCL CSQ to the Spanish language. Moreover, our findings support the original factorial structure of the scale, as we observed internal consistency and adaptation outcomes that were similar to those described in previous studies.^{7,8,10} However, the less than optimal internal consistency shown by this instrument could be attributed to the short length of its subscales. Nevertheless, our results confirm that the structure of this tool is robust, as data obtained using the SCL CSQ-S largely replicated the original theoretical framework. Although fit indices were acceptable, the correlation observed between

Table 4 Correlations among the study variables

	Abbreviation	Age	Time—l	SCIM	G QoL	Phys	Psych	Soc	Env	CIQ	HADS-A	HADS-D	Soc. Reliance	Acceptance	F. Spirit	
Age	Age	0.266**														
Time since injury	Time-l		-0.135**													
Global quality of life	SCIM II															
Physical health domain	G QoL			0.111*												
Psychological domain	Phys				0.225**											
Social relationships domain	Psych					0.156**										
Environment domain	Soc						0.129**									
Community Integration	Env							0.130**								
Anxiety	CIQ								0.596**							
Depression	HADS-A									0.432**						
Social reliance	HADS-D										-0.294**					
Acceptance	Soc. Reliance											0.707**				
Fighting spirit	Acceptance												0.208**			
	F. Spirit													0.272**		
															-0.400**	
															-0.525**	
															-0.433**	
															-0.186**	
																0.639**

Abbreviations: Acceptance, SCL-CSQ-R Acceptance; CIQ, Community Integration Questionnaire; Env, WHOQOL-BREF Environment domain; F. Spirit, SCL-CSQ-S Fighting Spirit; G QoL, WHOQOL-BREF Global Quality of Life rating; HADS-A, Hospital Anxiety and Depression Scale—anxiety symptom; HADS-D, Hospital Anxiety and Depression Scale—depression symptom; Phys, WHOQOL-BREF Physical domain; Psych, WHOQOL-BREF Psychological domain; Soc. Reliance, SCL-CSQ-S Social reliance; Soc, WHOQOL-BREF Social relationships domain.
Note: *correlations are significant at $\alpha < 0.05$ level.
**Correlations are significant at $\alpha < 0.01$ level.

Table 5 Results of the hierarchical regression analyses

Dependent variable	R ²	Predictor variables	β	t-value	P-value
Global QoL	0.292	Cause of lesion	-0.130	-2.710	0.007
		Acceptance	0.370	6.620	<0.001
CIQ	0.581	Gender	0.71	2.347	0.019
		Marital status	0.075	2.175	0.030
		Actual age	-0.226	-0.974	<0.001
		Educational level	0.123	3.842	<0.001
		SCIM II	0.366	11.199	<0.001
		Social reliance	-0.205	-6.066	<0.001
		Acceptance	0.151	3.935	<0.001
		Fighting spirit	0.117	2.979	0.003
		Gender	0.146	3.530	<0.001
HADS Anxiety	0.219	Marital status	-0.098	-2.053	0.041
		Educational level	-0.089	-2.029	0.043
		Social reliance	0.117	2.508	0.011
		Acceptance	-0.312	-5.878	<0.001
HADS Depression	0.354	Social reliance	0.121	2.846	0.005
		Acceptance	-0.350	-7.246	<0.001
		Fighting spirit	-0.169	-3.575	0.001

Abbreviations: CIQ, Community Integration Questionnaire; Global QoL, WHOQOL-BREF Global quality-of-life rating; HADS-A, Hospital Anxiety and Depression Scale—anxiety symptom; HADS-D, Hospital Anxiety and Depression Scale—depression symptom.
Note: Only significant effects are shown.

Acceptance and Fighting spirit was high. Thus, an overlap between these coping strategies could be hypothesized. Indeed, it is possible that SCI individuals accept the consequences of their disability (Acceptance) through achieving goals (Fighting spirit). Although future investigations will be needed to verify the possible connection between these coping mechanisms, the three-factor form of the scale allowed us to predict the impact of coping strategies on psychosocial adaptation outcomes.

Our findings have suggested the existence of two well-differenced patterns of coping. Well-educated individuals, who suffered a traumatic injury when they were young, were able to effectively utilize

Acceptance as a coping strategy. On the other hand, Social reliance represented the main coping mechanism used by married individuals with a low education level, who displayed a non-traumatic aetiology. Therefore, in view of these results, it is feasible that people with higher educational levels can visualize themselves in occupational roles that are more dependent on their cognitive abilities, which are not impaired, whereas those with lower educational levels often perform physically demanding jobs that require abilities that they no longer possess following injury (for example, cleaner, waitress, workman).

Our findings also confirm previous data suggesting that injury characteristics do not constitute the main predictors of psychosocial

adaptation.^{2,6} In the past studies, adjustment was described as the absence of anxiety and depression. Here we rely on a model that centres on a broader definition of psychosocial adaptation, taking into account not only the absence of disorders but also the positive indicators (for example, QoL and community integration).¹⁵ Furthermore, the results of the present study suggest that functional and injury characteristics do not represent decisive factors in the adaptation process to disability. In contrast, coping mechanisms appear to be related to adaptation, especially the strategy of Acceptance. However, we observed that traumatic injuries tended to yield better results when considering global QoL. This might be explained by the fact that non-traumatic lesions, which possibly result from medical processes (for example, tumours, degenerative conditions, and vascular problems), could be associated with a longer adjustment process than traumatic type injuries (that is, individuals with SCI may be able to accept the prognosis more quickly in the case of an accident). In this regard, future research should focus on trying to identify the role that aetiology has in the adaptation to disability.

According to Lazarus and Folkman,²¹ individuals are more likely to engage in Acceptance and active coping strategies when they perceive a stressful situation as treatable/manageable and estimate the degree to which they have the skills and/or resources to cope with their situation. Thus, those who accept the situation might be more likely to gain psychological well-being, thereby facilitating social integration into the community. As in previous reports,^{12–14} Acceptance in this study seemed to be beneficial with regard to psychosocial factors and promoted adaptive changes. Indeed, Elfström *et al.*¹² found that Acceptance displayed standardized β coefficients of 0.38 for general QoL, 0.40 for social functioning and -0.37 for depression. Therefore, when compared with Fighting spirit and Social reliance, Acceptance seemed to be the most powerful coping strategy with regard to adaptation outcomes.¹³ Social reliance was associated with increased levels of psychological distress in the present study. Likewise, Elfström *et al.*¹² found that Social reliance contributed to depression ($\beta = 0.12$) and, in an inverse manner, social functioning ($\beta = -0.21$). Therefore, they suggested that the use of Social reliance could involve externalization of the perception of control over the situation. Additionally, Kennedy *et al.*¹⁰ found that Acceptance ($\beta = -0.22$) and Fighting spirit ($\beta = -0.12$) could predict depression, whereas Social reliance was linked to anxiety ($\beta = 0.18$) and depression ($\beta = 0.20$).

In accordance with previous studies,^{10,12–14} Acceptance and Fighting spirit coping strategies appeared to predict adaptation to disability in our study, ultimately protecting the individual from anxiety and depression. Also, in line with our hypothesis, the Social reliance coping mechanism was negatively related to community integration but positively associated with anxiety and depression. As shown in previous investigations, Social reliance was significantly related to lower functional outcomes and difficulties during social interactions.^{11,14}

Our descriptive analysis revealed that our sample was similar to other previously examined cohorts as well as to the general SCI population. However, the participants in the present study displayed an increased mean age in comparison to other investigations.⁵ This might be explained by the fact that most SCI studies have focused on traumatic injuries, which tend to occur at younger ages, whereas in the present study we have included non-traumatic injuries, which tend to occur at older ages. However, a recent study has described a trend toward increased traumatic aetiologies among the elderly in the Spanish population.²²

Here, normal levels of anxiety and depression were observed, and QoL scores were similar to those described by previous studies.¹⁰ Therefore, our sample appeared to be psychologically well adjusted, with a low proportion of individuals showing clinical levels of anxiety and depression (approximately 12% and 6%, respectively).

The current work was subject to several limitations. Indeed, the findings of this study should be interpreted with caution owing to the sampling strategy (that is, follow-up assessment) and the cross-sectional design. For this reason, we found it difficult to generalize our results to other SCI populations and determine causality. Although the SCL CSQ performed psychometrically well when utilized for patients 6 weeks post injury,¹⁰ further research will be needed to test the efficacy of the scale when used during the early stages following injury. Furthermore, the high correlation that we observed between the Acceptance and Fighting spirit coping strategies in Spanish SCI individuals will need to be corroborated by further investigation.

In summary, this study supports the use of the SCL CSQ-S as a tool to measure the use of coping strategies in Spanish SCI individuals. Indeed, knowledge obtained from this scale can be utilized for both research and clinical work. Our study has contributed to the overall goal of adapting measurement instruments to local language and culture in order to facilitate the use of these important tools in diverse clinical settings. Furthermore, the results of the present study have provided further support for the positive effect of psychological factors (for example, coping strategies) during adaptation to physical disabilities.

Although the SCL CSQ previously demonstrated acceptable psychometric properties, only a few studies have analysed its sensitivity to change.^{11,14} Therefore, future research should focus on addressing this topic with regard to the SCI population as well as improving psychological interventions (for example, coping effectiveness training).¹¹ Moreover, further research will be needed to evaluate the psychometric properties of the SCL CSQ-S in other Spanish-speaking populations in order to evaluate transcultural validation of the questionnaire.

DATA ARCHIVING

There were no data to deposit.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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APPENDIX

Items in Spanish from each coping factor:

Acceptance

He sido capaz de ver mi lesión como un aspecto más de la vida.

Mi lesión me ha hecho aprender a apreciar aspectos de la vida que no valoraba anteriormente.

Creo que he aceptado mi lesión.

Lo que he perdido físicamente lo he ganado en muchos otros aspectos.

Fighting spirit

Es importante para mí marcarme objetivos por los que pueda luchar para conseguir.

A pesar de mi lesión hago todo lo que puedo en la vida para estar lo mejor posible.

No acepto que mi lesión gobierne mi vida.

Intento arreglármelas solo siempre que puedo.

Siempre busco nuevas maneras para hacerme la vida más fácil.

Social reliance

Ahora debo depositar mi confianza en los demás para que me ayuden.

Me sentiría completamente indefenso sin el apoyo de los demás.

Mi lesión me ha enseñado que ahora soy dependiente de los otros.

Appendix III

ORIGINAL RESEARCH

Depression in Individuals With Traumatic and Nontraumatic Spinal Cord Injury Living in the Community



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Abstract

Objective: To assess depression in a sample of individuals with spinal cord injury (SCI) living in the community, and to determine the prevalence of probable major depressive disorder (PMDD) among those with traumatic spinal cord injury (T-SCI) and those with nontraumatic spinal cord injury (NT-SCI).

Design: Cross-sectional.

Setting: Data were collected on individuals with SCI now living in the community, who completed a comprehensive follow-up assessment at the hospital.

Participants: Individuals with T-SCI or NT-SCI (N=831) completed the Patient Health Questionnaire-9 (PHQ-9) and were included.

Interventions: Not applicable.

Main Outcome Measure: The PHQ-9 was used to detect the presence of PMDD and to measure the severity of the depression.

Results: The most frequent etiology of SCI was T-SCI (66.9%). Overall, 16.2% of participants met the criteria for PMDD; however, a higher prevalence was noted for individuals with NT-SCI (21.1%) than for individuals with T-SCI (13.8%). Risk factors between T-SCI and NT-SCI did not differ greatly. Female sex, chronic pain, and lower levels of difficulties in participation were associated with the presence of PMDD.

Conclusions: PMDD appears to occur at a higher rate in individuals with NT-SCI, with greater symptom severity. The finding that problems with participation are directly associated with depression raises the need for specific treatment goals, with the aim of empowering individuals with SCI to reintegrate into the community. Potential stress factors (eg, environmental barriers, limited participation options) should be addressed accordingly.

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The psychological effect of spinal cord injury (SCI) is unmistakable, with individuals living with SCI 3 times more likely to suffer from probable major depressive disorder (PMDD) than the general population.^{1,2} A recent prospective study found major depression to be among the most prevalent psychological conditions experienced post-SCI.³ However, estimated rates of depression within the SCI population vary widely from study to study. In

a review by Bombardier et al,⁴ the point prevalence of PMDD in studies using diagnostic interviews was found to range from 9.8% to 37.5%. In a more recent meta-analysis of studies using diagnostic criteria based on the *Diagnostic and Statistical Manual of Mental Disorders, Fourth edition*⁵ (DSM-IV) this was estimated at 22.2%.⁶ Furthermore, for individuals living in the community, rates reportedly range from 11% to 60%.¹

Most of the existing research into psychosocial issues post-SCI is based on individuals with predominantly traumatic spinal cord

Disclosure: none.

injury (T-SCI). However, damage to the spinal cord can arise from many causes other than trauma, which is referred to as non-traumatic spinal cord injury (NT-SCI).^{7,8} In recent years, several studies have highlighted differences in the profiles of these etiologic groups.⁹⁻¹⁵ T-SCI is most commonly caused by transportation-related accidents,¹³ whereas NT-SCI is usually a result of tumors, degenerative diseases, or vascular problems.¹⁴ Consequently, NT-SCI tends to be incomplete and more likely to result in paraplegia. Furthermore, although T-SCI occurs mostly during adolescence and early adulthood, with an approximate male to female ratio of 4:1, the incidence of NT-SCI is higher in older adults, with a more even distribution between sexes.^{13,15} Given the aging population, the incidence of NT-SCI is projected to rise substantially over the coming decades,¹⁶ making it an increasingly important area of SCI medicine.

There is little research specifically examining the rate and symptom severity of depression in the NT-SCI population, and even fewer studies comparing them with T-SCI individuals.¹⁷⁻¹⁹ One existing study suggests that NT-SCI could be associated with a longer adjustment period than T-SCI because of the nature of the injury.²⁰ This, in conjunction with the aforementioned characteristic differences, leads us to hypothesize that individuals with NT-SCI may have an increased risk of psychological complications (eg, depression). More worldwide studies involving individuals with SCI from both etiologies are required to enable more appropriate comparisons.¹⁰

The objectives of this study are (1) to determine the prevalence of PMDD among independent samples of individuals with NT-SCI and T-SCI; (2) to describe the different aspects of depression between the etiologies; and (3) to examine the risk of depression through sociodemographic, injury-related, and psychosocial variables.

Methods

Design

A cross-sectional observational study was conducted.

Participants and procedures

A total of 1036 individuals were enrolled in this study. These participants were living in the community and attended an annual comprehensive hospital checkup between April 2, 2007, and October 8, 2008. Those with congenital conditions, including spina bifida (n=28), Guillain-Barré syndrome (n=2), or neurodegenerative disorders (n=2), were excluded. Only those who completed the Patient Health Questionnaire-9 (PHQ-9) were

included, giving a total of 831 individuals. The participants were aged between 18 and 89 years, were fluent in Spanish, and had completed the rehabilitation process. Notably, participants with concomitant brain injury or communication issues were excluded. Two individuals were excluded because of comorbidity diagnosed as schizophrenia. Data for this cross-sectional study were collected in person via structured interviews (approximately 30min) conducted by a psychologist. The study was revised and approved by the hospital ethics committee. All participants gave written informed consent.

Measures

Demographic and injury-related data

Demographic characteristics and injury data were extracted from medical records. We used the International Standards of Neurological Classification of SCI and its ASIA Impairment Scale to describe neurological levels and completeness of injury.²¹ Cause of injury was used to classify individuals as either T-SCI or NT-SCI, for comparison.

Depression

The PHQ-9^{22,23} was developed to facilitate identification and diagnosis of major depression disorder (MDD) in medical samples. To maintain consistency with MDD diagnostic criteria, each of the 9 depression items is rated according to how persistent the symptom has been during the last 2 weeks, from 0 (not at all) to 3 (nearly every day). The PHQ-9 can be used as a continuous measure of depression severity (scores ranging from 0 to 27). We used the cutoff value of ≥ 10 to define PMDD, which is the optimal cutoff for identifying independently diagnosed MDD (sensitivity, .88; specificity, .88) in primary care patients.²⁴ Alternatively, the PHQ-9 can be scored in a manner parallel to the DSM-IV diagnosis of MDD.⁵ In this case, an MDD diagnosis is defined as at least 5 symptoms being endorsed on more than half the days (suicidal ideation is considered endorsed at the level of several days), with at least one being a cardinal symptom of either anhedonia or depressed mood. The sensitivity and specificity of these criteria are .73 and .98, respectively.²³ In this study, we considered those who met these categorical criteria to be depressed. The PHQ-9 has been shown to have good internal consistency and construct validity in SCI and other samples.²³⁻²⁶

Participation

The Craig Handicap Assessment and Reporting Technique Short Form^{27,28} was used to measure 4 domains of societal participation: physical independence, occupation, social integration, and community mobility. The test-retest reliability coefficients have been reported to range from .80 to .95, with good discriminant validity obtained when using the test with contrasting groups.^{29,30}

Environmental barriers

We used the Craig Hospital Inventory of Environmental Factors-Short Form (CHIEF-SF)³¹ criteria in this study. It assesses the frequency with which people with disabilities experience problems with environmental factors, and the severity of these problems. The CHIEF-SF has 5 subscales: attitude and support barriers, services and assistance barriers, physical and structural barriers, policy barriers, and work and school barriers.³² The validity and reliability of CHIEF-SF for identifying the perceived barriers of disabled and nondisabled persons have been previously demonstrated.³¹

List of abbreviations:

CHIEF-SF	Craig Hospital Inventory of Environmental Factors-Short Form
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition
MDD	major depression disorder
NT-SCI	nontraumatic spinal cord injury
PHQ-9	Patient Health Questionnaire-9
PMDD	probable major depressive disorder
SCI	spinal cord injury
T-SCI	traumatic spinal cord injury

Pain

Chronic pain (neuropathic or musculoskeletal pain) related to trauma or disease of the spinal cord was diagnosed by a rehabilitation physician following the diagnostic criteria suggested by the International Association for the Study of Pain.³³ Participants who reported pain with a duration of at least 3 months were considered to have chronic pain.³⁴

Functional status

The FIM^{35,36} assesses an individual's ability to perform functional daily living tasks. In this study, only FIM scores related to motor independence were analyzed.^{36,37} The FIM has good reliability, has good construct validity, and is sensitive to changes in independence over time.³⁸

Statistical procedures

Data were analyzed in the following sequence. First, descriptive analyses were performed by calculating means and SDs for continuous variables and frequencies for categorical variables. Second, a normality test was performed (Kolmogorov-Smirnov test) because normality was not assumed for the variables included in the analyses (all $P < .05$). Chi-square analysis was used to detect any significant differences in categorical variables between groups (T-SCI vs NT-SCI), whereas a Mann-Whitney U test was used for continuous variables. An α level of .05 was used to determine statistical significance, except for the multiple comparisons with the PHQ-9 items, where the Bonferroni correction was applied (α level of .005). Third, a set of logistic regression analyses were performed to determine the variables associated with PMDD. The first logit model included the T-SCI sample only, and the second included the NT-SCI sample only. In these models, the sample sizes were reduced because of missing data for Craig Handicap Assessment and Reporting Technique Short Form and/or CHIEF-SF criteria. Data were analyzed using SPSS version 16.0.1.⁴

Results

Sample characteristics

Traumatic injury was the most frequent cause of SCI (66.9%) and was most commonly caused by motor vehicle collisions. The most frequent cause of NT-SCI was degenerative disorders, followed by neoplastic processes (table 1).

The results showed clear differences in most of the socio-demographic and injury-related variables between individuals with T-SCI and NT-SCI. Participants with NT-SCI were significantly older than participants with T-SCI. On average, individuals with T-SCI were significantly younger at the time of injury than individuals with NT-SCI. When divided according to age group, most individuals with T-SCI (51.3%) were young or were young adults between 16 and 30 years of age at the time of injury, whereas in the NT-SCI sample, most participants (51.7%) were between 46 and 75 years of age at the time of disability acquisition. Moreover, those with NT-SCI were significantly more likely to be women, have a lower level of education, be less engaged in currently productive activities (work, study, and homemaking), less likely to be single, and have lower level incomplete injuries (table 2). Samples based on etiology did not show any differences in terms of time since injury and level of independence (FIM motor). A rather large

Table 1 Range and percentages of traumatic or nontraumatic etiologies responsible for the SCI in community-residing persons (N=831)

Etiology	n (%)
Type of trauma	
Motor vehicle collisions	305 (36.7)
Sport and leisure activities	18 (2.2)
Violence, assaults	11 (1.3)
Falls	138 (16.6)
Water-related (including diving)	20 (2.4)
Suicide attempts	25 (3)
Other trauma	38 (4.6)
Type of NT-SCI etiology	
Neoplastic	61 (7.3)
Infection	27 (3.2)
Vascular disorders	51 (6.1)
Medical/surgical complication	20 (2.4)
Degenerative disorders	64 (7.7)
Inflammatory	40 (4.8)
Metabolic disorders	1 (0.1)
Syringomyelia	7 (0.8)
Other miscellaneous	5 (0.6)

proportion of individuals with NT-SCI suffered from chronic pain (55.3%), whereas a lower proportion of individuals with T-SCI suffered from this condition (42.2%). When investigating participation and barriers to participation (see table 2), individuals with T-SCI gave significantly higher scores on the CHART mobility and social integration scales than the participants with NT-SCI. On the other hand, individuals with NT-SCI gave significantly higher CHIEF-SF total scores and higher services assistance subscale scores. In contrast, there were no differences in Craig Handicap Assessment and Reporting Technique Short Form physical independence and occupation scales or in environmental factors (CHIEF-SF) related to policies, physical and structural factors, work/school factors, and attitude and support factors among individuals with T-SCI and NT-SCI (all $P > .05$).

Prevalence, severity, and symptoms of depression between T-SCI and NT-SCI

Of the 831 participants, 135 (16.2%) were considered to have PMDD (PHQ-9 score ≥ 10). Significant differences were found between T-SCI and NT-SCI groups for the prevalence of PMDD (13.8% vs 21.1%, respectively) and PHQ-9 total scores. When considering more stringent criteria for depression (DSM-IV criteria for MDD), the prevalence was 8.4% in the total sample. In this case, the proportion of individuals with depression identified in the NT-SCI group was almost double that found in the T-SCI group (12.4% vs 6.5%, respectively).

Of the total sample, 16.3% experienced moderate to severe depression (table 3). Within the NT-SCI group, 8% experienced moderately severe or severe depression (PHQ-9 score ≥ 15), compared with only 5.3% of the T-SCI group. However, no significant differences in depression severity were found between the 2 groups. Suicidal ideation was reported for 19% of the total sample. Although a slightly higher percentage of participants with NT-SCI reported suicidal ideation compared with individuals with T-SCI, no statistically significant differences were observed. For

Table 2 Sociodemographic and clinical characteristics of community-residing persons with T-SCI and NT-SCI

Variables	Total (N=831)	T-SCI (n=556)	NT-SCI (n=275)	P
Sex [†]				
Male	597 (71.8)	436 (78.4)	161 (58.5)	
Female	234 (28.2)	120 (21.6)	114 (41.5)	<.001*
Marital status [†]				
Married	429 (51.6)	246 (44.2)	183 (66.5)	
Single	346 (41.6)	284 (51.1)	62 (22.5)	
Divorced	31 (3.7)	18 (3.2)	13 (4.7)	
Widowed	25 (3)	8 (1.4)	17 (6.3)	<.001*
Primary occupation [†]				
Employed/student	397 (47.8)	280 (50.5)	117 (42.5)	
Unemployed	434 (52.2)	276 (49.6)	158 (57.5)	.034*
Education level [†]				
Illiterate	10 (1.2)	5 (0.9)	5 (1.8)	
Read/write	65 (7.8)	35 (6.3)	30 (10.9)	
Primary	369 (44.4)	234 (42.1)	135 (49.1)	
Secondary	238 (28.6)	172 (30.9)	66 (24)	
Graduate	149 (17.9)	110 (19.8)	39 (14.2)	.006*
Level of impairment [†]				
Complete paraplegia	294 (35.4)	247 (44.4)	47 (17.1)	
Incomplete paraplegia	265 (31.9)	109 (19.6)	156 (56.7)	
Complete tetraplegia	106 (12.8)	98 (17.6)	8 (2.9)	
Incomplete tetraplegia	166 (20)	102 (18.3)	64 (23.3)	<.001*
Age at injury (y) [†]				
0–15	31 (3.7)	13 (2.3)	18 (6.5)	
16–30	327 (39.4)	285 (51.3)	42 (15.3)	
31–45	208 (25)	144 (25.9)	64 (23.3)	
46–60	170 (20.5)	87 (15.6)	83 (30.2)	
61–75	81 (9.7)	22 (4)	59 (21.5)	
≥76	14 (1.7)	5 (0.9)	9 (3.3)	<.001*
Time since injury (y) [†]				
1–5	240 (28.9)	149 (26.8)	91 (33.1)	
6–10	182 (21.9)	130 (23.4)	52 (18.9)	
11–15	143 (17.2)	93 (16.7)	50 (18.2)	
16–20	117 (14.1)	82 (14.7)	35 (12.7)	
21–25	50 (6)	29 (5.2)	21 (7.6)	
≥26	99 (11.9)	73 (13.1)	26 (9.5)	.11
Chronic pain [†]				
Yes	381 (45.8)	229 (42.2)	152 (55.3)	
No	450 (54.2)	327 (58.8)	123 (44.7)	<.001*
Age (y) [‡]	49.84±15.55	45.63±14.30	58.36±14.48	<.001*
Age at injury (y) [†]	37.14±17.09	32.75±14.41	46.02±18.60	<.001*
Time since injury (y) [†]	12.74±10.15	12.92±9.82	12.39±10.79	.17
FIM motor [‡]	68.06±23.42	66.83±24.14	70.54±21.72	.10
CHART-SF physical independence ^{‡,§}	90.17±22.74	90.09±22.93	90.32±22.41	.55
CHART-SF mobility ^{‡,§}	82±22.67	84.06±21.65	77.91±24.10	<.001*
CHART-SF occupation ^{‡,§}	43.16±33.91	44.80±34.78	39.88±31.95	.12
CHART-SF social integration ^{‡,§}	86.75±21.9	88.26±21.35	83.75±22.68	.001*
CHIEF-SF total score ^{‡,§}	0.27±0.33	0.25±0.32	0.31±0.34	.004*
CHIEF-SF policies subscale ^{‡,§}	0.27±0.84	0.27±0.86	0.26±0.80	.44
CHIEF-SF physical structural subscale ^{‡,§}	0.65±0.89	0.62±0.86	0.73±0.94	.17
CHIEF-SF work/school subscale ^{‡,§}	0.01±0.17	0.02±0.20	0.006±0.07	.36
CHIEF-SF attitudes support subscale ^{‡,§}	0.16±0.57	0.14±0.55	0.20±0.61	.080
CHIEF-SF services assistance subscale [†]	0.11±0.33	0.08±0.28	0.17±0.39	.001*

NOTE. Values are expressed as mean ± SD for continuous variables and n (%) for all categorical variables. A total of 127 (15%) participants with missing data for CHART-SF and CHIEF-SF.

Abbreviation: CHART-SF, Craig Handicap Assessment and Reporting Technique Short Form.

* $P \leq .05$.

† Chi-square test.

‡ Mann-Whitney U test.

§ n = 704.

the participants that reported any symptoms of depression ($n=698$), there was no significant difference between NT-SCI and T-SCI groups in relation to difficulties with functioning on a daily basis.

The symptoms most frequently reported by participants with T-SCI were sleep disturbance (19.8%), feeling tired or having little energy (15.3%), depressed mood (12.6%), and anhedonia (12%). For individuals with NT-SCI, these were feeling tired or having little energy (28%), sleep disturbance (26.5%), depressed mood (24%), and anhedonia (19.3%). When comparing the 2 groups in terms of each individual PHQ-9 symptom of depression (fig 1), statistically significant differences were found for depressed mood and poor energy. In contrast, there were no significant differences in anhedonia, sleep disturbance, appetite change, feelings of failure, trouble concentrating, psychomotor changes, or suicidal ideation.

Depression-related aspects

Logistic regression analysis performed on the data for the T-SCI sample (table 4) showed that depression was associated with female sex, chronic pain, occupation, social integration, and environmental factors (CHIEF-SF total score). In this case, the model classified 98.8% of the no PMDD correctly and 17.6% of the PMDD correctly (87% of the overall sample). The model explains 25% of the variance.

In the second model (table 5), performed for the NT-SCI sample, the results of the logistic regression analyses showed that female sex, social integration, and environmental factors (CHIEF-SF total score) were significant variables related to depression (PHQ-9 score ≥ 10). In this case, the model classified

96.8% of the no PMDD correctly and 8.3% of the PMDD correctly (78.8% of the overall sample). The model explains 15.7% of the variance.

Discussion

The first aim of this study was to determine the prevalence of PMDD according to etiology. This was found to be significantly higher for individuals with NT-SCI (21.1%) compared with those with T-SCI (13.8%). These results are comparable with those reported by Scivoletto et al¹⁷ (NT-SCI: 21%; T-SCI: 15%); however, small sample sizes (NT-SCI: $n=19$) appeared to limit the significance in their case. Conversely, Migliorini et al¹⁹ found the prevalence of depression to be 33.9% for NT-SCI, with even higher rates reported for T-SCI (37%). However, the authors did not detect any significant association between SCI etiology and depression. Symptoms of depression in SCI have been related to older age, more secondary complications,^{39,40} female sex,⁴⁰ pain,⁴¹ lower levels of physical and leisure activities,⁴² and less community and social participation,^{3,43} many of which are known to apply to individuals with NT-SCI.^{7,13-16} The current study reveals the existence of clear differences between the 2 etiologies, which may be related to increased rates of depression in individuals with NT-SCI. Consistent with prior research, individuals with NT-SCI were significantly older at the time of the study and at the time of injury acquisition; were more likely to be women, married, and not currently studying or working; and tended to have less-severe, incomplete injuries and a higher incidence of paraplegia in comparison with those with T-SCI.^{10,44,45} Because NT-SCI was the etiology for a larger percentage of older adults, it

Table 3 Depression severity on the PHQ-9 and differences between traumatic and nontraumatic etiology

Measure	Total (N=831)	T-SCI (n=556)	NT-SCI (n=275)	P
PHQ-9 total score	4.91±4.85	4.57±4.60*	5.60±5.25*	.011†
Probable MDD				
Probable MDD ≥ 10	135 (16.2)	77 (13.8)	58 (21.1)	
No probable MDD < 10	696 (83.8)	479 (86.2)	217 (78.9)	.008†
DSM-IV criteria for MDD				
Depressed	70 (8.4)	36 (6.5)	34 (12.4)	
Not depressed	761 (91.6)	520 (93.5)	241 (87.6)	.004‡
PHQ-9 score				
Minimal (0–4)	495 (59.6)	348 (62.5)	147 (53.5)	
Mild (5–9)	201 (24.2)	131 (23.6)	70 (25.5)	
Moderate (10–14)	84 (10.1)	48 (8.6)	36 (13.1)	
Moderately severe (15–19)	37 (4.5)	22 (4)	15 (5.5)	
Severe (20–27)	14 (1.7)	7 (1.3)	7 (2.5)	.056
Suicidal ideation				
Endorses suicidal ideation (item 9 > 0)	158 (19)	96 (17.3)	62 (22.5)	
No suicidal ideation	673 (81)	460 (82.7)	213 (77.5)	.06
Difficulty with daily functioning‡				
No at all difficult	380 (54.4)	262 (57.1)	118 (49.4)	
Somewhat difficult	228 (32.7)	147 (32)	81 (33.9)	
Very difficult	68 (9.7)	38 (8.3)	30 (12.6)	
Extremely difficult	22 (3.2)	12 (2.6)	10 (4.2)	.10

NOTE. Values are mean \pm SD, n (%), or as otherwise indicated.

* Cohen $d = .20$.

† $P < .05$.

‡ Only subjects who reported at least 1 symptom of depression were asked this question ($n=698$).

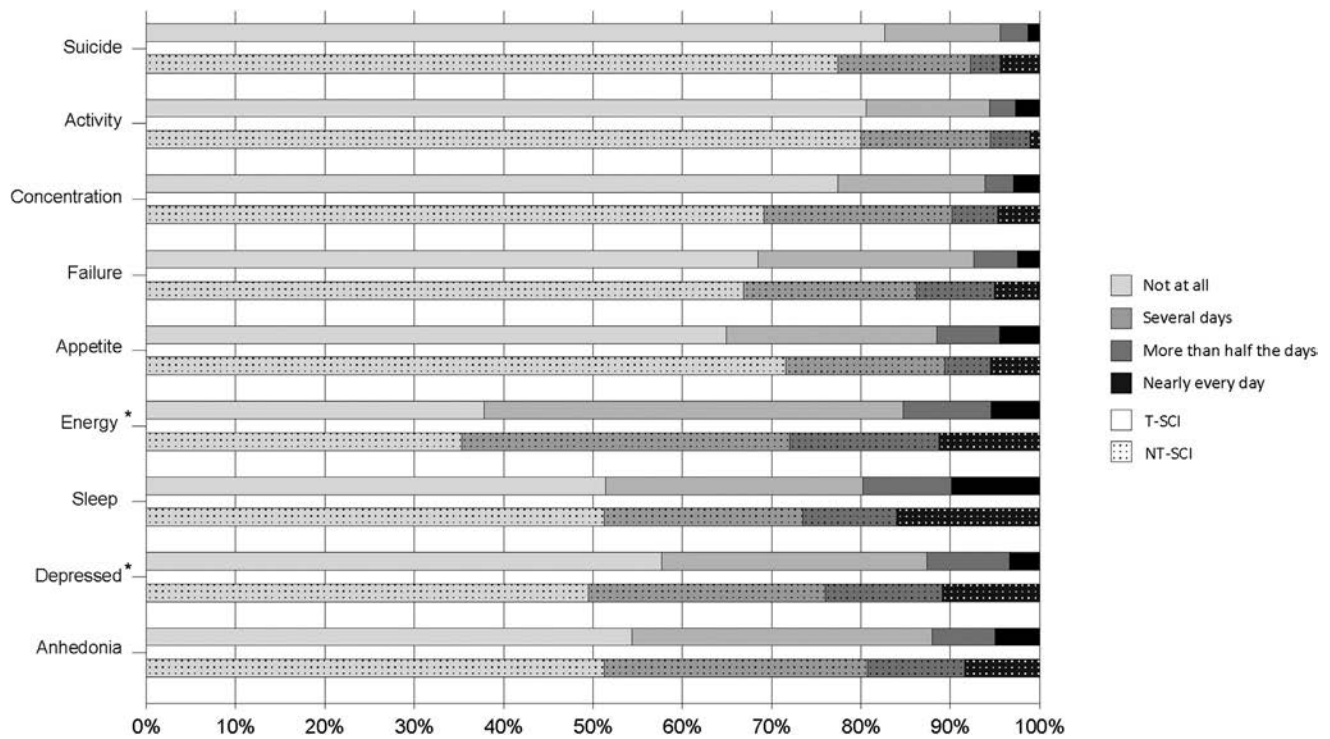


Fig 1 Reports of PHQ-9 depression symptoms in T-SCI and NT-SCI groups. * $P \leq .005$ is significant after adjusting for the multiple comparisons using the Bonferroni correction.

is possible that they had a wider range of comorbid medical conditions linked to aging and, in turn, an increased risk of suffering from depression. Another possible explanation for the higher rates of depression among individuals with NT-SCI may be related to the cause of injury itself (ie, tumors, degenerative conditions, vascular problems). Such factors could be associated with an uncertain prognosis, possibly involving a longer adjustment process, compared with traumatic injury, where a diagnosis is made in the early stages after injury.²⁰ Taking our results into account, we suggest that the distinct sociodemographic and injury-related characteristics associated with NT-SCI may result in an increased vulnerability to depression.

Our second objective was to observe the differences in depression characteristics between the 2 etiologies. We found that the average PHQ-9 score was significantly lower in the T-SCI group than the NT-SCI group. Interestingly, moderate depression

was significantly higher in individuals with NT-SCI than individuals with T-SCI. When analyzing the severity of each symptom, our results indicate that there was a greater intensity of depressed mood and poor energy in individuals with NT-SCI than individuals with T-SCI. When analyzing the rate of suicide ideation, Bombardier,⁴ Fann,² and colleagues reported a figure of approximately 15%, which is lower than those found in the present study (total sample: 19%; T-SCI: 17.3%; NT-SCI: 22.5%). This difference in magnitude cannot be explained by rates of PMDD and intensity of depression because these were similar or even lower in the present study. It is possible that the interpretation of suicide by our participants was “whether it would be better to be dead” rather than “injuring myself.” Either way, the data obtained alert us to the previously identified high suicide risk in these individuals^{46,47} and the consequential need for assessment using more specific instruments (eg, Paykel questionnaire,⁴⁸ SAD PERSONS scale⁴⁹) to lower this risk more effectively.

The third aim was to examine the risk of depression within SCI etiology groups, through a series of logistic regression

Table 4 Summary of hierarchical logistic regression analysis for T-SCI (n = 468)

Variable	OR	Wald	P	95% CI
Constant	1.143	0.009	.925	
Sex	2.252	5.829	.016	1.160–4.353
Chronic pain	0.312	13.11	.002	0.166–0.586
CHART-SF Occ.	0.985	6.102	.014	0.974–0.997
CHART-SF SI	0.984	5.479	.016	0.971–0.997
CHIEF-SF total score	4.875	16.41	<.001	2.266–10.49

Abbreviations: CHART-SF Occ., Craig Handicap Assessment and Reporting Technique Short Form occupation subscale; CHART-SF SI, Craig Handicap Assessment and Reporting Technique Short Form social integration subscale; CI, confidence interval; OR, odds ratio.

Table 5 Summary of hierarchical logistic regression analysis for NT-SCI (n = 236)

Variable	OR	Wald	P	95% CI
Constant	0.521	0.110	.740	
CHART-SF SI	0.98	6.24	.012	0.97–0.99
Sex	2.361	4.683	.030	1.084–5.139
CHIEF-SF total score	3.474	6.334	.012	1.371–9.160

Abbreviations: CHART-SF SI, Craig Handicap Assessment and Reporting Technique Short Form social integration subscale; CI, confidence interval; OR, odds ratio.

analyses. The first logit model identified female sex, chronic pain, lower levels of/difficulties in participation (eg, occupation, social integration), and higher scores in terms of environmental barriers as factors associated with PMDD. The second logit model showed that difficulties associated with environmental barriers, low levels of social integration, and female sex were the independent factors associated with PMDD in individuals with NT-SCI. Several previous studies have reported a greater vulnerability to depression among women than men.^{2,40,50} Similarly, our results suggesting an association between pain and depression were consistent with research by Hoffman et al,⁵¹ who reported that higher pain scores were associated with increased odds of depression at 5 years post-SCI.⁵² In addition, it has been noted that women with SCI tend to suffer more from pain⁵³ and depression.³⁹ Taken together, the logit models provide insight into sociodemographic characteristics, secondary problems, and participation variables associated with PMDD in persons with SCI living in the Spanish community. Our findings highlight that risk factors do not differ greatly between individuals with T-SCI and individuals with NT-SCI.

Neither impairment nor injury-related variables were identified as predictors of PMDD. Concurrently, researchers have found that while the level and extent of neurologic preservation predict independence in activities of daily living, certain medical complications,⁵⁴ and mortality,⁵⁵ it does not predict outcomes such as depression.⁵⁶ Previous literature has reported symptoms of depression to be linked to factors as diverse as environmental barriers, sex, pain, limited mobility, poor social integration, and fewer occupational pursuits (eg, work, studying).^{43,57} Similar to the report by Scivoletto et al,¹⁷ our results demonstrate that depression in individuals living with SCI in the community is related to the difficulties of everyday life, which may result from factors such as barriers to participation and lack of social support. It seems that these obstacles maintain depression over time.

Study limitations

A significant limitation of this study is its cross-sectional nature, which prevents detection of causal relations. Prospective data and the use of criterion standard DSM-IV psychiatric interviews may provide more sensitive results. Furthermore, because of the time between data collection and the present analysis, aspects associated with changes in epidemiologic trends (ie, an increase in nontraumatic etiologies, decreasing traffic collisions compared with other types of trauma) cannot be distinguished. Furthermore, this was a monocentric study conducted at a Spanish SCI center for adults living with long-standing injury. Therefore, these results may not be generalizable to other Spanish SCI centers, populations, or individuals in the initial stages after injury. Additionally, we assume that choosing a nonparametric and Bonferroni correction to reduce the risk of a type 1 error, increased the risk of a type 2 error. Finally, we did not measure several important factors, including use of medications, prior psychological and/or psychiatric disorders, pre-morbid psychological and/or psychiatric treatment, prior suicide attempts, comorbidity with other psychological and/or psychiatric disorders, secondary complications (eg, pressure ulcers, urinary tract infections), coping strategies, or self-efficacy. It is therefore unknown whether participants were receiving care that could have affected pain or other key study variables. Given the importance of pain and its relation with depression, we may also

have considered more specific, validated tools to measure these factors. If we consider the overall low predictive capacity of logit models to predict PMDD, it is clear that future research should consider the inclusion of these factors in the models used.

Clinical implications

This study suggests that people with NT-SCI may be more vulnerable to depression than those with T-SCI. This highlights the need for greater awareness and implementation of treatment aims to empower individuals with SCI and facilitate their smooth reintegration into the community. Consequently, scheduling periodic follow-up assessments is essential to monitor, maintain, and improve the health of individuals with SCI, and to maximize opportunities for community integration, avocational and vocational achievement, and psychosocial adjustment. Psychological interventions (eg, cognitive behavioral therapy, coping effectiveness training) are efficacious for reducing depression either as stand-alone strategies or in combination with antidepressant medication, with some being effective for improving overall quality of life and psychosocial functioning after SCI.⁵⁸⁻⁶⁰ Finally, as shown in this study, the demographics of the SCI population are changing, highlighting the need for rehabilitation systems and health care providers to make appropriate adjustments to adapt to the requirements of the individuals with different outcomes and trajectories.⁶¹

Conclusions

This study highlights the higher prevalence of PMDD among individuals with NT-SCI living in the community compared with those with T-SCI. Female sex, chronic pain, environmental barriers to participation, low mobility, low occupation score, and difficulty integrating socially should alert clinicians to an increased risk for PMDD. Although we cannot conclude that SCI etiology is a risk factor for depression, several demographic and injury-related aspects seem to indicate a greater emotional vulnerability. These aspects may coexist at a greater frequency among individuals with NT-SCI. Prospective studies are needed to analyze the possible role of etiology in emotional responses and adaptation to SCI.

Supplier

a. SPSS version 16.0.1; SPSS.

Keywords

Depression; Rehabilitation; Spinal cord injuries

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