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**BASES FOR ENHANCING PHYSICAL ACTIVITY
PARTICIPATION IN PEOPLE WITH SPINAL CORD INJURY:**

ASSESSMENT, MEDIATORS TO PSYCHOSOCIAL OUTCOMES AND BARRIERS

Alex Castan Delshorts

PhD Thesis



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*A la Nika, el meu tresor.
I a la M^a José i en Joan, els meus pares.*

*To Nika, my treasure.
And to M^a José and Joan, my parents.*

"La finalitat més noble de l'esport per a les persones amb discapacitat és ajudar-les a restaurar la connexió amb el món que les envolta".

"The noblest purpose of sport for people with disabilities is to help them restore their connection to the world around them".

Sir Ludwig Guttmann

FOREWORD / PRÒLEG

Foreword (English Version)

It is often said, that you cannot improve what you cannot measure. Alex Castan has taken that statement to heart. Through a programmatic series of studies, he has addressed a significant barrier to understanding and supporting the physical activity participation of people with spinal cord injuries living in Spain: the lack of a validated, Spanish-language measure. Working within the esteemed Institut Guttmann Hospital, a European leader in SCI rehabilitation, Alex has produced and published a validated Spanish-language adaptation of the PARA-SCI measure of physical activity for people living with spinal cord injury.

Alex's research program draws on his extensive clinical experience as a dedicated healthcare specialist. His frontline experience with SCI patients has given him a unique perspective on the physical activity values, needs and preferences of people who live with SCI. These perspectives are woven into his research questions—such as the role of self-efficacy, and how physical activity barriers vary across demographic characteristics. Alex's dissertation studies provide new information, paving the way for new evidence-based interventions and transformative practices for Spaniards living with SCI.

Over the past 3.5 years of working with Alex, I have developed a deep appreciation of his scientific creativity, his perseverance in the face of challenges, and his passion for his work. Also, from our correspondence, I have taken pleasure in learning about Catalan traditions—particularly, the strange legend of “Caga Tió”.

International partnerships and collaborations make better scientists and foster more fulfilling scientific careers. I am truly delighted that Alex's projects have laid the foundation for a robust partnership with Dr. Joan Úbeda Colomer and the University of Valencia.

I congratulate Mr. Alex Castan Delshorts on completing this dissertation. I have no doubt that his studies will inspire other SCI scientists and clinicians, and lead to further discoveries that will advance SCI knowledge and care in Spain and beyond.



Dr. Kathleen A. Martin Ginis

Reichwald Family UBC Southern Medical Program Chair in Preventive Medicine
UBC Distinguished University Scholar
Director, UBC Faculty of Medicine Centre for Chronic Disease Prevention and Management
Professor, Division of Physical Medicine and Rehabilitation, Department of Medicine
Professor, School of Health and Exercise Sciences
Principal Investigator, ICORD (International Collaboration on Repair Discoveries)
Fellow of the Royal Society of Canada
Fellow of the Canadian Academy of Health Sciences
Ontario Medal for Good Citizenship

Pròleg (versió en català)

Sovint es diu que no es pot millorar allò que no es pot mesurar. L'Alex Castan s'ha pres a pit aquesta afirmació. A través d'una sèrie programada d'estudis, ha abordat un obstacle important per a comprendre i donar suport a la participació en l'activitat física de les persones amb lesions medul·lars que viuen a Espanya: la falta d'un instrument de mesura validat en llengua espanyola. Treballant al prestigiós Hospital Institut Guttmann, líder europeu en rehabilitació de lesions medul·lars, l'Alex ha elaborat i publicat una adaptació validada en llengua espanyola de la mesura PARA-SCI d'activitat física per a persones amb lesió medul·lar.

El programa de recerca de l'Alex s'ha basat en la seva àmplia experiència clínica com a especialista dedicat a l'atenció sanitària. La seva experiència a primera línia amb pacients amb lesió medul·lar li ha donat una perspectiva única i singular sobre els valors, les necessitats i les preferències en matèria d'activitat física de les persones amb lesió medul·lar. Aquestes perspectives s'entretreixeixen en la seva activitat de recerca, amb l'abordatge de qüestions com el paper de l'autoeficàcia, o com les barreres a l'activitat física varien segons les característiques demogràfiques. Els estudis que componen aquesta Tesi Doctoral proporcionen nova informació, aplanant el camí cap a noves intervencions basades en l'evidència i cap a pràctiques transformadores per als espanyols que viuen amb lesió medul·lar.

Durant els últims tres anys i mig de treball amb l'Alex, he desenvolupat una profunda estima per la seva creativitat científica, la seva perseverança davant els reptes i la seva passió per la feina que fa, però a través de la nostra correspondència, també he gaudit aprenent sobre les tradicions catalanes i, en particular, sobre la curiosa tradició del "Cagatió".

Les associacions i col·laboracions internacionals fan millors científics i fomenten carreres científiques més satisfactòries. Estic realment encantada que els seus projectes hagin establert les bases d'una sòlida col·laboració amb el Dr. Joan Úbeda Colomer i la Universitat de València.

Felicito el Sr. Alex Castan Delshorts per haver completat aquesta Tesi. No tinc cap dubte que els seus estudis inspiraran altres científics i clínics especialitzats en lesió medul·lar i conduiran a nous descobriments que faran avançar el coneixement i l'atenció de la lesió medul·lar a Espanya i més enllà.



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Acknowledgements (English Version)

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LIST OF ABBREVIATIONS

SCI	Spinal Cord Injury
LTPA	Leisure Time Physical Activity
PA	Physical Activity
ASIA	American Spinal Injury Association
ZPP	Zone of partial preservation
VAC	Voluntary Anal Contraction
AIS	ASIA Impairment Scale
QoL	Quality of Life
GSE	General Self-Efficacy
SE	Self-Efficacy
IMU	Inertial Measurement Unit

ABSTRACT / RESUM

Abstract (English version):

The population with spinal cord injuries (SCI) frequently indicates limited participation in leisure time physical activity (LTPA), often engaging in very low-intensity activities or remaining inactive for most of their waking hours. Additionally, merely 32% of this population maintains consistent physical activity (PA) levels. Considering that approximately 31.000 people with SCI live in Spain, the main aim of this Thesis is to contribute to establishing the bases and key points to promote PA participation in people with SCI living in the community. For this purpose, having adequate assessment tools, deciphering what type of PA is beneficial and how, and identifying what are the main barriers to the practice of PA were considered necessary.

Thus, this Thesis is divided into three separate studies that have generated four publications, three indexed scientific articles that make up the compendium of publications and a clinical manual (Appendix):

- I. Adaptation to Spanish and validity by wearable sensors of the Physical Activity Recall Assessment for people with spinal cord injury.
- II. Psychosocial outcomes associated with types and intensities of physical activity in people with spinal cord injury: the mediating role of self-efficacy and functionality.
- III. Socio-ecological barriers to leisure time physical activity in Spanish wheelchair users with spinal cord injury: associations with sociodemographic characteristics and functional independence.
- IV. PARA-SCI-Spanish. Administration and scoring manual. How to assess and quantify physical activity in people with spinal cord injury (APPENDIX)

Publication I is a paper published in *Measurement in Physical Education and Exercise Science*. It encompassed 235 people with SCI living in the community and 22 SCI experts and translators, and proved through a systematic process of translation, cultural adaptation and various reliability and validity studies, that the Spanish version of the Physical Activity Recall Assessment for Spinal Cord Injury (PARA-SCI-Spanish) is a reliable and valid tool to measure and to quantify PA in SCI population.

In publication II, a paper published in *Journal of Physical Activity and Health*, a total of 159 participants were enrolled to describe which types of PA and at what intensities were most related

to psychosocial health, as well as to examine the possible mediating role of functionality and general self-efficacy in these relationships.

In publication III, a paper published in *Archives of Physical Medicine and Rehabilitation*, 207 participants were enrolled to identify the severity and prevalence of barriers to LTPA and their associations with sociodemographic characteristics and functional independence using a socio-ecological framework.

Publication IV, edited by Institut Guttmann Foundation, is an administration and scoring manual of the PARA-SCI in Spanish language which provides to the clinician and/or researcher who deals with Spanish-speaking SCI population with all the necessary material for the use of the PARA-SCI-Spanish as well as detailed information for its correct use.

With the results obtained, this Thesis concludes that PA assessment measures specific to spinal cord injury population are needed, as well as assessing PA by type and intensity as a first step in creating conceptual frameworks to promote programs and strategies for increased participation in PA in this population.

Furthermore, it supports the importance of mild LTPA on psychosocial health and the key role of general self-efficacy as a mediator between LTPA and psychosocial outcomes, suggesting that designing LTPA programs with a first phase considering mild LTPA and a second phase considering moderate to vigorous LTPA, both accompanied by general self-efficacy training, would facilitate progressive adherence to the program and provide psychosocial and physical benefits.

And finally, to design these programs conceptually, it is also necessary to consider that pain, fatigue, the lack of adapted programs or activities in the gym, economy, streets and pavements in poor condition, and the lack of adaptation of outdoor spaces are the most prevalently perceived barriers to PA. Moreover, in designing programs for specific subgroups within the spinal cord injury population, functionality must be considered, as it is a variable that is negatively associated with barriers and moderates the relationship between intrapersonal barriers and participation in LTPA.

Resum (versió en català):

La població amb lesió medul·lar sovint indica una participació limitada en activitat física del temps de lleure, comproment-se en activitats de baixa intensitat o mantenint-se inactius durant la major part de les seves hores de vigília. A més a més, només el 32% d'aquesta població manté nivells apropiats d'activitat física. Tenint en compte que aproximadament 31.000 persones amb lesió medul·lar viuen a l'Estat espanyol, l'objectiu principal d'aquesta Tesi és contribuir a establir les bases i els punts clau per promoure la pràctica d'activitat física en aquest col·lectiu. Per aconseguir-ho, es va considerar necessari disposar d'eines d'avaluació adequades, desxifrar quin tipus d'activitat física i a quina intensitat era beneficiosa, així com de quina manera, i quins eren els principals impediments per a la pràctica d'aquesta activitat física.

Com a resultat, aquesta Tesi es divideix en tres estudis que han generat quatre publicacions, tres articles científics indexats que conformen el compendi de publicacions i un manual clínic:

- I. Adaptació a l'espanyol i validesa mitjançant sensors intel·ligents del qüestionari *Physical Activity Recall Assessment* per a persones amb lesió medul·lar.
- II. Resultats psicosocials associats als tipus i intensitats d'activitat física en persones amb lesió medul·lar: el paper mediador de l'autoeficàcia i la funcionalitat.
- III. Barreres socioecològiques a l'activitat física del temps de lleure en persones espanyoles usuàries de cadira de rodes amb lesió medul·lar: associacions amb característiques sociodemogràfiques i independència funcional.
- IV. *PARA-SCI-Spanish*. Manual d'administració i puntuació. Com valorar i quantificar l'activitat física en persones amb lesió medul·lar (ANNEX).

La publicació I, article científic publicat a *Measurement in Physical Education and Exercise Science*, en què van participar 235 persones amb lesió medul·lar que vivien a la comunitat i 22 traductors i experts en lesió medul·lar, va demostrar mitjançant un procés sistemàtic de traducció, adaptació cultural i diversos estudis de fiabilitat i validesa que la versió espanyola del qüestionari *Physical Activity Recall Assessment for Spinal Cord Injury (PARA-SCI-Spanish)* és una eina fiable i vàlida per mesurar i quantificar l'activitat física en aquesta població.

A la publicació II, article científic publicat a *Journal of Physical Activity and Health*, hi van participar 159 persones amb lesió medul·lar que vivien a la comunitat amb l'objectiu de descriure entre quins tipus d'activitat física i en quines intensitats s'establien més relacions positives amb la salut psicosocial, així com d'examinar el possible rol mediador de la funcionalitat i l'autoeficàcia generalitzada en aquestes relacions

A la publicació III, article científic publicat a *Archives of Physical Medicine and Rehabilitation*, hi van participar 207 persones amb lesió medul·lar que vivien a la comunitat per identificar la gravetat i la prevalença de les barreres a l'activitat física en el temps de lleure utilitzant un marc socioecològic, així com les seves associacions amb característiques sociodemogràfiques i amb la independència funcional.

La publicació IV, editada per la Fundació Institut Guttmann, és un manual d'administració i puntuació del PARA-SCI en llengua espanyola que proporciona al clínic i/o investigador que treballa amb persones amb lesió medul·lar hispanoparlants tot el material necessari per a l'ús del PARA-SCI-Spanish, així com informació detallada per al seu correcte ús.

Amb els resultats obtinguts, aquesta Tesi Doctoral conclou que són necessàries mesures d'avaluació de l'activitat física específiques per a la població amb lesió medul·lar, així com que cal avaluar l'activitat física segons tipus i intensitat com a primer pas per crear marcs conceptuals que promoguin programes i estratègies per augmentar la participació en l'activitat física en el col·lectiu.

A més, també conclou que l'activitat física d'intensitat lleu en el temps de lleure és important per a la salut psicosocial, així com que l'autoeficàcia generalitzada té un paper clau com a mediador entre l'activitat física en el temps de lleure i els resultats psicosocials. Es suggereix que el disseny de programes d'activitat física inclogui una primera fase amb activitats més lleus, i una segona fase amb activitats d'intensitat moderada/vigorosa, ambdues acompanyades d'entrenament de l'autoeficàcia generalitzada, procurant d'aquesta manera l'adhesió progressiva al programa i l'assoliment de beneficis psicosocials i físics.

I, finalment, per dissenyar conceptualment aquests programes, també cal tenir en compte que el dolor, la fatiga, la manca de programes o activitats adaptades als clubs esportius, l'economia, i els carrers i voreres en mal estat, així com la manca d'adaptació dels espais exteriors, són les barreres a l'activitat física percebudes amb més prevalença pel col·lectiu. Tanmateix, pel disseny de programes d'activitat física per subgrups concrets dins de la població amb lesió medul·lar cal tenir en compte la funcionalitat, ja que és una variable que s'associa negativament amb les barreres i modera la relació entre barreres intrapersonals i la participació en l'activitat física del temps de lleure.

LIST OF PUBLICATIONS

Compendium of Publications:

- I. Castan, A., Opisso, E., Chamarro, A., Martin Ginis, K. A., & Saurí, J. (2023) Adaptation to Spanish and validity by wearable sensors of the Physical Activity Recall Assessment for people with Spinal Cord Injury. *Measurement in Physical Education and Exercise Science*, 27(4), 362-376 <https://doi.org/10.1080/1091367X.2023.2192194>
- II. Castan, A., Bonilla, I., Chamarro, A., & Saurí, J. (2024). Psychosocial outcomes associated with types and intensities of physical activity in people with spinal cord injury: The mediating role of self-efficacy and functionality. *Journal of Physical Activity and Health*, Advance online publication <https://doi.org/10.1123/jpah.2023-0404>
- III. Castan, A., Úbeda-Colomer, J., Chamarro, A., Vidal, J., Benito-Penalva, J., & Sauri, J. (2024). Socio-ecological barriers to leisure time physical activity in Spanish wheelchair users with spinal cord injury: associations with sociodemographic characteristics and functional independence. *Archives of Physical Medicine and Rehabilitation*, in press <https://doi.org/10.1016/j.apmr.2024.02.719>

Supplementary publication (Appendix):

- IV. Castan A. (2023). PARA-SCI-Spanish. Manual de administración y puntuación. Cómo valorar y cuantificar la actividad física en personas con lesión medular. (1ª edición). Fundació Institut Guttmann. ISBN: 978-84-09-53038-0. Barcelona. Available: <https://siidon.guttmann.com/ca/registro/sci-spanish-manual-administracion-puntuacion-como-valorar-cuantificar-actividad-fisica>

CHAPTER 1

SPINAL CORD INJURY

1.1 What is Spinal Cord Injury?

The spinal cord is the major conduit through which motor and sensory information travels between the brain and body (Rupp et al., 2021). Spinal cord injury (SCI) occurs when there is damage to the spinal cord that blocks communication between the brain and the body. After a SCI, a person's sensory, motor and reflex messages are affected and may not be able to overcome the damage to the spinal cord. The consequences of a SCI go beyond the nervous system, as it is a life-changing event that impacts health, functioning, societal participation, quality of life (QoL), and in many cases a new body identity that includes the wheelchair (Noreau et al., 2000; Majamäki et al., 2022; Lund et al., 2007; Dijkers, 1999; Monforte et al., 2021).

1.2 Classification of Spinal Cord Injury

The severity of the SCI is determined clinically by the completeness of the lesion, and the neurological level of injury (NLI).

Completeness of the lesion: According to the Standards for Neurological Classification published by the American Spinal Injury Association (ASIA), the criterion for complete SCI depends on the neurological level of injury (NLI) and the width of the zone of partial preservation (ZPP). 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 (Rupp et al., 2021; Waters et al., 1991). Motor ZPPs are now defined and should be documented in all cases including patients with incomplete injuries with absent no voluntary anal contraction (VAC). The sensory ZPP on a given side is defined in the absence of sensory function in S4-5 (light touch, pin prick) on this side as long as deep anal pressure is not present (Rupp et al., 2021)

The ASIA Impairment Scale (AIS) is used to classify lesions according to their degree of completeness. There are 5 levels:

- **ASIA A:** Complete. No sensory or motor function is preserved in the sacral segments S4-5.
- **ASIA B:** Sensory Incomplete. Sensory but not motor function is preserved below the neurological level and includes the sacral segments S4-5 (light touch or pin prick at S4-5 or

deep anal pressure) and no motor function is preserved more than three levels below the motor level on either side of the body.

- **ASIA C:** Motor Incomplete. Motor function is preserved at the most caudal sacral segments for VAC or the patient meets the criteria for sensory incomplete status (sensory function preserved at the most caudal sacral segments S4-5 by LT, PP or DAP), and has some sparing of motor function more than three levels below the ipsilateral motor level on either side of the body. (This includes key or non-key muscle functions to determine motor incomplete status). For AIS C – less than half of key muscle functions below the single NLI have a muscle grade ≥ 3 .
- **ASIA D:** Motor Incomplete. Motor incomplete status as defined above, with at least half (half or more) of key muscle functions below the single NLI having a muscle grade ≥ 3 .
- **ASIA E:** Normal. 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.

Neurological level of injury (NLI): Depending on the location of the NLI, we can classify SCI as paraplegia or tetraplegia.

- Tetraplegia 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 (Rupp et al., 2021)
- Paraplegia 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 (Rupp et al., 2021).

1.3 Spinal cord injury incidence

According to the World Health Organization, every year 250.000 to 500.000 individuals internationally experience a SCI. There is no reliable estimate of global prevalence, but estimated annual global incidence is 40 to 80 cases per million people (World Health Organization & International Spinal Cord Society, 2013).

The collection of statistical data on the population with SCI in Spain is complicated due to the decentralization of the Spanish Health System (Avellanet & Gonzalez-Viejo, 2017; Van Den Berg et al., 2011). However, we have territorial data on the incidence of traumatic injury per year and million inhabitants: 12,1 in Aragón, in northeastern Spain (Van Den Berg et al., 2011); 9,3 in the Canary Islands (Bárbara-Bataller et al., 2018); 21,7 in Galicia, in northwestern Spain (Montoto-Marqués et al., 2017); 10,1 in the total of 8 Autonomous Regions (Balearic Islands, Canary Islands, Cantabria, Castilla La Mancha, Castilla y León, Extremadura, Murcia and Navarra) (Mazaira et al., 1997).

At the overall country level, the incidence of traumatic cases is slightly higher: 24 according to the report of the Ministry of Health (Pérez et al., 2011), and 23.5 according to Avellanet & Gonzalez- (2017) and Pérez et al. (2012). Regarding traumatic and non-traumatic injuries, the latest available data reports 26.5 cases/million/year (Huete García & Díaz Velázquez, 2012).

In total, approximately 31.000 people with SCI live in Spain, 66.6% men and 33.4 % women (Huete García & Díaz Velázquez, 2012) with a trend in recent decades indicating a decrease in traumatic etiology and an increase in non-traumatic etiology (Torres Alaminos, 2017; Huete García & Díaz Velázquez, 2012), as well as an increase in the average age at lesion acquisition (Frontera & Mollett, 2017).

1.4. Secondary medical complications and clinical manifestations of SCI

People with SCI experience a range of secondary medical complications beyond the loss of sensation and movement below the level of injury:

- **Alteration of respiratory function**

In cervical and upper thoracic SCI, the respiratory function is impaired due to total or partial denervation of the musculature involved in the respiratory function (diaphragm, intercostal muscles, accessory respiratory muscles, and abdominal muscles) (Randelman et al., 2021). Clinically, this respiratory insufficiency translates into a reduced capacity to inhale air into the lungs, as well as a reduced capacity for expiratory force, and thus for secretion clearance (Roth et al., 2006, 2010).

- **Osteoporosis**

Osteoporosis is a long-term consequence of SCI that leads to a high risk of fragility fractures. Although there are several factors that cause osteoporosis in the SCI population, the most obvious is mechanical unloading (Jiang et al., 2006). Fractures resulting from osteoporosis are mostly caused by minor trauma during transfers, turning in bed, or during rehabilitation sessions (Gifre et al., 2014;

Freehafer, 1995; Filippo et al., 2015). The risk of fracture increases with time since injury, and are more frequent in women and in people with complete injuries (Bethel et al., 2016).

- **Neurogenic bowel dysfunction**

Neurogenic bowel dysfunction is a dysfunction of the colon due to the absence of nerve control, resulting in constipation, incontinence, and uncoordinated defecation. This dysfunction occurs in 68-80% of people with SCI (Ozisler et al., 2015). The degree of dysfunction may depend on the level of completeness of the lesion, comorbidities or even medication. This dysfunction can be a major socioeconomic burden, affect QoL, and even cause mortality in people with SCI (Ozisler et al., 2015).

- **Spasticity**

Spasticity is a sensorimotor disorder characterized by increased tonic reflexes, increased muscle tone and the presence of spasms. Approximately 70% of the SCI population suffers from spasticity (Noreau et al., 2000). The presence of spasticity negatively influences QoL, and can lead to the presence of pain as well as increased fatigue (Adams & Hicks, 2005).

- **Orthostatic hypotension**

According to The Consensus Committee of the American Autonomic Society and the American Academy of Neurology, orthostatic hypotension is a decrease in systolic blood pressure of 20 mmHg or more, or diastolic blood pressure of 10 mmHg or more, when adopting an upright posture from a supine position (Schatz et al., 1996). It is one of the most frequent secondary impairments in the SCI population (Noreau et al., 2000), and it represents a complicated clinical condition, which can severely affect QoL, and that is typically difficult to manage (Claydon et al., 2006).

- **Changes in sexual function, sexual sensitivity and fertility**

SCI can affect several areas of sexual function, such as sexual desire, achieving and maintaining an erection, ejaculation and orgasm (Zizzo et al., 2022). Approximately 90% of men with SCI are unable to have children naturally as 75% suffer from erectile dysfunction and 95% suffer from ejaculatory problems and/or poor semen quality (Ibrahim et al., 2016; Giuliano et al., 2007; Hess & Hough, 2012). In the face of this problem, it will be necessary to have mechanisms and strategies that favor sexual rehabilitation after the injury (Kathnelson et al., 2020). However, in the case of women with SCI, complications in the fertility are not as present, and they can have children at rates similar to the female population without SCI (Alexander et al., 2017).

- **Neuropathic pain**

Neuropathic pain is the result of damage or dysfunction of the peripheral or central nervous system, rather than stimulation of the pain receptors. There is a high prevalence in people with SCI (Burke et al., 2017). The majority of people with SCI displays combinations of neuropathic pain symptoms. The most common pain symptom overall are pins and needles, followed by burning pain, brush-evoked pain and electric shocks (Soler et al., 2017). Neuropathic pain interferes with daily life and reduces QoL and has a negative impact on the perception of psychological well-being (Felix et al., 2007; Soler et al., 2007).

- **Psychosocial difficulties**

People with SCI experience poorer QoL than people without such an injury (Dijkers, 1999). Low rates of participation (Lund et al., 2007) and general self-efficacy (GSE) (Carrard et al., 2021), as well as a high presence of anxiety symptoms and depression are also common in this population (Bonanno et al., 2012; Saurí et al., 2017; Sakakibara et al., 2009; Le & Dorstyn, 2016)

CHAPTER 2

THE LEGACY OF SIR LUDWIG GUTTMANN.

FROM STOKE MANDEVILLE TO BARCELONA

2.1 Sir Ludwig Guttman

Sir Ludwig Guttman, of Jewish origin, was born in Tost (Germany) on 3 July 1899 (Rademeyer, 2015). By the 1930s, Guttman was already considered a great neurosurgeon on the entire European continent. However, his professional career was severely limited, as Hitler's policies did not allow Jewish doctors to work in German hospitals (Rademeyer, 2015; Silver, 2013). But despite these limitations, he enjoyed international prestige and began to receive offers to work in other countries. Therefore, Guttman decided to move with his family to England in 1939. There, he became a lecturer at Oxford University (Rademeyer, 2015).

2.2 Stoke Mandeville, specialization in SCI

In 1944 the National Spinal Injuries Unit was established at Stoke Mandeville Hospital, near Aylesbury. It was the first unit in Europe to specialize in the treatment of patients with SCI, of which Guttman was appointed director. For the next 22 years, all of Guttman's medical activity was focused on solving the problems that arose in the pathology, physiology and treatment of people with SCI (Rademeyer, 2015; Silver, 2013).

But to understand Guttman's contribution and legacy in the treatment of SCI, it is necessary to be aware of the state of knowledge on the subject at the time. In 1939, people with SCI had a life expectancy of two years. The probability of death after SCI was between 47 and 65 percent in the first few months, rising to 80 percent three years after injury, with complications from urinary tract infections and pressure ulcers being the main causes of early death (Rademeyer, 2015). Faced with this problem, Guttman set a twofold objective. In the short term, for the initial phases after the injury, it aimed to reduce complications. And in the long term, it aimed for the full social reintegration of patients despite their high degree of disability (Silver, 2012). To this end, he introduced revolutionary new methods for the treatment of SCI:

- **Pressure ulcers:** Guttman was a proponent of simple surgery to heal ulcers. He did this by placing the skin over the wound to provide a healthy base. In cases of more severe ulcers,

he used skin grafts and when the skin had healed, patients were gradually mobilized and taught to prevent new ulcers by getting up regularly (Silver, 2012).

- **Bladder management:** Guttman personally performed intermittent catheterization on his patients four times a day and whenever the bladder became distended. In doing so, he took all possible sterilization measures, as if it were a surgical procedure (Silver, 2012).
- **Early mobilization and physiotherapy:** Before Guttman's arrival, patients were lying in bed for days on end. He initiated early mobilization with active physiotherapy sessions and recovery exercises to avoid muscle contractures, joint stiffness, pressure ulcers and deep vein thrombosis in the lower limbs (Silver, 2012).
- **Patient reintegration:** Guttman also pioneered the concept of reintegrating the patient back into society after the injury. To this end, the first measure he took was to discharge patients when they had learned to care for their skin, dress and undress themselves, to move around in a wheelchair or with technical aids, and to manage their bladder (Silver, 2012).
- **The use of sport as a rehabilitation tool:** Guttman used to tell patients and hospital staff "*Games, sport, that's what we must have*". Sports and recreational activities became an increasingly important part of the rehabilitation process, as beyond their contribution to the physical and functional sphere of the patient, they have an incalculable value in his/her emotional and social sphere (Rademeyer, 2015).

2.3. Stoke Mandeville Games

The introduction of sport as an element of the rehabilitation process was a success at the hospital. Following its establishment, Guttman and his staff organized the first Stoke Mandeville Games for people with paraplegia in 1948. It was a wheelchair archery competition between patients from Stoke Mandeville and the Star and Garter Home in Richmond in which 14 people competed. The date chosen for this event was 28 July 1948, exactly the same day that King George VI inaugurated the 1948 Olympic Games in London. Guttman wanted his Games to have a wider forum and his long-term goal was to create an elite sporting competition for people with disabilities that would be equivalent to the Olympic Games.

The success was such that the Games were held annually thereafter, with more sports being added each year. In 1952 the Games became international, as a delegation from the Military Rehabilitation

Centre in Doorn (Netherlands) also participated. A year later, a Canadian team joined the Games and, in 1954, delegations from Australia, Finland, Egypt and Israel took part in them. The 1957 Games saw the first representation from five continents.

In the late 1950s, Guttmann and Dr. Antonio Maglio, medical director of a SCI treatment unit in Rome, agreed to organize the 1960 International Stoke Mandeville Games in the Italian capital. They were the first Paralympic Games, as they are known today, since they were held in the same city where the 1960 Rome Olympic Games had ended a few days earlier. Four hundred athletes from 23 countries competed in eight sports: archery, athletics, "dartchery", billiards, swimming, table tennis, wheelchair basketball and wheelchair fencing.

Guttmann summed up the Paralympic Games by saying: *"The vast majority of competitors and accompanying persons have fully understood the significance of the Rome Games as a new model for the reintegration of paralyzed people into society as well as into the world of sport"* (International Paralympic Committee Archive).

Guttmann's ingenuity in creating the Paralympic Games movement changed the perception of sport for people with disabilities forever. Pope John XXIII summed it up best, when he met Guttmann at the 1960 Games and described his work as *"the transformation of a desperate and helpless individual with spinal paralysis into a contributor"*.

From 1960 the Stoke Mandeville International Games continued to be held every year in Stoke Mandeville, except in the Olympic year (every four years), when they were held in the same city or at least in the same country as the Olympic Games.

Guttmann's legacy revolutionized the perception of people with disabilities and their ability to be included in sport (Rademeyer, 2015).

2.4. The Institut Guttmann Neurorehabilitation Hospital, the context of this Thesis.

The Institut Guttmann Foundation was created in Barcelona in 1962 by Mr. Gonzallez Gilbey, who, after becoming a tetraplegic in a traffic accident in 1958, travelled to England to be treated by Dr. Guttmann. There he also met a young Catalan doctor, Dr. Sarrias, who was learning Dr. Guttmann's innovative methods. After returning to Barcelona, González Gillbey, faced with the lack of centers in Spain specializing in the treatment of people with SCI, founded the Institut Guttmann Neurorehabilitation Hospital in 1965, appointing as director Dr. Sarrias (Sarrias et al., 1998).

Dr. Guttmann attended the inauguration of the hospital center in Barcelona, an event covered by one of the most important newspapers in Spain, *"La Vanguardia"*, which the following day published an

interview, where Dr. Guttmann once again stated the objective of social reintegration of people with SCI: *"We can rehabilitate these patients on condition that they have been properly treated from the beginning, avoiding the complications I alluded to earlier. For this we need this type of center, in which the patient must be admitted from the very beginning. In spite of the paralysis, the patient can manage to get by in a wheelchair or with a walking aid. The point is that, in time, he will be able to connect with society and be considered, through his work, a respectable citizen"* (del Arco, 1965).

Almost 60 years later, Institut Guttmann Hospital is a highly specialized center in the medical-surgical treatment and comprehensive rehabilitation of people with SCI and other neurological injuries. Since 2005 it has been internationally accredited by the Joint Commission International, which certifies that the Institut Guttmann meets international standards of quality care and organizational management.

2.5. The Hospital Guttmann SCI Unit

The SCI Unit at the Institut Guttmann Hospital is responsible for the care, treatment and lifelong follow-up of people with SCI. This unit is recognized by the Spanish Ministry of Health, Social Services and Equality as a National Reference Centre (CSUR) for the treatment of complex SCI. After initial rehabilitation in hospital, patients usually move to an independent living situation at home but continue their rehabilitation in the hospital's day care program.

During 2022, 221 adult patients with SCI completed their neuro-rehabilitation process at the Guttmann Institute, of whom 17% had complete paraplegia, 41% had incomplete paraplegia, 10% had complete tetraplegia and 32% had incomplete tetraplegia. In 60% of the cases, the origin of the injury was of non-traumatic etiology compared to 40% with a traumatic origin. The average age was 51 years and the majority were men (64%). Of the total patients discharged, 4.7% were readmitted for complications (within 2 years of discharge), mostly urological and traumatological (Fundació Institut Guttmann, 2023).

The care and treatment of patients with SCI in Institut Guttmann is approached on a global and comprehensive basis (rehabilitation doctors, urologists, traumatologists, nurses, physiotherapists, PA and sports professionals, psychologists, social workers, assistants, and occupational therapists), always seeking the involvement and participation of families in the rehabilitation process.

Following Ludvig Guttmann's legacy, PA and sport play an important role at Institut Guttmann in the treatment of people with SCI. Four PA and sport professionals work daily for two to three hours with each patient, strengthening the preserved musculature, improving cardiovascular capacity as well as educating and introducing adapted sport both in the hospital and community environment (sports

centers, climbing facilities, public swimming pools, golf courses, ski resorts or in the natural environment, such as the beach and the sea) (Yepes-Baldó et al., 2022)

In addition, over the last decade, Institut Guttmann has created different programs for people with SCI who have already completed their rehabilitation process in which PA and sport play a key role:

- ***Sports&Life Guttmann Club***: This is a program of sporting, cultural and social activities aimed at former patients of the hospital (including SCI patients), their families and friends, in order to enable them to practice sport and other social and cultural activities in a different environment and in a normalized way.
- ***Camp Spinal H2O***: Training camp based on the concept of Active Rehabilitation (Divanoglou et al., 2019) in which water sports activities are the common thread. This camp is specifically aimed at people with recently acquired SCI but who have already completed their rehabilitation process. Participants live together with health professionals and peer instructors, both experts in SCI, during one week in community environment.
- ***Delfines de colores***: It is a telematic project addressed to education professionals and sports center instructors that aims to promote the inclusion and socialization of children and adolescents with disabilities (including SCI) in the physical education and sport environment through cooperative pedagogy. The website has more than 500 inclusive activities and facilitating tips grouped into three typologies (aquatic activities, playground games and motor games) (Finestres, 2020).
- ***Back to the origins***: "Back to the origins" is the name of the initiative, promoted by Institut Guttmann, which has led 4 patients to travel to England to participate in the *WheelPower Inter Spinal Unit Games* at the hospital of Stoke Mandeville. For a week, patients, accompanied by professionals from the Institut Guttmann, competed in this event in the UK, taking part in a wide variety of sports including athletics, archery, badminton, boccia, canoeing and basketball, among others.

2.6 Periodic comprehensive assessments for people with SCI.

Once rehabilitation at Institut Guttmann is completed, people with SCI receive health check-ups approximately every 18 months for approximately 4 hours by different health professionals to monitor and prevent possible complications and detect factors that determine QoL in the short, medium, and long term.

During the year 2023, a total of 791 check-ups were conducted on people with SCI. 534 corresponded to people with paraplegia and 257 to people with tetraplegia. As explained in the section “*Material and Methods*” of this PhD Thesis, the periodic comprehensive assessments for people with SCI was the recruitment context of the studies of this Thesis.

CHAPTER 3

ASSESSMENT OF PHYSICAL ACTIVITY IN SPINAL CORD INJURY POPULATION

3.1 What is physical activity?

Physical activity (PA) is a general term referring to any type of bodily movement, produced by skeletal muscles, which results in energy expenditure (Caspersen et al., 1985), such as daily life activities and professional activities that require energy exertion, fitness exercise, and recreational and competitive sports. All these activities can be grouped according to the context in which they take place and are usually classified by type or purpose:

- A) Lifestyle activity includes all activities that are part of one's daily routine: personal hygiene, household chores, work-related activity, passive leisure activity (Buchholz et al., 2003).
- B) Leisure time physical activity (LTPA) encompasses activities that require physical exertion and that people choose to do in their free time, such as playing a sport, exercising at a gym, or going for a wheeling (Martin Ginis, Phang et al., 2012).

Exercise is a type of PA that is planned, structured and repetitive and is done to improve or maintain one or more of the components of physical fitness (Caspersen et al., 1985).

Physical fitness is a set of attributes that individuals have or achieve that are health-related (cardiorespiratory and muscular endurance, muscular strength, body composition and flexibility) or skill-related (agility, balance, coordination, speed, power and reaction time).

Simply stated, exercise is PA that people typically do with a plan in mind, and that they perform on a repeated basis to improve some aspect of their physicality. Not all PA is exercise, but both activity and exercise can contribute to fitness.

3.2. Assessment of PA in populations with disabilities or chronic health conditions

Assessment and quantification of PA, as well as factors influencing PA, is an important part of health promotion efforts to address physical inactivity (Bauman et al., 2006). Therefore, knowing the benefits that the practice of PA can bring in all dimensions to the general population (Warburton, 2006; Saxena et al., 2005), to the population with some type of disability (Martin Ginis, Van Der

Ploeg, et al., 2021; Medina et al., 2013), and, in particular, to the SCI population (Martin Ginis et al., 2008; Todd et al., 2021), there is a need for tools to quantify PA. This is why structuring, elaborating and developing programs that make this practice possible, and, at the same time, carrying out lines of research in all related fields that provide conclusions at an international level will only be feasible with the right assessment tools. But evidently, because of the particularities of each population, the PA assessment tools cannot be the same in different population groups, and more specifically in the SCI population, whose particularities and characteristics will also require specific PA assessment methods (Warms, 2006).

Thus, generalizing the use of assessment tools created for health conditions in SCI population would be a mistake (Van der Scheer et al., 2018). Selecting the most appropriate assessment tool in relation to the specific population under investigation is crucial. The only valid PA measure for a population with neurological problems is one developed for that specific population (Warms, 2006; Kriska & Caspersen, 1997). Consequently, assessment tools designed for healthy people should not be used across the board in people with SCI.

The variety of methods and/or techniques used to assess PA is extensive. These include: a) self-reports, b) movement sensors such as pedometers and accelerometers, c) direct observation systems, d) heart rate monitors, and e) indirect calorimetry and the doubly labeled water technique (Cervantes & Porretta, 2010). However, the most widely used methods for quantifying PA in both healthy and disabled populations are questionnaires and accelerometers (Cervantes & Porretta, 2010). Both questionnaires and accelerometers are valid tools for the measurement of PA in people with disabilities and the researcher or clinician must decide which type of tool to use based on the particular context.

An accelerometer is an electronic device that serves not only to measure and quantify the amount of movement, but also to measure the intensity of that movement (Westerterp, 1999). However, questionnaires are often the tool of choice for population studies as they possess the characteristics of non-reactivity (i.e., do not alter the behavior of the individual being surveyed), practicality (study costs are reasonable and they are convenient for participants), applicability (the instrument can be designed to fit the particular population in question), and accuracy (it is reliable and valid) (Kriska & Caspersen, 1997). It is also important to note that the accelerometer-based PA assessment reports cumulative daily PA and do not capture potentially important domain information. This differs from self-report measures that collect PA by type or dimension. The type or dimension is a valuable information to promote the improvement of health through specific programs or recommendations (Quinn & Barone Gibbs, 2023).

Beyond their application as an assessment tool, both questionnaires and accelerometers have also been used as a validation tool for other measures. Accelerometers have been used to test and

demonstrate the validity of questionnaires or scales to assess PA in people with disabilities (Cervantes & Porretta, 2010) and, equally, questionnaires have been used to validate electronic devices such as accelerometers (Warms & Belza, 2004).

In terms of cost, questionnaires and self-report records are the most cost-effective for measuring PA and have a clear advantage for use in large population-based or epidemiological studies (Warms, 2006), since they are highly reliable as epidemiological measures of PA in large populations (Laporte et al., 1985).

3.3 Questionnaires for the assessment of PA in people with disabilities and populations with chronic health conditions.

The most scientifically valid questionnaire used internationally to measure PA in healthy populations is the *International Physical Activity Questionnaire (IPAQ)* (Hagströmer et al., 2006). It has also been used to measure PA in SCI populations (Piira et al., 2020). However, as mentioned above, it is not recommended to generalize the use of assessment tools created for healthy conditions in SCI population (Van der Scheer et al., 2018). In accordance, several questionnaires have been developed and validated for the assessment of PA in people with disabilities or populations with specific health conditions and used for PA assessment in SCI populations:

- ***Physical Activity Scale for the Elderly (PASE):***

It is a short (5 minutes) and easy to administer (by email, telephone or in person) self-administered questionnaire specifically designed and validated to assess PA in people aged 65 or more (Washburn et al., 1993, 1999). It collects information on leisure activities, household chores and occupational activities. It consists of 12 items assessing PA of older adults (walking, recreational activities, exercise, housework, gardening and caring for others). It is scored using the frequency, duration and intensity level of each activity during the week prior to administration, with a possible final score ranging from 0 to 793, with higher scores indicating greater PA (Logan et al., 2013). This questionnaire has been the base questionnaire from which other questionnaires for the assessment of PA in people with disabilities have been developed.

- ***Physical Activity Scale for Individuals with Physical Disabilities (PASIPD):***

The PASIPD was developed in English language by adapting the PASE questionnaire for use in epidemiological studies of PA, health and functionality specifically in people with physical disabilities.

A study group of people with different disabilities was included in its development: post-polio, paraplegia, tetraplegia, cerebral palsy, amputees, muscular dystrophies, spina bifida, visual and hearing impairments, as well as people with other pathologies such as epilepsy, hemophilia and diabetes. It is a short questionnaire of 13 items: 6 for leisure time activities, 6 for household activities and one for paid work. Like its predecessor, it can be administered in person, by e-mail or by telephone with the aim of collecting PA data for the last 7 days (Washburn et al., 2002).

- ***Physical Activity Inventory-SCI (PAI-SCI):***

The PAI-SCI is a PA questionnaire specifically for people with SCI. It is derived from the PASIPD questionnaire, where the original items were reformulated to adapt to the specific group of people with SCI (Butler et al., 2008). It consists of 14 items, which refer to the 7 days prior to administration, and in which the participant indicates the number of days in the last week in which he/she participated in specific activities. As in its predecessor questionnaires, individuals are asked to indicate the number of minutes or hours spent on a particular activity. Total scores are calculated as the sum of the daily/average hours at a particular intensity multiplied by a previously measured equivalent metabolic value.

- ***Physical Activity and Disability Survey (PADS):***

The PADS questionnaire was specifically designed to measure the PA behavior of people with disabilities and chronic health conditions. It includes three subscales: a) exercise (16 items); b) LTPA (7 items); c) activity at home (16 items), and two complementary sections (Demographic data and Choice). The Screening section, which consists of four pre-interview screening items, is used to determine the person's primary disability and the extent to which respondents were physically affected by their disability. The results of the psychometric properties' assessment support the reliability and validity of the PADS as a measure of PA in sedentary and disabled groups (Rimmer et al., 2001).

- ***The Physical Activity and Disability Survey – Revised (PADS-R):***

PADS-R is a revised modification of the PADS in which one of the main new features is the use of matrices that classify the type and intensity of exercise and LTPA, so that participants report on the type and intensity of each of their activities, whereas in the PADS a global assessment of intensity was reported for all activities (Kayes et al., 2009).

- ***The Physical Activity Recall Assessment for People with Spinal Cord Injury (PARA-SCI):***

The PARA-SCI is the most commonly used questionnaire to assess PA in people with SCI (Martin Ginis et al., 2005). It was developed to measure the type, frequency, duration, and intensity of PA by persons with SCI who use a wheelchair as their primary mode of mobility. It can be used among people with paraplegia or tetraplegia, and is designed to capture three categories of PA: LTPA, lifestyle activity and, cumulative activity (the combination of LTPA and lifestyle activity).

Construction of the PARA-SCI involved developing (a) a semi structured interview protocol for collecting PA information and (b) a *Physical Activity Intensity Classification System*.

The participant should recall the activities performed in the 3 days prior to the interview and classify them according to the PA Intensity Classification System (which he/she will have previously reviewed with the interviewer) in the corresponding intensity: "*Nothing at all*", "*mild*", "*moderate*" or "*heavy*", resulting in the minutes per day and total of LTPA, and lifestyle activity total for each of the intensity categories (Martin Ginis et al., 2005). This questionnaire performed well in test-retest reliability and has a good construct validity (Martin Ginis et al., 2005; Latimer, Martin Ginis, Craven et al., 2006).

- ***Leisure Time Physical Activity Questionnaire for People with SCI (LTPAQ-SCI):***

The LTPAQ-SCI is a self-administered questionnaire developed specifically for SCI population that uses the same *Physical Activity Intensity Classification System* as the PARA-SCI ("*Nothing at all*", "*mild*", "*moderate*" or "*heavy*"), but unlike the PARA-SCI it only reports minutes of LTPA (Martin Ginis, Phang et al., 2012). Its structure is based on the Godin Leisure Time Exercise Questionnaire (Godin & Shephard, 1985) and the short version of the International Physical Activity Questionnaire (Hagströmer et al., 2006), reporting activity in the last 7 days. It has demonstrated reliability and construct validity as a measure of LTPA among people with SCI (Martin Ginis, Phang et al., 2012; Martin Ginis, Úbeda-Colomer, et al., 2021).

- ***Leisure Time Physical Activity Questionnaire for People with Disability (LTPAQ-D):***

It is a new questionnaire based on an adaptation of the LTPAQ-SCI for use with the general population with disabilities. Although more studies are still needed to verify its psychometric characteristics, the French-Canadian version has good test-retest reliability when self-administered or administered by interview to people with physical disabilities (Cummings et al., 2019).

3.4 Choice of a PA questionnaire for the development of this Thesis

Although all the questionnaires presented above have been used to assess PA in SCI populations, only 3 (PAI-SCI; PARA-SCI and LTPAQ-SCI), were developed specifically for this population. Comparisons between them in the scientific literature conclude that the PARA-SCI is the most valid questionnaire for predicting the energy expenditure derived from PA in people with SCI who use wheelchairs as their main means of transportation being the one with the best criterion validity and reliability (Tanhoffer et al., 2012; Lankhorst et al., 2020; Nightingale et al., 2017). In the reliability study, intraclass correlations ranged from 0.45 to 0.91 for the various PARA-SCI activity categories and intensities (Martin Ginis et al., 2005). The convergent validity study provided evidence of validity for the PARA-SCI LTPA and cumulative activity categories. This has been demonstrated by the positive correlation between aerobic fitness and muscle strength parameters and LTPA and cumulative activity category scores (Latimer, Martin Ginis, Craven, et al., 2006), a strong level of correlation for total PA and 3-day MVPA between accelerometer data and PARA-SCI interviews (Štěpánová et al., 2021), and by extreme group analyses that provided further evidence of the validity of the LTPA category by demonstrating differences between them (Latimer, Martin Ginis, Craven, et al., 2006), as well as the significant correlation observed in Vo₂ max. calculated using the 12-minute wheelchair test and the PARA-SCI subcomponent (Joshi et al., 2020).

In addition, the PARA-SCI is the only questionnaire where people with SCI were involved in its development (Martin Ginis et al., 2005), and its *Physical Activity Intensity Classification System* was developed expressly for the SCI population. Kriska and Caspersen (1997) consider this to be entirely positive since in any assessment of the relationship between PA and the outcome of a given disease, the assessment tool must obtain accurate information on the components of energy expenditure that comprise the largest proportion of total energy expenditure in the particular study population.

Laporte et al (1985) also made specifications in this regard, as one source of variability in adequately characterizing PA is the accuracy of intensity attribution. Therefore, people with SCI, due to the physiological consequences of their injury, should be attributed an intensity of PA specific to their group.

And also Warms (2006), in the more specific field of PA assessment in disability, reached the conclusion that selecting the most appropriate questionnaire in relation to the specific population under investigation is crucial, specifying that the only valid energy prediction formula for a population with neurological or physical problems should be developed according to the characteristics of that population.

And, in this regard, the authors of the PARA-SCI undertook a systematic process to develop definitions of three different PA intensities (mild, moderate and heavy) specifically for people with

SCI (Martin Ginis et al., 2005). The empirical development of intensity-based definitions alone suggests that the PARA-SCI may be the most effective self-report questionnaire for measuring PA intensity in people with SCI.

However, the non-specific questionnaires for SCI (PASIPD, PADS, PADS-R, PASE, and recently LTPAQ-D) have also been used in studies of the SCI population. This has led to constant comparisons in the scientific literature, trying to define the best tool according to different conditions.

On the one hand, Tanhoffer et al. (2012) compared the PASIPD and the PARA-SCI as methods of assessing energy expenditure and PA in people with SCI. They concluded that the PARA-SCI is the best questionnaire for predicting energy expenditure from PA in people with SCI who use wheelchairs as their main mode of mobility. On the other hand, de Groot et al. (2010a; 2010b), after examining the construct validity between the PASIPD and measures of physical fitness and activity, found divergent validity in an heterogeneous sample of 139 people with SCI living in the community.

Also, Lankhorts et al. (2020) conducted a systematic review of the evidence assessing the validity or reliability of self-reported instruments for measuring PA in individuals who use a wheelchair. They included the PASIPD, the PAI-SCI, the PARA-SCI and the LTPAQ-SCI, concluding that the PARA-SCI is the most suitable questionnaire for assessing PA in people with SCI and wheelchair users. However, they were critical of the lack of data confirming the internal consistency of the PARA-SCI. But it should be noted that the PARA-SCI is a multidimensional measure (frequency, intensity, duration and type of activity) in which not necessarily each of the dimensions assessed must be correlated with the others (Lyons & Martin Ginis, 2024).

Nightingale et al. (2017) analyzed four questionnaires to predict PA and energy expenditure in people who use wheelchairs as their main means of transportation: the PADS, the PASIPD, the PARA-SCI and the LTPAQ-SCI. They concluded that the PARA-SCI had the highest criterion validity and reliability.

Cervantes and Porreta (2010), analyzed a total of 27 studies reporting on the validity and reliability of the instrument used to measure PA. Of these 27 articles, a total of 13 had used a self-reported questionnaire as a tool for assessing PA. Only in two of these, the population within which the validity and reliability assessments of the instrument had been carried out consisted of people with SCI. These two studies were the studies related to the development and validity of the PARA-SCI (Martin Ginis et al., 2005; Latimer, Martin Ginis, Craven, et al., 2006)

Van der Scheer et al. (2018), in a systematic review of aerobic exercise assessment measures in adults with SCI, also found acceptable test-retest reliability of the PARA-SCI in a well-developed study with respect to the *Physical Activity Intensity Classification System*.

And in another line of research, in the assessment of the determinants of participation of people with SCI, Noonan et al. (2009) found that the PARA-SCI was the only tool for the assessment of

participation indicators specifically developed for SCI population, highlighting that the PARA-SCI was not only developed for SCI population, but that people with SCI had been directly involved in its development, so that comparisons using the scores derived from this instrument will provide meaningful information that can be used in intervention projects and programs, as well as to create public health guidelines for people with SCI.

But beyond the comparison between different PA measurement tools, the scientific literature has also shown that the failure to use the most appropriate PA assessment measure has been a weakness of the particular study or project.

Kawanishi and Greguol (2013) made considerations about the tools used to assess PA, since of all the studies included in their systematic review on the correlation of PA and QoL, only two used validated tools for the assessment of PA, the PASIPD in the work of Stevens et al. (2008), and The Leisure Time Exercise Questionnaire (LTEQ) in the study by Manns & Chad (1999). However, as mentioned above, when assessment measures are used, they must be valid for the specific population being assessed. PASIPD has provided limited validity in the SCI population (de Groot et al., 2010a; 2010b), and LTEQ is designed for the general population (Godin & Shephard, 1985); it is not recommended to generalize the use of assessment tools created for the general population in the SCI population (Van der Scheer et al., 2018). In this vein, Kim et al. (2020), after finding a negative relationship between the level of participation in PA and anxiety and depression, stated that a limitation of their study was that they used the Godin Leisure Time Exercise Questionnaire to assess PA because it was developed for a population with health conditions. In addition, Martin Ginis, Jetha et al. (2010), in a review on PA and subjective well-being among people with SCI, detected a lack of information on the psychometric properties of the PA assessment measures used in the included studies. For this reason, they urged researchers to use PA measures that have been validated for use in the SCI population.

It is consequently very important to select the most appropriate assessment tool in relation to the specific population under investigation, specifying that the PA measure for a population with neurological problems should be developed for that specific population (Warms, 2006; Kriska & Caspersen, 1997) and based on the criteria of validity, reliability, practicality and non-reactivity defined by Laporte et al. (1985) as criteria for evaluating the potential of an assessment tool.

Consistent with the above scientific evidence, this thesis will use the PARA-SCI questionnaire as tool to assess PA in people with SCI.

3.5. Use of PARA-SCI in the scientific literature

The PARA-SCI questionnaire has been used to quantify PA levels in the SCI population, both those already living in the community and those undergoing sub-acute rehabilitation treatment.

At the community level, it has been found that people with SCI spend most of their waking time in very low intensity activity or inactivity (Perrier et al., 2016), with only 32% of the population being stably active (Sweet et al., 2012), and that specific programs and strategies are therefore necessary to reduce this inactivity in the collective (Perrier et al., 2016).

By demographic groups in relation to age, the use of the PARA-SCI has shed light on PA performed by older adults with SCI, showing that many of them do not achieve the amount or intensity of LTPA necessary to obtain cardiovascular benefits (Jørgensen et al., 2017; Martin Ginis, Latimer, et al., 2010).

It has also been identified that there is more PA practice when the injury has been in pediatric age than when it has been in adulthood (Ma et al., 2016) and when the injury is a complete motor paraplegia (Martin Ginis, Latimer, et al., 2010). Additionally, in these cases, greater wheelchair skills correlate with more participation in LTPA (Phang et al., 2012).

In contrast, participation in LTPA is lower in power wheelchair users and in people with incomplete motor impairment who use walking aids (Martin Ginis, Latimer, et al., 2010; Martin Ginis et al., 2017). Thus, different predictors of PA can be established according to the severity of the injury and the usual mode of mobility.

In relation to gender, women spend less time on LTPA than men (Martin Ginis, Latimer, et al., 2010; Stapleton & Martin Ginis, 2014), and they contrarily spend more time on lifestyle activity (Hetz, Latimer, & Martin Ginis, 2009). Therefore, women will also be a subgroup that requires specific intervention programs for increased participation in LTPA (Martin Ginis, Latimer, et al., 2010).

In terms of barriers to PA, PARA-SCI has been used to find that people with SCI who live within 30 minutes of an accessible facility are less likely to participate in high-intensity LTPA (Arbour & Martin Ginis, 2009), but instead a more accessible and friendly perception of the architecture of the neighborhood or area of residence plays an important role in the confidence to participate in LTPA (Arbour-Nicitopoulos et al., 2010).

The PARA-SCI has also shown evidence that people with SCI report lower participation in LTPA during winter (Perrier et al., 2012), that the presence of pressure ulcers is a setback for the performance of PA (Sweet et al., 2012), that the perceived risk of chronic pathologies such as diabetes can modify PA planning habits (Bassett & Martin Ginis, 2011), as well as that correct PA planning plays a positive role on the execution of PA in relation to the Theory of Planned Behaviour (Latimer & Martin Ginis, 2005; Latimer, Martin Ginis, & Arbour, 2006).

The PARA-SCI has also been used to assess the impact of PA on metabolic functioning (Yarar-Fisher et al., 2019; Pelletier et al., 2018), on diabetes and on cardiovascular functioning, showing greatest levels of LTPA in relation with lower levels of cardiovascular disease (Buchholz et al., 2009), and also that the more movement and activity there is in transfers and movements, the lower the concentration of plasma total cholesterol and LDL (Hetz, Latimer, Buchholz, et al., 2009; Hetz et al., 2010).

At physical level, the use of the PARA-SCI has helped to demonstrate the positive impact of PA on reduced breathlessness (Garshick et al., 2016) and fatigue (Tawashy et al., 2009), the benefits of PA on functionality (Sweet et al., 2013), the impact on improving dynamic sitting balance (Kim et al., 2014), and the positive impact of moderate PA on reducing pain levels (Tawashy et al., 2009).

It has also been used to assess psycho-social aspects; for instance, sport participation has a positive influence on life satisfaction (Garshick et al., 2016; Mulroy et al., 2016), QoL (Sweet et al., 2013), self-efficacy (Tawashy et al., 2009), decreased levels of depression (Sweet et al., 2013), as well as in the study of the relationship between PA and body image perception (Bassett, Martin Ginis, & Buchholz, 2009; Bassett, Martin Ginis, & The SHAPE-SCI Research Group, 2009).

The PARA-SCI has also been used in people with SCI at hospital level during the sub-acute rehabilitation process to show that the cardiovascular work incurred during physiotherapy and occupational therapy sessions is low and is not sufficient to obtain a cardiovascular training effect that optimizes their neurological, cardiovascular or musculoskeletal health (Zbogar et al., 2017), which is a lost opportunity to optimize rehabilitation. At the same time, it also shows that in the free time, once the physiotherapy and occupational therapy sessions are over, most of the time is devoted to sedentary activities (Zbogar et al., 2016).

CHAPTER 4:

LEISURE TIME PHYSICAL ACTIVITY PARTICIPATION AND CORRELATES IN SPINAL CORD INJURY POPULATION

4.1 Leisure time physical activity index's participation

The SCI population often reports low levels of LTPA (Martin Ginis, Latimer, et al., 2010; Van den Berg-Emons et al., 2008), being in very low intensity activity or inactivity for most of their waking time (Perrier et al., 2016). Also, only 32% of such population is stably active (Sweet et al., 2012). These low levels of LTPA participation do not meet the minimum necessary amount or intensity of LTPA needed to achieve cardiovascular benefits (Jørgensen et al., 2017; Martin Ginis, Latimer, et al., 2010). In brief, compared to the general population and people with other types of disabilities and chronic diseases, people with SCI are considered to be at the lower end of the PA spectrum (Van Den Berg-Emons et al., 2010).

Therefore, in order to develop strategies and programs that foster greater participation in LTPA, it is crucial to investigate which are the reasons for this low participation in LTPA and in which segments of the population this low participation is most pronounced.

4.2. Physical benefits through physical activity

There is strong scientific evidence of the benefits of PA for people with SCI, such as reducing fatigue (Tawashy et al., 2009), and the sensation of dyspnea (Garshick et al., 2016), improving general health in case of diabetes (Buchholz et al., 2009), and improving muscle strength (Martin Ginis, Jørgensen, et al., 2012), metabolic health (Yarar-Fisher et al., 2019; Pelletier et al., 2018), and cardiovascular functioning. Evidence shows that greatest LTPA correlates with lower levels of cardiovascular disease (Buchholz et al., 2009), and also that more movement and activity in transfers and displacements correlates with lower concentration of plasma total cholesterol and LDL (Hetz, Latimer, Buchholz, et al., 2009; Hetz et al., 2010). It has also been shown that PA has a positive impact on improving dynamic sitting balance (Kim et al., 2014), functionality (Sweet et al., 2013), and that when PA is performed at a moderate to vigorous intensity pain levels are reduced (Tawashy et al., 2009).

As described before, PA can be classified into LTPA and lifestyle activity. Note that in the context of the SCI population, most research has focused on LTPA, since most lifestyle activities are not

performed at a duration or intensity level that confer fitness or health benefit expectations (Perrier et al., 2017). Thus, participating in regular LTPA is especially relevant for SCI population.

Concerning intensity, evidence shows that moderate to vigorous LTPA is necessary to achieve physical improvements. For cardiorespiratory and muscle strength benefits, adults with SCI should perform at least 20 minutes of moderate to vigorous intensity aerobic exercise 2 times per week and 3 sets of strength exercises for each major functional muscle group, at moderate to vigorous intensity, 2 times per week. For cardiometabolic health benefits, adults with SCI are recommended to perform at least 30 minutes of moderate to vigorous intensity aerobic exercise 3 times per week (Martin Ginis et al., 2018).

4.3 Psychosocial benefits through physical activity

Scientific literature has shown the impact of PA on psychosocial variables in people with SCI. In relation to QoL, well-being and life satisfaction, different studies have proven a positive relationship between these and PA participation. For instance, Sliwinsky et al. (2020) showed that an 8-week supervised post-rehabilitation exercise that includes resistance exercises, aerobic conditioning, trunk stability, and health education may positively impact QoL. Mickens et al. (2022) displayed how different levels and intensities of LTPA significantly improve multiple aspects of QoL. Hicks et al. (2003) reported a decrease in general body pain and depressive symptoms, as well as an overall improvement in QoL, after a 9-month intervention of progressive aerobic and resistance exercise training. Shem et al. (2016) also observed a reduction in overall bodily pain and an improvement in emotional well-being following a 12-week seated tai chi exercise programme. Garshick et al. (2016) showed how an active lifestyle characterised by spending more time outdoors or in the garden and participation in sports is associated with higher life satisfaction.

Concerning anxiety and depression, Kim et al. (2020) found that symptoms of depression and anxiety were higher in people with lower participation in PA, and, similarly, Tawashy et al. (2009) showed that higher amounts of mild intensity PA correlated with lower levels of depression. In the same line, Mulroy et al. (2016) showed that longer daily wheelchair propulsion distance correlated with lower levels of depression, and Silveira et al. (2017) found that greater frequency of wheelchair rugby participation was associated with lower levels of depressive symptomology and perceived stress.

Concerning community integration and participation, Hanson et al. (2001) demonstrated that people with SCI who were more involved in sports and exercise also reflected greater community integration than those with less involvement. Van der Westhuizen et al. (2017) found that people with SCI who have better physical fitness experience higher satisfaction with their perceived community

participation, and ultimately better community participation than those who have poor physical fitness and endurance.

4.4 General self-efficacy and physical activity

Bandura's social cognitive theory (Bandura, 2001) awards great importance to the concept of self-efficacy (SE). SE is broadly defined as the overall confidence in one's ability to cope with a wide range of demanding or novel situations. In the same vein, SE refers to beliefs in one's capabilities to organize and execute courses of action required to produce given attainments. Consequently, GSE links to a wide and steady feeling of personal competence to adequately confront a multiplicity of trying situations (Scholz et al., 2002). In other words, it is the self-confidence to claim "I can do it" (Geyh et al., 2012).

Scientific literature has shown the impact of PA on GSE. For instance, Martin Ginis et al. (2013) demonstrated that people with SCI who had done regular PA in the last 6 months had significantly higher GSE than those who had not. Tawashy et al. (2009) found that greater heavy-intensity activity was related with higher levels of SE.

Furthermore, scientific evidence highlights the importance of SE for the mental health of people with SCI. Middleton et al. (2007) found that SE is strongly associated with QoL, showing that low levels of SE reported significantly lower levels of QoL compared to higher levels of SE. Hill et al. (2017) also revealed that SE is associated with functionality, showing that lower perceptions of basic mobility and fine motor function were correlated with lower SE. Geyh et al. (2012) found that greater levels of SE were related to higher participation rates. Moreover, Van Diemen et al. (2021) demonstrated in a cohort study that SE trajectories were interrelated with depressive mood and anxiety. Participants who adjusted well could be identified by their high SE scores and reported low scores in depressive mood and anxiety. The authors concluded that concurrent screening for SE and emotional distress might best identify people at risk for adjustment problems.

Additionally, previous research in SCI population sustains the mediating role of SE in ameliorating self-care and softening the negative impact of health problems cushioning the impact of chronic pain on mood (Craig et al., 2013; 2022). SE has also been pointed at as a potential intervention target to boost participation (Geyh et al., 2012). Literature has also demonstrated that SE is a powerful mediator of the relationship between secure attachment and employment status (Umucu et al., 2016).

4.5 Functionality and physical activity

Functional independence or functionality has been defined as the ability of the person to carry out activities of daily living and to perform activities that enable independent living (Hobart et al., 2001).

There is strong scientific evidence that PA positively influences functionality in SCI population. For instance, Szeliga et al. (2022) showed that physically inactive subjects with SCI are more dependent on third persons, and are probably unable to fend for themselves due to low functional fitness. In the same line, Sliwinsky et al. (2020) demonstrated that an 8-week supervised post-rehabilitation exercise that includes resistance exercises, aerobic conditioning, trunk stability, and health education positively impact on functionality. De Oliveira et al. (2016) found significant improvements in functional goals after supervised PA programs twice a week for 30 to 60 min for 8 to 12 weeks. Kawanishi & Greguol (2013) stated that there is a strong correlation between PA and variables of QoL and functional independence.

In addition, previous research in SCI population supported the mediating role of functionality in improving psychosocial health. For example, in the longitudinal study by Sweet (2013), the possibility raised was whether depression, functional independence, social integration/participation, and SE mediate the PA–QoL relationship. Their results showed that PA can improve QoL in adults with SCI through its influence on functional independence and depression.

4.6 Barriers to leisure time physical activity

Barriers to LTPA refer to the reasons or restrictions why people do not participate in LTPA, discontinues LTPA, or have negative experiences with LTPA. Thus, identifying barriers to LTPA among people with SCI is crucial to facilitate their participation and so that they can benefit from its practice.

Several studies have analyzed barriers to LTPA. For instance, Kehn & Kroll (2009), in a qualitative study showed that the biggest barriers identified by non-physically active people were perceived low return on physical investment, lack of accessible facilities, unaffordable equipment, lack of personal assistance and fear of injury. Cowan et al. (2013) identified not knowing where to exercise, lack of motivation, cost of program, lack of energy and lack of time as the five most prevalent barriers in a sample of 180 people with SCI. Mat Rosly et al. (2018) identified as top three barriers to moderate to vigorous LTPA in a sample of 70 people with SCI expensive exercise equipment, pain when exercising, and lack of access to facilities. Tiu et al. (2022), in a qualitative study with participants with SCI in a 16-week virtually delivered, peer-supported intervention, found that the main barriers were lack of time, lack of motivation, accessibility problems and SCI-specific barriers (difficulties with temperature control, skin breakdown and pain).

Furthermore, previous studies have shown that one of the motivating factors for PA was achieving the maximum possible functional independence and reduction of personal assistance (Kehn & Kroll, 2009), and that several barriers to PA that have been identified for this population (e.g. SE, lack of adaptation of fitness facilities and public spaces) are related to the individual's ability to perform tasks or manage in the physical environment independently.

Few studies have considered differences between individuals with different degrees of dependence following SCI. Robertson et al. (2011) examined the association of barriers with functional independence and ambulatory capacity and showed differences concerning the barriers that were most frequently endorsed varied between ambulatory and non-ambulatory participants. Barriers most frequently endorsed by ambulatory participants were lack of energy and pain; those for the non-ambulatory group were lack of a personal care attendant, concerns about incontinence, lack of access to an appropriate facility, and feeling uncomfortable in a fitness center. Only the cost was identified as a barrier for both ambulatory and non-ambulatory. There was also variation between individuals who could transfer independently and those who required assistance. Barriers most frequently endorsed by individuals in the independent-transfer group were cost and lack of access to an appropriate facility; those most frequently endorsed by the assisted-transfer group were lack of a personal care attendant and concerns about incontinence. Other studies have focused on the level of injury to examine differences in the perception of barriers. This is the case of Scelza et al. (2005) who showed that significantly more individuals with tetraplegia than with paraplegia indicated that exercise was too difficult and that health concerns prevented them from exercising.

Besides, only the studies of Hwang et al. (2016) and Hansen et al. (2021) have examined possible correlations between PA barriers and levels of PA performed. Hwang et al. showed that personal barriers, such as lack of financial resources, lack of planning, or presence of pain, demonstrated a significantly high negative correlation with the levels of PA. Environmental barriers, as inability to access specialized facilities or activities, lack of community resources, and lack of specialized staff had significant moderate negative correlations with PA. In turn, activity barriers and lack of specialized equipment, adapted activities and accessibility had significant low negative correlations with PA (Hwang et al., 2016). Hansen et al. (2021) showed that the self-reported level of PA decreased as health barriers increased and specifically found an independent negative association between health subdomain barrier impact and level of PA.

CHAPTER 5

PURPOSE AND AIMS OF THIS THESIS

General Purpose:

Given that SCI population frequently indicates limited participation in PA and considering that approximately 31.000 people with SCI live in Spain, the main aim of this Thesis is to contribute to establishing the bases and key points to promote PA participation in people with SCI who have already completed their acute rehabilitation process and who live in the community in the Spanish context. Its overall purpose is to establish an initial basis for enhancing PA participation in this population.

To this end, the following objectives were defined:

- To provide the scientific and clinicians working in Spanish language with a validated tool for the assessment of PA in people with SCI to evaluate future interventions effectively.
- To examine and identify which types of PA and at what intensities are most able to generate positive relationships with psychosocial outcomes such as perception of QoL, participation, and psychological distress. All this, considering the possible mediating role of functionality and SE.
- To identify, from a socio-ecological perspective, the prevalence and severity of barriers to LTPA, as well as which population groups are most vulnerable and consequently should be taken into account when developing strategies to encourage participation in LTPA.

Aim of Publication 1 (indexed scientific article):

As stated in chapter 3, this Thesis uses the PARA-SCI to measure PA. However, taking into account that the sample comes from Spain and that less than 30% of the Spanish population is able to communicate in English (Alcalá & Lirola, 2018), submitting the PARA-SCI to a process of translation, cultural adaptation and validation in Spanish prior to its use with the intended sample was needed. In addition, with the increase in the number of multinational and multicultural research projects, the need to adapt PA measures for use in other than the source language has also grown rapidly. Most questionnaires were developed in English-speaking countries (Beaton et al., 2000). The PARA-SCI has been translated into different languages such as Hindi (Joshi et al., 2020), Brazilian-Portuguese

(Santana Rodrigues, 2018), Czechoslovakian (Štěpánová et al., 2021), Thai (Eitivipart et al., 2021), and Swedish (Jørgensen et al., 2011), but not Spanish. Therefore, taking into account that beyond Spain, there are a total of 580 million Spanish-speaking people in the world, 7.6% of the world's population (Instituto Cervantes, 2019), the first aim of this Thesis is to provide a reliable and valid adaptation in Spanish language of a PA measure for people with SCI: the PARA-SCI-Spanish.

Aim of Publication 2 (indexed scientific article):

Taking into account the impact of PA on psychosocial variables, the different relationships that can be established between these variables, as well as the possible mediating role of SE and functionality, the second aim of this Thesis is to determine if functionality and/or GSE mediate the relationships between PA and participation, psychological distress and perception of QoL.

However, two considerations are necessary:

- a) The first consideration is, as explained above, that in the context of the SCI population, most research has focused on LTPA, but considering that studies such as those by Tawashy et al. (2009), and Stevens et al. (2008), found that cumulative PA (lifestyle and LTPA) was significantly related to higher levels of SE and lower levels of depression, and higher levels of QoL respectively, it is necessary to study also lifestyle activity and not only LTPA.
- b) The second consideration concerns the intensity of PA. As explained above, there is strong scientific evidence that PA needs to be performed at moderate to vigorous intensity to improve fitness and cardiometabolic health in adults with SCI (Martin Ginis et al., 2018). However, an LTPA intervention protocol that produces improvements in one type of physiological or psychosocial outcome may not produce changes in another physiological or psychosocial outcome (Todd et al., 2021; Tomasone et al., 2013; Van der Scheer et al., 2017). Thus, it should not be ruled out that mild intensity may also improve participation and perception of QoL, or decrease levels of psychological distress. In fact, previous research studying the impact of PA according to its intensity has found that the number of mild LTPA days per week predicted psychological QoL and the amount of mild LTPA per day predicted environmental QoL (Mickens et al., 2022). Also, that higher amounts of mild-intensity activity were related to fewer depressive symptoms (Tawashy et al., 2009). These findings indicate that mild intensity, and not only moderate and vigorous PA, should be studied in the possible correlates of PA and psychosocial variables.

Thus, in accordance with previous scientific research and the considerations formulated, the second aim of this Thesis is to determine if functionality and/or SE mediate the relationships between the various intensity (mild, moderate, and heavy) of PA (lifestyle and LTPA) and participation, psychological distress and perception of QoL.

Aim of Publication 3 (indexed scientific article):

The third objective of this Thesis is the study of severity and prevalence of barriers to LTPA and their association with socio-demographic characteristics, taking into account that participants' PA levels depend on a combination of motivational and socio-environmental factors. For this purpose, the conceptual framework on barriers to PA for people with disabilities created by Vasudevan, Rimmer & Kviz (Vasudevan et al., 2015) has been used. This socio-ecological model goes beyond individual factors and considers barriers to LTPA in individuals with mobility impairments across these four levels of influence:

- **Intrapersonal influences**, which operate at the personal level and involve health, attitude and impairment.
- **Interpersonal influences**, which encompass social relationships with family, friends and professionals.
- **Organizational influences**, which encompass elements of community institutions, such as programs and staff.
- **Community influences**, which involve variables in the wider community, such as public transportation and the natural and built environment.

Furthermore, considering that participation in LTPA differs by mode of mobility (e.g. manual versus power wheelchair users) (Perrier et al., 2017) and that people with more severe injuries may be less able to perform PA (Latimer, Martin Ginis, Craven, et al., 2006), it is crucial to explore how functional independence is associated with barriers to LTPA in order to identify people at higher risk of being inadequately active.

In addition, identifying which socio-ecological levels of barriers are associated with PA and being able to develop future programs and interventions targeting individuals who may be at higher risk of experiencing barriers while mitigating the barriers that have a stronger association with self-reported LTPA is critical.

Aim of Publication 4 (Clinical Manual; Appendix)

The main purpose of this Manual, beyond providing the clinician and/or scientist who deals with the Spanish-speaking population with all the necessary material for the use of the PARA-SCI-Spanish, is to provide all the necessary and detailed information for the correct use of the questionnaire, as well as to give multiple tips that will facilitate an adequate and easier administration of it.

The drafting of this manual, beyond incorporating the recommendations of the PARA-SCI manual in English (Martin Ginnis et al., 2015), is based on the experience of the author of this Thesis, who in addition to being the coordinator of the whole process of translation and cultural adaptation into Spanish of the PARA-SCI as well as of the reliability and validity studies of the PARA-SCI-Spanish, has administered it to date to more than 250 people with SCI to assess and quantify their PA.

CHAPTER 6

MATERIALS AND METHODS

The studies included in this Thesis follow the Declaration of Helsinki and were approved by Institut Guttmann Neurorehabilitation Hospital Ethics Committee of Clinical Research.

6.1. Recruitment Strategy: Periodic comprehensive assessments for people with spinal cord injury

The participants enrolled in this study lived in the community and attended an annual comprehensive checkup at Institut Guttmann Neurorehabilitation Hospital, Badalona, Spain. One week before the hospital checkup, if they met the inclusion criteria, potential participants were contacted by telephone to explain the studies. Those who agreed signed informed consent forms on the day of the hospital check-up.

As Lesser et al. (2023) showed, active recruitment techniques, such as direct referral, may result in a higher attrition rate. Therefore, due to the context and recruitment strategy used, the samples of the studies that make up this Thesis are very diverse in terms of age, gender, socio-economic status, types and levels of injury, as well as participation or interest in PA.

6.2 Participants

The inclusion criteria for participants who were enrolled in the studies of this Thesis were as follows:

- More than one year post injury.
- 18–65 years old.
- Using a wheelchair as the main method of mobility.
- Fluent understanding of the Spanish language.
- The absence of any type of cognitive impairment.

A total of 235 participated in the first study, *Adaptation to Spanish and Validity by Wearable Sensors of the Physical Activity Recall Assessment for People with Spinal Cord Injury*. These participants were distributed in different sub-studies as follows:

- Pilot testing: n = 30
- Inter-rater reliability: n = 25
- Test-retest reliability: n = 50
- Validity using wearable sensors: n = 13
- Validity by known groups analysis: n = 235

In addition, 3 translators and 19 experts in SCI participated in the translation and cultural adaptation process.

For study 2, *Psychosocial outcomes associated with types and intensities of physical activity in people with spinal cord injury: the mediating role of self-efficacy and functionality*, 159 participants were enrolled.

Finally, 207 participants were enrolled in the third study of this Thesis, *Socio-ecological barriers to leisure time physical activity in Spanish wheelchair users with spinal cord injury: associations with sociodemographic characteristics and functional independence*.

6.3 Measures

For the studies of this Thesis different measures and assessment instruments were used.

For the adaptation to Spanish and validity of the PARA-SCI, language assessment measures as the *Comparability and interpretability rating scale*, the *Flesch-Szigriszt Index* and the *Scale INFLESZ*. Also, wearable sensors were used.

For studies 2 and 3, psychosocial outcomes associated with PA and socio-ecological barriers to LTPA, the PARA-SCI-Spanish result of the first study was used to quantify PA as well as different psychosocial measures to assess GSE, participation, perception of QoL and psychological distress. Also, measures were used to assess the degree of functional independence and perception of barriers to LTPA.

The Comparability and Interpretability Rating Scale (CIRS) (Sperber, 2004). This is a 7-point Likert scale used for the identification of common problems and pitfalls that might have threatened the validity of the retrospective translation in the PARA-SCI translation and cross-cultural adaptation procedure. It comprises two sections, comparability of language and similarity of interpretation, each ranging from 1 (extremely comparable and extremely similar, respectively) to 7 (not at all comparable and not at all similar, respectively). The CIRS was applied by eight SCI specialists from different countries who were fluent in English and not part of the research.

Flesch-Szigriszt Index (Pazos, 1992). This is a validated Spanish adaptation of the Flesch equation (Flesch, 1948). It is a readability test designed to indicate the difficulty of understanding a text and it has a score from 0 to 100, where lower scores indicate a more difficult level of linguistic readability. The formula used is $206.835 - 62.3 \times (\text{Syllables/Word} - \text{Words/Phrases})$.

Scale INFLESZ (Barrio-Cantalejo et al., 2008). It classifies the linguistic readability of Spanish texts according to the Flesch-Szigriszt index score in the following categories: "Very Difficult" (0-40), "Somewhat Difficult" (40-55), "Normal" (55-65), "Fairly Easy" (65-80) and "Very Easy" (>80).

ZurichMOVE wearable sensors. It is a novel 10-degrees-of-freedom inertial measurement unit (IMU) specifically designed for assessing PA in SCI individuals. The energy expenditure estimation models used has been validated for wheelchair-bound SCI individuals (Popp et al., 2016; 2018) based on non-obstructive IMU recordings in a natural setting. The sensor (ZurichMOVE, Zurich, Switzerland) module comprises a motion processing unit including a 3-axis accelerometer, a 3-axis gyroscope, and a 3-axis digital compass. The ZurichMOVE system includes 5 sensor modules that can continuously record data for 65 h at a sampling rate of 200Hz (>72 h at 50Hz) while synchronizing the modules in real time. Data transfer to the computer, battery charging, as well as sensor configuration are done through the corresponding docking station. Data were collected with a sampling frequency of 200 Hz.

PARA-SCI-Spanish. The Spanish version of the PARA-SCI (PARA-SCI-Spanish) (Castan et al., 2023) was validated in the first study of this Thesis and was subsequently used in the two remaining studies to assess and quantify PA. The PARA-SCI-Spanish is a reliable and valid tool in telephone and face-to-face interviews. It is administered in a semi structured interview format to measure the type (LTPA, lifestyle activity, and cumulative activity), frequency, duration, and intensity of PA. It can be used among people with paraplegia or tetraplegia. The original PARA-SCI has demonstrated reliability and validity as a measure of PA through comparisons with indirect calorimetry and doubly labelled water (Latimer, Martin Ginis, Craven, et al., 2006; Martin Ginis et al., 2005; Tanhoffer et al., 2012)

General Self-Efficacy Scale (Schwarzer & Jerusalem, 1995). It is a self-report measure used to assess GSE that contains 10 items. Responses are made on a 4-point scale (1-Not at all true; 2- Hardly true; 3- Moderately true; 4- Exactly true). The total score is calculated by finding the sum of all items, and

it ranges from 10 to 40. Higher scores indicate greater GSE. This tool has shown good reliability and validity as has the Spanish-language version (Baessler & Schwarzer, 1996).

The Community Integration Questionnaire (CIQ) (Willer et al., 1993) was used to assess participation. It is a 15-item instrument consisting of three subscales: home integration, social integration, and productive activity. Scores for these domains are generated based on the frequency of engaging in roles and activities, and responses are weighted according to the level of independence in performing roles and activities. The total score ranges between 0-29, and higher scores indicate higher levels of participation. The validity of this tool has already been demonstrated (Gontkovsky et al., 2009), as well as the adequate psychometric properties of the Spanish version (Rintala et al., 2002).

The short version of the World Health Organization Quality of Life Scale (WHOQoL-BREF) (The WHOQOL Group, 1998) was used to assess the perception of QoL rating through the first scale's item. 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). The WHOQoL-BREF has been shown to be an appropriate tool for measuring the QoL perceived by a person with SCI (Jang et al., 2004). The Spanish version of the WHOQoL BREF has shown good results of internal consistency reliability and evidence of validity (Lucas-Carrasco, 2012; Salvador-De La Barrera et al., 2018).

The Hospital Anxiety and Depression Scale (HADS) (Zigmond & Snaith, 1983) was used to assess psychological distress. It is a 14-item, self-reporting screening scale that contains two 7-item Likert scales, one for anxiety and one for depression; the scores of both scales range from 0 to 21. Subscale scores are added up to create a total psychological distress score (range 0–42), with higher scores indicating greater frequency and severity of symptoms of anxiety and depression (Hyland et al., 2019). The psychometric integrity of the HADS scores well in a SCI population (Woolrich et al., 2006), and the Spanish version demonstrated good reliability and validity (Quintana et al., 2003).

The Functional Independence Measure (FIM) (Granger et al., 1986) was used to assess the degree of independence in the daily life activities of self-care, mobility, sphincter control, locomotion, communication and social cognition. The 18 items of the FIM are scored from 1 (total assistance from another person is required to achieve the task) to 7 (total independence). The internal consistency and excellent intra-rater reliabilities have been demonstrated in people with neurological disorders (Hobart et al., 2001).

The Spinal Cord Independence Measure III (SCIM III) (Iitzkovich et al., 2007) was used to measure independence to manage self-care, respiration and sphincter needs, and mobility. Scores range from 0 to 100; self-care (0–20), respiration and sphincter management (0–40), and mobility subscales (0–40). Higher scores indicate greater overall independence. The SCIM III has evidence of reliability and validity in a multi-cultural sample of people with SCI (Iitzkovich et al., 2007). The Spanish version of the SCIM, the eSCIM III was found to be culturally equivalent to the original version, as reliability and validity of this tool were demonstrated (Aguilar-Rodríguez et al., 2015).

The Barriers to Physical Activity for People with Mobility Impairments (BPAQ-MI) (Vasudevan et al., 2015) was used to measure the barriers to LTPA. It measures barriers across four socio-ecological levels (intrapersonal, interpersonal, organizational, and community). Each barrier is rated from 0 (“It has not been a barrier for me”) to 4 (“It has been a very important barrier for me”). The reduced Spanish version of this questionnaire, previously validated for the Spanish context, was the version used (Úbeda-Colomer et al., 2018).

CHAPTER 7:

COMPENDIUM OF PUBLICATIONS

PUBLICATION 1

Type of publication: Indexed scientific article

Title: Adaptation to Spanish and validity by wearable sensors of the Physical Activity Recall Assessment for people with Spinal Cord Injury

Authors: Alex Castan, Eloy Opisso, Andrés Chamarro, Kathleen A. Martin Ginis & Joan Saurí

DOI : <https://doi.org/10.1080/1091367X.2023.2192194>

Publication Journal: Measurement in Physical Education and Exercise Science

Impact factor at the time of publication: 2.1

Editorial: Taylor & Francis

Submission: 8th October 2022

Major revision: 29th November 2022

Minor Revision: 2nd March 2023

Accepted: 14th March 2023

Published on-line: 21st March 2023

PUBLICATION 2

Type of publication: Indexed scientific article

Title: Psychosocial outcomes associated with types and intensities of physical activity in people with spinal cord injury: The mediating role of self-efficacy and functionality

Authors: Alex Castan, Ivan Bonilla, Andrés Chamarro & Joan Saurí

DOI: <https://doi.org/10.1123/jpah.2023-0404>

Publication Journal: Journal of Physical Activity and Health

Impact factor at the time of publication: 3.1

Editorial: Human Kinetics Journals

Submission: 31st July 2023

Major revision: 7th September 2023

Minor Revision: 10th December 2023

Accepted: 17th January 2024

Published on-line: 28th February 2024

PUBLICATION 3

Type of publication: Indexed scientific article

Title: Socio-ecological barriers to leisure time physical activity in Spanish wheelchair users with spinal cord injury: Associations with sociodemographic characteristics and functional independence

Authors: Alex Castan, Joan Úbeda, Andrés Chamarro, Joan Vidal, Jesús Benito & Joan Saurí.

DOI: <https://doi.org/10.1016/j.apmr.2024.02.719>

Publication Journal: Archives of Physical Medicine and Rehabilitation

Impact factor at the time of publication: 4.3

Editorial: Elsevier

Submission: 10th August 2023

Major revision: 6th November 2023

Minor Revision: 5th February 2024

Accepted: 13th February 2024

Published on-line: 26th February 2024

CHAPTER 8:

DISCUSSION

This Thesis has studied PA in people with SCI who have already completed their acute rehabilitation process and who live in the community in the Spanish context. Its overall purpose was to establish an initial basis for enhancing PA participation in this population. To this end, three specific objectives were considered.

- The first was objective to provide the scientific and clinicians working in Spanish language with a validated tool for the assessment of PA in people with SCI.
- The second objective was to examine and identify which types of PA and at what intensities were most able to generate positive relationships with psychosocial outcomes such as perception of QoL, participation and psychological distress. All this, with the possible mediating role of functionality and GSE.
- The third objective was to detect, through a socio-ecological perspective, which are the main barriers to LTPA, as well as which population groups are the most vulnerable and which should be taken into account when developing strategies to encourage participation in LTPA.

These three objectives were addressed in the three papers that make up this Thesis. They respond to a gap in the scientific literature on the SCI population in the Spanish context. At the same time, they are a starting point for establishing the foundations to implement specific programs to increase participation in LTPA and take advantage of the benefits that this participation can generate.

The findings of the first paper supported the good psychometric properties of the Spanish version of the Physical Activity Recall Assessment -Spinal Cord Injury (PARA-SCI-Spanish). The knowledge gained from the validated measurement instrument has contributed to the other aims of the present Thesis. The first finding using the PARA-SCI-Spanish in all three studies is that PA levels are low in the SCI population. There is strong scientific evidence that PA needs to be performed at moderate to vigorous intensity to improve fitness and cardiometabolic health in adults with SCI (Martin Ginis et al., 2018). However, the three studies in this Thesis demonstrate, as in other contexts (Martin Ginis, Latimer, et al., 2010), that the Spanish population does not reach the minimum levels necessary, especially in LTPA, to achieve these benefits. Therefore, it would be important to establish strategies for the SCI population to increase levels of LTPA participation.

As mentioned above, and as stated in the SCI guidelines (Martin Ginis et al., 2018), adults need to perform at least 20 minutes of aerobic exercise and 3 sets of strength exercises for each of the major working muscle groups at moderate to vigorous intensity twice a week, and at least 30 minutes of

moderate to vigorous intensity aerobic exercise 3 times a week to achieve cardiorespiratory fitness, muscle strength and cardiometabolic health benefits. In fact, scientific research has focused on the study of moderate vigorous PA, and there is little literature on mild intensity PA (Mickens et al., 2022) (Tawashy et al., 2009). However, as the results of Paper 2 show, mild-intensity LTPA is of vital importance. Thus, we add evidence to the importance of mild LTPA as a good option to achieve benefits at the psycho-social level, in particular, an increase in the perception of QoL and participation, and a decrease in psychological distress.

This is not to say that LTPA must always be at a mild intensity, since, as already mentioned, moderate to vigorous LTPA is necessary. But, considering that in recent years the patterns of SCI are changing with older populations (Frontera & Mollett, 2017), we have to adapt PA prescriptions to the current population and situation. In addition, studies in healthy populations have shown that a mild intensity of PA interventions improves participation rates and adherence to the programme (King et al., 1998). In fact, one of the most common barriers to exercise among people with SCI who do not exercise is the perception that aerobic exercise has "limited cost effectiveness" because the amount of time and energy required to achieve perceived beneficial levels of activity was considered too demanding or unrealistic and did not motivate some people (Kehn & Kroll, 2009)

Therefore, regarding a population with little participation in LTPA, the first objective that institutions and clinicians must set is to bring this population closer to PA, so that individuals see it accessible and achievable, and that they incorporate it little by little into daily routines, including with a recreational component.

Consequently, it is plausible to think that a good strategy for the implementation of programs to increase participation in LTPA is to start these interventions with mild-intensity activities, which lead to improvements in psychosocial qualities and favors adherence to the program. And, in a second stage, to increase or gradually introduce activities of moderate-vigorous intensity that will provide cardiovascular and cardio-metabolic benefits.

In addition, as shown in paper 2, the key role of the GSE as mediator involved in the relationships between LTPA with participation, psychological distress, and the perception of QoL has to be taken into account. This finding has important clinical implications for psychological interventions in the promotion of LTPA. Comprehensive treatment and rehabilitation should include attention to the psychological needs of individuals with SCI (Wegener et al., 2012). Effective clinicians providing psychological care are essential to avoid psychological distress and to mobilize individual strengths such as SE. Furthermore, developing programs for the promotion and practice of LTPA with GSE training is necessary. One strategy that demonstrates greater gains in GSE is to receive intensive peer mentoring during and after rehabilitation (Gassaway et al., 2017). Thus, one of the options that institutions could promote is training camps, based on the concept of Active rehabilitation, where

promotion and practice of LTPA is combined with the participation of peer mentors (Divanoglou et al., 2019).

Furthermore, in the conceptual design of any program aimed at increasing participation in LTPA, the results shown in paper 3, i.e. the perception of barriers to LTPA, will have to be taken into account. For instance, pain was the most prevalent barrier. Paradoxically, however, there is evidence that PA may be helpful in reducing pain (Todd et al., 2021) and that PA behavior changing interventions may be effective in reducing these barriers (Dinwoodie et al., 2022). Therefore, it is important that PA professionals adopt strategies to effectively communicate the role that regular LTPA could have in ameliorating these problems. In addition, some sociodemographic factors (e.g., sex, employment, age) were found to be associated with different levels of barriers. However, functionality, which did not show a key mediating role between LTPA participation and psychosocial outcomes, was negatively associated with intrapersonal, interpersonal and organizational barriers, and moderated the relationship between intrapersonal barriers and LTPA. This will need to be considered when designing interventions aimed at encouraging physically active lifestyles in specific sub-groups within the SCI community.

CHAPTER 9:

CONCLUSIONS

- The systematic process used for translation and cultural adaptation, as well as reliability and validity studies, demonstrate that the PARA-SCI-Spanish is a reliable and valid instrument to quantify PA according to intensity and type, which can be used face-to-face and by telephone, in practice by health professionals for clinical follow-up.
- The number of multinational and multicultural research projects has increased in recent years. This raises the need to adapt measures so that they can be used in languages other than the language in which they were created. The Para-SCI-Spanish fills a gap in the Spanish-speaking context that will make it possible for Spanish-speakers to participate in these projects.
- As lifestyle activity is not associated with improved psychosocial benefits even through the mediation of SE and functionality, people with SCI are advised to engage in regular LTPA
- Consideration should be given to designing LTPA programs in two phases: a first phase of mild LTPA and a second phase of moderate to intense LTPA. This progression will provide psychosocial and physical benefits and facilitate progressive compliance with the program.
- The key role of GSE in combination with LTPA in psychosocial health is an important finding that suggests the importance of programs that combine LTPA participation with GSE training.
- The conceptual design of programs to encourage participation in LTPA needs to consider the most prevalent perceived barriers, such as pain and fatigue at the intrapersonal level, inactivity of friends and family at the interpersonal level, lack of adaptation of sports programs and venues at the organizational level, as well as inaccessibility of pavements and streets at the community level.
- Minimising barriers that are inversely associated with LTPA participation, such as intrapersonal and interpersonal levels, should be a priority for public health policy.

- To design interventions aimed at promoting physically active lifestyles in specific subgroups within the SCI community, functionality must be considered. This is a variable negatively associated with intrapersonal, interpersonal, and organisational barriers, and moderates the relationship between intrapersonal barriers and LTPA.

CHAPTER 10:

IMPLICATIONS FOR THE FUTURE

Assessment of LTPA. This Thesis provides a validated Spanish version of the most widely used questionnaire to assess PA in people with SCI, the PARA-SCI-Spanish. It measures the type, frequency, duration and intensity of PA. On average, it takes 20-30 minutes to complete the PARA-SCI and some active respondents need more than 45 minutes. Therefore, including it in studies where researchers or clinicals are only interested in the LTPA performed can be time-consuming. The Leisure Time Physical Activity Questionnaire for People with Spinal Cord Injury (LTPAQ-SCI) was developed for these situations. It is an SCI-specific, self-report measure of LTPA that assesses minutes of mild, moderate, and heavy intensity LTPA performed over the previous 7 days. The LTPAQ-SCI takes less than 5 minutes to complete and can be self-administered (in contrast, the PARA-SCI must be administered by a trained interviewer). Future research is needed to demonstrate the reliability and validity of the Spanish version of the LTPAQ-SCI to have another tool and to choose the most appropriate one for each purpose.

Quality of PA participation: The studies conducted in this Thesis have been based, using the PARA-SCI, a quantitative assessment of participation in PA through frequency, intensity and duration of PA. However, the meaningful experience of this participation has not been assessed. It could be plausible that some PA interventions or participations could have negative effects because they are not being carried out under the right conditions (too many users, prioritizing quantity over quality, poor organization, erroneous objectives and interventions). Emerging theorizing and research in rehabilitation science and PA in people with disabilities distinguishes between performance-related and experience-related aspects of PA participation. Thus, future research that studies the quality of PA participation beyond quantity are needed.

Interventions in the community: The relationships between the different variables, the key role of mediators, and moderators and correlates of barriers to LTPA, provide important direction for the development of interventions to improve PA. Considering these results it is crucial to act on these findings/recommendations and to use them to improve LTPA participation of people with SCI in Spain by creating specific interventions, clinical practice guidelines, and programs to this end.

Longitudinal studies: Given the cross-sectional design of the studies conducted in this Thesis, the results represent associations and correlations rather than causal effects. Therefore, future research is needed to design tailored interventions for different phases of LTPA programs and specific subgroups within the SCI population. Longitudinal or prospective studies would give us more information in this regard.

Transferring research to the context of acute rehabilitation: This thesis has studied PA in people with SCI who have already completed their acute rehabilitation process and who live in the community. The results give us a good orientation and starting point for the development of programmes to increase the participation of LTPA in these people living in the community. However, it is necessary to extend the studies to the context of acute post-injury rehabilitation and to study what interventions are needed in this context in order to:

- a) establish the most physically beneficial PA guidelines in the first few months' post-injury
- b) establish a favourable attitude towards PA prior to discharge from rehabilitation that will enhance LTPA participation when the person is discharged from RHB and living in the community.
- c) connect and involve individuals with SCI in active rehabilitation programs and community resources that favour their inclusion and social participation.

Research in other populations with disabilities. Although this Thesis has focused on the study of the SCI population and its relationship with PA, it is necessary that research of this nature also focuses on other types of disabilities, or even on disability in general. The Leisure Time Physical Activity Questionnaire - Disability (LTPAQ-D) is a new measure of LTPA participation in adults living with physical and/or sensory disability. Thus, future research is also needed to demonstrate that the original and the Spanish versions of the LTPAQ-D are reliable and valid instruments to measure PA in people with disabilities.

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APPENDIX

PUBLICATION 4 (SUPPLEMENTARY PUBLICATION)

Type of publication: Clinical Manual

Title: PARA-SCI-Spanish. Manual de administración y puntuación. Cómo valorar y cuantificar la actividad física en personas con lesión medular.

Author: Alex Castan

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