



European Spinal Psychologists Association

10th ESPA Meeting

Spinal Cord Injury: Looking after Body and Mind



@ halfpoint | 123RF

**Thursday, 12th May and
Friday, 13th May, 2022**

**Hosted by: The National Rehabilitation
Hospital Dublin Ireland**



10th

ESPA Meeting

SUPPORTED BY:



STEWARTS



EXECUTIVE COMMITTEE

Dr Jane Duff, National Spinal Injuries Centre, Stoke Mandeville Hospital, Buckinghamshire Healthcare NHS Trust, UK

Dr Peter Lude, Kalaidos University of Applied Sciences, Zurich, Switzerland

Dr Magnus Elfström, Mälardalen University, Eskilstuna, Sweden

Dr Jasmine Hearn, Department of Psychology, Manchester Metropolitan University, UK

SCIENTIFIC COMMITTEE

Dr Maeve Nolan and Dr Claire Keogh, National Rehabilitation Hospital Dublin, Ireland

Dr Tijn van Diemen, Sint Maartenskliniek, Nijmegen, Netherlands

Dr Katherine Finlay, University of Reading, UK

Olivia Barrett, Pinderfields Spinal Injuries Centre, UK



Brainworx is a professional service providing resources and information to Allied Health Professionals working in clinical, health, education, and private settings in Ireland. Our aim is to provide you with efficient psychometric test material, in order to compliment your professional skills.

At Brainworx we guarantee professional and experienced advice on all your resource needs. From comprehensive and reliable psychometric tests to books and a range of therapeutic material, Brainworx is your one-stop shop for all!

We at Brainworx are on hand to cater to your needs at www.brainworx.ie or by phone on 00353 402 35125.

Dear Delegate Colleague,

As always ESPA embraces and rises to new challenges and never more so than in the past two years: providing our highly successful first online conference in 2021 and now a hybrid conference for 2022. I am delighted to welcome everyone, those attending in person for both days and those who are attending the first day virtually, or viewing recordings later on demand, to our 10th European Spinal Psychology Conference at the National Rehabilitation Hospital in Dublin, Ireland.

On behalf of ESPA, I would like to thank and acknowledge many people for enabling this event to take place. The determination of Dr. Maeve Nolan and Dr. Claire Keogh for extending their hosting of the 2021 event to make the inperson conference happen this year. Also, immense thanks to Dr. Tijn van Diemen, Keynote presenter, and all the presenters for their confidence and bravery to submit an abstract at a very uncertain time. I know you will be enthralled by our dinner speaker Mark Pollock, who will encourage us to continually challenge and go above and beyond expectations. Finally, to our sponsors for their immense generosity which has provided us with the surety needed to organise the meeting with the unpredictable and additional costs of the virtual format.

There are psychologists in many European nations that we have yet to connect with. Please help us with this endeavour as the warmth, knowledge and sharing of the ESPA community is one of our many strengths and one we want to continue to foster and develop.

I am delighted to announce that our 2024 meeting will be in Nijmegen in the Netherlands and the Executive Committee are grateful for the support of Dr. Tijn van Diemen and Professor Marcel Post alongside the newly formed ESPA Scientific Committee for this event.

Yours sincerely,

Dr. Jane Duff, ESPA Chair
Head of the National Spinal Injuries Centre Clinical Psychology Department
Stoke Mandeville Hospital
Buckinghamshire Healthcare NHS Trust

10th

ESPA Meeting

Thursday, 12th May, 2022

LOCATION: Lexicon Theatre | Dun Laoghaire
<http://venuehire.dlrlexicon.ie/>

hybrid
event

Programme overview

BST timezone

09.00

Registration and Coffee

09.30 – 09.50

Welcome and Introduction

09.50 – 10.50

SCIENTIFIC SESSION:
Whole Person Rehabilitation

10.50 – 11.20

Break

11.20 – 12.20

KEYNOTE SPEAKER

12.20 – 13.20

Lunch

13.20 – 14.20

SCIENTIFIC SESSION: Health Equality

14.20 – 15.00

Anette Johansen-Quale ESPA
Scholarship Presentation

15.00 – 15.20

Break

15.20 – 16.00
Sponsored by
STEWARTS

Professor Paul Kennedy ESPA
Scholarship Presentation

16.00 – 16.30

Reflections on the day

16.30

Close

19.00

DINNER:
Royal Saint George Yacht Club
Dun Laoghaire

Friday, 13th May, 2022

LOCATION: National Rehabilitation Hospital, Dublin
<https://www.nrh.ie>

BST timezone

| | |
|---|---|
| 09.00 | Networking and Coffee |
| 09.30 – 10.30 | SCIENTIFIC SESSION: Emotional Wellbeing |
| 10.30 – 10.50 | Break |
| 10.50 – 12.00 | SCIENTIFIC SESSION: Lived Experience |
| 12.00 – 12.25 | ESPA Bi-Annual General Meeting |
| 12.30 – 13.30 | Lunch |
| 13.30 – 15.00 | Workshop |
| 15.00 – 15.10 Sponsored by STEWARTS | Presentation of the Linda Hall Presentation Award |
| 15.10 – 15.30 | Plenary and Closing Remarks |
| 15.30 | Tour of National Rehabilitation Hospital Spinal Injuries Centre |

Saturday, 14th May, 2022

GUIDED TOUR OF DUBLIN
(optional)



www.sakhanphotography.com

10th

ESPA Meeting

Thursday, 12th May, 2022

hybrid
event

Scientific programme

BST timezone

09.00

Registration and Coffee

09.30 – 09.50

Welcome and Introduction

09.50 – 10.50

SCIENTIFIC SESSION: Whole Person Rehabilitation

Chair: Dr. Jane Duff

09.50 – 10.10

Whole person rehabilitation – interactions between appraisals and mood for selfcare skill development in rehabilitation and the prevention of secondary health conditions

Dr. Margaret Tilley

10.10 – 10.30

May patients with acute spinal cord injury and additional traumatic brain injury present a higher level of depressive symptoms than patients without associated brain injury? A retrospective analysis

Dr. Ingo Pals

10.30 – 10.50

Mindfulness training for persons with spinal cord injury (SCI) during in- and outpatient rehabilitation: a pilot study in the Netherlands

Dr. Christel van Leeuwen

10.50 – 11.20

Break

11.20 – 12.20

Keynote Speech: Body and Mind: The role of self-efficacy in secondary health conditions

Dr. Tijn van Diemen

Chair: Dr. Maeve Nolan

12.20 – 13.20

Lunch

13.20 – 14.20

SCIENTIFIC SESSION: Health Equality

Chair: Dr. Katherine Finlay

13.20 – 13.40

Social inequalities and health in persons with spinal cord injury: The mediating role of psychosocial resources

Dr. Caroline Debnar

13.40 – 14.00

Blazing a trail to participation: Preliminary results of PARTICIPA Project

Dr. Joan Sauri

Thursday, 12th May, 2022

BST timezone

14.00 – 14.20 Seriously-injured rugby players' perspectives on patient and public involvement in preclinical spinal cord research: An interview study
Pádraig Carroll

14.20 – 15.00 Anette Johansen-Quale ESPA Scholarship Presentation:
Validity and reliability of the French Self-Efficacy Scale (MSES-Fr): a measure of self-efficacy for people with spinal cord injury based on the Moorong Self-Efficacy Scale

Marion Gounelle
Chair: Dr. Claire Keogh

15.00 – 15.20 Break

15.20 – 16.00 Professor Paul Kennedy ESPA Scholarship Presentation:
Fatigue: multidimensional impact on whole body and mind

Rebecca Eaton
Chair: Dr. Jane Duff
Sponsored by **STEWARTS**

16.00 – 16.30 Reflections on the day

16.30 Close

19.00 **DINNER:**
Royal Saint George Yacht Club, Dun Laoghaire



Speaker: Mark Pollock

10th

ESPA Meeting

Friday, 13th May, 2022

hybrid
event

BST timezone

09.00 **Networking and Coffee**

09.30 – 10.30 **SCIENTIFIC SESSION: Emotional Wellbeing**

Chair: Dr. Tijn van Diemen

09.30 – 09.50 **'She didn't know what to do with me.' People with spinal cord injury's experiences of accessing mental health support in the community**

Phoebe Brook-Rowland

09.50 – 10.10 **The therapeutic disconnect: the challenge of seeking support from generic mental health services when living with spinal cord injury in the community**

Dr. Katherine A. Finlay

10.10 – 10.30 **Associations between personality traits and anxiety and depression in persons with SCI in first inpatient rehabilitation**

Dr. Christel van Leeuwen

10.30 – 10.50 **Break**

10.50 – 12.00 **SCIENTIFIC SESSION: Lived Experience**

Chair: Dr Peter Lude

10.50 – 11.10 **Adolescent and Young Adults' experiences of living with a parent with a spinal cord injury**

Dr. Emma Brennan

11.10 – 11.30 **'You feel a bit unsexy sometimes': The psychosocial impact of a spinal cord injury on sexual function and sexual satisfaction**

Olivia Barrett

11.30 – 12.00 **'Holding on to your mind when your body doesn't work': Living life when the dichotomy between mind and body is continually in focus**

Dr. Michele Cahill | Dr. Maeve Nolan

Scientific programme

Friday, 13th May, 2022

BST timezone

12.00 – 12.25 **ESPA Bi-Annual General Meeting**

12.30 – 13.30 **Lunch**

13.30 – 15.00 **Workshop**

Patient's beliefs about their spinal cord injury during first rehabilitation and how to apply the results

Prof. Marcel Post
Dr. Christel van Leeuwen
Dr. Tijn van Diemen
Dr. Jane Duff

15.00 – 15.10 **Presentation of the Linda Hall Best Presentation Award**
Sponsored by **STEWARTS**

15.10 – 15.30 **Plenary and Closing Remarks**

15.30 **Tour of National Rehabilitation Hospital Spinal Injuries Centre**

Scientific programme

Whole person rehabilitation – interactions between appraisals and mood for self-care skill development in rehabilitation and the prevention of secondary health conditions

Margaret Tilley | Kevin Jones | Katherine Finlay | Jane Duff

Introduction:

Rehabilitation for people with spinal cord injury (PwSCI) supports collaborative and shared decision making, knowledge and skill gain for the individual to reduce the risk of debilitating secondary health conditions (SHCs) which impact on quality of life (QOL) and increase risk of re-hospitalisation in 77% of PwSCI (Street et al., 2015). Skin and bladder management have been noted to be of greatest impact with urinary tract infections (UTIs) occurring in a third of PwSCI (Street et al., 2015), the significant association between UTIs and functional independence (Stampas et al., 2018), with pressure ulcers and UTIs impacting on length of stay, negative impact on activities of daily living and reduced QOL (Gedde et al., 2019).

Objective:

This study sought to determine whether psychological health at admission would predict skin and bladder management at time of admission and prior to discharge and whether this relationship was mediated by injury appraisal.

Methods:

Baseline and outcome data was collected from the psychological health, skin and bladder management domains of the Stoke Mandeville Spinal Needs Assessment Checklist (SMS-NAC) for 213 inpatients at the National Spinal Injuries Centre, Stoke Mandeville Hospital.

Results:

Injury appraisals, as measured by the ADAPSSsf, mediated the relationship between symptoms of anxiety at admission and skin and bladder management prior to discharge. Symptoms of depression were a significant predictor of skin and bladder management, but the relationship was not mediated by injury appraisal. Injury appraisals also significantly mediated symptoms of depression and anxiety, skin and bladder management, when all were assessed prior to discharge.

Implications:

This study highlights the importance of psychological screening on admission, during and at discharge from inpatient rehabilitation, with health factors changing over time, the importance of appraisals of injury in mood symptoms and self-management and of differentiating and treating mood during rehabilitation.

**May patients with acute spinal cord injury and additional traumatic brain injury present a higher level of depressive symptoms than patients without associated brain injury?
A retrospective analysis**

Ingo Pals

Since Spinal Cord Injury (SCI) patients seem to be less challenged by depressive symptoms in comparison to other neurological disorders that also involve brain function (Hassanpour et al., 2012), it is hypothesized that SCI patients who additionally sustained a traumatic brain injury (TBI) present a higher level of depressive symptoms, measured using the Beck Depression Inventory II, than SCI patients without additional brain injury. All patients participated in the European Multicenter Study for Human Spinal Cord Injury (EM-SCI). SCI patients with diagnosed TBI were respectively matched with SCI patients without TBI by age, gender, Spinal Cord Independence Measure (SCIM), and neurological impairment (ISNCSCI). Data sets of participants at 1 month and at 3 months post-injury were included in the analysis. The results show that SCI patients with TBI did not exhibit an increased level of depressive symptoms relative to SCI patients without TBI. More than half of patients showed minimal to mild depressive symptoms. A clinical-psychological examination is recommended following acute spinal cord injury.

Mindfulness training for persons with spinal cord injury (SCI) during in- and outpatient rehabilitation: a pilot study in the Netherlands

Christel van Leeuwen | Tineke van der Veeke | Irene Verhoeven
Loes de Kruijff | Janneke Stolwijk | Marcel Post

Background:

The Mindfulness training is based on the 8-week Mindfulness Based Stress Reduction (MBSR) programme.

Aim:

The aim of the pilot study is to evaluate the MBSR training in persons with SCI during in- and outpatient rehabilitation. The hypotheses are that Mindfulness can help persons with SCI to better deal with their thoughts, emotions, pain and mood.

Study Design: Pilot study

Methods:

Feedback was collected from trainers and participants in order to get an overview which lessons were learned and which recommendations could be made based on the results of this pilot. Exercises of the MBSR training were applied with some small adaptations considering the body exercises to make the exercises feasible for SCI.

Results:

Four women and two men started with the training, one woman dropped out. Mean (SD) age of the participants was 54 (10) years. Both participants and trainers were positive about the content, length (8 sessions of 2 hours) and organization of the training. Participants reported that they coped in a different way with pain, sadness, and emotions after the training and had received tools to better deal with their SCI, such as stop forcing themselves and listen to body signals. Participants would recommend the training to other persons with SCI and consider it as an advantage that the training was held in the rehabilitation center.

Conclusion: Based on the, in general, positive reactions of the participants and the trainers, we propose to do a second pilot group based on the MBSR programme and decide afterwards whether the Mindfulness training should be implemented as usual care for persons with SCI. Recommendations for a next pilot group are to focus more on practicing with Mindfulness every day, and to do a short exercise at the start of each session to ventilate emotions experienced at that moment.

Keynote Speech: Body and Mind: The role of self-efficacy in secondary health conditions

Tijn van Diemen

During Dr. Tijn van Diemen's keynote talk on Body and Mind: The role of self-efficacy in secondary health conditions, he will discuss the course of self-efficacy from admission to rehabilitation to one year after discharge. The different trajectories that can be found for self-efficacy but also for depressive mood and anxiety will be discussed, which are particularly important secondary health conditions, from a psychological point of view. Tijn will discuss his longitudinal data to explore how depressive mood and anxiety one year after discharge can be predicted based on data gathered at admission and how these can influence participation. Tijn will also discuss data gathered during interviews with both people with SCI and professionals about the way self-care was learned/taught. The keynote will end with a way of improving the self-efficacy of people with SCI during their rehabilitation, by educating the professionals.

Social inequalities in mental health of persons with spinal cord injury: The mediating role of psychosocial resources

Caroline Debnar

Background:

An impressive body of research documents that persons with lower socio-economic status (SES) have poorer health and die earlier than persons from higher SES groups. Social inequalities in health are mainly caused by the negative effect of low SES on mediating health-relevant behavioral, psychosocial, and material factors. Although social inequalities in health have also been documented in persons with spinal cord injury (SCI), little is known about the mechanisms leading to this unequal distribution of health. Previous research in the field of SCI has shown that psychological resources are associated with mental health and well-being. Understanding mediating paths is indispensable for developing targeted interventions to reduce health inequalities. Therefore, the overall objective is to investigate the mediating role of psychosocial resources in the association between SES and mental health in persons with SCI.

Method:

Cross-sectional data from 1294 participants who completed the Swiss Spinal Cord Injury Cohort Study community survey 2017 was analyzed by using structural equation modeling to test direct effects between SES and mental health and to investigate the potentially mediating path through psychosocial resources (i.e., self-efficacy, self-esteem, purpose in life, hope, social support, sense of belongingness, optimism).

Preliminary results:

Higher SES was significantly associated with better mental health. Moreover, higher self-efficacy, self-esteem, purpose in life, optimism, sense of belongingness, and purpose in life positively mediates the association between SES and mental health.

Discussion:

This study provides evidence to inform future research and psychosocial treatment targets to reduce social inequalities in mental health inequalities in individuals with SCI. In this regard, strengthening psychosocial resources may be a suitable intervention target to specifically support persons from low SES groups with mental health issues.

Blazing a trail to participation: Preliminary results of PARTICIPA Project

Joan Saurí | Blanca Cegarra | Alejandro García-Rudolf | Javier Solana
Alina Ribes | Eloy Opisso | Jose María Tormos

PARTICIPA Project is a research program on disability and social innovation that aims to analyze the facilitators and the most relevant barriers to participation of people with disabilities in Spain and Andorra.

Literature has shown that people with disabilities such as Spinal Cord Injury (SCI) experience systematic restrictions on participation due to disability. This situation implies a violation of rights for the group and can generate social exclusion. In this context, it is relevant to study the factors that prevent the full participation in society of people with disabilities, as well as the facilitators, to generate useful knowledge to design innovative response strategies.

Objective:

The PARTICIPA project focuses on the analysis of the participation in society of people with disabilities and to analyze barriers and facilitators to participation of individuals with disabilities living in the community.

Design:

A prospective longitudinal cohort study with around 1,500 people with disabilities (including those with SCI). A data collection methodology through a web-app created specifically for the project allow the collection and analysis of data on barriers and the facilitators to participation. The study proposes a minimum duration of 3 years extendable. The study collects information on the determinants of participation through a series of online questionnaires. Qualitative data is also collected through an online forum.

Results:

In process. It will be showed the preliminary results during the first year of the project. Sociodemographic profile of the cohort, information about participation in society of people with disabilities in its different domains and data on the main barriers and facilitators to participation reported.

Keywords:

Participation; disabilities; cohort study; barriers; facilitators.

Seriously-Injured Rugby Players Perspectives on Patient and Public Involvement in Preclinical Spinal Cord Research: An Interview Study

Pádraig Carroll

Introduction:

Involving patients and the public (PPI) in research has many benefits including increasing relevance and impact. While benefits have been shown in clinical research, PPI in preclinical research is more challenging. For example, with our project that focuses on spinal cord repair much of the research takes place in a laboratory setting, quite removed from patients' day-to-day experiences. This study, conducted as part of a wider PPI project, aimed to gather seriously-injured rugby players' perspectives on involvement in pre-clinical spinal cord injury (SCI) research.

Methods:

A qualitative methodology was used. Data were gathered via semi-structured interviews conducted by telephone with 11 (all male) participants with experience of rugby-related SCI. Participants were recruited using a convenience sampling approach via a charitable organisation that supports seriously-injured players. The interview topic guide was designed with input from a PPI advisory board comprising researchers, clinicians, and seriously-injured players. Interviews were transcribed verbatim and analysed using an inductive thematic approach.

Results:

A number of themes were identified that reflected participants' perspectives on preclinical PPI in SCI. 1) Existing Networks: Participants felt researchers should engage with current SCI groups that already possess the infrastructure and links to establish successful PPI initiatives. 2) Managing Expectations: This theme calls attention to the potential for research findings to be misunderstood, necessitating clear communication between researchers and PPI collaborators. 3) Sharing experiences: This theme highlights the role that participants felt they could play in preclinical SCI research, and discussing their stories with researchers would help ground their work in the day-to-day experiences of people with SCI.

Conclusion:

Participants reported their confidence in PPI in preclinical SCI research, outlining their desire to see their daily experiences inform research most relevant to their lives. These findings offer direction for preclinical PPI, which we will incorporate into our ongoing PPI project.

Validity and reliability of the French Self-Efficacy Scale (MSES-Fr): a measure of self-efficacy for people with spinal cord injury based on the Moorong Self-Efficacy Scale.

Marion Gounelle, PhD Student | V. Leynaert | J. Middleton, MBBS, PhD,
A. Gélis Md, PhD | F. Cousson-Gélie, PhD.

Study A:

French adaptation of the Moorong Self-Efficacy Scale (MSES)

Introduction:

Self-Efficacy plays a key role in individual behaviors after Spinal cord injury (SCI). The MSES is a 16-item scale evaluating self-confidence in performing everyday activities. The patient had to respond with a 7-point Likert-type scale ranging from 1 (very uncertain) to 7 (very certain). Brooks et al (2014) and Middleton et al (2016) found a 3-factor structure but their work did not reach consensus regarding the distribution of items by dimension.

Objectives:

To translate and adapt the MSES into the French language and culture.

Results:

- The Likert measurement was changed into a 5-item scale from 1 "Not confident at all" to 5 "Extremely confident".
- The acceptability score was 85% for patients and 82% for experts.

Conclusion:

The French version of the MSES resulting from this synthesis served as the basis for the next stage.

Study B:

Psychometric Validation of the French version of Moorong Self-Efficacy Scale (MSES-Fr).

Objectives:

To determine the psychometric properties of the MSES-Fr and its factor structure.

Results:

- The sample consisted of 157 men and 44 women with SCI (mean age 48±14y). The majority of them had paraplegia (59%) with a SCI >10years (44%).
- CFA confirmed a 3 dimension scale as recommended by Brooks et al (2014) with Interpersonal Self-Efficacy (4 items), Instrumental Self-Efficacy (4 items) and Participation Self-Efficacy (6 items).
- The internal consistency was excellent and the convergent validity was strong.
- Fair correlations were established between the MSES-Fr scores and psychological resources and ability to handle stressful situations, mental health and sensation of being overwhelmed and QOL and mental score of QOL.
- Reproducibility was good.

Conclusion:

The MSES-Fr is a valid and reliable tool to assess self-efficacy in French speaking persons with spinal cord injury.

Fatigue: multidimensional impact on whole body and mind

Rebecca Eaton

Abstract:

Within the literature, adaptive cognitive appraisals are more predictive of adjustment following a spinal cord injury (SCI), over and above biological predictors (Craig et al., 2015; Eaton et al., 2018; Geyh et al., 2016; Kennedy et al., 2006). Research has shown that 56% of individuals with a SCI living in the community have excessive fatigue levels with increased levels of negative affect in comparison to control group (Craig, Tran, Wijesuriya, & Middleton, 2012). Evidence has demonstrated that fatigue within executive functioning impacts on down-regulation or re-appraisal of emotions within a normal population (Grillon et al., 2015). Taken together, there has been evidence of a high prevalence of fatigue within the SCI population and high fatigue having negative consequences on appraisals in a non-SCI population. However, there is currently no research investigating the relationship between fatigue and appraisals in SCI.

The presentation will present current literature overview, prevalence rates, demographic variables, practical and clinical interventions in acute SCI rehabilitation and present results from a mixed methods approach, examining:

Research Questions:

1. Do SCI individuals with high fatigue report more negative cognitive appraisals than those with low fatigue?
2. To explore whether there is a significant interaction between depression and fatigue on negative cognitive appraisals among individuals with SCI.
3. Qualitative interviews to find from a first person-perspective experience of fatigue and how they have managed this within SCI rehabilitation

The current research is part of a Doctorate in Clinical Psychology in the NSIC, Stoke Mandeville Spinal Centre. Forty individuals with SCI participated. Exploratory analysis examined depressed mood and fatigue appraisals using Duff and Kennedy 2003 model of SCI adjustment.

Current data demonstrates that 21 people score within a clinical range for fatigue and represent the high fatigue group. Using statistical analysis, compared with low fatigue group there appears to be more negative appraisals and lower coping based on ADAPSS. Initial results appear to support the hypothesis and align with Duff and Kennedy 2003 model of SCI adjustment. Further analysis including a mediation will aim to explore whether depression impacts on the relationship.

‘She didn’t know what to do with me.’ People with Spinal Cord Injury’s experiences of accessing mental health support in the community.

Phoebe Brook-Rowland | Katherine A. Finlay | Margaret Tilley

Objectives:

This study sought to understand the mental health challenges experienced by people with SCI in the UK, and their experiences of accessing, or attempting to access, mental health support services.

Methods:

An exploratory qualitative research design with semi-structured interviews was used. Participants were 20 members of The Spinal Injuries Association (10 female, 10 male) with SCI, living in the community in the UK. Interviews lasted between 62 and 124 minutes (M=83.2, SD=13.45), were analysed using thematic analysis (Braun & Clarke, 2006) and a coding framework was developed (Ando et al., 2014). Two coders developed and applied the coding framework, and an inter-rater reliability score was calculated (KAPPA 0.72).

Results:

Three core themes were evident:

- (1) Ongoing difficulties post discharge;
- (2) A disconnect with standard services; and
- (3) Successful support systems.

Conclusions:

The difficulties experienced during the inpatient-outpatient transition are further exacerbated by transitioning away from SCI-informed practitioners, peers and mental health support. However, the life-long and unique nature of SCI, and the ongoing stressors it presents, necessitates access to SCI-informed mental health support throughout the lifespan. Current IAPT standard services are not equipped to support people with SCI due to a lack of specialised knowledge, which can cause people with SCI to terminate support early. Thus, leaving a population, with increased mental health needs, with limited access to appropriate mental health services. Solutions for this may involve providing peer mentors with additional mental health training, facilitating people with SCI to train as mental health practitioners, or the inclusion of SCI-specific training for IAPT practitioners.

The therapeutic disconnect: the challenge of seeking support from generic mental health services when living with Spinal Cord Injury in the community

Katherine A. Finlay | Phoebe Brook-Rowland | Louisa Dosanjh
Suzanna Miles | Adam Madhani | Margaret Tilley

Objectives:

Mental health after Spinal Cord Injury (SCI) represents a significant challenge due to the complex interplay of clinical, physical, psychological and social stressors experienced. Though mental health is typically well-supported during inpatient rehabilitation, the experience of seeking treatment for mental health difficulties after discharge has been minimally researched. This study aimed to identify how people with SCI in the outpatient community experience seeking mental health support from generic mental health services not specifically tailored to SCI.

Methods:

137 people (78 females; 57 males) living long-term with SCI in the community and not currently undergoing in-patient rehabilitation were recruited through the Spinal Injuries Association. Participants completed a qualitative survey with open text boxes asking about their usage and experiences of (generic, non-SCI-specific) mental health services. A qualitative thematic analysis was undertaken.

Results:

Three major themes were evident in responses: (1) Unseen by services; (2) Therapeutic disconnect; and (3) A practitioner who 'got me'. The first two themes focused on the experience of feeling invisible to mental health services due to prolonged waiting times and difficulties with physical accessibility to service buildings. Where services had been received, they were strongly experienced as mismatched to the needs of people with SCI due to strict application of inaccessible, manualised CBT and lack of knowledge of SCI by practitioners. This unfamiliarity with SCI interrupted the development of therapeutic rapport between practitioner and client. By contrast, SCI-specific counselling improved mental wellbeing and enabled participants to better managing their SCI and mental health.

Conclusions:

Standard mental health services in the United Kingdom are not positively experienced by people with SCI. Manualised CBT was particularly problematic if delivered by mental health practitioners without relevant training in long-term conditions/SCI. There is a specific need for increased access to tailored outpatient mental health services suitable for people with SCI.

Associations between personality traits and anxiety and depression in persons with SCI in first inpatient rehabilitation

Christel van Leeuwen | Erika Papazoglou | Janske van Eersel
Janneke Stolwijk | Marcel Post

Background:

Depressive and anxiety symptoms are commonly reported among people with SCI during and after the inpatient rehabilitation phase. Personality traits have been associated with psychological adjustment in the SCI population and can potentially be used to screen vulnerable persons and tailor psychological interventions. To our knowledge, no recent study has examined associations between personality traits and depressive and anxiety symptoms in persons with SCI.

Aim:

To explore the associations between personality traits and depressive and anxiety symptoms in persons with spinal cord injury (SCI) in first inpatient rehabilitation.

Study Design: Retrospective analysis of medical files.

Methods:

Using the data of a routine psychological screening (N=67), administered in the first weeks of admission. Measures included the Hospital Anxiety and Depression Scale and the Dutch Personality Questionnaire, with seven scales: Neuroticism, Social Inadequacy, Self-Esteem, Rigidity, Hostility, Egoism and Dominance. Linear regression analyses were conducted.

Results:

Mean (SD) age of the participants was 58 (17) years. The majority were male (62%), had incomplete lesions (70%) and had paraplegia (56%). Participants scored lower on the personality traits Hostility and Egoism and higher on Social Inadequacy and Dominance in comparison with the general population. In the bivariate regression analyses, Neuroticism (beta=0.41, $p<0.001$), Social Inadequacy (beta=-0.29, $p<0.05$) and Self-Esteem (beta=0.25, $p<0.05$) were significantly associated with depressive symptoms. Furthermore, Neuroticism (beta=0.53, $p<0.001$) and Self-Esteem (beta=0.29, $p<0.05$) were significantly associated with anxiety symptoms. In the hierarchical regression analyses, only Neuroticism was significantly associated with both depressive (beta=0.40, $p<0.05$) and anxiety (beta=0.53, $p<0.001$) symptoms.

Conclusion:

Personality traits in persons with SCI seem to differ from personality traits in the general population. Assessment of personality traits early in inpatient rehabilitation can help to identify individuals at risk to develop mood problems. Moreover, Neuroticism, Social Inadequacy and Self-Esteem are traits that could be targets for interventions to tailor rehabilitation treatment.

Adolescent and Young Adults' experiences of living with a parent with a spinal cord injury

Emma Brennan | Claire Keogh | Maeve Nolan | Lorraine Swords

Purpose:

Parenting with a spinal cord injury (SCI) is challenging for parents at both a personal/familial and community/societal level. The impact on children being parented also warrants consideration. Children's experience of living with a parent with SCI has not been the focus of much research despite the potential impact on education, health, wellbeing and relationships. This study explores young people's lived experience of having a parent with an acquired SCI.

Materials and methods:

An Interpretative Phenomenological Analysis was used to analyse semi-structured interviews conducted with nine adolescents and young adults (6 female and 3 male, aged 13-22 years) from families where a parent had acquired a SCI.

Results:

Four main themes were identified: 1. 'The event' and the aftermath 2. Suppressing feelings to protect self and others: The pressure-cooker effect 3. Continuities and changes in parent-child roles and relationships 4. Strengthening connection through open communication. Participants described feeling frightened and alone in the immediate aftermath of their parents' injury and an appreciation of the support received from family, peers and school. Suppressing emotions in order to protect self and parents was a common and troubling response. Role changes, and the perceived role reversal in providing care, support and protection to a parent with SCI was challenging for some participants. Variability in coping styles was reported by participants. Insights from the Family Systems Illness Model and Kubler Ross's model of grief are used to interpret findings.

Conclusions:

Conversation and open communication with the family promotes acceptance and adjustment to a 'new normal' for children when a parent acquires a sudden disability. Rehabilitation professionals can play a significant role in modelling age appropriate family communication. However, the reality of living with a parent with SCI and individual trajectories of adjustment also indicate the importance of post discharge, ongoing support for children when a parent experiences SCI.

“You feel a bit unsexy sometimes”: The psychosocial impact of a spinal cord injury on sexual function and sexual satisfaction

Olivia Barrett

Study Design:

A qualitative interview study using semi-structured interviews.

Objectives:

This study aimed to identify, from the perspective of people living with a Spinal Cord Injury (SCI), the primary psychosocial barriers and facilitators that impact on their sexual function and sexual satisfaction post-injury.

Setting:

Community-dwelling sample of people with SCI in England, United Kingdom

Methods:

Semi-structured interviews with twenty people with SCI (15 males; 5 females) were conducted using an 8-item interview schedule. Inductive thematic analysis was undertaken of verbatim transcripts coded using Braun and Clarke's (2006) six phases of thematic analysis.

Results:

Six inductive themes were generated, collectively describing the psychosocial barriers and facilitators impacting on sexual function and sexual satisfaction post-SCI: (1) Internalising societal views and stigmatisation; (2) Diminished sexual confidence; (3) Navigating communication; (4) Managing relationship dynamics; (5) Lack of sexual support provision; and (6) Intervention development recommendations.

Conclusion:

Sexual function and sexual satisfaction are highly problematic areas of rehabilitation for males and females living with SCI. Increased efforts are needed to educate others in society, alongside those with SCI, in order to overcome the negative stereotypical attitudes obstructing acceptance of sex despite disability. Countering sexual stigmatisation for people with SCI would facilitate growth in sexual confidence. Techniques to enhance interpersonal sexual communication and involve the partner/spouse in regaining mutual sexual satisfaction are foundational. The current study highlighted key outpatient-based recommendations for intervention development, clarifying primary targets for future SCI-focused sexual therapeutic work.

**'Holding on to your mind when your body doesn't work':
Living life when the dichotomy between mind and body
is continually in focus**

Michele Cahill | Maeve Nolan

This paper aims to provoke reflection on the experience of living with a cervical injury and the challenges it poses to previously held personal and professional assumptions. It explores the experience of cervical SCI from the perspective of a psychiatrist and a psychologist, both of whom are trained psychotherapists. It will be presented in the form of a conversation between Michele, a psychiatrist who sustained a C4 SCI following a fall in 2018 and Maeve who worked in SCI rehabilitation for 20 years prior to her recent retirement.

Acquiring a sudden cervical injury is a profound experience necessitating considerable re-evaluation of aspirations, assumptions and personal and professional understandings. This presentation highlights the unique voice of an able minded person grappling with exclusion from an able bodied world after a career supporting others in distress.

What happens when a mental health professional becomes a patient? How does theoretical understanding of adjustment and wellbeing assist or impede the process of coming to terms with significant disability? What can psychologists learn from a psychiatrist's lived experience? How are current approaches to service provision following acquired disability experienced by an experienced clinician?

This novel presentation poses questions relating to the compatible but sometimes contradictory and conflicting agendas of those living and working with quadriplegia. Our shared musings, based on many robust conversations, offer observations and emphasise the need to focus on the human encounter at the heart of clinical work. This paper paradoxically asked professionals to acknowledge helplessness as well as competence, to listen and learn as intervene and guide. In the face of cervical injury the words of WB Yeats, one of our great Irish poets to 'Tread softly because you tread on my dreams' has a real resonance.

Patient's beliefs about their spinal cord injury during first rehabilitation and how to apply the results?

Marcel Post | Christel van Leeuwen | Tijn van Diemen | Jane Duff

Workshop:

Individuals with a similar level of SCI may report strongly diverging levels of quality of life. A core element of the adaptation process after SCI consists of the beliefs that individuals have about their SCI, including their experience and interpretation of symptoms and the consequences that it will have for their future health and well-being. Such beliefs are known as 'reflections of illness perception', 'illness cognitions' or 'appraisals' in models of psychological adaptation. They influence coping strategies and, thereby, long-term outcomes of individuals with SCI. Negative appraisals are also potential targets for psychological interventions.

In this interactive workshop we will present four measures of perception and appraisals of SCI, with data on individuals with SCI in first inpatient rehabilitation. Further, we will discuss how to apply these measures and use the results in clinical practice.

1. Models and measures 25 minutes (Marcel Post)

An overview of relevant models of psychological adaptation will be presented. After that, the contents and psychometric characteristics of measures of appraisals/perception used in SCI research will be reviewed.

2. Application in clinical practice, 60 min (Jane Duff, Christel van Leeuwen, Tijn van Diemen)

This will be an interactive part, requiring active participation by the attendees. We will illustrate the application of these measures using video clips and discussion statements (polls).

- ADAPSSsf case presentation (Jane Duff)
- Level of threat measured by the BIPQ in clinical practice (Christel van Leeuwen)
- Psychological screening and risk profile (Tijn van Diemen)

3. Wrap-up 5 min (chair, speakers)

Olivia Barrett

Olivia Barrett is a third year PhD student at The University of Reading. Her research is focusing on sexual function and sexual satisfaction following spinal cord injury. In addition to her academic studies, Olivia has also worked as a case manager specialist in spinal cord injury for the past 6 years.

Emma Brennan

Emma Brennan is a recently qualified clinical psychologist from Trinity College Dublin. She has experience working with all age groups, across a wide variety of settings from primary care to tertiary settings. She spent 2 years working in the National Rehabilitation Hospital as an assistant psychologist and has a keen interest in rehabilitation following physical disability. Emma and her co-authors experience of working with young people, highlighted the potential impact of a parents injury on their children, and so this research grew from there. This research was Emma's doctoral thesis, supervised by her co-authors. Emma currently works with children in a paediatric hospital setting and hopes to continue contributing to the field through her clinical work and research. Maeve and Claire both have many years' experience working in the field of SCI and contributed heavily, both practically and through their expertise, to the completion of this valuable piece of work. Lorraine is a lecturer at Trinity College Dublin who supervised Emma throughout the thesis process.

Phoebe Brook-Rowland

Phoebe Brook-Rowland is a Trainee Health Psychologist and Research Assistant working between the University of Reading and University of Bedfordshire. Phoebe's special areas of interest are mental health in chronic health conditions, physical activity and behavioural science.

Pádraig Carroll

Pádraig Carroll is a 1st year Clement Archer Scholar in the School of Pharmacy and Biomolecular Sciences and a member of the Tissue Engineering Research Group (TERG) at the Royal College of Surgeons in Ireland, University of Medicine and Health Sciences. He is supervised by Dr. Michelle Flood, Dr. Éimear Smith, Dr. Frank Moriarty, and Professor Fergal O'Brien.

His research focuses on Patient and Public Involvement (PPI) in preclinical spinal cord research.

Caroline Debnar

Caroline Debnar obtained a Bachelor of Science in Health Psychology from the Foundation Rehabilitation University Heidelberg (Germany), a Masters degree in Cognitive Psychology from the Albert-Ludwigs University of Freiburg (Germany), and a PhD in Health Sciences from the University of Luzern (Switzerland). During her PhD she conducted research on resilience and vulnerability following the onset of a physical chronic health condition. Currently, she is working as a Post Doc at the research group 'Society & Health' at Swiss Paraplegic Research (Switzerland). Her research focuses on social inequalities and health in persons with spinal cord injury.

Tijn van Diemen

Dr. Tijn van Diemen has been a Healthcare psychologist in the Sint Maartenskliniek in Nijmegen, the Netherlands since 2003. He is currently working for the spinal cord injury department. He studied Psychology with specialization neuro- and rehabilitation psychology, and graduated in 1994 at the Radboud University in Nijmegen. From 1994 till 2002 he worked mostly as a neuropsychologist in different organisations.

After completing a cognitive behavioural therapy training in 2008, he began to do research besides his clinical work as a psychologist. First a cross-sectional study with respect to coping flexibility, later this was studied longitudinal. In May 2015 Tijn was able to start as a PhD candidate at De Hoogstraat rehabilitation in Utrecht combined with the University of Groningen. The title of his theses: self-management, self-efficacy and secondary health conditions in people with spinal cord injury. This mix-methods study includes all 8 rehabilitation centres in the Netherlands with a specialization in spinal cord injury. After he completed his PhD in 2020 he is doing research in the Sint Maartenskliniek, beside his clinical work.

Tijn is the chair of the workforce psychology of the Dutch and Farnish Society of Spinal Cord Injury and member of the board. He is on the scientific committee for ESPA and member of the ISCoS Psychosocial special interest group and ISCoS data set group.

Jane Duff

Dr. Jane Duff is a Consultant Clinical Psychologist and Head of the NSIC Clinical Psychology Department at Stoke Mandeville Hospital. She has worked in spinal cord injury rehabilitation for over 25 years providing direct clinical therapy, research, teaching/training and consultancy. Jane is Chair of the UK and Ireland Spinal Injury Psychologists Advisory Group (SIPAG), European Spinal Psychologists Association (ESPA) and ISCoS Psychosocial Special Interest Group. She is an expert panel member on the SCI Development Group of the WHO Rehabilitation 2030 Package of Rehabilitation Interventions and a member of the ISCoS Psychosocial Dataset Group. Jane has published widely on spinal cord injury coping and adjustment, appraisals, quality of life, rehabilitation/goal planning and the development of self-management skills. She provides post graduate research supervision and lecturing for the University of Oxford. Jane holds a dual qualification as a health coach and works alongside the Back Up Trust, Spinal Injuries Association and Aspire in the UK to promote personalised care.

Rebecca Eaton

I am currently a Third Year Trainee Clinical Psychologist. Prior to training I worked as an honorary assistant psychologist and an assistant psychologist in two spinal centres in the UK. I have always been interested in working with individuals who have a spinal cord injury and the associated research field. On training I have had the opportunity to return to the spinal centre to work psychologically. My theory driven project attempts to explore the impact of fatigue on negative appraisals and the relationship with depression in an acute setting.

Katherine A. Finlay

Katherine Finlay is a Chartered Psychologist and Lecturer in Psychology at the University of Reading. Katherine has a special interest in neuropathic pain and Spinal Cord Injury. Her research focuses on enabling people with chronic health conditions to improve their capacity to self-manage their health long-term after discharge from rehabilitation or inpatient care. Katherine has expertise in building peer-to-peer social support networks for people living with pain and her research in Health Psychology and Behaviour Change means that she has a keen interest in developing tailored interventions for SCI, inclusive of pain management programmes, mindfulness, sexual health and community-based support groups. Katherine supervises multiple PhD and MSc students undertaking research in SCI and publishes regularly on SCI, pain and health psychology. Katherine is a core member of the Pain Lab at the University of Reading, an Associate Fellow of the British Psychological Society and sits on the Scientific Committee of the European Spinal Psychologists' Association.

Marion Gounelle

Marion Gounelle, psychologist, graduated in 2010 with a Master's degree in Clinical Psychology, specializing in clinical psychopathology and neuropsychology of aging.

In order to enrich her care offer, Marion has completed training courses in clinical neuropsychology, law and health, art and music therapy, and the Snoezelen relaxation technique.

Following various experiences, she currently works at the Propara Neurological Center in Montpellier (34), where she accompanies individuals with neurological disorders following a spinal cord injury, a head injury, a stroke, a neurodegenerative or developmental pathology. She works with patients, their families and professional teams.

In parallel to her activity, Marion is doing a PhD in Health Psychology at the University Paul Valéry (Montpellier, France). She wishes to develop her clinical and research activities in order to help people to better live their handicap situation, to adapt to it and to integrate their new needs in daily life.

She also works with the association Comète France to promote the socio-professional reintegration of people with disabilities (validation of entry into training, evaluation of driving skills, adaptation of the workstation and tasks assigned).

Christel van Leeuwen

Christel van Leeuwen studied neuro- and rehabilitation psychology at the Radboud University Nijmegen in the Netherlands, and graduated in 2007 cum laude. In 2011, she finished her PhD thesis on quality of life in persons with spinal cord injury at the University of Utrecht. In 2011, she worked in Switzerland to obtain more experience in spinal cord injury research in Notwil. She has always combined clinical work with scientific work. Her main focus is on implementing psychological factors in treatment programmes of spinal cord injury. Since 2013, she has been working as a post-doc researcher and healthcare psychologist in Rehabilitation Centre De Hoogstraat in the Netherlands. She implemented a psychological screening at the spinal cord department and is currently involved in three innovation projects concerning self-efficacy, mindfulness and neuropathic pain. Currently, she supervises two PhD students and several students (medicine, psychology, health sciences). She is, among others, a member of the Dutch-Flemish Spinal Cord Association and is a (co)author of 28 international publications with a H index of 17.

Maeve Nolan

Maeve Nolan is a recently retired clinical psychologist. She worked in the National Rehabilitation Hospital on the spinal

Team for 20 years. She also worked as the Academic Lead for the hospital since 2018. Maeve is particularly interested in the lived experience of SCI, teamwork, gender and qualitative approaches to research. Maeve has attended every ESPA conference since the first one held in Stoke Mandeville in 2002. She values hugely the contribution that this conference has made to her work, personal insights and professional network.

Ingo Pals

Ingo Pals is working as a clinical psychologist at the Trauma Center Murnau, Germany i.a. with patients who had sustained a spinal cord injury. He is professor of applied psychology at IB University of Applied Health and Social Sciences.

Mark Pollock – Explorer, Speaker & Collaborator

Unbroken by blindness in 1998, Mark became an adventure athlete competing in ultra-endurance races across deserts, mountains, and the polar ice caps including being the first blind person to race to the South Pole. He also won silver and bronze medals for rowing at the Commonwealth Games and set up an international motivational speaking business.

In 2010, a fall from a second story window nearly killed him. Mark broke his back and the damage to his spinal cord left him paralysed. Now he is on a new expedition, this time to cure paralysis in our lifetime by exploring the intersection where humans and technology collide.

Chairman of Collaborative Cures and founder of the global running series Run in the Dark, Mark was selected by the World Economic Forum as a Young Global Leader, served on the Global Futures Council on Human Enhancement and as a UBS Global Visionary. He is on the Board of the Christopher and Dana Reeve Foundation (USA) and is a Wings for Life Ambassador (Europe).

Author of 'Making It Happen', Mark is the subject of the acclaimed documentaries 'Blind Man Walking' and 'Unbreakable – The Mark Pollock Story'. He has been awarded honorary doctorates by The Royal College of Surgeons in Ireland and also from Queens University Belfast. Furthermore, he holds a diploma in Global Leadership and Public Policy for the 21st Century from Harvard University, degrees from Trinity College Dublin and UCD Smurfit Graduate Business School.

Marcel Post

Marcel Post (1958) studied psychology. His Doctoral Dissertation concerned the health status and life satisfaction of people with spinal cord injury (SCI). He is leader of the SCI research at De Hoogstraat Rehabilitation, the Netherlands. Since 2014 he is also special professor in SCI rehabilitation at the University Medical Center Groningen, the Netherlands. His research interests concern psychological factors, social participation and quality of life of people with SCI or other physical disabilities, and measurement of these concepts.

Joan Saurí

Dr. Joan Saurí has a degree in Psychology from Universitat Ramon Llull (URL), a PhD in Psychology from Universitat Autònoma de Barcelona (UAB), and a master's degree in Neuropsychological Rehabilitation and Cognitive Stimulation (UAB). He has trained in clinical psychology and has worked in a professional capacity at Institut Guttmann Hospital of Neurorehabilitation in Barcelona since 2005, where he combines clinical practice with research and teaching. His doctoral thesis focused on the long-term process of psychosocial adaptation after the acquisition of a spinal cord injury. He has participated in Spanish and international conferences and has published several research articles in indexed journals of impact. Currently, he is the responsible of the Social Research and Innovation Program of the the Institut Guttmann's.

Margaret Tilley

Margaret has worked as an assistant psychologist in a number of roles within the NHS, primarily in mental health teams providing cognitive behavioural based therapy. Margaret changed to an academic career as a part-time visiting lecturer at the University of Buckingham between 2007 and 2009 before returning once again to work for the NHS in adult mental health. She returned to join the psychology department in 2012 as a graduate teaching assistant and is now a Lecturer in Psychology and Director of Preliminary Studies. She is also module lead for the Introduction to Psychology 1 and Biological Psychology modules, and is a Fellow of the Higher Education Academy. Margaret is part of the Centre for Health and Relationships at the university, whose research falls under the umbrella of Health Psychology. Margaret's research focuses on spinal cord injury and in particular focuses on biopsychosocial factors that contribute to the experience of spinal cord injury.



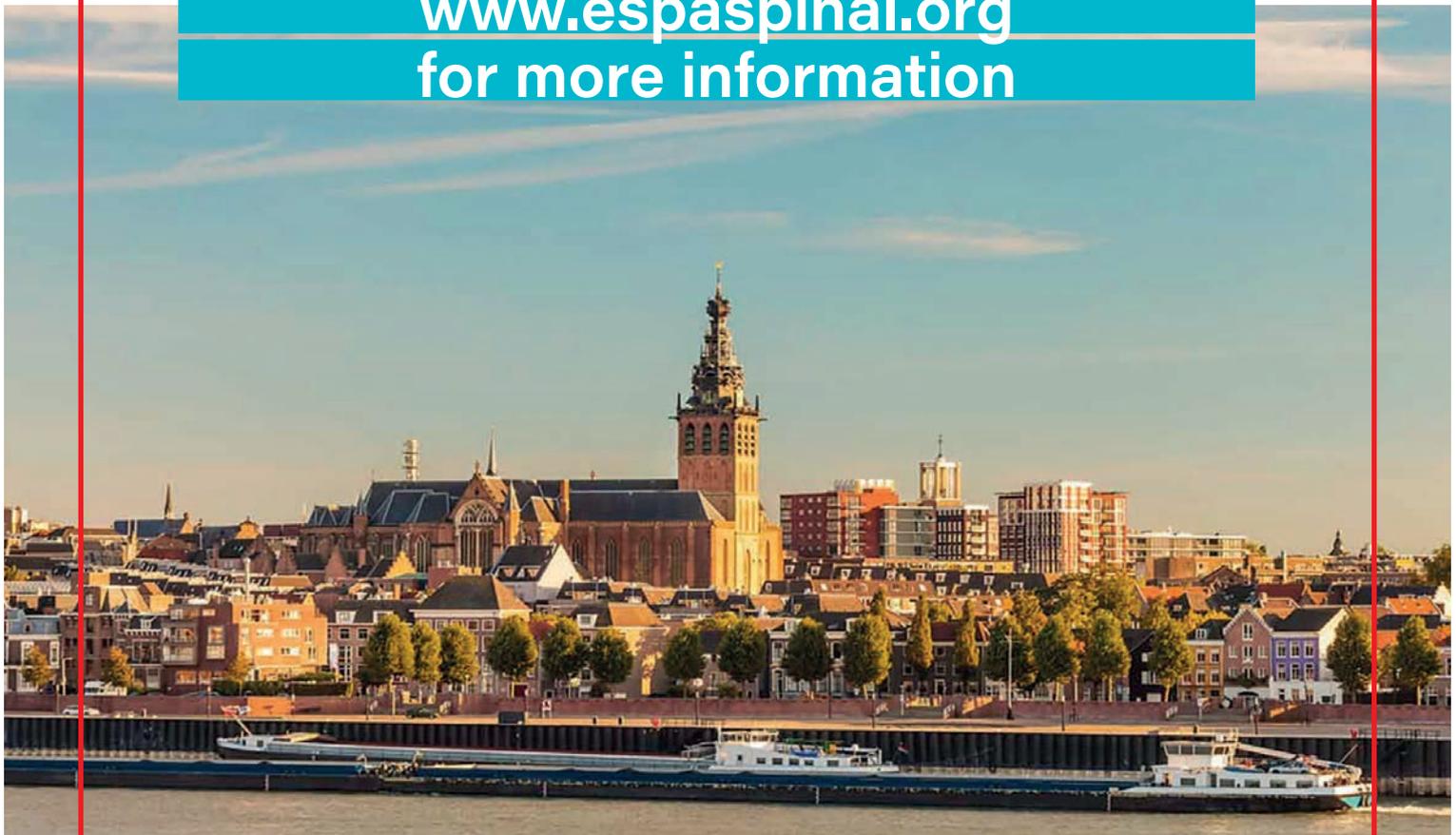
European Spinal Psychologists Association

ESPA's 11th Conference

Join us Spring 2024

www.espaspinal.org

for more information



Nijmegen | the Netherlands

