

9th ESPA Meeting



Decision Making About Living with SCI Complications: Pre-Post COVID-19 Clinical and Research Implications



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Thursday, 6th May 2021
e-ESPA | via Zoom

SUPPORTED BY:



SCIENTIFIC COMMITTEE

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

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Manchester Metropolitan University, UK



**Dear Delegate,
Dear Colleague,**

I am delighted that you have been able to join us for our virtual eESPA meeting. The conference was to have been hosted in person by Maeve Nolan and her team from the National Rehabilitation Hospital, Dublin, Ireland. I am grateful to Maeve for her support for this event and continued support for our in person meeting in Dublin, Spring 2022. Maeve has been an attendee and dedicated presenter at ESPA since its inception in 2005. She will be retiring in June so we are very pleased to be able to formally thank and acknowledge her enormous contribution towards the psychological support for people with spinal cord injury (PwSCI) in Ireland over the past 20 years.

We've consciously planned eESPA to be different from our usual conference to stimulate your interest and interaction. I hope you have enjoyed reading the posters and celebrating the research of members of our network and have some questions ready for the presenters to bring your thoughts and context to each.

We are very fortunate for the creative insight and wisdom of Professor Denise Tate, from the University of Michigan's Department of Physical Medicine & Rehabilitation, in adapting her talk on body and mind decision making to discuss the interconnection between these skills and COVID for PwSCI. Professor Tate is joined by two colleagues, Tom Hoatlin, who will be sharing how he has translated his considerable SCI peer mentor experience to virtual support during the pandemic. Dr Carrie Pilarski, rehabilitation psychologist and associate professor, will be sharing her insights on the impact of the disparity of provision and how to best support, advocate and empower PwSCI who have been substantially impacted and more vulnerable than most in all our nations.

On behalf of Peter, Magnus and Jasmine, I thank you for your commitment and support of ESPA and hope that through our new website we can continue to build on our connection between meetings. We look forward to continuing our knowledge about body and mind connection in Spring 2022, with Dr Tijn van Diemen's keynote developing this theme further and considering the role of self-efficacy in secondary health conditions.

Yours sincerely,

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

Thursday, 6th May 2021**BST timezone**

13.45 – 14.00

14.00 – 14.10

14.15 – 14.20

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16.15 – 16.30

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16.35 – 16.40

16.40 – 16.45

16.45 – 16.50

16.50 – 17.00

17.00 – 17.30

TIME FOR NETWORKING

Welcome Address and Housekeeping

Poster 1

Poster 2

Poster 3

Poster 4

Break

Film

BAGM

KEYNOTE

Expert by Experience

Expert by Experience

PANEL DISCUSSION

Break

Poster 5

Poster 6

Poster 7

Poster 8

Closing Remarks

TIME FOR NETWORKING

Posters will be shared with registered delegates on 22nd April (2 weeks before the live event). Please review these in advance of the conference and prepare your questions for submitting in the chat function of zoom. The zoom link for the event will be sent prior to the conference.

Thursday, 6th May 2021

BST timezone

13.45 – 14.00 **TIME FOR NETWORKING**

14.00 – 14.10 **Welcome Address and Housekeeping**
Dr Jane Duff

14.15 – 14.35 **SESSION I:**

14.15 – 14.20 **POSTER 1:**
Mental health, quality of life, and psychosocial resources of individuals living with spinal cord injury in Switzerland compared to the general population
Dr Valerie Carrard

14.20 – 14.25 **POSTER 2:**
A systematic review of the associations of acceptance with quality of life and mental health following spinal cord injury
Anders Aaby

14.25 – 14.30 **POSTER 3:**
Longitudinal course and predictors of psychological adaptation outcomes: An exploration of the clinical rehabilitation setting
Mayra Galvis Aparicio

14.30 – 14.35 **POSTER 4:**
Adaptation to adult attachment and intimacy following a spinal cord injury: a systematic review
Luned Mair

14.35 – 14.50 **Break**

14.50 – 16.15 **SESSION II:**

14.50 – 15.00 **Film: The Patient Experience Project**
Dr Maeve Nolan, Claire Keogh

15.00 – 15.10 **BAGM**
Dr Jane Duff

15.10 – 15.25 **KEYNOTE:**
Decision Making About Living with SCI Complications: Pre-Post COVID-19 Clinical and Research Implications
Prof Dr Denise Tate

Thursday, 6th May, 2021**BST timezone**

15.25 – 15.35

Expert by Experience:

Sharing and learning from each other's lived experience of having an SCI
Tom Hoatlin

15.35 – 15.45

Expert by Experience:

SCI Clinical Care and Advocating for Disability Justice During a Pandemic
Dr Carrie Pilarski, PhD

15.45 – 16.15

PANEL DISCUSSION:

Prof Dr Denise Tate
Dr Carrie Pilarski
Tom Hoatlin
Dr Tijn van Diemen

16.15 – 16.30

Break

16.30 – 17.30

SESSION III:

16.30 – 16.35

Poster 5:

Illness perception representations during admission and discharge of SCI rehabilitation
Heleen Kuiper

16.35 – 16.40

Poster 6:

Self-efficacy training in persons with SCI
Dr Christel van Leeuwen

16.40 – 16.45

Poster 7:

"You were lying in limbo and you knew nothing": A thematic analysis of the information needs of spinal cord injured patients and family members in acute care
Clodagh Cogley

16.45 – 16.50

Poster 8:

Adjustment to Disability: Exploring What It Means, How It Feels and How It Is Done through Two Qualitative Techniques
Laura Sanmiquel-Molinero

16.50 – 17.00

Closing Remarks

Dr Jane Duff

17.00 – 17.30

TIME FOR NETWORKING

Mental health, quality of life, and psychosocial resources of individuals living with spinal cord injury in Switzerland compared to the general population

Author: Valerie Carrard

Introduction:

Despite the fact that individuals react differently to the onset of a spinal cord injury (SCI), individuals living with SCI have on average higher rates of depression and lower quality of life compared to the general population. However, many past studies compared individuals with SCI to un-matched or un-standardized general population samples, which might imply biased results. Moreover, this comparison has never been done in the Swiss context. The objective of the present study was to compare mental health, quality of life, and psychosocial resources of people living with SCI in Switzerland to a matched general population sample.

Methods:

Data from the 2017 community survey of the Swiss Spinal Cord Injury Cohort Study was compared to two matched general population datasets collected in the same year. Measures psychological distress, mental health, vitality, energy, quality of life, self-efficacy, and social support (relationship satisfaction, living alone, and civil status) were compared across datasets using regression adjusted for non-response correction weights. The analyses were then replicated in subgroups defined by sociodemographic, lesion-related, and secondary health issues factors.

Results:

Individuals living with SCI in Switzerland have significantly higher psychological distress as well as lower mental health, vitality, energy, and quality of life compared to the general population with medium to large effect sizes (Cohen's d between 0.35 and 1.08). They also had lower self-efficacy and relationship satisfaction, lived more frequently alone, and were more frequently single. Individuals with less severe secondary health issues reported mental health and quality of life more similar to the general population than those reporting more severe issues.

A systematic review of the associations of acceptance with quality of life and mental health following spinal cord injury

Author: Anders Aaby

Introduction:

Spinal cord injury (SCI) is a severe and chronic condition often accompanied by long-term psychological distress. The presence and severity of negative psychological outcomes are influenced by many factors, including acceptance of the injury, which has been defined as perceiving the injury as an integral part of life going forward and a re-evaluation of life values. A wealth of empirical studies has explored the role of acceptance in the psychological adjustment process following SCI. The aim of the present systematic review was therefore to identify, critically appraise, and synthesize relevant research findings on how acceptance was associated with quality of life and mental health outcomes.

Methods:

Five databases (PubMed, PsycINFO, Embase, Web of Science, and Scopus) were systematically searched. Studies were included if they provided findings on the association between acceptance and QOL, mental health outcomes, or both in an SCI population aged 16 years or older. Peer-reviewed original quantitative and qualitative studies were included.

Results:

Forty-one studies were included. Greater acceptance was consistently associated with greater global and psychological QOL, life satisfaction, sense of well-being, mental health, and with lower levels of depression and anxiety. Inconsistent evidence was found with regards to social QOL and post-traumatic stress disorder. Acceptance was generally not associated with adjustment outcomes further than 2 years into the future. Study quality of the quantitative studies was mostly fair (n = 17) followed by good (n = 13), and poor (n = 9).

Conclusion:

Health-care professionals may regard acceptance as a psychological resource they can aim to support in improving QOL and mental health following SCI. A range of methodological and conceptual limitations were present in the research. Future studies should prioritize longitudinal designs, consider dyadic effects, explore subjective meaning(s) of acceptance, and investigate the effectiveness of therapeutic approaches that stimulate the acceptance process.

Longitudinal course and predictors of psychological adaptation outcomes: An exploration of the clinical rehabilitation setting

Authors: Mayra Galvis Aparicio

Sustaining a spinal cord injury (SCI) demands ongoing psychological adaptation. Despite important efforts made to understand the impact of an SCI shortly after its onset, the evolution of the psychological adaptation process during inpatient rehabilitation remains underexplored and mostly limited to single adaptation outcomes, which disregards its multidimensionality. Moreover, substantial individual differences exist in how individuals adapt to SCI, but only few studies have addressed them. Thus, the present study aimed at: (1) determining average changes in depressive symptoms, anxiety symptoms, general distress, and life satisfaction between admission to spinal cord injury inpatient rehabilitation and discharge. (2) Identifying individual patterns of change in each adaptation outcome, and (3) identifying factors associated with average changes.

Using data from the SwiSCI inception cohort study (N=281), latent change score models were implemented to analyze changes in the psychological adaptation outcomes and reliable change indexes were calculated to identify individuals' patterns of change. Several biopsychosocial factors were included in the models as covariates of change.

On average, participants showed improvements in all analyzed psychological adaptation outcomes. Several subgroups of participants were identified following patterns that indicate improvement, worsening, resilience, or vulnerability. The proportion of individuals following each pattern varied depending on the analyzed outcome. Predictors of positive psychological adaptation were: self-efficacy (for depressive symptoms), optimism (for general distress and life satisfaction), and social support (for depressive symptoms), whereas tetraplegia and female sex were related to a more negative course of anxiety symptoms and general distress respectively.

Findings of this study highlight the need for ongoing psychosocial support during inpatient rehabilitation and the importance of screening processes that consider several adaptation outcomes to offer interventions tailored to individuals' specific needs. Self-efficacy, social support, and optimism may be intervention targets during inpatient rehabilitation to promote a favorable psychological adaptation process.

Adaptation to adult attachment and intimacy following a spinal cord injury: a systematic review

Author: Luned Mair

Background:

Experiencing a spinal cord injury (SCI) can be life-changing for individuals and their families. Previous reviews have focused on post-SCI coping and psychological adjustment (e.g. Chevalier, Kennedy & Sherlock, 2009), the factors that facilitate or impede interpersonal relationships following a SCI (Amsers et al., 2016) and sexual adjustment and sexuality following an injury of this kind (Earle et al., 2020; Ostrander, 2009).

Although research has shown that adult attachment changes during the life-span (Chopik et al., 2019) and that having a partner is a protective factor for life satisfaction and psychological well-being following a SCI (Holicky & Chalifue, 1999), there is very little work synthesising papers that focus on changes to adult attachment and emotional intimacy following a SCI.

Aims:

To review research to examine the mechanisms of change in adult attachment and intimacy in romantic relationships following a spinal cord injury.

Method:

Four online databases were searched for relevant qualitative papers focusing on changes to romantic relationships, attachments and intimacy following a SCI. After the removal of duplicates, of the 433 papers found, 15 papers met inclusion criteria. These were quality assessed and analysed using meta-ethnography methodology.

Results:

The main themes that emerged from the analysis were: a) the strengthening of adult attachment; b) changes in roles and support; c) changing definitions of intimacy; and d) the injury as a threat to intimacy and attachment.

Conclusion and recommendations:

There are significant changes to adult attachment and intimacy for many couples following a SCI. Some experience these as positive, whilst the changes and adaptation needed posed great difficulty for other couples and individuals. It is recommended that healthcare providers, charities and other agencies that support couples following a SCI are aware of these processes and provide couples with appropriate support to negotiate challenges.

The Patient Experience Project

Author: Maeve Nolan, Claire Keogh

Background:

The Patient Experience Project (PEP) grew out of the recognition by the Psychology Department at the National Rehabilitation Hospital, Dublin of the need to creatively capture the patient experience, provide much valued peer support and be consistent with a self-management rehabilitation ethos. This brief presentation will show an animation and an extract from a patient video to illustrate the project.

Objective:

- Develop a range of online, patient friendly, educational resources including animations, patient and family interviews and short professional inputs on various aspects of rehabilitation and living with acquired disability.
- Expand the availability of self-management tools that can be accessed in peoples own time in an increasingly preferred format, thereby counteracting barriers to learning including timeliness, readiness and health literacy.
- Increase disability awareness and provide a valuable teaching resource for community professionals.

Method:

- Collaboration with students of film at a local college to develop short, lively animations on topics including adjusting to rehabilitation, managing anger and fatigue and accepting long-term care.
- Commissioning a series of patient and family experience videos complemented by brief 'teaching' inputs from the Psychology Department.

Results:

11 animations and an expanding range of patient experience videos (currently 22) capturing real life stories of rehabilitation and living with disability for use with patients, families and healthcare professionals.

Conclusion:

Patient experience and empowerment is at the heart of this ongoing project which seeks to enrich the lives of patients and be responsive to their changing and complex needs. Patients are 'experts by experience' and stories from those who have experienced rehabilitation and life altering injuries have much to offer others going through similar experiences. In addition, they offer listeners the opportunity to expand understanding of the profound identity transformation imposed by sudden disability.

**KEYNOTE PRESENTATION:
Decision Making About Living with SCI
Complications: Pre-Post COVID-19 Clinical
and Research Implications**

Author: Denise Tate

Living with spinal cord injury (SCI) requires extensive personal decision making to address the many health issues and complications. People with SCI make daily decisions about their care that directly and indirectly affect the management of their condition and related complications. These decisions become particularly complex in that neurogenic bowel and bladder (NBB) broadly affect the whole person across multiple domains of daily life including social participation, sense of control, competence and wellbeing. Research in SCI suggests that strong self-efficacy and resilience may protect individuals from symptoms of depression, stress and anxiety associated with managing complications. Similarly, researchers have found that a sense of control was protective of psychological wellbeing during COVID-19 crisis in a non-SCI sample. This presentation compares these results in relation to new findings from a recent study being conducted to examine decision making about living with NBB complications after SCI.

Learning Objectives:

1. Discuss factors associated with decision making when experiencing negative consequences from SCI complications and uncertainties due to a pandemic crisis.
2. Examine a conceptual model for decision making in relation to self-efficacy and other individual characteristics
3. Discuss treatment approaches during times of social isolation and directions for future research

Sharing and learning from each other's lived experience of having an SCI

Author: Tom Hoatlin

Individuals with SCI are at an increased risk for social isolation during the COVID-19 pandemic. Typical ways of learning through peer mentoring and support groups have had to be adjusted to virtual formats. Peer mentoring in a virtual world has brought up new complexities and challenges. The social contact of a support group is further complicated with virtual groups, but offers new opportunities to connect in an alternative format. Groups members are bringing up new needs and concerns due to the pandemic in addition to the more typical education and support needs. Sharing personal experiences of managing activities of daily living continues to be a powerful means of education. Learning from the successes and failures from others provides a comfort in knowing that no one is alone, even in the personal experiences of managing neurogenic bladder and bowel issues.

Learning Objectives:

1. Explain the transition to a virtual format for mentoring and support groups.
2. Identify unique concerns from the SCI community during the pandemic.
3. Learn how to discuss and teach self-management and social problem-solving related to bladder and bowel complications.

SCI Clinical Care and Advocating for Disability Justice during a Pandemic

Author: Carrie R. Pilarski

During the COVID-19 viral pandemic, individuals with spinal cord injury (SCI) may be at increased risks for poorer physical and mental health. The unique experiences with SCI place individuals at greater risk for reductions in routine care and supplies, exposure risk with home care or personal care assistance, as well as stress and isolation with stay-home precautions. The provision of health care services changed for both acute care with newly acquired SCI or emergency services for individuals with comorbid disabilities. As providers, the importance of understanding the unique needs and advocating for disability justice became even more apparent as several examples of medical rationing guidelines in the context of COVID-19 demonstrated discrimination. Rehabilitation psychologists and providers in physical medicine and rehabilitation can play an integral role in supporting approaches to maximize care, support resiliency, and advocate.

Learning Objectives:

1. Discuss unique considerations for SCI care during the COVID-19 pandemic.
2. Identify ways to adjust care to meet physical and mental health needs during a pandemic.
3. Identify action steps for advocacy for disability justice.

Illness perception representations during admission and discharge of SCI rehabilitation

Author: Heleen Kuiper

Background:

Besides the variety of health problems and consequences of a SCI, the way the persons involved think about or view a similar SCI, might be just as diverse. Individual ideas or mental representations of a health problem, are regularly referred to as 'illness perception'.

Aim:

- (1) to present the outcomes on illness perception by eight representations of illness according to the Brief Illness Perception questionnaire (B-IPQ), during admission and discharge of clinical rehabilitation, and
- (2) to analyse demographic, injury-related, and mental health history-related determinants of illness perception.

Methods:

Included were inpatients with a recently acquired SCI admitted to one of seven Dutch SCI-specialized rehabilitation centres. The B-IPQ was used to assess the level of threat on eight illness representations/ items. Differences between illness representation at admission and discharge were analysed with the non-parametric Wilcoxon signed rank test. Associations between overall illness perception (analysed with a SCI-tailored B-IPQ total score) and participant characteristics, were tested with bivariate regression analyses.

Results:

270 participants completed the B-IPQ at admission and 119 at discharge. At admission, highest scores were found for the impact of the SCI on life and symptom burden. At discharge, most participants showed a significant decrease or no change in threat on: impact of the SCI, personal control, symptom burden, concern, illness comprehensibility, and emotions. Yet, more participants thought their SCI was permanent and fewer thought that treatment will help. Total scores were significantly lower at discharge. A complete SCI was weakly associated with a more threatening illness perception.

Conclusion:

Overall, most of the individual illness representations, positively and significantly changed and this for most of the participants. Completeness of the injury was weakly associated with illness perception. Stronger associations are expected with mental health status and coping strategies and this will be tested in the near future.

Self-efficacy training in persons with SCI

Author: Christel van Leeuwen

Background:

This poster presents the first results of a self-efficacy training in persons with Spinal Cord Injury (SCI) in the Hoogstraat Rehabilitation. This training is based on the “Re-inventing Yourself after Spinal Cord Injury” treatment programme for improving self-efficacy after SCI (Coker et al., 2019).

Aim:

The aim of the poster is to present the first results of a self-efficacy training to enhance self-efficacy in persons with SCI in order to deal with their changing life circumstances after SCI.

Methods:

Pilot pre-post design. At the start and the end of the self-management training, depression and anxiety were assessed with the HADS and self-efficacy was assessed with the University of Washington-Self-Efficacy Scale. Moreover, qualitative interviews with participants and the 3 trainers took place at the end of the training to evaluate the content of the programme, the trainers, the procedure, and the training overall.

Results:

On average, participants scored higher on self-efficacy at the end of the self-efficacy training than at the start. Participants in the training were enthusiastic about the programme. They told they learned skills to cope with the SCI, e.g. to ask for help and to speak openly about their situation. Moreover, participants learned more about their personal strengths and weaknesses, and to actively cope with daily problems they encountered. The trainers of the self-efficacy training noticed a process of mental growth in the participants of the training due to discussing theory, practicing together and learning from peers. The trainers replaced some of the original English movies by movies that better fit the Dutch context.

Conclusion:

A self-management training stimulates self-efficacy in persons with SCI and seems a valuable part of a rehabilitation programme after SCI. Based on these results, the self-efficacy training will be continued in the SCI rehabilitation programme of The Hoogstraat rehabilitation.

**“You were lying in limbo and you knew nothing”:
A thematic analysis of the information needs of spinal
cord injured patients and family members in acute care**

Author: Clodagh Cogley

Abstract:

Purpose: In the context of long waiting lists for rehabilitation, this study aimed to redress the lack of research on the information needs of spinal cord injured (SCI) patients and family members in acute care, in order to inform the provision of appropriate information supports during this time.

Methods:

Semi-structured interviews were conducted with seven traumatic SCI patients and six of their family members. Reflexive thematic analysis was used to analyse and interpret the data.

Findings:

Five themes were generated: 1) “You were lying in limbo and you knew nothing”: describes how the patient being situated in non-specialist acute care significantly limited participants’ access to information; 2) “You’ll never walk again” is not enough: describes the need for information about the effects of SCI on the patient’s functional independence, the management of secondary conditions, and what to expect in rehabilitation; 3) “The delivery was awful”: demonstrates the importance of explaining information clearly and empathically, to reduce confusion and distress; 4) “It was going in one ear and out the other”: highlights the need for information to be continuously repeated, reinforced and clarified by healthcare professionals, as participants often had difficulty retaining information provided in the early stages post-injury; and 5) “Hope” not “false hope”: discusses the importance of promoting realistic hope for SCI patients and family members even in the absence of neurological recovery, by focusing on what the patient is still capable of while simultaneously being honest about their prognosis.

Conclusion:

SCI patients and family members had significant unmet information needs in acute care, which often caused considerable distress and negatively impacted patients’ recovery. Addressing the issues raised in this study should enhance patients’ and family members’ access to, satisfaction with, and understanding of SCI-related information, and may reduce psychological distress during this difficult time.

Adjustment to Disability: Exploring What It Means, How It Feels and How It Is Done through Two Qualitative Techniques

Author: Laura Sanmiquel-Molinero

In recent years, rehabilitation psychologists (Wright, 1983; Gill, 2001), medical sociologists (Williams, 2000), and several authors in the interdisciplinary field of Disability Studies (Goodley & Lawthom, 2006) have pointed out the need for a critical approach to concepts such as “adjustment to disability” and “biographical disruption” in the event of a disability (Bury, 1982). Specifically, they have emphasized that previously overlooked elements such as subjective experience of adjustment and the social factors that condition it (Reeve, 2000) have to be taken into account. In this communication, I present a qualitative research project currently taking place with this aim at the Institut Guttmann (Barcelona) with six people who have acquired a spinal cord injury (SCI) in the last two years and who are going through the transition process from the rehabilitation hospital to the community.

The main goal is to identify meanings, practices and affects that people with an SCI, their families and the healthcare professionals who work with them hold with regard to what a “good adjustment” and a “satisfactory reintegration” into the community entail. To do so, I am combining two techniques: (1) Shadow ethnography (Jirón, 2012).

This entails following the participants with an SCI through their daily routines once a month to observe their relationships with the physical and social environment during the transition phase to the community.

(2) Chronotopic diffraction. This is a modified version of the Narrative Productions technique (Balasch & Montenegro, 2003). Based on the concept of chronotope, this technique aims to account for the changes in narratives of participants with an SCI through time and space.

In this presentation, I present the strengths and weaknesses of both techniques to explore the process of adjustment to disability, exemplifying their use with the results obtained so far.

Valerie Carrard

She is a health psychologist who completed her PhD with highest distinction at the Institute of Work and Organizational Psychology of the University of Neuchâtel in Switzerland. Her research focusses on humans' ability to adapt to different medical situations and the resources facilitating this adaptation. Dr. Carrard's PhD studies investigated the facilitators and beneficial effects of physicians' behavioral adaptation to patients' preferences in general practice interactions. As a postdoc researcher, she pursues the study of physicians' interpersonal competences in the Lausanne University Hospital and supervises two PhD projects exploring patients' longitudinal psychological adaptation to the onset of chronic health conditions in the Swiss Paraplegic Research of Nottwil in Switzerland.

Anders Aaby

Anders Aaby, MSc Psychology, is currently working as a PhD fellow at Specialized Hospital for Polio and Accident Victims, Denmark, and Department of Psychology, University of Southern Denmark. Anders has a brief background in Acceptance and Commitment Therapy (ACT), and he initiated the current PhD project focusing on the acceptance process following spinal cord injury. The project covers a range of studies, including a systematic review, exploring dyadic effects in the adjustment process, and the subjective meanings of acceptance.

Mayra Galvis

She holds a Bachelor and Master degree in Psychology (Universidad Pontificia Bolivariana, Colombia; Universidade Federal do Rio Grande do Sul, Brazil). She has research experience in the area of health psychology, focusing on topics such as quality of life and well-being of patients with chronic health conditions and caregivers. She is currently a PhD student at the Swiss Paraplegic Research and the department of Health Sciences and Medicine at the University of Lucerne (Switzerland). The focus of her current project is the process of psychological adaptation to Spinal Cord Injury in the clinical setting.

Luned Mair

She is a final year trainee clinical psychologist on the South Wales Doctoral Programme in Clinical Psychology. Her doctoral research is in the field of spinal cord injury and she is particularly interested in how romantic relationships are maintained following an injury of this kind. Luned's interest in clinical health psychology began when working as an assistant psychologist in a chronic pain service.

Luned is supervised by Dr Jenny Moses, academic director of the South Wales Doctoral Programme in Clinical Psychology and consultant clinical psychologist at the Welsh Spinal Cord Rehabilitation Centre. Jenny has over 25 years' experience of working in spinal cord injury. She is interested in how clinical health psychology can be applied in neurorehabilitation settings. Jenny has supervised a number of clinical doctorates in spinal cord injury and other areas of clinical health psychology.

Maeve Nolan

She is a clinical psychologist and psychotherapist who has worked on the spinal injury team at the National Rehabilitation Hospital, Dublin since 2001. Trained as a psychoanalyst, Maeve is particularly interested in the lived experience and meaning of spinal cord injury for people and families. In 2011, she completed her D.Clin Psych at Essex University on 'The experience of living with spinal cord injury in the early months following discharge from rehabilitation: A qualitative study on a male sample'.

Maeve contributed to the longitudinal, European study of coping and adjustment (Kennedy, Lude and Elfstrom, 2011) and co-authored a paper with Paul Kennedy on the Irish sample. She is particularly interested in the patient experience of rehabilitation and spinal cord injury. Other areas of interest include gender and SCI, pain management, challenging behaviour, psychological issues facing 'walkers' with SCI, resilience and patient and carer education. Maeve was appointed as part time Academic Lead to the NRH in 2019, a role which involves the development of a newly established academic centre within the hospital.

Keynote Speaker: Denise Tate

Prof Dr Tate is a Professor and Associate Chair for Research in Physical Medicine and Rehabilitation (PM&R) at the University of Michigan Medical School, Ann Arbor. She served as the PI of the University of Michigan Spinal Cord Injury Model System (SCIMS) program, established in 1986 which was funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR), Washington DC. This center, now called the Michigan Spinal Cord Injury System (MSCIS) continues to be funded by NIDILRR as a data center for SCIMS. Dr. Tate also directs the Advanced Rehabilitation Research Training Program for post-doctoral training focusing on community participatory based research. Her research focuses on the prevention of risk factor to complications after SCI, psychological adaptation after injury, community reintegration and on measuring health and quality of life outcomes. Past research focused on the association of injury severity to functional outcomes after SCI. She served as a member of the Board of the American Spinal Injury Association (ASIA), the American Congress of Rehabilitation Medicine (ACRM) and a member of the Advisory Board of the National Center for Medical Rehabilitation Research at the NIH and of the Board of Scientific Counselors for CDC. Dr. Tate has authored more than 150 peer-reviewed publications and participated in several national research review committees. Most recently, she began focusing her research on international efforts and collaborations with other centers conducting research driving and SCI.

Tom Hoatlin

His life changed in an instant when he sustained a spinal cord injury in 1991. While seeking out SCI services and resources from the Ann Arbor Center for Independent Living he found his next career. He has served as the Ann Arbor CIL's lead spinal cord injury peer support and mentoring program since 1997. Working on Michigan Medicine's Rehabilitation Unit he has co-lead and teaches an independent living curriculum to inpatients and their families while providing peer mentoring services to inpatients preparing for successful community reintegration. He served as the Director of Development from 1998-2019 and currently provides development, mentoring and disability awareness support for the Ann Arbor CIL.

Since 1995 Hoatlin has served as a SCI consultant and research assistant for the Michigan Medicine's SCI Model System and provided leadership as the Chair and Co-Chair of the SCI Model System Advisory Board bridging the gap between stakeholders and clinical staff. He has contributed to the SCI Access newsletter, website and other publications for the Physical Medicine and Rehabilitation spinal cord injury support system.

Hoatlin served as the Midwest Regional Coordinator for the Christopher and Dana Reeve Foundation's Peer and Family Support Program from 2014 – 2017. He recruited, trained and certified people living successfully with paralysis throughout the Great Lakes states and nationally.

Tom has been a long-standing consultant and Ambassador for NuStep an adaptive and inclusive cross training exercise equipment manufacturer. He is a community advocate, award winning speaker and mentor in the disability community.

Carrie R. Pilarski

She is a Rehabilitation Psychologist and Assistant Professor in the Department of Physical Medicine & Rehabilitation at the University of Michigan. Dr. Pilarski received her PhD from Central Michigan University and completed a post-doctoral fellowship at the University of Michigan in 2010. She worked for several years at a brain injury rehabilitation center until returning to the University of Michigan in 2015 where she is the attending psychologist on the inpatient spinal cord injury and complex medical services as well as providing outpatient services for a wide range of disabilities. In a recent publication of the American Psychologist, Dr. Pilarski and colleagues addressed medical rationing and discrimination in an article titled, "No Body Is Expendable: Medical Rationing and Disability Justice During the COVID-19 Pandemic." Dr. Pilarski identifies as a disability advocate and is always eager to discuss disability as an aspect of life.

Heleen Kuiper

She started as a PhD-student at the Center of Excellence for Rehabilitation Medicine at in The Netherlands in February 2018. Heleen is a registered nurse and studied Health Sciences at the VU University in Amsterdam. For her master thesis she went to Brazil where she did a pilot study with a toolkit aimed at assessing and monitoring morbidity and disability across neglected tropical diseases. Both fields showed her the mental and emotional burden due to dysfunction, changes in functioning, or exclusion. Additionally, it also showed her the strength of people to cope with such situations. Altogether, this made a huge impression on her, resulting in the motivation she currently puts in her work. The main focus of her PhD is on evaluating the psychological screening that is performed by psychologists in eight rehabilitation centres among people with a spinal cord injury.

Christel van Leeuwen

She studied neuro- and rehabilitation psychology at the Radboud University Nijmegen in the Netherlands, and graduated in 2007. 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 Nottwil. Her main research focus is on the implementation of psychological factors in treatment programmes of spinal cord injury. Since 2013, she has been working in Rehabilitation Centre De Hoogstraat in the Netherlands, as a psychologist and researcher in the spinal cord department.

Clodagh Cogley

Clodagh is a PhD student currently conducting research in the areas of end-stage kidney disease and improving access to healthcare for individuals with mental health difficulties. Clodagh is also an Assistant Psychologist in neuropsychology. Her research on the information needs of spinal cord injured patients and family members during acute care was prompted by Clodagh's own experience of sustaining a spinal cord injury.

Laura Sanmiquel-Molinero

She obtained a Bachelor of Arts in Psychology from the Autonomous University of Barcelona (UAB) in 2017, after completing the dissertation “Sujeción, des-sujeción y subjetivación del cuerpo discapacitado. Entre el orgullo, la vergüenza y la superación [Subjection, de-subjection and subjectification of the disabled body. Between pride, shame and overcoming]”. This work was her first contact with Disability Studies, and explores how the currently available disability models influence how “disabled” people construct their identities. Afterwards, she approached Critical Disability Studies while taking the Master’s Degree in Psychosocial Research and Intervention (2017-2018). In July of 2018, she defended her Master’s Thesis titled “Putting Emotions to Work: The Role of Affective Disablism and Ableism in the Constitution of the Dis/abled Subject”, published in the journal *Disability & Society* in 2019. This work continues to explore disabled identity, and emphasises the importance of affects in the constitution of the “disabled subject”. In September 2018, she started a PhD in Social Psychology at the UAB, and obtained a Grant for University Professors’ Training (FPU) from the Spanish Ministry of Education, Culture and Sport. Her current research focuses on problematizing the “transitions” that happen during the advent of a “disability” and, especially, the so-called “adjustment to disability”. Her aim is to produce valuable knowledge, so that the professionals who tend to disabled users during these transitions do not reproduce ableism.



To Dr Maeve Nolan's Retirement, from National Rehabilitation Hospital, Dublin

With ESPA members in over 22 nations, 2021 was the year we hoped to welcome this wonderful community of psychologists working in spinal cord injury to Dublin Ireland, hosted by Dr Maeve Nolan.

While the pandemic has not allowed us to physically come together, to visit the new National Rehabilitation Hospital in Dublin, the cultural sights of Ireland's capital city and the warm welcome of its citizens, thankfully the sharing of clinical practice and dissemination of research prevails.

There is added significance to hosting ESPA in Dublin this year, this being the year of retirement for our cherished colleague, Dr Maeve Nolan.

Maeve has worked as Clinical Psychologist on the spinal team at the National Rehabilitation Hospital (NRH) Dublin since 2001. Prior to working in rehabilitation, after completing post-graduate training in clinical psychology at University College Dublin, Maeve pursued further training as a psychoanalytic psychotherapist. She subsequently worked in public and private clinical practice and as well lecturing in psychology to undergraduates and post-graduates.

Maeve has always been interested in research and integrating this with her clinical practice and in 2011, she completed her D. Clin Psych at Essex University exploring the experience of men in the early months following discharge from rehabilitation. In true Maeve style she presented this at conferences (including ESPA), generated a number of papers and wrote a book which she proudly gave to each of the participants.

For twenty years Maeve has dedicated herself to providing the highest standards of care to people with spinal cord injury and is a central and much respected figure in the Spinal Injury Programme. It is only in speaking of her daughters, and now her new grandson, (and films, books and good restaurants) that Maeve exudes as much passion as her work in spinal cord injury.

In her clinical role, Maeve is a fierce defender of the time needed for adjustment to SCI, time to care for patients and look after the needs that can often be overlooked in favour of the physical needs and as services change, and the need to address them. As well as her clinical work, establishing events such as “Women’s Day” in 2010. This event continues to be celebrated annually until 2020 when it was cancelled due to COVID restrictions. This wonderful annual event welcomed former patients on a day in May with a programme of education, peer support and good fun including ice creams...when we could do such things. Maeve’s contribution to both staff and patient education has been very significant. Maeve is a natural IDT player and her support and inclusivity towards new team members is known across the hospital. It would not be unusual to hear staff across the hospital say “did you talk to Maeve”.

In addition to her contribution to the Spinal Programme, Maeve has similarly made enormous contribution to her colleagues at the Department of Psychology, to the organisation of the NRH and was a member of the board for three years. In 2020, she was appointed as Lead for the new Academic Department at NRH. Here she has ‘broken ground’ in contributing to NRH becoming a university hospital as well as being someone who is accessible and supportive for students and clinicians embarking on research and education at professional, doctorate or masters level nationally and internationally.

Maeve is passionate about the patient experience of healthcare and education for rehabilitation staff and patients. This is evident through her clinical, academic work, and research in the area of Spinal Cord Injury and Acquired Disability.

With her many publications such as ‘Being a ‘Sit-down Mummy’: the experience of parenting of mothers with SCI’, ‘After Rehabilitation: 5 Men’s experience of living with spinal cord injury.’, and “The Accordion and the Deep Bowl of Spaghetti: Eight Researchers’ Experiences of Using IPA”, Maeve has contributed generously to the knowledge base of this community.

Maeve lectures at many third level courses including MSc in Disability & Rehabilitation, University College Dublin, Doctorates in Clinical Psychology at Trinity College Dublin, University College Galway, and Dublin Business School.

She is an enthusiastic and contributing member of ESPA, ISCOS, MASCIP, IARM, Guttmann and the Psychological Society of Ireland. Maeve has been a leader and role model in her work with the NRH team, within the health care sector community in Ireland and to international colleagues in her dedication to the provision of the highest standards of care for people with spinal cord injuries and acquired disability and development of psychological knowledge in this area.



European Spinal Psychologists Association

ESPA's 10th Conference

Spinal cord injury: looking after body and mind

Dublin, Spring 2022



Keynote Speaker: Dr Tijn van Diemen

Body and Mind:

the role of self efficacy in secondary health conditions