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INSTRUCTIONAL COURSES ABSTRACT BOOK

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Managing distress in people with SCI in inpatient and community settings: best evidence and effective strategies.

Professor Ashley Craig¹, Dr Jane Duff², Professor James Middleton³

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Speakers

Ashley Craig, PhD, Professor of Rehabilitation Studies, JWCRR, Faculty of Medicine and Health, The University of Sydney, Kolling Institute of Medical Research, NSW, Australia; Fellow, College of Clinical Psychologists, Australian Psychological Society.

Jane Duff, PhD, Consultant Clinical Psychologist and National Spinal Injuries Centre Head of Clinical Psychology, Department of Clinical Psychology, Stoke Mandeville Hospital, Buckinghamshire Healthcare NHS Trust, Mandeville Road, Aylesbury, UK

James Middleton, PhD, Professor of Rehabilitation Medicine, JWCRR, Faculty of Medicine and Health, The University of Sydney; NSW, Australia; Clinical Director, State SCI Service, NSW, Senior Medical Specialist, Spinal Outreach Service, NSW.

Learning objectives

1. Review the latest evidence on the extent of psychological distress and disorder in people with SCI
2. Describe sources and triggers of distress and strategies used to manage them.
3. Describe translational strategies for managing distress in the UK and NSW, Australia

Outline of the Course

Speaker 1: Ashley Craig: (20 minutes plus 5 minutes questions)

1. Evidence from meta-analysis and prospective data on extent of psychological distress in adults with a SCI will be presented, including information on psychological disorder and co-morbidities.
2. Based on the SCI Adjustment Model, strategies for managing distress will be discussed that can be used by multi-disciplinary staff working in SCI rehabilitation/community settings.

Speaker 2: Jane Duff (20 minutes plus 5 minutes questions)

Evidence for strategies used in UK and presentation will include:

1. A case study of psychological assessment of mood and appraisals with cognitive intervention supporting an individual's and family adjustment during inpatient SCI.
2. The presentation will include group data and interim results from community follow-up psychological assessments up to 2-years post injury. Recommendations for enhancing psychological preparedness and transition support from inpatient admission will be included.

Speaker 3: James Middleton: (20 minutes plus 5 minutes questions)

1. Evidence from an extensive national survey will be presented to describe the lived experience and how people are managing their SCI.
2. Expanding on this evidence, strategies employed by the New South Wales Spinal Outreach Service (covering urban and rural areas) to assist in managing distress will be explored.

Summary (15 minutes)

Discussion will focus on when strategies can best be used, with takeaway tips for managing distress.

The following papers are recommended:

Craig, A., et al. (2015). A prospective study of the occurrence of psychological disorders and co-morbidities following spinal cord injury. *Archives Physical Medicine Rehabilitation*, 96, 1426-1434.

Duff, J. and Kennedy, P. (2003). Spinal Cord Injury. In S. Llewelyn & P. Kennedy *Handbook of Clinical Health Psychology*. (pp 251-275). Chichester: Wiley and Sons.

Eaton, R., et al., (2018). Cognitive appraisals and emotional status following a spinal cord injury in post-acute rehabilitation. *Spinal Cord*, 56, 1151–1157

Material for participants

Any level is suitable

Target audience

This instructional workshop will be of interest to health professionals who are involved in the rehabilitation of people with SCI, in inpatient or community settings.

The Biopsychosocial Approach to Sexual Rehabilitation for the Health Care Professional

Dr Stanley Ducharme¹, Dr. Stacy Elliott²

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The Biopsychosocial Approach to Sexual Rehabilitation for the Health Care Professional

Stanley Ducharme, Ph.D.

Stacy Elliott, MD

The importance of sexual health as an integrated part of spinal cord injury rehabilitation has been well documented over the last two decades. Multiple studies have demonstrated that this aspect of rehabilitation is one of the greatest concerns for people with spinal cord injury but yet remains one of the most neglected areas. Often, health care providers identify themselves as having little knowledge of the topic, are embarrassed or feel that it is the responsibility of the person with the disability to raise the topic. Yet, time and time again people with spinal cord injury have expressed their desire and need for their health providers to take the initiative in raising the topic. This insures the patient that sexuality, pleasure and reproduction are legitimate concerns in rehabilitation and appropriate areas for questions, education and counseling.

Sexuality is a multidimensional concept that encompasses cultural, social, psychological, physical and relational qualities. It evolves and changes through the developmental life of the individual and is not constricted by disability, gender, age, sexual orientation or sexual expression. Like all activities of daily living, it is a natural expression of who we are and how we relate to ourselves and to other people. Given the fluidity and complexity of the issue, no single discipline can manage the entirety and totality of an individual's sexual questions, needs and inquiries. We are each constrained by our individual experiences, values and the confines of our chosen professional disciplines. Thus, addressing sexual health in spinal cord injury rehabilitation requires a multi-disciplinary approach in which discipline specific goals are identified and addressed within the context of team case conferences and multi-disciplinary rounds. To meet the needs of the patient in these areas, we must all work in unison with one another.

This instructional course is based on the concept that all members of the rehabilitation team have a role in assisting the person with a spinal cord injury, and their partner, in adjusting to the sexual changes after such an injury. Using a Sexual Rehabilitation Framework (SRF), specific issues of the person with a spinal cord injury can be addressed by the most appropriate team member who has expertise in this area. In addition to introducing the Sexual Rehabilitation Framework, this course will also explore the interface of culture and sexuality as well as the particular details of sexual education and counseling. In this regard, questions such as when, what and how specific sexual and fertility related topics should be introduced to the patient and partner will be discussed.

40 Minutes, Ducharme- Cultural Issues and Practical Strategies to Sexuality Counseling and Education

40 Minutes, Elliott-Multidisciplinary Approach to Sexual Education

The Troublesome Trio of Spasticity: Clonus, Spasms, Stiffness – Attributes, Pathophysiology, and Non-Pharmacologic Management

Prof Edelle Field-Fote¹, Dr Steven Kirshblum²

¹Shepherd Center, Crawford Research Institute, Atlanta,, United States, ²Kessler Institute for Rehabilitation, West Orange,, United States

Spasticity is one of the most prevalent and problematic secondary conditions experienced by persons with spinal cord injury (SCI). It is reported by a majority of those with chronic SCI, and usually develops within the subacute phase following injury. There are several neurophysiologic mechanisms that account for the development of spasticity, and there is some evidence that spasticity may share some mechanisms in common with neuropathic pain. There are multiple definitions of spasticity, some of which have a limited relationship with the way this phenomenon is experienced by persons with SCI. For example, hyperactive stretch reflexes (ie, clonus) are rarely the reason individuals with SCI seek treatment. While the clinical presentation of spasticity varies from person to person, stiffness and spontaneous spasms are more likely to be the characteristics cited as problematic. While spasticity can have a detrimental influence on function and quality of life, it can be associated with some benefits, such as preservation of muscle mass, postural support, or triggering a spasm to assist with limb movement. Investigators at six SCI Model System Centers in the United States collaborated on a survey study to identify what features are most problematic and whether there are patient-reported beneficial aspects. Survey results from over 1,200 individuals with SCI will be presented, along with a discussion of current theories related to the underlying mechanisms, and recent evidence regarding physical therapeutic interventions that are promising for the management of spasticity after SCI.

Course Outline (90 mins):

20 min: definitions of spasticity, why definitions matter, and the qualities of spasticity as characterized by individuals with SCI (Kirshblum)

20 min: relationship between self-reported spasticity, and perceived functional and quality of life measures (Kirshblum)

20 min: physiologic mechanisms of spasticity (inhibitory modulation, Cl⁻ disequilibrium, 5HT receptors) (Field-Fote)

20 min: promising physical therapeutic interventions for spasticity management (Field-Fote)

10 min: Open Forum

Systematic reviews of intervention research: an introduction to the essentials (Presented on behalf of the journal: Spinal Cord)

Prof. Lisa Harvey¹, Dr Marcel Dijkers²

¹University of Sydney, Sydney, Australia, ²Wayne State University, Detroit, USA

Overview:

This instructional workshop will provide a summary of the essential aspects of systematic reviews. It should be of interest to those who read and conduct systematic reviews. The focus will be on key methodological issues related to defining the purpose of a systematic review, finding the relevant studies, and extracting and pooling data. Time will be allocated throughout the workshop for questions and discussion.

Plan:

15 mins

Speaker: Lisa Harvey

- Why systematic reviews?
- The dangers of merely paraphrasing authors' results'/conclusions or p values
- Defining the aim/scope of a systematic review in terms of a PICO or similar statement
- The protocol
- PROSPERO

5 mins

Discussion and questions

20 mins

Speaker: Marcel Dijkers

- Finding primary studies: search strategies
- The cull process
- Rating included trials for bias
- The file drawer problem and funnel plots

5 mins

Discussion and questions

20 mins

Speaker: Lisa Harvey

- Extracting data
- Introduction to meta-analysis and forest plots

5 mins

Discussion and questions

15 mins

Speaker: Marcel Dijkers

- PRISMA and AMSTAR II
- Getting your systematic review published in Spinal Cord

5 mins

Discussion and questions

Using SCI-QOL to Guide Ongoing Care and Improve Outcomes in SCI

Dr David Tulsy¹, Dr Sara Ahmed², Dr Susan Bartlett², Ms. Pamela Kisala¹, Dr. Allen Heinemann^{3,4}

¹University Of Delaware, Newark, United States, ²McGill University Faculty of Medicine, Montreal, Canada, ³Shirley Ryan AbilityLab, Chicago, USA, ⁴Northwestern University Feinberg School of Medicine, Chicago, USA

Patient-centered spinal cord injury (SCI) care focuses on outcomes that are meaningful to people living with SCI and their families. Use of patient-reported outcome measures (PROMs) is a key element of patient-centered care that captures symptoms, experiences, and function in day-to-day life from the perspectives of patients to assess health and monitor treatment progress. PROMs also facilitate the discussion of patient needs, preferences, and values to guide shared decision-making.

While PROMs are increasingly used for monitoring patient outcomes and to guide and evaluate care across many chronic health conditions, uptake has been slow in SCI care. Part of the challenge is in identifying what to measure, and how to measure outcomes in ways that account for language and cultural differences and are minimally burdensome to patients and providers. PROMs used in diverse patients (e.g., languages, cultures) and settings also must have evidence of the relevance and validity of PROMs (i.e., “fit for purpose”). Over the last 17 years, a state-of-the-science measurement system has been developed for SCI research known as SCI-QOL. SCI-QOL measures 22 aspects of physical, emotional, and social health. There is growing interest in using SCI-QOL in ongoing SCI care. Recently, this team of presenters has received 5 different grants from foundations in the US and Canada to prepare these measures for full integration into SCI clinical practice.

This instructional course will describe research from four grants funded by the Craig H. Neilsen Foundation work examining the feasibility, effectiveness, and sustainability of implementing SCI-QOL PROMs as part of ongoing care in diverse clinical settings. Our diverse, international group of presenters will highlight our work to identify barriers and facilitate implementation of SCI-QOL across different health care systems and settings. Dr. David Tulsy will be presenting the US collaborators' work, including how actionable cut points have been identified for SCI-QOL scales assessing Mobility, Self-Care, Bladder and Bowel Management, Depression, Anxiety, Resilience, and Participation in Social Roles and Activities, attempts to integrate into a clinical rehabilitation setting, and use in self-monitoring/self-management applications [35 minutes]. Drs. Sara Ahmed and Susan Bartlett will discuss efforts to integrate SCI-QOL in SCI clinical care in three Canadian provinces, including efforts to translate SCI-QOL measures into French and compare their performance with English versions [35 minutes]. Throughout these four studies, integrated participatory action approaches have been used to engage patients, families, clinicians, patient advocacy groups, and decision makers at every step of the research process. The course will conclude with a discussion of the benefits of using PROMs in real world settings to improve patient self-management, outcomes, and satisfaction; patient-clinician communication, and shared decision making; and clinical team satisfaction, function, workflow [Discussant: Dr. Denise Tate, 20 minutes].

DISCLOSURES: This work is funded by the Rick Hansen Institute and the Craig H. Neilsen Foundation. Dr. Tulsy holds copyright of the SCI-QOL but the measures are free and Dr. Tulsy does not receive any financial remuneration for this copyright. Drs. Tulsy and Ahmed are on the board of the PROMIS Health Organization but do not receive compensation.

Pulmonary Infections as Outcome Modifying Factors after Spinal Cord Injury – Mechanisms and Objective Markers of Neurogenic Immune Depression and Definition of Infections for Acute Management and Clinical Research

Dr Marcel Kopp^{1,2}, Prof. James Guest³

¹Department of Neurology & Experimental Neurology Charité - Universitätsmedizin Berlin, Berlin, Germany, ²Berlin Institute of Health, QUEST – BIH Center for Transforming Biomedical Research, Berlin, Germany, ³The Miami Project to Cure Paralysis, Miami, USA

1) Marcel Kopp - Mechanisms and objective markers of the Spinal Cord Injury-induced Immune Deficiency Syndrome (SCI-IDS) and the impact of infections on outcome after SCI (20 min + 5 min questions)

Respiratory infections are a prevalent and major cause of death during acute care and also in the chronic stage after SCI. The SCI-IDS facilitates the development of infections through decreased host defenses correlated to the neurological level and injury severity independent of other risk factors for pneumonia such as mechanical ventilation¹. Pneumonia acquired during acute care and the first inpatient rehabilitation after SCI is recognized as an outcome modifying factor associated with poorer long-term neurological and functional recovery and a constant increase in mortality.² The SCI-IDS can be objectified by laboratory markers such as HLA-DR expression on monocytes that is significantly decreased after complete or cervical SCI as compared to vertebral trauma patients without SCI. HLA-DR is a key molecule involved in antigen presentation critical for the induction of a specific immune response.

2) James Guest – Epidemiology of infections as prevalent SCI associated complications and challenges for comparative clinical research (20 min + 5 min questions)

Given the limited numbers of subjects enrolled to randomized controlled trials on SCI, observational studies are important to gain sufficient data for clinical research. Prospectively designed registries and observational studies can capture the multiplicity of acute care complications, e.g. the North American Clinical Trials Network, Rick Hansen SCI Registry. Data from these sources have contributed to understanding the epidemiology and clinical relevance of acute care complications.³ However, defining infections may require disease specific approaches as exemplified by consensus recommendations for stroke associated pneumonia. The definition and diagnosis of SCI-associated pneumonia in SCI will be discussed: Are definitions based on clinical criteria, decisions made by clinicians, or diagnostic codes such as ICD-10? How does the data source (administrative versus clinical data) influence the reported incidence and accuracy? Establishing consistent standards for the diagnosis and care of pulmonary complications is essential to improve the quality of SCI-specific pulmonary management, evaluation of treatment efficacy and future clinical studies on immune therapies.

3) James Guest and Marcel Kopp – Expert discussion: Available options for prevention and therapy of pulmonary infections and future targets for immune therapies (20 min + 5 min questions)

We review the evidence for current measures for prevention of respiratory infections such as contact precautions, circumstances of vulnerability (e.g. intubation, mechanical ventilation), the use of antibiotics,

and strategies to reduce the individual SCI patient's susceptibility. In addition, we provide a perspective on current research on immune therapies aiming to modulate the SCI-IDS.⁴

4) Participants and speakers: General discussion (15 min)

Interactive discussion in order to develop an interdisciplinary perspective on how future SCI research, clinical decision-making and medical care regarding pulmonary infections can be improved.

References:

1. Prüss H et al., 2017. *Nature Neurosci* 20:1549-59.
2. Kopp, MA et al. 2017. *Neurology* 88:892-900.
3. Grossman RG et al. 2012. *J Neurosurg Spine* 17:119-128.
4. Noble BT et al. 2018. *J Neuroimmunol* 321:1-11.

Women with SCI and Conditions that Impact Fertility

Dr Amie McLain¹, Dr. Marcalee Alexander², Nora Sandholdt Sandholdt³, Erika Nilsson³

¹University Of Alabama At Birmingham, Birmingham, United States, ²Veterans Administration of Birmingham Alabama, Birmingham, United States, ³Karolinska Institutet, Stockholm, Sweden

As the number of women with Spinal Cord Injury (SCI) has increased over the years, a much-needed focus on fertility of these women has emerged. The changes that a woman undergoes neurologically may have an influence on her sexual function, reproductive health, pregnancy and psychosocial health. Furthermore, acute and long-term neural responses to traumatic SCI are affected by the female reproductive neuro-endocrine system.

The evolution of a female's fertile life covers about 30 years in which a woman can become pregnant. These years can be divided into stages consisting of Stage 1: Early Reproductive, Stage 2: Peak Reproductive, Stage 3: Late Reproductive, Stage 4: Early Perimenopausal, and Stage 5: Late Perimenopausal. All stages may be impacted by the changes that an SCI has on a woman. Depending on the age of the woman and the time in her life that she sustained an SCI, providers should be prepared to offer advice on pre- and post-conception. This instructional course will review the state-of-the art research of the impact of SCI on the female's continuum of becoming pregnant and having children.

I. Sexual Function: (25 minutes) Marcalee Alexander, MD

SCI has a significant impact on sexual behavior and function in women. Participation in sexual intercourse decreases after SCI. Reasons for this are multifactorial and related to SCI dependent physiological and psychological issues.

II. Pregnancy, Labor and Delivery: (25 minutes) Amie (Jackson) McLain, MD

Reproductive health and disability affect each other in such a way that the conditions of pregnancy and SCI must be managed together. A woman's fertility may not be directly affected after SCI but other age-related issues are relevant as women with SCI are at later fertility stages than ablebody women when the decision is made to become pregnant. Obstetrical conditions including labor and delivery, can have unique challenges due to the sequela of SCI.

III. Fertility, Having Children, and Lactation: (25 minutes) Nora Sandholdt and Erika Nilsson

These experts will discuss Sweden's SCI-parenting project and their efforts to gather and spread knowledge about fertility, pregnancy and parenting with SCI. Since 2007 a wealth of information has contributed to the creation of networks online and IRL across Sweden. They have advocated the necessity of being an expert on your own body when living with a SCI and having health care issues. The goal has been to strengthen and support women with SCI and offer a platform as a model for the exchange of experiences.

IV. Questions/answers with panel.

Learning Objectives:

1. Describe how changes in sexual function after SCI may directly or indirectly affect a woman's ability to conceive.
2. Explain the way an SCI interferes with normal pregnancy and how pregnancy may exacerbate the secondary conditions from SCI.
3. List 4 ways mothers with SCI face challenges with parenting.
4. Give preconception information to women with SCI who are considering becoming pregnant and having children.

The Official Positions of the International Society for Clinical Densitometry: Indications for Bone Density Testing in Spinal Cord Injury

Dr Leslie Morse¹, Dr Cathy Craven², Dr. Fin Biering-Soerensen³, Dr. Therese Johnston⁴

¹University Of Minnesota School Of Medicine, Minneapolis, United States, ²University of Toronto, Toronto, Canada,

³University of Copenhagen, Copenhagen, Denmark, ⁴Jefferson University, Philadelphia, USA

Dr. Leslie Morse, DO (25 minutes) will review the results of a systematic review focused on indications for initial DXA, diagnosis of osteoporosis, and fracture risk prediction by DXA in SCI. She will present newly developed positions statements created by a task force and endorsed by the International Society for Clinical Densitometry.

Dr. Cathy Craven, MD (25 minutes) will review a protocol for determination of bone density by DXA at the distal femur and proximal tibia. She will present a newly developed calculator to determine T- and Z-scores at both regions that will be made publicly available.

Dr. Fin Biering-Soerensen, MD (25 minutes) will review the results of a systematic review focused on DXA to monitor response to therapy in SCI. He will present newly developed positions statements created by a task force and endorsed by the International Society for Clinical Densitometry.

Dr. Therese Johnston, PhD (25 minutes) will review the results of a systematic review focused on DXA based contraindications to weight-bearing therapies in SCI. She will present newly developed positions statements created by a task force and endorsed by the International Society for Clinical Densitometry.

15 minutes: Speakers will facilitate an audience discussion focused on implementation of these position statements into clinical practice and research protocols.

Trunk control in spinal cord injury: from evaluation to intervention

Dr Jimena Quinzaños¹, M Ing Isaac Pérez-Sanpablo Pérez-Sanpablo¹, Dr Ana Valeria Aguirre Guemez¹, Dr Eng Yannik Quijano¹, Dr Ramiro Pérez-Zavala¹

¹Instituto Nacional De Rehabilitación, Cdmx, Mexico

Spinal cord injury (SCI) results in alterations in the postural control system. It is well-known that an efficient postural control is of utter importance for standing and for walking, as well as for providing support to the voluntary movements during daily life activities. Furthermore, trunk stability has been identified as the third most important achievement in treatment that can substantially improve the patient's quality of life.

Learning Objectives:

- To describe trunk control alterations in SCI and to identify the advantages and disadvantages of the most used evaluation tools (clinical and instrumented).
- To learn application of a validated clinical trunk control test as an evaluating and predicting tool for gait and independence in SCI.
- To recognize some finished and on-going research about interventions to improve trunk control in spinal cord injury.
- To plan a research line using as example the one we have built on trunk control in SCI and start a collaboration network.

Description:

A brief revision of the trunk control alterations in SCI will be carried out as introduction.

A comprehensive description of the most used clinical and instrumented evaluation tools focusing on advantages and disadvantages depending on the objectives of the evaluation will be carried out. A systematic review of the interventions to improve trunk control in spinal cord injury will be presented then. Finally, to conclude we will share the design and results of our research line that includes the following studies:

- Proposal and Validation of clinical trunk control test in individuals with spinal cord injury (published article, Spinal Cord, 2014).
- Trunk control test as an early predictor of gait and independence in individuals with spinal cord injury (published article, Journal of Spinal Cord Injury, 2018).
- Validation of the instrumented evaluation of trunk control in individuals with spinal cord injury (on revision)
- Effect of training in a kayak ergometer on trunk control, independence and cardiovascular function in individuals with spinal cord injury (on-going research).

An Interactive, Professionally Curated, Website for People Living with SCI, as well as Health Care Professionals, to Guide the Selection of Specific SCI Clinical Trials (<https://SCITrialsFinder.net>)

Ms Jane Hsieh³, Dr Daniel Lammertse², Prof John Steeves¹, Ms Linda Jones⁴

¹ICORD, UBC & Vancouver Coastal Health, Vancouver, Canada, ²Craig Hospital, Englewood, USA, ³Wings for Life, Salzburg, Austria, ⁴University of Colorado, Boulder, USA

Over the past 15 years (Steeves et al. 2004. *Spinal Cord*, 42: 591), there has been a concerted effort to provide guidelines for the effective translation of preclinical findings to human clinical trials. While much progress has occurred, there are still continuing challenges to define more effective study designs, enhance participant recruitment, and improve accurate study outcome endpoints. Recent 2016 meetings in Canada and Switzerland galvanized an international group of scientists and clinicians, with backing from several SCI Foundations, to update and extend the SCI clinical trial guidelines first published in 2007. A recent series of peer-reviewed papers have been published and a summary of the findings will be presented by Jane Hsieh (15 minutes).

In addition, it was agreed that the current clinicaltrials.gov website is inadequate to the needs of people living with SCI looking to understand and participate in clinical studies appropriate to their injury, as well as most health care professionals charged with advising consumers on options for improving their functional outcomes. Dan Lammertse will recap the recent history and expansion of SCI clinical study efforts. He will also outline the development of more effective formats for understanding those trials listed on clinicaltrials.gov, leading to the SCOPE tables for clinical investigators and the need to develop a website for consumers where the essential information about trial interventions is explained in simple lay-person language (20 minutes).

John Steeves will provide the audience a tour of the new interactive website (SCITrialsFinder.net) outlining the features available to people living with SCI, as well as all Health Care Professionals. SCITrialsFinder.net will enable a person to understand what each trial is about, what are the eligibility criteria for participation, and what is required of a participant during the study. He will explain the curation process and interactive algorithms that enable a person living with SCI to directly review only those studies that are appropriate to their interests, their level and severity of SCI, as well as the time since their injury. The SCITrialsFinder.net website also facilitates easy (one click) application to the study investigators of any trial that an individual might qualify for participation (25 minutes).

Linda Jones will then lead the audience in a discussion of the SCITrialsFinder.net website to understand any difficulties that might occur while navigating the website, as well as how it might be best disseminated and developed further. Feedback from all instructional course participants is important for the effective development of this tool. (30 minutes).