

The Howard H. Steel Course on Pediatric Spinal Cord Injury/Dysfunction

Provided by the Steel Assembly | 2018 ISCoS Meeting Pre-Course
Wednesday, September 12TH | Sydney, Australia

Poster Directory

*Presenting Author

Longitudinal Outcomes

Poster Abstract # 2348

10 Year Experience Of Intra-Detrusor Botulinum Toxin Type A Injections In Children And Young People With Neurogenic Detrusor Over-Activity Following Spinal Cord Injury – Is It A Long Term Management Solution?

Sarah Louise Knight, MA, MSc, PhD; Natasha Wallace, RN*; Angela Gall, MB, BS; Frank Lee, MD; Rizwan Hamid, MD

Poster Abstract # 2355

Long Term Physical, Psychosocial, Participation Outcomes And Burden Of Disability In Childhood Onset Transverse Myelitis

Jodie Thompson, BN*; Kathryn Banerjee, MBChB, MRCPCH, MSc, FAFRM; Karen Burton, Bach of Psy, Mast of Clinical Neuropsychology; Anne Marie Sarandrea, Bachelor and Masters Degree in Clinical Psychology

Poster Abstract # 2370

Quality Of Sleep And Psychosocial Functioning In Pediatric-Onset Spinal Cord Injury

Alicia M. January, PhD*; Kathy Zebracki, PhD; Kathy Chlan, BA; Lawrence C. Vogel, MD

Measurement and Outcomes

Poster Abstract # 2346

Appraisals Of Disability In Middle Adulthood Following Pediatric-Onset Spinal Cord Injury

Kathy Zebracki, PhD*; Kathy Chlan, BA; Paul Kennedy, D.Phil, MSc, FBPsS, C.Psychol; Lawrence C. Vogel, MD

Psychosocial and Environmental

Poster Abstract # 2340

Barriers in Accessing Adult Healthcare for Transitioning Youth with Spinal Cord Injury

Kathy Zebracki, PhD*; Alexander Porto, BA; Lara Anderson, Student; Lawrence C. Vogel, MD

Poster Abstract # 2381

Self-Report Of Happiness In Adults With Pediatric-Onset Spinal Cord Injury

Kyle C. Deane, PhD*; Kathy Chlan, BA; Lawrence C. Vogel, MD; Kathy Zebracki, PhD

Rehabilitation and Rehabilitation Research

Poster Abstract # 2363

Spinal Cord Injury In The Pediatric Population - An International Multicenter Study In Norway, Sweden, China, Usa, Russia, Israel And Palestine

Kirsti Skavberg Roaldsen, PhD*; Vivien Jørgensen, PhD; Susanne Sällström, MSc; Peter New, MBBS, Mst Clin Epi, PhD, FAFRM (RACP); Johan Stanghelle, Prof.; Marika Augutis, PT/PhD

Poster Abstract # 2378

Organizing A Pediatric Sci Follow-Up In Sweden

Marika Augutis, PT/PhD*; Eva Sandvall, MD; Per Ertzgaard, MD

Spine

Poster Abstract # 2377

Is Autonomic Dysreflexia A Cause Of Respiratory Dysfunction After Sci?

Kirsti Skavberg Roaldsen, PhD*; Vivien Jørgensen, PhD; Susanne Sällström, MSc; Maria J. Andrade, PhD*; Filipe Quintas, MD; André Silva, MD; Patrícia Cruz, MD

The Howard H. Steel Course on Pediatric Spinal Cord Injury/Dysfunction

Provided by the Steel Assembly | 2018 ISCoS Meeting Pre-Course
Wednesday, September 12TH | Sydney, Australia

Poster Abstracts

*Presenting Author

10 Year Experience Of Intra-Detrusor Botulinum Toxin Type A Injections In Children And Young People With Neurogenic Detrusor Over-Activity Following Spinal Cord Injury – Is It A Long Term Management Solution?

Poster Abstract # 2348

Sarah Louise Knight, MA, MSc, PhD; Natasha Wallace, RN*; Angela Gall, MB, BS; Frank Lee, MD; Rizwan Hamid, MD

London Spinal Cord Injury Centre, Royal National Orthopaedic Hospital
Stanmore, Middlesex UNITED KINGDOM

Summary: 10 year experience of intra-detrusor botulinum toxin injections for neurogenic detrusor over-activity in pediatric spinal cord injury.

Data:

Introduction:

Intra-detrusor injections (IDI) of botulinum toxin type A (BTXA) have been used for many years in the management of patients with neurogenic detrusor over-activity (NDO). There is anecdotal evidence to suggest that the duration of effect reduces with time in adults. However, there is a paucity of data relating to the long term use of IDI in children and young people (CYP) with NDO. In this study we present 10 years of follow up of CYP who have received IDI of BTXA subsequent to spinal cord injury (SCI). The aim of the study was to investigate whether IDI of BTXA is an effective and tolerated long term management solution.

Methods:

The study was a retrospective analysis of the clinical records of CYP in a Spinal Cord Injury Centre (SCIC) who have received IDI of BTXA as part of bladder management for NDO.

Results:

20 CYP's (8 female and 12 male) were identified from discharge summaries of the SCIC. The mean current age is 16.6 (range 2-26) years with mean age at injury 8.35 (range 0-15) years and mean time since injury 7.85 (range 2-20) years IDI of BTXA were administered through a paediatric cystoscope under general anaesthesia. Onabotulinum toxin type A (50-300 units) and abobotulinum toxin type A (200-750 units) were used based on child's weight and previous efficacy. The injections were distributed equally around the bladder avoiding the trigone. The mean age at first injection was 11.25 (range 6-19) years. The mean number of repeat injections to date is 3.85 (1-12). The maximum follow up is 120 months. The initial results (after 1 or 2 injections) were satisfactory for the majority of the patients based on urodynamics results and patient reporting. Three patients were not re-treated after the first injections either due to inefficacy or patient choice. A further 2 discontinued treatment after 2-5 injections. Patients who have received more than 5 repeat injections reported decreasing efficacy of treatment with shorter duration of effect and increased incontinence. In patients who have received more than 5 repeat injections, the dose has gradually increased to the maximum permitted dose, and the frequency of injection has increased from annually to every 6 months. 2 patients have been offered bladder reconstruction surgery due to inefficacy; a further 3 patients are continuing with IDI of BTXA. The 2 patients who have received more than 10 injections both reported that the treatment has reduced duration of effect with increased incontinence and smaller capacity. One (performing IC) has been offered bladder augmentation (ileocystoplasty) and one (using SPC) is continuing but at the highest dose, and more frequent intervals.

Intra-detrusor injections of botulinum toxin type A are effective in the short term in children and young people with NDO after SCI. However, we have shown that the duration of effect appears to diminish with repeated injections suggesting that this treatment may not provide a long term solution for CYP.

The Howard H. Steel Course on Pediatric Spinal Cord Injury/Dysfunction

Provided by the Steel Assembly | 2018 ISCoS Meeting Pre-Course

Wednesday, September 12TH | Sydney, Australia

Long Term Physical, Psychosocial, Participation Outcomes And Burden Of Disability In Childhood Onset Transverse Myelitis

Poster Abstract # 2355

Jodie Thompson, BN*; Kathryn Banerjee, MBChB, MRCPCH, MSC, FAFRM; Karen Burton, Bach of Psy, Mast of Clinical Neuropsychology; Anne Marie Sarandrea, Bachelor and Masters Degree in Clinical Psychology

The Children's Hospital at Westmead
Sydney, NSW AUSTRALIA

Summary: This study aims to examine the impact of transverse myelitis on participation in leisure and academic activities. It further seeks to understand the impacts in terms of pain, fatigue, levels of functioning and psychological difficulties, and their relationship to participation after childhood transverse myelitis.

Data: Transverse myelitis is a rare, immune-mediated inflammatory disorder which causes demyelination of the spinal cord. It affects approximately 2 children in every million under the age of 16 years.

Although there is a clear literature about the physical sequelae of childhood transverse myelitis, the psychosocial and participation outcomes have not been investigated.

This study aims to understand the impact on individuals in terms of pain, fatigue, levels of functioning and psychological difficulties, and their relationship to participation in leisure and academic activities after childhood transverse myelitis.

This study aims to delineate more clearly the wider longitudinal outcomes of transverse myelitis in the paediatric age group.

Data will be collected in the coming months by telephone, questionnaires and clinical notes review on patients aged 5-18 years admitted to The Children's Hospital at Westmead, a tertiary specialist paediatric facility with a diagnosis of Transverse Myelitis between 2007 - 2017.

Data collected will include information gathered using the :

- * Weefim (Functional Independence Measure for Children)
- * Strengths and Difficulties Questionnaire (Goodman, 1997, 1999)
- Peds-QL Paediatric Quality of Life Inventory (Varni, 2014; Varni, Burwinkle, & Szer, 2004)
- * Pain Questionnaire developed by the investigators incorporating a Body Chart published by Grunenthal Ltd and the Faces Pain Scale-Revised from the International Association for the study of Pain (IASP; Bieri, Reeve, Champion, Addiocat, & Zeigler, 1990; Hicks von Bayer, Spafford, van Korlaar, & Goodenough, 2001)
- * Bladder and Bowel Function Questionnaire developed by the investigators
- * Participation Survey developed by the investigators
- * Demographic and medical history information.

Using validated tools such as the Weefim and Peds-QL may allow us to make comparisons between other patient groups. The pain, bladder and bowel and participation questionnaires will help to further enhance our understand of the longitudinal outcomes of this patient group.

The Howard H. Steel Course on Pediatric Spinal Cord Injury/Dysfunction

Provided by the Steel Assembly | 2018 ISCoS Meeting Pre-Course
Wednesday, September 12TH | Sydney, Australia

Quality Of Sleep And Psychosocial Functioning In Pediatric-Onset Spinal Cord Injury **Poster Abstract # 2370**

Alicia M. January, PhD*; Kathy Zebracki, PhD; Kathy Chlan, BA; Lawrence C. Vogel, MD

Shriners Hospital for Children
Chicago, IL UNITED STATES

Summary: Sleep quality gets worse over time for individuals with pediatric-onset SCI and is associated with decreases in psychosocial functioning and well-being.

Data:

Objectives: To examine change in sleep quality over time for adults with pediatric-onset spinal cord injury (SCI) and to identify clinical and demographic characteristics associated with sleep-related difficulties.

Methods: The study included 151 adults who sustained a SCI prior to age 19 (M=13.4, SD=4.7; 0-18). Participants had been injured for an average of 18.9 years (SD=7.8; Range 2-41). Average age at baseline was 32.8 (SD=6.8; Range 19-48). Participants completed interviews on an approximately annual basis, for a total of 580 interviews (range 2-7). Interviews included questions on demographic information, injury characteristics, and health problems experienced within the previous year. Participants also completed standardized measures of sleep quality, depression, anxiety, life satisfaction, and perceived mental and physical health. Analyses were conducted utilizing mixed effect models to explore sleep quality across time.

Results: Participants tended to have complete injuries (AIS A, 72%) and tetraplegia (58%), and were predominantly male (66%) and Caucasian (82%). Average sleep scores at initial status were above the cutoff for "poor" sleep quality (M=6.25, SD=3.75) and scores increased significantly over time ($p=.012$). Several factors emerged as significant predictors of poor sleep quality including tetraplegia ($p=.01$), age ($p<.01$), presence of another chronic medical condition ($p<.01$), and unemployment ($p=.04$). Additionally, within individuals, as depression and anxiety symptoms increased sleep scores worsened ($p<.01$). Similarly, increases in perceived physical health ($p<.01$), perceived mental health ($p<.01$), and life satisfaction ($p<.01$) resulted in improved sleep scores for individuals.

Conclusion: Overall, the results from the current study suggest that average sleep quality gets worse over time for individuals with pediatric-onset SCI. Further, decreases in psychosocial functioning and well-being is associated with decreasing sleep quality. These findings underscore the importance of understanding the longitudinal course of sleep after pediatric SCI and highlight the need for future research exploring strategies to foster positive mental health and well-being.

Support: Shriners Hospitals for Children®-Chicago Grant #84202; Craig H. Nielsen Foundation #324671

The Howard H. Steel Course on Pediatric Spinal Cord Injury/Dysfunction

Provided by the Steel Assembly | 2018 ISCoS Meeting Pre-Course
Wednesday, September 12TH | Sydney, Australia

Appraisals Of Disability In Middle Adulthood Following Pediatric-Onset Spinal Cord Injury

Poster Abstract # 2346

Kathy Zebracki, PhD*; Kathy Chlan, BA; Paul Kennedy, D.Phil, MSc, FBPsS, C.Psychol; Lawrence C. Vogel, MD

Shriners Hospitals for Children
Chicago, IL UNITED STATES

Summary: This presentation reports on the ADAPSS SCI-specific appraisal scale to describe cognitive appraisals in individuals with pediatric-onset spinal cord injury during middle adulthood and the relationship between appraisals and demographic and injury-related factors which identifies those at-risk of maladaptive appraisals.

Data:

Objective: To describe cognitive appraisals in individuals with pediatric-onset spinal cord injury (SCI) during middle adulthood and examine the relationship between appraisals and demographic and injury-related factors.

Design/method: A cross-sectional survey of 112 individuals ages 35-51 (M=41.0, SD=5.1) who sustained an SCI prior to age 19 (M=14.1, SD=4.0; range=0-18) completed a structured telephone interviews. In addition to demographic and medical questionnaires, cognitive appraisals were assessed using Appraisal of Disability: Primary and Secondary Scale (ADAPSS). The ADAPSS is a 33-item SCI-specific appraisal scale that assesses individuals' initial evaluations of an event and their evaluation of their own coping strategies for dealing with this event. The scale consists of 6-factors; three negative: fearful despondency, overwhelming disbelief, negative perceptions of disability and three positive: determined resolve, growth and resilience, and personal agency. Higher levels of negative appraisals and lower levels of positive appraisals represent likelihood to appraise injury in terms of loss and threat and as unmanageable. At-risk groups are identified by the highest category of the negative appraisals and the lowest category of the positive appraisals.

Results: Overall, participants fell in normal to very good ranges for all factors with the strongest factor being very high levels of determined resolve, followed by low levels of negative perceptions of disability, fearful despondency, and overwhelming disbelief, and high levels of growth and resilience. The weakest factor was personal agency but still fell within the normal range. Participants at-risk for maladaptive appraisals were minimal for each group: 2/112 (1.8%) for fearful despondency, overwhelming disbelief, and personal agency; 1/112 (0.9%) for determined resolve; 0/112 at risk for growth and resilience; and 5/112 (4.5%) for negative perceptions of disability. Differences were seen in appraisals and level of injury with those with tetraplegia having significantly higher growth and resilience levels ($p=0.030$) but also significantly higher levels of negative perceptions of disability and lower levels of personal agency ($p=0.033$ and 0.047 , respectively) than those with paraplegia. Those with incomplete injuries had significantly higher levels of fearful despondency and overwhelming disbelief scores ($p=0.018$ and 0.016 , respectively) than those with complete injuries. There were no differences in appraisals found for age at injury, duration of injury, current age, gender, or race.

Conclusion: Overall, individuals in middle adulthood appraise coping to injury as manageable. However, there are subgroups of individuals who are at-risk of maladaptive appraisals, including those with tetraplegia or incomplete injuries. Cognitive behavior therapy is recommended to address maladaptive appraisals and consequently, improving coping and reducing risk for symptoms of depression and anxiety.

Support: Shriners Hospitals for Children-Chicago and Craig H. Neilsen Foundation #324671

Barriers in Accessing Adult Healthcare for Transitioning Youth with Spinal Cord Injury

The Howard H. Steel Course on Pediatric Spinal Cord Injury/Dysfunction

Provided by the Steel Assembly | 2018 ISCoS Meeting Pre-Course
Wednesday, September 12TH | Sydney, Australia

Poster Abstract # 2340

Kathy Zebracki, PhD*; Alexander Porto, BA; Lara Anderson, Student; Lawrence C. Vogel, MD

Shriners Hospitals for Children
Chicago, IL UNITED STATES

Data: This presentation reports on the ADAPSS SCI-specific appraisal scale to describe cognitive appraisals in individuals with pediatric-onset spinal cord injury during middle adulthood and the relationship between appraisals and demographic and injury-related factors which identifies those at-risk of maladaptive appraisals.

Summary:

Objective: To describe cognitive appraisals in individuals with pediatric-onset spinal cord injury (SCI) during middle adulthood and examine the relationship between appraisals and demographic and injury-related factors.

Design/method: A cross-sectional survey of 112 individuals ages 35-51 (M=41.0, SD=5.1) who sustained an SCI prior to age 19 (M=14.1, SD=4.0; range=0-18) completed a structured telephone interviews. In addition to demographic and medical questionnaires, cognitive appraisals were assessed using Appraisal of DisAbility: Primary and Secondary Scale (ADAPSS). The ADAPSS is a 33-item SCI-specific appraisal scale that assesses individuals' initial evaluations of an event and their evaluation of their own coping strategies for dealing with this event. The scale consists of 6-factors; three negative: fearful despondency, overwhelming disbelief, negative perceptions of disability and three positive: determined resolve, growth and resilience, and personal agency. Higher levels of negative appraisals and lower levels of positive appraisals represent likelihood to appraise injury in terms of loss and threat and as unmanageable. At-risk groups are identified by the highest category of the negative appraisals and the lowest category of the positive appraisals.

Results: Overall, participants fell in normal to very good ranges for all factors with the strongest factor being very high levels of determined resolve, followed by low levels of negative perceptions of disability, fearful despondency, and overwhelming disbelief, and high levels of growth and resilience. The weakest factor was personal agency but still fell within the normal range. Participants at-risk for maladaptive appraisals were minimal for each group: 2/112 (1.8%) for fearful despondency, overwhelming disbelief, and personal agency; 1/112 (0.9%) for determined resolve; 0/112 at risk for growth and resilience; and 5/112 (4.5%) for negative perceptions of disability. Differences were seen in appraisals and level of injury with those with tetraplegia having significantly higher growth and resilience levels ($p=0.030$) but also significantly higher levels of negative perceptions of disability and lower levels of personal agency ($p=0.033$ and 0.047 , respectively) than those with paraplegia. Those with incomplete injuries had significantly higher levels of fearful despondency and overwhelming disbelief scores ($p=0.018$ and 0.016 , respectively) than those with complete injuries. There were no differences in appraisals found for age at injury, duration of injury, current age, gender, or race.

Conclusion: Overall, individuals in middle adulthood appraise coping to injury as manageable. However, there are subgroups of individuals who are at-risk of maladaptive appraisals, including those with tetraplegia or incomplete injuries. Cognitive behavior therapy is recommended to address maladaptive appraisals and consequently, improving coping and reducing risk for symptoms of depression and anxiety.

Support: Shriners Hospitals for Children-Chicago and Craig H. Neilsen Foundation #324671

The Howard H. Steel Course on Pediatric Spinal Cord Injury/Dysfunction

Provided by the Steel Assembly | 2018 ISCoS Meeting Pre-Course
Wednesday, September 12TH | Sydney, Australia

Self-Report Of Happiness In Adults With Pediatric-Onset Spinal Cord Injury

Poster Abstract # 2381

Kyle C. Deane, PhD*; Kathy Chlan, BA; Lawrence C. Vogel, MD; Kathy Zebracki, PhD

Shriners Hospitals for Children
Chicago, IL UNITED STATES

Data: The objective of this study is to explore the self-report happiness in individuals who sustained SCI in childhood, as well as to identify the correlates of happiness relating to demographics, etiology, level of injury, and mental health.

Summary:

Introduction: While the negative psychological sequelae following a spinal cord injury (SCI) have been well-documented, individuals do not uniformly report deleterious outcomes. Indeed, the majority of individuals with pediatric-onset SCIs are psychologically resilient and report positive psychological growth (January, Chlan, Zebracki, & Vogel, 2015). The objective of this study is to explore the self-report happiness in individuals who sustained SCI in childhood, as well as to identify the correlates of happiness relating to demographics, etiology, level of injury, and mental health.

Methods: Structured telephone interviews were completed with a total of 234 adults who had sustained pediatric-onset SCI. Mean age of the participants was 36.41 years (SD = 7.73, range = 19-52). Sixty-three percent of the participants were male, 85% were white, 56% had tetraplegia, and 67% had complete injuries. Participants completed questionnaires relating to demographic information, nature of injury, and current mental health. Happiness was measured using the General Happiness Scale (GHS; Lyubomirsky & Lepper, 1999), a subjective measure of happiness. The GHS is comprised of 4 items ranging from 0 (not at all) to 7 (a great deal) for each item.

Results: Individuals in the current study reported a mean happiness level of 5.55 (GHS mean scores range 0-7; SD = 1.23). A one-way analysis of variance (ANOVA) and bivariate correlations were utilized to examine the relation between the variables under study. No significant associations were found between happiness and participant age, sex, ethnicity, education level, or employment status. Participant happiness was significantly and positively associated with life satisfaction ($r = .56, p < .001$) and posttraumatic growth ($r = .32, p < .001$). Happiness was negatively associated with depression ($r = -.43, p < .001$) and anxiety ($r = -.35, p < .001$). In terms of the nature of injury, there were no correlations between happiness and age of injury, completeness of injury, or injury level (tetraplegia or paraplegia). A one-way ANOVA was conducted to compare the effect of injury etiology on happiness across five etiology types: 1) vehicular/pedestrian, 2) violence, 3) fall/flying object, 4) sports, and 5) medical/surgical. There was a significant effect of etiology on happiness for the five conditions [$F(4, 229) = 3.99, p = .004$]. Post hoc comparisons using the Tukey HSD test indicated that the mean happiness scores for the fall/flying object form of injury ($M = 4.74, SD = 1.88$) was significantly lower than the vehicular/pedestrian ($M = 5.66, SD = 1.10$), violence ($M = 6.02, SD = .81$), and sports ($M = 5.68, SD = 1.18$), but did not significantly differ from medical/surgical etiology ($M = 5.09, SD = 1.23$).

Discussion: The majority of individuals with pediatric-onset SCI report high levels of happiness. Level of happiness does not appear to be related to a variety of clinical factors, such as completeness of injury, injury level, or age of injury. However, it appears that the nature of injury may contribute to happiness level, with vehicular/pedestrian, violence, and sports injuries constituting the highest levels. Those injured by a fall or flying object may be at increased risk for lower levels of subjective happiness.

Financial disclosure: this study is supported by Shriners Hospitals for Children, Chicago and Craig H. Neilsen Foundation, grant #324671.

The Howard H. Steel Course on Pediatric Spinal Cord Injury/Dysfunction

Provided by the Steel Assembly | 2018 ISCoS Meeting Pre-Course
Wednesday, September 12TH | Sydney, Australia

Spinal Cord Injury In The Pediatric Population - An International Multicenter Study In Norway, Sweden, China, Usa, Russia, Israel And Palestine

Poster Abstract # 2363

Kirsti Skavberg Roaldsen, PhD*; Vivien Jørgensen, PhD; Susanne Sällström, MSc;
Peter New, MBBS, Mst Clin Epi, PhD, FAFRM (RACP); Johan Stanghelle, Prof.; Marika Augutis, PT/PhD

Sunnaas Rehabilitation Hospital
Oslo, NORWAY

Summary: Spinal Cord Injury in the Pediatric Population - an international multicenter study in Norway, Sweden, China, USA, Russia, Israel and Palestine.

Data:

INTRODUCTION: Due to the low incidence of pediatric spinal cord injury (SCI) and the high demand for knowledge and research, international cooperation is needed to build a solid and shared understanding of the extent of the problem, and also uniformity in treatment and measurement methods. The aim of the study is to map organization of care and rehabilitation of children and adolescents <18 years of age with SCI, to explore qualitatively psychosocial aspects of individuals and to establish use of common outcome measures in 10 rehabilitation units from seven countries, cooperating within the Sunnaas International Network in Rehabilitation (SIN); China, USA, Russia, Israel, Palestine, Norway and Sweden.

METHOD: In Phase I of the project (2018-2019) two cross-sectional studies is conducted to set the scene for the outcome studies following in Phase II (2020-2022). Phase I consists of a quantitative descriptive study using a web-survey to describe and compare the systems of care and delivery of inpatient rehabilitation services for pediatric SCI patients. In addition, a qualitative study will explore the psychosocial aspects of living with a childhood acquired SCI. Two adolescents, aged 13-16 years and at least 6 months post-acute treatment, from each unit will interviewed using a semi-structured interview guide. Ethical approval has been applied for in each unit, and the study is registered at ClinicalTrial.gov. A workshop for the 24 study team members, where the main focus was to ensure that data collection is conducted in a good manner, was held in May 2018, and data collection is expected finalized by 2019. Phase II will consist of methodological outcome studies.

DISCUSSION: Phase I of the study will broaden the body of knowledge on pediatric SCI internationally, thus enabling comparison, discussion and development of organizational models and quality of care and rehabilitation for young persons with SCI. Phase II will contribute to the use of common and reliable outcome measures for these patients.

The Howard H. Steel Course on Pediatric Spinal Cord Injury/Dysfunction

Provided by the Steel Assembly | 2018 ISCoS Meeting Pre-Course
Wednesday, September 12TH | Sydney, Australia

Organizing A Pediatric Sci Follow-Up In Sweden

Poster Abstract # 2378

Marika Augutis, PT/PhD*; Eva Sandvall, MD; Per Ertzgaard, MD

Department of Rehabilitation Medicine and Department of Medicine and Health Sciences,
Linköping University
Linköping, SWEDEN

Summary: The challenge to provide follow-up for children with SCI when the injury is rare and the care is scattered.

Data: Spinal cord injury (SCI) is a medically complex condition, with large impact on functioning. Pediatric SCI is further complicated by issues related to ongoing physical and emotional growth that further impact the manifestation and complications. The incidence of pediatric traumatic SCI in Sweden is rare, 2.4/million children/year in the ages (0-15 years). The incidence of pediatric non-traumatic injuries is yet unknown in Sweden. However, we can approximate the prevalence to be around 75 children below 16 years living with sequel after a traumatic SCI. Care and rehabilitation in Sweden is decentralized and non-systematized. After initial care, children with SCI are referred to a nation-wide organization of Habilitation centers that provide services, typically for children with congenital conditions, mainly on an outpatient basis. A non-published survey requesting de-identified data from the Habilitations centers confirmed that pediatric SCI is rare and indicates that there is a need to centralize care, create national guidelines, improve cooperation with adult SCI care-providers in Sweden, and to increase collaboration between countries. This would likely benefit professionals but most important children with SCI and their families.

At the University Hospital of Linköping we have started a yearly follow-up program now including 12 children with SCI, but being open for referrals from all of Sweden. The program includes medical follow-up of all aspects of the SCI and specialists involved (including urology, neurosurgery, pediatric neurology, spine surgery, plastic surgery, hand surgery and pediatric orthopedics. In addition, focus is also put on parent education, peer to peer learning for the children and inspirational training/playing. The poster will present results and our experiences from the first two years of the follow-up program.

The Howard H. Steel Course on Pediatric Spinal Cord Injury/Dysfunction

Provided by the Steel Assembly | 2018 ISCoS Meeting Pre-Course

Wednesday, September 12TH | Sydney, Australia

Is Autonomic Dysreflexia A Cause Of Respiratory Dysfunction After Sci?

Poster Abstract # 2377

Kirsti Skavberg Roaldsen, PhD*; Vivien Jørgensen, PhD; Susanne Sällström, MSc;
Maria J. Andrade, PhD*; Filipe Quintas, MD; André Silva, MD; Patrícia Cruz, MD

Medical School, Instituto de Ciências Biomédicas Abel Salazar, Porto University, Spinal Cord Injury Unit, Department of Physical Medicine and Rehabilitation, Hospital Santo António, Porto Hospital Centre Porto, PORTUGAL

Summary: Spinal cord injury (SCI) often leads to an impairment of the respiratory system. Respiratory insufficiency is a significant cause of mortality and morbidity after SCI and is related to the extent and level of the neurologic injury and its effects on respiratory muscles. Less commonly recalled is the fact that autonomic dysfunction also plays a role.

Data:

Background: Spinal cord injury (SCI) often leads to an impairment of the respiratory system. In fact, respiratory insufficiency is a significant cause of mortality and morbidity after SCI and is related to the extent and level of the neurologic injury and its effects on respiratory muscles (reduction in respiratory muscle strength and fatigue with a reduction in inspiratory capacity, atelectasis and ineffective coughing). Less commonly recalled is the fact that autonomic dysfunction (as a result of parasympathetic imbalance) also plays a role by causing decreased mucociliary activity, bronchospasm and pulmonary oedema. It is not surprising that during an autonomic dysfunction such as autonomic dysreflexia (AD), parasympathetic compensation for a massive sympathetic response could lead to respiratory insufficiency. However, this is not described in medical literature, although breathing difficulty is named as a common symptom and sign.

Objective: To describe for the first time a clinical case, T4 AIS (American spinal injury association impairment scale) A in which AD leads to acute respiratory insufficiency.

Case report: A patient with a prior history of spinal cord injury since childhood, secondary to dorsal medulloblastoma, T4 AIS A, was admitted to the Inpatient Unit to improve her respiratory function and autonomy and to discontinue the ventilation that was maintained after an episode of pneumonia. During the rehabilitation programme, namely during hamstring stretching exercises, the patient developed AD. Beyond persistent hypertension, cutaneous rash, hyperhidrosis and light-headedness, she manifested acute respiratory insufficiency with desaturation and hypercapnia. The patient recovered totally from the AD signs and symptoms with the cessation of noxious stimulation and oxygen administration.

Conclusions: To date, the association between AD and acute respiratory insufficiency has not been described in spinal cord or rehabilitation literature. This case draws attention for the first time to the possibility of respiratory insufficiency being one of the signs associated with episodes of autonomic dysreflexia and highlights the need to look at this possibility. We wonder if the start of SCI in childbirth could contribute to this clinical picture.