

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

COURSE PROCEEDINGS

*Presenting Author

Keynote

Activity-based Therapy Targeting Neuromuscular Recovery after Pediatric Spinal Cord Injury

Andrea Behrman, PhD USA

Introduction and scientific tenets

The lens(es) with which we view the problem of paralysis

Foundation for physical rehabilitation after SCI

New knowledge and another lens

The smart spinal cord

Activity-dependent plasticity

Understanding the intrinsic biology and its principles

Accessing the smart spinal cord

Foundation for development of a new generation of therapies

Need for parallel outcome measures

Neuromuscular capacity as an objective and outcome

Adult Neuromuscular Recovery Scale (NRS) to Pediatric NRS

Ardolino et al. 2016

Segmental Assessment of Trunk Control (SATCo)

Butler et al. 2010, Argetsinger et al. 2017

Adults first, preliminary evidence in pediatrics

Translation to clinical practice and program of care

Clinical outcomes

Patient population

Clinical protocol

Outcomes

Parent report – meaningfulness of outcomes

Re-visiting the lenses with which we view the problem/challenge of paralysis

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International Data Sets and NINDS CDE: Overview and Application in Pediatric SCI **Vanessa Noonan, PhD CANADA**

This presentation will discuss the importance of data standards in SCI research and care. Specifically it will provide an overview of the International SCI Data Set project which was initiated in adult SCI in 2002 and the subsequent project led by the National Institute of Neurological Disorders and Stroke (NINDS) of National Institute of Health (NIH) to develop common data elements (CDEs) in 2006. The most recent work led by Mulcahey and colleagues to systematically review the utility and relevance of these data standards to children and youth (0 to 21 years) will be presented as well as the gaps identified from this work. Finally, the ongoing work to promote the implementation of these data standards in research and care across the lifespan will be discussed.

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Psychometric Examination of the International SCI Basic Caregiver Data Set and the International SCI Basic Bowel Data Set in Pediatric SCI **Lawrence C. Vogel, MD USA**

Background: The International SCI Data Sets were developed to capture the minimal amount of information to an individual's medical status and experience living with SCI. Revision of data sets such as the International SCI Basic Bowel Data Set Version 2.0 modified certain items in order to make them appropriate for children and youth. Because of the important role of caregivers in SCI, the International SCI Basic Caregiver Data Set Version 1.0 was developed.

Objective: Describe preliminary assessment of the reliability and validity of the International SCI Basic Caregiver Data Set Version 1.0 and the International SCI Basic Bowel Data Set Version 2.0 in Pediatric SCI.

Participants/Methods: Youth with SCI aged 7-17 years of age and who were at least 3 months post-discharge from initial rehabilitation and their caregivers. Individuals were interviewed on two separate occasions separated by at least 15 minutes by two different qualified clinical personnel; in the case of the International SCI Basic Bowel Data Set Version 2.0, a third administration was administered 12 -72 hours later.

Results: For both data sets, the test-retest reliability was good for most items (ICC: 0.53-1.00). For the International SCI Basic Bowel Data Set Version 2.0, the inter-method reliability was also good.

Conclusion: The results support the reliability of the International SCI Basic Caregiver Data Set and the International SCI Basic Bowel Data Set for Pediatric SCI.

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Illustration and Application of the International SCI Basic Education Data Set
Marika Augutis, PhD SWEDEN

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Development of a SCI Module for the Pediatric Quality of Life Inventory (PedsQL™)
Kathy Zebracki, PhD*; Lawrence C. Vogel, MD; MJ Mulcahey, PhD, OTR/L; James Varni, PhD

**Shriners Hospitals for Children
Chicago, IL UNITED STATES**

Summary: Development and Initial Validation of the PedsQL - SCI Module.

Data: Health-related quality of life (HRQOL) measures an individual's perceptions of the impact of their disease or disability and associated treatments on a variety of dimensions, including physical, mental, social, and academic domains. Measuring HRQOL in the pediatric population must take into account the tremendous changes in all spheres of life (physical, physiological, and psychosocial) as well as the various developmental changes throughout the different stages of childhood and adolescence.

For example, HRQOL in younger children may primarily focus on physical activities, whereas social roles and independence may be more appropriate for adolescents. In addition, measurement of HRQOL should be tailored to emerging adults (young adults aged 19 to 25) who are making the tumultuous transition from adolescence into adulthood. There are no reliable and valid measures of HRQOL for youth and emerging adults with pediatric-onset spinal cord injury (SCI).

Therefore, we aim to develop and validate the PedsQL- SCI Module for youth and emerging adults with SCI in order to monitor and to ultimately increase their HRQOL. A SCI-specific HRQOL measure is needed to address unique features of youth and emerging adults with SCI, providing greater relevance to patients and their caregivers, and with the ability to detect small, but clinically meaningful changes. We propose to develop the PedsQL-SCI Module which will be feasible, relevant, valid, and measure HRQOL longitudinally throughout childhood, adolescence and emerging adulthood. In addition to self-report in the following age groups: 5-7, 8-12, 13-18, and 19-25, proxy report from caregivers will be obtained for all of those age groups plus those 2-4 years. The purpose of this presentation will describe the process of developing the PedsQL-SCI Module.

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Measures of Physical Function, Activity and Participation for Children and Youth with SCI
MJ Mulcahey, PhD, OTR/L USA

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The Steven M. Haley Memorial Lectureship

Abdominal Functional Electrical Stimulation to Reduce Respiratory Complications in Spinal Cord Injury **Bonne Lee MBBS, PhD AUSTRALIA**

Key areas: Respiratory Complications, Rehabilitation, Clinical Trials, Epidemiology, Urinary Tract Infection after Spinal Cord Injury and facilitating the Global Mapping Subgroup of the ISCoS Prevention Committee with Dr Raymond Cripps and Dr Peter New

While tetraplegia is often characterised by paralysis of all four limbs, paralysis also affects the major respiratory muscles, namely the diaphragm and abdominal and intercostal muscles. This reduces respiratory function, with associated respiratory complications, such as pneumonia and atelectasis. Such complications are a leading cause of illness and death for the tetraplegic population. Up to 68% of patients with tetraplegia have a respiratory complication in the first 6 weeks (i.e. the acute stage) of injury. A reduction in respiratory complications in acute tetraplegia would decrease illness and death, reduce rehabilitation time, improve quality of life, and result in a large cost saving for global health systems.

Surface electrical stimulation of the abdominal muscles, termed Abdominal Functional Electrical Stimulation (FES), can contract the abdominal muscles, even when paralysed. We have shown that the repeated application of Abdominal FES improves the respiratory function of people with tetraplegia. However, while respiratory function is a predictor of respiratory complications in tetraplegia, evidence that Abdominal FES reduces respiratory complications is only anecdotal. We will undertake the first prospective, multi-centre, randomised placebo controlled trial, to determine whether Abdominal FES reduces respiratory complications in acute tetraplegia.

Definitive evidence of the effectiveness of Abdominal FES to reduce respiratory complications in tetraplegia will drive the rapid worldwide translation of this low cost and easily applied technology for this vulnerable patient group. This will decrease illness and death, reduce rehabilitation time, improve quality of life, and result in a large cost saving for global health systems.

Dr Lee has an ongoing collaboration over more than a decade with the Gandevia and Butler laboratories at NEURA, looking at Respiratory muscle function and stimulation after Spinal Cord Injury and improving clinical translation. The work presented for the Stephen M. Haley Memorial Lecture, brings together an international collaboration of leading research and medical teams from: Neuroscience Research Australia, the Prince of Wales Hospital, and the Royal North Shore Hospital in Australia; The Indian Spinal Cord Injury Centre; Chang Mai University Hospital in Thailand; The Queen Elizabeth National Spinal Injuries Unit and the University of Glasgow in Scotland; and Bach Mai Hospital in Vietnam.

Dr Lee and his colleagues from NeuRA will be offering a hands-on practical Abdominal FES workshop as part of the ISCoS conference, that aims to provide participants with a better understanding of how Abdominal FES works, when it should be used, and how to apply it. This will be run at 11.30 am on Thursday the 13th September 2018 in Room C2.1 of the Sydney International Convention Centre.

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Traumatic Spinal Cord Injuries: A Retrospective Cohort Study of Children Seen in Western Australia Between 1996 and 2016

**Rachel Anne Dwyer, MBBS*; Roslyn Ward, PhD; Emma Richardson, FAFRM; Sue-Anne Davidson, BSc;
Anna Thetford, BN; Jane Valentine, FAFRM**

**Princess Margaret Hospital for Children
Perth, WA AUSTRALIA**

Summary: Paediatric traumatic spinal cord injury patients have a high burden of care, are complex and require intensive specialised multidisciplinary rehabilitation team input for well being and to make functional gains while undergoing continual growth and development.

Data:

Purpose- To describe the medical complexity of traumatic spinal cord injury (TSCI) in paediatric patients in Western Australia. Secondly, to determine if Princess Margaret Hospital for Children is meeting the Australasian Rehabilitation Outcomes Centre (AROC) paediatric rehabilitation minimum data set.

Methods- Retrospective cohort study of patients seen at PMH between 1996-2016, framed within the AROC minimum dataset. Functional status and rehabilitation outcomes were assessed using Functional Independence Measure for Children (weeFIM), Canadian Occupational Performance Measure (COPM) and Goal Attainment Scaling (GAS). Patient complexity was captured by documenting the specialty teams involved, the number of readmissions and the International Statistical Classification of Disease and Related Health Problems Z codes.

Results- Data from 19 patients was available consisting of 13 males (age range 6months-15years) and 6 females (age range 4years-13years). There were 10 cervical TSCI with a median length of stay of 213 days and 9 thoracic TSCI with a median length of stay of 49 days. Patients had between 0 and 6 comorbidities prior to their TSCI.

Conclusions- Children with medical complexity are responsive to rehabilitation but have a high burden of care; and require multiple specialty care and hospital re-admissions. PMH patient documentation complies with the AROC minimum data set.

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Teens & Trauma: A Ten-Year Review of Etiologies of Adolescent ABIs and SCIs

Cathi Dugger, BS, PT*; **Herndon Murray**; **Katie Kimball, MS-OT, OTR/L**; **Anna Elmers**; **Patricia Antcliff, MOT**;
Emma Harrington

Shepherd Center
Atlanta, GA UNITED STATES

Summary: Explores the impact of risk-taking behaviors during adolescence and guides future prevention efforts to reduce SCI and ABI in this population.

Data:

Introduction

Adolescence is a developmental period categorized by self-exploration, increased independence, and consequently, risk taking behavior. As a result, many teenagers are involved in catastrophic accidents leading to neurological injury. Many of these injuries result in acquired brain injury (ABI), spinal cord injury (SCI), or a combination of both. To design injury prevention programs for this population, precise information on how these injuries occur is needed. Initially, Shepherd Center embarked on a ten-year retrospective review of adolescent admissions for SCI rehabilitation and is now expanding the data to include analysis of ABI and dual diagnosis (DD) in order to guide further prevention programming. We looked at the following data to identify high-risk activities for this age group: age, gender, injury etiology, and categorized road traffic accidents (RTA).

Methods

Admissions data of 1,088 individuals from 2005-2015 was reviewed, including patients aged 10-19 years old admitted with a SCI, ABI, or dual diagnosis.

Results

Of the 1,088 individuals, 498 had a SCI, 521 had an ABI, and 69 had both an SCI and an ABI, resulting in DD. When looking at those individuals with SCI, most patients are male, totaling 378 versus 119 who are female. Within this group, 252 are paraplegic and 246 are quadriplegic. Of the 521 individuals with ABI, the trend is similar, with 342 males being affected compared to 179 females. When looking at individuals with DD, 53 are male and 16 are female. The highest number of SCI occurred in the summer months and December. The majority of ABI occurred in the spring and summer months and DD were most common in the spring months. Overall, most catastrophic accidents occur in months where teenagers are participating in more outdoor activities.

We found common etiologies of these catastrophic accidents for SCI were road traffic accidents (RTA) (48%), sports and recreation (29%), gunshot wound or violence (11%) and falls (4%). The most common etiologies for ABI were similar and include RTA (71%) and sports and recreation (12%); however, many ABI were also caused by a wide array of other etiologies (17%).

Within RTA, only 1/5 of adolescents were wearing a seatbelt across both SCI and ABI. Approximately 1/3 of adolescents involved in an RTA were not wearing a seatbelt that resulted in a SCI (35%) or an ABI (29%). Both groups had a large amount of accidents in which seatbelt use was unknown. In regard to sports and recreation injuries, nearly 50% of them were due to diving accidents in pools or shallow bodies of water.

Conclusions

Adolescents are participating in risky behaviors. RTA and diving are two of the leading causes of SCI and ABI. Restraining passengers with seatbelts may help prevent some catastrophic accidents, but continued prevention efforts need to focus on safety enforcement targeting younger adolescents. Furthermore, this suggests increased measures to ensure teenage drivers are required to use seatbelts before operating vehicles. Continued prevention can also be directed at jumping feet first into bodies of water to decrease the number of diving accidents. More research is needed to assess effectiveness of these interventions and their impact on catastrophic injuries.

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Teamwork, Innovation and Inclusion: A Case Study

Toni Blanch, BAppSc (OT)*

Rehabilitation Options

Sydney, NSW AUSTRALIA

Summary: An 'energetic, unstoppable' child with a T10 SCI and extensive degloving injuries to her abdomen, lower back and pelvis, collaborates with her multidisciplinary team to design a powered prone wheelchair for her to start school, stay at school, play and learn; A case study about teamwork, innovative product design and inclusion.

Data: How does an 'energetic, unstoppable' 5-year-old with a T10 SCI and extensive degloving injuries to her abdomen, lower back and pelvis, start school, stay at school, play and learn?

The hope was for Belle's skin integrity to improve sufficiently to allow her to sit in a wheelchair, although achieving this was complicated. Belle's team was set a seemingly impossible task to design a school friendly, prone-lie mobility aid.

With Belle starting school in just two weeks, there was a race against time. There was no commercially available child size prone wheelchair so the first prototype of Belle's 'buggy' was born.

The design was guided by multidisciplinary opinions, feedback from family, school and most importantly Belle herself. Trials were conducted with Belle engaged in activities appropriate to her age. The team built on product strengths and eliminated weaknesses in subsequent design tests. After four prototypes major changes included: transition from manual to power operated; attendant propel to self-drive; the inclusion of powered height and tilt adjustability for function and skin care; and improved postural supports to reduce asymmetry and upper body strain. Belle was now able to travel safely in her prone wheelchair in the family's modified vehicle with her siblings, eliminating the need for costly patient transport for Belle and measured community outings!

The eventual aim for Belle is to achieve sustained sitting in a wheelchair. There have been brief windows where Belle's skin has allowed some sitting and wheelchair use, although at age 8, Belle is at school, playing, learning (and dancing!) on her prone 'buggy'.

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Neuromuscular Scoliosis Panel

**Randal R. Betz, MD; Isabel Chapman, Physiotherapist; Andrew Cree, MD; John Ferguson, MD;
Michael Johnson, MD; MJ Mulcahey, PhD, OTR/L**

Summary: In summary, patients with neuromuscular scoliosis, including that resulting from spinal cord injury, myelodysplasia, or other neurologic conditions, can benefit from different strategies for both nonoperative and operative treatment.

Data: The purpose of this panel is to discuss some new concepts for both nonsurgical and surgical care of scoliosis in the child with spinal cord injury (SCI) and neuromuscular scoliosis through a case presentation format.

Spine deformity develops after SCI in over 90% of children and adolescents, and the risk of progressing to surgery when their injury occurs before skeletal maturity is approximately 67%. Prophylactic bracing beginning at the time of injury (before the curve reaches 20 degrees) may prevent surgery in approximately 50% of patients. If it does not prevent surgery, it can delay it an average of six years, allowing the child to grow to a more adult height. Bracing plays a lesser role in larger curves (21 to 40 degrees) and probably no role in curves over 40 degrees. Despite some success with prophylactic bracing for spine deformity, there are issues with compliance and also problems with documented decrease in work space.

Indications for surgery include curves greater than 40 degrees in the growing child, preferably older than 10 years of age, and functional problems or pain in the patient who has already reached skeletal maturity. Results of outcomes after spinal fusion generally report 92% satisfaction with minimal decrease in function. However, activities probably require more effort and, therefore, most patients prefer their pre-fusion flexibility. It is most important to maintain the sagittal sitting position of the spine with special rod bending during surgery, especially for patients who are dependent on compensatory strategies for hand to mouth. New concepts for correction of spine deformity without fusion have been shown to be safe and moderately effective, especially for the younger patient needing continued growth despite development of a severe deformity.

In summary, patients with neuromuscular scoliosis, including that resulting from spinal cord injury, myelodysplasia, or other neurologic conditions, can benefit from different strategies for both nonoperative and operative treatment of their spinal deformity. These strategies include prophylactic bracing (beginning at the time of injury), bending the rods into a sitting posture during spinal fusion, and possibly correcting the deformity without fusion.

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Lunch Symposium: *Overcoming Implicit Bias and Other Barriers to Better Adherence to Bladder Management Following Spinal Cord Injury* **Andrei Krassioukov, MD, PhD, FRCPC CANADA**

For many years, the international medical community has been engaged in strong debates on issues related to urinary tract infections (UTI) and re-use of catheters during the management of neurogenic lower urinary tract dysfunction among individuals with spinal cord injury (SCI). Despite the data from numerous clinical studies and presence of multiple clinical practice guidelines we still did not reach a consensus on intermittent catheterization and use of single versus re-use of catheters in urinary bladder management. In this respect, the 2014 Cochrane review "Intermittent catheterization for long-term bladder management (Review)" by Prieto et al became one of the leading documents that captured mind and attention of clinicians around the world. Although numerous countries completely switched to single use catheters as the guidelines for management of individuals with SCI, the opinion that was expressed in the above-mentioned review has the potential to make a significant negative impact on the future management of individuals with SCI.

During this presentation, participants will explore the following key topics:

- What are the potential biases and barriers in our decision making process? Decision making is inherently a cognitive activity, the result of thinking that may be either rational or irrational (i.e., emotional, based on assumptions not supported by evidence). We will explore how an individual's predispositions can either be an obstacle or an enabler to the decision-making process.
- Can we see beyond the visible disabilities? Issues of invisible disabilities, frequently hidden behind the paralysis, will be explored.

A different perspective and an independent appraisal of the data presented in the 2014 Cochrane review "Intermittent catheterization for long-term bladder management (Review)" by Prieto et al will be discussed. Evidence of crucial discrepancies of data extraction and analysis within the review will be presented. In contrast to opinion of Prieto and colleagues' review, our analysis revealed a trend to favor single over multiple use of catheters.

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Perspective on Spinal Bifida

Inge Eriks-Hoogland, MD, PhD*; Jens Wöllner, MD, PhD

**Swiss Paraplegic Centre
Nottwil, SWITZERLAND**

Spina bifida results in problems in the function of many organ systems. An interdisciplinary medical and rehabilitative care program across the lifespan is needed to prevent secondary health problems and early mortality but also to ensure optimal functioning and quality of life (QOL). The biopsychosocial model of the international classification of functioning disability (ICF) can be used as a framework across the lifespan. Were medical and rehabilitative care in childhood is usually warranted in an interdisciplinary or team, in adulthood teams with experience in treatment of persons with spina bifida and guidelines hardly exist. This paper gives an overview of aspects that should be included in regular check-up, with a focus on transition to adult medical and rehabilitation care.

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Parental Perspectives Regarding Prenatal Surgery for Myelomeningocele **Amy Joy Houtrow, MD, PhD, MPH*; Ryan Antiel, MD**

Children's Hospital of Philadelphia
Philadelphia, PA UNITED STATES

Summary: Parents report a wide range of experiences after prenatal surgery for myelomeningocele.

Data: Background: Prenatal surgery for myelomeningocele has been demonstrated to have benefits over postnatal surgery including improved motor function in early childhood and a lower likelihood of needing a shunt for hydrocephalus. Nevertheless, prenatal surgery requires a significant emotional, physical, and financial commitment from the entire family. To better understand the experiences of parents who decided to proceed with prenatal surgery, we conducted a survey of these parents.

Methods: Parents of children with myelomeningocele who underwent prenatal surgery were surveyed about their experiences and perspectives using an online survey instrument that allowed for open-ended responses. Parents were recruited in the spring of 2016 from a social media group for families who had experienced maternal-fetal surgery. Inclusion criteria included age over 18 years and ability to read and write in English. Subjects were excluded if they were involved in the Management of Myelomeningocele Study. Consent was obtained for all subjects and this study was approved by the Children's Hospital of Philadelphia Institutional Review Board.

Results: In total, 109 parents completed questionnaires. Parents reported that after the diagnosis of myelomeningocele, their obstetrician spoke to them about surgery after birth (84%), termination (80%), and prenatal surgery (71%). Of 24 (22%) total parents who reported that when speaking to their physicians about their treatment choices they felt pressure to take one option: 19 (79%) felt pressure to terminate, 7 (30%) felt pressure to have postnatal surgery, and 1 (4%) felt pressure to have prenatal surgery. Parents reported learning about the option of prenatal surgery from the internet (39%), health care providers (33%), family (8%), friends (7%), magazine/newspaper articles (6%), and from television (4%). Half of parents (49%) report that having a child with SB has had a positive impact on their family, while 51% report both positive and negative impacts. The most commonly reported positive impacts were changes in parent's attitudes and new opportunities and relationships. The most commonly reported negative impacts were on the child and on familial relationships and financial stress. No parent reported that having a child with SB has had only a negative impact on their family. Parents were asked, knowing what they know now, if they were able to go back in time, would they still undergo prenatal surgery. 99 (91%) report that they would definitely still undergo surgery, 5 (5%) report that they would probably still undergo surgery, 3 (3%) were unsure, and 2 (2%) reported they would not.

Conclusions: Parents of children with MMC who have undergone prenatal surgery have a broad range of experiences and perspectives. These data should further enhance providers understanding of the experience of our patients and help to further develop models of counseling that effectively address parental experience. A better understanding of the parental experiences and perspectives following prenatal surgery will play an important role in providing overall support for parents and family members.

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Neurodevelopmental Outcomes at 30 Months of Age for Children Enrolled in the Moms Trial by Presence of Hydrocephalus and Shunt Status

Amy Joy Houtrow, MD, PhD, MPH*; Pamela Burrows, MS; Elizabeth Thom, PhD

**Eunice Kennedy Shriver NICHD MOMS Trial Group
Bethesda, MD UNITED STATES**

Summary: Severity of hydrocephalus associated with worse neurodevelopmental outcomes.

Data:

Background: Hydrocephalus causes axonal damage and decreased cerebral perfusion pressures and is linked to delayed myelination, endocrine derangements, and a constellation of deficits in cognitive, sensory, and motor functions. The impact of hydrocephalus is highly variable. While shunting is a well-established treatment modality for hydrocephalus, variability exists regarding who to shunt and when. Studies have suggested that shunt placement in patients with myelomeningocele is associated with a decrease in IQ and an increase in mortality as compared to patients who were not shunted. Whether this is due to shunting and its complications or due to the severity of hydrocephalus requiring shunting is controversial and many neurosurgeons are hesitant to place shunts unless deemed absolutely necessary.

Purpose: To evaluate for differences in neurodevelopmental outcomes at 30 months of age for children enrolled in the Management of Myelomeningocele Study (MOMS) based on the presence of hydrocephalus and cerebral shunts.

Methods: Data from the subjects enrolled in MOMS were analyzed for this study. MOMS was a multisite study evaluating prenatal surgery compared to standard postnatal repair of myelomeningocele. In MOMS, shunt criteria based on expert consensus were predetermined to decrease the influence of biases among treating neurosurgeons. The analyses presented utilize the differing shunting patterns of the MOMS children to evaluate neurodevelopmental outcomes at 30 months by the presence of both hydrocephalus (based on the predetermined criteria) and shunts. Children with no hydrocephalus (N=27), children with shunted hydrocephalus (N=108), and children with unshunted hydrocephalus (N=36) were compared at 30 months of age on the Bayley-II Mental and Psychomotor Indices, the Peabody Developmental Motor Scales-2 and the Preschool Language Scale, 4th edition. Generalized linear models were used to adjust for factors significantly different between the groups at baseline. Additional analyses were conducted to evaluate the impact of the severity of hydrocephalus.

Results: In unadjusted comparisons, statistically significant differences were noted between the medians of the three groups on the Peabody Gross Motor Quotient (No hydrocephalus=72, Shunted hydrocephalus=61, Unshunted hydrocephalus=64) and thus the Total Motor Quotient (No hydrocephalus=78, Shunted hydrocephalus=71, Unshunted hydrocephalus=74.5) After adjustment, no statistically significant differences were identified. In subanalyses, children with more severe hydrocephalus (defined by the number of hydrocephalus criteria met) fared worse on the Peabody Fine Motor Quotient (88 versus 94), the Total Motor Quotient (70 versus 73) and both Preschool Language Scale subtests: auditory comprehension (93 versus 104) and expressive communication (95 versus 104.5) and thus the total score (92 versus 105). These results remained significant in the multivariable adjusted model.

Conclusion: No neurodevelopmental differences were noted with children enrolled in MOMS across the three hydrocephalus/shunt groups, but severity of hydrocephalus was associated with poorer neurodevelopmental outcomes. Developing a standardized method of determining hydrocephalus severity may help determine which patients require shunting and predict their anticipated neurodevelopmental outcomes.

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Principles of Neuro-Urological Treatment Across the Life Span in Persons with Spina Bifida **Jens Wöllner, MD SWITZERLAND**

The function of the lower urinary tract (LUT) is to ensure a sufficient storage and voiding phase. These contrary functions are regulated by the central and peripheral nervous system. As a consequence of spina bifida, these network is disturbed and implies neurogenic lower urinary tract dysfunction. Depending on the lesion level and severity various types of bladder dysfunction occurred. In order to identify the exact dysfunction, it is necessary to perform urodynamic diagnostic. Depending on the type of bladder dysfunction a therapy (e.g. intermittent catheterization, antimuscarinics) is needed. Aim of the therapy for the whole life span in these patients is to protect the upper urinary tract function, achieve continence and improve quality of life. In order to ensure a complete therapy, it is necessary to accompany the patients from childhood to old age and to adapt the therapy to the respective life situation.

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The Spina Bifida Association Guidelines for Quality of Life and Sexual Health and Education

Kathleen Sawin, PhD, CPNP-PC*; Amy Joy Houtrow, MD, PhD, MPH; Timothy J. Brei, MD; Michele Roland, MD

**University of Wisconsin & University of Pittsburgh
Milwaukee, WI; Pittsburgh, PA UNITED STATES**

Title: *Development Of The Spina Bifida Association Guidelines For Quality Of Life*

Summary: Quality of life measure measurement should take place to assure that treatment is aligned with quality of life.

Data: Introduction: Quality of life is defined by the World Health Organization as “an individual’s perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations and concerns.” In addition, “Health Related Quality of Life (HRQOL) is considered a sub-domain of Quality of Life (QOL) and measures a subjective perception of the impact of a health condition and/or its treatment on the individual.” There is little research evaluating when and how to evaluate QOL or HRQOL of life among children and adults with spina bifida. To address these gaps, the Spina Bifida Association developed a process to create consensus guidelines for quality of life, among others.

Methods: In 2016, the Spina Bifida Association convened international experts in spina bifida care and research to develop consensus-based healthcare guidelines for individuals with spina bifida across the life span. The International Classification of Functioning, Disability and Health framed the Guideline development. The Spina Bifida Association conducted a literature review and Workgroup members synthesized the literature to inform the development of candidate guidelines. Single Text Procedure and Nominal Group Techniques were used as they are effective within the context of data available for creating the Healthcare Guidelines and the complexities of working across a large, multinational group of experts. The Workgroup identified goals and relevant clinical questions. From there, the Workgroup created candidate guidelines aligned with available evidence. When evidence was lacking, expert clinical consensus was used. In 2017, international experts from the Healthcare Guidelines Steering Committee and the Workgroups convened prior to the Spina Bifida Association’s 3rd World Congress for Spina Bifida Research and Care meeting to review candidate measures using Nominal Group Technique. After the meeting, the Quality of Life Workgroup reviewed the recommendations and developed the set of guidelines for review by an ad hoc committee of reviewers who were tasked with identifying redundancies across the sets of Guidelines. After revisions and approval, the Guidelines will be published by the Spina Bifida Association on their website later in 2018.

Results: The Quality of Life Workgroup based their Guidelines on the following goal: to improve quality of life for individuals with spina bifida across the lifespan. Using a life course perspective, the Workgroup developed guidelines related the measurement of and enhancement of QOL/HRQOL throughout the lifespan. The Workgroup identified the need for empowerment of individuals with spina bifida and their families. The Guidelines focused on actionable activities that health care professionals can do to help improve QOL/HRQOL for the children and adults with spina bifida that they serve. The Workgroup identified numerous research gaps during the guideline development process.

Discussion: QOL/HRQOL should not be assessed in isolation. If clinicians are going to successfully address these concepts, they also need to address the factors important to the individual with Spina Bifida and their families that impact QOL/HRQOL. Additional research is needed to assess these concepts and evaluate interventions that optimize QOL/HRQOL.

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Title: *Spina Bifida Association Healthcare Guidelines: Sexual Health And Education*

Summary: Using a life course perspective, the Workgroup developed guidelines related to Sexual Health and Education

Data: Introduction: There is ample evidence that children, youth and adults with spina bifida do not receive adequate information about sexuality and sexual health. Additionally, many individuals with spina bifida report lack of satisfaction with their sex lives. To address these gaps, the Spina Bifida Association developed a process to create consensus guidelines for sexual health and education, among others.

Methods: In 2016, the Spina Bifida Association convened experts in spina bifida care and research from around the globe to develop consensus-based healthcare guidelines for individuals with spina bifida across the life span. To achieve consensus, Single Text Procedure and Nominal Group Technique were selected because they can be effective within the context of data available for creating the Healthcare Guidelines, the work already done in terms of guideline content available, and the complexities of working across a large, multinational group of experts. Guideline development was framed using the International Classification of Functioning, Disability and Health. The Spina Bifida Association conducted a comprehensive literature review that was enhanced by Workgroup members who then used the existing literature to inform the development of candidate guidelines. The Sexual Health and Education Workgroup identified goals and relevant clinical questions. From there, the Workgroup created candidate guidelines aligned with existing guidelines and available evidence. When evidence was lacking, the Workgroup indicated that the guideline would be supported by clinical expert consensus. In 2017, international experts from the Healthcare Guidelines Steering Committee and the Workgroups convened prior to the Spina Bifida Association's 3rd World Congress for Spina Bifida Research and Care meeting to review candidate measures using Nominal Group Technique. After the meeting, the Sexual Health and Education Workgroup reviewed the recommendations and developed the set of guidelines for review by an ad hoc committee of reviewers who were tasked with identifying redundancies across the sets of Guidelines. After revisions and approval, the Guidelines will be published by the Spina Bifida Association on their website.

Results: The Sexual Health and Education Workgroup based their Guidelines on the following goal: to optimize sexual health outcomes for individuals with spina bifida. The Workgroup identified the need for education and empowerment of individuals with spina bifida to maximize the likelihood that individuals with spina bifida are able to participate as desired in meaningful and fulfilling sexual relationships in adulthood. Using a life course perspective, the Workgroup developed guidelines related to the care of infants, children, youth and adults with spina bifida, many of which were based on existing recommendations for all children. The Workgroup identified numerous research gaps during the guideline development process.

Conclusions: Given that approximately half of adults with spina bifida report dissatisfaction with their sex lives and that sexual education provided to individuals is deemed inadequate, these the Sexual Health and Education Guidelines can advance the healthcare professional's ability to provide education and services to maximize sexual health outcomes for people with spina bifida.

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Helping Children Breathe: The Important Role of Diaphragm Pacing Raymond Onders, MD USA

Summary: This research reports that minimally invasive Diaphragm Pacing can be safely used to free and decrease the use of mechanical ventilation in children when there is intact lower motor neurons.

Data: Background: Chronic invasive mechanical ventilation(MV) in children increases medical complexity of care and adds to familial depression, anxiety and health care dollars. Diaphragm Pacing(DP) has shown clinical utility in decreasing or replacing MV in multiple adult applications. This is a report of the world's largest group of pediatric patients.

Design/Methods: Prospective, nonrandomized, interventional experience under IRB approval. Patients underwent laparoscopic implantation of four intra-muscular electrodes to deliver electrical stimulation to allow diaphragm movement for ventilation. Diaphragm conditioning was then started for weaning from MV.

Results: From January 2009 to March 2018, 25 patients were implanted. Three additional patients were assessed in the operating room but had non stimulable diaphragms and not implanted. Ages ranged from 14 weeks to 17 years with an average of 8.6 years. Age at time of injury occurred from day of birth to 17 years with an average of 5.72 years. The average weight was 33.2 Kg(range 5.8 to 81 kg). Mechanism of injury is as follows: MVA 13, Sports 2, unknown Neuromuscular Disease 2, Brain Tumor 2, Forceps Delivery 1, Brittle Bone Disease 1, Transverse Myelitis 1, Bacterial Meningitis 1, and Acute Flaccid Myelitis(AFM) 2. Time spent on MV prior to DP implant averaged 31.4 months(range 11 days to 91.8 months). Nineteen patients had gastrostomy tube(PEG) prior to DP surgery with 4 additional patients having simultaneously PEG and DP, 1 had a baclofen pump, and 3 had VP shunts. Twenty-four patients were dependent on full time MV. One NMD patient was having increasing hypercarbia despite increasing NIV usage (up to 12 hours daily). There is an average of 45.4 months of cumulative use of DP with longest use of 110 months. There have been no internal wire infections requiring IV antibiotics or electrode replacement. There have been no internal wire breakages. Ten of the 24 MV patients achieved full time pacing with another 4 patients replacing MV for at least 12 hours daily. Six patients have not achieved 4 consecutive hours of pacing. Three of these had traumatic SCI and only one hemi-diaphragm that responded to stimulation intraoperatively. Two of the patients with AFM had stimulable but weak diaphragm response. One recently implanted NMD patient on IV is still conditioning and has significantly weaned from ventilator support. The other NMD patient is normocarbic and ceased increasing NIV usage. Two patients were decannulated. One early implanted patient avoided tracheostomy altogether. Two patients recovered automatic breathing and DP was removed. The patient with brittle bone diagnosis never weaned. DP electrodes can be utilized to monitor and assess for diaphragm strength and recovery.

Conclusions: DP is easily implanted in children, has no deleterious effects and can decrease or replace MV. DP is the preferred breathing method by patients and their families, even when compared to non-invasive ventilation. Similar to adults, early implantation decreases wean time and identification of denervated diaphragms can save untoward effects from physiologically impossible ventilator weaning. For pediatric populations with intact phrenic motor neurons DP can be an option in a wide group of patients.

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Health and Life Priorities for Children and Young Persons With Spinal Cord Injuries and Their Parents and Caregivers

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Summary: Pan-European Paediatric Spinal Cord Injury (PEPSCI) Collaboration: Research Priorities for Paediatric Spinal Cord Injury

Data: Introduction: Children, adolescents and young adults with paediatric spinal cord injuries (pSCI) have specific daily living, health and psychosocial needs. The integration of the views of these patients as well as their families and caregivers to guide research activities into pSCI is important for targeting socially and clinically relevant issues. For the first time the Pan-European Paediatric Spinal Cord Injury (PEPSCI) Collaboration aims to identify service-user priorities across Europe and beyond to establish a pSCI research agenda.

Methods: Signed consent/assent was obtained from children, adolescents and young adults with acquired or congenital pSCI (aged 0-25 with onset of SCI before the age of 18) and from their parents/caregivers. Age-appropriate surveys were completed by the participants either online or on paper to provide information related to demographics, quality of life, health and life domains and neurological impairment. Brief clinical information was obtained from the healthcare professional.

Results: Participating hospitals in Europe have consented in excess of 100 parents/caregivers and patients with pSCI aged between 2-25 years with a neurological level between C1- S4 and AIS between A-E. Participants reported several priority issues regarding life domains including problems with general health and relationships with friends/family members. Health-related issues included problems with physical functioning and management of pressure sores/ulcers and bladder and bowel.

Conclusion: Life and health-related research priorities emerging from the PEPSCI Collaboration can potentially help healthcare professionals and researchers address unmet needs of young individuals with pSCI in addition to their families and caregivers.

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Information and Communication Needs of Families of Children With an Acute Spinal Cord Injury: A Qualitative Meta-Synthesis

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Summary: This is a meta-synthesis attempting to deduce the most important information and communication needs of families with children with acute spinal cord injury.

Data: Background: Pediatric rehabilitation professionals face multiple challenges in meeting the information needs of families of children with an acute spinal cord injury (SCI) as they move toward reintegration. Psychological trauma, coordination of interdisciplinary specialists, health literacy, and caregiver fatigue all present unique obstacles for the delivery of effective, efficient, and caring communication. A better understanding of our caregivers' experiences with information and communication during hospitalization is necessary in order to improve family-centered care in pediatric SCI rehabilitation.

Methods: We use a meta-synthesis approach to analyze qualitative literature on caregiver- and patient-identified information and communication needs for patients with acute traumatic long-term disability. Through inductive analysis and reciprocal translation, we aggregate and interpret themes from the literature into categories and subthemes.

Results: We describe five categories (and accompanying subthemes) that represent the communication needs of families caring for patients with acute traumatic long-term disability. The categories include: expectations for contact with healthcare professionals, methods for retention and organization of information, sufficient information provision, communication coordination, and increased intentionality during times of transition of care.

Conclusions: We explore how these categories and subthemes apply to families caring for children with acute SCI as they move toward reintegration. Utilizing a trauma-informed communication model, we outline a "caring communication roadmap" that can help interdisciplinary teams coordinate to meet these needs.

Keywords: spinal cord injury, communication and information needs, coordinated care, trauma-informed communication, communication in pediatric rehabilitation.

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The Newton C. McCollough Lecture: *Pediatric Non-Traumatic Spinal Cord Lesions* Peter New MD, AUSTRALIA

Introduction

The causes of spinal cord damage not due to trauma, henceforth referred to as non-traumatic spinal cord dysfunction (SCDys), are varied and heterogeneous. Research involving SCDys is important because it is generally not well studied in comparison with traumatic spinal cord injury (SCI).

The first issue discussed is terminology issues, because there is no internationally accepted term for spinal cord damage not due to trauma. Second, a brief history of SCDys will be presented, focusing on conditions relevant to pediatrics. Thirdly, the classification of SCDys will be outlined, based on the International non-traumatic SCI datasets. Then a summary will be given of the epidemiology of pediatric SCDys, focusing on the incidence and etiology, along with a comparison to SCI. Next I will highlight some important clinical rehabilitation principles unique to children with SCDys. Then I will discuss opportunities for the prevention of pediatric SCDys. Finally, I will cover trends, challenges and opportunities regarding research in SCDys.

Terminology Issues

There is no internationally accepted term for spinal cord damage not due to trauma. Many different terms have been used in the literature to describe these conditions, including: non-traumatic spinal cord injury, spinal cord damage, spinal cord dysfunction, spinal cord lesion, medical paraplegia, myelopathy and spinal cord myelopathy.(1)

The Medline and Embase classification systems for medical search terms and the Centre for Disease Control in the USA(2) define SCI as only due to traumatic conditions. An important implication arising from the lack of an accepted term for spinal cord damage not due to trauma is that this negatively impacts on the ability to identify relevant publications when searching the literature.(1) In addition, participants in different studies may not be comparable if different terms and inclusion criteria are used, restricting the generalizability of research and the ability to pool results.(3) An international consensus process is needed to adopt an agreed term for non-traumatic SCDys.

History of Spinal Cord Dysfunction

A brief history of SCDys will be outlined, taking a broader historical perspective and the increasing awareness of the role of the spinal cord and knowledge of neuroanatomy.(4) Key milestones in the history of the diagnosis and management of the most common and important pediatric causes of SCDys will be mentioned. An appreciation of the history of SCDys increases our understanding of the large number of people who contributed to our current knowledge of these conditions, and in some situations, helps guide efforts regarding prevention of SCDys.

Classification of Spinal Cord Dysfunction

The International Spinal Cord Injury Data Sets for Non-traumatic Spinal Cord Injury consist of a basic and extended data set,(5) and includes a classification system for the many heterogeneous causes of SCDys based on a two-axis approach. The first axis uses a two-tier (congenital-genetic and acquired), five-level hierarchy. The hierarchy allows for increasing detail regarding the classification of the etiology. The conditions in the second level of the acquired tier are: vertebral column degenerative disorders; metabolic disorders; vascular disorders; inflammatory and auto-immune diseases; radiation related; toxic; neoplastic; infection; and other miscellaneous causes. The non-traumatic datasets are recommended when classifying the etiology of SCDys in clinical practice and research to facilitate an improvement in comparative research.

Global Mapping for the Epidemiology of Paediatric Spinal Cord Damage

The results of comprehensive literature search regarding the epidemiology of paediatric spinal cord damage will be presented.(6) 862 abstracts were reviewed and data from 21 articles were included from 13 countries

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in 6 of the 21 Global Regions. Twelve studies involved paediatric SCI and six were regarding SCDys. An additional three articles provided both paediatric SCI and SCDys data. The incidence and etiologies for SCI and SCDys will be presented.

Important Clinical Rehabilitation Principles Unique to People with Spinal Cord Dysfunction

Although most aspects of rehabilitation for SCI and SCDys are the same, because of age, gender and etiological differences, people with SCDys face some unique rehabilitation issues that are important to consider in order to optimize their outcomes.(7) These considerations include the following:

- classification issues: regarding the classification of etiology of SCDys (as already mentioned above) and the International Standards for Neurological Classification of Spinal Cord Injury)
- general rehabilitation issues: predicting survival, improvement and rehabilitation outcomes; admission to spinal rehabilitation units, including selection decision issues; participation in rehabilitation; and secondary health conditions
- etiology-specific issues: SCDys due to tumors and infections
- important role for the rehabilitation physician as a diagnostic clinician.

Prevention of Spinal Cord Dysfunction

Compared with SCI, there is very limited activity by the international spinal cord medicine community regarding research or intervention programs into the prevention of SCDys. Reasons for this will be outlined and key opportunities for the prevention of pediatric SCDys, including Spina Bifida, infections, tumours, deficiencies and toxins will be highlighted.(8)

Trends, Challenges and Opportunities Regarding Research in Spinal Cord Dysfunction

There has been a substantial increase in publications on SCDys over the past four decades, from 1,825 (1974 – 1983) to 11,887 (2004 – 2013), along with an improvement in research methodology. Numerous challenges to research in SCDys rehabilitation and opportunities for addressing these are grouped into the following themes: 1) identification of cases; 2) study design and data collection; and 3) funding, pre-clinical, and international research.(3)

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