Journal of Pediatric Rehabilitation Medicine: An Interdisciplinary Approach 10 (2017) S23–S25
DOI 10.3233/PRM-170417
IOS Press


# Abstracts

# General Care Issues Session 1

## The Experience of Families with Children with Spina Bifida who Underwent Prenatal Surgery

Antiel, Ryan[1], Janvier, Annie[2], Feudtner, Chris[3], Blaine, Kallie[4], Fry, Jessica[5], Howell, Lori J.[3], Houtrow, Amy[6]
[1]*Mayo Clinic*
[2]*University of Montreal*
[3]*Children's Hospital of Philadelphia*
[4]*Physical Therapy Consultants Inc.*
[5]*Northwestern University Feinberg School of Medicine*
[6]*University of Pittsburgh School of Medicine*

**Background** Prenatal surgery for Spina Bifida (SB) has been demonstrated to have benefits over postnatal surgery. Yet, prenatal surgery requires a significant emotional, physical, and financial commitment from the entire family.
**Methods** We surveyed parents of children with SB who underwent prenatal surgery to describe their experiences and perspectives.
**Results** One hundred and nine parents completed questionnaires. Parents reported that when their child was first diagnosed with SB their obstetrician spoke to them about surgery after birth (84%), termination (80%), and prenatal surgery (71%). Twenty-four (22%) parents reported that when speaking to their physicians about their treatment choices they felt pressure to take one option: 7 (30%) felt pressure to have postnatal surgery, 1 (4%) felt pressure to have prenatal surgery, and 19 (79%) felt pressure to terminate. Parents reported learning about the option of prenatal surgery from the internet (39%), other health care providers (33%), family (8%), friends (7%), magazine or 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. 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%) said that they would probably not still undergo surgery.
**Conclusions** A better understanding of the parental experiences and perspectives following prenatal surgery will play an important role in educating physicians and counseling patients regarding how prenatal surgery for SB may impact families.

## Sociodemographic Characteristics, Health Literacy and Care Compliance in Families with Spina Bifida

McLeod, Daryl J., Gonzalez, Dani., Cooper, Jennifer, Chisolm, Deena, Baxter, Cheryl
*Nationwide Children's Hospital*

**Background** Although infant survival rates in Spina Bifida (SB) have improved over the last half century, children continue to experience a high risk of disease complications, many of which may be preventable with better care compliance. Research in other chronic diseases suggests that compliance and disease control varies by sociodemographic characteristics and may be influenced by health literacy. Little is known about these relationships, however, in a care intensive disease like SB, which may require a higher understanding of health information.
**Methods** Parent caregiver/patient dyads were recruited from a SB clinic. Patients over 21 years of age, non-English speaking, or not accompanied by a parent caregiver were excluded. Data on sociodemographic characteristics, medical management and compliance were collected. The Newest Vital Signs (NVS) was administered to evaluate health literacy.
**Results** A total of 105 parent caregiver/patient dyads agreed to participate and completed all materials. Twenty-six (24.8%) parent caregivers had scores consistent with limited health literacy. Nearly half (46.9%)

of parents of children on clean intermittent catheterization (CIC) reported that their child missed at least one catheterization during the previous week. Medicaid insurance, less parental education and lower household income were associated with lower health literacy (all $p < 0.001$). Parent caregivers who missed 4 or more catheterizations per week had lower NVS scores than parents whose children missed fewer or none ($p = 0.03$).

**Conclusions** Medicaid insurance, less parent caregiver education and lower household income are associated with lower health literacy, which is in turn associated with decreased compliance with CIC. These results demonstrate the importance of considering family sociodemographic characteristics and health literacy when tailoring care plans to ensure barriers to care compliance are minimized.

## Depressive Symptoms in Parents of Children with Spina Bifida: A Review of the Literature

Ridosh, Monique[1], Sawin, Kathleen J.[2,3], Klein-Tasman, Bonnie[2], Holmbeck, Grayson[1]
[1]*Loyola University Chicago*
[2]*University of Wisconsin-Milwaukee*
[3]*Children's Hospital of Wisconsin*

**Background** To review the literature on the prevalence of depressive symptoms in parents of children with Spina Bifida (SB) and factors related to these symptoms.

**Methods** A search was conducted using the major health databases (CINAHL, MEDLINE, and PsycINFO). Nineteen studies were identified that met inclusion and exclusion criteria. A context, process, and outcome framework was used to organize the findings. Context was the environment in which parental adaptation outcomes occurred and process included the perceptions and activities that led to parental adaptation outcomes.

**Results** This review identified both: (a) a high prevalence of parental depressive symptoms (PDS); and (b) specific factors: demographics, condition factors, child factors, family functioning, and parent factors that explained 32–67% of parent depressive symptoms (PDS). Although contextual factors were important, they alone were not sufficient to explain PDS. Process factors accounted for more variance in PDS than context factors. This body of literature was limited by the small number of studies and design challenges to internal and external validity.

**Conclusions** Although a significant portion of variance remains unexplained, findings warrant implementation of parent depression screening in families of children with Spina Bifida. This review identified factors related to PDS and highlighted gaps in the literature to guide future research on families of children with chronic conditions.

## Assessment of the Impact of Medical Condition on Families of Adolescents with Spina Bifida

Rocque, Brandon G., Graham, Anna, Hopson, Betsy D., Davies, Susan, Blount, Jeffrey
*University of Alabama at Birmingham*

**Background** The transition to adult health care for adolescents with chronic disease is both crucially important and understudied. In an effort to better understand the environment in which healthcare transition takes place for adolescents and young adults with Spina Bifida, we have studied the impact of Spina Bifida on their families.

**Methods** We administered the PedsQL 2.0 Family Impact Module (FIM) to the accompanying family member of all individuals over the age of 12 seen for a routine annual visit in the Children's of Alabama Multidisciplinary Spina Bifida Clinic between June 2015 and March 2016. We extracted clinical and demographic data from the research electronic medical record associated with the National Spina Bifida Patient Registry, collected routinely on all patients. We then constructed linear regression models to examine the relationship between clinical and demographic variables and the FIM total score and sub scores.

**Results** Family members of 59 individuals completed the assessment. The majority of the individuals with Spina Bifida were white non-Hispanic (69%) and had a diagnosis of myelomeningocele (76%), and had a CSF shunt (69%). 53% were female. The mother completed the form in 86% of cases.

History of CSF shunting was significantly associated with lower scores (indicating higher level of family impact) on the FIM total score, physical and social functioning scores, communication and daily activities scores, and the summary scores for parental quality of life and family functioning. Diagnosis of myelomeningocele was significantly associated with higher physical function score. Increasing age was significantly associated with lower level of worry regardless of diagnosis or shunt history.

**Conclusions** Among family members of adolescents with Spina Bifida, the presence of a CSF shunt appears to increase the impact of the child's chronic condition on the family across multiple domains.

**Crawling Onset Facilitates Spatial Cognition in Infants with Lumbar Spina Bifida**

Rivera, Monica J.[1], Campos, Joseph[2], Anderson, David[3]
[1]*California State University, Fresno*
[2]*University of California Berkeley*
[3]*San Francisco State University*

**Background** Previous infant studies show that the onset of crawling increases spatial cognitive (SC) performance in typical developing (TD) infants. Additional studies found that pre-crawling infants use of mobility devices spurs SC development. Thus, there is evidence for mobility onset and increases in spatial cognition. However, it is not known if there is a negative phenomenon taking place in infants with mobility delays. Therefore the purpose of this study is to clarify whether the onset of crawling in infants with lumbar SB demonstrates a significant increase in SC tasks from pre-crawling to crawling.
**Methods** The study was performed at the University of California Berkeley, Infant Study Laboratory. Seven infants with lumbar SB were recruited and tested longitudinally at intervals of 6 to 8 weeks from sitting to the onset of crawling. At each visit, infants were videotaped in three SC experiments: Moving Room (MR), Joint Visual Attention (JVA) and Extraction of Invariant Form (EIF). Two independent coders were blinded to crawling status and quantified the video data using the software programs Interact and Noldus Observer XT. Analysis of the pre and post crawling data was performed using two-way repeated measures ANOVA for JVA and EIF and the t-test for the MR. Significance level was set at 0.05.
**Results** The results for the JVA revealed a main effect for looking at the correct target F (1,24) $= 11.06$, $p < 0.01$. Also, there was a signficant interaction, F (1,24) $= 4.01$, $p = 0.05$. The results for EIF revealed no main effect for looking at the novel form, however there was a significant interaction, F (1,20) $= 8.31$, $p < 0.01$. The results for the MR revealed no significant findings from pre to post crawling.
**Conclusions** In JVA and EIF there were significant spatial cognitive increases from pre to post crawling. These findings provides evidence that in spite of mobility delays, the onset of crawling in infants lumbar SB facilitates SC skills.

**A Model for the Process of Task Performance to Explain Difficulties' in Daily Life in Persons with Spina Bifida**

Peny-Dahlstrand, Marie[1,2]
[1]*Sahlgrenska University Hospital*
[2]*Institute of Neuroscience and Physiology, University of Gothenburg, Sweden*

**Background** Persons with Spina Bifida, adults as well as children, experience problems to carry out the process of doing activities in everyday life, due to executive dysfunctions. Their problems in daily life is often subtle and difficult to understand, both for the persons them self's and for people around them .They are often capable to do many things but still things are often "somehow just never done". There is a need for a model describing the general process of performing a task from idea to goal, i.e. of the *doing*, to explain and discuss ways to overcome this shortcoming in the person's everyday life in a more tangible way. the aim was to describe and discuss the problems in performing everyday activities found in children with Spina Bifida using a model for the general process of task performance.
**Methods** Analyzing the result from recent literature concerning task performance in persons with Spina Bifida, with a six step model that describes the general process of performing tasks.
**Results** Children with Spina Bifida commonly have difficulties with the three first steps of this model (to generate ideas, to plan and to initiate). The fourth step, the actual enacting, is often (at least in familiar activities) the easiest step, once started. But if something's goes wrong, the fifth step (to respond to feedback and problem solve) is difficult for a majority of the group and they need guidance for this. Children with Spina Bifida might know how to do things but they still often don't get tasks done on their own. This affects every type of task/activity.
**Conclusions** The use of a model of general process of task performance can be beneficial to use as a base for the assessment process but also toward the person with Spina Bifida to enhance the understanding of him/herself.