Assessment of the impact of medical condition on families of adolescents with spina bifida

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Myelomeningocele is a complex diagnosis

- Sensory and motor impairments
- Decreased functional mobility
- Respiratory difficulties
- Bowel and bladder dysfunction
- Orthopedic deformities
- Intellectual deficits
- Unique allergy concerns
- Obesity
Spina Bifida Life Expectancy

What is Health Care Transition?

- The process of changing from a pediatric to an adult model of health care.

- **GOAL:** to optimize health and assist youth in reaching their full potential.

- Requirements
  - An organized transition process
  - Support in acquiring independent health care skills
  - Preparation for an adult model of care
  - Transfer of care to new providers without disruption
What is the impact of spina bifida on families of adolescents with spina bifida?
Methods

• PedsQL 2.0 Family Impact Module (FIM)
• Family member of all patients in SB clinic
  • June 2015-March 2016
  • Adolescents with SB (age 13 or over)
• Clinical and demographic data from the research EMR

• Explore relationship between clinical and demographic variables and family impact
  • Linear regression models
PedsQL Family Impact Module

• “Designed to measure the impact of pediatric chronic health conditions on parents and families.”
• 36-item, self-report

• Domains
  • Physical Functioning
  • Emotional Functioning
  • Social Functioning
  • Cognitive Functioning
  • Communication
  • Worry
  • Daily Activities
  • Family Relationships
  • Parent HRQoL
  • Family Functioning
### Results

- **59 completed surveys**

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>N=59</th>
</tr>
</thead>
<tbody>
<tr>
<td>Race/ethnicity</td>
<td>White/non-Hispanic</td>
<td>41 (69%)</td>
</tr>
<tr>
<td></td>
<td>Other</td>
<td>18 (31%)</td>
</tr>
<tr>
<td>Sex</td>
<td>Female</td>
<td>31 (53%)</td>
</tr>
<tr>
<td></td>
<td>Male</td>
<td>28 (47%)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td>myelomeningocele</td>
<td>45 (76%)</td>
</tr>
<tr>
<td></td>
<td>other</td>
<td>14 (24%)</td>
</tr>
<tr>
<td>Relative completing survey</td>
<td>Mother</td>
<td>51 (86%)</td>
</tr>
<tr>
<td></td>
<td>other</td>
<td>8 (14%)</td>
</tr>
<tr>
<td>Age</td>
<td>Mean 17.2 y +- 2.3</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Min 13, Max 21</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>--------------------------</td>
<td>--------------</td>
<td>--------------</td>
</tr>
<tr>
<td>Hydrocephalus (VP shunt)</td>
<td>41 (69%)</td>
<td>18 (31%)</td>
</tr>
<tr>
<td>History of Chiari 2</td>
<td>7 (13%)</td>
<td>50 (87%)</td>
</tr>
<tr>
<td>decompression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>History of tethered cord</td>
<td>22 (39%)</td>
<td>35 (61%)</td>
</tr>
<tr>
<td>release</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ambulation</td>
<td>26 (44%)</td>
<td>4 (7%)</td>
</tr>
<tr>
<td></td>
<td>4 (7%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>2 (3%)</td>
<td></td>
</tr>
<tr>
<td></td>
<td>27 (46%)</td>
<td></td>
</tr>
</tbody>
</table>
Results

• Linear regression modeling

• All collected variables vs…
  • FIM Total score and subscores

• Diagnosis, age, hydrocephalus vs….  
  • FIM Total score and subscore
Results

• Predictor Variables
  • Race, sex, diagnosis, age, hydrocephalus, Chiari 2 decompression, tethered cord release, ambulation, insurance, functional level

• Outcome Variables
  • FIM total score, and all domain subscores

• Significant correlation:
  • Hydrocephalus and
    • Physical
    • Emotional
    • Daily Activities
Results

- **Predictor Variables**
  - Diagnosis, hydrocephalus, age

- **Outcome Variables**
  - FIM total score, and all domain subscores

- **Significant correlation:**
  - **Hydrocephalus** and
    - FIM Total score
    - Physical
    - Social
    - Communication
    - Daily Activities
    - Parent HRQoL
    - Family Relationships
Results

• Predictor Variables
  • Diagnosis, hydrocephalus, age

• Outcome Variables
  • FIM total score, and all domain subscores

• Significant correlation:
  • **Diagnosis** and
    • Physical
  • **Age** and
    • Worry
FIM Total score v. Age and Diagnosis

- No significant correlations
FIM Total Score v. Age and Hydrocephalus

- Significant effect of hydrocephalus ($p=0.01$)
- Similar for
  - Physical
  - Social
  - Communication
  - Daily Activities
  - Parent HRQoL
  - Family Relationships
Physical Function Score v. Age and Diagnosis

• Significant effect of Diagnosis (p=0.01)
Worry Score v. Age and Diagnosis

• Significant effect of Age (p=0.02)
Summary

• The presence of hydrocephalus (CSF shunt) appears to increase the impact of the child’s spina bifida across multiple domains
Summary

• The presence of hydrocephalus (CSF shunt) appears to increase the impact of the child’s spina bifida across multiple domains

• Family ”worry” may decrease with increasing age
VP shunt:
Associated with lower overall ambulation and cognition scores
Literature

- Rich literature on family impact of chronic disease
  - Activities of Daily Living
  - Work
  - Time consumption
  - Parental responsibility
  - Confidence
  - Feelings and emotions
  - Mental health
  - Stress
  - Social Impact
  - Psychological Adjustment
  - Relationships

Factors associated with parent depressive symptoms and family quality of life in parents of adolescents and young adults with and without Spina Bifida.

- Multi-center cross-sectional survey
  - 209 participants
- Having a child with SB is not predictive of parental depression
- Child with SB is a component of family QoL

Conclusions

• Having a child with spina bifida has an impact on the family

• Hydrocephalus appears to increase the magnitude of the effect

• More work is necessary to define best practices
Thank you

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