IMPACT OF URINARY INCONTINENCE ON SELF-CONCEPT IN CHILDREN WITH SPINA BIFIDA

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ABSTRACT

Purpose: Low self-concept and self-esteem are thought to be the main predictors of psychological problems in children and adolescents. Children with spina bifida are thought to be at an increased risk for low self-concept and self-esteem given their disabilities. We examined the impact of urinary continence on self-concept in children with myelomeningocele.

Materials and Methods: A total of 50 patients 7 to 19 years old with spina bifida were evaluated using the Hartner self-perception profile. Each patient was asked to self-rate on a scale of 1 to 4 using specific domains of self-concept, including scholastic competence, social acceptance, athletic competence, physical appearance, behavioral conduct and global self-worth. Continence and several other factors, namely ambulatory status, family situation and insurance status, were reviewed simultaneously.

Results: There were no statistically significant differences between continent patients with spina bifida and controls. Overall children with spina bifida rated lower in scholastic competence, social acceptance and behavioral conduct than controls. Girls with spina bifida scored lower in perceived athleticism, physical appearance and global self-worth than boys with spina bifida. Continent girls were self-rated higher in social acceptance and global self-worth than incontinent girls. Continent boys were self-rated higher in scholastic competence, social acceptance, physical appearance and behavior compared to incontinent boys.

Conclusions: Continence is associated with better self-concept in children with spina bifida and incontinent girls are at particularly high risk for poor self-esteem. Urologists’ efforts to promote continence are likely to have a positive effect on self-concept in boys and girls with spina bifida.

KEY WORDS: abnormalities, meningomyelocele, urinary incontinence, self concept, questionnaires

Low self-concept and self-esteem are believed to be significant predictors of psychological problems in young children and adolescents. How individuals with disabilities value themselves (self-esteem) and view themselves (self-concept) are considered central aspects of psychological functioning. Children and adolescents with spina bifida are thought to be at an increased risk for low self-concept given their physical disabilities and functional impairment. However, studies of self-concept in children with spina bifida are equivocal. The studies of MacBriar and Murch and Cohen failed to demonstrate a difference between patients with spina bifida and controls. On the other hand, others found significant differences in self-concept between children with spina bifida and matched controls.

Zurmohle and Appleton et al also assessed the effect of gender on self-concept. In these 2 studies female patients with myelomeningocele were at greater risk for poor self-image than males and controls. This finding suggests that psychological support and counseling may be particularly valuable for girls, starting at an early age.

It is not surprising that urinary continence would be associated with better self-concept in children. Hinde et al found that self-esteem scores in children with primary nocturnal enuresis were significantly lower than in healthy children. Moffatt et al found improvements in self-concept after treating children with nocturnal enuresis. They concluded that enuresis was a chronic stressor in these children and its alleviation had a positive impact on self-concept. Similarly, Lie et al found that urinary incontinence is a significant life stressor in patients with spina bifida. Of their patients with spina bifida 59% reported that urinary incontinence was a moderate to severe stressor. Interestingly the impact of urinary continence on self-concept in children with spina bifida has only been examined in 1 other study. That study showed no apparent correlation between urinary continence and self-concept.

A more obvious form of physical disability and functional impairment is ambulatory status. Ambulatory status may impact the sense of independence of an individual, how one is treated by peers and in turn on self-concept. Socioeconomic status may also have a significant impact on self-concept by determining access to health care, medications and medical supplies.

To determine whether there is a relationship between continence and self-concept in our population and ascertain whether the severity of the medical disability has a significant role in self-perception we evaluated the impact of urinary incontinence, ambulatory status and socioeconomic status on self-concept.

PATIENTS AND METHODS

Consecutive patients 6 to 19 years old with spina bifida attending the pediatric urology clinic at our institution were asked to complete a 2-part questionnaire in clinic. Patients who did not complete a questionnaire in the clinic were mailed a questionnaire. Two families refused to participate in the study and 15 others failed to return the questionnaire. Part 1 (medical assessment) asked 6 questions regarding urinary and fecal function, and ambulatory status (see Appendix). Continence was defined as dry without diapers or pads. Patients were considered ambulatory if they were able to ambulate.
to walk with or without braces. Part two consisted of the Hartner Self-Perception Profile for Children, entitled “What I Am Like.” A total of 24 girls and 26 boys participated. Information on socioeconomic status was obtained from insurance information given at the time of patient registration.

**Test instruments.** Self-concept was measured using a validated psychological tool, the Hartner Self-Perception Profile for Children, which is a revision of the 1982 Perceived Competence Scale for Children. This questionnaire measures self-concept by focusing on 6 domains, namely scholastic competence, social acceptance, athletic competence, physical appearance, behavioral conduct and global self-worth. Each domain is evaluated using 6 questions that attempt to determine how the participant perceives competence in that domain. For each question subjects self-rate themselves on a scale of 1 to 4. A score of 1 indicates low perceived competence, whereas a score of 4 indicates a high degree of perceived competence.

**Analysis procedures.** Participant scores were compared with published gender specific normative values for each scale. The normative sample consisted of school children in grades 3 to 8. The t test was performed to compare mean values in children with spina bifida vs controls, male vs female patients with spina bifida and continent vs incontinent patients with spina bifida. Statistical significance was defined by p < 0.05.

### RESULTS

A total of 24 girls and 26 boys participated in the study. Table 1 lists patient age and sex distributions. Eight girls and 2 boys were completely continent (no diapers or pads), while 33 patients had high bladder pressure and were on anticholinergic medication. Continent patients tended to have undergone fewer total operations than incontinent patients and yet there was no difference in the total number of urological surgeries between the 2 groups. Ten girls and 13 boys were ambulatory with or without braces. Of the 50 patients 33 had private insurance vs 17 who had Medicaid as primary insurance.

Significant differences were noted between patients with spina bifida and controls (table 2). In particular, patients scored lower in behavioral, scholastic and social competence than controls. Gender also had an impact on self-concept. Girls with spina bifida tended to be lower in perceived athleticism, physical appearance, social acceptance and global self-worth than boys. However, only the difference in athleticism attained statistical significance.

Significant differences were found between continent and incontinent patients with spina bifida. Continent patients scored higher in global and social acceptance, and scholastic competence than incontinent patients. Indeed, there were no statistically significant differences between continent patients with spina bifida and controls. On the other hand, incontinent patients scored lower in social acceptance and global self-concept than controls. Results in girls in particular were even more obvious. Incontinent girls scored lower than controls in social acceptance, scholastic and athletic competence, and behavioral conduct, while there were no statistical differences between continent girls and controls.

### DISCUSSION

We found that our population of children with spina bifida had lower self-concept than controls. This was particularly true for girls. Furthermore, urinary continence was associated with normal self-concept.

Our finding that children with spina bifida have lower self-concept than controls is similar to the findings of King et al. and Borjeson and Lagergren. However, our results differ from those in the studies by MacBriar, and Murch and Cohen, which failed to demonstrate a difference between patients with spina bifida and controls. An explanation of these differences may be related to the survey instrument. We used a validated questionnaire, whereas the latter 2 studies used test instruments that may not be as accurate. Further support for our findings in spina bifida is shown in studies of children and adolescents with other chronic illnesses and disabilities that demonstrated a higher risk of poor self-concept. Using a different survey Hayden et al also found that adolescent girls with spina bifida expressed more social concerns, including isolation and loneliness, than control girls. Interestingly, it is true also for children with other chronic illnesses. In the study of King et al girls with cerebral palsy and cleft palate also had lower self-perception of social acceptance, athletic competence and romantic appeal than controls. Magill and Hurlbut also found that girls with cerebral palsy had lower self-esteem than female controls.

### Table 2. Self-concept data on continent vs incontinent patients with spina bifida

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mean Controls ± SEM</th>
<th>Mean Incontinent ± SEM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Athletic</td>
<td>3.00 ± 0.80</td>
<td>3.06 ± 0.20</td>
</tr>
<tr>
<td>Boys</td>
<td>2.50 ± 0.80</td>
<td>2.46 ± 0.22</td>
</tr>
<tr>
<td>Girls</td>
<td>3.30 ± 0.60</td>
<td>3.27 ± 0.15</td>
</tr>
<tr>
<td>Behavioral:</td>
<td>3.50 ± 0.60</td>
<td>3.40 ± 0.29</td>
</tr>
<tr>
<td>Boys</td>
<td>3.15 ± 0.70</td>
<td>3.22 ± 0.40</td>
</tr>
<tr>
<td>Girls</td>
<td>3.10 ± 0.80</td>
<td>2.83 ± 0.24</td>
</tr>
<tr>
<td>Physical:</td>
<td>3.30 ± 0.60</td>
<td>3.29 ± 0.20</td>
</tr>
<tr>
<td>Boys</td>
<td>3.20 ± 0.70</td>
<td>3.39 ± 0.09</td>
</tr>
<tr>
<td>Girls</td>
<td>3.50 ± 0.70</td>
<td>2.86 ± 0.38</td>
</tr>
<tr>
<td>Scholastic:</td>
<td>3.50 ± 0.60</td>
<td>3.31 ± 0.20</td>
</tr>
<tr>
<td>Boys</td>
<td>3.40 ± 0.60</td>
<td>3.48 ± 0.14</td>
</tr>
<tr>
<td>Girls</td>
<td>3.50 ± 0.60</td>
<td>3.44 ± 0.24</td>
</tr>
<tr>
<td>Social:</td>
<td>3.10 ± 0.70</td>
<td>2.71 ± 0.13</td>
</tr>
<tr>
<td>Boys</td>
<td>3.20 ± 0.60</td>
<td>3.27 ± 0.20</td>
</tr>
<tr>
<td>Girls</td>
<td>3.10 ± 0.70</td>
<td>3.15 ± 0.20</td>
</tr>
</tbody>
</table>

* p < 0.05.

### Table 3. Self-concept data on ambulatory vs nonambulatory patients

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mean Ambulatory ± SEM</th>
<th>Mean Nonambulatory ± SEM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Athletic</td>
<td>2.43 ± 0.13</td>
<td>2.81 ± 0.15</td>
</tr>
<tr>
<td>Behavioral:</td>
<td>2.90 ± 0.11</td>
<td>3.14 ± 0.13</td>
</tr>
<tr>
<td>Physical:</td>
<td>2.91 ± 0.16</td>
<td>3.07 ± 0.16</td>
</tr>
<tr>
<td>Scholastic:</td>
<td>3.02 ± 0.16</td>
<td>3.27 ± 0.17</td>
</tr>
<tr>
<td>Social:</td>
<td>2.80 ± 0.14</td>
<td>2.82 ± 0.16</td>
</tr>
<tr>
<td>Global:</td>
<td>2.96 ± 0.15</td>
<td>3.24 ± 0.11</td>
</tr>
</tbody>
</table>

* p < 0.05.
In our study gender also had a strong relationship to self-concept with girls having lower scores than boys. Using the same survey instrument King et al found that adolescent girls with spina bifida had lower self-esteem than males with spina bifida. Similarly, Appleton and Zurholme et al found that gender had a powerful influence on self-concept with female patients with spina bifida at higher risk for poor self-concept than their male counterparts. These studies suggest that physical appearance and social acceptance are more strongly associated with self-worth in girls than in boys with spina bifida.

Based on these studies an obvious explanation of our findings is that the physical appearance of these children with spina bifida is noticeably different, which may be an important influence on self-concept. To test this explanation we compared self-concept in ambulatory vs wheelchair bound patients with spina bifida. Our data show no difference between these 2 groups. Because it is the most obvious sign of physical disability, our finding argues against the theory that physical appearance is the most important determinant of self-concept in our patients.

In contrast to the results of Minchom et al, our data show that urinary continence is associated with a significantly better self-concept in our population. In particular, continent patients with spina bifida rated themselves with normal social acceptance and global self-worth. An explanation of the difference in our findings from those of Minchom et al may be related to our strict definition of continence. In contrast to many studies that used dry intervals or patient reported history for this definition, we chose to consider children continent only when they required no diapers or pads.

Additional support for our results comes from a recent study of the psychosocial functioning of children with myelomeningocele before and after the Malone antegrade continence enema procedure. In that study 20 children completed the Hartner Self-Perception Profile prior to surgery and then 6 months after the procedure. Postoperatively these children reported increased self-reliance, independence and a feeling of security, leading to significant improvements in self-esteem. These results are in concordance with our findings that better continence is associated with better self-concept.

A weakness of our data is that our study was cross-sectional. Although our data show an association between continence and improved self-concept, it would be more convincing if we were able to demonstrate improvements in self-concept after successful pharmacological or surgical intervention to improve continence. This project is ongoing at this time.

Another potential weakness of this study is that we compared our data with those on a previously reported normative group. The use of normative controls has some risks, although it would not have been feasible to obtain matched data from a large enough series of normal children to make a valid comparison. It is also important to remember that control data were collected from schoolchildren in the United States. Hence, the conclusions may not be generalizable to other cultures.

Although we specifically assessed the impact of gender on self-concept, we did not evaluate age specific differences in self-concept. The age range in our study is broad at 7 to 19 years. Undoubtedly there are differences in the degree of body awareness as one matures. However, there were too few patients to divide into age groups.

Given the small number of patients, we did not perform multivariate analysis. Therefore, a number of confounding variables, namely the number of operations, family situation, medication compliance and adherence to clean intermittent catheterization regimens, were not analyzed. These factors may impact self-concept and it would be worthwhile to investigate them in the future.

CONCLUSIONS

We found that our population of patients with spina bifida was at risk for low self-concept. It was particularly true for girls. On the other hand, patients who were totally continent and did not require any protective undergarments had a self-concept similar to that of normative controls.

APPENDIX: MEDICAL ASSESSMENT QUESTIONNAIRE

1) Number of operations since birth: __________

2) Number of urological operations: __________

3) Number of hospitalizations: __________

4) Number of parental caretakers: __________

5) Please circle which best describes your situation:

   a) Ambulation
      1) Wheelchair bound
      2) Urinary continence
      1) No control
      2) Bowel continence
      1) No control
      2) Insurance
      1) Private insurance

   b) Urinary continence
      1) No control
      2) Bowel continence
      1) No control
      2) Insurance
      1) Private insurance

2) Walks with braces
3) Walks without braces
2) Good control
3) Complete control
2) Good control
3) Complete control
2) Medicaid


10. Lie, H. R., Lagergren, J., Rasmussen, F., Lagerkvist, B., Hagelsteen, J., Borjeson, M. C. et al: Bowel and bladder con-