Guidelines for the Care of People with Spina Bifida Research Priorities

Brad E. Dicianno, MD
Associate Professor
Dept. of Physical Medicine and Rehabilitation
University of Pittsburgh Medical Center
• No conflicts of interest to report.
• This project is supported by:
  • The Spina Bifida Association
  • Spina Bifida Collaborative Care Network
  • The Centers for Disease Control and Prevention
• Prior guidelines published in 2006
• 14 sections
9 new topic areas suggested:
• Medical Director
  • Tim Brei

• Steering Committee Co-Chairs
  • Pat Beierwaltes
  • Brad Dicianno
  • Nienke Dosa

• Patient Advisory Group

• Executive Committee
  • Sara Struwe
  • Judy Thibideau
  • Julie Bolen
  • Adrienne Griffin
  • Lisa Raman
  • Jerome Chelliah

• 24 Working Group Chairs
  • Working Group members

• CDC Staff
• SBA Staff and Students
Recognized consensus-building methodologies for the development of clinical practice guidelines
  - Single Text Procedure
  - Nominal Group Technique

More than 80 experts participated in the process

Multi-disciplinary groups

Spans newborn to adult

For both SB providers and PCPs
• **Outcomes** – what we wish to achieve with good care

• **Clinical questions** – important questions that were targets of the lit review

• **Guidelines** – recommendations for care that are based on the lit review and clinical consensus

• **Research gaps** – important topics where research and clinical consensus are lacking
  - Synergistic areas with NSBPR
• 2018 Guidelines for the Care of People with Spina Bifida
  • [https://www.spinabifidaassociation.org/resource/guidelines/](https://www.spinabifidaassociation.org/resource/guidelines/)

• Methodology
HEALTHCARE GUIDELINES RESEARCH GAPS
- Publish Guidelines - research gaps identified
- Publish community- research priorities identified

RESEARCH PRIORITIES OF PEOPLE LIVING WITH SPINA BIFIDA
- Use community’s research priorities to advocate for funding (NIH, PCORI, etc.) and to identify Calls for Proposal that investigators can pursue

HIGH PRIORITY RESEARCH

RESEARCH THAT CAN BE DONE WITH NSBPR
- Review community priorities and opportunities for research in NSBPR
- Review Guidelines and opportunities for research in NSBPR
Survey Methodology

• Online survey
  • Emailed survey link to SBA database of +/-20,000, and posted on SB Facebook pages April/May, 2019
  • Survey was offered in English and Spanish

• 1717 total responses
  • 1,607 among “qualified respondents” (parents of children under and over 18 with SB, adults with SB, and caregivers of person with SB)

• Follow up focus groups conducted in May, 2019 during Teal on the Hill event
  • Parents of child with SB, and Adults with SB
Respondent Characteristics

**Person Surveyed**

- Adult with SB - 45%
- Parent of Child <18 with SB - 32%
- Parent of Child >18 with SB - 17%
- Caregiver of person with SB - 6%

**Gender**

- Females - 82%
- Males - 18%
<table>
<thead>
<tr>
<th>27 Items Evaluated</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Accessing Coordinated Care b/w PCPs &amp; Specialists</strong></td>
</tr>
<tr>
<td><strong>Finding Doctors who care for Adults/Children with SB</strong></td>
</tr>
<tr>
<td><strong>Obstructive Sleep Disorders /Sleep Apnea</strong></td>
</tr>
<tr>
<td><strong>Encourage Self-Management Behaviors in Children</strong></td>
</tr>
<tr>
<td><strong>Independence/Ability to Care for Oneself</strong></td>
</tr>
<tr>
<td><strong>Ensuring Daily Physical Activity</strong></td>
</tr>
<tr>
<td><strong>Mobility</strong></td>
</tr>
<tr>
<td><strong>Pain Related to Mobility</strong></td>
</tr>
<tr>
<td><strong>Use of HGH/Human Growth Hormone</strong></td>
</tr>
</tbody>
</table>
Questions

How much of an issue is ________________

• A very big issue
• Somewhat of an issue
• Not much of an issue
• Not an issue at all
Choose up to 5 items from the list below that are the biggest issues or concerns you have about living with Spina Bifida.*

*Respondents were provided previous list of items; order of items were rotated for each respondent
Top 5 Biggest Issues/Problems Overall*

<table>
<thead>
<tr>
<th>Parents of Child &lt;18 with SB</th>
<th>%</th>
<th>Parents of Child &gt; 18 with SB</th>
<th>%</th>
<th>Adults with SB</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bowel Incontinence</td>
<td>64</td>
<td>Finding Doctors</td>
<td>50</td>
<td>Finding Doctors</td>
<td>55</td>
</tr>
<tr>
<td>Urinary Incontinence</td>
<td>51</td>
<td>Bowel Incontinence</td>
<td>49</td>
<td>Bowel Incontinence</td>
<td>51</td>
</tr>
<tr>
<td>Independence</td>
<td>50</td>
<td>Independence</td>
<td>44</td>
<td>Managing Weight</td>
<td>44</td>
</tr>
<tr>
<td>Encourage Self Mgt</td>
<td>48</td>
<td>Managing Weight</td>
<td>40</td>
<td>Urinary Incontinence</td>
<td>43</td>
</tr>
<tr>
<td>Learning Disabilities/Attention Disorders</td>
<td>41</td>
<td>Learning Disabilities/Attention Disorders</td>
<td>32</td>
<td>Depression/Mental Health</td>
<td>42</td>
</tr>
</tbody>
</table>

*Multiple responses
Respondents were asked to mention any other/additional issues that were problems for themselves or their children with SB. Some of the areas mentioned included:

- Issues related to out-of-pocket expenses and items not covered by insurance
  - Medical supplies
  - Medical equipment
  - Mobility equipment
- Not enough SB clinics for adults, or physicians with SB expertise
- Transitioning from pediatric to adult care
- Employment/jobs for people with SB
- Socialization opportunities for children and adults with SB
How or where do Adults/Parents get information about SB?

- Online Searches: 49
- Physicians/Specialists: 48
- SBA Website/National Resource Center: 47
- Other People with SB: 43
- Support Groups: 25
- PCP/Primary Care Physicians: 18
- Local SB Chapter Meetings/Events: 14
- SBA Programs & Education Days: 7
- Centers for Disease Control (CDC): 6
- IFSBH: 3
- Other: 15

*Multiple responses*
Breakouts

- Bowel Management
- Nutrition, Obesity & Metabolic Syndrome
- Urology
- Mobility & Orthopedics
- Neuropsychiatry & Neurosurgery
- Skin Breakdown
Ongoing and New Research Opportunities

- Effects of medications and bowel interventions on continence
- Effects of a defined bundle of prevention strategies on skin breakdown
- Accurate assessment of body composition, growth curves and weight classification
- Relationship between continence and quality of life
- How do patients define continence?
- Is there a “threshold” for social continence? Quantity vs. Frequency.
- What orthopedic issues/surgeries affect mobility outcomes?
- Relationships between neurosurgical interventions and neuropsych outcomes
Questions & Comments
Respondent Demographics

<table>
<thead>
<tr>
<th>Age of Person &gt;18 with SB*</th>
<th>%</th>
<th>Age of Child &lt;18 with SB</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>18-24</td>
<td>17</td>
<td>0 - 11 months</td>
<td>5</td>
</tr>
<tr>
<td>25-34</td>
<td>25</td>
<td>1 - 2 years</td>
<td>10</td>
</tr>
<tr>
<td>35-44</td>
<td>28</td>
<td>3 - 5 years</td>
<td>19</td>
</tr>
<tr>
<td>45-54</td>
<td>16</td>
<td>6 - 12 years</td>
<td>45</td>
</tr>
<tr>
<td>55-64</td>
<td>10</td>
<td>13 - 17 years</td>
<td>21</td>
</tr>
<tr>
<td>65+</td>
<td>4</td>
<td>Total</td>
<td>100%</td>
</tr>
<tr>
<td>Total</td>
<td>100%</td>
<td>Total</td>
<td>100%</td>
</tr>
</tbody>
</table>

*Includes Adults with SB and Adult Children >18 with SB
### Respondent Demographics (continued)

#### Education

<table>
<thead>
<tr>
<th>Education</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than High School</td>
<td>2</td>
</tr>
<tr>
<td>HS Graduate</td>
<td>12</td>
</tr>
<tr>
<td>Technical/Trade School</td>
<td>4</td>
</tr>
<tr>
<td>Some College/2-year degree</td>
<td>28</td>
</tr>
<tr>
<td>College Degree (BA. BS)</td>
<td>32</td>
</tr>
<tr>
<td>Master’s/PhD</td>
<td>21</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

#### Race/Ethnicity*

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>African American/Black</td>
<td>3</td>
</tr>
<tr>
<td>Caucasian/White</td>
<td>87</td>
</tr>
<tr>
<td>Asian American/Asian</td>
<td>2</td>
</tr>
<tr>
<td>American Indian/Alaskan Native</td>
<td>1</td>
</tr>
<tr>
<td>Native Hawaiian/Pacific Islander</td>
<td>&lt;1</td>
</tr>
<tr>
<td>Multi Racial</td>
<td>3</td>
</tr>
<tr>
<td>Other/DK</td>
<td>7</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>100%</strong></td>
</tr>
</tbody>
</table>

*Multiple responses

| Hispanic/Latino                  | 10 |

* Totals may not sum to 100% due to rounding.