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Evaluation of Spina Bifida Transitional Care Practices in the US

Maryellen S Kelly¹, Sara Struwe², Judy Thibadeau³, Lisa Ramen², Lijing Ouyang³, Jonathan Routh¹

¹Duke Medicine, Durham, NC; ²Spina Bifida Association, Arlington, VA; ³Centers for Disease Control and Prevention, Atlanta, GA

• Does not intend to discuss commercial products or services.

• Does not intend to discuss non-FDA approved uses of products/providers of services.
Background

Spina bifida has seen increased survival into adulthood
Estimate 75% of children survive into adulthood

Changing care for different life stages

Lack of continuity for adult-centered care can have health consequences
• National Survey of Children with Special Health Care Needs
  • Half of families had conversations about changing health needs
  • 1:5 discussed transition with providers

• Increasing proportion of SB patients seeking medical attention at ED than scheduled providers
Objective

• Describe the current transitional care services offered within the US
Methods

Survey development

- Modeled after validated transition survey for Cystic Fibrosis
- Revised to spina bifida needs
  - Following Life-Course conceptual model for transition
  - Three domains:
    - Health and condition self-management
    - Social and personal relationships
    - Education/ income support
- 120 questions (Phew!)
Methods

**Completion**

- Voluntary survey completion
  - Clinic directors/coordinators
  - US only

- Distributed via the SBA listserv

- Multiple responses were averaged
Results

- 34 clinics responded (completely)
- 19/21 NSBPR clinics
Results

2/3 have a transitional care program

2/3 discuss transition at least 75% of the time with pediatric patients

Av. Age =15 years (Range 10-25)

Prompted by age ~50%

Other factors:
Provider availability
Stability
Geography
Cognitive level
Social changes
We have some transitional care programs and we discuss transition.....

What’s included?
### Adolescent/Young adult needs

<table>
<thead>
<tr>
<th>Topic</th>
<th>Discussed &gt;75%</th>
<th>50%</th>
<th>&lt;25%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Home/Family</td>
<td>82%</td>
<td>13%</td>
<td>5%</td>
</tr>
<tr>
<td>Social relationships</td>
<td>89%</td>
<td>9%</td>
<td>2%</td>
</tr>
<tr>
<td>Dating</td>
<td>60%</td>
<td>31%</td>
<td>9%</td>
</tr>
<tr>
<td>Educational plans</td>
<td>96%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>Extracurricular</td>
<td>96%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>Weight/Diet</td>
<td>87%</td>
<td>11%</td>
<td>2%</td>
</tr>
<tr>
<td>Substance use</td>
<td>58%</td>
<td>29%</td>
<td>13%</td>
</tr>
<tr>
<td>Mental health</td>
<td>77%</td>
<td>18%</td>
<td>5%</td>
</tr>
<tr>
<td>Sex</td>
<td>67%</td>
<td>17%</td>
<td>16%</td>
</tr>
<tr>
<td>Fertility</td>
<td>53%</td>
<td>26%</td>
<td>21%</td>
</tr>
<tr>
<td>Mobility</td>
<td>96%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td>96%</td>
<td>4%</td>
<td></td>
</tr>
<tr>
<td>Self-advocacy</td>
<td>82%</td>
<td>18%</td>
<td></td>
</tr>
</tbody>
</table>
### Assessing independence

<table>
<thead>
<tr>
<th>Discussed:</th>
<th>&gt;75%</th>
<th>50%</th>
<th>&lt;25%</th>
</tr>
</thead>
<tbody>
<tr>
<td>List medical providers</td>
<td>45</td>
<td>30</td>
<td>25</td>
</tr>
<tr>
<td>List meds and use</td>
<td>60</td>
<td>27</td>
<td>13</td>
</tr>
<tr>
<td>Contact pharmacy</td>
<td>36</td>
<td>36</td>
<td>28</td>
</tr>
<tr>
<td>CIC</td>
<td>96</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Bowel routine</td>
<td>96</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Medical supplier</td>
<td>56</td>
<td>30</td>
<td>14</td>
</tr>
<tr>
<td>Transportation</td>
<td>49</td>
<td>40</td>
<td>11</td>
</tr>
<tr>
<td>Plan and attend visits</td>
<td>50</td>
<td>41</td>
<td>9</td>
</tr>
<tr>
<td>Preventative care</td>
<td>56</td>
<td>30</td>
<td>14</td>
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<tr>
<td>Emergency care identification</td>
<td>80</td>
<td>14</td>
<td>6</td>
</tr>
<tr>
<td>Identify source of insurance</td>
<td>42</td>
<td>35</td>
<td>23</td>
</tr>
<tr>
<td>Contact insurance</td>
<td>26</td>
<td>38</td>
<td>36</td>
</tr>
<tr>
<td>Developmental maturity for adult-centered care</td>
<td>67</td>
<td>19</td>
<td>14</td>
</tr>
</tbody>
</table>
Things we are good at!

We are involving families in planning! (78% do this consistently)

We are giving out educational information! (67% do this consistently)

We ask about patient’s health goals! (53% do this consistently)
Things we are good at!

We assess understanding of transition in patients AND families! (47%/53% do this consistently)

Communicating with the PCP! (>80% do this consistently)
Things we aren’t that great at:

We don’t assess patient’s readiness to transition well
(38% do this consistently)

If we do assess it
  Peds team reviews it consistently only 30% of the time
  Adult team reviews it consistently only 8% of the time
We share the results in the medical record only ~25% of the time
Make a plan to address needs 50% of the time
Things we aren’t that great at:

Following a standard process

<60% have a protocol for transition

Confirming that a patient has transferred care <30%

Discussing insurances changes and how to maintain benefits
46% of clinics provide a written medical summary consistently. 66% of these are standardized.

Most commonly included items:
- Medication list
- Names of health providers
- Current therapies (CIC, AFOs etc)
- Evaluation of self-sufficiency at therapies
- Surgical history
- Relevant psycho-social concerns

Things we often leave out:
- Adherence concerns
- History of communication barriers
Evaluating ourselves

Over 25% have never evaluated their transition process
Another 30% do this less than annually

When we do we generally evaluate:
  Patient satisfaction
  Family satisfaction
  Individual patients’ experiences
  Communication between adult and pediatric teams

What we leave out:
  Clinical outcomes
  Health provider satisfaction
Self reflection

Less than 7% have hired a staff member to work on transitional care needs

Most report placing “very little” effort on improving process

Overall clinics self-rated their process as average in fulfilling patients’ needs (5 out of 10)
Things we aren’t that great at:

Clinics report they are weakest at
- Receiving institutional support
- Having resources for families
- Discussing insurance changes
- Communicating between adult and pediatric providers
- Following up to ensure transition has occurred
Conclusion

• Broad range of services offered at clinics
• Little consistency and evaluation

• Need for investigation into how patients are fairing after transition to guide models for ideal transitional care practices