The Experience of Transition to Adulthood for Youth with a Neurological Condition

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Study Funding

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• M. Bellin, PI. University of Maryland School of Social Work
Background

• The purpose of this study was to examine the transition to adulthood in young adults with spina bifida.

• Grounded in the Ecological Model of Secondary Conditions and Adaptation in spina bifida.

(Sawin, Buran, Brei, & Fastenau, 2003a)
Transition is defined as the developmental period when the adolescent becomes a young adult while increasing self-management of their chronic condition and independence in their social environment.
Why We Were Interested in this Study

• Program of research for team members:

  – Previous studies conducted and publications in this field of participants living with spina bifida.
  – Middle range theory of Inner Strength in Women with Chronic Health Conditions developed by Roux & Dingley 2002.
Spina Bifida

• Congenital chronic health condition caused by a failure of neural tube closure in a critical period of fetal development.

• Approximately 2 of every 10,000 live births.  
  (CDC, 2009)

• Advances in care have increased life expectancy into adulthood.
Aims of the Study

Explore two specific dimensions of the transition experience:

1) self-management

2) independence & the role of inner strength in the pursuit of independence
Concepts in the Literature

• **Role Negotiation** - Parental role negotiation & overwhelming stress related to incontinence.  
  
  (Sawin & Thompson, 2009)

• **Stigma** - Living with a disability and potential of accidents impacts the level of social interaction experienced.  
  
  (Sawin & Thompson, 2009)

• **Moderating Factors impacting Adaptation** - family factors (resilience, family resourcefulness, and care adequacy).  
  
  (Sawin et al., 2003)
Method

- Narrative inquiry was the qualitative design used for this study
- Researcher is interpreter of the participants’ voice focusing on the relationship between individuals’ life stories and the quality of their lives
- “Retrospective meaning-making”
Participants

• 10 participants aged 18-25 years living in a Midwest U.S. metropolitan city & receiving care at a large teaching hospital.

• Site was one of the five sites in the longitudinal multi-site study on transition in young adults with spina bifida.

(Bellin et al., 2010)
<table>
<thead>
<tr>
<th>Characteristic</th>
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<tbody>
<tr>
<td>Gender</td>
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<tr>
<td>Male</td>
<td>6 (60%)</td>
</tr>
<tr>
<td>Female</td>
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<tr>
<td>Age of participants</td>
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<tr>
<td>18-20 yrs</td>
<td>2 (20%)</td>
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<tr>
<td>22-24 yrs</td>
<td>7 (70%)</td>
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<tr>
<td>25 yrs</td>
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<tr>
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<tr>
<td>Myelomeningocele</td>
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<td>Lipomyelomeningocele</td>
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<tr>
<td>Functional Motor level</td>
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<td>High lumbar</td>
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<tr>
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<td>2 (20%)</td>
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<tr>
<td>Low lumbar</td>
<td>2 (20%)</td>
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<tr>
<td>Sacral</td>
<td>3 (30%)</td>
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</table>
Results

Themes capturing dimensions of the participants’ experiences emerged in their responses.

1) Struggling for independence
2) Limiting social interactions & experiences with stigma
3) Building inner strength
Struggling for Independence

“My parents should have made me do it sooner.”

I didn’t want to do it. I was really scared I’d hurt myself even if it hadn’t hurt when he or my mom did it before. I didn’t want to do it at school either. I didn’t want anyone to see. But I had an accident one time when I didn’t do it and wet my sleeping bag at a sleepover. I rolled it up but always catheterized after that. My dad made sure too. . . my parents should have made me do it sooner. I was almost in 6th grade when I started catheterizing.
Limiting social interaction and stigma
"the looks"

I didn’t want to get up if I messed. They really thought I could control or should . . . and I did try new things but in gym it was hard because I wore a diaper . . . people not feeling I could do normal things because I was in a chair, just the kids making fun, the looks. I didn’t really know anybody else with spina bifida unless I came to clinic.
Building Inner Strength

“I believe I can accomplish most things”

It’s no ones fault I have spina bifida. It just happens. I have friends who have diabetes, have been in car accidents. Life isn’t easy for them all the time either. My family has always been there for me. I believe I can accomplish most things. I might have to make an adjustment here and there but most things I can do. I go to church and I know this helps my family too.
Discussion

• Fluctuation of transition between individuation and dependence on parents.

• Financial independence further prolonged as participants were seeking opportunities to gain employment and “move forward.”
Discussion

• Limited social interaction affected building relationships with peers of their own age.

• Plea for meaningful participation in care management decisions was heard as need for improved communication patterns with family, school nurses, and school teachers.
Discussion

The Ecological Model of Secondary Conditions and Adaptation’s protective processes:

– adolescent/young adult resilience
– family resourcefulness
– health care adequacy

(Sawin et al. 2003a; Sawin & Thompson 2009)

This study suggests expansion to include:

– peer relationships
– community engagement (e.g. school, camp, wheelchair basketball)
Limitations

• Themes that emerged from this analysis may be influenced by the interview guide.

• Qualitative interview data was collected at only one of the five study sites in the larger transition study.

• Limited geographic, ethnic, and family diversity.
Implications for Practice

Targeted interventions for individuals and families to promote:

- social & peer relationships
- early building of job skills
Implications for Practice

• Need for interdisciplinary tailored care models to promote self-management in adolescence

Common care issues in research findings:

• Social stigma
• Lack of peer interaction
• Limited involvement in care decisions
• Improved continence programs
• Need for employment opportunities
Implications for Practice

Building interdisciplinary transition programs in the community

• Schools
• Health Systems
• Transition from acute children’s medical centers to primary clinics in the community
Future Research Implications

Intervention studies & outcome research designs to include:

- Development of online support mechanisms.
  - Online education for parents  http://www.sbpreparations.org/
  - Online support communities  http://www.sbtween2teen.org/

- Evaluation of interdisciplinary models of tailored care for families with children with spina bifida prior to transition period.
Themes and Implications for Interventions

**Adaptation & Self-management & Independence**

*Struggling for independence*
- Promote early role negotiation
- Improve family & community communication patterns
- Create opportunities to practice independence
- Support employment opportunities

*Limiting social interaction & stigma*
- Educate against labeling
- Foster peer relationships

*Building inner strength*
- Foster connectedness

Figure 1 Themes and Implications for Interventions

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References


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