SBA Educational Summit: Building Collaborative Ties to Create Seamless Access from Pediatric to Adult Services

Suzanne Fortuna, MSN, RN, APRN-BC, CNS-BC, FNP-BC
Mary Beth Zeni, ScD, RN - Associate Professor, Ursuline College

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Disclosures

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• Presenter does not intend to discuss commercial products or services either presenter.

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

• Spina Bifida (SB) is a neural tube defect

• Problem: Since population living longer into adulthood, need to establish transition into adult-based services

• Lack of adult clinics/medical homes in parts of Ohio

• Spina Bifida Association of America sponsored northeast Ohio Adult Education Day
Needs Assessment

• Phone interview 7 children’s hospitals in Ohio

• Status of adult-based care

• Successful Transition Teams noted in parts of the state

• Not as common for adult-based programs compared to pediatric-based programs

• Unclear what happens after an adolescent/young adult ages out of pediatric programs
Purpose

• Provide an Educational Summit for people living with SB, families, and both pediatric and adult health care professionals.

• Identification and education of key stakeholders involved in transition services is first needed to promote engagement toward a common goal.

• Aim to establish a core group of people committed to plan, implement, and evaluate adult transition services for adolescents and young adults living with SB.
Systematic Literature Review

• PICOT question: Does participation in an Adult Spina Bifida Transition Program improve quality of life (QOL) and decrease Emergency Department (ED) visits compared with no participation over a 5 year period?

• Based on Melnyk and Fineout-Overholt framework

• Databases searched: Medline, Pub Med, CINAHL, Cochrane, ProQuest, and Virginia Henderson

  • Search focused on key words
  • Inclusion/Exclusion criteria
  • Time frame: 2010 – 2015

• Results
### Systematic Literature Review

**Table 1: Transition to Spina Bifida Adult Care: Evaluation Table**

Source: [http://links.lww.com/AJN/A10](http://links.lww.com/AJN/A10)

<table>
<thead>
<tr>
<th>First Author (Year)</th>
<th>Conceptual Framework</th>
<th>Design/Method</th>
<th>Sample/Setting</th>
<th>Major Variables Studied (and Their Definitions)</th>
<th>Measuremen</th>
<th>Data Analysis</th>
<th>Findings</th>
<th>Appraisal: Worth to Practice</th>
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<tbody>
<tr>
<td>Sawin, K. 2015</td>
<td>TCM</td>
<td>Qualitative evaluation obtained from telephone interviews Descriptive longitudinal study</td>
<td>Convenience sample AYA with SB 18-35 yrs n= 24 parents with children with SB aged 41-63 n=16</td>
<td>Themes: PE=positive experience ET=Establishing Trust UB=Unexpected Benefits C=Communication PW=Potential Worries SI=Suggestions for Improvement</td>
<td>semi-structured interview guide</td>
<td>Descriptive stats, Content Analysis: Interview Analysis</td>
<td>Six overall themes: PE: 82% seamless transition ET: minority adopting “wait and see” attitude; difficulties with engagement and getting to know newer provider UB: “treated like an adult” and “focus of care” C:18% difficulty establishing pattern PW: “system for NS access” SI: “transition was challenging”; requesting ‘wrap up’ add psychology services and resources</td>
<td>Begin transition early. Pediatric and Adult providers need to partner to develop transition programs Limitations: themes may have emerged from the participants involved those with less positive perceptions declined participation Interviews by separate association but may have been uncomfortable sharing negative experiences Convenience sample limits generalizability Limits in geographic ability to participate Limited diversity</td>
</tr>
<tr>
<td>Ridosh, M. 2011</td>
<td>EMSCA</td>
<td>Narrative inquiry qualitative design study from multi-site study of adaptation in YA with SB</td>
<td>Multi-site study of YA SB interviews ages 18-25 yrs</td>
<td>Self-management independence Inner strength</td>
<td>Guided interviews Field notes</td>
<td>Quantitative Analysis</td>
<td>Struggle for I Limiting SI and E with stigma</td>
<td>Knowledge about transition issues important to assist in developing adulthood independence goals Increased Advocacy and</td>
</tr>
</tbody>
</table>
Project Overview

- Project Goal: Develop SBA Educational Summit for healthcare professionals and adolescents/young adults living with Spina Bifida (SB) (ages 11-24 years and older) to address transition of services from pediatric to adult health care.

- For Summit participants, does the implementation of a one time, all day Educational Summit about transition from pediatric to adult services for adolescents/young adults living with Spina Bifida and their families
  - increase knowledge of need for transition services
  - increase provider awareness of their current practice limitations in regards to transition
  - lead to identification of core planning group to address transition?
Project Learning Outcomes Objectives

• Develop leadership skills in role of Licensed Independent Provider (LIP) multidisciplinary team member.

• Collaborate with specialty team providers that care for adults with special healthcare needs (SHCN).

• Assist clients/caregivers to access appropriate primary care providers and community resources to establish medical home into adulthood.

• Evaluate attendance at multidisciplinary clinics to improve health outcomes and decrease emergency department (ED) visits for preventable care conditions.
Intended Improvement Measures

• Increase knowledge and awareness of providers regarding importance of planning, implementing, and evaluating transition models from pediatric to adult services

• Establish a Transition Task Force consisting of providers, families, and adolescents/youth living with SB who are committed to plan, implement, and evaluate transition services in northeast Ohio

  • Include development of SBA chapter and support group for adolescents/young adults and families

• Increase % of adolescents/young adults living with SB who received initial transition planning by age 14

• Increase % who completed successful transition by age 22
Evidenced Based Interventions

- Literature Review-Healthy People 2020
- Analysis of Current State of Affairs
- Health Care Transition Survey: Provider Version
- AAP 2015 Module 4: Facilitating the Transition From Pediatric to Adult Care resource
- SBAA “Preparations”
- Transition Readiness tools www.gottransition.gov
Educational Summit

• 14 speakers provided content about transition from pediatric to adult programs, transition obstacles and challenges, mental health assessments, and bowel program innovations.

• Breakout sessions for teen/young adult sexuality were also provided.

• Sponsorship for the conference was provided by 4 vendors.
Methods: Data Collection

• Demographic Data

• Pre-post Educational Summit Transition Survey
  • Survey modified with permission from Dr. Geenen

• Post program evaluation
Demographic Data

• Birth year of provider
• Type of provider
• Practice location (urban, suburban, etc)
• Patient Payor source
• Employment setting practice activity type (self-employed, multi-specialty group, private hospital).
• Professional Activity spent typical work week (direct patient care, research, etc).
Results

• 29 participants attended the Educational Summit
• 21 of 29 attendees (72%) were registered nurses or advanced practice registered nurses (APRNs) who work with youth and families living with Spina Bifida
• Pre and post conference transition surveys were received from 18 (62%) of the 29 participants
• Participants reported increased awareness and commitment to transition practice
• Wilcoxon signed rank test was used to test for increase between pre and post conference surveys (alpha = 0.05)
  • Significance was found for 12 of 13 questions addressing transition practices and beliefs
• All attendees (100%) reported satisfaction with the program and 95% rated speakers on the Likert scale as either excellent or very good.
Follow up Plans

• Repeat Educational Summit Spring 2017 to educate SB community re: transition needs/readiness

• Establish Grassroots Transition Initiative with identified champions

• Develop SBA community chapter for patients and families to access resources/services
Conclusion

• The SBA Educational Summit on transition for youth and young adults living with Spina bifida was successful and many requested another opportunity to attend future transition events.

• The Educational Summit met the aim to educate participants to commit and contribute to active transition planning and assistance in their practices.
Summary

• The increased life expectancy of adolescents and young adults with SB necessitates the continued provision of coordinated care throughout their lifespan.

• Transition from pediatric to adult based services, primary and subspecialty areas requires a collaborative effort to make the process seamless and unencumbered by barriers.

• Advanced Practice Registered Nurses (APRNs) are a key component in bridging this transition gap between SB population, caregivers, and professionals.
Selected References

THANK YOU

Please feel free to contact me at sfortuna@ursuline.edu