From Transition Challenges to Successes: Establishing a Spina Bifida Adult Care Clinic

Faculty

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Background

- **Spina Bifida**
  - **Neural tube defect**
    - **Myelomeningocele**
    - **Lipomyelomeningocele**
    - **Meningocele**
    - **Other spinal dysraphism**

Background

- **Complications caused by Spina Bifida**
  - **Bowel and bladder incontinence**
  - **Hydrocephalus**
  - **Chiari II Malformation**
  - **Degree of paralysis and loss of sensation in the legs and feet**

Background

- **Tethered cord**
- **A degree of sexual dysfunction**

Background

- **People living with Spina Bifida**
  - **Estimated 166,000**
  - **Estimated 1,500 babies born each year**
  - **Approximately 1 out of every 1,000 pregnancies**

Background

- >90% of people living with Spina Bifida are expected to live well into adulthood

Challenges Adults with Spina Bifida Face

- Intimacy and sexual well-being
- Obesity
- Cardiac disease
- Pregnancy
- Mental disorders
- Health-risk behaviors

Pediatric vs. Adult Care

- Is a pediatric institution the best place to care for adults with Spina Bifida with adult issues?
  - Risks?
  - Optimal?

Pediatric vs. Adult Care

- What is the best way to care for individuals with long-term health needs?
- Transition
  - Change in services
  - Change in orientation

Pediatric vs. Adult Care

- Transfer
  - Relocation of care and health information

Main Goal of Transition

"The implicit goal of transition to adult care is to maximize lifelong functioning and potential through the provision of high quality, developmentally appropriate health care that continues to adulthood."

– Sawyer and Macnee: Transition to Adult Health Care for Adolescents with Spina Bifida: Research Issues. Dev Dis Research Reviews 16:60 (2010).

Background to Transition at Children's of Alabama and UAB

- In 2008 we began to look at our population and our options
- Previous study for 1st World Congress on COA transition
  - Purpose of first study to establish current transition protocol

Background to Transition at Children's of Alabama and UAB

  - Determine options for transition
  - Describe transition challenges
- Outcome of first study used to develop method for better transition

Previous Method for Transition

- Transition patients determined by one of the 12 providers feeling as if patient could be better served from adult facility
- Patients sent to Spain Rehabilitation to be followed by a physiatrist as well as urologist

Previous Method for Transition

- No care coordination or method for tracking patients after transition
- No proper plan for neurosurgical or orthopedic transition
- Records not forwarded to all offices
- Pediatric provider available but limited communication

Challenges Observed in Previous Study

- Lack of standardized plan for transition
- Lack of accurate data relevant to transition or infrastructure to track patient progress, successes, and challenges available to measure outcome within systems of care

Challenges Observed in Previous Study

- Lack of communication between organizations and community agencies
- Lack of easy access to timely transition services

Challenges Observed in Previous Study

- Lack of evidence-based methods to predict and target those who will need the most support for transition and to define success

Needs Identified

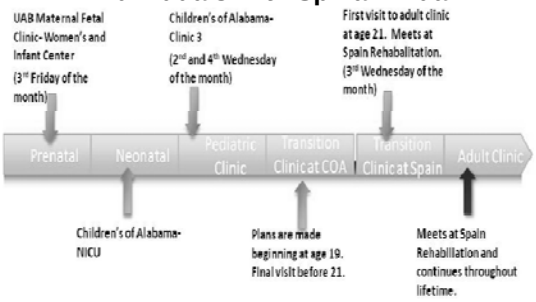
- Standardized transition plan
  - All team members to agree
  - Parents to be made aware

Needs Identified

- Shift in current model
  - From a children's hospital multi-disciplinary pediatric clinic to a Spina Bifida program that begins at prenatal diagnosis and extends into adulthood
  - Required developing partnerships with existing adult clinics

Lifetime Care Model

Timeline Illustrating Care Locations for Individuals with Spina Bifida



Method to Address Challenges

Challenges Observed	Method to Address Challenge
Lack of standardized plan for transition	Developed a plan for transition based on real age not "adult-like" behavior.
Lack of accurate data to track patients after transition	Developed method for tracking transitioning patients through use of Webtracker and excel.
Lack of infrastructure	Began utilizing UAB systems to facilitate ease of access to adult records to aid in care coordination and tracking.
Lack of easy access to a process for timely transition	Utilized willing participants at Children's of Alabama to facilitate proper transition (Dr. Jeffrey Blount, Betsy Hopson)
Lack of evidence based methods for adult patients with SB.	Began enrolling patients in the CDC project to begin tracking outcomes in adults with SB and began developing plan of care guidelines for adults.

Current Model for Transition

- Begin discussing and preparing for transition at 19
  - Provide educational tools to prepare for transition
    - Copy of transition guidelines, Health Guide for Adults Living with SB

Current Model for Transition

- Last visit to Children's clinic in the 20th year
- First visit to Adult Spina Bifida clinic in the 21st year

Current Model for Transition

- Rehabilitation Medicine
  - Patients seen by one of two adult physiatrists
- Urology
  - Patient is seen by one of two adult urologists

Current Model for Transition

- Neurosurgery
  - Pediatric neurosurgeon attends adult clinic in a non-surgical role
    - They facilitate coordination with adult neurosurgeon for surgical needs which requires one visit to establish care

Current Model for Transition

- Orthopedics
  - Patients are referred on an as needed basis

How We Define "Successful, Completed Transition"

- Patient attends adult clinic
- Patient exhibits and verbalizes confidence in where to go and how to respond in case of emergency
- Patient has initial visit with adult neurosurgeon to establish care

Number of Patients Transitioning

- 2011 was the first year we transitioned more adult patients than we had new patient births
- We are transitioning ~ 3-5 patients each month into the adult clinic

Results

- We have transitioned and / or began following 125 patients in the Transition Clinic
  - 72 patients meet our definition for successful transition

Results

  - 53 patients have either not completed at least one of the three criteria to be considered transition complete
- 4 patients have delivered child
- We have collected CDC data on 68 patients

Results: Feedback

- No patient seen in adult clinic has presented to Children's ER
- No emergent calls to Ped NSG provider

Results: Feedback

- Feedback uniformly positive
  - More confidence in system
  - Enjoy two pronged neurosurgical approach
  - Adult neurosurgeons are more confident in approach

Lessons Learned and New Plans

- Develop method for collecting patient satisfaction with transition process
  - Developing patient satisfaction survey in Survey Monkey will begin with patients > 19

Lessons Learned and New Plans

- Health Related Quality of Life
  - In May 2012 we began using HUI-III utilities index to look at 8 dimensions of health-related quality of life:
    - Vision, speech, hearing, dexterity, ambulation, cognition, emotions, pain

Lessons Learned and New Plans

- Early stages of analyzing and understanding data
- Retrospective institutional review to ascertain adult MMC
  - Needs / demands on adult neurosurgical service

Lessons Learned and New Plans

- Documentation / Educational resources needed to aid in transition process
  - Document created and given to each patient at transition age

Conclusion

- Collaboration between pediatric and adult care providers create an atmosphere for successful transition
- Transition model must be clearly defined and agreed upon by all team members

Conclusion

- Qualities of successful transition must be identified and written for clinic team members and patients / families to understand
- Continued care coordination is needed for adults

Conclusion

- Method for tracking patient satisfaction is needed
- Quality of life measures are needed

Questions

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