Evolution of a Lifetime Care Model in Spina Bifida Transition

Jeffrey P Blount MD FAANS
Professor/ Chair, Pediatric Neurosurgery
Medical Director
Spina Bifida Program at Children’s of Alabama/UAB

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Evolution/Course of Transition/Adult SB Clinic at UAB

1. Born of necessity - graduate to cliff’s edge
2. Add on to existing Adult Spinal Cord Injury Clinic - gracious collaborator
3. Early enthusiasm - depressing early results - “the dog days”
4. Development and Refinement of the Lifetime Care Model
5. Growth and Quantitative Evaluation of Patient Outcomes - “School and Stool”
6. Evolving view of the temporal course of care for Spina Bifida
7. Next steps - Evolving Course
Previous “Transition” Model

• Transition patients determined by ANY 1 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.

• 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.
“Graduation to the Cliff’s Edge”-congratulations!!
The Comprehensive Spina Bifida Program Transition Process
Pediatric to Adult Care

Our Goals for Transition
The overarching goal of our transition program is to set the national standard for excellence in care in transition from pediatric comprehensive ambulatory care to equally dedicated, comprehensive multidisciplinary adult care in Spina Bifida.

The Children’s of Alabama Spina Bifida Clinic manages care coordination, as well as all surgical and clinical needs, until age 21.

Transition plans will be initiated and transition goals defined when you reach 15 years of age. This provides time to deal with any potential issues, answer all of your questions and help build your confidence with the upcoming changes.

It is important that you and your family work consistently with the transition team so that the transition process proceeds as smoothly as possible.

At your next Children’s Spina Bifida Clinic visit, the transition team will schedule your first visit at the adult clinic. From that point on, you will attend the Adult Spina Bifida Clinic, held at Spina Bifida Rehabilitation on UAB’s main medical campus.

Spina Bifida Comprehensive Lifetime Care Model

BY THE NUMBERS
19-20 You will begin planning for transition while still attending Spina Bifida Clinic at Children’s of Alabama. Your pediatric team will continue to manage your care and meet your surgical and clinical needs.

All transition activities should be completed by your 21st birthday.

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21 Your last visit to the Children’s Spina Bifida Clinic must occur while you are 20 years old; all transition activities must be completed by age 21.
Results

- Currently following **225** patients in the Transition/Adult Clinic.
  - 78 patients transitioned for COA.

- Gender
  - Adult Clinic
    - 63% Female
    - 37% Male
  - Peds Clinic
    - 53% Female
    - 46% Male

- Insurance
  - 75% Public
  - 25% Private

- Diagnosis
  - 83% Open MMC
  - 14% Closed defect
Summary - HUI-3 Outcomes in NTDs

**Adult:**
- MMC \( n=25 \)
- Closed Dysraphism \( n=6 \)

**Pediatric:**
- MMC \( n=125 \)
- Closed Dysraphism \( n=33 \)

**Peds:**
- Diagnosis greatest contributor
- QOL declines with age
- Shunts and C2MD both a/w significant decrease QOL

**Adults:**
- Min difference open/closed
- Surg procedures min impact
- Emotion, cognition, pain domains dominate
Peds HUI 3
Results

• (Open) MMC <<Closed Defect
  • Largest overall contribution to QOL was diagnosis
  • Domain subscores implicate cognition and ambulation

• QOL declines with age across childhood into adolescence
• One third continent (32%bowel/35%urinary) and continence a/w QOL
Assessing health-related quality of life in children with spina bifida

Brandon G. Rocque, MD, MS,1 E. Raley1 Bishop, BS,1 Mallory A. Scogin, MD,1
Betsy D. Hopson, MSHA,1 Anastasia A. Arynchyna, MPH,1 Christina J. Boddiford, MPH,1
Chevis N. Shannon, MBA, DrPH,2 and Jeffrey P. Blount, MD1

1Pediatric Neurosurgery, Department of Neurosurgery, University of Alabama at Birmingham, Alabama; and 2Department of Neurosurgery, Vanderbilt University, Nashville, Tennessee

FIG. 1. Overall HRQOL, ambulation, and cognition subscores contrasting myelomeningocele patients with closed spinal dysraphism patients. The solid lines denote the mean; boxes, the interquartile range; bars, range; and asterisks, outliers. Figure is available in color online only.

FIG. 2. Overall QOL comparing patients with normal bowel continence to those with incontinence. Figure is available in color online only.
Education predicts Disability

Odds Ratio

- Some College
- College Degree
- Advanced Degree
Stool incontinence predicts Disability

Odds Ratio

- Daily incontinence
- More than weekly
- More than monthly
- Less than monthly
- Cannot assess
Independent association with “permanent disability”

“School and Stool”

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Predictors of permanent disability among adults with spinal dysraphism

Matthew C. Davis, MD¹, Betsy D. Hopson, MSHA², Jeffrey P. Blount, MD¹, Rachel Carroll, MPH³, Tracey S. Wilson, MD³, Danielle K. Powell, MD, MSPH⁴, Amie B. Jackson McLain, MD⁴, and Brandon G. Rocque, MD, MS¹
What is lifespan care?

• Begins with an honest assessment of where patients’ needs aren’t being met.
• Includes well thought out plan for each stage
• Includes coordination of care throughout the lifespan
• Care strategies and goals at each stage
• Dedicated providers throughout the lifespan
• Deliberate communication between care teams

Even if I am not the one delivering the care at every stage what is the plan?
Lifetime Care Model

UAB Maternal Fetal Clinic
Women’s and Infant Center (3rd Friday)
- High risk- OB/GYN
- Neurosurgery
- Rehabilitation Medicine
- Genetics
- SB Coordinator

Children’s of AL
Clinic 15 (2nd and 4th Wed.)
- Urology
- Neurosurgery
- Rehabilitation Medicine
- Orthopedics
- SB Coordinator
- Support staff (SW, orthotics, wound care)

- First Visit to Spain at 21
- Transition readiness teaching con’t
- Increase frequency of visits temporarily to establish goals.

- Shift to patient run visits
- Transition readiness
- Teaching and goal setting
- Final Visit to COA at 20

Children’s of AL NICU

Spain Rehabilitation Clinic
(1st and 3rd Wed.)
- Urology
- Neurosurgery
- Rehabilitation Medicine
- SB Coordinator
- Support staff

- Support staff (SW, orthotics, wound care)
What is lifespan care?

- Begins with an honest assessment of where patients’ needs aren’t being met.
- Includes well thought out plan for each stage.
- Includes coordination of care throughout the lifespan.
- Care strategies and goals at each stage.
- Dedicated providers throughout the lifespan.
- Deliberate communication between care teams.
Current Model for Transition

• Begin discussing and preparing for transition at 19
• Educational tools to prepare for transition:
  • copy of transition guidelines,
  • Health Guide for Adults Living with SB
• Last visit to Children’s clinic in the 20th year.
• First visit to multi-disciplinary adult Spina Bifida clinic by the 21st year
  • Routine f/u annual eval in ASBC
  • Urgent needs through ER as needed
Current Model for Transition

- Transition Readiness Assessment at 13.
- Transition Initiated at 14.
- Develop Transition Plan/Goals.
- Last visit to Children’s clinic in the 20th year.
- First visit to adult Spina Bifida clinic in the 21st year.
- Members of the pediatric team attend adult clinic.
- Clinic is multi-disciplinary including, rehab, urology, and neurosurgery.
Transition at COA

- TRAQ-SB
- PHQ-9
- Goal Setting
- Education/Career Planning

Summary- UAB experience

• Born of necessity- no model at that time. Many lessons learned hard way
• Early impressions dampened initial enthusiasm
• Studied patients and outcome predictors: BOWEL and EDUCATION (”Stool and School”)
• Prioritized preparations for transition- started earlier-
  • Transition readiness- ITP analogous to IEP in the school environment
  • Start early, involve families holistically, prioritize
• Neurosurgical needs evolve and acute needs decline
Why this model works

1. Unmet need/great demand for these supportive services
2. Flexibility and willingness to work beyond established “boundaries of service”
3. Supportive mission/service oriented fiscal infrastructure
   • Room to pursue/explore pursuits with initial modest reimbursement
4. Excellent collaborative partners- ownership/ professional identity
   • Danielle Powell MD- UAB Physical Medicine and Rehabilitation
   • Amy McLain MD- UAB Physical Medicine and Rehabilitation
   • Tracy Wilson MD – UAB Department of Urology
5. Exceptional Program Coordinator- Betsy Hopson
UAB Transition/Adult Clinic Observations

- Neurosurgical acute needs decline over the life span
- Urology and PMR needs persist/ threaten
- Orthopedic/ Plastic-wound needs are sporadic
- Bowel and Depression evolve to dominate QOL
- Adults with Occult Dysraphism live with constant pain that has never been comprehensively studied
- Pending crisis of providers as aging parents losing capacity to care for adult aged patients
Spina Bifida Lifetime Care Model

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Prenatal

Neonatal

Pediatric Clinic
- Shift to patient run visits
- Transition readiness
- Teaching and goal setting
- Final Visit to COA at 20

Transition Clinic at COA

Adult Clinic
- Urology
- Neurosurgery
- Rehabilitation Medicine
- SB Coordinator
- Support staff

Children’s of AL NICU

Adult Clinic

Children’s of Alabama

UAB Maternal Fetal Clinic
- OB/GYN
- Neurosurgery
- Rehabilitation Medicine
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Children’s of AL Clinic
- Urology
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NEUROSURGERY IN MYELOMENINGOCELE ACROSS THE LIFE SPAN

- C2M
- HCP
- TSC
- Bowel/Bladder
- Depression
The Next/Evolving Steps- 3 part approach to transition

1. UAB Medical Home for Transitioning Patients
   • Outpatient Clinic with primary dedication to pediatric patients with medical complexity transitioning to adult care
   • Staffed by Med-Peds physicians at UAB Clinic spaces

2. UAB/COA Surgical Center for Transition Patients
   • Specifically targets surgical needs that arise from extension of developmental or pediatric illnesses in early adulthood
   • Candidates are young adults with primary needs related to pediatric conditions
   • Advantageous Medicaid reimbursement for COA may make cost advantageous to both

3. UAB Transition Consultation Service
   • One stop call for any/all needs arising in patients who are involved in transitional care (young adults with chronic medically complex conditions that arose in childhood)
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Thank you