Lecture title: Practice Preferences for Neurosurgical Management in Spina Bifida: a survey of the American Society for Pediatric Neurosurgery
Part 1- Neonatal and Infancy Issues/Challenges
Part 2- Issues of Childhood through Transition
Part 3- Neurosurgical Perspective on Transitional Care

Jeffrey Blount, MD, Birmingham, AL
Chief of Pediatric Neurosurgery, UAB

• Does not intend to discuss commercial products or services.

• Does not intend to discuss non-FDA approved uses of products/providers of services.
Practice Preferences for Neurosurgical Management in Spina Bifida: a survey of the American Society for Pediatric Neurosurgery

Part 1- Neonatal and Infancy Issues/Challenges
Part 2- Issues of Childhood through Transition
Part 3- Neurosurgical Perspective on Transitional Care

Jeffrey Blount, MD
Division of Pediatric Neurosurgery
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Betsy D. Hopson, MSHA
Anastasia A. Smith, MPH
Fredrick Safyanov
Robert Bollo, MD
Todd Hankinson, MD
Brandon Rocque, MD
OBJECTIVE OF PRESENTATION

• Summarize practice preferences regarding strategies of management for children and young adults with MMC from a group of senior North American Pediatric Neurosurgeons
Part 1- Neonatal and Infancy Issues/Challenges

Cohort
- Background/Introduction
- Cohort overview/ Clinic characteristics

IUMC
- Availability
- Referral

Closure/ Placode Management
- Screening/ Exclusion closure
- Timing to closure
- Closure technique
- NICU, Positioning, Antibiotics
• Evidence Based Practice in SB- 2003 “Green Book”
• Interim Neurosurgical Progress Clustered/Diminishing
  • MOMs trial
  • ETV/CPC role in HCP management
  • (Xiao Procedure)
  • NSBPR
  • however...
    a.) limited studies on conventional management/approaches AND...
    b.) evidence of significant variation in practice (anecdotes, discussions, letters etc.)
• Management of Myelomeningocele Practice Parameters Meeting, Birmingham 2014 – confirmed suspicion of variability in practice
• Survey developed to understand practice preferences
Methods

- 47 question Survey created in Survey Monkey (goal 10-12 min)
- Distributed October, 2016 via email link to 232 members of American Society of Pediatric Neurosurgery (ASPN)
  - 32 ASPN members not available or retired
  - 14 day response window
  - Responses from 90 members (90/200=45% response rate)
- Survey Questions
  - Self reported
  - Not validated
  - Clinical scenarios and images
Participants/Clinic Characteristics

- ASPN- senior, experienced North American Pediatric Neurosurgeons
  - ABPNS/ ABNS certified
  - >95% members of all major Neurosurgical organizations
    - American Association of Neurological Surgeons
    - Pediatric Section of the AANS
    - ASPN

- 30 states, 3 Provinces (CA), most major Ped NSG centers represented
- Some centers had more than 1 member- no requirement for center “expert”
• Clinics:
  • 80% Multi-Disciplinary, 20% solo NSG
  • ~One third protocol driven - remainder preference driven (variability?)
Multi-disciplinary SB Clinics-ASPN Perspective 2017

Urology 98.88%
Orthopedics 98.88%
PhysTherapy 86.52%
Social Work 82.02%
Rehabilitation 70.79%
Orthotist 69.66%
Wheelchair Tech 57.30%
Dev Pediatrics 42.70%
OB/GYN 40.45%
Nutrition 37.08%
Neurology 31.46%
Geneticists 28.09%
Gastrointestinal 20.22%
Nephrology 17.98%
Endocrinology 7.87%
Cardiology 5.62%
Rheumatology 3.37%
Center experience-volume new MMC

Q3 Approximate number of newborns with myelomeningocele closed per year at your center?

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<th>10-15</th>
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<td>&gt;15</td>
<td>15%</td>
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</table>

Even distribution with 60% of centers closing 5-15 MMC/year.
Part 1- Neonatal and Infancy Issues/Challenges

Cohort
  Background/Introduction
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IUMC
  Availability
  Referral
  Closure/ Placode Management
  Screening/ Exclusion closure
  Timing to closure
  Closure technique
  NICU, Positioning, Antibiotics
Fetal Closure- availability and referral

Q11 Is fetal closure performed at your center?
Answered: 89 Skipped: 1

- Yes 46.85% (15)
- No 83.15% (74)

Q12 Do you refer patients for in utero closure of their myelomeningocele?
Answered: 68 Skipped: 22

- Yes 66.18% (45)

Referral for IUMC-
Distribution Analysis

<table>
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<tr>
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<tr>
<td>97.5%</td>
<td>92.5</td>
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<tr>
<td>90.0%</td>
<td>72.5</td>
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<td>75.0%</td>
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<td>Median 20</td>
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<td>10.0%</td>
<td>3</td>
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<tr>
<td>2.5%</td>
<td>1</td>
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<tr>
<td>0.5%</td>
<td>1</td>
</tr>
<tr>
<td>0.0%</td>
<td>Minimum 1</td>
</tr>
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</table>

Summary Statistics

- Mean 24.55556
- Std Dev 24.23522
- Std Err Mean 3.297958
- Upper 95% Mean 31.170497
- Lower 95% Mean 17.940614
- N 54

Fetal closure available on-site in <20% but 66% claim to refer for IUMC however estimated 20-25% patients (wide distribution) seen are referred across cohort
Part 1 - Neonatal and Infancy Issues/Challenges

Cohort
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   Timing to closure
   Closure techniques
   NICU, Positioning, Antibiotics
Q16 What pre-op screening tests do you have performed on your patients prior to myelomeningocele closure? Check all that apply.

Answered: 84  Skipped: 6

Preferred tests:
- Head US
- Serum labs
- Renal US
Pre-closure screening

Q17 Are there any exclusion criteria for back closure? Check all that apply.

Answered: 84  Skipped: 6

- Lethal anomaly: 85%
- Severe co-morbidity: 13.10% (11)
- Moderate multiple systems: 1.5%
- None: 0.0%
- Other (please specify): 42.86% (36)

85% <= 1 exclusion in career due to screening
Timing and positioning

- 98% close within 48 hours
- Strong preference for prone positioning post op

<table>
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<tr>
<th></th>
<th>Insist</th>
<th>Prefer</th>
<th>Option</th>
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<th>Weighted Average</th>
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<td>Prone</td>
<td>35.37%</td>
<td>41.46%</td>
<td>19.51%</td>
<td>3.66%</td>
<td>82</td>
<td>1.91</td>
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<tr>
<td></td>
<td>29</td>
<td>34</td>
<td>16</td>
<td>3</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Supine (w/padding or &quot;donut&quot; to protect closure site)</td>
<td>3.39%</td>
<td>5.08%</td>
<td>33.90%</td>
<td>57.63%</td>
<td>59</td>
<td>3.46</td>
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<tr>
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<td>3</td>
<td>20</td>
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<tr>
<td>Lateral</td>
<td>8.33%</td>
<td>31.94%</td>
<td>44.44%</td>
<td>15.28%</td>
<td>72</td>
<td>2.67</td>
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<td></td>
<td>6</td>
<td>23</td>
<td>32</td>
<td>11</td>
<td></td>
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</table>
Imbrication/ Layered Closure

Q22 Do you imbricate ("roll up") the placode?
Answered: 84, Skipped: 6

Q24 How many layers do you strive for in your closure?
Answered: 84, Skipped: 5

Imbrication and 3 or 4 layered closure preferred
Part 1- Neonatal and Infancy Issues/Challenges

- Antimicrobial prophylaxis

Q15 Do you routinely administer antibiotics pre-closure?

Answered: 85  Skipped: 5

- 81.18% Always
- 10.59% Usually
- 3.53% Occasionally
- 4.71% Never

Prophylactic antibiotics >90%

Q28 Antibiotics use/duration post closure?

- 53.57% (45) 12-24 hours
- 25.00% (21) >24 hours
- 13.10% (11) 0-12 hours
- 8.33% (7) None

Majority prefer post op antibiotics –variable duration
Controversy- Placode Resection

Q23 Do you (ever) support resection of the placode?

- Yes 41.67% (35)
- No 58.33% (49)

60/40 against placode resection “ever”

Distal cordectomies as treatment for lumbosacral myelomeningoceles

Clinical article

A. LELAND ALBRIGHT, M.D., AND HUMPHREY OKECHI, M.B.CH.B.

Division of Neurosurgery, Department of Surgery, Kijabe Hospital, Kijabe, Kenya

Object. The purpose of this study was to evaluate the effect of distal cordectomies on motor function in the lower extremities of infants with lumbosacral myelomeningoceles.

Methods. Medical records were reviewed in 32 infants with lumbosacral myelomeningoceles who were 1 day to 7 months old, who had some lower-extremity function preoperatively, and who were treated by distal cordectomies, dividing the cord between its exit from the intact spinal canal and the neural placode. Neurological function was evaluated before and after operation by therapists who were unaware of the surgical technique.

Results. Neurological function was unchanged after operation in 29 of 32 cases. For the others, hip flexion, foot plantar flexion, and toe movement were lost in 1 case each.

Conclusions. The majority of infants treated by distal cordectomies retain preoperative motor function after operation.

(http://thejns.org/doi/abs/10.3171/2013.11.PEDS13378)
Part 2- Issues of Childhood through Transition-

Management of Hydrocephalus

Acute/ Early Management of Hydrocephalus
  Temporize
  Availability of ETV/CPC
  Criteria used to determine acute hydrocephalus management
  Case studies in acute decision making

Ongoing management of HCP
  Surveillance imaging
  Criteria to trigger shunt exploration/revision-
  symptoms alone,
  imaging alone
  broken shunt without symptoms

Preferred criteria in chronic HCP management
Part 2- Issues of Childhood through Transition-

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Preferred criteria in chronic HCP management
Initial treatment of hydrocephalus: role for temporizing?

- 70% never temporize
- 30% temporize
  - Improved wound healing
  - Less pressure to shunt
- Only 2% routinely temporize
ETV/CPC availability

Q8 Is ETV- CPC (Endoscopic Third Ventriculostomy-Choroid Plexus Cauterization) performed at your center?

Answered: 88  Skipped: 2

Yes

No

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

- ETV/CPC= potential intervention to ameliorate HCP without shunt
- Long term follow up not yet available
- Procedure under study by HCRN

70/30 available in this cohort

Combined endoscopic third ventriculostomy and choroid plexus cauterization as primary treatment for infant hydrocephalus: a prospective North American series

Clinical article

SCHELLIG S. D. STONE, M.D., PH.D., AND BENJAMIN C. WARF, M.D.
Department of Neurosurgery, Boston Children's Hospital, Boston, Massachusetts
Initial Treatment of Hydrocephalus- treat vs observe

<table>
<thead>
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<th>Absolute indication</th>
<th>Highly contributory</th>
<th>Moderately contributory</th>
<th>Low contribution</th>
<th>No contribution</th>
<th>Total</th>
<th>Weighted Average</th>
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<tr>
<td>Apnea or bradycardia</td>
<td>28.92%</td>
<td>51.81%</td>
<td>15.66%</td>
<td>2.41%</td>
<td>1.20%</td>
<td>83</td>
<td>1.95</td>
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<tr>
<td>CSF leak from back wound</td>
<td>40.96%</td>
<td>50.60%</td>
<td>8.43%</td>
<td>0.00%</td>
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<td>1.67</td>
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<td>Extraocular movement abnormalities</td>
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<td>34.15%</td>
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<td>23.17%</td>
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<td>2.91</td>
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<td>Macrocephaly</td>
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<td>54.22%</td>
<td>30.12%</td>
<td>6.02%</td>
<td>1.20%</td>
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<td>Progressive ventricular enlargement, by image and/or head circumference</td>
<td>33.73%</td>
<td>55.42%</td>
<td>10.84%</td>
<td>0.00%</td>
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<td>1.77</td>
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<td>43.37%</td>
<td>37.35%</td>
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<td>3.61%</td>
<td>83</td>
<td>1.87</td>
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<td>Swallowing dysfunction</td>
<td>37.80%</td>
<td>42.68%</td>
<td>13.41%</td>
<td>2.44%</td>
<td>3.66%</td>
<td>82</td>
<td>1.91</td>
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<tr>
<td>Syrinx</td>
<td>17.07%</td>
<td>46.34%</td>
<td>19.51%</td>
<td>13.41%</td>
<td>3.66%</td>
<td>82</td>
<td>2.40</td>
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</table>

1.) CSF leak from back
2.) Progressive ventricular enlargement
3.) Brain stem symptoms
   a.) stridor
   b.) swallow dysfunction
   c.) bradycardia/apnea
4.) Syrinx
5.) Head growth
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<th>no</th>
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<tr>
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<td>1</td>
</tr>
<tr>
<td>Full font, 97%, following growth curve</td>
<td>80</td>
<td>20</td>
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<tr>
<td>Full font, 75%, following growth curve</td>
<td>30</td>
<td>70</td>
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<table>
<thead>
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<td>stridor</td>
<td>80</td>
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<td>Full font, split sutures, crossing %</td>
<td>75</td>
<td>25</td>
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<tr>
<td>Full font, 97%, following growth curve</td>
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<td>66</td>
</tr>
<tr>
<td>Full font, 75%, following growth curve</td>
<td>5</td>
<td>95</td>
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</table>
Part 2- Issues of Childhood through Transition-

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- Case studies in acute decision making

Ongoing management of HCP
- Surveillance imaging
- Criteria to trigger shunt exploration/revision-
  - symptoms alone,
  - imaging alone
- broken shunt without symptoms

Preferred criteria in chronic HCP management
Role for surveillance imaging in the well child

Clinical evaluation and surveillance imaging in children with spina bifida aperta and shunt-treated hydrocephalus

Clinical article

Joshua J. Chern, M.D., Ph.D.,1,2 Mitchel Muhleman, M.D.,3 R. Shane Tubbs, Ph.D.,3 Joseph H. Miller, M.D.,1 James M. Johnston, M.D.,1 John C. Wellons III, M.D.,1 Jeffrey P. Blount, M.D.,1 W. Jerry Oakes, M.D.,1 and Curtis J. Rozzelle, M.D.1

1Pediatric Neurosurgery, Children’s Hospital, Birmingham, Alabama; 2Children’s Healthcare of Atlanta, Georgia; and 3St. George’s University, Grenada, West Indies
**Q33 What percent of shunt revisions are based on patient symptoms alone (i.e. no image change)?**

<table>
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<tr>
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<th>Never</th>
<th>&lt;1%</th>
<th>1-10%</th>
<th>10-25%</th>
<th>&gt;25%</th>
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</thead>
<tbody>
<tr>
<td>%</td>
<td>3.75%</td>
<td>5.00%</td>
<td>27.50%</td>
<td>42.50%</td>
<td>21.25%</td>
</tr>
</tbody>
</table>

20% of surgeons surveyed feel that > one quarter of shunt revisions performed are for symptoms of shunt failure with no radiographic change.

**Q34 What percent of shunt revisions are based on a patient’s images alone (i.e. no symptom change)?**

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<th>1-10%</th>
<th>10-25%</th>
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</thead>
<tbody>
<tr>
<td>%</td>
<td>3.75%</td>
<td>10.00%</td>
<td>38.75%</td>
<td>28.75%</td>
<td>18.75%</td>
</tr>
</tbody>
</table>

significant percent of experienced surgeons will occasionally revise shunt for radiographic change alone.
Q35 Based on the image above, if this patient with spina bifida was asymptomatic with a broken shunt and had no imaging change, would you...Check all that apply if needed.

Answered: 78   Skipped: 12

- Continue to observe the patient: 46.15%
- Revise the shunt: 34.62%
- Order other studies to be done: 35.90%
Q32 What criteria is used for the chronic (post infancy/childhood) management of hydrocephalus in shunt revision decision making?

Answered: 81   Skipped: 9

<table>
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<th>Criterion</th>
<th>Absolute indication</th>
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<th>Moderately contributory</th>
<th>Low contribution</th>
<th>No contribution</th>
<th>Total</th>
<th>Weighted Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apnea or bradycardia</td>
<td>33.33%</td>
<td>45.68%</td>
<td>16.05%</td>
<td>4.94%</td>
<td>0.00%</td>
<td>81</td>
<td>1.93</td>
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<tr>
<td>Bowel/bladder function deterioration</td>
<td>2.27%</td>
<td>13.58%</td>
<td>24.69%</td>
<td>39.51%</td>
<td>19.75%</td>
<td>81</td>
<td>3.60</td>
</tr>
<tr>
<td>Deteriorating cognition or change in personality</td>
<td>7.41%</td>
<td>43.21%</td>
<td>33.33%</td>
<td>13.58%</td>
<td>2.47%</td>
<td>81</td>
<td>2.60</td>
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<tr>
<td>Headaches</td>
<td>2.27%</td>
<td>64.20%</td>
<td>30.86%</td>
<td>2.47%</td>
<td>0.00%</td>
<td>81</td>
<td>2.33</td>
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<td>Image change</td>
<td>12.50%</td>
<td>72.50%</td>
<td>15.00%</td>
<td>0.00%</td>
<td>0.00%</td>
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<td>2.02</td>
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<td>Increased head circumference</td>
<td>11.11%</td>
<td>74.07%</td>
<td>13.58%</td>
<td>1.23%</td>
<td>0.00%</td>
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<td>2.05</td>
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<td>Shunt infection</td>
<td>86.42%</td>
<td>12.35%</td>
<td>1.23%</td>
<td>0.00%</td>
<td>0.00%</td>
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<td>32.10%</td>
<td>58.02%</td>
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<td>2.47%</td>
<td>0.00%</td>
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<td>1.80</td>
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<td>Nausea/vomiting</td>
<td>9.88%</td>
<td>62.96%</td>
<td>23.46%</td>
<td>3.70%</td>
<td>0.00%</td>
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<td>12.35%</td>
<td>2.47%</td>
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<td>2.64</td>
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<tr>
<td>Pain at myelomeningocele closure site</td>
<td>1.23%</td>
<td>20.99%</td>
<td>32.10%</td>
<td>33.33%</td>
<td>12.35%</td>
<td>81</td>
<td>3.35</td>
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<td>Seizures</td>
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<td>23.79%</td>
<td>50.00%</td>
<td>18.75%</td>
<td>80</td>
<td>3.80</td>
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<td>Sensorimotor deterioration</td>
<td>0.00%</td>
<td>17.72%</td>
<td>34.18%</td>
<td>36.71%</td>
<td>11.39%</td>
<td>80</td>
<td>3.42</td>
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<td>Scoliosis or increase in scoliosis</td>
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<td>12.50%</td>
<td>37.50%</td>
<td>45.00%</td>
<td>5.00%</td>
<td>80</td>
<td>3.42</td>
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<td>28.75%</td>
<td>47.50%</td>
<td>16.25%</td>
<td>6.25%</td>
<td>1.25%</td>
<td>80</td>
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<tr>
<td>Swallowing dysfunction</td>
<td>18.75%</td>
<td>52.50%</td>
<td>21.25%</td>
<td>7.50%</td>
<td>0.00%</td>
<td>80</td>
<td>2.17</td>
</tr>
<tr>
<td>Syrinx</td>
<td>13.58%</td>
<td>32.10%</td>
<td>41.98%</td>
<td>11.11%</td>
<td>1.23%</td>
<td>81</td>
<td>2.54</td>
</tr>
</tbody>
</table>
Part 3- Neurosurgical Perspective on Older Child/ Teen and Transitional Care

C2M Management
  Shunt before C2MD
  Prior to C2MD
  C2MD in newborn
  C2MD in older child

TSCR Management
  Criteria for TSCR in children/teens

Transition Issues
  Age range in clinics
  Transition programs
Part 3- Neurosurgical Perspective on Older Child/Teen and Transitional Care

C2M Management
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Evaluation before C2MD

Q39 Prior to performing Chiari II Malformation Decompression do you: Please check all that apply

Answered: 81   Skipped: 9

- Check brain imaging for...
- Surgically explore the...
- Monitor ICP
- None - just decompress...
- Other (please specify)

[Bar chart showing the percentage of responses for each option]
Shunt revision before C2MD

55% always perform operative shunt revision before C2MD

45% do NOT always explore shunt before C2MD
### Thresholds to treat C2M

<table>
<thead>
<tr>
<th>Diagnoses</th>
<th>Absolute indication</th>
<th>Highly contributory</th>
<th>Moderately contributory</th>
<th>Low contribution</th>
<th>No contribution</th>
<th>Total</th>
<th>Weighted Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apnea/bradycardia</td>
<td>27.16%</td>
<td>48.15%</td>
<td>13.58%</td>
<td>6.17%</td>
<td>4.94%</td>
<td>81</td>
<td>2.14</td>
</tr>
<tr>
<td></td>
<td>22</td>
<td>39</td>
<td>11</td>
<td>5</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vocal cord paralysis</td>
<td>29.63%</td>
<td>55.56%</td>
<td>6.17%</td>
<td>3.70%</td>
<td>4.94%</td>
<td>81</td>
<td>1.99</td>
</tr>
<tr>
<td></td>
<td>24</td>
<td>45</td>
<td>5</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Arching/opisthotonus</td>
<td>24.69%</td>
<td>45.68%</td>
<td>16.05%</td>
<td>8.64%</td>
<td>4.94%</td>
<td>81</td>
<td>2.23</td>
</tr>
<tr>
<td></td>
<td>20</td>
<td>37</td>
<td>13</td>
<td>7</td>
<td>4</td>
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<tr>
<td>Sleep apnea</td>
<td>13.58%</td>
<td>48.15%</td>
<td>25.93%</td>
<td>7.41%</td>
<td>4.94%</td>
<td>81</td>
<td>2.42</td>
</tr>
<tr>
<td></td>
<td>11</td>
<td>39</td>
<td>21</td>
<td>6</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Swallowing dysfunction</td>
<td>21.52%</td>
<td>49.37%</td>
<td>16.46%</td>
<td>7.59%</td>
<td>5.06%</td>
<td>79</td>
<td>2.25</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>39</td>
<td>13</td>
<td>6</td>
<td>4</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stridor</td>
<td>34.57%</td>
<td>45.68%</td>
<td>11.11%</td>
<td>3.70%</td>
<td>4.94%</td>
<td>81</td>
<td>1.99</td>
</tr>
<tr>
<td></td>
<td>28</td>
<td>37</td>
<td>9</td>
<td>3</td>
<td>4</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

1.) stridor/vocal cord paralysis  
2.) opisthotonus  
3.) swallowing dysfunction
Q40 Based on the image above, if this patient was a newborn with myelomeningocele, progressively worsening stridor and small ventricles would you...

Answered: 81  Skipped: 9

- Place a shunt: 33.33%
- Perform a Chiari decompression: 35.80%
- Both: 11.11%
- Neither: 8.64%
- Other (please specify): 11.11%
Q41 If the patient was an older child with sleep apnea, smaller ventricles and had a shunt in place would you...

Answered: 81  Skipped: 9

- Perform a shunt revision: 49.38%
- Perform a Chiari decompression: 13.58%
- Both: 6.17%
- Neither: 6.17%
- Other (please specify): 24.69%
**Criteria for TSCR**

**Q42 What criteria are necessary to perform a tethered cord release?**

<table>
<thead>
<tr>
<th>Criteria</th>
<th>Absolute contribution</th>
<th>Highly contributory</th>
<th>Moderately contributory</th>
<th>Low contribution</th>
<th>No contribution</th>
<th>Total</th>
<th>Weighted Average</th>
</tr>
</thead>
<tbody>
<tr>
<td>Decreased leg strength/sensation</td>
<td>18.99%</td>
<td>65.82%</td>
<td>11.39%</td>
<td>3.80%</td>
<td>0.00%</td>
<td>79</td>
<td>2.00</td>
</tr>
<tr>
<td>Functional change in ambulation</td>
<td>13.75%</td>
<td>66.25%</td>
<td>20.00%</td>
<td>0.00%</td>
<td>0.00%</td>
<td>80</td>
<td>2.06</td>
</tr>
<tr>
<td>Urinary continence deterioration</td>
<td>21.25%</td>
<td>71.25%</td>
<td>6.25%</td>
<td>1.25%</td>
<td>0.00%</td>
<td>80</td>
<td>1.88</td>
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<td>Bowel continence</td>
<td>8.75%</td>
<td>55.00%</td>
<td>23.75%</td>
<td>12.50%</td>
<td>0.00%</td>
<td>80</td>
<td>2.40</td>
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<tr>
<td>Increased scoliosis</td>
<td>3.80%</td>
<td>49.37%</td>
<td>35.44%</td>
<td>11.39%</td>
<td>0.00%</td>
<td>79</td>
<td>2.54</td>
</tr>
<tr>
<td>Back pain</td>
<td>2.50%</td>
<td>47.50%</td>
<td>38.75%</td>
<td>8.75%</td>
<td>2.50%</td>
<td>80</td>
<td>2.61</td>
</tr>
<tr>
<td>Leg pain</td>
<td>2.50%</td>
<td>53.75%</td>
<td>33.75%</td>
<td>10.00%</td>
<td>0.00%</td>
<td>80</td>
<td>2.51</td>
</tr>
<tr>
<td>Increase leg/foot deformity</td>
<td>3.80%</td>
<td>59.49%</td>
<td>29.11%</td>
<td>6.33%</td>
<td>1.27%</td>
<td>79</td>
<td>2.42</td>
</tr>
</tbody>
</table>

**Less:**
- Bowel
- Scoliosis
- LBP
- Leg/foot deformity

1.) Urinary continence deterioration
2.) Decreased leg strength/sensation
3.) Functional change in ambulation
Q6 What is the age range of patients in your clinic?

Answered: 39 Skipped: 1

- Pediatrics only (0-18 or less): 20.22% (18)
- Pediatrics and Adults: 28.09% (25)
- Other (please specify): 2.25% (2)
- Pediatrics only (0-20's): 49.44% (44)

Clinic Characteristics - age/transition

70/30 with 70 percent of ASPN Pediatric Neurosurgeons following only “children”

1/3rd - Follow into adulthood
1/3rd - Have transition program
1/3rd – No transition program
Survey Conclusions

• Management practices center on well established principles that are widely accepted however substantial differences in practice preferences exist amongst senior neurosurgeons

• There is likely a role for continued study of accepted practices with improved study design and methodologies to continue to improve Neurosurgical practice patterns in the care of the patient with MMC/SB
Questions???

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