Lipomyelomeningocele for the Urologist: should we view it the same as myelomeningocele?

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• Do not intend to discuss commercial products or services.
• Do not intend to discuss non-FDA approved uses of products/providers of services.
Team Biases re: LMM

1. Early untethering ↓ risk of neurologic decline

2. Spina Bifida pts deserve long-term team F/U

3. Certain lipoma types memorable bad actors
Questions to consider:

• Do we need to treat all LMM like MM?

• How can we best prepare LMM families?
Our Objectives:

1. To identify high risk patient factors
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2. To better counsel regarding long term outlook
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2. To better counsel regarding long term outlook
   • Defining urologic outcomes in the setting of early TCR for lipomyelomeningocele (LMM)
1. To identify high risk patient factors

2. To better counsel regarding long term outlook
   • Defining urologic outcomes in the setting of early TCR for lipomyelomeningocele (LMM)

Our Objectives:

Predictors of continence, with or without CIC

Likelihood / Timing of CIC
Patient Selection

- 143 patients with TCR for LMM, 1995-2010
  - 2 neurosurgeons

- Longitudinal multidisciplinary clinic care >1 year

**Exclusions**
- Concomitant ARM/ GU anomaly
- Prior TCR

**Inclusions**
- Toilet trained / Continent OR Age ≥6 y last visit
Patient Selection

Starting Cohort
143 Unique Patients
1995 – 2010
(2 SB team neurosurgeons)

10 < 1 year follow up

11 Anorectal malformation or GU anomaly

60 previous TCR

5 <6yo/not toilet trained, 1 incontinent stoma

Final Cohort
56 Patients, ≥ 1 year follow up
Clinical Factors

- Demographics
- Clinical Presentation
- Age at TCR
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- Demographics
- Clinical Presentation
- Age at TCR

- Anatomic factors:
  - lipoma type
  - complete vs. incomplete untethering
Study Group

• 56 patients (27 M / 29 F)

• Median age at TCR: 4.4 month (1.0-224)

• Presentation:
  • Asymptomatic (cutaneous, screening): 68%
  • Urologic symptoms: 9% (5/56)
Urologic Status

- Median length of urologic follow up 10.7 years (1.3-19.1)
- 86% (48/56) are continent with or w/o CIC
Urologic Status

56 Patients

- 8 (14%) **Incontinent** at latest follow-up
  - 5 (9%) **without CIC**
  - 3 (5%) **with CIC**

- 48 (86%) ** Continent** at latest follow-up
  - 38 (68%) **without CIC**
  - 10 (18%) **with CIC**
Urologic Status

56 Patients

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Urologic Status

• Unique population ➔ 91% asymptomatic urologically
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• Long-term CIC rate = 23 %
Urologic Status

• Unique population ➔ 91% asymptomatic urologically

• Overall Long-term = 23 % CIC
  • Asymptomatic = 13% CIC
  • Symptomatic (uro/ortho) = 44% CIC
Urologic Status

• CIC started at median age 7.6 yr (1.6-17.4)
  • Urodynamic/voiding change (10), desire for continence (4)
Urologic Outcome

• Urologic presentation in 5 patients (9%)
  • TCR median age 108 months
    • (4.4 months in overall cohort)
  • All continent at latest FU, but 4/5 (80%) on CIC
  • All had dimple or cutaneous lipoma---? opportunity
Additional Surgical Needs

- Re-tethering occurred in 21%

- No patient required BNR or augmentation
### Predictive Factors?

<table>
<thead>
<tr>
<th>Continence at most recent visit</th>
<th>p- value</th>
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</thead>
<tbody>
<tr>
<td>Continent</td>
<td>Incontinent</td>
</tr>
<tr>
<td>Total (n=56)</td>
<td>48 (86%)</td>
</tr>
<tr>
<td>Male</td>
<td>23 (85%)</td>
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<tr>
<td>Female</td>
<td>25 (86%)</td>
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<tr>
<td>Median age at TCR (months)</td>
<td>4.9</td>
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<tr>
<td>Presenting Symptoms</td>
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<tr>
<td>Asymptomatic (cutaneous lesion only, incidental)</td>
<td>33 (87%)</td>
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<tr>
<td>Symptomatic (urologic, ortho)</td>
<td>15 (83%)</td>
</tr>
<tr>
<td>Untethering</td>
<td></td>
</tr>
<tr>
<td>Complete</td>
<td>36 (86%)</td>
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<tr>
<td>Partial</td>
<td>12 (86%)</td>
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<tr>
<td>Lipoma type</td>
<td></td>
</tr>
<tr>
<td>Dorsal</td>
<td>21 (84%)</td>
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<tr>
<td>Distal</td>
<td>14 (93%)</td>
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<tr>
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<td>12 (80%)</td>
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<tr>
<td>Chaotic</td>
<td>1 (100%)</td>
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<tr>
<td>Conus Position</td>
<td></td>
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<tr>
<td>Low lumbar (L4, L5)</td>
<td>18 (86%)</td>
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<tr>
<td>Lumbosacral</td>
<td>3 (75%)</td>
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Predictive Factors for CIC?
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- CIC required in 44% of any symptomatic, 80% of urologically symptomatic
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- CIC required in 44% of all symptomatic, 80% of urologically symptomatic

Anatomic:

- CIC required in 57% of Partial untether
  - (12% Complete)
- CIC required in 47% of Transitional lipoma
  - (8% Dorsal, 27% Distal)
Conclusions

• Continence (with or without CIC) is excellent = 86%

• CIC is required in 23% over long-term, by 3rd grade in majority but as late as 17y

• Presentation with urologic symptoms ➔ CIC
Conclusions

• No anatomic, surgical or functional variable predictive of **continence**
• Transitional lipoma / Partial untether increases need for **CIC**
LMM ≠ MM
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Still cannot predict individual outcomes.
Treat them the same.
Limitations and Next Steps
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• Early TCR in young largely asymptomatic cohort
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• Excellent continence and low CIC may not be enjoyed by all presentations
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• Early TCR in young largely asymptomatic cohort

• Excellent continence and low CIC may not be enjoyed by all presentations

• Examining continence and CIC in NSBPR LMM