Variation in Surgical Management of Neurogenic Bowel among Centers Participating in National Spina Bifida Patient Registry

Disclosures and Disclaimers

• We do not intend to discuss any commercial products or services
• We do not intend to discuss non-FDA approved uses of products or providers of services
• This project is funded by the Centers for Disease Control and Prevention. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention or the Department of Health and Human Services.
Introduction

• Significant variation in clinical care of children with spina bifida (SB)
  • Including bladder & bowel reconstruction for incontinence or neurogenic bowel

• Hypothesis: Surgery rates vary among SB clinics, due to both SB-related and non-related factors
Objective

• To assess variation in the frequency of neurogenic bowel surgeries among National Spina Bifida Patient Registry (NSBPR) centers
Data Source

• 2009 – CDC initiates National Spina Bifida Patient Registry
• 2014 – 5,596 pts seen at 21 clinics
Methods

• NSBPR 2009-2014
  • Low-volume clinics excluded

• Identified neurogenic bowel surgeries:
  • Continent: (M)ACE/cecostomy
  • Incontinent: Ileostomy/colostomy

• Multivariable logistic regression models
  • Any neurogenic bowel procedure?
  • Continent vs. incontinent procedure?
  • Age, gender, race, concurrent bladder surgery, insurance, SB type, functional level, mobility, NSBPR site
Selection bias a potential issue in registries
  - Eligible pts not randomly enrolled

Logistic regression model constructed using 2014 enrolled pts
  - Modeled aggregate & individual data on unenrolled pts

10,000 simulations

Selection probability ratios calculated using separate model

Odds Ratios for surgery re-calculated using these ratios
Results - Demographics

- 5,528 patients from 19 clinics
  - Mean age 11.7 years
  - 53% female
  - 64% non-Hispanic white
  - 53% non-private insurance
  - 80% myelomeningocele
  - 54% lumbar level lesion
  - 54% community ambulators
Results – Neurogenic Bowel Surgery

• 1,088 patients (20% of cohort)
• 1,305 procedures
  • 957 (88%) ACE or cecostomy tube
  • 155 (14%) ileostomy or colostomy
• Some patients underwent multiple procedures
Results – Bivariate Analysis

- Surgery associated with:
  - Certain NSBPR clinics
  - Older age
  - Non-Hispanic white race/ethnicity
  - Private insurance
  - Non-ambulatory status
  - Myelomeningocele
  - Higher lesion level
  - Female gender (p=0.006)

P<0.001
Results – Multivariable Analysis

• Predictors of surgical intervention:
  • NSBPR clinic (p<0.001)
  • Higher lesion level (p<0.001)
  • Older age (p<0.001)
  • Myelomeningocele (p=0.012)
  • Non-Hispanic white (p=0.002)
  • Reduced mobility (p=0.011)
  • Private insurance (p=0.002)
  • Female gender (p=0.015)
Results – Multivariable Analysis

• Predictors of Incontinent Surgery (ileostomy/colostomy):
  • NSBPR clinic (p<0.001)
  • Younger age (p<0.001)
  • Non-ambulatory patients (p<0.001)
  • Non-MMC lesion (p<0.001)
  • Bladder reconstruction (p<0.001)
  • Non-Hispanic black (p=0.004)
### Results – Selection Bias

<table>
<thead>
<tr>
<th>Variables</th>
<th>SPR, median (2.5, 97.5 percentiles)</th>
<th>Estimate of bias (median RSPR)</th>
<th>Observed odds ratio (95% CI)</th>
<th>Adjusted odds ratio (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Surgery</td>
<td>No surgery</td>
<td></td>
<td></td>
</tr>
<tr>
<td>odds of enrollment compared with referent group</td>
<td>Odds of being enrolled if the patient had surgery</td>
<td>Odds of having surgery compared with the reference group</td>
<td>Odds of having surgery compared with the reference group adjusted for enrollment</td>
<td></td>
</tr>
<tr>
<td>Age (years)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 10'</td>
<td>Referent</td>
<td>Referent</td>
<td>Referent</td>
<td>Referent</td>
</tr>
<tr>
<td>10 to &lt;18</td>
<td>1.52 (0.86, 2.54)</td>
<td>1.48 (1.32, 1.69)</td>
<td>1.02</td>
<td>4.28 (3.37, 5.44)</td>
</tr>
<tr>
<td>18 or older</td>
<td>0.73 (0.41, 1.20)</td>
<td>0.85 (0.76, 0.97)</td>
<td>0.86</td>
<td>3.10 (2.35, 4.08)</td>
</tr>
<tr>
<td>Sex</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>Referent</td>
<td>Referent</td>
<td>Referent</td>
<td>Referent</td>
</tr>
<tr>
<td>Female</td>
<td>1.20 (0.82, 1.76)</td>
<td>1.07 (0.99, 1.16)</td>
<td>1.12</td>
<td>1.18 (0.96, 1.44)</td>
</tr>
<tr>
<td>Race/Ethnicity</td>
<td></td>
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<tr>
<td>NH White</td>
<td>Referent</td>
<td>Referent</td>
<td>Referent</td>
<td>Referent</td>
</tr>
<tr>
<td>NH Black</td>
<td>0.77 (0.42, 1.87)</td>
<td>0.68 (0.61, 0.78)</td>
<td>1.13</td>
<td>0.74 (0.48, 1.11)</td>
</tr>
<tr>
<td>Hispanic or Latino</td>
<td>1.01 (0.60, 2.01)</td>
<td>1.09 (1.00, 1.20)</td>
<td>0.93</td>
<td>0.53 (0.40, 0.72)</td>
</tr>
<tr>
<td>Other</td>
<td>1.03 (0.57, 2.55)</td>
<td>1.70 (1.44, 2.11)</td>
<td>0.61</td>
<td>1.05 (0.72, 1.52)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
<td></td>
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<td></td>
</tr>
<tr>
<td>Myelomeningoccele</td>
<td>Referent</td>
<td>Referent</td>
<td>Referent</td>
<td>Referent</td>
</tr>
<tr>
<td>Other diagnosis</td>
<td>0.62 (0.36, 1.22)</td>
<td>0.54 (0.49, 0.59)</td>
<td>1.15</td>
<td>0.70 (0.51, 0.96)</td>
</tr>
<tr>
<td>Level of lesion</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Thoracic</td>
<td>Referent</td>
<td>Referent</td>
<td>Referent</td>
<td>Referent</td>
</tr>
<tr>
<td>Lumbar</td>
<td>1.16 (0.75, 1.75)</td>
<td>1.20 (1.01, 1.38)</td>
<td>0.97</td>
<td>0.72 (0.55, 0.93)</td>
</tr>
<tr>
<td>Sacral</td>
<td>1.25 (0.70, 2.53)</td>
<td>1.18 (0.99, 1.38)</td>
<td>1.06</td>
<td>0.41 (0.29, 0.58)</td>
</tr>
<tr>
<td>Insurance</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Private</td>
<td>Referent</td>
<td>Referent</td>
<td>Referent</td>
<td>Referent</td>
</tr>
<tr>
<td>Non-private</td>
<td>0.40 (0.26, 0.59)</td>
<td>0.46 (0.42, 0.51)</td>
<td>0.86</td>
<td>0.77 (0.62, 0.95)</td>
</tr>
</tbody>
</table>

Adjusted analysis not different from original data.
Conclusions

- **Significant variation** in neurogenic bowel surgery among NSBPR centers

- **No evidence of selection bias**

- Both disease-related and non-disease-related factors associated with both **whether or not surgery** is done, and **what kind of surgery** is done