A SURVEY OF PARENTAL DISCLOSURE AND ATTITUDES RELATED TO THE REPAIR OF HYPOSPADIAS

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*Authors have no conflict of interest to disclose*
HYPOSPADIAS

• Reconstructive repair is often used to improve cosmetic appearance and functional outcome

• For some the optimal outcome of hypospadias repair is a circumcised appearing penis, a procedure that many parents may decide upon electively.
  • Disclosure of repair may therefore, potentially be withheld.
  • Advantages / Disadvantages of disclosure of hypospadias repair
DISCLOSING CHILDHOOD ILLNESS AND SURGERY

• Lack of research regarding parental disclosure in pediatric surgery

• Most literature surrounds disclosure regarding pediatric cancers, HIV or issues related to adoption/assisted reproductive technology
PREVIOUS RESEARCH

• Only one study exists in the literature regarding parental disclosure of urological surgery
  • Included circumcision, orchidopexy, ureteral reimplant, ureterocele incision, pyeloplasty, etc…
  • Hypospadias was a small subset of the data (20 cases)

• 20% (4/20) of parents whose children underwent hypospadias repair answered that they would not disclose that they had undergone the procedure to their child

Ching et al. 2015
OBJECTIVES

• Determine the rate of parental disclosure in boys undergoing hypospadias repair

• Evaluate the parental perspectives regarding concerns and amount of support related to disclosure of hypospadias repair
METHODS

• Anonymous, cross-sectional, self-report web-based questionnaire

• Distributed in 2 settings:
  • Parents of post-operative hypospadias patients in the McMaster Children’s Hospital pediatric urology outpatient clinic
  • Parents of hypospadias patients belonging to various closed Facebook hypospadias parent support groups
  • All information recorded and stored on the Research Electronic Data Capture (REDCap) database.

• SPSS used for statistical analysis
# DESCRIPTIVE STATISTICS

<table>
<thead>
<tr>
<th>Relationship to child</th>
<th>% (N)</th>
</tr>
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<tbody>
<tr>
<td>Mother</td>
<td>165 (81)</td>
</tr>
<tr>
<td>Father</td>
<td>39 (19)</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Residential Setting</th>
<th>% (N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>North America</td>
<td>169 (83)</td>
</tr>
<tr>
<td>Urban</td>
<td>146 (72)</td>
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<table>
<thead>
<tr>
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<th>Mean ± SD (years)</th>
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<tbody>
<tr>
<td>Respondent's age</td>
<td>31.2 ± 11.1</td>
</tr>
<tr>
<td>Son's age at first surgery</td>
<td>1.5 ± 2.3</td>
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HYPOSPADIAS SEVERITY

- Distal
- Midshaft
- Proximal
ARE YOU NERVOUS TO TELL YOUR SON?

• No but........
• There was a significant difference in nervousness to disclose if the condition was distal (79%) versus proximal (100%) (p= <0.01).
WOULD SUPPORT BE HELPFUL WITH THE DISCLOSURE?

• 90% reported that they were not offered guidance on how/when to disclose

• 48% thought they would benefit from support on this
HAVE YOU ACCESSED ANY ONLINE HYPOSPADIAS INFORMATION OR GROUPS? FOR WHAT PURPOSE?

• 64% had accessed online information/support groups

• 43% of them for the purpose of education about hypospadias.
HAS ANYONE EVER DISCUSSED WITH YOU HOW TO DISCLOSE?

- Almost all parents (94%) said they had not been counselled on disclosing

- A significant difference was also observed regarding disclosure support with proximal being more likely to want formal support (p=0.05)
• Little to no information for counselling methods or education for parents planning on disclosing to their child

• Most patients would not have maintained constant follow up with their surgeon, creating a potential gap in continued support

• Implications of surgical intervention must be considered in terms of future repercussions for the parents and the growing child, especially in relation to disclosure
LIMITATIONS

• Response rate difficult to calculate
  • Window of recruitment was open for 12 months
  • Social media platforms (increased generalizability)

• Anonymous, self-report survey

• Selection bias
CONCLUSIONS

• Majority of parents will disclose to their child that they had undergone a repair as an infant

• While most parents are not overly nervous about disclosure, they have had no counseling regarding the optimal methods of disclosure

• There are important differences between families of distal or more proximal disease that should be accounted for

• Parents will seek out virtual sources for education gaps