

# 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

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- 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

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- 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

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- 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

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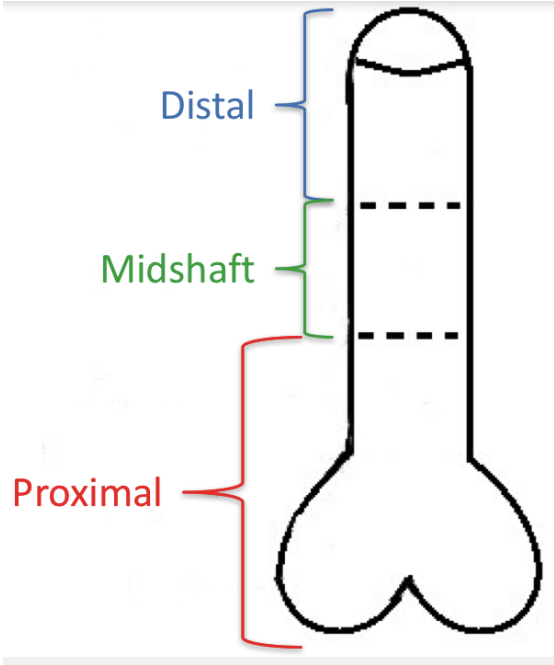
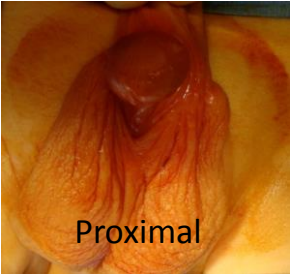
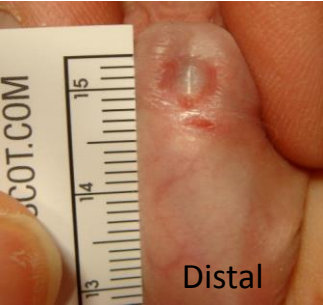
- Anonymous, cross-sectional, self-report web-based questionnaire
- Distributed in 2 settings:
  - Parents of post-operative hypospadias patients in the McMaster Children's Hospital pediatric urology outpatient clinic
  - Parents of hypospadias patients belonging to various closed Facebook hypospadias parent support groups
  - All information recorded and stored on the Research Electronic Data Capture (REDCap) database.
- SPSS used for statistical analysis

# DESCRIPTIVE STATISTICS

	N=204	% (N)
<b>Relationship to child</b>		
Mother		165 (81)
Father		39 (19)
<b>Residential Setting</b>		
North America		169(83)
Urban		146 (72)

	Mean $\pm$ SD (years)
Respondent's age	31.2 $\pm$ 11.1
Son's age at first surgery	1.5 $\pm$ 2.3

# HYPOSPADIAS SEVERITY



# ARE YOU NERVOUS TO TELL YOUR SON?

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- 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?

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- 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?

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- 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 ( $p=0.05$ )

# DISCUSSION

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- 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

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- 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

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- 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