



To tell or not: parental thoughts on disclosure of urologic surgery to their child

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ABSTRACT

Purpose: Literature pertaining to surgical disclosure to the pediatric patient is lacking. We hypothesized parents would find it difficult to disclose urologic surgery to a child.

Materials and Methods: Parents of patients <5 years old undergoing urologic surgery were contacted for telephone survey. Parents were asked about future plans of surgical disclosure, comfort with disclosure, and any support received.

Results: 98 parents consented to study participation. 87% of surgeries were on the genitalia with 62% being minor genitalia surgery (i.e. circumcision). 70% of parents would tell their child about minor genital surgery while 84% would tell about major genital surgery ($p=0.07$). 4 of 20 parents of children undergoing hypospadias repair (major genital surgery) did not plan to tell their child about surgery. All parents of children undergoing non-genital surgery would tell. Of all parents planning to tell their children about surgery, only 14% were nervous. 34% of parents would find guidance in talking to their child helpful despite the majority (90%) stating no guidance had ever been provided.

Conclusions: Parents seem comfortable discussing urologic surgeries with a child but about 1/3 would appreciate further counseling. 20% of parents of children undergoing hypospadias repair hope to avoid telling their child.

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INTRODUCTION

The current existing literature on medical disclosure to the pediatric patient tends to address disclosure of life-threatening illnesses such as pediatric cancers and the human immunodeficiency virus (HIV) or issues related to adoption and assisted reproductive technology (1-6). There is little in the literature about parental communication of a prior surgery to their child. Specifically, there is limited information on disclosure of urologic surgery which some

parents may find difficult to discuss as it often involves socially taboo parts of the body such as the external genitalia.

We decided to survey parents to see their thoughts on urologic surgical disclosure to their child—including their plan as to whether or not they would tell their child about surgery. We hypothesized that parents would find disclosure of urologic surgery and specifically genital surgery difficult and require more education and support on discussing such topics with their child than they are receiving now.

MATERIALS AND METHODS

After receiving institutional review board approval (#121876), we contacted parents of all pediatric patients <5 years old undergoing urologic surgery between February 2013 and May 2013 at Monroe Carell Jr. Children's Hospital at Vanderbilt University. This included patients of all 6 pediatric urologists at Vanderbilt. Parents consented at time of post-operative follow-up phone call. These calls were all performed the day after surgery as part of our standard post-operative follow-up phone call protocol at which time parents were then told about the study and asked to participate in a telephone survey. The survey questions are listed in Figure-1 and include whether parents ever plan to disclose such prior surgery to their child, the age at which parents would disclose such information, parental comfort with disclosing such information to their child, prior support given and desire for future support in how to tell their child about surgery, and the parent's own personal experience with childhood surgery. The exact type of surgery the parent underwent and surgical history of the other parental unit was not asked. The electronic medical record (EMR) of each pediatric patient was also reviewed for evidence of other prior surgeries and major patient co-morbidities. Categorical variables were compared with chi-square test while continuous variables were compared using Student's t-test. Significance was determined by a p value <0.05.

RESULTS

103 parents of children undergoing urologic surgery at <5 years of age were contacted in consecutive post-operative follow-up phone calls of which 98 parents consented to participate in our study. No patient parents were specifically excluded from the study. For all participants, only one of the parental units was questioned during the survey (the parent answering the phone) and the parents did not have time to consult each other at time of phone survey. The 5 parents declining to participate included 3 patients undergoing chordee lysis/circumcision, 1 undergoing inguinal hernia repair, and 1 undergoing labiaplasty for

congenital adrenal hyperplasia. The average age of patients included was 15.7 months (median 8.2 months, range 3.7-57.7 months). The majority of patients were male (95 patients); however, 3 were female. Table-1 lists the types of surgeries and corresponding parental decision about disclosure. There were 85 genital surgeries (penis and testicular surgery) and 13 non-genital surgeries (hernia surgery, bladder surgery, and kidney surgery). All parents of children undergoing non-genital surgery were planning on disclosing surgery to their child. 16 of 85 (18.8%) of parents of children undergoing genital surgery were not planning to tell their child about surgery; 4 of 85 (4.7%) were unsure. This difference in plans for disclosure between genital versus non-genital surgery was not statistically significant ($p=0.06$).

Among genital surgery, the majority of surgeries (53/85; 62.4%) were minor (circumcision, circumcision revision, chordee lysis, excision penile ski bridge/tag/adhesion, and meotomy) while the rest (32/85; 37.6%) constituted more major genital surgery (orchiopexy, orchiectomy, and hypospadias). 37/53 (69.8%) of parents of children undergoing minor genital surgery would definitely disclose the recent surgery to their child; 3/53 (5.7%) were unsure. 27/32 (84.4%) of parents of children undergoing major genital surgery would definitely disclose surgery to their child; 1/32 (3.1%) was unsure. There was not a significant difference in plans for disclosure based on whether a child underwent minor versus major genital surgery ($p=0.07$). Interestingly, 4 of the 20 parents of children undergoing hypospadias repair (major genital surgery) did not plan to tell their children. All 4 of the children underwent distal hypospadias repair. All parents of children undergoing mid or proximal hypospadias repair planned to tell their children.

The majority of parents questioned were female; 11 (11.2%) were male. The sex of the parent surveyed was not a significant factor in determining disclosure response ($p=0.68$). There was not a significant association between parental choice to disclose their child's surgery and if the parents themselves had ever had surgery ($p=0.25$) or specifically surgery at <5 years of age ($p=0.68$). Of those 4 parents of children undergoing hypos-

Figure 1 - Parental Disclosure of Surgery Questionnaire.

1.	How old is your child?		
2.	What surgery did your child just undergo?		
3.	Do you plan to tell your child about this surgery?	YES	NO
	a. If you plan to tell your child, Do you know <u>when</u> (ie how old) you will tell your child?		
	b. If you plan to tell your child, Do you know <u>how</u> you will tell your child?		
4.	Are you nervous or concerned to tell your child?	YES	NO
	a. If you are nervous or concerned, why?		
5.	Has anyone ever talked to you about telling your child?	YES	NO
6.	Would you find it helpful to talk to someone about telling your child?	YES	NO
7.	Before taking this survey, had you given any thought to talking to your child?	YES	NO
	a. Have <u>you</u> ever had surgery?		
8.	How old were you?	YES	NO

padias repair who did not plan on telling them about surgery, all had undergone surgery themselves but none at less than 5 years of age. Prior major surgery or major co-morbidity in the pediatric patient was not predictive of parental choice to disclose their child's recent urologic surgery, and neither was patient race ($p=0.56$). Parents seem to agree to tell their child about surgery "when they can understand" however the definition of this ranged in age from 2-16 years old (mean 9 years).

Of all parents planning to disclose surgery (78), only 11 (14.1%) of these parents were nervous to do so. Overall, 33/98 (33.7%) of parents would find it helpful to have guidance in talking to their child about surgery despite the overwhelming majority (88/98; 89.8%) reporting not having received any such guidance.

DISCUSSION

Our interest in parental disclosure of prior childhood urologic surgery began after attempting to reach teenage patients for long-term follow-up after childhood hypospadias repair and encountering one parent's refusal for participation due to the fact they had never told their

child about the initial surgery. We wondered the regularity of this occurrence and the literature that may exist on the topic of surgical disclosure. Overall, there is minimal information on disclosure of prior urologic surgery to a child, with the few articles that exist primarily focusing on disorders of sexual development. These tend to emphasize decisions of gender assignment and timing of surgical intervention (7-11).

The majority of literature on disclosing childhood medical conditions is primarily limited to grave illnesses such as HIV, cancer, Duchenne muscular dystrophy, and fetal alcohol syndrome (1-3, 12-17) where disclosure has important treatment ramifications. In HIV, disclosure of disease may improve patient medication compliance and the sharing of disease status to future sexual partners to prevent disease transmission (13, 14, 18).

While diagnoses related to urologic surgery are often not as grave as HIV, important lessons regarding potential medical compliance and necessary follow-up may follow with its disclosure.

Urologic surgery has the potential for delayed complications of which the patient should be aware. Urinary tract reconstruction such as hypospadias may result in voiding issues such as

Table 1 - Parental decision on whether or not to tell their child about surgery and the type of surgery the patient underwent.

Type surgery			Number patients	Plans to tell child patient		
				Yes (%)	No (%)	Unsure (%)
Genital Surgery	Minor	Chordee lysis	5	3 (60)	2 (40)	
		Chordee lysis/circumcision	14	11 (78.6)	1 (7.1)	2 (14.3)
		Circumcision	11	8 (72.7)	3 (9.1)	
		Circumcision revision	11	9 (81.8)	2 (18.2)	
		Excision penile skin bridge/tag/adhesions	8	3 (37.5)	4 (50)	1 (12.5)
		Meatotomy	3	3 (100)		
		Ureterocele incision+circumcision	1	1 (100)		
	Major	Hypospadias	20	15 (75)	4 (20)	1 (5)
		Distal	16	11	4	1
		Mid	1	1		
		Proximal	3	3		
		Orchidopexy	8	8 (100)		
		Orchidopexy+circumcision	1	1		
		Orchiectomy	4	4 (100)		
		Orchiectomy+circumcision	2	2		
Non-Genital Surgery	Cystoscopic incision of ureterocele	1	1(100)			
	Herniorrhaphy/hydrocele repair	7	7 (100)			
	Pyeloplasty	3	3 (100)			
	Ureteral reimplant	2	2 (100)			

obstruction or fistula. Prior hernia or orchiopexy may affect fertility. Some urologic conditions have a genetic association and could affect the patient's own future offspring: one mother in our study planned to tell her son about his hypospadias because it was "important for him to know if he has his own kids". Failing to disclose such information to a child may result in delayed feelings of resentment and deception (19).

One mother being interviewed expressed regret that she and her husband had only recently been told of the husband's prior childhood hypospadias repair; she intended to discuss her son's urologic surgery earlier in his life.

Some major concerns in disclosing prior urologic surgery to a child is the potential of drawing "unnecessary" attention to and emphasizing the potentially sensitive issue of a child's genitalia. Parents who were not intending to tell their child about surgery shared a common theme of only planning to inform their child if they specifically asked about a scar. Parents may be reluctant to talk to their child about a prior surgery in order to avoid drawing attention to an already sensitive topic—with the hopes of "normalizing" the child and not wishing to emphasize the original pathology that required surgery. One parent who was not planning to tell their child about surgery stated

they “did not want (their child) to feel different”. The potential sensitive nature of urologic surgery was evident by the response of one of the parents who declined participation in the study. The child had undergone labiaplasty for congenital adrenal hyperplasia and the parent specifically stated their desire to only discuss their child’s condition with the surgeon. None of the other 4 parents declining to participate gave such a strong explanation for their decision.

Given the possibility that parental disclosure could be influenced by the body part on which is being operated, we decided to evaluate parental response based on genital versus non-genital surgery. While we did not find that parental thoughts on disclosure between genital and non-genital surgery was significantly different, it did approach statistical significance ($p=0.06$) and was perhaps limited by the small number of patients in our non-genital surgery group (only 13). Again, this could suggest that parents may be more hesitant to discuss genital versus non-genital surgery with their child; however, it could also demonstrate a distinction in perceived severity of the surgery and need for continued follow-up. For example, some of the non-genital surgeries may require ongoing follow-up due to the risk of serious complications (i.e. vesico-urinary reflux and the possibility of associated reflux nephropathy) which may influence a parent’s attitude towards disclosure. While we did not have enough patients to do a meaningful comparison of overall major versus overall minor surgery, we did evaluate parental plan for disclosure based on major versus minor genital surgery but did not find a significant difference in disclosure plans.

Overall, we found that parents generally planned to discuss surgery with their child and felt relatively comfortable doing so. While 34% of parents would find it helpful to have some sort of guidance in talking to their child, some parents stated they thought the discussion of disclosure “should be between husband and wife” and “should not include a 3rd party.” It appeared a highly personal decision—that often involved talk amongst family members via anecdotal responses. One thing is evident, we as urologists do not do an adequate job of addressing this issue or at least

acknowledging the future need for disclosure. Of the 10 parents responding they had entered discussions of how to disclose surgery to their child, only 5 had been counseled by a medical professional while the other 5 had sought counsel with other family members or in their church. Approximately one-third of our parents would appreciate some counseling from a healthcare profession about talking to their child. One of the most commonly stated reason for being nervous to discuss surgery was being unsure “how” to tell their child or “what words to use”. Better collaboration with Child Life resources may help aid in choosing the most appropriate words to explain to a child about a prior surgery. This may help ensure a gradual, age appropriate discussion that would be most tangible and thus beneficial in conveying this information to the patient.

There is no data to help determine the best age of the patient at which to disclose medical information (19). Some argue that early discussions are important in order to create a sense of “teamwork” and establish open early channels of communication (20).

In the case of maternity or paternity as with donor reproduction, it appears disclosure to a child at a younger age is important (4, 5); however, this scenario is difficult to extrapolate to ours given the differences in the nature of information being conveyed with the latter case more directly affecting parent/child relationships when compared to our study.

When evaluating the literature for timing of disclosure on other issues, there does not appear to be a specific age where disclosure seems appropriate with most studies concluding there is no obvious appropriate age (6) other than just when it “seemed right” or when parents thought their child could optimally understand (4).

Our study had several limitations. First of all, the overall number of patient parents questioned was small and our study was not specifically powered to find a difference between the various subgroups noted. In addition, the majority of cases were circumcisions which do not generally necessitate long term follow-up or even specific disclosure, particularly in the United States where circumcision is relatively common.

Children undergoing circumcision clearly ultimately know they have been circumcised independent of whether the child's parents specifically tell them. We also chose to survey parents of children <5 years old. Arguably this included some children who already realized they were undergoing surgery and thus would not need specific disclosure of their surgery. A future study may want to include surveying parents of younger children.

One thing we did not specifically delineate when asking parents about their plan was if their plan of disclosure was specific to the surgery or just about disclosing a childhood surgery and whether they would specifically withhold information about surgery from their child. We also did not specifically ask parents why or why not they would tell their child of a prior surgery and did not include parental age and educational and socioeconomic status in our analysis.

A future study may want to probe further how exactly we as urologists can help counseling these parents and the potential role education/socioeconomic status may play in a parent's decision for disclosure. We are also relying on the ability of parents to recall prior guidance on disclosure which may not be completely accurate as to whether guidance was actually offered and given. This study was only a preliminary evaluation of this issue and can continue with evaluation of more complex surgeries such as hypospadias repair or even children with ambiguous genitalia or disorders of sexual differentiation in which these issues of disclosure are of more consequence. In addition, it would be nice to correlate the future plans as found in this study with the actual reality of disclosure in a prospective study. It will remain to be seen what the true impact of disclosing or not disclosing such information to former child patients will be.

CONCLUSIONS

Disclosure of a urologic surgical procedure is a personal decision for each parent.

Parents seem overall relatively comfortable telling a child about prior urologic surgery, although we as urologists could do a better job of discussing this issue with parents.

Those parents willing to avoid specifically telling their child about a surgery seem content to do so unless the child notices a physical difference post-operatively. Parents seem more reluctant to discuss hypospadias repair with their child when compared to other urologic surgeries which may necessitate a more informed discussion between urologist and parent about potential long-term complications of hypospadias surgery.

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CONFLICT OF INTEREST

None declared.

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