

Shared decision-making for pediatric elective penile surgery

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Abstract

Introduction: In pediatric surgery, proxy decision-makers are frequently involved in treatment planning and may experience decisional conflict (DC). Shared decision-making (SDM) approaches may be effective to remedy DC. This study investigates DC and SDM involvement in elective pediatric penile surgery.

Methods: Forty-four parents of children aged <8 years undergoing elective penile surgery consultations at a tertiary pediatric hospital were prospectively enrolled. Patient and physician questionnaires were used to assess the SDM process and the SURE (Sure of myself; Understand information; Risk-benefit ratio; Encouragement) screening test was used to assess DC.

Results: Thirty-seven (84.1%) mothers and seven (15.9%) fathers were enrolled for circumcision (n=33, 75.0%) and distal hypospadias repair (n=11, 25.0%) consultations, with 21 (47.7%) choosing to proceed with surgery. Seven (15.9%) participants experienced clinically significant DC. Participant gender was not associated with higher levels of DC (p=0.318). The average patient and physician SDM scores were 88.2±10.0 and 85.3±7.4, respectively, with no correlation found between participant and physician perception of SDM involvement (p=0.168, p=0.276). DC was significantly associated with lower participant and physician ratings of SDM.

Conclusions: There was a high perception of SDM involvement by both parents and pediatric urologists regarding elective penile surgery. Of the 15% of parents experiencing DC, there was an association with lower participant and physician levels of SDM involvement. Despite high SDM scores overall, discrepancies exist between the perceived physician and participant SDM involvement.

Introduction

In the pediatric population, parents often make proxy decisions for their children, which involves understanding the inherent risks, benefits, and treatment alternatives of a particular intervention.¹ In elective procedures, there exists an

KEY MESSAGES

- Pediatric urologists and parents of children undergoing elective penile surgery consultations both perceive high involvement in the shared decision-making (SDM) process.
- High perceived physician involvement in the SDM process was associated with participants proceeding with surgery and being less likely to experience decisional conflict.
- Parents of children undergoing consultation for elective circumcision were more likely to experience decisional conflict.

increased complexity in the decision-making process due to the potential for opposing opinions in the literature and the considerable involvement of personal values, which may lead to significant distress.²⁻⁴ This is especially true in elective penile surgeries without a clear medical indication, where parents may feel overwhelmed and conflicted when making decisions.^{5,6} This uncertainty experienced in the decision-making process is commonly referred to as “decisional conflict” (DC) and can lead to significant distress.^{7,8} This DC has been shown to increase when parents feel they have inadequate knowledge, unclear values, or feel uninformed.^{4,9,10}

Although DC is reported to be very high for elective pediatric surgeries, using a shared decision-making (SDM) process — a patient-centered approach to informed consent — has been shown to decrease DC.^{3,5,6,9-11} As SDM is a collaborative process between patients and healthcare providers that uses the most recent evidence while acknowledging patient values and preferences to reach a decision, parents report feeling more involved in the process and experience less DC.^{3,4} Applications of SDM in pediatric disorders of sexual development (DSD) have been explored, although there are limited studies investigating the impact of SDM on DC in this patient group.^{12,13} Additionally, the perceived

involvement of parents and providers in the SDM process remains understudied.

The primary objective of this study was to investigate parental DC associated with elective pediatric penile surgery — circumcision and distal hypospadias repair; additionally, we evaluated the level of perceived SDM between parents and pediatric urologists. Secondary objectives included determining if certain patient/parental characteristics or aspects of the decision-making process may predispose parents to experience DC.

Methods

Participants

After obtaining approval from the institutional research ethics board, parents of children seen in the pediatric urology clinic for possible elective penile surgery were approached for participation from January 2017 to February 2020. Inclusion criteria included parents/guardians of children aged <8 years who were being evaluated for possible elective penile surgery, including circumcision without a clear medical indication and distal hypospadias repair. Circumcision and distal hypospadias repair were included, as the main surgical focus was on restoring cosmesis. Exclusion criteria included parental inability to speak or read English, if the parent was not the decision-making authority for the child, or if the main surgical indication was based on a clear medical indication (e.g., balanitis xerotica obliterans, hypospadias with small meatus, or obstructed voiding) or religious beliefs. The pediatric urologist involved in the consultation was included for the analysis of SDM perception. Three fellowship-trained pediatric urologists at the same institution participated in this study.

Procedure

Upon registering in the pediatric urology clinic, qualified parents/guardians were approached by the clinic nurse and were informed of the study prior to the surgical consultation. If interested, the participants were provided further details on the study and informed consent was obtained by the research assistant. Participants completed a demographics form and then proceeded to their consultation. Following consultation, the consulting pediatric urologist and the participants completed questionnaires in dedicated separate rooms.

Measures

Demographic form

Information was collected on family composition, marital status, education, ethnicity, occupation, child's age, and past surgical history of the patient and their siblings. This informa-

tion was combined with a form completed by the pediatric urologist indicating the condition/diagnosis of the child and the potential surgical options discussed.

Shared decision-making questionnaire

Participants completed the nine-item (SDM-Q-9) patient-version questionnaire, assessing parental perception of involvement in the SDM process.¹⁴ The pediatric urologist completed the nine-item (SDM-Q-Doc) questionnaire assessing their perception of involvement in the SDM process.^{15,16} The level of SDM was quantified by completed questionnaire scores that range from 0 (no SDM) to 100 (extremely high SDM). These questionnaires have been shown to have high reliability in medical settings.^{3,17}

SURE screening test

After consultation, parent participants also completed the SURE screening test, a four-item validated survey using dichotomous responses to assess DC.¹⁸ Participants who answer “no” to one or more questions on the SURE test are screened as positive for DC. The SURE test has been shown to have moderate internal reliability (Cronbach's alpha=0.65) and has been frequently used to detect significant DC in clinical settings.¹⁷

Data analysis

Data was exported into the Statistical Package for the Social Sciences (SPSS) software (version 25) (IBM Corp, Armonk, NY, U.S.) and demographics were expressed using descriptive statistics. Participant and pediatric urologist perception of involvement in the SDM process were analyzed using descriptive statistics, and the correlation between parental and physician SDM measures were analyzed using Spearman rank-order correlation analysis. A sample size of 52 participants was determined, by analysis of the literature on DC and SDM, to provide 80% power to detect correlations between DC and SDM.^{3,15} To assess the internal reliability of the SDM-Q-9 and SDM-Q-Doc questionnaires in our study, Cronbach's alpha scores were calculated.

Normality of the data from the SURE screening test was assessed and total SURE and SURE subscales were examined using descriptive statistics. Participants with SURE scores ≤ 3 were defined as having clinically significant DC.¹⁹

Surgical and participant demographic factors were compared with the presence of DC using Mann-Whitney U tests, Kruskal Wallis tests, and Spearman rank-order correlation analysis to determine the relationship between patient demographics, DC, and SDM.

Results

Demographics

Forty-four participants were enrolled in the study. Participants included 37 (84.1%) mothers and seven (15.9%) fathers. The average maternal and paternal ages were 31.9 ± 5.8 years and 35.1 ± 6.5 years, respectively. Parental education was high, with 79.5% of participants having completed some form of postsecondary education. The average patient age was 3.8 ± 2.4 years, with eight (18.2%) patients undergoing a previous surgical procedure. All three pediatric urologists were involved in consultations (surgeon 1: 27.3%, surgeon 2: 61.4%, surgeon 3: 11.3%). Patients were referred for consultation for circumcision ($n=33/44$, 75%) and distal hypospadias repair ($n=11/44$, 25%), with 21 (47.7%) patients proceeding with surgery (circumcision: 12 and distal hypospadias repair: nine). Eight of 44 patients (18.2%) had noted previous surgical experiences, with one patient reporting postoperative anesthetic complications. An overview of participant demographics can be seen in Table 1.

Perception of shared-decision making

Cronbach's alpha for the SDM-Q-9 and SDM-Q-Doc questionnaires were calculated to be 0.80 and 0.76, respectively, indicating that there was good reliability for both of these measures. Both the SDM-Q-9 and SDM-Q-Doc cohort scores were negatively skewed, with a median SDM-Q-9 score of 88.2 (standard error [SE] 1.51, interquartile range [IQR] 16.7) and a median SDM-Q-Doc score of 85.3 (SE 1.12, IQR 12.9). SDM-Q-9 and SDM-Q-Doc scores did not differ significantly based on surgeon involved. Participant gender, age, and parental education level was not associated with any significant difference in either SDM-Q-9 or SDM-Q-Doc scores. Additionally, previous patient surgical experiences had no impact on SDM-Q-9 scores. Despite high SDM scores overall, there was no relationship found between participant and physician perception of SDM involvement ($p=0.168$, $p=0.276$) (Figures 1, 2). There was a higher perceived SDM involvement by physicians during hypospadias repair consultations compared to consultations for circumcision ($p=0.488$, $p=0.001$). Furthermore, higher physician perception of SDM involvement was strongly associated with patients proceeding with surgery ($p=0.531$, $p=0.0001$). Parental perception of involvement in the SDM process was not significantly associated with decision to proceed with surgery or not ($p=0.028$, $p=0.858$).

Decisional conflict

Seven (15.9%) participants experienced significant DC, with four participants having a SURE score of 3/4 and three participants having a SURE score of 2/4 (Table 2). DC was seen

Table 1. Participant demographic characteristics (n=44)

Demographic factors	n (%)
Participant relation to child	
Mother	37 (84.1)
Father	7 (15.9)
Participant race/ethnicity	
Caucasian	40 (90.9)
African Canadian	4 (9.1)
Parental education	
<High school	1 (2.3)
High school completed/equivalent	8 (18.2)
Community college	18 (40.9)
Undergraduate degree	14 (31.8)
Graduate degree	3 (6.8)
Reason for referral	
Circumcision – phimosis	32 (72.7)
Circumcision – cosmetic	1 (2.3)
Distal hypospadias	11 (25.0)
Previous patient surgical experience	
Yes	8 (18.2)
No	36 (81.8)
Previous patient surgical complication	
Yes	1 (2.3)
No	43 (97.7)
Proceeding with surgery	
Yes	21 (47.7)
No	23 (52.3)
Decisional conflict	
Yes	7 (15.9)
No	37 (84.1)

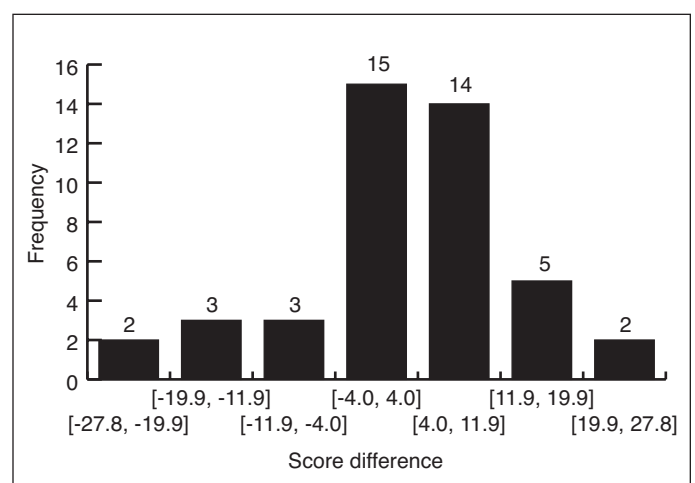


Figure 1. Histogram of the difference between doctor and parent assessed shared decision-making (SDM) scores, showing that most patients had SDM scores that were similar or greater than physician SDM scores. Positive values indicate parents perceiving higher SDM, while negative values correspond to instances where the physician had a higher rated SDM. Values of 0 indicate complete agreement between both parties.

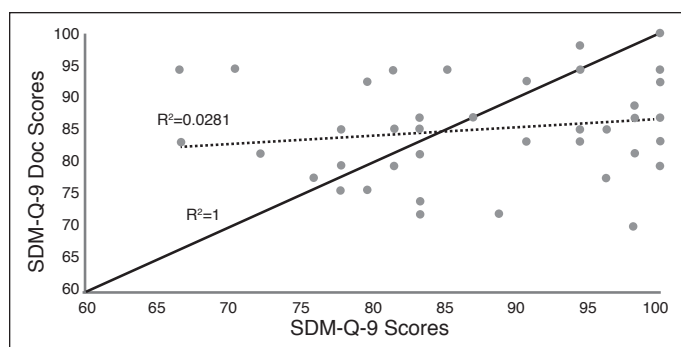


Figure 2. Physician and participant shared decision-making (SDM) scores demonstrating no significant linear relationship between physician and participant perceived involvement in the SDM process.

more in circumcision consultations ($n=6/7$) when compared to hypospadias repair consultations ($n=1/7$). Demographic factors and surgical factors, such as surgeon involved, procedure type, past surgical experience, and previous surgical complications, were not associated with participants experiencing DC. Additionally, patients undergoing a previous surgical procedure had no impact on DC. Participants with clinically significant DC had lower perceived involvement in the SDM process when compared to those without DC (SDM-Q-9: 81.5 ± 5.77 vs. 89.4 ± 10.2 , $p=0.023$). Similarly, in cases where participants had significant DC, the physician also reported lower perceived SDM involvement (SDM-Q-Doc: 79.9 ± 6.90 vs. 86.3 ± 7.1 , $p=0.029$). Finally, participants experiencing DC were less likely to proceed with surgery after consultation ($p=-0.291$, $p=0.05$).

Discussion

In our study, participants and physicians demonstrated high perceived SDM involvement. Despite this, there was no correlation between SDM scores for the parent and physician groups, highlighting the complexity of the SDM process. Although DC was low in our study population, participants were more likely to experience DC when there was lower patient and physician perceived involvement in the SDM process. When considering consultation type, physicians perceived greater SDM involvement during distal hypospadias repair consultations than for circumcisions. Furthermore, participants undergoing consultation for circumcision were more likely to have DC.

For proxy decision-makers, making medical and/or surgical treatment decisions on their child's behalf can be a difficult task, which may lead to DC and potential regret.^{4,10,20} For elective procedures, this decision-making process is further complicated by personal experiences and preferences involved when weighing the respective risks and benefits.^{2,6} For pediatric elective penile surgery, the complexity of the decision-making process is affected by many of these factors. To add to this difficulty, the literature on elective penile surgery

Table 2. Participant responses to the SURE screening test

SURE screening test	Yes n (%)	No n (%)
1. Do you feel SURE about the best choice for you?	41 (93.2)	3 (6.8)
2. Do you know the benefits and risks of each option?	42 (95.5)	2 (4.5)
3. Are you clear about which benefits and risks matter most to you?	40 (90.9)	4 (9.1)
4. Do you have enough support and advice to make a choice?	43 (97.7)	1 (2.3)
Total SURE score		
Cohort	37 (84.1)	7 (15.9)
Decisional conflict*		
Circumcision	6 (18.2)	27 (81.8)
Hypospadias	1 (9.1)	10 (90.9)

*Participants who answered "no" to one or more questions on the SURE test are screened as positive for DC.

has been controversial, with no strong recommendations for parents to follow.^{21,22} This has been shown to contribute to the degree of regret experienced by parents of children undergoing elective penile surgery.^{5,6,20,23,24} Implementing a SDM processes in clinic could remedy decisional regret but remains understudied in pediatric urology, despite being shown to be beneficial in other fields.^{3,25} Our study provides an insight into the SDM process and perceptions of physicians and parents of patients undergoing elective penile surgery, while also examining the role of SDM and patient factors on DC.

For non-therapeutic circumcision and distal hypospadias repair, using a SDM approach for operative vs. non-operative patient counselling is recommended, as there is no "correct" treatment decision due to the risk-benefit ratio being closely balanced for a majority of pediatric patients.^{26,27} Furthermore, there continues to be a lack of consensus on the adoption of elective pediatric circumcision, as opposing opinions exist from within both pediatric and urological associations.^{27,28} This is similar to elective distal hypospadias repair, as postoperative complications and impairments must be considered alongside the potential for sexual dysfunction and negative genital perception reported in patients with distal hypospadias treated non-surgically.^{27,29} Therefore, a patient-specific SDM approach, which includes a discussion of the relevant risks and benefits, is recommended for both circumcision and distal hypospadias repair counselling, as both operative and non-operative management are acceptable treatment options.²⁶⁻²⁸

In terms of respondents, there were substantially more mothers involved in the study compared to fathers. Despite this, there was no significant difference in our study between the parent groups, indicating that gender of the parent decision-maker had no implications on SDM perception. This finding was consistent with previous studies investigating decisional regret and perspectives on decision-making for

hypospadias repair surgeries, where mothers were more likely to be engaged in the decision-making process with no differences found between parental involvement.^{5,20} Additionally, although parental education was high in our cohort, with approximately 80% of respondents having some form of postsecondary education, there was no impact on DC. This finding was consistent with similar studies on elective penile surgery and decision-making, with education level not being shown to impact DC significantly.²⁰ Previous surgical experiences and past surgical complications have been shown to influence DC.³⁰ Although this was not found in our cohort, this may be associated with the low frequency of patients undergoing prior surgeries and experiencing postoperative complications.

Perception of involvement in SDM, an often unexplored factor in pediatric urology, was shown to be high for both parents and physicians, which may have contributed to the lower rates of DC in our study when compared to the literature.^{5,6,23} DC in elective pediatric urological consultations has been shown to occur in 28–58% of parents compared to our observation of 15.9%.^{5,6,23} The high SDM involvement supports that the surgical consultations were patient-centered and focused on patient preferences, which has been shown to reduce DC and regret.^{9,20,31} Despite high perceived SDM involvement by both groups, there was no association between perceived SDM involvement of parents and physicians. Therefore, it is important to analyze the perceptions of SDM involvement from both groups to gain better insight into the decision-making process.^{31,32}

When analyzing physician perception of SDM, physicians perceived higher levels of involvement in the SDM process during hypospadias repair consultations when compared to circumcisions. This may be due to the existence of deeply rooted cultural and personal values towards elective circumcision, whereas hypospadias tends to be treated more like a traditional medical condition, allowing physicians to become more effectively involved in the SDM process.^{21–23} Furthermore, when physicians felt more involved in the SDM process, patients were more likely to proceed with surgery. This was seen in our study, as parents were more likely to exhibit DC when considering circumcision for their child. Although the ultimate goal of effective SDM is not to make a specific decision regarding proceeding with surgery or not, it is likely that when a physician is more attuned to patient goals, they can decrease the stress and conflict associated with decision-making.^{22,31,32} This in turn may allow parents to proceed with more difficult decisions, such as proceeding with surgery for their child without DC and regret.^{31,32} This is supported by our findings, as when parents and physicians felt they were less involved in the SDM process, parents were more likely to experience DC.

This study serves to provide greater insight into the SDM process between physicians and parents in elective pediatric

penile surgery. As previous studies have focused primarily on consultations for hypospadias repair, this study adds to this literature while also expanding on the SDM process for elective circumcision procedures.^{5,23,24,30} Perception of involvement in the SDM process was high for both parents and physicians when compared to the literature. By introducing a SDM approach, lower rates of parental DC associated with proceeding with circumcision and hypospadias repair was found. SDM approaches for elective pediatric penile surgical consultations remains a promising approach for reducing DC and improving the experience for decision-makers involved.³³

Limitations

This study also has its limitations. Although the sample size was comparable to similar studies when considering study duration, the sample size remains low.²⁰ This low sample size, along with this study being carried out at a single institution may limit the generalizability of the results to larger populations or to different health centers. Furthermore, given this low sample size, inter-surgeon variability was unable to be fully explored. Despite surgeon involvement not impacting perception of involvement in the SDM process in our study, variability in physician-patient relationships and physician interview style may influence patient perception of the SDM process.³²

Additionally, parental opinions regarding proceeding with surgery prior to the actual consultation was not captured adequately through the survey tools administered. This factor has been shown to be a predictor of proceeding with surgery, and thus may have been an influencing factor.^{6,30} Furthermore, a difference may exist between perceived and “observed” SDM.³⁴ Although participants may report high perceived SDM involvement, studies analyzing SDM involvement through video recordings in the pediatric population have shown that actual involvement in the SDM process may be low regardless of high perceptions.³⁴

As there was significant DC involved in proceeding with circumcision, a comparative study directly examining the impact of SDM may improve our understanding of the decision to proceed with circumcision given the cultural context of this procedure. The use of a condition-specific decision aid for circumcision may also enhance the SDM process by better eliciting the values and preferences of the decision-maker.⁹

Future studies including a greater diversity of penile surgical procedures, such as proximal hypospadias repair and/or penoplasty for buried penis, may further increase our knowledge on the SDM process in pediatric urology. Despite SDM showing promise in pediatric elective penile surgery in this study, these inherent limitations can be better addressed through future large-scale studies.

Conclusions

In elective pediatric penile surgery consultations, both parents and physicians involved perceived high degrees of SDM. In our study, only 15% of these parents experienced DC with regards to deciding whether to proceed with surgery. For the parents with DC, there was a significant relationship with lower perceived SDM involvement, highlighting the importance SDM has on reducing DC for parents and improving the decision-making experience. The findings from this study can be used to improve the understanding of the relationship between SDM and DC in pediatric urology to better support parents in the decision-making process.

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This paper has been peer-reviewed.

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