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Parents making surgical decisions for their children: a pilot study

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Parents play a key role in medical decision-making for their children, who are limited by their intellectual development in understanding their own health status and treatment plans.[1] These decisions are challenging as they may have a lifelong impact on patients' physical and mental well-being, and a significant portion of parents are not satisfied with the informed consent process. Various factors affecting parental satisfaction with the informed consent process have been identified, including parents' knowledge base, the specific types of decisions and the presence of decisional conflicts.[2]

Decisional conflict is defined as uncertainty about which choice to make when facing health-related decisions. A previous study reported that a quarter of parents screened positive for decisional conflict immediately after a clinical encounter related to diagnostic tests and medications for their children.[3] Current research on parental decision-making related to surgeries for their children is scarce. This study aims to evaluate decisional conflicts in parents who consent to surgical procedures and to identify the factors that contribute to decisional conflicts.

We conducted a prospective qualitative study of 100 parents who consented to a broad spectrum of pediatric surgical procedures between 1 August 2019 and 12 November 2020. After receiving information about the risks and benefits of the proposed operation, the parents were invited to complete a survey that asked for information about their demographics and any decisional conflicts they were experiencing. This prospective qualitative study was reported according to the Standards for Reporting Qualitative Research (SRQR) guidelines for qualitative studies, where appropriate.[4] The primary outcome of the study was the degree of decisional conflict experienced by the parents, which was quantified using the Decisional Conflicts Scale (DCS). This is a validated, open-access scale that measures personal perceptions of effective decision-making and uncertainty in choosing options.[5] It consists of 16 statements and five response categories. Decisional conflict was considered to be present when the total DCS score was greater than 25.

Factors potentially influencing the degree of decisional conflict encountered by parents included parental age and gender, the number of offspring (including the gender composition), a family history of surgical conditions, any personal surgical history, the parents' education level, pre-visit research and self-reported knowledge and the level of training of the counseling surgeon. These factors were included in the questionnaire and analyzed using multivariable linear regression analysis. All data were statistically analyzed and compared. Data were expressed as the mean and SD. Continuous variables were analysed using the student's t-test and analysis of variance (ANOVA) test, as appropriate. A p-value<0.05 was considered statistically significant. The study was reviewed and approved by the hospital's institutional review board (reference number: UW 20–770).

A total of 100 parents participated in the study. Most of the participants (63%) were mothers with no personal (67%) or family (94%) history of surgery. Thirty-nine of the participants conducted pre-visit research, of which the majority (95%) was conducted via the internet. The most common surgical procedures were groin surgeries (28%) and endoscopies (26%).

After counseling with a surgeon, the parents' decisional conflict was not significantly high, with a mean score of 9.9±7.9. The parents' self-reported prior knowledge of the surgical procedure, which ranged from "good" (5.7±5.8) to "very poor" (20), slightly affected parents' decisional conflict with a significant difference among groups (p=0.043) (figure 1). The type of procedure that their child was to undergo also had a significant impact on the parents' decisional conflict scores (p=0.001) (figure 2). Interestingly, the parents' educational background, the seniority of the counseling surgeon

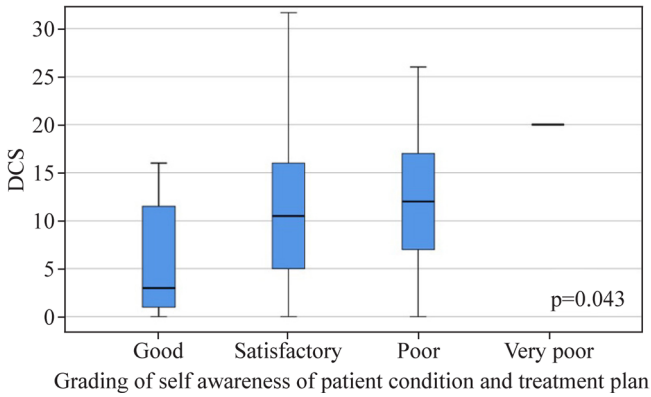

Figure 1 Box plot graph contrasts DCS total score for parents confronted with decision to proceed with surgery in children based on self-perceived knowledge. DCS, Decisional Conflicts Scale.

and the parents' own experience with surgery did not correlate with the parents' level of decisional conflict. Some of the procedures for example, circumcision and urethroplasty, are gender specific (male) and we aimed to see if having other offspring of the same gender of the patient may affect the parental DCS in consenting to surgical procedures. Yet the number and composition of gender of siblings appeared to be insignificant to the parental DCS. The impact of other various factors on the degree of decisional conflict experienced by the parents is shown in table 1.

Making medical decisions for children has always been a complex issue, given children's variable stages of development.[1] In most cases, informed consent is given by parents or other surrogates with the assumption that the parents/surrogates will act in the best interests of the child. There has been some discussion on the issue of decision-making in the context of oncology, gastrostomy and anesthesia in children. However, these are mostly narrative reviews with little objective data. The DCS has been used in patients with distal hypospadias. It is recognized as a valuable tool for understanding

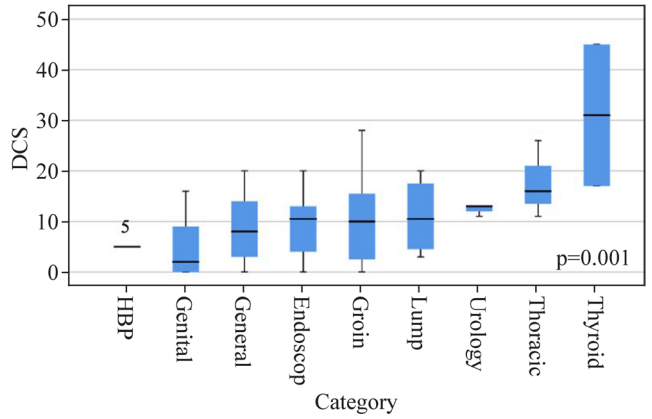

Figure 2 Box plot graph contrasts DCS total score for parents confronted with decision to proceed with surgery in children based on types of procedure. DCS, Decisional Conflicts Scale.

Table 1 Impact of various factors influencing the degree of decisional conflicts encountered by parents.

Variables	DCS	P value
Level of operation		0.51
Major	10.64±9.9	
Minor	9.52±6.7	
Mode of operation		0.108
Minimally invasive	10.84±7.1	
Open	8.19±8.8	
Education level		0.09
Primary school or less	5±6.9	
Secondary school	11.79±8.9	
Diploma or higher education	6.06±5.8	
Undergraduate	9.36±7.1	
Postgraduate or above	10.92±6.9	
Family history of operation		0.27
Positive	13.3±7.8	
Negative	9.6±7.9	
Personal surgical history		0.992
With	9.88±7.6	
Without	9.9±8.1	
Surgeons involved		0.39
Consultant	7.2±5.35	
Specialist	10.67±8.4	
Trainee	8.71±7.1	
Final decision maker		0.07
Father	8.33±7.8	
Mother	11.2±7.8	

Data are presented with mean±SD.
DCS, Decisional Conflicts Scale.

decision-making behavior and identifying areas for quality improvement.[6]

Our study identified significant factors that contribute to decisional conflict, including the type of operation and the parents' prior knowledge of the disease/procedure. To address the potential difficulties faced by parents during the consent process for complex conditions/procedures, efforts are needed to develop decisional aids, such as comprehensive information sheets, and to provide parents with more time to receive information and ask questions. Furthermore, an increasing trend for parents to obtain information about diseases and treatment options via the internet was observed, and this information could be of variable quality and accuracy. Researchers and clinicians should be cognisant of this phenomenon during counseling and ensure that parents are provided with the best available evidence.

A limitation of the current study is the small sample size, which may have weakened the statistical power of the analysis. The heterogeneity of surgeries parents

consented for also limited the statistical power of the study and decreased the generalizability of the findings. In addition, the actual impact of surgeon counseling on parental decisional conflict was not quantified; this could be demonstrated through longitudinal data collection (i.e., measuring the DCS before and after counseling). Furthermore, the current study did not enroll parents who opted against surgical treatment, which means that there was an inevitable systematic selection bias in that all the parents who presented for counseling were interested in surgical intervention. Despite these limitations, we believe that the current pilot study is valuable as it lays a foundation for future research efforts and clinical practice.

In conclusion, this is a novel pilot study on decision-making in parents in relation to pediatric surgery for their children. Identifiable factors that impact decisional conflict can facilitate future efforts to develop decisional aids. A holistic, parent-centered approach should be implemented in the informed consent process.

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Contributors Dr ACHF conceptualized and designed the study, drafted the initial manuscript and reviewed and revised the manuscript.Prof KKYW conceptualized and designed the study, coordinated and supervised the data collection and critically reviewed the manuscript for intellectual content.Both authors approved the final manuscript as submitted and agreed to be accountable for all aspects of the work.

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Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by Institutional Review Board of the University of Hong Kong/Hospital Authority Hong Kong West Cluster (HKU/HA HKW IRB) UW 20-770. Participants gave informed consent to participate in the study before taking part.

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