Parental Decision Regret after Consenting to or Refusing Hypospadias Repair: an Australian Survey

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Abstract

Background: Parental decision regret in hypospadias surgery is a recognised source of long-lasting psycho-social morbidity. Its reported prevalence is high but until now, it has not been studied in Australasian context or among parents who declined the repair for their son. The aim of this study is to report on decision regret in an Australian cohort of parents, including parents who accepted or who declined repair for their son and explore underlying factors for decision-making, satisfaction, and regret.

Methods: An online anonymous survey was administered to three groups: 1) parents who consented for hypospadias repair, 2) parents who declined repair and 3) a control group who requested circumcision for their child. Operations occurred between 2010 and 2020. The survey included a validated decision regret assessment tool and additional questions to explore the possible basis of the opinions.

Results: One hundred and eighteen parents (eligible 381, response rate 31%) participated. Decision regret was present in group 1 (n=89) – 55% (moderate-to-severe 15%), in group 2 (n= 14) – 71% (moderate-to-severe 57%), and in the control group (n=15) – 15% (moderate-to-severe 8%) of parents. There was a significant difference in the median decision regret score between all three groups. Parents who chose hypospadias repair were mostly concerned about function. They named the direction of the urine from the tip of the penis as the most satisfying outcome, and the appearance of the foreskin and the need for several operations as the least satisfying outcomes of the repair.

Conclusions: The prevalence of decision regret among Australian parents who consented for their son's hypospadias repair was lower compared with the mean decision regret reported in the literature to date (55% vs 65%). Decision regret and its severity were highest among parents who declined hypospadias repair. New strategies are needed to reduce decision regret in parents whether or not they elect for surgery.

Background

Decision regret (DR), defined as the psychological distress surrounding the diagnosis, operation, screening procedures or other interventions, is a well-recognised phenomenon in healthcare with prevalence varying significantly between studies [1]. In children's surgery, decisions are most commonly made by the parents on behalf of their child. In this context, parental DR has been shown to affect not only the parents but also transmit onto their child [2].

Our systematic review on parental DR in hypospadias surgery showed a high prevalence of DR in parents who consented to hypospadias surgery for their child (mean DR 65.2%, moderate-to-severe regret 20.3%) [3]. These data raise unanswered questions, as none of the studies included either a control group, or data about DR in parents who declined the operation.

To address these questions, we conducted a survey to assess parental DR in an Australian cohort. We included, as a control group, parents of children who had received an entirely elective procedure – a non-medically indicated circumcision, and a group of parents who had declined hypospadias surgery for their child.

Methods

The study was approved by the Hunter New England Human Research Ethics Committee (reference number: 2020/ETH01726).

1. Participant selection

The John Hunter Children's Hospital and the Children's Hospital at Westmead medical records database between 2010-2020 were accessed to create an eligibility list for groups 1 and 2 below.

Group 1 (consented for repair) consisted of parents of children operated on for hypospadias (distal or proximal).

Group 2 (declined repair) included parents who consulted a surgeon for their son's hypospadias and there is no record of a subsequent repair.

Group 3 (control) included parents whose children had a non-medically indicated circumcision. This list was developed from a surgeon's (GS) private practice database (also between 2010 and 2020) since this procedure is no longer provided in public hospitals in Australia.

2. Sample size calculation

The incidence of surgical complications is correlated with DR [4, 5]. The reported complication rate associated with neonatal and infantile circumcision is around 1.5% [6]. It was not possible to gather data for this group on other factors believed to be associated with postoperative parental DR (parental decisional conflict, education level etc). We made a conservative estimate that the prevalence of parental DR in the elective 'non-medical' circumcision group was unlikely to exceed 10%.

We expected this control group to be much smaller than the hypospadias group (10 times smaller). We allowed for a low response rate as previous similar studies have a response rate of 37.4% [4]. We also allowed for a further 10% attrition due to incomplete responses. Using power parameters of $\alpha=0.05$ and $\beta=0.2$, these assumptions produced a required sample size of 234 invitees for the repair group, and 34 for the control group. All parents who declined the repair were invited to participate in the survey.

3. Survey Design

The online anonymous survey was designed and administered using the secure web application tool REDCap, hosted at the Hunter Medical Research Institute (Newcastle, Australia) [7, 8]. After the introductory page providing the study information, and an electronic consent form, the questionnaire was specific to the group to which the respondent belonged. In addition to questions specific to their group, there were questions common to all three cohorts (See Additional file 1 for a full list of survey questions).

The construct of the survey is explained below.

3.1. Decision Regret assessment tool

The previously validated tool, the Decision Regret Scale (DRS), was used to assess Decision Regret. This tool has been consistently used in studies of parental DR in hypospadias [3, 9]. There are no rigid cut points for the severity of DR using this scale [10], however, previous studies have classified DR as no DR (0), mild (1-25) and moderate-to-severe (>25). We have followed this convention, but have also reported the numerical values (median, IQR, mean, SD).

3.2. Parental Perspectives and Open-Ended Questions

A series of three questions, specific to a hypospadias repair, was asked about the reasons parents opted for surgery, and the most and the least satisfying outcomes of the repair. These questions had multiple suggested answers as well as a free text option.

The parents from both hypospadias groups were offered a question about their preference regarding circumcision to explore if their views on completely elective surgery might influence DR. Parents were also asked whether they felt adequately supported in their decision, and whether there could have been anything to have helped them to be more content with the decision they made. Those questions also had a free-text option.

3.3 The Index of Relative Socio-economic Advantage and Disadvantage

The parents were offered to indicate the postcode they resided when the decision for their son was made. The postcode area then was located on the interactive map of the Australian Bureau of Statistic's Index of Relative Socio-economic Advantage and Disadvantage (IRSAD) [11]. We used the latest index published in 2011 which is based on the information from the five-yearly Census.

3.4. Demographics

Respondents were asked about their age, gender, and highest completed level of education.

4. Survey distribution

Parents were invited using an email (where electronic medical records provided an email address) or a text message from a phone number specific to the study. Parents who had neither email nor mobile phone number in the record were excluded from the study.

A total of three rounds of email invitations were sent two weeks apart. Parents with an invalid email address and/or only a mobile number available were texted once only. After that the access to the questionnaire was closed and the hyperlinks inactivated.

5. Statistical analyses

Descriptive statistics were utilised to characterise the groups, and the prevalence and severity of DR were calculated. A non-parametric test of significance (Mann-Whitney U test) was used to explore the difference in DR score between the groups, as well as the difference in IRSAD. The Chi-square test was applied to assess the difference in prevalence of DR and the effect of circumcision preference on parental decision.

For the qualitative analyses, the free-text answers were grouped into four categories based on whether parents had DR or not and whether their child had the repair or not, and they were uploaded into NVivo (released in March 2020) [12]. Using an inductive method, all mentioned references were coded and the number of mentions was counted [13].

Results

Participants' demographics and DR

A total of 411 eligible parents were identified of whom 381 were invited to participate (30 parents no valid email address or phone number). Eighty-seven parents from group 1 (33%), 14 from group 2 (15%) and 15 (71%) parents in group 3 completed the survey, of whom 82% were female parents or carers. Most respondents who completed the survey were between 25 and 44 years old at the time of the decision (88.6%). Participants' characteristics and the prevalence and severity of DR is presented in Table 1.

Table 1. Characteristics of participants, prevalence and severity of DR.

	Group 1 (repair)	Group 2 (declined)	Group 3 (circumcision)	Total	There was a significant difference in prevalence of DR between group 1 and control group ($p=0.007$) but not between group 1 and 2 ($p>0.05$). Median DR score in group 2 parents was significantly higher than in
Eligible parents	266	94	21	381	
Participated parents	89(33%)	14(15%)	15(71%)	118(31%)	
Completed survey	87(33%)	14(15%)	13(62%)	114(30%)	
Total DR	48(55.2%)	10(71.4%)	2(15.4%)	60(52.6%)	
Mild DR	35(40.2%)	2(14.3%)	1(7.7%)	38(33.3%)	
Moderate-to-severe DR	13(15%)	8(57.1%)	1(7.7%)	22(19.3%)	
DRS, mean	15(SD 21.2)	30.4(SD 28.1)	2.5(SD 8.9)	15.6(SD 21.3)	
DRS, median	5 (IQR 0-25)	30 (IQR 2.5-43.8)	0 (IQR 0)		

group 1 parents (30 vs 5, $U=399$, $p=0.02$) and significantly higher than in the control group (30 vs 0, $U=34$, $p<0.01$). Group 1

median DR was also higher than that of the control group (5 vs 0, $U=344$, $p=0.01$) (Figure 1). Total weighted *mean* DR for all three groups was 15.6 (SD 21.3).

Additional Data and Parental Perspectives

The main motivation to have surgery for their sons among the parent from group 1 ($n=89$) seems to have been concerns about function. Seventy-four parents named urinary function concern as a reason for their decision, 36 and 35 parents named penile appearance and sexual function concern respectively, and 23 patients named fertility and foreskin appearance each as their primary reason.

The most satisfying outcome of the hypospadias repair that 63 responding parents chose was the direction of the urine from the tip of the penis. Thirty-four parents valued the future body image, and 18 and 11 valued a straightened penis and the appearance of the foreskin respectively.

The least satisfying outcome of the repair appeared to be the appearance of the foreskin and the need for several operations (19 parents selected each of these two options). Eleven parents were unhappy with urine not coming out of the tip, and seven with the penis not having been made straight.

Seventy-three parents from the repair group (84%) and 11 parents from the declined group (79%) felt adequately supported in their decision. The question was formulated in the context of the existing hypospadias decision aid prototype [14].

When asked if it was their preference to have their son circumcised prior to them learning the diagnosis of hypospadias, 31 parents (36%) from group 1 and two parents (14%) from group 2 answered 'yes' ($p=0.1$).

Most parents of children with hypospadias (60 parents in group 1 and 12 parents in group 2) felt that more appointments with their surgeon and a decision-making aid could have made them more content with their decision (Refer to the Additional file 2 for the number of answers to each of the above multiple-choice questions).

Thirty-six parents from group 1 and three parents from group 2 used a free text option to answer some of the questions. Parents who had post-operative DR (group 1, $DR>0$) used this option the most ($n=21$). Function, appearance and desire for normalcy seem to be the primary motivating factors to go with the operative path. While the most satisfying outcomes of the procedure largely overlap in those who have and those who do not have DR, appearance was what parents with DR seem to be most unhappy with (Table 2).

Table 2. Common references and number of mentions by the parents, who used free text to answer questions with the open-ended option.

Group	DR vs no DR group (number of parents used free text)	Open-ended questions	References and number of mentions
Group 1 (repair)	DRS=0 (n=15)	Your decision was mostly guided by	Desire for normalcy - 2 Surgeon - 1
		The MOST satisfying part of the outcome is	Appearance - 3 Function - 4
		The LEAST satisfying part of the outcome is	Appearance - 1 Delayed diagnosis - 1 Function - 1 Lack of or poor follow up care - 2 Lack of public awareness - 1 Multiple surgeries - 1 Need for surgery in the first place - 1
		What could have helped you be more content with your decision?	Additional information - 2 Nothing more could have helped - 5
	DR>0 (n=21)	Your decision was mostly guided by	Appearance - 1 Function - 1 Desire for normalcy - 2
		The MOST satisfying part of the outcome is	Appearance - 3 Function - 5 Normalcy - 3
		The LEAST satisfying part of the outcome is	Appearance - 6 Abnormalcy - 2 Concerns about complications - 2 Function - 2 Information deficit - 1 Postop pain - 2 Recovery - 2 Untimely repair - 1
		What could have helped you be more content with your decision?	Better healthcare information and communication - 4 More successful repair - 1 Speaking to other parents - 2 Timely repair - 2 Earlier awareness - 1

			Nothing more could have helped - 4
Group 2 (refused repair)	DR>0 (n=3)	What could have helped you be more content with your decision?	More information on long-term outcomes - 1 Testimonials from patients – 2 Decision aid tool – 1 More discussion time with the surgeon - 1

Figure 2 demonstrates the highest completed level of education in three groups and the prevalence of DR in each educational stratum.

The median IRSAD index was the lowest in group 1 (relative greater socio-economic disadvantage) and the highest in group 3 (relative greater socio-economic advantage) Group 1 median IRSAD was also significantly lower than that of group 2 (U=401, p=0.04), indicating that parents from the areas of relative socio-economic disadvantage may be more likely to proceed with surgery rather than decline it (Figure 3).

Within group 1 there was no significant difference in median IRSAD between the parents who had DR and those who did not (U=797.5, p=0.3)

Discussion

This study adds novel and valuable data to inform the debate about the need for a childhood hypospadias repair by reporting high prevalence and severity of DR in parents who declined the repair in their child. The reporting and discussion of parental DR in hypospadias surgery has been increasing in the medical literature [3, 5, 9, 15-17]. We suspect this is partly due to the heightened attention to the subject of ‘non-essential’ childhood genital surgery. It is suggested that distal hypospadias repair in early childhood is pre-emptive surgery, performed in anticipation of future functional and/or cosmetic problems and can be safely postponed until the age of consent without any adverse consequences [18].

The prevalence of DR in parents who refused surgery is reported. Although it appears to be higher than in those who consented to surgery (55% vs 71%) it failed to reach statistical significance. The estimated DR score in both groups appears to be significantly higher than in a control group. In this Australian cohort, underlying views on circumcision and parental education levels do not seem to significantly impact decision making and/or DR. On the other hand, socioeconomic factors appear to, as people from more disadvantaged neighborhoods appear to have been more willing to have their child’s hypospadias operated on.

The mean prevalence of DR across four previously published studies by Lorenzo *et al.*, Ghidini *et al.*, Chan *et al.*, and Bethell *et al.* is 65.2% (moderate-to-severe - 20.3%) [3-5, 15, 17]. Our study demonstrated a lower prevalence of DR in parents from the repair group – 55% (moderate-to-severe 15%). In a recent addition to the growing body of literature by van Engelen *et al.* the prevalence of DR is reported at 50.5% (11.3% moderate-to-severe) [9]. Expectantly, the group of parents who had their children circumcised for the non-medical reasons tended to regret their choice less frequently – 15% (moderate-to-severe 8%) (p<0.05). Of note however, that even in this highly motivated group of parents, DR still occurred.

To our knowledge, this is the first attempt to explore the presence of DR in the parents who declined hypospadias repair for their son. Alarming, this group demonstrated the highest prevalence of DR at 71%, the highest prevalence of severe DR at 57%, and the highest mean DR score of 30.4 (SD=28.1). The response rate in this group was the lowest with only 15% of contacted parents completing the survey. It may be that parents who decline surgery want to put that decision behind them and do not want to be reminded of it.

When combined with the relative satisfaction with their repair reported by young adults who were operated as children [19, 20] it should be carefully considered when advocating for a conservative approach to surgery in infancy.

The second novel aspect of this study is the use of a control group of elective paediatric urology patients' parents, who had their children operated upon for non-medical reasons. This control group allows us to demonstrate that in this Australian setting a) parental DR in hypospadias surgery is related to the actual diagnosis of hypospadias, and b) is present amongst the parents who actively sought the circumcision for their son.

This is also the first study of its kind in Australia that includes a qualitative aspect by allowing parents to use free text to comment on the pertinent aspects around the decision-making and DR. Perhaps not unexpectedly, parents who had DR utilised this option more often (24 vs 15). Typical motives to have surgery were the desire for normalcy, concerns regarding function, and appearance. Parents with and without DR volunteered function, appearance, and normalcy as the most satisfying outcomes of the operation. Parents with DR tend to be least satisfied with the post-operative appearance, while parents without DR offered a variety of complaints such as lack of follow up care, delayed diagnosis, lack of public awareness, and that their child had to undergo multiple operations. Parents without regret generally do not think there could have been anything more to make them feel happier with their decision, while parents with regret mention a series of issues, including the desire for better information from, and communication with, healthcare workers, the option of speaking to other parents, getting a timely repair, and earlier awareness of the issues for their child. This information can inform clinicians' preoperative counselling and communication in the follow-up period.

This option of what more could have been done to improve your decision-making process was also the only open-ended option available to the group 2 parents (who refused the repair). Only three parents (all had DR) used free text and they believe patients' testimonials, more information on long-term outcomes, a decision-aid tool, and more discussion time with the surgeon would have been useful to them. These unique insights may allow the surgeons to fine tune their 'treatment package' for the parents as well as guide future translation research (such as introduction of a hypospadias decision-making aid).

This study has limitations. The overall response rate (31%) is lower than in other published surveys, although this might be due to the longer selected period (10 years) during which the decisions were taken by the invited participants.

We limited the range of topics that we explored as being potential contributors to DR. Preoperative parental decisional conflict and the presence of postoperative complications are the only two that are reported to be associated with DR in more than one study [4, 5, 9]. We consciously did not collect any clinical information pertinent to a child's surgery in order to increase compliance, as we considered that enquiring after these details would lengthen the survey and reduce the response rate.

Conclusion

Our study adds a unique and hitherto unreported perspective on parental DR in hypospadias surgery. It reports on a previously overlooked group of parents, who refused a hypospadias repair for their son and unveils a higher prevalence and severity of DR in this small but growing group of parents. Utilisation of a control group examines the association between the DR and hypospadias diagnosis and shows that for a proportion of decision-makers, regret is likely to always accompany the decision they made. Our study also gives an insight into parents' values and concerns via a qualitative component of the study, which might inform practice change and improvement in Australian settings.

Abbreviations

DR – Decision Regret

GS – Grahame Smith

DRS – Decision Regret Scale

IQR – Interquartile Range

SD – Standard Deviation

IRSAD – Index of Relative Socio-Economic Advantage and Disadvantage

Declarations

1. Ethics approval and consent to participate

This study has received an approval from the Hunter New England Human Research Ethics Committee (reference number: 2020/ETH01726).

2. Consent for publication

Not applicable

3. Availability of data and materials

All data generated or analysed during this study are included in this published article [and its supplementary information files].

4. Competing interests

The authors declare that they have no competing interests

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6. Authors' contributions

SV – conceptualised the study based on the previous work, designed the questionnaire, contributed to data interpretation and analyses, drafted and submitted the manuscript

ER - contributed into interpretation and analyses of qualitative data, revising and final approval of the manuscript.

GH - contributed into the project's conception and design, data interpretation and analyses, revising and final approval of the manuscript.

MS - contributed into the project's conception and design, data interpretation and analyses, revising and final approval of the manuscript.

PP - contributed into the project's conception and design, data interpretation and analyses, revising and final approval of the manuscript.

AD - contributed into the project's conception and design, survey distribution, data interpretation and analyses, revising and final approval of the manuscript.

All authors read and approved the final manuscript

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Figures

Figure 1

Number of participants and their highest completed level of education and DR in three groups of respondents.

Figure 2

Number of participants and their highest completed level of education and DR in three groups of respondents.

Figure 3

Index of relative socio-economic disadvantage in three groups of respondents.

Supplementary Files

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