

Decisional Regret among Parents Following Hypospadias Repair and Variables Affecting Regrets

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ABSTRACT

Background: Decisions in difficult situations may lead to a regret and one of the scales to assess this regret is Decisional Regret Scale (DRS).

Aim: To determine the regret of parents whose sons had undergone repair of distal hypospadias using DRS.

Methods: This cross-sectional study was conducted at Pediatric Surgery Department, Rawalpindi Medical University, Rawalpindi over a period of 4 years. All parents whose sons had undergone distal hypospadias repair with age <12 years from January, 2016 to December, 2019 were included. They were contacted and questions of DRS were asked on a 5-point Likert scale. Their responses were recorded and total DRS score was calculated. All data was analyzed using SPSS version 26.

Results: A total of 91 patient's details were retrieved, however, 50 patients were included into this study. The mean age was found to 6.48 (3.96) years. Twenty eight percent patients had some complication, most frequent (18%) of them was a fistula, followed by meatal stenosis (6%) and wound infection (4%). Twenty-seven (54%) patients were having regret, 13 (26%) had moderate to severe regret and 14 parents (28%) had mild regret. Following chi-square test, non-educated mothers (P=0.073), vaginal route of delivery of child (P=0.015), development of complications following surgery (p=0.001) and sad or grieved feelings following surgery (p=0.000) were found to be important factors leading to worsening DRS score. Finally, OR was calculated and most predictive factors for sever DRS included non-educated mothers [OR(95%CI) 2.953(0.769-11.340)], vaginal route of delivery [OR(95%CI) 3.667(0.763-17.619)], anomaly in another sibling [OR(95%CI) 2.06(0.303-13.971)] and development of complications following surgery [OR(95%CI) 21.333(0.240-4.918)].

Conclusion: DRS was quite frequent among parents following hypospadias repair of their sons. Among significant factors, most were related to family dynamics and only significant surgery related factor was development of complication. So as surgeons, we need to reduce our complication rate so that DRS may be lowered in these parents.

Keywords: Decision making; Clinical decision making; Shared decision making; Hypospadias

INTRODUCTION

Hypospadias is a relatively common congenital anomaly; yet its corrective procedures are complex. There are a lot many surgical procedures available and with varying complication rate. For hypospadias, none of the surgical procedures has yet been declared as gold-standard and all procedures carry their own complication rate ⁽¹⁾. The complications following hypospadias surgery owe to many reasons including location of meatus, age at surgery, width of glans penis, surgical procedure used, suture material used for reconstruction, patient's general health, hemoglobin level and a lot of other factors. Whatever the reason is, the complication rate varies from 10%- 66% in literature ^(1, 2). On the other hand, another perspective is to leave the anomaly as such if it does not interfere with the sexual functions and other daily activities of the person ⁽³⁾. So, in these perspectives, decision to go for surgery with a high complication rate or not to go for surgery becomes sometimes very difficult for the parents, particularly in those having distal variety of hypospadias. In such decisions, where outcome may be grave, decisional regret (DR) is

reported among parents and caregivers, as the outcome of this decision is going to be life-long. DR is defined as distress after making a health care decision and parents of children having hypospadias are potent to have DR as it may end in a complication following surgery ^(4, 5). DR is commonly measured using Decisional Regret Scale (DRS) devised by Beuret et al ⁽⁶⁾. The objective of this study was to determine the DR using DRS among parents whose sons had undergone distal hypospadias repair by any technique.

MATERIALS AND METHODS

This cross-sectional study was done at Pediatric Surgery Department of Rawalpindi Medical University, Rawalpindi following IRB ethical approval. All parents whose sons had undergone distal hypospadias repair by any technique within <12 years of age (at time of surgery) were included. Records of all patients who had been operated within last 4 years from January, 2016 to December, 2019 were retrieved. Their contact numbers and address were noted. For this study, we used DRS which is a 5-points Likert scale. It consists of five questions and they are answered by parents on a Likert scale where 1 is strongly agree to 5 being strongly disagree. These scores are then converted

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to a 0-100 scale by subtracting 1 from each item then multiply by 25. To obtain a final score, the items are summed and averaged. A score of 0 means no regret; a score of 100 means high regret. A total score is calculated and score of 0 was taken as no regret, 1-25 was mild regret and a score of 26 or more was interpreted as moderate to severe DR in accordance with previous studies⁽⁴⁾. As national language of our country is Urdu, so we translated the questionnaire to Urdu. For this purpose, two faculty members translated the questionnaire to Urdu, then two other faculty members translated that Urdu version into English and questions were compared. The final questionnaire was approved by the faculty of the department and all investigators. As follow-up of patients in our set-up is very poor owing to many reasons, so we decided to apply the questionnaire telephonically. One of the investigators called all 91 patients who were included into this study. He read a pre-written manuscript which included greetings, introduction of the investigator, confirmation of patient's identity, objective of the call, obtaining demographic data, current status of child and complications encountered, consent to be included into questionnaire and then administration of questionnaire. As it was telephonically administrated, so participants were told about consent to be included into this study verbally. If the contact number was not correct, parents were unwilling to be included into study, language of the parents was not understandable, they were excluded from this study. Such parents were not contacted again to be included into the study. All data was analysed using SPSS version 26. Univariate analysis was done using non-parametric test for continuous variables and chi-square test for categorical variable. Odds ratio (OR) was calculated in order to determine the predictors for moderate to severe DRS taking 95% confidence intervals (CI). $P < 0.05$ was considered significant.

RESULTS

A total of 91 patient's details were retrieved and they were contacted. Twenty-eight patients were not traceable because of wrong mobile numbers or the contact numbers were not reachable, language of 3 parents was not understandable and 10 parents did not give permission to be added into this study. So finally, 50 patients were included into this study. The mean age was found to 6.48 (3.96) years at the time of surgery. The mean age of father was 36.60 (9.53) years while mother's age was 30.92 (6.72) years. Eleven patients (22%) were previously circumcised, 10% participants had another anomaly in siblings and 11 patients (22%) had family history of hypospadias. The demographic variables (Table 1)

Most of the parents (58%) were counselled preoperatively by senior residents while 42% parents were counselled by the consultants. Twenty eight percent patients had some complication, most frequent (18%) of them was a fistula (table 2). When asked about the emotions and feeling of the parent, 3 (6%) reported to be feeling angry and 4% were feelings as deferred.

Regarding DR using DRS, mean DRS score was 17.4 (SD: 21.78) (Range: 0-65) and 54% parents had regret. Thirteen parents (26%) had moderate to severe regret (table

3). Next, chi-square test was done among groups of parents as per DRS to the demographic variable and non-educated mothers ($P=0.073$), vaginal route of delivery of child ($P=0.015$), development of complications following surgery ($p=0.001$) and sad or grieved feelings following surgery ($p=0.000$) were found to be significant factors leading to worsening DRS score (table 4).

Table 1: Demographic details of patients and parents/guardians

Mother's Qualification	
Yes	25 (50%)
No	25 (50%)
Mother's Qualification	
Yes	31 (62%)
No	19 (38%)
Mode of delivery	
Vaginal route	42 (84%)
Cesarean section	8 (16%)
Previously Circumcision	
Yes	11 (22%)
No	39 (78%)
Siblings	
≤3	32 (64%)
<3	18 (36%)
Any other congenital anomaly in siblings	
Yes	5 (10%)
No	45 (90%)
Family history of Hypospadias	
Yes	11 (22%)
No	39 (78%)
Any known cause of concern in parent's opinion	
Yes	3 (6%)
No	47 (94%)
Any exposure to medications during pregnancy	
Yes	1 (2%)
No	49 (98%)

Table 2: Currents status of child and parents

Complications	
None	36 (72%)
Wound dehiscence	2 (4%)
Fistula	9 (18%)
Meatal stenosis	3 (6%)
Feeling of parents following surgery	
Sad	1 (2%)
Angry	3 (6%)
Deferred	2 (4%)
None	44 (88%)

Table 3: Regret of parents as per DRS

Overall Regret	
Yes	27 (54%)
No	23 (46%)
Regret according to DRS	
None	23 (46%)
Mild	14 (28%)
Moderate	8 (16%)
Sever	5 (10%)

Finally, OR was calculated and most predictive factors for sever DRS included non-educated mothers (OR-2.953), vaginal route of delivery (OR-3.667), anomaly in another sibling (OR-2.06) and development of complications following surgery (OR-21.333). All these details are given in table 5.

Table 4: Chi-square test to predict the factors for regret

Variables	Regret according to DRS				P-Value
	None	Mild	Moderate	Severe	
Mother's Qualification	16	5	3	1	0.073
Yes	7	9	5	4	
Father's Qualification	17	6	5	3	0.311
Yes	6	8	3	2	
Mode of delivery	19	14	4	5	0.015
Vaginal route	4	0	4	0	
Cesarean section					
Previously Circumcised	6	2	2	1	0.858
Yes	17	12	6	4	
No					
Siblings	16	7	6	3	0.634
>3	7	7	2	2	
<3					
Any other anomaly in siblings	3	0	2	0	0.226
Yes	20	14	6	5	
No					
Family history of Hypospadias	7	1	3	0	0.152
Yes	16	13	5	5	
No					
Any known cause in parent's opinion	1	0	2	0	0.092
Yes	22	14	6	5	
No					
Counselling done by	11	9	4	5	0.169
Resident	12	5	4	0	
Consultant					
Complications	19	14	3	0	0.001
None	0	0	1	1	
Wound dehiscence	2	0	4	3	
Fistula	2	0	0	1	
Meatal stenosis					
Any exposure to drugs during pregnancy	1	0	0	0	0.754
Yes	22	14	8	5	
No					
Feeling of parents following surgery	0	0	1	0	0.000
Sad	0	0	0	3	
Angry	0	0	1	1	
Deferred	23	14	6	1	
None					

Table 5: Odd's ratio to predict the factors leading to moderate to sever regret

	OR	95% CI	P-Value
Illiterate Mother's Qualification	2.953	(0.769-11.340)	0.114
Illiterate Father's Qualification	1.027	(0.280-3.767)	0.962
Mode of delivery (CS)	3.667	(0.763-17.619)	0.104
Previously not Circumcised	0.920	(0.203-4.159)	0.913
Any other anomaly in siblings	2.06	(0.303-13.971)	0.740
Positive Family history of Hypospadias	1.08	(0.240-4.918)	0.913
Counselling done by resident Level of surgeon	0.522	(0.136-2.004)	0.344
Complications	21.333	(4.316-105.435)	0.000

DISCUSSION

DR had been noted particularly among caregivers of patients who had to undergo a difficult decision. There are studies in adult population which had included the caregivers or guardians of the patients who had undergone a complex decision-making process which may have an untoward effect. These studies had included caregivers of patients who had received chemotherapy⁷, patients undergone internal cardiovascular defibrillation⁽⁸⁾, caregivers of deceased patients with cancer⁹ and those

who had undergone general surgery procedures⁽¹⁰⁾. There had been few previous studies which included parents of children undergoing hypospadias surgeries^{4,5}.

We used DRS which is a validated scale to determine DR. It was devised by Brehaut et al and had been used in multiple studies since then. DRS has been translated and validated to English⁶, Spanish⁷ and Japanese version¹⁰. Although there are other scales to determine DR available including satisfaction with decision scale, inventory for complicated grief (ICG-D), Regret and maximization scale and patient health questionnaire for depression, but most of

the studies have used DRS which addresses regret particularly^{6,7}.

We found that 26% participants had moderate to severe DR and 46% had no regret as per DRS. In a previous study from Canada, 8.6% participants had moderate to severe DRS⁴. A report from Italy reported 39.6% parents having moderate to severe DR⁵. In a recent study from UK, 6.5% participants had moderate to severe DRS score following hypospadias surgery of their sons¹¹.

Lorenzo et al⁴ who included 100 couples whose sons underwent hypospadias surgery, found that significant factors leading to DR included complication following surgery, desire to avoid circumcision and operative decision conflict. Bethell et al¹¹ found distal location of the meatus, small glans size and development of complication as an import and significant factor leading to DR. Ghadini et al⁵ found that most important predictors of DR were intermediate parental education level, not being first born, family history of hypospadias and presence of lower urinary tract symptoms. We found that complication following surgery had the highest OR to develop sever DR which is similar to previous studies. In our local setup, all parents want their sons to be circumcised and most of the children undergo circumcision in neonatal life. So at times, we encounter children having hypospadias who had undergone circumcision before presenting to us unlike the factor reported by Lorenzo et al⁴ from Canada where desire to avoid circumcision was related to sever DR. In this study, mother being illiterate had an OR of 2.953 to develop DR. Mother's education level and understanding of the disease has been reported to be associated with complications following hypospadias surgery¹². Ghidini et al reported that middle level of education of mother was strongly associated with high DRS score⁵.

Regarding the methodology and administration of the instrument, we used a telephonic call because of the education level and understanding of our population. Generally, the questionnaire type of instruments is difficult to administer and to get a high response rate is difficult. This can be seen in our population particularly as in a study conducted on pediatric surgeons, response rate had been 36% only¹³. Therefore, authors decided to conduct a telephone follow-up of the patients. The resource limitation in general government hospitals within our region rendered this approach to be most pragmatic and cost-effective. Short message service (SMS) texting had been used by Bethell et al¹¹ and online survey tool was used but this would not have been available to the majority of our population.

We conclude that DRS was quite frequent among parents following hypospadias repair of their sons. Among significant factors, most were related to family dynamics

and only significant surgery related factor was development of complication. So as surgeons, we need to reduce our complication rate so that DRS may be lowered in these parents.

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