


The Impact of Colorectal Conditions on Psychosocial Well Being of Caregivers and Patients Presenting to A Tertiary Care Hospital

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Abstract

Introduction: Colorectal conditions such as Hirschsprung disease, anorectal malformation, fecal incontinence and spinal condition cause a significant stress among patients and their caregivers. Managing such disorders requires not only a one-time definitive surgery but a significant number of follow up visits, dietary modifications and long-term medication. The aim of this study was to estimate the psychosocial wellbeing of caregivers and patients suffering from these conditions.

Materials and Methods: This was a cross sectional study conducted in the Department of Pediatric Surgery, Holy Family Hospital from February 2021 to August 2021. After getting the approval from the ethical review committee of Rawalpindi Medical University, the participants were enrolled to be a part of this study after signing an informed consent. The identity of the participants and their caregivers was kept confidential.

Participants of this study were patients suffering from different surgical colorectal conditions and their caregivers. The colorectal conditions that were considered were Hirschsprung's disease, primary fecal incontinence, post-operative fecal incontinence, and anorectal malformation. Patients between the age of 2 and 12, irrespective of their gender were selected. After checking the diagnostic work-up for each of the disease through series of scans and thorough history, the patients were selected. Patients and caregivers who were unwilling to participate were excluded from the study. Patients who had colorectal conditions except the aforementioned or had associated comorbid were excluded from the study. After confirming that the patients fulfilled the selection criteria, the caregivers were asked to participate in the questionnaire-based interview. Taking into consideration that the caregivers and patients would better understand if communication will be done in Urdu, the questionnaires were translated by a professional translator. The principal investigator interviewed the caregivers and the patients based on the given questionnaire and the items were filled in accordingly.

Results: A total of 96 patients were enrolled and were interviewed using the translated version of SDQ and PSS questionnaires. A total of 57 (59.4%) males were a part of this study. The diagnosis encountered were anorectal malformation (49.0%), Hirschsprung disease (11.5%), primary idiopathic incontinence (22.9%) and post-operative incontinence (16.7%). The overall SDQ score and PSS score were 13.81 ± 7.13 and 41.0 ± 8.2 respectively. Based on diagnosis, patients with post-operative incontinence had the highest PSS score which was significantly more than patients with Hirschsprung disease, primary idiopathic incontinence and anorectal malformation (46.31 ± 5.99 vs 39.02 ± 7.63 , 40.82 ± 8.84 , 40.82 ± 9.17 , $p < 0.05$). Similarly, SDQ score was significantly

Keywords

- Colorectal conditions
- Psychosocial
- SDQ
- PSS
- anorectal malformation
- Hirschsprung disease
- incontinence

greater in case of anorectal malformation when compared to Hirschsprung disease, post-op incontinence and primary idiopathic incontinence (14.54 ± 6.34 vs 13.73 ± 7.84 , 12.47 ± 7.19 , 13.5 ± 8.87 , $p < 0.05$).

Conclusion: Parents of patients with post-operative incontinence had a greater psychosocial impact while patients suffering from anorectal malformation faced generally more difficulties as per the SDQ questionnaire. Proper rehabilitation and support for these patients is recommended to deal with the neglected psychological impact of these disease.

Introduction

Among the pathologies faced at the pediatric surgery floor, congenital colorectal conditions are frequently encountered and require long term care. Managing such disorders requires not only a one-time definitive surgery but a significant number of follow up visits, dietary modifications and long-term medication.¹ This eventually leads to a persistent psychological strain on the caregivers and the patients. If in any case, the patient does not adhere to the treatment plan then it could lead to worsening of complications, exacerbate the stress being faced and negatively impact the quality of life of the patient.²

Most of these disorders require bowel management programs to treat fecal

incontinence or in some cases surgeries like PSARP (Posterior sagittal anorectoplasty) and pull-through would suffice in case of anorectal malformation and Hirschsprung disease, respectively.³⁻⁴ However, those patients who have persistent incontinence despite undergoing surgery may have to endure a personalized bowel management program to treat the symptoms for a long period of time. In contrast to this group, there exist patients who have idiopathic incontinence which starts with constipation and ends with poor control. All in all, there is either requirement of surgery or bowel management programs for symptomatic treatment.⁵

Prevalence of ARM (anorectal malformation), Hirschsprung disease and

idiopathic fecal incontinence has not been clearly identified in Pakistan. However, according to international literature, ARM and Hirschsprung disease are found to occur in 1 in 4000-5000 births.⁶⁻⁷ Community prevalence of fecal incontinence ranges from 0.8% to 7.8% globally.⁸ Bowel management programs are complex plans which need maximum adherence from the patients and the caregivers for optimum results. It includes laxative medications such as polyethyleneglycol which can be given per oral, and in some resistant cases transanal suppositories and injectables are warranted. As the bowel management program is tailored according to the needs of the patients, it may be simple in some but extremely complicated in complicated cases. This leads to tension, distress and psychological impairment among the stakeholders involved.⁹

Behavioral impact on the patients and the stress incurred on their respective caregivers is an aspect which is neglected in Pakistan. Although international studies have been conducted which have showed increased behavioral troubles as well as stress among the patients with colorectal conditions.¹⁰⁻¹³ However, minimal studies have been conducted in Pakistan which

discuss the psychosocial impact of colorectal conditions on patients and caregivers, let alone a focus on behavioral impacts on patient and stress in their caregivers. Hence, this study provides evidence on a poorly discovered aspect which exist within our setup. The aim of this study was to estimate the psychosocial wellbeing of caregivers and patients suffering from these conditions using the parent stress scale for caregivers and strength and difficulties questionnaire for the patients.

Materials and Methods

This was a cross sectional study conducted in the Department of Pediatric Surgery, Holy Family Hospital from February 2021 to August 2021. After getting the approval from the ethical review committee of Rawalpindi Medical University, the participants were enrolled to be a part of this study after signing an informed consent. The identity of the participants and their caregivers was kept confidential. Participants of this study were patients suffering from different surgical colorectal conditions and their caregivers. The colorectal conditions that were taken into account were Hirschsprung's disease, primary fecal incontinence, post-operative

fecal incontinence and anorectal malformation. Patients between the age of 2 and 12, irrespective of their gender were selected. After checking the diagnostic work-up for each of the disease through series of scans and thorough history, the patients were selected. Patients and caregivers who were unwilling to participate were excluded from the study. Patients who had colorectal conditions except the aforementioned or had associated comorbid were excluded from the study. After confirming that the patients fulfill the selection criteria, the caregivers were asked to participate in the questionnaire-based interview. Taking into consideration that the caregivers and patients would better understand if communication will be done in Urdu, the questionnaires were translated by a professional translator. The principal investigator interviewed the caregivers and the patients based on the given questionnaire and the items were filled in accordingly.

The two psychosocial scales that were employed for the assessment of the patients were:

1. The Parent Stress Score

This questionnaire was implemented on the parents/caregivers of the patients to evaluate the stress faced by them due to the health condition of their child. This was an 18 itemed questionnaire with responses based on Likert scaling (strongly disagree, disagree, undecided, agree, strongly agree). The higher the score, the higher it is regarded to be representative of stress. The range of scores is from 18 to 90.

Strongly disagree = 1

Disagree = 2

Undecided = 3

Agree = 4

Strongly agree = 5

To compute the parental stress score, items 1, 2, 5, 6, 7, 8, 17, and 18 were scored in the opposite order follows: (1=5) (2=4) (3=3) (4=2) (5=1). The item scores were then summed. The rest of the items were scored in the order they were answered by the respondents. Parental stress scores range from 18 to 90, with lower scores indicating lower levels of parental stress.

2. Strengths and Difficulties Questionnaire

The strengths and difficulties questionnaire were implemented in patients who were above the age of 11 years while for those

who were below this age, the questionnaire was filled with assistance of the caregivers. The questionnaire is based on subscales and comprises of 25 items and has the

following sub-components.

- A. Emotional symptoms
- B. Conduct symptoms,
- C. Hyperactivity/inattention symptoms
- D. Peer relationship problems
- E. Prosocial behavior
- F. Impact score

The individual scores are then used to compute the following scores

- A. Internalizing score (Emotional Problems Score + Peer Problems Score)
- B. Externalizing score (Conduct Score + Hyperactivity Score)

Data Analysis

Data were entered and analyzed in IBM SPSS v.23.0. The quantitative variables which included age, SDQ score, parent

stress score was presented and mean and standard deviation. The qualitative variables such as gender, diagnosis, procedure, and surgical intervention were presented as frequency and percentage. The individual scores and the total scores of the SDQ subtypes and parent stress scale were calculated using validated guidelines by assigning each of the categories a score. Depending on the normality of the distribution, the scores were then analyzed using the T-test/Anova/Wilcoxon Rank Test/Kruskal-Wallis Test were used. The post-hoc analysis was conducted using Tuckey’s test. P-value less than 0.05 was considered statistically significant.

Result

A total number of 96 participants were recruited in this study out of which 57 (59.4%) were males. The mean age of the participants was 8.36±5.25 years. The diagnosis of the patients and the procedures that were conducted are shown in **Table 1**.

Table 1: Basic Demographic and Medical Profile of the patient

Gender	Female	39 (40.6%)
	Male	57 (59.4%)
Diagnosis	Anorectal Malformation	47 (49.0%)

	Hirschsprung's Disease	11 (11.5%)
	Fecal Incontinence	22 (22.9%)
	Post-op Incontinence	16 (16.7%)
Bowel Management Program	Yes	39 (40.6%)
	No	57 (59.4%)
Surgical Intervention	Yes	73 (76.0%)
	No	23 (24.0%)
Procedure	Conservative	23 (24.0%)
	Colostomy	1 (1.0%)
	Meningomyelocele Excision	2 (2.1%)
	PSARP	56 (58.3%)
	Pull Through	14 (14.6%)

the case of patients who underwent meningomyelocele excision, both developed post-operative incontinence. Lastly, the patients who under-went the pull through procedure 3 (21.42%) developed post-operative incontinence. This made a total of 16 patients with post-operative incontinence as shown in table I.

Parent Stress Score

Overall, the parent stress score of all the participants was 41.0. The maximum recorded PSS was 64 while the minimum recorded was 23. **Table 2** shows the parent stress score and its stratification according to gender, diagnosis, provision of BMP, surgical intervention, and type of surgery.

Among the 47 patients which presented with anorectal malformation, 7 (14.8%) had a perineal fistula, 8 (17.0%) had an anteriorly placed anus, 6 (12.8%) had a rectovestibular fistula, 9 (19.1%) had a rectovesical fistula, 11 (23.4%) patients presented without any fistula. Primary diagnosis leading to PSARP could not be identified in 6 (12.8%) patients.

One of the patients was presented with a sacrococcygeal tumors, while a patient was also presented with caudal regression syndrome. Among the patients who underwent PSARP, 2 developed post-operative anal stenosis and 11 (19.6%) developed post-operative incontinence. In

Table 2: Independent T Test

		Parent Stress Score	P-value
Gender of the patient	Male	42.04±8.51	0.118*
	Female	39.31±7.59	
Primary Diagnosis	Anorectal Malformation	39.02±7.63	0.026**
	Hirschsprung’s Disease	40.82±8.84	
	Fecal Incontinence	40.82±9.17	
	Post-op Incontinence	46.31±5.99	
Bowel Management	Yes	43.00±8.70	0.041*
	No	39.43±7.58	
Surgical Intervention	Yes	40.64±7.90	0.512*
	No	41.96±9.24	
Procedure Performed	Conservative	41.96±9.24	0.860**
	Others	38.33±7.81	
	PSARP	40.48±7.56	
	Pull Through	41.71±9.50	

**One-way Anova

Parents stress scores were higher in patients who were suffering from post-operative incontinence while the patients with anorectal malformations presented with a relatively lower parent stress score (Anova p=0.026). Adding further, parents of patients who were on bowel management program were having greater scores (p=0.041). The post-hoc Tuckey’s test showed that among the diagnosis there was a significant difference between anorectal

malformation and post-operative incontinence (p<0.001).

Strength and Difficulties ScaleThe total difficulty score that was computed using the SDQ scales was 13.81±7.13 for all the patients in this study. Internalizing score and externalizing scores were found out to be 6.04±4.04 and 7.75±3.91 respectively. The components of internalizing score, emotional problem score and peer problem score were 3.20±2.20 and 2.84±2.34,

respectively. **Table 3** shows the stratification of the different scales and their subtypes of the strength and

difficulties scores based on gender, diagnosis, provision of BMP, surgical intervention, and type of surgery.

Table 3:

Gender					
	Female		Male		P-value
Conduct Score	2.52±2.37		3.65±2.60		0.031
Hyperactivity Score	4.38±2.09		4.67±2.29		0.543
Emotional Score	3.29±2.46		3.14±2.21		0.764
Peer Score	2.73±2.22		2.92±2.45		0.701
Prosocial Score	6.92±2.67		6.48±2.89		0.466
Externalizing Score	7.27±3.65		8.09±4.09		0.338
Internalizing Score	6.05±3.94		6.04±4.20		0.985
Impact Score	2.50±1.95		2.43±2.03		0.888
Total Difficulty Score	13.50±6.65		14.04±7.52		0.731
Primary Diagnosis					
	Anorectal Malformation	HPD	Fecal Incontinence	Post-op Incontinence	P-value
Conduct Score	3.52±2.61	3.27±2.76	2.73±2.29	2.88±2.47	0.127
Hyperactivity Score	4.24±2.24	4.64±2.42	5.05±2.06	4.63±2.22	0.581
Emotional Score	3.64±2.23	3.36±2.50	3.00±2.25	2.13±2.28	0.065
Peer Score	3.07±2.27	2.45±2.58	2.73±2.39	2.67±2.50	0.845
Prosocial Score	6.21±2.63	6.09±3.14	6.82±2.94	8.00±2.56	0.152
Externalizing Score	7.81±3.90	7.91±4.28	7.77±3.65	7.50±4.41	0.993

Internalizing Score	6.71±3.67	5.82±4.51	5.73±4.32	4.80±4.51	0.446
Impact Score	2.03±1.77	3.38±2.67	3.06±2.08	2.20±1.78	0.172
Total Difficulty Score	14.54±6.34	13.73±7.84	13.50±7.19	12.47±8.87	0.072
Bowel Management					
	Yes		No		P-value
Conduct Score	2.85±2.33		3.44±2.63		0.260
Hyperactivity Score	4.92±2.09		4.27±2.26		0.162
Emotional Score	2.62±2.29		3.62±2.24		0.037
Peer Score	2.68±2.42		2.96±2.31		0.583
Prosocial Score	7.26±2.84		6.21±2.70		0.017
Externalizing Score	7.77±3.90		7.75±3.96		0.982
Internalizing Score	5.32±4.41		6.58±3.77		0.148
Impact Score	2.79±1.98		2.18±1.97		0.197
Total Difficulty Score	13.16±7.82		14.33±6.59		0.452
Surgical Intervention					
	Yes		No		P-value
Conduct Score	3.40±2.57		2.57±2.29		0.169
Hyperactivity Score	4.44±2.24		4.87±2.12		0.423
Emotional Score	3.30±2.31		2.91±2.31		0.491
Peer Score	2.99±2.36		2.43±2.29		0.333
Prosocial Score	6.56±2.76		6.96±2.95		0.558
Externalizing Score	7.87±3.99		7.43±3.75		0.649
Internalizing Score	6.48±4.00		5.15±4.29		0.145
Impact Score	2.19±1.96		3.28±1.87		0.042
Total Difficulty Score	14.39±7.10		12.58±7.31		0.021

Procedure Type					
	Conservative	Others	PSARP	Pull Through	P-value
Conduct Score	2.57±2.29	3.33±1.15	3.28±2.60	3.86±2.71	0.484
Hyperactivity Score	4.87±2.12	3.33±2.08	4.31±2.10	5.23±2.71	0.356
Emotional Score	2.91±2.31	1.67±2.08	3.26±2.26	3.79±2.52	0.458
Peer Score	2.43±2.29	3.67±2.08	2.90±2.30	3.14±2.77	0.730
Prosocial Score	6.96±2.95	8.00±1.00	6.60±2.68	6.08±3.30	0.697
Externalizing Score	7.43±3.75	6.67±3.21	7.65±3.83	9.00±4.80	0.037
Internalizing Score	5.35±4.29	5.33±4.04	6.16±3.81	6.93±4.84	0.698
Impact Score	3.28±1.87	0.67±1.15	1.95±1.70	3.60±2.50	0.007
Total Difficulty Score	12.78±7.31	12.00±6.56	13.88±6.58	15.85±9.11	0.077

The SDQ score and its subtypes had a few differences when stratified according gender, primary diagnosis, bowel management, surgical intervention and type of procedure. Among the males and females, the former had a greater chance of having a higher conduct score which was significant ($P=0.031$). When discussing the primary diagnosis, the SDQ scores varied according to the diagnosis, but were not significantly different from one another. However, in the post-hoc analysis using Tuckey's test, patients with anorectal malformation (14.54 ± 6.34) had a significantly greater total difficulty score

when compared to the patients with post-operative incontinence (12.47 ± 8.87) ($p=0.032$). The patients who underwent surgical intervention were likely to have a greater score when the total difficulty score was compared ($p=0.021$). However, the patients who did not undergo surgery had a relatively greater impact score ($p=0.042$). SDQ subscales also varied according to the management procedures the patients underwent. Patients who underwent pull-through procedure were likely to have a greater total difficulty score when compared to the conservative approach as per post-hoc analysis ($p=0.049$). However, there was no significant difference between

all the groups in terms of total difficulty score. Adding further, ANOVA was significant when applied on the impact score and procedure types ($p=0.007$). Patients who underwent the pull-through procedure were likely to have a greater impact score when compared to PSARP

Discussion

Colorectal conditions have been a source of psychological stress for patients and their caregivers alike. Not only does this stress leads to decreased quality of life of the affected but also results in chronic mental illnesses among caregivers. Constant stress, dissatisfaction and guild are among the many problems that are faced by these patients and their caregivers.¹⁰

Colorectal conditions have been proven to be a source of deterioration as reported previously. Hanneman and colleagues have reported deterioration in the quality of life of patients who suffered from anorectal malformation and Hirschsprung disease.¹¹ The study by Bedard et al. quantitatively proved that incontinence leads to decreased quality of life.¹² Moreover, Colares and colleagues identified bowel management program as a source of relief in the long term for patients and caregivers.¹³ We do generally appreciate that quality of life is impacted in these patients, but factors that

group (3.60 ± 2.50 vs 1.95 ± 1.70 , $p<0.001$) as per post-hoc analysis. There was a significant difference in the internalizing score among the procedure type group ($p=0.037$).

contribute to this a not reported widely in literature. Stress is one of the causes at not only affects the patients but also the caregivers. In addition to this, emotional and behavioral impact on patients with colorectal condition have an influence on the overall quality of life. The current study proves that parental stress (Parental Stress Scale) and emotional and behavioral (SDQ Scale) deterioration is common in pediatric patients with colorectal conditions in Pakistan.

Parental stress has been quantified previously in a study conducted by Glossy and colleagues. The study was conducted in USA and reported parent stress scores for patients with anorectal malformation, Hirschsprung disease, fecal incontinence, and spinal condition as 31.8 ± 8.5 , 32.8 ± 10.9 , 39.0 ± 10.2 and 33.9 ± 9.2 .¹⁴ These values were generally less than the stress reported in the Pakistani population as per our study which reported PSS as 39.02 ± 7.63 , 40.82 ± 8.84 , 40.82 ± 9.17 and

46.31±5.99 for Anorectal Malformation, Hirschsprung's Disease, Fecal Incontinence and Post-op Incontinence, respectively. While there was a significant difference in ARM and FI in the study by Glossy, our study reported significant difference in ARM and Post-operative IC. The results were comparable as both reported higher stress in case of incontinence, however, our study reported highest scores in case of post-operative IC. Post-operative IC PSS being higher than other conditions can be attributed to the fact that these parents have exhausted majority of their treatment options but still were not able to achieve.¹⁵ Furthermore, ARM has an organ etiology associated with it, while IC can be functional in nature and has an element of psychosocial dysfunction associated with it. This gives the perception to the caregivers that IC is partly under the Stress and difficulties assessment identify the behavioral problems faced by patients themselves. When assessing the total difficulty score it was found that in our study the score was maximum in case of primary diagnosis of anorectal malformation (14.54±6.34), among males (14.04±7.52), among patients not undergoing bowel management (14.33±6.59), patients who underwent

control of the patient. Hence no definitive treatment as well as physicians focus on behavioral intervention in case of IC may lead to greater stress.¹⁶ A study conducted in Greece reported that patients attending the pediatric surgery outpatient clinic reported of 79.8% of the patients having anxiety before the meeting. This was attributed to limited health literacy among these people.¹⁷ Similarly, a study on cases of spina bifida conducted in Uganda reported that half of the parents had >90% percentile score according to PSS, and this was linked to incontinence and bowel management program.¹⁸ In terms of pediatric surgery, a study reported high stress among families who are unprepared for surgery and post-operative pain. In these families preoperative counselling in terms of detailed preparatory information is recommended for better results.¹⁹ surgical intervention (14.39±7.10) and patients who underwent pull through surgery among the procedure type (15.85±9.11). The results were reported in a similar manner by the study conducted by Glossy and colleagues. However, they reported higher difficulty score in case on incontinence (15.4±4.4) as a primary diagnosis instead of anorectal malformation in our study. Like our study,

males were reporting to have greater behavioral difficulties (12.4 ± 6.4).¹⁴ However, the overall SDQ scores were greater in our population as compared to them. Adding further, our study further investigated how SDQ scores varied according to bowel management programs, surgical intervention and type of procedure done. Similarly, another study revealed that patients who suffered from anorectal malformation had 23.3% population which reported with elevated total difficulty scores.¹⁸

A prospective study conducted in Denmark reported that interventions such as bowel management leads to improvement in the behavioral state of the patients. The study reported that behavior scores decreased from 10.3 to 7.9 in boys while 10.0 to 7.4 among girls. While those patients who weren't successfully treated ended up having higher scores from 10.3 to 13.2.¹⁹ This was comparable to our study in terms that participants undergoing bowel management had lower scores compared to ones who did not undergo the procedure (13.16 ± 7.82 vs 14.33 ± 6.59 , $p > 0.05$).

Conclusion

Caregivers, Parents, and patients suffering from colorectal conditions presenting to the department of Pediatric Surgery, Holy Family Hospital have significant psychosocial and behavioral comorbid associated with it. Parent stress score reported to be higher than international studies and post-operative incontinence leads to a higher score relative to other diagnosis. Adding further, behavioral impact was comparatively more in patients who underwent surgical intervention and specifically pull through surgery for Hirschsprung's disease.

Ethical Consideration

This study was approved by the Institution research forum of Rawalpindi Medical University.

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Conflict of interests

There is no conflict of interest

References

1. Kyrklund K, Pakarinen MP, Rintala RJ; Long-term bowel function, quality of life and sexual function in patients with anorectal malformations treated during the PSARP era. *In Seminars in Pediatric Surgery* 2017 Oct 1 (Vol. 26, No. 5, pp. 336-342).
2. Yamada M, Sekine M, Tatsuse T; Psychological stress, family environment, and constipation in Japanese children: The Toyama birth cohort study. *Journal of epidemiology*. 2019 Jun 5;29(6):220-6.
3. Gupta DK, Khanna K, Sharma S; Experience with the redo pull-through for Hirschsprung's disease. *J Indian Assoc Ped Surg*. 2019; 24(1):45-51.
4. Nam SH, Kim DY, Kim SC; Can we expect a favorable outcome after surgical treatment for an anorectal malformation? *J Ped Surg*. 2016; 51(3):421-4.
5. Mackow AK; Congenital and Pediatric Anorectal Conditions. *In Fundamentals of Anorectal Surgery* 2019 (pp. 63-85).
6. Levitt MA, Peña A; Imperforate anus and cloacal malformations. *In: Ashcraft's pediatric surgery* 2010 Jan 1 (pp. 468-490).
7. Kessmann J; Hirschsprung's Disease: Diagnosis and management. *Am Fam Physician*. 2006; 74:1319-22.
8. Rajindrajith S, Devanarayana NM, Benninga MA; Faecal incontinence in children: epidemiology, pathophysiology, clinical evaluation, and management. *Aliment Pharmacol Therap*. 2013; 37(1):37-48.
9. Lim II, Cushing CC, Jenkins T, et al; Prospective quality of life outcomes in pediatric fecal incontinence following bowel management. *Journal of Pediatric Surgery*. 2021; 56(8):1459-1464.
10. Cushing CC, Martinez-Leo B, Bischoff A, et al; Health-related quality of life and parental stress in children with fecal incontinence: a normative comparison. *Journal of pediatric gastroenterology and nutrition*. 2016 Dec 1;63(6):633-6.
11. Hanneman MJ, Sprangers MA, De Mik EL, et al; Quality of life in patients with anorectal malformation or Hirschsprung's disease. *Diseases of the colon & rectum*. 2001 Nov;44(11):1650-60.

12. Bedard K, Heymen S, Palsson OS, et al; Relationship between symptoms and quality of life in fecal incontinence. *Neurogastroenterology & Motility*. 2018 Mar;30(3):e13241.
13. Colares JH, Purcaru M, da Silva GP, et al; Impact of the Bowel Management Program on the quality of life in children with fecal incontinence. *Pediatric surgery international*. 2016 May 1;32(5):471-6.
14. Judd-Glossy L, Ariefdjohan M, Ketzer J, et al; Analysis of patients' and caregivers' psychosocial functioning in colorectal conditions: comparison of diagnosis, gender, and developmental functioning. *Pediatric Surgery International*. 2021 Apr;37(4):437-44.
15. Pathak M, Saxena AK; Postoperative "complications" following laparoscopic-assisted anorectoplasty: A systematic review. *Pediatric Surgery International*. 2020 Sep 26:1-9.
16. Bongers ME, Tabbers MM, Benninga MA; Functional nonretentive fecal incontinence in children. *Journal of pediatric gastroenterology and nutrition*. 2007 Jan 1;44(1):5-13.
17. Kampouroglou G, Velonaki VS, Pavlopoulou I, et al; Parental anxiety in pediatric surgery consultations: The role of health literacy and need for information. *Journal of pediatric surgery*. 2020 Apr 1;55(4):590-6.
18. Winter S, Schmidt D, Lenz K, et al; Prospective evaluation of comorbidity and psychosocial need in children and adolescents with anorectal malformations. Part 2: evaluation of psychosocial need. *Pediatric surgery international*. 2009 Oct;25(10):895-900.
19. Modin L, Jakobsen IS, Jakobsen MS; Conventional treatment of functional constipation has a positive impact on the behavioral difficulties in children with and without fecal incontinence. *Acta Paediatrica*. 2016 Jun;105(6): e269-74.