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Evaluation of Bowel Function on Patient Post Operative Hirschsprung Disease

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ABSTRACT

Introduction: Hirschsprung's disease (HD) is a congenital disease in which Meissner and Auerbach's plexus ganglion cells are lost on the distal side of the digestive tract, thus interfering with defecation. The postoperative defecation process was assessed to describe the patient's quality of life. This study aimed to describe the quality of defecation in pediatric HD patients after surgery.

Methods: This was a descriptive study on pediatric PD patients who received surgery in Dr. Soetomo General Academic Hospital, Surabaya, from 2018 to 2021. Demographic data came from Dr. Soetomo General Academic Hospital, Surabaya. The incontinence evaluation was assessed using the Rintala Score.

Results: A total of 14 pediatric HD patients underwent definitive surgery and had good scores on the Rintala score. There were 2 (14.3%) patients with maximum scores, 6 (42.9%) patients with normal scores, and 6 (42.9%) patients with good scores. The highest distribution in patients was always being able to hold bowel movements (81.8%), uncertain in reporting the desire to defecate (40.9%), 1-2 times a day (68.2%), never dirty (54.5%), never constipated (77.3%), and had no social problems (77.3%).

Conclusion: Pediatric HD patients had a good outcome after a definitive operation. The most common demographics with high satisfaction rates were male and female patients with normal nutritional status, above one-year-old, normal birth weight, and term labor.

Highlights:
1. All HD patients have good defecation quality after surgery.
2. Almost all HD patients can control bowel movements without constipation or social problems after surgery.
3. The most common problem patients face after surgery is soiling, which sometimes requires diapers.

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Introduction

Hirschsprung's disease (HD) is a congenital anomaly of the digestive tract.[1] Meissner and Auerbach's plexus ganglion cells are lost on the distal side of the digestive tract.[2] The incidence rate of HD is 1 in 5,000 live births and is more common in men. It is also often encountered at an early age. 65% of cases are diagnosed before the age of one year old.[3,4] The prevalence of HD was estimated at 1 per 5,400– 7,200 newborns in America, while the exact number of cases worldwide remains unknown.[5]

Similar to the worldwide data, the number of cases of HD in Indonesia is yet unclear. If the incidence rate of HD is assumed to be around 1 in 5,000 newborns, there would be around 1,400 babies born with the disease each year. In Indonesia, the understanding of HD is still considered low, thus leading to increased morbidity and mortality rates in neonates.[5]

HD therapy is an operative action on the aganglionic gastrointestinal tract.[5] After definitive 1-stage or 2-stage surgery, pediatric HD patients still frequently experience complications such as constipation, soiling, anastomotic stricture, and anastomotic leak which have an impact on the patient's quality of life.[5] Not all cases have normal bowel function after definitive surgery.[6]

HD affects about 1 in every 5,000 live births.[3] The incidence varies depending on ethnicity, with Asians having 2.8 children per 10,000 live births, African-Americans having 2.1, whites having 1.5, and Hispanics having 1 child per 10,000 live births.[4] The frequency increases by 1 in every 150 live births, particularly in Indonesia.[3] Male patients make up the majority.[4] The rectosigmoid and rectum are the parts of the digestive tract that are most frequently impacted. However, the condition can affect the entire tract.[6] The absence of peristaltic causes difficulties with bowel movement in the colon or intestine that is affected.[6] Patients experienced a decreased quality of life due to impaired bowel function.[6]

The patient's defecation and social quality are used to assess the functional result of the post-definitive operation to understand long-term health-related quality of life among children. Therefore, other biopsychosocial factors must be examined.[7] Clinical symptoms and demographic factors did not predict health-related quality of life among children with HD.[7] Low parent-child health-related quality of life among children with HD highlights the value of getting both parents' and children's perspectives.[7,8] The psychosocial and physical quality of life of pediatric HD patients is lower than that of healthy children.[8] Parents described feeling helpless due to a lack of social support and uncertain about the future during the neonatal era. Primary grades were observed to have anxiety, peer rejection, and behavioral issues, while teenagers had depression, low self-confidence, and bad body image.[9] Young adults are left without support to manage a chronic condition due to a lack of long-term follow-up, an imperfect transfer to adult healthcare, and a lack of psychosocial service. For most parents, learning their child has HD comes as a surprise.[10]

While intraoperative biopsy can be used to diagnose HD, surgery can fix an anatomical bowel innervation deficiency associated with HD. Still, there is also a risk of Hirschsprung-associated enterocolitis (HAEC) and long-term functional difficulties.[11,12] Explaining this to parents is a crucial responsibility that comes with being a pediatric surgeon and calls for a methodical approach and talking points based on research.[11] If the diagnosis and treatment are not performed quickly and accurately, the treatment received will last longer and require more expensive costs, hence the mortality of HD can reach 80% and surgery can reduce mortality up to 2.5%.[13]

Rintala score or Krickenbeck classification can be used to determine the functional result.[7,14] In 1995, Rintala and Lindahl developed the Rintala score, which is based on a clinical score that evaluates fecal continence and is acquired via a standardized questionnaire without the use of a physical examination.[8] The score is based on seven parameters that evaluate social issues, defecation frequency, soiling the incidence, ability to describe the urge to defecate, and ability to retain feces.[8] Evaluation of bowel movements, constipation, and soiling is conducted using the Krickenberk criteria.[9] Although there was damage following the definitive operation, patients' quality of life is increasing.[10]

Functional and psychosocial results were reduced in HD patients.[13] According to a recent study, feces issues may pose barriers to social life even if patients do not experience social problems as a result of the function of defecation.[15] Most patients did not have social issues that interfered with their daily activities.[16] Defecation function affected adult patients, yet it will improve in young adulthood compared to when a person is younger.[16] On the other hand, as pediatric patients are less disturbed by defecation problems than adults, defecation problems that interfere with the patient's social life may not be inversely connected to the patient's age.[17]

Early research into the complaint yields effective solutions. By using this strategy, social issues for patients in later life can be avoided.[10] Incontinence, particularly in older children, can be socially uncomfortable, difficult for the family to manage, and result in poor academic performance, all of which have a detrimental effect on the child's quality of life.[12,16] Incontinence of increasing severity has an impact on all aspects of quality of life, including the psychosocial and physical aspects.[12] HD patients must also have their psychosocial needs met during treatment. When treating patients, psychologists and other mental health specialists should be considered.[12]

The study of fecal incontinence in pediatric HD patients is scant and infrequent. Therefore, this study aimed to describe the fecal incontinence of these patients. Measuring the quality of life of pediatric HD patients can increase public awareness of this disease.

Methods

This was a descriptive and observational study to measure the fecal incontinence of pediatric HD patients who received surgery in Dr. Soetomo General Academic Hospital, Surabaya. The study was conducted retrospectively using secondary data in the form of medical

records and primary data obtained through the Rintala score questionnaire that assessed the ability to hold back defecation, feel or report the urge to defecate, defecation frequency, soiling and its frequency, constipation, and social problems. Data was collected in a cross-sectional study to produce a conclusion.

Inclusion data used in this study was from pediatric HD patients under 2 years old who received definitive surgery in Dr. Soetomo General Academic Hospital, Surabaya. Total sampling yielded a total of 14 patients. Variables collected were sex, nutritional status, hospitalized age, birth weight, term characteristics, definitive operative technique, and fecal incontinence based on the Rintala score.

The data was processed and analyzed using Statistical Package for the Social Sciences (SPSS) 16.0, where a table was created containing various data that had been coded according to the required analysis. Data are presented descriptively through tables or graphs as needed.

Results

From a total of 14 children after surgery, 5 (35.7%) children were females, and 9 (64.3%) were males. Pediatric HD patients who received surgery when viewed from their nutritional status were dominated by children with normal nutritional status as many as 9 (64.3%) patients. Most pediatric HD patients who came to the hospital were in the age range of 1-12 months old as many as 9 (64,3%) patients, born weighing over 2.500 grams as many as 14 patients, and born at term as many as 13 (92.9%) patients, and all of them are born at term. Fourteen patients who underwent definitive surgery with Duhamel or transanal endorectal pull-through (TAEPT) procedures were each 7 patients.

Three patients were in the ‘good’ category and had an age range of above a month and 1-12 months old, respectively. Since every patient was born with a birth weight greater than 2.500 grams, there were 2 (14.3%) patients in the maximum category and 6 (42.9%) patients in the 'normal' and 'good' categories. Only one patient born in preterm labor had a ‘normal’ category of fecal incontinence.

Patients with the Duhamel procedure were in the maximum quality of life category as many as 1 (14.3%) patient, normal as many as 4 (57.1%) patients, and good as many as 2 (28.6%) patients, while patients with the TAEPT procedure were in the maximum quality of life category as many as 1 (14.3%) patient, normal as many as 2 (28.6%) patients, and good as many as 4 (57.1%) patients.

In the dimension of the ability to hold bowel movements, as many as 13 (92.9%) patients were always able to hold bowel movements. Five (35.7%) parents of patients perceived that their child wanted to defecate. In terms of the frequency of bowel movements, as many as 11 (78,6%) parents of patients who got surgery assessed that the child defecates every day or twice a day. In the soiling and its incidence dimension, as many as 8 (57.1%) and 7 (50%) parents perceived that their child had never experienced soiling. Only 1 patient (7.1%) experienced constipation and needed help from an enema, and the rest had no problem with constipation. Two (14.3%) of 14 patients experienced an unpleasant smell that interrupted their social lives.

Table 1. Demographic characteristics of study objects

Characteristics	Frequency	Percentage
Sex		
Male	9	64.3%
Female	5	35.7%
Nutritional status		
Very thin	4	28.5%
Thin	1	7.1%
Normal	9	64.3%
Overweight	0	0%
Hospitalized age		
<1 month	3	21.4%
1-12 months	9	64.3%
12-24 months	24	1.2%
Birth weight		
>2.500 gram	14	100%
1.500–2.500 grams	0	0%
<1.500 gram	0	0%
Term characteristic		
Aterm	13	92.8%
Preterm	1	7.1%

Source: Research data, processed

Table 2. Treatment characteristic of the study object

Characteristics	Frequency
Procedure	
Duhamel	7
TAEPT	7

Source: Research data, processed

Table 3. Rintala score results

Category	Frequency	Percentage
Maximum	2	14.28%
Normal	6	42.85%
Good	6	42.85%
Fair	0	0%
Bad	0	0%

Source: Research data, processed

Table 4. Analysis of Rintala score components

Components	Frequency	Percentage
Ability to hold back		
Always	13	92.9%
Problem less than 1/week	0	0%
Weekly problems	0	0%
No voluntary control	1	7.1%
Feels/reports the urge to defecate		
Always	5	35.7%
Most of the time	1	7.1%
Uncertain	4	28.6%
Absent	4	28.6%
Frequency of defecation		
Every other day to twice a day	11	78.6%
More often	1	7.1%
Less often	2	14.3%
Soiling		
Never	8	57.1%
Staining less than 1/week, no change of underwear required	3	21.4%
Often staining, need a change of underwear required	1	7.1%

Daily soiling	2	14.3%
Accidents		
Never		
Fewer than 1/week	7	50%
Weekly accidents, often require protective aids	5	35.7%
Daily, requires protective aids during the day and night	2	14.3%
Constipation		
No constipation	13	92.9%
Manageable with diet	0	0%
Manageable with laxatives	0	0%
Manageable with enema	1	7.1%
Social problems		
No social problems	12	85.7%
Sometimes (foul odors)	2	14.3%
Problems causing restriction in social life	0	0%
Severe social and/or psychic problems	0	0%

Source: Research data, processed

Discussion

HD patients in Dr. Soetomo General Academic Hospital, Surabaya, were dominated by male patients (Table 1), and similar incidents happened.[15,18–20] A similar outcome was seen in males with a ratio of 1.3:1. Likewise, it was found that the ratio of male–male to female in cases of HD was 3:1 to 4:1.[18]

The demographics of the nutritional status of patients in this study were in the normal category for as many as 9 patients out of 14 patients (Table 1). Most of the patients had good nutritional status after surgery. Following pull-through and Soave surgery, nutritional status alterations were generally stable. For 75% of the kids in the Duhamel group, it remained the same, while for 40% of the kids in the TAEPT group, it improved.[21,22]

HD is usually diagnosed when the patient is under 30 days old due to its classification as an anatomical disorder.[7,23] Interestingly, this study found that the age of patients when they came to the hospital based on the date of hospital admission was mostly in the range of 1-12 months (Table 1). Nevertheless, the results of another study obtained results with a dominant age range of 2 years old.[8]

This study found that the dominant birth weight was above 2.500 grams as much as 100% (Table 1). These results are in line with studies in which HD patients were predominantly of normal birth weight.[9,10,22] The prevalence of HD patients who were born prematurely as a risk factor in this study was 92.7% (Table 2) and this happened in similar studies.[10,12,24,25]

Definitive surgery is the therapy applied to HD patients. A definite pull-through operation is advised between 4 and 6 months after colostomy installation. There are numerous pull-through operations known. The standard Swenson's procedure entails a proctectomy, the removal of the healthy ganglionated colon, and the anastomosis of the colon to the anus. The delicate innervation of the rectum and bladder is preserved thanks to modern surgical techniques like Duhamel and Soave.[14]

The type of definitive surgery may have an impact on the long-term bowel functional result, according to a similar study. In particular, the TAEPT technique may have certain advantages over the transabdominal Soave and Duhamel operations.[26,27] Commonly used procedures include TAEPT, Soave, and Duhamel.[26,28] Fourteen patients who received definitive surgery received treatment with the TAEPT procedure, and Duhamel treated 7 patients each (Table 2).

In this study, it was found that all postoperative female patients were in the ‘good’, ‘normal’, and ‘maximum’ categories (Table 3). Female patients had better postoperative outcomes than males.[29] However, the female patients might have an increased risk of experiencing constipation, which can affect the patient's quality of life.[30] Likewise, nutritional status does not have a significant effect considering the small number of samples in this study.[30] Fewer patients were in the good category with an age at arrival under 1 month while the rest were in the normal and maximum categories (Table 3). Patients presenting in the neonatal or 30-day age range are more easily diagnosed by pediatric surgeons.[30] Neonatal patients have good postoperative outcomes because neonates also still have loose stools.[31] Clinicians need not to be afraid to treat patients with preterm characteristics because there are no patients with preterm births who are in the bad category (Table 3). The majority of patients who received definitive action in this study were in the good to maximum category (Table 3). Patients with definitive treatment affected the outcome of postoperative patients.[28]

If the patient is compared with healthy subjects, the patient will have poorer quality of defecation. The quality of defecation in question is rectal sensation, frequency of defecation, frequent stool incontinence, holding defecation, frequent soiling, and impaired social problems.[26] HD is one of the comorbidities of the patient with diarrhea.[17] Despite having a higher prevalence of incontinence and constipation, patients who received definitive treatment had good Rintala scores. The patient's parents think that their child can always hold bowel movements even though they cannot control the ability to defecate. Patients have the ability to hold and report the desire to defecate better at an older age considering that the patient has gone through a period of defecation training or toilet training.[32]

Most of the patients' parents reported that the frequency of defecation was 1-2 times per day (Table 4). Damage to the sense of sensation and the mechanism of sphincter function causes soiling in HD patients.[28] In this study, only a few patients required the use of diapers (Table 4). Soiling usually occurs after surgery in the short term.[16]

Constipation is defined as defecation less than three times per week or requiring regular laxatives, or co-occurring, and constipation is common in HD patients after surgery.[16,32] In this study, most of the patients were not constipated (Table 4).

This study also revealed that postoperative HD patients were most likely not to have social problems (Table 4). Patients do not experience social problems due to the function of defecation, even though defecation problems can still present as obstacles to social life.[32] There is still conflicting evidence on which procedure is associated with patients' social problems. HD has a long-term effect that

causes not only physical but also psychosocial disturbances in the patient's life.[12]

Through this study, suggestions that can be given include the criteria used in similar studies that can be more general given the small number of samples that can be used, conducting research on the quality of life of pediatric HD patients postoperatively based on the social or psychosocial quality of life, and requiring further research. Furthermore, related to the relationship between postoperative patient's quality of life and demographic characteristics.

Strength and Limitations

The strength of this study was that it had never been performed in Dr. Soetomo Academic Hospital, Surabaya. The limitation was that some medical records had incomplete data. Notably, this study was limited by the small number of participants. Small sample sizes could undermine the validity and significance of the study. The majority of parents declined to participate since their children were already healthy and the study would not directly affect their children's outcomes, which contributed to the limited sample size. Therefore, further studies are needed to learn more about HD.

Conclusion

Definitive therapy in pediatric HD patients gave a favorable quality of life with a different kind of demographic status.

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Conflict of Interest
The authors declared there is no conflict of interest.

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Ethical Clearance
This study was approved by the Ethical Committee for Health Research (KEPK) Dr. Soetomo General Academic Hospital, Surabaya, with the number 0325/KEPK/XII/2021 on 12 December 2021.

Authors' Contributions
Conception and design of study: AFA, IGBAH. Acquisition of data: ARF. Analysis of data: ARF. Interpretation of data: AFA, ARF, IGBAH. Drafting the manuscript: AFA, ARF, IGBAH. Reviewing the manuscript: AFA, ARF, IGBAH. All authors approved the manuscript to be published.

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