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Improving Health-Related Quality of Life in a Child with Hirschsprung Disease: A Public Health Approach to Rehabilitation

Pallavi Bhakney[1],

[1]*Assistant Professor, Department of Musculoskeletal Physiotherapy, Ravi Nair Physiotherapy College, Datta Meghe Institute of Higher Education and Research, Sawangi(M), Wardha, Maharashtra, India*

Corresponding Author:
Pallavi Bhakney
pallavi.bhakney@dpu.edu.in

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Abstract

Purpose- The purpose of documenting this case report is to explore the inpatient rehabilitation techniques in a case of Hirschsprung disease, primarily a rare congenital disease characterized by loss of peristaltic bowel movement as a result of absent ganglionic cells in the distal colon. Currently available literature highlights the presentation and surgical management of this rare disease; however, no evidence is present regarding the role and efficiency of physiotherapy rehabilitation in patients with Hirschsprung disease.

Method- We present a case of a 5-year-old baby who was previously confirmed with Hirschsprung disease at the age of 1. She underwent a high-sigmoid colostomy as a corrective surgery, but years later, she presented with prolapse and was admitted for a second colostomy. This documentation demonstrates the importance of inpatient rehabilitation after the colostomy is performed. Physiotherapy treatment included pre-operative and post-operative care focusing on maintaining bronchial hygiene, achieving early mobility, and improving the patient's and the parents' quality of life.

Result- As a result of pre-operative and post-operative inpatient physiotherapy treatment, the patient's general condition as well as quality of life have shown an improvement.

Conclusion- Physical rehabilitation has shown an enhancement in the patient's overall functioning. Despite the rarity of this illness, rehabilitation techniques should be considered to minimise adverse consequences.

Keywords: *Hirschsprung Disease, Rehabilitation, Physiotherapy, Critical Care, Case Report*

1. Introduction

Hirschsprung disease is a congenital disorder that is present in 1 among 5,000 live births. The condition is manifested with an absence of ganglia in the distal colon. It is usually considered in infants who fail to pass meconium in the first 24 hours of life. Hirschsprung-associated enterocolitis (HAEC) was first recognised in the late nineteenth century by Härald Hirschsprung, who included it in his hallmark description of congenital megacolon. HAEC is a condition of intestinal inflammation characterised clinically by fever, abdominal distention, diarrhoea, and sepsis [1].

Untreated disease usually causes death in childhood because bloodstream bacterial infections occur in the context of bowel inflammation (enterocolitis) or bowel perforation. Presently, the condition is managed with the surgical resection of the bowel to remove or bypass regions where the enteric nervous system is missing. Many patients have reported a list of complications after the surgery. Although the anatomy of Hirschsprung disease is simple, many clinical features remain enigmatic, and diagnosis and management remain challenging. Despite a common manifestation, the age of presentation and the type of symptoms vary dramatically among patients [2]. After careful preoperative management, the principle is to place the normal bowel at the anus and to release the tonic contraction of the internal anal sphincter. Swenson described the initial protocol in 1948, followed by a series of operative approaches that have been developed, such as the Soave and Duhamel procedures. In cases where the diagnosis is delayed, multiple staged surgeries are required. Colostomy in children is a time-honoured procedure used for several purposes; however, it is mainly used to divert the faecal stream for decompression, under emergency conditions, and to protect the lower colorectal tract after a reconstructive repair. Most patients with anorectal malformations receive a protective colostomy before the main repair to avoid contamination [3]. The author of this study believes that rehabilitation is just as important as the surgical intervention approach in ensuring a favourable outcome and fewer problems [4]. Rehabilitation of children with low anorectal malformation should take place during all stages of their examination and surgical treatment. The right choice and perfect execution of the surgery in the absence of postoperative complications will undoubtedly contribute to good functional results, but it is also necessary to determine the significance of rehabilitation measures in this case. The following are some ways that a stoma impacts quality of life (QoL), according to a recent systematic review, including psychosocial impact, physical impact, as well as acceptance and adjustment [5]. To our knowledge, there is a critical need to enhance the literature on Hirschsprung disease, particularly concerning the management.

2. Case Presentation:

A 5-year-old patient was admitted to our tertiary care hospital with a visible prolapse of the colostomy site. She was a previously diagnosed case of Hirschsprung disease. As reported by the parents, she had been born through a caesarean section after 37 weeks of gestation, with no significant complications immediately after birth. Third month of her life onwards, the parents started noticing long-standing constipation, and could only defecate 1-2 times per week. They did not think it was a matter of concern until she started developing progressive abdominal distention. Soon they visited a local paediatrician, where necessary investigations were done, and a high-sigmoid colostomy was planned. After a successful surgery, the patient was discharged with the stoma. Years later, the parents started noticing the presence of a structure around the stoma site. They visited the same paediatrician and, after initial examination, were referred to our hospital. On admission, observation revealed the presence of prolapse at the colostomy site. Cystogenitoscopy was performed, which revealed the presence of a fistula distal to the vaginal opening. Radiographic imaging of the abdomen has shown dilatation of the descending and transverse colon up to the hepatic flexure (Figure 1). A pull-through surgery with colostomy with re-suturing of the burst abdomen and perforation repair was planned and performed. Post-operative x-ray has shown normal patency of distal bowel loops (Figure 2). The timeline of the events in the course of hospitalization is mentioned in Table 1. Physiotherapy rehabilitation was commenced before the surgery, as discussed in a later section. Before the physiotherapy treatment and documentation of the case, the parents gave their consent.

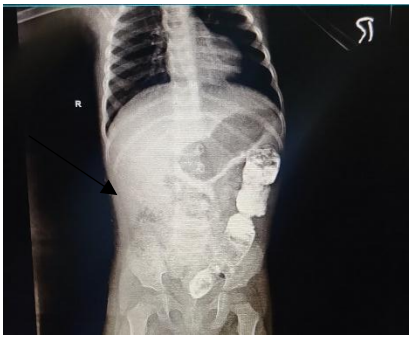

Figure 1: Pre-operative dilatation of the descending and transverse colon up to the hepatic flexure.

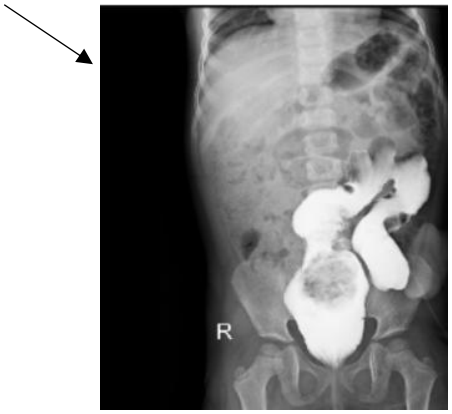

Figure 2: Post-operative normal patency of distal bowel loops.

Sr.No.	Date of events	Consultation	Description of events
1.	10/04/2025	Hospital admission	Visible prolapse of the colostomy site
2.	11/04/2025	Preoperative physiotherapy	Relative's education and counselling
3.	12/04/2025	Surgery	Colostomy with perforation repair
4.	13/04/2025	Post-operative physiotherapy	Splinting, breathing exercises, and early ambulation
5.	02/05/2025	Discharge	Home exercise program

Table 1 shows the course of hospitalization of the patient.

Followed by taking informed consent from the parents of the patient, the assessment was done in a supine lying position (Fig. 3). On general examination, the respiratory rate was 24 breaths per minute with the thoraco-abdominal type of breathing, the heart rate was 89 beats per minute, and oxygen saturation was 97% on 6 liters of oxygen support via nasal cannula. On inspecting the respiratory system, the shape of the chest was normal; the position of the trachea appeared to be normal; chest movements were bilaterally equal. Pallor was present while inspecting for the positive findings. Chest expansion revealed a difference of 1 cm, 1 cm, and 1 cm at axillary, nipple, and xiphisternum levels, respectively. Auscultation revealed reduced air entry bilaterally in the lower zones of the chest.

Figure 3: Patient in supine position, with visible stoma.

3. Physiotherapy Management:

Physical therapy was commenced before and after the surgery to maintain the lung function, bronchial hygiene, enhance post-operative tolerance for feeding, and improve the quality of life of the patient. The benefits and significance of rehabilitation after surgery were also explained to the parents (Tab. 2).

Goal	Physiotherapy treatment
Pre-operative intervention	
To educate the parents about the medical condition, the significance of physical therapy, and its efficacy.	Parental education and counselling regarding acceptance and comprehension of the patient's current state
To improve the adherence of the patient to physical therapy	Diaphragmatic breathing, deep breathing with splinting, colourful balloon blowing, and an incentive spirometer
Post-operative intervention	
To prevent secondary complications	Every 2 hours, rolling on either side, active range of motion exercises
To maintain bronchial hygiene	Nebulization 4 hourly, huffing and coughing technique with proper splinting of the surgical site
To improve respiratory function and prevent atelectasis	Deep breathing exercises, diaphragmatic breathing exercise, incentive spirometer with 2-second hold, later progressed to 5-second hold, colourful balloon blowing exercise to engage the child (10 repetitions, thrice a day)
To teach the patient defecation skills	Pelvic tilting exercises, contraction, and relaxation of the pelvic floor muscles
Home exercise program	Deep breathing exercises, continuous use of an incentive spirometer, upper and lower extremity exercises, progressive hall ambulation, and stair climbing

Table 2 shows the treatment protocol for the patient

The effectiveness of physiotherapy rehabilitation was documented using the following outcome measures, as listed in Table 3.

Outcomes Measures	Day 1	At discharge
ICU mobility scale	0	8
Incentive spirometer (Lung capacity)	<600cc	900cc
6-minute walk test	-	400 meters
Oxygen support	6 litres of O_2	Room air

Table 3 shows the outcome measures of the patient

4. Discussion:

Hirschsprung disease patients frequently experience exercise intolerance, difficulty carrying out daily duties, and a decreased quality of life while obtaining the proper medical care. Avoiding exercise creates a cycle of idleness and functional decline in such cases. Rehabilitative care addresses these concerns and accelerates the healing process. This case study addresses the importance of physiotherapy protocol in improving the physical condition of a patient who underwent a recurrent colostomy procedure in a case of Hirschsprung disease. Limited literature exists that mentions the supportive evidence for the rehabilitation of a child in such rare cases. This case study contributes valuable evidence to the literature related to Hirschsprung disease. Shokirovich et al (2023) have studied the influence of Hirschsprung disease one year after being surgically treated on quality of life and functional activity, which was concluded to be improved using the modified De La Torre-Ortega operation [6]. Another study was done by Hoel et al (2023) on educating the adult patients on self-care management strategies with Hirschsprung disease, which has shown results of high satisfaction within the group [7]. A cross-sectional study by Balela et al (2023) has concluded that even after a pull-through surgery, a moderate frequency of symptoms is seen [8]. The findings of the mentioned study provide insight into the need for rehabilitation as well as the evidence of its effectiveness in patients with Hirschsprung disease. Gagnon et al (2023) in their study also mentioned that patients who are surgically treated after being diagnosed with Hirschsprung disease are prone to develop bladder and bowel dysfunction [9], thus making it crucial to explore rehabilitative measures to prevent such complications.

5. Conclusion

The general quality of life of the patient who has undergone colostomy surgery for Hirschsprung disease is significantly improved by rehabilitation. This case study highlights a thorough, closely supervised physical rehabilitation program that improved the patient's exercise tolerance, pulmonary function, and behavioural status after having corrective colostomy surgery.

Data Availability: No data were generated during the study.

Author Contribution: PB has ideated and written the manuscript. Also, reviewed for submission.

Conflict of interest: The authors declare no conflict of interest.

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