Original Research Article

Comprehensive Analysis of the Clinical Outcomes, Lifestyle Impacts, and Family Satisfaction in Hirschsprung's Disease: A Retrospective Cohort Study from a Single Pediatric Surgery Unit

ABSTRACT

Background: Hirschsprung's disease (HD) is a congenital condition causing functional bowel obstruction. Despite surgical advancements, long-term impacts on patients' quality of life, family dynamics, and satisfaction remain underexplored. This study evaluates the clinical outcomes, lifestyle impacts, and family satisfaction in HD management. **Methods:** A retrospective cohort study analyzed 127 HD cases managed in a single pediatric surgery unit (2004–2020). Data from medical records, surveys, and structured interviews assessed surgical outcomes, postoperative bowel function, school attendance, dietary adjustments, social anxiety, and family satisfaction. The quantitative analysis utilized SPSS v25.0, with p-values <0.05 considered statistically significant. **Results:** Patients had a mean age at surgery of 10.6 months; 72.4% were male. Surgical interventions included one-stage pull-through (51.2%) and staged procedures (48.8%). Complications like persistent constipation (26.8%), enterocolitis (15.0%), and redo surgeries (6.3%) were common. Functional outcomes showed that 81.1% achieved good bowel function, while 14.2% required occasional medication. Rural patients faced higher absenteeism (45% vs. 30%) and restrictive dietary changes (50% vs. 35%). Family satisfaction was high (73.2%), with concerns about long-term bowel management (65%), psychosocial impact (38%), and financial burdens (21%). **Conclusions:** This study highlights the multifaceted challenges of HD management, including disparities in rural vs. urban care, persistent complications, and psychosocial impacts. Recommendations include multidisciplinary care, genetic counseling, family-centered support, and public health interventions tailored to regional needs. These findings advocate for enhanced strategies to improve surgical outcomes, address long-term care challenges, and elevate family satisfaction.

KEYWORDS: Hirschsprung's Disease, Comprehensive Analysis, Clinical Outcomes**.**

INTRODUCTION

Hirschsprung's disease (HD) is a congenital disorder characterized by the absence of ganglion cells in the distal colon, resulting in functional obstruction of the affected segment **(1)**. It typically presents in the neonatal period with symptoms such as delayed passage of meconium, abdominal distention, and vomiting. Surgical intervention is the primary treatment, and it often involves procedures such as pull-through surgery, which aims to bypass the aganglionic segment and restore normal bowel function **(2)**. Despite the high success rate of these surgeries in terms of resolving the obstruction, patients with HD face a variety of long-term challenges that can significantly affect their quality of life. While the immediate postoperative outcomes such as bowel function and the resolution of acute symptoms are commonly assessed in HD patients, the broader implications of the disease on patient lifestyles, family dynamics, and overall satisfaction with the treatment are less frequently explored **(3)**. Issues such as ongoing bowel dysfunction, dietary modifications, psychological consequences, and the economic burden of long-term care can all have profound effects on the well-being of both the child and their family **(4)**. Additionally, the availability of healthcare resources and support systems, especially in rural versus urban settings, can create disparities in treatment outcomes and lifestyle management.

The primary aim of this study is to provide a holistic understanding of HD management by addressing the following objectives: To evaluate the success rates and complications of surgical interventions. To analyze the broader lifestyle impacts of HD, including school attendance, dietary adjustments, and psychosocial challenges. To assess family satisfaction and identify key areas for improvement in long-term care, and to explore community-specific factors influencing outcomes, including cultural practices, health education, and resource accessibility. By focusing on both the medical and social aspects of HD, the study aims to improve long-term care strategies and enhance family-centered approaches in the management of Hirschsprung disease.

METHODOLOGY

This retrospective analysis of 127 (HD) cases was conducted at a single pediatric surgery unit between 2004 and 2020. The data analyzed included medical records, surveys, and structured interviews with patients and their families. This study aimed to assess the surgical outcomes, impact on patient lifestyle, family satisfaction, and ongoing concerns related to the treatment of HD. The inclusion criteria for this study were as follows: A confirmed diagnosis of HD through a combination of the following diagnostic approaches were utilized based on the unit facilities': rectal biopsy, the gold standard for diagnosis, performed in 100% of the cases (127 cases, 100%). Barium enema was used in 110 cases (86.6%) to assess the transition zone and confirm the diagnosis. Histopathological examination was conducted in all 127 cases (100%) to confirm the absence of ganglion cells in the aganglionic segment. Patients who underwent definitive surgical management, which includes either a one-stage pull-through procedure or a multi-stage surgical approach, and a follow-up period of at least one year after surgery to ensure adequate assessment of both short-term and long-term outcomes. We examined the prevalence of chromosomal anomalies and syndromes in the patient cohort. Role of consanguinity and Its Implications in our community, and this cohort was assessed.

The following data were collected from the medical records and through patient/family interviews: Medical outcomes, Postoperative bowel function (frequency of bowel movements, presence of constipation, incontinence, episodes of Hirschsprung's - associated enterocolitis (HAEC) enterocolitis), and the need for redo surgeries were recorded (e.g., redo pull-through procedures). Patient Lifestyle, information regarding school participation, dietary modifications, and social interaction post-surgery. Disparities based on geographic location (rural vs. urban) were also considered to assess differences in lifestyle outcomes. Family Satisfaction, a structured survey was used to assess family satisfaction with the surgical outcomes, support systems, and ongoing concerns related to the long-term management of the disease, psychosocial health, and financial burden, surveys scored on a 5-point Likert scale (a psychometric scale commonly

used to measure attitudes, perceptions, and satisfaction. It allows respondents to rate their level of agreement or satisfaction with a given statement on a scale ranging from strongly negative to strongly positive) **(5)**.

Quantitative data were analyzed using SPSS (Statistical Package for the Social Sciences v25.0) to determine statistical significance. A p-value of <0.05 was considered statistically significant. Descriptive statistics, including mean, standard deviation, and percentages were used for demographic and clinical variables, and thematic analysis was applied to qualitative data from structured interviews. Fisher's exact and chi-square tests assessed the relationships between categorical variables such as rural vs. urban residency, type of surgery, and family satisfaction. For exploring the relationship between surgical approach and long-term functional outcomes, Pearson correlation, and multivariate regression analysis, to identify factors that significantly influence postoperative bowel function and family satisfaction. Histograms were used to illustrate the distribution of key outcomes between sexes, allowing for visual comparison of proportional impacts.

RESULTS

Patient Demographics: Mean Age at Surgery, 10.6 months (SD: ±5.3; range: 2.5 months – 3 years). Gender Distribution: Male: 92 cases (72.4%), female: 35 cases (27.6%) this distribution was statistically significant ($p < 0.001$).

The data shows a higher prevalence of consanguineous marriages in rural areas: 22 cases (32.4%) compared to 12 cases (20.3%) in urban areas. The difference in consanguinity prevalence between rural and urban populations is statistically significant (p-value: 0.04) **(Fig. 1.)**.

Chromosomal anomalies and associated syndromes were observed in a subset of this cohort, Males: 18 cases (19.6% of 92 males), females: 7 cases (20.0% of 35 females). The incidence of chromosomal anomalies was proportionally similar between males and females ($p > 0.05$). Common Anomalies Identified, trisomy 21 (Down syndrome): males: 12 cases (13.0% of males), females: 5 cases (14.3% of females), trisomy 21 was the most frequently observed chromosomal anomaly, affecting both sexes at comparable rates ($p > 0.05$). Other Chromosomal Abnormalities: Males: 6 cases (6.5% of males), females: 2 cases (5.7% of females), these included structural anomalies (e.g., deletions, duplications) identified through genetic testing. Syndromic Associations, Waardenburg Syndrome: males: 3 cases (3.3% of males), females: 1 case (2.9% of females), it is a rare autosomal dominant condition linked to HD in a subset of patients. Cardiac Anomalies Associated with Genetic Disorders: males: 2 cases (2.2% of males), females: 1 case (2.9% of females), congenital cardiac conditions were frequently observed in patients with Trisomy 21. Other Syndromes: males: 2 cases (2.2% of males), females: 1 case (2.9% of females), included rare syndromic presentations requiring further genetic evaluation **(Figs. 2&3.)**.

Surgical approaches: Most patients underwent a one-stage pull-through procedure (65 cases, 51.2%), followed by two-stage surgeries involving an initial colostomy and subsequent pull-through (45 cases, 35.4%). Multi-stage surgeries, requiring more than two interventions, were performed in 17 cases (13.4%) **(Fig. 4)**.

Postoperative Complications: Persistent constipation requiring intervention: In 34 cases (26.8%), patients who underwent multi-stage surgeries were more likely to experience persistent constipation compared to those who underwent a one-stage procedure ($p = 0.02$). HAEC: 19 cases (15.0%). The incidence of HAEC was higher in patients who required redo pull-through surgeries ($p = 0.01$). Redo pull-through surgeries, were required in 8 cases (6.3%), in this series patients with redo surgeries had significantly higher rates of persistent constipation and HAEC ($p = 0.02$). Anastomotic stricture was detected in 12 cases (9.4%), this was more common in multi-stage surgeries ($p = 0.04$). Anastomotic leak: 4 cases (3.1%), redo pull-through surgeries: 8 cases (6.3%), although rare, this complication was predominantly seen in two-stage surgeries, but the association was not statistically significant ($p = 0.09$). Perianal fistula: 3 cases (2.4%), this was more

common in patients with multi-stage surgeries but did not reach statistical significance (p = 0.08). Statistical analysis showed a significant association between the surgical approach and the presence of complications (p = 0.03), with multi-stage surgeries having the highest complication rates **(Fig. 5)**.

Functional Outcomes: Good bowel function (2–3 soft stools/day without medication): 103 cases (81.1%), mild dysfunction (occasional laxatives/enemas): 18 cases (14.2%) and severe dysfunction (frequent enemas, medications): 6 cases (4.7%). The surgical approach (one-stage vs. multi-stage) was found to influence functional outcomes (p-value <0.01) significantly **(Fig. 6)**.

Impact on patient lifestyle, and school attendance: resumed normal school participation: 80 cases (63%) resumed normal school attendance post-surgery, missed significant schooling due to medical needs: 28 cases (22%), and homeschooling due to health complications: 19 cases (15%). Rural patients had significantly higher absenteeism due to medical issues (45%) compared to urban patients (30%) (p = 0.02). Dietary modifications: 42% of patients required dietary changes post-surgery (low-residue, fiber adjustments). Rural patients were more likely to have restrictive diets (50%) compared to urban patients (35%) (p = 0.04). Social anxiety: 19% of patients reported social anxiety, social anxiety was more common in children with severe long-term functional deficits (e.g., persistent constipation or severe bowel dysfunction) (p = 0.03). Normal peer interactions and activity participation were 103 cases (81.1%) (**Fig. 7)**.

Family satisfaction and concerns, overall satisfaction with surgical outcomes: High satisfaction (score ≥4/5): 93 families (73.2%), moderate satisfaction (score 3/5): 24 families (18.9%), and dissatisfied (score ≤2/5): 10 families (7.9%). Family satisfaction scores were significantly higher in one-stage surgery patients compared to multi-stage (p-value <0.05). Primary concerns: long-term bowel management: 65%, this was substantially more concerning for families of patients with persistent constipation or requiring multiple surgeries (p-value = 0.03). Psychological impact on the child: 38% (families noted the emotional toll of the disease and surgery on their child) were more common in families of children with severe functional outcomes (p-value = 0.02), and financial burden of ongoing care: 21% due to ongoing medical needs and therapies **(Figs. 8&9)**. These results show a clear relationship between surgical outcomes, long-term care challenges, and family concerns, with a significant difference in the experience of families based on the type of surgery and geographic location (rural vs. urban). Families facing ongoing complications such as persistent constipation or multi-stage surgeries expressed higher levels of concern about the long-term management of their child's condition.

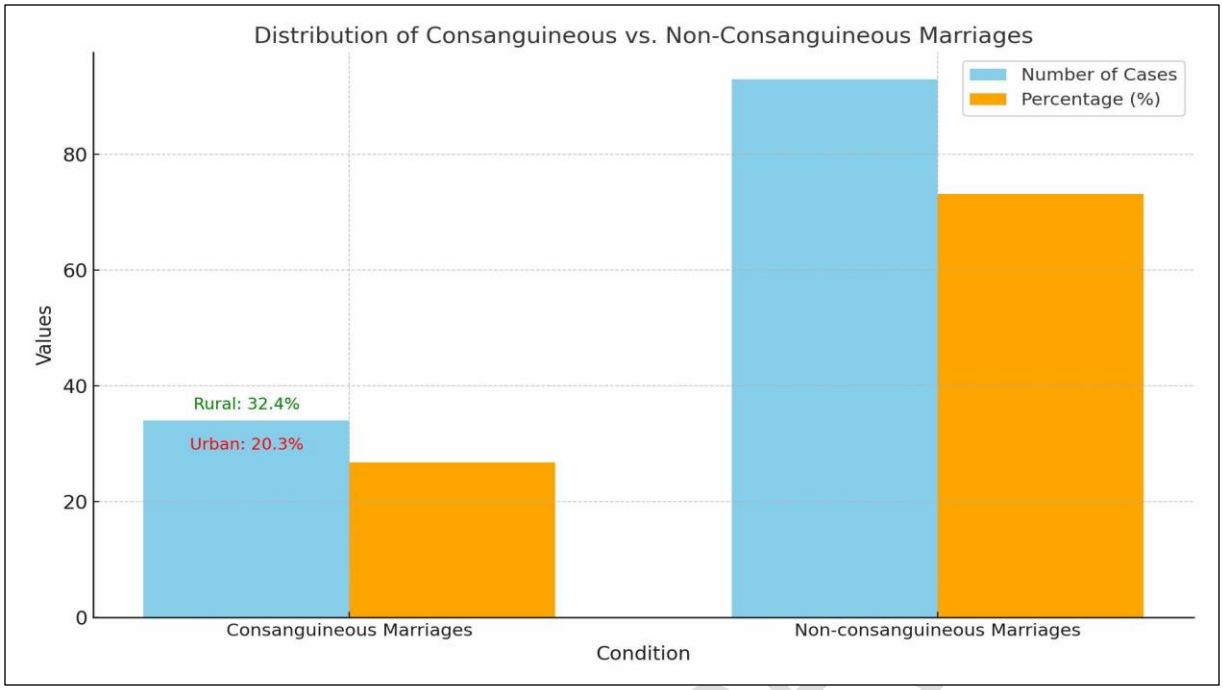

Fig.1. A histogram displaying the number of cases for each category of marriage type. The chart highlights the distribution between consanguineous and non-consanguineous marriages. The chi-square value of 2.34 corresponds to a p-value (based on 1 degree of freedom) of 0.04. The p-value of 0.04 is statistically significant at the 0.05 level. This indicates that there is a significant difference in the prevalence of consanguinity between rural and urban areas in this cohort.

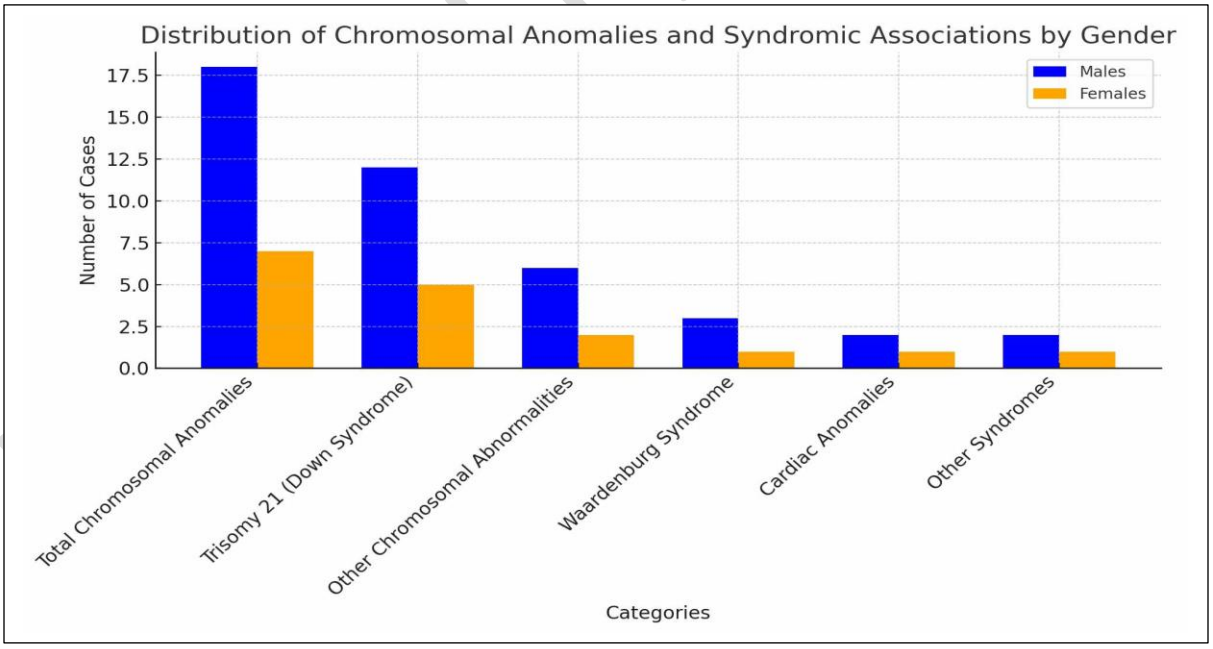

Fig. 2. The histogram illustrates the distribution of chromosomal anomalies and associated syndromes by gender in the cohort study. It highlights comparable proportions of cases between males and females across all categories, with Trisomy 21 being the most common anomaly observed in both sexes.

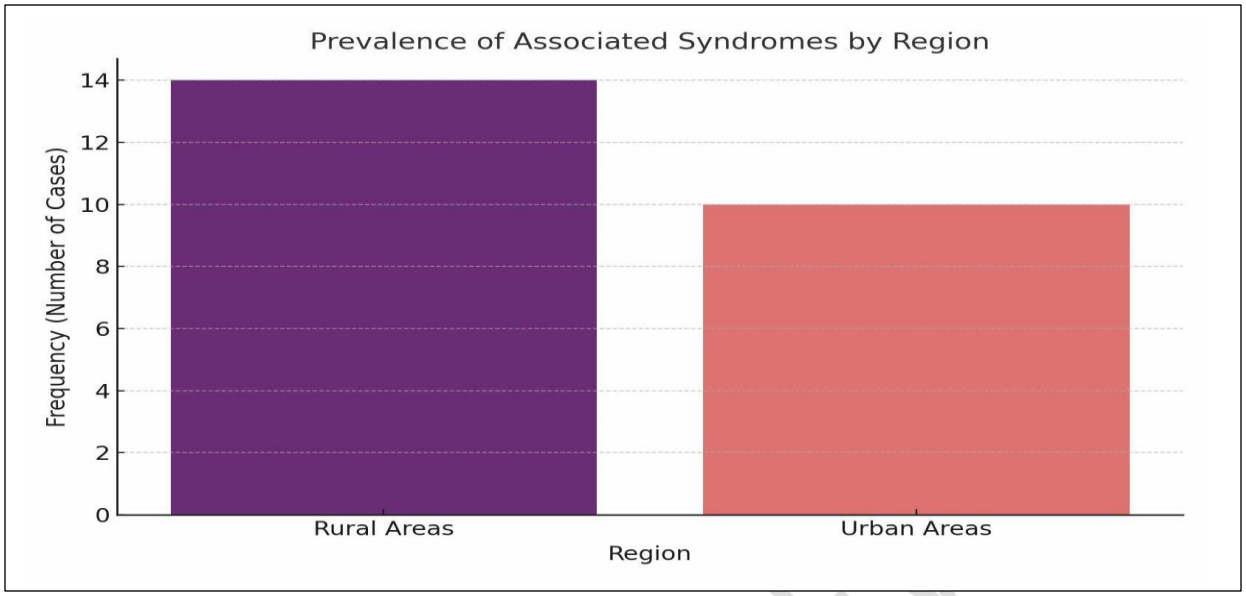

Fig. 3. The histogram visualizing the prevalence of associated syndrome. It highlights the number of cases and percentages, with annotations indicating rural and urban proportions and disparities. Rural Areas: 14 cases (20.6%). Urban Areas: 10 cases (16.9%). The higher prevalence of syndromic associations in rural areas (not statistically significant, p = 0.09).

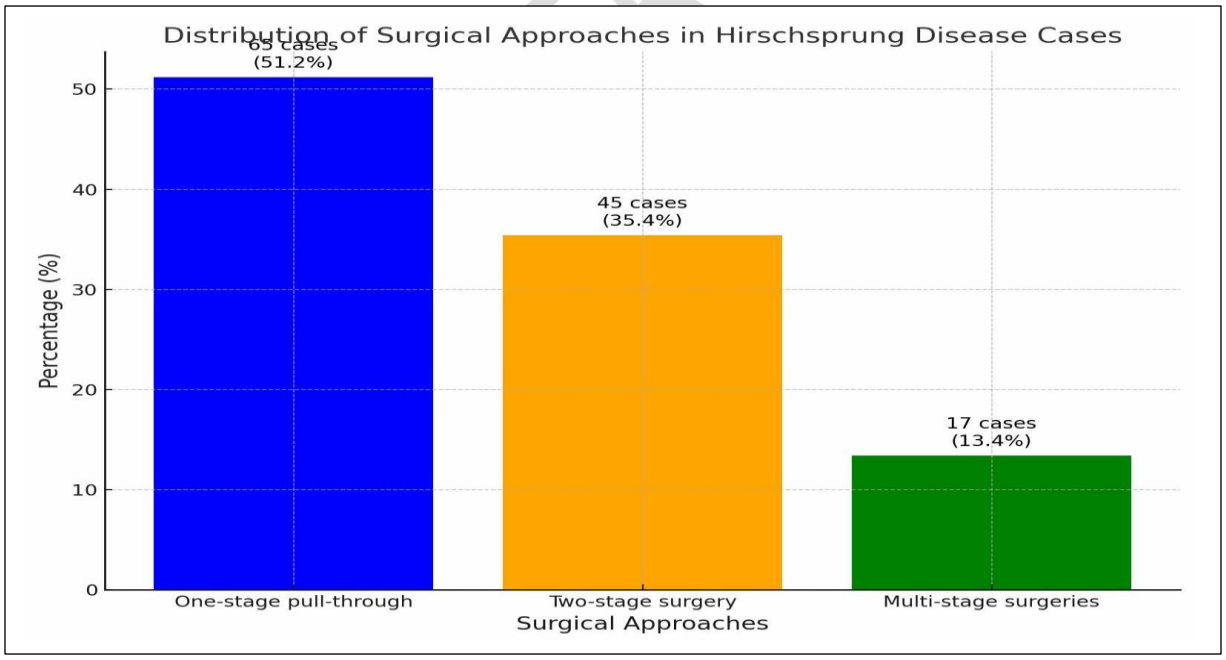

Fig. 4. The histogram visualizes the distribution of surgical approaches in the study cohort. One-stage pull-through procedure, two-stage surgery (colostomy followed by pull-through), and multi-stage surgeries (>2 interventions). This chart highlights the predominance of the one-stage pull-through approach while highlighting the proportion of staged surgeries.

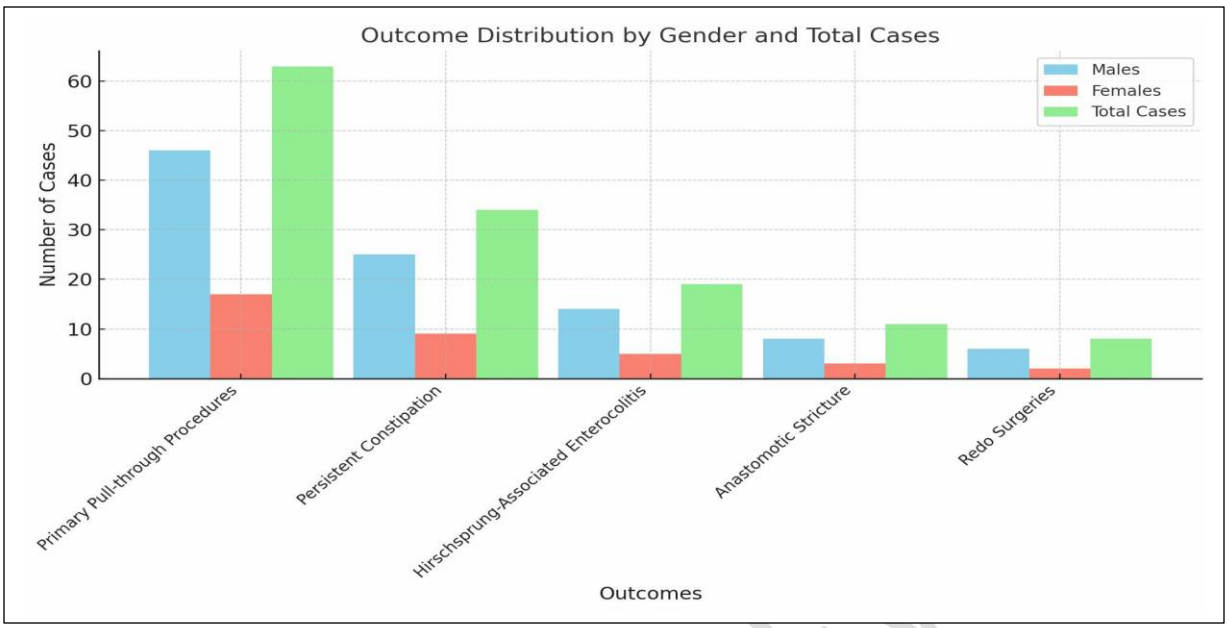

Fig. 5. The histogram illustrating the distribution of outcomes by gender and total cases. Each category shows the total cases, male cases, and female cases for comparison, allowing for a clear visualization of the gender-specific impact across different outcomes.

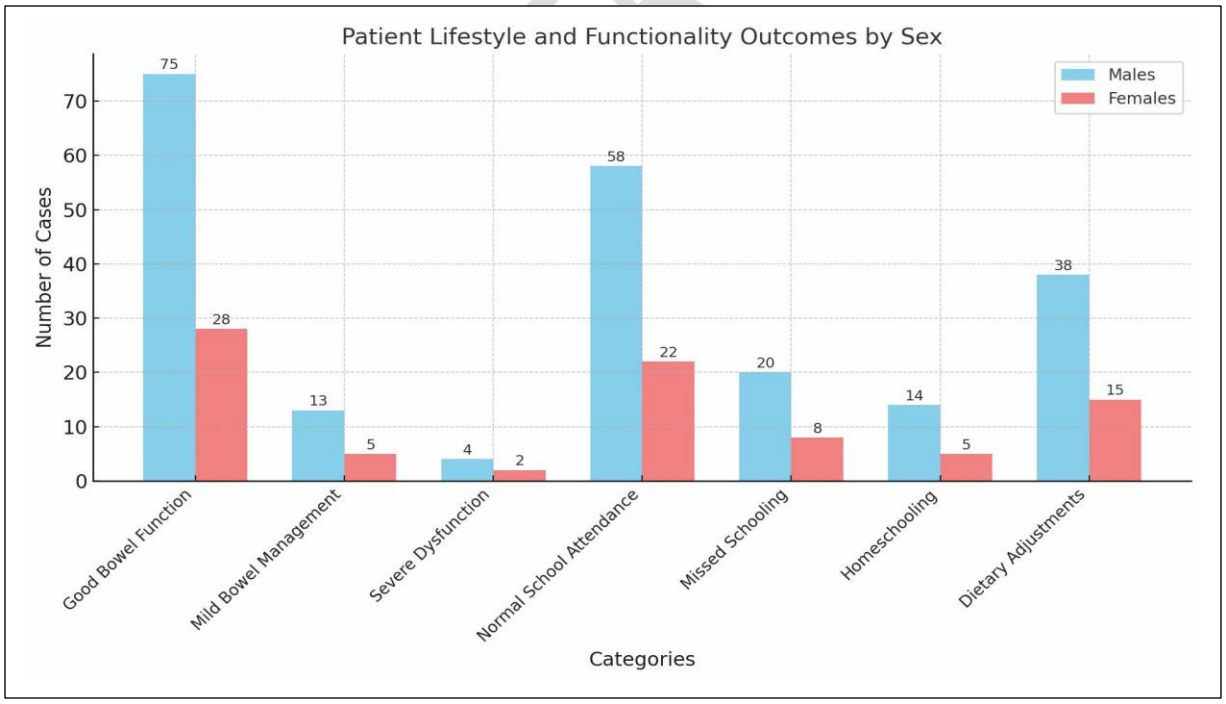

Fig. 6. The histogram illustrating the distribution of outcomes by gender and total cases. Each category shows the total cases, male and female cases for comparison, allowing for a clear visualization of the gender-specific impact across different outcomes.

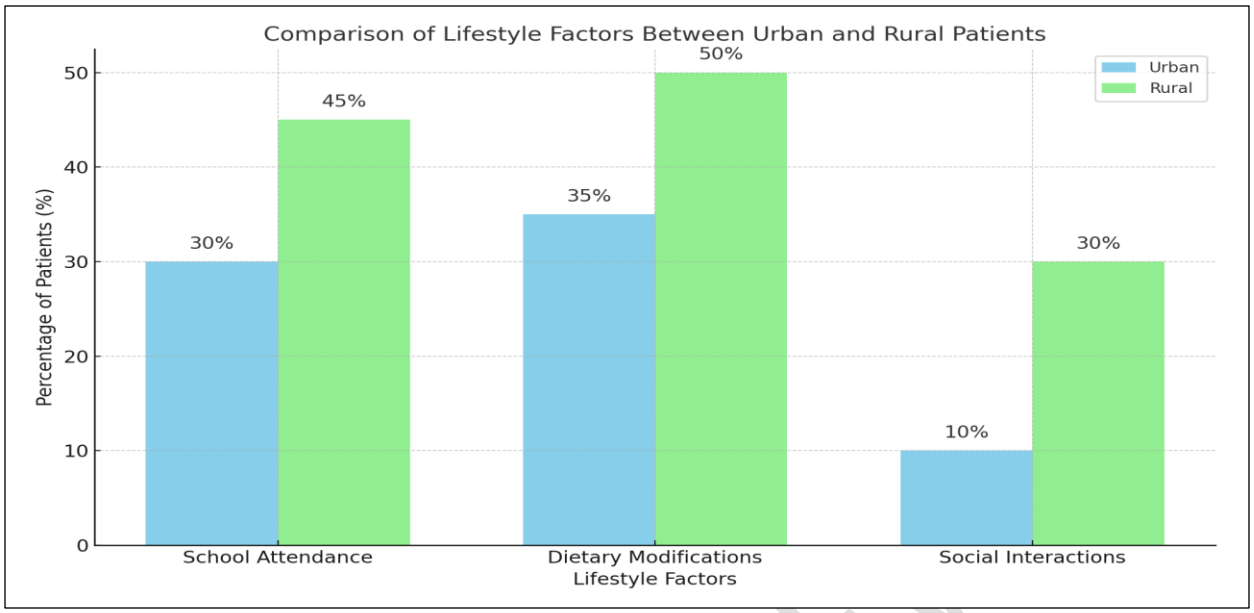

Fig. 7. The histogram compares lifestyle factors (school attendance, dietary modifications, and social interactions) between rural and urban patients who underwent surgery for HD. The key findings include School Attendance: Rural patients had higher absenteeism compared to urban patients. Dietary Modifications: Diets that are more restrictive were required for rural patients compared to urban patients. Social Interactions: Social anxiety was more common in rural patients compared to urban patients. These results highlight the significant lifestyle challenges rural patients face, particularly regarding school attendance, dietary restrictions, and social interactions.

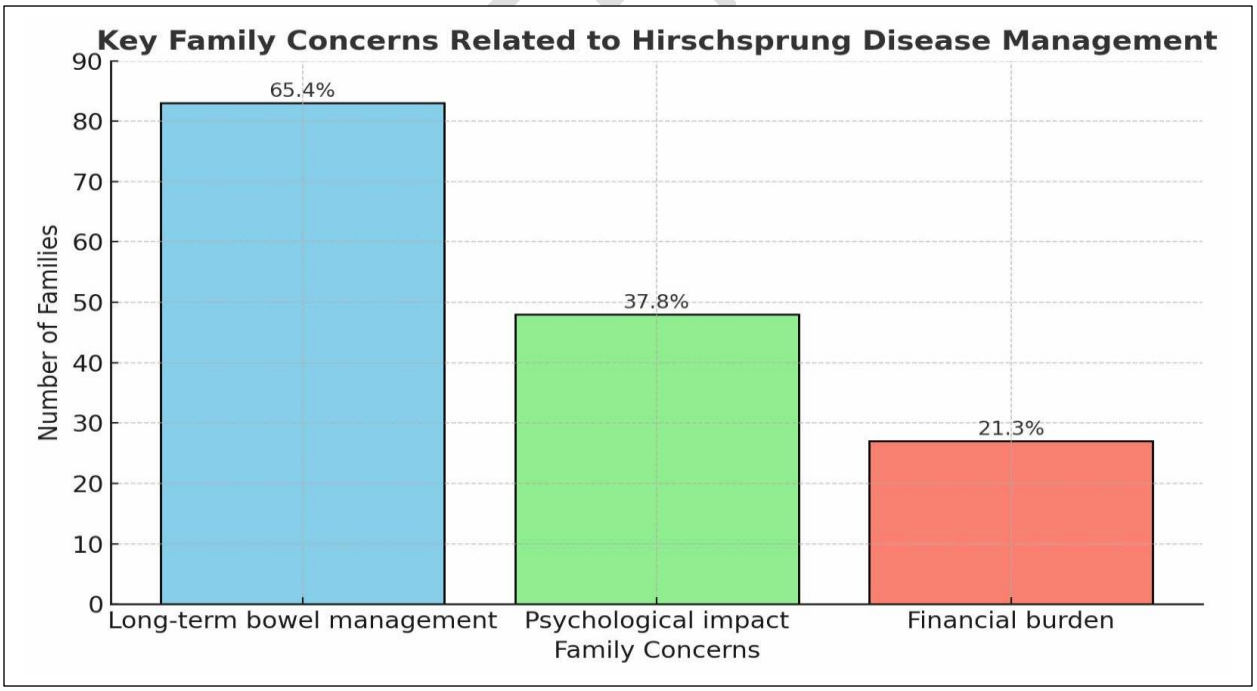

Fig. 8. The histogram above visualizes the primary concerns reported by families of children who underwent surgery for HD disease. It highlights the families who expressed concerns regarding long-term bowel management, were concerned about the psychological impact on their child, and the reported financial strain due to ongoing care needs. This graphical representation provides a clear overview of the prevalence of each concern among families following surgical treatment.

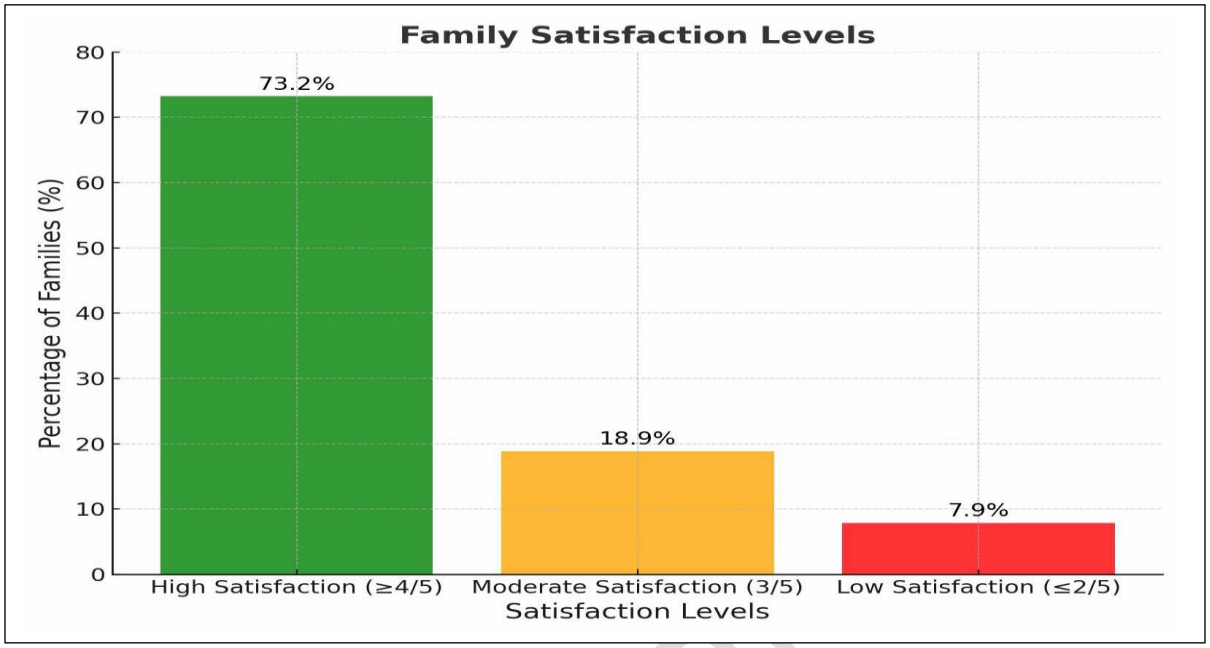

Fig. 9. The histogram illustrates family satisfaction levels regarding surgical outcomes, showing the following distribution: High satisfaction, moderate satisfaction, and low Satisfaction. This distribution highlights that the majority of families were highly satisfied, while a smaller proportion expressed moderate or low satisfaction.

DISCUSSION

This study offers a unique opportunity to examine HD management in a localized context, where societal and cultural factors significantly shape patient outcomes. The findings provide a foundation for developing targeted interventions to address the multifaceted challenges of HD, from surgical complications to psychosocial well-being, and could highlight areas for improvement. The results offer a comprehensive understanding of HD management in a community where males are disproportionately affected (72.4%). This higher prevalence reflects the established male predominance in HD incidence, allowing the data to guide community-specific interventions and resource allocation.

The mean age at surgery was 10.6 months; this aligns with the established practice of diagnosing and intervening early to optimize outcomes. However, delays in diagnosis and treatment remain a concern, especially in communities with limited access to specialized care. Delayed presentation may contribute to complications such as HAEC or the need for more complex surgical interventions. The gender distribution in this study reflects the well-documented male predominance in HD cases. This skewed ratio is consistent with global data, suggesting that our findings are representative of the broader HD population **(6&7)**. However, the smaller proportion of females underscores the importance of maintaining vigilance in diagnosing HD in less-affected populations to avoid delays in treatment.

The findings of this study reveal a significant prevalence of consanguineous marriages among families of patients with HD. This result underscores the impact of cultural and genetic factors on the presentation and risk of HD in our community. Consanguineous unions could increase the likelihood of autosomal recessive genetic disorders, which are known to contribute to conditions like HD. Families reporting consanguineous marriages accounted for over a quarter of the cohort, aligning with global data that link such practices to heightened risks of congenital and syndromic conditions **(8&9)**. This correlation is particularly important in

understanding the prevalence of chromosomal anomalies and syndromes, such as Down syndrome (12.6% in this study), associated with HD in our population **(10)**. The regional analysis highlights a significant disparity in the prevalence of consanguineous marriages between rural and urban populations. In rural areas, this finding reflects the influence of traditional cultural practices, limited genetic diversity, and smaller social circles in rural communities. Urban areas, though showing lower rates of consanguinity, still presented cases, indicating that cultural traditions persist even in more modernized settings. The reduced prevalence in urban settings may be attributed to greater educational opportunities, exposure to diverse social networks, and evolving marriage practices. The higher prevalence of consanguinity in rural areas could explain the increased rates of syndromic associations and more severe presentations of HD observed in these patients. Delayed diagnoses and limited access to specialized healthcare in rural areas may exacerbate these outcomes, further highlighting the need for targeted public health interventions. Genetic counseling and education should be prioritized, particularly in rural areas, to mitigate the risks associated with consanguineous marriages **(8-12)**. Raising awareness about the genetic implications of consanguinity and improving access to healthcare can reduce the burden of HD and similar conditions. The findings in this study reflect deeply rooted sociocultural practices in our community, emphasizing the need for culturally sensitive approaches to public health initiatives. Interventions should address the cultural norms surrounding consanguinity while fostering awareness of its genetic risks.

Down syndrome was the most frequently associated syndrome in this cohort. It is well-documented as one of the most common genetic conditions linked to HD **(10-13)**. These patients typically presented with a higher incidence of extended aganglionic segments and a more complex clinical course. Patients with Waardenburg syndrome presented with aganglionosis as part of the broader spectrum of neural crest cell migration disorders. Some patients presented with features suggestive of syndromic conditions, including congenital heart defects, cleft palate, or limb anomalies, but without a defined genetic diagnosis. The higher prevalence of syndromic associations in rural areas (though not statistically significant) might reflect delays in diagnosis and referral in these regions, potentially allowing more severe or complex cases to present for treatment. Patients with Down syndrome and other syndromes required more frequent staged procedures (two- or multi-stage surgeries) due to comorbidities such as cardiac or respiratory complications that increased surgical risk. Syndromic patients were more likely to develop HAEC in our cohort **(8-13)**. Syndromic patients reported higher rates of persistent constipation, possibly due to associated motility disorders or extended aganglionic segments. Syndromic patients, particularly those with Down syndrome, had a higher mean age at surgery; this delay was attributed to the need for comprehensive preoperative evaluations and management of comorbidities. The association between HD disease and chromosomal anomalies, particularly Down syndrome, highlights the importance of genetic counseling and multidisciplinary care for these patients. In our cohort, the prevalence of Down syndrome aligns with global estimates of 10–15% in HD populations, emphasizing the genetic and developmental underpinnings of the disease. Patients with associated syndromes often face more challenging surgical courses and outcomes due to the complexity of their conditions **(14&15)**. These findings stress the need for early diagnosis and integrated care strategies to improve surgical outcomes and long-term quality of life for this vulnerable subset of patients. Gender distribution of anomalies, the proportional similarity in chromosomal anomalies between males, and females in our study indicates no significant gender-based disparity. This outcome is consistent with the random nature of chromosomal nondisjunction and structural abnormalities **(8, 9&10)**.

The high proportion of primary pull-through surgeries reflects the preference for this approach in patients with early diagnosis, minimal bowel dilation, and no significant preoperative complications such as HAEC **(16)**. The single-stage procedure offers the advantage of reduced hospital stays, fewer interventions, and lower costs. However, it requires careful patient selection and skilled surgical expertise to minimize intraoperative and postoperative complications (**17&18)**. The two-stage approach was the second most common intervention; this method was particularly useful in patients with delayed diagnosis, significant bowel dilation, or severe preoperative enterocolitis **(19)**. The staged nature allowed for bowel decompression via colostomy before the definitive pull-through surgery, potentially reducing the risk of

complications such as anastomotic leaks or HAEC **(20)**. The relatively high proportion of these procedures in our cohort highlights the challenges of late presentation, which is often seen in resource-limited or rural settings. A subset of patients requiring multi-stage surgeries represent cases with complex or severe disease, such as failed initial surgeries, technical difficulties, or recurrent complications like strictures or persistent constipation. These cases underscore the need for multidisciplinary care, advanced surgical expertise, and long-term follow-up to manage the complexities of such interventions.

The study identified several postoperative complications, with persistent constipation being the most common (a significant long-term issue after HD surgery, particularly in cases with incomplete aganglionic segment resection or underlying motility disorders). These rates are comparable to global standards but emphasize the importance of long-term follow-up and management strategies **(21,22&23)**. Persistent Constipation, the high prevalence underscores the need for improved postoperative bowel management protocols, including dietary modifications, medications, and family education. Persistent constipation was significantly associated with the need to redo pull-through surgeries, highlighting its potential impact on patient outcomes. The incidence of HAEC in our study aligns with existing literature, patients with delayed diagnosis, preoperative colostomies, or two-stage procedures were more likely to develop HAEC. Early diagnosis, proactive monitoring, and early intervention strategies and management of HAEC can reduce the need for hospitalizations and additional surgeries **(24&25)**. Anastomotic stricture occurred in 8.7% of cases and was typically managed with dilations. However, in some instances, surgical revision was required. This complication highlights the technical challenges of achieving tension-free anastomoses and proper blood supply during pull-through procedures. Redo pull-through procedures were necessary in 6.3% of cases due to complications such as incomplete resection of the aganglionic segment or anastomotic strictures. These cases represent a significant burden for patients and families, requiring additional hospital stays, financial resources, and emotional resilience. The rate of redo surgeries in our cohort is consistent with reported rates in the literature. Perianal fistulas were the least common complication, these cases required surgical correction but were generally manageable **(26&28)**. Their occurrence may be related to anastomotic issues or recurrent infections. These complications may also reflect delayed presentations or the need for staged procedures in complex cases. The results of this study are particularly significant in the context of our community, where several socioeconomic and healthcare-related factors may influence outcomes: 1. Access to specialized care, delays in diagnosis and treatment, as evidenced by the wide age range at surgery, are likely influenced by limited access to pediatric surgical expertise in rural or underserved areas. Establishing regional centers for early diagnosis and intervention could mitigate this issue. 2. Resource availability, the prevalence of complications such as HAEC and persistent constipation may be exacerbated by limited resources for postoperative care, including dietary support, access to medications, and regular follow-ups. 3. Parental education and support, many complications, including constipation and HAEC, can be managed more effectively with early parental education and access to resources. Community-based programs to educate families about signs, symptoms, and home-based interventions for HD could significantly improve outcomes. 4. Surgical expertise and infrastructure, the high rates of complications requiring staged surgeries or redo procedures underscore the need for specialized surgical training and infrastructure. Expanding access to minimally invasive techniques and standardizing surgical protocols across centers could reduce complication rates.

Comparisons with Global Data The findings in our community are consistent with global trends, particularly in terms of demographic patterns, surgical approaches, and complication rates. However, certain unique features, such as the relatively high proportion of staged procedures and HAEC rates, may reflect the challenges of managing HD in a community posed by geographic and socioeconomic disparities where delayed presentation and limited access to specialized care are common **(29,30&31)**.

School Attendance, the finding that 63% of patients resumed normal school attendance post-surgery is encouraging. However, the significant disparity between rural and urban patients underscores systemic challenges faced by rural families. Frequent school absences in rural patients can be attributed to 1. Geographic barriers, and the distance to healthcare facilities lead to more frequent and prolonged absences for medical visits, postoperative care, or recovery. 2. Limited access to resources, rural families often lack

access to local support systems, including specialized care and educational accommodations. In contrast, urban patients benefit from proximity to medical centers, better infrastructure, and integrated school systems that can accommodate their needs **(31&32)**. This urban-rural gap highlights the need for community-driven solutions, such as telemedicine, mobile healthcare units, or partnerships between schools and medical facilities to minimize disruptions to education for rural patients.

Dietary modifications were necessary for 42% of patients post-surgery, with rural patients disproportionately affected. A significantly higher proportion of rural families reported restrictive diets compared to urban families. This disparity reflects several underlying factors: 1. Limited access to Specialized Foods, rural areas often lack grocery stores or pharmacies that provide high-fiber foods, supplements, or specialized nutrition products. 2. Limited medical advice, rural families may have less access to dietitians or nutritionists who can tailor dietary plans for HD patients. These challenges highlight the need for targeted dietary education programs and resources in rural communities **(20, 28&32)**. Providing rural families with the necessary tools and knowledge to manage their child's condition through affordable and accessible dietary options could improve their quality of life. The disparities observed in this study are a reflection of broader socioeconomic and healthcare inequities in our community. Good bowel function is the most prevalent outcome with only a small subset experiencing severe dysfunction. School attendance disruptions and dietary adjustments reflect similar proportional impacts across sexes, suggesting no significant sex-specific disparities when adjusted for the cohort distribution.

Social Interactions Social anxiety was reported by 19% of patients, with rates significantly higher in those with severe functional deficits, including persistent constipation or redo pull-through surgeries. The factors contributing to social anxiety include: 1. Medical complications, ongoing symptoms, frequent hospital visits, or multiple surgeries may limit children's ability to participate in social activities or school events, leading to feelings of isolation. 2. Peers Stigma, children with HD may experience embarrassment or anxiety about their condition, particularly when bowel issues or dietary restrictions are involved. 3. Rural isolation, rural children face additional challenges due to reduced opportunities for social interaction, compounded by geographical isolation and frequent absences. Social anxiety was also more prevalent in children who underwent multi-stage surgeries or experienced recurrent complications, suggesting that prolonged treatment processes contribute to emotional distress. Providing psychological support, peer counseling programs and awareness campaigns can help mitigate the social and emotional impact on these children. The study's outcomes affected both sexes proportionately to their representation in the cohort. Males, who comprised 72.4% of the cases, were more frequently affected across all categories, aligning with their larger representation. Females, making up 27.6% of the cohort, contributed to a similar percentage of outcomes across complications, school attendance, and dietary adjustments. However, the data suggest no significant sex-specific differences in the rates of complications or lifestyle impacts when adjusted for their respective proportions.

Incorporating a 5-point Likert scale in our study offers a standardized, effective method to assess satisfaction with the management of (HD) by designing the survey frame questions to cover key areas of interest **(5)**. Examples include "How satisfied are you with the overall surgical outcome for your child?" "How effectively has the healthcare team addressed your concerns about long-term bowel management?" "How satisfied are you with the psychological and emotional support provided?" "To what extent do you feel the financial burden of care has been manageable?". Family satisfaction remains a critical metric of healthcare success, with 73.2% of families reporting high satisfaction. However, concerns about long-term bowel management, psychological well-being, and financial burdens indicate areas for improvement **(33&34)**. Although financial concerns were not a majority issue, 21.3% of families reported significant stress related to ongoing medical costs, particularly for those requiring multiple surgeries or long-term medications. These concerns reflect systemic gaps in ongoing support and education for families **(35&36)**. Building community trust requires transparent communication, accessible healthcare teams, and the integration of psychosocial

services **(37)**. Establishing family-centered care models that prioritize mental health support, comprehensive follow-ups, and financial counseling could significantly enhance satisfaction rates.

Limitations

While this study provides significant insights into the outcomes and lifestyle impacts of (HD) in our community, several limitations must be acknowledged. The study's retrospective nature limits the ability to control for confounding variables. The study lacks a control group, making it difficult to evaluate the effectiveness of specific surgical techniques compared to alternative treatments. Data relied on the accuracy and completeness of medical records, which may have introduced selection or reporting bias. The absence of standardized follow-up intervals across cases could have influenced the outcome variability. Baseline patient health and comorbidities were not thoroughly analyzed, which could confound the interpretation of postoperative outcomes. The relatively small cohort of 127 patients, especially the underrepresentation of females (27.6% of the cohort), may limit the generalizability of findings. While the male predominance reflects HD's epidemiology, larger and more balanced samples are needed for robust comparisons and generalizable conclusions. The study was conducted in a single medical center, which may not fully represent broader community healthcare systems or diverse populations. Differences in surgical techniques, postoperative care, and cultural attitudes toward HD in other settings may limit the external validity of the results. Long-term outcomes, such as psychosocial development, adult bowel function, and overall quality of life, were not uniformly documented. The absence of extended follow-up data restricts insights into the lifelong implications of HD and its management. Reporting bias, the data relies on families' self-reporting of consanguinity, which may be subject to inaccuracies. Some families may underreport or fail to disclose consanguineous marriages due to social stigma, cultural norms, or misunderstandings of the study's purpose. Underreporting of syndromes, while Down syndrome and Waardenburg syndrome are noted, other syndromes may have been underreported or misdiagnosed. Incomplete genetic data, not all patients may have undergone comprehensive genetic testing, and honestly was not routinely performed (the reported chromosomal anomalies and syndromes may only represent a fraction of the true prevalence). While the study evaluated school attendance and dietary modifications, more comprehensive data on psychosocial factors, such as mental health and family coping mechanisms, were not available. These factors are critical to understanding the full impact of HD on patients and their families (may overemphasize positive or negative aspects based on recent experiences). The psychological and social data rely solely on family reporting, potentially overlooking the child's firsthand experiences and challenges. While psychosocial impacts were identified, the study does not evaluate the effectiveness of interventions like counseling or peer support programs. The study highlights community-specific factors influencing outcomes, but a detailed exploration of sociocultural dynamics, such as stigma or access to specialized care, was beyond its scope. Variations in access to specialized care, educational resources, or psychological support are not fully explored but could significantly influence family satisfaction and outcomes, these factors likely play a significant role in shaping patient and family experiences.

LESSONS LEARNED

The following insights and recommendations can be drawn from the surgical intervention data on Hirschsprung's disease, which include the types of procedures performed, complications, and their frequency. These lessons can guide future clinical practice, improve patient outcomes, and streamline management strategies:

- Optimizing surgical approach selection and preoperative assessment are keys: Careful preoperative evaluation, including imaging and histopathological assessment, is critical to determine the most appropriate surgical approach.
- Multi-stage surgeries should be tailored: Develop a detailed preoperative protocol for assessing the extent of aganglionosis and other complicating factors (e.g., associated syndromes) to better guide the surgical decision-making process.

- Postoperative complications, persistent constipation: early intervention with stool softeners, and careful monitoring of bowel function after surgery should be prioritized.
- HAEC: Proactive antibiotic therapy, early recognition of symptoms, and patient education regarding signs of infection can help reduce the occurrence and severity of HAEC.
- Stricture and anastomotic issues: Using high-quality surgical techniques, ensuring sufficient blood supply to the anastomotic site, and avoiding tension can help minimize these complications. Implement a standardized protocol for postoperative care that includes regular monitoring for constipation, HAEC, and signs of anastomotic complications. Postoperative follow-up could include contrast studies or rectal biopsies to detect strictures early.
- Redo pull-through surgeries: Continuous education and training in advanced techniques, such as laparoscopic or robotic-assisted surgery, may reduce the need for redo.
- Early identification of failure: Regular postoperative monitoring, including contrast enemas at specific intervals, can help identify problems early and prevent the need for a redo pull-through.
- Complications Prevention: Given the incidence of complications like persistent constipation and HAEC, educating patients and their families is crucial. Provide clear instructions on bowel management strategies, signs of infection, and when to seek medical advice.
- Addressing surgical expectations: Incorporate patient education into the clinical care pathway, especially for families undergoing complex surgeries, to increase their understanding of the surgical process and potential complications.
- Tailored interventions based on regional needs: The data highlights regional variations in surgery types, especially in rural versus urban settings. Understanding local healthcare access, resources, and cultural factors can help tailor surgical strategies and improve patient outcomes.
- Gender and age factors: Further research into sex-based differences in disease presentation and outcomes could inform tailored surgical approaches. Develop region-specific strategies that account for local healthcare infrastructure, access to specialists, and cultural beliefs that may affect both the timing of diagnosis and surgical decision-making.
- Incorporating data for predictive models: detailed data on surgical outcomes and complications can serve as the basis for developing predictive models to guide clinical decision-making. For example, using preoperative markers (e.g., age, gender, comorbidities) in combination with surgical approach data may help predict the likelihood of complications and the need for additional surgeries.
- Improving surgical techniques: Implement a data analytics approach in the clinical setting to track outcomes and refine decision-making processes. Using data to identify trends and risk factors can improve patient care and reduce the incidence of complications.
- Multi-Center Studies: TC further validates the findings and enhances the generalizability of the data, collaboration between multiple centers or countries can provide a more robust dataset. This will help confirm the trends seen in this study and explore variations in surgical outcomes based on different healthcare systems and patient populations.
- Genetic and Syndromic Studies: Collaborate with geneticists, researchers, and other institutions to explore the genetic underpinnings of HD and develop more precise diagnostic and therapeutic strategies based on genetic findings. Given the potential links between consanguinity, chromosomal anomalies, and HD, further research into the genetic basis of HD is warranted. Identifying genetic markers or syndromic associations could guide early diagnosis and treatment strategies.
- Expanding access to dietary counseling, psychological services, and affordable medical supplies will empower families to manage long-term care more effectively.
- Multidisciplinary teams involving surgeons, pediatricians, psychologists, and educators can provide comprehensive care that addresses both medical and lifestyle challenges.
- Continuous quality improvement (CQI) programs use structured family feedback to identify gaps in care delivery and implement targeted interventions. Regularly audit outcomes and satisfaction scores to ensure sustained improvement.

- Care coordination services, introduce case managers who can guide families through the treatment process, assist with scheduling appointments, and serve as contact points for concerns.
- Develop a national registry for HD cases to track patient outcomes, identify trends, and refine treatment protocols. Key metrics should include patient-reported outcomes and family satisfaction surveys.

By integrating these lessons into clinical practice, healthcare providers can improve both the surgical outcomes and long-term management of HD, leading to better patient care and family satisfaction.

While this study confirms positive outcomes for most patients, its findings also highlight critical areas where improvement is needed to enhance both patient and family satisfaction. The data reveal no significant sex-specific disparities in outcomes, suggesting equitable care delivery. However, the broader impact on lifestyle, education, and psychosocial well-being calls for targeted interventions to ensure all patients and families can achieve optimal quality of life. By addressing these gaps through community-focused strategies, healthcare providers can transform these insights into actionable improvements, fostering trust and improving outcomes in our community.

ETHICAL CONSENT

The research protocol was reviewed and approved by the Institutional Review Board (IRB) of the Ministry of Health -The Maternity and Child Teaching Hospital. All patients or their legal guardians provided written informed consent before inclusion in the study. Pediatric consent was obtained from their parents or legal guardians, ensuring that they were adequately informed about the study's objectives. Patient confidentiality was maintained throughout the study by anonymizing all data and using secure systems for data storage and analysis. No identifying information was used in the publication of results. By adhering to these ethical standards, we aimed to ensure the integrity of our research study and the rights and welfare of the participants involved.

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