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EXPLORING THE COPING MECHANISMS OF FAMILIES WITH PATIENTS DIAGNOSED WITH HIRSCHSPRUNG'S DISEASE: A COMPREHENSIVE ANALYSIS

A Master Thesis

Presented to

the Faculty of Graduate School of

SBLC

In Partial Fulfillment

of the Requirements for the Degree

Master of Arts in Nursing

LORAINE LLANTO-BRUSOLA, RN

APPROVAL SHEET

In Partial fulfillment of the requirements for the Master of Arts in Nursing, this thesis entitled "**Exploring the Coping Mechanisms of Families with Patients Diagnosed with Hirschprung's Disease: A Comprehensive Analysis**" was prepared and submitted by **Loraine Llanto Brusola, RN**, and is hereby recommended for _____ defense.

Jovencio M. Milan Jr., RM, RN, MAN, PHDNEd

Adviser

Joseph A. Tanagan, Ph.D

Course Facilitator

Approved as partial fulfillment of the requirements for the

BACCALAUREATE DEGREE IN NURSING by the

ORAL EXAMINATION COMMITTEE

Chairman

_____ _____

Member Member

Approved and accepted in partial fulfillment of the requirements for the _____ ___ degree.

John Flores, RN, MAN, Ph.D©

Dean, SBLC Graduate School

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LLB

CERTIFICATE OF ORIGINALITY

I hereby certify that this research paper entitled "**EXPLORING THE COPING MECHANISMS OF FAMILIES WITH PATIENTS DIAGNOSED WITH HIRSCHSPRUNG'S DISEASE: A COMPREHENSIVE ANALYSIS**" is entirely an original work and does not contain any previously published material or written work by another person, nor any material that has been substantially accepted for any degree or diploma in SBLC or other educational institutions unless I have given due acknowledgment in the thesis. Any contribution made to the research by others, with whom I have worked at SBLC or elsewhere, is explicitly acknowledged in the thesis.

_____

Loraine Llanto-Brusola, RN

Author's Name and Signature

Attested by:

_____

Jovencio M. Milan Jr., RM, RN, MAN, PHDNEd

Research Adviser

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This is to certify that I have edited this thesis manuscript entitled:

EXPLORING THE COPING MECHANISMS OF FAMILIES WITH PATIENTS DIAGNOSED WITH HIRSCHSPRUNG'S DISEASE: A COMPREHENSIVE ANALYSIS

Prepared by:

LORAINE L. BRUSOLA

and have found it thorough and acceptable with respect to grammar and composition.

JOANNA J. REYES

Signature over Printed Name

Bee-Verb Proofreading Services

Affiliation

09088190394/beeverbs@gmail.com

Contact Number / E-mail

April 20, 2024

Date

STATISTICIAN'S CERTIFICATION

This is to certify that the research instrument and data gathered for the Capstone Project entitled, "*Exploring the Coping Mechanisms of Families with Patients Diagnosed with Hirschsprung's Disease: A Comprehensive Analysis*" has been thematically reviewed and analyzed using QDA Qualitative Software and SPSS.

The undersigned declared that this certification issued on April 2, 2024, as requested by the researcher is valid and done by the undertaker for whatever purpose/s it may serve the proponent.



Annie C. Pama

ABSTRACT

This study explored the coping strategies of families with patients diagnosed with Hirschsprung's Disease. Interviews were conducted with two participants who shared their coping strategies, struggles, and experiences in caring for their child with the disease. The data collected from the interviews were organized into themes, including challenges faced by families, coping strategies, navigation of the healthcare system, social support, and finding meaning and purpose in caring for a child with Hirschsprung's Disease. The findings shed light on the impact of the disease on families, including their understanding of the condition, effects on daily routines, emotional well-being, and quality of life.

The study highlighted the importance of providing families with comprehensive information and education to help them comprehend the challenges associated with the disease. It also emphasized the need for support and resources to assist families in navigating challenges, especially during times of crisis. The study revealed disruptions and challenges in managing care and the financial burden imposed by the disease, underscoring the importance of practical support and resources. The emotional well-being and quality of life of families were significantly affected, emphasizing the need for comprehensive support, including counseling and mental health resources.

The study also highlighted challenges in accessing appropriate healthcare facilities and understanding necessary care practices, emphasizing the importance of accessible and affordable healthcare services and educational resources. The level of support and resources available to families varied, highlighting the need for accessible and approachable healthcare professionals who can offer emotional support and guidance. Overall, the findings underscore the importance of providing families with comprehensive support, education, and resources to improve their understanding, daily routines, emotional well-being, and ability to navigate medical care and access support networks.

Keywords: *Challenges, Coping Strategies, Hirschsprung's Disease*

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CHAPTER I

INTRODUCTION

Background of the Study

Hirschsprung's disease is a congenital disorder characterized by the absence of ganglion cells in the distal part of the colon, resulting in functional obstruction. The condition requires surgical intervention, and affected individuals often face long-term challenges related to bowel function and overall quality of life. However, it is not only the patients who are affected; their families also experience significant emotional, psychological, and social burdens as they navigate the complexities of caring for a child with Hirschsprung's disease (Tilghman et al., 2019).

Managing a sickness may be a daunting and demanding ordeal, affecting both the body and emotions. Sick persons might build approaches to coping to manage challenges and sustain well-being. Coping mechanisms are methods and skills used by individuals to handle stress, keep a good attitude, and improve their quality of life while dealing with a sickness. Constructing a robust support system is a crucial coping tool (Ambartsumyan et al., 2020). Engaging with family, friends, and support groups may offer a feeling of inclusion, empathy, and motivation. Benefiting from shared experiences, asking guidance, and obtaining emotional support from those who have encountered similar issues may be quite advantageous. Professional assistance from healthcare experts, therapists, or

counselors can provide direction and aid individuals in developing successful coping techniques (Kroeber, 2023).

Another essential coping strategy is embracing a positive mentality. Having a positive and optimistic attitude may greatly influence how well someone deals with a sickness. Utilizing positive self-talk, expressing appreciation, and staying mindful can enhance individuals' strength and resilience (McKinley et al., 2020). Embracing the truth of the illness while staying optimistic might allow people to confront obstacles directly and maximize their situation.

Participating in self-care activities is crucial for managing a condition. Emphasizing physical, emotional, and mental well-being can enhance overall resilience. This may involve engaging in regular physical activity, following a well-rounded diet, ensuring adequate sleep, and utilizing relaxation methods like meditation or deep breathing exercises (Kroeber, 2023). Participating in hobbies, exploring creative activities, and deriving happiness from tiny joys can offer a necessary feeling of routine and satisfaction.

Learning about the condition and how to manage it, is a helpful coping mechanism. Comprehending the disease, available treatments, and possible adverse effects might enable patients to engage effectively in their healthcare choices. Being knowledgeable allows individuals to successfully engage with healthcare professionals, ask pertinent questions, and make educated decisions regarding their treatment and care (McKinley et al., 2020).

Thus, it is essential to seek expert assistance for mental health support. Having a sickness can result in emotional anguish, anxiety, and sadness. Seeking guidance from mental health specialists may provide individuals with the essential tools and methods to

regulate their emotional well-being (Vijaywargiya, 2021). Cognitive-behavioral therapy (CBT) and mindfulness-based stress reduction (MBSR) can assist individuals in acquiring coping mechanisms, handling stress, and enhancing their mental well-being.

Coping techniques are crucial in assisting individuals in dealing with the problems of living with a sickness. Establishing a support system, cultivating a positive mentality, practicing self-care, pursuing education, and obtaining professional assistance are crucial methods for fostering resilience and well-being. By utilizing these coping strategies, people may improve their quality of life, efficiently handle their illness, and discover resilience and optimism in challenging situations (Kroeber, 2023).

In the Philippines, there is a lack of comprehensive research on the coping mechanisms employed by families with patients diagnosed with Hirschsprung's disease. Understanding the coping strategies utilized by these families is crucial for healthcare professionals to provide appropriate support and interventions that address their unique needs (Montalya et al., 2023).

The Filipino culture places a strong emphasis on family and community support. However, the impact of cultural factors on coping mechanisms in the context of Hirschsprung's disease remains largely unexplored (Langer & Levitt, 2020). Cultural beliefs, values, and practices may influence how families perceive and respond to the challenges associated with the condition. Therefore, it is essential to investigate the role of cultural factors in shaping coping strategies among Filipino families.

Furthermore, the availability and effectiveness of support systems for families with Hirschsprung's disease in the Philippines require examination. Identifying gaps in existing

support networks, such as healthcare provider guidance, community resources, and support groups, can inform the development of targeted interventions and services that address the specific needs of these families (Concepcion, 2022).

Meanwhile, the long-term coping strategies employed by families caring for patients with Hirschsprung's disease in the Philippines have not been extensively studied. Understanding how coping mechanisms evolve over time can provide insights into the challenges faced by families at different stages of their journey. This knowledge can guide healthcare professionals in providing ongoing support and interventions that promote resilience and well-being.

Lastly, the mental health impact on families caring for patients with Hirschsprung's disease in the Philippines also remains an underexplored area. The emotional and psychological toll of managing a chronic condition can significantly impact caregivers' mental well-being. Identifying potential risk factors and understanding the mental health needs of these families can inform the development of targeted interventions and support services.

By addressing these research gaps, people can gain a comprehensive understanding of the coping mechanisms employed by families with patients having Hirschsprung's disease in the Philippines. This knowledge will contribute to the development of culturally sensitive and tailored support interventions that enhance the overall well-being of both patients and their families. Ultimately, the findings of this study have the potential to improve patient outcomes and promote a higher quality of life for families affected by Hirschsprung's disease in the Philippines.

Review of Related Literature

Hirschsprung's Disease

Congenital megacolon, or Hirschsprung's disease, occurs when migrating cells fail to reach the colon during gestation. Functional colonic obstruction is characterized by the inability of certain segments of the distal colon to relax. Hirschsprung's disease most commonly affects the rectosigmoid region of the colon, although it can also affect the whole colon and, rarely, the small intestine. While most individuals with this ailment often suffer from constipation throughout childhood, others may develop severe constipation at a later stage in life (Thakkar & Curry, 2020).

Symptoms that newborns may suffer include feeding difficulties, constipation, delayed weight gain, and stomach distention. Early diagnosis is essential to prevent complications like enterocolitis or colonic rupture. A rectal suction biopsy can confirm the diagnosis by identifying hypertrophic nerve trunks and the absence of ganglion cells in intestinal submucosa. Enterocolitis is a significant cause of mortality associated with Hirschsprung's disease, affecting up to one third of patients (Puri & Nakamura, 2019).

Patients who have had surgery for Hirschsprung's disease should be closely monitored for enterocolitis for an extended period. With proper treatment, most patients will not have any adverse long-term consequences and can live a typical life. 1 in 5,000 newborns is born with Hirschsprung's disease (Harwood et al., 2022). If ganglion cells fail to migrate beyond the neural crest during the fourth to twelfth weeks of gestation, causing a deficiency of ganglion cells in the colon or a portion of it, it results in the condition. Inadequate

relaxation of various segments of the distal colon causes a gradual functional obstruction of the colon.

The aganglionic segment usually begins close to the anus and expands towards the posterior. Short-segment colon disease typically occurs in the rectosigmoid region. When this region is impacted, the entire colon may be susceptible to long-segment disease. Occurrence of the large and small intestines involvement is rare (Höllwarth & Grosfeld, 2019). Early detection is essential to avert complications, as most patients present in infancy. Many individuals can have typical adult lives with appropriate therapy.

Hirschsprung's disease can be hereditary or occur spontaneously; it has several probable causes. It impacts guys more frequently than girls. In the general community, short-segment sickness affects around 3% to 5% of male siblings and 1% of female siblings of children with the condition. Siblings of children with total colonic involvement face a much-increased risk, ranging from 12.4 to 33 percent (Jensen & Frischer, 2022).

While Hirschsprung's disease is generally not considered hereditary, eight specific genomes have been associated with the ailment. Investigation of the RET proto-oncogene on chromosome 10q11.2.2 is now under progress. This gene is associated with Hirschsprung's disease, a type IIA endocrine neoplasia characterized by thyroid medullary carcinoma and adrenal tumors (Matsufuji, 2019). Research on the effectiveness of this mutation screening for type IIA multiple endocrine neoplasia is ongoing.

Potential side effects of Hirschsprung's disease include abnormalities in the brain system, heart, kidneys, and intestines. Down syndrome (trisomy 21) is the most common chromosomal defect associated with the illness, occurring in around 10% of cases. Other

diseases linked to Hirschsprung's disease include congenital deafness, hydrocephalus, diverticulum of the bladder, imperforate anus, ventricular septal defect, renal agenesis, cryptorchidism, psychosis, neuroblastomas, and Ondine's curse (Ambartsumyan et al., 2020).

Treatment and Diagnosis for Hirschsprung's Disease

Imaging can assist in diagnosing Hirschsprung's disease. An ordinary abdominal radiograph can detect an enlarged small bowel or proximal colon. Colon radiographs with contrast enema often do not reveal any abnormalities during the first three months of life and remain normal in situations with full colonic disease (Taylor et al., 2020). During the dilatation operation, the larger, more proximal colon will become visible, while the unhealthy part of the colon will appear normal. Contrast enema radiographs can reveal a "*transition zone*" when normal intestine transitions into ganglionic tissue, however in around 10% of instances, the ganglionic colon extends beyond this point (Taylor et al., 2020).

Anal manometry can be used to demonstrate that the internal anal sphincter does not relax when the rectum is distended. Contrast enema and anal manometry have similar levels of specificity and sensitivity (Jensen & Frischer, 2022). A rectal suction biopsy can confirm the diagnosis by identifying thicker nerve trunks and the absence of ganglion cells. While patients are often sent to a pediatric surgeon or gastroenterologist for a biopsy, family doctors should have a good understanding of the procedure to evaluate the operation's effectiveness and choose the most suitable treatment plan. The biopsy site should be positioned 1.5 cm (0.6 in) above the dentate line due to the usual absence of ganglion cells in the distal rectum.

One reason to consider a full-thickness biopsy might be the lack of swollen nerve trunks (Granström et al., 2021).

Surgery is usually required for those diagnosed with Hirschsprung's disease. Doctors should possess a thorough understanding of standard procedures to effectively interact with the patient's family and the surgeon (Benzamin et al., 2020). Rectal irrigations are administered to prevent enterocolitis and alleviate bowel constriction prior to surgery. The definitive ileoanal pull-through anastomosis can be performed in healthy newborns with short-segment Hirschsprung's disease and intact colons. A temporary colostomy may be performed to aid in the recovery of a child suffering from Hirschsprung's-associated enterocolitis or a significantly dilated colon. The pull-through procedure is typically performed four to six months following the colostomy placement. The complication rate for different pull-through techniques varies between 4% and 16% (Kapur et al., 2020).

Swenson's treatment involves the removal of the rectum and the connection of the healthy ganglionated colon to the anus. Recent treatments like the Duhamel or Soave surgeries are utilized to safeguard the intricate nerve supply to the bladder and rectum. The patient's parents can execute the necessary dilations of the anastomosis at home for several months after the Soave treatment to avoid the development of strictures. All these therapies are characterized by little morbidity and great success rates (Ostertag-Hill et al., 2024).

Some surgeons do a one-stage transanal Soave surgery on infants with short-segment disease to prevent abdominal incisions and colostomies. Despite similar complication rates to the more invasive Soave treatment, outcome studies of this approach have been limited by short follow-up periods (Pan et al., 2022).

Hirschsprung's Disease in the Philippines

Hirschsprung disease, also known as congenital aganglionic megacolon, is a condition that affects the colon and large intestines and is extremely rare. It is a dangerous condition that can have significant consequences. Since certain regions of the colon do not contain sufficient nerve cells, it results in difficulties with bowel movements. Even though the condition is extremely uncommon, people who are affected by it and their families are confronted with significant challenges in the Philippines (Lopez et al., 2020).

Those who are afflicted with Hirschsprung's disease in the Philippines have several challenges, the most notable of which being the general public's lack of awareness of the condition. Due to the rarity of the condition, a significant number of medical workers may be inexperienced with it (Deogracias et al., 2019), which may result in unnecessary delays or errors in diagnosis. It is possible that this will lead patients and their families to experience unwarranted distress and possibly repercussions if it is not addressed promptly.

In addition, persons who suffer from Hirschsprung's disease in the Philippines face a significant challenge in gaining access to professional medical care (Villanueva et al., 2021). In certain healthcare facilities, particularly those located in more remote or rural areas, it may be difficult to acquire the expertise and equipment required to provide an accurate diagnosis and offer the appropriate treatment. Therefore, people who are affected may be forced to face emotionally and financially draining excursions to major cities to receive medical treatment. This may result in a lack of choices for those affected (Akhter, 2020).

Additionally, Villanueva et al. (2021) emphasized that the exorbitant cost of Hirschsprung's disease treatment and surgical treatments may be an impediment that is

insurmountable for a great number of Filipino families. The expenses associated with diagnosis, surgery, and long-term management may be overwhelming for those who have fewer financial resources at their disposal. Because of this, those who are affected by the illness could not obtain treatment in a timely manner or might receive insufficient care, both of which could be detrimental to their health.

The Philippines has achieved progress in the fight against Hirschsprung's disease, despite the challenges that have been presented. To enhancing people's comprehension of the condition, a public education campaign has been initiated, with the target audience consisting of healthcare practitioners, parents, and the general community (Estrada et al., 2020). The dissemination of information, as well as the improvement of early detection and management of the illness, have been accomplished through the implementation of educational initiatives, medical conferences, and seminars. People who suffer from Hirschsprung's disease today have easier access to expert care, which is largely attributable to the collaboration between healthcare providers and organizations about healthcare (Garber et al., 2019).

Patients who live in more remote areas now have easier access to medical professionals because of telemedicine programs (Hall & Wright, 2021). These programs enable physicians and other medical professionals to consult with patients remotely. In addition, several organizations that are not-for-profit and support groups have emerged to aid individuals who are in need, both financially and emotionally, and to lobby on their behalf.

In conclusion, families and individuals in the Philippines experience significant challenges because of Hirschsprung's Disease. These challenges include a lack of understanding about the illness, difficulties in accessing medical treatment from specialists, and financial constraints. Despite this, there has been progress made in terms of increasing access to healthcare, drawing more attention to the problem, and providing help to those who have been positively affected. In the Philippines (Moreno et al., 2021), continual educational programs, collaborations, and lobbying are very important to enhance the care that is provided to people who are living with Hirschsprung's disease and the outcomes that they experience. Experts will be able to make progress toward improved healthcare and a greater quality of living for individuals who are afflicted with this condition if they are successful in overcoming these challenges.

Coping Mechanisms: Problem-Focused and Emotion-Focused

Chronic disease is common in modern developed nations. Several infectious diseases such as tuberculosis, pneumonia, and influenza, which were formerly deadly, are now treatable and some have been eradicated due to medical progress. Enhanced resistance of people to diseases such as cancer, cardiovascular disease, stroke, and diabetes has resulted in a rise in the impact of these illnesses on society (Cong et al., 2021). Individuals in the middle-aged and older demographics are significantly more impacted by chronic illnesses, leading to a severe decline in their quality of life due to the substantial difficulties they face in adapting and managing these conditions.

Most people with chronic diseases can expect to have a lengthy quality of life despite the risk of deaths connected with their condition. An emerging area in healthcare is

researching and enhancing strategies for managing chronic health problems. Functional loss issues frequently arise during the initial phases of psychological adaptation to a diagnosis of a chronic illness (Nakahara, 2020). Upon receiving a diagnosis, individuals come to terms with the reality that their health and physical capabilities have changed and are likely to remain impaired. The speed at which individuals experience this loss can be significantly influenced by the nature of the illness. It is typical for individuals to only realize they have a chronic condition like heart disease after experiencing a heart attack. (Nakahara, 2020).

Coping mechanisms are practices individuals employ to mitigate the effects of stressful situations and navigate challenging periods. An individual's coping strategies can be categorized as either problem-focused or emotion-focused. To apply problem-focused methodologies, one must initially pinpoint the issue and then strive to create feasible solutions. By employing this approach (Ogoma, 2020), one may go into the root of the issue and begin rectifying it from inside. Understanding the situation completely is the initial stage in this coping strategy. Individuals employing this coping strategy assess their environment, identify the core issue, and subsequently break it down into smaller, manageable components. An individual's capacity to formulate a targeted approach relies on their understanding of the situation.

After identifying the problem, the following phase in issue-focused coping is to generate potential solutions through brainstorming. Activities like brainstorming, seeking advice, and conducting research on relevant subjects can all be considered part of this group. To discover a solution, one must explore all possible possibilities and alternatives (Crowe & Van Puymbroeck, 2019).

Individuals using problem-focused coping mechanisms generate solutions and evaluate them based on their feasibility, effectiveness, and potential outcomes. They contemplate their possessions, potential outcomes, and the probability of success (Mujahidah & Astuti, 2019). By completing this examination, individuals may select the optimal and most feasible choice.

Individuals that utilize problem-focused coping techniques implement the remedies they have chosen. The chosen solution is implemented, its progress is monitored, and adjustments are made as necessary. Active participation in problem-solving enables individuals to grasp the situation and advance towards a solution (Siddiqui & Soomro, 2019).

When individuals can influence the progression or result of a problem to some degree, problem-focused coping strategies are much more effective. They utilize it when faced with challenges in their professional life, academic pursuits, or personal relationships. Individuals can enhance their sense of action and reduce feelings of impotence by focusing on seeking solutions.

While problem-focused coping is beneficial (Zhang et al., 2019), it is important to keep in mind that no obstacle is impossible to overcome. Integrating issue-focused coping with emotion-focused coping, which involves managing emotional distress related to the circumstance, may be essential in some cases. Engaging in social support, mindfulness, or relaxation techniques are emotion-focused coping strategies that can aid in managing stress and enhancing emotional wellness.

In conclusion, problem-focused coping is a successful approach for individuals to address and conquer obstacles. Individuals may regain a sense of control and move towards

effective solutions by recognizing the problem, generating potential solutions, evaluating options, and taking actions (Pawson, 2020). Although certain problems may remain unsolved, employing problem-focused coping strategies can enhance individuals' independence, resilience, and determination in overcoming challenges.

On the other hand, Lim et al. (2019) defined emotion-focused coping as recognizing and embracing one's emotional condition. Individuals employing this coping approach strive to identify and understand their emotions to effectively regulate them in difficult times. Self-awareness is crucial for managing and regulating ones' emotions.

Validating and accepting one's emotions is crucial in emotion-focused coping once they have been recognized. Individuals acknowledge that their emotions are valid and justified given the circumstances, instead than attempting to suppress or disregard them. With this level of comprehension (Georgeta, 2019), individuals may effectively manage their emotions in a constructive manner. Seeking assistance from others is another aspect of emotion-focused coping. Individuals that possess the ability to listen, show empathy, and provide guidance might be a friend, family member, or mental health professional. During challenging circumstances, confiding in reliable individuals may provide insight, validate emotions, and offer support (Caga et al., 2021).

Another crucial aspect of emotion-focused coping involves engaging in self-care activities. Enhanced emotional regulation is achieved by those who give precedence to their physical, mental, and emotional well-being. Engaging in physical activity, practicing mindfulness, pursuing hobbies, or acquiring relaxation techniques are all examples of activities that fit into this category (Van den Brande et al., 2020). Engaging in these activities

can help individuals relax and achieve a sense of balance, ultimately promoting self-soothing.

Cognitive reframing is one of the several techniques employed to manage strong emotions. This involves deliberately replacing unrealistic or negative beliefs with more acceptable and positive alternatives. Individuals can alter their perspective and reduce the emotional burden of a problem or stressor by reevaluating their thoughts (Akhrina & Febriani, 2020).

Emotion-focused coping mostly emphasizes regulating emotions, yet problem-solving remains a significant component of it. Individuals may need to utilize both emotion-focused and problem-focused coping skills to effectively manage a circumstance (Cong et al., 2021; Ogoma, 2020; Pawson, 2020). Emotional regulation enhances individuals' ability for logical thinking and reasonable problem-solving. Emotion-focused coping is an effective method for individuals to regulate and handle their emotions during challenging or stressful situations. Enhancing emotional well-being and resilience may be achieved through self-awareness, self-acceptance, seeking assistance, self-care, cognitive reframing, and problem-focused coping mechanisms. Managing stressful events by directing attention to one's emotions enhances emotional and mental well-being.

Synthesis of the Study

This study aims to determine the coping mechanisms of families with patients diagnosed with Hirschsprung's Disease. As such, the researcher gathered relevant studies conducted in the past to discuss the prevalence of the disease and series of actions undertaken by the stakeholders. The researcher divided the literature review according to their relevant

themes, namely: *Hirschsprung's Disease*, *Treatment and Diagnosis for Hirschsprung's Disease*, *Hirschsprung's Disease in the Philippines*, and *Coping Mechanisms: Problem-Focused and Emotion-Focused*.

In the context of coping mechanisms of families with patients having Hirschsprung's disease in the Philippines, there are several existing research gaps that can be explored. First, there is a scarcity of research specifically focused on the coping mechanisms of families with patients diagnosed with Hirschsprung's disease in the Philippines. This gap highlights the need for more comprehensive studies to understand the unique challenges faced by Filipino families in coping with this condition.

Moreover, the influence of cultural factors on coping mechanisms is an area that requires further exploration. Understanding how cultural beliefs, values, and practices impact coping strategies can provide valuable insights into tailoring support and interventions for Filipino families. Further, research gaps exist in examining the availability and effectiveness of support systems for families with Hirschsprung's disease in the Philippines. Exploring the role of healthcare providers, community resources, and support groups can shed light on the gaps and potential areas for improvement.

Thus, there is a need to investigate the long-term coping strategies employed by families as they navigate the challenges associated with Hirschsprung's disease. Understanding how coping mechanisms evolve over time can inform healthcare professionals in providing ongoing support and interventions. Notwithstanding that, limited research has been conducted on the mental health impact on families caring for patients with Hirschsprung's disease in the Philippines. Exploring the psychological well-being of

caregivers and identifying potential risk factors can contribute to the development of targeted interventions and support services.

Addressing these research gaps can enhance our understanding of the coping mechanisms employed by families with patients having Hirschsprung's disease in the Philippines. This knowledge can inform healthcare professionals in providing tailored support, improving patient outcomes, and enhancing the overall well-being of families.

Philosophical Underpinning

Individuals with Hirschsprung's Disease might benefit greatly from the insights offered by existentialism (Allen, 2020), which provides a philosophical foundation, when it comes to coping techniques. When dealing with a long-term health condition, it might be helpful to adopt a philosophical stance that places an emphasis on the autonomy, responsibility, and meaning making of the person.

According to existentialist theory, people with Hirschsprung's Disease have special difficulties and restrictions because of their illness. Nevertheless, it stresses that people still have agency over how they react to and think about their situations, even with these constraints. Taking an active part in coping with disease and finding meaning in one's experiences is encouraged from this approach (Simpson et al., 2019). Individuals with Hirschsprung's Disease might find solace in the idea of authenticity, which is central to existentialism. Authenticity, according to existentialists, is paramount, and this means accepting and being true to one's own identity and the world as it is. Accepting the sickness for what it is, naming the feelings it causes, and discovering methods to adapt and live a full

life despite the obstacles are all parts of being authentic when dealing with a chronic illness (Wang et al., 2019).

Individual accountability is emphasized by existentialist thought as well. By trying to find support, information, and treatment alternatives that can enhance their quality of life, individuals with Hirschsprung's Disease can take charge of their own health (. Doing things for oneself, reaching out to friends and family for emotional support, and taking an active role in one's own healthcare decisions are all ways to achieve this goal.

Finding one's life's true calling is also a central tenet of existentialism (Sartre, 2020). A person's identity and values might be influenced by their experiences with Hirschsprung's disease. They get the opportunity to think back on what they have learned, how they have grown as individuals, and how their experiences have added value to their lives (Van Dung, 2020). The existentialist perspective does not downplay the severity of the problems experienced by people with Hirschsprung's disease. Rather, it lays forth a conceptual framework that empowers people to face these difficulties head-on, knowing that they can choose how they respond. It encourages people to persevere through tough times by reflecting on their principles and finding purpose in life. Ultimately, existentialism's philosophical foundations can shed light on effective coping strategies for those living with Hirschsprung's Disease. Individuals are encouraged to actively participate in their coping process, discover significance in their experiences, and live honestly despite the obstacles presented by their condition through the principles of existentialism, which emphasize human freedom, responsibility, authenticity, and the search for meaning.

Conceptual Framework

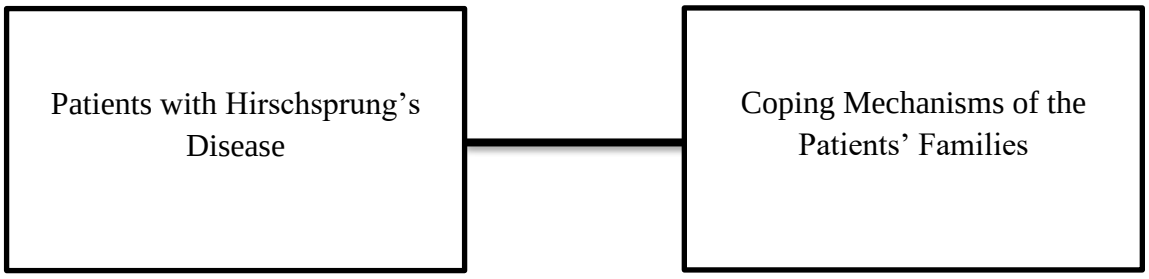


Figure 1. *Conceptual Paradigm*

The figure above shows the conceptual paradigm of the study. Patients with Hirschsprung's Disease serve as the independent variable, while coping mechanisms of the patients' families will serve as the dependent variable.

In this study, the researcher seeks to deepen the understanding of the coping mechanisms employed by families with patients having Hirschsprung's disease in the Philippines. This will contribute to the existing knowledge base and provide a comprehensive understanding of the challenges faced by these families.

By identifying the specific coping strategies utilized by Filipino families, the project aims to inform the development of tailored support interventions. This outcome will enable healthcare professionals and support networks to provide targeted assistance that addresses the unique needs of these families. Moreover, by identifying gaps and challenges in the current system, the project can inform the development of guidelines, protocols, and training programs that enhance the quality of care provided to these families.

Theoretical Framework

Richard Lazarus and Susan Folkman's Transactional Model of Stress and Coping (Gieselmann et al., 2020) provides a useful theoretical framework for analyzing how people with Hirschsprung's disease deal with stressful situations. This model explains in detail how people deal with difficult circumstances, including dealing with a chronic sickness.

The Transactional Model states that coping is an interactive process between the person and their surroundings. It postulates that people use cognitive assessment, in which they weigh the pros and cons of a given circumstance and the means at their disposal to deal with it. Individuals' coping techniques are impacted by this assessment process (Sharma & Gupta, 2023).

Two forms of cognitive evaluation may be used by people with Hirschsprung's disease: *primary* appraisal and *secondary* appraisal. Assessing the impact of the disease on their life is an important part of primary care. Part of this process may involve looking at how the illness has affected their physical health, ability to go about their everyday lives, and general happiness (Gao et al., 2021).

The accessible resources and coping mechanisms for managing the condition are assessed in a secondary manner. Evaluations of social support, healthcare availability, and coping abilities may be part of this process. Many coping mechanisms are available to people with Hirschsprung's Disease, depending on the evaluation procedure.

Two main types of coping strategies are identified by the Transactional Model: dealing with problems and coping with emotions. Some examples of problem-focused coping strategies include getting medical help, sticking to a treatment plan, or taking care of

oneself to alleviate symptoms (Vos & van Rijn, 2021). However, seeking social support, practicing relaxation methods, accepting one's disease as it is, and reframing one's perspective in a positive light are all examples of emotion-focused coping strategies.

Both internal (such as one's character, values, and experiences) and external (such as one's social network, cultural standards, and access to medical treatment) elements impact coping, according to the Transactional Model (Sharifabad et al., 2020).

Every one of these factors can affect how people who have Hirschsprung's disease cope with the challenges that they face daily, as well as how well the solutions they employ are implemented. Through the utilization of the Transactional Model of Stress and Coping, researchers and medical practitioners can get a deeper understanding of the experiences and responses of individuals who are afflicted with Hirschsprung's illness. By utilizing this approach, it is possible to build therapies and support networks that will assist those who are coping with this chronic disease in a more effective manner, feel better, and have an overall improved quality of life.

Statement of the Problem

This study aims explore on the coping mechanisms employed by families with patients having Hirschsprung's disease in the Philippines. The output of the study will be used to establish interventions and action plans to support the families of the patients.

Specifically, the researcher seeks to answer the following questions:

1. How do families with patients diagnosed with Hirschsprung's Disease perceive and understand the challenges associated with the illness?

2. What coping strategies do families employ to manage the emotional and practical aspects of caring for a child with Hirschsprung's Disease?
3. How do families navigate the healthcare system and access necessary resources to support their child with Hirschsprung's Disease?
4. What role does social support play in the coping process for families with patients diagnosed with Hirschsprung's Disease?
5. How do families find meaning and purpose in their experiences of caring for a child with Hirschsprung's Disease, and how does this contribute to their coping mechanisms?

Assumptions of the Study

In this study, the following assumptions are presented:

1. Families with patients diagnosed with Hirschsprung's Disease employ a variety of coping mechanisms to manage the challenges associated with the illness.
2. Social support plays a significant role in the coping process of families with patients diagnosed with Hirschsprung's Disease, providing emotional, practical, and informational support to help them navigate the complexities of the illness.

Significance of the Study

The findings of the research on coping mechanisms of families with patients diagnosed with Hirschsprung's Disease might offer various advantages to different parties:

Patients and their Families. The study's results can provide a thorough insight into the coping strategies used by families dealing with Hirschsprung's Disease. Empowering

patients and their families with knowledge can offer a variety of coping skills to handle the emotional, practical, and social challenges of living with the disease. It can also help individuals feel validated and understood, decreasing feelings of loneliness, and fostering a sense of community.

Nurses. Nurses are essential in providing treatment and assistance to patients with Hirschsprung's Disease. The study's results can improve nurses' comprehension of the coping strategies used by families, allowing them to offer more focused and efficient assistance. Nurses may use this knowledge to customize their treatments, deliver suitable education, and provide emotional support to families, thereby enhancing the overall quality of care.

University. The study's findings can offer useful insights to universities in comprehending the distinctive obstacles encountered by patients with Hirschsprung's Disease and their families. This understanding can assist universities in creating suitable support systems.

Future Researchers. Future researchers may use the study's thorough examination of coping techniques in families affected by Hirschsprung's Disease as a basis for further research in the subject. It can stimulate more research on certain coping methods, their efficacy, and the lasting results for patients and their families. This can aid in creating evidence-based therapies and support programs to improve the well-being and quality of life for persons with Hirschsprung's Disease and their families.

Scope and Limitation of the Study

Families dealing with patients' diagnosis of Hirschsprung's Disease are the focus of this qualitative research. The study's overarching goal is to offer a thorough evaluation of the numerous coping mechanisms by which families do with the difficulties brought on by the disease. To collect comprehensive data on families' coping mechanisms, it will include in-depth interviews and participant observation with a wide variety of families.

The study's overarching goal is to shed light on these families' real-life experiences by developing a knowledge of the social, practical, and emotional components of coping. Contrarily, the researcher will address the study's weaknesses. The results may not apply to all families dealing with a Hirschsprung's disease diagnosis because this research is qualitative in nature. To generalize about coping techniques in all families with this illness may be challenging due to the sample size and selection methodology. Not to mention that the researcher's interpretations and self-reported data are the study's further limitations. Researcher's own biases and the participants' subjective experiences might impact the results. In addition, people may be prone to recall bias when giving retrospective recollections or may struggle to remember certain coping mechanisms. The acquired data might not be as accurate or dependable because of this.

However, the study will mainly look at how families cope and will not get into the larger contextual elements to which the researcher will only explore on the culture, socioeconomic status, or the healthcare system that impact coping mechanisms. Participants' privacy and confidentiality will be protected, and the study will follow all applicable ethical standards. Nevertheless, participants may still be hesitant to disclose too much personal information owing to the delicate nature of the subject.

Definition of Terms

To further understand the scope of the study, the researcher defined the following words operationally:

Coping Mechanism - these refer to practices an individual employs to mitigate the effects of stressful situations and navigate challenging periods.

Emotion-Focused Coping Mechanism - a type of coping mechanism that involves recognizing and embracing one's emotional condition. Individuals employing this coping approach strive to identify and understand their emotions to effectively regulate them in difficult times.

Existentialism - this refers to a philosophical stance that places an emphasis on the autonomy, responsibility, and meaning making of the person.

Hirschsprung Disease - a congenital disorder characterized by the absence of ganglion cells in the distal part of the colon, resulting in functional obstruction.

Problem-Focused Coping Mechanism - a type of coping mechanism wherein an individual must initially pinpoint the issue and then strive to create feasible solutions.

Transactional Model of Stress and Coping – this model explains in detail how people deal with difficult circumstances, including dealing with a chronic sickness. The Transactional Model states that coping is an interactive process between the person and their surroundings.

CHAPTER II

METHODOLOGY

This chapter presents the step-by-step process to be undertaken by the researcher to answer the questions posed in the study. Specifically, this chapter discusses the research design, research site, sample and sampling design, research instrument, data gathering procedure, data analysis, and ethical considerations to be followed.

Research Design

This study uses a phenomenological approach for the qualitative setting. Phenomenology is a study technique that aims to describe the fundamental nature of a thing by examining it through the eyes of those who have encountered it. Phenomenology aims to emphasize on the significance of an experience by detailing both the content and the way it was experienced (Malinay, 2020). Thus, the researcher will utilize transcendental phenomenology to analyze the coping mechanisms employed by the families of the patients diagnosed with Hirschsprung's Disease.

Transcendental phenomenology is a type of phenomenological study that examines the fundamental characteristics of the social environment from the perspective of the individuals involved. It aims to steer clear any preconceptions, biases, and scientific hypotheses that might alter the genuine significance of the firsthand experience (Malinay, 2020). It posits that experience, memory, and sensation are transcendental occurrences, originating from something that has surpassed its material nature.

Research Site

This study will be conducted at Our Lady of Peace Hospital in Paranaque City. This private hospital is funded by charitable organizations to support the patients with Hirschsprung's Disease and other chronic illnesses. Further, Our Lady of Peace Hospital (OLPH) in Parañaque is a healthcare facility in the Philippines that provides comprehensive medical services, including care for patients with Hirschsprung disease. OLPH is committed to delivering high-quality healthcare and ensuring the well-being of its patients.

In terms of helping patients with Hirschsprung disease, OLPH offers a range of services and interventions:

1. **Diagnosis and Assessment**: OLPH has a team of skilled healthcare professionals who specialize in diagnosing and assessing Hirschsprung disease. They utilize various diagnostic tools, such as rectal biopsies and contrast enemas, to accurately diagnose the condition and determine the extent of the affected area.

2. **Surgical Interventions**: OLPH has experienced surgeons who perform the necessary surgical procedures for patients with Hirschsprung disease. These procedures typically involve removing the affected portion of the colon and creating a new connection between the healthy colon and the anus (pull-through procedure). The surgical team at OLPH ensures that patients receive appropriate preoperative preparation, surgical intervention, and postoperative care.

3. **Postoperative Care**: OLPH provides comprehensive postoperative care for patients with Hirschsprung disease. This includes monitoring vital signs, managing pain, and ensuring proper wound care. The nursing staff at OLPH closely monitors the patient's

bowel function and passage of stool, providing necessary support and interventions as needed.

4. **Nutritional Support**: OLPH recognizes the importance of proper nutrition in the management of Hirschsprung disease. The hospital has a team of dietitians who work closely with patients and their families to develop appropriate feeding plans and ensure optimal nutrition. They provide education on proper nutrition and feeding techniques to support the patient's overall health and well-being.

5. **Patient and Family Education**: OLPH places great emphasis on patient and family education. The healthcare professionals at OLPH provide comprehensive education to patients and their families about Hirschsprung disease, its management, and potential complications. They ensure that families are well-informed about proper bowel management, signs and symptoms of complications, and strategies for coping with the challenges associated with the condition.

6. **Emotional Support**: OLPH recognizes the emotional impact that caring for a child with Hirschsprung disease can have on families. The hospital provides emotional support to both patients and their families, offering counseling services and connecting them with support groups or resources for additional support. This helps families cope with the challenges they may face and find the necessary emotional support during their healthcare journey.

Overall, Our Lady of Peace Hospital in Parañaque provides comprehensive care and support for patients with Hirschsprung disease. Through their skilled healthcare

professionals, specialized services, and patient-centered approach, OLPH aims to improve the quality of life for individuals and families affected by this condition.

In line with this, the researcher will seek permission to the administration of the hospital to gather pertinent data and conduct interviews among the families of the patients with Hirschsprung's Disease.

Sample and Sampling Design

The selected families of the patients with Hirschsprung's Disease will be gathered and selected using purposive sampling. Purposive sampling is a non-probability sampling strategy commonly used in research. This sampling involves deliberately selecting individuals or groups based on certain characteristics or criteria that align with the study's goals, as opposed to random sampling which chooses participants at random from a population.

Further, purposive sampling allows researchers to select individuals or groups with certain characteristics or knowledge relevant to the study topic. This sampling technique is particularly advantageous for studying a particular group or enlisting individuals with unique experiences or expertise (Campbell et al., 2020). Researchers can get precise and focused data by intentionally selecting persons who can provide pertinent viewpoints.

Purposive sampling is beneficial because of its effectiveness. Researchers can optimize time and resources by selectively targeting individuals with the necessary features or characteristics. This targeted approach ensures that the sample effectively reflects the specific population being studied, hence improving the relevance and application of the research results. Moreover, researchers may choose the participants based on their expertise

or distinctive perspectives. This flexibility allows for a diverse range of participants, enhancing and intensifying the collected data. Purposive sampling enables researchers to study several subgroups within a community, resulting in a comprehensive understanding of the research topic (Andrade, 2021).

Using this technique, the researcher will set an inclusion and exclusion criteria to set qualifications for the selection of the participants. Thus, the following criteria must be met:

Inclusion Criteria

- A resident in NCR
- Male or female
- 18 years old and above
- With a child or family member diagnosed with Hirschsprung's Disease

Participants who fail to meet any of the set criteria will be automatically excluded from participating in the interview process of the study.

Research Instrument

The researcher will construct a semi-structured interview questionnaire for the participants, which will be patterned to the research questions in this study. A semi-structured interview questionnaire designed for research is an important tool in qualitative research for gathering in-depth information from participants. The design seeks to guide the interview process while allowing participants to share their perspectives and experiences. It provides a framework of open-ended questions that may be tailored to each participant's responses, as opposed to a structured questionnaire that has fixed response options. This

approach enhances the interview by fostering a conversational and engaging atmosphere, leading to a deeper understanding of the research topic (Adeoye-Olatunde & Olenik, 2021).

Moreover, a semi-structured interview questionnaire designed for research purposes encourages active involvement and collaboration from participants. Participants feel empowered to share their perspectives and engage in the study process. The participatory nature of the interview fosters a calm and open setting (Ruslin et al., 2021), which improves trust and rapport between the researcher and participant. Collaborating in this manner can lead to more authentic and meaningful responses, enhancing the quality of the collected data.

Ensuring Trustworthiness

Ensuring trustworthiness is crucial in qualitative research to demonstrate the legitimacy and dependability of the findings. Trustworthiness pertains to the reliability, dependability, and validity of the research method and results. To investigate coping mechanisms of families with patients diagnosed with Hirschsprung's Disease, several measures will be used to improve trustworthiness.

Credibility is a crucial component of trustworthiness. Thus, the researcher must prove that their findings authentically represent the participants' experiences and viewpoints to gain credibility. This will be accomplished through methods like extended engagement, in which the researcher will invest ample time with individuals to establish rapport and get a profound comprehension of their coping strategies. The researcher will establish trust and credibility by deeply engaging with the participants' life, which helps ensure the authenticity and representativeness of the acquired data.

Member checking is a practice that boosts credibility. Therefore, the researcher will solicit feedback and confirmation of their interpretations by engaging individuals in the study process. Participants can evaluate the findings to confirm that their perspectives are appropriately portrayed. Member checking enhances research credibility and empowers participants by granting them ownership and control over their narratives.

Reliability is another essential component of trustworthiness. The researcher will then maintain consistency, transparency, and thorough documentation throughout their study process. This is accomplished by providing thorough documentation of research techniques, including data gathering methods, coding processes, and analytical judgments. The researcher will establish the reliability of their study through an audit, enabling openness and reproducibility.

Confirmability is a crucial factor in establishing credibility. It pertains to the impartiality and neutrality of the research process. Thus, the researcher will recognize their biases and preconceptions and work to reduce their impact on the results. Moreover, transferability refers to the degree to which the results of the study may be generalized to different settings or groups. Therefore, the researcher will include comprehensive and complete accounts of the research setting, participants, and data collection techniques to improve transferability. This will enable readers to evaluate how relevant the findings are to their specific situations.

Ultimately, it is essential to establish credibility in studies investigating coping mechanisms of families with patients diagnosed with Hirschsprung's Disease to provide dependable and significant results. The researcher will generate trust in their study method

and outputs by using measures to improve credibility, reliability, confirmability, and transferability. This gives to a better understanding of coping mechanisms in families dealing with Hirschsprung's Disease and helps in creating efficient support systems and therapies.

Data Gathering Procedure

Various procedures will be implemented to gather the necessary information for the study. The researcher will first seek permission from the school and hospital administration to conduct an interview with the families of patients who are diagnosed with Hirschsprung's Disease. The questionnaire will undergo external and content validity as it is created by the researcher. Consultation with experts will be conducted to validate the study instrument. After validation and confirmation of reliability, a real interview will be given to the selected participants that have met the qualifications for the data gathering, once consent is received from the hospital administration. The researcher will encode the questionnaire and disseminate it as needed.

Participants will get instructions to read before answering the questionnaire, along with a consent letter stating that participation is voluntary, and their thoughts are valued. Afterward, the results will be gathered and tallied, and participants will be informed about the significance, aim, and impact of the research, which aimed to explore on the coping mechanisms of the families of the patients diagnosed with Hirschsprung's Disease.

Data Analysis Procedure

Since this study is qualitative, thematic analysis will be utilized to analyze participants' responses on their coping mechanisms. Thematic analysis is a widely used qualitative research method that involves identifying, analyzing, and interpreting patterns or

themes within a dataset. This is a systematic approach for organizing and analyzing qualitative data, such as interview transcripts, focus group discussions, or written documents.

This analysis involves several steps, including familiarizing oneself with the data, establishing initial codes, recognizing themes, assessing, and refining themes, and eventually, constructing a coherent and valuable analysis (Kiger & Varpio, 2020). This approach allows researchers to uncover hidden meanings, patterns, and connections in the data, providing valuable insights into the research topic. Thematic analysis is a versatile method that offers flexibility and adjustment for tackling complex research challenges and generating in-depth qualitative results. The interview replies will be transcribed and analyzed using qualitative data analysis software by the researcher with the help of a statistician to identify key themes and detailed subthemes for the study. The researcher will assess the facts with the help of a review of pertinent literature, studies, and the theoretical framework.

Ethical Consideration

There will be no physical, psychological, economic, or legal hazards that will be involved in the study because the researcher will only carry out the procedures that are necessary to meet the study's goals. The researcher will also take full advantage of the participants' willingness to participate, and they will not be exploited, coerced, or manipulated in any manner during the research process. There will be no personal or financial conflicts of interest in the study that could have jeopardized the study's findings. After completing the interview process, the participants will not be compensated in any way by the researcher. Finally, the researcher will ensure that the gathered data and the treatment for analysis are accurate and authentic.

CHAPTER III

PRESENTATION, ANALYSIS, AND INTERPRETATION OF RESULTS

This chapter presents the analysis and interpretation of the results of the data gathered from the interview conducted among the parents and guardians of the patients with Hirschsprung's Disease.

Demographic Information of the Participants

In line with this, the purpose of this study was to determine the coping mechanisms of families with patients diagnosed with Hirschsprung's Disease. As such, the researcher gathered relevant data through the conducted interviews among the parents/guardians of the patients with Hirschsprung Disease.

Due to time constraints and ethical considerations to be followed, the participants of the study were limited to two (2) cases in total. These were determined based on their willingness to participate in the study and talk about their coping mechanisms, struggles, and overall experiences prior to caring for their child with Hirschsprung Disease. The researcher distributed the interview questionnaires among the parents and collated the generated data according to their relevant themes. The tables below present the narratives of the patients, following the themes generated to answer the research questions posed in this study.

Specifically, the researcher patterned the themes according to the research questions of the study, namely: (1) Perception and Understanding the Challenges Encountered by the Families of Patients Diagnosed with Hirschsprung's Disease; (2) Coping strategies to Manage the Emotional Practical Aspects of Caring for a Child with Hirschsprung's Disease;

(3) Families' Navigation of the Healthcare System and Access to Necessary Resources to Support the Patient; (4) Social Support's Role in the Coping Process for Families with Patients Diagnosed with Hirschsprung's Disease, and (5) Finding Meaning and Purpose in Caring for a Child with Hirschsprung's Disease.

Table 1. Profile of the Participants

Participant	Case of their Child	Final Diagnosis	Status
Participant 1	Hirschsprung's Disease	Hirschsprung's Disease with a history of anoplasty, redo posterior sagittal anorectoplasty (PSARP) with transverse loop colostomy, and closure of the colostomy	Currently Admitted
Participant 2	Hirschsprung's Disease	Hirschsprung's Disease slated to exploratory laparotomy to evaluate the state of the colon and ascertain the possible necessity of a pull-through treatment	Currently Admitted

Table 1 shows the profile of the patients according to their case, final diagnosis, and status. According to the data, **Parent 1** has a child with a case of imperforate anus, with a history of anoplasty, redo posterior sagittal anorectoplasty (PSARP) with transverse loop colostomy, and closure of the colostomy. Currently, the patient is admitted at Our Lady of Peace Hospital at Paranaque City, with all this information recorded as February 11, 2024.

The case involves a patient with Hirschsprung disease who underwent two surgical procedures. The first procedure was a posterior sagittal anorectoplasty (PSARP) performed

on August 5, 2023. PSARP is a surgical technique used to correct anorectal malformations, including imperforate anus. The second procedure, performed on November 22, 2023, involved the excision of a mucosal prolapse. Mucosal prolapse refers to the protrusion of the inner lining of the rectum through the anus.

Additionally, the patient's case indicates that they have Hirschsprung disease and are scheduled for an exploratory laparotomy with a possible pull-through procedure. An exploratory laparotomy is a surgical procedure that involves making an incision in the abdomen to visually inspect the abdominal organs and identify any abnormalities. In the context of Hirschsprung disease, an exploratory laparotomy may be performed to assess the extent of the affected area and determine the feasibility of a pull-through procedure.

A pull-through procedure is a surgical intervention commonly used to treat Hirschsprung disease. It involves removing the affected portion of the colon and creating a new connection between the healthy colon and the anus. This procedure aims to restore normal bowel function and alleviate the symptoms associated with Hirschsprung disease.

Overall, the case involves a patient with Hirschsprung disease who has undergone previous surgical interventions (PSARP and excision of mucosal prolapse) and is now scheduled for an exploratory laparotomy with a possible pull-through procedure.

Meanwhile, **Parent 2** has a child with Hirschsprung's Disease and is also currently admitted at Our Lady of Peace Hospital in Paranaque City, with the date of admission recorded as April 5, 2024, at 8:17 AM. The situation pertains to a patient diagnosed with Hirschsprung disease who is slated to have an exploratory laparotomy, which may be followed by a pull-through surgery. An exploratory laparotomy is a surgical technique where

an incision is made in the belly to visually examine the abdominal organs and detect any abnormalities. In the setting of Hirschsprung disease, an exploratory laparotomy may be conducted to evaluate the scope of the afflicted region and ascertain the viability of a pull-through procedure.

A pull-through operation is a frequently employed surgical surgery for the treatment of Hirschsprung disease. The procedure entails excising the impacted segment of the colon and establishing a fresh link between the intact colon and the anus. The objective of this surgery is to reinstate regular bowel function and reduce the symptoms linked to Hirschsprung disease.

The patient's exploratory laparotomy will enable the surgical team to assess the state of the colon and ascertain the suitability of a pull-through procedure. The choice to proceed with the pull-through technique will be based on the results of the exploratory laparotomy and the patient's overall health and suitability for surgery. In summary, the case pertains to a patient diagnosed with Hirschsprung disease who is slated to have an exploratory laparotomy to evaluate the state of the colon and ascertain the possible necessity of a pull-through treatment. The objective of this surgical procedure is to enhance the patient's gastrointestinal function and reduce the symptoms related to Hirschsprung disease. The information provided is limited and may not include all relevant details about the patients' conditions and treatments due to their privacy and data that was willing to share.

Thematic Analysis

Thematic analysis was employed in this study to analyze the data and identify patterns that corresponded to the research questions. The researcher systematically examined

the data and identified five main themes based on the research questions. The first theme focused on understanding the perception and understanding of the challenges faced by families with patients diagnosed with Hirschsprung's disease. The researcher analyzed the data to identify common challenges and variations in how families perceived and understood these challenges.

The second theme explored coping strategies employed by families to manage the emotional and practical aspects of caring for a child with Hirschsprung's disease. The data were analyzed to identify the various coping mechanisms utilized by the participants and how they contributed to their overall well-being. The third theme centered around families' navigation of the healthcare system and their access to necessary resources to support their child. The researcher examined the data to identify the challenges, barriers, and facilitators that families encountered in accessing healthcare services and resources.

Furthermore, the fourth theme focused on the role of social support in the coping process for families with patients diagnosed with Hirschsprung's disease. The data were analyzed to identify the types of social support received, its impact on coping mechanisms, and the sources of support relied upon by the families. Lastly, the fifth theme explored how families found meaning and purpose in caring for a child with Hirschsprung's disease. The researcher analyzed the data to identify the factors contributing to finding meaning, the strategies used by families to derive meaning from their experiences, and the impact of finding meaning on their coping mechanisms.

Thematic analysis allowed for a systematic examination of the data, enabling the researcher to identify recurring patterns and themes related to the research questions and

gain a deeper understanding of the experiences and perspectives of families caring for a child with Hirschsprung's disease.

Perception and Understanding the Challenges Encountered by the Families of Patients Diagnosed with Hirschsprung's Disease

In the study, one of the research questions focused on the perception and understanding of the challenges encountered by the families of patients diagnosed with Hirschsprung's Disease. The data from two participants shed light on this theme.

Parent 1 has a child diagnosed with Hirschsprung's Disease and has undergone multiple surgical interventions, including anoplasty, redo posterior sagittal anorectoplasty (PSARP) with transverse loop colostomy, and closure of the colostomy. The child is currently admitted, indicating that the family of P1 is likely facing ongoing challenges related to the condition. Their perception and understanding of the challenges may be influenced by their child's specific medical history and the experiences associated with the surgical procedures.

Parent 2 also has a child diagnosed with Hirschsprung's Disease. Their child is currently admitted and scheduled for an exploratory laparotomy to evaluate the state of the colon and determine the potential need for a pull-through treatment. This parent's perception and understanding of the challenges revolves around the uncertainty and anticipation associated with the upcoming procedure, as well as the potential implications for their child's future treatment and well-being.

These two cases highlight the diverse experiences and perspectives of families dealing with Hirschsprung's Disease. The challenges faced by each family may vary based

on the specific circumstances of their child's diagnosis, treatment history, and current medical status. Understanding the perception and understanding of these challenges is crucial for providing appropriate support and interventions to help families navigate the complexities of caring for a child with Hirschsprung's Disease.

Table 2. Understanding of Hirschsprung's Disease

Participant	Statement	Theme	Subtheme
P1	*"Ang sabi ng doctor sa amin, 'yung Hirschsprung's Disease ay hindi madaling proseso at may mga cases na pwedeng namamana siya. Pinanganak ko kasi itong anak ko nung pandemic. Kaya sobrang hirap kami nung time na 'yun dahil may mga quarantine tapos hindi rin kami masyadong makalabas nun para makapagpacheck up. Medyo kapos rin talaga kami sa budget nung mga panahon na 'yun. Nung pinanganak ko siya, siguro mga two days na hindi siya dumudumi kahit na binebreast feed ko naman siya. Kaya nagtaka kami ng asawa ko nun kasi malakas nga sa gatas 'yung bata pero hindi siya dumudumi. Nung pinacheck up naming siya, dun na naming nalaman agad na may Hirschsprung's Disease siya… hindi rin kami sigurado nun kung ano ba 'yung sakit na 'yun kaya umasa talaga kami na*	Perception and Understanding the Challenges Encountered by the Families of Patients Diagnosed with Hirschsprung's Disease	Understanding of Hirschsprung's Disease

	maiintindihan naming mag-asawa kung paano ba nagagamot 'yung sakit na 'yun."		
P2	*"Nung nalaman ko na may Hirschsprung's Disease 'yung anak naming, parang gumuho 'yung mundo ko. May COVID pa nung mga panahon na 'yun kaya sobrang hirap po na humingi ng tulong. Kaya 'yung pamilya naming nung mga panahon na 'yun, gulong-gulo talaga kung pa'no naming [haharapin] 'yung ganitong dagok na dumating…"*	Perception and Understanding the Challenges Encountered by the Families of Patients Diagnosed with Hirschsprung's Disease	Understanding of Hirschsprung's Disease

In Table 2, the understanding of Hirschsprung's Disease is explored through the statements of two participants. Participant 1 (P1) shares their experience of learning about the disease and the challenges they faced. They mention that the doctor informed them that Hirschsprung's Disease is a complex condition that can be hereditary. They recall the difficulties they encountered during the pandemic, with quarantine restrictions and limited access to medical check-ups.

P1 also mentions their financial constraints during that time. They became concerned when their child did not have bowel movements for two days, despite being breastfed. It was during the check-up that they learned about their child's diagnosis. P1 emphasizes their lack

of understanding about the disease and their reliance on their hope to comprehend its treatment.

On the other hand, Participant 2 (P2) discusses the emotional impact that the diagnosis of Hirschsprung's disease has had on their child. Upon hearing the news, they express feeling utterly saddened and completely overpowered, particularly when taking into consideration the extra difficulties brought about by the COVID-19 public health crisis. P2 emphasizes the challenges they encountered in attempting to seek assistance and support at that period, as their family was experiencing a great deal of upheaval and was unclear of how to handle this unforeseen circumstance.

The statements made by P1 and P2 offer valuable insights into the perceptions and comprehensions of the difficulties that are experienced by relatives of patients who have been diagnosed with Hirschsprung’s disease. The immediate shock and confusion that both participants had upon learning about the sickness is expressed by both. In addition, they highlight the extra challenges that they encountered, such as limited access to healthcare resources and budgetary restraints during the pandemic. These accounts highlight the significance of giving families with support and knowledge to assist them in better comprehending the difficulties associated with Hirschsprung's disease and aiding them in coping with those difficulties.

Table 3. Effects on Family’s Daily Routine

Participant	Statement	Theme	Subtheme

P1	*"Sobrang laki po ng naging epekto nito sa pamilya naming. May dalawa pa po akong anak kaya nung time na 'yun sobrang hirap po kami kung pa'no naming aasikasuhin 'yung bunso ko na may HD."*	Perception and Understanding the Challenges Encountered by the Families of Patients Diagnosed with Hirschsprung's Disease	Effects on Family's Daily Routine
P2	*"'Yung asawa ko po kailangan niya pang rumaket at maghanap ng additional na income kasi hindi talaga biro 'yung gastos…"*	Perception and Understanding the Challenges Encountered by the Families of Patients Diagnosed with Hirschsprung's Disease	Effects on Family's Daily Routine

Table 3 presents the effects of Hirschsprung's Disease on the family's daily routine through the statements of two participants. Participant 1 (P1) shares that the disease had a significant impact on their family. They mention having two other children, which made it challenging for them to manage the care of their youngest child with Hirschsprung's Disease. This suggests that the daily routine of the family was disrupted as they had to allocate time and resources to address the specific needs of their child with the condition.

Participant 2 (P2) highlights the financial impact of Hirschsprung's Disease on their family. They mention that their spouse needed to find additional sources of income to cover the expenses associated with the disease. This suggests that the family's daily routine was affected as they had to adjust accommodate the financial burden imposed by the condition.

These statements from P1 and P2 provide insights into the effects of Hirschsprung's Disease on the family's daily routine. Both participants indicate that the disease has caused disruptions and challenges in their day-to-day lives. P1 emphasizes the difficulty of managing the care of their child with Hirschsprung's Disease alongside their other children. P2 highlights the financial strain that the disease has placed on the family, necessitating additional work to meet the increased expenses.

These accounts underscore the need for support and resources to help families cope with the practical implications of Hirschsprung's Disease on their daily routines. It is crucial to aid and guidance to families to help them navigate the challenges and make necessary adjustments to their routines to ensure the well-being of their child with the condition and the entire family.

Table 4. Impact to Family's Emotional Well-Being and Quality of Life

Participant	Statement	Theme	Subtheme
P1	*"'yung stress po at gabi-gabing pag-iisip kung paano gagaling 'yung anak ko at mabubuhay ng normal 'yung palagi kong iniisip. Kasi nakailang surgery narin po kami, kung saan-saang charity na kami lumapit para matulungan kami…"*	Perception and Understanding the Challenges Encountered by the Families of Patients Diagnosed with Hirschsprung's Disease	Impact to Family's Emotional Well-Being and Quality of Life
P2	*"Nagkaroon po ako ng post-partum depression… sinisi ko ['yung] sarili ko nun… baka po dahil sa'ken kaya siya nagkaroon non… pero*	Perception and Understanding the Challenges Encountered by the Families of Patients	Impact to Family's Emotional Well-Being and Quality

	nagpapasalamat ako sa pamilya ko at sa mga doctor na patuloy na tumutulong sa amin…"	Diagnosed with Hirschsprung's Disease	of Life

In Table 4, the impact of Hirschsprung's Disease on the family's emotional well-being and quality of life is explored through the statements of two participants. Participant 1 (P1) shares the emotional stress and constant worry they experience regarding their child's recovery and ability to live a normal life. They mention multiple surgeries and seeking help from various charitable organizations, indicating the financial and emotional strain they have endured. This suggests that the family's emotional well-being and quality of life have been significantly impacted by the challenges associated with Hirschsprung's Disease.

On the other hand, Participant 2 (P2) reveals their experience of post-partum depression, attributing it to the circumstances surrounding their child's diagnosis. They express self-blame but also express gratitude towards their family and the doctors who continue to support them. This suggests that the family's emotional well-being has been affected, with P2 experiencing mental health challenges because of their child's condition.

These statements from P1 and P2 provide insights into the emotional impact of Hirschsprung's Disease on the family's well-being and quality of life. Both participants express feelings of stress, worry, and emotional strain. P1's statement reflects the constant preoccupation with their child's health and the challenges they face in accessing necessary resources. P2's statement highlights the psychological toll of the situation, with post-partum depression affecting their emotional well-being.

These accounts emphasize the need for comprehensive support for families dealing with Hirschsprung's Disease, addressing not only the physical aspects but also the emotional and mental health needs. Providing resources, counseling, and assistance to families can help alleviate the emotional burden and improve their overall quality of life. It is crucial to recognize and address the emotional impact of the disease on families to ensure their well-being and resilience throughout the journey of caring for a child with Hirschsprung's Disease.

Table 5. Specific Challenges Encountered in Managing Medical Care and Treatment

Participant	Statement	Theme	Subtheme
P1	*"siguro po 'yung pagkakaroon po ng sapat na facilities at available na medication ang pinakachallenge naming, pati hindi naming din po namin ganoon naintidihan ng una kung paano aalagaan din 'yung bata dahil sa kondisyon niya…"*	Perception and Understanding the Challenges Encountered by the Families of Patients Diagnosed with Hirschsprung's Disease	Specific Challenges Encountered in Managing Medical Care and Treatment
P2	*"…sa totoo lang po financial po talaga 'yung pinaka problema naming dito… aside po dun sa… ano po… sa hindi namin gets masyado nun ano ba 'yung Hirschsprung.."*	Perception and Understanding the Challenges Encountered by the Families of Patients Diagnosed with Hirschsprung's Disease	Specific Challenges Encountered in Managing Medical Care and Treatment

Table 5 exhibits the specific challenges encountered in managing medical care and treatment for Hirschsprung's Disease through the statements of two participants. Participant 1 (P1) mentions the lack of sufficient facilities and available medication as their primary challenge. They also express initial difficulty in understanding how to care for their child due to the condition. This suggests that accessing appropriate medical care and treatment, as well as understanding the necessary care practices, pose significant challenges for families dealing with Hirschsprung's Disease.

Participant 2 (P2) highlights financial constraints as their main problem in managing medical care and treatment. They also mention a lack of understanding about Hirschsprung's Disease. This indicates that the cost of medical care and treatment, as well as a lack of knowledge about the condition, present specific challenges for families.

These statements from P1 and P2 provide insights into the specific challenges families face in managing medical care and treatment for Hirschsprung's Disease. Both participants mention financial difficulties, with P1 emphasizing the need for adequate facilities and medication. P2 adds the additional challenge of limited understanding about the condition.

These accounts underscore the importance of addressing the specific challenges faced by families in managing medical care and treatment for Hirschsprung's Disease. Providing accessible and affordable healthcare services, as well as educational resources to enhance understanding, can help alleviate the burden on families. It is crucial to support families in navigating the complexities of medical care and treatment, ensuring that they

have the necessary resources and knowledge to provide the best possible care for their child with Hirschsprung's Disease.

Table 6. Level of Support and Resources Available

Participant	Statement	Theme	Subtheme
P1	*"Malaking tulong po 'yung Our Lady of Peace sa amin, kung wala 'yung ospital na ito, hindi ko po alam kung paano makasurvive ang pamilya naming. Lahat ng support ng mga nurse, doctor, talagang nagpapalakas po ng loob naming na magagamot ang anak namin…"*	Perception and Understanding the Challenges Encountered by the Families of Patients Diagnosed with Hirschsprung's Disease	Level of Support and Resources Available
P2	*"Sobrang approachable po ng ospital, sa mga nurse po at staff nila, hindi po kami pinapabayaan at lagi pong [pinapaintindi] sa amin na kahit 'rare' 'yung ganitong sakit, may solusyon po sa kanya.."*	Perception and Understanding the Challenges Encountered by the Families of Patients Diagnosed with Hirschsprung's Disease	Level of Support and Resources Available

In Table 6, the level of support and resources available to families dealing with Hirschsprung's Disease is explored through the statements of two participants. Participant 1 (P1) expresses gratitude for the support they receive from Our Lady of Peace hospital. They mention that without the hospital's assistance, they would not know how their family could

survive. P1 emphasizes the support provided by the nurses and doctors, which strengthens their resolve that their child can be treated.

Participant 2 (P2) highlights the approachability of the hospital staff, particularly the nurses. They mention that they are never neglected and are always provided with a clear understanding that there are solutions available for their child's rare condition.

These statements from P1 and P2 provide insights into the level of support and resources available to families dealing with Hirschsprung's Disease. Both participants express appreciation for the support they receive from the hospital and its staff. P1 emphasizes the emotional support and encouragement they receive, while P2 highlights the accessibility and reassurance provided by the hospital staff.

These accounts underscore the importance of providing comprehensive support and resources to families dealing with Hirschsprung's Disease. Accessible and approachable healthcare professionals, along with emotional support, can greatly alleviate the challenges faced by families. It is crucial to ensure that families have the necessary support and resources to navigate the complexities of managing the condition and to provide the best possible care for their child.

Coping strategies to Manage the Emotional Practical Aspects of Caring for a Child with Hirschsprung's Disease

The second theme of the study focuses on the coping strategies employed by families to manage the emotional and practical aspects of caring for a child with Hirschsprung's Disease. The data from two participants shed light on this theme.

Table 7. Emotional Challenges

Participant	Statement	Theme	Subtheme
P1	*"Nung una po hindi ko talaga matanggap na ganun 'yung nangyari sa anak ko. Andami kong tanong nun, hindi ko talaga matanggap…"*	Coping strategies to Manage the Emotional Practical Aspects of Caring for a Child with Hirschsprung's Disease	Emotional Challenges
P2	*"Siguro po shock? Kasi hindi ako makapaniwala na ganito kalala 'yung nangyari sa anak ko..."*	Coping strategies to Manage the Emotional Practical Aspects of Caring for a Child with Hirschsprung's Disease	Emotional Challenges

Through the remarks of two participants, Table 7 provides an examination of the emotional challenges that are encountered by families that are responsible for the care of a child who has Hirschsprung's disease. The first participant, who will be referred to as P1, communicates their initial challenges in accepting and comprehending the diagnosis of their child. It is mentioned that they are experiencing a feeling of being overpowered by questions and that they are having difficulty accepting the truth of the situation. P1 may have encountered substantial emotional hurdles while digesting and accepting their child's illness, as indicated by this situation.

Meanwhile, after learning about the seriousness of their child's health, Participant 2 (P2) describes their emotion as being one of astonishment. They are unable to fathom the full scope of what has occurred to their child and voice their incredulity towards the situation.

The fact that this is the case suggests that P2 also experienced emotional difficulties when it came to embracing and comprehending the effects that Hirschsprung's disease had on their child's health.

These statements from P1 and P2 provide insights into the emotional challenges experienced by families caring for a child with Hirschsprung's Disease. Both participants express feelings of disbelief, shock, and difficulty in accepting the diagnosis. These emotional challenges can have a significant impact on the well-being and coping abilities of the parents or caregivers.

The need of supporting families who are dealing with Hirschsprung's disease with emotional support and resources is brought to light by these accounts. To enable them to successfully navigate the emotional path of caring for a kid who has a chronic condition, it is essential to recognize and address the emotional obstacles that they confront. This can be accomplished by providing them with therapy, advice, and an environment that is supportive. It is possible for healthcare providers and support networks to assist families in the development of effective coping strategies and boost their overall resilience regarding the management of the problems that are associated with Hirschsprung's disease if they acknowledge and promote the emotional well-being of families.

Table 8. Coping Strategies to Manage Emotional Stress and Anxiety

Participant	Statement	Theme	Subtheme

P1	*"Ngayon po kasi 4 years old na siya, kaya naiintindihan na niya kahit papaano 'yung kapag ineexplain naming sa kanya kung ano 'yung condition niya… Ako po bilang magulang, pinipilit ko po na maging positibo palagi"*	Coping strategies to Manage the Emotional Practical Aspects of Caring for a Child with Hirschsprung's Disease	Coping Strategies to Manage Emotional Stress and Anxiety
P2	*"Lagi po akong nagdadasal para sa pamilya naming, kasi kahit anong mangyari, 'yung Diyos lang naman po talaga 'yung magdidikta at magpaplano ng lahat…"*	Coping strategies to Manage the Emotional Practical Aspects of Caring for a Child with Hirschsprung's Disease	Coping Strategies to Manage Emotional Stress and Anxiety

Table 8 displays the coping strategies employed by families to manage emotional stress and anxiety while caring for a child with Hirschsprung's Disease through the statements of two participants. Participant 1 (P1) mentions that their child is now 4 years old and starting to understand their condition to some extent. They express their efforts as a parent to maintain a positive outlook and attitude. This suggests that P1 copes with emotional stress and anxiety by focusing on positivity and ensuring that their child understands their condition in an age-appropriate manner.

Participant 2 (P2) reveals that they rely on prayer for their family. They express their belief that regardless of what happens, it is ultimately God who dictates and plans everything. This indicates that P2 copes with emotional stress and anxiety by finding solace and strength through their faith.

These statements from P1 and P2 provide insights into the coping strategies employed by families to manage emotional stress and anxiety while caring for a child with Hirschsprung's Disease. Both participants emphasize the importance of maintaining a positive mindset and seeking support from their faith. These coping strategies can help families navigate the emotional challenges associated with the condition and find strength in difficult times.

Recognizing and supporting the coping strategies that families employ, such as maintaining positivity and relying on faith, can contribute to their overall well-being and resilience. Healthcare providers and support networks can play a crucial role in acknowledging and reinforcing these coping strategies, ensuring that families have the necessary resources and support to manage emotional stress and anxiety effectively.

Table 9. Navigating Practical Aspects of Caring a Child with Hirschsprung's Disease

Participant	Statement	Theme	Subtheme
P1	*"Ano po… minemake sure naming palagi ng pamilya ko na andiyan lang kami para sa anak naming, pati narin sa ibang anak pa naming. Kasi importante talaga 'yun bilang magulang na pinapakita mong nakasuporta ka lang sa kanila."*	Coping strategies to Manage the Emotional Practical Aspects of Caring for a Child with Hirschsprung's Disease	Navigating Practical Aspects of Caring a Child with Hirschsprung's Disease
P2	*"Nag-uusap kami ng asawa ko palagi kung ano 'yung gagawin. Kunware, 'oh kapag ganitong oras ikaw*	Coping strategies to Manage the Emotional Practical Aspects of Caring	Navigating Practical Aspects of Caring a Child with

	magbabantay sa kanya, tapos ako naman sa gabi' 'yung mga ganung bagay po kasi malaking tulong siya bukod sa pag-assist po ng nurses o ng doctor.. mahalaga po… mahalaga po na alam po namin 'yung ginagawa naming kasi hindi naman po 24/7 makakausap din naming lahat ng staff tungkol sa mga bawal at dapat na gawin naming para maalagaan ng maayos 'yung bata…"	for a Child with Hirschsprung's Disease	Hirschsprung's Disease

In Table 9, the practical aspects of caring for a child with Hirschsprung's Disease and the strategies employed by families to navigate these challenges are explored through the statements of two participants. Participant 1 (P1) mentions the importance of their family's constant presence and support for their child, as well as their other children. They emphasize the significance of demonstrating unwavering support as parents. This suggests that P1 navigates the practical aspects of caring for their child by ensuring a supportive and nurturing environment within the family.

Participant 2 (P2) describes how they and their spouse constantly communicate and coordinate their caregiving responsibilities. They discuss and assign specific times for each of them to be with their child, considering the assistance provided by nurses and doctors. P2 emphasizes the importance of being knowledgeable about their child's care because they cannot always rely on round-the-clock communication with the hospital staff.

These statements from P1 and P2 provide insights into the strategies employed by families to navigate the practical aspects of caring for a child with Hirschsprung's Disease. Both participants highlight the importance of family support and communication in managing the practical challenges. P1 emphasizes the significance of being present and supportive, while P2 emphasizes the need for coordination and knowledge about their child's care.

These accounts underscore the importance of providing comprehensive support and resources to families dealing with Hirschsprung's Disease. Supporting families in navigating the practical aspects of care, such as coordinating responsibilities and ensuring knowledge about their child's condition, can greatly alleviate the burden on parents or caregivers. Healthcare providers and support networks can play a crucial role in providing guidance, education, and resources to help families effectively navigate the practical challenges of caring for a child with Hirschsprung's Disease.

Table 10. Specific and Beneficial Support System

Participant	Statement	Theme	Subtheme
P1	*"'yung asawa ko po at pamilya ko 'yung pinakasinasandalan naming ng mga anak ko... pati narin po 'yung iba naming kamag-anak, kasi ilang taon narin po, simula pa ng pandemic nangyari ito, kaya malaki 'yung pasasalamat ko sa kanila."*	Coping strategies to Manage the Emotional Practical Aspects of Caring for a Child with Hirschsprung's Disease	Specific and Beneficial Support System
P2	*"...pamilya po talaga at 'yung Diyos. Lalo na po sa charity na*	Coping strategies to Manage the Emotional Practical	Specific and Beneficial Support

	tumutulong at sa mga doctor…"	Aspects of Caring for a Child with Hirschsprung's Disease	System

In Table 10, the specific and beneficial support systems utilized by families caring for a child with Hirschsprung's Disease are explored through the statements of two participants. Participant 1 (P1) mentions that their spouse and family, as well as other relatives, are their main sources of support. They express gratitude for their unwavering support, particularly during the pandemic. This suggests that P1 relies on their immediate and extended family as a specific and beneficial support system in managing the challenges of caring for their child.

One of the participants, P2, emphasizes the significance of their family and their faith as part of their support system. They add that the required support is provided to them by their family, as well as by the assistance of humanitarian organizations and medical professionals. This demonstrates that P2 receives help from their family, nonprofit groups, and healthcare experts that is both personalized and beneficial.

The statements made by P1 and P2 offer valuable insights into the specialized and advantageous support networks that families who are caring for a kid with Hirschsprung's Disease utilize. One of the participants, P1, also expressed thankfulness for the help of extended relatives, even though both participants underline the necessity of family support. In addition, P2 incorporates the additional help that is obtained from healthcare professionals and philanthropic organizational donors.

The statements highlight the significance of acknowledging and providing assistance to the specialized support networks that families rely on in order to manage the problems that are associated with Hirschsprung's disease management. In addition to the assistance provided by charitable organizations and medical experts, the strain that is placed on families can be significantly reduced via the support of family members. It is of the utmost importance for healthcare practitioners and support networks to recognize and strengthen these support systems. This will ensure that families have access to the resources and assistance they require to effectively manage the emotional and practical aspects of caring for a child who has Hirschsprung's disease.

Table 11. Personal Experiences and Adapted Coping Strategies

Participant	Statement	Theme	Subtheme
P1	*"...sa kinakain po niya kasi strict diet po talaga madami pong bawal, kaya ayun po, hindi siya 'yung normal na bata na kahit ano pwede mong ipakain, sobrang selan. Ayun po 'yung natutunan namin sa family na dapat talaga sinusunod 'yun."*	Coping strategies to Manage the Emotional Practical Aspects of Caring for a Child with Hirschsprung's Disease	Personal Experiences and Adapted Coping Strategies
P2	*"Ang nakasanayan na po namin lagi po talagang nakaready 'yung mga gamutan, nakikinig po sa nurse at doctor, tsaka sa relatives po may mga pray over din umaattend kami dun, mas lumakas 'yung tiwala naming sa Diyos na malalagpasan naming ito..."*	Coping strategies to Manage the Emotional Practical Aspects of Caring for a Child with Hirschsprung's Disease	Personal Experiences and Adapted Coping Strategies

In Table 11, the personal experiences and adapted coping strategies of families caring for a child with Hirschsprung's Disease are explored through the statements of two participants. Participant 1 (P1) discusses the strict diet their child must follow due to the condition, noting that there are many restrictions on what their child can eat. They emphasize the importance of adhering to this diet and how their family has learned to adapt to it. This suggests that P1's coping strategy involves adapting their child's diet and ensuring strict adherence to it.

Participant 2 (P2) shares their experience of always having medications ready and listening to the advice of nurses and doctors. They also mention attending prayer sessions and finding strength and trust in God to overcome the challenges they face. This indicates that P2's coping strategy involves being prepared with necessary medications, seeking guidance from healthcare professionals, and finding solace in their faith.

These statements from P1 and P2 provide insights into the personal experiences and adapted coping strategies of families caring for a child with Hirschsprung's Disease. P1 highlights the adaptation of their child's diet as a coping strategy, while P2 emphasizes being prepared with medications, seeking medical advice, and finding strength through prayer and faith.

These accounts underscore the importance of personal experiences and adapted coping strategies in managing the challenges of caring for a child with Hirschsprung's Disease. Each family may develop their own unique coping strategies based on their

experiences and the specific needs of their child. It is crucial for healthcare providers and support networks to recognize and support these adapted coping strategies, providing families with the necessary resources and assistance to effectively manage the emotional and practical aspects of caring for a child with Hirschsprung's Disease.

Families' Navigation of the Healthcare System and Access to Necessary Resources to Support the Patient

The third theme that was investigated in this research is the way families navigate the healthcare system and the resources that they have access to to provide support for their kid who has Hirschsprung's disease. This theme investigates the difficulties that families encounter while attempting to gain access to healthcare services and the resources that they require to effectively support the care of their child. It is possible to draw the conclusion that families may face a variety of challenges when attempting to navigate the healthcare system and gain access to the resources that are required.

Table 12. Experiences in Navigating Healthcare System

Participant	Statement	Theme	Subtheme
P1	*"Pandemic po kasi nun eh. Kaya sobrang hirap po para sa amin nun na maghanap ng makakatulong na ospital o doctor para magamot 'yung sakit ng anak ko…"*	Families' Navigation of the Healthcare System and Access to Necessary Resources to Support the Patient	Experiences in Navigating Healthcare System
P2	*"Kung kani-kanino po kami lumapit pero hirap kami sa financial po… Mabuti nalang*	Families' Navigation of the Healthcare System and Access to	Experiences in Navigating Healthcare

	po at may mga handa talagang tumulong nun…"	Necessary Resources to Support the Patient	System

In Table 12, the experiences of families in navigating the healthcare system and accessing necessary resources to support their child with Hirschsprung's Disease are explored through the statements of two participants. Participant 1 (P1) mentions the challenges they faced during the pandemic in finding a hospital or doctor who could provide treatment for their child's condition. This suggests that P1 encountered difficulties in navigating the healthcare system and accessing appropriate care for their child.

Participant 2 (P2) shares their experience of reaching out to various sources for help but facing financial constraints. They express gratitude for the assistance they received from individuals or organizations willing to provide support. This indicates that P2 encountered challenges in accessing necessary resources due to financial limitations but found relief through the help of others.

These statements from P1 and P2 provide insights into the experiences of families in navigating the healthcare system and accessing necessary resources for their child with Hirschsprung's Disease. Both participants highlight the challenges they faced, including difficulties in finding appropriate healthcare providers and financial constraints in accessing necessary resources.

These accounts underscore the importance of addressing the barriers families face in navigating the healthcare system and accessing necessary resources. It is crucial to improve access to specialized healthcare services, provide financial assistance or insurance coverage,

and enhance support networks to help families overcome these challenges. By addressing these issues, families can more effectively navigate the healthcare system and access the necessary resources to support their child with Hirschsprung's Disease.

Table 13. Challenges Encountered in Accessing Healthcare Services and Resources

Participant	Statement	Theme	Subtheme
P1	*"Personally po, 'yung limited lang po na kaalaman tungkol sa Hirschsprung's Disease ng mga tao. Kasi pandemic po nun kaya ang nagagawa naming din nun, Google natin 'to, check natin online 'to, habang naghihintay tayo ng update sa ospital ganun. Pero inadvise din po kami ng doctor na mas mainam po talaga kapag may consultation at natitingnan po talaga 'yung bata…"*	Families' Navigation of the Healthcare System and Access to Necessary Resources to Support the Patient	Challenges Encountered in Accessing Healthcare Services and Resources
P2	*"Sa probinsiya po kasi kami nakatira kaya para samin ng asawa ko, ayun po 'yung pinakachallenge naming nung mga oras na 'yun. Tapos syempre hindi naman po kami pwedeng magdemand ng kung anoa no rin sa ospital o mga doctor, kung ano lang po available, kaya palipat lipat po kami…"*	Families' Navigation of the Healthcare System and Access to Necessary Resources to Support the Patient	Challenges Encountered in Accessing Healthcare Services and Resources

Table 13 delineates the the challenges encountered by families in accessing healthcare services and resources for patients with Hirschsprung's Disease are explored through the statements of two participants. Participant 1 (P1) mentions the limited

knowledge about Hirschsprung's Disease among people, particularly during the pandemic. They express the reliance on online sources and waiting for updates from the hospital. However, they also highlight the importance of consulting with a doctor for accurate information and proper evaluation of the child. This suggests that P1 encountered challenges in accessing accurate and reliable information about the condition, relying on online sources while waiting for updates from healthcare providers.

Participant 2 (P2) discusses the challenges they faced as residents of a province. They mention the difficulty of accessing healthcare services due to their location and the need to transfer between different healthcare facilities. This indicates that P2 encountered challenges in accessing specialized healthcare services and had to navigate the healthcare system by moving between different facilities.

These statements from P1 and P2 provide insights into the challenges faced by families in accessing healthcare services and resources for patients with Hirschsprung's Disease. P1 highlights the limited knowledge about the condition and the reliance on online sources, while P2 emphasizes the challenges of accessing specialized healthcare services in a provincial setting.

These accounts underscore the need to address the challenges in accessing healthcare services and resources for patients with Hirschsprung’s Disease. Improving awareness and education about the condition among healthcare professionals and the public can help address the limited knowledge issue. Additionally, efforts should be made to improve access to specialized healthcare services in rural or provincial areas, ensuring that families have convenient access to the necessary resources and support.

By addressing these challenges, families caring for a child with Hirschsprung's Disease in the Philippines can have improved access to accurate information, appropriate healthcare services, and necessary resources, leading to better health outcomes for the patients and reduced stress for the families.

Table 14. Challenges Encountered in Accessing Healthcare Services and Resources

Participant	Statement	Theme	Subtheme
P1	*"Siguro po mas pondohan pa ng gobyerno 'yung mga hospital lalo na po hindi naman lahat ng pamilya kaya pong tustusan 'yung gastos sa ganitong kaso po ng sakit eh. Mas ano po… [suportahan] ng gobyerno 'yung mga ospital…"*	Families' Navigation of the Healthcare System and Access to Necessary Resources to Support the Patient	Improvements or Changes to be Made to the Healthcare System
P2	*"Samin po kasi since hindi po namin ganun kaaware… hindi po sa kwan.. hindi po ganun kagets 'yung sakit nun? Mas ano po siguro… magbigay pa po sila information.. tungkol po dun sa sakit at suportang financial po sa mga kagaya po naming na mahihirap na pamilya…"*	Families' Navigation of the Healthcare System and Access to Necessary Resources to Support the Patient	Improvements or Changes to be Made to the Healthcare System

In Table 14, the challenges encountered by families in accessing healthcare services and resources for patients with Hirschsprung's Disease are explored through the statements of two participants. Participant 1 (P1) suggests that the government should allocate more

funding to hospitals, particularly for families who cannot afford the expenses associated with the condition. They emphasize the need for government support to hospitals. This indicates that P1 encountered challenges related to the financial burden of managing Hirschsprung's Disease and believes that increased government funding for hospitals could alleviate this issue.

Participant 2 (P2) mentions their lack of awareness and understanding about the condition. They suggest that the healthcare system should provide more information about the disease and offer financial support to families from low-income backgrounds. This suggests that P2 encountered challenges related to limited awareness and financial constraints and believes that improvements in information dissemination and financial support would be beneficial.

These statements from P1 and P2 provide insights into the challenges faced by families in accessing healthcare services and resources for patients with Hirschsprung's Disease. P1 highlights the financial burden and the need for government support to alleviate the expenses associated with the condition. P2 emphasizes the lack of awareness and financial constraints, suggesting that improvements in information provision and financial support would be beneficial.

These accounts underscore the need for improvements or changes to the healthcare system to address the challenges faced by families. Increased government funding for hospitals could help alleviate the financial burden on families. Additionally, efforts should be made to improve awareness and understanding of Hirschsprung's Disease among healthcare professionals and the public. Providing accessible and accurate information about

the condition and offering financial support to families from low-income backgrounds can help ensure equitable access to healthcare services and resources.

By addressing these challenges and making improvements to the healthcare system, families caring for a child with Hirschsprung's Disease in the Philippines can have improved access to necessary resources, reduced financial burden, and better support, leading to improved health outcomes for the patients and reduced stress for the families.

Social Support's Role in the Coping Process for Families with Patients Diagnosed with Hirschsprung's Disease

The fourth theme of the study explores the role of social support in the coping process for families with patients diagnosed with Hirschsprung's Disease. Within this theme, two sub-themes are identified: the influences of social support on the coping process and overall well-being as a family, and the barriers or challenges in accessing social support. This theme was divided into two subthemes. The first subtheme focuses on how social support positively impacts the coping process and overall well-being of families. Social support from family members, friends, healthcare professionals, and support groups can provide emotional support, practical assistance, and information. Meanwhile, the second subtheme explores the barriers or challenges families may face in accessing social support.

Table 15. Influences of Social Support to Coping Process and Overall Well-Being as a Family

Participant	Statement	Theme	Subtheme
P1	*"Sobrang laking tulong po na laging nandyan ang asawa ko para sa pamilya naming, kung ako lang po kasi mag-isa hindi ko po talaga kakayanin…"*	Social Support's Role in the Coping Process for Families with Patients Diagnosed with Hirschsprung's Disease	Influences of Social Support to Coping Process and Overall Well-Being as a Family
P2	*"'yung pamilya ko po at pamilya ng asawa ko madami pong nagawa para mabawasan po 'yung problema naming. 'yung mga kaibigan po namin na hindi nagsasawa tumulong, lalo na po 'yung pinapahiram pa kami ng pera kapag may mga emergency na kailangan bilhin 'to, kailangan madala sa ospital 'to.. 'yung ganung mga bagay po sobrang laking tulong para magkaro'n ng pag-asa 'yung pamilya naming na malagpasan 'to…"*	Social Support's Role in the Coping Process for Families with Patients Diagnosed with Hirschsprung's Disease	Influences of Social Support to Coping Process and Overall Well-Being as a Family

In Table 15, the influences of social support on the coping process and overall well-being of families with patients diagnosed with Hirschsprung's Disease are explored through the statements of two participants.

Participant 1 (P1) emphasizes the significant support provided by their spouse to their family. They express that without their spouse's presence and assistance, they would not be able to handle the challenges they face. This statement highlights the positive influence of

social support within the family unit, as the presence and support of a spouse can greatly contribute to the coping process and overall well-being of the family.

Participant 2 (P2) mentions the support they received from both their own family and their spouse's family. They express gratitude for the help and assistance provided by friends and family members, particularly in times of emergencies or financial needs. This statement emphasizes the positive influence of social support from extended family and friends, as their assistance and generosity have helped the family maintain hope and overcome challenges.

These statements from P1 and P2 provide insights into the influences of social support on the coping process and overall well-being of families. The presence and support of a spouse, as well as the assistance and generosity of extended family and friends, have a positive impact on the family's ability to cope with the challenges of caring for a child with Hirschsprung's Disease. Social support provides emotional support, practical assistance, and a sense of hope, reducing feelings of isolation, stress, and burden.

These accounts underscore the importance of fostering and nurturing social support networks for families caring for a child with Hirschsprung's Disease. Healthcare providers and support networks should recognize the positive influences of social support and actively encourage the involvement of family members, friends, and other support systems. By strengthening social support networks, families can experience improved coping abilities, enhanced overall well-being, and a greater ability to navigate the challenges they face. By acknowledging and harnessing the positive influences of social support, families can receive the necessary support to cope with the challenges of caring for a child with Hirschsprung's

Disease. This, in turn, can contribute to their overall well-being and resilience as they navigate the journey of managing the condition.

Table 16. Barriers or Challenges in Accessing Social Support

Participant	Statement	Theme	Subtheme
P1	*"Sa totoo lang po, minsan syempre nagkakaroon kami ng hindi pagkakaintindihan ng asawa ko, kaya nag-aaway ganun. Ayun po 'yung pinakamahirap kapag 'yung sariling partner mo 'yung hindi mo masandalan, pero ginagawa naman po naming 'yung makakaya naming palagi na intindihin 'yung isa't-isa para sa anak namin…"*	Social Support's Role in the Coping Process for Families with Patients Diagnosed with Hirschsprung's Disease	Barriers or Challenges in Accessing Social Support
P2	*"Kapag po nagkakasakit ako o kaya 'yung ibang anak ko, nahihirapan po kaming mag-asawa na asikasuhin 'yung mga bata talaga, lalo na po na nakaadmit ngayon itong anak ko, kapag po masama ang pakiramdam ng asawa ko, syempre hindi ko naman po siya pwedeng pilitin din na tulungan ako dito. Ang ginagawa nalang po namin, 'yung kapatid ko po o kaya sa relatives naming nakikiusap po kami na tulungan o kaya samahan kami sa ospital para may katulong din na magbantay…"*	Social Support's Role in the Coping Process for Families with Patients Diagnosed with Hirschsprung's Disease	Barriers or Challenges in Accessing Social Support

In Table 16, the barriers or challenges faced by families in accessing social support for patients diagnosed with Hirschsprung's Disease are explored through the statements of two participants.

Participant 1 (P1) mentions the difficulty they face in understanding and getting along with their spouse. They express that disagreements and conflicts arise, making it challenging to rely on their partner for support. However, they emphasize that they do their best to understand each other for the sake of their child. This statement highlights a barrier in accessing social support within the family unit, as conflicts and lack of understanding can hinder the ability to rely on a partner for support.

Participant 2 (P2) discusses the challenges they face in caring for their sick child and other children while their spouse is also unwell. They express that it becomes difficult for them as a couple to manage the needs of the children, especially when their spouse is not feeling well. They mention seeking help from relatives or siblings to assist or accompany them to the hospital. This statement highlights a barrier in accessing social support within the immediate family, as the illness or unavailability of a spouse can limit their ability to provide support to one another.

These statements from P1 and P2 provide insights into the barriers or challenges families face in accessing social support. Conflicts and lack of understanding within the family unit can hinder the ability to rely on a partner for support. Additionally, the illness or unavailability of a spouse can limit the support they can provide to one another. These barriers highlight the importance of addressing communication issues within the family and finding alternative sources of support when immediate family members are unavailable.

Recognizing and addressing these barriers is crucial for healthcare providers and support networks. They should provide resources and interventions that focus on improving communication and understanding within the family unit. Additionally, alternative sources of support, such as extended family members, friends, or support groups, should be made available to families facing these challenges. By addressing these barriers and providing appropriate support, families caring for a child with Hirschsprung's Disease can overcome these challenges and access the social support they need. This can enhance their coping abilities, reduce stress, and improve their overall well-being as they navigate the complexities of managing the condition.

Finding Meaning and Purpose in Caring for a Child with Hirschsprung's Disease

The fifth theme of the study explores the finding of meaning and purpose in caring for a child with Hirschsprung's Disease. Within this theme, two sub-themes are identified: the influence on the sense of meaning and purpose in life, and the contributions to coping strategies and resilience. The first theme focuses on how caring for a child with Hirschsprung's Disease can influence the sense of meaning and purpose in life for parents or caregivers, while the second theme explores how caring for a child with Hirschsprung's Disease can contribute to the development of coping strategies and resilience in parents or caregivers.

Table 17. Influence to Sense of Meaning and Purpose in Life

Participant	Statement	Theme	Subtheme

P1	*"Bilang magulang po, mas nakilala ko 'yung sarili ko at tsaka po 'yung mga kaya kong gawin para sa pamilya ko. Bilang ano po, individual ganun… narealize ko po na minsan talaga may mga hindi tayo inaasahang mangyari sa buhay natin na nakikita nating negative siya, pero nagagamit po natin 'yun para mas maging matatag bilang nanay rin…"*	Finding Meaning and Purpose in Caring for a Child with Hirschsprung's Disease	Influence to Sense of Meaning and Purpose in Life
P2	*"Naisip ko po na 'yung ganitong pagsubok sa buhay, hindi sinusukuan. Mas iniintindi ko po na ah, sige, eto 'yung nangyari samin ng pamilya ko. Sa una kasi mahirap siyang tanggapin… opo… kasi lahat naman ng magulang ang wish nila sana healthy ang baby, sana walang kumplikasyon, kumbaga normal na lumabas.., pero nagpapasalamt parin po ako na may mga tumutulong talaga sa amin kahit gano kahirap 'yung buhay…"*	Finding Meaning and Purpose in Caring for a Child with Hirschsprung's Disease	Influence to Sense of Meaning and Purpose in Life

In Table 17, the influence of caring for a child with Hirschsprung's Disease on the sense of meaning and purpose in life is explored through the statements of two participants.

Participant 1 (P1) reflects on their role as a parent and how caring for their child with Hirschsprung's Disease has allowed them to discover their own capabilities and strengths for the sake of their family. They express that through this experience, they have come to realize that unexpected and seemingly negative events can be used as opportunities for personal

growth and resilience. This statement highlights the influence of caregiving on the sense of meaning and purpose in life, as it has allowed P1 to discover their own strength and determination as a mother.

Participant 2 (P2) shares their initial struggle in accepting the challenges that come with caring for a child with Hirschsprung's Disease. However, they express that they have come to understand that these trials should not be given up on. P2 emphasizes the importance of embracing the situation and finding gratitude for the support they receive; despite the difficulties they face. This statement highlights the influence of caregiving on the sense of meaning and purpose in life, as it has led P2 to develop a mindset of resilience and gratitude, allowing them to navigate the challenges with determination.

Furthermore, these statements from P1 and P2 provide insights into the influence of caring for a child with Hirschsprung's Disease on the sense of meaning and purpose in life. The experience of caregiving can lead parents or caregivers to discover their own strengths, capabilities, and resilience. It can also prompt a shift in perspective, where challenges are seen as opportunities for personal growth and gratitude.

Understanding this influence is crucial for healthcare providers and support networks. They can provide resources and interventions that address the emotional and existential aspects of caregiving, helping parents or caregivers find meaning and purpose in their role. This can include opportunities for self-reflection, support groups, and counseling services that focus on personal growth, resilience, and finding gratitude in the face of challenges.

By acknowledging and supporting the influence of caregiving on the sense of meaning and purpose in life, healthcare providers and support networks can empower parents or caregivers to navigate their caregiving journey with a renewed sense of purpose, resilience, and improved overall well-being.

Table 18. Contributions to Coping Strategies and Resilience

Participant	Statement	Theme	Subtheme
P1	*"Mas lumalawak po 'yung pang-unawa ko bilang tao, mas naiisip ko po kung ano 'yung mga dapat kong gawin, pati kung paano maging mas positive po sa buhay…"*	Finding Meaning and Purpose in Caring for a Child with Hirschsprung's Disease	Contributions to Coping Strategies and Resilience
P2	*"Sa pag-aalaga po ng anak ko, narealize ko po na mas dapat pa akong maging responsableng magulang…"*	Finding Meaning and Purpose in Caring for a Child with Hirschsprung's Disease	Contributions to Coping Strategies and Resilience

In Table 18, the contributions of caring for a child with Hirschsprung's Disease to coping strategies and resilience are explored through the statements of two participants.

Participant 1 (P1) reflects on how caring for their child has broadened their understanding as a person. They express that they have become more thoughtful about their actions and have developed a more positive outlook on life. This statement highlights the contribution of caregiving to coping strategies and resilience, as it has prompted P1 to

develop a deeper understanding of themselves and their ability to navigate challenges with a positive mindset.

Meanwhile, Participant 2 (P2) shares their realization that they need to become a more responsible parent through the process of caring for their child with Hirschsprung's Disease. They express that this experience has prompted them to reflect on their role as a parent and the importance of being accountable. This statement highlights the contribution of caregiving to coping strategies and resilience, as it has motivated P2 to develop a sense of responsibility and adaptability in their parenting approach.

These statements from P1 and P2 provide insights into the contributions of caring for a child with Hirschsprung's Disease to coping strategies and resilience. The experience of caregiving can prompt individuals to develop a deeper understanding of themselves, adopt a more positive mindset, and become more responsible in their roles as parents or caregivers.

Understanding these contributions is crucial for healthcare providers and support networks. They can provide resources and interventions that focus on developing coping strategies and resilience in parents or caregivers. This can include education on stress management techniques, self-care practices, and support groups that foster a sense of community and shared experiences. By acknowledging and supporting the contributions of caregiving to coping strategies and resilience, healthcare providers and support networks can empower parents or caregivers to navigate the challenges of caring for a child with Hirschsprung's Disease with strength, adaptability, and improved overall well-being.

Proposed Output of the Capstone Project

Infographics are essential in increasing awareness about Hirschsprung's Disease in the Philippines. In this study, the researcher proposes an awareness infographic to effectively communicate information in an appealing way. Infographics make complex medical information more accessible to a broader audience by simplifying it. This initiative aims to enhance public knowledge of Hirschsprung's Disease in the Philippines by providing essential information such as vital facts, statistics, and symptoms of the disorder.

Infographics help inform persons about the initial indications and symptoms, facilitating prompt identification and quick medical care. The article emphasizes proactive efforts, such as genetic counseling, to decrease the occurrence of the condition. Infographics empower parents and caregivers by offering crucial information regarding the ailment, available treatment options, and support networks. They can be disseminated across multiple platforms to promote enhanced healthcare services, research, and assistance for those affected by Hirschsprung's Disease. They also function as educational aids for healthcare practitioners, augmenting their comprehension and proficiency in diagnosing and efficiently managing the illness. Infographics aid in dismantling the negative perception surrounding Hirschsprung's Disease by fostering comprehension, empathy, and acceptance. They offer useful resources to provide direction, assistance, and emotional support, including contact details for support groups and healthcare professionals.

Overall, infographics are an effective tool for increasing awareness, encouraging early detection, empowering individuals, and lobbying for better care and support for those affected with Hirschsprung's Disease in the Philippines. The figure below thereby shows an example of Infographic to strengthen the awareness of the public on Hirschsprung's Disease.

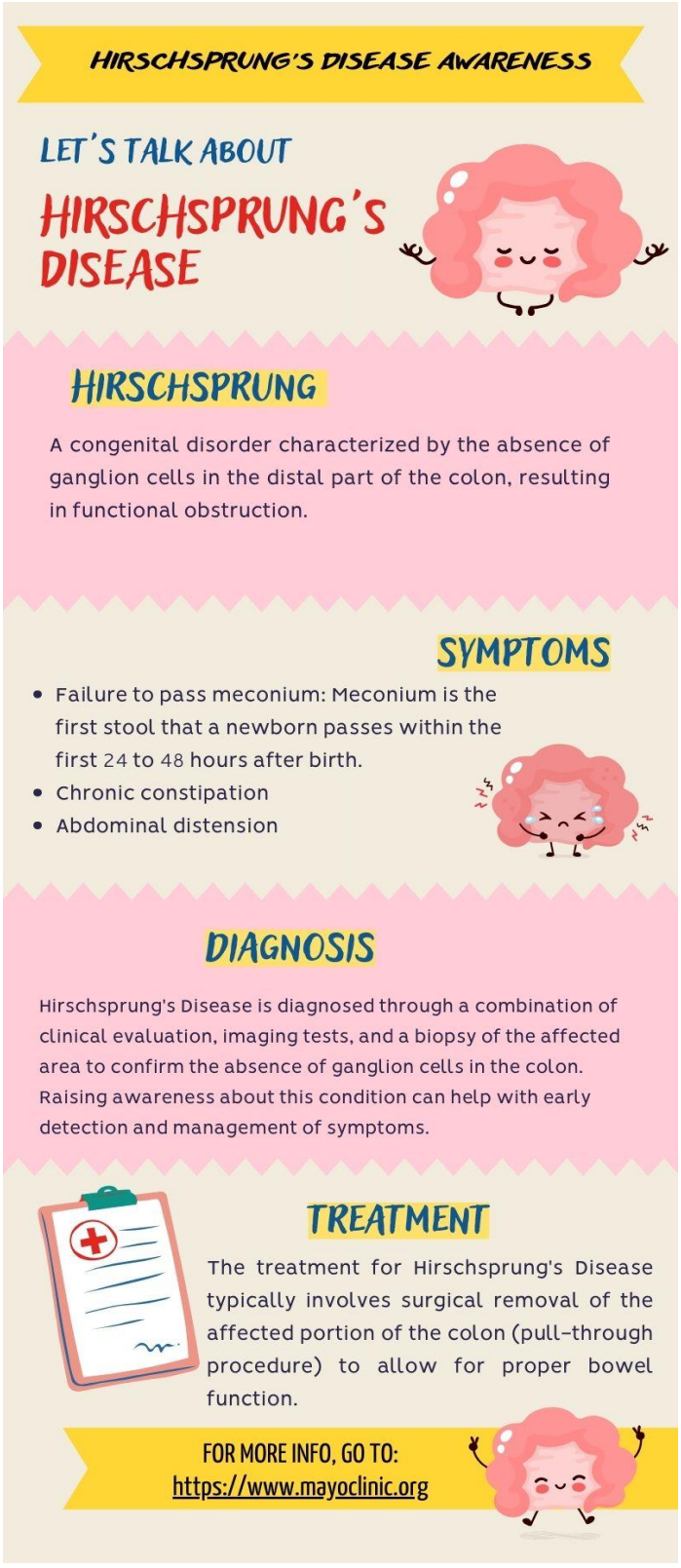


Figure 2. *Infographic for Hirschsprung's Disease Awareness*

CHAPTER IV

DISCUSSION OF FINDINGS, CONCLUSIONS, RECOMMENDATIONS, IMPLICATIONS OF RESULTS/FINDINGS TO PROFESSION, AND SELF-ACTUALIZATION

Discussion of Findings

The purpose of this study was to explore the coping mechanisms of families with patients diagnosed with Hirschsprung's Disease. Thus, the researcher conducted interviews with the parents/guardians of the patients to gather relevant data. Due to time constraints and ethical considerations, the study included a total of two participants who were willing to share their coping mechanisms, struggles, and experiences in caring for their child with Hirschsprung's Disease. The data collected from the interviews were organized into relevant themes to address the research questions of the study. These themes included the challenges faced by families, coping strategies, navigation of the healthcare system, social support, and finding meaning and purpose in caring for a child with Hirschsprung's Disease.

Parent 1 had a child with imperforate anus and a history of surgical procedures including anoplasty, redo posterior sagittal anorectoplasty (PSARP) with transverse loop colostomy, and closure of the colostomy. The patient was currently admitted at Our Lady of Peace Hospital in Paranaque City. The case involved Hirschsprung's Disease and the patient was scheduled for an exploratory laparotomy with a possible pull-through procedure. The exploratory laparotomy is a surgical technique to visually inspect the abdominal organs and assess any abnormalities. The pull-through procedure is a common surgical intervention for

Hirschsprung's Disease, aiming to remove the affected portion of the colon and restore normal bowel function.

Parent 2 also had a child with Hirschsprung's Disease, currently admitted at Our Lady of Peace Hospital in Paranaque City. The patient was scheduled for an exploratory laparotomy followed by a possible pull-through surgery. The exploratory laparotomy is performed to visually examine the abdominal organs and detect any abnormalities. In the context of Hirschsprung's Disease, it helps evaluate the extent of the affected area. The pull-through procedure is a surgical intervention that aims to treat Hirschsprung's Disease by removing the affected portion of the colon and creating a new connection between the healthy colon and the anus.

The findings from this study provide valuable insights into the coping mechanisms and experiences of families dealing with Hirschsprung's Disease. The participants' statements shed light on various aspects of the disease's impact on families, including their understanding of the condition, its effects on their daily routines, emotional well-being, and quality of life, as well as the challenges they face in managing medical care and the level of support and resources available to them.

Regarding the understanding of Hirschsprung's Disease, both participants expressed initial confusion and lack of knowledge about the condition. This highlights the importance of providing families with comprehensive information and education to help them better comprehend the challenges associated with the disease and cope with them effectively. The participants also mentioned the additional difficulties they faced during the pandemic, such as limited access to healthcare resources and financial constraints. These findings emphasize

the need for support and resources to assist families in navigating these challenges, especially during times of crisis.

The impact of Hirschsprung's Disease on the family's daily routine was evident in the participants' statements. They mentioned disruptions and challenges in managing the care of their child with the condition, as well as the financial burden imposed by the disease. These findings underscore the importance of providing families with practical support and resources to help them adjust their routines and alleviate the financial strain associated with the condition.

The emotional well-being and quality of life of families were significantly affected by Hirschsprung's Disease, as indicated by the participants' statements. They expressed feelings of stress, worry, and emotional strain, with one participant even experiencing post-partum depression. These findings highlight the need for comprehensive support, including counseling and mental health resources, to address the emotional impact of the disease on families and improve their overall well-being.

Managing medical care and treatment for Hirschsprung's Disease posed specific challenges for the participants. They mentioned difficulties in accessing appropriate facilities, medication, and understanding the necessary care practices. These findings emphasize the importance of providing families with accessible and affordable healthcare services, as well as educational resources to enhance their understanding of the condition and improve their ability to manage the medical aspects of care effectively.

The level of support and resources available to families varied, but both participants expressed gratitude for the support they received from the hospital and its staff. This

highlights the importance of providing families with accessible and approachable healthcare professionals who can offer emotional support, guidance, and reassurance. These findings underscore the need for comprehensive support networks and resources to ensure that families have the necessary support to navigate the challenges of caring for a child with Hirschsprung's Disease.

Thus, the findings from this study provide valuable insights into the coping mechanisms and experiences of families dealing with Hirschsprung's Disease. The results highlight the importance of providing families with comprehensive support, education, and resources to help them better understand the condition, manage their daily routines, cope with the emotional impact, navigate the complexities of medical care, and access the necessary support networks. By addressing these needs, healthcare professionals and support organizations can greatly improve the well-being and resilience of families dealing with Hirschsprung’s Disease.

Conclusion

In conclusion, this study has provided valuable insights into the challenges faced by families with patients diagnosed with Hirschsprung’s Disease and the coping mechanisms they employ to manage the emotional and practical aspects of caring for their child. The findings highlight the importance of providing families with comprehensive information and education to help them understand the condition and navigate the challenges associated with it effectively. The study also emphasizes the need for support and resources to assist families in managing their daily routines and alleviating the financial burden imposed by the disease.

Furthermore, the emotional well-being and quality of life of families were significantly affected, underscoring the importance of comprehensive support, including counseling and mental health resources. The study also revealed the challenges families face in accessing appropriate healthcare facilities and understanding necessary care practices, emphasizing the need for accessible and affordable healthcare services and educational resources. Lastly, the study highlighted the importance of providing families with accessible and approachable healthcare professionals who can offer emotional support and guidance. Overall, by addressing these needs and providing comprehensive support, healthcare professionals and support organizations can greatly improve the well-being and resilience of families dealing with Hirschsprung's Disease.

Recommendations

Based on the conclusion of this study, the following recommendations can be made:

1. Develop comprehensive educational materials and resources about Hirschsprung's Disease for families, including information about the condition, its effects, and available treatment options.
2. Provide financial support and resources to alleviate the financial burden imposed by the disease, such as assistance with medical expenses and access to insurance coverage.
3. Establish support groups and counseling services specifically tailored to the needs of families dealing with Hirschsprung's Disease, to address the emotional impact and improve overall well-being.

4. Improve access to healthcare facilities and ensure that families have access to appropriate medical care, including specialized facilities and healthcare professionals experienced in treating Hirschsprung's Disease.

5. Enhance communication and collaboration between healthcare professionals and families, ensuring that families have access to approachable and supportive healthcare professionals who can offer guidance and emotional support.

6. Provide accessible and affordable mental health resources, including counseling and therapy services, to address the emotional strain experienced by families caring for a child with Hirschsprung's Disease.

7. Develop and implement educational programs for families to enhance their understanding of necessary care practices, including medication management, dietary considerations, and post-operative care.

8. Establish partnerships with community organizations and support networks to provide additional resources and assistance to families, such as financial aid, respite care, and transportation services.

9. Conduct regular assessments of the needs and challenges faced by families dealing with Hirschsprung's Disease to ensure that support services and resources are tailored to their specific needs.

10. Foster a multidisciplinary approach to care, involving healthcare professionals from various specialties, to provide comprehensive and holistic support to families dealing with Hirschsprung’s Disease.

Implications of Results/Findings to Profession

Nurses and hospitals in the Philippines have a vital role in managing and providing treatment for patients with Hirschsprung disease. The interventions and treatments offered may differ based on the seriousness of the ailment and the resources accessible at each healthcare facility. Nevertheless, nurses and hospitals in the Philippines must employ the following strategies while caring for patients diagnosed with Hirschsprung disease:

Diagnosis and assessment: Nurses aid in the diagnosis of Hirschsprung disease by gathering the patient's medical history, conducting physical examinations, and organizing diagnostic procedures such as rectal biopsies or contrast enemas. They also assess the patient's symptoms, gastrointestinal function, and overall health state.

Surgical interventions: These are typically necessary for Hirschsprung disease to excise the damaged segment of the colon and establish a new link between the unaffected colon and the anus using a pull-through technique. Nurses have a crucial function in preparing patients for surgery, since they offer instruction to both the patient and their family regarding the process. Additionally, they ensure that the patient is adequately prepared both physically and emotionally for the operation.

Postoperative Care: Following the surgical operation, nurses diligently observe the patient's vital signs, evaluate for any potential complications, and administer postoperative pain relief. In addition, they provide support in wound management, provide drugs according to prescription, and closely monitor the patient's gastrointestinal function and bowel movements.

Dietary adjustments or nutritional assistance: This may be necessary for patients with Hirschsprung disease. Nurses cooperate with nutritionists to formulate suitable feeding strategies, oversee the patient's nutritional condition, and deliver instruction to the patient and their family regarding optimal nutrition and feeding methods.

Ostomy Care: In certain instances, individuals with Hirschsprung disease may necessitate a temporary or permanent surgical procedure known as a colostomy or ileostomy. Nurses offer instruction and assistance to patients and their families regarding ostomy care, encompassing the correct washing of the stoma, application of the pouch, and handling of issues such as skin irritation or leaking.

Nurses have a vital responsibility in providing education to patients and their families regarding Hirschsprung disease, including its treatment and possible complications. They offer guidance on effective bowel control, indicators and indications of potential issues, and approaches to enhance the patient's general health and wellness. Nurses offer emotional assistance to both patients and their families during the whole course of diagnosis, treatment, and recovery. They attend to any concerns or anxieties, offer counseling, and facilitate the connection of patients and families with support groups or organizations for supplementary assistance.

It should be emphasized that the interventions and treatment given can differ based on the unique requirements of each patient, the available resources at the healthcare facility, and the proficiency of the healthcare professionals involved. In the Philippines, nurses work in close cooperation with the healthcare team to guarantee optimal treatment for patients diagnosed with Hirschsprung disease.

Self-Actualization

This has provided me with valuable insights into the challenges faced by families dealing with Hirschsprung's Disease and the coping mechanisms they employ to navigate the emotional and practical aspects of caring for their child. It has highlighted the importance of providing families with comprehensive information and education to help them understand the condition and effectively manage the associated challenges. I now recognize the need for support and resources to assist families in their daily routines and alleviate the financial burden imposed by the disease.

The study has also shed light on the significant impact of Hirschsprung's Disease on the emotional well-being and quality of life of families. It has emphasized the importance of comprehensive support, including counseling and mental health resources, to address the emotional strain experienced by these families. Additionally, the challenges faced by families in accessing appropriate healthcare facilities and understanding necessary care practices have been brought to my attention. This underscores the need for accessible and affordable healthcare services and educational resources to ensure that families receive the care they require.

Furthermore, the study has highlighted the crucial role of accessible and approachable healthcare professionals in providing emotional support and guidance to families. It has reinforced the importance of being a compassionate and supportive nurse, ready to offer assistance and reassurance to families dealing with Hirschsprung's Disease.

Overall, this study has motivated me to address the needs of families dealing with Hirschsprung's Disease more comprehensively. I am committed to providing families with

the necessary support, education, and resources to enhance their well-being and resilience. By addressing these needs, I believe that as a nurse, I can make a significant positive impact on the lives of these families and contribute to their journey of self-actualization in managing Hirschsprung's Disease.

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APPENDIX A

INTERVIEW QUESTIONNAIRE

Name (Optional):

Age:

Reminder: This is an open-ended questionnaire, thus, if you would like to share additional insights or key takeaways, please feel free to do. Thank you for your participation!

For SOP 1: How do families with patients diagnosed with Hirschsprung's Disease perceive and understand the challenges associated with the illness?

1. Can you describe your understanding of Hirschsprung's Disease and the challenges it presents for your family?
2. How has your family's daily routine been affected by the challenges associated with Hirschsprung's Disease?
3. In what ways do you feel that Hirschsprung's Disease has impacted your family's emotional well-being and overall quality of life?
4. Can you share any specific challenges or difficulties you have encountered in managing the medical care and treatment of your loved one with Hirschsprung's Disease?
5. How do you perceive the level of support and resources available to your family in navigating the challenges of Hirschsprung's Disease?

For SOP 2: What coping strategies do families employ to manage the emotional and practical aspects of caring for a child with Hirschsprung's Disease?

1. Can you describe some of the emotional challenges you and your family have faced while caring for a child with Hirschsprung's Disease?
2. What coping strategies have you found helpful in managing the emotional stress and anxiety associated with caring for a child with Hirschsprung's Disease?
3. How do you and your family navigate the practical aspects of caring for a child with Hirschsprung's Disease, such as medical appointments, dietary restrictions, and managing symptoms?

4. Are there any specific support systems or resources that you have found beneficial in helping you cope with the challenges of caring for a child with Hirschsprung's Disease?
5. Can you share any personal experiences or examples of how you and your family have adapted or developed coping strategies to effectively manage the emotional and practical aspects of caring for a child with Hirschsprung's Disease?

For SOP 3: How do families navigate the healthcare system and access necessary resources to support their child with Hirschsprung's Disease?

1. Can you describe your experiences in navigating the healthcare system to access necessary resources and support for your child with Hirschsprung's Disease?
2. What challenges have you encountered in accessing healthcare services and resources for your child with Hirschsprung's Disease?
3. How do you go about finding and accessing the specific resources and support systems that your child needs for their condition?
4. Can you share any strategies or approaches that have been effective in advocating for your child's healthcare needs within the healthcare system?
5. In your opinion, what improvements or changes could be made to the healthcare system to better support families in accessing necessary resources for their child with Hirschsprung's Disease?

For SOP 4: What role does social support play in the coping process for families with patients diagnosed with Hirschsprung's Disease?

1. Can you describe the types of social support that you and your family have received while coping with your child's diagnosis of Hirschsprung's Disease?
2. How has social support from friends, family, or support groups influenced your coping process and overall well-being as a family?
3. Can you share any specific instances where social support has made a significant impact on your ability to cope with the challenges of Hirschsprung's Disease?
4. In what ways do you feel that social support has helped to alleviate stress and provide emotional support for your family during this journey?

5. Have you encountered any barriers or challenges in accessing social support, and if so, how have you navigated or overcome them?

For SOP 5: How do families find meaning and purpose in their experiences of caring for a child with Hirschsprung's Disease, and how does this contribute to their coping mechanisms?

1. Can you describe how caring for a child with Hirschsprung's Disease has influenced your sense of meaning and purpose in life?
2. In what ways do you find meaning and purpose in your experiences of caring for your child with Hirschsprung's Disease?
3. Can you share any specific moments or experiences that have contributed to a sense of meaning or purpose in your role as a caregiver?
4. How does finding meaning and purpose in your experiences of caring for your child with Hirschsprung's Disease contribute to your overall coping mechanisms and resilience?
5. Have you discovered any strategies or practices that have helped you cultivate a sense of meaning and purpose in your caregiving journey, and if so, how have they influenced your ability to cope with the challenges?

APPENDIX B

CURRICULUM VITAE

CURRICULUM VITAE



Name	**Loraine Llanto Brusola**			
Date of Birth	November 16, 1984			
Contact Number	+639175026654			
Email Address	lbrusola@sblc.edu.ph			
Affiliation	Our Lady of Peace Hospital	Program/Department	Nursing Service	
Highest Educational Attainment	Name of Institution University of Sto. Tomas-Legazpi	Course Degree BSN	Years Attended 2002-2006	Awards
Research Trainings and Seminars	Organizers 1. BCTC (PHICNA)	Title Member	Month and Year 2022-present	

LORAINE LLANTO BRUSOLA
Name and Signature

Date: MAY 2024

APPENDIX C

CERTIFICATE OF MEMBER CHECKING

Certificate of Member Checking

This is to confirm that the transcript of the interview conducted last _____ has been validated. It entails accurateness and resonance with my understanding and experiences related to the study,
_____

_____ _____

Signature over printed name(initials) Date