

Empowering Stoma Care: Enhancing Knowledge, Confidence, and Support Through Collaborative Approaches Between Doctors and Parental Communities for Children with Stomas

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Introduction: Effective postoperative care is pivotal, and parents play a vital role in managing complications and outcomes. Despite their importance, parents often struggle with the complexities of stoma care. Managing pediatric stomas necessitates a collaborative effort between healthcare professionals and community support, forming a multidisciplinary team that empowers parents with the knowledge and confidence required for effective stoma management.

Purpose and Objectives: This study assesses the impact of collaborative efforts between doctors and community support systems on children's quality of stoma care.

Methods: A cross-sectional study involving 224 participants evaluated the influence of stoma support communities in Jakarta. The study used a validated 11-question questionnaire to measure community impact and stoma care knowledge.

Results: Spearman Correlation analysis indicated significant relationships between doctor-patient communication and factors such as the stoma's condition ($r:0.285$, $p<0.001$), knowledge ($r:0.417$, $p<0.001$), support in stoma care ($r:0.458$, $p<0.001$), self-confidence ($r:0.440$, $p<0.001$), support systems ($r:0.407$, $p<0.001$), and ease of access to care ($r:0.357$, $p<0.001$). Multivariate analysis highlighted that the quality of doctor-patient communication significantly affects stoma condition, support systems, self-confidence, and access to care ($p<0.025$). ROC prediction analysis showed that effective doctor-patient communication through Komunitas Stoma Pada Anak Jakarta (KOSPAAJ) significantly enhances support and self-confidence in stoma care ($A>0.70$).

Conclusion: The collaboration between doctors and community support significantly enhances parents' knowledge, confidence, and support in managing their child's stoma, leading to improved care quality and reduced complication rates.

Keywords: children, doctor, parental community, stoma, stoma care

Introduction

Stoma or ostomy originates from the Latin word ostium, meaning "opening" or "mouth." The intestinal stoma is the most common surgical procedure among the various stomas.¹ A stoma is commonly established in the small intestine (ileostomy) and large intestine (colostomy) to facilitate bowel evacuation.² Surgical openings were created on the anterior abdomen from the urinary tract or the bowel to create intestinal stomas. Depending on their type, it is defined as end stomas and loop or double-barreled stomas. The choice of stomas depends on the specific medical situation.³ Creating an intestinal stoma is a life-saving procedure, frequently performed and crucial in managing congenital and acquired gastrointestinal diseases.² Creating a stoma includes diverting fecal output, decompressing the intestines, protecting anastomotic sites, or a combination of these procedures. Unlike adults, pediatric stomas are temporary and serve as an initial procedure to address congenital disorders in children.⁴ Conditions necessitating stoma creation in children for survival include Anorectal Malformation (ARM),

Hirschsprung's Disease, Jejunoileal Atresia, Intussusception, perforated Necrotizing Enterocolitis (NEC), Trauma, and Intestinal tumor.^{2,4} The number of stomas used in the United States ranges from 750,000 to 1 million. An estimated 15,000 new ostomies are created each year. A stoma may be created as a colostomy or an ileostomy, either planned or as an emergency procedure. The Michigan Surgical Quality population-based study included 4250 patients. 37% had elective ostomy cases, and 55% had emergency ones.⁵

Stoma formation can help patients return to a healthy life and prolong their lives. However, this may cause patients living with a stoma to face both social and psychological challenges. Social problems include decreased working activities, less participation in social activities, worsening in partner relationships, avoidance of traveling, and reduced contact with relatives. Individuals with a stoma, such as low self-esteem, depression, changes in body image, anxiety, and stagnation, may experience psychological issues. Physical problems are often the common focus of healthcare professionals, and they mostly neglect the psychological aspects. Building a community for stoma users to experience understanding, care, and shared experiences is essential for the continuous care of patients with stomas.⁶ Caring for a child with a stoma requires more intensive attention due to the anxiety and fear experienced by both the child and the parents. Preparedness for stoma creation is crucial in enhancing the child's quality of life. The care of a child with a stoma involves a multidisciplinary team that can guide the family to feel more confident in managing the child's stoma condition.⁷ The recovery process for a child with a stoma depends not only on perioperative and operative conditions but also on effective family care. Research indicates that parents' ability to provide postoperative care can reduce complication rates and contribute to positive outcomes. Parents, as the primary caregivers, when the child leaves the hospital, may encounter challenges in stoma care due to a lack of knowledge and training from medical professionals, resulting from a short hospital stay.⁸

Methods

Place and Ethical Clearance of Research

This research was conducted at Tarakan General Hospital, West Java, and has received ethical approval from the ethics committee at Tarakan General Hospital (No.051/KEPK/RSUDT/2024).

Research Design

This cross-sectional study, conducted in August 2024 at Tarakan Regional Hospital, Jakarta, involved 224 research respondents.

Sample and Sampling Method

This study's sample consisted of parents who were members of Komunitas Stoma Pada Anak Jakarta (KOSPAJA) and had children with a history of stoma care or installation. The sampling method was total sampling, or all parents were invited to participate. The recruitment process followed a standardized protocol: all eligible parents were invited to participate in the study through an official communication distributed by the KOSPAJA administrators.

The invitation included a brief explanation of the study objectives, ethical considerations, and questionnaire instructions. Participants who agreed to participate were provided with a structured self-administered questionnaire, which they completed voluntarily. The questionnaire was distributed electronically via a secure link during scheduled community gatherings. Responses were collected anonymously to ensure confidentiality. This standardized approach ensured participant engagement and data collection consistency across the study sample.

Exclusion Criteria

The exclusion criteria in this study were parents who had difficulty speaking Indonesian or refused to participate.

Data Collection Methods

The questionnaire outline in the study is as follows:

1. Since when did you join the KOSPAJA group?
2. Reasons for creating a stoma

3. Stoma Condition
4. The community plays a vital role in increasing knowledge about stomas
5. Receiving Support and Assistance in Caring for a Stoma
6. Have a friend to share the condition of a child with a stoma
7. Feeling more confident in caring for a child with a stoma
8. Get additional knowledge from experts
9. Ease of obtaining stoma supplies
10. Regular Consultations
11. The Ways to Interact with Doctors

Questions 1–3 are only for personal and medical reasons for stoma research respondents. Questions numbers 4–11 are based on opinions and are responded to using a Likert scale of 1 (Strongly Disagree) and 5 (Strongly Agree).

Pilot Testing

This questionnaire was conducted as a preliminary study involving 20 research respondents outside the KOSPAJA community. The validity testing method used the Pearson Product-Moment test and reliability testing using Cronbach's Alpha (margin: 0.6). The entire questionnaire, totaling 11 questions, had a Cronbach's Alpha value > 0.8 .

Consent

This study was conducted offline after obtaining parental consent. It was piloted on twenty parents whose children had stomas. Parents who consented to participate in the study were asked to complete a questionnaire. They were also asked to sign an integrity pledge stating that they would not discuss the answers in this study with anyone else and would not refer to external sources while completing the questionnaire. Each parent was contacted in advance via email, and written consent was sent to their email for approval.

Data Management

Data were entered into Microsoft Excel and analyzed using IBM SPSS Version 21 for Windows, Armonk, NY. They were presented as descriptive statistics and analyzed, and free-text comments were collected.

Demographic characteristics of respondents were tabulated. Median stoma perception scores were calculated based on respondents' level of agreement with eight statements. The statements were rated on the following scale: strongly disagree = 1, disagree = 2, neutral = 3, agree = 4, and strongly agree = 5. Median scores were compared among subgroups of respondents based on demographic characteristics and background. Other responses were analyzed descriptively. Respondents' perceptions of the role of the community, support in stoma care, and confidence in caring for a child with a stoma were assessed by their level of agreement with the statements.

Respondents' perceptions regarding the importance of community support, consultation with a physician, and ease of obtaining stoma supplies were also recorded based on responses to the Likert scale. Further analysis was conducted if more than 20% of the respondents selected "agree" or "strongly agree" to a particular question. The training period in stoma competency and interactions with physicians were also recorded. Free text comments are invited to provide additional insights.

Data Analysis

Data were analyzed using descriptive methods, receiver operating characteristic (ROC) curve, and Spearman correlation analysis. This study involved 11 questions, with questions 1–3 focusing on the personal and medical reasons behind stoma installation. Questions 4–9 measured respondents' perceptions of the role of the community, support received, and confidence in caring for children with a stoma using a Likert scale. Questions 10 and 11 evaluated the relationship between doctors and patients using a Likert scale, where a scale of 1 indicates the best doctor-patient relationship.

Qualitative data from questions 1–3 were presented in proportions to describe the general reasons for stoma installation. For questions 4–9, data were analyzed by comparing the median scores of respondents' perceptions of

various aspects of support and confidence in stoma care. This analysis provides an overview of how the community and external support play a role in improving parents’ ability to care for their children.

Furthermore, ROC analysis was used to evaluate the doctor-patient variables (questions 10 and 11) as a reference line in determining the relationship quality between doctors and parents. The ROC curve allows researchers to evaluate the sensitivity and specificity of the doctor-patient relationship score. The Area Under the Curve (AUC) is calculated as a measure of the predictive accuracy of the independent variable being tested.

The interpretation of the AUC value in this context is as follows:

- 1. An AUC of 0.5 indicates that the model is no better than a random guess predicting the outcome, suggesting a non-significant doctor-patient relationship.
- 2. An AUC between 0.7 and 0.8 indicates moderate performance, indicating that the doctor-patient relationship is starting to play a role in determining stoma care outcomes.
- 3. An AUC between 0.8 and 0.9 indicates excellent performance, indicating that the doctor-patient relationship strongly and significantly influences parental support and confidence.
- 4. An AUC above 0.9 indicates excellent performance, and the doctor-patient relationship is a key factor in determining stoma care.

Result

This study revealed that among the 224 members of the Stoma Community for Children in Jakarta, 64.3% were male and 35.7% were female. Most members (61.6%) had been part of the community for less than a year, 22.8% had been involved for one to three years, and 15.6% for over three years. Regarding stoma conditions in children, 84.8% had closed stomas, whereas 15.2% still had open stomas. Most respondents (84.8%) emphasized the importance of regular doctor consultations, and 92.9% preferred face-to-face interactions at outpatient clinics over messaging (7.1%) (Table 1).

This study revealed that in the Stoma Community for Children in Jakarta, Hirschsprung’s disease was the leading cause of stoma creation, accounting for 50% of cases. Anorectal malformation (ARM) closely followed, contributing to 30.3% of stoma cases. Intestinal atresia was the third most common cause, representing 16.9% of cases (Figure 1).

Table 1 Characteristics of the Stoma Community for Children in Jakarta

Parameter	Frequency	Percentage (%)
Age (Mean, months)	224 (22.84)	100
Gender		
Male	144	64.3
Female	80	35.7
Community Join Duration		
<1 Years	138	61.6
1 – 3 Years	51	22.8
>3 Years	35	15.6
Stoma Conditions in Children		
Closed	190	84.8
It has not closed yet	34	15.2
Regular Doctor Consultations		
Strongly Agree	77	34.4
Agree	113	50.4
Neutral	31	13.8
Disagree	2	0.9
Strongly Disagree	1	0.4
The Ways to Interact with Doctors		
Outpatient Clinic	208	92.9
Message	16	7.1

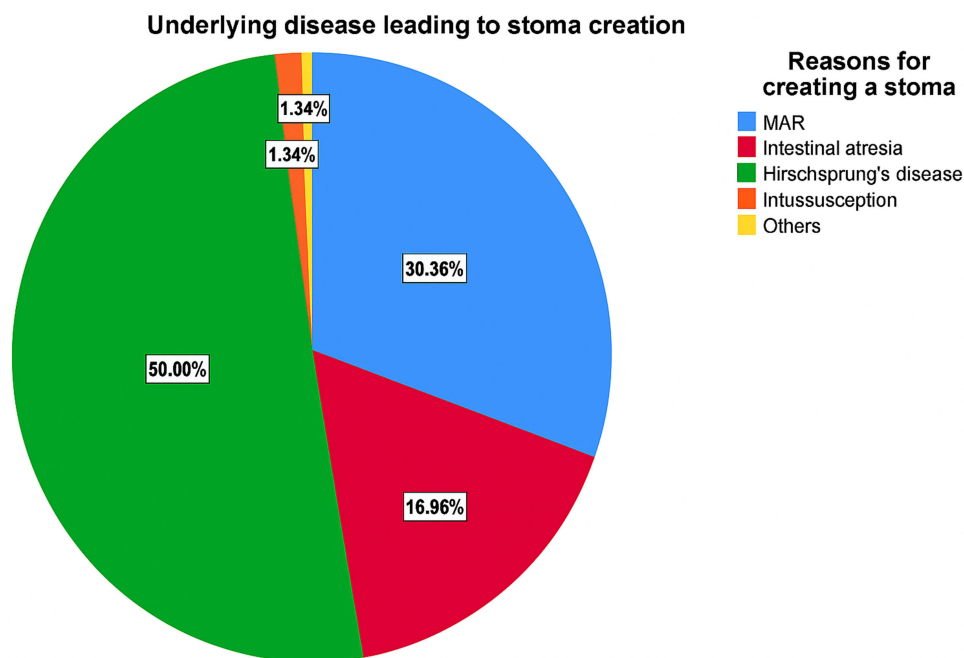


Figure 1 Underlying Disease Leading to Stoma Creation in the Stoma Community for Children in Jakarta.

This study underscored the pivotal role of parental communities in enhancing stoma empowerment. Most respondents valued gaining additional knowledge from experts, with 85.2% agreeing. Furthermore, 75.9% reported increased confidence in managing stoma care as a result of expert advice, and 84.4% appreciated the support and assistance they received. The findings also indicated that 82.6% found it beneficial to have peers with whom they could exchange information about stoma conditions, while 82.2% noted that stoma supplies were readily accessible. The results highlighted how community support and accessible resources significantly improved stoma management and empowerment (Table 2).

Table 2 The Role of Parental Communities on Stoma Empowerment

Parameter	Frequency	Percentage (%)
Get Additional Knowledge from Experts		
Strongly Agree	76	33.9
Agree	115	51.3
Neutral	31	13.8
Disagree	1	0.4
Strongly Disagree	1	0.4
Feeling More Confident in Caring for a Stoma		
Strongly Agree	60	26.8
Agree	110	49.1
Neutral	52	23.2
Disagree	1	0.4
Strongly Disagree	1	0.4
Receiving Support and Help in Caring for a Stoma		
Strongly Agree	78	34.8
Agree	111	49.6
Neutral	34	15.2
Disagree	1	0.4

(Continued)

Table 2 (Continued).

Parameter	Frequency	Percentage (%)
Sharing Information About Stoma Conditions		
Strongly Agree	79	35.3
Agree	106	47.3
Neutral	36	16.1
Disagree	3	1.3
Easy Accessibility of Stoma Supplies		
Strongly Agree	68	30.4
Agree	116	51.8
Neutral	38	17
Disagree	2	0.9

Multivariate analysis further highlighted that the collaborative approaches between doctors and parental communities significantly affected stoma condition, support systems, self-confidence, and access to care ($p < 0.025$). ROC prediction analysis indicated that, as assessed by KOSPAJA, doctor-patient communication was a robust predictor of support and assistance as well as self-confidence in stoma care, with an area under the curve (AUC) exceeding 0.70 (Figure 2 and Table 3).

Spearman Correlation analysis demonstrated significant relationships between collaborative approaches by doctors and parental communities and several key variables: reason for a stoma ($r = 0.280$, $p < 0.001$), stoma condition ($r = 0.285$, $p < 0.001$), stoma knowledge in the community ($r = 0.417$, $p < 0.001$), support and assistance in stoma care ($r = 0.458$, $p < 0.001$), self-confidence ($r = 0.440$, $p < 0.001$), support system ($r = 0.407$, $p < 0.001$), special knowledge ($r = 0.357$, $p < 0.001$), and ease of access to care ($r = 0.471$, $p < 0.001$) (Table 4).

Discussion

Living with a stoma can essentially influence the quality of life (QoL), affecting them physically, mentally, and socially. Physically, children with a stoma frequently confront challenges such as overseeing stoma care, managing skin irritation, and adapting to changes in physical abilities. These physical issues can lead to inconvenience and require continuous therapeutic consideration, which can disturb their daily activities and routines.⁹ Mentally, the nearness of a stoma can

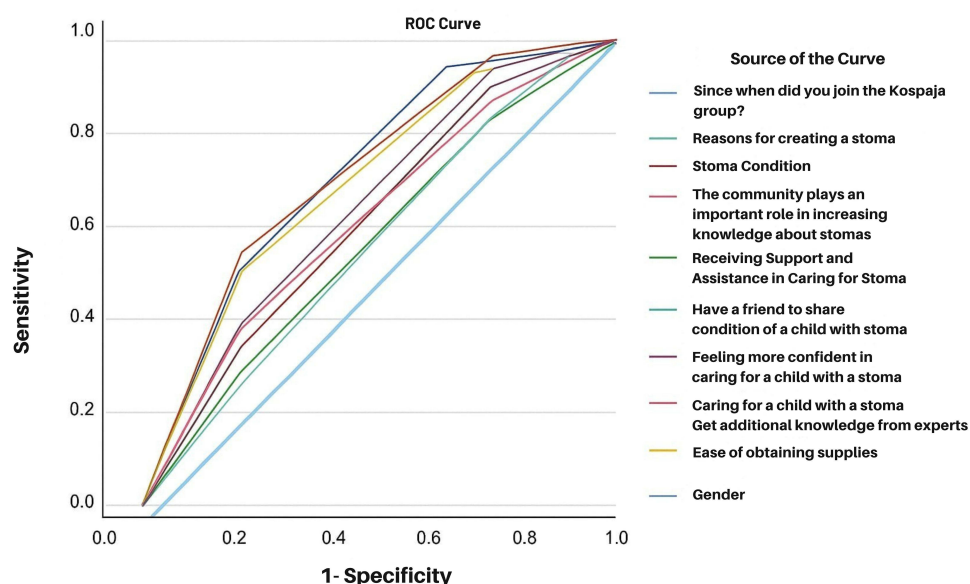


Figure 2 Receiver Operating Characteristic (ROC) Curve of Collaborative Approaches Between Doctors and Parental Communities.

Table 3 Area Under the Curve of Collaborative Approaches Between Doctors and Parental Communities

Parameter	Area	Std. Error	p-value	95% Confidence Interval	
				Lower	Upper
Since when did you join the KOSPAJA group?	0.509	0.042	0.822	0.427	0.592
Reasons for creating a stoma	0.608	0.041	0.010	0.528	0.689
Stoma condition	0.556	0.040	0.181	0.477	0.635
The community plays a vital role in increasing knowledge about stomas	0.655	0.038	0.000	0.581	0.730
Receiving Support and Assistance in Caring for a Stoma	0.723	0.036	0.000	0.652	0.794
Have a friend to share the condition of a child with a stoma	0.644	0.040	0.001	0.565	0.722
Feeling more confident in caring for a child with a stoma	0.704	0.037	0.000	0.632	0.776
Get additional knowledge from experts	0.647	0.041	0.000	0.566	0.728
Ease of obtaining stoma supplies	0.693	0.038	0.000	0.619	0.768

Table 4 Spearman Correlation Analysis of Collaborative Approaches Between Doctors and Parental Communities

Spearman Correlation		
		Doctor-Community-Patient Communication
Reasons for creating a stoma	Correlation Coefficient	0.280
	Sig. (2-tailed)	0.000
Stoma condition	Correlation Coefficient	0.285
	Sig. (2-tailed)	0.000
The community plays a vital role in increasing knowledge about stomas	Correlation Coefficient	0.417
	Sig. (2-tailed)	0.000
Receiving Support and Assistance in Caring for a Stoma	Correlation Coefficient	0.458
	Sig. (2-tailed)	0.000
Have a friend to share the condition of a child with a stoma	Correlation Coefficient	0.407
	Sig. (2-tailed)	0.000
Feeling more confident in caring for a child with a stoma	Correlation Coefficient	0.440
	Sig. (2-tailed)	0.000
Get additional knowledge from experts	Correlation Coefficient	0.357
	Sig. (2-tailed)	0.000
Ease of obtaining stoma supplies	Correlation Coefficient	0.471
	Sig. (2-tailed)	0.000

lead to sentiments of uneasiness, sadness, and a diminished sense of self-esteem in children. They may battle with body image issues and feel self-conscious about their appearance, which can be incredibly challenging over a long time.¹⁰ Getting support from family, companions, and healthcare specialists is noteworthy in changing how children investigate these social challenges.¹¹ Socially, the effect of a stoma amplifies to include family, companions, and classmates. Children may find engaging in social activities, attending school regularly, or participating in sports challenging due to concerns around stoma management and potential injuries.¹²

Some studies have indicated that ostomy patients encounter numerous issues post-stoma creation, primarily due to insufficient knowledge, inadequate pre-operative preparation, and suboptimal postoperative management. Notably, 73% of ostomy patients report skin-related problems. Effective stoma education is crucial for achieving proficiency in management and minimizing complications. Early intervention in stoma care management significantly enhances quality of life and reduces the incidence of complications.¹³

Providing holistic support, children can better adapt to their new reality and achieve a higher quality of life.¹⁴ Living with a stoma requires long-term adjustment and complex treatment, essentially affecting patients' QoL. According to the British Diary of Nursing, stoma surgery is an invasive procedure that influences the standard of living not fairly quickly post-operation, but throughout the patient's life. The changes in substantial capacities, body image, and individual care needs require continuous adjustment and can disturb social, emotional, and work-related life perspectives.¹⁵

Parents play a crucial role in the healing process and care of stomas. When caring for stomas, families must gain knowledge and develop various skills.¹⁶ They require assistance to alleviate the caregiving load. Enhanced preparation and support for the responsibilities they undertake are essential. The psychological impact on the whole family should be a key consideration in the preparation and support given to parents. Utilizing resources from trauma-informed care literature can help families manage challenging procedures and emergencies at home.¹⁷

Stoma patients' ability to care for themselves is significantly enhanced by community assistance, including peer networks and specialized stoma care. Based on the British Journal of Nursing Research, those with community assistance and structured instruction could adjust to their surroundings more skillfully and lead better lives.¹⁸ Parents and children face the dual challenge of adapting to the stoma and managing stoma care. Children's responses will vary depending on their age and developmental stage. Therefore, when establishing a therapeutic relationship with parents and children, it is essential to consider numerous factors to choose strategies that best fit the child's and family's unique circumstances. Typically, children in their first two years are wary of unfamiliar faces and tend not to trust strangers. Therefore, building a strong rapport with the parents is crucial, allowing the child to see this trust before any physical care is administered. Engaging in play and gentle physical contact can help form a positive relationship with the child beyond invasive procedures.¹⁹

Statutory services aim to assist parents in fulfilling their responsibilities, including coordinating care and navigating the system.²⁰ However, the practical implementation of this mandate is challenging. Recognizing the potential benefits of greater integration between healthcare services, various care models for children with medical complexities are currently being evaluated in Canada and the United States, emphasizing the importance of healthcare coordination.^{21,22}

Accessible and high-quality training is essential for parents to feel at ease when leaving their child in the care of others, whether paid carers, family members, or respite services. Increased access to respite care, peer support, and financial aid has been shown to reduce the burden on families. Reductions in services supporting families, such as respite care, can lead to acute problems and higher costs in the long term when families struggle to cope.²³ Community paediatricians and palliative care often play a significant role in care coordination, while charitable funds support nurses coordinating care, daily emotional and practical support, and parent/carer training. However, there is a need for the expansion of these services.^{24,25}

Communities play a crucial role in assisting families in navigating the challenges of stoma care. They offer vital resources that can significantly enhance the experience for these families and provide immediate assistance. This support encompasses emotional and practical needs and includes valuable training and information that make the caregiving process more manageable. Community care addresses the most basic human needs, both emotional and practical. Local support groups serve as a lifeline for families dealing with the emotional challenges of stoma care. These groups provide parents and caregivers with a safe space to connect with others who can relate to their situation. They can share their experiences, exchange advice, and find support, comfort, and encouragement in these environments.

Training and education are fundamental in effectively supporting families and caregivers managing stoma care. Educating parents of children with stomas can significantly boost their understanding of care through a family-centred approach, empowering them to manage and prevent potential side effects more effectively.^{26,27} Support from community health care services on proper stoma care techniques, the use of medical devices, and strategies for handling everyday challenges associated with stoma management benefits the patient's life and families. Participating in these programs gives them valuable knowledge and skills that enhance their confidence and competence in caregiving. Overall, communities play a crucial role in assisting families in navigating the complexities of stoma care by providing the necessary tools, knowledge, and support that help to increase people's quality of life.^{12,26,27}

This study has several limitations that should be considered when interpreting the findings. One key limitation is the absence of comparative data on complication rates between patients who received comprehensive parental and community support and those who did not. This restricts our ability to evaluate the potential influence of social support systems on clinical outcomes. Additionally, most participants (85%) had already undergone stoma closure during data collection. This may have introduced recall bias, as participants may not have accurately remembered the details of their stoma-related experiences. Furthermore, the emotional and physical distance from their period of living with a stoma may have affected the way they perceived and reported their experiences, potentially influencing the study results.

Conclusion

Collaboration between healthcare professionals and community support networks is vital in enhancing parents' understanding and confidence in managing their child's stoma. By combining medical expertise with community resources, parents gain crucial knowledge and hands-on guidance, which improves their ability to deliver effective care. This integrated approach helps parents navigate the complexities of stoma management and provides essential emotional and practical support. Consequently, this partnership results in higher-quality care, fewer complications, and better outcomes for children with stomas. This holistic support system ensures that families are well-equipped to handle the challenges of stoma care.

Acknowledgments

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Ethical Declaration

This study complied with the ethical standards outlined in the Declaration of Helsinki. The research protocols were reviewed and approved by the appropriate institutional ethics committee, ensuring the protection of the respondents' rights, safety, and well-being throughout the study. Respondents were informed of their rights, including the right to provide informed consent, the right to withdraw at any time without penalty, and the right to ask questions and receive clear information about the study. Confidentiality was strictly maintained, with no identifying information used or disclosed at any stage of the research process. All respondents were treated with respect and dignity, and measures were taken to minimize any potential risk or harm associated with participation.

Disclosure

The authors report no conflicts of interest in this work.

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