

Parental Experience of the Children with Gastrointestinal Stoma in Kanti Children Hospital, a Tertiary Level Children Hospital in Nepal

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ABSTRACT

Background: The gastrointestinal stomas are seen as the obligatory condition for the treatment of children with gastrointestinal malfunction where their parents have to face various challenges. The lived experience of parents having children with gastrointestinal stomas was explored in this study

Methods: Qualitative phenomenological research design was used. Data were gathered by interviewing total 11 mothers with children having stoma for at least 2 weeks and admitted in a hospital. Thematic analysis was done with obtained data.

Results : Six major emergent themes from the study were the parent's journey with child's health, challenges faced, resilience in caring the child, change in family life, support system and socio-cultural perception and influence.

Conclusion: Parents of the children with the stoma face a range of problems and challenges. So, to sustain a better and conducive life of the parent and their children with stoma, parental resilience must be enhanced by developing an integrated support in the journey of the parenthood.

Keywords: Gastrointestinal stoma, Children, Parental experience

INTRODUCTION

Gastrointestinal (GI) stomas are temporary or permanent openings of the bowel pass through the anterior abdominal wall created through surgery and can be temporary and permanent as per its function.^{1,2} formation, common complications Anorectal malformations (ARM) and Hirschsprungs disease (HD) are still to be considered as the most common indications for colostomy in newborns and infants. Globally 1 in 3000-5000 live births have ARM and HD, the leading indications for GI stoma in paediatrics.^{3,4} In Nepal, data from Kanti children Hospital (KCH) indicated that the proportion of GI stoma cases were around 125 out of 736 i.e. 17% of admitted surgical cases were of ARM and HD (as per the hospital record from November 2017- April 2018).

Stoma is also one of the complex or long term health conditions amongst children and their parents, being the

primary care taker are mostly accountable for providing respective technical health care. Parents, especially mothers, have much more difficulty in handling and coping with all new demands of the new child by lack of sleep and feeding demands as well as coping with a stoma, as children are mostly dependent and physically different in compare to muscular structure of adults.³

Gilligan⁵ referred to a spectrum of resilient outcomes for the children and his family in special care conditions ranging from survival, coping and thriving. Many qualitative researchers have discovered that parents put in their own internal coping resources along with array of skills and strategies as an active effort for caring themselves and their families.^{6,7} However, there is lack of study on this subject in Asian countries including Nepal. Therefore, this qualitative study was conducted with the purpose of exploring the lived experience of parents who are having children with GI stomas. The findings of the

Article information		
Received: 8 July 2022	Accepted: 30 July 2023	Published online: 31 August 2023
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study would be helpful to develop a holistic view of the parental perspectives that can be useful in the care of children with stomas.

METHODS

This study used qualitative phenomenological design. The populations of the study consisted parents of children who had temporary or permanent GI stoma formation in Kanti Children's Hospital, the only tertiary level government children's hospital of Nepal. The sample population was any parent of children who have had GI stoma formation in Kanti Children's hospital at least 2 weeks ago.

Non-probability purposive sampling was used for the selection of participants. Since, mothers were the primary caretakers, all parents preferred mothers to be the participant for the study. For In depth interview, Creswell recommends 5 – 25 and Morse suggests at least six.^{8,9} So, altogether 11 mothers were included for in-depth interview. Approval of the research proposal was obtained from institutional review board of National Academy Medical Sciences and ethical committee of Kanti Children's hospital. Informed written consent was obtained from each participant. Confidentiality of the information was assured and participants were free to discontinue from the study anytime during data collection if they wished. The interviews were taken at the hospital in a separate room to ensure privacy. Permission was taken for audio taping of the interview. The in-depth interview of each participant using an open ended in-depth interview guidelines was taken 1-3 times as per the need. Data were collected during the period of one month from June 25 to July 23, 2019.

The audio-taped verbatim were transcribed and read repeatedly until familiarization with the text in order to hold the comprehensive knowledge of the participant's lived experience. This was followed by clustering the noteworthy facets for creating concrete categories; then analysis of these categories and assessing the expression of their experience. The analysed data were validated by an external expert through review of data analysis process and review of the identified subcategories, categories and themes.

RESULTS

Socio-demographic characteristics of the participants included in in-depth interview revealed that 6 out of 11 were living in joint families. All of them were literate and 10 out of 11 had secondary and/or bachelor level education and five out of 11 were service-holders.

Table 1 illustrates the demographic and stoma –related information of the children of the participants. All children had GI stoma done for congenital deformities. Four of them were operated due to HD and remaining 7 for ARM. The age group of the children ranges from infancy to adolescence. The age of the stoma formation varied in HD cases whereas in ARM, stomas were formed within first few days of life. Four out of 11 children had siblings.

In-depth interview data from 11 participants were analyzed using thematic analysis. In total 32 subcategories and 27 categories were identified with emergence of six main themes.

DISCUSSION

The discussion section includes the in-depth analyzing of the findings by utilizing existing theoretical and research literature to enhance the understanding of these findings

Theme 1: The Parents' Journey with Child's Health

Stoma formation was perceived as the critical period by all parents. In this study, stoma formations were primarily associated with congenital causes of children. These causes usually include abnormal formation of anal tract or any deformity in nerve supply in the gastrointestinal tract. The parents expressed their journey by relating to their experience of caring the children in various states of illness and the health conditions of their children. In this study, the parents had expressed their perception of their child's health as a journey from the identification of the disease condition until how they had thought for the upcoming future. The parents were stressed by the disease condition of the child. The parents expressed their difficulty in identifying the child's disease in Hirschsprungs disease in which normal anatomy was seen and definite disease could not be identified. A similar scenario was explained in a research done in Brazil where the mothers were aware about own child's problem but neither clearly describe about the child's actual disease not understand the pathology.¹⁰

Theme 2: Challenges Faced

The parents of this study experienced a number of challenges due to having a child with congenital abnormality who had undergone surgical ostomy procedure. These challenges included emotional, financial, physical and transportation challenges. The parents faced the physical and transportation challenges as they had to bring their child from different parts of the country with limited transportation services. The parents also faced difficulty in caring the child in the long route of the vehicles since the vehicles were not ill-child friendly. They dealt with many emotional challenges like uncertainty, anxiety, stress and anger. This finding is similar to the study about family experiences which indicated the parental emotional state with continuous feeling of loneliness, irritability, frustration, anxiety and guilt.⁷ Another study by Sanchez identified that the child's poor condition made parents speechless and lonely.¹¹

Financial challenges and crisis were faced by all of the parents in this study. The financial crisis included all aspects of daily earnings and spending in different aspects of care including treatment of the child. Lemacks et al. had also indicated a similar financial impact in the family like travelling expenses for care which included the hotel stays, meal, travel cost, the time away from work, and other expenses like medical costs and health related costs.¹² One of the mothers in the present study stated financial loss on colostomy bag too. These findings are consistent with the findings of the study conducted by Sanchez et al. which stated that the cost also includes the cost of colostomy bag which caused financial worries.¹¹

Theme 3: Resilience in Caring the Child

Resilience, the capacity to recover from difficult situation was done by mothers by changing perception towards the disease condition, acceptance of the stoma, caring techniques and dealing with the associated disease

Table 1: Child related Information of the Participants of In-depth Interview (n=11)

Pseudonym participant	Sex of the child	Age at stoma formation	Stoma indication	Hospital admission	Current age group	Number of siblings	
1.	Ms. Radha	Female	4 days of life	ARM	2 times	Infant	-
2.	Mrs. Mira	Female	2 days of life	ARM	3 times	Preschooler	-
3.	Mrs. Maya	Female	2 days of life	ARM #	3 times	Toddler	-
4.	Mrs. Sarita	Male	1 year	HD	3 times	Toddler	-
5.	Mrs. Sita	Male	2 days of life	ARM ##	4times	Infant	-
6.	Mrs. Gita	Male	1 day of life	ARM	2 times	Toddler	1
7.	Mrs. Rita	Male	1 day of life	ARM	3 times	Toddler	-
8.	Mrs. Nita	Female	1 day of life	ARM	2 times	Infant	-
9.	Mrs. Mina	Male	2 months	HD	2 times	Toddler	1
10.	Mrs. Kanchan	Male	7 years	HD###	6 times	Adolescent	2
11.	Mrs. Reena	Male	5 months	HD	2 times	Toddler	1

Note: ARM = Anorectal malformation, HD = Hirschsprungs Disease, # =associated Down syndrome, ## = associated UTI, ### = associated impacted stool In-depth interview

Table 2: Thematic Findings of the In-Depth Interview of Participants

Themes	Category
1. The parents' journey with child's health	i. Experience before diagnosis of disease ii. Experience after diagnosis of disease iii. Experience during operation iv. Health status of the child
2. Challenges faced	i. Physical and transportation problems ii. Financial challenges iii. Emotional Challenges iv. Coping with challenges
3. Resilience in caring the child	i. Perception of disease. ii. Acceptance of stoma iii. Caring the child iv. Caring techniques v. Challenges with associated disease vi. Challenges in caring the child vii. Improving self -assurance viii. Perception of the child ix. Future plan
4. Support system	i. Spouse support ii. Support from health professional iii. Other support system
5. Changes in family life	i. Work and managing leisure activities ii. Daily routine iii. Change in life style iv. Challenges in caring the siblings v. Perception of owns state.
6. Socio-cultural perception and influences	i. Social perception ii. Cultural influences

conditions. Sense of coherence is a part of resilience.¹³ Three components; Comprehensibility, manageability and meaningfulness are included in the sense of coherence.¹⁴ In this study the parental comprehensibility was gained by the perception of the disease. Manageability along with the comprehensibility of the parents was revealed by the acceptance of the stoma and caring the child, and identifying child's perception. Meaningfulness was expressed as the motivational statement of the parents for improving self- assurance and future plans.¹³

The parents of this study perceived the disease condition of their children as a fate and this helped them accept the situation, resilience for caring, continuous treatment of their child and carrying out normal activities. Menezes et al. in Uruguay had presented similar ideas of adapting with the child's condition and having faith on god as an act of overcoming the stress.¹⁵

All of the participants in this study had used the soft cotton clothes, called "malmal ko kapada" or "taloo", as an abdominal binder or wrapper for caring the stoma. They were concerned about the hygiene and care of the stoma by applying vaseline, cream or oils as lubricants. Use of the cotton balls in cleaning was not preferred by some participants due to its stickiness in the stoma and fear of infection. They had preferred the cotton clothes as it was more convenient to make, easily available, reusable and more cost effective. This practice corresponded to the findings of a study, in Bangladesh, which states that the most commonly used barrier ointment was the petroleum jelly which was locally available, acceptable and affordable.¹⁶

This study showed that the mothers viewed diverse reactions of children. Adolescent were more concerned and required more privacy; infants were only concerned in oral gratifications; whereas toddlers were more curious and exploratory. The mother had found challenges with the changing behaviour of the toddlers like exploration of the stoma and crawling. Menezes et al. and Sanchez et al. also had described similar context of behaviour of children while developing their own autonomy and mother's response to child behaviour in similar context.^{15,17}

While colostomy bag were used by few mothers only in this study, they had stated many problems in using the bag. The bag in school going child caused smelling and the stool used to remain there, whereas in smaller children, it caused irritation and multiple bags were required causing financial problems. A study in UK also found the problem of smells and skin irritation in children.¹⁸

Theme 4: Support System

The support system included the help and support gained by the participant from their spouse, family, friends, and their relatives and even from the health professionals. Whilst in this study, the spouse support was found to be the primary support for the mother as they shared

their responsibilities and managed their work for the child. Wigander also identified that the mothers hold the primary responsibility and father helped in being responsive and adapting in the situation.¹⁹

The findings of this study showed that the health professional were the experts for providing guidance to the parents. Other studies also showed similar findings i.e. the guidance of health professional seemed as one of the sources of helping how to deal with such cases.^{10,20,18} Menezes et al. also indicates in their study that health professional's interaction and encouragement supported the families and helped mothers to accept their child's situation better, provided confidence and helped to understand and accept the chronicity of the condition in the child.¹⁵

The participants' children were being repeatedly admitted in the hospital. The support from other parents whose children are being admitted had enhanced their practice and the way of their thinking. This scenario seemed to be alike in Asian countries. In a study in Japan, the participants stated similar experience as the relationship with other parents was important and the sharing of knowledge helped in their coping especially for the new parents.²¹

Theme 5: Changes in Family Life

Change in family life included the change in life style of parents and family, daily routine, work and in caring the siblings. This study revealed that the life style of the mothers had entirely been scheduled with the child and engaged in child without caring for the self. Mothers had felt some restriction on going outside. Some of the working mothers had changed their work or left the job to give enough time for the child whereas the fathers were obliged to work to earn money for treatment. This findings are alike with other studies where there were indications of change in family lifestyle, leaving job for staying with the child and financial circumstances.^{7,10,11} The leisure activities were quite negligible and only possible with other support system.

This study showed that the siblings of the child with stoma had also faced the change in the care they received. The regular treatment and care of the child with stoma had impacted on the siblings to be cared by relatives and their study was hampered. This finding is supported by the study conducted by Lemacks et al. which also showed that the siblings felt being neglected which could result in behavioural issues and/or depression.¹² The mothers in this study had also experienced the family conflicts. Zacarin et al. in their study also found that the mothers expressed themselves to be helpless and self-inefficacy in some extent in the beginning and subsequently having courage to deal with the situation while developing self-assurance.⁷

Theme 6: Socio Cultural Perception and Influences

This includes the cultural influences and beliefs verbalized by the participants and the social influences, perception and the challenges that the mothers felt while caring their child. The parents were being affected by the society around them while having the social integration. The cultural influences were usually regarding the practices the society had thought in treating the child. These practices usually differ from one area to another. The parents from rural areas had expressed their cultural

influences like taking the child to dhama jhakris for treatment, applying ghee, and even providing instruction for cutting the unformed anal area with blade or piercing with the sharp wood. The literature supports the possible attempts of the parents to search alternatives like visiting traditional healers than going to health centres is usually common in low and middle income countries.²²

In this study, the society seems to have the curiosity as well as negative perception regarding the abnormalities in the child, which had emotional effect on the mothers for being socially isolated. The mother of Down syndrome baby had expressed her higher level of emotional stress due to dual morbid condition. Such social impact and isolation were also noted by other related literature.^{7,11} On the contrary, society had even provided the emotional support to some mothers in this study which had enhanced their adaptation.

CONCLUSIONS

This study concludes that a child with stoma require continuous care, attention, efforts and self-resilience in the parent, and parents tend to face a huge array of problems. An integrated support system is essential for their effective adaptation. The findings of this study have implications for health professionals to be aware of challenges and difficulties that the parents of children with stoma face and to facilitate and support parents in their coping and in providing effective care to their children.

Acknowledgements: We would like to express our gratitude to Ms. Margaret Walsh, for her invaluable suggestion and expert view in data transcription and coding. We are grateful to all the participants for their valuable time and information.

Ethical approval: The approval for this research was obtained from the Institutional Review Board (IRB) of NAMS and Institution Review Committee of Kanti Children Hospital for ethical clearance.

Data Availability: The data that supports the findings of this study are available as a part of this paper.

Source of Funding/ Support: This study was a self-supported study conducted for the educational purpose of the principal author.

Conflicts of Interest: Authors declare no conflict of interest.

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