


Explaining the Care Experiences of Mothers of Children with Hirschsprung's Disease: A Qualitative Study

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Hourieh Abbasiasl¹, Ashrafalsadat Hakim¹ ,
and Kourosch Zarea¹

Abstract

Hirschsprung's disease is a gastrointestinal anomalies that disrupts excretion. In this disease, like other chronic diseases; mothers undergo a lot of care. Considering the concept of nursing care, it is important to understand the care and its effects on the parents, the child, and care improvement. The purpose of this study is to understand the care experiences of parents of children with Hirschsprung's disease. In this qualitative study which was performed by content analysis approach, 12 participants were selected from mothers of children with Hirschsprung's disease who were referred to pediatric surgeries through purposeful sampling. The data collection method was a half-structured interview. All interviews were recorded and then were handwritten word by word and data were analyzed using Elo and Kyngas qualitative content analysis method. Data analysis began from the time of the first interview and in parallel to the next interviews (simultaneous analysis). At the beginning, the first-level coding was done. Data analysis led to the emergence of 3 main themes: "erosion care, socio-economic challenges, acceptance, and position-matching;" and each of the themes included several sub-themes. The results of this study showed that parents of children with Hirschsprung despaired of concern and suffering from care which these suffers included physical, psychological, social, and material dimensions, but was also associated with satisfaction and acceptance of the disease. These findings emphasize that one of the most important tasks of nurses in clinical institutions, especially in relation to these children, is to provide proper family-centered care.

Keywords

Hirschsprung's disease, care experiences, mother, children, qualitative study

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Introduction

Hirschsprung's disease is the most common congenital disorder of bowel movement which its incidence is 1 out of every 5000 to 10 000 live births.¹ A variety of clinical demonstrations can also range from a minor or severe constipation with or without specific diets at different ages to failure to excretion of clear meconium and distention, even if perforation of the proximal colon and peritonitis varies in the first few days of birth.² Children with Hirschsprung's disease are placed in the group of chronic diseases throughout their lives due to chronic intestinal disorders.³ As a result, post-operative defects in these children will have negative effects on the child

and the family.^{3,4} Therefore, long-term follow-up of these children is essential for improving intestinal function.⁵

However, these problems affect the quality of life of the child and the family and in fact, they affect the whole social system of the child and the family.¹ So that more

¹Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran

Corresponding Author:

Ashrafalsadat Hakim, Nursing Care Research Center in Chronic Diseases, Department of Nursing, Ahvaz Jundishapur University of Medical Sciences, Ahvaz, Iran.
Email: hakim3448200@yahoo.com



than half of the parents of children with this disease are worried and confused about their child's future, and supporting their parents will hope and ensure the future of the child.⁶ Parents' care of the child actually includes activities that parents take care of their child, including physical, mental or social care, and in line with improvement of the child's health or psychological well-being.⁷ Also, due to the nature and condition of children's illnesses, families should have a pivotal role in the care plan.⁸ Researches show that supporting the family and providing information and education to parents make them feel more controllable and more powerful on different situations and a realistic view of their child's status.⁹ Therefore, parental experience is important in the participation and care of the child.¹⁰ In this regard, nurses are in a unique position to interact with people and family members. Nursing care is effective if in addition to the patient, the family will be regarded and the world will be seen from their eyes.^{11,12} The results of the study showed that important factors are in the role of nurses as providing support to family members, helping family members to express their feelings and pushing the family to a balanced position.¹³ Because the families have an important rule for patients, they should be regarded as patients in the nursing intervention program. Understanding the needs of the patient's family helps the nurse to identify the main elements of the crisis and use them in designing the appropriate treatment measures.¹⁴ For this reason, it is recommended to study the experience of groups of caregivers, especially the patient's family.¹⁵ Due to limited researches in this area, the researchers proceeded to perform a qualitative study of content analysis to determine the real experiences of parents of children with Hirschsprung's disease. Ultimately, the implementation of this research may lead to improved quality of care and optimal management of the disease by the health team.

Methods

This research is a qualitative study whose results were derived from qualitative content analysis and continuous comparison of data. Content analysis has a wide application in qualitative research, and this method is a suitable approach to provide evidences, clear and summarized descriptions of intended phenomenon.¹⁶ The researcher has deeply examined the care experiences of parents of children with Hirschsprung's disease. A total of 12 Participants were selected among the mothers who had a care experience of child with Hirschsprung's disease in 2 educational hospitals of Ahvaz. Sampling was based on purpose. Thus, parents

who were willing to participate in the study were interviewed individually and it was continued until data saturation and lack of access to new data. Before the parents were interviewed, it was talked about the aim of this study and a written informed consent was given to them to participate in the study. The conversations were recorded on the audio file and then they were written on the paper. Content analysis was used to analyze the study. Data analysis began from the time of the first interview and in parallel to the next interviews (simultaneous analysis). In this way, the notes were studied several times in order to obtain a general understanding of the text, and then the text was read line by line. At the beginning, the first-level coding was done, so that the sentences in which the questions were answered were identified. Then, a theme was given to the main concepts in these sentences. By comparing the themes together, a list of main themes and sub themes was obtained. In the second-level coding, the main themes and sub-themes were read out, and then the main themes with the same meaning were classified together and the categories were formed.

The coding and determining the categories were performed by the researchers, and then the themes determined by the researchers were compared with each other. In order to validate the results, the interviews were repeatedly read and the opinion of the professors was repeatedly used. Also, external monitoring was used to increase its reliability. So that a part of the data was given to a researcher who was not related to the study as a foreign observer, to determine whether he has a similar understanding of the data or not. The length of each interview varied from 20 to 70 minutes depending on the participants' circumstances.

“Ethical Approval and Informed Consent”

The ethical considerations included getting informed written consent from parents to participate in the study, giving parents reassurance in confidentiality of their conversations, and deleting audio files after writing their conversations on paper.

Results

The demographic characteristics of the participants are shown in Table 1.

Three main themes were obtained from the analysis of handwritten text about the career experiences of mothers in children with Hirschsprung's disease (Table 2).

Table I. Demographic Specifications Participant.

No.	Duration from diagnosis	Education	Age (years)
1	13 years	Diploma	40
2	4 years	Diploma	33
3	2 years	Diploma	30
4	3 years	Elementary	40
5	2 years	Elementary	28
6	15 month	Diploma	26
7	6 years	High school	32
8	14 month	High school	18
9	2 years	High school	33
10	6 month	college education	23
11	2 years	Diploma	25
12	8 month	High school	27

A) Erosion Care

1) The need for constant care

This disease made parents especially mothers to take care of their child for a long time due to its chronic nature. The common follow-up of this disease was its recurrence which caused mothers to be involved regularly.

2) The child's lack of tolerance

On the 1 hand, the sick child also suffered. This finding was the result of parents' statements and their experiences of child care. These sufferings were due to various factors, such as surgical or care procedures, such as enema.

3) Parental frustration

Parents are the most important people who are in direct and continuous contact with their sick child, so that sometimes the hardships of care, especially washing the area of colostomy and the lack of definitive treatment of their child's disease were painful to them.

4) Parents' confusion

Naturally, parents are worried about the future of their children. If it is accompanied by a chronic and persistent disease, this concern will be twice. On the other hand the lack of sufficient information about their child's future and sometimes contradictory information about the disease of child and the way of care also will be added to this confusion.

"I say in the future this child wants to go to school, what will be his/her future,

"The nurse said that their children will always be involved, one says they won't be healed," one says, "they will be healed" (second participant).

5) Physical care

Physical care, including medical, surgery, and nutritional care, was very prominent in these children. So that the provision of care caused long-term involvement of the parent.

In the case of nutritional care, the parents, especially the mother had useful activities.

B) Socio-Economic Challenges

1) Call for support

In fact, according to the parents' statements, their sick child causes issues beyond the individual's challenges, and the scope of these issues is drawn to the society, and there are always economic issues in these families, and almost all the families have paid attention to it. Support included the spouse, especially the father and family members, associates, as well as the medical and hospital staff, which was sometimes positive and sometimes there was not any support by mentioned groups.

2) Cost-creating positions

Due to continuous surgery and care as well as procedures such as enema and colostomy and its equipment, this disease is costly and causes financial pressure to the family. (3) Social stigma and its influence on families' relationships

Parents tend to refuse to disclose their child's disease because they believe that others are stigmatize their child sick and mocking her/him and this impression may remain in their minds for years.

Children suffering from this disease, due to special circumstances and frequent and long-term care, cause the whole family to be involved in child care and, consequently, it affects the whole of the family.

C) Compatibility with Position

(1) The need for awareness

Having information about the disease and the conditions ahead is effective in improving child care.

Table 2. Care Experiences of Mothers of Children with Hirschsprung's Disease.

Main themes	Secondary themes	Concepts extracted from interviews
Erosion care	The need for continued care	Chronic disease, continuous follow-up in treatment, recurrence of the disease after surgery, consequences of colostomy, resistance to medical treatments
	Child indifference	Symptoms of a debilitating illness, unfavorable physical and mental conditions, frequent malaise of the child, the child's resistance to the necessary care, the urgency of the child's condition after the initial diagnosis
	Mother's helplessness	The difficulty of caring for a child, unfavorable mental state, physical helplessness from the treatment of the child, unfavorable conditions when transferring a child
	Mother confusion	Wandering from contradictory information, violation of maternal cognition and awareness, consequences of disease awareness, concerns about colostomy and excretory function, lack of hope for the child's prognosis, paying too much attention to the baby's weight gain
Socio-economic challenges	Permanent physical care	Medical and surgical care, nutritional care, ostomy care and self-medication
	Want support from around you	Support from those around the parents, the level of support of fathers in care, lack of proper understanding of parents by medical staff
	Costing arrangement	Cost of colostomy treatment and care, financial problems associated with frequent visits
Compatibility with situation	Social stitch and impact on social relationship	The effect of disease on family relationships, bad conditions when attending community, pretending that the disease is not obvious in appearance, not exposing the disease in the community, the discomfort of being born with a stigma
	Acquiring awareness	Awareness of the nature of the disease, thirst for more training, awareness of disease accelerators and chronology in treatment
	Acceptance and hope	Child adoption, mother's hope for recovery, acceptance of the action by the mother, help god
	Earn special skill	Increase skills in care, effective for, special diet, provide special conditions for defecation of the child, implementation of treatment methods

Parents tend to have this information. Parents have tried to communicate with other families with infected children, that is, to use experience of each other in taking care of their child.

(2) Acceptance of disease and hope

Parents tolerate many problems faced by children, but still, besides this situation and performing their other duties, do their best to improve the health of their child.

Sometimes religious beliefs have made the mother better compromise with the child's hard conditions.

(3) Earn skills

The passage of time has improved parental care and they were better able to take care of their child.

Discussion

Based on the results of this study, the most important care experiences gained by parents, especially the

mother for being the main responsible person in care were suffering and difficulty for the parents and the child's extreme suffering, so that the child's suffering caused the physical and mental pressure of the parents. The role of parents in the lives of children suffering from anorectal malformation is difficult as one who should monitor and adapt to the child's disability.¹⁷ This cause of chronic disorders with prolonged functional problems in Hirschsprung's patients may have an impact on the quality of life of the child.¹⁸ The results of the study, with other studies related to health and care issues, indicated that the disease needs to be tracked because in addition to surgery and subsequent care; there was a probability for recurrence of the disease, and all of these items along with other parental care have caused special physical and mental pressures on the parents and even on the child.

In this study, the nature of the disease and its type of treatment and care led parents to devote a lot of time to their child's health and wellness, and this disease has undeniably put a lot of pressures on the family and the child including physical and mental

pressures on the child due to the pain and suffer from the type of care and fear and concern, as well as the change in the natural environment of life and subsequent frequent admissions. So that in other studies, it has been seen that performed procedures are some of causes of mental stress on mother and child.¹⁹ Therefore, it can be said that the special care and frequent admissions of these children caused many concerns for both the family and the child. As mentioned, parents suffer most from the care of their child, however mothers are more likely to be subjected to physical and mental stress than fathers. The results of this study showed that awareness of the disease, especially at birth, caused disturbance and even had shocked parents due to the lack of meconium excretion, especially when surgery was needed with stoma. In a study, the birth and hospitalization of a child at birth along with an emergency surgery has created a stressful emotional experience for couples.²⁰

The results also showed that, in addition to the physical burden of child care, mental stresses bothered the family such as fear and anxiety due to the chronic disease, frequent and prolonged hospitalization, post-treatment complications, and sometimes re-surgery. Also showed that mothers of these children are in high risk of mental disease compared with fathers and require professional counseling.²¹ The results of the study also showed the confusion of participants, as mothers stated that the controversial information was forwarded to them by the health team and caused them distress. In this regard, research results also showed that doctors' lack of understanding needs and improving adequate care has led to dissatisfaction among parents.²² One of parents' concerns about the child's future was school attendance due to excretion issues. A study also found that excretion disorders in children and communication issues in the child's future, such as attending school, cause emotional disorders in the family and the child.²³ Among the participants' statements in the present study they asked for information about their child's future performance. In this regard, the results of the study showed that parents need information about the future performance of the child after treatment.²¹ From the results of this study and other studies, it is clear that parents are incapable of understanding the disease and care required for children. Thus, according to the above results, it is important to conduct research in relation to the educational needs of parents.

On one hand, mothers were complaining of inadequate care-education providers in clinical settings. Therefore, these conditions require the full attention of

the health team, which means that care before and after surgery is critical due to special circumstances of the child to prevent severe complications. In the present study, nutritional counseling was an important care factor which has led to satisfactory results. On the other hand, the child's resilience or the neglect of parents in observing a particular diet led to exacerbation of symptoms. In another study, along with this result, nutritional counseling has led to child's health.²⁴ It is worth mentioning that dietary advice should be considered for these children. Another important care in these children was the care of the stoma and its dressing which caused long-term involvement of the parents especially the mother; therefore, the related care needs long-term attention at a short interval by the parents. In this regard, a study also showed that responsibility for managing intestinal programs was carried out by the mother, which this care has a high level of concern in association with enduring treatment follow-up for her.²⁵ From the results of the study, the abnormal excretion condition of the child was a concern for the mother, however she has tried to normalize her child's excretion condition.

The study showed that the disease burden was transmitted to all members of the family. Other results from this study revealed that parents were reluctant to reveal their child's disease because they believed that their child will be mocked by others, although it was not satisfied for all participants. Another study found that parents of children with chronic incontinence had limited social relations.²¹ The results of this study showed that physical and mental stress had been transferred more to the mother so that her health and support expectations from the health team had been increased. In a research, fathers of hospitalized children were also marginalized, and this care was restricted only to the mother.²⁶ Therefore, playing this role as a father for supporting child and his spouse should be accompanied by health professionals.²⁷ Physicians must understand that parents of a child with anorectal malformation have not enough experience and knowledge about education and care of their children.²⁸ The results from other studies have also shown that the relationship distance between nurses and parents has led to relation and informal supports of parents from each other as a way to meet their needs.²⁹ In fact, the nurse plays a supportive role by providing the necessary resources and information and provides holistic care.^{30,31} Excessive financial pressure, especially surgical costs and equipment for certain procedures, and especially dressing the area of colostomy, was a major problem for parents in care. The financial and social aspects of life for parents of children with

chronic disease are difficult and overwhelming.³² The result of another study in relation to patients with ano-rectal anomalies were the main concerns that included the economic and social weakness of the majority of parents.²⁰ So, it can be said that this disease has a lot of financial burden on the family, which ignoring it make a lot of problems for them.

The results of this study were increasing parents' perception of the disease and the factors that influenced it. More knowledge about the disease made parents' tendency to increase awareness, and they better understood the conditions of the disease and try to adapt to it. All of these beneficial effects require time lapse and increased experience, especially initial support from others. In the study of Hartman et al³³ Awareness of the nature of the disease has led parents to better acceptance the disease and try to adapt to it and move toward proper treatment. In fact, effective care requires awareness of factors affecting child care. In another study, parental experiences included the development of psychological character among members and a positive change in mental principles and improved relationships among members.³⁴ Parent's statements indicated that religious beliefs help family because of the reduction of tensions and the provision of care with a better mentality. In a study parents used to participate in spiritual exercises to alleviate pre-surgery anxiety.³⁵ Therefore, health professionals need to pay more attention to the religious and divine beliefs of parents and use it to strengthen their care programs. The limitation of this study, like other qualitative studies, is the lack of generalization the results to other parents. In this regard, it is recommended that despite the brief education material given to the parents of these children by doctors and nurses, it is better to provide the continues education related to the support and care needs with regular follow-up by health care centers.

Conclusions

Although the results of this study point to a lot of negative experiences, as a result, most parents referred to the positive effects of this experience, including increased participation of family members, relatives in care, increased family consolidation, and coping with situation.

Key-points

- Hirschsprung's disease is a gastrointestinal anomalies that disrupts excretion.
- In Hirschsprung's disease, like other chronic diseases; mothers undergo a lot of care.

- Considering the concept of nursing care, it is important to understand the care and its effects on the parents, the child, and care improvement.
- Although the results of this study led to a lot of negative experiences, most parents referred to the positive effects of this experience, including increased participation of family members, relatives in care, and increased family consolidation.

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Authors Contributions

Conceptualization: Hourieh Abbasiasl, Ashrafalsadat Hakim, kouros zarea.

Writing – original draft: Ashrafalsadat Hakim

Data collection: Hourieh Abbasiasl

Data analysis: kouros zarea, Ashrafalsadat Hakim

Reviewing the final edition: Ashrafalsadat Hakim.


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ORCID iD

Ashrafalsadat Hakim  <https://orcid.org/0000-0002-5050-005X>

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