

Education of Parents When a Child Born with an Imperforate Anus; Does It Improve the Health of the Child?

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Abstract

Objectives: To describe and investigate the value of an education program for parents of children born with an imperforate anus in order to help them cope with the new situation of having a stoma. A comparison is made with a group of parents following routine hospital. A secondary aim was to illuminate the parents' feelings and concerns in the first month after the birth of the child. **Subjects and methods:** The program was tested in 20 Vietnamese mothers of babies born with an imperforate anus; 10 followed an intervention comprising an education program and 10 the ordinary routine hospital. The study design is both qualitative and quantitative. The mothers were interviewed, using open-ended questions, within a week of their child's birth and then repeatedly for up to one month. Finally, the conditions of children were assessed on their return to the hospital for the second operation after one month of care at home. The qualitative data were subjected to content analysis. **Results:** All mothers felt sad and worried in the beginning, but this quickly changed to confidence, particularly among mothers in the intervention group who received education. While at home, mothers in both groups had financial concerns, as they were unable to work as much as expected and also had to buy equipment for colostomy care. The mothers in the control group complained about a lack of knowledge and how it affected the care of their child. The mothers in the intervention group, however, felt confident in their caring even at home. When the families returned for the second operation, the children in the intervention group were significantly healthier, had increased more in weight, and had fewer complications and emergency return visits to hospital compared to the control group. In the control group skin problems around the stoma, diarrhea, bleeding or constipation while at home were reported ($p < 0.01$). **Conclusion:** The education improved the care at home resulting in healthier children and more confident parents.

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Keywords

Imperforate Anus, Participation, Education for Parents

1. Introduction

Becoming a parent for most of people implies a transition to something new and important in life. If the child is born with a malformation, it is usually very stressful for the parents. In order to offer the best treatment for the child, guidelines based on scientific results and recommendations are created and followed. Involving parents in decisions, and the treatment and care of their child are highly recommended in order to increase attachment and encourage parenthood [1]-[5]. The present study investigates the value of such guidelines for parents of children born with an imperforate anus living in Vietnam.

Imperforate anus is a malformation affecting 1 in 5000 babies and is slightly more common in males [6]. Its exact cause is unknown. Environmental factors or drug exposure during pregnancy may play a role in some cases, but have remained unclear. Imperforate anus may occur at a high or low level; in the high level the rectum is too short and ends above the levatorani muscle while in low level the rectum ends below the levatorani. Treatment depends on the type of abnormality present, but the first measure that has to be taken is to ensure fecal drain age [6]-[8]. All infants with imperforate anus need to have same surgery in order to correct the problem. At the National Hospital of Pediatrics (NHP) Hanoi, for most of children stool drainage is ensured by means of a colostomy as a first step to enabling recovery from delivery and growth.

When a child is diagnosed with anal malformation, it usually results in a traumatic period for a family, especially if the parents are new and young and it can be difficult for them to accept or comprehend the information [3] [9]. Information and support from health care personnel need to be ongoing as open communication between caregivers and parents is an important factor in pediatric care [10] [11]. Once discharged from hospital after the colostomy operation, the parents are responsible for the care of their child's stoma. In the hospital the parents are shown in general how to carry out the care, but in Vietnamese hospitals there are nospecific guidelines for stoma care in infants at home. This means that parents may often go home without sufficient experience of changing bags or knowledge about aids or where to buy them. In the present study such guidelines were created and tested. The aim was to describe and investigate the value of an education program for parents to a child born with an imperforate anus in order to help them cope with the new situation of caring for a child with a stoma. A comparison is done with a group of parents following the routine of the hospital. A secondary aim was to illuminate the parents' feelings and concerns during the first month after the child was born.

2. Participants

Twenty consecutive parents of newborn infants with anorectic malformations waiting colostomy operations (within 2 - 3 days after birth) at the surgical department of NHP were informed about the study design and invited to participate.

They were selected to either the intervention or the control group in consecutive order.

3. Method

The study was qualitative in design. Interviews with the parents followed an interview guide and asked open-ended question. In addition, an infant health protocol was used and analyzed in quantitative terms. The parents' experience of being the parent of a child born with an anal malformation was investigated continuously over one month. The usefulness of the intervention was investigated by comparing findings from the infant health protocol together with the interviews of parents who received the education program with a control group of parents followed the routines of the hospital. The interviews were tape recorded and then transcribed verbatim [12].

The interview guide was developed and tested before being used in the field for appropriateness and completeness with reference to the aim of the study. Supporting questions were used such as, Please tell me more; What exactly did you mean? Please explain?

The parents were interviewed four times. The first time was at the point of inclusion in the study, after delivery. They were asked about their experience of being the parents of a baby with special needs. After congratulating them to their beautiful baby the opening question was, "*How do you feel after the delivery? Would you*

like to tell me about your feelings concerning your child's illness?

The second interview took place after the surgery and they were again asked about their feelings, “*How do you feel now?*” The third interviews, for the intervention group, was after they have received the education program and just before discharge when they were asked about the program “*What is your opinion about participating in your child's care from the beginning? Can you tell about it?*” The control group was asked about how they felt when they were discharged from hospital, “*How do you feel now that you are going home?*”

The final interviews took place approximately one month later when the families returned to hospital for the next planned surgery on their child. An open question was used, “*Can you tell me how things have been at home? Did you have any problems when caring for the child at home?*” The interviews were conducted by the study nurse in the ward's meeting room, and each parent was interviewed for about 20 - 30 minutes. The child was also examined with reference to health status, skin, weight and height, following the health protocol.

4. Intervention

The guidelines for the education program for parents included oral and written information about the malformation disease and care based on the child's health and wellbeing, as well as how to clean and dress the colostomy to prevent complications and should these occur, how to treat them at home. The doctor informed the parents about the malformation and they were invited to participate in the care of their child, including practicing cleaning and changing the colostomy appliance. They were able to practice step-by-step supported by the staff, so that before leaving the hospital they were able to perform the whole procedure for their child. During this learning period, an experienced nurse supported them with the aim of making them feel confident and they were encouraged to ask about anything they wanted to. The parents were also informed about nutrition and breast-feeding practical aids that could be used. The control group, treated according to the routine at NHP, had the ability to give the child basic care. The doctor gave them information about the malformation. Before discharge from hospital they were given oral information about stoma and shown how to clean the colostomy and how to apply the bandage.

5. Ethics

Permission to carry out the study was obtained from the head of NHP and the Ethics Committee of the hospital approved it. After informed consent was given and participation was voluntary and participants were aware that they could withdraw from the study at anytime. All information about subjects has been kept confidential. Data were reported in such a way that no one outside the study would be able to recognize who had said what.

6. Analysis

Content analysis was applied to the data [12]. The transcription was checked against the audio-recorded data for accuracy and to gain a holistic overview of the material. The analytic technique was based on reviewing data from all the interviews and from field notes in order to determine the essential meanings in relation to the aims of the study. The main author, in collaboration, carried out the initial search for meaning units and coded the interview text with the co-worker on the project. The primary themes were classified into sub-categories and then divided into categories. The findings were translated into English with the help of a professional Vietnamese-English translator to ensure that the original meaning in Vietnamese was not lost. Validity and reliability are ensured by describing the analysis process, and using quotations but also by independent analysis and discussion back and forth until agreement within the research group was reached. The infant health protocols were analyzed and compared using non-parametric statistics. Mann-Whitney was used for continuous variables (weight, height) and Fisher's exact test for categorical variables. The limit for statistical significance was set at $p < 0.05$.

7. Results/Findings

All the 20 parents invited gave their informed consent, however; only the mothers participated despite both parents being invited. Eight children in the intervention group were born with a high anal malformation and 2 with a low malformation. In the control group 7 had high malformation and 3 low malformations. Both groups had the same colostomy operation. The educational intervention following the guidelines, took place in the hospital after surgery. The mothers in the control group participated in the basic care of their child during their stay in hospital, but did not participate in the care of the stoma. The intervention and control groups were similar with

no significant differences between them regarding demographic conditions (Table 1). In order to avoid affecting the result they had no opportunity to meet each other during the study period.

8. Parents' Feelings about the Situation before and after the First Operation

The findings from the analysis of the first interviews, which took place within 2 - 3 days after delivery, and the second interview, on the day after the first surgery, are presented in two categories, "Sadness" and "Worries", derived from the 5 subcategories; disappointed, sad, why, poorness and uncertainty. Both groups of mothers revealed similar feelings. Examples of the analysis process are given in Table 2. When they were informed that their newborn child had an anal malformation they felt sadness, disappointment and guilt, and had problems accepting the situation. Some mothers said they thought it was their fault, that they had been born with bad luck or that they had made mistakes and were being punished.

"I was doing very well during pregnancy" "I haven't used drugs and my first child was healthy, so I and my family can't accept this malformation in the baby...". "I think I always have bad luck, my first child had a heart disease and this child has malformation of the anus".

When the child had colostomy surgery the mothers were more or less in a state of acceptance and their feelings changed. They started to worry about the health of the child, his/her future life and how they could afford to care for the child at home: *"I'm worried.... because he's weak after the operation and has a fever"*. When they were interviewed concerning their knowledge about anal malformation, they revealed uncertainty; the condition was new for them as was how to care for a colostomy. *"I don't know about this illness, the first and second children are healthy. I think caring at home will be very difficult for me. Can you help me?"*

9. Knowledge of Parents and Education, Following Guidelines, before Discharge from Hospital

The mothers in the intervention group felt confident and were satisfied with the education. They knew what an anal rectal malformation meant and how to care for the child at home. They knew about feeding, colostomy care, prevention of complication and how to treat them if they occurred.

One category, "Confidence" emerged from interview text, derived from four subcategories; better mood, abil-

Table 1. Demographic data from 20 mothers who participated in interviews.

	Intervention group	Control group	P value
	n = 10	n = 10	
Age of the mother			0.23
<20 years old	2	2	
20 - 30 years old	5	6	
>30 years old	3	2	
Occupation			0.61
Farmer	5	4	
Worker	3	4	
Official	2	2	
Standard of living			0.08
Low	2	1	
Middle	6	7	
High	2	2	
Number of children			
Range	1 - 3	1 - 4	

Table 2. Demographic data from 20 mothers who participated in interviews.

Meaning units	Codes	Sub-categories	Categories
I'm very sad, I wanted a son but now this is a girl with imperforate anus.	Sad Disappointed	Disappointed	Sadness
Everything around me is very bad. Don't understand the reason for the malformation	Feels bad Doesn't understand why	Why	Sadness
The baby is weak after the operation don't know what happened	Weak baby Worried	Uncertainty	Worries
My family hasn't enough money to care for a sick child. I haven't any knowledge about this condition	Lack of money, Lack of knowledge about care	Poverty Uncertainty	Worries

ity, not damaging life and useful education. After the education the mothers' emotion had changed emotions from worries and sadness to feeling confident. They felt they could take care for their child by themselves and they were also able to show other parents what to do: *"I'm fine now, I feel better having received information about this disease and how to manage the care... now I think this disease has not damaged the life of the baby."* *"I am prepared enough to care for him at home. I am not worried now"*. The education was useful and important for the caregiver: *... is necessary for all parents.*

The parents who followed the general routines received information about how to change the colostomy bag but had less knowledge and skill regarding prevention and treatment of complications. On the day they were discharged from the hospital they still felt worried about caring for the baby at home: *"I still worry a lot, although I know how to change and clean the colostomy. But I haven't got enough knowledge about this disease, so I think caring at home will be difficult for me"*.

10. Factors Affecting the Wellbeing of the Child at Home

When they returned to hospital for the next operation both groups of mothers were asked how things had been at home and if they had had any problems concerning the care. From the analysis of this interview text the category "Concern" emerged, derived from five subcategories; uncertainty, need to work, accessibility to medical and social help, lack of knowledge. The concern now had its origin in their experiences at home. Some first-time mothers lacked experience in taking care of a newborn child and this, together with their baby's special needs, led to them having difficulties in caring for their babies at home. Mothers from both the control and the intervention groups felt uncertain and uncomfortable because of the child's frequent bowel management. All day and at any time it was about stools, they felt dirty and afraid. *"... bowel movements anytime and anywhere, I'm always busy dealing with it and feel dirty. Sometime I don't want go to crowded places"* (CG).

A lot of the parents were farmers (see [Table 1](#)) and both parents needed to work in order to earn enough money to run the household. They had problems providing for the child's special needs.

Some were poor and also had problems feeding the child when out working. They could not buy high quality bandages and colostomy bags or medicine when the child developed complication: *"My family is small and nobody can help to take care of him, we need to work to earn money to live, ... so my child can't gain weight, he is weak, easily gets other diseases and complications. I think these things affect the result of the treatment"* (IG). These concerns were present in both groups but the babies in the IG had fewer complications including fewer costs, see [Table 3](#).

Accessibility to medical and social help was important factors for the CG. *"My home is far from a medical centre..... I can't go to hospital so my child usually has irritated skin around the colostomy"* (CG). Belonging to a social organization could be helpful but only some parents lived in a city and could benefit from such help. *"At home, I received money from the social organization and health care centre; immunization, special food for my child, examinations and check ups... my child is developing well and has a good immune defense"* (CG).

Table 3. Condition of the children after one month's participation in the study. The first ten are children in the intervention group (IG) and the following ten are children following routine case, the control group (CG). The p value shows the difference between IG and CG groups.

	Birth Weight (kg)	Weight after 1 month (increase in kg)	Birth Height (cm)	Height after 1 month (increase in cm)	Skin around stoma	Character stool	Diarrhea number	Bleeding stoma	Vomiting	Acute return to hospital
IG1	3	1.1	43	3.5	Soft healthy	Normal	0	0	0	0
IG2	3	1.3	44	3	Soft healthy	Normal	0	0	0	0
IG3	3	1.3	43	5	Soft healthy	Normal	0	0	0	0
IG4	2.5	1.2	40	5	Soft healthy	Liquid	1	0	1	1
IG5	2.2	0.8	40	3	Soft healthy	Normal	1	0	0	0
IG6	2.5	0.9	42	3	Soft healthy	Normal	0	0	0	0
IG7	3	0.9	42	3	Soft healthy	Liquid	1	0	0	0
IG8	2.5	1.1	42	3	Soft healthy	Normal	0	0	0	0
IG9	3	1.3	43	4	Soft healthy	Normal	0	0	0	0
IG10	2	1	40	3	Red	Normal	0	1	0	0
CG1	2.5	0.5	43	3	Red wet	Liquid	0	1	0	0
CG2	2.5	0.7	43	2	Irritated	Normal	1	0	1	0
CG3	3	0.5	42	3	Soft healthy	Liquid	2	0	0	1
CG4	3	0.6	40	3	Irritated	Liquid	1	0	0	0
CG5	2.8	0.5	43	3	Irritated	Liquid	1	0	0	0
CG6	3.2	0.8	43	3	Soft healthy	Normal	0	0	1	1
CG7	3.4	0.6	42	3	Irritated	Normal	1	1	0	0
CG8	3	1.1	43	3	Irritated	Normal	0	0	1	1
CG9	2.7	0.8	42	3	Irritated	Liquid	1	0	0	1
CG10	3.1	0.6	42	3	Soft healthy	Liquid	0	0	1	1
P value	0.19	0.001	0.18	0.02	0.01	0.08	0.1	0.5	0.1	0.07

Centimeters (cm), kilograms (kg).

11. Does Education Affect the Complications with the Child at Home?

All the mothers in the intervention group changed regarding how they felt about the colostomy after the education; they felt competent and confident about their knowledge of the malformation and the care of the colostomy when back home. This is shown by the results of the examination of the children and interviews with the mothers. **Table 3** shows the condition of the child on return to the hospital for the next surgery.

The assessment included: general condition (weight, height), the condition of the colostomy (skin color, irritated or not), and complication that occurred while the child was at home (**Table 3**). The differences in findings show that children in the IG might be healthier. The mean weight at birth was 2.6 kg in the IG and 2.9 kg in the CG, a slight but not significant difference. However, after 1 month there was a significant difference; the IG had gained weight by a mean 3.7 kg, range 0.8 - 1.3 kg (increase in weight 1.090 kg). The corresponding values for the CG were 3.5 kg, range 0.4 - 1.1 kg (increase in weight 0.067 kg). The difference in increased weight amounts to more than 1 kg ($p \leq 0.001$, Fisher's exact test).

According to the interviews the mothers in the IG were happy about breast feeding and said that their child had hardly any complications and therefore was able to eat and grow. However, the mothers in the CG said that

their child was not exclusively breast-fed despite them having enough milk. Their child had complications caused by the stoma: diarrhea, fever, sometimes bleeding. They felt they lacked suitable knowledge about how to care for their child and the colostomy and thought that this had the effect of the child getting complications. This is also shown in **Table 3**.

All except one child in the IG had soft and healthy skin around the colostomy, normal stool movement and no bleeding or vomiting, just one had had diarrhea, while seven children in CG had had irritated skin, six had had diarrhea, four had had vomiting and constipation to such an extent that they had had to return to the hospital for help. The differences between the groups were significant ($p \leq 0.05$, Fisher's exact test).

12. Discussion

The results of this paper agree with those of other authors: parents of a child with anal malformation need a lot of attention [10] [13]. The present study follows the parents from 2 - 3 days after delivery, to after colostomy surgery and education and ultimately to one month after surgery. The findings show that their emotions change over, even within the short perspective of one month. Participation, education and taking part in the child's care made the parents feel confident, resulting in a child who was healthy despite the colostomy.

The present study, which has both a qualitative and quantitative design, investigates 20 parents of children born with an imperforate anus, all of them underwent colostomy surgery. Both parents were invited to participate but traditional thinking and practical circumstances meant that only mothers were involved.

Comparison were made between a control group' which followed hospital's normally routines and an intervention group, who were trained in caring for the colostomy at home, preventing complications and, if they occurred treating them. They also received nutrition advice. These mothers had been given the opportunity to discuss matters with the staff and to practice under observation at the hospital. The control group had not practised at the hospital and was given only basic information about care of the colostomy.

The interviews reveal that for all the mothers the initial feeling about the situation was sadness. They experienced feelings of guilt, were disappointed and looked for reasons why this had happened to them. Their feelings were in the beginning overwhelming but soon changed to worries about their child's health and their economy. The mothers in the intervention group gained a more optimistic view of their situation earlier than those in the CG. Similar findings have been reported from other studies concerning colostomy care in children [3] [9] [10].

Vietnam is a developing country and many of the participating families were poor. In Vietnamese culture old traditions dictate how should act being a good mother. We have shown earlier how mothers potty train infants with good outcomes from when they are newborn, even in infants born with posterior urethra valves [14] [15]. The mothers in the present study knew they needed to work to earn money to cover family costs; there was no money to meet extra costs. In Vietnamese society a healthy child principally a son, is a guarantee that the parents will be cared for in their old age. Despite the differences in living standards and wealth between countries people in Western countries also worry and feel sad [3] [9] [10].

Stressful factors and uncertainty about their child's illness and recovery, disrupt the parental role, and this is exacerbated by being in an unfamiliar environment. These were the findings from Kristensson-Hallström's study in a surgical ward and could also be seen in our study [1]. In recent years, pediatric health care has shifted toward family-centered care based on the close and continuous involvement of the child's family members. Parental participation is beneficial for children, parents, and healthcare facilities, based on communication among all parts. To achieve this goal ongoing quality control of routines and outcomes is mandatory [16].

In order to be responsible for the care at home the parents need confidence. In earlier studies children and parents have described how they were insufficiently informed and prepared for the necessary procedures at home and how they felt excluded from decision making regarding themselves or their children which resulted in anxiety, indignation, anger and fear [17] [18]. In the intervention studied, the staff tried to respect and meet the parents' needs, when they invited them to participate in the care and in decisions making; they tried to listen to them and support them. This is in accordance with the United Nations Convention of the Rights of the Child [19]. However, the actual process of person-centered care was not investigated in the present study. The mothers were satisfied with the education and support they received and the outcomes were good but the study did not reveal much about the interaction between the nurses and the parents.

When parents returned for the second surgery, parents in both groups had concerns arising from their experiences of daily life at home. According to the findings almost all the mothers in the IG could change the co-

lostomy bag satisfactorily. They could prevent and treat complications at home, such as bleeding, diarrhea, irritated skin and they knew when it was necessary to take the child to hospital. Mothers from the CG felt uncertain due to insufficient knowledge and skill regarding caring for their child in the best way and they complained about extra costs.

Some families had been offered help from a social centre, which had helped. Money was a major factor concerning treatment. The farmers and families living in the mountains were often poor and their incomes come from the agriculture. If the mothers did not work in the fields there was less to eat, and they could not buy proper colostomy bags or other equipment necessary for the care. The health care centre was usually far from their homes so when the children developed problems it was difficult to take them to the hospital. The families in the cities had easier access to medical or social help. Our findings show that the parents' ability to overcome obstacles depended largely on their knowledge and confidence. In this case, the education program in the intervention led to the parents feeling well prepared for caring for the child at home.

In the assessment of the children when they returned to the hospital for the second surgery we found significant differences between the groups (**Table 3**). The children in the IG had had fewer complications than those in the CG. The intervention group children were healthier and had grown more quickly. The children in the CG often returned to hospital before time because of diarrhea, bleeding or absence of stool movement.

These complications could probably have all been prevented if the mothers had had enough knowledge and skill to manage the care of the colostomy successfully. Many studies have shown that parents play an important role in the care of the child [2] [4] [13] [20]. In children with anal malformation this is particularly true, as the parents have to take a lot of responsibility for the follow-up treatment [3] [13].

Our findings show that the mothers' ability to overcome problems and obstacles depended largely on their knowledge and confidence. The results of this study illuminate the importance of attention, education and participation, in agreement between the care provider and the mother, for improving health outcomes related to person-centered care (PCC) [16] [21] [22]. The families living with a child who has a long-term illness need care and support which addresses their own researches and need. The education program in the intervention was a useful tool in making parents feel well prepared before leaving hospital.

This study had a small number of mothers, but the findings were significant and clear. In order to help families with a child born with an imperforate anus to cope with the new situation, we still need more research on this topic, particularly about the education process and the interaction between the nurses and the parent.

13. Conclusions

Education of parents when a child is born with an imperforate anus improves the health of the child.

Worries and feelings of sadness about their child and the future are common among mothers.

The emotions of the mothers in the intervention group changed and became more positive earlier than the case for mother in the control group.

All mothers had concerns regarding the care for economic reasons.

Education and practice, step by step, supported by the staff resulted in a confident mother with the competence to take care of her child and a healthier child with significantly fewer complications and emergency return visits to the hospital compared to the situation in a control group. Ultimately this meant lower costs for both the family and the healthcare system.

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