



Living With My Baby With Congenital Anomaly: A Qualitative Case Report

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Nazife Gamze Özer Özlü^{1,2} , Fatma Vural, PhD²,
and Zafer Dökümcü, PhD³

Abstract

This case report was made to understand the emotions, thoughts, and experiences of the mother, who was lying in the long-term neonatal intensive care unit. An individual in-depth interview was conducted once with the mother of the infant with the diaphragm hernia. The interview recorded and lasted approximately 30 min. The data were analyzed by inductive method and themes and codes were created. The mother of the infant with a diaphragmatic hernia was 31 years old, married with 2 children, and employed full-time. The infant was diagnosed antenatally at 37 weeks old, weighed 3.000 g, and was male. As a result of the interview, 3 main themes were identified: "Facing the disease," "Experiences in intensive care," and "Change in family life." The results show that having an infant with congenital anomaly affects the life of all family members and shows the problems experienced strikingly.

Keywords

congenital diaphragmatic hernia, maternal, neonatal intensive care units, qualitative research

Introduction

Congenital diaphragmatic hernia (CDH) is a complex congenital anomaly, whereby a defect in the diaphragm allows for the herniation of abdominal viscera into the thoracic cavity (1,2). The incidence of CDH ranges from approximately 0.8 to 5/10.000 births (3). Respiratory distress symptoms due to oxidative stress in affected infants usually appear in the first few hours or days leading to a prolonged stay in the hospital, and these symptoms require a multidisciplinary approach for their management (3–5).

Description

Background

Understanding the needs of parents with infants and children in the neonatal intensive care unit (NICU) contributes to effective communication between them and health care workers, reduces the families' stress levels, has positive effects on the infants, and improves the quality of care (6). The treatment of the infant by the hospital, the fact that the mother is separated from her child and unable to care for the infant herself results in an increase in feelings such as anxiety, unhappiness, or a sense of emptiness and insensitivity in the mothers (7–14). In a qualitative study conducted with mothers of infants born at 32 weeks and younger, it

was determined that they could not breastfeed and care for their infants. In addition, mothers stated that visits were limited because their infants were in the NICU. In this process, mothers explained that there were changes in the mother role, coping strategies, and family life (15). Feeding infants with CDH does not mean breastfeeding directly from the breast. It should also be given enterally to infants by expressing breast milk. Infants with CDH face a multitude of short- and long-term health morbidities, which deeply affect the mother (16).

This case report was designed to understand the feelings, and experiences of the mother of an infant who was treated for CDH, which is one of the rare congenital anomalies that have a high risk of morbidity and mortality, in the long-term NICU.

¹ Dokuz Eylül University, Institute of Health Sciences, İnciraltı, İzmir, Turkey

² Faculty of Nursing, Department of Surgical Nursing, Dokuz Eylül University, İnciraltı, İzmir, Turkey

³ Department of Pediatric Surgery, Ege University, İzmir, İzmir, Turkey

Corresponding Author:

Nazife Gamze Özer Özlü, Dokuz Eylül University, Institute of Health Sciences, İnciraltı, İzmir 35210, Turkey; Faculty of Nursing, Department of Surgical Nursing, Dokuz Eylül University, İnciraltı, İzmir 35210, Turkey.
Email: gamzeozerozlu@gmail.com



Case Presentation

The mother of the infant with a CDH was 31 years old, married with 2 children, and employed full-time. The infant was diagnosed antenatally at 37 weeks old, weighed 3.000 g, and was male. On the fifth day of his life, the infant underwent primary repair with laparoscopic mesh. He received nitric oxide inhalation for a total of 6 days: 5 days before surgery and 1 day after surgery. The infant was monitored in mechanical ventilators for a total of 27 days before and after surgery. Since the infant was in the long-term mechanical ventilator, a pressure wound occurred in the occipital area. Because the infant had malposition in the stomach due to diaphragmatic hernia, long-term nutritional problems were experienced. While attached to the mechanical ventilator, the enteral diet from the nasogastric probe was not successful. Therefore, a nasoduodenal tube was inserted into the infant and he was enterally fed through the nasoduodenal tube. After being extubated, he tried to breast-feed from his mother. On the 45th day of his life, he was taken from the NICU to the service follow-up with his mother because of the absence of cardiac and respiratory problems and his improvement in feeding. After the infant and his mother were in the service follow-up for 11 days, the infant and his family were discharged as a result of his recovery.

Methods

The interview with the mother occurred while her infant was being treated in the NICU where the author worked as a nurse. A semi-structured patient interview form was used. The semi-structured interview form was prepared by the author in line with both clinical experience and literature. Afterward, a meeting was held to criticize the interview questions prepared with other researchers. The final version of the interview form has been created.

The semi-structured interview questions were as follows:

- How did you feel when your infant was diagnosed with diaphragmatic hernia during pregnancy?
- How did you feel when your infant was taken into intensive care after he was born?
- How did you feel when your infant had surgery due to the diaphragmatic hernia?
- What did you experience when the mechanical ventilator was connected to your infant in the neonatal intensive care unit?
- What did you feel after your infant was taken off the mechanical ventilator?
- What did you experience during the feeding process?
- How did this affect your family relationships?

Verbal consent was obtained from the infant's physician before the interview. After the physician had given permission, the purpose of the do interview was explained to the

infant's mother and verbal and written consent was obtained. This case report is not a biomedical study. Therefore, IRB approval and ethics committee approval were not obtained. The interview was held in a quiet room in the ward of the pediatric surgery clinic where the infant was treated. The interview with the mother lasted about 30 min and the interview was recorded on a voice recorder.

The interview was transcribed and themes and codes were created by the inductive method (17–19). The questions, the transcribed interviews, and the mother's comments were put into written form in a computer environment. In addition to these documents, the notes taken during the interview were organized. The interview, which had been transferred to the computer environment, was read repeatedly until it was fully understood. The researcher (first author) created the inductive coding and categorization from the actual statements of the mother in the text. After the codes and themes had been determined, they were reviewed and revised. Excerpts from the mother's statements were chosen to convey the basic meaning of the codes and themes determined.

An expert review, also known as peer debriefing (16,17,20,21), was requested to critically evaluate the themes and codes obtained from the mother interview. An evaluation meeting was scheduled for expert review. In this meeting, the second researcher examined the interview made by the first researcher and the analysis of the interview. Thus, a consensus was reached on the main and sub-themes. The third author checked the reliability of the generated codes, sub-themes, and themes. Thus, the theme, sub-themes, and categories in Table 1 were created.

Results

Three main themes were identified from the mother's data: "Facing the disease," "Experiences in intensive care," and "Changes in family life" (Table 1). Sub-themes supporting these main themes were created. Direct quotes from the mother were included in the content of the specified theme.

Theme 1. Facing the Disease

In the literature, parents whose children or infants are diagnosed with the disease have been found to go through a process of shock, denial, adjustment, and acceptance (9,10). In the shock phase, parents experience uncertainty about what it might mean for their infant to recover or even to survive (10). Congenital anomalies such as diaphragmatic hernia have high mortality and require long-term NICU. Respiratory and cardiac failure develops due to severe pulmonary hypertension and hypoxia in the newborn. Therefore, a prenatal diagnosis affects the prognosis for the infant after birth. Increasing the rate of prenatal detection and evaluating the right risk factors are important in terms of counseling families (2,6). In the present case report, this theme was created based on the mother's statements. The

Table 1. Themes, Subthemes and Direct Quotes from the Mother.

Themes	Codes	Quotes
Theme I: Facing the disease	<p>She was taken aback when she first heard about the disease.</p> <p>The belief that the infant would survive increased when she learned about the disease in detail</p> <p>She did not buy clothes and other items for her infant during pregnancy</p> <p>The mother's family thought he was healthy until the infant was born</p>	<p>My husband and I learned about my baby's disease when I had a detailed ultrasound at the 20th week of my pregnancy. Naturally, we didn't know anything about that at first. ... Of course, I was extremely taken aback when I first heard it, because I never had a bad situation during my pregnancy until then.</p> <p>When I first came here, I met the doctor ... After you told me about the disease, my faith increased even more. He said we can't take away your baby's chance to live. If there's a chance, he is going to have a 50% chance of survival; I wouldn't rule it out. That's why we moved on.</p>
Theme II: Experiences in intensive care Ambiguity	<p>Breakdown of the mother after surgery</p> <p>Excessive stress of the mother on the day the infant is extubated and reintubated</p> <p>The infant's long-term stay in the intensive care unit frightened the mother</p> <p>Her husband told her that her infant was alive despite everything</p>	<p>I don't want to go all the way to the pediatric surgery clinic in the hospital. Because I am afraid that they will say that there is no positive development in your baby's health in the hospital. They always measured the right-hand side. However, I always knew that my baby had a diaphragmatic hernia on the left side. But my baby's diaphragm is completely absent. The doctors said it had completely disappeared. I was very devastated about that. What awaits us going forward?</p> <p>My husband was angry when I cried when he was intubated again when they were extubated. He said he is alive after all. My husband said, "Why are you so sad?". The doctor said that your baby may be intubated for a third time, don't be surprised. But you want it to get better, still. As the process goes on, it wears people out.</p>
Theme II: Experiences in intensive care Being strong	<p>Mom and dad never cry</p> <p>Wish to continue their life</p> <p>Not thinking about the other child</p> <p>Continuing to work until giving birth</p>	<p>From the 20th week of my pregnancy, I did not feel sad. I kept working. I've moved on because I have another child. I didn't want to think about disease of CDH.</p>
Psychosocial need	<p>Facebook group for mothers with infants with diaphragmatic hernias</p> <p>Getting information from other mothers on the WhatsApp group</p> <p>Familial support</p> <p>Spousal support</p>	<p>There was something on Facebook when I searched the internet. It was a group under the heading of diaphragmatic hernia. I became a member. Then a lady there said that they had set up a WhatsApp group for mothers in Turkey. They signed me up to this group ... Again, I wrote to the mothers in that group. I said we have this problem do you have any of you have this? When they said to me that all our surgical mesh were attached to our ribs, I stood up there again. [She laughed]</p> <p>My family was incredibly supportive. From the moment I entered the delivery room, all my family and relatives were here. They were with me when the child was born. They were all there when I had surgery. They always supported me.</p>
Nutrition	<p>Weight gain during enteral feeding</p> <p>Worrying about infant being hungry when he can't feed</p>	<p>I feel unbelievably bad things. I'm unhappy, frankly. One child breastfeeds, one doesn't and is fed with the feeding tube in his nose. I thought my baby didn't want to breastfeeds me. I feel sorry that he was hungry. Because he couldn't feed, in the long term he dropped to 2,700 g. When he was fed through his nose, he gained some weight.</p>
Theme III: Change in family life Change in the role of the mother	<p>Affecting the care of the other child in the home</p> <p>Inability of the mother to see both of her children fully</p>	<p>During this period of my stay in this hospital, I have two children, but I cannot see either of them. Even though there were days when I didn't stay here, we used to come to the hospital every day from the morning and stay here until the evening. My other son was going to nursery at that time.</p>

(continued)

Table 1. (continued)

Themes	Codes	Quotes
Change in the role of the spouse	Not having negative experiences More bonding with spouse	I can say that we are more connected to each other. As husband and wife, we were worried about our baby's health, but we didn't cry so as not to upset each other. Because when I wanted to cry, my husband wanted to cry too. That's why we never cried.

mother stated that she first learned of this disease when she was 20 weeks pregnant. The mother reported that she was shocked when she first heard about it because she had had no problems with her pregnancy until then, and that she was saddened when she learned the details of the disease. Direct quotes from the mother are given in Table 1. She stated that although she knew that the chance of the infant's survival was low, she did not lose her belief that the infant would live after he was born. However, she stated that she did not make prenatal preparations for the possibility of the infant dying. The mother stated that her own family did not believe that the infant was sick until the infant was born. This theme relates to the life of the mother when she first encountered the disease. The high mortality of infants with CDH and the difficult treatment process deeply affected the mother and her family.

Theme 2. Experiences in Intensive Care

This is the theme that most intensely reflects the emotions experienced by the mother, as the infant is treated in the NICU for 45 days. Within this theme, 4 sub-themes were created: "Uncertainty," "Being strong," "Psychosocial need," and "Nutrition." The mother's quotes are included in Table 1.

Subtheme 1. Ambiguity. The mother stated that she had ambiguous feelings about the infant's illness and prolonged intensive care process. She had anxieties about the future but also happiness at having a child. Oxidative stress in the infant due to diaphragmatic hernia plays a role in pulmonary hypertension and hypoplastic lung injury. Mechanical ventilator follow-up, preductal saturation follow-up, and positive pressure ventilator are followed to take care of oxidative stress, and this process takes a long time. In the literature, the psychological needs of mothers of infants who have been treated for a long time increase and there are uncertainties about the prognosis for their child (7–16). It was thus normal for the mother in this case report to experience these feelings.

Subtheme 2. Being Strong. One of the sub-themes about the experience of the intensive care unit was the mother's feeling that she had to be strong. In the interview, the mother stated that she had another child and that she had to stand up for herself due to the prognosis of the infant in NICU (7).

Subtheme 3. Psychosocial Need. The mother's psychosocial needs had increased, and she was seeking psychological support. She had become a member of a Facebook group established by other mothers of diaphragmatic hernia infants. They talked about their experiences in a WhatsApp group and exchanged ideas. Her husband and family were her biggest supporters in the process. In this respect, it is important that the support provided by husbands and relatives to mothers of infants with chronic diseases is supplemented by peer or nurse support group interventions (9,11).

Subtheme 4. Nutrition. The infant had problems during both enteral and oral nutrition since the stomach was mispositioned after surgery due to diaphragmatic hernia. It was a sad situation for the mother that her infant had difficulty breastfeeding. In general, infants with diaphragmatic hernia may experience nutritional problems. Therefore, enteral feeding is often chosen to feed the infant (3,5). Nurses should emphasize that the mother needs to be patient about this. Mothers of infants with CDH who aim to breastfeed their infants directly should start with milking. The length of time that mothers continue to express milk varies according to the health status of the infant. After birth, the infant with CDH is stabilized, intubated, and given enteral feeding via a nasogastric feeding tube. Post extubation, non-nutritive sucking at the breast, and oral feeding may begin. For some mother and infant couples, direct breastfeeding may not occur for weeks. This is because the hernia in the diaphragm allows the abdominal organs to slide into the chest cavity, restricting the development of the infant's lungs. For surviving infants, short- and long-term morbidities are numerous and include respiratory failure, gastroesophageal reflux, neurodevelopmental delays, poor growth, and hernia recurrence (16).

Theme 3. Changes in Family Life

Two subthemes were created in this theme: "Change in the role of the mother" and "Change in the role of the spouse."

Subtheme 1. Change in the Role of the Mother. In this sub-theme, the changing role of the mother was emphasized. Loss of the parenting function and a lack of information were a common complaint and source of stress. The

mother stated that she felt bad because she had 2 children and she thought that she did was not fully mothering either of them. As in similar studies (7,10,14), the support of the family is important in chronic diseases or infants in hospital. In addition, other children should remain with the mother so that they do not feel distant from her.

Subtheme 2. Change in the Role of the Spouse. In this sub-theme, the mother stated that her relationship with her husband had become stronger. In a qualitative study with the families of infants in neonatal intensive care, they stated that the parents' family, work and social lives, and general mental health had been negatively affected (6,8,14). But the mother in the present study resolved this crisis by strengthening her bond with her husband. Studies have also reported that having a supportive husband strengthens the mother's coping mechanism (12,15). The journey through the NICU can be considered a traumatic event and both parents need as much support and encouragement as possible.

Lessons Learned

Parents of infants born with a congenital disease with a high risk of mortality (1–5) have been found to want to receive psychosocial counseling (8), including information about the treatment process after the infant's birth. In addition, it is important to provide regular information about the infant's condition and the mother should be supported by a multidisciplinary team (pediatric surgeon, nurse, dietitian, psychologist, etc.) (1–5). Nurses should remain with their mothers from the moment a prenatal diagnosis is made (9,10). In order to protect the integrity of the family, a room should be created in the hospital where parents and other children can stay (14). The support of the father should be included in the care of infant (12,15).

Limitation. This study sought to understand the experiences and thoughts of a mother while her infant was being treated in the intensive care unit. The mother's thoughts about the infant's physiological condition and the nursing care provided could also have been included. This is a limitation of the study.

Conclusion

This case report defined 3 main themes with regard to the challenging experiences that families face and the coping strategies they develop. It has been determined in the literature that the mothers of infants who are treated in the NICU experience shock, and have to deal with issues including feeding, general care, holding and visiting the infant, uncertainty, loss of mother, managing expectations and how to cope (6–16). In this case report, unlike in other studies, the fact that diaphragmatic hernia is seen in 1 of 0.8 to 5/10.000 births, the mortality is very high, and the

treatment process is both difficult and long (1–5), meant that the emotions and experiences of the mother were very intense. It can be said that the mother had a complex emotional response to this challenging process, which she had never thought about at all until the 20th week of her pregnancy, that the changes that occurred in family life were both positive and negative. Therefore, it can be said that the mother expects support from the intensive care unit nurses and their own families and uses emotional coping strategies. In line with these results, nurse-led support should be provided and a multidisciplinary team approach should be provided from the moment the prenatal diagnosis is made in order to protect the mood of the mothers.

In order to protect family integrity as a whole, it is recommended to open a room in the hospital where parents and other children can stay, and fathers to take an active role in the care of the infant.

Authors' Note

In this case report, verbal permission was obtained from the patient's physician. Verbal and written consents were obtained before interviewing the patient's mother.

Declaration of Conflicting Interests

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Ethical Approval

Verbal consent was obtained from the infant's physician before the interview. After the physician had given permission, the purpose of the interview was explained to the infant's mother and verbal and written consent was obtained. This case report is not a biomedical study. Therefore, IRB approval and ethics committee approval were not obtained. The original language of the informed consent form is Turkish. Attached is the original informed consent form.

ORCID iD

Nazife Gamze Özer Özlü  <https://orcid.org/0000-0003-1144-2472>

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