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Original Article

# The phenomenological examination of Turkish mothers who have hemophilic sons

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## ABSTRACT

**Objective:** Hemophilia is a coagulation disorder characterized by bleeding episodes that are genetically transmitted from mothers to sons. The disease affects the family psychologically and socially, especially the mothers, who are closely involved in the care of the affected child. We aimed to question the experiences of Turkish mothers with children diagnosed with hemophilia.

**Method:** The study is based on phenomenology, one of the qualitative research designs. We conducted and recorded face-to-face interviews with nine mothers of patients with severe hemophilia A. Each of the semi-structured interviews, in which the interview form consisting of 23 questions was used, lasted approximately 40 minutes. After the recorded data were deciphered, the interviews were analyzed using qualitative analysis methods and presented under six themes.

**Results:** There is long-term anxiety in the daily life of mothers. Fatalism in Islam and the presence of a hemophilic individual in the family were the most important factors in accepting the disease. However, the mothers have the potential to live an uneasy and anxious life. It limits the social life of both the hemophilic son and the mother. Children are placed in a "glass bell" like a lonely fish during early childhood. The glass bell suddenly breaks at the beginning of school, and children face various social-emotional risks. In the adolescent period, children's social life expands, and mothers' anxiety about the future of their children begins to increase.

**Conclusion:** As we know, treatment compliance can improve the quality of life in children with hemophilia. To ensure this compliance, knowing and identifying the psychosocial burden of the disease on the mother and finding solutions will increase her child's compliance with hemophilia treatment and life expectancy.

**Keywords:** mother, son, hemophilia, phenomenology, psychosocial, life, treatment

## INTRODUCTION

Hemophilia is an X-linked recessive coagulation disorder disease caused by coagulation factors (F)VIII (hemophilia A) and FIX (hemophilia B) deficiency.[1] When mothers are carriers, boys get sick, and girls become carriers.[2] The prevalence of hemophilia A and B is reported as 1 in 5,000 and 1 in 30,000, respectively, in males.[3,4] The most effective treatment option all over the world is the intravenous replacement of the missing factor as a prophylaxis. This causes frequent vascular access 2-3 times a week.[5-8]

The fear of bleeding that spreads throughout life, and the limitation in physical activity affect hemophilic individuals

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physically as well as restrict them psychosocially.[9] Parents begin to share all these difficulties experienced by the hemophilic individual.[10] This situation affects the family psychologically and socially, especially the mothers who are closely taking care of the child. Knowing the difficulties experienced by the hemophilic individual and their mothers and identifying their needs are the most important factors that increase compliance with the treatment.[11,12]

Phenomenology is a qualitative research method that allows people to express their understanding, feelings, perspectives, and perceptions about a certain phenomenon or concept. It is used to describe how they experience this phenomenon.[13,14] As in many other chronic diseases, we know that hemophilia does not affect the individual alone but rather affects the whole family, especially the mothers who are primarily responsible for their care and restrict them psychosocially.[15,16] Therefore, in this study, we aimed to phenomenological reveal the experiences of mothers about their son with hemophilia and how these experiences are reflected in their daily lives and psychological states.

## METHODS

The aim of this study is to question the experiences of mothers who have children with hemophilia regarding their children's diseases. The study's design is based on phenomenology, one of the qualitative research designs. The experiences of the mothers were questioned in depth. Face-to-face semi-structured interviews were conducted with nine mothers. Interviews were held with the mothers of hemophilic patients who were followed up at the European Hemophilia Comprehensive Care Centre (EHCCC) of KANKA Pediatric Hematology-Oncology and Bone Marrow Transplantation Hospital of Erciyes University. Each interview was recorded on tapes and lasted about 40 to 45 minutes. An "Interview Form" consisting of 23 questions (Appendix 1) prepared by the research team focusing on the experiences of the mothers was used. The interviews ended when the data reached saturation.

### Qualitative analysis

The deciphered data was first encoded line by line in the form of open coding. The data whose coding was completed were combined around certain axes. Within the axis codes, divergences and overlaps were determined, and the data were arranged according to these divergences and overlaps. Finally, the data was abstracted and interpreted. Various methods were used to ensure the validity and reliability of the research. The reference adequacy of the study was evaluated by getting the opinions of various professional peers. In addition, the analysis of one of the interviews within the scope of the study was left to the end, and the data belonging to this interview were placed in the categories and themes created. Afterward, it was evaluated whether the data related to these categories and themes also emerged in this interview. To evaluate the predictability of the study, another academician's opinion was taken to evaluate whether "we could reach these results from these answers." Finally, the findings on six themes were presented to the reader. This study was approved by Erciyes University Ethic Committee with the approval code (2022/130).

## RESULTS

Nine mothers of children diagnosed with severe hemophilia A were enrolled in the study. The median age of the mothers was 41 (31 to 47 years). Four mothers had a family history of hemophilia. Only one mother had twin hemophilic sons, while the others had one hemophilic son. The median age of the children diagnosed with hemophilia was 12 (7–16) years. The themes were constructed in the context of the child's diagnosis process, the difficulties experienced by the mothers, their coping methods, the risks experienced by the child and the measures taken, the relationship between the mother and the child, school processes, and psychological protection methods of the mother and child.

### Theme 1- Standard Sequence in the Diagnostic Process: Shock, Denial, Acceptance:

According to the experiences of mothers of children diagnosed with hemophilia; although individual differences are at the forefront, the diagnostic process usually begins after a trauma or medical intervention. If there is another hemophiliac in the family, diagnosis is easier and takes less time. However, the most important problem experienced in diagnosing and delaying the diagnosis is misleading diagnostic tests.

*Participant(P)1- "He was 14 months old. He fell, his mouth and gum bled, and it did not stop for 2–3 days. Interventions were done in the hospital, but they did not stop easily. He was diagnosed with hemophilia at last."*

*P2-"Small bruises began to appear in certain areas of his body. At first, we thought his brother was pinching him. Then we went to the doctor; he was diagnosed with hemophilia three days later."*

*P7- "When he was 3 years old, he fell on his knee. A doctor in the private hospital said the fluid was collected in the knee. We couldn't trust the doctor because his uncle had hemophilia. We applied to a university hospital. After the evaluation, we learned that there was bleeding in the knee, and he was diagnosed with hemophilia. I was shocked."*

After the diagnosis, a challenging process begins for the diagnosed child and his mother. The post-diagnosis period is described as the "most difficult period in the life" by the mothers. In the first period, shock and denial are observed in mothers; they tend to reject the disease. There are various factors that facilitate and delay the mother's acceptance. The most important factor facilitating acceptance is the presence of a hemophilic individual in the family. While this reduces the age of diagnosis, thanks to the mother's previous knowledge and experiences, it supports the shortening of the shock and denial phases. Belief is another important factor that facilitates the acceptance process. The mother's belief that everything is under Allah's initiative and her devotion to destiny has a positive effect on the acceptance process.

*P3- "I'm a bit of a fatalist. Destiny says everything. If Allah has written that I am destined to have 10 children with hemophilia, I have no complaints."*

*P4- "I spoke to my uncles. They always guided me because they were experienced in this field."*

*P9- "We were shocked when we learned he was hemophilic. Over time, we said, everything comes from Allah, and we will do everything for the treatment."*

Husbands and their relatives generally tend to accept it easily because of their belief that the disease is caused by fate. Sometimes, mothers who are at risk of being criticized for being carriers prefer not to share any information.

*P1- "I was very upset, but my husband supported me. Nothing bad happened between us."*

*P9- "I didn't listen to anyone's criticism. My family is already aware of the hemophilia due to my brother. And I explained to my husband what was going on. They assumed this child would always bleed. Then they saw that this was not so."*

Mothers tend to blame themselves or be blamed by their children diagnosed with hemophilia when their children have a problematic event such as bleeding

*P7- "Sometimes I wonder if I am to blame for his condition, 'why didn't I get him checked earlier,' but I never expected this."*

*P8- "Sometimes my son says that the disease was transmitted from me, so I get sad."*

**Theme 2- What Children Experience: Lonely Fish in a Glass Bell**

Although the age at diagnosis of hemophilia varies, the diagnosis is usually made within the first year. The infancy period is dangerous because of the risk of physical trauma. There is uncontrolled mobility, and they may experience many accidents. For this reason, babies are put in a "glass bell" like a "lonely fish" after they are diagnosed. Their playgrounds, play materials, and play opportunities are limited. Both the physical movements and social lives of children are restricted.

*P1- "There is a park on our site. We check it through the window. If there are no children, we go there. We prefer to go during the school hours."*

*P4- "I don't go where there are many children. I can keep him safely when we are alone at home, but it is difficult to keep him away from other children."*

There will be no significant changes in restrictions as time progresses. Regardless of the age of a child with hemophilia, there are always limitations in their life. However, as the child's awareness increases in parallel with his cognitive development, problems begin to come along. The more the child's awareness of the process increases, the more their reactions, such as questioning, rebelling, and rejection increase. However, although it is seen as a contradiction, there is also a positive relationship between the child's cognitive development and adaptation to the disease. While some children experience an intense adaptation process and accept routines as of adolescence, some children begin to question and tend to refuse treatment during this period. In this developmental period, the child begins to question and ask why. The answer to this question may have a negative impact on the mental health of the child.

*P2- "Mom, why me?" was the one thing I could never really answer."*

*P7- "First, he forced himself. He was getting tired, and so was I. Now I say 'come on, you'll receive your medicine.' He comes, we're getting it done, and then we're leaving. Everyone has accepted this now. But he*

*sometimes asks, "Mom, why me? Why can't I play ball like my friends? Why can't I run outside like my friends? Why does my body hurt?"*

They may exhibit an introverted and aggressive character during adolescence or may have difficulties belonging to a peer group. Social labelling in this period is also a negative factor for the child's social life.

*P8- "He can't express himself and can't speak in a social group. He says, 'I'm ashamed, mom'."*

*P6- "His relations with friends aren't so great. He's shy. He doesn't have many friends anyway. He pulls himself back since he's ill."*

The overprotective attitude of the mother is a risk for the mother-child relationship in every period. However, as the child gets older, this risk becomes larger and spreads over the child's whole life.

*P5- I did not let him play ball and ride a bike. I always asked my brother because he had experienced it before. The doctor also said, if necessary, take him with you and make him sit beside you so that nothing happens to him.*

*P7- "My relationship with him is very close. For instance, he cannot do without me, he always wants to go out with me."*

*P9- "He gets angry at me, shouts, but never gives up on me. Since he was little, we grew up together. He is all I have, and I am all he has."*

**Theme 3- What Mothers Experience: A Life on Tenterhooks**

After the diagnosis, the mother builds her life on hemophilia and her son. She makes many sacrifices (leaving work, postponing personal needs, reducing social life, organizing the whole day for her diagnosed son, etc.). They are afraid to take risks and try to continue with a "zero error policy" by taking precautions.

*P1- "I always keep an eye on my child. We control his steps as if we are constantly taking those steps. Maybe we pay too much attention while walking on the road or something."*

*P2- "I was so scared that something might happen to him, I started working as a "helper mom" at the kindergarten just to protect him."*

The psychological problems that begin with the diagnosis decrease in the future. However, the mother's mental health never becomes "very good". Mothers have the potential to experience mental distress due to their worries about the traumas, future lives, education, and employment opportunities of their sons.

*P6- "We look for secluded places and watch over our children. So that they wouldn't do anything to our kids, like throwing a ball to my son."*

The mother experiences conflict between her thoughts and practices, and this causes her to fall into various contradictions. The child, who must be restricted in terms of heavy physical activity, has to be directed to different activities. Technological devices and the internet are considered and preferred by mothers.

*P6- "I am afraid that my son, who has been diagnosed with hemophilia, will have financial difficulties. How will he be able to support his family when he wants to get married in the future? Will he be able to work? I have a lot of worries."*

Although fatalism appears to be a positive factor in acceptance of the reactions against the mother and in the protective mental health of the mother, such fatalism also has a negative effect. Due to the fatalism, mothers refuse to implement protective and preventive measures, and this causes the mother to give birth to a second, third, and even fourth child with hemophilia.

**Theme 4- Breaking the Glass Bell: Starting School**

The biggest challenge for any hemophilic child is beginning school. By the beginning of elementary school, the glass bell is suddenly broken. The children begin to experience social interactions, get in touch, and spend some time with their peers. Children's awareness about hemophilia also increases. A new friendship brings the possibility of peer bullying.

*P3- "His friends were saying to him, "You are sick; don't play with us; you will fall and get us into trouble."*

*P6- "I went to school and had to administer the factor due to bleeding. The classmates told my child, 'You are sick.'"*

Beginning school comes with challenges for all three parties: the hemophilic child, his mother, and the school professionals. The first difficulties experienced by the mother begin in the process of sharing the child's diagnosis

with school staff. Teachers and school staff are often unaware of hemophilia. Therefore, the process starts with anxiety for both them and their mothers.

*P1- "He started school in the first year. I went during breaks and waited with him. I take him to class every time. Every break I go, I wait 15 minutes, and then I come back home."*

The beginning of school does not mean only negativity for hemophilic children or their mothers. The process begins to "normalize" for both the child and the mother after adaptation. The various requirements of being a hemophiliac have a negative effect on the child's adaptation to education. Especially for the children diagnosed with hemophilia who live in the countryside and have to go to a central hospital for follow-ups and treatments, there are problems with continuing the education.

**Theme 5- Practices: How? Where? Why?**

Hemophilia treatment consists of vascular access and factor administration. Most parents prefer that the interventions be done in a health institution. Sometimes, interventions can be done by parents or as a self-infusion at home. Mothers are afraid of making mistakes and hurting their children.

*P3- "The emergency is so close to us, about 15–20 minutes away. We prefer to go there every three days a week: Monday, Wednesday, and Friday."*

*P5- "I would try to access an intravenous line for my child 10 times. It was very traumatizing to hurt him as his mother."*

*P8- "I began infusion at home a few years ago. I tried it on myself first. Then, I did it on him a few times. Then, when I couldn't find one of the veins, I broke off and took a break. I was having a hard time going to the hospital, and this time, I had the courage to establish vascular access."*

Treatment in a health institution causes various difficulties, such as transportation. Despite that, the fact that the interventions are carried out by experienced healthcare personnel provides comfort to the mothers. However, encountering healthcare professionals who do not know about hemophilia can make the situation even more difficult.

*P3- "Even in the hospital, we tell the nurses how to do the administration. They try to shake the vial of factor; we warn them that they should do it in their palm gently."*

**Theme 6- Family Dynamics**

After the diagnosis of hemophilia, family dynamics never return to their normal state. Over time, the main focus of the family becomes their child, which causes conflicts in relationships. Compared to the hemophiliac, less attention is paid to the other children. This causes the sibling to be negatively affected. In addition, restrictions on the hemophilic child negatively affect relationships.

*P6- "I was spending and still spend more time with him. Sometimes, I think I pay less attention to my other child."*

## DISCUSSION

Having a hemophilic individual in the family and "religious belief" facilitates the diagnosis process.[17-19] The primary caregiver who cares, monitors, and takes responsibility for the preventive measures and treatment process is the mother.[20] The father comes in now and then as a support power for the mother. Although the literature supports that, Limperg et al. did not show any difference in anxiety and depression between mothers and fathers for hemophilia.[17,21,22] Rumours about hemophilia are one of the most important factors complicating the acceptance and adaptation process.[23] The mother may be blamed by her husband and relatives because of carrying the affected gene. We know that this situation was more common in the past since access to treatment was difficult and bleeding was more frequent.[24] We observed that this psychological pressure has decreased with new treatment options and "fatalism" .[17,25]

The glass bell in which the children are placed after the diagnosis suddenly breaks with the beginning of primary school, and children begin to experience social relations; they meet and spend longer time with their peers.[26] The hemophilic child, who begins to understand that he is "different" from others, begins to oppose authority and resist restrictions. The child diagnosed with hemophilia is most exposed to peer bullying during this period.[27]

There are some changes in the daily routines of hemophilic patients, such as treatment interventions, follow-up, and admission to a hospital.[26,28] The focus of a mother's attention is her son with hemophilia.[29] The mother gives up a lot in her life, such as retiring from her job, postponing

her personal needs, and reducing her social life to almost nothing. The mother prefers not to go into crowded places, so she can't socialize and becomes lonely.[28]

Although the facilitating behavior of healthcare professionals and positive developments in the health system (easy application, low frequency of treatment, etc.) are factors that ease life. Mothers have the potential to experience mental distress due to their worries about trauma, bleeding episodes, their son's future lives, education, and employment opportunities.[30,31] This begins with the wrong information about hemophilia and the uncertainty of the treatment process, which spreads through all of life.[22,24,25]

By the beginning of school, the mother has concerns such as the risk of accidents, poor peer relations, and the child's potential to drop out or refuse to go to school.[32] After the adaptation to school, the process begins to "normalize" for both the child and the mother. While the school environment brings many risks for children, it also offers a positive experience in terms of social development. The child begins to spend time with his peers, gets to know new people, and engages in different activities.[26,27,32]

After the son is diagnosed with hemophilia, family dynamics never return to their original state.[12] The unrestricted behavior to the healthy child (absence of restrictions, a more social life, etc.) causes the hemophilic son negatively.[28] Other anxiety states include mothers telling their daughters that they may be carriers, the marriage processes of carrier girls, and possible hemophilia in their sons in the future.[33] However, with a good plan, a well-organized daily life, good precautions, regular prophylactic factor administration, and high motivation, it is possible to establish a near-normal life for people with hemophilia and their families.

## CONCLUSION

Hemophilia is a chronic disease that affects patients, their parents, healthy siblings, and carrier sisters psychosocially. The basic condition of leading a healthy life in hemophilic individuals is to reduce bleeding and prevent disability with strong adherence to treatment. To achieve this, the mother, who is primarily responsible for the care, and the hemophilic individual need high motivation for life. We think that the psychological status of hemophilic boys and their mothers, their adaptation to hemophilia, and their social lives are very important in terms of adherence to treatment for hemophilia.

## Ethical approval

This study has been approved by the Erciyes University Ethic Committee (approval date 09.02.2022, number 2022/130). The mothers in this study were informed and informed consent in the format was obtained.

## Author contribution

The authors declare contribution to the paper as follows: Study conception and design: VG, EÜ, MK; data collection: VG, BFK, SA, AÖ; analysis and interpretation of results: SA, VG, EY, BFK; draft manuscript preparation: VG, SA, BFK, EÜ. All authors reviewed the results and approved the final version of the article.

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## Conflict of interest

The authors declare that there is no conflict of interest.

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