



Experiences of Mothers with a Child with a History of Esophageal Atresia at Preschool Age: a Phenomenological Study

Forouzandeh Dashti¹, Masoumeh Shahbaz Ghahrouei^{2*}, Heidar Ali Abedi³

1-Midwifery Instructor, Community Health Research Center, Islamic Azad University, Isfahan Branch (Khorasgan), Isfahan, Iran

2- Nursing MSc, Isfahan medical of science university, Alzahra Hospital, Isfahan, Iran

3- Nursing Professor, Heidar Ali Abedi, Community Health Research Center, Islamic Azad University, Isfahan Branch (Khorasgan), Isfahan, Iran

*Corresponding Author: Masoumeh Shahbaz Ghahrouei, Email: shahbaz@yahoo.com

Abstract

Background: Esophageal Atresia is one of the neonatal malformations that has contradiction with life and is neonatal surgery emergency. This anomaly makes many problems for mothers because they have to look after their operated babies. Due to this illness in digestion system and negative effect on infant nutrition, growth and development, it might result in mother's and child's unsuitable quality of life for many years.

Methods: The study uses a qualitative approach to phenomenology. Sampling method is based on objective and is done until data saturation. Information from 16 unstructured interviews with 10 mothers who have children with a history of Esophageal Atresia surgery has been collected. Colaizzi method is used for data analysis.

Results: Interviews were extracted and analyzed. Seven themes and sub concepts were identified which were: 1- knowledge and awareness, 2- readiness for acceptance and compatibility with the child's medical condition, 3- support and companionship, 4- effective services of health care system, 5- concern and anxiety, 6- tough and difficult moments of living with pediatric patients and complications 7- disease problems of Esophageal Atresia in children.

Conclusions: The results of this study represent a wide range of problems and needs of mothers with a child with Esophageal Atresia. Child's parents often have not adequate education, support of the treatment team, and don't follow up after they leave hospital. Therefore, with forming multipurpose group in hospital and home visiting mother and child as a cure, attention was paid until child's health condition recovered.

Keywords: Child Atresia Esophageal, Mothers Experience. Phenomenological Study.

Introduction

Esophageal atresia is one of the abnormalities that endangers the baby's health from the very beginning of birth and is a serious threat to his life. Esophageal atresia is the most common

congenital malformation of the esophagus in babies. In this malformation, the esophagus is not formed as a single tube and this malformation may also be associated with an abnormal connection between the esophagus and trachea



(fistula). In these children, the esophageal tube is interrupted and has two separate upper and lower parts that are not connected due to the defect that exists. As a result, the correct transfer of food from the mouth to the stomach is problematic and many other problems arise regarding feeding the infant and sometimes their breathing. This abnormality, which may not be unique, is one of the emergencies of newborn surgery, and after surgery, there is a need for specialized nursing care and maintenance in these children even after discharge from the hospital (1).

The initial symptoms of esophageal atresia associated with the trachea (fistula) in infants include foamy and abundant saliva in the mouth and nose, cyanosis, respiratory distress, and cough, which usually begin or is intensified with the first feeding of the infant due to regurgitation. Milk or saliva flows from the esophagus into the trachea or bronchus. (2)

This disorder may be single or multiple. In more than 50% of the cases, this disease is accompanied by other congenital abnormalities, such as heart abnormalities 29%, spinal problems 10%, anal-rectal problems 14%, respiratory distress 6%, neurological problems 12%, genetic disorders 14%, gastrointestinal abnormalities 13% and other organ problems 11%. Statistics have shown the prevalence of this congenital anomaly to be one in 3500 live births (2).

In Iran, there is no exact statistic of the prevalence of this congenital anomaly, but during the limited studies that have been conducted regarding the frequency of this disease, it is shown as a common disease (5).

Esophageal atresia has many complications such as pneumonia, aspiration and leakage from the surgical repair site. Respiratory complications

before and after surgery are a serious threat to the baby's life. These complications include respiratory distress, atelectasis, pneumothorax, and laryngeal edema. The reason why these children should be hospitalized in the special care department in expensive specialized hospitals is that esophageal atresia is usually not a single abnormality, accompanied by congenital heart diseases with a high prevalence in these infants and is accompanied by cyanosis or increased blood pressure. Pulmonary disease can affect the prognosis of surgery (3).

Many characteristics of the mother's interaction with a child with esophageal atresia are special and, compared to other mothers, the mothers of affected children had special abilities such as positive participation, sensitivity, attention and concentration while feeding the child along with constant worry and the possibility of reducing uncomfortable experiences. This has been proven with the increase of medical services for mothers (4).

Today, the survival rate of babies born with esophageal atresia has increased, and it is natural that mothers of affected children are always afraid of new problems and how to deal with them. It seems that the effects of the disease on the child and his family are widespread. Surely, the pressure and anxiety that a mother suffers from nursing an abnormal, sick and operated child is extremely high. Despite the members of the treatment team may have a lot of experiences based on specialized information in their career, it is necessary to understand the human's pains so that they can provide appropriate medical services along with empathy and affection (6). Caregivers are responsible for providing effective services to the patient and his family, and the importance of research in the field of care is to improve nursing performance.

MATERIALS AND METHODS

This research was conducted with the aim of knowing more about the experiences of mothers with children with esophageal atresia at birth. By examining the experiences and through understanding the needs and problems of these mothers, a suitable solution can be found to create a coherent educational care organization by family health nurses. This can provide better support for the mother, child and a follow up on their affairs in many cases of training. A university with the latest and most reliable scientific resources is not as useful and effective as examining clinical cases based on the conditions of a city's health and treatment center, considering the economic and social situation and local culture of the clients. To solve the health problems of each region, experiences must be used. Needless to say that recognizing the problems is the first step to solve them, nursing researches in this field may be able to provide a clear picture of the problems experienced by mothers with children with esophageal atresia. It can also formulate instructions and guidelines for the performance of nurses and help to solve the problems of children with esophageal atresia. The surgery at the beginning of the digestive system should be examined from the mother's point of view, who is responsible for feeding her child. So, nursing care and support services should be improved. As a result, many of the complications of this disease will either not occur or be minimized. More importantly, a child's life, development and growth follows a normal process.

All interviews, 25 to 45 minutes, were recorded and notes were taken, where necessary, for the non-verbal states of the participants. After completing the interview, all items were carefully examined and written on paper to be used in subsequent analyses. In order to ensure the

correctness of the interpretations of the mothers' statements, they were referred again. The correctness of the interpretations was checked against the opinion of the mothers and changes were made accordingly. In this research, open-ended, broad and principal questions were used, without guidance and direction. Questions like "What are your mothers' experiences with such a disease like esophageal atresia in your child and its surgery?" and then the following questions were posed based on the given answers. It was designed to gain access to the individual's experiences as they were acquired.

After interviewing the participants, the data was analyzed using the 7-step Colaizzi method and after interviewing 10 mothers information saturation was done (7).

In the first stage of Colaizzi, all descriptions provided by mothers with children with esophageal atresia in the study, which is conventionally called the protocol, were read in order to get an image and to familiarize with them.

In the second stage of Colaizzi i, References, sentences and phrases that were directly related to mothers' experiences were extracted from each of the protocols. This stage is known as "extraction of important sentences".

In the third stage of Colaizzi, an effort was made to understand the meaning of each of the important sentences. This step is known as "formulating the meanings".

In the fourth step, Colaizzi repeated the above steps for each protocol and put the formulated and related meanings into clusters of themes (main themes). Two methods were used: a) by referring to the main protocols, the validity of the clusters was checked and b) contradictions between or

within several clusters were noticed, which the researcher should not ignore at this stage.

In the fifth stage of Colaizzi, the results were combined in the form of a comprehensive description of the research subject which means formulating the comprehensive description of the phenomenon under study in the form of an explicit and clear statement of the basic structure, which is often called the "intrinsic structure of the phenomenon".

And in the seventh and the last stage of Colaizzi, by returning to each of the participants and conducting a single or multiple interview sessions, they were asked about their opinions on the findings and their reactions were taken regarding the final validation of the findings. Of course, Colaizzi believes that researchers should be flexible about these steps. (8)

According to the qualitative research procedure of phenomenology, instead of the validity of the data, the reliability of the statement of the fact was used, which means the correct report of the experiences of the participants in the study.

Therefore, 10 participants were referred again and their agreement with the subject categories compared to the main protocol was checked. Then, possible important contents were discussed and clarified by which the participants' agreement was reached. Finally, the dependability was checked.

The present article was prepared from the nursing master's thesis number 2381040391003 and IR.MUI.REC.1391.2.33.

RESULTS

Table 1 shows the demographic characteristics of the participants. The experiences of mothers with children with esophageal atresia in six main themes namely important information about the disease, acceptance and adaptation to the condition of the disease, support and companionship, effective services of the medical care system, Worry and anxiety, and Difficulties of complications and problems of the disease were reflected in Table 2.

Table 2. Primary and central categories of experiences of mothers with children with esophageal atresia

Axial classes Primary classes

1-Important information about the disease
Basic information on children's diseases
Learning the principles of special care for sick children before discharge
Teaching the right ways to feed a child

2-Acceptance and adaptation to the child's illness
Diagnosis in pregnancy to accept the baby's disease
- Appeal to spiritual and religious matters for healing
Accepting reality by being in the intensive care unit

3-Support and companionship - Assistance and financial support of social centers
Participation and companionship of spouse and relatives in child care matters

4-Effective services of the medical care system
There is an urgent need for the proximity of the mother and child room in the hospital
The need for empathy and companionship of the nursing staff

5 Experiences of Mothers with a Child with a History of Esophageal Atresia

Table 1. Demographic characteristics of the participants

Property	Options	Number	Percent
Mother's age	20-25	7	70%
	26-30	2	20%
	31-45	1	10%
Children's age	1-4	4	40%
	5-6	6	60%
Education of mothers	Elementary	3	30%
	High schooler	7	70%
Monthly family income	10 -15 Million	9	90%
	16- 20 Million	1	10%
Mother's job	Housewife	8	80%
	Manual worker	2	20%
Child rank	1	2	20%
	2	6	60%
	3	2	20%
Pregnancy care	Positive	10	100%
Awareness of the abnormality of the child during pregnancy	Negative	10	100%

Table 2. Primary and central categories of experiences of mothers with children with esophageal atresia

Primary classes	Axial classes
Basic information on children's diseases Learning the principles of special care for sick children before discharge Teaching the right ways to feed a child	1-Important information about the disease
Diagnosis in pregnancy to accept the baby's disease Appeal to spiritual and religious matters for healing - Accepting reality by being in the intensive care unit	2-Acceptance and adaptation to the child's illness
Assistance and financial support of social centers - Participation and companionship of spouse and relatives in child care matters	3-Support and companionship
There is an urgent need for the proximity of the mother and child room in the hospital The need for empathy and companionship of the nursing staff	4-Effective services of the medical care system
Fear of repeating the disease experience in the next child Worrying about taking care of the child Concerns about the child's future health	5-Worry and anxiety
The difficulty and time-consuming feeding of a child Multiple surgeries	

Frequent infections Slow growth of the child	6-The severity of complications and problems of the disease
---	---

5-Worry and anxiety Fear of repeating the disease experience in the next child
Worrying about taking care of the child
Concerns about the child's future health

6-The severity of complications and problems of the disease The difficulty and time-consuming feeding of a child
Multiple surgeries
Frequent infections
Slow growth of the child

Each of these experiences had several sub-concepts, which are presented along with mothers' quotes.

1) Important information about the disease

The findings of this study showed that one of the perceived experiences of mothers with a child with esophageal atresia is receiving important and basic information about the child's disease, such as the symptoms and complications of the disease, managing critical incidents caused by the disease, and family-oriented care. This concept had 3 sub-concepts as follows.

1-1) - Basic information on the child's illness

There was a lack of necessary information and awareness regarding the complications of esophageal atresia surgery among the experiences of these mothers. This surgery is operated at the beginning of the digestive tract (input of milk), and one of its common complications is frequent aspiration, which often causes the mother to panic instead of receiving proper care.

In this regard, Participant No. 6 stated: "when I was feeding my baby one day, he suddenly raised

the milk in a leaping manner, his face went all black and he started coughing. I was horrified, I didn't know what to do. I tapped him hard on his back, but it didn't help. We brought him to the hospital as quickly as possible."

2-1) - Learning the principles of special care for a sick child before discharge

Another experience of mothers was the inability to perform part of the nursing care of their sick child, such as gentle and frequent suctioning of secretions, relief of post-operative pain, prevention of infection, and keeping the child's body temperature constant.

Participant No. 3 stated, "I was very afraid of the secretions getting down my child's throat, I kept focusing on the upper bag as not to get filled up and my child's breathing would not be difficult..."

3-1) Teaching the right ways to feed a child

One of the most important experiences of these mothers in feeding their babies was taking care of the gastrostomy tube and fearing the displacement and infection of the tube.

Participant number 2 stated, "I clean the tube and the wound around my baby's stomach with betadine at leisure and apply sticking plaster lest the tube get damaged and as a result they change it frequently."

2) Acceptance of and adaptation to the condition of the baby's illness

Another finding of this study was the experience of acceptance and acceptance of the baby's illness by the mother. This hard and difficult experience created resistance to immediate surgery while it

was necessary to save the baby's life. This concept has 3 sub-concepts as follows:

1-2) Diagnosis during pregnancy to accept the baby's disease

The experience that the mothers under study had, was a sudden and shocking encounter with the child's illness after delivery, while the care during the pregnancy period had reported the fetus as healthy.

Participant number 7 stated, "When I saw my child in the hospital on the third day of his birth, while he was connected to various devices, I couldn't believe it! It was very difficult for me to admit this and I was not at all ready to accept the reality! I was under observation throughout my pregnancy and they said the baby was healthy..."

2-2) Resorting to spiritual and religious matters for healing

One of the common experiences of all the mothers was to adapt to the conditions of the baby and then to resort to God and pray for the baby's health. This was more in the format of begging God, repenting, and making pledges.

Participant number 1 stated, "When I saw my sick child under these devices, I said, God forbid, this child is suffering because of my sins! If God brings my child's health back, I will make all of my pledges..."

2-3) Accepting the reality of being in the intensive care unit

Among other experiences of accepting infant's esophageal atresia disease was the frequent presence in the special treatment department for newborns and getting to know the problems of other mothers and babies. Also, these mothers compared their child's status with others' especially those with more serious disease.

Participant number 4 said, "Over the last few days, I have been doing my child's care in this ward and I see that some children have a lot of problems. They have had several operations on their brains! Yet, thank Goodness, my child's brain is all right..."

3) Support and companionship

According to the findings of this study, the hospitalization and surgery of the child was a stressful experience for the mother. Along with caring for the sick child, they had many awful experiences such as not having enough supporting facilities, inability to pay the treatment costs, and feelings of loneliness and unsatisfactory relationship between the parents. This experience had 2 sub-concepts.

1-3) Assistance and financial support of social centers

Due to the fact that the research was conducted in a highly specialized educational center which received patients from the surrounding small towns, the mothers were often in low economic and social class. As a result. Among the experiences of the mothers in this study was the lack of proper financial support from the hospital during the child's illness.

In this regard, participant number 5 stated, "Our expenses are too high, just a sterile gauze that we put for his neck hole costs a lot of money! Other expenses are back-breaking, as well. I wish we would be helped!"

2-3) Participation and companionship of the spouse and relatives in child care matters

The cooperation of parents, accompanying relatives and medical staff with the mother in caring for the sick child was another experience of mothers that was valuable for parents, children and care providers.

Participant number 2 stated, "I really wish my husband was by my side and helping me. By God! Having a child is very difficult, especially if your child is sick..."

Participant number 3 stated, "If my parents hadn't helped me, I would not have been able to overcome my child's illness..."

4) Effective services of the medical care system

One of the main concepts resulting from the experiences of mothers regarding the care of a sick child was the provision of necessary care facilities in the hospital. This includes 2 sub-concepts.

1-4) There is an urgent need for the proximity of mother and child rooms in the hospital

One of the problems was the distance between the postpartum floors and the newborn surgery ward. Mothers with postpartum injuries had to travel through many floors to visit and care for their babies.

Participant number 10 statement was as follows: "The nursing mother's room was on the second floor, but my baby's ward was on the fourth floor. I was going up and down the stairs on most of the time with my cesarean wound, it was very difficult for me..."

2-4) The need for empathy and companionship of the nursing staff

Another important concept derived from the experiences of mothers while taking care of the newborn in the neonatal surgery department was the mothers' complaint about the indifference of the nurses working in the neonatal surgery department, who, regardless of the difficult conditions of the mother, did not provide her with a proper care and accompaniment. The experience of a participant in this field was as follows:

Participant number 8: "When I wanted to take my baby out of the machine for the first time and breastfed her, it was very difficult for me. I was scared, yet the nurses didn't help me..."

5)) Worry and anxiety

The findings of this study indicated the experiences of fear, stress and mental and emotional struggles of mothers with sick children, the concept of worry and anxiety of mothers had the following 3 interpretations:

1-5) Fear of experiencing the disease again in the next child

These mothers had the fear of pregnancy again. All of them were unaware of the child's illness despite prenatal care, didn't trust this care and were worried about the recurrence of this disease in the next child. Participant number 8 stated: "I would like to have a child again, but I am afraid that the child will be the same..."

5-2) Worrying about taking care of the child

Among the experiences that the majority of the mothers participating in this research were involved in was being unable to take care of the child, especially when special problems of this disease occur. They often bore the costs of hospitalization and became anxious about the child's discharge.

Participant number 9: "When I gave him the first helping hand, I was afraid that it would jump into his throat and choke him, I couldn't do anything..."

5-3) Concern about the child's future health.

One of the important concepts derived from the experiences of the mothers of this study was the abnormality of the child in later stages of life and the disabilities caused by this disease. The mothers were concerned that this child would always need care and support of others and due to

gastrointestinal surgery they would never have normal eating behavior.

In this regard, the experiences of a participant in the study were as follows:

Participant number 1: "I take my child from doctor to doctor. I am afraid that he will keep turning black every time he tries to eat solid foods for the rest of his life..."

6) Difficulty of complications and problems of the disease

The findings showed that the experience of esophageal atresia in a child was a challenge that threatened comfort and convenience of the mother, which played an important role in the relationship and interactions between the mother and the child. On the other hand, the early and late consequences of esophageal atresia corrective surgery seemed very difficult for the mother. Most of these complications were present in the first year of life and the rest of them remained until preschool time. Leakage and narrowing of the surgical site, esophageal reflux, lung infections with other abnormalities and finally the slowness of the child's growth were the reported experiences. This experience had 4 sub-concepts as follows:

6-1) Difficulty in and the amount of time spent feeding the baby

Most of the mothers spent a lot of time feeding the baby. Breastfeeding and then auxiliary food eating took a lot of time. The child was never left alone while eating, even later in pre-school age and the gradual shift to auxiliary and solid foods was much slower than healthy children. An example of the statements of 2 participants:

Participant number 7: "Because of my child, I spend most of my time at home and take care of him/her..."

Complainer number 10: "It is very difficult and painful for a mother to see that her child cannot easily eat by mouth at the table..."

6-2) Multiple surgeries

Usually, esophageal atresia is not treated with a single surgery, it is common to be accompanied by other abnormalities. On the other hand, there is also adhesion, leakage and narrowing of the operated area, which cause these children to be hospitalized again, and this was an experience that most mothers faced from the beginning. 2 participants stated the same problems:

Participant number 2: "My child has a heart problem in addition to the esophagus problem, he has had surgery once..."

Participant No. 6: "Because of my baby's vomiting, they have punched his esophagus with a balloon several times so far! they say his esophagus is tight..."

3-6) Frequent infections

The occurrence of respiratory infections is common in children with a history of esophageal atresia surgery, which is mostly due to the return of digestive contents to the lungs. This complication causes the child to become ill immediately and be re-hospitalized. 2 participants stated:

Participant number 9: "Our child's lungs are very sensitive. With a very mild cold, he gets a severe infection, and the doctor sends him to the hospital..."

Participant number 4: "My child wheezes all the time. He has shortness of breath. The doctor says he has reflux, I often set an aerator for him..."

4-6) Slow growth of the child

One of the common experiences of the mothers in this research was their child's developmental

delay which bothered them. Feeding problems, co-morbidities, re-admissions to the hospital and complications of esophageal atresia surgery in all of these children caused slow growth and none of the children were in the normal range of the health road. An example of the statements of two participants was as follows:

Participant number 7: "My son is very petty towards me and his family, I don't know if he will grow up one day or not..."

Participant number 9: "My child compares himself to his peers and says why am I so small..

Discussion

Mothers of children with esophageal atresia at birth experienced a wide range of problems in different concepts. One of these experiences was "important information about the disease". If parents have a sick baby, they need to know and acquire basic information about their child's disease such as symptoms and complications resulting from the disease, crisis management caused by the disease and family-oriented support. In this regard, the findings of Ardengi et al. in 2022, which investigated children with esophageal atresia, showed that the scope of the needs of these people is very wide and different and includes the need for information and awareness regarding the diagnosis. Child illness, treatment of child illness, need for knowledge and awareness regarding child care program at home and also need for information regarding prognosis of child illness are indicated. Most parents stated in their interview that providing this information by health care providers has been inadequate. (4)

Isselstein et al. in 2015 state that community health nurses should reduce subsequent unconventional visits and referrals by home follow-up and special educational interventions for the care of a sick child. If parents' awareness

and knowledge of their child's illness increases there is much less to worry about and less important cases refer to health centers (17)

Although education about the child's illness during hospitalization is very valuable for parents, the short period of education cannot meet all the educational needs of parents, especially mothers. So information about the illness should be provided as the child grows in the form of visits. Home visits should also be provided periodically and regularly by the nurse.

Another experience of these mothers was "accepting and adapting to the child's illness".

Nathanal et al showed in 2023 that not diagnosing the disease during pregnancy makes it very difficult for the parents, especially the child's mother, to accept the disease. They don't admit this and sometimes there comes an argument with the treatment staffs to move the child to another medical center hoping that the child will be diagnosed as healthy (2).

In 2021, Van Horn et al. state that in cases where the infant needs surgery, the parents should consult with a specialist and the mother should visit the surgical intensive care unit in order to better adapt to the complications of the surgery. By doing the above, it is possible to make a significant impact on the preparation of parents, and this preparation reduces their denial and resistance about the child's illness (6).

Prenatal diagnosis of babies in need of urgent surgery can prepare the provision of the best equipment and facilities for the nurse in the special neonatal ward, and on the other hand, the mother can have a more appropriate acceptance of the treatment decisions about her sick child. Also, she can manage the child's illness more easily, accept and adjust herself to the existing conditions related to his child's illness.

Among other findings of this study, there appeared mothers' perceived experience of "support and companionship". The admission and surgery of a baby at birth, taking care of a sick child, lack of enough supporting facilities, loneliness, the decrease in the intimacy of the couple due to the emotional and psychological pressures and care reduction of other offsprings are all stressful for parents and can have negative influence on the care of the sick child.

In 2015, Frago et al showed in their research that having more social support is associated with less stress and fewer problems in the stage of having children. Also, based on their studies, they found that the adaptive behavior of the mother is largely affected by the amount of support she receives. Therefore, benefiting from the support of her husband, family, friends and society can be effective in facilitating the achievement of the role of mother and by reducing stress and promoting may the mother and her child be healthy (21).

The results of the study by Muller et al. in 2021 state that access to social support includes family support, support from spouse and relatives' network, support from government systems, spiritual and psychological support. Also, economic support during the child's illness due to special needs and problems are very important regarding the care of a sick child (9).

Hospitalization and surgery of a child is a stressful experience for parents. On their way to care for the sick child, parents face many problems that are caused by not knowing their roles, not having enough support facilities, feeling alone, and ineffective and unsatisfactory relationships between the husband and wife. The findings of this the study showed that some of the sufferings experienced by the mother of a hospitalized child were insufficient and

inappropriate facilities in the hospital such as food, the distance between the mother' room and her child's, the inappropriateness of the mother's room condition, and the fact that the nurses of the ward also lacked necessary cooperation and participation due to the crowdedness of the center. The support and companionship of the family with the aim of empathy and help in care, expressing affection to the child's mother on behalf of her husband, the financial assistance of the treatment staffs, friends, nurses' advice, guidance and proper instruction are very effective in achieving the goals regarding child's treatment. Another part of the experiences of mothers with a child with esophageal atresia was related to "effective services of the medical care system".

In order to treat and follow up a sick child, parents need specialized counseling and treatment centers or institutions. In this regard, expectations from nurses in the form of emotional support, politeness, cooperation and participation in child care, responsiveness to the mother's request for help are needed.

In 2014, Konferti et al. stated that the necessary care facilities such as the need for sanitary equipment, food, sleeping place, suitable roommate for mother and child are absolutely necessary for parents. In their study, half of the parents declared the hospital facilities to be insufficient. (25).

In 2014, Natician et al. explained that considering that a healthy baby needs the mother's warm embrace and feeding with her milk to survive, babies who are born with different life-threatening abnormalities need support for their survival. They need a lot of services and facilities from the healthcare system which should be provided for their care (26).

Fallahi et al. showed in 2022 that one of the main concepts resulting from the experiences of parents regarding the care of their sick child is providing necessary care facilities which includes the need for proper food facilities in the hospital, sleeping facilities and a suitable roommate for the mother and child. In their study, more than half the parents said that hospital facilities were insufficient (5).

Among other findings of this study, the perceived experience of "worry and anxiety" was one of the main experiences of mothers of children with esophageal atresia. This research showed that during the child's illness, parents' anxiety may hinder the support of the child. Usually, when the mother enters the hospital, her tension increases due to fear of the unknown, fear of what will happen in near and far future to the child, fear of people hurting the child's and her mother's feeling and the fear of the financial burden caused by the child's illness.

The findings of Yi Chan Sun et al.'s study in 2015 showed that infants and children with esophageal atresia experience many problems which cause parents to worry. one of these worries is about the future of the child and his probable eating problems (15).

Wang et al. in 2014 state that as soon as parents with a sick child enter the hospital and see their child's hospitalization and surgery, their role changes, their anxiety and worry make them vulnerable and sometimes aggressive. Likewise, with a worsening prognosis of illness, this state becomes more severe so that sometimes they are no longer able to support their sick child. Awareness of this is essential for the treatment staffs (22).

The experiences of the participants of this study showed "the severity of complications and problems of the disease". It showed that the parents of these children are exposed to difficult and frightening conditions. This was due to the early and late complications, consequences of the disease, long care and the sudden death of their child or failure to care for their child. This disease is a threatening challenge for the comfort and convenience of the family, especially for the mother. Chronic fatigue and helplessness in taking care of the child had negative impacts on the mother-child relationship.

Shaver et al.'s findings in 2014 showed that mothers have to change their daily family schedule during the child's illness in order to adapt to these difficult conditions. Many other tasks interfere with child care and there are multifaceted concerns (23).

"Symptoms and problems of esophageal atresia in children" was the last sad experience of all research subjects under study. This is because children with esophageal atresia suffer from the consequences of this disease throughout their lives. They got continuously involved in the respiratory and gastrointestinal problem such as frequent pneumonias, esophageal strictures, constant refluxes, multiple surgeries to remove the complications and prolonged child's hospitalization years after the newborn's surgery. These were the experiences of all the participants. The results of the study by Sar and colleagues in 2021 also showed that the survival rate of esophageal atresia patients, whether related to the trachea or not related to the trachea (fistula), is highly related to life-threatening abnormalities associated with esophageal atresia (7).

Balvin and Yada in 2023 showed that complications such as difficult swallowing,

esophageal adhesions, recurrent lung infections, return of stomach contents to the esophagus, inflammation of the esophagus, cancer of the esophageal lining cells are among the complications of esophageal atresia in childhood. These situations can cause an increase in chronic lung and digestive diseases, increase in the mortality of these children, and impairment in the quality of life even up to old age (1).

In 2012, Hong et al. showed in a study that esophageal atresia has early and late complications that is 46% of esophageal atresia complications occur in the first year of children's lives while 54% of complications occur after the first year. One of the most common and early complications is leakage from the repair site of esophageal atresia, and one of the common late complications is reflux. The cause of reflux is the thickening of the esophageal sphincter valve to the stomach, which can be cured 50% with medicine and 50% with surgery. Two-thirds of these children suffered from recurrent lung infections (31).

The mothers blamed the treatment staffs and care services for the following problems: difficulty for the child to swallow solid food for a long time after the operation, the appearance of a hole in the repair site (fistula), esophageal adhesion, food jumping into the throat (aspiration) and frequent lung infections, while these problems were expected complications of the surgery and have been mentioned in all studies. Therefore, this showed the importance of educating and informing these mothers about the common complications of this surgery.

Among the limitations of this study, we can mention several points such as the bitter and unpleasant experiences of taking care of a sick child, the memories which bothered the mothers

which caused them to be often deeply affected and crying during the interview. The researcher had to stop the interview, soothed and relaxed the mother.

Many mothers were reluctant to recount their experiences, and most of the studied units accused the hospital staff of not doing enough regarding the child's illness. This notion hindered the nurse interviewer's sincere communication with the mothers during the interview.

Conclusion:

The aim of this research was the investigation of mothers' experiences with children with esophageal atresia repair surgery, which involved the child, mother, family and society, despite the prenatal care of all the participants. None of the mothers was aware of their fetus's esophageal atresia. This indicated that the methods of examining the health of the fetus during pregnancy should be carried out with more seriousness and precision in order to detect abnormalities of the fetus, increase the mother's acceptance of and adaptation to the child's illness so that she does not consider the health care system to be inefficient. Many problems were due to the lack of necessary knowledge and information related to this disease and the principles of caring for a sick child. The experiences of the mothers during the hospitalization, surgery and discharge of the child with esophageal atresia corrective surgery showed that multiple support groups in the hospital. These groups include surgeons, neonatal intensive care nurses, social workers, and psychologists who should follow up on the medical care of these children and accompany their families. Proper training should be done according to the mother's needs. Frequent and periodic visits on a regular basis should be done after discharge to minimize the complications caused by the surgery and the

disease. The mothers under study expected effective medical services and financial support from social organizations. They expected to cover and protect vulnerable (poor) social class referring to medical centers and to the above mentioned hospitals financially, socially and educationally.

ACKNOWLEDGMENT

The researchers cooperated with the respected members of the Faculty of Nursing and Midwifery of Islamic Azad University (Khorasgan) Isfahan Branch, the respected staff of the Neonatal Surgery Department of Isfahan Hospital and dear mothers. We would like to express our gratitude to the children with esophageal atresia who helped us in this research.

Conflict of interest: "No conflict of interest has been declared by the authors."

REFERENCE

- 1-Baldwin,D. Yadav,D. Esophageal Atresia,National Library of medicine, April 24, 2023.
- 2-Natnael Moges ,M. N,Ahmed,K. Birhanu,D. Belege,F. Dimtse,A. Kerebeh,G. Kassa,BD. Geta,K. Oumer,KE. Zewde,EA. Dessie,AM.Anley,DT. Demis,S. GebreEyesus,FA. Bantie,B.Surgical outcome and predictors of neonates with esophageal atresia admitted at Tikur Anbesa Specialized Hospital ,Plos one Journal, May 16, 2023.
- 3-National Center on Birth Defects and Developmental Disabilities, Centers for Disease Control and Prevention, Facts about Esophageal Atresia, June 28, 2023.
- 4-Ardenghi,C. Vestri,E. Costanzo,S. Lanfranchi.G.Veremati,M.Destro.F. Pierucci,UM.Calcaterra,V. Pelizzo,G. Congenital Esophageal Atresia Long-Term Follow-Up—The Pediatric Surgeon’s Duty to Focus on Quality of Life, *Child Health and Surgery*, 1 March 2022.
- 5-Fallahi , M.Babaei ,Gh. SinaKazemian ,S.SalehTajalli , Noripour ,Sh.Rouzrokh , M.Hajipour ,M Kazemian,M.Predictors of Early Mortality in Esophageal Atresia: A 12-year Cohort Study in Tehran Iranian Journal of Pediatrics: Vol.32, issue 6; e129266, November 11, 2022.
- 6- Vanhoorn,CE. Kate,CAT. Rietman,AB. Toussaint-Duyster,LCC. Stolker,RJ. H Wijnen,RM. Graaff,JCD. Long-term neurodevelopment in children born with esophageal atresia: a system article review, *Diseases of the Esophagus*, Volume 34, Issue 11, November 2021.
- 7- Intissar,Ch. Faouzi,N. Yosra,B. Mariam,M. Tarek,B. Awatef,Ch. Said,J. Esophageal atresia with tracheoesophageal fistula: A novel rare variant, *Journal of Pediatric Surgery Case Reports*, Volume 64, January 2021, 101691.
- 8-Abedi,HA. Application of phenomenological research method in clinical sciences, *Strategy Quarterly*, volume 19, issue 52, 2009, page 207-224
- 9- Muller,H.Weiss,CH.wanger,A.Schellere,v.Hoe rnina,A.Diez,s.Association clinical factors with postoperative complications of esophageal atresia, *pediatrics and Neonatology journal*, volume 62,issue 1.january 2021
- 10- Mackenzie, C. Lees, a. Ioana Bratu, b . Maryna Yaskina ,c . Michael van, M. Oral feeding outcomes in infants with esophageal atresia and tracheoesophageal fistula, *Journal of Pediatric Surgery*,53,2018,929-932.
- 11-Morini,F. Conforti,A. Zani,A. Sindjic-Antunovic,S. Koivusalo,A. Friedmacher., F.vanHeurn, E. Pierro,A Hollwarth,M . Bagolan,.P. the EUPSA Esophageal Atresia Registry. Diagnostic Workup of Neonates With Esophageal Atresia: Results From the EUPSA Esophageal Atresia Registry, *Sec. Pediatric Surgery*, Volume 8, 2022.

- 12- Garabedian, C, Sfeir, R. Langlois, C. Bonnard ,A. Khen-Dunlop, N. Gelas, T. Does prenatal diagnosis modify neonatal treatment and early outcome of children with esophageal Atresia? American journal of obstetrics and gynecology. 2015;212(3):340. e1-. e7
- 13- Prato, AP. Carlucci, M. Bagolan ,P. Gamba, P. Bernardi, M. Leva, EA, cross-sectional nationwide survey on esophageal Atresia and trachea esophageal fistula. Journal of pediatric surgery. 2015;50(9):1441-56.
- 14- Sadreameli, SC. McGrath-Morrow ,SA. Respiratory Care of Infants and Children with Congenital Trachea esophageal Fistula and esophageal Atresia. Pediatric respiratory reviews. 2015.
- 15- Sun, LY-C. Laberge, J-M. Yousef ,Y. Baird, R. The Esophageal Anastigmatic Stricture Index (EASI) for the management of esophageal Atresia. Journal of pediatric surgery. 2015;50(1):107-10.
- 16- Zhu, H. Shen, C. Xiao X, Dong K, Zheng S. Reoperation for anastigmatic complications of esophageal Atresia and trachea esophageal fistula. Journal of pediatric surgery. 2015;50(12).
- 17- IJsselstijn ,H. Giscler ,SJ. Toussaint, L. Spoel, M. van der Cammen-van, MH. Tibboel ,D. Growth and development after esophageal Atresia surgery: Need for long-term multidisciplinary follow-up. Pediatric respiratory reviews. 2015.
- 18- Mahoney, L. Rosen, R. Feeding Difficulties in Children with Esophageal Atresia. Pediatric respiratory reviews. 2015.
- 19- Rosati, SF. Maarouf, R. Oiticica, C. Lange, P. Haynes, J. Lanning D. A treatment program for babies with esophageal Atresia in Belize. Journal of Surgical Research. 2015;199(1):72-6.
- 20- Connor, MJ. Springford, LR. Kapetanakis ,VV. Giuliani, S. Esophageal Atresia and transitional care, a systematic review and meta-analysis of the literature to define the prevalence of chronic long-term problems. The American Journal of Surgery. 2015;209(4):747-59.
- 21- Fragoso AC, Martinez L, Estevão-Costa J, Tovar JA. Lung maturity in esophageal atresia: Experimental and clinical study. Journal of pediatric surgery. 2015;50(8):1251-9.
- 22- Wang, B. Tashiro, J. Allan, BJ. Sola, JE. Parikh, PP. Hogan, AR. A nationwide analysis of clinical outcomes among newborns with esophageal Atresia and trachea esophageal fistulas in the United States. Journal of Surgical Research. 2014;190(2):604-12.
- 23- Sawyer, AC. Pemberton, J. Flageole, H. Post-operative management of esophageal atresia–tracheoesophageal fistula and gastro esophageal reflux: A Canadian Association of Pediatric Surgeons annual meeting survey. Journal of pediatric surgery. 2014;49(5):716-9.
- 24- Nabzdyk, CS. Chiu, B., Jackson, C-C. Chwals, WJ. Management of patients with combined trachea esophageal fistula, esophageal Atresia, and duodenal Atresia. International journal of surgery case reports. 2014;5(12):1288-91.
- 25- Conforti ,A. Morini ,F. Bagolan, P. Difficult esophageal Atresia: Trick and treat. Seminars in pediatric surgery; 2014: Elsevier.
- 26- Nateghian ,A. Delshad, S. Nasiri, SJ. Farhood ,P. Javanbakht ,M. Investigating respiratory complications and anomalies after esophageal Atresia treatment in Aliasghar Hospital in Tehran during 1995-2009. Razi Journal of Medical Sciences. 2014;21(123):75-82.
- 27- Sulkowski ,JP. Deans, KJ. Asti ,L. Mattei, P. Minneci ,PC. Using the Pediatric Health Information System to study rare congenital pediatric surgical diseases: development of a cohort of esophageal Atresia patients. Journal of pediatric surgery. 2013;48(9):1850-5.

- 28-Black, JM. Hawks ,JH. Medical Nursing clinical management for positive outcome .9th: In PAMacdoland Mosbey-Elsevier; 2012.
- 29-Streubert, HJ. Carpenter, DR. Qualitative Research in Nursing Advancing the Humanistic Imperative 5th: Philadelphia lippincott William and Wikins; 2011.
- 30-Hiradfar ,M. Bazrafshan, A. Judi, M. Gharavi, M. Shojaeian ,R. An 8-year experience of esophageal Artesia repair in Sarvar children hospital (Mashhad-IRAN). Iranian Journal of neonatology. 2012;3(1):20-2.[in Persian].
- 31-Huang ,J. Tao, J. Chen, K. Dai, K. Tao, Q. Chan, I. Thoraces scopes repair of esophageal Artesia: experience of patients from two tertiary referral centers. Journal of pediatric surgery. 2012;47(12):2224-7.
- 32- Martins Pinheiro,PF. Simões ,E. Silva,AC, Pereira,RM. Current knowledge on esophageal atresia, World J Gastroenterol. 2012 Jul 28; 18(28): 3662–3672
- 33- khalesi ,N. taghipour, R. aflatoonian, M. Frequency of Anomalies in Neonates with Esophageal Atresia in Aliasghar Children's Hospital from 2005 to 2007. Journal of Medical Science Iran. 2009;16(67):40-5.[in Persian]..
- 34-De Jong, EM, Felix< JF, Deurloo< JA, Van Dooren, MF. Aronson ,DC. Torfs ,CP. Non-VACTERL-type anomalies are frequent in patients with esophageal atresia/tracheo-esophageal fistula and full or partial VACTERL association. Birth Defects Research Part A: Clinical and Molecular Teratology. 2008;82(2):92-7