

A Qualitative Study: Determination of the Opinions and Expectations of the Families with Infants Treated at the Newborn Intensive Care Unit

Nitel Bir Çalışma: Yenidoğan Yoğun Bakım Ünitesinde Tedavi Gören Bebeklerin Ailelerinin Görüş ve Beklentilerinin Belirlenmesi

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Abstract: The study was conducted to determine the problems, opinions, and expectations of parents in the treatment process when their infants were hospitalized in the newborn intensive care unit. It is a qualitative study. The study sample consisted of the parents of the infants who were treated at the Newborn Intensive Care Unit of a hospital in Konya Province between 3 April 2017 and 1 May 2017. The study was completed with a total of 7 individuals including 4 mothers and 3 fathers. Semi-structured interview method was used as the data collection method. As a result of the interviews, it was determined that the families were not informed well enough the diseases of their infants. It was identified that the most important issue was parents' being apart from their newborns for a long time. Parents reported that their business lives, social lives, family lives, and their psychological statuses were adversely affected during this process. In addition, the majority of the parents stated that the ICU setting needed to be appropriately set to allow the parents to stay with the infant. Our recommendation is that first, the healthcare team will communicate more with the parents whose newborns are treated in the intensive care unit, secondly, the families will be provided regular information on the condition of their newborns, third, the physical conditions of the intensive care unit will be arranged to include the families, and especially the fourth, the mothers will be ensured to see their newborns whenever they would like to.

Key Words: neonate, parent, hospitalization, opinions

Ayvaz E, Acikgoz A. 2019, A Qualitative Study: Determination of the Opinions and Expectations of the Families with Infants Treated at the Newborn Intensive Care Unit, *Osmangazi Journal of Medicine*, 41(3): 271-278 **Doi:** 10.20515/otd.426794

Özet: Araştırma, bebeği yenidoğan yoğun bakım ünitesinde yatan ebeveynlerin tedavi süreci boyunca yaşadığı problemleri, görüş ve beklentilerini belirlemek amacıyla yapılmıştır. Nitel bir çalışmadır. Örneklemi 3 Nisan – 1 Mayıs 2017 tarihleri arasında Konya İli'ndeki bir hastanenin Yenidoğan Yoğun Bakım Ünitesinde tedavi gören bebeklerin ebeveynleri oluşturmuştur. Araştırma 4 anne ve 3 baba olmak üzere toplam 7 kişi ile tamamlanmıştır. Veri toplama yöntemi olarak yarı yapılandırılmış görüşme yöntemi kullanılmıştır. Görüşme hastane ortamında sessiz bir odada, her bir kişi ile bireysel olacak şekilde gerçekleştirilmiştir. Yapılan görüşmeler sonucunda ailelerin bebeklerin hastalıkları konusunda yeterli düzeyde bilgiye sahip olmadıkları belirlenmiştir. Ebeveynlerin yaşadıkları en önemli sorunun bebeklerinden uzun süre ayrı kalmak olduğu saptanmıştır. Ebeveynler bu süreçte iş hayatlarının, sosyal hayatlarının, aile yaşantılarının ve psikolojilerinin olumsuz yönde etkilendiğini ifade etmişlerdir. Önerimiz, bebeği yoğun bakım ünitesinde tedavi gören ebeveynlerle sağlık ekibinin daha fazla iletişim kurması, ailelere bebeklerinin durumu ile ilgili düzenli bilgilendirme yapılması, yoğun bakımın fiziki koşullarının aileler için düzenlenmesi ve özellikle annelerin her istediğinde bebeklerini görmelerinin sağlanmasıdır.

Anahtar Kelimeler: yenidoğan, ebeveyn, hastanede yatma, görüşler

Ayvaz E, Açıkgoz A. 2019, Nitel Bir Çalışma: Yenidoğan Yoğun Bakım Ünitesinde Tedavi Gören Bebeklerin Ailelerinin Görüş ve Beklentilerinin Belirlenmesi, *Osmangazi Tıp Dergisi*, 41(3): 271- 278 **Doi:** 10.20515/otd.426794

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1. Introduction

In all societies, the child is the most precious asset of the mother and the father. As the conception is confirmed, the plans to welcome the new member of the family will commence. The most important expectation of the families is to have a healthy infant. However, things may not proceed smoothly at times and the newborn may be born with a health problem or may develop a health problem after birth. These issues sometimes may require the newborn to be hospitalized in the intensive care unit (ICU) (1).

Rather than staying with the mother, spending the first days of life with a life-threatening disease in ICU is a very difficult situation for an infant. This situation may adversely affect the parents, too (2). The baby's lying in an incubator isolated but connected to several cords is a scary sight for the parents. In addition, the fragile and unhealthy appearance of the infants together with the opinions of the family that they cannot control the situation may lead to feelings of helplessness (3). In this process, families may experience many other negative emotions altogether as well. Among these negative emotions, fear and stress are the leading ones. In order to facilitate coping of the families with this situation and to relieve the severities of fear and stress, the requirements should be defined (4) and mothers should be allowed to take part in the care of their infants (5).

This study was conducted in order to determine the opinions and expectations of the mother and father in the newborn intensive care unit (NICU).

2. Material and Method

This is a qualitative case study. The study was conducted with 7 parents with infants who were treated at the NICU of a hospital in Konya Province between 3 April 2017 and 1 May 2017. This eighteen-bed ICU has been staffed with two doctors and 15 nurses. In this unit, the newborns have not been allowed to stay with caregiver and the parents have been allowed seeing their babies only once a day for a duration of 5 minutes.

Interview method was used as the data collection method in the study. Institutional permission and the Ethics Committee permission was granted prior to the commencement of the study (the latter dated 03.04.2017 and registered by 2017-2). The individuals were included in the study only if they volunteered to participate. Following the permission of the Ethics Committee, the families were informed about the study and their consents were obtained. A semi-structured interview form consisting of 14 questions, which was developed by the investigator, was used as the data collection tool. The interview was conducted in a silent room in the hospital environment, individually with each person. A voice recorder was used during the sessions. Each family was assigned a number so that the names of the parents and the children were not used during the interview.

Descriptive methods were used to analyze the data and the results were studied under 6 main headings. These titles are as follows: Disease perception, intrafamily processes and support systems, difficulties experienced during the treatment, physical set-up of the ICU, communication with the healthcare team, and the mother-infant bonding.

3. Results

The study was completed with a total of 7 individuals including 4 mothers and 3 fathers. The education levels of the mothers and fathers participating in the study were variable including primary school, middle school, and university graduates. All parents were married having a nuclear family structure and none of the parents were blood-related. The parents reported their income status as either equal income-outcome or lower income than the outcome. All fathers worked at regular jobs. Of the mothers, only one of them worked at a job providing an income. The number of the children each family had varied between 1 and 3. No acute or chronic diseases were present in none of the other siblings in the family. The diagnosis of newborns; 5 for

prematurity, 1 for diaphragmatic hernia and 1 for Gallen ven aneurysm.

Part 1: The Study Findings on the Disease Perception of the Parents

Under this heading, the following were addressed: The parents' initial reactions when they were informed of their infant's disease, whether the parents were informed

well enough about the disease of the infant, and the emotions, which the parents experienced, because their baby was in an intensive care setting.

The parents' initial reactions when they were informed of their infant's disease: The families reported that they experienced confusion and stress when they were initially informed about the disease of the infant, however, they added that they had accepted the situation in time.

"...I was surprised and afraid. I was scared..." (A6)

"...It was so sudden, I was so startled, it was a situation I had never anticipated..." (A3)

"...I was so startled, it was the first time I saw such a small baby, I had never given he a thought that it could have lived..." (A2)

"...She was such a small baby, I was afraid of looking at she, but I am used to she now and I sometimes hold she in my arms..." (A1)

The informational status of the parents, whether they were informed well enough about the disease of the infant: The parents reported that they were informed about the disease of the infant generally. They reported that they acquired the information from the healthcare team, from the internet, and by information sharing with the families of infants having the same disease. On the other hand, some parents reported that they had no information on the disease of the infant.

"... yes, I have a general concept of the issue..." (A6) "...I think I have some knowledge to some extent..."(A2)

"...No, I do not have any information. I do not know what is the disease, what is the

status of the disease or whether it can recover. I am not at the condition at present that I can understand even if you explain it..." (A3)

The emotions experienced by the parents, because their baby was in an intensive care setting: All of the interviewed mothers or fathers stated that they felt unpleasant and weak because the infant was treated in the ICU, that they wished the infants to be with them rather than being treated in the ICU, and that they felt sorry since they met the infant first at the ICU settings.

"... I feel unpleasant and weak, it would have been better if he were healthy and with me..."(A6)

"...I generally feel unpleasant but it makes me happy to receive good news ..." (A4)

Part 2: The Study Findings on the Parents' Opinions About the Intrafamily Processes and Support Systems

Under this heading, the following issues were studied: The impact of having an infant treated at the ICU on the family lives, social lives, and on the relations between the spouses; the presence of supportive people around during this process, and the communication and support among other families.

Parents' opinions whether the family lives, social lives, and the relationship with the partner were impacted: All parents in the study reported that having an infant hospitalized in an ICU adversely affected their family and social lives, however, they added that the relations with the spouse were affected positively. Parents reported that going to the hospital every day and thinking that the infant was in a risky situation stressed them. Furthermore, they added that they projected this stress onto the other family members unintentionally. They stated that they could not fulfill their other family responsibilities well enough as they spent all their times commuting to the hospital.

"...because we work outside of our town, we commute to the hospital and work alternately.

No spare time has been left for our social lives...”(A2)

“...I feel stressed as my baby is in the ICU and I project my stress onto my family life...”(A5)

“The bond with my spouse has got stronger. We try to be more supportive of each other...”(A3)

Parents' opinions on the support systems: All parents in the study reported that they received psychological support from their close relatives, friends, and the healthcare personnel at the NICU. The parents who suffered from financial difficulties reported that they received support from their parents, adding that when they were at the hospital to see their infants, their mothers and mothers-in-law supported them in doing housework and in caring for the other children.

“...our families reassure us saying that the infant will get better...”(A1) “...you supported and reassured us very much as a team, thank you...”(A4)

“... Commuting to the hospital regularly and the meeting the needs of our infant challenged us somehow financially. Thank god our parents are alive. We would have been in trouble without them...” (A5)

“...my parents provided a lot of support. I have another child, who is 3 years old, at home. When we go to the hospital, the maternal grandparents take care of my 3-year-old child. Otherwise, it would have been very difficult to entrust my child's well-being to someone else...” (A2)

Part 3: The Study Findings on Parents' Opinions Regarding the Challenges, Which They Experienced During the Treatment Process

Under this heading, the parents' challenges associated with the ICU and the parents' opinions on the ICU visiting hours have been studied.

Parents' opinions on the challenges they experienced associated with the ICU: All

parents in the study reported that they have not experienced any difficulties associated with the ICU.

“... A considerably understanding team assists us. I have not experienced any difficulties...”(A4)

“...I have not experienced any difficulties...”(A6)

Parents' opinions on the ICU visiting hours: 3 study participant parents were in the opinion that the allowed frequencies and duration of the visits were insufficient, whereas, the other parents in the study found them sufficient and added that they would not like to risk the infant's well-being with their presence at the ICU.

“...I mean, as we are coming out of the town, we cannot attend the visiting hours in the morning. The duration of our stay with the infant can be longer and the visiting schedules can be more flexible...”(A5)

“...would be better if they were longer; however, we put up with this situation considering the sake of the infant ...” (A6)

“...I think the schedules are appropriate and sufficient ...”(A1)

Part 4: The Study Findings on the Parents' Opinions About the Physical Set-up of the ICU.

Opinions about the appropriateness of the ICU setting to provide quality care: All parents who participated in the study stated that the ICU setting was appropriate to provide quality care.

“...I personally think that it is a very appropriate setting. We could not have provided this set-up at home. All devices are very new...” (A5)

“... I think that it is appropriate, everything seems to be sufficient despite the fact that we were not fully informed. The devices are new, everywhere is clean, the setting is spacious. I think the set up is as it should be. We are satisfied....”(A3)

Part 5: The Study Findings on the Parents' Opinions About the Healthcare Team.

Under this heading, the following issues were studied: The parents' perception of themselves as a member of the healthcare team; parents' receiving sufficient information from the healthcare staff about their infants; parents' expectations of the healthcare team, and parents' receiving information from the healthcare personnel about the procedures of home care settings.

Parents' opinions on receiving sufficient information about their infants: Only one parent in the study stated that s/he could not receive sufficient information about the infant. On the other hand, the remaining 6 parents reported that they could receive information sufficiently and as much as required.

"... yes, yes, I'm provided with sufficient information every day..." (A1)

"...we can not get information from the nurses. We receive information from the physicians only during the working hours, which is not sufficient, and sometimes we do not understand the terms used ..." (A2)

Parents' opinions about their expectations on their infants: The parents who participated in the study generally reported that they did not have any expectations from the healthcare staff other than providing good care to their infants. One parent stressed that the information provided needed to be more comprehensible.

"...we would like them to take good care of my infant. We do not have any other expectations ..." (A4)

"...after seeing my baby, I excitedly go to see the doctor to receive good news, however, sometimes I do not understand what they tell me. A little more explanatory information would be better..." (A3)

Parents' opinions on being a part of the health team: Only one interviewee reported that s/he felt herself/himself as a part of the team.

"..... I feel as a part of the team. The doctor told me that breastmilk was very important for the infant. I'm doing my best. You take care of my baby and I nurse it..." (A2)

Parents' opinions on receiving sufficient information about home care settings from the healthcare personnel: This question was asked only to 3 study participants, whose infants' time for discharge from the hospital was approaching. All of these parents who were asked this question reported that they were trained on this issue as much as it was required.

"... I have not received much training in the first place, but to tell you the truth, as my infant's time for discharge approaches, they started training how to take care of the infant at home..."

The Study Findings on the Parents' Opinions About the Mother-Infant Bonding

Under this heading, the parents were studied first whether the mother-infant bonding was impacted due to the infants' being treated at the ICU. Secondly, the parents' willingness to accompany their infants in the ICU during the treatment was addressed.

Opinions of the parents whether the mother-infant bonding was impacted due to the infants' being treated at the ICU: All parents participating in the study stated that their bonding with the infant was adversely impacted due to the infants' being treated at the ICU, while a parent added that there was no bonding between herself/himself and the infant.

"...I wish it had felt my smell at first place. And, I am afraid of my breastmilk production will stop as I am not with the infant all of the time. I am afraid of not getting used to each other when it is discharged from the hospital..." (A3)

Opinions of the parents whether they would like to stay with the infant in the ICU: While three parents in the study would not like to stay with their infants in the ICU, the remaining four parents reported that they would like to stay with their infants. It is

considered that the parents, who replied that they would not like to stay with their infants, would actually like to do so, however, they replied negatively because they were afraid of harming the infants.

“... no, I would not like to stay with the infant not to disturb its well-being...” (A2)

“... no, I would not like to do so as I would not like to disturb the well-being of my infant as well as the others...” (A5)

“...I mean, I would like to stay with it. We would get used to each other more favorably. I am afraid of the infant not getting used to me when it is discharged from the hospital...” (A1)

4. Discussion and Conclusion

It is known that the families with infants treated in the NICU manifest symptoms of increased anxiety, depression, and trauma. The underlying reasons of this fact include having a patient baby in the family, the stressful environment in the unit, and parents being physically and emotionally separated from their babies (6). In order to reduce the stress of the mothers and fathers and to facilitate their coping with the situation, several important tasks must be assigned to the healthcare staff. Health care professionals should provide parents with sufficient information on the health status of the infants, on their treatment phases, and on the overall course of the diseases. Parents should be allowed to enter the ICU frequently to see their infants and if possible, they must be allowed to stay with the infants in the ICU (7,8). Parents should also be involved in the decision making processes on their babies. In this process, it is also important to identify the parents' anticipations and their problems by collecting their feedbacks. This study was conducted with the aim of determining the opinions and expectations of the parents with infants treated in the NICU and it provides important information in identifying the parents' experiences, satisfaction, and needs.

In our study, the parents reported that they experienced feelings such as shock and confusion when they first encountered the

disease and they reported that having their infants being treated in the ICU caused them to experience anxiety and sadness. In the literature, it has been defined that parents go through 4 stages when the infant was diagnosed with a disease. These stages have been determined to be shock, denial, adjustment, and acceptance (9). Our study shows similarities to the reports in the literature regarding this aspect.

The parents participated in our study reported that having an infant hospitalized in an ICU adversely affected their social and work lives. On the other hand, this situation strengthened the relationship of the spouses with each other. The major drawback is that this process affects the mother-infant bonding in a negative way. The literature review within the context of our study did not reveal any studies evaluating the impact of having an infant treated in the ICU on the families' work and social lives. A study (10) has reported that hospitalization of the infant in the ICU after the delivery negatively affects the maternal attachment as the initial touch of the mother and the infant is prevented.

In our study, the parents reported that they were supported both financially and morally by their close relatives and friends. Furthermore, they reported that they received support associated with the care of their other children as well. In the literature, it has been reported that (11) the families with infants treated in the NICU had higher levels of anxiety and they received support from their families, relatives, and healthcare personnel in order to cope with stress.

In our study, it was noted that parents would like to spend more time with their infants, they reported that the visit times should be longer and more flexible, and they reported that they would like to receive more information about the infants, and they would like to have more comprehensible information. Our study shows similarities to the reports in the literature regarding this aspect. A study (12,13) found that the parents of the infants in the NICU mostly experienced difficulties in participating the care of the infant in the intensive care unit, in receiving

sufficient information from the healthcare personnel, in seeing the infant in the ICU when they would like to, in receiving information about the treatments and interventions applied to the infant, in adjusting themselves to the condition of the infant, and in identifying with the maternal or paternal roles.

In our study, parents evaluated the ICU setting as appropriate for quality care. In addition, the majority of the parents stated that the ICU setting needed to be appropriately set to allow the parents to stay with the infant. They reported that, in this way, they would be able to participate actively in the care of the infants and be able to feel better. Parallel to this result, the Ministry of Health's communiqué dated 22.03.2017 and numbered 30015, states that "mother adjustment rooms must be allocated for the mothers of the premature babies so that they would stay with their infants before the discharge from the hospital." It is stated in the communiqué that these rooms should be preferably on the same floor with the inpatient service. Further, it is stated that there should be at least one bed in the room and for additional 10 incubators to the first ten incubators, one more bed could be added (the room could have three beds at most) (14). However, in the hospital where the present study was conducted, there was not a mother adjustment room due to the physical conditions.

It was concluded that all but one parent participated in our study did not feel like a member of the healthcare team. The concept of feeling like a part of a healthcare team consists of several elements like being involved in the care of the infant, nursing, being involved in the decisions associated with the infant, and planning the care of the infant. These factors form the basis for the family-centered care. Several other studies

(15,16) demonstrate that although family-centered care is recognized in our country, some insufficiencies are found in practice. In addition, the studies report that the families experience limitations in medical decision-making processes and the health care personnel does not allow the parents to participate the treatment process. In many hospitals in our country, families can only participate in the physical care of their infants.

In our study, it was concluded that the parents of the infants, whose time of discharge from the hospital approached, found the homecare training sufficient. A study

reported that mothers did not think that the homecare training was not sufficient. In this regard, our findings in the present study are different.

A study similar to ours (18) identified three main factors in determining the satisfaction of the parents of the NICU. These factors are as follows: 1) the involvement of parents (to look after their infants, difficulties in nursing, and easy access to the infants), 2) personnel competence and efficiency (communication, experience, trust, knowledge, and explanation), 3) interpersonal relations with staff (sensitive and emotional support, assurance, and courage).

In conclusion, we are of the opinion that understanding the emotions and opinions of the parents with infants at the ICU and being knowledgeable about their needs will lead to favorable results for both the families and the infants. In this context, we recommend that communication with the healthcare personnel should be increased, the physical conditions of the ICU should be arranged for families who would like to stay with the infant, sufficient and comprehensible information should be provided to the families, and the visiting hours must be flexible for the parents.

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