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Experiences of mothers during child's hospital stay in intensive care unit

Diana Aitugulova

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JAMK University of Applied Sciences

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Background: The birth of a child is a significant event in the life of every family. However, when a child is in a critical condition and needs to be hospitalized, mothers experience various difficulties. When a child is hospitalized in the intensive care unit, the family becomes especially vulnerable and frightened.
Aim: To describe and better understand the experience of mothers whose children were hospitalized in the ICU, and to find out what kind of relationship develops between mothers and healthcare professionals during this period.
Method: A qualitative research method and semi-structured interviews were used. A total of 10 participants were interviewed during January 2020. The interviews were analyzed using qualitative content analysis.
Results: Data analysis identified 4 themes that answered the research questions: (1) Mothers trying to adapt into an ICU environment; (2) Perform to the unexpected new role of mother; (3) Relationship is like a rollercoaster between spouses; and (4) Living in a relationship with healthcare professionals.
Conclusions: It was discovered that mothers experience different feelings about their children and their stay in the ICU. They also have feelings about their relationship with their spouse, their shift to a mother's role, and relationship with healthcare professionals. They tend to have feelings of hope, guilt, confusion as well as rejection of undesirable situations, and frightening scenes from the ICU environment accompany them throughout the entire period of their stay in the ICU. In general, relations with healthcare professionals are defined as quite good. Awareness of the maternal experience and suffering in a critical situation could help nurses develop interventions to assess mothers' needs for communication and give support, thus helping to actively introduce family-centered practices in intensive care units.

Keywords/tags (subjects)
Intensive care unit, nursing, mother, child, nurse, experiences, qualitative studies

Miscellaneous (Confidential information)

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1 Introduction

In every family, the birth of a child is a significant event in their life. At the birth of a child with a disease or critical conditions, joyful emotions are replaced by anxious and sad ones. (Malakouti, Jabraeeli, Valizadeh, & Babapor 2013.) Parents cannot be prepared for the intensive care unit (ICU) environment (Steyn, Poggenpoel, & Myburgh 2017). The ICU for children is part of a medical institution that provides highly specialized medical care and intensive care under round-the-clock monitoring of vital indicators and supervision by medical specialists (Torres 2015). When a child is hospitalized in the ICU, the family becomes especially vulnerable and scared (Crawford & McNee 2012, 361). During this period, they need support. Despite the fact that the healthcare providers sympathizes with the mothers, they still cannot fully understand them, having not been in their place. It is important for parents to learn about the experience of other parents who have had to endure the hospitalization of their children. (Smith, Steelfisher, Salhi, & Shen 2012.) This will make them understand that they are not alone in this situation, and that there have been people who have had the same difficulties (Steyn et al. 2017).

Parents experience different feelings and thoughts related to hospitalization, which can be due to both financial and social difficulties, as well as the absence from home (Pieszak, Paust, Gomes, Arrué, Neves, & Machado 2017). Being in the ICU, they are deprived of live and physical communication with their family remaining at home, and therefore, only a nurse can provide emotional and practical support throughout the stay in the ICU (Crawford & McNee 2012, 361). So, during this period, it is important to establish a trusting relationship between nurses and mothers (Pieszak et al. 2017). Information on the experience of mothers will help nurses in their practice to increase sensitivity and relate to the position of the parents. A nurse can help the family make the intensive care experience less frightening. (Crawford & McNee 2012, 361.)

This study will examine the experience of mothers of children who were hospitalized in an ICU hospital in Kazakhstan. Potential participants were mothers whose children

were from newborn to 18 years old, who have been hospitalized in the ICU for at least 3 days. Participants were selected using the targeted sample and will describe their experience with the child in the ICU. Data were collected using unstructured interviews with mothers. The knowledge gained will benefit the family-centered care in the ICU (Busse, Stromgren, Thorngate, & Thomas 2013).

2 Background

2.1 Child admission to ICU

Premature babies or children born with a pathology need specialized care and require hospitalization in the ICU (Abuidhail, Al-Motlaq, Mrayan, & Salameh 2016). The resuscitation and intensive care unit of children provides specialized monitoring and treatment for children with diseases requiring surgical treatment, as well as for critically ill children (Clark 2012, 3). In a Dutch study, researchers described the experience of parents in the ICU, comparing it with being in darkness (Latour, van Goudoever, Schuurman, Albers, van Dam, Dullaart, Heerde, Verlaat, Vught, & Hazelzet 2011). Most mothers are faced with this situation for the first time. The child's admission to the ICU causes emotional changes in parents (Abuidhail et al. 2016). They experience a change in their parental role as well as mood swings and feelings of insecurity, which can also affect brothers and sisters (Crawford & McNee 2012, 361). The Parental Stress Model offers three main parental stress factors that are related to each other: child, parent and environment. These stressors together contribute to the total amount of stress and thus to the stress response of the parents. (Lisanti, Golfenshtein, & Medoff-Cooper 2017.)

The first meeting of a mother with her baby in the ICU can be a shock to her (Crawford & McNee 2012, 361). This is due to the resuscitation environment itself and the child's unusual appearance. The appearance of the child is changing, due to the specifics of the department and the need for assistive devices after surgery (Abuidhail et al. 2016). Parents of intubated children were also more concerned about painful procedures than those whose children breathed on their own (Shudy, de Almeida, Ly, Landon, Groft, Jenkins, & Nicholson 2006). Unfamiliar external devices next to the child may be bothering them (Crowford & McNee 2012, 362). It is

hard to see so many different devices on their young child (Steyn et al. 2017), and the healthcare providers need to provide information for the parents to reduce their anxiety (Crawford & McNee 2012, 362). In addition to the fact that the child looks unusual, his behavior can also change due to possible consequences of treatment or equipment of the ICU, which can also be a source of stress for the mother (Lisanti et al. 2017). Parents have said that they felt more comfortable when their child was in a single room, and not in a shared room with other children, so they could express their emotions more freely (Latour et al. 2011) The design of a single room for one family as a way to bring the family together has been noted as an important element of architecture (Flacking, Lehtonen, Thomson, Axelin, Ahlqvist , Hall Moran , Ewald ,& Dykes 2012).

2.2 Mothers' stress about hospitalization

Rybojad, Aftyka, and Samardakiewicz (2018) summed up several studies (Allenou et al. 2010; Ballufi et al. 2004; Bronner et al. 2008; Franck et al. 2015) to conclude that hospitalization of a child always has a detrimental effect on the mental health of parents. Prolonged hospitalization of the child in intensive care may not bring the expected positive results. Prolonged exposure to traumatic events can be a risk for parents to experience post-traumatic stress. This is because parents feel helpless in this situation and are not able to influence the course of events in the hospital. (Rybojad et al. 2018.) According to another study by Helfricht, Latal, Fischer, Tomaske, and Landolt (2008), parents of the children undergoing a cardiopulmonary bypass were at increased risk of developing post-traumatic stress disorder.

In a study by Cantwel-Bartl and Tibbals (2013), all studied parents reported stress after diagnosis, and this continued throughout their stay in the ICU for children (Cantwell-Bartl & Tibballs 2013). An association has been established between stress experienced during hospitalization of a child with maternal fatigue, anxiety, and depression. Parental stress associated with hospitalization of their child in the neonatal intensive care unit (NICU) causes changes in the emotional background and in the behavioral response. (Busse, Stromgren, Thorngate, & Thomas 2013.)

The review study by Shudy and colleagues (2006) about the “Impact of Pediatric Critical Illness and Injury on Families” also reported that parents whose children were hospitalized on an emergency basis experience significantly greater stress than parents whose children were hospitalized electively (Shudy et al. 2006). According to Steyn and colleagues (2017), the ICU is characterized by its inconsistency, and a risk of worsening of the child’s condition. The variable state of children in intensive care leads to a state of constant anxiety of their parents. (Steyn et al. 2017.) The sound of alarm from different devices inherent in the ICU is a stressor for parents (Lisanti et al. 2017). Finding a child in conditions of an increased level of sound exposure seemed more stressful for parents, but gradually they could get used to it, manifesting it by muting the sounds of alarms themselves (Wigert, Hellström, & Berg 2008).

However, in the study by Steyn and colleagues (2017), some parents said that from this experience they also highlighted the positive points for themselves regarding their spirituality and worldview. Some parents described their experience of being in the ICU as a preparatory moment before taking the child in full, since half of the responsibility lay with the healthcare providers. They also claimed that during this period, their spirituality increased, and they were closest to God. During this experience, they were also able to rethink many things differently and set other life priorities. (Steyn et al. 2017.)

In addition to emotional problems and effects on the psychological state, hospitalization of the child affects the financial component of the family. Due to the long hospitalization of the child, it is necessary to spend a large amount of time with the child and this requires significant financial expenses. (Rybojad et al.2018.) For parents who are not able to visit their child often, it was proposed to use virtual communication using digital technologies such as a web camera (Yeo, Ho, Khong, & Lau 2011).

According to Brødsgaard, Pedersen, Larsen and Weis (2019), Agerholm, Rosthøj & Ebbesen (2011) state that, among other things, parents are disturbed by the fear of the child's survival and possible disability. Parental stress is associated with the fatigue, stress, and anxiety they experience while hospitalizing their child in the intensive care unit (Busse et al. 2013). To reduce the stress of parents, they need to be informed about their child’s condition, treatment, and permission to participate in

deciding on their children. Healthcare professionals must be trained to support parents and provide information on sounds and equipment around their child. (Musabirema, Brysiewicz, & Chipps 2015.)

2.3 The role of the mother during hospitalization

While the child is in the ICU, the role of the parents is changing, and they may feel insecure about their ability to protect and help the child (Crawford & McNee 2012, 362). Under the influence of external undesirable phenomena, such as the critical state of the child or their hospitalization, the situation leads to a decrease in the mother’s feelings regarding her confidence in her role, but the mother’s personality continues to form (Mercer 2004). They need to know that they can be helpful to their child during this period (Crowford & McNee 2012, 362). The involvement of mothers in the process of caring for a child helps to cope in this difficult period of their life (Abuidhail et al. 2017). Mothers caring for their baby feel their worth and feel gratitude to the healthcare professionals for their education (Soares, Rosa, Molina, Higarashi, & Marcon 2016). Positive feedback from both the mother and the healthcare professionals regarding the mother’s participation in childcare was identified in another study (Coyne 2013) since children with severe diagnoses require constant proper care after discharge. Without knowledge, mothers are afraid and unsure of the correct procedures that must be continued at home. Mothers seek support from healthcare providers. Childcare training will be useful knowledge for a mother who will provide home care after discharge. (De Lima, de Arruda, Vicente, Marcon, & Higarashi 2013.) The involvement of parents in caring for their critically ill child softens the process of adaptation to the conditions of the hospital. However, their desire to participate in this should also be considered. (Saria, Mselle, & Siceloff 2019.)

It has been found by Shaw, Deblois, Ikuta, Ginzburg, Fleisher and Koopman (2006) that changing parental roles is the main source of parental stress. Consequently, the active participation of parents in the process of caring for a sick child, including seriously ill young patients, will lead to positive results for parents. (Shaw et al. 2006.) According to Coyne and Cowley (2007), however, this participation should not completely replace nursing care. The parent’s psychological state affects the child’s

development through parent-child relationship (Franich-Ray, Bright, Anderson, Northam, Cochrane, Menahem, & Jordan 2013). The negative feelings of mothers are reduced when they participate in caring for their child, feel useful and needed by them, thereby strengthening the mother's role (Soares et al. 2016). Tourigny and Chartrand (2015) noted that when providing medical services, it is necessary to take into account the wishes and interests of parents, which is an important element of evidence-based practice (Tourigny & Chartrand 2015).

In most European countries, in particular in northern Europe, families practice unlimited visits to their children hospitalized in the intensive care unit, with the exception of some points, such as bypassing doctors to prevent the disclosure of confidential information of other children, in the case of general wards (Greisen, Mirante , Haumont, Pierrat, Pallás-Alonso, & Warren 2009). However, other studies have shown that most intensive care units do not allow the parent to be with the patient for a long time. This approach significantly reduces the quality of care and parental confidence. (Tourigny & Chartrand 2015.) As the results of the study by Obas, Leal, Zegray, and Rennick (2016) show, parents described mixed feelings of happiness and uncertainty when they learned that their child would be transferred to the regular ward.

2.4 Survival strategy in ICU

Being close to one’s critically ill child is one of the needs in the survival strategy. This desire helped to adapt to the atmosphere of the hospital and the adoption of an undesirable situation. (Saria et al. 2019.) The separation of mother and child for a long period of time can affect the development of cognitive and emotional functions of the child (Flacking et al. 2012).

According to Turner, Chur-Hansen, and Winefield (2015), parents may be physically limited to care for their babies due to treatments and equipment the baby needs. In animal studies, it has been noted that long or repeated physical separation of mother and newborn affects brain development (Braun 2011, according to Flacking et al. 2012) and may have long-lasting effects, for example, on emotional responses in future (Sullivan et al. 2011, Hofer 2006, according to Flacking et al. 2012).

According to Flacking and colleagues (2012), Latva, Lehtonen, Salmelin, and Tamminen (2007) noted that rare maternal visits can affect the psychological development of the child. Another study notes that the absence of a loving parent during stressful situations may affect the child’s perception of the ICU experience negatively. Close contact with parents is important for a child with psychological needs since this helps to reduce the level of stress both in the child and in the parent. Participation in caring for a child in the ICU has a tendency to more sensitive care, which favorably effects the child and helps develop parental feelings of affection. (D’Agata & McGrath 2016.) Turner and colleagues (2015) emphasize the importance of emotional and physical closeness between parents and the child during the treatment. There is no doubt that the improved results of the child caused positive feelings in mothers. (Turner et al. 2015.) According to Harbaugh, Tomlinson, and Kirschbaum (2004), parents noted that nurses can help them in their stressful situations by reinforcing the mother's role. Hospital organizations should consider all possible ways to bring the family and the child closer together, such as frequent visits, bodily contact with the mother, and creating conditions for rapprochement, since the presence of the mother has been repeatedly proved to have beneficial effect on the child (Flacking et al. 2012).

2.5 Communication with healthcare professionals

Communication with healthcare professionals affects how parents perceive and cope with stress (Latour et al. 2011). The relationship between the nursing personnel and the family was an important component of a trusting relationship (Pieszak et al. 2017). Each family is unique and has different backgrounds and needs support from healthcare professionals (Barreto, Sakamoto, Magagnin, Coelho, Waterkemper, & Canabarro 2016). Hospitalization of the child is not a familiar procedure for parents. Introductory brochures and brief instruction may be useful for parents. This can help make hospital policies more transparent and understandable. (van Manen 2011.) According to Steyn and colleagues (2017), De Rouck, and Leys (2009) and Lou, Pedersen, and Hedegaard (2009) argue that despite the fact that the healthcare professionals did all the technical work for the child, no work with mothers was

carried out and the parents felt they were expected to cope with their experiences on their own.

The relationship of the couple with each other, and between the healthcare professionals and the other community, determines how much mothers can rely on or trust the nurses and their words. (Steyn et al. 2017.) Especially with immigrant families, the healthcare providers may experience barriers in relationships and communication with families, such as intercultural misunderstanding, particularly during critical situations, for instance making decisions about treatment. At this point, the relationship becomes the most fragile. (Hendson, Reis, & Nicholas 2015.) Stress can also be caused by difficult communication with healthcare providers (Shudy et al. 2006). Hendson and colleagues (2015) argue that in order to create healthy partnerships, it is necessary to build respectful relationships with each other, as well as the perception by nurses of each family as a unique family with their moral beliefs and values. According to Brødsgaard, Pedersen, Larsen, and Weis (2019), Fegran and colleagues (2008) argue that close relationships between a nurse and parents were recognized by parents as one factor in overcoming stress.

It was revealed that the nurse's respectful attitude to families, active listening and sympathy, and recognition of the importance of their emotions made the family trust the healthcare professionals. They felt important and useful. (Brødsgaard et al. 2019.) In another study, the nurse’s awareness of the child’s condition and interest in their personality and the parent’s knowledge of the nurse who provides care helped to establish mutual understanding between nurses and parents (Espezel & Canam 2003). On the other hand, when a nurse lacks respectful competence, the parent feels a sense of detachment, uselessness, and futility of their presence (Brødsgaard et al. 2019). There is a need to maintain the awareness of nurses that they have the power to help parents with their mental health during their stay in the hospital, with simple methods, such as constructive communication and the ability to listen and understand them (Steyn et al. 2017). Healthcare professionals should help parents cope with this procedure during a difficult time for the family and help them continue to function as a family within the walls of the hospital. This should be part of the ethical responsibility of healthcare providers to shape sensitive healthcare

practices. (van Manen 2011.) It was noted that during this period, parents needed special support from their loved ones, family, and friends (Steyn et al. 2017).

The interaction of the nurse with the patient's family, especially in pediatric wards, is an important element of family-oriented care (Costa, Magroski Goulart Nobre, Gomes, Rosa, Nornberg, & Medeiros, 2018). Healthcare professionals should provide qualified and accessible care tailored to the individuality of each family (Soares et al. 2016). Nurses carry out their technical work professionally, but it has been noted that sometimes nurses still lack humanized care, sensitivity, and patience (Costa et al. 2018). Parents' respect for nurses is associated not only with the technical skills of the nurse, but also with the sensitivity of the nurse and their family's knowledge of the hospitalization of the child (Hill, Knafl, & Santacroce 2018). It was revealed that conversations not related to the condition of the child also positively influenced the emotional state of the mother. Small talk conversations, easy conversations, i.e. not about illness, gave a sense of respite between reality. A conversation accompanied by humor could erode the difficult atmosphere of the hospital. Conversely, the lack of healthcare providers communication with the family developed a sense of remoteness and loneliness. (Wigert, Dellenmark Blom, & Bry 2014.) The essential elements in an effective collaboration between a healthcare provider and a parent are the art of communication and conversation management (Tourigny & Chartrand 2015).

Building mutual knowledge is one aspect of effective partnerships. When the nurse and family pursue the same goal, this is the maximum positive assistance for the child. They need to consider the experience of both parties. The nursing personnel all the necessary skills and knowledge that fall within the nurse's competence, and on the other hand, the family shares its experience regarding their lives, since no one knows their child better than their family. A joint effort by both sides to share knowledge will build trust between them. (Brødsgaard et al.2019.) According to Brødsgaard and colleagues (2019), Trajkovski and colleagues (2012) described how healthcare providers created a space and supportive atmosphere in which they could share baby care skills and share experiences with their family. A study by Blankenship and colleagues (2015) talked about positive experiences in a hospital, where nurses formed a group where mothers were invited, and with whom they discussed how to

be the mother of a child who was hospitalized in the intensive care unit. Eventually, the results were that mothers took responsibility for participating and taking care of their child. (Blankenship et al. 2015.) The lack of communication between healthcare providers and mothers contributes to the emergence of a sense of isolation and refusal to accept the situation (Wigert et al. 2014).

2.6 Solution to mothers' hardships in ICU

In the Code of the Republic of Kazakhstan about marriage (matrimony) and family (2011), the concept of a family is defined as "a circle of persons associated with property and personal non-property rights and obligations arising from marriage (kinship), kinship, property, adoption or other forms of adoption of children and are intended to contribute to the strengthening and development of family relations". According to Brødsgaard and colleagues (2019), Hutchfield, (1999), Shields, Pratt, Davis, and Hunter (2007) and Shields, Pratt, and Hunter (2006) argued that an approach based on family care has been increasingly used that includes—in addition to mother and father—brothers, sisters, and other significant relatives. Bagnasco, Aleo, Timmins, Begley, Parissopoulos, and Sasso (2017) define Family-Center Care (FCC) as "a way to care for children and their families as part of a health service that provides care planning for the whole family, and not only for an individual child/person and in which all family members are recognized as beneficiaries." Family care in the ICU is one of the components of healthcare that provides a care plan for the whole family, and not just for one part of it or only for the patient. In this approach, the family is considered as a beneficial recipient of the service. (Bagnasco et al. 2017.) The FCC focuses on the direct involvement of parents in caring for their child. According to Brødsgaard and colleagues (2019), Griffin (2006) and Mikkelsen and Frederiksen (2011) note that FCC forms a shared responsibility between family and healthcare providers who strive to achieve a common goal.

A study by Wigert and colleagues (2013) described the strengths and weaknesses in relation to the communication between parents and healthcare professionals from the parents' point of view. Parents described that nurses have more opportunities for emotional support for parents, as they are more in care with the patient. It has been found that incorporating family care elements into nursing practices, such as

sharing care, reduces worry and anxiety among parents (Curtis, Foster, Mitchell, & Van 2016). According to Coyne's (2013) study on FCC, parental involvement in care was beneficial for both the nurse and parents. However, there were obstacles to the implementation of the FCC, such as nurses' excessive dependence on the parents' help, and lack of communication between the parent and the healthcare providers. (Coyne 2013.) An obstacle to the full implementation of family-oriented care is the inability to visit the department due to the existing work, housekeeping, and other daily duties, as well as caring for other children at home and coordinating the time set by the department to visit (Pieszak et al. 2017).

Modern healthcare needs new models of care. Increased life expectancy and incidence of chronic diseases associated with increased levels of technical assistance require new models of family care. (Tomlinson, Peden-McAlpine & Sherman 2011.) Although there is a lot of information about families and family models, in practice nurses still use a personal approach. Moreover, families are considered something that interferes with health care. (Rowe Kaakinen & Harmon Hanson 2014, 15.) According to Rowe Kaakinen and Harmon Hanson (2014, 8), family care is defined as a process that satisfies the family's need for care. Families are different, and they are constantly changing over time. Therefore, it is important for nurses to know the principles of family care. Nurses can use different models to interact with families. (ibid., 13). Family-oriented practice is important for patient recovery, reducing stress experienced by parents, and satisfying them (Smith 2018). According to Rowe Kaakinen and Harmon Hanson (2014, 21), trained family nurses can help the families to overcome the disease-related changes in their family. Nurses can help families deal with stress. Depending on the degree of tension in the family, the nurse uses different strategies (ibid., 25). A study by Coyne (2013) reported that nurses had a positive perception of FCC but experienced some difficulties. The implementation of the FCC was somewhat problematic, which was due to the lack of healthcare providers, the lack of sufficient knowledge and skills of nurses about the FCC, the potential of families, some organizational issues, and others. (Coyne, 2013.)

3 Purpose, Aim, and Research Questions

The purpose of the study is to identify the possible challenges faced by mothers of children who had been hospitalized in the pediatric intensive care unit (PICU) or Neonatal Intensive Care Unit (NICU) for more than 3 days. The findings will be used to develop nursing education as well professional continuing education for nurses who work in intensive care units.

The aim of the study is to describe and better understand mothers' experiences of intensive care, and in addition, to reveal what kind of relationship is formed between mothers and healthcare providers.

Research questions

1. Do mothers whose child was in the NICU/PICU encounter/face any challenges during child's hospital stay? And if they do, what kind of challenges they face?
2. What kind of relationship is formed between mothers and healthcare providers (in particular, a nurse) within the PICU/NICU?

4 Methodology

4.1 Qualitative Research Approach

Qualitative research refers to social research, including the lives of people who have directly experienced subjective reality, their perception of a phenomenon, and thesignificance that they attach to events in their lives (Holloway & Galvin 2016, 3). According to Taylor, Bogdan, and DeVault (2015, 18), Corbin and Strauss (2008) state that qualitative research shows the importance that people attach to events in their lives, focusing on their perceptions, experiences and belief systems in this period. Qualitative researchers develop ideas, concepts, and insights from the data. (Taylor, Bogdan, & DeVault 2015, 18.) The purpose of the interview will be to study the experience of the mothers of children in the ICU regarding the hospitalization of their child. The qualitative study approach was adopted in this research as the aim of the research was mainly to concentrate on personal experiences of mothers, individual feelings, and opinions.

4.2 Data collection method and procedure

The respondents in this study were from a one big hospital located in Kazakhstan. This hospital was chosen because it is one of the largest children's institutions in the city, providing emergency care to children, including patients with surgical pathology from birth to 18 years. It was carried out in two departments of pediatric: neonatal ICU and ICU after cardiac surgery operation. The hospital building is a natural place for the mother to stay during her child's illness, and therefore, the interview was conducted within the hospital to preserve the natural context of the phenomenon (Streubert, 2011, 20).

The method of individual interviewing is considered the gold standard of qualitative research, and it is also one of the best ways to penetrate into the depths of a person (Oltmann 2016). Semi-structured interviewing was chosen as it is more suited to the goal of my research—an understanding of the context and the formation of a hypothesis or theory to explain the experience of mothers in the ICU (Tod 2015, 388). Semi-structured interview uses both open and closed questions. The main questions can be complemented by additional ones, such as why or how, to reveal the answer. It has pre-prepared topics to rely on during the interview, but it can move away from the topic more deeply if necessary. No more than an hour was planned for an interview since it is more appropriate for conducting a semi-structured interview. (Adams 2015, 493.) The interview template consisted of pre-prepared open-ended questions, and the researcher asked other additional questions when they arose during the dialogue. The interview schedule contained 15 open-ended questions; 10 about experience and 5 about relationships with the healthcare providers. Sample questions for interviewing mothers are presented in Appendix 4, which were prepared for planning an interview and subsequent analysis of the data. Data was collected in January 2020 through semi-structured interviews. The meeting was held face to face with the interviewer in order to delve into the personal questions of the respondent, understand their experience, and have an idea of the event in their life. (DiCicco-Bloom & Crabtree 2006.) The heads of the two resuscitation and intensive care units were informed about the study and gave permission to conduct it, with a signed consent form of their chief chairman of the organization's board (Appendix 2). Before the interview, respondents were informed

about the details of the study and certified in accordance with ethical principles, such as anonymity and confidentiality. Mothers were informed that their answers did not contain correct and incorrect answers and would not affect the attitude of healthcare providers to their child.

In order to preserve the integrity and accuracy of the interview data, it was recorded on a mobile voice recorder and field observations during the interview. Digitally recorded interviews were transcribed verbatim. The total duration of all recorded interviews is about 178 minutes. The average interview duration was 17.8 minutes. Of these, the longest interview was 29 minutes, the shortest was 5 minutes. All interviews were translated into print format, which amounted to 20 pages, using the Calibri font in Russian and size of a font 12. Most of the short interviews were collected from mothers who came from home to visit the child in the hospital, because they were in a hurry to return home. Respondents who were in maternity wards had more time. Data collection was stopped when data saturation occurred, that is, when new categories or topics stopped appearing, which indicated data saturation (DiCicco-Bloom & Crabtree 2006).

4.3 Participants

For the selection of participants, certain inclusion and exclusion criteria were selected. Inclusion criteria was: mothers of children, whose child had been hospitalised in the PICU for at least 3 days. Exclusion criteria was: mothers, whose children died in the ICU, and mothers under the age of 18. Nationality or religion was not a restriction. Since the experience will be to be investigated from the moment she found out about the diagnosis or critical situation and during the whole stay in the ICU, mothers whose children are admitted to ICU from three days will be selected. During this time, she will meet with the nurse and be able to understand how she can help her. All respondents were informed about the study and gave their verbal consent to participate (Appendix 2). A total of 13 mothers were invited to conduct the interview, and 3 of them refused to be interviewed for various reasons. Ten mothers responded positively by reading the consent form (Appendix 1). An individual interview was conducted with these mothers. All 10 mothers survived the care of their child in the ICU. This was their first experience of their child receiving

treatment in the intensive care unit. Most women were married (90%). The age of mothers ranged from 27 to 40 years. The youngest child was 6 days old and the oldest was 8 months.

4.4 Data analysis

Data analysis used the content analysis method with an inductive approach. The content analysis method is widely used in nursing research (Elo & Kyngäs 2008). Content analysis one of the methods of interpreting text documents (Bengtsson 2016). The purpose of content analysis is to transform a large chaotic amount of information into compressed, more manageable data with the goal of highlighting meaning and transforming into theoretical generalization. The analysis process starts from shorthand texts to hidden meanings in categories and topics. (Erlingsson & Brysiewicz 2017.) The inductive method was chosen because this is consistent with the purpose of my research, where the researcher conducted the study in order to identify new knowledge. The researcher went from specific semantic units to general themes. (Elo & Kyngäs 2008.)

After completing the data collection, the interviews were printed verbatim. All interviews were translated into written form as electronic documents of the Word program. Printed interviews were read several times to understand the general content. Then the entire text was read to determine the meaning units, focusing on the purpose of the study. Then a table was compiled with the meaning units, condensed to units, codes, categories, and themes. Categories were selected based on research questions, for the purpose of classification and generalization. (Erlingsson & Brysiewicz 2017.) After the unit values were compressed, they were transferred to codes that were combined into subcategories and categories, and then themes were defined for each category group.

5 Strenghts and Limitations

According to Streubert (2011, 48), Lincoln and Guba (1985) have identified trustworthiness to include credibility, transferability, dependability, and confirmability. Correctly selected interview questions to obtain relevant information

for the purpose of the study can serve as the reliability of the study. Inclusion criteria were carefully defined for study validity, and targeted sampling was determined. (Elo, Kääriäinen, Kanste, Pölkki, Utriainen, & Kyngäs 2014.)

The study was conducted in two departments: intensive care units after surgery and the intensive care unit for premature infants in one hospital in Almaty, which limits the possibility of generalizing the data. Also the limitation of this study will be that the experience of mothers whose child died in the ICU will not be covered. Perhaps this would have been a completely different experience. However, conducting face-to-face interviews gave mothers the opportunity to openly express their experiences when her child was hospitalized in the ICU which increases the reliability of the results.

According to Collins, Shattell, and Thomas (2005), Lawler (1993) states that “the personality of the nurse is so strong that it can structure social interactions, and some nurses believe that people respond to them not as separate individuals, but as nurses”. In this study, the fact that the researcher was not a nurse in this hospital was a positive thing. In order to reduce the phenomenon of social desirability bias, the participants are guaranteed confidentiality and anonymity of the data received from them, and it is mentioned that there are no right or wrong answers (Collins et al. 2005).

The phenomenon of social desirability may be inherent in some cultures. The nature of research interviews can increase the tendency of people to be positively impressed by answering questions in a way that pleases the researcher. (Collins et al. 2005.) In this study, all the mothers who were interviewed spoke quite positively about the healthcare providers. This could be influenced by the fact that during the conversation, their child was still receiving treatment. Perhaps flattery was expressed in the usual thanks to the healthcare providers for the work done.

The mother’s visit to the in the ICU was short after the operation, not exceeding 20 minutes. It is possible that they did not have time to wittness any flaws and so it was difficult to evaluate the care. Therefore, it would be more socially desirable to give positive answers about the healthcare providers.

6 Research Ethics

This study was conducted after obtaining the approval of Kazakh Medical University of Continuing Education Ethics Committee data, and informed consent was ensured before conducting the research. The principles of voluntariness, confidentiality, and anonymity were respected during the research process.

Informed consent was including information on the purpose and scope of the study, the types of questions that can be asked, how the results will be used, and how will their anonymity be protected. (Carpenter 2011, 61.) Participants were informed why we chose them to participate. ("You are being invited to take part in this research because we feel that your experience mothers can contribute much to our understanding and knowledge of local health practices").

When collecting data, participants were informed that their answers do not contain correct or incorrect answers and will not affect the attitude of medical personnel to their child. Prior to the interview, respondents were informed about the details of the study and certified in accordance with ethical principles, such as anonymity and confidentiality.

The participants were informed that his participation in the study is voluntary. Informed consent was obtained. The confidentiality and anonymity of the study participants was also respected. Thus, the three ethical principles of autonomy, beneficence, and justice were respected. (Carpenter 2011, 61.) Principle of beneficence states that if the researcher feels that the participant may be emotionally harmed, they may end the interview or reschedule it for another time. The participant has the right to interrupt the interview at any time without explanation.

7 Results

A total of 10 mothers were interviewed. Three of them came from home to visit the child in the ICU after the cardiac surgery operation. At the time of the survey, seven mothers were placed in different postpartum departments on other floors, three were visited from home. More information on children is available in Appendix 3.

Seven mothers were in the hospital in the maternity ward and six of their children were in the intensive care unit for premature babies and one in the ICU after cardiac surgery. On a NICU, the mothers were allowed to visit every 3 hours, but in the ICU after cardio surgery operation, the visiting time was only once a day at 2 pm for no more than 30 minutes. All mothers began the description with what happened to their child and why he/she was now in the ICU. Their child's average stay in the unit was 23 days. (Appendix 3)

All mothers reported multiple feelings that began with their child's diagnosis and continued throughout his/her stay at ICU. Mothers experienced feelings of stress, guilt, separation, anxiety, surprise, feelings of hope, and others. At the end of each interview, mothers tried to give advice to mothers in a similar situation. During the data analysis, 4 themes were identified that answered the research questions: (1) Mothers trying to adapt into an ICU environment; (2) Perform to the unexpected new role of mother; (3) Relationship is like a rollercoaster between spouses; (4) Living in a relationship with healthcare providers (Table 1). Themes and categories are shown in the figures below and supportive quotes accompany each section.

Table 1 Theme and categories regarding mothers' experiences during child's hospital stay in ICU

Themes	Category
Mothers trying to adapt into an ICU environment	-Mothers experienced emotional hardship about general child situation -Mothers "feeling shock and sympathy" about appearance of the child and his environment
Perform to the unexpected new role of mother	- Feeling like a robot - Feeling "like a squirrel in a wheel" - Lack of confidence in childcare - To be involved and helpful
Relationship is like a rollercoaster between spouses	-Positive -Negative
Living in a relationship with healthcare providers	- Mutual support and cooperation - Thankful and sympathy for healthcare providers - Neutral relationship as a "provider-recipient" service

7.1 Theme: Mothers trying to adapt into an ICU environment

Emotions have a significant role in the process of adapting a person to changing conditions. Mothers experienced different emotions from the moment they learned about the diagnosis and throughout their stay in the ICU. (Fig.1)

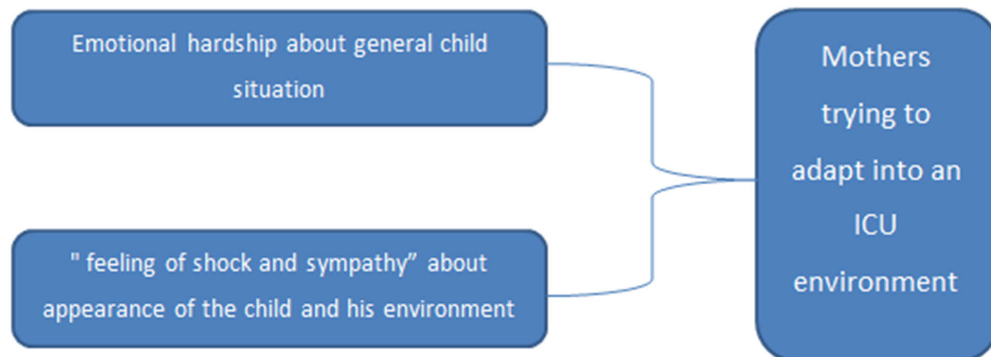

Figure 1 Mothers trying to adapt into an ICU environment

Category: Mothers experienced emotional hardship about general child situation.
This category shows the emotional shocks mothers experience from the moment they find out about the diagnosis and during the entire period of hospitalization. For a mother, learning about a baby's disease for the first time can be a huge shock. They experience different emotions from feelings of not having expected something like this, refusal to accept an undesirable situation to feelings of sadness and guilt. Mothers described the illness as a surprise, since there had not been anything like it in the family.

"The first ultrasound scan was done 7 months age, but I didn't believe it then, how it is, nobody in our family ever got sick" (M1)

Some mothers hoped for an erroneous ultrasound, comparing their situation with the situation of another family, whose ultrasound was not accurate.

"We heard that the ultrasound may be wrong. We hoped that would happen to us as well. But it turned out not so."(M8)

Others, since the baby was long-awaited, did not even think about aborting the pregnancy and decided to give birth to the child no matter what, and relied on the operation to be successfully carried out.

"*We didn't dare to terminate the pregnancy because it is a long-awaited baby. Such operations are carried out successfully and we decided that we would take a chance" (M4)*

The mother also noted that she did not fully realize the seriousness of the disease, and only after the birth of the child and his hospitalization in intensive care did they feel the severity of the sick child in the family.

"I knew his diagnosis before delivery, but the realization of how difficult it is to have a sick child came only after his birth, when the child lies on the device" (M8)

Various feelings do not leave mothers during the entire hospitalization period. However, they already acquire a more negative connotation. So, the mothers said that they experienced conflicting feelings, reminiscent of hysterical, where a smile could change dramatically to sadness and vice versa.

"At first my condition was hysterical. I could be smiling, and I could be crying. It was hard". (M1)

For the first time in the hospital, awareness was gradual. The feeling of disappointment did not allow to accept the situation and denied the existence of an undesirable phenomenon, experiencing a feeling of guilt, where the sensitive nature of the mother closes in on herself and moves away from others.

"The first week there was not depression, but stress, I was silent, I left all myself, cried". (M7)

And then mothers feel guilty for the condition of the child, for the fact that they did not correctly observe the time between the pregnancy of the first and second child, or for their negligent behavior during pregnancy, immersed in the search for reasons and blaming themselves. They cannot believe and accept this undesirable situation.

"I could not accept... I even said to the doctors in the ICU: "wake me up as if it were my dream." (M7)

Participants expressed their frustration and guilt associated with the pregnancy, explaining the reasons that could entail premature birth such as the term after the first child being too short.

“Of course there is a feeling of guilt, it was necessary to observe the interval” (M7)

One mother plunged into thoughts and feelings. She was overcome by sadness associated with guilty feelings. Constant worries, anxiety and thoughts about the child haunted her and caused insomnia. To combat insomnia, she resorted to taking medications and sedatives.

" I will never be calm. I cannot sleep during the day and cannot sleep at night” (M2)

Category: Mothers expected “feeling shock and sympathy” about appearance of the child and his environment. The specific atmosphere of the ICU with all the devices and monitors escalates fear and horror on a person who was not previously familiar with such an environment. Infants had various equipment around and inside them. The predominant feelings regarding the appearance of the child and his environment were horror, sympathy, pain, guilt, and anxiety. They experienced strong emotions from the fact that their children were vulnerable and fragile among the technologies of resuscitation devices. They showed deep pity and empathy for him/her. They felt guilty for the child’s condition and bitterness that they could not change the situation and help them not to feel pain.

“The first thing that came to mind: "why did this happen?!" I so wanted to pick it up and put it back in my stomach, in the womb it would be more comfortable for him than in these sensors, gastric tube... when I saw for the first time, it was as if these sensors were hurting him, as if all this discomfort was giving him this probe..., and you are painfully accepting it.”(M7)

“... I won’t advise anyone, honestly, even to see it, ... He was completely in the tubes, in the devices. .. everywhere in the nose and mouth.” (M1)

“… heart is breaking... Could not hold back tears. Appliance, these hoses. For the first time I see it all. It was unexpected for me” (M8)

A mom got a sense of anxiety when she was near her child and his monitor suddenly began to make sounds.

"When the saturation falls, it scared me, the sound of resuscitation, when you hear an alarming sound, you look at your child right away, are you okay with him" (M7)

7.2 Theme: Perform to the unexpected new role of mother

When a child is admitted to an ICU, mothers change their lifestyle and role as mothers. (Fig.2)

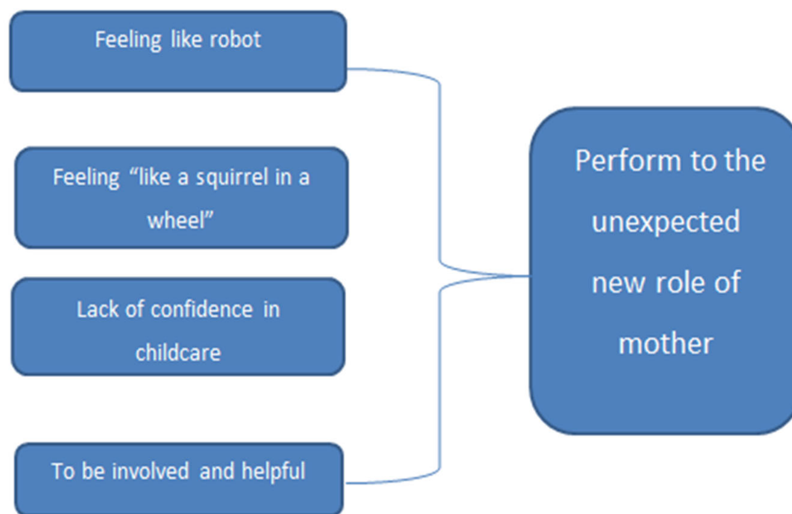

Figure 2 Perform to the unexpected new role of mother

Category: Mother like a robot. Mothers felt they are undergoing changes regarding their lifestyle and the new role of the mother, and they must adapt to the new reality after their child's admission to ICU. Mothers described that their role as a mother became different and this affected their external life outside the hospital. Many described that their mother's role in the ICU was concentrated only as a "robot"—a delivery man delivering certain things to the child.

"At first I was like a robot. What I was told and did. Bring this or that, I walked and brought. I have to buy medicine, and I bought. You perform some functions and that's it (M1)."

Category: feeling “like a squirrel in a wheel”. More than half of the mothers had other children at home. The mother, who came from home to visit her child, said that she had to preserve her maternal role both for this child and for the child who stayed at home. Even though they faced such a situation, the role of mother and wife had not been canceled and life outside the hospital continued.

“I have one more child at home, who is also sick, I’m running between these, and I’m alone at home, and I have to go to school and come here. But I need to keep up with all this”. (M8)

Category: Lack of confidence in childcare. Mothers felt helpless due to lack of knowledge on caring for their baby, but with each subsequent time it became easier for them to look after their child.

"I can’t do anything so that he don’t feel pain, so that he recover quickly, I can’t do anything, just pray to God. I'm helpless." (M8)

“In the beginning, diapers were scary to change. When you open infant incubator, it as if the microbe is coming in. I tried not to open, I tried especially not to contact with the child. Outside only. Then after 10 days I began to change diapers, now I do everything myself, I measure the temperature” (M7)

Category: To be involved and helpful. Participants expressed the need to be present and participating for their child, as well as the desire to be useful for both the child and the healthcare providers. Participants reported that things like bringing things evoked a sense of joy and instilled hope.

“… we were told to bring clothes, such a joy to bring clothes.” (M7)

”Mothers is a help to nurses ...there are many children, but few nurses” (M9)

7.3 Theme: Relationship is like a rollercoaster between spouse

The participants reported how the situation with the admitted of their child in the ICU influenced their relationship with their spouses. This situation influenced some couples in a positive way and strengthened their relationship, but others had obvious tensions. (Fig.3)

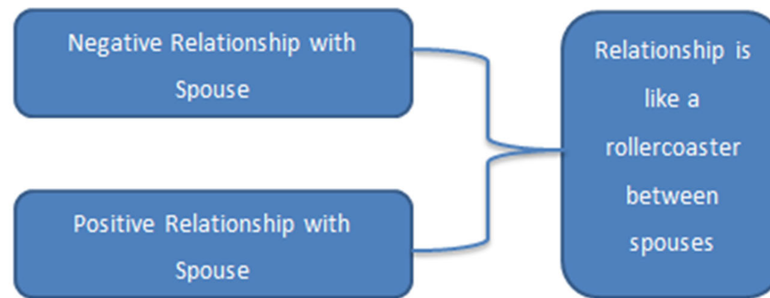

Figure 3 Relationshop with spouse

Category: Negative effect on the relationship with the spouse**.** The birth of a sick child affects the whole family, especially the relationship between spouses. In this study, some mothers described difficulty in the relationship with their partner, which often lead to quarrels due to the fact that they did not know whether they could deal with it together or not.

"There was such a moment of disagreement and misunderstanding. We were nervous and constantly cursing. We did not know if we could handle this." (M1)

"The husband is very worried, he became nervous, he's hard time to endure this period" (M8)

Category: Positive effect on the relationship with the spouse. Other participants said that, on the contrary, they felt support from their spouse, and claimed that their family became close and it got even stronger.

"...My husband, on the contrary, supports. It seems to me that the family has become stronger."(M4)

"There are such marriages when children are born with cerebral palsy, for example, marriages that break up. Men are afraid of difficulties, and therefore it happens, they run away. My husband, on the contrary, supports. It seems to me that the family has become stronger. "(M4)

7.4 Theme: Living in a relationship with healthcare providers

The relationship between mothers and health workers is one part of life in the ICU. Three categories were identified in the relationship between them. The most common are mutual support and cooperation. Here, the nurse supports mothers, and mothers try to help them, expressing this in active cooperation with them. The second category is as an absolute gratitude to the healthcare providers and empathy for their difficult profession. In the third less common type, these are neutral relationships, more like a provider-receiver relationship. (Fig.4)

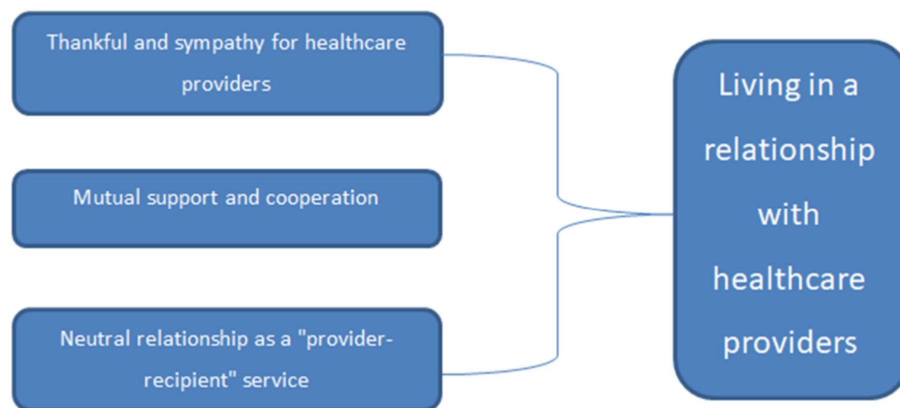

Figure 4 Living in a relationship with healthcare providers

Category: Mutual support and cooperation. Mothers reported that they received support not only from the family and relatives, but support was also provided by healthcare professionals. Mothers noticed that every nurse has an individual approach to each mother. Their support was expressed in the form of advice, appropriate words so as not to lose heart.

"... She will give the necessary advice and the right words, so that I quickly get together. If not for her, I would have stuck..." (M1)

"Everyone has their own approach, not only to children but also to mothers. They do not only do their work, but they also learn about mothers" (M5)

The affection of the healthcare providers for their child and the positive reaction of their child gave the mothers a sense of confidence about the good care of their child. The reverent attitude of the healthcare providers towards their children evoked a sense of trust on the part of the mother.

They called affectionately each child, giving them cute nicknames. My son probably loves doctors and girls more (nurses), etc., than me. Because when he sees them, he begins to smile. (M1)

"They are talking to the child. They each have names. They come up to one and say "baby", "bunny", "little inch". (M5)

Support was also manifested through training mothers to care for their children, which gave them confidence in their maternal abilities.

"the nurse says: do it! do, change! ... I start to do and I learned faster with him" (M5-NICU)

The participant was worried about being transferred to another specialized department. She believed that in the ICU, the child was safe and well-looked after.

"In ICU, generally wonderful healthcare providers. I was afraid of transfer from ICU to another department because I thought that this would not be a care, well, in principle, now and in the another department they are perfectly looking for the children. Nursing personnel- I admire them. "(M10)

Category: Thankful for healthcare providers. The participants described positive feelings about the healthcare providers, they also expressed their gratitude to them and showed sympathy and compassion in their profession. Mothers had no doubt that their child was well-looked after.

"Because it's not to look after your child, I think this is a feat" (M1)

"Thank you for such work. This is the smallest thing I can do to say thanks every second." (M1)

"The child looks very good, I have no doubt that she is looked after well. This is evident from the child. She even smiles" (M4)

Mothers noted that the number of nurses was small and that they were overworked and showed deep empathy for them. They also noted that the work of nurses is very difficult, and this can cause variability in their moods, but mothers showed understanding towards them.

"…They [healthcare providers] remain, but we leave, others come, children always change and they can be understood. They are people, not robots…" (M9)

"Their work is not easy mentally and physically. They are people too. And there such heavy people arrive." (M7)

According to respondents' answers to the second research question, it was revealed that, in general, all mothers are happy with what they already have. Mothers claimed that it is enough for nurses to professionally fulfill their usual role—this is helpful for mothers.

Category: Neutral relationship as a "provider-recipient" service. One can feel the character of the traditional healthcare model in the description below, where an authoritarian style is present. The healthcare providers had clear advantages over mothers. The "community of the medical team" is perceived as something inaccessible to mothers, "another society" in which the mother is only a visitor.

"They are other people. I am completely different. Together will not work. I will never be them. I am a stranger. They are a team among themselves" (M2)

The participant was persistent to the nursing personnel and the nurses corrected some problems with her child after she asked them about it.

"If I don't like something, I tell them that. Syringes, if they run out, change the adhesive plaster, if the child does not like, position if not, the tube if it pops up. They do everything. Depends on their professionalism. They provide all this to me" (M9)

"I come up and say: I want to learn, and they find time and show how to do it." (M5)

It was noted that the main requirement from a mother to the nurse was to professionally perform her nursing work. Careful childcare has been identified as an important component of nursing professionalism. A participant said that she distinguished her favorites among nurses, depending on how much she devotes herself to her work.

“I feel when nurse do without a soul, she’s horrible, she’s stuck on her sides, the probe will stick out, and the adhesive plaster is incorrectly glued on the child. And those who do it from the heart, everything is neat. And when everything is neat with the child, the mother's soul is calm. As they pipe, they patch the patch. These are trifles, but on trifles you can make an overall picture of a nurse” (M9)

Mothers noted that there were not enough nursing personnel and that they were always busy. Most of the time, nurses arrive in chaos and bustle due to the large number of patients and cannot pay attention to each mother, and therefore, mothers should take the initiative in receiving information or learning something.

"...if there are a lot of children - they will not have time to explain everything to everyone. (M5)

“...when you are new to the ICU, nurses have no time for you, it’s apparently hard to explain all this to them too… when i ask a question they try to avoid me “(M9)

8 Discussion

This study was the first on this topic in Kazakhstan. In this study, it was found what difficulties mothers had to face, what emotional shocks they had to endure, and what needs they experienced during this period and what mattered to them, thereby answering the first question of the study—what problems mothers face. Mothers reported feelings of surprise, fear of the unknown, guilt, and hope. This is consistent with previous studies on changes in the emotional background of mothers (Abuidhail

et al. 2016). It falls in line with other studies that focus on parents' perceptions and revelations about nursing care (Pieszak et al.2017).

The second question was what kind of relationships develop between healthcare providers and mothers, which would help nurses to consider moments for improving their relationship. The results of the study indicate that the number of children in the department and the nurses' amount of work affects the time nurses can devote to the mother. According to respondents' answers, it was revealed that, in general, all mothers are happy with what they already have, which was also the conclusion in another study (Espezel & Canam 2003). Mothers claimed that it is enough for nurses to professionally fulfill their usual role; that alone is helpful for mothers. The experience of mothers regarding their relationships with healthcare providers was more positive than in previous studies (Costa et al. 2018). It was concluded that overall, the relationship with the healthcare providers was good enough and mothers are happy with the role of the nurse in their life as it was at that time. An interesting fact is that most mothers talked about empathy for medical workers and their profession, which was not highly concentrated mentioned in other studies.

Despite the fact that mothers do experience difficult times during the hospitalization of their child, which was described in this study, they do not believe that the nurse needs to increase their intervention in overcoming difficulties, on the contrary, they expressed a desire to help the nurse. Interpretation of this may consist in the fact that most mothers believe that the healthcare professionals provide them a great service by the fact that they help them with their sick child. And so they cannot impose themselves and be an additional burden for the healthcare providers. They put themselves in the background after their child, forgetting about their needs, so that more attention is paid to the child. And therefore, independently or with members of their family, they cope with their emotional, psychological and other difficulties. It is likely that mothers do not even know how other relationships can be formed. In the relationship, which was called collaboration, the accuracy of their role in relation to the small patient was not discussed between nurses and mothers. Many mothers spoke of understanding between them and the healthcare professionals, juxtaposing this with collaboration, however it is worth agreeing with the conclusions made in the study, which indicated that mutual understanding was

not yet cooperation (Espezel & Canam 2003). Mother's reactions to healthcare professionals may also be due to the fact that their child was still receiving treatment at that time. It can also relate to the psychology and the peculiarities of the local mentality—the desire not to offend a person.

The results of the mother's experience in ICU are not exceptional for this study and confirm the results of other studies (Steyn et al. 2017). However, the results cannot be generalized due to the small number of respondents, as well as the territorial coverage, i.e., despite the participants being from different departments, they were still from the same medical institution. Therefore, more research is needed on this topic about awareness of mothers and nursing personnel about Family Centred Care. The results can be used by nurses to be aware of the difficulties that mothers face in the ICU, and what interventions will help support mothers and provide best care. This result may also be relevant in terms of increasing family-centered care in Kazakhstan's healthcare.

9 Conclusion

This study found out what difficulties mothers face from the moment that they learned about the diagnosis or critical condition of the child and during his/her stay in the ICU: having difficulty in relationships with her spouse, trying to adapt to life in the ICU and perform their role as a new mother. On the second question of the study, the topic was defined as "Living in a relationship with healthcare providers" in three categories, such as: gratitude and sympathy, mutual support and cooperation, neutral supplier-recipient relations. Each experience is unique, and mothers experience a number of shocks during this period. This study contributes by raising awareness of maternal experiences and suffering in a critical situation, which will help nurses develop interventions to assess mothers' need for conversation, support, and help in the active implementation of family-oriented practices in the ICU.

Despite the fact that the results showed general satisfaction with the current state of the medical service in the unit, this study offers some recommendations for intervention: to consider a possible development of "A mother-nurse partnership program", including information programs to prepare mothers for meeting their

children in ICU conditions, including visual material about what awaits them, describing their expected role in participating in care, what kind of questions they could ask the healthcare providers. It is also recommended to conduct trainings for nursing personnel to solve the practical and emotional problems that mothers face when their children are hospitalized in the ICU.

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Appendices

Appendix 1. Informed consent to participate in this study

Dear mothers of children hospitalized in the intensive care unit

The Purpose of this study is to identify the possible challenges faced by mothers when their child is in the children's intensive care unit. The findings will be used to develop nursing education as well professional continuing education for nurses who work in intensive care units. The aim of the study is to describe mothers' experiences of intensive care nursing from their point of view, and in addition, to reveal how nurse can help them.

I would kindly ask for your consent to examine your documents at Almaty city in the Center and in your primary health care center. Participation in the study is completely voluntary and refusal to provide dossier information has no effect on the treatment your child receives. The records of people who have agreed to the research are collecting records of the I.

The research material will be supplemented by an interview for the selection of a small part of the participants. During the interview, we would like to receive information about the mothers' experience regarding their child's stay in the intensive care unit. The choice of the interviewed mothers is made for volunteers who agreed to this form, with whom we will personally contact in the winter of 2019. The interview is conducted in the form of an individual interview, which takes about an hour. The interview is recorded.

The study material collected from mothers' documents is classified by codes, so that the information of a single parents is not visible at any time, and parents cannot be identified. The research material is kept in a locked closet, only the researcher has the key. The researcher undertakes to comply with the existing guidelines for retention of research material and data protection legislation. The results of the

research will be doctoral dissertations and articles will be published in international scientific journals. The research material will be lost by cutting appropriately after the studies have been completed.

Sincerely,
Diana Aitugulova, Researcher

Letter of Consent

Dear ____________________

JSC Kazakh Medical University of Continuing Education expresses its respect to you and asks to consider the possibility of anonymous intervention of mothers during their child's visit to the intensive care unit for undergraduate 2 years of study on the educational program M141- "nursing" D. Aitugulova as part of a dissertation research on : The challenges encountered by the mothers during child's hospital stay in Intensive care unit.

Appendix 2. Participants information

Mother	age	marriage status	Reason for admission (history/co-morbidities)	ICU (hospital) LOS	Child ages	Other child at Home	status
1	27	married	heart disease	2 month	2 month	1	from home
2	40	married	heart disease	12 day	8 month	2	in the hospital
3	37	married	prematurity	20 day	20 day	2	in the hospital
4	33	married	heart disease	6 day	6 day	2	from home
5	35	married	prematurity	30 day	30 day	-	in the hospital
6	37	Married	prematurity	10 day	10 day	3	in the hospital
7	34	Married	prematurity	30 day	30 day	1	in the hospital
8	32	Married	heart disease	24 day	24 day	1	from home
9	32	Single	prematurity	20 day	20 day	-	in the hospital
10	34	married	prematurity	20 day	20 day	-	in the hospital

Appendix 3. Questions of the interview

1. Difficulties, challenges or problems associated with hospitalization

• Tell me what happened to your child.

• What feelings did you experience when you learned about your child's diagnosis and further hospitalization?

• What can cause these feelings?

• Have you encountered any problems? What kind of problems were you?

• Do you visit your child daily?

2. Problem Solving

• How do your spiritual beliefs and values affect how your family deals with this situation?

• Are there anyone who helped you during this period?

3. The impact of experience

• How has your experience affected you, your life, and your family? (husband, other children)

• How has this situation affected your role as a parent (for your child in the hospital)?

4. Relations with healthcare providers

• How do your family and healthcare providers work together to care for your child?

• How are your relationship with a nurses, how would you described?

• How can health workers (nurses) help a family feel part of a team?

What are/were expectation from nurses?

Appendix 4. The process of inductive content analysis

Meaning unit	**Condensed**	**Code**	**Category**	**Theme**
Even when we had such a moment when the discord ... they didn't understand, they swore constantly, because everyone was nervous, that he, that I. That we did not know at all able or not able(m1).	There was a moment of discord,misunderstanding,Quarrels of nervousness and ignorance can we handle	tension and discord between spouses due to stressful situation	Negative Relationship with Spouse	relationship is like a rollercoaster between spouse