

# **Developing Pediatric Nursing Care for Families of Infants with Heart Disease**

Kuralay Battalova

Master's thesis

August 2019

Social services, Health and Sports

Degree Programme in Advanced Nursing Practice

Author(s) Battalova, Kuralay	Type of publication Master's thesis	Date August 2019 Language of publication: English
Number of pages 35		Permission for web publication: x
Title of publication <b>Developing Pediatric Nursing Care for Families of Infants with Heart Disease</b>		
Degree programme Degree Programme in Advanced Nursing Practice		
Supervisor(s) Hopia Hanna, Ospanova Dinara		
Assigned by for nurses of cardiac surgery departments		
Abstract  <p>           Congenital heart disease (ChD) is a relevant issue for Kazakhstan. Having a child suffering from ChD in the family causes a lot of stress for parents. The study was one of the pilot projects in Kazakhstan to identify the problematic issues of the family with an ill child and their solutions. The purpose of this study is to improve the quality of pediatric nursing via finding out parent's perceptions and expectations of nursing care during the hospitalization of their infant in pediatric cardiac surgery department. Objectives were: To explore the parent's perceptions and expectations about nursing care and to develop recommendations for pediatric nurses to support parents during hospitalization in pediatric cardiac surgery department. Qualitative research was applied. The data was collected by using the focus group technique. Thirty parents with children suffering from heart disease were interviewed in six different groups. The data were analyzed by using the inductive content analysis method. Results were grouped in three main categories: the feelings of parents, the perception of nursing care during hospitalization, expectation of parents from nursing care. Conclusion: pediatric nursing care needs to be improved by increasing nurses' knowledge of characteristic issues of children with ChD and developing nursing autonomy.         </p>		
Keywords: Parent's perception of nursing care, parent's expectations, family nurse, nursing support, nursing care of chronically ill children, a qualitative study,		
Miscellaneous ( <a href="#">Confidential information</a> )		

## Contents

<b>1</b>	<b>Introduction.....</b>	<b>3</b>
<b>2</b>	<b>Background.....</b>	<b>4</b>
2.1	Relevance of infant’s heart disease .....	4
2.2	Stress in families with infants with heart disease .....	5
2.3	Parental perception and nursing care .....	7
2.3.1	Nursing support for parents during child’s hospitalization .....	9
2.3.2	Parental perception towards nursing ICU care .....	10
2.3.3	Expectation of parents and satisfaction of treatment .....	11
2.4	Situation in Kazakhstan .....	13
<b>3</b>	<b>Purpose, Objectives, and Research Questions.....</b>	<b>13</b>
<b>4</b>	<b>Method .....</b>	<b>14</b>
4.1	Qualitative research .....	14
4.2	Ethical issue .....	15
4.3	Participants and data collection .....	15
4.4	Data analysis .....	18
4.5	Limitations of the study .....	20
<b>5</b>	<b>Results .....</b>	<b>20</b>
<b>6</b>	<b>Discussion .....</b>	<b>26</b>
<b>7</b>	<b>Conclusion .....</b>	<b>30</b>
	<b>References.....</b>	<b>31</b>
	<b>Appendices.....</b>	<b>35</b>
	Appendix 1. Open question for interview .....	35

**Figures**

Figure 1. Content analysis application 1. .... 18  
Figure 2. Content analysis application 2. .... 19

**Tables**

Table 1. Data of participants. .... 16  
Table 2. Content analysis result..... 19

## 1 Introduction

The whole family is exposed to stress and anxiety when a child is in the hospital, mainly because a child's illness and hospitalization can lead to parents' negative emotions like anxiety, insecurity, guilt, fear, and grief (Hopia, Tomlinson, Paavilainen, & A°stedt-Kurki 2005). Both families and child go through a traumatic situation due to the illness of a child. That is why the quality of nursing care from the parents' perspective plays a significant role related to the development and improvement of the performance and image of health services, where parent or patient satisfaction is an important indicator that evaluates the care quality provided by healthcare services. (Tsironi, Bovaretos, Tsomakas, Giannakopoulou, & Matziou 2012.)

Moreover, parents and children are stressed because of hospitalization since children's sense of wellbeing, security, independence, and self-control are under threat (Okunola, Olaogun, Adereti, Bankole, Oyibocho, & Ajao 2017). Therefore, the nurse should be constantly beside the patients, communicating with their parents and taking into consideration their mental characteristics, feelings, experiences, judgments, and their psychosomatic state in order to shape effective solutions and target practice improvements to the care-delivery experience (Commodari 2010; Curley, Hunsberger, & Harri 2013; Hall, Neely-Barners, Graff, Kreek, Roberts, & Hankins 2011). So, patients and families are accepted as a valuable source of information to explain the influence of the child's illness on their lives and the quality of the care received by the family (Salmani, Bagheri, & Mandegari 2017).

To sum up, the main purpose of this study is improving the quality of pediatric nursing by finding out parents' perceptions and expectations of the needs of infants with congenital heart disease during hospitalization in the pediatric cardiac surgery department. Besides, the quality of nursing care cannot be improved without parents who are the main stakeholders and observers of the nursing care. Consequently, hopefully, this study will be one of the pilot projects in Kazakhstan to identify the problematic issues of the nurse-the patient's family and their solutions.

## 2 Background

### 2.1 Relevance of infant's heart disease

Congenital heart disease (hereinafter ChD) is thought to be a major cause of morbidity and mortality (Hoffman 2013; Ruggiero, Hickey, Leger, Vessey, & Hayman 2018). It is also defined as clinically significant structural heart disease, presenting at birth (Silva, Guimarães, Cavalcanti, Pereira, Queluci, & Santana 2014; Smith 2011). The incidence of congenital heart disease is similar worldwide. (Hoffman 2013). According to national statistics for 2018, ChD is the first case defect in the UK affecting 8/1000 live births (British Heart foundation 2018). Furthermore, 35 types of ChD are medically recognized. The types of congenital heart disease have some minor differences by country (Ruggiero et al. 2018).

The incidence figures constitute from five to eight per 1000 live births before the introduction of echocardiography, yet better diagnosis has represented many more with milder forms (Smith 2011). As for the current figures, they range from eight to 12 per 1000 live births (British heart Foundation 2018). It is expected that infants and children with ChD will live longer due to the fact that medical therapies and surgical innovations continue to evolve (Newburger, Sleeper, Bellinger, Goldberg, Tabbutt, Lu, Mussatto, Williams, Gustafson, Mital, Pike, Sood, Mahle, Cooper, Dunbar-Masterson, Krawczeski, Lewis, Menon, Pemberton, Ravishankar, Atz, Ohye, & Gaynor 2012). However, it is complicated to forecast the influence on the family in the long term (Ruggiero et al. 2018). Despite detecting ChD with the help of routine antenatal screening, considerable proportions are identified only in case of life-threatening symptoms, which may result in irreversible efficacy of routine fetal ultrasound screening for congenital heart disease in normal pregnancy (Smith 2011). So, diagnosis is associated with morbidity and mortality rates (Ruggiero et al. 2018; McCormick, Escobar, Zheng, & Richardson 2008).

In general, care differs significantly between major and minor cardiac lesions. Cardiac malformations are revealed ranging from 3% to 5% of newborns, being severe in one out of every thirty-three births with ChD and other cardiac malformations (Rosa, Rosa, Zen, & Paskulin 2013). Hence, the neonatal period is critical for the patients

with congenital heart disease, which is the main cause of death in early childhood in developed countries (Ruggiero et al. 2018; McCormick et al. 2008). Generally, ChD is the first cause of death from a birth defect, taking twice as many children's lives as cancer annually (British Heart foundation 2018).

In Brazil, in 2008, the deaths of children under one year accounted for 19%, which was the second main cause of death in this age group (Silva, Guimaraes, Cavalcanti, Pereira, Queluci, & Santana 2014). Additionally, patients with ChD must monitor their heart for the rest of their lives since ChD cannot be cured (McCormick et al. 2018; Melion, Uzark, Drolar, Wemovsky, Newberger, Mahoney, & Marino 2014).

In other cases, multiple open-heart surgeries or a heart transplant are necessary for most people. The first open-heart surgery is even performed on babies born with ChD at just a few hours or days old. Currently, 250,000 adults are suffering from ChD in the UK, while the number is 1,000,000 in the USA, being similar to Europe and the rest of the world in proportional terms. There is similarity in the abnormality of the heart for everyone with ChD, although everyone is affected differently as each person is unique. (Hoffman 2013.) Besides, surgery is not always the solution to the problem related to ChD. Along with heart surgery it is necessary to raise awareness towards ChD as for nurses as for families. So raising awareness is the key for the families and sufferers to hope with the aim of surviving. (Smith 2011.)

## 2.2 Stress in families with infants with heart disease

Anyone may face a diagnosis of ChD, changing the family's response to the child (Mellionet et al. 2008; Ruggiero et al. 2018; Okunola et al. 2017). For example, while one family can become overprotective towards an infant, another one becomes distant, warranting further investigation (Weerd, Tol, Albers, Sauer, & Verkerk 2015; Golfenshtein, Einav, & Medoff-Cooper 2016). Both mothers and fathers affect chronically ill children negatively, which means that families have to meet lifelong care needs due to a child's physical or mental disability, witnessing their child experiencing periods of suffering (Golfenshtein et al. 2016, Smith 2011, Hoffman 2013). Some regular outpatient appointments are necessary for these families (Homer, Marino, Cleary, Alpert, Smith, Robert, Brustowicz, & Goldmann 1999)

Some research has been done related to families' feelings and the risk for newborn infants and their relationship with health professionals (Curley et al. 2013; Salmani, Bagheri, & Mandegari 2017). So, in a study by Silva et al. (2014), an integrative review was conducted of the feelings of parents whose children had serious health problems. The study illustrated some main feelings experienced by families. They were guilt, pity, fear, anger, helplessness, disappointment, incomprehension, and mourning because of the loss of their idealized child. As a result, experts concluded that parents had contradictions because of the contraposition between the idealized child and the actual one, and health professionals were the interlocutors, helping to solve the parents' internal conflicts. (Silva, Guimarães, Cavalcanti, Pereira, Queluci, & Santana 2014.)

For instance, after giving birth, many mothers tend to ask the health care team if the child cried, whether the child is perfect, and so on. All these questions are common to ensure that her child was born without complications or malformations. However, all dreams and desires can be broken due to the possibility of developing severe complications after the birth of the child. Afterwards, mother and family feel anxiety, leading to emotional distress. (Zani, Golias, Martins, Parada, Marcon, & Tonete 2013.) Consequently, the child and the family feel the implications as a functional unit due to the suffering (Weerd et al. 2015).

Another study showed that family stress appears owing to medical diagnoses, with respect to therapeutic decisions and in answer to the care which is necessary for children with congenital heart disease facing the resulting limitations in their everyday life (Lam, Mu & Hsieh 2014). So, nursing professionals appreciate these studies because they represent how nursing care is vital for emotional support and health education so that they can assist the family to adapt to the health-illness transition process of the child (Robertson-Malt, Chapman, & Smith 2007).

Diagnosis can also demonstrate a dilemma for the family, contributing to conflict between individuals and feelings of guilt during the decision-making process (termination, reconstructive surgery, or palliation) (Mortensen, Simonsen, Eriksen, Skovby, & Dall 2015). Besides, the influence on the family is relative to the severity of the defect inherent ChD (Robertson-Malt et al. 2007). There is a disadvantage related to surgical correction, which makes infants experience difficulties of surgery years



later, proving to be a considerable burden for child and family (Newburger et al. 2012). This is the time when parents are exposed to great stress. Namely, pre-operative effects on the family on diagnosis of ChD can lead to a mixture of shock, disbelief, fear, blame, anger, and sadness (Smith 2011; Silva et al. 2014). All the procedures following diagnosis, including care, may become life changing (Golfenshtein et al. 2016).

During the post-operative period, there might be some complications like infection, ventilation-associated pneumonia, and blood infection associated with invasive line placements which are acquired in the hospital (Smith 2011). Most families need to be reminded that they provide their child with vital emotional support in spite of the fact that they feel helplessness (Commodari 2010). Eventually, to evaluate care needs, it is essential for professionals to recognize the continuing effects that the defect may have on the family and the variables that influence these from the diagnosis onwards, including ethnic origin, social class, religion, and access to a specialist center (Sanjari, Shirazi, Heidari, Salemi, Rahmani, & Shoghi 2009).

### 2.3 Parental perception and nursing care

Nurses play a significant role in the care of sick infants, softening parental stress via establishing caring relationships (Papastavrou, Efstathiou, Tsangari, Suhonen, Leino-Kilpi, & Patiraki 2012; Curley et al. 2013; Golfenshtein et al. 2016). The caring relationships are based on sharing knowledge and information, paying attention to supporting parents psychologically and physically, involving parents in decision making (Curley et al. 2013; Hopia et al. 2005). However, poor relationships with nursing staff can become a source of stress when there are contradictions between expectations and perceptions among nurses and parents (Lam et al. 2014). Hence, this subdivision illustrates the results of several studies concerning the mutual dependence of nurses and parents of patients during hospitalization (before preparing for surgery, in the intensive care unit, and before preparing for discharge) (Latour, Van Goudoever, Duivenvoorden, Van Dam, Dullaart, & Albers 2009).

The perceptions of parents, physicians, and nurses regarding suffering overlap but they are various, which are rooted in the relationship with and the kind of

responsibility (parental/professional) for the child (Tayray 2009). Similarly, the child's illness, suffering, and hospital admission bring suffering to parents (Weerd et al. 2015; Hofman 2013). Curing or stopping a decline in health status is the purpose of treatment and interventions in medicine which includes preventing or relieving suffering (Weerd et al. 2015).

Occasionally, medical treatment is thought to be only augmenting suffering, causing burden without benefit. In these incidents, treatment might not be initiated or may be withdrawn in order to prevent suffering. Along with medical staff, parents are observers taking part in the treatment process of their children. (Kelo, Eriksson, & Eriksson 2013.) Sixty-six observational studies investigating sources of parenting stress in parents of young children with congenital heart defects, cancer, and Autism Spectrum Disorder have been yielded with the help of a systematic review Golfenshtein (2016). Clearly, such stress on parents can potentially interfere with normal family life. That is why stressors were categorized and analyzed for the diagnostic characteristics of the population in focus. In accordance with findings, parents across all illness groups feel increased levels of parenting stress. (Golfenshtein et al.2016.)

The quality of nursing care from the parents' perspective really matters in respect to the development and improvement of health services performance and image. Accordingly, the parents' perception of the quality of nursing care was explored because parents' and patients' satisfaction is a considerable indicator in evaluating the care quality given by healthcare services. (Tsironi et al. 2011.) Kam et al. (2008) informed that age and length of stay did not explain the differences between the responses of parents of hospitalized children with sick cell disease who perceived their child's care as of lower quality than parents of children with cancer. So, this is different from the study of Commodari (2010) who illustrated that length of hospital stay and age influenced the respondents in the form of stress and anxiety.

Okunola et al. (2017) conducted research on parents' and nurses' perception of family centered care. In concordance with his study, it was found that there was no significant relationship between nurses' characteristics (age and years of pediatric experience) and their perception of family centered nursing behaviors. In the end, the investigation illustrates specific information regarding the family centered

Nursing Care behaviors, where the parents of hospitalized children are interested in perceiving nurses' caring behavior as important for family centered care, included in their daily practice. The following result of this study revealed statistical differences in the perception of Family Centered care behavior by age and level of education where length of hospital stay did not influence it. An appropriate demonstration is that most parents had experienced that factor in the hospital with other siblings of the sick child. (Okunola et al. 2017.)

### 2.3.1 Nursing support for parents during child's hospitalization

The whole family feels a high level of stress and anxiety having a child in hospital (Hopia et al. 2005). During pediatric health crises, family care requires appropriate sensitivity to the family's needs and a kind of complex nursing care (Tomilson 2002; Mortensen, Simonsen, Eriksen, Skovby, & Dall 2015). Psychologically, the parents encounter a difficulty to nurses owing to uncertainty that accompanies hospitalization. Despite the fact that research in pediatric critical care proved that family stress is a considerable clinical phenomenon, it demonstrated that few nurses have the requisite family intervention skills to support family members adequately during crises. (Tomilson 2011.)

The parents' ability to predict how they can provide their child with support in a critical situation may be impeded due to the prospect of rapid and disadvantageous change in the child's medical state. Obviously, nurses are responsible for showing the parents how to support their child. (Mortensen 2015.) The study towards the perceptions and parents' expectations in this situation is focused on identifying factors which could be manageable for nurses (Kelo et al. 2013). Hence, it would enable the parents and newborns to reduce the stress of hospitalization in the clinic (Zani et al. 2013).

In terms of hospitalization, feeling stressed, parents have pointed out that they have been treated as an outsider, experiencing the sense of helplessness and powerlessness, having an infant who needs surgery or a medical intervention (Salmoni et al. 2017; Lam et al. 2007; Golfenshtein et al. 2016).

This is the situation when understanding parental needs is vital in order to develop effective nurse-parent relationships and help minimize parental stress (Lam et al. 2007). Hopia et al. (2005) have also described the process of family health promotion during the child's hospitalization. The research took place in 2002 with 29 families having a child with a chronic illness who received treatment in the pediatric wards of two Finnish hospitals. The outcome covered 5 parts in the promotion of family health. They were: (1) reinforcing parenthood, (2) looking after the child's welfare, (3) sharing the emotional burden, (4) supporting everyday coping, and (5) creating a confidential care relationship. (Hopia et al. 2005.) The findings of a study by Lam et al. (2007) showed that parents had insufficient information concerning tests, treatment, and uncertainty whether nurses would inform them about changes in their baby's condition, feeling incredibly stressed. According to some data, most parents (84%) found insufficient information regarding tests and treatment as their most stressful experience due to frequent changes occurring in the infant's condition while they were waiting for surgery or in the immediate post-operative period. In addition to this, parents (79%) felt uncertainty related to being informed by nurses about any changes in baby's condition. (Lam et al. 2007.) So, both these situations were perceived as highly stressful experiences, where parents felt less supported when they needed considerable emotional or psychological support in respect to their feelings, worries, and concerns (Lam et al. 2007; Harbaugh et al. 2004; Mortensen et al. 2015; Golfenshtein et al. 2016).

### 2.3.2 Parental perception towards nursing ICU care

Nursing support is thought to be a key role in the neonatal intensive care unit (NICU) where the environment is perceived by parents as stressful. When the admission of a sick infant into the NICU takes place, parents feel various feelings, such as shock, fear, anxiety, guilt, and helplessness. (Mortensen et al. 2015.)

Admittedly, it is difficult to meet parents' needs in a neonatal care unit (NICU) within an average short length of stay, which is about 12 days (Lam et al. 2007). The pilot study was held in a children's hospital in Australia with families of English, Chinese, and Arabic speaking backgrounds with infants admitted primarily for a cardiac or surgical problem. Exploring the level of stress experienced by parents towards

nursing staff behavior and communication during their infant's hospitalization and assessing their perception of the support received from nursing staff were the main goal of this study. It is necessary to help nurses to realize parents' perceptions of pediatric intensive care hospitalization, which can assist nursing staff with addressing the need to humanize the experience.

There is also another qualitative study, describing parents' perceptions of nurses' care giving behaviors in a Pediatric Intensive Care Unit (PICU) in the Midwestern United States. (Tomlinson 2011.) Parents informed that nurses engaged in nurturing and watchful behavior, showed affection, caring, watching over, and protection. Considering parents' reports, it has been found that the best nursing behaviors are facilitating and complementing critical aspects of the parental role, reinforcing family integrity over a time of turmoil and uncertainty. Integrating this knowledge into practice can contribute to nurses' awareness of PICU hospitalization as a family event, informing about interventions to improve family-centered care in the PICU. (Tomlinson 2011; Harbaugh 2004.)

### 2.3.3 Expectation of parents and satisfaction of treatment

Parents whose children need neonatal surgery frequently encounter a very stressful and difficult period (Robertson-Malt et al. 2007; Lam et al. 2007). That is why it is important for hospitals to find out how parents view their child's hospital experience in order to improve the quality of care that hospitals provide. Besides, internal motivation, external regulation, and competitive pressure force hospitals and health care organizations to focus on caring for these children in a more appropriate way. Furthermore, parental satisfaction is an essential result of pediatric care, which is based on identifying and responding to the parents' concerns as one strategy in an overall program of quality improvement. In comparison with resource-intensive methods such as medical record review or videotaping parents' reports related to their children's care can also efficiently give information about processes of care. (Homer 1999.)

The goal of a descriptive study by Thornton (1994) was determining the degree of congruence between parents' satisfaction with nursing care on a pediatric neurosciences unit and nurses' perceptions of parent satisfaction. Twenty parents

and 20 nurses from the neurosciences unit took part in this study. A 25-item self-administered satisfaction with nursing care instrument and socio-demographic tools contributed to collecting data. It was found that satisfaction with nursing care is a reliable predictor of overall hospital satisfaction. Therefore, satisfied health care consumers show better rates of compliance with treatment regimens, being more willing to seek health care services. The findings of this research have revealed that it is necessary for nurses to ask consumers (patients and families) explicitly if their expectations of nursing care are being met or not. Consequently, nurses must provide the consumers with consistent care. Otherwise, nursing interventions can lead to the consumers' erroneous perceptions, meaning that their expectations are unlikely to be satisfied. (Thornton 1994, 26-29.)

Nursing care behavior consists of the professional nurses' activities and manner concerning patients which influence the patients' perception of these behaviors (Papastavrou, Efstathiou, Tsangari, Suhonen, Leino-Kilpi, & Patiraki 2012). Regarding nurses, they represent the largest group of health-care providers, playing a significant role in achieving the health-care system's goals (Salmani et al. 2017). Despite spending considerable amounts of time dealing with patients and their families, their understanding of nursing care behaviors is different from the care receivers' views. As a result, it can lead to dissatisfaction with nursing care, where the receivers' needs are not met. (Papastavrou et al. 2012.)

Provision of family-centered care can become an effective method to assess the health-care system in order to identify the experiences of hospitalized children's parents, which would be a basis for evaluating the quality of care and development of family centered care (Latour, van Goudoever, Duivenvoorden, van Dam, Dullaart, & Albers 2009). Additionally, the health-care receivers' perceptions are important in the assessment of the given care, affecting the behavioral responses regarding the care providers. Moreover, the behaviors perceived by the care receivers are necessary to be determined and clarified as caring behaviors. (Tayray 2009.) What is more, care providers often either overestimate or underestimate the parents' satisfaction and needs when the parents' perception of the provided care is not analogical to that of the members of the health care team. Thereby, these biases are a substantial obstacle in respect to providing optimal care. Unless the pediatric

patients' and their parents' perceptions of optimal care and care standards are assessed, meeting the patients' and their parents' needs may fail. (Salmani et al. 2017.) It was reported by parents that difficulties happened in the hospital discharge planning and pain management (Newburger et al. 2017; Homer 1999). Finally, only 26% of parents evaluated the response to a call for pain control in adequately effective (Homer 1999). Thus, parental evaluation of inpatient pediatric care is focused on the quality of communication between the clinician and parent (Lam et al. 2007; Sarapat et al. 2017).

## 2.4 Situation in Kazakhstan

These issues are also true for Kazakhstan where no research has been conducted in this area. Also, the decision of such questions as quality of treatment or satisfaction from the received treatment often depends on the expectations and perceptions of patients and their families, not only on the successful treatment of the process. Currently, the role of nursing care in this matter is growing because the responsibility is spreading from not only saving the baby's life but also keeping a comfortable emotional environment in the family. The results of the study can be taken as recommendations for changing the quality of pediatric nursing care concerning children with congenital heart disease. Expanding the competence of nurses will develop the practice of advanced nurses.

## 3 Purpose, Objectives, and Research Questions

### **Purpose:**

To improve the quality of pediatric nursing via finding out parents' perceptions and expectations of nursing care during hospitalization in the pediatric cardiac surgery department.

### **Objectives:**

1) To explore parents' perceptions and expectations of nursing care during hospitalization in the pediatric cardiac surgery department when their infants have congenital heart disease.

2) To develop recommendations for pediatric nurses to support parents during their infant's hospitalization in the pediatric cardiac surgery department.

### **Research Questions**

- 1) What kind of perceptions and expectations do parents have about pediatric nursing during infant's hospitalization in pediatric cardiac surgery department?
- 2) What kind of recommendations for pediatric nursing interventions are made based on parents' perceptions and expectations?

## **4 Method**

### **4.1 Qualitative research**

Qualitative research examines subjective human experience via using non-statistical methods of analysis. The purpose of this study is exploring parents' feelings, and qualitative research is in agreement with the goal. (Ingham-Broomfield 2014.) The advantage of the qualitative approach is that it has a holistic focus, illustrating flexibility and the attainment of a deeper and more valid understanding of the subject achieved through a more comprehensive approach. Also, the approach of qualitative research understands human experience holistically in definite conditions, for example, in the case of hospitalization. In addition, an interpretative research approach is thought to be an ideographic research and the study of individual cases or events, demonstrating the abilities to understand various people's voices, meanings, and events. (Hsieh & Shanon 2005.) Qualitative research enables the researchers to discover participants' internal experience, learning how to influence the quality of nurses' work with the help of this method (Andersona, Leahyb, DelValleb, Shermanb, & Tanseyc 2014).

Whereas the disadvantage of qualitative methodology relates to the possible effect of the researchers' presence on the people that they are studying, referring to investigating people's experience, emotions, and feelings. So, the qualitative research approach was employed to collect data using unstructured interviews. (Hsieh & Shanon 2005.) Finally, the qualitative research design represents a flexible



structure since the design may be constructed and reconstructed to a wider extent (Clarke 2014). This research will employ the qualitative research method, which is suitable for the research questions and the fulfillment of the goal of this study.

## 4.2 Ethical issue

The approval for conducting this investigation has been given by the ethical committee from Kazakh Medical University of Continuing Education. Initially, the researcher contacted the head of the clinic, explaining the goal of the research. Afterwards, the approval was received from administration. Subsequently, all the families whose children were operated due to congenital heart defect (for the moment of research in October-November 2018) were informed about the research project and given written material.

After the first contact, the family was given some time (one week) to think about participation in the research. The researcher dealt with the families personally. The families were also assured that their participation was voluntary and anonymous, having an opportunity to stop the interview and their participation, which would not influence the further treatment of the child at the hospital (Hopia et al.2005). Clearly, it is difficult for the parents to describe their experiences of nurses' actions in hospital since they are dependent on receiving health care. Despite the fact that the interviews are emotional for the families, they are useful to deal with parents' grief over the child's illness and hospitalization. The interviews were carried out as focus group interviews, which were recorded and coded with the help of numbering.

## 4.3 Participants and data collection

There were six focus interviews conducted in total. All the interviews were held by the researcher, which took place at the clinic in October-November 2018. There were 30 parents participating in the interview. All the respondents' data are given in Table 1. The interview was carried out in focus groups consisting of five people. In general, there were six interviews in total. The families were recruited personally by the researcher during their child's hospitalization in the department of pediatric heart surgery. The parents were given a brochure with the research description. They were

also asked to give a written approval of participation in the interview, in which their involvement was voluntary and anonymous.

Owing to the chosen approach, there was a focus group interview, mainly because a group process helps people to identify and specify their views, where the focus group is an advantage compared to an individual interview (McLafferty 2004). The group acted as a propagandist of synergies and spontaneity, motivating the participants to comment, explain, disapprove, and share their opinions. Therefore, they shared their experience and expressed their views, which could not have appeared during an individual interview (Roberts & Woods 2000). Also, the number of the group including 5 people influenced communication positively in a familiar location, where they felt comfortable in during the interview, which was conducted non-stop within 45 minutes (Rasika & Jayasekara 2012).

The interviews were organized according to themes relating to the subject of research, developed based on studied articles and presented in Appendix 1. Open questions were used during the interview and the groups were recorded on audio. The interview lasted from 20 to 35 minutes. The questions of research, individual experience of receiving medical care, and suitability of nursing care to meet patients' expectations were considered in the focus group. A wide range of research questions were important for this research, since it turned out to be essential for respondents' evaluation of nursing care in pediatrics.

Table 1. Data of participants.

	Frequency (N)	Percentage (%)
<b>Gender</b>		
Male	0	0
Female	30	100
<b>Age</b>		
<19	1	3,3
20 -29	12	40
		36,7

30-39	11	16,7
40-49	5	3,3
>50	1	
<b>Nationality</b>		
Asian	27	90
European	3	10
<b>Level of education</b>		
Low	8	26,7
Middle	10	3.3
HIG	12	40
<b>N of children in the family</b>		
one	16	53,33
two	9	30
three	3	10
four	1	3,33
six	1	3,33
<b>Diagnoses of children</b>		
Ductus arteriosus	3	10
Ventricul Septal Defect ( +Pulmonary ArteryStenosis)	8	26.7
Tetralogy Fallot	5	16.7
Total Anomaly Drainage Pulmonary Vien	2	6,7
AtrioVentricularKanal	4	13,3
DoubleOutlet MA from RightVentricular	2	6,7
Coarctation +StenosisAo	2	6,7
Atrial Septal defect	4	13,3

#### 4.4 Data analysis

A qualitative content analysis is one of several qualitative methods, which is available for data analysis and interpretation of its meaning. The goal of data collection is knowledge provision and understanding of the phenomenon under study. (Schreier 2012.) Text data from audio files were transferred onto printed and electronic forms, which were received from descriptive answers to open interview questions in focus group.

After all the interviews were collected into one file, they amounted to 23 pages 11 italic font Calibri. The analysis was carried out with the help of inductive content analysis. Namely, data analysis began with reading all data in order to reach immersion and get an idea about integration. Then the data were read word by word for finding codes by highlighting exact words from the text, expressing key ideas or concepts. Furthermore, the text was analyzed, making notes about first impressions, thoughts, and analytical analysis. As continuing this process some codes appeared from the notes, reflecting more than one key thought. On average, there were ten of them which originated from the text and later became an original coding scheme. The codes were then sorted into categories based on several code connections. (Hsieh & Shanon 2005.) The process of applying content analysis is demonstrated in Figures 1 and 2.

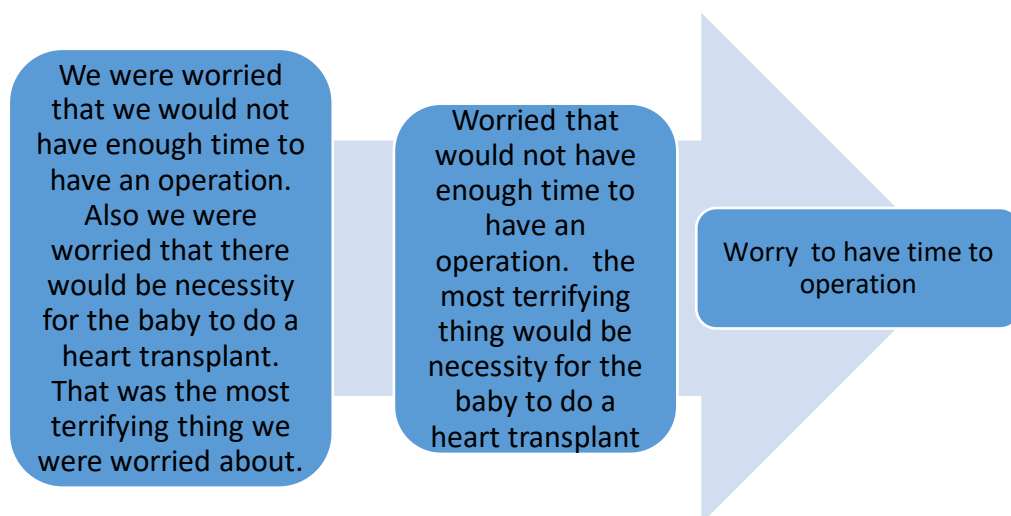


Figure 1. Content analysis application 1.

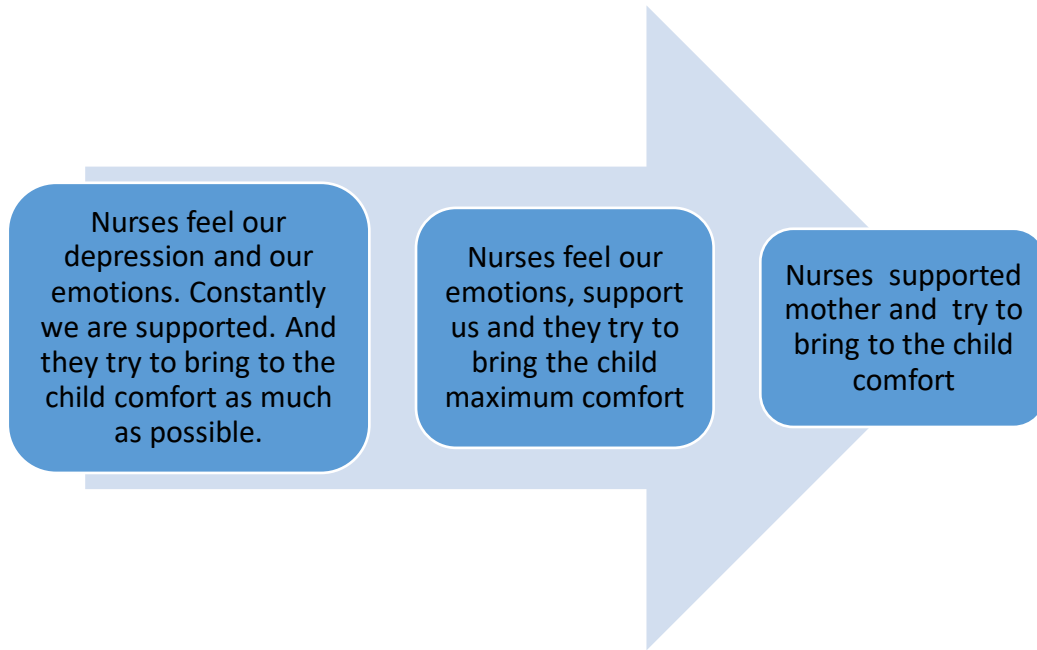


Figure 2. Content analysis application 2.

The eleven identified subcategories were combined into three main categories according to the purpose and objectives of the study. The generated analysis results are presented in Table 2.

Table 2. Content analysis result.

parents ' feelings related to the child's disease	perception of nursing care	expectations of nursing care
<ul style="list-style-type: none"> <li>• <u>stress</u></li> <li>• belief in a better outcome</li> <li>• fear of losing a child</li> </ul>	<ul style="list-style-type: none"> <li>• emotional support for patients and parents</li> <li>• high-quality professional skills (shots, pills, inhalations, massage)</li> <li>• completely dependent on the instructions of doctors</li> <li>• uncertainty and lack of information in PIKU</li> </ul>	<ul style="list-style-type: none"> <li>• improve nursing knowledge</li> <li>• be under nursing control</li> <li>• nursing autonomy</li> </ul>

#### 4.5 Limitations of the study

Document search was carried out in databases of CINAHL, Pub Med, Google scholar, and MEDLINE with the use of key words, such as feelings, family, newborn, and perception. From January 2002 to the present, more than 70 documents were revealed of which 48 were chosen. Representing the results and further discussion will be descriptive. The reliability of the findings was provided via multiple readings of the interviews, audit and open coding of the participants' interview in the focus group.

Before the beginning of the main interview, two pilot tests were conducted. In terms of the first test, the interviewer tested his role among familiar people. The second one was held with one family in order to evaluate parental response to a question. All the interviews were recorded on audio, where the moderator was the researcher. Audio recordings were transcribed, and data derived from one source, which were analyzed, coded, and classified by one investigator.

Strengths of this research were similar patients (age, diagnostics, conditions of hospitalization, and treatment). Also, before the main investigation a pilot test was held. In addition, materials were tested in the research based on reliable sources. The whole interview was recorded on audio. Disadvantages of this research were limited study with only one clinic, the lack of experience regarding interviewing focus groups by the researcher, as well as participation of only one researcher (for example, it is impossible to use the rule of triangulation).

## 5 Results

The interview's purpose related to studying questions of perception and parents' expectation towards nursing care, whose children suffered from congenital heart defect and were hospitalized for surgery at the moment of the interview. Eleven subcategories were highlighted, which were combined into three main categories: parents' feelings connected with the child's disease, perception of nursing care at the clinic, and parents' expectation of the process of nursing care.

### 5.1 Feelings connected with a child's disease

In the atmosphere of the interview, there were questions connected with the parents' feelings on being informed about a child's disease for the first time. Mothers started sharing their impressions by opening up emotionally and moving closer together.

The feelings were mainly linked to parental responsibility, rejection of the disease, and fear for the child's life and future. They asked themselves why it had happened to them. Additionally, they wanted to know what they were punished for, thinking about mistakes they made during pregnancy. Most of them had waited for a healthy child and they could not imagine anything else.

*"- when I learnt about my child's defect I was incredibly upset; I also cried until my milk disappeared. (Interview 1, Respondent 3)*

*"- I had resentment and bitterness due to having a child with heart defect." (Interview 2, respondent 2)*

*"- I was shocked and stressed". (I 2, R1)*

There was a category of religious parents who viewed the birth of the child as a test of strength.

*"- in spite of being upset we thought that everything was in God's hands and we would be fine." (I 2,R 4)*

After realizing the illness of their child, they started looking for solutions to help their child regarding operations, which resulted in fear of failure, fear of inoperability, or fear of losing a child during the operation or in the future.

*"- we were afraid of operation outcome and operational consequences for the child." (I 3, R 2)*

Thus, there was stress in the family because of a child's disease. Instead of the joy of motherhood, they had to search for ways to solve the problem, doing paperwork for hospitalization. All the things contributed to additional stress.

*"- we were afraid of not having enough time to do medical analyzes for 10 days, torturing a child." (I 1, R 2)*

## 5.2 Parents perception of nursing care

Nursing care was conducted for parents from the first arrival at the hospital. During hospitalization, they faced a great number of nurses, beginning with the admission department of the clinic, intensive care unit, and before discharge.

Parents' impression of nursing care begins to form from admission to hospital. Patients pay attention to how the nurse meets them, whether they are polite, whether the subsequent clearance steps are explained, whether they help with hospitalization and transfer to the ward.

*"- the nurses took us very well, documents were checked and accepted. They immediately took us to the ward. The nurses were very polite, and they were good to us." (I 2 R1)*

First of all, they perceived nurses as people with whom to discuss and talk about the condition, getting support in a difficult time for them (for instance, when a child had heart surgery). Parents can ask questions from the nurses, ask for help in the process of caring for the child, find out about the condition of the baby in intensive care, and talk and share their personal questions.

*"- The nurses support us, talk to us; they are also interested in our mood, worrying about our children. "(I6, R2)*

*"- The nurses also reassure us about good results"(I1, R 4)*

*"- They support us morally, explaining about the care, talking to a child. They encourage us and our children."(I2, R3)*

Parents become observers, constantly seeing the work of the nurses. They notice their skills, evaluating their competence related to child care, injections, and bandaging. Parents note how warmly the nurse treats their child patients, trying to do their work carefully and quickly to avoid pain for the child.

*-“They also give support when they do manipulations. For example, when they put an IV. The nurses sympathize with patients. I see it from their faces. They are afraid of*



*hurting as well. The nurses are good and skilled. They do everything well including catheters and IV" (I4, R2)*

Parents notice that there are not enough nurses because they are always busy.

*"- There are few nurses, who are extremely busy as in the department as upstairs (intensive chamber)"(I 6, R 3)*

Nurses' lack of independence is noticed. An appropriate illustration is that nurses cannot change or tell anything without a doctor's permission.

*"- During hospitalization my child turned blue. The nurse called the doctor who came very quickly, giving oxygen and some medicine. After this paroxysm I was not calm. So, the nurses visited me, cared about me and the baby." (I 2, R1)*

*"Nurses cannot do anything independently" (I5,R2)*

There is nurses' dependence on doctors' instructions, too. Parents understand that a nurse collects and gives information, discussing a child's disease, forecast, and the course of the disease without any real power. A nurse cannot make decisions about the condition of the child, the need for emergency help, or make changes in treatment plan based on the results of their observations. Analysis of the ongoing therapeutic process is not conducted by them. They only receive information from doctors or patients and are an intermediate in the transfer of information.

*"- we do not discuss defects with nurses. Mainly, we do it with doctors. For instance, when I was hospitalized, I did not know what defect my child had. In two days, I asked a doctor to visit to explain since I had some questions. Then the doctor visited me and explained about the defect my child had." (I3, R2)*

*"- Possibly, firstly, nurses study themselves and then they inform about blood pressure with heart disease and the standards of blood pressure. They are familiar with details, following doctors' instructions concerning injections for patients and so on." (I1, R3)*

*"Parents also need to be explained about care after operation like handling a wound and holding a baby comfortably. I noticed how to hold a kid and followed it."(I6, R2)*

Most of all, they distinguish and mark the care of their child and the way of communication towards the child, and so on. The nurse is kind and polite towards the child and their mothers. For the patient, this is very important.

*"- Nurses examine the child, asking about physical condition and checking blood pressure."(I4,R2)*

*"- Nurses hold the baby, wondering if parents need any help"(I1, R2)*

Parents really appreciate nurses for morale and discussion support concerning problems linked to feeding tips, wound treatment, inhalation, and so on. Taking care of a child after surgery is an additional stress due to parents' illiteracy regarding helping the child. Therefore, the role of the nurse during this period is very important for the parent.

*"- we can also discuss some domestic and trivial things." (I2,R1)*

*"- If I see any baby's changes, which frighten me I immediately call a nurse.(I3, R1)*

According to the parents, the nurse should be available for help and instructions related to caring for the baby. Parents are frightened by everything new and incomprehensible related to child care.

*"-I was explained how to deal with an inhaler." (I2, R1)*

The greatest grief for parents is that they cannot always be with their child in the intensive care unit of a hospital. Knowing little about the state of their child frightens parents. This is the most stressful period for parents. They do not often receive information about the condition of the child in intensive care. The inability to see the child scares them, because there is uncertainty.

*"- we would like to get more information, especially in the intensive care unit of the hospital. Also, we would like more openness in the intensive care unit."(I3, R1)*

*"- It would be great to spend more time with the child in the intensive care unit. It is not enough to be with the child only once at 2 p.m. We are asked to leave the place when the baby is taken to the intensive care department. We would appreciate if we could visit our child twice or three times for 5-10 minutes just to look at the child."(I3, R2)*

*"- We are worried about the uncertainty of the child's state, thinking about the child. We are distressed for the whole day from 2 to 2 since we speak to the doctor only once a day. If anyone informed us about the child's state in the evenings, we would feel much better. Due to being worried, we often ask about the child."(I1,R4)*

### 5.3 Parents expectations of nursing care

Parents are thankful for nurses' help and support during hospitalization. They think that it would be useful for their child if they were consulted by nurses after leaving hospital. The mothers believe that the nurse helps them survive the difficult period. They would like to stay in touch with them, but they know that this is impossible.

*"- we would like to get nurses' consultation". (I1, R1)*

Additionally, parents think that nurses could give more information or perform more manipulations. However, possibly in parents' eyes, doctors limit nurses' activities. Parents believe that many of the procedures and processes of care would become easier and would be performed faster if the nurse were responsible for them. Since doctors see their patients much less frequently than a nurse, they are often busy with operations; patients sometimes have to wait long for them. A nurse on the contrary is always there, and many issues could be resolved on time.

*"- If we could be explained how to deal with bandaging and care about the child after the operation."(I5, R2)*

*"- It would be good if a nurse could support the families and be available during postoperative period. As parents we do not know much. Doctors give instructions very quickly and leave the families due to the fact that they cannot explain and tell all the things in details, which could be given by nurses."(I2, R1)*

Parents think that nurses are limited with knowledge on explaining the purpose of the operation, the risks, giving instructions for caring for the wound in the postoperative period, and explaining the rules of home care, etc.

*“- a nurse is more available to help with correct instructions. Moreover, the knowledge is necessary for nurses in order not to wait for doctors or examination.”(I3, R4)*

*“- a nurse could explain all the stages of the operation, which would not be difficult.”(I1, R5)*

## **6 Discussion**

In this research, parents' perceptions and their expectations of pediatric nursing care were considered at the time of their children's hospitalization due to congenital heart disease. Congenital heart disease is a serious pathology, influencing the duration and quality of life of the child. Owing to this, expeditious treatment and hospitalization were very stressful for families. The existing risks of the child's loss and lack of knowledge in this field added to the stress of parents. Therefore, parents were sensitive to emotional support of nurses and preferred to address them for council. Contrary to expectation, parents positively estimated the skills of nurses, concerning performance of manipulations. According to the views of parents, nurses appear to have demonstrated complete dependence from instructions of doctors and insufficient knowledge for specific features of nursing care of children with ChD. As expected, parents expect nurses to have knowledge and give instructions about the features of care of children with ChD before and after operation. In expectations leaving the hospital, the parents' underlined that they would like things to be under control and need nurses' tips and instructions concerning the care of the child.

ChD might influence each family differently, because predictions for every child's life are unique. Of course, for achieving satisfaction of needs, each patient demands a professional and individual approach; it is difficult to completely understand expectations and the situation of family. The influence of the diagnosis may forever change the family, and the difficult decisions that they make demand courage (Smith 2011). Presence of the child's illness causes a lot of negative emotions. Most parents were afraid to lose the child during hospitalization and wanted always to be near them. It is necessary to see the child daily (when they and the child are separated, for example, in PICU) in case their fear of losing the child amplifies. (Sarapat et al. 2017.)

Health workers are considered as coordinator-intermediaries in this conflict process in the family (Zani et al. 2013). Practicing nurses make all efforts to support children and their families while they are in hospital and beyond its limits as the process is long (Smith 2011). Parents highly appreciated the support of nurses and their competence in the conducted research; parents demonstrated a high level of support from the nurse (Sanjari et al. 2009). Parents want their children to receive best care. Respondents noted nurses' caring attitude, attentiveness, and competence toward the children. Parents connected this caring behavior of nurses to their commitment, responsibility, and frequent monitoring of children's health. (Salmani et al. 2017.)

The period of a child's stay in the intensive care unit, when mothers were separated from the child and they felt that the uncertainty was oppressing, became one of problem aspects of the research. The research confirmed that hospitalization of the child, operations, and stay in resuscitation is stressful for parents. Uncertainty of a situation and lack of information causes them additional stress. In total, 84% of parents estimated insufficient information about treatment as the most stressful experience. (Lam et al. 2007.) Workers of health care in children's intensive care units have to know about these phenomena in daily practice that the admission of the child in PICU and his/her suffering can inflict suffering on parents, too (Weerd et al. 2015).

On the contrary, if the share of psychosocial and emotional communication during educational rounds of intensive therapy was insignificant, so parents in group of intervention were less satisfied with leaving. It once again confirms the high level of parental uneasiness and that emotional and information communication is appreciated by parents. (Clarke-Pounder, Boss, Roter, Hutton, Larson, & Donohue 2014.) Family-oriented care developed in the way when parents are more helped by nurses, including parent's ability to help nurses technically in some cases. But nevertheless, dissatisfaction of parents for the lack of information, inconsistency, and ambiguity of roles in clinic remain. (Coyne 2013.) Reviewed medical records demonstrated that the majority of documents report negative feelings of families during hospitalization and emphasize the need of support for families (Zani et al. 2013).

The descriptions of parents indicate that the key elements of effective interaction between the nurse and the parent related to child care are the establishment of mutual understanding and joint care for the child. These elements have been influenced by the parental expectations of nurses. Parents argued that the degree of understanding that was established between the parent and the nurse is influenced by the knowledge of the child's nurse, the knowledge of the parents' and the ability to find common communication. A nurse's interest in studying the state of a child and seeing the child as a person were key aspects of establishing mutual understanding from the point of view of parents. The interaction of parents with nurses was usually more positive when their expectations from nurses were met, although they did not always understand the extent of the role of nurses. (Espezel & Canam 2003.)

The stress sources checked by parents and children during or after inclusion in PICU, and methods of overcoming the stress are unique external and internal characteristics of parents and/or the child that depend on interaction. External factors included the PICU environment, hospital, country, and culture, gravity of a disease, the diagnosis, the forecast, LOS, reception type, the procedure, the intra family and cross-disciplinary relations, and participation of parents. Internal factors included internal beliefs of parents and the child, force, stability, resources, temperament, level of psychosocial development, and the effective or inefficient strategy of overcoming difficulties. (Foster, Whitehead, & Maybee 2016.)

When stress is high, parents appreciate support of nurses more. (Mortensen et al. 2015.) Nurse's supports in PICU enable parents to help their children in terms of care, oriented on family. Results of this research show that positive estimates, resources, and the ability to participate in the solution of problems and to cope with them promote stability of families, acting as protective factors from stress. Therefore, the resources available to parents of disabled children, gain a bigger value for the stability of the whole family. (Hall et al. 2011.)

Contrary to expectations, there are studies showing the difference in nursing care depending on the disease. There are chronic diseases associated with a decrease in the quality of medical care. For example, studies related to sickle cell anemia showed that parents reported lower satisfaction with nursing care than patients with other

diseases. Previous adult reports of mistrust on the part of health workers and the feeling that they treat them differently from other patients may have taken root because of the treatment that sickle-cell children receive in the early stages of treatment. Parents of these children can compare the differentiated approach, especially in hospital settings where children with other chronic diseases may be in close proximity.(Kam et al. 2008)

It is a challenging task to support parents. The shock of a child's illness was manifested in two ways: the emotional reactions of parents associated with shock, and their limited ability to function. When a child became chronically ill, parents described suffering from negative emotions such as fear, sadness, uncertainty, confusion, despair, panic, and denial. In addition, some were unable to obtain information, ask questions, or remember the information. Empowerment is about providing parents with sufficient information, the ability to manage the disease and satisfaction with education, and that children have positive experiences and learn to cope with the disease. Insufficient opportunities include situations where parents receive limited education, are forced to seek information elsewhere, are discouraged in their efforts to combat disease or where children have negative educational experiences.(Foster et al. 2016.)

The competence of nurses was assessed by mastering the knowledge and ability to care for children and families meant that the whole family situation was considered. The shock and emotional burden were alleviated by offering appropriate emotional support and encouraging patients to process their feelings. Collegial support was provided by informing about the activities of the Association of patients. In addition, cooperation with other professionals, such as doctors, social workers and occupational therapists, continued. Follow-up treatment after discharge was also arranged. Knowledge of the disease and its treatment was another core element of nursing competence. This included a deep, experiential knowledge of disease control, spanning the disease, symptoms, testing, and treatment. In addition, this knowledge was manifested in the skillful examination of children and the adaptation of disease management to normal daily life.(Kelo et al. 2013.)

Thus, parents of patients are a valuable source of information and can influence change of quality of the rendered services in nurse business to compensate failures and inefficiency of a health care system (Coyne2013; Vincent & Davis 2012).

## **7 Conclusion**

In conclusion, it is clear that parents who have a child with congenital heart defect are under great stress. It is known that parents make great efforts to get medical care of high quality in order to provide their child with appropriate treatment and hope organize a child's quality life. Nurses are considered as assistants and psychologists who support parents during surgical treatment and care after operation. Parents responded to nurses for their competence, tolerant, and kind attitude to the child. Despite the workload of nurses, parents appreciate nurses' skills in performing their work. They would also like to be in constant contact with the nurses for advice on the condition of the child.

However, parents noted some moments when a nurse could be more effective in teaching parents how to care about the child after the operation, explain the goal of the operation, and provide first aid in a critical situation. They also should be aware that nurses are not enough to meet the needs of the parents to care for the child.

As a result, the physician-nurse-based ethical-deontological standards adopted in Kazakhstan do not satisfy parents. The importance of changing this status is noted by the patients, as participants in the treatment process of their children are interested in the effectiveness and success of this process.

The following recommendations are suggested based on the results of this thesis study. First, the results of the study can be used for continuous education, training pediatric nurses to increase their knowledge about specific issues in caring for children with ChD.

Second, nurses need to clear up the exact duties and instructions about its competencies, on the basis of which it is possible to develop staff standards corresponding to the needs of a particular clinic in the context of development and implementation of an advance practice nurse. Third, the nurses have to study to



apply critical thinking and be responsible. The results of this study are limited because the study was conducted on the basis of a high-profile department of a city clinic. Such studies can be carried out on a larger scale as the results can affect the assessment of the quality of nursing care and show ways to improve it. It is recommended to be carried out by specialists outside the clinic as patients are a sensitive category and experience fear about expressing their opinion.

## References

- Andersona, C., Leahyb, M.J., DelValleb, R., Shermanb, S., & Tanseyc, T.N. 2014. Methodological application of multiple case study design using modified consensual qualitative research (CQR) analysis to identify best practices and organizational factors in the public rehabilitation program. *Journal of Vocational Rehabilitation*, 41, 87–98.
- Clarke, S. 2014. The value and contribution of qualitative research to inform nurse education and policy in response to the child's experience of hospital. *Issues in Comprehensive Pediatric Nursing*, 37, 153–167.
- Clarke-Pounder, J.P., Boss, R.D., Roter, D.L., Hutton, N., Larson, S., & Donohue, P.D. 2014. Communication Intervention in the Neonatal Intensive Care Unit: Can It Backfire? *Journal of Palliative Medicine*, 17, 1-5.
- Commodari, E. 2010. Children staying in hospital: a research on psychological stress of caregivers. *Italian journal of pediatrics*, 36, 36-40.
- Coyne, I. 2013. Families and health-care professionals' perspectives and expectations of family-centred care: hidden expectations and unclear roles. *John Wiley & Sons Ltd Health Expectations*, 18, 796–80.
- Curley, M.A., Hunsberger, M., & Harri, S.K. 2013. Psychometric evaluation of the family-centered care scale for pediatric acute care nursing. *Nursing research*, 62, 160-168.
- Espezel, H.J.E. & Canam, C.J. 2003. Parent–nurse interactions: care of hospitalized children. *Journal of Advanced Nursing*, 44, 34–41.
- Foster, M., Whitehead, L., & Maybee, P. 2016. The Parents', Hospitalized Child's, and Health Care Providers' Perceptions and Experiences of Family-Centered Care Within a Pediatric Critical Care Setting: A Synthesis of Quantitative Research. *Journal of Family Nursing*, 22, 6–73.
- Golfenshtein, N., Einav, S., & Medoff-Cooper, B. 2016. REVIEW ARTICLE Investigating Parenting Stress Across Pediatric Health Conditions - A Systematic Review. *Comprehensive child and Adolescent Nursing*, 39, 41–79.
- Hall, H.R., Neely-Barners, S.L., Graff, J.C., Kreek, T.E., Roberts, R.J., & Hankins, J.S. 2011. Parental stress in families of children with a genetic disorder/disability and the

resilient model of family stress, adjustment, and adaptation. *Issue in Comprehensive Pediatric Nursing*, 35, 24-44.

Harbaugh, P., Tomlinson, P., & Kirshbaum, M. 2004. Parents' perceptions of nurses' caregiving behaviors in the pediatric intensive care unit. *Comprehensive child and adolescent nursing*, 27, 163-178.

Homer, C.J., Marino, B., Cleary, P.D., Alpert, H.R., Smith, B., Robert, M., Brustowicz, M.D., & Goldmann, D. 1999. Quality of Care at a Children's Hospital. The Parents' Perspective. *Archives of Pediatrics and Adolescent Medicine*, 153, 1123-1129

Hoffman, J. 2013. The global burden of congenital heart disease. *Cardiovascular Journal of Africa*, 24, 141-145.

Hopia, H., Tomlinson, P., Paavilainen, E., & A°stedt-Kurki, P. 2005. Child in hospital: family experiences and expectations of how nurses can promote family health. *Journal of Clinical Nursing*, 14, 212-222.

Hsieh, H. & Shannon, S. 2005. Three Approaches to Qualitative Content Analysis. *Qualitative health research*, 15, 1277-1288.

Ingham-Broomfield, R. 2014. A nurses' guide to mixed methods research. *Australian Journal of Advanced Nursing*, 33, 46-53.

Kam, J., Panepinto, J.A., Brandow, A.M., & Brousseau, D.C. 2008. Parental perception of quality of hospital care for children with sickle cell disease. *Wisconsin Medical Journal*, 107, 131-135.

Kelo, M., Eriksson, E., & Eriksson, I. 2013. Perceptions of patient education during hospital visit – described by school-age children with a chronic illness and their parents. *Scandinavian Journal of Caring Sciences*, 27, 894-904.

Lam, J., Spence, K., & Halliday, R. 2007. Parents' perception of nursing support in the neonatal intensive care unit (NICU). *Neonatal pediatric and child health nursing*, 10, 19-25.

Latour, J.M., van Goudoever, J.B., Duivenvoorden, H.J., van Dam, N.A., Dullaart, E., & Albers, M.J. 2009. Perceptions of parents on satisfaction with care in the pediatric intensive care unit: the EMPATHIC study. *Intensive care medicine*, 35, 1082-29.

McCormick, M.C., Escobar, G. J., Zheng, Z., & Richardson, D.K. 2008. Factors Influencing Parental Satisfaction with Neonatal Intensive Care Among the Families of Moderately Premature Infants. *The Journal of Pediatrics*, 121, 1111-1118.

McLafferty, I. 2004. Focus group interviews as a data collecting strategy. *Journal of Advanced Nursing*, 48, 187-194.

Melion, K., Uzark, K., Drolar, D., Wemovsky, G., Newberger, J., Mahoney, L., & Marino, B.S. 2014. Health-Related quality of life outcomes in children and adolescents with congenital heart disease. *The Journal of Pediatrics*, 164, 781-788.

Mortensen, J., Simonsen, B.O., Eriksen, S.B., Skovby, P., & Dall, R. 2015. EMPIRICAL STUDIES: Family-centred care and traumatic symptoms in parents of children admitted to PICU. *Nordic College of Caring Science*, 29, 495-500.

- Newburger, J.W., Sleeper, L.A., Bellinger, D.C., Goldberg, C.S., Tabbutt, S., Lu, M., Mussatto, K.A., Williams, I.A., Gustafson, K.E., Mital, S., Pike, N., Sood, N., Mahle, W.T., Cooper, D.S., Dunbar-Masterson, C., Krawczeski, K.D., Lewis, A., Menon, S.C., Pemberton, V.L., Ravishankar, C., Atz, T., Ohye, R.G., & Gaynor, W. 2012. For the Pediatric Heart Network Investigators Early Developmental Outcome in Children With Hypoplastic Left Heart Syndrome and Related Anomalies The Single Ventricle Reconstruction Trial. *Circulation*, *1*, 2081-2091.
- Okunola, I., Olaogun, A.A., Adereti, S.C., Bankole, A., Oyibocho, E., & Ajao, O. 2017. Pediatric Parents and Nurses Perception of Family – Centered Nursing Care in Southwest Nigeria. *International Journal of Caring Sciences*, *10*, 67-76.
- Official for National Statistics. British Heart Foundation, upgrade 2018. ONS, London [Bhf.org.uk/heart-health/conditions/coronary-heart-disease](http://Bhf.org.uk/heart-health/conditions/coronary-heart-disease)
- Papastavrou, E., Efstathiou, G., Tsangari, H., Suhonen, R., Leino-Kilpi, H., & Patiraki, E. 2012. A cross cultural study of the concept of caring through behaviours: patients' and nurses' perspectives in six different EU countries. *Journal of advanced nursing*, *68*, 1026-37.
- Robertson-Malt, S., Chapman, Y.B., & Smith, V. 2007. The praxis clinical Knowledge: learning to care for pediatric patients with a congenital heart anomaly. *International Journal Nursing Practice*, *13*, 132-138.
- Roberts, P. & Woods, M. 2000. Alternative methods of gathering and handing data: maximizing the use of modern technology. *Nurse researcher*, *8*, 84-95.
- Rosa, R.C.M., Rosa, R.F.M., Zen, P.R.G., & Paskulin, G.A. 2013. Congenital heart defects and extracardiac malformations. *Revista Paulista de Pediatria*, *31*, 243-51.
- Ruggiero, K.M., Hickey, P.A., Leger, R.R., Vessey, A., & Hayman, L.L. 2018. Parental perceptions of disease-severity and health-related quality of life in school-age children with congenital heart disease. *Journal Specific Pediatric Nursing*, *12204*, 1-10
- Rasika, S. & Jayasekara, B.A. 2012. Focus group in nursing research: Methodological perspectives. *Nursing outlook*, *60*, 411-416.
- Schreier, M. 2012. Qualitative content analysis in practice. Thousand Oaks, CA : Sage.
- Salmani, N., Bagheri, H.S., & Mandegari, I.Z. 2017. Nursing Care Behaviors Perceived by Parents of Hospitalized Children: A Qualitative Study. *International Journal of Pediatrics*, *5*, 5379-5389.
- Sanjari, M., Shirazi, F., Heidari, S., Salemi, S., Rahmani, M., & Shoghi, M. 2009. Nursing support for parents of hospitalized children. *Issues in Comprehensive Pediatric Nursing*, *32*, 120–130.
- Sarapat, P., Fongkaew, W., Jintrawet, U., Mesukko, J., & Ray, L. 2017. Perceptions and Practices of Parents in Caring for their Hospitalized Preterm Infants Pacific Rim. *International Journal Nursing Research*, *21*, 220-233.
- Silva, V.G., Guimarães, T.C.F., Cavalcanti, A.C.D., Pereira, J.M.V., Queluci, G.C., & Santana, R.F. 2014. Terms of nursing: human responses of children hospitalized with heart disease – a cross-sectional study. *Online brazil journal nursing [internet]*, *13*, 162-170.

- Smith, M. 2011. Congenital heart disease and its effects on children and their families. *Pediatric Nursing*, 23, 30-35.
- Tayray, J. 2009. Art, science, or both? Keeping the care in nursing. *Nursing Clinics of North America*, 44, 415-421.
- Thornton, N. G. 1994. Congruence between parent satisfaction with nursing care of their children and nurses' perceptions of... *The university British Columbia, Thesis*, 86.
- Tomilnson, P.S. & McAlpine C.P. 2011. A family systems nursing intervention model for pediatric health care. *Journal of Advanced Nursing. Discussion paper*, 705-714.
- Tomilnson P.S., Tomilnson, E., Pedan- McAlpine, C.P., & Krischbaum, M. 2002. Clinical innovation for promoting families care in pediatric intensive care: demonstration, role, modeling and reflective practice. *Issue and innovation in Nursing Practice*, 38, 161-170.
- Tsironi, S., Bovaretos, N., Tsomakas, K., Giannakopoulou, M., & Matziou, V. 2012. Factors affecting parental satisfaction in the neonatal intensive care unit. *Journal of Neonatal Nursing*, 18, 183-192.
- Vincent, C. & Davis, R. 2012. Patients and families as safety experts. *Canadian Medical Association or its licensors*, 184, 15-16.
- Weerd, W., Tol, D., Albers, M., Sauer, P., & Verkerk, M. 2015. Suffering in children: opinions from parents and health-care professionals. *European Journal of Pediatrics*, 174, 589-595.
- Zani, A.V., Golias, C.A.R., Martins, F.S.T., Parada, G.L., Marcon, C.M., Pamplona, S.S., & Tonete, V.L. 2013. Feelings experienced by the family of an art-risk newborn infant: Integrative literature review. *Journal Nursing UFPE online*, 7, 269-78.

## Appendices

### Appendix 1.

### Open question for interview

#### introductory questions

- Tell me the reason entering in clinic? What did you feel when you learned that your baby is suffering from a heart condition?
- How do you think what to change your life in this situation?
- What kind of feelings did you experience during hospitalization to the clinic?

#### perceptions

- Could you describe how did you feel about nurses at hospitalization?
- With what feeling (perceptions) do you leave the clinic?
- Tell me about the behavior of nurses during hospitalization?
- What kind of perceptions did you experience during hospitalization to the clinic?
- How the nurse help you understand your feelings and concerns? care?
- How did the nurse take care of your child?
- Can you participate in the care of your child and how did the nurse react to it?
- How did nurse take of you child?
- How nurses pay attention to your situation as amother?
- With what feeling (perceptions) do you leave the clinic

#### Final question

- Is this an adequate summary?
- Have we missed anything?"

- What was your expectations of nurses?
- What kind of help did you expect from nurses?
- What are your expectations from them during treatment process of your child ?
- Expect that nurses would do to help you to manage in this situation?
- Tell me you expect the nurses be sensitive to your child's needs?
- What kind of care did you expect the nurses respond to your care and concerns?
- Can you expect the nurses to you about changes in your child's condition?
- What help do you expect from nurses when you leave the clinic?

#### expectations