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Research Article

Family-Centered Care from the Perspective of Pediatric Intensive Care Nurses

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Abstract

Objective: Family-centered care has a vital importance for the children and families especially in specialized units such as pediatric intensive care clinics. The aim of this study was to explore the perspectives of nurses regarding the practice of family-centered care.

Method: This was a qualitative study. Participations are nurses who were working in a pediatric intensive care unit of a hospital were included in the study. Using semi-structured interviews, data were collected from 12 participants. Each interview lasted for 30 to 60 minutes. Data were analyzed by using thematic content analysis.

Results: Three main themes and subthemes emerged following data analysis. First of main themes included children cannot be thought apart from their families. The second main theme included participation of the families is beneficial for everyone. The third main theme included the barriers and difficulties for family-centered care.

Conclusion: Nurses reported the benefits and difficulties association with the adoption of a family-centred care approach for children who were hospitalized in pediatric intensive care unit and their families. In the study, they emphasized that nurses required time to provide family-centered care effectively and it was necessary to raise specialized nurses to help them.

Keywords: Family centered care, pediatric intensive care unit, nurse.

INTRODUCTION

Family-centred care is a care philosophy that aims to provide for the health and well-being of the child through a family-professional association that focuses on understanding patients as part of a family and supports the participation of parents in the decision-making process regarding their children (Arango, 2011; Institute for Healthcare Improvement, 2018; Shields et al., 2006). Active members of family-centred care are families and healthcare professions, with both parties having strengths, cultural backgrounds, traditions and expertise included in the care of the patient (American Academy of Paediatrics, 2003; Wright and Leahey, 1990).

Family-centred care is based on the premise that the views and participations of the family and child are equally important the views and participations of healthcare professionals (Corlett and Twycross, 2006; Neal et al., 2007; Blake 1954; Knafl et al., 1988). Parents who participated in family-centred care could ask questions about the condition of their children, access information more easily, participate in the decision-making process and were better informed and more satisfied with the care their child received. Furthermore, improvements have been noted in patient safety and clinical outcomes when parents and children were included in care activities (Aronson et al., 2009; Cameron et al., 2009; Hovey et al., 2010; Longtin et al., 2010).

Family-centred care aims to change the shape of care given to children in the paediatric ICUs by putting the family into the centre of the care and providing care to the children in cooperation with the family (Just, 2005; Kuo et al., 2012). Thus, parents can communicate with healthcare providers, share information with them and play a role in the decision-making process regarding their children (Jacobowski et al., 2010). In a systematic review, sharing information with parents, hearing parental voices, making decisions for or with parents, individualizing communication and negotiating roles have been identified as key elements of family-centred care in the paediatric intensive care unit (Richard et al., 2017). Although defined key elements of family-centred care, paediatric intensive care units (ICUs) are the areas in which families have limited involvement and interaction with their children. Despite nurses play an important role in eliminating these limitations, sometimes nurses underlie these limitations. This is because nurses' attitudes toward family-centred care are not always positive, and the practice of family-centred care has not always been possible due to such difficulties as a discrepancy between nurses' and parents' perceptions of their roles, staff shortages, heavy workloads, time limitations, restrictive family presence and a poor understanding of family needs (Sisterhen et al., 2007; Butler et al., 2014).

In addition, there is also insufficient information in the literature about the practices regarding family-centred care in Turkey. Thus, it is obvious that there is also a lack of information about the experiences and difficulties of family-centred care in paediatric ICUs. Therefore, this study aimed to understand paediatric ICU nurses' perceptions of family-centred care practices.

METHOD

In this study used a descriptive qualitative design based on a phenomenological approach that was conducted to determine the views of the nurses working in a paediatric ICUs of a hospital, regarding family-centred care. The aim of choosing this design was to allowed participants to express their thoughts freely, researchers to gain rich information, the researcher to examine an event that the researcher cannot control and to determine experience about family-centredcare and what meaning they give

to this practice (Yıldırım and Şimşek, 2013; Matua, 2015).

Setting

Data were collected from nurses working in a paediatric ICUs in a hospital in the Aegean region of Turkey. In the unit where the study was done, there are 10 beds, one of which is in an isolation room. An average of 500 patients are admitted during a year. The children were admitted to the paediatric ICUs mainly due to respiratory disorders, need of mechanical ventilation or dialysis, life-threatening illnesses. The unit patient population has a wide range of diagnoses, ranging from cerebral palsy to suicide, ketoacidosis, acute and chronic renal failure. In recent years a wide range of ethnic children due to the increasing number of migrants coming into the country. A total of 14 nurses work in the unit. The majority of nurses (8 nurses) had bachelor's degree and no one had paediatric intensive care certificate. These nurses provided direct clinical nursing care. Each nurse provides care to three patients on average during their working hours. One or all of these patients may be receiving mechanical ventilator support.

The family visit hours of the clinic where the study is conducted are limited to 15 minutes per day for each parent. Parents receive information and visit their child within 15 minutes. Other family members (grandparents, siblings, etc.) are not allowed to visit. There is no place where parents can stay in a hospital or hospital. Families coming from outside of the city have to either return to their homes or to arrange accommodation.

Participants

For this study, a volunteer sample of nurses working in an paediatric ICUs at a hospital in Turkey were used to explore their personal thoughts and feelings. Inclusion criteria were voluntary participation, at least one year of work experience and at least six months working in the paediatric ICUs at the hospital. All nurses in the unit who met the inclusion criteria were invited to participate in the study.

Data Collection

The semi-structured interviews allow for in-depth examination of complex issues on an individual basis. This is an effective method to obtain information regarding the experiences, attitudes, views, complaints, emotions and beliefs of the individuals (Erdogan et al., 2014). Data were collected during in-depth face to face semi-structured interviews. Data collection process was semi-structured interviews were held with nurses who agreed to participate in the study, and data saturation was achieved after the 12th nurse. Nurses were provided information about the aim of the study before the semi-structured interviews were held, and they were told that the semi-structured interviews would be recorded using a voice recorder and that they could end the semi-structured interviews whenever they wanted. Semi-structured interviews with nurses who agreed to participate in the study were carried out in a silent room within the paediatric ICUs at a predetermined time. Semi-structured interviews were performed by a single researcher to provide standardization. Semi-structured interviews lasted between 30 and 60 minutes.

A semi-structured interview form was used during the semi-structured interviews for this study (Table 1). The form was sent to three paediatric nursing specialists for evaluation. Questions were revised as a result of the feedback.

Data Analysis

Data were analysed using qualitative content analysis as described by Graneheim and Lundman (2004). The aim of this analysis was to identify a concept that might explain collected data and the relationships between these concepts. Content analysis was carried out by

coding data, classification of data and finding themes, respectively (Erdogan et al., 2014; Braun and Clarke, 2006; Graneheim and Lundman, 2004; Cohen et al., 2011).

Firstly, the semi-structured interviews were transcribed verbatim, after the researchers carefully listened to them. The verbatim transcripts of 12 semi-structured interviews covered 93 A4 pages with 1.5-line spacing. Then, the transcripts were carefully, repeatedly and separately read by three researchers. Based on the aim of the study 'meaning units' were extracted from the material to ensure each meaning unit could provide understandable context. Then, they abstracted, and every meaning unit received a code of meaning. After that, they compared the codes in terms of their similarities and differences and arranged them into to represent the content. The next step, categories were identified, which reflected the content (Table 2). Based on these categories, the authors identified three themes (Table 3).

Table 1. Interview Guide.

-What do you think about family-centred care?
-Are paediatric ICUs suitable units for family-centred care?
-Can you tell me about your family-centered care practice experiences? Please tell us what happened. Can you describe how it felt?
-What are the barriers for the implementation of family-centred care? What was the obstacle? Can you describe how it felt?
-What are the benefits of family-centred care? What did you feel as you saw the benefits of family-centered care practice? Can you describe how it felt?
-What are your views about parental participation in the care activities of their children?
-What are your views about parental participation in the nursing bedside rounds?
-Supplementary questions:
*Can you tell me more?
*Can you clarify?
*In what way?

Table 2. Example of meaning units and categories.

Meaning units	Categories
The child begins crying along with calling mother and father from the first minute. They continuously smile and talk when their mothers come; they do not talk and they pull a long face when they go *Most of the time, it is not possible for me to understand the child as his/her family Especially with children who cannot express themselves, families can understand easily what she/he wants from a look or sound from the child.*	child's need for family

Table 3. Analysis themes, subthemes, and categories.

Themes	Subthemes	Categories
Children cannot be thought of as separate from their families		Child's need for family The importance of the family for the child Family and child desire to be together
Participation of the families is beneficial for everyone		Beneficial for child Beneficial for parent Beneficial for nurses
Barriers and difficulties to establishing family-centred care	Lack of sufficient time Cultural variability and immigrants	Extreme workload Shortage of nurses Families' different care practices Language issues

Validity and Reliability

Analysis of the data was conducted independently by more than one researcher and combined thereafter. Data were recorded and listened to at least two times to include correct statements while generating transcripts. The data collection process continued until data saturation was reached. All semi-structured interviews were conducted by a single researcher (Yıldırım and Simsek, 2016).

RESULTS

Participants

The age of the nurses was between 22 to 49 years old, and the mean age of nurses was 30.66±7.52 years. The duration of work experience varied between 6 to 14 years, and the mean duration of work experience was 5.25 ± 4.30 years.

Interview

Data analysis identified three main themes. The first main theme was that children cannot be thought of as separate from their families. Almost all the nurses included in the study put emphasis on a widely accepted view in Turkish culture that 'family becomes a family with a child, and the child cannot be thought of as apart from his/her family'. The second main theme that emerged was that participation of the families is beneficial for everyone. It was emphasised that children who were treated in ICUs had limited contact with their families, and this negatively affected them; therefore, family-centred care was very crucial. Moreover, frequently informing the family of the well-being of children under 18 years old for legal authorisation was reported to as one of the reasons the nurses preferred family-centred care. The third main theme included the barriers and difficulties to establishing family-centred care. Nurses described the difficulties in monitoring and controlling care provided by the families within the intensive care environment and that the training period was very time-consuming. It was observed that family participation caused fear, anxiety and stress for the nurses. Furthermore, it was indicated that immigrants and cultural variability in Turkey also caused difficulties in the practice of family-centred care.

Children cannot be thought of as apart from their families

All the nurses declared that children cannot be thought of as apart from their families; thus, they cared about family-centred care.

"First, the child begins crying along with calling mother and father from the first minute. They have difficulties at each procedure and they say that they want their mother beside them. It is impossible to keep the child apart from their families. Also, families always ask about their children. When you integrate the family into the

care, both sides become more comfortable and you can work easily" (Nurse 5).

Also, since the families know their children better, it was a common belief to think that they are the best decision makers on their child's behalf.

"*Especially with children who cannot express themselves, families can understand easily what she/he wants from a look or sound from the child. I have to try to find out what to do for child for minutes. Most of the time, it is not possible for me to understand the child as his/her family. I wish it would be possible to have families in the unit all the tim*"" (Nurse 2).

Nurses often stated that family-centred care allowed the child to calm down and discharge from hospital more quickly. It was indicated that children felt comfortable and safe with their families and rejected communication when their families left.

"*They continuously smile and talk when their mothers come; they do not talk and they pull a long face when they go.… Sometimes they do not even want to eat food. It is not only conscious patients; there are also unconscious children whose saturation levels drop and experience respiratory/cardiac arrest when their families go. In fact, older nurses always tell [the story] that once they called the family of a one-year-old child when his condition got worse, and [then] all vital findings of the child returned to normal. Family has such magical effects*" (Nurse 9).

Therefore, the participation of the families in all treatment procedures and care and their interaction with their children is highly important.

Participation of the families is beneficial for everyone

Participation of the parents in the decision-making process and care makes them feel more self-confident and important. Thus, they can better understand and interpret the health conditions of their children. This also enables them to prepare for any deterioration that may occur. Moreover, they can observe and interpret the changes in their children themselves day by day. Their active participation in the clinic allows them to experience less stress when discharge approaches.

"*While [a] mother who provides care for her child is scared of touching when she first comes, then she starts doing [it] with asking us. Families who continuously ask questions about [the] health conditions of their children become families that give information to us regarding their children. Especially when [the] discharge period approaches, we can discharge comfortably. Anyway, [the] family keeps control over the whole situation*" (Nurse 11).

"*I wish we [could] discharge each child who is hospitalised in intensive care in healthy state, but we also have losses. Families can become aware of the course of their children and interpret [it] due to family-centred care. They can accept their losses more quickly*" (Nurse 12).

"*Once a family thanked us very much; thanks to us that they could see their child, touch her and stay besides her... Families feel better in spiritual ways due to family-centred care*". (Nurse 3)

Nurses stated that children did not experience feelings of abandonment and separation anxiety when their families took care of them.

"*Some children think that they are abandoned here since they have been naughty. Being in contact with their families continuously relieves them and us*" (Nurse 6).

In addition, family-centred care is considered beneficial to the nurses because consent cannot be given from individuals under 18 years of age according to the laws in Turkey.

"*I am not stressed during the consent process since the family knows the whole process in*

family-centred care. It provides legal protection for us" (Nurse 8).

"*It becomes easier to obtain consent with family-centred care because families know what we need to do and when*" (Nurse 10).

Barriers and difficulties to establishing family-centred care

Nurses often mentioned barriers and difficulties in implementing family-centered care. The analysis of these barriers and difficulties resulted in two sub-themes. These two subthemes are 1) lack of sufficient time and 2) cultural variability and immigrants.

1. Lack of sufficient time

In Turkey, nurses work varying shifts and with varying number of patients. They generally work between 08:00-16:00 during daytime and between 16:00-08:00 during the night. ICUs have a more complex structure compared to the other wards. In our study, almost all the nurses declared that they had difficulties in completing the routine work of the unit, so they could not find sufficient time to deal with the families.

"*Sometimes I cannot find enough time to eat a meal; how can I inform the family and integrate them into care?*" (Nurse 1).

"*Actually, I would like to tell you, but you may not believe. Sometimes I cannot finish my work although I work without any rest all day. It would be great if nurses, who are specialized in family-centred care, are provided. In the unit, it is impossible for us to provide that*" (Nurse 10).

"*Time… I wish to have more, and then we can do the best of everything"* (Nurse 4).

The nurses also indicated that more time was needed to provide education and thereafter.

"Providing education for family-centred care means making observations during the practices, and all of this means time" (Nurse 6).

2. Cultural variability and immigrants

Nurses stated that families having distinct cultural characteristics were coming to the unit, and all of them had different requests and expectations. It was declared that the presence of different practices in each culture was making the practice of family-centred care impossible.

"We try to support the participation of the families with distinct cultures in family-centred care, but this is very difficult in our culture. Once we gave information to a mother as we wanted her to participate in care. She said that she would not do that without getting permission from her husband, and we waited for consent from her husband for two hours" (Nurse 1).

"Sometimes when we turn our back, they start performing different practices. There has not been so much since I came here, but I saw many distinct practices. For that reason, it is sometimes risky to include family in the care. Once a mother tied the waist of the baby very tightly without asking us" (Nurse 10).

Moreover, the presence of immigrants prevents family-centred care due to language barriers.

"Sometimes I pass on including them in the care. I just wish to be able to communicate with them. How can I inform that family and provide [an environment] for their participate?" (Nurse 6).

DISCUSSION

Paediatric ICUs in Turkey are clinics that include a great number of beds and do not have space for the families to stay beside their children. Therefore, families can see their children only during the visiting times determined by the units. This may cause families to experience negative feelings of stress, frustration over prevention, exclusion and inability to help their children. Children are cared for by different nurses during the day and can only see their families for a limited period of time. This causes children to experience separation anxiety and feelings of abandonment (Çavuşoğlu, 2011; Meert et al., 2013). Therefore, it is highly important to provide

family-centred care, especially in the paediatric ICUs in our country. Three main themes emerged at the end of this study that was performed to identify the perspectives of nurses working in paediatric ICUs regarding family-centred care. Themes described the views of the nurses regarding the practice of family-centred care and the barriers for its practice.

Family-centred care results in a decrease in the stress of individuals, makes them ready for the period after discharge, decreases the duration of hospitalization and reduces the level of depression following discharge (Saunders et al., 2003). Since the approach of family-centred care allows parents to pay closer attention to the care of their children and to become informed, families become more competent and feel more sure of themselves (Franck and Spencer, 2003; Peterson et al., 2004). In the results of one study, there was a decrease in anxiety and negative thoughts with the inclusion of paediatric patients' families in clinical practices, and this resulted in a respect-based relationship brought about by enhanced cooperation between the family and the healthcare team (Meuthing et al., 2007). A small, randomized, controlled trial in a PICU also found that parents preferred bedside rounds and felt more well-informed when they were present for rounds (Landry et al., 2007). The nurses included in our study advocated for the view that family-centred care was beneficial for everyone. Similar to the literature, at the end of our study, according to the views of the nurses, it was found that parental participation in the decision-making process and care allowed the parents to feel more self-confident and important, and their active participation in the unit allowed them to feel less stress when discharge approached. Besides its benefits for the parents, family-centred care was also found to be beneficial for the nurses in legal terms since individuals under 18 years of age are not authorized to provide consent according to Turkish law. Tomlinson et al. (1999) reported that parents' responses to surrendering their primary caregiving role in the PICU were not only affected by how nurses supplemented their role, but by how effectively nurses aided them in retaining their role as a parent. So As a result of our study, it was very important for nurses to consider family-centered care as useful. In the study performed by Boztepe and Kerimoğlu-Yıldız (2017) paediatric ICUs nurses stated they had positive views about the participation of parents in their children's care activities. Despite these positive findings that paediatric ICUs rarely use FCC activities and family presence in paediatric ICUs continues to be a topic of debate. (Macdonald et al., 2012).

In the study performed by Shields and Nixon (2004), the results indicated that nurses who were working in developing and developed countries accepted the continuity and importance of the presence of family in a child's life. Similarly, in our study, nurses emphasised that the main feature of a family was having a child, and the children should never be considered as apart from their families. Coyne (2015) reported that nurses exhibited a positive attitude toward family-centred care, and they supported the help from the parents in childcare and in some nursing care practices when required. Also, the nurses in our study reported that they found family participation in care positive due to the inability of obtaining consent from the children under 18 years old and the magical effects of the families on the children. Also, in the other studies, it was reported that parental support was necessary to manage the responses of the children and to provide a positive hospital experience (Roden 2005; Boztepe and Kerimoglu-Yıldız, 2017).

In previous studies, barriers for family-centred care were reported to be resistance of the nurses, the view that it might cause infections, violations of patient confidentiality, heavy workload of the personnel, deficiencies of newly graduated nurses regarding family-centred care and the

physical features of the clinic (Maxton, 1997; Benzein et al.,2008; Petersen et al.,2004; Subramony et al., 2014). In this study, two subthemes, lack of sufficient time and the impact of cultural variability/immigrants, emerged in the theme regarding barriers to practising care In similar studies, nurses reported that they did not have enough time to focus on the psychosocial needs of the parents and patients (Foster et al., 2010; MacKay and Gregory, 2011). In a study conducted in different countries there were also some barriers for providing family-centered care: lack of knowledge, small number of nurses, and lack of institutional family-centered care policies (Feeg et al., 2016).

Different from the literature, problems such as communication problems due to the use of different languages by the immigrants or an inability to strike a balance in clinical care as a result of distinct cultural practices due to cultural variability were described as barriers for practising family-centred care in our study. According to the data of the Turkish Red Crescent, a gradual increase was observed in the number of foreigners in our country during the last ten years; and a total of 3.258.207 people were given a residence permit (Turkish Red Crescent, 2017). Since people who come from various countries have their own languages and practices, nurses define these situations as barriers to the implementation of family-centred care practices. Nurses' willingness to provide family-centered care and strengthening communication with families helps eliminate family-centered caregiving barriers (Feeg et al., 2016).

CONCLUSION

The results of this study show that although nurses accept the benefits of family-centred care for everyone for everyone and the necessity of practising it, barriers prevented it from occurring. Barriers such as insufficient time and language and cultural variability related to the large increase in migrant population in Turkey over the past 10 years, negatively affected nurses providing family- centred care. An international increase in migrant population over recent years, will likely affect paediatric ICUs throughout the world; effectively overcoming barriers to patient-centred care, particularly in the migrant population, is an important subject for future research.

Limitations of the Study

There are some limitations in the study. One limitation is that the results of qualitative study findings cannot be generalised to all PICU nursing in Turkey, with the results being specific to the context of the study (Streubert and Carpenter, 2011). Another limitation was that the study was done in just one hospital.

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