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The Views of Parents of Premature Babies Hospitalized in Neonatal Intensive Care Unit about the Implementation of Family-Centered Care in This Unit

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ABSTRACT

Background and Objective: Family-centered care is a new healthcare standard that allows parents to be involved in their baby's healthcare. Considering that parents play an important role in caring for the baby in the hospital as well as at home after discharge, family-oriented care is always emphasized. Therefore, the aim of this study is to investigate the viewpoint of parents of newborns hospitalized in neonatal special care unit about the implementation of family-oriented care in this unit.

Methods: This cross-sectional study was conducted on 100 mothers and fathers of newborns hospitalized in the neonatal intensive care unit of selected hospitals of Shahid Beheshti University of Medical Sciences in Tehran. After obtaining informed consent, the researcher completed the questionnaires in a period of three months by explaining the objectives of the research as well as family-oriented care in groups and individually. The demographic information of the parents and the newborn was collected and analyzed using a researcher-made questionnaire to examine the views of the parents in different areas about the implementation of family-centered care in the neonatal special care unit.

Findings: The mean score of the questionnaires for the mothers of babies was 172.7±19.8 and the mean score of the questionnaires for the fathers was 152.5±30.9. In the area of education and information provision, the mean score of mothers was 49±3.5 and the mean score of fathers was 42.6±3.5; mothers score was significantly higher than that of fathers ($p<0.001$). In the area of respect for parents' rights, the mean score of fathers was 16.7±1.6 and the mean score of mothers was 11.3±5.8; in this area, the mean score of fathers was significantly higher than the score of mothers ($p<0.001$). In other areas, there was no statistically significant difference between the views of fathers and mothers.

Conclusion: The view of fathers and mothers in the field of family-centered care in special care units for newborns has been positive and satisfactory. This shows the necessity of different programs in order to improve the views of fathers and mothers.

Keywords: *Family-Centered Care, Premature Baby, Parents, Neonatal Intensive Care Unit*.

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Introduction

After major improvements in care and medical equipment in the Neonatal Intensive Care Unit (NICU), the survival of premature babies has increased significantly (1). Parents of premature babies experience stress, anxiety, helplessness, and depression and find the NICU environment alien and scary (2, 3). Therefore, the family is considered an integral part of newborn care in the neonatal intensive care unit. Family-Centered Care (FCC) is a mutually beneficial and cooperative partnership between the patient, the family, and the health care system. Involving parents in active caregiving activities enables them to feel more supported, have a better relationship with their infants, and also increases their self-confidence in the area of infant care (4, 5). Research has shown that family-centered care results in better growth parameters at discharge and shorter NICU stays. Babies who receive the necessary care in the NICU with family support show better neurological responses such as reduced physiological stress and less pain (6). Parents have a positive perception of family-centered care and feel competent to care for the infant and prepare for discharge (7). The health system will benefit from a better connection between parents and babies through family-centered care in order to reduce the hospitalization time in the intensive care unit and the necessary preparation for discharge and post-discharge care (8, 9).

In the last few decades, so much emphasis has been placed on the implementation of family-centered care in the pediatric and neonatal departments. As the first principle, the physical presence of parents and participation in the care of the baby form the basis of family-centered care. In this regard, the family-centered care is defined as the provision of care and partnership services between clinical and therapeutic staff and the baby's family. Family-centered care is implemented with the aim of supporting the family to reduce their stress, develop parenting skills, develop the psychological relationship between parents and the baby, and also with the aim of improving the recovery process of the baby's physical condition (10, 11). Maintaining parents' attachment to the baby, considering the preparation of parents for post-discharge care, parents' participation and familiarity with the needs of premature babies and their support are the most important issues that have been considered in family-centered care (6, 12).

The combination of a special care plan for newborns with family-centered care plus a culture of care can reduce health care costs by shortening hospital stay and infant morbidity (13). Family-centered care is directly the best way to provide newborn care in the hospital environment, and this type of care has been implemented in different ways (14). Family-centered care includes evaluating the level of knowledge and ability of parents to care, unlimited visitation schedule for parents, clear definition of family members including parents, siblings, grandfather and grandmother, entrusting the pain relief of the baby to the parents, feeding, bathing, changing diapers, hug care and creating continuous interactions between parents and babies and providing a healthy environment in the ward (light, sound), group cooperation and evidence-based care policy. Another principle of family-centered care emphasizes that caregivers should actively pay attention to the individual needs of parents and understand these needs (15, 16). Active listening allows caregivers to provide comprehensive and unique instructions to parents and infants based on the infant's specific care and treatment conditions (4). Caregivers on the care team should consider parents as providers of important information and treat parents as equal to professional caregivers in infant care. The safety of infants and families is threatened without family-centered care (17). Also, family-centered care is both a method of providing care and a philosophy that values the vital role of the family in ensuring the health and well-being of the child, planning and providing care for the whole family, collaborative work of the family and providing complete and continuous services (14).

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Several findings have shown that premature babies who have received family-oriented care, their neurological and physiological functions have been strengthened and they have also experienced better sleep quality (18, 19). On the other hand, family-centered care helps to better understand the clinical training of parents, reduce stress and increase parental satisfaction. Caring for a premature baby leads to physical fatigue and exhaustion of the parents and overshadows the psychological aspects of the parents. Family-centered care causes attachment and dependence of parents towards the baby, and this improves parents' participation in care and family integrity (20, 21).

Family-centered care strengthens effective communication between parents and nurses and increases parental understanding. Mothers who have participated in the care of their babies have better self-efficacy, and their babies spend less time in the neonatal intensive care unit, and as a result, reducing the length of hospitalization reduces the nurses' workload (13, 22).

The implementation of family-oriented care, emphasizing the presence of family members, especially the father beside the mother, leads to the improvement of the premature baby's family performance more than the usual care methods. This intervention is cost-effective, feasible, practical and effective, and the effective participation of parents in taking care of the baby will have positive effects on his/her recovery process (19). Therefore, from this point of view, the parents' perspective on family-centered care becomes necessary.

Due to the high importance of family-centered care principles from the parents' point of view, it can be concluded that following these principles and providing care in a family-centered way can meet the care needs of parents and their hospitalized babies and increase their satisfaction with the care system (6). Various studies have been conducted on family-centered care in the population of premature babies, but research has not been done on the parents' point of view, so this study was conducted with the aim of determining the parents' point of view about the implementation of family-centered care in neonatal intensive care units.

Methods

After being approved by the ethics committee at Faculty of Nursing and Midwifery of Shahid Beheshti University of Medical Sciences with ethics code IR.SBMU.PHNM.13690858, this cross-sectional study was conducted on 100 mothers and fathers with premature babies admitted to neonatal intensive care units in selected hospitals of Shahid Beheshti University of Medical Sciences in 2019. Mothers and fathers with premature babies hospitalized in the intensive care unit for at least more than 48 hours and at most one week, gestational age of 34-37 weeks with a weight of at least 1500 kg, not suffering from mental illness such as depression and anxiety according to the parents themselves, willingness and ability to participate in the research, reading and writing literacy and completing the informed consent form were included in the study, and if the baby died and the parents withdrew from the study, they were excluded from the study. In this study, convivence sampling was adopted. To determine the sample size at the error level of α=0.05 and test power of 80% (β=0.2) and 0.3 minimum value of the correlation coefficient for significance of the relationship in the hypothesis test of ρ=0 versus $0 \neq \rho$, and considering 10% additional samples due to the possible loss or distortion of the questionnaires as well as the sampling conditions (presence of corona virus), 100 people were selected to participate in the sample (23).

After obtaining the necessary permissions from the research assistant and department supervisors, the researcher attended the neonatal intensive care unit in Mahdieh and Mofid hospitals every day in three shifts, morning, evening, and night. After obtaining informed consent from the parents, the researcher gave the necessary explanations about the research objectives and the concept of family-centered care individually

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and in groups for the parents. In addition to these explanations, the questionnaire questions were also explained to the parents. Information was collected using a demographic information questionnaire and a researcher-made questionnaire to examine parents' views on the implementation of family-centered care in neonatal intensive care units. The demographic questionnaire includes questions about the age of the mother/father, education of the mother/father, occupation of the mother/father, number of children and gender of the baby. The questionnaire for examining the views of parents about family-centered care was designed according to the review of the literature and also based on the specific culture and attitude of Iranians. This questionnaire contains 52 questions in seven areas of parents' views on physical care of the baby, education and information provision, facilities and amenities, emotional and spiritual support, participation in decisions and care, preserving family integrity and respecting the rights of parents. The options in this questionnaire are always (4), often (3), sometimes (2) and never (1). The overall score of the questionnaire is between 52-208, the higher the overall score of the questionnaire, the more positive the parents' view of family-oriented care in the neonatal intensive care unit.

In addition, in regard with parents' views on the physical care of the baby in the family-oriented care process, the maximum score is 20 and the minimum score is 5. In the area of parents' opinion about education and information provision, the maximum score is 56 and the minimum score is 14. In the area of parents' opinion about facilities and amenities, the maximum score is 36 and the minimum score is 9. In the area of parents' opinion about emotional and spiritual support, the maximum score is 44 and the minimum score is 11. In the area of parents' opinion about maintaining family integrity, the maximum score is 16 and the minimum score is 4. In the area of parents' views about respecting parents' rights, the maximum score is 20 and the minimum score is 5.

In this study, the validity of the questionnaire was examined by 14 mothers and fathers of premature babies admitted to the hospital and in order to determine the face validity of the tools and evaluate the simplicity and clarity of their expressions, 5 faculty members and professors of the Faculty of Nursing and Midwifery of Shahid Beheshti and Tehran Universities of Medical Sciences were consulted.

The content validity index (CVR) of the questionnaire created by the researcher with the cooperation of 8 academic staff members was determined to be 75% and the content validity index (CVI) of the questionnaire was determined to be 87% with the cooperation of the same 8 academic staff members.

In order to determine the reliability of the internal homogeneity of the tools, Cronbach's alpha coefficient was calculated with the cooperation of 10 fathers, mothers and babies hospitalized in neonatal intensive care units, and it was determined to be 0.82. The obtained data were analyzed in SPSS 21 using independent t-test, and $p<0.001$ was considered significant.

Results

The results of findings related to demographic information showed that the minimum age of mothers of hospitalized babies is 15 years and the maximum age is 41 years, and the minimum and maximum age of fathers is 19 and 42 years. Most of the parents of babies hospitalized in neonatal intensive care units had high school diploma (42.5%). Most of the mothers (82%) who participated in the study were housewives and most of the fathers (78%) were self-employed (Table 1). The results related to the mothers' views showed that the mothers of hospitalized babies gave the highest score to the area of education and information provision and the lowest score to the area of respect for parents' rights. Also, the scores of the areas, in order from the highest to the lowest, include education and information provision, physical care of the baby, participation in decision-making and care, maintaining family integrity, emotional and spiritual support, facilities and amenities, and respect for parents' rights (Table 2).

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Table 1. Demographic information of mothers, fathers and babies

Variables	Frequency distribution
Gender of the baby	
Girl	55
Boy	45
Education level of mother and father	
School	32.5
High school diploma	42.5
Bachelor's degree	20
Masters and above	0.05
Mother's employment status	
Housewife	82
Employee	14
Self-employed	0
Other	4
Father's employment status	
Unemployed	0
Employee	22
Self-employed	78
Other	0

Table 2. Determining and differences in the views of fathers and mothers of newborns regarding the implementation of family-centered care in neonatal intensive care units

Area	The minimum and maximum score of each area in the questionnaire	Score Mean±SD	p-value
Physical care of the baby			
Mother	5-20	17.27±1.9	>0.001
Father		16.55±1.5	
Education and information provision			
Mother	14-56	49±3.5	<0.001
Father		46.25±3.5	
Facilities and amenities			
Mother	9-36	27.86±3.5	>0.001
Father		27.5±3.8	
Emotional and spiritual support			
Mother	11-44	35±5	>0.001
Father		34.27±4.9	
Participation in decision making and care			
Mother	4-16	13.68±6.1	>0.001
Father		13.5±2	
Maintaining family integrity			
Mother	4-16	13±2	>0.001
Father		13.4±2.2	
Respect for parents' rights			
Mother	5-20	11.34±5.8	<0.001
Father		16.77±1.6	
Mean score of the questionnaire			
Mother	52-208	172.7±19.8	<0.001
Father		152.5±30.9	

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The results of the opinion of fathers about the implementation of family-centered care showed that the fathers of hospitalized babies assigned the highest score to the area of respect for parents' rights and the lowest score to the area of facilities and amenities; the scores of the areas, in order from the highest to the lowest, include respect for parents' rights, physical care of the baby and education and information provision, participation in decision-making and care and preservation of family integrity, emotional and spiritual support, and facilities and amenities (Table 2).

The results of the comparison of mothers' and fathers' views showed that the mean score of the questionnaire and the area of education and information provision was higher in mothers than in fathers. Moreover, regarding respect for parents' rights, the mean score of fathers is significantly higher than that of mothers ($p<0.001$) (Table 2).

Discussion

The results of the data analysis showed that the mothers of babies hospitalized in special care units assigned the highest score to the field of education and information provision and the lowest score to the field of respect for parents' rights. It is noteworthy that the mean scores of mothers' questionnaires in these two areas are far from each other.

In fact, it seems that the efforts of the care and treatment team to share information with mothers of hospitalized babies have been successful. Of course, it is necessary to pay attention to the fact that education is a continuous and step-by-step process that no matter how much effort is made in this field, there is still some lack of information and knowledge and more work should be done in this field.

In this regard, a study by Akbarbegloo et al. showed that the amount of communicative-informational and also emotional support had the highest mean score (24). In a study by Negarandeh et al. that is not in line with the present study, mothers stated that education, information provision, and answers to their questions about treatment and care are not enough (25).

In a study by Marino et al., the availability of nursing personnel when needed to answer parents' questions and concerns, honesty in caregiving, answering questions at the level of families' understanding, giving importance and attention to caregiving skills and parents' suggestions, involving parents in health care, timely response to the needs of the baby and the family, and education during the discharge of the parents have brought the most satisfaction to the patients' families (26). Contrary to the present study, the results of a study by Rasti et al. showed that most parents did not have enough knowledge and information about the baby, and solving these needs can help them have a better sense of control over the conditions. Understanding these needs also helps the baby care and treatment team to provide better services to the parents and the baby (27).

Also, another point that needs attention in the results of the present study was that in the category of family-oriented care areas, the mothers of hospitalized babies assigned the lowest score in the area of respect for parents' rights. This result reveals two issues; First, mothers are aware of their rights and express their dissatisfaction if these rights are neglected, and secondly, it seems that the care and treatment team need to be more aware of the dimensions of parents' rights and how to protect these rights. In this context, Vasli et al. in their qualitative study point out that the role of mothers in family care is not clear from the nurses' point of view (28).

The results of the present study on the fathers' point of view showed that the fathers of hospitalized babies assigned the highest score to respect for parents' rights and the lowest score to facilities and amenities. In the study of Abdeyazdan et al., focusing on the support of parents of newborns hospitalized in the neonatal intensive care unit, consistent with the present study, fathers in the qualitative study expressed their most

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important challenges as emotional support and the need for information (29). In this regard, in the study of Rasti et al., the need to acquire knowledge and skills was one of the most important needs mentioned by parents (27).

The fact that fathers assigned the lowest score to the field of facilities and amenities indicates that in hospitals, mothers' rooms and beds and welfare facilities are provided to mothers, even to a small extent. But in cases where fathers are allowed to be in the neonatal intensive care unit, they stand next to the incubator and watch the baby. In fact, the results of this study emphasize paying more attention to fathers in the special care department of newborns in all dimensions, especially in the field of facilities and amenities.

The results of the statistical analysis in the present study in comparing the views of fathers and mothers about family-oriented care showed that the mean score of the questionnaire in mothers and fathers has a significant positive difference. In other words, mothers' view of family-oriented care is significantly more positive compared to fathers. In addition, mothers' views were more positive in the area of education and information provision, and fathers' views were more positive in the area of respect for parents' rights.

The results of a study by Værland et al. showed that fathers gradually expand their relationship with children, and fathers who spend more time in the intensive care unit better understand the child's condition and experience less mental and emotional stress (30). This article shows that the point of view of fathers may be different from that of mothers. Therefore, this research is consistent with the present study. In another study aligned with the current study conducted by Terp et al., the findings showed that the mothers' point of view is slightly different from the father's point of view, but the existing differences were not mentioned (31).

In this study, the experiences of the nurses in the neonatal intensive care unit indicate that the care and treatment team in our country still recognize the mother as the baby's companion and usually consider the father as a visitor. Therefore, this difference in parents' views in this field can be justified. In addition, it seems that mothers themselves are more willing to participate, learn and care, which can be rooted in the specific culture of our country, which considers the mother to be responsible for taking care of the baby and the father to be responsible for financing the family. In fact, this social culture has an impact on both the mothers and fathers' point of view and the care and treatment team's point of view, which are members of this social and cultural context. According to the mentioned reasons, the positive view of mothers compared to fathers can be justified.

The results of this study show that despite the great emphasis on the implementation of family-centered care in neonatal intensive care units and its proven positive impact on all aspects of the existence of the infant and the family, this issue still faces challenges in its implementation. In fact, from the parents' point of view, the implementation of different care-oriented aspects needs investigation, goal-setting, planning, targeted interventions and more accurate evaluation for reducing the existing challenges. Parents should know that they are members of the care team and the care team should accept the parents as members of the team. Besides, it is necessary to pay attention to the differences in the views and needs of fathers and mothers and to consider this difference in views and needs in planning.

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