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Effect of Family-Centered Care on Maternal Caring Burden in Premature Infants Admitted to Intensive Care Unit

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ABSTRACT

Background: Birth of a preterm newborn profoundly challenges the mother to play her parenting role. The care burden of the mother affects the entire family system. This study aimed to identify the impact of family-centered care on the care burden of mothers with preterm newborns hospitalized in neonatal intensive care unit (NICU).

Methods: In this quasi-experimental study, 59 mothers of preterm newborns hospitalized in the NICU of the Hafiz hospital in Shiraz,Iran, were assessed. A four-stage family-centered care program was implemented in the first seven days of the infant's hospitalization. The control group received routine care. The amount of care burden of the mothers was measured using Caregiver Burden Scale (CBS). The control and experimental groups filled out the questionnaire at the baseline (third day after admission) and the seventh day after hospitalization.

Results: After the intervention, the mean score of care burden in mothers in the control and experimental groups were 62.73 ± 7.44 and 58.13 ± 8.17, respectively. The mean score of care burden in mothers in the experimental group was significantly lower than before the intervention. The results of the univariate analysis of covariance (ANCOVA) showed a significant difference in mean scores of care burden and their subscales in two groups (P=0.04).

Conclusion: Family-centered care reduces the care burden of mothers of preterm newborns by emphasizing the helpful presence of the other family members, especially fathers in the NICUs. The family-centered care approach is effective and it has positive effect on parental involvement in the care of the newborn on the process of recovery.

Introduction

Annually, 15 million preterm births happen. Preterm birth means any pregnancies that end before 37 weeks.[1]In recent decades, the survival of newborns has increased due to advances in knowledge and technology of medical care in NICUs (neonatal intensive care unit).[2] In modern day care approaches, part of the care of a preterm newborn is entrusted to family members, especially mothers. However, mothers and other family members may not be ready to take on this responsibility, which may take time.[3]The burden of care is defined as the physical, psychological, social, and economic responses to the stress or negative experiences during the long period of caring.[4]

Preterm birth affects the role of mothers and the natural process of taking on the parenting role.[5] The stress and anxiety resulting from the uncertainty about the survival and health of the baby influences the acceptance of the mothering role and providing proper care to the infant.[6] During the first months of life, unsuccessful attempts by mothers establish a responsive, intimate, and caring relationship which can lead to stress, anxiety, a feeling of frustration, and a care burden.[7] According to evidence, social support is an influential factor with a positive effect on the care burden.[8] There is a negative correlation between the level of care burden and mothers' well-being.[9] According to Lee and Kimble (2009), mothers' emotional responses cause fatigue, fear, and helplessness, and most of them do not know how to manage and deal with them. A successful adaptation to these health responses is unlikely without the support of other family members.[10]

Family-centered care is an innovative approach to health care planning, implementation, and evaluation based on mutually beneficial collaborations between patients, families, and health care providers. Family-centered care changes the role of parents in caring for their newborns, and involves them effectively in the process of care. In the family-centered model of care, each patient and the patient's family form a care unit.[11]

The opportunity of being with the newborn in the NICU has many benefits for the infant and parents.[12] Several countries have established programs to support the presence of parents in the NICUs. These programs improve the long-lasting health outcomes of infants, reduce their vulnerability, and decrease parental stress.[13] Despite the family-centered care benefits for the health of infants and families and regardless of the recent efforts in implementing this approach by the Ministry of Health and Medical Education in Iran, most of the care in NICUs is done by the mother while other family members have less attendance and presence. As a result, family members cannot support the mother and reduce her care burden. Considering the emphasis on promoting family-centered care in NICUs and the inconsistency of the current situation with the care approach that meets the needs of newborn's families, especially mothers, the researchers decided to evaluate the effect of family-centered care on maternal caring burden in premature infants admitted to intensive care unit.

Materials and Methods

The present study was a quasi-experimental pretest-posttest study with a control group. Hafiz Hospital, Shiraz, Iran was selected as the study setting, a referral educational hospital affiliated with Shiraz University of Medical Sciences. It has two NICUs (level I & II) with 33 active beds. The study population consisted of all the mothers of preterm newborns hospitalized in the NICUs of Hafiz Hospital, Shiraz, Iran.

The research sample included those mothers of preterm newborns hospitalized in one of the NICUs of the hospital from April to September 2020. The required sample size was determined using the following formula, considering the 95% confidence interval and power of 80% ($\alpha = 0.5$ & $\beta = 0.20$).[14] The

final sample size, considering a probable attrition rate of 10%, was determined as 30 participants in each group.

$$n = \frac{(Z_{1-\frac{\alpha}{2}} + Z_{1-\beta})(S1^2 + S2^2)}{d^2}$$
$$\frac{(1.96 + 0.84)^2 \times (2.3^2 + 2.8^2)}{1.9^2} \cong 29$$

The inclusion criteria included: age of 18 years or older in mothers, willingness to participate in the study, fluency in the Persian language, being literate, not having a hospital-related job, having a hospitalized newborn with history of birth with gestational age between 30-38 weeks, hemodynamicaly stable according to the vital signs of newborn(Heart rate: 120-160 beats per minute, respiratory rate: 40-60 per minutes, saturation of peripheral oxygen (SPO2) between 85-95%, and normal skin color).Moreover, the exclusion criteria included for this study were as followed: having a history of psychological health problems that interfere with effective communication, having a previous hospitalization history of a newborn in NICUs, reluctance to continue participating in the study; partially filled out questionnaires; death, discharge, or hemodynamic instability of the newborn; a congenital medical health condition being diagnosed for the newborn at any stage of the study.

The convenience sampling method was used. All the mothers who met the inclusion criteria engaged in our study. Then, they were briefed on the research procedure and a written informed consent was obtained. Consequently, a random sequence was created using the Random Allocation Software, considering an allocation ratio of 1:1. A person not involved in the data collection and intervention of the study randomly allocated the participants to the control (n = 30) and intervention groups (n = 29), according to the designed sequence.

The code of ethics (no. IR.SSU.REC.1398.204) was obtained from the Ethics Committee of Yazd Shahid Sadoughi University of Medical Sciences, Yazd, Iran.

The intervention was planned to begin on the third day after admission of the newborn to the NICU through a four-step program which was provided during four days (until the seventh day after admission).[14] The control group received common care.[14] In the first step, in a face-to-face meeting with the parents of each newborn, they were asked to express their concerns in experimental group. The content of family centered care showed in Table 1.

Table 1. Content of Family Centered Care

Step	Content
One	-Express concerns of parents -Given training in the NICU routine, such as washing their hands before contacting the newborn - Some explanations were provided for parents to become familiar with environment of the NICU. - The necessary information about appearance, characteristics and behavior, sleep and wake patterns, stress symptoms in premature infants and ways to resolve it. - The role of the family, especially the mother in caring for premature infants - Explanation about the incubator and how to work with it, the change of position and movement of the baby in a principled way.
Two	- The principles and methods of proper routine daily care of premature infants, nutrition, breastfeeding training, bathing, maintaining body temperature and proper clothing, changing diapers, umbilical cord care and kangaroo care were presented to parents in a practical way. -They learned what was practiced in the presence of the researcher and the checklist was completed. -The role of the mother in the proper transfer of the newborn from the hospital to the home and the effective understanding of the infant's behaviors were explained.
Three	-The importance of screening tests, prescribed medications, vaccination schedule, how to communicate with the infants, and items that need to be referred to a medical center were also discussed.
Four	-The items trained by the parents were evaluated and their questions answered.

Following intervention, the study questionnaires were filled out by mothers. It was noteworthy that during the intervention phase, any changes in the newborn's condition were reported to the family, considering their opinions in any clinical decision-making issues of the newborn. On the other hand, all the educational contents suggested to mothers were given to fathers or other family members. If it were not possible to refer to them in person, the contents were provided through WhatsApp, and in case of no internet access, it was conveyed in the form of an educational CD, booklet, or pamphlet, so that they could assist mothers in caring for the newborn. During the hospitalization period, the infant's parents were able to contact the researcher via text message at specific times of the day and ask their questions. Also, the infant's family members like father, siblings were allowed to visit the baby at specific times of the day set by the ward. The mothers of the experimental group connected with each other through a group on WhatsApp and exchanged information and experiences with each other. All mothers in the control group received discharge instructions in the form of pamphlets or CDs after they filled out the study questionnaire.

The data were collected using demographic characteristics questionnaires and the Persian version of the Caregiver Burden Scale (CBS). Demographic characteristics questionnaires included 10 questions about age, sex, and birth gestational age of the newborn; and job, education, marital status, number of children, and monthly income of the parents. The questionnaires were filled out based on self-reports of mothers. The CBS was developed by SölveElmståhl and colleagues, in 1996. [14, 15] It is a 22-item scale that measures the subjectively experienced burden by caregivers to chronically ill persons. The caregiver ticks one of the four boxes (not at all, seldom, sometimes, often) score 1 to 4 for each item. The instrument comprises five dimensions: general strain (8 items with 8-32 scores), isolation (3 items with 3-12 scores), disappointment (5 items with 5-20 scores), emotional involvement (3 items with 3-12 scores) and environment (3 items with 3-12 scores). The areas of care, such as health, mental wellbeing, relationships, and social support, were covered by the items of this questionnaire.[14,15] Important areas for care, such as health, mental wellbeing, relationships and social support were covered by the items of this questionnaire.

The Persian version of the CBS was validated by Farajzadeh et al. (2017) in a population of 110 caregivers (men = 60 and women = 50) to patients with spinal cord injuries. The confirmatory factor analysis supported the five-factor model of the CBS. The internal consistency values of the dimensions were between 0.69 and 0.75 except for environment dimension (0.55). Test-retest reliability for the dimensions was between 0.74 and 0.90 based on Cronbach's alpha for all subscales.[16]

The data were analyzed using SPSS 21 software. Independent t-test and Chi-square were used to compare demographic and newborn-related variables. Paired sample t-test, and independent t-test were used to compare the change of the scores of the CBS within and between-group. The ANCOVA test was used to compare the mean scores of CBS and its subscales in two groups. A p-value of less than 0.05 was considered statically different.

Results

The results indicated no significant differences between the two groups in terms of socio-demographic variables (Table 2).

Table 2. Comparison of Socio-demographic Characteristics of two study groups

Variables		Subgroups	Control group		Intervention group		P value
			Frequency	%	Frequency	%	
Occupation	Mother	Housewife	18	60	18	62	0.593
		Employer	12	40	11	38	
		Self-employer	0	0	0	0	
	Father	Unemployed	14	46.6	22	75.8	0.795
		Employer	16	53.4	7	24.2	
		Self-employed	0	-	0	-	
Level of education	Mother	High school diploma	12	40	10	34.5	0.592
		University degree	18	60	19	65.5	
	Father	High school diploma	9	30	8	27.6	0.774
		University degree	21	70	21	72.4	
Gender of newborn		Female	13	43.3	12	41.4	0.99
		Male	17	56.7	17	58.6	
Age (years)					Mean ± SD	Mean ± SD	
		Mother			28.30 ± 3.91	28.06 ± 4.27	0.940
		Father			32.26 ± 5.90	33.06 ± 4.32	0.316
Gestational age of newborn (weeks)			Mean ± SD		Mean ± SD		
			32.86 ±1.81		33.83 ± 1.55		0.202

According to the independent t-test, the mean score of the research variable had a significant decrease in post-test measurement in both groups (Table 3).

Table 3. Comparison of the Mean Care Burden Score of Mothers in Control and Test Groups Before and After the Intervention

Variable	Group	Before intervention	After intervention
		Mean ± SD*	Mean ± SD*
Care burden	Test	72.33 ± 6.16	58.13 ± 8.17
	Control	64.10 ± 8.45	62.73 ± 7.44

*paired t- test

In this study, to investigate the research hypothesis (The effect of family-centered care on the care burden of the parents of premature infants in NICU), a Univariate Analysis of Covariance was used. Where the care burden variable was considered as a dependent variable, the value of F is the effect of the independent variable (group), (4.11), which according to the significance level was obtained (0.047), is less than 0.05 and is meaningful. After removing the effect of the pre-test, there was a significant difference between the mean post-test scores of care burden in the experimental and control groups. Therefore, the effectiveness of the intervention in reducing the care burden was supported. It means that family-centered care reduced the care burden (Table 4).

Table 4. The Results of Univariate Analysis of Covariance for the Mean of Care Burden in the Two Groups

Variable	Sum of squares	df	Mean of squares	F	P
Care burden	255.68	1	255.68	4.11	0.047

Discussion

Findings of the present study showed that family-centered care reduced the level of care burden of mothers of preterm newborns admitted to the NICU. The mean score of care burden of the participants in the experimental group was significantly less than the control group. Also, it was found that mothers experienced care burden related to a lack of involvement of other family members in infant's care.

The results of a study by Crespo, et al. showed that with increasing family-centered care, the care burden for parents of children with cancer decreases.[17] In another study by Shoghi, et al., family-centered empowerment was also associated with a reduction in care burden in mothers.[18] According to the

researchers of the above studies, more understanding of the family-centered approach in nurses working with families of sick infants and children results in more engagement in a supportive role. Providing a social resource for these families leads to less prevalence of stress, care burden, anxiety, and depression.[19] The presence of parents in the NICUs is necessary for improving the interaction between infants and their parents. Giving information to parents and performing family-centered care will reduce their stress.[20] It can be interpreted that the illness of a family member can cause stress and care burden or the support. When parents are more cooperative and involved in the care and supported by others, they experience less stress and care burden. This is consistent with the results of the present study.[21] However, the results of some studies are not consistent with our results, which could be due to the differences in design, research setting, and intervention method. In the study of Sikorova and Kokova (2012), which aimed to assess the needs of parents of newborns admitted to the NICUs, mothers stated that attention to the supportive needs is their least priority. The insignificance of this need in this study may be due to cultural differences in that country and better supportive care to meet the needs of this area.[22]

In the study of Borimnejad et al. (2012), there was no statistical difference between the caring behaviors of the two groups[23] which is inconsistent with our results. A different content provided in the educational materials for parents can be a reason.

The newly introduced approach to family-centered care in Iran has weaknesses in its implementation and compliance with its underlying principles. The barriers and obstacles have been investigated in several studies. One of the cultural barriers is assigning the responsibility as the primary caregiver to mothers of infants. The researchers of the present study aimed to shift care from mother-centered to family-centered and involve other family members in care.

A preterm birth adds to the caring burden of mothers. While they spend their post-natal period accompanied by physical exhaustion and emotional hypersensitivity, infant hospitalization, adds to their tension that may make caring for an infant an overwhelming task.

One of the recommendations is to encourage nurses and nursing managers to interact with parents, be more flexible to family members' presence in the NICU, and involve them in the care of the infants. Nurses can also reduce the care burden by encouraging all family members consisting of fathers and siblings, to participate in the care and support of the mother. All of them need to be involved in clinical decision-making for the infant. The cultural barriers should be identified and considered in care plans. Effective communication with family members should be enhanced in neonatal settings. Active participation of parents enables and empowers them to have an awareness and active role in the caring of infants, react skillfully to the different clinical situations, and experience less stress.[24]

After removing the pre-test effect, there was a significant difference between the mean scores of the control group and the intervention in the post test. Therefore, the effectiveness of the intervention in reducing the burden of care was supported. It means that family-centered care is effective in reducing the care burden.

Insufficient cooperation of nurses for the presence of parents next to the infant and reluctance of some fathers to be with their infants and wives for personal reasons were the study limitations. The researcher tried to control them by explaining the importance of the presence of parents in the NICU and its correlation with more positive health outcomes for newborns for both groups. The low income of some families could affect the results, and it was beyond the control of researchers. Also, insufficient and inappropriate hospital amenities and

accommodations for parents staying were uncontrolled variables.

Conclusion

Family-centered care reduces the care burden of mothers of preterm newborns by emphasizing the helpful presence of the other family members, especially fathers in the NICUs. The family-centered care approach is effective and it has positive effect on parental involvement in the care of the newborn on the process of recovery.

Conflict of Interests

Authors have no conflict of interests.

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