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Original Article

Assessing Family-Centered Care in Iranian NICUs from Perspective of Neonatal Individual Developmental Care

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ABSTRACT

Background: Preterm deliveries and premature babies are among challenges for families and communities. A family-centered care model is a model that helps families become less challenged by preterm birth and learn how to care for their premature infants. The aim of this study was to evaluate the implementation of family-centered care in the Iranian neonatal intensive care units (NICUs).

Methods: This national cross-sectional study was conducted on a total of 23 NICUs of 9 universities of medical sciences, where students were trained in the neonatology fellowship course, in seven provinces of Iran. Family-centered developmental care was assessed in six different domains, including the philosophy of nursery, family communication, family support, family resources, admission and discharge planning, and decision-making. In addition, a total of 29 items were asked. The data were analyzed using Stata software (version 13) using descriptive statistical tests.

Results: The mean scores in all domains were weak, and the total score for all domains was 34.18 (95% CI: 33.75-34.60) out of 100. The mean scores were 30 in the philosophy of nursery, 43.47 in family communication, 26.71 in family support, 35 in family resources, 45 in admission and discharge planning, and 25 in decision-making. The lowest score was reported for decision-making, and the highest score was reported for admission and discharge planning.

Conclusion: Since family-centered developmental care in Iran is not favorable, the obtained findings suggest the development of a suitable plan to upgrade family-centered developmental care as well as comprehensive NICU care, including developmental care, with regard to other domains.

Keywords: Developmental care program, Family-centred care, Iran, NIDCAP, NICU

Introduction

Preterm birth is considered a crisis for a family. Parents expect the pregnancy to bring the whole family home and take care of the baby since birth. However, a family faces many challenges with the birth of a premature baby and hospitalization in a neonatal intensive care unit (NICU) (1). Studies have shown that a mother feels guilty about giving birth to a premature baby. The mother feels inefficient because she is in a place separate from her baby and cannot take care of her baby directly. The existence of hospital rules regarding a specific time to visit the baby and no possibility of embracing the baby at any time as much as a mother wants strengthens the sense of inefficiency in mothers (2).

The prohibition of infant feeding due to problems caused by preterm birth or feeding by the nurse and a person other than the mother disrupts her parenting role (3). An unfamiliar hospital and NICU environment, equipment, tubes, incomplete information about the baby's clinical condition, small size of the premature infant, and fear of falling infants at the time of embracing, all are stressors of parents, especially in mothers (4, 5). A lack of privacy to keep up with the baby and concern about the care of other siblings are other

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factors threatening family relationships and premature infants.

A family-centered care model is a model that helps a family faces fewer challenges in their family life with premature birth so that they can learn how to care for a premature baby as they cope with this crisis. This model is for family engagement with the medical team in the care of a premature infant during hospitalization (3). This pattern of care is also a part of developmental care. This model of care emphasizes the role of a family in infant care to empower them (6). The results of a study carried out by Cooper et al. showed that this care model leads to more family satisfaction (7). The results of another study confirmed these findings (8).

Several studies have also been carried out in Iran and suggested that supporting mothers can help reduce their stress (9, 10). A study conducted in Brazil obtained similar results in this regard (11). It seems that the best way to support families at this time is to inform the family of their role in the care of a neonate. Involving parents (especially mothers) in caring for a premature baby helps with their parenting role; however, there has been no study that could comprehensively show the extent of its implementation. Therefore, the aim of this study was to evaluate the implementation of family-centered care in Iran.

Methods

Study design

This cross-sectional descriptive study was conducted in the NICUs affiliated to Iran universities of medical sciences in 2015. Some more details were reported elsewhere (12-14).

Study Centers

In this study, a total of 23 NICU centers of 9 high-rank universities of medical sciences were studied. These included the universities of Tehran, Shahid Beheshti, Iran, Tabriz, Mashhad, Isfahan, Shiraz, Ahvaz, and Kerman, Iran. In order to achieve the research goals, the developmental care program checklist was completed in 23 NICUs affiliated to the universities of medical sciences with residents of neonatal specialty.

Data Collection Tools

To collect the required data in this study, the checklist included 29 items in six different domains, including the philosophy of nursery with 4 items, family communication with 4 items, family support with 8 items, family resources with 4 items, admission and discharge planning with 4 items, and decision-making with 5 items, so that they could be rated as yes or no. These items were extracted from the family-centered part in the standard checklist of The Newborn Individualized Developmental Care and Assessment Program (NIDCAP) Federation International. Finally, the total points obtained in each domain were expressed in a percentage of 0-100. A higher average score (closer to 100) indicates a better family-centered care situation. Furthermore, the scores above 70 are considered favorable.

Validity of the tool

The aforementioned checklist is a tool for evaluating the implementation of developmental care in NICUs. Initially, the checklist was presented to 10 faculty members with a doctoral degree in pediatrics, infant nursing, and neonatology, and the required content validity adjustments were made. Seven faculty members had NIDCAP professional certification.

Methods

After obtaining the necessary authorization from the Department of Neonatal Health in the Ministry of Health and Medical Education (MOHME) and correspondence with the target universities, the implementation stages of the research and sampling of the research units began. The present study evaluated the NICUs, including 23 tertiary NICUs in 3 hospitals affiliated to Tehran University of Medical Sciences, 3 hospitals affiliated to Shahid Beheshti University of Medical Sciences, 3 hospitals affiliated to Iran University of Medical Sciences, 3 hospitals affiliated to Tabriz University of Medical Sciences, 3 hospitals affiliated to Mashhad University of Medical Sciences, 3 hospitals affiliated to Shiraz University of Medical Sciences, 2 hospitals affiliated to Isfahan University of Medical Sciences, 2 hospitals affiliated to Ahvaz University of Medical Sciences, and 1 hospital affiliated to Kerman University of Medical Sciences, Iran. To improve the quality of data gathering, a group of nine experienced NICU experts was selected and received two-day training on how to complete a checklist. The checklist was completed in 23 hospitals within a 2-month time frame in 2015.

Data Analysis

In this study, after data collection, the data were analyzed using Stata software (version 13) and descriptive statistics. Mean (standard deviation) was used to describe the data.

Ethical Considerations

This research was registered by the Department of Neonatal Health in the MOHME and approved by the Ethics Committee of Shiraz University of Medical Sciences, Shiraz, Iran (Code 7110-93). In doing so, all ethical standards adhered to in the Helsinki Declaration.

Results

In this study, 23 NICUs affiliated to 9 universities were surveyed on the status of family-centered care. Family-centered developmental care was evaluated in six different domains, including the philosophy of nursery, family communication, family support, family resources, admission and discharge planning, and decision-making, which included a total of 29 items. The total score of family-centered care in the six domains was 34.18 out of 100, and the score in each of the domains was 45 or less than 45 out of 100. In other words, the highest obtained score of different domains was 45 out of 100.

As shown in Table 1, in the philosophy of nursery domain, the mean total score was 30 out of 100. In this domain, the highest score was given to parents' access to care information and parent participation in care with score 40, and the lowest score was given to nursery mission statement regarding support for families and respect and protection of dignity and privacy of families with score 20 (Table 2).

The second domain in this study was family

Table 1. Mean scores of subgroups of family-centered care in hospitals and neonatal intensive care units in Iran

Subgroups	Mean (standard deviation)	95% CI
Philosophy of nursery	30 (0)	30-30
Family communication	43.47 (5.09)	41.27-45.68
Family support	26.71 (2.12)	25.79-27.63
Family resources	35 (0)	35-35
Admission and discharge planning	45 (0)	45-45
Decision-making	25 (0)	25-25
Total	34.18 (0.98)	33.75-34.60

Table 2. Mean scores of items of family-centered care in hospitals and neonatal intensive care units in Iran

Item	Mean (standard deviation)	95% CI
A: Philosophy of nursery		
Nursery mission statement regarding support of families	20 (0)	20-20
Respect and protection of dignity and privacy of families	20 (0)	20-20
Parents' access to care information	40 (0)	40-40
Parents' participation in care	40 (0)	40-40
B: Family communication		
Emotional relationship among staffs, parents, and other family members	42.61 (6.89)	39.63-45.59
Parents and family members' role in their hospitalized infants' lives	48.70 (10.14)	44.31-53.08
Family-staff communication, including participation in medical rounds	40 (0)	40-40
Tone of nursery communication	42.61 (6.89)	39.63-45.59
C: Family support		
Anticipatory support around time of delivery	29.56 (17.95)	21.79-37.33
Developmental support at time of delivery	29.56 (17.95)	21.79-37.33
Nursery support staff	20 (0)	20-20
Parent support groups	20 (0)	20-20
Informal and nursery-sponsored parent-to-parent support opportunities	40 (0)	40-40
Inclusion of siblings in nursery and infants and family care	21.73 (5.76)	19.24-24.23
Availability of sibling care spaces	20 (0)	20-20
Bereavement support for families at the loss of their fetus or infant	20 (0)	20-20
D: Family resources		
Family resource library	40 (0)	40-40
Financial support for maternity and paternity leaves	20 (0)	20-20
Professional mental health and psychological support services	40 (0)	40-40
Resources for families in high-risk social circumstances	40 (0)	40-40
E: Admission and discharge planning		
Hospital admission plan	60 (0)	60-60
Transport to nursery	40 (0)	40-40
Family involvement in discharge plan	40 (0)	40-40
Written plans for family support at discharge	40 (0)	40-40
F: Decision-making		
Validation of parent and family effectiveness and competence	40 (0)	40-40
Family meeting with primary caregiving team	0	0
Family participation in decision-making councils and committees	20 (0)	20-20
Family advisory board	20 (0)	20-20
Family representatives to nursery leadership team	20 (0)	20-20

communication where the national average score was 43.47 out of 100 (95% CI: 41.27-45.68). In this domain, 4 items were scored, with the highest score given to parents and family members in their hospitalized infant's lives with an average of 48.70 out of 100. Moreover, the lowest score belonged to family-staff communication, including participation in medical rounds with a score of 40 out of 100.

The third domain was family support with an average of 26.71 out of 100. Eight items were evaluated in this domain with the highest score in informal and nursery-supported parent-to-parent support opportunities with an average of 40 out of 100. In addition, as it is shown in Table 2, the lowest mean score was 20 which was obtained for four items in this domain.

The next assessed domain was family resources with a national average score of 35 out of 100. In this domain, the item financial support for maternity and paternity leaves with a score of 20 was the lowest score. In this domain, there was limited financial support for parents with premature babies. The mean score of all other items in this domain was 40 out of 100.

In the admission and discharge planning domain where 4 items were measured, the national mean score was 45 out of 100. The highest score was obtained, compared to those reported for other domains. The highest score in this domain was for the item of hospital admission plan with a score of 60. The sixth studied domain was decision-making with 5 items. The national mean score in this domain (25 out of 100) was the lowest obtained score, compared to those reported for other domains. In this domain, the lowest mean score was 0 which belonged to the item of family meeting with the primary caregiving team.

Discussion

The main results of this study suggested that family-centered care in NICUs is poor in Iran, and the overall scores of family-centered care and its six domains were less than 50 (out of 100). The highest score was reported for the domain of admission and discharge planning with 45 out of 100, and the lowest score was reported for the domain of decision-making with 25 out of 100. Since the results of studies have shown that family-centered care plays an important role in the development of preterm infants, attention to this aspect of care and its improvement in Iran can have favorable outcomes regarding preterm birth for infants and their families.

Parents' role in infant care should be determined by hospitals so that they can carefully perform their infant care. Cares, such as touching and embracing the baby, and daily cares, such as arranging the infant's bed, swaddling the baby, and changing the diaper, increase the self-confidence of parents, especially mothers. Parental involvement can start since birth and even develop into their participation in nasogastric feeding via tube, bathing, and embracing the baby during invasive procedures and ultimately decision-making on the infant's therapeutic process. Therefore, some facilities for a family stay in hospitals must be provided during the infant's hospitalization. Also, family-centered care workshops should be held for the healthcare team so that relevant staff can understand the importance of the family role in infant care as a behavioral model for all infant care services.

The birth of a premature baby raises concerns in the family, especially for the baby's parents. It is important to involve parents in the care plans of a premature baby, which will reduce the problems caused by parental separation from the baby during hospitalization. Several studies have been carried out on the positive role of families' active presence and awareness in reducing their stress and anxiety leading to families' satisfaction. However, problems, such as trauma to the infant by parents in the NICUs, are some of the barriers that make families less likely to attend these centers.

Family-centered care implies that a healthcare system focuses on the participation of the family in neonatal care and involvement in decision-making on the infant's therapeutic process. In a study carried out by Kleberg (15), mothers with preterm infants (<32 weeks of gestation) were divided into two groups, namely routine care and developmental care with the NIDCAP approach. The mothers were significantly more satisfied with their infant care and developmental care and felt more closeness to their infants, compared to the routine care recipients. In another study conducted by Cooper et al. (7), the results showed that family-centered care leads to family satisfaction, stress reduction, and parental comfort and self-esteem. It should be noted that the study by Cooper et al was conducted with a quasi-experimental posttest-only design.

In another study, Westrup et al. in Switzerland examined the benefits of using the family-based developmental care program with the NIDCAP approach (8). The results of another study carried out by Wielenga et al. showed that parental satisfaction in the NIDCAP-based developmental care group was greater than routine care (16). Studies performed in Iran have also shown that supporting mothers helps them reduce preterm birth induced stress and anxiety (9, 10).

One of the best methods to support families with preterm birth is to inform them of their role in the care of their neonates. Involving parents (especially mothers) in caring for the baby helps them with their parenting role. Several studies have highlighted the importance of developmental care (e.g., family-based care and mental care) in NICUs, while our study in Iran showed that the status of NICUs in terms of family-based care is poor and needs more attention and policymaking in this area.

One of the limitations of the present study was the low number of NICUs (i.e., 23 centers), and it is recommended to conduct similar studies in more centers. Concerning the generalizability of the results, since this study was conducted in the NICUs of educational hospitals where the neonatal specialists were trained, the results might not be generalizable to the whole country.

Conclusion

In summary, since the family-centered developmental care in Iran is not favorable, the findings suggest the development of a suitable plan to upgrade family-centered developmental care as well as comprehensive NICU care, including developmental care, with regard to other domains.

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Conflicts of interest

All the authors declare that there is no conflict of interest.

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