DOI: 10.14235/bas.galenos.2021.5689

Difficulties for Mothers: Premature Baby Care at Home **Anneler İçin Zorluklar: Evde Prematüre Bebek Bakımı**

Özberk et al. Premature Baby Care at Home

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11.02.2020

15.01.2021

Cite this article as: Özberk H, Çiçek Ö, Ayar D, Okumuş H. Difficulties for Mothers: Premature Baby Care at Home.

ABSTRACT

Mothers who had preterm labor were determined to face difficulties in baby care in the postnatal period. This study aimed to review studies on difficulties experienced by mothers who gave premature birth regarding childcare at home during the postnatal period. The literature review was carried out between 2000-2019 using PubMed, Medline, CINAHL, Cochrane library, ULAKBİM, Google Scholar and Elsevier's EMBASE databases. Mothers who had preterm labor experiences difficulties about diaper use, bathing, umbilical cord care, baby feeding, skin-to-skin contact, recognition of newborn crying. Therefore, mothers need support for the health status of the newborn, lack of self-confidence regarding the care of the baby by health professionals. However, the lack of home care guidelines leaves mothers helpless in meeting these needs. Mothers should be ready for the care of premature babies.

For this reason, mothers who diagnosed preterm labor should be informed about the difficulties that they may have experienced or will later experience during their stay in the hospital. Mothers also need to be informed about the premature infant care in the postnatal period. Thus, mothers can experience the home care process positively by getting fully prepared to take responsibility for home care. Developing clinical guidelines for postnatal care of premature babies can help reduce the concerns of mothers, shorten hospital stay, and reduce morbidity risks.

Keywords: Preterm labor, prematurity, baby care, difficulties

ÖZ

Erken doğum yapan annelerin doğum sonu süreçte bebek bakımı konusunda güçlüklerle karşılaşmaktadırlar. Bu derlemede, erken doğum yapan annelerin doğum sonu dönemde bebeklerinin evde bakımı konusunda yaşadıkları güçlükleri incelemektir. Literatür taraması 2000-2019 yılları arasında PubMed, Medline, CINAHL, Cochrane kütüphanesi, ULAKBİM, Google Akademik ve Elsevier'in EMBASE veri tabanları kullanılarak yapılmıştır. Erken doğum yapan anneler, bebek bezi kullanma, banyo, göbek kordonu bakımı, bebek beslenmesi, ten tene temas, yenidoğan ağlamalarının tanınması konusunda zorluklar yaşamaktadırlar. Bu nedenle anneler, yenidoğanın sağlık durumu, bebeğin bakımında öz güven eksikliği ve sağlık profesyonellerine ihtiyaç duyma gibi konularda desteğe ihtiyaç duymaktadırlar. Ancak, evde bakım rehberlerinin olmaması annelerin bu ihtiyaçlarının karşılanamamasına neden olmaktadır. Prematüre bebeklerin bakımı için annelerin hazır olmaları gerekmektedir. Bu nedenle erken doğum tehdidi olan annelere hastanede kaldıkları süre içerisinde, yaşadıkları ya da daha sonra yaşayabilecekleri güçlüklerle ilişkin eğitimler ve bilgilendirmeler yapılmalıdır. Annelerin prematüre bebek bakımı ile ilgili doğum sonu dönemde de bilgilendirilmeye gereksinimleri vardır. Böylelikle anneler evde bakım sorumluluğunu tam olarak üstlenmeye hazır hale gelerek evde bakım sürecini olumlu yönde deneyimleyebilir. Prematüre bebeklerin doğum sonu bakımları ile ilgili klinik rehberlerinin geliştirilmesi, annelerin endişelerinin azaltılması, hastanede kalış süresinin kısaltılması ve morbidite risklerini azaltmada fayda sağlayabilir.

Anahtar Kelimeler: Erken doğum, prematürite, bebek bakımı, güçlükler

Introduction

A normal pregnancy lasts approximately 40 weeks, and infants born before 37th gestational week are defined as “preterm” or “premature” (1,2). According to the World Health Organization (WHO), preterm babies are classified as extreme preterm (<28th gestational

week), very preterm (28-32th gestational week), and moderate to late preterm (32-37th gestational week) (2).

According to the World Health Organization, nearly 15 million babies are born prematurely each year, and this number is increasing every year (2). The most common anxiety experienced by mothers hospitalized in maternity wards with the diagnosis of threatened preterm labor has been reported to be infant care (3-6). Therefore, mothers expect support from nurses for during-pregnancy care and postnatal home care of the baby (7). It is recommended that mothers diagnosed with preterm labor should be educated about the starting from the onset of gestation, including the neonatal intensive care (NIC) process if the baby is in the intensive care after the birth, and the discharge process. Also, comprehensive home care plans should be developed, support services should be determined, and the continuity of care should be ensured and maintained (8,9). This raises the fact that there is a need for evidence-based care guidelines that will support parents and eliminate their anxieties so that home care of the premature baby can be maintained appropriately.

Guidelines for neonatal intensive care and discharge process are mostly related to treatment and follow-up of infants (10-13). Appropriate guidelines, in which the family is also involved, are needed to provide quality care to babies after discharge. Lack of home care guidelines may cause mothers who have premature births to have difficulty providing care due to lack of information (14). Therefore, mothers who give premature birth should be informed accurately and adequately about how to care for their babies before discharge (15). The difficulties that mothers will experience will be prevented when they are informed well before the discharge. Nurses have important roles in helping mothers who give premature birth adapt to the home care of the baby after discharge (16). These roles include assessment and direct care of the baby in the hospital and at home (17), training mothers on threatened preterm labor and preterm labor (18), assessment of the home environment, assessment of maternal health (19), and provision of support (17). However, the provision of adequate information about home care of preterm babies and extension of the appropriate care also home by nurses have not found a place among options that nurses give enough priority to.

This literature review aimed to reveal the difficulties experienced by mothers who gave premature birth regarding infant care at home.

Method

The literature review conducted between 2000-2019 in Turkish and English by scanning PubMed, Medline, CINAHL, Cochrane library, ULAKBİM, Google Scholar and Elsevier's EMBASE databases. The following keywords were used: "prematurity", "premature infant", "neonatal intensive care", "threatened preterm labor", "premature birth", "discharge from neonatal intensive care", "home care of premature neonatal", "baby care", "challenge", and "difficulty" and their Turkish translations. As a result of the screening, thirty-six articles that met the inclusion criteria were included in the review. Five of these articles are about the psychological conditions experienced by mothers with babies in NICU, six of these are the difficulties of mothers in the care of their babies in NICU, seven of these are the psychological conditions experienced by mothers due to preterm birth, three of these are the difficulties experienced by healthcare professionals in adapting mothers to NICU, and fifteen of these are home care challenges of premature newborns.

Difficulties in Home Care of Preterm Infants

Mothers who have premature babies experience emotions mixed with happiness and sadness. The reason for this is the thought of being separated from the baby after birth (20) because the natural process expected to develop between mother and baby may be disrupted during the treatment of premature babies in the neonatal intensive care unit (NICU), and families may face difficulties related to baby care (21). During the NICU process, mothers giving a premature birth are reported to experience difficulties such as concerns about the health of the

infant, loss of the maternal role, performing parenting roles for other children, limited visiting hours, transportation barriers, balancing other aspects of family life, and financial problems (22-24). Unclear medical explanations made during the NICU treatment process, technological equipment used during the care, and changes in the physical appearance of the baby are quite stressful factors for parents (25). Hemati et al. (2017) reported that mothers had difficulty in achieving the home care of the infant after discharge from the NICU, they experienced a sense of incompetence regarding breastfeeding, they felt dependence on the hospital and the nurse, and that they felt stressed and anxious constantly (26). In another study, mothers who had their baby treated in the NICU were found to feel alienated towards their babies while caring for them. As a result of this study, it is suggested that, in addition to mothers' training regarding the treatment and care of the baby in the NICU, interventions for understanding mothers and preventing them from feeling alienated should be arranged (21). Nevertheless, a considerable number of mothers report that their emotional state is not understood by nurses and physicians working in the NICU (27). This may lead to new problems that need coping for mothers who have premature infants and who feel that they are not understood by healthcare workers.

The leading difficulties experienced after discharge include feeding and breastfeeding the premature baby (28-30). Nutritional problems, sudden death, and hyperbilirubinemia risk are higher in infants discharged from the NICU than infants in term (31,32). The difficulties such as the need for oxygen therapy as in the hospital, tube feeding, medication administration, and apnea follow-up increase the difficulties experienced by mothers after discharge from the NICU (14). All these practices bring about an uncertain and anxious process for mothers giving a preterm birth (14,33). In a study conducted in our country, mothers and fathers who have premature infants were determined to experience a mild level of anxiety. Their anxiety was found to increase especially while counting and assessing baby's breathing (34). These complications, which may occur after discharge, increase the risk of postpartum depression in mothers giving a premature birth (35). On the other hand, the depressed state of women during and after the labor may adversely affect the mental health of their spouses/partners and cause difficulties in terms of family integrity (36). Another difficulty affecting family integrity is the material losses that occur during the treatment at NICUs (37,38). In addition to spiritual stress felt after discharge from the NICU, failure to continue working due to the care of the baby and failure to find alternative solutions for working conditions such as part-time employment also cause financial stress in families (37,38). It is thought that parents may experience psychosocial problems as a result of material and spiritual difficulties.

As stated in recent research, the difficulties experienced by mothers are similar. Nurses should address any difficulties before discharge and explain potential problems systematically to mothers in a quiet environment without waiting for the day of discharge. To do this, if mothers are facing threatened preterm labor, they should be educated and informed about the difficulties that they have experienced during their stay in the hospital and that they may experience later. Thus, on the day of discharge, the missing care services of mothers should be offered gradually without exposing them to a bulk of information.

The Role of Healthcare Professionals in Home Care of the Premature Baby

For mothers who give birth prematurely, the discharge of the baby from the NICU means going back to their daily lives and making self-decisions about baby care. Mothers state that social (spouse, family, friends) and professional support is an important factor in adapting to the transition from hospital to home (39). In the study of Aldirawi et al. (2019) determined that nurses were the leading information sources of mothers after discharge (40). However, a standard guide on the care offered by nurses, who rank the first in terms of information sources, could not be found.

In a qualitative study conducted by Raffray et al (2014), healthcare workers were found to have difficulty in preparing the family for discharge from the NICU, diaper use, bathing the baby, umbilical cord care, feeding the baby, the skin-to-skin contact, and recognizing normal and abnormal states in baby's crying (41). Batman and Şeker (2014) used web-based training to prepare parents for discharge. As a result of the study, the web-based education given by health personnel was found to increase self-confidence and to decrease anxiety levels of parents with premature infants for baby care (42). Also, other studies recommend that health professionals should develop programs that provide both education and support to mothers before discharge (18), nurses should arrange home visits and keep in contact with mothers (14), and video conferences should be held so that mothers can contact the nurse when necessary (17), and a written control list should be made for customized training programs and home use as the birth weights of premature infants are different from each other and they make heterogeneous groups depending on birth weeks (9).

The recommendations of international associations and studies on the topic accessed during the literature review are as follows:

- Premature infants and mothers should have skin-to-skin contact (43),
- The first home visit to the premature infant and the mother who have been discharged should be conducted within 72 hours if possible (44),
- The premature infant should be re-visited one month after the first home visit, the mother should be followed for breastfeeding, and that the infant should be assessed for feeding problems (45),
- The importance of breastfeeding the infant at least 10-12 times or feeding it with a formula 8-10 times a day should be explained to the mother (46),
- Mothers should be informed that premature infants may be prone to sleeping and should be fed even if it is asleep (46).

Conclusion

The NICU treatment of premature babies and the discharge period are a complex process due to complications that may be faced. During this process, mothers experience physiological, psychological, and financial difficulties. Mothers' preparation is very important for baby care after discharge. For this reason, it is important for mothers to see their babies regularly during the period from the treatment process in the NICU to their discharge and to participate in the care of the baby so that sustainable home care can be achieved. Nurses should understand, empathize, empower mothers, and facilitate their participation in care. Nurses who give care for premature infants are advised to train families, communicate with them regularly, and place the mother-infant relationship to the center of their care by considering the care needs of the baby and complications that may occur after discharge.

Concerns that mothers will have about baby care in the postnatal period will adversely affect their physiological changes, especially breastfeeding. The support of physicians and nurses for this area, in which we have some deficiencies, and preparation of guidelines for home care will be a highly valuable service for parents.

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