



Difficulties for Mothers: Home Care of Babies Born Preterm

Anneler için Zorluklar: Evde Prematüre Bebek Bakımı

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ABSTRACT

Mothers who had preterm labor were expected to face difficulties with baby care during the postnatal period. This study aimed to review studies on difficulties experienced by mothers who had premature labor regarding childcare at home during the postnatal period. The literature review was carried out between 2000 and 2019 in databases of PubMed, Medline, CINAHL, Cochrane library, ULAKBİM, Google Scholar, and EMBASE. Mothers who had preterm labor experienced difficulties with diaper use, bathing, umbilical cord care, baby feeding, skin-to-skin contact, and recognition of newborn crying. Therefore, mothers need the support of health professionals for the health status of the newborn and their lack of self-confidence regarding baby care. However, the lack of home care guidelines leaves mothers helpless in meeting these needs. Mothers should be ready for the care of babies born preterm. For this reason, mothers who had preterm labor should be informed about the potential difficulties during their stay in the hospital. Mothers also need to be educated about the care of infants born preterm in the postnatal period. Thus, mothers can experience the home care process positively by becoming fully prepared to take the responsibility for home care. Developing clinical guidelines for postnatal care of babies born preterm 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 prematür 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 Sözcükler: Erken doğum, prematürite, bebek bakımı, güçlükler

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Introduction

A normal pregnancy lasts approximately 40 weeks, and infants born before the 37th gestational week are defined as “preterm” or “premature” (1,2). According to the World Health Organization (WHO), preterm babies are classified as extremely preterm (<28th gestational week), very preterm (28th-32th gestational week), and moderate to late preterm (32th-37th gestational week) (2).

According to the WHO, nearly 15 million babies are born preterm each year, and this number is increasing annually (2). Mothers hospitalized in maternity wards with a diagnosis of threatened preterm labor are most commonly anxious about infant care (3-6). Therefore, mothers expect support from nurses for pregnancy care and postnatal home care of the baby (7). Mothers diagnosed with preterm labor should be educated starting from the onset of gestation, including the neonatal intensive care unit (NICU) process if the baby requires intensive care after the birth, to the discharge process. Moreover, comprehensive home care plans are needed, support services should be determined, and continuity of care should be ensured and maintained (8,9). This raises the issue of the need for evidence-based care guidelines that will support parents and eliminate their anxieties so that home care of the baby born preterm can be maintained appropriately.

Guidelines for neonatal intensive care and discharge process are mostly related to the treatment and follow-up of infants (10-13). Appropriate guidelines, which involve the family, are needed to provide quality care to babies after discharge. The lack of home care guidelines may cause mothers who had premature births to have difficulty providing care due to the lack of information (14). Therefore, mothers who had premature birth should be informed accurately and adequately about how to care for their babies before discharge (15). Potential difficulties will be prevented when mothers are informed well before 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 at home is not among the priority options of nurses.

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

Methods

The literature review was conducted between 2000 and 2019 in Turkish and English by scanning databases of PubMed, Medline, CINAHL, Cochrane library, ULAKBIM, Google Scholar, and EMBASE. 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, 36 articles that met the inclusion criteria were included in the review. Of these articles, five were about the psychological conditions experienced by mothers with babies in the NICU, six focused on the difficulties of mothers in the care of their babies in the NICU, seven investigated the psychological conditions experienced by mothers because of preterm birth, three reported about the difficulties experienced by healthcare professionals in adapting mothers to the NICU, and 15 presented home care challenges of premature newborns.

Difficulties in Home Care of Preterm Infants

Mothers who have babies born preterm experience a mixture of happiness and sadness. The reason is the thought of being separated from the baby after birth (20) because the natural process expected to develop between the mother and baby may be disrupted during the treatment of babies born preterm in the NICU, and families may face difficulties related to baby care (21). During the NICU treatment, mothers who had 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, 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. (26) reported that mothers had difficulty in achieving the home care of the infant after discharge from the NICU, they felt a sense of incompetence regarding breastfeeding, they recognized dependence on the hospital and the nurse, and they felt stressed and anxious constantly. In another study, mothers who had their baby treated in the NICU were found to feel alienated toward their babies while caring for them, and this result 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, several mothers report that their emotional state is not understood by NICU nurses and physicians (27). This may lead to new problems that need coping for mothers who have infants born preterm and who feel that they are not understood by healthcare workers.

The main difficulties experienced after discharge include feeding and breastfeeding the baby born preterm (28-30). Nutritional problems, sudden death, and hyperbilirubinemia risk are higher in infants discharged from the NICU than infants born at term (31,32). 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 the baby’s discharge from the NICU (14). All these practices bring about an uncertain and anxious process for mothers who had a preterm delivery (14,33). In a study conducted in our country, parents who have infants born preterm were expected to experience a mild level of anxiety. Their anxiety was found to increase especially while counting and assessing the baby’s

breathing (34). These complications, which may occur after discharge, increase the risk of postpartum depression in mothers who had a premature delivery (35). By contrast, the depressed state of women during and after delivery may adversely affect the mental health of their spouses/partners and may disrupt family integrity (36). Moreover, the material losses that occur during the treatment at NICUs may affect family integrity (37,38). In addition to spiritual stress felt after the baby was discharged from the NICU, failure to continue working to care for the baby and failure to find alternative solutions for working conditions such as part-time employment also cause financial stress in families (37,38). Parents may experience psychosocial problems as a result of material and spiritual difficulties.

Recent research presented that 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. If mothers are facing threatened preterm labor, they should be educated and informed about the expected difficulties during the hospital stay and later upon discharge. Thus, on the day of discharge, missed care services of mothers should be offered gradually without overloading them with information.

Role of Healthcare Professionals in the Home Care of the Baby Born Preterm

For mothers who had premature delivery, 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, and friends) and professional support is an important factor in adapting to the transition from hospital to home (39). Aldirawi et al. (40) determined that nurses were the leading information sources of mothers after discharge. However, a standard guide on the care offered by nurses, who rank the first in terms of information sources, could not be found.

The qualitative study conducted by Raffray et al. (41) revealed that healthcare workers had difficulty in preparing the family about discharge from the NICU, diaper use, bathing the baby, umbilical cord care, feeding the baby, skin-to-skin contact, and recognition of normal and abnormal states of baby's crying. Batman and Şeker (42) used web-based education given by health personnel to prepare parents for discharge and found that the intervention increased the self-confidence and decreased the anxiety levels of parents with infants born preterm. Moreover, other studies have recommended 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), 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 infants born preterm are different from each other and they make heterogeneous groups depending on birth weeks (9).

The recommendations of international associations and related studies are as follows:

- Infants born preterm and mothers should have skin-to-skin contact (43).
- The first home visit to the infant born preterm and the mother who had been discharged should be conducted within 72 h if possible (44).
- The infant born preterm should be re-visited 1 month after the first home visit, the mother should be followed for breastfeeding, and the infant should be assessed for feeding problems (45).
- The importance of breastfeeding the infant at least 10-12 times or feeding it with formula 8-10 times a day should be explained to the mother (46).
- Mothers should be informed that infants born preterm may be sleeping all the time and should be fed even if asleep (46).

Conclusion

The NICU treatment of babies born preterm and the discharge period are complex processes due to potential complications. During this process, mothers experience physiological, psychological, and financial difficulties. Mothers' preparation is very important for baby care after discharge. For this reason, mothers should see their babies regularly during NICU treatment until discharge and to participate in the care of the baby so that sustainable home care can be achieved. Nurses should understand, empathize, and empower mothers and facilitate their participation in baby care. Nurses who care for infants born preterm are advised to train families, communicate with them regularly, and place the mother–infant relationship at 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, which has some deficiencies, and preparation of guidelines for home care will be a highly valuable service for parents.

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