

The Role of Nurses in Preparing Mothers of Premature Infants for Discharge and Home Care

Abstract

More than 1 in 10 infants worldwide are born each year prematurely. Premature infants are at risk in terms of mortality and morbidity. Premature infants typically need special and intensive care in a Neonatal Intensive Care Unit (NICU). Similarly, mothers need training provided by nurses for discharge and home care. Following the discharge from the NICU, mothers often become primary caregivers who will provide 24-h care. Essential nursing activities are to consider the needs of mothers of premature infants, to make the necessary preparations before discharge, to ensure the transition from the NICU to home in a comprehensive, coordinated, and conscious manner, and to monitor of maternal and infant health. Nurses can use nursing roles such as educator, caregiver, communicator, coordinator, researcher, manager, advocate, and consultant while providing this care to mothers of premature infants. This review article aims to provide nurses with a perspective on preparing the mothers of premature infants for discharge, transition to home, and home care. The study consists of four titles: The preparation of the mother of the premature infant for discharge and the role of the nurse, the preparation for the transition to home and the role of the nurse, the preparation for home care and the role of the nurse, and the methods that can be used in the preparation.

Keywords: Discharge, home care, mother, nurse, premature infant, transition to home

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Introduction

Premature infants are at risk in terms of mortality and morbidity.¹ An estimated 1.5 million infants worldwide are born before 37 weeks of gestation each year.² Premature infants generally need special and intensive care in a Neonatal Intensive Care Unit (NICU).³ Treatment of premature infants in the NICU after birth affects mother-infant attachment, maternal roles, and the mother's readiness for infant care. Because technological and complex instruments, multiple treatments, restrictive rules, and uncertainty of the infant's appearance and health are essential factors.⁴⁻⁶

Scientific and technological developments in neonatal intensive care have improved the survival rates of premature infants. Thanks to these developments, the length of hospital stay of premature infants has also decreased. However, this may result in mothers being discharged without sufficient knowledge and skills in infant care.^{6,7} Following the discharge of premature infants from the NICU, mothers often become primary caregivers.^{8,9} For home care of premature infants, mothers should have sufficient knowledge and skills on issues such as nutrition, hygiene, clothing, sleep, communication, preparation/management of the home environment, use of drugs and medical equipment, health checks, growth, development, management of emergencies, and safety.^{6,7,10-12} Health-care teams could be created for holistic and continuous care to determine, implement and evaluate the care needs of premature infants. Therefore, it is critical for nurses in the teams to prepare mothers for the home care of premature infants (Figure 1).¹¹ This preparation should begin in the hospital and continue in the transition to home and home care. However, no comprehensive study could be accessed in Türkiye that could guide nurses in preparing mothers of premature infants for discharge, transition to home, and home care. This review article aims to provide nurses with a perspective on preparing the mothers of premature infants for discharge, transition to home, and home care. The study consists of four titles: The preparation of the mother of the premature infant for discharge and the role of the nurse, the preparation for the transition to home

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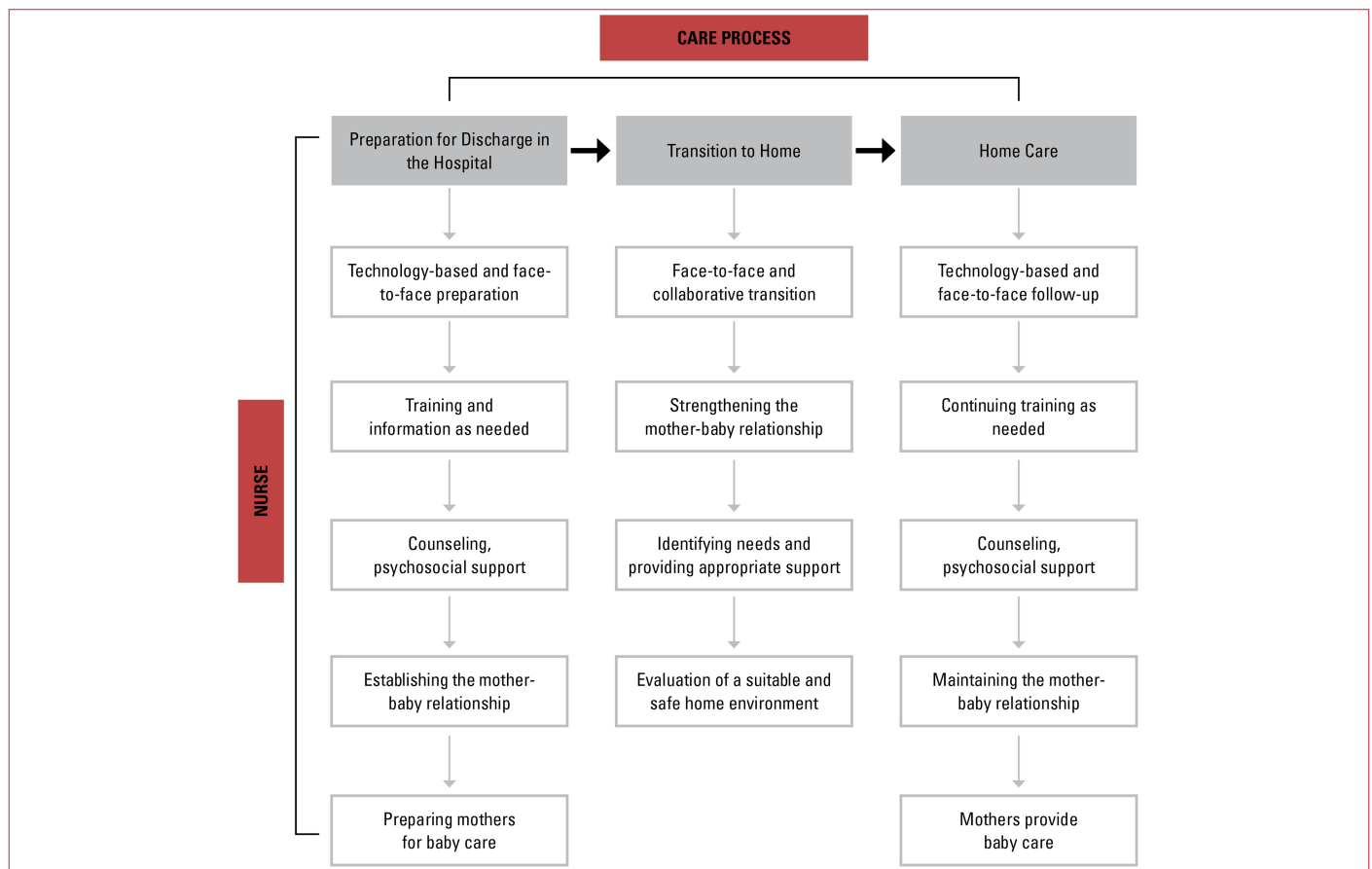


Figure 1. The role of nurses in preparing mothers of premature infants for discharge, transition to home, and home care.

and the role of the nurse, the preparation for home care, and the role of the nurse and the methods that can be used in the preparation.

Preparation for Discharge and the Role of the Nurse

For families, the discharge of a premature infant is not only a happy event but also a stressful, sensitive, and risky one.⁴ Discharge should be at the right time and with the adequate preparation. Discharge training should begin as soon as possible after the newborn is admitted to the intensive care unit. The following issues should be considered while determining the discharge time of a high-risk infant: The infant's thermoregulation (Patients can be discharged when they are capable of maintaining a normal body temperature [36–37°C] when fully clothed in an open cot at a room temperature of 20–25°C. *Level of evidence: 3b. Grade of recommendation: B.*), respiratory stability (Observation of infant, following discontinuation of caffeine, for a period of 7–13 days (from greater to lesser GA) from the last event to consider the patient to be apnea-free. *Level of evidence: 2b, Grade of recommendation: C.*), oral feeding ability (The administration of fresh maternal or donor human milk should be promoted and facilitated from the beginning of enteral feeding, and this milk will be fortified. *Level of evidence: 1. Grade of recommendation: A.*), self-regulation skills and behaviors (The transfer from the incubator to the cot can be based on the stability of the patient, and can take place in patients with weights of <1700g, although doing so does not guarantee an earlier discharge. *Level of evidence: 4. Grade of recommendation: C.*),

adequate weight gain, infant care skills of mothers (feeding, sleeping, dressing, bathing, skin care, safe environment, use of special drugs and equipment, etc.).^{9,13,14} According to the American Academy of Pediatrics (AAP), factors such as the infant's showing the necessary physiological maturity, planning for discharge, completing the arrangements for follow-up and home care, mothers receiving the necessary training, and gaining the basic knowledge and skills for care should be considered.¹⁰ For this reason, mothers should be ready for discharge as much as the infant while making the discharge decision.^{11,15–17}

Readiness for discharge will be a combination of the processes involved in the transition from the neonatal unit to home, with the family feeling confident in taking the infant home and feeling competent to provide ongoing care for the infant.¹⁸ The readiness of mothers should be evaluated before discharge in a holistic and comprehensive way. The mother's psychological, social, economic and educational needs, readiness for discharge, available resources, strengths, and aspects that need to be developed should be evaluated together as a whole, starting from the infant's hospitalization.¹⁰ Garfield et al., in a quasi-experimental study in 2022, examined the effectiveness of mobile health application and standard health care application in supporting parenting self-efficacy of parents of premature infants. The effectiveness of the applications was evaluated on the 7th day in the hospital, 1 day before the discharge, and 14 and 30 days after the discharge. Evaluations showed that the self-efficacy of the parents

in the group using the mobile application was high.⁷ In a qualitative study in 2022, Petty et al. evaluated parents' views on preparation for home care of extremely premature infants. In the study, five themes were determined within the scope of parental views: Emotional and mental health of the parents, uncertain outcomes, the continuing health needs of the infant, the training needs of the health-care professionals, parental support, and preparation for the transition to home.¹⁹ Nurses should prepare mothers for discharge with a program based on current literature, appropriate for the needs and the age, and with improved teaching quality.¹¹ It is recommended that two caregivers be present at discharge, if possible.¹⁰ Issues that can be addressed in preparation for discharge may include the ones in Table 1.^{6,7,11,12}

Premature infants and their mothers need significant support for discharge in the neonatal unit during the multidimensional discharge preparation.^{18,20} Preparation for discharge should begin as soon as the infant is hospitalized and continue until the mother is ready to assume full care functions. Current and potential needs of mothers for discharge preparation should be determined and appropriate care, training and counseling should be provided.^{11,12,18} While preparing mothers for discharge, nurses should provide family-centered and individual care using their roles as educators, caregiver, communicator, coordinator, researcher, manager, advocate, and counselor.²¹ It has been observed that mothers, whose knowledge, skills, and proficiency in infant care have increased thanks to the activities carried out by nurses to prepare mothers for discharge, feel strongly about their participation and interaction in infant care. Moreover, it has been reported that mother-infant communication strengthened, parental confidence increased, stress levels and maternal depression decreased, and satisfaction levels and readiness for discharge increased (Parent-child interaction and the integration of parents in NICUs will be promoted so

that they participate in the day-to-day care of their children in the unit and develop the necessary competencies to care for them after discharge. *Level of evidence: 1b. Grade of recommendation: B.*)^{7,22-25} Yılmaz and Alemdar, in a randomized and controlled study in 2021, examined the effect of supportive nursing interventions in reducing the stress levels of mothers of infants in the NICU. They found that the total score of the parental stress scale in the mothers in the supportive nursing intervention group was lower than the mothers in the control group.²³ A meta-analysis study by Mendelson et al. on the subject in 2017 shows that cognitive behavioral therapy interventions for parents with infants in the NICU have positive effects on maternal depressive symptoms. Parental depression and anxiety can have negative short- and long-term consequences for parents and their infants. For this reason, it is very important for NICU nurses to consider this in their planning.²² The use of up-to-date learning approaches and models suitable for the individual's learning skills in discharge preparation programs and training is essential for success. For this reason, it is critical for NICU nurses to consider this in their planning.²²

Transition to Home and the Role of the Nurse

Premature infants and their mothers need intensive medical care, preparation for discharge and psychological support, along with special care that facilitates the transition from hospital to home. The transition from hospital to home can be facilitated by the discharge planning process.⁹ It is a critical milestone in the continuity of care.⁵ However, the management of the infant's transition is typically left to the parents in the routine health-care service. The literature on the transition to home of premature infants indicates that mothers are typically unprepared enough for their infants with medical needs to be discharged from the hospital and transferred home. Ineffective preparation for discharge and transition to home increases the physical, psychological, and economic burden of the mother, may lead to higher-than-expected use of

Table 1. Issues that can be addressed in the preparation for discharge

Basic infant care skills	Feeding (breastfeeding and/or bottle) and feeding supplies (e.g., a device for breast milking, nipples/bottles, formula, etc.), flatulence, choice of clothing, seasonal dressing, bathing, skin care, sleep, diaper change, diaper rash care, umbilical cord care, eye care, and parasite care. Create opportunities for mothers to repeat care information and develop new skills.
Treatment and use of medical equipment	Drug use, thermometer use, complex care needs (gastrostomy, tracheostomy colostomy care), O ² condenser, pulse oximetry, monitor use, NG/OG feeding, etc.
Preparation of the home environment	A safe sleeping environment (e.g., crib, bedding, blankets, etc.), selection of furniture of appropriate standards, care equipment appropriate for the age of the infant, equipment for disease management (e.g. thermometer, suction bulb, etc.), smoke-free area, clean, good ventilated and suitable temperature environment, and visitor restriction
Normal and abnormal conditions of the infant	Disease symptoms, feeding, excretion, and sleep-wake cycles, conditions that require going to a health institution. Inform mothers about the condition of their infants.
Planning for emergencies	Emergencies and their management, communication with institutions or persons to be contacted in case of emergency, CPR training for newborn mothers
Safe transport and travel	Appropriate car seat selection, car seat testing, car seat use, and vehicle safety
Follow-up, checkups, and medical guidance	Number and frequency of healthcare visits, immunization, community resource use and potential growth and development monitoring, technological support and/or significant outpatient medical follow-up, outpatient treatments, or other diagnostic procedures
Psychological and social support for the family	Ensure the cooperation of the mother. Ensuring the adaptation of the infant to the family and family to the infant, supporting the mother-infant-relationship and communication between the mother and the infant, psychological support for the mother (Coping with stress, positive thinking, goal setting, helping protect hope, etc.), social support for mothers, and non-governmental organizations

health-care resources, and may increase the likelihood of rehospitalization of the premature infant.^{3,8,19,20}

A well-planned and comprehensive home transition is invaluable for infant health and maternal preparedness. The suggested ideas to support the transition include providing adequate support systems, interventions using mobile health technology, providing family-centered care, better communication with the mother, and information on practical support at home.^{17,26} For this reason, nurses should be with mothers during the transition to home and should continue their follow-ups after discharge.^{9,16} In line with the determined needs, they should cooperate with the mothers and be transitioned to home with the developed strategies.¹¹ Nurses can advise mothers on the following issues in preparation for the transition to home.

- Evaluation of mothers' care skills (nutrition, hygiene, skin care, mother-infant communication, sleep, etc.),
- Evaluation of the infant's nutrition,
- Developing a list of medical equipment and supplies to be used at home and accessible resources,
- Preparation of infant's supplies and nutritional supplements, medicines, and/or devices,
- Follow-up by a qualified health-care professional within 72 h,
- Follow-up of the infant and mother in the 1st days at home (first 3 days) and providing counseling, when necessary,
- Planning daily routines and using support systems, when necessary,
- Counseling to meet the needs of siblings (if any),
- Identifying and communicating with the institutions and/or health personnel where follow-up and controls will be made (birth history of the infant, summary of NICU treatment and care),
- Planning of controls and follow-ups,
- Planning medical or surgical treatment follow-up,
- Providing guidance on the use of health systems and community resources,
- Evaluation of the prepared home environment,
- Evaluation of infection control measures,
- Providing training on recognizing and managing abnormal situations,
- Providing training on recognizing and managing emergency situations,
- Preparing mothers emotionally, socially, and economically for the transition to home,
- Making the necessary preparations for the safe transfer of the infant to the home (appropriate car seat selection, stroller to carry the infant, necessary infant care materials, safety, etc.).

A recent update of the recommendations of the Canadian Paediatric Society did not recommend the routine performance of the car seat challenge (Level of evidence: 3, Grade: C). In any case, we do recommend advising and training parents or other caregivers so that they develop adequate practices and skills in the use of car seats before hospital discharge (Level of evidence: 3, Grade: C).^{10,11,27,28}

Training and counseling are critical during the transition of premature infants from the hospital to home. Therefore, a nurse who accompany, train, and support mothers can help mothers increase their knowledge about care, reduce their depression, stress, and anxiety, and improve their independence in providing care.⁶ Although there are various studies on discharge, the number of studies on transition from NICU to home is quite limited. A randomized and controlled study conducted by Keyvanfar et al. in 2020 evaluated the effect of

accompanying parents of premature infants discharged from the NICU on the mood of the mother during the transition from hospital to home. Each mother in the intervention group was accompanied by a nurse for up to 3 h immediately after discharge from the hospital. The nurse also supported the mother for the first 3–4 days after discharge. The mothers in the intervention group had significantly lower depression, anxiety, and stress scores compared to the mothers in the control group.⁶ Moreover, it has been reported that training during the transition to home and monitoring the infant with a smartphone application increase self-efficacy in-home care.¹⁵ A qualitative study by Aydon et al. in 2018 determined that parents needed to receive pre-transition training, an effective communication with health-care professionals, continuity of care with the nurse who knows their infants, and continuing care and support services at home.²⁹ It is thought that the nurses accompanying the mother during the transition will help improve the health outcomes of the mother and infant after discharge from the hospital.^{6,8,15} Although various studies have been conducted on the preparation for discharge from the NICU, more studies are needed on the transition from the NICU to home and the follow-up at home.

Home Care and the Role of the Nurse

Continuing the care given to the premature infant in the NICU at home without interruption can support the health of the infant, the mother-infant relationship, the infant's physiological stability, and age-appropriate growth and development.⁵ Ghazi et al., in a randomized and controlled trial in 2021, examined the effect of home visitation based on The Kangaroo Mother Care, which began in the NICU and continued at home, on maternal resilience and the development of the premature infant. In the study, kangaroo care was given to the control group, and kangaroo care was continued until 1 month after discharge in the intervention group, and home visits were made twice. Resilience score was found to be higher in the intervention group. Moreover, the baby's 2-month developmental score at adjusted age was found to be significantly higher in the experimental group than in the control group.⁵ Viera et al., in a systematic review in 2022 that examined the effects of parental self-efficacy on the growth of preterm infants after hospital discharge, found that perceived maternal self-efficacy was an important determinant of infant growth.³⁰ Bahmanpour et al., in their study in 2023, investigated the effect of telenursing service on the hope and self-efficacy of mothers of premature infants discharged from NICU. This randomized, controlled, and clinical trial found that post-discharge telenursing increased hope in mothers of premature infants and improved their perceived self-efficacy.³¹ Following the discharge of premature infants from the NICU, mothers often become primary caregivers in home care. Home care needs are different from those of term infants and mothers.²⁰ These differences can be listed as follows: nutrition, medication, and medical equipment support, hygiene, sleep requirement, vaccination, follow-up-controls, protection from infection, growth-development characteristics, safety requirements, possible health problems, communication, management of unexpected situations, and emergencies. However, for mothers, they may occur in areas such as psychological, social and familial support, time management, and stress management.^{11,20,32}

The morbidity and mortality rate may increase if a premature infant discharged from the NICU is not properly cared at home. Rio et al. in their descriptive study conducted in 2021, examined health-care use and readiness for discharge of parents with unscheduled discharge from NICU. Evaluation was carried out by telephone interviews 28 days after discharge. The study found that most of the parents felt ready

at discharge; however, about half of the parents used health services in the next month.³³ With a holistic and evidence-based hospital care, it will be possible to avoid this.³⁴ Most of the mothers in our country have to take care of their infants without the support of a health-care professional after their infant is discharged from the NICU. Transition to home and home follow-up services may be interrupted due to the lack of cooperation between the neonatal care team and community-based health professionals. For this reason, it is essential to establish communication between the NICU team that conducts the discharge planning and the primary care health service providers.⁹ In cases where this cannot be achieved, this process can be monitored by a nurse from the NICU team, who has information about the infant and mother and is equipped in the field of discharge, transition to home, and home follow-up. According to the AAP 2008 guidelines, although the content of a home care plan varies according to the infant's diagnosis, medical condition, and the mother's individual needs, the common elements are as follows:

- Identification of the person(s) who will provide care at home and their preparation,
- Supporting mothers' independence in care and parenting roles,
- Ensuring the continuity of communication and bond between mother and infant,
- Evaluation of caregivers who will administer the necessary drugs,
- Evaluation of the implementation of the plan created for nutrition,
- Evaluation of the use of medical equipment and materials to be used at home,
- Identification and mobilization of primary health-care personnel, necessary, and qualified home care personnel and community support services,
- Establishment of strong communications with mothers and ensuring continuous communication between mother and nurse,
- Evaluation of the adequacy of physical facilities at home,
- Development of emergency care and transportation plan,
- Evaluation of available financial resources to ensure the capacity to cover home care costs,
- Evaluating the psychological state of the mother and ensuring its management,
- Evaluating the social needs of the mother and ensuring its management.^{10,35}

Although most of the mothers of premature infants feel ready for discharge, it has been determined that approximately half of the them are hospitalized again after they start to take care of the infant at home and apply to the hospital due to health problems.³² It has been determined that the support provided by a nurse improves the mothers' ability to care for their preterm infants, reduces the risk of rehospitalization of the infant, and supports the growth and development of the infant during the first 6 months.^{34,36,37} Moreover, it has been determined that home visits to mothers of premature infants after discharge positively support the resilience of the mother and the development of the premature infant.⁹ Determining the needs of the premature infant and parents at home after discharge and nursing care provided a holistic and individual approach are important practices in improving infant and maternal health.

Methods That Can Be Used in Preparation for Discharge, Transition to Home, and Home Care

The methods used in training are as important as the starting time and content of discharge, transition to home, and home care education.^{9,18}

In this context, in addition to traditional discharge training, group training sessions, written training materials, audio recordings, videos, web-based preparation programs, smartphone applications, telehealth services, online counseling, simulations, video recordings, video counseling, individual infant care practice experiences, and new methods such as rooming-in can be used.^{11,15,17,35,38} Garfield et al. conducted a randomized and controlled trial in 2016 with parents of very low birth weight infants in transition home. They compared standard care practice with a smartphone app that included discharge checklists, educational material, and an infant tracking tool at the hospital 1 day before discharge and 14 days after discharge. As a result, it was determined that the time to be ready for discharge was shortened and self-efficacy in home care increased in the intervention group in which the smartphone application program was applied.¹⁵ Raines, in a study in 2017, prepared the parents of babies to be discharged from the NICU by simulation method and determined that when parents perform their own care practices with the simulation method, their feelings of trust increase.¹⁶ The discharge training should be customized and based on the mother's learning style. In addition to the methods used in discharge training or preparation programs, up-to-date learning approaches and nursing models can be integrated into nursing care. This integration contributes to the achievement of goals in the training offered to mothers, the implementation of evidence-based interventions, and ensuring that the care is based on scientific foundations.^{18,39-41} Using up-to-date teaching methods, techniques, and models in preparation for discharge, transition to home, and home care preparation programs offered by nurses can be effective in increasing the quality and success of the training. Printed and digital copies of essential and important information should be shared with the mother.

Conclusion

Considering the needs of mothers who have infants in the NICU, making the necessary preparations before discharge, providing a comprehensive, coordinated, and conscious transition from the NICU to home, and monitoring the health of the mother and infant with home follow-ups are critical nursing care services.¹⁶ The NICU team should be aware that the symptoms that can be seen in the mother and infant due to the hospitalization may reoccur even weeks after the discharge. For the continuity of care, the care initiated in the NICU should continue after discharge with a holistic approach in line with the needs of the mother and infant.³ Therefore, mothers should be supported in discharge, transition to home, and home care through an approach that integrates systematic, individualized, evidence-based, and up-to-date learning methods.^{11,18}

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