

# RIASE

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## **STRATEGIES IN THE CONTINUITY OF POST-DISCHARGE CARE TO PREMATURE OR LOW-WEIGHT NEWBORNS**

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## ABSTRACT

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**Objective:** to identify in articles published by nurses in the database, the strategies used in the continuity of nursing care for premature or low-birth weight newborns after hospital discharge.

**Methodology:** study of Integrative Literature Review, with a qualitative approach, the research being carried out in the CINAHL, MEDLINE, MEDICLATINA and SciELO databases with the 2009-2017 timeline. The PICO method was used in the elaboration of the research question and in the definition of inclusion criteria for the selection of articles.

**Results:** after analyzing the articles, four themes emerged: Discharge planning; Parents' concerns and difficulties in home care; Strategies for continuity of care after discharge; Family and social support network in the transition of care.

**Conclusions:** home visits is an important and effective strategic component of care after discharge, always including the assessment of the newborn's health status and parental skills. It must be performed in the first week after discharge, by a nurse from the Neonatal Intensive Care Unit, in conjunction with Primary Health Care, maintaining follow-up by telephone contact in the 2nd and 4th weeks.

**Descriptors:** prematurity; hospital discharge; continuity of care; parental training; nursing.

## INTRODUCTION

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Prematurity as a cause of infant mortality has been studied in different countries, considering the synthesis coefficient of quality of life and a general indicator of the level of health and development of a population<sup>(1)</sup>. Technological advances combined with scientific knowledge have allowed the survival of newborns (NBs) who are increasingly premature, with the reduction of morbidity being currently one of the major objectives in neonatology<sup>(2)</sup>.

According to the World Health Organization<sup>(3)</sup> babies born alive before 37 weeks are called premature. Many of these babies are born with a weight suitable for gestational age (GA). However, if birth weight is less than the 10th percentile or two standard deviations below the average, they are considered Light for the Gestational Age (LGA). Even if they are term, they have a higher risk of developing complications in the neonatal period<sup>(4)</sup>.

NBs are also classified according to birth weight: extremely low-weight (<1000g); very low-weight (1000g-1500g) and low-weight (<2500g). Given the GA, three categories of premature newborns are considered: <28 weeks and/or weighing <1000g, they are classified as extreme prematurity and very high risk; between 28-32 weeks and/or with birth weight between 1000g-1500g, they are classified as moderate prematurity and high risk; between 33-36 weeks and/or with birth weight between 1500g-2500g are classified as preterm threshold and low risk<sup>(3)</sup>.

Depending on the GA and the weight with which the premature newborn was born, he can develop several complications related to his prematurity, the most frequent of which are: changes in cognitive, motor and respiratory development, requiring prolonged care due to visual, auditory, neuromuscular, cognitive, verbal and behavioral problems, of growth and development that can persist during adolescence and adulthood<sup>(5)</sup>.

The global rate of premature births is 11% worldwide, ranging from 5% in European countries to 18% in Africa. Annually worldwide, about 30 million babies are born premature or with low birth weight<sup>(3)</sup>. In Portugal an average of 17 premature babies are born every day, with an increase in the crude rate of prematurity in the country in recent years, with official statistics pointing to 8.4% and the prevalence of premature babies below 32 weeks of 1.2%<sup>(6)</sup>.

The complex process of premature birth directly affects the family structure, changing expectations, making it difficult to adapt to parenting<sup>(1)</sup>. The term parenting can be defined as a maturation process that leads to a psycho-affective restructuring allowing two adults to become parents, implying a transition with increased responsibilities, being influenced by the parental models of each of the elements of the couple, built by the family of origin<sup>(7)</sup>.

Chick and Meleis<sup>(8)</sup> define transition as a change of life, passage or movement from one state to another, referring to both the process and the very objective of the client-environment interaction. The transition implies a change in health status, relationships, expectations and skills, so the client, depending on the context and the situation, has to incorporate new knowledge.

The transition to parenting as a phase of change has an even greater impact with premature birth and hospitalization imposed by the newborn's clinical status. Parents feel incomplete and lost looking at him as a shock to which they do not know how to react. In addition to the impact of delivery being ahead of schedule, the real baby does not correspond to what was dreamed of, which often implies a crisis of parental identity<sup>(9)</sup>.

According to Meleis and Trangenstein<sup>(10)</sup> nurses are the key to the identification and understanding of these phenomena, providing nursing actions within this transition process, acting as “facilitating” agents, assuming a predominant role of help, so that parents can overcome these changes in a positive way.

In this context, this study aims to identify, in articles published by nurses in the database, the strategies used in the continuity of nursing care for premature or low-weight newborns after hospital discharge.

## METHODOLOGY

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### *Study design*

With the intention of synthesizing the state of knowledge about continuity of care after discharge, for premature or low-weight NBs, the principles of an Integrative Literature Review on the theme were used.

The integrative literature review has been referred to as an important tool in the synthesis of the available evidence on a given theme and directs practice based on scientific knowledge, that is, towards evidence-based practice<sup>(11)</sup>. This type of review has six stages: identification of the theme and elaboration of the research question, sampling or research of the literature, data collection, critical analysis of the included studies, interpretation and discussion of the results and presentation of the review/synthesis of knowledge<sup>(11-12)</sup>. It contributes to the construction of health policies.

### *Population, inclusion and exclusion criteria*

Articles published between the years 2009 and 2017, available in full, with free access, in English, Spanish and Portuguese, which addressed the proposed theme and in which at least one of the authors was a Nurse, were included. Editorials, letters to the editor, review studies, theses, dissertations, repeated articles and studies that did not correspond to the theme relevant to the purpose of the review were excluded.

*Study protocol and data sources*

The PICo method<sup>(13)</sup> was used in the elaboration of the guiding question and in the definition of inclusion criteria for the selection of articles (Table 1). Following this guiding thread, the following research question was formulated: What are the strategies to adopt in the continuity of nursing care (I) for premature or low-weight (P) newborns after discharge (Co)?

Table 1 – Criteria for formulating the PICo question<sup>(13)</sup>.

<b>P</b>	<b>Participants</b>	Study target	Premature NBs Low-weight NBs
<b>I</b>	<b>Interest area</b>	What was intended to know	Ways of carrying out/strategies Continuity of care after discharge
<b>Co</b>	<b>Context</b>	Where it was conducted	Residence (after discharge)

Source: Authors.

From the question structured according to the acronym PICo and from the MeSH Browser descriptor, the following keywords were obtained: Premature; Low-birth weight; Patient discharge; Transitional Care; Home nursing care, which were organized with the addition of the Boolean OR and AND, in English and Portuguese. The research was carried out in the CINAHL, MEDLINE, MEDICLATINA and SciELO databases inserted in the EBSCO and B-ON platforms.

*Extraction and Analysis of Results*

For the analysis of the information, a spreadsheet was used in the Microsoft Excel® software, composed of the items: database, journal, language, author(s), year of publication, country, study objective, methodological approach used and level of evidence, type of intervention that was performed and conclusions.

The proposal of the Joanna Briggs Institute, 2014<sup>(14)</sup> was used to define the level of evidence (LE): Level 1 – Experimental study designs: 1.a – Systematic review of randomized controlled trials; 1.b – Systematic review of randomized, controlled trials and other study designs; 1.c – Random controlled trial; 1.d – Controlled, randomized pseudo-assays. Level 2 – Quasi-experimental designs: 2.a – Systematic review of quasi-experimental studies;

2.b – Systematic review of quasi-experimental and other less evident study designs; 2.c – Prospectively controlled studies of quasi-experimental; 2.d – Pre-test and post-test or retrospective historical controlled group studies. Level 3 – Observational – analytical designs: 3.a – Systematic review of comparable cohort studies; 3.b – Systematic review of comparable cohorts and other study designs with less evidence; 3.c – Cohort study with control group; 3.d – Case control study; 3.e – Observational studies without a control group. Level 4 – Observational – descriptive studies: 4.a – Systematic review of descriptive studies; 4.b – Cross-sectional study; 4.c – Case series; 4.d – Case study. Level 5 – Expert opinion – Laboratory studies: 5.a – Systematic review of expert opinion; 5.b – Expert consensus; 5.c – laboratory studies/expert opinion.

#### *Ethical aspects*

As this is an integrative literature review and does not involve human beings, it was not necessary to obtain an opinion from an ethics committee. However, the ethical principles to be observed in this type of research were taken into account, such as rigor, integrity and reliability, throughout the methodological process, in referencing the authors, as well as in the analysis and presentation of data.

## **RESULTS**

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In a total of 24 articles found, 11 were selected that met the inclusion criteria and that fit the proposed objective. In order to obtain the data of the selected articles, a collection instrument was elaborated for further analysis, considering as variables: Authors/Year/Country; Type of study/Level of evidence/Sample and Objectives (Table 2).

The 11 articles analyzed were found in their entirety in health journals, of which 72.7% (8) were published in nursing journals. As for the language, 81.8% were published in Portuguese (8 in Brazil and 1 in Portugal) and 18.2% (2) in English from Germany and Thailand.

Regarding the methodological approach, most research resulted in descriptive studies 72.7% (8) of which 54.5% (6) used a qualitative approach and 18.1% (2) quantitative, 18.1% (2) arose from integrative reviews. With 9% of representativeness, a randomized controlled study appears.

Table 2 - Summary matrix of the studies analyzed.

Authors/Year/Country	Type of Study/Level of evidence and sample	Objectives
Morais AC, Quirino MD, Almeida MS <sup>(15)</sup> 2009/Brazil	Qualitative descriptive study (LE=4b) Interview and observation N=7 mothers	To identify and to describe the home care provided by the mother and/or guardians to the premature child and the aspects that interfere in this process.
Souza NL, Fernandes ACP, Costa ICC, Enders CB, Carvalho JBL, Silva MLC <sup>(16)</sup> 2010/Brazil	Qualitative descriptive study (LE=4b) Interview N=24 mothers	To explore maternal experiences in caring for premature newborns at home and analyze their difficulties in maternal and child care after discharge.
Sassá AH, Rosa TCS, Souza SNDH, Rossetto EG <sup>(17)</sup> 2011/Brazil	Quantitative descriptive study (LE=4b) N=86 families	To characterize families and very low birth weight newborns who received the visit and systematize the problems encountered and the interventions performed.
Fonseca EL, Marcon SS <sup>(18)</sup> 2011/ Brazil	Qualitative descriptive study (LE=4b) Interview N=6 mothers	To identify the difficulties perceived by mothers in caring for low-weight newborns at home and know the resources used in the face of health complications.
Lopez GL, Anderson KH, Feutchinger J <sup>(19)</sup> 2012/Germany	Integrative review study (LE=4a)	To describe the results of a literature review that examines the continuity and safety of post-discharge care for premature infants and how it is ensured.
Braga PP, Sena RR <sup>(20)</sup> 2012/Brazil	Integrative review study (LE=4a)	To identify the strategies used to provide continuity of care for premature children after discharge.
Wangruangsathid R, Srisuphan W, Picheansathian W, Yenbut J <sup>(21)</sup> 2012/Thailand	Randomized controlled study (LE=1b) N=72 mothers, N=81 premature 2 groups (experimental and control)	To assess the effects of a transitional care program developed by nurses for premature newborns of mothers in the hospital's transition to the home and physical illness, growth and development of newborns.
Frota MA, Silva PFR, Moraes SR, Martins EMCS, Chaves EMC, Silva CAB <sup>(22)</sup> 2013/Brazil	Qualitative descriptive study (LE=4b) Interview N=9 mothers	To know the mother's perception of hospital discharge and the care of premature newborns at home after the first week of discharge.
Sassá AH, Gaíva MAM, Higarashi IH, Marcon SS <sup>(23)</sup> 2014/Brazil	Qualitative descriptive study (LE=4b) Interview and observation N=9 families	To describe the nursing actions implemented in the home context, based on the needs presented by the families of newborns born with very low birth weight.
Santos LC, Balaminut T, Souza SNDH, Rossetto EG <sup>(24)</sup> 2014/Brazil	Qualitative descriptive study (LE=4b) N=21 mothers	To understand the meaning of the visits made by neonatal nurses before and after discharge for mothers of premature newborns.
Roque SG, Costa GA <sup>(25)</sup> 2014/Portugal	Quantitative descriptive study (LE=4b) N=83 computer processes of newborns admitted to the Neonatal Intensive Care Unit (NICU)	To describe the teachings addressed and recommended in the preparation of parents to care for the newborn after discharge and identify the most used annotation locations.

Source: Authors.

## DISCUSSION

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After analyzing the articles in full, four themes emerged: Discharge planning; Parents' concerns and difficulties in home care; Strategies for continuity of care after discharge; Family and social support network in the transition of care.

### *Discharge planning*

The construction of a discharge plan in conjunction with the parents must be initiated at the moment of reception, and maintained throughout the entire hospitalization. The training of parents begins after the newborn's clinical stability and the availability to learn, covering specific care during hospitalization and its continuity at home, directed to their difficulties and the concrete needs of newborns<sup>(15,17,19,21-23,25)</sup>.

The skills of parents/family are related to the ability to care, their understanding of the child's satisfaction responses and factors such as family culture, educational level, psychosocial and financial factors that influence the understanding and acceptance of the NB<sup>(15,19-22)</sup>. Taking these factors into account, nurses should favor the development of skills and the acquisition of specific knowledge, using motivating training strategies (emotional, psychological and social) that can help to acquire security and increase family competence in home care. The mastery of the skills and behaviors necessary to provide care to newborns and integrate a reformulated identity are essential for the family to move (essentially the mother) successfully from the hospital to the home.

When the mother has mastered the skills and behaviors needed to care for her child, she will be successful in integrating the child's care and identity in her life, improving the health of the dyad, reflecting on the child's growth and development<sup>(16,18-23)</sup>.

The nurse is recognized as a facilitator of the process of building family autonomy in the care of the newborn after discharge. For this process to be successful, it is necessary to clearly define the teachings to be carried out, as well as the evaluation of their understanding. As topics of incidence of teaching were pointed out: characteristics of prematurity, bathing, umbilical cord, skin, airway cleaning, breastfeeding, artificial feeding, positioning, safety, child development, crying, sleep, vaccination, warning signs, bonding, parenting and common newborn problems<sup>(17,19,21,24-25)</sup>.

During the hospitalization period, parents are encouraged to participate in the preparation for discharge and gradually trained to perform general care, such as administering medications, feeding the NB, hygiene and comfort care, sleep and rest, involving them in the care process learning, not only as passive recipients of information, but as active subjects of education<sup>(19,22,24-25)</sup>.



As an integral part of this transition care process, group sessions with parents proved to be effective<sup>(19,21,25)</sup>, as well as home visits (HV) at pre-discharge in order to support and assist the family in the preparation of the home<sup>(17,24)</sup>.

### *Parents' concerns and difficulties in home care*

Parents' concerns in caring for premature or low-weight NBs in a family context are mainly related to complications, because they are associated with a fragile and helpless being and more likely to fall ill. For parents, the concern after birth and during hospitalization focuses on their survival and after discharge is replaced by maintaining their health. This is due to the perception that even if clinical stability is obtained, these NBs can present complications, with risks to their health<sup>(15-16,18,22-23)</sup>.

The mother is the family member who suffers the greatest impact from changes in daily routine<sup>(15-16,18-22)</sup>. Although they were satisfied with having their children at home, they mentioned the burden of the responsibility to care for vulnerable newborns without the support of hospital teams<sup>(16-19,22-23)</sup>. Going home causes difficulties, regardless of the context of life, previous experiences or age of the parents. The difficulties referred by the families were changes in family dynamics, changes in daily routines, home and environment conditions, issues related to health services, characteristics of the NB, the increase in housework as a cause of inadequate rest, which influences puerperal recovery, milk production and the identification of the maternal role<sup>(15-16,18,21-22)</sup>.

Arrival at home is a critical period of adaptation for the newborn and parents to the new environment. The allocation of roles to each family member indicates the sharing of responsibilities and the emotion shown in the face of difficulties arising from prematurity.

### *Strategies for continuity of care after discharge*

The premature or low-weight NB is a high-risk child, susceptible to a series of complications resulting from the immaturity of multiple systems and who needs special care, after discharge, for neurological abnormalities, growth and development delays especially during the first year of life<sup>(26)</sup>.

Families as care-producing units need to feel supported and protected after leaving the hospital, so that the transition from specialized professional care to care in the family context, takes place in a safe and peaceful way, mediated by the presence and performance of the patient in this new context of life and care<sup>(23)</sup>.

In this sense, the monitoring of these newborns and their families by specialists has become one of the main focuses of neonatal nursing care at home. Being the strategy and the most pointed resource in the continuity of Caring for the HV it is understood as the displacement of the professional to the home for the purpose of health promotion, favoring family groups in their training, making them more independent in their own health production and safety in care.

This follow-up is a continuous, flexible process of dialogue and evaluation, and should be the first nursing consultation initiated within a week after discharge (critical period) to assess the newborn's health status, adaptation to the family environment, including observation of the child during the visit, parental skills, signs of interaction, participation, appreciation of parental opinion and emotional state<sup>(15-24)</sup>. The monitoring must be maintained by telephone contact in the 2nd and 4th weeks and whenever necessary, allowing parents to verbalize the difficulties felt<sup>(17,19-21,24)</sup>.

In order to maintain the quality of care, the visit should be carried out by NICU nurses, since the parents expressed their feelings of being more comfortable interacting with those who established a bond during their children's hospitalization, creating a relationship of mutual trust<sup>(19,21,25)</sup>. This monitoring, if it is impossible to do it in person, can be carried out by videoconference<sup>(19)</sup>.

The articulation between the different levels of health care is pointed out as a strategy to guarantee the continuity of care, allowing the effectiveness of the integrality and intersectoriality of services. The elaboration of disclosure leaflets and protocols of nursing actions as instruments to support HV, in partnership with Primary Health Care (PHC)<sup>(15,20,24)</sup> including contact in the post-discharge period to share the main data relative to newborns<sup>(17,19-21,23-24)</sup>, are possible strategies for an adequate and global assistance.

The visit, in addition to reinforcing the teachings previously made about prematurity, improves parenting skills, reduces maternal anxiety and postpartum depression, conditions success with breastfeeding, prevents risky situations and readmissions, contributing to cost reduction with fewer episodes urgency, fewer unscheduled medical appointments, shorter length of stay in case of readmissions and decreased suffering, its effectiveness being evident<sup>(17,19-21,23-24)</sup>.

### *Family and social support network in the transition of care*

The social context and family support must be considered by the health professional when planning assistance in home care that is intended to be comprehensive<sup>(15-17,19-24)</sup>. In addition to health services, other constituent elements of care are identified as neces-

sary for their effectiveness, acting as facilitating resources after discharge, such as the family support network (family and family friendship bonds such as friends and neighbors) and the network social support (composed of different institutions, such as schools, health services, community, churches). The support of the network is identified as essential for families as an element that helps strengthen the family by attending to their life experiences, helping them in transitions, overcoming crises, such as the birth of a premature or low-weight child.

The mother is the main caregiver in the care of her child, reaffirming that caring for the child is a task culturally delegated to the woman, especially when it requires specific monitoring, a fact that reinforces the importance of preparing mothers for hospital discharge, reducing the anxiety and helping to build maternal self-confidence in caring<sup>(15-17,19-24)</sup>.

The support offered by the family was described in the studies mentioned as a safety reference in meeting the newborn's needs, through the transmission of the experience of previous generations, having a significant role in adapting the parents to the new reality in the family dynamics and in maintaining emotional balance. The mother feels more comfortable and safer to perform daily care when receiving support from close and experienced people, such as her grandmother, mother and aunt, who collaborated in indirect care, with auxiliary actions in the daily care of the newborn.

Thus, support networks should be strengthened at all levels of assistance, enabling the aggregation of formal and informal care. Care starts to be improved as families realize that the responsibility for care is theirs, but it can be shared with the health service that becomes a support network and not the main responsible for their child's growth and development.

### *Contributions to the area of Nursing, Health or Public Policy*

The demonstrated evidence of the effectiveness of the visit is related to the improvement of parental skills, decreased morbidity, health service costs and the suffering of newborns and their families. The monitoring of the family must be maintained by telephone contact in the 2nd and 4th weeks and whenever necessary, allowing parents to communicate continuously.

There is a need for more research on the subject, in order to favor a more comprehensive understanding of post-discharge care for premature or low-weight newborns and their families, as well as the impact, costs and benefits of visiting long term, and can be a valuable contribution to the construction of new health policies.

*Study limitations*

The limitations of this review include the fact that it used two platforms to access the databases, despite being a resource with wide scope.

Regarding the results found, the limitation is due to the size of the research samples, since they are small and mostly of convenience, which limits the degree of evidence found.

## CONCLUSIONS

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The studies analyzed in this review presented care strategies that proved to be useful and effective in the transition of premature or low-weight newborns, parents and family from the hospital to the home. Since admission and gradually, parents should be prepared for the discharge of their children, improving autonomy, safety and parental skills visible afterwards in care in a family environment.

The HV emerged as an important and effective strategic component of care, in the follow-up of these NBs and families. It must be performed in the first week after discharge, by a nurse from the NICU for maintaining the bond and the trust established during hospitalization, in conjunction with the PHC. Visits should reinforce previous teaching on prematurity, prevention of infections and warning signs, always imposing an assessment of the newborn's health status, family environment/situation, interaction between parents-newborns and parenting skills, thus ensuring continuity care and a successful transition.

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