



## Strategies for implementing continuity of care after discharge of premature infants: an integrative review\*

*Estratégias para efetivar a continuidade do cuidado pós-alta ao prematuro: revisão integrativa*

*Estrategias para efectivizar la continuidad del cuidado post alta al prematuro: revisión integrativa*

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### ABSTRACT

**Objective:** To identify the strategies used to implement continuity of care for premature infants who were discharged from Neonatal Intensive Care Units (NICU). **Methods:** An integrative literature review with search in the databases of: Cumulative Index to Nursing and Allied Health Literature, Literature of Latin American and Caribbean Health Sciences, Scientific Electronic Library Online, and Web of Science, for the period of 2001 to 2011. Of the 22 articles selected for reading, nine were explored, considering the proposed objective. **Results:** The need for further research on continuity of care for those discharged from the NICU is evident in the articles analyzed and confirmed by the level of scientific evidence of the studies included in this review. **Conclusion:** Intersectionality, technoscientific knowledge of professionals to care for those discharged from the NICU, public policy, multicenter research, as well as building ties between health care professionals and families, are important strategies for the construction of assistance for preterm infants and their families, after hospital discharge.

**Keywords:** Infant, premature; Child care; Patient discharge

### RESUMO

**Objetivo:** Identificar as estratégias utilizadas para efetivar a continuidade do cuidado às crianças nascidas prematuras egressas de Unidades de Terapia Intensiva Neonatal. **Métodos:** Estudo de revisão integrativa com busca nas bases de dados Cumulative Index to Nursing and Allied Health Literature, Literatura Latino-Americana e do Caribe em Ciências da Saúde, Scientific Eletronic Library on-line e Web of Science no período de 2001 e 2011. Dos 22 artigos selecionados para leitura, nove foram explorados, considerando o objetivo proposto. **Resultados:** A necessidade de desenvolvimento de pesquisas sobre a continuidade do cuidado aos egressos de Unidades de Terapia Intensiva Neonatal (UTIN) é evidente nos artigos analisados e confirmado pelo nível de evidência científica dos estudos incluídos nesta revisão. **Conclusão:** A interseccionalidade, o conhecimento tecnocientífico dos profissionais para cuidar dos egressos de UTIN, políticas públicas, pesquisas multicêntricas, bem como a construção de vínculo entre profissionais dos serviços de saúde e famílias, são estratégias importantes para a construção da assistência aos prematuros e suas famílias, após a alta hospitalar.

**Descritores:** Prematuro; Cuidado da criança; Alta do paciente

### RESUMEN

**Objetivo:** Identificar las estrategias utilizadas para efectivizar la continuidad del cuidado a los niños nacidos prematuros egresados de Unidades de Cuidados Intensivos Neonatal. **Métodos:** Estudio de revisión integrativa con búsqueda en las bases de datos Cumulative Index to Nursing and Allied Health Literature, Literatura Latino-Americana y del Caribe en Ciencias de la Salud, Scientific Eletronic Library on-line y Web of Science en el período de 2001 y 2011. De los 22 artículos seleccionados para lectura, nueve fueron explorados, considerando el objetivo propuesto. **Resultados:** La necesidad de desarrollo de investigaciones sobre la continuidad del cuidado a los egresados de Unidades de Cuidados Intensivos Neonatal (UCIN) es evidente en los artículos analizados y confirmado por el nivel de evidencia científica de los estudios incluídos en esta revisión. **Conclusión:** La intersectorialidad, el conocimiento tecnocientífico de los profesionales para cuidar a los egresados de UCIN, políticas públicas, investigaciones multicéntricas, así como la construcción de vínculo entre profesionales de los servicios de salud y familias, son estrategias importantes para la construcción de la asistencia a los prematuros y sus familias, después del alta hospitalaria.

**Descriptor:** Prematuro; Cuidado del niño; Alta del paciente

\*Study extracted from doctoral research in progress, entitled: "A rede de atenção à criança nascida prematura". School of Nursing, Federal University of Minas Gerais.

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## INTRODUCTION

In the world, the incidence of prematurity is 9.6% (12.9 million) of the total number of births<sup>(1)</sup>; in Brazil, this incidence is 6.7% of live births<sup>(2)</sup>.

It is relevant to consider that these births are accompanied by vulnerabilities and morbidities that account for the majority of deaths in the first year of life<sup>(1,3-5)</sup>.

Pre-term birth is defined as that in which gestation terminates between the 20th and 37th weeks, or between 140 and 257 days, after the first day of the last menstrual period<sup>(6)</sup>.

In developed countries, the causes of the increase in prematurity are associated with the increase in multiple gestations, increase in the use of assisted reproduction techniques, and larger number of babies born to women over the age of 34 years. In developing countries, the weakness of prenatal care is pointed out as the main cause of prematurity. Studies have revealed that in underdeveloped regions, such as part of Africa and Asia, prematurity is probably associated with the lack of health care and unfavorable socioeconomic conditions<sup>(1,3)</sup>.

When thinking of prematurity, one must consider that preterm newborns (PTNB) present singular characteristics because they required complex adaptation to the extra-uterine environment, with reference to biologic, social and psychological aspects. From this perspective there is a need for resolute care that should start in the hospital and have continuity after discharge from hospital<sup>(7)</sup>.

Theoretically, any premature newborn may develop with future problems, however, it is necessary to perform triage for follow-up based on better knowledge of the groups at greater risk. The goals of continuity of care for the newborn at risk may be translated as follows: follow-up the child's adaptation to the environment after discharge from hospital; encourage the child-family tie; follow-up the weight-structural growth, monitor development, diagnosing and treating deviations at an early stage, observing the particularities of each case; manage the follow-up activities of other professionals involved in caring for the child and analyze the data of out-patient follow-up, seeking to correlate it with pre- and post-neonatal care, in order to promote improvements in the perinatal health service<sup>(8)</sup>.

It is well known that continuity of care after discharge from hospital is fundamental for the quality of life of the prematurely born child and its family, however, to effectuate this care demands support from the health care and social support networks, which have weaknesses in the context of health care for the child in Brazil<sup>(9-13)</sup>.

The need for developing researches in the field of continuity of care for the premature infant leaving a Neonatal Intensive Therapy Unit (NITU) is evident in Brazilian and international studies. It has been found

that there are technical-scientific advancements in neonatal care, however, it is necessary to develop researches that allow the long term visibility of the impact of care provided for the premature newborn, which reveal the strategies used for effectuating the care after discharge from hospital<sup>(1,2,4-5,8)</sup>.

Considering that prematurity is recognized as a public health problem and requires instruments of care that potentiate the quality of life of prematurely born children and their families, and knowing that there are gaps in the production of scientific studies with respect to the strategies to be adopted to effectuate post-discharge care for this population, the aim of the present article was to identify the strategies that are being used to implement the continuity of care of the premature newborn child on leaving the neonatal intensive therapy unit.

## METHODS

The option was taken to perform an integrative review, because this is the broadest type of research review method, which allows the inclusion of experimental and non experimental studies, favoring broad scope of understanding of post-discharge care of the premature infant. This method has the potential to contribute with evidence-based practice, point out the need for further researches, in addition to contributing to the construction of health policies<sup>(14)</sup>.

For the development of this integrative review, the following stages were carried out: identification of the theme; formulation of a guiding question; literature search and selection; categorization and evaluation of the studies and presentation of the review<sup>(15)</sup>.

The study was developed, based on the following guiding question: Which strategies are being used to implement care of premature newborn children, after they are discharged from the neonatal intensive therapy units?

For the literature search and selection, the following databases were defined: Cumulative Index to Nursing and Allied Health Literature, "Literatura Latino-Americana e do Caribe em Ciências da Saúde", Scientific Electronic Library online and Web of Science. The inclusion criteria of the studies were defined as follows: the period of publication between 2001 and 2011, electronically available full text studies; and in the following languages: English, Spanish and Portuguese. The option for this publication period was justified by the finding, based on the bibliographic search, that researches in the neonatal field were more expressive from the beginning of the 1990s, and the majority of specific studies about the continuity of care after discharge from hospital, and long term repercussions of care in NITU, were found from the beginning of 2001.

The key words "prematurity", "discharge" and "technology" were used in an associated manner, and for the

search in LILACS, the same terms were used, and were translated into the Portuguese language.

In the initial search, 213 articles were found, 64 in LILACS, 134 in CINAHL, 11 in SciELO and 4 in the Web of Science. After reading the abstracts, duplicate studies in the different data bases; or in different languages from those defined as inclusion criteria. and those, as perceived after they were read, did not meet the requirements of the proposed theme, were excluded. Of the 22 articles, read in full, only nine answered the guiding question and defined the final sample of this review.

The data were organized<sup>(15)</sup> into a chart, and afterwards, based on the definitions, the items of information pertinent to the objectives proposed in this review were extracted. (Note: Chart 1 does not present all of these aspects)

The Level of Evidences (LE) of the studies was attributed based on the classification proposed by Stetler *et al.*<sup>(16)</sup>: Level I – evidence obtained from the result of metanalysis of clinical controlled studies and with

randomization; Level II – evidence obtained from a study with an experimental design; Level III – evidence obtained from quase-experimental researches; Level IV – evidence obtained from descriptive studies or those with a qualitative methodological approach; Level V – evidence obtained from case reports or reports of experiences ; Level VI – evidence based on the opinions of specialists or based on rules or legislation.

## RESULTS

Among the nine articles included for analysis, the authors of six were doctors and three nurses; as regards the place of publication, two studies were developed in Europe, three in the United States of America, and four in South America. With regard to the period of publication, four articles were published in nursing journals, three in journals in the medical field, and two in interdisciplinary journals in the area of health. The data in Chart I sum up the information in the articles analyzed.

**Chart 1** – Articles about the strategies used to implement the continuity of post-discharge care of the prematurely born child, discharged from the Neonatal Intensive Therapy Unit, 2001-2011

Article Title	Type of Study	Authors	Periodical/Year	Level of Evidence
Folow-up care of high-risk infants	Report on experience	American Academy of Pediatrics. Supplement	Pediatrics /2004 Supplement	V
Building a System of child find a 3 – Tiered Model of follow-up.	Report on experience	Jackson, B.J.; Needelman, H.	Infants & Young Children /2007	V
The Medically Complex Premature Infant in Primary Care	Updating Study	Kelly, M.M.	Journal of Pediatric Health Care /2006	VI
Folow-up of infants following discharge from the neonatal unit: structure and process	Review of the Literature	Dorling, J.S., Field, D.J.	Early Human Development /2006	VI
Seguimento del prematuro/gran prematuro em Atención Primária	Not Defined	Carbonero, S.C., Pallás Alonso, C.R.	Revista de Pediatría de Atención Primaria /2009	VI
Crescimento e desenvolvimento a longo prazo do prematuro extremo	Review of the Literature	Rugolo, L.M.S.S.	Jornal de Pediatria /2005	VI
O seguimento da saúde da criança pré-termo e de baixo peso egressa da terapia intensiva neonatal	Qualitative Descriptive	Vieira, C.S., Mello, D.F.	Texto & Contexto Enfermagem /2009	IV
Prematuros de muito baixo peso: do nascimento ao primeiro ano de vida	Quantitative Descriptive	Tronchin, D.M.R.; Tsunehiro, M.A.	Revista Gaúcha de Enfermagem /2007	IV
Rede de apoio social familiar no seguimento do recém-nascido pré-termo e baixo peso ao nascer.	Qualitative Descriptive	Vieira, C.S., Mello, D.F., Oliveira, B.R.G., Furtado, M.C.C.F.	Revista Eletrônica de Enfermagem /2010	IV

With regard to the research design, the following were identified: two qualitative descriptive studies<sup>(10-11)</sup>, one quantitative descriptive study<sup>(17)</sup>, two review of the literature<sup>(18,19)</sup>, two reports on experiences<sup>(20-21)</sup>, on updating study<sup>(22)</sup> and in one study it was not possible to identify the research design<sup>(23)</sup>, due to lack of clear definition by the authors.

The Level of Evidence – LE of the articles was: three with LE IV<sup>(10-11,17)</sup>, two with LE V<sup>(20-21)</sup>, and four with LE VI<sup>(18-19,22-23)</sup>.

## DISCUSSION

Parallel to the technological advancements that contributed to the survival of increasingly smaller premature newborn infants, there was an increase in the indices of morbidities that accompany these children throughout life. The risk for developing diseases increase with the reduction in gestational age at birth, which justifies the need for post-discharge follow-up of this population, in an endeavor to favor the quality of life of the premature infant and to act at an early stage in the face of alterations found<sup>(10,11,17-23)</sup>.

Considering the strategies that should be implemented to guarantee the continuity of care of the infant discharged from NITU, it is pertinent to show evidence of the dysfunctions presented in the analyzed studies, which premature infants, particularly the extreme cases with a gestational age of under 29 weeks – may present, namely: cerebral palsy<sup>(19,21-23)</sup>, visual impairment and blindness<sup>(17,19,21-23)</sup>, hearing problems<sup>(17,19,22-23)</sup>, learning difficulties – cognitive<sup>(17,19,21-23)</sup>, attention deficit<sup>(17,19,21-23)</sup>, motor coordination problems<sup>(19,21,23)</sup>, psychiatric – behavioral<sup>(17,21-23)</sup> and social interaction problems – family<sup>(10,22,23)</sup>, elevated respiratory morbidity<sup>(17,19,21-22)</sup>, inadequate growth<sup>(10,19,21)</sup>, language problems<sup>(17,19)</sup> and feeding difficulties<sup>(22)</sup>.

In view of these evidences, the analyzed studies presented as the goal of and justification for following up the child at risk, as the possibility of improving its condition in the medium and long term, considering that the continuity of care may enable early treatment and prevention of any delay in growth and development; that is to say, guarantee the premature infant's survival with good quality of life<sup>(10,17,18-20,22-23)</sup>.

In addition to following up the child, preferably until the period of adolescence, another goal of continuity of care is to provide support for the family, in order to favor care of their child at risk<sup>(10,18,22-23)</sup>. The construction of a link and taking responsibility are pointed out as fundamental strategies for successful follow up and reduction in the chance of evasion of children from the follow-up programs<sup>(10,18)</sup>.

In order to achieve the objectives of following up the premature infant, the analyzed studies pointed out the need

for a structure to care for children discharged from the Neonatal Intensive Therapy Unit and affirm that the multiprofessional team<sup>(18-19,22-23)</sup>, composed of social assistants, nurses, pediatricians, psychologists, occupational therapists, nutritionists, physiotherapists and phonoaudiologists, with the support of specialists from the areas of cardiology, ophthalmology, neurology and otorhinolaryngology<sup>(10)</sup>, must be apt to care for the child at risk, considering its specificities of growth and development.

The care strategies must begin in the first week after the children are discharged. They must be included a continuous, flexible and dialogic process<sup>(10)</sup> of evaluation, including observation of the children during consultation, participation and appreciation of the parents' opinion<sup>(10,17,19,21-23)</sup>, systematic neurological exam, evaluation of the landmarks of development with the use of triage tests and growth evaluation based on anthropometric data<sup>(17,19,22-23)</sup>.

With respect to the nurse's action, as protagonist of the strategies to implement the care of the premature infant, the authors of the analyzed studies thought that this professional has the ability to manage the care of the infant discharged from the NITU, in addition to developing activities in conjunction with the team, thereby making it feasible for the family to adhere to follow-up. In this context the nurse is recognized as facilitator of the process of constructing the family's autonomy in taking care of the premature infant after discharge from hospital<sup>(10-11,20)</sup>.

The authors warn that one of the strategies that must be adopted by health professionals in caring for the prematurely born child, is to adjust its chronological age to the corrected gestational age, up to 2 years of age, and thus, not underestimate the results expected for growth and development<sup>(18-19,21,23)</sup>.

Another strategy for monitoring a child at risk is telephone contact, particularly right after discharge, to check any doubts, or problems the family may have with the child. In this contact, a questionnaire may be used to verify the child's vulnerability to morbidities, however, this must be used by trained persons, because the parents may overestimate their child's condition<sup>(18,21)</sup>.

Four studies analyzed pointed out the need for integration between Primary Health Care and the program of follow-up and implementation of the intersectoriality of services, as strategies to guarantee the continuity of care of the child at risk and its family<sup>(10,20,22-23)</sup>.

One of the strategies used to guarantee the continuity of care, by means of a system of monitoring children discharged from NITU was described in one of the studies analyzed. The partnership between health services, social services, education and families to operationalize an articulated structure and continuity of care, is the axis of structuring this strategy for following up premature infants, created in the State of Nevada (USA). In this experience with the implementation of the *Developmen-*

tal TIPS (*Tracking Infants' Progress Statewide*), the children discharged from an ITU are monitored<sup>(20)</sup>.

In the implantation of *Developmental- TIPS*, which has presented favorable results up to now, in addition to intersectoriality, a fundamental factor was financing of this program by the American Academy of Pediatrics, in addition to the involvement of representatives (doctors and nurses) from hospitals in the State of Nevada, State congressmen and coordinators of social and educational services<sup>(20)</sup>.

In contrast to this successful experience, it was verified in Brazilian studies, that families of prematurely born children are distanced from the primary health care services<sup>(10-11,17)</sup>. The centrality on biologic aspects was also evidenced in three studies, and reflects a fragmented care, as there is no space for interaction with the family, which a strategy is pointed out as being favorable to the continuity of care<sup>(10-11,20)</sup>.

The programmatic vulnerability of the child at risk was the conclusion of two of the studies developed in Brazil. This vulnerability is a reflection of the weakness between integration of the services and absence of activities of reference and counter-reference and intersectoriality shown, as important strategies for effectuating the continuity of care<sup>(10,20)</sup>.

Researches revealed that evasion from the follow-up program was between 20% and 25%<sup>(19,23)</sup>. The nonexistence of active strategies to seek out these children is an aggravating factor of this process<sup>(17)</sup>.

One of the strategies mentioned for maintaining this adhesion, is permanent disclosure of the actions of the follow-up program, which must be carried out with family members, right from the period of hospitalization with continuity after discharge<sup>(17,20)</sup>. Another strategy pointed out for maintaining the adhesion of the children's families in the program is building a tie with them<sup>(10,20)</sup>.

One of the studies analyzed presented the following strategies for reducing evasion: provide the parents with information during the period of hospitalization; keep records of various addresses, such as those of other family members and parents' place of work, after discharge; keep in touch until the first visit to the out-patient clinic takes place; strengthen communication among the professionals of the health services at primary, secondary and tertiary levels; make available a reference professional who the family can contact after working hours; offer care, according to the availability of the family, using the home visit strategy<sup>(18)</sup>.

In addition to the health services, other constituent elements of care are pointed out as being necessary to implement post-discharge care, such as a social support network (ties of friendship with the family) and the social network (composed of different institutions, such as schools, health, community and church services). The social network is identified as an element that helps to

strengthen the family in the face of their life experiences, acting in reducing the mortality rate, preventing damage to and in recovering health. The backing of a support network is identified as being fundamental to families in facing crises, such as the birth of a premature child<sup>(11,22)</sup>.

The need for the development of researches to evaluate the care provided and monitor the actions developed after discharge from hospital is pointed out as being a strategy for the maintenance of programs to follow-up premature infants<sup>(17-21)</sup>. There is a need for long term studies, such as randomized controlled trials, cohort studies and multicentric researches, since perinatal interventions may alter the growth and development of the premature infant<sup>(21)</sup>, however, the high cost of these proposals associated with the cost of follow-up programs have been shown to be obstacles.

This review made it evident that the strategy for vigilance was to establish mechanisms for systematically monitoring the care of high risk infants during hospitalization and after discharge, comprising a panorama of the development and growth of the children, which would allow the planning of care and propose improvements in interventions in the ITU and out-patient clinics<sup>(20-21)</sup>.

## CONCLUSION

The level of evidence of the analyzed studies indicates that it is opportune to invest in controlled clinical researches with randomization, and studies with an experimental design to contribute to improvement in neonatal care during hospitalization and after discharge from hospital.

The risk of morbidities and mortality, to which the premature infant is exposed, demand the production of programmatic actions capable of meeting its needs and those of its family.

In order to implement the network of care for prematurely born infants, the studies showed that actions in conjunction with different services and sectors (health, education, nongovernmental organizations, community) are necessary, in addition to systematization of follow-up of the child, based on protocols, monitoring the results obtained and on the development of researches.

Management of care and guidance for the family, in order to exercise autonomy in taking care of the premature infant after discharge from hospital, are strategies performed by nurses to favor continuity of the care.

By means of this study, it is emphasized that the construction of ties, taking responsibilities, intersectoriality, technical scientific knowledge of the professionals for the care of infants discharged from the ITU and favorable public policies are important strategies to consider in the construction of programs for the follow-up of premature infants and their families.

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