Care transition of preterm infants: from maternity to home

A transição do cuidado do recém-nascido prematuro: da maternidade para o domicílio La transición del cuidado del recién nacido prematuro: de la maternidad al domicilio

> Nalma Alexandra Rocha de Carvalho¹ https://orcid.org/0000-0003-2545-1636 José Diego Marques Santos² https://orcid.org/0000-0001-7973-7678 Isabela Maria Magalhães Sales¹ https://orcid.org/0000-0002-4687-0197 Agostinho Antônio Cruz Araújo¹ https://orcid.org/0000-0003-0996-0385 Anderson da Silva Sousa³ https://orcid.org/0000-0003-3818-3247 Fernanda Ferreira Morais¹ https://orcid.org/0000-0001-9746-6883 Silvana Santiago da Rocha¹ https://orcid.org/0000-0002-1325-9631

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Descriptores

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Corresponding author

Nalma Alexandra Rocha de Carvalho E-mail: enf.nalma.carvalho@hotmail.com

Abstract

Objective: To synthesize evidence about maternal care for preterm infants at home and develop a framework that guides the transition of care of preterm infants from maternity to home.

Methods: This is an integrative literature review that followed methodological recommendations to answer the question: "What is the scientific evidence about maternal care for preterm infants at home?". To select the articles, LILACS and BDENF were used via the VHL Portal, PubMed/MEDLINE, Scopus, CINAHL and Web of Science via the CAPES Journal Portal.

Results: A visual synthesis of results was obtained through a framework. This synthesis facilitates knowledge translation and the applicability of nursing interventions during care transition from maternity to home, based on evidence. Analysis of these studies revealed three categories: Feelings of mothers during the care of preterm infants at home; Caring for preterm infants at home; Support network for caring for preterm infants

Conclusion: During the transition from maternity to home, families face a whirlwind of feelings that can be paradoxical. The joy due to hospital discharge can also emerge with anxiety and insecurity about the family's' new role. The framework on care transition of preterm infants from maternity to home presented in this study is relevant for facilitating the understanding of the health interventions' finding and its applicability to promote a safe transition for preterm infants.

Resumo

Objetivo: Sintetizar evidências acerca do cuidar materno ao recém-nascido prematuro no domicílio e elaborar um framework que oriente a transição do cuidado do recém-nascido prematuro da maternidade para o domicílio.

Métodos: Revisão integrativa da literatura que seguiu recomendações metodológicas para responder à questão: "Quais são as evidências científicas acerca do cuidado materno ao recém-nascido prematuro no domicílio?". Para seleção dos artigos, utilizou-se seis bases de dados: LILACS e BDENF via Portal BVS; PubMed/ Medline, Scopus, CINAHL e Web of Science via Portal de Periódicos CAPES.

Resultados: Por meio do famework, é possível obter uma síntese dos resultados de forma visual, facilitando a tradução do conhecimento e a aplicabilidade de intervenções de enfermagem durante a transição do cuidado do prematuro, da maternidade para o domicílio, baseados na síntese de evidências. A análise desses estudos revelou três categorias: Sentimentos de mães durante o cuidado do prematuro no domicílio; O cuidar do prematuro no domicílio e Rede de apoio no cuidado do prematuro no domicílio.

¹Universidade Federal do Piauí, Teresina, PI, Brazil. ²University of Saskatchewan, Saskatoon, Canada 3Universidade Federal do Rio Grande do Norte, Natal, RN, Brazil.

Conclusão: Durante a transição da maternidade para casa, a família enfrenta um turbilhão de sentimentos que podem ser paradoxos, tendo em vista que o regozijo por conta da alta-hospitalar pode emergir também com a ansiedade e insegurança sobre o novo papel. O *framework* sobre a transição do cuidado do recém-nascido prematuro da maternidade para o domicílio apresentado nesse estudo é relevante por facilitar o entendimento dos achados e a aplicabilidade de intervenções de saúde para promover uma transição segura do recém-nascido prematuro para domicílio.

Resumen

Objetivo: Sintetizar evidencias sobre el cuidado materno al recién nacido prematuro en el domicilio y elaborar un framework que oriente la transición del cuidado del recién nacido prematuro de la maternidad al domicilio.

Métodos: Revisión integradora de la literatura que siguió recomendaciones metodológicas para responder la pregunta: "¿Cuáles son las evidencias científicas sobre el cuidado materno al recién nacido prematuro en el domicilio?". Para la selección de los artículos, se utilizaron seis bases de datos: LILACS y BDENF vía Portal BVS; PubMed/ Medline, Scopus, CINAHL y Web of Science vía Portal de Periódicos CAPES.

Resultados: Por medio del *framework*, es posible obtener una síntesis de los resultados de forma visual, lo que facilita la traducción del conocimiento y la aplicabilidad de intervenciones de enfermería durante la transición del cuidado al prematuro de la maternidad al domicilio, basadas en la síntesis de evidencias. El análisis de estos estudios reveló tres categorías: Sentimientos de las madres durante el cuidado del prematuro en el domicilio, Los cuidados del prematuro en el domicilio y Red de apoyo en el cuidado del prematuro en el domicilio.

Conclusión: Durante la transición de la maternidad a la casa, la familia enfrenta un torbellino de sentimientos que pueden ser paradójicos, ya que la alegría por el alta hospitalaria puede aparecer junto con la ansiedad y la inseguridad sobre el nuevo rol. El framework sobre la transición del cuidado del recién nacido prematuro de la maternidad al domicilio presentado en este estudio es relevante porque facilita la comprensión de los descubrimientos y la aplicabilidad de intervenciones de salud para promover una transición segura del recién nacido prematuro al domicilio.

Introduction

Prematurity is a condition related to the birth of babies before 37 complete weeks of gestation and has been identified worldwide as the main cause of neonatal morbidity and mortality for about a decade; currently, it is also associated with infant mortality up to the age of five. Universally, 15 million babies are born preterm each year, accounting for approximately 11% of all births; these numbers have been increasing in most countries.⁽¹⁾

Brazil had more than 279 thousand preterm births in the last decade, totaling about 17.7% of deliveries, and presented startling rates of prematurity that results in neonatal death in approximately 70% of cases. Early or late pregnancy are among the main causes of preterm birth, followed by malnutrition, low birth weight, infertility treatments, infections and obstetric complications in general, in addition to quality prenatal care. (2)

Preterm babies often need intensive neonatal care as well as technological support so that they can adapt satisfactorily to extrauterine life and often face a long period of hospitalization. Even after Neonatal Intensive Care Unit (NICU) discharge, the unit responsible for maintaining the physiological balance of preterm babies, there is still a marked risk of morbidity and mortality for infants. They are patients with unpredictable clinical conditions

and who need daily care from parents who may be unprepared. These circumstances prolong the risk of morbidity and mortality even after hospital discharge.⁽³⁾

Against this backdrop, it is necessary to plan appropriate actions so that preterm babies are assured a safe and comfortable transition from hospital to home. Discharge planning must be developed and implemented by physicians, nurses, psychologists, physiotherapists, nutritionists, pharmacists, social workers, together with parents and other family members. Moreover, discharge planning should count on support and reference of primary health care professionals that will carry out a follow-up. This joint work for hospital discharge facilitates family readiness and improves the results of this transition. (4)

Thus, actions should be developed that involve support, guidance and instrumentalization to parents or companions for daily care with preterm babies since their admission. This information must be reinforced during hospitalization taking into account the individualities and the ability to understand each family, in order to strengthen coping at hospital discharge.⁽⁵⁾

Therefore, it is up to health professionals to face all challenges of promoting health education actions, such as guidance to mothers about care related to hospital discharge of preterm infants.

However, the scientific literature still reveals a need for knowledge translation about the needs of families of preterm infants in the practice of health professionals. (6) A study conducted in Iran found that nursing professionals still cannot fully understand the needs of families of preterm infants. (7) Moreover, a survey conducted in China highlighted the need for health professionals to be able to hear complaints from preterm infants' parents. (8)

Facing this, this work aims to synthesize evidence about maternal care for preterm infants at home and to develop a framework that explains care transition of preterm infants from maternity to home.

Methods

This is an integrative literature review. (6,7) To this end, the "Population/Problem, Interest and Context" (PICo) strategy was used. (8) "P" corresponding to "preterm infants' parents"; "I" is equivalent to "maternal care"; "Co" means "transition from hospital to home". Keywords and their respective controlled descriptors are described in Chart 1.

Chart 1. Research question according to the Population/ Problem, Interest and Context strategy (PICo) (English and Brazilian Portuguese)

Acronym/ Definition	Study's proposal	Keywords	NCD	Туре
P Population/ Problem	Maternal care	"Comportamento Materno"	"Comportamento Materno", "Cuidado Materno", "Cuidado da mãe"	DeCS
		"Maternal Behavior"	"Maternal Behavior", "Behavior, Maternal", "Maternal Care Patterns", "Care Pattern, Maternal", "Maternal Care Pattern", "Pattern, Maternal Care"	MeSH/ Títulos CINAHL
I Interest	Preterm infant	"Recém-Nascido Prematuro"	"Recém-Nascido Prematuro", "Bebê Prematuro", "Neonato Prematuro", "Neonato Pré- Termo", "Prematuridade", "Prematuro", "Pré-Termo", "Prematuros", "Recém- Nascido Pré-Termo"	DeCS
		"Infant, Preterm"	"Infant, Preterm", "Infants, Preterm", "Preterm Infant", "Preterm Infants", "Infant, Preterm", "Infants, Preterm", "Preterm Infant", "Neonatal Prematurity"	MeSH
Со		"Habitação"	"Habitação", "Domicílio"	DeCS
Context	Home	"Home nursing"	"Home nursing"	MeSH

NCD – non-controlled descriptor

Thus, the guiding question developed based on the PICo acronym was: "What is the scientific evidence about maternal care for preterm infants at home?". Six databases were used for article selection: LILACS (Latin American & Caribbean Literature in Health Sciences), BDENF (Brazilian Nursing Database) via the VHL Portal (Virtual Health Library), PubMed/MEDLINE (National Library of Medicine), Scopus - Elsevier's multidisciplinary database, CINAHL (Cumulative Index of Nursing and Allied Health Literature) and Web of Science via CAPES Journal Portal.

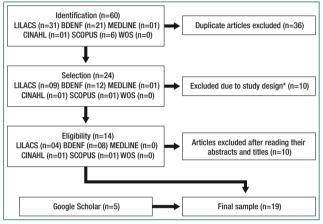
Article search took place between April and May 2019, using controlled, non-controlled descriptors and keywords. The combination of descriptors and keywords was performed using the Boolean operators "AND" and "OR," aiming to expand the number of studies. Descriptors were gathered from DECS (Brazilian Health Sciences Descriptors) on VHL Portal and from MESH (Medical Subject Headings) in the National Library. "OR" was used between descriptors/keywords of PICo strategy's same acronym, and "AND," for the combination of different acronyms.

The selection was carried out independently by two reviewers, and the search and selection process of the studies followed the PRISMA recommendations⁽⁹⁾. Primary, qualitative studies that addressed the subject in question have been included. Studies that did not address maternal care transition for preterm infants at home or duplicate articles were excluded. In order to cover the maximum number of studies for the review process, there was no delimitation of time or language during searches. Qualitative studies were included regardless of their methodological approaches.

Qualitative studies were delimited due to their methodological ability to bring aspects and perceptions about feelings and experiences about maternal care for preterm infants at home. (10)

Thus, a sample of 24 articles was obtained at the end of the first assessment stage, being 15 from LILACS, 05 from BDENF, 01 from MEDLINE, 01 from CINAHL, 02 from SCOPUS and none from WOS. In the second step, the 24 studies were read in full to identify those who answered the re-

search question satisfactorily and/or had relevance to the study objective. A sample of 14 articles was obtained from this process. As the review's partial sample had an underrepresented number of international articles, a third researcher conducted searches via Google Scholar in order to add articles that contributed to the answer to the research question. Thus, five international articles from other searches were added, totaling a final sample of 19 articles. A flowchart detailing the research steps is shown in Figure 1.



*Quantitative and non-primary studies have been excluded

Figure 1. Flowchart of the study identification, selection and inclusion process, adapted from PRISMA.

The framework was elaborated after a collective construction of the authors based on readings and correlation of the results obtained. Frameworks correspond to visual representations that help to understand complex issues. (9) This method of graphic explanation has been used internationally to explain health determinants and to understand the impact of these determinants on individuals', communities' and populations' well-being. (10-12) Through clear descriptions of the complex factors that interfere with care transition of preterm infants, the proposed framework has quality and depth because it is based on a systematic review process of the literature, and has specificity because it was developed by experienced health professionals in maternal and child health and public health.

The first author and the supervisor of this work met in the maternal and child nursing study group at *Universidade Federal do Piauí* (UFPI) to

discuss the selected articles and carry out the synthesis of knowledge. The other authors carried out their reviews and sent their comments and discussion points through email. The authors created the framework figures, protected by copyright.

Results =

It was found that the 19 selected studies were published between 2004 and 2018; most (four) was published in 2012 (21.05%), and three were published in 2010 (15.79%). Two articles were published in 2014, 2017 and 2018, representing a sample of 10.53% each year; only one article was published in 2004, 2008, 2009, 2011, 2013, 2016 (5.26% each).

Concerning the main results, it was evident that all articles dealt with issues related to professional support/guidance to parents both at admission and during and after discharge. Furthermore, the relevance of family/social support in care transition for preterm infants from hospital to home was reported. They also addressed issues related to concerns, feelings, difficulties and facilities when caring for preterm infants at home. These data were presented in Chart 2.

Regarding the feelings experienced, most articles reported that mothers facing home care presented mainly feelings of fear (13,15,16,22-24,26,28,30,31), insecurity, (13,15-18,20-24) anxiety, (13,18,20,23,26,29,31) concern (15,17,18,27), and guilt. (13,19,27) Joy (24,27,30,31) and self-confidence (16,20) stood out as paradox and negative feelings as they contrast with the family's insecurity during hospital-home transition.

The most frequent home care in the publications analyzed were related to the use of medications, (13,16,23,24,28) cleaning the home environment, (24) visits, (13,14,27) returning to outpatient consultations (24) and with specialists to monitor preterm infants' growth and development (16,22), vaccination, (20,22,23,26) neurological sequel prevention (16) and infection prevention. (13,15) With regard to routine daily care, the most cited were related to food (breastfeeding and other forms), (13,15,17,18,21–23,26,28) hygiene, (20,22,28,31) sleep (13,16,24), and clothing. (13,22)

Chart 2. Synthesis of articles included in the integrative review

n°	Authors/ Year	Type of study	Country/ Language	Main results
01	2004(13)	Participatory methodology	Brazil/ Portuguese	Through an educational booklet, guidance was given to mothers on simplified care for their preterm children.
02	2008(14)	Descriptive	Brazil/ Portuguese	The mothers' perception reveals predominantly intra-family support, mainly by the grandmother, responsible for building and managing the nest and social inclusion.
03	2009(15)	Descriptive	Brazil/ Portuguese	Mothers performed care according to their needs in view of their child's growth and development.
04	2010(16)	Exploratory- descriptive	Brazil/ Portuguese	Mothers appear as an important figure during their child's hospitalization period. Family support was a difficulty encountered; however, it was based on past situations with other children.
05	2010(17)	Descriptive	Brazil/ Portuguese	Preterm children's development can be hindered by the lack of family psycho-emotional support.
06	2010 ⁽¹⁸⁾	Descriptive	Brazil/ Portuguese	Negative feelings interfere with family life, work and social life, as well as the health team's lack of preparation on the guidelines for care transition from hospital to home.
07	2011(19)	Phenomenological	USA/ English	Hospital to home transition was marked by fear; however, as her son's health improved, there was a gain in confidence by mothers.
08	2012(20)	Social Representations Theory	Brazil/ Portuguese	Family dynamics and the environment at home are configured as influencers in the recovery of preterm babies' health, as well as their development.
09	2012(21)	Descriptive	Brazil/ Portuguese	Mothers' insecurity was observed in caring for their children at home since there is a judgment by caregivers about the need for a health team to assist them.
10	2012(22)	Descriptive	Brazil/ Portuguese	The importance of an educational booklet offered by service is highlighted, as well as the relevance of social support, especially family support, for caring for babies at home.
11	2012(23)	Descriptive	Brazil/ Portuguese	The need to apply a flowchart to inform the formal support networks that will monitor preterm infants after discharge stood out.
12	2013(24)	Descriptive	Brazil/ Portuguese	It was observed that some mothers did not receive guidance on home care from the team that provided assistance to their children.
13	2014(25)	Descriptive	Iran/ English	At the time of hospital discharge, parents had doubts about home care to be performed on their children.
14	2014(26)	Convergent- assistance research	Brazil/ Portuguese	Nurses provided guidance aimed at parents' doubts and insecurities, mostly related to the babies' weight.
15	2016(27)	Descriptive	USA/ English	Interference was observed in family dynamics, marked by fatigue, social isolation and concern regarding caring for babies.
16	2017(28)	Descriptive	Uganda/ English	Mothers who gave birth at the hospital had a better understanding of appropriate home care practices for low birth weight babies, compared to mothers who had children at home or at a lower level health facility.
17	2017(29)	Descriptive	Brazil/ Portuguese	The importance of properly assisting mothers in this initial and critical phase of hospitalized preterm infants is emphasized, emphasizing welcoming and permanent guidance for care as strategies that promote maternal autonomy and home adaptation.
18	2018(30)	Narrative investigation	England/ English	The parents' experience of being discharged at home with a preterm baby can be emotionally challenging and requires a series of support mechanisms to cope with the transition period, such as the participation of health professionals.
19	2018(31)	Convergent- assistance research	Brazil/ Portuguese	A folder was elaborated that contemplated themes related to the Kangaroo Position, skincare and hygiene of infants, and respiratory changes as a warning sign, so that care could continue at home.

Figure 2 shows the care transition framework of preterm infants from maternity to home, elaborated through literature review. It is possible to obtain a synthesis of results in a visual way through the framework, facilitating knowledge translation and the applicability of nursing interventions during care transition of preterm infants from maternity to home, based on evidence.

Discussion

The graphic structures presented here in the form of a framework can support innovative planning and development of health interventions for the population in question. To that end, positive/negative feelings, home care and the support network that influence the success of the care transition of preterm infants from maternity to home are crucial. Based on the framework, three main axes of discussion are

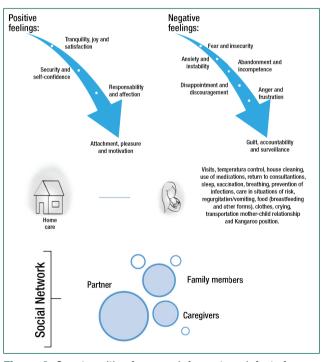


Figure 2. Care transition framework for preterm infants from maternity to home

highlighted: Mothers' feelings during care for preterm babies at home; Caring for preterm infants at home; Support network for caring for preterm infants at home. Groupings in the framework allow an easy visualization of paradoxical feelings: two arrows angled downwards, containing a synthesis of negative and positive feelings. The arrows point towards home care, as if expressing about them and, in a way, influencing the home and preterm babies' mothers. Finally, the support network is represented with circles of different sizes, drawing attention to partners, family members and caregivers, whether they are formal (healthcare professionals) or informal (family or friends).

Mothers' feelings during care for preterm babies at home

Arriving at home with babies represents a break with the world of hospitalization and creates home-specific situations. All of these issues stem from paradoxical expectations that land among the concerns of families right after the birth of preterm babies. The first expectation is birth with life (positive) followed by hospitalization that comes together with separation between mothers and children (negative). Families recognize their limitations, trust the health team that over time they will feel better, and their babies will be discharged, which is the most awaited moment by parents. Upon discharge, other feelings arise, which can also generate both positive and negative impacts. While there is a relief for having children at home, there is anguish on the part of mothers due to the fact that they no longer have a health team in care. In this way, feelings of concern are revealed due to possible complications, as parents attribute to their children a greater degree of fragility when compared to a term child. Therefore, they think of their babies as more susceptible to serious illnesses or recurrent hospitalization. (21,24,30)

The deficiency in the process of preparing for discharge may be responsible for feelings of insecurity and fear in home care. Although the expectation before discharge involves conflicting feelings, it is clear that when mothers receive consistent guidance during the babies' hospitalization, the transition and adaptation process for carrying out home care becomes milder. (15,17,19,23,29,31)

Thus, efforts dedicated to encouraging the insertion and regular participation of families in caring for preterm children during hospitalization must be constant. Creating educational programs in neonatal units can facilitate mothers' learning about the care that should be provided to preterm infants at home, strengthening the affective bond and reducing the feeling of insecurity, which is a frequent complaint of parents in this situation. (16,21,23,24)

Thus, the transition of a preterm baby from hospital to home is multidimensional, complex, and a dynamic phenomenon for parents. Parents' stress, concern and anxiety exist; however, they can be minimized by the safety that health professionals transmit during the hospital-home transition. (15,24,27)

Support network for caring for preterm infants at home

Social support is an important factor in home adaptation and a source of overcoming the difficulties encountered, even if the individual conditions of each family are considered. Such support is necessary, mainly, in adjusting the family to possible changes. Thus, the actors who contributed most to this adjustment or adaptation process were family members. (23,24)

For example, the help of a partner in sharing care contributes to maternal well-being in caring for babies at home. With active participation of fathers in home care, the burden of caring for children is alleviated. It is outdated to expect only mothers should be responsible for basic baby care such a view is sexist and should be discouraged; therefore, it is up to health professionals to be aware of the visibility of fathers in the transition process and encourage the inclusion of fathers in care. A gradual insertion of fathers in the role of caregivers can also be established at a neonatal unit so that both professionals and parents can identify the learning and adaptation needs in preparation for home care for preterm children. (16,22) Grandmothers are perceived by mothers as the most significant sources of support and responsible for the social construction of families. (14,29) Grandparents' participation is particularly important, especially in families of primiparous mothers; they contribute by having experience in caring for children, adding confidence to parents who are experiencing a new role.

A professional support network must start even when preterm infants are admitted; during this period of hospitalization, professionals must gain confidence to understand the families' desires, and this can allow nurses to provide more appropriate, directed and focused information and instrumental support. (19) A study carried out in England with 14 parents of preterm infants showed a need for health professionals to carry out in-hospital training on the differences and specific needs of preterm infants. In the study setting, several strategies were used to prepare participants to care for their infants at home, including resuscitation training, parentcraft and the opportunity to stay with their babies overnight. (30)

Beliefs about caring for preterm babies were raised in a study of 16 Ugandan mothers. Mothers who gave birth at home and had no hospital assistance believed that their children are like any other baby and do not need special care unless they appear weak and inactive. They believed that physical inactivity, rather than birth weight, was the indicator that babies were not normal. On the contrary, mothers who received assistance from health services believed that babies, as they were born with low weight, are delicate, prone to disease and need special care even when they do not appear to be sick.⁽²⁵⁾

The discharge of preterm neonates from the NICU without the necessary professional support can cause parents to be insecure about the provision of home care. Failure of the health team to pass on information to parents and to elucidate timely and appropriate questions in relation to care can lead to irrecoverable consequences in neonates. (27,28)

Caring for preterm infants at home

Although parents can predict that going home will be a positive and stimulating event, it also means that they will no longer have the support they received during their stay at NICU. Not counting on this care can be scary and unsettling for the family. (30) In this regard, the philosophy of care centered on the person and family stands out for reinforcing the importance of intrafamily care and being important to strengthen values, beliefs and the culture established in each home. (32)

Home care involves several particularities arising from prematurity and specific needs of at-risk babies; even if they are considered basic care, as related to hygiene and comfort, they generate doubts and burden on caregivers. (23) By recognizing the susceptibility of preterm infants to the fragility of their immune system, mothers prevent infections by restricting visits, taking care of utensils, and assuring vaccination. (15)

Issues related to food, hygiene, heating and infection prevention are commonly described in the literature when addressing preterm care at home. Regarding food, mothers prioritize exclusive breastfeeding. Thus, breast milk is valued, and mothers are able to identify the necessary changes regarding the quantity and frequency of breastfeeding. Concerns still arise about the time of weaning, hygiene and weight gain of infants. (15,18,25,29)

Despite the fact that caring for low birth weight infants has challenges, mothers are able to overcome them with proper health education. (25) Health professionals must recognize the complexity of the transition of infants from hospital to home, know how to hear complaints, and simplify care through health education practices by using booklets, for instance. (13,31)

Conclusion

This integrative literature review summarizes evidence about maternal care for preterm infants at home. During the transition from motherhood to home, the family faces a whirlwind of feelings that can be paradoxical. The joy due to hospital discharge can also emerge with anxiety and insecurity about the family's new role. Regarding home care, there is an emphasis on food, hygiene and use of medications. Regarding actors who build the support network in this transition process for mothers, the following were highlighted: family members, partners, and health professionals. The framework on care transition of preterm infants from maternity to home presented in this study is a novelty for health knowledge translation at hospital discharge for preterm infants. This framework is relevant for

facilitating the understanding of the health interventions' findings and its applicability to promote a safe transition for preterm infants. Although relevant, this research finds as limitations the construction of search terms for databases and a shortage of international articles on some researched bases.

Collaborations:

Carvalho NAR, Santos JDM, Sales IMM, Araújo AAC, Sousa AS, Morais FF and Rocha SS contributed to study design, analysis and interpretation, writing of the article and approval of the final version to be published.

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