

VIVÊNCIAS DAS FAMÍLIAS NO CUIDADO DOMICILIAR ÀS CRIANÇAS PREMATURAS: REVISÃO SISTEMÁTICA QUALITATIVA

FAMILIES' EXPERIENCES IN HOME CARE FOR PREMATURE CHILDREN: A QUALITATIVE SYSTEMATIC REVIEW

EXPERIENCIAS FAMILIARES EN EL CUIDADO DOMÉSTICO PARA NIÑOS PREMATUROS: REVISIÓN SISTEMÁTICA CUALITATIVA

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RESUMO

Objetivo: Analisar como as famílias vivenciam o cuidado domiciliar às crianças prematuras egressas da Unidade de Terapia Intensiva Neonatal. **Método:** Revisão sistemática qualitativa, realizada em 7 bases eletrônicas de dados e construída conforme as diretrizes propostas pelo Joanna Briggs Institute e o guia internacional PRISMA. Incluíram-se 27 estudos, considerando-se: tipo de estudo; ano de publicação; idioma; população e contexto do estudo e artigos disponíveis *em fulltext*. Os estudos incluídos foram avaliados quanto à qualidade metodológica e, posteriormente, lidos na íntegra. Os dados qualitativos extraídos foram agrupados em códigos e, seguidamente, analisados. **Resultados:** O cuidado às crianças prematuras egressas da UTIN exige mudanças na organização familiar e os profissionais de saúde são identificados como a principal fonte de informação e segurança. Nota-se o envolvimento de todos os membros da família nos cuidados iniciais, e a criança torna-se o foco da família, que compartilha sentimento de alegria e felicidade, medo e insegurança no que tange aos cuidados com as crianças. **Conclusão:** A proximidade com o filho após a alta é relatado pelos pais como positivo, entretanto, o cuidado pode ser permeado por dificuldades e incertezas, reforçando a importância do apoio dos familiares e dos profissionais de saúde.

Descritores: Recém-nascido Prematuro; Família; Assistência Domiciliar; Alta do Paciente; Cuidado do Lactente.

ABSTRACT

Objective: To analyze how families experience the home care of premature children recently discharged from the Neonatal Intensive Care Unit (NICU). **Method:** A systematic qualitative review performed in 7 electronic databases and built according to the guidelines proposed by the Joanna Briggs Institute and the PRISMA international guide. It included 27 studies considering: type of study; year of publication; language; population and context of the study, and articles available in full text. The included studies were evaluated as to methodological quality and, later, read in full. The extracted qualitative data were grouped into codes and then analyzed. **Results:** The care for premature children recently discharged from the NICU requires changes in family organization and the health professionals are identified as the main source of information and safety. The involvement of all family members in early care is observed, and the child becomes the focus of the family, as they share joy and happiness, as well as fear and insecurity, about child care. **Conclusion:** The proximity to the child after discharge is reported by parents as positive; however, care can bring difficulties and uncertainties, reinforcing the importance of support from family members and health professionals.

Descriptors: Premature Infant; Family; Home Nursing; Patient Discharge; Infant Care.

RESUMEN

Objetivo: Analizar cómo las familias experimentan el cuidado en casa de niños prematuros en la Unidad de Cuidados Intensivos Neonatales. **Método:** Examen cualitativo sistemático, realizado en 7 bases de datos electrónicas y construido según las directrices propuestas por el Instituto Joanna Briggs y la guía internacional PRISMA. Incluyó 27 estudios considerando: tipo de estudio; año de publicación; idioma; población y contexto del estudio y artículos disponibles en texto completo. Los estudios incluidos se evaluaron en cuanto a su calidad metodológica y posteriormente se leyeron íntegramente. Los datos cualitativos extraídos se agruparon en códigos y luego se analizaron. **Resultados:** El cuidado de niños prematuros que fueron dados de alta de la UCIN requiere cambios en la organización familiar y se identifica a los profesionales de la salud como la principal fuente de información y seguridad. Se observa la participación de todos los miembros de la familia en la atención temprana, y el niño se convierte en el centro de atención de la familia, que comparte una sensación de alegría y felicidad, miedo e inseguridad sobre el cuidado del niño. **Conclusión:** La proximidad al niño después del alta hospitalaria es considerada por los padres como algo positivo, sin embargo, la atención puede estar permeada por dificultades e incertidumbres, lo que refuerza la importancia del apoyo de los miembros de la familia y los profesionales de la salud.

Descriptores: Recién Nacido Prematuro; Familia; Atención Domiciliar de Salud; Alta del Paciente; Cuidado del Lactante.

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INTRODUCTION

About one in ten children are born premature worldwide, representing 11.1% of all births. Brazil is among the ten countries with the highest rates of premature births⁽¹⁾. With regard to the repercussions on the use of health services, it is the main cause of hospitalization in Neonatal Intensive Care Units (NICU) and its complications are responsible for the high rate of mortality and morbidity of children born early⁽²⁾. Due to the increased risk of developing morbidities, such as stunting and delayed neurodevelopment, the follow-up of children born prematurely must extend after discharge, and continuity of care in specialized follow-up is extremely important⁽³⁾.

Considering that prematurity increases the vulnerability to the health of newborns and children⁽¹⁾ and the demand for care, throughout life, the magnitude of this situation is demarcated when it impacts on health services and also on the people's lives, be they children, those responsible for their care and the society in which they are inserted.

The initial demands of care for a premature newborn are especially for maintaining life. The intensive and specialized care offered in the environments of the Neonatal Intensive Care Units, are decisive for the survival and prognosis of children. This entire care process is usually accompanied by the parents, with repercussions on the wider family context. Emotional, biological, physical efforts and financial expenses are some of the situations that the newborn's parents and family need to deal with, in this initial phase⁽⁴⁾.

The child's departure to the home requires the family to be prepared to assume the responsibility of managing and providing care in the home environment⁽⁵⁻⁷⁾. According to authors, after hospital discharge, premature infants need basic care related to food and hygiene⁽⁸⁻⁹⁾, as well as administration of medication for continuous use⁽⁸⁾, even more complex care, such as handling devices for oxygen therapy and diet administration, when the child's condition requires the use of these technologies⁽¹⁰⁾. In addition, tasks related to special follow-up are needed, such as speech therapy, physiotherapy, neurology, among others⁽¹¹⁾.

The increased demands for care can bring greater burdens on the family, especially for the mother, who is the main caregiver in most cases^(3,12). Because it is a condition of variable course, prematurity can cause significant changes in the lives of caregivers, such as interrupting work

routines⁽⁹⁾, changing the domestic routine, due to the priority of care⁽¹³⁾, bringing significant repercussions regarding economic conditions family⁽⁹⁾, social isolation⁽¹⁴⁾ and worsening sleep quality of caregivers⁽⁶⁾. Therefore, a family reorganization must be established, which is essential for the maintenance of care⁽⁶⁾. The way the family faces this situation can influence in the way they deal with the challenge of home care⁽⁴⁾.

The care provided by the family is fundamental for the survival of the child born prematurely⁽¹⁴⁻¹⁵⁾. Therefore, monitoring the family after hospital discharge is necessary so that they can meet the child's demands⁽¹⁴⁾ and also have the opportunity to have their demands and those of their members met so that they reach a good care⁽⁴⁾.

The good family functioning in situations of demands for continued care by one of the members is favored through an ethical professional care, attentive to the experiences of this social group, recognizing it as capable of guaranteeing care⁽¹⁶⁾.

Therefore, considering the repercussions that the transition from premature newborn care to the home can produce in families, this is a topic that deserves to be investigated. We understand its contribution to a better understanding of the impact factors of this phenomenon over time⁽¹⁷⁾.

In this review, the situations experienced by families are explored for the provision of care at home. It is assumed that a better understanding of the context of home care can promote the development of new professional potential and contribute to the identification of gaps in the literature. Thus, the aim of this study was to analyze how families experience the care of their premature children, discharged from the Neonatal Intensive Care Unit in the home context.

METHOD

This is a qualitative systematic review based on the guidelines proposed by the JBI (Joanna Briggs Institute). All stages of the preparation of the article, such as the synthesis of qualitative evidence regarding the identification of the research problem, as well as the formulation of the guiding questions, the search strategy for the articles, the evaluation of their methodological quality, and the analysis the extracted data were conducted according to the manuals proposed by JBI⁽¹⁸⁾.

The review question was elaborated following the PICO strategy: (P - population; I -

phenomenon of interest; Co - context). Thus, it was considered: P - Premature children, those ones who were born before the 37th week of pregnancy, discharged from the Neonatal Intensive Care Unit, a highly complex therapeutic environment for high-risk newborns; I - Family care, which is understood as the care provided by the family to meet the child's needs in the home environment; Care co-experiences lived by parents or other family members in the home context. Thus, the review question is: how do families experience the care of their premature children, discharged from the Neonatal Intensive Care Unit in the home context?

The studies were selected from the following electronic databases:

PubMed/MEDLINE, from the National Library of Medicine, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Latin American and Caribbean Literature in Health Sciences (LILACS), SCOPUS (Elsevier), Web of Science, BDNF (Nursing Databases) and EMBASE on March 28, 2020.

Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH) were used to search electronic databases. To ensure a broad search, the descriptors and keywords were combined in several ways. The strategies developed to search for articles, in their respective databases, are described (Figure 1) allowing the repetition of the entire process.

Figure 1 -Search strategies for articles in selected databases. Belo Horizonte (MG), Brazil, 2020.

Database	Search strategy
LILACS e BDNF	(tw: caregivers OR cuidadores OR cuidadores OR cuidador OR "Cuidador de Família" OR "Cuidador Familiar" OR "Cuidadores Familiares" OR "Cuidadores de Família" OR "Cuidadores Cônjuges" OR "Cônjuges Cuidadores" OR
LILACS e BDNF	"Familiar Cuidador" OR "Familiares Cuidadores" OR "Patient Discharge" OR "Alta del Paciente" OR "Alta do Paciente" OR "Alta Hospitalar" OR "Alta do Hospital" OR "Home Nursing" OR "Atención Domiciliar de Salud" OR "Assistência Domiciliar" OR "Home Nursing" OR "Atención Domiciliar de Salud" OR "Continuity of Patient Care" OR "Continuidad de la Atención al Paciente" OR "Continuidade da Assistência ao Paciente" OR "Acompanhamento dos Cuidados de Saúde" OR "Cuidado familiar" OR "Cuidado pela família" OR "Familiar cuidador" OR "Family care" OR "Cuidado domiciliar" OR "Atenção domiciliar" OR "Home Care" OR "Dinâmica familiar" OR "Family Dynamics" OR "Cuidado pós-alta" OR "Manejo familiar" OR "Family management" OR "Adaptação familiar" OR "Family adaptation" OR "Ajustamento familiar" OR "Family adjustment" OR "Apoio familiar" OR "Family support") AND (tw: "Infant Care" OR "Cuidado del Lactante" OR "Cuidado do Lactente" OR "Infant, Premature" OR "Recien Nacido Prematuro" OR "Recém-Nascido Prematuro" OR "Lactente Nascido Prematuramente" OR "Lactente Nascido Pré-Termo" OR "Lactente Prematuro" OR "Lactente Pré-Termo" OR "Lactentes Nascidos Prematuramente" OR "Lactentes Nascidos Prematuros" OR "Lactentes Nascidos Pré-Termo" OR "Lactentes Prematuros" OR "Lactentes Pré-Termo" OR "Neonato Prematuro" OR "Neonato Pré-Termo" OR "Neonatos Prematuros" OR "Neonatos Pré-Termo" OR prematuridade OR "Prematuridade Neonatal" OR prematuro OR "Pré-Termo" OR prematuros OR "Recém-Nascido Pré-Termo" OR "Recém-Nascidos Prematuros" OR "Recém-Nascidos Pré-Termo" OR "Premature Birth" OR "Nacimiento Prematuro" OR "Nascimento Prematuro") AND (instance:"regional") AND (db:("LILACS" OR "BDNF" OR "IBECs" OR "INDEXPSI" OR "BINACIS" OR "coleccionaSUS" OR "tese" OR "PERNAL" OR "SES-SP")) AND (instance:"regional") AND (year_cluster:(("2013" OR "2010" OR "2009" OR "2017" OR "2015" OR "2011" OR "2014" OR "2012" OR "2018" OR "2016" OR "2019") AND type:(("article"))
MEDLINE via PubMed	((("Caregivers"[Mesh] OR "Patient Discharge"[Mesh]) OR "Home Nursing"[Mesh]) OR "Continuity of Patient Care"[Mesh]) AND ((("Infant Care"[Mesh] OR "Infant, Premature"[Mesh]) OR "Premature Birth"[Mesh]) OR ("Infant Care"[Title/Abstract] OR "Infant, Premature"[Title/Abstract] OR "Premature Birth"[Title/Abstract]))) AND (("2009/01/01"[PDAT] : "2019/12/31"[PDAT]) AND "humans"[MeSH Terms])
EMBASE	(caregiver:ti,ab,kw OR 'hospital discharge':ti,ab,kw OR 'home care':ti,ab,kw OR 'patient care':ti,ab,kw) AND ('infant care':ti,ab,kw OR prematurity:ti,ab,kw)
CINAHL	
Scopus	("Caregivers" OR "Patient Discharge" OR "Home Nursing" OR "Continuity of Patient Care" OR "Home Care") AND ("Infant Care"
Web of Science	OR "Infant, Premature" OR "Premature Birth")

Source: Research data, 2020.

In the inclusion criteria the following factors were considered: primary qualitative studies focusing on care experiences developed by the family of premature children at home; papersthat were published from 2009 to 2019 in Portuguese, English or Spanish; papers that are

available in full text. The exclusion criteria were: quantitative studies, studies of mixed methods, meta-synthesis, comments, letters, theses, dissertations, abstracts published in conference proceedings, journal editorials, experience reports, articles focusing on pathologies, articles by intervention, review, and opinion articles. It is justified to include articles published in this period, in view of the new forms of analysis created and used by health sciences in recent years, enabling the production of new studies. In addition, this period of time provides for the selection of relevant materials on the topic.

After applying the search strategy, all retrieved articles were exported to the Rayyan Software, a tool designed to manage the process of screening and selecting studies⁽¹⁹⁾. At this stage, two independent reviewers read the titles and abstracts in order to verify the studies that met the established inclusion criteria.

Subsequently, the eligible articles were read in full. In cases where there was disagreement, a third reviewer critically evaluated the articles and contributed to the decision-making process. It is worth noting that the three reviewers who performed the screening and selection of articles are authors of the present review.

The qualitative data were extracted from the studies and organized in an instrument prepared by the authors based on the recommendations of the JBI, containing the following information: title of the article, author; year of publication; parents; publication periodical; goal; theoretical framework/conceptual bases; methodological characteristics; sample characteristics; studied condition; data collection location; duration of data collection with each participant; definition of family; results and conclusion of studies related to the questions and objectives of the review. In this stage, two independent reviewers extracted data and analyzed the texts, and a third reviewer accompanied the entire process and, in cases where there were differences, an attempt was made to establish a consensus.

Eligible studies were critically evaluated for methodological validity before inclusion in the review, using the JBI Critical Appraisal Checklist for Qualitative Research^(18,20). This instrument is composed of questions that are essential to test the methodological quality of the articles. In this review, studies that answered positively to questions related to the congruence of objectives, data collection and analysis, interpretation of results and consistency in the elaboration of the conclusion, were included.

After this stage, the MaxQDA[®] software, version 2018, was used as a tool for the coding and analysis of the extracted data. After reading the selected articles in full, themes common to the productions were identified, out of which eight codes were defined. This set of codes was used by two researchers, simultaneously, in five papers to verify its adequacy. After adjusting some of the codes, a final version was obtained, consisting of four codes, namely: "Preparing families for home care"; "Changes in family dynamics and the family's needs for care"; "The family and its social support network"; "Feelings of the family when caring at home".

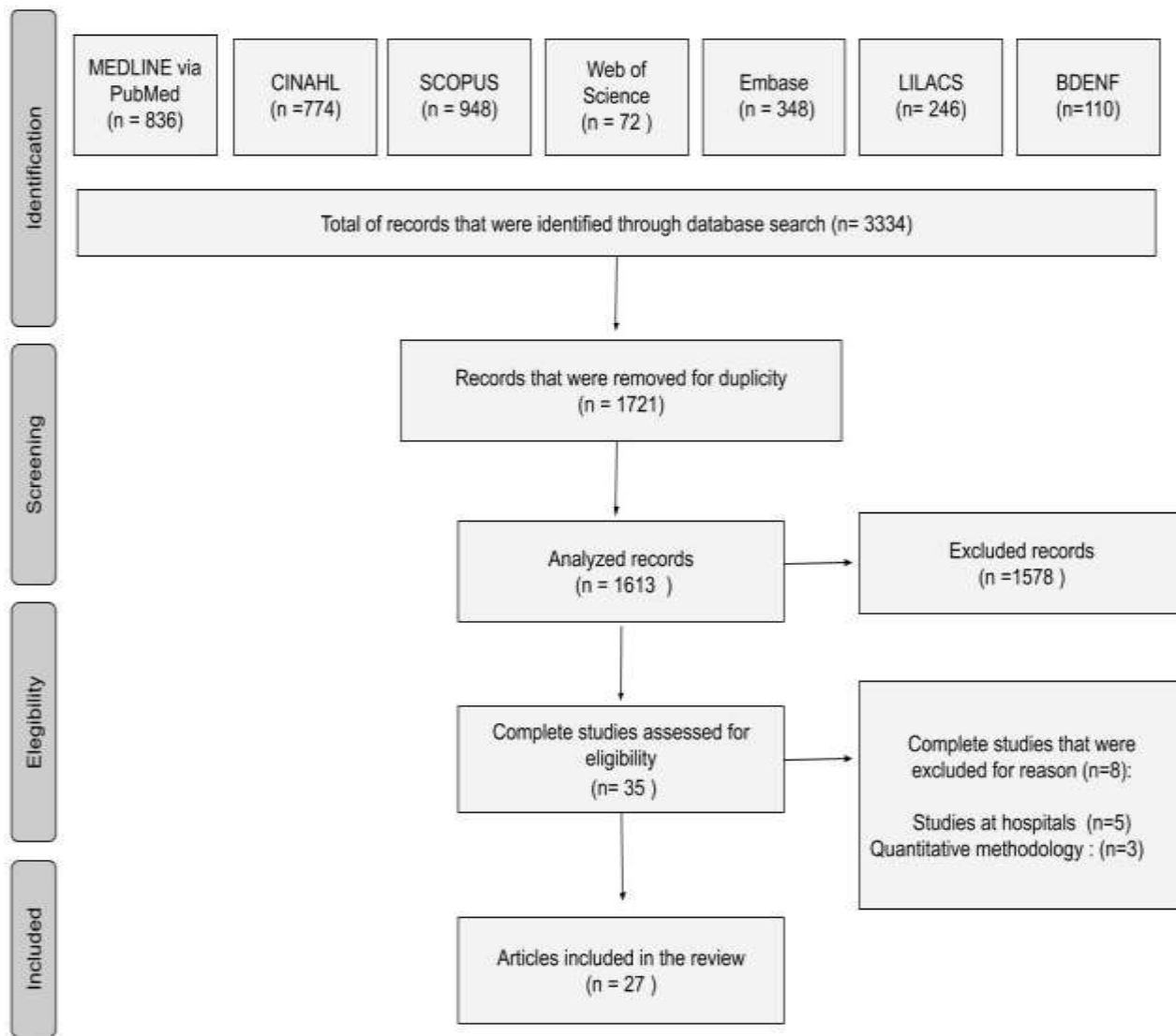
A definition was developed for each of the codes in order to reduce subjectivity, at the time of use by researchers, for example, the code called "Family feelings when caring at home" was defined as positive and negative emotions related to experiences experienced by the family in the care of premature children from the NICU.

The codification process was carried out by two of the authors of the article independently. The codifications were compared using the MaxQDA software[®], version 2018. A Kappa coefficient of 0.86 was obtained, considered an excellent significance level in relation to the inter-coder agreement⁽²¹⁾.

RESULTS AND DISCUSSION

To present the research results and the study selection process, the PRISMA recommendation was used (Figure 2)⁽²²⁾.

Figure 2 -Selection process of studies included in the systematic review, based on the PRISMA* recommendation. Belo Horizonte (MG), Brazil, 2020.



Source: Research data, 2020.

*Adaptation of the Flow Diagram of the selection process of the integrative review articles, according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA).

Characteristics of included studies

The 27 studies that made up the final

sample of this research are characterized in Figure 3, below:

Figure 3 -Characterization of the studies included in the review. Belo Horizonte (MG), Brazil, 2020.

Paper Code	Theoretical Reference	Sample	Place of Data Collection	Main Results
A01 ⁽²³⁾	Methodological framework of hermeneutic phenomenology	20 mothers of premature babies	University	Need for maternal adaptation and skills development. Restriction of visits to protect the child, with loss of social relationships.
A02 ⁽²⁴⁾	Systems theory of the Bowen family (1974)	18 premature families (10 mothers and 8 fathers)	Interviews conducted via telephone connection.	Needs for support from parents by health professionals and other parents of premature children.
A03 ⁽²⁵⁾	Methodological framework of Narrative Research	21 mothers and 9 fathers of premature babies	Residence	The study showed that grandparents provided support to preterm infants at home.

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Paper Code	Theoretical Reference	Sample	Place of Data Collection	Main Results
A04 ⁽²⁶⁾	Social Representation Theory and Methodological reference of the Collective Subject Speech.	7parentsofpremature babies.	Residence	The first days at home with the premature baby are filled with feelings of insecurity, as parents need to adapt to the new home environment.
A05 ⁽³⁾	Subjectivation Theoretical Reference; Deleuze and Guattari Reference.	10 mothers of premature babies	Residence	Home care is permeated by contradictory feelings, as caregivers claim to want to be at home with their children, but report feeling insecure. Faith allowed them to have a feeling of hope, support and comfort.
A06 ⁽²⁷⁾	Absence of theoretical reference	23 mothers of premature babies	Outpatient follow-up of premature infants.	Inadequate experiences of mothers in caring for their children in the NICU caused a decline in confidence and competence to develop care actions.
A07 ⁽²⁸⁾	Methodological Framework for Narrative Research described by Clandinin and Connelly (2000)	9parentsofpremature babies	Residence	The effect of the non-involvement of parents in the care of their children, during hospitalization, was felt during the initial phases after hospital discharge.
A08 ⁽²⁹⁾	Symbolic Interactionism	9 families (9 mothers and a grandmother)	Residence	Social support, especially from family members, proved to be important for the adaptation of parents in the context of home care.
A09 ⁽³⁰⁾	Bioecological Theory of Human Development, by Urie Bronfenbrenner.	11 mothersand1grandmother	Outpatient follow-up of premature infants.	The family as a support network contributes to the provision of good care for the child.
A10 ⁽³¹⁾	Collective case study (Stake, 1994).	3parentsofpremature babies	Hospital and Residence	In the third month, after hospital discharge, several interaction activities were highlighted: dance, lap, walks and playing.
A11 ⁽³²⁾	Absence of theoretical reference	9families	Residence	The health team is seen as a source of support and guidance for the continuity of care for premature children at home.
A12 ⁽³³⁾	Absence of theoretical reference	15 mothers and 10 fathers of premature babies	Interviews conducted via telephone connection.	The parents expressed persistent concern about issues of diet, breathing problems and insufficient weight gain.
A13 ⁽³⁴⁾	Methodological reference: Transcendental phenomenology adopted by Moustakas	8mothersofpremature babies	Home or other place of choice of mother	The first months at home were marked by exhaustion and overload by the mothers. For mothers, the support of family and friends was considered a mitigating factor in the management of feelings of isolation and stress.
A14 ⁽³⁵⁾	Interpretative phenomenology Philosophy by Martin Heidegger.	10 mothers of premature babies	It is not specified	The experience of taking care of the child on the first night at home was experienced by fear, anguish and insecurity.
A15 ⁽³⁶⁾	Absence of theoretical reference	9mothersofpremature babies	Outpatient follow-up of premature infants.	Family support has a significant role in adapting the mother to the new family dynamics and in acquiring self-confidence in caring.
A16 ⁽³⁷⁾	Methodological reference: Bardin's Content Analysis Guidelines	18 mothers of premature babies	Hospital and residence	The construction of intra-family support networks was found to be fundamental to mitigate mothers' insecurity. Spirituality was also highlighted as an important source of comfort in the experience of home care.
A17 ⁽⁸⁾	Methodological Reference of the Collective Subject Discourse	12 mothers of premature babies	Hospital	Mothers reproduce home care actions as learned in the hospital environment.
A18 ⁽¹⁰⁾	Social Support and Support Network	7mothersofpremature babies	Residence	Only mothers took full care of their children, giving up all personal duties. The social support provided was centered on the

				performance of household activities by family members.
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Paper Code	Theoretical Reference	Sample	Place of Data Collection	Main Results
A19 ⁽³⁸⁾	Absence of theoretical reference	4mothersofpremature babies	Residence	The mother stands out as the central character of the care teaching-learning process. The deficiency in the process of preparing for discharge may be responsible for feelings of insecurity and fear in home care.
A20 ⁽³⁹⁾	Absence of theoretical reference	4mothersofpremature babies	Residence	The care for premature children was marked by the presence of the family, with grandmothers as assistants in care.
A21 ⁽⁴⁰⁾	Absence of theoretical reference	21 mothers of premature babies	Outpatient follow-up of premature infants.	Most women felt anxiety, insecurity and doubt about their ability to perform daily home care. They reflected on the importance of training at the NICU.
A22 ⁽⁴¹⁾	Colaizzi's phenomenological methodology (1978)	10 mothers of premature babies	Universityand residence	Several feelings emerged in the first few weeks. Among the negative feelings emerged: concern, nervousness and frustration. Regarding positive feelings: happiness, optimism, enthusiasmandlove.
A23 ⁽⁴²⁾	Absence of theoretical reference	24 mothers of premature babies	Hospital	Negative aspects of adapting to the new routine were mainly related to exhaustive routines at home. The positive aspects were mainly the mother-child proximity and the development of maturity and faith through the care experience.
A24 ⁽⁴³⁾	Absence of theoretical reference	28 mothers of premature babies in the first meeting e 24 mothers of premature babies in the second meeting.	Hospital	Premature feeding was revealed as the main difficulty faced by mothers after hospital discharge. Parents experience difficulties in care actions because they have not been included in the NICU care routine.
A25 ⁽⁴⁴⁾	Absence of theoretical reference	3mothersofpremature babies	Residence	Some factors hinder the care process at home, such as maternal tiredness, absence of support from the spouse, readmissions of the children and lack of support from the family.
A26 ⁽⁴⁵⁾	Theory of Symbolic Interactionism (SI). Methodological framework: Grounded Theory - GT	5familiesofpremature babies	Outpatient follow-up of premature infants.	The family wants to share and get involved in the care of the premature baby. However, the main caregiver is the mother, who is often overwhelmed.
A27 ⁽⁴⁶⁾	Based on care for human beings, with an emphasis on in caring for the premature and in the Mother-Kangaroo method as a care strategy for low weight children.	7mothersofpremature babies	Residence	The mother is the main caregiver of the children. Grandmothers and parents help, however in indirect care, with auxiliary actions.

Source: Research data, 2020.

When characterizing the scientific papers included regarding the year of publication, two papers were published in 2009, 2014, 2015 and 2018; three papers in 2010, 2011 and 2013; four papers in 2012 and 2017; one paper in 2016 and 2019. Regarding the country of publication, 18 studies are Brazilian, followed by the United States ⁽⁴⁾,

Ghana ⁽²⁾, Iran, Spain and Colombia with a paper published in each country. The Portuguese language prevailed in the articles included, with 17 publications. The other papers ⁽⁸⁾ were published in the English language.

As for the content of the studies, of the 27 articles included, only one defined what family is. In

addition, 16 studies are guided by some theoretical reference. In 20 of the 27 analyzed papers, only one of the family members participated, with four studies involving two or more members and three studies with the whole family. For the most part, the investigation unit of the papers included was a family member, as occurred in 24 studies, and only three studies presented the family as an investigation unit. In five studies, the mother is not the participating member, and in 22, she is the investigated member. Only four studies reported the age of the children who were included.

Interviews were conducted with families and/or members in 24 studies and the duration varied between 30 to 160 minutes. In two studies, there was also observation in addition to the interview. Only one study was conducted with focus groups. As for the location of data collection, three studies took place in hospitals, 13 in the families' residence and two in both locations. Only five studies used the outpatient context to perform data collection. Finally, a study was carried out at a university and another carried out at the university and also at home.

Methodologic Quality

Table 1 summarizes the methodological quality of the 27 studies included in the review. Most of the evaluated criteria were met. Ten studies do not mention the philosophical orientation or research methodology, and one partially met this criterion. All twenty-seven studies met criteria 2, 3, 8 and 9 which correspond, respectively, to the congruence between the research methodology and the research question or objectives; congruence between the research methodology and the methods used for data collection; representativeness of participants and their voices appropriately; presentation of ethical approval of studies. One study partially met the criterion on the congruence between the research methodology and the representation and analysis of data. Two studies partially met the congruence criterion between the research methodology and the interpretation of the results. Twenty-two studies do not meet the criterion on the statement that locates the researcher culturally or theoretically. Twenty-three studies do not address the influence of the researcher in the study. A study partially met the criterion on the elaboration of the conclusion based on the analysis and interpretation of the data. No study was excluded after the critical evaluation.

Table 1 - Methodological quality*: Results of the critical evaluation of eligible studies. Belo Horizonte (MG), Brazil, 2020.

Papercode	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10
A01 ⁽²³⁾	S	S	S	S	S	N	N	S	S	S
A02 ⁽²⁴⁾	S	S	S	S	S	S	S	S	S	S
A03 ⁽²⁵⁾	S	S	S	S	S	S	S	S	S	S
A04 ⁽²⁶⁾	S	S	S	S	S	N	N	T	S	S
A05 ⁽³⁾	S	S	S	S	S	N	N	S	S	S
A06 ⁽²⁷⁾	N	S	S	S	S	N	N	S	S	S
A07 ⁽²⁸⁾	S	S	S	S	S	N	S	S	S	S
A08 ⁽²⁹⁾	S	S	S	S	S	N	N	S	S	S
A09 ⁽³⁰⁾	S	S	S	S	S	N	N	S	S	S
A10 ⁽³¹⁾	S	S	S	S	S	N	N	S	S	T
A11 ⁽³²⁾	T	S	S	S	T	N	N	S	S	S
A12 ⁽³³⁾	N	S	S	S	S	N	N	S	S	S
A13 ⁽³⁴⁾	S	S	S	S	S	N	N	S	S	S
A14 ⁽³⁵⁾	N	S	S	S	S	N	N	S	S	S
A15 ⁽³⁶⁾	S	S	S	S	S	S	N	S	S	S
A16 ⁽³⁷⁾	N	S	S	S	S	N	N	S	S	S
A17 ⁽⁸⁾	N	S	S	S	S	N	N	S	S	S
A18 ⁽¹⁰⁾	S	S	S	S	S	S	S	S	S	S

A19 ⁽³⁸⁾	N	S	S	S	S	S	N	S	S	S
A20 ⁽³⁹⁾	N	S	S	S	S	N	N	S	S	S
A21 ⁽⁴⁰⁾	N	S	S	S	S	N	N	S	S	S
A22 ⁽⁴¹⁾	S	S	S	S	S	N	N	S	S	S
A23 ⁽⁴²⁾	N	S	S	S	S	N	N	S	S	S
A24 ⁽⁴³⁾	S	S	S	S	S	N	N	S	S	S
A25 ⁽⁴⁴⁾	N	S	S	T	T	N	N	S	S	S
A26 ⁽⁴⁵⁾	S	S	S	S	S	N	N	S	S	S
A27 ⁽⁴⁶⁾	S	S	S	S	S	N	N	S	S	S
Total %	59,3	100	100	96,3	92,6	18,6	14,9	100	100	96,3

Source: it was created by the authors, 2020.

* JBI Critical Assessment Checklist for Qualitative Research

S: Yes (*sim*); T: Maybe (*talvez*); N: No.

Q1: Is there congruence between the stated philosophical perspective and the research methodology?

Q2: Is there congruence between the research methodology and the research question or objectives?

Q3: Is there congruence between the research methodology and the methods used for data collection?

Q4: Is there congruence between the research methodology and the representation and analysis of data?

Q5: Is there congruence between the research methodology and the interpretation of the results?

Q6: Is there a statement that locates the researcher culturally or theoretically?

Q7: Is the researcher's influence on the study addressed?

Q8: Are participants and their voices adequately represented?

Q9: Are the ethical criteria respected?

Q10: Was the conclusion drawn from the analysis and interpretation of the data?

Preparing families for home care

The performance of health professionals in the hospital and in other areas of health care is essential for the preparation of family members of premature children to perform home care. Thus, the training carried out by health professionals directly influences the ability and confidence of these families to carry out child care at home.

Authors defend that the preparation for home care should start even in the hospital context, during hospitalization in the Neonatal Intensive Care Unit^(3,10). Thus, the presence of the family in this environment is essential for them to develop the skills necessary to care for the child at home^(10,32).

The training developed by the multi-professional team contributes to the promotion of mothers' safety and confidence in carrying out care actions^(3,23,38). Studies show that nurses are fundamental professionals for the educational process of families, especially in relation to instructions on basic care and danger signs^(26,45). Health professionals in the hospital environment must identify the best time for the training of mothers in relation to home care, allowing the development of greater security⁽³⁹⁾.

Some investigations show that the Mother Kangaroo Method is a strategy that collaborates with the promotion of the training of family members for home care, at which time health

professionals can develop educational strategies during the hospitalization period^(10,46). In addition, the contact between mother and child in the hospital environment contributes to the learning process in relation to child care, especially with regard to the transmission of security and trust^(40,45).

The premature baby's arrival at home is an important moment for the whole family, and the ideal is that parents carefully follow the guidelines given by the health team^(27,32,35). However, the literature shows that despite being guided, mothers still felt that the information offered by professionals was insufficient and that this fact caused insecurity in relation to the care of premature babies^(27,42).

The lack of paternal guidance is identified in a study as a hindrance to home care, since parents feel anxious and unable to help mothers⁽²⁸⁾. Thus, for greater cooperation and care at home, training for both fathers and mothers is important⁽²³⁾.

Because they do not believe that they have the potential to successfully provide care for their children, due to insecurity, fathers and mothers can deprive themselves of this care at home^(31,35,37,42). For this reason, the learning process in the hospital environment becomes essential to help parents in their daily lives at home⁽¹⁰⁾.

With the challenges found for home care, parents say they feel safer in the hospital

environment, as it is a place with equipment and professionals that offer and facilitate all care management ⁽³³⁾. However, despite the insecurity and difficulties faced, families report proximity to their children as a positive factor at this time ⁽³⁹⁾.

Thus, for a positive adaptation of the family to the new reality, support for obtaining confidence and developing skills is essential, as well as assistance for the care of premature infants ⁽³⁰⁾.

Changes in family dynamics and the family's needs for care

To meet the home care needs of children born prematurely, families adopt new routines and modify their family functioning. Many care actions are identified as challenges for families, which can be related to physical, structural, emotional, social, support and health services. Thus, changes are experienced by these families, in a process of adapting to the new context of care.

Mothers are the main caregivers at home and abdicate from chores or personal needs for the full dedication to the care of the child, in addition to being responsible for many other activities, causing physical and emotional overload ⁽¹⁰⁾. A study found that mothers consider that premature children need extreme care, what makes them to provide more time for baby's care ⁽⁴²⁾.

Feeding the child, especially at night, is a task that requires greater family care, so they need to get adapted to the breastfeeding routine. Studies point out that this care can be seen as a challenge for parents, since many of them are unable to know what to do when the child is unable to reach the nipple ^(35,39).

Breastfeeding is essential for the child's growth and development, especially in the first months of life ⁽²⁷⁾. When they are well trained, mothers follow the guidance of health professionals ⁽⁸⁾. However, studies have identified insufficient training on breastfeeding ^(27,38,40,43).

Studies indicate that in addition to food, other care can also be challenging for families, such as bathing, changing diapers, identifying crying, sleep, rest, hygiene, frequent consultations with specialists or even the absence of specialist monitoring ^(3, 39,41,45-46). In addition, after hospital discharge, in the initial periods of parents' adaptation, medication management and the use of technologies are also reported as difficulties ⁽²⁷⁾.

Parents reported they feel exhausted, during adaptation and for the initial care of premature babies ⁽³⁴⁾. Faced with the challenges experienced, families enter a new reality of routines and social relationships ^(3,29,36,39,42,44). Thus, health care for children becomes the focus of family members' attention, which can cause overprotection ⁽²⁹⁾.

Initial home care is one of the major difficulties reported by parents. On the other hand, this experience shows great significance for mothers who emphasize behavioral changes arising from this process, such as the meaning of childbirth, the adaptation phase and also changes in the family nucleus ⁽³⁹⁾. It is an experience that provides continuous learning, both in terms of caring for children and in the process of recognizing the difficulties faced in families' daily lives ⁽⁴⁴⁾.

In some studies, mothers revealed that time was essential to overcome the unpreparedness and fear experienced in the adaptation process in the care of premature infants at home ^(3,40). Concomitantly, a study states that the adaptation phase requires the support of the whole family, being a process of overcoming and learning for all members ⁽³⁸⁾. However, even in the face of the challenges faced by parents and family members, adapting to the new daily routine can positively influence the family nucleus ⁽⁴²⁾.

The people who collaborate most with mothers in care actions are fathers and grandmothers ^(10,25). However, the results indicate that parents are not inserted by health professionals in care routines even in the hospital environment, what reflects on their non-involvement in the initial phases of home care ^(28,42).

Fathers stand out in helping with domestic activities, while mothers can dedicate themselves more in the care for the child ⁽²⁹⁾. As a result of these actions, the mother feels less overwhelmed, obtaining a longer time for rest and reducing the psychological and physical pressure put into everyday life ^(26,36). It is worth noting that the role of the father as a resource provider so that a caregiver is more available for direct care of the child can also be understood as a form of care.

However, in the face of so many tasks, the parents' relationship can be affected, due to excessive monitoring and also to the unfolding aimed at changes and adaptations in the family environment ⁽²³⁾.

The family and their social support network

When the child goes home, all family members are involved in initial care^(8,29-30,33,36,38-39,45). The positive family bond solidifies the relationships between parents and children, which is an important process for the child's development⁽⁴³⁾. Thus, these relationships contribute to making children feel welcomed and supported by the family⁽³⁰⁾.

The interaction between the parents and the child is a care action aimed at the development and support of family relationships. Thus, it is important for parents to act with children through walks, games and conversations⁽³¹⁾. These studies also reinforce that the bond established between parents and children can provide satisfactory results in the development of children's cognitive abilities.

The social support network also contributes to the strengthening of family bonds, in order to qualify child care. One study describes that this support network can be activated in different ways⁽²⁴⁾. The author demonstrates in his study that parents receive support from their partners in order to teach them about caring for their children, as a student-teacher relationship. They, in turn, practice care when they arrive from work, in addition to carrying out domestic chores, so that the wives can take care of the child⁽²⁶⁾.

The academic literature demonstrates that the non-involvement of the spouse in caring for the child is considered as one of the main factors of maternal tiredness⁽⁴⁴⁾. In addition, the authors reinforce that the stress generated by these family relationships also contributes to the intensification of this tiredness.

Aspects of mothers' overprotection can trigger negative consequences for social relationships. A study identified that some mothers avoid direct contact of neighbors or strangers with their child, in order to protect them from undesirable comments⁽⁴²⁾. Another study found that due to the concern with child safety and overprotection, mothers limit the participation of family members in care actions⁽⁴⁵⁾. Restrictions on visits from family and friends are detrimental to social relationships, and may accentuate the feelings of isolation experienced by mothers⁽²³⁾.

In contrast to these restrictions, the support of people close to the parents as a support network, especially the family, is beneficial to care, since it supports the mother in her needs and anxieties⁽³⁰⁾. One study describes that many

parents had the support of family, partner or friends⁽³³⁾. Social support, when originated from the family, is a strong ally for parents to adapt to the new routine, contributing to safety in child care^(29,36,38).

Studies show that grandmothers help in the process of adapting home care routines^(10,25,39,46). However, a study found that care actions by grandmothers could affect family relationships⁽²⁵⁾. The authors point out that fathers and mothers try to follow medical prescriptions as much as possible, but grandmothers tend not to follow literally the recommendations of health professionals, promoting instability in relationships⁽²⁵⁾.

The investigations also point out to a new source of social support at home: in addition to contributing to the development of skills, health professionals also offer emotional support to families⁽³²⁾. Thus, the relationship established between health professionals and the family allows for a welcoming and resolute dialogue⁽³⁾.

Family feelings when caring at home

The child's arrival at home brings feelings of joy and happiness, in addition to the parents' relief in having the child close to them^(31,35,39). However, this moment can also cause negative feelings that are related to the concern with care, feelings of uncertainty and anxiety^(10,23,41). Above all, there is also the presence of fear and insecurity when it comes to caring for children, because many families still do not feel prepared to assume and to perform care at home⁽³⁵⁾.

According to a survey⁽²⁴⁾, parents are concerned about whether marital relationships are at the expense of childcare. Another study showed aspects related to emotional overload, to drastic changes in lifestyle and also to the time of exclusive dedication to childcare, which contributed to the dissatisfaction of family and social relationships⁽¹⁰⁾.

The family shares the feeling of gratitude for the care and support provided by health professionals in caring for their children⁽³⁴⁾. However, even in this context, mothers report a feeling of isolation, due to the excessive concern to do the best for children⁽³⁴⁾.

Another feeling exposed by family members, in the context of the home, is the fear of unpredictability in relation to the development of complications related to the stability of the premature's health⁽²³⁾. In this reality, spirituality can be related to the comfort of parents⁽³⁷⁾. Thus,

some families emphasize faith in God to encourage hope and believe in the evolution of the care trajectory⁽³⁾. This feeling demonstrates comfort and support in the family's daily life⁽³⁾. In this sense, a study identified that parents attribute the recovery of their sick child to a Supreme Being⁽³⁹⁾.

Mothers express feelings of fear, stress and insecurity regarding their parents' ability to balance work and household chores. In contrast, the reality is that parents are concerned with the family's well-being⁽³³⁾. In this context, the importance of the feelings experienced by the family as actors in the situations specific to home care is highlighted, directly influencing the management of the care provided to the child⁽²⁹⁾.

FINAL THOUGHTS

Families experience the care of their children in the home context as an adaptation process, permeated by feelings of joy, relief, insecurity and fear. The arrival of the child at home generates changes in the family organization and it becomes the focus of the family, which strives to provide the necessary care. The proximity to the child after discharge is a positive point reported by the parents. However, care can be permeated by difficulties and uncertainties, especially for mothers who, in most cases, assume primary care. This fact reinforces the importance of the support of other family members and health professionals as a source of information and security for this care.

The lack of paternal guidance makes it difficult for the father to approach the child as well as his participation in the child's daily care. Thus, it is increasingly noticeable that although the investigations refer to a situation experienced by the family group in most cases, they have the mother as an informant for assuming the main care.

In this study, it will enable a broader view of families and children graduating from the NICU by nursing, in addition to meeting the demands of this group of people, in order to plan care. In addition, it supports the preparation of the family for home care to start in the hospital environment, in a timely manner to develop skills and generate trust. Another contribution is to establish reference and counter-reference so that the primary care networks are attentive to these families and establish actions that support these individuals.

As methodological limitations of the study there are the scientific papers that were published in Portuguese, English and Spanish were considered. Thus, productions may not have been included, due to this criterion, limiting the information produced here.

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