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Review Article
Artigo de Revisão
Artículo de Revisión

Parents' and family members' hope in the face of extremely premature births: a scoping review

A esperança de pais e familiares diante do nascimento prematuro extremo: revisão de escopo

La esperanza de padres y familiares ante un nacimiento extremadamente prematuro: revisión de alcance

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ABSTRACT

Objective: to map the hope experience undergone by parents and family members of extremely premature newborns hospitalized in a Neonatal Intensive Care Unit. **Method:** a scoping review conducted according to the methodology proposed by the Joanna Briggs Institute and the PRISMA-ScR guidelines. The search was performed in September 2024 and updated in February 2025 in the MEDLINE, CINAHL, PsycINFO, Embase, Scopus and LILACS databases. The materials included were qualitative, quantitative and mixed-methods studies addressing hope among parents and family members of extremely premature newborns. **Results:** a total of 12 out of all 4,067 studies found were included. Hope was identified as a core element in the extreme prematurity experience and encompassed the Affective, Cognitive, Behavioral, Temporal, Contextual and Spiritual dimensions. **Final considerations:** hope strengthens parental and family resilience and is essential to adapt to extreme prematurity. It is recommended to invest in research studies and neonatal care models that sustain hope centered on families. **Descriptors:** Intensive Care Units, Neonatal; Infant, Extremely Premature; Family; Hope.

RESUMO

Objetivo: mapear a experiência de esperança de pais e familiares de prematuro extremo hospitalizado na Unidade de Terapia Intensiva Neonatal. **Método:** revisão de escopo realizada de acordo com a metodologia do Instituto Joanna Briggs e as diretrizes PRISMA-ScR. A busca foi realizada em setembro de 2024 e atualizada e fevereiro de 2025, nas bases de dados MEDLINE, CINAHL, PsycINFO, Embase, Scopus e LILACS. Foram incluídos estudos qualitativos, quantitativos e de métodos mistos que abordaram a esperança de pais e familiares de prematuros extremos. **Resultados:** de 4.067 estudos encontrados, 12 foram incluídos. A esperança foi identificada como elemento central na experiência de prematuridade extrema e abrangeu as dimensões afetiva, cognitiva, comportamental, temporal, contextual e espiritual. **Considerações finais:** a esperança fortalece a resiliência parental e familiar e é essencial para a adaptação diante da prematuridade extrema. Recomenda-se investimento em pesquisas e modelos de cuidado neonatal sustentadores da esperança centrados na família.
Descritores: Unidades de Terapia Intensiva Neonatal; Lactente Extremamente Prematuro; Família; Esperança.

RESUMEN

Objetivo: mapear la experiencia de esperanza entre padres y familiares de recién nacidos extremadamente prematuros hospitalizados en la Unidad de Cuidados Intensivos Neonatales. **Método:** revisión exploratoria realizada de conformidad con la metodología del Instituto Joanna Briggs y las guías PRISMA-ScR. La búsqueda se realizó en septiembre de 2024 y se actualizó en febrero de 2025 en las bases de datos MEDLINE, CINAHL, PsycINFO, Embase, Scopus y LILACS. Se incluyeron estudios cualitativos, cuantitativos y de métodos mixtos que abordaron la esperanza de padres y familiares de bebés prematuros extremos. **Resultados:** de 4067 estudios encontrados, se incluyeron 12. La esperanza fue identificada como un elemento central en la experiencia de la prematuridad extrema y abarcó las dimensiones afectiva, cognitiva, conductual, temporal, contextual y espiritual. **Consideraciones finales:** la esperanza fortalece la resiliencia parental y familiar y es esencial para la adaptación a la prematuridad extrema. Se recomienda la inversión en investigación y modelos de atención neonatal que sostengan la esperanza centrados en la familia.
Descriptores: Unidades de Cuidado Intensivo Neonatal; Recien Nacido Extremadamente Prematuro; Familia; Esperanza.

INTRODUCTION

At the global level, prematurity is the main cause of mortality among children aged less than five years old. It is estimated that there were 13.4 million premature births in 2020 and that 5% of them were extremely premature, defined as those that take place before the 28th gestational week[1-4]. In the Americas region, the incidence of prematurity reaches 1.2 million cases a year. In this scenario, Brazil is among the ten countries with the most premature births: 31,351,324 births were recorded between 2012 and 2022, with 3,530,568 premature ones; in turn, the percentage of extremely premature neonates was 4.9%[5,6]. High prematurity rates represent an important Public Health problem, such as the need to overcome regional

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inequalities in access to the services, unfavorable social, economic and environmental conditions and qualification of neonatal care obstetric practices[5].

The advances in neonatal intensive care improved survival in extremely premature newborns during the neonatal period. However, these newborns frequently face severe clinical complications and need to be hospitalized for extended periods of time, which makes extreme prematurity be considered as a life-threatening condition eligible for perinatal and neonatal Palliative Care[7]. This care philosophy is combined with intensive care, with the objective of providing comfort and relief from distress[7]. It is developed in a collaborative way, centered on the neonates and the families and respecting the parents' autonomy and choices; in addition, its premise is to promote hope[8].

Parents and families alike experience overload and profound emotional distress, in addition to also wishing and needing to maintain some possible hope in the face of the uncertainties inherent to extremely premature births[9]. In this context, hope is the dimension and process to be explored and promoted; it is a coping resource, an active and realistic response to a given situation[10].

It is known that extremely premature births are events that trigger broad and profound psychosocial and emotional repercussions in parents and families[11]. The experiences when facing a risk birth are marked by negative emotions, grief, losses, guilt, impotence, lack of control and absence of personal and parental autonomy (Ireland, Ray, Larkins et al, 2019). On the other hand, it is also known that hope is a protective resource, a positive mediator in maternal mental health and an internal parental and family resilience factor[12-14].

The devastating impact of extremely premature births on parents and families should be acknowledged, and the way in which they will lead with the unavoidable emotional distress depends on their life histories and experiences, values, spiritual beliefs and support systems. These factors can predispose parents and families to adapting, to striking a balance or to prolonged distress[11,14]. Therefore, the way in which they will try to make sense of an extremely premature birth and to their child's hospitalization, survival and sometimes death is unique and requires personalized, flexible and adapted professional support, duly respecting each person's/family's values[11].

The hope-hopelessness dynamics is a phenomenon that is present in these experiences with a positive association with the coping, grieving and post-traumatic growth processes[14]. Hope is a complex concept that can be understood as an essential cognitive process for a person to identify their personal objectives and develop strategies to attain them[15]. According to Snyder, it represents the ability to perceive viable paths to achieve target objectives, simultaneously motivating the necessary courses of action to follow these paths. In other words, hope not only defines what a person wants to achieve; it also allows devising a plan and a course of action to attain these objectives[16]. Hope has individual and collective components. In a group, it can be experienced when sharing the view that joint efforts can lead to achieving a common objective[17].

In the scope regarding the theoretical development of the hope construct in the Nursing field, the multidimensional model proposed by Dufault and Martocchio[18] stands out, which conceptualizes hope in six dimensions: (1) Affective (feelings and emotions); (2) Cognitive (object desired and outcome intended), (3) Behavioral (guidance to take actions and motivation); (4) Affiliative (social interaction and self-transcendence); (5) Temporal (past, present and future); and (6) Contextual (life circumstances and situations). This model expanded the perspectives to understand and assess hope, as well as the intervention possibilities.

Considering that assessments and interventions in terms of hope are fundamental components of neonatal intensive and palliative care and expecting to contribute to equipping the professionals for them to address hope in parents and families and in signaling paths to develop new research studies in this area, in addition to the possibility for the professionals to perform an active role in improving hope among parents and families, the objective of this study was to map the hope experience undergone by parents and family members of extremely premature newborns hospitalized in a Neonatal Intensive Care Unit.

METHOD

This is a scoping review conducted according to the methodology proposed by the Joanna Briggs Institute (JBI)[19]. The methodological process followed these stages: Definition of the research question; Search and selection of studies; Data extraction and organization; Analysis; and Presentation of the results. In order to ensure methodological rigor and transparency, the review was conducted as per the *PRISMA Extension for Scoping Reviews* (PRISMA-ScR)[20] guideline and the process to select the studies followed the PRISMA 2020 flowchart[21].

An exploratory search was made in the *International Prospective Register of Systematic Reviews* (PROSPERO) and in the Cochrane Library during the second half of 2024, not identifying any previous review on the topic. The protocol

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corresponding to this review was registered in the Open Science Framework (OSF) platform on September 10th, 2024, and is available in the following electronic address: https://doi.org/10.17605/OSF.IO/F5CKD.

The guiding question for the review was formulated based on the PCC mnemonic (Population, Concept and Context). Population: the materials considered were studies developed with families of extremely premature newborns (less than 28 gestational weeks), including parents, siblings and other family members considered relevant in the primary studies. This definition encompasses an expanded concept of family as "that whose members assert belonging to", understood as a unit, system and network of significant people[22] with emotional ties and involved in the premature birth experience. Concept: the hope experience undergone by parents and family members of extremely premature newborns. Hope is defined as an essential cognitive process for a person to identify their personal and collective objectives and develop strategies to attain them[16]. Context: studies developed in neonatal intensive care units or in neonatal palliative care units. Thus, the guiding question was as follows: "Which is the available evidence on hope among parents and family members of extremely premature newborns that experience neonatal intensive and/or palliative care?".

The search was conducted in three stages, as per the JBI recommendations[19]. As a first step, a preliminary search was conducted in the *Medical Literature Analysis and Retrieval System Online* (MEDLINE) via PubMed and *Cumulative Index to Nursing and Allied Health Literature* (CINAHL) databases to identify indexing terms used to describe the relevant articles and descriptors. Based on these terms, an encompassing search strategy was developed for Medline and the other databases selected. This strategy was tested and refined with the help of a librarian from *Universidade de Brasília* that has a Biblioteconomy degree, specializes in information literacy and is an MSc in education, with vast experience in health sciences databases. This strategy was adapted to the other databases included in the study. The search strategy was prepared based on a combination of Controlled Descriptors in Health Sciences (*Descritores Controlados em Ciências da Saúde*, DECS), Medical Subject Headings (MeSH) and free terms, using Boolean operators and inverted commas for compound terms. The full search strategies are presented in Figure 1.

Database	Used strategy	Articles found (n)
PUBMED	((infant, newborn) OR neonate OR newborn OR (premature birth) OR (birth premature) OR (preterm birth)) AND ((parents) OR parent OR parenthood OR family OR families OR relatives OR filiation) AND ((neonatal intensive care) OR NICU OR (intensive care unit)) AND ((hope) OR (coping strategies) OR (life experience) OR resiliency OR resilience OR belief OR hopefulness OR (coping skills) OR (life change events) OR (resilience, psychological)) AND ((hospitalization) OR admission OR internment)	881
CINAHL	("infant, newborn" OR neonate OR newborn OR "premature birth" OR "birth premature" OR "preterm birth") AND (parents OR parent OR parenthood OR family OR families OR relatives OR filiation) AND ("neonatal intensive care" OR NICU) AND (hope OR "coping strategies" OR "life experience" OR resiliency OR resilience OR belief OR hopefulness OR "coping skills" OR "life change events" OR "resilience, psychological") AND (hospitalization OR admission OR internment)	1,314
PsycINFO	("infant, newborn" OR neonate OR newborn OR "premature birth" OR "birth premature" OR "preterm birth") AND (parents OR parent OR parenthood OR family OR families OR relatives OR filiation) AND ("neonatal intensive care" OR NICU) AND (hope OR "coping strategies" OR "life experience" OR resiliency OR resilience OR belief OR hopefulness OR "coping skills" OR "life change events" OR "resilience, psychological") AND (hospitalization OR admission OR internment)	16
EMBASE	("infant, newborn" OR neonate OR newborn OR "premature birth" OR "birth premature" OR "preterm birth") AND (parents OR parent OR parenthood OR family OR families OR relatives OR filiation) AND ("neonatal intensive care" OR NICU) AND (hope OR "coping strategies" OR "life experience" OR resiliency OR resilience OR belief OR hopefulness OR "coping skills" OR "life change events" OR "resilience, psychological") AND (hospitalization OR admission OR internment)	185
SCOPUS	("infant, newborn" OR neonate OR newborn OR "premature birth" OR "birth premature" OR "preterm birth") AND (parents OR parent OR parenthood OR family OR families OR relatives OR filiation) AND ("neonatal intensive care" OR NICU) AND (hope OR "coping strategies" OR "life experience" OR resiliency OR resilience OR belief OR hopefulness OR "coping skills" OR "life change events" OR "resilience, psychological") AND (hospitalization OR admission OR internment)	1,655
LILACS	("infant, newborn" OR neonate OR newborn OR "premature birth" OR "birth premature" OR "preterm birth") AND (parents OR parent OR parenthood OR family OR families OR relatives OR filiation) AND ("neonatal intensive care" OR NICU) AND (hope OR "coping strategies" OR "life experience" OR resiliency OR resilience OR belief OR hopefulness OR "coping skills" OR "life change events" OR "resilience, psychological") AND (hospitalization OR admission OR internment)	16

Figure 1: Search strategies, databases and number of studies found. Brasília, DF, Brazil, 2025.

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The searches were conducted on September 30th, 2024, and updated on February 26th, 2025, in the following databases: Medical Literature Analysis and Retrieval System Online (MEDLINE) via PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), Psychological Information Database (PsycINFO), Excerpta Medica Database (Embase), Scopus and *Literatura Latino-Americana e do Caribe em Ciências da Saúde* (LILACS). In order to access the Gray Literature, searches were made in the Theses and Dissertations Library belonging to *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior* (CAPES) and in the Open Access Theses and Dissertations (OATD) platform. These databases were chosen for presenting a broad variety of articles in the Nursing, Social Sciences and Health Sciences fields and higher retrieval of articles considering the theme and strategies adopted.

They were conducted independently by two reviewers and the results were compared to ensure scope and consistency of the data retrieved. Finally, a manual search was made in the lists of references from the eligible studies. No time restrictions or related to study type were applied. As for language, the materials considered were studies published in Portuguese, English and Spanish, considering the reviewers' linguistic mastery.

All the resulting references were imported into the Rayyan software for systematic reviews (https://www.rayyan.ai/), free version. The first stage corresponded to removing duplicates and the articles were screened in two stages: in the first one, the titles and abstracts were read by two independent reviewers (SLMSM and FMGSA) that are graduate students attending a university from the Midwest region, with the blinding resource activated; in the second stage, the full texts were assessed to verify the eligibility criteria. In both stages, any and all divergences between the reviewers were solved by consensus and a third reviewer (AOS) was consulted when necessary. This third party was the study advisor and had experience in the scoping review method and theme.

Data extraction was performed independently by two reviewers (SLMSM and FMGSA) by using the "JBI Template Source of Evidence Details, Characteristics and Results Extraction Instrument"[19] and recording the information in a Microsoft Excel spreadsheet. The information extracted included the corresponding study identification (ID), publication country and year, objective, participants and method. The materials included were primary studies researching hope among parents and family members of extremely premature newborns in NICUs, with qualitative, quantitative or mixed methodologies and aiming at a broad understanding of the hope process in parents and family members. The studies excluded were those focused exclusively on technical and clinical aspects inherent to an NICU and not addressing hope in parents or family members, as well as opinion texts and documents, for not been relevant to the review objective.

The data extracted from the primary studies were analyzed from a quantitative point of view considering their main characteristics in terms of population, context, method and publication time trends. The findings (results and implications of the studies) were analyzed from a qualitative perspective focusing on identifying diverse evidence related to hope and its manifestations in the experiences undergone by parents and family members of extremely premature newborns hospitalized in NICUs. All such evidence was organized in thematic nuclei, considering the dimensions from the multidimensional hope model proposed by Dufault and Martocchio[18]. The results obtained in the scoping review are presented in a diagram, in synthesis tables and in a descriptive format representing the data mapping and a summary of all the evidence, in order to answer the review question and identify research gaps.

RESULTS

The search in the scientific databases yielded 4,067 records. A total of 765 were removed for being duplicates, leaving 3,302 studies for the first screening. In all, 3,270 records were excluded in the screening phase corresponding to reading titles and abstracts for not meeting the inclusion criteria established for this review. As a result, 32 articles were selected for full-reading and 8 were considered eligible and included in the review. Complementarily, a manual search was conducted in the references of the studies selected, identifying 5 additional articles and considering 4 of them as eligible. It is noted that, in the process to search for other methods, the Gray Literature was researched in the Theses and Dissertations Library belonging to *Coordenação de Aperfeiçoamento de Pessoal de Nível Superior* (CAPES) and in the Open Access Theses and Dissertations (OATD) platform, not identifying new studies. Thus, 12 studies were included in this review, as illustrated in Figure 2.

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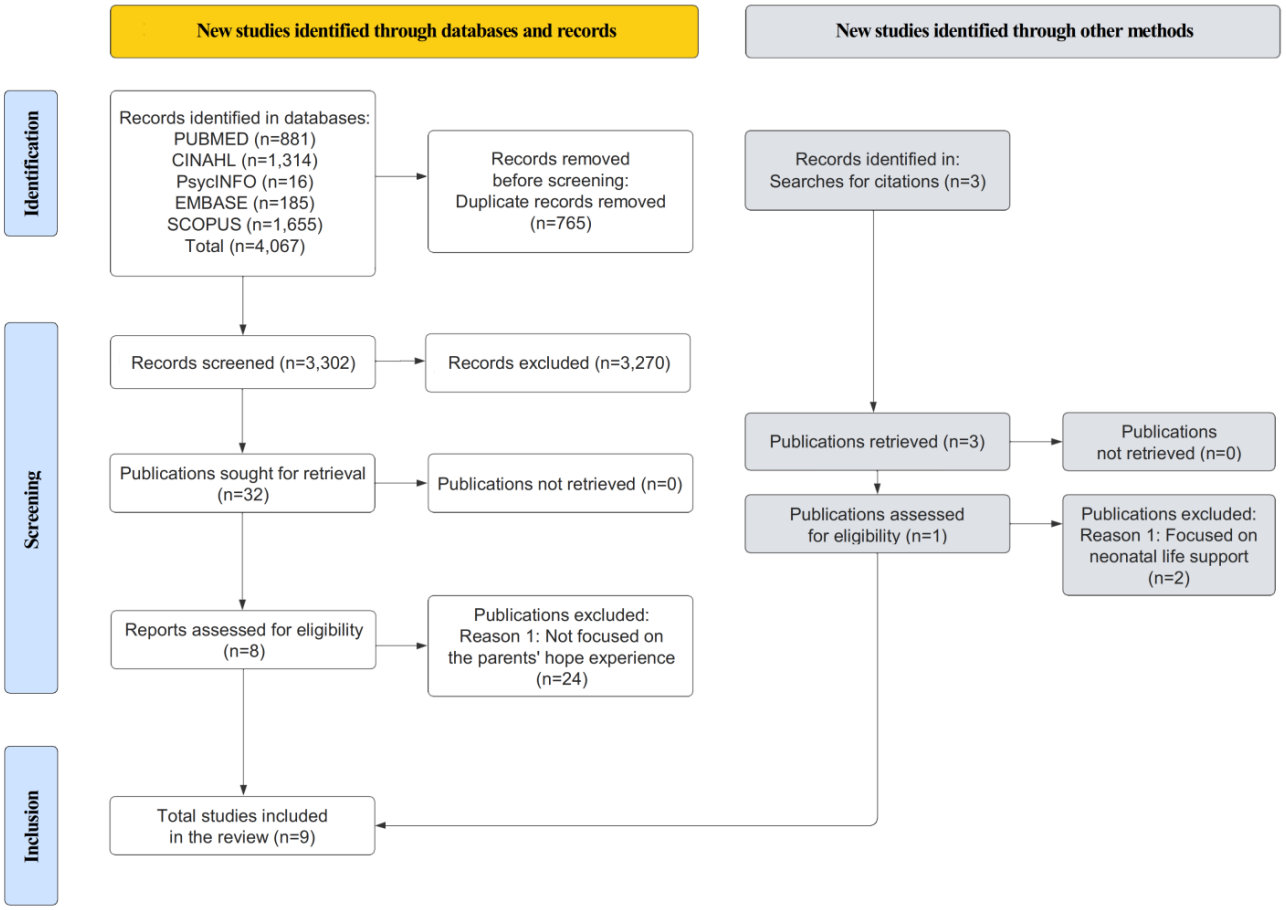

Figure 2: PRISMA flowchart corresponding to selection of the studies. Brasília, DF, Brazil, 2025.

In order to standardize and organize the way in which the results were presented, the studies included were identified with the letter "S" followed by an Arabic number: "S1" for Study 1, "E2" for Study 2, and so on. The main characteristics of the studies and a synthesis of the findings are presented in figures 3 and 4, respectively.

ID	Country and year of publication	Objective	Participants	Method
S1[23]	Canada, 2023	To explore the parents' perspectives about the impacts of extreme prematurity on their lives and their families'.	248 parents of 213 extremely premature newborns	Mixed-methods research study
S2[24]	Finland, 2023	To retrospectively explore the testimonies of parents of extremely premature newborns (23-24 gestational weeks) about the bonding process and related experiences during hospitalization in Neonatal Intensive Care Units (NICUs) and in the subsequent years.	29 mothers and 8 fathers of infants born at the 23rd-24th gestational weeks and hospitalized in an NICU	Qualitative and descriptive study
S3[25]	Canada, 2021	To research the parents' perspectives about their extremely premature newborns' health.	248 parents of 213 extremely premature newborns	Mixed-methods research study
S4[26]	Finland, 2021	To explore the maternal experiences in terms of raising children born at the 23rd gestational week and the challenges faced.	8 mothers of children born at the 23rd gestational week	Qualitative and descriptive study

Figure 3: Characterization of the studies published between 2021 and 2023 included in the scoping review. Brasília, DF, Brazil, 2025.

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ID	Country and year of publication	Objective	Participants	Method
S5[27]	Australia, 2019	To explore the experiences undergone by mothers of extremely premature newborns during their hospitalization in a Neonatal Intensive Care Unit (NICU) and the hospital-home transition.	10 mothers of extremely premature newborns	Qualitative and descriptive study
S6[28]	Australia, 2019	To explore the experiences undergone by parents of newborns in an NICU, contextualizing memories and identifying negative and positive aspects.	17 parents (21 extremely premature newborns and 1 neonate with a congenital malformation)	Qualitative study supported by the Grounded Theory
S7[29]	Spain, 2018	To describe and understand the experiences undergone by mothers of extremely premature newborns in an NICU in relation to the bonding process.	16 mothers of extremely premature newborns hospitalized in an NICU for at least 30 days	Qualitative study grounded on Phenomenological Hermeneutics
S8[30]	Switzerland, 2017	To explore the experiences undergone by parents during the death process of extremely premature newborns in an NICU.	20 parents (7 couples, 1 father, 5 mothers) of extremely premature newborns that died in an NICU	Qualitative study grounded on Hermeneutics
S9[31]	Colombia, 2014	To identify the meaning parents attribute to their extremely premature newborns' hospitalization.	8 parents of extremely premature newborns hospitalized in an NICU	Qualitative study grounded on Ethnonursing
S10[32]	Canada, 2012	To describe the parents' perceptions about the decision-making process in relation to their extremely premature newborns.	7 parents of extremely premature newborns	Qualitative and descriptive study
S11[33]	United States, 2010	To assess and compare the presence of perceived stress and depressive symptoms in parents of premature newborns hospitalized in an NICU as time went by.	35 parents of premature neonates born before the 30th gestational week and hospitalized in an NICU	Qualitative, longitudinal and prospective study
S12[34]	Switzerland, 2008	To examine the impact of extremely premature births on parents' mental health, comparing those that lost their newborns and those whose children survived.	92 parents of extremely premature newborns (54 grieving, 38 non-grieving)	Cross-sectional and quantitative study

Figure 4: Characterization of the studies published between 2008 and 2019 included in the scoping review. Brasília, DF, Brazil, 2025.

A total of 12 studies published between 2008 and 2023 were reviewed, mostly concentrated in the 2017-2023 period (n=8), indicating a recent increasing trend in scientific production on the topic. The first study that was identified was published in 2008 in Switzerland and addressed the impact of premature births on parents' mental health. From 2017 onwards, the papers started to present greater diversity in terms of methodologies and approaches. Canada leads in number of publications (n=3), followed by Australia, Switzerland and Finland (n=2 each). Spain, Colombia and United States contributed one study each, showing the global interest in the theme.

Most of the studies adopted qualitative approaches (n=8), resorting to semi-structured interviews, content analysis and phenomenology. Two studies followed a quantitative methodology, focusing on variables such as stress and childhood development. Another two papers adopted mixed methods, evidencing an increasing trend for integration between objective and subjective data.

The participants were fathers and mothers of Extremely Premature Newborns (EPNs) with less than 28 gestational weeks and extended hospitalizations in neonatal intensive care units. The number of participants in the studies varied between 7 (S10) and 248 (S3), including different family configurations, which expanded understanding about the challenges faced and about hope as a coping resource. Figure 5 presents the categories related to the experience of hope and the outcomes found.

Hope emerged as a core element in the experiences undergone by parents of extremely premature newborns, articulating itself in the six dimensions proposed by Dufault and Martocchio, namely: Affective, Cognitive, Behavioral, Temporal, Contextual and Spiritual[18].

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ID	Scope category	Hope experience	Outcome
S1[23]	Family frailty and resilience after prematurity	Hope articulates positive (gratitude, family strengthening, personal growth) and negative (fear, stress, concern about the future) aspects, in addition to promoting strength and resilience.	Positive coping with extreme prematurity, with implications for psychosocial support and family-centered care.
S2[24]	Parental bonding on the viability threshold (23-24 weeks)	Hope promotes resilience, especially in overcoming the initial challenges during the bonding and parenthood process in an NICU. It is related to the emotional and practical support provided by the team.	It promotes gratitude for the child's survival and development.
S3[25]	Parental priorities in health outcomes	Hope is associated with appreciation of the bond, quality of life and the children's survival. It remains strong even in the face of uncertain prognoses and promotes focusing on small achievements and on the long-term developmental potential.	It generates resilience and confidence in the children's developmental potential.
S4[26]	Parental resilience and gratitude when facing challenges	Hope is reflected as gratitude and linked to maternal dedication, to the children's strength and to social/institutional support.	Maternal dedication and family/society support are determinants of hope.
S5[27]	Experiences undergone by mothers neglected in NICUs	The mothers' hope fluctuates between “active hope” (foreseeing control) and “resigned hope” (accepting impotence). Hope is weakened when mothers are not duly recognized as their children's caregivers in an NICU, corroborating for feelings such as isolation and despair.	The children's survival and developmental hope sustains hope, whereas lack of emotional and psychological support threatens it.
S6[28]	Meanings attributed to hope as time goes by	Religion, culture, family support and NICU practices (open communication, welcoming and **milestone praising**) are participating factors of hope.	Family resilience aspects and religious/cultural meanings are part of the hope experience.
S7[29]	Maternal bonding in NICUs	Hope is essential in coping with extreme prematurity, assists in emotional bonds and is related to lessons learned and participation in neonatal care.	Hope promotes and eases maternal bonding and care.
S8[30]	Parental grief and bonding in end-of-life situations	Hope manifests itself in an ambivalent way: at first, it is a force targeted at believing in the children's survival and, subsequently, as comfort and dignity in their dying process.	Hope eases the parents' affective bond with their children at the end of life and assists both in grieving and in the farewell processes.
S9[31]	Paternal adaptation to extreme prematurity	Hope assists in dealing with hospitalization, where adaptations in everyday life, bonding in the NICU and involvement in caring for the children stand out, with impacts on the parents' health.	Hope is a protective factor for paternal mental health.
S10[32]	Communication, relationships and emotional support	Hope becomes a reality from experiencing and establishing genuine relationships with NICU teams.	The children's clinical conditions, the NICU culture and the relationships with the professionals are determinant factors for the hope experience.
S11[33]	Paternal emotional responses in NICUs	Hope assists in handling parental stress and depression, favors a positive prospect about the newborns' future and promotes overcoming difficulties.	The parents' active participation, acknowledgment and appreciation of their emotional experience strengthen family hope.
S12[34]	Parental mental health after extreme prematurity	Hope presented different patterns in grieving and non-grieving parents; in the former, it was associated with acceptance and with reconstructing the meaning of their children; in the latter, it served as a motivating force to face challenges. Hopelessness was correlated to higher depression risks in both groups.	Hope proved to be a protective factor for the mental health of grieving and non-grieving parents alike.

Figure 4: Findings from the studies included in the scoping review. Brasília, DF, Brazil, 2025.

Linked to feelings and emotions, the Affective dimension proved to be ambivalent. It included positive emotions such as gratitude (48%), strengthening of bonds (31%) perceiving the children as miracles (28%) strengthened hope (S1). On the

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other hand, negative feelings such as stress (42%), fear (35%) and concern about the children's development (18%) also permeated the reports, especially among grieving parents (S5, S9). Lack of emotional support intensified psychological distress and maternal solitude (S5); in turn, even when in difficult situations such as the death of other newborns, hope persisted as a sustaining force.

Related to the perception of reality and future prospects, the Cognitive dimension was present in critical decisions such as newborn resuscitation, influenced by hope and by religious beliefs (S10). Even when facing challenges, the parents upheld the positive assessment about their children's health (Note 9/10 in S3) and considered hope, love and faith as essential for their survival (S6). The experience was attributed a new meaning with gratitude and bonding after discharge (S2).

Referring to the actions motivated by hope, the Behavioral dimension was evidenced through the parents' involvement in care (S4) and by physical contact as a bonding and emotional strengthening strategy (S7). The parents sought to learn from the team and adapted to the NICU environment as a way to connect with their children (S9). They also took on multiple responsibilities in everyday life, balancing family and emotional care (S11).

Hope proved to be dynamic in the Temporal dimension, from pregnancy and hospitalization to after hospital discharge. The present time was valued. The parents reported overprotection, intense attachment and continuous involvement in the routines and acknowledged resilience traits in their children (S4). Bonding with the neonates was strengthened as time went by (S10) and, even after their death, hope assisted in emotional reconstruction and personal growth (S12). Despite their anxiety about the future, the parents expressed gratitude for the progress made and the time spent with their premature children (S3).

The Contextual dimension, which considers the social and environmental aspects, highlighted the NICU role as a welcoming space. Humanized care strengthened hope and bonding with the teams (S8, S9). Changes in lifestyle, religion and values were also reported (S9). In turn, lack of emotional support weakened distressed mothers (S5), whereas involvement in care and welcoming were pointed out as crucial to sustain hope (S2). Grieving mothers reported personal growth mediated by strengthened relationships and life appreciation (S10, S6, S4, S12).

Finally, the Spiritual dimension can be conceived as an interconnection between the Affiliative (interactions) and Cognitive (beliefs) dimensions. In this study, it reflected the role of faith and self-transcendence in sustaining hope. Parents with different beliefs reported spirituality as a force when facing uncertainty, considering clinical improvements as miracles (S6). Indigenous parents also resorted to their cultural beliefs (S3), whereas others found comfort in connecting with God (S10). Faith was associated with trusting in the children's survival and with maintaining hope (S2).

DISCUSSION

The study findings confirm the central role of hope in the experiences undergone by parents of extremely premature newborns, working as an element that sustains resilience in the face of adversities. The relationships with health professionals proved to be essential in maintaining this hope, mainly when communication was sensitive and personalized[35].

In this context, it was noticed that, even when facing reserved prognoses, it is fundamental for health professionals to balance openness and encouragement, resorting to respectful and humanized language to preserve parental bonding and hope[11]. According to the World Health Organization (WHO)[36], comprehensive pediatric Palliative Care should encompass adequate control of symptoms and spiritual/social management of patients and their families, in addition to specific interventions for psychological distress. These aspects are deeply interconnected with the concept of hope, which transcends cure expectations in the Palliative Care context[37].

When holistically addressed, hope not only involves physical distress relief but also emotional and spiritual support, providing children and families with a sensation of dignity and comfort[36]. In this scenario, the perception about the newborns' distress exerts profound effects on the decisions about life support continuity or interruption[38]. Support from the family and external networks, such as communication media and information resources, can both reinforce and distort the parents' hope. Thus, interventions that involve the parents in their children's care (such as skin-to-skin contact and participation in routines) are pointed out as effective strategies to strengthen the bond and the feeling of paternal competence[39].

In addition to that, cultural sensitivity and customized care also proved to be relevant, allowing for significant figures to take part in the decision process and respecting individual values[40]. Hospitalization in an NICU impairs the typical parental experience, requiring forceful adaptation to a medical environment from the parents, which can generate psychological traumas and distress, even after discharge[41]. In the emotional aspect, hope can mitigate postpartum depressive symptoms, working as a mediator between adversity and parental well-being. Hopeful

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parents present better coping ability and greater positive involvement with their children, in addition to strengthening family cohesion[42].

In this context, factors such as socioeconomic level, hospitalization time and maternal mental health exert an influence on parental stress, with hope as an important mediator for the parents' quality of life and competence in vulnerable environments[43]. During the COVID-19 pandemic, for example, hope proved to be a protective factor against parental stress, especially when associated with self-compassion[44].

In addition, hope is also identified as an adaptation factor in parents of children with disabilities or chronic diseases, despite taking on particular characteristics in extreme prematurity cases given the high uncertainty of the prognoses[42]. In pre-natal decisions about newborns in the “Grey Zone”, parents weigh intensive interventions against comfort care, many times motivated by hope[26,45].

Social and spiritual support also emerges as a mainstay for parental hope, even when facing emotional, economic and ethical challenges. However, the literature shows that neonatologists tend to pessimism when informing prognoses, which reinforces the importance of more balanced approaches that incorporate hope as a care component[10].

Consequently, both in neonatal contexts and in chronic pediatric conditions, hope works as a coping factor, allowing parents to attribute meaning to the situation and to preserve their leading role and autonomy in the face of uncertainty. Thus, hope-centered interventions are essential to provide emotional and psychological support to the families, from birth to the possible outcomes[8,46].

The studies addressing life-threatening conditions share some similarities, especially in terms of the emotional impacts on the parents, to the uncertain prognoses and to the role of hope as a resilience factor[8]. Both in life-threatening neonatal conditions and in pediatric chronic diseases, hope emerges as a core mechanism to deal with stress and uncertainty, helping parents find meaning in the care path and to maintain a sense of agency in the face of challenges. In addition to that, these studies highlight the importance of social support and of getting involved in support networks to sustain hope and improve parental adaptation[46].

Nevertheless, hope acquires some specific characteristics in the extreme prematurity context. Unlike many pediatric chronic conditions with defined diagnoses and more foreseeable clinical progression, extreme prematurity is marked by highly uncertain prognoses, which can vary from significant recovery to severe sequelae or even death[47]. This unpredictability scenario makes the parents' hope fluctuate between survival expectations or search for developmental milestones to acceptance of possible limitations[24]. In addition to that, medical decision-making during the neonatal period (many times involving difficult ethical choices such as vital support limitation) renders hope construction even more challenging[48]. Thus, if in chronic diseases hope can be more related to adapting to a new reality, in extreme prematurity it is constantly constructed and transformed, according to each newborn's clinical evolution.

Consequently, all this evidence highlights the need for interventions that offer continuous emotional and psychological support to parents, prioritizing approaches centered on hope and on family care, both in the clinical recovery context and in Palliative Care[8]. It is essential to implement public policies that integrate clinical resoluteness with biopsychosocial and spiritual aspects, thus promoting comprehensive care. Training programs for health professionals should qualify teams and nourish hope, improve empathetic communication and create welcoming environments in NICUs. Finally, family monitoring programs can strengthen parental bonds and minimize the negative impacts exerted by extreme prematurity throughout a child's life.

Study limitations

Despite the relevant contributions about parental hope, this study presented some limitations. The language restriction implemented in the search and the diversity of cultural contexts stand out among them, which can hinder generalization of the findings. Scarcity of research studies that consider the family as analysis unit was also observed, neglecting the relational nature of hope in the extreme prematurity context.

FINAL CONSIDERATIONS

This study showed that hope is a core element in the experiences undergone by parents and family members of extremely premature newborns hospitalized in intensive care units. This scoping review identified that hope is strongly related to parental resilience, exerting an influence on coping with the adversities and in adapting to the extreme prematurity experience. The findings reinforce that hope is not only a passive feeling but a dynamic force that allows parents to construct positive meanings, strengthen affective ties and actively engage in their children's care.

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The literature reviewed revealed that hope manifests itself in multiple dimensions, from spirituality and search for information to social support and participation in hospital routines. In addition to that, strategies that favor closeness between parents and newborns contribute to sustaining hope and to promoting more welcoming environments.

The findings detected in this review have implications for neonatal assistance and for devising humanization policies that guide neonatal intensive and palliative care, by investing in models and approaches that sustain hope centered on the family. Hope can be promoted through emotional support, empathetic communication and continuous parental and family involvement.

Although the study has identified important evidence about parental hope experiences, a number of incipient aspects and gaps in knowledge were identified, thus recommending future studies about the experience and relational dynamics of hope considering the family as analysis unit.

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Authors' contributions:

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Use of Artificial Intelligence tools

Authors declare the use of the DeepSeek® Artificial Intelligence tool (https://www.deepseek.com/), in an ethical and responsible way, to improve writing and organization of the manuscript. AI use was limited to the text review, focusing on improving its clarity and cohesion and on ensuring that originality, integrity and interpretation of the results were fully preserved.