

Factors influencing hope in parents of children with chronic illness

Fatores influenciadores da esperança nos pais de crianças com doença crónica
Factores que influyen en la esperanza de los padres de niños con enfermedad crónica

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Descriptores

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Abstract

Objective: To map in scientific literature studies that lead to the identification of factors that influence the experience of hope in parents of children with chronic illness.

Methods: A scoping review literature review was carried out, following the methodology proposed by the Joanna Briggs Institute in the PubMed, CINAHL Plus with Full text and MEDLINE Plus with Full text databases, in the chronological interval between 2009 and 2019, to respond to the question: what are the factors that influence the experience of hope in parents of children with chronic illness?

Results: After applying the inclusion and exclusion criteria, ten studies were selected, from which it appeared that hope is a positive and motivating internal resource and that it is oriented towards the present and the future. There are factors that promote hope, such as the focus on positives, faith/religion and social support; and factors that threaten parental hope, such as physical and emotional exhaustion, perceived negativity on the part of others, fear and uncertainty.

Conclusion: Parental hope is influenced by children's health status, effectiveness of treatments and psychosocial context, playing a significant role in adapting parents to children's health condition.

Resumo

Objetivo: Mapear na literatura científica estudos que conduzam à identificação dos fatores que influenciam a vivência de esperança em pais de crianças com doença crónica.

Métodos: Realizada uma revisão da literatura do tipo Scoping Review, seguindo a metodologia proposta pelo Joanna Briggs Institute, nas bases de dados Pubmed, CINAHL Plus with Full texto e na MEDLINE Plus with Full text, no intervalo cronológico compreendido entre 2009 e 2019, para responder à questão: quais os fatores que influenciam a vivência de esperança em pais de crianças com doença crónica?

Resultados: Após aplicação dos critérios de inclusão e exclusão, foram selecionados dez estudos, dos quais se depreendeu que a esperança é um recurso interno positivo e motivador e que está orientada para o presente e para o futuro. Existem fatores promotores de esperança, como o foco nos pontos positivos, fé/religião e apoio social; e fatores ameaçadores à esperança parental, como o esgotamento físico e emocional, negativismo percebido por parte dos outros, medo e incerteza.

Conclusão: A esperança parental é influenciada pelo estado de saúde dos filhos, eficácia dos tratamentos e contexto psicossocial, tendo um papel significativo na adaptação dos pais à condição de saúde da criança.

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Resumen

Objetivo: Mapear en la literatura científica estudios que conduzcan a la identificación de los factores que influyen en la vivencia de esperanza de los padres de niños con enfermedad crónica.

Métodos: Se realizó una revisión de la literatura tipo *Scoping Review*, siguiendo la metodología propuesta por el Joanna Briggs Institute, en la base de datos Pubmed, CINAHL Plus with Full texto y en la MEDLINE Plus with Full text, en el período cronológico comprendido entre 2009 y 2019 para responder la pregunta: ¿qué factores influyen en la vivencia de esperanza de los padres de niños con enfermedad crónica?

Resultados: Luego de aplicar los criterios de inclusión y exclusión, se seleccionaron diez estudios, de los cuales se dedujo que la esperanza es un recurso interno positivo y motivador y que está orientada hacia el presente y el futuro. Existen factores que promueven la esperanza, como el énfasis en los puntos positivos, la fe/religión y el apoyo social; y factores que amenazan la esperanza parental, como el agotamiento físico y emocional, el negativismo percibido por parte de los otros, el miedo y la incertidumbre.

Conclusión: La esperanza parental está influenciada por el estado de salud de los hijos, la eficacia de los tratamientos y el contexto psicosocial, factores que tienen un papel significativo en la adaptación de los padres a la condición de salud del niño.

Introduction

Children are the focus of pediatric care; however, parents are also assumed to be a full part of caring.⁽¹⁾ Chronic illness can be defined as a long-term illness with disabilities and residual deficits in the medium and long term, expressed in a greater or lesser percentage of the need for health care and its supervision.⁽²⁾

Hope is a concept that has been addressed for several decades and in different scientific areas; however, its recognition as an essential phenomenon to nursing course and, on which studies need to fall, is more recent.⁽³⁾ As a concept it has emerged with increasing interest and gradual recognition, being defined as an experience of meaning and purpose for life,⁽⁴⁾ with a multidimensional and highly complex character.⁽⁵⁾ Some theories developed within nursing course refer that there are four elements that define hope in a procedural way, such as experimental, spiritual, rational and relational process.⁽⁵⁾ This is a phenomenon characterized by the possibility of a person being responsible for their own existence, directing their life and transcending the simple aspects of reality.⁽⁶⁾

Due to its individual and multidimensional character, hope is essential in the health-disease process. This contributes to empowering individuals to face moments of crisis, to maintain their quality of life, contributing to health promotion and determination of realistic goals, assuming itself as one of the central aspects in nursing care.⁽⁷⁾ Hope can still be experienced as comfort, and as a possibility to get out of a cycle of suffering.⁽⁷⁾

Despite the research developed and the growing interest in the subject, studies that address the experience

of hope in parents of children with chronic illness are still scarce.⁽⁶⁾ For example, Charepe's study⁽⁸⁾ analyzed the influence of "(...) mutual aid groups in the development of hope in parents of children with chronic illness".⁽⁸⁻¹³⁾ Other authors have focused on hope as an essential and life-sustaining resource from parents' perspective in contexts of care for children with chronic, incurable and potentially fatal disease.^(6,9,10)

Sisk, Kang & Mack⁽¹⁰⁾, in a study carried out with parents of children with a clinical diagnosis of oncological disease, conclude that the sources of parental hope go beyond hope of cure, and it is crucial to understand how it persists during the trajectory disease of children with poor prognosis.

Care aimed at promoting hope plays an important role, considering the nature of chronic disease, the limitations and challenges imposed by the daily management of symptoms, the therapeutic regimen and the needs for health care and available resources.

Considering the dispersion of scientific literature on parental hope, it is important to clarify the definitions and conceptual limits through existing research. Thus, the relevance of conducting a scoping review is evidenced, with the aim of mapping studies in scientific literature that lead to the identification of factors that influence the experience of hope in parents of children with chronic disease.

A preliminary research was carried out of systematic reviews published on this topic, in the PROSPERO, Cochrane Database of Systematic Reviews, JBI Evidence Synthesis, PubMed and CINAHL databases; and no current or ongoing systematic reviews on the topic have been identified. This research was conducted on January 12, 2020 and repeated on February 20, 2020.

Methods

The present literature review used the method described by the Joanna Briggs Institute (JBI).⁽¹¹⁾

In formulating the review question, “what are the factors that influence hope in parents of children with chronic illness?”, was based on PCC mnemonic (participants - parents of children with chronic illness; concept - experiences of hope; context - any context of pediatric health care, in the hospital, in primary care or at home). Each acronym became decisive for guiding the review and construction of the research strategy, in order to obtain reliable scientific information.

Regarding the type of sources, primary studies of qualitative, quantitative or mixed nature, published in a chronological interval between 2009 and 2019 in English, Brazilian Portuguese and Spanish were included. This time frame is justified given that this review is part of a larger research work carried out in 2009, which included a systematic review of the factors that promote parental hope.⁽⁸⁾

Studies on parents of children with acute illness, parents with adult children, parents of premature children and/or with behavioral changes, given the specifics of their clinical conditions were excluded.

In the research, the strategy was used in three stages.⁽¹²⁾ Initially, a search was carried out in the databases (MEDLINE with full text and CINAHL with full text), followed by an analysis carried out by two independent reviewers of the words contained in the studies’ titles and abstracts as well as key terms. After identifying the descriptors to be used, the search equation was created and applied to the following databases of the electronic platform EBSCOhost: Cumulative Index to Nursing and Allied Health Literature Complete (CINAHL), MEDLINE Complete, Nursing & Allied Health Collection: Comprehensive, Cochrane Central Register of Controlled Trials, Cochrane Database of Systematic Reviews, Cochrane Methodology Register, Library, Information Science & Technology Abstracts (LIST), and MedicLatina. Additionally, research was performed on the PubMed, SciELO and Web of Science platforms. The bibliographic reference list of the selected articles was systemati-

cally consulted as a way of identifying relevant articles for this review.

After the search, all identified records were grouped for analysis and duplicate articles were removed using the EndNote bibliographic management software. The two reviewers analyzed the full text of the articles that met the inclusion criteria. In a situation of disagreement among reviewers, a discussion was carried out based on the objectives of the review using a third independent reviewer.

Twenty-four articles were included, and after careful analysis and application of the inclusion and exclusion criteria, 11 were rejected. There were 13 studies left for critical assessment, which were analyzed and relevant information was extracted to answer the question asked. After reading and individualized integral analysis, ten scientific articles were kept (Figure 1).

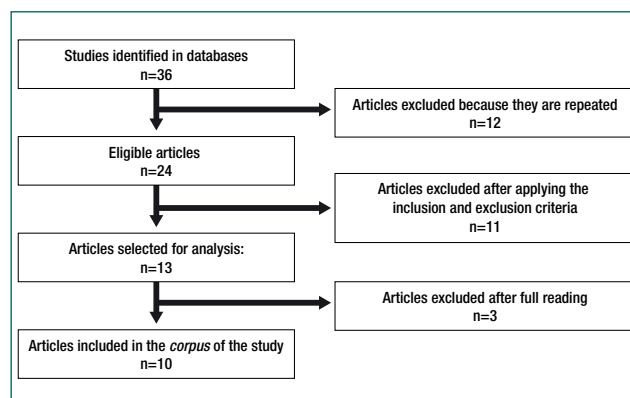


Figure 1. PRISMA⁽¹³⁾ flowchart of the study selection process

Results

The results were analyzed according to the review question and the methodological nature of the studies. A characterization of articles included in the theoretical sample of this review was made (Chart 1).^(6,9,14-21)

From data analysis, it was concluded: from 2010 to 2012 inclusive, and in 2017 and 2019 no relevant publications were found; 2013 was the year with the highest number of relevant publications on the topic (three articles published); in 2009 and 2015 two articles were published per year, while in 2014, 2017 and 2018 there was one article.

Chart 1. Characterization of studies analyzed in the literature review

Authors/Year/ Country	Title	Objectives	Study Type	Results	Main factors
Samson et al ⁽⁶⁾ 2009 Canada	The lived experience of hope among parents of a child with Duchenne muscular dystrophy: perceiving the human being beyond the illness	Describe the experiences of hope among parents of children with Duchenne muscular dystrophy (DMD), in a specific context of psychosocial adaptation; Describe and understand how hope emerges in the trajectory, considering the fatal outcome.	Qualitative: Phenomenological Approach	The parental experience of hope emerges from the cognitive assessment of children with DMD. Parents' perceptions of children's illness (severe loss; need for adaptation; spiritual and intangible experience that allowed them to meet up with their child) lead to different forms of hope.	Parents' perceptions about children's illness.
Lloyd & Hastings ⁽¹⁴⁾ 2009 United Kingdom	Hope as a psychological resilience factor in mothers and fathers of children with intellectual disabilities	To explore the relationship of hope as a potential for resilience in the well-being of parents of school-age children with intellectual disabilities, based on Snyder's Hope Theory.	Quantitative	Hope was measured with two components: the perception that objectives can be achieved (goals) and alternative routes to can be found to reach them, if necessary (routes).	Anxiety and depression in the father. Positive affection in the father. Mothers' well-being.
Granek et al ⁽¹⁵⁾ 2013 Israel	Trajectory of parental hope when a child has difficult-to-treat cancer: a prospective qualitative study	Realize parental hope when a child with cancer is undergoing treatment after the first year after diagnosis.	Qualitative: Grounded Theory	Parental hope changes over the first year after diagnosis. It is considered a positive, motivational internal resource that guides the present and the future. Two categories were identified: future-oriented (having no suffering or complications) and present-oriented hope (for healing, for the future, for a miracle and for longer with end-of-life children).	Illness progression Children's pain and suffering.
Barrera et al ⁽¹⁶⁾ 2013 Canada	The Tenacity and Tenuousness of Hope	Explore parental hope during children's cancer treatment process; identify facilitators and barriers in their maintenance.	Qualitative: Grounded Theory	Parental hope is related to the healing of children. Their future is generally dependent on children's response to treatment and the psychosocial context. There are facilitators and barriers to maintaining hope identified by parents.	Awareness of the positive or negative aspects related to children's illness. Positive thinking. Effects of treatment on children. Focus on a positive gift. Spirituality. Psychosocial care. Information overload. Negativity from others. Physical and emotional exhaustion. Fear and uncertainty.
Markward, Benner & Freese ⁽¹⁷⁾ 2013 Colombia	Perspective of parents on Making Decisions about the Care and Treatment of a Child with Cancer	Understand parents' perspective in relation to decision-making regarding care and treatment of children with cancer.	Literature review	Hope influences parents' decision-making regarding treatment and care of children with cancer. It helps in preparing for the negative aspects of treatment and can be promoted through appropriate communication by health professionals. It is important in decision-making at the end of life. For parents, hope is an increase in their children's time and quality of life.	Support perception. Communication. Information and knowledge. Parental participation in child care. Quality of life and well-being of children. Sense of control. Trust. Financial situation. Satisfaction with the care received.
Bally et al ⁽⁹⁾ 2014 Canada	Keeping Hope Possible	Understand the experience of hope in parents who care for children undergoing treatment for cancer.	Qualitative: Grounded Theory	Parental hope is defined as essential, deliberate, life-sustaining, dynamic and cyclical. The hope process goes through sub-processes: accepting reality, rebuilding hope and intentional positive thoughts. The main concern of parents is to lose hope.	Access to child health information. Increased experience and knowledge. Connection with others. Be on the circuit. Reaffirmation of faith.
Popp, Conway & Pantaleao ⁽¹⁸⁾ 2015 USA	Parents' Experience with Their Child's Cancer Diagnosis: Do Hopefulness, Family Function, and Perceptions of Care Matter?	Distinguish the experiences of resolved and unresolved parents with their children's cancer diagnosis in relation to hope, family adaptation, and perception of care.	Quantitative	Parents who are not resolved with the clinical diagnosis of their children show a decrease in hope and ability to act in the face of the disease. Parents who manage to combine hope and the capacity to act in the face of the disease are able to outline goals and a plan to achieve them.	Setting goals and a plan to achieve them.
Kamihara, Nyborn, Olcese, Nickerson & Mack ⁽¹⁹⁾ 2015 USA	Parental Hope for Children With Advanced Cancer	Identify the expectations of parents of children with cancer in relation to the experience of hope.	Qualitative	Parents hope for a cure (88%), for a long life, for their children (66%), for the tumor to stabilize or shrink with treatment (47%), for the treatment to prolong life (38%), quality of life (94%), normality (88%), minimization of suffering (75%), love and relationships for the children (66%), hope on the part of other family members (28%) and hope for better treatment (25%).	Negation. Life prolongation. Quality of life. Perception of normality. Suffering. Establishing meaningful relationships.

Continue...

Continuation.

Authors/Year/ Country	Title	Objectives	Study Type	Results	Main factors
Borgestig, Rytterström & Hemmingsson ⁽²⁰⁾ 2017 Sweden	Gaze-based assistive technology used in daily life by children with severe physical impairments - parents' experiences	Describe and explore the experiences of parents when children with cerebral palsy receive eye-guided therapy.	Qualitative: Phenomenological Approach	Gaze-guided therapy leads to increased hope in children's parents. Hope is related to the time when children start using this technology and the conception of a better future for their children. Parents show hope that others will understand their children and help them develop.	Perception of a better future for children.
Illum, Bonderup & Gradel ⁽²¹⁾ 2018 Denmark	Parents' Expressions of Concerns and Hopes for the Future and Their Concomitant Assessments of Disability in their Children	Assess parents' ability to express their concerns and hope for the future of their children with disabilities; assess children's disability and list the data obtained.	Mixed Methods	Parents can express valid and reliable data about their concerns and hope for the future and safely assess their children's disability. Most frequent concerns: education, understanding, goodwill and communication between parents, and community support. Parents expressed hope that children will have a good future life.	No worries for the future Perception about disability assessment.

The selected studies focused on the relationship between hope and the experiences of parents of children with chronic illness, verifying that six studies (60%) followed a qualitative methodology (inductive paradigm), two studies (20%), a quantitative methodology (deductive paradigm), a study using the methodological approach of mixed methods (10%) and a review literature (10%).

Studies that made up the corpus of the study presented significant data, which support the conceptualization of hope in the experiences of parents of children with chronic disease, with the emergence of factors that influence it. Of these, the factors related to children stand out, namely: perception or concerns about the future; disease progression; presence of pain and suffering; quality of life and well-being; denial; treatment effects; extending life and setting goals and a plan to achieve them; fear and uncertainty; psychosocial support; thinking/focusing on a positive gift; awareness of the positive or negative aspects related to children's illness.

With regard to factors related to parents, studies identify the following: anxiety, depression and well-being; support perception; establishing meaningful relationships; spirituality; information overload; physical and emotional exhaustion. This perspective is integrated in the role function, so the factors related to the parental role's performance seem to be conditioning the experiences of hope. At this level, parents valued: communication with health professionals; information and/or knowledge about the disease and treatments to which children will be submitted; parental participation in child care;

sense of control; confidence and satisfaction with the care received; perception of normality.

Although the interview was the data collection technique used in most of studies under analysis, we highlight the use of both studies of a quantitative nature to hope assessment tools. Two different assessment instruments were applied: "The Trait Hope Scale", which consists of 12 specific items that after being filled out, result in a fluctuating score between 12 and 96;⁽²²⁾ "Herth Hope Index", also consisting of 12 items, however its score varies between 12 and 48, "(...) as the higher the score, the higher the level of hope".⁽²³⁾

Both instruments assess hope for the future in adults. Considering the objective of the review, items identified as factors that influence hope in the studies analyzed: perception of reaching set goals and/or tiredness and concern about the future.

Discussion

The evidence of the research carried out and the consequent applicability of its results allowed a greater understanding of the concept of hope, showing that in the vast majority of articles it is defined as positive and motivating.^(9,15,21) It is also described as essential, powerful, deliberate, which sustains life, dynamic and seen as a cyclical process, influenced by time.⁽⁹⁾ The same author adds that it is empowering and provides internal guidance, preparing for the challenges and the worst that could possibly happen.⁽⁹⁾ Hope is an internal and motivational resource that guides

us towards the present and the future. On the other hand, it helps parents in the coping process in relation to their children's illness, even if there is a bad prognosis or possibility of death.⁽¹⁵⁾ This will contribute decisively to preparation for negative aspects of both the disease and treatment.⁽¹⁵⁾ Hope fluctuates over time due to the psychosocial context in which parents are inserted, and is influenced by personal characteristics, external resources and children's response to treatment.⁽¹⁵⁻¹⁶⁾

In a study that looks at parents of children diagnosed with cancer, it is concluded that parents resolved with their children's diagnosis have a resilience factor that facilitates the coping process.⁽¹⁸⁾ On the other hand, those who are not resolved show a decrease in hope and the ability to act in the face of the disease.⁽¹⁸⁾ Parents who manage to combine hope and the ability to act in the face of the disease set goals and outline a plan to achieve them.⁽¹⁸⁾ In another study also related to children with cancer, the authors report that one of the factors that influence parents' decision-making in relation to treatment, and child care, is parental hope.⁽¹⁷⁾ Also, in an investigation with children with intellectual disabilities (Down Syndrome, Cerebral Palsy and Intellectual Disability of Unspecified Etiology), hope was measured as a goal in the face of directed behavior, where agency-based thinking (necessary motivation to use routes that lead to desired goals) was interpreted as a factor of resilience and psychological well-being for parents.⁽¹⁴⁾

The cyclical nature of hope over time is justified in an investigation carried out with 35 parents of children diagnosed with cancer, using three different interviews, with two distinct categories emerging: future-oriented and present-oriented hope.⁽¹⁵⁾ Within these categories, specific themes were defined.⁽¹⁵⁾ For the hope oriented towards the future, parents' statement was: hope for the cure of their children, for a future, for a miracle and for more quality time with the child.⁽¹⁵⁾ Present-oriented hope has subcategories as children having no suffering or complications.⁽¹⁵⁾ In addition to the statement, they concluded that it changes during the first year after the diagnosis of the disease.⁽¹⁵⁾ Parental hope is also characterized as a dynamic, multidimensional life

force and guidance for life and for the future, when managing child care.⁽⁶⁾

Another characteristic of this concept is that it is a constructive process.⁽⁹⁾ In a study carried out with 16 parents of children with cancer, using interviews with open-ended questions, the authors concluded that the hope process goes through four sub-processes: accepting reality, stabilizing, reconstructing hope and thoughts intentional positives.⁽⁹⁾ Accepting reality consists of parents feeling that they need to accept their children's diagnosis and the slowness inherent in the treatment process. The second phase is about stabilization, providing some control, assessing circumstances and managing care needs. There is a rebuilding of hope that motivates parents to hope for the best and resolve their fears of losing hope. The last step described is the intentional positive thoughts that go through finding a positive side in the experience.⁽⁹⁾

Despite being an individual and dynamic process and experience, there are factors that influence parental hope such as assessing the health of children, gaining experience, knowledge about the disease, contact with others, being aware of the circuit treatments and reaffirmation of faith.⁽⁹⁾ In a study conducted with 35 parents of children diagnosed with cancer, using an interview, researchers identified facilitators and barriers to maintaining hope.⁽¹⁸⁾ Parental awareness about the positive evolution of the disease and the effects of children's treatments, the focus on the positive variables of the present, spirituality/religion and social support were appointed as facilitators for hope maintenance, while parental awareness about the negative evolution of illness and treatments, information overload of health professionals, the negativity of other close people, physical and emotional exhaustion and fears and uncertainties were barriers to continuity of hope.⁽¹⁶⁾ These results corroborate what has been described in the most recent scientific literature.⁽²⁴⁻²⁶⁾

The focus on the positive variables of the present is also addressed in a study that includes 11 parents of children with cerebral palsy who are the target of eye-guided therapy.⁽²⁰⁾ The authors found that hope is influenced by the time when children start using

this technology, relating it to a conception of the future for these children.⁽²⁰⁾

Parental hope, in general, is related to the healing of children and to a better future,^(16-17,19,25) with hope for healing predominantly in parents, followed by the possibility of a long life and the stabilization of the disease with treatment.⁽¹⁹⁾ Hope, related to quality of life, normality, minimization of suffering and better treatment is added.⁽¹⁹⁾ When parents have no hope of a cure, they find other reasons to keep it.⁽¹⁵⁾ The main concern of parents is the possibility of losing hope, which is seen as a basic social process.⁽⁹⁾

In an investigation carried out with 119 parents of children with spina bifida, spinal muscular atrophies, muscle disorders, cerebral palsy and various deficiencies, it was concluded that they express concerns related to the quality of care provided. These include understanding the family's needs, social support, coping strategies and involvement in decisions.⁽²¹⁾ Hope is related to quality of life, well-being and future health, education, medical assistance and support from health professionals.⁽²¹⁾ The same study related the severity of children's disability, with the freely expressed concerns and hopes.⁽²¹⁾ It was concluded that the concern that the children do not feel satisfaction with adult life is more often expressed by parents of children with more severe disabilities, who maintain the hope that their children will accept their own disability and have self-confidence.⁽²¹⁾

Health professionals are fundamental in promoting hope, despite the fact that clinicians often have difficulty in approaching this topic, sometimes with fear of the prognosis of the disease, being contradictory to hope promotion.⁽¹⁹⁾ These need to identify the stages and perceptions related to the theme, in order to perceive and guide parents in their experiences of hope.⁽¹⁵⁾ Moreover, effective communication by health professionals is imperative as it acts as a promoting factor.⁽¹⁷⁾

Conclusion

From the result of an analysis of studies that constituted this research, several facts emerged that

allowed to evidence what influences the experience of hope in parents of children with chronic illness, allowing to answer the question initially raised. It was found that hope is multidimensional due to having several characteristics such as being powerful, essential to life, cyclical over time, providing internal guidance. It is seen by most parents as a strengthening internal resource. Hope, associated with diagnosis acceptance, is essential for setting goals and elaborating a sensible plan that leads to its achievement. It is influenced by a number of factors, including children's response to treatment and the family's psychosocial support. Some of the strategies that promote hope are positive awareness about the disease and treatments, adequate family social support, recourse to spirituality, gaining experience and mastery in relation to children's treatments and the focus on the positive factors of the present. The barriers/factors of threat to hope identified are negative awareness about the current situation of children in relation to health status and treatments, information overload, tiredness/physical and emotional exhaustion of parents and negative thoughts of the people around them. Health professionals and nurses, in particular, when taking into account in their professional practice the factors that promote or threaten hope, can find numerous opportunities to promote parental hope. The continuity of the investigation about these factors will allow to improve nursing diagnoses' accuracy as well as the interventions that promote parental hope. The need for further research studies was demonstrated with the observation of a continuous production of knowledge. Thus, it is possible to conclude that this is an emerging theme, with direct implications for health care and that needs constant updating to improve the course and practice of nursing. The limitations described in most of studies constituted the impossibility of generalization for the entire population due to the fact that they are samples that are not very representative in relation to globality (either due to their size or specificity of some pathologies), which constitutes a weakness in this systematic literature review.

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