Hope promoting interventions in parents of children with special health needs: a scoping review
Intervenções promotoras de esperança em pais de crianças com necessidades especiais de saúde: uma revisão scoping
Intervenciones promotoras de esperanza en padres de niñnos con necesidades especiales de salud: una revisión scoping

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ABSTRACT:
The concept of hope has been identified as central to nursing and have gained visibility in the caring of children with special health needs and their families. With the emergence of new challenges in pediatric nursing and knowing the needs and adversities parents are facing in their daily life, interventions that promote hope should be highlighted.
Objective: to map the interventions that have been implemented and evaluated to promote hope in parents of children with special health needs.
Method: a scoping review was held, following Joanna Briggs Institute methodology, in the databases Pubmed, CINHAL complete and SciELO, in portuguese, english and spanish and in the time window from 2008 to 2018.
Results: Seven studies were included in this review. The research that was found is mostly qualitative, dispersed in time and differentiated in terms of conceptual framework. Mostly evaluated in individuals, the studies encompass either group and individual interventions, with a large variability of contexts and intervention characteristics.
Conclusion: discussions about hope promoting interventions in pediatric nursing care are currently occurring, the need for more research persists for the validation of hope promotion interventions in parents of children with special health needs.

Key-Words: Hope; Pediatric Nursing; Special Health Needs.

RESUMO:
O conceito de esperança tem sido identificado como central para a enfermagem, ganhando visibilidade no âmbito da prestação de cuidados à criança com necessidades especiais de saúde e suas famílias. Surgindo novos desafios na enfermagem pediátrica e constatando as necessidades dos pais diante as
adversidades que enfrentam, as intervenções promotoras de esperança deverão ser vistas em destaque.

**Objetivo:** Mapear as intervenções que foram implementadas e avaliadas para promover a esperança em pais de crianças com necessidades especiais de saúde.

**Método:** Realizou-se uma revisão scoping, seguindo a metodologia proposta pelo Joanna Briggs Institute, nas bases de dados Pubmed, CINHAL complete e SciELO, nos idiomas português, inglês e espanhol e na janela temporal de 2008 a 2018.

**Resultados:** Foram incluídos nesta revisão 7 estudos. A investigação encontrada é maioritariamente qualitativa, dispersa em termos temporais e diferenciada no quadro conceptual. Maioritariamente avaliada em indivíduos, os estudos englobam intervenções de caráter grupal e individual, com variabilidade de contextos e características de intervenção.

**Conclusão:** mantém-se a discussão sobre intervenções promotoras de esperança nos cuidados de enfermagem pediátrica, existindo necessidade de mais investigação para a validação de intervenções que promovam a esperança em pais de crianças com necessidades especiais de saúde.

**Palavras-Chave:** Esperança; Enfermagem pediátrica; Necessidades especiais de saúde.

**RESUMEN:**

El concepto de esperanza ha sido identificado como central para la enfermería, ganando visibilidad en el ámbito de la atención al niño con necesidades especiales de salud y sus familias. Surgiendo nuevos desafíos en la enfermería pediátrica y constatando las necesidades de los padres ante las adversidades que enfrentan, las intervenciones promotoras de esperanza deberán ser vistas en destaque.

**Objetivo:** Mapear las intervenciones que se han implementado y evaluado para promover la esperanza en los padres de los niños con necesidades especiales de salud.

**Método:** Se llevó a cabo una revisión scoping, siguiendo la metodología propuesta por el Joanna Briggs Institute, en las bases de datos PubMed, CINHAL completa y SciELO, en portugués, inglés y español y en el marco de tiempo 2008-2018.

**Resultados:** Fueron incluidos en esta revisión 7 estudios. La investigación encontrada es mayoritariamente cualitativa, dispersa en términos temporales y diferenciados en el marco conceptual. En la mayoría de los casos, los estudios engloban intervenciones de carácter grupal e individual, con variabilidad de contextos y características de intervención.

**Conclusión:** Se mantiene la discussión sobre intervenciones promotoras de esperanza en los cuidados de enfermería pediátrica, existiendo necesidad de más investigación para la validación de intervenciones que promuevan la esperanza en los padres de niños con necesidades especiales de salud.

**Palabras clave:** Esperanza; Enfermería pediátrica; Necesidades especiales de salud.

**INTRODUCTION**

Hope, although widely explored in health literature, has just appears in nursing literature in the late eighties of the twentieth century, defining the concept for specific populations and listing the first hope inspiring strategies (1). Currently defined as a dynamic, multidimensional, central to life, highly personalized and forward-looking concept, hope confers empowerment, is related to external help, to care and to the concept of faith (2) and have, as well, implications for action (3). The International Council of Nurses, in the International Classification for Nursing Practice (ICNP), defines hope as the feeling of having possibilities, confidence in others and in the future, enthusiasm for life, as well as expressing reasons and willingness to live, inner peace and optimism associated with goal setting and energy mobilization (4).

The concept was also defined in two spheres and six dimensions (3). The spheres are characterized as generalized hope, a hope with a broad, unspecified focus; and particularized hope, that is oriented toward objects of hope and concrete goals. On the other hand, dimensions of hope refer to a set of components that structure the experience of hope, being framed in terms of the affective dimension (emotions and
feelings related to hope); cognitive dimension (the way each individuals wish, imagine, perceive, think, learn, generalize, interpret and judge their experiences of hope); behavioural dimension (corresponding to the actions that are performed in order to achieve the expected objectives); affiliative dimension (focusing on sense of involvement with the self, others and God, and can be reflected in the objects of hope); temporal dimension (that is reflected in the notion of the past experience, the presence of hope in the present and its orientation towards the future); and contextual dimension (corresponding to the person' life experiences and its influence as a part of the experience of hope)\(^{(3)}\). Each dimension can belong to any of the spheres of hope \(^{(3)}\).

Several other definitions of the concept have been constructed, such as by Owen (1989), which describes a conceptual model for understanding the meaning of hope in people with cancer. Along with the described, the concept of hope has been identified as central to nursing and linked to other concepts, such as hopelessness and despair \(^{(5)}\). The conceptual frameworks described by Travelbee (1971) and Morse, Penrod (1999), which contain hope as the central element \(^{(5)}\), are an example of the centrality of the concept to nursing. Likewise, Jean Watson, in her Philosophy and Science of Care, describes 10 factors of caring, among which is the Installation of Faith-Hope \(^{(6)}\). Associated to the concept of Hope, the International Council of Nurses at ICNP identifies the diagnosis of Hope and Hopelessness \(^{(7)}\). On the other hand, NANDA-I identifies as diagnosis: readiness for enhanced hope, as a pattern of expectations and desires for mobilizing energy on one’s own behalf, which can be strengthened; and hopelessness, as a subjective state in which an individual seen limited or no alternatives or personal choices seemed to be available and is unable to mobilize energy on own behalf \(^{(8)}\).

Since it has been seen that the measurement of levels of hope can improve nursing care \(^{(9)}\), the need to evaluate hope has encouraged the construction and validation of measurement instruments, such as Herth Hope Index\(^{(10)}\), validated for the Portuguese population, and the Snyder Hope Scale \(^{(11)}\).

In the scope of the intervention, the International Council of Nurses, at ICNP, defines intervention lines to promoting hope such as Counselling about Hopes and Promoting Hope \(^{(12)}\). Likewise, NIC defines as hope-promoting interventions those that result in an improved belief in one's ability to initiate and maintain actions \(^{(13)}\). As activities that promote hope, are defined: helping the person / family to identify reasons for hope in life; inform the person about being temporary or not, the current situation; to demonstrate hope by recognizing the person's intrinsic value and seeing his illness as just an aspect of himself; expand the repertoire of coping mechanisms of the person; to teach the person to recognize reality, and to make contingency plans; to assist the person to establish and to revise goals related to his object of hope; to help one to expand one's spirituality; avoid masking the truth; facilitate the incorporation by the person of a personal loss of his or her body image; facilitate the person / family to remember and appreciate past achievements and experiences; emphasize lasting relationships by mentioning the names of loved ones; promote memory or oriented memory of life, as appropriate; actively involve the person in their own care; develop a plan of care that involves the achievement of goals, starting from the simplest to the most complex; encourage therapeutic relationships with important people; to teach the family the positive aspects of hope; offer opportunities for the person / family to get involved in support groups; create an environment that facilitates religious practice, as appropriate\(^{(13)}\).
The concept of hope has gained increasing visibility in the caring for children with special health needs and their families. A child with special health needs is defined as the one who have or is at risk of having a chronic physical, emotional, behavioural or developmental condition \(^{(14,15)}\); as well as the one that requires health care beyond what is generally required by children in general \(^{(14)}\).

It is clear that Pediatric Nursing faces major challenges arising from contemporary changes likewise the increase average life expectancy, morbidity, chronic illness and the number of children with disabilities or risk of developmental delay \(^{(16)}\). The pertinence of promoting hope interventions emerges from the daily realization of parents needs in the face of adversity\(^{(17)}\). Under the performance of a specialized pediatric nurse may arise specific strategies for promoting hope in pediatric population, like the evaluation of interaction patterns and resources of hope in the established relationship between the young child and the nurse or the implementation of hope promoting strategies\(^{(16)}\).

Research on the implementation and evaluation of promoting hope interventions in pediatric nursing care is growing, in spite of being a relatively recent phenomenon in the nursing literature\(^{(1)}\), nevertheless some systematization is still lacking. For this matter, the present Scoping Review was carried out, with the aim of mapping the interventions that were implemented and evaluated to promote hope in parents of children with special health needs. The primary review question was: “What interventions have been implemented and evaluated to promote hope in parents of children with special health needs?”; and the secondary review questions were the following: 1. What are the conceptual frameworks of promoting hope interventions in parents of children with special health needs?; 2. What is the type of intervention (individual, group)?; 3. What are the characteristics (dose, duration and frequency) of interventions implemented and evaluated to promote hope in parents of children with special health needs?; 4. In which contexts (acute / chronic hospital care, day hospitals, mutual help groups), are hopeful interventions implemented and evaluated?; 5. In which populations (individuals, groups), are hope interventions implemented and evaluated?.

**METHOD**

This review was based on the methodology proposed by Joanna Briggs Institute for the conduct of Scoping Reviews \(^{(18)}\), and had as inclusion criteria the following:

Population: were considered all studies focusing on the parents and / or family of the child and young people up to the age of 21 \(^{(16)}\), with special health needs. It is understood as parents and / or families the set of individuals who have the responsibility to provide care to the child/ young person \(^{(16)}\); it is understood as child / young people with special health needs: the one who has or is at risk of having a chronic physical, emotional, behavioral or developmental condition \(^{(14,15)}\); as well as the one that requires health care beyond what is generally required by children in general, regardless of diagnosis \(^{(14)}\).

Concept: were considered all studies referring to interventions that promote hope. It was defined as hope promoting interventions the ones that result in an improvement on one's belief in own ability to initiate and maintain actions \(^{(13)}\).
Context: were considered studies carried out in the various care contexts of pediatric nursing care, namely hospitals, health centres, schools, community care, home care and home care network\(^{(16)}\).

Type of studies: were considered qualitative and quantitative studies, published in Portuguese, English and Spanish, in the time window from 2008 to 2018.

The search strategy used was based on 3 steps and aimed to obtain published and unpublished studies. An initial search was carried out, limited to PubMed and CINHAL databases, followed by the analysis of the keywords and index terms that were used to describe them. Were then selected the boolean operators and descriptors to be used. Subsequently, another search was done using the selected Boolean descriptors and operators, in all included databases. Finally, a third search was carried out, through bibliographical references of the included articles, in order to reach the maximum possible results.

The following equation describes the interaction between the indexed terms / MeSh descriptors used, the Boolean operators and the priority of each descriptor in order to perform the search: “(hope) AND (Pediatric nursing OR Pediatric care OR maternal-child nursing OR neonatal nursing) AND (parents OR mother)”. The research was carried out in the following databases: Pubmed; CINAHL complete (by EBSCO); SciELO - *Scientific Electronic Library Online*. Unpublished studies were conducted using Google Scholar. The search was carried out on 4 May 2018 and repeated on 18 May 2018. The results were evaluated and selected as to their relevance for inclusion based on the information provided in the title and abstract. Subsequently, selected articles were the subject of an integral reading that precedes their integration in the selected final sample. The flowchart presented (image 1) describes the selection process to which the articles were submitted.
Records identified through database searching (n= 148)

Additional records identified through other sources (n = 21)

Records Identified in bibliographic references of the selected articles (n = 72)

Records after duplicates removed(n = 233)

Records excluded after title screening ( n = 131)

Reasons: non-compliance with the inclusion criteria established

Records excluded after abstract screening (n = 73)

Studies excluded after full text screening (n= 22)

Reasons: non-compliance with the inclusion criteria established

Studies included in review (n = 7)
The results of the seven included articles in this review are summarized below. The synthesis of data for the presentation was performed according to an instrument adapted from the one proposed in the methodological manual for Scoping Reviews of Joanna Briggs Institute (18). Of the seven presented articles, two concern the same intervention (19,20). It was decided to include both, since they pertain to different methodological approaches that bring different contributions to the eligibility of the intervention.

Chart 1 presents the results regarding the publication year, research design and aims of the study. Some of the included studies belong to the same authors, suggesting their research course in this field. The research is dispersed in temporal terms, and the studies presented are essentially of a qualitative nature.

Chart 2 presents the included studies regarding their population, intervention context, conceptual framework and type of intervention. In terms of populations (individuals, groups), the interventions were mostly evaluated in individuals (father, mother) (19,21,23-25) or in the mother-father dyad (26), and there was a study who resorted to group (22). With regard to the context of the intervention, outpatient clinic (19,20,23), hospital care (21,22,23,25) and mutual help groups (23,24) were identified, showing the variability of intervention contexts.

**Chart 1 – Results regarding year of publication, research design and aims of the study**

<table>
<thead>
<tr>
<th>Author</th>
<th>Year</th>
<th>Design</th>
<th>Aims of the study</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hendricks-Ferguson VL, Haase JE(19)</td>
<td>2018</td>
<td>Qualitative, descriptive design</td>
<td>To describe parental experiences of parents of children with a brain tumor and a poor prognosis who received an early palliative care and end-of-life communication intervention entitled “Communication Plan: Early through End of Life Intervention (COMPLETE)”</td>
</tr>
<tr>
<td>Beasant L, Fleming P, Ingram J, Johnson D, Manns S, Pontin D, Redshaw M(21)</td>
<td>2017</td>
<td>Qualitative, descriptive design</td>
<td>To describe the perceptions and experiences of parents and professionals applying a family-centered planning process (Train-to-Home)</td>
</tr>
<tr>
<td>Almeida LM, Barbosa MA, Munari DB, Oliveira C, Santos LF, Peixoto MK(22)</td>
<td>2012</td>
<td>Qualitative, descriptive design</td>
<td>To describe the Therapeutic Factors present in the sessions of a Parent and Family Support Group (GRAPF) of Children hospitalized in a pediatric inpatient unit, from the point of view of the participants and group coordinators.</td>
</tr>
<tr>
<td>Author</td>
<td>Population</td>
<td>Intervention Context</td>
<td>Conceptual Framework</td>
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<tr>
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</tr>
<tr>
<td>Hendricks-Ferguson VL, Haase JE</td>
<td>Individuals: father or mother of children diagnosed with brain tumor and poor prognosis</td>
<td>Clinic appointments (omitted)</td>
<td>Individual</td>
</tr>
<tr>
<td>Beasant L, Fleming P, Ingram J, Johnson D, Manns S, Pontin D, Redshaw M</td>
<td>Individuals: parents of preterm newborns</td>
<td>Hospital Care (omitted)</td>
<td>Individual</td>
</tr>
<tr>
<td>Almeida LM, Barbosa MA, Munari DB, Oliveira C, Santos LF, Peixoto MK</td>
<td>Group: parents and family of children hospitalized in a pediatric inpatient unit, participants in the self-help</td>
<td>Hospital Care</td>
<td>Group</td>
</tr>
</tbody>
</table>

Chart 2 – Results regarding to their population, intervention context, conceptual framework and type of intervention

To identify the factors that influence hope in mutual help groups; to present the utilization of genogram and ecomap to identify resources for hope for mothers of children with chronic disease.

To identify which factors interfere with the process of effective improvement of at least one dimension of hope of parents of children with chronic disease, by taking advantage of the formative, emotional and instrumental support activities developed in mutual help groups.

Provide an in-depth understanding of the meaning for parents who were present or absent during an reanimaion attempt on their child in the PICU.
<table>
<thead>
<tr>
<th>Author</th>
<th>Characteristics of intervention</th>
<th>Main results of the intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hendricks-Ferguson VL, Haase JE&lt;sup&gt;(19)&lt;/sup&gt;</td>
<td>Intervention composed by 3 sessions: Session 1 occurs in routine appointment after diagnosis; sessions 2 and 3 during subsequent appointments. Objectives of the sessions: (1) provide hope sustaining and non-abandonment messaging messages of maintenance of through a scripted dialogue and accompanied by visual support; (2) facilitate the expression of hope-for realistic goals; (3) normalize difficult discussions regarding prognosis using a scripted dialogue, discussing &quot;hope in healing&quot; versus interventions to delay the evolution of the disease and promote comfort; (4) foster parent-expressed realistic hope through dialogue based on a script adapted to the family's needs and concerns; (5) prevent The following themes were identified: (a) nurturing realistic hope and enhancement of a meaning dialogue while connecting with health professionals; increased parental confidence in health professionals; increased understanding of the information provided; the meaningful dialogue has promoted increased levels of hope; (b) the intervention encouraged parents to make informed decisions.</td>
<td></td>
</tr>
</tbody>
</table>

Chart 3, 4 and 5 present the results regarding the characteristics and main results of the intervention.

Chart 3 – Results regarding the characteristics and main results of the intervention

<table>
<thead>
<tr>
<th>Author</th>
<th>Characteristics of intervention</th>
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</tr>
</thead>
<tbody>
<tr>
<td>Hendricks-Ferguson VL, Pradhan K, Shih C, Gauvain KM, Kane JR, Liu J, Haase JE&lt;sup&gt;(20)&lt;/sup&gt;</td>
<td>It was identified a tendency for the decrease of self-reported uncertainty by parents (P = 0.0432); a significant increase in the levels of hope (P ≤ .0001) over time; and a significant decrease in the level of parents´ decision regret (P = 0.0089).</td>
<td></td>
</tr>
</tbody>
</table>
**Chart 4 (cont.) – Results regarding the characteristics and main results of the intervention**

<table>
<thead>
<tr>
<th>Author</th>
<th>Characteristics of intervention</th>
<th>Main results of the intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Beasant L, Fleming P, Ingram J, Johnson D, Manns S, Pontin D, Redshaw M(^{(21)})</td>
<td>Intervention comprises a laminated baby’s train graphic for the baby’s cot, with colored stickers (red-yellow-green) indicating the criteria for discharge and its stage of preparation, as well as the expected date of discharge. The &quot;Train&quot; was kept up to date by parents, always in discussion with the team. Intervention accompanied by gestational age appropriate parent booklets, as an incentive to parents’ questioning about newborn care and development.</td>
<td>It was identified that mothers considered that viewing the train, reviewing the criteria for discharge, changing the stickers and sending photographs of the same to the family were beneficial activities for parents and other children of the family, increasing their levels of hope and feeling of control; for parents, the existence of a planned discharge date is seen as positive, increasing the possibility of working for it; it was identified as a difficulty that professionals do not explicitly the objective of the intervention, reducing parents’ adherence.</td>
</tr>
<tr>
<td>Almeida LM, Barbosa MA, Munari DB, Oliveira C, Santos LF, Peixoto MK(^{(22)})</td>
<td>Support group with the following characteristics: open format, allowing the entry of new elements in each meeting; recurrence of 1-2 times per week; each session lasting 60 minutes; it was promoted the sharing of the lived experiences of having a child hospitalized, with the objective of offering support, welcome and information.</td>
<td>The following therapeutic factors were identified: (by participants) interpersonal learning, instillation of hope, altruism, imitative learning, (by coordinators) impairing information, group cohesion, universality and existential factors.</td>
</tr>
<tr>
<td>Charepe ZB, Figueiredo MH, Vieira MM, Neto LM(^{(23)})</td>
<td>Application of the genogram and ecomap of hope</td>
<td>It was identified that the application of the described instrument allows the identification of hope factors; of patterns of interaction in hope and of resources of hope. The application of the instrument allowed the creation of spaces for the expansion and celebration of families competences, as resources for the development of their hope.</td>
</tr>
</tbody>
</table>
Chart 5 (cont.) – Results regarding the characteristics and main results of the intervention

<table>
<thead>
<tr>
<th>Author</th>
<th>Characteristics of intervention</th>
<th>Main results of the intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Charepe ZB, Figueiredo MH, Vieira MM, Neto LM (24)</td>
<td>Providing social support (emotional, formative and instrumental) in the meetings of mutual help groups</td>
<td>It was identified that mutual help groups constitute a strategy that promotes hope, for the emotional, formative and instrumental support provided; It were identified factors that interfere with the process of improving at least one dimension of mothers' hope, such as the evolution of the children's illness, dealing with the children’s illness, the experiences and relationships of support and encouragement, a positive, optimistic and courageous attitude, and positive memories.</td>
</tr>
<tr>
<td>Maxton FJ (25)</td>
<td>Permission for parents to choose whether or not to be present during a resuscitation attempt with the support of a professional</td>
<td>Four central themes were identified in the parents experiences: (1) being only for a child (providing comfort and support, comforting themselves and participating in decision-making); (2) making sense of a living nightmare (dealing with the anguish and uncertainty of being present versus the desire to understand the procedure, in a struggle to find meaning); (3) keeping hope in the face of reality (optimism versus recognition of the futility of the procedure); (4) living in a relationship with professionals.</td>
</tr>
</tbody>
</table>

Regarding the intervention characteristics, these were quite distinguished, wish was plausible by the variability of the application contexts. All of the interventions presented had positive results in the promotion of hope, as well as for other results, such as increased parental trust in health professionals (19), decreased parents' uncertainty (20), and increased feelings of control (21).

**DISCUSSION**

The number of studies included in this review constitute a small sample, however, it is consistent with the proposed framework, showing the cross-cutting results of various practice contexts. This sample justifies the need presented and encourages future research in the context of hope promoting strategies in parents of children with special health needs.
It was verified that the interventions presented fall under the Promoting Hope, as a line of intervention described by the International Council of Nurses (12); as well as agree with the hope promoting activities presented by NIC, namely with regard to expanding the repertoire of coping mechanisms for the person; to assist the person to establish and to revise goals related to his object of hope; avoid masking the truth; actively involve the person in the care; develop a plan of care that involves the achievement of goals, starting from the simplest to the most complex; encourage therapeutic relationships; and provide opportunities for the person / family to engage in support groups (13).

It was also verified that, despite the existing knowledge that the measurement of levels of hope leads to improvements in nursing care (9), only in one of the presented studies was used a hope assessment scale (Herth Hope Index) (20).

Thereby, it was corroborated that the research regarding implementation and evaluation of hope promoting interventions in pediatric nursing care is growing, being a relatively recent phenomenon in the nursing literature (1).

Several limitations were experienced during the study, mainly because most of the results obtained in the search were related to the experiences of parents of children with special health needs and not to the implementation and evaluation of interventions. Some of the interventions presented are limited in their application in other contexts of practice, according to the limitations of the studies mentioned by the authors (20, 25), while another one will require specific training for their application (22).

As recommendations for future research, it is suggested to extend the search strategy to other databases and others resources of unpublished literature in order to obtain a greater range of results and to make a more sensitive evaluation of the existing literature.

**CONCLUSIONS**

Hope promoting interventions are currently discussed in various contexts of pediatric nursing care, comprising a large variety of populations and characteristics. Although it is not the central concept in some of the studies obtained, it was recognized that has added value to the obtained results. There is a highlighted need for more research to validate interventions that promote hope in pediatric nursing care.

Therefore, it’s concluded that nursing team’s play a crucial role in promoting hope in parents of children with special health needs.

It was possible to fulfill all the review questions, so an appropriate methodological approach is concluded. However, due to the limitations already described and according to the recommendations presented, it is necessary to broaden both the investigation and the search carried out.

**REFERENCES**


