The experience of hope in families of children and adolescents living with chronic illness: A thematic synthesis of qualitative studies

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Abstract
Aim: To synthesize qualitative studies on the experience of hope in families of children and adolescents living with chronic illness.

Background: Hope is multidimensional, dynamic, and varies according to experienced events, cultural environments and stage of life. The qualitative synthesis of the experience of hope in the paediatric population with chronic conditions is scarce.

Design: Thematic synthesis of qualitative studies.

Data sources: A systematic literature search in PubMed, CINAHL, LILACS, PsycINFO, Scopus, and Web of Science was performed supplemented by manual search strategies. Thirty-one studies from fifteen countries, published between 1981-2018, were included.

Findings: Findings were integrated into an analytical theme "FAMILY HOPE: KEEPING THE DAY-TO-DAY BALANCE", encompassing the following five descriptive themes: Uncertainty; Support; Information; Between "dark thoughts" and positive thoughts; and Hoping to go back to normality.

Conclusion: This thematic synthesis brings a new dimension of hope among families of children and adolescents living with chronic illness. "Family Hope" highlights the influence of the relationships between relatives and the chronically ill child in the balance of hope. It is recommended that health professionals use a family-focused approach to support these families.

Impact: Shifting the focus to a family dimension of hope is a promising pursuit that has the potential to inform future nursing practices to support the experiences of families living with chronic illness in the paediatric context. A better understanding of the role and characteristics of family hope will promote the development of more effective interventions for families to adapt to long-term paediatric conditions.

KEYWORDS 
adolescent, child, chronic disease, family nursing, hope, paediatric nursing, qualitative research, review
1 | INTRODUCTION

Children and adolescents living with chronic illness experience long-term treatments and periods of exacerbation that can lead to prolonged hospitalizations (Moreira, Gomes, & Sá, 2014). The family reconfigures to adapt to the needs of their sick children or adolescents, experiencing a range of feelings such as impotence, fear, sadness, revolt, stress, anxiety, and guilt at the same time (Polita et al., 2018; Silva-Rodrigues, Pan, Pacciulio Sposito, de Andrade Alvarenga, & Nascimento, 2016; Smith, Cheater, & Bekker, 2015). Questioning the purpose of life, valuing family relationships and experiencing feelings such as faith and hope also integrate this experience (Juvakka & Kylmä, 2009; Polita et al., 2018; Silva-Rodrigues et al., 2016; Smith et al., 2015). Hope is one of the psychological resources used by these families to deal with chronic illness and the experience of caring for the ill, which brings stress to those involved (Herth, 2000).

2 | BACKGROUND

Health professionals should promote hope because it helps in sustaining life (Kylma & Juvakka, 2007). However, identifying the factors that influence hope is a challenge for professionals because they are linked to context and culture (Hamilton & Thomas, 2016), which makes it difficult choosing and implementing interventions to promote or maintain hope in patients and their families. The literature presents reviews on hope with varied samples of age groups and diagnoses. One systematic review explored the influence of hope and optimism on the prevention and treatment of chronic diseases in patients of various ages (Schiavon, Marchetti, Gurgel, Busnello, & Reppold, 2017). One integrative review synthesized the role of hope in adolescents with chronic diseases (Griggs & Walker, 2016). Five meta-syntheses on hope included populations such as: (a) sick and healthy people (Hammer, Mogensen, & Hall, 2009); (b) adults with HIV (Kylmä, 2005); (c) older people who are physically ill (Wiles, Cott, & Gibson, 2008); (d) elders with chronic diseases (Duggleby et al., 2012); and (e) caregivers of individuals with chronic diseases (Duggleby et al., 2010).

Nevertheless, none of the reviews about hope synthesized the qualitative evidence of how hope has influenced families of children and adolescents living with chronic illness. The synthesis of qualitative evidence in the experience of hope can help nursing professionals planning effective interventions, identifying knowledge gaps for future studies and contributing to the establishment of public policies for clinical practice (Sandelowski & Barros, 2007). Hence, the question for this review is: How do families of children and adolescents living with chronic illness experience hope?

3 | THE REVIEW

3.1 | Aim

This study aimed to synthesize qualitative studies on the experience of hope in families of children and adolescents living with chronic illness.

3.2 | Design

A thematic synthesis of qualitative studies was developed to identify, analyse, and synthesise primary qualitative studies for the construction and presentation of a new interpretation about the phenomenon. Thematic synthesis allows to “go beyond” the conclusions of the original analyses (Thomas & Harden, 2008). The ENTREQ (Enhancing transparency in reporting the synthesis of qualitative research) guidelines were used in the construction of this review (Tong, Flemming, McInnes, Oliver, & Craig, 2012). This thematic synthesis of qualitative studies is registered at the International prospective register of systematic reviews (Prospero), reference number CRD42019119869.

3.3 | Search method

The SPIDER tool was used to structure the search strategy (Figure 1) (Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014) using descriptors and keywords related to paediatrics, family, chronic disease, hope, experience, and qualitative studies and combining them with Boolean operators (AND, OR). The search was conducted in six databases, namely: PubMed, CINAHL, LILACS, PsycINFO-APA, SCOPUS, and Web of Science. Articles published in English, Portuguese, Spanish, and French, regardless of the initial publication date and until 31 December 2018 were considered for this review.

3.4 | Search outcome

The selected studies met the following inclusion criteria: (a) published qualitative primary research; (b) included chronically ill children and adolescents (up to 19 years of age) (World Health Organization, 2018) and/or their family members (such as mothers, fathers, grandparents, uncles, aunts, siblings, stepmothers, stepfathers and

![FIGURE 1 Examples of terms used in search strategies, from the SPIDER tool](https://example.com/spider.png)
others); (c) were focused on the experience of hope as the primary aim of the study or as one of the themes of findings.

Relatives are those who the children and adolescents consider as part of their family and who spend time with sick children and adolescents participating in the care and process of chronic illness (Wright & Leahey, 2012). The following types of studies were considered: those that presented the experience of hope in the isolated perspectives of children and/or adolescents and their relatives; those that presented a joint perspective of children, adolescents and their relatives; those presenting the experience of hope reported by health professionals, children, adolescents, and/or their relatives, if results were reported separately; and those including one or more pediatric chronic illness.

The exclusion criteria were as follows: theses, dissertations, books, reviews, book chapters and abstracts published in annals of events; studies reporting adult survivors who experienced childhood cancer; articles reporting the experience of relatives with the death of a child and/or adolescent with chronic illness; and articles presenting joint results on the perspective of adolescents and young adults.

The screening phase was initiated after the replication of searches by two independent reviewers (ACABL; RRN). The ENDNOTE® reference manager was used to remove duplicates and assist each reviewer with independent screening. These two reviewers independently read titles and abstracts of articles selected to be included.

A manual search was performed of the reference list in selected articles to extend the chances of finding articles for this thematic synthesis. Moreover, searches (from “no initial” date to 2018) were conducted in five journals (Quantitative research; Journal of Advanced Nursing; Journal of Family Nursing; Journal of Pediatric Nursing; Care of Children & Families; and Journal of Pediatric Health Care) to identify possible studies that were not captured in the databases. The authors met regularly and discussed their decisions until a consensus was reached.

A PRISMA flowchart was used to report the selection process of the 31 studies included in the review (Liberati et al., 2009) (Figure 2).

### 3.5 Quality appraisal

The quality appraisal of included studies was performed independently by two reviewers (ACABL; RRN) based on the Critical Appraisal Skills Program (CASP) checklist (CASP, 2013). Divergences were resolved with the participation of a third experienced reviewer (LCN). All included studies reported clear objectives and appropriate and delineated research to achieve the proposed objectives. However, only five studies fully reported all items recommended by the CASP. The studies received a low-quality evaluation when: (a) participants and the recruitment strategy were not clearly reported; (b) the relationship between researcher and participants was not adequately considered, did not critically examine the role and influence of the researcher during data collection, or did not reported included sample recruitment and choice of study site; (c) ethical issues such as approval by an ethics committee and acquisition of informed consents were not reported; and (d) data analysis was insufficiently reported with no detailed description of the methods selected and analysis process (Table 1).
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3.6 | Data abstraction and synthesis

The data abstraction was performed using a form developed by the authors based on previously published reviews (Table 2; Figure 3) (Duggleby et al., 2012; Polita et al., 2018; Reis et al., 2017).

The synthesis of findings of qualitative studies followed the thematic synthesis approach (Thomas & Harden, 2008). This approach is a three-stage process for the identification and development of themes, encompassing, first the free line-by-line coding of findings in primary studies and creation of “free codes”; second the organization of these “free codes” into related areas to construct descriptive themes; and third, the development of analytical themes (Thomas & Harden, 2008).

The results of primary studies were coded line-by-line according to its meaning and content (ACABL). The QDA Miner Lite software was used to facilitate the management and coding. Codes were then organized by hierarchy and similarity into a tree structure. Finally, five descriptive themes were developed and sufficiently abstracted, generating an analytical theme (ACABL; CGV; LCN). Subsequently, the authors (ACABL; CGV; RRN; WAA; LCN) reached a consensus about the thematic synthesis.

<table>
<thead>
<tr>
<th>TABLE 1</th>
<th>Quality assessment of included studies according to the Critical Appraisal Skills Program (CASP)</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Was there a clear statement of the aims of the research?</td>
<td>✓</td>
</tr>
<tr>
<td>2. Is a qualitative methodology appropriate?</td>
<td>✓</td>
</tr>
<tr>
<td>3. Was the research design appropriate to address the aims of the research?</td>
<td>✓</td>
</tr>
<tr>
<td>4. Was the recruitment strategy appropriate to the aims of the research?</td>
<td>✓</td>
</tr>
<tr>
<td>5. Was the data collected in a way that addressed the research issue?</td>
<td>✓</td>
</tr>
<tr>
<td>6. Has the relationship between researcher and participants been adequately considered?</td>
<td>■ ■</td>
</tr>
<tr>
<td>7. Have ethical issues been taken into consideration?</td>
<td>✓</td>
</tr>
<tr>
<td>8. Was the data analysis sufficiently rigorous?</td>
<td>✓</td>
</tr>
<tr>
<td>9. Is there a clear statement of findings?</td>
<td>✓</td>
</tr>
<tr>
<td>10. How valuable is the research?</td>
<td>✓</td>
</tr>
<tr>
<td>Total score</td>
<td>9 9 10 9 7 10 10 9 9 9 8 8 9</td>
</tr>
</tbody>
</table>

Note: ✓, Yes; ■, No; ?, Cannot tell.
4 | FINDINGS

4.1 | Study characteristics

This thematic synthesis included 31 qualitative studies from 15 countries. The first study was published in 1988 and most studies were developed in the context of cancer and included parents (Figure 3). The grounded theory methodology was used in most of the studies and in-depth interviews were the main technique of data collection (Table 2).

4.2 | Family Hope: Keeping the day-to-day balance

The thematic synthesis allowed us to identify five descriptive themes concerned characteristics of the experience of hope in the families of children and adolescents living with chronic illness - “Uncertainty; Support; Information; Between ‘dark thoughts’ and positive thoughts; and Hoping to go back to normality”. These descriptive themes are understood through an analytical theme entitled “FAMILY HOPE: KEEPING THE DAY-TO-DAY BALANCE” (Table 3; Figure 4).
<table>
<thead>
<tr>
<th>Authors and year of publication</th>
<th>Country</th>
<th>Aim</th>
<th>Design, data collection and analysis</th>
<th>Participants/Sample</th>
<th>Chronic illness, stage of the disease or context</th>
<th>Table 2 Characteristics of the studies included in the thematic analysis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Kane and Fearon (2018)</td>
<td>Mauritania</td>
<td>To understand how children experience chronic illness in Mauritania, West Africa.</td>
<td>Descriptive qualitative study, with interviews, pictures and draws as a data collection technique. Thematic analysis</td>
<td>Children and adolescents between 6 and 18 years old (7 with sickle cell disease, two with diabetes and one with HIV)</td>
<td>Chronic illness, stage of the disease or context</td>
<td>Studies included in the thematic analysis</td>
</tr>
<tr>
<td>Pourghaznein et al. (2018)</td>
<td>Iran</td>
<td>To understand the meanings of care for children undergoing hemodialysis based on mothers’ lived experiences.</td>
<td>Hermeneutic phenomenological approach, with semi-structured interviews. Hermeneutic phenomenology analysis</td>
<td>Mothers of children and adolescents between 5 and 15 years old (N = 11 mothers)</td>
<td>Chronic renal failure. Hemodialysis treatment</td>
<td>Participants/Sample, Design, data collection and analysis, Chronic illness, stage of the disease or context</td>
</tr>
<tr>
<td>Hinton and Kirk (2017)</td>
<td>United Kingdom</td>
<td>To explore the experiences of parents of children with multiple sclerosis</td>
<td>Constructivist grounded theory approach, with semi-structured conversational style interviews. Inductive analysis using the constant comparative method</td>
<td>Parents of children and adolescents between zero and 17 years old (N = 31; 20 mothers and 11 fathers)</td>
<td>Multiple sclerosis. Context not reported</td>
<td>Authors and year of publication, Country, Aim, Design, data collection and analysis, Participants/Sample, Chronic illness, stage of the disease or context</td>
</tr>
<tr>
<td>Vindrola-Padros and Brage (2017)</td>
<td>Argentina</td>
<td>To illustrate the additional layers of meaning that can be uncovered from illness stories when attention is paid to what did not happen, but yet, is still part of the story.</td>
<td>Narrative study with in-depth interviews. Narrative analysis</td>
<td>Children and adolescents between 7 and 18 years old (N = 17, 13 mothers and 4 fathers)</td>
<td>Cancer. Treatment at the hospital</td>
<td>Authors and year of publication, Country, Aim, Design, data collection and analysis, Participants/Sample, Chronic illness, stage of the disease or context</td>
</tr>
<tr>
<td>Cornelio et al. (2016)</td>
<td>India</td>
<td>To explore the experiences of mothers on parenting children with leukemia</td>
<td>Phenomenological design, and semi-structured interviews. Type of analysis not reported</td>
<td>Parents of children between zero and 13 years old (N = 36; 16 mothers and 4 fathers)</td>
<td>Leukemia. Hospitalization for chemotherapy</td>
<td>Authors and year of publication, Country, Aim, Design, data collection and analysis, Participants/Sample, Chronic illness, stage of the disease or context</td>
</tr>
<tr>
<td>Nyborn et al. (2016)</td>
<td>United States of America</td>
<td>To prospectively evaluate responses to prognosis communication among parents of children with cancer</td>
<td>Exploratory descriptive study, with open-ended interviews. Content analysis</td>
<td>Parents of children between 3 and 13 years old. (N = 42)</td>
<td>Cancer. Center for support to the children and living with cancer.</td>
<td>Authors and year of publication, Country, Aim, Design, data collection and analysis, Participants/Sample, Chronic illness, stage of the disease or context</td>
</tr>
<tr>
<td>Amador et al. (2013)</td>
<td>Brazil</td>
<td>To analyze the conceptions of care and the feelings which permeate the daily life of the family caregiver of children with cancer</td>
<td>Exploratory descriptive study and open-ended interviews. Data analysis used the constructivist grounded theory procedures</td>
<td>Family caregiver of children between two and twelve years old. (N = 9 parents: 8 mothers and 1 father)</td>
<td>Cancer. During hospitalization</td>
<td>Authors and year of publication, Country, Aim, Design, data collection and analysis, Participants/Sample, Chronic illness, stage of the disease or context</td>
</tr>
<tr>
<td>Sposito et al. (2015)</td>
<td>Brazil</td>
<td>To analyze coping strategies used by children with cancer undergoing chemotherapy during hospitalization.</td>
<td>Exploratory descriptive study, with open-ended interviews. Content analysis</td>
<td>Children and adolescents, between 7 and 18 years old (N = 10; 5 girls and 5 boys)</td>
<td>Cancer. Hospitalization for chemotherapy</td>
<td>Authors and year of publication, Country, Aim, Design, data collection and analysis, Participants/Sample, Chronic illness, stage of the disease or context</td>
</tr>
<tr>
<td>Abreu et al. (2014)</td>
<td>Brazil</td>
<td>To identify quality of life impacting attributes related to health of children and adolescents with chronic renal failure</td>
<td>Exploratory descriptive study and open-ended interviews. Data analysis used the constructivist grounded theory procedures</td>
<td>Children and adolescents, between 7 and 18 years old (N = 32; 26 mothers and 6 fathers)</td>
<td>Chronic renal failure. Hemodialysis treatment</td>
<td>Authors and year of publication, Country, Aim, Design, data collection and analysis, Participants/Sample, Chronic illness, stage of the disease or context</td>
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<table>
<thead>
<tr>
<th>Authors and year of publication</th>
<th>Country</th>
<th>Aim</th>
<th>Design, data collection and analysis</th>
<th>Chronic illness, stage of the disease or context</th>
<th>Participants/Sample</th>
</tr>
</thead>
<tbody>
<tr>
<td>Barrera et al. (2013) Canada</td>
<td>To explore parental hope when a child is being treated for a malignancy resistant to treatment and to identify facilitators and barriers to maintaining hope</td>
<td>Grounded theory approach with prospectively semi structured interviews. Data analysis used grounded theory methodology</td>
<td>Cancer. During the treatment at the hospital</td>
<td>Parents of children between three months and 16 years old. (N = 35; 26 mothers and nine fathers)</td>
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<tr>
<td>Chinchilla-Salcedo (2013) Colombia</td>
<td>To describe the concept of hope in parents of children between 0 and 15 years of age who have been diagnosed with cancer</td>
<td>Exploratory descriptive study, semi-structured interview and field diary. Type of analysis not reported</td>
<td>Cancer. During treatment but not hospitalized</td>
<td>Parents of children and adolescents, between zero and 15 years (N = 11; 7 mothers and 4 fathers)</td>
<td></td>
</tr>
<tr>
<td>Granek et al. (2013) Israel</td>
<td>To further the understanding of parental hope when a child is being treated for a malignancy resistant to treatment</td>
<td>Grounded theory method, interviews in three time point (3 months of the initial diagnosis; 6 months; and 9 months). Type of analysis not reported</td>
<td>Cancer. Hospitalized children with poor prognosis</td>
<td>Parents of children and adolescents between 3 months and 16 years. (Time 1 N = 35; time 2 N = 30; time 3 N = 27)</td>
<td></td>
</tr>
<tr>
<td>Winger et al. (2013) Norway</td>
<td>To explore the experience of being an adolescent with chronic fatigue syndrome</td>
<td>Phenomenological hermeneutical design, with in-depth interviews. Phenomenological hermeneutical analysis</td>
<td>Chronic fatigue syndrome. Treatment in the hospital or primary care unit</td>
<td>Children and adolescents between 12 and 18 years old. (N = 18; 12 girls and six boys)</td>
<td></td>
</tr>
<tr>
<td>Bratt et al. (2012) Sweden</td>
<td>To describe the experiences of children and adolescents being screened positive for hypertrophic cardiomyopathy and how this impact their daily life</td>
<td>Descriptive study with qualitative generic approach and private interviews. Content analysis</td>
<td>Hypertrophic Cardiomyopathy. Treatment at the outpatient clinic</td>
<td>Children and adolescents between eight and 18 years old. (N = 12; 11 boys and 2 girls)</td>
<td></td>
</tr>
<tr>
<td>Ringnér et al. (2011) Sweden</td>
<td>To describe parents’ experiences of acquiring and using information to create knowledge about their child’s cancer</td>
<td>Qualitative study, that used mixed data collection method, using data from focus group interviews and individual interviews. Qualitative content analysis</td>
<td>Cancer. During hospitalization</td>
<td>Parents children between one and 18 years old. (N = 14; 10 mothers and 4 fathers)</td>
<td></td>
</tr>
<tr>
<td>Silva et al. (2011) Brazil</td>
<td>To describe the experience of a family caregiver of a child with cancer</td>
<td>Qualitative study with open interviews. Content analysis</td>
<td>Cancer. During the treatment at the hospital</td>
<td>Family caregiver of children under 12 years old (N = 19; 16 mothers and the others participants are not reported)</td>
<td></td>
</tr>
<tr>
<td>dos Santos et al. (2010) Brazil</td>
<td>To understand the meaning of the palliative cares for the parents of the child’s cancer</td>
<td>Grounded theory approach, and interviews. Data analysis used the grounded theory</td>
<td>Cancer. Palliative care.</td>
<td>Parents of children between two and 12 years old. (N = 12)</td>
<td></td>
</tr>
<tr>
<td>Grossoehme et al. (2010) United States of America</td>
<td>To describe whether parents understand a relationship between their religious beliefs and their follow-through with their child’s</td>
<td>Grounded theory with interviews by telephone or by person. Theoretical models of grounded theory method for data analysis</td>
<td>Cystic Fibrosis Home treatment regimen</td>
<td>Parents of children between one and 55 weeks (N = 15 parents of 9 children, 9 mothers and 6 fathers)</td>
<td></td>
</tr>
<tr>
<td>Authors and year of publication</td>
<td>Country</td>
<td>Aim</td>
<td>Design, data collection and analysis</td>
<td>Chronic illness, stage of the disease or context</td>
<td>Participants/Sample</td>
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<tr>
<td>de Andrade et al. (2009)</td>
<td>Brazil</td>
<td>To understand the family’s experience in the child’s hydrocephalus situation when trying to identify the changes that the illness caused in family life and what coping mechanisms the family uses and/or used</td>
<td>Grounded theory with Symbolic Interactionism as theoretical reference and semi-structured interviews. Qualitative process of data analysis based in the symbolic interactionism theory</td>
<td>Hydrocephalus. Type of treatment not reported</td>
<td>Families of children between two months and 13 years old. (N = 13; 4 mothers; 3 fathers; 1 stepfather; 3 grandmothers and 2 brothers)</td>
</tr>
<tr>
<td>Nicholas et al. (2009)</td>
<td>Canada</td>
<td>To examine the experiences of fathers of children diagnosed with cancer</td>
<td>Grounded theory with semi-structured interviews. Type of analysis not reported</td>
<td>Cancer. Treatment at the hospital or at home</td>
<td>Fathers of children between one and 17 years old. (N = 16)</td>
</tr>
<tr>
<td>Samson et al. (2009)</td>
<td>Canada</td>
<td>To describe the lived experience of hope among parents of a child with Duchenne muscular dystrophy</td>
<td>Qualitative phenomenological approach with semi-structured interviews. Empirical phenomenological psychological data analysis method</td>
<td>Duchenne muscular dystrophy. Any clinical stage during the treatment at the hospital</td>
<td>Parents of children between 7,5 and 17 years old. (N = 12; 7 mothers and 5 fathers)</td>
</tr>
<tr>
<td>Wu et al. (2009)</td>
<td>Taiwan</td>
<td>To describe the essence of the coping experiences of Taiwanese adolescents with cancer.</td>
<td>Qualitative phenomenological approach with in-depth interview. Data analysis used phenomenological method.</td>
<td>Cancer. Any clinical stage during the treatment at the hospital</td>
<td>Adolescents between 12 and 18 years old. (N = 12; 8 boys and 4 girls)</td>
</tr>
<tr>
<td>De Graves and Sanchia (2008)</td>
<td>Australia</td>
<td>To explore the experiences of families when a child with cancer relapses</td>
<td>Prospective critical ethnography with in-depth interviews. Content analysis</td>
<td>Cancer. During the relapse's treatment</td>
<td>Parents and children aged 12 years or older (N = 12 families; 17 parents, 12 mothers; 5 fathers and 7 children)</td>
</tr>
<tr>
<td>Huang et al. (2008)</td>
<td>Taiwan</td>
<td>To investigate the family resources available to assist family adjustment among single-parent families with a child with cancer</td>
<td>Phenomenological approach, with open question interviews Analysis with Colaizzi's method</td>
<td>Cancer. Hospitalization for chemotherapy or radiotherapy</td>
<td>Single-parent of children and adolescents under 18 years old. (N = 9; 5 mothers and 4 parents)</td>
</tr>
<tr>
<td>Kylma and Juvakka (2007)</td>
<td>Finland</td>
<td>To describe hope in parents of adolescents with cancer</td>
<td>Qualitative study with inductive design and on open in-depth interviews. Content analysis</td>
<td>Cancer. Context not reported</td>
<td>Parents of adolescents between 12 and 17 years old. (N = 9; 5 mothers and 4 fathers)</td>
</tr>
<tr>
<td>Pizzignacco and de Lima (2006)</td>
<td>Brazil</td>
<td>To identify the routine of children and adolescents with cystic fibrosis through their experiences and identify situations that can affect these routines</td>
<td>Descriptive exploratory, qualitative study with open interview. Type of analysis not reported</td>
<td>Cystic Fibrosis. Inpatient and outpatient treatment</td>
<td>Children and adolescent between seven and 18 years old (N = 8)</td>
</tr>
<tr>
<td>Björk et al. (2005)</td>
<td>Sweden</td>
<td>To elucidate the family’s lived experience when a child in the family was diagnosed with cancer</td>
<td>Descriptive inductive design with a hermeneutic phenomenological approach and interviews at three times point (diagnosis, treatment and after the treatment) A detailed line-by-line approach was used to analysis data</td>
<td>Cancer During treatment</td>
<td>Families of children under 13 years old (N = 17 families; 17 mothers, 12 fathers, 5 patients – 4 boys and 1 girl and 5 siblings - 3 girls and 2 boys between seven and 16 years)</td>
</tr>
</tbody>
</table>
Family hope is characterized by being a connected unit that is dynamic and strengthened in the context of chronicity. These characteristics are common to the concepts of hope and family unit, which are dynamic and usually connected, respectively. The dynamicity of family hope is represented in Figure 4 through the mobile movement, which is influenced by the experiences of living with a chronic illness and time (past, present, and future). Families experience the dynamism of hope through the continual search for balance because this experience is like being on a roller coaster of emotions. This scenario can be exemplified in a father’s speech: “I think of my hope every day and yet I never know from day-to-day what hope will mean for me that day. It is just a journey in our lives. But hope is always possible. I will never lose my hope.” (Bally et al., 2014, p. 367).

4.3 Uncertainty

The search for constant hope begins at the moment of diagnosis. The family feels anger, sadness, frustration, disappointment, fear, pain, shock, loneliness, and loss of confidence (Bally et al., 2014; Björk, Wiebe, & Hallström, 2005; Chinchilla-Salcedo, 2013; Cornelio, Nayak, & George, 2016; De Graves & Aranda, 2008; Pourghaznein, Heydari, Manzari, & Valizadehzare, 2018; Sällfors, Fasth, & Hallberg, 2002; Winger, Ekstedt, Wyller, & Helseth, 2013). All these feelings diminish family hope (Andrade, Dupas, & Wernet, 2009; Chinchilla-Salcedo, 2013; Cornelio et al., 2016) and may lead to treatment non-adherence or abandonment (Chinchilla-Salcedo, 2013). Meanwhile, the family maintains the hope that the diagnosis might not be real (Bally et al., 2014; Sällfors et al., 2002; Sposito et al., 2015).

Soon after the diagnosis, children and adolescents lose hope in the future and think their lives are ruined (Bratt, Sparud-Lundin, Östman-Smith, & Axelsson, 2012). Over time, they rethink their future and dreams according to the limitations imposed by the illness (Bratt et al., 2012; Pizzignacco & Lima, 2006; Winger et al., 2013).

The family structures the positive attitudes to reduce uncertainty and fear. For parents, this occurs after acceptance of the diagnosis when they develop skills to care for their chronically ill child and feel more confident. At this stage they have the strength to re-establish control, face future uncertainties, and restructure the balance of hope (Bally et al., 2014; Björk et al., 2005; Cornelio et al., 2016; Hinton & Kirk, 2017; Huang, Mu, & Chiou, 2008; Samson et al., 2009). Adolescents resist the loss of hope and seek to be confident and rebuild hope, imagining a promising future (Wu, Chin, Haase, & Chen, 2009).

Daily life is unpredictable and uncertain (Hinton & Kirk, 2017) and it will vary according to disease intensity and difficulties experienced (Winger et al., 2013). There is a constant uncertainty about diagnoses, treatment efficacy, prognosis (Amador, Reichert, Lima, & Collet, 2013; Barrera et al., 2013; Cornelio et al., 2016; De Graves & Aranda, 2008; Hinton & Kirk, 2017; Huang et al., 2008; Nyborn, Olcese, Nickerson, & Mack, 2016), exacerbation, relapse (Amador et al., 2013; Cornelio et al., 2016; Granek et al., 2013; Hinton & Kirk,
2017; Sällfors et al., 2002; Sposito et al., 2015), and impacts on family life (Hinton & Kirk, 2017; Pizzignacco & Lima, 2006). Hence, the family cannot plan their future (Granek et al., 2013; Hinton & Kirk, 2017; Nicholas et al., 2009) and try to live day-by-day in the present: “have to take things slow and day to day” (Barrera et al., 2013, p. 412) because “things can change in an instant and so does hope” (Bally et al., 2014, p. 367).

4.4 | Support

This review highlights that family support, external support, and spirituality are resources that the family uses to balance hope. The intrinsic family connection (parent-child support) occurs when parents are by their children’s side taking care and encouraging them to continue with treatment (Bally et al., 2014; Björk et al.,...
Children and adolescents are affected by the feelings of the people around them; therefore, they cannot sustain hope without support (Hinds & Martin, 1988; Sällfors et al., 2002). Parental hope provides support for children and adolescents during moments of affliction and makes them feel safe (Bally et al., 2014). This reciprocity is identified by children and adolescents, who also want to transmit hope to their parents (Hinds & Martin, 1988). The lack of hope in one of the family members can affect the whole family unit because of the connection between members (Bally et al., 2014; Chinchilla-Salcedo, 2013; Hinds & Martin, 1988; Huang et al., 2008; Kylmä & Juvakka, 2009).

Families also demonstrate that they need external support to promote or maintain hope by sharing difficult moments and being influenced by the hope of others (Bally et al., 2014; Barrera et al., 2013). Conversely, the lack of support leads family hope to decrease (Cornelio et al., 2016). One study described that healthy siblings find support in friends and teachers (Björk et al., 2005). Another study highlighted the importance of financial support for maintaining parental hope (Kylmä & Juvakka, 2009). Support also comes from the extended family (Bally et al., 2014; Barrera et al., 2013; Björk et al., 2005; Chinchilla-Salcedo, 2013; Dupas & Angelo, 1997; Samson et al., 2009; dos Santos et al., 2010; Wu et al., 2009), friends (Bally et al., 2014; Barrera et al., 2013; Chinchilla-Salcedo, 2013; Samson et al., 2009; dos Santos et al., 2010), support groups (Sällfors et al., 2002), pets (Kylmä & Juvakka, 2009), the healthcare system (Cornelio et al., 2016), the community (Bally et al., 2014; Barrera et al., 2013), peers (Kylmä & Juvakka, 2009), other parents (Barrera et al., 2013; Ringnér, Jansson, & Granheime, 2011), online groups (Barrera et al., 2013), and health professionals (Bally et al., 2014; Björk et al., 2005; Kylmä & Juvakka, 2009; dos Santos et al., 2010). The following excerpt from an adolescent exemplifies how nursing support can foster hope: “One time I said [adolescent] I wanted to die and one nurse said: “No, you don’t. There is hope for you and I’m here to help you.” I realized she was trying and I wasn’t. That made me want to try” (Hinds & Martin, 1988, p. 338). Although nurses can offer support to sustain family hope, there are situations such as during relapses when the family believes nurses were no longer able to promote hope (Ringnér et al., 2011).

Spirituality is another source of support and hope (Kylmä & Juvakka, 2009; dos Santos et al., 2010). Families foster their hope by expressing spirituality through prayer, religion, faith, connections with the divine (Amador et al., 2013; Andrade et al., 2009; Bally et al., 2014; Barrera et al., 2013; Björk et al., 2005; Bratt et al., 2012; Cornelio et al., 2016; Hinds & Martin, 1988; Huang et al., 2008; Nicholas et al., 2009; dos Santos et al., 2010; Sposito et al., 2015), or through personal beliefs (Kylmä & Juvakka, 2009). The belief that there is a reason for experiencing chronicity (Chinchilla-Salcedo, 2013; Kylmä & Juvakka, 2009; dos Santos et al., 2010), that their future can be promising (Hinds & Martin, 1988), or exist a life after death without disease (Grossoehme, Ragsdale, Wooldridge, Cotton, & Seid, 2010; Kylmä & Juvakka, 2009) helps the maintenance of family hope. For parents who do not believe in the divine, hope lies in health professionals or future research that can heal their children (Bally et al., 2014; Kylmä & Juvakka, 2009; Samson et al., 2009).

4.5 | Information
Families can experience uncertainty and abandonment when access to information is lacking (Hinton & Kirk, 2017). Receiving contradictory information generates anxiety and the need to confront misunderstandings (Ringnér et al., 2011). Information should be empathically conveyed by the health team, especially to children and adolescents who are in particular stages of development (Nyborn et al., 2016). Although they want to hear that everything will be all right, they know that this cannot always be promised (Ringnér et al., 2011). Families want honest information and do not want “sugarcoating” or “trying to cover the sky with their hands” (Nyborn et al., 2016, p. 629), as an attempt to not develop a truthful communication.

At the same time, families want to gradually receive information because excessive information can be overwhelming and lead to feelings of being in shock and lost, affecting hope (Barrera et al., 2013). Consequently, families need to receive the correct information at the right time to reduce uncertainties (Huang et al., 2008; Ringnér et al., 2011). To promote hope, families seek information and advice from other parents (Ringnér et al., 2011), friends, family members, the internet, charity centres (Hinton & Kirk, 2017; Ringnér et al., 2011; Samson et al., 2009), and health professionals (Hinton & Kirk, 2017; Samson et al., 2009).

4.6 | Between “dark thoughts” and positive thoughts
Families may feel without the necessary resources to cope with the treatment of their children (Hinton & Kirk, 2017). Imagining their child in a wheelchair, with the need for institutionalization or hospitalization, or dying and torment and generates suffering that stimulates negative thoughts (Chinchilla-Salcedo, 2013; Hinton & Kirk, 2017; Samson et al., 2009). Adolescents also cultivate negative thoughts about death and future possibilities (Hinds & Martin, 1988; Wu et al., 2009). A mother describes thoughts when someone lives with chronicity: “You do a lot more thinking, you tend to overthink things and these are dark thoughts” (Barrera et al., 2013, p. 414).

To promote hope, the family builds mechanisms such as deliberately altering thoughts to guide them towards a promising and optimistic future (Bally et al., 2014; Hinds & Martin, 1988; Hinton & Kirk, 2017; Wu et al., 2009). Adolescents seek distraction and relaxation in physical activities or thoughts about homework and housework and thus achieve mental relief with neutral or positive thoughts (Chinchilla-Salcedo, 2013; Kylmä & Juvakka, 2009; dos Santos et al., 2010; Sposito et al., 2015).
2013; Hinds & Martin, 1988). Even if adolescents cannot completely forget about the disease, they can remain hopeful after experiencing the discomfort of dark thoughts; they are constantly seeking hope (Hinds & Martin, 1988). To not lose hope and resist concerns, parents turn away from dark thoughts (Bally et al., 2014) and change their attitude towards positive perspectives (Barrera et al., 2013; Björk et al., 2005; Nicholas et al., 2009). Switching from dark thoughts to positive thoughts is possible by training that conditions hope, which establishes a positive pattern of thoughts (Bally et al., 2014).

The family knows that even while waiting for the best, the worst can become a reality (Sällfors et al., 2002); nevertheless, thoughts about the possibilities help dealing with the situation (Bally et al., 2014). Having the presence of others generates hope and the greater the hope, the greater the connection between those involved (Barrera et al., 2013; Kylmä & Juvakka, 2009) and triggers a process that disrupts negative thoughts. However, if support becomes a source of doubt through reminders about future uncertainties, the family blocks the connections with these people, "cutting people off" (Barrera et al., 2013, p. 413) to re-establish the balance of its hope (Hinton & Kirk, 2017; Wu et al., 2009).

The results of this review evidence the differences in families’ beliefs about the experience of hope. Knowing stories about less favourable prognosis can help some families to maintain a positive focus (Bally et al., 2014; Hinds & Martin, 1988) while for other families, that knowledge leads to a decrease in hope (Amador et al., 2013; Hinds & Martin, 1988; Ringnér et al., 2011). Conversely, other families can increase their hope and optimism when they know stories of patients who have been successful in treating and coping with the disease (Björk et al., 2005; Wu et al., 2009).

4.7 | Hoping to go back to normality

The balance of family hope seems to be related to time. Families remember their past and project it into the future in search of the desired normality experienced before the diagnosis. This can be verified in the following discourses: “I did have a life before cancer” (Hinds & Martin, 1988, p. 338); “I will get her [the sick child] back” (Cornelio et al., 2016, p. 12). The participants hope that their child will be able to resume his previous way of life and live again in the realm of normality as defined before the illness onset” (Samson et al., 2009, p. 108). The possibility of living like healthy children and adolescents resides in the achievement of normality: going to school and college, choosing a profession for the future, marrying and having children (De Graves & Aranda, 2008; Dupas & Angelo, 1997; Granek et al., 2013; Hinds & Martin, 1988; Kylmä & Juvakka, 2009; Samson et al., 2009; Vindrola-Padros & Brage, 2017).

Meanwhile, the family knows that the present is the only guaranteed moment they have and they try to enjoy it to the fullest (Bally et al., 2014; Granek et al., 2013). Everyday activities, such as going to school and spending time with the family are more valued than before (Andrade et al., 2009; Granek et al., 2013; Nicholas et al., 2009; Winger et al., 2013). Focusing on the positive aspects of the present helps the family to maintain hope (Barrera et al., 2013).
TABLE 3

Descriptive themes developed from the analysis of the included studies

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<thead>
<tr>
<th>Study</th>
<th>Normality</th>
<th>Support</th>
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There are also parents who feel frustrated for not believing in the healing of their children (Nyborn et al., 2016). There are also parents who feel frustrated for not believing in the healing of their children (Nyborn et al., 2016).

5 | DISCUSSION

This thematic synthesis of qualitative studies presents a new perspective on hope, identified as “Family Hope”, that highlights the influence of relationships between family members and the chronically ill child. This characteristic of family connection has not been addressed in previous reviews about the experience of hope. Our review synthesis highlights hope as an extrinsic and systemic phenomenon because family members are likely to influence each other’s balance of hope. The intrinsic characteristic of hope has also been identified in another study with adolescents and young adults (Juvakka & Kylmä, 2009).

The characteristic of multidimensionality, identified in this thematic synthesis, is consistent with the following definition of hope: “multidimensional dynamic life force characterized by a confident yet uncertain expectation of achieving future good which, to the hoping person, is realistically possible and personally significant” (Dufault & Martocchio, 1985, p. 380). In our review, the multidimensionality of hope was represented by five factors arising from the family experience in the context of chronicity: uncertainty, support, information, types of thoughts, and the desire to return to normality. These factors will be experienced according to the perspective that families have about time in their lives – past, present and future.

The dynamicity of hope identified in this review was also reported in other reviews based on adults and elderly living with chronic conditions. In particular, hope was related to uncertainties, desires for the future, spirituality, connection with others, life purpose and search for quality of life (Duggleby et al., 2010, 2012; Hammer et al., 2009; Kylmä, 2005). For the older people with chronic illness, hope for healing is replaced by the hope to live in peace and harmony (Duggleby et al., 2012). However, in our study, families dream about the possibility of a cure and a return to the normal life they lived before the diagnosis of a chronic condition.

Our results are consistent with those reported in others studies developed in the contexts of paediatric and chronic disease demonstrating that the families’ experience of hope was related to uncertainty, need of information and support, thoughts about illness and treatment, and wishes to reach normality (Kluthe et al., 2018; Polita et al., 2018; Smith et al., 2015). The possibility of cure encourages families to hope for a disease-free future, which is also reported in other studies (Kluthe et al., 2018; Polita et al., 2018; Smith et al., 2015). Although some patients can achieve a cure, cancer is considered and viewed by families as a chronic disease because of its long-term and late effects derived from treatment, the need of follow-ups and the permanent fear of recurrence (McCorkle et al., 2011).
5.1 Strengths and limitations

To our knowledge, this is the first review to present a thematic synthesis of qualitative studies on the experience of hope in families of children and adolescents living with chronic illness.

The use of the SPIDER tool for structuring the search strategy, the inclusion of six databases supplemented by manual searches, and the non-limitation of the initial publication date are considered strengths that were intended to cover as many relevant studies as possible. The research team represents another strength by being composed of novice and expert researchers from different countries and with different linguistic abilities allowing the inclusion of studies in four languages (English, Spanish, French, and Portuguese), enlarging the sample. Hence, the findings of this review can be considered valuable additions to the present knowledge about family hope in the context of paediatrics and chronic illness.

The predominant sample of families of children and adolescents with cancer could represent a limitation in this study influencing the review findings. However, the inclusion of some studies with different chronic illnesses strengthened the findings of this thematic synthesis because it allowed us to construct a qualitative synthesis with a non-categorical approach (Stein & Jessop, 1989). Most studies did not address hope as their main objective; however, since the experience of hope has been poorly explored in the paediatric context, it was decided to include studies that presented hope as part of their findings. Nevertheless, it was considered that some studies contribute substantially in the qualitative synthesis. Although most studies had an adequate methodological quality, some studies presented methodological limitations about reflexivity, recruitment, ethical issues, and data analysis, which could have had an impact on the confidence in the findings. Future studies should address these methodological concerns to contribute to the construction of knowledge in this area of study. Finally, although this thematic synthesis aimed to include different family structures, the included studies only presented information about nuclear families. Therefore, this might be a limitation for the generalization of findings to all types of families.

6 CONCLUSION

This review suggests the need for future studies that explore the experience of hope in different family structures. We also recommend conducting studies that consider different types of chronic conditions to identify similarities and differences in the experience of family hope. About the theoretical and methodological approaches, we suggest the development of longitudinal qualitative in-depth research to explore the singularity of hope according to the trajectory phase families are facing. We also recommend that researchers use interactive data collection techniques (such as photographs, drawings, puppets, etc.) to achieve enriched data from the paediatric population. Finally, ethnographic studies would be valuable to explore the meaning of hope according to the different social and health contexts of families.

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CONFLICT OF INTEREST

The authors have declared no conflict of interest.

AUTHOR CONTRIBUTIONS

ACABL, CGV, RRN, WAA, LCN made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; involved in drafting the manuscript or revising it critically for important intellectual content; given the final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content; agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

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