



A Metasynthesis: Uncovering What Is Known About the Experiences of Families With Children Who Have Life-limiting and Life-threatening Illnesses☆



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ABSTRACT

Purpose: To conduct a metasynthesis of qualitative research exploring parents' psychosocial experiences during complex and traumatic life transitions related to caring for a child with a life-limiting (LLI) or life-threatening illness (LTI).

Background: Parents' experiences of caring for a child impacted by an LLI or LTI are not clearly understood, and holistic, comprehensive pediatric nursing care for parents who have children with LLI and LTIs continues to be developed as treatment improves and survival is extended.

Review Methods: Predetermined inclusion and exclusion criteria were used to review qualitative studies. Those included were appraised, classified, and synthesized using systematic procedures guided by Sandelowski and Barroso (2006).

Data Sources: A systematic search of qualitative research was conducted by an experienced librarian to identify and retrieve studies from 10 databases.

Results: Of the 3515 studies screened, 23 were included. A synthesis of the findings demonstrated that parents experience profound and pervasive uncertainty, leading to their own illness experience being described as a dual reality in which fighting for survival and recognizing the threat of their child's death were daily challenges. Three key processes emerged: the devastation of living with uncertainty, the emergence of hope, and moving forward.

Conclusion: The integration of findings adds to the current body of knowledge by highlighting the very complex experiences that parents undergo. These findings can support a more comprehensive pediatric nursing plan of care that accounts for the intricacies of the parental experience and the importance of hope.

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Introduction

Life threatening illnesses (LTIs) such as cancer, are those illnesses that may respond to curative treatment. However, that treatment may not always be successful (Together for Short Lives, 2017). In addition,

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Together for Short Lives (2017) defined life limiting illnesses (LLIs) in children and youth as those conditions for which there is no hope of a cure and from which probable death will occur. Often these illnesses result in progressive decline in health and function, thus increasing parental caregiving responsibilities. Parents of children who have been diagnosed with a LTI or LLI undergo persistent traumatic transitions in which the threat of their child's death is relentless. Ample empirical evidence demonstrates these transitional experiences evoke profound and persistent uncertainty (Bally et al., 2014; Clarke, 2006; De Graves & Aranda, 2008; Hinton & Kirk, 2017; Rempel et al., 2012). As a result, parents caring for their child are fearful (Bally et al., 2014; Björk, Wiebe, & Hallström, 2005; Kerr & Haas, 2014; Nicholas et al., 2009) and

experience loss and grief as well as a lack of control. The importance of parental hope to parents' caregiving activities and health has become clear (Ångström-Brännström, Norberg, Strandberg, Söderberg, & Dahlqvist, 2010; Bally et al., 2014; De Graves & Aranda, 2008; Nicholas et al., 2009; Samson et al., 2009). However, what remains unclear is how these emotions and experiences translate to day-to-day life when caring for a child with a LTI or LLI, what the long-term effects are, and how they co-exist. There are few reviews that have synthesized the findings from qualitative studies of parents' experiences when caring for a child with LTI or LTIs.

A qualitative metasynthesis is an "interpretative integration of qualitative findings that are themselves interpretive syntheses of data, including the phenomenologies, ethnographies, grounded theories, and other coherent descriptions or explanations of phenomena, events, or cases that are the hallmark findings of qualitative research" (Sandelowski & Barroso, 2006, p. 18). The value of a metasynthesis is the "ability to generalize from and about cases across a range of cases" (Sandelowski, 1996). Such works increase the availability of a quality body of empirical knowledge (Sandelowski & Barroso, 2006).

The overall purpose of this metasynthesis was to synthesize, interpret, integrate, and, hence, gain a more comprehensive understanding of the qualitative findings related to parents' experiences when caring for a child diagnosed with a LTI or LLI. This unique and novel insight cannot be gained from reviewing individual studies in isolation. Therefore, the specific aims were to identify relevant qualitative research and synthesize the findings, using the explanatory, interpretive insights from all included studies to facilitate the continued development of holistic pediatric family nursing care. Additionally, the findings will be used to guide future research by making empirical research findings more accessible.

Methods

Design

This metasynthesis of qualitative research exploring psychosocial experiences of parents of children with LTIs or LLI followed procedures outlined by Sandelowski and Barroso (2006). As such, the metasynthesis involved: a) a comprehensive search of all relevant reports, b) a systematic appraisal of qualitative studies, c) a classification of the study findings, and d) a synthesis of the findings.

Search Methods

The following databases were searched via the OVID interface: MEDLINE (from inception to January 14, 2014), Embase (from inception to May 6, 2014), and PsycINFO (from inception to May 6, 2014). Additional databases searched were CINAHL (from inception to May 5, 2014), Scopus (from inception to July 30, 2014), Web of Science (from inception to August 26, 2014), Academic Search Premier (from inception to September 17, 2014), the Cochrane Central Register of Controlled Trials (CENTRAL) in the Cochrane Library (September 17, 2014), and the Joanna Briggs Institute EBP Database (September 17, 2014). The MEDLINE search strategy was developed by a librarian experienced in systematic review searching, and peer reviewed by another librarian using the PRESS standard. Research team members provided feedback for the search strategy, and amendments were made to optimize the search results. The MEDLINE search strategy was adapted for the other databases. Because the focus was to explore the experiences of parents of children with LTIs and LLI, only qualitative studies were included. The librarian used the University of Texas School of Public Health filter for retrieving qualitative studies (<https://sph.uth.edu/current-students/library/search-filters/>). No lower limit was placed on the search dates in order to maximize the diversity of our sample by capturing the differences in survival rates relative to advanced treatment and technology over the last several decades. Studies focusing

on families of children aged three months to 15 years old were included as it was thought that the experience of parents may be vastly different during the neonatal period, and due to the increased independence of youth over the age of 15 years. Due to budget restrictions, only studies in English were retrieved. Studies based in developing nations were excluded because the research team hoped to have results that could be applied to populations with similar healthcare contexts to Canada. Search strategies were saved, and set up as "alerts" to notify the team if new articles were published up until May 2017.

Grey literature and unpublished studies were found using Google and Google Scholar, and on the websites of relevant organization such as the Canadian Institutes of Health Research, Health Canada, Public Health Agency of Canada, the National Institutes of Health, the National Health Service, OpenSIGLE (Europe), and the World Health Organization. These were searched in the Proquest Dissertations and Theses database as well as within the University of Alberta Electronic Theses & Dissertations. To ensure identification of all relevant studies, the reference lists of included studies or relevant reviews were scanned.

DistillerSR (Evidence Partners Incorporated, Ottawa, Canada) was used to support data collection and analysis. Distiller SR is an online software application that allows multiple researchers to participate in a review and may improve the strength of reviews such as metasyntheses. Using DistillerSR for all screening and data extraction activities, a team of three registered nurse researchers used specific inclusion and exclusion criteria to systematically review each article identified. The articles included were primary, interpretive qualitative studies: a) of parents of children aged three months to 15 years with LTIs or LLI; b) of parental experiences; c) that were psychosocial in nature; and d) that did not include healthcare team member perceptions of parental experiences. Reviews, quantitative, or mixed method articles were excluded, as were studies that focused on third world populations and/or reported on end of life decision-making experiences.

Search Outcome

A total of 3428 articles were identified through the library database search, and an additional 87 records were identified through a search of other sources such as Google Scholar, reference list checks, and the Proquest Dissertations and Theses database, for example (see Fig. 1). A total of 802 duplicates were removed, leaving 2713 studies. An initial review of titles and abstracts was conducted to identify studies that did not fit the inclusion criteria, after which 290 articles remained. The second review included a full review of each article by two of the authors and led to the final inclusion of 23 interpretive qualitative studies (see Table 1) that examined the experiences of parents who cared for a child with a LTI or LLI.

Quality Appraisal

Appraising Reports of Qualitative Studies

According to Sandelowski and Barroso (2006), appraising reports helps researchers to confirm inclusion criteria are capturing findings that meet the objectives of the metasynthesis and to become familiar with the content of each report. It also provides an opportunity to evaluate and appreciate research findings. The completion of this metasynthesis used Sandelowski and Barroso's (2006) reading guide and the Critical Appraisal Skills Programs (CASP) to appraise each study. The CASP was developed by the Joanna Briggs Institute to provide a standardized tool for appraising qualitative studies. The CASP consists of 10 questions to screen reports, including two that screen for inapplicable studies and eight that evaluate research design, data collection methods and analyses, ethics, reflexivity, and implications of qualitative research.

A three-point rating system developed by Duggleby et al. (2010) was employed in this metasynthesis. In keeping with this rating system, a score was calculated for each of the eight questions using the CASP

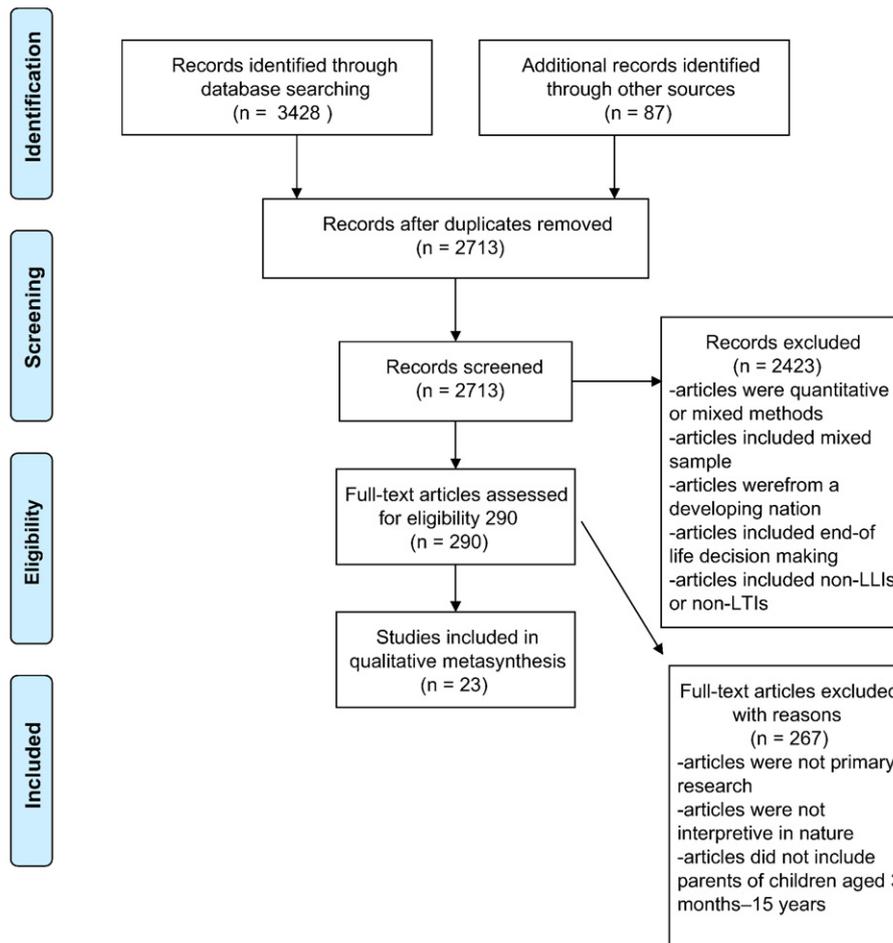


Fig. 1. Prisma flow diagram.

system. For example, a weak score of one point was assigned to studies that offered little to no justification or explanation of a particular issue. This included studies in which information regarding where, when, or how data were collected was missing. A moderate score of two points was awarded to studies that addressed issues related to the research conducted but did not elaborate. This included studies in which, for example, the justification for using constant comparisons was presented but the procedure itself was not explained. A strong score of three points was given to articles that comprehensively justified and explained research issues. For example, this included studies in which the authors explained that semi-structured interviews were used, transcribed verbatim, and modified part way through the study, and offered some example interview questions. Once a score for each question was given, all scores were tallied and a final CASP score out of a possible 24 was assigned.

Classifying the Findings

Using Sandelowski and Barroso's (2006) classification system, the findings from each study were classified as a) no finding, b) topical survey, c) thematic survey, d) conceptual/thematic description, or e) interpretive explanation. The inclusion criteria for this metasynthesis took into account Sandelowski and Barroso's (2006) suggestion that qualitative research requires a higher level of interpretation and Thorne's (2000) belief that, when looking at complex clinical issues, a

higher level of research is needed for the results to be applicable to practice. Therefore, only reports revealing interpretation were included.

Synthesis of Findings

As suggested by Sandelowski and Barroso (2006), findings were synthesized using taxonomic analysis, constant targeted comparison, and reciprocal translation. Taxonomic analysis allows for an in-depth synthesis because it shows theoretical properties of the findings in each study as well as what might have been anticipated given the theoretical findings but was not actually identified. The process of taxonomic analysis is very similar to grounded theory coding procedures (Sandelowski & Barroso, 2006). Constant targeted comparison was also employed to identify similarities, differences, and relationships among the findings (Sandelowski & Barroso, 2006) related to parents' experiences. In this case, once the findings were reduced into the taxonomy, they were compared and then conclusions reached regarding the shared key features of parental experiences when caring for a child with a LLI or LTI. Last, reciprocal translation was used to conceptually synthesize and integrate the findings interpretively. During this process, the reviewers concentrated on in vivo concepts to synthesize the data from all studies and to integrate them (Sandelowski & Barroso, 2006). The final synthesis is reported herein, including an integrated diagram of the findings.

Table 1
Summary of studies included in the metasynthesis.

Source	Objective	Methodology	Data Collection method	Participants	CASP score	Findings Classification
Ångström-Brännström et al. (2010) Sweden	To describe parents' narratives concerning what they find comforting when they have a child suffering from cancer and provide care for them while in hospital and at home	Qualitative descriptive research	Interviews	Nine parents (8 mothers and 1 father) of children diagnosed with cancer aged three to nine years <i>n</i> = 9	18	Conceptual/thematic description
Bally et al. (2014) Canada	To gain an understanding of the experience of hope for parents who care for their child at home who is in treatment for cancer	Grounded theory	Open-ended interviews (repeating), parent journals	Sixteen parents (12 mothers and 4 fathers) of children aged 3–13 years, diagnosed with cancer <i>n</i> = 16	22	Interpretive explanation
Barrera et al. (2013) Canada/Israel	To explore parental hope when a child is being treated for a malignancy resistant to treatment and to identify facilitators and barriers to maintain hope in this context	Grounded theory	Semi-structured interviews	Thirty-five parents (26 mothers and 9 fathers) of children with difficult to treat cancer <i>n</i> = 35	20	Interpretive explanation
Björk et al. (2005) Sweden	To elucidate the families' lived experience when a child in the family is diagnosed with cancer	Phenomenology	Semi-structured interviews	Thirty-nine parents (17 mothers and 12 dads; 5 children and, 5 siblings) of children aged nine to eleven who were diagnosed with cancer <i>n</i> = 17	21	Conceptual/thematic description
Brody and Simmons (2007) U.S.A.	To understand the experience of fathers during childhood cancer, with specific focus on resources and capabilities that contribute to resiliency and constructive coping	Qualitative descriptive research	Semi-structured interviews	Eight fathers of children aged four to sixteen who were diagnosed with cancer <i>n</i> = 8	20	Interpretive explanation
Carpenter and Narsavage (2004) U.S.A.	To describe the lived experiences of families caring for a child at home with cystic fibrosis (CF) at the time of initial diagnosis	Phenomenology	Focus groups, written narratives	Nine family members caring for a child with CF at the time of initial diagnosis <i>n</i> = 9	20	Interpretive explanation
Clarke (2006) Canada	To examine how mothers manage the moral imperatives of mothering at home when a child has cancer	Qualitative descriptive research	Focus Groups	Forty-nine mothers of children aged fourteen months to twenty-one years diagnosed with cancer <i>n</i> = 49	21	Conceptual/thematic description
De Graves and Aranda (2008) Australia	To explore the experiences of families when a child with cancer relapses without exploration of their social context	Critical ethnography	4 in-depth interviews over 6–13 months, field notes	Seventeen parents (12 mothers and 5 fathers) of children with cancer after relapse who were aged two to sixteen years, and 3 children <i>n</i> = 12 families	21	Interpretive explanation
Gravelle (1997) Canada	Explored day-to-day experiences of parents caring at home for a child with a progressive life-limiting illness (LLI) at a specific stage of their disease, when the child lives with a complex chronic condition, and is in need of specialized and time-consuming care	Phenomenology	Interviews	Eleven parents (5 mothers and 3 couples) of children aged twenty six months to sixteen years with a variety of LLI and LTI conditions <i>n</i> = 11	15	Interpretive explanation
Hill, Higgins, Dempster, and McCarthy (2009) Ireland	To explore how fathers of children diagnosed with acute lymphoblastic leukemia perceived and understood the roles they had within their family over the course of their child's illness and treatment	Interpretive phenomenological analysis	Semi-structured interviews	Five fathers of children aged eighteen months to seven years who had completed treatment for ALL and were in remission <i>n</i> = 5	21	Conceptual/thematic description
Kars, Duijnste, Pool, van Delden, and Grypdonck (2008) the Netherlands	To gain insight into the lived experience of parenting a child with acute lymphoblastic leukemia (ALL) during treatment	Grounded theory	Interviews	Twenty three parents (12 mothers and 11 fathers) of children aged two to twelve years in different stages of treatment for ALL <i>n</i> = 23	21	Conceptual/thematic description
Klymä and Juvakka (2007) Finland	To describe hope in parents of adolescents with cancer	Qualitative descriptive	Open-ended interviews	Nine parents (5 mothers and 4 fathers) of adolescents aged twelve to seventeen years with cancer <i>n</i> = 18	23	Interpretive explanation
McGrath (2002) Australia	To report the perspectives of parents during the initial stages of diagnosis and treatment for their children's acute lymphoblastic leukemia	Interpretive phenomenological analysis	Open-ended interviews	Sixteen parents (12 mothers and 4 fathers) of children aged birth to ten years who were undergoing treatment for ALL <i>n</i> = 16	19	Interpretive explanation
Nicholas et al. (2009) Canada/U.S.A.	To examine experiences of fathers of children diagnosed with cancer and explore their perceptions of fatherhood in the context of childhood cancer	Grounded theory	Semi-structured interviews	Sixteen fathers of children aged one to seventeen years who is in active treatment for cancer <i>n</i> = 16	19	Interpretive explanation
O'Brien (2001) U.S.A.	To examine the experience of providing long-term care at home for the child who is technology dependent	Descriptive qualitative research	Unstructured interviews	Fifteen families (11 mothers, four couples and once child) with a child who was technologically dependent and living at home for at least one year <i>n</i> = 15 families	16	Conceptual/thematic description

(continued on next page)

Table 1 (continued)

Source	Objective	Methodology	Data Collection method	Participants	CASP score	Findings Classification
Rallison and Raffin-Bouchal (2013) Canada	To explore the experiences of families caring for their child with progressive neurodegenerative disease at home	Phenomenology	Interviews	Twenty seven family members (4 couples, 4 mothers, 2 siblings, 1 ill child, and 2 caregivers) of children with progressive neurodegenerative disease <i>n</i> = 27	21	Conceptual/thematic description
Rempel and Harrison (2007) Canada	To describe the parenting experience of mothers and fathers whose child with hypoplastic left heart syndrome (HLHS) underwent treatment that included the Norwood surgical procedure soon after birth	Grounded theory	Unstructured interactive interviews	Sixteen parents (7 fathers and 9 mothers) of children aged two months to five years who were diagnosed with HLHS and at various stages of treatment <i>n</i> = 16	21	Interpretive explanation
Rempel, Rogers, Ravindran, and Magill-Evans (2012) Canada/India	To describe the process of parenting young children who have survived hypoplastic left heart syndrome to inform parent focused interventions	Grounded theory	Interviews	Twenty five parents (10 mothers and 5 fathers), twenty eight grandparents (17 grandmothers and 11 grandfathers) of children aged six months to four and a half years who had undergone the Sano surgical approach to HLHS <i>n</i> = 53	17	Interpretive explanation
Samson et al. (2009) Canada	To describe the lived experience of hope among parents of a child with Duchenne Muscular Dystrophy (DMD)	Phenomenology	Semi-structured interviews	Twelve parents (7 mothers and 5 fathers) of children aged two and half years to eight years diagnosed with DMD <i>n</i> = 12	17	Conceptual/thematic description
Schweitzer, Griffiths, and Yates (2012) Australia	To explore the experiences of parents who have a child with cancer	Interpretive Phenomenological Analysis	Semi-structured interviews	Eleven parents (9 mothers and 2 fathers) of children aged eight to sixteen years diagnosed with cancer <i>n</i> = 11	18	Conceptual/thematic description
Steele (2005) Canada	To describe families' perceptions and experiences of living with a child who has a neurodegenerative life-threatening illness (LTI), and how those experiences change over time	Grounded theory	Interviews Observation	Twenty nine family members of children aged three to thirteen diagnosed with neurodegenerative LTI <i>n</i> = 8 families	19	Conceptual/thematic description
Ware and Raval (2007) UK	To gain an understanding of fathers' experiences of having a child with a LLI, its impact on them, and their perceptions of service provision	Interpretive phenomenological analysis	Semi-structured interview	Eight fathers of children with a LLI <i>n</i> = 8	16	Conceptual/thematic description
Young, Dixon-Woods, Findlay, and Heney (2002) UK	To investigate the experiences of mothers living with a child with cancer	Descriptive qualitative research	Semi-structure interviews	Twenty mothers of children aged four to seventeen years with a diagnosis of cancer <i>n</i> = 20	17	Interpretive explanation

Validity

Validity was sought throughout this metasynthesis by adhering to Sandelowski and Barroso's (2006) suggestions for descriptive validity. This included a) employing strong communication among the researchers to ensure use of all resources to complete an exhaustive search, b) consulting an experienced health sciences librarian, c) employing more than one team member to conduct searches and appraisals, d) holding regular meetings to discuss inclusion terms, search methods, and ongoing analysis, e) keeping an audit trail of search results and decisions, and f) the participation of every team member in narrowing the search using DistillerSR that recorded and tracked all levels of decision making.

Results

A comprehensive search revealed 23 studies that examined and described parents' experiences when caring for a child with a LLI or LTI and were interpretive in nature (see Table 1). This included 11 conceptual/thematic descriptive studies and 12 interpretive explanation studies, classified according to Sandelowski and Barasso (2006) typology. The 23 articles had a mean CASP score of 19.26 within a range from 15 to 23. The CASP scoring revealed an overall moderate to high quality of research, and provided additional context for this metasynthesis. However, no articles were excluded from the study based on CASP findings as per Sandelowski and Barroso (2006). The total sample was 412, of whom 233 were mothers, 110 were fathers, 35 were 'families', 34

were children, 28 were grandparents, and 11 were 'couples' interviewed as a dyad. The range of childhood diagnoses included cancer, hypoplastic left heart syndrome, cystic fibrosis, and neurodegenerative disease. Some studies addressed multiple LLI and LTI diagnoses. The samples came from a number of countries, including Canada, the USA, the UK, Australia, Israel, Sweden, the Netherlands, Ireland, and Finland; three studies involved two countries (Canada/USA, Canada/Israel, and Canada/India). While the context of parental caregiving is important in qualitative research, very few articles presented enough information to ascertain where such care was provided. For those articles in which the context of care could be discerned, the authors focused on the home (see Table 1), while one focused on both home and hospital. Therefore, a detailed description of the theoretical context follows.

The Context: A Dual Reality of Death and Survival

Parents of a child diagnosed with a LLI or LTI described a dual reality that alternated between two dominant experiences: the highs associated with focusing on their child's and their own survival, and the lows related to their fear of their child's death (Ångström-Brännström et al., 2010; Bally et al., 2014; Barrera et al., 2013; De Graves & Aranda, 2008; Klymä & Juvakka, 2007). Parents lived in a constant state in which the threat of their child's death was relentless and an ongoing daily challenge (Bally et al., 2014; Björk et al., 2005; Clarke, 2006; McGrath, 2002; Nicholas et al., 2009). Most parents described this experience as a roller coaster ride in which they felt persistent stress

(Ångström-Brännström et al., 2010; Carpenter & Narsavage, 2004; Kars et al., 2008; McGrath, 2002; Nicholas et al., 2009), anxiety (Carpenter & Narsavage, 2004; De Graves & Aranda, 2008; McGrath, 2002; Rempel et al., 2012; Schweitzer et al., 2012), and isolation (Clarke, 2006; Nicholas et al., 2009; Ware & Raval, 2007). Parents also described a life of chaos (Björk et al., 2005; Carpenter & Narsavage, 2004; Steele, 2005; Young et al., 2002), loss (Gravelle, 1997; Kars et al., 2008; Rallison & Raffin-Bouchal, 2013; Rempel et al., 2012; Samson et al., 2009), and, particularly, uncertainty (Bally et al., 2014; Björk et al., 2005; Clarke, 2006; De Graves & Aranda, 2008; Hill et al., 2009; Rallison & Raffin-Bouchal, 2013; Samson et al., 2009; Ware & Raval, 2007). Rallison and Raffin-Bouchal (2013) described the experience of parents of children with a progressive neurodegenerative disease as “holding the duality of joy and sorrow” (p. 201). The parents in their study used an invisible strength to relish every happy moment, all the while living in fear of death. A clearer understanding of the ‘invisible strength’ can be obtained by integrating the findings from the research included in this metasynthesis, as follows.

The results of this metasynthesis indicate that three main processes seem to facilitate parents finding strength in their illness experience to provide care for their child. Within the paradoxical context of death and survival, parents described an illness experience that, by virtue of being a parent, became their very own experience. The first process in this complex illness experience was described as *the Devastation of Living with Uncertainty*, which was characterized by two subprocesses: *acknowledging their disrupted world and reconciling with uncertainty*. Many parents then turned to hope as a resource; it was not only strengthening and supportive but specifically guided them through the profound and pervasive experience of uncertainty. Thereby, through the second process, *the Emergence of Hope*, parents were able to manage the tension created by living between death and survival through two subprocesses: *changing priorities and salvaging family relationships*. Hope appeared to be transformational in that parents were ultimately able to reconcile with uncertainty and begin the third process, *Moving Forward*, which included two subprocesses: *finding normal and attaching new meaning* to their experiences. In short, the parent illness experience appears to develop out of *the Devastation of Living with Uncertainty* and, with *the Emergence of Hope*, they are supported in *Moving Forward*.

Parental Illness Experience

The Devastation of Living with Uncertainty

The parents' traumatic illness experience was permeated by profound and unremitting uncertainty, which was described as devastating and included feelings of fear, loss and grief, lack of control, and intense emotions. For example, Ware and Raval (2007) found that fathers of a child diagnosed with a LLI or LTI experienced “personal work (that) had become completely uncertain and unpredictable. All their hopes, expectations and plans no longer seemed to pertain” (p. 554). Initially, parents very clearly described the time of diagnosis as a pivotal life experience that included feelings of tremendous uncertainty. Unfortunately, parents also identified uncertainty as one of the most consistent experiences in their lives throughout diagnosis and treatment, which often lasted for many years. Uncertainty related to many aspects of their child's illness, including consideration of life and death, symptoms related to treatment and the illness, success or failure of treatment, the care and well-being of other children, psychosocial support, personal abilities, and prognosis, and ultimately led to the inability to plan for the future.

In each of the studies included in this metasynthesis, parents described *the Devastation of Living with Uncertainty* by *acknowledging a disrupted world* when faced with their child's diagnosis of a LLI or LTI, which was followed by *reconciling with uncertainty* related to their child's often ambiguous diagnosis.

Acknowledging a Disrupted World

In Steele's (2005) grounded theory study of parents whose child was dying of neurodegenerative disease, parents faced a relentless situation in which they had to navigate an uncharted journey, beginning with “entering unfamiliar territory” (p. 104). Similarly, in a study involving mothers whose children had cancer, a parent clearly described the persistent and profound experience of uncertainty when she stated “there isn't anything in this world scarier than not knowing. It is just like running down a blind alley in the dark, just so scared all the time” (Clarke, 2006, p. 62). In Clarke's (2006) study, mothers of children with cancer also described uncertainty as a roller coaster of fear and wavering trust. De Graves and Aranda (2008) also described the profound effect that uncertainty had on parents whose child relapsed following a cancer diagnosis. Parents in this study described a “constant sense of uncertainty about their child's ultimate survival” (De Graves & Aranda, 2008, p. 295).

As a result of the tremendous uncertainty, parents reported feeling a plethora of intense emotions, including feeling frozen (Barrera et al., 2013), isolated and lonely (Nicholas et al., 2009; Ware & Raval, 2007), and guilty and powerless (Carpenter & Narsavage, 2004) as well as experiencing inner turmoil and periodic emotional breakdowns (Nicholas et al., 2009). The emotions were intense and painful, included many worries (Nicholas et al., 2009), and were described as an emotional roller coaster (Bally et al., 2014; Barrera et al., 2013; Clarke, 2006; McGrath, 2002). From the persistent experience of uncertainty, parents described tremendous loss and “overwhelming grief that was like a bottomless pit” (McGrath, 2002, p. 992), in which they felt they lost their foothold and experienced a ‘broken life world’ (Björk et al., 2005). Similarly, mothers of children diagnosed with cancer described their shock as a moment when “the bottom drops out of your world” and a “horrific time where everything you know is tipped upside down” (Young et al., 2002, p. 1837). It is also a time in which parents described the loss of their previously healthy child and sense of future (Barrera et al., 2013; McGrath, 2002; Rempel et al., 2012), and the profound loss of “all the joys and expectations associated with parenthood” (Samson et al., 2009, p. 107). Carpenter and Narsavage (2004) interviewed family members of children diagnosed with cystic fibrosis and found that they felt as though their world had fallen apart and required constant adjustment. Similarly, families of children with long-term technology dependence lived a life of unpredictability and frequent change, and they described this as “living in a house of cards” (O'Brien, 2001, p. 15) where there was a fine balance, requiring family members to restructure at any given time.

Reconciling with Uncertainty

Although the uncertainty was very difficult to manage, parents were often able to find strength in their illness experience. This was accomplished through coming to terms with their child's diagnosis and the associated treatment, as well as subsequently making the choice to live with uncertainty. For example, Gravelle (1997) discovered that parents who cared for a child with a progressive life threatening illness had to accept their child's illness. As one mother in this study stated, “we don't spend a whole lot of time dwelling on it. It is what it is” (p. 741). Similarly, Bally et al. (2014) found that parents had to first accept the reality of their child's cancer diagnosis to keep hope possible. For these parents, coming to terms with their child's diagnosis seemed to facilitate the management of adversity and uncertainty.

Once parents came to terms with their child's diagnosis and the realities of caring for their child, they also had to accept living with the related uncertainty. In many of the studies, parents had to adjust to the unexpected and a persistent sense of uncertainty (Barrera et al., 2013). For example, McGrath (2002) stated that parents lived with an “all-pervading sense of uncertainty” (p. 190). Furthermore, Rallison and Raffin-Bouchal (2013) contended that parents of children with neurodegenerative diseases had to live “in-between”, meaning they had to balance the tension between suffering and hope and live in a place

where they were able to experience “happiness, love, courage, grief, extreme sadness, and particularly fear” (Rallison & Raffin-Bouchal, 2013, p. 201) all at once. While parents seemed to find the strength to reconcile uncertainty and manage caregiving through their own illness experience, many parents described *the Emergence of Hope* as the critical psychosocial resource that supported their purposeful adjustment and adaptation for *Moving Forward*.

The Emergence of Hope

Of the 23 articles included in this metasynthesis, 14 referred to hope as a critical resource and the constant in parents' lives that emerged from their experiences of uncertainty (Bally et al., 2014; De Graves & Aranda, 2008; Klymä & Juvakka, 2007; Rallison & Raffin-Bouchal, 2013) as well as daily caregiving activities (Bally et al., 2014; Samson et al., 2009). Hope was seen as life sustaining (Klymä & Juvakka, 2007), essential (Bally et al., 2014; De Graves & Aranda, 2008; Klymä & Juvakka, 2007), and a constant even in the face of lingering despair (Klymä & Juvakka, 2007; Nicholas et al., 2009). Additionally, hope was described as dynamic and ever changing (Bally et al., 2014; Barrera et al., 2013; Nicholas et al., 2009; Samson et al., 2009) and of a dual nature. That is, the parents of children in treatment for a malignancy in Barrera et al.'s (2013) study found hope to be tenuous and elusive when they were aware of negative outcomes related to their child's health and experienced information and emotional overload (Barrera et al., 2013). On the other hand, hope was also tenacious and robust when parents had good social support, could be tied to spirituality, and allowed parents to focus on positive outcomes and experiences (Barrera et al., 2013). Similarly, Bally et al. (2014) described parents' hope as being sometimes easy and sometimes harder to find, oscillating between preparing for the worst and hoping for the best. This oscillation depended on factors such as the assessment of their child's health, knowledge, connecting with others, being in the loop, and faith. Other parents described the focus and content of hope as that which changed, often shifting from a hope for a cure to hope for a comfortable quality of life (Nicholas et al., 2009). For example, Ångström-Brännström et al. (2010) stated that parents' hope grew and changed from hoping for treatment to work to hope for the survival of their child.

As Klymä and Juvakka (2007) succinctly stated, “hope helps parents to endure the challenging situation” (p. 267). Parents described finding strength and power in hope, and viewed hope as being a guide through the daily challenges of fighting for survival and preparing for their child's death. The well-being of parents who care for a child with a LLI or LTI was often very difficult to maintain as their own needs became the lowest of priorities and they were challenged in ways never imagined. However, the emergence of hope appeared to be transformational in that it provided an orientation towards life and the future, and therefore, guided parents towards their desire for *Moving Forward* by two important subprocesses: *changing priorities* and *salvaging relationships*.

Changing Priorities

Having a child diagnosed with a LLI or LTI forced parents to reorganize, modify, and rethink priorities. For example, parents of children suffering from cancer experienced growing hope and were able to look ahead and plan for the future, which allowed “a new everyday life to emerge step by step for child, parents, and siblings” (p. 273). Additionally, parents of children with cancer in the study conducted by Björk et al. (2005) began to reflect on what was important in life and established new priorities. Similarly, O'Brien (2001) found that parents of children with chronic illness often reframed their beliefs, values, and priorities, maintaining hope for the future. Steele (2005) found that parents of children who were diagnosed with and dying from a neurodegenerative disease also had to change their priorities. They did so by slowing down their lives, focusing on their child, making the most of their lives, disengaging from others, and redefining their child as disabled.

Salvaging Family Relationships

Providing care for a child with a LLI or LTI often dominated family life (Björk et al., 2005), and placed a great deal of strain on spousal relationships (Young et al., 2002) and time with extended family members (Hill et al., 2009). As one parent stated, “you don't have a life, just an existence” (McGrath, 2002, p. 993). However, parents of children with cancer sought to feel hope and have a positive focus such that they could reduce chaos and gain control in life, including “feeling close to others to reduce feelings of loneliness” (Björk et al., 2005, p. 270). Similarly, O'Brien (2001) noted the importance of finding time for the family for those with children who were technologically dependent. Specifically, parents identified the importance of redefining relationships such that the priority was placed on repairing and restoring relationships as well as spending time with those who were positive and affirming (Brody & Simmons, 2007; Clarke, 2006; O'Brien, 2001; Rempel & Harrison, 2007). Relationships such as these supported parental hope and made it easier to remain positive.

Parents also discovered a deeper relationship with their child. Fathers in one study experienced an elevated feeling of love for their child, often wishing to spend more time together (Ware & Raval, 2007). In a study by Kars et al. (2008), parents of children with leukemia reported experiencing a new understanding that they may not have the chance to provide care for their child and share time together again, knowing that death may not be too far ahead of them. Thus, parents seemed to re-evaluate their priorities, surround themselves with positive family members and friends, and use hope as a guide to realize the worth and meaning of life to facilitate *Moving Forward*.

Moving Forward

Ultimately, parents' illness experience and the emergence of hope supported many parents in the process of *Moving Forward* beyond the feeling of being paralyzed by uncertainty to be able to adjust and adapt to their uncertain circumstances. Specifically, both hope and parents' experiences associated with caring for a child with an LLI and LTI appeared to lead to two outcomes—survival and transformation—that supported parents in coping with the uncertainty that impacted and pervaded their lives.

Moving Forward included two subprocesses, *finding normal* and *attaching new meanings* to their precarious situation, such that they experienced positive personal growth and found new value in life.

Finding Normal

Finding normal permitted a feeling of control, sense of power, and supported positive coping. Samson et al. (2009) stated that “parents are experiencing a crisis and their goal is to find an emergency exit that will bring them back to normality” (p. 112). Other parents described the need for maintaining normality as one way in which to gain control and manage the everyday roller coaster related to their child's illness and their otherwise uncertain circumstances (Björk et al., 2005; De Graves & Aranda, 2008). Similarly, fathers of children with acute lymphoblastic leukemia (ALL) in a study conducted by Hill et al. (2009) attempted to keep everything, including family life, as normal as possible to reduce the impact that cancer had on their lives; this included taking breaks and carrying on with usual routines.

In addition to attempting to find the normal in their circumstances and everyday life, parents also sought to find the normal within their child. Not only did parents feel it natural to view their child as normal, but “as much as possible, they directed their minds to think of their children as normal to alleviate their worries about their child's present and future health” (Rempel & Harrison, 2007, p. 830). In fact, parents felt joy when they felt their child was improving and returning to some degree of normalcy by participating in typical daily activities (Schweitzer et al., 2012).

Attaching New Meaning

Once parents were successful in *finding normal*, they also began to find ways of *attaching new meaning* to life. By realizing the fragility of life, some parents were able to make the most of each precious moment with their child, got to know their child better, and placed deep value in life. This provided a renewed sense of meaning and happiness (Schweitzer et al., 2012). For example, Nicholas et al. (2009) found that fathers of children with cancer became “more appreciate for, aware of, and engaged in life,” and this was described as a “perceived sense of enlightenment” (p. 270). Bally et al. (2014) found that, through hope, parents of children with cancer were able to think positively and develop a new kind of normal in which they did not take things for granted. Furthermore, Rallison and Raffin-Bouchal (2013) found that parents of children with a progressive neurodegenerative disease came to the realization that they needed to make the best of life and that quality of life was not measured by time. Parents in the studies conducted by O’Brien (2001) and Björk et al. (2005) developed a new outlook on life that included recognizing the many blessings apparent and having hope for the future. In Ware and Raval’s (2007) study, a father exclaimed “it has probably made me a little more pragmatic, the whole experience has made me empathetic as well” (p. 554).

Summary of the Integrated Findings

Parents in all of the studies included in this metasynthesis described a difficult illness experience in which a dual reality existed. They described this dual reality as a relentless roller coaster of highs and lows in which they contemplated their child’s survival along with their own, and ruminated over their child’s possible death. This experience was permeated with tremendous uncertainty that was characterized by fear, loss and grief, anxiety, lack of control, stress, and isolation. Fig. 2 aims to capture the complex processes experienced by parents who are navigating their child’s LLI or LTI. *The Devastation of Living with Uncertainty* and its subprocesses (*acknowledging a disrupted*

world and reconciling with uncertainty) are depicted at the base of the figure by a horizontal bidirectional arrow. The upward bidirectional arrows indicate both the illness experience and the *Emergence of Hope*. The illness experience may exist on its own but, for many parents, is facilitated by the *Emergence of Hope*, which appears to be transformational and accomplished through the cyclical tasks of *changing priorities* and *salvaging family relationships*. These are illustrated in the middle of the figure using cyclical bidirectional arrows, and support parents in the important process of *Moving Forward*. *Moving Forward* to manage the uncertainty and challenging emotions through two subprocesses (*finding normal* and *attaching new meaning*) is depicted at the top of the model.

Discussion

A metasynthesis of the literature about parental experiences when caring for a child with LLI and LTIs has not previously been reported, and therefore, the present study expands and adds clarity to previous findings described in individual studies. In addition, integration of the findings from the included studies offers an interesting and unique view of parents’ experiences and features three interrelated concepts: uncertainty, hope, and moving forward.

Uncertainty

The concept of uncertainty has been examined in studies related to parenting children with chronic illnesses (Clarke-Steffen, 1993; Mishel, 1988; Santacroe, 2003) as well as in diverse contexts. Similar to the findings from this metasynthesis, previous studies indicate that uncertainty exists in situations featuring unpredictable outcomes. Mishel’s (1988) middle range theory of uncertainty in illness highlighted four types of uncertainty, including ambiguity about the state of the illness, complexity regarding treatment and systems of care, lack of information regarding the diagnosis and outcomes of the illness, and unpredictability of the prognosis. Additionally, uncertainty can arise from

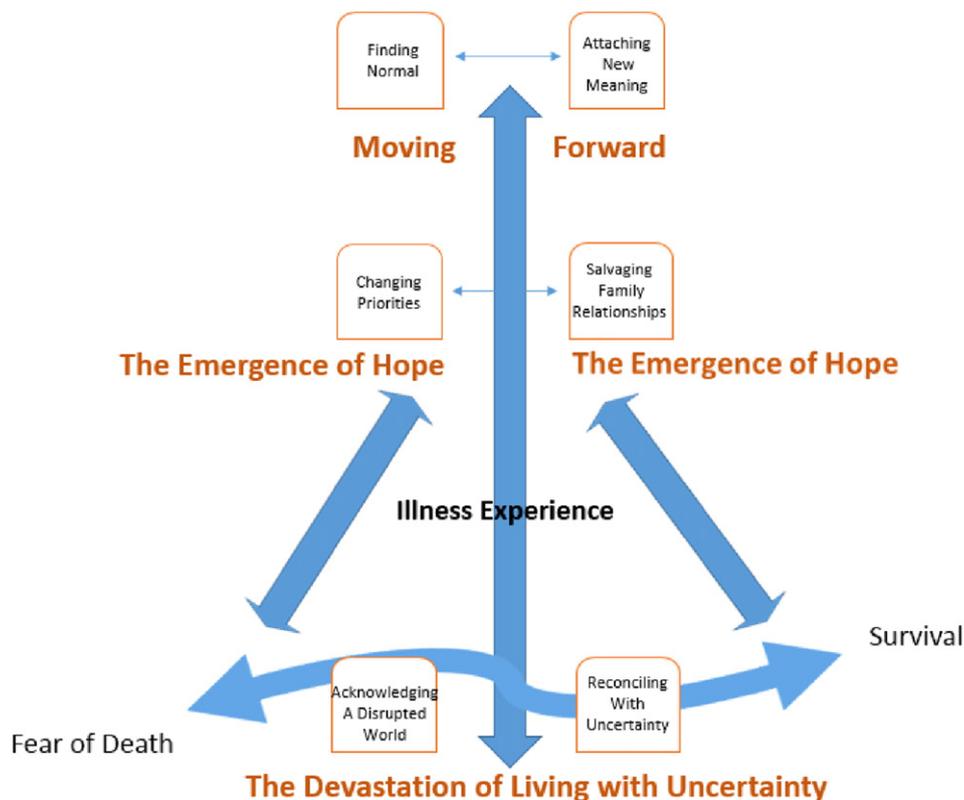


Fig. 2. The duality of parents’ illness experience.

parents' wishes to articulate their child's future, and is particularly heightened at the time of diagnosis (Clarke-Steffen, 1993; Santacroe, 2003) when this is no longer possible due to the unpredictability stemming from lack of knowledge of the disease, treatment outcomes, and prognosis. This metasynthesis corroborates these findings and highlights two additional aspects of parents' experiences when caring for a child who has a LLI or LTI. First, the integration of the findings demonstrates that parents experience unremitting uncertainty not only at diagnosis but throughout their child's illness. Perhaps because parents take on their child's illness experience as their own, they experience high levels of uncertainty that cause feelings of fear, loss and grief, anxiety, lack of control, isolation, and intense emotions. Second, the experience of intense uncertainty leads to the emergence of hope for parents. In a metasynthesis about the hope experiences of family caregivers of persons with chronic illness, Duggleby et al. (2010) defined hope as a "transitional dynamic possibility within uncertainty" (p. 152), and found that a major influence on hope was uncertainty. Similar to the findings in this metasynthesis, Duggleby et al. (2010) noted that "uncertainty was a precondition for hope" (p. 153). The present metasynthesis adds additional insight into hope as described specifically by parents, including the relationship of parental hope to parents' survival and their own transformation, as they navigate through their very difficult dual reality.

Hope

Hope has been investigated and defined in previous research, although not always specific to parents. Current theories of hope emphasize the importance of and critical nature of hope, especially for those dealing with difficult life circumstances (Farran, Herth, & Popovich, 1995; Jevne, 2005; Snyder, 2000). A number of extant descriptions of hope have been offered. For example, Dufault and Martocchio (1985) defined hope as a "multidimensional, process-oriented, dynamic, life force characterized by a confident yet uncertain expectation of achieving a future good, which, to the hoping person is realistically possible and personally significant" (p. 380).

The present metasynthesis provides more clarity about parental hope specifically. Hope has been described as highly individualized (Samson et al., 2009), dynamic (Bally et al., 2014; Barrera et al., 2013; Klymä & Juvakka, 2007), and supporting an orientation towards life and the future (Bally et al., 2014; De Graves & Aranda, 2008); these are essential components of parental survival and caregiving and, ultimately, support the child's wellbeing. This metasynthesis also identified factors that make parents' hope easier to find and more tenacious, including focusing on positive experience and outcomes, positive social support, perceived well-being of their child, acquiring knowledge, and spirituality (Ångström-Brännström et al., 2010; Bally et al., 2014; Barrera et al., 2013; Klymä & Juvakka, 2007). Hope can also be tenuous or harder to find when the health of the child is deteriorating, parents perceive that they lack knowledge and resources, or they perceive social support to be negative or healthcare to be ineffective (Bally et al., 2014; Barrera et al., 2013; Klymä & Juvakka, 2007).

This information is essential for healthcare providers to effectively support parents. Furthermore, the findings from this metasynthesis highlight innovative and useful knowledge about parental hope in that it appeared to be transformational. Hope was used by parents to transform their illness experience through the subprocesses of *changing priorities, salvaging family relationships, and attaching new meanings*; this is a new finding with regard to parents who have children with LLIs and LTIs. The purposeful use of hope supported parents in *Moving Forward* by adjusting and adapting to uncertainty and their related feelings of fear, loss and grief, lack of control, and intense emotions.

Moving Forward

By experiencing illness and hope, many parental caregivers in this metasynthesis were supported in *Moving Forward*, making successful

adaptations, and adjusting to uncertainty. Although the integration of these processes and subprocesses are new to the existing literature regarding parental caregiving, there are similarities to post-traumatic growth in parents of children with complex medical challenges and other adult populations. Calhoun and Tedeschi (1998, 2004, 2006) developed a model of post-traumatic growth that occurs out of a highly stressful and challenging situation often involving suffering and loss. The challenging event(s) create the process of rumination about the individual's assumptive world, leading to positive growth. Experiences of post-traumatic growth have been reported among caregivers of children with life-limiting illness such as cancer (Cadell et al., 2014; Ogińska-Bulik & Ciechomska, 2016; Picoraro, Womer, Kazak, & Feudtner, 2014), in which parents experienced an enhanced appreciation of life, relations with others, personal strength, recognition of new possibilities in life, and spiritual or religious growth.

As noted, many of the papers included in this metasynthesis referred to the growth and change that occurred during parental caregiving for a child with an LLI or LTI involving an increased sense of compassion, intimate closeness, and a changed philosophy of life including priorities, appreciation, and spirituality (Calhoun & Tedeschi, 2006). As such, the process of *Moving Forward* includes aspects of post-traumatic growth as described by other researchers, although studies with this population have not labelled parents' experiences in this way. Post-traumatic growth is clearly possible for parents who undergo the complex and precarious illness experience related to their child's diagnosis and treatment for a LLI or LTI. However, the findings in this metasynthesis warrant additional research to better understand post-traumatic growth in this population of parental caregivers, and the potential relationships between growth and parental caregiving, uncertainty, and hope.

Strengths and Limitations

The strengths of this metasynthesis include collaboration with an experienced librarian who conducted a comprehensive search that was PEER reviewed, the use of DistillerSR to support a systematic review of sources with respect to inclusion criteria and a thorough audit trail, the inclusion of the highest order of qualitative research (conceptual/thematic descriptive and interpretive description studies), and a quality appraisal conducted by three researchers. The integrated findings from 23 studies provide new knowledge that is useful, accessible, and can inform future healthcare practice and research.

In terms of limitations, the context within which this metasynthesis was carried out was specific to parents of children with LLIs and LTIs, and therefore, may not be transferable to other populations. Also, the majority of the studies included in this metasynthesis focused on childhood cancer ($n = 14$), maternal ($n = 20$), and North American ($n = 13$) samples, so the findings may not be transferable to populations and settings that differ. Similarly, the findings were synthesized from existing qualitative studies and, as such, the interpretive nature of qualitative research may be continued, and thus transferred, to the results of this metasynthesis. Focusing on those studies that were written in English and were interpretive in nature may have excluded some studies that would have allowed additional examination of parental experiences, such as quantitative studies or those from cultures other than those included.

Implications for Research and Practice

The implications for future research directly relate to the limitations of this metasynthesis, as well as the studies included herein. A review of literature associated with children and families who are predominantly from cultures other than a Caucasian, North American culture and who are bereaved would foster a broader perspective of parental experiences. Father and sibling experiences are largely missing in the literature, and therefore, future research may focus on these family

members to develop an appropriate literature base from which to plan holistic care. Future research that uses the conceptual foundation derived in this metasynthesis, specifically the three processes (the *Devastation of Living with Uncertainty*, the *Emergence of Hope*, and *Moving Forward*) may facilitate the development of novel interventional and supportive methods to effectively care for parents who are caregivers of a child diagnosed with a LLI or LTI.

Clearly understanding the transitions that parents go through when caring for a child with a LLI or LTI, as well as the critical nature of parental hope, is crucial for developing holistic and comprehensive family care. For example, the role of uncertainty cannot be overlooked, particularly its persistent nature. In fact, parents endure what most would consider to be the impossible: a relentless journey through uncertainty in which thoughts of their child's death are a daily challenge. Understanding this in terms of the three related processes discussed herein would support timely and appropriate nursing assessment and care. Effective nursing assessments should include consistent, ongoing consideration of uncertainty, hope, and strengths as important aspects of parents' overall coping and well-being. Similarly, because hope is critical but dynamic, supporting parental hope and attempting to find ways to mitigate those factors that make hope difficult for parents are crucial endeavors. For example, supporting effective social connectedness, spirituality, the delivery of frank communication using a collaborative team approach, keeping parents in the loop with adequate information, and helping parents to focus on both the negative and the positives in their experiences are all effective ways to support parental hope. An organizational binder or online applications to track lab or test results, self-administered reflective writing, mindfulness activities, and supporting parents in finding time to care for themselves are examples of effective ways in which parents may be supported. Additionally, it is important for pediatric nurses to facilitate connections with other parents caring for a child with a LLI or LTI to encourage support systems outside of the family. Although these aspects of care may seem commonplace or logical, parents have demonstrated the precarious balance that is very dependent on the place in which they find themselves on the pervasive and inevitable roller coaster.

Conclusion

The authors of this review synthesized the work contained in 23 qualitative studies that examined parents' experiences when caring for a child with a LLI or LTI. The objective was to gain a more comprehensive understanding of their experiences by synthesizing the findings of the literature and drawing conclusions that could not be attained by reviewing single studies (Sandelowski & Barroso, 2006). Parents' experiences are underscored by the *Devastation of Living with Uncertainty* and are very complex, yielding persistent feelings of fear, loss and grief, anxiety, loss of control, isolation, and many other intense emotions. Out of this traumatic illness experience emerged hope, which acted as an important source of survival and was transformative. Parents found strength in hope, and it supported them in facing the daily challenge of their dual reality in which they fought for their child's survival while also preparing for possible death. *The Emergence of Hope* appeared to support the important process of *Moving Forward*. The complexities of this experience, as well as the critical importance of hope for parents, necessitate the need for healthcare providers to develop a deeper understanding of the parental illness experience. With such knowledge, healthcare providers can better assess parents' experiences and support them by creating supportive environments and considering those factors that make hope easier, such as social support, spirituality, positivity, and focusing on positive aspects of their child's health. Future research can add to the literature base by focusing on fathers' experiences, sibling perspectives, the role of hope, and the connections between hope and other aspects of the parental experience, such as uncertainty, fear, and post-traumatic growth.

Conflicts of Interest

None.

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