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ANA CAROLINA ANDRADE BIAGGI LEITE

Esperança nas famílias de crianças e adolescentes que convivem com doenças crônicas

RIBEIRÃO PRETO

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Tese apresentada ao Programa Interunidades de Doutoramento em Enfermagem da Escola de Enfermagem da Universidade de São Paulo e da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo para obtenção do título de Doutor em Ciências.

Linha de Pesquisa: Fundamentos Teóricos e Filosóficos do Cuidar

Orientadora: Profa. Dra. Lucila Castanheira Nascimento

Coorientadora: Profa. Dra. Cristina García-Vivar

RIBEIRÃO PRETO

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DEDICATÓRIA

Dedico esta tese aos amores da minha vida:
Ao meu pai ***Efraim****, à minha mãe* ***Janete****, à minha irmã* ***Gabriela*** *e ao meu "Kochanie"* ***Albert****. Agradeço por sonharem meus sonhos. Eles se realizaram somente porque vocês me amam e me apoiam incondicionalmente. Vocês são meu propósito de vida, e esse título também será de vocês. Amo vocês!*

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Não há esperança na pura espera,
nem tampouco se alcança o que se
espera na espera pura, que vira,
assim, espera vã [...]
A esperança não é um cruzar de
braços e esperar. Movo-me na
esperança enquanto luto e, se luto
com esperança, espero.

Paulo Freire

RESUMO

LEITE, A.C.A.B. **Esperança nas famílias de crianças e adolescentes que convivem com doenças crônicas.** 2021. 173 f. Tese (Doutorado) – Escola de Enfermagem de Ribeirão Preto, Universidade de São Paulo, Ribeirão Preto, 2021.

O objetivo geral desta pesquisa é analisar a esperança de famílias de crianças e adolescentes que convivem com doenças crônicas. Para alcançá-lo, foram elaborados três artigos, norteados pelas seguintes questões de pesquisa: Quais são as evidências qualitativas presentes na literatura sobre as experiências relacionadas à esperança das famílias de crianças e adolescentes que convivem com doenças crônicas?; Como coletar dados sobre esperança, de forma interativa, de famílias de crianças e adolescentes com doenças crônicas?; Quais são as narrativas de famílias, no contexto da doença crônica pediátrica, sobre suas experiências de esperança? O primeiro artigo é uma síntese temática, que objetivou sintetizar e interpretar estudos qualitativos que apresentem a experiência do recurso da esperança pelas famílias de crianças e adolescentes que convivem com doenças crônicas. Realizaram-se buscas sistemáticas em seis bases de dados, complementadas por buscas manuais. A amostra final de 31 estudos foi sintetizada no tema analítico "Esperança Familiar: mantendo o equilíbrio do dia a dia", composto por cinco temas descritivos: incerteza; apoio; informação; entre pensamentos "sombrios" e positivos; e esperança de retornar à normalidade. O segundo estudo, metodológico, objetivou refletir e discutir considerações metodológicas e pragmáticas sobre a utilização de entrevistas com foto-elicitação para coleta de dados com famílias de crianças e adolescentes que convivem com doença crônica. Aspectos metodológicos do uso destas entrevistas foram discutidos de acordo com evidências identificadas na literatura, complementadas com considerações pragmáticas e ilustradas com a experiência das autoras. Denominamos nosso método de "entrevista familiar com foto-elicitação", reconhecendo que ele vai além da técnica de entrevistas com foto-elicitação, pois integra aspectos das teorias de enfermagem familiar ao conduzir entrevistas com famílias, além de fortalecer a interação familiar e permitir que seus membros compartilhem suas perspectivas. Por fim, desenvolvemos um estudo qualitativo narrativo para analisar narrativas sobre a experiência de esperança de famílias no contexto da doença crônica pediátrica. Tal estudo adotou a teoria de sistemas familiares aplicada à enfermagem como referencial teórico e utilizou como método de coleta de dados entrevistas familiares com foto-elicitação com três famílias de crianças e adolescentes com diagnóstico de doença crônica complexa. As narrativas foram construídas e analisadas segundo análise temática indutiva, e os dados sintetizados no tema analítico "Ondas de esperança familiar no contexto das doenças crônicas pediátricas". Este tema é composto por quatro tipos de esperança: esperança incerta, esperança cuidativa, esperança latente e esperança expectante. O movimento suscitado por essas esperanças gera uma energia motriz e depende de uma série de fatores, tais como apoio, informação, busca pela normalidade e pensamentos e comparações. Os resultados dos estudos apresentados nesta tese destacam a esperança como um recurso familiar, e não apenas como um recurso individual utilizado para lidar com as demandas da doença crônica. Isso se deve à conectividade entre os membros da família e à capacidade que possuem de influenciar a esperança uns dos outros. A esperança também é considerada um recurso dinâmico, por meio do qual as famílias buscam encontrar o equilíbrio diariamente.

Palavras-chave: Criança. Adolescente. Família. Esperança. Doença Crônica. Revisão. Pesquisa Metodológica em Enfermagem. Fotografia. Pesquisa Qualitativa. Enfermagem Pediátrica. Enfermagem Familiar.

ABSTRACT

LEITE, A.C.A.B. **Hope of families of children and adolescents living with chronic illness.** 2021. 173 p. Doctoral Dissertation, University of São Paulo at Ribeirão Preto College of Nursing, Ribeirão Preto, 2021.

The general objective of this research is to analyze the hope of families of children and adolescents living with chronic illness. To achieve this, three articles were elaborated, guided by the following research questions: What are the qualitative evidences in the literature on experiences related to the hope of families of children and adolescents living with chronic diseases?; How to collect data about hope, in an interactive way, from families of children and adolescents with chronic illnesses?; What are the narratives of families, in the context of pediatric chronic illness, in regard to their experiences of hope? The first article is a thematic synthesis, which aimed to synthesize and interpret qualitative studies that present the experience of the resource of hope by families of children and adolescents living with chronic diseases. Systematic searches were developed in six databases, complemented by manual searches. The final sample of 31 studies was synthesized in the analytical theme “Family hope: keeping a day-to-day balance”, consisting of five descriptive themes: uncertainty; support; information; between “dark thoughts” and positive thoughts; and hoping to go back to normality. The second study, being methodological, aimed to reflect and discuss methodological and pragmatic considerations about the use of interviews with photo-elicitation to collect data from families of children and adolescents living with a chronic illness. Methodological aspects of the use of these interviews were discussed according to evidence identified in the literature, complemented with pragmatic considerations and illustrated with the authors' experience. We denominated our method as the “family photo-elicitation interview”, recognizing that it goes beyond the technique of photo-elicitation interviews, as it integrates aspects of family nursing theories when conducting interviews with families, in addition to strengthening family interaction and allowing its members to share their perspectives. Finally, we developed a qualitative narrative study to analyze narratives about the experience of hope of families in the context of pediatric chronic illness. This study adopted the theory of family systems applied to nursing as a theoretical framework and used as a method of data collection family interviews with photo-elicitation with three families of children and adolescents diagnosed with a complex chronic illness. The narratives were constructed and analyzed according to inductive thematic analysis, and the data were synthesized in the analytical theme “Waves of Family Hope in the Context of Pediatric Chronic Illness”. This theme is composed of four types of hope: uncertain hope, caring hope, latent hope, and expectant hope. Movement through these types of hope generates a driving energy and depends on a number of factors: support, information, searching for normality, and thoughts and comparisons. The results of the studies presented in this thesis highlight hope as a family resource, and not just as an individual resource used to deal with the demands of chronic disease. This is due to the connectivity between family members and their ability to influence each other's hopes. Hope is also considered a dynamic resource through which families seek to find a day-to-day balance.

Key words: Child. Adolescent. Family. Hope. Chronic Disease. Review. Nursing Methodology Research. Photograph. Qualitative Research. Pediatric Nursing. Family Nursing.

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RESUMEN

LEITE, A.C.A.B. **Esperanza en las familias de niños y adolescentes que conviven con enfermedades crónicas.** 2021. 173 h. Tesis (Doctorado) – Escuela de Enfermería de Ribeirão Preto, Universidad de São Paulo, Ribeirão Preto, 2021.

El objetivo general de esta investigación es analizar la esperanza de las familias de niños y adolescentes que conviven con enfermedades crónicas. Para lograrlo, se elaboraron tres artículos, guiados por las siguientes preguntas de investigación: ¿Cuáles son las evidencias cualitativas en la literatura sobre experiencias relacionadas con la esperanza de las familias de niños y adolescentes que conviven con enfermedades crónicas?; ¿Cómo recopilar datos sobre la esperanza, de forma interactiva, de familias de niños y adolescentes con enfermedades crónicas?; ¿Cuáles son las narrativas de las familias, en el contexto de la enfermedad crónica pediátrica, sobre sus experiencias de esperanza? El primer artículo es una síntesis temática, que tuvo como objetivo sintetizar e interpretar estudios cualitativos que presentan la experiencia del recurso de la esperanza de familias de niños y adolescentes que conviven con enfermedades crónicas. Se realizaron búsquedas sistemáticas en seis bases de datos, complementadas con búsquedas manuales. La muestra final de 31 estudios se sintetizó en el tema analítico "Esperanza familiar: mantener el equilibrio diario", que consta de cinco temas descriptivos: incertidumbre; apoyo; información; entre pensamientos "oscuros" y positivos; y esperanza de volver a la normalidad. El segundo estudio, metodológico, tuvo como objetivo reflexionar y discutir consideraciones metodológicas y pragmáticas sobre el uso de entrevistas con foto-elicitación para recoger datos con familias de niños y adolescentes que conviven con una enfermedad crónica. Los aspectos metodológicos del uso de estas entrevistas fueron discutidos de acuerdo con la evidencia identificada en la literatura, complementados con consideraciones pragmáticas e ilustrados con la experiencia de las autoras. Nombramos a nuestro método "entrevista familiar con foto-elicitación", reconociendo que va más allá de la técnica de la foto-elicitación de entrevistas, ya que integra aspectos de las teorías de enfermería familiar al realizar entrevistas con familias, además de fortalecer la interacción familiar y permitir a sus miembros compartir sus perspectivas. Finalmente, desarrollamos un estudio narrativo cualitativo para analizar narrativas sobre la experiencia de esperanza de las familias en el contexto de la enfermedad crónica pediátrica. Este estudio adoptó la teoría de los sistemas familiares aplicada a la enfermería como marco teórico y utilizó como método de recolección de datos entrevistas familiares con foto-elicitación a tres familias de niños y adolescentes diagnosticados con una enfermedad crónica compleja. Las narrativas se construyeron y analizaron según análisis temático inductivo, y los datos se sintetizaron en el tema analítico "Olas de esperanza familiar en el contexto de la enfermedad crónica pediátrica". Este tema se compone de cuatro tipos de esperanza: esperanza incierta, esperanza cuidadora, esperanza latente y esperanza expectante. El movimiento a través de estas esperanzas genera una fuerza motriz y dependiente de varios factores: apoyo, información, búsqueda de la normalidad, pensamientos y comparaciones. Los resultados de los estudios presentados en esta tesis destacan la esperanza como un recurso familiar, y no solo como un recurso individual utilizado para hacer frente a las demandas de la enfermedad crónica. Esto se debe a la conectividad entre los miembros de la familia y su capacidad para influir en las esperanzas de los demás. La esperanza también se ve como un recurso dinámico a través del cual las familias buscan el equilibrio diario.

Palabras-clave: Niño. Adolescente. Familia. Esperanza. Enfermedad Crónica. Revisión. Investigación Metodológica en Enfermería. Fotografía. Investigación Cualitativa. Enfermería Pediátrica. Enfermería de la Familia.

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LISTA DE SIGLAS

APA – *American Psychological Association*
CAPES - Coordenação de Aperfeiçoamento de Pessoal de Nível Superior
CASP - *Critical Appraisal Skills Programme*
CEP – Comitê de Ética em Pesquisa com Seres Humanos
CINAHL - *Cumulative Index to Nursing and Allied Health Literature*
CNPq - Conselho Nacional de Desenvolvimento Científico e Tecnológico
COREQ - *Consolidated criteria for reporting qualitative research*
EE – Escola de Enfermagem
EERP – Escola de Enfermagem de Ribeirão Preto
ENTREQ - *Enhancing transparency in reporting the synthesis of qualitative research*
FPEI - *Family photo-elicitation interviews*
LILACS - Literatura Latino-Americana e do Caribe em Ciências da Saúde
OMS – Organização Mundial de Saúde
PEI – *Photo-elicitation interviews*
PRISMA - *Preferred Reporting Items for Systematic Reviews and Meta-Analyses*
PROSPERO - *International prospective register of systematic reviews*
SUS – Sistema Único de Saúde
TA – Termo de Assentimento
TCLE – Termo de Consentimento Livre e Esclarecido
UNAV – *Universidad de Navarra*
UPNA – *Universidad Pública de Navarra*
USP - Universidade de São Paulo

SUMÁRIO

APRESENTAÇÃO

Sou enfermeira, bacharel em enfermagem pela Escola de Enfermagem de Ribeirão Preto (EERP) da Universidade de São Paulo (USP) desde 2015. Ingressei na EERP-USP em 2011 para cursar Bacharelado em Enfermagem. No ano seguinte, fui aprovada como bolsista do Programa Aprender com Cultura e Extensão da USP para o período de 2012 a 2013, para desenvolver o projeto intitulado "Integrando os familiares e acompanhantes em enfermaria de pediatria: uma proposta de ação". Na época, o projeto era supervisionado pela Prof.ª Dr.ª Lucila Castanheira Nascimento, minha orientadora desde 2012, e participar das atividades possibilitou meu primeiro contato com a minha área de interesse, a pediatria. Foi quando pude me aproximar das famílias, do ambiente hospitalar, e comecei a desenvolver minhas habilidades como futura enfermeira de família, identificando a importância da família no cuidado. Com a minha participação no projeto de extensão, tive a oportunidade de inserção no grupo de pesquisa em Enfermagem no Cuidado à Criança e ao Adolescente (GPECCA), cadastrado no Diretório do Grupos de Pesquisas do CNPq. Destaco que até hoje sou membro deste grupo e utilizo este espaço para constantemente compartilhar e apreender sobre pesquisas na área pediátrica.

Ao término da minha bolsa de cultura e extensão, fui aluna voluntária de iniciação científica (IC), novamente sob supervisão da Prof.ª Dr.ª Lucila Castanheira Nascimento, cuja pesquisa foi desenvolvida entre os anos de 2013 e 2015. Na IC, desenvolvi uma revisão integrativa e validação de um instrumento sobre a necessidade de pais de crianças hospitalizadas, o que originou meu trabalho de conclusão de curso. Neste projeto, trabalhei com alunos de mestrado e de graduação e comecei a me interessar pela pós-graduação.

Concomitantemente à iniciação científica, fui comtemplada pela USP com uma bolsa de intercâmbio devido ao meu mérito acadêmico. Realizei intercâmbio na *Universitat de Rovira i Virgili, Tarragona*, Espanha, entre setembro de 2013 e fevereiro de 2014. O intercâmbio proporcionou que cursasse disciplinas da graduação no exterior (inclusive na área pediátrica), conhecesse como a enfermagem se insere em outro contexto e cultura, além do desenvolvimento das habilidades com a língua espanhola e realização de visita técnica no Hospital Universitário de Joan XXIII.

Ao retornar ao Brasil, fui contemplada com uma bolsa de iniciação científica do CNPq (2014-2015), no projeto intitulado "Fadiga em crianças e adolescentes com câncer". Mantive-me envolvida em duas iniciações científicas, uma como voluntária e outra como bolsista, no grupo de pesquisa da Prof.ª Dr.ª Lucila Castanheira Nascimento.

No último ano da Graduação, 2015, fui contemplada com bolsa do Santander, para realizar um curso de curta duração de língua e cultura espanhola na *Universidad de Salamanca* (USAL), Salamanca, Espanha, durante as férias acadêmicas do mês de julho. Este curso me auxiliou no aprimoramento no idioma espanhol. Neste mesmo ano, realizei o estágio supervisionado na pediatria. No estágio, tive diversas oportunidades de aprendizado, e em uma delas presenciei a morte de uma criança que tinha câncer. Decidi que gostaria de estudar aspectos positivos da experiência da doença, e os recursos utilizados pela família para enfrentar essas experiências. Foi quando surgiu o interesse por estudar o recurso da esperança.

Finalizei a graduação em 2015, e recebi o prêmio *Prof.ª Emília Luigia Sparoti Angerami*, como a aluna que mais se distinguiu nas disciplinas de Enfermagem Hospitalar da turma de 2015 da EERP-USP e Fundação de Apoio ao Ensino, Pesquisa e Assistência do Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto da Universidade de São Paulo (FAEPA-HCFMRP).

Devido às habilidades desenvolvidas durante a graduação, minha orientadora e eu decidimos que eu poderia me inserir na pós-graduação, por meio do curso de doutorado direto. No ano de 2016, continuei envolvida com as atividades acadêmicas na EERP, cursando disciplinas na pós-graduação como aluna especial, e participando do grupo de pesquisa para aprimorar meu projeto e prestar o processo seletivo para o doutorado direto. Em outubro de 2016, fui aprovada no processo seletivo do doutorado direto no Programa de Pós-Graduação Interunidades de Doutoramento em EE e EERP, como bolsista da CAPES, modalidade dedicação exclusiva, sob orientação da Prof.ª Dr.ª Lucila Castanheira Nascimento. Durante o curso de doutorado, realizei um estágio no exterior, modalidade sanduíche, com fomento PDSE-CAPES que durou 6 meses (novembro de 2018 – abril de 2019). O estágio foi realizado na Facultad de Enfermería da Universidad de Navarra, Espanha, sob supervisão da minha coorientadora Prof.ª Dr.ª Cristina García-Vivar.

Destaco que durante o desenvolvimento do doutorado tive diversas oportunidades de crescimento e aprendizagem. Além das citadas anteriormente, sublinho a participação em eventos científicos; apresentação de pesquisas em eventos científicos nacionais e internacionais, auxílio na coorientação de alunos de graduação e mestrado; auxílio na coordenação de projetos de pesquisa; participação no programa de aperfeiçoamento de ensino (PAE); construção de relatórios técnicos; apresentação de aulas, cursos e oficinas; participação em bancas de trabalho de conclusão de curso, revisão de manuscrito para periódicos; avaliação de pôsteres e estudos em eventos científicos, dentre outras. Em relação aos eventos científicos, os artigos contidos nesta tese foram apresentados em congressos nacionais e internacionais. Em 2021, o trabalho intitulado *Narrativas de famílias sobre as “ondas de esperança familiar” no contexto das doenças crônicas pediátricas*, que corresponde ao terceiro artigo apresentado nesta tese, recebeu menção honrosa na categoria de pesquisa do IX Congresso Brasileiro de Enfermagem Pediátrica e Neonatal.

Ademais, publiquei mais de 25 artigos durante o curso de doutorado, em revistas nacionais e internacionais com seletiva política editorial e de alto impacto. Essas publicações foram realizadas com a colaboração de alunos de graduação, mestrado e doutorado, pesquisadores brasileiros da USP e de outras instituições, e pesquisadores internacionais (espanhóis, canadenses, estadunidenses, portugueses e alemães). Também foram publicados cinco capítulos de livros, dos quais dois sou primeira autora e estão relacionados com temática da minha tese (LEITE et al., 2020a; LEITE et al., 2019a)

Diante do exposto, considero que estou apta para defender esta tese, visto que tive oportunidades para desenvolver as habilidades e competências necessárias durante o doutorado. Neste exemplar, apresento os três artigos desenvolvidos que compõem a minha tese, que está inserida nas áreas da enfermagem pediátrica e da enfermagem familiar.

1 INTRODUÇÃO

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1.1 Doenças crônicas pediátricas

O estatuto da criança e do adolescente, lei brasileira de 1990, define que crianças são pessoas até 12 anos, e adolescentes pessoas até 18 anos de idade (BRASIL, 1990). Consequentemente, é na infância, principalmente nos primeiros 5 anos, que ocorre o processo maturacional, visto que as crianças apresentam uma extensa janela de desenvolvimento para adquirir habilidades perceptivas, motoras, cognitivas, de linguagem, socioemocionais e de autorregulação (BLACK et al., 2017; BRITTO et al., 2017). O processo das crianças e adolescentes para alcançar o desenvolvimento potencial na fase adulta é influenciado por seu contexto social, econômico, político, climático e cultural (BLACK et al., 2017; BRASIL, 2018). A promoção deste desenvolvimento depende, portanto, do recebimento de proteção dos pais, família e comunidade, o que resultará em saúde, bem-estar e capacidade de aprendizado (BRITTO et al., 2017).

Ainda assim, apesar dessa proteção, o processo desenvolvimental das crianças e adolescentes também pode ser impactado pelo adoecimento. As mudanças sociais e culturais, e os avanços tecnológicos e no conhecimento científico, foram responsáveis pela transição epidemiológica da morbimortalidade infantil, levando a uma diminuição das taxas de mortalidade infantil, no Brasil e no mundo (BRASIL, 2018). Especificamente no Brasil, isso se deve também à implementação do Sistema Único de Saúde (SUS) e das políticas nacionais de saúde (BRASIL, 2018). No entanto, novos desafios contemporâneos necessitam ser enfrentados no que se refere à saúde (BRASIL, 2018), como o cuidado das crianças e adolescentes com condições crônicas complexas de saúde.

As condições crônicas complexas de saúde são o desafio do cuidado em saúde, uma vez que têm aumentado devido ao decréscimo das doenças transmissíveis e/ou agudas, à diminuição da mortalidade infantil, ao avanço da tecnologia e do conhecimento científico e ao envelhecimento da população (MOREIRA et al., 2017; ORGANIZAÇÃO MUNDIAL DA SAÚDE, 2003). São consideradas condições crônicas de saúde as doenças crônicas (como o câncer, a doença renal crônica e a fibrose cística), as doenças infecciosas (como a tuberculose e a AIDS) e as diferentes deficiências. Essa classificação foi determinada pela similaridade entre essas condições: cuidado contínuo, necessidade de controle e alteração das atividades diárias (MOREIRA et al., 2017; MOREIRA; GOMES; SÁ, 2014; ORGANIZAÇÃO MUNDIAL DA SAÚDE, 2003).

Doenças crônicas pediátricas complexas são limitantes da vida e mantêm-se presentes para além de 6 ou 12 meses, com períodos de agudizações que podem gerar a necessidade de hospitalizações. São complexas, pois afetam múltiplos sistemas do corpo, têm uma trajetória dinâmica e acrescentam complexidade para os cuidados da vida diária (AZAR et al., 2020; MOREIRA; GOMES; SÁ, 2014). Além disso, requerem o cuidado de diversos especialistas da equipe multidisciplinar, podendo ser dependentes de dispositivos médicos e/ou medicamentos (AZAR et al., 2020; LEITE et al., 2019b; WIJLAARS; GILBERT; HARDELID, 2016). Geralmente não possuem cura, e são resistentes ao tratamento (AZAR et al., 2020; MOKKINK et al., 2008; VAN DER LEE et al., 2007). Embora os cânceres infantojuvenis possam apresentar cura após o tratamento oncológico, esses tratamentos geram efeitos tardios nas crianças e adolescentes sobreviventes de câncer, que passam a necessitar de cuidados similares àqueles prestados às pessoas com outras doenças crônicas, que até o momento não possuem cura (LEITE et al., 2019b; NERIS; NASCIMENTO, 2021).

Em 2016, pesquisadores evidenciaram que o número de famílias que convivem com doenças crônicas infantojuvenis aumentou quatro vezes desde a década de 60 (LEEMAN et al., 2016). A asma e a obesidade foram as mais prevalentes nesse período (LEEMAN et al., 2016). Porém, no Brasil e no mundo, os cânceres foram responsáveis pela primeira causa de morte por doença nessa população (BRASIL, 2019; CUNNINGHAM; WALTON; CARTER, 2018):

- **Cânceres infantojuvenis**: ocorrem na população entre zero e 19 anos, quando células anormais se proliferam de forma descontrolada em algum local do organismo. Os cânceres que mais acometem essa faixa etária são as leucemias (28%), os tumores cerebrais e outros tumores de sistema nervoso central (26%) e os linfomas de Hodgkin e não-Hodgkin (8%). Outros tipos de cânceres diagnosticados nessa população são: neuroblastomas, tumores de Wilms, rabdomiossarcoma, retinoblastomas, osteosarcomas, sarcomas de Ewing, tumores gonadais e extragonadais de células germinativas (AMERICAN CANCER SOCIETY, 2021; BRASIL, 2019). Com o avanço da tecnologia e com o diagnóstico precoce, 80% dos casos alcançam a cura (BRASIL, 2019). No entanto, a incidência mundial frequentemente aumenta. Em 2021 serão diagnosticados 10.500 casos em crianças e 5090 casos em adolescentes, e se espera um total de 1780 mortes (AMERICAN CANCER SOCIETY, 2021). No Brasil, entre 2020 e 2022, são estimados 4310 novos casos em meninos, e 4150 em meninas. Assim como tem sido constatado mundialmente, no Brasil essa é a primeira causa de morte por doença, e a segunda por causas gerais, ficando atrás somente dos acidentes (BRASIL, 2019).

Outras doenças crônicas, apesar de não serem as mais prevalentes ou apresentarem altas taxas de mortalidade na população infantojuvenil, precisam ser destacadas, pois requerem cuidados complexos e especializados em função das demandas que geram, como a fibrose cística e a doença renal crônica (COMPAS et al., 2012; LEEMAN et al., 2016; VAN DER LEE et al., 2007):

- **Fibrose cística:** é uma doença complexa e progressiva, de herança autossômica recessiva. Acomete múltiplos sistemas, como o respiratório, o digestório, o hepático e o geniturinário (GRUPO BRASILEIRO DE ESTUDOS DE FIBROSE CÍSTICA, 2018; ROYAL BROMPTON HOSPITAL PAEDIATRIC CYSTIC FIBROSIS TEAM, 2020). Sua potencial letalidade gera uma expectativa de vida com média de 45 anos em países desenvolvidos (ROYAL BROMPTON HOSPITAL PAEDIATRIC CYSTIC FIBROSIS TEAM, 2020). Apesar de a morte por fibrose cística ser considerada rara na infância, no Brasil, a média de vida é de 21,6 anos. O último relatório brasileiro sobre a doença evidenciou que 73,56% dos casos (n=2367) no país se referem a menores de 18 anos, e um, a cada 3500 caucasianos nascidos vivos, é diagnosticado com fibrose cística (GRUPO BRASILEIRO DE ESTUDOS DE FIBROSE CÍSTICA, 2018). Apesar da incidência da doença ser rara, o tratamento por ela demandado é complexo e de alto custo, exigindo um tratamento diário, composto por dietas especiais, fisioterapia respiratória, suplementação de vitaminas, antibióticos orais e inalados (GRUPO BRASILEIRO DE ESTUDOS DE FIBROSE CÍSTICA, 2018; HIGHAM; AHMED; AHMED, 2013). No Brasil, ainda há uma dificuldade de encontrar centros especializados e preparados para oferecer atendimento qualificado para as famílias de crianças e adolescentes com fibrose cística (BRASIL, 2020; SANTOS LUZ; SILVA; DEMONTIGNY, 2016).
- **Doença renal crônica:** a doença renal é caracterizada pela perda da função renal, que passa a ser crônica quando esse processo perdura por mais de três meses. A doença renal crônica é classificada em estágios de I a V, que variam conforme a severidade da perda da função renal, sendo que o estágio V representa a insuficiência renal (RUTKOWSKI, 2000). O diagnóstico precoce auxilia na prevenção da insuficiência renal e progressão para o estágio terminal (BARAKAT, 2012). Quando ocorre na infância, a doença renal crônica gera várias consequências, como alteração no crescimento e desenvolvimento, que exercem impacto a longo prazo na vida adulta (BECHERUCCI et al., 2016). A taxa de mortalidade para crianças

com doenças renal crônica é cerca de 30 a 150 vezes maior que em seus pares saudáveis (BECHERUCCI et al., 2016). A escassez de dados epidemiológicos sobre a doença permanece, principalmente na América Latina (LISE et al., 2017; SOARES et al., 2008). Os dados epidemiológicos disponíveis geralmente são subestimados, uma vez que a doença renal crônica pode ser clinicamente assintomática, especialmente em estágios iniciais (BECHERUCCI et al., 2016). Logo, as estimativas epidemiológicas consideram os pacientes com quadros clínicos moderados ou severos. Na Europa, a prevalência da doença na infância nos quadros graves foi estimada em 60 casos por milhão (BECHERUCCI et al., 2016). Nos Estados Unidos, em 2017, essa estimativa em pessoas entre zero e 21 anos chegou a 98,7 casos por milhão (UNITED STATES RENAL DATA SYSTEM, 2019). No Brasil, os dados são escassos, mas pesquisa realizada no estado de São Paulo estimou prevalência de 23,4 casos por milhão de crianças com doença crônica terminal (NOGUEIRA et al., 2011).

As doenças crônicas pediátricas geram um ônus econômico mundial, visto que requerem gerenciamento contínuo, que pode levar anos ou décadas. Sabe-se que a aderência ao tratamento das condições crônicas é baixa, o que gera impactos negativos para as sociedades, governos e famílias (MOREIRA et al., 2017; ORGANIZAÇÃO MUNDIAL DA SAÚDE, 2003). Além disso, não há país que esteja isento do impacto das doenças crônicas e que não precise adequar seus sistemas de saúde para atender as demandas das crianças, adolescentes e seus familiares (ORGANIZAÇÃO MUNDIAL DA SAÚDE, 2003; VAZ et al., 2019).

1.2 Famílias de crianças e adolescentes que convivem com doenças crônicas

A Organização Mundial da Saúde (OMS) definiu família como um grupo com relações de confiança estabelecidas, que apresentam suporte mútuo e com objetivos em comum (ORGANIZAÇÃO MUNDIAL DA SAÚDE, 1994). Eles não precisam estar unidos apenas por laços legais ou biológicos. Por ser uma entidade mutável, a estrutura familiar dependerá do contexto em que está inserida e das afinidades emocionais com pessoas significativas (WRIGHT; LEAHEY, 1990). De acordo com Wright e Leahey, no contexto do cuidado de enfermagem, deve-se considerar a opinião do paciente sobre sua família, pois ele dirá com quem convive e quais são os integrantes que considera parte de sua família (WRIGHT; LEAHEY, 1990, 2012, 2019).

Diante dessa perspectiva e considerando a família como uma unidade familiar, composta por subsistemas que são maiores que a soma das suas partes (WRIGHT; LEAHEY, 1990, 2012, 2019), sabe-se que receber o diagnóstico de uma doença crônica pediátrica complexa impacta todas as pessoas da família. Tal diagnóstico estabelece um marco na trajetória familiar e, consequentemente, os fazem sentir como se tivessem perdido o sonho familiar de experienciar uma vida com todos os membros saudáveis (HJELMSTEDT et al., 2021; MU et al., 2015; STEIN et al., 2019). Diante desse contexto caótico e de estresse, a família geralmente experiencia uma grande carga emocional, com medo, tristeza, angústia, ansiedade, incerteza devido ao diagnóstico, preocupações e perda de controle da rotina familiar (BALLY et al., 2014; BENEDETTI; HIGARASHI; SALES, 2015; LEWANDOWSKA, 2021; SILVA-RODRIGUES et al., 2020; TANNA et al., 2020; VAZ et al., 2018).

Os pais passam a se concentrar no cuidado do filho adoecido. Em famílias nucleares, geralmente a mãe assume o papel de cuidadora principal (SALVADOR et al., 2015; SILVA-RODRIGUES et al., 2016; VAZ et al., 2018), e o pai tende a buscar uma reformulação dos seus papéis tradicionais, para além de provedor e protetor, desenvolvendo habilidades que permitam o seu envolvimento neste cuidado (ESPER et al., 2021; POLITA et al., 2018; REIS et al., 2017). Ambos têm suas vidas profissionais afetadas, com a diminuição ou interrupção das tarefas laborais, o que interfere diretamente na renda familiar (HJELMSTEDT et al., 2021; (SALVADOR et al., 2015; VAZ et al., 2018). Ao mesmo tempo, os gastos aumentam em decorrência das novas necessidades relacionadas ao cuidado da criança ou adolescente com doença crônica. Por alguns pais, o trabalho também é visto como atividade que os distancia dos pensamentos do adoecimento do filho, sendo este um contexto de apoio e interação social (HJELMSTEDT et al., 2021). Portanto, em alguns casos, há pais que se envolvem mais no trabalho.

Independentemente da situação laboral dos pais, o fato de ter um filho com doença crônica é fator que abala a saúde física e mental (HJELMSTEDT et al., 2021; LEWANDOWSKA, 2021). Outro impacto é observado na relação conjugal, pois a mãe, na maioria dos casos, prioriza seu papel de mãe e cuidadora, e abandona o de esposa. Com os esforços voltados ao cuidado do filho, o relacionamento conjugal fica em segundo plano (SILVA-RODRIGUES et al., 2016). Apesar da complexidade dos cuidados que os pais precisam manejar, há um aumento no engajamento e cumplicidade para proporcionar o melhor cuidado ao filho (HJELMSTEDT et al., 2021; PINTO; MORRISON, 2021; POLITA et al., 2018). A perspectiva de prioridade muda, sendo a família e o bem-estar dos filhos o centro das preocupações (HJELMSTEDT et al., 2021). Os pais ficam mais preocupados e vigilantes (KINGOD; GRABOWSKI, 2020; LEITE et al., 2020b; VAZ et al., 2018).

As crianças e adolescentes com doenças crônicas percebem a superproteção dos pais, e sentem-se obrigados a assumir responsabilidades relacionadas ao tratamento e o autocuidado (LAMBERT; KEOGH, 2015). Além disso, vivenciam restrições pela doença e tratamento, e precisam alterar sua rotina diária no que se refere a aspectos como alimentação, exercícios físicos, uso de medicamentos, frequência escolar, idas a centros de saúde para consultas ambulatoriais ou hospitalizações (LAMBERT; KEOGH, 2015; LEITE et al., 2019b). Na adolescência, o habitual questionamento das mudanças identitárias, físicas, dos relacionamentos e do futuro fica exacerbado com a experiência da doença crônica (KIRK; HINTON, 2019). Outras demandas específicas da hospitalização também precisam ser enfrentadas, como o isolamento, a solidão, o incômodo físico dos procedimentos, a falta de privacidade e a interrupção da vida diária, inclusive da frequência escolar e interação social (LINDER; SEITZ, 2017). Diante disso, essas crianças e adolescentes sentem-se diferentes de seus pares saudáveis e, consequentemente, podem não aderir ao tratamento, em busca da falsa sensação de não necessitarem de cuidados de saúde específicos como seus pares saudáveis (LAMBERT; KEOGH, 2015).

Outro membro da família afetado pelo diagnóstico da doença crônica é o irmão saudável, que geralmente experiencia acessos de raiva, dificuldade de aprendizado e problemas de comportamento ao observar o funcionamento familiar afetado pela doença do irmão. Isso ocorre pela dificuldade que os pais sentem para reorganizar a vida familiar e equilibrar as necessidades de todos os membros (LEWANDOWSKA, 2021). Nesse contexto, a família enfrenta a necessidade de mudanças de papéis, e alguns irmãos saudáveis precisam aumentar sua maturidade e envolver-se no cuidado, para alcançar a harmonia do funcionamento familiar (LUMMER-AIKEY; GOLDSTEIN, 2020). Dentre os papéis que precisam desenvolver estão: de professores do irmão enfermo, de protetores, de ajudantes nas tarefas domiciliares e de vigilância do irmão enfermo, por exemplo auxiliando na monitorização de sinais e sintomas; alguns atuam até mesmo como "pais substitutos" (LUMMER-AIKEY; GOLDSTEIN, 2020).

Diante do exposto, a família busca se reorganizar para enfrentar as novas demandas de cuidado impostas pela doença crônica. Há uma busca por estratégias que os permitam alcançar uma harmonia e retomar os planos para o futuro (MU et al., 2015). Essa responsabilidade mútua de enfrentamento familiar faz com que busquem um recurso auxiliar, capaz de diminuir os efeitos negativos da doença em suas vidas e alterar a perspectiva, em busca do lado positivo desta experiência (BALLY et al., 2014; MU et al., 2015). Muitas vezes, o recurso disponível para as famílias é o da esperança.

1.3 O recurso da esperança

A esperança é inerente às experiências humanas (DOE, 2020). Pesquisadores a consideram um fenômeno complexo para ser estudado, sendo infactível determinar uma definição comum, passível de ser aplicada universalmente (DOE, 2020; GRIGGS; BAKER; CHIODO, 2019). Geralmente, o conceito da esperança destaca os pensamentos e sentimentos positivos de um indivíduo sobre o futuro, bem como sua capacidade de tornar seu futuro melhor (LOPEZ; SNYDER; PEDROTTI, 2003; MARQUES; LOPEZ, 2018). Na perspectiva antropológica, a esperança está relacionada com a cultura e as relações sociais dos indivíduos, principalmente com suas crenças sobre a vida e a morte (VAN DONGEN, 1998). Isso a torna um fenômeno difícil de ser estudado, uma vez que está associada a valores socialmente construídos e culturalmente determinados (SNYDER, 2002). Portanto, para explorar o fenômeno da esperança, pesquisadores e profissionais de saúde necessitam considerar o contexto dos estudos ou dos cuidados (HERRESTAD et al., 2014).

Quando analisada a etimologia da palavra esperança na língua portuguesa, identifica-se um substantivo feminino, que também pode ser apresentado no plural “esperanças”, definido como: 1) Ato de esperar aquilo que se deseja obter; 2) Expectativa na aquisição de um bem que se deseja; 3) Aquilo que se espera, desejando; 4) A segunda das três virtudes teologais, simbolizada por uma âncora ou pela cor verde (as outras duas são a fé e a caridade) (“Dicionário Michaelis On-line”, 2020). Portanto, por meio da definição etimológica, concluiu-se que a esperança está relacionada a um desejo.

No entanto, a palavra esperança também pode-se apresentar como verbo “esperançar”. Por sua definição, transforma-se de substantivo de desejo para ação: “Dar ou ter esperanças”. O termo estar de esperanças/andar de esperanças significa que a pessoa está no período de gestação (“Dicionário Michaelis On-line”, 2020). Com isso, identifica-se que a esperança é unicamente do indivíduo, ou pode ser transmitida dele para outros. Além disso, também pode ser adjetivo, com as palavras “esperançado”/“esperançoso”: “Que ou quem tem esperança” (“Dicionário Michaelis On-line”, 2020). Com os adjetivos, é possível descrever a esperança presente em algo ou em alguém.

Na literatura de saúde também existem definições para o termo esperança. O *Medical Subject Headings* (*MESH*), dicionário de vocabulário controlado de saúde, utilizado para indexar estudos na base de dados *PubMed*, apresentou, em 2014, uma breve definição de esperança: *"Belief in a positive outcome*" ("crença em um desfecho positivo") (MEDICAL SUBJECT HEADINGS, 2014). As traduções dessa definição, para a língua portuguesa, espanhola e francesa, estão disponíveis no Descritores em Ciências da Saúde (DeCS) (DESCRITORES EM CIÊNCIAS DA SAÚDE, 2014). Porém, diferentemente do MESH, no DeCS há um destaque para a esperança ser contextualizada como um processo mental, de motivação. Esse destaque de processo mental também está presente nos descritores controlados da base de dados *CINAHL (Cumulative Index to Nursing and Allied Health Literature)* (ASSUNTOS CINAHL, 2021), que reúne estudos específicos da área de enfermagem e correlatos. No que se refere à classificação internacional para a prática de enfermagem (CIPE®), a esperança é considerada uma emoção e é definida como o "sentimento de ter possibilidades, confiança nos outros e no futuro, entusiasmo pela vida, expressão de razões e vontade para viver, paz interior, otimismo, associado à definição de metas e mobilização de energia" (CIPE, 2017, p. 81).

Além da questão etimológica e da indexação na área da saúde da palavra esperança, a enfermagem possui um diagnóstico relacionado ao fenômeno da esperança. De acordo com as definições e classificações de 2018-2020 dos diagnósticos de enfermagem da NANDA-I, desde 2006 os enfermeiros podem diagnosticar os pacientes com "Disposição para esperança melhorada" (HERDMAN; KAMITSURU; EDITORAS, 2018). Segundo a definição, os pacientes que apresentam esse diagnóstico de enfermagem têm um "Padrão de expectativas e desejos para mobilizar energias em benefício próprio que pode ser melhorado". Os enfermeiros definem esse diagnóstico de acordo com as seguintes características: "expressão de desejo de aumentar a coerência entre expectativas e metas; expressão de desejo de aumentar a crença nas possibilidades; expressão de desejo de aumentar a esperança; expressão de desejo de aumentar a percepção de sentido da vida; expressão de desejo de melhorar a capacidade de estabelecer metas alcançáveis; expressão de desejo de melhorar a conexão com os outros; expressão de desejo de melhorar a espiritualidade; e expressão de desejo de melhorar a resolução de problemas para alcançar as metas" (HERDMAN; KAMITSURU; EDITORAS, 2018). Esse diagnóstico é classificado como de disposição, para a promoção da saúde, e possui somente características definidoras. A NANDA-I possui o diagnóstico de enfermagem de “desesperança”, considerado um diagnóstico de problema de saúde (HERDMAN; KAMITSURU; EDITORAS, 2018). O diagnóstico de “desesperança” é o que apresenta maior relação com o de “Disposição para esperança melhorada”.

Os enfermeiros podem realizar o diagnóstico de enfermagem de “desesperança” desde 1986. Segundo sua definição, trata-se de um “estado subjetivo no qual um indivíduo vê alternativas limitadas ou não vê alternativas ou escolhas pessoais disponíveis e é incapaz de mobilizar energias em benefício próprio” (HERDMAN; KAMITSURU; EDITORAS, 2018). Como características definidoras, tal diagnóstico apresenta: “alterações no padrão de sono; apetite reduzido; contato visual insuficiente; dar as costas a quem está falando; diminuição no afeto; encolher os ombros em resposta a quem está falando; envolvimento inadequado no cuidado; indicadores verbais de desânimo; iniciativa diminuída; passividade; resposta diminuída a estímulos e verbalização diminuída”. Esse diagnóstico de enfermagem está relacionado a fatores como estresse crônico; isolamento social; perda da crença em um poder espiritual; perda da fé em valores transcendentais; e restrição prolongada de atividade. Pacientes com história de abandono são considerados de risco; além disso, associa-se o diagnóstico a pessoas que apresentam deterioração da condição fisiológica (HERDMAN; KAMITSURU; EDITORAS, 2018).

Geralmente, os enfermeiros planejam que o paciente alcance o diagnóstico “disposição para esperança melhorada” após apresentar o diagnóstico de “desesperança”. Apesar da esperança e da desesperança serem fenômenos distintos, estão correlacionados, principalmente por abrangerem as expectativas orientadas para o futuro (HUEN et al., 2015). Porém, diferentemente da esperança, os indivíduos com desesperança não possuem objetivos específicos (HUEN et al., 2015). A desesperança é um recurso psicológico manifestado diante de um evento negativo. Algumas pessoas a manifestam como um estado, e outras como um traço. Os indivíduos que manifestam a desesperança possuem uma expectativa negativa sobre o futuro e um desamparo para alterá-lo, o que pode ocasionar comorbidades e aumentar a mortalidade (DUNN, 2005).

Portanto, em relação aos cuidados de enfermagem, para se alcançar um cuidado integral e holístico os enfermeiros devem considerar as necessidades psicobiológicas, psicossociais e psicoespirituais dos indivíduos (HORTA, 1974). A esperança está inserida nas necessidades psicoespirituais, as quais são atendidas quando o cuidado espiritual é prestado (PETERSEN, 2014). Diante dessa perspectiva, o conceito de espiritualidade considera o recurso da esperança.

Para crianças pequenas, sua espiritualidade está conectada com um ser transcendental e com pessoas significativas, através do amor, respeito, fé, esperança, compaixão e empatia (HLATSHWAYO; MUTHUKRISHNA; MARTIN, 2018). No contexto das doenças crônicas, foi identificado que as crianças e adolescentes necessitam encontrar seu propósito de vida para sustentar a esperança (ALVARENGA et al., 2021). Para as famílias dessa população, a espiritualidade é fonte de conforto e de esperança (LIMA et al., 2013), e facilita a atribuição do significado da transcendência e da esperança (NICHOLAS et al., 2017). A interseção desses conceitos se confunde, e algumas famílias de crianças e adolescentes com doenças crônicas consideram a esperança e a fé como sinônimos (SUPERDOCK et al., 2018).

Diversos estudos objetivaram conceituar o fenômeno da esperança. Pesquisadores de várias disciplinas estudaram este fenômeno e, em comum, sinalizaram dificuldades na compreensão da dinamicidade e das características da esperança (DOE, 2020). Na área da Enfermagem, DeFault e Martocchio publicaram, em 1985, um dos mais importantes estudos sobre esperança, no qual a conceituaram como: "Força vital dinâmica e multidimensional, caracterizada por uma expectativa confiante, porém incerta, de alcançar o bem futuro que, para a pessoa que espera, é realisticamente possível e pessoalmente significativa" (DUFAULT; MARTOCCHIO, 1985, p. 380).

Na área da psicologia, o psicólogo americano Snyder se destacou pelas diversas publicações com colaboradores na área da esperança (SNYDER; IRVING; ANDERSON, 1991; SNYDER, 1994, 1995, 2000, 2002; SNYDER et al., 1996, 1997). A teoria da esperança de Snyder (*Snyder's Hope Theory*) apresentou uma definição que foi a base de pesquisas na área da saúde por décadas (GALLAGHER; LOPEZ, 2018). Na época, a esperança foi por ele identificada como um conjunto de crenças ou pensamentos para obtenção de resultados positivos, afastando os indivíduos de perspectivas negativas. Portanto, em sua teoria, definiu a esperança como a capacidade cognitiva de um indivíduo identificar caminhos (*pathways*) para alcançar os seus objetivos desejados. A motivação para isso se dá através da agência de pensamentos que os auxiliam no planejamento para percorrer esses caminhos e atingir as metas (SNYDER, 2002). Por agência, entende-se a capacidade de alguém identificar caminhos que auxiliem no alcance dos objetivos desejados (SNYDER, 2002). O indivíduo que possui agência diante de um obstáculo segue tendo esperança, pois consegue encontrar outro caminho para seguir (SNYDER, 1994). Consequentemente, pessoas que têm mais esperança possuem a capacidade de identificar caminhos alternativos (SNYDER, 2002; SNYDER; RAND;

SIGMON, 2018). Indivíduos que têm menos esperança experienciam efeitos negativos quando não atingem seus objetivos (SNYDER, 2002). Diante dessa teoria, a esperança não é considerada uma emoção, mas um processo motivacional, capaz de gerar retornos secundários (SNYDER, 2002; SNYDER; RAND; SIGMON, 2018).

Para as crianças, o pensamento esperançoso diante de um objetivo é fundamental para sua sobrevivência e desenvolvimento (SNYDER, 2000; SNYDER; RAND; SIGMON, 2018). Para possuir um pensamento esperançoso, a pessoa deve ter a capacidade de prever os caminhos viáveis e a energia que deve empregar para alcançar um objetivo (SNYDER; IRVING; ANDERSON, 1991). Portanto, pensar nas alternativas disponíveis para o alcance de determinado objetivo é o primeiro componente da esperança que as crianças desenvolvem (MARQUES; LOPEZ, 2018). Elas experienciam a esperança por meio de caminhos específicos (GRIGGS; BAKER; CHIODO, 2019; SNYDER, 2002), que vão sendo refinados durante o desenvolvimento infantil (MARQUES; LOPEZ, 2018). Isso está relacionado ao ganho de vocabulário e ao desenvolvimento da memória e abstração de ideias (MARQUES; LOPEZ, 2018). Contudo, não é possível desassociar o desenvolvimento da esperança do contexto social (MARQUES; LOPEZ, 2018; SNYDER, 2002), que é a base da construção do pensamento contingencial, ou seja, o pensamento sobre as possibilidade que podem ou não ocorrer (SNYDER, 1994).

Conjuntamente com os estudos sobre a teoria da esperança, Synder e colaboradores desenvolveram escalas para mensurar este fenômeno. A *Trait Hope Scale* (SNYDER; IRVING; ANDERSON, 1991) mensura a característica da esperança em adultos; a *State Hope Scale* (SNYDER et al., 1996) mensura a esperança do momento em adultos, ou seja, fornece um panorama atual da esperança dos indivíduos estudados; e a *Children Hope Scale* (SNYDER et al., 1997) mensura a esperança de crianças e adolescentes de 8 a 16 anos. As escalas de esperança foram validadas para diversos contextos, incluindo o Brasil, e são amplamente utilizadas. No entanto, o fenômeno da esperança é complexo, e muitas vezes não é possível realizar estudos quantitativos com diferentes populações. Ademais, as escalas apresentam fraca confiabilidade ou validade (DOE, 2020).

Na área da enfermagem, desde a década de 80, a enfermeira americana Dra. Herth, em conjunto com colaboradores, desenvolveu renomados estudos sobre esperança. Ela é pioneira em pesquisas de esperança com pacientes com doenças crônica, na área de enfermagem familiar (CUTCLIFFE; HERTH, 2002a, 2002b, 2002c; HERTH, 1989, 2001, 1990, 1991, 1992, 1993,

1995, 1998, 2000; HERTH; CUTCLIFFE, 2002a, 2002b, 2002c; REVIER; MEIERS; HERTH, 2012; VANDECREEK; NYE; HERTH, 1994). No início do século 21, Dr. Herth e colaboradores escreveram uma série de estudos, nos quais destacaram a importância de considerar o recurso da esperança no cuidado de enfermagem. Além disso, foram ressaltadas as lacunas de conhecimentos existentes na temática, principalmente na área de saúde mental, cuidado paliativo, cuidados de final de vida, gerontologia e cuidado crítico. A série de estudos concluiu que tal fenômeno deveria continuar a ser explorado pelos pesquisadores, principalmente para que as evidências encontradas pudessem embasar os currículos dos cursos de enfermagem e as políticas públicas de saúde (CUTCLIFFE; HERTH, 2002a, 2002b, 2002c; HERTH; CUTCLIFFE, 2002a, 2002b, 2002c).

Outra contribuição do grupo de pesquisa da Dra. Herth foi o desenvolvimento de um instrumento autoaplicável para mensurar esperança (Herth Hope Index). Trata-se de uma escala de fácil e rápida aplicação (HERTH, 1992), que possibilita identificar o nível de esperança do indivíduo. A escala foi traduzida e adaptada para o Brasil em 2008, para população adulta com doença crônica, e é composta de 12 afirmativas, nas quais a pontuação varia de 1 a 4. As respostas são subdividas em: discordo plenamente, discordo, concordo plenamente e concordo (SARTORE; GROSSI, 2008). A pontuação total varia de 12 a 48, sendo que quanto maior o escore, maior o nível de esperança presente (SARTORE; GROSSI, 2008). A escala também já foi adaptada, traduzida e validada para outros países e idiomas, no entanto, sempre para ser utilizada com a população de adultos.

2 JUSTIFICATIVA

2 Justificativa

Além do exposto anteriormente, na contemporaneidade, diversos autores ao redor do mundo realizaram estudos na temática da esperança na área da enfermagem, dentre os quais destaco alguns a seguir, devido à sua expressiva produção científica:

No Canadá, a Dra. Wendy Duggleby e colaboradores desenvolveram diversos estudos de enfermagem sobre esperança. Os principais são estudos mistos, qualitativos e quantitativos com cuidadores de pessoas com câncer avançado (DUGGLEBY et al., 2011a, 2013b, 2014b; DUGGLEBY; WILLIAMS, 2010; WILLIAMS et al., 2013); estudo qualitativo com pessoas com câncer avançado e seus cuidadores (DUGGLEBY et al., 2010b); estudos qualitativos e misto com pessoas com demência (DUGGLEBY et al., 2009, 2011b; DUGGLEBY; SCHROEDER; NEKOLAICHUK, 2013); estudos quantitativos e qualitativo com cônjuges de mulheres com câncer de mama (DUGGLEBY et al., 2012b, 2014a, 2015); estudo quantitativo com adultos e idosos recém-diagnosticados com câncer (DUGGLEBY et al., 2013a); estudo qualitativo com cuidadores de pessoas em cuidado paliativo (HOLTSLANDER et al., 2005); estudo de intervenção e estudo qualitativo com idosos em cuidado paliativo domiciliar (DUGGLEBY et al., 2007; DUGGLEBY; WRIGHT, 2004); e estudo misto com profissionais de saúde (DUGGLEBY; COOPER; PENZ, 2009). No que se refere às revisões, o grupo da pesquisadora Duggleby realizou uma metassíntese sobre a esperança de idosos com doenças crônicas, que inclui 20 estudos publicados até 2010 (DUGGLEBY et al., 2012a); uma metassíntese sobre a esperança de cuidadores de pessoas com doenças crônicas, com 14 estudos incluídos, publicados entre 1993 e 2009 (DUGGLEBY et al., 2010a); e uma revisão integrativa com 34 estudos sobre a esperança no cuidado paliativo (KYLMÄ et al., 2009).

Na Noruega, a Dra. Vibeke Lohne é a enfermeira de referência no desenvolvimento de estudos de esperança. Seu grupo de pesquisa devolveu diversos estudos qualitativos que exploraram a esperança sob a perspectiva de adultos que sofreram lesão medular aguda, em diversos momentos do tratamento (LOHNE, 2008; LOHNE; SEVERINSSON, 2004a, 2004b, 2005, 2006). A esperança sob a perspectiva de familiares também foi explorada em estudo qualitativo com familiares de adultos gravemente doentes hospitalizados em unidade de cuidado intensivo (VALLE; LOHNE, 2020) e em ensaio clínico randomizado com cuidadores familiares de adultos com câncer avançado (LOHNE; MIASKOWSKI; RUSTØEN, 2012). Dra. Lohne também desenvolveu duas revisões, uma delas publicada em 2001, para analisar os conceitos da esperança de acordo com a perspectiva de pacientes que sofreram lesão medular. Esta revisão incluiu 26 estudos, publicados entre 1951 e 2000 (LOHNE, 2001). Recentemente, Dra. Lohne publicou uma metassíntese sobre os aspectos comuns da esperança em diversos contextos de cuidado de enfermagem. Os 17 estudos incluídos auxiliaram no avanço da compreensão clínica e teórica do contexto da esperança, sintetizando o fenômeno da esperança como um farol para as pessoas que estão lidando com enfermidades (LOHNE, 2021).

Na Suécia, destaca-se o grupo de pesquisa da Dra. Eva Benzein, que desenvolve pesquisas na temática da esperança. Dentre as pesquisas qualitativas estão: estudo sob a perspectiva de enfermeiros sobre a esperança de pacientes em cuidado paliativo (BENZEIN; SAVEMAN, 1998a); estudo com suecos não religiosos (BENZEIN; SAVEMAN; NORBERG, 2000) e com suecos adultos saudáveis pentecostais sobre suas experiências de esperança (BENZEIN; NORBERG; SAVEMAN, 1998); estudo com casais que vivenciam o câncer no contexto do cuidado paliativo e que passaram por um programa de conversas sobre esperança e sofrimento (BENZEIN; SAVEMAN, 2008); e estudo com pacientes com câncer em cuidado paliativo domiciliar sobre suas perspectivas de esperança (BENZEIN; NORBERG; SAVEMAN, 2001). No que se refere aos estudos quantitativos, vale destacar uma pesquisa que objetivou analisar a relação entre esperança, desesperança e fadiga nos pacientes em cuidado paliativo e seus familiares (BENZEIN; BERG, 2005); e outra que buscou a associação entre a esperança, ansiedade e sintomas de depressão em pessoas com câncer em cuidado paliativo e seus familiares (MÖLLERBERG et al., 2019). Outras duas contribuições relevantes da Dra. Benzein e seu grupo de pesquisa são: uma análise de conceito da década de 90, que analisou o conceito de esperança independentemente do contexto (BENZEIN; SAVEMAN, 1998b); e a validação da escala Herth Hope Index para a população adulta da Suécia (BENZEIN; BERG, 2003).

Em Portugal, a Dra. Zaida Charepe é referência na condução de estudos sobre esperança. Sua tese doutoral explorou o impacto dos grupos de ajuda mútua no desenvolvimento da esperança dos pais de crianças com doença crônica (CHAREPE, 2011). Na sequência, em 2014, publicou um livro intitulado “Promover a esperança em pais de crianças com doença crônica. Modelo de intervenção em Ajuda Mútua”, no qual compilou as intervenções por ela exploradas durante a realização de sua tese (CHAREPE, 2014). Outros estudos de destaque na temática da Dra. Charepe e colaboradores são: um estudo qualitativo para identificar fatores que influenciam a esperança de pais de crianças com doenças crônicas através do genograma e ecomapa (CHAREPE et al., 2011); uma revisão de escopo para mapear intervenções que promoveram a esperança de pais de crianças com necessidades especiais de saúde (SILVA CARVALHO et al., 2019); e um estudo qualitativo que explorou a esperança de pais de crianças com condições crônicas complexas, no qual receberam cartas terapêuticas (FONSECA et al., 2021).

Nos Estados Unidos, no início de sua carreira, a Dra. Pamela Hinds publicou estudos sobre a esperança de adolescentes com doenças crônicas. Além disso, realizou estudos para definição da esperança sob a ótica de adolescentes enfermos e saudáveis (HINDS, 1984, 1988b) e para explorar as características da esperança de adolescentes com câncer (HINDS; MARTIN, 1988) e os mecanismo que eles têm para alcançá-la (HINDS et al., 1999). Em relação ao cuidado de enfermagem, publicou três estudos que exploraram como esses cuidados poderiam influenciar a esperança de adolescentes (HINDS, 1988a, 2004; HINDS; MARTIN; VOGEL, 1987).

Ademais, na literatura existem outros estudos fundamentais sobre esperança, como os estudos qualitativos que exploraram: a perspectiva de enfermeiros na identificação das necessidades de esperança de pacientes adultos com prognóstico de vida limitada (REINKE et al., 2010); as perspectivas de médicos, enfermeiros, adultos com diagnóstico de câncer avançado ou doença pulmonar obstrutiva crônica grave e seus familiares sobre a necessidade de apoio em sua esperança diante do prognóstico (CURTIS et al., 2008); e as perspectivas sobre esperança de adolescentes e adultos jovens com câncer (JUVAKKA; KYLMÄ, 2009). Com relação às revisões, cabe destacar: uma análise de conceito sobre a esperança no contexto de cuidado de enfermagem (TUTTON; SEERS; LANGSTAFF, 2012); e uma metassíntese sobre como a esperança é identificada em estudos de enfermagem com pessoas enfermas e saudáveis (HAMMER; MOGENSEN; HALL, 2009);

Diante do exposto, identificamos que a maioria dos estudos sobre a temática da esperança na enfermagem foram realizados com adultos em contexto diversos. Os poucos estudos sobre esperança no contexto da pediatria apresentaram uma lacuna, no que se refere a explorar a experiência do fenômeno sob a ótica da unidade familiar no contexto da doença crônica. Portanto, partindo do pressuposto de que o diagnóstico da doença crônica na infância impacta no funcionamento familiar, e que o recuso da esperança, apesar de ser passível de alteração devido ao contexto, é utilizado pela família para lidar com as demandas decorrentes do diagnóstico, questionamos: Quais são as evidências qualitativas presentes na literatura sobre as experiências relacionadas à esperança das famílias de crianças e adolescentes que convivem com doenças crônicas? Como coletar dados sobre esperança, de forma interativa, de famílias de crianças e adolescentes com doenças crônicas? Quais são as narrativas de famílias, no contexto da doença crônica pediátrica, sobre suas experiências de esperança?

3 OBJETIVOS

3 OBJETIVOS

3.1 Objetivo geral

Analisar a esperança de famílias de crianças e adolescentes que convivem com doenças crônicas.

3.2 Objetivos específicos

I) Sintetizar e interpretar estudos qualitativos que apresentem a experiência do recurso da esperança pelas famílias de crianças e adolescentes que convivem com doenças crônicas.

II) Refletir e discutir considerações metodológicas e pragmáticas sobre a utilização de entrevistas com foto-elicitação para coleta de dados com famílias de crianças e adolescentes que convivem com doença crônica.

III) Analisar narrativas sobre a experiência de esperança de famílias no contexto da doença crônica pediátrica.

4 RESULTADOS

4 Resultados

Os resultados dessa tese estão apresentados em três artigos. O primeiro deles, de revisão, contempla o objetivo específico I, mediante o desenvolvimento de uma síntese temática de estudos qualitativos. O objetivo específico II foi alcançado através do segundo artigo, no qual o método de coleta de dados utilizado para alcançar o objetivo específico III foi discutido, no que se refere às considerações metodológicas e pragmáticas. Por fim, o objetivo específico III foi alcançado por meio do desenvolvimento de uma pesquisa qualitativa narrativa, apresentada no terceiro artigo. As contribuições dos autores de cada artigo estão listadas no Apêndice A.

4.1 Primeiro artigo - Revisão. *The experience of hope in families of children and adolescents living with chronic illness: A thematic synthesis of qualitative studies*

Neste tópico apresento a síntese temática de estudos qualitativos realizada para contemplar o objetivo específico I da tese. Esta revisão foi realizada durante o período do meu estágio sanduíche e é intitulada: *The experience of hope in families of children and adolescents living with chronic illness: A thematic synthesis of qualitative studies*. O artigo foi publicado no *Journal of Advanced Nursing*, em 2019 [https://doi.org/10.1111/jan.14129] (LEITE et al., 2019c). O *Journal of Advanced Nursing* é uma revista internacional que contribui para o avanço da enfermagem baseada em evidências, e no momento da publicação do artigo seu fator de impacto foi 2.561 (2019), atualmente apresenta 3.187 de fator de impacto. Segundo o JCR 2019 *NURSING-SCIENCE*, o *Journal of Advanced Nursing* estava classificado no primeiro quartil das revistas de enfermagem, ou seja, foi classificado como a sexta melhor revista da área de enfermagem, de um total de 151 revistas.

Referência: LEITE, A.C.A.B. et al. The experience of hope in families of children and adolescents living with chronic illness: A thematic synthesis of qualitative studies. **Journal of Advanced Nursing**, v. 75, n. 12, p. 3246–3262, 4 dez. 2019c. https://doi.org/10.1111/jan.14129

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

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 within the pediatric 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 and 2018, were included.

Finding: Findings were integrated into an analytical theme "FAMILY HOPE: KEEPING THE DAY-TO-DAY BALANCE", encompassing 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 pediatric 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 pediatric conditions.

KEYWORDS

review, qualitative research, family nursing, pediatric nursing, hope, child, adolescent, chronic disease.

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).

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) elderly people who are physically ill (Wiles, Cott, & Gibson, 2008); d) elderlies 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 &

Barroso, 2007). Hence, the question for this review is: How do families of children and adolescents living with chronic illness experience hope?

THE REVIEW

Aim

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

Design

A thematic synthesis of qualitative studies was developed to identify, analyze, and synthesize 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 analyzes (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.

Search method

The SPIDER tool was used to structure the search strategy (See Figure 1) (Methley, Campbell, Chew-Graham, McNally, & Cheraghi-Sohi, 2014) by using descriptors and keywords related to pediatrics, family, chronic disease, hope, experience and qualitative studies, and combining them with Boolean operators (AND, OR). The search was conducted in six databases: 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 12/31/2018 were considered for this review.

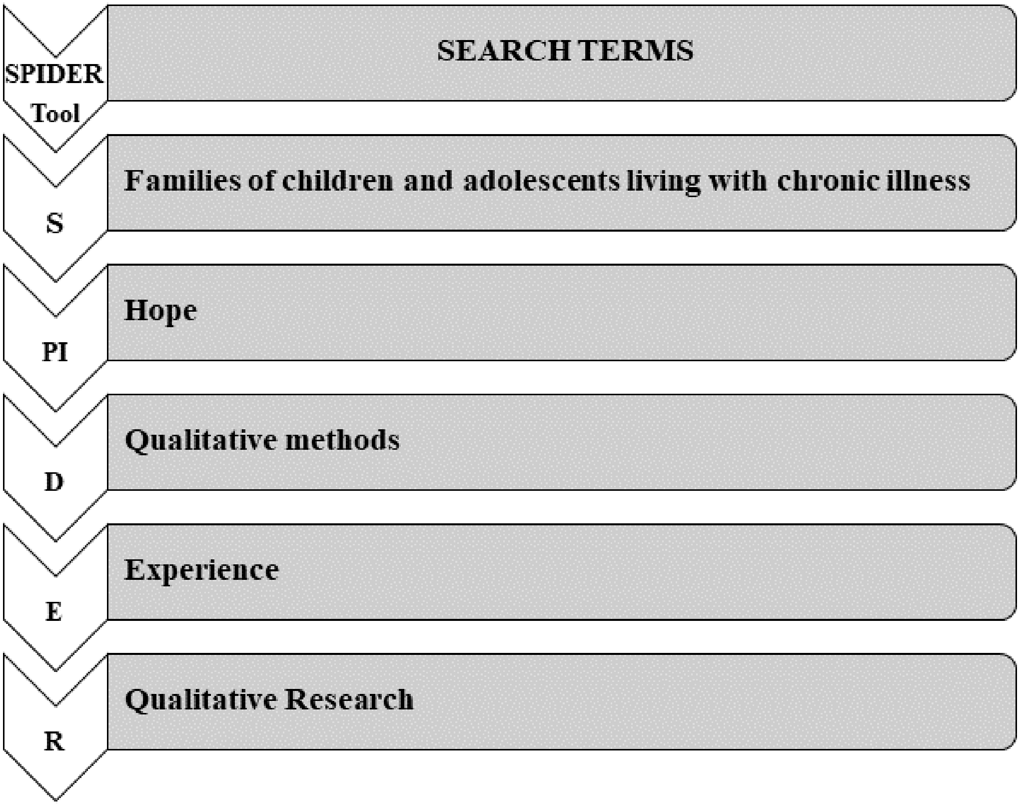


FIGURE 1 Examples of terms used in search strategies, from the SPIDER tool

Search outcome

The selected studies met the following inclusion criteria: (i) published qualitative primary research; (ii) 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 others); (iii) 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 that 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.

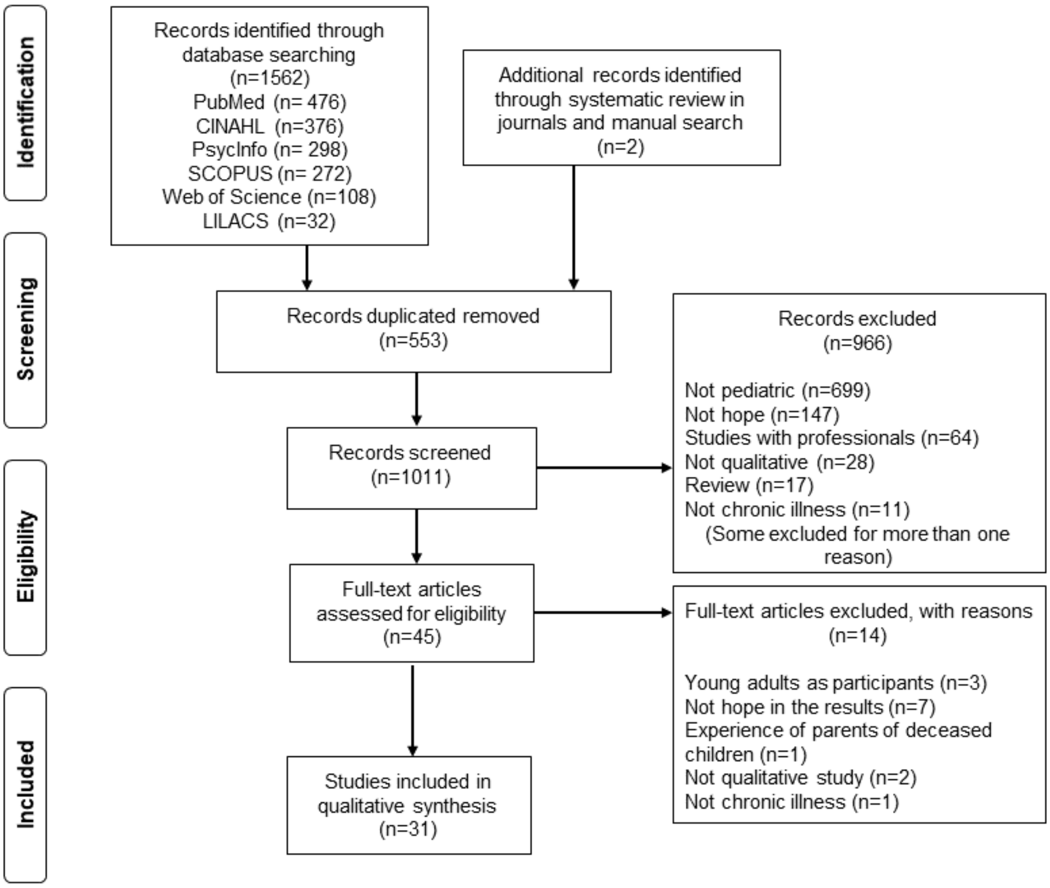
The exclusion criteria were: theses, dissertations, books, reviews, book chapters, and abstracts published in annals of events; studies reporting adult survivors who experienced childhood cancer; articles reporting the experience of relatives with the death of a child and/or adolescent with chronic illness; 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) (see Figure 2)

FIGURE 2 PRISMA flowchart (Liberati et al., 2009) of the search process and selection of the studies for the thematic synthesis.



Quality appraisal

The quality appraisal of included studies was performed independently by two reviewers (ACABL; RRN) based on the Critical Appraisal Skills Program (CASP) check-list (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: 1) participants and the recruitment strategy were not clearly reported; 2) 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; 3) ethical issues such as approval by an ethics committee and acquisition of informed consents were not reported; and 4) data analysis was insufficiently reported with no detailed description of the methods selected and analysis process (See Table 2).

Data abstraction and synthesis

The data abstraction was performed using a form developed by the authors based on previously published reviews (See Table 1 and Figure 3) (Duggleby et al., 2012; Polita et al., 2018).

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).

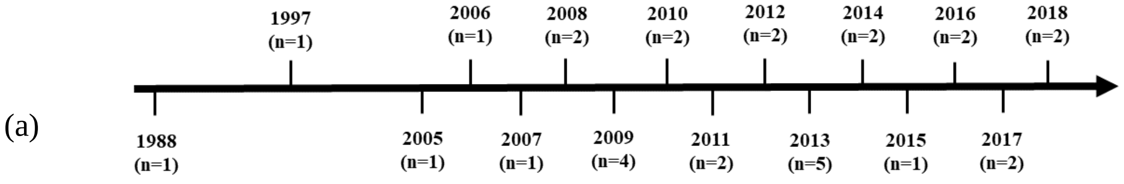
The results of primary studies were coded line-by-line according to its meaning and content (ACABL). The QDA Miner Lite software was used to facilitate the management and coding. Codes were then organized by hierarchy and similarity into a tree structure. Finally, five descriptive themes were developed 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.

RESULTS

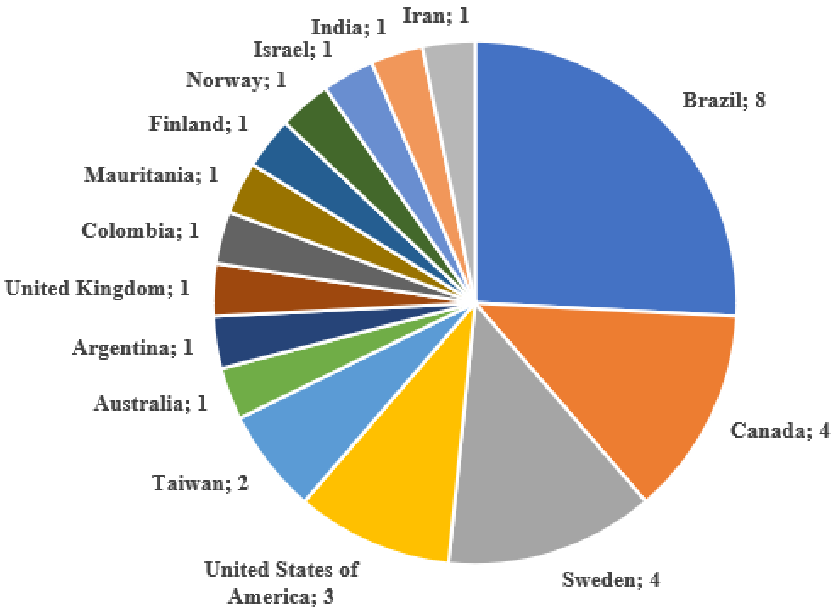
Study characteristics

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 was the main technique of data collection (Table 1).

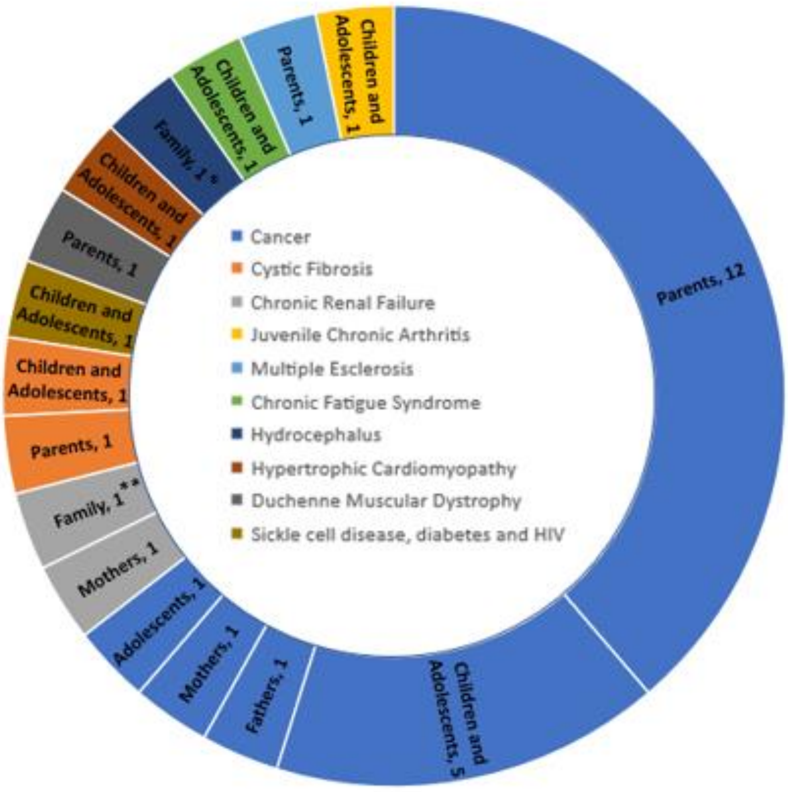
FIGURE 3 Characteristics of studies: year of publication (a), country where it was developed (b), chronic illness studied and sample (c).



(b)



(c)



* Family refers to: mothers, fathers, stepfather, grandmothers and brothers.

** Family refers to: mothers, fathers, siblings and the children and adolescents living with chronic renal failure.

TABLE 1 Characteristics of the studies included in the thematic analysis

First author and year of publication	Country	Aim	Design, data collection and analysis	Chronic illness, stage of the disease or context	Participants/Sample
Kane, 2018	Mauritania	To understand how children experience chronic illness in Mauritania, West Africa.	Descriptive qualitative study, with interviews, pictures and draws as a data collection technique. Thematic analysis	Sickle cell disease, diabetes and HIV Receiving medical care	Children and adolescents between 6 and 18 years old (7 with sickles cell disease, two with diabetes and one with HIV)
Pourghaznein, 2018	Iran	To understand the meanings of care for children undergoing hemodialysis based on mothers' lived experiences	Hermeneutic phenomenological approach, with semi-structured interviews. Hermeneutic phenomenology analysis	Chronic renal failure. Hemodialysis treatment	Mothers of children and adolescents between 5 and 15 years old (n=11 mothers)
Hinton, 2017	United Kingdom	To explore the experiences of parents of children with multiple sclerosis	Constructivist grounded theory approach, with semi-structured, conversational style interviews. Inductive analysis using the constant comparative method	Multiple sclerosis. Context not reported	Parents of children and adolescents between zero and 17 years old (n= 31; 20 mothers and 11 fathers)
Vindrola-Padros, 2017	Argentina	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	Narrative study with in-depth interviews. Narrative analysis	Cancer. Treatment at the hospital	Parents of children between zero and over 15 years old (n= 17; 13 mothers and 4 fathers)
Cornelio, 2016	India	To explore the experiences of mothers on parenting children with leukemia	Phenomenological design, and semi-structured interviews Type of analysis not reported	Leukemia. Hospitalization for Chemotherapy	Mothers of children and adolescents between one and 16 years old (n=10 mothers)
Nyborn, 2016	United States of America	To prospectively evaluate responses to prognosis communication among parents of children with cancer	Prospectively study with generic qualitative approach and semi-structured interviews. Content analysis	Advanced Cancer. During hospitalization	Parent of children and adolescents under 18 years old (n= 32; 26 mothers and 8 fathers)

Sposito, 2015	Brazil	To analyze coping strategies used by children with cancer undergoing chemotherapy during hospitalization	Exploratory study, semi-structured interviews with puppets. Inductive thematic content analysis	Cancer. Hospitalization for chemotherapy	Children and adolescents between 7 and 18 years old (n= 10; 5 girls and 5 boys)
Abreu, 2014	Brazil	To identify quality of life impacting attributes related to health of children and adolescents with chronic renal failure	Exploratory descriptive study, with focal group. Thematic content analysis	Chronic renal failure. Hemodialysis treatment	Children and adolescents, between 8 and 18 years old and their parents or caregivers (mothers, fathers and siblings) (n= 42)
Bally, 2014	Canada	To gain an understanding of the experience of hope for parents who care for their child in treatment for cancer	Symbolic interactionism and open-ended interviews. Data analysis used the constructivist grounded theory procedures	Cancer. During hospitalization	Parents of children between 3 and 13 years old. (n=16; 12 mothers and 4 fathers)
Amador, 2013	Brazil	To analyze the conceptions of care and the feelings which permeate the daily life of the family caregiver of children with cancer	Exploratory and descriptive study, with a generic qualitative approach and semi structured interviews. Discourse analysis	Cancer Center for support to the children and living with cancer.	Family caregiver of children between two and twelve years old. (n= 9 parents; 8 mothers and 1 father)
Barrera, 2013	Canada	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	Grounded theory approach with prospectively semi structured interviews. Data analysis used grounded theory methodology	Cancer. During the treatment at the hospital	Parents of children between three months and 16 years old. (n=35; 26 mothers and nine fathers)
Chinchilla-Salcedo, 2013	Colombia	To describe the concept of hope in parents of children between 0 and 15 years of age who have been diagnosed with cancer	Exploratory descriptive study, semi-structured interview and field diary. Type of analysis not reported	Cancer. During treatment but not hospitalized	Parents of children and adolescents, between zero and 15 years (n= 11; 7 mothers and 4 fathers)
Granek, 2013	Israel	To further the understanding of parental hope when a child is being treated for a malignancy resistant to treatment	Grounded theory method, interviews in three time point (3 months of the initial diagnosis; 6 months; and 9 months). Type of analysis not reported	Cancer. Hospitalized children with poor prognosis	Parents of children and adolescents between 3 months and 16 years. (Time 1 n= 35; time 2 n= 30; time 3 n= 27)

Winger, 2013	Norway	To explore the experience of being an adolescent with chronic fatigue syndrome	Phenomenological hermeneutical design, with in-depth interviews. Phenomenological hermeneutical analysis	Chronic fatigue syndrome. Treatment in the hospital or primary care unit	Children and adolescents between 12 and 18 years old. (n= 18; 12 girls and six boys)
Bratt, 2012	Sweden	To describe the experiences of children and adolescents being screened positive for hypertrophic cardiomyopathy and how this impact their daily life	Descriptive study with qualitative generic approach and private interviews. Content analysis	Hypertrophic Cardiomyopathy. Treatment at the outpatient clinic	Children and adolescents between eight and 18 years old. (n= 12; 11 boys and 2 girls)
Sällfors, 2012	Sweden	To elucidate the life situation and psychosocial processes of living with chronic pain in children suffering from juvenile chronic arthritis	Qualitative study, with semi-structured interview. Classic grounded theory method analysis	Juvenile chronic arthritis. During treatment but not hospitalized	Children and adolescents between six and 17 years (n=22; 16 girls and 6 boys)
Ringnér, 2011	Sweden	To describe parents' experiences of acquiring and using information to create knowledge about their child's cancer	Qualitative study, that used mixed data collection method, using data from focus group interviews and individual interviews. Qualitative content analysis	Cancer. During hospitalization	Parents children between one and 18 years old (n= 14; 10 mothers and 4 fathers)
Silva, 2011	Brazil	To describe the experience of a family caregiver of a child with cancer	Qualitative study with open interviews. Content analysis	Cancer. During the treatment at the hospital	Family caregiver of children under 12 years old (n= 19; 16 mothers and the others participants are not reported)
dos Santos, 2010	Brazil	To understand the meaning of the palliative cares for the parents of the child's cancer	Grounded theory approach, and interviews. Data analysis used the grounded theory	Cancer. Palliative care.	Parents of children between two and 12 years old. (n=12)
Grossoehme, 2010	United States of America	To describe whether parents understand a relationship between their religious beliefs and their follow-through with their child's	Grounded theory with interviews by telephone or by person. Theoretical models of grounded theory method for data analysis	Cystic Fibrosis Home treatment regimen	Parents of children between one and 55 weeks (n= 15 parents of 9 children, 9 mothers and 6 fathers)

Andrade, 2009	Brazil	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	Grounded theory with Symbolic Interactionism as theoretical reference and semi-structured interviews. Qualitative process of data analysis based in the symbolic interactionism theory	Hydrocephalus. Type of treatment not reported	Families of children between two months and 13 years old. (n= 13; 4 mothers; 3 fathers; 1 stepfather; 3 grandmothers and 2 brothers)
Nicholas, 2009	Canada	To examine the experiences of fathers of children diagnosed with cancer	Grounded theory with semi-structured interviews. Type of analysis not reported	Cancer. Treatment at the hospital or at home	Fathers of children between one and 17 years old. (n=16)
Samson, 2009	Canad**a**	To describe the lived experience of hope among parents of a child with Duchenne muscular dystrophy	Qualitative phenomenological approach with semi-structured interviews. Empirical phenomenological psychological data analysis method	Duchenne muscular dystrophy. Any clinical stage during the treatment at the hospital	Parents of children between 7,5 and 17 years old. (n=12; 7 mothers and 5 fathers)
Wu, 2009	Taiwan	To describe the essence of the coping experiences of Taiwanese adolescents with cancer.	Qualitative phenomenological approach with in-depth interview. Data analysis used phenomenological method.	Cancer Any clinical stage during the treatment at the hospital	Adolescents between 12 and 18 years old. (n = 12; 8 boys and 4 girls)
De Graves, 2008	Australia	To explore the experiences of families when a child with cancer relapses	Prospective critical ethnography with in-depth interviews. Content analysis	Cancer. During the relapse’s treatment	Parents and children aged 12 years or older (n= 12 families; 17 parents, 12 mothers; 5 fathers and 7 children)
Huang, 2008	Taiwan	To investigate the family resources available to assist family adjustment among single-parent families with a child with cancer	Phenomenological approach, with open question interviews Analysis with Colaizzi’s method	Cancer. Hospitalization for chemotherapy or radiotherapy	Single-parent of children and adolescents under 18 years old. (n= 9; 5 mothers and 4 parents)
Kylma, 2007	Finland	To describe hope in parents of adolescents with cancer	Qualitative study with inductive design and on open in-depth interviews. Content analysis	Cancer. Context not reported	Parents of adolescents between 12 and 17 years old. (n=9; 5 mothers and 4 fathers)

Pizzignacco, 2006	Brazil	To identify the routine of children and adolescents with cystic fibrosis through their experiences and identify situations that can affect these routines	Descriptive exploratory, qualitative study with open interview. Type of analysis not reported	Cystic Fibrosis. Inpatient and outpatient treatment	Children and adolescent between seven and 18 years old (n=8)
Björk, 2005	Sweden	To elucidate the family's lived experience when a child in the family was diagnosed with cancer	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	Cancer During treatment	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)
Dupas, 1997	Brazil	To understand the meaning that the experience of getting sick and of treating has for the child with cancer	Grounded theory with Symbolic Interactionism as theoretical framework with interviews. Data analysis was based on the theoretical model	Cancer. During the treatment at the hospital	Children between seven and 12 years old. (n= 29)
Hinds, 1988	United States of America	To explore the process through which adolescents with cancer move to achieve hopefulness	Grounded theory with interviews and observations. Type of analysis not reported	Cancer Inpatient and outpatient treatment	Adolescents between 12,4 and 18,9 years old (n= 58; 13 inpatient and 45 outpatient)

TABLE 2 Quality assessment of included studies according to the Critical Appraisal Skills Program (CASP)

Studies CASP Questions	Kane, 2018	Pourghaznein, 2018	Hinton, 2017	Vindrola-Padros, 2017	Cornelio, 2016	Nyborn, 2016	Sposito, 2015	Abreu, 2014	Bally, 2014	Amador, 2013	Barrera, 2013	Chinchilla-Salcedo, 2013	Granek, 2013	Winger, 2013	Bratt, 2012	Sällfors, 2012	Ringnér, 2011	Silva, 2011	dos Santos, 2010	Grossoehme, 2010	Andrade, 2009	Nicholas, 2009	Samson, 2009	Wu, 2009	De Graves, 2008	Huang, 2008	Kylma, 2007	Pizzignacco, 2006	Björk, 2005	Dupas, 1997	Hinds, 1988
1. Was there a clear statement of the aims of the research?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
2. Is a qualitative methodology appropriate?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
3. Was the research design appropriate to address the aims of the research?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
4. Was the recruitment strategy appropriate to the aims of the research?	√	√	√	√	**?**	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	**?**
5. Was the data collected in a way that addressed the research issue?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
6. Has the relationship between researcher and participants been adequately considered?	■	■	√	■	■	√	√	■	■	■	■	■	■	■	√	√	■	■	■	**?**	**?**	■	√	**?**	■	■	■	■	√	■	■
7. Have ethical issues been taken into consideration?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	■	■
8. Was the data analysis sufficiently rigorous?	√	√	√	√	**?**	√	√	√	√	√	√	**?**	**?**	√	√	√	√	√	√	√	**?**	**?**	**?**	√	√	**?**	√	**?**	√	■	**?**
9. Is there a clear statement of findings?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
10. How valuable is the research?	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√	√
Total score	**9**	**9**	**10**	**9**	**7**	**10**	**10**	**9**	**9**	**9**	**9**	**8**	**8**	**9**	**10**	**10**	**9**	**9**	**9**	**9**	**8**	**8**	**9**	**9**	**9**	**8**	**9**	**8**	**10**	**7**	**6**

√ Yes; ■ No; ? Cannot tell

Family Hope: Keeping the day-to-day balance

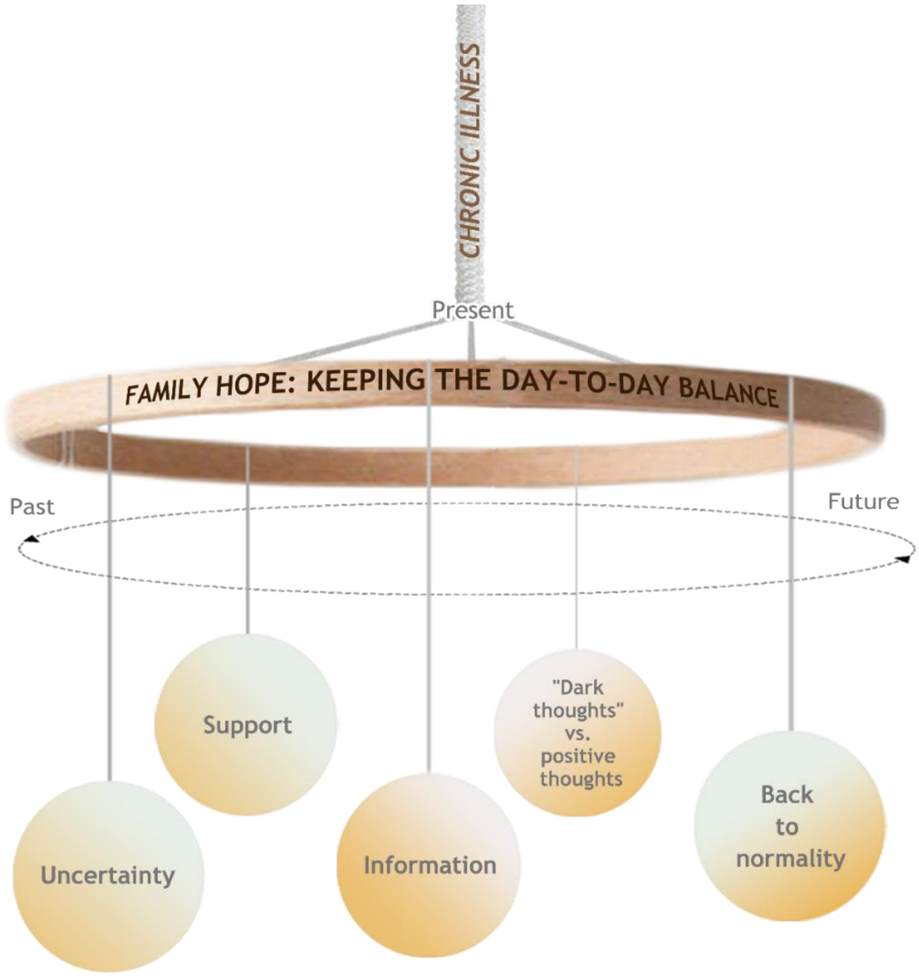
The thematic synthesis allowed us to identify five descriptive themes concerned characteristics of the experience of hope in the families of children and adolescents living with chronic illness – “Uncertainty; Support; Information; Between "dark thoughts" and positive thoughts; and Hoping to go back to normality.” These descriptive themes are understood through an analytical theme entitled “FAMILY HOPE: KEEPING THE DAY-TO-DAY BALANCE” (Table 3 and Figure 4).

TABLE 3 Descriptive themes developed from the analysis of the included studies

Studies Descriptive themes	Kane, 2018	Pourghaznein, 2018	Hinton, 2017	Vindrola-Padros, 2017	Cornelio, 2016	Nyborn, 2016	Sposito, 2015	Abreu, 2014	Bally, 2014	Amador, 2013	Barrera, 2013	Chinchilla-Salcedo, 2013	Granek, 2013	Winger, 2013	Bratt, 2012	Sällfors, 2012	Ringnér, 2011	Silva, 2011	dos Santos, 2010	Grossoehme, 2010	Andrade, 2009	Nicholas, 2009	Samson, 2009	Wu, 2009	De Graves, 2008	Huang, 2008	Kylma, 2007	Pizzignacco, 2006	Björk, 2005	Dupas, 1997	Hinds, 1988
Uncertainty		X	X		X	X	X		X	X	X	X	X	X	X	X	X		X		X	X	X	X		X	X	X			
Support					X		X		X	X	X	X	X		X		X	X	X	X	X	X	X	X	X	X	X	X	X	X	X
Information						X			X		X		X				X									X					X
"Dark thoughts" vs. positive thoughts			X		X	X				X	X	X			X	X	X		X			X	X	X		X	X				X
Back to Normality	X	X	X	X	X	X	X	X	X	X	X	X	X				X	X	X			X	X					X	X	X	

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 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., 2013, p.367).

FIGURE 4 Family hope of children and adolescents living with chronic illness and their families.



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., 2013; Björk, Wiebe, & Hallström, 2005; Chinchilla-Salcedo, 2013; Cornelio, Nayak, & George, 2016; Pourghaznein, Heydari, Manzari, & Valizadehzare, 2018; Sällfors, Fasth, & Hallberg, 2002; Winger, Ekstedt, Wyller, & Helseth, 2014). 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., 2013; 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., 2014).

The family structures 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., 2013; 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., 2014). There is a constant uncertainty about diagnoses, treatment efficacy, prognosis (Amador, Reichert, Lima, & Collet, 2013; Barrera et al., 2013; Cornelio et al., 2016; 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., 2013, p.367).

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., 2013; Björk et al., 2005; Chinchilla-Salcedo, 2013; dos Santos, de Oliveira, Pereira de Lima, & Barbosa da Conceição, Miriã Fernandes, 2010; Hinton & Kirk, 2017; Huang et al., 2008; Kylmä & Juvakka, 2007; Samson et al., 2009). This connection is demonstrated when parents continue to believe in their children's future and dreams (Kylmä & Juvakka, 2007).

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., 2013). 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., 2013; Chinchilla-Salcedo, 2013; Hinds & Martin, 1988; Huang et al., 2008; Kylmä & Juvakka, 2007).

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., 2013; 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, 2007). Support also comes from the extended family (Bally et al., 2013; Barrera et al., 2013; Björk et al., 2005; Chinchilla-Salcedo, 2013; dos Santos et al., 2010; Samson et al., 2009; Wu et al., 2009), friends (Bally et al., 2013; Barrera et al., 2013; Chinchilla-Salcedo, 2013; dos Santos et al., 2010; Samson et al., 2009), support groups (Sällfors et al., 2002), pets (Kylmä & Juvakka, 2007), the health care system (Cornelio et al., 2016), the community (Bally et al., 2013; Barrera et al., 2013), peers (Kylmä & Juvakka, 2007), other parents (Barrera et al., 2013; Ringnér, Jansson, & Graneheim, 2011), online groups (Barrera et al., 2013), and health professionals (Bally et al., 2013; Björk et al., 2005; dos Santos et al., 2010; Kylmä & Juvakka, 2007). 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 (dos Santos et al., 2010; Kylmä & Juvakka, 2007). 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., 2013; Barrera et al., 2013; Björk et al., 2005; Bratt et al., 2012; Cornelio et al., 2016; dos Santos et al., 2010; Hinds & Martin, 1988; Huang et al., 2008; Nicholas et al., 2009; Sposito et al., 2015), or through personal beliefs (Kylmä & Juvakka, 2007).

The belief that there is a reason for experiencing chronicity (Chinchilla-Salcedo, 2013; dos Santos et al., 2010; Kylmä & Juvakka, 2007), that their future can be promising (Hinds & Martin, 1988), or exist a life after death without disease (Grossoehme, Ragsdale, Wooldridge, Cotton, & Seid, 2009; Kylmä & Juvakka, 2007) 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., 2013; Kylmä & Juvakka, 2007; Samson et al., 2009).

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). In order to promote hope, families seek information and advice from other parents (Ringnér et al., 2011), friends, family members, the internet, charity centers (Hinton & Kirk, 2017; Ringnér et al., 2011; Samson et al., 2009), and health professionals (Hinton & Kirk, 2017; Samson et al., 2009).

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, torments 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).

In order to promote hope, the family builds mechanisms such as deliberately altering thoughts to guide them toward a promising and optimistic future (Bally et al., 2013; 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; 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). In order to not lose hope and resist concerns, parents turn away from dark thoughts (Bally et al., 2013) and change their attitude toward 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., 2013).

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., 2013). 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, 2007) 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 favorable prognosis can help some families to maintain a positive focus (Bally et al., 2013; 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).

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 (Granek et al., 2013; Hinds & Martin, 1988; Kylmä & Juvakka, 2007; Samson et al., 2009).

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., 2013; 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., 2014). Focusing on the positive aspects of the present helps the family to maintain hope (Barrera et al., 2013).

Living in the present helps families to have hope in treatments. Despite the side effects and sometimes low treatment effectiveness, it brings optimism and confidence that the future may reflect the life before diagnosis (Hinds & Martin, 1988; Kane & Fearon, 2018; Sällfors et al., 2002). To adapt to treatment demands, the family changes habits and routines (Bratt et al., 2012) related to feeding, types of games, and school activities (Chinchilla-Salcedo, 2013; Hinton & Kirk, 2017; Nicholas et al., 2009), in the hope of enhancing their effects. The changes also aim to maintain the family quality of life, increasing the hope that the child or adolescent will survive (Granek et al., 2013; Nicholas et al., 2009).

For families living with cancer, the ideal future presents a cure, disease remission, and full recovery for their ill child (Cornelio et al., 2016; dos Santos et al., 2010; Granek et al., 2013; Nicholas et al., 2009; Silva, Barros, & Hora, 2011). This spectrum of possibilities is different for families living with other chronic diseases when the cure is not a real possibility.

For these families, research that could provide cure and reduction in the consequences of the disease is their hope in the future (Bally et al., 2013; Björk et al., 2005; Hinton & Kirk, 2017; Kane & Fearon, 2018; Pizzignacco & Lima, 2006; Samson et al., 2009). For children and adolescents living with chronic renal failure, transplantation represents a possibility of cure and a source of hope to return to the life before diagnosis (Abreu et al., 2014; Pourghaznein et al., 2018). Sometimes, the hope for a cure is so intense that children and adolescents with cancer already feel cured, even while still being treated: “My cancer has already died” (Sposito et al., 2015, p. 147). There are also parents who feel frustrated for not believing in the healing of their children (Nyborn et al., 2016).

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 elderlies 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 elderly 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 pediatric 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).

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 pediatrics 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-categorial 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 pediatric 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 regarding reflexivity, recruitment, ethical issues, and data analysis, which could have impacted 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.

CONCLUSION

This thematic synthesis of qualitative studies brings new understanding about hope in the pediatric context by presenting the experience of hope from a family system perspective. 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 pediatric context. A better understanding of the role and characteristics of family hope will promote the development of more effective interventions for the adaptation of families to pediatric long-term illness conditions. Furthermore, this new perspective of family hope can be used in education as a framework to understand the influence of family members and the reciprocity of family hope in the experience of living with chronic illnesses.

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 pediatric 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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4.2 Segundo artigo - Metodológico. *Using Photo-Elicitation Interviews with Families of Children and Adolescents with Chronic Illness*

Neste tópico está apresentado o segundo artigo da tese, que contempla o segundo objetivo específico II. Este artigo metodológico é intitulado *Using Photo-Elicitation Interviews with Families of Children and Adolescents with Chronic Illness* (LEITE; GARCÍA-VIVAR; NASCIMENTO, 2021). Encontra-se publicado no periódico *Nursing Research* [doi: 10.1097/NNR.0000000000000501], que possui fator de impacto de 2.381 (2020). Esse periódico internacional da área da enfermagem publica estudos quantitativos, qualitativos e sobre técnicas e metodologias inovadoras em pesquisa. Segundo o JCR 2020 *NURSING-SCIENCE*, a *Nursing Research* estava classificada no segundo quartil das revistas de enfermagem, ou seja, foi considerada a 38ª melhor revista da área de enfermagem, de um total de 146 revistas.

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Methodological and Pragmatic Considerations for Photo-Elicitation Interviews with Families of Children and Adolescents with Chronic Illness

ABSTRACT

Background: Despite the increasing number of studies that use photo-elicitation for data collection in qualitative research, there is a gap and need to further explore its use among families of children and adolescents living with chronic illness.

Objective: To reflect and discuss methodological and pragmatic considerations about the use of photo-elicitation interviews for data collection with families of children and adolescents living with chronic illness.

Methods: We discussed methodological aspects of using photo-elicitation interviews as reported in publications. A search of the literature was carried out to identify articles that presented information on methodological aspects of the use of photo-elicitation interviews in qualitative data collection, regardless of age group. In pursuit of complementing the evidence with pragmatic considerations of using photo-elicitation interviews, we illustrate this with an example of a recent empirical qualitative research of our own which aimed to understand the narratives about hope of families of children and adolescents living with chronic illness.

Results: We synthesized common aspects that need to be considered when using photo-elicitation interviews with different populations: ethical issues; cameras; guidance; and interviews. We also presented our experience of using photo-elicitation interviews technique to collect data from families. Due to our experience we denominate our method as the "Family Photo-Elicitation Interview". It goes beyond photo-elicitation interviews technique, because it integrates aspects of family nursing theories when conducting interviews with families. Family photo-elicitation interview strengthens family interaction and allows family members to share their perspectives.

Discussion: We present a new perspective of photo-elicitation interviews, known as the *"Family Photo-Elicitation Interview"* in the pediatric context. Previous studies have not addressed considerations about using photo-elicitation interview specifically for families. We describe family photo-elicitation interview as a powerful method to use with families in the pediatric and chronic illness context. We hope our results to assist novice researchers in planning and implementing family and photo-elicitation interviews in qualitative research. We recommend that future studies explore the use of the family photo-elicitation interview in other contexts, different from pediatrics, such as geriatrics or palliative care.

Key Words: qualitative research; nursing methodology research; pediatric nursing; family nursing; photographs.

INTRODUCTION

The well-being of children and adolescents is related to their family structure and functioning (Alderfer et al., 2019). Receiving diagnosis of a chronic illness in childhood impacts on the family unit and its functionality. Consequently, dealing with the demands of the illness requires the mobilization of family resources for promoting adequate interactions and relationships within the family. Additionally, better adherence to treatment is related to the family's communication skills, problem solving, family conflicts, cohesion and flexibility, which are components of family functioning (Alderfer et al., 2019). Therefore, using a family-centered care philosophy is recognized to be central to the lives of families of children and adolescents (Shields, 2015), particularly because this approach considers families as partners in care and it focuses on the particular needs of the family.

To understand the experiences of families living with a chronic illness, qualitative research is a key tool for reporting the particular needs and narratives of these families (Greenhalgh, 2016). However, conducting qualitative research with families is complex, as researchers have to consider the characteristics of families, which vary according to their culture, beliefs, history, and needs. Therefore, when planning a study with families, researchers must choose and use a data collection method that allows for an investigation with multiple participants and understanding of the family members' interactions (Blinded for peer review). Drawings, music, photos and puppets are data collection techniques that compose the creative art-based method (Gillies & Robinson, 2012). These data collection techniques are playful, participatory, and adequate to give voice and value to the interactions of family members, particularly children and adolescents (Stafford, 2017). However, the effectiveness of using these data collection techniques will depend on how the studies are designed and the researcher's ability to use them (Blinded for peer review; Stafford, 2017). The sharing of experiences by children and adolescents is related to their age, stage of development, clinical condition, socio-cultural context and the object of study (Blinded for peer review; Stafford, 2017). Therefore, researchers should consider these aspects when choosing qualitative data collection methods and techniques for families with children or adolescents.

One of the data collection techniques used in the creative art-based method is the photo-elicitation interview (PEI). PEI consists of inserting photos or any visual image into interviews (Harper, 2002), in order to assist in its performance, eliciting memories and information (Murray & Nash, 2017). It also allows for the participant's direct or indirect participation and greater expression of their emotions (Blinded for peer review). Researchers choose who will select the photos to be used in the interview (Torre & Murphy, 2015), and they can be taken by the participants to help build their perspective on the phenomenon (Murray & Nash, 2017). PEI strengthens the relationship between researcher and participants, minimizing the rigid dynamic of questions and answers (Blinded for peer review).

Recent studies show the use of PEI in Health Sciences allowing for the active involvement of participants during the development of qualitative research. They were conducted in ten countries from six continents, including: Australia (Murray et al., 2019), Brazil (Ribeiro et al., 2018), Canada (Backman et al., 2018), England (Armstrong-James et al., 2019; Denford et al., 2019; Marsh et al., 2019; Pini et al., 2019; Wells et al., 2013), France (Lachal et al., 2012; Lecomte et al., 2019), Kenya (Kyololo et al., 2019), Portugal (Calha et al., 2019), Spain (Oter-Quintana et al., 2017), Sweden (Alvariza et al., 2020; Hajradinovic et al., 2018; Olausson et al., 2013), and the United States of America (Kantrowitz-Gordon & Vandermause, 2016; Latta et al., 2014; Stutey et al., 2016).

With regard to the participants, the studies were developed with: a) family members of adult patients at end-of-life (Hajradinovic et al., 2018), and in the intensive care unit (Olausson et al., 2013); b) adolescents, in the context of dialysis treatment (Wells et al., 2013); cystic fibrosis (Denford et al., 2019), bulimia nervosa (Lecomte et al., 2019), and during the school return after cancer treatment (Pini et al., 2019); c) underage siblings of children with autism (Latta et al., 2014); d) children who have lost loved ones (Stutey et al., 2016)_; e) parents of premature children (Kantrowitz-Gordon & Vandermause, 2016); e) mothers of newborn children (Kyololo et al., 2019) and healthy children (Murray et al., 2019); f) elderly people attending a day hospital (Calha et al., 2019); g) homeless women (Oter-Quintana et al., 2017); h) health professionals (Alvariza et al., 2020; Marsh et al., 2019; Ribeiro et al., 2018); i) families of burned children and adolescents (Armstrong-James et al., 2019), families of obese children (Lachal et al., 2012); and j) families of elderly patients with multiple chronic conditions (Backman et al., 2018).

Despite the increasing number of studies using PEI in different health contexts, none of the studies presented above had the specific aim to discuss its use. Likewise, a gap in a methodological and pragmatic discussion in PEI use was identified in the population of families of children and adolescents living with a chronic illness. Hence, there is a need to further explore the use of PEI among this specific population, with regard to identifying necessary aspects to collect meaningful qualitative data that bring new perspectives of the lived experiences of these families. Also, our goal is to identify and explain what matters most in using PEI, in the hope to assist novice researchers in planning and implementing PEI in qualitative research. Therefore, the aim of this study was to reflect and discuss methodological and pragmatic considerations about the use of photo-elicitation interviews for data collection with families of children and adolescents living with chronic illness.

METHODS

The scope and nature of this paper is to discuss the methodological and pragmatic elements of using PEI for data collection in qualitative research and not to present detailed information about the identification of studies and analysis processes as though it were a narrative review. To achieve this goal, this paper is divided into two sections. In the first, we discuss the methodological aspects of using PEI as reported in publications. A search of the literature was carried out to identify articles that presented information on methodological aspects of the use of PEI in qualitative data collection, regardless of age group. In pursuit of complementing the evidence with pragmatic considerations of using PEI, we illustrate this with an example of a recent empirical qualitative research of our own which aimed to understand the narratives about hope of families of children and adolescents living with chronic illness (Ethical approval: 2.902.779). Our aim was not to present the results of our empirical qualitative research, but to present it as an example of research that considered the use of PEI in its method.

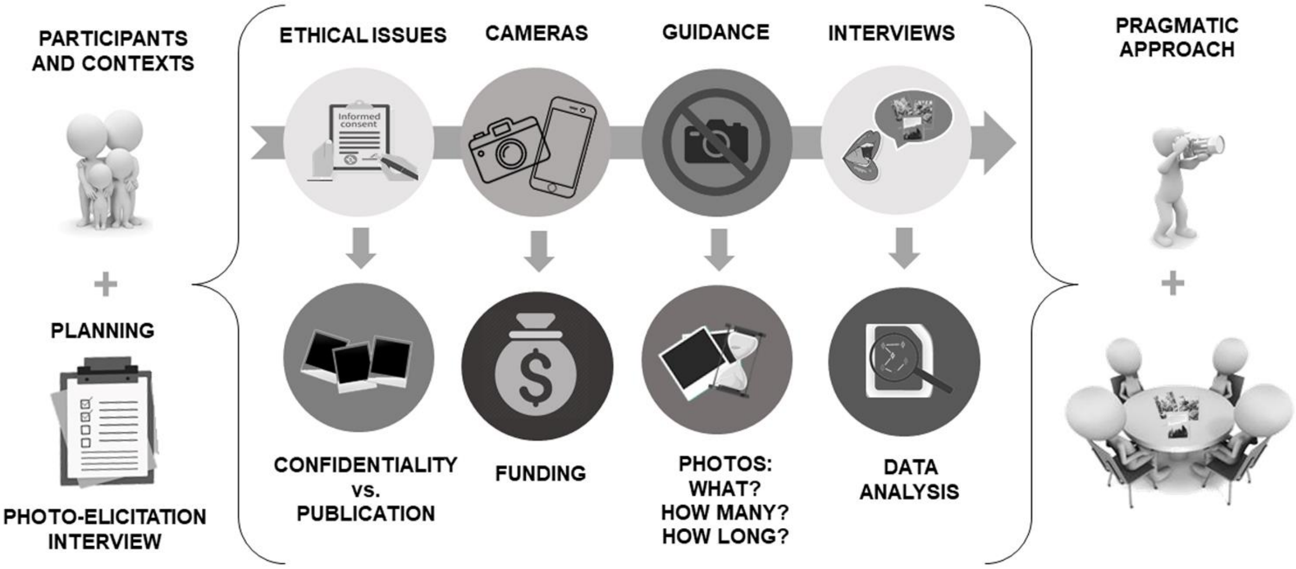
RESULTS

Methodological Aspects of the Use of Photo-Elicitation Interviews

As with all research, at first investigators must decide what is the aim of the study, and what methodology will be most appropriate. From this decision, they also need to define who will be the participants and the context of the study. Therefore, if researchers decide to use PEI for collecting qualitative data, they need to plan all the aspects involved in its implementation (Figure 1). We synthesized common aspects that need to be considered when using PEI with different populations: (I) Ethical issues, including the confidentiality of the participants and publication of data and photos; (II) The electronic devices with a camera that will be used to take the photos and the funding for the development of the study, mainly to purchase electronic resources; (III) Guidance given to participants on data collection, including what types and the number of photos that should be taken, and how long participants will have to produce them;

and (IV) How the interviews will be conducted and how the data analysis will be developed. This information will be presented in detail below to guide novel researchers who intend to use PEI.

FIGURE 1. Aspects to be considered in planning a study with photo-elicitation interviews.



Ethical Issues

When developing the ethical proposal, researchers need to consider the issues surrounding their data collection technique, such as the PEI. An ethical proposal will contain what is the definition of the PEI that researchers are adopting and how this is used (Mandleco, 2013). All the procedures have to be clearly described (Mandleco, 2013), especially the process of obtaining consent (Ford et al., 2017; Liebenberg et al., 2014; Mandleco, 2013; Marsh et al., 2016; Oliffe & Bottorff, 2007; Pyle, 2013; Radley & Taylor, 2003; Whiting, 2015; Woolhouse, 2019). Children and adolescents need to be consulted about their assent to participate in the study, and their assent form ought to be obtained after the consent of their parents/legal guardians (Ford et al., 2017; Liebenberg et al., 2014; Mandleco, 2013; Pyle, 2013; Whiting, 2015; Woolhouse, 2019). Children under seven years old can have their assent obtained verbally (Pyle, 2013).

The consent form must clearly state how the photos produced by the participants will be used, such as being published or used in presentations (Mandleco, 2013; Marsh et al., 2016;

Radley & Taylor, 2003). Therefore, some researchers commit to not publishing photos that can identify participants (Whiting, 2015). They can offer edited image through blurring, pixelating, or covering the face with a black strip (Ford et al., 2017; Woolhouse, 2019) and also editing them out completely with the effect of cartooning (Woolhouse, 2019). Other researchers ask for permission to publish faces, if participants do not want edits made to their photos (Liebenberg et al., 2014). There is also an option to encourage participants to avoid producing images with people or that include information that can identify someone, such as tattoos, scars and geographic locations (Marsh et al., 2016; Radley & Taylor, 2003). Regarding confidentiality, researchers also need to be sure to consider issues involving the production of photos with strangers or in public and private places (Ford et al., 2017).

Carefully following ethical standards in preparing the research proposal using PEI is key to preventing delays in approval from the ethics committee, especially if the study involves data collection in different countries (Ford et al., 2017). It is also important to note that requests received from ethics review boards, with extensive experience in ethical issues, help researchers to refine and clarify the research project (Ford et al., 2017).

Cameras

To organize the study, researchers have to be aware which camera the participants will use to take the photos. Among the options, researchers can provide disposable cameras (Liebenberg et al., 2014; Mandleco, 2013; Whiting, 2015; Woolhouse, 2019), cameras with a limited number of frames (Radley & Taylor, 2003), and digital cameras (Ford et al., 2017; Pyle, 2013). Although the researchers can plan to offer cameras, participants can decide to use their own cell phone cameras (Marsh et al., 2016). Another strategy was the use of instant cameras (polaroid) which allowed researchers to conduct PEI following production of photos (Radley & Taylor, 2003).

The choice of camera will depend on the purpose of the study and whether there is a limit on the number of photos that can be taken by the participants (Mandleco, 2013). It is necessary that researchers consider participants' skills in handling such equipment. The later generations of children and adolescents can be considered as digital natives (Woolhouse, 2019), and generally have no difficulties in handling cameras.

Although PEI is considered inexpensive (Mandleco, 2013), researchers have to plan the budget available for the purchase of the cameras and eventual prints of the photos, and this may require a study that is funded. To reduce the costs, researchers may consider asking participants to use their cell phone cameras, if they have one.

Guidance for Photo-Elicitation Interviews

Researchers need to guide participants on the procedures that will be performed during the PEI (Ford et al., 2017; Mandleco, 2013; Pyle, 2013; Radley & Taylor, 2003; Whiting, 2015; Woolhouse, 2019). Written guidance for taking the photos can be provided to participants (Ford et al., 2017; Radley & Taylor, 2003), but some researchers were concerned that written guidance could limit the production of the photos and preferred to provide guidance verbally (Marsh et al., 2016; Woolhouse, 2019). Providing written guidance does not prevent researchers from reinforcing it verbally.

When cameras are provided by researchers it is important to give clear guidance on their use (Whiting, 2015). When planning it is also important to consider whether the participant will be able to take the photos themselves, or would need assistance from others (Woolhouse, 2019). Clear guidance include the focus of photos that will be produced by the participants (Ford et al., 2017; Mandleco, 2013; Pyle, 2013; Radley & Taylor, 2003; Whiting, 2015; Woolhouse, 2019). Information contained in the consent can be reinforced, such as what is not allowed to appear in the photos: people, specific places or objects (Radley & Taylor, 2003; Woolhouse, 2019).

The purpose of the study guides the number of photos that must be produced. Some researchers did not want to limit the amount of photos produced and left participants free to register their experiences (Marsh et al., 2019; Oliffe & Bottorff, 2007; Whiting, 2015). However, other researchers limited the number of photos produced (minimum 2; maximum 12), to be able to control the amount of materials to handle (Pyle, 2013; Radley & Taylor, 2003; Woolhouse, 2019).

The time that the participants had to produce the photos depended on the context of the study, in addition to the aim. There were researchers who decided that the participants would take pictures in their presence (Pyle, 2013; Radley & Taylor, 2003). When the participants did not take the photos in the presence of the researcher, they had a set time to do it, e.g.: two weeks or less (Mandleco, 2013) or three to nine weeks (Whiting, 2015). Despite the varying time interval, researchers can provide extra time for participants who want to take pictures of specific situations (Ford et al., 2017).

Interviews

Before interviews, cameras can be collected by researchers and photos can be printed or organized (Mandleco, 2013; Oliffe & Bottorff, 2007; Pyle, 2013; Woolhouse, 2019). When participants used their own cameras, researchers requested participants to send photos in advance by email (Marsh et al., 2016). Furthermore, at the time of the interview, researchers allowed participants to choose the photos and the order in which they would be discussed (Marsh et al., 2016; Pyle, 2013).

Researchers conducted group (Marsh et al., 2016; Pyle, 2013; Woolhouse, 2019) or individual interviews (Ford et al., 2017; Liebenberg et al., 2014; Mandleco, 2013; Oliffe & Bottorff, 2007; Radley & Taylor, 2003; Whiting, 2015). Regarding the questions, semi-structured interviews can be used (Liebenberg et al., 2014). However, it is common for researchers to use explanations about the photos to guide interviews (Ford et al., 2017; Liebenberg et al., 2014; Mandleco, 2013; Oliffe & Bottorff, 2007; Pyle, 2013; Radley & Taylor, 2003). Probing questions can be asked when researchers realize that participants are being more introspective and need another stimulus (Mandleco, 2013; Marsh et al., 2016; Pyle, 2013), or when it is necessary to explore other aspects that are not captured in the photos (Ford et al., 2017). With regard to the location of the interviews, the researchers valued safe and private environments (Mandleco, 2013; Whiting, 2015). Participants had preferred locations (their homes) (Mandleco, 2013; Whiting, 2015) or the place where the study was being conducted, e.g: schools or wards (Pyle, 2013; Radley & Taylor, 2003).

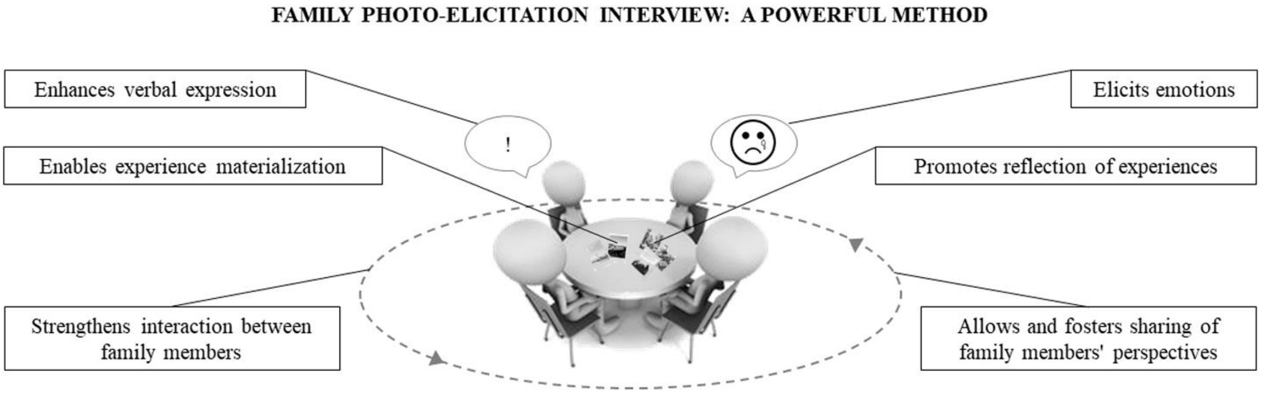
Generally, interviews are recorded and transcribed (Liebenberg et al., 2014; Mandleco, 2013; Marsh et al., 2016; Pyle, 2013; Radley & Taylor, 2003). Researchers analyzed the transcribed data and not the photos themselves (Marsh et al., 2016; Radley & Taylor, 2003; Whiting, 2015; Woolhouse, 2019). When there were many photos that represented an analytical category, researchers chose which one best represented the data before publishing it (Mandleco, 2013).

Pragmatic Aspects of Using Photo-Elicitation Interviews

In this section, we will focus on the discussion of pragmatic aspects based on our experience of using PEI to explore the narratives about hope of families of children and adolescents living with chronic conditions. Families of children and adolescents, between 8 and 18 years old, with chronic illness were recruited at a Brazilian pediatric hospital, during their hospitalizations or follow-up appointments. Children and adolescents determined who they considered their family members, and only those undergoing chronic illness experience were invited to participate. Family members choose their preferred place to be interviewed (e.g.: home or hospital environment). We tried to involve as many family members as possible during the interviews, but they were not always available. Hence, at least one dyad from each family was included.

The particularity of our empirical qualitative research was to use the PEI technique to collect data from families. Due to our experience we denominate our method as the "Family Photo-Elicitation Interview" (FPEI). FPEI goes beyond PEI technique, because it integrates aspects of family nursing theories when conducting interviews with families. Therefore, we consider FPEI as a method and not just a technique of data collection that use photos in interviews (Figure 2).

FIGURE 2. Family Photo-Elicitation Interview: characteristics identified by the authors.



FPEI is a powerful method because it can enhance engagement of family members in interviews. By using the FPEI, it was possible to involve families in the activity of taking photos, consequently they reflected on their experience before sharing it in interviews. This reflection was specifically beneficial for children and adolescents, who found that the photos enabled experience materialization and enhanced verbal expression of their experiences, therefore the interview duration increased.

Families did not have any difficulties in taking the photos. They were using their own smartphones cameras, and they were already familiar with the device. Families also did not demonstrate difficulties in following FPEI instructions. This may be related to the researchers' approach and the information provided in the consent and assent forms. The assent form included figures and suitable language for the pediatric population, which facilitated the process of explaining procedures and obtaining consent. All procedures and meetings conducted before the meeting for the family interview allowed for the strengthening of the researcher-participant relationship.

When conducting the interview with several family members, it was important to be in a place where they felt safe and comfortable to share their experiences. It was also important that the position that the participants and the researcher were sitting in favored the exchange of looks and the viewing of the photos. Photos shared were not necessarily taken for the empirical qualitative research, because some families chose to present photos produced before the research invitation. This allowed for knowing the experience of the phenomenon from the perspective of a longer period, such as from before the diagnosis.

FPEI strengthens interaction between family members, since it encouraged participants to talk and hear about theirs and others' experiences. Participants were able to choose who would start to share photos and the photos' sequence. The explanations for the photos guided the interviews. However, probing questions were asked by researchers to go deeper into some themes and generate more interaction between participants.

In the interviews it was the researcher's role to ensure that all family members had the opportunity to speak and be heard. We were also aware of the power of FPEI to elicit emotions. These were identified through voice tone, facial expressions, laughter and tears. Despite FPEI promoting emotion sharing, there were moments where we thought that it was necessary to interrupt the interview and offer emotional support. This included such actions as offering a tissue, asking if participants wanted to change the subject of the conversation, or offering a hug. These strategies were used to ensure the therapeutic potential of interviews for participants. After a short interruption, interviews were restarted.

Furthermore, this method allowed family members to talk about some topics for the first time, and this enabled family member to know each others opinion and interact with each other. These aspects can be illustrated by the following comments, from an interview conducted at the family home. The mother presented a photo of the whole family, taken before her daughter's cancer diagnosis. For her the photo refers to the hope of returning to the normality prior to diagnosis. The photo elicited memories and emotions about the moment of diagnosis and allowed the researcher to explore family interaction, revealing unknown experiences and emotions:

> ***Mother:*** *Immediately after diagnosis, wow! I was really, really bad (she speaks with an emphatic voice). I came home, I left her in the hospital, and I was really bad. I couldn't think of anything other than bad things.*
> ***Researcher:*** *What did you feel at the moment of your diagnosis? [directing the question to the child]*
> ***Mother****: I think she didn't even know what was going on [mother replies before the child].*
> ***Child:*** *I was sad, because I was worried if I was going to walk afterwards. Then I felt normal, because the doctors said I was going to have chemotherapy. But at the same time, I was sad, because the doctor said that I would have to start to be hospitalized.*
> ***Researcher:*** *What do you think your mom was feeling at the time?*
> ***Child:*** *It's because at the time she was very strong (...) [mother interrupts child's speech].*
> ***Mother:*** *I never let her see anything [emphatic speech].*
> ***Child:*** *I realized that she was sad. She was devastated when the doctor said it was a malignant tumor. She made sure not to cry. My father was also very sad. I felt very sorry for her. Then I started to laugh and said: Oh mom, don't be sad!*
> ***Researcher:*** *Did you know that? [directing the question to the mother].*
> ***Mother****: No, No, No! I though she didn't understand the seriousness [surprised voice].*

Due to the method of eliciting topics for discussion, aspects of the interview environment can refer to past experiences and significant objects can be added, even when they were not represented in photos. Therefore, the interview environment can empower participants to share deeper data.

DISCUSSION

We present a new perspective of PEI, known as the *"Family Photo-Elicitation Interview"* (FPEI) in the pediatric context. Previous studies have not addressed considerations about using PEI specifically for families. We describe FPEI as a powerful method to use with families in the pediatric and chronic illness context. This method aims to give voice to all family members, especially children and adolescents. FPEI, besides being playful and participatory as in PEI, strengthens family interaction and allows family members to share their perspectives. By eliciting emotions, FPEI becomes a therapeutic method, in which family members reflect about experiences, from each other and their own perspectives.

The FPEI method gave voice to all family members, mainly children and adolescents, as photos enabled them to materialize their experiences. Participants choose the photos that they would present and what they would like to share with family members, allowing researchers to interfere less in the interviews. Other studies with PEI demonstrated that participants can control the interviews (Ford et al., 2017; Oliffe & Bottorff, 2007; Pyle, 2013; Whiting, 2015;

Woolhouse, 2019). Participant control started with the production of the photos and continued when they decided what they wanted to share in the interviews, mainly when they used digital cameras that allowed for the review and deletion of photos (Ford et al., 2017; Marsh et al., 2016). This whole process made participants active, minimizing the traditional role of the interviewer, which encouraged a reliable self-representation of the experiences through the conversation about the photos. Also it is effective when used with people who have difficulty to verbally express or share abstract ideas, such as children (Ford et al., 2017; Mandleco, 2013; Marsh et al., 2016; Pyle, 2013; Whiting, 2015; Woolhouse, 2019).

With photos, during the PEI, there is no need to maintain direct eye contact with the interviewer, which facilitates the expression of experiences (Ford et al., 2017). This also happens with FPEI, where family members do not need to maintain eye contact as there are photographs to look at. This process can also be considered similar to sharing a family album, adding the aspect of knowing the other's perspective about the subject of the photo.

It is known that photos invite the participants to engage in a collaborative interaction, to express their beliefs, feelings and opinions, challenging the assumptions made by others (Mandleco, 2013; Marsh et al., 2016; Pyle, 2013; Radley & Taylor, 2003; Woolhouse, 2019). Although FPEI enhances interactions between family members, there may be participants who do not feel comfortable sharing certain information with their family members. Therefore, as evidenced by other methods of performing a family interview, it is important that researchers evaluate the possibility of conducting individual interviews with the participants (Eggenberger & Nelms, 2007; Voltelen et al., 2018).

FPEI is a fun and engaging method, and it helps to elicit a longer and more comprehensive interview than the more traditional methods. In fact, FPEI enabled the elicitation of emotions and the interaction between family members, so they could know aspects about each other, previously unknown. By using photos researchers can have a clear image of the participant's experience, including time and space. Thus, photos transform the invisible into the visible (Radley & Taylor, 2003), that is, make the experience tactile (Oliffe & Bottorff, 2007; Whiting, 2015). This method is “cathartic”, as it allowed the participants to reflect on their previous experiences even before the interview started (Marsh et al., 2016; Oliffe & Bottorff, 2007).

Our pragmatic experience showed that children and adolescents and their families were able to reflect on their experiences. When the photos did not show all the child’s reflections, it was possible to integrate elements of the environment into the interview. Another study also reported that this occurred with participants, who presented, in addition to photos, toys, art work, or playrooms to illustrate their experiences (Ford et al., 2017). Environment can influence FPEI conduction. Hence, researchers must know the advantages and disadvantages of their interview environment. The interview environment is related to the study’s aim, however, whenever possible, it would be better if participants choose where they feel most comfortable to be interviewed (Eggenberger & Nelms, 2007; Voltelen et al., 2018).

In our results we presented methodological aspects that can guide the construction of studies with PEI, and pragmatic aspects of FPEI use. However, a study’s success depends on the correct conduct of all the steps and also on the researcher's ability to implement a technique or method of qualitative data collection (Blinded for peer review). As with other studies with family (Eggenberger & Nelms, 2007; Voltelen et al., 2018), researchers will face challenges in conducting the FPEI, since there are difficulties in recruiting family members and scheduling an interview with all the family. Although the FPEI has proved to be an appropriate method for the pediatric context, we agree with other authors that it is important to have a flexible approach and consider that this data collection method may not suit everyone (Ford et al., 2017; Pyle, 2013; Whiting, 2015).

CONCLUSIONS

This article presents a new perspective of PEI, the FPEI method, highlighting its use in studies with families in the pediatric context. FPEI seems to be an effective method for qualitative data collection, especially when researchers aimed to identify subjective phenomena, family interactions and perspectives of children and adolescents. Methodological aspects of the PEI presented in this article can guide novel researchers to construct future studies. Furthermore, pragmatic aspects described in this article may help researchers to know the process of using FPEI, mainly with families living with chronic illness in the pediatric context. Our experience with the FPEI showed us that its use promoted the expression of beliefs and feelings of family members, including pediatric patients, more easily, in addition to allowing us to understand better family interactions and experiences with chronic illness. Therefore, we recommend that future studies explore the use of the family photo-elicitation interview in other contexts, different from pediatrics, such as geriatrics or palliative care.

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4.3 Terceiro artigo - Estudo qualitativo empírico. *“Waves of Family Hope”: Narratives of Families in the Context of Pediatric Chronic Illness*

Este tópico contém o terceiro artigo, estudo qualitativo empírico, que compreende o objetivo específico III da tese. Este estudo narrativo publicado na Revista Latino-Americana de Enfermagem (RLAE), está intitulado como *“Waves of Family Hope”: Narratives of Families in the Context of Pediatric Chronic Illness* (LEITE et al., 2021). A RLAE é um periódico brasileiro, de alcance internacional, que publica pesquisas científicas de enfermagem e de outras áreas de interesse para profissionais da área de saúde. Esse prestigioso periódico brasileiro possui 1,442 de fator de impacto (2020). Segundo o JCR 2020 *NURSING-SCIENCE*, a RLAE estava classificada no segundo quartil das revistas de enfermagem, ou seja, foi considerada a 68ª melhor revista da área de enfermagem, de um total de 146 revistas.

Referência: LEITE, A. C. A. B. et al. Waves of family hope: narratives of families in the context of pediatric chronic illness. **Revista Latino-Americana de Enfermagem**, v. 29, p. e3504, 2021. doi: 10.1590/1518-8345.5515.3504

Waves of family hope: narratives of families in the context of pediatric chronic illness

Objective: To analyze narratives about the experience of hope of families in the context of pediatric chronic illness. **Method:** A narrative research using Family Systems Nursing as a conceptual framework. Three families of children and adolescents diagnosed with complex chronic illness participated in this study, totaling 10 participants. Data collection was developed using family photo-elicitation interviews. Family narratives were constructed and analyzed according to inductive thematic analysis with theoretical data triangulation. **Results:** The analytical theme – *Waves of Family Hope in the Context of Pediatric Chronic Illness* – is composed of four different types of hope: uncertain hope, caring hope, latent hope, and expectant hope. Movement through these hopes generates a driving energy and depends on a number of factors: support, information, searching for normality, and thoughts and comparisons. **Conclusion:** The results highlight the interaction and reciprocities of the members of the family unit, and the dynamics of hope, and illustrate the different types of hope and the factors that influence them. This study highlights the experience of hope as a family resource rather than just an individual resource, and supports health professionals in the planning of family care considering hope as an essential and dynamic family resource.

Introduction

In pediatrics, complex chronic health conditions include chronic illnesses and infectious diseases(1). They are characterized by long duration and continuous care. During chronic illnesses, there are periods of clinical instability, which can lead to hospitalizations and complex care. Usually, there is no cure and children and adolescents need continuous health monitoring and support(1). Due to this, the diagnosis of a pediatric chronic illness impacts all family members, which alters family relationships and dynamics(2-3). The diagnosis affects children and adolescents on physical, emotional, and psychosocial levels(4-5). Therefore, families recognize that the disease requires changes in routine and responsibilities(6). In this context, the family needs to adapt, and hope is one of the resources used in times of crisis(4,7-8).

Hope is an inherent resource of human experiences(9). Several authors have explored the concept of hope, in different contexts and from different perspectives(8,10–12). From the point of view of psychology, hope may be related to resilience(13). However, as it is a complex concept, there is no common definition to be applied universally(9,14). In the pediatric context, recently a thematic synthesis of qualitative studies identified the experience of hope in families living with pediatric chronic illness(15). The review included 31 studies, and evidenced hope as a family resource. Family hope is dynamic, and its changes depend on the family's experiences with chronic illness, time, and relationships between family members. Unlike other studies, the review highlighted the connectivity of hope among family members, and how they seek to balance it(15).

In addition, the review highlighted that most of the included studies presented only one family member's perspective on hope. It was recommended for future qualitative studies to: include the family unit; identify the experience of hope in different types of chronic conditions; and use iterative data collection to explore deeper children's and adolescents' narratives(15). Alongside these knowledge gaps, research priorities in pediatric nursing have indicated the need for studies with families, which include the perspectives of several members. Also, there is a need for research on long-term illness, family-centered care, the impact of the illness on families, and resources that support the family in the context of the illness(16-17). Hence, the question for this study was: How do families in the context of pediatric chronic illness experience hope? This study aimed to analyze narratives about the experience of hope of families in the context of pediatric chronic illness.

Conceptual Framework

This study adopted the conceptual framework of Family Systems Nursing(18-19). This framework highlights that the family is a care unit, and that the family system is a part of a larger suprasystem and is composed of several subsystems. The family unit is greater than the sum of its parts – that is, its individual members. When a family member is affected (with a diagnosis of a chronic illness, for example) its members are also affected to varying degrees(19). Family organization and functioning are altered, and family members seek a balance between change and stability. The family balance is in the coexistence between change and stability in the different phases of the life cycle(19).

Families studies that use this theory are able to explain individual and family functioning through observation and analysis of family interaction and how they use the resources available to achieve a family goal(19). Because of the recognition and disseminated use of this theory both in practice and in research, this study uses Family Systems Nursing as the conceptual framework to explore how the family unit uses the resource of hope.

Method

Type

This is a narrative research(20) which used family photo-elicitation interviews(21). Narrative research is a complex and dynamic method that provides an overview of research based on constructing and interpreting narratives as stories of experience. We chose Squire's (2013) experience-centered narrative approach to explore the phenomena of this study. These types of narratives involve movements, successions, progressions, or sequences, usually temporal, and are connected with a significant fact, which is a changing point in the narrator's life – for example, a diagnosis of chronic illness(20). In the present study, narratives were structured as follows: introduction, development and conclusion. They contained elements such as characters, time, space, environment and plot. The process of narrating introduced the representation of the *I*, because everything that was told had a meaning. Therefore, this method aimed to understand the experience of individuals through the reports of experienced events and the co-constructed narratives that were stories and statements constructed from dialogues between the participants(20).

Scenario

A convenience sample of participants was recruited face-to-face in 2019, when the children or adolescents were hospitalized in the pediatric wards of a public university hospital, located in the interior of the state of São Paulo, Brazil.

Population

Children and adolescents diagnosed with complex chronic illness and their families were invited to participate in the research. In this study we considered "family members" as all people that children and adolescents described as such(19). Considering the experience of the diagnosis, children and adolescents were excluded if they had been newly diagnosed (less than six months). Family members who did not actively participate in the care or daily routines of the child or adolescent were excluded, as were family members under eight years old. To participate in this study, at least one family dyad was included. The number of family members interviewed varied according to their availability. The determination of the number of participants included in this study and the interruption of recruitment occurred when the data collected were sufficient to achieve the aim proposed(22). This was possible because of the exhaustive data analysis conducted concurrently with data collection, which provided an in-depth analysis of the data of each participant and of the families, as well as the similarities and uniqueness of the experience among them.

Data collection

In the pediatric hospital in 2019, families were personally invited to participate in the study. In this first meeting, after explaining about the study and obtaining the written consent/assent, a female researcher built a genogram and ecomap of the family with the child or adolescent. The guiding question was: Tell me about who is your family? In the end of first meeting, the researcher invited the family to take photos about their perspective of hope, using their own smartphone cameras. The photos were used in the second meeting to perform a family photo-elicitation interview(21). This method of data collection elicited narratives and promoted reflection of the family experiences(21). When necessary, questions (see Figure 1) were used to deepen data collection. Some family members preferred individual interviews, without using their own photos to elicit the narratives (Father, Family A and Aunt, Family B). At least two meetings with each family were held, each meeting lasting about an hour and a half. The detailed data collection process is illustrated in Figure 1.

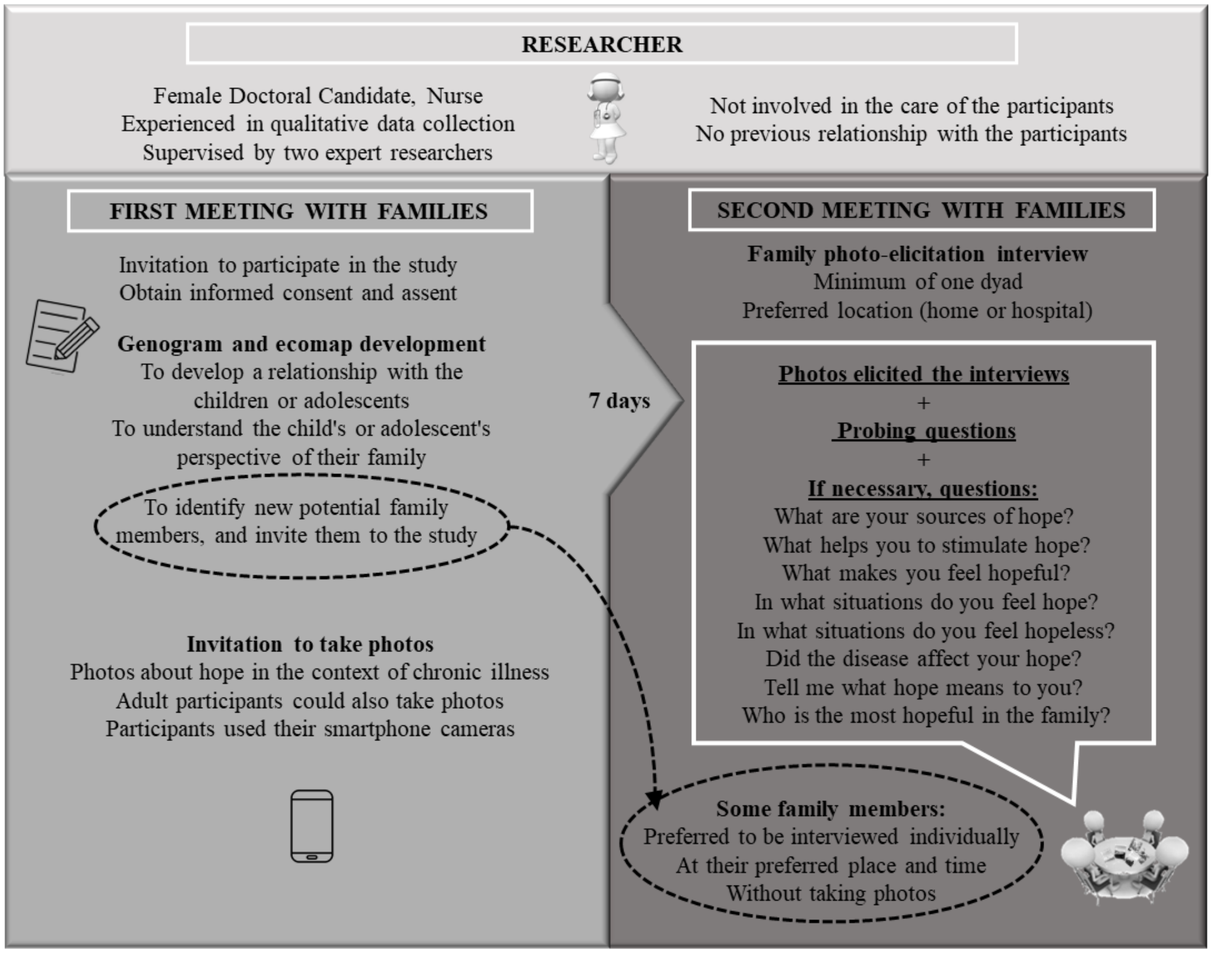


Figure 1 - Process of data collection

Data analysis

Inductive thematic data analysis was used to analyze family narratives, and the following phases were performed(23): (I) Familiarization of data from repeated readings of the transcribed interviews. Subsequently, narratives of each family were constructed. Each family narrative was composed of family and/or individual interviews. Family narratives were structured with introduction, development, and conclusion, and they contained elements such as characters, time, space, environment, and plot. (II) Initial codes were identified inductively from the narratives. The QDA Miner Lite®, qualitative data analysis software, was used in this stage; (III) From the similarities and differences between the initial codes, a narrative synthesis was constructed inductively. In this step, it was possible to identify the different types of hope, the factors that influence them, and the similarities and uniquenesses in the families' experiences. (IV) An analytical theme was developed inductively from the narrative synthesis, according to the conceptual framework chosen. The analytical theme was also constructed based on theoretical data triangulation(24), with the results from the thematic synthesis of qualitative studies about hope(15); (V) The analytical theme was named and refined.; (VI) The results were constructed, presenting the analytical theme: "Waves of Family Hope in the Context of Pediatric Chronic Illness". The analytical steps were performed by the first author and discussed and validated by the three other authors, who are experts in this type of analysis. The photos elicited the participants' narratives, but these images were not analyzed, only their narratives. The set of families' narratives is 55 pages long. The family genogram and ecomap helped the researchers to contextualize the data and to better understand the family structure and dynamics. Field notes helped researchers reflect on the data. Transcripts and analyses were not shared with participants.

Ethical issues

This study was approved by the ethics committees (Ethical Approval Numbers: 2.902.779: 2.902.779; 2.911.296; 9146418.7.0000.5393). The written consent of adult participants was obtained. Children and adolescents affirmed their desire to participate in the study by signing the Assent Form when a responsible adult allowed their participation.

Rigor

The rigor of this study was ensured by(25-26):

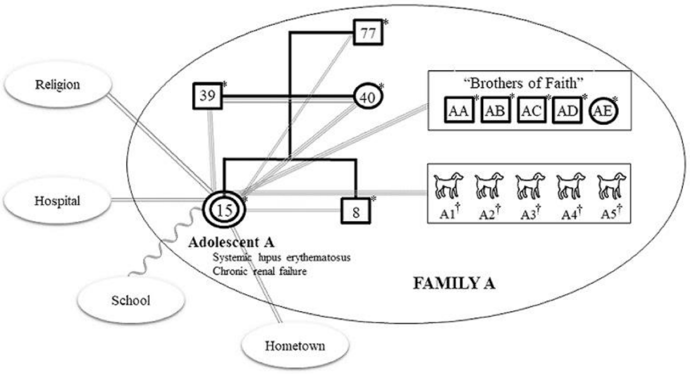
- Credibility - rigorous data analysis developed by a research team, supported by the quotes that illustrate the findings and audit trail.
- Transferability - presentation of families' sociodemographic data.
- Reliability - detailed description of the method, following the consolidated criteria for reporting qualitative research (COREQ)(27).
- Confirmability - presentation of the limitations and strengths of the study and by the researchers' reflexivity.

Results

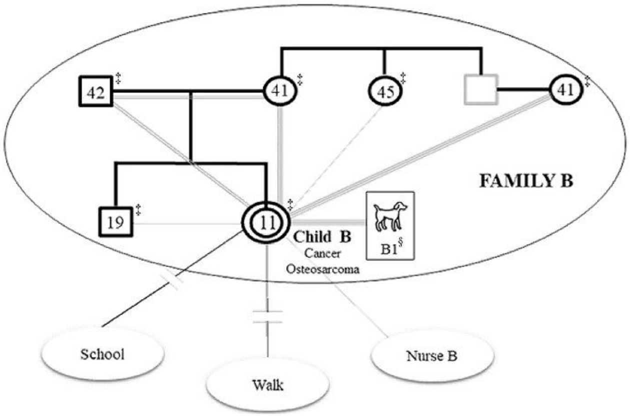
This study included 10 participants from three families - Family A: Adolescent A, Mother and Father (n=3); Family B: Child B, Mother, Father and Aunt (n=4); Family C: Child C, Mother and Sister (n=3). Only one family refused to participate as they did not want to bring up memories of the treatment. Figure 2 shows in detail the description of family characteristics and their genograms and ecomaps.

Figure 2 - Description of family characteristics and their genograms and ecomaps. Ribeirão Preto, São Paulo, Brazil, 2019

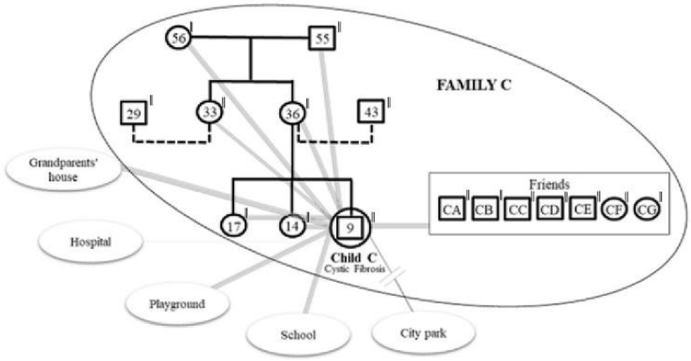
Family A: Adolescent A, a 15-year-old girl diagnosed with systemic lupus erythematosus which triggered chronic renal failure. She considered as family members her healthy 8-year-old brother, her mother, her father, and her maternal grandfather. Beyond blood ties, she mentioned as part of her family her 5 dogs and her brothers of faith, who are people she met through her religion, Jehovah's Witnesses



Family B: Child B, an 11-year-old girl diagnosed with osteosarcoma in her right knee. She indicated as her family members her healthy older brother, father, mother, mother's sister (aunt by consanguinity), and the wife of her maternal uncle, her aunt by marriage. She also highlighted the very strong bond she has with her dog, which she considers as a family member



Family C: Child C, a 9-year-old boy diagnosed with cystic fibrosis. He considered his family members to be his two healthy older sisters, mother, aunt, maternal grandparents, mother's boyfriend, and aunt's boyfriend. His 7 friends, including his 5 male friends, a female friend, and his teacher were also considered part of the family, and he highlighted a very strong bond with them



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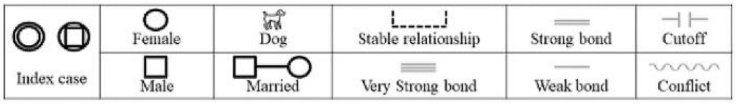

*77, *39, *40, *15, *8, *AA, *AB, *AC, *AD, *AE = Family members of Family A; †A1, †A2, †A3, †A4, †A5 = Dogs of Family A; ‡42, ‡41,‡45, ‡41,‡19, ‡11 = Family member of Family B; §B1 = Dog of Family B; ‖56, ‖55, ‖29, ‖33, ‖36, ‖43, ‖17, ‖14, ‖9, ‖CA, ‖CB, ‖CC, ‖CD, ‖CE, ‖CF, ‖CG = Family members of Family C

Waves of Family Hope in the Context of Pediatric Chronic Illness

The analytical theme is presented through a metaphor with ocean waves, which we entitled: *Waves of Family Hope in the Context of Pediatric Chronic Illness* (Figure 3). The family unit is represented by the wave, and the dynamics of family hope by its movement. There are different types of ocean waves; depending on their movement, they are able to propel, immerse, or keep people afloat, representing the same parallel of *waves of family hope*. The characteristics of each wave represent the individuality of the experience of each family.

Waves of family hope are composed of four different types of hope: uncertain hope, caring hope, latent hope, and expectant hope. The movement through these types of hope depends on factors such as: support, information, searching for normality, and thoughts and comparisons. In Figure 3, these factors are compared to those that influence the formation and movement of waves: sun, wind, seabed, and moon. Therefore, the waves of family hope are the result of the interaction of family members (their relationship, roles, alliances, power, affiliations and cohesion), time (past, present and future related to lived and expected experiences), and context (such as cultural context and type of chronic illness) which present factors that influence their dynamics. Because the waves of hope are dynamic, they will not always be composed of the 4 types of hope, or they will be experienced by the family in a longitudinal way. The waves of hope are forming and breaking constantly.

The waves of family hope in the longitudinal experience of chronic illness begin with the diagnosis. At this moment, the family experiences *uncertain hope*. The rise in family hope occurs over time. When the child reaches a stable clinical condition during treatment, the family experiences *caring hope*. *Latent hope* occurs when there is a worsening of the child's clinical condition, and the family feels that hope has been lost, even though it is still present without manifesting. *Expectant hope* is experienced by the family as they project a desired future, in which the only remaining resource is hope.

The waves always generate energy due to their driving movement. In our results, this energy represents a family member who is able to drive energy through wave movements to propel family hope. Wave formations and movements occur constantly. Due to this dynamic process, families experience at different times the different types of hope throughout the illness trajectory.

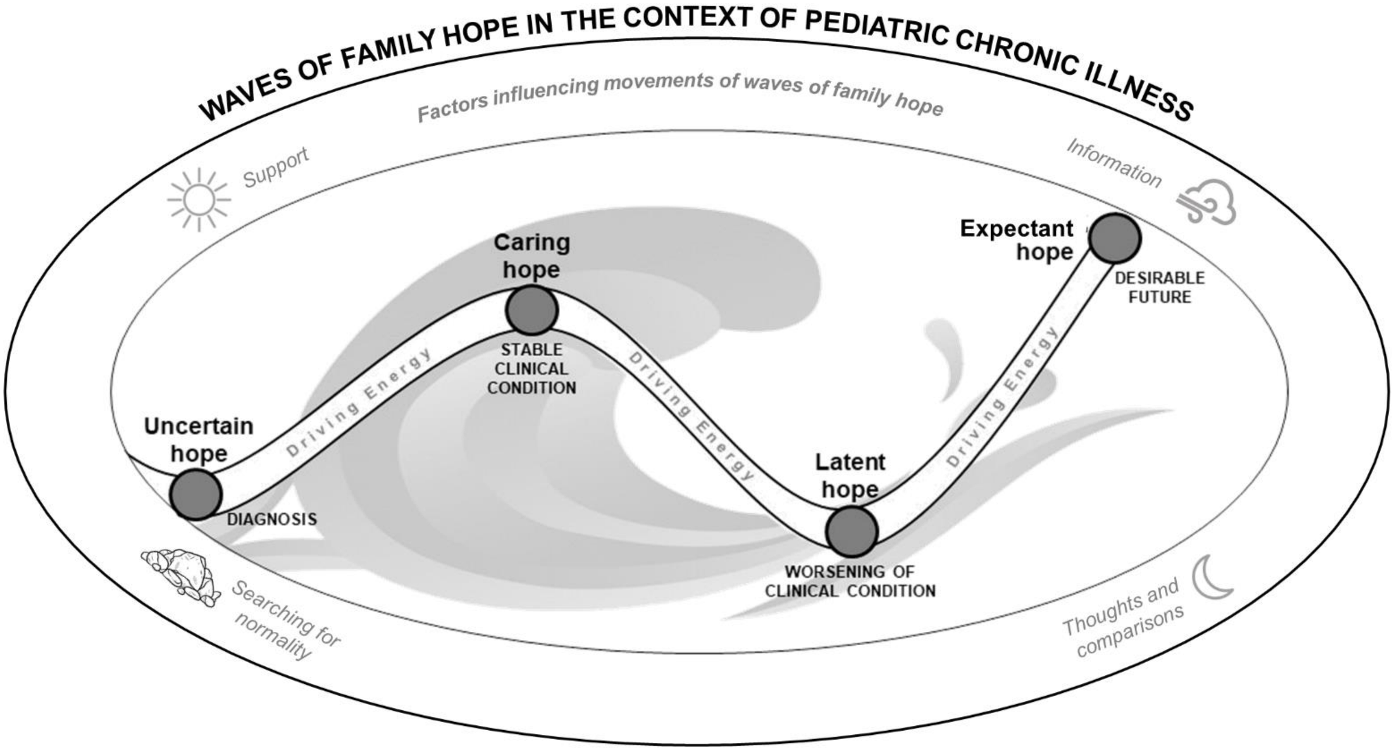

Figure 3 - Waves of Family Hope in the Context of Pediatric Chronic Illness

The types of hope identified in this study are described below. Table 1 presents the similarities between the narratives of types of hope among the families. Table 2 shows the unique experiences within the family related to the types of hope.

Table 1 - Similarities in family narratives (n=10) according to types of hope. Ribeirão Preto, São Paulo, Brazil, 2019

Types of Hope	Similarities in family narratives
Uncertain hope	*At the time of diagnosis, there was a no hope of having my daughter here with me. I was very scared, very afraid of losing her* (Mother, Family A). *When my brother was born, doctors said he was not going to live past three months. It was quite shocking at the time* (Sister, Family C). *Lupus is a disease. Losing a kidney and having a chronic kidney disease is a second disease. Then I realized that I would have to deal with two diseases. Lupus is a very serious disease and it does not come alone. It comes and triggers other diseases* (Mother, Family A).
Caring hope	*After the doctors told me that the tumor is getting a lot smaller, it gave me more hope* (Mother, Family B). *I love to play with my friends on the street. I also enjoy playing online games with them* (Child, Family C). *I feel a lot of joy, love, and I am happy around my dogs* (Adolescent A). *We are also happy, but we do not forget the illness. The important thing for us was that she was walking, that she was normal* (Father, Family B). *As long as the information is correct, I'd rather receive it* (Mother, Family B). *My faith increased when I went through difficulties* (Father, Family A). *Nurse B told me several cases of people with osteosarcoma who started walking again and that gave me hope* (Child B).
Latent hope	*There was a day when my wife came to bring my daughter and I had to come to help. One boy helped us to take my daughter out of the car to put her in the wheelchair. Wow, what I saw there, broke my heart* (Father, Family B). *My worry holds back my hope. I see a lot of cases in the hospital, so I keep thinking if I have to amputate my knee, I get worried* (Child B). *Prayer helps me in the moments of hopelessness* (Father, Family B). *He had relatives, friends, brothers of faith from another city who collected money to help us* (Mother, Family A).
Expectant hope	*I have to hope, so you have no other option. That's what I tell you, there is no other option, there is only hope* (Mother, Family B). *My hope was that I could stay at home, thus having a more normal life, have a better way of life* (Adolescent A). *I think that after Child B has surgery, physiotherapy, she'll soon be fine. Normal, walking. So, it will be a normal life. She will be a worker, she will study, she will be like my daughters. Go to college, do everything* (Aunt, Family B).
Driving energy	*Sometimes I feel guilty because I think he came to the hospital because I missed something. Sometimes I see that I missed something, and I could have been better* (Mother, Family C). *For us, hope is in our belief that there will be a new land, that there will be no more diseases, no more pain* (Adolescent, Family A). *I wanted my son to be a normal boy. But he really isn't, but I wanted him to be. That he didn't have to undergo this treatment, that he was a boy with impeccable health* (Mother, Family C).

Table 2 - Uniqueness in family narratives (n=10) according to types of hope. Ribeirão Preto, São Paulo, Brazil, 2019

Types of Hope	Uniqueness in family narratives
Uncertain hope	*At the time I thought: What is this? I had never heard about this. The doctor told us that if it was leukemia it would be good. She said that lupus is worse than cancer, because there is no cure* (Father, Family A). *I remember when my daughter had a biopsy to see if the tumor was malignant or benign. I chose not to think about the malignant option. So, I ran away from what could be reality* (Mother, Family B). *I did not accept my son's diagnosis. It was a shock! I arrived here at the hospital and they were very short and rude: "Your son has cystic fibrosis. This is a disease and he can live for three months, or until you take care of it." That was when my floor fell away* (Mother, Family C).
Caring hope	*I wanted to have a dog to play with, but my mom doesn't want to give it to me* (Child C). *He says that he really wanted a dog, that he wanted to have a transplant to have a dog. But my son is not a transplant case. I like dogs, but not in my house because of dirt, of being smelly. I have a cleaning compulsion* (Mother, Family C). *Animals do not affect my hope. My hope is based on my faith* (Father, Family A).
Latent hope	*Now, when my son was hospitalized, I was no longer needed in my work. It affects my hope* (Mother, Family C).
Expectant hope	*The possibility of transplantation gives me hope for something better. If she does it and it works, my daughter will have a much better quality of life than she is having (*Mother, Family A). *The hope that I have, in fact my hope is in God to heal it* (Father, Family B). *I would not like my son to have a transplant because there are many risks. I am not focused on healing because I already know that it is a disease that has no cure. I expect new remedies to take more effective action* (Mother, Family C).
Driving energy	*"Brothers of Faith" provided spiritual, emotional, and practical support. They come to visit me when I am hospitalized. Some send comfort messages, that I will improve soon, that I will go home soon, so that I can be well* (Adolescent, Family A). *My aunt is the most hopeful, because when I'm sad, sometimes she tries to cheer me up. She tries to get me up, she takes me for a ride. She doesn't let me be sad, she is always trying to do something to make me happy* (Child B). *My aunt, my mother's sister, gives me a lot of hope, because she has a lot, a lot of faith. She says that we should never be thinking about the bad side of things* (Sister, Family C). *My sister is the most hopeful of the family. Because she prays a lot, she says: Think about God, have faith in God. God is everything for us. Sometimes her hope gives strength. You talk to a person who is positive, you will feel positive too* (Mother, Family C). *If I have faith, I have hope. The text in the Bible brings comfort to me and my family* (Father, Family A). *Sometimes my mother takes away my hope, because she cries a lot, she receives the information [of my brother's hospitalization] and instead of thinking about the positive side, she starts to cry* (Sister, Family C).

Uncertain Hope

At diagnosis, families begin a wave of experiences and emotions. Hope seems invisible because uncertainty prevails. Therefore, families experience *uncertain hope,* which is related to fear of the unknown, fear of death, suffering, and emotional shock. Family members try to protect the child from *uncertain hope* by hiding emotions and avoiding talking about the seriousness of the situation. *I didn't even cry during the diagnosis consultation. But it is so difficult. My daughter cried. If I cry in front of her it seems that it gets even more complicated. I was holding on, so as not to show that the situation is so serious* (Father, Family B).

Uncertain hope was evidenced by questions about the cause of the illness and the family's difficulty in accepting the diagnosis. Uncertainty was also related to the type of diagnosis. Diagnosis of cancer has a stigma, although it is the only chronic illness included in this study with the possibility of a cure, and cystic fibrosis is associated with early death. To reduce uncertainty, families need to obtain information about the diagnosis. However, this did not always help to promote family hope, but in fact reinforced the thoughts of uncertainty, especially when the information was related to negative outcomes, such as death.

Gradually, after the diagnosis, family members reorganized their responsibilities and family plans to take care of the child. The family looked for situations and factors that could propel family hope, so that they could move on from uncertainty. However, the maintenance or return to *uncertain hope* was related to the possibility or discovery of new diagnoses.

Caring Hope

Families experienced *caring hope* when children had a stable clinical condition. The possibility of an effective treatment, and positive impact of the treatment on the child's clinical condition helped to propel and maintain the wave of *caring hope*. *Caring hope* was also related to the decrease in the length of the child's hospitalization and their well-being and happiness. *It gives me a lot of joy and happiness to know that my brother doesn't need to be hospitalized. Because the other children with cystic fibrosis practically live in the hospital* (Sister, Family C).

This context allowed children to maintain a positive perspective and *feel normal,* as well as their peers, when they performed daily activities and forgot about their treatment and diagnosis. As a daily activity, all children mentioned playing with dogs. For them dogs could promote hope by providing happiness and a feeling of normality. Child C expressed a desire to have a dog, but his mother would not allow it because she thought it would hinder his treatment. Other family members evidenced the positive impact that dogs had on the child's and family's well-being. The exception was the father of Family A, who believed that the maintenance of *caring hope* come from faith.

Family members did not have the same feeling of normality as children. The responsibility for care, signs of illness, and symptoms and concerns about episodes of urgency or worsening of the clinical condition constantly reminded them of the fragility of the child's health and the dynamism of family hope. Upon receiving clear, empathetic, and realistic information about treatment, families felt more optimistic. Support for religious beliefs and faith were also factors that maintained the family's optimistic outlook and helped them cope with treatment. In addition, the families wished to have similar experiences with good outcomes, to have positive thoughts, and consolidate their *caring hope*.

Latent Hope

Families experienced *latent hope* when the child's clinical condition worsened. The decline in their optimistic perspective affected the movement of waves of family hope, and families felt as if they had lost hope. Invasive treatment, or situations that evidenced the child's fragility, reinforced *latent hope*. *When she lost her kidney, she started hemodialysis, which is a very aggressive treatment. So, my hope was unsettled* (Mother, Family A).

Latent hope was also reinforced with thoughts about death and comparisons with bad outcomes. One of the families' lack of financial support was a factor that influenced the maintenance of *latent hope*. Families considered the hospital context to be a constant reminder of the child's health condition. During hospitalizations, it was difficult for families to maintain optimistic thoughts, or to distance themselves from negative cases or information about the illness. In an attempt to protect themselves from *latent hope*, families tried to neutralize thoughts about worries and death, and avoid people who would make negative comments about the child's condition.

The resources used by families to let go of *latent hope* were faith, and support among family members. Beliefs arising from faith in the divine brought comfort in times of crisis, and a more optimistic view of the situation. The emotional, financial, and instrumental support among family members helped to cope with the crisis and search for the propulsion of family hope.

Expectant Hope

When a family's resources to maintain family hope were depleted, what remained was *expectant hope,* which was directed towards the future. For the near future, families expected a daily routine without the need for treatment, or, at least, a decrease in the complexity or amount of care. Families' plans for the future were affected by the illness and treatment. Therefore, families replanned their dreams and started to value the small things in life. *I had a lot of dreams and after the diagnosis I lost my dreams. After the diagnosis everything changed in my life. Everything was normal. Before I did not value small things, today I do* (Child B).

The future projected by families with expectant hope envisioned the health of the child - as well as of the other healthy members of the family, or as being the same as it was prior to the illness. Also, in this desirable future, children would live a *normal* life just like their healthy family members; they would study, work, and be happy. However, families knew that the reality of the future depended on the type of treatment available.

For Family A, a kidney transplantation would be a source of hope, but it would not bring the cure, because the need for treatment would remain. Family B wanted the cure for cancer, and they redirected their lives and hopes towards reaching this possibility. Family C believed that lung transplantation would not be the best treatment; however, research about new medications could offer more effective treatment. They desired a long, high-quality life for Child C. The dynamics of expectant hope were related to changes in the child's clinical condition, which led to new perspectives for the future, or a return to other types of hope.

Driving Energy

The waves of hope are dynamic and generate *driving energy*. This is represented by a hopeful person in the family, who is able to promote family hope in times of crisis. Family members reorganized their responsibilities and family plans to take care of the child. Mothers assumed the responsibility of being the primary caregiver of the child. Although mothers were hopeful, they felt overburdened with the primary caregiving responsibilities. Due to the responsibility of care, mothers also felt guilty during periods of worsening of the child's clinical condition. Given this scenario, mothers were not able to be the family reference for the responsibility of promoting the *driving energy* of family hope.

All family members were able to identify the person who could *drive the energy* of family hope in times of crisis. This was accomplished through speeches and optimistic thoughts, faith in empowering beliefs, prayer, emotional support, financial support, visits, and playing with the child. Each family identified the *driving energy* person: for Family A, it was the *brothers of faith*; for Family B, the aunt; and for Family C, also the aunt. These persons had a strong emotional bond with family members, but they did not have the responsibility of daily care, which led them to have a more optimistic perspective. "*Brothers of Faith" are always on hand to help us. They have always supported us, through the words of God. This strengthens me. They also help me with money. They were with open arms to help us* (Father, Family A).

Although Family B's aunt believed she could influence family hope, she did not identify her hope as being influential. Some family members identified who was able to interrupt the propulsion of waves of family hope and, consequently, the driving energy. For the members of Family A, their religious beliefs protected them from the influence of others' hopelessness. In Family B, Child B identified his brother as the promoter of her hopelessness. Sister C believed that her mother promotes hopelessness in the family. *My brother takes away my hope. He and I fought a lot, he is very sincere. Then one day we were talking, that I forgot to take the capsule, my medicine in the morning. He said something that hurt me: If you continue like this, you will lose your leg! It takes away hope* (Child B).

Discussion

This study enabled us to identify the narratives about the experience of hope of families of children and adolescents living with chronic illness. The results showed that the illness impacts family members differently throughout the chronicity process. However, individual hope developed into a family resource due to connectivity between family members. Family processes are based on interactions between family members, who support each other, share affection and communicate. In this process there can also be conflicts, so families look to their strengths to face challenges and crises(28-29). Our results demonstrate that families used family hope to maintain a positive perspective. Emotions, behaviors, and positive thoughts from adult relatives, especially parents, generate security, emotional regulation, and less suffering for children, and in addition restore hope(9,28).

The results showed the dynamics of family hope through the experience of different types of hope during the process of chronicity. Hope is a resource with many faces, that is always present, even if it its presence is not consciously registered(9). This characteristic appeared in the study results and was related to the family crises being experienced, such as the moment of diagnosis and worsening of the child's clinical condition, represented by uncertain hope and latent hope.

The feeling of uncertainty is usually present in the families of children and adolescents living with chronic illness. A study developed with parents in the context of pediatric palliative care showed that their experience of hope was based on uncertainty(30). The uncertainty was related to the concern about the worsening of the child’s health, and his death, leading to an abrupt loss of hope(30). However, another study showed that hope was a resource used by parents in anticipatory grief, which is the feeling of grief that occurs before an imminent death. Even after the child’s death, parental hope was present through the belief that the child would be in a better place, or that one day the parents would find them again(31). Differently from the study mentioned before, family hope was promoted by avoiding thinking about the possibility of the child's death. Our results also demonstrated that uncertainty was the feeling that promoted uncertain hope and was mainly related to the moment of diagnosis.

Corroborating our results, hope is considered by parents of children and adolescents with chronic diseases as the first and last strategy for dealing with moments of crisis(30). We highlighted that types of hope act as waves of family hope, changing in the face of different factors and unique family experiences. Other studies also presented the perspective of different types of hope, highlighting this process as a constant metamorphosis(9,30). The factors that influence hope change according to the context in which it is experienced(32). Our study showed four factors that influenced family hope. Further research should investigate how these factors act in hope, highlighting those that can be protective.

The results of this study demonstrate that information can promote or decrease family hope. Therefore, families need to receive information, and it is the responsibility of the healthcare team to inform them in a clear and empathetic way, emphasizing that information can change according to the child's therapeutic plan and ongoing clinical condition(33). Health professionals help to promote family hope by giving information in a clear and empathetic way, while omitting information or lacking empathy during communication can decrease family hope. This process can affect the families' well-being(34). For families, thoughts and comparisons can bring a positive or negative perspective to the situation. Studies indicate that when there is a positive perspective due to thoughts and comparisons, there is restoration of hope and family functioning(9,28). Thoughts or comparisons that generate a negative perspectives are able to decrease family hope(15).

With regard to support, the presence of this factor was able to promote or maintain family hope throughout the chronicity process. This factor was related to the connection between family members and beliefs, such as faith in the divine. In the country where the participants of this study are from, most people are Christians, Catholics or Protestants affiliated with some religion(35). However, in this context, there is an increase in evangelicalism(35-36). The country's social, cultural, and historical issues, mainly related to colonization and immigration, affected the importance of religion in people's lives. At the same time, the population experiences a plural spiritual identity(36).

Metamorphic spiritual identity is like a mosaic of beliefs in Brazil. The population's spiritual identity is diverse and essential in the lives of those who experience it, hindering the accuracy of official census data on this topic(36). Given this context, health professionals need to identify and stimulate the family source of support, and consequently, family hope may be promoted. Nurses and other health professionals can initiate interventions to identify family strengths that help families express their feelings and beliefs related to their cultural context(37-38).

In our results, families sought normality through activities that generated the feeling that the child would not be sick anymore. This search was related to the moments in the child's clinical condition – caring hope – or in the projection of the ideal future – expectant hope. The lack of this feeling was exacerbated in uncertain hope and latent hope. Hope is an indispensable resource, and acts as the vital force for parents(30). It anticipates that the future will bring better possibilities than the past and the present(9). Among these mysterious possibilities is a sense of normality, which is usually linked to a cure, that can be associated with a miracle(39). For the families in this study, the ideal future would not have moments of crisis related to the illness. It would be like stepping out of the dynamics of waves of family hope, through its propelling movement, to achieve the safety of the shore.

Due to the dynamics of the waves of family hope, the search for moments of full hope is constant. However, achieving this is a fragile process, as the context and factors that led the family to that moment can change abruptly, starting a new wave. Despite this, our study contributes to a new perspective on the influence of family members on family hope. The waves of family hope generate driving energy, which can be illustrated by a hopeful family member who is able to promote or maintain family hope. Hope is recognized as a unitary human experience(9). However, when presenting hope as a family resource, care for the family can be planned, considering it as a systemic unit. By changing the perspective, nurses and other health professionals will be able to identify and evaluate hope through the lens of the family system and their unique experiences. Family Systems Nursing theory acknowledges that *illness is a family affair*(19); with our study, we extend that acknowledgement by saying that *hope is also a family affair*.

This study has strengths and limitations. We consider as its strengths: a) the inclusion of the family unit(21); b) the conducting of family photo-elicitation interviews which allowed for iterative data collection to obtain family members', children's, and adolescents' narratives(21); c) the rigor used in the development of this study and the detailed description of the method, which may serve as a model for future qualitative research; and d) the use of a theoretical framework and theoretical data triangulation, which allowed for a deeper data analysis. As a limitation, we highlight the inclusion of a homogeneous sample, due to the small variability in family structures, the context of living, and diagnosis of chronic illness. However, the inclusion of different complex chronic diseases as well as the deepening of the experience of hope in each family has contributed to new knowledge about the characteristics of hope in these families, which can guide future qualitative studies.

The results of this study can help health teams to plan a systemic family care while considering hope as an essential and dynamic family resource. Our results contribute with the proposal of the *Waves of Family Hope*, explaining how family hope is dynamic in relation to the context, time, and family structure. In the educational field, this perspective can be used to teach nursing students to consider the aspects mentioned above in family-centered care. We emphasize that this study presents similarities and uniquenesses of the experience of hope of families in the context of pediatric chronic illness and the transferability and interpretation of its results need to consider the context in which it was developed.

With regard to future research, this study highlights the need to develop studies with different family structures, and in different cultural and care contexts, such as with families from eastern cultures, or in the context of pediatric end-of-life care. Also, there is a need to develop studies with health professionals, especially with nurses, to identify their perspectives about family hope, and the barriers they come across and the strategies they use to overcome them.

Conclusion

This study analyzed the narratives about the experience of hope of families in the context of pediatric chronic illness and contributed to the perspective of *Waves of Family Hope*. The results corroborated with the theoretical framework and theoretical data triangulation used, which highlight the interaction and reciprocities of the members of the family unit, and the dynamics of hope. The family narratives allowed us to go deeper into the experience of family hope in the trajectory of chronic illness, and reveal evidence that it was composed of different types of hope and that its dynamics were influenced by four factors. Moreover, the movements of waves of family hope generated a *driving energy* that is able to promote family hope in times of crisis. These results can help health team to plan family care considering hope as an essential and dynamic family resource.

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5 CONSIDERAÇÕES FINAIS

5 Considerações finais

Esta tese analisou a esperança de famílias de crianças e adolescentes que convivem com doenças crônicas. Os resultados dos estudos apresentados destacam a esperança como um recurso familiar, e não somente como um recurso individual utilizado para lidar com as demandas da doença crônica. Isso se deve à conectividade entre os membros da família e à capacidade que possuem de influenciar a esperança uns dos outros. A esperança também é considerada um recurso dinâmico, por meio do qual as famílias buscam encontrar o equilíbrio diariamente.

Os resultados desta tese contribuem para compreender a esperança familiar com base em duas metáforas que se complementam: 1) A conexão e dinamicidade da esperança familiar, representada por um móbile, que está em constante movimento; 2) A dinamicidade da esperança familiar, composta por quatro tipos de esperança (esperança incerta, esperança cuidativa, esperança latente e esperança expectante), representada por ondas do mar, que se formam e se quebram constantemente.

O tempo (presente, passado e futuro) e as experiências vivenciadas pela família (como o diagnóstico, melhora ou piora do quadro clínico e expectativas para o futuro desejado) são aspectos que influenciam a dinamicidade da esperança familiar. Ademais, fatores como apoio, informações, busca por normalidade, pensamentos e comparações podem auxiliar na promoção, manutenção ou diminuição da esperança familiar.

Os resultados também evidenciam a possibilidade de identificar o familiar que atua na impulsão da energia motriz da esperança familiar. Diante das evidências aqui apresentadas, profissionais de saúde, principalmente enfermeiros, poderão compreender o fenômeno da esperança familiar nas famílias de crianças e adolescentes que convivem com doenças crônicas e, ao conhecê-lo, terão a oportunidade de planejar um cuidado que considere a esperança como um recurso familiar essencial, bem como implementar intervenções adequadas para manter ou promovê-la. Dentre as possíveis intervenções de enfermagem para promover e/ou manter a esperança familiar estão: compartilhar informações de forma clara e sincera, proporcionar o contato de famílias com experiências semelhantes, dispor de tempo de qualidade com as famílias e estar disponível para atender suas necessidades, conquistar a confiança da família e construir vínculos, apresentar competências técnicas durante o cuidado, respeitar crenças relacionadas ao milagre de cura, reforças as fortalezas das famílias, prestar cuidado de enfermagem no que se refere aos aspectos físicos, promover conversas terapêuticas entre os familiares e/ou pessoas significativas, promover momentos de distração (principalmente no contexto de hospitalização), proporcionar reflexão familiar sobre a situação atual e auxiliar os membros da família no estabelecimento de metas realísticas (LEITE et al., 2020a).

Políticas públicas para famílias de crianças e adolescentes que convivem com doenças crônicas também poderão ser desenvolvidas com base nos resultados desta tese, uma vez que as evidências identificadas destacam a importância de incluir o recurso da esperança familiar no planejamento do cuidado em saúde.

Ademais, os resultados apresentados reforçam a importância de realizar estudos com famílias que utilizem um método congruente e adequado para a coleta de dados. A utilização de entrevistas familiares com foto-elicitação possibilitou o aprofundamento dos dados, a interação familiar e o envolvimento da população pediátrica na construção dos resultados.

No que se refere à educação em enfermagem, nossos resultados poderão auxiliar na construção de uma nova perspectiva de ensino, que evidencie a importância de considerar a esperança durante o cuidado das famílias de crianças e adolescentes com doenças crônicas, por ser um recurso familiar essencial e dinâmico. Futuras pesquisas poderão utilizar esta tese como modelo para desenvolvimento de estudos, incluindo sínteses temáticas de estudos qualitativos, estudos qualitativos que utilizem o método de entrevista familiar com foto-elicitação e estudos qualitativos narrativos com famílias. Para finalizar, as lacunas de conhecimento aqui apontadas poderão guiar o desenvolvimento de futuros estudos na temática de esperança.

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[1] As referências estão elaboradas de acordo com ABNT NBR 6028 (ASSOCIAÇÃO BRASILEIRA DE NORMAS TÉCNICAS, 2003)

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APÊNDICE A

CONTRIBUIÇÕES DOS AUTORES EM CADA ARTIGO

- **Primeiro Artigo**

Autores: Ana Carolina Andrade Biaggi Leite, Cristina García-Vivar, Rhyquelle Rhibna Neris, Willyane de Andrade Alvarenga, e Lucila Castanheira Nascimento

Contribuições: ACABL, CGV, RRN, WAA, LCN fizeram contribuições substanciais para concepção e desenho do estudo; aquisição de dados; análise e interpretação de dados; e estiveram envolvidas na redação do manuscrito e na sua revisão crítica. CGV e LCN orientaram esse estudo.

- **Segundo Artigo**

Autores: Ana Carolina Andrade Biaggi Leite, Cristina García-Vivar, e Lucila Castanheira Nascimento

Contribuições: ACABL, CGV, LCN fizeram contribuições substanciais para concepção e desenho do estudo; aquisição de dados; análise e interpretação de dados; e estiveram envolvidas na redação do manuscrito e na sua revisão crítica. CGV e LCN orientaram esse estudo.

- **Terceiro Artigo**

Autores: Ana Carolina Andrade Biaggi Leite, Cristina García-Vivar, Francine De Montigny, e Lucila Castanheira Nascimento

Contribuições: ACABL, CGV, LCN fizeram contribuições substanciais para concepção e desenho do estudo; e aquisição de dados. ACABL, CGV, FDM, LCN contribuíram com a análise e interpretação de dados; e estiveram envolvidas na redação do manuscrito e na sua revisão crítica. CGV e LCN orientaram esse estudo.

APÊNDICE B

PubMed		
Sample (S): Children and/ or adolescents with chronic diseases and their families **#4**	#1	"Family"[Mesh] OR (Families) OR (Family Members) OR (Family Member) OR (Stepfamily) OR (Stepfamilies) OR (Family, Reconstituted) OR (Families, Reconstituted) OR (Reconstituted Families) OR (Reconstituted Family) OR (Relatives) OR (Extended Family) OR (Extended Families) OR (Families, Extended) OR (Family, Extended) OR (Family Research) OR (Research, Family) OR "Parents"[Mesh] OR (Parent) OR (Parenthood Status) OR (Status, Parenthood) OR (Step-Parents) OR (Step Parents) OR (Step-Parent) OR (Stepparent) OR (Stepparents) OR "Caregivers"[Mesh] OR (Caregiver) OR (Care Givers) OR (Care Giver) OR (Family Caregivers) OR (Caregiver, Family) OR (Caregivers, Family) OR (Family Caregiver) OR "Mothers"[Mesh] OR (Mother) OR "Fathers"[Mesh] OR (Father) OR "Grandparents"[Mesh] OR (Grandparent) OR (Grandmother) OR (Grandmothers) OR (Grandfather) OR (Grandfathers) OR "Siblings"[Mesh] OR (Sibling) OR (Sisters) OR (Sister) OR (Brothers) OR (Brother)
	#2	"Child"[Mesh] OR (children) OR "Adolescent"[Mesh] OR (Adolescents) OR (Adolescence) OR (Teens) OR (Teen) OR (Teenagers) OR (Teenager) OR (Adolescents, Female) OR (Adolescent, Female) OR (Female) OR (Adolescent) OR (Female Adolescents) OR (Adolescents, Male) OR (Adolescent, Male) OR (Male Adolescent) OR (Male Adolescents) OR "Child, Preschool"[Mesh] OR (Preschool Child) OR (Children, Preschool) OR (Preschool Children)
	#3	"Chronic Disease"[Mesh] OR (Chronic Diseases) OR (Disease, Chronic) OR (Diseases, Chronic) OR (Chronic Illness) OR (Chronic Illnesses) OR (Illness, Chronic) OR (Illnesses, Chronic) OR (Chronically Ill) OR (Chronic health condition) OR "Diabetes Mellitus, Type 1"[Mesh] OR (Diabetes Mellitus, Type I) OR (Type 1 Diabetes Mellitus) OR (Diabetes Mellitus, Insulin-Dependent, 1) OR (Insulin-Dependent Diabetes Mellitus 1) OR (Insulin Dependent Diabetes Mellitus 1) OR (Type 1 Diabetes) OR (Diabetes, Type 1) OR (Diabetes Mellitus, Insulin-Dependent) OR (Diabetes Mellitus, Insulin Dependent) OR (Insulin-Dependent Diabetes Mellitus) OR "Neoplasms"[Mesh] OR (Neoplasia) OR (Neoplasias) OR (Neoplasm) OR (Tumors) OR (Tumor) OR (Cancer) OR (Cancers) OR (Malignant Neoplasms) OR (Malignant Neoplasm) OR (Neoplasm, Malignant) OR (Neoplasms, Malignant) OR (Malignancy) OR (Malignancies) OR "Asthma"[Mesh] OR (Asthmas) OR (Bronchial Asthma) OR (Asthma, Bronchial) OR "Renal Insufficiency, Chronic"[Mesh] OR (Chronic Renal Insufficiencies) OR (Renal Insufficiencies, Chronic) OR (Chronic Renal Insufficiency) OR (Kidney Insufficiency, Chronic) OR (Chronic Kidney Insufficiency) OR (Chronic Kidney Insufficiencies) OR (Kidney Insufficiencies, Chronic) OR (Chronic Kidney Diseases) OR (Chronic Kidney Disease) OR (Disease, Chronic Kidney) OR (Diseases, Chronic Kidney) OR (Kidney Disease, Chronic) OR (Kidney Diseases, Chronic) OR (Chronic Renal Diseases) OR (Chronic Renal Disease) OR (Disease, Chronic Renal) OR (Diseases, Chronic Renal) OR (Renal Disease, Chronic) OR (Renal Diseases, Chronic) OR "Cystic Fibrosis"[Mesh] OR (Fibrosis, Cystic) OR (Mucoviscidosis) OR (Pulmonary Cystic Fibrosis) OR (Cystic Fibrosis, Pulmonary) OR (Pancreatic Cystic Fibrosis) OR (Cystic Fibrosis, Pancreatic) OR (Fibrocystic Disease of Pancreas) OR (Pancreas Fibrocystic Disease) OR (Pancreas Fibrocystic Diseases) OR (Cystic Fibrosis of Pancreas) OR "Gastrointestinal Diseases"[Mesh] OR (Disease, Gastrointestinal) OR (Diseases, Gastrointestinal) OR (Gastrointestinal Disease) OR (Functional Gastrointestinal Disorders) OR (Disorder, Functional Gastrointestinal) OR (Disorders, Functional Gastrointestinal) OR (Functional Gastrointestinal Disorder) OR (Gastrointestinal Disorder, Functional) OR (Gastrointestinal Disorders, Functional) OR "Heart Diseases"[Mesh] OR (Disease, Heart) OR (Diseases, Heart) OR (Heart Disease) OR (Cardiac Diseases) OR (Cardiac Disease) OR (Disease, Cardiac) OR (Diseases, Cardiac)
Phenomenon of Interest (PI): Hope	#5	"Hope"[Mesh] OR (Hopes) OR (Hopefulness) OR (Hopeful) OR (hope experience) OR (parental hope) OR (child hope) OR (children hope) OR (adolescent hope) OR (adolescents hope) OR "Optimism"[Mesh]
Desing (D): Qualitative Methods	#6	"Focus Groups"[Mesh] OR (Focus Group) OR (Group, Focus) OR "Anthropology, Medical"[Mesh] OR (Medical Anthropology) OR "Grounded Theory"[Mesh] OR (Theory, Grounded) OR Culture OR (Thematic synthesis) OR "Hermeneutics"[Mesh] OR (Hermeneutic) OR (Ethnographic) OR (ethnographic research) OR (Phenomenology) OR (phenomenological research) OR (Narrative) OR "Interviews as Topic"[Mesh] OR (Interviewers) OR (Interviewer) OR (Interviewees) OR (Group Interviews) OR (Group Interview) OR (Interview, Group) OR (Interviews, Group) OR (in-depth interview) OR (qualitative interview) OR (content analysis) OR (semantic analysis)
Evaluation (E): Experience	#7	(Experience) OR (Experiences) OR (Sense) OR (Senses) OR (Meaning) OR (Meanings) OR "Life Change Events"[Mesh] OR (Event, Life Change) OR (Events, Life Change) OR (Life Change Event) OR (Life Experiences) OR (Experience, Life) OR (Experiences, Life) OR (Life Experience) OR (live experience) OR (perspective) OR (perspectives) OR "Attitude"[Mesh] OR (Attitudes) OR "Attitude to Health"[Mesh] OR (Health, Attitude to) OR (Health Attitude) OR (Attitude, Health) OR (Attitudes, Health) OR (Health Attitudes) OR (Subjectivities) OR "Behavior"[Mesh] OR (Behaviors)
Research Type (R): Qualitative Research	#8	"Qualitative Research"[Mesh] OR (Research, Qualitative) OR (Qualitative studies) OR (Qualitative) OR "Empirical Research"[Mesh] OR (Research, Empirical)
((#1 OR #2) AND #3) = #4) / (#4 AND #5 AND #6 AND #7 AND #8)		

CINAHL		
Sample (S): Children and/ or adolescents with chronic diseases and their families **#4**	#1	(MH "Family") OR (Families) OR (Family Members) OR (Family Member) OR (Stepfamily) OR (Stepfamilies) OR (Family, Reconstituted) OR (Families, Reconstituted) OR (Reconstituted Families) OR (Reconstituted Family) OR (Relatives) OR (MH "Extended Family+") OR (Extended Family) OR (Extended Families) OR (Families, Extended) OR (Family, Extended) OR (Family Research) OR (Research, Family) OR (MH "Parents+") OR (Parent) OR (Parenthood Status) OR (Status, Parenthood) OR (Step-Parents) OR (Step Parents) OR (Step-Parent) OR (Stepparent) OR (Stepparents) OR (MH "Caregivers") OR (Caregiver) OR (Care Givers) OR (Care Giver) OR (Family Caregivers) OR (Caregiver, Family) OR (Caregivers, Family) OR (Family Caregiver) OR (MH "Mothers+") OR (Mother) OR (MH "Fathers+") OR (Father) OR (MH "Grandparents") OR (Grandparent) OR (Grandmother) OR (Grandmothers) OR (Grandfather) OR (Grandfathers) OR (MH "Siblings") OR (Sibling) OR (Sisters) OR (Sister) OR (Brothers) OR (Brother)
	#2	(MH "Child+") OR (children) OR (MH "Adolescence+") OR (Adolescents) OR (Adolescence) OR (Teens) OR (Teen) OR (Teenagers) OR (Teenager) OR (Adolescents, Female) OR (Adolescent, Female) OR (Female) OR (Adolescent) OR (Female Adolescents) OR (Adolescents, Male) OR (Adolescent, Male) OR (Male Adolescent) OR (Male Adolescents) OR (MH "Child, Preschool") OR (Preschool Child) OR (Children, Preschool) OR (Preschool Children)
	#3	(MH "Chronic Disease") OR (Chronic Diseases) OR (Disease, Chronic) OR (Diseases, Chronic) OR (Chronic Illness) OR (Chronic Illnesses) OR (Illness, Chronic) OR (Illnesses, Chronic) OR (Chronically Ill) OR (MH "Diabetes Mellitus, Type 1+") OR (Diabetes Mellitus, Type I) OR (Type 1 Diabetes Mellitus) OR (Diabetes Mellitus, Insulin-Dependent, 1) OR (Insulin-Dependent Diabetes Mellitus 1) OR (Insulin Dependent Diabetes Mellitus 1) OR (Type 1 Diabetes) OR (Diabetes, Type 1) OR (Diabetes Mellitus, Insulin-Dependent) OR (Diabetes Mellitus, Insulin Dependent) OR (Insulin-Dependent Diabetes Mellitus) OR (MM "Neoplasms") OR (MH "Childhood Neoplasms") OR (Neoplasia) OR (Neoplasias) OR (Neoplasm) OR (Tumors) OR (Tumor) OR (Cancer) OR (Cancers) OR (Malignant Neoplasms) OR (Malignant Neoplasm) OR (Neoplasm, Malignant) OR (Neoplasms, Malignant) OR (Malignancy) OR (Malignancies) OR (MH "Asthma" OR (Asthmas) OR (Bronchial Asthma) OR (Asthma, Bronchial) OR (MH "Renal Insufficiency, Chronic") OR (MH "Kidney Failure, Chronic") OR (Chronic Renal Insufficiencies) OR (Renal Insufficiencies, Chronic) OR (Chronic Renal Insufficiency) OR (Kidney Insufficiency, Chronic) OR (Chronic Kidney Insufficiency) OR (Chronic Kidney Insufficiencies) OR (Kidney Insufficiencies, Chronic) OR (Chronic Kidney Diseases) OR (Chronic Kidney Disease) OR (Disease, Chronic Kidney) OR (Diseases, Chronic Kidney) OR (Kidney Disease, Chronic) OR (Kidney Diseases, Chronic) OR (Chronic Renal Diseases) OR (Chronic Renal Disease) OR (Disease, Chronic Renal) OR (Diseases, Chronic Renal) OR (Renal Disease, Chronic) OR (Renal Diseases, Chronic) OR (MH "Cystic Fibrosis") OR (Fibrosis, Cystic) OR (Mucoviscidosis) OR (Pulmonary Cystic Fibrosis) OR (Cystic Fibrosis, Pulmonary) OR (Pancreatic Cystic Fibrosis) OR (Cystic Fibrosis, Pancreatic) OR (Fibrocystic Disease of Pancreas) OR (Pancreas Fibrocystic Disease) OR (Pancreas Fibrocystic Diseases) OR (Cystic Fibrosis of Pancreas) OR (MH "Gastrointestinal Diseases") OR (Disease, Gastrointestinal) OR (Diseases, Gastrointestinal) OR (Gastrointestinal Disease) OR (Functional Gastrointestinal Disorders) OR (Disorder, Functional Gastrointestinal) OR (Disorders, Functional Gastrointestinal) OR (Functional Gastrointestinal Disorder) OR (Gastrointestinal Disorder, Functional) OR (Gastrointestinal Disorders, Functional) OR (MH "Heart Diseases") OR (Disease, Heart) OR (Diseases, Heart) OR (Heart Disease) OR (Cardiac Diseases) OR (Cardiac Disease) OR (Disease, Cardiac) OR (Diseases, Cardiac)
Phenomenon of Interest (PI): Hope	#5	(MH "Hope") OR (Hopes) OR (Hopefulness) OR (Hopeful) OR (hope experience) OR (parental hope) OR (child hope) OR (children hope) OR (adolescent hope) OR (adolescents hope) OR (MH "Optimism")
Desing (D): Qualitative Methods	#6	(MH "Focus Groups") OR (Focus Group) OR (MH "Interviews") OR (MH "Narratives") OR (MH "Semi-Structured Interview") OR (MH "Unstructured Interview") OR (Medical Anthropology) OR (MH "Anthropology, Cultural") OR (MH "Culture") OR (MH "Grounded Theory") OR (MH "Ethnographic Research") OR (MH "Phenomenological Research") OR (MH "Ethnonursing Research") OR (MH "Thematic Analysis") OR (Hermeneutics) OR (MH "Phenomenology") OR (MH "Unstructured Interview Guides") OR (Group Interviews) OR (Group Interview) OR (qualitative interview) OR (MH "Content Analysis")
Evaluation (E): Experience	#7	(MH "Life Experiences") OR (MH "Health Behavior") OR (MH "Life Change Events") OR (Experience) OR (Experiences) OR (Sense) OR (Senses) OR (Meaning) OR (MH "Life Purpose") OR (Meanings) OR (MH "Life Style Changes") OR (Life Change Event) OR (Life Experience) OR (Experience, Life) OR (live experience) OR (perspective) OR (perspectives) OR (MH "Attitude") OR (MH "Attitude to Illness") OR (MH "Attitude to Health") OR (MH "Attitude to Life") OR (MH "Behavior and Behavior Mechanisms") OR (MH "Behavior") OR (Subjectivities) OR (Behaviors)
Research Type (R): Qualitative Research	#8	(MH "Qualitative Studies") OR (MH "Empirical Research") OR (Qualitative Research) OR (Qualitative) OR (Research, Empirical) OR (Qualitative studies)
((#1 OR #2) AND #3) = #4)/ (#4 AND #5 AND #6 AND #7 AND #8)		

PsycInfo - APA		
Sample (S): **Children and/ or adolescents with chronic diseases and their families**	#1	(Family) OR (Families) OR (Family Members) OR (Family Member) OR (Stepfamily) OR (Stepfamilies) OR (Family, Reconstituted) OR (Families, Reconstituted) OR (Reconstituted Families) OR (Reconstituted Family) OR (Relatives) OR (Extended Family) OR (Extended Families) OR (Families, Extended) OR (Family, Extended) OR (Family Research) OR (Research, Family) OR (Parents) OR (Parent) OR (Parenthood Status) OR (Status, Parenthood) OR (Step-Parents) OR (Step Parents) OR (Step-Parent) OR (Stepparent) OR (Stepparents) OR (Caregivers) OR (Caregiver) OR (Care Givers) OR (Care Giver) OR (Family Caregivers) OR (Caregiver, Family) OR (Caregivers, Family) OR (Family Caregiver) OR (Mothers) OR (Mother) OR (Fathers) OR (Father) OR (Grandparents) OR (Grandparent) OR (Grandmother) OR (Grandmothers) OR (Grandfather) OR (Grandfathers) OR (Siblings) OR (Sibling) OR (Sisters) OR (Sister) OR (Brothers) OR (Brother)
#4	#2	(Child) OR (children) OR (Adolescent) OR (Adolescents) OR (Adolescence) OR (Teens) OR (Teen) OR (Teenagers) OR (Teenager) OR (Adolescents, Female) OR (Adolescent, Female) OR (Female) OR (Adolescent) OR (Female Adolescents) OR (Adolescents, Male) OR (Adolescent, Male) OR (Male Adolescent) OR (Male Adolescents) OR (Child, Preschool) OR (Preschool Child) OR (Children, Preschool) OR (Preschool Children) OR (Preschool Students)
	#3	(Chronically Ill Children) OR (Chronically Ill Adolescent) OR (Chronic Disease) OR (Chronic Diseases) OR (Disease, Chronic) OR (Diseases, Chronic) OR (Chronic Illness) OR (Chronic Illnesses) OR (Illness, Chronic) OR (Illnesses, Chronic) OR (Chronically Ill) OR (Diabetes Mellitus) OR (Diabetes Mellitus, Type 1) OR (Diabetes Mellitus, Type I) OR (Type 1 Diabetes Mellitus) OR (Diabetes Mellitus, Insulin-Dependent, 1) OR (Insulin-Dependent Diabetes Mellitus 1) OR (Insulin Dependent Diabetes Mellitus 1) OR (Type 1 Diabetes) OR (Diabetes, Type 1) OR (Diabetes Mellitus, Insulin-Dependent) OR (Diabetes Mellitus, Insulin Dependent) OR (Insulin-Dependent Diabetes Mellitus) OR (Neoplasms) OR (Neoplasia) OR (Neoplasias) OR (Neoplasm) OR (Tumors) OR (Tumor) OR (Cancer) OR (Cancers) OR (Malignant Neoplasms) OR (Malignant Neoplasm) OR (Neoplasm, Malignant) OR (Neoplasms, Malignant) OR (Malignancy) OR (Malignancies) OR (Asthma) OR (Asthmas) OR (Bronchial Asthma) OR (Asthma, Bronchial) OR (Renal Insufficiency, Chronic) OR (Kidney Diseases) OR (Chronic Renal Insufficiencies) OR (Renal Insufficiencies, Chronic) OR (Chronic Renal Insufficiency) OR (Kidney Insufficiency, Chronic) OR (Chronic Kidney Insufficiency) OR (Chronic Kidney Insufficiencies) OR (Kidney Insufficiencies, Chronic) OR (Chronic Kidney Diseases) OR (Chronic Kidney Disease) OR (Disease, Chronic Kidney) OR (Diseases, Chronic Kidney) OR (Kidney Disease, Chronic) OR (Kidney Diseases, Chronic) OR (Chronic Renal Diseases) OR (Chronic Renal Disease) OR (Disease, Chronic Renal) OR (Diseases, Chronic Renal) OR (Renal Disease, Chronic) OR (Renal Diseases, Chronic) OR (Cystic Fibrosis) OR (Fibrosis, Cystic) OR (Mucoviscidosis) OR (Pulmonary Cystic Fibrosis) OR (Cystic Fibrosis, Pulmonary) OR (Pancreatic Cystic Fibrosis) OR (Cystic Fibrosis, Pancreatic) OR (Fibrocystic Disease of Pancreas) OR (Pancreas Fibrocystic Disease) OR (Pancreas Fibrocystic Diseases) OR (Cystic Fibrosis of Pancreas) OR (Gastrointestinal Disorders) OR (Gastrointestinal Diseases) OR (Disease, Gastrointestinal) OR (Diseases, Gastrointestinal) OR (Gastrointestinal Disease) OR (Functional Gastrointestinal Disorders) OR (Disorder, Functional Gastrointestinal) OR (Disorders, Functional Gastrointestinal) OR (Functional Gastrointestinal Disorder) OR (Gastrointestinal Disorder, Functional) OR (Gastrointestinal Disorders, Functional) OR (Heart Disorders) OR (Heart Diseases) OR (Disease, Heart) OR (Diseases, Heart) OR (Heart Disease) OR (Cardiac Diseases) OR (Cardiac Disease) OR (Disease, Cardiac) OR (Diseases, Cardiac)
Phenomenon of Interest (PI): **Hope**	#5	(Hope) OR (Hopes) OR (Hopefulness) OR (Hopeful) OR (hope experience) OR (parental hope) OR (child hope) OR (children hope) OR (adolescent hope) OR (adolescents hope) OR (Optimism)
Desing (D): **Qualitative Methods**	#6	(Focus Group) OR (Group, Focus) OR (Anthropology) OR (Medical Anthropology) OR (Grounded Theory) OR (Theory, Grounded) OR (Culture) OR (Culture (Anthropological) OR (Thematic synthesis) OR (Hermeneutics) OR (Hermeneutic) OR (Ethnographic) OR (ethnographic research) OR (Phenomenology) OR (phenomenological research) OR (Narrative) OR (Narratives) OR (Interviews) OR (Interviewers) OR (Interviewer) OR (Interviewees) OR (Interviewing) OR (Group Interviews) OR (Group Interview) OR (Interview, Group) OR (Interviews, Group) OR (in-depth interview) OR (qualitative interview) OR (content analysis) OR (semantic analysis)
Evaluation (E): **Experience**	#7	(Experience) OR (Experiences) OR (Sense) OR (Senses) OR (Meaning) OR (Meanings) OR (Life Change Events) OR (Event, Life Change) OR (Events, Life Change) OR (Life Change Event) OR (Life Experiences) OR (Experience, Life) OR (Experiences, Life) OR (Life Experience) OR ((live experience) OR (perspective) OR (perspectives) OR (Attitude) OR (Attitudes) OR (Attitude to Health) OR (Health, Attitude to) OR (Health Attitude) OR (Attitude, Health) OR (Attitudes, Health) OR (Health Attitudes) OR (Subjectivities) OR (Behavior) OR (Behaviors) OR (Emotions)
Research Type (R): **Qualitative Research**	#8	(Qualitative Research) OR (Research, Qualitative) OR (Qualitative studies) OR (Qualitative) OR (Empirical Research) OR (Research, Empirical)
((#1 OR #2) AND #3) = #4) / (#4 AND #5 AND #6 AND #7 AND #8)		

SCOPUS		
Sample (S): **Children and/ or adolescents with chronic diseases and their families** **#4**	#1	(family) OR (family AND members) OR (stepfamily) OR (reconstituted AND families) OR (relatives) OR (extended AND family) OR (parents) OR (step AND parents) OR (caregivers) OR (mothers) OR (fathers) OR (grandparents) OR (siblings) OR (sisters) OR (brothers)
	#2	(child) OR (children) OR (adolescent) OR (adolescents) OR (teens) OR (preschool AND child) OR (preschool AND children)
	#3	(chronic AND disease) OR (chronic AND illness) OR (Diabetes Mellitus, Type 1) OR (Neoplasms) OR (Asthma) OR (Renal Insufficiency, Chronic) OR (Cystic Fibrosis) OR (Gastrointestinal Diseases) OR (Heart Diseases)
Phenomenon of Interest (PI): **Hope**	#5	(hope) OR (hopes) OR (hopefulness) OR (hopeful) OR (hope AND experience) OR (parental AND hope) OR (child AND hope) OR (children AND hope) OR (adolescent AND hope) OR (adolescents AND hope) OR (optimism))
Desing (D): **Qualitative Methods**	#6	((Focus Groups) OR (Anthropology, Medical) OR (Grounded Theory) OR (Culture) OR (Thematic synthesis) OR (Hermeneutic) OR (Ethnographic) OR (Phenomenology) OR (Narrative) OR (Interviewer) OR (qualitative interview) OR (content analysis) OR (semantic analysis)
Evaluation (E): **Experience**	#7	(Experiences) OR (Sense) OR (Senses) OR (Meaning) OR (Meanings) OR (Life Change Events) OR (Life Experiences) OR (Life Experience) OR (perspective) OR (perspectives) OR (Attitude) OR (Attitudes) OR (Attitude to Health) OR (Subjectivities) OR (Behavior)
Research Type (R): **Qualitative Research**	#8	(Qualitative Research) OR (Research, Qualitative) OR (Qualitative studies) OR (Qualitative) OR (Empirical Research) OR (Research, Empirical)
((#1 OR #2) AND #3) = #4) / (#4 AND #5 AND #6 AND #7 AND #8)		

Web of Science		
Sample (S): **-Children and/ or adolescents with chronic diseases and their families** **#4**	#1	(Family) OR (family AND members) OR (stepfamily) OR (reconstituted AND families) OR (relatives) OR (extended AND family) OR (parents) OR (step AND parents) OR (caregivers) OR (mothers) OR (fathers) OR (grandparents) OR (siblings) OR (sisters) OR (brothers)
	#2	(Child) OR (children) OR (adolescent) OR (adolescents) OR (teens) OR (preschool AND child) OR (preschool AND children)
	#3	(Chronic AND disease) OR (chronic AND illness) OR (Diabetes Mellitus, Type 1) OR (Neoplasms) OR (Asthma) OR (Renal Insufficiency, Chronic) OR (Cystic Fibrosis) OR (Gastrointestinal Diseases) OR (Heart Diseases)
Phenomenon of Interest (PI): **-Hope**	#5	(Hope) OR (hopes) OR (hopefulness) OR (hopeful) OR (hope AND experience) OR (parental AND hope) OR (child AND hope) OR (children AND hope) OR (adolescent AND hope) OR (adolescents AND hope) OR (optimism))
Desing (D) **-Qualitative Methods**	#6	((Focus Groups) OR (Anthropology, Medical) OR (Grounded Theory) OR (Culture) OR (Thematic synthesis) OR (Hermeneutic) OR (Ethnographic) OR (Phenomenology) OR (Narrative) OR (Interviewer) OR (qualitative interview) OR (content analysis) OR (semantic analysis)
Evaluation (E) **-Experience**	#7	(Experiences) OR (Sense) OR (Senses) OR (Meaning) OR (Meanings) OR (Life Change Events) OR (Life Experiences) OR (Life Experience) OR (perspective) OR (perspectives) OR (Attitude) OR (Attitudes) OR (Attitude to Health) OR (Subjectivities) OR (Behavior)
Research Type (R) **Qualitative Research**	#8	(Qualitative Research) OR (Research, Qualitative) OR (Qualitative studies) OR (Qualitative) OR (Empirical Research) OR (Research, Empirical)
((#1 OR #2) AND #3) = #4) / (#4 AND #5 AND #6 AND #7 AND #8)		

LILACS
((("CHILDREN") OR "ADOLESCENT") OR "PARENTS") OR "FAMILY" [Words] AND ("HOPE") OR "HOPE/OPTIMISM" [Words] AND ((((((("CHRONIC DISEASE") OR "DIABETES MELLITUS") OR "NEOPLASM") OR "ASTHMA") OR "RENAL INSUFFICIENCY, CHRONIC") OR "CYSTIC FIBROSIS") OR "GASTROINTESTINAL DISEASES") OR "HEART DISEASES" [Words]

APÊNDICE C
Termo de Consentimento Livre e Esclarecido
(Pais, responsáveis e familiares adultos)

Prezado(a) Senhor(a)

Meu nome é Ana Carolina Andrade Biaggi Leite, sou enfermeira e aluna de pós-graduação, doutorado, da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo (EERP/USP). Este estudo é de minha responsabilidade, sob orientação da Professora Dra. Lucila Castanheira Nascimento da EERP/USP.

Por meio deste termo, gostaríamos de informá-lo(a) sobre os objetivos e procedimentos da pesquisa **"Esperança nas famílias de crianças e adolescentes com doenças crônicas"**, e convidá-lo(a) para participar deste estudo

O objetivo deste estudo é identificar os sentidos atribuídos à experiência do recurso da esperança pelas famílias de crianças e adolescentes com doenças crônicas por meio de foto-elicitação e entrevistas. Quero conhecer como o(a) senhor(a) vivencia a esperança em relação à doença crônica de seu(sua) filho(a) ou familiar. Caso concorde com a sua participação, precisaremos nos encontrar algumas vezes. Nosso 1º encontro está sendo hoje, para verificar o seu interesse em participar e conversar sobre os seus dados de caracterização. Neste primeiro encontro, agendaremos o próximo, com um intervalo de aproximadamente sete dias, na data e local de sua preferência. Neste período, convido o(a) senhor(a) para tirar fotografias sobre o que é ter esperança em relação à doença crônica de seu familiar. O(a) senhor(a) é livre para produzir quantas fotos achar necessário, desde que abordem a temática da esperança. Caso o(a) senhor(a) não possua um aparelho digital para realizar as fotos, eu lhe fornecerei uma câmera fotográfica, a qual será devolvida no nosso próximo encontro. No 2º encontro, irei transferir as fotos para um *notebook* e conversaremos sobre o que elas representam para o(a) senhor(a). Pode ser que eu precise conversar com o(a) Senhor(a) mais uma vez para esclarecer algumas dúvidas ou para pensarmos juntos sobre alguma questão importante para meu estudo; caso isso ocorra, entrarei em contato para marcarmos mais um encontro. Desta forma, o tempo de cada encontro dependerá de sua disponibilidade. Solicito autorização para audiogravar as entrevistas, para garantir que todos os detalhes da nossa conversa sejam registrados. O áudio e as fotografias serão guardados em um local seguro, sob minha responsabilidade e serão utilizados somente para fins de estudos. Caso a fotografia possua dados que possam identificar pessoas ou informações sigilosas elas serão editadas, com intuito de "cobrir ou desfocar" este tipo de informações, sem que haja prejuízo do conteúdo da imagem. Será mantido em segredo (sigilo/anonimato) seu nome e, caso não queira responder ou relatar alguma de suas experiências, não haverá problemas. Se durante os encontros o(a) Senhor(a) sentir algum desconforto ao responder a qualquer questão solicitada, a pesquisa poderá ser interrompida e, se necessário, estaremos à sua disposição para lhe oferecer apoio. Retomaremos nossa conversa depois, se ainda for do desejo do(a) Senhor(a). A participação do Senhor(a) nesta pesquisa é voluntária e não haverá custos por isso, ou seja, não gastará dinheiro por isso. Além disso, o(a) Senhor(a) tem a liberdade de se recusar a participar ou poderá retirar seu consentimento durante qualquer etapa da pesquisa, sem ser necessário justificar o motivo da sua desistência e sem prejuízo algum para o(a) Senhor(a) e seu(sua) filho(a). O Senhor(a) também tem o direito de receber nossa orientação para esclarecer qualquer dúvida relacionada a esta pesquisa. Acrescentamos, que o(a) Senhor(a) não terá benefícios diretos ao participar dessa pesquisa, mas sua participação será muito importante, pois, por meio dos resultados desse estudo, gostaríamos de descrever e entender como a esperança é experienciada pelas famílias de crianças e adolescentes com doenças crônicas. Esses resultados serão divulgados em eventos e revistas científicas, sempre mantendo o seu nome em segredo.

Se concordar em participar da pesquisa, vou pedir para assinar duas vias originais deste documento que estamos entregando ao(á) Senhor(a), que se chama Termo de Consentimento Livre e Esclarecido. O(a) Senhor(a) receberá uma via original deste termo assinada pela responsável pela pesquisa, citada logo no início deste documento. Ao assinar este Termo de Consentimento, o(a) Senhor(a) não perderá nenhum direito, inclusive o de obter indenização, se isto acontecer. Você tem direito à indenização por parte das pesquisadoras e da instituição envolvida na pesquisa por eventuais danos decorrentes da sua participação, conforme a Resolução 466/2012, item IV.3-h.

Esta pesquisa foi analisada e aprovada pelo Comitê de Ética em Pesquisa com Seres Humanos (CEP) da Escola de Enfermagem de Ribeirão Preto/USP (EERP/USP), instituição proponente da pesquisa, e pelo CEP do Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto/USP (HCFMRP/USP), instituição coparticipante, pois respeita as questões éticas necessárias para a sua realização. O CEP também tem a finalidade de proteger as pessoas que participam da pesquisa e preservar seus direitos. Assim, se for necessário, entre em contato com o CEP da EERP/USP pelo telefone (16)3315-9197, que funciona de segunda a sexta-feira, em dias úteis, das 10 às 12h e das 14 às 16 h. Caso deseje falar conosco, você poderá nos encontrar por meio do telefone (16) 3315-3435, de segunda a sexta-feira, em dias úteis, das 8h às 17h, ou pelo endereço da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo, na Avenida Bandeirantes, no 3900 - Campus Universitário, Ribeirão Preto – SP, CEP: 14040-902.

Colocamo-nos a disposição para qualquer informação adicional no telefone anteriormente citado e nos e-mails: lucila@eerp.usp.br ou ana.andrade.leite@usp.br.

Agradecemos a sua colaboração.

Ribeirão Preto, _____de _____________ de 201__.

Após ter conhecimento sobre como poderei colaborar com esta pesquisa, concordo com a minha participação, que decidi por livre e espontânea vontade. Eu, ____, aceito participar desta pesquisa. Estou ciente de se eu não quiser mais participar, eu posso desistir sem qualquer prejuízo a mim. Sei também que ao final desta pesquisa o meu nome será mantido em segredo. Recebi uma via original deste Termo, assinada por mim e pelas pesquisadoras responsáveis e tive a oportunidade de discuti-lo com pelo menos uma delas.

____

Assinatura do(a) Participante

____________________________________	____________________________________
Enfermeira e Doutoranda	Orientadora
Ana Carolina Andrade Biaggi Leite	Prof.ª Dr.ª Lucila Castanheira Nascimento

APÊNDICE D

Termo de Consentimento Livre e Esclarecido

(Pais ou responsáveis de crianças ou adolescentes)

Prezado(a) Senhor(a)

Meu nome é Ana Carolina Andrade Biaggi Leite, sou enfermeira e aluna de pós-graduação, doutorado, da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo (EERP/USP). Este estudo é de minha responsabilidade, sob orientação da Professora Dra. Lucila Castanheira Nascimento da EERP/USP.

Por meio deste termo, gostaríamos de informá-lo(a) sobre os objetivos e procedimentos da pesquisa **"Esperança nas famílias de crianças e adolescentes com doenças crônicas"**, e solicitar sua autorização para a participação de seu (sua) filho(a) neste estudo.

O objetivo deste estudo é identificar os sentidos atribuídos a experiência do recurso da esperança pelas famílias de crianças e adolescentes com doenças crônicas por meio de foto-elicitação e entrevistas. Quero conhecer como o(a) seu(sua) filho(a) vivencia a esperança em relação a doença crônica dele ou de um familiar infatojuvenil. Caso concorde com a participação de seu (sua) filho(a) precisaremos nos encontrar algumas vezes. Em nosso 1º encontro verificarei o interesse do(a) seu(sua) filho(a) para participar, e conversarei sobre os seus dados de caracterização. Neste primeiro encontro agendaremos o próximo, com um intervalo de aproximadamente sete dias, na data e local de sua preferência. Neste período convidarei seu(sua) filho(a) fotografias sobre o que é ter esperança em relação a doença crônica dele ou de um familiar infantojuvenil. Ele(a) é livre para produzir quantas fotos achar necessário, desde que abordem a temática da esperança. Caso não possua um aparelho digital para realizar as fotos, eu lhe fornecerei uma câmera fotográfica, na qual será devolvida no nosso próximo encontro. No 2º encontro, irei transferir as fotos para um *notebook* e conversaremos sobre o que elas representam para seu(sua) filho(a). Pode ser que eu precise conversar com ele(a) mais uma vez para esclarecer algumas dúvidas ou para pensarmos juntos sobre alguma questão importante para meu estudo, caso isso ocorra entrarei em contato para marcarmos mais um encontro. Desta forma, o tempo de cada encontro dependerá de sua disponibilidade. Solicito autorização para audiogravar as entrevistas, para garantir que todos os detalhes da nossa conversa sejam registrados. O áudio e as fotografias serão guardados em um local seguro, sob minha responsabilidade e será utilizado somente para fins de estudos. Caso a fotografia possua dados que possam identificar pessoas ou informações sigilosas elas serão editadas, com intuito de "cobrir ou desfocar" este tipo de informações, sem que haja prejuízo do conteúdo da imagem. Será mantido em segredo (sigilo/anonimato) seu nome e de seu(sua) filho(a), e caso ele(a) não queira responder ou relatar alguma de suas experiências não haverá problemas. Solicitamos também sua autorização para consultar algumas informações no prontuário de seu(sua) filho(a), como por exemplo: diagnóstico e tratamento. Se durante os encontros ele(a) sentir algum desconforto ao responder a qualquer questão solicitada, a pesquisa poderá ser interrompida, e se necessário, estaremos à sua disposição para lhe oferecer apoio. Retomaremos nossa conversa depois, se ainda for do desejo de seu(a) filho(a). A participação de seu(a) filho(a) nesta pesquisa é voluntária e não haverá custos por isso, ou seja, não gastará dinheiro por isso. Além disso, o(a) Senhor(a) e o seu(sua) filho(a) tem a liberdade de recusar-se a participar deste estudo ou poderão retirar seu consentimento durante qualquer etapa da pesquisa, sem ser necessário justificar o motivo e sem prejuízo algum para o(a) Senhor(a) e seu(sua) filho(a). O Senhor(a) e o seu(sua) filho(a) também tem o direito de receber nossa orientação para esclarecer qualquer dúvida relacionada a esta pesquisa.

Acrescentamos, que o(a) Senhor(a) e seu(sua) filho(a) não terá benefícios diretos ao participar dessa pesquisa, mas sua participação será muito importante, pois por meio dos resultados desse estudo gostaríamos de descrever e entender como a esperança é experienciada pelas famílias de crianças e adolescentes com doenças crônicas. Esses resultados serão divulgados em eventos e revistas científicas, sempre mantendo o seu nome em segredo.

Se concordar e autorizar a participação de seu(sua) filho(a) nesta pesquisa, vou pedir para assinar duas vias originais deste documento que estamos entregando ao(á) Senhor(a), que se chama Termo de Consentimento Livre e Esclarecido. Somente com a sua aprovação, iremos nos aproximar do seu(sua) filho(a) e convidá-lo(a) para participar da pesquisa, que será iniciada quando ele(a) aceitar participar. O(a) Senhor(a) receberá uma via original deste termo assinada pela responsável pela pesquisa, citada logo no início deste documento. Ao assinar este Termo de Consentimento o(a) Senhor(a) não perderá nenhum direito, inclusive o de obter indenização, se isto acontecer. Você tem direito à indenização por parte das pesquisadoras e da instituição envolvida na pesquisa por eventuais danos decorrentes da sua participação, conforme a Resolução 466/2012, item IV.3-h.

Esta pesquisa foi analisada e aprovada pelo Comitê de Ética em Pesquisa com Seres Humanos (CEP) da Escola de Enfermagem de Ribeirão Preto/USP (EERP/USP), instituição proponente da pesquisa, e pelo CEP do Hospital das Clínicas da Faculdade de Medicina de Ribeirão Preto/USP (HCFMRP/USP), instituição coparticipante, pois respeita as questões éticas necessárias para a sua realização. O CEP também tem a finalidade de proteger as pessoas que participam da pesquisa e preservar seus direitos. Assim, se for necessário, entre em contato com o CEP da EERP/USP pelo telefone (16)3315-9197, que funciona de segunda a sexta-feira, em dias úteis, das 10 às 12h e das 14 às 16 h. Caso deseje falar conosco, você poderá nos encontrar por meio do telefone (16) 3315-3435, de segunda a sexta-feira, em dias úteis, das 8h às 17h, ou pelo endereço da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo, na Avenida Bandeirantes, no 3900 - Campus Universitário, Ribeirão Preto – SP, CEP: 14040-902.

Colocamo-nos a disposição para qualquer informação adicional no telefone anteriormente citado e nos e-mails: lucila@eerp.usp.br ou ana.andrade.leite@usp.br.

Agradecemos a sua colaboração.

Ribeirão Preto, _____de _____________ de 201__.

Após ter conhecimento sobre como poderei colaborar com esta pesquisa, concordo com a participação do(a) meu(minha) filho(a), caso ele(a) também aceite participar da pesquisa e, que decidi por livre e espontânea vontade. Eu, ____, aceito que meu(minha) filho(a) participe desta pesquisa. Estou ciente de se eu não quiser mais participar, eu posso desistir sem qualquer prejuízo a mim. Sei também que ao final desta pesquisa o meu nome e será mantido em segredo. Recebi uma via original deste Termo, assinada por mim e pelas pesquisadoras responsáveis e tive a oportunidade de discuti-lo com pelo menos uma delas.

____

Assinatura do(a) Participante

______________________________	______________________________
Enfermeira e Doutoranda	Orientadora
Ana Carolina Andrade Biaggi Leite	Prof.ª Dr.ª Lucila Castanheira Nascimento

APÊNDICE E
TERMO DE ASSENTIMENTO

(Crianças e adolescentes – caso índice)

Pesquisa: **"Esperança nas famílias de crianças e adolescentes com doenças crônicas: análise de aspectos conceituais e subjetivos"**

O que é esta pesquisa?

A pesquisa é sobre sua doença e como você sente esperança, eu vou fazer algumas perguntas para você responder e para eu poder conhecer melhor você e sua família. Gostaria de saber como você sente a esperança em relação a sua doença e para isso vou pedir para você tirar fotos. Depois vamos conversar sobre as fotos que você tirou.

De quem é a pesquisa?

A pesquisa é da Ana Carolina Andrade Biaggi Leite, enfermeira e aluna de pós-graduação, doutorado e de sua professora, a Dra. Lucila Castanheira Nascimento, que são da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo.

O que eu tenho que fazer?

No nosso 1º encontro que está sendo hoje vamos conversar sobre você e sobre quem é a sua família. Vamos escrever e desenhar em um papel quem são as pessoas da sua família. Depois vamos agendar um próximo encontro para a próxima semana no local de sua preferência. Vou pedir para que neste tempo, entre os nossos encontros, você tire fotografias sobre o que é ter esperança em relação a sua doença. Você é livre para tirar quantas fotos quiser. Caso você não tenha uma câmera digital eu vou te emprestar uma e no nosso próximo encontro você me devolverá. Na próxima vez que nos encontrarmos eu vou colocar as fotos em um computador e vamos conversar sobre elas. Se você quiser vamos nos encontrar mais de uma vez para conversarmos sobre as suas fotos.

O que vai acontecer com essas informações?

Quando terminarmos, o resultado final dessa pesquisa será divulgado em revistas científicas e apresentado em encontros científicos, como congressos.

Tudo será confidencial?

Sim. Nós não iremos pedir para você dar o seu nome. Não teremos como relacionar você com as informações que nos der. Somente os pesquisadores poderão ver as informações que você nos disser, mas eles não conseguem saber de quem são aquelas informações. As fotos que você tirar vão ficar guardadas em segurança, e se tiver alguma informação que possa identificar você ou sua família vamos editar para apaga-las.

Eu sou obrigado a participar do estudo?

Não. Você pode escolher não participar do estudo, mesmo que seus pais ou responsáveis tenham deixado você participar da pesquisa. Você não vai ser prejudicado e ninguém vai ficar triste ou chateado com você. Você também poderá deixar de participar da pesquisa a hora que quiser, mesmo já tendo começado, sem problema nenhum e sem ser prejudicado por isso. A sua participação na pesquisa só vai acontecer se você quiser e sua mãe ou responsável autorizar.

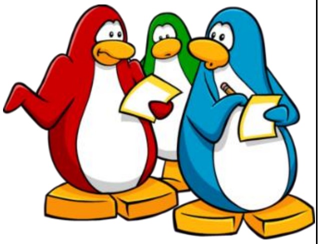
Eu vou ganhar alguma coisa por participar?

Não. Você não receberá qualquer quantia por participar da pesquisa e também não terá que pagar nenhum dinheiro. Os resultados dessa pesquisa não irão te beneficiar nesse momento, mas sua participação será importante para entendermos como as crianças e os adolescentes sentem a esperança.

O que eu faço se eu me sentir prejudicado?

Durante a nossa conversa você pode se sentir cansado ou se lembrar de situações ou momentos difíceis e estes podem ser um risco por você participar da pesquisa. Se isso acontecer, poderemos parar e continuar depois, se você quiser. Nesse momento, eu estarei pronta para te ouvir e ajudar. Se você sofrer algum dano à saúde como resultado da participação nesse estudo ou se sentir prejudicado, de alguma forma, como por exemplo, por se sentir triste por ter falado sobre você, nós iremos ajudar você a ter o atendimento necessário no serviço de saúde de forma gratuita. Ao assinar este Termo de Assentimento você não perderá nenhum direito, inclusive o de obter indenização por danos à saúde, se isto acontecer. Você tem direito à indenização por parte das pesquisadoras e das instituições envolvidas na pesquisa por eventuais danos decorrentes da sua participação, conforme a Resolução 466/2012, item IV.3-h.

Com quem eu posso falar se eu tiver dúvida sobre o estudo?



Se você tiver alguma dúvida, poderá nos perguntar ou pedir para os seus pais nos ligarem ou mandar um e-mail pelo endereço ou telefone que está escrito logo abaixo. Este estudo segue a Resolução CNS 466 de 2012, do Conselho Nacional de Saúde, que define as diretrizes e normas regulamentadoras de pesquisas envolvendo seres humanos. Esta pesquisa foi analisada e aprovada pelo Comitê de Ética em Pesquisa com Seres Humanos (CEP) da Escola de Enfermagem de Ribeirão Preto/USP, pois respeita as questões éticas necessárias para a sua realização. O CEP também protege as pessoas que participam da pesquisa e cuida dos seus direitos. Assim, se for necessário, entre em contato com este CEP pelo telefone (16) 3315-9197, de segunda a sexta-feira, nos dias úteis, das 10h às 12h e das 14h ás 16h. Caso deseje falar conosco, você poderá nos encontrar por meio do telefone (16) 3615-3435 ou procurar-nos na Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo, Avenida Bandeirantes, 3900 - Campus Universitário, Ribeirão Preto – SP, CEP: 14040-902, de segunda a sexta-feira, nos dias úteis, das 8h ás 17h. Pesquisadora responsável: Ana Carolina Andrade Biaggi Leite. E-mail: ana.andrade.leite@usp.br

Li tudo e agora?

Se você concorda em participar desta pesquisa e após tirar suas dúvidas, por favor, assine duas vias deste papel, que se chama Termo de Assentimento. Você receberá uma cópia desse Termo assinada por mim e pela minha professora.

Após ficar sabendo sobre como eu vou poder ajudar nesta pesquisa, eu concordo com minha participação sem ninguém ter me obrigado. Entendi o estudo e tive a oportunidade de ler o Termo de Assentimento ou alguém o leu para mim. Tive a oportunidade de pensar, fazer *perguntas e falar a respeito do documento com outras pessoas quando precisei. Autorizo a minha inclusão neste estudo. Sei, também, que ao final deste trabalho meu nome vai ser guardado em segredo. Sei que quando eu não quiser mais participar posso desistir sem qualquer problema para mim ou para minha família. Recebi uma cópia deste papel que estou assinando e que está assinada pela pesquisadora do estudo e sua professora, e pude conversar sobre este documento com uma delas.*

______________(SP), ____ de _____________ de 201__.

____

Ana Carolina Andrade Biaggi Leite

Pesquisadora

____

Participante

____

Profa. Dra. Lucila Castanheira Nascimento

Orientadora

☑

APÊNDICE F
TERMO DE ASSENTIMENTO
(Familiares entre 8 e 17 anos)

Pesquisa: “Esperança nas famílias de crianças e adolescentes com doenças crônicas: análise de aspectos conceituais e subjetivos”

O que é esta pesquisa?

A pesquisa é como você sente esperança em relação a doença de seu familiar (irmão, irmã, primo, prima, etc.). Eu vou fazer algumas perguntas para você responder e para eu poder conhecer melhor você. Gostaria de saber como você sente a esperança em relação a doença de seu familiar e para isso vou pedir para você tirar fotos. Depois vamos conversar sobre as fotos que você tirou.

De quem é a pesquisa?

A pesquisa é da Ana Carolina Andrade Biaggi Leite, enfermeira e aluna de pós-graduação, doutorado e de sua professora, a Dra. Lucila Castanheira Nascimento, que são da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo.

O que eu tenho que fazer?

No nosso 1º encontro que está sendo hoje vamos conversar sobre você. Depois vamos agendar um próximo encontro para a próxima semana no local de sua preferência. Vou pedir para que neste tempo, entre os nossos encontros, você tire fotografias sobre o que é ter esperança em relação a doença de seu familiar. Você é livre para tirar quantas fotos quiser. Caso você não tenha uma câmera digital eu vou te emprestar uma e no nosso próximo encontro você me devolverá. Na próxima vez que nos encontrarmos eu vou colocar as fotos em um computador e vamos conversar sobre elas. Se você quiser vamos nos encontrar mais de uma vez para conversarmos sobre as suas fotos.

O que vai acontecer com essas informações?

Quando terminarmos, o resultado final dessa pesquisa será divulgado em revistas científicas e apresentado em encontros científicos, como congressos.

Tudo será confidencial?

Sim. Nós não iremos pedir para você dar o seu nome. Não teremos como relacionar você com as informações que nos der. Somente os pesquisadores poderão ver as informações que você nos disser, mas eles não conseguem saber de quem são aquelas informações. As fotos que você tirar vão ficar guardadas em segurança, e se tiver alguma informação que possa identificar você ou sua família vamos editar para apaga-las.

Eu sou obrigado a participar do estudo?

Não. Você pode escolher não participar do estudo, mesmo que seus pais ou responsáveis tenham deixado você participar da pesquisa. Você não vai ser prejudicado e ninguém vai ficar triste ou chateado com você. Você também poderá deixar de participar da pesquisa a hora que quiser, mesmo já tendo começado, sem problema nenhum e sem ser prejudicado por isso. A sua participação na pesquisa só vai acontecer se você quiser e sua mãe ou responsável autorizar.

Eu vou ganhar alguma coisa por participar?

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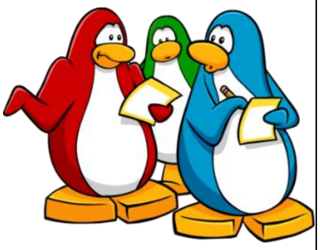
Com quem eu posso falar se eu tiver dúvida sobre o estudo?



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Li tudo e agora?

Se você concorda em participar desta pesquisa e após tirar suas dúvidas, por favor, assine duas vias deste papel, que se chama Termo de Assentimento. Você receberá uma cópia desse Termo assinada por mim e pela minha professora.

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______________(SP), ____ de _____________ de 201__.

____

Ana Carolina Andrade Biaggi Leite

Pesquisadora

____

Participante

____

Profa. Dra. Lucila Castanheira Nascimento

Orientadora

☑

APÊNDICE G

QUESTIONÁRIO DE CARACTERIZAÇÃO

Data da Entrevista: ___/___/____
Local:
Nº da Família:

Familiar (adulto)
Nº do participante: ________

Grau de parentesco ao caso índice: Mãe ( ) Pai ( ) Avó ( ) Outro (especificar):____________

Idade:______anos Data de nascimento: ___/___/____

Sexo: Feminino ( ) Masculino( )

Procedência – Cidade: _____________________ Estado: ( )

Estado Civil: ______________

Escolaridade (em anos): ______________

Nível escolar: Educação Infantil ( ) Ensino Fundamental I ( ) Ensino Fundamental II ( )
Nível Médio ( ) Superior ( ) Não sabe ( )

Profissão:_______________

Religião: ___________________ Praticante: Sim ( ) Não ( ) Não se aplica ( )

Há quanto tempo convive com a criança ou adolescente diagnosticado com doença crônica?
____

Data da Entrevista: ___/___/____
Local: Nº da Família:

Criança ou adolescente (caso índice)
Nº do participante: ________

Idade:______anos Data de nascimento: ___/___/____

Sexo: Feminino ( ) Masculino ( )

Procedência – Cidade: _____________________ Estado: ( )

Escolaridade (em anos): ______________

Nível escolar: Educação Infantil ( ) Ensino Fundamental I ( ) Ensino Fundamental II ( )
Nível Médio ( ) Superior ( ) Não sabe ( )

Religião: ___________________ Praticante: Sim ( ) Não ( ) Não se aplica ( )

Diagnóstico Médico: ______________________ Tempo de diagnóstico:_____________

Tratamento atual: _________________________

Data da Entrevista: ___/___/____
Local: Nº da Família:
Familiar (Entre 8 e 17 anos)

Nº do participante: ________

Grau de parentesco ao caso índice: irmão/irmã( ) primo/prima( )
Outro(especificar):____________

Idade:______anos Data de nascimento: ___/___/____

Sexo: Feminino ( ) Masculino ( )

Procedência – Cidade: _____________________ Estado: ( )

Escolaridade (em anos): ______________

Nível escolar: Educação Infantil ( ) Ensino Fundamental I ( ) Ensino Fundamental II ( )
Nível Médio ( ) Superior ( ) Não sabe ( )

Religião: ___________________ Praticante: Sim ( ) Não ( ) Não se aplica ( )

Há quanto tempo convive com a criança ou adolescente diagnosticado com doença crônica?
____

ANEXOS

ANEXOS

ANEXO A: OFÍCIO DE APROVAÇÃO ÉTICA DA INSTITUIÇÃO PROPONENTE.

ANEXO B: OFÍCIO DE APROVAÇÃO ÉTICA DA INSTITUIÇÃO COPARTICIPANTE.

ANEXO C: AUTORIZAÇÃO DO USO DO DIREITO AUTORAL DO ARTIGO 1 – REVISÃO. THE EXPERIENCE OF HOPE IN FAMILIES OF CHILDREN AND ADOLESCENTS LIVING WITH CHRONIC ILLNESS: A THEMATIC SYNTHESIS OF QUALITATIVE STUDIES

ANEXO D: AUTORIZAÇÃO DO USO DO DIREITO AUTORAL DO ARTIGO 2 – METODOLÓGICO. USING PHOTO-ELICITATION INTERVIEWS WITH FAMILIES OF CHILDREN AND ADOLESCENTS WITH CHRONIC ILLNESS.

ANEXO E: ARTIGO 3 APROVADO PARA PUBLICAÇÃO EM REVISTA DE ACESSO ABERTO – WAVES OF FAMILY HOPE: NARRATIVES OF FAMILIES IN THE CONTEXT OF PEDIATRIC CHRONIC ILLNESS

ANEXO A
OFÍCIO DE APROVAÇÃO ÉTICA DA INSTITUIÇÃO PROPONENTE

UNIVERSIDADE DE SÃO PAULO
ESCOLA DE ENFERMAGEM DE RIBEIRÃO PRETO

Centro Colaborador da OPAS/OMS para o
Desenvolvimento da Pesquisa em Enfermagem

Avenida Bandeirantes, 3900 - Ribeirão Preto - São Paulo - Brasil - CEP 14040-902
Fone: 55 16 3315.3382 / 55 16 3315.3381 - Fax: 55 16 3315.0518
www.eerp.usp.br - eerp@usp.br

Ofício CEP-EERP/USP nº 227/2018, de 19/09/2018

Prezada Senhora,

Comunicamos que o projeto de pesquisa abaixo especificado foi analisado e considerado **aprovado "ad referendum"** pelo Comitê de Ética em Pesquisa da Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo (CEP-EERP/USP) em 18 de setembro de 2018.

Protocolo CAAE: 91461418.7.0000.5393

Projeto: Esperança nas famílias de crianças e adolescentes com doenças crônicas

Pesquisadores: Ana Carolina Andrade Biaggi Leite
Lucila Castanheira Nascimento (orientadora)

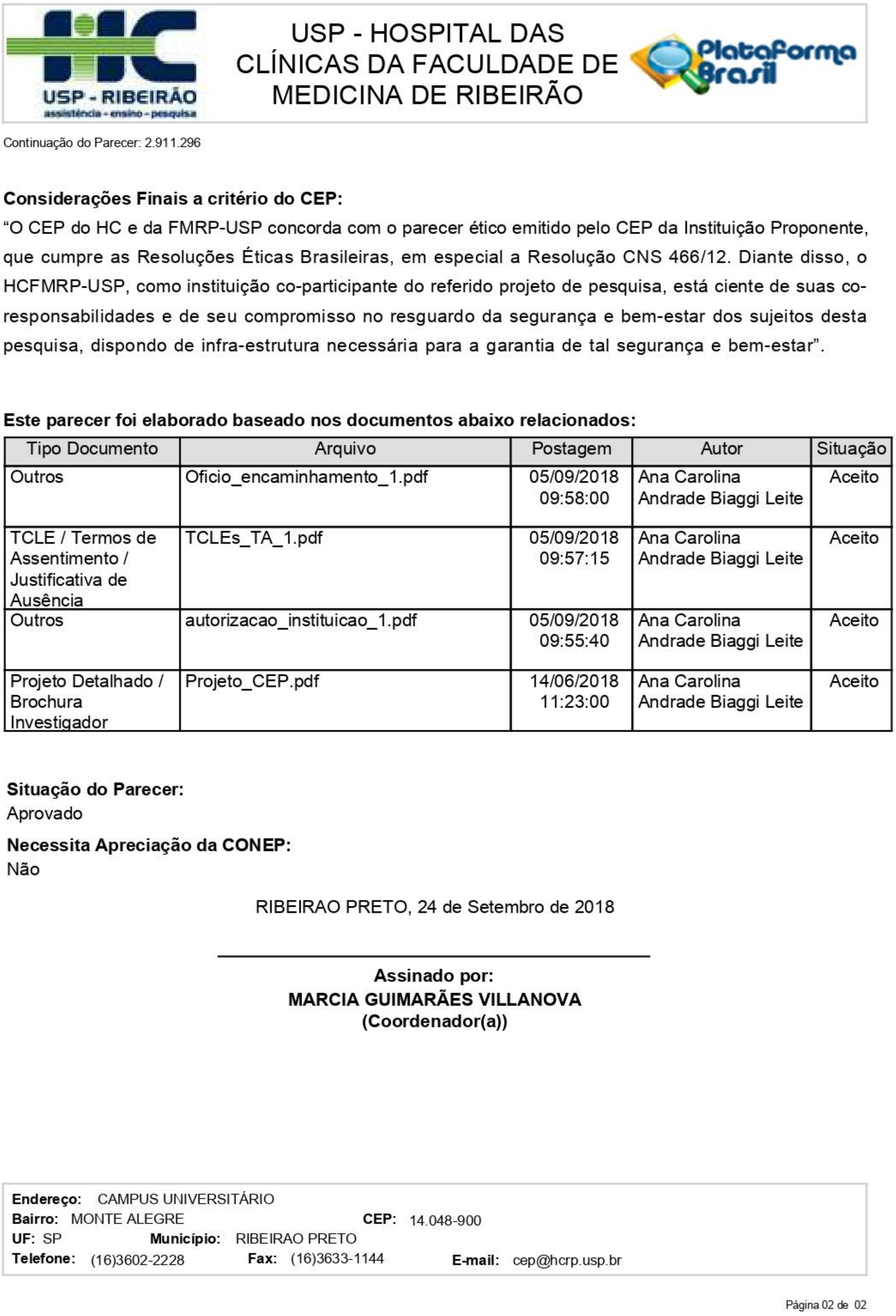
Em atendimento à Resolução 466/12, deverá ser encaminhado ao CEP o relatório final da pesquisa e a publicação de seus resultados, para acompanhamento, bem como comunicada qualquer intercorrência ou a sua interrupção.

Atenciosamente,

Prof.ª Dra. Angelita Maria Stabile
Coordenadora do CEP-EERP/USP

Ilma. Sra.
Prof.ª Dra. Lucila Castanheira Nascimento
Departamento de Enfermagem Materno-Infantil e Saúde Pública
Escola de Enfermagem de Ribeirão Preto - USP

ANEXO B
OFÍCIO DE APROVAÇÃO ÉTICA DA INSTITUIÇÃO COPARTICIPANTE



USP - HOSPITAL DAS CLÍNICAS DA FACULDADE DE MEDICINA DE RIBEIRÃO

Continuação do Parecer: 2.911.296

Considerações Finais a critério do CEP:

“O CEP do HC e da FMRP-USP concorda com o parecer ético emitido pelo CEP da Instituição Proponente, que cumpre as Resoluções Éticas Brasileiras, em especial a Resolução CNS 466/12. Diante disso, o HCFMRP-USP, como instituição co-participante do referido projeto de pesquisa, está ciente de suas co-responsabilidades e de seu compromisso no resguardo da segurança e bem-estar dos sujeitos desta pesquisa, dispondo de infra-estrutura necessária para a garantia de tal segurança e bem-estar”.

Este parecer foi elaborado baseado nos documentos abaixo relacionados:

Tipo Documento	Arquivo	Postagem	Autor	Situação
Outros	Oficio_encaminhamento_1.pdf	05/09/2018 09:58:00	Ana Carolina Andrade Biaggi Leite	Aceito
TCLE / Termos de Assentimento / Justificativa de Ausência	TCLEs_TA_1.pdf	05/09/2018 09:57:15	Ana Carolina Andrade Biaggi Leite	Aceito
Outros	autorizacao_instituicao_1.pdf	05/09/2018 09:55:40	Ana Carolina Andrade Biaggi Leite	Aceito
Projeto Detalhado / Brochura Investigador	Projeto_CEP.pdf	14/06/2018 11:23:00	Ana Carolina Andrade Biaggi Leite	Aceito

Situação do Parecer:
Aprovado

Necessita Apreciação da CONEP:
Não

RIBEIRAO PRETO, 24 de Setembro de 2018

Assinado por:
MARCIA GUIMARÃES VILLANOVA
(Coordenador(a))

Endereço: CAMPUS UNIVERSITÁRIO
Bairro: MONTE ALEGRE **CEP:** 14.048-900
UF: SP **Município:** RIBEIRAO PRETO
Telefone: (16)3602-2228 **Fax:** (16)3633-1144 **E-mail:** cep@hcrp.usp.br

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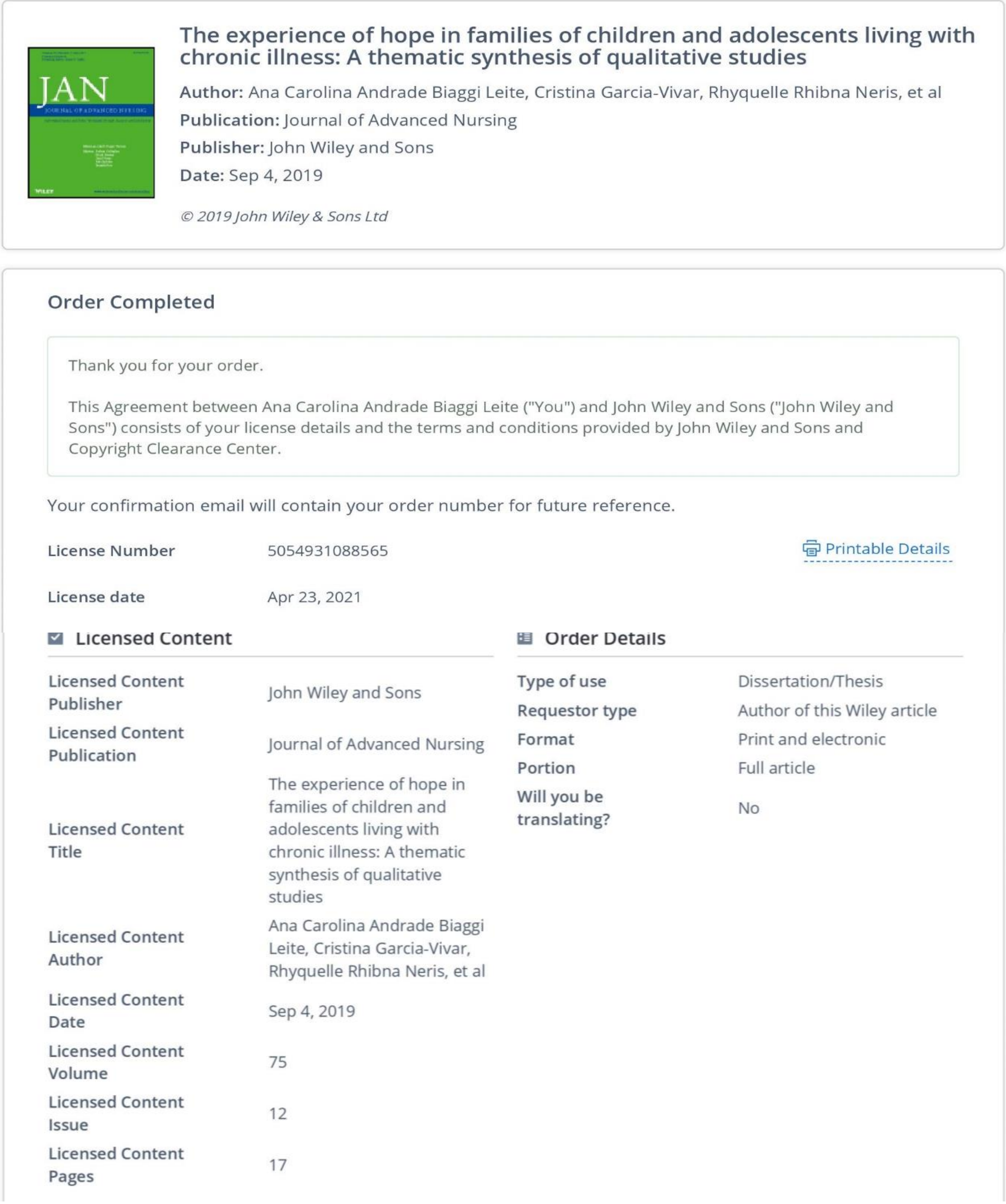
ANEXO C

AUTORIZAÇÃO DO USO DO DIREITO AUTORAL DO ARTIGO 1 – REVISÃO. THE EXPERIENCE OF HOPE IN FAMILIES OF CHILDREN AND ADOLESCENTS LIVING WITH CHRONIC ILLNESS: A THEMATIC SYNTHESIS OF QUALITATIVE STUDIES



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

Author: Ana Carolina Andrade Biaggi Leite, Cristina Garcia-Vivar, Rhyquelle Rhibna Neris, et al

Publication: Journal of Advanced Nursing

Publisher: John Wiley and Sons

Date: Sep 4, 2019

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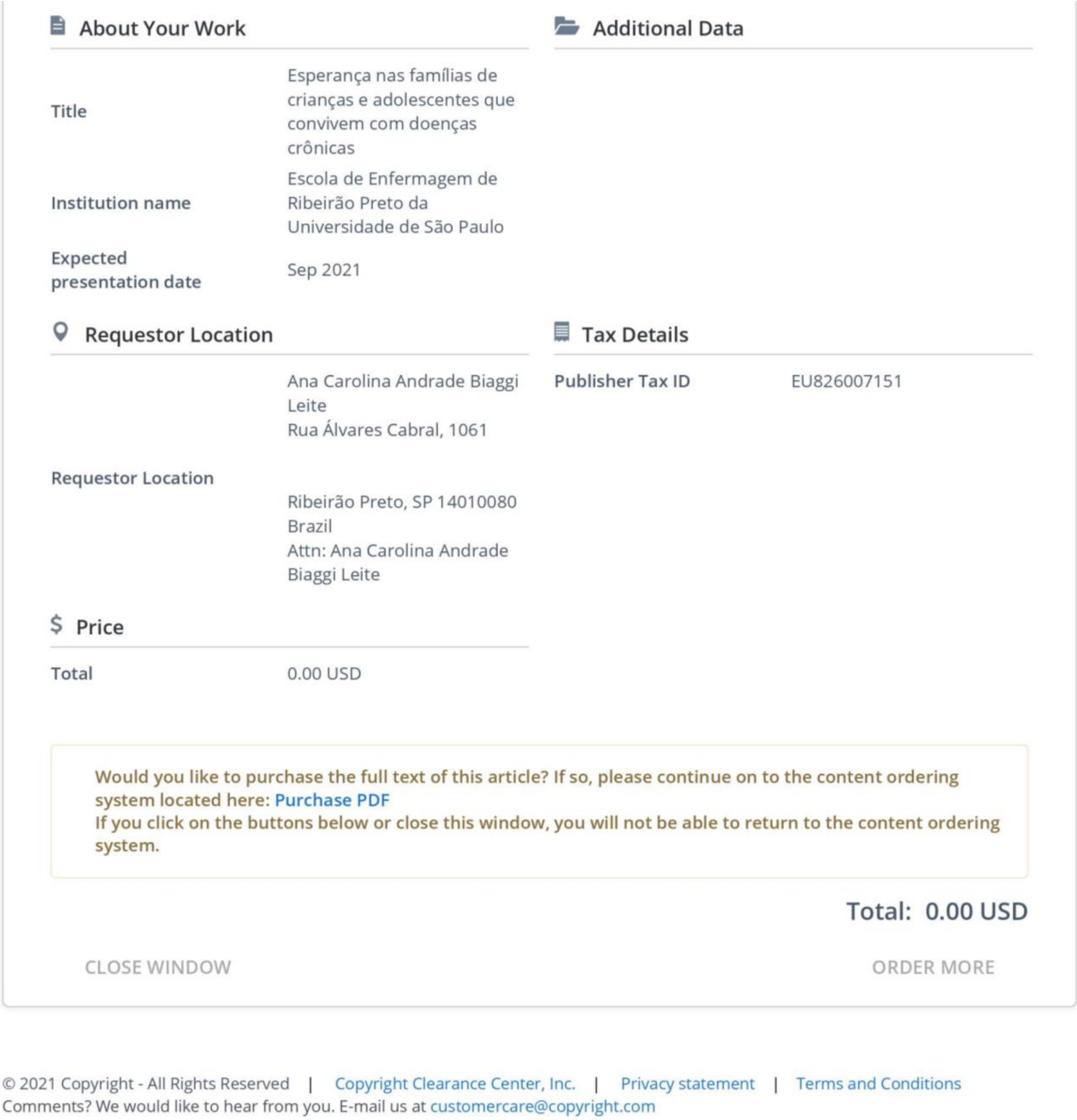

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Title	Esperança nas famílias de crianças e adolescentes que convivem com doenças crônicas
Institution name	Escola de Enfermagem de Ribeirão Preto da Universidade de São Paulo
Expected presentation date	Sep 2021

Additional Data

Requestor Location

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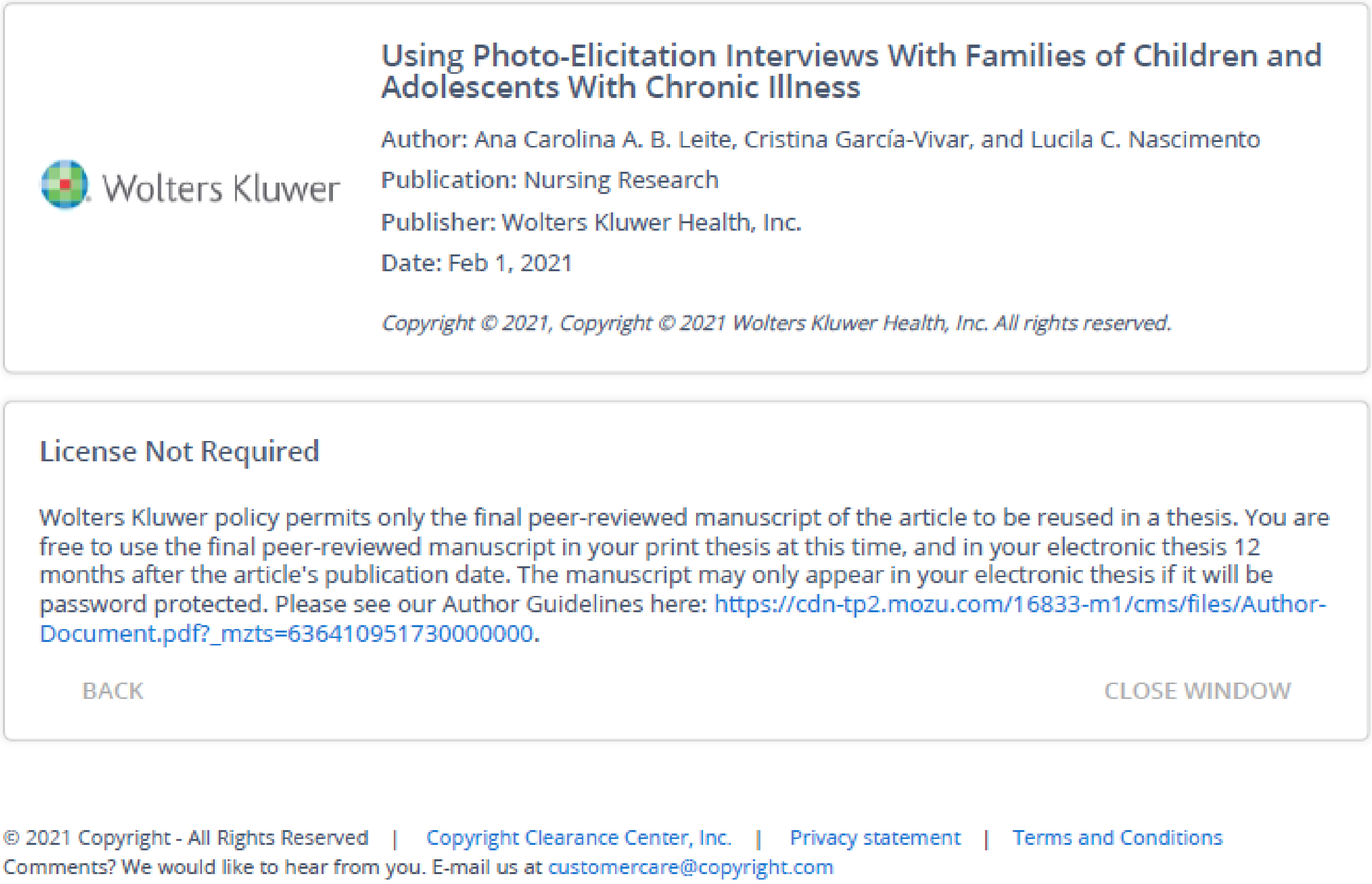
ANEXO D

AUTORIZAÇÃO DO USO DO DIREITO AUTORAL DO ARTIGO 2 – METODOLÓGICO. USING PHOTO-ELICITATION INTERVIEWS WITH FAMILIES OF CHILDREN AND ADOLESCENTS WITH CHRONIC ILLNESS.



Wolters Kluwer

Using Photo-Elicitation Interviews With Families of Children and Adolescents With Chronic Illness

Author: Ana Carolina A. B. Leite, Cristina García-Vivar, and Lucila C. Nascimento

Publication: Nursing Research

Publisher: Wolters Kluwer Health, Inc.

Date: Feb 1, 2021

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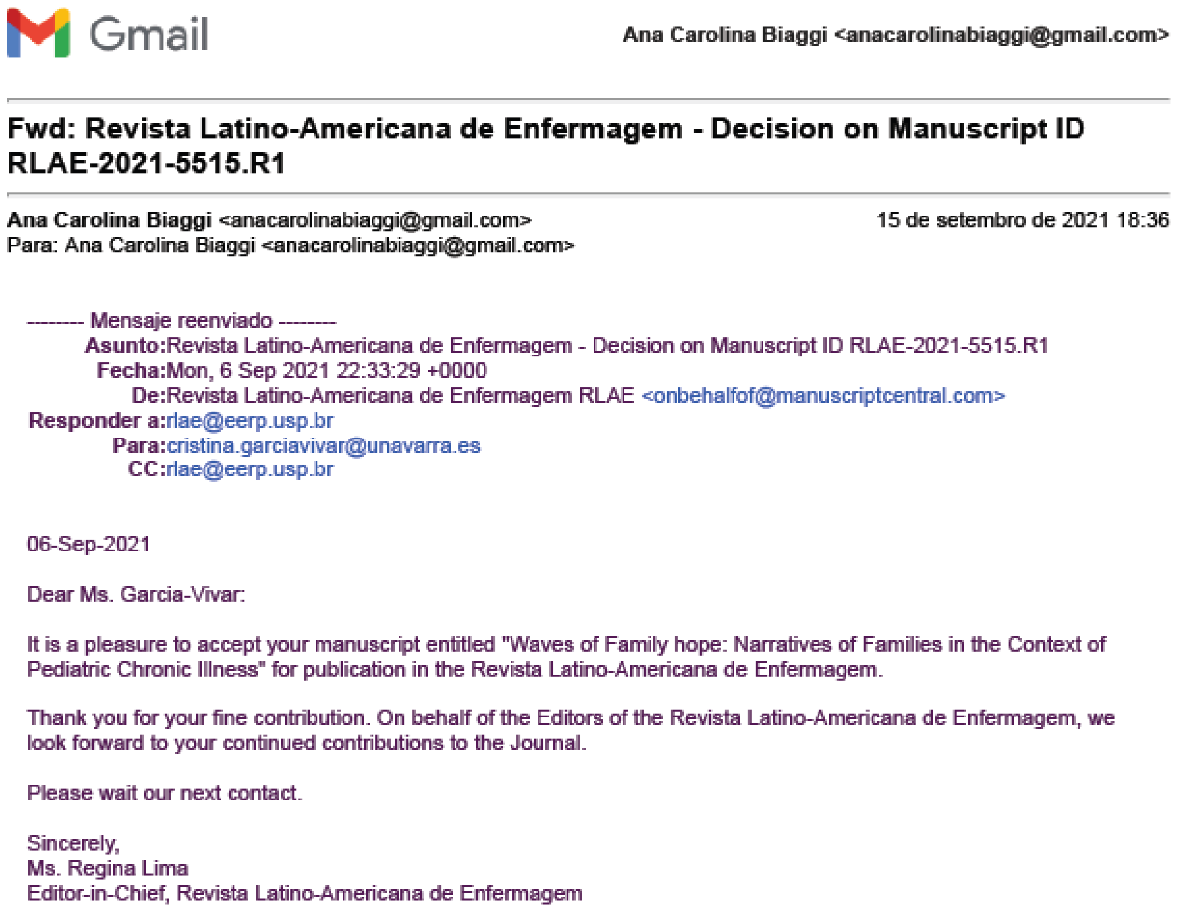
ANEXO E

ARTIGO 3 APROVADO PARA PUBLICAÇÃO EM REVISTA DE ACESSO ABERTO – WAVES OF FAMILY HOPE: NARRATIVES OF FAMILIES IN THE CONTEXT OF PEDIATRIC CHRONIC ILLNESS



Gmail **Ana Carolina Biaggi <anacarolinabiaggi@gmail.com>**

Fwd: Revista Latino-Americana de Enfermagem - Decision on Manuscript ID RLAE-2021-5515.R1

Ana Carolina Biaggi <anacarolinabiaggi@gmail.com> 15 de setembro de 2021 18:36
Para: Ana Carolina Biaggi <anacarolinabiaggi@gmail.com>

-------- Mensaje reenviado --------
Asunto: Revista Latino-Americana de Enfermagem - Decision on Manuscript ID RLAE-2021-5515.R1
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De: Revista Latino-Americana de Enfermagem RLAE <onbehalfof@manuscriptcentral.com>
Responder a:rlae@eerp.usp.br
Para:cristina.garciavivar@unavarra.es
CC:rlae@eerp.usp.br

06-Sep-2021

Dear Ms. Garcia-Vivar:

It is a pleasure to accept your manuscript entitled "Waves of Family hope: Narratives of Families in the Context of Pediatric Chronic Illness" for publication in the Revista Latino-Americana de Enfermagem.

Thank you for your fine contribution. On behalf of the Editors of the Revista Latino-Americana de Enfermagem, we look forward to your continued contributions to the Journal.

Please wait our next contact.

Sincerely,
Ms. Regina Lima
Editor-in-Chief, Revista Latino-Americana de Enfermagem