



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

Jill M.G. Bally ^{a,*}, Nicole R. Smith ^{a,b}, Lorraine Holtslander ^{a,c}, Vicky Duncan ^d, Heather Hodgson-Viden ^e, Christopher Mpofu ^f, Marcelline Zimmer ^g

^a College of Nursing, University of Saskatchewan, Saskatoon, SK, Canada

^b Saskatoon Health Region, Saskatoon, SK, Canada

^c University of the Witwatersrand, Johannesburg, South Africa

^d Health Sciences Library, University of Saskatchewan, Saskatoon, SK, Canada

^e College of Medicine, University of Saskatchewan, Saskatoon, SK, Canada

^f Saskatoon Cancer Centre, Saskatoon, SK, Canada

^g Ronald McDonald House Saskatchewan, Saskatoon, SK, Canada

ARTICLE INFO

Article history:

Received 28 August 2017

Revised 25 October 2017

Accepted 3 November 2017

Available online xxxx

Keywords:

Parent experiences

Life-limiting illness

Life-threatening illness

Hope

Metasynthesis

ABSTRACT

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

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

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

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

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

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

© 2017 Elsevier Inc. All rights reserved.

Introduction

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

☆ The authors acknowledge the Royal Bank of Canada Nurses for Kids Community Development Program and the College of Nursing, University of Saskatchewan for providing funding for this research. We also thank Laurie Schimpf for her expertise and support during this review.

* Corresponding author at: College of Nursing, University of Saskatchewan, 104 Clinic Place, Saskatoon, SK S7N 2Z4, Canada.

E-mail address: jill.bally@usask.ca (J.M.G. Bally).

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

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

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

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

Methods

Design

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

Search Methods

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

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

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

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

Search Outcome

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

Quality Appraisal

Appraising Reports of Qualitative Studies

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

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

Download English Version:

<https://daneshyari.com/en/article/8574140>

Download Persian Version:

<https://daneshyari.com/article/8574140>

[Daneshyari.com](https://daneshyari.com)