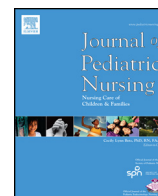




Contents lists available at ScienceDirect

Journal of Pediatric Nursing



Blogs Written by Families During Their Child's Hospitalization: A Thematic Narrative Analysis

Carolyn W. Jones *, Mary R. Lynn

University of North Carolina at Chapel Hill, Chapel Hill, NC 27599, United States

ARTICLE INFO

Article history:

Received 13 November 2017

Revised 19 March 2018

Accepted 26 March 2018

Available online xxxx

Keywords:

Neonatal intensive care

Pediatric intensive care

Coping

Stressors

Illness blogs

ABSTRACT

Purpose: To identify stressors experienced by parents whose child is hospitalized in an intensive care unit, and identify coping mechanisms utilized to ameliorate those stressors.

Design and Methods: Using Lazarus and Folkman's Transactional Model of Stress and Coping as a framework, 20 publicly available blogs written by parents while their child was a patient in intensive care were analyzed using thematic analysis techniques. Stressors and coping techniques were identified, and grouped by theme for further analysis.

Results: The most frequently noted types of stressors were related to information; both knowing and not knowing information related to their child's condition was reported as stressful, as well as waiting for information and when the information was not what was expected. Reframing was the emotion-focused technique most often identified by the parents, and seeking support was the most frequently noted problem-focused coping mechanism.

Conclusions: Illness blogs represent a rich source of information regarding the experiences of families with a child in the hospital. Parents transitioned from more emotion-focused coping strategies to problem-focused strategies during their child's hospital stay.

Practice Implications: When nurses give information to parents, they should be aware that knowing information can be stressful as well as not knowing, and care should be taken to provide support for parents after information is given. Nurses can also help parents identify sources of support. Writing about their experiences, either online or in a journal, may help parents cope in stressful situations.

© 2017 Elsevier Inc. All rights reserved.

Introduction

Having a child or infant in the hospital is one of the most stressful events parents can experience. They may be overwhelmed by the stress of the child's illness, complicated medical information, and/or worry about their child's future while trying to balance other family demands and maintain some continuity in their daily lives (Maghaireh, Abdullah, Chan, Piaw, & Kawafha, 2016). As they encounter stressors, they must find ways to cope and harness resources to maintain stability (Franck et al., 2015; Gregory, 2015).

When a child is hospitalized, parents are concerned about their child's eventual outcome and if there will be any long-lasting consequences (Lisanti, Golfenshtein, & Medoff-Cooper, 2017). There may be uncertainty as to what caused the illness, shock about the gravity of the situation, or guilt if the hospitalization was due to an accident or something perceived as having been under the parents' control

(Maghaireh et al., 2016). Usual routines are disrupted and they may feel isolated, even if surrounded by family members and friends. This disruption has been identified as a source of stress for families that may influence how they adjust to their new situation (Stremler, Haddad, Pullenayegum, & Parshuram, 2017; Yaman & Altay, 2015). Another concern is that often parents must sort through large volumes of unfamiliar medical or diagnostic information, and may have to make decisions based on incomplete understanding. To do this, they must trust the healthcare professionals, with whom they may be unfamiliar. In short, they are placed in an unfamiliar, unexpected, unwanted, and frightening environment.

Stresses experienced by individuals during the acute illness of a family member are profound and may lead to adverse health and psychological consequences (Franck et al., 2015). Brehaut et al. (2009) found that caregivers of children with health problems were twice as likely to report chronic health conditions, depressive symptoms, and poorer general health than caregivers of healthy children. Muscara et al. (2015) reported that half of the parents of a child hospitalized with a life-threatening illness met criteria for acute stress disorder and had increased rates of depression and anxiety. It is important for nurses to

* Corresponding author at: University of North Carolina Wilmington, 601 South College Road, CB#5995, Wilmington, NC 28403, United States.
E-mail address: jonescw@uncw.edu. (C.W. Jones).

understand what parents identify as stressful during their child's hospitalization as well as their potential coping strategies to help them avoid the negative consequences of stress.

Lazarus and Folkman (1984) formulated a theory of psychological stress based on the idea that stress and emotion are influenced by how a person appraises their transactions with the environment. This led to their development of the Transactional Model of Stress and Coping (TMSC) (Lazarus, 1999). The TMSC provides a framework for understanding the process of appraising and coping with stressful events, and the interplay between the environment, resources, and strategies used for coping. Stress is conceptualized as the result of a transaction between a person and the environment that the person appraises as taxing or exceeding his or her resources (Lazarus & Folkman, 1984). Coping is defined as cognitive and behavioral efforts to manage demands; these efforts are further classified as problem-focused and emotion-focused. After coping efforts are employed an individual again appraises the stressor (secondary appraisal) to determine a stressor still exists. An individual can apply either or both types of coping to a situation (Lazarus & Folkman, 1984).

Parents who have an acutely ill infant or child who is hospitalized experience a wide range of stressors, including reactions to the appearance of the child (Balluffi et al., 2004; Board & Ryan-Wenger, 2003), alteration in the parental role (Aamir, Mittal, Kaushik, Kashyap, & Kaur, 2014), financial burden (Long, 2003), and the infant/child's emotions (Jee et al., 2012). Events such as uncertain outcomes and the possibility of the child's death are stressors identified by parents (Jee et al., 2012). Multiple studies have identified transfers within the hospital as a source of stress for parents (Colville et al., 2009; Hall, 2005).

A relatively new social media phenomenon is the use of blogs to write about personal experiences. A blog provides a format for individuals' articulation of their thoughts in a time-sequenced manner to create an Internet-based journal. The prevalence of blogs about patients and their family members' experiences with illness has increased dramatically in recent years (O'Brien & Clark, 2010). Many parents write about their experiences when their child is hospitalized (Heilferty, 2011). There is little research on these online narratives of the family's experience of illness, yet they represent a potentially rich source of information for learning what families go through. The purpose of this study was to use thematic narrative analysis techniques to analyze blogs authored by parents of an infant or child hospitalized in an intensive care unit to identify stressors perceived by the parents and measures used by them to cope with these stressors.

Methods

It was hypothesized that narrative analysis of blogs written by parents during their child's hospitalization would provide a rich description of how they appraised and coped with this stressful situation. Approval for the study was granted by the Office of Human Research Ethics at the University of North Carolina at Chapel Hill, where it was deemed exempt from further review due to the use of existing public data. In seeking to understand the process of appraisal and coping, four research questions were addressed: (1) What stressors do parents report? (2) What coping strategies are identified? (3) How do the stressors and coping strategies described by parents change over the course of their infant or child's hospitalization? (4) Is there evidence in the blogs to support or challenge the supposition that secondary appraisal leads to problem- and emotion-focused coping strategies?

Sampling and Data Collection

Data were collected from publicly available blogs on the Internet, so no formal recruitment of participants was needed. Although blogs were associated with names, no names or identifiers are reported in this research study. A purposive sampling strategy was used to obtain the sample for this study; blogs were found using the search engines Google

and Yahoo using the terms *parent, blog, neonatal intensive care, and pediatric intensive care*. Additional blogs were found through links on selected blogs to other similar types of blogs (called blog-rolling). Blogs were hosted on WordPress, Typepad, or individual domains. The rationale for using purposive sampling was to obtain a representative, heterogeneous sample (Maxwell, 2012). Purposive sampling also included seeking some variety of the children's primary diagnoses. The language, presentation, and punctuation of the bloggers was preserved, and spelling or grammatical deviations were presented as they were in the blogs.

Inclusion criteria were: 1) the blog was written in English by someone who self-identified as a parent whose child or infant was hospitalized; 2) the blog's primary focus was the child's illness; 3) at least five entries were made; 4) the blog was started no more than 10 years prior to the data collection; 5) blog entries must contain dates and older posts needed to be available; and, 6) the blog was publicly available and did not require a password or approval for access. Children with a diagnosis of cancer were not included as the focus of this study was the parents' experience(s) during hospitalization of an acutely ill child. The research plan was for 15–20 blogs to be analyzed or until saturation was reached (Miles & Huberman, 1994). Blogs were read in their entirety to obtain an overview of the story told in each one.

Data Analysis

A combination of thematic narrative analysis as described by Riessman (2008) and applied thematic analysis described by Guest, MacQueen, and Namey (2012) was used and allowed for a better understanding of the emerging themes and for finding common thematic elements across different cases. Using the TMSC as the framework, the experiences of parents with a hospitalized infant or child identified their appraisal of events, what they identified as stressors, and details of their coping processes, were examined.

In qualitative analysis, themes can be determined inductively from the data or deductively by applying *a priori* themes derived from previous research and theory. For this study, both deductive and inductive methods of theme development were used. Blogs were re-read to identify types of stressors described by the parents. Coping strategies were also evaluated for the identified themes, starting with the broad categories of emotion-focused and problem-focused coping identified in the TMSC framework. Natural divisions occurred within a blog entry when the author of the blog separated the entry into paragraphs, within which a different idea or topic was discussed. Paragraphs were the units of analysis and were coded with one or multiple codes as appropriate.

More descriptive sub-categories of emotion-focused and problem-focused coping behaviors were added, and the coding scheme was revised. Each emerging code was added to the code list and defined in the codebook; revision was ongoing. This process included referencing the research questions to ensure that the new codes were in alignment with the purpose of the research. Blogs were then compared for similarities and differences in the significance of stressors and the methods of coping of different individuals experiencing somewhat similar crises. Within case analysis included changes in coping behaviors over time.

After coding 13 blogs, no new codes were noted, with 156 unique codes having been identified pertaining to stressors, emotion-focused coping, problem-focused coping, and a group of non-categorized codes. The codes were reviewed by five nursing and social work faculty/researchers with qualitative analysis experience to determine the consistency of the coding as well as that the coding reflected the reality described by the blogger. This was accomplished using a card sorting technique where data segments were printed on index cards and assigned to codes by the consulting researchers. The codes were then discussed with possible schema for sorting the codes into cohesive categories. Codes that were thought to reflect the same content were combined, and any codes with fewer than five occurrences specifically

Download English Version:

<https://daneshyari.com/en/article/8573828>

Download Persian Version:

<https://daneshyari.com/article/8573828>

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