Journal of Pediatric Nursing 37 (2017) 108–116

Contents lists available at ScienceDirect

Journal of Pediatric Nursing

Chronic Sorrow in Parents of Children with a Chronic Illness or Disability: An Integrative Literature Review

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ARTICLE INFO

Article history:
Received 15 March 2017
Revised 17 May 2017
Accepted 19 June 2017

Keywords:
Chronic sorrow
Children
Chronic illness
Disability
Parents

ABSTRACT

Problem: This integrative review aims to synthesize the findings of studies on chronic sorrow in parents, to analyze the findings along three specific research questions, and to identify areas for future research.
Eligibility Criteria: Studies of parents, mothers and/or fathers of non-adult children published in peer-reviewed journals that answered the research questions: 1) How does the experience of chronic sorrow differ between mothers and fathers? 2) What factors have been identified to impact the experience of chronic sorrow over time? 3) What strategies by health care providers for helping parents cope with chronic sorrow have been identified to be most and least helpful?
Sample: Nineteen studies from a literature search within the databases of CINAHL, MEDLINE, PsycINFO, Psycarticles and SocIndex were included in the review.
Results: Findings suggest that mothers experience more intense chronic sorrow compared with fathers. Health care crises and developmental milestones are potent triggers for resurgence of chronic sorrow. Helpful strategies by healthcare providers include providing information, helping to procure respite and being empathetic and compassionate.
Conclusions: Healthcare providers need to understand that chronic sorrow is a normal consequence of having a child with a chronic illness or disability.
Implications: Family-centered interventions should be individualized and aimed at providing increased comfort to parents in times of need. Further research that looks at the effectiveness of interventions is needed.

The prevalence of chronic illness, including developmental and behavioral problems in children, has continued to increase over the past 30 years (Van Cleave, Gortmaker, & Perrin, 2010). Parents are challenged with the responsibility of managing their child's health problem alongside the demands of everyday living. Studies have demonstrated that parents suffer a negative impact on their psychological and physical health as a result of these demands (Cousino & Hazen, 2013; Kratz, Uding, Trahms, Villareale, & Kieckhefer, 2009; Raina et al., 2005). While studies often include both parents, mothers have been more widely studied because they tend to be the primary caregivers.

Over the last several decades, the concept of chronic sorrow has emerged as a context within which caring for a child with a chronic illness or disability can be understood. Studies on chronic sorrow include parents of children with progressive neurodegenerative disease (Bettle & Latimer, 2009), multiple births and special needs (Bolch, Davis, Umstad, & Fisher, 2012), type 1 diabetes (Bowes, Lowes, Warner, & Gregory, 2009), Down syndrome (Damrosch & Perry, 1989), prematurity (Fraley, 1986), neural tube defects (Hobdell, 2004), epilepsy (Hobdell, et al., 2007), congenital heart disease (Leon, Wallenberg & Holliker, 2013), cancer (Nikfarid, Rassouli, Borimnejad, & Alavimajd, 2015), sickle cell disease (Northington, 2000), and cerebral palsy (Whittingham, Wee, Sanders, & Boyd, 2013). Both qualitative and quantitative designs have been employed. The research to date reveals that parents caring for a chronically ill or disabled child experience chronic sorrow.

Background

Chronic sorrow is a concept that has been explored among caregivers of adults and parents of children with chronic illness or disability. First conceptualized by Olshansky (1962) as a normal psychological response in parents with mentally disabled children, it wasn't until decades later that researchers began to study the concept in other

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http://dx.doi.org/10.1016/j.pedn.2017.06.011
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populations. In 1991, the *Nursing Consortium for Research on Chronic Sorrow* (NCRCS) was formed to expand the study of chronic sorrow beyond a primary focus on parents of children with disabilities to include individuals with chronic illness and their caregivers (Burke, Hainsworth, Eakes, & Lindgren, 1992; Eakes, Hainsworth, Lindgren, & Burke, 1991). Work by the consortium included refining the conceptual definition of chronic sorrow to include characteristics of the experience as permanent, periodic and progressive and differentiating chronic sorrow from grief and depression (Burke et al., 1992; Eakes, Burke, & Hainsworth, 1998).

Parents seek fulfillment in having children and watching them grow into responsible human beings. However, the joy of becoming a parent can be quickly diminished by the profound realization that the child has a lifelong illness or disability. When parents become aware of the impact that illness or disability will have on the child's potential to live a full and happy life, there is often a profound feeling of loss, resentment and a longing for the desired child (Patrick-Ott & Ladd, 2010; Vitale & Falco, 2014; Young, 1977). Numerous studies have looked at this phenomenon within the framework of chronic sorrow. Findings demonstrate that these feelings persist over time as the child grows and fails to meet expected developmental milestones, as the child has periodic relapses of illness, repeated hospitalizations, or as medical demands increase (Bowes et al., 2009; Gordon, 2009; Hewetson & Singh, 2009). The accumulation of research on chronic sorrow in parents over the last three decades, gives rise to a clinical problem facing those caring for children and their families. A deeper understanding of the impact of chronic sorrow on parents can guide interventions and provide a framework for family-centered care of children with a chronic illness or disability.

Purpose

The purpose of this integrative review is to synthesize the findings of studies on chronic sorrow in parents, to analyze the findings along three specific research questions, and to identify areas for future research. An integrative review was chosen as the appropriate method to examine this topic because it allows for analysis of diverse sources of data (Whittemore & Knafl, 2005). The research questions for this integrative review are: 1) How does the experience of chronic sorrow differ between mothers and fathers? 2) What factors have been identified to impact the experience of chronic sorrow over time? 3) What strategies by health care providers for helping parents cope with chronic sorrow have been identified to be most and least helpful?

Method

Data Sources and Screening

A search using the terms *chronic sorrow* and *parents* within the databases of CINAHL, MEDLINE, PsycINFO, Psycarticles and SocIndex was conducted between the spring and fall of 2016. The initial search for articles in peer-reviewed journals revealed 71 results. After removing duplicates, the number of records was 59. At that point, journal titles and abstracts were read for relevancy to this review. This brought the total number of articles down to 43. The inclusion and exclusion criteria were then applied which led to a final sample of 19 articles for review (see Fig. 1).

Inclusion/Exclusion Criteria

Inclusion criteria were studies of parents, mothers and/or fathers of non-adult children with a chronic illness or disability, parent experience of chronic sorrow, published after 1962 when the term chronic sorrow was first introduced, written in English, that employed a qualitative or quantitative approach, were published in peer-reviewed journals and were able to answer any of the research questions. Exclusion criteria included studies of parents of adult children with a chronic illness or disability, of caregivers that were not parents, that included parents of children with a terminal diagnosis or whose child had passed away, and unpublished studies. Ancestry searching of downloaded articles did not yield any additional studies which contributed to the assessment that the search was exhaustive.

Data Analysis

Of the nineteen studies in the sample, four were quantitative, eleven were qualitative and four were mixed methods. Critical appraisal was conducted for methodological rigor following the criteria described in Hawker, Payne, Kerr, Hardey, and Powell (2002). The studies were appraised along nine measures: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability/generalizability, and implications/usefulness with each measure having four options of either good (4), fair (3), poor (2) or very poor (1). The rating of each measure was summed according to the published guidelines for a total score between 9 and 36 for each article (Hawker et al., 2002). To increase the reliability of the appraisal, both authors appraised the articles separately for quality until there was 100% agreement supporting inter-rater reliability.

The scores for the sample in this review ranged from a low of nineteen to a high of thirty-six out of a possible thirty-six. These raw scores were then converted back to the qualitative description of either poor (scores below 20), fair (scores from 20 to 28) and good (scores above 28 to 36). None of the studies were rated at very poor (under 10). This conversion allowed for a more readily interpretable assessment of the overall quality of each included study.

A review matrix was created with a row for each study and columns for the parts of the research process. Each study was abstracted one at a time. Initially, data was extracted from the sample studies in chronological order to gain an appreciation of how the research has evolved over time and to answer the three research questions. See Tables 1–3. The tables provided an organized way to synthesize the findings using a *rule of columns* approach (Garrard, 2014).

Results

Gender Differences in Chronic Sorrow

Seven studies, two qualitative, four mixed methods and one quantitative, addressed the differences in the experience of chronic sorrow between mothers and fathers. Five of the studies had a quality rating of good with relatively large sample sizes. Two studies were rated fair due to lack of sampling criteria description and a poor description of ethics and bias criteria (see Table 1). In nearly all the studies, it was reported that mothers had a more intense or more significant experience of sorrow due to their child's illness or disability (Damrosch & Perry, 1989; Fraley, 1986; Hobdell, 2004; Hobdell & Deatrick, 1996; Hummel & Eastman, 1991; Mallow & Bechtel, 1999). Explicit emotions or behaviors reported to be displayed by these mothers included feelings of emptiness, guilt or self-blaming (Fraley, 1986; Hummel & Eastman, 1991), sadness (Hobdell, 2004), fear (Fraley, 1986; Hobdell & Deatrick, 1996; Hummel & Eastman, 1991), and depression (Hobdell & Deatrick, 1996; Hummel & Eastman, 1991).

In fathers, depression was not reported, but Hobdell and Deatrick (1996) found that fathers felt confused and were more concerned with potential future problems and with the stigma that can be associated with visible physical disabilities. Their descriptive study looked specifically at parental differences in mood states, intensity, number of responses and in precipitating events. The results were categorized along gender lines with responses to three open-ended questions related to emotions experienced, times when those feelings emerged and any times that caused those findings to re-emerge. The major differences between mothers and fathers in this study included the type and intensity of emotions, with mothers reporting greater health care concerns and fathers reporting a decrease in emotions over time