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When a Child Dies: Parents' Experiences of Palliative Care—An Integrative Literature Review



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The aim of this integrative review was to increase knowledge about parents' experiences of palliative care when their child is dying or has died due to illness using Whittemore and Knafl (2005) analysis process. Computerized databases were used to search the literature. Nine papers met the inclusion criteria. The analysis resulted in five categories: genuine communication, sincere relationships, respect as an expert, and alleviation of suffering and need of support, including 15 subcategories. Health professionals need education to provide high-quality pediatric palliative care. They especially need training concerning existential issues, and further studies need to be performed.

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LOSING A CHILD due to illness is one of the worst crises that can happen to a family. The family faces great difficulties, and it is stressful for pediatric palliative care staff to care for a child with a terminal illness. Such care requires a great deal of knowledge, understanding and compassion for the child and the parents' situation (Hallström & Lindberg, 2009).

Background

In Sweden, 556 children between the ages of 0 and 19 years died in 2011. The causes of death varied greatly among different age groups, but deaths due to accidents were the most common, followed closely by death from disease (The National Board of Health and Welfare [NBHW], 2011). Despite the circumstances, an overall goal of pediatric

palliative care is to support the children to live as normal a life as possible (NBHW, 2011). According to the World Health Organization, palliative care for children is a specialized area, albeit related to adult palliative care. Effective palliative care for children entails an extensive multidisciplinary approach and can be provided in hospitals, in hospices or in the home, and can be effectively applied even if resources are inadequate (WHO, 2013). The results reveal that parents of children at the end-of life prefer the child to be cared for at home rather than at a hospital (Kassam, Skiadaresis, Alexander, & Wolfe, 2013). Palliative care for children begins when illness is identified and analyzed, and continues during the entire illness trajectory, aiming to alleviate physical, psychological, and social suffering (WHO, 2013). According to health care professionals, palliative care is deemed to be of a high quality when personnel are able to create a close relationship with the child and their families (Klassen, Gulati, & Dix, 2012; McCloskey & Taggart, 2010). On the other hand, these close relationships may cause sadness and a sense of loss when the child dies (Contro, Larson, Scofield, Sourkes, & Cohen, 2004; McCloskey & Taggart, 2010).

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The parents of dying children face difficult situations, such as having to make decisions about the child's treatment, informing relatives and friends, providing information to the child and explaining the disease and possible treatments (Enskär, 1999; Kars, Grypdonck, & van Delden, 2011). An integrative literature review on the parents' perspective on end of life care for their child found that communication, information and relationships were poor or inadequate and that the impact of care on quality of life was essential (Aschenbrenner, Winters, & Belknap, 2012). Parents are torn between wanting to be with their sick child as much as possible while also being forced to continue with everyday tasks. Daily routines are nevertheless a necessary break to gather strength and continue being a responsive and caring parent to the dying child (Kars et al., 2011). Together, parents and children undergo emotional phases during palliative care. For parents, this means not only managing their own emotions but also serving as a support system for their sick child and any siblings (Enskär, 1999; Kars et al., 2011).

How families are acknowledged by health care professionals is important for their well-being and has implications for how parents deal with grief after the death of their child. Few studies examine how parents of children deal with incurable disease and experience palliative care. This integrative literature review is therefore important, and is the basis for the design of a future intervention study consisting of training health professionals in pediatric palliative care and parents of children with incurable cancer.

Aim

The aim of this integrative literature review was to contribute to the knowledge and understanding of parents' experiences of palliative care when a child in the family is dying or has died due to illness.

Method

Design

This study used an integrative literature review method to confirm, extend and/or refute qualitative and quantitative studies. The analysis of the literature was supported by the Whittemore and Knafel (2005) method of process to meet the general research question.

Literature Searches

Scientific papers were searched for in the PubMed, PsycInfo and CINAHL databases. Searches in The Cochrane Library yielded no relevant results. All searches were performed with the keywords *Pediatrics* and *Child* or using the filter 'child 0–18 years'. No time limits for years

were used. Peer-reviewed papers in Swedish or English were screened. All abstracts were reviewed. Papers were also searched manually, and the related citations in the papers found in the PubMed database were checked. No new relevant papers were found using these other methods. A total of 52 papers that met the study aim were selected and reviewed in their entirety for further analysis (Figure 1).

Sample

Papers were excluded if they did not focus primarily on parents' experiences of the care of the child, only described the experiences after the child died, were about acute deaths and deaths in intensive care units, only focused on parents' perceptions of the medical care, or described experiences of special care programs. A total of nine papers (six qualitative and three quantitative studies) were finally included and selected for analysis.

Classification and Quality Assessment

Papers that met the inclusion criteria were read and classified using a tool published by the Swedish Council on Health Technology Assessment SBU (1999). In this manual, quantitative studies are divided in randomized controlled studies, clinical trials, and descriptive studies (DS). Qualitative studies are termed Q. The included papers were quality checked using a template by Willman, Stoltz, and Bahtsevani (2011) to obtain a detailed and systematic assessment of the content. To be rated as a high-quality study, at least 75% of the questions asked in the template should be answered with a 'yes'. For a medium quality study, 50–75% should be answered 'yes', and any study with below 50% 'yes' answers was assessed to be of low quality. None of the studies were assessed to be of low quality. An overview of the included papers is presented in Table 1.

Data Analysis

The nine papers used descriptive methods that did not allow data to be interpreted or abstracted on a higher level. They were read in their entirety several times to obtain an overall picture of the content. The papers results were translated into Swedish and compared to minimize misinterpretations and to ensure that no information was lost. The analysis was guided by the research question: "What does this study tell us about parents' experiences when a child in the family is dying or has died?" Data were compiled in a matrix and reduced by extracting relevant meaning units and checked with the original source repeatedly. Meaning units were carefully encoded and compared with each other to find patterns of similarities and differences. Related codes were identified, grouped and compared with each other. Data were combined and categories with subcategories were created, and synthesized. The process of the analysis was discussed continuously among the authors.

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