*Original Article*

# Parents' Experiences of Pediatric Palliative Care and the Impact on Long-Term Parental Grief

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## Abstract

**Context.** Approximately 25% of children diagnosed with cancer eventually die. Losing a child puts parents at increased risk for developing psychological problems.

**Objectives.** To explore parents' perceptions of the interaction with health care professionals (communication, continuity of care, and parental involvement) and symptom management during the pediatric palliative phase, and to investigate the influence on long-term grief in parents who lost a child to cancer.

**Methods.** A total of 89 parents of 57 children who died of cancer between 2000 and 2004 participated in this retrospective cross-sectional study by completing a set of questionnaires measuring grief (Inventory of Traumatic Grief), parents' perceptions of the interaction with health care professionals (communication, continuity of care, and parental involvement), and symptom management during the palliative phase. Care was assessed on a five point Likert scale (1 = disagree and 5 = agree).

**Results.** Parents highly rated communication (4.6 ± 0.6), continuity of care (4.3 ± 0.6), and parental involvement (4.6 ± 0.7) during the palliative phase. Parents' most often reported physical and psychological symptoms of their child during the palliative phase were fatigue (75%), pain (74%), anxiety to be alone (52%), and anger (48%). Higher ratings of parents on communication ($\beta = -9.08$, $P = 0.03$) and continuity of care ($\beta = -11.74$, $P = 0.01$) were associated with lower levels of long-term parental grief. The severity of the child's dyspnea ($\beta = 2.96$, $P = 0.05$), anxiety to be alone ($\beta = 4.52$, $P < 0.01$), anxiety about the future ($\beta = 5.02$, $P < 0.01$), anger ($\beta = 4.90$, $P < 0.01$), and uncontrolled pain ($\beta = 6.60$, $P < 0.01$) were associated with higher levels of long-term parental grief. Multivariate models combining the interaction with health care professionals and symptom management showed a significant influence of both aspects on long-term parental grief.

**Conclusion.** Both interaction with health care professionals, especially communication and continuity of care, and symptom management in children

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dying of cancer are associated with long-term parental grief levels. J Pain Symptom Manage 2014;47:1043–1053. © *2014 U.S. Cancer Pain Relief Committee. Published by Elsevier Inc. All rights reserved.*

***Key Words***
*Cancer, children, palliative care, parental grief, symptom management*

## *Introduction*

Despite increased survival rates for childhood cancer, approximately 25% of the children diagnosed with cancer eventually die because of the disease or its treatment.[1] Losing a child puts parents at increased risk for developing psychological problems such as anxiety, depression, prolonged grief, and poor quality of life,[2–4] which for some parents may even be present 15 years after the loss of their child.[5] Although the specific impact of the loss of a child may differ for parents, a child's death is often considered the "ultimate loss."[6] Compared with bereaved spouses and bereaved adults losing their parent, bereaved parents show more intense and longer-lasting grief reactions.[7,8] Several parent- and child-related factors that put parents at increased risk for adverse grief outcomes have been identified, such as the child's age,[9] parent's gender,[10–13] cause of death/unexpectedness of death,[9,14,15] and the number of remaining children.[9]

Palliative care is defined by the World Health Organization as "the active total care of the child's body, mind, and spirit," and also comprises care for the family during and after the child's death.[16] According to the World Health Organization, "palliative care begins when illness is diagnosed and continues regardless of whether or not a child receives treatment directed at the disease."[16] An integrated model of palliative care is also supported by the American Academy of Pediatrics.[17] For the purpose and understanding of this study, we have conceptualized that palliative care starts when the child and parents receive the news of the incurability of the disease. We consider the time period thereafter as the "palliative phase."

In general, parents are satisfied with palliative care for their child with cancer,[18–22] although the need to improve pediatric palliative care has been stressed repeatedly.[21–26] Research has identified several domains of care that are important to parents of a terminally ill child, such as communication[20,23,27] and continuity of care,[17,28] which consists of two elements: *care over time and the focus on individual patients.*[29] Continuity of care is regarded by parents as proof that health care professionals know and care about their child.[28] A third domain centers around involvement in decision making about their child's treatment and care, which is essential for parents during the palliative phase.[22,23,30–32]

Lastly, the child's suffering from physical and psychological symptoms is reported as an important theme of pediatric palliative care, and illustrates the significance of adequate symptom management during the palliative phase.[22,24,32,33] Unfortunately, symptom control, despite efforts of health care professionals, is sometimes unsuccessful.[22,24,32,33]

Until now, the number of studies investigating the impact of the interaction with health care professionals, such as communication, continuity of care, and parental involvement, and symptom management during the pediatric palliative phase on the long-term psychological functioning of bereaved parents is limited. A qualitative study by Contro et al.[23] showed that an insensitive way of delivering the bad news and poor communication of important information during the palliative phase can cause long-lasting emotional distress in parents. Furthermore, quantitative studies have shown that the child's pain that could not be relieved[34] and the child's anxiety during the palliative phase[35] can potentially impact parents' long-term psychological functioning.

A previous study investigating parents' and physicians' perceptions of quality of care showed that for parents, quality of care is mainly determined by communication, whereas for health care professionals, quality of care is mainly determined by biomedical aspects, such as pain management.[20] These aspects can be considered as

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