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Being a Parent of a Child With Cancer Throughout the End-of-Life Course

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Death can be anticipated for most children with progressive cancer. Parents often are aware of their imminent loss (Kars et al., 2011) and enter an end-of-life (EOL) phase in which all curative options have been exhausted and care is focused on preparing for the anticipated death (Nuss, Hinds, & LaFond, 2005). In most western countries, EOL care increasingly comprises cancer-directed therapy to prolong life or phase I or II studies (Liben, Papadatou, & Wolfe, 2008; Ulrich, Grady, & Wendler, 2004). In contrast, care for the dying is referred to as terminal care.

Because of the preferences of the child, parents, and medical staff, the EOL phase increasingly occurs at home (Davies et al., 1998; Vickers & Carlisle, 2000). In the Netherlands, 63% of children who die from cancer pass away at home (Pousset et al., 2010). Whether nurses are involved in palliative care provided at home depends on the individual situation.

In the authors' experience within the Dutch care system, palliative care for children who reside at home is provided primarily by the regular healthcare institutions that are responsible for home care. As a consequence, all children and their parents transfer from the multidisciplinary team of the pediatric oncology ward (with nurse specialists as their primary caregivers) to the general practitioner. Once at home, parents can call on homecare nurses or nurses from technical homecare services. In practice, care arrangements at the EOL vary from no nursing care at all to the simultaneous involvement of nurses from all sources: transmural care by specialist nurses from the oncology ward, nurses that provide technical support, and regular homecare nurses.

The role of parents as decision makers and care providers at home is extensive (Martinson, 1996; Molenkamp, Abu-Saad, & Hamers, 2002). Previous research has focused on their problems and needs. Parents

Purpose/Objectives: To elucidate parents' experiences when caring at home for their child with incurable cancer and to show how parents give meaning to their experiences throughout the end-of-life (EOL) phase.

Research Approach: Interpretative qualitative study.

Setting: Five academic pediatric oncology centers.

Participants: 42 parents of 22 children with incurable cancer, cared for at home.

Methodologic Approach: An inductive thematic analysis of single and repeated open interviews using phenomenological techniques.

Findings: Four EOL stages were identified: becoming aware of the inevitable death, making the child's life enjoyable, managing the change for the worse, and being with the dying child. The essence of parenting during those stages was captured by the notion of being meaningful to the child and preserving the parent-child relationship. Parents were able to cope better with the EOL phase and to sustain their parenting role because of their ability to postpone grief, enjoy their child's expressions of happiness, see the child's identity despite physical impairment, and enjoy the rewards they experienced from being there for their child.

Conclusions: Parenting while losing a child brings parents to the point of an existential crisis. The child's deterioration forces parents to redefine their traditional parenting role. Although the way parents give meaning to their caregiving experience helps them cope, it can decrease their ability to acknowledge the child's needs.

Interpretation: Nurses can help parents to face the reality of their child's situation and redefine their role accordingly, such as by providing information and alternative perceptions that fit the child's changed needs while preserving the parent-child relationship. Attention to signals indicating stress disorders is needed.

report EOL decisions to be the most difficult treatment-related choices they face during their child's cancer experience (Bluebond-Langner, Belasco, Goldman, & Belasco, 2007; Hinds et al., 1997). However, parents