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Physical Symptoms of Children Receiving Pediatric Hospice Care at Home During the Last Week of Life

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This article has been chosen for a podcast conversation with Verna Hendricks-Ferguson, PhD, RN. Hendricks-Ferguson lectures on and studies palliative and end-of-life care communication with children diagnosed with cancer and their parents. She has experience in pediatric oncology working with nurses during this difficult period of care. To access the podcast, visit www.onsforum.org.

Purpose/Objectives: To identify symptoms of greatest parental concern on the last day and during the last week of their children's lives, the five most common symptoms of parental concern, and symptom-management strategies used during the last week of the children's lives.

Research Approach: Descriptive, exploratory, and retrospective.

Setting: A pediatric hospice program in St. Louis, MO.

Participants: Convenience sampling of 28 bereaved parents.

Methodologic Approach: The Krippendorff method for semantical content analysis of data collected from semistructured telephone interviews with parents.

Main Research Variables: Parents' perceptions of their children's symptoms and symptom-management strategies.

Findings: On the last day of life, change in the children's breathing was the most frequent symptom of concern. During the last week of life, loss of motor function was the most frequent symptom of concern. Physical comfort actions and use of pharmaceutical agents were the strategies perceived as most helpful in managing symptoms.

Conclusions: The study is the first to document parents' perceptions of their children's symptoms and of symptom-management strategies during the last week of life while receiving care in the home from staff of the pediatric hospice program.

Interpretation: Symptoms experienced by dying children during the last week of life and symptom-management strategies used by pediatric hospice programs to support dying children and their families have not been well described. Additional research is warranted to further identify pediatric symptoms at the end of life and effective symptom-management strategies.

A growing national concern of healthcare professionals is to improve the end of life (EOL) for children (Field & Behrman, 2003; Kane, Hellsten, & Coldsmith, 2004). Each year in the United States, approximately 55,000 children die from cancer (Carter et al., 2004; Troug, Meyer,

Key Points . . .

- ▶ A universal desire of parents is that their children are comfortable and without pain when receiving care from a pediatric hospice program.
- ▶ Little research has been conducted about the symptoms suffered by dying children in the last week of life.
- ▶ Symptom management is a key concern for parents during their children's pediatric hospice care.

& Burns, 2006). Approximately 72% of deaths occur in the hospital (56% inpatient and 16% in outpatient hospital sites), 11% at home, and 0.4% in nursing homes (Bartell & Kissane, 2005; Institute of Medicine, 2003). Suffering is at greater risk for dying children in a cure-focused culture, such as that of hospital settings without a palliative care program (Kane & Primomo, 2001). Parents' perceptions of the quality of their children's EOL has not been well documented (Davies et al.,

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