Expectations and Beliefs About Children’s Cancer Symptoms: Perspectives of Children With Cancer and Their Families

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Purpose/Objectives: To describe the childhood cancer symptom course experienced by children with cancer from the perspectives of the children and their families.

Design: Longitudinal, qualitative research approach.

Setting: The participants’ homes and inpatient and outpatient pediatric cancer units in western Canada.

Sample: A theoretical purposive sample of 39 children (4.5–18 years of age) with a variety of cancer diagnoses and their family members.

Methods: Open-ended formal interviews with children and their family members (N = 230) and participant observation of children and their family members for more than 960 hours during various periods during their illness, at various locations, and at different points in time during the study period.

Main Research Variables: Children’s and their families’ perspectives of cancer symptom experiences by children with cancer.

Findings: Children and families had definite beliefs and expectations about the cancer symptom experiences, including (a) short-term pain for long-term gain, (b) you never get used to them, (c) they all suck, (d) it sort of helps, and (e) they are all the same but they are all different. Underpinning all of the participants’ beliefs and expectations was the experience of suffering. Their beliefs and expectations contributed to and were a direct result of cancer symptoms that were ignored, unrelied, or uncontrolled.

Conclusions: Children with cancer live with symptoms on a daily basis and have experiences of unrelied cancer symptoms. Although cancer symptoms resulted in suffering by the children and families, they accepted the symptoms as an integral part of overcoming cancer and never expected complete symptom relief.

Implications for Nursing: Oncology nurses need to be more vigilant in their assessment and management of children’s cancer symptoms. Further research is warranted detailing not only children’s and family’s beliefs and expectations of cancer symptom experiences but also nurses’ understanding and interpretations of children’s cancer symptom experiences. Intervention studies designed to relieve all types of cancer symptoms experienced by children must be undertaken.

Key Points . . .

➤ Children with cancer experience many symptoms that contribute to their suffering and the suffering of their families; however, to date, only a few symptoms of the cancer symptom trajectory have been recognized in research and practice.

➤ The beliefs and expectations held by children and families and the effect they have on their seeking and attaining symptom relief have received minimal attention in research and practice.

➤ Children and their families expect suffering related to the children’s cancer symptoms.

Significant gains have been achieved in the treatment of childhood cancer since the 1960s (Canadian Cancer Society, 1996; Hockenberry, Coody, & Bennet, 1990; Kazak & Nachman, 1991; Smith & Gloeckler, 2002). Many childhood malignancies once considered to be fatal are curable because of the initiation of multimodal therapy (Hockenberry et al.; Kazak & Nachman). However, the aggressiveness of treatment makes cancer a difficult and trying phenomenon for children with cancer and their families to experience and can result in the suffering of the children and their families (Kane & Primomo, 2001). Treatment- and cancer-related symptoms that children experience, such as pain, sleep disturbances, fatigue, nausea, constipation, anxiety, and poor outlook, contribute to the sense of suffering (Enskär, Carlsson, Golsäter, Hamrin, & Kreuger, 1997a; Hogan, 1997). Children undergoing therapy can experience severe symptom distress (Schneider, 1999), which can negatively affect their emotional, cognitive, social, and physical development. This, in turn, can adversely affect the children’s and families’ quality of life (Eiser, 1994; Hinds, 1990; Simms, 1995; Whyte & Smith, 1997). To help children and families experience a cancer trajectory that is less threatening and traumatic, healthcare providers should strive for complete symptom relief. To improve

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