Children with cancer and their families believed and expected that symptom suffering was necessary to overcome cancer


**How do children with cancer and their families experience cancer symptoms?**

**DESIGN** Grounded theory and illness narratives.

**SETTING** Participants’ homes and inpatient and outpatient paediatric cancer units in western Canada.

**PARTICIPANTS** 39 children with cancer at varying stages (age 4.5–18 y, 54% girls, 95% Caucasian) and their families. All children received chemotherapy alone or in combination with surgery, radiation, or bone marrow transplant.

**METHODS** Data were collected from 230 individual or joint interviews with mothers (117 interviews), fathers (46 interviews), siblings (48 interviews), and children (103 interviews); and 960 hours of participant observation of children and their family members. Audiotapes and field notes were transcribed, and data were analysed using constant comparison and illness narratives.

**MAIN FINDINGS** Children and their families described 5 common beliefs and expectations. (1) *Short term pain for long term gain* emphasised how children and their families equated cancer with suffering, and the belief that suffering was necessary to fight the cancer. “Fighting symptoms” was more tangible and less frightening to children than “fighting cancer.” Parents and children felt anxious when treatment was completed because they saw treatment as a “safety valve that prevented death from entering their lives.” Children had more difficulty accepting symptoms than parents and were more expressive and angry about their experiences. (2) *You never get used to them.* Although children and families adapted to cancer symptoms, they never became completely used to them. Remaining uncomfortable with cancer symptoms was important because “getting used to the symptoms means you learn to like them” and in learning to like them, “you would not fight them.” Parents wanted their children to suffer less, but surviving the cancer was more important than reducing suffering. (3) *They all suck* was a sentiment expressed by children, parents, and siblings regarding difficult symptoms, and it underscored the belief that each symptom experience contributed to their suffering. Children had difficulty identifying their worst symptoms, in part because they could not separate symptoms and perceived all symptoms as “bad.” (4) *It sort of helps* was a key phrase used by children, parents, and siblings to indicate that symptoms were not completely eliminated. Reducing symptom distress became more successful as children and families became more experienced. Rest or sleep offered the only relief as it “took the children out of the realm of the world of suffering,” albeit temporarily. Children and families used a “trial and error” approach to symptom management; children identified and used the most effective self-initiated strategies to reduce symptom distress. Children and parents minimised the severity of symptoms and tried to incorporate “everyday” unrelieved symptoms into their lives. (5) *They are all the same but they are all different.* Although parents and children believed that each child’s experience was unique, suffering was “the common thread.”

**CONCLUSIONS** Suffering underpinned the beliefs and expectations of children with cancer and their families about the cancer symptom experience. They believed that symptom suffering was necessary to overcome cancer, and although they learned to adapt, they never “got used to” everyday symptoms. They felt that all symptoms “sucked” and were never completely eliminated.

**Commentary**

The 5 categories of expectations and beliefs identified by Woodgate and Degner provide important insights into ways of thinking that shape the meaning of various symptoms. The meaning given to symptoms influences family and child behaviours, such as when to seek symptom relief. Woodgate and Degner show that suffering in cancer is an extremely important expectation. Suffering is revealed as a complex, individually experienced phenomenon, and the study’s findings need to be incorporated into nursing practice in thoughtful ways. For instance, the assumption of families and children that symptom suffering is integral to overcoming cancer is too important to the architecture of meaning to be simply negated. Nurses should not assume the meaning of symptoms to a child and family without considering other explanations. Suffering is not simply the sum of individual symptoms. Rating discrete symptoms such as pain, nausea, and fatigue, may therefore be a futile exercise when all symptoms are “bad.” Simple rating scales cannot adequately address the many dimensions of children’s suffering and should not be assumed to capture children’s symptom experiences.

Eliciting children’s perspectives on such symptoms offers a unique contribution to the field of oncology nursing. Using interpretative interactionism supports the intricate analysis of the influence that beliefs and expectations have on the experience of cancer symptoms. However, the age range of the child participants may need to be considered when applying the findings to nursing practice. Although, the only reported difference in the accounts of younger and older children was that older children provided more detailed explanations of their experiences, most children were school aged.

Woodgate and Degner’s study expands our understanding of children’s cancer symptoms, revealing the complexity of their suffering. These findings support a multidimensional approach to understanding children’s suffering and to supporting children and families as they experience cancer illness and treatment trajectories.