

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 symptoms experienced 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, unrelieved, or uncontrolled.

Conclusions: Children with cancer live with symptoms on a daily basis and have experiences of unrelieved 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.

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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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 now 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

symptom control, a comprehensive knowledge base of symptoms in children with cancer must be established, especially from the perspectives of children and families (Woodgate & McClement, 1998).

Literature Review

The Ill Child's Perspective

The literature points to three main areas of study in pediatric cancer symptom research in which children with cancer are the primary participants: (a) procedural-related pain (Adams, 1990; Bradlyn et al., 1993; Jay, Elliot, Katz, & Siegel, 1987; Jay, Ozolins, Elliot, & Caldwell, 1983; Katz, Kellerman, & Siegel, 1980; Reeb & Bush, 1996), (b) treatment-related nausea and vomiting (Cotanch, Hockenberry, & Herman, 1985; Jacknow, Tschann, Link, & Boyce, 1994; LeBaron, Zeltzer, LeBaron, Scott, & Zeltzer, 1988; Relling, Mulhern, Fairclough, Baker, & Pui, 1993; van Hoff, Hockenberry-Eaton, Patterson, & Hutter, 1991; Zeltzer, Dolgin, LeBaron, & LeBaron, 1991), and (c) psychosocial symptoms such as anxiety (Anholt, Fritz, & Keener, 1993; Bull & Drotar, 1991; Butler, Rizzi, & Bandilla, 1999; Greenberg, Kazak, & Meadows, 1989; Mulhern, Fairclough, Douglas, & Smith, 1994; Neville, 1996, 1998; Rynard, Chambers, Klinck, & Gray, 2000; Sanger, Copeland, & Davidson, 1991; Van Dongen-Melman, Pruyn, Van Zanen, & Sanders-Woudstra, 1986; Van Dongen-Melman & Sanders-Woudstra, 1986; Varni, Katz, Colegrove, & Dolgin, 1994, 1995). Work in these three areas has produced valuable findings with respect to symptom assessment and management; however, researchers tend to rely solely on standardized instruments (Woodgate & McClement, 1998). A meaning-centered approach in which researchers seek to understand children's experiences as they are lived and grounded in the children's meanings and interpretations is missing.

In addition to minimal attention being given to understanding children's perspectives about their cancer symptoms, research of the complete cancer symptom trajectory is lacking. Only recently have other cancer symptoms received attention. Most notable is the development of research programs directed at the symptom of fatigue (Davies, Whitsett, Bruce, & McCarthy, 2002; Hinds & Hockenberry-Eaton, 2001; Hockenberry-Eaton et al., 1998). A strength of such programs is that the researchers seek to understand fatigue from the children's, families', and nurses' perspectives. Hinds and Hockenberry-Eaton and Hockenberry-Eaton et al. (1998) have demonstrated that children with cancer-related fatigue describe fatigue in terms of physical and mental symptoms, feel both sad and angry, experience changes in activities, and need to rest or take more frequent naps to relieve their fatigue. Davies et al. determined that children with cancer may experience three subjectively distinct types of fatigue that represent different levels of energy: typical tiredness, treatment fatigue, and shutdown fatigue (i.e., the profound and sustained loss of energy). The work in this area will help nurses in their assessment and management of children's cancer-related fatigue and reinforce the importance of studying all treatment- and cancer-related symptoms in children with cancer.

Parents' Perspectives

Although research has focused on detailing how parents adapt to their children's cancer in general, research exploring

parents' experiences with their children's cancer symptoms is in its infancy and tends to focus on pain. One qualitative study revealed that, in dealing with their child's cancer and pain, parents experienced a "community of suffering" (Ferrell, Rhiner, Shapiro, & Dierkes, 1994; Rhiner, Ferrell, Shapiro, & Dierkes, 1994). Parents described pain in physical terms or used metaphors and graphic statements such as "nightmare" or "horror." Research also has determined that despite parents' attempts to cope with their child's cancer pain by using a variety of strategies (e.g., distraction, imagery, cold compresses, hot baths, massage, hot packs, letting the child gain control), parents still experienced feelings of helplessness, guilt, and failure (Bossert, Van Cleve, & Savedra, 1996; Ferrell et al.; Rhiner et al.). Ferrell et al. noted that parents also felt that their child's pain was not taken seriously by health-care providers. The pain affected all family members and often disrupted the family system even in the strongest families.

In another qualitative study, Enskär et al. (1997b) found that watching their child suffer was the most difficult aspect of having a child with cancer for Swedish parents. Parents felt powerless in relation to the amount of fear, pain, and suffering that their child experienced. The parents also expressed that their child's disease in relation to treatment, hospitalization, and check-ups governed their everyday lives and affected their opportunities to work, financial circumstances, and ability to get insurance. Parental feelings about and reactions to their child's cancer depended on their child's feelings and reactions to a great extent. Uncertainty surrounded the parents' experiences. With few exceptions (Enskär et al., 1997b; Ferrell et al., 1994; Rhiner et al., 1994), parents' thoughts and feelings in relation to their child's cancer symptom experiences are described minimally in the literature.

Siblings' Perspectives

The study of the impact of childhood cancer on siblings is in its early stages (Barbarin et al., 1995; Murray, 2001a, 2001b; Ross-Alaolmolki, Heinzer, Howard, & Marszal, 1995; Sloper, 2000; Sloper & While, 1996). Research is lacking regarding siblings' perspectives about cancer symptoms and their involvement in the care of their ill brothers or sisters. However, research describing siblings' experiences with their terminally ill brothers or sisters revealed that siblings who participated in their ill siblings' care and in activities centered on those children's death (e.g., attending the funeral service) had higher self-esteem in comparison to those siblings who were not involved in such activities ($p = 0.001$) (Michael & Lansdown, 1986). Lauer, Mulhern, Bohne, and Camitta (1985) reported similar findings and determined that siblings who participated in the care of their ill siblings found the experience more comforting, felt less isolated, and perceived that relationships with their parents improved. These studies underscore the importance of providing siblings with the opportunity to become more involved in their ill brothers' or sisters' symptom management.

In their qualitative study that described the changing appraisals of siblings and parents related to childhood leukemia, Brett and Davies (1988) revealed that early symptoms in the ill child were dismissed by siblings or ignored as unimportant. However, as the illness progressed, older siblings saw enough parental anxiety to concern them about their brother's or sister's health. Worrying and "keeping an eye" on their ill brother or sister became a part of the siblings' experiences. Awareness

of painful procedures, the presence of special and protective rules, or restrictions in the family caused siblings to continue to appraise cancer as actively threatening. Another study found that watching their ill brother's or sister's physical appearance change was the worst thing about cancer for some siblings (Havermans & Eiser, 1994). Children's cancer symptoms appear to have a definite impact on their healthy siblings and warrant further research.

Summary

Research in the symptom trajectory of childhood cancer is in its infancy. Unfortunately, only certain symptoms have received attention, and research is inadequate with respect to children's perspectives, thoughts, and feelings. Research also is limited regarding the experience of parents and siblings who respond to and care for the symptoms of children with cancer. Therefore, the purpose of this study was to describe the childhood cancer symptom course experienced by children with cancer from the perspectives of the children with cancer and their families (Woodgate, 2001). This article focuses specifically on findings related to the beliefs and expectations about the symptom experiences that all children and families shared.

Methods

Design

A longitudinal, qualitative research design was adopted. The study was guided by the philosophy of interpretive interactionism, which afforded the researchers the opportunity to study the lived experience of children with cancer and their families as it was grounded in their meanings, interpretations, activities, and interactions (Denzin, 1984, 1989). Theoretical foundations from the qualitative methods of grounded theory and illness narratives facilitated the interpretive research process.

Sample and Setting

Child and family participants (i.e., parents and siblings) were selected using the grounded theory method of theoretical purposeful sampling. This method helps to optimize the probability of describing the full range of the phenomenon and recognize contextual conditions and cultural norms (Field & Morse, 1985; Patton, 1990; Strauss & Corbin, 1990, 1994). Because symptoms differ depending on the type of cancer, illness stage, and other child-related characteristics (e.g., developmental status), children of varying ages with different cancer diagnoses who were at different stages of their cancer trajectories were sampled to capture core experiences that cut across participant and phenomenal variation (Patton). To allow for an in-depth understanding of the phenomenon under study and data collection that was effective and efficient, a subset ($n = 15$) of the families participating in the study ($N = 39$) was examined more closely, yielding more data.

The study was conducted in three settings: the participants' homes and an inpatient and an outpatient pediatric cancer unit located in a western Canadian province. The outpatient and inpatient units are the main pediatric cancer treatment areas for children residing in the province.

Procedure

After receiving permission to conduct the study from a university-based ethical review committee and the participat-

ing units, a designated nurse intermediary assisted in participant recruitment. The nurse intermediary was responsible for asking potential participants (i.e., parents) for their permission to allow their names to be released to the primary investigator. For those who provided their permission, an explanation of the study was provided, followed by obtaining both informed parental consent and assent from the children. The first author was responsible for all data collection.

Two major types of data collection were used. In moderate participant observation, the researcher seeks to maintain a balance between participation and observation. Compared to pure observation, moderate participant observation involves a more active, interactive, and ambiguous role as the researcher tries to fit into the setting (Prus, 1996). The key to this approach is assuming a relationship that is as close as possible while retaining an alertness to events that allows the researcher to step back and interpret the situations (van Manen, 1990).

Participants were observed during various periods in their illness, at various locations, and at different points in time during the study. The researcher spent two six-hour days per week for approximately 80 weeks in the outpatient clinic; this yielded a total of 960 observation hours. When hospitalization was necessary, the children also were observed in the inpatient unit anywhere from two to five hours per day, depending on the circumstances. Observations were unstructured to permit flexible exploration and recorded as unstructured field notes. To facilitate the process of participant observation, Spradley's (1980) descriptive matrix was used, which focuses on nine major dimensions of every social situation: space, object, act, activity, event, time, actor, goal, and feeling. Informal interviewing took place during periods of participant observation. Questions flowed from the immediate context and helped to verify what meanings the participants assigned to their situations (Patton, 1990).

The second major source of data stemmed from formally interviewing the children and their family members. An open-ended technique was used to elicit detailed responses and focus participants' responses on areas previously unanticipated by the researchers (Field & Morse, 1985). Three different interview guides with a list of potential questions based on key themes identified from the literature and from the investigators' clinical experience were developed for the parents, children with cancer, and siblings (see Figures 1, 2, and 3). Care was taken to ensure that the interview guides for the children with cancer and their siblings were developmentally appropriate. Similar questions were asked for younger and older children; however, phrasing of the questions varied according to the children's developmental levels to facilitate expression of all of the children's thoughts.

The initial interviews allowed for a basis of understanding the participants' thoughts and feelings. More than one set of interview sessions was planned to follow up on significant themes and validate the interpretations of the findings. Questions evolving from the first set of interviews helped to guide subsequent interviews.

During the course of the study, a total of 230 interviews were conducted. Mothers were interviewed 117 times, fathers 46 times, siblings 48 times, and children 103 times. The researchers originally intended to interview family members individually; however, some members of the participating families requested to be interviewed with another family

- What types of symptoms does your child have?
- What words do you use to describe your child's (name symptoms)?
- How does your child act when he or she is in (name symptoms) or feels (name symptoms)?
- How does it make you feel when your child is in (name symptoms)?
- What does it mean to you when your child is in (name symptoms)?
- What do health professionals do for your child when he or she is experiencing (name symptoms)? What would you like the health professionals to do for your child?
- Is there anything you do or others do that helped you deal with your child's (name symptoms)? Was there anything that was not helpful?
- How are things different in your life now since your child felt or experienced (name symptoms)?
- What advice would you give to other parents whose children with cancer are experiencing (name symptoms)?
- What experience(s) has occurred over the last two weeks that you consider significant?
- Is there anything else you can tell me about your child's experiences with cancer and his or her cancer symptoms that is important for me to know?

Figure 1. Sample Open-Ended Questions Used in the Parents' Interview Guide

member (e.g., husband-wife dyads). When joint interviews were conducted, steps were taken to ensure that all members involved were given the opportunity to voice their views and perspectives. Although joint interviews potentially could result in participants covering up some of their feelings and thoughts about the childhood cancer experience, joint interviewing provided the first author with an opportunity to observe how participants interacted and responded to each other. The adults' interviews lasted 40–180 minutes, and the children's interviews lasted 20–120 minutes, with the younger children usually participating in shorter interviews. All interviews were tape-recorded. Field notes were made during all interviews and included describing nonverbal behaviors and the context in which the interviews took place. Both the audiotapes and field notes were transcribed and entered into a computer.

- Some kids with cancer tell me that they sometimes have pain or feel like throwing up or feel tired. Have you ever felt like them? Tell me about those times. Are there other things that make you feel different?
- What is it like to have or be in (name symptoms)?
- What does it feel like, and what do you think about?
- What do you think caused your (name symptoms)?
- What words can you use to tell me how your (name symptoms) feels to you?
- What makes your (name symptoms) bad or better?
- What do others do when you have (name symptoms)? (Others include your siblings, friends, teachers, parents, and nurses and doctors.)
- How different is your day when you have or feel (name symptoms)?
- How do you feel today?
- How are things different since you got cancer? (Talk about the good and bad things that have happened.)
- What has happened over the last two weeks that you consider most important or made you feel happy or sad?
- If you could have three wishes, what would they be?
- Is there anything else that you would like to tell me about your cancer and your (name symptoms) that is important for me to know?

Figure 2. Sample Open-Ended Questions Used in the Children's Interview Guide

Data Analysis

All transcribed data were analyzed by the constant comparative method of grounded theory. Analysis involved making comparisons within the data to discover patterns or categories that were supported by the emerging data. Coding or giving meaning to all units of information was ongoing. Asking questions and making memos related to code notes and data comparisons were part of the process of coding and involved revising codes as necessary. Data analysis was complete when theoretical saturation occurred, that is, when all of the paradigm elements were accounted for and the relationships among categories were well established and validated.

In addition to the constant comparative method, development of illness narratives helped to confirm the paradigmatic relationships of the emerging categories. The researchers' goal was to retell and inscribe stories of the children's cancer symptom experiences as told by the children and their families. Narratives provided a basis for understanding how illness affects the children's and families' biographies by contextualizing illness events and illness symptoms (Hydén, 1997; Kleinman, 1988).

Results

Sample

In total, 39 children and their families were recruited. Of the 39 children, 21 participants were female (54%) and 18 were male (46%). Ninety-five percent of the children were Caucasian. Although most children did not vary by race, a variety of ages and educational levels were included. Children ranged in age from 4.5–18 years, with a mean age of 10 years. Most of the children had two parents (87%) and at least one sibling (87%). Twenty-six families (70%) resided in the city, and 13 families (30%) were in the rural areas. The majority of the children were diagnosed with leukemia or lymphoma (72%). All of the children received chemotherapy alone (56%) or in combination with surgery (18%), radiation (5%), radiation and bone marrow transplant (BMT) (8%), radiation and surgery (10%), and surgery, radiation, and BMT (3%). During the course of the study, five children (13%) relapsed. At completion of the study, 90% of the 39 children remained in remission and four children had died (10%).

Introduction to Children's and Families' Expectations and Beliefs

Although this study's purpose was directed at the children's cancer symptoms, children and their family members nonetheless needed to talk about all of their experiences related to cancer. Children and their families consistently emphasized that many aspects or events of cancer made life more difficult. However, in telling their stories, the children and families inevitably referred to the cancer symptoms. The symptoms were a very big part of the cancer experience for the children and their families. When symptom experiences became more pronounced in their lives, other cancer events became more difficult to endure. Simply put, the symptom experiences led to increased sorrow and suffering for the children and families.

How the children and families responded to the cancer symptoms was determined, in part, by their beliefs and expectations about the symptoms. To the children and families in this study, beliefs referred to their attitudes and assumptions

- When your brother or sister gets his or her medicine or treatment, how does it make him or her feel?
- When your brother or sister is (name symptoms) or in (name symptoms), what do you think about? How does it make you feel?
- What is the worst thing about your brother or sister feeling (name symptoms) or being in (name symptoms)?
- What words does your brother or sister use for (name symptoms)?
- What words do you use that describe your brother's or sister's (name symptoms)?
- How are things different when your brother or sister is in (name symptoms)?
- How does it make you feel? What things are different? What is different about yourself? How have you changed? Do or did things change between you and your mother or father, your sister or brother, friends, or at school? What is the worst thing about your brother or sister having (name symptoms)?
- What has happened over the last two weeks that you consider most important or made you feel sad or happy?
- What would you tell other children whose brother or sister is in (name symptoms) or feels (name symptoms)?
- If you could have three wishes, what would you wish for?
- Is there anything else you would like to tell me that is important for me to know?

Figure 3. Sample Open-Ended Questions Used in the Siblings' Interview Guide

Note. Additional questions were developed for all three interview guides. For a complete list of questions for all three interview guides (parents, children, and siblings), please contact the first author.

about the cancer symptoms. Expectations referred to what the children and families anticipated with respect to the children's cancer symptoms and symptom relief. Throughout the study, children and their families shared many of their beliefs and expectations with the primary author. Their expectations understandably were influenced by their beliefs and vice versa. Although the children and families participating in the study each had their own unique beliefs and expectations about the cancer symptoms, they were in agreement about some of their beliefs and expectations that contributed to symptom-related suffering. Regardless of age and developmental stage or role, children and parents shared five major beliefs and expectations: (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. The only difference between the younger and older children was that the older children were more expressive in discussing their beliefs and expectations.

Short-Term Pain for Long-Term Gain

This theme referred to the children's and families' belief and expectation that children with cancer had to feel a lot worse before they could feel and get better. Perhaps of all the beliefs and expectations, this one emphasized how much the children and families equated cancer with suffering. All family members believed that suffering was necessary. Accepting the suffering that resulted from fighting the cancer was important.

Mother: You can't breeze through it. If you breeze through it, other families say . . . "you're more likely to relapse." The sicker you are, the better [your] chances [are] of getting better. Like, if he had gone through it and never thrown up, I would think something was wrong.

You expect him to be sick. Like, if he had went through it and just sat there and, like, looked normal, felt normal, I would have wondered. It [the chemotherapy] wouldn't be working. That's what I would have thought.

Father: Yes, she is going to be sick; but if we want her to get better, we have to do it.

Sibling (seven-year-old female): Well, when, like, your brother or sister takes some medicine, they might throw up cause it might go down the wrong way or it doesn't agree with them. And that they might just not feel good after, sometimes. Well, it actually makes you better but it makes you feel worse at first and then you feel better. I thought medicine was like you're supposed to take it and right away you feel better, but it takes a while to work.

In the end, parents and children may have been less accepting of the symptoms if the children were diagnosed with an illness that was not life threatening. Additionally, children and their parents believed that the increased suffering, although expected, was the direct result of the cancer treatment and not the cancer itself. In other words, cancer symptoms resulting from the treatment of cancer were expected, but symptoms resulting from the cancer (e.g., tumor pain) were not, especially once treatment had commenced. Families were comforted to know what symptoms to expect and why they occurred.

Mother: So, there was always these episodes that you can't possibly anticipate and that you dread.

Mother: Unpredicted symptoms, yeah, are big things cause I don't know where the hell they are coming from, like, what is this? [long pause] Symptoms are important. . . . Yeah! [pause] To me, symptoms are like signs of trouble. I mean [pause] something is happening.

Focusing on the symptoms resulting from the cancer treatment was easier for the children and families because those symptoms were perceived as necessary to rid the body of cancer. Although cancer treatment-related symptoms made life harder to live and caused changes in the children's and families' day-to-day lives, fighting the symptoms as opposed to fighting the cancer was more tangible and less frightening to the children. The suffering was still present, but it became more bearable.

Child with cancer (14-year-old male): I had to fight how bad it felt, but I didn't have to fight the cancer. I had to fight the pain.

Although both the parents and children believed that to get better the children would have to experience increased symptom distress, the children had a harder time accepting their symptoms in comparison to their parents. When they talked about their symptoms, the children were more expressive and angry than their parents. Nonetheless, the children accepted that they would have to experience pain to rid them of the suffering resulting from the cancer. They viewed treatment-related pain as necessary. Asking children questions such as, "Most medications are supposed to make you feel better, yet with chemotherapy, it makes you feel worse . . . how do you deal with that?" seemed irrelevant and even irrational to them. Hearing the children, regardless of age, respond with "because

you have no choice” or “well, if you’re not going to take it, then you won’t get better” was not uncommon. However, the children never resented the nurses and other professionals who carried out their treatments.

Parents rationalized that the symptoms resulting from the cancer treatment were expected, considering some of the potential treatment-related side effects. This understanding enabled parents to cope with letting their children go through treatment that could be more damaging than the cancer.

Mother: And that drug is another one that makes it really difficult for a mom because it’s highly toxic. It is highly corrosive to your skin. Drop it on the floor, it will burn a hole in it. I am supposed to inject this into my daughter. This makes me feel comfortable? You have a hard time with it, but if I don’t, she will die!

Father: Like one of the doctors said, “You’re going to feel like we’re killing her. And we basically are knocking her down to bring her back up.” That’s a scary time for a parent.

Acceptance of symptom experiences was dependent on whether the symptoms were short term (i.e., temporary) or long term (i.e., permanent). Children and families had less difficulty accepting symptoms viewed as relatively short term that did not lead to permanent damage. In contrast, symptoms believed to be long term and associated with permanent damage or disability were not accepted without difficulty. Parents could not easily justify suffering if it meant that treatment would result in permanent or long-term disabling symptoms. Parents found long-term changes related to their children’s mental abilities or any changes that prevented the children from functioning as “complete” human beings especially difficult to accept.

Father: I think the biggest thing I can say is her motor skills; she was a very active child, and now she is only able to just sit up. Quite often, her and her sister were mistaken for twins and you can’t, there is no resemblance now. . . . So, like pictures on the piano, if you would look at them, you could see there is a resemblance between the two and they are quite often mistaken for twins. I think the hardest part now is seeing the difference in the change with her motor skills.

Children also feared and resented cancer treatments that resulted in long-term changes. For example, one 11-year-old childhood cancer survivor talked with regret and sadness about the effect that extensive treatments, including cranial radiation treatment, had on her mental abilities. She blamed the treatment for her inability to do math in school. She found this difficult to accept because it made her feel different from her peers. However, even long-term and undesired symptoms and problems were accepted if they meant that children would survive. The immediacy of death and preventing it took precedence over everything else. Interestingly, although parents were eager for their children’s treatment course to end because of the array of symptoms experienced, parents, to some extent, felt even more unrest on its completion. Many wished their children were on treatment because it was like a safety valve that prevented death from entering their lives. The safety valve was known to be working by the presence of the symptoms. Despite suffering from cancer treat-

ment-related symptoms, children also felt a little anxious when they no longer received the medications that fought the cancer cells. They were suffering but for different reasons. Children and families did not have to fight the symptoms anymore; instead, they had to fight the thought that the cancer may return.

Mother: The panic maybe isn’t there anymore. The panic is gone, but the anguish is still there. The thought of the future, yeah, it is still there but it is not healthy. It is terrifying; I can’t explain it.

Child with cancer (11-year-old female): When I am on treatment, it is killing all the cancer cells. . . . I think I’ll be a little bit nervous, and then, in a way, I’ll be glad [when treatment is completed].

Understandably, families of children who experienced more severe, lengthier, and damaging symptoms were less likely to support the belief that short-term pain yielded long-term gain. Instead, they were more likely to express the view that the long-term pain resulted in short-term gain. Their suffering became less bearable.

You Never Get Used to Them

The children and their families believed that no one ever got used to the cancer symptom trajectory and should not expect to. “Getting used to” cancer symptom experiences was considered to be unrealistic because the suffering always would be present.

Father: I think you never get used to it. You can get into the routine and know what to anticipate so that it lessens some of the fear and the unknown, but it still hurts and it still breaks up your routine and you still know two days later, “I am going to be sick,” you know?

Frequently, children and their families responded to questions related to coping with the cancer symptoms and cancer in general by expressing, “You get used to it (or them).” However, a sense of uncertainty was underlying their responses. Part of progressing through the cancer symptom trajectory involved parents and children accepting the symptom experiences; at the same time, this did not mean truly becoming comfortable with the symptoms. Instead, what they really meant was that although they learned to adjust or adapt, they never became completely accustomed to them.

Child with cancer (16-year-old male): You don’t really get used to [cancer and its symptoms] . . . you adapt to it. . . . I mean, you have to adapt because if you don’t, you’re going to die. And I don’t think there’s any way that you can totally prepare because there are no actual guarantees.

Child with cancer (17-year-old male): You learn to adjust to it . . . and then, we stopped, and then it started all over again.

Sibling (eight-year-old female): Like, you adjust to it but you’re not really used to it, and you don’t really feel like doing [cancer treatment] but you know you have to.

Remaining uncomfortable with the cancer symptoms was important for the children and families because, as one adolescent male with cancer expressed, “Getting used to the symptoms means you learn to like them” and in learning to

like them, “You would not fight them.” Then, children and families would not need to apply strategies to help them to get through the cancer and cancer symptom experiences. Although the children and their families adapted to cancer and its symptoms as well as a new routine to life, they still experienced pain and suffering. Unlike their old routine, the new routine was not carried out unconsciously.

Father: You do the things that you have to do, but it is still a pain every time! It is still a conscious thing. It, it is not like you slip unconsciously like going to work every day! It is a very different kind of routine.

Children who had relapsed and undergone numerous treatment courses never completely adjusted to the cancer symptom trajectory. This was because a new type of cancer symptom to adapt to always developed with each new treatment regimen. Even if some sort of routine or symptom pattern was established, the difficult nature and suffering associated with the cancer symptom trajectory always were present.

Child with cancer (17-year-old male): Well, every time, like, after I had about three remissions and they were short. So, after each one, it kind of changed a different treatment protocol and stuff, but as it got to the end, it sort of was the same. You would go in every Friday and get this done and that done. Every week or every second week or something, we’d have a bone test or every month you’d have a bone marrow or spinal tap or something like that. It got sort of predictable, but it was still hard!

When the symptoms became especially overwhelming and uncontrollable, some children questioned whether getting through the cancer treatments was worth it. The children sometimes found the symptoms especially hard to adjust or adapt to. The symptoms were no longer easily recognized and accepted as part of the territory of getting better. During such times, children of all ages would question continuing on with the present treatment course and considered the possibility of switching to a different type of chemotherapy regimen or method of receiving therapy. One mother noted that her daughter wanted to change the type of chemotherapy agent that she was receiving because it caused too much symptom distress and suffering.

Mother: The doctor said what they would normally do is just use whatever treatment they have used in the past that seems to work, but if you are part of this research project, then you are either A, B, C, or D of the clinical trials. So, Celine’s [her daughter] question is, you know, “If I was just going on the previous best or whatever, how would it be different and would it be this long, this that and so on.” She knows that arm D seems to be the toughest one.

Parents also had a hard time accepting and adjusting to the children’s continual and increased suffering and symptom distress. However, they were more hesitant to change their children’s chemotherapy regimen. Although parents wanted to see their children suffer less and be psychologically and physically comfortable, surviving the cancer took priority over reducing short-term suffering.

Mother: But then, you know, we [child and parent] have talked; we talked about what may be the toughest treat-

ment is the one that will do the most good. Well, you know, you need to think whether she is going through more torture than necessary but, on the other hand, if it is going to be the one that works best in the end.

They All Suck

“They all suck” was a phrase frequently expressed by the children when asked to talk about the symptoms they found most difficult to experience. This phrase was in keeping with the children’s and families’ belief that each symptom experience in its own way contributed to their suffering. Although each symptom experience resulted in different feelings such as extreme fatigue or increased fear, they all brought varying degrees and types of extra physical, social, emotional, and psychological effort in managing the symptoms, additional restrictions (e.g., not being able to go to school or work), and increased uncertainty and worry. Accordingly, children and families had difficulty determining which symptom experience was the most difficult to bear.

Child (17-year-old male): You couldn’t go out and play, and nausea—it’s not fun at all—and you’d like to take that away. But then there’s the headaches, which you can live with, but some were so great that I just kind of said I don’t want to live anymore. You kind of look at them and try and stage them, but they’re all pretty bad cause if you look at tiredness, you’re laying around and wasting your day, kind of not fun with those either. Nausea, headaches. [pause] I don’t know if there was one worse than another one. [pause] The headaches at times were, like, really, really bad, like the whole head hurt. The nausea was . . . really bad.

Interviewer: Of all those [symptoms] you mentioned, being tired and everything, what is the worst part for you?

Child with cancer (11-year-old male): All of them, yeah, yup! Mostly, just [pause] all of them.

At times, children had no difficulty and would not hesitate to identify certain symptoms as being the worst to experience. However, on reflection, children had more difficulty in identifying the symptom experiences considered to be most hurtful and unpleasant.

Child with cancer (14-year-old female): I don’t know because for me it is so weird because while it is happening I could just tell this is the worst I ever experienced but then afterwards, “So, I guess it wasn’t that bad!” I guess thinking back you would ask me then I would have said, “I feel so horrible,” but now I am saying I guess, compared to other things, it wasn’t that bad.

Child with cancer (15-year-old female): Well, when you are going through it, it is the worse symptom in the world. But then, when you are going through something else, it is the worse thing.

Part of the difficulty in having to pick and choose the worst symptom experiences was that many children and families could not separate one symptom from another. Each symptom experience was believed to be connected and related to others.

Child with cancer (17-year-old male): So, they’re [symptoms] all kind of intertwined. . . . It would depend on the day and situation and how bad they [the symptoms] were.

Sibling (eight-year-old female): But then when you're really sick it's like you have, like, quite a few things at once, like, maybe a headache and dizzy and stomach-ache. Lots of things.

The children's difficulty in separating or dividing up symptom experiences was reflected in their disinterest in using a scale to rate their symptoms (e.g., visual analog scale [VAS]). Rating symptoms was difficult because each symptom contributed to the children's overall affect. Children also found rating one symptom after another difficult because they perceived all symptoms as "bad." Rating each of their symptoms seemed irrelevant.

Child with cancer (14-year-old male): They were all bad [laughs] cause they all sucked!

The children found rating just one symptom difficult. For example, when a nurse asked one hospitalized nine-year-old boy to rate his mouth pain using a VAS, he hesitated and then responded by stating, "I can't use that [the scale]. . . . I can't do that." The nurse interpreted this to mean that he did not understand and therefore asked him to rate his pain on a different scale, the Wong-Baker Faces self-report scale (Wong & Baker, 1988). This time, the child said nothing and just stared at the nurse. He seemed to become increasingly frustrated and angry as indicated by his facial expression. The nurse responded by stating that he would need time to learn how to use the scale. Later, the child confided to the investigator that he understood how to use the scale, but he did not believe it could describe how he was feeling. To the children, assigning a number or level to a particular symptom could not capture how they truly felt.

Child with cancer (16-year-old female): When I was in the hospital before with my bone marrow transplant, they were always asking me to rate my pain, and you can't really measure pain. So, if you are feeling bad, then it doesn't really matter how intense it hurts or whatever. It feels bad, and when you are feeling the pain, you don't really want to have people asking you, "How are you feeling?" [mocking tone, laughs] I feel like [saying] I don't feel good, thank you very much!

Parents and siblings, like the children, found all symptoms difficult to cope with, including any symptom that resulted in the child with cancer experiencing physical distress (e.g., pain from a needle poke, nausea and vomiting). Symptoms related to limiting the children's favorite activities were painful for families. Most importantly, parents and siblings found those symptom experiences in which they could not do anything to help the children especially difficult to accept. Parents felt that they could not help, which only made the symptom experiences more troubling. Parents, especially fathers, felt helpless when they were unable to relieve their children's distress.

Father: Because, as a parent, you feel that you can do everything for your child, and not being able to fix something that your child is going through is very, very difficult. I mean they break something, you'll find a way of fixing it. They cut their self, and you fix it. You run against something like this, and you can't fix it. You have to, you originally walk into a building of total strangers and say, "Here. I'm putting my child in your hands. Fix it." And it's a different view for a parent to go through that. It's, "You can't do it for your child." You have to rely on other

people's knowledge and other people's experience, and you're so unprepared for it. It scares you to a point.

Father: You didn't like seeing her laying there sick, in pain. It was hard too and not being able to do nothing about it. Yeah, that's the hard part, is not being able to do nothing about it.

Siblings especially expressed a sense of helplessness in not being able to care for or help their ill brothers or sisters when they experienced unrelieved symptoms. Siblings felt extreme sadness as a result of these unrelieved symptoms.

Sibling (six-year-old female): I was sad when Cory was sick. I was sad that he might die!

Mother: His sister felt so bad for seeing him the way he was, for hurting him [in her attempt to help him feel better]. It was important for her to see him the following weekend when he was feeling better.

In the end, like the children, parents and siblings felt that all the symptoms, especially those they could do nothing about, "sucked." Families of children who experienced more severe, lengthier, and damaging symptoms felt that the overall symptom experience "sucked."

It Sort of Helps

"It sort of helps" refers to how the children and families evaluated most symptom management strategies. Key phrases such as "sort of," "a little less," "a little," and "I guess" were found frequently in the children's, parents', and siblings' discussions of symptom management and were indicative of the fact that many of the children's symptoms were not completely eliminated. Total relief rarely was achieved.

The difficulty in managing and controlling symptoms resulted in the children and their parents believing or accepting that some amount of unresolved symptom distress was to be expected. According to the children and families, "There is not much you can do" and "Nothing really helps." They did not expect complete symptom relief. Just as children and families expected it was necessary to feel sick in the process of getting better, they also expected that complete symptom relief was not achievable. Nonetheless, they tried anything and everything to reduce and eliminate all symptoms. The more experience children and families had with the cancer symptoms, the more successful they were in reducing symptom distress. Time and experience provided them with a better sense of what was happening and what needed to be done. As time passed, children and families had at least some idea how to make these experiences less difficult or they knew what helped to reduce the symptom distress.

Child with cancer (15-year-old female): Like, I can remember if I was sick to my stomach and was going to throw up, I usually feel better right after I threw up, you know, because it, I don't know, it just makes you feel better right afterwards. I don't know if it makes you feel better in the long run [laughs], long term.

Time and experience may have helped families to cope with the symptom experiences; however, on certain occasions, even the most experienced child or family had problems reducing symptom distress. In some instances, rest or sleep offered the only relief. The children valued sleep not because it helped to

relieve specific symptoms but because it took the children out of the realm of the world of feeling, even if just temporarily.

Interviewer: What things helped you the most when you had cancer?

Child with cancer (nine-year-old male): Sleeping—that's because my mind was totally off things right!

Child with cancer (7.5-year-old male): Mm [pause] having sleep.

Interviewer: Anything that you could do to make yourself feel better?

Child with cancer (seven-year-old female): No, I just laid in bed. Just lay in bed.

Child (five-year-old female): My sore tummy, I just could not get to my bed fast enough!

To arrive at a degree of symptom relief, the children and their families often used some type of trial-and-error approach.

Child with cancer (16-year-old female): They just told me to take [acetaminophen for headaches]. They told me to take two extra strength, and I was taking three extra strength. And it didn't really, it just kinda made it a little bit less. Yeah, I even tried having morphine for it, like, I had mouth sores, so I had morphine, right? But when I was done with my mouth sores, I still had some morphine left so I even tried taking that with my headaches and that didn't work. And so, I just laid down a lot and put pressure on my head. That sounds kind of weird, but it felt good to, like, kind of push on my head. I just figured it out [laughs].

At times, treatments to relieve the children's symptoms made the children feel even worse.

Child with cancer (4.5-year-old female): They give me special stuff that makes me goopy in the head. I hate that stuff.

When new symptoms emerged as a consequence of symptom management, children and families returned to the trial-and-error approach.

Child with cancer (14-year-old male): I was kind of almost ticked off cause they were using Maxeran [metoclopramide, an antiemetic or antinauseant drug] and [diphenhydramine for nausea] and then finally after I refused to take it, cause, it would be like I would take it and then my parents would either have to scrape me off the ceiling or scrape me off the floor. And then my last treatment, they found out that what was easier and worked better was Gravol [dimenhydrinate].

The trial-and-error approach also involved the children figuring out and using the most effective self-initiated strategies to relieve their symptom distress.

Interviewer: Did anything help to take away the headache?

Child with cancer (7.5-year-old male): Calming down, I just talked. I used to do that all the time.

Child with cancer (4.5-year-old female): My brain just kept on thinking just to get rid of this pain. And it helped me not think about dying.

The children viewed self-initiated strategies as an integral component to a multidimensional symptom management plan.

Child with cancer (4.5-year-old female): Yeah, but the bug [cancer] hated that so it tried to get rid of the medicine.

Interviewer: So, the bug was fighting the medicine, but who won?

Child: The medicine and also my brain. It sends its own medicine down. Yeah. It helped that other medicine.

Unfortunately, except for engaging in discussion about the strategies that helped them to deal with painful procedures (e.g., bone marrow aspirations), children rarely shared their thoughts with their nurses about their use of self-initiated strategies. These strategies were not always recognized or known by nurses and others; therefore, children could not be encouraged to use them.

Children and families only sought help for certain cancer symptom experiences. Although they usually sought help for symptoms deemed severe in intensity, this was not always the case with mild to moderate symptoms. Unsuccessful attempts to relieve certain symptom experiences sometimes resulted in children and their parents giving up on managing subsequent experiences with such symptoms. At times, the children and families just did not seek help. Instead, they tried to incorporate the unrelieved symptom experiences into their everyday lives and view them as a normal part of daily life. This was especially the case for symptom experiences labeled by children and families as "everyday," that is, symptoms that occurred on a continual basis (e.g., a headache of moderate intensity). Children and families rarely talked to nurses about such symptoms. When children and their parents talked about the symptoms, they tended to assign an ordinariness to the everyday symptoms or minimize their severity. These symptoms were described as "not too bad" or "tolerable." The children were able to function fairly well, but these symptom experiences eventually wore them down.

The never-ending nature of the symptoms and symptom suffering made ignoring any of them more difficult for children and families. Understandably, families of children who experienced more severe, lengthier, and damaging symptoms were less likely to accept the attitude of "it sort of helps." They were more persistent in seeking out help. "It sort of helped" symptom relief became less tolerable for these families.

They Are All the Same but They Are All Different

Sharing their experiences with the children's symptoms was important to the families. Often, parents in the inpatient and outpatient units discussed how each course of treatment affected their children. Less-experienced parents questioned the more-experienced parents about treatment side effects. Information about warning signs and symptoms that indicated that something was not quite right was especially important. Parents needed to know what they had to watch for with respect to their children's symptoms. However, parents believed that their children could experience similar symptoms, but they nonetheless believed that each child's experience was unique.

Mother: But symptoms-wise and ailment-wise, you look around and you have four other kids with the exact same thing, they're all at different levels; well, that could be because of time starts, but they're all different. They're all the same, but they're all different.

Parents constantly reinforced that the children's symptom experiences were unique. Likewise, the children themselves reinforced that every child with cancer experiences the disease and its symptoms in unique ways. All families who viewed the cancer symptoms as unique maintained an "it all depends" attitude with respect to how children would respond to treatment. Even when parents and children knew what to expect regarding symptom experiences in response to particular treatment courses, they still believed that they could never be absolutely sure about the symptoms. In the end, "it all depends" because too many factors existed to consider.

Father: It depends on what you are going through. I mean, if you go through two or three courses of the same thing, you can start to predict a little bit of what's going to happen. . . . If you had the med [medication] once . . . [you experienced a] side effect. . . . You have the med again, and you get that side effect again; well, you kind of expected it and not panic about it. . . . [You] deal with it as a side effect and sort of move on. I think that's something that's difficult for doctors to really relate to the patients or the parents, exactly what's going to happen because they don't all react the same way.

Child with cancer (14-year-old male): Like, it was, like, for me, it was almost predictable cause I would be okay. I'm going in for this drug whatever, and then it would be like, okay, I'm, I would prepare myself almost.

Father: It is variable with the kid, with the dosage, with so many things.

Although children and families believed each child's experience was unique, they all felt that the experience of suffering was the common thread that made the experiences similar in many ways.

Summary

Throughout the course of the study, a uniqueness to how all of the children and families transitioned through the cancer symptoms trajectory was apparent. Although the study participants had their own unique beliefs and expectations about the cancer symptoms, they nonetheless shared certain beliefs and expectations related to the cancer symptom experiences. Underpinning their beliefs and expectations was the "suffering experience." All of the children and families equated cancer not only with death but also with the phenomenon of suffering that was associated greatly with the children's cancer symptoms. The children's and families' beliefs and expectations contributed to and were a direct result of unrelieved or uncontrolled symptom experiences. Figure 4 summarizes how the children's and families' beliefs and expectations affected their suffering experience.

Discussion

Although research has reinforced that children with cancer still experience uncontrolled or unrelieved symptoms (Pederson, Parran, & Harbaugh, 2000), findings from the current study suggest that children's and families' beliefs and expectations, in part, may be responsible or contribute to the children's symptom distress. Most disturbing are the findings that children and families expected and believed that symptom suffering was necessary to overcoming the cancer and that containing all symptoms was not possible. Maintaining such

- Suffering related to the children's cancer symptoms is seen by children and their families as something to be expected.
- Suffering related to short-term or temporary symptoms was accepted more readily than suffering from long-term or permanent symptoms.
- Families of children who experienced more severe, lengthier, and damaging symptoms were less likely to support the theme "short-term pain for long-term gain." Instead, they were more likely to express the view "long-term pain for short-term gain."
- Families of children who experienced more severe, lengthier, and damaging symptoms were less likely to accept the attitude of "it sort of helps."
- The beliefs "you never get used to them" and "they all suck" were associated with the ability to contain the children's symptoms. Suffering was more prominent in parents and siblings who felt helpless in managing the children's symptoms.
- Although children and families accepted suffering as part of the cancer symptom experience, they never got used to it. At best, the suffering sometimes was more bearable, and at worst, it was less bearable.
- Although families and children believed that each child experiences symptoms in his or her own unique way, they all believed that the experience of suffering was the common thread to each child's experience.

Figure 4. Dimensions of Suffering in Relation to the Beliefs and Expectations About Children's Cancer Symptoms

beliefs may have contributed to children and families not always actively seeking help.

Despite the finding that children and families accepted suffering as part of their cancer symptom experiences, this belief did not make the cancer experience any easier for children and families. At best, the suffering sometimes became more bearable. At worst, it became harder to bear. Although children and their families reported that they learned to adapt to the cancer symptoms, especially the everyday symptom experiences, they never got used to them or the cancer experience. This finding contrasts research describing how children get used to the cancer, treatment, and resulting side effects and symptoms (Hockenberry-Eaton & Minick, 1994). These conflicting findings, in part, may be explained by how the children defined "getting used to." In Hockenberry-Eaton and Minick's study, "getting used to" was equated with becoming accustomed to cancer and its treatment. In the present study, children viewed "getting used to it" as an experience that involved not only becoming accustomed to the symptoms but also learning to like them or becoming comfortable with them. Children in the current study stressed the importance of remaining uncomfortable, otherwise the incentive to continue to fight the cancer experience and the difficulty of its symptoms would be very small. Becoming too comfortable is in opposition to fighting the cancer.

Tarr and Pickler (1999) noted that even with familiarity, childhood cancer treatment does not become routine but instead becomes more tolerable. They suggested that adaptation to the treatment routine acts as an insulator to constant confrontation of the reality of the diagnosis. Researchers could speculate further that suffering because of the symptom experiences helped families to live in the real world and establish routine and some sort of normalcy. Kane and Primomo (2001) examined the perspectives of healthcare professionals and determined that the suffering of seriously ill children and their families may be seen as a vehicle for professionals to encounter themselves. Suffering provides healthcare professionals with the opportunity to reflect on some existential and spiritual questions about life (Kane & Primomo). Part of the reflection, however, should be directed

at how healthcare professionals can best relieve the suffering caused by the children's symptoms.

Another finding previously unreported in the literature was that the children and families found that all of the symptoms basically "sucked." Although certain symptoms, such as fatigue (Hinds & Hockenberry-Eaton, 2001), are more distressing than others, the current study revealed that children believed that all of their symptoms were distressing in different ways, depending on the context of the children's and families' experiences. Children and their families in this study never really got used to the symptom experiences and only when they rated symptoms as extremely intense did they seek assistance. Children and families usually sought help for symptoms deemed severe in intensity, but this was not always the case with mild to moderate symptoms. The more subtle symptom experiences received less attention. This concurs with a study of cancer symptoms that focused mainly on symptoms that were experienced by children dying from cancer (Wolfe et al., 2000) or associated with more overt distress, such as pain related to procedures (e.g., bone marrow aspirations) (Adams, 1990; Bradlyn et al., 1993; Jay et al., 1983, 1987; Katz et al., 1980; Reeb & Bush, 1996). Labeling certain symptoms as "acceptable" most likely contributed to the children's and families' lack of attention to the more subtle symptom experiences; a hierarchy of symptoms warranting immediate attention was constructed by children and families. Perhaps labeling certain symptoms as more acceptable made them more bearable for children and families.

Even when children and families did seek symptom relief, they settled for outcomes that did not completely alleviate symptom distress. "It sort of helps" seemed to be an acceptable level of care. This lack of striving for greatly improved or complete symptom relief could be related partially to children's and families' belief that experiencing symptom distress was part of the cancer experience and achieving complete symptom relief was not possible. Experiencing unsuccessful symptom relief may have caused families and children to believe that nothing could help to control the symptoms, which prevented their seeking assistance. In effect, their beliefs and expectations served as self-fulfilling prophecies. The finding that children were able to function fairly adequately while experiencing certain symptoms may have contributed further to children and their families not seeking help. However, this raises the question about how much better children could have functioned if such symptom experiences were managed.

Children and their families struggled to manage the symptoms. When children implemented self-initiated strategies, others, including nurses, did not always appear to be aware of these strategies. At times, the only way for children to cope with their symptoms was to sleep. Although this strategy did not relieve symptoms, it nonetheless afforded the children a break. Parents felt that any strategies they implemented only somewhat helped to relieve their children's symptom distress. Acknowledging their feeling of helplessness is important, especially because suffering was more prominent in parents and siblings who felt helpless in managing the children's symptoms. Fathers, in particular, felt that their contribution to their children's symptom relief was minimal. Previous research has documented that symptom management in children with cancer is associated with feelings of helplessness in families (Bossert et al., 1996; Ferrell et al., 1994; Rhiner et al., 1994). McGrath (2001) noted that parents of children with acute lymphoblastic leukemia felt powerless that they could not protect their children from dis-

treasing medical experiences; in some way, the parents felt implicated in causing the children's distress. Clearly, families and children in the present study believed that each child experiences symptoms in his or her own unique way; however, the condition of helplessness was shared by all.

Although the assessment and management of pediatric cancer symptoms by nurses were not the focus of this study, the researchers pondered the effect of children's and families' beliefs and expectations on nurses' approach to the children's symptoms. Research to date has not considered how the beliefs of children and families affect nursing care. Research also has not been directed at nurses' beliefs and expectations about containing children's cancer symptoms within the context of the children's and families' suffering. Instead, studies have focused on examining nurses' knowledge and attitudes about pediatric pain. Findings from this line of inquiry consistently have reinforced that research knowledge about pediatric pain has increased, but the knowledge is not always applied by nurses in practice (Ely, 2001; Jacob & Puntillo, 1999a, 1999b; Manworren, 2000). Unfortunately, most of the research on pediatric pain is not specific to cancer-related pain. However, one study that was specific to pediatric cancer pain found that although pediatric nurses cared for patients with cancer regularly, they had a poor understanding of the general principles of cancer pain management and exaggerated concerns regarding the risk of addiction and respiratory depression associated with narcotic analgesics (Schmidt, Eland, & Weiler, 1994). Such work is invaluable; however, the study of nurses' beliefs about the assessment and management of the complete cancer symptom trajectory in children with cancer is warranted.

Study Limitations

This study's limitations were mainly related to the underrepresentation of certain child- and family-related characteristics, in particular, the demographic characteristic of race. The majority of children and families who agreed to participate were Caucasian (95%). Mothers and children with cancer were more likely to participate in interviews compared to fathers and siblings. The sample representing the children with cancer included more school-age (49%) and adolescent (38%) children in comparison to preschool-age children (13%). Therefore, the findings cannot be generalized. Future research addressing the study's limitations is needed to add to these findings and provide a more comprehensive understanding of children's and families' beliefs and expectations related to the cancer symptom experiences.

Implications for Nursing Practice

From a practice perspective, the study's findings lend support for nurses and other healthcare professionals to be more vigilant in assessing and managing children's symptom experiences. Successful care of children with cancer requires a comprehensive assessment; all symptoms warrant attention by nurses regardless of patients' degree of distress. Therefore, all those caring for children with cancer must be cognizant of and consider all of the children's symptom experiences. Even if children and families do not complain of any symptoms, nurses should inquire about the absence or presence of potential symptoms. Anticipatory guidance is key to symptom management. Nurses need to be careful and thorough in their assessments of children's symptom experiences, especially considering the children in this study found that rating their symptoms on any type of self-assessment scale was not always helpful. Relying

solely on self-assessment scales limits understanding of what children may be feeling and may not be able to truly capture the children's suffering. During the assessment process, healthcare providers must ascertain the beliefs and expectations of children and families in relation to symptom experiences and symptom containment. Obtaining a comprehensive assessment is the first step for nurses to promote the attitude of "it really helps" and not "it sort of helps" with respect to symptom management in children with cancer.

Nurses must reinforce to families that suffering in relation to symptom distress should not be perceived as a requisite to overcoming cancer. Nurses should work with families and children in easing their suffering. This includes nurses becoming aware of strategies used by children and families to relieve symptoms. Integrating nurse-initiated symptom relief strategies with child- and family-initiated strategies will result in a more comprehensive approach to symptom containment.

Implications for Nursing Research

This study reinforces the urgent need to research all cancer symptoms experienced by children, including day-to-day symptom experiences and those symptoms that are more subtle but nonetheless still a source of discomfort and suffering. Striving for complete symptom relief in children will be achieved only by understanding the beliefs and expectations about symptoms throughout the complete symptom trajectory in children with cancer. Further research that focuses on spe-

cific types of childhood cancers and specific stages of development in children will add to the understanding of children's and families' beliefs and expectations about cancer and its symptoms. Research directed at nurses' beliefs and expectations in relation to children's cancer symptoms and symptom relief is warranted. Determining how much suffering nurses expect in children and families would be worthwhile. Do nurses feel that certain symptom-related suffering is inevitable? Perhaps they support the belief that striving for complete symptom relief is unrealistic. Would nurses' views be similar to those of the children and family members? If they are, this would further compound achieving complete symptom relief.

Intervention studies facilitating positive beliefs and expectations and dispelling myths about symptom relief in children and families are needed and could involve support groups that focus on children, siblings, or parents sharing their experiences, beliefs, expectations, and fears about symptom experiences. In addition, intervention studies that build self-esteem in children and families with respect to symptom management by giving them the means to better manage or control the symptoms are necessary. Such research may help to relieve a sense of helplessness in children and their families and lead to beliefs and expectations that are more positive to achieving symptom relief.

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