Cancer symptom transition periods of children and families

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Background. Children with cancer are reported to experience many symptoms during the cancer trajectory. However, minimal qualitative research has been conducted that explores children’s and families’ experiences of symptoms. An understanding of the symptom trajectory, grounded in children’s and families’ experiences, is essential to providing comprehensive and sensitive care to children with cancer and their families.

Aim. This paper reports a study designed to explore and describe the symptom course in childhood cancer as experienced by children and their families.

Design. Guided by the philosophy of interpretive interactionism, a longitudinal qualitative study was undertaken. A purposive sample of 39 families of children with cancer who resided in Western Canada participated. The children ranged in age from 4.5 to 18 years and varied in their cancer diagnoses.

Methods. Multiple data collection methods included formal and informal interviewing and participant observation. Data were analysed by the constant comparative method. Development of illness narratives added to an understanding of children’s and families’ experiences.

Findings. A substantive theory entitled ‘Children’s and Families’ Lived Experience of Childhood Cancer Symptoms’ emerged from the findings. This depicts the experience of cancer in relation to children’s changing symptom trajectory. A core category of the theory, ‘passage through the transition periods’, shows how changing symptom experiences affected children’s and families’ ways of being in the world. These were reflected in six transition periods: (1) it is just the flu; (2) it is more than the flu; (3) it hits home; (4) it is nasty; (5) it is not so bad, it is pretty good; and (6) it is ‘dragsville’. The changing roles and responsibilities of family members, and how the family existed in the cancer world, varied depending on the transition period through which they were passing.

Conclusions. Transition periods not only reinforce the dynamic nature of the experience of childhood cancer but, more importantly, show how symptoms can greatly affect the quality of children’s and families’ day-to-day living. Interpreting cancer in the context of the symptom trajectory provides nurses with a new perspective for understanding childhood cancer, and will assist in the development of symptom relief strategies that will help to contain symptoms and improve overall quality of life for children and families.
Introduction

No longer considered an inevitably fatal disease, childhood cancer is nonetheless very threatening for children and families to live through. All family members, not only the children, are confronted with the distress associated with cancer (Houtzager et al. 1999). Contributing to the threatening nature of cancer are the array of symptoms that these children must endure (Hinds 1990, Hinds et al. 1992, Gauvain-Piquard et al. 1999, Hinds et al. 1999, Liossi 1991, Schneider 1999, Collins et al. 2000, 2002, Pederson et al. 2000, Hockenberry-Eaton & Hinds 2000, Hinds & Hockenberry-Eaton 2001, Hedström et al. 2003), including lethargy, pain, and insomnia (Collins et al. 2000, 2002). Also, symptom distress has been reported to be relatively high among inpatients, children with solid tumours, and those who are undergoing antineoplastic treatment (Collins et al. 2002). Not surprisingly, children identify changes in their physical abilities, appearance and moods as major concerns (Freeman et al. 2003). Unrelieved symptom distress is not only associated with physical changes in their bodies, but also contributes to weakening of the sense of self in children (Ritchie 1992, Woodgate 2001a).

Research also reveals that families are not immune to children’s symptom experiences. Uncontrolled symptoms can cause much suffering for families and impact on their sense of self, normality, and stability (Ross-Alaolmolki et al. 1995, Enskär et al. 1997, McGrath 2001). This suffering experienced by families has been referred to as a ‘community of suffering’ by parents of children with cancer (Ferrell et al. 1994, Rhiner et al. 1994). Not being able to protect children from distressing medical experiences leaves parents feeling helpless and powerless (McGrath 2001, Woodgate 2001a). Siblings may also experience much emotional distress if they know that their ill brother or sister may be suffering from uncontrolled symptoms, especially if they are unable to comfort them (Brett & Davies 1988, Woodgate 2001a, Freeman et al. 2003). Worrying about their ill brother’s or sister’s changing physical appearance, personality, and moods also contributes to their distress (Havermans & Eiser 1994, Freeman et al. 2003). Overall, siblings and parents experience many losses because of children’s symptom distress (Sloper 2000, Woodgate 2001a, McGrath & Pitcher 2002).

Although the literature on childhood illness supports the idea that children’s symptoms impact upon the entire family unit (Woodgate & Kristjanson 1996), research that seeks to gain an understanding of children’s and families’ perspectives about cancer symptoms is in its early stages.

The study

Aim

We acknowledged the importance of and need to access children’s and families’ perspectives about the symptom trajectory of childhood cancer and, therefore, we undertook a research study to discover what it was like for children with cancer and their families to experience this trajectory.

Design

A longitudinal qualitative research study, guided by the philosophy of interpretive interactionism, was undertaken in order to arrive at meaningful interpretations of children’s and families’ experiences. Theoretical foundations from the qualitative methods of grounded theory and illness narratives were integrated into the study.

Participants

Child and family participants (parents and siblings) were selected using the grounded theory method of theoretical purposive sampling, with the aim of describing the full range of children’s symptom experiences. In total, 39 families were recruited, and 15 families were studied more intensely (i.e. were involved in more interviews and observation periods). Twenty-one children were female and 18 were male, and they ranged in age from 4½ to 18 years (mean age 10 years). Thirty-seven of the children were white. Thirty-four families were two-parent families and 34 of the 39 children had at least one sibling. Twenty-six families resided in the city and 13 in rural areas.

The majority of children (n = 28) were diagnosed with either leukaemia or lymphoma. All received chemotherapy either alone (n = 22), or in combination with surgery (n = 7), radiation (n = 2), radiation and bone marrow transplant (BMT) (n = 3), radiation and surgery (n = 4), and surgery, radiation and BMT (n = 1). During the course of the study five children had a relapse.

Data collection

The study was conducted in a city in western Canada between July 1998 and December 2000. Although multiple data collection methods were used to facilitate arriving at a comprehensive understanding of the phenomenon under study, there were two major sources of data. In the first, moderate participant observation, RLW observed participants in their natural settings. In comparison with pure observation, moderate participant observation affords a researcher the opportunity to assume a more active and interactive role (Prus 1996) and a fairly close, yet non-disruptive, relationship with participants that requires constant reflection on the meaning of observed situations (van Manen 1990). A total of 960 observation hours took place in the outpatient unit of the city’s main cancer treatment centre where children are treated. The 15 children who were studied more intensely were also observed in the inpatient unit when they were hospitalized. Questions emerged from the immediate context and were addressed in informal interviewing. Observations were unstructured and were recorded in field notes.

The second major source of data collection involved children and their families participating in audio-taped, open-ended formal interviews. The open-ended technique helped to elicit detailed responses as well as to focus participants’ responses on areas previously not anticipated (Field & Morse 1985). Three different interview guides with a list of potential questions about childhood cancer and its symptoms were developed for parents, children with cancer, and siblings. Key themes, identified from the literature and our clinical experience, helped to focus the line of inquiry. Developmentally-appropriate strategies were undertaken with child participants to facilitate expression of thoughts, as well as to ensure that, regardless of age, they viewed their participation positively throughout the research process (Woodgate 2000, 2001b).

Family members were interviewed individually as well as with other family members. More than one set of interview sessions was planned, in order to follow-up significant themes. During the course of the study a total of 230 interviews were conducted, with mothers being interviewed 117 times, fathers 46 times, siblings 48 times and children 103 times. Adults’ interviews lasted between 40 and 180 minutes. Children’s interviews lasted from 20 to 120 minutes. Field notes were made during all interviews.

Ethical considerations

Permission to carry out the study was received from a university-based ethical review committee and from the participating facility where recruitment took place. Both parental consent and assent from all child participants were obtained.

Data analysis

All interviews and field notes were transcribed and then analysed by the constant comparative method used in grounded theory (Strauss & Corbin 1990, 1994, Morse & Field 1995, Creswell 1998). Interpretation of data was achieved by the development of inductively-derived theoretical categories. Key steps in this method include: coding or giving meaning to all units of information; revising codes and/or recoding previously coded data; and aggregating and clustering codes into theoretical categories.

The second type of interpretive work, the development of illness narratives, involved retelling and inscribing the illness stories of children and families (Kleinman 1988). Illness narratives helped to confirm the paradigmatic relationships of the categories present in theory development (Creswell 1998). Arriving at the core narrative (Viney & Bousfield 1991) was critical to reconstructing children’s and families’ biographies. Preparing the core narrative involved arranging symptoms of illness and events in temporal order, and relating them to other events in the participant’s life (Hydén 1997).

Findings

Although children and families felt that there were many ‘rough spots’ in ‘getting through cancer’ (Woodgate & Degner 2003a), it was the children’s symptoms that were consistently identified by children and families as major ‘rough spots’. Children’s and families’ thoughts and feelings about cancer often paralleled the changing symptom course. Accordingly, it was important to refer to children’s illness trajectories not exclusively as symptom or cancer trajectories, but as cancer symptom trajectories.

The significance that symptoms had in making cancer and life more difficult to ‘get through’ led to the emergence of the substantive theory: Children’s and families’ lived experience of childhood cancer symptoms. This theory provided direction in comprehending how children and families experienced cancer within the context of symptom experiences. Two core categories form the foundation of this theory. The first core category, ‘personal meanings of the symptom experiences’, represents how symptoms were experienced by children and their families based on the meanings assigned to them (Woodgate 2001a, Woodgate et al. 2003). The second core category, labelled ‘passage through the transition periods’, is
the focus of this paper. Whereas symptoms could be equated to the ‘many bumps in the road’, ‘passage through the transition periods’ represented how children and families moved through the cancer symptom trajectory. Passage through the transition periods relates to children and families integrating personal meanings into their daily lives so that they could survive and maintain a ‘sense of spirit’. Symptoms contributed to children’s and families’ way of being in the world, as reflected in their changing roles and responsibilities, and how they existed as a family. They experienced the different ways of being in the world by passing through six transition periods (Table 1). The next six sections of this paper describe these periods.

It is just the flu…anything but cancer

Symptoms in this transition period were viewed as ‘something normal’. Although it could occur at any time during the cancer course, for most families it was experienced either during the prediagnosis stage or once the children had successfully completed treatment. When this transition period occurred during the prediagnosis stage, parents said that they felt that ‘something was not quite right’. However, although the symptoms warranted their attention, parents were not too worried about them; they were a reflection of ‘growing pains’ or a lifestyle habit that could easily be resolved. Many families thought that children had a common childhood illness or even a bad case of the flu. Siblings often teased their ill brother or sister when they complained and thought they were ‘putting on an act’ in order to get some extra attention. This view of symptoms as not representative of anything serious was often supported by children’s physicians:

Well, mom took me to a doctor and they said it was probably just that I got a cold or flu in my bones. [7-year-old male with acute lymphocytic leukaemia (ALL)]

During their first encounters with cancer symptom(s), most families were able to continue to maintain their usual responsibilities, roles and activities. Their sense of self did not really alter much. They continued to view the symptoms not in the context of a serious illness such as cancer, but in the context of a ‘normal’ childhood illness. Children and families also carried on in a similar manner when this transition period occurred after completion of the cancer treatment programme. However, without question, they now considered the possibility that the symptoms could be associated with cancer, although children remained in remission. If they hoped to contain their fears, they once again needed to situate the symptoms within the context of ‘normal’ childhood illnesses.

It is more than the flu

In this period, symptoms were no longer considered to be a ‘normal’ part of childhood. Instead, they were viewed to be more serious in nature and were approached with more fear:

I was, like, ‘Oh cool, I have the flu so no more school for a while!’ Then I went back to school for about a month out of the whole second term and then spring break came along and I got sick again. I was feeling fine for a little while and then all of a sudden I just started feeling really dizzy and I felt like I was going to, like, get sick all the time and I couldn’t walk a lot... I was, like, really scared because I didn’t know what was happening to me. (16-year-old female, ALL, prediagnosis)

As with the ‘it is just the flu…’ transition period, this period was more often associated with the prediagnosis stage. However during this period, children’s symptoms had an even greater impact on families’ way of life. Families were now making changes in their lifestyles, such as not going out as a whole family. Children were missing more school through illness and were not able to participate in their favourite activities. Likewise, siblings needed to restrict their extracurricular activities. One of the most significant changes was that the children were described as not acting or looking like their usual selves:

We were at the lake for about ten days and for about a week he just wasn’t himself... He wouldn’t go into the water and that’s not like Ken. Ken lived in the water when we were at the lake. (Mother of a 12-year-old male with non-Hodgkin’s lymphoma)

Although children and families viewed the symptoms as representative of something serious, most did not suspect cancer. Hence, once a diagnosis of cancer was made, an overwhelming sense of disbelief prevailed. With the diagnosis of cancer, the symptoms and the associated suffering were made legitimate.

In addition to the prediagnosis stage, this transition period was associated with active treatment and the post-treatment stage of cancer. As in the prediagnosis stage, symptoms, were perceived to be something serious. However, unlike in the prediagnosis stage, symptoms were often associated with the return of cancer and, in fact, were referred to as ‘comeback’ symptoms. When children did relapse, they and their parents often knew that the cancer had come back even before it was medically confirmed. This knowledge was based on the return of symptoms that had led families to seek help in the first place:

It was one of the worst times because of the fact that we were seeing the symptoms coming back that actually got us to the doctors in the first place. (Father of a 4½-year-old female with ALL)
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<tr>
<th>Transition period</th>
<th>Predominant cancer stage(s)</th>
<th>Beliefs about symptoms</th>
<th>Cancer symptom connection</th>
<th>The family’s way of being in the world</th>
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<td>It is just the flu…</td>
<td>Precancer diagnosis</td>
<td>Symptoms seen as a normal part of growing up as a healthy child</td>
<td>Symptoms not associated with the threat of cancer</td>
<td>Way of being remains the same for the most part; parents (usually the mother) assumes a familiar role of caring for the child experiencing a normal childhood illness</td>
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<td>Postcompletion of treatment programme with child in remission</td>
<td>As above</td>
<td>Symptoms potentially related to cancer and are a constant reminder of cancer</td>
<td>Way of being is the same but different in comparison with life before cancer entered the child’s and family’s life; symptoms are no longer taken for granted</td>
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<td>It is more than the flu</td>
<td>Precancer diagnosis</td>
<td>Symptoms no longer seen as a normal part of growing up as a healthy child</td>
<td>Symptoms related to something serious but not necessarily cancer</td>
<td>Way of being is focused more on the ill child’s health status</td>
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<td>Active or postcompletion treatment stages when there was the question of relapse</td>
<td>Warning sign that something is not quite right</td>
<td>Symptoms definitely associated with the comeback of cancer; symptoms seen as the enemy returning</td>
<td>More restrictions, losses, and uncertainty experienced by family members but still a functioning as a unit Family members assume the role of the protector and detective</td>
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<td>It hits home</td>
<td>Any time during active treatment but especially during the more intense treatment courses</td>
<td>Symptoms seen as an integral and normal part of getting through cancer</td>
<td>Symptoms become the child’s and family’s guide to understanding the stages of cancer</td>
<td>Way of being is focused on fighting the child’s cancer; extra physical, psychological, emotional, social, and spiritual work in caring for the children’s symptoms. Focus on the child’s needs. More restrictions and losses. Family members assuming the role of the protector but each in their own way Mother’s sense of self is slowly being defined within the context of the child’s sense of self</td>
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<td>Associated with being ‘really sick’</td>
<td>Symptoms seen as a guest, albeit a guest who is not completely trusted or welcomed</td>
<td>Suffering due to the symptoms is accepted to some degree</td>
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**Table 1 The cancer symptom trajectory**

R.L. Woodgate and L.F. Degner

It hits home

In this transition period, life was no longer viewed in the context of a 'normal' childhood, but within the context of cancer. Although symptoms were never welcomed, families, nonetheless, put the symptoms in their proper place by reasoning that experiencing symptoms was an integral step in getting through the cancer. Comments such as 'short-term pain was necessary for long-term gain' or 'one has to feel a lot worse before one feels a lot better' reinforced the idea that some degree of suffering was justified (Woodgate & Degner 2003b).

The degree to which children felt 'sick' or ill helped to determine how 'hard' the impact of cancer was on children’s and families’ daily lives. This transition period was often

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associated with the active treatment stage of cancer, especially during heavier treatment courses. However, there were some who experienced this transition period in the prediagnosis period, especially if the child’s first symptoms were so severe and/or unusual that an immediate cancer diagnosis was made. There were also some children who experienced increased symptom distress during the less intense stages of active treatment.

In this transition period, the focus of daily life for families was mainly determined by the symptoms and how ill they made children feel. Despite trying to make plans based on the needs of what was good for the family unit, it was the needs of the ill child that took priority. This resulted in restrictions and losses in their daily lives, and fewer plans:

We said ‘Well, we can’t make any plans’. Anybody phones you up and says ‘Well, do you want to go to a movie..?’ I said ‘Call us that day, we will see what Lynn [ill child] is like’. (Father of a 4½-year-old female with ALL)

Things that you want to do, you just can’t...It is ‘can’t’ if you want to go somewhere. Can’t do that many things... (Brother of a 4½-year-old female with ALL)

More and more, the mother’s way of being in the world was closely associated with the ill child’s existence. Mothers became more vigilant in taking care of ill children, and gave increased attention to watching closely for any unusual or serious symptoms and protecting them from any additional distress. Most fathers also assumed some aspects of caring for the ill child, such as seeking out ‘special’ snacks or take-out dinners for both the ill and healthy children. Likewise, siblings also would do whatever they could to make their brother or sister feel more comfortable, such as being quiet when they were trying to sleep. Nonetheless, ‘taking care’ of ill children became the priority of mothers, although many fathers and siblings wanted to become more involved. Not surprisingly, fathers and siblings experienced a sense of loss and sadness in relation to their limited involvement, as well as having to give up some of their ‘normal’ family activities. However, they also realized that it was important for them to support the increasing closeness between mother and child. They viewed their support as not only necessary to protect the ill child from any more suffering, but also as a way of protecting the family unit from coming apart.

It is nasty

In this transition period symptoms were no longer viewed as a valuable guide, but as the ‘enemy.’ It was in this period that families’ way of being was defined solely by the children’s symptoms because these dominated their worlds. Although this occurred when children were receiving the most intense treatment, it also happened at any time throughout the illness when bothersome or troubling symptoms could not be contained.

It was during this period that life was described by children and families as ‘being on hold’ or ‘living in limbo’. Families spent most of their energies, either directly or indirectly, in ‘taking care’ of the ill child. Maintaining some sense of family routine and life became increasingly difficult. Understandably, having the opportunity to ‘be with’ the ill child, even if it was only for brief periods, helped family members to feel more secure and connected. For many mothers, their way of being in the world was strictly defined within the context of the ill child’s needs. The mother’s sense of self was merging with the ill child’s sense of self; the mother’s voice of ‘I’ was slowly being replaced by the voice of ‘we.’ It was as if two new families existed within the overall family unit; the family of the mother and ill child and the family of the father and siblings. In addition to feeling isolated within the family, families also became more isolated from the outside world. Even when family members spent time with friends or relatives, their minds were on the ill child and their own family unit. All their energy was directed at protecting the ill child, as well as the family unit.

It is not so bad, it is pretty good

In this transition period, symptoms were viewed as an integral and normal part of the child’s growing up. However, this time it is not just a ‘healthy’ child, but a ‘healthy’ child with cancer who is experiencing symptoms that are ‘not too bad’. A few children experienced the ‘pretty good’ period when it was least expected, such as during a more intensive time of the cancer treatment. However, most children experienced ‘it is pretty good’ periods inbetween treatment courses or during times when treatment was not as heavy and did not involve a lot of changes, such as the maintenance phase of treatment. Although they did experience ‘feeling sick’ (ill) during this transition period, it was for a shorter duration in comparison with other transition periods. It was during ‘pretty good’ periods that children realized and appreciated what it felt like to feel relatively well again, even if it was not permanent:

Like, you get so used to feeling sick, that when you finally feel better, you know, it is, like, ‘Wow! I feel so much better and different, I didn’t even know how [ill] I felt before because I got so used to it!’ (14-year-old female with ALL)
In this period, families did not define their worlds solely in terms of the sick child. In fact, children were seen to be healthy to varying degrees, although they were still being treated. Although families stressed that ‘life would never be the same as it was before the cancer diagnosis’, nonetheless, they did try to regain some aspects of their old way of family life. They were able to function as a ‘whole’ family unit and took advantage of this period by taking time to do ‘family things’.

We actually managed to go on a family vacation last winter in March, and suddenly we got to feel normal again or as close as ever it was. She was still having her problems but you know it was pretty darn good [laughs], relatively speaking. (Father of a 15½-year-old female with ALL and central nervous system involvement)

For parents and siblings, relief from symptoms meant that the ill child could do ‘kid things’ or ‘be a kid’ again. It allowed time for parents and siblings to breathe a sigh of relief and helped them to maintain their sense of hope:

You just have to believe it, you know, it’s going to be okay. If I see her swimming in a pool, it’s easier to believe than when your child is in a wheelchair. (Father of a 12-year-old female with ALL)

Seeing her happy! That is what makes me happy, when she is running and playing. (12-year-old brother of a 4½-year-old female with neuroblastoma)

Parents and their healthy children also took advantage of this period by trying to spend more time with each other. One mother of an adolescent on maintenance treatment for ALL recalled a weekend spent with one of her other adolescent daughters and noted how much this meant to her. The daughter had told her that she was glad that she ‘had her mother to herself’.

**It is dragsville**

The period labelled as ‘dragsville’ by children and families was experienced as a time of physical and mental tiredness. Tiredness was experienced by those children who had more frequent experiences of severe symptoms, as well as those whose symptoms were not as severe but remained constant. Symptoms that lingered inbetween treatments or near the end of the treatment programme also became tiring. One mother, whose son’s headaches and nausea persisted throughout the cancer course, would frequently express that both she and her son were ‘tired of the never-ending symptoms’ and that the ‘cancer experience was dragging on way too long for them’.

As unbearable as it was to experience symptoms inbetween treatment courses, experiencing them after treatment was completed was especially hard. At least, during active treatment, children and their families held on to the belief that symptoms would resolve after treatment was completed. However, when symptoms still lingered, families were living the same life as they did during cancer treatment. They were still prisoners of the symptoms, and the symptoms now became the illness. Lingering symptoms served as constant reminders to families that they were not really living life:

I have no life. [Laughs] School and doctor appointments...I only have school half of the time...Because I’m still feeling [ill]... (14-year-old male with Hodgkin’s lymphoma, 6 months after completion of treatment)

Although support from others during this time was especially important to families, some felt that friends were giving up on them and no longer wanted to be part of their cancer symptom journey. Families believed that others felt that their children’s symptoms were no longer justified. It became important to put the symptoms in their proper place by rationalizing that things could always be worse:

Nothing has changed and we don’t know if it will, but at least his cancer is under control. Things will get back on track once this thing [symptom distress] is under control. (Mother of a 13-year-old male with non-Hodgkin’s lymphoma)

**Discussion**

Increasingly, the paediatric cancer literature is providing us with a picture of what it is like to be a family going through the childhood cancer experience, and the many changes that transpire (Clarke-Steffen 1993, 1997, McGrath 2001, McGrath & Pitcher 2002). Our study lends further support to the view that childhood cancer is a major turning point or ‘epiphany’ for families. However, a new perspective on families’ transition through cancer emerged, as a result of interpreting cancer within the context of the symptom trajectory.

The findings from our study support the idea that an interdependent relationship exists between symptoms, cancer, and children’s and families’ way of being in the world. In fact, symptoms in and of themselves served as major turning points that led to interactional moments in the lives of children and families; interactional moments that leave either positive or negative impressions on people’s lives (Denzin 1989). In responding to symptoms, families strove not only to protect their ill children, but also the family...
unit. However, ‘taking care’ of both ill child and family became increasingly difficult during periods when symptoms predominated.

In addition to having an impact on day-to-day life, symptoms affected individual family members’ sense of self, as well as the whole family unit. Young et al. (2002) note that the biographical disruption that occurs in families as a result of childhood cancer may be better understood by drawing on sociological literatures on motherhood, childhood, caring and chronic illness. For instance, the notions of maternal self-sacrifice in ‘putting the children first’ and acting in children’s ‘best interests’ remain powerful in both public and private discourses about motherhood and childhood (Young et al. 2002), and may help to explain why mothers in our study became immersed in children’s personal identities and fathers and siblings formed a new configuration of the family unit. Further study of the biographical disruption that occurs is warranted and may lead to interventions that support the family unit.

Although the transition periods did, to some extent, parallel stages of the cancer and its treatment course, differences between the two did exist. Children and families experienced transition periods as a more fluid and individualized type of movement; movement that was not always fixed in one direction. For some families, certain transition periods occurred simultaneously or could be experienced more than once or were not applicable to their situation. It is, therefore, premature to conclude that transition periods are a direct reflection of cancer and its treatment course. As transition periods are dependent on the meanings that children and families assign to symptoms, one could hypothesize that relationships between these periods and cancer stages will remain individualized for each child and family. Further study is warranted to identify the degree of correlation between transition periods and cancer and its treatment course. This may lead to the design of intervention and prevention programmes.

Although this study is preliminary work, the detailed information that emerged could provide some guidance to nurses caring for children with cancer. In order to provide comprehensive and sensitive care, nurses should consider both the child’s treatment stage and symptom trajectory. Questions relating to the type of symptoms that children are experiencing, as well as their impact on children’s and families’ day-to-day lives should be part of the nurse’s ongoing assessment. Research has shown that parents have valuable insights about their child’s symptoms that, when acknowledged by health professionals, could facilitate a diagnosis of childhood cancer (Dixon-Woods et al. 2001).

Equally important is for nurses to recognize that children’s changing symptoms affect the whole family unit. This includes not only those usually responsible for the care of children (i.e. mothers), but also those involved on the periphery of the ‘caring circle’ (i.e. fathers and siblings). In developing symptom-relief plans, nurses need to incorporate the philosophy of family-centred care. Considering that all family members experience feelings of powerlessness and helplessness in trying to relieve children’s symptoms, more needs to be done. Nurses need to be aware that children and families can experience problems related to symptoms throughout the entire cancer course. It is especially important to recognize that symptoms that occur after completion of the treatment regimen can be extremely stressful for families.

Limitations

Study limitations mainly relate to the under-representation of certain child- and family-related characteristics. Most notable was the demographic characteristic of race. The majority of children and families who agreed to participate were Caucasian (95%). Also, more school-age (49%) and adolescent (38%) children participated in comparison with preschool children (13%). Additionally, mothers and children with cancer were more likely to participate in interviews as compared with fathers and siblings. Future research that addresses the study’s limitations is warranted, in order to provide a more comprehensive understanding of the childhood cancer symptom trajectory.

Conclusion

A longitudinal, qualitative research approach provided children and families with a vehicle for telling us their stories. Findings from our study afford a greater understanding and appreciation of the cancer symptom trajectory as experienced and lived by children and their families. While previous research has revealed various aspects of the transition processes of children and families who go through childhood cancer experiences (Clarke-Steffen 1993, 1997), the impact that symptoms have on how children and families make these transitions has not been documented in such detail. Although further work is necessary to confirm or refute the relevance of these transition periods, linkage of symptoms to families’ responses to cancer will help nurses to develop therapeutic interventions, not only for symptom containment, but for helping families to deal with the overall cancer experience. Overall quality of life for children and their families may be improved.
What is already known about this topic

- Children with cancer experience a high prevalence of symptoms and symptom distress.
- Uncontrolled symptoms cause much stress and suffering for children with cancer, as well as their families.
- Research interest in children’s and families’ perspectives on symptoms experienced by children with cancer is in its early stages.

What this paper adds

- In childhood cancer, an interdependent relationship exists between presence or absence of symptoms, cancer, and children’s and families’ ways of being in the world.
- Children with cancer and families not only transit through the stages of cancer and its treatment, but also make transitions that are specific to cancer symptoms.
- To ensure that paediatric cancer care is both comprehensive and sensitive, nurses need to consider not only cancer treatment stages, but also the symptom trajectory.

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