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Children's cancer symptom experiences: Keeping the spirit alive in children and their families

By Roberta Lynn Woodgate

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Good afternoon, my CANO colleagues. It is truly a privilege to be here today and to be part of such an important and vital conference. It is a privilege to be a part of an association that promotes expertise in oncology nursing practice to its members and the public. It is a privilege to be amongst my fellow oncology nurses whose wealth of knowledge and gift to care have helped many an individual and family to "get through" the arduous cancer journey. It is a privilege to be one of so many who strive to ensure the highest quality of care. I thank you for this special opportunity. I am truly honoured to be able to share a part of my work that has been and continues to be a very big part of my life.

In my many years as a pediatric nurse, I have had the privilege to be invited into the lives of many ill children and their families. While I have found no greater satisfaction than caring for ill children and their families, at times and for many reasons it was and can be quite hard to do. This is especially the case when children and families experience suffering in relation to the child's relentless symptoms. While it is accepted that suffering is an inevitable part of life, it is still hard to accept and witness the suffering of a child. After all, children are not supposed to suffer. Watching their suffering, and feeling helpless at times to relieve their suffering, led me to seek out answers. I needed to understand the pain and distress that children experience because of illness. While the literature provided answers to some of my questions, there were and still are many unknowns in the literature. Accordingly, part of seeking answers to my questions involves me conducting research that helps to bring understanding to the suffering nature of illness in children and their families. This includes my PhD study that focused on exploring and describing the childhood cancer symptom course as interpreted and experienced by children and their families, including their parents and siblings. Guided by the philosophy of

interpretive interactionism, a longitudinal interpretive qualitative research design was used. In qualitative interpretive research, one seeks to arrive at building meaningful interpretations of a specific social and cultural problem (Denzin, 1989). This approach was appropriate as it afforded me the opportunity to study the children's cancer symptoms as they were lived and grounded in the children's and families' experiences. Thirty-nine families of children with cancer participated. The children ranged in age from four and one-half to 18 years and varied in their cancer diagnoses and stages of treatment. Multiple data collection methods were used, including formal and informal interviewing and participant observation.

From this study, many highly personalized stories emerged. Today, I will retell some of the children's and families' stories related to the children's cancer symptom experiences; experiences that were part of their overall life story, part of their life narrative; narratives that speak to their will and courage to get through cancer. By sharing their stories with you, I hope at the end of my presentation your spirits will be as inspired as mine was throughout my study.

Many layers of sadness: A deeper sadness

Childhood cancer, a life-threatening illness, is described by families of children with cancer as a very overwhelming phenomenon to experience. Children and their families must face many stressors and challenges because of childhood cancer. More than ever, physical and mental suffering become a part of their lives. Contributing to their suffering are the cancer symptoms that children experience. The symptoms can have an adverse effect on the children's and families' quality of life (Hinds, 1990). Hence the need to study how children with cancer and their families experience childhood cancer symptoms. However, although I had originally intended to discover meaningful interpretations of children's and their families' experiences with childhood cancer symptoms, children and their families needed to talk about the "whole" cancer experience (Woodgate, 2001; Woodgate & Degner, 2003a). That is, they were unable to deconstruct their experiences with symptoms from the overall cancer experience. Understanding of the impact that cancer symptoms had on their lives could only be arrived at

Roberta Lynn Woodgate is Assistant Professor, Child Health and Illness, Faculty of Nursing, Helen Glass Centre for Nursing, University of Manitoba, Winnipeg, MB.

by interpreting and giving meanings to symptoms within the larger context of the illness trajectory. The meanings ascribed to the cancer illness influenced the information children and families perceived and communicated about particular symptom experiences. Frequent phrases expressed by families, such as “The whole enchilada!”, “The whole gamut!”, or “It is astronomical!”, reinforced the complexity of experiencing childhood cancer. Moreover, parents and siblings could not answer the question, “Tell me what stood out for you or what was the most difficult aspect about having cancer?”, because they could not deconstruct their experiences:

The whole thing, yeah, the whole thing and then we don't know if she is going to be like with the cancer. She is going to beat the cancer for sure, but because of the chemotherapy, what is going to happen to her? Is she going to recover good? Is her body and things going to be okay? (Father)

I think it's just the whole situation “altogether!” Like she's so young. (Sibling)

The children with cancer also supported similar sentiments. The phrases: “The whole thing sucks!” or “It is everything!” were voiced by children of all ages. Children and families expressed that there were many difficult events or “rough spots” that made life “so hard” or “scary” to live through. This included having to endure the disclosure of the diagnosis as well as having to get past the diagnosis; deal with the fear of death; adjust to the multiple changes that take place; balance family life with hospital life; keep the family unit together; and adjust to the “ups and downs” of the childhood cancer experience.

With the “rough spots” came increased uncertainty; added restrictions; extra physical, mental, social, and emotional work; and a new sense of loss. But perhaps most poignant of all, as one mother noted, were “the many layers of sadness.” To say that having cancer in one's family was complex and caused a great deal of sadness for all involved would be an understatement. The children's and families' narratives reinforced that the cancer resulted in more sadness in their lives than they had been accustomed to in the past. Throughout the cancer course, children and their families had many sad days and nights, and with each subsequent “rough spot” their sadness was felt even deeper. Children and their families did not become numb to the sadness. In fact, the sadness had become and remained with them, often hidden from others, as one mother reinforced:

It is like peeling an onion! The layers, as you peel the layers off, the layers have gotten deeper now, now it has gone right to the core of you. Before, it was getting used to it, just surviving. Now, it is part of you, it has taken a year to become that sadness, now it is part of us. It (sadness) will always be there. It changes your whole life. I can't even explain it. I don't look at anything like I have before...It is a deeper sadness, I think. It is not on the surface any more. It is where nobody can see it, it has become inward now...It is not something you say to people. Before, people would say 'how are you?' But everything seems normal now, nobody says that anymore, and nobody gives you that understanding anymore, that leeway. It is more of a deeper sadness, it is a deeper sadness, it is more inward.

The sadness and anguish experienced by children and their families underscore the suffering nature of their experience with cancer. To hear parents refer to cancer as a “living nightmare,” or “hell on earth” underscores their suffering. In a study conducted by

Ferrell and colleagues (Ferrell, Rhiner, Shapiro, & Dierkes, 1994; Rhiner, Ferrell, Shapiro, & Dierkes, 1994), they revealed that parents experienced a “community of suffering” in having to deal with their child's cancer and cancer pain. Parents in my study not only experienced a “community of suffering,” but also became a “family of suffering.” Likewise, children of all ages also experienced the suffering, as is evident by the following statements:

It is not a pleasant or fun experience! (17-year-old male, osteogenic sarcoma)
THE HORROR OF IT ALL! (five-year-old female, acute lymphocytic leukemia [ALL])

Perhaps even more difficult to bear than one's own pain was the pain that was experienced by others. It was the suffering experience of others that led to deep feelings of sadness, as is reinforced by the following comment expressed by a six-year-old sibling, “I was sad when Cory was sick...I was sad that he might die!”

Understandably, families felt that it was the child with cancer who experienced the greatest degree of suffering in relation to the overall cancer experience. Family members perceived that the children's suffering was to some extent much more valid and painful compared to their own suffering. Yet, the children themselves were the first to acknowledge how hard it must be for their families to have to witness their child's pain and distress:

It is terrible going through it, but I can see it being more terrible, not more terrible, but really terrible to be part of the family who has to watch somebody go through it, cause like you know you feel so bad, like there is just no way you can help them. It's just that you feel really helpless not being able to do anything as a family member. (15-year-old female, ALL)

Children's cancer symptoms: The bitter nature of cancer

It is worse, it is like a shark biting me all over!

There are sometimes when I just feel like crap, and, you know, I just...Sometimes I just feel like I wish it was all over you know? But not very often.

I just didn't care really how I got wherever I got (because of a severe headache and extreme fatigue). Like, I mean I wanted my mom to like carry me because I couldn't walk and I just...I just kinda gave up like I was like, “I don't care, I just want to go home and lay down” you know?

These comments expressed by the children with cancer reinforced how much the cancer symptoms contributed to the suffering nature of cancer. While children and families consistently emphasized that there were many “rough spots” to cancer that made life more difficult, it was certain that they would always refer to the cancer symptoms in the telling of their stories. The symptoms were a very big part of the cancer experience for the children and their families, as one adolescent diagnosed with ALL noted:

Symptoms are the big part of cancer! Well because there's a lot of symptoms. So I guess and I feel that most of the time, at least once a day, I have a headache or at least once a day I feel nauseated or, you know whatever. And that really sucks. Like I've only thrown up once but...

Other cancer-related events, and life in general, just became much more difficult to bear for children and families when the children's symptoms became especially distressful. Often, the children and their families would emphasize that the symptom experiences greatly contributed to the difficulty or "hardness" of the cancer experience, affecting their quality of life. As Kleinman (1988) noted, each time a cycle of symptoms begins, the individual may lose faith in the dependability and adaptability of basic bodily processes that are necessary for his or her general sense of well-being. This held true for the children and families participating in my study.

How children experienced symptoms and symptom relief proved to be a complex phenomenon that was affected by their own perceptions as well as their families' views about symptom experiences. Children and families identified many facets to what constitutes a symptom, and what made a symptom difficult to get through. Symptoms were more than side effects (e.g., nausea) or singular physical and psychological states devoid of any context. Instead, children experienced and described their symptoms as overall feeling states based on the meanings that they assigned to them (Woodgate, 2001). When symptoms were deconstructed, it limited children's abilities to convey the impact that the symptoms had on them. As well, they found it difficult to identify what symptoms qualified as the most distressing. All symptoms were labelled as distressing, although the context in which they occurred and the meanings assigned to them varied. A commonly-held sentiment expressed by the children that was congruent with their overall view of cancer was that "they (symptoms) were all bad cause they all sucked!" and that "all symptoms of cancer are all bad and quite painful." Part of the difficulty in having to pick and choose the worse symptom experiences was that children and their families viewed all the symptoms as being intertwined (Woodgate, 2001; Woodgate & Degner, 2003b).

Although children and families learned to adjust or adapt to symptoms, they reinforced that one never "totally gets used to them" (Woodgate, 2001; Woodgate & Degner, 2003b). Children and families stressed that there was a clear difference between learning to adjust versus getting used to cancer and its symptoms:

You don't really get used to it (cancer). You really don't get used to it, you adapt to it. You don't really get used to it. I mean you have to adapt because if you don't you're going to die. I don't think there's any way that you can totally prepare cause there is no actual guarantees. (16-year-old male, osteogenic sarcoma)

I think you learn to adjust to it (cancer and its symptoms). I don't think you ever get used to it really. You learn to adjust to it, but get used to it is kind of like you sort of do but its kind of like I felt that we got used to it sort of and then, we stopped and then it started all over again. (17-year-old male, Hodgkins lymphoma)

Like you adjust to it, but you're not really used to it and you don't really feel like doing it (cancer treatment) but you know you have to. (eight-year-old sister)

A new routine was established by families in order to deal with the uncertainties and lack of control that resulted from the cancer and its symptoms. However, the new routine was very fragile at times and, even with the new routine, families and children still found it very difficult to deal with the symptoms.

Children and families wanted nurses and other professionals to acknowledge that it was unrealistic to even consider that children and families could ever become "totally used to the cancer and its symptoms." This was because the suffering experienced by them always remained with them; the hurt would always be there to some degree:

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 everyday! It is a very different kind of routine. (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? (father)

Mostly, I live with it (cancer), but I don't like it. And I'd rather not...I live with it. (15-year-old male, non-Hodgkins lymphoma)

You learn to cope with it, but you don't necessarily enjoy it. (mother)

Children especially found it "hard" to adjust or adapt to the cancer trajectory when symptoms became overwhelming and uncontrollable. They had a more difficult time justifying the commonly-held belief of families that, although unpleasant, short-term pain was necessary for the long-term gain of beating the cancer (Woodgate, 2001; Woodgate & Degner, 2003b). During these times, some children would question whether or not to continue on with their present treatment because the symptoms caused so much distress and suffering.

Parents also found it difficult to accept those symptoms that became continuous and overwhelming in their child. The increased suffering experienced by the child only led to more anguish and distress in parents. It was especially difficult for parents because they felt that they could not do anything to help their child. Feelings of helplessness pervaded parents in relation to them not being able to contain their child's symptoms. Fathers especially felt helpless and ineffectual in providing care:

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 in to 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 is now, "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)

However, although parents wanted their children to be psychologically and physically comfortable, having their child survive cancer took priority over reducing their child's short-term suffering (Woodgate, 2001; Woodgate & Degner 2003b). The "toughest treatment" and the "torture" associated with it, as one mother noted, was still "the best treatment if it worked."

Siblings not only experienced a sense of helplessness in relation to their ill brother or sister, but also a sense of isolation

from being minimally involved in the ill child's care. While children were part of the "family of suffering," they were often not considered to be part of the "circle of caring," and hence feelings of extreme sadness were experienced by them.

"Cancer is very painful inside. Lonely. Very sad. It is the symptoms..." (10-year-old brother).

It sort of helps

In addition to the sadness and helplessness, an attitude of "it sort of helps" contributed to the children's and families' suffering (Woodgate, 2001; Woodgate & Degner, 2003b). "It sort of helps" was in reference to the type of relief that children experienced from symptom management. For the most part, children and their families expressed that achieving complete symptom relief was not the norm. It was not uncommon for children, parents, and siblings to express phrases such as "sort of," "a little less," "a little," and "I guess" when referring to management of the children's symptoms. Compounding the children's and families' suffering was that they believed some degree of unresolved symptom distress was inevitable.

Accordingly, seeking out help was not always warranted in a family's opinion, especially in those circumstances where the child was experiencing mild to moderate symptom distress. Instead, families and children tried to incorporate the unrelieved symptom experiences into their everyday lives by viewing the symptoms as a normal part of daily life. Such symptom experiences, especially those that occurred on a rather continual basis (e.g., a headache of moderate intensity), were labelled by children and families as "everyday" symptom experiences (Woodgate, 2001). Not surprisingly, children and families rarely talked to nurses about their experiences with "everyday" symptoms. Like the sadness and suffering, such symptoms were hidden from others. Even when children and their parents talked about these symptoms, there was a tendency for them to downplay the intensity of distress resulting from them. Words or phrases such as "not too bad" and "tolerable" were used when they talked about them. While children were able to function fairly well, such symptom experiences did eventually wear them down.

Although children and families accepted that achieving complete symptom relief was not always possible, and so they did not seek out help, they themselves tried anything and everything to reduce the degree of symptom distress experienced by the children. Children and families often adopted a "trial and error" approach in trying to minimize the symptom distress. The trial and error approach included children figuring out and using the most effectual self-initiated strategies to relieve their symptom distress:

They just told me to take Tylenol (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 (headaches), 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). (16-year-old female, ALL)

Well I'd be very focused, very interested so I would probably be all right...Computers are a big thing, a big help. (15-year-old male, Hodgkins lymphoma)

My brain just kept on thinking "just to get rid of this pain." And it helped me not think about dying. Yeah, the medicine and also my brain. It sends its own medicine down. Yeah. It helped that other medicine. (four-and-a-half-year-old female, neuroblastoma)

Unfortunately, children's self-initiated strategies were not always recognized or known by nurses and others, and therefore, children could not be encouraged to use them. This lack of knowing in others was attributed to children rarely sharing their thoughts with nurses about their use of self-initiated strategies. Except for engaging in discussion about the self-initiated strategies that helped them to deal with painful procedures (e.g., bone marrow aspirations), it appeared that there was no joint effort to promote the use of self-initiated strategies.

Understandably, the more experience children and families had with the cancer symptoms, the more successful they were in reducing the degree of symptom distress. However, even the most experienced child or family had problems reducing the symptom distress. Rest or sleep became the only option in helping children get through those cancer symptoms that children and families were unable to contain. While rest or sleep did not resolve the symptom distress or remove symptoms, it allowed the children, for brief periods, not to feel anything. Moreover, it gave the children a break from having to deal with the cancer and life in general:

Sleep, for everything, as you don't feel it any more! Sleep doesn't take away the crappy feeling, it is just that the time you sleep, you don't feel crappy or don't feel anything. Sleep is good because even though you miss out on things, if you were awake you still would miss out on things because you feel so crappy! (14-year-old female with ALL)

In the end, a sense of helplessness remained with children and families, as evidenced by comments such as, "there is not much you can do" or "nothing really helps."

Maintaining a sense of spirit: Keeping the spirit alive!

While children and families spoke of their need to fight the cancer, they had another battle to conquer: the need to maintain a sense of spirit within the individual and the family. Comments made by families such as, "at least John still has his spirit with him" or "it is important not to give up the spirit" reinforced the importance of the need to maintain the spirit. Maintaining some sense of spirit involved the children's and families' ability to not let the cancer and its symptoms get the better of them, or more specifically, not letting the cancer destroy their spirit (Woodgate, 2001; Woodgate & Degner, 2003a). No matter how rough the times became, it was important for children's and families' spirit not to be totally overwhelmed by the cancer symptom experiences because the spirit was what helped children and families to endure the suffering nature of cancer. As unbearable as the cancer became at times for children and their families, they nonetheless persevered. Families attributed their perseverance to the spirit within the child and family. In fact, during times of increased physical, psychological, or emotional stress, such as periods of uncontrollable symptom experiences, it was especially important to maintain some sense of spirit:

It just amazes me, the depth of it you know...Like you think of her personality and how you have raised her and that. You hope that if you are faced with something so awful as

a life-threatening disease that THEY CAN FIGHT AND MAINTAIN SOME SENSE OF SPIRIT! But the, the depth of her courage was really quite amazing, quite amazing. I do not think that I could hope to expect that from too many people. You know what I mean. And for such a young person you know. (mother)

Although families had difficulty articulating what they meant by “spirit,” they nonetheless viewed the spirit as one of the many components that made the individual or family unique; that made them who they were. “Cathy was always a beautiful child. She was beautiful in every way, her looks, her hair, her spirit, her physical prowess, and so on.” (father)

The spirit was equated with one’s will to live and a “zest” for life. It was the individual’s inner voice telling him/her to fight on and not to give in, despite all the bad things related to cancer. To have a spirit meant the person was still fighting and still had meaning in their life and could use that meaning to get through the cancer symptom trajectory. Often, children who maintained their sense of spirit were described as “fighters”:

He is a fighter and knows he has a job to do! (mother)

Peter wants to go out fighting...(mother)

I always knew you were a fighter...good for you ! (nurse to an adolescent child)

Even the children described themselves as fighters and stressed the importance of being spirited, “I’m pretty bubbly. Like I know that I, I feel like I have to be bubbly or else my family won’t be able to be really positive, you know? I have to be positive so that my family could be positive.” (16-year-old female, ALL)

Nurturing the spirit

Keeping the spirit alive involved children nurturing and protecting it. Just as they cared for the child’s body, they had to care for the “spirit within.” Maintaining some sense of spirit involved the children and families using the following strategies: 1) Coming to know what to expect; 2) Holding on to the belief that you will get through; 3) Making some sense out of a “bad” situation; 4) Taking one day at a time; 5) Being present; 6) Taking care; 7) Taking time for yourself; and 8) Cherishing the special moments (Woodgate, 2001; Woodgate & Degner, 2003a). These strategies could be used directly by the individual to help maintain: his or her sense of spirit; the spirit in others; or spirit of the family unit. Both child and adult participants relied on the same strategies, in spite of developmental differences. This makes sense, considering the use of the strategies affected the individual’s way of being in the world and, regardless of age, the desired way of being was to be able to “really” live life, maintain one’s sense of self, and feel connected to family and friends. In effect, a way of being in the world could be equated with the need to feel human, a need shared by young and old alike.

Coming to know what to expect

This strategy refers to the children and families discovering or increasing and developing one’s sense of knowing and awareness within the world in which they lived. In coming to know what to expect, children and their families had to seek out information about the unknowns, and did so in a variety of ways. Knowing what to expect was necessary in order for children and families to be able to better deal with all events

related to the cancer. It helped to prepare them for the rough times associated with the symptoms. Not knowing only resulted in more uncertainty in their lives, as this mother noted:

Unpredicted symptoms, yeah, are big things cause I don’t know where the hell they are coming from, like what is this? Symptoms are important. Yeah! (Pause) To me symptoms are like signs of trouble. I mean (pause) something is happening (long pause) and...

But being prepared for the rough times helped to protect their sense of spirit. Knowing what to expect was a way to inform the spirit.

Holding on to the belief that you’ll get through it

It means to believe that something’s gonna be all right, even if like something was really bad. (10-year-old sibling)

As reinforced by this sibling, “holding on to the belief...” refers to the children and families developing and maintaining an overall faith that they were going to get through all the rough times of the cancer symptom trajectory. It involved the children and their families believing that no matter how bad things were or became, there was a light at the end of the tunnel. In the case of the symptom experiences, this meant believing that the pain would not last forever. Believing there was a light at the end of the tunnel helped to protect the children and families from becoming too discouraged or dispirited.

Making some sense out of a “bad” situation

This strategy refers to the children and their families trying to find reason and give meaning to having to accept and live with cancer in their lives and get through the painful symptom experiences. Making sense out of a horrible situation, or putting the cancer in its proper place, was necessary if they hoped to move forward. Uncovering or discovering meanings helped children and their families to maintain a purpose in life and, accordingly, further helped to protect and maintain their sense of spirit. Many families rationalized that cancer became a part of their lives because they had the fortitude to get through all the suffering:

Well the reason why we got, I got cancer was because we are very strong and we are good people. (11-year-old female, ALL)

In many ways, if God forbid that to happen to anyone, I think in a lot of ways we are the ideal couple for it to happen to, however crazy that sounds. (father)

Another common belief was that symptom distress was a necessary part of getting through the cancer experience and beating the cancer (Woodgate 2001; Woodgate and Degner, 2003b). This belief was consistently reinforced by statements such as, “short-term pain for long-term gain” or “it comes along with the territory” or “getting better but feeling worse.” Expecting unrelieved symptoms reinforced how much the children and families equated cancer with suffering, and was tied into the meaning of cancer and its connection with dying. That is, the very notion that one could die from cancer justified

the suffering that resulted from symptoms because it was a way to avoid the ultimate suffering experience: the death of a child. For this reason, children and their families returned dutifully to the clinic to receive their treatments (Woodgate 2001). Suffering was seen to be essential to fighting and beating cancer:

You can't breeze through it. If you breeze through it, other families say, 'if you breeze through it, you're more likely to relapse.' The sicker you are, the better your chances 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. (mother)

Yes, she is going to be sick, but if we want her to get better, we have to do it. (father)

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. (seven-year-old sister)

However, acceptance of symptoms' experiences was dependent on whether or not the symptoms were short-term or temporary in nature versus long-term or permanent. Children and families had less difficulty making sense out of symptoms that were considered relatively short-term and did not lead to permanent damage. In contrast, parents and children found it much more difficult to justify the suffering if it meant that treatment would result in permanent or long-term disabling symptoms.

Taking one day at a time

This strategy refers to children and their families having to live life more in the present, or in the very moment, as reinforced by one adolescent:

I think just to like don't think about the future but take it one step at a time and don't worry about what's going to happen like a week from now, like just worry about today and just try and make it the best you can.

Taking one day at a time involved focusing all their energies and efforts in getting through the cancer symptom trajectory day by day. Taking one day at a time gave children and their families time to deal with all the roughness of the cancer experience, including the uncertainty of not being able to plan, all the emotions, extra work, and the potential losses that could occur because of cancer. Taking one day at time helped to prevent the sense of spirit from becoming too overwhelmed. It helped them to deal with all the treatment and the adverse effects. "It was the chemo we were riding through like trying to get through, and step-by-step, step-by-step, page-by-page." (mother) Taking it slow was the only way to get through it. During those times of extreme symptom distress, it was necessary to take it minute by minute.

Being present for those you love

This strategy referred to children's and their families' needs about "being with" and "being there" for others, as well as them "just being." It referred to maintaining a presence with oneself, as well as maintaining a presence with others. The need to be with, be there, and just be, was important to feeling connected, as opposed to feeling alone or abandoned in the world.

"Being with" referred to the children and their families being around individuals who were significant to them. Being with others not only helped children and their families develop and maintain a sense of being in the world, but more to the point brought a sense of pleasure or enjoyment into their lives. Associated with "being with" was "being there" for others. This involved parents, children, and siblings needing to be there for one another in order to help them get through the cancer symptom trajectory in a safe and comforting manner. For the children, the most important and valued way that a member of their family could "be there" for them was staying close to them when they were not feeling well:

Yeah, just being there and (pause) my parents were, they always stay over night with me if I'm in the hospital and if I want to talk to them I can. (16-year-old female with ALL)

And if she is tired, she'll come home (from school) and then her sister will be there for her...so with that system we've been able to cover her off in the afternoon and a few times when she hasn't been feeling well I have stayed home with her. (mother)

"Just being" was related to the individual maintaining some sense of presence in the world and feeling needed and loved. "Being with" and "being there" helped to achieve a sense of "just being." "Just being" was important, as it helped the individual feel alive, confirming that they still were part of the world. It helped the individual feel connected with others, as well as helping the individual feel connected to his/her own inner self.

Taking care

This strategy refers to the need of the children, siblings, and parents to try to help ensure an environment that was physically and psychologically safe for each of their family members. It involved doing whatever one could do to prevent any distress or harm happening to the spirits of the ill children, as well as every other family member. "Taking care" involved focusing on protecting and comforting the spirit. When protecting the spirit, it was important for parents and siblings to watch over the ill child for any impending and additional distress or harm. Protecting also involved containing the symptoms, as reinforced by one mother:

Then you watch, you ask and you watch and then you see a mistake and then you see another mistake and ... So that's how we protect her by limiting a procedure to only what is necessary even if it's painful. (pause) If you are going to draw blood, take it all at once, don't ask in the afternoon again to take some more like before she had her line. You know they would think nothing about ordering blood for one reason in the morning and then for a different reason in the afternoon and the third reason in the evening. So we try and reduce how much pain and make sure that whatever medications are being given are given correctly.

Families also focused on finding ways that would make the children as comfortable as possible. Any act that made the children feel secure and relaxed was explored. This included interventions that were specifically used to relieve any symptom distress.

Taking time for yourself

This involves children, other family members, and the family unit finding time for themselves amongst or in between fighting the cancer symptoms. It included anything that was directed at conserving, preserving, or revitalizing the spirit and involved the families or individuals doing things that they liked to do. Taking time for yourself meant doing something that was not always directed at fighting the cancer, but was focused on pleasing the self and finding time and personal space for one's sense of self. "It used to be my whole life...but you can't make it the only thing to do or else you'll lose yourself. You have to add other things." (14-year-old female, ALL). Taking time for yourself helped to make day-to-day life more bearable and served to give the spirit a time to rest from the cancer, even if it was only temporary.

Cherishing the special moments

This strategy involved the children and families learning to appreciate and celebrate, as well as hold on to those moments in life that they referred to as "special." The special moments were often perceived to be small miracles or small successes of life, such as the ill child for the first time in a long time being able to ride his or her bike down the street. Cherishing the special moments involved families learning to sit back and appreciate what was really important to them. Understandably, it often involved those moments that made family members feel closer to one another, as was reinforced by this mother's comment:

I mean you have to live...You know I cherish every moment with those kids now. And like we joke around a lot when we're home together and they (her children) don't want to get up and go to school. Like I just make my rounds jumping from bed to bed to get in with them and they just love it and we sit and talk for hours you know. I don't know, I think we're closer. And before when John (child with cancer) was younger we never had the talks. Like he was too young he didn't really, he just wanted to play with you and my girls were very, "come lay with us, let's talk, let's talk girl talk." But now, just before I went to Toronto, he called me into his room and said "Mom come lay with me and let's have a talk." And so I did and we were there for half an hour and had our little mother-son talk and it was quite good.

You have to do what you have to do: Doing whatever it takes

While all the children, parents, siblings, and families relied on "maintaining a sense of spirit" strategies to keep their spirits alive, they nonetheless all had their own unique way to approach the strategies. For example, for one father, coming to know involved getting factual information from research papers. In contrast, his wife valued the information offered to her from other parents. In short, families expressed it was important "to find the best system," "to do what you have to do," and "to do what you can and that's all that you can do." Whatever it took to get them through was what mattered. One adolescent with cancer reinforced that, because children and their families really had no choice in whether or not to go through the cancer symptom course, all that one could really do was to try their very best, if one hoped to succeed. "You have no choice. Kinda like you're dammed if you do and you're dammed if you don't. You know. You might as well do the best that you can."

Children and families all reinforced that the cancer symptom experience is different for all. Hence, children and their families felt uncomfortable at times in giving advice to others experiencing cancer. Children and their families believed that each individual and

family were the experts in their own journey of getting through the cancer symptom trajectory. Children and their families wanted others to know that families did the best they could and that whatever way they approached the cancer symptom trajectory was the right way or, more importantly, not a wrong way. That is, children and families felt it was important not to judge or be judged:

And another thing would be I guess no one's perfect. Do not walk into thinking "that the kids will judge you." Cause that's what I thought. But like I said, no one judged me. I have helped out a lot of kids who were worse than me, so I liked that fact. I'd get along with a lot of them. (17-year-old male, osteogenic sarcoma)

Nursing the spirit: Nursing's role

Although children and families spoke to the many ways that nurses helped them to maintain their sense of spirit, such as information-sharing, providing practical resources, and ensuring safe care, it was the nurses' ability to care in a gentle manner that families stressed was the key to nurturing the spirit. "Gentle caring," as it was referred to by children and families, involved the nurses approaching children and families in a manner that conveyed respect, kindness, concern, and trust. For one mother, the "gentle caring" was experienced when a nurse offered her a cup of tea:

Well I remember because it was (pause) it was just before Christmas time so you are spending Christmas at the hospital basically. Christmas Eve she had leukemia. I just remember one year she (the nurse) offered us tea, I think it was like the first or second night, just you know "would you like some tea?" And it was so nice. That little, you know kindness. There was just that little connection.

"Gentle caring" embodied the spirit of caring and involved caring from the heart, as this father had reinforced, "I don't know. (pause) You can tell who is putting some heart in their work and who is there just for the money. You can really tell who really cares and who you know. (pause) I think the nurses do a good job."

Also critical to the process of "gentle caring" was the nurses' recognition and acceptance of integrating the following strategies into their plans of care: *being present, making us (i.e., the child and family) laugh, going that extra mile, accepting us, and conveying hope.* "Being present" involved nurses being there for the children and families when it really mattered or counted, as is evident by the following comments:

There is this one nurse in the recovery room and her name is Ann and she said that anytime she is at work and Cathy is going to the operating room, she would go in with her and she did that the times previously and now this time and she is always there when Cathy is waking up, so that is good. (mother)

I don't remember a lot of being in the hospital, I don't remember much of it. Like I remember one night, I don't know where my mom was, I think she was driving my dad home and then she was coming back to stay the night and I couldn't sleep because she wasn't there and stuff like that. And I remember one of my nurses, um I think her name was like Rachelle or something like that. She came in and sat with me until I fell asleep. (16-year-old female, ALL)

"Making us laugh" involved the nurses bringing some laughter into the children's and families' lives. Having a sense of humour was especially valued and was considered an integral part of the caring connection for children. However, how nurses conveyed their humour made a difference in that the humour had to be

genuine as well as gentle or not rough. Children and families did not appreciate humour that demonstrated little respect for them.

“Going that extra mile” involved nurses going out of their way to make the children and families feel safe and comfortable. The care provided went way beyond the basics:

I mean Linda (the nurse clinician) will come up to the ward to take Carla's IV out whenever Carla is in the hospital cause Linda knows it's important. Carla had a bad experience in the hospital where one nurse ripped it out, left it lying there, and she saw the blood and she just freaked out. To this day, she is terrified of IVs and she never used to be...But she will let Linda take out her IVs. (mother)

Related to “going that extra mile” was the ability for nurses to make things a little easier for children and families. Children and families also valued the nurses doing special things for them. On reflection, the children would have many stories of all the special things that nurses had done for them. When they would retell their stories, they did so in a loving, caring, content manner:

She (referring to a nurse on the hospital unit), she brought me a “Special Moments” picture frame. And that's like eight bucks. I couldn't believe she, you know, she went and bought something for me. So I bought her a cup with some jewellery in it. And then um, what else, she brought me a purse, like a really glamorous, like a really nice purse from Eatons and it was really nice because I had a wedding to go to. And it was, I don't know she's just a real sweet lady. (16-year-old female, ALL)

“Accepting us” involved the nurses acknowledging that each family is unique and that they have their own unique approach to dealing with the cancer. It was important to families that nurses did not judge them negatively because of their uniqueness and different ways of coping.

Lastly, and perhaps the most important quality of “gentle caring” was the nurses' ability to instill some degree or sense of hope in the children and families; hope that conveyed to the children and families that they would be able to get through the cancer experience, regardless of the final outcome.

Gentle caring brought the children, families, and nurses, as well as other professionals and non-professionals, closer together; it helped them to feel connected. In fact, many of the children and families referred to the nurses and other caregivers as members of their family or simply as their “second family.” The nurses were also referred to as “living angels” by some of the families. Although children and families did not like having to spend their time in the hospital, hospitalization was made a lot easier when a strong connection existed between them and their nurses. As one parent revealed:

Cancer is a nightmare too. And you know you find too, I mean if it wouldn't have been for Linda (nurse clinician), I mean Linda has been, I mean just to be able to connect with a person like Linda has been the most important thing in the world to us, I think. You know she's really just been wonderful. Ann (their child) trusts her. It's so important. It's essential. I mean I could say that's the most important thing to have one person for a child to be able to trust, having some consistency...and her temperament, she's just amazing. Um, you know calm and clear thinking and not panicked and you know!

The children, regardless of age, also expressed how the nurses made the hospital stay not as distant or foreign, “The nurses spoil me. When we do the overnights, they play with me, they like me.” (four-and-a-half-year-old female, ALL).

A testament to the bond that developed between specific nurses and children was that, to some extent, children always looked forward to coming to the clinic or the hospital, despite knowing that they were going to undergo painful procedures and treatments. They needed to see and be with their “second family.”

It really helps!

Through the process of “gentle caring,” the children's nurses helped to maintain and nurture their spirit. As oncology nurses, we must continue to make every effort to nurture children and families. Most important with respect to containing the children's symptoms is encouraging the attitude of “it really helps” in children and families (Woodgate, 2001; Woodgate & Degner, 2003b). Nurses need to teach and encourage children and their families that an “it sort of helps” attitude to cancer-symptom management is not acceptable. Successful care of children with cancer requires a comprehensive assessment; all symptoms warrant our attention, regardless of the degree of distress that results from the symptoms. In understanding and relieving a child's suffering, Thurston and Ryan (1996) point to the importance of being mindful observers and respectful listeners when interacting with children. We need to be vigilant in being mindful observers and respectful listeners.

The invincible spirit: A deeper joy

Despite the suffering, and perhaps maybe because of the suffering, children and their families expressed that not everything about the cancer experience was, so to speak, “bad.” They reinforced that along with the “bad” came the “good.” To most families, cancer was more than a “bitter” experience, it was a “bittersweet” experience. That is, amongst the layers of suffering were layers of joy, as reinforced in the following comments:

Yeah. Well, well a lot of bad things were happening and a lot of good things happened in those years. I'm working on my fourth year of remission. (18-year-old male, ALL)

It is an experience that we wouldn't want anybody else to go through (pause) but with the son that we had that went through his cancer, it was a good experience. (mother)

You wouldn't wish that on anybody, but the point is that our (pause) experience was good you know, the whole thing is I mean you can't even say it is finished because he is only in remission. I would say it was a positive experience in the way for only in the way that everything went well for us. Everything turned out right from bad at the start to good at the end and even if everything in between was not always good, we had (pause) because you had to do it anyways. We had fun, we had a good time, we made friends and everything was good that way. (father)

Some of it is pretty cool (in reference to getting things and people being kinder when he felt sick) and some of it is pretty bad (in reference to feeling sick)! (11-year-old male, ALL)

You don't get to have fun cause you're not feeling well. But I had lots of fun. (four-and-a-half-year-old female, neuroblastoma)

It is just finding some joy in the middle of it and maybe some boredom or some (pause) routine or control of your day. (mother)

The bad stuff, how nauseated I was. The good stuff, all the kind nurses and all the support from our church. (15-year-old non-Hodgkins lymphoma)

This phenomenon of perceiving that something “good” could exist in something so “bad” reinforced the resilient nature of the children and families. Even in those situations where children had a poor chance of surviving, it was possible to find some good in the situation, as was evident by the following exchange that I had with a brother whose sister’s prognosis was not very good:

Researcher: So you think cancer has two sides? There is a dark side and what would you call the other side?

Sibling (13-year-old brother): Joyful.

Researcher: Joyful okay. So what’s the dark side?

Sibling: Having some, having the person that has cancer suffer and having pains and aches and having to go through it 24 hours a day, seven days a week.

Researcher: And what’s the joyful side?

Sibling: Either having them die or survive.

Researcher: And when you say die, what’s joyful about that?

Sibling: Like it’s, like a reward. That, cause if you really suffer a lot...

It was important not only to recognize that there were some good things about experiencing cancer, but it was also important to let others know about the good things and to try to concentrate on the good things, as one 11-year-old noted in answering the question, “Okay, if one of your friends got diagnosed with cancer, what would you tell them?”:

That you are going to be okay and (pause) don’t think of the bad things, think of the good.

Summary

Despite the finding that each child and family experienced cancer in their own unique way, they all shared the need to maintain a sense of spirit. Just as the suffering united the families, so too did their sense of spirit. Talk of the spirit is not foreign in the pediatric oncology literature. Statements such as “the children’s responses suggest a resolute spirit that accepts cancer and goes on with life” (Hockenberry-Eaton & Minick, 1994, p.1030) are dispersed throughout the literature and reinforce the importance of the spirit in children and families experiencing childhood cancer. Yet despite this, the spirit in children with cancer has received minimal attention from researchers (Woodgate, 2001). The focus has been solely directed at studying

the sense of self in children. In fact, some would even argue that the spirit can be equated with one’s sense of self. There is also the feeling that the spirit is something that does not exist. How could it be “real” when it has never been seen or even measured in research? However, just because something cannot be seen or measured, does not mean that it does not exist. As was revealed by the families participating in my study, there was a spirit within them that got them through the cancer experience, especially during times of increased symptom distress. Research that seeks to describe the “spirit within” of children and families who are going through many of life’s challenges is warranted. This includes understanding the conceptualization of the spirit from the perspectives of children experiencing illness. Although understanding spirituality and spiritual distress is beginning to be studied in children experiencing illness (Pehler, 1997), children’s perspectives are usually not accessed. By developing a deeper understanding of the “spirit within,” oncology nurses and other professionals caring for children with cancer may be able to provide more sensitive and comprehensive care. They will have a better understanding to nursing the spirit.

So to conclude, let us as oncology nurses continue to help families maintain their sense of spirit. And yes, let us maintain a sense of spirit within ourselves. We could learn from the families we care for with respect to how to nurture our spirits and the spirits of those close to us. *Taking care, holding on to the belief, taking one day at a time*, and so on, are all strategies that we could learn to incorporate more frequently into our daily lives. May a part of the spirits of those we care for be with us and live on in us forever, because their lingering spirits are sources of hope and strength, as this mother reinforced:

Oh, there are reminders of Tommy (her deceased child) in the house...it is strange. Like Lyn (the child’s sister) found his “Slurpee” spoon in the freezer the other night. She was OK with it. At first when Tommy died, it was tough going for her. But now she is OK. The kids are busy, but are able to talk about Tommy. He’ll always be with them (his siblings). He is still the hero and the fight is still going on! THE ESSENCE OF HIS SPIRIT WILL ALWAYS BE WITH ME, WILL ALWAYS BE THERE. The other day I felt him holding my hand in church. And when we went fishing with the “A” family (another cancer family) it was the first time without him, it was strange for all of us! But it was a sunny day and we all said “Tommy must have been responsible!” 🍀

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