THE IMPACT OF CHILDHOOD CANCER ON THE FAMILY: A QUALITATIVE ANALYSIS OF STRAINS, RESOURCES, AND COPING BEHAVIORS

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SUMMARY

Clinical research has led to tremendous improvements in treatment efficacy for most childhood cancers; overall 5-year survival is now greater than 75%. Long-term consequences of cure (i.e. adverse medical and psychosocial effects) have only recently begun to emerge as a primary focus of clinical research, including studies of health-related quality of life among survivors. Usually lacking in such efforts, however, is consideration of the impact of the cancer experience on the family, and the influence that the family's response to cancer has on quality of life in the child. From this qualitative analysis of seven focus groups with 45 parents of children a year or more out of cancer treatment, we report those aspects of a child's cancer diagnosis, treatment, and recovery that parents perceived as particularly difficult for their family, and the resources and coping behaviors parents perceived as helpful to their family in dealing with and managing the cancer experience. Using the Family Adjustment and Adaptation Response theoretical model to organize the data, the domains of strains and resources were delineated into themes and sub-themes related to the cancer, child, family, health-care system, and community. Within a third domain, coping, sub-themes were identified within the themes of appraisal-focused, problem-focused, and emotion-focused coping behaviors. Integration of this information should serve to improve future studies of health-related quality of life among children who survive cancer. Copyright © 2003 John Wiley & Sons, Ltd.

INTRODUCTION

Cancer is generally thought of as a disease of adults, especially the elderly, but approximately 12 400 children and adolescents are diagnosed with a malignant neoplasm each year in the United States (Ries *et al.*, 1999), and many more children experience tumors that are not considered pathologically malignant but require clinical intervention (Gurney *et al.*, 1999; Dahlin and Unni, 1986). Usually not appreciated is the fact that the highest rates of childhood cancer occur during the first year of life when the infant's developmental processes are advancing rapidly (Gurney *et al.*, 1995; Reaman and Bleyer, 2002), and the parents are often in the early stages of their family life cycle. Childhood cancer is comprised of a wide variety of malignant diseases, each representing different epidemiologic characteristics, biological features, treatment approaches, and survival probabilities (Pizzo and Poplack, 2002). Most childhood cancers, however, share an important common feature: the treatment course can be long, painful, and dangerous. Accordingly, the afflicted child's family, as well as the child, is exposed to a great deal of disruption and distress throughout the cancer experience.

Clinical research leading to more effective treatment has realized many successes in improving cancer survival rates, particularly for those with acute lymphoblastic leukemia, the most common malignancy of childhood (Greenlee

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et al., 2000; Ries et al., 1999). Comprehensive scientific knowledge related to the long-term psychosocial consequences of childhood cancer is less available (Crom et al., 1999). Such information is essential for two primary reasons. First, when considering treatment options that may have only minimal survival differences, outcomes other than survival and relapse, such as adverse medical and psychosocial late effects, are important factors that should be included in the decision-making processes. Second, understanding common challenges that arise after the difficult cancer experience may lead to better strategies and interventions for anticipating and mitigating the adverse impact of cancer on the child and his or her family. Research specific to quality-of-life outcomes among childhood cancer survivors has been advancing, albeit slowly (Crom et al., 1999; Elkin et al., 1997; Eiser et al., 2000; Fuemmeler et al., 2002; Hobbie et al., 2000; Meister and Meadows, 1993; Stuber et al., 1996; Weigers et al., 1998; Zebrack and Chesler, 2002). Unfortunately, most studies of health-related quality of life in children who survive cancer do not account for the influences of family adjustment and adaptation.

The family's ability to cope with the multiple sources of stress and uncertainty associated with their child's cancer diagnosis and treatment is likely to affect a child's quality of life. From a family systems perspective, what happens to one family member affects the other members. In turn, how a family responds to adversity influences the child's responses and functioning, in a circular sequence of effects (Patterson and Garwick, 1994). For example, a bidirectional effect has been observed in the correlations between parental psychopathology and psychosocial dysfunction in child cancer survivors (Brown et al., 1993). Similarly, others focusing on the negative impact of this traumatic experience long after treatment and remission have reported correlations between post-traumatic stress disorder (PTSD) symptoms in child survivors of cancer and PTSD symptoms in their parents (Barkat et al., 1997; Kazak et al., 1997; Van Dongen-Melman et al., 1995).

Family responses, in addition to adverse effects, may also be positive and adaptive, and can potentially buffer or protect the child and other family members from negative psychosocial sequelae. Effective parental coping, for example, was found to protect children from feeling hopeless following treatment for cancer (Blotcky et al., 1985). To adequately study and understand the full range of quality of life outcomes in childhood cancer survivors, it is important to consider parent and family responses, both positive and negative. Understanding the relative balance between perceived positive and negative aspects of the parental cancer experience may help explain how variability in family responses potentially affects the quality of life of childhood cancer survivors.

In reviewing the broad, diffuse literature describing the effects of childhood cancer on families, we were unable to identify a reliable and valid measure that systematically assessed the nature of the negative and positive aspects of a child's cancer experience on families. Hence, to aid us in our research on psychosocial outcomes of childhood cancer survivors, the specific aims of this qualitative study were to gain knowledge on: (1) what aspects of a child's cancer diagnosis, treatment, and recovery do parents perceive as particularly difficult for their family? and (2) what do parents perceive as helpful to their family in dealing with and managing the cancer experience? Our longer-term goal was to use the information learned in this analysis to identify domains and themes for development of a structured questionnaire to assess variability in family responses to a child's cancer, which could then be used in conjunction with quality-of-life studies among childhood cancer survivors. In this report, we present the results of our qualitative analysis of family impact of childhood cancer.

METHODS

An inductive, qualitative method was used to address our research questions. Seven focus groups were conducted with parents of 26 children who had successfully completed their cancer treatment. Each focus group had five to nine participants and lasted for approximately 2 h. Criteria for inclusion as a focus group participant were: (1) parent of a child who had completed cancer treatment at least 1 year before the focus group, (2) child was still alive, (3) child was not currently undergoing treatment for a recurrence of cancer, and (4) family lived within 100 miles of the site for the focus groups. The informed consent process and all study procedures were approved by the Human Subjects Institutional Review Board of the University of Minnesota.

Theoretical model

This inquiry was guided by a theoretical model that has emerged from studies of families adapting to other stressful life experiences, including chronic illnesses—the family adjustment and adaptation response (FAAR) model (Patterson, 1988). In the FAAR model, individual and family outcomes are conceptualized as the result of a process whereby a family balances their demands (cumulative stressors and strains coming from individual, family and community sources) with family capabilities, which include resources (from individual, family and community sources) and coping behaviors (see Figure 1). This balance (i.e. ratio) of capabilities to demands is influenced by the interpretations and meanings the family gives to their circumstances. These meanings can focus on the demands or resources a family is experiencing, as well as their worldview or perspective

about life. In explicating the FAAR model, a range of sources of demands and capabilities have been described—some of which are generic and cut across most families and circumstances, such as death of a relative (stressor) or family cohesion (resource). However, many sources of demands and capabilities are specific to a given experience, such as a child's cancer diagnosis and treatment. We were interested in identifying the cancer-specific demands (stressors and strains) and capabilities (resources and coping behaviors) that could potentially explain variability in child and family adaptation (including quality of life). The FAAR model was used to guide the focus group questions and the analytic strategy used.

Sampling procedures

Potential participants for this convenience sample were identified by a nurse involved in the care and research of pediatric cancer patients at the authors' academic medical institution. Parents of 99 children who were diagnosed with cancer between 1990 and 1998 and who met the inclusion criteria were sent a letter describing the study and asking them to return a response card if they were interested in receiving information about participating in a focus group. No follow-up contacts or additional strategies were used to recruit participants. From the 99 letters sent, 49 (49.5%) response cards were returned. All parents who returned a response card were contacted by telephone to answer questions about the study and to schedule participation in a focus group if possible. Owing to scheduling conflicts, parents of only 26 of the 49 children were actually able to attend a focus group.
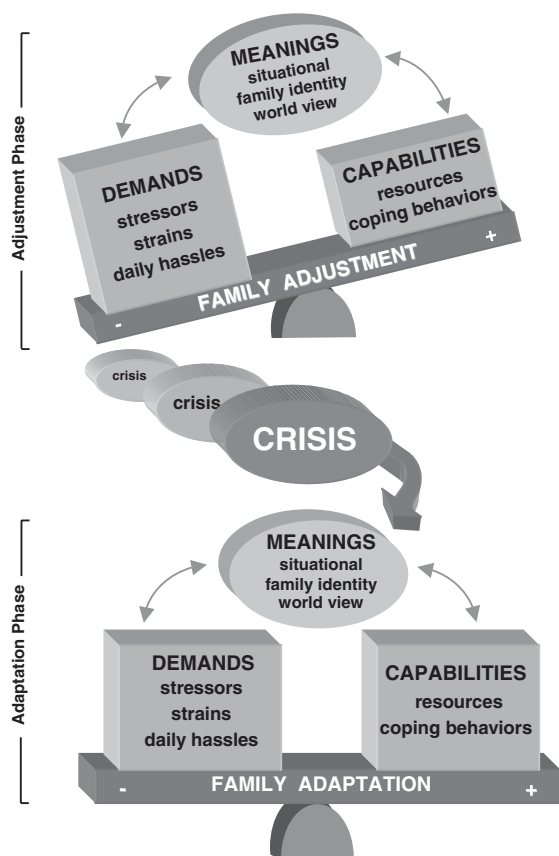
Participants

Description of participants' children with cancer. Of the 26 children, 14 (54%) were male, seven (27%) had bone cancer, six (23%) had leukemia, six (23%) had lymphoma, three (12%) had retinoblastoma, two (8%) had neuroblastoma, one (4%) had brain cancer, and one (4%) had Wilms' tumor. Their average age at diagnosis was 9.6 years (range, <1–18 years) and their average current age was 14.8 years (range, 3.8–26 years). On average, their treatment had lasted 1.2 years (range 3 months to 3.2 years). The mean length of

Figure 1. The family adjustment and adaptation response (FAAR) model.

time since the completion of treatment was 4 years (range, 1–9 years). All the children were treated with chemotherapy. Additionally, 17 (65%) had surgery, 11 (42%) received radiation, and two (8%) received a bone marrow transplantation. One child had experienced a recurrence of cancer, but was now in remission.

Parent demographic information. There were 45 parents who participated in a focus group: 19 were married couples, four were married mothers who participated without their husbands, and three were single, divorced mothers (who also were divorced at the time of their child's diagnosis and treatment). Thus, 26 family units were represented and 23 had two-parent households. The mean age of the parents was 43.6 years (range, 32–56 years). On average, each family had 2.8 children (range, 1–6 children). Fifty-eight percent of the participants were mothers, and the remaining 42% were fathers. One participant was African American, and the remainder Caucasian. Their educational levels included 13% who had completed high school, 31% with some college or a technical college degree, 40% with a 4-year college degree, and 11% with a graduate or professional degree.

Focus group procedure

All seven focus groups were conducted by a facilitator and an assistant. The facilitators were doctoral level psychologists trained in focus group methodology. The facilitators introduced themselves, discussed confidentiality, and described the purpose of the study. Study participants signed consent forms and completed one page of demographic information prior to the discussion. Participants introduced themselves and talked briefly about the composition of their families. After the introductions, the following primary questions were asked: (1) describe what happened at the time you learned about your child's diagnosis of cancer, (2) what were the difficulties you and your family have had to deal with—from the time of your child's diagnosis through the treatment phase and up to the present? (3) what has been most helpful to you and your family in managing these challenges and difficulties? (4) please describe the ways you and your family have coped with the difficulties you have described, and (5) how has the way you look at yourself, others,

or the world around you changed as a result of this experience? There were numerous follow-up questions asked, based on parents' responses, to obtain more detail about the impact of cancer on these families and their members.

Data analysis procedures

All focus groups were audiotaped and transcribed verbatim. A content analysis of the transcribed interviews was conducted using the method described by Miles and Huberman (1994) and further described by Ryan and Bernard (2000). First, the transcripts were read in their entirety several times by three members of the research team to get a sense of the whole. These initial readings of the data confirmed the utility of using the theoretical domains of the FAAR model to group the central domains. Descriptive themes and sub-themes were identified within each of the following FAAR domains: strains, resources, and coping. Within the domains of strains and resources, the responses were further organized by the source of the strain or resource—child, family, community—which is consistent with the FAAR model emphasis on individual, family, and community sources. A fourth source, the cancer itself, emerged as a distinct source of strains.

Once the themes and sub-themes within the FAAR domains were identified, the original transcripts were reviewed in their entirety to gather support for each theme and its sub-themes. This process was followed by coding at the sub-theme level. Following Krippendorff's (1980) recommendations, a complete statement or thought reflecting one of the sub-themes was coded indicating who made the statement. Themes and sub-themes were exhaustive in that they represented all statements pertaining to the impact of cancer on these families. Themes and sub-themes were also mutually exclusive in that there were clear distinctions between themes. For example, the distinction between coping and resources was based on the FAAR model distinction that resources are something a family *has* and coping is something family members *do*.

To facilitate the coding process, the software QSR NUD*IST Vivo (2000) was used to manage and organize the qualitative data. To ensure rigor and reliability of analysis, three of the seven transcripts were coded independently in their

entirety by two coders using the established coding system. Additional sub-themes emerged in this process, which were reviewed with the first author and approved. Any coding discrepancies between these two coders were resolved through discussion and consensus. The remaining four transcripts were coded by one of these two coders with no additional changes to the coding system.

Frequencies of statements at the sub-theme level were calculated. Detailed tables were used to track the extent to which each sub-theme was prevalent across the individual members of all focus groups. When multiple statements related to the same sub-theme were made by the same individual, the sub-theme was tabulated as occurring just once for that individual. Three units of analysis were examined: individual parent, family, and focus group. This is important because individual comments are often clustered when conducting focus groups. When one person brings up an issue, others in the same group are more likely to contribute on this issue. In addition, within families, it is not uncommon that one parent will be the spokesperson on a given issue and the other parent will remain silent or non-verbally agree (non-verbal communication is not recorded in the transcript). It is important to note that the themes presented in the results emerged from our analysis of what the parents *chose* to bring up during the focus groups, thus the percentages do not represent how many parents actually had a given experience, thought, or emotion reflected in a theme, but rather, how many times it naturally emerged in the discussion. This is in sharp distinction to frequency counts when every study participant is given a structured questionnaire with exactly the same items.

A final step in our analysis was to examine the ratio of perceived demands to capabilities reported by each parent. Potentially this is a way to determine the degree to which parents emphasized difficulties versus positive aspects of the cancer experience. The total number of distinct cancer, child, family, community and health-care strains mentioned by each parent was summed, as were the number of capabilities mentioned by each person, which included child, family, community and health-system resources plus coping behaviors. A ratio of capabilities to strains was calculated; hence, a number greater than 1 indicated that more capabilities than strains were mentioned by a parent.

RESULTS

The results of the qualitative analyses are presented for each of the following domains corresponding to the FAAR model: (1) cancer-related strains, (2) child strains, (3) family strains, (4) community strains, (5) child resources, (6) family resources, (7) community resources, and (8) coping behaviors.

Cancer-related strains

Within this domain, there was one overarching theme: treatment effects of the cancer. Only objective events described by parents are included in this domain; their emotional reactions to the cancer are included as part of child or family strains below. The sub-themes in this domain included: (1) sickness related to chemotherapy or radiation, infections, weakness, fatigue; (2) losing hair; (3) loss of limb or functional ability; (4) recurrent surgeries; and (5) attention deficit problems (see Table 1). In all seven focus groups, at least two cancer-related strains emerged; 84.6% of the family units identified cancer strains, and 64.4% of the individual parents reported at least one strain, suggesting the pervasiveness of remembering this source of strain. Seeing and dealing with their child's extreme sickness and fatigue during and following treatment was the most frequently mentioned aspect of this strain (by 40% of the parents). Although losing hair as a result of treatment was mentioned less frequently (by 20% of the parents), it was described with intensity and in considerable detail by those who talked about it. Several parents felt that the staff should have been more proactive in suggesting to parents that it might be a good idea to cut their children's hair before it began to fall out. Several parents talked about potential infertility and how they considered using the sperm bank, although their sons did not want to do this. In some instances, parents were not sure if the learning problems their children experienced were related to loss of cognitive functioning secondary to chemotherapy. Similarly, when attention deficit problems emerged following chemotherapy, parents were not sure if it was caused by the treatment or due to some other factor.

Child strains

Parents reported four main themes related to their children's responses to their cancer

Table 1. FAAR model demands: strains experienced by families of children treated for cancer.

Sources of strain by system level:	Parents $n = 45$	Families $n = 26$	Groups $n = 7$
Cancer-related strains			
Illness secondary to chemo, radiation	18 (40.0%)	13 (50.0%)	7 (100%)
Losing hair	9 (20.0%)	8 (30.8%)	4 (57.1%)
Loss: limb, functional ability; infertility	7 (15.6%)	6 (23.1%)	4 (57.1%)
Recurrent surgeries	5 (11.1%)	5 (19.2%)	4 (57.1%)
Attention deficit problems	3 (6.7%)	3 (11.5%)	2 (28.6%)
Total noting any cancer-related strain	29 (64.4%)	22 (84.6%)	7 (100%)
Child strains			
Strong emotions (fears of treatment, nightmares, fears of CA recurrence)	15 (33.3%)	12 (46.2%)	7 (100%)
Self-conscious about reactions of others (being on pedestal, looking different)	8 (17.8%)	7 (26.9%)	5 (71.4%)
Loss of normal life and activities	5 (11.1%)	5 (19.2%)	4 (57.1%)
Worry about expense of treatment	3 (6.7%)	2 (7.7%)	1 (14.3%)
Total noting any child strains	23 (51.1%)	18 (69.2.%)	7 (100%)
Family strains			
Strong parental emotions during treatment (feeling numb, devastated, overwhelmed; helpless, loss of control; fear child would die; grief re pain, losses; guilt)	32 (71.1%)	22 (84.6%)	7 (100%)
Current emotions (fear of relapse; uncertainty about future; invasive thoughts)	23 (51.1%)	20 (76.9%)	7 (100%)
Balancing multiple family needs (time for other kids; work; other family roles)	18 (40.0%)	11 (42.3%)	7 (100%)
Parent-child relationship strains (being overprotective of child; uncertainty re child's independence; telling child dx; conflict over taking meds)	18 (40.0%)	14 (53.8%)	6 (85.7%)
Extended family conflicts	11 (24.4%)	6 (23.1%)	4 (57.1%)
Loss of normal family life	10 (22.2%)	9 (34.6%)	5 (71.4%)
Sibling issues (anger, resentment, jealousy; or sib feeling over responsible	10 (22.2%)	7 (26.9%)	5 (71.4%)
Financial strains	9 (20.0%)	7 (26.9%)	3 (42.9%)
Couple's different coping styles clashed	8 (17.8%)	5 (19.2%)	4 (57.1%)
Conflict, no support from former spouse	3 (6.7%)	3 (11.5%)	3 (42.9%)
Total noting any family strains	43 (95.6%)	26 (100%)	7 (100%)
Community strains			
Parents' friends' insensitive or avoidant	12 (26.7%)	7 (26.9%)	5 (71.4%)
Child's peers insensitive or avoidant	11 (24.4%)	8 (30.8%)	5 (71.4%)
Lack of formal support in community	8 (17.8%)	6 (23.1%)	2 (28.6%)
Other children dying of cancer	7 (15.6%)	4 (15.4%)	3 (42.9%)
School not being supportive/flexible	6 (13.3%)	4 (15.4%)	2 (28.6%)
School being too easy on child	3 (6.7%)	2 (7.7%)	1 (14.3%)
Government funders demeaning to family	3 (6.7%)	2 (7.7%)	1 (14.3%)
Private insurance problems	3 (6.7%)	2 (7.7%)	2 (28.6%)
Total noting any community strains	27 (60.0%)	20 (76.9%)	7 (100%)
Health-care systems strains			
Lack of skills, competence	16 (35.6%)	11 (38.5%)	5 (71.4%)
Insensitive communication	15 (33.3%)	9 (34.6%)	5 (71.4%)
Delays: diagnosis, test results, referrals	15 (33.3%)	9 (34.6%)	6 (85.8%)
Inadequate time to make medical decisions	12 (26.7%)	8 (30.8%)	4 (57.1%)
Total noting any health system strains	34 (75.6%)	19 (73.1%)	7 (100%)

Mean strains per individual = 8.6 (range 1–23); median = 8.

experience: (1) strong emotions, such as fear and anxiety, (2) self-consciousness about others' reactions, (3) loss of a normal life and activities, and (4) worry about the expense of treatment. In all focus groups, some child strain was mentioned, with at least one of these child strains being present in over two-thirds of the 26 families (69.2%), even though just 51% of the 45 parents in the focus groups articulated them. The strong emotional reactions of these children were reported by 33.3% of the parents. These emotions included fears about going through more treatments, nightmares about past treatments, and fears that the cancer would recur. In two families, parents thought the fears were because the child was too young to understand; whereas, in five other families, parents thought their children became more fearful as they got older and could understand what was happening to them. Two families reported that their children kept pain and symptoms to themselves to avoid returning to the hospital. Only three parents reported that their child was worried that the cancer would come back, although it is unclear if reporting the child's fear was dwarfed by parents' reporting their own fears related to recurrence.

The primary way parents reported that their children were self-conscious about others' reactions was not wanting to be put on a pedestal and have others fuss over them (five parents). A mother reported: '*He felt like people always still looked at him as being that sick kid...once he had left and was off in college, he'd come home for a weekend, and he'd come to church. Everybody's all over him, and how are you and how's your health. And it's like he wants to be past that. He just wants to be a regular person now.*' In addition, children were bothered by people staring and knowing they looked different because of their hair loss or because they were so thin: '*...and all the kids were sitting there at the swim meet and she's sitting like this* [hands crossed over her chest] *because in the swimming suit, it looked like someone just put a hole in her chest...she never talked about it, but you could tell she was very self-conscious...she would sit like that all the time...and she eventually quit swimming.*'

Five parents reported that their children experienced sadness because of missing out on normal activities—school, extra-curricular activities, and time with their friends. A mother said, '*So then it went from limited activity to no activity with a brace, you know. So he's gotta sit and watch his*

classmates in gym. He can't go play on the playground. And you know, like that or not, that involves his social activity 'cause they don't have time during school to talk, that's when they play. And so, you know, that's a big part of his life.' Other parents described their child's anger in being unable to participate in sports like they used to do: '*He got really angry...'cause they were all into hockey...he had to sit on the sidelines and he didn't like that... so he pushed them away.*'

Three parents reported that their children worried about how much their cancer treatment was costing the family. One father said about his son: '*He's worried that we have to sell our house and our trucks to keep him up with his medication and stuff.*' The parents in these two families also reported the financial strain that their child's illness created for them (see below). Either the child knew about the parents' worries, or perhaps saying the child worried was another way the parents were saying that they felt the strain. Child financial worries only emerged in one of the focus groups.

Family strains

The parents in these focus groups were the most articulate about the strains they experienced at the family level, with 10 themes and many sub-themes emerging. All of the focus groups, 100% of the families, and 95.6% of the parents described at least one family strain. The first family strain theme relates to the strong emotional reactions parents felt during the diagnosis and treatment (71.1% of the parents). When parents described an emotional response they had, we placed it in this domain because their subjective definition of the situation is implied (i.e. from the FAAR model perspective, the event interacts with the meaning given to it by a person in the family). This is in contrast to objectively described cancer strains (noted above) where no family member's emotional reaction was noted. The specific parental emotions were grouped into five sub-themes: (1) feeling numb, devastated and overwhelmed (21 parents); (2) a sense of helplessness and loss of control (15 parents): '*You wanted to help as much as possible, because you could see they were in pain...there was nothing you could do for them and that was one of the hardest things;*' (3) fear that their child would die (nine parents); (4) grief due to their child's pain and losses (e.g. hair, functional

ability, a normal life) (14 parents): '*So I remember the day before that* [leg surgery], *I watched him go up to his friend's house and I dropped him off and he ran in. And I just sat in the street and watched him just—I knew that was the last time I'd see him run*;' and (5) a sense of guilt and self blame for the child's cancer (five parents): '*Well, I must have missed it. How could I do that? …two months ago when she complained about something and I just blew it off…you think, Oh my God! What have I done. I didn't watch close enough.*'

The second theme was related to emotions parents currently were experiencing. There were three sub-themes: (1) worry about relapse (19 parents): '*I have 100 little 3-year-olds pictured and I think, 10 of them are going to get this back and you know it could be my little girl—that's always in the back of my mind…and when the Dr. says she is going to be fine, I think, but you're not God and if I forget this and not worry any more, then it's going to come right back and hit me just like it did the first time*;' (2) fears about the future (12 parents): '*…you find that with the rest of your children, you get overly worried. Every little thing bothers me, because I guess I never thought anything would happen to us*;' and (3) recurrent invasive thoughts (two parents).

During the active treatment phase of the cancer, 40% of the parents reported that they struggled with balancing multiple family needs—work, school, other children, finding child care, being at the hospital, etc.: '*I'm in the hospital. I mean, I'm crying going, 'OK, I got this kid here, and I got the other one on the phone crying she wants Mom home.' I'm like, I can't be in two places, you know. And it was just—it was really tough.*' Trying to stretch themselves across all their family's needs contributed to exhaustion: '*You get to the point where you collapse. I mean, it's like somebody take over for me. I need a day off. But you don't have the day off.*'

Inadequate time for other children was related to another theme: sibling issues (reported by 22.2% of the parents). Seven parents reported that siblings expressed anger, resentment or jealousy at the amount of attention the child with cancer received: '*…and I don't think those feelings that he had then have gone away to this day. I think there's still some resentment. It was always, 'Well, I wish I'd get cancer cause then I'd get…''* In contrast, four parents thought a sibling either felt overly responsible or had to take on too much responsibility for the child with cancer or others in

the family: '*…we needed her to be there to watch the younger two and she found that hard to kinda get a bunch of the responsibility, you know, shifted to her.*'

Forty percent of the parents reported that they experienced strains in their relationship with their child with cancer. The four sub-themes included: (1) concern that they were overly protective of their child (12 parents): '*…and I'd say, 'No, wait! You need to slow down,' and he'd say, 'No, I don't. I need to live because for a moment I was almost dead. And now I need to live.' And I'm like, 'Whoa, I wasn't ready for that one;''* (2) uncertainty or conflict with their child regarding how much child independence to allow (five parents): '*And that was hard at that age, a junior in high school when they are supposed to be out on their own more, and she had to revert back to this—almost like infancy stage and be dependent… this was probably harder for me than her*;' (3) telling their child his/her diagnosis (three parents); and (4) conflict with their child regarding taking medications (two parents).

A fifth theme, conflicts experienced with extended family members, was reported by 24.4% of the parents. These conflicts related to disappointment in not receiving support from relatives, having relatives be too intrusive in trying to help, or feeling the pressure of always having to answer their questions and provide information: '*It was tough telling my brothers because right away they started pumping me with questions. And I wasn't in the mood for answering questions.*'

Closely related to the child strain of losing out on normal activities, 22.2% of the parents talked about the loss of normal family life, primarily during the active treatment phase: '*…everybody was in their own little world trying to lick their wounds…*' This non-normality lingered for some due to uncertainties related to the cancer. They talked about how cancer invaded everything about their lives and how they felt like they were *in a different world*—almost a *surreal experience* or like being suspended in time and space.

In three focus groups, 20% of the parents acknowledged the financial strains they experienced. These were related to one parent being unable to work or working fewer hours, the expense of treatment ('*…we have a $10,000 deductible on our health insurance and so it's like anything that happens, is out of pocket*'), and the expense of co-payments.

There were two themes related to couple or marital conflict. Among the married couples,

17.8% indicated that their different coping styles clashed and created strain for them, or they had to re-learn how to work together again after the crisis of the active treatment phase: '...*it took us probably a good month or two to finally mesh again and learn how to work together because we both had just become independent*.' Most of the focus group participants were married, but the three single mothers experienced conflict or no support from their former spouses: '*I didn't have that significant other to fall back on. I really felt alone, really, really alone*.'

Community strains

In all of the focus groups and in 76.9% of the families at least one strain emerging from a community source was reported. Of the eight themes identified, insensitivity or avoidance by parents' friends was the most frequent (26.7% of parents): '*People just back off. They don't ask one question*.' This same avoidant behavior was experienced by many of the children from their peers (reported by 24.4% of the parents): '*Kids find out she had cancer and it's like she's got the cooties. They don't want to talk to her*.' Parents talked about these insensitivities in a forgiving way, noting that most people just don't know what to say, even more so than if someone had died.

The lack of any community support group/ system for parents experiencing cancer was noted by 17.8% of parents, particularly those living in rural areas or small towns. Given the extensive amount of time parents spent in hospital cancer units, they became acquainted with other families and children with cancer. When some of these other children died, it was particularly stressful for the parents. Some felt guilt that their child was still alive or they worried this could happen to them too.

Two types of strains related to their children's schools were noted by a small number of parents: (1) not being supportive and flexible: '*He had to delay his Phys Ed requirement until the last semester of his senior year. So here he is with his leg cut open, recovering from surgery, getting chemo and the Phys Ed teacher said, 'You gotta do something physical; that's the requirement. We can't promote him if he doesn't satisfy that;*" or conversely, (2) being too easy on their child with cancer: '*They were too accommodating, they let him*

slide. And now he's in a special school because he's a year behind in math.'

Two themes related to payment sources for health services were noted: (1) problems getting treatment or services covered by private insurers, or (2) being treated in a demeaning way when seeking public funding: '*Filling out all those forms every six months and you're already on such a low income anyway. I mean, it's real humiliating*.'

Health-care system strains. Although conceptually a part of community strains, the strains emerging from the health-care system were coded separately. All focus groups and 73.1% of the families talked about health system strains. Approximately a third of the parents complained about the lack of competence and skills among health providers in their local communities (not the cancer specialists who were highly valued). Some of this related to delayed diagnosis –'*So we kind of blamed our original pediatrician for not picking up the signs earlier*' or to poor follow-up care after the child had been discharged home. About a third of the parents also complained about the insensitive way some physicians (including cancer specialists) communicated with their family: '*One doctor was very short with our daughter and shamed her...I am still trying to forgive him for shaming her*.' Parents also felt the strain of delays in getting diagnoses or test results, and the strain of having inadequate time to make complex medical decisions: '*It's like when they diagnosed it, they just barrel you into this protocol and you don't have time to think...they needed that signature on the consent forms to start it, but we still had plenty of questions...*'

RESOURCES

Parents in the focus groups also were able to identify many positive things and characteristics of people that helped their families in dealing with the many strains associated with the cancer experience. These positive factors associated with the cancer experience are organized using the FAAR domains of child, family, and community resources (see Table 2 and Figure 1).

Table 2. FAAR model capabilities: resources identified by parents of children treated for cancer.

Resources identified for each system level	Parents $n=45$	Families $n=26$	Groups $n=7$
Child resources			
Responsible, mature about circumstances	14 (31.1%)	9 (34.6%)	4 (57.1%)
Strong with ability to tolerate pain	13 (28.9%)	10 (38.5%)	5 (71.4%)
Positive attitude and sense of humor	4 (8.9%)	3 (11.5%)	2 (28.6%)
Total number noting any child resource	30 (66.7%)	21 (80.8.%)	7 (100%)
Family resources			
Extended family support	20 (44.4%)	17 (65.4%)	7 (100%)
Religious beliefs	14 (31.1%)	12 (46.2%)	6 (85.7%)
Parenting competence, effectiveness	14 (31.1%)	11 (42.3%)	6 (85.7%)
Family interaction style (cohesiveness - 9, open communication - 7, flexibility - 2)	12 (26.7%)	8 (30.8%)	4 (57.1%)
Sibling support	11 (24.4%)	7 (26.9%)	4 (57.1%)
Strong marital relationship	4 (8.9%)	4 (15.4%)	3 (42.9%)
Total number noting any family resource	36 (80.0%)	23 (88.5%)	7 (100%)
Community resources			
Support from people at church	12 (26.7%)	9 (34.6%)	5 (71.4%)
Support from parents' friends/co-workers	19 (42.%)	15 (57.7%)	7 (100%)
Support from child's peers	8 (17.8%)	5 (19.2%)	4 (57.1%)
Support from other parents living with CA	12 (26.7%)	9 (34.6%)	5 (71.4%)
Supportive school	11 (24.4%)	10 (38.5%)	6 (85.7%)
Parents of children with CA on the internet	6 (13.3%)	4 (15.4%)	4 (57.1%)
Community programs for kids with CA	5 (11.1%)	4 (15.4%)	2 (28.6%)
Total number noting any community resource	35 (77.8%)	24 (92.3%)	7 (100%)
Health-care systems resources			
Competent and caring doctors	24 (53.3%)	19 (73.1%)	7 (100%)
Support from nurses, social workers	24 (53.3%)	18 (69.2%)	7 (100%)
Flexible scheduling	10 (22.2%)	8 (30.8%)	4 (57.1%)
Financial help	4 (8.9%)	3 (11.5%)	2 (28.6%)
Total noting any health system resource	33 (73.3%)	23 (88.5%)	7 (100%)

Mean resources per individual = 5.5; median = 8.

Child resources

Two-thirds of the parents talked about specific aspects of their child's personality or demeanor that were helpful to their families in dealing with the cancer experience. A third of the parents reported that their child was very responsible and mature in facing and accepting what was happening to them: '*She wasn't even 14 years old and she would get up in front of 300 kids and tell them their problems—drugs, sex, family problems—were worse than what she was going through because there was an end to what she was doing and she didn't know how they were going to get out of their dilemmas.*' Closely related to this maturity was seeing their child as strong and enduring or tolerating the pain courageously. This often

inspired parents to be strong too, at least in their outward demeanor: '*…he was so strong about it…and I said I can't weaken up in front of him. I gotta let him know that everything's going to go right.*' A smaller number of parents talked about their child's *sense of humor* and positive attitude: '*…your attitude is central to your quality of life no matter what your circumstances are and his attitude has been remarkable.*'

Family resources

Even though extended family members were mentioned as a source of strain in some families, many parents (44.4%) talked about their extended family members as a source of support.

Interestingly, seven parents who reported strain or conflict with their extended family also reported that relatives were a source of support for them: '*We both had the support of our families...we have a tight, large family...I don't know how people can do it without any family support—it's a big factor in getting through it.*' Similarly, a quarter of the parents mentioned siblings provided support even though siblings were also identified as a source of strain by four of these 11 parents: '*Her sister really was special through this, very special... she would rather been laying in that bed than her...the bond that formed between them was unbelievable.*' A strong marital relationship was noted as a helpful factor by four of the parents, even though one of these parents also acknowledged conflict with her spouse.

Religious beliefs were frequently mentioned as helpful (by 31.1% of parents): '*Oh, you have to give it to God*—'*Here you go, God, it's yours right now because I can't have these thoughts right now because I have to be there for my son.*' While beliefs provided comfort for many, they also mobilized active coping: '*I think we're pretty much people of action, besides people of faith, and so we had to put that faith into action... and we had to do it right away.*' Many families searching for why *their* child got cancer and for the strength to accept the uncertainty and challenges they faced, turned to (or reconnected with) their belief in a higher power. It is part of the process of searching for meaning in events that defy understanding, which many others have observed among those facing life-threatening events (Park and Folkman, 1997).

Several of the parenting behaviors that were described were coded as evidence of parental competence and effectiveness (for 31.1% of the parents). For example, one father said, '*We raised our children to be people, not children...we treated her as a person and respected her that way. So now—and all through her adolescence, she was always able to come to either of us and ask us a question without feeling threatened by it.*'

Although family interaction patterns are frequently examined in empirical studies as family resources moderating the impact of stressful life experiences, only 26.7% of these parents specifically mentioned the helpfulness of family patterns, such as cohesiveness ('*It's amazing how the family does kinda pull together and get stronger*'), flexibility, and/or open communication ('*We didn't*

go through the '*I hate you Mom and Dad stage*' because we were so dependent on each other and so supportive of each other and talking all the time and supporting each other.*')

Community resources

Most of the families (92.3%) and parents (77.8%) noted at least one community resource, which had been helpful to them in managing their child's cancer experience. Primarily, these resources involved social support—from co-workers ('*My boss told me that nothing we're doing at work is important, so take as much time as you want*') and friends ('*A lot of friends just kind of stepped up to the plate and took over a lot of things for us—they were bringing meals to our house...hired a cleaning lady for us...filled my cupboards with groceries...helped get our son to appointments...*'); from people at church ('*We had more people say they were praying for us, and you know, them saying that, whether they were or not, we just felt a lot of peace through that*'); and from other parents with a child with cancer ('*We talked to someone who had the same prosthesis as our son and that gave me so much comfort...she gave me great ideas on what to anticipate in the hospital, tricks to get him to eat...she was a great assistance...and just because they'd been through it*'). A small number of parents used on-line resources that connected them with other families whose children had cancer ('*It's a wonderful group on the internet...people that know exactly what you are feeling and going through...you can't vent to people at work or just another parent because they don't understand... these people on the internet do...it was a tremendous resource*'). School staff was another source of support ('*The things our school did were just incredible...they had fund raisers—a dance that raised money...they bought him a computer...I think the school and his teachers just felt like they would do what they could to get him through that year*').

A few parents (17.8%) reported that their children with cancer received support from peers ('*When he lost his hair, his buddies all shaved their heads and they went to the mall and walked around in their letter jackets and scared people—not on purpose, but it just did*'), although this was reported less frequently than the insensitivity of peers.

Health-care system resources. Although parents noted strains that emerged from the health-care system, approximately the same number (73.3%) noted resources in the health-care system that were helpful to them. Competent, caring doctors were noted by 53.3% of the parents: '*. . .and the doctor said, 'If this is what we think it is, we can treat it' And I just thought, My God, I can breathe. . .it's so important that doctors know that we want hope, whether it's a little bit of hope. . .I mean, we need the truth too. That's important, but hope is just as important as anything else that we can have.*' They noted how doctors went out of their way to help and reassure them: '*There were 7 or 8 of them on the team. . .all of them took the time to come to the school and explain to the other kids what was going on. . .I didn't think that was something they would do—take the time off work to come down. . .it was awesome.*'

Support from nurses and social workers was mentioned by 53.3% of the parents: '*I think the staff doesn't realize the impact they have on our lives. You know, we look to them for guidance and for friendship because that's your whole life for a year.*' Or from another parent, '*the nurses, I mean, for years we went to visit them every time we came to the cities—you know, they became like family.*' One parent said the reason she chose to come to the focus group was to acknowledge the gratitude she felt toward the oncology staff.

Two additional health-care resources mentioned were flexible scheduling so that other family needs could also be accommodated, and financial help when bills mounted and became difficult to pay. One parent '*couldn't believe that they would just write it* [$4,000 bill] *off.*'

Coping strategies

In addition to the resources that parents described as helpful to them throughout the cancer experience, they also described specific behaviors of family members. These behaviors complemented the resources families *had*. In some instances, coping behaviors involved accessing new resources or strengthening existing resources. The literature on coping often differentiates between appraisal-focused, problem-focused, and emotion-focused coping strategies. Appraisal-focused coping refers to the way a person thinks about the stressors or circumstances they are experiencing. Problem-focused coping involves doing something to help

resolve the distress, and emotion-focused coping helps to regulate overwhelming emotions (Lazarus and Folkman, 1983). The coping themes that emerged from this analysis were classified into these three domains.

Appraisal-focused behaviors. There were six themes that fit into the appraisal domain of coping (see Table 3). Slightly over 77% of the parents found at least one way to 'think' about their circumstances or give meaning to them as a way to manage the difficulties and strain. The most frequently used appraisal behavior was trying to be positive and maintain hope, which was used by 42% of the parents. For example, '*All I focused on was that he was going to live. . .and we tried to have a real upbeat, positive attitude through the whole thing;*' or '*They said she had a 21% chance of making it and so I just figured she was one of the 21%. You gotta think positive.*' Closely related to being positive and hopeful was making comparisons with others' circumstances as a way to be positive, which was a strategy used by 18 parents: '*You walk around and beat yourself against the wall, asking why, and you feel so bad. . .and then you listen to other folks' stories, you say, 'Wow! Whoa, wait a minute, this is not really bad'. . .you listen to these other parents' stories and you find that you need to count your blessings. . .as hard as things seem, there's always somebody going through something a heck of a lot worse than yours.*'

Believing and trusting in God was an important behavior described by 17 parents: '*I truly believe it's by the grace of God. If I did not have a personal relationship with the Lord, I never could have done this.*' Or combining her trust in God and having hope, one mother said, '*At first we were really distraught and then my husband and I just prayed and said, 'God, we can't handle this. We're going to turn it over to the doctors. You give them peace and wisdom to treat him and we're not going to worry about it'. . .and the next day, we just woke up and went to the museum, we laughed, had the best time, not even knowing the outcome yet. . .and we knew we could get through it.*' The remaining three appraisal behaviors were used less frequently and included living in and focusing on the present—rather than thinking about the possibility of their child dying (four parents); denying what was happening (three parents), and seeing the 'good' in their

Table 3. FAAR model capabilities: coping strategies used by parents of children treated for cancer.

Coping strategies	Parents $n=45$	Families $n=26$	Groups $n=7$
Appraisal-focused coping behaviors			
Being positive and maintaining hope	19 (42.0%)	14 (53.8%)	7 (100%)
Making positive comparisons	18 (40.0%)	13 (50.0%)	4 (57.1%)
Believing/trusting in God	17 (37.8%)	14 (53.8%)	7 (100%)
Living (focusing on) the present	4 (8.9%)	4 (15.4%)	3 (42.9%)
Denying what is happening	3 (6.7%)	3 (11.5%)	1 (14.3%)
Seeing the 'good' in the experience	2 (4.4%)	2 (7.7%)	2 (28.6%)
Total noting any cognitive coping strategy	35 (77.8%)	23 (88.5%)	7 (100%)
Problem-focused coping behaviors			
Advocating for child	14 (31.1%)	10 (38.5%)	5 (71.4%)
Seeking information about cancer	12 (26.7%)	11 (42.3%)	7 (100%)
Balancing family needs; being normal	11 (24.4%)	7 (26.9%)	3 (42.9%)
Being organized; planning ahead	11 (24.4%)	9 (34.6%)	5 (71.4%)
Moving; quitting a job	3 (6.7%)	3 (11.5%)	2 (28.6%)
Total noting any behavioral coping strategy	33 (73.3%)	21 (80.8%)	7 (100%)
Emotion-focused coping behaviors			
Humor; fun; celebrating	13 (28.9%)	10 (38.5%)	5 (71.4%)
Crying	12 (26.7%)	10 (38.5%)	6 (85.7%)
Seeking and giving support	11 (24.4%)	8 (30.8%)	4 (57.1%)
Hiding difficult feelings	3 (6.7%)	2 (7.7%)	2 (28.6%)
Being strong	3 (6.7%)	2 (7.7%)	2 (28.6%)
Writing	1 (2.2%)	1 (3.8%)	1 (14.3%)
Total noting any emotional coping strategy	25 (55.6%)	17 (65.4%)	7 (100%)

experience (two parents): '*You know, there's a sense that you don't really want to forget it all either, because as painful as it is, so much good comes out of it…we grew so much as a family…there's just too many positives—I truly believe that the person he is today is because of what he's been through.*'

Problem-focused coping behaviors. There were five specific problem-focused behaviors described by parents, and 73.3% used at least one of them. The most frequent of these was advocating for their child, which 14 parents described. The many aspects of treatment can create a dilemma for parents, as one father said, '*You know what your kid needs, but you also don't know how to spell what they just told you that they have…when they give you something, you think 'that's what we gotta do'…and then his wife said, 'but then, with some things, you realize you can say no to whatever you want…it's important that parents know they don't have to put their kid through things.*' Parents became astute at learning how to walk the line between hearing exactly

when something critical needed to be done right away and when they needed to assert themselves and question the timing of something or say 'no.' In addition to advocating with health providers, some parents had to advocate for their children at school: '*The school said he was not going to be in school and should have a tutor that whole year and I said, 'No way, he's not sick every day and when he wants to go to school, he'll be there…they didn't tell me anything about IEPs and I did all the research on that and called some advocacy groups, figured it out, and called a meeting with teachers and counselors at school…and they finally agreed.*'

Actively seeking information about cancer (over and above what was automatically given to them by health professionals) was mentioned by 12 parents: '*I got on the internet, just started researching as much as I could*' or '*You have to get informed and be a key part of the whole process.*' In response to the strain of competing family needs and loss of normalcy, 11 parents emphasized that they *tried to maintain some normalcy in family life* and tried to attend to the needs of other members. Trying to be organized and planning ahead to the

extent that they could was a coping behavior mentioned by 11 parents: '*We had to make a plan…and the plan was that we would rotate days*.' Several parents kept notebooks of details related to the treatment, which they always carried with them and often used to augment information not readily found in medical records. It gave them some sense of having control of the situation. The final problem-focused behavior involved moving (to be closer to medical care) or quitting a job to care for the child (three parents).

Emotion-focused coping behaviors. Slightly over half of the parents described coping behaviors that helped to regulate their emotions. In spite of their dire circumstances, 13 parents were able to engage humor and fun or celebrate small treatment successes as a way to cope: '*He had this smoke-breathing dragon and it was going down the hall…and the nurses came running…all the kids were in an uproar and just having a ball and the nurses were in a panic*.' Another family celebrated: '*On the anniversary of his remission, we have cake, ice cream—like a birthday…and make it a joyous celebration instead of a real bummer, you know, so that we can be elated. Made it another year*!' Twelve parents acknowledged that crying was helpful to them as a way to release feelings of sadness and worry.

Just as having support was acknowledged as a resource, *seeking* and *giving* support were acknowledged as a way to cope. Usually seeking support was a way to manage difficult feelings: '*I went to my pastor at church and sat all afternoon…and got the prayers of the church…it gave me strength*.' One mother sought emotional support (and information) from a relative: '*I called my sister, a nurse in Chicago, because I could understand what they* [the doctors] *were saying, but I didn't hear it because I didn't want to hear it…so you* [sister] *need to talk me through this because I am lost*.' It is a paradox of social support that giving it can be as helpful as receiving it, or perhaps, it is the reciprocity of informal social connections that makes it beneficial. As one mother said, '*When we see a fund raiser for someone with cancer, we'll go…we don't know the people, but we still go, just for the support*.'

The remaining emotion-focused behaviors were used by a smaller number of parents: hiding difficult feelings from other family members (three parents), outwardly being strong as a way to support their child (three parents), and writing in a journal to sort out difficult feelings (one parent).

Balance between demands and capabilities

The ratio of perceived demands to capabilities for each parent was examined. Of the 45 parents, one-third reported more strains than capabilities (ratios ranged from 0.25 to 0.88). Seven parents reported an equal number of strains and capabilities (ratio of 1). The remaining 22 parents had ratios greater than 1 (range: 1.13–3), indicating an emphasis on describing capabilities over strains. In two of the seven groups, all scores were ⩾1 and in one group, all scores were <1, suggesting that group dynamics may shape the relative emphasis of positive versus negative aspects of the experience. In the other four groups, ratios varied more with some greater than and some less than 1. Taken alone, these ratio scores have less meaning than they would have if examined in relationship to some child or family functioning outcomes, which were not included in this qualitative study.

DISCUSSION

The results of this qualitative study corroborate many aspects of the cancer experience for families that have been reported in the literature. However, the results provide greater insight and detail about many of the strains families encounter, and even more importantly, the results draw attention to specific resources and coping behaviors that parents use to manage these strains. Some aspects of family impact reported by these parents were unique to childhood cancer, but most of the strains, resources, and coping behaviors were similar to what has been described in studies of families experiencing other childhood chronic conditions, or even experiencing stressful life events in general. This finding provides support for the observation that the psychosocial impact of childhood chronic conditions is more similar across conditions rather than unique to each diagnosis (Perrin *et al.*, 1993; Stein *et al.*, 1993).

Cancer-related strains were specific to this diagnosis. The severity of the children's pain and illness was described by parents as an intense experience, and was understandably related to strong emotional reactions, such as a sense of

supportive to them. In many instances, it was because these sources did nothing—did not reach out and show their concern or willingness to help—in the ways that parents expected, which created the strain. In other instances, it was because individuals actually did something that was unkind or insensitive. Parents described this lack of support with strong feelings, suggesting that it was indeed painful—then and now. Generally, this nonsupport or hurtful behavior has been under-reported or assessed as a factor in child and family adjustment to cancer and other chronic health conditions.

In a few instances, parents described the very same people as both a source of strain and a source of support. While seemingly inconsistent, this is not unusual in that the closest personal ties can be simultaneously supportive and stressful (Coyne *et al.*, 1990). This is especially the case for family relationships where their intimate nature and close proximity make this understandable, especially under stressful circumstances.

Although lack of support was an issue, it was more frequently the case that parents would describe another person in the family, the community, or the health-care system that was supportive. When one looks through the list of resources identified by these parents, it is clear that support was the most frequently mentioned resource. This is consistent with the literature on adaptation to stress in general, and to chronic health conditions in particular (Katz, 2002). This support manifested itself as emotional, informational, and in the form of tangible assistance. Parents in these focus groups talked about receiving all of these forms of support, and they did so indicating that it was indispensable in their overall ability to get through this difficult experience.

Two-thirds of the parents described their child's personal attributes as a major resource. This may reflect the parents' gratitude that their child was currently in remission, and their attribution that their child's strength and positive attitude contributed to this outcome. Since parents could not substitute themselves and bear their child's pain, but could only stand by and observe it, they seemed to view their child with awe for what he/she had endured. Many also expressed that their child was a better, more competent person because of what he/she had been through.

While most parents did mention at least one family resource that helped them get through the

acute phases of the cancer treatment, they were not as verbose about these aspects of the experience as they were about the strains. In particular, general family functioning characteristics (such as communication, cohesiveness, flexibility), which are frequently assessed in studies of family factors associated with child outcomes, were only mentioned by a quarter of the parents. Once again, however, these family resources were not systematically assessed and hence may have been a resource available to more of the families.

While parents did mention their use of some problem-focused coping behaviors, such as advocating for their child, seeking information, and being organized as a way to feel some sense of control of their situations, it was striking how many parents used appraisal-focused coping behaviors. Here again, this is consistent with studies of coping with other chronic health conditions. There is a growing and extensive literature about the role of making meaning out of situations that defy understanding and about which there is a limit as to how much we can solve the problem by finding resources (Antonovsky, 1987; Folkman and Moskowitz, 2000; Park and Folkman, 1997; Patterson, in press; Taylor, 1989; Thompson and Janigian, 1988; Turnbull *et al.*, 1993). There are myriad ways that families do this and the parents in these focus groups described some of the most common: being positive and hopeful, believing in God and in doctors, viewing the circumstances of others as worse than their own, and blocking out what is too painful by denying the possibility of death or living only in the moment. These are active behaviors that allow families to carry on and sustain their emotional energy. None of the coping behaviors described by these parents is specific to cancer, but rather have emerged in response to other chronic health conditions.

Overall, these analyses confirm the utility of the FAAR model as a framework for considering family response to childhood cancer. In particular, the notion of considering the balance of perceived stressors relative to capabilities may be a useful approach in future studies where family response is examined as a mediator or moderator of quality of life for children surviving treatment for cancer.

Limitations and conclusions

While the focus group strategy used for this study provided rich detail about a range of family

experiences surrounding childhood cancer, our sample was limited to volunteers with surviving children from one specialized treatment institution; we cannot assume that their experiences necessarily represent all families who had or will have a child with cancer. It is also possible that the year in which the child was diagnosed and treated, as well as the amount of time that had elapsed since treatment, may have affected what parents reported. Improvements in treatment and an increasingly greater emphasis on family centered care may account for differences in what parents reported. It is precisely this variability in family experiences and family responses that could be assessed in future quantitative studies using structured questionnaires to assess family impact and responses in examining the quality of life of childhood cancer survivors.

The information offered from this qualitative study provides a valuable window into the impact of childhood cancer on families—both the factors that cause distress to families and those that help them to successfully cope with the experience. Formal integration of variables related to family impact should serve to improve future studies of health-related quality of life among children who survive cancer. In addition, these findings should further inform the clinical practice of oncology providers about some of the important issues facing families throughout this stressful period and provide insight into the ways that many families are able to successfully manage these challenges. The rich detail provided by families in our study can serve to enhance family centred clinical care—the very outcome that motivated many of these families to participate in this study.

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