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Parental Involvement and Family-Centered Care in the Diagnostic and Treatment Phases of Childhood Cancer: Results From a Qualitative Study

Kristen E. Holm, MS, Joän M. Patterson, PhD,
and James G. Gurney, PhD

Few research studies have addressed the ways parents participate in their child's medical care, particularly in relation to the cancer experience. The purpose of this study was to explore parents' descriptions of their participation in medical care for their children with cancer. For this study, seven focus groups were conducted with 45 parents of 26 children who had completed cancer treatment at least one year prior, and who were still alive. Data were coded using thematic analysis procedures. It was found that parents emphasized their role as advocates during the diagnosis and treatment phases, by informing themselves about their child's medical conditions, making medical care decisions, limiting the actions of medical professionals, and affirming and supporting medical professionals. These results emphasize the need to employ a family-centered approach in cancer care medical settings, by fostering and supporting the active inclusion of parents in their child's treatment and management.

Keywords: neoplasm, children, psychosocial, epidemiology

Background

Nurses and other clinical professionals report that many parents are highly involved in their chil-

dren's medical care. Such participation is consistent with family-centered care, a model of health care delivery that emphasizes providing information, giving parents control over decision making, and respecting and supporting parents (King, King, Rosenbaum, & Goffin, 1999). The International Society of Paediatric Oncology (SIOP) working committee on psychosocial issues in pediatric oncology has highlighted the importance of a therapeutic alliance between medical providers and the patient's family (Masera et al., 1998). Although models of health care delivery, such as family-centered care, endorse the inclusion of parents in medical care, little research exists about specific ways parents participate in their children's medical care. Using data from a

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qualitative study of family stress and coping in response to childhood cancer (Patterson, Holm, & Gurney, 2003), the purpose of the present analysis was to explore parents' descriptions of how they participated in their children's medical care surrounding the diagnosis and treatment for cancer.

Family-Centered Care

In the United States, the concept of family-centered care emerged in the 1980s as part of a conference of the Surgeon General that was focused on children with special health care needs (U.S. Department of Health and Human Services, 1987). It calls for a model of health care in which families and medical professionals work collaboratively to determine the content and process of children's health care services (Letourneau & Elliott, 1996; Macnab, Thiessen, McLeod, & Hinton, 2000; Woodside, Rosenbaum, King, & King, 2001). Family-centered care has become a standard for providing quality health care for children (Hutchins & McPherson, 1991; Tomlinson, Thomlinson, Peden-McAlpine, & Kirschbaum, 2002). Family-centered care received a legislative mandate in 1986 with passage of U.S. Public Law 99-457, which requires that the whole family be treated as the recipient of services for children with special needs, with family members deciding ways they want to be involved in decision making about health and education services for their child (Rosenbaum, King, Law, King, & Evans, 1998; Woodside et al., 2001).

Outcomes of Parental Involvement in Children's Health Care

Parental involvement in children's health care is generally associated with positive outcomes for both parents and children (Letourneau & Elliott, 1996; Rosenbaum et al., 1998; Woodside et al., 2001). Parents of children with disabilities (King et al., 1999) or with chronic illnesses (King,

Rosenbaum, & King, 1996) have reported less stress and better emotional well-being when they rated care as more family centered. In addition, mothers of preterm infants who rated their relationships with medical providers as family centered have reported higher psychological well-being (Van Riper, 2001).

With regard to pediatric cancer, parental distraction of their child during venipuncture has been shown to be associated with higher amounts of child coping behavior and lower amounts of momentary distress and crying/screaming (Manne et al., 1992). When children with cancer were distressed at the beginning of a procedure, explanation by the parent of what would happen during the procedure was related to reduced child distress (Jacobsen et al., 1990), and encouraging the child to engage in coping behavior was associated with less distress later in the procedure (Manne et al., 1992). Parents have been included as coaches/cotherapists in interventions to reduce pain, anxiety, and distress during cancer-related medical procedures such as venipuncture, lumbar puncture, bone marrow aspiration, intramuscular and intravenous injections, and accessing ports. Studies of the efficacy of these interventions indicate that they are successful in reducing child pain, anxiety, and distress (Barrera, 2000; Broome, Rehwaldt, & Fogg, 1998; Manne et al., 1990; Powers, Blount, Bachanas, Cotter, & Swan, 1993; Smith, Barabasz, & Barabasz, 1996).

Although studies have addressed parent behaviors during specific, well-defined procedures that are part of cancer treatment, research has not focused on parents' descriptions of ways they participate more broadly in the entire process of their children's medical care, beginning with their search for a diagnosis and extending through the completion of treatment. The purpose of the present study was to address this gap in the literature of the parental perspective, with the expectation that information derived directly from parents' subjective narratives of their families' experience with cancer would provide additional insight for medical professionals who

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encourage parental involvement in children's cancer care as a way to enhance outcomes for child patients.

Method

Seven focus groups were conducted with 45 parents of 26 children who had completed treatment for cancer at least 1 year prior to the focus group and who were still alive and not currently undergoing treatment for a recurrence or subsequent primary neoplasm. Each focus group included 5 to 9 participants and lasted for approximately 2 hours.

Recruitment Procedures

After approval of study procedures and materials from the Human Subjects Research Review Committee, a letter was sent to parents of children ($n = 99$) who had been treated for cancer at an academic children's hospital between 1990 and 1998, who were currently alive, and who lived within a 100-mile radius of the hospital. The letter introduced the study and asked parents to return a response card if they were interested in receiving information about participating in a focus group. No additional recruitment strategies were used. 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. Although the parents of 49 children returned response cards, only the parents of 26 children were able to participate in a focus group due to scheduling conflicts.

Participants

Demographic and treatment information about the children with cancer. Of the 26 index children, 14 were male; mean age at diagnosis was 9.6 years (range 1-18 years); mean age at the time of the parent focus groups was 14.8 years (range 3.8-26 years); mean treatment duration was 1.2 years (range 3 months to 3.2 years); and mean time since treatment completion was 4 years (range 1-9 years). The diagnoses included 7 children with bone cancer, 6 with leukemia, 6 with lymphoma,

3 with retinoblastoma, 2 with neuroblastoma, 1 with brain cancer, and 1 with Wilms tumor. One child had previously experienced a recurrence but was not currently being treated for cancer. All children received their primary cancer treatment at the same hospital, but most children also received some diagnostic services and/or treatment at other facilities.

Demographic information about the parents. Forty-five parents participated in the focus groups: 19 married couples, 4 married mothers who participated without their husbands, and 3 single mothers. The mean parent age was 43.6 years (range 32-56 years). On average, each family had 2.8 children (range 1-6 children). One participant was African American, and the remainder Caucasian. With regard to the highest level of education completed, 13% had completed high school, 31% had some college or a technical college degree, 40% had a 4-year college degree, and 11% had a graduate or professional degree.

Focus Group Procedure

Data were collected using focus groups, which have the potential to generate rich narrative descriptions based on participants' personal experiences. When focus group participants have been through the same profound experience, group solidarity is increased and there is greater openness and self-disclosure than is likely to emerge in individual structured interviews (Krueger, 1994). A doctoral-level psychologist trained in focus group methodology facilitated each focus group.

Following a brief introduction to the study by the facilitator, participants introduced themselves and talked briefly about the composition of their families. The remainder of the focus group involved discussion based on the following questions posed to the parents: (a) Describe what happened at the time you learned about your child's diagnosis of cancer. (b) 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? (c) What has been most helpful to you and

your family in managing these challenges and difficulties? (d) Describe the ways you and your family have coped with the difficulties you have described. (e) How has the way you look at yourself, others, or the world around you changed as a result of this experience? Each parent was compensated \$25 for his or her participation.

Data Analysis Procedures

All focus groups were audiotaped and transcribed verbatim. For the original study (Patterson et al., 2003), which was designed to gather data regarding the impact of pediatric cancer on the family, 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. Descriptive themes and subthemes were identified, and coding was done at the subtheme level. To ensure rigor and reliability of analysis, three of the seven transcripts were coded independently in their entirety by two coders. 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.

The present analysis focuses only on those subthemes related to ways in which parents participated in their children's medical care. This included specific interactions parents had with the medical staff, including their specific efforts to gather and compile medical information. Only recurrent subthemes were included, which required that each subtheme emerge in more than one focus group and be represented by different words used to express the same idea. Concepts that were mentioned only once or twice were not considered recurrent and thus are not included as themes. Six independent themes were identified. In the final step, the original transcripts were re-reviewed in their entirety to ensure that all text that met the definition of each

of the six themes was included. Detailed tables were used to track the extent to which each theme was prevalent.

The units of analyses were both the focus group and the child, which made it possible to examine the number of focus groups in which each theme surfaced as well as how many of the 26 children had a parent who mentioned each theme. Parents were not identified as units of analysis because it was not possible to determine whether parents spoke solely about their own perceptions or whether they spoke for themselves and their spouses. However, it was clear that parents spoke about their experiences with regard to their own child, making the child a clear and unambiguous unit of analysis.

Results

Advocacy was the overarching theme that emerged to describe how parents participated in their children's medical care. Advocacy is defined as parents speaking and acting on behalf of their child, as an intercessor and champion, to ensure that their child's needs are met. Advocacy efforts were apparent across two important time periods: (a) the diagnosis phase and (b) the treatment phase. Six themes are descriptive of the strategies of advocacy that were used by the parents, two during the diagnosis phase (*seeking* and *persisting*) and four during the treatment phase (*informing*, *deciding*, *limiting*, and *affirming*) (see Table 1).

Overarching Theme: Advocacy

Parents were involved in their children's medical care through speaking and acting on behalf of their children. They emphasized the importance of being active, informed, involved, and "a key part of the whole process." Parents stated that they "made critical decisions" and participated as "an incredibly important member of their child's medical team." Or as another mother explained, "You're your child's only advocate. You've got to stay on top of it. You have to explain, because no one knows what your child is feeling or going through."

TABLE 1.
Themes Related to Parental Participation in Medical Care for Their Children With Cancer

<i>Theme</i>	<i>Definition</i>
Overarching theme: parent advocacy	The practice of speaking and acting on behalf of their child, as an intercessor and champion to ensure that their child's needs were met.
Strategies of advocacy during the diagnosis phase	
Seeking a medical explanation for symptoms	Noticing that something is wrong with their child and presenting their child to medical professionals
Persisting to get an accurate diagnosis	Continuing to pursue an accurate diagnosis even in the face of inconclusive results, dismissal, or opposition
Strategies of advocacy during the treatment phase	
Informing themselves about their child's medical status and needs	Gathering, organizing, and managing medical information about their child and his or her diagnosis
Deciding about their child's medical treatment	Determining a course of action related to all aspects of their child's medical care
Limiting medical procedures for their child	Restricting some activities of medical staff performed on behalf of their child
Affirming their child's medical professionals	Actively and intentionally supporting and fostering relationships with medical staff

Some parents were emphatic that they wanted to encourage other parents to advocate too. One mother stated, "That is why I wanted to come here, for people to know that you have to be the voice for your child. You have to be there. You have to pay attention and know what's going on." Even during the focus group, they encouraged each other to speak out about their roles as advocates: "learning to be an advocate for your child. That's something—keep going on that. [speaking directly to another parent:] That's something we haven't touched on, and I think that was really, really important. The advocacy part of this."

Parents also discussed ways in which it is difficult to advocate for their children, given the medical context. As one father stated, "You know what your kid needs, but you also don't know how to spell what they just told you that they have." The disconnect between parents' intimate knowledge of their children and limited knowledge of medical terms and procedures made it difficult for some parents to advocate for their children. Furthermore, given the high regard for medical professionals in our culture, some parents said

they did not know whether it was okay to press the medical team, particularly the physicians, when they had questions or concerns because they did not want to be disrespectful. Other parents talked about being intimidated by the environment or by the physicians. As stated by one mother, "You don't know what questions to ask. I just never knew to say 'No. I don't like what you're doing. I don't think that's right.' I never knew. I never grew up that way, so I didn't know." Despite these difficulties, parents used various strategies to advocate for their children throughout diagnosis and treatment.

Advocacy During the Diagnostic Phase

Parents expressed two main strategies of advocacy during the diagnostic phase: seeking a medical explanation for their child's symptoms, and persisting to obtain a diagnosis.

Seeking a medical explanation for symptoms. Parents of 23 children in all seven groups described the period when they noticed that something was wrong with their children and took their children to medical professionals to find out what the problem was. In doing so, they

functionally initiated the process of testing, diagnosis, and treatment. For example, one mother described noticing that her daughter had a cough, "So we went in and saw a pediatrician, and they did a chest x-ray." The x-ray showed a mass in her daughter's chest, and further testing led to a diagnosis of neuroblastoma. Parents noticed symptoms in their children such as sore throats and painful limbs, difficulty sleeping and eating, an elevated temperature, and a lack of energy. Many of these symptoms were not especially unusual, but because parents know the nuances of their own child's behavior, many insisted that doctors view their children's symptoms as something beyond a common or nonserious illness.

Persisting to obtain a diagnosis. After seeking a medical explanation for their children's troublesome symptoms, parents of a third of the children ($n = 9$) in six different groups described their persistence in pursuing an accurate and complete diagnosis. Persisting was described as continuing in the face of opposition.

In some instances, parents pursued the diagnosis despite the fact that their children were already receiving treatments. In part, this was driven by parents' realization that these treatments were ineffective. One mother and father described how their 2-year-old son was given several rounds of antibiotics before being diagnosed with cancer:

We went through several weeks where he had fevers and was sick. And we went through a 10-day cycle of one antibiotic. That didn't work. And then it came right back. And so they just gave another antibiotic and many trips to the doctor before they—it even dawned upon them to check anything beyond that it was just another infection. Once a week for 4 weeks, for a month, we went to the doctor. Kept coming back there. This is not getting any better. He still has a high fever.

Parents also persisted despite the fact that doctors were testing their children for various

problems and the tests were coming back negative. One set of parents took their 12-year-old daughter for a series of tests (for mono, kidney problems, etc.) over a period of approximately 5 months before she was accurately diagnosed.

One painful obstacle described by several parents was being treated in a patronizing or disrespectful way by medical professionals. A mother whose 17-year-old son was cocaptain of his school swim team when he first showed symptoms described a physician's behavior:

They were working on his stroke with him. All he did was get worse and worse and worse. And then he was just tired. Well, I thought the coach was working him too hard. Then he got a low-grade temp. And he had it for two weeks. Took him in. Basically told, you know, it was the pat on the head. "You're overreacting. Go home." Well, 2 weeks later, it was like, I had had it. That was it. Took him in and I said, "You know, just do whatever." They took a chest x-ray and they found a mass. And so the doctor just said, go home, decide where you want to go [for treatment]. Go home, pack your bags, and be prepared to stay up there for a week.

A mother described a doctor's shaming behavior toward her 16-year-old daughter when they initially sought help because her daughter was complaining of sore shoulders; the diagnostic process took more than 6 weeks:

We went back to our family doctor several times because this didn't get any better, and didn't get any better. And then we saw different doctors in the group. We saw one doctor that was very short with [daughter's name] and shamed her, and that was very hard. I still, to this day, I still am really trying to forgive this doctor for being so shaming of our daughter.

Once their children were diagnosed with cancer, parents transitioned into the treatment phase. This was typically a long process (lasting a year or more for 12 children), throughout which parents advocated for their children.

Advocacy During the Treatment Phase

Parents expressed four main strategies of advocacy during the treatment phase: (a) informing themselves about their child's medical status and needs, (b) deciding about their child's medical treatment, (c) limiting medical procedures for their child, and (d) affirming their child's medical professionals.

Informing themselves about their child's medical status and needs. Parents of 21 children from all seven groups mentioned ways in which they informed themselves by gathering, organizing, and managing medical information following diagnosis. They believed that their ability to be effective advocates was based on being well informed on medical issues. One father of a 3-year-old daughter with cancer illustrates the importance of being an informed parent: "Tell us more. Give us everything you can get. We want it all. We want to know. We want it. We want the information." Later, this father indicated what he did with the information: "They gave me this booklet. And I read it. I read that thing. I had it memorized. I had everything memorized."

Two major types of information were gathered and managed by parents: information specific to their child's health and medical status, and general information about pediatric cancer and treatment. The following quote illustrates both types of information:

The thing that you bring to the team that nobody else does, is you can notice those little finite differences in your child that may indicate something significant in their health care. You need to be aware of that. You need to document those things. You need to ask questions about those things. Write it down. Write the question down when it occurs to you. Get an answer as soon as you can. If you don't understand the answer, you ask it again. And if they still can't straighten that out for you, then you have to ask to talk to somebody else about it. And then you write down the answer.

Several aspects of informing are illustrated in the quote above. First, the mother talks about

tracking her child's health. Then, she talks about gathering information from medical professionals. She also mentions strategies for getting information (such as noticing differences in her child and asking questions), as well as strategies for managing information (such as documenting differences in her child, writing down questions, and writing down answers to questions).

What were the important sources of information? For information pertaining to the child's health and medical status, the child was a vital source of information. Parents described tracking changes in their children through observing them, taking their temperature, noting when their children complained or mentioned that something hurt, and noticing when movement was impaired. In other words, parents were vigilant.

For information about pediatric cancer and treatment, parents described accessing books and the Internet. The father of a son with cancer described the Internet as a source of information but one that needs to be evaluated carefully:

I got on the Internet, just started researching as much as I could. What I read wasn't good, but we then learned that what you read is outdated so quickly. So you kinda learn to sort through that a little bit, too.

In addition to accessing books and the Internet, parents gathered information about cancer and treatment by talking to medical staff. In some cases, parents had to insist that medical staff slow down and answer their questions. A father described how he and his wife gathered information from medical professionals immediately after their 2-year-old son was diagnosed with leukemia:

They had this entire plan of attack mapped out and they were ready to begin, and we weren't ready to—we didn't know anything about it and what this involved and how serious it was. So we made them stop and talk to us, and answer some basic questions 'cause things were moving so fast. We wanted to see if there were any other options.

Parents also talked to other parents of children with cancer for hints, ideas, and tips, and in several instances, parents talked to family members and friends with medical expertise.

How did parents manage information? Parents described writing down questions to ask as well as answers to their questions, writing their children's medications and dosages, and writing the results of children's medical tests. Several parents mentioned the importance of keeping a journal with all of this information. A mother described carrying information about her 17-year-old son's leukemia treatment in her purse:

I carried my son's counts in my purse at all times. I never took them out of my purse. I knew what his counts were from every time he went in because in case something came up. No matter what it was.

Managing information may involve skills for remembering to ask questions as well as skills for tracking information once it is gathered. A father described how he and his wife worked together to gather and track information about their daughter's treatment for cancer: "I remember a lot of stuff, but she'd [his wife] write down the questions to ask for the next time. I wouldn't remember questions to ask, but it was easier for me to keep the information catalogued."

As advocates, parents used the information they gathered in the course of their children's treatment and in making decisions regarding their children's medical care.

Deciding about their child's medical treatment. Parents of 13 children in all seven groups discussed decisions they made with regard to their children's medical treatment. Deciding was defined as determining a course of action that was related to their child's medical care. As stated by the mother of a 4-year-old son with cancer, "I was making the decisions." Parents reported deciding which medical facility to use for treatment and, to an extent, choosing members of their children's medical team (such as doctors and nurses). When parents became aware of changes in their children's symptoms or health status,

such as their temperature, they decided when it was necessary to bring their children for additional medical care. Parents of a 2-year-old with cancer decided to seek specialty care when local emergency care proved inadequate:

We had [daughter's name] line come out. We thought it was out. We went to the emergency room and the doctor there said, "This is a secure line. It's fine." The next day, I went to school. [Father] stayed home with [daughter] and called the surgeon, and he [the surgeon] said, "I want to see her." And her line was—it was out. And so you have to go with your gut.

Parents also decided whether to allow experimental treatments. A mother described how she and her husband decided to try an experimental chemotherapy treatment for their 1-year-old daughter's eye cancer:

We had to decide what kind of treatment to give her. . . . It was caught early enough. And a miracle there was. At that time, [daughter's name] was one of the first to be treated with chemo for retinoblastoma at this early stage. And so that was kind of new. . . . So by the time we left the hospital, we had told them we'll do the chemo. So we had made a major decision.

Another mother described having the option of whether or not to treat her 7-year-old daughter's cancer, which was at an advanced stage when it was diagnosed:

I remember them giving us the option, you don't have to have treatment, and then she has 2 to 3 months to live. It was like, oh! How can you not do anything. Then you think, well 20% [chance of survival with treatment], it's better than nothing.

These parents chose to treat their daughter. She survived and was 11 years old at the time of the focus group.

In many cases, parents described working with medical staff to make decisions about scheduling treatment, such as accommodating special events

in their children's lives (homecoming, prom, graduation, etc.), or the parents' work schedules, as indicated by this mother:

So the doctor and I decided, this is what we'll do. . . . We just had to work out a schedule. That was the hardest thing for me and for them [the medical staff] because they were trying to work with me.

Limiting medical procedures for their child. Parents of 7 children in four of the focus groups reported limiting the work of medical professionals by restricting specific treatment activities of medical staff. These limits were based on information parents had gathered or on gut feelings. As stated by a father whose son was 1 year when he was diagnosed with cancer, "Whenever you got out of your comfort zone, then you really got to get your fingers in there and say 'no.'"

Parents also limited medical staff by insisting on changes in timing. A mother of a 2-year-old with cancer told medical staff, "You're not going to check her blood pressure right now. She's sleeping."

Parents also described placing limits on how staff interacted with their children. One mother described learning how to speak up and intervene when she felt that a nurse was pushing her 7-year-old daughter too hard to swallow pills:

On her shift, she [the nurse] was going to make her [the daughter] swallow a pill. It was horrible. To this day, [daughter's name] will not even try to swallow a pill. She had to taste all those horrible medications because she got pushed the wrong way. I think if we could have tried to intervene, if we had learned—after I observed this for awhile, I pulled the nurse aside and said, "You know what? This isn't going to work. And you need to just lay off." And we—so we learned to be forceful in those kinds of situations.

In some cases, parents intervened to stop medical staff from proceeding with what they believed to be an incorrect treatment. A mother who carried written records of her 17-year-old son's cancer treatment in her purse at all times indicated,

There were a couple of times I had to have them pull the blood right out of him 'cause they were giving him the wrong stuff. And I was very specific. I wrote everything down. I knew everything about it. Everything.

Affirming their child's medical professionals. Parents of 6 children in five groups described ways in which they affirmed the medical professionals who worked with their children. Affirming was defined as actively and intentionally supporting and fostering relationships with medical staff. As described by one mother whose daughter was 15 years when she was diagnosed with cancer,

What we also did as part of that team is that we were really affirming of everybody on the team. We weren't negative towards them. Like teachers in school, the more involved you are as a parent in your child's education, the more involved you are in the medical care, affirming of them. [Husband's name] would go and bring cafe lattes and we'd bring flowers or jokes. Given the choice of working with two people and two families, human nature being what it is, who are you going to work with? You're going to work with the affirming family. You're going to work with the involved family. You're going to work with somebody that's going to work with you.

Other affirmations described included intentionally thanking medical staff, sending holiday cards, and purchasing or making gifts.

The relationships that parents established with medical professionals extended throughout treatment and sometimes continued after treatment was over. As one mother indicated, "For years, we went to visit them every time we came, to run up and see who was on the floor. They became like family. Christmas time, I was making gifts for them. They were like family." Parents mentioned maintaining these relationships through activities such as seeking out medical staff during follow-up visits, meeting them for lunch or dinner in conjunction with follow-up visits, and in one case, inviting a doctor to their child's wedding.

Discussion

These results highlight two important guidelines from the SIOP working committee on psychosocial issues in pediatric cancer: (a) the stressful nature of the diagnostic period and the need for careful communication between health care staff and family members of the child (Masera et al., 1997) and (b) the need to develop a therapeutic alliance between the family and the treatment team (Masera et al., 1998). This study describes ways in which parents advocated for their children through the diagnostic and treatment phases of cancer. It contributes to the discussion in the medical field about family-centered care, which emphasizes collaboration with the family and views the family as members of the medical team.

In many ways, advocating for your child is part of the expected role of being a parent. Generally, parents try to ensure that their child is treated fairly and is given the same opportunities as other children in their social context. What sets these parents apart is that they faced a life-and-death situation, which added to their vigilance, active support, and intercession on their child's behalf. Furthermore, the very nature of cancer, with its uncertain prognosis and painful treatments, contributes to the vulnerability and powerlessness parents felt. Actively advocating for their children's needs appears to be one important way parents were able to restore some small sense of control and a sense that they were protecting their child the best that they could. It was a way to cope with their own grief and uncertainty.

Parents' descriptions of ways in which they participated in their children's care are consistent with the key elements of family-centered care. One such element is the importance of information, both general and specific to the child (King et al., 1996, 1999; Rosenbaum et al., 1998; Woodside et al., 2001). This study confirmed that information is important to parents—general information about cancer and information specific to their child's health status. In addition to providing information to parents,

medical teams are encouraged to seek child-specific information from parents.

The results of this study lend support to another tenet of family-centered care: shared decision making and supporting parents in making medical-related decisions (Dunst, Trivette, Davis, & Cornwell, 1988; King et al., 1996, 1999; Macnab et al., 2000; Rosenbaum et al., 1998; Woodside et al., 2001). The parents in this study implicitly were acknowledging their own expertise when they sought medical advice for their children's symptoms and when they persisted in getting an accurate diagnosis. Throughout the treatment process, parents maintained their expertise by being vigilant and noticing and responding to small changes in their children that they deemed potentially important to treatment. The parents in these focus groups were adamant in wanting to communicate to other parents how important it is to provide active support for your child by interceding on their behalf when some procedure seems ill timed or unwarranted.

Another element of family-centered care is the view that parents are members of the health care team with whom medical professionals collaborate (Dunst et al., 1988; King et al., 1996; Macnab et al., 2000; Rosenbaum et al., 1998; Woodside et al., 2001). Most of the parents in this study viewed themselves as active members of the health care team, an identity that is consistent with seeing themselves as decision makers and as experts on their children. In many instances, parents were encouraged and supported in this role by the health care team. The SIOP guidelines for developing a therapeutic alliance (Masera et al., 1998) also are consistent with respect and support for parents' active collaboration with medical professionals. The therapeutic alliance is strengthened when this respect is mutual and was evidenced by parents' descriptions in this study of their affirmations of medical staff.

Limitations

These results must be considered within the context of several limitations. The study partici-

pants were a convenience sample and not a randomly selected sample of parents with children who survived cancer. They were volunteers from a single academic health care institution who responded to a single letter asking for their participation. Parents who chose to participate may have been more active in advocating for their children compared with those who did not respond to our letter of invitation or those who were not represented in the patient base. It also should be acknowledged that the questions posed to the focus group participants were not originally designed to elicit information about how parents were involved in their children's medical care. Hence, the transcripts of the focus groups may not have captured the full range of ways parents potentially were involved. Furthermore, there were no specific probes about differences between medical professionals in various roles (e.g., doctors, nurses, social workers). However, it is significant that general information about medical professionals did surface within the context of the broader discussion of families' experiences, including stressors and coping behaviors, with respect to their children's cancer. Furthermore, our data only reflect parents' descriptions of their experiences, without the balance of input from medical professionals' perspective.

Data also are based on recall and are subject to the limitations of parents' memories. There was considerable variability in the period of time (1 to 9 years) that had elapsed since these children were treated for cancer. Hence, the length of time since diagnosis, the time in remission, as well as subsequent and cumulative life experiences may have influenced their retrospective reports. However, the intensity of these experiences often leaves an indelible memory in parents' minds, readily accessible in rich, descriptive terms when asked about it—even years later. It is also possible that in the 9-year span during which these children were treated, the way medical professionals relate to parents may have changed. Certainly, the emphasis on family-centered care has increased during this time period. However, the

small size of our sample precluded any meaningful analysis of differences in parents' descriptions in terms of elapsed time since diagnosis and treatment.

Limitations associated with focus group research also are applicable to the present analysis: Some themes were discussed more thoroughly in certain groups, and the topics discussed were influenced by the comments of other group members (Krueger, 1994). In this case, some parents may have presented themselves as more active and involved in their children's medical care in response to comments of other group members. It is quite possible that some parents do not advocate for their children or that some parents advocate in ways other than the strategies identified here.

These limitations, as well as our study results, point to future research directions. Within a qualitative framework, sampling by developmental stage of the child, time since cancer treatment or time in remission, or parent/family demographics such as level of education may shed additional light on variability in parents' involvement in their children's medical care. The perspective of health care professionals about parent involvement would also be informative. Furthermore, a quantitative analysis of the relationship between key elements of parent-professional collaboration and child and family outcomes is warranted.

Implications and Conclusions

One mother recommended that medical staff explicitly tell parents that they are members of the medical team and outline for them their roles as parent members of the team:

I think when they [parents] are first brought in and they're told all these thousands of things, they need to be told what their role is. People don't know what their role is. . . . So right away, the medical team needs to identify them as you're an important part of this team, a nonmedical person, but there's a lot of nonmedical people on your team—and tell them how important it is to be that

advocate, to learn what they can, to pay attention, to document.

This quote suggests that parents want nurses and other medical professionals to help socialize them into actively participating in their children's medical care. What messages might the medical professionals pass on to parents that are consistent with the results of this study? First, they could help parents define themselves as members of the medical team. Second, medical professionals could encourage parents to pay attention, learn everything they can, and document changes in their child's condition and response to treatment. Parents could be encouraged to use a tablet or notebook to gather and manage information, including medications and dosages. Third, parents could be encouraged to be the voice for their child by explaining changes in the child or describing what the child is experiencing. Fourth, and perhaps most challenging, would be for medical professionals to remind parents that they can say no, and they can set limits on certain aspects of the treatment and encounters with medical staff.

Clearly, many medical professionals, particularly nurses and social workers, already engage in this kind of family-centered care to the benefit of both patients and their family members. As new medical professionals are being trained, active inclusion of parents as members of the medical team should be encouraged, and skills should be taught for effectively engaging a range of different types of families in their children's treatment. Family involvement is one manner in which parents can feel some sense of control in a context where many feel helpless and hopeless. As stated by one mother, "I think it's important that parents know that they have [some] control over what's going on."

It is expected that the benefits of this kind of family involvement in the diagnosis and treatment phases of childhood cancer will be evidenced in positive medical outcomes, including reduced stress and higher psychological and emotional well-being for both parents and children.

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