Making the Right Decision for My Child With Cancer

The Parental Imperative

**KEY WORDS**
Child
Decision making
Parent

**Background:** Making major treatment decisions with life-altering consequences is a significant challenge faced by parents of children with cancer. The unique experience of parents is not well represented in the growing literature on cancer treatment decision making (TDM). **Objective:** The objective of this study was to describe the process of parents making major treatment decisions for their children with cancer. **Methods:** Using grounded theory methods, we interviewed 15 parents of 13 children with cancer facing major treatment decisions. **Results:** Parents’ determination to make the right decision was both a demanding responsibility and a natural extension of the parental role. Everything parents encountered and undertook during the TDM process was in the service of making the right decision for their child. All parents expressed conviction that they had made the right decision, but conviction was tempered by doubts triggered by the pervasive uncertainty of the childhood cancer experience. Parents described limited TDM participation by extended family members and the affected children themselves, asserting their primary responsibility to act as their child’s surrogate in partnership with the child’s medical team. **Conclusions:** Making the right decision for one’s child under challenging conditions is an extension of the parental obligation to act in the child’s best interest and a responsibility that parents claim as their own. **Implications for Practice:** The findings from this study can serve as the
ne of the most significant challenges faced by parents of children with cancer is making major, life-altering treatment decisions. These decisions take place in the context of pervasive uncertainty, acute emotional distress, and complex relationships among family members and healthcare providers. Having responsibility for decisions that will affect their child throughout the life span, the challenge of discerning and representing the perspectives of younger children, and the responsibility to act in their child’s best interest distinguishes parents from adults making decisions about their own healthcare. Understanding the treatment decision making (TDM) process is critical to designing interventions to support parents facing this major challenge and promote families’ optimal well-being.

The childhood cancer literature identifies several important factors that can complicate the TDM process. A child’s cancer diagnosis generates intense emotional distress, strains resources, and disrupts personal and family equilibrium. The intense emotional milieu that surrounds TDM has been characterized as “stress unbelievable,” places family members at risk for clinical levels of anxiety and depressive symptoms at times when decisions must be made, and can impair their ability to participate optimally in making informed decisions. The life-threatening nature of the illness, the harsh demands and risks associated with treatment, and the need to act quickly can undermine parents’ sense of decision-making competence and render them dependent on healthcare providers for information and guidance. Having to make critical decisions under these difficult conditions heightens parents’ awareness of the uncertainty inherent in the childhood cancer experience and intensifies their emotional distress.

The emerging parental TDM literature suggests that participating in such high-stake decisions could have an impact on parents and families. Whereas there is a strong belief among healthcare providers that increased participation in TDM is desirable, parents’ preferences for how they participate vary both by individual and across contexts. There is also concern that participating in TDM could lead to negative outcomes, including regret. However, there is limited empirical evidence for specific TDM outcomes that should be targeted for intervention, and the largely descriptive literature has not yet led to theory development, which could direct interventions to facilitate optimal decision making.

The purpose of this grounded theory study was to describe and explicate the TDM process from the perspectives of parents of children with cancer.

**Methods**

**Design**

This qualitative study utilized grounded theory methods to describe and explicate the TDM process from the perspectives of parents of children with cancer.

**Procedures**

Using a semistructured interview guide developed by the investigators, we asked parents to reflect on the treatment decision they had most recently made as well as others they had made since their child’s diagnosis. Interview questions focused on parents’ thoughts and feelings leading up to, during, and following the decision; participation of others in the process; and the impact participating in TDM had on themselves and their family (Figure 1). The interview guide underwent several revisions throughout the course of the study as the constant comparative analytic technique identified additional threads of inquiry.

The institutional review boards for the participating sites approved the study. Physicians and nurses identified potential subjects and determined their willingness to talk with an investigator about the study. The investigators met with willing parents in the clinical facility and obtained written informed consent. Parents were interviewed by the investigators in private clinical or academic offices close to the treatment setting, and

---

Copyright © 2012 Lippincott Williams & Wilkins. Unauthorized reproduction of this article is prohibited.
the interviews lasted an average of 45 minutes. Interviews were audiotaped and transcribed verbatim. Parents were given a $15 gift card as a token of appreciation.

Data Analysis

Transcripts, written field notes, and memos documenting analytic insights constituted the data for analysis. Each investigator read deidentified transcripts and generated general impressions about the interviews. Transcripts were entered into a qualitative analysis software program (ATLAS.ti) to facilitate collaborative coding. Analysis began following the first interview and continued simultaneously with data collection. The 3 investigators worked collaboratively to establish codes, identify emerging themes, and refine data gathering techniques, with weekly conference calls and 5 face-to-face meetings during the study period. Extensive memos documented coding and sampling decisions made at each step in the data analysis.

All 3 investigators coded the first 3 interview transcripts independently, then discussed each significant passage and collectively arrived at first-level codes. For subsequent interviews, 1 investigator who had not conducted the interview undertook primary coding, after which the transcript and codes were circulated to the other 2 investigators for discussion and commentary. Earlier interviews were reexamined and recoded as new first-level codes were identified. Axial coding began following completion of the first 6 interviews and was used to establish higher-level codes and examine relationships among families of codes. Selective coding was used to establish the core category and refine relationships among concepts and categories. Accrual to the study was closed when new no codes or relationships emerged; that is, data saturation was achieved.

The collaborative approach to grounded theory analysis contributed to the scientific rigor of the study in several important ways. Using meticulous peer debriefing throughout the constant comparative analytic process, individual investigators were challenged to support every new insight, emerging theme, and link between codes with substantial evidence from the interviews, thereby ensuring that the analysis remained grounded in the data. The extensive combined clinical experience of the investigators provided a solid foundation upon which to confer meaning to the parents’ narratives. Consultation with an established nurse researcher with extensive experience in both grounded theory analysis and pediatric oncology practice provided additional oversight and feedback.

Setting and Sample

Participants were recruited from the pediatric oncology clinical practices affiliated with the authors’ institutions, one each in the mid-Atlantic, Midwest, and Pacific coast regions. We initially targeted parents of children with cancer who had made a major treatment decision within the previous 8 weeks, but quickly realized that this time frame was insufficient for the impact of participating in TDM to become evident. We therefore broadened the eligibility criteria to include parents who had made major treatment decisions within the previous 6 months. Variation was sought in analytically relevant variables such as the child’s age, diagnosis, and prognosis; the nature of the decision made; and family structure.

Fifteen parents (9 mothers and 6 fathers) of 13 children participated in the study (Table). The couples who participated were interviewed separately. One mother was interviewed twice, 10 months apart, at 2 different decision points; the other parents were interviewed once. Ten parents had participated in the decision whether to enroll their child on a clinical trial (2 mothers had declined the trial) and 5 parents in the decision to treat their child with hematopoietic cell transplantation (HCT) following 1 or more relapses of leukemia.

One parent who agreed to participate in the study withdrew before being interviewed because of her son’s deteriorating condition. Two parents who were identified as potential subjects by clinicians chose not to participate in the study, one because she felt overwhelmed by the demands of her child’s illness and the other because of lack of interest.

Findings

The central theme that distinctly characterized parents’ TDM experiences was making the right decision. Parents spoke compellingly about the imperative they felt to make the right decision, and it was this determination that drove the decision-making process. Making the right decision was both a demanding
responsibility and a natural extension of the parental role. Several noted that it was one of the hardest things they would ever do, but all willingly assumed the burden because it was their job. The centrality of this theme was underscored by the use of the word *right* in phrases such as “right decision,” “doing what was right,” and “doing the right thing,” by every parent in the study.

The process of making the right decision is represented in Figure 2. The factors that motivate parents to make the right decision are depicted as antecedent to the process, and the emotional and spiritual aftermath of participating in the decision constitutes its outcomes. Additional elements of the conceptual model are the decision-making strategies parents use to make the right decision and conditions that either challenge or support parents’ efforts to make the right decision.

### Parents’ Motivation for Making the Right Decision

#### PARENTAL ROLE

All parents described their compelling sense of responsibility to do what was in the best interest of their child. They reflected on what it meant to be a parent in general, focusing on the nature and defining qualities of their relationship with their child. They also described the advocacy and protectiveness that came along with being the parent of a child with cancer. Making the right decision was consistent with all the other responsibilities they undertook on their ill child’s behalf, such as protecting their child from harm, putting the child’s needs first, and disciplining or disappointing the child when it was for his/her own good. Parents felt strongly that their children trusted them to act in their best interest, which increased their motivation to make the right decision. This obligation to act as their child’s surrogate in making decisions could feel daunting, but parents never considered shirking this critical responsibility. As one mother stated:

> You find yourself asking, why am I making this decision? I just learned about these drugs in the last 24 hours…but you have to do it as a parent.

#### CHILD QUALITIES

Parents described specific qualities manifested by their child that in part determined which treatment option they chose. Parents described their child’s positive qualities, such as strength of character, willingness to help others, or positive attitude. In addition, a few parents acknowledged the degree to which being ill challenged their child’s adjustment and/or quality of life, which put additional burden on the parent to make the right decision. For one mother, her daughter’s aversion to prolonged

---

**Table ** Sample Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Frequency (%)</th>
<th>Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent age, y</td>
<td>39.7 (6.0)</td>
<td>(range, 33–54)</td>
</tr>
<tr>
<td>Parent gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>6 (40)</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>9 (60)</td>
<td></td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hispanic</td>
<td>5 (33)</td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>10 (67)</td>
<td></td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married</td>
<td>9 (60)</td>
<td></td>
</tr>
<tr>
<td>Unmarried</td>
<td>6 (40)</td>
<td></td>
</tr>
<tr>
<td>Parent education level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>High school/GED</td>
<td>5 (33)</td>
<td></td>
</tr>
<tr>
<td>College degree</td>
<td>7 (47)</td>
<td></td>
</tr>
<tr>
<td>Graduate degree</td>
<td>3 (20)</td>
<td></td>
</tr>
<tr>
<td>Parent employment</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Employed</td>
<td>11 (73)</td>
<td></td>
</tr>
<tr>
<td>Full-time caregiver</td>
<td>4 (27)</td>
<td></td>
</tr>
<tr>
<td>Child age, y</td>
<td>10 (4.2)</td>
<td>(range, 3–17)</td>
</tr>
<tr>
<td>Child diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Leukemia</td>
<td>10 (77)</td>
<td></td>
</tr>
<tr>
<td>Solid tumor</td>
<td>3 (23)</td>
<td></td>
</tr>
<tr>
<td>Decision context</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical trial</td>
<td>10 (77)</td>
<td></td>
</tr>
<tr>
<td>HCT</td>
<td>3 (23)</td>
<td></td>
</tr>
</tbody>
</table>

Abbreviations: GED, general educational development; HCT, hematopoietic cell transplantation.

---

**Figure 2** The process of parents’ making the right decision for their child with cancer.
hospitalization influenced her choice to proceed with HCT, which she saw as preferable to several years of treatment:

She hates having to stay here, you know.... That’s the hardest part on her, and, um, that’s why, you know, that decision was—I’m not saying that it was easier for me to make it, but I just I felt like that was the right thing to do....

Parents’ privileged knowledge of their child and the intimacy of the parent-child relationship put them in the position of knowing their child best and acting in their child’s best interest.

ALTRUISM

An additional attribute identified as a critical antecedent to the decision-making process was parents’ sense of altruism. Parents spoke about the importance of potential improvements in care for future children with cancer, particularly in the context of whether their child would participate in a clinical trial. One parent whose decision was not to have her child participate in a clinical trial still emphasized the value of contributing to other children’s well-being if doing so conveyed no additional risk or burden for her child.

Challenges to Making the Right Decision

Parents consistently identified 2 factors that intensified the stress of making the right decision, and constrained parents’ ability to use their usual decision-making strategies.

EMOTIONAL CONTEXT

The intensely negative emotions that surrounded the illness pervaded the TDM process. Parents’ rich descriptions of these high-stakes decisions included strong words such as “overwhelming,” “scary,” “heavy,” and “gut-wrenching.” They acknowledged the major impact of the child’s illness on their mood, including anxiety, depression, helplessness, and anger. One parent described experiencing

...exhaustion—emotional exhaustion—is pretty much it. I mean, it’s always on your mind, whether it’s on the forefront or somewhere simmering on the backburner, but it’s always there, something you always have to deal with no matter what.

This intensely emotional context not only increased parents’ level of stress but also undermined their confidence in being able to make the right decision.

UNCERTAINTY

Uncertainty, like negative emotions, pervaded the childhood cancer experience and defined the context within which decision making took place. Many parents were encumbered by their lack of knowledge about their child’s illness and treatment, particularly if their child was recently diagnosed, which compromised their ability to make the right decision:

It’s that unknown... of not knowing. You know, you get as much information as you can possibly get, and use that so you’re making the right decision for him. And the unknown, the not knowing—because right now you still can’t see the progress—and the not knowing is probably the hardest thing to go through.

Parents had difficulty expressing the potential life threat their child faced. Few were as frank as this mother, whose son faced a second HCT:

Just not knowing if it is going to kill him—the transplant—or if it’s going to be alright, or if he is going to have major complications. You know, the unknown is more present this time—well, the first time it was too, but I think we’ve been through so much already, and we’re tired, so the unknown is harder.

Uncertainty made the decision making more difficult and intensified its emotional impact.

The Process of Making the Right Decision

Despite the formidable emotional and cognitive disruption created by their child’s condition, parents engaged fully in the TDM process. They endeavored to understand every aspect of the decision and consider its impact on their child and family.Parents saw their primary goal as affording their child the best chance of cure, but when possible, they also considered secondary goals such as preserving the child’s present and future quality of life. Interestingly, several parents described the goal of these major treatment decisions as indistinguishable from other, day-to-day cancer decisions, such as how to manage adverse effects—the universal goal was to provide the best possible outcome. However, being aware of the magnitude of the consequences of the treatment decisions contributed to the intensity of the TDM process. As one mother described,

...so it’s not so much the choice, it’s just you are making decisions about your child’s life with cancer.... It’s a very, very hard and stressful thing to know that you are making decisions on your child’s life.

DECISIONAL CONTROL

The degree to which parents felt they exerted control over the decision varied along a continuum from entrusting the decision to the physician to making the decision independently. All respondents described an interactive process between themselves and the oncologist, even those that described near decision-making autonomy. Several parents noted that they asked for or were given a recommendation by their physician and, following the physician’s recommendation, promoted their satisfaction and confidence that they had made the right decision. For one couple, the physician’s reluctance to make a recommendation (in an attempt to remain neutral about whether the child went on a clinical trial) was problematic. Although they understood the physician’s position, it was disconcerting not to feel guided by the physician’s knowledge and expertise.
Well, coming in, you just expect the doctor to say, “This is the treatment, here is what we’re going to do.” We appreciate there was a study available, but then we had to make the decision—which looking at now, I’m glad we had the options, I’m glad we got to pick, but at the time, when you’re under that much stress, you don’t want to make that decision… that’s when you prefer that somebody who’s in their profession makes the decision.

**DEGREE OF DIFFICULTY**

Most respondents described the decision-making process as very difficult, particularly in the context of their child having just been diagnosed with cancer or the disease returning despite aggressive treatment.

The treatment decision was really the most pronounced and difficult decision. Everything else is pale in comparison to that because of the risks that are involved in this treatment.

However, some parents felt the decision itself was not so difficult once they understood the options and could see a clear path to doing what was right.

To be honest with you, the decision that her mother and I made was actually pretty simple. It was rough getting to the point, finding out what she actually had, but…. Dr [doctor’s name] gave us the study information, we looked it over, and any questions we had she completely answered.

Several parents were presented with only 1 option they considered viable and described the decision as a “no-brainer.” Generally, the more options there were to choose from, the more parents struggled to make the right decision.

**CHILD’S INVOLVEMENT IN THE DECISION**

Most parents discussed their child’s involvement only when specifically prompted by the investigator. There was considerable variability in the degree to which parents elected to involve their child in the decision-making process. Some parents deliberately excluded their child, either because they felt their child was too young to participate or to spare even older children from the burden of participating in the decision. Parents carefully considered the child’s best interests in acting as surrogate decision maker and then kept them informed during the process or after the decision was made. Few parents actively sought their child’s input, and only 2 parents characterized their child as having made the actual decision (aged 9 and 17 years, both facing a second HCT for relapsed leukemia). Although there was the expected trend toward children being more actively involved in the decision with increasing age, the degree to which parents chose to involve their child was more reflective of whether they thought active involvement was in their child’s best interest.

**Strategies for Making the Right Decision**

The TDM process was clearly a painstaking one that required hard work, diligence, effective communication, self-examination, and heightened vigilance. In the face of limited evidence for the best course to follow, parents used familiar as well as novel decision-making skills. These strategies and skills contributed to parents’ confidence that they had met the challenges and indeed made the right decision.

**BEING CAREFUL**

Parents were meticulous and conscientious in making their decision, particularly when there were several viable options to be considered. They worked hard to be as careful as possible under difficult circumstances and an often limited time frame. The language they used to describe the process included such phrases as “considering all the possibilities,” “covering all the bases,” and “thinking it through.” Most parents explicitly described balancing risks and benefits in a deliberate effort to understand each option and consider what was best for their child. For some parents the process also included taking extra time, asking repeated questions, actively searching for additional information, and/or seeking a second opinion.

**LOOKING FOR SIGNS**

The uncertainty surrounding the TDM process was clearly reflected in many parents’ attempts to find signs, or markers, that they were on the right path. They sought inferential evidence to support a particular option, most notably by closely scrutinizing the physician’s behavior and emotional state when presenting key information. Parents remarked on the confidence or hesitancy with which physicians presented the options and attempted to interpret the mood of these key informants. One mother described her reliance on nonverbal language in evaluating the physician’s motivation in offering the option of a clinical trial and whether it represented the best option for her child: “It’s just—there is something in your eyes that tells. Body language is a lot harder to fake than words.” Several parents who were facing the decision of whether to proceed with high-risk HCT procedures saw as highly symbolic the availability of at least one matched sibling donor: “Since she was a match… we’ll take it as a good sign that things will come out good.”

**INVOLVEMENT OF OTHERS**

Very few parents turned to their social network of family and friends for assistance in making the decision; most talked about involvement of others only when specifically queried by the interviewer. Whereas a few parents explicitly sought information, supportive presence, and tangible assistance during the TDM process, most limited the interaction with their social network to keeping them informed once the decision had been made. In a few families, this was because of preexisting conflict, but even when parents described their social network as uniformly supportive, they emphasized that they had sought input only from the medical professionals most involved in their child’s care.

**PERSONAL FAITH**

In addition to the largely cognitive strategies parents used in being careful, most parents relied heavily on their personal belief.
systems and faith in God throughout the process. They described actively praying for guidance, feeling comforted by God’s presence, and putting their child’s life into God’s hands. In this way, they were relieved of some of the burden of decision making and derived a sense of peace that with God’s help they had made the right decision. Parents also described deliberately focusing on the positive in their child’s situation, remaining optimistic about the outcome, as a means of coping with the process and promoting their sense of confidence that they were making the right decision.

**Clinician Support for Making the Right Decision**

Parents spoke at length about their relationship with professional caregivers, focusing largely on the physician primarily responsible for their child’s cancer treatment. Parents described specific attributes that contributed to their perception that caregivers were caring and trustworthy, particularly availability, patience, personal involvement, honesty, and specialized knowledge. These attributes inspired parents to build therapeutic relationships with caregivers, which to some degree mitigated the negative impact of emotional arousal and uncertainty. Parents relied heavily on these relationships during the decision-making process and felt supported in their quest to make the right decision. A few parents described negative attributes that limited individual caregivers’ value and made the process more difficult, specifically emotional distance, apparent lack of knowledge and expertise, and coercion or pressure to make a decision. Parents marginalized caregivers who exhibited these attributes and formed stronger relationships with more caring and trustworthy caregivers.

When parents spoke specifically about trust, they referred to both individual caregivers and the profession of medicine generally or pediatric oncology specifically. Parents felt that the individuals and institutions they encountered had demonstrated their trustworthiness, although a few acknowledged that they really had no choice but to trust, given the situation. For these parents, granting trust eased the pressure they felt to make the right decision. Only 1 parent articulated a lack of trust in her child’s caregivers, specifically voicing skepticism about their motives in presenting the clinical trial in a positive light, which intensified the difficulty of the decision-making process.

**Beyond the Decision: Looking Forward**

Despite the neutral language we used to ask about parents’ experiences since making the decision, most parents responded defensively, questioning whether we were trying to uncover any second thoughts or regrets. Many parents said they had not looked back once the decision was made, experiencing relief that they could focus on the treatment now that it was underway:

> It was just the fact that we made the decision and were moving forward, getting the treatment. It’s such a tough disease, it’s such a shocking diagnosis that we were just ready to get on the road to a treatment and be able to do something.

Parents’ descriptions of the time since making the decision illuminated 2 powerful outcomes: the conviction that they had made the right decision, albeit tempered by doubt, and an emotional toll beyond that which was imposed by the diagnosis and treatment.

**CONVICTION TEMPERED BY DOUBT**

Virtually every parent used strong language to express their conviction that they had made the right decision. They said such things as “I feel confident,” “I know it was the right decision,” “I have no regrets,” and “I would make the same decision again.” Because the interviews took place within several months of parents having made the decision, most of them had no way of knowing what the outcome of their child’s treatment would be. Of note is that parents who had faced multiple major treatment decisions over time never questioned that their previous decisions had been the right ones for their child, even though their child’s disease had progressed or returned.

The intensity with which parents expressed the conviction that they had made the right decision came through most strongly in response to direct questioning about the time since the decision had been made. But throughout the interviews, parents repeatedly spoke about feeling at peace with the choice they had made:

> It’s just like a peace, a peace that I know I’m making the right decision. And that whatever happens, you know, I can accept it.

This sense of peace was the light at the end of the decision-making tunnel, the reward for working so diligently on their child’s behalf. It was promoted by their faith in God, their confidence in their child’s clinical team, the symbolic meaning they found in the details of their individual situation, and ultimately by their conviction they had made the right decision.

However, this conviction was typically tempered by doubt. Whereas a few parents claimed utter confidence and denied any second thoughts, most parents acknowledged that occasional doubts could creep in, particularly when uncertainty was triggered by something related to their child’s diagnosis or progress through treatment. Maintaining conviction about the decision often required deliberate reframing in the face of intrusive thoughts. As parents discussed their thoughts and feelings since making the decision, conviction and doubt were frequently juxtaposed in the same passage, reflecting ongoing efforts to manage the uncertainty:

> Well, you think about, “Is she on the right treatment; is it working?”—that is it. You don’t go backward, you don’t second guess, you don’t do anything like that. You go forward, you stay positive, and you pray every day that it is working.

**EMOTIONAL TOLL**

The TDM process took an emotional toll on parents beyond the impact of their child’s cancer diagnosis and treatment. The imperative to act in their child’s best interest and make the right decision intensified the emotional milieu of fear, grief,
worry, sadness, and anxiety within which they already functioned. The TDM process itself acted as a trigger of the uncertainty that parents might otherwise hold at bay, heightening the emotional arousal parents already felt from their child’s diagnosis or relapse. Despite expressing the conviction that they had made the right decision, parents acknowledged feeling overwhelmed and exhausted by the process:

You feel like, “I just want to run away and I never want to look back…” And it’s like a twisting, gut-wrenching type, hard decision-making thing, because as much as you don’t want to do, as much as you have to do it, it’s really, really hard.

■ Discussion

The primary contribution of these findings to the understanding of parental TDM is the illumination of the intensity and commitment with which parents seek to make the right decision on behalf of their child with cancer. Making the right decision is a natural extension of the parental role, of acting in one’s child’s best interest, and ensuring the best possible outcomes. Similar to Shilling and Young’s28 description of parental permission in pediatric clinical trials, parents acknowledge the profound weight of this responsibility, but they claim it as their own and diligently work under daunting circumstances to carry it out. Several studies have reported that making decisions in their child’s best interest is a critical aspect of what it means to be a “good parent” of a child with cancer.3,5 Together with our findings, these studies underscore the assertion of Bluebond-Langner et al29 that life-threatening illness and the decision making it engenders become the context within which parenting is defined.

The pervasive uncertainty described by parents in our study echoes findings from multiple studies characterizing uncertainty as one of the most stressful aspects of parenting a seriously ill child.14,30,31 Whereas uncertainty related to limited knowledge and experience can often be ameliorated, having to make decisions when the consequences and outcomes of various treatment options are unknown—a prime element of decisional conflict24—is inevitable for parents of children with cancer.14

The nature of parents’ relationships with clinicians, particularly the physician most responsible for their child’s cancer care, was central to the TDM process. Clinician attributes that conveyed trustworthiness ameliorated the emotional stress associated with uncertainty and decisional responsibility. Regardless of whether parents described making the final decision themselves or following a clinician’s clear recommendation, most described an intensely collaborative relationship in which they felt supported by clinicians’ commitment to and engagement in the process of making the right decision. The importance of these relationships to parents’ appraisal of the TDM process is consistent with both Thorne and Robinson’s37 representation of parent-provider relationships as central to families’ experiences with chronic illness and Degner’s23 description of TDM as a negotiation between the patient (here, parent) and provider. Two aspects of parents’ intense engagement with clinicians have particularly important implications for clinical practice. First, parents derive significant meaning from clinicians’ behaviors, nonverbal communication, and personal involvement in navigating the TDM process. Second, the variability in parents’ desire for clinician input and guidance requires that clinicians tailor their collaborative approach in order to meet individual parents’ expectations.

In contrast, parents mostly marginalized the participation of their extended family and social network. The predominant pattern was to accept emotional and tangible support but seek neither information nor opinions about various options, then informing others once the decision was made. Given the frequency with which social support is noted as a critical aspect of managing the childhood cancer experience, it is interesting that parents’ interaction with their social network was limited during the actual TDM process. Findings from a subsequent study of parental TDM in structurally diverse families clearly identified TDM as solely the responsibility of biological parents, to the exclusion of stepparents or current life partners.32 O’Connor24 identifies pressure from others as a major contributor to decisional conflict; it is possible that parents’ primary focus on the partnership with their child’s clinicians serves to limit the number of stakeholders and thereby reduce the potential for decisional conflict. Clinicians should acknowledge the primacy of parents’ responsibility for TDM and provide intensive support during the decision-making process.

Parents also largely limited the child’s involvement in the TDM process. Several studies have described similar patterns of limiting even older children’s involvement in the service of protecting them from the psychological burden of making decisions under conditions of uncertainty.3,4,28 In a study of family decision-making styles in various medical contexts, adolescents endorsed parents retaining primary responsibility for the most serious medical decisions.33 Our findings provide additional support for the growing recognition that parents take on TDM responsibility not to marginalize children’s involvement but to carry out their duty to protect their child and act in their best interest.34

The most challenging aspect of elucidating the parental TDM experience was capturing the outcomes, or consequences, of making the right decision. Regret has been proposed as a significant outcome in classic decision-making research,35,36 and the potential for decisional regret has been noted as particularly high for parents versus adults making decisions for themselves.6,37 In our study, parents were hyperalert to any suggestion that they might have second thoughts about their decision and explicitly denied regret, even though we avoided asking about it directly. However, notes of doubt tempered their conviction that they made the right decision as they acknowledged the pervasive uncertainty that accompanies cancer diagnosis and treatment. An intriguing and potentially illuminating insight from work by Mack et al38 is that only 24% of parents endorsed a feeling of “peace of mind” during the childhood cancer experience. The pervasive doubts expressed by the parents in our study, while falling short of an acknowledgment of regret, could represent a significant threat to peace of mind. A longitudinal study combining qualitative and
quantitative approaches could make a significant contribution to clarifying the relationships among doubt, peace of mind, and regret and identifying the most appropriate outcome measures for future intervention studies.

The current study had several limitations that could have constrained the conceptualization of parental TDM that emerged. Most of the interviews were conducted with only 1 parent even when more than 1 parent participated in the decision; the couples that participated in the study were likewise interviewed individually. There was no attempt made to directly elicit the perspectives of child patients or clinicians. This sampling strategy significantly underrepresents the complexity of how decisions get made within families or the exchange between parents and clinicians, which is clearly central to the TDM experience. Likewise, although Hispanic parents constituted a third of our study sample, our findings nonetheless underrepresent the cultural, racial, and socioeconomic variability of the population. Given the centrality of values, beliefs, and patterns of communication to the parental TDM process, it is very possible that a different picture would emerge from a study sample that represented a different cultural group or a sample that was more culturally diverse. It will be critical to examine the TDM process through a more deliberately cultural lens in future studies.

**Directions for Future Research**

Making the right decision is a complex, emotionally taxing process for parents of children with cancer, and clinicians play a crucial role in guiding and supporting parents through the process. The study findings and the model of parental TDM they yield provide the conceptual foundation for further studies and the development of interventions to support parents in their critical TDM role. As noted above, capturing the true complexity of TDM within the childhood cancer context will require longitudinal studies that incorporate multiple decision makers, represent the voice of the child, and consider how decision making evolves over time. Critical points to address in future intervention studies include acknowledging the imperatives that parents feel to make the right decision, the challenges of making decisions under conditions of uncertainty, and the impact of the parent-physician relationship on the TDM process and the resulting emotional toll.

**ACKNOWLEDGMENTS**

The authors thank Dr Pam Hinds for her expertise on collaborative qualitative analysis and Dr Mary Beth Happ for her thoughtful review of the manuscript.

**References**


