

Beginning Treatment for Childhood Acute Lymphoblastic Leukemia: Insights From the Parents' Perspective

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Purpose/Objectives: To report the perspective of parents during the initial stages of diagnosis and treatment for their children's acute lymphoblastic leukemia (ALL).

Design: Descriptive and phenomenologic.

Setting: Royal Children's Hospital, Brisbane, Australia.

Sample: Parents (mothers, $n = 12$; fathers, $n = 4$) of 12 children (ages 0–10) undergoing treatment for ALL.

Methods: Open-ended, audiotaped interviews were transcribed verbatim and analyzed.

Main Research Variables: Parents' experiences of their children's initial diagnosis and treatment of ALL.

Findings: The parents' insights provided a clear indication that the initial stage of treatment is highly stressful and parents may be overwhelmed by the experience. The situational stress translated into three potentially overwhelming emotional states: the stress of uncertainty, the shock of diagnosis, and a feeling of being trapped in an unpleasant emotional roller-coaster ride. Honesty from healthcare professionals, the opportunity to share feelings, and an affirmation of the harshness of the situation were reported as helpful in dealing with the sense of being overwhelmed.

Conclusion: Parents need honest information and sensitive emotional support to come to terms with the stresses associated with their children's diagnosis and initial treatment of ALL. Parents must have access to a safe environment where they can express their feelings and have the harsh reality of the initial stage of treatment affirmed.

Implications for Nursing: Parents need considerable emotional support to negotiate the initial stage of treatment for ALL. Parents of children diagnosed with ALL must have honest information about diagnosis and treatment, as much information as possible for planning their daily lives, an opportunity to express real feelings, access to moments of personal space where feelings can be processed, and compassionate understanding of the emotional difficulties associated with this difficult life journey.

In the 1950s, children diagnosed with acute lymphoblastic leukemia (ALL) were expected to die in just over a year. Today, 60%–80% of all newly diagnosed children are cured (Pui, 2000; Rubnitz & Pui, 1997). In fact, ALL has provided a landmark in cancer therapy as the first disseminated and otherwise lethal malignancy to be curable in the majority of patients (Greaves, 1993; Keene, 1999; Nygaard & Moe, 1989). Because of the advances in treatment, the psychosocial focus of healthcare has changed from exclusive concern about the dying process to the examination of issues associated with diagnosis, treatment, and sur-

Key Points . . .

- ▶ The initial stage of treatment for childhood acute lymphoblastic leukemia is highly stressful, and parents may be overwhelmed by the experience.
- ▶ The treatment brings situational stresses, including the stress of uncertainty, the shock of diagnosis, and a feeling of being trapped in an unpleasant emotional roller-coaster ride, which are exacerbated by difficult inner feelings associated with the ability to cope with the situation.
- ▶ Honesty from healthcare professionals, the opportunity to share feelings, including having the space to cry, and an affirmation of the harshness of the situation are helpful to parents in dealing with the sense of being overwhelmed.

vival (Keene; Macner-Licht, Rajalingam, & Bernard-Opitz, 1998; McGrath, 2000).

Although pediatric ALL treatments achieve great success, this benefit is gained at the cost of a long, invasive, and very arduous treatment protocol that parents perceive as being as problematic as the actual disease (Adams, 1992). A standard protocol for ALL extends over a 2–3 year period and involves intensive chemotherapy treatments of remission induction, consolidation, and maintenance (Keene, 1999; Souhami & Tobias, 1995). Children with ALL must spend lengthy periods of time in the hospital (Henderson, Goldacre, Fairweather, & Marcovitch, 1992; Keene), and many families have to cope with relocation to a metropolitan area for specialist treatment (McGrath, 1998, 1999a, 1999b). The experience of undergoing such intensive treatments affects not only children with ALL but their entire families (McGrath, 1999b, 2000).

Research on parental adaptation to children's chronic illnesses is scant, particularly on the experience of treatment for pediatric ALL (Cayse, 1994; McGrath, 2000). Healthcare providers have come to understand that the stress and distress

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Digital Object Identifier: 10.1188/02.ONF.988-996

associated with cancer affect surrounding family members and caregivers (Bluglass, 1991). However, early work in this area only began to describe the depth and breadth of the impact that children's life-threatening diagnoses and the challenges involved in coping with the stress of pediatric treatment protocols have on parents (Brown et al., 1992, 1993; Hillman, 1997; McGrath, 1999c, 2000; Speechley & Noh, 1992). The preliminary research is fraught with contradiction, with some results reported by the same authors at different times coming to disparate conclusions ranging from evidence of parental adjustment (Brown et al., 1992) to indications of high levels of psychiatric dysfunction (Brown et al., 1993). The early indications are, however, that a strong association will be found between parental distress during treatment and later parental adjustment (Kazak & Barakat, 1997). Indeed, the stresses associated with the experience of treatment for childhood cancer are so severe that the concept of posttraumatic stress disorder is considered an effective conceptual model for studying parental reactions (Barakat et al., 1997; Kazak et al., 1997, 1998; Pelcovitz et al., 1996; Stuber, Christakis, Houskamp, & Kazak, 1996). Despite the seriousness of these findings, scant qualitative work exists that describes the actual experience of treatment for childhood ALL from the parents' perspective. The present discussion addresses this gap in research by reporting qualitative findings on parents' perspective taken from the initial stage of a longitudinal study exploring the experience of treatment for childhood ALL from the viewpoint of all members of patients' families.

Methods

The data were gathered for the first stage of a longitudinal study of the experience of pediatric ALL treatment from the perspective of children with ALL and their parents and well siblings. Royal Children's Hospital Foundation and the Financial Markets Foundation for Children jointly funded the study. A psychosocial researcher at the Centre for Public Health Research conducted the multidisciplinary study in association with research clinicians from the hematology and oncology unit of Royal Children's Hospital.

The university ethics committee provided ethical consent to conduct the study. Participants were informed verbally of their rights in research, and written consent was obtained for participation.

Sample

Consecutive patients diagnosed with ALL, aged from birth to 16 years, and enrolled at Royal Children's Hospital were enrolled in the study. During the initial stage of treatment, the parents and siblings of these children were approached with regards to participation in the research. The findings presented cover the interviews with the parents of the first 12 children with ALL enrolled in the study. Of the initial 13 families approached, only one declined to participate, resulting in a response rate of 92% ($n = 12$).

Procedure

The experience of treatment was documented using open-ended interviews with children with ALL and their parents and well siblings at key points in the treatment trajectory: end of induction remission, end of reconsolidation, continuation therapy, end-of-treatment assessment, and post-treatment. The findings presented in this article are from interviews con-

ducted at time 1 (the end of induction remission) with the parents of 12 patients. A psychosocial researcher with a counseling background and many years' experience working with families coping with hematologic malignancies conducted the interviews. The participants chose the time and location of the interviews. The interviews focused on the experience of treatment and its impact on all family members. Participants were encouraged to tell their stories from the point of prediagnostic symptomatology to the present experience with treatment. The interviewer presented the following opening prompt question: "Could you tell me of your experience, in your own words and in your own way, from the time you became aware that your child was ill?" An iterative approach (Coffey & Atkinson, 1996; Grbich, 1999) was taken with this longitudinal qualitative study so that issues emerging from early open-ended interviews with parents could be prioritized as focus points in later interviews. However, researchers must note that participants voiced all of the issues covered in this article spontaneously and without additional prompt questions as they told their stories in their own way. This fact has been taken as evidence of the commonality and importance of these issues.

Qualitative analysis is based on the principle of saturation of data; that is, common or reliable themes emerge when a number of participants say the same things (Polit & Hungler, 1995). By the time of the third or fourth interview, parents were reporting very similar issues. However, because the study was longitudinal, the researchers had the opportunity to follow up with consecutive enrollments over the first year to affirm the original themes. Consequently, at the point of the twelfth interview, a high level of confidence had been achieved as to the importance and relevance of the issues to the families involved. The data from the first 12 interviews conducted at time 1 are presented as the first cross-sectional findings from the study.

The interviews were audiotaped and transcribed verbatim. The language texts then were entered into the NUD*IST (QSR International Pty Ltd, Victoria, Australia) computer program and analyzed thematically. A phenomenologic approach was taken to the recording and analysis of the data. All of the participants' comments were coded into "free nodes," which then were organized under thematic headings. An experienced qualitative researcher established the coding. The project officer, a child life specialist who had gained intimate knowledge of the interviews through transcription, validated the coding. The researchers had complete agreement on the coding and emergent themes. Thirty-four of the free nodes related directly to the issues of emotional coping with the experience of treatment.

As inductive, phenomenologic, qualitative work, the reporting of findings was based on a commitment to the participants' points of view with the researcher playing the role of coparticipant in the discovery and understanding of the realities of the phenomena studied (Crombie, 1996; Greenhalgh & Taylor, 1997; Holloway, 1997; Streubert & Carpenter, 1995). Thus, the narrative account dominates, with a clear separation between the presentation of the exact words of the participants in the findings section and the interpretations in the discussion section (Grbich, 1999). For economy of presentation, the selected nodes have been organized under categories that, when juxtaposed, build an outline of the issues (Coffey & Atkinson, 1996; Marshall & Rossman, 1995).

Findings

Sample

The children with ALL (n = 12) ranged in age from nine months to 10 years, and male children predominated (male, n = 7; female, n = 5). All were diagnosed with ALL (ALL, n = 8; ALL/T-cell lymphoma, n = 2; infant ALL, n = 1; ALL/Philadelphia chromosome, n = 1). The majority (n = 11) were on the Australian and New Zealand Children's Cancer Study Group (ANZCCSG) Study VII Protocol (standard risk group, n = 7; high risk group, n = 4), and one child was on Medical Research Council, United Kingdom, Acute Lymphoblastic Leukaemia (MRC UKALL) Infant 1 Protocol.

All of the patients were from two-parent families. All of the patients' mothers (n = 12) and four (n = 4) of the fathers participated. The age range of the parents was from 28–44 years. With the exception of three, all parents had other dependents (four other dependents, n = 1; three other dependents, n = 1; two other dependents, n = 3; one other dependent, n = 4) who ranged in ages from newborn to 20 years. The majority of families had at least one of the parents in full-time employment (father, n = 8; mother, n = 3). Seventy-five percent (n = 9) of the families had to relocate from their hometowns to a metropolitan area to obtain treatment for their children. About half of the mothers (n = 7; 58%) ceased employment (full-time, n = 2; part-time, n = 5) at the point of diagnosis because of the demands of relocation.

Living With Uncertainty

Figure 1 represents how situational stress translates into three potentially overwhelming emotional states: stress of uncertainty, shock of diagnosis, and feeling of being trapped in an unpleasant emotional roller-coaster ride. All of the participants made statements about the stress that comes with the all-pervading sense of uncertainty associated with initial diagnosis, treatment, and prognosis. Prior to the point of referral to the treating hospital, most parents had struggled with uncertainty about their children's diagnosis. All partici-

pants related their difficult journey of confronting their worst fears and seeking an accurate diagnosis of their children's conditions. In descriptions of the process of confronting this uncertainty, parents made strong statements indicating that they appreciated honesty rather than unrealistic but comforting comments. Describing the input of doctors at this stage, one participant stated, "[The doctor] was terrific; he said this is what we're looking at . . . no ifs or buts. . . . Said [what] it was right from the word go . . ." Another parent commented, "We didn't want [the doctors] to say 'Ah, it sounds like a virus, don't worry.' We wanted them to say, 'This is not leukemia.'" At another level, however, parents typically held out hope that the uncertainty would mean that they would not have to confront the worst-case scenario. One parent expressed this notion by stating,

But we still didn't know and I think deep down you actually don't want to say . . . 'yes, that is what it is' . . . you think it is an option, it could be, but you don't really want to accept that it is.

At the significant moment of leaving the comfort of their own homes to travel to a distant metropolitan treatment center, all of the patients and their families who had to travel were uncertain as to the exact nature of the diagnosis. A typical statement describing this situation was "When you leave up there you know the doctors did say, 'Yes, it could be an option.' It may be leukemia, but . . . they couldn't say yes or no. . . . That is just what it is all about." Consequently, parents did not know how long they would be away or even "what they should pack." Even when the diagnosis was confirmed, parents then were confronted with the uncertainty about whether their children were at standard or high risk, whether their children were carrying the Philadelphia chromosome, or what the cell classification would be.

In discussions about coping with treatment, participants indicated that a key stress factor was not knowing. This uncertainty was related to not knowing how their children would react to the medications offered, the implications of the side effects on their children's total health and treatment plans, and

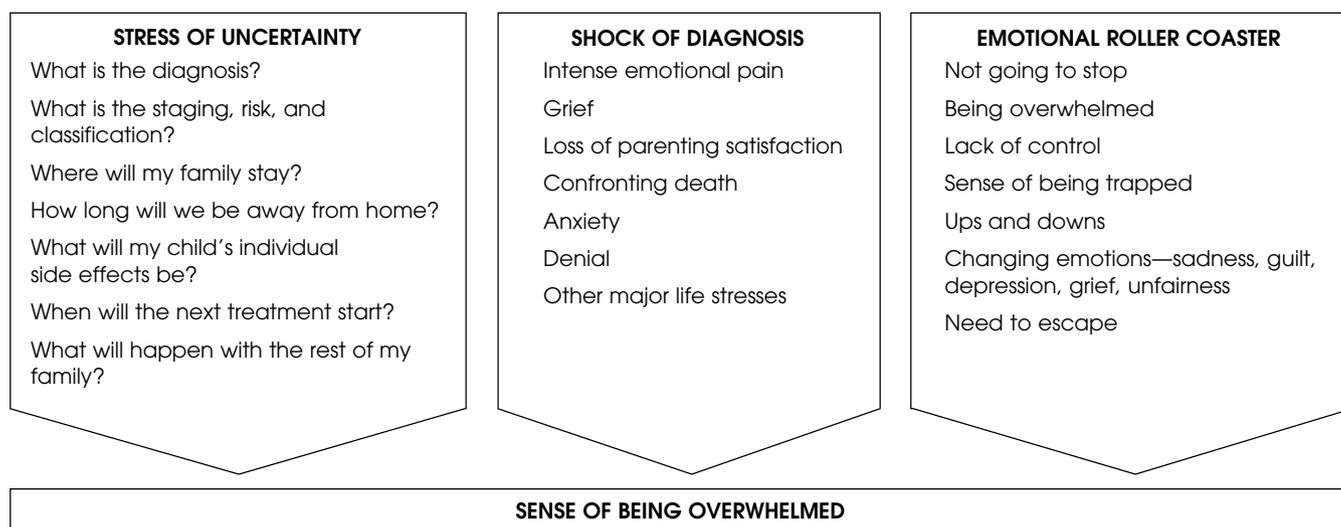


Figure 1. Emotions Associated With Situational Factors

the risks of serious complications. A core statement made by most parents was “We really don’t know.”

The uncertainty statement made in relation to treatment was demonstrated by the following statement: “I don’t know if the next stage will start on time or not. We really don’t know . . . we have to wait for her [symptoms] to clear up before we can get out.” Another parent spoke of a desire for the doctor to provide “any idea of the next start of treatment.” A key issue for these parents was the uncertainty of not knowing “how long they will be down here”; this meant that they were unable to plan for the future of their children or their families. Although parents could be well informed about the possibilities of side effects from treatments, parents were uncertain of the outcome for their own children. Even when side effects were minimal, the stress of uncertainty hovered. As one parent stated, “. . . like he had no reaction at all, which, you know, was great, thank goodness. But, you never know, next time he might have all the side effects.” For parents of very young children, this uncertainty extended to not knowing what their children were feeling or experiencing from the treatment because they could not communicate verbally.

This uncertainty statement also was made in relation to the uncertainty of leaving home to go to a metropolitan hospital and not knowing when they would return. As one participant stated,

You know, I wondered how long. When we go, if we do get to go home, how long [can] we go home for? And when do we come back? Yes, sometimes I think I’d like to know. How long?

The practicalities of living, such as accommodations or organizing return trips home, also were uncertain, as was demonstrated by the statement, “But we still don’t know. We are still arranging where to stay. I don’t even know when we’re going home.” One participant described the initial disorientation as a sense of “feeling lost. You feel lost there in the woods at first, when you come in.”

Finally, the uncertainty was reflected in relation to planning for the future. As one participant stated, “You just don’t know what’s down the track.” Parents spoke of the difficulty of planning for schooling and employment in the vacuum of uncertainty. The time spans parents talked about in terms of future planning were not years but weeks. As one parent stated, “You just don’t know what’s gonna be around the corner in a couple of weeks’ time.”

The sense of uncertainty was pervasive and permeated all aspects of coping with the experience. As one participant summed up the situation, the hard part about the uncertainty was that it pervaded “every day, every week, every month.” For parents, having to deal with their children’s concerns and questions was difficult because clear and definite answers were not possible.

In such a state of uncertainty, the importance of test results was paramount. In talking about the anxiety of waiting to hear test results, parents made comments such as, “You have no idea, it is a stress. . . . We are dying to find out the results.” When the medical staff ordered extra tests, parents’ anxiety could increase because this was interpreted as a signal that something was wrong. Parents indicated that they looked for clues in body language to guess the severity of findings and worked on the assumption that no news usually was good news.

The Shock of Diagnosis

Participants spoke of shock at the time of initial diagnosis. Examples of such descriptions included the following.

It is like a bomb goes off and all of a sudden everything around you is affected.

The shock of when we first heard . . . I didn’t know which end my head was on or which way I was going.

I couldn’t believe it happened to her.

It’s a nightmare and it’s unreal. . . . It still hasn’t sunk in. . . . You think, gee, this is a nightmare.

It was shock treatment.

It just feels like one big roller-coaster ride that’s not going to stop at all. It just feels like a big, bad dream and one you don’t want to wake up to every day.

It is very hard. The hardest part of it is why.

I couldn’t cope with it. I thought, no, you can’t take [the child] away from me.

It was a real bolt from the dark. We are still coming to terms with it.

Part of the initial shock was confronting the seriousness of the disease and the possibility of death. Some of the parents could pinpoint an exact moment when the reality of the diagnosis “hit.” Such moments typically were at the time of being told of the results of tests. Many of the parents, however, indicated that they received the message about the seriousness of the situation from situational clues rather than doctors’ exact words. For example, one participant stated, “The doctor came in and said, ‘Can I steal mummy for a moment?’ And then that was the moment . . . the time when your heart just sort of sinks to the floor.” Reactions varied from immediate anxiety reactions, such as “not being able to sleep a wink all night,” to more gradual reactions of “being alright for a while and then sort of couldn’t cope with it.” Two of the parents noted that they thought they were in some sort of denial as the reality had not “sunk in.” One participant felt the denial was a defense for “not letting anything overwhelm me. I just keep pushing it aside.” Participants made statements indicating that they understood that everyone in the family would handle the shock of diagnosis differently.

The feelings associated with the shock of diagnosis were described as disturbing and challenging to the parents’ own sense of normality. Parents found comfort in the message that such a profound reaction was to be expected, which “affirmed that the way they felt was normal.” Suggestions by friends or family that they were “not really coping with it . . . or needed antidepressants” were seen as pathologizing the situation and not considered useful.

Most of the parents made statements indicating that they eventually were able to face the reality while acknowledging that this was very difficult. This acceptance was evident in statements such as, “I guess it comes back to that old saying, ‘You can’t change it so you have to deal with it.’” One parent, however, made the qualifying statement that “If they ever wrote a diary or book about children’s illnesses and you read it before you had a child, you wouldn’t have a child.”

Intense Emotional Pain

An emotion closely associated with the shock of diagnosis was that of grief, “overwhelming grief, like a bottomless pit.” Some parents made clear statements that expressing the emotional pain of the experience in words was impossible. Others attempted to describe their emotional states as the following examples show.

How would I describe this? Having been through my mum dying, I can say this is far and away much worse. This is about your whole life going. Nothing left in your life.

[The grief] was unfathomable. No one could even touch it. No one could make it better. It was just so bad that I really wanted [suicide], and I was [suicidal], and I’ve never had a suicidal thought in my life. . . . and I just thought, I can’t live with this. I don’t want to live with it. I would rather be dead.

It is like this is just a nightmare!

The first aspect of the grief reaction related to the sense of loss of their previously healthy children. Some parents produced photographs of what their children looked like prior to diagnosis and treatment, showing stark differences between the before and after physical appearances of the children. Parents spoke of the change in the children’s activities, telling stories of how their previously very athletic children could not now sustain even a short game of ball and how toddlers were no longer able to play as usual in the sandpit or wading pool with their siblings. These situations were exacerbated in situations where the children were so ill that “nothing is a pleasure, nothing.” Parents reported a sense of loss in regard to their parenting roles that previously had been built on the satisfaction of making their children happy.

The second aspect of the grief reaction was about confronting death. As one parent explained, “There is also the unknown; you just don’t know what is down the track, and you think, ‘please God, don’t let that be us.’” Most parents (n = 11) talked openly about their concerns about the possibility that their children could die. Parents were acutely aware that some children have not survived. They stated that the “[dedication plaques] on walls or whatever” at the hospital were a constant reminder of this reality. The fear of death was reported to be “always at the back of your mind,” and grim reminders came with the relapse of other children at the hospital or were “picked up in the outpatient area where mothers talk.” The discussions of the risks of death were couched in the statistics associated with the children’s diagnostic group, risk level, and the presence or absence of the Philadelphia chromosome. As one parent stated, “We just believe that [the child] will be in the 70% that survive.”

A high level of acceptance of the possibility of death was evident in the language texts, with parents stating that their coping strategy was to look at the positive and pray. As one parent stated, “I just get on with what goodness is happening, and I’ve got good reason to be really positive.” Others found coming to terms with the reality very difficult. “I want a guarantee that when you finish with [the child], the child will be walking out of here.” Parents made other comments indicating that the whole issue was too difficult to process and if they were confronted with losing their children, they “couldn’t cope with it.” Parents spoke of talking openly to their children about the possibility of death, as could be observed in the

comment, “[The child] knows that there is a chance of death in treatments.” Parents expressed anxiety over the fact that because the treatment protocols were so difficult for children, parents carry a real concern about the ordeal being “worth it.” As one parent stated, “If we don’t even get to the end of it . . . what are we doing this for?”

The grief reaction was described as inescapable. As one parent noted, “The other night I took myself out . . . but you can’t forget it.” One parent mentioned the need for grief counselors at this stage. Many of the women spoke of their need to cry during this time of adjustment.

The Emotional Roller Coaster

All of the parents made reference to “one big roller-coaster ride that is not going to stop at all.” A recurring theme in the description of this emotional roller coaster was that they had “good days and the next day it just hits big time.” Parents indicated that they had a wide range of feelings associated with the ups and downs of the constant roller-coaster ride, including sadness, a sense of guilt, a need for escapism, depression, a sense of being overwhelmed, lack of control, a sense of being trapped without space to think, a feeling of nightmarish unreality, a sense of unfairness, a feeling of lack of choice, overwhelming grief, and a loss of a sense of future. Participants spoke of days when they “don’t want to wake up or could walk around crying all day.”

Being Strong and Positive for Others

Many of the participants spoke of their desire to try to “be strong” for their children and other family members. Indeed, many of the mothers described “holding everyone up.” Parents spoke of the pressure to be “bright and cheery or always cheery.” These parents admired the strength in their children. “The kids get their strength from somewhere; I don’t know where they get it from.” Consequently, parents expressed a need to reciprocate with an equal display of strength. “If the kids can find that deep inner strength, I guess we owe it to them to do the same.” These parents tried to be brave for their children.

Many parents spoke of the burden of having to be positive and “look on the bright side” all the time. This was particularly difficult during “that first week in the hospital when you sort of knew you had to walk in all brave and cheery.” Parents saw this cheerfulness as an unrealistic front that was difficult to maintain and said, “those who say, ‘think positive’ . . . they’ve never ever had anybody have this.” One parent gave the following detailed statement about this issue.

There is no bright side when your child has leukemia. [The child] has a disease that in some cases kills; [the child’s] life [is] worthless at the moment; [the child] is in constant pain, won’t eat food and gags at the sight of it; [the child] can’t talk to us and tell us where it hurts. There is sterility later . . . and the siblings will never forget that they did without a full family all this time.

Because of this pressure, the mothers spoke of the difficulty of wanting the emotional release of crying but felt they were not able to do this in front of their children for fear that the sight of their parents crying would distress them unfairly. For parents who were with their children in treatment all day, this could be exhausting. “It is hard to do because you’re with [the child] 24 hours a day, and you want to have

those breakdowns, you know, when you just want to cry for an hour.” This struggle was reduced at night back at their units where “it’s sort of a little bit more relaxed.” Other parents acknowledged to their children that “sometimes we are going to want to cry” and shared the experience with their children.

Parents indicated that people supporting them should acknowledge this very difficult journey in life. The parents acknowledged that people do not know what to say and that when others tried to encourage them to be positive, they were “telling you that they’re not capable of coping with [the difficult feelings]” or worried that they did not know how to react.

Sharing the Feelings

Most of the parents spoke of the importance of an emotional release, especially through tears. Special times existed when parents who were coping at the hospital all day would look forward to an emotional release when they could cry. Such times usually occurred when they walked out the door, on the way home, at night when speaking with relatives or close friends, or in talking to other parents going through similar situations. On occasion during an interview, parents would cry and the tape recorder would be turned off. The chance to express feelings was seen as a positive event. “It helps to off-load a bit; the good part is that you get relief.” Parents gave descriptions of times when they “just sat down and cried and cried.” Some parents stated that crying was essential. Fathers also spoke of crying or wept openly during interviews.

Participants spoke of the importance of sharing their feelings about the situation with others. Sharing their feelings not only made parents feel good but also helped by allowing them to “learn from everyone’s different feelings.” Sharing difficult feelings helped to affirm the parents’ reality and was appreciated.

Descriptions of Feeling States Associated With Coping With Treatment

Some parents indicated that when they were confronted with the huge existential task of relocating and coping with a two-year treatment protocol, they questioned their ability to cope with the situation. Most of the parents made reference to the very long treatment protocol. The challenge of this “long haul” was daunting, with concerns about whether the outcomes would justify the struggle. Family life was placed on hold and life revolved around the needs of the sick children. Consequently, parents reported a total disruption of future planning. Life was put on hold and future plans had to be put aside. At times, the situations seemed overwhelming and parents worried about how they would cope.

Parents made comments suggesting that additional problems could multiply the stress and cause them to act in less effective ways (e.g., locking themselves out of the house). The findings from this study indicated that the families were coping under numerous other stresses (McGrath & Rogers, in press). This stress was compounded by the considerable difficulties associated with the initial stages of treatment (McGrath & Rogers). One participant indicated that even though she still was eating well, she lost weight from the sheer stress of the experience. Parents made comments about trying to develop strategies to deal with the worry and stress, such as “not worrying about things until they happen.”

Participants mentioned that they had to put life on hold because of the medical drama. As one participant summed up the situation, “We still haven’t formulated a life. . . . You don’t have a life, it is just an existence.” Parents noted that their new existence centered completely on their sick children. One parent expressed the desire to regain her parenting role and “be in control of more than an IV machine and a hospital bed.” All of this happened at a time of severe sleep deprivation. Three participants spoke in detail about this aspect.

Despite the difficult time parents were experiencing, many ($n = 6$) made compassionate comments about the plight of others and managed to develop an outlook based on being more fortunate than others. “We are better off than others” and “I don’t know how those people cope” were typical comments.

Why Me?

Participants reported that one of the hardest parts of coming to terms with the seriousness of the diagnosis was thinking about why it happened. Statements indicated that parents and children felt in some way spiritually responsible for the disease. Some participants had a strong sense that the disease was in some way a punishment for wrongdoing. Participants indicated that although they understood that this reasoning was not realistic at a rational level, they also indicated that they thought about those things at some level. Parents were able to speak about this with humor. “I thought it was because I passed the donation box for cancer!” Some comments indicated that all members of the family experienced this, including children with ALL, parents, and siblings. Participants stated that because no documented cause for leukemia exists, the mystery of not knowing made the situation harder. “See, there is just nothing, and that part plays on your mind.” Some parents mentioned the unfairness of the situation, especially when parents had made sacrifices to ensure that their children would have every chance in life. This questioning was hardest when the participants had time to sit and think.

Discussion

The parents’ insights clearly indicated that the initial stage of treatment for pediatric ALL is highly stressful and parents are at risk for being overwhelmed by the experience. The key situational factors contributing to the stress included having to deal with the news of a serious and potentially life-threatening diagnosis, the necessity to relocate for specialist treatment, the demands of “high-tech” treatment in a busy tertiary setting, the problems associated with being in a constant state of not knowing the side effects and outcomes of treatment for individual children, and the challenge of caring for all family members when the demands of looking after children with ALL are so time-consuming and intense.

Uncertainty is a significant factor associated with stress in both chronic and acute illnesses (Mishel, 1984, 1990, 1997, 1999; Mishel, Padilla, Grant, & Sorenson, 1991; Padilla, Mishel, & Grant, 1992), particularly in pediatric cancer (Carpenter et al., 1992; Sterken, 1996). Parents reported that such uncertainty was pervasive in the initial stages of treatment for pediatric ALL. In terms of the diagnosis, the uncertainty was associated not only with the process of obtaining a diagnosis but also with confirming significant associated factors, such as staging, risk, and classification. This uncertainty of “waiting and not

knowing” was reported previously (Clarke-Steffen, 1993). For many participants, the uncertainty pervaded the relocation experience, as parents typically left the comfort of their own homes, unaware of what would be happening at the tertiary center, where and how long they would be staying, or what would happen to other family members in their absence. This echoed similar research in regard to relocation for adult hematology patients (McGrath, 1999b).

The shock of diagnosis is well documented in the literature (Carpenter et al., 1992; Mott, 1990). Parents in this study spoke of the intense emotional pain involved. This pain was associated with confronting possible death and the subsequent grief that came with the potential loss of life as well as the loss of their previously “normal” child. These intense emotions came at a time when the parents had lost much of their previous satisfaction from parenting because their children, distressed from the disease and forced to undergo arduous treatments, were difficult to comfort. For many, all of this was happening at a time when the parents were coping with other major life stresses.

A metaphor for this experience, expressed by all of the parents, was that of an emotional roller-coaster ride. From the parents’ perspective, the experience brought an overwhelming sense of being trapped in a frightening journey that was out of their control and could not be stopped. Parents described the endless changes of emotions, from sudden downturns to sadness, guilt, depression, grief, and a sense of unfairness, followed by more uplifting moments of a sense of coping and positive hopefulness. Understandably, parents reported being overwhelmed and stressed by a “ride” that they did not choose and was out of their control. As documented in the literature (Baxandall & Reddy, 1993), the chance for any time out or escape from the “ride” was seen as much needed and desirable.

As Figure 2 demonstrates, parents provided insights as to the internal emotional pressures they dealt with in responding to the myriad demands of the situation. Parents reported that an endless stream of questions pervaded their minds—Can I cope? Why me? Will it all be worth it in the end? Despite such doubt and uncertainty, parents reported the desire to be strong for others. In particular, they indicated the need to be strong for their sick children, who they admired for their ability to cope. A pressure to be positive and cheery particularly was strong in the hospital setting. Accompanying this positivity were the negative internal pressures of dissatisfaction with the role of parenting sick children, the feeling of being overwhelmed by the situation, exhaustion from sleep deprivation, and having to put life on hold. Parents reported a need to express their feelings and have personal space to think and work out their emotions. In the midst of such confusion, however, parents reported compassion and understanding for the plight of others.

Early work on the psychosocial aspects of childhood cancer noted that a diagnosis of childhood cancer poses major challenges to parents’ adaptive and coping skills (Chesler & Barbarin, 1987; Figley, 1983; Stehbens, 1988). The present findings indicate that parents could have a sense of being overwhelmed not only from situational pressures but also from the difficult inner feelings they must process. Parents reported that honesty from healthcare professionals, the opportunity to share feelings, including the space to cry, and an affirmation of the harshness of the situation were helpful in dealing with the sense of being overwhelmed.

PARENTS’ INNER FEELINGS AND EXPERIENCE OF DEMANDS

- Questioning
 - Can I cope?
 - Why me?
 - Will it all be worth it in the end?
- Need to be strong for others
- Pressure to be positive and cheery
- Loss of parenting satisfaction
- Admiration for the sick children’s strength
- Feeling overwhelmed by demands of treatment in an unfamiliar situation
- Putting life “on hold”
- Exhaustion from sleep deprivation
- Inability to plan for future
- Need to express feelings about situation
- Need for personal space
- Compassion for others

SENSE OF BEING OVERWHELMED

Honesty from healthcare professionals

Opportunity to share feelings, including the space to cry

Having the harshness of the situation affirmed

Figure 2. Factors for a Supportive Environment

Implications for Practice

These findings indicate that parents need considerable emotional support to negotiate this stage of treatment. The parents made clear suggestions of how healthcare providers could assist them during this process. Healthcare professionals should provide parents with honest and sensitive information about the diagnosis and treatment of ALL. Nurses should provide parents with as much information as possible for planning their daily existence. Although parents accepted that they had to “put life on hold,” the demands of day-to-day and long-term planning, especially when other young children were involved, could be very stressful. Any information on issues such as accommodations, travel, expected side effects, test results, and timelines for treatment protocols can assist parents in coping with the all-pervasive uncertainty. This reflects Mishel’s (1995) model, albeit in regard to adults, which stated that the goal of nursing should be to promote a greater level of predictability.

Parents described in detail the intense emotional pain they were experiencing as well as the consequent need for an emotional release, including crying, and the personal space to process the emotions. Sensitive, compassionate care requires a respect for the difficulty of this experience and a relationship

with parents that is built on a realistic understanding of the emotions involved. Crying, the need to share feelings, and the expression of emotional pain all should be accepted as normal responses to a very difficult situation. As Baxandall and Reddy (1993) reported, caregivers stated that healthcare providers' understanding of their needs was one of the most helpful factors in caring for family members with cancer.

Parents spoke of the need to have their reality affirmed. The suggestions by well-meaning others to be positive or to view the intensity of their emotions as abnormal (or the implication that they were not coping) were seen as unhelpful. Research indicated that parents see nurses as key providers of support (Adams, 1992; Chesler & Barbarin, 1987). Thus, nurses who acknowledge the difficulty of the situation will make an important contribution in helping parents to cope. At all times, nurses should be mindful of the huge personal sacrifices these sleep-deprived parents are making and, consequently, relate to them with sympathy and compassion. Sensitive support requires the provision of a safe psychological environment in which parents can speak honestly about their situations and come to terms with the intensity of their emotions. As Baxandall and Reddy

(1993) noted, for some parents, meeting this need will require the additional support of allied healthcare professionals, such as social workers or occupational therapists.

Conclusion

Looking at the experience of the initial stage of treatment for ALL through the eyes of sick children's parents highlights the enormous difficulties they must confront. Parents need sensitive understanding and compassionate support. An essential element of the total care of children with ALL is ensuring that the hospital is a place where parents' feelings are understood and respected.

The author would like to express her appreciation for the work of Nicole Huff, BSSc (Child Life), and Janet Brown, BA, research assistants for this project.

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For more information . . .

- The Leukemia and Lymphoma Society
www.leukemia.org
- National Cancer Institute—Leukemia Home Page
www.cancer.gov/cancer_information/cancer_type/leukemia
- Childhood Acute Lymphoblastic Leukemia—What Is It?
www.cml.upmc.edu/internet/leukemia/cancer/child-lymph/what.cfm

These Web sites are provided for information only. The hosts are responsible for their own content and availability. Links can be found using ONS Online at www.ons.org.