

## Self-Understanding and Reaching Out to Sick Children and Their Families: An Ongoing Professional Challenge

Patricia Taner Leff, Joan M. Chan, and Elaine M. Walizer

Health care professionals face a series of taxing, emotionally wrenching, painful experiences as they begin to care for frightened, ill children and their families. Loss, grief, overidentification with patients, and overwhelming anxiety are among their "occupational hazards." Open, frank discussion of intense feelings and reactions and mutual support are essential elements in helping caregivers to cope in ways that do not result in withdrawal from children and families. By developing strategies that reach out to patients and their families, professionals enhance their own personal professional gratification and self-esteem. The insights of parents are used extensively both to illustrate concepts and to emphasize the critical role parents can play as "resources" for professionals and "partners in care."

As health care professionals embark on their careers, they encounter a series of painful, emotionally wrenching experiences. The care of increasing numbers of children with chronic illnesses whose lives depend upon advanced medical and surgical interventions has placed burdens on health care providers. Uncertainties may multiply as responsibilities mount; child patients are frequently admitted in crisis, ethical dilemmas are ever present, traumatized parents seek understanding and help from staff.

*Patricia Taner Leff, MD, is Attending Child Psychiatrist, Coney Island Hospital, Brooklyn, New York. Joan M. Chan, MSW, CCLS, is Education Consultant, Child Life Department, Schneider Children's Hospital of Long Island Jewish Medical Center, New Hyde Park, New York. Elaine M. Walizer, MEd, is the mother of a child with special needs, Chagrin Falls, Ohio.*

*The authors gratefully thank Michael Jellinek, MD, Child Psychiatry Services, Massachusetts General Hospital, for his helpful reading of the manuscript. We also wish to thank the following parents for their insightful contributions and support: Kathy Allely, Shereyn Campbell, Sylvia Dunne, Patty Houghland, Kristine Jablonski, Mary Tatro, Valerie Vogeler, Shannon Ward, and Connie Wells. Requests for reprints should be addressed to Patricia Taner Leff, MD, 468 Fifth Street, Brooklyn, NY 11215.*

Inexperienced professionals must assimilate technical data and master new, lifesaving skills as they simultaneously confront overwhelming, emotionally charged situations. Apprehensions run high: Will I ever learn all that I must know?; Will my mistakes cause harm?; How do I deal with the results of my errors within myself? The intensive care environment, where technical competence is challenged moment by moment, places especially severe personal demands on staff. Initiation into the care of children with catastrophic illnesses becomes a "trial by fire" (Frader, 1979):

A preadolescent boy, hospitalized with leukemia, became severely immuno-compromised by his chemotherapy. He developed *Pneumocystis carinii* pneumonia, and his condition rapidly deteriorated. . . . One morning after a long and complicated presentation of [data], a staff physician commented that everything seemed "all right." The weary resident who had made the presentation replied uncomfortably, "Yeah, except the kid." (Frader, 1979, p. 12.)

Many of the quotations that follow were made by physicians in training, but the feelings they express are common to health care professionals of varied disciplines. Painful situations are part of ongoing professional work in the care of children and families in crisis. Our goal is to help health care professionals develop coping strategies that nurture empathy and understanding. The blunted feelings and withdrawal from patients that may result from constant exposure to sorrow and suffering harm all those involved: patients, families, and professionals. Personal professional gratification and self-esteem can be diminished. The identity as a healer may be in jeopardy.

Narratives of real life situations are drawn from (a) correspondence with parents, (b) discussions with patients, (c) intern logs, and (d) pediatric literature. Parents contacted through various self-help organizations and the Parent

Resource Directory (ACCH, 1988), responded to several basic questions including: What have been your most positive experiences within the health care system? What have been your most negative experiences within the health care system? What would you like to say to young professionals?

Current literature increasingly emphasizes the enormous pressures on health care professionals in training and the need for support in coping with harsh and complex physical and emotional realities (Bergman, 1988; Berman & Villarreal, 1983; Sack, Fritz, Krener, & Sprunger, 1984; Werner & Korsch, 1976). Helping staff members find the necessary tools to deal with the anxiety inherent in their work remains a crucial task of pediatric education.

Professionals can begin to develop an openness to children and parents which leads to positive communication rather than to withdrawal and dissatisfaction. A healing atmosphere is created. The ways treatments are administered and the sensitivity and concern shown to children's emotional needs profoundly affect the child's attitude toward his or her caregivers as well as the professionals' own self-esteem.

### UNDERSTANDING ROLE-RELATED CAREGIVER STRESS

#### Grief and Mourning

A health care professional confronts multiple losses in his or her daily work (Shanfield, 1981). Themes of loss, death, intensive responsibilities, and mourning are rarely acknowledged and discussed with colleagues during the arduous years of training. In many situations, the caregiver is left to cope alone with manifold losses: for example, death of a child under his or her care who has come to be special; loss through a child's diminished aspirations, functions, and capacities; loss through unmet, at times unrealistic, expectations of oneself (Sack et al., 1984; Sahler, McAnarney, & Friedman, 1981; Werner & Korsch, 1976). An intern recounted her first, stark experiences with a dying newborn:

Images of the dying baby—his last gasps for breath, his mottled, blue skin—are very much alive. The eerie, bumpy, 3:00 a.m. ambulance voyage is a nightmare come true. The Ambu bag falls and slips; the isolette bounces open—15 endless minutes. Not even 2 weeks into my internship and I am brutally exposed to my own helplessness. No monitor. No laryngoscope. The painful images remain—fresh, clear, bare.

The guilt remains and rests at the core of a new reality. I am in a state of shock and disbelief as we tell the mother. The night and her tears envelop me. (P. Leff, personal communication, 1979.)

#### Fear

Fear and uncertainty, usually unstated, bracket the health care professional's world. Fear of failure, fear of humiliation before colleagues, and fear of revealing anxieties and guilt at causing pain may diminish sensitivity to the needs of patients and their families in acute distress. Unintended outcomes for both staff and child may result. A health care professional described such a situation:

My colleagues and I dreaded Joey's treatments. We wondered why he wasn't "used" to the procedures. We feared his screams and protests. I know it was hard for us to comfort him. We basically wanted to run away. (Personal communication.)

#### Overidentification

Painful overidentification occurs when caregivers constantly "see" themselves or members of their families in the seriously ill patients they treat. Troubling ways of coping, such as focusing solely on mechanical disease processes, may arise as inexperienced professionals attempt to shield themselves from feelings of intense, overwhelming vulnerability. Detachment from children and parents may develop. A medical student confided after finding that he was treating himself in each patient:

Every new patient I saw I would try to figure out some reason why he had gotten sick that would not apply to me. Well, he's old, I'm not old yet so I won't get that disease. He smokes, I don't smoke. She's fat. She's a woman . . . every way I could, I tried to make a big difference between myself and my patients. (Werner & Korsch, 1976 p. 323.)

Humanely reaching out to sick children and families while maintaining emotional boundaries is a difficult and complex task. Awareness of this necessary balancing act can help providers find ways of relating to patients with compassion and sensitivity. Although caregivers are not the suffering children or parents under their care, the shared human longings and need to be treated with respect and caring can serve as common ground.

### Guilt and Blame

The death or deterioration of a child may send shock waves throughout one's being and poignantly affect basic beliefs and values. A resident described such a painful experience:

I lost a child with Reye's syndrome when she was four. I was completely involved with her and the family as a first-year resident. Both that child and another child . . . [under my care] died the same night. I was exhausted. The child's mother was pregnant. That picture got to me. The child had so much done to her. I felt exhausted and guilty that I'd done all of that to her . . . (Sack et al., 1984, p. 679.)

Permission to grieve—to cry with parents, to attend the funeral if desired, to make follow-up phone calls to parents, to express feelings of helplessness and despair openly with peers—begins a process of healing. Hospital memorial services for children who have become part of the "hospital family" can help bring staff members together in their mourning and affection for the child and family. A nurse recalled:

Several years ago a child whom I had known since I was a nursing student died. She was a very little girl with a trach who had been abandoned by her teen mother. Maggie longed for a home and real mommy. For years, she was "our baby" while the various agencies fought among themselves. We, *too*, had major disagreements about letting her go with the trach. We dressed her, rocked her to sleep, bought her her favorite foods, played with her. But no institution could give Maggie what she cried and prayed for as she watched children go home with their families.

Finally, wonderful, competent parents were found. Maggie was the happiest little girl I had ever seen. She now had her own home and special, loving mommy. For a full year, she lived a normal life and progressed beautifully. Then around Christmas time while driving home from a party, a terrible accident happened with her trach. Maggie died in the hospital lobby.

Her foster mom was devastated. The whole staff grieved. A memorial service in the hospital helped all of us. Without our coming together, there might have been recrimination and nasty bitterness. We cried and remembered Maggie. We remembered her one year of happiness with her own mom and family. (Personal communication.)

Guilt and blame can flourish when avenues of

healing and institutional support do not exist (Werner & Korsch, 1976). Physicians and nurses as well as other professionals who have been intimately involved in the child's daily care may bear the brunt of the guilt-blame response. Poor communication among colleagues may exacerbate an already painful situation. Sack and coauthors (1984) reported the following:

Another resident recalled an incident in which the neonatologist asked, after an infant's death, why she had "killed" the baby. She was devastated by the remark. (Sack et al., 1984, p. 679.)

### RECOGNIZING UNHELPFUL REACTIONS TO STRESS

Blunting of feelings may develop when health care professionals struggle alone to manage the cumulative impact of unresolved grief and fear within themselves (Frader, 1979; Gorlin & Zucker, 1983; Shanfield, 1981; Werner & Korsch, 1976). When anxiety and helplessness in the face of patient pain and loss are not openly discussed or recognized, caregivers may deal with their distress in ways that are not helpful.

- using inappropriate "humor" and vocabulary directed at the child or family,
- giving painful information to patients and parents hurriedly while walking by in the hallway or abruptly over the telephone,
- using medical jargon in an attempt to control the frightening situation and reduce parents' questions,
- relying on false reassurance, or
- ignoring the child's presence while speaking to parents.

The first step in changing nonsupportive approaches is to recognize that they are happening and why. Few parents and children directly confront health care professionals and talk to them about uncaring responses. Patients and families may fear reprisals and may feel helpless; however, their anger remains. Nonverbal cues, such as tense body language and anxious facial expressions may indicate distress and a breakdown in communication. At this point, it is crucial for health care professionals to step back, take another look at the painful situation, and honestly ask, "What has been my contribution?"

### GROWING AND DEVELOPING AS HEALTH CARE PROFESSIONALS

Self-examination and identification of barriers to open communication with patients and families encourage health providers to seek alternative, more effective ways of handling anx-

ity-provoking encounters. The professional who has helped a child master a difficult, painful event benefits greatly as does the child and family. A relationship based on mutual respect replaces one based on anger, frustration, and rejection.

### Welcoming Feedback

Seek feedback from patients and parents. This is a caring behavior that demonstrates respect and concern. Such openness and willingness to accept honest responses *are* difficult and courageous. However, the ultimate rewards of working through this process both enhance professional satisfaction and lead to improved communication with children and families. A parent reflected:

Of course, it takes courage to look back and really see if you've said or done something that has, in fact, provoked parents' justifiable anger. Parents repeatedly tell us about thoughtless remarks made to them, evasiveness, poor or nonexistent communication with professionals. It takes guts to admit such an error. Real guts. Apologies can go a long way! You will be long remembered as an ally and healer.

Another parent emphasized:

It never hurts to ask the parent and child, to welcome feedback. It would have been wonderful had anyone ever said to me, "When we talked about Laura's problems, it was tough for both of us. Looking back, were there things you wished I had done differently? Could I have helped more?"

### Entering the Child's World

When children enter the frightening hospital environment, they experience a major disruption in their normal routines and activities. Significant aspects of their lives are taken out of their control. Intrusions by large numbers of strangers, however well intentioned, are common. For children of any age, loss of control is a devastating aspect of being ill (Koocher & Berman, 1983).

In establishing rapport with the child, initially ask questions about safe, general topics. Learn about the child's interests. Once the child feels comfortable in the relationship, he or she may wish to talk about private feelings, fears, and misconceptions, if gently asked. A youngster who has had multiple hospitalizations shared:

When patients are in the hospital, they wonder what's going to happen next. What tests will be done? What medicines do I have to

take? Who's going to take out my blood? Will he get my vein? How many times will he stick me? Will I be able to sleep? What will I be able to eat? Will I get an IV? Do I have to stay in bed? I feel afraid, confused, upset, in pain, and sometimes mad. But I still have to live with it. But, please doctor, can you please be more of a partner, more like a friend? And I know it will make it easier. (Personal communication.)

Paying attention to the child's cognitive and emotional reactions to treatment and care enhances the healer's own identity. How does the child understand what is happening in the hospital or clinic environment? Have we listened to his or her worries and possible misconceptions? Are we aware of his or her pain or discomfort? Have we considered the importance of the timing of the procedure? Will he or she be embarrassed—his or her privacy invaded? Has he or she been offered some degree of control?

### Talking With Children About Health Care Procedures

Prepare the child for painful procedures: ease his or her distress with calm, comforting words, give the child as much control as possible over the frightening experience, and encourage the child to practice simple relaxation techniques. Time with the child is well spent (Brunnquell & Hall, 1982). The child and professional share nurturing moments that resonate throughout the child's health care experience and become part of a sick child's world. The dividends in both patient and professional satisfaction and well-being help to counter the stress inherent in treating devastating childhood illnesses.

The child who requires repeated invasive treatments presents health care professionals with intense emotional and physical challenges. The caregiver may underestimate the vulnerability of children who have endured multiple invasive procedures. There is often an assumption that these children are "prepared" for the procedure when in reality their references are to past pain and struggle. Anxiety is heightened or masked (Kunzman, 1972). Children may appear open and cooperative until the time of the actual procedure when they react negatively—screaming, kicking, cursing. Under similar stress, other children may withdraw, quietly suffering within themselves, believing that no one is there to help them through the ordeal. The following illustrates one way of reaching out to a school-age child with leukemia.

We know that you've had many, many

spinal taps. They hurt. No one likes them. But it's important to keep very still. It's hard for kids. Some kids tell me that listening to music or thinking about something else, something really good that happened to you, helps a lot. What have you found helpful?

Although a child initially appears unable to listen to this or a similar message and continues to cry, scream, and move about, the child may remember and incorporate the empathy and concern expressed by his or her doctor or nurse. It is crucial for staff members to value their efforts and appreciate long range results. The caregiver's tone of voice, calm demeanor, and attempts to "meet" the child at his or her level of understanding forge a positive bond between child and professional. Parents rarely forget a professional who has treated their child with care and respect. A parent shared:

Before one of Amber's eye operations, the physician remembered that Amber hated the mask and had been terrified by it. He decided to use another method. We appreciated his concern for our daughter's feelings. He was pleased that she was less frightened.

Children with developmental disabilities are particularly vulnerable to a brusque, hurried approach. Calm words, gentle touch, eye contact with the child, time to explore medical instruments, and simple explanations of what the child will experience go a long way in quelling fears and engaging children who may be unable to express their intense worries. A parent emphasized:

The doctor upon seeing my daughter for the first time in an emergency situation treated her as a child first. He talked to Mary knowing full well she could not answer him. He was the first health care professional to attempt to communicate directly with Mary. Mary doesn't fuss with him.

### Sharing Painful Information

For children, information about their illness and treatment becomes a handle, a tool, a way of regaining some sense of control over lives spun into chaos. Seriously ill youngsters turn to their caregivers for honesty. Anything less may cause major rifts in communication, and children's faith and trust in their care may be irrevocably shaken. Practitioners lose the opportunity to be allies of their patients—"allies" through the pain and disfigurement these

youngsters often endure. The healing role is diluted; one's own identity as a caring professional is threatened.

Staff may withhold information in a futile attempt "to protect" patients from harsh facts. Despite good intentions, the sick youngster's experiences of his or her reality are thus negated. He or she may feel betrayed or infantilized. Such children or adolescents may come to believe that they are nothing more than faceless experimental data, devoid of individual hopes and dreams. A youngster who was denied honest information throughout the course of his illness commented:

All my life I've been used as a medical guinea pig. The doctors never told me the consequences (of cancer drugs). After I started reading about them, I knew what was keeping me from growing and keeping my hair from growing. They also sterilized me. Now I'll never be able to have children. To have someone take away your power to have children, it upsets me a lot. It really makes me mad. But there's nothing that can be done now. That's all ruined for me. (Pendleton, 1980, p. 146.)

Due to their own discomfort, caregivers may avoid spending time with young patients in sharing difficult news. A teenager suffering from end-stage renal disease described a painful experience:

The doctor told me as he was walking by in the hall that I needed to go back on dialysis and that I would go home the next day but have to come back for a fistula. Then he left. I felt shocked because I didn't think my kidneys were doing so bad. I'd been running around and had been told I was going home. I went to my room and cried. (Personal communication.)

The emotional costs of conveying painful information truthfully with compassion must never be minimized or ignored. "Bearers of bad news" face enormous stress. For example, witnessing the grief, tears, and anguish of a young teen just told that she may be unable to have children is excruciatingly difficult.

When the doctor told me I might not be able to have kids, I cried and cried. I've always wanted to have kids. That was my one dream of my life. (Pendleton, 1980, p. 146.)

Inexperienced professionals need help in listening to such a patient, in understanding that her reactions of despair and anger are aspects of normal grief, and in offering ongoing con-

cern, information, and availability despite overwhelming anxiety. By embracing such a role, caregivers actively join patients in their struggles for dignity and self-respect—"health" in the midst of devastation and pain.

### **The Child as "Helper" and "Partner," the Professional as "Ally" and "Guide"**

Health care professionals who respond to their patients' helplessness and powerlessness and provide sick children with some measure of choice and control over their treatment greatly reduce patient anguish. Considerate professionals on the front lines of care can play a major role in helping children who are chronically ill develop skills to cope with the unrelenting loneliness and terror of illness and hospitalizations. The mother of a youngster with a chronic illness has invited professionals to participate in the life of her child in a very special way.

What our children need from you is something entirely different from what you are asked to give your other pediatric patients. They need an ally, a knowledgeable and caring friend outside the family; one who will help them understand and learn to live with their illness.

Given pressing time demands and responsibilities for management and care, staff may often understandably forget what loss of control means to sick children. Reminders may be helpful. Notes to oneself might include: Is my patient comfortable? Has my patient had many tests today? Have we given the child some choices in his care? Have we protected as far as possible, his routines of eating and sleeping, his favorite TV programs, his need for parental comfort? For example, a school-age child requires several blood drawings a day. Staff members can and should support the resident as he or she sets a positive tone for the interaction with the child.

Time spent preparing the child and parents is important time. At the beginning of the day, the physician sitting at eye level, honestly talks with him and the parents about what is scheduled for the day. Questions are answered simply and briefly. If appropriate or possible, the child is asked if he would like the test done before or after one of his meals. There is an ongoing conversation with the child:

My name is Dr. \_\_\_\_\_ and I know this is the first time we've met. I noticed you have a Mets cap on your table. Who's your favorite Met? Did you have a chance to watch the game last night?

It's hard being in the hospital. What do you miss most?

I want to tell you what's going to happen today. I need you to be my helper. Your blood will be drawn from your arm three times today. Would you like one of those times before or after lunch? What do you think you will do the rest of the day?

During the actual procedure in the treatment room, the child is offered simple choices: which arm will be used, whether or not he wishes to watch or turn away. The child is encouraged to help; participating actively in his care fosters his sense of mastery over the painful event. Reminding the child of simple relaxation techniques such as visualizing a happy time reinforces his participation and cooperation. The conversation with the child continues according to his developmental level:

I know it hurts to have needles and blood tests, but I hope it will be a small hurt for you and over quickly. Then you'll be able to get back to the playroom if you'd like. Which arm is best to start? Would you like to help me clean your arm? Some kids like to see what's going on. Others don't. What's good for you? Some kids tell me that taking deep breaths or counting backwards very slowly helps them a lot. Maybe you and your Mom can practice.

### **Encouraging a Partnership With Parents**

For all children, especially those exposed to multiple invasive treatments over a prolonged period of time, parental participation fulfills a crucial need. Children's cries and protest occur within the safety of their parents' presence. They have not been abandoned to face their fate alone. The most important people in their world, their parents, are there to help them through the terrifying ordeal. In the vast majority of situations, as few barriers as possible should stand between parents and their children in need.

Parents must be supported in their roles, adequately prepared, and regarded as invaluable partners in their child's total care. Attention to parents' well-being is an important aspect of good care. Sensitivity to the worries and concerns of parents results in improved parent-professional collaboration. Professionals and parents "working together" significantly reduces the child's distress and fear even under the most difficult, trying circumstances. Parents know their child best; with the support of caregivers, they can devise unique ways of aiding and com-

forting their child. Elaine R. Abramson (1990), writing in *AboutFace*, poignantly described her family's experience:

Just over one year ago we were preparing our little girl for surgery. At first, we were having quite a time dealing with this ourselves, but thanks to all the information given to us by our doctor and all the support of the AboutFace office and other families, we came to grips with the situation and were able to give positive and compassionate guidance to her.

... I think the absence of sight is one of the scariest parts of [this] surgery for young children.

A couple of weeks before the surgery we gathered up her favorite stories, reading them in great length and looking hard at each and every picture. . . .

We explained that when her eyes were swollen shut that if we read the stories and looked at the pictures she would be able to see these pictures in her mind really well. She loved this way of reading, and it worked extremely well for us. . . . (Abramson, 1990, p. 4.)

Parents, as active members of the health care team, act as a major resource for other team members in conveying crucial information concerning their child's specific ways of handling painful circumstances and treatments. Parents must be respected and valued as they participate in reducing their child's distress and anguish. The mother of a toddler with a chronic illness openly and clearly advocated for her child:

At times, painful things were done to Ryan that could have been avoided. For example, a young physician started to give my son a shot for surgery before Ryan's IV had been placed. I suggested that the IV be done first and that medication be given through the IV. The doctor agreed it was a good idea, but not official orders. I got the orders changed.

Parents not only provide help and support for their sick child, but also "know" their child in many different settings—at play, at home with other family members. Parental observations may offer staff critical, lifesaving data. Margaret King Saphier (1984), writing in *The Candlelighters* newsletter, reported the following vignette told by the mother of a critically ill boy:

I could always tell when his condition was going to worsen a half hour before it did—during those times he didn't want me to leave his side (not even to go to the bath-

room). He wanted me to hold his hand and touch his head. The way he wanted me to stay, to hold him, I knew he was afraid. It was a fear I had never seen in him before that time or since. He had four life-threatening crises during his illness. I was able to alert the nurses and doctors about the last two crises. Sure enough, his vital signs changed within half an hour after he became so clingy and afraid. (Saphier, 1984, p. 14.)

Parental observations became vital sources of information when the sick child has severe communication difficulties. Parents of children with developmental disabilities perform an invaluable service as they interpret the child's play and behavior for staff. Parents offer staff a baseline of what "normal," comfortable play is for their child with special needs. Molly's foster care mother has urged staff to value parental observations. Molly's foster care mother "knew" Molly—knew her play, knew when she was happy and comfortable, knew when she was in severe distress.

When a child with special needs is admitted to the hospital, the hospital staff should carefully document what parents tell them is "normal" behavior and activity for that child. It's too easy to lump all special needs kids into a category.

Parents may independently investigate new approaches or methods for their child. Willingness to accept parents' valid discoveries and ideas both improves care for their child and broadens the professional's knowledge base. Amber's mother stressed:

When Amber was 5, our doctors still had her in long, metal braces with little white shoes that did not come off. After hearing a brace man at one of our parent workshops, we took her 140 miles to see him. He watched Amber walk holding onto bars. Together we decided to see how she would do in knee-length plastic braces. With the plastic braces, she flew. When we returned to our hospital, every doctor agreed that there was no reason why Amber should have been held down by those clunkers! Don't be afraid to try something new.

Parents as teachers and resources offer professionals intangible, though profound, experiences and images of love and commitment. Quietly observing a mother comforting a child with severe health impairments may forever alter preconceived values and expectations. Watching an angry, mistrustful parent slowly, almost

imperceptibly, over days and weeks become an ally and partner is a lesson never to be forgotten. An intern has recounted such experiences with parents:

Four severely damaged babies—four children suffering as few adults would ever suffer. A young mother gently hugs her rigid, motionless baby. Her eyes are filled with love and longing. I watch her caress her child. She does not know how much she will teach me. (Leff, personal communication, 1979.)

### **Acknowledging Parents' Frustration and Helplessness**

Parents find comfort and relief in the presence of health care professionals who express honest, heartfelt feelings openly and sincerely. Genuine tears of sadness; kind, simple words—"This just isn't fair"; gentle touch mean a great deal to bereft parents. A mother reaffirmed the significance of basic compassion and communication in reaching out to parents:

I think it is important for health care providers to feel comfortable baring their human side especially when families are undergoing significant emotional trauma. Such communications will not erode the professional-client relationship. If anything, the relationship will be enhanced.

During times of heightened stress, tensions may arise between parents and professionals (Green, 1979; Waller, Todres, Cassem, & Anderden, 1979). Remaining with parents during times of crisis and pain enhances the parent-professional relationship. A mother urged:

We as parents need to understand that doctors and nurses are human, too. Don't be afraid to sit and talk to parents. Even crying is OK. Parents need to know you really care about their child. Parents will be more understanding and accepting if things go wrong if you don't abandon them or avoid them. . . .

A mother of twins described her own experiences:

One night while I was in the hospital with my sick babies, a nurse and I talked for a very long time. We ended up both crying and laughing. . . . It felt so healing. Healing occurred when anyone of the staff—my obstetrician, a nurse, the social worker—showed genuine kindness or concern for our feelings, when caregivers emotionally and/or physically touched us.

Commitment to open parent-professional

communication, respect for parents' courage and love, and parent-professional collaboration in developing guidelines that clearly describe the role of parents are critical initial steps in resolving and alleviating damaging conflicts and misunderstandings (Brown & Ritchie, 1990; Leff, Chan, & Walizer, 1989). Professionals who value and respect the struggles and triumphs of their patients and families leave a legacy of care and concern that counteracts despair. Professional gratification and satisfaction deepen: one's role as a helper and healer expands. Such awareness begins with self-understanding and acceptance of one's own fragility—and humanity. A mother stressed:

Parents appreciate some recognition and appreciation for all they do, and for who they have become under the difficult circumstances of a child's illness. A timely word of praise, a compassionate remark, a hug, or an unexpected phone call/note will render you truly unforgettable as a caring professional.

### **Dealing With Your Own Sense of Frustration or Helplessness**

Parents greatly value professionals who are able to acknowledge the limits of personal knowledge and ask for help. Professionals who openly seek assistance for both themselves and parents during times of painful uncertainty in a child's treatment convey a powerful message of concern and caring. Parents urge practitioners to view such openness and honesty as a courageous act—not as a sign of incompetence or weakness. A mother of a child who is chronically ill and technology dependent observed:

When you are feeling helpless and anxious, you could bring a new face to our appointments—not just for a second opinion, but someone with whom to share your own feelings of frustration. Another doctor, social worker, nurse, or technician would diffuse the overwhelming intensity of our time together and allow me to ask someone else the questions I may have asked you a dozen times or more.

Sharing one's concerns with parents often enhances this ongoing process. A mother honestly stated:

When you are getting frustrated with my child's care, please convey this to me in direct terms. I am probably feeling the same way and would enjoy the company! I will feel free to share my real feelings with you. The following kinds of statements will help



both of us, "I'm not sure what direction to go right now" . . . "I wish I knew what else to do" . . . "I am stumped, but we are in this together, and we will keep on trying."

### CONCLUSION

Professionals confront an unrelenting series of taxing, painful experiences as they begin to care for frightened children with serious illnesses. Loss, grief, overidentification with patients, and overwhelming anxiety become emotional hazards of their difficult work. Consistent support in reaching out to children and families in distress provides an antidote to intense, grinding, professional stress.

Experienced practitioners and teachers are in a unique position to provide information and guidance to junior colleagues facing sensitive, painful encounters with patients and families. In integrating the emotional aspects of patient care into daily clinical work, experienced professionals who are able to share their expertise and concern alleviate the sense of "dealing alone" with many of life's most tragic and trying blows. The grueling intensive care and emergency room environments highlight staff's need for senior support and understanding. A sensitive pediatrician noted:

Keeping a "stiff upper lip" is the credo of teaching hospitals. Last year I helped care for a drowning victim in the emergency room. While the residents participated in the unsuccessful resuscitation attempt, I listened to the mother talk about her daughter, who happened to be the same age as my own. After it was over, I spoke briefly with the residents about some technical matters and then went out to my car and wept. I later thought how much more instructive the case would have been for the residents had they witnessed my crying. (Bergman, 1988, p. 261.)

Despite the turmoil staff members experience as they begin their professional journey, teaching institutions have responded slowly: a code of silence has been the expected norm. It is hoped that recognition of the magnitude of caregivers' exposure to loss and death will open the door to relevant institutional support. The welfare of professionals, both inexperienced and experienced, is at stake. The pressures and demands of caring for children and families in crisis never cease. The following recommendations may be helpful in countering caregiver stress and creating a healing environment for all—children, parents, and staff.

- Encourage programs that embody both compassion and competence. Recognition and honest examination of "occupational hazards" are essential. Peer group support, retreats, and an advisor-mentor system that invites open discussion of feelings in a nonjudgmental, safe forum assist caregivers as they struggle with often insoluble medical, ethical, and psychosocial dilemmas (Bergman, 1988; Berman & Villarreal, 1983; Gorlin & Zucker, 1983; Sack et al., 1984; Sahler et al., 1981; Shanfield, 1981).

- Invite parents to participate as "resources" in caregivers' earliest clinical experiences. By collaborating with families, health care providers enhance their own professional self-esteem and minimize withdrawal from traumatized children and parents in need. Meaningful support of family-centered care must extend throughout training years and beyond and must permeate clinical teaching and practice. Guiding sick children and their families through agonizing crises and stressful medical events is a life-long challenge to all entrusted with their care. A parent shared:

Ten years from now, I may not remember the particular test or therapies administered to my son, but I will most definitely remember the interaction I had with you. I will strive to remember your name and especially the way in which you spoke with me and my child—the compassion and realism you exhibited.

- Develop daily unit routines and expectations that actively help and encourage professionals in training. A supportive atmosphere sends a powerful healing message to children, parents, and staff. Concern for the health care provider directly affects children and parents. A father, and family physician, illustrated this crucial concept with a vignette from his own child's care:

My son was in the hospital for a prolonged and complicated illness. One afternoon, a few days after his surgery, I finally succeeded in getting him comfortable enough to sleep. As I began to doze as well, a medical student walked in and prepared to listen to his lungs. My son had already been rounded on that morning by seven subspecialty services, each with a student, a resident or two, and [sic] attending, and a fellow.

I reached over and grabbed the stethoscope as it neared my son's chest.

"What are you doing?" I asked the student. . . . "I need to examine your son."

"You are not going to wake him up . . . I just got him to sleep."

"I need to examine him," he repeated. "It's necessary for his care that I do so."

At that point, I again firmly stated, "You are not going to examine my son."

The student paused, looked confused, then nearly broke down. "What will I do? We are going to have rounds in 20 minutes, and if I can't tell them how his lungs sound, they will think I am a bad student, and . . . I'll get a bad grade. . . If I don't do well on this rotation, I might not get into a good residency."

The student was lost. He didn't know what to do. To him, his entire career depended on disturbing my sleeping son. We need to make an environment in which the student could confidently say on rounds, "I didn't examine the child because he had just fallen asleep and his father said it wasn't the right time." We need to have role models around who will say, "Good choice, you did well." (Schwab, 1990, p. 5.)

#### References

- Abramson, E. R. (1990). Helping children prepare for a hospital stay or visit . . . what parents have done. *AboutFace*, 4, 4.
- Association for the Care of Children's Health. (1988). *Parent resource directory: For parents and professionals caring for children with chronic illness or disabilities* (2nd ed.). Washington, DC: Author.
- Bergman, A. B. (1988). Resident stress. *Pediatrics*, 82, 260-263.
- Berman, S., & Villarreal, S. (1983). Use of a seminar as an aid in helping interns care for dying children and their families. *Pediatrics*, 22, 175-179.
- Brown, J., & Ritchie, J. (1990). Nurses' perceptions of parent and nurse roles in caring for hospitalized children. *Children's Health Care*, 19, 28-36.
- Brunnquell, D., & Hall, M. (1982). Issues in the psychological care of pediatric oncology patients. *American Journal of Orthopsychiatry*, 52, 32-44.
- Frader, J. E. (1979). Difficulties in providing intensive care. *Pediatrics*, 64, 10-16.
- Gorlin, R., & Zucker, H. (1983). Physicians' reactions to patients: A key to teaching humanistic medicine. *New England Journal of Medicine*, 308, 1059-1063.
- Green, M. (1979). Parent care in the intensive care unit. *American Journal of Diseases of Childhood*, 133, 1119-1120.
- Koocher, G., & Berman, S. (1983). Life-threatening and terminal illness in childhood. In M. Levine (Ed.), *Developmental-Behavioural Pediatrics*. Philadelphia: Saunders.
- Kunzman, L. (1972). Some factors influencing a young child's mastery of hospitalization. *Nursing Clinics of North America*, 7, 13-26.
- Leff, P., Chan, J. M., & Walizer, E. H. (1989). Talking to parents: enhancing parent-professional relationships. *Children's Hospital Quarterly*, 1, 171-174.
- Pendleton, E. (1980). *Too old to cry, too young to die*. Nashville, TN: Thomas Nelson.
- Sack, W. H., Fritz, G., Krener, P. G., & Sprunger, L. (1984). Death and the pediatric house officer revisited. *Pediatrics*, 73, 676-681.
- Sahler, O. J., McAnarney, E. R., & Friedman, S. B. (1981). Factors influencing pediatric interns' relationships with dying children and their parents. *Pediatrics*, 67, 207-216.
- Saphier, M. K. (1984). When being challenged, know your role as a parent. *The Candlelighters Childhood Cancer Foundation: Progress Reports*, 4, 13-15.
- Schwab, W. (1990). *Physician Education Forum Report*. Bethesda, MD: Association for the Care of Children's Health.
- Shanfield, S. (1981). The mourning of the health care professional: An important element in education about death and loss. *Death Education*, 4, 38-395.
- Waller, D. A., Todres, D., Cassem, N. H., & Anderten, A. (1979). Coping with poor prognosis in the pediatric intensive care unit. *American Journal of Diseases of Childhood*, 133, 1121-1125.
- Werner, E. R., & Korsch, B. M. (1976). The vulnerability of the medical student: Posthumous presentation of L. L. Stephen's ideas. *Pediatrics*, 57, 321-328.

#### ARE YOU MOVING?

Please give at least two months notice of a CHANGE OF ADDRESS to the ACCH Office so you will not miss an issue of the Journal, Newsletter, or other ACCH mailings. Send change of address notice to: 7910 Woodmont Avenue, Suite 300, Bethesda, MD 20814.