

Parenting the Chronically Ill Child in the Hospital: Issues and Concerns

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Chronic childhood illness and hospitalization are stressful events within the family unit. Parental response to the crisis of hospitalization profoundly affects the child's recovery process. This article discusses a team approach toward assessing and understanding parental reactions, methods of offering assistance and guidance, and basic issues and problems concerning staff-parent relationships. The focus is on the pediatric health care "team" as an agent for aiding families.

Serious childhood illness and hospitalization create a profound family crisis. Historically the modern hospital complex has virtually excluded the family from its concern and expertise. In emphasizing the physical and technological care of our child patients, we have artificially removed children from the family unit, the developing child's source of nurturance and strength. Current clinical research (Belmont, 1970; Freud, 1952; Korsch, Fine, Grushkin, & Negrete, 1971; Lansky & Gendel, 1978; Robinson & Clarke, 1980; Waechter, 1977) has demonstrated that we do so to the detriment of both the ill child and his or her family. Rooming-in policies for parents, parental care of premature hospitalized infants, parental presence during procedures, and parental support groups are practical, concrete steps we have taken to translate knowledge into action and to invite parents and families to be our allies in the care of their sick children.

The union of families and health care workers is not an easy one and entails flexibility and willingness to change our perspectives. As we learn to understand the child as a member of his or her family, we begin to function as advocates for the family and the affectional ties so crucial for psychosocial development.

The purpose of this paper is to present relevant knowledge concerning the impact of childhood illness, handicap, and deformity on the family. Each stage of childhood and family life, beginning with birth itself, demands its own developmental

tasks and adaptations. Illness not only interrupts the growth and maturation of the child, but also severely disrupts the growth and maturation of his or her parents. Parental helplessness, guilt, depression, withdrawal, anger, and demandingness are all potential reactions to the crisis of illness or handicap. Parents who formerly had protected and comforted their children are now at the mercy of illness, medical technology, and unfamiliar hospital routines. In understanding and dealing with intense parental feelings and, at times, difficult behavior, the job of aiding the family in its struggle to cope and master is begun. Developmental guidance and support are tools we offer to our patients and families.

Scope of the Problem

Chronic illness and handicap pose a major problem, if not the most important problem, for those who provide health care for children. With the advent of antibiotics, immunization, and better living conditions, infectious disease, the old scourge of childhood, no longer devours pediatric wards. Modern surgical techniques and medical advances have given new hope to children with life-threatening illnesses and severe congenital anomalies. Children who 5 years ago would have died of leukemia, advanced renal disease, or cystic fibrosis are now living and functioning as members of their families and communities.

Researchers have estimated that as many as 5 to 20% of children suffer from chronic illness and handicap. Sperling (1978) defines chronic illness as an illness which lasts over 3 months in any given year or which requires 1 month or more of continuous hospitalization. Kessler (1977) focuses on the child with chronic physical disease or disability, the mentally retarded child, and the child with one of the developmental disabilities, such as autism, dyslexia, cerebral palsy, or epilepsy.

Statistics and definitions cannot capture the severe trial to child and family that serious illness or handicap imposes. We have found the concept of "stress," both "acute" and "chronic," helpful in understanding the anxiety and grief that may overwhelm our patients and families.

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In addition to the discomfort and pain of the illness itself, the ever present threat to life, loss of function, and changes in appearance become haunting daily realities. Sperling (1978) poignantly describes the world of stress that must be dealt with by the child, family, and professionals.

Such an atmosphere constitutes its own world, in which reality takes on a different aspect—more somber, charged, threatening, and unpredictable. The helping nurse can become an instrument of pain. The cooperative parent may be transformed into an explosive antagonist. A reasonable child can become a protesting, rejecting patient. A trivial lapse in hospital routine may loom as an extraordinary breach of professional care. (p. 54)

Professionals involved with the inpatient care of children and families are frequently called upon to deal with the acute phase of chronic illness. These are times of high intensity and emotional pain. The parents of a previously healthy 4-year-old are told their child has leukemia. A cystic fibrosis patient, who has been doing well for months, suddenly decompensates and requires inpatient care for pneumonia. A young burn patient, who has been home and well for months, now requires further painful surgery to release scar contractures.

Periods of acute stress alternate with the chronic phase, the day-in, day-out strain of coping with the limitations of illness: for example, special diets, insulin injections, medications, clinic and therapy visits, special schooling. The chronic phase insinuates itself into the very core of family life.

It may be difficult for those of us who work in acute care settings to appreciate the unrelenting quality of chronicity.

Eddie, a 2½-year-old boy with hemolytic uremic syndrome, has been undergoing twice weekly hemodialysis for the past 6 months. His kidneys failed at the age of 3 months.

Since then he has had two cadaveric transplants, both of which he has rejected. He was put on peritoneal dialysis. The present plans are to continue hemodialysis for another year and then, perhaps, try another transplant. The donor will be his father.

Meanwhile, Eddie's mother, father, and 3-year-old sister have long since relocated from the Midwest to New York. "It's hard," says his mother, "especially when the nurse and I hold his legs still so that the needle can be inserted into the plastic tube in his leg. He shrieks, cries, struggles the whole time! But, we have to be strong for him. If the family can't be strong, who will do it?"

Robinson and Clarke (1980) emphasize current social factors that further influence the world of stress for families of chronically ill children. Mass migration of families to the cities has resulted in

the loss of the extended family. The widespread acceptance of birth control and abortion has been associated with the return of women, including mothers of young children, to the work force. Rising divorce rates and the acceptance of alternative relationships to marriage have rapidly increased the number of single parent families and "blended families" involving the integration of parts of previously established families. The burdens and responsibilities of parenthood, especially for single parents, have increased markedly and are most profoundly experienced when the child of a single parent has a handicap or serious illness which requires long-term care.

Ms. James is a 24-year-old single parent whose 8-year-old son, Robert, has been hospitalized numerous times for a seizure disorder. The child's grand mal seizures have increased in frequency. The mother has become increasingly concerned about his condition and feared that he might suffer a cardiac arrest, which previously occurred 1 year ago. She, therefore, requested that the child be rehospitalized to control his seizures. Currently, his seizures are being controlled by intramuscular medication and the mother is vastly relieved that the child is actually smiling, babbling, and beginning to take some steps again. Despite the fact of being told that her son would only live for a maximum of 2 years, it is difficult for her to accept the poor prognosis.

She has two other well children, a 7-year-old daughter and a 23-month-old son, at home. She understands that her younger son is vying for her attention by imitating her sick son. He wants a tongue depressor put in his mouth and keeps rolling his eyes back when he craves attention. She recognizes her daughter's resentment of the patient. Her daughter assumes a great deal of responsibility for Robert's care but several times was found biting and hitting him.

Ms. James admits that, at times, she has contemplated giving Robert more phenobarbital than the doctor has prescribed and letting him "just go to sleep" permanently. At other times, she thinks about leaving the children and never returning.

Within the world of chronic childhood illness, what factors determine the overall adjustment of the child? The nature of the illness itself is crucial. The age of onset, course and severity, visibility and degree of handicap the illness imposes are important variables. However, a child is more than his or her illness. Personality traits, intelligence, sense of humor, and developmental level will guide responses to the stress of illness (Sperling, 1978).

Of vital concern is the family. Several long-term studies have emphasized that children, particularly handicapped children, are very sensitive to how their parents view the disability (Kessler, 1977).

Through the normal process of identification, the child incorporates the parents' views of him or her and thereby forms a concept of self. Except in the case of relatively rare, extreme forms of disability, parental attitudes are far more important than the disability per se. Parents walk a constant tightrope between allowing the child to develop independence and autonomy and respecting the limitations illness imposes. The two traps are overprotection, leading to infantile regressed behavior, and unrealistic expectations, leading to frustration and anger.

An important factor affecting development is the family's support system including extended family, medical care, community resources, school, and friends. It is in this area that the health "team" can provide important long-term services. We must understand the very real needs of our families.

How is this family dealing with the diagnosis? Our job is to observe and assess parental reactions and coping abilities. Before intervening, we must have knowledge of the socioeconomic factors affecting the family, the presence or absence of extended family members, and basic housing and living conditions. Are there siblings in the home? How has the diagnosis affected the marital relationship?

What are the parents' deepest fears and worries? Lack of information is often a major cause of worry. Do the parents understand in simple, direct terms, diagnosis, treatment, and prognosis? How have they been told? The physician's role is to share the initial diagnosis with parents and family members in a way that explains relevant facts of the child's condition without denying hope, if, indeed, there is hope. This is a difficult task especially for young house officers. Wiener (1970) has pointed out that many physicians, particularly those with less experience, are likely to avoid discussion of prognosis even after the parents have asked.

After the initial shock, parents are often unable to ask questions or assimilate information. They have little time to grieve. Crittenden, Waechter, and Mikklesen (1977) interviewed mothers of children in renal failure and noted the following concerns:

"I never knew what to ask"; "I didn't think of questions until later"; "My mind always shuts down after the first word"; and "We were all mixed up, just signed the papers and left." (p. 8)

Is there a professional who will be available to answer future questions and address worries as they arise? Nurses or other health professionals who have established a close relationship with the parents can best assess how parents have incorporated the medical information received from the pedia-

trician. In supporting the physician's viewpoint and clarifying parental distortions, staff begins the task of helping and guiding the parents throughout the illness. The staff's concern and commitment will lessen parental anxiety and, in turn, enhance the critical parent-child bond.

In exploring the social and emotional needs of parents and their families, the health team, including pediatricians, child psychiatrists, nurses, child life workers, occupational and physical therapists, teachers, and social workers, develops a comprehensive approach. In dealing with chronicity, the skills of various team members will be called upon at different times in the course of the illness. The clinical case conference, on a regular basis, is a focal point for all professionals involved in the child's care. Who of the team will handle the educational and supportive needs of the family? Who will coordinate medical services and offer feedback? Often the family best relates to one staff member who will guide the family to relevant team members.

Nicki is a 3-year-old child with a tracheoesophageal fistula and a diagnosis of failure to thrive who must be fed through a gastrostomy tube. Her parents have two older well siblings and the mother is pregnant. Nicki has spent most of her life in an acute care hospital or extended care facility. The mother, insecure and frightened, has felt unable to handle the child's basic feeding, wound care, and suctioning. The mother and older siblings have visited frequently and have taken the child home for overnight stays. Since the beginning of the pregnancy, the mother's visits have decreased markedly in length and frequency. The child, seeking to maintain her mother's love, calls daily from the hospital, but the mother is often unavailable. The siblings visit sporadically and feed the child inappropriately. However, the mother continues to want the child home as soon as the gastrostomy tube is removed.

The health team has met to devise a plan to reach out to the family. Since the mother has rejected foster care for the child, the team has enlisted the assistance of a nursing student who will make weekly home visits for a minimum period of 1 year. The mother has agreed to this plan and wants to keep her child at home.

The nursing student is a nonthreatening, supportive person concerned with the needs of the mother and other children. She assesses the home situation, family interaction, schooling needs of the other children, and financial resources and reports back regularly to the team. Specific team members advise the student how to handle problems and obtain concrete assistance. The nursing student, recognizing the mother's fatigue, has relieved her

by caring for the children while the mother goes shopping or keeps her appointments to maintain welfare assistance. She, at times, accompanies the mother to special programs for Nicki's diet and informally discusses ways to help Nicki deal with her restrictions. Follow-up clinic visits are kept with the student's assistance.

Rooming-in: Staff-Parent Interactions

The very core of a family-centered approach to pediatrics is a rooming-in policy which encourages parents not only to stay in the hospital, but to continue the parenting role. Over the past 30 years, hospital policies concerning parental presence have changed drastically. In 1954, most New York hospitals limited visiting to 1 hour twice per week. In 1974, 54% of general hospitals and 83% of children's hospitals provided at least a few beds for parents (Hardgrove and Kermoian, 1978).

How has this change come about? Over the past several decades, clinical researchers (Escalona, 1971; Robertson, 1958) have studied both the subtle interrelationships between child and parent beginning from birth itself and the long-term sequelae of separation from parents during early childhood. New knowledge has provided an impetus to reevaluate hospital policy despite institutional inertia and entrenchment. The tragedy is that we know so much more about the psychological impact of hospitalization and chronic illness than we use in clinical practice.

The pioneering work of Klaus and Kennell (1976) and of Robertson (1958) clearly demonstrates that the infant, toddler, and preschool child are most vulnerable to separation from family and home environment. The neonate and new mother create a highly unique bond that will affect the mother-infant dyad for years to come. The first days and even hours of life set the stage for the development of a mother-infant relationship in which each partner responds to specific cues, touch, taste, smell, sound, and sight of the other. Over the past decade, community pressure has forced obstetrical wards to modify policies which have routinely separated mother from newborn and have thereby disturbed the formation of their very special bond.

During the second half of the first year of life when separation issues are at the fore, hospitalization seriously interrupts the budding mother-child relationship. The child has barely established a lasting image of the mother or of himself or herself and reacts with profound separation anxiety in her absence. The child, increasingly aware of mother as a specific source of pleasure and comfort, cannot maintain an image of her when she is gone. The child has not yet developed "object constancy"

(Belmont, 1970) and is overwhelmed by fears of desertion.

For the child in the latter part of the second and third year of life, parents have achieved a relative greater degree of permanence. However, the child experiences separation deeply and painfully. He or she has no understanding of illness and may see hospitalization as punishment, loss of love, for "bad" thoughts or wishes.

The young 3- to 6-year-old child who is ill cannot distinguish between the hurt which is part of the illness and in the child and that hurt which is part of the treatment and outside of the child, a good and helpful kind of hurt (Freud, 1952). In the child's magical way of thinking, forced medication may be seen as poison and being kept in bed becomes imprisonment. For the young child, swamped by frightening fantasies and painful feelings, alone in the hospital, Robertson's (1958) words ring true today as they did years ago.

All he knows is that the mother he needs so intensely, the mother who should respond to his cries, is not there. He is grief-stricken and angry against those, who to his limited understanding, have let him down. (p. 5)

Prugh, Staub, Sands, Kirschbaum & Lenihan (1953) in their study of 100 child patients found that the distress of younger patients was eased little if at all by improved management which significantly reduced the incidence of disturbance in the older children. For the very young child not even the most loving care from strangers can compensate for the absent mother-person whether she be skillful or unskillful in staff's eyes (Escalona, 1971).

We now know that the so-called "well-adjusted" toddler who has "settled-in" during the hospital stay and no longer cries angrily for mother may be in actuality a baby who is resigned, regressed, and depressed. As long as the young child does protest, feelings for the mother or primary caretaker remain alive. Her consistent visiting enables the child to understand, at a concrete level, that she has not abandoned him or her.

Why, in very practical, day-to-day, management terms are parental involvement and participation on a pediatric ward being advocated? Better care results (Hardgrove & Kermoian, 1978). Parents often have the skills to counteract the frightening and painful experiences the child encounters. For example, the parents of an 18-month-old girl, hospitalized for prolonged intravenous antibiotic treatment of osteomyelitis, cleverly devised a way of maintaining the intravenous infusion while allowing the child to sit up. They used a cardboard box to elevate the hand and arm with the intravenous infusion.

Parents often prepare the child for painful pro-

cedures and remain to comfort the child and offer support. Parents who can cope with a crying, distressed child in crisis need to be present during painful procedures. One sensitive, articulate mother poignantly noted:

I couldn't, it was true, be sure that my presence was comforting her. Wouldn't it be easier to join other mothers who cry quietly outside the treatment room as their children yelled within? But being there felt better than surrendering Carrie to her fate alone. Whatever else was happening, she wasn't being abandoned. (Holmes, 1980, p. 46)

The studies of Visintainer and Wolfer (1975) have shown that when information is supplied to the child by the parents, children recuperate faster, parents express greater satisfaction with hospital and medical care, and both children and parents are more cooperative.

Parents support other parents. Often the most distraught, angry parent, unable to communicate with staff, will be able to relate to another parent who is facing a similar crisis.

The concerned, caring mother of a 14-month-old hydrocephalic baby gently helped a teenage mother to begin to accept and care for her hydrocephalic infant. She physically stood by the young, single mother and encouraged her to touch her baby, feed him, and comfort him. She demonstrated to this inexperienced, angry, guilt-ridden teenager how to wash, handle, and hold her baby despite his scalp vein intravenous infusion. As the young mother began to feel more comfortable in her mothering role, her anger at staff lessened, and she was able to trust in their care and learn from them. She eventually mastered difficult techniques such as suctioning her baby.

The mature mother was able to share her own feelings of loss for a normal child, shock at hearing the diagnosis, withdrawal, confusion, and bewilderment. The sharing process helped the young mother to deal with her own negative feelings which then allowed her to take the first steps toward loving her child. The experienced mother was able to kindle hope and offer concrete information concerning community resources such as infant stimulation programs and parent support groups.

In structuring an environment which encourages parents to help and aid one another, staff decreases the intense isolation experienced by parents of chronically ill children. Yalom (1975) emphasizes the "curative" factors of altruism and universality inherent in all psychotherapeutic group work. Those who "help" benefit as much as those who are "helped."

What, then, are the present difficulties in implementing parental inclusion in treatment and care

of their hospitalized children? As health professionals, we have trained in and are familiar with the hospital environment. We understand its rules, hierarchical structures, and priorities for patient care. We work in a busy, demanding setting where emergencies and life-threatening events are ever present. We need the structure and sterility of the hospital in order to function and be competent in our professional role.

On the other hand, parents, anxious and frightened, enter the hospital to encounter unexpected crises where they are out of control and can no longer protect their child from pain. Often they are fearful of staff's power over their child and uncertain of their own role in this strange, forbidding, cold environment. They feel helpless, vulnerable, and guilty and may attempt to deny their pain by becoming angry and demanding. One mother recalled the agony of having a baby hospitalized:

It was like being swallowed by a whale. When I walked through the hospital doors and followed the directions to pediatric admissions, I felt the despair and aloneness that must have been Jonah's. (Holmes, 1980, p. 42)

Parents of chronically ill children who have had multiple admissions face the unknown of frequent staff changes and rotations. In large municipal hospitals, poor staffing and insufficient facilities and equipment present especially difficult problems.

A 10-year-old child with sickle cell anemia required blood transfusions every 3 weeks as an inpatient. To avoid an overnight stay, the staff asked the mother to bring the child to the ward before 8:00 a.m. The early morning appointment necessitated waking the child at 6:00 a.m., feeding and clothing him, and taking two city buses to the hospital. When the mother and child finally arrived on the ward, they were often asked to wait for as long as 3 hours before the transfusion was started.

The mother exploded with rage at the staff's insensitivity to her and her child. Can we blame her? On the other hand, while she and her child waited and her needs went unmet, understaffed nurses dealt with their priorities of feeding hungry infants, preparing children for the operating room, and dispensing medications. The harried medical staff completed blood tests, answered emergency calls, and satisfied the demands of attending physicians.

Recognizing these difficulties, how do we reconcile the needs of all? In our very real attempts to create order and efficiency on the busy ward, we become desensitized to the individual patient's needs and fears. We neglect to communicate the

reasons for delays to parents in a warm, supportive way.

In the situation described above, the parent became so enraged at her own helplessness that she threatened not to bring her child for further treatment. Regular weekly parent meetings on the ward provided an effective way for her to ventilate feelings, share experiences with other parents, and educate the staff to her individual needs.

In addition, we as staff need a forum in which to discuss communication gaps with parents as well as communication gaps among ourselves. Planning for the emotional and psychological needs of the ward community demands time in our busy schedules and cannot be left to chance alone. The formal case conference needs to be supplemented by regular, informal problem-oriented meetings where communication can be open and differences among staff resolved.

During difficult procedures, the anxieties of parents may transfer to the staff. Staff feels threatened by being observed and fearful of exposing problems with technical skills. New interns may be especially vulnerable with an active, crying toddler, angry outbursts from parents, and their own guilt at causing pain. In an attempt to circumvent this volatile situation, staff may prohibit all parents from being present during procedures. Unfortunately, we thereby deprive the young patient of the comfort and support of his or her parents just at the time when the child is most needy.

Although expedient, asking parents routinely to leave the treatment room is a poor solution to a difficult problem (Mason, 1978). We remove the child's remaining island of security, further intensify his negative reactions, and create a situation fostering ultimate despair and hopelessness. How do we prevent this profound deprivation? A necessary first step is the development of a clear ward policy concerning parental right to inclusion as well as parental responsibility to staff.

Acknowledgement by staff of heightened parental anxiety during stressful procedures will usually engage most parents and help them to support the child. Communicating with parents in crisis is, indeed, difficult work and requires time, energy, and patience.

Parents as well as children need to be prepared for stressful procedures. For example, when we insert an intravenous infusion, do we tell the parents that we expect the child to scream, cry, and perhaps kick? Do we tell them that we may need to make several attempts? Do we tell them that the child may need to be held down? Do we tell them that, despite the child's behavior, their presence is helping and comforting? Do we give parents the choice whether to remain with their child or remove themselves?

In certain stressful situations, parental anxiety may so interfere with care that staff must use an authoritarian approach. However, we must not forget that for most of our patients this is temporary and that parents have the final responsibility for care of their child.

A 2-year-old asthmatic child with severe eczema was admitted on an emergency basis to the pediatric ward. The parents, observing the child in severe respiratory distress, were confused and agitated. An intravenous infusion was started with much difficulty and the parents accused staff of hurting the child needlessly. The following morning, the child was still in respiratory distress with the parents hovering over the crib. The intravenous infusion had become dislodged and the parents refused attempts to reinsert it. The only recourse for medical staff was physically to remove the crib away from the parents and to proceed with proper care. Once the child began to improve, the parents relaxed their vigil and permitted staff to carry out treatment.

The child's intern empathized with parental distress and the need to protect their child from pain. Using her knowledge of parental reactions to life-threatening situations, she reached out to the parents. The intern and mother eventually developed a close alliance during the hospitalization. Together they worked out a mutually acceptable schedule for outpatient medication and follow-up care in the allergy clinic.

In coping with chronic illness, wherein hospitalizations and medical procedures are repeated, prolonged, and recurrent throughout many years of the child's life, the need to have a loving and protective caretaking adult near at hand is all the more important (Sperling, 1978). However, it is impossible for parents, especially single parents, of chronically ill children who require long hospital stays to live continuously in the hospital with the young patient. Parents of children who undergo prolonged, repeated hospitalizations with only brief, intermittent periods at home are torn in many directions. Work responsibilities and responsibilities for other siblings present unbearable stress and conflict.

Visiting is extremely difficult for these parents who must constantly witness the acute protest and despair of the sick and needy child. The child cries, clings with the whole being, and wails mournfully for the "lost" parent. Staff often needs to help the mother handle guilt engendered by separation from the sick child and support her in her efforts to parent well siblings.

There is a tendency for many of these parents to flee the sick child. Staff then becomes resentful and angry at the parent. Staff can prevent the buildup of resentment toward distraught, insecure parents

by arranging regular visiting patterns, helping the parents to prepare the child for leave-taking, and assuring the parents that staff can handle the child's expected crying and protest.

We must help the mother understand that despite the child's misery and distress at her leaving, her visits are vital to the child's well-being. This is one instance where frequent and acute distress, interspersed with the contentment of having her near, is far healthier and safer for the young child than a state of resignation (Freiberg, 1972).

John is a 2-year-old boy born with an imperforate anus. He has required many hospitalizations for surgery as well as for alleviation of intestinal obstructions. Every 3 to 4 months John returns for inpatient care and remains for as long as 4 to 6 weeks. He is then discharged home to his family. The mother is a concerned, caring parent who visits almost daily but has found leave-taking increasingly difficult. The child cries and wails despairingly. He wildly clings to her as she walks to the door. At these times, she becomes increasingly distressed and prolongs the leave-taking in an attempt to comfort John. Recently, to avoid this excruciating pain, she has begun to leave the ward by a back staircase without telling the child.

The staff has reached out to the mother by acknowledging her distress and by helping her to prepare the child. Staff verbalizes the child's feelings of loss when mother leaves, encourages her return visits at regular times, and constantly reinforces her role as a caring mother who plays an important part in the recovery of her child.

Although staff works toward the establishment of a loving bond between parent and chronically ill child, there are situations where parents do abandon their children for weeks or even months. Nurses and other members of the staff become very attached to and emotionally invested in these children. Severe conflicts arise when natural parents reappear, and exercise parental rights. Resolution of these conflicts through supportive team conferences will help lessen anger and negative attitudes toward the parents with the goal of reuniting parents and child whenever possible.

Conclusion

In the majority of hospitals which service children and families, knowledge of developmental needs vastly outstrips application in clinical practice. Schowalter (1974) forthrightly confronts several conflicts in adults which prevent the full implementation of knowledge concerning the young patient's psychological vulnerability: (a) basic disregard for children, who have no political-social impact, and low prestige for the caretakers of hospitalized children, (b) condescending or fearful attitudes to the sick or troubled resulting in with-

drawal from patients, and (c) competition among adults, self-serving behavior that detracts from child/family centered care. For professionals who work with children, these conflicts, largely unconscious, are difficult to face. If, with courage and much trepidation, we begin tentatively to observe ourselves during team meetings and during discussions with parents, we may begin to uncover and cope with obstructions to our work.

A fourth conflict involves the very nature of our training. For the most part, we are trained to deal with the individual child patient's physical illness. For many of us, the family is, at best, extraneous to our work and, at worst, a nuisance or impediment to efficiency and proper use of our time. We do not recognize distraught, angry, belligerent parents as our patients. We may want to avoid them and their pain.

In reorienting our view of illness to include the child's family, the "vulnerable" parent becomes our patient as well as the "vulnerable" child. We need the full commitment of all health team members to family-centered care in order for pediatric health care to be effective.

References

- Belmont, H. S. Hospitalization and its effects upon the total child. *Clinical Pediatrics*, 1970, 22, 590-600.
- Crittenden, M., Waechter, E., and Mikklesen, C. Taking it day by day. *Children Today*, 1977, 6-35.
- Escalona, S. The personality of normal infants and children. In *Needs of children*. 6th Annual Conference ACCH, 1971, 15-22.
- Freiberg, K. How parents react when their child is hospitalized. *American Journal of Nursing*, 1972, 7, 1268-1272.
- Freud, A. The role of bodily illness in the mental life of children. *The Psychoanalytic Study of the Child*, 1952, 7, 69-81.
- Hardgrove, C., & Kermoian, R. Parent-inclusive pediatric units: A survey of policies and practices. *American Journal of Public Health*, 1978, 68(9), 847-850.
- Holmes, K. My child is in the hospital. *Parents Magazine*, 1980, 42-50.
- Kenny, T. J. The hospitalized child. *Pediatric Clinics of North America*, 1975, 22(3), 583-593.
- Kessler, J. Parenting the handicapped child. *Pediatric Annals*, 1977, 6(10), 62-72.
- Klaus, M. H., & Kennel, J. J. *Maternal-infant bonding*. St. Louis: Mosby, 1976.
- Korsch, B., Fine, R., Grushkin, C., & Negrete, V. Experiences with children and their families during extended hemodialysis and kidney transplantation. *Pediatric Clinics of North America*, 1971, 18(2), 625-637.
- Lansky, S., & Gendel, M. Symbiotic regressive behavior patterns in childhood malignancy. *Clinical Pediatrics*, 1978, 17, 133-138.
- Mason, E. Hospital and family cooperating to reduce psychological trauma. *Community Mental Health Journal*, 1978, 14, 153-159.
- Prugh, D. G., Staub, E., Sands, H. H., Kirschbaum, R.

- M., & Lenihan, E. A. A study of the emotional reactions of children and families to hospitalization and illness. *American Journal of Orthopsychiatry*, 1953, 23, 70-106.
- Robertson, J. *Young children in hospitals*. New York: Basic Books, 1958.
- Robinson, G., & Clarke, H. *The hospital care of children*. New York: Oxford University Press, 1980.
- Schowalter, J. Working together: Is a children's hospital for children and staff? *Association for the Care of Children in Hospitals Newsletter*, 1974, 3, 3.
- Sperling, E. Psychological issues in chronic illness and handicap. In Gellert, E. (Ed.), *Psychosocial aspects of pediatrics*. New York: Grune and Stratton, 1978.
- Visintainer, M. A., and Wolfer, J. A. Psychological preparation for surgical pediatric patients: The effect on children's and parents' stress responses and adjustment. *Pediatrics*, 1975, 56, 187-202.
- Wacchter, E. H. Congenital anomalies. *Nursing Forum*, 1977, 16(3), 299-318.
- Wiener, J. M. Attitudes of pediatricians toward the care of fatally ill children. *Journal of Pediatrics*, 1970, 76, 700.
- Yalom, S. *Theory and practice of group psychotherapy*. New York: Basic Books, 1975.