

# The Chronically Ill Child: A Challenge to Family Adaptation\*

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Why should psychiatrists and other mental health professionals be concerned with physical illness in children and teen-agers? Aren't we kept busy enough with the emotionally disturbed young patients and their families? There are at least two compelling reasons why child mental health workers should devote some of their time to children suffering from chronic physical illness:

As mental health professionals we have much to learn from studying children and parents who have successfully mastered the hardships associated with a chronic illness in childhood. These are families who illustrate Robert Louis Stevenson's saying, "Life is not a matter of holding good cards, but of playing a poor hand well." Common life contingencies such as serious illness, accidents, the threat of death, and natural disasters create significant emotional stress in addition to the physical ones. In recent years, there have been many reports on the coping techniques that an individual and his family use in order to master such threats to their psychological stability so that they can continue to function effectively. Coping behavior includes the use of cognitive functions, motor activity, emotional expression, and certain psychological defenses. All these techniques are involved in the individual's attempt to master the challenge, for instance, of a chronic illness.

The second reason for our interest in chronically ill children and teen-agers reflects our desire to prevent psychological complications from long-standing physical conditions. Such physical disorders are associated with a variety of distressing emotions and interferences with normal life activities that may lead to social crippling more disastrous to an individual than the effects of his primary physical

illness. As mental health specialists, we are often asked to be on the firing line together with our medical and surgical colleagues in preventing such socio-psychological complications. This is a good investment in time as we often can promote the chronically ill child's growth toward becoming a responsible and productive citizen.

*The prevalence of long-term physical illness* in children is impressive. Recent American and British surveys show that 7% to 10% of young persons up to 21 years of age suffer from chronic physical disorders. The most common ones are asthma, epilepsy, heart conditions, cerebral palsy, orthopedic problems, bleeding disorders, diabetes mellitus, blindness, and deafness.

The last two decades have seen over 100 studies on children's adaptation to chronic physical illness. Many authors have been impressed by the relatively good psychosocial adaptation of these young patients and by the fact that early mastery of distressing emotions on the parents' part, leading to realistic child-rearing attitudes toward the child, is positively correlated with the adaptation of the child. A serious illness in any family member disturbs the family equilibrium and makes it especially difficult for the mother to meet the needs of the other family members.

When a serious long-term illness afflicts a child, the initial reaction of the parents is usually one of acute anxiety and fears related to the possible fatal outcome of the child's disease. The second phase is one of trying to minimize or deny the situation, particularly if there are few obvious signs of illness. During this stage, the parents might complain that "no one ever tells me anything" and also show a tendency to "shop around" for additional professional opinion which would disprove the initial diagnoses. Behind such negative, often uncooperative parental attitudes, we frequently see

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\* Presented at the Tenth Annual Spring Forum for Child Psychiatry, May 26, 1972, at the Medical College of Virginia, Richmond.

underlying feelings of sadness and self-blame, which the parents tend to project upon the medical profession in an accusatory way. As this stage of denial fades, the parents often will begin to verbalize their feelings of hopelessness, guilt, and self-blame. This guilt-ridden, depressed stage will hopefully subside, too; otherwise parental attitudes of self-sacrifice and overprotection of the child might develop and jeopardize the child's psychosocial adaptation.

Let us turn to *some clinical examples* of the effects of a chronically ill child on family adaptation. The recent best seller, *Nicholas and Alexandra*, by Robert K. Massie, and its subsequent movie, portray the tragic influence that hemophilia, the so-called European royal disease, had upon the family of the last Czar of Russia. The son of Nicholas and Alexandra, Alexis, born 1904, was the heir to the Russian throne. The boy was found to suffer from hemophilia in his first year of life, and the diagnosis came as a shock to his parents despite the known hemophilic trait in the family of Queen Victoria, Alexandra's grandmother. From that point on, Alexis was continually overprotected, surrounded by round-the-clock nurses, and from age 5, by two Navy sailors who followed the Czarevitch around at all times so they could reach out and catch him in case he fell and risked hemorrhaging. The two sailors also provided him with affection, distraction, and sedentary activities. He was denied playing with children his age as his mother feared he would get hurt. Alexis frequently objected to his restricted life and was overheard crying to his mother, "Why can other boys have everything and I nothing?" At times he rebelled against all restraints and was described as a rather spoiled, often insolent child. His parents attempted to make up for his frustrations by lavishing expensive, mechanically operated toys on him.

Empress Alexandra was an oversolicitous, always worrying mother like any inexperienced parent of a seriously ill child. She was repeatedly fatigued due to her 24-hour attendance to Alexis during his bleeding episodes. For a long time she refused to accept that there was no cure for hemophilia, and she consulted specialist after specialist. Deeply religious and feeling that God seemed to reject her prayers for her son, she was plagued by guilt for having transmitted the illness. When Grigori Rasputin, the Siberian peasant and faith healer, arrived in St. Petersburg, Alexandra viewed him as a God-sent agent able to stem the course of Alexis' illness. In the fall of 1912, Alexis sustained prolonged, serious bleeding and was close to death for over a

month. His moaning was heard all over the royal palace, and he spoke to his mother about his impending death, "When I am dead it will not hurt me anymore, will it?" All Russia thought he was dying, and the London Daily Mail reflected many Europeans' opinion when they suggested that Alexis had been fatally wounded by an anarchist's bomb. Feeling desperate, Alexandra called upon Rasputin who responded by cabling back, "God has seen your tears and heard your prayers. The little one will not die. Do not allow the doctors to bother him too much." As Alexis began to recover the day after this message, Empress Alexandra was convinced of Rasputin's healing and mystical powers; a conviction which led to his increasing influence on both the Empress and the Czar regarding political matters in Russia. Any requests for parliamentary reforms and a sharing of the Imperial power were consistently turned down by Alexandra, goaded by Rasputin, and Nicholas gave way to his wife's objections. At the time of Rasputin's death in 1916 it was too late for any turn toward an enlightened monarchy. The revolution was inevitable as was the eventual triumph of Lenin and the ruthless killing of the Czar and his family in 1918.

The contemporary case of 14-year-old Sam, also a severe hemophiliac, illustrates the relationship between strong maternal guilt and an inhibited, fearful teen-ager. Sam was a quiet, cooperative, and "ideal" patient on the ward. During remissions he insisted on using crutches or a wheel chair because, "I want to spare my ankles." His mother allowed him to stay indoors all winter so he wouldn't run the risk of slipping on ice and hurting himself. In the hospital, he moaned and cried at times of pain, but only when his mother was around. Sam's strong fears and self-imposed restrictions seemed related to his mother's marked anxiety and overprotective attitudes. She had never let him out of sight in his preschool years and always felt reminded of the fate of her two hemophilic brothers who died from bleeding at a young age. In addition, she had lost an older hemophilic son before Sam's birth. Sam would at times tell his mother, "I wish you could have taken this illness instead of me," which upset the mother greatly due to her guilt over being a carrier. She stated her main purpose in life, "to care for my bleeding son," in a depressed, resigned way. Sam's father tried to question the mother's over-involvement with Sam, but he had little influence on her handling of him and spent less and less time with Sam.

The guilt-infested interaction between Sam and his mother can be compared to the interaction in

Peter's family. Peter, a 10-year-old hemophiliac, had for several years known about the genetic background of his illness. At times he would tell his parents, "I wish I were dead," when acute bleeding caused him severe pain. One day, as Peter was taking a bath, his mother entered the bathroom wanting to check his body for possible fresh hematomas (an unnecessary procedure, which the mother intellectually knew). Peter looked at her seriously and said, "I wish I could have got another mother." The startled mother felt tears welling up and left the bathroom. After having collected herself she returned and told Peter, "I am very sorry, too, that you are a bleeder, and that you got it from me. I understand how you feel about me at times. It's o.k. to tell me." Obviously Peter's mother had mastered her own conflicting feelings about being the transmitter of hemophilia. Both she and the father had told Peter as well as Peter's 3-year-old hemophilic brother about the hereditary aspects of the illness, and also stressed with their sons that they had to learn to watch themselves in play and take care of minor bleeding episodes as much as possible. Peter was an outgoing 10-year-old, participating in many games and sports, often with his father's guidance. The parents stressed that they wanted their hemophilic sons to grow up as normal as possible, to attend public school, and to be rather firmly disciplined.

Many chronic disorders of an episodic character, such as diabetes, epilepsy, hemophilia, at times cause family members to become quite concerned that a medical crisis might result from the child being emotionally provoked and upset. Emotional arousal can of course precipitate a convulsion in an epileptic child or cause a diabetic patient to develop ketoacidosis. There are many instances, however, when a child or a teen-ager, suffering from a chronic illness, takes advantage of his knowledge of the importance of emotional factors, and frustrates parental attempts at discipline, telling the parents for instance, "Don't yell at me like that, you know what might happen." An example is a 12-year-old epileptic boy who commonly would start faking an epileptic attack by shaking his arm whenever the father scolded him. The father was becoming increasingly confused and angry at his son. Considerable work with both the boy and his parents was required in order to open up family communication about the boy's intentional seizure-like movements as his response to an authoritarian, rigid home environment.

Let us review *some characteristics of chronically ill children and teen-agers who show a good psychosocial adaptation* to their illness and life situ-

ations. These youngsters function effectively at home, at school, and with peers. They accept those limitations that are realistically imposed by their illness and its complications. They have little need for secondary gains offered by the illness. From age 5 to 6 such coping mechanisms (ego functions) as memory, speech, reasoning, and reality testing assist them in learning more and more about the nature of their illness and its cause and effects. These mechanisms help them to develop an ability to accept limitations and show responsibility for their own care and assist in the medical management. In other words, they early develop a sense of self-protection which serves the vital function of self-preservation. These well-adapted chronically ill children seek and find satisfaction in many compensatory physical and intellectual activities. Here the parents' encouragement and guidance are of great importance. We also note that the well-adjusted, chronically ill child can allow himself expression of negative emotions at appropriate times, that is, he will show sadness, fear, anger, and impatience at times of physical discomfort, changed plans, and interfering treatment procedures. The defense mechanism of denial is employed to some degree by all well-adapted chronically ill children. Denial helps them to cope with the common chronic discomfort, their uncertain future, and the frequently guarded prognosis. Such an adaptive use of denial assists them in maintaining hope for speedy recovery in times of medical crises, hope for more effective medical treatment, and hope for a relatively normal, productive adult life. Many of the well-adjusted older children and teen-agers display certain pride and confidence as they have successfully mastered many critical exacerbations of their illness. We often observe that serious chronic illness in children seems to spur their maturation and heighten their sensitivity and sense of compassion for other human beings.

Children with *prolonged poor adjustment to their chronic disease* seem to fall into three groups. One group is characterized by the patients' fearfulness, inactivity, lack of friends and outside interests, and their prolonged dependency on their families, especially their mothers. In other words, these youngsters impress as early passive-dependent personalities. These patients have commonly been raised by constantly fearful and overprotective mothers.

The second group of poorly adjusted children with chronic illness contains the overly independent, highly active, often daring patients. They may engage in prohibited or risk-taking activities, making strong use of denial of realistic dangers and fears. At times they are true counter-phobics and their reality sense

seems impaired. (For instance, the diabetic adolescent, refraining from taking any insulin for a series of days in order to prove to himself and to his family that "I can do it.") Many of these rebellious, risk-taking patients have since early childhood been raised by oversolicitous and guilt-ridden mothers. At puberty, they rebel against maternal interference and turn into overly active, defiant teen-agers.

The third, less common group of chronic maladjustment comprises older children and adolescents with congenital physical deformities and handicaps. They often impress as shy and lonely patients with hostile attitudes towards the environment of normal appearing persons who seem to owe them an excuse for their lifelong sufferings. These patients harbor feelings of having suffered unjustly all their lives. Such attitudes of a physically disabled person commonly are related to early parental attitudes of embarrassment and shame about having a defective child. Obviously such a child tends to identify with the family's view of him and develop a self-image of a defective outsider.

In turning to the *parents who show good adaptation* to the burden of raising a chronically ill child, we note that the crucial factors in determining their acceptance of their child's illness appear to be their ability to master self-accusatory and guilt feelings over having transmitted or in some way "caused" the child's affliction. Parents of chronically ill children display the use of some common adaptational methods to cope with their distressing emotions associated with the constant stress related to raising a seriously ill child. These methods can be presented by way of some well-known tension-relieving mechanisms of the ego, namely, the psychological defenses of isolation, denial, rationalization, intellectual processes (control through thinking), reaction formation, and identification.

The mechanism of isolation seems particularly useful for parents of chronically ill children when they deal with acute emergencies. Many parents describe how they become almost unfeeling toward their ill child during a medical crisis; the mothers in particular become efficient nurses. This provides a detachment from painful emotions and helps the mothers to function effectively. When the crisis is over, a rebound phenomenon of a few hours to a few days often occurs, and the parents may feel depressed, irritable, "of no use to anyone."

The defensive mechanism of denial is frequently employed by the parents to avoid distressing aspects of acute situations and the constant strain of having a chronically ill family member. Parents often quickly

forget crucial information about the child's illness, including realistic precautions against future problems. A sense of helplessness may also be warded off by denial. It is common among parents of handicapped children to exhibit attitudes of superiority toward physicians, particularly toward house officers. Some of the criticism is of course valid, but one also senses that the parents are trying to master some of their long-standing helpless feelings in this manner. They deny such feelings and also displace and project helpless and angry feelings onto various medical staff members.

Denial is closely associated with rationalization, that is, the defensive use of rational explanations, valid or invalid, in an attempt to hide true emotions or real motives for certain behavior. One commonly hears from parents of chronically ill children that it is a "wonderful thing" to raise a sick child. One is reminded of "myth-building" when such parents state, for instance, that their child's illness has "emotionally sharpened" the parents or made their lives "spiritually richer." While indeed there might be some truth in such statements, these attitudes also assist parents in hiding from themselves and their children sad, angry, and helpless affects related to their unique burden. We also note that many siblings of chronically ill children rationalize inconveniences and hardships that have been imposed on them due to their sick brother or sister.

All effectively coping parents, along with their children, use intellectual processes to master distressing emotions related to the illness, that is, they rely on the cognitive coping strategy of "control through thinking." In this way they prepare themselves for what might be happening next during the course of a chronic illness and thus lessen their anxiety. Most parents of chronically ill children make it a point to learn all they can about the medical, physiological, and even the psychological aspects of the disease. These are the parents who are genuinely grateful to those physicians who provide them with repeated dosages of factual information regarding the illness, its course, and future plans.

The use of reaction formation allows an individual to turn unacceptable impulses or feelings into their opposites, which become permissible to express. Reaction formation may be helpful for any parents of chronically ill children who harbor affects of anger, guilt, and sadness regarding their child. It allows them to reverse these feelings and devote their energy to the care of their child. Reaction formation may become detrimental to the parents' adaptation when it is employed to such a degree that no aware-

ness of their painful feelings is possible. This might lead to martyr-like attitudes of the parents where they direct their whole lives to caring for their suffering children. Such attitudes can also be seen in siblings of chronically ill children when the siblings have been expected always to be understanding, forgiving, and loving towards their suffering brother or sister. It is not uncommon to find that parents who show devoted, martyr-like attitudes experience periods of feeling bitter and resentful about their fate as parents of a handicapped child. Such feelings often betray to the parents their underlying desire to be completely free of parental responsibilities, that is, they are close to the prohibited and guilt-producing thought of "wanting their child unborn," which borders on wishing the child dead. In general, fathers seem better able to verbalize anger and frustration regarding their children's disease. This seems related to the fact that mothers tend to feel more responsible for a genetic transmission or—unrealistically—"having caused" their child's handicap.

Identification with other parents of chronically ill children is an important adaptational mechanism among parents. Through association with other parents, informally or through various national organizations, they learn to adopt more realistic and relaxed attitudes towards caring for their ill children. They can also share the various distressing emotions related to their burdens and pass on some of their positive experiences to other parents of chronically ill youngsters. It is also of interest to observe that parents of children with a long-term illness often gain strength by identifying with their growing child's positive and stoic attitudes in the face of repeated crises and an uncertain future. Their maturing child's effective adaptation to his illness has become a helpful source of strength. Behind this recognition is often the awareness that the parents have "done a good job" in raising their ill child and that their long-standing ordeal has paid off.

In conclusion, by studying the emotional stress and the coping behavior of children with chronic physical illness, we can learn considerably about how

these patients and their families learned to "play a poor hand well." In this regard, it is noteworthy how often adolescent patients relate their good adjustment and positive outlook on life, despite their handicap, to their parents' early and consistent attempts to raise them with realistic and minimal restrictions. As one 16-year-old boy put it, as he was lying in bed receiving plasma infusion during a hemophilic bleeding episode, "Don't worry about the kids, Doc, but help the parents with their worries, so they can treat us like normal children." There is our challenge—to help the parents to readjust to the problems posed by their child's serious illness, to achieve a new family equilibrium, and to promote continuous family growth and integration.

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