
The Chronically Ill Child and Recurring Family Grief

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Chronically ill children and their families are increasingly seen in health care practices as the incidence of infant mortality and formerly fatal childhood diseases has decreased. These children present special challenges to the physician's perceived role as healer. Unlike the sequenced predictable stages of grief that families go through in facing terminal illness, the grief experienced by parents of the chronically ill is recurrent and cyclical. The physician who understands and can anticipate the causes and nature of this grief will be subject to less frustration in treating these children and their families and will be able to offer them more effective care.

As the Joneses and their child left the office, the physician reflected: *Why are these parents, and evidently the entire family, having such a difficult time accepting this child's chronic condition? One month I see them and they seem to have adjusted very well. Two months later and they all seem to be depressed. Another month, and they are hostile toward anyone that even looks like a doctor. How can I get them to accept their child's condition and make the best of it? By now they should have worked their way through this.*

This physician's reflections are not atypical, for chronically ill children and their families pose a continuing challenge for the health care provider. This challenge results in part from a number of circumstances that may contradict the physician's perceived role as healer. Working with families may be even more difficult if the physician is not aware of the often dramatic differences between the predictable stages of grief that families go through in facing terminal illness and the changeable stages of grief that confront families facing chronic illness. The purpose of this paper is to explain these differences and to explore a

model of recurring grief that may help physicians anticipate, understand, and offer more effective care for families of children with chronic illness.

THE CHRONICALLY ILL CHILD

The past few decades have seen virtually an end to many childhood diseases. Smallpox, scarlet fever, whooping cough—one by one these and other dread diagnoses have decreased as antibiotics, increased access to care, and technology have assumed prominence. Mass immunizations have long been accepted. Prenatal care, if not yet available to all the population, is certainly far more prevalent than in previous years and has helped greatly to reduce the infant deaths so common earlier in this century. One need only remember the steady increases in the average life expectancy to know that children of today have a far greater chance of a longer, healthier life than their parents did at birth.

Medical advances have helped prevent many early deaths; ironically, the number of children with chronic illness is growing. Many of these children have survived and most will continue to survive because of the dramatic improvement and increasing availability of medical care. Chronically ill children and their families increasingly will be seen in health care practices.

The increase in chronic illness has been substantiated in medical literature. Thomas,¹ for example, recently described a number of increases in survival rates and longev-

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ity of children with various chronic illnesses. Ireys² and Elbert and Willis³ also have anticipated an increase in the number of chronically ill children. Koop,⁴ in an address to a Surgeon General's Workshop, noted that technology has created a new population dependent on that very technology for survival. According to Stein and Jessop,⁵ chronic health problems will be seen increasingly in pediatric practices. Bronheim and Jacobstein⁶ conclude that "as a result of progress . . . the medical community will find its time and attention devoted increasingly to the chronically ill child." Similarly, Weitzman⁷ notes that "the decline in infant mortality and death due to infections has been accompanied by a marked increase in the prevalence of chronic illnesses."

CHRONIC ILLNESS: CARING VS CURING

Even without the complex emotional states that often accompany chronically ill children and their parents when they visit the physician, chronic illness itself is a challenge, if not a threat, to the role most physicians are accustomed to assuming. First, the centuries-old definition of physician is "one who heals," or in more modern terms, one who finds a cure for the illness presented. By definition, chronic illnesses are incurable, barring some future technological breakthrough. Often this lack of a cure places the physician in a role that is unfamiliar, one generally not considered during residencies, which are concerned with acute, curable, episodic care.

Another difference in the care of the chronically ill child is the degree of control many parents wish to have over their child's care. Unlike acute illnesses, for which parents generally can expect their primary care physician to have relatively quick solutions, chronic illnesses may be treated by a variety of physicians. Parents are more familiar with negotiating the health care system and, because physicians rarely see some chronic illnesses, may be frustrated by a physician's initial inability to have all the answers.

These difficulties are pointed out by Thomas,¹ who notes that "families of children with chronic conditions quickly become expert in the care of their child." Going further, Thomas says that "families of patients with chronic conditions and the patients themselves are often seen as most troublesome because they have experience negotiating the health care system, they do not see an end to their need to negotiate the system, and they also desire control over their life and environment." Hobbs and colleagues,⁸ in a detailed look at the families of chronically ill children, observe that the physician and the parents are frustrated by the fragmentation of care resulting from specialization. They note that often the diagnosis of a chronic illness is made by a subspecialist who generally will not be readily available.

The more accessible generalist must then treat a disease that is relatively unfamiliar. Stein and Jessop⁵ suggest that families may take out their frustrations on physicians who represent hope as well as disappointment, since no cure is available.

THE WRONG MODEL FOR EVALUATING GRIEF?

Families with chronically ill children seem to undergo drastic shifts in their ability to cope with their situation. At various times the families are "on top of things," they are depressed, they seem to feel guilty, or they are very angry. The physician who expects the family to have worked through its dilemma and to have reached a good degree of stability is likely to be frustrated if family feelings affect communication with the family or treatment of the child.

It seems likely that some physicians may not understand grief as it relates to chronic illness. Instead, expectations may be based on a model more suited to grief associated with terminal illness.

Perhaps the classic model of grief and terminal illness is that developed by Kubler-Ross⁹ in her seminal work, *On Death and Dying*. In her model, patients and their families face a diagnosis of terminal illness in a sequence of stages: denial and isolation, anger, "bargaining," depression, and, finally, in most situations, acceptance. Kubler-Ross finds that during the acceptance stage, the patient "will contemplate his coming end with a certain degree of quiet expectation."

Families who have a chronically ill child may go through some of these stages, but the paths of terminal illness and chronic illness are often remarkably dissimilar. As Collins-Moore¹⁰ points out, while a great deal of literature says that mourning is completed in 6 to 12 months, there is often no such end-point apparent in chronic illness. Drotar et al¹¹ describe the vacillating status of chronic illness as "often marked by disease-related crises of acute illness, physical deterioration, or the threat of death." Unlike most cases of terminal illness, in chronic illness these acute episodes and threats of death may be broken by uncertain periods of relative stability. An example is the juvenile hemophilic who, after an injury, must be hospitalized for a period before returning home to await the next hospitalization.

In discussing family adaptation to chronic illness, Thomas¹ concludes: "When a child has a chronic condition, particularly one that presents the family with daily evidence of its existence or requires significant daily health care practices, it may be unrealistic to expect final closure on the family sadness or grief." If, indeed, the expectation is unrealistic, the physician must use a different model for understanding and dealing with chronic grief.

CAUSES OF CHRONIC GRIEF

In developing a model for assessing grief associated with chronic illness, it is helpful to review the initial causes of grief for families who have a child with chronic illness. These causes further differentiate the nature of chronic illness and grief from terminal illness and grief. One major cause of grief is that many parents with a chronically ill child grieve for the perfect child they did not have. Collins-Moore¹⁰ reports that, prior to their child's birth, parents often have vivid pictures and expectations of what their child will look or be like. A father, for example, may already have thoughts of camping with a son or daughter, or a mother may have an image of the child's face or hair color. Mercer¹² and Lax¹³ agree that this idyllic image is shattered when parents learn their new child is to be far different. The parents are likely to begin a period of mourning for the loss of their vision. It is hoped that the intensity of this mourning will abate over time, but it seems reasonable to assume that these feelings will be with the parents for a long time.

A second major cause of grief for parents centers on the child they now have. To learn suddenly that this small, tube-and-technology-surrounded child is theirs is a devastating blow for parents. Neonatal literature is filled with studies of the difficulties in bonding between parents and these infants. The realization of the surgeries likely to accompany spina bifida, of the constant care required to postpone the scourges of cystic fibrosis, or of the seemingly unending treatments for other chronic diseases are major sources of sadness for families. This grief is exacerbated by the uncertain life expectancy or quality of life, which often, as Kornblum and Anderson¹⁴ point out, will make a child's future unknowable. This terrible lack of closure will produce long-lasting grief. Olshansky,¹⁵ one of the first to describe this state, referred to it as one of "chronic sorrow."

A third major source of grief is the impact chronic illness has on the normal demands of family life. Collins-Moore¹⁰ maintains that the family is at risk because of "the complex and multifaceted adjustments required to successfully cope with the psychological, practical, and financial impact of the initial crisis." Hobbs et al⁸ confirm this multifaceted impact of childhood chronic illness. Certainly the financial stress of chronic illness is easily understandable, but Stein and Jessop⁵ point out that even relatively common family events such as moving have far greater impact on parents who must rely on extensive medical and therapeutic services for their child. Sibling jealousy may occur, and while the effect of chronic illness on divorce rates continues to be debated, it is safe to conclude that marital stress must increase at times as the chronically ill child "requires parents to negotiate parental roles and responsibilities, time, energy, and finances, and to reconcile career versus family demands."⁵ Career mobility may also

be threatened because parents must be certain that their child would be covered under various health care plans.

Finally, the extent or duration of grief is influenced by the attitude the family has about chronic illness. Wright and Leahey¹⁶ note that families may perceive chronic illness as a threat, as an enemy, or as a challenge. This perception has implications for the well-being of the child as well as for the psychological well-being of the parents. The view that chronic illness is a threat or an enemy may color attitudes toward health care providers in contrast with the view of families who may look to providers as sources of support in meeting the demands of chronic illness.

CHRONIC ILLNESS AND RECURRING GRIEF: A CYCLICAL MODEL

The chronically ill child and his or her family pose a challenge for the health care provider, a challenge complicated by the dynamic process of grief. To understand and work with these families, providers may have to view stages of grief as recurring, that is, as stages that can be worked through by most families but that may repeat, particularly when crisis of illness occur or when threats to the child's development are imminent.

A number of authors have debated whether chronic illness is associated with stages of grief or whether grief is recurring. This debate is summarized well in Leifson.¹⁷ Most writers, however, now see more evidence that grief is recurring. Wright and Leahey,¹⁶ for example, note that "there are predictable points of family stress" that seem to force families into stages of anger, guilt, or denial. These stages, according to Wright and Leahey, occur generally when developmental milestones are not met. Hymovich¹⁸ finds that with chronic illnesses, school age and early adolescence are critical times that threaten family stability. Hobbs et al⁸ see the emotions of families as ebbing and flowing as their child's condition temporarily improves or worsens. Sabbath¹⁹ concludes that, while parents may learn to accept their child's condition, the acceptance process is more likely to be complex and often unclear. Bronheim and Jacobstein⁶ argue similarly that clear-cut acceptance is difficult because emotional distress is likely to flare as the chronically ill child does not keep pace intellectually or physically with his age group. Weitzman⁷ sees that the cyclical crises of chronic illness provoke repeated emotional struggles for families of chronically ill children.

For the health care provider, it becomes important to recognize where families are in the grieving process. Parents who seem continually hostile, for example, may have a substantial problem that could be detrimental to their

child's care. Parents who generally are not hostile, however, but who display hostility during an office visit, may be experiencing a sudden crisis that places them at a different point in the grief cycle. Careful observation and questioning may help the physician and the family explore the crisis and help the family resolve it.

Knowledge about recurring grief also may help the physician anticipate problems that could confront families of chronically ill children. For example, if a child will not walk at the normal time, or if a child will not be able to enter public school at the usual age, the physician should be aware of the impact of these events on the family and be prepared to help the family work through difficult periods.

The ability to help families through these crises is a type of healing that is perhaps most helpful for families with chronically ill children. Stein and Jessop⁵ point out the value of this healing for the family: "Even when there is limited potential for improving the physical condition, there may be a great deal the [physician] can do to ameliorate the psychological and social consequences of the condition that will help families work through the more difficult stages of recurring grief." Caring may be the closest thing to curing for many of the difficulties associated with chronic illness.

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