

Chapter 17

A Mother's Perspective: The Grieving Process and the Physician's Role

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The Grieving Process

The realization that one's child, children or spouse suffers from a life-threatening illness triggers a grieving process. This process can begin at the moment of a child's birth, when parents realize that physical anomalies could well signify a serious underlying problem. Or grieving can begin later, when baffling physical symptoms finally lead to the diagnosis of Fanconi anemia.

The knowledge that one's precious child or beloved spouse suffers from a condition which usually leads to premature death represents a terrible loss. The grief one experiences often proceeds in predictable stages, as one struggles to cope with this devastating reality. Since this illness often progresses slowly and patients sometimes live for years or decades after diagnosis, the family suffers from chronic grief. With every acute crisis of this illness, loved ones experience again the most painful phases of the grieving process.

Experts who study stages of grieving often refer to four phases, which usually proceed in order, but can co-exist in the same time frame. It is also possible to survive one phase only to find oneself experiencing feelings or behaviors characteristic of an earlier phase. Any one individual may experience this process very differently.

Stages of the Grieving Process

Shock or denial

The first stage of grieving is usually described as shock or denial. This phase is characterized by numbness and an inability to accept the diagnosis. Some individuals appear calm and can appear to be functioning normally. They carry on with their daily routine, perform regular tasks, ask appropriate questions, but in fact are functioning on “automatic pilot.” Often they cannot hear, remember or process information accurately. This phase can last from hours to months and is often intermingled with the second stage of grief.

Protest

Shock and denial give way to or alternate with protest. This phase is characterized by a roller-coaster of emotionality. Emotions commonly experienced are crippling sadness, anger, guilt, anxiety, despair, terror, and feeling out of control. Sudden outbursts of tearfulness or expressions of rage are common. With any loss one frequently experiences some level of guilt. When parents have unknowingly passed lethal genes on to their children, feelings of guilt can be quite intense, however irrational. The protest phase usually lasts for months. And even much later, whenever a patient’s stability gives way to periods of precarious health, the intense emotionality of this period may return.

Disorganization

The third phase of the grieving process is often referred to as a period of disorganization. Gradually the intense emotionality described above slows down. The emotions of the second phase continue, but the waves of sadness, anger, anxiety, and other disabling emotions are less intense. This period is characterized by feelings of low self-esteem, dread about the future, and physi-

cal and emotional fatigue. Most parents feel that part of their role is to protect their children from dangerous, unhappy experiences. They often feel quite helpless when confronted with the knowledge that they are unable to protect precious children from a life-threatening condition. Feelings of isolation and loneliness are common, as one realizes that others usually deal with problems of a much smaller magnitude. Many parents experience chronic depression at this stage.

Parents who live for years or decades with a life-threatening, chronic illness can get “stuck” in different phases of the grieving process. Many can manage to lead productive lives, but, with new symptoms and the onset of dreaded or unexpected medical problems, they must deal, again, with the most painful phases of grief.

Reorganization

For those who have experienced the finality of a loss (for example, the death of a loved one), earlier phases of grieving are experienced once again and a final phase of grieving occurs, which is often called reorganization or reintegration. Some eventually come to peace with the loss and learn to live with grief. Many gradually find increased energy to attach to other people, work and new pursuits. The pain of the loss may continue for many years, sometimes forever, but many are able to get on with their lives. For others, tragically, this is not possible. Self-destructive behavior, such as alcoholism or suicide, may result.

Other complications of the grieving process

Some behavioral and emotional characteristics of the grieving process are outlined above. In addition, a grieving parent or spouse can experience cognitive and physical changes. One can suffer forgetfulness, short-term memory loss, slowed thinking, confusion, short

attention span, and difficulty in making decisions or problem-solving. Common physical symptoms include insomnia, headaches, respiratory problems, higher blood pressure, gastro-intestinal problems, and weight gain or loss. Those experiencing chronic grief are themselves at higher risk for serious health problems.

Spouses often react in different ways to the illness of their child. Some cry frequently and need to express their emotions constantly. Others compartmentalize their grief, not showing their distress outwardly most of the time. Some are uncomfortable expressing their feelings and believe they must project “strength” to their family and friends. Differences in coping often lead to marital stress, as spouses can feel misunderstood, unappreciated and resentful of one another. Each may feel that the other spouse is unable or unwilling to provide sufficient emotional support. The grieving process can even threaten a previously strong marriage. Marriage counseling may be crucial to help couples learn to be more tolerant, understanding and supportive of one another throughout this extremely painful time.

Several factors influence one’s ability to cope with a long-term, chronic illness. Past experiences with loss may make this process even more difficult. A support network (family, friends, co-workers, and therapists) can help enormously. Many family members affirm that their religious beliefs have been crucial to their emotional survival.

The Physician’s Role: What Helps and What Hurts

How physicians can help

A patient’s physician is not expected to “treat” the emotional distress of the grieving parents or spouse,

although it may be appropriate for the physician to refer the parents or spouse to a support group (e.g., The Fanconi Anemia Research Fund), grief counselor or other appropriate professional. The power of the patient's physician to affect the emotional state of the caregivers is nonetheless enormous. The physician can play a crucial role in helping the family move from the depths of despair, anger and self-blame into understanding the disease, making and participating in a treatment plan, and maintaining hope.

Physician Characteristics Which Help

Almost all pediatricians or family doctors and many hematologists have had no prior experience in treating FA patients. The treating physician needs to be willing to learn, eager to explore current literature and seek out information from experts, and able to invest the time to learn new therapeutic approaches. It is also helpful if he or she is a caring, warm individual, concerned about the welfare of this patient and the stress the family is experiencing.

Treating physicians must be good at both explaining and listening. They must communicate in a language the family will understand. Physicians need to listen to fears and concerns, and answer questions in understandable terms. It is all right for doctors to admit they don't know all the answers, but they will try to find out.

Maintaining hope

The treating physician must be honest, straightforward, and frank in discussing the diagnosis of Fanconi anemia. The family needs to know that this is a very serious, life-threatening disorder. False reassurances are not helpful. At the same time, doctors should encourage families to be hopeful. The literature on Fanconi anemia

and the dire statistics presented reflect past treatment approaches. Statistics do not include the possibility that bone marrow transplant outcomes will continue to improve, that new methods of gene therapy could change life expectancies, and that future discoveries could improve overall survival rates. Families need to know that scientific discovery concerning this rare disorder has progressed at a very rapid pace over the past few years and that many laboratories are actively pursuing new, hopeful approaches. When appropriate, they need to know that new discoveries could greatly improve the prognosis for their child or spouse.

Depressed parents (and FA parents have reason to be depressed) must work harder than most to be great parents. They can unwittingly create an atmosphere of sadness and worry which permeates every day. As a result, the time a patient has may not be quality time at all. By emphasizing progress and helping to instill hope, physicians can greatly assist in improving the patient's quality of life.

Entering into a partnership with families

Family members should be encouraged to educate themselves about this disorder and to play an active role in the treatment plan. Becoming a part of the decision-making process enables many to cope with the anxiety, depression, and loss of control they are experiencing. The relationship between physician and family should be one of mutual respect, shared information, and joint decision-making. Caretakers know the patient well, are aware of subtle or abrupt changes in the patient's condition, and can be an invaluable source of information.

Family members may need permission to voice their concerns or disagreements. Some are intimidated by medical authority, or fear appearing foolish by asking

inappropriate questions. But parents or spouses must live with the results of any medical intervention, so they must understand and agree with decisions. Often, decisions are not clear-cut. Outcomes are unknown and risks are enormous. Parents must believe that the most appropriate decisions were made, given what was known at the time. When parents are ill-informed and have never voiced their questions or concerns, they may forever feel guilty if the outcome is not good.

Being responsive to patient needs

A doctor's responsiveness and empathy with the patient helps foster a good relationship with other family members. When the physician is warm, caring and concerned about the patient, parents feel positively towards that provider. Whether the patient's immediate concerns are about pain, nausea, fear, or side effects of treatment, these concerns need to be addressed in a caring manner. Parents are terrified that their child will experience unmanageable pain. It is this writer's belief that a great deal of pain can be eliminated when pain management is a priority. Bone marrow aspirations and biopsies can be performed under very short-term, total anesthesia, leaving the patient with a painless experience. Bone marrow transplant centers have done this routinely for years. But outpatient clinics, aware of the importance of this issue, may be able to offer the same service. Even though total anesthesia is more costly, and the assistance of an anesthesiologist is mandatory, the children who must experience these procedures on a regular basis should not have to endure unnecessary pain. On very rare occasions, a patient's clinical status makes total anesthesia unusually risky. However, in many cases in which patients are not provided with total anesthesia, it is because it is not suggested or offered.

Communicating diagnostic results in a timely way

Much of the distress family members experience occurs while waiting for the results of tests. From a simple CBC to a full-body CAT scan or MRI, parents or spouses wait with excruciating anxiety for results which may tell them if their loved one is doomed to die soon or has dodged a terrible diagnosis. For many, the waiting process is more painful than dealing with the results. Once you know the extent of the problem, you can begin to deal with it. The treating physician should make sure that family members get crucial information as soon as possible. If the news is catastrophic, it is important that the patient's primary doctor deliver the bad news if at all feasible.

Encourage normalcy while remaining alert to unusual symptoms

When appropriate and within prudent medical guidelines, physicians should encourage patients to live as normally as possible. Sometimes it is necessary to curtail physical activity, but simple measures such as a protective helmet might make normal activities possible. Consideration should always be given to maximizing the quality of a patient's life.

On the other hand, physicians need to be alert to a wide variety of symptoms which seem unusual, and should be more aggressive in pursuing a diagnosis. For example, physicians should inform patients and their families of changes which might suggest a malignancy, and work together to monitor a patient's clinical status.

Being "there" for a family when patient's condition worsens

When a patient's condition worsens suddenly or when he or she approaches death, a physician should not suddenly withdraw from the family. Many families

believe this occurs regularly, and suspect that doctors need to protect themselves from the family's emotional response and their own feelings of grief. But families desperately need support at this time, and are deeply appreciative when physicians are able to empathize with them during the hardest times.

Attitudes and Behaviors Which Do Not Help

Family members are well aware of physicians' behaviors which have not been helpful to them. The doctor who knows little or nothing about Fanconi anemia and has no time to become informed is not helpful. Doctors who appear cold, distant, and unsympathetic do not gain the family's confidence. Physicians who speak in complicated medical terms, have little time to answer questions, are rushed or impatient, deal with families in a condescending way, or do not consider the family's input are not appreciated.

Many parents tell stories of doctors who informed them that their child would probably die within a specific period of time or before reaching a certain age. These comments have devastated parents and have frequently proven to be untrue. Too much is unknown about how any one individual will progress. The positive impact of future therapies is obviously unknown and cannot be addressed in the medical literature available today.

Doctors who are noticeably missing when bad diagnostic news is delivered or who never come to see a dying patient bring additional pain to a grieving family.

The physician with endless time to research an orphan disease and provide ideal patient care may be difficult to find in these times of work overload, HMOs, and pressures from other patients equally in need of quality care. But having dealt with this illness for over twenty

years, this writer has experienced enormous variance from one physician to another in terms of ability to work with families burdened with a life-threatening, chronic illness. Families should try to locate physicians who can best meet the patient's physical and emotional needs. Physicians should become more aware of and responsive to the needs of this unique group of families.

