
Problems in Family Practice

The Dying Child and the Family

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The physician involved in the care of a child with a fatal disease has an obligation not only to give the best possible medical care to the child but also to provide emotional support and guidance for the family and the patient. Many emotional problems can be resolved or prevented by discussions with the parents and by encouraging them to express their anxieties and questions. The death of a child is the ultimate tragedy, and everything should be done to prevent further problems which add to the anguish the parents must endure.

Support of the parents begins when the diagnosis is first presented, must be continued throughout the child's course, and should often extend beyond the death of the child. Understanding the child's reactions to death is important and helps the physician respond appropriately to the child's questions. Some older children wish to discuss their disease with the physician and in such cases their questions should be answered honestly, while at the same time offering hope.

The family physician can play a vital role in the emotional support of a dying child and the family. Although many times the treatment of a serious and potentially fatal disease is coordinated with a large medical center, the families will often turn to their own physician for help in coping with the tragedy. It is the goal of this review to identify the types of emotional problems such patients and families experience and to point out how important it is for these families to have the support and understanding of their physician.

Presenting the Diagnosis

When the diagnosis is confirmed, it should be presented to both parents in a quiet, private setting, removed from the noise and interruptions of the hospital ward. Every effort should be made to have both parents present, as one parent will often not accurately convey the information to the spouse and the absent parent may regret not having shared the initial shock. Each parent may also support one another at this time of family crisis.

There is no easy way to inform parents that their child has a fatal or potentially fatal disease. The information should be presented clearly and factually, and the physician should continue to talk after stating the diagnosis. If the physician merely states "your child has leukemia" and then

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stops, the parents may be overcome with grief and, rarely, hysteria. It is then much more difficult to explain the various aspects of the disease and to mention positive features of the disease which can soften the shock. If the child has acute lymphocytic leukemia, for example, one can state that there is an improved outlook with modern treatment, that most children with the disease will go into remission and return to normal activities, and that there usually is not a great deal of pain. The actual facts of the disease should be presented and the parents should not be misled with false hopes or expectations.

A number of problems can be anticipated and often avoided by a thorough discussion at this time. The parents should be advised to continue appropriate discipline of their child. Children want and need discipline and if it is suddenly withdrawn they will become confused and unhappy. It will also cause problems with the siblings who suddenly see the patient allowed to do things they cannot do. Most parents understand and agree to continue the pre-illness rules of discipline.

Parents frequently have guilt feelings when they hear the diagnosis and will think or ask, "What did I do that caused this?" or "What could I have done to prevent this?" They should be told that there is absolutely no justification for such feelings and this reassurance often has to be repeated on more than one occasion.

The family should be cautioned that relatives, particularly grandparents, often cannot accept the diagnosis and may insist that it cannot be correct. The parents, by accepting the diagnosis as correct, may then feel that they are condemning their child. By forewarning the parents about such reactions, this additional anguish can be minimized. It is often helpful to bring such grandparents into the discussions as they will then be more likely to accept the diagnosis. Unlike the parents, grandparents have two people to be concerned about: their child and their grandchild.

How much is covered in the first interview depends on how well the parents handle the shock of the diagnosis. If the parents are overcome with grief, it would be best to withhold further discussion until the following day and ask if they would like to see a clergyman. It should be realized that much of the information presented will not be remembered and should be reviewed again in further conferences with the parents. Booklets describing

the disease in layman's terms are often very helpful if available.

Interim Period

Often there is an intervening period between the time of diagnosis and the time the child dies. The physician must provide support as the family faces the reality of the impending loss. Some parents may deny the reality of the diagnosis, and when this occurs they will have a much more difficult time when their child does die. Families who accept the reality of a fatal disease often live from day to day, enjoying each good day when they have their child and, overall, are much happier than those who cannot adjust and accept the inevitable. Occasionally, parents may seek to understand the disease to the "nth" degree or to "intellectualize" the disease. Both mechanisms are the result of inability to cope with the fact that their child will die. More than the usual support and guidance should be given in such circumstances.

Many families will be inundated with advice from friends about seeking treatment at other centers or quoting newspaper articles citing a new treatment for the disease. They usually will have confidence in the center where they are receiving care, but they may have guilt feelings if they do not follow such advice. It is best to encourage frank discussions of the advice or article and the true significance or lack of significance should be given. The parents are usually relieved after such exchanges, and they will most often continue with the original treatment plan. If they do wish a consultation, the physician should not take it as a personal affront and should reassure them that he/she would be happy to forward the reports.

On a number of occasions the author has observed "the isolated wife syndrome."¹ The mother will complain that she cannot talk to her husband about the disease and that when she does he will walk out of the room or abruptly terminate the conversation. In such cases it is the mother who usually brings the child to the clinic and must face the reality in discussions with the physician. The father, by avoiding the visits, either intentionally or of necessity, may find it easier to deny the child's illness. Men also are much more reluctant

to show their emotions and may have considerable difficulty in expressing their true feelings about the child's illness. Unfortunately, the wife may then feel that she is carrying the entire burden of the child's illness and is without the much-needed support. On occasion, however, the mother may push the father out of the picture, using the child's illness as a weapon against the husband and as a reason for ceasing to be a wife.

The parents may occasionally, sometimes in subtle ways, express hostility to the physician for no obvious reason. This is understandable, in that he/she is the one who tells them that they will lose their child. The physician can compassionately not react to such expressions, as he justifiably might in a more benign situation. If the hostility is so great that it interferes with rapport, the parents should be encouraged to frankly discuss their feelings with the physician. In the event the above reasons are the cause, the irrationality will often become obvious to the parents as they discuss it in the open, and the tensions may be relieved.

Irrational hostility can, on occasion, be directed against the child. One mother complained that she was overzealous in disciplining her child and did not understand the reason for the sudden change in her attitude. During the discussion it was apparent that the mother was blaming the child for getting sick and for the anguish that the child's death would cause. The mother's overt hostility toward the child disappeared following the open discussion. One may need to caution parents not to devote all their time to the patient at the expense of the other children in the family. Sometimes the siblings are, in substance, punished because they are well. This just adds to the family stress.

There is an increased incidence of school phobia in children with malignancy and very likely also in other life-threatening illnesses in children.² Separation anxiety in both the mother and the child is the primary cause. The phobia begins with complaints of headache or abdominal pains. The mother responds by allowing the child to stay home for a period of time and both the mother and child fear that he/she will die if he/she is away from the mother. With the mother and child housebound, the intense relationship fosters hostility in both of them, promoting more anxiety and intensifying the problem. Regression then occurs and in some cases may be severe, with the child assuming the fetal position. The child may be more de-

bilitated by the isolation and regression than by the disease itself.

Treatment may be difficult, but the child should be promptly returned to school and counseling sessions given for the child and family. The physician can assure the family that there is no medical reason to keep the child home and that he is physically able to attend school. Contact should be made with the school to enlist its cooperation in keeping the child in the classroom whenever possible. The most effective treatment, however, is prevention, and during the early stages of the disease the potential psychological problems should be discussed with the parents.

What the Child Should Be Told

It is now known that many children, four years of age and older, are aware they have a serious disease and often know the diagnosis without being told directly. Some of these children wish to discuss and ask questions about the disease, and the child may feel isolated and lonely when he cannot communicate his concerns.

At the time of the initial interview, parents will often ask what they should tell their child if he is out of the toddler age group. They should be told the merits of telling the child the truth if the child asks appropriate questions, indicating he really wants to know. Some children, however, will cope by denying the disease and ask only vague, superficial questions, or ask no questions at all. This author does not see any merit in forcing the diagnosis on such children, but does attempt to convey to such children that he would be happy to discuss their concerns if they wish. Occasionally, parents may be quite vehement, insisting that their child never be told the diagnosis, even if he wants to know. Often, they will change their minds over a period of time as the physician discusses the greater difficulties that often arise when such children are not told. Some physicians feel that children should be told their diagnosis even though they may not know or ask the implications of the disease. The concern is that the children will often be told the diagnosis by a playmate and, if the child has already heard it, he will not be shocked or upset.

If the parents consent, the basic facts about the disease and treatment should be outlined for the child who wants to discuss his diagnosis. The availability of a number of effective drugs or treatments (if applicable), extensive research efforts, and other positive aspects should be emphasized to the child. Often, the child will not follow the line of questioning to its logical conclusion—what will happen when there are no more drugs or treatments. The fatally ill child is sustained by hope and often avoids any confrontation with his physician which would lead to its denial. The child is satisfied with the knowledge that further responses to treatment are possible, and that the staff is constantly working to get him well.

The Child Faces Death

Children under the age of three or four equate death with the absence of human love objects on which they depend. The four- and five-year-old is curious about burial, dead animals and flowers, and the accidental features of death. Preschoolers fear dying because of a loss of the love and attention necessary for feeling cared for physically and emotionally.

The dying preschool child recognizes the fact of death but does not understand it. The child commonly believes the illness is a retribution for bad thoughts or actions and if he accepts the guilt, the child often becomes passive and withdrawn. If the guilt is denied, it may be projected onto others and the child becomes angry and rebellious. Anger may also be directed at the supposedly omniscient and omnipotent parents for allowing him to be ill.

If a preschool child asks, "Am I going to die?" the answer could point out that he is not going to die today or tomorrow.³ This reply supports the child's need to deny, but also tells him truthfully what will happen today or tomorrow. The preschooler should be dealt with on the basis of day-to-day reality because he cannot understand something that may happen in three months' time or even two weeks hence. Although a strong death concern has been reported in a 3¹/₂-year-old, anticipation of death is rare prior to the age of five or six. A five-year-old female patient of the author,

however, gave instructions to her mother as to which of her playmates she was to give each of her various dolls. Thus, several days before she died, she was aware she was going to die and had, in essence, made out a will.

During the early primary school years, the child begins to comprehend the permanency of death. The concept of terminal illness first makes its impact, and death anxiety is greatest during this period. The grade school child feels that he is being punished when faced with the prospect of his own dying. The child must be assured by the parents' actions and words that he is not being punished or sent away by them. If the grade school child asks about the reality of the situation, he should be told the truth in terms that he can understand, with the agreement of the parents. Children generally should not be told more than they ask, and hope should never be totally abolished. Some children in this age group will ask if they are dying. What they are usually asking for is an explanation of why they feel so bad and the assurance that they will be cared for. Occasionally, however, when the child is doing poorly, he may mince no words with: "Am I ever going to get well?" or "Am I going to die?" At such times, the physician may state that some children do die when they become very ill but that many others recover, and that the staff is diligently working to get him well. This statement conveys the truth, which the child already knows in most cases, as well as offers hope and assurance that the physician will not abandon him.

The specific treatment of the dying young child is the management of separation anxiety. The child fears separation from loved ones, and therefore he should be reassured that he will never be left completely alone. The child may ask the parents questions about death, and the parents may be told that although they may not be able to answer all their children's questions, answers are not what the children need as much as talking to someone and realizing they are not alone.

The dying experience is extremely traumatic for the adolescent, who can appreciate the meaning of dying but cannot accept the reality of personal death. As the teenager strives for self-sufficiency and for independence, he can appreciate clearly the total passivity and the absolute dependence of the dying experience. Since he has struggled so long to become independent of the family, the

teenager often sees death as a punishment for his presumptuousness. The adolescent may frequently ask, "What have I done to deserve this?" The newly emancipated teenager may have too much personal pride to accept the support and the understanding needed as he copes with death. Death, therefore, may be a very lonely experience for the adolescent. Depression or regression to a dependent childlike state may occur if the mechanisms for coping with the anxiety are inadequate. Rage may be directed inward by the patient for being so weak and imperfect that he cannot direct his life to fulfillment.

Adolescents usually cannot tolerate dishonesty, and it is preferable to give them the facts of the situation, if they request them and the parents do not object. The patient will usually indicate by his questions what kind of answers he wishes. If the teenager emotionally needs to deny absolutely, the patient should be allowed to maintain his emotional defenses. He should not be obliged to face unpleasant and unbearable realities he cannot tolerate.

If the adolescent is days or weeks away from death and asks, "I am not going to die, am I?" he is obviously pleading for support for his process of denial. The patient should not be told a lie, but he can be answered, "No, you are not going to die right now." The adolescent who is strong enough emotionally to face the reality more directly might ask how long he has to live. If the prognosis is for three months, he could be given the truth and also hope, by a response pointing out that patients with the same illness may die in three to six months but may live longer.

Terminal Period

When it is obvious that the child is entering the terminal stage of the disease, the physician should offer the parents every opportunity to discuss any problems and feelings they have. It is also a crucial time to discuss potential problems that often can be avoided by anticipating them. For example, it is a common reaction for the parents to have feelings of "looking forward to the end." It is understandable that parents may anticipate relief when their child is no longer suffering and also look forward

to the release of the anxiety about the death they have coped with for so long. The point is that they may condemn themselves for having these thoughts: "What kind of mother am I who looks forward to my child's death?" Thus, reassuring them that this is a completely normal reaction does much to eliminate this source of anguish. One father exclaimed, "I would have never gotten through the funeral if I hadn't been told such thoughts were normal!"

On occasion, the child might have considerable pain that cannot be adequately managed at home. If he is hospitalized, and relief is forthcoming, he might then react against the parents. A mother of such a child became extremely upset when her child said, "I do not want to see you any more, Mommy." She knew the child was dying and to be told this by the child was intolerable for her. It was explained that her child's omnipotent image of her had been replaced by the doctors and nurses who had relieved the child's pain. The explanation of what had happened gave her immediate relief, and when she was allowed to give the pain medication herself, the previous close relationship was reestablished later that same day.

It is often very helpful to allow parents to participate as much as possible in the medical management of the child. Giving oral medication, taking the temperature, bathing the child, etc., gives the parents the feeling that they are helping and is often very therapeutic emotionally for the parents.

As the end approaches the question of where the child will die should be discussed frankly with the parents. It has been customary in the past for the terminal patient to die in the hospital. However, some parents may wish to have the child die at home, and they should be supported if this is their preference. They often feel that it has more meaning for the entire family, and also they can be in constant attendance if the child is at home. If an older dying child expresses a preference, it should be followed, if at all possible.

The parents may start to show more interest in other patients on the ward than in their own child as the end approaches. This is due to anticipatory grief and is often misinterpreted by ward personnel. It should be understood and accepted. Inquiring as to how the parents are doing is often appreciated during this critical period. Although all the attention and care is focused on the child, the parents are going through one of the most stressful

periods they will ever have to endure. A sincere, "How are you doing, Mrs. Smith?" affords them knowledge that you understand their anguish and suffering. Complimenting them on the fine job they are doing will also be appreciated. Some parents, however, immediately shrug off such compliments and wish to concentrate every word of the conversation on the condition of the child.

Occasionally, the physician may be asked how the child will die, and often the parents' fantasies are worse than the realities. If the disease is leukemia, they may be told that the children usually will die from infection or from bleeding, neither of which is associated with much pain. The parents often seem somewhat relieved after such frank discussions.

Philosophy of Terminal Care

To illustrate specific points, the author's philosophy will be discussed as it applies to the management of leukemia. When it is obvious that the child is becoming resistant to the last available drug, the philosophy of terminal care should be discussed with the parents in general terms. Occasionally, the parents may ask questions about terminal care at the time of the initial interview and express concern about unnecessary prolongation of suffering. The author takes no medical measures (blood transfusions, intravenous fluids, antibiotics) to prolong the life of a child whose leukemia is resistant to the available antileukemic drugs and who is in significant pain. Narcotics and sedation are used liberally to make the patient as comfortable as possible.

Occasionally the leukemic process may be out of control for many weeks in the terminal phase and yet the child may feel relatively well and take part in most of his usual activities. Such a child would receive full supportive medical care, as useful life would be prolonged, rather than prolongation of suffering. The decision to follow this philosophy is made by the physician with the agreement of the parents. It is not appropriate to put the burden of the decision on the parents as they may later feel guilty or may receive disapproval from their friends. If parents object to this philosophy of terminal care, their wishes are fully

supported, and the child is given complete medical therapy to the time of death.

In the author's experience, the majority of families (approximately 80 to 90 percent) express relief and approval when this philosophy is discussed with them. Other physicians may feel that everything should be done medically to the time of death. However, there is agreement that there is no place in these circumstances for cardiac resuscitation or use of respiratory ventilators. Each physician must decide for himself what he believes is the best way to serve the dying leukemic child, but should guard against vigorous supportive therapy if the sole basis for this is his own anxiety about being medically helpless. The author must question principles, however lofty and moral, that dictate active intervention which results in the terminal patient continuing to live so he can suffer. As someone has commented, "No one nowadays is allowed to die without being cured."

There is no justification for failing to use whatever doses and frequency of narcotics and sedation are necessary to relieve pain. Nurses and house officers often have to be reminded and supported in this regard. They sometimes are reluctant to deviate from the standard doses and standard intervals of administration. Reassurance can be given that there is a range between that needed to relieve pain and that which might directly cause death. If a child needs narcotics for a considerable time before the anticipated terminal period, a concern for addiction is not justified when viewed in perspective.

The Child Dies

Parents who have faced the reality of the disease usually have a normal grief reaction, and a majority feel a sense of relief when the child dies. Those who have not faced it often feel the loss all at once and have more difficult grief reactions.

At the time of death it is wisest to allow the parents to do what they feel like doing rather than impose one's own wishes on them. It is often difficult to find appropriate words to soften the fact that the child is dead. It can be stated simply that one is sorry and that the parents can be grateful

that he is no longer suffering. The parents can be complimented at this time on the excellent care they gave their child. Small talk seems to help sometimes, but the author feels that after a few appropriate words, compassionate silence may often be a better approach. A member of the clergy can then take over, although some parents may not desire this, and their preference should be respected.

It is important for the physician to be sympathetic, but he should always be in control of his feelings. Most parents become angry with the physician who cries openly and feel that the physician is burdening them unreasonably with his own tensions.

After approximately 10 to 15 minutes the physician should return to the family and request an autopsy. Appropriate explanations of what is done and why it is done should be given. It is unusual for the family to refuse; most are quite positive in their feeling, "If it will help some other child, we want you to do it."

At this time it can be stated that many parents may have lingering questions that may continue to disturb them. They should be encouraged to call the physician in the future for a meeting if they have such questions. Many of them will appreciate such an opportunity, and to many it adds a note of finality to the entire experience. Parents who have more than the usual difficulty facing their child's death should be seen in follow-up to evaluate the adequacy of their grieving reaction. Occasionally they may have serious emotional difficulties requiring psychiatric care.

After the child's death, the parents should tell the siblings the truth in terms appropriate for their age. Many parents realize that the introduction of the traditional idea of heaven creates far more problems than it solves. The siblings should be allowed to cry and should be encouraged to express themselves about their feelings. Telling the child to be brave or to be a man places an impossible burden on a boy and interferes with the natural emotion of grief. Siblings often have feelings of guilt, and they should be reassured they had nothing to do with their brother's or sister's death. Children above six years of age should be encouraged to go to the funeral but should not be forced to go. The details of the funeral should be explained to the child in advance. Children are more relaxed and less disturbed by observing the

funeral than by the fantasies their fertile minds create in lieu of the actual event.

Death of a Newborn

The difficulties parents face when they have a stillborn or when a newborn infant dies are often not appreciated. The mother experiences the classic grief reaction and it may be more severe if she has lost a previous infant or had a miscarriage. Many mothers feel guilt over a fantasized cause of death (coitus during pregnancy, a fall, not taking iron pills, etc)⁴ and thorough discussions are necessary to relieve the guilt, and the feeling that they are being punished for wrongdoing. There may also be lack of self-esteem if the mother feels that something is wrong with her because the child they produced failed to survive.

Viewing and touching the dead infant may have a profound salutary effect, helping the mother cope with the reality of the death without fantasizing. The mother may grieve more intensely but is usually better able to master her grief in the long run. It is important to prepare the mother for what she will see when she is shown the dead infant. Mothers who do not view the infant may fantasize about what could have been so horrible that she should not be permitted to see the infant. The association with other mothers of live healthy babies is extremely difficult for the grieving mother and room assignments should be adjusted accordingly.⁵

Fathers also grieve and may feel anger because they had eagerly anticipated the child or guilt because they had been unenthusiastic. Some fathers feel they cannot allow their emotions to show and, thereby, they may inhibit their normal grieving reaction. The other children in the family should be encouraged to talk about their feelings. Siblings may harbor guilt because of feelings of rivalry towards the fetus. The parents should be encouraged to talk to each other and the children and be united in the grieving process. Friends and relatives are surprisingly often not supportive to such families because they view the baby as replaceable and grief as inappropriate.⁶ This often leaves the parents only each other for support and increases the need of support from the physician.

Sudden Infant Death Syndrome (SIDS)

This syndrome (crib or cot death) of unknown etiology kills approximately 10,000 babies in the United States each year and kills more infants between one week and one year of age than any other disease. The emotional reactions of parents following SIDS are usually worse than those from other diseases because the death is sudden and unexpected and because there is mystery surrounding the syndrome. With most diseases the family has the time to prepare and begin the grieving process before death, whereas in SIDS, the entire grieving process must take place after death.

In the acute phase, disbelief is followed by considerable testing of reality and parents will often speak of the infant in present and past tenses.⁷ The parents frequently feel anger, helplessness, and loss of meaning of life. They become fearful for the safety of their surviving children. A fear of "going insane" often occurs in the first few days and may last several weeks. Guilt may be overwhelming and parents may feel responsible for the death of their baby. Special attention should also be given to the reactions of the siblings as well as the parents, as the former also have feelings of guilt and characteristic grief reactions.

Physicians can do a great deal to prevent the crippling guilt reactions of parents. In some communities the disease is confused with child abuse and the parents may receive cruel and inhumane treatment rather than the compassion and consolation they desperately need. SIDS can be certified on the basis of gross autopsy findings and the family should be promptly informed and not kept in suspense until the microscopic and laboratory studies are completed.

The physician should make every effort to be available for repeated counseling sessions following SIDS. The two important points to convey to the family are: "Your baby died of a definite disease entity (SIDS)," and, "It could not be predicted or prevented; you are in no way responsible for the death."⁷ Other information about the disease is also helpful to the parents, ie, there is no sound or cry of distress, the cause is not suffocation or aspiration, it is often preceded by a minor illness, it is not hereditary or contagious, and there is no suffering. The National Foundation for Sudden

Death, Inc. (1501 Broadway, New York, NY 10036) has chapters around the country and will provide information to physicians and parents.

Comment

The author had been impressed with how well a majority of parents reacted when faced with the tragedy of their child's death, when they were given appropriate emotional support.⁸ Others, however, have found that in 50 percent of affected families, at least one member had an emotional problem requiring psychiatric help.⁹ The author's subsequent experience in another state was significantly different from previous experiences, and the incidence of severe emotional problems more closely approximated that of other studies.⁹ Personal communication with other colleagues has also supported the impression of geographic differences in the ability of parents to cope. A study of the reasons for these apparent geographic differences would be most interesting.

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