

The Dying Child

Helping the Family Cope with Impending Death

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AS advances in medical science mount, an increasing of children with chronic terminal diseases are being taken care of and being kept alive. Sophisticated chemotherapy and more effective radiation technics, for example, enable children with leukemia and other malignancies to survive much longer in comparative good health, while complex apparatuses similarly prolong the lives of those with chronic lung or kidney diseases. Such developments are directing attention more and more not only to the reactions of the child to his illness and impending death but to the reactions of his parents and of the hospital staff members as well.

Whenever death threatens to take a child, parents, hospital staff and others closely involved continue to hope that this will not occur for a long time. They may neglect to examine their own feelings, and may even fail to consider realistically how best to help the child. Our purposes in this paper are to discuss the child's concept of death, to explore the feelings of those around him, and through brief case histories, survey various ways of helping the dying child through his greatest time of need.

The Child's Concept of Death

Our observations were made at the University of Michigan Hospital and concern children with a protracted fatal illness, not those who die suddenly. It is the practice at University Hospital not to inform children

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"Death in children is both a timely and appropriate topic in most pediatric centers, where more and more boys and girls are being seen with protracted fatal diseases. I was impressed with the sensitivity of Misses Ann Smith and Lois Schneider, authors of this paper "The Dying Child." They taught me a great deal, looking at fatal disease as they do from their nonmedical viewpoint.

"Their perceptive description of the attempt by the hospital staff to remove themselves from the death situation, and the revealing behavior of relatives of the dying child are particular attributes and contributions of this paper. Even the case presentations bring life to this scientific manuscript."

These were the comments of Doris A. Howell, M.D., Professor of Pediatrics, The Women's Medical College of Pennsylvania, Philadelphia, when she reviewed the paper which appears here. Dr. Howell, whose own thoughts on this topic are well known to those who have had the privilege of hearing her speak, noted in a recent statement:

"No one enjoys the heartbreak and emotional chaos associated with impending death; no physician enjoys the death room, talking with the family, making appropriate small talk. In fact, most physicians run away from it and salve their conscience by working inordinately hard in areas other than the one where understandably they feel so helpless. Nevertheless, the physician must face up to his role in handling the dying patient. Physicians are not ministers, and yet in our profession if we minister to a person's body, we must minister to all of him. We can serve a patient fully only by caring for him when he is dying as well as when he is living." *Pediatric Currents* 17: 49, June 1968 (Ross Laboratories).

of their diagnosis or prognosis; discussion of the pros and cons of this is a separate topic and will not be considered here.

Personality development is related to a satisfactory identification with parents. A child's ability to trust stems from the security and love he receives at home. The child is dependent in most instances on his parents for fulfillment of his needs. He feels that his future lies in the hands of adults. His psychologic vulnerability to the fear of death is in large measure related to the quality of trust he has in his parents.¹ To understand a child's vulnerability to the fear of dying, we must understand the developmental stages which lead to the establishment of his concept of death.

The child under age three and four equates death with the absence of a human love object on whom he depends.² While recognizing physical death, he does not understand that consciousness and life have also ended; he believes that the dead person goes on living in another environment. Four- and five-year-olds are curious about burial, characterizations of dead animals and flowers and the incidental features of death. On the whole, preschool children experience the fear of dying as being equivalent to separation from the love and attention necessary to feel secure.

For children five through nine years, death is *personified*. They express curiosity about death indirectly; they sublimate their inquisitiveness through a superstitious and investigative approach. Death frequently has a distinct personality or is looked upon as a separate person; skeletons and ghosts are personified as "death"; death is invisible.

In school, as they develop more logical thinking, in contrast to magical thoughts, they begin to distinguish between memory and fantasy, between dying and absence. Gradually the concept grows of death as cessation as all bodily activities and the end of human experience.

To have a complete concept of death, children must also understand the implications of inevitability. The very young child magically believes that his parents, with sufficient effort, can prevent or protect him from every sort of frightening experience. With time he

learns gradually that parents are not omnipotent and that even they cannot prevent certain events and feelings.

A child's intellectual development, experiences and sense of time—both present and past—must reach a certain level for him to understand that as there is a beginning of life, there is also an end. This usually becomes fully apprehended around the time of puberty, and is preceded by the ability to *conceptualize* such phenomena as size, weight and texture even when the object is absent.³ Not until adolescence do the child's ideas of death come to resemble those which he will have as an adult.

Reactions of Children

Most of these children never ask directly if they are going to die, though they frequently act fearful and apprehensive. Younger children seem to be more concerned about *feeling safe*, about being with a trusted person and free from pain than they are about actual survival. With older children there often seems to be success in repression of this anxiety, rather than a lack of awareness.

Illustrative Case Observations

Sometimes a child expresses anxiety through curiosity:

Michael, age 11, was hospitalized for palliative radiation of a malignancy. Several times he was found looking through his medical record. He declined to enter the activities program on the ward, preferring to stand out of sight near the nurses' desk, as if he were eavesdropping.

A child's behavior and reactions are frequently related to his disease. A change in the level of his energy or a physical abnormality may influence how he sees himself or how he interacts with others. Decreased energy, a passive acceptance, and resignation or depression are regularly noted in children with terminal symptoms.⁴

All members of the hospital staff can be helpful by recognizing with him that he is in pain and uncomfortable. Medical procedures should be explained in enough detail to satisfy his curiosity. He should be permitted to ask as many questions as he wants to express his concerns, anger and fears. Reassur-

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ance and comfort are important; children frequently complain about being alone, cold, in the dark or behind a closed door:

Betty Lou, aged seven, was hospitalized frequently before her death from metastatic sarcoma of the arm. As her weakness and pain increased, she showed a marked need to be always in a brightly lighted room with the door open. On several occasions, she fought desperately at being placed in an oxygen tent, shouting "Don't put me in that box."

Jimmy, aged three, permitted only his mother to give him his medicine, his food, or his bath during the final weeks of his illness. He had an overwhelming need for a familiar and loved figure to be always nearby. The needs of both patient and parent were met through the mother's ministrations. A sensitive nursing staff supported this arrangement.

Reactions of the Parents

Parents of a dying child are usually overwhelmed, and in a state of acute crisis. Previous patterns of personality and family functioning become clearly apparent. Guilt, anger, bewilderment and sorrow are feelings which the parents may experience simultaneously. What may appear on the surface to be appropriate behavior, may be a desperate attempt at control or a fragile veneer under which lies deep despair:

Larry, aged nine, was dying of inoperable brain cancer. His mother constantly denied that he was not responding. To the staff, she appeared more concerned with his manners and her inability to get her hair done. She met everyone with a bright, artificial smile and the comment "he is better every day." Constant talking, denial and physical activity were her only defenses against the impending crisis of Larry's death. The entire staff feared a breakdown, for she had surrounded herself with an impenetrable wall.

The individual hospital staff members are in a unique position to provide assistance. They cannot change the inevitable, but their recognition and understanding of parents' feelings can be meaningful and very helpful.

The behavior of the parents may range from a warm supportive approach toward the child to withdrawal or to inconsistent indulgence:

Danny, aged 11, had had several siblings who had died after protracted illnesses. Once his parents learned that he, too, had a terminal disease,

they no longer visited him in the hospital. Remembering their previous painful experiences, they were unable to give Danny the support and love he needed.

We can accept a wide range of parental behavior, if we realize that the way people handle crises is influenced by both personality structure and previous life experiences.

A delicate balance exists between understanding and support and an inappropriate identification with the family. An over-involved staff member who displays grief or who becomes personally involved, fails to offer the support that is needed:

Miss Henry, an aide, became more and more emotionally attached to Carol and her family during Carol's long hospitalization. She brought the child gifts and clothes, acting more like a relative than a professional. She truly wanted to help, but could not; she was reacting to her own sense of loss.

Role of the Parents

Parents not only should be made to understand the child's illness, but should be given full opportunity to express their concerns and anxieties. Many parents feel guilty or partly responsible for the child's disease. A concerted effort should be made to relieve these feelings. Physicians, of course, carry the primary responsibility for the making and explaining of medical decisions, but the ultimate sanction for procedures must be given by the child's parents. Physicians who provide the parents with guidelines and a realistic understanding can help them reach decisions without increasing their sense of guilt.

Some parents respond with hostility when the medical and nursing staff assume total responsibility for the treatment and care of their child from the first admission to the hospital. Other parents, unable to face their own feelings, may develop a sense of anger toward the hospital staff. A display of hostility by a parent is usually a reaction to the crisis, not a personal vendetta.

Parents who are allowed to participate in the care of their child usually have a feeling of having done everything they could; the personal effort also relieves their guilt. In the long run, they tend to be grateful for the

opportunity to spend time with the child and to support and help him.

Parents informed of the prospect of their child's death feel that their hopes and dreams are shattered. Devastation comes with a feeling of emptiness.⁵ Out of their great despair, some parents after being told of the fatal diagnosis may suddenly take an all-permissive approach to the child. This sudden alteration in many or all of the former behavioral controls frightens the child. He may react by testing his parents, using more and more obnoxious behavior. Parents may at first respond with anger, then with guilt at having felt angry toward a dying child.

Much of this cycle can be prevented. Parents must be helped to maintain the same demands in a consistent manner, always keeping in mind realistic expectations for a sick child:

When Bobby returned home after palliative hospital treatment, his parents allowed him to do as he wished. As his behavior became intolerable, his parents couldn't help feeling angry towards him. They felt that they were wrong to react so negatively toward him since he had only a few months to live. They were made to realize that controls which they had previously maintained gave Bobby a feeling of security. They were then able to reinstate certain limits, and Bobby's behavior showed marked improvement.

Final Thoughts

Not surprisingly, hospital staffs frequently try to remain emotionally uninvolved with patients, hoping to protect themselves from the constant impact of working with dying children. Certainly, caring for dying children is difficult and demands a high degree of understanding, skill and warmth. The death of a child is a devastating experience, awakening in each of us one of man's deepest fears—death before fulfillment.

We may see relatives and others closely involved begin to withdraw from the patient in anticipation of his death. They are thereby

beginning the reparative process associated with mourning. The staff should watch for this behavior and act to prevent or attenuate this withdrawal. Parents, friends and all others should be encouraged to maintain their friendly relationships with the child.

References

1. Solnit, A. G. and Green, M.: The pediatric management of the dying child; Part II. The child's reaction to the fear of dying. *In* *Modern Perspectives in Child Development*, Albert Solnit (ed.), Sally Provence, New York Universities Press, Inc., 1963, p. 218.
2. Nagy, Maria H.: The child's theories concerning death. *J. Genet. Psychol.* 73: 3. 27.
3. Solnit and Green, p. 219.
4. Richmond, J. and Waisman, H.: Psychologic aspects of management of children with malignant diseases. *Amer. J. Dis. Child.* 89: 43, 1955.
5. *Ibid.*, p. 44.

General Bibliography

- Anthony, Sylvia: *The Child's Discovery of Death*. London, Kegan, Paul Trench, Trubner & Company, Ltd., 1940.
- Bergmann, Thesi: *Children in the Hospital*. New York, International Universities Press, Inc., 1965.
- Bergman, A. B., Schulte, C. J. A.: Care of the child with cancer. *Pediatrics* 40: 3, 1967.
- Fiefel, Herman (ed.): *The Meaning of Death*. New York, McGraw Hill Book Company, 1959.
- Knudson, A. G., Jr. and Natterson, J. M.: Practice of pediatrics, participation of parents in hospital care of fatally ill children. *Pediatrics* 26: 482, 1960.
- Morrissey, J. R.: Children's adaptation to fatal illness. *Social Work* 8: 81, 1963.
- Norton, Janice: Treatment of a dying patient. *In* *The Psychoanalytic Study of the Child* 18: 541, 1963.
- Plank, Emma: *Working with Children in Hospitals*. Cleveland, Western Reserve Universities Press, Inc., 1962.
- Richmond, J. and Waisman, H.: Psychologic aspects of management of children with malignant diseases. *Amer. J. Dis. Child.* 89: 42, 1955.
- Solnit, A. J. and Green, M.: The pediatric management of the dying child: Part II. The child's reaction to the fear of dying. *In* *Modern Perspectives in Child Development*. New York, International Universities Press, Inc., 1963, pp. 217-228.
- Vernick, J. and Karon, M.: Who's afraid of death on a leukemia ward? *Amer. J. Dis. Child.* 105: 393, 1965.
- Yudkin, S.: Awareness of dying. *Lancet*, I 780: 37, 1967.