



[ REVIEW ]

# Helping the Angels: A Review of Understanding and Helping Dying Children

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## ABSTRACT

According to the World Health Organization, 53,000 children die every year in United States because of a chronic medical condition. Physicians have to face various ethical and psychological challenges while managing these conditions. These challenges range from disclosure of diagnosis to effective grief counseling to the family. In this article we have discussed some of these challenges and strategies to effectively meet these challenges.

## INTRODUCTION

According to a report from the World Health Organization,<sup>1</sup> approximately 400,000 children in the United States are living with a chronic, life-threatening condition. Of these children, 53,000 die every year. During the terminal phase of illness, physicians are faced with many complicated psychological and ethical challenges. These challenges can be difficult and emotionally draining for the health professional, especially when they do not have enough prior training to cope with terminally ill children. The clinician managing the terminally sick child has more responsibility than the physical management of the illness. The clinician must assume the roles of educator, patient advocate, and supportive confidant. He or she must assume the responsibility of dealing

with the patient and family members. Knowledge of child development and psychopathology along with physical illness are also important.<sup>2</sup> This article seeks to address these responsibilities and provide strategies to effectively meet these challenges.

## DISCLOSURE OF THE DIAGNOSIS

### Disclosure to the parents.

Disclosure of a terminal diagnosis is a difficult task for physicians. Physicians should first recognize the depth of shock and despair the parents will feel. The physicians should then explain the basis for the diagnosis and the nature of disease, including its causes, with an emphasis on relieving possible paternal guilt. The physician should attempt to gain paternal support both in the physical and emotional care of the child, and while emphasizing any hope possible, the physician should discourage excessive optimism. The physician can further assist the parents by informing them of any programs, organizations, community resources, and mutual or self-help groups that are available. Such measures obviously will not take away the sorrow, pain, and anguish these parents undoubtedly will feel, but they can help to ameliorate some of these feelings.

### Disclosure to the child.

According to Spinetta,<sup>3</sup> terminally ill children are aware of their condition

even if parents try to hide the truth or tell them otherwise. Children do not need to have an accurate concept of death's finality to realize that something dreadful is happening to them.

A clinician must tailor any communication with the child according to the child developmental status. Allowing children to ask questions and attempting to provide developmentally appropriate answers creates the setting of mutual trust necessary in these stressful situations. Also a due consideration must be given to the child's and family religious and cultural beliefs. The parents and close family members should be involved in the disclosure process, which helps to assure the child that he or she is not alone in this process and will not be abandoned by his or her loved ones.

There are several myths about communicating end-of-life information to children that may create barriers between the children and their physicians and loved ones. One is the belief that talking about death and dying will always send children into a deep depression, and another is that children are not able to understand concepts of death. Children are actually more anxious and can feel a greater sense of isolation, compared to adults, when they are shielded from the truth.<sup>4</sup> Therefore, such attempts to protect them by hiding the truth of their condition from them can actually place barriers between the children and the people who can best help them understand and deal with their experience.

Uncertainty is a major psychological burden for children with serious illnesses because they are limited in their capacity to obtain information that could potentially reassure them. Thus it is incumbent on those caring for children who are seriously ill to frequently assess and address the children's concerns.

Issues of transference and countertransference, if not handled well, can lead to certain barriers in dealing with these patients. The child

may transfer feelings of love or hate to the clinician, and similarly the clinician may unconsciously identify in the child attributes that belonged to a significant person in his or her own early life. This phenomenon of transference may lead to very intense emotional feelings, both positive and negative, which if not identified and understood may lead to over involvement with the patient and a loss of objective compassion or to outright withdrawal and rejection.

### **THE CHILD'S REACTION**

The psychological and emotional response of a terminally ill child varies greatly with child's developmental age and family factors. Some of the common responses shown by these children include anxiety, fear, withdrawal, anger and depression.<sup>5,6</sup> Sources of anxiety in these children differ according to their developmental level. For example, separation anxiety may occur in children aged 1 to 5 years, mutilation anxiety may occur in those aged 5 to 10 years, and death anxiety can occur in those aged 10 years and older.<sup>7</sup> From late childhood through adolescence, the dying child may be more concerned with the physical aspects of the dying process than a younger child, with the fear of pain and physical disability emerging as central concerns.<sup>8</sup> Dying teens may see themselves as being cheated out of a future, which may be difficult for them to accept. Hostility and aggressive behavior is not unusual dying teens, and these feelings should be addressed by the clinician.<sup>9,10</sup> Sometimes children develop adaptive defenses (e.g., avoidance, suppression, repression) that help them cope better with the illness. Such defenses should not be challenged unless they interfere with the process of treatment.

### **THE FAMILY'S REACTION**

Terminal illness of a child can potentially endanger the family equilibrium due to extreme parental responses of rejection and over

protection.<sup>11-13</sup> Nothing is more devastating to a family than the fatal illness of a child. It tears into the life of the family as a functioning unit and confronts each family member with a crisis of coping with the loss and grief. The shock extends from parents and siblings to grandparents, other extended family members, and friends. Studies have shown that terminal illness in a child can lead to several catastrophic responses in the family.<sup>2</sup> Some of these responses include serious marital problems, increased alcohol consumption, sibling adjustment problems, and increased rates of stress-related illness (e.g., ulcers).<sup>2</sup>

### **THE CLINICIAN'S REACTION**

The impending death of a child may also engender powerful emotions in the professional caregiver, such as guilt for having failed to save the child, a sense of personal helplessness, sadness for a life unfulfilled, and anticipatory grief. These feelings need to be acknowledged and explored. Avoidance or attempts to block them out or only partially address them can lead to clinician becoming detached from the child.<sup>4</sup>

### **PSYCHOTHERAPEUTIC INTERVENTIONS**

**Main goals of therapy.** Therapy for the dying child must be adjusted to the developmental level of each patient. In general, therapists seek to provide information and support for the dying child. The child needs accurate facts about the illness and treatments, but obviously communications of this sort must be appropriate to the child's capacity for understanding. The discussion of death and dying with the young child is best approached by letting the child lead with questions, and providing direct answers without overloading the child with information too advanced for comprehension. The major goals of therapy with the dying patient are as follows:<sup>8</sup>

1. To allow open communication with patients regarding their conditions and to provide honest, factual information about those conditions
2. To facilitate the expression of important emotions and to help patients learn to manage these emotions as well as possible under the circumstances
3. To provide a relationship in which patients can experience support in confrontation with death
4. To intervene between patients and other significant people, such as family, friends, and medical staff.

### Types of intervention.

Literature reveals numerous therapeutic interventions using the foregoing variables that are designed to impact patients and their families. Various therapies that have been used effectively in this unique patient population include play therapy, individual therapy, group therapy and family therapy.

*Play therapy.* Play therapy has been used effectively with the children with terminal illness. Play therapy programs help in the expressions of anxiety-provoking feeling. It is used to enhance a sense of mastery, to foster adaptive behaviors, and increase cooperation with the medical team.<sup>16</sup> According to Gibbons,<sup>14</sup> play programs act as a buffer against the stresses of hospitalization and treatment, and they also tend to reduce social isolation.

*Individual therapy with parental involvement.* Individual therapy has been useful in providing expressive outlets for children. It is helpful in providing crisis intervention during extremely labile periods. It can also help children cope with invasive medical treatments. Individual therapy should always be boosted by close involvement of the parent to provide emotional support.

Young children may experience death as abandonment.<sup>15</sup> The therapeutic interventions should be directed toward dispelling this

feelings. This can be best done by a parent through the demonstration of love and care. This may involve holding the child and cuddling and stroking the skin. Any talking should center on the emotional quality of sound producing a calming effect in as many dimensions of sensory response as possible. While it is important to understand where the child is in the emotional development, it is even more important to do things that child can immediately integrate into basic emotional needs.<sup>15</sup>

*Group therapy.* According to Belle-Isle & Conradt,<sup>16</sup> most types of group therapy seem to provide an outlet for the expression of feelings and the development of social support. Any type of group intervention must have a clearly defined theme based on the need of the group members. It should be well structured with clearly defined goals. Informal process-oriented goals do not help much. The primary emphasis in the group might be problem solving, education, and/or peer counseling.<sup>2</sup> Some of the group themes may include parental responses to diagnosis, coping with treatments, and the repercussions of illness on family.

*Family therapy.* In a family therapy approach, the dying child and his or her family learn to communicate openly with one another. Parents often must be helped to manage their feelings of anger, guilt, and helplessness as they learn to help their child.<sup>8</sup> Family therapy offers an experience that may enable everyone to accept the facts and to work together to enhance the quality of life for the dying person. In family therapy, members are encouraged to express their feelings in anticipation of the death of their loved one.<sup>17</sup>

### CONCLUSION

Helping a child face death can be a stressful and daunting challenge for a clinician. We must remember that each child is unique. To help a child cope with fears and anxieties

surround illness and death, we must treat each child on an individual basis. A clinician must be sensitive and tuned to a child's feelings, thoughts, and actions. Any work with the dying child should be crafted as compassionate and palliative care with child's best interests foremost in mind. The goal should be to add life to the child's years, not simply years to the child's life. It is impossible to find a comprehensive answer that will be universally valid for all children. However, in this article we have attempted to alert clinician to special needs of dying children and offer some measures for effectively helping to reduce the suffering in these children and their families.

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