

PERSPECTIVE

Care of Terminally Ill Children With Cancer

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Since 1974, the Jimmy Everest Center for Cancer and Blood Disorders¹ of the Children's Hospital of Oklahoma has recognized the critical importance of assisting terminally ill children and their families and has developed a formal supportive intervention program for the period prior to the child's death. Our experience as described here is complementary to the Guidelines for Assistance to Terminally Ill Children with Cancer: SIOP Working Committee on Psychosocial Issues in Pediatric Oncology [1]. In the early 1970s, we originated a conference (Final Stage Conference; FSC) with parents when it became evident that their child would be unresponsive to further therapy. Typically this clinical situation occurred after failure of frontline therapy and first salvage treatments. Guided by patients' requests, our observations, and the literature, we soon came to recognize that; 1) diagnosis and poor prognosis can rarely be concealed from children [2], 2) children with advanced disease realize that death is a final event and they are able to face their own death [3], and 3) white lies and half-truths told by the physician or parents are unsatisfactory because they interrupt the personal relationship between child, parent, and physician. Therefore, in 1974 with the parents' permission, we began to include some children aged 5 years and older in the conference, giving them the opportunity to express their concerns and to formulate their wishes on how to spend the remainder of their lives [4].

Our initial experience convinced us of the benefit of this open approach. In 1977, we began to invite all children and families to participate in the FSC. By 1984, 78 families had participated [5,6]. We will briefly summarize our previous experience, outline several new observations, and finally present a concept that should facili-

tate understanding of the child's and family's reaction to the final stage conference and encourage therapeutic interventions.

Today's team consists of four physicians, two physician assistants, five nurses, a social worker, a faculty psychologist, a psychology hematology/oncology fellow, and support personnel. Our hospital-based chaplain, his staff, and a patient advocate also work closely with many of our patients.

The FSC is initiated by our physician, usually in the presence of a physician's assistant or nurse. Frequently we talk first with the parents alone and include the child later. Parents may prefer to talk to the child at home. After reviewing the course of the disease, the present clinical status, poor prognosis, and future alternatives are explained openly in concrete terms to the older child (age >6 years): "Our treatment is not working. You will die from your cancer and death will most likely happen within the next 6 months without further cancer therapy. You have the option to choose either investigational chemotherapy if available or supportive care." A young child, depending on his intellectual development, may be informed that his disease is progressing and parents may choose one of the two therapeutic options. Under this circumstance the fatal outcome is communicated to the child by physician or parent at a later time. The differences between the two therapeutic options are outlined in Table I. Although meaningful antitumor response may occur with phase II drugs, the potential for cure is negligible. The primary objective of phase I trials is to establish the maximum tolerated dose. If supportive care is chosen, a remission or cure is impossible. According to our own records the estimated survival time varies from hours to 7 months, with a median of 7 weeks.

Topics covered in the conference include pain medication, progression of the disease, possible complications, and physical/mental changes before death. Chil-

¹The Center was dedicated to Jimmy Everest, a 17-year-old high school student. He was aware of his impending death (1992) and made his decision about further therapy. He also planned with his parents to have a memorial fund established as seed money for a new, desperately needed outpatient clinic. His foundation succeeded in building a beautiful center, which is completely child- and adolescent-oriented. He represents many other cancer patients who have had to face death early in life. Our team feels deeply obligated to all of them. They have shown us how to improve effective care of terminally ill children.

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TABLE I. Final Stage Conference: Two Therapeutic Options

| | Further investigational intervention (phase I/II trials) | Supportive care only |
|--------------------------------|---|--|
| Remission | Small possibility | Not possible |
| Cure | Anecdotal reports | Not possible |
| Altruism of patient and family | Often a major factor | |
| Life expectancy | Brief unless unexpected response | Brief |
| Side effects of intervention | Likely | None |
| Tumor symptoms | Frequent but usually controllable (fewer symptoms if unexpected response) | Frequent but usually controllable |
| Blood transfusion | Possible; may be required for support of investigational therapy | Optional; often withheld except for symptoms |
| IV antibiotics | Possible; may be required for support of investigational therapy | Optional |
| Hospitalization | Probable | Not required except for symptom control |
| Time spent at home | Decreased | Maximized |
| Cause of death | Usually progressive disease | Progressive disease |

dren can be cared for by the primary care physician or by our team, usually now with the assistance of a hospice. Regardless of the primary caretaker, our team stays in contact with the family.

Between 1974 and 1984, we asked 78 parents for permission to have their children included in the FSC [6]. The ages varied between 6 and 21 years, with a median of 13 years. Five parents refused. Sixty-six children were still feeling well. Twenty-six children decided to continue experimental chemotherapy, whereas 36 asked for supportive care. Two children were unable to make a decision, and two children let the parents decide. A shortened form of the FSC was held with seven severely ill children. All of them asked to be discharged home or to a hospital closer to their home.

No serious psychological disturbances were seen in 68 of the 73 children during and after the FSC. Two of the sixty-six children who were still feeling relatively well did not understand the content of the FSC or forgot it. One boy had no preconception of his imminent death, and he was horrified when he was so informed. An 11-year-old girl who had been emotionally unstable during the course of the disease became severely depressed after the FSC. A 9-year-old boy developed severe behavior problems because of conflicts between his mother and his grandparents [5].

It is difficult to assess precisely the FSC's effect on patients and their families. We noted that two children who were prevented from receiving information on their impending death died in isolation and in fear. The children participating in the FSC accepted the new reality and died in a composed state of mind, except for the three mentioned in the preceding paragraph [6]. In addition, a small sample of parents answered a questionnaire after the death of their child [7]. The parental responses indicated that, regardless of the children's therapeutic choice, fewer than one-third of our patients reacted to the FSC with sadness, anxiety, and anger. At least half of our

patients continued their routine activities and communication with their families and friends. A similar percentage expressed concerns about the grief of family members caused by their imminent death.

One essential observation was not emphasized enough in our prior publications. Children who are informed that they will die soon choose unexpected moments when they wish to discuss their impending death. They often pick times when their parents are very busy and preoccupied. If the parents are not prepared for these unexpected but most important questions, they may miss the opportunity to share their child's fears and concerns, or they may inadvertently thwart open discussion. These heart-to-heart conversations have a deep effect on the family. As a mother stated so well, "It was just like all of a sudden he [a 14 year old] was at peace; he never cried; he was the strong one" [6].

The death of a child is a devastating experience, which most of us have not had to face in our lives. Our team attempts to assist the families in finding their own way of communicating with the dying child depending on their beliefs, their culture, and the child's developmental stage. Many of our parents pass on their Christian belief to their children and explain death to them according to their emotional and cognitive development. For example, a stepfather of a 4.5-year-old boy, who knew he would die, had the following conversation with his stepson: "Would you like to go fishing with God?" The boy answered, "Yes, but does God have fishing poles?" "I don't know," his stepfather said, "but if he doesn't he can fish with his hands." "Won't the snapping turtles bite him?" "Freddie, there are no turtles that bite in heaven. There are nice turtles in heaven that don't hurt people. Besides God would throw them back. No snapping turtles." Silence. "Do you remember that God paints rainbows after it rains?" "Who helps him? Can I help him?" the boy asked. "Yes, you can." "Won't I need a paintbrush?" "Freddie, don't worry about a paintbrush. He will have

one for you to use. Are you worried about anything else?" "Yes, Mommy, will Snow White be there?" "Yes, Freddie." "That is all I am worried about. Goodnight."

For families with different beliefs or no religious background, we often draw on the experiences of other families and patients; for example, a 16-year-old girl had a near-death experience while she suffered from severe sepsis. Afterwards she told her teacher, "I am not afraid of dying anymore, only of being depressed while I am still alive" [8].

We have found that one of the key fears that children have is that of being left alone. The following interaction demonstrates this issue: After we had informed the parents that their acutely sick 9-year-old boy would not survive his severe sepsis and had suggested that they should talk to him about his impending death, his caring but gruff father said: "Son, listen to me. You are very sick and the therapy is not working. You will die soon." His mother intuitively continued, "We love you; we will be here and your grandparents will greet you there" [6].

During the FSC, the patient and the family experience deep grief over the imminent loss. To deal with this news requires a change in perception for everyone involved. This effort can succeed only if the loss is accepted as a reality and if it is recognized that an adjustment to the psychological pain of loss is possible. The main goal in this terminal stage is to find a new meaning in life and to live in a new mindset. We believe that the recognition of this process is vital in caring for terminally ill patients. Not much attention has been paid to this in the literature. However, without specifically stating that part of the care for terminally ill patients is initiating and facilitating the grief process, Ira Byock in his book "Dying Well" formulates eloquently the dynamics of grief in his patients' lives [9].

Hope is essential for life. After our first publication about terminal illness in children, concerns were voiced about whether our open approach denied children their hope [10]. These critics have equated hope with hope for a cure. The hope for a cure is unrealistic in a child in the terminal stage of illness. It must be replaced by a new

objective, chosen by the child, consciously or unconsciously. This objective may vary: It may consist of participation in phase I or phase II studies, with the expectation of achieving further remission and/or assisting other children with cancer. It may be the return to daily activities, i.e., going to school, working or pursuing hobbies, taking Make-a-Wish trips, or just being with family and friends, caring for their future, distributing one's possessions, planning the memorial service and burial, or learning more about God.

In summary, we have found that an open, honest discussion with children older than age 4 years is possible. It enables the vast majority of children and their families to spend their last days together creating final memories, giving final gifts, finding spiritual peace, and saying goodbye.

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