

Guidelines for assistance to terminally ill children with cancer

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This is the sixth document of the SIOP Working Committee on Psychosocial Issues in Paediatric Oncology. Several members of the ICCCPO took part in the workshops where this document was drafted and discussed.

Introduction

These guidelines refer to two time periods in the final phase of life for the child dying of cancer. The first is the period when treatment is judged as no longer effective and the difficult group decision must be made to move from the curative to the palliative phase of care. The second is the period from the beginning of palliative care to the death of the child.

Key issues in the treatment of the terminally ill child during the transition from the curative to the palliative phase of care and during the palliative phase are the duration and quality of life, and the rights of the child to careful, compassionate management that includes the best palliative care the staff can provide.

It should be possible for a child to die without unnecessary physical pain, fear, or anxiety. Whatever the state of the child entering the terminal phase of the illness, it is essential that he or she receive adequate medical care and psychological support, and that the child at no point feel abandoned either by the health centre or by the family.

The task of helping a child pass through and into the terminal phase of an illness is extremely trying both from the emotional and the practical aspects. The personal, philosophical and cultural values of the family and of the hospital health care team members all influence what happens. The staff members should be especially aware of their own personal stance on each of these underlying values.

Children in general understand death at a level different from that of adults. However, children with cancer often reach an understanding of what death means at a much younger age than their healthy peers. As a result of their experience with the illness and its treatment, even children as young as four years of age can be aware of the threat of death.

Children have their own way of expressing their knowledge and emotions about death. Regardless of the child's level of cognitive understanding, the emotional response of the child with cancer to impending death is strong and must be dealt with. An open environment where the child feels free to express his concerns and worries is essential for the child's emotional well being.

The guidelines presented here are suggestions. Absolute guidelines for reaching this goal do not exist. Each centre and each physician must find solutions based on their own cultural and spiritual resources and traditions, religion, philosophy, and family values. Palliative care, in the terminal phase of cancer, should be tailored to the different needs and expectations of the child and the family, with the goal of providing the best possible quality of life for the days that remain. When possible and where appropriate, the spiritual leader of the family's community (priest, rabbi, minister) should be asked to offer spiritual support to the child and the family throughout the child's final days. What is truly essential is commitment, love, an understanding of the main aspects of the situation, and above all a human touch.

The following are recommended guidelines for assisting the dying child both in the transition phase from curative to palliative care, and in the palliative phase of his terminal illness.

(A) Guidelines for assisting the terminally ill child during the period of transition from curative to palliative care

A child with cancer is considered by his physician to be moving from curative to palliative care when:

- (i) the child cannot be cured by presently available treatments, and
- (ii) the child needs specific treatments, which are palliative, for physical or mental distress.

There can be a long delay between the moment when the physician determines that the child will not be cured and the moment when everyone involved agrees that the child has entered his last or final phase of life.

In managing this transition from the curative to the palliative phase of the child's treatment, it is critical to protect the child. The expectations of the family must be considered to help them avoid a feeling of guilt for not having done everything possible. However, a real dilemma is created for everyone if therapy is continued when the possibilities of cure are virtually non-existent.

With these caveats in mind, we suggest the following guidelines for an effective assistance program during the time of transition from the curative to the palliative phase.

1. Each centre should develop a uniform philosophy on key issues regarding the final phases of care for the dying child, producing local recommendations regarding treatment and care based on group discussion for achieving a final agreement.
2. Along with the extended health care team, the parents of the child and the family physician should be involved in the decision-making process from the very beginning of treatment throughout the course of the disease, and most especially at point of transition to the terminal phase. All of the members of the health care team should continuously be up-dated on the course of the treatment. The decision to move from the intent to cure to the phase of palliative care should be made with the parents and the full health care team, including the nurses. Depending on age and level of development, the child should also be involved in the decision, with older children participating more actively. The child should know as much as is possible and developmentally appropriate about the seriousness of his situation. However, if the child wishes to remain less informed, the wish should be respected, and whatever information is given should allow the child to retain a margin of hope.
3. The wishes of some of the families may not always be in the best interest of the child. A conflict may arise when the family wishes to continue pursuing an unrealistic possibility of cure or, the opposite, when the family wishes to stop the curative treatment prematurely. When the members of the health care team take the time to try to understand the reasons for the family's wishes, the inevitably painful conflicts can usually be overcome.
4. The continuation of curative treatment beyond the point when cure is no longer possible should be avoided (the so-called "ruthless obstinacy" treatment).

(B) Guidelines for assisting the terminally ill child during the period of palliative care and for assisting the family post-death

The following are suggested as guidelines for the terminal phase of care, once the decision to move from the curative to the palliative phase of treatment has been made and agreed upon by parents, siblings, the child, and the extended health care team.

- 1 Medical decisions regarding palliative treatment should be made by consultation within the larger group and not by one physician acting alone. When a group decision has been made that treatment should be discontinued and palliative care initiated, the control both of physical and of psychological pain becomes paramount. Physical pain control must be carried out with professional competence.
- 2 Children should be allowed to die at home as their first choice. But the parents and the children themselves should remain the ultimate arbiters in this decision. Some parents cannot handle having their child die at home. For those families who do decide to have their child die at home, the physician should insure continual support either directly or through other supportive entities, depending on cultural customs and resources (for example: home care unit, hospice, visiting nurses).
- 3 The parents and the health care team members should listen to the child in the terminal phase, and reflect on what the child communicates, both verbally and non-verbally.
- 4 During the palliative phase of treatment, follow-up visits and telephone calls by the physician should be offered to the parents whose child is dying at home, so that they do not feel abandoned.
- 5 There should be post-death reflection (bereavement counselling) on the part of physicians and nurses to help clarify past care and guide future care. Parents (and when possible also siblings) should be invited after their child's death to discuss with the physician both the level of care given to their child and the surviving family members' present needs. Follow-up and counselling sessions for surviving siblings should be offered and pursued actively if accepted.
- 6 Centres should try to encourage bereaved parents and siblings to found self-help groups which give concerned family members the possibility of discussing the psychosocial issues raised by the cancer treatment and by the death of the child, and for sharing the deep mourning and grief with other concerned persons. If necessary, professional psychological help should also be offered for those parents who feel the need.
- 7 After a child dies, that individual child's medical history should be evaluated. This evaluation should be made by the health care team as a group. It is very important to reflect on all events, even minor ones, that occurred during the course of the child's treatment. It is critical to reflect on the choices that were made and why, in order to help the staff make necessary adjustments for future cases.

8 The centre's health care team should modify its overall philosophical goals and reset directions and guidelines when appropriate, based on the staff's and parents' reflections on past cases.

Summary table of essential recommendations for assisting a terminally ill child

1. Develop a uniform policy and approach within the centre.
2. Develop a specific plan of care for the child, involving the entire health care team, especially the nurses.
3. Reach a group decision with the health care team about the type of treatment best for the individual child.
4. Avoid a "ruthless obstinacy" approach; know when to move from cure-oriented therapy to palliative care.
5. Listen to the child, keep in touch with the family, develop and retain a good relationship with everyone involved.
6. Include in the final decision-making process the parents, the siblings, and the child (depending on the child's age and level of development), and the physician who usually takes care of the family.
7. Evaluate each individual child in adopting the most appropriate palliative therapy for that specific child.
8. Control both physical and psychological pain
9. Enable the child to die at home when possible and if desired by the family.
10. Deal with issues of bereavement among the members of the health care team.
11. Encourage post-death follow-up visits for parents and siblings, reflecting on the medical history of the child and acknowledging the ongoing needs of parents and siblings.