CARE OF A CHILD DYING OF CANCER: The Role of the Palliative Care Team in Pediatric Oncology

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The last period of life of a child suffering from cancer is of crucial importance not only for the child himself but for his parents and relatives as well. The way the child dies will remain in the memory of his parents for ever. Multiple problems in management of dying child may arise during this last phase. Timely and sensitive discussion of such aspects of management as implementation of Do Not Resuscitate order, possible provision of fluids and parenteral nutrition, initiation of palliative sedation and management of depression is necessary and may help parents to better cope with this tragic situation. Palliative care team consisting of medical and psychosocial staff plays vital role conveying comprehensive and timely management of all these problems and providing all necessary assistance for parents and other involved during one’s last weeks, days, and hours of child’s life. The palliative care team cannot avert approaching death but it is responsible for making it as peaceful and as free of suffering as possible. This is achieved by vigorous control of all physical symptoms in the dying child and by paying close attention to all existential, emotional, and social demands of both the child and his relatives.

Keywords. depression, DNR/DNAR, nutrition/hydration, palliative care team, place, sedation

The goal of therapy for the dying child is to maintain, comfort, and support the child and the family [1, 2]. It is responsibility of the health care team to provide adequate pain control along with control of other noxious symptoms during the last phase of the child’s life. In spite of the significant success that has been achieved in the past two decades in the treatment of children with cancer, it is estimated that long-term survival may be achieved in only 75–80% of patients [3], which means that every fourth child suffering from cancer will eventually die.

The life of a child lasts to its last second. The loss of a child is a tragic and illogical event for all those involved, especially the parents, who are accustomed to believing that it is the children who should witness their parents’ death and not vice versa. The last days, hours, and minutes of the child’s life will most probably remain forever in the parents’ minds, and how their child dies is of critical importance for the parents’ further lives. Therefore,
competent, comprehensive, and sensitive management of the terminal phase of the child’s life is difficult to overestimate.

**DNR/DNAR ORDERS**

Parents are frequently reluctant to discuss Do Not Resuscitate (DNR) orders regarding their children, perhaps equating in their mind such a decision with the abandonment of hope and capitulation before impending death. Sometimes, parents see such a decision as disloyalty to their child. The responsibility of a palliative team is to help parents make the correct decision in the best interests of the child. It may be prudent to initiate such conversations with parents well in advance, before a child suffering from progressive cancer approaches imminent death. Such an approach goes well with the modern concept of incorporating palliative care from the initial stages of the child’s cancer [4].

It is noteworthy that resuscitative measures may be successful in the ‘technical’ sense of the word, allowing the treating team to sustain vital functions, but rendering the child unconscious and without the ability to communicate with parents and other loved ones. Given the progressive nature of the child’s cancer and the almost always irreversible nature of causes resulting in this situation, the net result of resuscitation may have devastating effects on both the ill child and his relatives. Thus, it is vital to introduce to the parents the concept of Do Not Attempt To Resuscitate (DNAR) [5]. In certain instances, avoiding unnecessary interventions is more appropriate than ‘going to the end,’ thereby prolonging suffering.

In any event, it would be prudent to discuss all the issues regarding possible interventions in the end of the child’s life before the critical moment approaches, and written notification to forgo or to initiate (and to what extent) resuscitation should be placed in the patient’s medical chart. A planned discussion of DNAR orders before the patient’s final deterioration, which may be rapid and not always anticipated, allows parents to consider the possibility of their child’s final phase of life without the enormous psychological and emotional strain which usually accompanies the witnessing of the dying process of a beloved child. This allows parents to take a more weighted decision in the best interests of the child. It is very useful to clarify with the parents all aspects of this order, such as not initiating intubation and indirect cardiac massage, while not foregoing drug therapy, such as antiseizure medications and oxygen supply. In discussing the various aspects of the treatment of a child during his last days and hours, it is useful to remember that the parents are the primary decision-makers. This is true not only because of the legal aspects of this situation, but mainly because no one knows better what the child would prefer if he were able to decide for himself in a given situation. Hence, in most circumstances, parents should clearly clarify their intention to initiate or forgo resuscitation during the terminal phase of their child’s cancer.
Unfortunately, too frequently in clinical practice, the DNR order is written in close proximity to the child’s death. McCallum et al. [6] noted that the median time from DNR to death was less than 24 hours among 77 pediatric patients with cancer and other life-threatening diseases; in 8% of cases, the DNR order was not given. Only in 13 cases did death occur in pediatric or oncology wards or at home, while the majority of deaths were registered in intensive care units. Wolfe et al. [7] noted a significant discrepancy in understanding of the ultimate prognosis between physicians and parents of pediatric cancer patients. Generally, physicians realized that there was no realistic chance for cure significantly earlier than the parents of children with progressive cancer (mean 106 vs 206 days before the child’s death, \( p = .01 \)). Earlier recognition of incurability and earlier initiation of discussions concerning all aspects of management of the terminal phase enabled both treating physicians and parents to come to terms with the institution of DNR orders long before the approach of the final phase.

Problems may arise when clearly clarified written permission from parents is not procured in time and the child in the terminal phase of cancer rapidly deteriorates and develops cardiopulmonary arrest. In such a situation, it may be advisable to initiate resuscitation using indirect cardiac massage and artificial ventilation with the Ambu bag. Concurrently, an emergency session with the parents, sometimes near the patient’s bed, conducted in a sensitive and empathic manner by the treating pediatric oncologist who was in close contact with the family along the whole course of the child’s disease, can be decisive regarding continuation or withdrawal of resuscitative measures. However, if parents do not give their permission to abandon life-supporting therapy, the full range should be continued.

It should be stressed that even if parents choose to proceed with resuscitation despite the apparent futility of such a mode of action, they should not and cannot be blamed for this. It is more a failure of the palliative team in not coming to terms with the parents when such a possibility was contemplated, rather than the parents who are at fault.

Despite the apparent finality of DNAR orders, this is sometimes not so in clinical reality. There may be situations when even a child with widespread, resistant-to-treatment glioblastoma multiforme of the brain, one who has lost consciousness and deteriorated hemodynamically and respiratory, may sometimes regain cognitive status and resume cardiorespiratory functioning if all the necessary supportive measures were properly instituted. Given the current status of our medical knowledge, we are not always able to assess the clinical situation correctly. Thus, even a child with a widespread brain tumor may deteriorate because of seizures or transient elevation of intracranial pressure, causes which are potentially treatable but may go unrecognized in a child with cancer, which might be referred to as ‘terminal.’ Provided such a child is treated promptly and correctly with antiseizure drugs and mannitol,
he may be stabilized and even discharged home for a quite a long period of
time. The correct decision in such situations is a matter of the art of medicine
and clinical experience.

DEPRESSION DURING THE TERMINAL PHASE OF CANCER

The prevalence of depression in children suffering from progressive can-
cer has not been evaluated in detail so far [8, 9]. There are several possi-
ble sources of depression in children, both physical and existential [9, 10].
The most common physical cause of depression is unremitting and poorly
controlled pain [9]. In young children suffering from neuroblastoma with
bone metastases and neuropathic pain, the signs of depression may become
evident not only on the verbal level but non-verbally too. Such children fre-
fently look sad; they cry even when they are still and not moving, and they
usually withdraw from playing even with their favorite toys, activities which
had been pleasurable for them earlier. Other sources of pain in children may
be the adverse effects of antitumor treatment, such as mucositis resulting
from palliative chemotherapy and radiotherapy in a child with locally ad-
vanced rhabdomyosarcoma of the head. Thus, paradoxically, palliative treat-
ment itself may become a source of further suffering. Other physical causes
of depression may be nausea and vomiting, increasing respiratory difficulties,
and other distressing symptoms.

There are many non-physical, psychological, and existential causes of
depression in children with advanced cancer. Younger children may suffer
from fear [11], but there are at least two non-physical sources of fear: 1) fear
of abandonment (this can be seen when a parent leaves the room where the
child is spending his last period of life), and 2) fear of separation, when a child
is afraid of losing his loved ones due to approaching death. However, basically,
we know little about existential sources of suffering in young children [2, 10].

Older patients may suffer from depression caused by many aspects of ex-
istential crisis [10, 12]. It is well known that adolescence is a crucial period
of life when understanding of the surrounding world is formed. A child’s
concept of death evolves with age, and it is during adolescence that children
become able to fully comprehend the irreversibility and inevitability of death
[13]. The resulting existential crisis in an adolescent with cancer facing im-
iminent death is even more profound and may lead to severe depression,
sometimes with a devastating outcome.

It is for these reasons that a palliative team should initiate treatment of
suspected depression as soon as the clinical concern is raised. At times, a
short therapeutic trial of antidepressants helps to clarify whether the patient
is suffering from depression or not [14]. In the context of terminal cancer,
when many such children have neuropathic pain, antidepressants might be
helpful adjunctive drugs even if the clinical suspicion of depression is not
proved to be correct.
PALLIATIVE SEDATION

Most children with progressive cancer in the terminal phase of life suffer from various symptoms, pain being the most common [4, 8, 15, 16]. With modern treatment modalities, the effective control of pain, vomiting, and other symptoms of physical distress is achievable in more than 90% of pediatric cancer patients [15, 16]. Those symptoms which are amenable to alleviation, despite their severity, by standard, sometimes rather rigorous, therapy, without causing unbearable side effects, are designated as difficult symptoms. The therapy does not cause sedation or excessive side effects which outweigh the positive effects of therapy itself. The therapy should be effective within an acceptable time frame when applied to a dying patient [17]. When all our interventions are incapable of providing adequate relief or are associated with excessive and intolerable side effects, or if we do not have enough time to provide relief to the dying child within a relevant period of time, the symptoms of suffering are designated as refractory [17].

When all interventions directed to the alleviation of suffering of a child in the terminal phase of cancer are proved to be ineffective, conducting therapy accompanied by sedation may be the only and the last mode of action we have to use. This therapy is frequently designated as terminal sedation, but the definition of terminal sedation is elusive. Firstly, we do not always know if the child has entered the terminal phase of his disease because our ability to predict survival in patients with advanced cancer is sometimes limited. Secondly, there is an opinion that terminal sedation is aimed at terminating the suffering of a patient by hastening death. According to this opinion, terminal sedation is a form of slow euthanasia [18]. However, Morita et al. [19] have shown that palliative sedation does not affect survival of adult cancer patients and this therapy may even prolong life, since alleviating suffering decreases severe physiologic stress, which may exhaust the patient and accelerate death. Alleviating pain in dying children enhances their quality of life and eases the distress of the grieving parents.

There is a major difference between palliative sedation and euthanasia: palliative sedation is intended to alleviate existing symptoms of physical and existential suffering, while euthanasia is primarily a course of action initiated by the physician and intended to hasten death [20]. Problems which may be encountered that could serve as indications for the initiation of palliative sedation are:

- Severe uncontrollable pain, refractory dyspnea, refractory seizures
- Various psychiatric disturbances, such as confusion, agitation, restlessness
- Existential suffering

To provide a moral justification for applying palliative sedation, a particular moral code has been established and termed 'the principle of double effect'
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Palliative sedation in terms of this principle means that:

1. Our primary and only aim is to help the patient.
2. Palliative sedation is undertaken with the intention of achieving alleviation of suffering without intending to shorten life even though this may be foreseen.
3. We do not want to end suffering by terminating life.
4. Palliative sedation is undertaken in a dying child when all other interventions are unsuccessful.

Ideally, a decision regarding palliative sedation is a multi-step process. Firstly, the palliative team should perform a thorough clinical and laboratory reevaluation of the patient and, if needed, restaging of the disease. The primarily goal of the reevaluation is to reassure everyone that we are dealing with refractory symptoms in a child with terminal cancer. Secondly, revision of all therapies, including psychological intervention directed at alleviation of suffering, is performed. Further, with the agreement of all the involved medical and psychosocial staff, including the senior physician, nurses, psychologist, and social worker, the possibility of proposing palliative sedation to the child’s parents is discussed; if such a decision is made, the next step is discussing the issue with the parents.

Not all parents are immediately ready to accept such a proposal because of the immense emotional charge inherent in such a decision. Hence, the performance of other investigations, usually some imaging studies, may be useful in helping the parents to understand and to accept reality. Only with their approval is palliative sedation commenced.

There are various methods of palliative sedation. Usually it is a combination of an opioid with some other drug with sedative properties [17, 22]. Because the majority of cancer patients at the end of life suffer from pain, one of the components is usually morphine given intravenously or subcutaneously. If the patient was not placed on an opioid earlier and is in pain, one usually applies a loading dose of morphine at the beginning of palliative sedation in order to switch off the child’s consciousness, with a subsequent continuous intravenous drip of morphine aimed at keeping the patient unconscious but without causing respiratory depression. This is usually achieved with doses of morphine between 0.5–5 mg/hour with upward titration when needed. Significantly higher doses are sometimes used to achieve the desired effect. Morphine is especially convenient when the patient suffers from cancer with lung metastases causing respiratory distress and feelings of air hunger [16]. Along with its sedative effect, midazolam has prominent anticonvulsive properties, so it is especially useful in patients with present or past seizures and for those with intracranial metastases or a primary brain tumor [16]. After a loading dose of 0.2–0.3 mg/kg of midazolam, it should be continued by IV drip.
It must be stressed that initiating palliative sedation is not always dictated by unbearable and uncontrolled pain and, therefore, morphine or another opioid should not always be an integral part of this kind of treatment. For example, if palliative sedation is initiated because of intractable seizures in a child with a brain tumor, sedation with midazolam only or other sedative agents may be sufficient.

**ROLE OF NUTRITION AND HYDRATION DURING THE TERMINAL PHASE**

The provision of fluids and food to the ill are the basic requirements of human and compassionate care [23–27]. Nutritional support in the practice of pediatric palliative care is associated with immense ethical and emotional considerations. It is common judgment that forgoing nutrition and fluids to the terminally ill child contradicts the principle of compassionate care. This point of view is frequently supported by parents and other lay persons whose common thinking is that withholding fluids and food may lead to the accelerated demise of a patient. Given the fact that most pediatric cancer patients have a central line in place during the last phase of life, it might seem tempting to use it as a vehicle to provide nutrition and hydration. Nevertheless, one must keep in mind the possible and, unfortunately, not rare drawbacks of total parenteral nutrition (TPN), which may be encountered with higher frequency in debilitated cancer patients [28]. Given the fact that, in most instances, the projected longevity of life is very short, and bearing in mind that TPN may be useful when given for a sufficiently long period of time (weeks to months), it is clear that there is no place for TPN in the practice of palliative medicine. Exemptions are those rare instances when the terminal phase of cancer is expected to be prolonged in a child who cannot be fed by any other way (e.g., surgically uncorrectable intestinal obstruction or severe respiratory distress in a child with pulmonary metastases after insertion of a nasogastric tube).

It has been shown that most patients with progressive cancer do not feel hunger and thirst. McCann et al. [25], in their study of 32 adult patients with a life expectancy of 3 months or less (31 patients suffered from cancer), found that 63% of patients never experienced hunger and 34% of patients complained of hunger only during the initial phase of starvation. Similarly, 62% of patients experienced either no thirst or thirst only initially during their terminal illness. For those patients who had some complaints of either hunger or thirst, it was possible to achieve alleviation by very simple measures such as providing small amounts of food or water and moistening of the lips. In another study [29], Torelli et al. tried to determine if the provision of TPN could improve quality of life and alter the ultimate outcome of adult terminally ill cancer patients. The authors evaluated the possible influence of TPN provided either as an adjunct to in-hospital intensive therapy
for cancer or for in-hospital supportive treatment and found that, in both settings, the provision of TPN was of no value on quality of life or on the ultimate outcome of these patients. There are no similar studies on terminally ill pediatric cancer patients, but common sense and clinical experience are witnesses that the same holds true for pediatric oncology patients as well.

Much thought has been given to the ethical considerations of forgoing nutritional support [23, 24, 26, 27]. The current concept prevailing in medicine is that nutrition and hydration are as much medical interventions as any other treatment modalities and, therefore, should be instituted according to the same moral and ethical principles [24, 30]. It is ethically justified to withhold or even withdraw some medical interventions in patients suffering from progressive cancer in the terminal phase in order to avoid unnecessary suffering by providing futile treatment [30]. According to this postulate, providing nutrition and hydration should be ruled only by medical indications.

In the reality of pediatric palliative oncology, this apparently clear decision to forgo the provision of nutrition to the child dying of cancer is not so easily accepted. For parents and sometimes for treating medical personnel, it is frequently too difficult emotionally to agree not to provide food or fluids to a dying child. In certain instances, when there is no consensus between the parents and the treating physician, it may be prudent to provide the child with hydration through either a nasogastric tube [31] or via a central/peripheral line and forgo nutritional support. Explaining to the parents that fluids contain an amount of glucose necessary for providing energy may facilitate parental agreement to accepting the physician’s proposal.

**PLACE OF DEATH**

It is generally agreed that most people would prefer to die at home surrounded by close family members and friends, and it is logical to assume that children are not exempt from this general rule [32, 33]. As McCallum et al. [6] put it, “death in hospital is the default situation when support for death in the home is inadequate.” Unfortunately, we seldom witness the death of a child at home. There are several possible explanations for this. Firstly, the nature of progressive cancer with its accompanying multiple symptoms, which are sometimes difficult to control, necessitates the hospitalization of a dying child. Secondly, the immense psychological impact that imminent death poses for other family members may preclude keeping an ill child at home. Thirdly, at times there are human, financial, and/or other shortages that limit or even completely preclude the possibility of managing the terminal phase of cancer in an ill child at home. There is a need for the creation of a palliative care team specifically dedicated to the successful management of terminal care of the child with cancer at home [34]. Optimally, this multidisciplinary team should consist of a pediatric oncologist, pediatric oncology
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nurse, clinical psychologist, and social worker. The presence of a chaplain or other spiritual authority may be very helpful as well.

If death at home is not an option, the child spends his/her last days in hospital, and medical personnel should do everything possible to create a sense of ‘home’ for the dying child and his relatives. The responsibility of the palliative team is to do whatever is necessary to mask signs of agony by properly performed medical assistance to the dying child. It may be useful to explain tactfully to the parents about physiologic changes that their child is undergoing during the process of dying as soon as they occur, while constantly reassuring parents that all possible sources of suffering during this period are being properly addressed and controlled.

It is very rare in the clinical practice of pediatric oncology to see parents who do not want to be present at the bed of their dying child. In that event, the parents’ wishes should be respected and a quiet place not far from the ward should be provided. The presence of a psychologist or other person close to the grieving parents is very helpful.

CONCLUSION

Witnessing the death of a child is a tragic event for a parent, an event which cannot be compared in its gravity to anything else. The palliative care team cannot avert this death but it is responsible for making it as peaceful and as free of suffering as possible. The ultimate gratification for their work as palliative care team specialists is in finding meaning in the death of a child by the bereaved parents. This is achieved by vigorous control of all physical symptoms in the dying child and by paying close attention to all existential, emotional, and social demands of both the child and his relatives.

REFERENCES


