

# End-of-Life Management in Pediatric Cancer

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**Abstract** Pediatric palliative care at the end-of-life is focused on ensuring the best possible quality of life for patients with life-threatening illness and their families. To achieve this goal, important needs include: engaging with patients and families; improving communication and relationships; relieving pain and other symptoms, whether physical, psychosocial, or spiritual; establishing continuity and consistency of care across different settings; considering patients and families in the decision-making process about services and treatment choices to the fullest possible and desired degree; being sensitive to culturally diverse beliefs and values about death and dying; and responding to suffering, bereavement, and providing staff support. Any effort to improve quality of palliative and end-of-life care in pediatric oncology must be accompanied by an educational strategy to enhance the level of competence among health care professionals with regard to palliative care and end-of-life management skills as well as understanding of individualized care planning and coordination processes.

**Keywords** Pediatric oncology · Life-threatening illness · Quality of life · Palliative care · End-of-life management · Death · Bereavement · Multidisciplinary approach

## Introduction

Cancer is a life-threatening illness that may possibly end in death. A prolonged period of living with the disease may

thus precede death, if it occurs. Whether or not the threat of death transforms into actuality, profound uncertainty prevails. The growing sophistication of advanced medical practices has meant that patients are living longer with knowledge that they may be dying [1]. Despite substantially improved prognoses, greater complexity has led to more uncertain consequences for dying patients and their families.

Within the illness trajectory, a critical phase is reached when the patient no longer responds to conventional treatment. The emphasis of therapy shifts from a curative approach to palliative care. This information is painful to give and receive, since there is no further alternative for prolonged time [2]. Both family and patient are usually aware of the diminishing or nonexistent options. Yet the patient may still continue to live quite productively for weeks or even months, either on experimental treatment or on no treatment at all. Anyway, this period refers to the terminal phase when, regardless of the status of treatment, the death is imminent. In response to internal body deterioration, the patient begins a final withdrawal from all that is familiar and loved [3]. At a time so difficult for the patient, family, and caregiver, complex decisions must be handled.

Today, palliative care at the end-of-life has been identified as a key component of high-quality medical care for children and adolescents with advanced illness. This process must consider the impact on the quality care delivered (indicators for comfort care, multidisciplinary collaboration, enhanced health care team communication, care of the imminently dying patient, etc.) and on patient and family outcomes (family cohesion and coping, satisfaction with care, improved symptom control, patient and family participation in decision making, optimal quality of life for patient and family, uncomplicated bereavement, etc.) [4, 5].

Thus, end-of-life care management should include enhanced care coordination to facilitate a multidisciplinary

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approach to the patient and family [6]. During this period, a coordinated multidisciplinary effort is crucial in working with the patient and family to address their specific needs. Physical, psychological, and spiritual support is of utmost importance near the end of life. Supportive care and pain control are central concerns and in all instances, the patient (and family) should be assured that he or she will be kept as comfortable and as pain free as possible [7]. Despite the patient's clinical condition, some families may continue to hope for a miracle. Although wishing for a miracle cure might seem incongruous with simultaneously accepting the reality of patient's impending death, these opposing thoughts can co-exist and do not necessarily signal denial [8]. Open, honest, thoughtful, and caring communication at this time can provide emotional comfort in a situation filled with uncertainty and fear.

### End-of-Life Care

The death of a child or adolescent affects emotionally family members for the rest of their lives and events that occur around the time of death, either positive or negative, are highly important.

The end-of-life care process includes care of the imminently dying patient and the family but should be implemented well before death is imminent. Competent and sensitive care at end-of-life demands ongoing multidisciplinary patient and family-centered assessment of emotional, social, and spiritual needs [9, 10]. This approach requires that team members listen intensely and respectfully to understand the patient's and family's beliefs, attitudes, values, relationships, priorities, dynamics and allows them, health care team, patient (when possible), and family, to formulate jointly a comprehensive care plan to deal appropriately with the immediate clinical situation [5, 11].

End-of-life decisions are among the most difficult the parents can face on behalf of their ill son or daughter—the parents do not want him or her to suffer more, yet they often cannot tolerate the thought of ending treatment [12]. The choice between cessation versus experimental treatment usually revolves around a quality-of-life decision for the patient's remaining time. In most instances, the parents make the decision; however, to varying degrees, the child or adolescent may be involved in such discussions [13, 14]. The physician's attitude has a great influence in the parental decision process. Nevertheless, sometimes the physician may be not prepared to stop treatment and “over treating” beyond constructive limits may reflect his/her difficulty in admitting having failure [15]. In these cases, frequent weighing of the benefits and burdens of medical interventions with the help of the multidisciplinary team is recommended [16].

Cancer patients near death have symptoms that are often not treated or are treated unsuccessfully. Pain, poor appetite, and fatigue are usually cited as the most common symptoms among children and adolescents who die of cancer [17]. The patient's symptoms at the end-of-life are better controlled when a provider with a specialized level of training in palliative care is available. Physicians with expertise in symptom management should be integrated into the oncology team to develop an ongoing therapeutic relationship with the patient and family in order to promote an effective symptom control.

From the time of diagnosis, pain is the most significant patient fear of his or her cancer experience. Therefore, aggressive pain control is crucial at the end of life because many patients suffer during this time and such reality may contribute to poor family outcome. Rather than treat pain, the aim is to anticipate and prevent that symptom from being experienced [18, 19].

Aside from physical suffering, psychosocial, spiritual, and existential distress is identified as very important to patients and their families—patients usually experience sadness, anxiety, fear of being alone, and difficulty in talking about death and parents most frequently experience excessive worry, depression, and fear of the patient's physical symptoms and death [20]. Optimal end-of-life care should also include distressing symptoms management. Generally, all team members given education, training, and motivation have the capacity to provide a certain level of emotional, social, and spiritual care.

During the terminal phase, the patient's awareness of dying becomes more focused. There is sufficient evidence today to concede that all patients, even very young children, know they are dying and that they are able to discern the exceptional distress among family and caregivers around them when death becomes imminent [1, 20]. References to its proximity can be quite direct and explicit, however most patients quickly come to perceive adults' difficulties to talk to them about end-of-life issues, death, and dying, so they begin to feel isolated and alienated [21]. If an open and honest climate has been established from the beginning of the illness, it will be reflected in the willingness of the child or adolescent to talk about fears and uncertainties regarding their own death [22]. The endpoint of this phase is marked by the patient's withdrawal from the external world—the patient may talk very little and may even retreat from physical contact. Health-care professionals' intervention can be critical in helping the family to be able to give the patient implicit “permission” to die [15].

The family needs information about how the patient is likely to die and, many times, support in coming to a decision about a home or hospital death. The pain management is a critical concern and its effective control must be assured. The parents may be frightened at the prospect of the

patient dying at home and can choose the security of the hospital; the patient may also express a preference about where he or she likes to be, even if not referring explicitly to death [23]. All these factors must be taken into consideration—identifying the patient’s and family’s preferences may help to determine referral to hospice care, the desired location of death, the avoidance to referral to intensive care unit, the adoption of “do not resuscitate” order, and plans for funeral arrangements [24].

The benefits of early integration of palliative care practices and the many needs of young patients and their families into the continuum of care emphasize the importance of a multidisciplinary approach that links hospital, home, and hospice settings [25]. However, one of the most significant barriers to early integration of palliative care in the treatment plan of children and adolescents with cancer is the families’ fear of losing contact with the primary oncology team, yet fear of abandonment [26••]. Ideally, professionals with expertise in palliative care should be part of the primary oncology team from the point of diagnosis onward. The care continuity process provides high-quality end-of-life management in which key therapeutic interpersonal relationships are maintained throughout the illness trajectory and across various settings helping the patient and family keep a sense of personal control over their care [27].

Home is where most patients and families choose to be near the end-of-life and in particular there is evidence that these families cope better after the patients’ death. End-of-life care at home allows the patient and family greater control over the environment with involvement of fewer professionals and increases opportunities for privacy and time together. Yet it is much easier to include siblings and to discuss difficult issues [24, 28]. However, if end-of-life care at home offers many benefits for the patient and family, it also poses significant challenges. It is important not to underestimate the physical and emotional burden of end-of-life care—some families feel isolated, unable to cope at home and difficulties with symptom control, psychological distress, or socio-economic problems may require the patient to be transferred to the hospice or hospital.

Pediatric hospice has a specialist role for end-of-life care if dying at home is not a possible option or choice and for short break care, in order to give the family a break from routine and stress of caring. Hospice care is particularly relevant in preventing family breakdown or unnecessary admission to hospital [29]—as qualified team staffs the hospice, short breaks and supportive care can be offered when the patient is unwell, but hospital treatment is not appropriate. The admission for short-breaks increase according to the patient’s care needs and the admission for end-of-life care is the natural sequel to recognition of the irreversible deterioration of patient’s condition. The hallmark of the hospice movement is the best use of pain medication,

including narcotics, during the terminal phase to give the patient as pain-free an existence as possible, while maintaining his or her maximum alertness [15, 30]. Thus, this alternative can offer a much more homely environment with excellent symptom management for the patient and support for a family who prefer not to be at home [30, 31].

Although the hospital ward is not generally considered to be a desirable place for the patient’s death, mainly for resource-limited families there are no other realistic possibilities. The hospital provides reassurance of highly trained staff and a secure environment. During prolonged oncology treatment, this comfort along with other issues may mean that a hospital death is preferable for a particular family [24]. Nevertheless, some parents of patients dying in hospital identify confusing, inadequate, or uncaring communication, oversights in procedures, and failure to include siblings, extended family, friends, and peers.

Communication is of utmost importance at all times throughout the disease trajectory, but its significance is heightened during the final days of a patient’s life. As death becomes imminent, many parents notice less interaction with the medical team. When curative efforts are replaced by comfort measures, parents report feeling abandoned. On the other hand, health providers find it extremely difficult to shift from treating the patient to watching his or her suffering and death [32]. A focus on collaborative working relationships, multidisciplinary team meetings, and care coordination is essential to effectively maintain the lines of communication and provide the support needed by patients and families [33].

### Bereavement Care

The death of a son or daughter is one of the most difficult experiences for any parent—parents’ reactions are always complex and painful [34]. All pediatric deaths provoke complicated grief responses almost by definition, but it is essential to differentiate expected grief responses from pathological grief [26••]. The family members face anticipatory grief, and then bereavement after the patient dies. Parents’ and siblings’ responses to loss and grieving vary widely depending upon individual, cultural, and circumstantial factors. These variables provide the context within which each grieves in his or her own way [35]. Research and clinical experience suggest that parents and siblings of patient who dies of cancer take many different paths, over many years, to incorporate the loss and continue with their lives. Most of them seem to be able to integrate their feelings and thoughts about the loss experience with the demands of daily life—they often find the necessary internal and external resources to cope on their own [36]. Many bereaved parents may, at some point, find it helpful to share their experiences with other bereaved families. Other

families, however, present an intense or complicated process of mourning and will benefit from appropriate and timely professional help [37]. Major depression and generalized anxiety disorder are some of the problems that parents may develop following bereavement [36]. On the other hand, the most common immediate or long-term effects of the death of a brother or sister from cancer on the healthy siblings include poor school performance, depression, severe separation anxiety, distress, and fear for their own health [11, 38].

Aside from stated above, given the intense emotions experienced at the time of the patient's death, events surrounding it can play a significant role in the parent's and sibling's outcomes of acute and long-term grief. They will provide the raw material from which the family will create memories and narratives of the patient's life and death. After the patient's death, parents need to reengage in daily routines altered throughout the illness. At this time, they may experience a significant change in their relationship with the treatment team, which may worsen their sense of loss—as some parents come to depend on the staff members for their psychosocial needs, they may feel helpless [39]. Although some families want to maintain continued contact with hospital health care providers for support and find it meaningful to them, others prefer to avoid anyone or anything that reminds them of the patient's recent experience and death.

A practical approach for providing care for bereaved families should begin when the patient is first admitted for treatment. Initial assessments can alert the team to families whose coping may be less than adaptive [40]. The care continuity process enables health providers to prepare a family for loss, which, in turn, may lower the risk of psychological disturbance after the patient's death. Thus, the goal of integrating bereavement care into the mainstream of pediatric cancer care is to identify and help those people who may be suffering from complicated bereavement [5]. Although it is not expected that all members of the patient's care team be skilled providers of bereavement interventions, it is essential that they be sensitive to the varied course and styles of grieving, be aware of potential risk factors for complicated grieving, be able to recognize complicated mourning, be familiar with appropriate resources to facilitate long-term care, provide some emotional support, and make appropriate referrals [41]. In order not to interfere with a normal family grieving process, time and regular contact over several months may be needed for health care providers to consider in deciding whether additional professional help would be useful [36].

### Professionals' Implications

Effective terminal care presupposes high emotional investment on the part of health professionals. Members of the

health care team who are involved in caring for dying children or adolescents and bereaved families may be at risk for developing compassion, fatigue, and burnout [42]. Some common stressors include chronic nature of the disease and the uncertainty of its development, emotional impact of the long-term involvement with young patients and families, continuous exposure to suffering and death, team conflicts when the goal of intervention becomes of caring instead of curing, and ethical challenges experienced in end-of-life care [43]. Many times, however, grieving of health care professionals remains hidden, because society expects them to be strong and insensible in the face of death, while institutional culture and regulations discourage the appearance of vulnerability through the expression of grief [8].

The death of a young patient invites care providers to confront and come to terms with their strength, limitations, and personal suffering. If these issues are recognized, accepted, and processed, then their vulnerability may become a source of maturity and growth [44]. In contrast, if left suppressed, unattended, or ignored, they may become a source of distress, of alienation, and, eventually, of dysfunction. Health care providers should recognize the risk of being affected and create the necessary "room" to reflect, understand, and process their losses and grieves. The patient's death should not be neither idealized nor denied, but rather experienced within a holding environment which helps care providers to integrate loss into a narrative that is coherent and meaningful, both personally and collectively [45]. A functional team should develop in its members a sense of belonging to the group, which can tolerate suffering, handle emotional fragility, and learn from experience. Finally, regular end-of-life debriefing sessions and multidisciplinary bereavement rounds for those involved in the care of the patient who died can provide a forum for health care providers to share their thoughts, feelings, and experiences regarding the death as well as facilitate coordination of follow-up with the family [5, 46].

### Conclusions

The primary objective of palliative care is to support children and adolescents with life-threatening illness and their families from the point of diagnosis, enhancing quality of life, and maintaining resilience and coping, particularly at times of crisis and at the end-of-life [47]. Health care providers must understand patients' and families' beliefs, values, hopes, and fears to guide them through the treatment process. Parents and patients (when possible or indicated) also need complete, accurate information about prognosis to weigh the benefits and burdens of treatment options and prepare to make difficult decisions, mainly at the end-of-life

[48]. Clearly a vast number of different professionals should be involved in the care of pediatric cancer patients and their families. It is important to emphasize that provision of palliative care and end-of-life management is essentially a multidisciplinary approach. At this time the multidisciplinary team should help family members make the transition from hoping for the patient's recovery to hoping for a peaceful and pain-free death [23].

Some of the basic needs regarding end-of-life care should include clear, honest communication and information, ongoing relationship and access to staff, adequate pain and symptom management, coordination of services, emotional and practical support, family short breaks from caring, preservation of the integrity of the parent-patient relationship, and faith and meaningfulness [8, 49].

The optimum configuration for the provision of care will depend on the needs of the patient and family, the care setting, and the structure and extent of the health care system, but the fundamental role of palliative care at end-of-life should remain the same wherever the child or the adolescent may be [50•]. Successful care must be flexible enough to anticipate and cope with changes in the patient and family's needs and to move seamlessly between home, hospice, or hospital.

The treatment of children and adolescents with cancer places many burdens on families, including the patient's death. Families are profoundly affected by this experience prior to an anticipated grief, at the time of the death, and sometimes, many years thereafter. Health providers usually can offer some emotional and spiritual support, reframe potentially negative perceptions, and perhaps help bereaved family members to create memories that will, over time, encourage healing [1, 51]. It is important, however, to recognize those individuals who may be at risk for developing complicated grief and make appropriate referrals [52].

All individuals are vulnerable in the face of illness, suffering, and death, including health care professionals. These experiences affect everyone in different ways and to different degrees. Therefore, professionals directly involved in the care of dying patients and bereaved families should recognize how they are affected by the situation and process the impacts that loss and death-related experiences have upon themselves [53]. They must be aware of their own limitations, and be able to access appropriate advice and support from other professionals where need is identified to cope with the challenges and grief they encounter when providing care at the end-of-life. Careful attention to boundary issues is also of primary importance. If questions about appropriate boundaries arise, discussion within the multidisciplinary team can help determine a reasonable approach that is respectful of professional roles and family boundaries [26••].

One of the greatest challenges for health professionals is to learn how to care for themselves and to maximize the

quality of living for themselves as well as their patients. The stress experienced by caregivers must be fully understood so that preventive interventions can be designed and implemented to help these people in their work [54]. The palliative care philosophy suggests that in addition to the needs of patients and families, equally important are the needs for education, ongoing support, and supervision of the health professionals [55, 56••].

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