Palliative Care and Palliative Sedation in Pediatrics

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A. Introduction

The practice of medicine has long followed the precept that even when a patient cannot be cured, as may be the case with some cancers, there is still work to be done to alleviate suffering. For this reason we health professionals must keep abreast of new therapies as they emerge, not only to increase the cure rate among children and adults with cancer but also to improve our ability to ease their pain and suffering. We need to apply the necessary supportive care to optimize quality of life while respecting a patient’s dignity.

Although children feel pain, they often do not know how to express their feelings in words. It is the mission of pediatric caregivers to interpret what pain their patients may be feeling, administer to them the correct medication to relieve that pain, and show them that they are appreciated and loved.

This mission is the foundation of pediatric palliative care (PPC), which is a mixture of science and humanities. Unfortunately, despite the importance of PPC, it seldom receives adequate attention in undergraduate studies. To offset this deficiency, it is necessary for all professionals who care for seriously ill or terminally ill children to acquire a basic knowledge of PPC. We believe that all hospitals managing children with cancer should have experts in PPC on their cancer care teams.

The main objective of PPC is to control the pain and suffering of the whole patient, that is, to treat not only physical or organic pain but also psychic, social, intellectual, emotional, and spiritual pain. In this context, when the patient is a child it is necessary to include the family in the process of care and to give special support to parents and siblings. We must recognize that the patient does not exist as an isolated entity but as part of a family and social environment that must be given consideration.

Emotional support is extremely important for children with cancer. Children need the closeness and affection of parents or close relatives, and they should never be left alone.
Children are attuned to nonverbal expressions of feelings and respond to hugging or caressing or simply being with company. When it comes from the helping hand of a parent or friend, touch, which can be as simple as laying a hand on the child’s wrist, usually gives the patient a sense of security.

We should not forget that children may be more aware and perceptive than adults realize—they listen and hear even when we think they are distracted. They are usually able to understand and accept being sad; that is why when they ask questions about their illness, we must tell them the truth, but always in an age-appropriate way.

The presence of a psychologist on the interdisciplinary team is most important. These are the professionals best suited to understand and manage the feelings of children, parents, siblings, and relatives, and to guide the behavior of health personnel, caregivers, and volunteers when these helpers need direction. Interestingly, young volunteers are often key to alleviating the suffering of small children as they are sometimes able to make the little ones forget their diseases, even in the last days of the patient’s life.

B. History of Palliative Care in Children

In 1990 the World Health Organization (WHO) defined palliative care as “comprehensive care” for patients whose diseases do not have curative treatments. The goal of palliative care is to achieve the best possible quality of life for these patients and their families.

In 1993, the Children’s Hospice International introduced a new concept in which PPC begins during the curative phases of therapy, thereby facilitating simultaneous symptom control. It was also suggested that a rigid distinction between curative and palliative treatment should be avoided. In the same year, as part of PPC, some groups began monitoring siblings, parents, and other significant family members through the end of the mourning phase.
In 1998, the WHO reaffirmed that the main goal of PPC was to ensure quality of life for the patient and his or her family. The WHO considered it essential to control pain and associated symptoms caused not only by the disease itself but also by adjuvant psychosocial problems. Since then, the WHO has recommended treatment for healing complemented by holistic treatment of the child and his/her family. WHO has emphasized that PPC should be initiated when the severity of the disease has been diagnosed and that it should continue throughout the whole treatment process, whether or not the child receives therapy aimed at cure.

Similarly, the American Academy of Pediatrics, in 2000, proposed a comprehensive model of PPC, which would start at the time of diagnosis and continue throughout the disease, regardless of whether the expected outcome was cure or death of the child. A position against the practice of assisted suicide or euthanasia for children was included in that statement.

It is important for primary care pediatricians, family physicians, nurses, anesthesiologists, pain specialists, surgeons, and pediatric oncologists to consider that the basic principle of PPC—“It is not always possible to eliminate symptoms, but you can always eliminate suffering”—is for all caregivers.

Health professionals involved in the delivery of PPC should be able to do the following:

- To maintain, at all times, good communication between patients and their families.
- To know how to manage grief and uncertain prognosis.
- To understand on an individual basis how each patient and each family member thinks about life and disease in the context of spirituality.
- To know how to make optimal decisions about life support and the field of alternative medicine.
C. Characteristics of Pain in Children

Although children are often unable to express their pain in words, they feel pain just as adults do. Pain is an unpleasant sensory and emotional experience, which involves perception, suffering, and externalization. Sometimes, especially if it is chronic, pain can be difficult to detect and catalog because of the various ways that it can manifest in children—little desire to play, irritability, weakness, difficulty in learning, insomnia, anorexia, an introverted and quiet attitude, and so on.

In children, as in adults, there are many different sources of pain. It is necessary then to know its causes to determine the appropriate therapy. The pain may be:

- Neuropathic
- Nociceptive (somatic or visceral)
- Iatrogenic (caused by treatment)
- Post-surgical

Furthermore, pain is usually associated with other symptoms such as nausea, vomiting, constipation, fissures, stomatitis, dyspnea, and fatigue. All of these must be treated as soon as possible. We should be aware of the side effects produced by consecutive treatment with cytotoxic drugs and opiates. Psychological disorders such as depression, insomnia, or anxiety due to personal, family, social, and spiritual problems usually exacerbate the perception of pain. Sometimes a child complains about a fear of tests or treatments that have previously been painful experiences. In these cases, they need even more optimal individual treatment with good emotional support from professionals and the people around them. In these cases, drug therapy for pain or other supportive medications may be also indicated.
C.1 Myths About Pain in Children

Surprisingly, among some health professionals there are still persistent myths and misconceptions about pain in children. These myths are harmful and should be completely dispelled. They are:

- “Very young children do not feel pain.” This notion is seriously mistaken; in fact, the pain of a child or infant is immediately recognized by his or her brain. It has been shown that if young children’s pain isn’t treated, they grow up to be much more vulnerable and sensitive to pain because of the painful experiences they had when they were small.
- “The fear of the child is greater than the pain.”
- “Pain and suffering make children stronger.”
- “The pain caused by diagnostic or therapeutic procedures can’t be avoided, so complete them as quickly as possible.”
- “It is not appropriate to give opioid painkillers because they are going to become addictive.”
- “Many children are not really in pain, because when you give them a placebo, they stop complaining.”

Unfortunately, there are still some professionals who believe such myths and are not sensitive to children’s pain, who ignore the pain assessment scales from the WHO and the pain management options available through the use of medication.
C.2 How to Control Pain in Children

The following are steps to take to control pain in children:

- Identify its cause. You need to determine if the origin of the pain is neuropathic, visceral, skeletal, etc. in order to administer the appropriate treatment.
- Approach pain from a holistic point of view, considering its physical, psychosocial, emotional, and spiritual aspects.
- Prescribe analgesia at scheduled intervals. Analgesia is not advisable “on demand” or at nurses’ or caregivers’ “discretion.”
- Manage analgesic doses on a case-by-case basis according to the characteristics and level of pain, regardless of the child’s estimated survival.
- Select drugs that have maximum effectiveness with minimal side effects.
- When possible, avoid intramuscular administration of drugs, which is painful.
- Simultaneously prevent or treat side effects of opioid medication.
- Consider the spiritual dimension of the child’s disease. Many children brought up in their faiths need an approach that acknowledges their religion so that it helps them and gives them greater peace.
- Provide the necessary vital support while maintaining good communication with patients and families.
- Facilitate the presence and assistance of parents involved in the patient’s care, providing psychological treatment as needed so that they can offer the greatest emotional support possible.
- Perform continuous evaluation of the different factors that affect pain during the course of the disease, because circumstances normally change over time.
- Following these premises and using proper medication, we can control pain in 90% of patients without great expense.
• You must know also the possibility of applying traditional and alternative medicine. Every approach may be reconsidered, with one exception—the doctor’s participation in assisted euthanasia.

• It is important to note that sedation is not usually necessary to control pain, since the ideal is to keep the patient awake and undisturbed. The appearance of a difficult symptom does not immediately call for sedation, and its use for that purpose should be carefully evaluated by an expert. We should try to avoid unnecessary sedation.

C.3 Evaluating Pain

C.3.1 Pain Evaluation Forms: Scales

You may perform an accurate assessment of a child’s pain by using “pain scales,” which help patients to describe their pain intensity according to their developmental level. There are 3 types of scales: behavioral physiology scales, visual analogue scales, and verbal numerical scales.

1. Children 1 month to 2-3 years old

Behavioral Physiology Scales.

Behavior physiology scales are based on observation of the following features:

• Physiological parameters such as blood pressure, respiratory and heart rates, and oxygen saturation.
• Assessment of whether the child is crying
• Sleep patterns
• Facial expression
• Spontaneous motor activity
• Body language
• Children 2-3 years old are often able to localize the site of pain.
2. **Children 3 to 7 years old**

Visual Analogue Scales.

Visual analogue scales have an added advantage because children don’t need to fully understand the concept of numbers to use these scales to express their pain. They are most useful for assessing the pain of children aged 4 years and older. The most frequently used visual analog scales are color scales and pain intensity scales (Wong-Baker faces pain scale) that use facial expressions to show pain.

C. **Figure 1**

![Color Scales](image)

None (0); Mild (10-30); Moderate (40-60); Strong or Maximum (70-100)

Using this color pain scale, we can ask the children to point in the scale: "No pain: 0; mild, moderate, strong, or maximum pain: according to "select the
category that describes the pain,” from no pain in white to maximum pain in red.

Scales with facial designs that express different degrees of pain are often used. It should be noted that with the use of these figures, children may confuse sadness with pain. So, we have to explain to the child that we want to know how intense the pain is and explain clearly that we are not asking if he or she is sad.

C. Figure 2
The scale is from 0 to 10; 0: smiling, not in pain; 2: very little pain; 4: in pain; 6: in some pain; 8: in much pain; 10: intense crying, feel the worst pain imaginable.

There are many adaptations of these scales, some of which have even been created by children themselves.
C. Figure 3

Verbal numerical scale

A visual analogue scale consists of a straight line whose left end represents “no pain” and right end represents “worst pain.” When using this scale, we ask the patients to mark the point on the line that corresponds to their pain always in relation to the 2 extremes (0: no pain and 10: maximum pain).

C. Figure 4
Children from 7 to 12 years old

To assess the pain of children between the ages of 7 and 12 years, use a numerical scale, visual analogue scale, or verbal scale.

Children over 12 years old

As with younger children, to assess the pain of children aged 12 years and older, the use a numerical scale, visual analogue scale, or verbal scales are appropriate. Verbal numerical scales are often used to assess the pain of older children. They reflect the verbal expression of pain intensity with ranges from 0 (no pain) to 10 (maximum pain).

C.4 The WHO Analgesic Ladder for Pain Medications

The analgesic ladder for pediatric pain is similar to the one for adults.

First step (mild to moderate pain)

Medication: Dosage in children (<60 kg body weight); maximum daily dose (dose/kg/day)

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dosage for children &lt;12 years</th>
<th>Maximum dosage for children</th>
<th>Dosage for adults or children aged &gt;12 years</th>
<th>Maximum daily dosage for adults</th>
</tr>
</thead>
<tbody>
<tr>
<td>Acetaminofen/Paracetamol</td>
<td>10-15 mg/kg/4-6 h orally</td>
<td>75 mg</td>
<td>500-1000 mg/4-6 h orally</td>
<td>4000 mg</td>
</tr>
<tr>
<td>Naproxen*</td>
<td>5-10 mg/kg/12 h orally</td>
<td>20 mg</td>
<td>250-500 mg/12 h orally</td>
<td>1000 mg</td>
</tr>
<tr>
<td>Ibuprofen</td>
<td>5-10 mg/kg/8-12 h orally</td>
<td>40 mg</td>
<td>400-600 mg/6 h orally</td>
<td>3200 mg</td>
</tr>
<tr>
<td>Choline Trisalicylate</td>
<td>10 mg/kg/8-12 h orally</td>
<td>No information</td>
<td>1000-1500 mg/12 h orally</td>
<td>3000 mg</td>
</tr>
<tr>
<td>Ketorolac*</td>
<td>0.5 mg/kg/6 h intravenously</td>
<td>Not recommended for periods longer than 5 days</td>
<td>15-30 mg/8 h intravenously</td>
<td>Not recommended for use longer than 5 days</td>
</tr>
</tbody>
</table>
Naproxen, ketorolac, and ibuprofen may interfere with platelet function; therefore, their use should be avoided when there is severe thrombocytopenia, coagulation disorders, or bleeding. All anti-inflammatory drugs must be used with caution in patients with renal dysfunction who are receiving diuretics and in the case of hypovolemia. Likewise, they should be avoided when the patient is receiving high-dose methotrexate.

**Second Step (moderate pain)**

Examples of opiate dosing for minors:

- Codeine: 0.5-1.0 mg/kg/dose every 4 hours orally
- Oxycodone: 0.1 mg/kg/dose every 4 hours orally
- Morphine: 0.15-0.3 mg/kg/dose every 4 hours orally
- Tramadol: 0.5-1.5 mg/kg/dose on every 6-8 hours orally

**Third Step (severe pain)**

Strong opioids (fentanyl, oxycodone, methadone)

The use of strong opioids should begin with a low initial dose that should be titrated to reach the individual optimal dose. There is no ceiling effect for these drugs, and the adequate dose depends on the pain and tolerance to side effects in each patient. For example, initial doses might be as follows:

- Morphine orally: 0.3 mg/kg/dose every 3-4 hours
- Morphine intravenously: 0.1 mg/kg/dose every 3-4 hours
- Morphine: Continuous infusion, 0.02 mg/kg/hour
- Fentanyl: Continuous infusion, 0.5 mg/kg/hour

Fentanyl has the advantage of maintaining a constant level in blood, and it is available in transdermal patches, which are very comfortable because they are small, thin, flexible, and thus adaptable to the patient’s movements. They adhere well to skin, and the local tolerance is excellent. The patches should not
be modified given that they are prepared in the laboratory to be used in their original form. If they are cut or altered, a disruption of their release mechanism may occur and can lead to toxic levels in blood.

In neuropathic pain, gabapentin can be used initially at a dose of 5 mg/kg per day in 3 daily doses, which may be gradually increased according to pain control and tolerance. In adolescents, the dose may be increased to a total of 3600 mg. Amitriptyline at 0.1 mg/kg orally may also be used, given preferably at night.

**D. Withdrawing Curative Treatment**

In pediatrics, it is sometimes hard to decide when to stop curative treatment with chemotherapy and to direct efforts exclusively to achieve pain relief. This decision should always be reached by a consensus between the multidisciplinary team caring for the child and the family. At this important time futile therapies should be avoided. Occasionally, physicians can be influenced by the enormous suffering of the affected families and their sense of failure in efforts to save their child. Under such circumstances, it is important to be realistic about the chances of cure and to acknowledge and accept the limitations of medical therapy for the affected child. It is important to include the palliative care specialist at these moments and avoid continuing with unnecessary chemotherapy. The American Academy of Pediatrics recommends withdrawing conventional treatment when:

- It is not effective for tumor control.
- It does not produce palliation of symptoms.
- It only prolongs life with a poor quality.
- There is a clear worsening of the general condition.
- It is made at the request of patients or their families, and when this request is reasonable.
E. Palliative Sedation in Pediatrics

Palliative sedation consists of the administration of drugs to reduce consciousness as much as necessary to alleviate one or more refractory symptoms. Patient or parental consent is needed for this approach.

Sedation can be continuous or intermittent, allowing pain-free intervals. It can be superficial or deep. The intensity of sedation must always be graduated, and refractory symptom control should be a consideration at the same time that the highest possible level of consciousness is maintained.

Palliative sedation of a dying patient is also called "sedation in the last days of life" because it is administered to patients whose death is clearly very close. It must be continuous and as deep as needed to relieve the severe physical or psychological suffering. The term terminal sedation should be avoided "because it can be confused with assisted suicide or euthanasia.

E.1 Specific Concepts and Nomenclature

Pediatric palliative care (PPC) deals with comprehensive care of children with terminal illness and their families. The approach is holistic, taking into account their values and disregarding their social position, race, religion, and origin. PPC considers death as a natural process, which should not be hastened or postponed abnormally.

However, in the last stages of a disease (including conditions other than cancer), difficult symptoms that require intensified therapeutic measures or consultation with other professionals may appear to create ethical dilemmas. Refractory symptoms that require palliative sedation may also occur. This treatment is called sedation in agony and is used when pain is agonizing.
E.1.1 Refractory Symptoms

Refractory symptoms include those that cannot be adequately controlled without compromising the patient’s consciousness. We have to distinguish between these symptoms and difficult symptoms that can be controlled by intensive pharmacological, instrumental, and psychological therapy.

E.2 Indications for Palliative Sedation

Candidates for palliative sedation include the following:

- Children with advanced, terminal diseases who are dying of cancer or other conditions.
- Children with one or more refractory symptoms in a condition of agony.
- Children with acute episodes with a high degree of suffering (massive bleeding, seizures, hallucinations, etc.).
- Children with important refractory symptoms.

Anxiety of the family or the medical team who treat the patient in the absence the abovementioned conditions are not an indication for palliative sedation. In cases for which palliative sedation is indicated, it is essential to record the decision to sedate in the medical chart along with the following information:

- Previous diagnostic and therapeutic procedures. Information about the decision to limit therapeutic efforts and with whom this has been discussed and agreed upon.
- Period of time during which medical palliative treatment was used.
- If there is a procedure that cannot be used in the patient, explain in detail why not.
- Whenever possible, record the consensus reached among team members and experts consulted to treat the symptoms in question.
• It is mandatory also to record the signs and symptoms in the state of agony. In these situations, scales such as the Menten may be useful, although it is seldom possible to score the signs of imminent death. A day-to-day assessment of the patient’s treatment outcome should be recorded.

Before administering palliative sedation to children, it is necessary to obtain the informed consent of the parents and give information the child or adolescent on the procedure to be performed, always according to their age, maturity and ability to understand, (without offering unwanted information that was not requested)

E.3 Fields of Application

Palliative sedation may be initiated in different settings, according to the patient and family situation. A team competent to manage the sedation is absolutely mandatory. It is usually performed at the hospital; however, it can be administered at home when clinical and family conditions allow such.

E.4 Treatment Recommendations

The choice of the route of drug administration depends on the patient´s situation, the characteristics of the drug, and the urgency to relieve a specific symptom. The intravenous route provides the fastest onset; however, it is inconvenient for patients who are at home, where intravenous lines are not easily set up. In some circumstances, the subcutaneous route might be preferred.

Drugs can be administered by continuous infusions or by bolus. Intravenous or subcutaneous infusion keeps drug levels steady, thereby avoiding decreased drug concentrations at the nadir, which could cause the return of the symptoms.
Induction dose is a term applied to the total dose that produces the level of sedation needed to control the symptoms. Rescue dose is a term applied to the “extra” dose that must be used in the case of a crisis or an exacerbation of symptoms. It is usually similar to the induction dose. It is also convenient to adjust drug dosages every 24 hours by adding the rescue doses of the day to the scheduled daily dose.

E.4.1 Practical Tips for Drug Selection

When sedation is indicated because of dyspnea, pain, bleeding, anxiety, or other symptoms, the drug of first choice is midazolam. If an adequate response is not achieved, the second option is levomepromazine.

If refractory delirium occurs, the drug of first choice is levomepromazine, with midazolam being the second choice. If an adequate response is not obtained, it is important to try to identify the possible causes of failure (obstruction, viscera perforation, etc.). When other drug options are needed, propofol, ketamine, and phenobarbital are possible considerations. It should be kept in mind that most patients who require more sedation need analgesia, so that those drugs with a dual effect (sedation and analgesia) may be preferred. It is important to remember that palliative sedation should not be carried out exclusively with opioids. Moreover, in children already receiving opioids, dosing does not necessarily have to be increased when initiating palliative sedation.

E.5 Drug Information

E.5.1 Midazolam

Midazolam is a water-soluble benzodiazepine with a short half-life. It is available in vials of 1 mg/ml and 5 mg/ml. It is the drug of choice for any of the symptoms mentioned previously, except for delirium.
Its half-life is 2-5 hours, and it needs to be administered every 4 hours. It should be diluted and administered within 10 minutes of being prepared.

In children weighing <40 kg, it is recommended to start with a dose of 0.05-0.1 mg/kg/dose (maximum 5 mg per dose), and doses can be repeated until symptoms are controlled. The total dose used would be the induction dose and the dose to be administered per hour. In children weighing >40 kg, a starting dose of 2.5-5.0 mg should be used.

If the patient previously received benzodiazepines, an increase of 30%-50% of the dose is recommended until the optimal dose to achieve symptom control is found.

E.5.2 Levomepromazine

Levomepromazine is a phenothiazine with antipsychotic, analgesic, antiemetic, and sedative action. Presented in ampoules of 25 mg/ml, its half-life is 15-30 hours. It is the drug of first choice for palliative sedation in cases of refractory delirium. It is also used when midazolam fails; in this case, the dose of midazolam should be gradually reduced to 50% within 24 hours to avoid withdrawal that would occur with sudden interruption. After that period of time, its dose should be titrated according to response.

The dose in children younger than 12 years is 0.5-1 mg/kg day divided into 2 to 4 doses. The maximum dose is 40 mg/day. In children older than 12 years, the starting dose is 12.5--50 mgrs/day in 2-4 divided doses. The dose may be escalated according to tolerance up to 100-200 mg/day. This drug can be administered orally, intravenously, or subcutaneously en even intranasally.
E.5.3 Propofol

Propofol is an ultra-fast-acting anesthetic that should be used exclusively after the failure of midazolam and levomepromazine or in case of allergy to these drugs. It is available in vials of 10 mg/ml and 20 mg/ml (2%). It is not possible to mix it with other drugs in the same vial for administration. When used, the doses of benzodiazepines, neuroleptics, and opioids should be reduced 50%. The most commonly used dosages include induction: 2-3 mg/kg by slow IV infusion followed by 0.5-4 mg/kg/h for maintenance, adjusted according to response.

E.5.4 Other Drugs That Can Be Used Concomitantly

During palliative sedation in agony, it may be necessary to use other drugs such as antiemetics, antisecretory drugs, and opioids. When using a continuous subcutaneous infusion, not more than 3 drugs should be mixed in the same infusion. If morphine is included, it must be protected from light. Haloperidol is not frequently used in palliative sedation because of its lower sedating action. It is occasionally recommended for refractory delirium and vomiting. Hyoscine butylbromide and hyoscine hydrochloride (scopolamine) are both anticholinergic and antisecretory drugs that can be used along with fluid restriction in the treatment of bronchial secretions that appear premortem. Because it does not cross the blood-brain barrier, hyoscine butylbromide is used when increased sedation is to be avoided. Its intravenous dose is 0.2 mg/kg/dose/8 hours. Scopolamine has a greater antisecretory effect, but it causes sedation. Both can be used by intravenous or subcutaneous bolus or continuous infusion. The scopolamine injection dose is 0.4-0.6 mg/4-8 hours.
F. How to Prepare Children and Their Families for Death

It is impossible to describe in a few lines the complexity of the supportive care of terminally ill children and their closest relatives. It is especially difficult in our culture to prepare the family for the final days of the life of a child. It is usually a time of painful and deep emotion, filled with both questions and silences. Some guidelines, however, can be applied to most cases. As a premise, we must bear in mind that although our purpose is focused on helping children in the process of death, when we face this issue, somehow we are convinced that each one of us is a child. Despite our age, we have the wisdom or experience we have gained in life; as we peer into the abyss of the end, we all become children. It is said that Francis of Assisi, on his deathbed, was babbling in French the lullabies his mother sang to him when he was a child.

First, we as caregivers must learn how to communicate, knowing that human suffering and death are realities that have not been grasped fully by humans. In a society that values development and progress, life and death are the 2 poles that make us realize how limited we are. In this sense, there are many questions that everyone will answer depending on their own background. In a society that deifies childhood, understanding and accepting the fact that a child can get sick or die is even more difficult. On occasion in our role as caregiver for a terminally ill child, we have to talk to someone (a parent, relative, or patient) who has a background, beliefs, and values very different from ours, and this lack of common ground also poses a challenge in this difficult situation. We are sometimes asked questions we don’t know how to answer. It is difficult to explain the inexplicable, but that does not mean that the issue is not to be addressed, communicated, and made the subject of dialogue. Sometimes, it is adequate simply to stay at their side and bear the silence, knowing how to acknowledge the different emotions (anger, sadness, helplessness, fear, anxiety, etc.) that emanate from the child who is suffering, emotions that usually also affect us directly.
Always, the issue of death must be talked about as clearly as possible. When the child is an infant (0 to 2 years approximately), dying is an experience of separation, abandonment, and loneliness. It is believed that infants can’t cognitively understand death as adults do and they do not possess the intellectual development necessary to conceptualize or explain the phenomenon. However, fear of separation may add to a child’s real suffering, and preparation for death in this age group should always require explicit information and attitudes that counter fears of emotional and physical separation. This is an attitude required not only for parents but also for professionals working with these children. Until they are about 6 years old, children usually create myths about death (you can return from it, it can be a punishment for being bad, it’s something that hurts a lot, I go to a place where my parents are not there, etc.).

At this age, children manage only the very immediate present; however, they may present different and seemingly contradictory reactions (to mourn and a few minutes later to play as if nothing had happened, for example). In times of crisis, the clarity and security of our words are always a balm. However, paternalism and protectionism not only will be useless, but also may contribute to suffering. At the end of childhood, there is a greater capacity to understand death as a concept and as a reality. Still, at that age, it is much easier to understand the death of others than one’s own. Our culture introduced the idea that “children do not die.” At this stage, clarity becomes a true communicative tool. It is advisable to explain the process, when the attitude of the minor permits it. We must help them to express emotions without repression or silence. It may be damaging to silence a child with the aim to spare him or her from suffering, so they may feel that there is no permission or possibility for them to communicate anything they need to say.

In preadolescence and early adolescence, death is experienced as something that is inevitable. When considering one’s own death, defense mechanisms that arise already at this age are more elaborate and complex.
To support children at this stage, it is important to treat these children with empathy and care. There is an art to effective dialogue with adolescents, especially those with a terminal illness. Knowing how to accommodate their needs requires a high level of consistency and coherence in the actions and words of the agents of health (doctors, nurses, etc.) and human relationships (counselors, psychologists, etc.).

To benefit both children and their families, we must create an environment that offers quality and warmth as a whole. This space should ensure humane care based on the principles of bioethics.

F.1 Principles of Bioethics in Pediatric Palliative Care

- **Nonmaleficence (“Do no harm”):** If we are sure of this principle, we will examine in detail all interventions. Many communicative relationships are harmful, although that is not our intention. Support must be well done or it will lead to someone’s being hurt. When it comes to being supportive, it is impossible to be neutral.

- **Justice:** For children and their families, we must provide an environment in which a high-quality, professional team acts on their behalf. A basic premise of emotional intelligence that would cement the principle of justice is: “Treat others as you would like them to treat you.” The 1991 film entitled “The Doctor” is an excellent portrayal of this idea.

- **Autonomy:** Avoid paternalism, as well as its opposite, easement. No matter how young the child is or how broken the family, they are the true protagonists of the process. Acknowledging this reality requires us to take into consideration their decisions, their preferences, and even their denials.

- **Beneficence:** This principle involves the balancing of the benefits versus the risks and costs of treatment. We must always act for the good of children and their families.
To accomplish that, we must explain the purpose of our interventions (i.e., educate patients and families) as well as provide care. We educate in order to do good.

When interacting with children and their families, we should be attentive to all aspects of “care”. Such care is reflected in each of the professional attitudes listed below:

- Giving personalized and personalizing attention
- Assessing and promoting tenderness and loving relationships
- Exercising understanding and empathy
- Organizing the patient’s routine and always thinking about his/her welfare
- Being tolerant, flexible, and respectful
- Learning that relationships require a great deal of creativity and that each person is different and has his/her own emotional needs at that particular time. Action protocols are not useful given that each experience is unique.
- Helping patients to maintain contact with their reality, favoring coping with what causes anxiety or depression
- Establishing channels to participate in decisions
- Promoting hope, optimism, and good humor
- Ensuring the quality of life until the end
- Involving families in care. Family members should be given information and preparation. Working through the grieving process is much easier if parents have been involved in preparing for the death of their child.

Preparing children, their parents, and other family for death is an essential part of the care continuum. Not only is it the right of all patients to receive humanizing assistance, but it is also a fundamental part of a loving civilization, which we would like to help to implement.
Even for those who believe that there is another life after this one, in our own lifetime, we must not lose hope and must be the guardian angels for those who are suffering.

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