Medical decisions at the end of a child’s life

Armando Garduño Espinosa, Ofelia Ham Mancilla, Alejandra Cruz Cruz, Estela Díaz García, Cristina Reyes Lucas

Abstract
This paper presents the general concepts regarding the terminal phase of a child’s illness and the therapeutic approach undertaken at a third-level care institution. We discuss how this information is transmitted to parents and children along with the bioethical aspects and the medical, emotional and spiritual support required during this complex situation.

Key words: terminal phase, information transmission, bioethical aspects, support.

Introduction
The impact produced by the death of a child on the family and society is of great importance. This event can deeply affect any person because all cultures regard the death of a child as unnatural. Children represent the future of any society; therefore, the effect produced by their death is very intense. Death in the elderly is regarded as a natural process because the elderly person has experienced a long life, but that is not the case with children. This particular situation produces a very different perception of the final stage of a child’s life when compared to the feelings produced by the same stage in adults or elderly persons.

Palliative care currently offers a great option of integral care for both the child and family who face the possibility of a child’s death. Usually, patients who have chronic-degenerative, progressive and incurable diseases notice that their quality of life has been affected. Classic examples include infants with terminal cancer, those with neurological diseases, severe congenital malformations or lethal genetic disorders. However, this is not an absolute situation because there are acute diseases such as fulminant septicemia, cranial trauma, fulminant hepatitis and others that threaten a child’s life.

In Mexico, the chapter on care of terminally ill patients is yet to be written because this subject has received little attention and there are few specialized units to assist these patients. These services have been operational for more than two decades in the National Oncology Institute, National Nutrition and Medical Sciences Institute and the National Medical Center “20th of November” among others, for adults with cancer and other incurable diseases. However, there are isolated efforts to assist the pediatric population in Guadalajara and in the National Institute of Pediatrics (INP).1

WHO through its Fairness Strategy, the Hastings Center (New York), the INP (Mexico) and the American Academy of Pediatrics propose basic and objective points on medical care according to patient needs and perspectives:1-3
1) Prevention of diseases, trauma and health promotion; this purpose has undoubtedly the highest priority because it allows health preservation and avoids suffering

2) Relief of pain and suffering produced by diseases; receive opportune medical care and preserve health and carry out safe medical practices

3) Care and assistance to patients with chronic diseases to achieve the best possible quality of life and avoid premature death

4) When death is imminent, provide effective palliative care for children, provide opportune treatment, avoid therapy obstinacy and persevere to look for a gentle death either at home or at the hospital.

Concepts
In general, a terminally ill patient is “one who suffers an acute, subacute or chronic illness without cure or adequate treatment and who is subject to palliative treatment only.” The Ethics Manual of the American College of Physicians defines it as “a patient whose condition is classified as irreversible, either if she/he receives treatment or not and who will possibly die within a period of three to six months”. Velis defines this phase as an evolutionary and final process of chronic diseases when all available resources have been exhausted. We consider a patient with leukemia is in a terminal phase when he/she presents three or more relapses (unpublished observations).

The terminal adjective might be applied to patients with cancer without oncological treatment, e.g., when physicians consider there is no known cure available. Most of these patients die within 6 months, but there are patients who survive for longer periods of time. Other children with advanced, incurable diseases that seriously affect their quality of life (neurological disorders, vegetative state) may survive for months or years. It is incorrect to use the term illness for children during their terminal phase but should rather be considered as patients with limited quality of life from advanced progressive and incurable diseases.

Patients who attend a palliative care unit or service may be classified as follows:6

- Stable chronic patients: they can be cared for at home by their family, e.g., children with neurological diseases or severe congenital malformations. It is possible that these patients are fed through gastrostomy or that they have a tracheostomy, but they are aspirated efficiently by their relatives. Some children with cancer and other diseases are classified into this group. Patients with leukemia and severe anemia may go to the hospital to receive transfusions and then return home.

- Seriously ill patients with multiple needs: they require major care because of severe hemorrhages, severe respiratory insufficiency, or seizures and cannot be cared for by their relatives; therefore, these children should remain hospitalized.

- Dying patients: patient with a prognosis of a short time of life remaining who will die within hours or days; they can be at home or at hospital.

- Patients with prolonged mechanical ventilation, e.g., children with type-1 Werdig-Hoffman disease who might be discharged once relatives have received proper training on ventilators that can be used at home as well as on integral care of the child.

Although most parents prefer to have their child at home to spend his/her last days with their family, some parents cannot bear the idea and suffer from anguish. In these cases it is advisable to hospitalize the child.
Causes and epidemiology
The most frequent diseases leading children to terminal phases are cancer, diverse neurological lesions, degenerative diseases, congenital malformations, lethal genetic syndromes (trisomy 13, trisomy 18), cardiopathies, hepatopathies, and AIDS.

In Mexico, cancer represents a serious and growing public health problem. Cancer has been identified as one of the chief causes of morbidity and mortality. In 2003 cancer represented the second leading cause of death in children between 5 and 14 years of age with 1066 cases and the fifth leading cause of death in preschool children with 522 cases. It has been estimated that cancer will represent the leading cause of death in 2010 for this age group. In Mexico, 8000 new pediatric cancer cases appear every year. Of the first 650 cases cared for at the Palliative Care Unit (PCU) of the INP, 30% were associated with cancer, 38% with neurological diseases (including brain dysgenesis), and 10% with congenital malformations. Leukemias are the most frequent form of cancer followed by central nervous system tumors, lymphomas, osteosarcomas and retinoblastomas.1,7

To diagnose a child as a terminally ill patient is a major responsibility. Diagnosis should be carried out by an expert group to avoid limited judgment. It has been estimated that 2-10% of children who attend a tertiary-care hospital are already in a terminal phase of their illness. At INP, 1333 clinical files were reviewed of patients who were admitted on duty shifts by emergency service. This represented half of the admissions on this service in 1993. Of these patients, 2% met the criteria of terminally ill patient (Garduno EA, unpublished observations).

Who should diagnose a terminal phase?
This should be done by the treating physician because of the close relationship maintained with the child. The treating physician has been involved in the follow-up care of the child, gaining the confidence of both the child and parents. Although this is a hard task to accomplish, it is the treating physician’s responsibility to inform the child and family of the diagnosis. Palliative care personnel can advise on how information is given, but it is not recommended that they provide this type of information because they are not familiar with the patient and family members. If treating physicians inform parents that there are no alternatives for cure and that the child will receive only palliative care to reduce pain, this will facilitate the initiation of palliative therapy. Initiation of palliative care for children is very important in order that the patient receives treatment aimed to improve quality of life and avoid suffering, instilling confidence in children and family. Treating physicians should introduce the palliative care team to parents and family.

Signs and symptoms
Clinical data depend on the disease because terminal phase manifestations are vague and imprecise, having progression as the common denominator. Patients experience severe weakness, general discomfort (infrequently reported by children), drowsiness, fatigue causing movement, self-cleaning and feeding difficulties, incontinence, inability to carry out daily tasks, insomnia, constipation, vomiting, inadequate management of secretions, hemorrhage and pain (experienced at least by 50% of cancer patients). Osteosarcomas and intracranial tumors are the neoplasms accompanied by the most pain; cachexia and respiratory insufficiency appear in the final phase accompanied by anguish. Patients also present other expressions such as dependence, violation of individuality, disfigurement, loneliness and indifference, all menacing their well-being.

In our experience, the main signs and symptoms are inappropriate management of secretions (mainly in children with neurological disorders), pain (from moderate to very intense), dyspnea,
constipation and decubitus ulcers. Adolescents who account for 15% of cases as observed by Garduno et al. experience depression and fear of dying (unpublished observations); however, most children face the terminal phase of their illness with integrity. They are more serene than adults and even ask for the help of physicians so that their parents experience less suffering from the situation. These manifestations require planning for an interdisciplinary team that covers physical and emotional needs of the terminally ill patient and his family.

Care approach
The life of terminally ill patients can currently be prolonged by days, weeks or even months and that seems to comply with the primary duty of the physician to preserve life under any circumstance; however, this approach produces a number of ethical conflicts related with the limits of medical treatment when all available scientific and technological resources are used to maintain and prolong life of patients who have no possibility of cure or recovery. Only the agony is prolonged. The patient frequently suffers from the obsession of the physician and therapeutic obstinacy.

Limits of action
Because life is considered sacred according to the Hippocratic Oath, this principle has ruled medical practice. However, if we adhere strictly to these practices we would be subjecting these patients to a series of therapeutic measures without benefit, thus incurring therapeutic obstinacy. We would be trying to cure the incurable, unable to recognize the limits of life and medicine and admit that death is not a synonym of failure. This approach only generates anguish in patients and their family and is equivalent to senseless medical care known as futility, dysthanasia or unnecessary overtreatment. This excess of medical treatment prior to death has generated a growing clamor in society in favor of euthanasia by considering it a death with dignity. There is also the fear of dying in intensive care units connected to various types of equipment, tubes, probes, catheters, needles and often in deep solitude. In Mexico euthanasia has not been legalized.7-16

It is often complicated to establish limits on therapy; therefore, it is necessary to become familiar with the following concepts.

Ordinary or proportionate measures
These are all diagnostic and/or treatment measures applied to a patient with cure or recovery possibilities (e.g., children with cancer who may survive for several months or years). These patients require the use of all measures with potential benefit. This is equivalent to complete support.

Extraordinary, disproportionate or futile measures
These are all those measures used for diagnosis and/or treatment applied to a patient without cure or recovery possibilities and their use only prolongs the dying process. Examples of the above are use of a mechanical ventilator to treat respiratory insufficiency; apply peritoneal dialysis to a terminally ill patient with hyperkalemia, use of parenteral nutrition for these patients, etc.

Diagnosis and/or treatment measures should be constantly evaluated because extraordinary measures are promptly perceived as ordinary; for instance, a liver transplant for a cirrhosis patient is no longer regarded as extraordinary.

Bioethics aspects and values
Terminally ill patients represent one of the greatest dilemmas for bioethics whose supreme statement is to preserve the health and well-being relationship under prima facie principles that regulate and are targeted towards patient well-being,
maintaining respect for the patient’s rights and the rights of others. A central purpose of this concept is human dignity from conception to death. Human beings should be treated as such and their rights are inalienable under any circumstances. With this approach in mind, healthcare personnel should act with honesty and carefulness to care for terminally ill patients without contempt for ending life. While there is hope, preservation of life is a moral and medical obligation, but when a patient is in a terminal phase it is essential to recognize the limitations of medical interventions and we should accept that there are no curative therapies in order to avoid unnecessary treatments and overtreatment that do not help the patient. Therefore, the approach should be aimed towards helping the child to have a peaceful death without disproportionate interventions. This approach is known as orthothanasia, whose essential purpose is to relieve patients from suffering. This type of care is also known as passive euthanasia, which is ethical and legally accepted in most countries. In summary, the purpose is to bring more life to days and no more days to life.9,11

There are several situations that generate conflicts associated with treating children in terminal phases of illness, serious congenital malformations or severe and irreversible neurological damage. Such situations are extremely complex and this is associated with feelings and values of healthcare personnel so it is not appropriate to provide absolute criteria. However, we should provide the following recommendations:9,11

1) Parents or guardians should have full responsibility for decision making and complete interaction with the treating physician. It is possible that the involvement of the ethics committee and courts may be required.

2) Children should participate in decision-making when possible or at least to consider their point of view. Adolescents frequently are able to make decisions.

3) All patients with severe malformations, irreversible neurological damage and in a terminal phase of their illness have an intrinsic dignity, value and rights as any person, and all reasonable medical care should be administered in order to provide the best possible life experience.

4) The essential principle is to act in the best interest of the child. The decision to remove or apply intensive treatment is justified only when it aids in the well-being of the patient (when prognosis is unfavorable and there is suffering).

5) Once the child has reached a terminal or dying phase, it is possible that healthcare personnel become discouraged and abandon the patient. Therefore, it is important to insist that children under such circumstances require special care and should not be isolated for any reason.

Palliative care as well as minimal care should be provided under the following scenarios:

1) When the dying process is prolonged

2) When the child suffers intense and unbearable pain

3) When the child is in a persistent vegetative state

4) When the child is dying

Ethical evaluation of these patients should include the application of prima facie principles from the bioethics model of principlism: beneficence, autonomy, justice and non-maleficence as useful standards for decision making. Together they express that all medical actions will be aimed at the benefit of the patient, providing appropriate information to parents and relatives (who as guardians should make the best choices for their
Children will receive the best available treatments considering what is good, proper and fair for the child, keeping in mind the best interest of the patient and avoiding unnecessary suffering. In the short term we should focus on the role children have in decision making because autonomy can only be exercised by parents; however, there are children who have sufficient maturity to make decisions they regard as the most appropriate for their own well-being.4,7,9

Sometimes parents are confronted with these principles because they abuse autonomy and make decisions that endanger their children. Therefore, we should stress limits of autonomy when parents refuse curative treatment or palliative care for their child.

WHO defines palliative care as the active and complete care of patients from the time their disease stops responding to curative treatment. Its main purpose is to control pain and other symptoms as well as emotional, social and spiritual problems. The goal of palliative care is to offer the highest possible quality of life to the patient and family. Sometimes quality of life is so precarious that it can be little improved.2,4,5

Palliative care represents a valuable instrument that offers healthcare teams the possibility to better fulfill the needs of their patients. The purpose is to alleviate symptoms and to provide comfort and emotional support for the child and family in order to improve the quality of life that becomes increasingly precarious. Palliative care should be provided while keeping in mind each patient’s needs by a professional team who will administer this care. One advantage is that many patients can be cared for at home, which considerably reduces the emotional burden and costs. This mitigates patient suffering when death is unavoidable and family support is also offered.

Children in terminal phase of their illness have specific organic, psychological, family, social and spiritual needs. In order to fulfill these needs, intervention is provided by a multidisciplinary healthcare team comprised of physicians, nurses, psychologists, visiting physicians, paramedics, social workers and even a pallbearer and, if necessary, a priest or a thanatologist may participate at the request of family or patient.

Palliative measures can be specific or nonspecific:

a) Specific: those where patients may require surgery, radiotherapy, chemotherapy, etc. (advanced cancer, congenital malformations such as hydrocephalus in patients with Arnold-Chiari malformation, among others).

b) Non-specific: analgesia, treatment for depression, anxiety, insomnia, anorexia, infections, pressure ulcers, rehabilitation (physical, psychological, social), management of other organic signs and symptoms.

In order to alleviate organic needs, we include feeding, hygiene, pain management, movement, management of excreta, management of tubes, etc., all basic needs for the child’s comfort. Under this situation, most physicians and nurses display deep solidarity and compassion and are willing to...
help, protect and avoid unnecessary suffering for the child who becomes the primary mission of the pediatric healthcare team. At the same time, other feelings appear such as frustration, discontent and impotence before the imminent death of their patients. When the child is in the final phase of their illness, physicians’ efforts vanish; however, nurses always maintain their duties under any situation and become true foster mothers for their pediatric patients. In contrast, young physicians become discouraged and frequently do not know how to act, making evident their impact and sadness.

One of the most important aspects is pain relief, which is often underestimated in children. Pain should be treated completely with necessary drugs, bearing in mind that every patient is different and requires an individualized dosage. Most patients require participation from pain clinics. The palliative care team should pay special attention to the alleviation of pain for their patient.\textsuperscript{17}

Also, there are a series of psychological techniques that help to manage certain symptoms such as anxiety, fear, sadness and inappropriate behavior that is difficult to understand for the family. It becomes even harder to accept the imminent loss of their child, making the family vulnerable. Multiple conflicts may arise while dealing with the dying and grieving processes. The interdisciplinary team benefits from having trained and experienced personnel in these areas.

**Cognitive behavioral therapy in palliative care**

The explicit recognition of emotional needs and the interest to incorporate psychological aspects in patient care have been ever present in palliative care. One of the most effective interventions in psychological care is cognitive behavioral therapy, which is based on the analysis of three interconnected elements: thought, emotion and behavior. Therefore, if any of these elements is altered before a stressful situation, the patient’s overall performance will be affected. For instance, when a mother shows patterns of distorted thought (why me? I must be paying for my sins with my child for something I did in the past, even before I was a mother), this will impact her emotions (sadness, concern, anguish, anger) and modify her behavior before her dying child (the mother might avoid the hospital, blaming herself and thinking her presence harms her child).\textsuperscript{18}

With the administration of palliative care, cognitive behavioral therapy proposes modifying one of the main components (e.g., a distorted thought pattern) through a series of interventions aimed to improve the overall functional condition of the patient. This is to modify other components that are affected by the problem.

This kind of psychological care is comprised of three steps:

1) **Assessment**–in this phase the case is examined through interviews and clinical observation, records, self-recording, standardized instruments, etc. in order to formulate a hypothesis on the case and outline treatment objectives.

2) **Intervention**–when therapeutic techniques and strategies are used to achieve goals.

3) **Follow-up**–during this stage we evaluate the effectiveness of therapy and adjustments are made to maintain positive changes up to assessment.

These care phases can be carried out as a single or as a recurrent procedure. We should mention that these phases are used throughout the therapy plan or at each session.

In the second intervention phase we use therapeutic techniques or strategies that are specific for each element that will be modified, either cognitive, emotional or behavioral. The cognitive component includes those strategies aimed at modifying how to deal with problems, problem-solving, psychoeducation and cogni-
tive restructuring approaches. Identification and emotional expression are techniques used to deal with emotional regulation and also relaxation through guided imagery or guided emotional self-regulation. Techniques that comprise behavioral therapy focus on offering patients a self-regulating technique to manage their stressful experiences and improve their adjustment before diagnosis of a terminal illness. Some of these techniques are progressive muscle relaxation, diaphragm breathing and biological feedback.¹⁹

Bad news

The imminent loss of a child is the most dramatic event that a human being can experience. It represents a major challenge for healthcare personnel to provide this information appropriately to the patient and parents. Treating physicians should report that therapy failed, whether it was oncological, hematological, neurological, etc. This can be reported to parents together with the palliative care team. The information provided by the Palliative Care Unit from the INP is offered in a private, comfortable and intimate atmosphere for the family. In general, the palliative care team participates in this action, but sometimes the information is so sensitive that it is reported by PCU physicians. The interview with the parents begins by asking them what they have understood from the information given by the treating physician. We listen to them and then explain in detail by using laymen’s terms that therapeutic measures have failed and we can offer only palliative care to the patient, including relief and comfort. Information is provided completely and truthfully in order for the parents to know what to expect, what actions should be taken and the possible types of help. We emphasize from the beginning that every action is oriented towards the “patient’s best interest” and that we will help the patient in every way possible to avoid suffering and we will refrain from overtreatment (punctures, tubes, tests, studies, etc). Parents are encouraged to explain in a calm manner what the situation actually is. In our experience, treatment works better when the child is aware of the illness, the therapeutic failure and that everything possible will be made to avoid suffering and that the palliative care team will support the child in every way possible. Parents frequently believe it is better for their child to have partial information on the illness, fearing they may experience more suffering; however, children frequently realize the situation and the poor prognosis and have seen other children die from the same disease. In most cases, patients accept the news calmly and acquire control of their life in this phase. When children pose questions to the palliative care personnel, information is provided in a simple and natural way, especially with children >8 years of age.¹

This first interview with the child’s parents gives them sense of the terrible situation, the spiritual transcendence of their child’s life, without including specific religious topics. Most parents receive this difficult and transcendent information well and accept the palliative care that will be focused on the child and deal with parents’ grief.

Palliative care objectives

The objectives of palliative care for providing comfort and quality of life are as follows:

- Integral, individualized and continuous care
- Children and relatives are a single unit
- Promote autonomy and dignity
- Active and positive therapy perception
- Promotion of truthfulness
- Symptom control
- Continuous emotional support
- Flexible therapeutic approach
- Multidisciplinary care
- Grief management
Minimum care
Considering the value and dignity of terminally ill patients and based on the inalienable rights of humans, we consider necessary the following types of care:

Feeding: We recommend a natural approach, preferably indulging the patient. According to each child’s situation, it can be applied by oral tube, transpyloric tube or gastric tube. Parenteral nutrition should be avoided.

Proper hydration: Liquids and electrolyte administration make patients feel better and help them eliminate bronchial and oropharyngeal secretions, also avoiding thirst and drying of the mucosa. During the dying process, it is possible that hydration is no longer required, but placing a humid gauze or ice over the patient’s lips helps to avoid thirst.

Oxygenation: Apply oxygen if required by patient without using mechanical ventilation. The patient can receive oxygen at home using an oxygen tank or an oxygen concentrator, which is more cost effective.

Pain management: The patient should be relieved from pain using all necessary resources in order to avoid suffering. It is important to remember that each patient should receive the proper dosage as well as rescue dosages.

The presence of relatives and even friends generates a comfortable environment. Children should not be left alone. Comfort, hygiene, posture changes, excreta management, etc. should all be attended to.

Transfusions should be considered in patients with severe anemia (INP Ethics Committee, unpublished observations). Many children with leukemia who remain at home are transported to the hospital to receive transfusions and then return home, thus improving their quality of life.

Palliative care units do not avoid death but relieve the patient from pain and make the situation more bearable while preserving the patient’s dignity. If this approach could be applied to all terminally ill patients, the dying process would be dignified and some practices would be avoided such as active euthanasia and assisted suicide. It is mandatory to work diligently to learn and operate this concept, to raise awareness with healthcare authorities that the dying process is part of life and medicine and that palliative care is essential if we consider basic medical principles, the progress of medical science, teaching and research. Use of these techniques can reduce the costs associated with this increasingly growing patient group.

Costs
Costs associated with terminally ill patients are not precisely known because the situation presents variations and depends on the patient’s disease as well as the length and complexity of the hospitalization period. Several European countries have documented that the cost bed/day in PCU was similar to the cost bed/day in ICU.6 PCUs have demonstrated that hospital care and medication expenses are reduced when the patient is cared for at home, improving the quality of life for the patient and family.

At INP, the palliative care team integrally supports the patient and is integrated with other services. It is an interconsultation service without specific beds and we consider that this system is working well. There are PCUs in other countries with specifically assigned beds and these also work properly; however, this is a painful stigma for patients because everyone who uses those beds dies. Each hospital should generate internal policies and establish the most adequate program.

It is worth mentioning that having a hospice intervention would be appropriate because the hospice organization has material and human resources to provide integral care for terminally ill patients and allows them to recover sufficiently
and to return home to complete the dying process or to die in the institution with maximum possible care.

**Home visits**

Once children are discharged, they receive visits from palliative care personnel at home to resolve the needs of the child and family. We apply this program at INP and are promoting this program so that most patients can receive palliative care at home. At the present time, 25% of patients cared for by our PCU die in their homes surrounded by family.

**Correspondence to:** Dr. Armando Garduño Espinosa

Unidad de Cuidados Paliativos

Instituto Nacional de Pediatría

México, D.F., México

E-mail: armandogarduno@hotmail.com

---

**References**


