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## Palliative Care and Terminal Care of Children

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### 1. Introduction

While modern palliative care movement began with the opening of St. Christopher's Hospice in London in 1960, it was not until 1990 that became widely used, when the World Health Organization adopted the definition of Palliative Care European Society for Care Palliative as "the active total care of patients whose disease does not respond to curative treatment", even if it is in advanced stage and progressive, yet pediatricians took longer to recognize the needs of some pediatric patients who require this type of attention, these patients still do not have access to specialists in palliative medicine than adults do have. As in all pediatric specialties, palliative medicine in children can not simply be imported, the more aspects are examined, children and adults look less and that is why palliative care should be developed from practice and experience pediatricians.<sup>1</sup>

While adults often terminally be referred to specialized equipment, in contrast, pediatricians continue to accompany the patient and family. The advantages of this approach include the combination of skills and knowledge, professional presence known and felt that the patient and his family are not neglected.

Palliative care in children should be considered as an integrated model of care to seriously ill patient or a medical condition that may threaten your life and your family. Begins at diagnosis and continue to be the result of survival or death of the child, or coexisting with healing therapies that prolong life. The model must meet the physical, psychological, social and spiritual needs of children and their families, in order to enhance their quality of life while supporting members of the family members. That is why palliative care can be integrated into care plans of children and their families, whether the goal is to get the cure, prolong life, or only palliate and provide comfort until death.

Terminal illness is defined when a medical condition expected to cause death in a short period of time (three to six months), no matter whether treated or not. There are diagnostic criteria for establishing the condition of terminal illness, such as the presence of a progressive and incurable disease, there is no reasonable likelihood of response to specific treatment, the presence of numerous problems or severe symptoms, multiple, multifactorial and changeable and a great emotional impact on the patient, family and treatment team, with the possibility of death.<sup>2</sup>

This diagnosis should be performed for at least two doctors, one of which is in charge of the patient or physician, and (the) other (s) unrelated to the patient. To make the diagnosis of terminal illness we can support the therapeutic proportionality principle, this principle holds that there is a moral obligation to implement all those measures which have a therapeutic

relationship due proportion between the means employed and expected outcome and those measures that this relationship is not met ratio is found to be disproportionate and would not be morally obligatory. Importantly, the trial about the proportionality of a medical intervention should be determined by reference to the overall benefit of therapy, and not just in relation to possible physiological effects that she is able to induce.

As a child, when the family receives the news that one of his sons is in a position incurable and fatal disease in a relatively short time the entire structure is turned upside down: there will be uncertainty, fear, change roles, and changes family functioning and way of life of each of its members is for them that during the course of the disease the family will need psychosocial support of various kinds: information, facilitating the organization, access to social support structures, hold on stages of internal conflict and timely recognition of the moments of "exhaustion family."

This chapter points out the importance of integrating pediatric palliative care in the process of care of hospitalized children, and reviewing the needs of pediatric patients as family and medical staff who serve them. In addition, some recommendations that can help health personnel to serve these children and families.

## 2. Characteristics of palliative care in the pediatric patient

The terminal phase of disease is a destructive experience for the child and their family members, especially in long-term diseases, inexorable course, where curative options are no longer a reality. Therefore the focus of attention must change radically and move to help pediatric patients and their family, have a better quality of life possible time left to live, through a multidisciplinary effort and qualified. The short life of a child, spent her brief and limited future, deprived of opportunities to see him live and enjoy their existence can generate anxiety, sadness, despair, anger, helplessness in the people around him, including both their parents and close relatives and health personnel in charge of your care is why it is considered palliative medicine as active and total care of patients and their families by a multiprofessional team when the disease is no longer responds to curative treatment and life expectancy is relatively short. The word "palliative" comes from the Latin word pallium, meaning blanket or deck. Thus, when the cause can not be cured, the symptoms are "covered" or "covered" with specific treatments, such as analgesics, and so on.

The traditional view is that the main objectives that must be considered in palliative medicine are:

- Relieve pain and other distressing symptoms;
- Address psychological pediatric patients according to their chronological age;
- Offer a support system to help the child understand his illness to promote active communication between family members and health personnel;
- Provide a support system to help families cope with the patient's illness and cope with the mourning period.

Palliative care affirms life and recognizes that dying is a normal process, seeks neither to hasten nor postpone death, and this requires health professionals with high-level skills and expert care, individualized for each patient, attentive to details and sensitive, which is time consuming and palliative medicine is an attempt to restore the traditional role of doctors and nurses "to heal the sick, relieve when you can not cure, but always follow."

Whatever the type of care should be implemented the philosophy of palliative care in five specific categories, which provide evidence for discussions, evaluations and reflections and contribute to learning:

1. Initial assessment of the patient. Vital as it provides the physical, pathophysiological, social, environmental and spiritual illness.
2. Developing a work program. Options should include medical, ethical and humanitarian offers palliative medicine. Share concerns and perspectives of the patient's family, and medical equipment contributes to the pursuit of consensus and formulate a plan of care.
3. Review monitoring and updating treatment plan. Evaluates the information of the multidisciplinary team, patient and family, to judge the medical component of the treatment plan.
4. Assistance in the terminal phase and elaboration of grief. Allows to acquire knowledge about the symptoms of approaching death, fears, and beliefs of the family, preparing for the outcome, physical care of the dying, relief from suffering and elaboration of mourning for who is dying, with spiritual help needed.
5. Take an active role in her interdisciplinary group. It relates to supporting the work of other members, participation in the development and growth of the multidisciplinary team and training health staff and community about the philosophy, importance, needs and scope of palliative medicine.<sup>3</sup>

In general, states that a patient is terminally ill with a disease that acute, subacute or chronic, the most common, of course subject to inexorable and palliative care, but also could be considered as a patient whose condition is classified as irreversible, treated or not and probably will die in a period of three to six months. Many ailments can lead to children prematurely to the terminal phase, mostly cancer, neurological damage, kidney disease, the immunopathy, congenital malformations, acquired immunodeficiency syndrome and liver disease, each with specific characteristics that share similarities end.

Cancer is largely responsible for the terminal phase in the pediatric age and is considered a serious public health problem and a major cause of morbidity and mortality worldwide. The mere mention of the word cancer mortified generates distress and immediate relationship with an incurable disease, although at present the cancer in children is no longer lethal, and many will have a chance to heal, but other have an unrelenting course and reach the terminal phase, though it is used all available treatments, testing new strategies and even experimental, but without the possibility of cure. In these particular cases life expectancy is very short, perhaps a few months and most patients die shortly after diagnosis. An estimated 2 to 10% of patients attending a highly specialized hospital are terminally ill, so accept that a child is at this stage involves a great responsibility, so the diagnosis must be made by a group of experts and staff in a trial.

It is difficult to establish a precise definition of palliative care to include all children in need and to provide international standards for their implementation, as each country has different health resource models, models of care, philosophy, culture, politics, legal rules, and so on. However, there are children dying from cancer or other diseases that fail to be addressed in all their needs, and there are many reasons why this happens, among others, that childhood is not the age of death (kills more adults) seems easier to care for the children by their parents, but not the pain and other symptoms that society, medicine, have taken less severe disease and death in children, which allegedly curative treatments are rarely abandoned, and yet, even in intensive care units raises increasingly limited therapeutic child care from the palliative approach is increasing in importance.

Death has always been something that people tend to ignore out of fear. When death occurs in children is more striking because the parents expect to see healthy growth and development, represents the continuation and perpetuation of individuals, families, cultures, nations, even said that people who do not treat their children have no future also be considered "the hope of humanity." In addition to the immeasurable suffering in those parents happen all kind of feeling guilt, helplessness, failure, anger and punishment. For medical and paramedical staff, the meaning of the death of a child usually involves feelings of failure, helplessness and guilt, just as a great sense of grief for parents who suffer from this devastating loss. That is why parents are an essential part of palliative care of children, contributing to the care of affected are receiving care and instructions by the medical staff and paramedics should be encouraged so assertive communication, and and offer all possible facilities for this purpose.

### **2.1 Care for the relief of physical suffering of the child**

Children have needs in end-organic, psychological, familial, social and spiritual order to fulfill specific and if possible, requires the participation of a multidisciplinary team of health professionals. Palliative care is divided into specific and nonspecific. First used in surgery, radiotherapy, chemotherapy, blood transfusions, and so on. (Large tumors, hydrocephalus in children with Chiari syndrome Arnold, among others) in non-specific changes are analgesia, nutrition, hydration, constipation, management of pressure sores, vomiting, hygiene, insomnia, anxiety, depression treatment, counseling , social and spiritual management of other organic symptoms and signs.

Respecting the former management types (specific and nonspecific), we must also consider what you are like kittens maneuvers needed to integrate them into the following four aspects:

- The power, which can be provided in natural form or by nasogastric tube, instead of parenteral nutrition is not part of palliative treatment only if patients with short bowel and intestinal absorption problems.
- Maintaining the hydration status of patients, through a baseline fluid intake, contributing to the welfare of children, as well as the best removal of bronchial secretions and oropharyngeal. This type of hydration is preferably orally.
- Good oxygen through their various modes of application, but preferably without mechanical ventilatory support. Otherwise when the patient is under the support of a ventilator, when establishing its terminal state, extubation is part of the palliative management, but must be considered the minimum respiratory parameters assists.
- It is necessary to consider the child's comfort, this can be done by placing it in a bed with adequate support for the patient with appropriate clothing. The comfort should be extended to visiting relatives, seeking a physical area of privacy in which to have a child living in an environment as comfortable as possible. In any case the room should be adequately ventilated. Try to avoid many people stay in the room and the presence of noise. It is important to maintain physical contact with the patient, touch is the last sense to the patient loses.
- The child's hygiene is also critical, which is needed for both the nursing staff that treats you like family doing their daily bathroom cleaning personal clothing and bedding. To hydrate the skin can be massaged with moisturizing cream soft, provided it does not bother the child or cause pain.
- Frequent changes of position, which must be common to modify support points that reduce circulation which may predispose to the appearance of scars and / or pressure ulcers.

- Finally, consider the use of blood transfusions for severe anemia, when the child is likely to live for several days or weeks. The wet mouth and lips there for that commercial preparations that may be useful as parenteral hydration is not improving xerostomia.<sup>4</sup>

It is also necessary to establish what are the purposes of a hospice program in pediatrics which should consider the following points:

- The income of a pediatric patient to a hospice program should be considered only if it is highly unlikely that the child reaches adulthood.
- It is not intended to shorten life, but to control the physical and emotional symptoms in dignity for the patient and his family.
- Do not hasten or postpone death.
- Start from the beginning supported the diagnosis.
- Seek to improve the quality of life of children and their families.
- Provide comfort and pain relief is a fundamental right of the sick child and their management to be an essential part of treatment.
- Provide comprehensive care, individual and continuing, accepting the values, desires and beliefs of the child as part of a whole.
- Promote values and humanism.
- There should be promotion of the truth.
- Management should be made by a multidisciplinary team, 24 hours a day, 365 days a year, with the proviso that any of the team members are trained to provide support in the child's needs or their families.
- Provide tools to parents, guardians and other family members for communication and interaction with the child about his illness, condition, expectations, etc.
- Provide ongoing emotional and spiritual support.
- Complement the curative treatment when applicable.
- Reaffirm life and see death as a natural process.
- Palliative care does not end with the death of the patient, support the duel should take place as long as necessary to all those affected by the death of the child.
- Set goals and limits for therapy in a child with chronic illness.
- Make appropriate decisions at the end of life.<sup>5</sup>

The management of symptoms is a vital part of palliative care. Pain is the most prominent symptom, its frequency and impact on patient and family, but should not be left aside other symptoms such as dyspnea, nausea, vomiting, salivation and convulsions. Pain is a prominent symptom, not only in cancer patients, but also in other diseases such as cystic fibrosis, acquired immunodeficiency syndrome (AIDS) and neurodegenerative diseases. It is essential for the management of pain, knowing the cause of it, since the treatment will depend on having a correct diagnosis. Opioids are of great value for moderate to severe pain. Neuropathic pain is caused by direct irritation of nerves and drugs such as amitriptyline, nortriptyline and gabapentin have demonstrated efficacy in controlling this type of pain. Another type of pain is somatic, which affects the bone and soft tissue treatment for this is given with nonsteroidal antiinflammatory drugs. Visceral pain, which can be caused by distention or obstruction, requiring treatment with glucocorticoids or octreotide.

The relief of pain and other distressing symptoms of is considered, rightly, the primary goal of palliative care in this way is considered palliative medicine as an expert in the management of end-stage patients to keep them virtually free of pain. You can also expect a

high degree of relief from many symptoms. However, not being distracted and exhausted by unrelieved pain, patients may experience greater emotional and spiritual anguish when contemplating the nearness of death. Few do it with balance, most are psychologically defend themselves in various ways, and some are overwhelmed by anxiety, anger or fear of what is happening as the relatives and it is necessary to offer a personalized attention. The health team should seek to assist the patient has given his best, according to their personality, their family, their culture, beliefs, age, disease, its symptoms, anxieties and fears. It is necessary flexibility you need to know to find the patients where they are socially, culturally, psychologically, spiritually and physically.

Sometimes the patient's symptoms in the dying phase can not be controlled with standard treatments and have to use palliative sedation which is defined as the deliberate administration of sedative drugs specifically to reduce intolerable suffering, derived from refractory symptoms, by decreased level of consciousness of the patient. The intolerable suffering should be determined by the patient as a symptom or condition which can not continue to endure. When the patient can not communicate is the opinion of caregivers and / or family members who must determine the nature intolerable suffering. Refractory symptoms are those for whom all possible treatment has failed or, at least, the use of other measures is not appropriate given the margin benefit / risk from the patient's situation. Because palliative sedation is done with refractory symptoms always mean a situation of great anxiety for the health care team. In the days that passed from the onset of sedation until the end of treatment, usually marked by the death of the patient, many decisions are taken to try to achieve the ultimate goal of a good death. Physicians should be aware of the anxiety from this situation and the importance that their anxiety has no effect on the decisions taken with the patient. The consensus in the health team for each of the decisions is essential to prevent an emotional overload at the time

## **2.2 Psychological needs, emotional and spiritual**

In addition to pain management specialists in this symptom, there are alternative therapies such as biofeedback (which corresponds to behavioral therapy for the relief of human suffering, with empirical and theoretical foundations, solidly scientific, which is an essential feature in your application ), hypnosis, massage and acupuncture, all play a vital role, more always go hand in hand with other therapies. Agitation can be treated with benzodiazepines; itching with a variety of oral antihistamines, nausea and vomiting with prochlorperazine or ondansetron. Seizures with diazepam and secretions with hyoscyamine.

There are countless situations that generate conflict related to the treatment of children in its terminal phase, with serious birth defects, with severe or irreversible neurological damage and the complexity of this situation presents a series of feelings and conflict of values between the medical staff and paramedics so that you can not give absolute criteria but a series of recommendations to parents of these children, including:

1. Parents or guardians are solely responsible for the decisions about treating your child in appropriate interaction with the treating physician who knows the child's illness. In these cases it is recommended the participation of the Ethics Committee of the institution for advice relevant to each particular case.
2. All children in the terminal phase have inherent dignity, values and rights as human beings and must receive all medical care considered reasonable to take them to the best possible existence.

3. The moral obligation of health workers towards the child is always sick, so the decision to withdraw or not to apply intensive management can be justified when it serves the best interests of the child, that is, when your near future is grim, full suffering or when new interventions only cause greater risks.
4. You should always consider the application acceptable minimum of palliative care in the following cases: those involving greater agony of the child or prolong the life of the unnecessary if, when suffering severe pain and intolerable only if the child is in state persistent vegetative or in the agonal phase of the disease. <sup>6</sup>

In these cases it is also important ethical review but with certain peculiarities of the characteristics of his being in development and maturation. First and foremost, remember that life and human health have intrinsic value derived from the same human dignity. For the sanctity of life, every person, regardless of age and psychophysical characteristics, has-without exception-the same basic right to life and deserves respect and protection of society and all professionals dedicated to your care. This is helpful to the implementation of a set of ethical standards including casuistry, virtue ethics (aretológico), utilitarianism, the ethics or medical duties, however we must consider the bioethical model and of paramount are beneficence, autonomy, justice and nonmaleficence that might work well at the time of decision making by physicians and can be summarized in the fact that all the therapeutic actions tend to benefit patients, avoid damage with an appropriate and relevant information to parents or legal guardians choose the best decisions for their children that children receive the best treatments available to date and supported by quality scientific research proven methodology, but not excessive when is in final stage, always consider the good, proper and fair to them, thinking only in their best interests and to avoid unnecessary suffering.

The contribution of psychology in this context includes aspects of care both for children with terminal illness and their families as different members of the multidisciplinary team. Psychological intervention can be carried out in at least four periods with both patients and relatives, before the impact caused by the onset of the disease after diagnosis of the disease and the start of the intervention during the disease progression and the process of death and finally after the death of the child.

In relation to the patient, the task from the psychological point of view, focuses on the welfare assessment, pain and suffering as a result of the situation which is in addition to psychopathological symptoms such as anxiety, fear of death, depression or loss of control of the situation, this can be directed to the alleviation of the emotional impact while facilitating the process of adaptation to the disease. This assessment should be carried out continuously and flexible, as there are rapid changes in disease evolution, adapting to the characteristics and needs of each individual child.

In relation to family assessment and intervention focus on work overload and emotional impact that occurs as a result of the proximity of the disease and its possible consequences. Do not forget that many times family members are the only ones who know the patient's diagnosis, hidden so that it does not suffer. Therefore, psychological intervention will aim to reduce psychosocial problems that this causes in family functioning and to assist the family in anticipation of mourning.

As it relates to health workers providing palliative care, the action aims to facilitate both the management of emotions to the terminal as the communication situation between the different members of the health team towards further professional effectiveness. The latter at the organizational level is a powerful resource that can help prevent or reduce the risk of



discouragement and decreased quality and quantity of efficiency. In this sense, communication skills with patients, families and among health professionals is essential from the first contact established to give the diagnosis to the patient's death. It is therefore necessary to raise the team development through techniques such as counseling, both to encourage training in assertive communication that allows people to show what they feel, what they think and what they need.<sup>7</sup>

Finally the doctors and parents, with proper informed consent, must make decisions taking into account the benefits and burdens then they mean, also assessing alternative treatments. But as we have seen, with due respect for the thoughts, feelings or wishes of the child when their age and maturity you gain experience and judgment. Therefore desirable to add palliative care units in all hospitals and pediatric primary care teams working so that, with the terminal disease, lengthen or shorten not intended life but provide comfort while the child left to live while helping his family.

### **2.3 Legal aspects of palliative care in children**

Once the provider accepts medical services patient care, it also establishes a legal relationship (doctor-patient relationship) and is required to provide appropriate service and quality, conforms to the rules of law applicable in each country. It must be emphasized the need to recognize and protect the right to palliative care, likewise, is a responsibility of governments to ensure that palliative care accessible to all who need them. These recommendations emphasize the need to develop a coherent national policy framework and comprehensive palliative care that includes the following sections: principles and guidelines on palliative care services and structures that should tell the health care system, welfare policy and organization of the plan of palliative care, quality improvement and research on relevant issues in health care programs, education and training of specialist staff for the care of terminally ill patients, family support, communication, teamwork and mourning.

Palliative care should be an integral part of the Health Committee of the countries and as such should be an element of general health plans, and on specific programs, such as cancer, AIDS, or any patient in a terminal. The implementation of government programs should meet the need of any health system where there are patients in advanced stages and terminals of any kind, in all care settings and where it is considered a fundamental right and a priority in health programs public.<sup>8</sup>

### **3. Role of paediatrician in the provision of palliative care**

The role of pediatricians at the death of a child in the hospital is not easy to define, and the lack of guidelines leads to question if it works correctly. Supporting families after a sudden and unexpected death is particularly difficult. No time to prepare families and health personnel for the event, and it is likely that any further contact with the family involving the staff who do not know well. Offering a bereavement follow-up meeting to the families is an accepted part of clinical practice and is perceived as useful to help them. Unfortunately, there is little guidance on the objectives of these meetings or training to carry them out.

The pediatric specialists we bring in our own references to death, which are formed along personal and professional experiences. Starts walking toward death when born, talk about it so widespread and yet death is a preventable and ignored issue. For many it is difficult to talk about death in a society that denies and trying desperately to forget their finitude and

that is why death is just means suffering. Always without medical training to defend life against the death of patients. In the last hundred years there was an important step to reduce mortality at all levels, purpose made significant steps in terms of public health as well as major advances in diagnostic and therapeutic resources so the emphasis in medical education but the scientific and biomedical research as the basis of scientific knowledge applicable to the medical activity in contrast to the hitherto prevailing empirical knowledge in courses at the beginning of last century, this new model of medical education introduced significant advances in the effectiveness and efficiency of treatments, as well as contributing to the improvement of health indicators in the world.

However as a result of technological development in medicine was a fragmentation of knowledge within the medical training that led to multi-specialty discipline, which today produce serious difficulties in communicating with each other, along came the disintegration of the individual as a patient, an approach that little organ systems interact with each other, and that has led to the dehumanization of medical education. Pain, anxiety, suffering and death are concepts that are not included in the process of care and therefore has no place in the curricula of medical schools. Only sometimes the emphasis is on techniques and medical management to save lives and little or nothing to the development of clinical skills to deal with the pain and suffering, the death of patients and support for families facing the loss of a loved one.

Pediatricians in their education in schools and hospitals where they perform their clinical fields learn to engage with life, all their training is geared towards healing and save the patient, not letting die, so the healing is the meaning of learning or reward the effort. That is why when death occurs, it brings frustration, feelings of inadequacy and limitation, may perceive the child's death as a particularly stressful event. There may also be feelings of helplessness, stress, moral and spiritual suffering, and the emergence of depressive symptoms and burnout syndrome. These aspects must be recognized and addressed proactively to prevent the loss of highly skilled medical personnel. The lack of respect between doctors of different environments, poor interdisciplinary communication, a hierarchical structure of authority, and feelings of helplessness in morally problematic situations contribute to stress and burnout of medical staff, rather than the death of children per se, It is therefore necessary supporting staff work better health while learning to develop adaptive responses to the demands of their work. In environments where demands are particularly intense a reasonable starting point would be to acknowledge this point and go beyond crisis intervention. So the challenge that is the pediatrician is to encourage interdisciplinary and collaborative nature of clinical practice and training to improve pediatric palliative care and child-centered family.

Can you give some examples of ways to improve the quality of the workplace for medical staff that handles children in their terminal phase, including clear orders recorded as well as the following:

- Establish a systematic interdisciplinary meetings.
- Create and actively maintain an atmosphere of open communication and respect.
- Conduct regular ethical discussions between the medical and paramedical personnel.
- Assign experienced clinicians with whom it is safe to discuss concerns and emotional responses on the patient or care plan.
- Have team meetings relief after difficult cases, providing access to crisis intervention teams and psychologists when desired.
- Carrying out acts of commemoration after the death of some patients.

- Encourage follow up with the grieving families.
- Recognize the grief associated with personal and professional losses.
- Recognize the value of the provision of palliative care.<sup>10</sup>

Health staff and particularly the pediatrician also goes through a grieving process, you may feel overwhelmed by having to help the bereaved parents as they have to develop their own grief, so it is necessary to the development of programs aiming at monitoring the mourning families and the healthcare professional. It takes scientific research to learn the process of learning to cope with multiple losses and accumulated health professionals and also consider interventions designed to improve the kind of education and support needed in the experience of dueling doctors in particular pediatricians who have daily contact with children in its terminal stage, such as oncologists, nephrologists, intensivists, and so on.

Medical schools, including the chairs of Pediatrics, the importance of what has been the subject of this dissertation, should be included as part of medical training, content related to child rights and family informed consent of parents and patients less capable of understanding the duty to maintain the privacy of children, protect their identity and knowledge of the behaviors for the care of critically ill children or risk death.

#### **4. The role of family in palliative care of the child**

We know that living the illness of a loved one, suffering and death is one of the most difficult life events faced by humans. When a boy joins innocence, helplessness and think he has not had time to live. The death of a child is the loss more traumatic for a parent as it also faces the experience of destruction of a part of himself, the most linked to projects and future hopes. The father's feelings are mixed feelings towards himself, towards the child and toward the couple. The death of a child can affect physical health and psychological well-being of members of the family for the rest of their lives.

When a family is informed that the child will die, a process of confusion and anguish in which decisions about the care and treatment of disease of a child and in desperate need of hope mixed.

Their children do not suffer pain or disability. Parents can express feelings of worthlessness and guilt for having subjected her son to treatments that have not had the expected outcome. It is essential that before the change of therapeutic approach for parents to have confidence that has done everything possible to cure disease and save the life of her son and that he will provide comfort and symptom control. They may also feel conflicting emotions: protection / decoupling; hopelessness / guilt for surviving, disbelief and denial by the change in prognosis, fear of pain and suffering, the capacity to provide care, the emotional loss of control.

Studies of grief in parents suggests that pain control, care during the time of death, and conducting follow-up after the death of the child are factors that may reduce long-term distress in the grief of parents . In other words, improving the care of the sick child, symptom control and care in the dying can also be beneficial for long-term parents. In addition to caring for a child at the end of life at home facilitates the development of mourning. The family perspective is critical to advancing healthcare quality of pediatric palliative care.

There is a cultural trend, especially in urban areas, to set aside the brothers of these situations and sometimes they are not even explain what is happening. But children are highly sensitive

to the mood of your family and know that something is happening, then replace the lack of information on their fantasies and draw their own conclusions, for example, that your loved one have been abandoned or their misbehavior is the cause of the disease. Siblings may fear for the life of his ailing brother, to be able to get sick and die. Also face a loss of parental attention they can get angry, less time at home when the child is hospitalized, fewer gifts to his ailing brother, difficulty in understanding the gravity if no physical changes in the patient, shame about being a different family because his brother is disfigured. Sometimes they feel guilt for having escaped the disease, or have wished for the death of his brother. You will need to adapt to being provided with information tailored to their level of development, to be included in care, and that their care is delegated to trusted people and stable.

The child can be cared for at home at the end of his life will facilitate the involvement of the brother in the situation, strengthen the bond between brothers and share games and joint activities, and farewell. Reactions to the death of a brother are varied: from no apparent response to the presence of somatic problems, nightmares, aggression, manipulation, learning difficulties, resentment toward parents for failing to be closer or more time with his brother. The clear and open communication, attention to the needs of the brothers for the rest of the family and maintaining a more normal life as possible, integrated into the serious situation of the sick sibling, will facilitate the adaptation process of dying, fired and the elaboration of grief.

Other significant family for the child and grandparents also suffer at the news of the evolution of the disease and its end of life, and will also be essential support for parents and siblings. The health team must identify the family dynamics and to address the emotional needs of siblings and other relatives integrating them into care when treating the sick child.<sup>11</sup>

#### **4.1 Communication with the family physician's**

The final stage of the disease is the stage when the family needs more support as they go through the same stages as the patient but in different ways, trying to deny even imminent death, it is here to provide privacy, access to patient, show kindness, give comfort as with the patient. The doctor and the multidisciplinary team should get the patient to die decently in explaining a positive way to face death, treating patients in their dignity, not dependence. It is often the physician in charge of announcing the death and should provide the best conditions to face this task, this way the family will be satisfied with the care they provide.

The contribution of psychology in this context includes aspects of attention both to terminally ill patients and their families as different members of the multidisciplinary team. In relation to family assessment and intervention focus on work overload and emotional impact that occurs as a result of the proximity of the disease and its possible consequences. Do not forget that many times family members are the only ones who know the patient's diagnosis, hidden so that it does not suffer. Therefore, psychological intervention will aim to reduce psychosocial problems that this causes in family functioning and to assist the family in anticipation of mourning.

Many families are unfamiliar with medical information, and are facing their own shock and anxiety during this critical hospital. Being aware that these circumstances may contribute to the confusion of families, many physicians state that all personnel involved and their different styles of communication, contribute to these difficulties. Very often, parents are lost with the new concepts, detailed explanations and unfamiliar terms when they need time

and clear communication to assimilate and process information, so that improvements in communication increase the sense of parental control.

Parents whose child is in the terminal stage of their disease may develop PTSD, and emotional disorders (anxiety and depression). Admission to a hospital medical establishment also negatively affects the family unit. The severity at admission and length of stay in services or departments of a hospital may have negative consequences for the family.

Several studies have documented the psychological benefits for parents and children, medical and economic needs emotional parents whose children are admitted to a hospital in terminal stage, so the medical and paramedical staff should be more sensitive to the needs of aid psychological family members to seek the help of the most qualified professionals in this work and also to provide, within its capabilities, continuous emotional support.

In recent years, has developed an awareness on the emotional and spiritual needs all patients, their families and support staff. Terminal in each patient, these issues must become an indispensable part of treatment. That is why the doctor needs the support of parents, guardians and other staff responsible for patient care because it is important to keep routines before detection of the disease. The first step in treating depression and anxiety is the recognition thereof through communication with the child, which requires knowledge of normal development and spiritual development. To work with these patients is necessary to evaluate based on drawings, games, stuffed animals, stories, music and creating rituals, allowing children to express their fears and anxieties, and thus manage their emotional distress.

The attitude of medical and health personnel to the severely ill or dying in a hospital, and to his family, and the type of information that these professionals provide can have a direct effect on the family's ability to adapt the loss of a loved one and spending a proper grieving process. Parents perceived slights or emotional distance from the health staff usually show a dual inadequate short and long term. Also, a caring emotional attitude has beneficial effects in the short and long term.

#### **4.2 Recommendations to support the child's family in terminal stage**

Despite the lack of specific guidelines that help medical personnel how to act in the last moments of a child's life so that they can support the family, some authors have proposed some recommendations:

- Try to predict questions that may have parents but are afraid or unable to verbalize.
- It is helpful for any family to know the expected course of death, even the unpleasant physical circumstances.
- Leave plenty of time for goodbyes, visits and rituals. Privacy and familiar presence, if they want the child and family is another important aspect to provide comfort to both parties.
- It is important to tell the family that may or may not happen during and after the withdrawal of life support. Moreover, even if parents do not accept the possibility of abandoning the medical interventions that extend life, the evidence suggests that some families do not only want, but can also benefit from the opportunity to be present during resuscitation efforts.
- Do not forget to ask family members if they want to hold your baby with you or be with them in bed.

- Should be told that the child will not feel pain and the medical staff will provide all necessary medication to ensure patient comfort.
- The answer to the question of how long the child will survive after the limitation of life support is very important information, since families may develop unrealistic expectations about the time of death. It is very important to prepare for the fact that the child might not die, or death can occur within minutes or weeks, depending on many conditions associated with the disease and the patient's general condition.
- Some children do not die in the highly complex services such as intensive care units so they must communicate this to parents and the medical team to properly ascertain both the transfer of the patient and the services they receive child .
- Children need to know that they are not going to forget and parents shared experiences to remember. (Ensuring the importance, the continuing legacy and love are important aspects of parenting the child who will die). When death can be anticipated, measures to create memories during times of relative health or ongoing claims that they are loved and that they are not going to forget, are important.
- For a child who dies suddenly, for example victims of trauma, some innovative approaches may be to create molds the child's hand, save a lock of hair, or take pictures or videos at moments when the family visit the child. Those involved in caring for the child will die, should seek to provide opportunities to create legacies or inheritances.
- When the child was deeply sedated, parents may have the opportunity to see your child smile and see with open eyes before his death, an experience that sometimes has a great value.
- Parents, siblings, other family members and friends may have to spend the final moments of the dying child, so that policies restricting visits to the different services of a hospital need a thorough discussion and review. <sup>12</sup>

## 5. Conclusion

For the management of end-stage patients is necessary to integrate a multidisciplinary and interdisciplinary team who can take charge of the complex needs of these children, and the problems they face inside and outside the health institutions, especially in view of relieving their suffering and achieve an improvement in quality of life standards. It is essential for teamwork (which would include pediatricians or neonatologists, nurses, pain specialists, psychologists, thanatologists, social workers, physiotherapists, occupational therapists and a spiritual leader within the team), which must prevail in a spirit binding, collaboration among its members, and a shared competence, ie a single goal, and a great patience and high tolerance for frustration.

Undoubtedly optimal care to patients and families in the service environment that serve patients in terminal stage, would also imply an institutional sensitivity to allow or permit the reflection of the team, including structural and organizational changes and the provision minimum financial resources that would enable the adequacy of care according to need.

Finally, the necessarily humanistic medicine, palliative care and a multidisciplinary unit that should work with the patient and his family twenty-four hours a day, 365 days a year, it is desirable that all members involved in the process to be the same philosophy and specific goals for the welfare and tranquility of the children and their families.

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## **Contemporary and Innovative Practice in Palliative Care**

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This book is designed to provide a comprehensive insight into the key and most prevalent contemporary issues associated with palliation. The reader will find viewpoints that are challenging and sometimes discerning, but at the same time motivating and thought-provoking in the care of persons requiring palliation. This book is divided into three sections. Section 1 examines contemporary practice; Section 2 looks at the challenges in practice; Section 3 discusses models of care. This book is an excellent resource for students, practising clinicians and academics. By reading the book, reflecting on the issues, challenges and opportunities ahead, we hope it will create within the reader a passion to take on, explore and further develop their palliative care practice.

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