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REVIEW ARTICLE

Pediatric palliative care

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Abstract

In Pediatrics , Palliative Care are those that prevent , identify and treat children suffering with chronic, progressive and advanced , their families and Health teams that serve them. They are suitable , in any phase of the disease. However, PC offer further advantages as offered earlier , along with other targeted therapies to cure or control the underlying disease.

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"The value of things does not lie in their duration, but in the intensity of their occurrence. This is why unforgettable moments, inexplicable things, and incomparable people exist."
Fernando Pessoa

1 – DEFINITION

Palliare is a Latin verb that means "to protect, support, cover, shelter." This nomenclature brings a new perspective into traditional Western medicine: that of caring beyond curing. Palliation implies the relief of the suffering of patients, and a palliative action signifies any therapeutic measure, without a curative purpose, that aims at reducing the negative repercussions of the disease on the general well-being of the patient.

In this perspective, in 2002, the WHO issued the following definition: "palliative care consists in the assistance provided by a multidisciplinary team with the objective of improving the quality of life of patients and their families in the context of a life-threatening disease, via the prevention and relief of suffering and the early detection, impeccable evaluation, and treatment of pain and other physical, social, psychological, and spiritual symptoms."

In pediatrics, palliative care pertains to the services that prevent, identify, and treat children who suffer from chronic, progressive, and advanced disease, as well as the services provided to their families and attending teams. They are appropriate at any stage of the disease and are more advantageous when offered early on, together with other therapies aimed at curing or controlling the underlying disease.

Moreover, palliative care has the mission of promoting the well-being of the patient, thereby allowing us to address the concept of death without pain, in peace, and in a dignified manner, without taking away from the individual any other existential possibility.

2 – HISTORICAL ASPECTS

The redemption of the concept of palliative care dates from the 5th century, with *hospices*, which were shelters (inns) that were dedicated to receiving and caring for pilgrims and travelers. In Europe, such places were organized by religious institutions, both Catholic and Protestant, and in the 9th century transitioned to having hospital characteristics. In 1905, St. Joseph's Hospice was founded in London by an Irish religious order.

The Modern Hospice Movement was launched in the United Kingdom by Cicely Saunders, a physician and a humanist, with the creation of St. Cristopher's Hospice (1967). This movement spread the new philosophy of caring worldwide. It included two fundamental elements: the effective control of pain and other symptoms stemming from treatment in advanced stages of disease, and the care pertaining to the psychological, social, and spiritual dimensions of the patients and their families. In the 1970s, the meeting between Cicely Saunders and Elisabeth Kübler-Ross in the United States propelled the growth of the Hospice Movement in that country as well. Thus, a new concept of caring in addition to curing began to be introduced that focused on the patient until the end of his/her life. The first pediatric hospice was founded in 1982 in the United Kingdom: the Helen House in Oxfordshire.

In 1982, the Cancer Committee of the World Health Organization (WHO) created a workgroup that was responsible for defining policies for the relief of pain and for palliative care (PC). The WHO published its first definition of PC in 1990, as follows: "active and total care of patients with a disease that is not responsive to curative treatment. The control of pain, other symptoms, and psychosocial and spiritual problems is paramount." This definition was revised in 2002 and replaced by the current definition.

In Brazil, palliative care was standardized with Ordinance no. 3535 of September 2, 1998, which undertook the registering of all institutions that worked in palliative care in oncology. Subsequently, Ordinance no. 19 of January 3, 2002 included the National Program for Pain Care and Palliative Care in the national health system (Single Health System – SUS in the Portuguese acronym). Furthermore, Ordinance no. 1 of July 23, 2002, created the reference centers for the treatment of pain ("Centros de Referência em Tratamento da Dor") within the SUS, and Ordinance no. 881 of July 19, 2001, created the National Program for the Humanization of Hospital Care, which gives government backing to the implementation of palliative care in Brazil.

3 – BIOETHICAL ASPECTS AND FUNDAMENTAL PRINCIPLES

Among children with disabling or life-threatening diseases, two distinct moments can be identified over their lifespan: the initial stage of life, during which care is focused on preventive and curative medicine, and the stage at which death becomes inevitable. In the former stage, medical practice must prioritize beneficence, without neglecting the autonomy of the patient and his/her family. Non-maleficence is a secondary ethical value at this stage: invasive measures are justified here, even if they cause a certain degree of suffering, because the primary objective at that moment is the preservation of life.

In the stage at which death becomes inevitable, palliative medicine prevails and the priority of care shifts toward the relief of suffering, non-maleficence. In the case of children and patients with mental disability, the principle of autonomy must be carried out by the family or legal representative, in defense of the patient's best interests. The principle of justice, which is considered a basic ethical principle, must always govern medical practice, by applying common sense regarding the prioritization and indication of

therapeutic resources at each stage. The indication of palliative care also applies to the neonatal period.

Initially, palliative care prioritized adult patients with oncological disease. Pediatric palliative care is different from that provided to adults in various aspects and is characterized by several particularities, as follows:

- The number of children who die in pediatric palliative care is low compared with the number of adults who die while receiving palliative care.
- Pediatric diagnoses are generally rare and occur only during childhood; however, some of those children may survive into adulthood.
- The period of intervention in pediatric palliative care is different from that observed for adults, and may be days, months, or many years.
- These diseases are often familiar, with more than one sibling being affected, which implies a need for genetic counseling.
- The care provided generally involves the whole family, with siblings being particularly vulnerable.
- The parents experience a situation of ambiguity, as they feel an anticipatory pain regarding their probable loss, while being simultaneously the caretakers of the child.
- These diseases occur during a life stage in which there is a marked physical, emotional, and cognitive development; therefore, it is essential to ensure the continuity of the learning process. It is also important to pay attention to the extent to which the disease may affect the child's ability to communicate and understand his/her pathological situation and death.

Pediatric palliative care, as a specific field in healthcare, expands certain aspects of the palliative care provided to adults, as follows:

- It consists in an active and comprehensive care of the body, mind, and spirit of the child, while also providing support to the family.
- It starts at diagnosis and continues throughout the duration of the disease, regardless of whether the child is receiving treatment to control the underlying disease.
- It requires the evaluation and alleviation of the physical, psychological, and social suffering of the child by the health professionals involved.
- It requires a broad, interdisciplinary approach.
- It includes the family and uses resources that are available in the community; it can be implemented successfully even in cases of limited resources.
- It can be provided in institutions with any level of care, in nursing homes, or at home.
- It must be adapted to the child's development level and must comply with the family's values.

The World Health Organization has proposed the following principles to guide the practice of palliative care in general (adults and children). Palliative care:

- provides relief of pain and other symptoms that cause suffering;
- affirms life and considers death a natural process;
- is not aimed at either rushing or delaying death;
- integrates the psychological and spiritual aspects of patient care;
- provides a support system aimed at helping patients lead a life that is as active as possible until their death;
- provides a support system aimed at helping the family go through both the disease process of the patient and their own grief;
- uses a team approach to attend to the needs of the patients and their families, including the follow-up of their mourning;
- improves quality of life and may also affect positively the course of the disease;
- is applicable from the early stages of disease, together with other therapies directed at the underlying disease, including the investigations that are necessary to understand and manage any clinical complications that may cause suffering.

4 – ELIGIBLE PATIENTS

In Latin America, the classification developed by the Association for Pediatric Palliative Medicine (APPM) and the Royal College of Pediatrics and Child Health (RCPCH) from the United Kingdom is generally used. This classification divides patients into four groups according to their expected clinical course, as follows:

I) Conditions for which curative treatment is possible but may fail. Examples: oncological diseases that either are progressive or advanced, or have a poor prognosis; complex congenital or acquired heart disease, and diseases that qualify for transplantation.

II) Conditions without a realistic probability of cure, but in which survival may be significantly extended (by intensive treatments that allow long periods of normal activity). Examples: HIV infection, cystic fibrosis, progressive muscular dystrophy, chronic respiratory failure, severe immunodeficiency, and advanced epidermolysis bullosa.

III) Progressive diseases without a realistic probability of cure (progressive deterioration from or before diagnosis). Examples: progressive metabolic diseases, severe osteogenesis imperfecta, and neurodegenerative diseases.

IV) Non-progressive but irreversible diseases (with a high probability of premature death because of complications). Examples: non-progressive chronic encephalopathy, severe anoxia, severe cerebrospinal malformations, and severe sequelae after trauma.

5 – PILLARS OF PEDIATRIC PALLIATIVE CARE

a) Management of pain and other symptoms

The main pillar of pediatric palliative care: relief of suffering via the adequate management of the physical symptoms and emotional grievances of patients and their families.

In 1967, Cicely Saunders formulated the concept of total pain, which includes the physical, psychological, spiritual, mental, social, and financial suffering of the patient, and also encompasses the suffering of family members and of the medical/hospital team. Thus, the American Academy of Pediatrics considers that the social, spiritual, and emotional suffering of the patient may affect their experience of the symptoms. The main pediatric physical symptoms are pain, anorexia, fatigue, dyspnea, gastrointestinal symptoms, and psychological symptoms, among others.

The International Association for the Study of Pain (IASP) conceptualizes pain as an unpleasant sensorial and emotional experience associated with real or potential tissue injuries, or described in terms of tissue injuries. The adequate management of pain is fundamental for care in these patients, and represents the starting point for all subsequent approaches.

In the investigation of the parameters of pain, it is important to identify its characteristics (localization, intensity, quality, duration, frequency, and associated symptoms); relief and exacerbation factors; use and effect of pharmacological and non-pharmacological measures; manners of communication or expression of pain; previous traumatizing experiences and fears; coping abilities and strategies; behaviors of the child in the family environment; effects of pain on daily living; and emotional and socioeconomic impact.

In the management of pain, it is important to take the following steps:

- 1st step: Evaluation and explanation of the pain
- 2nd step: Therapeutic management and monitoring
- 3rd step: Attention to detail

The evaluation of pain must be performed regularly, using scales that are adequate for each age group and clinical situation. It should be noted that these scales may be hard to use in some clinical situations, such as in children who are under sedation, with restricted movement, or under tracheal intubation.

In the neonatal period, the Neonatal Infant Pain Scale (NIPS) is normally used both for preterm and term newborn infants; the Premature Infant Pain Profile (PIPP) is used to evaluate pain during procedures; and the Neonatal Pain, Agitation & Sedation Scale (N-PASS) is used for newborns receiving assisted ventilation. For children younger than 4 years or those who exhibit difficulties in verbalizing pain, the Face, Legs, Activity, Cry, Consolability (FLACC) scale is used. For children older than 4 years, the Facial Pain Scale-Revised (FPS-R) is used, and from 6 years of age onward, the Visual Analogue Scale, among others, can be used.

The treatment of symptoms must include both pharmacological and non-pharmacological approaches. The pharmacological treatment of pain includes non-opioid analgesics, opioid analgesics, and adjuvants (such as antidepressants, anticonvulsive drugs, and corticosteroids). The WHO revised the analgesic pain scale for the pediatric population in 2012, and gave preference to small doses of strong opioids, rather than using mild opioids such as codeine and tramadol, in cases in which non-opioid analgesics were insufficient to relieve pain. The main aspects of this therapeutic guideline are:

a) The use of a biphasic strategy, depending on the intensity of the measured pain (by analgesic ladder);
b) Use of the appropriate dose of analgesic that relieves pain effectively, in an individualized manner (by the child);
c) Use of the appropriate route of administration of the medication, avoiding routes that are painful or invasive (by appropriate route);
d) Use of a drug administration schedule that is regularly defined, with additional doses used to treat incidental pain, when needed (by the clock);

In this way, the WHO recommends the following drugs for children:

- Paracetamol and ibuprofen are the drugs of choice for mild pain. Both drugs must be available in the initial phase of treatment. In infants younger than 3 months, paracetamol alone should be used.
- Opioids are the drugs of choice for moderate to severe pain. The primary option is morphine, but other options must be considered when its side effects are not tolerated. The selection of alternative opioid analgesics must be guided by considerations of safety, availability, cost, and adequacy.
- Treatment with opioids must be individualized and adjusted in a progressive manner.
- When pain is constant, the drug must be administered at regular intervals and not on demand, and side

effects should be monitored. Intermittent and intercurrent pain can be treated with rescue doses.
- The route of administration should be the simplest, most efficacious, and less painful one; in general, this is the oral route. When the oral route is not available, the selection of alternative drug administration routes (IV, SC, rectal, or transdermal) must be based on clinical judgment, availability, viability, and patient preference. The intramuscular route should be avoided.
- A switch of opioid and/or administration route is recommended in the presence of an insufficient analgesic effect with intolerable side effects. The systematic rotation of opioids is not recommended.

The non-pharmacological aspects of symptom treatment include integrative interventions, such as psychotherapeutic/behavioral techniques (relaxation, hypnosis, therapeutic imagination, meditation, music therapy, art therapy, and yoga); physical interventions (massage, transcutaneous electrical nerve stimulation [TENS], positioning, and hot/cold treatment); and energy therapies (acupuncture, Reiki, and therapeutic touch), among others.

The choice of therapy should be based on individual clinical criteria. It is essential to take a proactive approach with regard to the treatment of symptoms and side effects of medication, which should be anticipated as much as possible, and to ensure good communication with the child and the family.

b) Communication and decision processes

Communication Process

To communicate means "to make common" and presupposes comprehension and understanding between the parties concerned. It is the capacity to exchange or discuss ideas and to dialog with the aim of establishing good entente between people. It is different from informing, which means to give information or an opinion, to instruct, to warn and to make aware.

Effective communication is based on a harmonious, balanced, respectful, and tolerant physician-patient/family relationship. The communicator should be able to listen, respect values, and include others in cases where the decisions concern their own lives. Humility, transparency, patience, assurance, and good didactic skills are all elements of good communication.

The health professional should respect and recognize the patients' and their relatives' capacity to comprehend and absorb information, i.e., their competence. He/she should promote decision-making that is autonomous, free, and without external influences, when such decisions become necessary. The role of the health professional is to help patients and/or families choose the health-related values that are best for them, accept their choices and support them during treatment, even if such choices are based on values and beliefs that differ from those of the professional.

Communication between human beings is complex and occurs at three levels:

- Verbal (words);
- paraverbal (how we say the words – silences, sounds, emphasis, pauses between sentences and words);
- nonverbal (facial expressions, body postures, touching, interpersonal distances, gestures).

Some cues indicate that the message is not being comprehended: shaking the head in disagreement, averting the gaze, leaning backwards, crossing the arms, expressions such as "no" and "but." Other cues may indicate that the information is being understood and that the listening is effective: nodding the head in agreement, attentive and empathetic gaze, leaning the body forward and using expressions such as "yes" and "of course." In general we do not voluntarily control all nonverbal cues and, even when we do not say everything we think or feel, unconscious nonverbal cues express the hidden emotions.

The communication of bad news is often a delicate situation in palliative care. Being honest without, however, dashing the patient's hopes is deemed the most difficult aspect in this process. The following are some principles of communication of bad news:

- Choose a moment when both patient and physician are relaxed and have the appropriate time;
- Assess the emotional and psychological state of the patient;
- Prepare the patient or the family by telling them that there is a difficult subject they have to discuss;
- Use clear and simple language;
- Express empathy for the patient's pain;
- Be humane and compassionate;
- Give information gradually and schedule a later meeting;
- Be realistic and avoid minimizing the problem without, however, dashing all hopes;
- Observe how patients and their relatives feel after receiving the news;
- Ensure the continuity of care, no matter what;
- Ensure that the patient receives emotional support from other people.

Protocols have been developed to help physicians in their task of disclosing bad news, with the goal of reducing the risks and the harm of non-empathetic communication. The SPIKES approach, a six-step protocol of communication set

up by a group of American oncologists, summarizes the main guidelines that health professionals should follow (Baile, 2000).

The following are the concepts behind these six steps:

First step: "Setting up the interview" (S)

This step concerns the setting, which in this case translates into the context. The preparation (preparing the family/patient by telling them they need to have a difficult conversation), the moment (in which the family, the patient and the physician are relaxed and have time to converse), the place (appropriate and private to avoid interruptions), and diligence (the communication should be initiated as early as possible to avoid the anxiety of the wait) are all part of the ideal setting.

Second step: "Assessing the patient's perception" (P)

Assessing the patient's expectations, perceptions, and beliefs is possible when the health professional is available to listen. The goal is to find out how much the family/patient knows and wants to know about the illness, and to understand how the patient perceives what is happening to him/her and how ready he/she is to hear the unfavorable news.

Third step: "Obtaining the patient's invitation" (I)

Being attuned with the patient's wishes allows the physician to give information according to the patient's inferred willingness to allow this process. The objective is to share the information gradually by observing the understanding of the family/patient, checking how they feel after receiving the news, being attentive to verbal and nonverbal communication. When there is denial and ambivalence, the physician should not argue with or oppose the family. Ambivalence is common in such moments and the physician should accept it.

Communicating news to children requires the parents' agreement and complicity. To protect their children, parents may sometimes want information to be omitted. The pediatrician should understand the situation, be supportive of the parents, help them in this decision, assess the child's level of understanding and facilitate the communication between the parents and the child.

Fourth step: "Giving knowledge and information to the patient" (K)

It is the physician's duty to tell the truth to the patient, in the best way possible. Language should be clear and simple, resorting to audio-visual materials to facilitate comprehension if necessary. The physician should be realistic and avoid minimizing the problem, but should never use negative words that show hopelessness. When informing the patient, the physician should try to give his/her support by using communication skills that reduce emotional stress and lessen the receiver's experience of isolation when he/she listens to the bad news.

Fifth step: "Addressing the patient´s emotions with empathic responses" (E)

The health professional should constantly assess the emotional and psychological state of the family/patient and express empathy for their pain, be humane and compassionate, and ensure that there is emotional support from other people, if necessary. Empathy is also expressed through actions, inasmuch as paying attention to the opinions and requests of the family/patient is implied in the physician's commitment to assist them whenever possible.

Sixth step: "Strategy and summary" (S)

The development of a treatment plan that includes the patient's full cooperation should not establish limits or deadlines. Decisions should be made with the complicity and collaboration of the family/patient. Scheduling later meetings with the family/patient is part of the commitment to be involved in the process and assures them of the continuity of active care during all stages of the illness, no matter what.

DECISION-MAKING

The process of decision-making involves all the individuals committed to the child's well-being, from the professionals directly involved in care (the healthcare team), to relatives, administrative bodies, government institutions, and even those working in bioethics committees in hospitals.

Parents usually have strong emotional bonds and concerns for their children. Therefore, they are the most capable of recognizing and fighting for their interests. In addition, they are committed to the family's dynamics and to the biopsychosocial, emotional, spiritual and cultural development of their children. However, the reflections about death, a life-threatening condition, or the suffering of a child are profoundly complex and painful for the parents, who often find themselves in denial and may experience contradictory feelings, sadness, anger, and guilt. Because they are involved in the decision-making process, having to cope with uncertainty without any previous experience in this type of situation, they need to trust the healthcare team.

Health professionals tend to believe they should "protect" parents from complex situations and from the ethical dilemmas that involve their children. This protective attitude seeks to prevent parents from having feelings of guilt or remorse in situations of fatal or undesirable outcomes. However, it is the parents and relatives who have to live everyday with the decisions (that were not theirs at first) and with all the medical and non-medical implications. The subject of the treatment (patient and relatives) should be perceived as a singular biopsychosocial and cultural entity that has expectations, susceptibilities, anxieties, and fears in this moment of great vulnerability.

In the Deliberative Model of physician-patient/family relationship, the ideal attitude of the health professional is

to integrate information and values to provide a therapeutic recommendation, promoting dialog, the patient's autonomy, and reflection. This process of joint and humane deliberation enables the moral development of each individual. It should be noted that the health professionals' values are important to the patient, and a basis for the patient to choose the physician as his/her career.

Sociocultural and religious differences between the parents and the health professionals can hinder the communication process and, in an asymmetrical power relationship, the family's opinions can be underestimated. Respecting differences, without prejudice and with empathy, regardless of the patient's diagnosis or prognosis, is essential for the establishment of a relationship of mutual trust.

From a legal point of view, children in Brazil are considered autonomous to make decisions about their lives only once they are 18 years of age. The determination of this age limit may not be in line with the patient's growth, cognitive development, and maturity. The perception of the child's and adolescent's autonomy, which allows them to manifest their full capacity, creates dilemmas between beneficence and autonomy. Children with chronic illnesses are in an even more delicate situation because it is common for parents and professionals to downplay their growing ability to participate in decisions. However, it is essential to observe their development, taking into consideration their maturity and perception if these individuals' self-determination is to be properly respected. The boundaries between dependence and independence, and between competence and incompetence are often blurred.

In addition to respecting the parents' and child's wishes, health professionals have an ethical and legal obligation to safeguard their patients' "best interest," according to their age and maturity. Any discussion related to children care should include the ethical, legal, social, contextual, cultural and developmental aspects.

Sharing the decision-making process between parents and health professionals is the ideal strategy to allow the best possible choices in complex and difficult situations. This attitude requires respect and understanding for the delicate and difficult moment the family is going through, as well as full awareness of their decision rights.

c) Spirituality

Spirituality and religiosity are fundamental aspects of caring for patients with serious, debilitating and terminal illnesses. They can influence the process of giving meaning to and coping with the illness, as well as the patient's decisions with regard to the proposed treatment. Religion and spirituality are not interchangeable terms.

Spirituality is what gives meaning and purpose to an individual's life. According to Jung (1986), it refers to the transcendental relationship between the soul and the divine, and to the ensuing changes, i.e., spirituality is associated with an attitude, an internal action, a broadening of the conscience that may occur, for example, through prayer, mentalization, or meditation. Individuals may be in touch with their spirituality through formal religious rituals or through an interaction with nature, humanity, or the arts.

Religion usually refers to a system of faith organized in the form of beliefs, practices, rituals, and language that characterizes a community in search for transcendental meaning in a particular way, and is usually based on the belief in a divine being. Religion is only one of many forms of spiritual expression.

A serious illness represents a crisis for the spirit, and spiritual questions arise about the meaning of life. Ambiguous questions about human existence that are not answered by our rational and pragmatic abilities gain meaning when the individual develops the spiritual side; the person then comes in contact with higher feelings and thoughts, thereby strengthening his/her personality and developing more mature strategies to cope with adversities.

If the pain of patients receiving palliative care is not relieved, the mind is overwhelmed with negative and obsessive thoughts, with little room for spiritual thoughts. Therefore, once the symptoms are adequately controlled, it is important to address the emotional and spiritual issues. Children are able to express them through verbal and non-verbal language, depending on their personality and degree of maturity. In general, the spiritual side, which only appears in adolescence, emerges earlier to compensate for the loss of physical capacities. However, it is common for the healthcare team not to address the issue of religiosity/spirituality because the professionals do not know how to do it. They thus neglect an important component of the care.

Spiritual "anamnesis" is the space where patients and families can tell their stories and share their values. It is also the place that helps them reveal their sources of strength and hope, in addition to the coping and resilience mechanisms they already have. This is precious information for planning the multidisciplinary approach to the treatment. We should identify the patients' concerns, their anxieties, beliefs, fears, and spiritual pains. To address the spiritual aspects of children receiving palliative care, Davies suggests asking some questions, such as the following:

- What is the most difficult thing about being sick as you are?
- Who or what gives you the most support to cope with your illness?
- What gives you a sense of hope?
- Why do you believe you are sick? (Sometimes children/adolescents think it is because of something they did). Have you asked yourself about that?
- What do you think "God" (or use the name of Allah or Buddha, depending on the case) is like? (Which

toy, object, or animal the child has that reminds him/her of what God looks like?)
- How do you think God feels about your illness?
- What scares you when you think of the future?

Spirituality/religiosity have been shown to help people by giving them a sense of control and strength, allowing them to be reconciled with themselves and with others, and, above all, redefining the meaning of death. This process of acceptance is fundamental at the end of life.

d) Multidisciplinarity

Human beings are born in a socially organized environment, in which people are interconnected and where no task is executed by one individual alone. Palliative care, whose goal is to address the physical, mental, emotional, social, cultural and spiritual dimensions of the human being, is a set of multiprofessional actions. Therefore, a comprehensive approach is required that involves professionals who are specialized and trained in the various dimensions of the individual.

The multidisciplinary team should be composed of the following professionals: physician, nurse, social assistant, chaplain/spiritual assistant, physiotherapist, occupational therapist, nutritionist, psychology professional (psychologist, psychotherapist, psychiatrist, psychoanalyst); speech and hearing specialist, educator, dentist, pharmacist, art therapy specialist, music therapy specialist, among other professionals who can contribute to the holistic care of the child and his/her family. These professionals should act in an interdisciplinary manner, with reciprocity, mutual enrichment, and a trend toward leveling out the relationships of power, promoting exchanges between different areas of knowledge by participating in the decision-making process and treatment planning.

The fundamental role of informal caregivers (mother, father, grandparents, etc.) in the palliative approach should be emphasized. They help to ensure a more comprehensive, comfortable, and loving treatment environment for the child with a life-threatening illness.

6 – SUPPORT DURING GRIEF

Grief is the set of reactions to a significant loss. Parents of children who were in palliative care programs and who participated in decision-making during the process, being thus involved in the care and establishing good communication with the healthcare team, have a better chance of redefining the meaning of death and processing it in a less pathological way.

In palliative care, the process of grief begins as soon as a life-threatening illness is diagnosed, with the subsequent concrete or symbolic losses that the illness may bring to the person and the family. Therefore, anticipatory mourning is gradually processed by the family as the individuals experience disease progression and the end of life. Moreover, in this context the family experiences the ambiguity between the threat of losing the child and the need to care for his/her life.

According to Franco (2008), there are facilitating factors in this process of coping with illness, such as an adequate communication between the health team and the family members; a flexible family structure that allows readjusting the roles and participating in the different stages, to achieve a sense of control, knowledge of the symptoms and the progression of the disease, and the availability of informal and formal support systems.

On the other hand, complicating factors such as dysfunctional patterns of relationship, interaction, communication and problem-solving; non-existent or inefficient formal and informal support systems, other concurrent family crises, lack of economic and social resources, poor-quality medical care, difficulties in communicating with the medical team, and the presence of stigmatizing illnesses can compromise the process of mourning.

It is important that the child and the family receive psychological and spiritual support so they are able to redefine life, the process of illness and death. The child should feel that he/she is an important and loved member of the family unit, rather than a burden. The child should be understood, his/her feelings should be listened to, and silence and isolation (conspiracy of silence) should be avoided. After the child's death, the family needs support and time to process it, and the healthcare team should be available and support their grief by offering empathetic spaces for the expression of feelings of grief and the psychotherapeutic work on them.

In this sense, it is part of the work of the palliative care team to:

- Develop interventions to treat the parents' pain and promote coping skills;
- Develop grief support groups to better attend to the needs of parents who have lost their child;
- Value the availability of grief support groups to promote the parents' participation after a child's death;
- Encourage and support acts of kindness from professionals and celebration during the period of mourning.

7 – FINAL REMARKS

Palliative care is an important reality and advance in medicine as a whole. The act of caring for patients, within their limitations and expectations, is pivotal in the assistance to children and adolescents. In addition, participation of the family and multidisciplinary team in the set of actions to be implemented leads to a path where joint actions increase the quality of the assistance provided to young patients, based on the principles of knowledge, respect, and dignity.

The concept of caregiving suggests an idea of being cautious, which means not doing something that could harm someone or something. This is why the concept of palliative care is so noble; it is a human right of great relevance being put into practice. Palliative care encompasses a very important set of technical, scientific, and humanitarian palliative care services that, as shown above, are provided by multiprofessional and interdisciplinary teams. Medicine is obviously part of this multiprofessional and interdisciplinary care.

Resolution 1973/2011 by the Brazilian Federal Council of Medicine (CFM), published in the federal government's Official Gazette, created three new fields of medical practice: sleep medicine, palliative medicine, and tropical medicine. A "field of practice" is defined as a branch of one or more medical specialties.

That CFM resolution associates the field of palliative medicine with the specialties of clinical medicine, oncology, geriatrics and gerontology, family and community medicine, pediatrics, and anesthesiology.

Pediatric palliative care, which is the title of the present article, in addition to being an indispensable field of knowledge, reflection, and ethical and bioethical consensus, is thus regulated in the formal setting of Brazilian medicine.

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