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Dilemmas and difficulties involving end-of-life decisions and palliative care in children

Dilemas e dificuldades envolvendo decisões de final de vida e oferta de cuidados paliativos em pediatria

Adding life to the remaining days instead of days to the remaining life.

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ABSTRACT

This review discusses the main dilemmas and difficulties related to end-of-life decision's in children with terminal and irreversible diseases and propose a rational sequence for delivering palliative care to this patients' group. The Medline and Lilacs databases were searched using the terms 'end of life', 'palliative care', 'death' and 'terminal disease' for articles published in recent years. The most relevant articles and those enrolling pediatric patients were selected and compared to previous authors' studies in this field. The current Brazilian Medical Ethics Code (2010) was analyzed regarding end-of-life practices and palliative care for terminal patients. Lack of knowledge, insufficient specific training, and legal concerns are the main reasons

why end-of-life decisions in terminal children are based on medical opinion with scarce family participation. The current Brazilian Medical Ethics Code (2010) fully supports end-of-life decisions made consensually with active family participation. Honest dialogue with the family regarding diagnostic, prognostic, therapeutic and palliative care measures should be established gradually to identify the best strategy to meet the child's end-of-life needs. Treatment focused on the child's welfare combined with the family's participation is the basis for successful palliative care of children with terminal diseases.

Keywords: Palliative care/psychology; Terminal care/psychology; Intensive care units, pediatric; Parent-child relations; Professional-family relations; Child; Decision making

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INTRODUCTION

The development of medical science in the last 50 years has changed the prognosis and survival for many diseases. New technologies, more effective therapies, new pediatric subspecialties and a growing number of pediatric intensive care units (PICU) and neonatal intensive care units (NICU) have contributed to the survival of children previously considered as not viable. This increased survival rate has led to the emergence of a group of children with chronic diseases and severe sequelae who are dependent on technology and have short life expectancies.⁽¹⁻³⁾ Many of these children eventually require repeated hospital admissions, including in their terminal phase of disease preceding death.

This review article examines the main dilemmas and difficulties involved in end-of-life decisions for children with irreversible terminal

diseases. The last section of this review discusses some crucial phases of pediatric palliative care planning and implementation. Medline and Lilacs databases were searched for articles published within recent years using the terms 'end of life', 'palliative care', 'death' and 'terminal disease'. The most relevant articles involving children were selected, analyzed and compared to the previously published authors' studies. The current Brazilian Medical Ethics Code (2010) was also analyzed regarding end-of-life and palliative care practices for irreversible terminal patients.

Most children's deaths take place in a PICU or NICU or, to a lesser extent, in the surgery or emergency room or in oncology and pediatric wards.^(1,3,4) Although PICUs assist children with a high risk of death, mortality in PICUs is dropping dramatically and is currently between 4% and 10%.^(1,2,4,5) The vast majority of European, Canadian and North American PICU deaths involve some limitation of vital support (withdrawal or non-offer of exception therapies or non-resuscitation), indicating that these deaths were expected and attributed to the natural course of a terminal therapy-refractory disease.⁽⁶⁻⁸⁾ The proportion of limitation of therapy in Brazilian PICUs ranges between 35% and 55%.⁽⁹⁻¹²⁾

Additionally, many children with irreversible terminal diseases who are admitted to PICUs undergo cure-focused therapy (which in this case is unfeasible), disregarding palliative care and effective end-of-life needs.⁽⁶⁻¹³⁾ The difficult management of children's end of life is even more pronounced in Brazil for several reasons.^(6,9-12) First, there may be insufficient teaching and training (either during medical graduation or residency training) in dealing with end-of-life issues, such as bioethical bases, communication skills and assistance strategies. Second, although palliative care was prioritized by the World Health Organization (WHO) more than a decade ago,⁽¹⁴⁾ it has only recently been defined as an operative area in several Brazilian medical specialties (Geriatrics, Oncology, Internal Medicine, and Pediatrics, among others). Consequently, pediatricians, neonatologists and pediatric intensive care specialists do not receive this training, and their activity is limited to the limits of curative medicine, even when ineffective. Finally, due to a lack of knowledge, some physicians question the ethical and legal support for providing palliative care and limitation of therapeutic effort in terminal patients.

End-of-life needs in children and provisions for palliative care

Reports from families of children who died in PICUs describe the difficulties they experienced during their children's last moments. Meyer et al. described six priorities reported by parents of children who died in three U.S. PICUs (Table 1).⁽¹⁵⁾

Table 1 – End-of-life priorities reported by 56 parents of children who died in three U.S. PICUs

Priority	Quotation
1. Complete and honest information	<i>'We have to manage a situation we have no idea where is going to'</i>
2. Regular and easy medical access	<i>'Please, give us a regular time for reaching and talking to the assisting doctor(s)'</i>
3. Coordination of communication	<i>'There are many doctors explaining different things'</i>
4. Emotional involvement and signs of solidarity from the team	<i>'We need to feel that the team really cares, and that it is not only about a job'</i>
5. Preservation of the integrity of the parent/child relationship	<i>'Show compassion for parents and child's needs'</i>
6. Spiritual support (faith)	<i>'Then I seriously doubted my faith'</i>

Modified from Meyer et al.⁽¹⁵⁾

These results are similar to the findings of a recent study involving parents of 34 children who died in two PICUs in Porto Alegre.⁽¹⁶⁾ Among other results, we highlight the following: a) a lack of accurate disease and prognosis information; b) unilateral decisions based exclusively on the physician's opinion with no opportunity for parental participation in therapeutic decision discussions; c) a hostile environment, with excessive technology and lack of human solidarity; d) excessively rigorous and unalterable routines with no consideration for the child's minimal needs at the end-of-life time (e.g., prohibiting visits from a younger brother/sister or a schoolmate).

The WHO's current palliative care concept is 'an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.⁽¹⁴⁾ The WHO emphasizes that palliative care for chronically ill children and their families includes

‘active total care of the child’s body, mind and spirit, and also involves giving support to the family. It begins when illness is diagnosed, and is incremented as the condition worsens, being concomitant with curative care. Healthcare professionals should evaluate and relieve a child’s physical, psychic and social stress; this requires a multi-professional approach, which includes the family, including available community resources.’

A determining aspect of palliative care in children is that children are markedly different from adult patients in several ways:⁽¹⁷⁻²⁰⁾ a) several illnesses are age-specific, with (consequent) specific requirements; b) high emotional dependency and an immature personality to face the consequences of a fatal disease; c) developing physiological compensation mechanisms; d) different reactions to pain and anxiety; and 4) specific metabolic requirements and pharmacokinetics in each developmental phase. Thus, the use of adult palliative care guidelines is neither applicable nor sufficient for children’s needs.⁽¹⁷⁻²⁰⁾

Until very recently, it was understood that palliative care should be offered only when death was imminent.^(1,4,9,21,22) Therefore, curative and palliative care have been placed on opposing and mutually exclusive poles. As knowledge has increased regarding care for technology-dependent children with progressive, debilitating diseases and for acute but therapy-refractory cases, these therapies have come to be seen as complementary and integrated (Figure 1).⁽¹³⁻²¹⁾

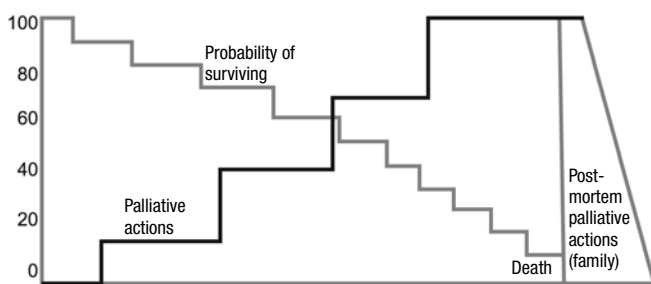


Figure 1 – Illustration of palliative care in children, considering the disease prognosis until the time of death. Please note that even after the death, palliative actions are implemented to support the family.

Even in developed countries, it has been shown that palliative care is often requested late and for a small portion of suitable candidates. In a study involving children younger than one year old who died in PICUs and NICUs, palliative care was

requested and provided approximately 2.5 days before death and in less than 15% of cases.⁽²¹⁾ To address this issue, in 2000, the American Academy of Pediatrics emphasized that ‘general pediatricians and respective pediatric subspecialties should be familiarized and trained to provide palliative care to children under their responsibility’.⁽¹⁷⁾ The American Academy of Pediatrics and the WHO proposed that the model for children should simultaneously adopt curative and palliative care (as proposed in Figure 1), including physical, psychological and spiritual care. This involves multidisciplinary care including physicians, nurses, social assistants, chaplains, physiotherapists and occupational therapists.^(14,17) The goal is to offer better quality of life for patients and their families that is consistent with the best medical science has to offer and to meet their values and needs.^(14,15,17-20) Furthermore, palliative care should be extended beyond the child’s death, as the family will need support in the subsequent days and months. In the above-mentioned studies⁽¹⁶⁾ and in similar studies,⁽²³⁻²⁶⁾ the parents reported feeling reassured and comforted by returning to the hospital to discuss unclear details related to their child’s death with the medical team.

Ethical support for limitation of therapeutic effort in irreversible terminal disease patients

Some physicians express their fears and misconceptions regarding the legality and legal support for limiting curative therapeutic effort in case of terminal irreversible and progressive disease.⁽²⁷⁾ They understand that limitation of therapeutic effort in this group of patients may represent an infraction of certain articles in the past (1988) and current medical ethics code (2010), such as Article 1 (*The physician cannot harm a patient either by action or omission possible to be categorized as malpractice, imprudence or negligence*) or Article 32 (*The physician cannot fail to use all scientifically acknowledged available diagnostic and therapeutic resources to favor the patient*).⁽²⁸⁾ Obviously ‘favor the patient’, as written in Article 32, is related to ‘interventions which are beneficial to the patients in their specific disease status, and not a compulsory act to offer everything that is available’.

To clarify this and other doubts, the current Brazilian medical ethics code (2010) made explicit in several articles and clauses the doctor’s ethical duty to provide palliative care for patients with incurable and terminal disease, as in Chapter 1 – Clause XXII (*In irreversible and terminal conditions,*

the physician should refrain from using unnecessary diagnostic or therapeutic procedures, and provide patients under his responsibility with all appropriate palliative care). Article 36, Paragraph 2 prohibits doctors from abandoning their patients (*Except for legitimate reason, communicating the patient or family; the physician shall not abandon a patient for having a chronic or incurable illness, and will continue to assist the patient, even if for providing palliative care*). Article 41 emphasizes that a doctor is 'Prohibited of shortening the patient's life, even upon request of either the patient or family', but it adds: 'In cases of incurable or terminal disease, the doctor should provide all available palliative care, without insisting on useless or obstinate diagnostic or therapeutic measures, always considering the patient's expressed will or if incapable, legal representative's will'.⁽²⁸⁾ Therefore, when a doctor is responsible for terminal irreversible disease patients, it is the doctor's duty to avoid therapeutic obstinacy as well as to offer palliative care. Failing to comply with this guideline in such a situation is effectively an ethical fault.

Additionally, it should be noted that in Article 41 of the above-mentioned current ethics code and in many others (Articles 24 and 34; Clause XXI), it is emphasized that this is a shared decision involving the patient and family (as in the case of children and incompetent patients). Decisions exclusively centered on the medical team are not allowed. These decisions should be appropriately and clearly recorded in the patient's medical chart.

Palliative care for children: planning and choosing

Palliative care for children is progressively implemented and adjusted to the needs imposed by the disease and its therapy (progression, complications, limitations) and should be customized for each specific child (adjusted to the binomial family/child values and wishes). Figure 2 represents some phases in the planning and implementation of palliative care for children.

Some fundamental phases in planning and successfully implementing palliative care for children include the following:

a) Understanding the disease, the available therapy and possible limitations

Ultimately, the possibility of cure in a given child is estimated. Several prognosis scores have been shown to be very sensitive and specific for groups

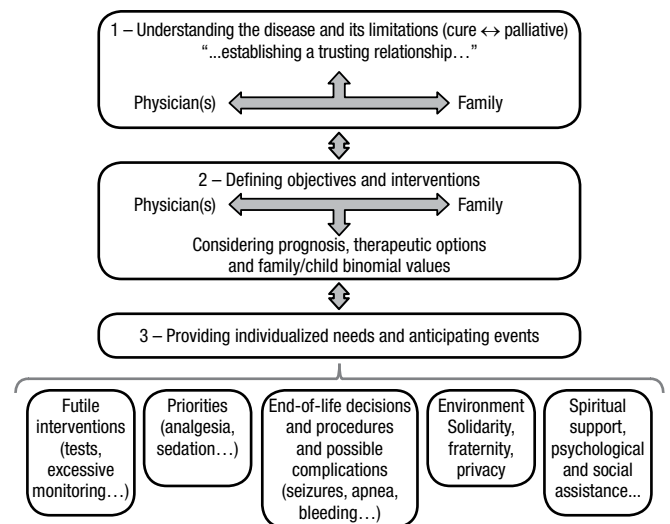


Figure 2 – Illustration of the phases involved in palliative care for children.

of patients but are not sufficiently specific (safe) when used for a single individual.^(1,10,13,18,29,30) The degree of reversibility of a disease is based on both objective information (e.g., computed tomography, pathologic anatomy reports, etc.) and subjective information (response to therapy, clinical staging, previous experience, prognostic scores in similar case reports).^(10,22,29) From this set of data, a consensus is established among the medical team on the potential disease reversibility of that specific patient.^(10,13,22,29)

A consensus on irreversibility is frequently a slow process among the medical team. Antagonistic information and conflictive perspectives of medical team members on therapeutic possibilities may become disaggregating issues and cause anxiety that influences long-term decisions. Therefore, this uncertainty should not be extended to the family before a consensus is reached within the medical team.^(10,22,29)

As a consensus is established by the medical team, the family is progressively involved in the decision-making process through honest, objective and calm discussion. Regardless of their educational levels, family members want to be heard, to understand and to participate in decisions related to their child's end of life. However, the family, like the medical team, needs time and information to be convinced that the condition is irreversible or does not respond to therapy or that the disease is terminal. To facilitate this process, the medical team should maintain an environment of trust, respect, and solidarity that contributes to understanding. This is the time to

hear and answer as objectively, directly and simply as possible the family's questions, avoiding technical language and vague statistics that do not contribute to this time. It should be clear that each person (or family) requires different times to understand the situation.^(10,13,15,22-26, 29)

Conflict during this time is almost a rule. It is not surprising that rage and despair are directed at the messenger of ill tidings. This feeling is transient, but it may be prolonged if the medical team responds aggressively or indifferently.^(10,13,15,16,23-26,31) To help during this crucial and sensitive time, the team should be kind and solidary; they should avoid responding to provocations and keep the focus of discussion on looking for the best to meet that child's needs in that situation. As the family realizes that this is the medical team's objective and motivation, the relationship progressively changes to one of trust and participation.^(10,22,29,31)

It is expected that the family's understanding of the irreversibility of the condition will advance and retreat. The progression is slow, and the status of the disease has to be confirmed repeatedly through tests or clinical evidence. Until this understanding is achieved, it is impossible to progress to a discussion that defines curative and palliative therapy priorities.^(10,22,29)

b) *Definition of objectives and medical interventions.*

The family is obviously grieving their child's irreversible disease and imminent death. Support and help in discussing curative and palliative therapy must be offered.^(10,15,22-26) A frequent mistake involves a unilateral decision by the medical team limiting the life support to be offered without family involvement in the decision-making process. In studies conducted in Brazil, the involvement of the family in end-of-life adult and pediatric patients' decision-making process ranged from 8% to 50%.⁽⁹⁻¹²⁾ An example of this negligence was mentioned in a testimony collected in a recent study involving a Porto Alegre (Brazil) PICU:⁽¹⁶⁾

[...] Actually, they asked me, but just communicating. After they explained, asked if I had any objection... But they didn't really ask, they just told me what was about to be done [...]

On the other hand, the opposite must also be avoided. The vast majority of families want to be heard, but they do not want to be in control or responsible

for the final decision on each therapeutic measure.⁽¹⁵⁾ The medical team's skill in conducting this discussion may represent the difference between the family's peace of mind (understanding that the best available treatment was offered for their child's last moments) and permanent guilt (feeling responsible for their loved one's suffering and death).^(10,22-26,29)

The medical team should conduct the discussion through an honest dialogue in an environment of trust, solidarity and understanding, where the advantages and disadvantages of each therapeutic option are presented.^(10,13,15,17,29) It is crucial that the medical team hear and understand the family's (conscious or unconscious) values and priorities to guide and motivate their decisions. With this information, the most appropriate therapeutic options can be selected and suggested to meet the needs of the family and the child. At that point, the transition from curative to palliative care is begun.^(8,10,23-26,29,31-35)

c) *Provide individualized needs and anticipate events.*

Palliative care is instituted that considers the disease status (progression, possible complications, short- and long-term prognosis) and adjusts to the family/child's values and expectations:

i. *Identification and exclusion of futile interventions.* These interventions do not contribute to disease control or to improving the patient's quality of life.^(8,10,13,18,21,29,34-36) They should be evaluated on a case-by-case basis. How necessary are daily laboratory tests? Is there a rationale for invasive monitoring? Is it necessary to measure vital signs hourly and disturb sleep? Are inotropes and vasopressors actually necessary now? What is the benefit of antibiotics, antifungals and leukocyte-stimulating factors?

ii. *Therapeutic priorities.* Therapeutic interventions (curative or palliative) appropriate for each case should be defined. Early tracheostomy can be a priority to avoid long-term use of a tracheal tube and excessive sedation. There is no standard list of which interventions are effective or futile. This decision is made on an individual, case-by-case basis, considering all issues involved in the disease (the stage and benefit of each given intervention in terms of cure, progression and delay or quality of life) in combination with the family/child's expectations.

As 'care' becomes the priority, analgesia and sedation receive special focus.^(4,8,10,13,18,19,29,36-38) Analgesia may be maintained with intermittent use of con-

tinued opioid infusions (morphine, fentanyl) and non-opioid analgesics (metamizole, acetaminophen, ibuprofen). For interventions that cause pain (e.g., tube replacement, change of decubitus, tracheal aspiration), a supplemental dose of another short-acting analgesic (e.g., ketamine) can be added. Some advanced diseases (such as tumors with bone metastasis) require progressively more analgesics. In such cases, from ethical, moral and legal points of view, fear of side effects should never prevent the use of increasing analgesic doses.^(7,8,10,13,18,19,24,35-37)

Frequently, due to prolonged opioid use, even small children may not achieve appropriate sedation (leading to sleep deprivation) or may have psychomotor agitation.^(8,10,18,37-39) For appropriate sedation, mild sedatives (diazepines, chloral hydrate, promethazine), anti-psychotics (haloperidol and/or risperidone) or even continued dexmedetomidine infusion may be used.^(38,39)

iii. Anticipated end-of-life decisions and possible interurrences. Doctors with experience in the care of severely ill children may anticipate disease complications or manifestations. The interventions for these events should be discussed in advance with the family and this therapeutic plan recorded in the medical chart. The management of situations such as seizure, worsened respiratory conditions and/or apnea and digestive bleeding should be agreed upon in advance with the doctor on duty.^(8,10,29,32,34,35,40,41)

Because there is no specific recommendation in the medical ethics code, end-of-life directives (such as non-resuscitation or not implementing some therapies) should be appropriately recorded in the medical chart⁽²⁸⁾ as well as measures to be adopted instead of these procedures (e.g., for worsened dyspnea, non-invasive ventilation (with previous definition of the respective parameters) associated with increased opioid dose to reduce discomfort and ease non-invasive ventilation cycling).^(7,8,10,28,29,37,40,42)

iv. Environmental changes. Obviously, this is a very stressful time for the child, family and healthcare team. Keeping the family in a private room, possibly with natural light and ventilation, and away from the noise of the ICU is a priority.^(4,13,15,16,18,24,32-34,39) Helpful measures may include allowing some objects the child values (e.g., videogames, computer, portable music device), encouraging family visits and interactions, and allowing the child out of bed.^(8,17,24,32,39,43)

v. Multidisciplinary team involvement. Palliative care is based on active, multidisciplinary team

participation, which varies according to the site and situation.^(4,15,17,18,20,21,32) In addition to physicians and nurses involved in the child's care, active participation is required in the form of social assistance, psychological and/or psychiatric support, spiritual support (support groups, priests, chaplains, rabbis), occupational therapists, and teachers (music, recreation), among others.^(4,15,17-19,23,43)

Over time, the multidisciplinary team becomes part of a 'big family', so their visits and support to the family and child are important and expected. Each team member should understand that any small gesture will strengthen the family and child and be cherished forever.^(15,23-25,34-36) The testimony below, from a recent study involving parents of children who died in two of Porto Alegre's (Brazil) PICUs, clearly shows the importance of the team's caring attitude:⁽¹⁶⁾

[...] the nurses there, so sweet, cared for us and supported me; this was a painful time... but their attention helped me the most [...].

On the other hand, a team that is unprepared to deliver bad news, has difficulty dealing with the complexities of this time or exhibits behavioral lapses may leave permanent scars on the family. An example of this lack of preparedness was reported in the testimony of a parent whose child died in one of two studied PICUs:⁽¹⁶⁾

[...] They just got in and out the room as if there was nobody there. The day of the death was the same. They just delivered the news, looked at us saying that nothing else could be done... then just turned back and went away talking on the ring she was about to buy! [...]

The family's fragility in this time of loss is evident, requiring solidarity, respect and comfort from the entire PICU team. Therefore, any person entering the room (including cleaning and nutrition teams, nurses, doctors, laboratory staff, X-ray technicians, etc.) should maintain an attitude of solidarity, respect and spiritual support.^(14,17-19,23,43)

vi. The child who faces a terminal disease phase. We have learned that adults 'recede' when severely ill, becoming needy, insecure and highly dependent on their partners and families. Insecurity and dependency on the family is characteristic of children and obviously reaches very high levels in this situation.⁽³⁹⁻⁴³⁾ However, children have a very peculiar way of interacting with their environment. Instead of dialoguing, they interact through gestures, games and attitudes. Therefore, a child who suffers a series of aggressive treatments (venous/arterial punctures,

tubes, mechanical ventilation) and sees everyone around them in a reserved mood (including their parents) clearly understands that ‘there is something wrong’.^(8,19,24,32,39,40,43) Consequently, the child interacts less (with an effect on nutrition), becomes passive (suffering progressively more in an attempt to ‘not show pain’), may refuse to cooperate with the therapy and frequently assumes guilt for what is ‘wrong’. This vicious circle should be averted.^(8,19,24,28-30,32,37-39,40,43)

The environment should be as favorable as possible. The parents, the family, and the entire team should be sources of confidence, spiritual support and solidarity. We have noted that children in a favorable environment are able to bravely overcome the difficulty of their last days. They allow themselves to interact until their last moments.^(14,17,18,19,23,32,34,43)

A question to be answered is when the terminality of the disease should be discussed with a child. The American Academy of Pediatrics recommends, whenever possible, including the patients in the discussion.⁽¹⁷⁾ Healthcare professionals, parents and/or caregivers should have a sufficiently rational discussion to avoid causing harm or psychological stress in children with life-limiting diseases. The child or adolescent’s age and cognitive development should be considered. Obviously, each therapy to be implemented should be explained and ‘demystified’.^(17,19,24,26,31,32,34,39)

Communication with children has a special complexity. Children and adolescents do not usually manifest their curiosity using words, but by means of similar situations (stories) or playing ‘games’. Therefore, the parents and the medical team should ‘feel the ground’, identifying (and decoding) and discussing children’s questions while taking the ‘magical’ childhood universe into consideration. Detailed explanations should be avoided, as these generate more anxiety, fear and fantasies. The responses should stay within the child’s apparent limits.^(4,13,15,17,19,20,24,32,34,39)

vii. *Support to the family after the child’s death.* This palliative care action has received little attention, but several reports in the literature show the families’ deep need for support.^(15,17,23,25) In interviews with the parents of 34 patients who died more than 6 months earlier in two of Porto Alegre’s (Brazil) PICUs, a significant portion reported that⁽¹⁶⁾ a) they felt comforted and valued by being able to discuss their children’s death with the attending doctors; b) these new discussions helped them to better understand and proceed in their mourning; c) they understood

this initiative as evidence that ‘the best was done for their child’; d) even having experienced this terrible time, they believed that they should contribute (by taking part in the study) to the improvement of end-of-life children’s care.

After the death, special attention should be given to the healthcare team itself. Some days later, a meeting should be held where the members of the team can express their feelings and criticism on the care offered. This meeting helps with mourning and is an opportunity to improve the palliative care. If the hospital has a bioethical and/or palliative care committee, it is highly recommended that they coordinate or actively participate in this meeting.^(14,18,20,21,25) Some studies have shown that young physicians and residents report important benefits from these meetings.⁽⁴⁴⁾

It may be concluded that, despite current advances in medical science, our main commitment remains the same as we swore at our graduations: *‘I will provide therapy for the patient’s good, according to the best of my understanding, and never to injure or harm anyone’* (Hippocrates ~460 BC). We were not considering only curable patients; we also swore this oath to care for patients with irreversible diseases with no chance of a cure. Society expects pediatricians, neonatologists and pediatric intensive care specialists to use their knowledge, leadership and reputation to provide palliative care strategies to moribund patients, relieving their suffering, respecting their dignity and meeting their needs within the best scientific and ethical parameters.

RESUMO

O objetivo deste artigo é discutir os principais dilemas e dificuldades nas decisões de final de vida de crianças com doença irreversível em fase terminal, assim como, propor uma sequência racional para a instituição de cuidados paliativos nesse grupo pediátrico. Foi realizada busca na base de dados Medline e Lilacs dos artigos publicados nos últimos anos tendo como palavras chaves “final de vida”, “cuidados paliativos”, “morte” e “doença terminal”. Foram selecionados os mais relevantes e aqueles envolvendo crianças, os quais foram analisados em conjunto com publicações prévias dos próprios autores sobre o assunto. O atual código de ética médica brasileiro (2010) é analisado em relação às práticas de final de vida e cuidados paliativos ofertados a pacientes com doença fase terminal e irreversível. A falta de conhecimento e treinamento aliado a receios legais são os principais motivos para que as decisões de final de vida em crianças com doença em fase terminal sejam centradas

na opinião médica e com escassa participação da família. O atual código de ética médica dá pleno suporte para essas decisões desde que tomadas de forma consensual com participação da família. O diálogo franco com familiares em relação ao diagnóstico, prognóstico, terapêutica e cuidados paliativos devem ser estabelecidos gradualmente, para definir a melhor estratégia que atenda às necessidades da criança em fase final de vida. O tratamento centrado no

bem estar da criança com pleno envolvimento da família é a base para o sucesso do tratamento paliativo em crianças em final de vida.

Descritores: Cuidados paliativos/psicologia; Assistência terminal/psicologia; Unidades de terapia intensiva pediátrica; Relações pai-filho; Relações profissional-família; Criança; Tomadas de decisões

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