Ethics related to therapeutic decision in cases of extreme prematurity

Andrezza de Lemos Bezerra [1], *Giselle Machado Magalhães Moreno* [2], *Adriana Carla Costa Ribeiro Clementino* [3], *Anna Paula Chaves Chagas* [4], *Isis Suruagy Moura* [5], *Josimário Silva* [6]

Abstract

Limits of viability for premature infants and survival with minimal consequences are current themes of great importance for ethics and bioethics. Extreme prematurity may result in many consequences and chronic injuries that limit the infant functionality. When prolongation of a very immature newborn's life is opted, there is a greater exposure of premature infants and their family to pain, distress and physiological stress situations. The present review approaches ethical aspects related to this decision-making, considering the limit of viability and neuromotor sequelae derived from extreme prematurity. At present, it is considered not only the survival of extreme premature infants, but also the maintenance of their quality of life, since they are more likely to have sequelae at short, median and long time.

Keywords: Premature infant. Ethics. Extremely low birth weight infant. Child development.

Resumo

Ética na decisão terapêutica em condições de prematuridade extrema

Os limites de viabilidade na prematuridade e a sobrevivência com mínimo de sequela são temas atuais de grande importância ética. A prematuridade extrema pode resultar em inúmeras sequelas e danos crônicos que limitam a funcionalidade. Ao se optar pelo prolongamento da vida de recém-nascidos muito imaturos, há maior exposição do prematuro e da família a situações de dor, desconforto e estresse. A presente revisão trata dos aspectos éticos relacionados a essa tomada de decisão considerando o limite de viabilidade e as sequelas neuropsicomotoras decorrentes da prematuridade extrema. Atualmente, a questão gira em torno da importância da valorização não só da sobrevivência desses prematuros, mas também da manutenção de sua qualidade de vida, uma vez que são mais predispostos a sequelas em curto, médio e longo prazos.

Palavras-chave: Prematuro. Ética. Recém-nascido de peso extremamente baixo ao nascer. Desenvolvimento infantil.

Resumen

Ética en las decisiones de tratamiento en condiciones de prematuridad extrema

Los límites de la viabilidad de la prematuridad y la supervivencia con secuelas mínimas son las principales cuestiones éticas de actualidad . La prematuridad extrema puede dar lugar a numerosas secuelas y daños crónicos que limitan la funcionalidad. Cuando se opta por la prolongación de la vida de los recién nacidos muy inmaduros, aumenta la exposición del prematuro y de la familia a situaciones de dolor, malestar y estrés. Esta revisión discute los temas éticos relacionados con esta toma de decisión teniendo en cuenta el límite de la viabilidad y las secuelas neuropsicomotoras como consecuencia de la prematuridad extrema. En la actualidad, la cuestión gira en torno a la importancia de valorar no sólo la supervivencia de los bebés prematuros, sino también el mantenimiento de su calidad de vida, ya que son más propensos a las secuelas en el corto, mediano y largo plazo.

Palabras-clave: Prematuro. Ética. Recién nacido con peso al nacer extremadamente bajo. Desarollo infantil

---

1. **Doutoranda** alemos4@gmail.com 2. **Doutoranda** gisellemachado_mm@yahoo.com.br 3. **Doutoranda** aribeiro@hotlink.com.br 4. **Doutoranda** annachagas@hotmail.com 5. **Doutoranda** isis_suruagy@yahoo.com.br 6. **Doutor** josimario.bioetica@gmail.com – Universidade Federal de Pernambuco, Recife, PE/Brasil.

Correspondência
Andrezza de Lemos Bezerra – Rua do Espinheiro 685/1.602, Espinheiro CEP 52020-020. Recife/PE, Brasil.

Declaram não haver conflito de interesse.

Palliative care (CP) are a set of practices and discourses facing the final period of life of patients with no therapeutic possibilities of cure. This new health specialty reflects the paradigm shift and concepts on the human body, illness and death [1]. The CP does not have curative purpose or seek to extend or advance the death of the patient, since its focus is to control signs and physical and psychological symptoms own advanced stage of the incurable disease and improve quality of life [2.3].

According to the World Health Organization (WHO), in concept defined in 1990 and updated in 2002, palliative care consist of active and comprehensive care to patients whose disease no longer responds to curative treatment. The main objective is to ensure better quality of life both for patients and their families. Palliative care is intended to control the pain and other symptoms, preventing the patient from suffering [4].

The practice is still little discussed, and even neglected in many countries. It is necessary determination and social policy, in order to create public policies and introduce practices for offering well-being and quality of life for these patients as well as to provide them with full and dignified care as much as possible until the end of life [5]. Take care of these patients involves acts of responsibility, solidarity and dedication, as well as skills and abilities concerning the interpersonal relationship. It is important that, in its operations, health staff to recognize the individual who will provide assistance - what are your needs and limitations - enabling thus adopt conduct humanistic and sensitive to it [6].

It is necessary, therefore, to think the assistance and care from the construction of new meaning to these terms, more comprehensive and integral, which can overcome the dominance of mechanized practice and recover the value of human existence. In a world devoted to the care, the attention paid to the individual considering how to act, think, feel and express [7].

In view of the professional-patient-family relationship, the focus of care should not be directed only to the person terminally process, but the whole family group [8], since the family must also be careful, given its auxiliary role in patient care activities. Therefore, we can say that at that stage, the health team must also look back to the family that prepares to lose your loved one [9].

Considering the problems that arise with the care at end of life, exposes the need to deepen the debate about the proximity of death and human terminal illness, in order to assess the evolution of practices of society and ethical conduct of health professionals with respect to palliative care. This debate is motivated by the possibility of giving greater visibility to the theme in order to provide theoretical basis for the construction of arguments that condigam with the incorporation of bioethical references.

Method

This is a literature review study conducted by specialized literature survey on “palliative care”, “bioethics”, “terminal care”, “death” and “regret”. Various databases were used, as Brazilian and foreign bibliographies, which included not only published books and articles, but also academic works. In databases the above descriptors were explored. In terms of the cut needed for the construction of this scientific work, it was decided to not define the timeframe, as palliative care is relatively new topic in the history of public health.

Palliative care: brief digression

For a long time, patients out of therapeutic possibilities of cure were forgotten by the health services, since the biomedical model, widely used at the time, did not care about the quality of life of patients, whereas the main focus of medicine was in healing the sick [10,11]. The effects of this reductionist conception of biomedical paradigm brought up ethical questions about the care provided to terminally ill, which led to the emergence of social movements for death less painful, more dignified and with greater autonomy for the patient, thus allowing development of palliative care [10].

Palliative care developed largely due to the excesses committed by tecnologicista medicine, leading the patient to a final medicalized life and full of suffering, as opposed to the quality of living. The process of growing medicalization of death in the cold environment of hospitals established what critics of “modern death” and palliative care often called “therapeutic cruelty”. This situation is related to the ideas of “futility” and “therapeutic obstinacy”, used to define the excess of technological resources, apparently with curative purposes, who value the continuity of life of the patient, even if it brings the effect of increasing its suffering [12].

Considering the above, it is understood that for a long time, health professionals had attitudes rather sedimented in a mechanistic conception of life, which is why you can now observe the numerous difficulties in recognizing the complex and multidimensional reality of health care. It was precisely this mechanistic thinking that led to the biomedical model, according to which the body was seen as machine and the disease, as damage to the machine, and doctor's exclusive function repair / heal the damage caused [13].

Faced with the challenge of the growing medical power conveyed by the movement in defense of euthanasia and criticism of the "therapeutic cruelty" of patients, practitioners were taken to position itself on the production from the care given to the patients, so that palliative care have grown in significance [12]. However, Pessini [14] states that the care provided to patients without therapeutic possibilities of cure occurs since antiquity. According to him, the first records of palliative care date back to the fourth century of the Christian era. However, care for the dying distinguished considerably the CP we know today.

At that time, assistance to people in the final stage of life was based on hospitality and mercy practiced by ordinary citizens. Only later this characteristic of hospice movement of antiquity was taken over by the Church, which started to take charge of caring for the poor and sick, a fact that continued throughout the Middle Ages [14].

It was only in the twentieth century that palliative care became institutionalized model of health care. This occurred in London, England, with the creation in 1967 of the first modern hospice - the St. Christopher Hospice - the nurse, doctor and social worker Cicely Saunders. Considered a pioneer in palliative care, she has devoted his working life to cancer patients in the terminal phase, in order to give them a dignified death, spreading the concept of caring and the proposal to keep the focus on the patient's needs until the end of his life [12.15].

Before St. Christopher foundation existed other hospices for the terminally ill. However, in them there was concern for the relief of suffering or with improved quality of life of the sick, whose suffering (physical, psychological, social and spiritual) were often ignored by the staff who attended the [16.14]. Thus, palliative care emerged over time as a result of broad changes in social relations and representations of the death and dying process, as well as due to changes inherent in the medical field [12].

Initially, the practice was almost restricted to cancer patients and terminals; however, in the late 1980s, the CP gained visibility and became key issue of public health, including those with an illness that causes severe pain and other physical, emotional or spiritual symptoms that acarretassem suffering and that would make the life intolerable [6.12]. In 1990, WHO defined palliative care, emphasizing and facilitating their application. In 2002, the concept was reviewed and its definition, readequada the new perception of the dying process [4].

In Brazil, Rio Grande do Sul was the first state to have the Palliative Care Service [12]. But only in 1997, with the founding of the Association of Palliative Care (ABCP), took up the initiative to introduce and promote the CP by training health professionals [17]. the following year, the Ministry of Health launched the National Cancer Institute (INCA) its first Hospital Palliative Care Unit, whose philosophy was later expanded to other institutions and states [18,19]. In 2005, a group of doctors founded the National Academy of Palliative Care (PCNA), in order to stimulate the performance of palliative care professionals in the country [17]. And December 12nd, 2006, the Technical Board was established in Pain Control and Palliative Care by the Ministry of Health [20].

Although the history of palliative care is relatively recent in Brazil, the trajectory of this discussion has contributed to the knowledge of health professionals on the philosophy provided to patients no healing prognosis, thus favoring the care process and valuing human.

Nearness of death and the human terminal illness

To Eizirik, Kapczinski and Bassol [21], death is the power over which we have no control; is for us indomitable and unknown. It is also a social fact inherent in human life, as well as birth, hunger, thirst, sexuality, laughter, and as such, has meanings that go beyond their representativeness [22].

The word "terminal" has many meanings. One of them relates to the patient which is *the final stage of a disease, so near death* [23]. Borges et al [24], the perception of death in the patient's vision of the terminal is different in each stage of the life cycle. According to the authors, childhood, death can be represented as are modified thought and language. For the adult, death may depend on the physical and psychological experience that is going on. Already, for the elderly, death can be configured in the prospect of greater resignation.

Most people are not prepared to face death, including patients and their caregivers. The lack of knowledge about aspects related to end of life can make assistance to terminally ill patients a terrifying experience for many professionals. And the younger the patient, the more difficult to handle the situation. Death is "expected" event for the elderly and therefore, the degree of acceptance of death in these patients is greater, because it is regarded as the final stage of the life cycle [25].

Death did not reach the healthcare team in the same way because of the perceived loss is determined by such factors as age, condition and death primarily by the degree of involvement with the patient [26]. However, although death is part of the context of life and routine of the hospital environment, the members of the multidisciplinary health team - in general - are not prepared to face death and deal with the loss of patients. Only safe individuals in relation to their feelings, and natural attitudes toward life and death, have reached the stage that gives them understanding capacity to assist others [26].

As support Costa Lima and [27], so you can give appropriate assistance to terminally ill patients, it is necessary to understand the reactions and behaviors that both patients and family members can come before the approach of death. The patient may react in various ways regarding their disease and terminal illness of his life. You can either accept or deny; may have the knowledge that is dying, but emotionally feel unable to accept; or you can accept it, but can not verbalize the situation [28].

According to Kubler-Ross [25], the diagnosis of a terminal disease is potentially a psychological factor disintegration, causing patients and family members undergo some stages emotional traits. Without necessarily be a linear process, strict sequence, as not all patients experience it in the same way], the stages systematized by Kübler-Ross for monitoring the process of dying of terminal patients, alleviating their suffering.

First stage: denial and isolation

Denial is temporary defense mechanism in the face of death. This occurs more often at the beginning of the disease, and patients and families who are prematurely informed of your diagnosis. The intensity and duration of this stage depends on the patient's ability, and other people living with him, to deal with this pain. In general, the denial does not persist for long. However, some patients may never exceed this stage, going from doctor to doctor, to find someone to assist it in its position. The wisest thing would be to talk about death with patients and families before it occurs and in fact since the want, because it is easier for the family to discuss these matters in times of relative health and well-being of the patient. Moreover, postpone this conversation does not benefit the patient in any way.

Second stage: anger

This stage may be related to impotence and lack of control over one's life. It is very difficult to deal with the patient at this stage: it demands, rebels, calls continuous attention is critical and has behavioral explosions if not met or feel misunderstood and disrespected. It is important that at this stage there is understanding of others on anxiety turned into anger in the patient who had to stop the activities of your life because of illness. Patients in this stage are difficult to treat. Generally rebel against God, fate or someone close. A common question is "*Why me? Why is this just happening to me?* ". Thus, the management of patients who are at that stage involves understanding that expressed anger can not be seen as something personal [29].

Third stage: bargaining

In this phase, the patient usually tries to negotiate with God implicitly or even doctors, going into some sort of agreement to postpone its inevitable outcome. Patients believe that, by being obedient, cheerful and not questioning, the doctor will make better. Normally, the person who is in this stage performs promises in secrecy, with the possibility of being rewarded for their good behavior. In general, the patient remains serene, reflective and docile [29].

Fourth stage: depression

This phase occurs when the patient is terminally ill and is aware of his physical weakness; therefore, can no longer deny his illness. At this stage, the individual is often forced to submit to another hospital or other surgery. Here depression takes characteristic clinical picture: discouragement, disinterest, apathy, sadness, crying etc. Previous attempts did not work: deny to no avail; It revolt and make bargains, either. Thus, you should leave it free to express his regret and so accept the situation more easily [25]. The patient is about to lose everything and all who love, so it is important to pass the final moments with their families and loved ones.

Fifth stage: acceptance

Kübler-Ross [25] comes to the conclusion that, in the last stage, patients who have had the disease and were supported can get to that stage accepting the process. Most of the time, the patient expresses great tranquility and can remain silent. No longer experiences the despair or reject your reality. This is the time when the family will need more support, help and understanding, and the responsible staff to be aware of the stage at which the patient is going through.

It is important to know the main factors involved in the process of becoming ill and dying. You can not give up the treatment of the patient, because, feeling abandoned or unattended, he surrenders and gives up too. The patient will feel comforted to know that was not forgotten, even when there is nothing else to do for him [7]. At this point, palliative care will meet the needs of terminal patients, since they may, instead, minimize pain and suffering, and at the same time meet their basic hygienic needs, nutrition and comfort, helping you to maintain your dignity as a person.

Bioethics and legal aspects of death

The most appropriate situation for the conduct of the end of life is directly related to the human dignity and respect for their decisions about the process of death and dying [6]. According Fabriz, although the right to life constitutes inviolable prerogative, should always be seen in the light of the principle of human dignity: *if life is a fundamental assumption, major premise, dignity is absolutizes due to a life that is only significant if worthy* [30].

In turn, Kloepfer [31] states that the right to life is, above all, the right to live. It covers bodily existence, biological and physical existence, which is vital prerequisite to enjoy all fundamental rights. Protection refers here to the individual life, not just human life in general. Life is understood, then, in purely biological and physiological sense.

The issue about the end of life, which mainly involves the definition of the treatment of terminal patients and the process of death and dying, implies ethical dilemmas and impasses of a legal, causing not only health professionals, but also students of several areas, and even the lay public, think critically about the ethical and legally appropriate course of action before the terminal illness of human life [32].

Bioethics is defined as transdisciplinary nature of reflection, focused primarily on the phenomenon of human life on the great advances in technology, biomedical sciences and care for the health of all people who need it, regardless of their social condition 33. The principialism is the most widespread current study of bioethics. According to Diniz and Guilhem 34, was with the publication of the book "Principles of biomedical ethics" by Beauchamp and Childress [35] that bioethics has consolidated its theoretical strength by proposing four guiding principles of the health professional: autonomy, beneficence, non-maleficence and justice. Also according to Diniz and Guilhem [34], the work represents the first *successful attempt to manipulate the dilemmas related to moral choices people in health and disease,* considering the approach to the patient and the decisions to be taken in relation to your situation.

The principle of respect for autonomy is the most relevant to bioethics, assuming that, for the exercise of morals, the existence of autonomous person is required [34]. The principle of beneficence is what establishes the moral obligation to act for the benefit of other. In the area of biomedical sciences, concerns not only the technical-care point of view, but also the ethical aspect 36. Already, in accordance with the principle of non-maleficence, the health professional has a duty to intentionally do no harm and / or damage to your patient [37].

The principle of justice defends the right of all people, both with regard to their status as human beings who deserve consideration and respect, as in regard to equal obtaining assistance and control the distribution of limited resources for health and the maximum benefits to the community [38]. in this context, the concept of justice is based on the premise that people have rights equal security, including the rights related to the care of their health [39].

Despite this, the role of health professionals in palliative care should turn to the relief of pain and suffering, even though in certain situations some procedures may influence the duration of life, whether in your shortening or extension [40].

The main ethical distinction observed in palliative care is given in monitoring the person in his finitude process, in order to maintain their dignity and relieve his suffering and pain at the end of life bioethics 6. In this perspective, aimed to palliative care and patients with no possibility of cure, euthanasia are discussed, dysthanasia and orthothanasia.

Euthanasia

According to Pine and Barbosa [41], the word "euthanasia" comes from Greek and means good death (I = good + thanatos = death). It was first used in the seventeenth century, for his alleged creator, philosopher and politician Francis Bacon English. Bizatto [42] states that, in practice, euthanasia is equivalent to medical action to shorten the lives of people in a state of severe suffering from incurable disease and no improvement prospects with the patient sentenced to progressive death. What is nothing more than promoting death by conduct able to employ efficient means to produce death in these patients, interrupting his life.

Euthanasia is intended to lead to the withdrawal of functioning by considerations taken as humanistic; however, is ethics violation and illegal conduct by Brazilian law [43]. In the developed world, the principle of quality of life is used to defend the notion that life without quality is not worth living, and that is justification for the practice of euthanasia [44].

Thus understood, euthanasia is seen as the pious death and, according to Villas-Boas [45] and Siqueira-Batista and Schramm [46], can be classified as active, passive or double effect. These settings are configured as the act and the consent of the patient. Active euthanasia is planned between the patient or relative and the health professional. The act is given by the doctor deliberate action. In passive euthanasia, death occurs by deliberate omission not to initiate life support medical therapy to the patient or the interruption of treatment available, even when it turns out that there are benefits for the treatment of disease or care of the symptoms. And the dual effect of euthanasia occurs when death is accelerated as a result of medical action that does not target the lethal effect, but the relief of suffering. It is also known as indirect active euthanasia.

There are also voluntary euthanasia, in which case the patient's life is shortened at will, and not voluntary, when it occurs without knowing the patient's wishes. The respect of the latter categorization, Siqueira-Batista and Schramm 46 speculated that, from the principle of consent, can be found moral justification for voluntary euthanasia and eventually for not voluntary, but never for involuntary, that is, the held against the patient's will, because then it would not be of any form of euthanasia, but simply murder.

As for the used method or course of action for your practice, euthanasia may be natural or induced. To Cabette 47 in the first case there is no suffering, in the second there is the interference of human conduct involving third parties.

Importantly, when death is caused autonomously, suicide is considered atypical fact the Brazilian legal system. However, it adds that in the case of death caused autonomously, criminal disinterest in the subject is not absolute according to Brazilian law, considering the crimes of inducement, instigation or assistance to suicide under Article 122 of the criminal Code [47]. in cases like this, there is talk of assisted suicide, which, despite not having the same meaning, is the most similar to the definition of euthanasia.

In Brazil, according to the Medical Code of Ethics and Nursing, is prohibited such action. Under Article [29] of the Code of Ethics of Nursing Professionals, is vetoed the promotion of euthanasia or participating in practice designed to anticipate the death of the patient [48]. According Cabrera [49], the Penal Code in force in the country does not specify the euthanasia crime. However, the doctor that shortens the life of his patient, even if moved by an act of solidarity, commits simple crime of murder under Article 121 of that law, being the author subject to penalty 6-20 years in prison for having hurt the principle of inviolability of the right to life guaranteed by the Constitution.

Recently, it was observed that the issue is not limited to cases of terminal patients, because it is common to speak under that procedure to cases of newborns with congenital anomalies, patients in irreversible vegetative state and 47 invalid.

Dysthanasia

Just as "euthanasia", the word "futility" also consists of words of Greek origin (dis = difficulty, deprivation + thanatos = death), and designates the exaggerated extension of life when there is no possibility of cure or improvement of the patient condition generating agony, pain and suffering, to prolong the process of dying [50.41].

Disthanasia, grown in Western society values the salvation of life at any cost, subjecting patients to therapies that do not prolong life, but rather the process of death [51,52]. Disthanasia prolonging the suffering of the person without her having healing expectation or improvement in their quality of life. Therefore, it is seen as idle treatment and no benefits for the patient terminal.

Investment in patient healing out of therapeutic possibilities can be considered assault upon personal dignity, compromising the quality of life of the patient and his family [53.41]. So dysthanasia as artificial prolongation of the dying process, resulting in the suffering of the patient, is opposed to euthanasia, used to abbreviate such a situation, it is concerned with the quality of human life in its final phase.

In dysthanasia not matter the conditions of humanization and dignity of the patient, since your goal is treatment with focus on existing technological realities, which characterizes the so-called therapeutic obstinacy (or “therapeutic cruelty”), as the practice is known in Europe [54]. in the United States it is more common to use the term medical futility.

Being the dignity of the human person the guiding principle of Brazilian law, dysthanasia is equivalent to degrading and inhuman treatment, even if results from the noble doctor feeling that you want to extend the life of the patient, and should be prevented by cause painful death and suffered [55]. Adoni [54] further states that although dysthanasia affect the physical and mental state of the patient due to its prolonged agony, often it is still lucid and master of his mental faculties.

In this context, from the reading of Pessini [14], you can understand that there is no obligation to start or continue a therapeutic intervention when the suffering and the effort not apply to real benefits. The most important thing is to live with dignity and, when the time comes, also die with dignity.

Orthothanasia

Unlike euthanasia and futility, there is the possibility of death on your own pace and circumstances: orthothanasia. This practice does not accelerate or postpone the death of the individual, but offers natural point of departure. Setting the death as part of the life cycle, ensuring the patient the right to die with dignity [56]. The term “orthothanasia” is also formed by Greek roots (orthos, right, right + thanatos, death), and means no artificial extension the natural process of death. It is, therefore, considered as good or desirable death death [41].

Santoro [55] states that orthothanasia is the medical behavior that, given the imminent and unavoidable death, suspend the execution of actions that prolong the patient’s life and that would lead to useless treatment and unnecessary suffering. In orthothanasia going to offer to the patient palliative care appropriate to come to die with dignity. So it can be considered as the correct conduct in death, not anticipating or delaying, but rather accepting that, once started the process of death, we must continue to respect the dignity of the human being, not submitting this patient unnecessary suffering.

The practice of orthothanasia respects the patient survival time is in terminal phase, so that the methods that artificially sustain life are eliminated, allowing it to follow its natural course [57]. Such conduct is considered atypical in the Brazilian penal law in order that corresponds to the promotion of lawful attitude, since not intended to shorten the patient’s life, but formalize irreversible situation of brain death. Moreover, orthothanasia find playing field when before dysthanasia frame [54].

For the Federal Council of Medicine (FCM), orthothanasia is the appropriate approach before patient who is in the final stage of life. The FCM Resolution 1.805/2006 [58] allows the doctor to limit or suspend procedures or treatments that delay the patient’s life in end-stage incurable disease, respecting the will of the person and his legal representative, may be made available to doctors to its realization by family consent.

Importantly, before the creation of the resolution authorizing the practice of orthothanasia, the doctor took the guarantor function of the non-occurrence of death, because if he only chose to use the palliative treatment and not the same maintenance of life the patient was terminal, could account for intentional homicide by omission, even if the patient in possession of his mental faculties authorize treatment discontinuation [53]. thus, with the technical support of FCM, the House of Representatives, through its Committee on Social Security and Family, adopted on 8 December 2010 a proposal that regulates the practice of orthothanasia and shall provide all basic and palliative care applicable. This proposal is a Member of the substitute José Linhares [59] to the Senate Bill 6715 of 2009 [60], which provided only for the decriminalization of conduct.

In order to provide comfort and relieve the intolerable anguish of the patient, sedatives can also be used [61.62]. In palliative sedation, the purpose is to alleviate suffering using sedatives recommended only for symptom control [61]. There is no evidence that palliative sedation administered properly, accelerate death. However, it is important that the patient’s level of consciousness is only reduced enough for the relief of symptoms [63].

Pain is one of the most common reasons of disability and suffering in dying patients. At some point in the evolution of their disease, about 80% of patients experience pain [64]. In painful experience, sensory, emotional and social aspects are inseparable and should also be investigated and the appropriate preparation of the team is a prerequisite for control pain and prevalent symptoms in patients under palliative care [64].

Final considerations

The study sought to reflect and encourage debate on the subject. Looking bring relevant issues to palliative care and bioethics, says the practice of humane terminal care with the perspective of the stages of grief and terminal illness. The purpose of the article was to show that death is a complex phenomenon and full of ethical and professional dilemmas, endowed with feelings that need to be worked through and discussed ethical principles which are summarized in the welfare and dignity of the patient.

Palliative care has earned its place gradually. In the Brazilian panorama, there is the enlargement process of its importance for the well-being of people who are in the last days of life. However, pain and suffering are still seen more from the perspective of acceptance of that questioning and coping with dignity, which prevents the patient to actively participate in decision-making processes and to have the opportunity to live the bit properly time you have left. The family support given the risk of loss, the potential suffering and mourning period is commonly neglected issue.

The performance of palliative care is presented as real challenge to health services and teams. Its importance is revealed in that it is able to respond to human needs, which indicates the need for further research to continuously improve their practice. Despite the ethical issues, the challenge is to consider human dignity before the approach of death beyond the physical-biological dimension and medical and hospital perspective, implying a new vision on the social reality in which the uniqueness of each individual, their biopsychosocial aspects and their autonomy is valued. In particular, when life is closer to death.

Referências

1. Kaempf JW, Tomlinson MW, Campbell B, Ferguson L, Stewart VT. Counseling pregnant women who may deliver extremely premature infants: medical care guidelines, family choices, and neonatal outcomes. Pediatrics. 2009 jun;123(6):1.509-15.
2. Committee on Fetus and Newborn. Noninitiation or withdrawal of intensive care for high-risk newborns. Pediatrics. 2007 fev;119(2):401-3.
3. Pignotti MS, Donzelli G. Perinatal care at the threshold of viability: an international comparison of practical guidelines for the treatment of extremely preterm births. Pediatrics. 2008 jan;121(1):e193-8.
4. Seri I, Evans J. Limits of viability: definition of the gray zone. J Perinatol. 2008 maio;28 (Suppl 1):S4-8.
5. Marlow N, Wolke D, Bracewell MA, Samara M, EPICure Study Group. Neurologic and developmental disability at six years of age after extremely preterm birth. N Engl J Med. 2005 jan 6;352(1):9-19.
6. Vincer MJ, Allen AC, Joseph KS, Stinson DA, Scott H, Wood E. Increasing prevalence of cerebral palsy among very premature infants: a population-based study. Pediatrics. 2006 dez;118(6):e1.621-6.
7. Wilson-Costello D, Friedman H, Minich N, Siner B, Taylor G, Schluchter M *et al.* Improved neurodevelopmental outcomes for extremely low birth weight infants in 2000-2002. Pediatrics. 2007 jan;119(1):37-45.
8. Poon WB, Ho SKY, Yeo CL. Short- and long-term outcomes at 2, 5, and 8 years old for neonates at borderline viability: an 11-year experience. Ann Acad Med Singapore. 2013 jan;42(1):7-17.
9. Hack M. Consideration of the use of health status, functional outcome, and quality-of-life to monitor neonatal intensive care practice. Pediatrics. 1999 jan;103(1 Suppl E):319-28.
10. Simard M, Gagné AM, Lambert RD, Tremblay Y. A transdisciplinary approach to the decision-making process in extreme prematurity. BMC Res Notes. 2014 jul 14;7:450-8.
11. Lorenz JM. The outcome of extreme prematurity. Semin Perinatol. 2001 out;25(5):348-59.
12. Charafeddine L, Ammous F, Kayle M, Arawi T. Survival at the threshold of viability: a nationwide survey of the opinions and attitudes of physicians in a developing country. Paediatr Perinat Epidemiol. 2014 maio;28(3):227-34.
13. Chervenak FA, McCullough LB, Levene MI. An ethically justified, clinically comprehensive approach to peri-viability: gynecological, obstetric, perinatal and neonatal dimensions. J Obstet Gynaecol. 2007 jan;27(1):3-7.
14. Hack M, Fanaroff AA. Outcomes of children of extremely low birth weight premature infants in the 1990s. Early Hum Dev. 1999;53:195-218.
15. García-Muñoz FR, García-Alix AP, García Hernández JA, Figueras JA. Morbidity and mortality in newborns at the limit of viability in Spain: a population-based study. An Pediatr (Barc). 2014 jun;80(6):348-56.

16. Doyle LW, the Victorian Infant Collaborative Study Group. Neonatal intensive care at borderline viability: is it worth it? Early Hum Dev. 2004 nov;80(2):103-13.
17. Markestad T, Kaaresen PI, Rønnestad A, Reigstad H, Lossius K, Medbø S *et al.* Early death, morbidity, and need of treatment among extremely premature infants. Pediatrics. 2005 maio;115(5):1.289-98.
18. Moriette G, Rameix S, Azria E, Fournié A, Andrini P, Caeymaex L. *et al.* Very premature births: Dilemmas and management. Part 1. Outcome of infants born before 28 weeks of postmenstrual age, and definition of a gray zone. Arch Pediatr. 2010 maio;17(5):518-26.
19. Parikh DO, Arnold C, Langer J, Tyson JE. Evidence-based treatment decisions for extremely preterm newborns. Pediatrics. 2010 abr;125(4):813-6.
20. Singh J, Fanaroff J, Andrews B, Caldarelli L, Lagatta J, Plesha-Troyke S *et al*. Resuscitation in the "gray zone" of viability: determining physician preferences and predicting infant outcomes. Pediatrics. 2007 set;120(3):519-26.
21. Rocha G, Guimarães H. On the limit of viability extremely low gestational age at birth. Acta Med Port. 2011 dez;24(Suppl 2):181-8.
22. Shah PS, Sankaran K, Aziz K, Allen AC, Seshia M, Ohlsson A *et al.* Outcomes of preterm infants <29 weeks gestation over 10-year period in Canada: a cause for concern? J Perinatol. 2012 fev;32(2):132-8.
23. Msall ME, Park JJ. The spectrum of behavioral outcomes after extreme prematurity: regulatory, attention, social, and adaptive dimensions. Semin Perinatol. 2008 fev;32(1):42-50.
24. Bremmer P, Byers JF, Kiehl E. Noise and the premature infant: physiological effects and practice implications. J Obstet Gynecol Neonatal Nurs. 2003 jul-ago;32(4):447-54.
25. Brown G. NICU noise and the preterm infant. Neonatal Netw. 2009;28(3):165-73.
26. Perlman JM. Neurobehavioral deficits in premature graduates of intensive care: potential medical and neonatal environmental risk factors. Pediatrics. 2001 dez;108(6):1.339-48.
27. Williams AL, Sanderson M, Lai D, Selwyn BJ, Lasky RE. Intensive care noise and mean arterial blood pressure in extremely low-birth-weight neonates. Am J Perinatol. 2009 maio;26(5):323-9.
28. Atkinson J, Braddick O. Visual and visuocognitive development in children born very prematurely. Prog Brain Res. 2007;164:123-49.
29. Braddick O, Atkinson J, Wattam-Bell J. VERP and brain imaging for identifying levels of visual dorsal and ventral stream function in typical and preterm infants. Prog Brain Res. 2011;189:95-111.
30. Graven SN. Early visual development: implications for the neonatal intensive care unit and care. Clin Perinatol. 2011 dez;38(4):671-83.
31. Ramenghi LA, Ricci D, Mercuri E, Groppo M, De Carli A, Ometto A *et al*. Visual performance and brain structures in the developing brain of pre-term infants. Early Hum Dev. 2010 jul;86 (Suppl 1):73-5.
32. Msall ME, Tremont MR. Measuring functional outcomes after prematurity: developmental impact of very low birth weight and extremely low birth weight status on childhood disability. Ment Retard Dev Disabil Res Rev. 2002;8(4):258-72.
33. Van der Weijer-Bergsma E, Wijnroks L, Jongmans MJ. Attention development in infants and preschool children born preterm: a review. Infant Behav Dev. 2008 set;31(3):333-51.
34. Christoffersen-Deb A. Viability: a cultural calculus of personhood at the beginnings of life. Med Anthropol Q. 2012 dez;26(4):575-94.
35. Kletemberg DF, Mantovani MF, Lacerda MR. Entre a teoria e as práticas do cuidar: que caminho trilhar? Cogitare Enferm. 2004;9(1):94-9.
36. Gaiva MAM. O cuidar em unidades de cuidados intensivos neonatais: em busca de um cuidado ético e humanizado. Cogitare Enferm. 2006;11(1):61-6.
37. Ribeiro CDM, Rego S. Bioética clínica: contribuições para a tomada de decisões em unidades de terapia intensiva neonatais. Ciênc saúde coletiva. 2008 dez;13 (Suppl 2):2.239-46.
38. Schramm FR. Cuidados paliativos: aspectos filosóficos. Rev Bras Cancerol. 1999;45(4):57-63.
39. Spittle A, Orton J, Anderson P, Boyd R, Doyle LW. Early developmental intervention programs post-hospital discharge to prevent motor and cognitive impairments in preterm infants. Cochrane Database of Systematic Reviews. 2012 dez;12:1-103.

Participação dos autores

Andrezza de Lemos Bezerra, Giselle Machado Magalhães Moreno, Adriana Carla Costa Ribeiro Clementino, Anna Paula Chaves Chagas e Isis Suruagy Moura participaram da pesquisa e da elaboração do texto. Josimário Silva orientou e revisou o trabalho.

Recebido: 6. 2.2014
Revisado: 9. 5.2014
Aprovado: 28.10.2014