Medical, ethical and legal considerations regarding end-of-life decisions in pediatric patients

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Abstract

To discuss, in the case of the baby Charlie Gard, aspects to be considered in medical decision making in pediatrics, especially in patients with incurable and terminal diseases. Bioethical principles and Palliative Care were considered, as well as legal issues related to parental authority and therapeutic obstinacy, from the perspective of the Brazilian legal system. Decisions related to end-of-life care in pediatrics should be a process of sharing responsibilities between the health team and parents, with the participation of the child whenever possible, seeking the principle of the best interest. Judicialization of medical issues must be avoided, as it is associated with attrition and suffering for all parties involved. End-of-life decision-making in pediatrics should be based on the search for the right to live with dignity, but, above all, to maintain it until the end of life.
Keywords: Mitochondrial diseases. Palliative care. Bioethics. Decision making. Medical futility.

Resumo

Considerações médicas, éticas e jurídicas sobre decisões de fim de vida em pacientes pediátricos

A partir do caso do bebê Charlie Gard, discutem-se aspectos relativos à tomada de decisão médica em pediatria, sobretudo em relação a pacientes portadores de doenças incuráveis e terminais. Foram considerados princípios bioéticos e do cuidado paliativo, além de questões jurídicas relacionadas a autoridade parental e obstinação terapêutica, sob a perspectiva do ordenamento jurídico brasileiro. O processo de tomada de decisões referentes a cuidado de fim de vida em pediatria deve contemplar compartilhamento de responsabilidades entre equipe de saúde e pais, com a participação da criança sempre que possível, buscando o princípio do melhor interesse. Deve-se evitar a judicialização de questões médicas, situação associada a desgaste e sofrimento de todas as partes envolvidas. Conclui-se que a tomada de decisão de final de vida em pediatria deve se pautar na busca do direito a viver com dignidade, mas, sobretudo, de mantê-la até o fim.
Palavras-chave: Doenças mitocondriais. Cuidados paliativos. Bioética. Tomada de decisões. Futilidade médica.

Resumen

Consideraciones médicas, éticas y jurídicas sobre decisiones de fin de la vida en pacientes pediátricos

A partir del caso del bebé Charlie Gard, se discuten aspectos relativos a la toma de decisiones médicas en pediatría, sobre todo en pacientes portadores de enfermedades incurables y terminales. Se consideraron los principios bioéticos y de los cuidados paliativos, además de las cuestiones jurídicas relacionadas con la autoridad parental y la obstinación terapéutica, desde la perspectiva del ordenamiento jurídico brasileño. El proceso de toma de decisiones referidas a los cuidados en el fin de la vida en pediatría debe contemplar responsabilidades compartidas entre el equipo de salud y los padres, con la participación del niño siempre que sea posible, buscando el principio del mejor interés. Se debe evitar la judicialización de cuestiones médicas, situación asociada a desgaste y sufrimiento para todas las partes involucradas. Se concluye que la toma de decisión de final de vida en pediatría debe guiarse por la búsqueda del derecho a vivir con dignidad, pero, sobre todo, de mantenerla hasta el final de la vida.
Palabras clave: Enfermedades mitocondriales. Cuidados paliativos. Bioética. Toma de decisiones. Inutilidad médica.

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The evolution of medicine, with all available medical technology, while allowing accurate diagnosis and early treatment of an increasing number of diseases, alters the natural history of these diseases, which makes the prognosis a more complex task. We will have a greater set of possibilities to maintain life, but we still know very little about the consequences of our actions in employing it. What does it mean for families, in the medium and long term, to opt for the use of artificial life support equipment capable of permanently replacing vital functions, such as breathing, but which are not capable of curing the disease itself? [1]

The increased availability of technological resources for the maintenance of lives of children with incurable diseases has potentiated conflicts between health teams and families. This sometimes causes the transfer of decision-making to the judiciary, often with disastrous consequences for all parties involved. In the first half of 2017, the case of the English baby Charlie Gard, afflicted by a serious, progressive and incurable genetic disease, sparked discussions around the world involving different areas of knowledge, including medicine, law and bioethics.

The aim of the present article is to use the case of the baby Charlie Gard to critically discuss aspects to be considered in medical decision making in pediatrics, especially in cases of patients with severe, incurable and terminal diseases. To that end, the application of the bioethical principles of autonomy, beneficence, non-maleficence and justice [1], the principles of palliative care and the legal issues involved, especially regarding parental authority and therapeutic obstinacy, will be analyzed from the perspective of the Brazilian legal system.

A brief account of the Charlie Gard case

Charlie Gard was born at full term, being apparently healthy, on August 4, 2016. At a few weeks of age, his parents, Chris Gard and Connie Yates, noticed the first signs of muscle weakness. At two months, he was admitted to the Great Ormond Street Hospital in London, with difficulties in feeding, hypoactivity and respiratory failure. Intensive care was started and investigations led to the diagnosis of a severe and rare mitochondrial disorder: mitochondrial DNA depletion syndrome.

In early 2017, Charlie's parents identified experimental treatment consisting of nucleoside supplementation that would theoretically replace the function of the damaged DNA, reducing the biochemical and clinical effects of the disease. Although this type of treatment had not previously been used in patients with the subtype of the genetic mutation that caused Charlie's disease, doctors initially considered the possibility of using it. However, as early as January 2017, Charlie had evidence of seizures and impaired brain function, and physicians were convinced that the treatment, both continuous intensive therapy with advanced life support and nucleoside replacement therapy, would be useless.

A North-American physician involved in nucleoside research volunteered to treat Charlie, and during that time, through campaigns, the child's parents raised the necessary financial resources to pay for Charlie's treatment and transportation to the United States.

However, the physicians who cared for the patient considered that transfer and submission to treatment were contrary to the best interests of the child, since the disease was in a very advanced stage.

On February 28, the physicians asked the Family Division of the High Court of Justice in London to withdraw artificial advanced living support and provide Charlie with exclusive palliative care. Although Charlie's parents did not agree to this decision, on April 11, Judge Francis decided in favor of the hospital [2]. Charlie's family appealed and the decision was reviewed and upheld by the Court of Appeal on May 23 [3], by the Supreme Court on June 8 [4] and by the European Court of Human Rights on June 20 [5]. Having all legal channels been exhausted, plans were made to remove artificial life support, according to the medical recommendation.

The case drew attention from society and the media around the world, to the point that US President Donald Trump and Pope Francis made public statements in support of Charlie's parents. In addition, several international medical and science experts submitted treatment proposals with seemingly new evidence, claiming that Charlie's chances of benefiting from nucleoside therapy could be greater than what had been said until then.

On July 10, Great Ormond Street Hospital decided to present this new evidence to the High Court in London, which ordered the US mitochondrial disease specialist to evaluate baby Charlie in London. After a multidisciplinary meeting and new evidence of the severity of Charlie's disease, including magnetic resonance imaging, on July 24, the parents accepted that the experimental

treatment might not bring benefits to the baby and decided to follow the indication of the Great Ormond Street Hospital.

Charlie's parents then requested that the baby be transferred home so that he could be close to the family and in his own room in the final moments of his life. However, for reasons not disclosed in the media, the hospital refused that the baby be taken home. Baby Charlie was transferred to palliative care institution where he was withdrawn from the artificial support that held his breath and died on July 28.

Medical aspects of the case

As described, baby Charlie Gard was the carrier of a mitochondrial disease, a genetically acquired disorder that determines expressive dysfunctions of the functioning of the organs and tissues and strongly affects survival. The mitochondrial disease is caused by the malfunctioning of mitochondria, organelles present in the cytoplasm of cells in all tissues of the human body. They play a fundamental role in the cellular energy metabolism through the respiratory chain, producing more than 90% of the adenosine triphosphate (ATP) necessary for the execution of cellular biological processes [6].

The respiratory chain is formed by a group of five enzymatic complexes, located on the internal membrane of the mitochondria, which participate in chemical chain reactions of which the whole process is called oxidative phosphorylation. This process is crucial not only for the production of energy in the form of ATP, but also for the formation and detoxification of free radicals important for the survival and programming of cell death.

Most of the proteins acting on the respiratory chain are encoded by cellular DNA (nDNA), but some of them are by mitochondrial DNA (mtDNA). Therefore, for the respiratory chain to function normally, both the cellular and mitochondrial genetic systems must be intact and functioning together. Alterations in nDNA or mtDNA cause changes in the cellular respiration phosphorylating complex, compromising the synthesis and transport of mitochondrial proteins, besides altering the capacity of nucleoside synthesis and renewal of the mitochondrial genome [7].

Mitochondrial diseases are present in about one in every 5,000 individuals and, because they originate in alterations of both nDNA and mtDNA, they may have different patterns of genetic inheritance: maternal, autosomal recessive or autosomal dominant. The fact that mitochondria are present in all tissues of the human body gives these diseases a multisystemic nature, compromising several organs and tissues simultaneously and progressively. There is a large number of genetically distinct mitochondrial diseases, each characterized by different signs and symptoms [6].

The clinical manifestations may vary and depend on the organs that are predominantly affected. There tend to be more pronounced signs and symptoms resulting from dysfunction in organs and tissues with higher energy demand, such as the muscles, the brain, the liver, the heart and the kidneys. The main clinical manifestations are: muscular weakness, peripheral neuropathy, encephalopathy, delayed neuropsychomotor development, convulsions which are difficult to control, cortical blindness, ophthalmoplegia and hepatic insufficiency [8-11].

The first mitochondrial disease was reported in 1959, and the discovery that mitochondria have their own DNA occurred in 1963. However, it was not until 1981 that the nucleotide sequence of human mitochondrial DNA was fully uncovered [12]. In 1989 the first diseases related to alterations of this DNA were reported.

There are different genetic alterations that cause mitochondrial DNA depletion syndrome characterized by reduced mtDNA copies and consequent mitochondrial dysfunction in the tissues affected. Charlie Gard was a carrier of one of the most serious subtypes of the disease, related to the mutation of the RRM2B mitochondrial gene, an extremely rare genetic disorder. Patients with this mutation develop intense muscular weakness associated with respiratory failure, microcephaly, delay in neurological development, difficult to control seizures, deafness and renal malfunction during the first months of life. The disease progresses rapidly, causing death after a few months [8].

The wide diversity of symptoms, the involvement of different organs and the various modes of disease progression are a challenge for the development of effective therapeutic interventions [13]. Moreover, because they are distinct and extremely rare genetic alterations, it is very difficult to elaborate controlled clinical trials involving an adequate number of patients, allowing the study of therapeutic alternatives.

There is a small group of mitochondrial diseases for which there is indication of supplementation with vitamins or cofactors such as Coenzyme Q10

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supplementation for biosynthesis defects of this molecule or supplementation of riboflavin, biotin and thiamine for changes in the specific deficiency of these vitamins [14]. Despite this, a recent review by the Cochrane Review Groups [15] concludes that to date there is no evidence to support any specific pharmacological intervention in patients with mitochondrial disease.

In the case of mitochondrial DNA depletion syndrome, studies are being developed in animal models and cell cultures in which nucleoside replacement therapy is associated with inhibitors of their metabolism [16]. This was the experimental treatment by which Charlie's parents fought in court, based on the information that this therapy would lead to reduced mtDNA depletion. However, such drugs were used in models whose mutation occurred in the TYMP and DGUOK genes, and not in the RRM2B gene responsible for Charlie's disease.

There is a lack of data on the clinical impact of reducing mtDNA depletion, as well as studies on possible side effects associated with treatment, especially regarding the use of inhibitors of nucleoside catabolism.

As there are still no human studies, it is not possible to assess the bioavailability of the drug in the body, the doses needed to achieve the desired effect, clinical benefits or side effects secondary to medication. Studies indicate that gene therapy and stem cell therapy are promising options for dealing with mitochondrial diseases [17], but to date there is no intervention that can cure the disease.

Legal aspects

From a legal point of view, the Charlie Gard case can be analyzed from the following perspectives: 1) the clash between parental authority and clinical indication; 2) the interference of the State in a private matter; and 3) the lawfulness of therapeutic obstinacy. However, it is not possible to dissociate these issues and treat them separately; for this reason, this topic will deal with the three perspectives together.

Charlie Gard, as a minor, is subject to parental authority, that is, to the parental duties to create, assist and educate the minor children. According to Konder and Teixeira [18], the function of the law is to instrumentalize the fundamental rights of the children, making them capable of exercising their personal choices with the corresponding responsibility. Thus, it is necessary to consider whether medical decision-making is within the limits of parental authority. Health issues are embedded in personality rights and, as such, can not be transferred to others, not even to parents or legal guardians.

It is true that parents respond for their younger children. However, this responsibility should be seen more as a duty than as an absolute right, and it is not possible for parents to assume the making of very personal decisions *a priori*, which must always conform to the principle of the best interests of the child in the particular case.

It happens that if it is customary to transfer decision-making power to parents in pediatrics, from a legal point of view this transfer is questionable. In the discussion on blood transfusion in child patients whose family is comprised of Jehovah's Witnesses, the understanding is pacified about the non-preponderance of parental will [19].

It seems that, from a legal point of view, it is accepted that the decision-making power in health matters is transferred to the parents when their interest is in the maintenance of the child's life and, on the other hand, this power is denied when their interest conflicts with the preservation of life. There is thus a contradiction in the treatment of the issue, which may be justified by the difficulty of Western culture in dealing with death [20].

Another common argument has been the alleged inadequacy of state interference in family-specific decision making. However, the English legal system, as well as the Brazilian legal system, provides for the possibility of triggering the Judiciary if the parents act against the best interests of the child. Thus, the judicialization of the case by the Great Ormond Street Hospital was supported by the current legislation.

It must be asked if taking this issue to court was really the best option. Unfortunately, few details of the relationship between physicians and family have been released so far, which allows for inferences about what happened. Has the communication of the health team been effective? Was there interference from the Hospital Ethics Committee? Or even the Bioethics Committee?

It is understood that leaving such personal decisions to the court of justice is part of a recent social phenomenon: the overvaluation of the Judiciary. If in the last century the Legislative Power was seen as responsible for social pacification, through the making of laws, in contemporary times the Judiciary has taken over this role, which

justifies the judicialization of private issues, such as medical decisions.

Indeed, the decision whether or not to support Charlie Gard's life support should not have been taken by the English Supreme Court, not even by the European Court of Human Rights, but by a decision-making process shared between medical staff and the family, always seeking the best interest of the child. Therefore, it is agreed that state interference was inadequate.

The legal discussion about the lawfulness of therapeutic obstinacy is very current and still finds little support in the literature, precisely due to the social difficulty in dealing with death. Thus, from the medical point of view, it is socially acceptable to prolong the biological life without further elaboration on the benefit to the patient of this artificial maintenance.

Thaddeus Pope [21] has stood out in the North American scene as fierce defender of the illicitness of obstinate therapeutics, relying on the bioethical principle of beneficence. In the United States, hospitals and physicians begin to be sued for obstinacy, but this movement is still incipient, becoming more common when the obstinacy was explicitly refused by the patient in an advance directive of will (ADW). In the case under review, the ADW would not apply because Charlie had no discernment to manifest his will. Therefore, the discussion focuses on who has decision-making power, but also on which is the best decision for the patient.

Technological advancement has modified the natural course of several diseases, in a positive way, as in the temporary replacement of organs intensely affected in patients with severe acute diseases, but also in a negative way, as in the artificial maintenance of biological life of patients with chronic and terminal diseases. In addition, the almost daily emergence of new experimental treatments fuels the hope of many patients and relatives about the possibility of winning the battle against the inexorable.

It must be noted that the Charlie Gard case is not the first one of divergence between parents of patients with irreversible health status and medical care team. In October 2004, another occurrence involving therapeutic obstinacy in a minor caused commotion in England. Charlotte Wyatt was born prematurely at the 26th week of gestation, and, at 11 months, she was kept alive by appliances in an irreversible coma [22]. The Portsmouth Hospital staff asked the Judiciary to order a non-resuscitation if the child had a cardiorespiratory arrest.

The physicians alleged that, at the request of the parents, they had already revived her three times, and that the procedure was futile, since there was no prospect of improvement of the clinical picture.

The parents, on the other hand, maintained that a miracle could happen and did not accept the medical decision of non-resuscitation. The London court upheld the arguments of the medical team and authorized it not to undertake any procedure to revive the child in case of cardiorespiratory arrest. It is thus perceived that the conflict involving physicians and parents of patients in irreversible conditions is not recent in the English courts, which have often remained against therapeutic obstinacy.

Palliative care, therapeutic obstinacy and decision making in pediatrics

In the opposite direction from super-specialized medicine focused on diagnosis and cure of diseases associated with the unrestricted use of technological resources for artificial life support, palliative care is increasingly important, especially in the context of the care of patients with chronic diseases and those that threaten the continuity of life.

Palliative care is an area of medical practice that, as defined by the World Health Organization and updated in August 2017, is *an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual* [23].

In order to approach and care for patients with chronic and incurable diseases, it is essential that health professionals be trained to focus their attention on the ill person and not on the disease. This focus is essential so that the patient and the family can identify all the sources of suffering and act in an assertive and interdisciplinary way with the purpose of relieving it, helping parents and other relatives to make decisions that are effectively aligned with the best interests of the child, as provided by the United Nations Organization [24,25].

Pediatric palliative care requires technical skills to treat physical symptoms such as nausea, pain, dyspnea, insomnia, *delirium* and fatigue. In addition, they require humanistic skills to care for other poorly addressed spheres of suffering, such

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as fear, loneliness, abandonment, sadness, lack of socioeconomic resources, as well as communication skills so that the goals of care for the patient can be defined with the family.

Characteristics such as empathy and compassion, time and dedication of a multi-professional team formed by a physician, nurse, social worker, psychologist, physiotherapist, occupational therapist, nutritionist, chaplain, among others, are required to work in an integrated manner and whose primary care objective is to alleviate the suffering.

For each proposed conduct it is essential that the potential benefits are analyzed by confronting them with the risks and suffering that may be inflicted. The professional must be alert to avoid therapeutic obstinacy and maintenance or introduction of futile measures that, because they do not have the potential to alter the natural course of the disease, will not benefit the patient at all, and may prolong and make the death process even more painful. The risk of practices that constitute therapeutic obstinacy is even greater when it comes to patients with progressive, incurable and terminal diseases.

In order to achieve the goal of providing children and adolescents with health care that is in their best interest, in addition to knowledge in palliative care, it is necessary to have adequate public policies. These legal instruments should enhance and expand access to this modality of care, foster legal discussions that support the practice of orthothanasia, and, above all, guide decisions within the principialist bioethical framework: autonomy, beneficence, non-maleficence and justice [26].

Autonomy is the ability to manage one's own will or seek what one thinks is best for oneself, free from the influence of other people. Beneficence refers to the ethical obligation to act seeking the greatest possible benefit, associated with lesser or non-maleficence, whose purpose is to reduce adverse or undesirable effects of diagnostic and therapeutic actions on the human being. Finally, the principle of justice seeks equity and balance in the use of resources in order to reach the greatest number of people more efficiently [27]. In the Charlie Gard case, as the resources to be employed were raised by the family, there would probably be no infringement evident to the latter.

When we apply the principles of bioethics to the pediatric age group, the discussion that involves the principle of autonomy loses part of its meaning, since, in this population, the development of characteristics necessary for decision making may not be present, especially in the case of babies who have not yet acquired the ability to speak or communicate fully. If the current legislation does not recognize individual autonomy before the age of 18, one must also consider the influences of the social environment, as well as the cultural and religious aspects preponderant in the family, that interfere in the decisions about medical care to be provided to the child.

Grootens-Wiegers et al. 27, based on studies of neuroscience report that, in order to develop the process of acquiring the necessary competences for decision making that begins in childhood and improves with age, the child or adolescent should develop four distinct abilities: 1) express a choice, which implies the ability to communicate preference; 2) to understand the medical treatment being proposed, which presupposes intelligence, mastery of language, attention directed to information and memory; 3) to reason about the risks, benefits and consequences of the proposed treatment; and 4) ability to appreciate, which implies that in addition to understanding the various options available, the individual can, using abstract thinking, understand the relevance of such alternatives to the clinical condition itself. In general, all of these skills would be present around the age of 12, provided that the child grows in an environment conducive to their development.

However, this age coincides with the onset of adolescence, the stage of life in which the individual tends to show behaviors that expose her or him to risks, such as impulsive attitudes, especially in emotional situations and when accompanied by peers. Such characteristics can make the adolescent's competence to make decisions vary according to the time and context. Therefore, it is important that the health professional and the parents be attentive to ensure that the adolescent's decision-making occurs with the least possible influence of social and emotional factors, offering adequate environment and time for a competent and, consequently, reliable choice [27].

The end-of-life decision-making process encompasses many cultural issues, including the culture of denial of death and struggle for life that must be maintained at any price. In Brazil, there is no tradition of valuing the patient's autonomy, and end-of-life decisions are taken by the medical staff based on the concept of beneficence and influenced by the cultural and moral values of health professionals.

Some Brazilian authors argue that the decision to limit or suspend procedures or treatments that prolong the life of the terminally ill patient should be a medical decision. This is because it is the professional who knows the beneficial and collateral effects of each intervention, as well as the possible evolution of the disease, being able to identify life support limitation conducts that best meet the interest of the child [28]. Such paternalistic approach also predominates in other countries of South America and Europe.

However, Resolution 1,805/2006 of the Brazilian Federal Council of Medicine (Conselho Federal de Medicina) [29] makes it clear that the suspension or non-introduction of measures that prolong the life of the terminally ill patient must be in accordance with the will of the person or his/her legal representative, valuing an autonomy-based approach. When applied to pediatric patients, it is understood that it is the responsibility of the parents or other legal guardian to represent the will of the patient. Similarly to the case of the baby Charlie Gard, situations in which there is a divergence between the wishes of parents or legal representatives and what the health team considers the best therapeutic alternative for the child or adolescent are common in clinical practice.

In decisions about life support for severely ill children, those who have to make the decision, whether they are parents, health professionals or magistrates, should be adequately informed of relevant facts. They must also be willing to use logic and find reasons for and against the solution, to be open-minded and to consciously strive to overcome their intellectual, emotional, religious, and moral prejudices [30]. The search for beneficence or the better interest of the child should be built on the dialogue between parents and the health team, with information related to diagnosis and prognosis, alignment of expectations, ideal and appropriate possibilities, and definition of care objectives.

The desires will certainly differ. Some families will value life in an absolute way, while others may believe that individuals with no ability to interact with others have a quality of life considered unacceptable, which makes the work of the health team even more complex. Therefore, it is necessary to know the preferences and values of the patient and the family so that one has the tools to seek the best decision. The ideal scenario is that the decision involving pediatric patients is taken by sharing responsibilities between health staff and parents, with the participation of the child whenever their development allows for this, aiming at achieving the best quality of life possible despite the limitations determined by the disease.

We can not neglect the fact that it is the parents, not the health team, who are most affected by the end-of-life medical decisions and their consequences: when decisions are taken to withdraw artificial life support, it is parents who will live with their grief. It is justifiable that their opinion predominates in situations such as these, and intervention is necessary only when the parents' choice can cause serious harm to the patient [31].

In the latter case, since it is not possible to resolve the conflict through dialogue, it is necessary to refer the discussion to other instances, which should preferably be the institution's bioethics committee, ethics committee, clinical board, the Regional Council of Medicine, the Federal Council of Medicine or a private mediation institution. The call to the Public Prosecutor's Office in the area of Childhood and Adolescence and/or possible judicial action should be considered as a last resort in the solution of the conflict.

Certainly, referring medical decisions to spheres that transcend the family and the care team creates a serious breach of trust, causing dissatisfaction for all parties involved. When considering the pertinence of adopting this route of conflict resolution, there is also a risk of even greater harm to the patient and the family, associated with the time needed to resolve the case, as well as the emotional stress related to the conflict.

When the situation involves decisions to withdraw life support, as in the case of Charlie Gard, the prolongation of the decision-making process with so many appeals in different legal instances may cause intense and futile suffering to the baby, subjected to well-known painful procedures applied to patients in intensive therapy. In addition, in the case at hand, this prolongation also generated a lot of emotional suffering to the family, especially the parents, who, in addition to having to deal with the illness and death of the child, were exposed by the media, judged and pressured by public opinion.

After a long process, Chris Gard and Connie Yates agreed that their son would no longer benefit from nucleoside replacement therapy but asked that artificial life support be removed after the baby was transferred home. The hospital's argument that prevented the transfer was not clear, but Charlie was deprived of going home and his parents were prevented from taking him to die at home. Although

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it seems common sense, the position held by the authors is based on the basic principles of palliative care, which are concerned not only with the patient but with the psychophysical well-being of the family.

In this way, since there was no indication that transferring Charlie home would worsen his situation, and as this was the will of the family, which, even from a financial point of view, continued to support him, it is understood that the stance of the hospital is contrary to the palliative care approach.

The occurrence of this additional fact creates a great chance that this family will suffer a complicated mourning process. It is fundamental that, at least during the preparation of mourning, the family can be effectively prioritized and cared for by the health team.

The Charlie Gard case from the point of view of the Brazilian legal system

In Brazil, as in England, there is no specific legislation for cases such as the Charlie Gard one. However, the Brazilian Federal Constitution [32], in dealing with the rights of children and adolescents, privileged the principle of the best interest. From a conceptual point of view, this principle is a corollary of the doctrine of integral protection, that is, of the need to protect vulnerable individuals from all possible situations that could inflict harm.

Historically, this principle comes from the Anglo-Saxon precept '*best interests of the child*'. However, Tânia da Silva Pereira [33] states that while the latter treats the protection of the child in a quantitative manner, the former is more concerned with a quantitative protection, that is, the largest possible number of rights.

The Brazilian Constitution [32] contains several rights of children and adolescents: the right to life, health, food, education, leisure, professional training, culture, dignity, respect, freedom, and family and community life. However, it was not exhaustive to the point of dealing with medical care issues. Analyzing the Charlie Gard case in the light of the Brazilian legal system, one could ask whether, in the face of the constitutional right to life and the duty of care of the parents towards their minor children, the will of the parents should not prevail and nucleoside supplementation be performed.

However, nowadays, the right to life acquires a new reading before the general clause of protection of human dignity, that is, the life protected in the Constitution is not merely a biological life, but a dignified life, which allows the discussion about the what would be a life with dignity for Charlie Gard. Thinking that the experimental treatment desired by Charlie's parents does not have any scientific proof of success, it is possible to state that the child had no chance of living with dignity: he had an incurable and terminal illness, and it would be better to allow him to die with dignity.

In Brazil, there is no normative treatment for a death with dignity, which has been recognized as a right by some judicial decisions, and there is no legal norm on the subject. This circumstance creates great legal uncertainty for all the actors that deal with the terminality - patient, family, health team and health institution.

Article 15 of the Brazilian Civil Code states that no one may be compelled to, at the risk of one's life, be submitted to medical treatment or surgical intervention [34]. The wording of this legal text has often been criticized for allowing different interpretations between law operators.

Diaulas Costa Ribeiro suggests that the best interpretation for this article should be that no one, not even at the risk of one's life, will be constrained to treatment or surgical intervention, with respect to their autonomy [35]. But in the analysis of the Charlie Gard case, this reading would not help, since the patient did not have autonomy.

The provisions of the Civil Code on parental authority, as well as the provisions of the Statute of the Child and Adolescent [36], also do not solve the issue, as they do not deal directly with the taking of medical decisions. This way, we are facing what Dworkin calls *hard case* 4 [37], it being necessary to integrate existing legal norms in order to solve the issue.

For the solution of this case according to the Brazilian legal system, it is understood that there are two antagonistic rights: Charlie's right to a death with dignity and the right to the exercise of parental authority by the parents, consubstantiated in the duty of care. Faced with this clash of rights, the English and European courts decided on the right to a dignified death at the expense of parental authority. While for some this solution, the withdrawal of the artificial support that kept Charlie alive seems to have been the right one, protecting him the right to a dignified death, for others the authority of the parents should have been respected, since, at first, they are the ones who know what is best for their children and it is their duty to care.

It is therefore necessary to broaden discussion forums so that we can reflect on these issues comprehensively and be able to evolve as a society seeking not only the right to live with dignity, but above all to maintain it until the end of life.

Final considerations

The Charlie Gard case presents a true bioethical dilemma, so there is no single possible answer. What was intended in this article was to explore the different perspectives and to deepen the discussion about decision making in pediatrics.

It was noticed that the humanist approach to the physician-patient-family relationship, especially in situations related to the care of patients with progressive and incurable diseases, should be taken into account by all agents involved in the treatment. This is aimed at avoiding the judicialization of medical decisions, with which there is a serious risk of causing intense suffering to all parties involved, since the relations between physician, patient and family are governed by nuances that are not accessible to the judges.

It is fundamental that, from the improvement of the communication techniques and the capacity to act with empathy and compassion, the health team be able to resolve more conflicts, seeking consensus with the family without the need for legal intervention. It is hoped that this will be Charlie's legacy.

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