Parental decisions that endanger children: a common form of child abuse that must be stopped

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Abstract
Children, as minors, depend on the choices made by their parents on their behalf. In the vast majority of cases, parental decisions are beneficial to their children but regarding health issues, harmful determinations are often made. This may result in total harm of children, which may even result in the death of a child. Thus, the legal situation of children in Mexico is presented here and grants them the right to receive the most optimal treatments, even against their parents wishes. This premise is also upheld internationally.

Key words: beneficial decisions, harmful decisions, parents, child abuse.

“Health is a constitutional right; moreover, it is a human right and the reason of the state.”

“It is the responsibility of parents to preserve the rights of children and to satisfy their physical and mental health needs.”

4th Constitutional Article of Mexico

Introduction
In the exercise of pediatric medicine, it is common to be presented with circumstances known as extreme situations because the decision to resolve them is difficult and creates dilemmas for both the physicians as well as the parents. Once the decisions have been made to address this situation, the result sometimes does not favor the children who are ill and who may even lose their lives because parents or guardians make determinations that go against the best interests of the child. This may be due to lack of knowledge, parental beliefs, or religious or cultural aspects. Thus, the child may die because potentially life-saving medical treatments were withheld due to the passivity and impotence of physicians and society.

On one hand, there are the rights that parents have over their children to make the best choices in order to have the best life possible. Under no circumstances, however, do parents have the right to cause the child any type of harm. On the other hand, there are the rights of minors that in Mexico and in many other countries must be protected with maximum priority, which sometimes does not occur in daily practice. Given the complexity of this situation, we present some examples that may help better understand these dilemmas.

Case #1
We present the case of a 3-year-old preschool male who was treated at the Specialty Hospital for Child-
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Children for advanced Langerhans cell histiocytosis, a disease that belongs to a group of neoplasms. The patient required chemotherapy. His clinical stage was curable if appropriate treatment was received and the complications were dealt with. The parents of this child are from a low socioeconomic level and based on their religious beliefs refused to allow their child to receive transfusions, which at that time were key to starting chemotherapy. The patient had severe anemia with a hemoglobin level of 2 g. Possibilities of recovery were high, but the parents continued with their negative stance for the transfusions and, in any case, accepted the death of the child “if that was the divine plan”. Institutional physicians were in disagreement with the parental decision, arguing that the child had the right to life and to receive the best treatment. Mexican law protects these rights and the ethics of medical practice were exercised in an attempt to convince the parents that the good, right and proper decision was for their child to receive the transfusions and medications that could cure him. Despite multiple attempts to convince the parents, they were not in agreement and the child, who required urgent attention, died a few days later before the inability of the healthcare personnel to further explore the alternatives and who are still unclear about the legal aspects of medical practice.

Case #2
We discuss a premature newborn male with extremely low weight of 700 g born at 29 weeks of gestation. He presented with hyaline membrane disease, typical for this gestational age and complicated with a grade III periventricular hemorrhage. There was a high risk of death but with 50% chance of survival with a good quality of life. The child’s father suggested that we withdraw all treatments and allow him to die because he did not want a child with future brain damage—he wanted a healthy child. The medical team disagreed with the position of the father and identified the rights a child has to receive the best treatments offered by medical and ethical standards. In that manner, limits of parents to exercise their autonomy in decision making for their children were specified because they retain this right as long as it is in the child’s favor. They have no right to harm the child by denying necessary treatments. The father was informed that no one has the right to harm anyone and even less so to a child, being the highest duties of care and protection of the parents. The father finally realized that he was wrong and agreed that his child should receive the indicated treatments and fought for his child’s life, even at the risk of not surviving. The patient died days later.

These two cases presented here occurred in a pediatric hospital in Mexico City in 2008.

Case #3
In the U.S. we present the case of a 22-year-old youth with multiple trauma and intracranial injury who needed to undergo immediate surgery due to the severity of his brain injury. The parents gave consent for the surgery but not for the transfusions. The hospital brought this case to court twice to obtain permission for the transfusions and finally was granted the permission. The Supreme Court of Pennsylvania considered that the courts had been correct to ignore the statements of the family, the fiancée, and the pastor about the patient’s religious beliefs because by not having rapid intervention, he could have died. The need to save a life was more important than the opinions of others about what the patient would have wanted. The Court held that in urgent cases only a full, conscious decision presented by the patient may override what constitutes what is medically necessary. These issues are clearly related to the violation of human rights, powers and privileges that persons have as a result of the mere fact of being human—in other words, inalienable rights and inherent human dignity.

There have been three generations of human rights. The first was consolidated in 1789 with the
French Revolution, ratified and extended in the Universal Declaration of Human Rights on December 10, 1948 in Paris. They include the right to live, to have physical integrity, to have security and freedom, and the state must do everything possible to guarantee these rights. The intention is by no means the defense of theoretical postulates but instead the response to serious human rights violations that occurred during WWII. However, human rights abuse is still rampant in various parts of the world, despite thousands of years of human evolution, as is the case of wars, famine, violence, abuse, among others, where children suffer undue stress. This International Declaration reflects a universal ethical consensus on the most basic aspirations shared by all humans worldwide regardless of ethnicity, socioeconomic status, gender, religion, sexual orientation, among others. It is the most powerful tool to defend the dignity and value of all humans.

This Declaration makes its appearance in history as a response to the barbarism in order that the abuse and cruelty imposed by humans would cease. In this regard to the right to life, it states that no one can deprive life to another or even endanger it. In the second and third generation of this Declaration it identifies social, political, labor, and healthcare rights, among others.

The worldwide situation of children is complex especially in developing countries such as the case of Mexico where children are subjected to arbitrary and unjustifiable abuse. Their situation is so difficult that in 1989 the United Nations approved the Declaration of the Rights of Children, which encompasses the right to life, protection, education, food, to be part of a family, to be healthy, among many others. Mexico signed as an involved party and is committed to comply.1,3,5

Autonomy is one of the fundamental ethical principles of social coexistence in humans and with other living beings and has an important role in medical decision-making relating to pediatrics. According to Mexican law and that of most countries, individuals acquire their autonomy legally until adult age, which is 18 years. Autonomy represents a great opportunity for all individuals to exercise their freedom and dignity, to choose what they see fit, to adopt a style of life, choose determined customs, choose a religion or not, and freely express their ideas. It is the ability of self-determination of man and one of the first-generation human rights.1,3 The principle of autonomy is the manifestation of human dignity in the fact of utmost importance for the life of the subject and is etymologically defined as the power to govern oneself. It presupposes the capacity for understanding, reflection, reasoning and independent choice.2,6 It is the legal and moral right to make one’s own life decisions. Its foundations can be traced to the philosophical position of Locke, who maintained the notion of negative rights, which are those that a person has in not having anyone involved in their personal and private affairs. To the idea of Kant, the dignity of the person is his ability to be free. For Mill, the only restriction on individual freedom is the harm to others.2,6 This marks the limit of autonomy because it can only be exercised by the person himself and ends where others begin. Freedom can be exercised without restrictions while not affecting anyone. When a subject has false or poorly calibrated ideas, we have an obligation to try to persuade him.2 This raises a broad and abstract obligation that does not allow exception. “We must respect the point of views and rights of other people, provided their ideas and actions do not pose a serious harm to others”. In this case, society may limit the exercise of autonomy.6 Autonomy is not an absolute value nor is it the only moral imperative.

Thus arise the limitations of the principle of autonomy in their philosophical and legal aspects:

1. When their right to autonomy enters into conflicts with the rights of others or the vital rights as dependents of the subject, the principle of autonomy cannot prevail against the circum-
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stances that endanger and harm others dependent on the individual (pregnant women, minor children, and destitute parents).

2. When the patient’s choice of behavior enters into conflict with the moral convictions of the society in which it operates, the right of autonomy should not injure society.

Minors and intellectually disabled persons are only subject to the law represented by the judge in the hearing. There are no religious, sectarian, or philosophical rights or customs that may place the life or physical or moral integrity at their mercy.

3. Judicial intervention assumes liability for the results of the acts and medical practices that contradict what is not allowed by religious groups.

4. The loss of freedom to professionals involved in the medical act of resuscitation or transfusions, not accepted by a particular belief, is replaced by the law, which prioritizes the right to life.

Since 1976, with respect to decision-making by representative persons, the courts have been very involved, but there are still many issues to resolve. The criteria for decision making are replacement trial, autonomy and the best interest of the patient.

- **Replacement trial.** If the patient is incompetent, the decision must be made by a representative (the decision should be the same as what the incompetent person would make if competent)

- **Autonomy.** What the patient decided when he was competent, with or without previous guidance

- **The best interest.** A search for the best benefit of all the possible options. The best term is used because the representative has an obligation to maximize the benefits, with an analysis of all the options. It is in pursuit of the well-being of the assessment of individual risks and benefits of the different options.

In relation to children, the responsibility of the parents towards their children is legally defined as an obligation to act in their best interest. The law assumes it as such and the State should not intervene except in those extreme cases where it disagrees with a parental decision, which may have serious consequences for the child. An example would be when parents who are Jehovah’s Witnesses refuse vital transfusions for their children. Thus, the principle of best interest may have supremacy over that of autonomy. In the U.S. the law on Child Abuse and Treatment Act defines child abuse as “not initiating indicated medical treatment”. A medically indicated treatment is one that can change the conditions that endanger the life of the child.

With respect to children, parents should make decisions for their children considering their obligation of protection and care. The vast majority of life-threatening situations do not present difficulties because, in general, parents act responsibly. Nevertheless, situations occur in everyday life where adults may abuse the right to decide for their children. This is the case in pediatric medicine where parents frequently opt for choices that are not conducive to the health of the child and may cause harm, even death, when parents refuse appropriate medical treatment for their children.

There are situations in which parents of children with cancer, whether or not at an advanced stage, refuse medical treatments proposed by physicians that provide a chance of recuperation or recovery. There are cases where parents refuse to allow seriously ill premature infants from receiving potentially curative treatments. Other parents may exclude their children from surgical treatments that can result in improvement of the health of their child. In other situations that are becoming
more common, some parents, citing religious reasons, refuse to allow sick children from receiving blood transfusions, such as is the case of Jehovah’s Witnesses. Sometimes parents of children with advanced chronic diseases do not want to subject them to any palliative surgical procedure that may help the child to eat or breathe better as is the case of gastrostomy or tracheostomy, procedures that can make the child better cope with their lives.

From the ethical and legal viewpoint, adults must give their consent when physicians will perform high-risk procedures in children, with prior, comprehensive, clear and precise information provided at their level of understanding. However, in cases of extreme urgency with a high-risk of loss of life, physicians have the authorization to carry out these procedures even without the usual approval. This is known as therapeutic privilege and is the only exception to informed consent.

In the case of adults, when they refuse to accept a proposed, even life-saving treatment, the physician has an obligation to respect that decision. In the case of minor children, it is assumed that parents make the choices for their children, considering that they act rationally, seeking the protection and the benefit of the child. The turning point occurs when the parents, having received complete information, then refuse to have their child receive the proposed medical treatment and even agree to allow the child die. This limiting situation represents a major dilemma for pediatricians because the first moral obligation is to provide the best treatments for the child. The physician responsible for the child may assume a passive attitude and accept the wishes of the parents, which may cause the death of the child. This represents an absolute injustice and this behavior displayed by many physicians is explained by ignorance of the laws and the ethical principles governing medical practice. Physicians do not want to be involved in legal situations. The fear of a lawsuit largely explains this situation. In several countries, due to this dilemma, physicians resort to judicial authority to attempt to save the lives of children.

In these cases, judges order parents that the child should receive treatment and by not accepting it they may be subjected to the removal of custody of the child. This has not happened in Mexico.8

Recently, the symbolic case of Hannah Jones occurred. She was a 13-year-old British teenager with leukemia and irreversible cardiac damage that, according to British physicians, required a heart transplant. The parents communicated to the physicians Hannah’s desire not to undergo the transplant. The physicians approached the judicial authorities who informed the parents that their parental rights were being withdrawn so that the child could undergo surgery. The Minister for the Protection of Children arrived at the home of the young patient to speak to the patient and her parents. The Minister met privately with the child who, with her arguments, convinced the Minister that surgery was not her best option because the transplant offered doubtful efficacy. She explained that she had already been subjected to multiple procedures and suffering and wanted to spend her last days in a better condition at home with her family. The minister respected her decision, which he considered to be mature, just as her parents had. Here arises one of the many arguments that teenagers have to defend their decision-making at crucial moments of their life because a chronic illness provides them with a high level of maturity that adults often do not have.8

The Council of the European Convention on Human Rights and Biomedicine convened in 1997 with rank of law in all member countries. This Council makes clear that a patient may reject the proposed treatment by physicians without having to justify his/her decision. It is an option that falls within the autonomy of each person and can be taken to the extreme, provided of course that the patient is in full command of his/her mental faculties.8 The intent is increasing that adolescents with sufficient maturity are able to make decisions and exercise their personal autonomy in matters concerning their physical well-being.8 This theory is in accordance with Article 12 of the Declara-
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Article 3° of the Universal Declaration of Human Rights defines the right of every individual to life, liberty and their personal security.² The first articles of the International Declaration on the Rights of Children point to the right to life and well-being as the principal rights and no one, not even the parents, has the right to violate these properties.³

On May 29, 2000 a new federal law entitled Law for the Protection of the Rights of Children and Adolescents was published in the Official Journal of the Federation, which has 47 articles and stipulates the commitment of Mexico for the fulfillment of their rights. This law states, in Article 2, that all children under 18 years of age are included. Article 3 specifies that the protection of the rights of children and adolescents is intended to assure a complete and full development. The guiding principles for the protection of these rights are as follows:

a) The best interests of children
b) NO discrimination under any circumstances and for any reason
c) The right to equality without any distinction (there are other principles that can be found at the original source).¹¹

Article 4 states that “In accordance with the principle of the best interest of children, the rules are applicable to children and adolescents deemed to have responsibility to primarily ensure care and assistance that they require to achieve full growth and development within an environment of family and social well-being”.

Following this principle, the exercise of the rights of adults cannot, at any time, or under any circumstances, influence the execution of the rights of children and adolescents. The application of this law will serve to respect this principle as well as to the guarantees and fundamental rights recognized in the Political Constitution of the United Mexican States.¹¹
Article 11 in paragraph N states: “It is the obligation of the parents and of any person who cares for children and adolescents to protect them against all forms of abuse, prejudice, damage, assault, abuse, trafficking and exploitation”. This implies that they cannot violate the right of persons exercising parental authority or custody of children and adolescents against their physical or mental integrity or act to the detriment of their development.

Article 21 states that children and adolescents have the right to be protected against acts or omissions that may affect their physical and mental healthcare, their normal development or their right to education, in the terms put forth in Article 3° of the Constitution. They will be protected when they are affected by carelessness, neglect, abandonment, or emotional, physical or sexual abuse.

Legally, children under 18 years of age cannot make decisions about the treatments that they must be submitted to, in case of a health matter. Parents, who have the primary responsibility for the children, should make decisions in accordance with the life of their children (including medical treatment), exerting their autonomy and freedom to choose what best benefits their children. Under those circumstances there is no conflict, and it is assumed that the parents will act responsibly and with reason to always decide in an appropriate manner for the minor children. But when parents refuse to accept treatment for their child, including transfusions, even at the expense of the lives of their children, putting their ideas, mistrust, doubts about the benefits of the treatments, or their religious beliefs, they are committing acts of wrongdoing that may cause harm to the child and abuse the autonomy that they legally have. In this case, they are abusing, literally and seriously, the unalienable rights of their children.

The behavior of parents to refuse medical treatment at that time are considered as suitable by medical sciences, including blood transfusions, are included in the doctrine of Radical liberalism, which allows individuals to do whatever they want but infringe upon the freedom of others. This is morally and legally unacceptable. It is unacceptable for a child to lose a life due to ignorance, dogmas and religious fundamentalist ideas. When there is intolerance, religious and political fanaticism of any kind, ethics is terminated, which precisely proposes respect for human rights.

In this situation, the bioethical principles from the model known as Principilism are strongly polarized. On one hand we find parental autonomy and, on the other hand, fundamental and inalienable rights of a minor child, which are the right to life, protection, safety, health and the enjoyment of life as fully as possible, which converge on justice, non-maleficence and beneficence.

Over time, pediatricians have taken a passive attitude in this complex situation and we have allowed what surely must be considered as abuse against children, causing many premature and unnecessary deaths. Abuse and neglect of children have grown such that in 1990, the Advisory Board on Child Abuse and Neglect created a national emergency plan to protect children. In the U.S. it is estimated that 1 to 1.5% of children suffer abuse or neglect. One form of child abuse is incompetency or neglect. Negligence may be defined as the inability of a caretaker to provide a child with healthy, educational, psychological, and nutritional conditions as well as adequate housing and protection against all hazards.

Worldwide we have found cases of serious abuse and neglect that threaten the health of minors because physicians and all personnel engaged in pediatric healthcare must increase their knowledge and their awareness of this major problem that concerns both poor and industrialized countries. In Kenya, for example, adults tend to refer more often to the abandonment and neglect when asked to define child abuse and, in this community, 22% of children feel that they have been victims of negligence by their parents. In the U.S. negligence is also the cause of 60% of abuse cases reported.
to the authorities, with a frequency estimated at 1.5%.\textsuperscript{15}

Dubowitz expresses that one can speak of neglect if the child’s necessities are left unattended, and appropriate measures are needed to identify and to correct these deficiencies. Examples of parental neglect can include passivity in the absence of growth, disobeying medical advice, failure to provide necessary medical care, alcohol and drug abuse during pregnancy and abandonment.\textsuperscript{14}

In 1999, following a consultation on child abuse prevention, World Health Organization arranged for a large number of national delegates to accept the following terms: “child abuse includes all forms of physical and/or psychological violence, sexual abuse, abandonment and negligence, commercial exploitation or otherwise, which involve an actual or potential damage to the child’s health, survival and development or dignity, in the context of a relationship of responsibility, trust or authority”.\textsuperscript{15}

Recently, Guillermo Ortiz Mayagoitia, president of the Supreme Court of Mexico, said: “For the Judiciary Authority of the Federation, 2009 will be the year for society to give space to the voices of it”.\textsuperscript{16} Against this background, it is necessary for pediatricians, as an important social sector who care for about 40 million Mexican children <18 years of age, to act to defend the best interests of these children. We take a step forward to provide security, we gain awareness of Mexican and international laws protecting children. Physicians will avoid legal problems because this fear has prevented us from acting.

It is desirable that hospitals throughout Mexico have a flexible and expedited strategy to obtain judicial orders so that children receive the best necessary medical treatments at any time. Various countries have this modality for the resolution of these dilemmas because they have the absolute decision of the protection of minors. There is no need to change the laws, but instead to implement them, because our Constitution protects the rights of Mexicans. The Religions Act law is clear, the Declaration of the Rights of Children serves as an international treaty, Civil Code Article 444 states that custody be terminated when “depraved habits of parents, ill treatment or abandonment of their duties could compromise health, safety or morals of children”.\textsuperscript{17}

Ensuring the safety of the child must be the priority of any strategy. No therapeutic project must set aside this requirement. If the child is not safe, it is likely that he/she will return to being a victim of abuse. Therefore, we must put into place mechanisms of protection with an adequate level of surveillance. If there are no possibilities to protect the child, then the child should be removed from the family unless a significant surveillance network has been established. The issue of child safety is frustrating for all those involved in the fight against abuse, for the frequent abuses that continue to be committed, for the abuse of the autonomy of the parents to those who have no rights, which is in flagrant violation of the rights of the children and often ends with the death of the child.

In pediatric care, a therapeutic modality does not exist that is more important than to guard the safety of the children and there should be no obstacles in the treatment for guaranteeing their safety.\textsuperscript{18}

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