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PEDIATRIC THEME

Informed consent and parental refusal to medical treatment in childhood. The threshold of medical and social tolerance. Part I[☆]

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Abstract Informed consent is a right of all individuals and no one can force anyone to receive treatment against their wishes. The right to accept or refuse treatment persists in individuals who are incompetent from a legal point of view; this is exercised on their behalf by a thirdparty. Children are considered incompetent to make medical decisions about their own health and their parents or legal guardians are empowered to make those decisions. However, parental authority is not absolute and there are situations where their decisions are not the best, sometimes leading to jeopardizing the well-being and even the lives of their children, forcing the state to intervene on behalf of the best interests of the child. This is the reason why it is necessary to ask the following questions: is it really the child's best interest that moves us to legally intervene when a parent refuses to accept the proposed medical treatment or is the damage done to make this decision? What kind of parental decisions are those that should not be tolerated? After a review of the theme, we conclude that if the decision of the parents regarding a medical decision is considered to be made with maleficence that is harmful to the child, it is justified that the State intervenes. Finally, we exposed four criteria that can be used in making decisions in complex cases where parents refuse treatment for their children.

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PALABRAS CLAVE

Interés superior;
Maleficencia;
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Consentimiento
informado del menor;
Negación paterna del
tratamiento médico;
Parens patriae;
Derechos del Niño

Consentimiento informado y rechazo de los padres al tratamiento médico en edad pediátrica. El umbral de la tolerancia médica y social. Parte I

Resumen El consentimiento informado es un derecho de todos los individuos y nadie puede obligar a ninguna persona a recibir un tratamiento en contra de su voluntad. Este derecho de aceptar o rechazar un tratamiento no desaparece en los individuos que son incompetentes desde un punto de vista legal: este se ejerce en su nombre por un tercero. A los niños se les considera incompetentes para la toma de decisiones médicas respecto de su propia salud, y son sus padres o tutores legales quienes en nombre del niño deben tomar estas decisiones. Sin embargo la autoridad de los padres no es absoluta, y existen situaciones en las que sus decisiones no son las mejores; en ocasiones incluso llegan a poner en riesgo el bienestar y hasta la vida de sus hijos, obligando al Estado a intervenir en nombre del mejor interés del menor. Es por ello que es necesario plantearse las siguientes preguntas: ¿es el interés superior del niño lo que nos mueve a intervenir judicialmente cuando un padre se rehúsa a aceptar el tratamiento médico propuesto, o es el daño que se le causa al menor con esta decisión? ¿Qué tipo de decisiones paternas son las que no deben de tolerarse? Después de hacer una revisión del tema concluiremos que si la decisión de los padres respecto a una decisión médica a tomar en relación con la salud de sus hijos se juzga hecha con maleficencia, es decir dañina para el menor, se justifica que el Estado intervenga. En la segunda parte de este artículo exponemos cuatro criterios que pueden ser utilizados en la toma de decisiones de casos complejos, dondelos padres rehúsan aceptar el tratamiento para sus hijos.

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1. Introduction

In Mexico, and in almost every country throughout the world, parents not only have the right but the obligation to make the best decisions for their children while they are minors. By definition and in accordance with Article 1 of the Convention on the Rights of the Child,¹ “child” should be understood as every human being (regardless of sex), <18 years of age, and who should be protected by parents, society and the State.

In this regard, it is important that everyone who works with children recognizes the obligation they have to respect their life and liberty and to ensure that they receive maximum protection and care that their condition requires, avoiding any damage or assault. It is our job to recognize when state intervention is justified before the decisions of parents and legal guardians of the rights of their children.

We will gradually enter the tortuous path of the complex decision about whether we as physicians should intervene and not tolerate the decisions of parents in regard to their children’s health. To do this, it will be necessary to clarify concepts that will allow a better understanding of the situation.

2. Informed consent with minors

Providing informed consent is a right for all regarding the provision of medical decisions. A competent adult who refuses the proposed treatment is fully supported by the Constitution. This right does not disappear in the case of the incompetent person from a legal point of view (mentally

handicapped, children, psychiatric patients); the difference is that it must be exercised by a third party.²

Minority is a disability established by law and constitutes a restriction on legal capacity, but those who are in this condition “*can exercise their rights and obligations through their representatives*”, considering that any individual is entitled to his identity and the State is obligated to guarantee it. That identity is formed by the proper name, the filial and genealogical history, recognition of legal personality and nationality.

Autonomy of the minor patient is the subject of gradual development until full acquisition. However, if we speak about a child, *former definition*, we speak of a subject under state protection. It is then the task of the State to protect the child and, in this case, provisionally protect him (until attaining full autonomy), even from his own decisions.³

It follows that every person from birth to death has the capacity for enjoyment, considered as the ability to have rights or be the subject of obligations. Although he may *lack the ability to exercise*, it does not mean he has no legal personality; therefore, it is undisputed that the rights of children are protected by law. This law recognizes that parents are the best to know the needs and desires of their children and family. They know what the best decisions are as they are empathetic with their children. It is also true that the decision making in the family strengthens and enables its growth, avoiding conflicts of interest among its members. These are reasons why it is clear that the development of the family is favored comprehensively.

Therefore, the replacing of decisions corresponds essentially to parents in the case of children. This is not because

they are those who love their children more than others, but because the family is a welfare institution. As the role of the State is that of non-maleficence, the family's role is welfare. Parents have to define the content of the welfare of their child but can never act in a maleficent manner. This is what the State must monitor. It follows to say that parental authority is not absolute in any way, and when the welfare and lives of children are at risk or in danger, the State has an obligation to intervene.^{4,5}

It is now appropriate to clarify the position of minors <18 years throughout their childhood and when should the physician and parents listen and take into account their wishes and preferences. Minors >16 years of age and <18 years of age are a group that should be considered especially as their ability to act is recognized, although not completed. Legislative doctrine has advised the risks of starting with a chronological approach in minor patients, without any clarification or adjustment because the key is that minors should be guaranteed the maturity and natural ability, which not always is directly related to age but must be analyzed in each case. In our country, it is not yet legislated under what conditions the child will have autonomy to decide on matters of health and the capacity to act in matters concerning his health.

Although we talk about a mature minor, maturity is the result of a gradual evolution, which in regard to issues as important as the decisions at the end of life, he continues to evolve well beyond even the legal age.^{6,7} What is established is that physicians and parents are required to listen to the views of minor children >8 and <18 years old.⁸ The pediatrician should properly inform the child because to realize the right of the child to be heard, it is absolutely essential that the information provided to the child is appropriately tailored to his personal circumstances, maturity (not necessarily dependent on age) and shall be adequate to his possibilities of understanding and insight. The difficulty arises in determining the time when we can understand that a child has sufficient judgment and full mental maturity. A major problem represents the value that the pediatrician gives to the will of the child, especially when it disagrees with the decision of the parents. We must assume that any value will be given to the opinion of the child because otherwise it not only would make no sense to the establishment of this assumption, but it would not be compatible with the basic idea of respect for the will of the patient.^{9,10} What is very clear is that if the child's opinion is contrary to his best interest (unmotivated refusal of medical treatment), this cannot be contemplated. Neither social maturation nor brain chemistry of a 16-year-old subject usually makes him mature enough to make these types of decisions.

In the case of children <8 years of age, replacement of their wishes and preferences according to the will of their parents or guardians is automatic, who make up for this lack of "capacity", corresponding to them not only the provision of informed consent but all decisions of their children to the extent that they can offer their opinion and be autonomous in decision making. Parental decisions, however, should not be considered as full and irrevocable. The first aspect to be monitored is that they must be beneficial to the child, which requires parents or guardians to make decisions always in favor, respecting their dignity and autonomy. The theme of

maturity and autonomy of children represents a complexity that cannot be fully analyzed in this paper; however, at least it is envisioned as it will be the subject of a further study.

The Civil Code, eighth title of parental authority, after attributing the power of unemancipated minors to parents, forces this to always be exercised for *the benefit* of the children. Therefore, the responsible person who replaces the child in the capacity to decide must consider the extent of the consequences that medical treatment may have on the child's life. These consequences obviously include a weighing of possible irreversible effects that medical intervention can produce, to the extent that treatments that have that character could eventually determine certain aspects of the future life of the child. The decision taken should be as objective as possible and proportionate to the needs that should be met, always in favor of the child and with respect for personal dignity.

There are medical treatments that have little impact on the autonomy of the child and represent obvious beneficial medical effects. In these cases it is clear that parents may decide for the child. For example, no objection could be made to the parents who hospitalize their child for appendicitis or who allow the use of vaccines despite that the minor refuses treatment and attempts to avoid it since the benefits are obvious. It is, therefore, reasonable to conclude that the autonomy of the child is not violated. The child, upon reaching adulthood, will recognize the importance of this action and be grateful. Dworkin calls it "*future-oriented consent*", i.e., parents will consent to something that children will be appreciative of in the future. On the contrary, it would not be admissible in any way that a parent force a child to undergo a medical intervention that profoundly affects his autonomy and is not necessary for maintaining his health, such as submitting to a gender-altering procedure or a surgery for aesthetic reasons (nose, ears, Bichat's fat glands).¹¹ In these cases, the parent imposes criteria that the minor is not yet able to refuse or share and do not represent an obvious benefit, possibly an assault on the child's autonomy. It is not the case, for example, of beliefs that when the child reaches the age of majority he could reject them and opt for other choices. In the case of medical interventions, consequences may be irreversible and undesirable for the future adult. There are examples that are not entirely clear. For example, there may be a parent whose child has a severe language delay and decides not to seek help due lack of time. In this situation, the parent is not acting in the best interest of the child. This will have severe repercussions on the child's education and later in the workplace and encompassing the person's economic future. Should we take legal action in this case?

We delve deeper into the winding and hilly course to determine the decision limitations for parents in relation to medical treatment proposed for their minor children. At the time of decision making, the importance of respecting the rights to identity, human dignity and the free development of the personality of children should be specifically evaluated. Because of the obligation to uphold these rights, it has become necessary to establish limits for parents when adopting medical decisions for their children. Children are not "property" and their life and freedom must be of their exclusive autonomy.

3. The interests of the child

The first criterion to consider should be acting in *the best interests of the child*. If the law and doctrine have dealt extensively to ensure that anyone can go to court to obtain protection or satisfaction of their rights in order to avoid any damage in the legal field, it is undeniable that, in a legal dispute, the legal interests of a minor are involved. This becomes a clear preeminence.

In this context it became necessary to protect with international legal instruments and domestic laws the *best interests of the child* in order to bind both individuals and authorities to respect and ensure the welfare of children beyond the positive prevailing national legal system.

Thus, we find that Mexico signed the Convention on the Rights of the Child, adopted by the Senate on June 19, 1990, according to the decree published in the Official Gazette on July 31, 1990 and ratified by the Chief Executive on August 10, 1990. Compliance is mandatory according to express provision of Article 133 of the Mexican Constitution and whose articles 2, 3, 9, 12, 19, 20, 21 and 27 show that the States "Parties" shall take all appropriate measures to ensure "...that the child is protected..." against all forms of discrimination or punishment on the basis of the status, activities, expressed opinions or beliefs of their parents, their guardians or their relatives, as well as the fundamental importance of the child to mature under the protection and responsibility of parents, particularly surrounded by affection and moral and economic security. Furthermore, the Convention proclaimed that "...the interest of the child is a guiding principle for those responsible for his education, health and nutrition..."

In this vein, on May 29, 2000 the Law for the Protection of the Rights of Girls, Boys and Adolescents was published in the Official Gazette, which itself is based on the sixth paragraph of Article 4 of the Mexican Constitution. Before the Convention on the Rights of the Child, there was no "catalog of rights", which caused that the notion of "best interests" seems to refer to a type of kindly interest and somewhat evanescent and particular that could impose solutions strictly of "right".¹² However, once a wide range of children's rights are recognized, it is not possible to continue supporting a vague notion of that interest. From the force of the Convention, the best interests of the child ceased to be a *desirable social objective* executed by a charitable authority and became a *guarantor legal principle* requiring the authority to respect it. Prior to the Convention, the function of the best interests of the child was to appeal to the conscience and benevolence of the authority to make the best decision. From the Convention, the best interest of the child was formulated as a guarantee of the rights of children. This principle reminds the authority of what it is, that it "is" a legal solution in strict compliance with the rights of children and non-compliance can be legally sanctioned.^{13,14}

4. The doctrine of *Parens patriae*

Parens patriae is the Latin phrase meaning "father of the nation" and refers to the public power of the State to intervene as a substitute parent for minors and incompetent adults in decision making. Acting as *guardian of the rights*

and welfare of minors, the State may restrict parental control over the children.¹⁵ A clear way to exemplify this is the existence of laws against child abuse and child labor. It is recognized that the rights of parents over their children are not absolute and are limited by the children's own rights, i.e., for their own interests.

The criterion of the best interests is not based on the value of self-determination but only in protecting the welfare of the child.¹⁶ The representative or legal guardian must take into account factors such as the relief of suffering, the preservation or restoration of functionality, quality and duration of life. In this respect, Buchanan and Brock expressed "...action should be taken so that the maximum welfare for the individual (child) is promoted."²

To date, many efforts have been made to determine the appropriate course of action focusing on those individuals who are considered incompetent to make their own decisions. The attorney involved in decision-making must have the ability and maturity to determine the best option for the client, one that reflects the wishes that the patient would choose if able, and if those wishes are unknown (being children) then it should be on behalf of their best interests.^{17,18}

If the parental decision regarding their child's health is deemed contrary to the interests of the child, i.e., harmful, State intervention is justified in the situation. The best interest of the child is currently the ethical and legal standard for determining in which cases the authorities must intervene. However, is it the best standard for situations in which medical decisions are not accepted by the parents? Might parents argue that their decision is in the best interest of their child and contrary to the decision of the physician? Parental decisions, until proven otherwise, always seek to benefit their child in every way.¹⁸

5. Threshold to intervene in the decisions of parents in regard to their children's health

In daily practice, pediatricians infrequently are confronted with cases in which the decisions of parents are opposed to medical decisions. For a number of reasons, the standard of the best interests of the child is difficult to implement and appropriately understand.^{18,19} It is much easier to argue for the interests of the child when the child's life is in danger. However, in situations where there is no danger, conflict may be generated between the perspective of parents and physicians.^{19,20}

There are several situations in which there are significant differences between medical and parental decisions. A common situation is that in which the interest of the child is linked to a question of family values. Parents express that these decisions are for the good of the child and are in the best interests of their child. In this case, we discuss the example of Jehovah's Witness parents who believe that the "no authorization" of blood transfusions (under any circumstances) is the best option, but thereby cause the death of the child. Parents will feel that their decisions are made in the best interests of their child and, for many, life after death is more valuable than earthly life. Therefore, it is a difficult conflict to overcome, arguing against parents who care for the spiritual salvation of their children.¹⁸

It should be noted that, in matters related to medical decisions, moral and religious concepts have a fundamental influence. However, neither the parents nor the legal representatives of a disabled person or relatives of someone who is in a state of unconsciousness and must be involved are entitled to impose their views.

In these cases, the third substitute or parent has no legitimacy with the patient to take their particular approach when it diverges from the medically indicated option. To this end, parents do not have a strictly subjective right concerning decisions about their child's health: parental rights are conditioned to the *welfare of the child*. In this sense, they are merely powers. Obviously, there are certain rights of parents in relation to children in which the State cannot interfere unreasonably (e.g., the right to see them and live with them). Parents' legal positions regarding the care of the child are powers but not rights. Therefore, in the words of De Lora: "The best justification for moving the religious criterion—in the case of refusing blood transfusions by Jehovah's Witnesses patients—is, in my opinion, to point to the conditions of possibility and the future exercise of the autonomy of the child"²³ so that the decisions of parents are refused in order to fully generate future autonomy in their children.

Another example is that where parents seek to identify life-threatening genetic diseases for functionality, but at the time of application there are no signs of disease.²¹ Physicians could refuse and argue that this could involve a substantial psychosocial risk, which would be the reason for their rejection.²⁰ The nature of the interest is often complex, and although the medical considerations are important, so are the interests of the family and the child, which are influenced by emotional, psychological and social aspects. A second situation that can occur is that where prospects vary depending on the angle from which they are observed. The physician cannot see the treatment imposed in the same way that parents see it. The physician will see the chances of a cure, but parents may see the suffering imposed by the burden of medical treatment. For example, in the case of an adolescent with leukemia, the physician will request chemotherapy, which "improves" the survival of the adolescent. However, for parents, the burden on their child may not be a decision that results in their best interests as well as for the patient. This treatment will prevent their child from attending school. It may perhaps involve changing their place of residence and leaving behind brothers or sisters, or being forced to sell their house and car to cover expenses. Although treatment will result, medically speaking, in survival for the patient, for parents it may not be ideal, concluding that perhaps the increased chance of survival does not justify the burden imposed by the treatment. It is not clear then that the best interests of the child is always the cornerstone in making medical decisions.^{2,5,22}

Therefore, many physicians, bioethicists and parents are in conflict. Physicians use the best interests of the child as a standard to be equally applied to everyone without observing contexts, without analyzing or reviewing individual situations. They may choose to apply for state intervention in situations where it is not warranted and that the disagreement could be resolved between parents and physicians. This worsens the relationship with the parents and the medical evolution of the child and does not guarantee a success-

ful solution. However, it is the product of uncertainty and ignorance and the fear of committing errors.

Using the example of the German legal doctrine, we can see how they adhere to collect the various cases in which there may be a conflict between the child and their environment to provide a simple guideline: although there may be other legitimate interests, the interest of the child must prevail or *the child's sake*, taking into account that every child, in every conflict, *deserves a specific and different solution depending on the situation*. Therefore, it is not possible to search concepts to define the best interests but to be concrete and focus on each course, in each particular case. Therefore, the German doctrine has stated that "child's sake" is the key to resolve the tensions created between parents and State authorities responsible for ensuring the rights of the child. *The basic guideline is the priority of the right of the minor over any other interest and the definition cannot be rigid and inflexible*. This alone is the principle that guides both the authorities and the entire society to take the necessary measures to ensure that the fundamental rights of minors are respected.

Throughout the history of diseases, classical medical doctrine has considered that the person best able to objectively understand the greatest benefit for the minor is the physician. Hence, no one, not the parents themselves, have the ability to intervene when life, health or the welfare of the child is at risk. Otherwise, it would be an immoral and illegal act. This manner of acting and thinking is unacceptable and wrong in our times. At present, the belief that the physician's decision is absolute is wrong because it is a violation of considerable magnitude in regard to individual rights. Contrary to what may be implied, there is no objective health or welfare concept because there are values involved. In pluralist societies these are not homogeneous or absolute and pluralism is protected by a human right for the right to freedom of conscience. The thesis that has been imposed over the last two centuries is that the world of values must be privately held, and public values that concern us all arise from rational consensus among members of society. Therefore, in his text entitled *Bioethics and Pediatrics*, Diego Gracia says "...that the modern world has had to divide the old *welfare* construct into two principles known as *beneficence and non-maleficence*." Beneficence remains as self-management of private individuals according to their particular set of values and life plan. In contrast, non-maleficence is established by means of rational consensus and should always be managed by the State. In the case of minors (at least younger than 12 years) who are assumed to not have their own system of values and therefore cannot define their own welfare, the decisions correspond to parents (the family) to provide child welfare values and to the State to ensure non-maleficence. The State must be concerned that parents (guardians) should not act to the detriment of the minor and this would be the threshold for intervention.²³

The dilemma is that the physician has the certainty to decide when it is important to ask for State intervention or when it is appropriate to tolerate the decisions of parents. The intervention of the State is fully justified when the actions and decisions of parents *damage* or are *maleficent* for their children. This is the point where the State, by necessity, must intervene without delay. The problem itself is to

then recognize when parental decisions that may be harmful to their children cannot be tolerated for any reason.^{19,24}

Defining the best interests of the minor can be impulsive and making a decision based solely on this concept may not be sufficient in cases where decisions between physicians and parents are in conflict. However, the threshold where the physician should not tolerate the decisions of parents will be when parents fail to act on behalf of their child, which automatically then comes under State management.

That said, and with the understanding that the family is the ideal environment for healthy childhood development, we entered a somewhat bleak field in which, as pediatricians, it is our turn to recognize what situations and under what conditions are justifiable to request State intervention. This will be addressed in the second part of this paper using typical cases for a better understanding of the proposal.

Conflict of interest

The authors declare no conflict of interest of any nature.

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