

PEDIATRIC THEME

The right of autonomy in children in regard to treatment: an integrated legal and ethical approach

Adalberto de Hoyos,^{1,2} Nelly F Altamirano-Bustamante,^{2,3} Myriam M Altamirano-Bustamante^{2,4}

ABSTRACT

In the case of an alteration of sex differentiation in which healthcare personnel must decide whether or not to reassign the patient's gender, an analysis of the recent modifications to Mexican law is considered along with how these modifications impact the child's treatment. Considering constitutional reforms and international conventions signed in Mexico, we studied the impact of the obligations to provide information and respect the opinion of children as well as the consequences that the parent or guardian of the minor has on pediatric practice. It is also established how respect along with ethical considerations for patient dignity together may provide answers to some difficult cases.

Key words: alteration of sex differentiation, integral approach of sex differentiation, higher interest of the minor, progressive autonomy, dignity, intrinsic dignity.

INTRODUCTION

A 7-year-old patient was seen to rule out premature puberty due to the presence of pubic hair from 4 months of age. On physical examination, the patient's height was 125 cm (75th percentile), weight 23 kg (50th percentile), target family height 1.55 cm (10th percentile), blood pressure 85/60, hyperpigmentation of the areolas and gums, folds of the hands, dark line and genital region; Tanner III pubic, Tanner III genital, Tanner breast I. Phallus measured 4 cm in length and 5 cm circumference, Prader 3, volume index 8 ml. The corpora cavernosa was palpated. The urethral meatus is noted in the perineum (hypospadias). Gonads are not palpated. There is no consanguinity or notable family history. The child was baptized and registered and identified as male. He is member of a family with four older sisters and is the male awaited by the fam-

ily. He is in the second grade with an average grade of 10 and lives in a community of 1000 inhabitants.

Upon completion of the diagnostic tests, a 46XX karyotype is obtained in 500 metaphases, bone age is 10 years, elevated adenocorticotropin hormone (ACTH), low cortisol, elevated androgenic precursors, normal serum and urine electrolytes. Ultrasound identified Mullerian remnants, presence of a urogenital sinus and short urethra. Testicular reserve test was negative.

Psychological study of the family (parents and sisters) concluded that the patient is the desired son and occupies the place of the beloved son and brother. The psychological evaluation concludes that the patient is a healthy boy who identifies, feels, perceives and behaves as a male.

The treating physician diagnosed non-salt wasting adrenal hyperplasia due to the deficiency of the 21 hydroxylase enzyme. The degree of virilization is a consequence

¹ Facultad de Estudios Superiores, Plantel Acatlán, Universidad Nacional Autónoma de México

² Grupo Transfuncional en Ética Clínica, Centro Médico Nacional Siglo XXI, Instituto Mexicano del Seguro Social

³ Instituto Nacional de Pediatría, Secretaría de Salud

⁴ Unidad de Investigación en Enfermedades Metabólicas, Centro Médico Nacional Siglo XXI, Instituto Mexicano del Seguro Social

México, D.F., México

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of the late diagnosis. Lifetime suppression with glucocorticosteroids is required along with surgical treatment. The dilemma faced is the reassignment of the gender (female), given the medical diagnosis that implies the possibility of normal puberty development and functional capacity and normal reproduction or remaining with the gender that the patient identifies with and was assigned (male). Due to the degree of hyperandrogenism, he has the possibility of functional capacity after various surgeries to correct the hypospadias, but without reproductive ability. He would also require hormonal treatment in order to induce puberty and lifetime hormone replacement therapy with exogenous testosterone.

WHAT SHOULD HEALTH PERSONNEL DO?

The ideal treatment for a patient cannot be exclusively determined as a result of clinical tests, but the diagnosis should take into consideration the will of the patient including interests, values and forms of life, i.e., the multidimensionality of the patient. From these characteristics the most appropriate treatment can be determined from a comprehensive ethical standpoint that would include moral, aretological and utilitarian considerations.¹ An important matter to be discussed is the best interest of the child and that should combine the physical and emotional health of the pediatric patient with the right of self-determination of the minor, whether the decision is surrogate or not.^{2,3}

Due to the nature of the problem, the first approach of the case presented is to apply the principle of respect of patient autonomy.⁴ This well-established premise of the principlist ethics could present problems when dealing with a minor who should receive treatment because it is assumed that the minor is incapable of making these types of decisions and one must approach the parents who will make a surrogate decision, thereby respecting the autonomy of the pediatric patient. This procedure is the standard and appears justified. It is common, even for adults who upon learning about a specific disease may be frightened and not completely understand what has been explained in order to obtain an informed consent for treatment. Occasionally, the biomedical aspects of a diagnosis or treatment are not easily understood without prior knowledge about the subject matter. Due to these inherent problems in decision making, when dealing with children such difficulties are greater because their perspective and experience are even more limited.

However, one must take into consideration that, in all cases, it is the life and health of the child that is at stake. Therefore, when possible, the obligation is to properly inform the child and, where appropriate, obtain their opinion. This is important for any decision making. One of the first actions to be taken by health personnel in the case presented is to interrogate the child. This paper discusses up to what point principlist ethics is sufficient or if it is necessary to deliberate from an integral ethical point of view (aretological, deontological and utilitarian) in order to accommodate the observance of the principle of the best interests of the child, their rights and their intrinsic dignity.^{2,5} The central question is, at what point is the child the person who should make the decisions and actively participate in their own treatment?

One should begin by reviewing the existing regulations in Mexico about children's treatment and rights to health, which have modified the way in which children are considered and up to what point a value such as the autonomy of the pediatric patient is protected.

THE LEGAL FRAMEWORK AND ITS CONSEQUENCES

In recent amendments to Article 4 of the Mexican Constitution, important regulations were added concerning the need of the State and its institutions to ensure the welfare and in particular the subject at hand, the health of a child. Such considerations are expressed in the constitutional text as follows:

- In all decisions and actions of the State, the best interests of the child will be ensured and met, fully guaranteeing their rights. Boys and girls have the right to satisfy their needs for food, health, education and recreation for their comprehensive development.

From these reforms to the constitutional text comes the Law for the Protection of the Rights of Girls, Boys and Adolescents (LPDNN), which was enacted in 2000 and underwent recent reforms in 2010. This law establishes the principles of the protection of rights of children in civil, political, educational and health arenas.⁶

This amendment to the constitutional text, and the law that followed, is recent and has an important precedent in the Convention on the Rights of the Child (CRC) of the

United Nations Organization (UN),⁷ which was ratified by Mexico in 1990. In this convention the rights of the child are contemplated, and a very important one is the right to health (which is referred to in Article 3). Both national and international law share the best interest of the child, which should be an important guide for the physician to provide treatment to a minor.

In any action concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the primary consideration will be to serve the best interests of the child. However, the difficulty lies in determining precisely what is in the best interest of the child. As in any physician/patient relationship, treatment is not established solely from the perspective of the physician, but the decisions and opinions of the patient should also be considered. For the specific characteristics of pediatric patients, their views are not considered in the first instance because of the initial presumption of incapacity.

THE OBLIGATION TO PROVIDE INFORMATION AND TO LISTEN TO AN OPINION

One of the innovations of this legislation is that it establishes the rights of children in those matters that directly concern them as well as that their opinions be heard. It is common practice for the pediatric patient to be placed aside and the discussion be held directly with the parents who are the representatives of the patient's will. Although the legal presupposition of the patient's incapacity is present, there is an obligation to explain to them what is happening, how they will be treated and what is the expectation. Obviously, the latter must be presented according to the capacity of the boy or girl. From this point of view, it is indispensable that in the case presented the child be informed of the diagnosis and the possible treatments for disorders of sexual differentiation.⁸

Article 40 of the LPDNNNA frames the obligation of the physician to directly inform the child, according to the child's capacity of understanding, about the child's condition. Frequently, it is during this important point in the physician/patient relationship where the child tends to be excluded, and the condition is only explained to the parents or guardian who in turn makes the decision whether or not to inform the patient. Of course, the only case in which it would be justified to exclude the patient would be in

the case of very young children with very limited language abilities. This creates a new dilemma in the case presented here. A very important discussion would be necessary as to whether or not to inform the patient at this stage of his development of the differences that exist between his genomic gender and his sexual identity and how useful it would be, or should this information be withheld to avoid confusion. In principle, there is no formal obstacle to informing him about this difference. However, it must be done from the perspective available to the child and all the concerns of the child must be heard. A multidisciplinary team that includes psychologists, social workers and physicians could evaluate how best to offer this information to the patient.⁹ This information will give him reasons for adhering to his treatment plan and to not perceive it as an unjustified demand from his physicians and guardians. Tact, patience and an appropriate vocabulary on the part of the physician in regard to the subject will have to be understandable to the child and are important aspects to take into consideration when speaking to the patient about his medical condition. In this case, the patient was explained that his disease was caused due to a "small gland" above the kidneys that is not functioning and not producing two hormones (prednisone and 9- α fludrohydrocortisone) that are indispensable to life. Therefore, he must take these for the rest of his life. In emergency situations, to avoid decompensation, the dosage should be increased to a double dose of prednisone and injecting hydrocortisone to prevent dehydration and hospitalization. He was also informed that in order to correct his genitals, a surgical procedure would be required. The medical team listened at all times to his opinions and concerns.

In many boys and girls, the presumption of their incapability for decision making is justified when they are unable to understand the situation they are facing due to the development of their intellectual capacity.¹⁰ Fear and lack of knowledge are the basis of their preoccupations. However, as the child grows, his capacity for reasoning and decision making increases. Perhaps it is not always possible for younger boys and girls to express their opinions, but as age increases it is clear that their emotional as well as intellectual capacities are being developed, allowing them to have a solid point of view and for their opinions be heard.

However, in discussing the physician's obligation to listen to the views of pediatric patients, Article 12 of the Convention on the Rights of the Child (CRC) states:

- The parties will guarantee the child who has the ability of forming his own judgment, the right of expressing his opinion freely in all matters affecting the child, depending on the age and maturity of the child.

Therefore, the opinion of the boy or girl should be heard, and no consideration should be given to whether the child is older or younger. In all cases in which an informed consent is required from the parents, it would be desirable that, after having met the obligation of informing the child, an informed consent is also obtained from the child.¹¹ However, as the CDN establishes, it will be dependent on the child's age and maturity that these be taken into account at the time the opinions are heard.¹² In the case presented, the child decided to continue with his male gender because he has a strong masculine identification.

Article 5 of the CDN states that both the State and the family should allow the child to know and exercise his rights according to his abilities being developed in what has been called a principle of progressive autonomy.¹³ If this culture of actively participating in the care of our health is encouraged, there will be better future prospects that boys and girls will grow with a medical and health culture that would allow them to not be passive patients, but citizens who are fully conscious of their rights and obligations in regard to their health issues and who act accordingly.

THE BEST INTERESTS OF THE CHILD

The legislation that we have reviewed proposes that children are not only objects for protection, but subjects with full rights. These rights need to be represented by a guardian or by the patient in cases where there is patient competence. However, at the time of invoking the wellbeing of the child, legislation did not comprehensively define this. Therefore, cases have arisen that seek to more precisely define this concept. A case arising from the Fifth Court on Civil Matters of the First Circuit stated the following: In the best interest of the child, the panorama of values, principles, interpretations, actions and processes is understood, directed at forging complete human development and a life with dignity as well as how to generate the material conditions that allow children to live fully and reach their maximal personal, familial and social wellbeing and whose protection should be promoted and guaranteed by

the State in carrying out its legislative, executive and judicial duties as a matter of public order and social interest.¹⁴

As we have mentioned, it is important that the best interests of the child be taken into consideration at all times during the relationship with a pediatric patient. Normally, it is assumed that the parents are the ideal representatives of the best interests of the child as well as of his rights because parents know the child better than medical personnel who have only had contact during several medical consultations. It is the parents who are responsible for the support, upbringing and education of their children.¹⁵ For this reason, parents have the knowledge of what is best for the child to adequately develop socially and culturally.¹⁶ The values and customs that we have depend on this upbringing; therefore, it is very important that any treatment respects the diversity of forms of life. Frequently, however, parents do not meet their responsibilities and occasionally the parents themselves do not allow their children to reach their maximum wellbeing.¹⁵ In such cases it appears that the physician, despite not being totally informed of what is happening with the child, may realize that the child's rights are being violated and that his present and future wellbeing are compromised. In these cases and based on the legal framework we have mentioned, the best interest of the child can be invoked, requesting a legal petition that the court (instead of the parents) will be the decision maker in regard to the health of the child.

An important consideration is that maximum wellbeing will always be reached by respecting the rights and progressive autonomy of the child. Therefore, we propose that in the best interest of the child one must combine both the self-determination of children who are able to formulate a concept of good and a plan for life. Because an older child could emancipate himself from his parents for making a decision contrary to his right and interests, medical decisions without the child's consent could also be easily questioned.

There is no simple equation for the physician to consider as being in the best interest of the child. The simplest approach, apparently, is to always protect the patient's health, considering only that which is the most efficient therapeutically from a biomedical perspective. However, the patient's best interests do not always coincide with those considered by the physician. Considering that in a culturally diverse society such as in Mexico, different forms of life, values and beliefs are legitimate, and it

should be understood that these forms of life provide an integral human development and a dignified life.¹⁷

In the case of the wellbeing of the child, one must not only protect the health of the child, but special emphasis should be placed on the actions of the physician that allow the child to develop in a manner that allows plans for their future lives. However, precisely because it is their own plans for life that one would seek to protect, the child has a legitimate interest in self-determination and in being able to decide for himself in areas as broad as possible, i.e., the power of being involved as a patient in his own care in cases as appropriate.

In the discussion of what would be in the best interests of the child in the clinical case presented, one may consider two possibilities. The first possibility would be to preserve the reproductive functions and assigned genomic sex, although this option does not consider the lifetime history and the patient's wishes. The second possibility is that the assigned gender would be preserved and hormonal therapy would be administered for life. In the case presented, the best interests of the child were protected by the family and treating physicians by informing and listening to him and deciding, after thoughtful and comprehensive analysis, that the patient would continue with the gender assigned from birth. This possibility leads to the continuation of the discussion about when, in effect, minors could participate in their care.

THE COMPETENCE OF CHILDREN AND THEIR PARTICIPATION IN TREATMENT

A rigid posture that considers all minors to be unable to make health care decisions runs the risk of abandoning the obligation to inform and seek the views of pediatric patients. Such a stance is particularly problematic in the case of adolescents who, if considered unable to give consent to treatment and without respect for confidentiality will abandon their affiliation with health institutions, affecting their own welfare and that of others.^{18,19} Typical examples of this are the failure to obtain medical advice without parental consent in matters of sexuality, not seeking medical care in teen-age pregnancy or sexually transmitted diseases and drug abuse.²⁰

The obligation to allow the patient to consent and participate independently in treatment may not be universal in the case of minors. However, older children may be

considered to participate actively and to consent to treatment. There has been discussion about the ability of children to make health decisions under extremely difficult conditions. In fact, it often happens that adult patients see their judgment clouded when there is the prospect of a serious illness and do not think rationally. However, although an attempt will be made to try to protect the child as much as possible, the views of patients are important and should be taken into consideration when the child demonstrates sufficient development to have a perspective of their own wellbeing.²¹

Although it is not possible to determine an exact age at which the competence for medical decision making arises, the criterion of variable competence presented by Buchanan and Brock can be considered.¹¹ According to these authors, decisions can be made responsibly in regard to health issues if the child shows the intellectual capacity for developing an abstraction that would allow him to choose in an autonomous and responsible manner. Similarly, it is required that the minor has developed a conception of good that is governed by certain values that could be projected to his own future and of those around him.

This approach may prove useful for evaluating the capabilities of a child because the empirical studies of the emergence of a moral conscience at a certain age are not definitive. In searching for the earlier limits of the appearance of these capabilities, it can be considered that children older than 8 or 9 years of age are patients who may be considered as older children.¹¹ However, it could be an absolute term as there are children who acquire these capabilities at a relatively early age and others who are well into adolescence and are not yet in possession of a concept of good. It is more likely that moral awareness is developed in adolescence.

Although expectations of the child and his own wellbeing are projected from limited experience, it is the expectations of the patient and therefore should be considered in a responsible manner.¹² Children who are older can generally show this concept of their own good and can project to a future beyond the discomfort and pain that may result from the required treatment.

In the case studied, according to the complete analysis² and based on the decision of the patient's family, it was decided to continue with the male allocation, perform a bilateral gonadectomy and mullerian resection and correction of the hypospadias.^{22,23} Currently, the patient attends secondary school and has demonstrated good compliance with care,

both with the glucocorticoids as well as with the monthly exogenous testosterone. The patient performs well in high school and is much loved by his family, teacher and friends.

In this case, the intrinsic dignity of the patient was also taken into consideration from a comprehensive ethical viewpoint.² This means that persons have absolute value due to the fact of being human.^{5,24} On the other hand, dignity, as understood in Western thinking and clinical ethics, is deeply linked to autonomy and the ability of persons to make decisions with respect to their own purposes and interests.²⁵ Sulmasy calls this type of dignity “flourishing” because it refers to the ability of individuals to make decisions regarding their own lives and their growth and development.⁵ The inherent dignity of the person to function in tandem with burgeoning dignity refers to a state of virtue in which the person appropriates the inherent dignity and, on that basis, develop virtues that lead to human excellence.^{5,26} In the present case, the preservation of the preferred male gender favored patient planning according to his life history and, at the same time, where an attempt has been made to protect his health and wellbeing.^{27,28}

In this case the idea of progressive autonomy is again presented as important and is narrowly related to patient dignity because it will allow him to establish a life plan that includes his medical condition, treatment and, from this life plan his development as a person. To be able to correctly discern in such complicated cases is difficult. The idea of an ethical rule that establishes a clear distinction between right and wrong is not very useful in the given context, making it more suitable via an ethical approach of the virtue.²⁹ In this, one can offer a close physician/patient relationship with the intention of not abandoning the patient and his family to make a decision alone or for the physician to impose a paternalistic point of view that would impede the patient from developing his own growth.^{30,31}

In recent times there has been an important change in the focus towards rights in childhood. This different concept establishes that in accordance with health matters, children can be considered as subjects with rights and not only as subjects to be protected. Although there is still much ground to cover, the field of pediatric medicine has fortunately been sensitive to these changes and has attempted to establish these considerations to maintain a physician/patient relationship that is respectful of the self-determination of those minors with self-interest and, at the same time, continue to look out for their best interests. It still remains to create a culture where pediatric patients

are aware that they are beneficiaries of these rights. Furthermore, an adjustment of institutional frameworks becomes necessary that incorporate these rights of children. From the ethical viewpoint, the clinical case analyzed demonstrates the possibility of the patient to make his own decision above and beyond his assent and listening to his views. However, the interests of the child were preserved by the decisions of the family and the medical team. It is clear that the combination of respect for autonomy, the inherent dignity and patient growth was imposed on the medical diagnosis and treatment choice resulted from a comprehensive ethical deliberation ensuring that the child attains the maximum possible potential expression.

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Correspondence: Dr. Adalberto de Hoyos
E-mail: ad_hoyos@yahoo.com

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