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ETHICAL ASPECTS IN PEDIATRIC GASTROENTEROLOGY

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Abstract
In a comprehensive manner, the authors approach the ethical problems of the medical procedure and implicitly the physician – patient relationship in the view of modern medicine, particularly in the field of Pediatrics and with an emphasis on pediatric gastroenterology. In this context, it is mainly pointed out the digestive endoscopy with its features from the perspective of the medical bioethics. It is emphasized the fact that based on the ethical principles, the child patient, depending on his/her age and the capacity of understanding, must be informed on his/her suffering and on the medical procedures which are necessary for the recovery of his/her health condition, even if from a legal point of view, his/her responsibility is limited or appointed to someone else. Besides the medical connotation of the informed consent, the pediatrics emphasizes its legal aspect, starting from the fact that there is a clear distinction between the medical humanism and the legal humanism.

Key words*: bioethics, child, digestive endoscopy*

Introduction

Medicine and public health, in a broader sense, have become along the time fields of the social life, which had to be taken into account by any type of social organization, and have permanently reoriented and reconsidered the relations between the partners in the structure, either the physician-patient relationship during the medical procedure, or the one between the system and the society within the public health. While the fundamental human rights have been

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provided by national and international regulations [1], the life itself, which means autonomy and freedom, has received the status of immutable and inalienable social value, the paternalist character itself of medicine, in which the physician decides and the patient executes, would be profoundly modified [2].

Although the medicine has been governed by moral and ethical principles, even from the beginning by commitments like the Oath of Hippocrates, the Prayer of Maimonide and numerous deontological codes, the evolution of society and particularly of medical sciences in the last century led to updating of principles and their adjustment to the new values [3]. Therefore, the two main ethical values: life and freedom are transformed in two ethical principles that flow from these values and namely the respect for life and the respect for individual's autonomy.

In time, this evolution has led to the change of patient-physician relations and society-health system, achieving the character of a contractual relation [4]. In the case of the society, this establishes a contract with the health system based on some rules provided by the law, while in the case of the physician-patient relation, the patient entrusts the physician with personal and intimate information regarding his/her health condition and life. In his turn, the physician must provide the patient with all the information regarding his/her suffering and the possibility to recover the health condition from the perspective of the medical procedure, along with the risks that it entails [4]. Thus, it created a partnership relation, in which the statute of patient is the one of well-informed beneficiary, partnership which takes the form of the informed consent, and the physician's statute is the one of the health care provider, whose services the patient can accept or not. Thus, the physician – patient relation, that had a paternalist character, is gradually transformed into a contractual relation with mutually binding rights and obligations, fully informed with regard to the stages of the medical procedure and its consequences [5].

The Informed Consent and its Features in Pediatrics

As a basic principle of the medical ethics, the informed consent has been established in the Universal Declaration on Bioethics and Human Rights at the 30th session of the General Conference of UNESCO of the 19th of October 2005. Article 6 of this declaration presents the consent based on the principle of autonomy in the spirit of the fundamental human rights (the right to life and freedom) and equally on the respect of the human dignity [2, 6]. Medicine, which presumes immediate interventions on the healthy or sick individual, directly affects these fundamental values regulated by the law, and as a consequence, their application involves the responsibility of both the physician or the system proposing them, and the patient or the community that accepts them. This responsibility also presumes the acceptance of the negative consequences of the medical procedure which involves at its turn the capacity to make decisions. Therefore, the procurement of the informed consent must rely on sufficient and accurate information.

When providing information, it must be taken into account the patient's level of understanding, his/her cultural values and the degree of tolerance regarding the knowledge of the truth [7]. That is why the language used, the manner of expression, the contents of information must be adapted to the level of understanding and perception of the patient, as the legal connotation of the consent must never be forgotten. We underline that, in legal terms, *the informed consent is an at-will agreement, either express or tacit, given by a person with discernment, which is not vitiated by fraud and represents a concordance between the intimate will and the one declared of the patient.*

Of course, these aspects get a special connotation in pediatrics, as it usually involves children, who are persons without discernment, or with limited capacity of understanding medical information. That is why the informed consent appears as a responsibility of the next-of-kin; parents or legal guardians. Article 4 of the Chart of Hospitalized Children issued by UNESCO, actually provides the child's right to be informed, of course, in a manner adapted to his/her age, provided that this informing is done by the physician, the caregivers and parents [8]. There is even a regulation, in the fourth article in the Hospitalized Child Carta of UNESCO, which stipulates the right of the child to be informed, of course in an accessible manner depending on his age [9]. This attitude is firstly justified under psychological aspect because the anxiety caused by silence and secrecy can induce a state of unease to the child and can even worsen the disease, and, secondly, it must be considered that nowadays the perception and intelligence of a child is superior to the previous generations, starting even since the childhood.

Therefore, if by the age of 4 a child fears the medical procedure and is looking for refuge and protection from parents, between the ages of 4 and 8, the curiosity and desire of socializing make the child accept and even take part to some medical manoeuvres and procedures, attitudes which are also stimulated by the communication with those surrounding him/her, so that after the age of 8 he/she would actively participate to the performance of some procedures and application of certain therapeutic schemes, even with the rigors entailed by the disease. Sometimes it is impressive the compliance to treatment of a child suffering from a chronic illness, either diabetes, bronchial asthma, innate disability or neoplastic disease, regardless it is a painful procedure, a diet restriction or a long-term medication therapy [3].

In this context, it is a mistake to underestimate the child's capacity to understand, accept and even cooperate for the success of the treatment, especially the school age child, if he/she is explained in his/her terms the suffering, its causes and the possible medical remedies. Starting from these facts, the Convention of the U.N. from New York in 1991, regarding the child rights, expressly provides that "*the states guarantee the child who is capable of discernment the right to freely express his/her opinion on all the problems regarding him/her, his/her opinion being taken into consideration depending on the age and the degree of maturity."*

This is due to the fact that the capacity of consent also presumes the capacity of understanding the implications of a decision and equally the capacity of rationally assessing the consequences of the decision made [10]. If by the age of 7-8 the child, even if he/she understands, prefers to "*do as mummy and daddy say*", while after the age of 9 he/she manifests the tendency of getting involved in an responsible manner, and starting with the age of 14-16 years his/her agreement and attitude must be taken into account [9]. When the consent cannot be guaranteed by parents or legal guardians, the society has the possibility to offer the agreement through its institutions, except for the emergency situations when the physician is authorized to make the most appropriate decision with the purpose of preserving life.

Features of the Informed Consent in the Pediatric Gastroenterology

It must be emphasized from the beginning the fact that, from the point of view of bioethics, there are major distinctions and particular shades in approaching different specialties and subspecialties within Pediatrics. In this context, gastroenterology has a special place especially due to the technical possibilities of which it disposes nowadays, from sequential and interventional endoscopic explorations to transplants. Besides the purely medical side in the diagnostic approach of the digestive pathology, extremely beneficial nowadays, the technical possibilities also involve risks through their invasive character which must be carefully assessed and offered as information to the patient [11]. This is why it is often necessary that each of these technical possibilities should rely on a separate ethical approach, despite the fact that, on the whole, the basic ethical principles are found in each of them.

A special place in the pediatric gastroenterology is taken by the endoscopic approach of digestive pathology, with its two sides: diagnostic endoscopy and therapeutic or interventional endoscopy, a new technical possibility that has quickly evolved in the last 40 years. We remind the fact that the first digestive endoscopy was performed in 1970 in Los Angeles on a newly born. The technical development of flexible endoscopes has allowed the extension of endoscopic investigations, so that nowadays pediatric gastroenterology can no longer be practiced without endoscopic exploration, whose main advantage is that it allows the visualization of the lesion, the in situ biopsy and even some immediate interventions [12]. Besides the huge benefits brought in the therapeutic exploration and approach of the alimentary duct, it must not be overlooked the fact that the procedure itself, even if it is minimum invasive, still induces a state of discomfort to the patient, related both to the pre-anaesthesia or anaesthesia and to the manoeuvres itself required by this procedure. Relatives must be informed on these aspects [13].

It is unanimously accepted the fact that presently the contribution of endoscopy plays a decisive role in the diagnosis of some diseases, formerly mentioned as hypothetic only, among which: the gastroesophageal reflux disease, unexplainable repeated vomiting, gastrointestinal haemorrhage dysphagia or odynophagia, ingestion of caustic substances or foreign bodies, the presence of polyps, thoracic or abdominal pains having an uncertain cause, chronic infections or the presence of chronic inflammatory diseases of the gastrointestinal tract, etc. [14]. It must be considered the fact that, besides the diagnostic aspect whose precision is incontestable, as it visualizes the lesion in real time, the digestive endoscopy also offers immediate therapeutic solutions, such as the endoscopic haemostasis of esogastroduodenal non-varicose acute bleedings, the extraction of foreign bodies, the sclerotherapy of esophageal varicose, the dilatation of esophageal stenosis, endoscopic polypectomy, percutaneous endoscopic gastrostomy etc. [15].

Although the endoscopy is generally considered a hypoaggressive procedure, it still presumes a series of risks which must be presented to the patient. Therefore, starting from vomiting produced by premedication or the discomfort related to the insufflation with air during the endoscopic manoeuvre, until the unwilling but possible complications, such as: the inflammation of the neck, retropharyngeal haematoma, detachment or loss of teeth, laryngeal trauma, esophageal and laryngeal perforations, although very rare, can occur. Of course, the percentage of complications can be higher in interventional endoscopy. Knowing the limits of endoscopy is absolutely compulsory to a physician because this prevents him from approaching assimilated situations, as contraindications such as: cardiovascular instability, breathing dysfunctions, the affectation of the cervical spine, the deterioration of the neurological status, suspicion of intestinal perforation, haemorrhagic diathesis, massive haemorrhage [16].

From an ethical point of view, the four basic principles governing the physician-patient relationship must also be observed in the pediatric gastroenterology. Therefore, the autonomy in the sense of respecting the option of the patient, the non-mischief – which corresponds to the ancient principle "primum non nocere", the principle of the benefit for the patient, in the sense that the procedure must contribute to the amelioration and healing of the disease, and finally, the spirit of justice and equity, in the sense of non-discriminatory use of resources which are often limited and represent a major dilemma for the physician when he knows that the economic reasons can influence his/her medical decision are aspects that must be taken into consideration [17, 18].

Consequently, one of the serious ethical problems of the physician is the answer to the questions: what is fair, what is the good and what is the correct way to be followed in solving medical problems. This way must follow the achievement of the maximum benefit to and minimum suffering of the patient and the reasonable use of the available resources [3].

Some Considerations Regarding the Informed Consent in Pediatrics

As in any other medical speciality, the pediatrics also involves ethical considerations regarding the medical procedure which must be taken into consideration, even if it is about assigned responsibility:

- the informed consent must be obtained for all procedures, sometimes even for parts of them, such as: anaesthesia, interventional endoscopy, superior or inferior endoscopy.

- the patient must be informed on the risks of the procedure,
- the therapeutic options, risks and benefits must be discussed,
- the economic restrictions must not influence the quality of the medical procedure,
- endoscopists must have the necessary competence for performing procedures,
- the quality standards must be complied with [19].

Although the informed consent has evolved along the time from an ethical concept to a legal obligation, as it is nowadays practiced, it is based on the same ethical principles, even if it is about the pediatric age. As a consequence, informing the child about his/her disease and the possible therapeutic remedies must be done even when his/her responsibility is limited or assigned. This information can have positive effects, as it answers to some specific needs existing even at the pediatric age, such as: the need to respect him/her as a human being, as a consequence to treat him/her as a subject and not as an object of the medical procedure, the need to know the reality that he/she must fight and bear, without humiliation and without shattering his/her trust, the need to actively and autonomously participate in the recovery, the need to have responses to his/her questions, regardless of the type of disease of which he/she suffers.

Of course, the achievement of these goals is a relatively simple problem for those who work with children, as their experience helps them build a language and an attitude adequate to the child's psychology, otherwise being a problem of time and availability [20]. These become necessary because, besides the medical aspect of the consent, rather human we would say, there is also its legal effect, somehow different. The difference consists in the fact that the legal aspect approves the act of will as an autonomous desired consent, fully aware of it and not inflicted [5].

We would also emphasize that although the humanitarian connotation goes through both aspects (medical and legal), there is a clear distinction between the medical humanism and the legal humanism, fact that makes the medical law oscillate between these two aspects. The medical humanism presumes the use of all the possibilities that can contribute to re-establishing the health condition of the patient, thus making the physician to assume the entire responsibility that he/she can afford. As a consequence, from the point of view of medical humanism, the patient is the person who trusts himself/herself to the physician for the recovery of health, based on a relation of full confidence. Unfortunately, the medical humanism is not found in the legal humanism. In the legal humanism prevails the patient's autonomy that does not refer to the physician in order not to give up to his/her autonomy. Moreover, for justice, the person who must represent the interest of the patient is the patient himself/herself (in the case of the children, the parents or the next-to-kin) and not the physician [3, 5].

Sometimes, this dilemma makes the physician hesitate when offering complete information to the patient, thus maintaining one more type of medical paternalism, because although the patient's interest is the one that determines the medical information, no one ever knows who is the judge of this interest particularly when undesired situations occur in the evolution of the disease or during the medical procedure [21].

To conclude:

1. The ethical principles of the medical procedure have assumed new valences in the conditions of the modern medicine that has become high-tech and interventional.
2. The informed consent becomes a compulsory instrument in pediatrics, with its features of communication, understanding and responsibility.
3. Endoscopy presumes a special ethical approach, having in regard its invasive character which, besides the actual benefits in the diagnostic and therapeutic approach, also presumes risks.
4. In modern medicine, communication and information are essential even in the relation to a patient of pediatric age, and from the ethical perspective of this relation, one must take into consideration the differences between the medical humanism – common to those who practice medicine and focused on the patient and his/her suffering, and the legal humanism – that is grounded on the person's autonomy and freedom.

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