



DOI: 10.5505/anatoljfm.2021.03064
Anatol J Family Med 2022;5(2):73–78

Ethical Issues in Pediatrics Practice

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ABSTRACT

It is widely accepted that children are not simply “small adults,” and pediatric medicine has been developed as a completely separate branch of medicine. Pediatric medicine involves many of the same ethical issues pertinent to adult medicine, but will also attract a range of ethical issues and, indeed, ethical controversies specific to dealing with children. Although some ethical problems in pediatrics have gained a legal basis over time, some problems continue to be discussed. It is important for pediatricians to be aware of the ethical issues they may encounter and seek medical ethics consultation regarding a contradictory situation when necessary, taking into account the legal regulations of their countries.

Keywords: Children, ethical issues, pediatrics



Please cite this article as:
Dağ H, Ertin H. Ethical Issues in Pediatrics Practice. Anatol J Family Med 2022;5(2):73–78.

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Received Date: 02.07.2021

Accepted Date: 15.10.2021

Published online: 31.08.2022

Anatolian Journal of Family Medicine - Available online at www.anatoljfm.org

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INTRODUCTION

Today, medicine affects many aspects of day-to-day human life, which is only likely to increase with medical progress.^[1] This promise of a healthier and longer life naturally involves a greater degree of intervention in everyone's life as technology advances, and medicine divides into even more specialized subdivisions impacting disease diagnosis, treatment and care approach models, and medical research. The importance and load of medical ethics also inevitably increases, as the relationship between medicine and humans becomes more complex both quantitatively and qualitatively.

The primary and predominant theme is the biology of humans that medicine deals with and wants to address.^[2] A recent good example of this was the introduction of the CRISPR-Cas9 technique to the field of genetics. This is a very good example of a typical ethical debate. American biochemists Jennifer Doudna and Emmanuelle Charpentier used a technique called “chemical knife” or “genetic knife” to treat cancer and hereditary diseases, where a system that allows the DNA of animals, plants, and microorganisms to be changed very precisely has a revolutionary effect on life sciences. All technical developments are brought before us with their positive aspects, but new techniques in the medical field sometimes bring unpredictable difficulties.^[3–5] As the list of what medicine can do gets longer, the list of what it should not do also gets longer. As we have seen, medicine deals primarily with the biological dimension of human beings. However, human beings do not consist of only this aspect but also produce value, live in society, and struggle for dignity and freedom. The rapid development of scientific progress and the rapid spread and adoption of the results of this progress

are also reflected in medical ethics. In proportion to this, the inadequacy of health professionals' ethical ability delays the ethical evaluation processes of some cases. This is especially important for ethical issues that concern children and those who cannot make their own free decisions. Health care professionals, due to the system, the institution, their education, or their understanding and attitude, tend to perform biological reductionism mechanically without thinking too much or questioning it and thus consider every human being using the same template. All health professionals should understand that the problems of human beings are not only biological but also have philosophical, social, political, and economic dimensions and should have a wide-angle view to consider each individual as a whole. This study aimed to review the general ethical principles and discuss some basic problems in pediatrics.

General Ethical Principles

Basic Principles of Medical Ethics

It is possible to divide the basic principles of medical ethics into two: rational and irrational.^[5] It should be noted that irrational does not imply illogical; irrational is used in the sense of "different from the systematic use of reason in the decision-making process." Irrational approaches are listed as obedience, emulation, feeling or willingness, intuition, and habit. Rational approaches consider deontology and medical ethics in favor of children. Individuals can make different choices between rational approaches and irrational approaches. It is necessary to fulfill the requirements and principles of contemporary medical ethics in terms of ethical evaluation and ethical decision-making in medical practice.^[6-8] It is possible to say that ethical principles are also necessary for forming the content of common academic and professional culture. The four-principle scheme proposed by two American bioethicists, Beauchamp and Childress, includes usefulness, being autonomous and respecting the autonomy of others, not harming, and being fair.

1. Respect for Autonomy

Autonomy means that everyone can play an active and fully independent role in the decision-making process.^[9] Thinking and evaluating on your own is being able to make personal decisions freely, in short, to have an awareness of self-management. Individuals with this quality can resist the impositions of others on any subject and make their own decisions. For Kant, this means "one's ability to take place in the world as one's legislator." However, ethically, it can be difficult to achieve autonomy that would require competence for children and those with developmental disabilities.^[10] The medical team and parents should play a role in this understanding.

2. The Usefulness Principle

The principle of usefulness is one of the main elements of medical ethics.^[7] This is due to a load of utilitarianism doctrine on the framework of contemporary ethics and the fact that medicine is an activity aimed at being useful due to its nature. In the context of the principle of usefulness guiding medical action, two situations that need to be addressed are the fine adjustment of the balance between usefulness and nonharming and the resolution of conflicts between autonomy and usefulness.

3. Nonharming

The principle of nonharming has been one of the basic principles of medicine since the day when moral value problems in the field of medicine first emerged.^[11] Hippocrates expressed this principle by saying "first, do no harm." This principle should not be understood as limited to avoiding harm to the patient. Health professionals, third parties, and society should be considered within the scope of the principle of no harm; in ethical evaluations, there should be a concern about not harming these groups.

4. Being Fair

The principle of fairness guides the use of limited resources and opportunities in medical practice.^[12-14] It is generally accepted that health is a fundamental human right, and everyone should benefit from health services fairly. The World Health Organization and the World Medical Association adopt an approach that gives importance to social justice and equality in the distribution of health resources in their regulations on patient rights. It is difficult to implement as it is not possible to provide expensive and limited medical resources and facilities to all patients. Therefore, there are serious problems in the distribution of medical resources equitably. This is because the distribution of medical resources is a moral business rather than a technical business. Whether the principle of equality or other fair sharing principles will prevail, especially in the allocation of limited medical resources, makes ethical debates inevitable. Another ethical issue in the allocation of resources is the selection of the person who will receive the service and who will make the distribution decision. In recent years, the formula for creating balances and allocating potentials and resources based on the needs and medical benefits of each patient has been generally accepted. Medical care should try to support the patient and be tailored to the individual's needs. It is ethically appropriate to appreciate the realistic goals that medical care can achieve, and it is wrong to target exaggerated or impossible expectations.

Some Basic Problems in Pediatrics

Informed Consent and Consent of the Pediatric Patient

Decision-making in pediatrics is a very challenging area for children, parents, and physicians.^[15] The concepts of consent and approval play an important role in decision-making in pediatrics. While informed consent is sufficient legally and ethically for adults, it can be more controversial and problematic for children as these limits must include the family.

Parents have legal and ethical authority on behalf of their children in many ways because, unless proven otherwise, parents want the best for their children.^[16] However, parenting alone does not qualify a person as a surrogate for another person. For this, some specifications must be met. It is essential to be competent to make reasonable decisions, to have sufficient knowledge, to be emotionally balanced, and to take care of the interests of those who cannot make decisions for themselves. In this case, it is up to the pediatrician to understand whether the parent is sufficiently competent or not. If the child is harmed by the family's decision, the pediatrician should take an active role in preventing it. At this point, the concept that pediatricians should pay attention to is the "best interest" principle.^[17] This principle, which should be understood as "best for the child," is key in ethical debates in pediatrics. If the family or the guardian of the child makes a decision that is not in the best interests of the child medically and insists, the physician may intervene in the situation and take the legal right to make a decision. This can be achieved by application to the legal authorities and the decision of the court.

Informed consent is a process based on respect for people. Autonomy is the right of a reasonable person to make his/her own decisions, providing the basis for the instruction of informed consent.^[16,17] The capacity to give consent is based on the ability to make a legally valid contract and to make psychological and developmental decisions. Therefore, minor children cannot give informed consent but can give approval. While informed consent is a legal term for adults depending on respect for autonomy, consent is a developmental term focusing on capacity. The ethical principle of pediatric consent is to acknowledge that children can participate in their treatment up to a certain extent and, above all, to respect the evolving capacity of the children. Although the child's consent to the treatment is an important goal, family consent is legally obligatory if it is incompatible with the best interests of the child. Although the consent of children is an ethical principle, the biggest obstacle to this decision is, unfortunately, the parents.^[18] Some families assume that they are the only ones

who make decisions about their children's health. Another important issue is that hospitalized children are vulnerable to decisions taken because of their patient role. For this reason, pediatricians and health professionals have an important role in terms of children's participation in decisions. Confirmation should be taken throughout a process, not as a one-off gesture.

For a decision to be valid, the person must be conscious and the decision voluntary.^[19] However, there is no universal standard for this. The American Academy of Pediatrics (AAP) encourages pediatricians to assess each child's consent capacity individually. Ideally, the AAP sees approval as a process in which all parties participate in the decision-making process. The AAP highlights this view by stating that mutual meetings provide a meaningful relationship between the child and the physician and that this is what is important in this process.

Even if parents have the right to give consent to, or refuse, treatment for adolescents, adolescents must have an ethical say in their treatment.^[15] Although adolescents have positive roles regarding treatment, legal consent and adolescents' approval do not correspond to the same meaning. The real balance between the approval of the adolescent individual and the consent of the parents depends on both the competence of the minor and the type of decision in question.

In case of refusal of recommended medical treatments, the physician should first contact the family again and correct any misunderstandings, if any.^[20] Despite this further contact, if the family again refuses treatment, if the parent risks the child with the decision taken, if it is highly likely that harm will occur, and if this recommended treatment is scientifically proven, then legislation should be applied, taking into account the best interests of the child, and taking into account the previous methods and approaches in similar issues.

As mentioned, the decision-making process in pediatrics is quite different from other branches of medicine.^[21,22] Perhaps the most important problem of medical ethics in pediatrics is the difficulties of the decision-making process. Childhood is between birth and age 18 in many countries, including Turkey. However, there is a vast gulf between the mental and personal maturity of 2-year olds and 17-year olds. In medical ethics, opinions have been expressed in the direction of the child's participation in the decision in recent years. In fact, it is said that the older the age, the more participation in the decision. However, children of all ages can take part in ethical discussions and be advisory.

Patient Privacy

As adolescents are sensitive, a reassuring and communication-oriented relationship should be established with them.^[15] For adolescents to receive consultancy services, confidentiality rules must be followed. On the other hand, breaching the patient's privacy may remain the only option to protect any member of the public, including an adolescent, from a serious and immediate danger, such as sexual abuse, even if confidentiality has been requested by the affected individual. Therefore, the physician may violate this confidentiality to protect the adolescent since he/she is underaged.

Faith of the Family and Medical Care of the Child

If the family wants to refuse treatment according to a religious belief, first of all, this family and the clergy should participate in the process, misunderstandings should be corrected, and treatment should be provided.^[5] However, if the family is not convinced, legislation should be included in the process, considering the best interests of the child. This is because a child's right to life and treatment cannot be taken away solely through religious belief. However, religious beliefs and cultural values can sometimes be confused. Pediatric medicine needs to consult and manage the process correctly. Ethical consultation is important in any dilemma.

Physician-Assisted Euthanasia

The etymology of the word "euthanasia" is from the words eu = beautiful and tanasium = death.^[23,24] It is a type of suicide and symbolizes a controlled death instead of dying in pain and distress. If physician-assisted death is in the best interests of the child and the child can understand this, this support can be provided if the family also gives permission. However, if there is a conflict between the family and the child, this cannot be done. Besides, it is necessary to know the legal regulations of the countries in this regard. Many countries do not allow this for different reasons. In Turkey, this constitutes a crime according to the Turkish Penal Code. Voluntary active euthanasia has been implemented in the Netherlands since 2002. Children over the age of 12 years have the right to demand active euthanasia if their parents give their consent and the patients have unbearable suffering and an incurable illness. Discussions on the bioethical application of this subject continue. In the future, this sensitive issue will seek a legal basis through the right to human dignity.

Euthanasia is practiced in different ways and is generally divided into active and passive euthanasia in the litera-

ture.^[25] Apart from these, it should be known that there are types, such as physician-assisted suicide, and voluntary and involuntary euthanasia, as close concepts or different classifications. Euthanasia is a debatable situation in terms of the nature of medicine and general acceptance, and it is not easy to accept in practice. Euthanasia in children greatly increases this difficulty. However, euthanasia, which had no statutory basis in most of the twentieth century and was enacted in 1994, even when the Netherlands did not have an active euthanasia law, and the door was opened. We mean that moral debates that are far away today can be thrown in another direction with the contribution of a number of factors. What these elements are is one of the main concerns of medical ethics and is the subject of another article. A different example of these moral position changes is, of course, the approach to child euthanasia, and the change started again in the two leading countries, the Netherlands and Belgium. However, this requires a multidimensional discussion.^[26] Generally, euthanasia in children is drawn to the level of moral acceptability with the end of unbearable pain and the absence of treatment possibilities. However, when the pain can be treated with palliative medicine methods, the acceptability of euthanasia in children decreases when the special conditions of the children are considered.

In the Netherlands, as in all other countries, taking the life of someone except in extreme cases is considered murder.^[27] A painful life that cannot be relieved in any way can be regarded as one of these extreme conditions. In some countries, it is considered good practice for doctors not to start treatment for newborns who have no chance of survival. Most neonatologists in the Netherlands and neonatologists in Europe believe that intensive care therapy is not an end in itself. Its purpose is not only to ensure the survival of the baby but also to provide an acceptable quality of life. However, the legal regulations of the countries and the consent of the families are very important in this regard. As a guide, the Groningen Protocol on the euthanasia of newborn babies states a number of principles regarding the euthanasia of newborns. In countries where the law permits, this guide will prevent malpractice and ensure the best interests of the patient.

Life Support and Critical Response

A competent and self-determined person has an almost indisputable right to refuse any care and treatment, even if it is life-saving.^[28] A well-known example of this is that Jehovah's witnesses refuse blood and blood products, even

if needed, despite the risk of death. However, this decision does not apply to children, dependent disabled people, and unconscious patients. The right to life is sacred, and when someone else endangers it, a problem is posed both legally and ethically. In such a situation, a good dialogue should be established with the patient's relatives under the guidance of good medical practice, and an attempt should be made to persuade the patient's relatives. However, if no results are obtained despite everything, legal support should be obtained. All these decisions should be documented and submitted to the relevant authorities when requested.

Life Quality

In cases where medical treatment does not provide any benefit and the patient's quality of life cannot be improved in any way, medical futility becomes pertinent.^[29] Cases such as when there are very severe organ anomalies at birth and the congenital absence of the brain (anencephaly) are leading ones. In determining the treatment strategies and goals in these situations, several ethical criteria should be taken into account, as well as medical knowledge and experience. If the treatments applied, especially in the intensive care unit, do not contribute to the recovery of the disease or improve the quality of life later, and such an application only postpones the moment of death, the treatment performed under certain conditions can be limited or even stopped. The argument here is again based on the principle of the best decision for the child, as explained above. The aim of limiting intensive care treatments in such a situation should be to reduce or alleviate the suffering of the child. Besides, such a decision should be made very seriously and sensitively, taking into account all medical criteria and with the consent of the parents. Treatment strategies that do not comply with the wishes and consent of the parents should be avoided. However, as much as possible, parents should be informed about this issue objectively and impartially.

Clinical Investigations in Children

The place and importance of scientific clinical research are

obvious, given the level that modern medicine has reached now.^[30] Although the results of scientific research in adults are often applicable to children, clinical studies are needed in many aspects for developing high-quality and high-standard treatment methods in pediatrics. While the research is being conducted, even if the children involved do not benefit directly from the research, investigations can be performed as long as good medical practice is followed and the Declaration of Helsinki is observed, that is, to benefit the next patients. Since the negative results of studies are also valuable, this should be considered in the methodology. Although the importance of clinical trials in the development of effective treatment modalities with high quality and low side effects for the diseases of children is not discussed, this research may involve many ethical problems. The most important of these is to trial a new treatment that has not been proven successful, but in a person who has not reached the age of deciding for themselves. Although this study consent can be given by the child's parents in some cases, it still involves many ethical problems. Ethical criteria in medical research on children are summarized in Table 1.^[31]

CONCLUSION

As children are not small adults and the approach to children requires a separate sensitivity, ethical issues in pediatrics differ from those which arise in adult medicine. In this study, we tried to address controversial issues in pediatrics from an ethical perspective. Each subject topic also opens the door to a broader discussion. Medical ethics is increasingly included in clinical practice. Technology is entering medicine faster than ever before. As the capability of medicine increases, the number of things that should not be done also increases. Therefore, medical ethics consultation should be sought when necessary for controversial and difficult decisions. Pediatricians should make use of good medical practice while taking into account the family-state, and the family-child axis will enable them to better deal with controversial ethical issues.

Table 1. Ethical criteria in medical research on children

- The high positive result expectation from the clinical study and as low as possible predictable risk and unwanted side effects
- Lack of available and effective treatment for the same disease
- The child participating in the research to benefit from this experimental treatment in the first degree, i.e., personally
- If the result of the research will be beneficial only to others and not to the child participating in the research, the risks of this research are either none or very little. If this situation cannot be guaranteed, the research should not be approved
- Including the child in the decision-making process based on its specific understanding and comprehension ability

Disclosures

Peer-review: Externally peer-reviewed.

Conflict of Interest: The authors declare no conflicts of interest.

Funding: The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this study.

Authorship Contributions: Concept – H.D., H.E.; Design – H.D., H.E.; Supervision – H.E.; Literature search – H.D., H.E.; Writing – H.D.; Critical review – H.E.

Acknowledgment: Unfortunately, Prof. Dr. Hakan Ertin, MD, passed away from a sudden illness shortly after we prepared this article together. I thank him profusely for his work in this article.

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