

Ethical dilemmas and conflicts in minor patients' care – general review

Andreea Salcudean¹, Marius-Catalin Cosma², Andreea-Georgiana Nan³, Monica Kiss⁴,
Maria-Melania Lica (Cozma)¹, Cristina-Raluca Bodo⁵, Gabriela-Elena Strete¹

¹ “George Emil Palade” University of Medicine, Pharmacy, Sciences and Technology, Targu Mures, Romania

² Institute of Cardiovascular Diseases and Cardiac Transplantation of Targu Mures- Pediatric Cardiology Department, Targu Mures, Romania

³ Psychiatry Clinic 1, County Clinical Hospital Mures, Targu Mures, Romania

⁴ Psychiatry Department, City Hospital, Odorheiu Secuiesc, Romania

⁵ Psychiatry Clinic 2, County Clinical Hospital Mures, Targu Mures, Romania

ABSTRACT

The aim of this review study is to analyze and describe the main moral and ethical aspects regarding the minor patients' healthcare related procedures. The Pediatric Ethics differentiate from that of the competent adults, such particularities including surrogate decisions, confidentiality issues, genetic testing and research related matters, end-of-life situations and legal framework. An important aspect is that the child is not entirely lacking capacity, in fact, the literature underlines the importance of listening, analyzing and taking into consideration the minor patient's opinions, statements or judgments according to their age and cognitive development. The approach of the minor patient should always take into account the triad “doctor-parent-child” without neglecting any of the participants and their role. The main responsibility of the healthcare professionals is to act guided by the best interests of the minor patient.

Keywords: minor patient, ethical dilemmas, decision making, beneficence

INTRODUCTION

General Ethical Principles including Autonomy, Beneficence, Non-Maleficence or Justice play a fundamental role in the minor patient's healthcare process. Some important ethical concerns include the unique management of the minor patients regarding the informed consent, parental permission and decision-making process, confidentiality, clinical research and genetic testing, controversies in managing end-of-life situations and dilemmas regarding legislative issues. Another important particularity is that of the developing capacity and so the ethical pediatric considerations should be in accordance with the minor's physical, intellectual and emotional development [1,2,3].

CORE ETHICAL ISSUES IN APPROACHING THE MINOR PATIENT

Informed consent, parental permission and child assent are some of the essential ethical concerns regarding the pediatric decision-making process. The process of obtaining consent involves the following steps: correctly informing the patient and the family on all aspects regarding the diagnosis, treatment, prognosis and alternatives, the perception and analysis of the received information in accordance with the family's moral values and level of education and last, but not least, reaching a conclusion [1,3].

Parents and children have the legal right to be informed about the diagnosis and the therapeutic

procedures in a precise, transparent and accessible form, in order to make the best decisions for the minor. Furthermore, the given information should be adapted according to age and understanding capacity. The concept of giving information in approaching a minor patient underlines the need of a good relationship between the physician and the minor, the physician and the parent or the minor's legal representative, and not least the relationship between the parent and the minor. This triad provides informations in order to identify the minor's best interests. The healthcare professionals have the moral and professional duty to find the most appropriate ways to correctly inform the family and the child about the minor's current medical situation. This duty refers to the healthcare professional's ability to find the appropriate ways to communicate informations including oral conversation, drawings or other complementary materials, based on the level of understanding, education and values of the family [3,4].

Even though there is the general tendency to consider the minor lacking capacity, whenever the minor is capable to have an opinion, statement or judgement, it should be taken into consideration. The process of investigating the competence of a pediatric patient requires the evaluation of the minor's maturity level, intelligence and the level of understanding the benefits and consequences of certain medical procedures. The law states that the parent or the legal guardian has the power to make decisions for minor patients [2,3,4,5].

The decision regarding the management of a pediatric patient should be considered only if it is in the best interests of the minor. The clinician has to ensure that the parental decisions reflect the child's best needs rather than the family's wishes and beliefs. In certain circumstances, such as life-threatening situations, the medical professional can act under the circumstances of implied consent if considered to be in the patient's beneficence [1,2],

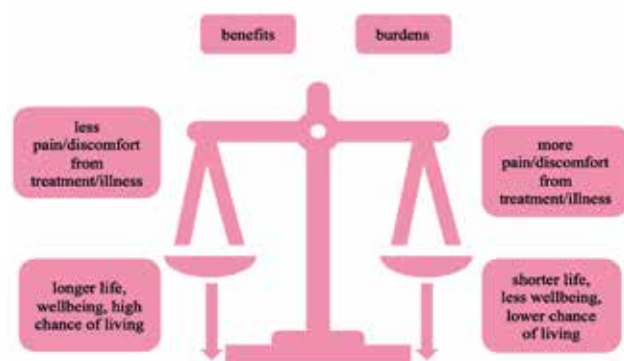


FIGURE 1. Balancing the benefits and burdens/risks in decision-making process [5]

Obtaining consent in pediatric emergencies can be a complex and challenging process. In emergency medicine, there is an exception to the rule that states that parental consent is required in order to proceed to a medical situation. Whenever the healthcare professional believes that a parent's refusal of consent places the child at risk, then consent is considered to be not necessary [6].

The **minor's confidentiality** should always be respected in relation to all persons other than those who are directly and actively involved in their healthcare and medical procedures. The implication of the minor patient's beliefs, emotions and behavioural aspects have a crucial role in understanding the interaction between the minor and his medical burden and consequently the factors that can influence this interaction, as well as treatment particularities [7,8,9].

Children who can give assent are recognized as having some degree of decisional autonomy, meaning that they are capable of deciding which medical treatments to undergo under certain circumstances. If the minor makes medical decisions considered against their best interests, healthcare professionals can notify child authorities or courts in order to minimize the harm risk.

On the other hand, when minors are considered competent and mature enough to make medical decisions independently, it is appropriate to accord them respect for their confidentiality and privacy as it is accorded to autonomous and competent adults. [9]

Adolescents are often worried about their privacy issues and their acceptance of suitable care is built on the promise of respecting confidentiality. In the emergency department, autonomous adolescents can be treated for reproductive care related issues without parental consent. It is necessary that the emergency department doctor understands the rules regarding the medical care of pediatric patients to avoid violating their privacy rights and compromising their well-being and trust in the medical system. [7,9,10]

The aim of respecting privacy is to develop trusting relationships with the minor patient, enhancing the long-term benefits of medical assistance. There are also certain circumstances in which the healthcare professional has the duty to breach confidentiality and inform the parents or the competent authorities (police/child services) about certain behaviours that can represent a serious and important threat for the minor or for the community members. Such examples include suicidal intent, murder and manslaughter, rape, child abuse or other situations where individuals can suffer serious harm or abuse [1,7,9].

GENETIC TESTING AND RESEARCH

The advances in technology and expended access to genetic testing resulted in more minor patients receiving genetic tests for diagnostic or prognostic purposes.

While genetic testing has many potential benefits, the literature has highlighted important ethical issues and concerns as well [3,11].

It is important that the genetics and ethics committees work together on specific case based guidelines to maximize the benefit for pediatric care, while preventing harmful situations [12].

Genome sequencing is nowadays becoming increasingly faster and affordable, with significant impact on scientific research and clinical practice. The utility of genetic testing in pediatrics is growing significantly, and it is believed that it will help discover undiagnosed and rare genetic diseases. [11,12]

Besides the benefits of genomic sequencing in pediatric practice, the literature has also underlined a number of important ethical dilemmas including minor's future autonomy, parental permission and autonomy, the best interests of the patient and his/her family [12].

The main ethical issues regarding genetic testing include:

TABLE 1. Ethical issues in genetic testing [12,13]

When to use genetic tests?	<ul style="list-style-type: none"> ethical issues related to the indications of genetic testing, potential risks and challenges for the clinicians/researchers.
Pretesting counselling	<ul style="list-style-type: none"> ethical issues regarding the informed consent process (what information to provide, different forms of consent necessary to the process, directiveness, counselling based on the urgency, parental decisions, disclosure concerns)
Interpretation	<ul style="list-style-type: none"> ethical issues including the infrastructure (the risk of inconsistencies and variability); challenges regarding the interpretation of variants (clinical context)
Communication	<ul style="list-style-type: none"> ethical issues related to the dilemma of reporting unsolicited findings, the challenge of balancing the best interests of the minor and his family regarding the disclosure of unsolicited findings, the risk of the diagnosis negatively impacting the parent-child relationship, the concerns of revealing the results.
Personal data use	<ul style="list-style-type: none"> ethical issues regarding data sharing, information storage and reanalysis, providing data access and reevaluation over time, privacy matters and potential benefits (insurance, medical intervention)

Finally, if testing is part of research, clear information to patients should be given regarding the risks and benefits of testing and what is the standard of care in research. In general, pediatric patients

can take part in a research programme or a biomedical research only if the outcome of the study it is directly beneficial to the minor. Otherwise, the participation of a minor in a research with no direct benefits for himself can be considered only if the following conditions are accomplished:

there is no major and predictable risk for the minor's health

the study is beneficial to other subjects with the same characteristics (age, disease, handicap)

there is no other possibility to conduct the study. [3,14]

ETHICALLY MANAGING END-OF-LIFE SITUATIONS

Medical care for terminally ill patients is directed to ease the suffering, stabilize the quality of life until death and comfort the patient until the last moment. However, achieving these targets is not always a simple matter. Because healthcare providers, minor patients (if possible), and patients' family members have to make important decisions regarding treatment options such as whether to prolong the patient's life by supporting vitals or allow the natural death process to continue, they often encounter ethical dilemmas related to end-of-life care. Parents experience negative emotions including sadness and fear, anxiety and stress when a loved one is terminally ill and so they will have a hard time to make such important decisions. Family usually feels hopeless, guilty and powerless when they cannot reduce, alleviate or end the suffering of their terminally ill child. [15]

In any decision-making process, people are influenced by cultural, social, religious and familial beliefs and values. In addition, end-of-life decisions in minor patients are even harder because the emotional implication of the family can hold back rational thinking. [16]

End of life decision-making in minor patients care is a complex, personalized and difficult process. The availability and development of ethics consultations in pediatric care centers has helped medical teams facing difficulties managing end of life situations. In some cases, advice from the ethics committee is not necessary when medical professionals and parents/guardians agree in the same decision about the patient's care process and in these cases it is important to prioritize the symptom management and the patient's best comfort. In general, difficult situations can be solved with effective communication. When difficult decisions need to be made regarding end-of-life care, giving minors and their parents/legal guardians enough time and understandable, clear information can also help managing issues. [15,16]

If the parents insist on a certain treatment considered not to be beneficial for the child, the medi-

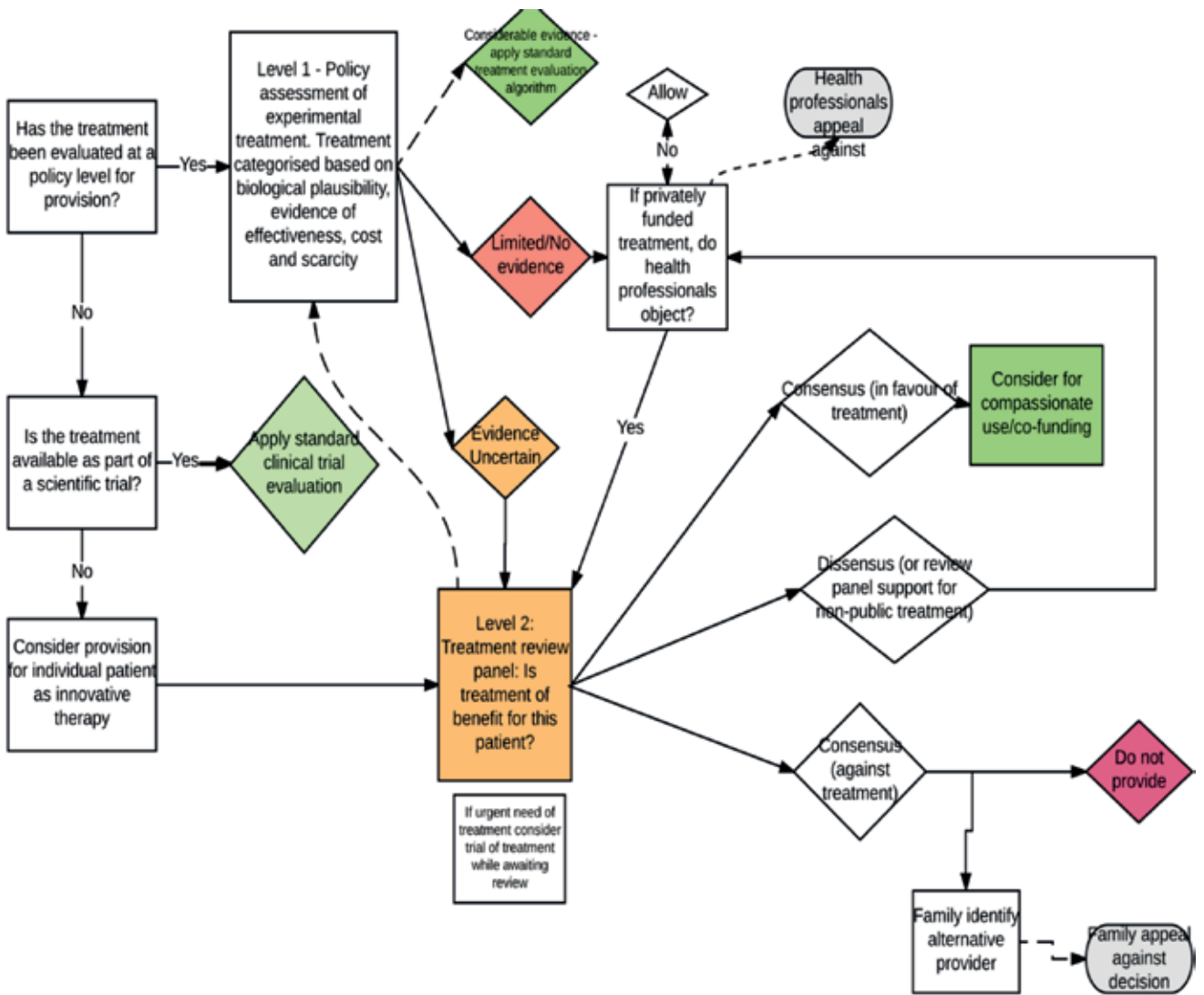


FIGURE 2. Making decisions for experimental treatment in children [5]

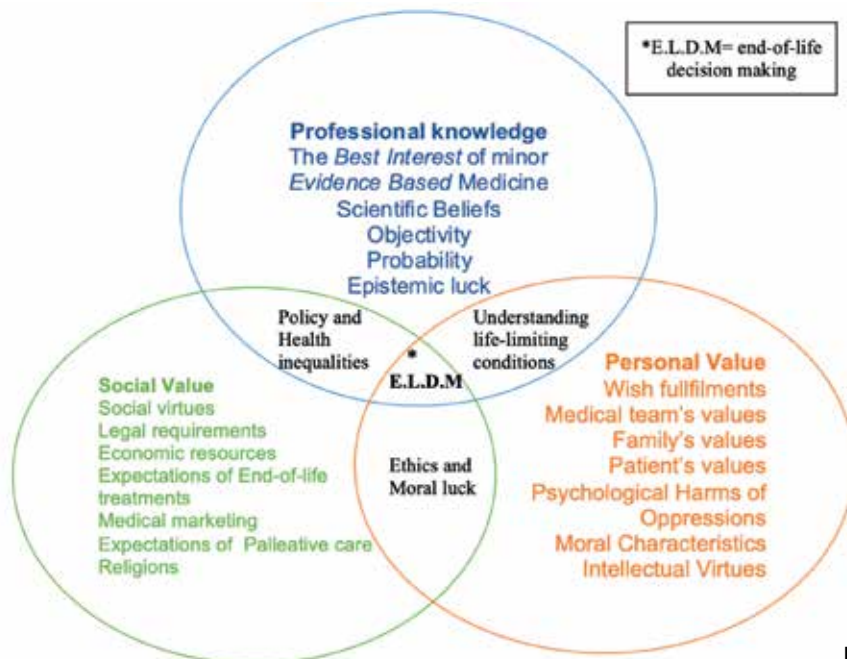


FIGURE 3. End of life decision-making factors

cal professional has the obligation to explain why the treatment will not represent the best interests of the minor, the possible damages the treatment may cause, and how the process will lead to an unnecessary using of resources. The healthcare provider has the obligation to protect the minor patient's life, but this duty should not be mistaken with the use of unnecessary resources, and the patient should not be harmed by maintaining futile medical treatments. It should be noted that the parental decisions are not absolute. In the circumstances when a parent firmly makes a decision that inevitably can harm the child, the physician can request assistance from the ethics committee or even go to court as last resort when the medical team concludes that the parents' decisions are becoming harmful to the minor. [1,3,5, 15,16]

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CONCLUSIONS

As seen above, several matters distinguish pediatric ethics from that of adults, including matters of consent, confidentiality, genetic testing and research and end-of-life care issues. Decision-making process involving minor patients is a unique process. Mostly, minors do not have the ability to ethically or legally give informed consent and approve to certain procedures. Regarding this decisional process, ethical principles such as beneficence should represent the core principle when deciding for minor patients. The principle of beneficence encourages acting in the minor's best interest through a common decision-making process involving the triad physician-patient-parents.