



## Mini Review

# Ethical problems in pediatric cardiology

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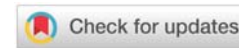
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## Abstract

The authors discuss new ethical problems associated with the use of modern diagnostic and therapeutic modalities in pediatric cardiology. They underline the role of pediatric cardiologists in the process of approaching specific ethical problems. In the assessment of specific medical problems, authors pay greater attention to ethical principles of beneficence and nonmaleficence, which continue to be problematic areas in pediatric cardiology.

## Introduction

Advances in pediatric cardiology and cardio surgery over the last decades allowed an accurate and prompt diagnostic process, surgical treatment and high-quality preoperative and postoperative management of patients with congenital heart anomalies [1]. The new diagnostic and therapeutic modalities improved the survival of these patients, but on the other hand, they opened a spectrum of new ethical problems [2]. Four basic principles of medical ethics have been postulated by the end of the last century: autonomy, justice, beneficence and nonmaleficence [3]. These principles have evolved and been postulated in the regions with high economical and industrial development, sharing at the same time similar cultural and regional values, as the European region, North America and industrialized areas of the British Commonwealth. The higher the industrial and economical development with more resources available for health care, the more apparent these ethical issues are.

Autonomy represents a right of a person (or their representatives) to decide what happens to their body, to accept or refuse, under certain circumstances, diagnostic

processes, or treatment. Justice means equal accessibility and quality of care for every child with the same heart disease [4]. In reality, it means, that a child with Down syndrome and congenital heart disease has an equal right to be operated on as a child with heart disease, but without genetic anomaly. Beneficence is based on Samaritan principles of doing good to people. In pediatric cardiology, it represents measures, that will improve the patient's clinical condition [5]. Currently, a significant number of pediatric cardiac surgery procedures are reevaluated, secondary to their late complications, which leads to improved benefits for patients. Nonmaleficence, not harm, is the cornerstone of medical ethics, incorporated in the Hippocratic Oath. It is mandatory to manage pain during diagnostic and therapeutic procedures.

In the past, several complicated congenital heart defects have been left uncorrected secondary to significant complications and high risk for death. After improvements in diagnostic procedures and surgical techniques, more patients are operated on, so the process of patient selection and intervention timing is becoming very important. The principles of beneficence and nonmaleficence in pediatric cardiology are currently becoming problematic. This process of

considering the “pros” and “cons” is not straightforward and involves physicians and patients representative. Physicians should provide objective and scientific information plus common experience and practice in that particular area and propose specific care. Patient representatives are informed about the proposed care with a discussion about the risks and benefits and other options and family opinions and wishes are considered. The final decision has to include countries legal regulations [6]. This universal approach is applicable in any area of the world with different economical, cultural, religious and legal aspects.

### Prenatal diagnosis of heart diseases

Fetal echocardiographic examination in pregnant women is a routine part of prenatal care in developed countries and in some areas it has already begun in 1980 [7]. The most optimal timing of the examination is between the 20<sup>th</sup> and 22<sup>nd</sup> week of gestational age. In case of suspected congenital heart problems, the examination should be repeated or the patient should be referred to a specialized pediatric institution. The presence of risk factors in the mother or family requires a detailed genetic investigation [8]. From an ethical standpoint, it is important, that the congenital heart defect may not always be detected at this time. As examples are hypoplastic left ventricular syndrome, ventricular septum defect, or cardiomyopathies [4]. Many authors also consider an ethical problem the potential side effect of prenatal ultrasound on the developing heart, especially during the first trimester [4]. Still, an unanswered question is, who should perform the prenatal diagnosis of congenital heart diseases.

The main goal of prenatal diagnosis of congenital heart diseases is to detect anomalies leading to acute heart failure and death after delivery [9]. Pregnant women with a diagnosed fetal critical heart defect should be centralized in pediatric cardiac centers, where prenatal and postnatal care is provided by specialized personnel, which reduces the risks of diagnostic delay and significantly improves the survival and prognosis of these patients [1]. This approach is in full accordance with the principle of beneficence for the patient and does not include any ethical problems [10]. Many studies have confirmed, that correctly provided prenatal diagnosis of congenital heart diseases significantly decreases neurological damage and improves prognosis [10]. From an ethical perspective, it is very important, how the physician presents the information about the finding of the congenital anomaly to parents. The information should include the character of the defect, prenatal and postnatal perspective, therapeutic options with indirect advice and respecting the wishes of the family. A significant ethical problem represents amniocentesis before the 20<sup>th</sup> gestational week for the diagnosis of Down syndrome, which is frequently associated with a major heart defect. Pregnancy is then often terminated, which is in ethical conflict with the fact, that children with genetic diseases are fully respectable human beings and have equal rights as healthy children [4].

### Children with congenital heart defects associated with another disease

Certain diseases, when associated with a congenital heart

defect, significantly worsen patient prognosis: prematurity, genetic and metabolic diseases and major congenital anomalies. A frequent ethical dilemma is a decision for or against surgical correction of a congenital cardiac anomaly in these patients [2]. Contraindication should be based on multidisciplinary decisions and supported by retrospective studies confirming the low benefit of the surgery. Patients after correction of complex cardiac anomalies often require long-term care involving high-tech devices and significant resources. In areas, where resources are limited, this creates a situation, where this device can not be used for the treatment of other sick children, who would need equal care otherwise. This brings up an ethical dilemma or so-called principle of selective justice, that requires a very sensitive and professional approach, always involving parents. According to Hippocratic Oath, health care personnel can not shorten a patient's life by active or passive euthanasia. At the same time, it is not ethically correct to prolong suffering and provide futile care, because it is against the basic principle of beneficence [4].

### Ethical problems in children with a genetic disease and congenital cardiac anomaly

Congenital cardiac anomalies are often associated with various genetic syndromes. Approximately 20% – 45% of children with congenital cardiac anomalies also have other inherited defects [8]. The decision-making process for or against surgical correction should be based on a complex evaluation of the health status. Recent advances in pediatric cardiology and cardiac surgery caused, that only a small number of complex congenital cardiac defects are not corrected [1]. Children with genetic diseases have the same rights as others and have to be provided with the same level of care. The frequent ethical problem can be when the parental decision is against the principle of justice. There is a “humanizing effect” of these children, that can be observed in the whole society [11]. The very important question in these patients is whether the other family members may also be affected. Patients or his/her representatives should decide based on complete information and respecting the principle of autonomy. Some patients refuse to be informed about their disease.

### Diagnosis of genetic syndromes

The goal of genetic counseling is to inform the patient about the character of the disease, the chance of its transfer to descendants and the therapeutic options. It is a standard part of prenatal diagnosis. Prenatal genetic diagnosis is performed in various gestational weeks. Some diagnostic methods involve a potential ethical conflict between the right of the parents to be completely informed and the benefit to the fetus [2,4]. These methods include:

1. **Amniocentesis:** A sampling of amniotic fluid under sonographic control is performed between the 16<sup>th</sup> and 18<sup>th</sup> week of gestational age. The ethical problem is the potential risk for induced abortion, which has been reported in the range of 0,3% – 0,8%. The most common reason for amniocentesis is the high risk of Down syndrome.

2. **Chorionic villi biopsy:** Sampling is done between the 9th and 11th week of gestational age
3. **Fetoscopy:** This method is used to sample fetal blood, skin, or other tissues. It is performed in the second trimester. It is being currently replaced by ultrasound as a non-invasive method.

### Ethical problems of cardiac surgery procedures

Advances in cardiology and cardiac surgery are leading to the reevaluation of established therapeutic modalities. Surgical procedures with a high rate of late complications have been modified with subsequently increased benefit for the patients. Currently, surgeries are performed on patients, who have been considered inoperable in the past. At the same time, the timing of the correction has been moved into an early age, even the neonatal period [3].

More and more anomalies are now corrected by methods of invasive cardiology, which shortens hospitalization, and eliminates the need for extracorporeal bypass and surgical scar [1].

From an ethical perspective, it is important, that only a minority of children with congenital cardiac defects are currently not referred to surgical services. The number of corrected critical and complex heart defects is increasing. In consequence, older children with less critical cardiac anomalies have to wait for their surgery for a longer time. An example, that often leads to ethical dilemmas, is hypoplastic left heart syndrome. It is one of the most serious cardiac defects, leading to death without surgery in 100% of cases [1]. These infants do not usually have another associated anomaly. There are three options for the management of these infants:

1. Conservative approach – the infant is left for the natural course of the disease
2. Stepwise surgical corrections
3. Heart transplantation in the neonatal period.

The preference for a specific approach is variable among cardiac centers worldwide. The decision should respect the principle of autonomy. Parents should be informed about the available options, should be given professional advice and should have the right to free decisions. Their refusal or acceptance of the advised approach should be respected as their moral right [12].

Prenatal diagnosis of hypoplastic left heart syndrome also frequently leads to ethical problems. The anomaly is usually easily diagnosed already by prenatal ultrasound screening [1]. Many parents make the subsequent decision to terminate the pregnancy. Such an approach is contradictory to current advances in cardiac surgery when the majority of infants after surgical correction survive and will achieve adulthood without major problems. The informing physician and his/her moral and ethical views play a very important role in the parental decision-making process.

### Disease effects on the child and family

Many studies have addressed the effects of surgical correction of cardiac defects on sick children [5]. The main results are that good psychological effects are determined by a stable family environment and low preoperative anxiety. Small children are significantly attached to their parents. Their separation during the time of therapy can lead to various psychological disorders. It may be perceived by them as a loss of parental love and betrayal. Children respond to this situation by anxiety, loss of communication, sleep disorders, or aggression against nursing personnel. Frequent sleep disorders have been reported especially in children after heart transplantation. Despite of complexity of the problems, children with complex cardiac diseases bring happiness and positive well-being to the family [4].

### Ethical problems of heart transplantation in children

Heart transplantation is nowadays a treatment option in children with end-stage heart failure secondary to congenital or acquired cardiac disease. Besides medical issues, heart transplantation brings significant ethical and legal problems. In many countries juridical system requires, that person explicitly refuses organ donation before his/her death, otherwise, the deceased body can be used for organ procurement [13]. A liberal interpretation of this law is that everyone would willingly agree with organ donation even when he/she has, in reality, not done it. Because the autonomy principle requires a real and explicit agreement from a living person, such a law may be considered to be in disagreement with ethics [2].

Indications for heart transplantation in pediatrics include medical and social aspects for a successful outcome and are different from adult criteria. The decision either to transplant or to leave the child to the natural course of the disease, is a significant ethical problem because of the high mortality and low beneficence of the procedure [1]. The medical and ethical problem is also the inability of organ procurement in newborns or infants secondary to insufficient criteria and process of brain death diagnosis [4]. Only about half of pediatric patients survive till a suitable donor heart is available. To overcome the lack of donors, alternative methods of cardiac support are more frequently used (ECMO, Berlin heart, pharmacological support). Unfortunately, for the majority of these procedures, there is not enough available information for evidence-based decisions. For a pediatric cardiologist, it creates medical, ethical, and legal dilemmas and contradictions. It should be a goal for medical societies in every country to establish guidelines for the application of alternative methods of cardiac support, that would be in accordance with medical, ethical and legal principles.

Contraindications of heart transplantations in children are absolute and relative. Some of the relative contraindications may be an ethical problem. These are low birth weight, prematurity and alcohol and drug abuse. Especially the last criterium is controversial and there is a need for more specific guidelines for heart transplantation in children with alcohol and drug dependence [4]. The ethical problem for a physician,

who indicates the transplantation, can also be the economic and social situation of the family. Poor economic status can be a contraindication in case there is no access to financial support or compensation from the government or other institutions.

Despite what was said, from an ethical standpoint we have to admit, that heart transplantations in children achieved a high level of beneficence with an acceptable level of negative effects [2,4].

## Conclusion

Medical ethics is not a rigid condition. It has been evolving along with the economical, social, scientific and technical development of human societies. It is influenced by culture and religion. It is a consensus that different cultures and religions have different ways to perceive the world. This difference also affects the definition of ethical problems as different cultures implement ethical values differently, sometimes placing more emphasis on family values than on individual autonomy.

The concepts of ethics referring to classification such as good-bad, beautiful-ugly and true-false are valid for all societies. The difference is in the characteristics, perceptions and definitions of these values. In this context, medical ethics is a set of norms and values applied to the behavior of medical care personnel in the same community [14]. The creation of these norms and rules is a historical and ongoing complex process and is done by society per se. Medical personnel and institutions should play a key role in this process. Medical and legal institutions then transform these rules into an administrative format of laws and regulations available for medical personnel and society.

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