REVIEW ARTICLE

Rethinking ethical decision-making in pediatrics

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Abstract

A challenge for 21st century medicine is to rediscover the value of philanthropy and philotechnia in contemporary clinical practice because both are terms that adapt to our more current understanding of how value-based medicine and evidence-based medicine must always go "hand in hand". Our proposal is to offer an integral ethical deliberation method that implies a holistic view of the ethical dilemmas in pediatric clinical practice.

Key words: ethical decision-making, clinical dilemmas, bioethics.

Introduction

Carolina is a 16-year-old female with various congenital cardiopathies and for the past 9 years has suffered from cardiac insufficiency. At birth she demonstrated a congenital cardiopathy of interatrial communication and interventricular communication. Persistence of the ductus arteriosus was also detected. She was surgically intervened at 8 months for closure of the ductus arteriosus and at 2 years of age for closure of the interatrial and interventricular communication. At 4 years of age subvalvular aortic stenosis was noted. At 11 years of age she had surgical resection of the subaortic ring. She developed postsurgical aortic insufficiency. At 15 years of age she had recurrence of the aortic stenosis and required a valvular prosthesis. She became pregnant at 16 years of age and developed cardiac insufficiency (NYHA Class II). A therapeutic abortion was offered to the patient in order to preserve cardiac function and to not subject her to cardiac overload. Carolina refused the therapeutic abortion.

How can we prepare to solve ethical dilemmas such as the one posed as they arise in pediatric clinical practice? We need continuous education in four areas that summarize the strengthening of the binomium evidence-based medicine-values based medicine (EBM-VBM):

a) Extensive knowledge of the pathophysiology of disease and availability of real therapeutic alternatives (EBM)

b) Know the rules governing clinical practice (VBM)

c) Increase familiarity with the principal ethical theories (VBM)

d) Develop ability to analyze and discern ethical dilemmas (VBM)

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One way to strengthen the binomium EBM-VBM is clinical ethics, which Jonsen et al. define as "clinical ethics is a practical discipline that provides a structured approach to assist physicians in identifying, analyzing and resolving ethical issues in clinical medicine".[1]

The central task of clinical ethics is to promote critical and systematized reflection of the ethical dilemmas of clinical practice and, in this way to instill in medical and health personnel practical wisdom and the ability to appreciate values and develop virtues that optimize the physician-patient relationship and patient care.[2] We must point out that no one speaks of "ethical problems" but of dilemmas in the logical sense of the word and should be understood as follows. A dilemma is presented strictly only when, after a thorough examination, two courses of action seem to be equally good or more frequently equally bad but inevitable, in the sense that one is forced to choose one of the two choices.[3] The aim is to foster and strengthen a culture of ethics at the patient's bedside and to also take into consideration the psychological, family, social and legal context.

The skills and abilities to make effective and sound ethical decisions in clinical practice require continuing education and constant vigilance in the physician-patient relationship and in our daily work attitudes. The development of skills and expertise in value-based medicine is achieved through discipline and practice as in evidence-based medicine. In this article we present some tools to recognize and be aware of the dilemmas, offer updated knowledge of the major ethical theories and provide general guidelines of ethical discernment and generation of ethical decisions. Making an ethical decision may cause sleepless nights even for the most talented physician or for healthcare personnel in general. Three methods of ethical discernment that exist in the scientific literature are described, analyzed and compared:

1) Clinical pragmatism
2) Nijmegen method
3) Integral method

Clinical pragmatism

Clinical pragmatism is a prospective method of ethical deliberation, which raises the question: **What should I do**?[4-6]

It is characterized by three factors:

1) Search for consensus
2) Based on the analogy that exists between science and ethics
3) Promotes democratic deliberation as a core of ethical decision

The proposed protocol is an equivalent of judgment and clinical reasoning:

1) Analysis of the patient's clinical situation
2) Moral diagnosis
3) Goals to be achieved, decisions that must be taken and their implementation
4) Evaluation

Analysis of the patient's clinical situation

Carolina is 16 weeks pregnant, is hemodynamically stable and with a 20% increase in heart rate. Fetal ultrasound (FU) indicates appropriate progress of the pregnancy. Taking into consideration that a fourth open-heart surgery for valve replacement itself has an elevated risk, during a medical meeting in which clinical cardiologists, cardiovascular surgeons and the social worker were present, Carolina's case was discussed. One possibility was to continue the pregnancy with an increased risk of cardiac decompensation until the

time of delivery or termination of pregnancy. The second possibility was to propose a therapeutic abortion, indicated due to critical health condition. By consensus, the medical team decided on therapeutic abortion, postponing valve replacement surgery.

Moral diagnosis

There is disintegration of Carolina's family. Carolina is an only child. Her father, a 40-year-old policeman, abandoned Carolina and her mother 5 years previously. Carolina's relationship with her mother is not good. Since before the pregnancy she has lived with her paternal grandmother (Carolina's father is an adopted son). Carolina's relationship with her husband (civil marriage) is stable and her 21-year-old husband is noted to be very supportive of her. They both live with her paternal grandmother and he covers the expenses for the couple. Nevertheless, they have much support from the grandmother and only little from the mother. At the time of proposing alternatives, without hesitation Carolina opted to have her son, saying that she would probably not have other opportunities and was determined to take risks. Her husband and her grandmother agreed.

Goals to be achieved, decisions that must be taken and their implementation

Valve replacement surgery was suspended because no major intervention is warranted under such circumstances. The medical profession recommends therapeutic abortion, but Carolina and her family refused to terminate the pregnancy despite the risks. However, it is important to consider Carolina's preferences, her desire to continue the pregnancy as the cornerstone of the plan of action. She was referred to the National Institute of Perinatology. The patient was reevaluated and supported on her decision to continue the pregnancy. Cardiac insufficiency threatened abortion twice and she required hospitalization two times.

Evaluation

Carolina's management began with medication and rest. There was threat of abortion on three occasions. Finally, cesarean section was done at 32 weeks with the delivery of a healthy newborn. Upon evaluation three factors were implemented: the preliminary nature of ethical principles, the variability of clinical situations and the freedom and flexibility of ethical deliberations.[7,8]

The Nijmegen method

The Nijmegen method is concerned with ethical debate in clinical practice. It was developed by the Department of Ethics at the University of Nijmegen (Netherlands) in collaboration with a multidisciplinary group of physicians. The objective is to analyze multiple cases to gain experience in ethical discernment. It focuses on the principle that the physician and health personnel responsible for the patient are the ones who must make ethical decisions and it does away with the standard of an American ethics consultant. In this case, the ethics expert serves as a facilitator during the ethical discussion.[9] There are five points in the Nijmegen method:

1. It is based on real clinical interpretation and assumes that the ethical questions are not external and are interrelated within the multidisciplinary clinical setting.
2. From the beginning of the deliberation, an ethical question should exist that is clear to all and meets the pattern to follow.
3. The problems and ethical dilemmas occur within a health system, i.e., within a complex professional organization. For a comprehensive analysis it is necessary to combine tools, approaches and ethical arguments.
4. Consensus is important but is not the cornerstone of ethical debate, and the most distinctive feature is the view that the consensus does

not necessarily mean the right thing, ethically speaking.

5. There must be facilities for the discernment to be effective and successful.

The protocol according to the Nijmegen method is as follows:[7]

1. **What is the dilemma or ethical issue?** The dilemma for the medical team is whether or not to interrupt Carolina's pregnancy.

2. **Facts.** At week 16, Carolina was hemodynamically stable, although there was a 20% increase in heart rate. FU showed that progression of pregnancy was adequate. Taking into consideration that a fourth open heart intervention for valvular replacement was itself an elevated risk, at a medical board meeting in which clinical cardiologists, cardiovascular surgeons and social worker were present, Carolina's case was discussed. One possibility was to continue the pregnancy with an increased risk of cardiac decompensation at the end of the pregnancy or to continue to delivery. The second possibility was to propose a therapeutic abortion, which due to her critical health condition was indicated. Valve replacement surgery was suspended because it was not justified under these circumstances. During the discussion there were contrasting views; however, most agreed that both options must be presented to Carolina and that she would have the support of the Cardiology Department for whichever option was chosen.

2.1 Nurse involvement. The nurses were not involved in medical issues or decisions.

2.2 Dimension of the patient's values and its social dimension. There is disintegration in Carolina's family. She is an only child. Her father is a 40-year-old policeman who abandoned Carolina and her mother 5 years prior. Carolina's relations with her mother are not good, and from pre-pregnancy she has lived with her grandmother (Carolina's father is an adopted son). Carolina's relationship with her husband (civil law marriage) is stable and there is great support from her 21-year-old husband. The couple now lives with her paternal grandmother and the husband covers the couple's expenses, as well as having much support from the grandmother and some from Carolina´s mother. When the alternatives were proposed, without hesitation, Carolina opted to continue her pregnancy and to deliver her son, expressing that there would not likely be another opportunity, and she was determined to accept the risks. Her husband and grandmother agreed with her decision.

3. Evaluation

3.1 The good of the patient---the greater good for Carolina is the preservation of her life and to reach her fullest potential as a person.

3.2 The autonomy of the patient---the patient decided to continue the pregnancy.

3.3 Responsibility of the health care professionals. Health personnel of the hospital fulfilled their responsibility by explaining to Carolina the risks and consequences of the continuation of pregnancy.

4. Decision making

4.1 Summary of the moral problem. Health staff considers on a weighted basis that abortion is the appropriate medical option; however, Carolina refuses therapeutic abortion.

4.2 Decision. The attending physician decides to respect Carolina's autonomy. She is considered to be a competent person who also has the support of the family network.

4.3 Assessment of the decision. Carolina was reevaluated and her decision to continue with the pregnancy was supported. There were threats of abortion with cardiac insufficiency and she required hospitalization on two occasions. Finally, at 32 weeks gestation, a healthy male was delivered by cesarean section with the participation of cardiology care.

The integral method

This is the method we propose for the analysis and discernment of ethical dilemmas in clinical practice. It originates from the tangible need to work in clinical practice with an ethic that ensures maximum human development and integrity in accordance with biomedical and biotechnological scientific advances.

It is an integral and maximal method that seeks the GOOD of the patient ideally integrating the three aspects of the action: as a moral agent, as subject to a process of rights and duties and the consequences of the action. This is achieved only from a holistic perspective, having analyzed the GOOD from various ethical perspectives. That discernment resembles a ballet dancer who has a foot on the ground, which are the different ethical currents determined by empirical circumstances, and one foot in the air, a sign of flexibility and search for ethical principles that will enhance the person in the relationship between health professional and patient that are universal. And the process from the ground to the air is the discernment or reflection of the case, and the process from the air to the ground is the process of believing and compromising with a course of action in the particular situation.

A key aspect of deliberation is that it encourages critical and cross-functional reflection in which the entire health care team, patient and family participate, allowing the attending physician to make a responsible decision, i.e., with knowledge, will and freedom deploying their full moral power. No consensus is sought because the ethics decision by consensus is anonymous, and no one is directly responsible.

The first product of the new method is that it makes the physicians aware of how they make their decisions and the values and virtues that are at stake. Thus, the physician becomes aware whether his/her decisions are utilitarian, deontological or self-praising. Second, the intellectual exercise to involve several ethical perspectives ensures that physicians exercise their hierarchy of values and ethics in a comprehensive, decidedly weighted manner and that they give more weight to those values, to self-praising values or utilitarian values.

This method proposes that, once the dilemmas are analyzed under different perspectives, the intellectual exercise is made to conduct a comprehensive ethical discussion having as the guiding principle, the involved person. In medicine we are concerned with all values and we are forced to comply with what is normal and to do well. When there is a hierarchy of values and it is acted accordingly, many dilemmas are only apparent and they prepare health personnel for a life or death decision that may need to be made in an emergency department.

Therefore, this method assumes that there is always a moral agent to make the decision, supported by a cross-functional analysis of the case in which health personnel, patient and family participate.

Through these pages the absolute value of the individual is reflected. It is a call to the physician to recognize him/herself as a person, to recognize the patient as a person and to search for good. With this cornerstone, regardless of the current philosophy that one be pro-utilitarian, deontological, aretological, situational, casuistry, among others, the moral agent is a constant value in the ethical debate. Therefore, the physician should improve not only his/her scientific and technical skills but his/her own moral perfection---in other words, become virtuous.

Virtue is an irreducible element of clinical ethics. Honesty, justice, kindness, humility and courage are virtues of a good physician and of a good patient and they affect the physician-patient relationship.

In a way the method allows awareness of the limitations as rational criteria of each criteria but also allows us to be aware of the way of implication and importance of such criteria in the actual

situation, in other words give us first a diagnosis of the moral tendency of the action to be able to correct it by the discernment.

The protocol is as follows:

1. What is the fact?

Carolina is a 16-year-old female with various congenital cardiopathies and for 9 years has suffered from cardiac insufficiency. At birth a congenital cardiopathy of interatrial and interventricular communication and persistence of the ductus arteriosus was detected. She was surgically intervened at 8 months for closure of the ductus arteriosus and at 2 years of age for closure of the interatrial and interventricular communication. At 4 years of age, subvalvular aortic stenosis was noted. At 11 years of age she had surgical resection of the subaortic ring. She developed postsurgical aortic insufficiency. At 15 years of age she demonstrated recurrence of the aortic stenosis and required a valvular prosthesis. She became pregnant at 16 years of age, and developed cardiac insufficiency (NYHA Class II). A therapeutic abortion is offered to the patient in order to preserve cardiac function and to not place overload on the heart. Carolina refused the therapeutic abortion.

2. What is the good that is sought?

- The greater GOOD is to protect the life of the patient and the baby.

3. Who are the beneficiaries of GOOD?

- The patient
- The baby
- Physicians, nurses and health staff in the cardiology unit
- The family

4. Who are the main players?

- The patient
- The baby
- Physicians, nurses and health staff in the cardiology department
- The family (husband, mother, grandmother)

5. Identify the ethical dilemmas and differentiate them from medical, technical and scientific and legal problems.

- The dilemma the medical team faces is the continuation or termination of pregnancy.
- Ethical analysis

Utilitarian

- The greatest benefit or aggregated good is the preservation of the life of the mother.
- From the standpoint of health personnel, the benefit outweighs the risk.
- From the cost-benefit point of view, termination of pregnancy is recommended.
- The main idea is to seek the most comfortable and reliable action.

Deontological

The duty of medical and health personnel is the preservation of life and, therefore, they fulfill their duty when they search for therapeutic conditions for continuing the pregnancy. The patient exercises her right to autonomy, subsidiarity and universality (NOM-007-1993-SSA2: Care of women during pregnancy, childbirth and postpartum and of the newborn).

The main idea is to act according to a system of rights and duties.

Aretology

The essential question is: Am I preventing evil? Something is good if it perfects, if it fulfills the inherent nature of the actor. Motherhood fulfills the patient and for the health personnel there will also be a perfect situation because they fulfill their vocation in the service of life. Priority is given to the synderesis, integrity, proportionality and virtue.

The main idea is to act in relation to what makes personhood flourish as such.

Integral

The continuation of pregnancy is a good action from the deontological and aretological points of view and, therefore, the challenge is to find the therapeutic conditions to preserve the lives of the two people. The ideal of integrity is that each criteria makes us aware of the limitations of the others and then have a regulative ideal of action that maximizes the good in the three senses, never forgetting that if there is no rational way to make the integration there has to be a hierarchy applied to the criteria that is supposed to be a truth in the method by an ontological perspective. This means first is the aretological, second the deontological and third the utilitarian. This means that human dignity is first of all an absolute value.

Results

The patient was hospitalized during pregnancy to avoid cardiac overload. She was given comprehensive interdisciplinary treatment. She underwent cesarean section at 32 weeks. The patient had a favorable evolution after delivery and is waiting for valve replacement. The baby is a healthy male with Apgar score 8-9. The Cardiology Department offers better options for women with cardiac insufficiency.

We can conclude with the following. There are different methods for ethical discernment and more are currently being developed daily. The methods described in this article have been evaluated in clinical practice. This paper is the result of the implementation of the new method, which is useful not only for prospective ethical discernment but also for retrospective discussions to optimize and evaluate the decisions taken.

Clinical ethics aims to solve practical questions that have, as a basis, what should I do in this particular case? Each case is unique and unrepeatable, something entirely new. For this reason it should be treated with respect and responsibility. Clinical ethics cannot be achieved in the abstract because the subject deals with real people and real situations. The main purpose of this paper is to provide methodological tools for the practicing physician on which to build a comprehensive scheme for his/her own ethical deliberations. The strengthening of the term "evidence-based medicine based on values" may be the product of a culture of clinical ethics in health personnel and result in a higher quality of patient care.

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