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Gazzola, Luciana de Paula Lima; Leite, Henrique Vitor; Gonçalves, Gláucio Maciel
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UPDATE

Communicating bad news about congenital abnormalities: bioethical and legal considerations

Luciana de Paula Lima Gazzola [1], *Henrique Vitor Leite* [1], *Gláucio Maciel Gonçalves* [2]

1. Programa de Pós-Graduação em Saúde da Mulher, Departamento de Ginecologia e Obstetrícia, Faculdade de Medicina, Universidade Federal de Minas Gerais (UFMG), Belo Horizonte/MG, Brasil. **2.** Programa de Pós-Graduação em Direito, Departamento de Direito e Processo Civil e Comercial, Faculdade de Direito, UFMG, Belo Horizonte/MG, Brasil.

Abstract

The communication to the pregnant woman that her fetus has congenital abnormality is framed by what is meant by bad news, surrounded by ethical conflicts experienced in fetal medicine and neonatology. The couple's breach of expectations about their idealized child arouses antagonistic feelings; The manner of elaboration of the news and even the eventual decision to terminate the pregnancy will be directly influenced as the fact was communicated by the team. For cases in which the child is born alive, the decision to adopt Palliative Care should also be shared, providing the exercise of responsible parenting. It is common, however, the request by the family of practices that configure dysthanasia and therapeutic obstinacy, when not adequately clarified about the prognosis of the disease. Aspects related to proper communication in the physician-patient relationship are discussed, fundamental to the exercise of autonomy and the duty to inform, whose violation leads to liability in the civil and ethical-professional spheres.

Keywords: Congenital abnormalities. Prenatal diagnosis. Neonatology. Personal autonomy. Communication. Physician-patient relations. Palliative care.

Resumo

Comunicando más notícias sobre malformações congênitas: reflexões bioéticas e jurídicas

A constatação de que o feto é portador de malformação congênita enquadra-se como má notícia, e sua comunicação à gestante envolve conflitos éticos relativos à medicina fetal e neonatologia. A quebra de expectativas dos pais quanto ao filho idealizado desperta sentimentos antagônicos, e o modo de processar a notícia e até mesmo a eventual decisão de interromper a gestação podem ser diretamente influenciados pela forma como o fato é comunicado pela equipe. Para os casos em que a criança nasce com vida, a decisão de iniciar cuidados paliativos também deve ser compartilhada, viabilizando o exercício da parentalidade responsável. Contudo, é comum que a família solicite distanásia e obstinação terapêutica, quando não adequadamente esclarecida sobre o prognóstico da doença. São discutidos no estudo aspectos relacionados à adequada comunicação na relação médico-paciente, fundamental ao exercício da autonomia e ao dever de informar, cuja violação é passível de responsabilização nas esferas cível e ético-profissional.

Palavras-chave: Anormalidades congênitas. Diagnóstico pré-natal. Neonatologia. Autonomia pessoal. Comunicação. Relações médico-paciente. Cuidados paliativos.

Resumen

Comunicación de malas noticias relativas a malformaciones congénitas: reflexiones bioéticas y jurídicas

La constatación de que el feto sufre una malformación congénita se enmarca en lo que se entiende por malas noticias, y su comunicación a la gestante implica conflictos éticos relativos a la medicina fetal y a la neonatología. La frustración de las expectativas de la pareja sobre su hijo idealizado despierta sentimientos antagónicos, y la manera de procesar la noticia e incluso la eventual decisión de interrumpir el embarazo pueden ser directamente influenciadas por la manera en que el equipo comunica el hecho. Para los casos en que el niño nace con vida, la decisión de adoptar cuidados paliativos también debe compartirse, para hacer viable el ejercicio de la parentalidad responsable. Sin embargo, es común que la familia solicite la distanasia y la obstinación terapéutica, cuando no se le aclara adecuadamente sobre el pronóstico de la enfermedad. En este estudio se discuten aspectos relacionados con la comunicación adecuada en la relación médico-paciente, fundamental al ejercicio de la autonomía y al deber de informar, cuya violación es pasible de responsabilidad civil y ético-profesional.

Palabras clave: Anomalías congénitas. Diagnóstico prenatal. Neonatología. Autonomía personal. Comunicación. Relaciones médico-paciente. Cuidados paliativos.

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Contemporary fetal medicine provides reliable medical data about severe congenital abnormalities of the fetus, and intrauterine diagnostic techniques are becoming increasingly widespread and safe. Diagnoses that were not feasible a few decades ago can be elaborated with safety and certainty, generating the ethical and legal responsibility for the physician to communicate the news to the parents, embodied in the duty to inform.

Pregnancy, a period of transition full of meanings in the woman's life, is full of ambivalent feelings, since, as Cabral states, *the pregnant woman wants the child, at the same time that she rejects and fears it*[1]. This phase is marked by expectations for the future based on an idealized parenting project. Long before conception, the baby already exists for the woman, who imagines herself as a mother and builds the image of the future child and family, after the child's arrival.

When there is risk in pregnancy and the fetus is found to have a congenital abnormality, fear and anxiety are increased. The idealized child, after the grieving process, will be replaced by the real child, who may not be born alive. The suffering caused to the parents is undeniable, as grief is not part of the normal and expected course of a pregnancy.

Thus, the idea that the couple will have a child that is different from the expected one breaks legitimate expectations, even if momentarily. The mourning for the irreparable loss of the imaginary child, the guilt for generating a malformed baby, and the fear of the difficulties inherent in the creation of a person with disabilities are some of the feelings experienced by the couple.

The reactions go through shock, disbelief and denial, frustration, anger, guilt and even irritation directed at the doctor who gives the bad news, at first. The sudden breach of expectations of the desired pregnancy and replacement by these feelings generate ambivalent reactions in the mother: sometimes she wants to protect her child, sometimes she rejects it, even questioning the possibility of not continuing with the pregnancy and also feeling guilty for this thought[2].

Communicating to the pregnant woman that her baby has a congenital abnormality is, therefore, difficult and delicate, which is understood as bad news, defined by Buckman as *any information that seriously and adversely affects an individual's view of their future*[3]. Feelings of fear, failure and helplessness are shared by the doctor and the family when the disease is severe and there is no curative treatment. In this context, evaluating the forms of communication and the mother-child and physician-patient relations established by the diagnosis is essential, since the absorption of the news by the mother will be directly influenced by how the fact was communicated to her by the medical team.

The same studies that show that doctors are poorly prepared in their academic training to communicate bad news demonstrate that patients have negative memories of the moment they receive them, not only because of their content, but because of the way they are transmitted, with inability, little empathy and insensitivity[4,5]. Those who receive traumatic information hardly forget the circumstances of communication: haste and lack of privacy are also seen as factors that influence the family's perception of the health team, impairing the physician-patient relationship and the absorption of the news by the affected people[6]. However, the way to report bad news can be learned and improved to understand how it interferes with the physician-patient relationship.

Autonomy of pregnant women and prenatal fetal abnormality

The physician-patient relationship – a pillar of medical care – abandoned asymmetry and verticality to become horizontal and to privilege the patient as the subject of their therapeutic and decision-making process. Although legally conceived as contractual, the patient is the main subject of this relationship, based on their informed consent form, which, in turn, justifies the physician's duty to inform. The health professional has to communicate the patient and clarify all the specifics of the case and, consequently, keep confidential the information obtained in the medical practice. Therefore, communication is one of the main aspects of this context, as it is a fundamental element of human relations.

An important assumption of the physician-patient relationship is autonomy, which Beauchamp and Childress[7] understand as one of the four moral principles that govern bioethics, together with beneficence, non-maleficence and justice. According to Pedro Pais de Vasconcelos, autonomy is based on ethical personalism, which, *by demanding the original and inherent recognition of the personality, equality and parity of all people, their dignity and freedom, implies the recognition of the autonomy of each and everyone*[8]. The exercise of autonomy demands knowledge and freedom, because, in order

for the patient to be the driver of their own decisions, they must know the possibilities to face the disease and be free to choose without any coercion.

Fetal diagnosis allows pregnant women and fathers to exercise their autonomy also in terms of reproductive rights and family planning, especially in countries whose abortion legislation is not restrictive and allows termination of pregnancy in cases of fetal congenital abnormalities. In Brazil, the free maternal option for termination of pregnancy is only allowed in cases of anencephaly diagnosis, as decided by the Supreme Federal Court in 2012 in the Statement of Noncompliance with the Fundamental Precept (ADPF) 54[9]. In other cases, involving several other congenital abnormalities with high rates of early fetal or neonatal lethality, such as trisomies 13 and 18 and some severe bone dysplasias, judicial authorization is required for the abortion to be filed in Brazilian courts[10].

In this context, due to the possible elective termination of pregnancy after finding fetal disease, a doctrinal approach questions the very ethics of the prenatal diagnosis of congenital abnormalities. Anne Dusart[11] adheres to this perspective and states that fetal propaedeutic methods have a double aspect, predictive and selective. The first stems from the possibility of predicting a disease that will affect the fetus, allowing some intervention, albeit little. The second, on the other hand, would provide for the elective termination of pregnancy in the countries where the act is permitted.

The author also touches on the ethically questionable idea of using these methods as part of a public disability prevention policy, stating that the diagnosis could legitimize a kind of "de facto eugenics"[11]. Adrienne Asch[12] is also opposed to the use of prenatal diagnoses for making feasible the practice of abortion of fetuses with abnormalities, assuming that life with a disability would be undesirable.

However, one should not consider that eugenic mentality is being discussed as a valid justification to deny the prenatal diagnosis or its communication. Regardless of the possible moral content of the parents' decision about the possibility of terminating the pregnancy, the duty to inform is unavoidable. The healthy physician-patient relationship depends on it, as well as the patients' autonomy, who without information cannot actively decide on their condition.

What should be cautiously evaluated is how to communicate the news, not the completion or elimination of the fetal diagnosis. Especially in cases of severe fetal congenital abnormalities, the way of informing the parents of the diagnosis can interfere in decision making, since the language adopted by the doctor influences the mother's idea of interrupting or maintaining pregnancy.

Medicine adopts its own terminologies that carry, for the common and lay ideas, notions that do not correspond exactly to what the scientific term means. Even when adopted in a technical sense by the speaker, words in this context can completely alter the recipient's perception. When the doctor categorically affirms the lethality of a condition, he or she interferes dangerously in the parents' judgment, predicting as an inexorable medical condition something that, in fact, is up to the parents' decision-making autonomy: whether or not to interrupt the pregnancy[13].

Terms as "lethal disease" and "incompatible with life" have been banned from medical counseling[14] because they have the potential to instill in the pregnant woman the idea that if death is certain, there is no choice. In this mentality, the woman and her family experience the grief of their imagined child, believing that it will certainly die in the uterus. If the child is born alive and survives, for example, for a few months – as it can occur in abnormalities usually considered[15] to be lethal – the mother will create strong emotional bonds with the disabled baby that she no longer expected and that requires intensive and additional care, experiencing a second mourning when the child dies, sometimes even more traumatic.

There are pregnant women who, even in cases of severe fetal abnormalities and usually considered to be lethal, choose to carry the pregnancy to term. The moment of delivery is distressing and anxiogenic, as it can immediately result in the baby's death. Cabral reports the case of a mother who stated: *if I could, I would have him in my belly forever, because here I know he lives*[16]. If the child is born alive, it must be ensured that the parents have loving and serene contact with their child as long as it lives. Palliative care becomes the place of respect and care. In the postpartum period, when the baby does not survive, it is also important to respect the woman's decision to see or not see the dead child, although the first option is relevant to the mourning and acceptance of the fact.

Thus, parents should be informed of all possible situations and outcomes, such as probable intrauterine death or survival for variable periods, as well as the impossibility of predicting with certainty the outcome of pregnancy or the moment of death

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of the fetus or of the child. Genetic counseling for future pregnancies can also be prepared and initiated through adequate communication in the prenatal period of gestation of an abnormal fetus. During counseling, parents should be informed of the future pregnancy risks, given that the subjective interpretation of these risks can influence the decision regarding the current situation. The Portuguese bioethicist Rui Nunes [17] states that counseling does not presuppose total neutrality of the counselor, who must, however, support and respect the couple's autonomy. As the author points *out, the counselor must have sufficient ability to tolerate the couple's different moods that may emerge throughout the counseling process* [18].

Communicating bad news to parents of newborns with congenital abnormalities

The importance of guiding and informing parents in a careful and comprehensive way persists and acquires new relevance after birth, involving neonatology with ethical and legal dilemmas that surround decisions in cases of children with congenital abnormalities. In order to minimize the difficulties and negative repercussions that inadequate communication of bad news can cause to patients and families, guidance protocols have been developed aimed at training the health team. The best known was published in 1992 by Buckman [19] which is called the Spikes protocol, an acronym in English that summarizes the six steps to be observed: *setting up*, *perception*, *invitation*, *knowledge*, *emotions* e *strategy/summary* [19,20]

The first step deals with the initial approach of the patient and the way the professional prepares the environment, preserving secrecy and privacy, aiming to welcome and support. The second recommends that the subject's conception and perception about their health condition and future possibilities be analyzed. In the third step, it is necessary to assess how much the individual wants to know about the disease so that in the fourth step the news be transmitted in language that is comprehensible to the patient, in a realistic, empathetic and affable manner. In the fifth step, after receiving the news, the doctor must support the patient's emotions, regardless of their reaction. And the sixth and final step refers to the strategies that can be adopted to conduct the patient's treatment and minimize the pain, fear and anxiety that the news causes [19].

One of the most difficult steps for the physician is the fifth phase of the Spikes protocol, when they must support the patient's most diverse emotional reactions and match them with their own emotions and experiences. In this phase, it is not uncommon for the patient to react with anger towards the doctor, bearer of the bad news, and start to see this person, at least in the initial moment, as a traitor, and not an ally [21]. To minimize this reaction, empathy, truth and language are fundamental, as it is necessary to ensure that the patient understood the disease to participate in the shared decision-making process.

Applying these recommendations to neonatology – which aim to provide a healthy environment for the patient to receive and assimilate the bad news –, a complicating factor arises: the impossibility of the right holder, the malformed newborn, to exercise their autonomy. For this reason, in routine practice in neonatology, divergences are common between the parents' will, in the exercise of parental authority, and what the medical team understands as the best therapeutic alternative for the newborn, especially when the family has not been properly informed about the disease that afflicts the child.

If the prognosis indicates that the child's death is imminent, communication of news and preparation of parents in the neonatal period should support and guide them about palliative care. In this phase, the circumstances of the disease can threaten autonomy, encouraging paternalism and overprotection by health professionals [22], without the family being properly heard about their wishes regarding the child's end of life. It is important to value subjectivity and the way the couple prepares for their child's death with empathy. Decent death – or its impossibility, in countries in which autonomy is not guided by the fundamental precept of medical relations – is a topic that deserves reflection in the scope of this work.

Palliative care or dysthanasia on demand?

Adequate relational communication in neonatology, especially in cases of end of life in congenital abnormalities, is a herculean task and made even more difficult by social impediments in coping with the death of children. One of the major problems is to find objective criteria that enable to reconcile the protection of the child's rights and best interests, the expectations of parents – who legitimately seek to minimize their suffering – and the doctors' attempt not to incur therapeutic obstinacy

and futility. Certainly, the solid physician-patient relationship, based on dialogical communication and trust, facilitates the achievement of this difficult golden mean.

The decision-making autonomy of the parents in the exercise of their parental authority cannot be disregarded by the medical team, although it should also not be considered as absolute when it conflicts with the child's best interest. Studies carried out with parents of severely malformed newborns, aiming to report their experiences and perspectives after receiving the diagnosis, demonstrate that it is common to request extraordinary medical interventions and the expectation of taking the child home and giving it a quality life, seeing it alive even for a short time [23,24].

The couple's legitimate expectations regarding living with the seriously ill and malformed child must be protected by the health team, respectfully and providing a welcoming environment for as long as possible. In this context, the importance of palliative care is expanded, as it protects the best interest of the child at the end of life, ensuring a dignified death.

Considering that severe abnormalities with high lethality before or after birth are often diagnosed during prenatal examinations, at this stage parents should be very well informed about all possible approaches to their child's condition. Assuring the family that they will not be abandoned and giving them time to reflect on the diagnosis are important measures. In addition, explaining that it is not possible to change the natural course of the disease, but that comfort and dignity can be offered to the newborn's short life is an empathic way of approaching palliative care as the best conduct.

Anita Catlin and Brian Carter [25] highlight that certain actions comfort and encourage the family to choose palliative care when there is no possibility of curing the newborn's serious and terminal illness. Among these actions they suggest validating as legitimate the feelings that involve the loss of the dream of having a healthy child, as well as explaining that interrupting extraordinary interventions that prolong the pain is a courageous and loving action of the parents in the face of their child's suffering. The authors also recommend that, when informing the child's news and prognosis, the doctor encourages parents to interact with the baby as a family as much as possible, referring to the newborn by name and helping them to plan what they would like to do while the baby is still alive [25]. It is an empathic communication that favors comfort and does not neglect the dilemmas that parents face when making decisions in extreme cases.

This approach is recommended because when communication fails and the family does not understand the severity and natural course of the disease, it is common for parents' requests and desires to conflict with the medical understanding of the best course of action. The practice of dysthanasia then becomes widely requested by parents, who see the baby's death as an outcome that can and should be prevented.

If the team does not impose limits on the medical conduct that is potentially harmful to the child at the end-of-life, therapeutic obstinacy is incurred, usually causing dysthanasia. The critical analysis proposed in limiting therapeutic efforts is consistent with the idea that procedures should be suspended if there is no indication to maintain them or when they only maintain the individual's biological and non-biographical life [26]. The great difficulty is to make the family understand that the adequacy or therapeutic limitation is not a negligent act of giving up or abandoning the child. However, since behaviors adopted in therapeutic limitation are not emergency or untimely measures, but decisions made progressively in chronic situations, it is possible to share information with parents through dialogue and clarification of guidelines [27].

Today it is possible to recognize that in end-of-life decisions, self-determination should prevail as an expression of the individual's autonomy in his personal fulfillment and not in the fulfillment of family expectations, due to the very personal character of such decisions [28]. However, this statement is not applicable to newborns. In this context of valuing autonomy as a fundamental principle of the medical duty to inform, how to reconcile the child's best interest with the parents' authority when expressed by the repeated request for dysthanasia? If the child cannot manifest autonomy, should it be completely replaced by the parents' heteronomy and the expression of parental authority?

The answer to such questions goes beyond the raison d'être of autonomy as the foundation of the individual's dignity. Autonomy is a principle par excellence and does not admit being constituted by heteronomous ethical determination, nor can it be reduced to the idea of mere competence to decide [29]. It also presents two important aspects from the ethical point of view: respect for individual's will and protection for those who have reduced autonomy [28].

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For the child, the impossibility of exercising autonomy imposes its substitution by its best or superior interest, an expression that encompasses medical and any other aspects related to its well-being, and its best interest is far from being understood as the prolongation of its process of death with suffering. Therefore, it is not a question of devaluing the parents' authority in the eventual choice of dysthanasia, but of considering the risk of harm and the probability of benefit in the analysis of the child's best interest. In addition, there are limits to parental authority regarding the child's existential rights, when dignified life and death are under debate.

Prudence guides the search for the solution that best contemplates the family context, and loyalty to the patient is fundamental to build a relationship of trust. As a result, there are no universally correct decisions, but prudent when it comes to content and information [30]. In this potential conflict of interest, the dialogical relationship between all the actors and the clear definition of the goals of care and the family's values and expectations should be the basis for determining the best conduct. Consensus must be sought and, if ethical differences and conflicts persist, the institution's ethics committee, bioethics committees and the Regional Medical Council can be consulted.

The Judiciary must be the last resort, since the judicialization of ethical conflicts in health, especially considering the deadlines for the processing of procedures in court, does not always provide the best solution. Luciana Dadalto and Carolina Affonseca affirm that *referring medical decisions to spheres that transcend the family and the healthcare team generates a serious rupture in the relationship of trust, causing dissatisfaction for all parties involved* [31].

Medical responsibility for the duty to inform

The right to information is the cornerstone of mandatory relationships and is also a corollary of the principle of objective good faith, present in physician-patient relationships and one of the basic principles of relational private law. Its other side is the duty to inform, whose non-observance can generate civil liability. Ruy Rosado de Aguiar Júnior states that, whereas the main role of the medical professional is the medical act, *the most important accessory is to provide adequate information and obtain the informed consent of their patients* [32]. This is because the duties to protect, inform, cooperate and care are lateral or attached to the main contractual duty to perform the medical act itself.

The obligation to clarify is instrumental as it gives freedom and knowledge to those who consent. It can be materialized in the informed consent form, a document that presents information on diagnosis, prognosis, available therapeutic options, means and purposes of treatment, as well as risks and benefits. The language must be accessible to the patient, and the doctor must make sure that the patient has understood all the information provided, without mandatory norms that the consent be registered in writing. This is because communication is gradually built, and it is practically impossible to reproduce it entirely in written documents. However, writing the consent is recommended, especially to prove the patient's agreement and respect for their autonomy, as well as to evaluate their perfect clarification, as provided in Recommendation CFM 1/2016 [33], which discusses the subject.

Applying the idea to fetal medicine, and since the right to information has a constitutional guarantee and is based on the principles of dignity and freedom, denying ethics to the performance of prenatal diagnostic methods – with the argument that they would make "eugenic choices" – is an unreasonable idea. The pregnant woman has an autonomous right to know her biomedical data, which underlies the doctor's duty to inform. Since every medical act must be consented, there is no way to remove the duty to inform. Furthermore, after the child's birth, parents have the right to know the newborn's medical condition so that they can exercise responsible parenting.

The physician-patient relationship is contractual, although considered special because it involves very personal rights and has bilateral legal nature. Being contractual, the principles of objective good faith and contractual freedom apply to it, the first imposing on contracting parties duties of trust, information and loyalty to guide their behavior [34]. The breach of duties attached to the medical contract is a form of positive breach of the contract, even though the main provision has been performed and there has been no malpractice in the main obligation of the medical act [35]. It is understood in the jurisprudential and doctrinal scope, that the duty to inform already constitutes an obligation of results, even though the medical duty is one of means [36].

The disrespect to the right to autonomy already represents moral damage in itself, subject to civil reparation. Therefore, when the patient's freedom of choice is injured, due to complete or partial omission

(when the information is provided incorrectly only to obtain the patient's consent) in the duty to inform, moral damage should be repaired [37].

Classic doctrinal criticisms of informed consent forms are summarized in the work of Lorenzetti [38], who mentions that information is usually given after the medical decision has already been made, not even changing the patient's decision. In addition, communication is done through complex means and the process only constitutes a ritualization and bureaucratization, aiming simply to "avoid judicial demands", not satisfying the real objective [38]. Such criticisms, in fact, concern especially the mistaken way of preparing the communication and fulfilling the duty to inform, and not the informed consent itself.

Also, in the ethical-professional sphere, failure to comply with the duty to inform is an illegal act. The new Code of Medical Ethics, introduced in the order by Resolution CFM 2.217/2018, has an article 13 that *prohibits the physician to fail to clarify the patient about the social, environmental or professional determinants of their disease* [39]. Additionally, article 24 prohibits the medical professional from failing *to guarantee the patient's exercise of the right to freely decide on their self or well-being, as well as exercising their authority to limit it* [39].

Thus, the duty to inform is positioned as an instrument for realizing the physician-patient relationship and private autonomy as a fundamental patient's right and its violation leads to liability in the civil and ethical-professional spheres.

Final considerations

The communication of bad news is not a simple task, especially in the fields of fetal medicine and neonatology, which encompass stages in a woman and couple's life that is naturally permeated with symbolism, high expectations and anxiety: pregnancy and the birth of a child. If the news to be communicated refers to the diagnosis of severe fetal congenital abnormality and high lethality before or after birth, the experience of grieving the idealized child, guilt and fear are complicating factors that require professional consideration, care and empathy in the act of communicating.

Considering private autonomy as a principle of the physician-patient relationship, the duty to communicate the truth is no longer analyzed under the prism of what news should be given to the patient, but how the information should be shared. Just as or more relevant than the information content is its quality.

Thus, it is possible to adopt guidance protocols on adequate communication of bad news, which should, however, be understood only as a parameter, since each patient is unique and the protocol forecast does not have the ability to cover all possibilities and complexity of physician-patient relations. Communication techniques can be improved and, due to their importance, must be learned from the beginning of medical training. A welcoming multidisciplinary environment, in which the family can be heard, supported and guided, is also extremely important.

Even during prenatal care, the way of communicating the diagnosis of severe fetal abnormality can have several consequences: interfering in the eventual maternal decision to terminate the pregnancy, guiding the family regarding the care of a child with varying degrees of disability and even preparing it for possible therapeutic limitation and adoption of palliative care.

When the couple chooses to terminate the pregnancy – whether or not it is necessary to obtain a court order, depending on the case and the legal system – the multidisciplinary team's attitude must be one of moral exemption, compassion and respect, as the decision to abort is also accompanied by a lot of pain and suffering. It is unreasonable to question the ethics of prenatal diagnostic methods, linking them to the moral content of the parents' decision to interrupt or not the pregnancy of a malformed fetus.

It is not for the physician to suppress the inalienable right of the parents to know the reality of their condition, to exercise private autonomy and to form their will free, spontaneous and free from coercion of any kind. The violation of the duty to inform, a corollary to the patient's right to information, constitutes a breach of objective good faith in the very personal contractual medical relationship, which leads to liability in the civil and ethical-professional spheres.

In cases of fetal abnormalities with high rates of prenatal lethality, the family should be fully informed about all possible outcomes of pregnancy. It is recommended that the use of terms such as "lethal disease" or "incompatible with life" be banned, as the eventual birth with life of the malformed child can generate mourning in two stages in the pregnant woman: for her fetus, upon being initially informed of its potential intrauterine death, and later by her living child, who demands intensive care and may die after some time.

After birth, the decision to adopt palliative care must be shared and may involve several

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ethical conflicts to be faced by the health team. In this situation, efforts must be made to overcome medical paternalism, respecting the parents' self-determination. However, conflicts are common between the family's desire to preserve the child's life for as long as possible and the medical opinion that it would be therapeutic obstinacy and dysthanasia. In these cases, the child's best interest and dignity should guide the search for the most appropriate solution, and it is interesting to consult the institution's medical ethics bodies.

The health team's attitude towards news involving congenital abnormalities and end-of-life decisions for newborns should therefore be to inform as accurately as possible, without trying to convince or persuade the family. It is essential that health professionals be prepared to support and give emotional support to parents, with a psychological approach and social assistance, also including genetic monitoring and family planning for future pregnancies, as sometimes the mother wants a new pregnancy, but she rejects the possibility for fear of the experience being repeated. Adequate communication is crucial for the pregnant woman to understand and form a critical judgment about the reality, providing the necessary support to face the diagnosis, the death of the expected child and the overcoming for the family's reconstruction.

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Participation of the authors

Luciana de Paula Lima Gazzola conceived the study and wrote the article. Henrique Vitor Leite and Gláucio Maciel Gonçalves guided the researches and contributed equally to the final review.

Correspondence

Luciana de Paula Lima Gazzola – Conselho Regional de Medicina de Minas Gerais. Departamento de Fiscalização. Rua dos Timbiras, 1.200, 6º andar, Boa Viagem CEP 30140-064. Belo Horizonte/MG, Brasil.

Luciana de Paula Lima Gazzola– PhD – prof.lu.gazzola@gmail.com
0000-0003-2896-9609

Henrique Vitor Leite – PhD – henriqueleite@globo.com
0000-0003-2806-8560

Gláucio Maciel Gonçalves – PhD – glauciomaciel@gmail.com
0000-0002-9318-5897

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