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Breaking bad news during prenatal care: a challenge to be tackled

A comunicação de más notícias durante o pré-natal:
um desafio a ser enfrentado

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Abstract *Communicating an unfavorable diagnosis during prenatal care is a growing challenge in clinical practice, as more and more tests are being performed to screen for the main conditions affecting the pregnant woman and her fetus. The way patients receive and subsequently deal with bad news is directly influenced by how the news is communicated by the attending physician. Unfortunately, physicians receive little or no training in communicating bad news, and they generally feel quite uncomfortable about doing so. Although many physicians consider the saying that “there’s no good way to break bad news” to be the truth, the maxim does not reflect the true picture. The scope of this article is to discuss, in light of the scientific literature and the experience of fetal medicine services, some recommendations that can help to deal with these difficult moments and improve patient care for the remainder of the pregnancy.*

Key words *Communication, Bad news, Ultrasound, Fetal medicine, Malformation*

Resumo *A comunicação de diagnósticos durante o pré-natal é um desafio crescente na prática clínica à medida que se realizam cada vez mais exames para o rastreio das principais patologias que acometem as gestantes e seus fetos. A recepção de uma má notícia e sua posterior elaboração pela paciente serão diretamente influenciadas pelo modo como ela foi comunicada pelo profissional assistente. Infelizmente, os médicos recebem pouco ou nenhum treinamento para transmitir más notícias e, em geral, sentem-se extremamente desconfortáveis com isso. Embora a máxima “não existe uma maneira boa de dar uma notícia ruim” seja admitida como verdade por muitos médicos, ela não é representativa da realidade. O objetivo deste artigo é discutir à luz da literatura científica e da prática em centros de medicina fetal algumas recomendações que podem facilitar a vivência desses momentos difíceis e melhorar o cuidado com os pacientes para o prosseguimento da gestação.*

Palavras-chave *Comunicação, Más notícias, Ultrassonografia, Medicina fetal, Malformação*

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Introduction

Communicating bad news to patients has been discussed by various specialists, focusing on the health professional's ethical, cultural, psychological, and legal involvement in this task¹. The literature shows that physicians are generally not prepared to transmit such information^{2,3} and that patients often hold bad memories of the moment when they received the news, not only because of the news itself, but because of the caregiver's inability, insensitivity, or both⁴.

In prenatal care, disclosing an abnormal diagnosis is unavoidable. Any health professional that attends pregnancies will have to transmit bad news some day. Such communication receives little attention during medical training, but it becomes essential when the physician enters routine clinical practice^{5,6}. In fetal medicine, where bad news is frequent, a rich body of experience has accumulated, thus highlighting the importance of reflecting on a topic that can be extremely useful⁷⁻¹⁰.

Brazil has slightly more than three million live births per year, of which some 200,000 are premature and 18,000 involve some congenital abnormality¹¹. The Fernandes Figueira Institute of the Oswaldo Cruz Foundation is a tertiary referral hospital for fetal high risk pregnancies, where approximately 20% of all liveborn infants with congenital malformations are born in the city of Rio de Janeiro¹². The majority of these cases are referred to the Institute's Fetal Medicine Department due to diagnoses of fetal malformations detected by routine ultrasonography, and bad news is not only frequently confirmed, but very often more serious additional news emerges.

Our daily practice shows that the diagnosis of a fetal abnormality or complication of pregnancy can change the future prospects of the woman and her family, corroborating the idea that one of the health professional's roles is to present the perspectives that allow the couple and their next of kin to understand that time goes on after the news and that life does not come to a standstill¹³. The identification of emotional demands and cultural values attributed to motherhood by the woman can help the physician in this difficult task of helping her find ways to proceed with the pregnancy or even to interrupt it when possible.

The prenatal diagnosis

Ultrasound examination is now routine practice in obstetrics, and most countries have clinical protocols on the number and objective of such tests during prenatal care. In France and others European countries, where the guidelines provide for three ultrasound tests during pregnancy, at weeks 12, 22 and 32 after the last menstrual period, thousands of malformations are detected per year, some of which are considered severe and raise the possibility of interrupting the pregnancy¹⁴⁻¹⁶. In Brazil, interruption of pregnancy due to congenital malformation is not officially available, due to legal restrictions¹⁷. Even so, prenatal ultrasound screening of malformations frequently performed, although without formal guidelines^{18,19}. This situation has led to an increase in the number of both prenatal diagnoses of malformations and court injunctions authorizing the interruption of pregnancies in cases of fetal abnormalities that are incompatible with life, especially anencephaly²⁰.

The supply of screening and diagnosis of maternal and fetal disorders during prenatal care is supported by basic bioethical principles²¹. During pregnancy, the exercise of key aspects of reproductive autonomy, like the right not to proceed with the gestation in what are considered unfavorable situations, cannot be dissociated from access to information on the fetus provided by ultrasound and invasive tests. By providing knowledge of the diagnosis, the couple is allowed to decide on potential treatment or whenever possible to opt to interrupt the pregnancy, thereby complying with the principle of beneficence²².

Information on an abnormal diagnosis generates anxiety for the parties involved. Thus, the way such news is broken should also follow the principles of beneficence and non-maleficence, thus avoiding the aggravation of traumatic situations. Anticipating the diagnosis during the prenatal period is also important for the medical team to be prepared to attend to the newborn under conditions consistent with the immediate needs of the given abnormality²³. When everyone is prepared, parents and physicians act in synergy, improving the care and preventing bad news from surfacing unexpectedly.

One of the most important aspects in dealing with the diagnosis and follow-up of fetal abnormalities is to provide emotional support to the woman, and the physician is in a position to do so, given his privileged knowledge. Still, the structure of clinical thinking as it is taught in medical

schools prioritizes the capacity for synthesis, precise associations, and rapid decisions, and the physician is always prone to give brief information in the expectation that it will be adequately understood. Meanwhile, the patient's attention tends to dissipate when she receives bad news, decreasing her capacity to record the information. The physician realizes that the information was not fully understood, since the patient loses her capacity to listen at the most critical moment of communication. This can also be an anguishing and discouraging situation at the moment of breaking the news. Thus, the physician must be aware that the content of what is said may only be fully understood later, and that he should not prepare what to say, but also consider all the other aspects involved in the circumstances²⁴.

The physician as creator of the fetal image

During an obstetric ultrasound examination, the woman and her family harbor great expectations about what the physician is looking for in the images that he produces. Thus, the power to make a diagnosis on the pregnancy and fetus is in the hands of the physician that performs the test. In an extensive anthropological study of obstetric ultrasound, Chazan²⁵ shows that although many women are informed about the test's objectives, the physician's test report is not always clearly understood. The author highlights that technology both relieves tensions and provokes anxieties, and that a vast output of non-medical truths reshapes maternal and fetal subjectivities through the images obtained during ultrasound examination. According to Chazan²⁵, by viewing the images, the actors involved in the examination (physician, patient, and family) construct the personification of the fetus and a meaning for the mother's sensations.

Viewed on a screen similar to that of a television, ultrasound images can look like the baby itself in the eyes of the pregnant woman and her family. These images are sources of speculation and pleasure for the parents, making the pregnancy seem more real, even before the mother feels her child's first movements. Viewed in real time, the fetus becomes a social being, unveiled to the public eye, acquiring individuality. The fetus also acquires the status of a patient, and can be examined and investigated independently of the mother's positive or negative perceptions of its health.

Individualizing the fetus as another patient, assigning it a personality, motivation, and interests of its own based on the interpretation of "concrete" images, transforms the woman's position during prenatal care to the extent that it undermines her role as intermediary between the fetus and the outside world. This demonstrates how technological command weighs in the balance, in the power relationship between physicians and patients, and leads us to consider this fact's influence on communicating the diagnosis and its understanding and acceptance by the patient and family²⁶.

Assuming the role of informant, as the one capable of seeing the baby inside the uterus, the physician (in the patient's eyes) is both the one who breaks the bad news and wields the power to intervene in the disease and alter its course, so that the diagnosis uttered by the physician carries the weight of a sentence²⁷.

Announcements during routine ultrasound

Examination of the fetus represents quite different situations for the physician and the patient. Ultrasound is the high point of prenatal care for many women, representing the encounter between the future baby, while inaugurating the family, with all its significance in our society²⁵. The pregnant woman does not prepare herself, nor does she want to be prepared, to hear bad news about her pregnancy. The physician's expectations towards the test are primarily different, since it is a routine situation with the usual equipment and images in which fetal malformations are relatively infrequent. Thus, when faced with some morphological alteration in the fetus, the physician himself feels destabilized: "What am I supposed to say now?"²⁸.

In this situation, where the paths for one and the other are so different, the physician has the responsibility to prepare everyone, saying for example: "Today we're going to examine your fetus to check whether there's some abnormality"; he can also explain that the examination is performed in silence, and that he will make his comments afterwards. During the examination, although the mouth is silent, the body speaks. Still, the perception one can have of a silent event, with no words, leads the woman to begin to feel that something is happening.

Announcing a fetal malformation detected by ultrasound has its particularities. The examining physician detects an anomaly by means of images

that he produced himself, and thus he not only becomes the bearer of bad news, but may also appear to have created it. Even though the vast majority of pregnancies are normal, the physician should always be prepared to break bad news, since the images are produced at the same time in which they are discussed, and there is little time to elaborate the announcement. Thus, unlike lab test results, there may not be time to add medical information before the announcement.

When couples realize there is something abnormal with the fetus, they often want the ultrasound examiner to explain everything about the problem, and as quickly as possible⁶. It is not simple to stop the work and begin what is often a long and sometimes dramatic conversation. However, excessive objectivity, limiting news of the diagnosis to purely technical language on the image found on the screen, can be harmful to patients and negatively influence their decisions on the future of the pregnancy²⁹. The examiner should be prepared to say what he knows about the alteration detected in the test and allow the couple to express their questions and frustrations. Thus, he will also be helping the obstetrician and other specialists to whom the patient may be referred later.

Talking with the specialist

Specialists in fetal medicine are generally called in to issue their opinions on a case when another professional has detected an abnormality in a routine examination. These professionals are used to dealing with high-complexity problems that involve dramatic situations for the parents. Even so, this learning process tends to be painful for physicians, who feel constantly frustrated and anguished in the face of persistent limitations in successfully dealing with more serious conditions. It is a key moment for reassessing positions and dealing with powerlessness in the face of an incurable situation or undefined diagnosis, which is not always easy because it exposes their own weaknesses³⁰. Yet the dialogue between specialist and patient can greatly relieve the anxiety for both, when they realize that an image or test result does not summarize the condition, existence, or future of a human being. Starting with the observation of a black-and-white image on the ultrasound screen, one should build a diagnosis, followed by a prognosis and an action plan, without allowing phantoms to overwhelm the thinking of the patient or her family³¹. Hearing their

complaints, allowing time for questions to surface, and guiding the conversation on the subject are useful measures for helping families deal with the more extreme events, and beyond the images, to reflect on the future of the pregnancy.

The reaction to bad news normally follows a given path: after the shock or disillusion comes denial, followed by revolt, argument, sadness, or depression, and finally acceptance. But the first phase, the shock, can prevent the patient from understanding the information given to her. Still, some tips can help turn these difficult moments into a time of rich communication and change perceptions concerning the issue, thereby facilitating ultimate acceptance.

Guilt is the first feeling that surfaces when a fetal anomaly is detected or an unexpected event occurs during pregnancy³². The feeling emerges like a giant beanstalk that grows all out of control, as in the children's tale. Such feelings are manifested in phrase like "Doctor, did I eat something wrong, could that be it?" or "Was it a trip I took, or something I thought?" Slowly, but with determination, the physician should rule out such conjectures to give the patient the opportunity to think ahead. This may not be so easy when the fetal condition involves transmission from the parents to the fetus.

When possible, anticipating bad news is less shocking and tends to attenuate the commotion that the words may cause. For example, when prescribing some test, appropriate information on the reason for the prescription anticipates the possibility of an abnormal result. There are two types of anxiety associated with bad news. The worst anxiety is when the person is not prepared; it's a suffocating, painful, oppressive anxiety that blunts thinking; the other kind is called signal anxiety: it is a vague, diffuse concern that something is about to happen. It allows one to maintain vigilance, trigger one's attention, and prepare for the possibility of bad news³³.

In France, before performing biochemical screening for aneuploidies, women must sign a consent form. In Brazil, some fetal medicine services and laboratories also use an informed consent form for both biophysical and biochemical screening of aneuploidies. When it is necessary to summon a patient to break the news of an abnormal result, one may consider a phrase like: "We need to talk about your test results." The woman thus has time to absorb the idea that perhaps something is not alright, so that after the appointment she will tend to say: "I already thought there was something abnormal" and will thus be quicker

to resume her ability to think and assimilate the news into her life. Otherwise, some news can trigger aggressiveness and disbelief and prevent the listener from reflecting on and experiencing the new situation in a non-traumatic way³⁴.

A necessary encounter

Abnormal test results should never be given over the telephone. A phone call can find people in various situations of which the physician is unaware. Breaking bad news is known to be a source of stress for the physician, who in his anxiety to get the weight off his shoulders may underestimate the patient and her desire for information on the diagnosis⁶. Breaking bad news by phone is typically a way of quickly dispensing with a difficult "job", rather than spending the time organizing information and considering a better way of telling the news.

When the tests are properly justified, setting an appointment to discuss the results is a natural sequence, in addition to providing the opportunity for the patient to come with her husband or another family member or friend. The presence of one or more accompanying persons can help both the woman and the physician. The commotion following bad news often prevents people from properly understanding the information. The accompanying person who also hears the information can help retrieve it after the appointment. His or her presence can provide an important source of solidarity, relieving the patient's sense of loneliness at this crucial moment.

During this indispensable encounter, we should also consider the opportunity to share our own humanity. The physician's physical presence bears a meaning that is impossible to achieve merely by his voice on the phone. Human communication goes far beyond verbal communication, and includes posture, gaze, tone and firmness of voice, gestures, touch. Our ability to communicate is incomplete on the telephone, whereas speaking face-to-face about difficult issues can help make them more acceptable³⁵.

In daily medical practice, appointments tend to occur in rapid sequence, with the waiting room frequently full, sometimes noisy, and with intense movement. When a difficult diagnosis needs to be transmitted, it should be done in a private office or quiet hospital consulting room, avoiding, insofar as possible, sudden entrances into the room, telephones ringing, and other similar interruptions. The physician feels better when he is not

pressured by time, and a favorable approach is to schedule with the patient at the end of the work shift, with more time and tranquility to deal with the situation. The physician needs a full command over the subject of the information to be transmitted. The harder the news to be broken, the better the caregiver needs to be prepared.

Planning an appointment means gathering the necessary information to say only certain things. No professional can know everything, but what is said must be precise, and the limits of medical knowledge must be disclosed. Referral to other specialists may be suggested. It is important to choose the words properly, since they can take on different connotations when they are heard, and they will remain in the families' memory³⁶. One should particularly reconsider the use of figurative terms frequently used in medical jargon, like "banana sign", "lemon sign", "cloverleaf skull", "strawberry skull", "frog face", and others. Such images generally provoke phantasmagoric, nightmarish ideas of huge deformities and can trigger panic in the pregnant woman.

The news should be given with the patient dressed and sitting. This is particularly important with information pertaining to tests like ultrasound, when the woman is lying in a dark room with her abdomen uncovered. The physician should sit in front of the patient, at the same height, look her in the eye, and keep in mind that most human communication is non-verbal. Body tension, hand movements, nods of the head, and frowns are perceived and interpreted by the patient. Knowing this part of human communication, and in the case of bad news, knowing the usual reactions like disbelief, repulsion, and silence, allows the professional to help the patient express herself and rethink the situation later³⁷.

The professional can use common-sense situations to make proposals, helping the patient find a meaning for the facts. A relationship of empathy can be established with phrases like: "I realize that you're very sad," "It's normal for you not to believe what I'm saying," and "In these situations some women feel very bitter or like victims of injustice."

No news should be given entirely, all at once. Without hiding anything, but respecting the individual pace of questions, new appointments can be scheduled and additional information provided. Other specialists can be summoned to assist the patient, in order to give her a broad support network. The subsequent appointments should always include time for the patient to express her feelings.

It is the woman and the family whose life is affected, and the subject pertains to them. The physician should leave room for everyone to express their interpretations when necessary, especially when the news is very serious³⁸. Thus, there are many ways of breaking bad news; no way is good, but some are better. They all require time and attention, and they challenge our creativity in practicing the true art of medicine.

Collaborations

FAR Guerra and V Mirlesse had equal participation in the conception, outline and composition of the article, critical review and approval of the version to be published; AER Baião participated in critical review and approval of the version to be published.

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