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Prenatal care policies: when the "outcome is unexpected"

Políticas de atenção ao pré-natal: quando o "desfecho é inesperado"

Ludmila Fontenele Cavalcanti 1

The "unexpected outcome" suggested as the title for this debate underscores what can arise from an ineffective and inefficient healthcare policy and what the tests conducted on pregnant women can reveal. Both situations can lead to an unexpected outcome. The debate about giving "bad news" in this sense, places the communication process squarely within the field of health policies.

The quality of prenatal healthcare is a historical concern in Brazilian healthcare policies (PAISM and PHPN), which define such care as a set of clinical and educational procedures designed to promote health and ensure the early identification of risks for the pregnant mother and unborn child¹.

In Brazil, prenatal care is usually the responsibility of municipal services and is of strategic importance in comprehensive healthcare for women. The National Policy for Comprehensive Healthcare for Women² sought to consolidate advances in the field of sexual and reproductive rights and also noted the improvement in the coverage of prenatal healthcare.

The comprehensive care approach seeks a complex focus on the motherhood process and, therefore, includes social, cultural and economic factors that affect pregnancy and its multiple aspects. From this perspective, the effectiveness of prenatal care is primarily related to the possibility that women are well informed about their situation and about their baby, are ready to give birth and are aware about possible complications.

In this respect, the communication of "bad news" as part of the right to information during prenatal care should be part of an interdisciplinary approach, incorporating a comprehensive approach to various fields of knowledge, visions and practices of women (prenatal care subjects) in order to ensure their autonomy in the experience of motherhood.

Healthcare professionals must provide support, guidance and information on reproductive health to the pregnant woman, which does not mean "medicalizing" and "pathologizing" their condition. The philosophy of care is that no woman should be treated as a "technical object," but

as a subject, an individual and a person. And this is achieved by a personalized exchange of information that can reduce the suffering of women and families in situations where the bad news is inevitable. Therefore, prenatal healthcare, besides the technical quality of care, falls within the context of humanization that emphasizes the link between professionals and service users.

However, among professionals working in prenatal care, especially physicians, one detects a marked difficulty in dealing with issues that are not related merely to the biomedical rationale. In this context, issues related to fetal anomalies and complications in pregnancy are often obfuscated behind technical discourse³. This ultimately makes the professional responsible for the examination, diagnosis, preparation for "bad news" and guidance regarding future decisions. This difficulty in establishing qualified sensitivity capable of creating adequate rapport is explained in part by perceptions regarding the professionals' role vis-àvis the outcomes of pregnancy, but also the shortfalls in their exclusively technical training.

This situation is aggravated when the outcome involves the interruption of pregnancy, because in Brazil, today, abortion is only permitted by law in cases of risk of life to the mother and in cases of pregnancy resulting from sexual violence. It is also legally accepted in some cases of fetal anencephaly. However, the search by women for services that perform abortions tends to exacerbate their suffering, due to the lack of preparation and prejudice of the health professionals who by not guaranteeing their human rights foster a form of institutional violence.

Thus, the need for effective institutional responses and a critical and comprehensive overview of the professionals about the reality of the population who are seeking prenatal care, and are attended by public healthcare, pose two major challenges for vocational training: the inclusion of debate on sexual and reproductive rights; and an interdisciplinary approach to interaction with the Unified Health System patients as an important component in humanized practices.

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Beyond words and science: contributions to a debate

Além das palavras e da ciência: contribuições para um debate

Elisabeth Meloni Vieira 2

The paper entitled "Breaking bad news during prenatal care: a growing challenge" brings to the fore the discussion on the issue of communication among physicians and patients, or more broadly between the healthcare team and patients. The disclosure of information is an important step for the patient, their family, parents and other kin to participate in difficult decisions about procedures and cares for terminating life or situations of very severe diagnosis and prognosis, such as when a fetal problem is detected.

The need for the individualized disclosure of bad news has been described as crucial and a standard for good communication between physicians and patients. It takes into account that the disclosures should be tailored to the expectations and needs of the patient, since individuals differ with respect to the amount of information they want and in their methods for coping. In addition, it also takes into consideration that for most people time is needed to absorb and adjust to bad news, and therefore disclosure should be a gradual process over time. Moreover it recognizes that mutual confidence, trust and respect are the basis for the relationship¹. Individualized dis-

closure was sanctioned by the Division of Mental Health of the World Health Organization in 1993.

Although the subject has been extensively studied over the last few decades, there is still a pressing need for research². This need can be identified as knowledge pertaining to the field of "soft" technology as opposed to "hard" technology, as defined by Merhy³.

In fact, the paper approaches the core of communicative interaction during a critical moment when the physicians find it difficult to speak and the patients find it difficult to listen. Although science and medicine are becoming more and more capable of detecting health problems at early stages of pregnancy, physicians do not appear to be prepared to deal with the communication of bad news. For some authors, medicine has lost sight of its original purpose, as it has been transformed into an efficient instrument for achieving technical goals, with little regard for their human or social implications⁴.

Reading the paper, it becomes clear that the introduction of a new hard technology should also bring into discussion the appropriate "soft" technology to cope with it. This combination should be regarded as part of the microethics defined as "the ethics that happens in every interaction between every physician and every patient"⁴.

Understanding patients' expectations and needs for those critical moments has been the focus of some studies, especially in the obstetric, pediatric and geriatric areas. In many cases, decision-making about the fetus and the pregnancy, such as interruption or continuation, resuscitation or compassionate measures for life support will be needed⁵. Discussion can help parents and relatives to grasp and accept the circumstances, especially when they participate in the decision-making process. Hope, spirituality and emotion are important values, which must be respected and talked over during these critical moments.

Studies have shown that when physicians pay close heed to emotions, there is an improvement of communication with patients. Therefore, it has been recommended that training programs should include this subject². However, because spiritual and emotional values are culture-spe-

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cific for each society, more studies should be developed in order to increase the understanding of patients' needs during the communication of bad news.

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The authors reply

Os autores respondem

The debaters raise important current questions regarding the role of healthcare professionals and the State vis-à-vis pregnant women and their families after an adverse diagnosis. In this article, we highlight the frequent difficulty of professionals in dealing with the issue, especially those who receive a diagnosis of fetal malformations. In addition to this, Elizabeth stresses in an interesting manner that the announcement of bad news does not involve only the physician and the patient, but also all of the family members involved with the pregnancy. This fact places the pregnant woman at center stage in a denouement that presupposes communication between the several actors in their respective roles in the scene, and consequently in decision-making relating to the pregnancy and the fetus.

The importance of being prepared for unfavorable situations and being trained to deal with them should be emphasized to the professionals responsible for prenatal diagnosis, since access to such diagnosis is through laboratory tests or

ultrasound images, news of which spreads rapidly throughout the collective group. If the professionals are unprepared, they may run the risk of causing harm to patients by omission or misconduct. We should stress that good technical knowledge, despite being essential, should be associated with the perception of the context in which the patient finds herself, both in individual and family terms. Understanding the state of preparedness to assimilate the bad news and perceiving that the dimension of a potential tragedy is private and unique in nature should be fundamental for these professionals in such situations.

It is at this exact juncture, as Ludmila rightly points out, that current medical practices - which are based on reason and technique - come into conflict with the nuances existing in the communication of an adverse prenatal diagnosis. The debater highlights the plight in which many Brazilian women find themselves when they receive the information about the diagnosis of a fetal malformation, either because of highly technical and impersonal medical terminology, or due to legal restrictions on abortion. The fact is that, the prenatal diagnosis of congenital anomalies is increasingly disseminated in Brazil, but in a rather perverse scenario when one considers the absence of universal access to good quality prenatal diagnosis, the lack of professional training to deal with adverse situations and the existence of extremely restrictive abortion laws. One might even question the ethical aspects of passing on the diagnosis of fetal malformations without there being the option of abortion¹.

We agree that comprehensive healthcare for women should take into account the various contexts in which they find themselves. Despite having advanced greatly in favor of more equitable public health², one might well ask: How many women have ultrasound tests during prenatal care in the public health system, and how many do so in private centers? As regards the promotion of education: Are women acquiring greater autonomy with respect to their own reproductive health? It therefore seems to us that there is a clear need to organize and ensure the access of public health patients to better quality prenatal diagnosis. To achieve this, we propose the formulation of public policies aimed at setting up prenatal diagnosis centers, in networks tailored to the regional demands of the area, for promoting access to tests and consultations. The physical and technological structure of these centers, as well as the qualification of the professionals working in them, should also be ensured.

Specifically on the communication of bad news, we add some key points to be taken into consideration by those professionals involved in the context: set aside sufficient time for the consultation: think carefully about the words to be used; study the subject before speaking; adapt the information to the reality of each person; maintain hope for a way out of the situation; respect and contribute to the autonomy of women; share responsibilities with other professionals; encourage care by the family; contribute to the organization of the local healthcare network and promote the professional teaching of humanized care and research on the subject by the social sciences.

We thank the debaters for the comments made on this article, the theme of which will receive ever increasing attention in Brazil's advance toward better quality prenatal care.

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