

Review

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## Bioethical and sociocultural aspects of diagnosis disclosure

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**Abstract. Aim:** The aim of the article was to analyze various approaches to diagnostic disclosure considering its bioethical, sociocultural, psychoemotional and sociolinguistic implications.

**Results:** Diagnosis disclosure is considered to be one of the major challenges of doctor – patient communication as it brings forth complex bioethical, legal, sociocultural, and psychoemotional tensions. The former non-maleficence approach to diagnosis delivery has been replaced with the one based on the bioethical principle of patient autonomy obliging physicians to reveal information truthfully and completely. The current bioethical approach has been refined to develop a number of protocols used for effective delivery of negative diagnostic information. However, alongside with the protocols building on this principle, alternative ways of diagnosis disclosure and patterns of diagnosis breaking are practised. The latter rest on culture specific norms, which are followed to balance the principles of non-maleficence and patient autonomy.

**Conclusion:** The rationale behind the selection of the best approach to diagnostic disclosure has to rest not only on the dominant bioethical principle, but also align with the sociocultural norms as this is the way to ensure greater flexibility, variability and optionality and achieve better management outcomes.

**Keywords:** diagnosis disclosure, non-maleficence principle, patient autonomy, culture specific approach

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Обзор

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## Биоэтический и социокультурный аспекты сообщения диагноза

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**Аннотация. Цель.** Проведение анализа различных подходов к сообщению диагностической информации, рассматриваемых в рамках биоэтического, социокультурного, психоэмоционального и социолингвистического контекстов.

**Результаты.** Сообщение диагностической информации относят к одной из наиболее сложных составляющих коммуникации «врач – пациент», так как оно сопряжено со сложными биоэтическими, правовыми, социокультурными и психоэмоциональными противоречиями и проблемами. В настоящее время применяемый ранее подход, основанный на этическом принципе «не навреди», сменился другим, базирующемся на биоэтическом принципе автономии пациента, который обязывает врача сообщать информацию пациенту правдиво и в полном объеме. В ходе усовершенствования настоящего подхода был разработан ряд протоколов для эффективной передачи негативной диагностической информации. Тем не менее, наряду с протоколами, основанными на данном принципе, на практике широко применяются альтернативные способы и модели информирования о заболевании. Последние создаются исходя из социокультурных норм, следование которым направлено на достижение оптимального баланса между принципами непричинения вреда и автономии пациента.

**Заключение.** При выборе наилучшего подхода к сообщению диагностической информации необходимо исходить не только из доминирующего в данную эпоху биоэтического принципа, но и учитывать социокультурные нормы. Именно таким образом можно добиться наибольшей гибкости, опциональности и адаптивности применяемого подхода, а также обеспечить наилучшие результаты в ходе оказания медицинской помощи.

**Ключевые слова:** сообщение диагноза, принцип непричинения вреда, автономия пациента, социокультурный подход

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### Introduction

Diagnostic disclosure has always been one of the most challenging issues of communication in medical settings as it is fraught with complicated medical, bioethical, legal, and psychoemotional problems. It becomes

especially problematic when it involves bad news delivery. The latter is defined as a transfer of information which has an adverse impact on the patients' expectations of their future [1]. The psychological experiments have demonstrated that a bad news breaker experiences

anxiety, is pressurized by the responsibility or even fear of the subsequent response.

Today, in many countries this procedure relies on clear-cut ethical and legal imperatives. However, there is significant discord between approaches and guidelines practiced to perform it as well as ethical and bioethical principles behind them in different healthcare systems.

The purpose of this article was to analyze various approaches to diagnostic disclosure considering its bioethical, sociocultural, psychoemotional and sociolinguistic implications.

### Results

The issue of diagnosis disclosure has been of the most debatable problems of interaction in medical settings. Its analysis rests on the multifaceted nature of this phenomenon as it has various dimensions to be considered: bioethical, biomedical, sociocultural, sociolinguistic, and psychoemotional ones.

As the diagnostic accuracy increases, the prognostic ability of medicine enhances, which makes health care providers more aware of what to expect and obliged to deliver this information to their patients. However, there are a number of factors which influence the way it can be done and at different times and in different environments some of them prevail giving rise to a certain preferable approach to doing this. Previously, in the era of paternalism, until the late 20<sup>th</sup> century, a generally accepted paradigm both in Western and other communities required to withhold a terminal diagnosis. It predominantly relied on the bioethical principle of non-maleficence. Consequently, the combination of lies and truth was exercised to promote and reinforce treatment [2].

However, the rise of bioethics brought about the process of redefining the ideas of both harm to the patient and their rights. Therefore, a noticeable shift in bioethical approaches to the disclosure of serious or terminal diseases has been observed in the last decades. I. Raicher et al. point out that the previous approach relying on medical paternalism is gradually being replaced with a greater emphasis on patient autonomy. Further, we are going to explore what this trend implies and how bioethical principles and sociocultural background impact it.

The current trend fosters sincere and total disclosure of diagnostic and prognostic information. This approach was first formulated in a Patient's Bill of Rights in the USA, which proclaimed the patient's right to obtain complete information about their condition in a way that can be adequately comprehended by them [3]. This way of informing the patient is considered by bioethicists as guaranteeing their autonomy.

Though determined to provide full disclosure physicians remained aware of psychological, emotional and

legal burden associated this procedure. Therefore, substantial efforts have been made to develop detailed guidelines regulating different steps and stages of this process. A number of protocols have been elaborated and introduced into clinical practice. Though they may slightly differ in details being adapted to their national healthcare systems, their basic principles are very much in common.

The Canadian disclosure guidelines proceed from the patient's perspective and safety and outline the most essential steps of this process. They regulate such aspects as settings, team, quality and quantity of information to be transmitted, techniques to provide support. The patient's autonomy is respected as the process involves taking in account the people, the patient wants to be present during the procedure, confidentiality guaranty, use of the terminology appropriate for the patient, care of their emotional, cultural and spiritual needs. The patient is also encouraged to actively participate in the discussion and not just go with the flow. An indispensable part of a diagnostic disclosure is its documentation outlining its date and settings, participants, presented facts, offered help and response, asked and answered questions and follow-up plans.

A few other generally accepted protocols used in cancer care are SPIKES, ABCDE, and BREAKS. The first is intended for oncological patients and includes detailedly elaborated steps to deliver bad news. As in case of Canadian guidelines, physicians build on the patient's perspective and start by gathering information from them. The next steps involve sharing medical information with the patient, providing support, and ensuring patients' involvement in developing a treatment or management plan [4]. The authors point out that a diagnostic disclosure is a comprehensive communication task as it does not only involve verbal skills but also the ability to identify and emphatically respond to patients' emotions, drawing the patient in decision-making and instilling hope without disguising the truth.

Currently, diagnostic information can be provided in three ways. In the first the physician asserts a diagnosis without trying to substantiate their conclusion. The second way involves making inexplicit references to the underlying evidence. In the latter case, substantial proof verifying the diagnostic assumption is provided.

Frequently, diagnostic statements consist of two parts: first, the diagnosis is delivered, and then the relevant facts or investigation findings confirming it are cited.

The era of the COVID-19 pandemic gave rise to new forms of providing diagnostic information to patients. This way of breaking bad news was imposed by the need to provide diagnostic information remotely and tended to

organize the main steps of communication in such events [5]. The major procedures involved included preparing health care providers for the conversation, ensuring technical facilities, working through the key points related to diagnostic disclosure, and offered support.

The preparation of both the medical staff and technical resources is of extreme importance in remote communication due to the limited share of non-verbal context (body language, facial reactions, vague eye contact, voice tone, and convenient communication distance). However, the verbal context also depends on both the quality of the connection and the possible interruptions and gains priority in giving off messages to patients. Therefore, alternative ways of communication have to be available, should any failure occur. Besides, physicians find it more difficult to identify and handle their patients' emotions.

Apart from technical facilities the preparation suggests going through the patient's medical records, proper medical outfit and a "mental rehearsal" of what and how the news has to be delivered. The requirements pertaining to handling emotions, counseling and care provision are generally the same as in most other protocols describing face-to-face communication. They urge physicians to elicit emotions, offer empathy and support, deliberate the proper questions and understandable words and terms, avoid medical jargon, discuss further management, make sure that a patient fully understands and attend to the patient's spiritual, social and psychological concerns [5].

However, even in the health care systems requiring complete and straightforward information no matter how harmful it may be, there are some concerns that patients may feel upset because of insensitive truth telling [6]. Moreover, full disclosure is regarded negatively in many cultural communities as doctors apprehend that by adhering to only the bioethical principle of patient autonomy, they will neglect another basic principle as it may do great harm by making the patient desperate, reluctant to adhere to treatment and provoke an earlier death. Instead, physicians are supposed to instill hope, encouragement and optimism.

This has given rise to differing behaviours practiced when delivering bad diagnostic information worldwide. The first type is associated with the blunt pattern of sharing difficult news. Doctors adhering to this pattern provide the negative information in 30 seconds. Their message is clear and explicit. This way of verbal behaviour is typical of physicians sharing the values of Western healthcare. The second type is known as forecasting pattern and implies staged delivery within the first 2 minutes. Though doctors using this way are also quite specific about the diagnosis they still tend to provide more descriptive data.

The next stalling pattern occurs when physicians delay the news delivery for more than 2 minutes. They avoid breaking the news directly, but rather encourage the patient to infer the diagnosis and come to a certain conclusion [7]. This verbal behaviour is associated with the abundant use of medical terminology and euphemisms. They frequently turn to circumlocution or oblique, elusive or vague ways of providing negative diagnostic information and deliberately use the language which the patient cannot understand thus hiding behind pathology-specific issues (*The treatment is not effective as we expected; The malignancy is not responding as we intended*). Another form of this behaviour is an attempt to mitigate the extent or severity of negative changes to cushion the patient's shock.

These different ways of disclosing behaviours may be prompted by sociocultural factors. Regarded as a form of miscommunication in Western communities the stalling pattern is widely acceptable in traditional Asian cultures as well as Russia.

There has been intensive research of diagnosis disclosure in cancer care [8, 9]. The authors point out, that despite the general trend towards truth-telling, numerous papers justify alternative approaches to diagnosis delivery ranging from concealment of such information to different types of elusion and circumlocution implying a strong bioethical and sociocultural impact on the problem resolution [10, 11, 12]. J. Shahidi highlights the fact that the differences in disclosure of cancer diagnosis result from cultural disparities, whereas reluctance to deliver a diagnosis openly is provoked by the apprehension of either inducing psychological harm to patients or their unwillingness to face negative information [13].

Thus, health care providers become trapped as they have to respect the principle of non-maleficence and comply with their cultural norms, on the one hand, and meet the professional ethical standard of truth telling and the principle of patient's autonomy, on the other hand. Therefore, not infrequently, they proceed from the bioethical principles of non-maleficence and beneficence when solving this dilemma [12, 14].

The cultural disparities are also implicated in such aspects as preferences for who will inform a patient, how soon the patient should be informed, the priority of informing a family member/a patient.

The findings of surveys exploring the willingness to face the negative diagnostic information have demonstrated a varying degree of eagerness in different cultural environments with the lower values in Middle Eastern and some Asian countries whose national values urge doctors to withhold the truth fully or partially [15]. Therefore, the attitude of patients and their readiness to

accept negative diagnostic information is culture specific and has to be considered when choosing the appropriate strategy of breaking bad news.

Another pressing issue related to the problem under discussion is the absence of any culture sensitive practical guidelines providing clear instructions for appropriate verbal behaviour patterns in such events in particular medical communities. Therefore, a few attempts have been made to develop culture oriented ethical guidelines and strategies [11].

The approach of Russian physicians to breaking bad news builds on Clause 22 of the Federal Law of 21.11.2011 On the Basics of Health Protection of Citizens in the Russian Federation which proclaims that every citizen is entitled to get informed about their health condition. The medical team, which can break bad news, includes medical professionals directly involved in the patient's treatment. However, the law specifies the sociocultural aspect of this procedure which is implicated in the fact that the diagnostic information cannot be imposed on the patient against their will. Instead, negative news must be disclosed tactfully to his close relatives unless the patient forbade the medical staff from doing so. This is not in complete accord with the Western protocols requiring that the patient must be informed alongside with their family members in any case. In contrast to the Western health care providers clinging basically to the principle of patient autonomy, Russian medical professionals build on the combination of bioethical principles of non-maleficence and patient's autonomy. In many cases potential psychoemotional impact tends to become the crucial factor determining whether and how sincerely the information should be provided.

Another factor, which significantly affects the process of diagnostic disclosure both in Russia and abroad is gender differences. However, very scarce information comparing gender styles of breaking bad news has been generated and analyzed. Consequently, the findings prove to be controversial and report different propensity to reveal negative information of males and females in differing medical settings, which means this issue has to be further explored.

It is noteworthy that Russian medical universities did not use to offer any courses to teach verbal communication in medical settings, which also implied that young doctors did not have any formal education about how to provide negative information to patients. Therefore, they had to struggle to discover the appropriate ways of bad news disclosure by a trial and error method and had to suffer emotional stress and burnout.

Recently, a few changes have been observed regarding this problem. Russian and Belarus healthcare and

medical education systems have started to show a strong trend towards adopting overseas protocols for diagnostic disclosure, which later undergo adaptation to the local sociocultural settings [16, 17]. Several universities have launched new courses to familiarize medical students with the basic verbal communication techniques and the ways to manage challenges in doctor-patient encounters.

### Conclusion

The analysis of different practices used in diagnosis disclosure worldwide has demonstrated that approaches to breaking bad news show historic and sociocultural variability depending on the dominating scientific and axiological paradigm. The approach based on the ethical principle of non-maleficence has lost its crucial importance giving way to a new bioethical perspective. The latter rests on the principle of patient autonomy and obliges physicians to disclose diagnosis fully and truthfully. However, sometimes this approach turns out to be conflicting with the non-maleficence principle, which results in the introduction of different patterns of actually practiced diagnostic disclosures. Alongside with the new standard of complete and truthful disclosure embodied in the generally accepted protocols, culture specific ways of breaking bad news are employed. The latter tend to balance the principles of both non-maleficence and patient autonomy and make them compliant with the culture-bound moral, ethical and spiritual norms. They show greater flexibility, variability and optionality and make it possible to make adjustments to both professional and community-based ethics which is likely to result in better management outcomes.

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