Access to Medical Records

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Introduction

Patients' ability to access their own medical records is a fundamental condition for exercising their right to know, and to be able to make informed decisions about their health. However, Mexican Official Standards (the Norma Oficial Mexicana—NOM—168-SSA1-1998) state that a doctor or medical institution is only required to give, "verbal information and a clinical summary," in response to a written request to access one's medical records, which must also, "clearly specify the reason for the request." This administrative regulation has created a broad barrier that blocks patients' access to the information in their medical records. Not only does it limit the extent to which patients can be informed about their own health care, reinforcing paternalism in the doctor-patient relationship, it also raises the costs of deciding to change one's doctor or asking for second opinions, and bolsters the medical profession's protection of its members in malpractice cases.

The Right to Access Medical Files: Progress

The Federal Law for Transparency and Access to Information (LFTAIPG in Spanish) and precedents set by the Federal Institute for Access to Information (IFAI in Spanish) have established a channel that could potentially allow patients to access their medical records when they are held by public health authorities. The existence of this direct access mechanism, and specific information requests that have been filed, created a possible avenue for confronting the regulation that was blocking access.

Medical authorities justified their denial of access by claiming that the official regulation (NOM) determined the amount and kind of information that they were obliged to provide. They also claimed that the NOM established that individuals' records were the property of doctors and the medical institutions. In response, a number of requestors appealed these denials to the IFAI, (citing the right to appeal agency information denials established in Article 39 of the LFTAIPG). The IFAI ruled favorably in their cases**,** but several problems emerged. One of the major issues raised through these appeals decisions was how to deal with the regulatory limit established in the NOM, and the question of what specific kinds of information patients should be able to access.

1. The NOM 168-SSA1-1998: a barrier to information access.

The NOM is a general administrative regulation, and applies to both individual health care personnel and public health institutions. Their objection to providing access to medical records is understandable, since failure to comply with official regulations can result in disciplinary action, including administrative sanctions. In these recent cases of information requests (and subsequent appeals to the IFAI) for access to medical records, filed following the passage of the LFTAIPG, the IFAI resolved the apparent contradiction between the NOM 168 and the LFTAIPG by arguing that the information law can over-rule the administrative regulation. Through appeals decisions 314/03 and 315/03, the IFAI rejected the initial agency rationale for denying access to medical records, arguing that:

> "[...] a federal law has precedence over an Official Mexican Standard (NOM). Since June 12, 2003, the Federal Law for Transparency and Access to Information is the specific law that protects personal information held by federal offices, and regulates access to these on behalf of the individuals to whom the information refers, or their representatives."[1]

The conflict was resolved by invoking a hierarchical criterion, which fundamentally altered the legal context for federal agencies covered by both laws. The requirement established by the NOM was trumped by an order from an authority that regulates access to information; in effect, this transformed health agencies and personnel from guardians of a legal requirement into its executors. This change of position is relevant in the sense that regulatory contradictions create dilemmas for public servants, which produce personal insecurity and affect job performance.

2. How far should access to information go?

Should the patient have access to all of the information? Should access be limited? If so, for what reasons? The IFAI's role in these issues has changed over time, demonstrating a learning process. In its first resolutions, the IFAI instructed health institutions to turn over a complete copy of the file.[2]

[1] IFAI, Appeals 315/03 and 314/03, available at: http://www.ifai.org.mx/resoluciones/anual.php (Viewed June 25, 2006).
[2] This is made clear in case numbers 314/03, 315/03, 476/03, 338/03, 285/05, among others.

The IFAI's decisions were based on the individual's right to his or her personal data. Under the LFTAIPG, information concerning physical or mental health are considered personal information (Article 4, fraction II). Therefore, even though this information is protected as confidential and therefore cannot be accessed by third parties, the individual in question has a right to it (Articles 20 through 25).

From a strict information access perspective, the fact that these are personal data is the central issue at hand. However, from a health perspective, much finer nuances are involved, and are not always taken into account in IFAI decisions. This is one of the main problems confronting the IFAI as it continues to exercise its function as a regulatory body whose main characteristic is "horizontality". The latter refers to the fact that the regulation of information access crosses a broad spectrum of fields and topics, including health care. Additionally, when the IFAI rules on specific cases in these fields, it must consider not just how the law applies, but what makes sense for that particular issue. Health regulations have been established according to specific values unique to the health care system, for example. Therefore, they are also accompanied by their own principles for public policy formation. As is the case with most policy arenas, general considerations regarding "public interest" or, "well-being" are also important considerations. Therefore, interpreting these issues solely through a lens of "access to personal data" is limited, and can even be counter-productive.

Medical records may contain a third party's personal data, such as: information that could harm the patient's self-image or relationships (for example, information given by a patient's family member); information on a treatment that is clinically acceptable but that, if it is made known to the patient, could be less effective (placebos, information that might put the patient in danger, etc.); and information that involves scientific research, or doctors' subjective notes. These issues are generating debate in legal forums as well as discussions regarding best practices within the profession. They involve particular models of doctor-patient relationships, the extremes of which are marked by paternalism on one end, and the informed patient who makes his or her own health decisions on the other. The challenge for the IFAI is going to be the reconstruction of this "horizontality" in regards to information access, and "verticality" when it comes to sector-specific regulations. The dilemma is whether transparency regulations support sector-specific rationale, or if sector-specific regulations bolster transparency. In this area, the IFAI's resolutions have just barely begun to shed light on the problems involved.

Limitations

1. Creation of regulatory asymmetry.

The IFAI's jurisdiction is limited to public government information, and therefore creates a division between medical personnel subject to the NOM in the public and the private sectors. Only doctors and health institutions in the public sector are subject to the IFAI's decisions. However, the NOM is fully applicable to private medical institutions as well: medical records still belong to them, and they are only obligated to give a summary. Of course, the IFAI cannot be asked to avoid generating such consequences, nor is it within their purview to resolve them.

2. Understanding sector-specific logics.

The "horizontality" of transparency and access to information allows it to cross the wide spectrum of issues and sectors within the public sphere. However, this implies a challenge for the IFAI because of its lack of specialization and thus limitations in knowledge about the rationale that has come to shape sector-specific regulation. IFAI staff are presumably knowledgeable, even expert, in matters pertaining to the Institute's area of responsibility, but not in matters of the environment, foreign investment, energy policy, telecommunications, health, etc. At some point, access to certain information may pose a conflict between public and private interests, or between a sector-specific goal and access to public information. As illustrated by the case of medical records, these conflicts may be very complex and not always adequately addressed in IFAI decisions. Deciding which criteria should prevail is difficult. The IFAI's objective will always be to privilege access to information, which could disrupt sector-specific public policies. Currently, we are in the fortunate position of being able to celebrate the IFAI's good judgment, but the situation is not without risks.

3. Grey areas: sub-contracted medical services.

Among the cases analyzed, none of them dealt with requests for information from a private doctor who had seen a patient who was also eligible for public services (for example, the IMSS). Such a case would pose a jurisdictional problem for the IFAI in regard to private doctors, who may contract with a public sector health institution to provide services on behalf of a government program.

Perspectives

At this point, the IFAI has established an important and positive set of criteria: patients have the right to the information in their medical records. However, it is important for the IFAI to refine its criteria, allowing for subtleties in cases in which, due to sector-specific needs and legitimate reasons, certain information must be kept from patients. Of course, there are issues to be debated, but these must be addressed.

Conclusions and Recommendations

On balance, the current situation is positive: citizens, at least those who have access to public services, can count on a powerful tool to improve the protection of their rights. The IFAI's role has helped to encourage patients who are more informed and better equipped to hold public servants accountable, as well as to generate incentives for better institutional performance. Nonetheless, that tool must be refined, in order to address its indirect effects.