

ETHICAL CONSIDERATIONS ABOUT UNEXPECTED FACTS DISCLOSED DURING
GENETIC ASSOCIATION STUDIES

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Family studies formulated for populational genetic purposes usually disclose the absence of genetic association among some individuals supposed to constitute one family. Although an informed consent was given aiming to a research, the communication of these findings to the individuals involved is meaningless; the importance of such data is restricted to the interpretation of the research in itself. On the other hand, in Forensic Medicine, disclosure of unsuspected absence of genetic association can interfere with the conclusions of the expertise.

We faced three of these experiences: a) maternity (or paternity) investigation, when the assumed and legal parent is excluded in relation to the offspring; b) paternity investigation, when a deceased alleged father is not the biological father (BF) of one or more of his legal offsprings; c) suspicion of swapped babies, when only the man is not the BF.

In Forensic Medicine, the expert's ethical problem is when an information omitted on the absence of kinship (kept by one of the involved individuals and about which there are no questions in the process) hinders the straight conclusion of the expertise. The expert's question is the fluctuation between someone's right to privacy, that can be invaded by the disclosure of a hidden fact, which was to remain a private secret on one hand, and his duty to present all results obtained ("visum et repertum") and to discuss the ones relevant to the conclusion of the expertise regardless of their other possible developments, on the other.

The relationship between a physician and his patient is based on the patient's confidence to his doctor. This includes not only technical-scientific aspects but full assurance that

he is allowed to behave open-heart without the fear of betrayal. In Forensic Medicine, the expert also faces another confidence compromise: the solicitant authority expects all obtained related information to reach, in the context of the process, a final decision. Although the general clinical confidence relationship does exist, the latter, with the authority, imposes an apparently contradictory procedure: it is necessary to investigate all possibilities, to analyse all results and to expose them, to discuss the relevant ones and, therefore, to conclude.

In this way, the expert is obliged to present an answer, as accurately and objectively as possible and, to use all available means to clarify the question. This includes, not only the performance of all available tests in individuals directly involved (and if necessary in all other related, as long as they agree to participate and/or give their informed consent) but also, to execute the proper "visum et repertum". It is part of the expert's compromise to present all observed results, whether or not directly requested, without concern on pleasing or not whoever, regardless of other implications they could bring. Nonetheless, the expert is linked to silence in relation to all facts and circumstances (he was occasionally aware of) not directly involved with the expertise itself. Consequently, regarding disclosure of absence of legally assumed kinship, all obtained results should be presented, but, in order to preserve the right to privacy, the expert should limit the discussion only to relevant information to reach the final conclusion.

In our opinion, in Brazil, the main reason for these situations is the lack of proper orientation of the parties due to poor knowledge and misinterpretation of scientific data: not only are there false expectancies about the interpretation of non-excluding results but also ignorance about the extension of their discriminating excluding power. The first of them usually leads to a deception because it will not be reported that X is actually Y's father and creates opportunities to extensive and confused inquiries. Although the certainty of genetic association is expected, the parallel high discriminating power of the used systems (that reaches almost certainty) is ignored.

In our experience, it seems that even in judicial cases, when the informed consent is assumed, there is a lack of information. Therefore, we suggest that, in Brazil, in order to minimize the problem, an active participation of the experts, close to the courts and parties, is necessary to clarify the possible results expected in genetic association studies, in order to have an actual informed consent.

2. Molecular biology of classical markers

