

SHOULD INFORMATION REGARDING THE ADOPTION OF THE PATIENT BE WITHHELD?

CLINICAL CASE

Isabel, age 52, has been diagnosed with breast cancer. Faced with the possibility of a genetic origin (her aunt and mother both died of breast cancer), a genetic study for BRCA1 and BRCA2 is performed to rule out hereditary cancer. The results turn out positive. Therefore, her closest relatives on her maternal side are referred to a genetic counseling consultation: her sister and her daughters Andrea and Elena. Dr. Jiménez has an appointment with 22-year-old Elena for consultation the following day. She plans to suggest a very close follow-up with imaging tests (MRI, mammography, echo), in order to, based on the findings, consider whether it is necessary to carry out the genetic test, which is expensive. Isabel, without a scheduled appointment, shows up at the genetic counseling office to speak with the doctor. She informs Dr. Jiménez that one of her daughters, Elena, is not her biological daughter. She was adopted, however, Elena is not aware of this. Isabel, tells Dr. Jiménez that she doesn't want Elena to know that she is adopted. She suggests that she tell Elena that "she doesn't need to have the tests done" because "there is no risk", or that she goes ahead with the tests in order to avoid telling her that in reality, she is not her biological daughter. Dr. Jiménez is concerned about withholding this information from Elena, in addition to having to carry out unnecessary tests and a follow-up, since Elena is not at an elevated risk of suffering from hereditary breast cancer. Should Dr. Jiménez conceal Elena's adoption information from her? Should she still request the test she planned to be done?

ETHICAL ANALYSIS

When assessing which values are in conflict in this case, we find that they are, on the one hand, the veracity of the information, the protection of health (non-indicated tests would be carried out, which are not innocuous and thinking that she is at risk of breast cancer may create anxiety to Elena) and the proper use of healthcare resources (unnecessary tests should not be carried out). On the other hand, we find respect for confidentiality and professional secrecy.

Regarding the values at stake, we must clarify that:

- One of the pillars of clinical relationships is confidentiality; which is an ethical requirement and a legal duty. Healthcare providers have committed to professional secrecy, but this commitment is not absolute and can be broken in the event of harm to third parties.

- There is a risk of harm to Elena because the tests are not indicated. Not knowing the identity of her biological parents, the real risk Elena is exposed to is unknown, however, the cases in which parenthood is unknown are not treated as high-risk cases but as conventional ones. Medical procedures are not free of risk and should only be performed when they are indicated, as otherwise the patient's best interest is not being sought, and, in addition, unnecessary tests may cause avoidable harm. Carrying out the tests is, therefore, maleficent due to both the exposure to radiation and because misinformation (and the consequent experience of risk) can cause moral damage.
- Conducting a non-indicated test is a misuse of resources and an unnecessary expense. The use of healthcare resources should be rational and responsible.

POSSIBLE COURSES OF ACTION

- Go along with the plan to not tell Elena anything, as her mother suggests: carry out the image tests, and the follow-up and hide from her that she is adopted. Additionally, it is not actually known if Elena is at an elevated risk for hereditary breast cancer as it is unknown who her parents are.
- Carry out the genetic test on Elena, which is expensive and would not be indicated as she could no longer be classified as a patient at high risk for hereditary breast cancer.
- Find out who Elena's biological parents are and see if there have been cases of breast cancer in their family, and then act accordingly after the findings.
- Call Elena to cancel her appointment and inform her that she doesn't need to come to the consultation because she isn't at risk, but without explaining to her why.
- Inform Elena that she is adopted, despite her mother's wishes, because this will avoid unnecessary tests and follow-ups which could be potentially harmful.
- Inform Isabel that no unnecessary test should be conducted on Elena, as they are not indicated and, if performed, they would imply a misuse of health resources.

RECOMMENDED COURSES OF ACTION

- Inform Isabel that unnecessary tests should not be carried out on Elena as they are not indicated and, in addition, doing so would represent a misuse of healthcare resources and cause unnecessary moral damage to Elena.
- Isabel must also be informed about the ethical and legal responsibility of the doctor to be truthful at all times and not cause intentional harm. Likewise, that the doctor also has a legal and ethical obligation to protect confidentiality and to maintain professional secrecy, but that this obligation can be broken in the event of damage to third parties.
- Therefore, Isabel must clearly understand that doctors cannot lie or cause avoidable damage.

- Isabel must be given time and the opportunity to speak with her daughter to explain that she is adopted, thus delaying the appointment with Elena. Help can be offered to Isabel to assist her in giving this information, including informing her that she may join the appointment with her daughter to inform her of the cancellation of the tests and the reason why.
- If after all this, Isabel is still not convinced, Dr. Jiménez will have to tell Elena that she is not at risk for hereditary breast cancer. Dr. Jiménez cannot subject Elena to unnecessary tests and have her falsely believe she is at risk. Should this situation occur, it would be highly advisable to consult with the legal team at the center.
- In no case would Dr. Jiménez unilaterally inform Elena about her adoption.

DISCUSSION

For Isabel to understand the ethical and legal conflicts at stake, it is important to communicate with her efficiently and effectively to optimize the information. We must explain that it is not acceptable to perform procedures that are not indicated, as they may have secondary effects because they can cause avoidable harm, without also forgetting the moral damage of having Elena falsely believe that she is at risk. In order to convince Isabel that she should change her mind, she must be given her time. The doctor can also offer to help inform Elena of the situation, even personally accompanying Isabel in the process of informing Elena about her true origin, so that she does not feel abandoned by Dr. Jiménez.

If after all this, Isabel is still not convinced, Dr. Jiménez will have to tell Elena that she is not at risk for hereditary breast cancer, as she cannot subject Elena to unnecessary tests and have her falsely believe she is at risk. However, without Isabel's permission, she cannot reveal the information regarding the adoption. If this situation occurs, it would be highly advisable to consult with the legal advice team at the center, in order to act, at all times, in accordance with the legal norm regarding adoption.

Sgd.: ASISA-Lavinia Bioethics and Health Law Committee

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