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Should doctors be allowed to disclose genetic information to patients' families?

OPINIONS

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The new International Code of Medical Ethics from the World Medical Association stipulates that doctors may, in exceptional cases, disclose confidential information even when the patient does not or cannot consent to it.

The World Medical Association (WMA) recently updated its International Code of Medical Ethics (1). The revision took place over four years, in close collaboration with the various countries' member organisations. The process concluded with a revised version, which was unanimously adopted at the 73rd WMA General Assembly in October 2022 (1).

One of the paragraphs that was amended was paragraph 22, which pertains to the conditions under which doctors can breach confidentiality. The new wording is as follows (2):

'The physician must respect the patient's privacy and confidentiality, even after the patient has died. A physician may disclose confidential information if the patient provides voluntary informed consent or, in exceptional cases, when disclosure is necessary to safeguard a significant and overriding ethical obligation to which all other possible solutions have been exhausted, even when the patient does not or cannot consent to it. This disclosure must be limited to the minimal necessary information, recipients, and duration.'

This revision entails several changes to the paragraph on confidentiality (1). In the first sentence, it is made explicit that confidentiality does not end when a patient dies. The justification for breaching confidentiality in extraordinary cases has also been amended. Previously, it stated that 'It is ethical to disclose confidential information […] when there is a real and imminent threat of harm to the patient or to others and this threat can be only removed by a breach of confidentiality.' (3. 2).

While the previous justification for breaching confidentiality was specific, the new wording of the paragraph is more general. Confidentiality can be breached when there is a significant and overriding ethical obligation to do so. As before, it states that confidential information can be shared with others if the patient consents. It is now also specified that, in exceptional cases, such information can be shared even if the patient does not or cannot consent (1, 2).

Should doctors be allowed to disclose genetic information to patients' families?

The disclosure of genetic information to patients' families involves determining whether, to what extent and on what grounds healthcare personnel should be permitted to share this information with the affected relatives of a patient who has been found to have a genetic predisposition to a health condition. The purpose of such disclosure is to inform or provide information to family members that a genetic disorder has been identified in the family that they themselves are predisposed to developing in the future.

> ***«If healthcare personnel do not breach patient confidentiality to disclose information to a patient's family, the family members are deprived of the agency to make informed decisions that could significantly impact their health and well-being»***

Under Norwegian law, healthcare personnel can inform the patient's family if the patient gives their consent, or (in special cases) if the patient cannot consent – if they are unconsciousness or deceased (4–6). In both cases, the five conditions outlined in section 5 - 9 paragraph 5 of Norway's Biotechnology Act (see Box 1) must be met, and the specific disorder must be approved for disclosure to the patient's family (4). The Norwegian Biotechnology Advisory Board is currently evaluating the Biotechnology Act (7), which means that changes to this provision may also be proposed.

Box 1 Section 5-9 paragraph 5 of the Biotechnology Act (4)

Before health personnel contact the relatives, they shall assess whether:

1. the disease in question has serious consequences for the individual's life or health,
2. there is a reasonable probability that the person's relatives are also genetically predisposed to the disease and may develop the disease later in life,
3. there is a documented link between genetic predisposition to the disease and the development of the disease,

4. the genetic tests used to determine whether a person carries a genetic predisposition to the disease are reliable, and

5. there are satisfactory methods of preventing or treating the disease.

What can we learn from paragraph 22 of the WMA's International Code of Medical Ethics? If a patient does not consent to affected family members being informed and the five statutory conditions are met, the question is whether such a situation triggers a 'significant and overriding ethical obligation' for the doctor. I have previously argued that this is indeed the case (5). If healthcare personnel do not breach patient confidentiality to disclose information to a patient's family, the family members are deprived of the agency to make informed decisions that could significantly impact their health and well-being (5. 994). The new WMA guidelines stipulate that in such exceptional cases, confidentiality can be breached even if the patient does not consent. Consequently, these guidelines can be interpreted as supporting the view that, if the legal conditions are met, doctors should be allowed to inform a patient's family even in cases where the patient objects.

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