

# **CONFLICTING LOYALTIES IN THE COMMUNICATING OF GENETIC INFORMATION: A TEST OF ISRAELI NURSES' ATTITUDES**

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## Who does genetic information belong to?

Information drawn from DNA analysis enables to predict the probability that a person will encounter a genetic disease and identify carriers of such diseases. However, the genetic testing also reveals information about the tested person's biologic relatives who can then be warned to take curative or preventive measures (if these are available) or at least to factor the knowledge of the disease potential into their life choices. The questions that arise are 1. Who does the information belong to? 2. What should be done in case where a patient refuses to share genetic information with their family?

The Israeli law affirms that patients have the right to privacy and autonomy of decision. The Genetic Information Act, 2000, in Article 18 stresses that no use may be made of this information without the permission of the tested person. Article 20 refers to the conditions that allow communicating genetic information to the tested person's relative caregiver in case where the person refuses to inform them.

## Is a Health Care provider legally bound to disclose genetic information about a patient to family members?

The patient's rights to privacy and autonomy of decision are two of the core values of the doctor-patient relationship. It follows that when patients receive medical information about themselves in the confidence that their doctor will not disclose the information to anyone. It has to be borne in mind that if this trust can be easily set aside many sick people will simply not seek medical treatment (Carmi, 2004).

However in the famous Tarasoff case in the USA (1976) the court found the physician guilty of negligence for not warning his patient's girlfriend of his murderous tendencies with respect to her. In the Safer case dealing with multiple polyposis, the court found the physician responsible for informing all individuals known to be at risk from a genetic disease. The court ignored the conflict between the patient's right to confidentiality and the physician's duty to warn of known dangers (ASHG, 1998). The American Society of Human Genetics has reaffirmed genetic information confidentiality; yet it laid down the conditions for the disclosure of genetic information to family members without the patient's consent (ASHG, 1998).

## Genetic Health Care Providers Attitudes

A study conducted among 12 physicians and 13 genetic counselors found that all physicians felt that genetic information should be shared with families but only one was willing to breach confidentiality in case the patient did not share the information by himself (Campbell & Friedmann-Ross, 2003). Another study, found that 70% of medical geneticists felt it was their duty to warn at risk family members and that 25% of them considered seriously to breach patients' confidentiality, however only four out of 206 participants took further steps to do so. (Falk, Dugan, O'Riordan, Matthew & Robin, 2003).

In all this discussion, nothing has yet been said of the nurses' role and duties. Researchers already ascribe a long list of functions to nurses in genetics, from identifying patients and families with a history of carrying/suffering from genetic disease and who can benefit from genetic services, through maintaining medical records to support the long-term care and follow-up of patients and family members (Terzoglue & Dinc, 2003). It can be assumed that in today's reality nurses encounter such dilemmas of non-disclosure of genetic information with family members. It is to be presumed that nurses share physicians' obligations with regard to genetic information disclosure.

The present study deals with the attitudes of Israeli nurses to the disclosure of genetic information in case where the person tested refuses to do so and to study the effect of different genetic diseases.

Seventy three registered nurses participated in the study, all were staff nurses working in hospitals mainly in internal, surgical and intensive care wards with at least one year of experience at work ( $M=8.9$   $SD=8.2$ ). All were female, aged from 22 to 55 years ( $M=32.4$   $SD=8.52$ ). 63% knew or cared for someone with genetic disease.

The questionnaire consisted of three scenarios each illustrating a dilemma as to disclosing genetic information or not. The first scenario dealt with a carrier of Fragile-X, the second with hereditary breast cancer and the third with Huntington disease. With respect to each scenario, the participants were requested to answer five questions referring to information disclosure. 1. Should the patient disclose the genetic information to his/her family? 2. Should the nurse encourage the patient to reveal the genetic information to his/her family? 3. If the patient refuses to inform his/her family, should the nurse respect the patient's confidentiality? 4. Is it your duty as nurse to inform professional colleagues about the patient's refusal to inform his/her family? 5. Should the nurse take steps to inform the patient's family if the patient refuses to?

The results show that although the nurses were, overall, very sure (between 92-95% depending on scenario) that patients should inform their families and that it was the nurses' duty to encourage them to do so (between 69-85% believed so) they were equally sure that (>84%), should patients refuse to disclose, they should respect this decision. Their support for disclosing genetic information to professional colleagues is much less than for maintaining patients' confidentiality (only 66%), while their agreement with the notion that nurses should initiate information disclosure to their patients' families was much less still (18-30% depending on scenario) (see Table 1).

The data were further analyzed for differences in the subjects' response to the three scenarios and for differences in the response to the five questions. A general homogeneity in the answers was found, with few exceptions. In the case of Huntington's Disease (HD), the respondents were less sure that the patient should disclose the information to their family as compared with Fragile-X ( $p<.001$ ). In addition, it seems that in the case of breast cancer, the nurses thought that it more important to encourage the patients to inform their family in comparison to Fragile-X and HD ( $p<.006$ ).

The clearly strongest trend in the data is that the nurses are, overall, very sure that patients should inform their families and that it is the nurses' duty to encourage them to do so. However, they are more or less equally sure that, should patients refuse to disclose, they should respect this decision. The data also shows that when curative or preventive measures are available, the nurses were more convinced about the need to inform the patients' family members.

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**Table 1: Percentage of Respondents Answering Each Question in the Affirmative:**

	Fragile X	Breast Cancer	Huntington's Disease
1. Should the patient disclose the genetic information to his/her family?	93.2	94.5	91.8
2. Should the nurse encourage the patient to reveal the genetic information to his/her family?	68.5	84.9	71.3
3. If the patient refuses to inform his/her family, should the nurse respect the patient's confidentiality?	86.3	83.6	84.9
4. Is it your duty as nurse to inform professional colleagues about the patient's refusal to inform his/her family?	65.7	65.8	67.1
5. Should the nurse take steps to inform the patient's family if the patient refuses to?	17.8	30.1	24.7