Occasional Survey

Disclosing Genetic Information to Relatives or Carriers?

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Abstract

Genetic information and counseling of relatives of carriers can be in conflict with traditional medical, legal and moral rules of confidentiality. A case study was mailed to 200 physicians, nurses, and students in medicine, philosophy and business in Asia (Hong Kong, Beijing) and Europe (Vienna, Frankfurt, Bochum). We asked about moral institutions in professional disclosure and moral obligations of carriers towards family members. A majority, even stronger in Asia, supported the 'right to know' versus a 'right not to know', also called for changes in health policy to make genetic testing and counselling affordable and more widely available.

Keyword: Confidentiality; Family ethics; Genetic information; Genotyping; Health care policy