Conclusion

Values are important parts of our lives. But values and conscience have different roles in public and private life. They should influence discussion on what kind of health system to deliver. But they should not influence the care an individual doctor offers to his or her patient. The door to "value-driven medicine" is a door to a Pandora's box of idiosyncratic, bigoted, discriminatory medicine. Public servants must act in the public interest, not their own.

Contributors and sources: JS is a professional medical ethicist with experience in practising general and emergency medicine. This article arose from reflections on the literature and his experience

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Ethics

Just a family medical history?

Dagmar Schmitz, Urban Wiesing

If you have a family history of inherited disease, giving details could lead to discrimination

A recent case in Germany has highlighted the use of genetic information obtained from family medical histories in employment decisions. Although laboratory genetic testing is rarely used in occupational health medicine, prospective employees are often asked about family medical history and may be unaware of the potential consequences. We argue that information obtained from family histories is similar to that from genetic testing and consent procedures should be the same.

Case

Teachers in Germany, like all civil servants, have to have a medical examination before getting a permanent job. In this case, a young female teacher was examined by the occupational health doctor and found to be in perfect health. But in response to questions about her family medical history, she indicated that her father had Huntington's disease. She refused genetic testing. Her risk of inheriting the disease from her father and still being in perfect health is 50% at most. At the same time, her chance of not having inherited the disease from her father is at least 50%. The doctor reported that she had an above average risk of future absenteeism because of her family history. The Hessen educational authorities then refused to give her a permanent job in the German civil service on the grounds of this medical report.^{1 2} The teacher has since successfully contested the decision in the German Administrative Court.

Legal position

Although the German Administrative Court abolished the decision of the Hessen educational authorities because it thought the risk had been wrongly interpreted, it explicitly approved the use of predictive

Family history can sometimes be as revealing as genetic analysis

medical information from a family history. Civil servants in Germany have particular privileges, which the court believes justifies questioning the future ability for performing the job.³ The occupational physician is therefore obliged to consider the future health of the applicant and to give a prognosis based on a physical examination and family history. The court also recommended that genetic testing should be prohibited in pre-employment medical testing because of the related ethical problems and their lack of legal regulation in Germany.³

The approval of family histories and disapproval of laboratory genetic testing in the workplace reflects the current opinion and legal practice in most of Europe. Countries such as Switzerland have implemented restrictions on the use of genetic tests in the workplace, and 22 US states have banned the use of genetic screening in making employment decisions. Bills

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currently in the US congress also aim to prohibit genetic discrimination in employment. Other countries, like France, have already adopted the ban on genetic discrimination from the European Convention on Human Rights and Biomedicine (Council of Europe 1997, article 11). But these regulations apply solely to laboratory tests.

The special situation of family histories in this context has already been acknowledged. The British Human Genetics Commission, for example, discussed whether an insurance moratorium should be extended to the use of family history information.⁴ The European Group on Ethics in Science and New Technologies to the European Commission even included family medical histories in their definition of genetic tests.⁵ Nevertheless, most national regulations, like the German draft legislation,⁶ do not mention family histories or explicitly exclude them from their definition of genetic tests.⁷ Only in countries where the regulatory framework encompasses all medical data (as in Denmark, for example), do guidelines apply to all genetic testing practices.

Treatment of family history and laboratory testing

Ethical debate about genetic testing usually focuses on genetic discrimination and the standards of informed consent (or informed refusal). Accordingly, these two topics appear in every international or regional regulation for genetic testing in the workplace.⁸

Informed consent

The German teacher exercised her right not to know her genetic status in refusing to have DNA analysis. With this decision she was referring to the ethical principle of respect for autonomy, understood as self determination of the individual.^{9 10} But what about her autonomy with regard to her family history? Did she have a chance to decide if she wanted her family medical history to be analysed? Or did she consent to the procedure by answering the questionnaire?

Every medical intervention or test requires the consent of the patient. Consent can be tacit, implicit, or expressed and written. Genetic testing usually requires informed and clearly expressed consent. The standards, based on recommendations from patient and professional organisations, are even higher for predictive genetic testing.¹¹ When the condition being tested for is neither curable nor substantially treatable and the medical testing might do more harm than good to the patient, the doctor should take a comprehensive family history, document the process of obtaining informed consent, and get written authorisation for the test. Furthermore, the patient should be offered a free and informed chance to refuse. One necessary precondition of a valid consent or refusal is the voluntariness of the decision, which is hard to realise in the workplace because of the structures of power.

For family medical histories consent is usually taken for granted if the patient or client answers questions from the doctor. No test is carried out; the doctor just interprets the information given. It is rightly argued that the self determination of the patient in this case does not need as much additional protection as in laboratory tests. However, not every patient will be

aware that a doctor might disclose predictive genetic information on the basis of a family history. In addition, family histories are often obtained by a questionnaire, which means that the patient has no chance to talk to the doctor about the details of this procedure and may not realise the consequences. If the resulting personal genetic information does not differ qualitatively from genetic information obtained by laboratory tests, the requirements for consent should differ only slightly. This means that the patient should be informed (by explaining the procedure and possible results of the questionnaire) before consent can be presumed on the basis of his or her actions.

One practical problem in this context is that family histories might show information about third parties who have not consented to the storage of their data. It is still unclear what informed consent should mean in the case of family histories. However, in situations where the right of informed refusal is substantially at risk (such as in the workplace), family medical histories as well as genetic tests should not be allowed.

Genetic discrimination

Although frequently used, the term unfair discrimination is seldom defined. The term is usually used to indicate a distinction that is socially unacceptable or an irrational distinction (or a combination of both).¹² The German philosopher Ernst Tugendhat defines primary and secondary forms of unfair discrimination. Primary discrimination is not dependent on certain actions, but precedes them—for example, racial or sexual discrimination. In our society primary (genetic) discrimination is not acceptable, irrespective of the origin of the information it is based on. In secondary forms of unacceptable discrimination, it is assumed that all individuals are of equal value. Nevertheless, they are treated unequally in certain situations.

Most actions that are judged as (unacceptable) genetic discrimination belong to the secondary type. Nobody would consider the teacher to be less worthy than other human beings because of her higher genetic risk. However, she has a higher risk of future absenteeism and it is not irrational to base unequal treatment on this fact. In contrast to primary discriminations, these secondary forms do not offer a clear limit to what is morally unacceptable. Rather, these limits must be the result of agreements which are constantly subject to discussion and changes within a society. Our society seems agreed that it is unacceptable or unfair to use predictive genetic testing in pre-employment decisions. The main argument in this context seems to be that applicants or employees who are equally healthy and fit to perform the job should not be treated unequally just because of possible future diseases or risks. Under this argument, family histories that can result in predictive personal genetic information, should also be banned from pre-employment testing.

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Summary points

Family medical history can give predictive genetic information similar to that obtained from genetic testing

Every effort should therefore be made to secure free and informed consent before taking family history

When this is not possible (as in workplace examinations), family medical histories should not be used

Discrimination based on information about genetic status should be prohibited, irrespective of the origin of the information

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Ethics

Implications of data protection legislation for family history

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Clinical geneticists currently collect and store information on family history without explicit consent. Are they flouting the Data Protection Act?

Family history is important in many areas of medicine, but particularly clinical genetics. The family tree is an important clinical tool for answering questions about a patient's risk of developing a genetic disorder and appropriate management. Such records contain sensitive information, including family relationships, the health status of family members, and dates of birth, marriages, and pregnancies. The names and contact details of family members may also be recorded to facilitate further investigation. Information about family members is usually gathered from individual patients and recorded without relatives' consent or knowledge. The tacit assumption has been that such data are in the public domain because they have been shared within the family and that explicit consent is therefore not required. The Data Protection Act 1998 and an increasing cultural focus on consent and confidentiality, however, question this assumption.

Case history

Ms White, a 27 year old woman, attends the genetic clinic because of a concern about her family history of cancer. Her father had bowel cancer at the age of 42 and a paternal aunt had a gynaecological cancer at a similar age. She has two further paternal aunts about whom she knows little (figure). Ms White is advised to try to find out

some more details about her family history since it could reflect a mutation in one of the genes predisposing to bowel or womb cancer. However, such details could also provide reassurance that there is a relatively low risk of such a mutation and Ms White's medical management therefore depends on such details. She is given standard consent forms for access to medical records to pass to her father and aunt.

Some time later, Ms White's aunt phones the department saying that she is disturbed to have been approached unexpectedly about a cancer she had five years ago and about which she preferred to have no reminders. She thought that the Human Rights Act prevented the genetics department from recording any information about her without her knowledge. She is concerned that such information could lead to discrimination and does not think either of her sisters would be pleased to learn that the department is storing information about them without their knowledge.

Some months after this Ms White's brother also attends the genetics department. He has not been contacted by Ms White but been independently referred by surgeons because of an episode of rectal bleeding. He is unaware of any family history of cancer except the cancer in his father; he asks to see his family tree, which is stored in the family notes he shares with his sister.

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