

Individuals with family history of genetic disease at risk of discrimination

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People with a family history of genetic disease are often discriminated against by insurance companies and their relatives and friends, according to research published in British Medical Journal.

Advances in genetic testing have meant that many individuals have been able to tailor treatment and inform reproductive decisions. However, these powerful new technologies have also caused fear about the misuse of genetic information including discrimination, say the authors.

Such fear led the US Government to pass legislation preventing health insurance companies and employers using genetic information.

The lead authors, Drs Yvonne Bombard and Michael Hayden based at the University of British Columbia, say the scale of genetic discrimination is largely unknown and this is the first study to focus on this issue in a genetically tested and untested population.

The authors surveyed 233 individuals in Canada who were at risk of developing Huntington's disease. None of the group had symptoms of the disease, 167 of them underwent testing (83 had the Huntington's disease mutation, 84 did not) and 66 chose not to be tested.

Huntington's disease is an inherited neurodegenerative psychiatric disorder for which there is no treatment or cure. The disease usually manifests itself in mid-life and individuals suffer from mood and personality changes, chorea (involuntary movements) and cognitive

decline. The disease ends in death, usually 15 to 20 years after diagnosis.

Around 40% of respondents said they experienced discrimination, primarily by insurance companies (1 in 3), their family and in social settings (1 in 5). Interestingly, there were not many reports of discrimination in employment, health care or public sector settings.

The findings show that it is family history that appears to be the major cause of genetic discrimination not participation in genetic testing. The authors conclude that "clearly, there is a need to shift the current focus of genetic discrimination as a genetic testing issue to one that equally highlights the role family history plays in people's lives."

The authors maintain that many individuals and families fear being unable to cope with the predictive test results, especially given no treatment exists to slow or prevent Huntington's disease. They add that the decision to test can become a "litmus test by which relatives judge each other's loyalty to the family" and that testing often causes disruption within the family.

In conclusion the authors say that "ultimately asymptomatic individuals at genetic risk are at similar risk for discrimination because their label of having a family history of [disease](#)."

In an accompanying editorial, Professor Aad Tibben from Leiden University in the Netherlands advocates the benefits of genetic testing and says it "gives a person at risk the opportunity to take more responsibility and control over their life, their health and their future. In general, the test brings relief from uncertainty and more control over people's future life, and no serious adverse consequences have been reported."

Tibben is intrigued by the study's findings related to [genetic](#)

discrimination within the family and social relationships and believes more insight is needed into the dynamics in these fields.

Source: BMJ-British Medical Journal

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