Nova Scotia Health Ethics Network

Fireside Chat Video Series
Discussion Questions

Ethics in Genetic Counselling

Erika Aberg, Genetic Counsellor, Maritime Medical Genetics Service, IWK Health Centre, Halifax NS

Discussion questions:

- Did the interview change your perception of ethical issues in genetic testing? If yes, how?
- Erika Aberg talks about the importance of exploring the patient's values during the pre-test counselling. In your opinion, which values might incline some patients to proceed with genetic testing and which values might prompt others to decline?
- Presymptomatic genetic testing or predictive testing – that is, testing for known genetic changes or mutations running in the patient's family – does not necessarily provide precise information about the likelihood of actually developing a disease. How might predictive testing impact the perception of a person's health? What ethical concerns arise from these shifts in perception? (Try to discuss this from various perspectives, such as the health care provider's perspective, the patient's perspective, and the family's perspective)
- Discuss some of the ethical implications of parents making decisions about genetic testing of their child. How are values different in the case of testing children?
- A person undergoes a predictive genetic test for a rare form of hereditary Alzheimer's disease and is found to have the familial mutation associated with disease in her family.
  - Discuss how one person's decision to undergo testing may affect other family members.
  - Other family members may carry the same mutations, but may not want to know this information. How can their right not to know be honored?
- Would you undergo a genetic test for a disease that is non-treatable, such as for example Huntington Disease? Why/why not?
- Erika Aberg talks about the limitations of genetic testing and give examples of how it is not always possible to provide any solid predictions based on the information that comes out of the test. Did that surprise you? Why/why not?

Resources:

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