Genetics + Ethics = Genethics

Teacher Notes

The area of **philosophy** focusing on the principles involved in making decisions about what is right and wrong is called **ethics**. **Bioethicists** study ethical decision-making in the context of biological information and biotechnology. Inthe past they have dealt with difficult medical decisions such as humanorgan transplants, however with today's explosion in knowledge in the fields of genetics and biotechnology, new issues are arising. "**Genethics" (genetics + ethics)** encompasses theethical issues associated with the applications of gene technology such as genetic testing, gene therapy, pharmacogenetics and cloning.

Medical genetics is an area within "**Genethics**" dealing primarily to date with genetic testing and diagnosis, therefore it has implications for individuals, familiesand society. Information obtained from genetictesting can affect the livesof individuals and their families because of the following special features:

- Genetic information is family information. By its very nature it is shared but does this mean it is collectively owned? ie it has direct implications for other family members.
- Implications for partners and the decision for couples tohave children.
- Predictiveness (for adult onset conditions) but also uncertainty and limitations of genetic testing.
- Inappropriate applications of genetic testing ie scope - a large range of information is potentially available from one small sample of biological tissue, some of which may be unexpected and unwanted such as the identification of a fetus's sex from an amniocentesis karyotype result, or non-paternity.
- Discrimination potential eg life insurance, health insurance, employment.

Basic principles of medical genetics ethics

- Justice can be interpreted as fair, equitable and appropriate treatment for all. It embodies respect for people with disabilities and for the patient's or family's decisions.
- Autonomy is the principle of being one's own person and choosing one's own course of action, including medical treatment. Autonomy implies a person's right to choose freely based on adequate information without coercion by family members. However as an individual right it may have to be balanced against the rights of others and therefore is not absolute. Autonomy requires consideration of the following ethical issues;
  - Privacy - the rights of individuals to maintain privacy. For example, some prenatal genetic tests are requested by parents for developing fetuses and newborn babies. If an infant is found to be a carrier or likely to develop or be affected by an inherited disease (adult onset condition such as HD), these findings may affect the future employability or be the basis of discrimination for an individual. Who should decide for the fetus and the child?
  - Informed consent - obtaining permission to do genetic testing. One must have knowledge of the risks, benefits, effectiveness, and alternatives totesting in order to understand the implications of genetic testing. Age and access to information must be considered.
  - Confidentiality - acknowledgment that genetic information is sensitive and access should be limited to those authorised to receive it. Future access to a person's geneticinformation also should be limited.
- Beneficence and Non-Maleficence are two sides of the same coin, or two sides of an argument.
  - Beneficence is the duty toconfer benefits and to prevent and remove harm. Knowledge of genetic results should do more good than harm, such as allowing you to get better medical care.
  - Non-Maleficence *Primum non nocere- above all, do no harm.* This is the dutyderived from beneficence and proposes that one ought not to inflict evil or harm. Does the provision of genetic information such as a positive gene test for a late onset adult condition such as Huntington Disease have the potential for harm when there is no current treatment?

The Guide to Ethical Decision-Making for Genetic Testing Procedures (overleaf) can be helpful in the processof analysing each dilemma as it encompasses the ethical principles of autonomy, justice, beneficence and nonmaleficenceassociated with bioethics.