

Consequentialism

From a consequentialist position the question of whether it is wrong to breach confidentiality is determined by the consequences of the breach. One of the consequences of a breach of confidentiality could be that the patient will lose trust in his/her doctor, and perhaps doctors generally, resulting in him/her not accessing healthcare in the future with a detrimental effect on his/her (and others?) health. On the other hand there may be situations where there are bad consequences of **not** breaching confidentiality, for example third parties may be denied information which would have serious implications for their health and treatment.

This is taken from a more detailed discussion of ethical issues of confidentiality to be found on the UK Clinical Ethics Network website:

<http://www.ethics-network.org.uk>

Ethical issues - Confidentiality

The following is taken from:

Medical Ethics Today - the BMA's handbook of ethics and law

(BMJ Publishing Group 2004, page 308)

“Does genetics raise different ethical issues?”

Emphasis on the need for doctors to understand the dilemmas raised by genetics has led to a general tendency to assume that genetics is somehow “different” from other areas of medicine and so inevitably requires special rules and added protection. Arguments to justify these differences, however, are frequently not articulated and, in fact, many of the ethical dilemmas that arise in genetics are the same as those that arise in other areas of medicine. They centre on the traditional duties of health professionals to act in the patient's interests and to avoid harm. Facets of those duties are embodied in the accepted obligations to respect patient confidentiality, to provide information in order to obtain valid consent, to evaluate risks and benefits of treatment, and to aim for justice and equity in decision making. In some ways, however, genetics is different, primarily because of its familial nature, which requires that these general principles are supplemented by other considerations such as the inevitable interdependence of interests and duties owed to other family members”.

information is familial e.g. spontaneous mutations). A person diagnosed with a serious genetic condition could, by informing relatives of the need for testing, alleviate worry and perhaps unnecessary diagnostic procedures. This could be considered a moral duty.

Paragraph 2.11

“Although considerations of genetic solidarity and altruism will generally take second place to the principle of respect for persons there may be exceptional circumstances in which the contrary is true. In such cases the social interest – or the common good – may be weightier than the individual interest, and certain rights of the individual may take second place”.

Respect for Patient Choice

“It is widely accepted that competent patients should have a control over decisions concerning their own medical care. Respect for patient choice means that they should also have a control over what happens to the information shared by them with their health professional. Patients in general accept that health professionals sometimes need to discuss this information with colleagues in the interests of their care, and perhaps too in the interests of training. But this is very different to the sharing of patient information with those not involved in their clinical care. Patients reasonably expect that, unless they have given specific permission, health professionals will not disclose the information revealed during the professional relationship to others. To take patient choice and patient autonomy seriously is to place great value on confidentiality in the doctor-patient relationship”

Confidentiality and serious harm in genetics – preserving the confidentiality of one patient and preventing harm to relatives. Anneke Lucassen and Michael Parker *European Journal of Human Genetics* (2004) 12, 93 – 97 (at page 94).

The right to know and the right not to know

A competent patient must give valid consent to be tested for genetic conditions. However, information about the genetic risk to family members may arise from testing of one person in the family (the index patient). Do family members have a right to know of a potential risk, or perhaps there is a ‘right not to know’? Some may prefer to live without the anxiety of knowing that they are at risk of a genetic disease, particularly if it is a disease of late onset and where the likelihood of manifestation of the disease (penetrance) is uncertain.

The BMA has stated that:

“Individuals should be encouraged to share genetic information with others for whom it has significant implications if they are likely to want to know it. Only in very extreme and exceptional circumstances, however, should information be disclosed contrary to the individual’s wishes”.

Human Genetics, Choice and Responsibility, BMA, Oxford University Press 1998

The Genetics Interests Group distinguishes between a situation where an individual knows he is at increased risk but does not want further information and the situation where the individual has no knowledge of a prior risk. GIG suggests professionals should have discretion to disclose information based on the principle of maximising benefit and minimising harm.

(Genetics Interest Group, Confidentiality Guidelines, 1998

http://www.gig.org.uk/docs/gig_confidentiality.pdf. Section 5. The right not to know).

Specific ethical considerations relevant to genetic issues in healthcare

Respect for persons

The Human Genetics Commission in its report 'Inside Information' suggests that the principle of respect for persons should be a core principle in considering the ethical use of genetic information (*Inside Information* Chapter Two: General Principles, paragraph 2.12).

Paragraph 2.13.

"The principle of respect for persons requires that we acknowledge the dignity of others and that we treat them as ends in themselves and not merely instrumentally as means to ends or objectives chosen by others. This means that we must respect the autonomy of others".

Paragraph 2.18

"In the context of genetic information, respect for persons requires us to be sensitive to the special role that genetic identity has come to play in peoples' lives. Along with their social and psychological identity, genetic identity has particular implications for the individual's sense of self.... If we are to respect persons, then in most circumstances we must respect that which is important to them. It is clear that amongst these important things is genetic identity".

Therefore the notion of respect for others entails respecting the autonomy of others. Respect for autonomy is reflected in the principle of consent. This raises particular difficulty with regard to genetic testing of children – can they give informed consent, should the possibility of their future choice be preserved?

Reproductive choice, the exercise of parental autonomy, and prenatal testing, for example, selecting for an embryo that will be a suitable match for a bone marrow transplant for a sibling with a genetic disorder, may conflict with the 'rights' of a foetus or future child.

A person may decide that he/she does not want his/her family members to be informed of the results of a diagnostic genetic test. The HGC states that:

"Private genetic information about a person should generally not be obtained, held or communicated without that person's free and informed consent". (*Inside Information* paragraph 2.26).

However the principle of respect for autonomy / respect for persons may, in some situations, be outweighed by consideration of welfare of others.

Welfare of others

One aspect of respect for persons/respect for autonomy is the notion that information about a person's genetic inheritance is that person's alone. The notion of genetic privacy is fundamental in engendering confidence in diagnostic genetic testing / screening. However, in some limited situations, the risk to others of not knowing about genetic information that is relevant to their health may be so great that it justifies disclosure without consent.

The HGC refers to **genetic solidarity** – "genetic knowledge may bring people into a special moral relationship with one another" (*Inside Information* paragraph 2.10).

Given the genetic basis of much disease, there may be great benefit to family members in sharing of relevant genetic information (although not all genetic