An overview of education and ‘new genetics’


Summary

Research and development in the field of genetics and the Human Genome Project will have a major impact on the future of health care and the services on offer for users. The authors discuss the importance of educating nurses about genetic developments so that they can apply this knowledge to practice.

Large amounts of human genetic material have been sequenced as a result of the Human Genome Project (Radford 2000). The human genome is becoming increasingly important for all health professionals in understanding disease and the prevention of ill health. Genetic developments such as the identification of specific genes for Alzheimer’s disease, cystic fibrosis, Duchenne muscular dystrophy and other conditions are being discussed in the media and in professional journals. Despite the fact that most nurses recognise that genetics will have a major impact on health care (Kirk 1999), there is little opportunity for nurses on academic programmes to become involved in learning more about these developments unless they are receiving special training, for example, in genetic counselling.

It is also apparent that many nurses have unanswered questions regarding genetics. These nurses and other health professionals could be the most important source of health information for patients and clients (Gannaway 2000). For example, health visitors might be asked about the risks of genetically modified soya used in baby milk. Mental health nurses might be questioned about the risks of family members developing schizophrenia. District nurses might have to address family concerns regarding Alzheimer’s disease and surgical or oncology nurses might be asked about the likelihood of other family members getting cancer.

Apart from technical questions, other major concerns centre on what is and what should be allowed under English or international law. Many of the new developments in genetics raise huge ethical concerns. These include debate about:

- Whether human cloning should be allowed.
- What genetic screening reveals about society’s attitudes towards disability.
- Whether parents have the right to a perfect baby.
- Whether food should be genetically modified.

Nurses need to be informed about the Human Genome Project to apply this knowledge to practice (Lessick and Williams 1994). However, while Kirk (1999) has identified that most pre-registration nursing curricula include some teaching on genetics, it is unclear to what extent post-registration nurses have the opportunity to develop their understanding of the rapid developments in this field.

Having identified a need for greater knowledge and understanding of these issues, the authors developed a genetics study day for post-registration nurses. The nurses were from a variety of specialties and on different parts of the UKCC register. They were all undertaking a course in ethical and legal issues in professional practice. The nurses were asked to choose whether or not the study day should form part of the course. They agreed unanimously that it would be interesting and beneficial in terms of their professional development.

Genetics study day

Before a reflective and critical approach can be taken, it is necessary to have a good understanding of genetic mechanisms, how they are made, what the different sequences mean and how to convert them into the proteins they produce (Fairbanks and Anderson 1999).

Nurses need to understand how faults in the genetic sequence can occur and what these mean in terms of a person’s health or susceptibility to a particular disease. These genetic ‘mistakes’ can have major implications in certain conditions. For example, a health visitor failed to test a neonate for phenylketonuria (a congenital deficiency of phenylalanine 4-monooxygenase). The child suffered serious brain damage and this led to an award of £2.5 million in damages (Jenkins 2000). The Human Genome Project is still in the...
process of identifying all human genetic codes, but the information generated is not freely available to all. Some researchers publish gene sequences as soon as they are identified to make this information freely available, but others do not. Instead, commercial interests mean some researchers patent gene sequences as fast as possible to recoup their costs. The processing and patenting of the genes raises concerns over genetic privacy and ownership of material common to all (Polland 2000).

The fact that commercial exploitation can create barriers to researching and finding cures for gene-linked illnesses, such as in some forms of cancer, is of particular concern to participating nurses. The cost of screening might mean that the NHS cannot afford to carry out such tests, which will have implications for health promotion and primary care. People might be unable to find out whether or not they are at risk of developing an illness or passing it on to their offspring (ACGT 1998).

Serious concerns have also been raised in relation to cloning, the effects of genetic manipulation and the creation of a genetics underclass that will be unable to obtain insurance and become stigmatised by society as a result of the Human Genome Project (Nelson 1994). Analysis of these concerns can be conducted using tools of ethical analysis, such as utilitarianism, deontology and rights. Exploring these issues in a focused and primary care. People might be unable to find out whether or not they are at risk of developing an illness or passing it on to their offspring (ACGT 1998).

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establishments. The difficulties in monitoring research mean that mavericks could be tempted in the interests of science, fame or money to go beyond what some countries have agreed as acceptable. While many find the idea of being cloned repulsive, several of the nurses we taught could understand why a grieving parent might want a dead child cloned or why the use of cloning for replacement of a defective organ could be acceptable. Having a scientific and ethical understanding of these issues helps nurses to identify the extent and nature of objections to cloning and to give a reasoned analysis in support of their views.

Genetic changes and modifications have always occurred and are part of how we have evolved as humans (Fairbanks and Anderson 1999). Exploring the process by which genes are modified naturally enables fears about genetic manipulation to be put into context. However, the media has contributed to public anxieties about genetic modification often in hysterical or poorly researched articles. For example, the same incident regarding genetically modified crop research was reported in two newspapers (de Bruxelles 1999, Gibbs 1999). Not only was there significant variability in the facts presented, but the language and style had a major effect on the response of the reader towards the research and the parties involved. It is important to recognise how our views can be manipulated in this fashion.

The media has raised fears that eating genetically modified plants or animals might be detrimental for humans, but these fears might be allayed by the fact that the digestive system breaks down proteins regardless of their source and all proteins are the products of genes.

However, cross-pollination and development of rogue plants is a real scientific concern because it is uncontrollable and can have long-term implications for natural plants and ecosystems (NCB 1999). If resistant crops are developed, developing countries could be exploited by commercial companies that could force them into having to buy modified seed at exorbitant prices. Such seed, if rendered sterile as part of the manipulation process, would have to be purchased every year, whereas at present many farmers save some seed from each harvest to grow the next year’s crop.

Nurses who have been associated with poor countries recognise the potential for further famine and child suffering if seed is unaffordable. This appears contrary to the aims of the World Health Organisation and UNICEF, which are working to improve world health.

The same scientific developments can be used to modify genetic sequences in humans and animals. Gene therapies have the potential to cure disease and have already been used in cystic fibrosis (Dobson and Leake 1999). Manipulation of one’s own genetic material might be a decision for the individual. However, altering germ cells and permanently changing the future gene pools of humans might be too scientifically and ethically contentious to be allowed.

Further education developments

The success of the genetics study day in furthering post-registration nursing competency in the science, law and ethics of genetics highlighted the interest and concerns of those participating. The authors would like to introduce similar courses for groups in mental health, learning disabilities and midwifery. While pre-registration nurses have had some genetic teaching, the authors sought to incorporate a similar course into the pre-registration law and ethics module.

Dedicating a whole day to the topic was not feasible because of the requirements for a balanced curriculum. But, having researched genetics and ethical issues beforehand, the students participated in a whole group discussion that centred on key questions. This format was chosen because it is currently a popular model for debating legal and ethical issues. It is important for students, as well as qualified nurses, to be able to participate in such debates in a professional manner. The enthusiastic response and high standards of discussion by the participants mean that subsequent groups will have similar, though not always identical, opportunities to research and debate genetics issues. The authors are actively seeking further ways to enhance nursing competency in this area.

Conclusion

Genetics education now forms an important part of the post-registration ethics and law curriculum and is being incorporated into the pre-registration nursing curriculum. Nurses have found that their ability to critically engage in discussions on genetics and to answer patients’ questions has been greatly enhanced. However, at present, only certain post-registration courses include genetics issues. As the Human Genome Project progresses, the implications for health will become more evident and it is likely that more courses within the post-registration framework will include genetics topics. The use of genetics in the diagnosis and treatment of disease will increasingly involve nurses and other health professionals (Skirton and Patch 2000). How these genetic developments and techniques will be used in health care and their effect on nurse education are issues of concern for health educators, providers and users. As the science develops, nurses should ensure that they keep up to date with the clinical, legal and ethical issues on behalf of their patients as well as themselves.