NURSING MATTERS

Nursing Matters *fact sheets provide quick reference information and international perspectives from the nursing profession on current health and social issues.*

Fact Sheet

Genetics and Genomics in Nursing

Introduction

Genetics is the study of individual genes and their heredity impact and how they are transmitted from one generation to the next.[1] Genetic study focuses on single gene diseases such as muscular dystrophy.[2] Genomics is the study of all genes in human genome and their interactions with each other, the environment, and other cultural and psychosocial factors. [3] An understanding of human genes will transform health care from diagnosis and treatment to prediction and prevention.

Today genetic and genomic studies are used to predict and diagnose many rare and common diseases, such as coronary heart disease, hypertension, diabetes mellitus, and some rheumatic, cancer and mental illnesses. Genetic and genomic tests are also used for predicting human behaviour such as depression, alcoholism and other substance addiction.[4] These can provide information that assist in effective disease management. Regular colonoscopy and cervical screening, for instance, can prevent thousands of deaths each year through early detection of disease. Genetics and genomics are increasingly being integrated into the screening, prevention, diagnosis and treatment of diseases, but there is a potential for harm and complex ethical, legal and social implications surround their application in health care.

Ethical, legal and social implications (ELSI)

Ethical issues of particular concern to nurses and other health care providers raised by genetics and genomics include privacy and confidentiality, informed consent and genetic testing, and discrimination based on genetic information. Examples of the concerns include:[5]

- **Privacy and confidentiality of genetic information.** Individuals own and control their genetic information and are entitled to privacy of genetic data just as other personal health data. However, there is concern about storage and retrieval of data.
- **Misuse of genetic information** by insurers, employers, courts, schools, adoption agencies, and the military, among others. There are major concerns about who should have access to personal genetic information, and how will it be used.

- **Stigmatisation and discrimination** due to an individual's genetic differences. There are concerns about use of personal genetic information to discriminate and deny people services such as health insurance.
- **Reproductive issues** including adequate informed consent, the use of genetic information in reproductive decision-making, and reproductive right. The challenge for health care personnel is to counsel parents about risks and limitations, use of genetic tests, and new reproductive technologies.
- **Clinical issues** including the education of health care providers, patients and public related to capabilities, limitation and social risks of genetic tests.
- **Uncertainties associated with gene tests** for susceptibilities to complex conditions (e.g. heart disease, diabetes and Alzheimer's disease). Key concerns include whether testing should be performed when no treatment is available or when interpretation is unsure and whether children should be tested for susceptibility to adult-onset diseases.
- **Conceptual and philosophical implications** regarding human responsibility, free will versus genetic determinism, and concepts of health and disease. Do our genes influence our behaviour, and can we control this? What is considered acceptable diversity? Where is the line drawn between medical treatment and enhancement?
- **Health and environmental issues** concerning genetically modified (GM) foods and microbes. Are GM foods and other products safe for humans and the environment? Will GM foods have adverse effects to humans in the future? How will these technologies affect developing nations' dependence on industrialised nations?
- **Commercialisation of genetic products** including property rights (patents, copyrights and trade secrets) and accessibility of data and materials. Who owns genes? Will patenting genetic materials limit their accessibility and development into useful products?

Nursing Competencies for Ethical Issues

Nurses are at the forefront of patient care, and will increasingly participate in genetic-based and genomic-based practice activities such as collecting family history, obtaining informed consent for genetic testing,[6] coordinating screening programmes, and counselling regarding patient genetic risk. Thus, nurses need to become knowledgeable about and competent in genetic and genomic related health care. According to the Consensus Panel on Genetic/Genomic Nursing Competencies, nursing competencies for providing genetic and genomic related issues include:[7]

Professional Responsibilities

- Recognize when one's own attitudes and values related to genetic and genomic science may affect care provided to clients;
- Examine competency of practice, and identify areas of strength and other areas in which professional development related to genetics and genomics would be beneficial;
- Incorporate genetic and genomic technologies and information into registered nurse practice;
- Demonstrate the importance of genetic and genomic information and services to clients; and

- Advocate for clients' right to autonomous, informed genetic and genomic related decision-making**,** voluntary action and access to desired genetic/genomic services and/or resources.

Professional Practice

- Identify credible, accurate, appropriate, and current genetic and genomic information, resources, services, and/or technologies specific to clients;
- Identify ethical, ethnic/ancestral, cultural, religious, legal, fiscal and societal issues related to genetic and genomic information and technologies;
- Define issues that undermine the rights of clients for autonomous, informed genetic and genomic related decision making and voluntary action;
- Provide clients with credible, accurate, appropriate, and current genetic and genomic information, resources, services, and/or technologies that facilitate decision-making;
- Provide clients with interpretation of genetic and genomic information or services; and
- Perform and uses genetic and genomic-based interventions and information to improve clients' outcomes.

Implications for National Nurses Associations (NNAs)

In the new era of genomic health care, there are many implications for NNAs to develop the nursing role in genetic services and ensure that nurses can play the crucial roles in order to provide quality and ethical nursing care. NNAs can:

- Develop education programmes related to human genetics and advances in biotechnology in order to raise public awareness;[8]
- Develop training of clinical genetic services, for instance, genetic counselling for nurses and other health care providers to ensure that they can provide appropriate information, guidance and support to patients and their families;
- Participate in the development of appropriate legislation;
- Collaborate in developing national practice guideline and standard related to genetic services;
- Support genetic research in nursing in order to increase scientific knowledge which can applied to address biological, behavioural, bio-behavioural, family, social and ethical issues emerging from genetic discoveries.

Advances in genetics and genomics present a great opportunity to improve health care. At the same time there is a potential for harm such as loss of privacy, erosion of human dignity, and inequity based on genetic information. Health professionals are challenged to practice in an ethical manner.

For further information, please contact: icn@icn.ch

The **International Council of Nurses (ICN)** is a federation of more than 130 national nurses associations representing the millions of nurses worldwide. Operated by nurses and leading nursing internationally, ICN works to ensure quality nursing care for all and sound health policies globally.

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3, place Jean-Marteau, 1201 Geneva, Switzerland