Obtaining and communicating information about genetics

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Summary

This article, the last in this series, focuses on the ways a nurse can acquire relevant genetic information for effective practice and how this information can be communicated successfully.

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Genetic disorders; Information technology; Literature search

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TO PRACTISE competently, nurses and midwives should know about genetic science because it is important to an understanding of the causes of disease, genetic testing, and the prevention and management of conditions (Skirton and Patch 2000). Increasingly, genetic testing will be used before the prescription of drugs and to inform management of the condition. For example, genetic testing for patients with maturity-onset diabetes of the young could clarify whether insulin is the required therapy (Shepherd and Hattersley 2004). However, genetic information is just one component of educating clients, and the practitioner requires true understanding and clarity of communication to support the client in integrating new and existing information to manage the condition (Box 1).

Knowledge can be acquired from a range of sources:

Academic programmes For many nurses and midwives a foundation in knowledge about health genetics will be gained during formal courses at pre-registration and post-registration levels. However, genetics, like ethics, cannot be taught in a few sessions – it should underpin the entire curriculum. Nurses and midwives learn to consider the psychosocial aspects of health, illness and disability as a matter of course. Similarly, the genetic basis of health and disease should become an integral part of practitioners' thinking through reference to relevant genetic issues and information.

Study days and conferences A knowledge of health genetics, particularly in relation to certain

BOX 1

Seventh of seven competency standard statements

Obtain and communicate credible, current information about genetics for self, clients and colleagues, and use information technologies effectively to do so.

Domain: professional and ethical practice

Suggested learning outcomes

a. Recognises the importance of updating genetic knowledge at frequent intervals and the consequent benefits for self, clients and colleagues.

b. Appreciates the limitations of information and its credibility and reliability.

c. Critically appraises information from different sources.

Suggested practice indicators

1. Demonstrates knowledge about accessing local or regional genetics resources.
2. Actively refers to research-based evidence about genetics related to client care.
3. Adopts a range of interpersonal skills while communicating with clients and colleagues about genetics issues.
4. Takes action to meet any deficit in identified knowledge and skills that is likely to affect the delivery of care in a nurse's sphere of practice.

(Kirk *et al* 2003)

conditions, can be obtained by attending study days or conferences offered in conjunction with regional genetics services or by disease-specific support groups. These occasions also provide the opportunity to identify colleagues in other local services who can be contacted when required.

Informal contact with specialist practitioners Genetic nurse specialists or genetic counsellors are usually willing to answer queries about a condition or a specific referral. Contact is usually expedited by fostering professional relationships. Specialist clinic observation may also enhance the practitioner's understanding of the clinical episode for the patient and can often be organised by contacting the local service.

Using the internet, textbooks and journals The internet can be used independently by the practitioner and is, therefore, one of the most accessible sources of information. Textbooks and journals can be used, but care needs to be taken when relying on books and journals that were published some years ago because they may contain out-of-date information, such as techniques for genetic testing for a particular disease. However, more general information, such as signs and symptoms of a genetic disorder, are unlikely to alter substantially over several years.

The internet is useful in locating different types of material to support learning (Box 2). All websites mentioned are included in the resources list (Box 3) and these should be checked before recommending them to families because the content may have changed in the interim. Nurses should use appropriate skills to critically appraise the quality of the information in these resources before using them, as required by *The NMC Code of Professional Conduct*, section 6.5, (Nursing and Midwifery Council (NMC) 2004). This is important because of the lack of governance over material posted on websites.

Searching the literature Information about disease genes and the potential for genetic testing in particular conditions is changing rapidly. Searching current literature is one way of obtaining the most up-to-date information (Veeramah 2004). A search on either OVID® (www.ovid.com) or PubMed (www.ncbi.nlm.nih.gov) will provide published abstracts of studies and many full text articles can be downloaded directly from the web. Many nurses still feel unsure about how to conduct a literature search (Veeramah 2004), and help can be sought from the librarian or information technology support staff in your organisation (Younger 2004). Organised teaching sessions or informal tutorials and support might be offered and can be available through local libraries. Increasingly, search engines, such as Google® (www.google.co.uk), provide a popular and accessible beginning to a literature search, although some of the information obtained through this type of search may not have been peer reviewed.

BOX 2

Scenario 1

Matt is a staff nurse working on an acute paediatric ward. Darren, a six-year-old boy, is admitted with a compound fracture of the humerus. He is a chatty boy and Matt is surprised when his mother says that Darren has learning problems. Matt asks Darren's mother about his diagnosis and she tells him that Darren has been diagnosed with Williams syndrome. Matt has never heard of the condition and discovers that colleagues on the ward are not familiar with it either. After his shift he uses the library computer to download some information from the Williams syndrome lay support group website. The next day, he is able to share the information with colleagues so that they have more understanding of Darren's condition. This is particularly important because Darren has a hypersensitivity to loud noises as part of the condition, and Matt is able to ensure that he is moved to a quieter part of the ward where noise is less likely to disturb him. Matt also realises that children with Williams syndrome are often able to converse socially and give the impression that their understanding of a situation is greater than it is in reality. Hence, Matt takes particular care to ensure Darren understands what is happening whenever he gives nursing care.

BOX 3

Useful texts for nurses and midwives

Skirton H, Patch C (2002) *Genetics for Healthcare Professionals. A Lifestage Approach*. Bios Scientific Publishers, Oxford.	Covers relevant practical clinical issues and basic genetic science for nurses and midwives. Uses case scenarios to demonstrate principles of practice.
Harper PS (2004) *Practical Genetic Counselling*. Sixth edition. Hodder Arnold, London.	Helpful text that can be used to quickly ascertain inheritance pattern and basic information about many rare genetic conditions.
Pritchard DJ, Korf BR (2003) *Medical Genetics at a Glance*. Blackwell, Oxford.	Good basic genetic science book.
Bennett RL (1999) *The Practical Guide to the Genetic Family History*. Wiley-Liss, New York NY.	Covers all aspects of taking a family history.

Databases For current information on specific types of genetic testing, databases are extremely useful. The Online Mendelian Inheritance in Man (OMIM™) database has detailed information on every single-gene disorder, although some of the information can be complex for non-specialists. More accessible disease-specific information can be obtained from patient support group websites, many of which are linked to the Genetic Interest Group website. Sites such as GeneTests or The University of Kansas are good sources of information (Table 1).

Lay support group sites These provide excellent sources of information on a range of topics, including the cause of the condition, options for good management and other sources of support. Because lay groups often provide financial assistance for research, many supply the latest research findings on their websites. For example, Contact a Family provides information for families as well as putting them in touch with others who have the same condition (Table 1).

Identifying local genetics services Local genetics services can be located using the directory of a professional organisation, such as the British Society for Human Genetics. Initially, contact with the clinical staff is suggested, but staff working in the NHS molecular and cytogenetic laboratories across the UK are helpful sources of information about specific tests.

Communicating genetic information

Communicating with families or individuals who have concerns about a genetic condition involves:

- Listening to gain an understanding of the family's concerns.
- Providing information relevant to the family's needs.
- Enabling the family to explore the options available to them.
- Providing the family with other sources of information if relevant.
- Referring the family for specialist advice if appropriate.

Basic communication skills are essential to help the client to express his or her individual needs, beliefs and values. The use of practical tools to explain unfamiliar scientific concepts can be helpful. The Greenwood Genetic Center (1995) has produced a book of diagrams for this purpose but many practitioners use their own diagrams or tools. The personal communication element is an important component in the

TABLE 1

Web-based resources

Contact a Family www.cafamily.org.uk	Information for families with disabled children
Genetic Interest Group www.gig.org.uk	National alliance group for more than 130 lay support groups and charities
The University of Kansas Medical Center, resource list Genetics Education Center www.kumc.edu/gec/	An excellent resource for scientific basics and genetic conditions
Online Mendelian Inheritance in Man (OMIM™) www.ncbi.nlm.nih.gov/entrez/query.fcgi?db=OMIM	Database of all single-gene disorders with detailed technical information on mutations
GeneTests www.genetests.org/	Updated information on options for gene testing and a full glossary of genetic terms with illustrations
Genetics Home Reference http://ghr.nlm.nih.gov/ghr/page/Home	Information on the basics of genetic science and conditions, easy to understand and suitable for families to access
GeneSense www.genesense.org.uk	Case study based educational site for health professionals, includes science, ethics and practice issues
The Wellcome Trust www.wellcome.ac.uk/en/genome/index.html	General information on genetics, ethics and the Human Genome Project
British Society for Human Genetics www.bshg2.org.uk/	Professional organisation site
(Last accessed: September 15 2005)	

education process. Clients in a study by Skirton (2001) indicated it was essential that the scientific information they were given was personalised to make it accessible and relevant. Mitchell and Sloper (2002) emphasised the need for a three dimensional approach by the practitioner. The three aspects of the approach involve personal guidance from a key professional, such as a community-based nurse who is known to the family, combined with high quality information that offers a review of local resources and more in-depth material, which is also considered to be helpful.

When explaining concepts in basic genetic science, the use of metaphors can be helpful, but the nurse should be wary of using too many different metaphors in the same explanation (Box 4).

BOX 4

Scenario 2

Christine is a midwife working in a busy antenatal unit. She is discussing a nuchal translucency result with a couple in their thirties. The ultrasound test has indicated that the couple has an increased risk of having a baby with Down syndrome. The father asks how Down syndrome occurs. Christine checks with them to see if they understand the term 'chromosome' and neither partner is familiar with the term. Christine explains that chromosomes are small packages of genetic material and shows them a photograph of a karyotype that illustrates the 46 human chromosomes arranged in pairs. She tells them that the genetic material is like a book, with each chromosome being like a chapter that contains certain genetic information.
She then explains that a baby with Down syndrome usually has one additional chromosome, having three copies of chromosome 21 instead of two.

Training in counselling skills is beneficial to nurses and midwives to enable them to support patients (Hawkins and Hollinworth 2003, Street *et al* 2004). In the context of genetic health care, it is particularly helpful in enabling a nurse or midwife to explore the family's feelings about the condition and to facilitate decision making (Skirton and Patch 2002). Experiential learning is the most effective learning method, and basic communication and courses on counselling skills are accessible via colleges of further education or via NHS training departments. Individual, or group-based counselling supervision, provides an opportunity to share experiences and explore ways of improving care, in a safe and confidential environment.

Conclusion

In recognition of the need to prepare nurses who are fit for practice in the genetics era, the Department of Health has established the NHS National Genetics Education and Development Centre (www.geneticseducation.nhs.uk) to take a central role in co-ordinating education initiatives to promote the integration of genetics into everyday practice.

This article is an introduction to all who are faced with acquiring knowledge of genetics that is necessary for competent practice. The authors of this series hope that, in acquiring this information, readers will gain confidence in their contact with families and share some of their enthusiasm for clinical genetic practice **NS**

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