Suggested components of the curriculum for nurses and midwives to enable them to develop essential knowledge and skills in genetics

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Abstract Nurses and midwives need to develop specific knowledge and skills in genetics to enable them to offer appropriate healthcare in a range of non-specialist settings. Studies on the topic indicate that while nurses acknowledged the importance of genetics knowledge to their work, both their knowledge and confidence in using such information are poor. Despite the existence of competence

frameworks, it appears that educators have struggled with the need to integrate genetics into nursing and midwifery curricula. An expert workshop on genetics education was held to determine the essential components of genetics knowledge and skills that should be incorporated into the pre-registration nursing curriculum in European countries. In this paper we present the essential topics for nurse and midwife pre-registration education and suggest ways in which genetics might be incorporated into the nursing and midwifery curriculum.

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Introduction

It is now many years since healthcare professionals first started to discuss the need for nurses and midwives to develop specific knowledge and skills in genetics to enable them to offer appropriate healthcare in a range of non-specialist settings (Lea et al. 1998; Jenkins et al. 2001). However, genomics increases the opportunities for genetics to be utilised within mainstream healthcare, for example through the use of pharmacogenomics to inform medication type and dosage (Ferraldeschi and Newman 2011), and therefore, the requirement for nurses to have a working knowledge of genetics is urgent.

There are few studies where the genetic knowledge of nurses has actually been assessed (Godino and Skirton 2012). In a recent systematic review of studies on this topic, Godino and Skirton (2012) identified only six relevant studies, and in the majority of these, knowledge was assessed only via nurses' self-perceptions rather than by any objective measure. While nurses generally acknowledged the importance of genetics knowledge to their work, both their knowledge and confidence in using such information were self-reported as

Table 1 Essential skills, knowledge and attitudes of nurses

Relevant competence(s)	Skill, knowledge or attitude	Detailed learning outcome	Specific topics to be included in curriculum	Suggested learning tools
Identify individuals who might benefit from genetic information and services Recognise the limitation of one's own genetic expertise	Be aware of the potential for a disease or condition to have a genetic basis and act accordingly	The student should be able to: – Recognise potential importance of family history – Know from whom and how to seek advice or guidance about a genetic condition or risk – Know when and where to refer to genetic services.	Potential relevance of a family history of a disease or condition (linked to inheritance patterns, as below) Differences between inherited disorder and genetic susceptibility	Use pedigrees to demonstrate inheritance of genes Test understanding by giving sample pedigrees with affected persons or carriers marked but no conditions shown and ask the students to identify potential inheritance patterns (see Fig. 1)
Tailor genetic information and services to the individual's culture, knowledge and language	Communicate effectively with a patient with a genetic condition or genetic concerns	The student should be able to: – Feedback genetic information appropriately to the patient – Understand that different individuals may interpret risk figures differently The student should have: – An awareness of the potential psychosocial impact of a genetic condition on the family the student should be able to recognise the familial nature of genetic information – Develop the skills to listen to the family's concerns – Understand risks may differ between individual family members.	Possibility of preventive actions or treatment, using key examples (e.g. familial colon cancer, inherited cardiomyopathy) Profile and location of local/regional/national genetic services Communication skills	Ask student to identify the genetics service local to their current or most recent practice placement and obtain the contact details of the staff there Use genetics based scenarios in communication skills practice sessions (see Fig. 2)
Demonstrate knowledge of the role of genetic and other factors in health and disease	Approach care from a 'whole family' perspective		Sources of relevant and reliable genetic information Ethical issues on right to know or not know about one's genetic status Listening/communication skills	Hold a student debate on an individual's right not to know their own genetic information Arrange a meeting with families that have a genetic condition, ask them to share how the disease affects their lives
Obtain and communicate credible current information about genetics for self, clients and colleagues			Information on potential psychological impact on the family, for example, guilt, distress, anxiety	Invite a genetic counselor sharing their experience with families reactions to genetic diseases
Demonstrate knowledge of the role of genetic and other factors in health and disease	Have a knowledge of patterns of inheritance	The student should be able to: – Read a pedigree – Recognise and differentiate between inheritance patterns,	Understanding of basic risk assessment, based on Mendelian inheritance patterns (autosomal dominant, autosomal recessive and X-linked recessive) The importance of patients' communicating genetic information to families Description of different causes of genetic disease, specifically: – Chromosomal abnormality – Single gene mutation	Hold a student debate regarding the nature of genetic information (familial vs. personal) Using prepared pedigrees, ask students to calculate the risk for an affected offspring in each inheritance pattern

Table 1 (continued)

Relevant competence(s)	Skill, knowledge or attitude	Detailed learning outcome	Specific topics to be included in curriculum	Suggested learning tools
Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information	Be familiar with genomic structures	<ul style="list-style-type: none"> – Understand the concept of penetrance – Sensitively discuss risks with family <p>The student should have an understanding of:</p> <ul style="list-style-type: none"> – How DNA, genes and chromosomes relate to each other – How DNA mutations affect proteins 	<ul style="list-style-type: none"> – Mitochondrial mutation – Multifactorial condition <p>Understanding of basic risk assessment, based on Mendelian inheritance patterns (autosomal dominant, autosomal recessive and X-linked recessive)</p> <p>Communication skills</p> <p>Description of chromosomes, genes and DNA and how they relate to each other</p>	Compare normal DNA sequence to mutant, examine the effect on the protein
Uphold the rights of all individuals to informed decision making and voluntary action	Be aware of applications of genetic testing	<ul style="list-style-type: none"> – The student should have an understanding of: <ul style="list-style-type: none"> – Basic principles of genetic testing – Limitations of genetic testing – Ethical issues in genetic healthcare – Practical realities of testing – Informed consent for testing or sharing information with family members <p>The student should be able to: -access patient support group information for families</p> <ul style="list-style-type: none"> – Access reliable sources of practical (e.g. local services) and theoretical information 	<p>Transcription of DNA to protein structure</p> <p>Effect of a mutation on protein structure</p> <p>Describe different forms of testing and their applications:</p> <p>Karyotype</p> <p>PCR for purpose of production of multiple copies of DNA</p> <p>Sequencing</p>	Discuss the meaning of the type of mutation on the protein function
Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information				Use a case study involving request for a genetic test with implications for other family members. Unfold the story gradually, asking students to consider the options at each step
Obtain and communicate credible current information about genetics for self, clients and colleagues	Know where to access reliable sources of information		Information on how to access patient support groups	Discuss guidelines for reliable sources of information for families
			Guidance on reliable sources of genetic information, e.g. professional organisations, national databases	Set task to search for reliable websites for information on a particular condition of interest to the student (see Fig. 3)

Table 2 Additional curricular material for midwifery students

Competence	Topics	Suggested learning activities
Be able to offer antenatal genetic screening and genetic testing in an ethical manner	The concepts of antenatal genetic screening and genetic testing Informed consent Risk figures and probability Ethical issues re rights of mother, father and fetus	Ask students to practise explaining risk of Down syndrome to the fetus to parents in role play Present risks in different formats, ask students to vote on one they prefer
Ability to understand and explain chromosomal conditions that could affect the fetus	Non-disjunction Recombination Medical and social aspects of the conditions for which screening/testing is offered	Practice interpretation of screening tests for Down syndrome, using simulated test result reports
Ability to understand the implications of results of ultrasound investigations	Have an understanding of ultrasound findings, including the potential importance of soft markers	Ask students to investigate the meaning of soft markers found on ultrasound in a set of scenarios
Be able to care appropriately for pregnant women affected by a genetic condition	Introduction to conditions that could have serious deleterious effect on maternal health and outcome, e.g. Ehlers–Danlos syndrome, Marfan syndrome, skeletal dysplasia achondroplasia	Present case studies for relevant conditions. Present condition with signs and symptoms, ask students to determine how the condition might affect the woman in pregnancy and labour

poor. For example, in a Turkish study (Tomatır et al. 2006), a high percentage (96.4 %) of the 86 nurses who responded admitted they had insufficient knowledge about the genetic basis of disease. The majority (93.9 %) of the 162 Turkish nursing students recruited to a different study (Vural et al. 2009) indicated that they needed more education related to genetic diseases and genetic counselling. In a large Canadian study, Bottorff et al. (2005) used a series of five simple questions to assess overall genetic knowledge and found that only 35 % of nurses responded correctly to four items and a small minority (14 %) answered all five items correctly. Results such as these indicate that nurses may require further input on genetics in their undergraduate and postgraduate education programmes.

Although much of the work on improving the genetics knowledge of nurses emanates from the USA (Jenkins et al. 2005), authors in European countries (Kirk 2004; Romanelli et al. 2010) as well as in Asia (Kirk et al. 2011) have also stressed the requirement for nurses to become genetically literate. These calls have been supported by considerable work in defining the core competences in genetics required by nurses and midwives. For example, Kirk et al. (2003)

used a consensus approach involving all relevant stakeholders (including practitioners, professional organisations and patient support groups) to develop a set of core competences for use in the UK. Later, Skirton et al. (2010) published core competences in genetics for a range of health professionals working at different levels of care provision (primary, secondary and tertiary). These were designed for use in the European context and were approved by the European Society of Human Genetics.

Despite the existence of competence frameworks, it appears that educators have struggled with the need to integrate genetics into nursing and midwifery curricula (Kirk 1999; Hetteberg and Prows 2004). Studies show that while nurses may perceive the relevance of genetics to their work, they lack both knowledge and confidence to perform tasks related to genetics or genomics appropriate to their setting (Skirton et al. 2012). Competences and learning outcomes must be translated into components of the nursing curriculum to enable learning to occur, but until now, it has been left to individual nurse educators, who may not have experience in genetic healthcare, to interpret the competences and insert relevant topics into the curriculum. It

The student is given a number of three generation pedigrees with affected family members marked in the usual way (by shading the symbols for those with the condition). There is no disease related information on the pedigree; this ensures that students are forced to consider all possible inheritance patterns rather than making a guess based on what they may know of the condition. Students are asked which of the inheritance patterns COULD be applicable to this family, which are MOST LIKELY and which could not apply. They should give their reasons for their responses.

For example, if the students are given a pedigree in which individuals of both sexes are affected and offspring of both males and female family members have the condition, they would be expected to reason that mitochondrial inheritance was not possible. In another example, if the condition affected three successive generations of the family, students would be expected to realise that recessive inheritance was unlikely, except if there was consanguinity in the family.

Fig. 1 Learning tool to test understanding of inheritance patterns

In a communication skills practice session, ask the students to role-play scenarios that are relevant to genetic healthcare. Students take turns to play the 'patient' and the 'nurse'. This enables them to develop greater understanding of the patient's perspective as well as to develop listening skills, practise explaining genetic concepts and explore how to suggest referral to a specialist when necessary. Examples:

1. The patient has just been told that her son has a serious genetic condition (such as Duchenne muscular dystrophy). She asks the nurse working in the paediatric ward how this could have happened, given there is no history in the family.
2. The patient has been told he has bowel cancer and asks the nurse if his family history (his mother and grandfather were affected) could be relevant.
3. A mother talks to the nurse about her feelings of guilt concerning her new baby's diagnosis of Down syndrome.

Fig. 2 Learning tool for developing communication skills

therefore appears that it may be useful to define the actual skills needed by nurses more concretely and suggest ways in which these can be integrated into existing curricula.

Method

An expert workshop on genetics education was held in June 2011 and was attended by seven experts (all authors of this paper) in the field of health genetics education, drawn from four countries (UK, Turkey, Sweden and Israel). One of the objectives of the workshop was to determine the essential components of genetics knowledge and skills that should be incorporated into the pre-registration nursing and midwifery curricula in European countries. The work was based on the core competences developed by the EuroGentest project team and the European Society of Human Genetics Education Committee (Skirton et al. 2007, 2010). While there was much general agreement, at each step in the process, we continued discussion if necessary until a consensus was reached among the participants.

At the beginning of the workshop, we conducted a 'brainstorm' session to ascertain the types of knowledge, skill or attitude considered necessary for nurses and/or midwives at the point of registration, to ensure they were 'fit for practice' (Kirk et al. 2003). Although all participants were familiar with genetic nursing and midwifery competences previously developed (Kirk et al. 2003; Skirton et al. 2010), we used the brainstorm session to ensure that we did not inadvertently overlook any important topic. The session resulted in a list of around 40 diverse items including 'take a family history', 'explain what a mutation is', 'know the difference between a gene and a chromosome', 'meiosis', 'need for confidentiality' and 'take a family approach'.

The workshop attendees then examined each genetic competence for general nurses (Skirton et al. 2010), as these

are applicable for nurses who have completed a pre-registration educational programme. Each item generated during the brainstorming session was discussed in terms of fit with each individual competence. For example, participants suggested that in order to enable nurses to 'demonstrate the role of genetic factors in health and disease', they required an understanding of the basic inheritance patterns as well as awareness of the psychosocial impact of genetic disease on the family. A basic table was completed separating the knowledge, skills and attitudes and aligning these to each competence. Items considered only relevant to midwives were separated and included in a different table. We then worked in small groups to examine in detail the knowledge, skills and attitudes and align these to the learning outcomes published with the core competences (Skirton et al. 2007), before discussing each in the larger group. There was obvious overlap across some competences, for example acquisition of effective communication skills are required to satisfy a number of the competences, and we included it under each appropriate competence. Finally, we examined each item (knowledge, skill or attitude) and discussed how it might be taught as a topic in the nursing and/or midwifery curriculum.

The participants discussed whether it was more appropriate to organise the material under curriculum topics or under competences. We made the decision to organise the topics under each competence, in alignment with the previous work undertaken by EuroGentest and the ESHG Education Committee (Skirton et al. 2010). We felt it was important to emphasise development of nurses' competence rather than simply covering topics within an educational programme.

Finally, we used the teaching experience of the participants to develop a set of suggested educational tools/strategies to accompany the list of topics. Participants worked in small groups to examine each topic and to suggest tools for ensuring these could be taught within existing components

Students work in pairs or small groups. They are asked to choose a genetic condition relevant to their current phase of study and to imagine they have a person with that condition in their own family. They start by generating a list of questions they would like to ask about the condition. They then do an Internet search for information resources suitable for patients and their families and compare the information available with their own list of questions. The students are then asked to identify gaps. If time allows, students can be asked to design a resource for patients.

Fig. 3 Learning tool to help students learn to obtain reliable resources for families

of the curriculum. This exercise began during the workshop, but participants contributed other ideas to successive drafts of the document, the final version of which is presented here (Table 1).

Results

Table 1 includes information on the learning outcomes, curricular topics and suggested tools for use in nurse education programmes. In Table 2, additional material considered to be relevant mainly to midwifery students is included. The learning tools suggested were those that had been previously utilised by the workshop participants in their educational activities, and we have included more detailed explanation of three learning tools in Figs. 1, 2 and 3.

Discussion

Core competences in the field of genetics have been available for some years to guide nurse education, but have not been presented with a list of specific topics to guide learning and teaching in pre-registration programmes. This has required nurse educators, who may have little prior education or experience in genetics, to interpret the competences and convert them to topics for teaching. A substantial document on nurse competences was produced for use in the USA (Jenkins et al. 2005), and this did include some suggested strategies and a list of resources for nurse educators. However, the actual topics to be covered within the programme were not specifically defined. It may also be that the level of detail within the document may deter educators from taking steps to enhance genetics knowledge and skills in pre-registration nurses. The authors acknowledge that the nursing curriculum is already under pressure; it may be that educators believe including genetics topics would require considerable changes and allocation of scarce resources in terms of time.

Other authors have reported the teaching of genetics courses within specific modules such as biology (Shuster and Grossel 2011). However the genetics content cited by those authors appeared to be limited to scientific and technical material, with no reference to the psychosocial, ethical and family implications that are so relevant to nursing practice.

We would emphasise that providing genetics education using this list of topics does not require a specific module or set of lectures focussed solely on genetics. Rather, we believe that genetics and genomics are so fundamental to healthcare that it is preferable to embed these topics into appropriate areas across the entire nursing curriculum, as has been achieved by staff at the Cincinnati Children's

Hospital (Maradiegue 2008). Unlike many other aspects of nursing, genetics is relevant to every life stage and therefore should be addressed within neonatal, paediatric, adult and geriatric care. It encompasses both physical and mental health, while the family approach will be common to other areas of nursing such as primary care and community health. It is therefore more appropriate to use an integrated, rather than a stand-alone, approach by embedding genetics into the entire programme. It is possible to enable students to develop a sense of genetic healthcare through use of genetically based examples within other teaching, for example within sessions on communication skills, ethics, history taking and long-term care. In addition, providing resources that are reliable and accessible to students throughout the programme may make it easier for them to obtain material relevant to their current study programme and practice experiences. One such example is provided by the University of Nottingham School of Nursing and Academic Division of Midwifery (<http://www.nottingham.ac.uk/nursing/genetics/>) where a dedicated webpage ensures that genetics is accessible to students. Other websites such as 'Telling Stories: Understanding Real-Life Genetics' (Kirk et al. 2011) have been specifically designed to support educators, students and practising nurses and midwives to develop their understanding of genetics through the vehicle of genuine patient stories.

These suggestions have been made by experienced practitioner nurse educators in the field of genetics and were based on existing competences. However, the working group was small and included members from only four European countries. We would welcome further comments and input on this topic from other educators.

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