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## **Genetics, ethics and education: considering the issues for nurses and midwives**

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The rapid advances and scope of the Human Genome Project bring into sharp focus the relevance of genetics and ethics for nursing and midwifery practice in the new millennium. This article offers a UK perspective on how education plays a crucial part in preparing practitioners to integrate clinical advances effectively and ethically, yet may be failing in this role. Provision for teaching genetics in the UK has been found to be largely inadequate and the ethical complications of this are reviewed. The context of genetics teaching is a further issue. Genetics is classified in the bioscience component of training courses in nearly 70% of UK nursing colleges; this may be of significance in its perceived relevance to practice. Finally, the ethical issues around the teaching of genetics will be discussed. Educators who are involved in delivering the genetics component of the curriculum are under an obligation to consider how learning is best achieved and how the delivery itself should be 'ethical'.

### **Introduction**

Much has been written about the implications of the Human Genome Project for health care and society in the new millennium. Clear statements have been issued about how advances in genetics, in combination with developments in technology, will impact on health care, leading to:

- A new disease taxonomy;
- Greater understanding of environmental risk;
- Decentralization of gene testing;
- Genotype-guided health management;
- A new pharmacopoeia for all diseases.<sup>1,2</sup>

Details of the scale and pace of innovation are debated, but there is broad agreement that developments in the first half of the new century, in what Kaku terms the 'third stage' of medicine - molecular medicine - will bring profound changes in health care.<sup>3</sup> Although more will be learned about the single-gene conditions, the characterization of the genetic components of common disorders will provide insight into the basic mechanisms of disease and information on targets for novel therapeutic interventions. By screening populations, opportunities will also be created to identify individuals at high risk of disease. Integrating this new knowledge into practice poses a major challenge for health professionals.

Ethical, legal and social dilemmas are also being created, and the 'very reductionism to the molecular level that is fuelling the medical revolution also poses the greatest moral challenge we face' (p.241).<sup>3</sup> Advances in information technology impact synergistically on these challenges, by

enhancing the ease with which volumes of information may be stored, accessed and shared electronically.

Genetics has been described as possibly ‘the most powerful example yet’ of how technological advances drive organizational changes in health care.<sup>4</sup> Nurses and midwives entering into professional education now will face major ethical problems in genetics<sup>5</sup> and experience unparalleled developments before they reach retirement. Midwives already frustrated at the medicalization of pregnancy may take further issue with its ‘geneticization’ and may experience personal conflict with attitudes to prenatal testing. Testing a fetus for a severe genetic condition may not be questioned, but what about testing for less severe conditions of adult onset, or for nonmedical characteristics? How will midwives adjust to individual clients’ wants and values? Nurses involved in testing and screening for predisposition to genetic conditions may feel uneasy about the appropriateness of testing and its impact on patients and other family members, particularly in the absence of any treatment options. How can they best protect patients from unwanted or unsolicited disclosure? The possibility of third-party access to information may also conflict with nurses’ role in maintaining privacy and confidentiality. The issue may present little of a dilemma if the ‘third party’ is not personally affected by being denied access to genetic information about an individual. However, the situation can become more problematic when a patient does not wish to share with other family members a test result that has clear implications for them or their offspring.

The potential impact of primary care has also been examined, with many authors identifying this setting as the most appropriate for the delivery of certain genetic services, despite concerns about how existing practitioners might cope with the anticipated increase in demand for genetic information.<sup>6,7</sup> Practitioners at primary care level will play a key role in the assessment and management of genetic risk, integrating ‘genetic thinking’ into routine practice. The involvement of practice-based nurses, midwives and health visitors in this has been acknowledged in the UK.<sup>8</sup> A comprehensive role for nongeneticists in delivering genetic services at the primary care level has been defined, although most health care providers have had limited training in genetics.<sup>9</sup>

It is against this backdrop that we have to reflect on why education is failing to equip nurses and midwives with the knowledge and skills needed for practice in this emerging era of ‘molecular’ medicine. Numerous authors, over a 30-year period, have called for genetics to have a higher profile in nursing and midwifery education as part of initial training and of continuing professional development, yet acknowledgement of the inadequacy of genetics education continues.<sup>10-12</sup> Is this because the call for enhanced genetics provision is seen by educationalists, who are already trying to juggle an overcrowded curriculum with other competing priorities, as yet another case of specialist pleading, or is it the case, as stated recently, that many health professionals outside of genetics consider that it is not relevant to most health care?<sup>9</sup>

This article sets out to examine the genetics education of nurses and midwives in the UK, paying attention to ethical considerations around the provision, context and delivery of teaching. In exploring some of these issues, an attempt will be made to identify how and why education may be inadequate, and to offer some suggestions to address this. In particular, it will argue that education is failing because it is not addressing adequately the broader implications of genetics, especially the ethical and social issues. The issues discussed may be of relevance to nurse education systems in other countries, but this article focuses on nursing and midwifery education in genetics in the UK.

### **Provision for genetics education**

There is little doubt that genetics will have a fundamental impact on individuals, health and society. A survey of all educational establishments offering diploma-level training courses in the UK sought for opinions about the impact of genetics on health and education.<sup>12</sup> A questionnaire was sent to all programme managers for adult, child, mental health and learning disability prequalifying nursing courses ( $n=238$ ), asking for information about provision for genetics education at their college and about their attitude to genetics. The response rate was 84%. A similar questionnaire was sent to programme managers for diploma-level midwifery training courses ( $n=32$ ; response rate 91%).<sup>13</sup> The majority (81% of nurses responding, 69% of midwives) agreed that advances in genetics would have a major impact on health care within five years, and that genetics education would become an increasingly important issue for nurses (81%) and midwives (76%).

An analogy often used likens the impact of genetics to that of a tidal wave, but this is misleading. The genetics revolution is not something that will happen overnight, confronting us suddenly with a wealth of genetic information and a bewildering array of gene tests. More likely, there will be a gradual increase in the availability and use of genetic testing. This makes it more important that educational programmes should be in place now and be sufficiently flexible to adapt to new information so that advances in genetics may be integrated into practice effectively and efficiently. Of equal importance is that this education should equip health professionals with sufficient knowledge and critical skills to participate in debate on the applications of new genetic technologies and to comment vigorously on controversial issues.

One concern arises where new tests may be ‘bolted on’ to existing tests or screening programmes without having an educational framework in place to prepare adequately the health professionals involved in obtaining informed consent from clients. Such health professionals may be at risk of practising outside their code of conduct.

The *Code of professional conduct* for nurses, midwives and health visitors in the UK states that each should act at all times to:

- Safeguard and promote the interests of individual patients and clients;
- Serve the interests of society.

Further, it states that each must:

- Ensure that no action or omission on the part of the professional is detrimental to the interests of the clients (clause 2);
- Maintain and improve professional knowledge and competence (clause 3);
- Acknowledge any limitations in knowledge and competence and decline any duties or responsibilities unless able to perform them in a safe and skilled manner (clause 4).<sup>14</sup>

Advances in genetics will challenge practice in all of these areas. Professionals will have to acquire and integrate new knowledge and skills into their practice such that clients’ interests are protected, with due consideration given to privacy and confidentiality and without undermining the interests of society. Without appropriate provision for education in genetics, will nurses and midwives be able to practice ‘ethically’ in this new decade?

An advisory panel of UK nursing experts from the fields of education, genetics, practice and policy was convened for two days in November 1998 at Cardiff, to review the future of genetics in nurse education.<sup>15</sup> The panel agreed that nurses were not being adequately prepared to meet the existing or future needs of patients, and that there was an urgent need to address this. A number of obstacles to the provision of genetics education were outlined, together with a series of recommendations to

overcome these. Other studies have indicated that midwives lack confidence in supporting women who are undergoing serum screening for Down's syndrome, and conclude that unless midwives are well informed, it is unlikely that women will be adequately supported during pregnancy.<sup>16,17</sup> Deficits in midwives' knowledge and understanding of antenatal screening, which may adversely affect the quality of care, have been identified by other authors,<sup>18</sup> with one survey carried out by the National Childbirth Trust revealing that 36% of women said that they needed more information, and 19% felt that they needed more support.<sup>19</sup>

Thus, there is mounting evidence of the knowledge deficit in genetics and further concern has been expressed that the disparity between educational provision and the knowledge needed will worsen unless improvements are made.<sup>9</sup> It is also important that developments in genetics education are considered and realistic.

Education providers need to work in collaboration with clinicians to identify what levels of knowledge and which skills are required for the different levels of practice and in different settings. The Welsh Strategy for Nursing identifies that new skills in ascertainment, treatment, care and counselling will be required,<sup>20</sup> but these must be made more explicit.

It may be helpful to use the Nursing Constant as the framework for developing provision that remains relevant to the core values of nursing<sup>21</sup>; the work of the nurse includes:

- 1) A co-ordinating function;
- 2) A teaching function, for carers, patients and professionals;
- 3) Developing and maintaining programmes of care;
- 4) Technical expertise, exercised personally or through others;
- 5) Concern for the ill, but also for those currently well;
- 6) A special responsibility for the frail and vulnerable.

The levels of knowledge or expertise appropriate for each function identified in the Nursing Constant would vary according to the level of practice; this could be reflected in the educational programme. For example, in carrying out a co-ordinating function, nurses may need to have the knowledge and skills for the collection and maintenance of family records or genetic registers. The teaching function requires sufficient understanding to convey technical information effectively and sensitively, as appropriate to the role of the nurse. The level of technical expertise may vary from an awareness of the referral pathways for patients at different levels of risk to an in-depth knowledge of genetic counselling. The final two functions (points 5 and 6), when applied to the issues around genetic testing and the advocacy role of the nurse, indicate the need to incorporate an awareness of ethical issues into educational programmes.

Scott argues that education should go beyond the acquisition of scientific knowledge and the relevant clinical skills, and also promote moral sensitivity.<sup>22</sup> Given that areas of practice that incorporate genetics involve sensitive issues such as decision making around prenatal testing, this is particularly relevant. Her point is in agreement with Fairbairn's contention that ethical practice demands not only knowledge of ethical thinking but also the ability to empathize with others.<sup>23</sup> This quality is surely essential to support decision making and in situations where decisions may have to be made on behalf of those who are unable to do so themselves. Supporting informed decision making is central to the process of genetic counselling.

One of the obstacles to reforming the provision for genetics education has been suggested as competition for curriculum space.<sup>15</sup> The difficulties of competing priorities must be acknowledged, but provision could perhaps be enhanced by considering two approaches.

First, there may be the potential to revise curriculum content without extending the curriculum hours already allocated. In the survey of colleges of nursing and midwifery in the UK, programme managers were asked to indicate which topics from a list provided were included in their genetics curriculum.<sup>12,13</sup> No respondents identified any topics that were additional to the list. The results are summarized in Table 1. Currently, the emphasis within the preregistration curriculum tends to be very much on the ‘traditional’ genetics topics and less so on the ethical and societal issues.

**Table 1** Genetics content of diploma-level preregistration nursing<sup>12</sup> and midwifery<sup>13</sup> training programmes

Topic	% courses including topic	
	Nursing ( <i>n</i> = 142)	Midwifery ( <i>n</i> = 29)
Genetic basis of disease	94	90
Inheritance patterns	92	97
Ethical and legal issues	69	83
Genetic counselling	65	93
Social issues	45	59
Professional issues	36	62
New genetics	35	56

Secondly, introducing a meaningful assessment to endorse learning may go some way to raising the profile and perception of the relevance of genetics to nursing and midwifery. In the UK, assessment means a formal, objective examination of an educational programme, while evaluation is the process of seeking students’ views on the strengths and weaknesses of a programme of study. Only a minority of nursing (25%)<sup>12</sup> and midwifery (14%)<sup>13</sup> diploma-level training programmes in the UK have a compulsory assessment that includes genetics, with approximately half of these taking the form of multiple-choice questions. It is perhaps unrealistic in these circumstances to expect students to place a high priority on learning about genetics.

In my experience, continuing education courses for nurses and midwives cannot assume any knowledge in genetics upon which to build learning. Whether this is due to a lack of teaching or a lack of learning is unclear but, in either case, the limited teaching time is thus compromised. Introducing appropriate strategies to assess competencies in the key skills may promote teaching and learning. In the absence of serious assessment, it is difficult to evaluate genetic knowledge and to monitor how education in genetics can facilitate nursing and midwifery practice within an ethical framework.

### **Genetics: the curriculum context**

The need to refocus on the place of genetics in the nursing curriculum has been identified.<sup>15</sup> Most diploma-level nursing and midwifery training courses in the UK place genetics within the bioscience component of the curriculum; although a minority also include it with ethics, the majority classify genetics solely within bioscience.<sup>12,13</sup> Yet the aspect of genetics that poses the greatest challenge is not in the science itself but in the application of the science: the ‘art’ of genetics, and what Pesut refers to as ‘health genetics’.<sup>24</sup> He states that the art of genetics requires clinicians to use ‘intuition and experience to build meaningful relationships with clients who struggle with the consequences and choices health genetics creates’. That nurses and midwives face ethical dilemmas in this respect has already been indicated.

Faced with this, we should question if it is desirable or even sensible to deliver genetics teaching initially from a bioscience base within the curriculum. The advisory panel reviewing genetics education in UK nursing programmes identified the low status of science, and the lack of scientific

literacy of students and educators, as a major obstacle to reform.<sup>15</sup> The absence of any clear assessment strategy for the majority of colleges in the UK indicates that, although the emphasis may be on teaching the science base of genetics, such knowledge is not considered to be essential.

We would take this question further and ask, given the competing priorities, are we best serving clients at all by teaching genetic science at preregistration levels? If, by focusing on the science, we run the risk of ‘switching off’ nurses and midwives to genetics (and this is perhaps more likely if resources limit the ability to teach applied genetics), would it not be better to leave Mendel to postregistration education and deliver ‘accessible’ genetics that would be perceived as nonthreatening and more interesting? This is most emphatically not to undervalue science, or to ‘write it off’ in the curriculum, but to consider alternative approaches to integrate genetics more substantially into nursing education, introducing scientific concepts as professionals progress through their career.

Perhaps teaching the history of eugenics, for example, would form a more useful foundation for an appreciation of the role of genetic counselling and the significance of concerns about the implications of developments in genetics for society. As a scientist and nurse I have come reluctantly to this conclusion, after years of being approached to ‘do an hour or two on genetics’ in which I am asked to cover the ‘biopsychosocial aspects’. The allocated time (and the majority of courses in the UK allocate 10 hours or less to genetics over three years<sup>12,13</sup>) invariably falls within a bioscience module where the emphasis is on science. In such circumstances, it is arguably more productive to ignore the molecular science and DNA and talk about what ‘genetics’ may mean for families, society and health professionals, in the hope that students may gain greater insight into the relevance of genetics to health, and seek further information. Stimulating interest in this way may help to develop a firmer foundation on which continuing education courses can build a more ‘balanced’ knowledge base, incorporating appropriate scientific knowledge. This approach could perhaps be revised if resistance to science declines.

It has been suggested that genetics needs to be taught as a cross-curricular subject at all levels of practice and education.<sup>9</sup> Integrating bioethics training into this may bring further benefit.<sup>25</sup> Changing the focus of genetics within the prequalifying curriculum, from a science base to an ethics base, may also help to improve nurses’ attitudes to the relevance of genetics. It is interesting to note that in nursing courses in which genetics is placed in both the ethics and the bioscience curricula more time is allocated to genetics.<sup>12</sup> This may be accounted for in part by what Lützén describes as the revitalization of ethics in education, precipitated by rapid advances in medical technology.<sup>5</sup> This increased focus on ethics has more recently been noted by Webb and Warwick in their discussion of appropriate strategies for teaching moral philosophy to nurses and midwives.<sup>26</sup> Their comments on the difficulties of introducing a relatively new discipline into the curriculum, and the need to consider the style of learning that may be required, could be applied to genetics. Certainly, the status of ethics has come a long way since Johnson’s scathing comments on the quality and perception of the place of ethics education in nurse training.<sup>27</sup> He suggested that nurses were prepared inadequately in ethical decision making, with some nurse teachers focusing on etiquette rather than ethics.

### **Teaching genetics: ethical delivery**

Greater recognition of the place of ethics in ‘health genetics’ education may also encourage reflection on the obligations of educators, particularly on the issues that those with responsibility for delivery should consider. Three key issues will be discussed here: the need for awareness of the constraints on teaching genetics; the need to consider how to encourage learning about genetics; and how the teaching approached themselves must be ethical.

### **Constraints on delivery**

The availability of and access to resources are key deficits in educational provision.<sup>15,28</sup> Central to this is the availability of teachers with both subject knowledge and relevant clinical experience. Most lecturers with responsibility for genetics teaching on preregistration nursing and midwifery courses in the UK do not have appropriate qualifications in genetics.<sup>12,13</sup> They are then further constrained by a lack of teaching resources, particularly those with a nursing or midwifery focus. This leads us to question the extent to which those who are teaching genetics are able to relay empathetically the impact on families of having, or being at risk of, a genetic condition, and have sufficient awareness, underpinned by scientific knowledge, to appreciate the implications for society. More importantly, it also behoves us to ask what support needs to be offered to lift the constraints placed on delivering current, relevant, practice-based courses. It may be that support is required in providing resources to address time constraints on the curriculum, or to provide access to expertise, particularly to nurses and midwives who are practising in clinical genetics. It could be that the first step, however, is to educate those with responsibility for commissioning, developing or delivering educational programmes about the relevance of genetics.

A further constraint on delivery may accompany a lack of confidence in genetics. Lecturers who may already feel vulnerable may be reluctant to acknowledge that they 'don't know' the answer to a query raised by students, even though, particularly in relation to decision making and ethical dilemmas, there are not necessarily any right or wrong answers. This may limit the scope of the interaction between lecturers and students.

### **Facilitating learning**

There is a dearth of literature on effective methods of teaching genetics. The majority of nursing and midwifery courses employ two approaches, lecture and seminar, with 32% and 34.5% respectively including case studies.<sup>12,13</sup> When viewed in the context of a focus on traditional science-based genetics topics and limited teaching time, it is difficult to see how such approaches can enable nurses or midwives to meet the ethical questions that are likely to arise in practice. The literature on teaching ethics may provide some relevant inspiration on approaches to teaching genetics. Durgahee describes a study based on the philosophy that nurses can learn ethics from the experience of clinical practice, incorporating reflection with story telling.<sup>29</sup> Sellman argues that method is less important than content as long as discussion and debate are stimulated and moral questioning is encouraged.<sup>30</sup>

The disadvantages of separating ethics teaching from real life have been identified.<sup>30</sup> Tschudin and Hunt stated that 'ethics education needs to be grounded in practice and the moral difficulties of nurses in their everyday lives'.<sup>31</sup> This approach was further supported by Lützn, who argued that ethical decision making about real-life genetics issues may not be reduced to abstract, ethical theories. She acknowledged the need for a context-sensitive approach, particularly cultural sensitivity.<sup>5</sup> Parker recommends a case-orientated approach, at the same time noting that more attention should be paid to the importance of systematic and institutional factors.<sup>25</sup> These authors indicate firm support for using case studies; perhaps frequent use of these should be made in the genetics curriculum.

The importance of developing empathy in dealing with genetic issues with clients has been mentioned. Fairbairn outlines three approaches that may be used to promote empathy: drama, simulation, and storytelling or narrative.<sup>32</sup> The use of narratives in teaching ethics has also been documented. Narrative ethics is said to offer meaning, context and perspective, is often memorable and encourages reflection.<sup>33</sup> Storytelling itself is a powerful communication tool that has been used

for centuries. Using narratives allows the stories of other people involved in a situation to be heard while recognizing the primacy of the patient's story.<sup>34</sup>

Fairbairn and Mead have outlined an approach to teaching ethics to nurses that focuses on the experience of moral problems.<sup>35,36</sup> They used storytelling not only as a teaching method but also as a therapy in helping nurses to come to terms with their experience of a moral dilemma. In a later article, they propose that beginning with student's experiences may be more effective in teaching ethics than commencing with a discussion of ethical concepts and theories.<sup>37</sup> They describe how 're-storying', when students are asked to rewrite a story from another's perspective, can help to promote empathy.

Anderson has further extended this approach in her powerful argument in support of the use of story-telling for the development of holistic practice by genetics nurses.<sup>38</sup> She conceptualizes the relationship between genetic nursing practice, holism and storytelling, and examines the benefits of practising within this theoretical framework. Storytelling is considered to make a critical contribution to holistic practice in genetic counselling by promoting personal empowerment and in helping storytellers to understand how their personal values influence why one course of action is chosen over another. Self-awareness is central to a practice that promotes autonomous decision making. Furthermore, storytelling helps genetics nurses to counteract reductionism by placing genetic information within a holistic framework. Anderson's approach is of clear relevance to the notion that narrative ethics is a useful method for teaching genetics to nurses at all levels of practice.

### **Ethical teaching approaches**

Very little has been written about unethical teaching behaviours and the potential for harm to students, although the concept of an educational intervention possibly harming students is not new. Rich and Parker identified potential harm to students who were utilizing reflection and critical incidence analysis as tools in education to facilitate the integration of theory and practice.<sup>39</sup> They emphasized that thorough curriculum planning and explicit preparation of both staff and students were needed before introducing such an approach. In the absence of good support systems for staff and students, and without knowledge of students' past experiences, they warned against using these tools. Other authors have urged similar caution in the use of storytelling techniques.<sup>36</sup> The need for caution and planning in curriculum development and delivery may be equally applicable in teaching genetics, particularly with interactive approaches that encourage students to examine their own chromosomes, identify their blood group, or study their family history. Something as apparently harmless as tracing a dominant trait through close family members may be inadvertently revealing, and taking a family history may provide a strong indication of a high risk of a genetic condition.

Not unrelated to this is clinical surrogacy, which is familiar to many lecturers who, after a teaching session, find a number of anxious students seeking consultation on the clinical topic just covered. Some may feel unable to approach the lecturer and go away, possibly to worry about the implications of the information for themselves or their family. Educational programmes need to be sensitive to students' concerns about existing and potential genetic conditions, or to the possibility that the content of the programme may reveal a hitherto unknown risk. It is clearly important for students' well-being that the lecturer is comfortable and competent in dealing with this situation, particularly as most students will be less familiar with the framework and referral pathways of the clinical genetics services and may be unaware that they can seek expert advice. The need to preface a teaching session with information of this kind is axiomatic, but less apparent to new teachers, or those outside the discipline.



Finally, in discussing the multitude of ethical issues that arise from the potential application of new genetic knowledge, for individuals, families and society, the lecturer needs to be aware of his or her own ethical values and to be sensitive to those of the students. To do less violates respect for the students. Self-awareness is a prerequisite to delivering an honest and balanced account of issues. Many nurse teachers and most, if not all, genetics nurses will have had some training in counselling, which would include development in self-awareness. This is less likely for lecturers from other disciplines outside health care.

## Conclusion

If genetics education was delivered at prequalifying level as an integrative discipline, rather than as a science, perhaps the continuing call for an improvement in genetics education might have abated. Instead, we could be focusing more on developing the evidence base for the skills and knowledge needed for all levels of practice. In his brief commentary, Pesut challenges the professions to fuse the science and art of health genetics into a practical science.<sup>24</sup> Perhaps we should consider this suggestion and explore the implications of teaching genetics as a skills-based applied subject. In addition, we could explore in greater depth the ethical dilemmas that nurses and midwives may face, both personally and professionally, with the application of new genetic technologies.

In the UK, the millennium has been ushered in with a flurry of reports that indicate that nursing and midwifery must once again revise their educational strategies, with greater emphasis being placed on clinical competence.<sup>20,40-42</sup> A common goal of the modifications proposed is to produce practitioners who are able to adapt to the changes in health care that the technological advances of the new millennium will bring, to deliver a high quality of service for all. We need to seize the opportunity to revise the place of genetics in educational programmes so that it may be integrated meaningfully and competently into practice. The ethical implications of not doing so will become increasingly evident.

This article has focused on the genetics education of nurses and midwives in the UK. There may be common issues that other countries are struggling similarly to resolve. It could be that genetics education is not seen as a priority by many, or some may have well-developed systems in place. Any opportunity to learn from nursing systems in other countries, and to share with colleagues, both in the UK and elsewhere, knowledge and experiences in developing appropriate and effective educational policies is to be welcomed.

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