Clinical practice in medical genetics

Recommendations for Education and Training of Genetic Nurses and Counsellors in the United Kingdom

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Abstract

Genetic nurses and counsellors work as part of the professional team providing clinical genetic services from regional centres in the United Kingdom. The education and training needs of genetic nurses and counsellors have not previously been formally identified. The guidelines presented have been devised to equip practitioners to fulfil their professional role as defined in a previous study, by identifying objectives, educational pathways, and means of assessment. While academic courses provide an essential framework, experiential learning in a clinical setting is also considered a vital component of the preparation for practice.

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In addition, the establishment of a Master of Science (MSc) course in genetic counselling has provided an alternative pathway to practice. There have been no statutory or generally recognised training requirements for specialist genetic nurses/counsellors; therefore each practitioner has received training dependent upon individual interest and motivation, and the resources and interest of the managers responsible. Both clinical genetics and nursing have altered enormously over the past decade, and this ad hoc approach to professional training is inadequate. In North America, genetic counsellors have developed a formal accreditation process using practice based competencies.²

Based on the previous study, the training and education of genetic nurses and counsellors must equip the practitioner to undertake the following aspects of practice.

Direct client contact

Preclinic contact to take a history and pedigree, give general information about the condition and the genetic service, and elicit the client's concerns.

Clinic consultation in conjunction with a doctor.

Nurse/counsellor consultation to give information, arrange tests, give results, arrange family studies.

Postclinic contact to reinforce information, provide support during decision making, or provide continuing contact as appropriate.

Client counselling, particularly at times of crisis, decision making, or after a new diagnosis has been made.

Education

Provision of education and training for colleagues in the health and social services.

Research

Initiation of research.

Collaboration with research led by colleagues.

Assessment and use of research findings for good practice.

Within the United Kingdom, clinical genetic services are provided by regional units as part of the National Health Service. The professional team providing the service generally consists of consultant doctors in clinical genetics, genetic nurses/counsellors, doctors training in genetics, and administration staff. Each unit may operate differently according to historical background, managerial style, and composition of the team. During 1994, discussion about the developing role of genetic nurses prompted the Association of Genetic Nurses and Counsellors (AGNC) in the United Kingdom (UK) to convene a working party to investigate the practice and role of genetic nurses and counsellors.¹

The report on the role and practice of genetic nurses and counsellors indicated that there was sufficient common ground between individual centres and practitioners to devise a set of training and educational guidelines. The decision to produce educational guidelines coincided with the initiatives by the United Kingdom Central Council (UKCC), the statutory regulatory body for nursing practice within the UK, to formalise requirements for specialist nurse practice in all areas of health

Table 1 Core recommendations for the education of genetic nurses and counsellors

Objectives	Educational recommendations	Means of assessment
A Counselling		
Establish an appropriate relationship with the client to facilitate the genetic counselling process	Basic accredited counselling training of at least 120 hours duration (Level 1: Counselling and Psychotherapy Central Awarding Body)	Supervised practice (Observation of practice in 20 cases either in clinic or home visit situation and supervision of 10 cases with feedback) Ongoing clinical supervision
Elicit and interpret client concerns		A reflective professional diary may be used as a focus for self-evaluation and supervision
Evaluate the psychosocial history and respond to client need appropriately		
Facilitate decision making		
Support appropriately through difficult situations		
Recognise and maintain professional boundaries		
Use professional supervision		
Refer clients to other agencies as appropriate		
B Genetics		
Before appointment		
Demonstration of aptitude for understanding of bioscientific concepts, by relevant first degree/academic record.		
Ability to:	Academic course (at level 2 (Diploma) or above) with significant human genetics component	Portfolio of evidence (such as case logbook)
Understand and interpret complex genetic information and apply to individual clinical situations	Observing clinical practice	Supervised practice
	Attendance at relevant conferences Ongoing personal study Structured clinical training in Department Relevant laboratory experience	Academic qualification
C Education		
Ability to:	Relevant course in adult learning (such as the Postgraduate Certificate of Education, ENB 998, or ENB 730 course)	Formal and informal feedback from clients
Effectively communicate genetic information to clients, appropriate to their individual needs		Written evaluation by professionals
Provide professional education on genetics	Supervised clinical and teaching experience	Clinical audit Clinical supervision
D Research		
Ability to:	First or higher degree incorporating research component	Should be evident before appointment
Demonstrate awareness of methodological and ethical issues surrounding research		Written evidence
Search for, and critically analyse, relevant published reports		Supervised practice
Apply research findings to clinical practice		
Contribute to research activity of genetics community		

Psychotherapeutic counselling

Psychotherapeutic counselling for issues related to the genetic condition in the family offered by some centres.

Administration

Administrative and managerial tasks in the department.

The prepared guidelines have been based on the findings of the AGNC study on nursing practice, which included the opinions of medi-

cal colleagues in clinical genetics, as well as current publications on specialist nurse practice and guidance from the statutory body governing the profession. After preparation of a draft by the AGNC Working Party on Education and Training, the opinion of members of the AGNC was sought, by means of an open workshop. Following revision, the draft was circulated to all members for further opinion before the final document was produced. This is, therefore, a document which represents the views of the entire membership of the AGNC. Recognising the differences in style between regional departments, the guidelines are not intended to be prescriptive, but to offer a pathway for professional development. They emphasise the core competencies considered essential for practice and acknowledge that these may be achieved by different educational pathways. The guidelines (table 1) consist of (1) specific knowledge or skill requirements; (2) the educational or training path recommended to achieve them; and (3) an appropriate means of assessment.

The study findings clearly indicated that genetic nurses fulfil the criteria defining specialist nursing practice published by the Royal College of Nursing³ (RCN) and reviewed more recently by the UKCC.⁴ According to the RCN, specialist nursing practice includes expert clinical practice, consultation, teaching, management, and research, the preparation for which must include both a graduate education and extensive experience. While higher education may equip the nurse with a scientific knowledge base and critical thinking skills, experiential learning will assist the development of the professional competency described by Benner⁵ as know-how. Benner is convinced that while academic education provides the necessary theoretical underpinning to practice, the higher skills can only be obtained through extensive practical experience within the field. Observation of good practice by other skilled practitioners, and reflection on personal practice is part of the experiential process. Humphris⁶ considers that the specialist role is one which enables the humanitarian concerns of patients to be considered "in the face of increasing technology", an issue of exceptional relevance in the field of clinical genetics. Schon⁷ divides clinical practice into two distinct zones, the technical aspects of care, and the more nebulous areas of human response and interaction. The genetic nurse/counsellor needs to be able to operate effectively in both spheres, to understand and explain the complex genetic information, and to deal sensitively and appropriately with the human response. The psychosocial issues can only be adequately addressed if training has included supervised clinical experience over a sufficient period of time, and where feedback and reflection is sought and given. The team structure in clinical genetics lends itself to the use of mentors, which facilitates this process.

At present, there are a number of practitioners in clinical genetics who will have achieved the necessary skill and knowledge to practice

by means of many years of clinical experience, and their expertise is acknowledged. While these recommendations define a foundation level of skill commensurate with safe practice, it should be recognised that some practitioners have expertise, knowledge, and responsibility which advances the boundaries of practice. Consideration needs to be given to the development of an appropriate career structure in this speciality. The AGNC endorses the increasing emphasis on professional accountability of all practitioners. Genetic nurses and counsellors have both a right and a responsibility to ensure that their educational preparation is appropriate to enable them to deliver an excellent standard of patient care.^{4 8 9} Discussion and comment from our clinical colleagues is invited.

- 1 Skirton H, Barnes C, Curtis G, Walford-Moore J. The role and practice of the genetic nurse: report of the AGNC Working Party. *J Med Genet* 1997;34:141-7.
- 2 Fine B, Baker D, Fiddler M, and ABGC Consensus Development Consortium. Practice based competencies for accreditation of and training in graduate programs in genetic counseling. *J Genet Couns* 1996;5:113-21.
- 3 Royal College of Nursing. *Specialities in nursing*. London: Royal College of Nursing, 1988.
- 4 United Kingdom Central Council for Nursing, Midwifery and Health Visiting. *The future of professional practice - the Council's standards for education and practice following registration*. London: UKCC, 1994.
- 5 Benner P. *From novice to expert*. New York: Addison-Wesley, 1984.
- 6 Humphris D. *The clinical nurse specialist*. Chapter 1. Basingstoke: Macmillan Press, 1994.
- 7 Schon DA. *Educating the reflective practitioner*. San Francisco: Jossey-Bass, 1987.
- 8 United Kingdom Central Council for Nursing, Midwifery and Health Visiting. *Code of professional conduct*. London: UKCC, 1992.
- 9 United Kingdom Central Council for Nursing, Midwifery and Health Visiting. *Scope of professional practice*. London: UKCC, 1992.