Genetic Counselling

About Cancer Genetics in the UK and the Role of the Consultant Genetic Counsellor

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Introduction
Over the last 15 years, recognition of the role of family history on cancer risk and the identification of genes conferring a high risk of certain cancers has resulted in a huge increase in the number of patients referred for genetic counselling regarding their risk of cancer. In consequence, genetic counselling in cancer has become an increasingly large part of the work of genetic counsellors (GCs) across the UK with a growing number of GCs developing specialist expertise in cancer genetics. This article will discuss the role of the GC in cancer genetics within the UK, and the role of Consultant Genetic Counsellor in Cancer Genetics at the South Thames Regional Genetics service based at Guy’s and St Thomas Hospital NHS Foundation Trust in London.

Background
Genetic counselling is ‘a communication process which deals with the human problems associated with the occurrence, or the risk of an occurrence, of a genetic disorder in the family’ (1). The central components of the role are to educate and inform clients about their genetic condition in a non-directive manner; provide support and help with coping and to facilitate informed decision-making.

Prior to the mid 1990s, the study of genetic predisposition to cancer was largely confined to the rarer cancer family syndromes. However, it had long been recognised that many common types of cancer show a tendency to run in families. Identification of the BRCA1 gene (2) in 1995 and the BRCA2 gene (3) in 1996 were important developments in understanding the significance of breast cancer family history and the risks associated with a genetic predisposition. Many more cancer predisposing genes have subsequently been isolated, leading to a greater understanding of the aetiology, risk and management of cancer. As a result of these advances, there has been a huge increase in awareness of the significance of family history amongst the general population and, in consequence, referral to genetics services now constitutes at least half of clinical genetics activity in the UK.

The role of the Genetic Counsellor in cancer genetics in the UK
There are 23 Regional Genetics Centres in the UK with many of these running satellite clinics. The role of the GC varies across the UK. In most centres GCs have their own clinical workload and are key members of the multidisciplinary team. In some centres there are specific cancer and general teams and in others GCs see both cancer and general patients.

There are two routes of entry into the profession in the UK: via an academic science background with a Masters degree in genetic counselling or as a Registered Nurse with a Masters degree. All GCs in the UK are now encouraged to undergo professional registration, which it is hoped will become statutory. The registration process includes training, experience and evidence of competence and continuing professional development in all areas of genetics.

The role of the GC in cancer genetics is to verify the family history, explore the patient’s concerns, explain the significance of the family history, provide personalised risk and screening advice, help the patient and family adjust to the cancer risk, provide support and counselling and, where appropriate, explore the option of genetic testing. In order to offer genetic testing for cancer susceptibility in the UK, there needs to be at least a 20% chance of a mutation being present, and in most cases, a relative with cancer who is willing to be tested. If a mutation can be identified in a relative with cancer, a predictive genetic test can then be offered to other relatives.

Genetic testing in the UK is only offered following genetic counselling and with informed consent. Inheritance and the risks associated with specific gene mutations, the possible outcomes and implications of genetic testing, confidentiality and the potential impact of a positive and negative result, and the psycho-social and support needs of the individual are all discussed prior to the test. The number of appointments offered pre and post testing will vary depending on the situation and needs of the individual.

Until the late 1990s, cancer genetics in the UK was funded entirely by research. The expansion of cancer genetics services within the National Health Service and the increasing number of GCs entering the profession from an oncology background lead to specialisation of some GCs and the development of specialist senior genetic counselling roles within the cancer genetics field.

The role of Consultant Genetic Counsellor in Cancer Genetics
The South Thames Regional Genetics Centre, serves a population of approximately four million people. Referrals are received from general practitioners, specialist clinicians and specialist nurses. The role of Consultant Genetic Counsellor in Cancer Genetics was developed at the South Thames Regional Genetics Centre in 2006 as a result of the increase in cancer referrals and the need for development of the cancer genetics service. The role includes providing expert practice, leadership, education, service development, liaison with other cancer specialists and research. This role poses many opportunities and challenges, some of which are described below.

One of the challenges of genetic counselling is to provide a service to those who need it without raising unnecessary anxiety and expectations. Within the South East of England, we have worked with specialist nurses to establish a network of cancer family history clinics in secondary care, ensuring that referral to genetics is appropriate and timely. Specialist nurses in breast, colorectal and gynaecology cancer are trained by GCs to take a three-generation family history and assess and explain cancer risk and management with direct referral to genetics for those at increased risk in accordance with local and national guidelines (4).
An annual eight-day course is run by GCs from the South London
Regional Genetics Centres, together with Kings College, London and the University of Kingston, to train specialist nurses in all aspects of cancer genetics and family history assessment. In addition, a competency-based assessment programme has been established for nurses who are setting up family history clinics with support and supervision from the GCs. An audit of our service in 2006 showed that referrals from the family history clinics to the South Thames Regional Genetics Centre were far more accurate and appropriate than referrals from primary care.

Recently we have completed a three-year pilot project setting up cancer risk assessment clinics in the local community (5). The area around Guy’s Hospital is one of the most socially deprived and ethnically diverse in the UK. Providing local clinics in the community to which patients could refer themselves increased the proportion of non White British patients accessing the cancer genetics service from 3% to 46%. Sixty three percent of the patients seen by the service were at moderately increased risk of cancer or greater and were referred on to screening or genetic counselling. We now have funding to build on this service in order to develop a comprehensive cancer risk assessment service across primary, secondary and tertiary care in the local area.

We have run a pilot project for two years setting up a multidisciplinary one stop clinic for patients who carry mutations in the high risk breast cancer predisposing genes (BRCA1 and BRCA2). Patients are offered an annual review with specialists in genetics (GC or geneticist), breast surgery, gynaecology, oncology and psychology in order to provide consistent information and counselling in liaison with their local clinicians. In addition, patients are offered the opportunity to take part in research studies and to access a support group, patient information days and an annual newsletter. The two year data is currently being evaluated, however interim data at 11 months showed that patients were highly satisfied with the service and the number of women opting for prophylactic surgery and entering research studies increased as a result of the clinic. This service also now has ongoing funding.

Conclusion
Developments in scientific understanding are involving cancer genetics even further in mainstream oncology practice. There is a growing demand for genetic testing amongst women who are newly diagnosed with breast cancer and have a strong family history of the disease in order to inform surgical management. In addition, the use of biomarkers in determining cancer treatment is becoming an increasingly realistic possibility. These developments highlight the importance of an understanding of cancer genetics amongst all health professionals in the field of oncology. Genetic counsellors in the UK are likely to play an increasing role in integrating cancer genetics into oncology, in developing patient pathways and targeting appropriate referral, raising awareness of the service amongst the public and educating other health professionals.

Cancer genetics is a rapidly expanding field and the future is exciting. The changing shape of genetics referrals has lead to a shift in the clinical workload of genetic counsellors and development of new roles within the profession. However, an understanding of the importance of family history on cancer risk is essential for all nurses working in the field of oncology and as further scientific advances are made cancer genetics will become even more integral to cancer management.

References
1. American Society of Human Genetics Ad Hoc Committee on Genetic Counselling: Genetic Counselling. American Journal of Human Genetics 27, 240-242, 1975