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Oncology nurse training in cancer genetics

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EDITOR—The rapid increase in understanding of cancer genetics in recent years means that few oncology nurses have sufficient knowledge to address the issues of patients concerned about inherited predisposition to cancer.[1–3] While some nursing curricula have recently incorporated cancer genetics, this does not assist the large body of oncology nurses already in practice. The need for an educational programme in cancer genetics was highlighted locally by a focus group of senior level nurses and social workers practising in oncology (unpublished data). All felt inadequately equipped to deal with enquiries regarding family history and cancer risk from patients and staff. Nobody in the focus group was aware of the Australian protocols for referral to familial cancer clinics within their employing organisations and family history was not routinely collected.

The Australian guidelines categorise families according to their level of cancer risk ("high", "moderate", or "low") based on family history and/or the presence of a germline mutation known to predispose to cancer.[4] In Australia, multidisciplinary Familial Cancer Centres provide genetic counselling, genetic testing, and risk management advice to those families judged to be at "high risk".

Those categorised at low or moderate inherited risk of cancer may also benefit from informed counselling but may not meet the criteria for referral to the Familial Cancer Centres. As cancers are common, a significant number of people in the community with a family history of cancer will be in these categories. Many will not have a single gene mutation, but are at somewhat increased risk of developing cancer and require surveillance advice.[5–7] The person's perception of this risk may not reflect reality. People at moderate risk for breast cancer often overestimate their level of risk.[8–10] After receiving counselling and a personal risk estimate, most report feeling less worried and their perception of risk is more accurate.[8] These issues may be addressed by services focusing predominantly on surveillance and management issues rather than inheritance.

The Australian model requires relevant health professionals to incorporate family history assessment into their practice. Oncology nurses are in an ideal situation to distinguish families at high risk from those who are concerned about their personal inherited risk but are in a low or moderate risk category. Ongoing involvement with patients and their families during the course of the treatment, post-diagnosis support, and palliative care leads to a trusting relationship between the patient and nurse and consequently the opportunity to discuss referral of family members. Some oncology nurses see genetics as an important facet of nursing practice[11 12] and a role for oncology nurses in family history collection and assessment has been proposed.[11 13 14]

Cancer genetics requires a shift in focus from the traditional nursing role. Oncology nurses have a patient centred approach and well developed skills with respect to care of the patient; genetics requires the consideration of the whole family. Not only is information about the extended family required for assessment, but information given to patients may be directly relevant to, or impact on, other family

Table 1 Syllabus and learning goals for "Counselling" module

Topic	*Time allocated (h)**	*Learning goals*
Revision of counselling skills	5	Review the skills of attending, listening, empathy, probing Practise these skills and developing rapport
Self-awareness	4	To understand the need for self-awareness in counselling To practise monitoring one's owns feelings and responses To understand "parallel process"
Crisis	4	To understand the nature and stages of crisis To be aware of the physical and emotional reactions to crisis To develop and practise counselling skills in relation to crisis
Grief	4	To review grief responses To be aware of the impact of grief over time To practise counselling skills in relation to grief
Psychiatric illness	1	To be aware of potential psychiatric presentations To be aware of appropriate referrals

*Time allocations are somewhat arbitrary as there was overlap between all topics.

members. Consequently, issues of confidentiality, disclosure, and autonomy are complex, and discussion needs to be based upon sound genetic knowledge and principles.

We developed a 16 week (60 hour) course entitled "Cancer Genetics Resource training course" designed to enable oncology nurses to assess a person's category of inherited cancer risk, facilitate appropriate referral, and identify psychosocial issues.

Course development

The philosophical basis of the course was that dissemination of information and development of skills throughout the health sector would increase accessibility of appropriate services to families. Specifically, educating health professionals about cancer genetics will assist in identification of high risk families and facilitate risk management of those in the low and moderate risk categories. The graduates will be able to assess a family's inherited risk category, facilitate referral to the relevant services, explore expectations of services, and provide brief counselling for issues such as anxiety and/or grief which may serve as a barrier to acceptance of a referral by the family members.

The course syllabus was developed based on feedback from a focus group comprising oncology nurses and in conjunction with the Anti-Cancer Council of Victoria. It was publicised through the local Oncology Nurses Society, major hospital oncology day centres, and focus group participants. The number of participants was limited to allow effective counselling skills training. Participants were all working in oncology and able to apply the course content in their work. After interview, 10 were accepted from various areas of oncology (education (1), palliative care (1), breast care support (2), cancer help line (2), research/registry (1), wards (3)). Six participants were subsidised by their employing hospital, indicating institutional support and recognition of the course.

Syllabus

Our experience in running workshops in cancer genetics emphasised a diversity of experience and a lack of familiarity with basic genetic concepts. Consequently, participants in the Cancer Genetics Resource training course were expected to complete a basic genetics workshop (12 hours) at the beginning of the course to ensure all had sufficient understanding of key genetic terms and concepts, including ethical issues.

In developing the core syllabus, we focused on skills that nurses could incorporate into their work. Graduates of the course would undertake counselling low and moderate risk families regarding their inherited risk and refer high risk families for specialised counselling. Detailed information about specific cancer predisposition genes, such as the mismatch repair genes, was therefore considered less important than a general understanding of the role of genes in cancer predisposition.

A syllabus was structured in three modules: Counselling Skills (six sessions), Science and Genetics of Cancer (six sessions), and Practice and Perspective (four sessions). Each session was of three hours' duration.

COUNSELLING SKILLS

The ability to explore issues underlying a person's concern about their history is essential in determining the services best able to meet a family's information and psychosocial needs. Questions by family members are often triggered by a recent critical event (for example, diagnosis, death, or an anniversary) and the emotions engendered by these events may affect the family member's acceptance of appropriate services.

Areas covered are outlined in table 1. Skills and issues were explored through discussion and role play. The nurses felt comfortable with the "task based" approach necessitated by their usual work and showed a desire to "fix it". The ability to live with uncertainty, necessary in so many areas of genetics, created problems for participants and was explored further in tutorials by a psychologist with extensive experience in education and supervision.

CANCER: SCIENCE AND GENETICS

This module was designed to enable participants to elicit and distinguish information relevant to family history assessment, to establish the inherited risk category, and identify people whose surveillance was insufficient. The course outline is presented in table 2. The majority of the tutorials focused on risk assessment for the common cancers (breast, bowel, gynaecological, and melanoma). Each was divided into two parts, the first being an overview covering incidence, benign and malignant conditions, inherited conditions, and surveillance. The second part was skill based, with participants assessing case studies. The tutorials relating to fundamental principles of cancer genetics were designed to provide participants with sufficient information to correct common misconceptions, but not to provide detailed genetic information to a patient. Tutors were medical specialists in the field associated with Familial Cancer Clinics. This had the additional benefit of increasing the familiarity and accessibility of participants to key practitioners in the area.

Table 2 Syllabus and learning goals for "Cancer: Science and Genetics" module

Topic	*Time allocated (h)*	*Learning goals*
Epidemiology of cancer and risk factors	1	Understanding of the population risk of cancer Appreciation of the risk factors for common cancers Awareness that the incidence of a cancer can fluctuate Awareness that different countries and racial backgrounds have different cancer risks
Cancer genes and genetic testing	5	Understanding of the two hit model (revision) Ability to distinguish tests that indicate a genetic predisposition from those that detect gene mutations (eg, microsatellite instability testing) Understanding of the practicalities of gene testing Understanding of "normal" and "abnormal" gene test results Awareness of rare familial cancer syndromes
Breast cancer	3	Knowledge of the population incidence
Gynaecological and prostate cancer	3	Recognition of risk factors
Colorectal cancer	3	Knowledge of risk prevention measures
Skin cancer and melanoma	3	Recognition of insufficient surveillance for a person's risk category Ability to ask appropriate questions to elicit relevant family history Recognition of medical events that are relevant to assessment of the family history Assessment of the inherited risk category of a family (low, moderate, high) Knowledge of cancer predisposition genes

PRACTICE AND PERSPECTIVE

This focused on incorporation of the previous modules into routine work (table 3), including discussion about the participants' individual workplace situations and challenges. Three common themes emerged. The participants had particular concerns about (1) raising the issue of familial cancer with people who were at high risk but had not indicated any interest in their genetic status, (2) raising the issue of referral with the clinician responsible for care, and (3) the potential increase in workload and need to document the work performed in this area.

Assessment of participants

A criterion referenced approach to assessment was adopted.[15] Participants were expected to show the required level of competency by completing set assessment tasks. If the necessary standard was not achieved, further study was required and competence reassessed until proven.

In the Cancer Genetic Resource course, the ability to determine inherited risk category accurately and competency in deciding the appropriate course of action were assessed. Three assessment strategies were used. The tutor for the counselling module evaluated the involvement and ability shown by the participants during the counselling tutorials. The other modules were assessed by a written examination comprising case studies, family history assessment, and construction of an accurate family tree. This examination was open book, as participants would be expected to access relevant information and resources in their own workplaces rather than rely on memorised information. Each participant was informed of areas of weakness identified by the examination and was then expected to show sufficient skill in that area. Finally, all participants conducted an "in service" training session at their workplace to educate their colleagues about application of their skills.

Evaluation of the Cancer Genetic Resource course

The course was evaluated by the students at the conclusion of each module, at the conclusion of the course, and six months after completion. The participants evaluated a number of parameters, including module content, teaching quality, applicability, expectations fulfilled, and practice of skills. Some parameters were assessed by open questions, but the majority were assessed by Likert scales. Those scores assessed by Likert

Table 3 Syllabus and learning goals for "Practice and Perspective" module

Topic	*Time allocated (h)*	*Learning goals*
Family history collection	3	Knowledge of the information required to collate a family tree Collection of a clear, informative, and accurate family tree Awareness that family history is evolving Appreciation of the cultural and social factors that affect collection of information Understanding of issues of ethics and confidentiality Awareness of verification and consent
Referral process	3	Understanding of Familial Cancer Clinic function Ability to arrange a referral to a Familial Cancer Clinic locally and interstate Ability to arrange a referral of a low or moderate risk person to appropriate services Some knowledge of the community resources available to families Some knowledge of current familial cancer research projects occurring locally
Incorporating cancer genetics	3	Improve and consolidate skills through role plays Appreciation of the influence of "family myths" on understanding of genetics Development of a plan for implementing cancer genetic skills into work practice Awareness of work place issues and boundaries
Review and assessment task	3	

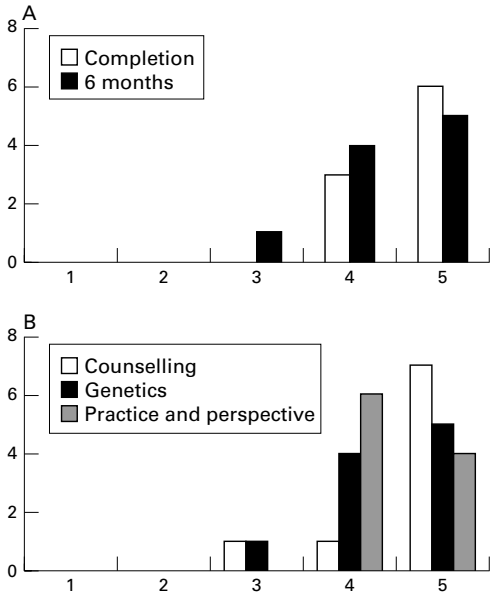

Figure 1 Participants' assessment of course usefulness. (A) Usefulness assessed at completion of the course and six months afterwards. (B) Relevance of modules assessed at completion of the module.

scales (1-5, with 5 being the highest rating) were averaged for each module separately.

The Counselling Module scored 4.5 (range 3.8-4.7), the Cancer: Science and Genetics Module scored 4.2 (range 3.9-5), and the Practice and Perspective module rated 4.4 (range 3.7-4.7). In particular, the teaching style rated highly for all units and tutorials were considered stimulating.

Overall satisfaction was high both immediately after the course and six months after completion, with participants indicating that the course overall was useful (fig 1A) and each module relevant to their work (fig 1B). Many participants felt before the course that their counselling skills were sufficient, but reported gaining additional skills during the course. Most commonly these were listening skills, self-awareness, and dealing with their own "fix it" mentality. The assessment of risk category and construction of family trees were regarded as the most helpful skills learnt overall and the participants commented on the supportive learning environment.

To assess the effectiveness of the Cancer Genetics Resource Course as a whole, the graduates were asked about their work practice six months after completion of the course. Nine of the graduates had patient contact in oncology and all had been asked about family history by patients or raised the issue of cancer genetics with patients. Three always asked patients about their family history, three asked only if the patient mentioned other affected relatives or asked directly, and three asked if time and the patient relationship permitted. All graduates reported receiving questions from other staff and applying the skills learnt. All had either facilitated a referral (6/9) to a familial cancer service or suggested to medical staff that a referral may be appropriate (6/9), compared with 11% (1/9) before the course.

A questionnaire was completed by supervisors six months after the course ended. One person had changed jobs during the six month period. Of the remaining nine, eight supervisors indicated that the graduates had incorporated new skills in their work and would recommend the course to other nurses. The remaining one had not observed any change, although the participant herself felt that she had been able to apply her new skills.

Future directions

The success of the course in meeting its aims was indicated by (1) the accuracy of the participants' family history assessment, (2) the sixfold increase in the number of participants facilitating referral, and (3) the assessment by participants and supervisors of the applicability of the skills learnt. We conclude that completing a skills based course improves assessment and appropriate referral of those who may be at risk of familial cancer.

Further evaluation is required to assess the extent to which learned skills have been applied and the effectiveness and appropriateness of counselling provided by the graduates. The possibility of holding a full time, intensive, two week course, enabling easier access for non-metropolitan nurses, has been considered. This benefit needs to be weighed against the reduced opportunities for the nurses to apply skills and reflect on their practice between tutorials.

Our course focuses on recognising and meeting the needs of families at low and moderate risk, which constitute the majority of patients and families encountered by oncology nurses. In contrast many training programmes appear to focus on high risk families.[16] Diverse roles for oncology nurses in cancer genetics have been proposed[11 17] and it is reasonable to expect that different programmes will be required to meet the varying educational needs of these roles.

In time the role of a "Cancer Genetics Resource Nurse" may evolve into a dedicated position, distinct from, but complementary to, the role of Genetic Counsellors working with high risk families in Familial Cancer Centres. This role need not be confined to oncology nurses. With this form of training, social workers would be well placed to elicit concern regarding family history and counsel accordingly. The Cancer Genetic Resource course can be readily adapted for allied health staff or medical professionals.

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Participation in preconceptional carrier couple screening: characteristics, attitudes, and knowledge of both partners

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EDITOR—Couples in which both partners are carriers for a particular autosomal recessive disease, such as cystic fibrosis, Tay-Sachs disease, or thalassaemia, have a 1 in 4 risk for each child to have this disorder. Population carrier screening programmes aimed at the identification of carrier couples make it possible to inform these couples about their risk and about the reproductive options that are available. Before beginning any genetic screening programme, it is important to assess community interest in screening.[1]

It is well known that the way in which carrier screening is offered and the timing, for example, during or outside pregnancy, determine participation in screening and the reasons for participation. Screening offered face to face with the possibility of immediate testing gives high uptake rates, whereas offers made by mailed invitation or poster announcements attract little interest.[2–6]

Most of the data on motives for participation have been obtained from programmes offering carrier screening during pregnancy.[7–15] In these studies, a high interest in screening was reported, although it has been argued that testing during pregnancy is often accepted just because it is offered.[16] The decision to participate was mostly made by women, who were often initially tested without discussing it with their partner. Anxiety has been reported among those who are tested positive, while waiting for their partner's results.[10 17 18] It can also cause distress when the partner is not available or does not want to be tested.[19] Furthermore, prenatal screening leaves limited reproductive options for a carrier couple and might impose time constraints when decisions about a prenatal diagnosis have to be made.[20] Offering carrier screening outside pregnancy shows low participation rates when no pregnancy is planned, but interest is higher when there are plans for having children (preconceptional).[4 7 21]

This study focused on the preconception period as the time for screening and considered couples as the screening unit. Determining why some couples participate in a preconceptional carrier screening programme while others decline provides insight into the desirability of screening. It may also give some indications of how to improve accessibility to screening for those who are interested. To investigate this, couples can be directly asked for reasons why they decided (not) to participate. In addition, determining differences in individual variables and attitudes between participants and non-participants can be used to explain participation. Early theories on health related behaviour suggest that intention to take a preventive health action is likely when people (1) view themselves as susceptible to the condition, (2) consider the disease to be serious, (3) perceive high benefits of the health action, and (4) perceive few disadvantages in undertaking it.[22] These four components are the earliest constructs of the Health Belief Model (HBM), which has been considerably expanded, as was reviewed by Janz and Becker.[23] The present study focused on a select group of variables derived from the HBM. This model was chosen because of its applicability to predicting behaviour towards voluntary action, such as carrier screening.

In this study, the determinants of participation in preconceptional cystic fibrosis (CF) carrier couple screening was investigated, focusing on the characteristics and attitudes of