

COMPONENTS OF A GENETIC CANCER RISK CLINIC

June A. Peters,^{1,2} Jennifer Graham,³ Mona Penles Stadler,^{1,4} and Kate Sargent⁵

¹UPMC/UPCI Magee-Women's Hospital Cancer Genetics Program

²University of Pittsburgh Graduate School of Public Health
130 Desoto Street, Crabtree A300, Pittsburgh, PA 15261

³Arthur G. James Cancer Hospital and Research Institute
Clinical Cancer Genetics

300 W. 10th Ave, Columbus OH 43210-1240

⁴300 Halket St, Room 3522, Pittsburgh PA 15213

⁵Barbara Ann Karmanos Cancer Institute
Cancer Risk Assessment Service

Harper Professional Building
Suite 612, 4160 John R., Detroit, MI 48201

INTRODUCTION

Because of wide publicity, many oncologists are aware of the availability of genetic susceptibility testing to detect mutations in cancer susceptibility genes such as *BRCA1*. One might innocently assume that the genetic test is as easy to order as filling out your standard requisition form for a blood count. This is not consistent with current practices. The daunting ethical, medical, legal, social, and technological challenges must be addressed. In order for a genetic test to benefit your patients, it should best be undertaken in the context of a well-organized, comprehensive Familial Cancer Risk Counseling program. Establishing such a program is the focus of this chapter.

^{1,2}412-624-7854, fax 412-624-3020, e-mail: jpeters@helix.hgen.pitt.edu

³614-293-6694, fax 614-293-2314, e-mail: graham-1@medctr.osu.edu

⁴412-641-4203, fax 412-641-1132, e-mail: mstadler@mail.magee.edu

⁵313-966-7780, fax 313-745-9609, e-mail: sargentk@kci.wayne.edu

Familial Cancer Risk Counseling

Familial cancer risk counseling (FCRC) is a communication process between a health care professional and an individual concerning the occurrence, or risk of occurrence of cancer in the individual's family.^{1,2} As such, FCRC addresses the genetic, medical, psychological, social, and ethical issues that arise in the context of cancer predisposition. The FCRC program may be established in a variety of settings to serve various different institutional and professional purposes. The program may be a free-standing clinical service, located in an academic medical center, an adjunct to general medical genetics, oncology practice, prenatal genetics service, high risk cancer clinic, or as an outgrowth of cancer registries, and genetic research protocols. There are both operational and programmatic aspects to developing such a clinical service. This chapter will emphasize the operational aspects of establishing such a program in the first section, with only brief mention of programmatic aspects of familial cancer risk counseling programs, as these are covered adequately elsewhere.

OPERATION OF A CANCER GENETICS PROGRAM

Program Justification

Those just beginning FCRC programs are often asked to justify the initial expenditure of resources. Table one outlines these. If 10–15% of patients with cancer have an underlying genetic mutation, there will be a significant number of individuals at your institution who will require specialized cancer management. The only way to identify this high-risk subset is through cancer risk assessment. Professional oncology societies such as American Society of Clinical Oncology (ASCO) have issued statements about the responsibilities of oncologists to take family histories that are adequate to ascertain families at risk for hereditary forms of cancer.³ The FCRC program extends the oncology service to the at-risk relatives thus identified. The family history is the most cost-effective cancer prevention measure available.⁴ While genetic counseling itself is not lucrative, families may remain loyal to medical centers that offer a complete package of oncology services. Spin-off services such as screening mammograms, colonoscopies, and laboratory testing can be profitable for the institution as a whole and may be used to subsidize the required genetic counseling and risk assessment. Relatives with average risk do not need to undergo unnecessary procedures. Finally, there is avoidance of negligence malpractice suits against physicians who fail to detect a hereditary cancer syndrome and to notify patients and family members of the medical implications of this diagnosis.

Table 1. Justifications for a Cancer Genetics Program

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- Volume of potential families
 - Professional standard of care
 - Complete package of services
 - Financial incentive
 - Fear of lawsuits
 - Wave of future practice
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Adapted from Schneider, 1998, unpublished.

Missions and Models

The overall mission of an institution's oncology program may be to reduce mortality, increase quality of care, increase direct and indirect institutional revenues, improve cancer control, or conduct research.^{1,5} Whatever the institutional mission, the FCRC program will facilitate its achievement.

Eeles⁶ has provided a comprehensive list of functions of the FCRC. The most obvious objectives are to provide cancer risk assessment, to detect whether a family pattern of cancers is likely to be hereditary, and to diagnose rare cancer family syndromes. In countries with centralized healthcare systems, the clinic may provide accurate records archives and link familial data via registries. Often, clinical functions include genetic counseling and testing, if indicated, giving advice on early detection and preventive options, and conducting or participating in clinical trials. Also, the FCRC program is a training site for professionals, is available to guide, support, and consult for other clinical services. The genetics staff may also offer expert advice for purchasers and providers of cancer genetics services in the institution and regionally. For the forward-thinking oncologist, the FCRC can be the venue of a new generation of oncology practice in which an individual's genetic profile will figure into every phase of cancer prevention, diagnosis and treatment.

Different models have been developed for offering the FCRC services noted above.^{1,2,6-11} Some FCRC services grow out of cancer registries,¹² international research collaborations¹³ or translate epidemiological research into a family service.^{14,15} Some centers will be primarily a single cancer type, e.g., breast or colorectal, and will be situated in a clinic dedicated to that disease, e.g., a Comprehensive Breast Center,^{1,2} Digestive Disease Clinic^{4,16} or Endocrine Clinic.¹⁷ These models are useful in starting up FCRC programs because they provide focus and a clear set of guidelines for referral. However, the single disease programs are challenged by the nature of genetic susceptibility syndromes, which generally confer risk for more than one type of cancer, each requiring different combinations of medical specialty care. A variation of the single disease genetics clinic is forming an add-on service to already-existing services such as oncology practice, women's health center,¹⁸ surgery consultation, or general medical genetics service.¹⁹ There are also genetics programs affiliated with prevention clinics such as the Strang Breast Cancer Prevention Clinic (G. Rosenthal, personal communication, 1998). Some risk assessment is provided through behavioral science research protocols.²⁰⁻²² The prototype of the more comprehensive model is the Hereditary Cancer Prevention Clinic, which handles a variety of cancer types.^{4,9,10,23}

While many FCRC programs are academically based, some are not. Kaiser Permanente is one of the first managed care organizations in the country to offer in-house genetic counseling on a routine basis, and, more recently, to initiate a systematic approach to handling FCRC and genetic cancer susceptibility testing. The Kaiser Permanente organization is also pioneering standardized clinical guidelines in regard to hereditary cancer.²⁴

Increasingly, the importance of research in hereditary cancers is being recognized. As Ponder²⁵ (p. 734) argues, "there is hardly an aspect of familial cancer which does not require further research". Therefore, the FCRC clinic, while providing a service, should also be organized to promote research, or at the very least, collect data that could later contribute to research efforts.

Institutional Infrastructure and Resources

The decision as to whether FCRC will be provided onsite with institutional resources or through another mechanism is critical. If a program is established within an institution, one resource-saving strategy is to distribute costs of staff and resources among several departments. Other strategies involve forming collaborative groups within a city or region¹⁹ or establishing a satellite network of affiliated clinics. Another alternative to establishing a local program is contracting with local geneticists or genetic counselors at a nearby institution to provide the FCRC service, or referral of cases to another institution. Finally, some commercial genetic diagnostic laboratories help to coordinate genetic counseling referrals for patients considering genetic susceptibility testing.

Infrastructure: Space, Human Resources, Budgets, Billing

Counseling and Office Space. The clinical consultation space should be quiet, private, comfortable, and large enough for lengthy discussions with multiple family members who may attend FCRC together. The traditional hospital setting and medical examination room are often sterile, cluttered, and an unwelcomed reminder of medical visits of ill relatives, and should be avoided whenever possible. A consultation space or small conference room is preferable. Access to an examination room is optimal for those patients who will require a physical examination, e.g., to evaluate dermatologic stigmata of Cowden's disease or Muir-Torre syndrome, or look for dysplastic nevi associated with hereditary melanoma. Empirical evidence from Stadler & Mulvihill^{26,27} confirms the importance to families of these recommendations about the appearance of the clinical space.

In addition to clinic space, staff members will require office space for paperwork, telephone contact, and data management. Often this is a different location than the consultation room. If not, then table and chairs placed in the office should be arranged to separate the work area from the consultation space.

The outreach clinic, where clients are seen at a site separate from the administrative institution, is an alternative to the centralized cancer genetics clinic. Offering service at alternate sites may create more difficult logistics for the FCRC team, but may be very convenient and beneficial to the client. It also has the advantage of promoting professional networking and referral patterns with local providers.

Team Structures, Functions, Individual Roles

Adopting a multi-disciplinary approach to cancer genetics is of paramount importance in achieving an effective cancer genetics program. Assessing familial cancers involves coordination of complex sets of activities that require input from a variety of specialists from different disciplines.^{8,11,14,19,25,28-34} The complementary expertise of oncologists, genetic counselors, medical geneticists, pathologists, molecular laboratory scientists, nurses, social workers, and/or psychologists is usually required. Each professional provides a unique perspective and information pertinent to their specialty.

One of the subtle challenges of setting up programs is to blend the distinct professional cultures of clinical genetics and medical oncology (Robin Clark, USC-CSU Northridge Cancer Genetics Conference, 1996). For example, the nature of diagnosis

differs dramatically in these two specialties. Oncologists use a combination of clinical examination, medical imaging, and pathology findings to make a definitive diagnosis of a malignancy or metastases in an individual who is then treated according to somewhat standardized guidelines. In contrast, geneticists rarely diagnose a cancer; rather, they are trained to make syndrome diagnoses based on recognizing constellations of physical characteristics and family history of certain associated cancers. Cancer etiology is not of primary concern to the oncologist in the fundamental way that it is to the geneticist, whose business it is to determine the relative contributions of heredity and environment. Only in the past few years has molecular genetic testing been able to augment the genetic diagnosis. Whereas an oncology diagnosis is definitive and leads to specific treatment, a genetic diagnosis is often uncertain and may not lead directly to treatment recommendations. An interesting study suggests the possibility of personality differences as well; e.g. geneticists often have a greater personal tolerance for ambivalence than other medical professionals.³⁵ While the oncologist is often seen as the general who aggressively “wages war on cancer”, the genetics professional will often use softer images of “learning to live with” the consequences of genetic disease. There is also an important difference in the definition of who is the patient. The oncologist takes the more traditional medical view of evaluating, diagnosing, treating, and hopefully curing a person with cancer, whereas the geneticist may view the whole family as the patient. These differences may have an impact on how professionals choose to form interdisciplinary teams, the goals they establish for the local cancer genetics program, and their marketing strategies to generate referral patterns.

The genetic counselor may act as clinic or program coordinator, research team leader, psychosocial crisis interventionist, or genetics expert. In the capacity of genetic counselor, he or she can help evaluate familial clusters of cancer. This might include presenting referrals to the core group; retrieving, reviewing, and summarizing medical records and relevant medical literature; and other information pertinent to the reason for referral. Genetic counselors and clinical geneticists have primary responsibility for constructing and interpreting pedigrees, recognizing known hereditary cancer susceptibility syndromes, calculating risk assessments, and communicating these to clients. The genetics team can also offer education about risk factors for cancer, the basic concepts of inheritance, and the significance of one’s unique family history. The genetic counselor may also delineate and work with family dynamics, social, and ethical concerns. The medical oncologist has primary responsibility for medical management. The psychologist, nurse, social worker, and genetic counselor raise issues relevant to both pre-symptomatic testing, cancer diagnosis and management.³⁶ In some programs, a clinical psychologist or social worker is also on staff to be available to families or individuals with specific psychotherapeutic needs. Together the team develops differential diagnoses and, if possible, determines cancer risk estimates, the likelihood of the family having a specific mutation in a particular cancer susceptibility gene, the appropriateness of offering DNA testing, and cancer prevention and screening recommendations.

There are significant differences in offering cancer risk assessment and testing in research settings. The translation and integration of clinically relevant research efforts into the clinical setting is also promoted through the multi-disciplinary approach.^{11,32}

Human Resources. There have been a number of commentaries on the need for primary care physicians, oncologists, and nurses to become knowledgeable about genetics.^{3,37-41} However, we are presently far from this ideal situation; hence, cancer

Table 2. Components of Genetic Counseling

The genetic counseling process helps families to:

- comprehend the medical facts of the condition, including the diagnosis, probable course of the disorder and available management;
- appreciate the hereditary contribution and recurrence risk for the disorder in specific relatives;
- understand their options for dealing with the risk of recurrence in terms of medical care, reproduction, testing, etc.
- choose which of the options, including doing nothing, is appropriate for them at this point in time in view of their risk, disease burden, and family goals and values; and
- make the best possible adjustment to the condition in oneself and/or one's loved ones and/or to the risk of recurrence of the disorder.

Definition adapted from the ASHG Ad Hoc Committee on Genetic Counseling, 1975.

genetics programs should always include genetics professionals. While genetic counselors and medical geneticists are well known and utilized in perinatology, obstetrics, neonatology, and pediatrics, they have been less visible in oncology, internal medicine, and primary care. Thus, it might be helpful to briefly describe the genetic counselor and medical geneticist.

Genetic Counseling. Who does genetic counseling? The majority of genetic counseling is performed by certified genetic counselors, medical geneticists, or advanced practice nurses with graduate genetics training.

One of the first formal definitions of genetic counseling was offered by Clarke Fraser in 1974, when he stated that genetic counseling is "a communication process which deals with the human problems associated with the occurrence, or risk of occurrence, of a genetic disorder in a family. This process involves an attempt by one or more appropriately trained persons to help the individual or family . . ." ⁴² (p. 637). A year later, in 1975, an Ad Hoc Committee of the American Society of Human Genetics accepted this definition ⁴³ and further defined the basic components of the genetic counseling process listed in Table 2.

Through the genetic counseling process, the family can learn about the features, natural history, and variability of a disorder, as well as possible genetic contribution to its occurrence; surveillance, diagnostic testing, treatment, and other medical management options, and reproductive options. The goals are to help the family feel competent in coping with the risk and impact of the genetic condition, diminish guilt or blame and restore self-esteem, make decisions about testing, treatment, and/or reproduction; anticipate and deal with medical and/or learning problems associated with the condition; and identify and utilize resources for psychological, social, and financial support.

As a distinct profession, genetic counseling has its own code of ethics, ^{44,45} nationally accredited master's level training programs and clinical internships. A national certification process leading to the privilege of using the "certified genetic counselor" (CGC) designation has been established by the American Board of Genetic Counseling. In the U.S., most genetic counselors belong to the professional society known as the National Society of Genetic Counseling (NSGC) and most attend an annual national education conference. Publications include the peer reviewed *Journal of Genetic Counseling*, and a newsletter, *Perspectives in Genetic Counseling*, as well as various informational materials.

Some health professionals think there is a lack of trained genetic counselors, leading them to offer risk assessment and genetic testing without adequate and qualified genetic counseling. This is a grave error. Schneider, a well-respected cancer genetics researcher has stated, "If and when there is a greater demand for cancer genetic counselors, the training programs will almost certainly respond accordingly by increasing the number of individuals trained"³⁶ (p. 97). Currently, in addition to more than one thousand genetic counselors working in prenatal and pediatric settings who can handle the rudiments of cancer genetics, there are at least several hundred genetic counselors in North America who are members of the NSGC Cancer Genetics Special Interest Group (CA-SIG). The NSGC CA-SIG provides genetic counselor members with starter packets of basic ingredients for starting FCRC programs, discussion via an active e-mail listserve and newsletter, and multiple continuing education and collaborative research opportunities.

Hiring, Job Descriptions, Support. Hiring new staff (professional, administrative, and clerical) for the FCRC program will require development of job descriptions and responsibilities, recruitment, training, and supervision. Cancer genetics is currently a highly competitive field appealing to both new and experienced counselors. New genetic counseling graduates have had cancer genetics coursework and training experience with hereditary and familial cancers. More experienced genetic counselors have had continuing education opportunities and bring essential clinical and administrative experience and judgement to the FCRC program and promote smooth day-to-day operations.

All health professionals need adequate time and resources to learn and remain current with new developments in the rapidly expanding field of cancer genetics. To do so, they will require resources for purchasing reference books and doing adequate library and electronic literature searches prior to consultations with patients with hereditary cancer diagnoses. It is essential to access genetic testing databases to locate and compare genetic testing laboratories, which usually differ from one another in cost, service, and type of test being offered. Designated resources should also include membership in appropriate genetics and oncology societies, travel expenses, and continuing education at appropriate genetics, oncologist, and behavioral medicine conferences.

Having support staff allows the FCRC program to optimize professional time and expertise. Nursing, database, computer, statistical staff along with administrative and clerical personnel should be considered essential to the efficient and thriving program.

Budgets

The development of operational and capital budgets should be accomplished prior to the initiation of the clinical service. Operational budgets generally include a one-year projection of estimated expenses for the following categories: salaries, medical, and non-medical supplies, postage, duplication, publications, and minor equipment, including software under \$500. Additional budgetary projections to consider are the extensive telephone consultations, travel, consultant, or physician services, professional memberships and certifications, reference books and periodicals, and seminar/conference/training expenses. It may be helpful to model your first operational budget after a similar sized program with a comparable mission.

While the operational budget can be thought of as the day-to-day expenses, the capital budget generally encompasses the large items, which have a longer shelf-life or

are sold as a system. Items such as expensive software, office furniture, and computers are considered capital expenses. The capital budget can be defined very differently from institution to institution so it is extremely important that one know the rules before making budget requests.

Both operational and capital budgets need justification for when, how, and why the funds are needed for a particular item or service. After the initial year of operation, budget increases often need to be justified using the same criteria.

Billing and Reimbursement

There are a variety of ways to handle billing for FCRC. Some programs bundle clinic costs together (e.g., oncology, genetics, psychology, nutrition). Others itemize the costs for each provider separately. Universally, this bill does not include the cost of DNA testing, which can range from \$200–\$2500 per person in the current market. Reimbursement often depends on receiving pre-approval for the FCRC service and testing from the patient's insurance carrier. Because of concerns about confidentiality and possible discrimination, many patients prefer to pay out-of-pocket for the consultation and/or genetic testing.

Often, institutions classify services provided by a specific practice group into "cost centers", complete with unique institutional account number. These cost centers make it possible to track revenues and expenses. If the program bills for services rendered, then the cost center is considered to be "revenue generating". Even if the FCRC program is provided as service or research only, without charge to the patient, establishing a cost center may be advantageous for tracking indirect costs and revenues from related services, e.g., the amount that the radiology cost center recovers from providing mammograms for patients and their relatives referred by the FCRC program.

FCRC programs are funded by a variety of mechanisms including private donors, institutional foundation funds, one-time start-up grants, support from one or more departments, direct service billing, public moneys, and research granting mechanisms. Standards have not yet been developed for billing for FCRC. A national survey was conducted in 1996 of 110 GC members of the NSGC Cancer Special Interest Group about their current billing and record keeping practices.⁴⁶ These genetic counselors saw families in clinical service clinics, research studies, or in settings where clinical care and research are undertaken, most often at a comprehensive cancer center or research institute.

About one third of genetic counselors billed for FCRC in 1996. There was a wide range of billing codes and fees summarized in Tables 3 and 4. Over 80% billed under a supervising or participating physician's name, according to who was present and the level of service, based on the amount of time, type, and complexity of service. When seeing multiple family members, half charged a flat family fee. The ICD-9 codes varied depending on who was seen, e.g., most counselors billed using the "V" ICD-9 codes for family history of cancer for unaffected individuals and cancer diagnosis for persons with cancer. Many programs were not able to obtain exact reimbursement rates from their institutions.⁴⁶

Billing and reimbursement experiences with genetic testing also varied widely. In 1996, the majority of counselees were at risk for hereditary breast cancer and were seen in a research setting, reflecting the state of test availability in 1995–6. Estimated rates of testing uptake among eligible persons varied from 0–75%, with an average of

Table 3. Familial Cancer Risk Counseling and Testing Billing and Reimbursement

Billing Method	Revenue To	Sources of Support
Group fee/superbill	Unique cost center	Patient billing, institutional support, grant funds
Fee for each service	Each cost center providing service	Patient billing, institutional support, grants
No bill	None	Grant funding, donations

30–40% of patients who were offered testing deciding to pursue it. The percentages of patients whose insurance company covered testing at that time depended on the disease being tested as well as national, state, and local insurance laws and the differing policies of specific insurance companies. Many genetic counselors had patients who chose not involve their insurance company and to pay for a visit, and/or testing, out of pocket.⁴⁶

There remain many potential barriers to successful billing and reimbursement in the current healthcare environment. These include:

- lack of a specific billing code(s) for genetic counseling, necessitating need to bill as physician consultation, out-patient office visit, or preventive care;
- no licensure for genetic counselors;
- the time-consuming nature of FCRC;
- the perception by third-party payers that genetic counseling falls into a category of prevention or education;
- specific billing idiosyncracies through different practice plans; and
- confusing billing mechanisms, e.g., for facility fees.

Other issues may also be addressed, including creating superbills inclusive of the team, using stacking codes, and choosing CPT/ICD-9 codes with highest reimbursement potential and favorable division of revenues.

Information Management

Patient Records. It has been a longstanding practice within the genetic counseling field to maintain within the genetics department “shadow files” on patients and families seen in genetics clinics. Genetic testing results should be treated as extremely

Table 4. Familial Cancer Risk Counseling Billing Types and Fees

Type of Billing Code	Charges
Consultation codes	\$50–\$340
Outpatient visit	\$30–\$226
Preventive Medicine	\$25–\$225
Other/Unsure	various

Adapted from Bernhardt, Peshkin, Yemiel, 1997.

private, and every effort should be made to guarantee confidentiality within the medical care and health insurance systems. Generally, limited portions of the genetics file are entered into the institutional medical record. However, the exact type and extent of cross-documentation varies widely. In their 1996 survey of genetic counselors, Bernhardt et al.⁴⁶ found that in FCRC, shadow charts are universal; however, only 20% send a complete consultation to the patient's institutional medical record. Even when a consultation summary is sent to the medical records department, references to testing decisions and genetic test results are often omitted. Incomplete charting can further complicate billing practices, as well as confuse efforts at achieving coordinated care. However, many feel that these steps are justified in order to protect the client's privacy, confidentiality, and minimize opportunities for employment or insurance discrimination. Others take the approach of fully documenting genetic assessment and testing in notes to the referring physician, but clearly mark these as being exempt from being copied or sent to other parties (Wendy Rubinstein, 1998, personal communication). Typically, results are released to a referring physician, other health professionals, insurers, or even family members only with a patient's written authorization.⁴⁶ The patient needs to be told and fully comprehend the implications of the fact that even in the most secure situations, complete protection can never be guaranteed.

Access/Privacy. There are different practices for research and clinical record-keeping in the U.S.⁴⁷ At a minimum, the privacy of clinical FCRC records should be as private as any medical records. It is best to keep records in locked files and secured computer databases, with access limited to members of the department who have a specific reason to read or handle them. Computer databases should have access limited by security codes. It is best that data sent to common databases be stripped of identifying information, whenever possible.

When FCRC occurs in the research setting, charts, records, and test results can be protected by certificates of confidentiality.⁴⁸ These are government issued documents that protect research files from release to third parties, except under specific legal conditions. However, once test results are given to the patient for medical management decisions, the certificate can no longer protect the genetic information from further disclosure in the healthcare system. Also, one family member may disclose information about another. Thus, genetic research also is not without risk of discrimination.

Referral and Scheduling Mechanisms and Processes

Generally, two types of clients will be referred to the FCRC: those with a personal cancer history and those with a family history of cancer. Specific relatives may be at average or at increased risk for certain cancers based on their family history and other risk factors.

The marketing and advertising strategies of the FCRC will determine how individuals become aware of, and are referred for, consultation (see Table 5). Mass marketing of the FCRC services through local and regional print and broadcast media could trigger a substantial number of inquiry calls that result in referrals. For example, Stadler and Mulvihill,²⁷ held a press conference with local TV and radio stations to announce the newly formed Cancer Genetics Program, a joint undertaking between the University of Pittsburgh Medical Center and Magee-Womens Hospital. In addition, a letter introducing the services of the program was mailed to more than 5000 physicians of different specialties. During the two weeks following the announcement, over

Table 5. Marketing and Advertising the Familial Cancer Risk Counseling Program

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- Direct mailing to current and previous patients
 - Direct mailing to professionals
 - Brochures and fact sheets in clinical areas
 - Cancer Information Services
 - Direct advertisement in newsletters, media
 - Mail materials in response to inquiries
 - Presentations at local, national, international meetings
 - Lecture to private lay and community health organizations
-

250 calls were received and 60 persons were scheduled for appointments. Over the next three years, the number of calls to the program monthly has been influenced by what marketing efforts were undertaken at that time (Stadler, personal communication, 1998).

Given the current environment of healthcare and the prevalence of managed care, most clients are referred by their physician. Patients under certain types of insurance plans need an authorization to be seen if they intend to submit the cost of consultation for reimbursement. It is also important to note that if a patient is physician referred, the CPT code for billing purposes allows one to bill at a higher rate as a consultation (vs. an out-patient visit) provided that other evaluation and management requirements are met.

Referrals to the FCRC originate from many different sources (see Table 6). They can be straightforward, such as a client calling to schedule an individual appointment based on physician recommendation or self-motivation. Referrals may also result from screening questionnaires that the FCRC program supplies to various specialty cancer clinics and private physicians' offices. No matter how the referral was made, an efficient scheduling mechanism is essential to the success of the clinic.

Clearly, the FCRC must have a clinical supervisor or program coordinator to oversee the daily operations and ensure a smoothly running service. Sometimes the coordination functions are divided between two individuals, one clinically oriented, and the other with administrative or operations expertise (Peters, personal communi-

Table 6. Sources of Referrals for Familial Cancer Risk Counseling Program

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- Genetics clinics
 - Oncology service
 - Direct self-referral
 - Cancer Information Service
 - NCI/PDQ Cancer Genetics Directory
 - Radiology and mammography
 - Surgery, general, oncological, and reconstructive
 - Gynecology/Obstetrics
 - Gastroenterology clinics
 - Managed care systems
 - Cancer support groups
 - Public health agencies
 - Professional organizations/networks
 - Clinical diagnostic laboratories
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tion). Preferably, the clinical coordinator will be a genetic counselor with a strong clinical background and experience in cancer risk consultation who can triage referrals, respond to professional inquiries, and provide clinical services. Generally calls come via a designated scheduling telephone line or information hotline to a central scheduling desk. At the time of referral, the scheduler records demographic information along with the reason for referral. Referral information should be entered into a computerized database so that a permanent and searchable record of all calls is available. It is important to record these referrals for compiling program statistical summaries, and for future reference. Sometimes, intake forms, questionnaires, and/or medical record requests for diagnosis documentation will be sent out at the time of scheduling so that the consultation time may be utilized efficiently.

Quality Assurance, Quality Control, Evaluation, Satisfaction

Quality assurance (QA) is obtaining an acceptable measurable level of performance; quality improvement (QI) is the incremental increase in level of performance; and total quality management (TQM) is the whole process which includes quality assurance and improvement.⁴⁹ The issue of quality medical care is a concern not only in the US but internationally. The World Health Organization definition⁵⁰ of quality assurance (QA) in healthcare was established in 1989:

... to assure that each patient receives such a mix of diagnostic and therapeutic health services as is most likely to produce the optimal achievable health care outcome for that patient, consistent with the state of the art of medical science, and with biological factors such as the patient's age, illness, concomitant secondary diagnoses, compliance with the treatment regimen, and other related factors; with the minimal expenditure of resources necessary to accomplish this result; and with maximal patient satisfaction with the process of care, his/her interaction with the healthcare system, and the results obtained.

On the national level, the NSGC held a workshop in 1992 to begin addressing QA efforts at the institutional, state, and regional levels.⁵¹ A 1996 survey by the QA sub-committee of the NSGC found that the most common QA measurements across different types of institutions are patient surveys or letter/chart review.⁴⁹ Few centers collect follow-up or outcome information. Fewer centers utilize a QA committee, peer review practices, survey referring physicians, hold case conferences or participate in a formal QA program. Efforts are under deliberation by the American College of Medical Genetics, the American Society of Human Genetics, NSGC and various regional genetics networks to describe and document the value of genetic services.

Evaluation of genetic counseling has been approached in a number of ways, depending on the aspects of genetic counseling which one most highly prizes. Some of these are similar to quality measures used in hospitals to satisfy state and federal regulators of healthcare. These types of measures may include assessments of professional competence, counting of clinic visits or contributions to lessening decreased morbidity and mortality due to genetic conditions. Decreased burden of disease is often difficult to demonstrate in health systems where quarterly or annual accounting are the norm; in contrast, genetic conditions may take decades or generations to develop. Despite these limitations, effectiveness of genetic counseling programs, which identify rare genetic disorders in individuals at risk, make it possible to use the knowledge of the natural history of the condition to design appropriate surveillance protocols to maxi-

mize the likelihood of desired health outcomes.⁵² For example, reductions in screening costs and disease morbidity have been demonstrated in von Hippel-Lindau syndrome,⁵³ MEN2,^{54,55} and HNPCC.⁵⁶ Genetic counselors are also actively involved in formulating meaningful, outcome-oriented guidelines for practice and developing methods to evaluate the effectiveness of genetic counseling.⁵²

With regard to the genetic educational and counseling aspects of genetics, there have been studies of patient knowledge, information retention, emotional reactions to genetic information or judgements regarding the influence of genetic counseling on risk perception, decision-making, and reproductive intentions. Some have criticized these approaches as shallow and irrelevant.⁵⁷

Uniform counseling guidelines for specific situations, self-assessment tools, elements required in genetics centers, standardized letters and glossary paragraphs to enable continued improvement, quality of care indicators, staff functions, and minimal standards of care are all in various stages of development. Additional methods include looking at formalized peer review of genetic counseling skills and consumer involvement in the development of genetic counseling materials.⁵² Several concrete issues to consider in establishing FCRC programs of high quality are addressed below.

Board Certification. The theory, practice, and professional development of genetic counseling has evolved over these past 25 years as advances in genetics have produced applications which require increasingly complicated healthcare decisions. In order for the purchaser and/or consumer of FCRC services to know that the professional has adequate training in genetics, it is useful to examine professional qualifications. Since 1996, genetic counselors have adopted practice-based competencies for accreditation of and training in graduate programs in genetic counseling.⁵⁸ The four domains of competency are communication skills, critical-thinking (including calculation of genetic risks), interpersonal counseling and psychosocial assessment, and professional ethics and values. Professionals offering genetic counseling are trained at the M.D., Ph.D., or M.S. level and are usually certified by the American Board of Genetic Counseling (ABGC) and/or the American Board of Medical Genetics (ABMG). Board certified genetic counselors are recognized by the CGC initials; medical geneticists are certified by the American Board of Medical Genetics, and may use the FACMG designation, referring to membership in the American College of Medical Genetics. Genetic counselors who specialize in cancer genetics can be identified by membership in the Cancer Genetics Special Interest Group (CA-SIG) of the NSGC.

Patient Satisfaction. While the flurry of genetics research has increased the possibilities for cancer genetic counseling and susceptibility testing, there has been little attention given to satisfaction with such services. Stadler & Mulvihill²⁷ argue that "periodic self-inspection and evaluation of nascent programs are needed to ensure that cancer genetics programs are meeting the needs of the physicians and patients they are intended to serve". Therefore, after one year of operation of a FCRC program, they surveyed participants about how the cancer genetics services were perceived and how much information was retained about the consultations in order to modify and enhance the counseling service.

Overall, Stadler & Mulvihill^{26,27} found that their clinical service met the needs and expectations of most counselees seen in the first year, 1995. They found that patient satisfaction was high with regard to the length of the consultation; along with the

summary letter and attached pedigree, it was worth the expended time and money, and met client expectations. Clients reported the best parts of the experience were having personalized information, learning that cancer risk was lower than thought, allowing cleansing of one's conscience of burdensome guilty feelings, realizing that one had been justified in suspecting the inheritance of cancer in one's family, and just having a chance to talk about cancer.

The satisfaction survey also allowed for feedback to improve the FCRC service. For example, clients placed a great emphasis on the size and appearance of office space, prompting the program to move to a larger counseling room. Other issues that clients mentioned were frustration about wanting DNA testing without having to involve certain family members, and collecting all family records before the appointment. Several found it difficult to revisit unresolved psychosocial and family issues around the family history of cancer. Many worried about possible insurance discrimination.

Solutions to some of these concerns are possible, others will require deeper systemic changes. Perhaps an enriched psychotherapeutic component might help to transform some of the unresolved emotional issues. In response to frustration about family records, the program relaxed the criteria as to which records were truly needed prior to consultation and focused efforts on reviewing records for ambiguous or crucial histories or key relatives. Staff also helped participants secure essential records. Other concerns about fair access to services, privacy and confidentiality of medical information, and the specter of discrimination will require economic and political solutions.

Other forms of outcome studies will also be needed to test the worth of FCRC programs. For example, while there are many studies on the amount of information that patients can remember following counseling, simple recall fails to assess the additional dimensions of interpretation, i.e., how patients make sense of medical information; and commitment, i.e., how patients evaluate the providers' ideas in the context of their own explanatory models and how they plan in using this information to guide their subsequent behaviors.^{57,59} Lea and colleagues⁵² have gone a step further in incorporating consumers in design of patient-oriented materials.

PROGRAMMATIC ASPECTS OF A CANCER GENETICS PROGRAM

While the call for genetic counseling for familial cancers has sounded for decades,⁶⁰⁻⁶² widespread establishment of FCRC clinics is just beginning. In fact, even within NCI-funded comprehensive cancer centers, deficiencies and inconsistencies in cancer genetics services have been identified.³⁹

Coordinating a successful FCRC program is analogous to irresistible cooking. Just as the successful chef requires ingredients of good quality, has the proper cooking appliances, a tested recipe, a sense of what flavors complement each other, and creative improvisation to create the many courses of a gourmet meal, so too the successful FCRC program director collects the essential ingredients mentioned in the operational section, identifies a proven recipe from other successful programs, adds a sense of what will work at the local institution, and exercises the creativity to craft a comprehensive program that satisfies creator and consumer alike. Next we shall consider the components of such a program (see Fig. 1).

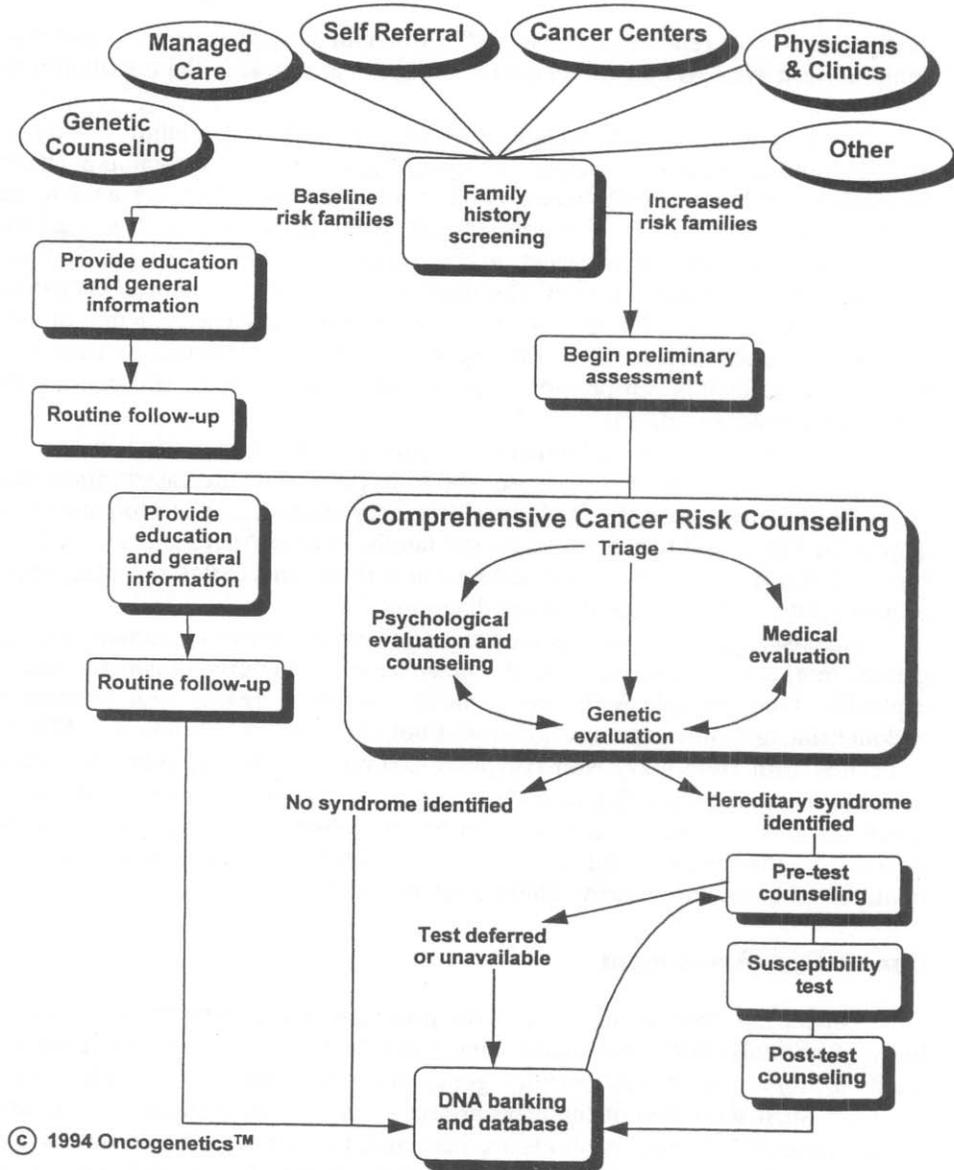


Figure 1. Cancer risk assessment and counseling protocol.

Ascertainment, Screening, and Triage

It has been estimated repeatedly that about 5–10% of most of the common cancers have strong hereditary components due inherited germline mutations.⁴ In addition to the public health import, this figure represents a significant number of families for any oncology practice. This places significant burden on the oncologist to correctly identify and treat these cases accordingly. One way to meet the challenge is by developing a useful family history screening tool to consistently monitor one's clinical population. The screening tool can range from a single sheet that

asks patients to list relatives and cancers^{25a} (Mulvihill & Stadler, 1996), to sophisticated, computerized systems that can generate pedigrees and stratify the population by risk category.⁶³

The preliminary report highlights this point about the use of family history screening. Mulvihill & Stadler²⁶ reviewed 187 gynecological and family planning charts and found that 47% had no family history of any kind noted, and 26% noted a family history limited to cancer. To correct this deficiency, they devised a two page self-administered family history questionnaire, which was completed by 266 out of the 269 patients approached in a six-week period. The forms took about five minutes for patients to complete. On review, 14% of completed questionnaires gave evidence of possible increased risk for cancer. This study suggests that self-administered cancer family history questionnaires can provide a quick and efficient way to aid identification of families for genetics referral.

The purpose of this preliminary screening is NOT to make a definitive genetic diagnosis, but rather, to identify those who have potentially increased cancer risk and merit further evaluation. In families with cancer clusters, it is customary to take a genetic pedigree, and further evaluate the family. Because there is evidence that self-reported family history may be inaccurate at certain cancer sites, the clinician, nurse, or geneticist should document cancer diagnoses.⁶⁴

Increasingly, there will be molecular means of screening tumors for specific genetic markers that may indicate the presence of an underlying genetic cancer susceptibility. One example is the microsatellite instability (MSI) seen in some colon, endometrial, and other cancers. Some (but not all) cases of high levels of MSI can be associated with Hereditary Non-Polyposis Colorectal Cancer (HNPCC).⁶⁵ While the yield of this genetic screening seems low at present, one could foresee a day when additional markers may be available to improve the sensitivity of molecular screening of tumors to enhance the oncologists' ability to understand biological responses, tailor treatment choices, and improve clinical outcomes.^{66,67}

Cancer Risk Assessment

Cancer risk assessment refers to the process of quantifying the statistical probability of an individual's developing cancer due to the presence of variables such as family history, cancer susceptibility genes, lifestyle, environmental exposures, and chance.⁶⁸ Most modeling of familial clusters of cancer has been done in relation to breast cancer.^{23,69-75} These methods are best suited to women who do not have a recognized hereditary cancer susceptibility syndrome; hence, these models are not reliable for a truly high risk woman carrying a germline mutation. In hereditary cancer families, women may be at significantly higher risk for more than one type of cancer, e.g., ovarian cancer in persons carrying *BRCA1* mutations or thyroid disease or cancer in those with *PTEN* mutations causing Cowden disease. Further, risk assessment should be offered in the context of genetic counseling, where the implications of risk notification can be explored and risk reduction discussions can occur.

Medical Management of Genetic Risk

Medical management of cancer is on the verge of a revolution. For example, in the traditional model, a colon cancer patient would be treated with standard

therapy determined by the size and stage of tumor. At-risk relatives might be identified through family history and offered screening. The advent of genetic testing changes the equation. Now genetic testing offers the prospect of customizing treatment for the cancer patient and identifying more accurately which relatives would benefit from enhanced cancer surveillance and prevention and which could be spared these costly and anxiety-producing strategies since they are not at increased cancer risk. Furthermore, those who know *prior* to developing cancer that they bear a deleterious, cancer-predisposing gene mutation could be prepared at the time of diagnosis to incorporate this genetic information into their treatment decision-making.

Medical management will vary with the situation and answers to questions such as the following. Does the proband have present or past cancer? Is the proband an unaffected relative at risk? Is the person a relative with cancer who is coming for genetic testing only for the sake of another relative, but who does not want to use genetic information personally for deciding medical management?

Clients seen in current FCRC programs usually assume that they are at high risk for developing cancer and are interested in what they can do about it. Many people seek cancer risk assessment, with or without testing, to pinpoint their cancer risk, get reassurance, and/or to help them decide what medical surveillance or preventive strategy to pursue. Often, people in families with many affected individuals may already be engaged in heightened surveillance; however, they may seek reassurance about the appropriateness of this strategy. Others with negative DNA test results may have difficulty abandoning their habits of heightened surveillance. While the medical management benefits of knowing genetic mutational status are clear-cut in some cancer predisposing disorders such as MEN2 or VHL, definite benefits have yet to be established in others, e.g. most notably, in hereditary breast or breast-ovarian cancer syndrome and HNPCC.^{76,77} Genetic testing is also an opportunity to deal with the emotional and relational aspects of coping with inherited cancer risk. The FCRC program should have current medical management options available at the time of counseling as well as referrals to colleagues in other specialty areas for ready referrals.

One venue where genetic screening can make a significant impact is in the multi-disciplinary case conference or the treatment planning conference.^{78,79} Cases being presented for consideration of treatment options should have very detailed family histories taken and evaluated to identify sub-groups at significantly increased risk for developing second primary cancers or malignancies at different organ sites due to a hereditary germline mutation. We predict that genetic information will increasingly be integrated into every aspect of clinical care.^{66,67} While the testing for genetic mutations in breast cancer susceptibility genes is still expensive, cumbersome, and too slow for making immediate clinical treatment decisions at present, genetic testing is already augmenting biochemical and imaging strategies for management of other cancers. For example, DNA testing for mutations in the *RET* gene in medullary thyroid cancer, for *VHL* mutations causing von Hippel-Lindau disease, and for protein-truncating alterations of the *APC* gene for classical Familial Adenomatous Polyposis (FAP) are being successfully integrated with medical screening into clinical care of patients within affected kindreds. Thus, having a cancer genetics program can potentially reduce medical liability of failing to recognize genetic diagnoses which could alter medical management.

Genetic Susceptibility Testing for Hereditary Cancer

Genetic testing is not like other tests where test batteries are ordered with minimal discussion between physician and patient and, subsequently, only abnormal results discussed. Therefore, the Task Force was created by the National Institutes of Health (NIH)-Department of Energy (DOE) Working Group on Ethical, Legal, and Social Implications (ELSI) of Human Genome Research to review genetic testing in the US and to make recommendations to ensure the development of safe and effective genetic tests. The Task Force's final report has expanded the discussions of safety and effectiveness from a narrow definition of validity and utility to include also genetic test delivery in laboratories of assured quality and their appropriate use by health care providers and consumers.⁸⁰

Genetic counseling should both precede and follow genetic testing.^{36,68,80-84} For this reason, genetic testing should be considered a multi-step process, first assessing risk and determining likelihood of positive results, then choosing a particular test and laboratory and discussing details of a specific test, disclosing test results, discussing implications, and dealing with reactions and medical management.

Patients should be told at the outset that genetic testing is not for everyone. Testing is most typically helpful in families likely to have a deleterious mutation. Each center should set its own policy establishing statistical and psychosocial thresholds for when testing will be offered. Before widespread genetic screening is undertaken in the general population, many scientific and ethical issues must be addressed. Questions remain regarding the role of genetic, nutritional, and environmental factors in modifying the expression of cancer susceptibility gene mutations, as well as the frequency and penetrance of these mutations in the population at large. We also need to know the safety and effectiveness of genetic screening and establish mechanisms to ensure high quality control of test laboratories, and for adequate genetic education and informed consent processes for every person considering testing.⁸³ Furthermore, improvements in prevention and treatment of inherited cancers are needed before the genetic tests can truly make large differences in disease rates and outcomes.

Genetic counseling plays a crucial role in the genetic susceptibility testing process.^{4,16,31,36,68,81} Genetic counseling in conjunction with quantitative risk assessment should be offered to evaluate the appropriateness of testing, and incorporated into pre-test and post-test discussions with the patient of the costs, risk, benefits, limitations, and implications of testing. It is especially important to discuss the worth of the test result for the individual and the family.

Pre-test Genetic Counseling and Informed Consent. Genetic discussions are woven into the informed consent process.^{3,37,82} Informed consent in genetic testing must accurately and completely describe the information necessary for individuals to make fully informed decisions regarding whether or not to partake in predisposition testing.⁸⁴ Informed consent often involves transmitting extensive information about the description of test procedures, specificity and sensitivity of a given laboratory method, possible test results, implications of results to the patient and relatives, and risks, benefits, and limitations of currently available tests. Counselees should understand that DNA testing is voluntary, and that there are viable alternatives to testing at present, e.g., medical screening or tissue storage for DNA testing at a future date when test characteristics and cost are likely to improve. The possible test outcomes typically are not

a clear all-or-nothing answer to questions about risk, but rather, they imply a relative increase or decrease in the probability for developing one or more neoplasms. The possibility of an inconclusive test result (either false positive or false negative) should be thoroughly discussed with counselees prior to testing in order to minimize later misunderstandings, disappointments, or outright errors in interpreting test results, as has already been demonstrated in APC screening for FAP.⁸⁵

Genetic Test Disclosure. Most people are nervous as they await test results, generally becoming more so as the disclosure date approaches. In cases of newly developed DNA tests, results may take months or even years to become available, while others are commercially available in a few weeks. For this reason, it may be necessary to maintain contact by telephone and/or to repeat some of the pre-test counseling and update the family or personal medical history when results are given. However, in all cases, genetic test results, whether positive or negative, should be disclosed in person to the individual tested in straightforward language and with a compassionate manner. Consultands are encouraged to bring a support person with them to provide emotional support, to ask questions that the consultand may not raise, and to help recall the details of the discussion afterwards. At disclosure of test results, individuals generally focus on their personal cancer risk, medical management options, and the testing of other at-risk relatives, including children. It is important that the counselor be attentive to subtle emotional reactions, and undercurrents of awkwardness, secrecy, avoidance, resentment or guilt in the family dynamics.

Follow-up to Genetic Counseling and Testing. The effects of genetic counseling and DNA testing have been demonstrated to be long-lasting in other genetic conditions,^{86,87} and we assume that hereditary cancers will be similar. Therefore, FCRC programs should make provisions for the availability of follow-up services for consultands and relatives for at least one year following testing. This follow-up should be offered to those with negative and inconclusive test results, as well as those with positive results, since adverse and unexpected effects have also been seen in those receiving decreased genetic risk.⁸⁸

Psychosocial Aspects of Genetic Counseling

As was mentioned in the genetic counseling section, the goals of genetic counseling go beyond medical goals of reducing disease incidence, morbidity, and mortality. Genetic counseling is also concerned with the adjustment of the individual and the family to the condition. Even the goals of education and medical decision-making are deeply influenced by psychological factors. For example, it has been long argued that counselees may not be able to hear, understand, remember, or assimilate information if they are having an emotional response to what is being presented.^{15,42,89,90} Despite this recognition, genetic counseling is often confused with genetic education, perhaps because the counseling aspect is more difficult to describe accurately. However, there is a slowly accumulating body of literature by social scientists who use participant observation, interviews, transcript analysis, and other qualitative methods to enrich our understanding of genetic counseling interactions.^{59,91,92}

Although genetic education is vital to ensuring informed consent for genetic testing, the psychosocial issues go far beyond the education process. Lerman and Croyle²⁰ emphasize that psychological processes permeate nearly all aspects of clinical

risk identification and reduction programs. To work successfully with patients and their relatives about genetic risk in meaningful ways, genetic counseling should be considered a process that deals simultaneously with informational content and psychological implications.

Lerman and Croyle²⁰ identified program components that can help prevent and manage adverse reactions to the disclosure of genetic status. These components include: providing pre-disclosure education and informed consent, bolstering coping skills, facilitating decision-making, identifying the need for referrals, and protecting patient privacy. Several of these issues will be discussed below.

Familial Cancer Psychosocial Assessment. Psychosocial evaluation within genetic counseling can be brief or comprehensive depending on the setting, reason for referral, the family needs, and the training and expertise of the genetic counselor, nurse, psychologist, or social worker. Assessment strategies should encompass individual, family, religious, and cultural considerations. This evaluation includes an assessment of the motivation for seeking genetic evaluation, the expectations of what would be gained from a genetics consultation, and the experiences, beliefs and attitudes about the condition in the family as well as standardized psychosocial information. It is important to get a sense of language usage, background knowledge, and level of medical sophistication in order to blend one's counseling style with their views and vocabulary. The psychosocial history also includes inquiry regarding previous emotional problems, current levels of functioning, and perception of one's own risk, as well as the responses to that risk on emotional state and daily function, general worldview of optimism or pessimism, and coping style and strategies.

In genetic conditions, the family is the patient. Because genetic conditions affect whole families, the spouse or family members may be invited to the counseling session. The genetic counselor, nurse, or social worker will often form a gestalt of family beliefs and attitudes, communication patterns, and family constellation and dynamics around information-sharing, secrecy, power distribution, and support systems. The counselor asks explicitly about employment, insurance status, native language, ethnicity, and educational level. The personal experience of genetic risk may be influenced by the closeness of relationship to affected individuals, psychological identification with affected individual, impact of disease on affected individuals, and one's developmental issues.

Testing for cancer susceptibility usually proceeds without undue psychosocial distress (Lerman, et al., 1996). However, there may be subsets of persons at emotional risk who exhibit fragility in the face of significant stressors. For example, Croyle, et al.⁹³ found that *BRCA1* gene mutation carriers manifested significantly higher levels of test-related psychological distress compared with non-carrier relatives; the highest levels were observed among mutation carriers with no personal history of cancer or cancer-related surgery. Recognizing persons who are psychologically vulnerable to becoming distressed through the counseling or testing processes is of paramount importance, since these are persons most helped by psychosocial interventions.⁹⁴ There should be psychiatric referral protocols and resources in place, prior to the need for them to handle unexpected crises. Providers should be prepared to defer the drawing blood for testing or providing test results if the person seems seriously depressed, suicidal, or unusually anxious, lacks all social support, or is dealing with intense grief reactions or other stressful life events. A consideration in the establishment of the FCRC is inviting a mental health professional to play a key role on the inter-disciplinary team, both on an ongoing basis, and as needed for crisis referrals.

Genetic Counseling Psychosocial Interventions. While the literature about psychological implications is growing, there is not yet a clear connection between psychosocial characteristics and interventions. Some believe that there is therapeutic value in the cancer genetic counseling experience, regardless of whether or not a person is considering having genetic testing.^{1,2,68} For instance, genetic counseling can be an opportunity for the individual to untangle confusions and misunderstanding about genetic risk for cancer and to face up to and make meaning of past history of cancer in oneself or one's family.²⁷ Some individuals appreciate the chance to talk openly about cancer, while others find this aspect of cancer risk assessment unpleasant or threatening. Positive test results may lead to increased feelings of control, relief from uncertainty, and greater motivation to pursue cancer monitoring. On the other hand, knowledge that one carries a mutation in a cancer susceptibility gene could result in closer identification with affected relatives and greater fear of cancer⁸² while negative results may engender relief and joy, and lessen depression, anxiety and cancer worry.^{20-22,36}

There are also family benefits from undergoing genetic evaluation and supportive counseling. "Testing is performed on an individual basis, yet each result has implications for other family members"³⁶ (p. 95). The FCRC program needs sufficient structure so that individuals and families know what to expect, yet be flexible enough to proceed differently with different families depending on their unique needs and preferences. For example, some families operate in secrecy about testing, while others prefer to attend counseling together, and openly share test results. As a general rule, the family members should be the ones to disseminate information through the family rather than the FCRC staff. Having adequate family systems assessment of family communication and decision-making patterns can help in planning a strategy that will be most likely to work well in a given family.

One of the most important ways that the genetic counselor may be helpful is identifying and working to remove psychological barriers to recommended medical screening. Kash et al.⁹⁵ have shown that women attending a high-risk breast cancer prevention program had impaired follow-through with cancer screening recommendation in inverse proportion to their anxiety levels. Addressing this observation, they found that a short, psycho-educational support group including genetic counseling helped to alleviate the anxiety and improve medical screening.

SUMMARY

Genetic counselors are uniquely prepared to offer FCRC service due to specialized education, counseling expertise, and technical understanding of genetic disease. In our experience, the following recommendations are most helpful in beginning a cancer genetics program.

- Establish a multi-disciplinary team with strong leadership, stable administration, collegial exchange, and close coordination of family services to handle the diverse needs of families with hereditary cancers.
- Set realistic goals. A FCRC program cannot be established quickly, or become an overnight success, but rather, should be considered a cornerstone for future oncology practice.
- Consider the mission statement the first step and develop the program around the mission.

- Shadow other programs of compatible size, resources, and goals to find the right recipe for your institution.
- Insist on program excellence.
- Plan ahead both for program success and growth and also for the increasing incorporation of genetic advances into all phases of cancer prevention, screening, diagnosis, and treatment.

RESOURCES

A timely and focused summary of other internet oncology resources is available.⁹⁶ For additional information about genetic counseling and cancer genetics, visit the following web sites:

- National Society of Genetic Counselors—<http://www.nsgc.org>
- Genetics Professional Societies—<http://www.faseb.org>
- American Cancer Society—http://www.cancer.org/index_4up.html
- Alliance of Genetic Support Groups—<http://www.geneticalliance.org>
- National Human Genome Research Institute (NHGRI)—<http://www.nhgri.nih.gov>
- National Cancer Institute (NCI) CancerNet—<http://cancernet.nci.nih.gov>
- OncoLink, University of Pennsylvania—<http://www.oncolink.upenn.edu>
- Genetic Education Center—<http://www.kumc.edu/gec>
- National Action Plan on Breast Cancer (NAPBC)—<http://www.napbc.org>

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