

Coming of Age in the Community Setting

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Coming of Age in the Community Setting

by Heather Hampel, M.S., C.G.C.

Cancer genetic counseling is a unique specialty that has found its niche in cancer centers across the country during the past few years. Prior to the 1990s, researchers had not yet identified any genes responsible for hereditary forms of the common cancers (e.g., breast and colon cancer). As a result, most clinical cancer genetics programs in existence prior to 1990 generally recorded the most dramatic cancer family histories, drew blood for research studies attempting to identify such genes, and waited. This type of research-oriented service did not generate revenue and was reserved for the larger cancer centers with research affiliations. The families who benefited from these services were usually well known to the cancer hospital because they were generally large families with multiple members affected by and being treated for cancer at their institution.

Genes that are responsible for hereditary forms of many of the common cancers have since been

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discovered. In particular, the discovery of the BRCA-1 and BRCA-2 genes responsible for hereditary breast-ovarian cancer (in 1994 and 1995, respectively) has heralded the beginning of the new service-oriented cancer genetics. Cancer genetic counseling has become a viable service that is increasingly in demand by patients with cancer and the general public as well, perhaps due to the strong voice of the breast cancer lobbyists, or the commercial interest of the laboratories benefiting from BRCA genetic testing. Whatever the cause of this strong demand, the media have publicized this story and the public is responding.

GENETIC TESTING MOVES INTO THE COMMUNITY

The larger academic centers continue to provide genetic counseling services for the known hereditary conditions, maintaining a strong research element and generating data on which the smaller centers rely for their counseling. However, with much trepidation, many smaller community cancer centers are entering the cancer genetics arena themselves. In this issue, Presant and Knell describe a comprehensive cancer genetics program in existence for two decades and closely resembling the larger research-oriented centers. In contrast, Halperin and colleagues explain how their smaller cancer center has teamed up with a larger, established genetics entity

to provide cancer genetic counseling for a single hereditary cancer susceptibility syndrome, hereditary breast-ovarian cancer. There are many models to follow, but they are all united by the participation of cancer genetic counselors who provide the counseling as members of the multidisciplinary cancer genetics team.

Many patients initially perceive genetic counseling as the means to attain their desired end result: genetic testing. These patients invariably find the counseling session valuable, and many decide not to pursue genetic testing as a direct result of the session. Many will discover that their family history reveals an extremely low probability of cancer related to hereditary causes, while others choose not to be tested after considering the potential for insurance discrimination. Some individuals receive a recommendation to begin the genetic testing process with another family member who has had cancer. Unfortunately, many others determine that they cannot afford to undergo genetic testing. Certainly many individuals do eventually proceed with genetic testing, but they do so having all the necessary information. True informed consent can be obtained only in a setting that includes genetic counseling.

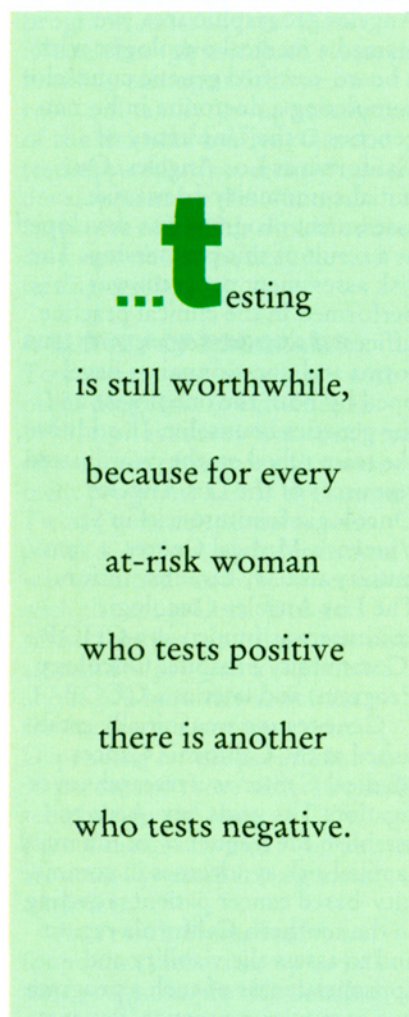
The decision to undertake prophylactic measures has been greatly facilitated by the availability of

genetic testing. Women with a BRCA gene mutation in their family now can determine whether or not they have inherited the family mutation before making decisions about screening and/or prophylactic surgeries. Women who do inherit a mutation can make these major decisions about screening and prophylactic surgery with the absolute knowledge that they are at increased risk. Women who do not inherit a known family mutation have the same risk for developing cancer as women in the general population. This type of reassurance is very powerful information.

Some opponents of cancer genetic testing argue that the medical community is unable to offer anything to a woman who learns that she has tested positive for hereditary breast-ovarian cancer. However, these same opponents will concede that testing is still worthwhile, because for every at-risk woman who tests positive there is another who tests negative.

THE PAYOFF

With lengthy counseling sessions, and traditionally poor levels of reimbursement, how can the small cancer center afford to provide this service? It is important to consider the indirect income that cancer genetic counseling programs bring to the institution. No one leaves a cancer genetic counseling session without receiving cancer surveillance guidelines. Most individuals



seen by the cancer genetics clinic will have a somewhat elevated risk for a particular cancer or cancers; thus, more often than not, referrals are made within the institution for these cancer screening

procedures. Some individuals at the highest hereditary risks for developing cancer will consider prophylactic surgery to remove at-risk organs. Individuals who are not at increased risk for developing cancer are given the American Cancer Society guidelines for screening in the general population.

For the small cancer center that elects to begin providing this service, perhaps the payoff will come in the form of gratitude from those who benefit from cancer genetic counseling. This type of service serves as an empowering process that puts individuals back in control of their cancer risk management.

For the centers that do begin to offer cancer genetics services, it is critical to hire experienced cancer genetic counselors and cancer geneticists. As with any medical specialty, if cancer genetics is not practiced with care, more harm may result than good. Clinical cancer genetics as evidence-based oncology and cancer genetic counseling remain in their infancy. Most importantly, all caregivers should recognize potential hereditary cancer and refer any individuals to competently trained cancer geneticists and cancer genetic counselors, working in partnership with oncologists, nurses, social workers, and other members of the oncology team, whether at their own institution or at other nearby medical centers. ■