Guest Editor’s Note

Hereditary Cancer: Fertile Ground for Collaborative Care

Mary Jane Esplen, RN, PhD

Recent genetic discoveries from the Human Genome Project are leading to new ways of assessing and managing health and disease. Gene-based diagnostic tests for the most common hereditary cancer syndromes are currently being performed and the benefits of risk evaluation are readily apparent. When a genetic mutation is present, healthcare providers can be vigilant for symptoms of disease and, together with the patient, can maintain active surveillance for early signs of illness. In addition, knowing that one is at substantial risk for developing cancer may help individuals avoid or prepare for it by taking steps that will prevent disease onset and by understanding that important psychosocial issues and concerns will need to be addressed at different life stages.

The presence of a genetic mutation for cancer will confirm a person’s sense of being at increased risk, resulting in a lifelong “continued uncertainty” as to whether or not they will develop the disease. Sometimes individuals who test positive are provided with options such as prophylactic surgery and/or chemoprevention that are difficult choices to make for individuals who are currently disease-free. Individuals who test negative may have difficulty integrating this new information into their “high-risk” personas and may feel out-of-place in their otherwise “high-risk family.” For those already affected with the disease, genetic testing involves the burden of notification to other family members, including offspring. Additional concerns of individuals and families include legal and ethical issues, such as insurance and confidentiality of the genetic information obtained through testing.

The global implementation of these new genetic services is driving the development of new policies in the area of ethics, clinical care guidelines and educational initiatives, for both professionals and the public. Primary care has the potential to play a key role in the delivery of genetic services in the future and the psychosocial implications of this personal genetic information will also naturally involve an intersection between primary care and psychiatry.

In the first article of this issue, Sean Blaine, BSc, MD, CCFP and colleagues, outline and highlight the key issues and challenges that the provision of genetic information for disease creates for individuals, families, and frontline healthcare providers, specifically primary care physicians. In many ways, this health-related information, and the provision of psychological support and screening recommendations, is a natural extension of the primary care providers’ traditional role. However, the probabilistic nature and uncertainty of the genetic information and the potential psychological and behavioral impact of this knowledge on patients and their families is unique in medicine and may require close collaboration between primary care providers, genetics specialists, and mental health service providers.

David K. Wellisch, PhD, notes that the prior experience of cancer in the family is powerful and can have a profound impact on a woman’s sense of self and her own cancer risk. Through his studies and clinical experience he identifies a number of important predictors of increased difficulties in adaptation and coping stemming from prior family experience with cancer. Important issues such as age of the woman at the time of the family member’s breast cancer diagnosis, the survival or death of the family member, the number of afflicted relatives, as well as the pre-cancer coping, support, and communication capacities of the family system can play a role in an individual’s adaptation to risk information. He describes specific clinical manifestations along with guidance on relevant and effective interventions.

Wendy K. Kohlmann, MS, CGC and Susan K. Peterson, PhD, provide an overview of two colorectal cancer syndromes: familial adenomatous polyposis (FAP) and hereditary non-polyposis colorectal cancer. They describe the genetic counseling process associated with these syndromes and key psychosocial issues. FAP is frequently diagnosed at a young age and brings forward specific issues involving youth and family in counseling. Key issues such as family communication patterns and barriers and the frequently encountered feelings of guilt associated with passing a disease on to offspring are highlighted through case examples and the literature. In addition, the case examples point to a number of ethical concerns faced by practitioners when family issues impede the disclosure of test results in a family.

Next, Chanita Hughes, PhD, brings a significant component to this issue through her synthesis of the current literature on cultural issues in cancer genetics. This is an area where further research is strongly needed. The role of culture in the genetic counseling process is becoming increasingly apparent. Individuals from different cultures may vary in their interest in genetic test/risk counseling, how they interpret a test result, how they cope with and adapt to risk notification, as well as in behavior.

Many women who have lost a close relative to cancer experience distress and inaccuracy around their breast cancer risk. Mary Jane Esplen, RN, PhD, and Jonathan Hunter, MD, report findings on loss and grief from a study of supportive-expressive group therapy developed specifically for women with a family history of breast cancer, with the goals of addressing the emotional impact of their prior experience. Supportive-expressive therapy with its focus on the emotional impact, prior loss, threat of mortality, support, and expression of emotions, appeared to be effective in dealing with prior loss and attending to the emotional impact, resulting in improvements in comprehension of risk.

It is my hope that this issue of Primary Psychiatry is timely in the sense that it will serve to highlight a number of key issues involved in dealing with individuals and their families who are at risk for developing cancer. The implementation of these new services will require careful planning and thinking about potential issues that may surface in order to promote optimal use of this new technology.

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