

The Need for Public Education: “Surveillance and Risk Reduction Strategies” for Women at Risk for Carrying BRCA Gene Mutations

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The “clinical management recommendations for surveillance and risk reduction strategies for hereditary breast and ovarian cancer among individuals carrying a deleterious BRCA1 or BRCA2 mutation”¹ provided by Canada’s National Hereditary Cancer Task Force will benefit women who have tested positive for the autosomal-dominant inherited BRCA gene mutation. However, as no public education campaign has made Canadian women aware of their risk, many will continue to develop BRCA gene-related premenopausal breast cancer and ovarian cancer without having had the opportunity to decide whether they want counselling regarding testing for BRCA gene mutations that could make them candidates for “surveillance and risk reduction strategies.”

It has been more than a decade since BRCA gene mutations were related to autosomal dominant-inherited premenopausal breast cancer^{2,3} and ovarian cancer^{4,5} and since their high prevalence (1–2%) and high penetrance (approaching 80%) in Jewish women was understood.^{6,7} (BRCA gene mutations have also been related to breast and ovarian cancer in other ethnic groups, including French-Canadians⁸ and Icelandics, although with lower prevalence and penetrance.⁹) It has been almost a decade since the Society of Obstetricians and Gynaecologists of Canada contributed to the only public education endeavour

in Canada regarding BRCA gene-related breast and ovarian cancer when it supported the workshopping of early scenes of the play *Sarah’s Daughters*.¹⁰ This play brought knowledge of BRCA gene-related cancer to more than 2000 Canadians in 10 cities. Research that used this play in 2003 and 2004 to explore the use of theatre in health-policy development¹¹ suggested a continued lack of knowledge of BRCA gene mutations among women at high risk, health professionals, and the general public.

Carroll et al.¹² and Warner et al.¹³ have identified the need to provide Canadian family physicians with information about BRCA gene-related cancers and have been developing educational materials that family physicians can use to inform their patients about risk and prevention strategies. Although family physicians are the most important source of health (and disease) information, risk determination, and disease prevention strategies, responsibility for education and determination should not rest solely with family physicians. Rather, a public education campaign is required.

A public education campaign providing information on the relationship of BRCA gene mutations and breast and ovarian cancer is important for several reasons. First, an increasing number of Canadian women do not have a family physician. Second, women have a right to know how to assess their own risk of breast cancer rather than having to rely completely on their family physicians. This is of particular importance when there are too few family physicians, and the time they can allot to their ongoing education is limited and variable. This is particularly important in relation to BRCA gene cancer, which was not part of medical school training for the vast majority of physicians. Similarly, variability exists in the time physicians can allot to the nuanced family history and ethnicity inquiries that are required for returning as well as new patients with respect to BRCA gene

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mutations. This is particularly important, as many of the ancestors of the Jewish women at risk may have perished in the Holocaust, and if the survivors and the majority of their descendants are male, a family history of breast cancer may not be apparent.

Women receiving public education will be able to participate in assessing their own risks and determine whether to ask their family physicians about access to genetic counselling and, potentially, surveillance and risk reduction strategies. For example, women who are informed that almost 2% of Jewish women carry a BRCA gene mutation¹⁴ and who believe they might be at risk can choose to disclose this to their family physicians and discuss their risk and the opportunity for genetic counselling.

A large-scale public education campaign analogous to that for the prevention of lung cancer is required so that all Canadian women at high risk will have access to "surveillance and risk reduction strategies for hereditary breast and ovarian cancer." In the United States, public education about BRCA gene mutations has been through the direct-to-consumer advertising of biotech companies, with provision of potentially confusing and even frightening information. In Canada, public education should occur through publicly funded strategies.¹⁵ Not all women at high risk will choose to have BRCA gene-related counselling and subsequently choose to know whether they carry a BRCA gene mutation. Not all of those found to carry a BRCA gene mutation will decide to employ surveillance and risk reduction strategies. However, all women at high risk deserve the choices education can provide.

More than a decade has passed since a large-scale public education campaign could have begun in Canada and provided information and strategies that ultimately could have prevented thousands of women from suffering premenopausal breast cancer or ovarian cancer (or both). Even one woman dying from these potentially preventable cancers, without the knowledge and therefore the opportunity to prevent them, is too many. Professional organizations such as the Society of Obstetricians and Gynaecologists of Canada should take a leadership role in promoting a public education campaign now. Only when this public education occurs will all Canadian women at high risk of developing BRCA gene-related breast and ovarian cancer be able to

benefit from the recommendations of the National Hereditary Cancer Task Force regarding surveillance and risk reduction.

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