

Addressing the psychological impact of BRCA testing

A genetic predisposition to cancer is not the same as having cancer. Support for patients with the BRCA gene mutation should meet these unique needs.



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REBECCA McLAMARA, RN, OCN

Oncology nurses are most often addressing an affected cancer patient when discussing treatment options. In the realm of genetics, however, often the same organizations that treat persons with cancer also address the needs of persons with a genetic mutation, or a hereditary predisposition to developing cancer: a *previvor*. But what is a cancer previvor?

FORCE (Facing Our Risk of Cancer Empowered), a national nonprofit organization dedicated to support and advocacy for persons at high risk for hereditary breast and ovarian cancers, defines a *previvor* as “a survivor of a predisposition to cancer.”¹ The risk of breast cancer for carriers of the *BRCA* gene mutation is up to 84%, compared with 8% for persons without the genetic mutation.^{2,3} A person whose risk for cancer is associated with a diagnosed genetic mutation would be considered a previvor.

Considering the difference between survivorship versus previvorship, the psychological distress of previvors could be distinctly different from that of survivors. The impact of weighing treatment options for a known cancer, or a history of cancer, may be different from the impact of weighing those same options as prevention strategies. For example, a woman who does not have cancer would be considering a radical procedure such as a bilateral oophorectomy. In effect, she will go into the surgery for the most part as a well person, but soon afterward, she will experience all the issues that come with menopause.

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TABLE 1. Quality of life of BRCA mutation carriers

QoL scale	Controls	Previvors	Survivors
Well-being (emotional)	80.0±2.6	70.6±2.3 ^a	74.0±2.21 ^a
Limitations/emotional	93.1±2.4	84.1±4.0 ^a	75.6±6.0 ^a
Physical functioning	89.3±4.8	91.9±2.1	85.1±3.4
Limitations/physical	95.5±2.1	92.0±3.02	70.3±6.5 ^{ab}
Pain	86.9±3.3	84.6±2.69	74.6±3.8 ^{ab}
General health	79.3±2.7	69.9±2.6 ^a	67.7±2.6 ^a
Social functioning	89.7±2.7	83.5±2.6	80.0±4.0
Energy/fatigue	62.8±3.3	54.3±2.6 ^a	52.2±3.6 ^a

Key: QoL, quality of life. ^aP<.05 Controls ^bP<.05 Previvors

Guilt and grief can also be associated with the diagnosis of a genetic mutation. Women, often in the position of caregiver and care promoter, are now confronted with the associated cancer potential not just for themselves, but their sisters, brothers, children, and other family members as well. However, other sources of psychological distress may also be factors in quality of life (QoL) for previvors. An interesting point to consider is whether these sources of distress are different from those of BRCA-positive cancer survivors, or do the two groups of mutation carriers experience similar amounts of psychological distress.

While developing a genetics program, we considered a few issues voiced by BRCA mutation previvors. One issue was referrals to cancer support groups as a source of support. The women expressed feeling out of place in those support groups and not able to voice concerns with cancer survivors, as they had not had cancer. Another issue articulated was frustration with making treatment decisions. The previvors stated many times that they were not prepared for the side effects of preventive surgery and the impact of those side effects on their relationships.

QUANTIFYING DISTRESS

In a study by the Center for Genetics and Hereditary Disease at Celebration Health, data were collected on the psychological needs of BRCA mutation carriers via surveys during the 2012 annual FORCE Conference. Surveys used were the Rand 36-Item Health Survey, Beck Anxiety Inventory (BAI), General Practice Physical Activity Questionnaire (GPPAQ), and a general questionnaire, as well as anthropometrics and a 3-day food diary. Other issues studied in relation to psychological well-being included vital signs, sleep, sex life, and associated impediments (ie, vaginal dryness,

reduced desire, and poor body image). The participants were given all the survey results in an information packet the same day they took the surveys as well as information on healthy lifestyles and disease prevention. A total of 107 people were included in the study: 36 survivors of breast and ovarian cancers who had the BRCA mutation, 45 previvors with the BRCA mutation, and 26 controls with no history of cancer or BRCA mutations.

In the domains associated with physical functioning, the cancer survivors reported a statistically significant decrease in quality of life compared with previvors and the control group (Table 1). Both groups of BRCA mutation carriers had a significantly greater level of anxiety than the control group (P<.0001). Emotional distress was also more prevalent in the BRCA mutation carriers than in the control group, as evidenced by their lower scores (P=.02) on the SF-36 emotional scales. Significant effectors of psychological status (P<.05) included BRCA mutation diagnosis, quality of sex life, and presence of associated impediments. These findings were consistent with the consensus of focus groups that took place during the FORCE Conference. Participants expressed anxiety and lower emotional status. Findings from the study support concerns voiced by BRCA mutation carriers.

Continued assessment of quality of life in BRCA mutation carriers is essential.^{4,5} Due to the significant decrease in cancer risk by many of the hereditary breast and ovarian cancer (HBOC) risk-reducing strategies, a strong argument can be made for BRCA testing. However, health care providers must also consider the emotional toll the decision to undergo testing, and the potential diagnosis, take on patients and their families. Providing adequate information

Resources for patients

These Web sites provide information, support, and resources that address the specific needs of patients with a genetic or hereditary predisposition to cancer.

FORCE Facing Our Risk of Cancer Empowered
www.facingourrisk.org

Bright Pink
www.brightpink.com

Myriad
www.myriad.com/patients/

In addition to referrals for support organizations, these patients need referrals for genetic counseling and behavioral health counseling.

prior to and after testing is the responsibility of anyone who recommends genetic testing. Genetic counselors should be consulted to ensure appropriate counseling is given to anyone who is considering testing or learning to cope with the results. Previvors and cancer survivors with BRCA gene mutations have greater psychological distress (lower emotional QoL, higher anxiety) than do people who do not carry the mutation.^{4,5}

CONCLUSION

A diagnosis of BRCA gene mutation has an adverse effect on psychological well-being. Nurse coordinators for patients who are BRCA mutation carriers need to consider the unique psychosocial needs of these patients. In addition to referrals to national and local support organizations and techniques for stress reduction, these patients need referrals for genetic counseling and behavioral health counseling.

Nurse coordinator support is invaluable to community physicians as well. Providing physicians with information on community resources and engaging them to ensure patient access to a nurse coordinator are important for maximizing support for patients with the BRCA mutation. Although physicians may understand the unique needs of these patients, they may not know where to direct patients to meet those support needs. Outreach to physicians, hospital staff, and the community are an intricate part of the coordinator role,

along with developing relationships with genetic counselors, social workers, therapists, and other psychological support specialists. Through these efforts, a safety net of support can be woven to help patients with the BRCA mutation make informed care decisions and address the effects on themselves and their families of their decisions.

The psychological stressors these patients experience should be acknowledged to ensure adequate access to support. Any health care provider who recommends genetic testing should understand these psychological stressors and plan for interventions that address the issues and impediments that can reduce patients' psychological quality of life. ■

Rebecca McLamara is the survivorship and genetics coordinator at Global Robotics Institute at Florida Hospital Celebration Health in Celebration, Florida.

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