Getting to the Point: What Women Newly Diagnosed With Breast Cancer Want to Know About Treatment-Focused Genetic Testing

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Purpose/Objectives: To identify young women's information preferences regarding treatment-focused genetic testing (TFGT) and to develop and evaluate a novel educational resource.

Research Approach: Qualitative interview study and pilot testing of a novel resource.

Setting: Two familial cancer services and one outpatient oncology clinic in Sydney and Melbourne, Australia.

Participants: 26 women with breast cancer aged 50 years and younger who either previously had TFGT (n = 14) or had a diagnosis of breast cancer within the previous 6–12 months.

Methodologic Approach: Participants were asked about their views of TFGT in semistructured interviews. A brief pamphlet on TFGT then was developed and pilot tested with 17 of the 26 women.

Main Research Variables: Women's attitudes and preferences with regard to timing, mode of delivery, and amount and format of information regarding TFGT were explored.

Findings: Most women wanted to be informed about TFGT at or around the time of their cancer diagnosis via a face-to-face consultation. No clear preference existed for which type of healthcare professional should provide information on TFGT. Brief written information about TFGT was viewed as important supporting material. The educational resource developed was well received.

Conclusions: The potential for more widespread TFGT in the future indicates a need for patient educational materials that enable women to make informed choices about TFGT. This pilot study has provided timely initial evidence on the efficacy of a brief written resource in preparing women for decision making about TFGT.

Interpretation: The resource developed in this study will assist oncology nurses to make important genetic risk information available to women newly diagnosed with breast cancer at a stressful time.

Traditionally, genetic testing for a germ-line mutation in the breast cancer protection genes (i.e., *BRCA1* or *BRCA2*) in women with a breast cancer diagnosis has been confined to those with a family history of breast and/or ovarian cancer. Testing of such women usually takes place after completion of active cancer treatment with the purpose of guiding their future risk management in relation to a new primary breast and/or ovarian cancer diagnosis. In addition, genetic risk information has significant risk management implications for a woman's unaffected genetic relatives who may themselves consider predictive genetic testing to clarify their risk of breast and/or ovarian cancer.

However, growing evidence shows that mutation status may influence breast cancer management recommendations and that benefits may arise from having genetic counseling and testing available shortly after a cancer diagnosis (Silva, 2008; Trainer et al., 2010; Tutt & Ashworth, 2008). The process, referred to in this article as treatment-focused genetic testing (TFGT), may help guide a woman's initial cancer treatment and future risk management. In the first instance, TFGT may assist with the complex decision-making process regarding a woman's surgical options, including the selection of breast conservation or a therapeutic mastectomy, with or without a contralateral risk-reducing mastectomy, based on the patient's mutation status and/or family history of cancer (Meiser et al., 2008).

In addition, evidence suggests that *BRCA*-associated tumors are more sensitive to platinum agents and potentially less resistant to taxanes (Quinn et al., 2007; Rottenberg et al., 2007; Trainer et al., 2010). Novel agents also are being tested that target *BRCA* tumors;