

Communication and Information Needs of Women Diagnosed With Ovarian Cancer Regarding Treatment-Focused Genetic Testing

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For women with an ovarian cancer diagnosis, genetic testing for mutations in *BRCA1* and *BRCA2* has traditionally been limited to those with a significant family history and only after completion of surgery and adjuvant therapy. The greatest benefit of the traditional process, arguably, has been for unaffected family members shown to be at increased risk of breast and ovarian cancer, particularly with regard to breast cancer screening and prevention, and bilateral risk-reducing salpingo-oophorectomy, which has been shown to reduce the risk of ovarian cancer by about 95% (Kauff et al., 2002; Rebbeck et al., 2002). However, new evidence suggests a change in current practice by determining a woman's mutation status at the time of her ovarian cancer diagnosis and using that information in her treatment plan (Trainer et al., 2010). This genetic testing, offered shortly after diagnosis while a woman's treatment plan is being considered, is referred to as treatment-focused genetic testing (TFGT).

Support for TFGT stems from preliminary findings that the presence of a germline *BRCA* mutation defines a genotypic subgroup of epithelial ovarian cancers (EOCs) that have distinct biologic and clinical behavior (Trainer et al., 2010). This behavior has the potential to directly impact treatment and maintenance of ovarian tumors. Importantly, the presence of a *BRCA* mutation is associated with a better prognosis compared to non*BRCA*-related EOCs of similar stage and histologic subtype (Bolton et al., 2012). *BRCA*-related EOCs are reported to have higher response rates to platinum-based chemotherapy (Chetrit et al., 2008; Tan et al., 2008) and may be less responsive to taxanes than nonhereditary EOCs (Foulkes, 2006; Quinn et al., 2007). In addition, results of phase 1 and phase 2 studies using poly (ADP-ribose) polymerase (PARP) inhibitors (i.e., novel agents that target *BRCA*-related tumors) in women with

Purpose/Objectives: To identify women's information and communication preferences about treatment-focused genetic testing (TFGT) in the ovarian cancer context.

Research Approach: A qualitative interview study.

Setting: Two familial cancer services and a gynecologic oncology clinic at a major teaching hospital in Australia.

Participants: 22 women diagnosed with ovarian cancer who had either advanced disease and had previously undergone TFGT (n = 12) or had been diagnosed in the previous 6–20 weeks with ovarian cancer and had not undergone TFGT (n = 10).

Methodologic Approach: Participants were interviewed individually about actual and hypothetical views of TFGT. The interviews were transcribed and organized into themes using qualitative analysis software.

Findings: Most women wanted to be informed about TFGT prior to their surgery for ovarian cancer. The majority preferred to receive the information verbally; slightly more women preferred their medical oncologist to deliver the information compared to a genetic specialist or oncology nurse. Women preferred the focus of pretest information to be on them and their treatment.

Conclusions: Women diagnosed with ovarian cancer want information about genetic testing early with focus placed on the potential benefits of genetic testing on treatment.

Interpretation: The findings of this study provide much-needed guidance to oncology nurses and other oncology healthcare professionals about when, what, and how information about TFGT should be delivered to patients diagnosed with ovarian cancer. Supportive patient education materials now need to be developed to assist these women in making informed decisions about genetic testing.

Knowledge Translation: Knowing that women do want TFGT, how they want it presented and by whom, and the content and level of detail that women want means that TFGT can now be presented as an option to women newly diagnosed with ovarian cancer, which may influence first-line treatment. The findings also provide the knowledge required to prepare education tools to assist oncology nurses involved in frontline care.