JMIR Cancer | The Information Needs of Patients With Ovarian Cancer

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JMIR Publications recently published *"Understanding the Information Needs of Patients With Ovarian Cancer Regarding Genetic Testing to Inform Intervention Design: Interview Study"* in JMIR Cancer, which reported that experts in gynecological cancer care recommend that all patients with invasive or high-grade ovarian cancer (OC) undergo genetic testing. However, even patients who intend to take or have taken genetic tests have many unaddressed information needs regarding genetic testing. Existing genetic counseling falls short of adequately addressing this challenge.

This study aims to investigate the genetic testing–related information needs of patients with OC to inform the design of interactive technology-based interventions that can enhance communication of genetic testing information to patients.

These JMIR Cancer authors interviewed 20 patients with OC who had taken genetic tests and gathered genetic testing–related messages from an active OC web-based community.

Data analyses produced a comprehensive taxonomy of the genetic testing–related information needs of patients with OC, which included 5 major topic clusters:

1. Knowledge of genetic testing as a medical test,
2. Genetic testing process,
3. Genetic testing implications for patients,
4. Implications for family members, and
5. Medical terminology

A multichannel information delivery solution that combines both provider-led and peer-to-peer education models is needed to supplement existing genetic counseling to effectively meet the genetic testing–related information needs of patients with OC.

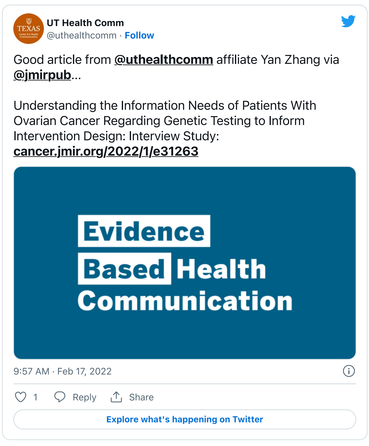
Dr. Marian Yvette Williams-Brown from The University of Texas at Austin said, *"Ovarian cancer (OC) is the second most common gynecological cancer in the United States."*

The National Comprehensive Cancer Network and The Society of Gynecologic Oncology recommend that all patients with invasive or high-grade OC undergo genetic testing as knowledge of gene mutations can inform targeted treatment as well as cancer screening and prevention options for at-risk family members.

Although attention needs to be placed on promoting genetic testing uptake among patients with OC and their family members, there are unmet information needs among those who intend to take or have taken genetic tests that also need to be addressed.

Studies have also found that some patients with cancer and patients at risk for cancer had concerns about genetic testing–associated risks, such as insurance discrimination, privacy infringement, and emotional distress.

Communication of information concerning cancer genetics and genetic services to patients needs to be improved to address patients' literacy gaps and risk concerns to enhance patient satisfaction and sense of empowerment.



These authors define patients' information needs regarding genetic testing as: *knowledge gaps that patients perceive or experience as preventing them from accomplishing genetic testing–related activities or goals.*

Yvette Williams-Brown and team concluded in their JMIR Publications Research Output that patients with OC have a need for information on various genetic testing–related topics.

Moreover, the information should be appropriate and sympathetic to the cognitive and emotional states of patients with cancer.

The patients' preferences for channels or platforms to receive information differed.

A hybrid multichannel information delivery model that combines both health care provider–led and peer-to-peer patient education efforts may be most effective in delivering genetic testing–related information to patients with cancer.

Future efforts are needed to explore the feasibility of the multichannel information delivery model and its effectiveness in promoting awareness and acceptance of genetic testing among patients and family members and in empowering them in cancer treatment and care.

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