Exploring Patient Treatment Decision Making in the Context of Ovarian Cancer Recurrence

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Purpose: The overall purpose of this program of research is to improve the shared decision making process for women diagnosed with an OC recurrence through1) Exploring the experiences of women making decisions about treatment for recurrent ovarian cancer 2) Exploring healthcare providers' experiences of clinical decision making for recurrent ovarian cancer 3) To triangulate the findings of aims 1 and 2 to provide a fuller picture of shared decision making in the context of ovarian cancer (OC) recurrence.

Methods: A descriptive qualitative study with thematic analysis of semi structured interviews and field notes related to the interview will be used to evaluate the process of decision making as experienced by women with OC recurrence and healthcare providers. The setting for this study will be the outpatient gynecologic oncology cancer care clinic at the University of Virginia Health System (UVAHS), Emily Couric Cancer Center (ECCC). The UVAHS is a research-intensive academic medical center and regional referral center serving much of central and southwestern Virginia. The ECCC is a National Cancer Institute designated institution with more than 130 researchers from multiple fields dedicated to cancer research. The gynecologic oncology program serves thousands of patients yearly, with approximately 30% being patients with OC recurrence. The clinic provides comprehensive services including laboratory, radiology, chemotherapy infusion, and consultation rooms within a single space. Women with a diagnosis of recurrent OC, including epithelial ovarian, fallopian tube or primary peritoneal cancer, and ECCC gynecologic oncology physicians and nurses will comprise the study sample. A target for patient enrollment is 30 women, although data collection will continue until saturation of findings is reached. Additionally, 8-10 healthcare providers will be recruited.

Qualitative descriptive approach using thematic analysis of semi-structured interviews and field notes will inform the exploration of recurrent ovarian cancer treatment decision-making. Trustworthiness (credibility, transferability, dependability and confirmability) will be ensured through the use of triangulation of data and persistent observation, detailed literature review and inquiry audits of process notes. Interviews will initially be read and re-read and notes written down of initial ideas. The interviews and field notes will be transcribed verbatim and imported into qualitative software to assist with data organization and analysis. Transcripts will be cross-checked for accuracy. Initial coding will be theory driven based on the decision support framework, and will include both semantic and latent codes. Collating and organizing relevant codes will lead to emergent themes. A thematic map will be developed to help visualize the analysis and to organize both candidate and sub-themes, which will then be compared to the overall data set to check for accuracy. Members of the team will cross check codes and emerging themes.

Results: To date, 19 patient participants and 8 provider participants have been interviewed. Early results reveal that patients rely heavily on the expertise of the provider for treatment decision making while maintaining open communication about values and quality of life. Concurrently, providers solicit feedback from patients about short and long term goals to determine next steps for treatment; for example, seeing a child graduate from college, or traveling abroad.

Conclusion: Exploration of the treatment decision making process for key stakeholders in an outpatient cancer clinic will provide important foundational knowledge for intervention development to build and support shared decision making for complex treatment decisions such as OC recurrence.

Title:

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References:

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Abstract Summary:

This research project explores the landscape and process of shared decision making for women diagnosed with ovarian cancer and their providers. Specifically women that have been diagnosed with a new recurrence, and how they manage that information as well as the decision to continue with treatment.

Content Outline:

Ovarian cancer is colloquially a term used for a heterogeneous variety of tumors that involve the ovary, fallopian tube, and peritoneum. (Kroeger & Drapkin, 2017). When most people use the term ovarian

cancer, it is meant to include fallopian tube and primary peritoneal cancers, and was originally thought to arise in the ovary due to repeated ovulation. It is now believed that the majority (60%) of cancers arise in the fallopian tube (Kroeger & Drapkin, 2017). However, it remains that the diagnosis of ovarian cancer includes fallopian tube and primary peritoneal cancers.

The lifetime risk of developing ovarian cancer is less than 2%, but ovarian cancer ranks fifth in cancer deaths for women and is the most lethal of the gynecologic malignancies (Oronsky, 2017). Federal Drug Administration (FDA) approved primary treatment for newly diagnosed ovarian cancer is surgery and chemotherapy with two to three agents. The response to the primary regimen is varied and depends on the stage of disease and other factors (Kim, Ueda, Naka & Enomoto, 2012), making it difficult to predict whether remission will be achieved. Approximately 80% of women diagnosed with stage III and IV ovarian cancer will experience recurrence after first line chemotherapy (Hanker, 2012).

The responses to primary treatment; platinum sensitive, platinum resistant, and platinum refractory, are used to frame decisions about treatment and disease trajectory and to determine eligibility criteria for clinical trials (Jelovac & Armstrong, 2011). The terms are defined by the progression free interval (PFI), which is from the time that the patient completes her last cycle of a platinum agent to the time that the cancer returns (progresses). Platinum sensitive disease is that in which a patient has a complete response (no evidence of disease) or a partial response (30% reduction in overall tumor burden) to chemotherapy that lasts for 6 months from the time she received her last platinum treatment. Patients with platinum resistant disease recur within six months of their last platinum treatment, and platinum refractory disease progresses during treatment. Typically patients with advanced disease at diagnosis will have resistant or refractory disease and the prognosis for patients with platinum refractory disease is poor. Response rates for refractory disease are approximately 10% with duration of less than 8 months (Spriggs, 2003; Oronsky, 2017).

With continued therapy, all patients become resistant to therapy and the duration of response diminishes with each treatment (Hanker et al., 2012). Depending on the treating institution, patients are given options for the type of treatment they would like to receive, which can be either a clinical trial or one of the FDA approved therapies. Each of the choices may have a different trajectory, side effect profile, and treatment schedule. Regardless of the option chosen, response rates are low, about 20-50% (Oronsky, 2017). The goal of treatment after recurrence is to slow progression, manage the growth of the cancer, and manage symptoms. With subsequent recurrences, the goal is to manage symptoms, prolong life, and maintain an acceptable quality of life. Because the response rates for treatment are similar but the regimens are vastly different, patient preference in terms of values, knowledge about treatment options, and her expectations for both treatment and quality of life play a major role in the decision (Jolicoeur, 2005).

Studies in related fields indicate that shared decision making can increase patient satisfaction with the decision and improve patient outcomes (Smith et al., 2011; O'Brien et al., 2009; Hollen et al., 2013). In a 2011 national survey of 1,134 adults, only 24%-38% reported a shared decision making process for cancer screening (Hoffman et al., 2014). Effective shared decision making involves a mutual understanding of treatment options, likely outcomes, and patient values and goals. Few studies have been done to evaluate shared decision making in the context of OC recurrence.

Conclusion

Exploration of the treatment decision making process for key stakeholders in an outpatient cancer clinic will provide important foundational knowledge for intervention development to build and support shared decision making for complex treatment decisions such as those experienced with recurrent ovarian cancer.

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Author Summary: I have been working with this patient population for over 10 years as both a research coordinator and nurse, with over 12 years of clinical research experience in oncology.

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Author Summary: Dr. Epstein has over 10 years of experience in moral distress research and moral distress consultation. She is an Associate Professor of Nursing at the University of Virginia School of Nursing and is Chair of the Department of Acute and Specialty Care. She is also a member of the faculty of the University of Virginia School of Medicine Center for Bioethics and Humanities.

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Author Summary: I am a nurse scientist with an interest in vulnerable cancer populations. Specifically, I am developing a program of research in the intersection of health literacy and health communication and the relationship to patient-centered outcomes.

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Author Summary: Dr. Mitchell is currently focused on the feasibility and acceptability of at-home, self-screening HPV tests as a route to upping detection of cervical cancer in underserved, rural areas, both domestically and internationally – centers on care access and cancer detection, health disparities, and

novel modalities for HPV vaccination and detection. Her current work involves a trial of a novel HPV screening test delivered by lay health navigators in rural Southwest Virginia.