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Increasing genetic counseling referral rates through bundled interventions after ovarian cancer diagnosis☆,☆☆

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HIGHLIGHTS

- Implementation of bundled interventions improved genetics referral in EOC patients.
- Genetics referrals from oncology providers yield a high rate of consult completion.
- There is a high rate of completing genetic testing after genetic counseling.

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ABSTRACT

Objective. To increase genetic counseling referrals for patients with newly diagnosed epithelial ovarian cancer (EOC).

Methods. A practice-gap analysis was performed after measuring baseline genetic counseling referral rates to identify barriers to referral from the multidisciplinary single institution EOC care group. A Genetics Referral Toolkit consisting of a referral template, a genetic risk checklist, family history worksheet and provider and patient awareness was developed to address identified gaps with the goal of increasing referral rates. Clinical characteristics, referral placement, completion of genetic counseling/testing were abstracted for a historic cohort and intervention cohort. Data for the two cohorts were compared using chi-square, Fisher's exact test, or *t*-test. Association with referral was determined by univariate logistic regression.

Results. Eighty one patients from July through December 2013 (historic cohort) and 62 patients from July through December 2015 (intervention cohort) were identified as having a new diagnosis of EOC. Among these women, genetic counseling referral rates increased from 48.1% (39/81) in 2013 to 74.2% (46/62) in 2015 ($p = 0.002$) after implementation of the toolkit. In a subset of patients without a previous genetic counseling referral, 87.9% (29/33) completed counseling and 79.3% (23/29) pursued testing from the historic cohort. In the intervention cohort, 60% (24/40) were seen for counseling and 100% (24/24) had testing.

Conclusion. Application of a quality improvement process to create a Genetics Referral Toolkit increased the genetic counseling referral rate in patients with a new diagnosis of EOC. The majority of patients who were referred completed genetics consultation and elected genetic testing.

1. Introduction

Epithelial ovarian cancer (EOC) is expected to affect 22,440 women in the United States in 2017 [1]. Of these women, nearly 15% will harbor an inherited genetic mutation in *BRCA1* or *BRCA2* [2]. Up to another 4% will be associated with mutations in other elevated risk genes in the *BRCA* or mismatch repair pathways [2]. These mutations have effects on the patient's risk of other cancers as well as implications for family members. Further, poly (ADP-ribose) polymerase (PARP) inhibitors,

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which target aberrant mismatch repair pathways, are treatment options recently FDA-approved that show increased benefit in patients with *BRCA* mutations [3]. Since 2007, the National Comprehensive Cancer Network (NCCN) has recommended that all patients with EOC be referred for genetic counseling and genetic testing [4]. The Society for Gynecologic Oncology (SGO) has also recommended universal genetic evaluation since 2014 [5]. Despite these national recommendations, genetic counseling referral rates in this population remain low ranging from 14.5% to 23.0% [6–9].

Not only are patients with EOC recommended to receive genetic counseling and testing, patients appear to consistently desire genetic testing with reports of 92.5–99.0% of counseled patients pursuing testing when offered [6,9]. Patients have also reported a desire for early genetic testing—as early as at the time of diagnosis—yet studies repeatedly demonstrate genetic counseling referrals are more often initiated far later and frequently not until first recurrence [10,11]. Patients cite evaluation of personal and family cancer risks, treatment decision making, and determining possible etiology for developing EOC as reasons to pursue genetic testing [10,12,13]. Given the high rate of patient acceptance of genetic counseling and testing, barriers to genetic testing need to be identified and mitigated.

Identified barriers to testing include lack of provider knowledge regarding genetic testing guidelines and services, reliance on provider initiation for testing, lack of patient knowledge about genetic testing and benefits of testing, patient fear about testing results and potential out of pocket costs [14,15]. In contrast to testing and referral for breast cancer, for which patients are required to meet additional criteria such as family history, early age of cancer diagnosis or specific hormone receptor expression to determine appropriateness of genetic counseling referral, women with EOC are universally recommended to undergo genetic testing, thereby removing the guideline checklist as a barrier [4]. Several centers have attempted to address other barriers and to increase genetic counseling referral rates. The University of Minnesota created an automated computer reminder program to alert practitioners of genetic counseling referrals for patients with EOC, and was able to increase their referral rates from 17 to 30% [16]. Princess Margaret Hospital increased their rate of genetic counseling by implementing automatic scheduling of genetic counseling appointments for patients referred with a diagnosis of EOC [10]. Kaiser Permanente Northern California employed automated, electronic letters to alert practitioners of patients' genetic counseling referral eligibility to improve referral rates [7].

Such quality improvement (QI) measures in healthcare employs processes aimed at identifying and rectifying areas of need at a systems-based level. Here we report on a multidisciplinary QI process to improve genetic counseling referral rates at Mayo Clinic. A preliminary analysis of our practice showed that 17% of all EOC patients, including those newly diagnosed, those with recurrence and those in remission, had genetic evaluation from January 2012 to December 2013. The primary goal of the QI project was to increase the rate of referral to genetic counseling to 75% for patients newly diagnosed with EOC seen at Mayo Clinic. A secondary aim was to determine if a patient's age, personal history of another cancer, serous histology, grade of cancer, stage at diagnosis or having a first or second degree relative with cancer were associated with genetic counseling referrals in our studied population.

2. Methods

2.1. Study setting

Mayo Clinic Rochester is a tertiary care center with a large referral base. Patients with EOC are seen in two settings: a) within the division of gynecologic oncology surgery where at the time of the project there were 7 board-certified gynecologic oncologists and b) within the division of medical oncology where 4 board-certified medical oncologists and 1 board-certified gynecologic oncologist saw all women with EOC undergoing chemotherapy. All patients referred to genetic counseling were seen by either one of three certified genetic counselors or one medical geneticist in 2013 or one of six certified genetic counselors or one medical geneticist in 2015 prior to undergoing genetic testing. Genetic testing was only ordered by a genetic counselor or medical geneticist. The genetic counseling practice is located in a separate setting from the gynecologic surgical practice and the medical oncology practice.

2.2. Project design

A multidisciplinary team was created to evaluate the genetic counseling referral process for EOC patients at Mayo Clinic. Team members included representatives from gynecologic surgery (surgeon, allied health staff, nurse, administrative, resident and fellow), medical oncology (oncologist, allied health staff, and nurse) and genetics (geneticist and genetic counselors). The team met five times over the course of four months to plan the project using DMAIC (Define, Measure, Analyze, Improve, Control) methodology. A goal was set to have at least 75% of women referred to genetic counseling following their EOC diagnosis.

2.3. Design of toolkit

The multidisciplinary team convened to develop a bundled toolkit to improve the rate of genetic counseling referrals for patients with a new diagnosis of EOC (Fig. 1). The toolkit consisted of measures to increase patient, Mayo Clinic provider and referring provider awareness of the guidelines for genetic counseling referral. Education sessions were held to familiarize providers from medical oncology, gynecologic surgery and genetics at Mayo Clinic with the national recommendations for referral, information regarding genetic testing, the goals of the quality improvement project, and components of the toolkit. This education was also incorporated into the quarterly gynecologic surgery resident/fellow orientation to ensure continuous reinforcement of guideline-based care.

Upon presentation to their outpatient preoperative or prechemotherapy appointment, patients with suspected or confirmed EOC were provided with a printed risk of hereditary breast and/or ovarian cancer checklist designed by the Minnesota Ovarian Cancer Alliance (MOCA) [17]. Following surgery, inpatients also received written recommendations in their hospital summary with the rationale for genetic counseling referral. For consistent messaging, these written recommendations were made available using a simple shorthand template. The provider-placed electronic order for outpatient genetic consultation was standardized to occur prior to hospital discharge. This prompted schedulers to coordinate the genetic consultation with the patient's 6-week postoperative examination appointment and mail the patient a family cancer history worksheet which allowed patients an opportunity to gather and complete the history information prior to their genetics consultation. Patients not planning to follow-up at the institution after surgery had a letter sent to their referring provider which included the genetic counseling referral recommendations.

2.4. Data capture

After obtaining Institutional Review Board approval, data on a historic cohort from July 1, 2013 to December 31, 2013 was retrospectively collected using chart and electronic order review. Clinical data generated after implementation of the Genetics Referral Toolkit was collected prospectively for patients seen from July 1, 2015 to December 31, 2015. All patients seen in gynecologic surgery or medical oncology with a new diagnosis of Stage I–IV EOC during these time periods were included in the analysis. Clinical pathology review was used to exclude patients with non-epithelial ovarian cancer, cancer metastatic to the ovary from other primary sites, and borderline ovarian tumors.

Data collected included age at EOC diagnosis, histology, stage, grade, primary treatment (neoadjuvant chemotherapy, primary debulking),

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