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Disparities in genetics assessment for women with ovarian cancer: Can we do better?

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HIGHLIGHTS

- Fifty-three percent of ovarian cancer patients are being referred for genetic services.
- Disparities exist for race/ethnicity and language in referral rates for genetic evaluation.
- Inclusion of genetic counseling into surgical pathways may help expedite patient navigation.

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ABSTRACT

Objective. We sought to characterize referral patterns for genetic counseling for women with ovarian cancer and hypothesized that differences in referral and testing rates are shaped by socioeconomic factors.

Methods. Patients were identified by pathology reports from August 2012 to January 2016 containing the words "serous" or "ovarian." Patient information was obtained via electronic medical record. Primary outcomes were placement of a genetics referral and completion of counseling. A secondary outcome was completion of genetic testing.

Results. We identified 246 women with a diagnosis of ovarian cancer. Ten were previously counseled and excluded. 53% of patients were referred for counseling with mean time from diagnosis to counseling of 4.6 months. Age and family history were not associated with referral, however rates differed by race with 61% of Caucasian and 40%, 38% and 33% of Asian, Latina and Black women, respectively, referred ($p = 0.035$). Overall, 36% of patients diagnosed underwent counseling, and 33% were tested. English language ($p < 0.0001$), high-grade serous histology ($p = <0.0001$) and private or Medicare insurance ($p < 0.0001$) were significantly associated with referral.

Conclusion. We have not yet reached the Society of Gynecologic Oncology recommendation for referral to genetics. Women of color and those with public insurance have lower referral rates. This disparity in care impacts cancer treatment options and prevents appropriate screening for other hereditary malignancies. To provide comprehensive oncology care, including genetic assessment, we recommend focusing on these barriers including improving outreach and interpreter services.

1. Introduction

Ovarian cancer is the second most common gynecologic malignancy in the United States. Approximately 22,000 women in the United States will receive a new ovarian cancer diagnosis each year with up to a quarter being associated with hereditary mutations [1].

BRCA1 and *BRCA2*, as well as other genes in the homologous recombination repair pathway, account for the majority of hereditary ovarian cancer syndromes and approximately 20% of ovarian cancer cases [2]. Other genes also increase the risk of gynecologic cancers including those implicated in Lynch Syndrome – accounting for up to 2% of ovarian cancer cases – and Cowden Syndrome [3]. In 2014, the Society of Gynecologic Oncology (SGO) issued a clinical practice guideline recommending genetic counseling and testing for all women with ovarian cancer [4]. Current National Comprehensive Cancer Network (NCCN) guidelines recommended genetic testing for all women with ovarian, fallopian tube or primary peritoneal cancer, regardless of family history [5].

The Surveillance, Epidemiology and End Results (SEER) data estimates that women in the general population have a 1.3% lifetime risk of developing ovarian cancer. In contrast, meta-analyses estimate the risk of an ovarian cancer diagnosis in women with *BRCA* mutations to be approximately 39–49% for *BRCA*1 and 11–18% for *BRCA*2 mutation

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carriers [6–8]. Assessment of patient risk for other malignancies directly informs further screening and management. Additionally, identification of certain mutations may affect choice of therapy for gynecologic cancer — for example, the use of platinum-based chemotherapy or PARP inhibitors [9,10].

The literature suggests that less than one third of ovarian cancer patients are referred to genetic counseling nationwide, and minority populations are underrepresented in these studies [11,12]. Since provider referral patterns affect patient access to genetic assessment, various interventions have been implemented to increase referral and testing rates including standardized referral forms, multi-disciplinary genetics lead conferences, integration of counseling into clinic or chemotherapy appointments and direct physician-ordered testing without counseling. The goal of this study was to characterize referral patterns for genetic counseling and testing, and to evaluate potential barriers for intervention and quality improvement.

2. Methods

This was a retrospective, descriptive study of women who presented to the UCSF Gynecologic Oncology practice with a known or suspected diagnosis of ovarian cancer between August 2012 and January 2016. As part of our quality assurance for the Gynecologic Oncology clinical program, we instituted a process to receive monthly pathology reports containing the words “ovarian” or “serous.” Through this mechanism, we were able to identify all cases of ovarian cancer, as well as all cases of high-grade fallopian tube and pelvic serous carcinoma. Women with benign diagnoses or who had <2 encounters at our institution were excluded as these were typically patients seen as second opinions who did not continue to receive care with us. Ten of the women identified had previously been counseled about hereditary risk and were also excluded from our cohort.

Patient demographic and diagnostic information was obtained by review of electronic medical records. Information collected included race, primary language spoken, prior and current cancer diagnoses, family history, primary insurance and zip code, which was used as a proxy for distance lived from the nearest UCSF clinic. Dates of referral to genetics, genetic counseling appointments and genetic testing were collected, in addition to disease-specific information including histologic diagnosis and stage.

Primary outcomes included placement of a genetics referral and completion of a genetic counseling appointment. A secondary outcome was completion of genetic testing. Univariate analysis was used to compare baseline patient characteristics between patients who were referred and/or completed genetic counseling and patients who were not. The Mann-Whitney *U* test was used for non-normally distributed continuous variables, the Student's *t*-test for normally distributed continuous variables and Pearson's chi square test for categorical variables. Logistic regression analysis was used to determine factors contributing to referral and completion of genetic testing. A p-value of <0.05 was considered statistically significant for all statistical comparisons. Analyses were performed using R(1) [13].

3. Results

During our three and a half year study period, we identified a total of 246 women with ovarian, fallopian tube or primary peritoneal cancer who presented to our gynecologic oncology practice and completed at least 2 visits. Ten of these women had previously been counseled about hereditary risk and were excluded from our cohort. The remaining 236 women comprised our study population and represented a diverse set of ages, racial groups, socioeconomic statuses and primary diagnoses, although the majority of patients were Caucasian and primarily English-speaking with a diagnosis of high-grade serous ovarian cancer. Full demographic information is found in Table 1. Fourteen percent of patients were Latina, 13% Asian and 4% Black, which is similar to the racial breakdown of both the surrounding San Francisco area as well as the UCSF gynecologic cancer patient population. Sixteen percent of patients were non-English speakers, including 7% Spanish-speaking and 2% Chinese-speaking patients.

Of these 236 patients, 126 (53%) were referred for genetic counseling. Of those referred, 86 (68%) completed genetic counseling, and 79 (92%) of those counseled underwent multi-gene panel genetic testing (see Fig. 1). Twenty-four percent [19] of those tested were found to have pathogenic variants including 10 *BRCA1*, 6 *BRCA2*, 2 *BRIP1* and 1 *NBN*. Twenty-one variants of unknown significance (VUS) were also identified. Two patients were found to have two separate VUS's, and one patient was found to have greater than three VUS's.

Overall, 36% of patients diagnosed with ovarian cancer received genetic counseling and were offered testing, and 33% of this total pursued multi-gene panel testing. The mean time from diagnosis to counseling completion was 4.6 months (SD 5.9).

With regard to race/ethnicity, 61% of Caucasian women were referred compared to 40% of Asian women, 38% of Latina women and 33% of Black women, respectively ($p = 0.035$). Of those referred for genetic counseling, 67% were Caucasian, 10% Asian, 10% Latina and 2% Black. Of the 86 patients who underwent counseling, 60% were Caucasian, 10% were Latina, and 10% were Asian. Fifty percent of Latina and 48% of Asian patients were non-English speakers, of whom only 31% (5 of 16) and 27% (4 of 15) were referred, respectively. Once referred, 7 of 9 (78%) underwent genetic counseling.

Age, family history, prior history of cancer and distance lived from nearest UCSF clinic were not significantly associated with presence of a genetics referral. However, referral rates differed by race, type of insurance, histology and primary language. Caucasian race/ethnicity, private or Medicare insurance, high-grade serous histology and English

Table 1
Comparison of patients with an ovarian cancer diagnosis who received genetic counseling referrals and who underwent counseling to those who did not. Data are presented in raw counts with percentages or means with standard deviations.

	Entire cohort ($N = 236$)			Referred patients ($N = 126$)		
	Referred ($N = 126$)	Not referred ($N = 110$)	p-Value	Counseled ($N = 86$)	Not counseled ($N = 40$)	p-Value
Age (mean, SD)	59 (13)	56 (16)	0.07	59 (13)	61 (15)	0.41
Race (n, %)			**0.035**			0.08
Caucasian	86 (67)	56 (51)		60 (70)	26 (65)	
Latina	12 (10)	20 (18)		9 (10)	3 (8)	
Asian	12 (10)	19 (17)		9 (10)	4 (10)	
Black	3 (2)	6 (5)		0 (0)	3 (8)	
Other	10 (8)	5 (5)		5 (6)	4 (10)	
Unknown	3 (2)	4 (4)		3 (3)	0 (0)	
Language (n, %)			**<0.0001**			0.79
English	112 (89)	86 (78)		75 (87)	37 (93)	
Spanish	5 (4)	11 (10)		4 (5)	1 (3)	
Chinese	1 (1)	3 (3)		1 (1)	0 (0)	
Other	8 (6)	10 (9)		6 (7)	2 (5)	
Insurance (n, %)			**<0.0001**			0.20
Private	69 (55)	42 (38)		51 (59)	18 (45)	
Medi-Cal	20 (16)	43 (39)		10 (12)	10 (25)	
Medicare	36 (29)	25 (23)		24 (28)	12 (30)	
Veteran's Administration	1 (1)	0 (0)		1 (1)	0 (0)	
Grade (n, %)			**<0.0001**			**0.02**
High grade serous	97 (77)	49 (45)		71 (83)	26 (65)	
Low grade serous	17 (13)	19 (17)		8 (9)	9 (22)	
Other/Unknown	12 (10)	42 (38)		3 (3)	5 (13)	
Stage (n, %)			**<0.0001**			0.75
I	22 (17)	52 (41)		13 (15)	6 (15)	
II	10 (8)	12 (11)		6 (7)	4 (10)	
III	76 (60)	36 (33)		54 (63)	22 (55)	
IV	19 (15)	9 (7)		12 (14)	8 (20)	