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ORIGINAL ARTICLE

Knowledge and psychosocial impact of genetic counseling and multigene panel testing among individuals with ovarian cancer

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Abstract

In a sample of individuals with ovarian cancer, we aimed to (a) identify factors associated with the psychosocial impact of genetic counseling and multigene panel testing, (b) identify factors associated with cancer genetics knowledge, and (c) summarize patient-reported recommendations to improve the genetic counseling and multigene panel testing process. Eligible participants in this secondary analysis of quantitative and qualitative survey data were English-speaking adults with ovarian cancer. Psychosocial impact was assessed using the Multidimensional Impact of Cancer Risk Assessment (MICRA) questionnaire. Knowledge of cancer genetics was assessed using the KnowGene scale. Significant predictors of MICRA and KnowGene scores were identified using multiple regression. Open-ended survey item responses were analyzed using conventional content analysis. Eighty-seven participants met eligibility criteria. A positive genetic test result was associated with greater adverse psychosocial impact ($B = 1.13$, $p = 0.002$). Older age ($B = -0.07$, $p = 0.044$) and being a member of a minority racial or ethnic group ($B = -3.075$, $p = 0.033$) were associated with lower knowledge, while a personal history of at least one other type of cancer ($B = 1.975$, $p = 0.015$) was associated with higher knowledge. In open-ended item responses, participants wanted clinicians to assist with family communication, improve result disclosure, and enhance patient and family understanding of results. A subset of individuals with ovarian cancer who receive a positive genetic test result may be at risk for adverse psychosocial outcomes. Tailored cancer genetics education is necessary to promote the equitable uptake of targeted ovarian cancer treatment and risk-reducing therapies. Interventions to enhance patient-clinician communication in this setting are a research priority.

Keywords Neoplastic syndromes · Hereditary · Ovarian neoplasms · Genetic counseling · Genetic testing · Psychological distress · Knowledge

Introduction

Ovarian cancer is one of the most heritable forms of cancer, with more than 20% of ovarian, fallopian tube, and primary peritoneal carcinomas associated with an inherited pathogenic variant (PV) [1, 2]. Between 30 and 44% of hereditary ovarian cancer cases occur in individuals without a known family history of breast or ovarian cancer[2, 3]; as such, the Society for Gynecologic Oncology and the National Comprehensive Cancer Network have recommended genetic counseling and testing for all individuals with epithelial ovarian carcinoma for over a decade [4, 5]. While PVs in *BRCA1* or *BRCA2* are implicated in the majority of hereditary ovarian cancers, advances in multigene panel testing have allowed for the identification of at least six additional PVs (*BRIP1*, *MLH1*, *MSH2/EPCAM, PALB2, RAD51C*, and *RAD51D*) associated with a moderate to high relative or cumulative lifetime risk of epithelial ovarian cancer [6–8]. Additional genes under investigation in epithelial ovarian cancer are *NBN* and *MSH6* [6, 9]. Accordingly, the use of multigene panel testing to identify individuals with or at increased risk for hereditary ovarian cancer is rising [10].

Clinicians have been called to adapt to evolving clinical practice guidelines and the advent of multigene panel testing [11]. Genetic test results have the potential to inform ovarian cancer treatment, prognosis, and personal and familial cancer risk [1, 4, 5]. The presence of a PV in *BRCA1* or

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BRCA2 is associated with increased sensitivity to platinum-based chemotherapy, increased sensitivity to poly-ADP ribose polymerase (PARP) inhibitors, and increased survival among individuals with epithelial ovarian cancer [1, 3]. In addition, recent studies have demonstrated that mismatch repair-deficient cancers are sensitive to immune checkpoint blockade, regardless of the cancer's tissue of origin [12].

The presence of a PV has cancer risk implications for an individual's relatives. Therefore, both positive and negative genetic test results have psychosocial implications for individuals with ovarian cancer and their families. Little research has evaluated the psychosocial impact of the multigene panel testing process on individuals with ovarian cancer, and knowledge of cancer genetics in this population has not been assessed. Given the developing role of precision oncology in ovarian cancer care, research that informs a patient-centered approach to genetic counseling and multigene panel testing in this setting is warranted.

Prior research suggests the experience of undergoing single gene or syndrome testing is not usually associated with a long-term increase in adverse psychosocial outcomes [13]. However, results from several studies suggest individuals with a prior psychiatric diagnosis may be more vulnerable to adverse psychosocial outcomes following genetic counseling and testing [14, 15]. Multigene panel testing differs from single gene or syndrome testing in that there is an increased likelihood of detecting a clinically non-actionable variant of uncertain significance (VUS). Likewise, risk profiles for PVs of many moderate-penetrance genes are not yet well-defined [16, 17], and the appropriate clinical management of individuals affected with one or more of these variants is often unclear. Given high rates of distress and uncertainty among individuals with ovarian cancer [18], improved understanding of the psychosocial impact of multigene panel testing is necessary to develop implementation strategies that preserve well-being in the face of ambiguous test results.

Multigene panel testing is essential to the identification of individuals and families affected by hereditary cancer syndromes other than Hereditary Breast and Ovarian Cancer (HBOC). Compared to single gene or syndrome testing, multigene panel testing has a higher diagnostic yield of PVs [19]. Regardless of genetic test result, the complex nature of cancer genetics information may lead to communication challenges during genetic counseling and clinical consultations. Individuals who are not confident in their knowledge of cancer genetics may be less likely to share genetic test results with relatives who may benefit from cascade testing [20]. Identifying gaps in cancer genetics knowledge among individuals undergoing multigene panel testing is therefore necessary to promote the uptake of preventive measures by individuals with hereditary ovarian cancer and their at-risk relatives.

The purpose of this study was to (a) assess the psychosocial impact of genetic counseling and multigene panel testing, (b) assess knowledge of cancer genetics, (c) identify factors associated with the psychosocial impact of genetic counseling and multigene panel testing, and (d) identify factors associated with knowledge of cancer genetics in a sample of individuals with ovarian cancer. In addition, this study aimed to summarize recommendations to improve the genetic counseling and multigene panel testing process provided by individuals with ovarian cancer. The results of this study may inform efforts to identify and assist individuals with ovarian cancer who may be at risk for adverse psychosocial or educational outcomes following genetic counseling and multigene panel testing.

Methods

This was a secondary analysis of quantitative and qualitative data collected as part of a larger study of cancer survivors' experiences undergoing genetic counseling and multigene panel testing [21]. The parent study used a convergent parallel mixed methods design. The Dana-Farber/Harvard Cancer Center Institutional Review Board approved the study procedures.

Participants

Eligible participants for the parent study were English-speaking adults with a personal history of breast or gynecologic cancer who underwent genetic counseling and multigene panel testing in the 18 months prior to study enrollment. Participants were included in the current analysis if they had a primary diagnosis of ovarian cancer.

Setting

Participants were recruited from a single National Cancer Institute-designated cancer center. The genetic counseling and multigene panel testing process at this institution has been described in detail elsewhere [21]. Briefly, genetic counseling and multigene panel testing at this institution are integrated into routine ovarian cancer care. Genetic counselors meet patients in the infusion setting or at an arranged outpatient appointment to collect a family history and provide pre-test genetic counseling prior to genetic testing. Following genetic counseling, patients select from several panels that are appropriate for their personal and family history. Genetic test results are disclosed during a telephone call from the genetic counselor, which is followed by a mailed report. Patients may request a follow-up appointment to review genetic test results, and those with findings indicative of a PV are strongly encouraged to be seen by a

cancer genetics physician and genetic counselor for in-depth discussion.

Measures

Demographic characteristics were obtained through self-report and included gender, race, ethnicity, marital status, annual household income, and educational attainment. Clinical characteristics were obtained through medical record review and included age, other cancer diagnoses, genetic test result, PV (if applicable), prior genetic testing, and number of months between genetic counseling and study enrollment. For the purposes of this study, a positive genetic test result was defined as the presence of any PV known to confer increased cancer risk, while a negative genetic test result was defined as the absence of any PV known to confer increased cancer risk. Categories of genetic test result were not mutually exclusive; for example, an individual may have received both a positive and a VUS result.

The psychosocial impact of multigene panel testing was measured with the Multidimensional Impact of Cancer Risk Assessment (MICRA) questionnaire [22]. The MICRA questionnaire is a valid, reliable measure comprised of three subscales: distress, uncertainty, and positive experience [22]. Possible total scores range from 0 to 95, with higher scores representing a more adverse psychosocial impact. Possible scores for the distress, uncertainty, and positive experience subscales range 0–30, 0–45, and 0–20, respectively. The positive experience subscale is reverse scored so that a higher score indicates a less positive experience. In the parent study, the MICRA was found to be reliable with a Cronbach alpha of 0.83 for the total scale, 0.88 for the distress subscale, 0.78 for the uncertainty subscale, and 0.77 for the positive experience subscale [21].

Cancer genetics knowledge related to multigene panel testing was measured using the KnowGene scale [23], which had a Cronbach alpha of 0.78 in the parent study [21]. The KnowGene scale was developed by members of our study team and is comprised of 19 items with three response options: "agree," "disagree," and "don't know" [23]. The total score is calculated by tallying the number of correct responses, with "don't know" being scored as an incorrect response. Scores can range 0–19, with higher scores representing greater knowledge. Items pertain to genetic test result interpretation, inheritance, screening and risk reduction, and clinical impact of genetic test results.

In addition to the above closed-ended survey measures, four open-ended survey items elicited suggestions to improve the genetic counseling and multigene panel testing process: (1) What parts of the process of genetic counseling and multigene panel testing do you think could be done differently? (2) What suggestions do you have to improve the process of genetic counseling and multigene panel testing? (3) What parts of the process of genetic counseling and multigene panel testing would you like to remain the same? (4) Is there anything else related to genetic counseling and testing that we have not discussed that you would like to share?

Data analysis

Demographic and clinical characteristics, MICRA total and subscale scores, and KnowGene scores were summarized using descriptive statistics. Specific cancer genetics knowledge needs were identified by calculating the proportion of participants who selected the correct response for each item on the KnowGene scale. Based on findings in the parent study, the following factors were assessed for potential associations with MICRA and KnowGene scores: marital status (married/partnered vs. not), educational attainment (college graduate vs. not), annual household income (less than $50,000 vs. $50,000 or more), race/ethnicity (white, non-Hispanic vs. not), pathogenic gene variant (BRCA vs. not), and genetic test result (positive vs. not, negative vs. not, and VUS vs. not) [21]. Consistent with the parent study, a square root transformation was applied to MICRA total and subscale scores to account for positively skewed distributions of these scores.

In univariate analyses, demographic and clinical characteristics associated with MICRA total, MICRA uncertainty, and KnowGene scores were identified using simple linear regression. Associations between MICRA total and subscale scores and KnowGene scores were also assessed using simple linear regression. Categorical demographic and clinical characteristics associated with MICRA distress subscale and MICRA positive experience subscale scores were identified using Wilcoxon's rank-sum test. Continuous demographic and clinical characteristics associated with MICRA distress subscale and MICRA positive experience subscale scores were identified using Pearson's correlation coefficient. Purposeful selection was used to identify variables likely to be significant predictors or confounders in multivariable models. Variables that were associated with MICRA total scores, MICRA subscale scores, or KnowGene scores with a p-value < 0.3 were entered into multivariable models. When more than one variable describing genetic test result (i.e., "positive vs. not," "negative vs. not," and "VUS vs. not") met this criterion, the variable with the lowest p-value was entered into the multivariable model. In multivariable analyses, demographic and clinical characteristics significantly associated with MICRA total, MICRA uncertainty, MICRA distress, MICRA positive experience, and KnowGene scores were identified using multiple linear regression. All statistical tests were two-tailed and defined statistical significance as $p \leq 0.05$. Given the exploratory nature of the study, no adjustments were made for multiple comparisons. Statistical

analyses were conducted using the statistical software environment R (R Core Team 2017).

Open-ended survey item responses were analyzed in NVivo Pro 11 (QSR International 2016) using conventional content analysis [24]. Author RAP conducted the initial analysis, while authors MUB and MMN reviewed and refined the coding framework. Coding discrepancies were resolved through discussion.

Results

Eighty-seven participants met inclusion criteria. Participant characteristics are provided in Table 1. Participants underwent multigene panel testing through the Ambry Genetics CancerNext, GYNplus, and OvaNext panels; the Invitae Common Hereditary Cancers and Multi-Cancer panels; and the Myriad myRisk Hereditary Cancer panel. Twenty participants (23%) had a positive genetic test result; of these, nine had a *BRCA*-associated PV and 11 had a non-*BRCA* -associated PV. Non-*BRCA*-associated PVs were identified in *BRIP1*, *MSH6*, *RAD51C*, *RAD51D*, *MUTYH*, *NBN*, and *RAD50*. Forty-three participants (49.4%) had a negative genetic test result. Twenty-seven participants (31%) had a variant of uncertain significance (VUS) on its own or in addition to a positive genetic test result. Twenty-one participants (24.1%) had previously undergone genetic testing for *BRCA1* and *BRCA2* only, and 25 participants (28.7%) had a personal history of at least one other type of cancer. The mean number of months between pre-test genetic counseling and survey completion was 12.6 (SD = 5.04).

Psychosocial impact

The mean total MICRA score was 20 (SD = 12.4) out of a possible 95, suggesting psychosocial impact varied significantly in this sample. The mean distress, uncertainty, and positive experience subscale scores were 3.93 (SD = 5.36), 10.3 (SD = 7.57), and 5.61 (SD = 5.58), respectively. MICRA score ranges and percentiles, which are provided in Table 2, suggest participants' ratings of distress, uncertainty, and positive experience were diverse. MICRA responses highlighted three stressors that were endorsed by the majority of participants who responded. Sixty-two of 84 respondents (73.8%) indicated that they "sometimes" or "often" worried about their risk of getting cancer again, 43 of 68 respondents (63.2%) indicated that they "sometimes" or "often" worried about the possibility of their children getting cancer, and 41 of 82 respondents (50%) indicated that they were "sometimes" or "often" uncertain about the impact of their genetic test result on their children's and/or family's cancer risk.

In univariate analyses (Tables 3 and 4), having a positive genetic test result was significantly associated with a higher MICRA total score, a higher MICRA distress subscale score, and a higher MICRA positive experience subscale score (indicating a less desirable genetic counseling and multigene panel testing experience). There were no statistically significant associations between any of the selected

Table 1 Participant characteristics

	N = 87 *n* (%)
Age	
Mean (SD)	65.2 (10.5)
Median [min, max]	65.0 [41.0, 91.0]
Marital status	
Not married/partnered	26 (29.9%)
Married/partnered	55 (63.2%)
Missing	6 (6.9%)
Educational attainment	
Not college graduate	30 (34.5%)
College graduate	51 (58.6%)
Missing	6 (6.9%)
Annual household income	
Less than $50,000	22 (25.3%)
More than $50,000	50 (57.5%)
Missing	15 (17.2%)
Race/ethnicity	
White, non-Hispanic	75 (86.2%)
Other	11 (12.6%)
Missing	1 (1.1%)
Ovarian cancer stage	
I/II	27 (31%)
III/IV	41 (47%)
Unknown	19 (22%)
Genetic test result	
Positive	20 (23%)
Variant of uncertain significance	27 (31%)
Negative	43 (49.4%)
Pathogenic variant (if positive genetic test result)	
Non-*BRCA*	11 (55%)
BRCA	9 (45%)
Prior genetic testing	
No	66 (75.9%)
Yes	21 (24.1%)
Personal history of ≥ 1 other type of cancer	
No	62 (71.3%)
Yes	25 (28.7%)
Months from pre-test genetic counseling to survey	
Mean (SD)	12.6 (5.04)
Median [min, max]	12.2 [4.2, 24.2]
Years from ovarian cancer diagnosis to survey	
Mean (SD)	5.4 (6.9)
Median [min, max]	2 [1, 38]

Table 2 Ranges and percentiles of MICRA and KnowGene scores

(*N* = 87)	MICRA total[a]	Distress[a]	Uncertainty[a]	Positive experience[a]	KnowGene[b]
n					
Valid	82	84	83	82	85
Missing	5	3	4	5	2
Range	1–56	0–22	0–30	0–20	3–18
Percentiles					
25th	10.25	0	5	1	10
50th	18	1	8	4	13
75th	27	6.25	16	10	14

[a]Higher scores represent a more adverse psychosocial impact

[b]Higher scores represent greater knowledge

factors and MICRA uncertainty subscale scores. In multivariable analyses (Table 5), having a positive genetic test result was significantly associated with a higher MICRA total score ($B = 1.13$, $p = 0.002$), MICRA distress subscale score ($B = 0.998$, $p = 0.012$), and MICRA positive experience subscale score ($B = 1.212$, $p = 0.002$). In addition, having an annual household income of at least $50,000 was significantly associated with a lower MICRA positive experience subscale score ($B = -0.689$, $p = 0.05$), indicating a more desirable experience among participants who reported a higher annual household income. None of the predictors entered into the model were significantly associated with MICRA uncertainty subscale scores.

Knowledge of cancer genetics

The mean KnowGene score was 11.9 (SD = 3.5) out of a possible 19. KnowGene percentile scores are provided in Table 2. Fewer than half of participants provided the correct response to five items pertaining to inheritance, clinical impact, and interpretation of genetic test results. Details regarding these items can be found in the first five rows of Table 6.

In univariate analyses, higher knowledge was significantly associated with younger age (Table 4) and an annual household income of $50,000 or more (Table 3). In multivariable analyses (Table 5), older age ($B = -0.07$, $p = 0.044$) and being a member of a minority racial or ethnic group ($B = -3.075$, $p = 0.033$) were significantly associated with lower knowledge, while having a personal history of at least one other type of cancer ($B = 1.975$, $p = 0.015$) was significantly associated with higher knowledge.

In univariate analyses, pathogenic variant type (*BRCA* vs. non-*BRCA*) met criteria for inclusion in the multivariable model. Given that pathogenic variant type only applies to participants with a positive genetic test result, a second multiple regression model assessed predictors of knowledge among these participants (Table 5). None of the predictors in this model were significantly associated with knowledge.

Responses to open-ended survey items

Four open-ended survey items elicited suggestions to improve the genetic counseling and multigene panel testing process, and participant responses to these items provided context for the quantitative survey results. Of 87 participants, 67 responded to at least one open-ended survey item, resulting in a total of 178 open-ended survey item responses. Of 178 responses, 124 (70%) were expressions of satisfaction with the genetic counseling and multigene panel testing process, while 54 (30%) were recommendations for improvement. Three major categories of recommendations for improvement were identified: (1) family communication and testing, (2) result disclosure and follow-up, and (3) understanding test results.

Family communication and testing

The largest category of recommendations for improvement related to family communication and testing. Several participants wished to have the option to engage family members early in the genetic counseling and multigene panel testing process. Family engagement was perceived to alleviate the participant's burden of processing and disseminating family genetics knowledge.

> "I think it would be helpful [if], along with the individual [being] tested, other family members who want to and should hear the results [are present during results disclosure]. …Then anyone with questions would have them answered right there and then, so it benefits all." (74 year old, negative genetic test result)

Other open-ended item respondents expressed a desire for written, audio, or visual materials that could be shared with

Table 3 Univariate associations between categorical participant characteristics and MICRA total, MICRA subscale, and KnowGene scores

	MICRA total[a]			Uncertainty[a]			Distress[b]		Positive experience[b]		KnowGene[a]		
	M (SD)	*B*	*p*	*M* (SD)	*B*	*p*	*M* (SD)	*p*	*M* (SD)	*p*	*M* (SD)	*B*	*p*
Married/partnered													
No	4.1 (1.11)	0.15	0.664	2.6 (1.3)	0.397	**0.226**†	1.21 (1.33)	0.613	2.14 (1.39)	**0.268**†	11.18 (3.67)	1.101	**0.184**†
Yes	4.25 (1.57)			3 (1.4)			1.43 (1.52)		1.8 (1.38)		12.28 (3.35)		
College graduate													
No	4.36 (1.46)	-0.253	0.451	3.03 (1.32)	-0.262	0.411	1.49 (1.54)	0.544	1.88 (1.38)	0.916	11.06 (3.36)	1.38	**0.084**†
Yes	4.11 (1.42)			2.77 (1.41)			1.28 (1.41)		1.93 (1.4)		12.44 (3.47)		
Annual household income													
< $50,000	4.37 (1)	-0.285	0.436	2.69 (1.4)	0.193	0.59	1.04 (1.39)	**0.275**†	2.41 (1.45)	**0.063***†	10.44 (3.24)	2.124	**0.014***†
≥ $50,000	4.08 (1.53)			2.88 (1.39)			1.4 (1.45)		1.71 (1.37)		12.56 (3.32)		
Racial/ethnic minority													
No	4.21 (1.45)	0.272	0.613	2.85 (1.42)	0.508	0.323	1.38 (1.47)	0.692	1.91 (1.39)	0.648	12.12 (3.32)	-1.923	**0.103**†
Yes	4.48 (1.33)			3.36 (0.8)			1.15 (1.46)		2.16 (1.29)		10.2 (4.44)		
Positive genetic test result													
No	3.96 (1.41)	1.167	**0.001***†	2.79 (1.36)	0.496	0.169	1.09 (1.38)	**0.002***†	1.7 (1.42)	**0.006***†	11.57 (3.55)	1.464	**0.108**†
Yes	5.13 (1.12)			3.28 (1.37)			2.26 (1.4)		2.7 (0.88)		13.03 (3.14)		
Negative genetic test result													
No	4.6 (1.4)	-0.764	**0.015***	3.11 (1.51)	-0.437	**0.149**†	1.82 (1.46)	**0.002***	2.05 (1.25)	0.446	12.35 (3.15)	-0.914	**0.23**
Yes	3.83 (1.37)			2.68 (1.19)			0.86 (1.3)		1.81 (1.51)		11.43 (3.81)		
Variant of uncertain significance result													
No	4.19 (1.42)	0.12	0.723	2.84 (1.29)	0.176	0.587	1.2 (1.42)	**0.191**	2.07 (1.42)	**0.183**	11.74 (3.64)	0.496	0.546
Yes	4.32 (1.48)			3.02 (1.56)			1.66 (1.52)		1.65 (1.26)		12.23 (3.21)		
Pathogenic variant (if positive genetic test result)													
Non-*BRCA*	5.05 (1.01)	0.189	0.727	3.18 (1.53)	0.242	0.715	2.05 (1.44)	0.619	2.71 (0.92)	0.74	12.29 (3.6)	1.759	**0.238**†
BRCA	5.24 (1.32)			3.42 (1.2)			2.55 (1.37)		2.68 (0.88)		14.05 (2.18)		
Prior genetic testing													
No	4.14 (1.46)	0.39	0.301	2.89 (1.35)	0.049	0.892	1.33 (1.48)	0.833	1.81 (1.36)	**0.153**†	11.71 (3.55)	0.749	0.398
Yes	4.53 (1.31)			2.94 (1.49)			1.41 (1.45)		2.34 (1.38)		12.46 (3.34)		
Personal history of ≥ 1 other type of cancer													
No	4.16 (1.43)	0.266	0.453	2.78 (1.44)	0.409	**0.221**†	1.22 (1.43)	**0.216**†	2.02 (1.4)	0.405	11.59 (3.5)	1.093	**0.197**†
Yes	4.43 (1.45)			3.19 (1.16)			1.68 (1.52)		1.72 (1.33)		12.68 (3.45)		

[a]Simple linear regression

[b]Wilcoxon's rank-sum test

*Significant at $p \leq 0.05$

†Entered into multivariable model

Table 4 Univariate associations between continuous participant characteristics and MICRA total, MICRA subscale, and KnowGene scores

	MICRA total[a]		Uncertainty[a]		Distress[b]		Positive experience[b]		KnowGene[a]	
	B	*p*	*B*	*p*	*r*	*p*	*r*	*p*	*B*	*p*
Age	− 0.016	**0.289**[†]	− 0.019	**0.183**[†]	− 0.114	0.302	− 0.022	0.841	− 0.11	**0.002**[*†]
Time from genetic counseling to study enrollment (months)	0.002	0.946	0.003	0.93	0.065	0.557	0.028	0.803	0.102	**0.19**[†]
MICRA total									− 0.12	0.664
Uncertainty									0.04	0.887
Distress									0.036	0.893
Positive experience									− 0.07	0.808
KnowGene	− 0.02	0.664	0.006	0.887	0.015	0.893	− 0.027	0.808		

[a]Simple linear regression

[b]Pearson's correlation coefficient

[*]Significant at $p \leq 0.05$

[†]Entered into multivariable model

family. As one participant who audio recorded her genetic counseling session explained:

> "I knew I was in no state of mind to remember all [the genetic counselor] would say…and it felt so very important to capture it for re-play for myself and for whomever in my family wanted to listen to the discussion." (57 year old, negative genetic test result)

Several open-ended item respondents expressed a desire for health care providers to facilitate follow-up genetic counseling and testing of at-risk relatives. Some of these participants felt that genetic testing services should be made immediately accessible to relatives following disclosure of a positive genetic test result, while others expressed a need for assistance conveying the need for follow-up testing to members of their families.

> "Until my sisters finally went through with the testing, there were many sleepless hours for me." (70 year old, positive and VUS genetic test result)
> "I wish you could send my son a letter telling him to go get his genes tested." (64 year old, positive genetic test result)

Result disclosure and follow up

Several participants identified needs related to the disclosure of genetic test results. For some, the wait to receive genetic test results was distressing. One 70-year-old participant with a negative result shared that she experienced significant "anxiety while waiting" to receive her genetic test results.

Once results were disclosed, some participants indicated that the timing and method of results disclosure served as a barrier to effective information exchange. Some explained that they would have preferred a follow-up appointment to a telephone call to review and discuss their genetic test results.

> "The first results were done via phone call, which caught me off guard. Therefore I didn't absorb all of the information." (53 year old, positive genetic test result)

Other participants expressed a desire for improved follow-up after results disclosure, both in terms of addressing psychosocial needs and assisting with the practical aspects of pursuing follow-up care. One 45-year-old participant with a negative result suggested providers "spend more time post-[results] report checking in and seeing how the patient is doing with the information."

Understanding test results

A number of participants suggested ways for clinicians to enhance patient understanding of genetic test results. These participants emphasized the importance of explaining results in simple, clear language; providing written materials to patients and families; and spending an adequate amount of time explaining genetic test results and their clinical implications. As one 66-year-old participant with a negative result shared, "for those who have no scientific background, [the explanation of results] was very difficult to understand."

Discussion

The results of this study suggest some individuals with ovarian cancer who receive a positive genetic test result report greater psychosocial impact, greater distress, and a less positive genetic counseling and multigene panel testing experience than those with negative or VUS results. Qualitative

Table 5 Multiple linear regression models to assess associations between participant characteristics and MICRA total, MICRA subscale, and KnowGene scores

	B	*p*
MICRA total		
Age	− 0.01	0.486
Positive genetic test result	1.134	**0.002***
Uncertainty		
Age	− 0.015	0.298
Married/partnered	0.413	0.221
Negative genetic test result	− 0.337	0.274
Personal history of ≥ 1 other type of cancer	0.505	0.145
Distress		
Annual household income ≥ $50,000	0.279	0.434
Positive genetic test result	0.998	**0.012***
Personal history of ≥ 1 other type of cancer	0.361	0.317
Positive experience		
Married/partnered	− 0.497	0.148
Annual household income ≥ $50,000	− 0.689	**0.05***
Positive genetic test result	1.212	**0.002***
Prior genetic testing	0.135	0.722
KnowGene (all participants)		
Age	− 0.07	**0.044***
Married/partnered	0.544	0.479
College graduate	0.799	0.293
Annual household income ≥ $50,000	1.458	0.073
Racial/ethnic minority	− 3.075	**0.033***
Positive genetic test result	1.577	0.068
Personal history of ≥ 1 other type of cancer	1.975	**0.015***
Time from genetic counseling to study enrollment (months)	0.014	0.851
KnowGene (participants with a positive genetic test result only)		
Age	0.04	0.717
Married/partnered	0.128	0.949
College graduate	0.019	0.992
Annual household income ≥ $50,000	4.319	0.13
Racial/ethnic minority	− 1.227	0.622
BRCA pathogenic variant	0.673	0.693
Personal history of ≥ 1 other type of cancer	1.076	0.51
Time from genetic counseling to survey administration (months)	− 0.044	0.777

*Significant at $p \leq 0.05$

responses to open-ended survey items may partially explain the association between genetic test result and psychosocial impact. Participants with a positive genetic test result described the psychological burden of being responsible for processing and disseminating their family's genetic information. Individuals whose genetic test results are negative may perceive fewer responsibilities related to family communication, which may explain the lower MICRA total and subscale scores in this group. Prior research assessing the psychosocial impact of single gene testing among individuals with ovarian cancer similarly found that carriers of a pathogenic variant reported greater psychosocial impact than non-carriers [25]. The current study corroborates this finding in the setting of multigene panel testing and adds the insight that receipt of a VUS result was not significantly associated with greater psychosocial impact, greater distress, or greater uncertainty.

The results of this study highlight several stressors that were encountered by participants as they underwent genetic counseling and multigene panel testing. These findings have important implications for the ovarian cancer care setting, where the prevalence of psychological distress has been estimated to range from 20 to 30% [26]. Responses to the MICRA questionnaire illustrate that nearly three-quarters of participants "sometimes" or "often" worry about their risk of getting cancer again, underscoring the prevalence of fear

Table 6 KnowGene items ordered by ascending proportion of correct responses

KnowGene item	Participant responses (*N* = 87); *n* (%)			
	Agree	Disagree	Do not know	Missing
If a person does not have a mutation found on genetic testing (negative result), interpreting results will depend on whether someone in the family has a known gene mutation associated with cancer risk (positive result)	15 (17.2)*	26 (29.9)	44 (50.6)	2 (2.3)
A variant of uncertain significance (VUS) will not likely influence recommendations for screening or prevention	23 (26.4)*	29 (33.3)	32 (36.8)	3 (3.4)
Some gene mutations mean a larger increase in the risk for cancer while others mean a smaller increase in the risk for cancer	33 (37.9)*	8 (9.2)	42 (48.3)	4 (4.6)
People with an inherited risk for cancer may get cancer at a younger age than people with average risk	38 (43.7)*	12 (13.8)	35 (40.2)	2 (2.3)
People with an inherited risk for cancer (and their at-risk relatives) are more likely to develop more than one type of cancer	39 (44.8)*	10 (11.5)	36 (41.4)	2 (2.3)
Female-specific cancer risk, such as ovarian cancer, can generally be passed on from either the father or mother	44 (50.6)*	8 (9.2)	33 (37.9)	2 (2.3)
The lifetime chance of getting cancer depends on which altered gene is inherited	47 (54)*	11 (12.6)	27(31)	2 (2.3)
If a genetic test does not identify inherited risk for cancer now, there is a chance that a mutation could be identified through future tests	48 (55.2)*	9 (10.3)	28 (32.2)	2 (2.3)
In most cases, the sisters and brothers of a person with inherited cancer risk have a 50–50 (50%) chance of having inherited risk for cancer too	48 (55.2)*	5 (5.7)	31 (35.6)	3 (3.4)
Most people who develop cancer do so because they have inherited risk for cancer	7 (8)	60 (69)*	18 (20.7)	2 (2.3)
Multigene panel testing could find a mutation in a gene that is not clearly associated with the pattern of cancer in the family	60 (69)*	2 (2.3)	22 (25.3)	3 (3.4)
All children of a person with inherited cancer risk will also have inherited cancer risk	11 (12.6)	64 (73.6)*	10 (11.5)	2 (2.3)
A person with inherited risk for cancer will definitely get cancer one day	3 (3.4)	65 (74.7)*	17 (19.5)	2 (2.3)
If inherited risk for cancer is found, there is nothing a person can do to change his/her cancer risk	4 (4.6)	68 (78.2)*	12 (13.8)	3 (3.4)
A person with an inherited risk for cancer may have distant relatives (for example, cousins) who also have increased cancer risk	68 (78.2)*	0 (0)	16 (18.4)	3 (3.4)
Knowing about inherited risk (passed down within a family) can affect choices about cancer treatments (for example, medications or surgery)	69 (79.3)*	3 (3.4)	12 (13.8)	3 (3.4)
In the future, more information could become available that could alter the meaning of genetic test results	71 (81.6)*	1 (1.1)	13 (14.9)	2 (2.3)
All of the gene mutations that could increase risk for cancer have been discovered	2 (2.3)	72 (82.8)*	11 (12.6)	2 (2.3)
The blood relatives (for example, sister, father, or child) of a person with a mutation in a cancer risk gene might share the same gene mutation	74 (85.1)*	0 (0)	11 (12.6)	2 (2.3)

*Correct answer

of cancer recurrence in this population [27]. In qualitative responses to open-ended items, participants indicated that delays in scheduling and delays in genetic test result disclosure exacerbated their concern. Indeed, in prior studies of women with ovarian cancer undergoing hereditary cancer risk assessment, participants have expressed a preference for genetic testing upon initial diagnosis [28, 29].

In the current study, some participants preferred to discuss genetic test results in person and expressed a desire for follow-up psychosocial care. A recent trial found that telephone disclosure of genetic test results is non-inferior to in-person disclosure for general and state anxiety immediately post-disclosure [30]. However, as the results of the current study indicate, face-to-face results disclosure may be preferable for some individuals. In a survey of 339 individuals who underwent *BRCA* testing, O'Shea and colleagues [31] found that participants perceived that face-to-face results disclosure facilitated information exchange and provision of emotional support. Likewise, Beri and colleagues [32] evaluated factors associated with preference for in-person result disclosure. They found that individuals who opted for in-person disclosure were more likely to be older and more likely to be undergoing multigene panel testing. Among those undergoing multigene panel testing, those who opted for in-person disclosure had lower baseline knowledge and higher distress.

While knowledge of cancer genetics was moderate in this sample of individuals with ovarian cancer, 50% of

participants reported that they were "sometimes" or "often" uncertain about what their genetic test result means for their children's and/or family's cancer risk. Confidence in one's ability to communicate genetic test results is related to the likelihood that an individual will share genetic test results with relatives [20]. In turn, individuals with limited knowledge of cancer genetics may be less likely to recommend cascade testing to relatives who may be at increased risk for ovarian cancer.

In the current sample, older adults had lower KnowGene scores than their younger counterparts. Given that older adults may serve as gatekeepers of family health information [33], intervening to increase cancer genetics knowledge in older adults is critical. Additionally, members of racial and ethnic minority groups had lower KnowGene scores than their white, non-Hispanic counterparts. Given that members of racial and ethnic minority groups comprised only 12.6% of the sample, this finding must be interpreted with caution. Nevertheless, prior research suggests Black and Hispanic individuals with gynecologic cancer face barriers to undergoing hereditary cancer risk assessment [34]. Development and testing of interventions to remediate racial and ethnic disparities in cancer genetics education, referral, and testing are needed to avoid exacerbating existing racial and ethnic disparities in ovarian cancer treatment quality [35].

In open-ended item responses, several participants identified a need for improved explanations of genetic test results and the clinical implications for themselves and their relatives. Indeed, although all participants in the current sample had undergone genetic counseling, KnowGene item scores indicate that many participants had limited knowledge of inheritance and interpretation of genetic test results. In a pilot randomized controlled trial, Vogel and colleagues [36] found that use of a mobile health application significantly improved hereditary cancer knowledge among women with ovarian cancer. Likewise, Tea and colleagues [37] found that the use of a visual tool significantly improved comprehension of cancer genetics information among individuals at high risk for HBOC. Beyond these interventions, development of educational materials that are culturally tailored and appropriate for individuals across the spectrum of literacy and numeracy is warranted. Accessibility of cancer genetics information is a priority consideration for clinicians and researchers engaged in the promotion of equitable uptake of targeted ovarian cancer treatment and risk reduction strategies.

Overall, the psychosocial impact- and knowledge-related needs expressed by participants in this study may reflect a desire for patient-centered communication, which aims to validate the patient's perspective and understand the patient within his or her own psychological and social context [38]. As Littell and colleagues recently observed [39], this approach to communication has the capacity to promote knowledge retention and alleviate anxiety. Moreover, patient-centered communication may assist patients for whom family communication of genetic test results is burdensome. Communication with health professionals may clarify the relevance of genetic test results to at-risk relatives [40], underscore the importance of genetic testing [41], and stimulate conversations within families about hereditary cancer risk [41]. However, health care providers in the oncology setting have reported challenges communicating about genetics [42]. Additional research that identifies best practices for meeting the communication-related needs of individuals undergoing multigene panel testing in the ovarian cancer care setting is warranted.

The extent to which the findings from this study are generalizable is limited by this study's cross-sectional design, recruitment from a single institution, and relatively small and homogenous sample. Nevertheless, these findings provide insight into opportunities to improve the genetic counseling and multigene panel testing process within the ovarian cancer care setting.

Conclusion

The psychosocial impact of genetic counseling and multigene panel testing on individuals with ovarian cancer may be highest among those with a positive genetic test result. Moreover, older adults and members of racial or ethnic minority groups may benefit from a personalized approach to cancer genetics education. Research that focuses on the development and testing of interventions that aim to promote patient-centered communication, enhance cancer genetics education, and facilitate family communication is necessary to meet the current and future needs of individuals with ovarian cancer and their families.

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Compliance with ethical standards

Conflict of interest Jill E. Stopfer reports personal fees from Astra Zeneca. Rachel A. Pozzar, Fangxin Hong, Niya Xiong, Manan M. Nayak, and Meghan Underhill-Blazey have no conflict of interest to disclose.

Ethical approval The Dana-Farber/Harvard Cancer Center Institutional Review Board approved the study protocol.

Consent to participate Informed consent was obtained from all individual participants included in the study.

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