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"I think that a brief conversation from their provider can go a very long way": Patient and provider perspectives on barriers and facilitators of genetic testing after ovarian cancer

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Abstract

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Declarations:

Ethics Approval: This study was performed in line with the principles of the Declaration of Helsinki. All procedures were approved by the Institutional Review Board at the University of South Florida (Protocol #00035939).

Consent to Participate: Written informed consent was obtained from all individual participants included in the study.

Availability of data and material: Anonymized data will be made available upon request.

Objective: Identify predisposing, enabling, and reinforcing factors impacting genetic counseling/testing among ovarian cancer patients guided by Green and Kreuter's PRECEDE-PROCEED model.

Methods: Gynecologic oncology providers (N=4), genetic counselors (N=4), and ovarian cancer patients (N=9) completed semi-structured qualitative interviews exploring participants' knowledge of and experiences with genetic counseling/testing. Interviews were audio recorded, transcribed verbatim and analyzed using inductive content analysis by two independent raters.

Results: Thematic analysis identified predisposing, enabling, and reinforcing factors impacting referral for and uptake of genetic counseling/testing. Predisposing factors included participant knowledge, beliefs, and attitudes related to genetic counseling/testing. Both patients and providers also cited that insurance coverage and out-of-pocket cost is a major concern for ovarian cancer patients considering genetic testing. Finally, both patients and providers emphasized that genetic counseling/testing would provide additional information to an ovarian cancer patient. While providers emphasized that genetic testing results were useful for informing a patient's personal treatment plan, patients emphasized that this knowledge would be beneficial for their family members.

Conclusion: Barriers to genetic testing for ovarian cancer patients exist at multiple levels, including the patient (e.g., knowledge, attitudes), the provider (e.g., workload, availability of services), the institution (e.g., difficulty with referrals/scheduling), and the health care system (e.g., insurance/cost). Interventions aiming to increase genetic testing among ovarian cancer patients will likely need to target multiple levels of influence. Future quantitative studies are needed to replicate these results. This line of work will inform specific multilevel intervention strategies that are adaptable to different practice settings, ultimately improving guideline concordant care.

Keywords

ovarian cancer; genetic counseling; genetic testing; *BRCA1/2*

Introduction

Germline mutations in the *BRCA1* and *BRCA2 (BRCA1/2)* genes are responsible for 15–20% of epithelial ovarian cancer cases [1], and have significant implications for ovarian cancer patients and their family members. Ovarian cancer patients with *BRCA1/2* mutations are eligible for treatment with polyADP-ribose polymerase (PARP) inhibitors [2] and tend to have chemotherapy sensitive tumors and longer survival compared with *BRCA1/2* negative patients [3–5]. Additionally, given improved survival among ovarian cancer patients over the last 40 years [6], *BRCA1/2* testing is important to identify those at increased risk for secondary malignancies (e.g., breast cancer) [2]. Finally, if a *BRCA1/2* mutation is identified, genetic testing is recommended for first-degree biological relatives [7]. This approach, known as "cascade testing", is critically important given the absence of effective population-based early detection strategies for ovarian cancer. Once identified, women at high risk for ovarian cancer may undergo risk-reducing surgeries that substantially decrease mortality [8].

Guidelines from the Society for Gynecologic Oncology, National Comprehensive Cancer Network, National Society of Genetic Counselors, United States Preventive Services Task Force, and the American Society of Clinical Oncology, recommend universal genetic counseling and genetic testing for epithelial ovarian cancer patients [9–12]. The American Society of Clinical Oncology also acknowledges the opportunities for targeted therapeutics based on positive *BRCA1/2* mutations and recommends that women are offered FDA-approved treatment in both the frontline and recurrent setting based on mutational data [13]. Despite these recommendations, only 20–30% of ovarian cancer patients receive genetic counseling/testing [14], suggesting significant missed clinical opportunities.

Previous research has examined patient and provider sociodemographic characteristics that are associated with referral for genetic counseling/testing [15–19]. However, the majority of these findings are based on retrospective secondary analysis of medical record and insurance claims data. To our knowledge, there has been limited study of patient and provider-reported barriers to genetic counseling/testing for ovarian cancer patients.

To address this gap, we utilized in-depth, qualitative interviews with gynecologic oncology providers (4 total; MDs=2, advanced practice professionals [APPs]=2), genetic counselors (n=4), and ovarian cancer patients (n=9). As there is relatively little literature on this topic, we utilized in-depth, semi-structured qualitative interviews as an exploratory option in order to understand the experience of genetic counseling and testing for ovarian cancer patients [20, 21]. Interviews were guided by Green and Kreuter's PRECEDE-PROCEED model [22], which provides a comprehensive structure for assessing health and quality of life needs. Specifically, this study represents Phase 3 of the model: educational and ecological assessment to identify modifiable factors that will most likely result in behavior change. *Predisposing factors* are any characteristics of a person or population that motivate behavior (e.g., knowledge, beliefs, values, attitudes). *Enabling factors* are characteristics of the environment that facilitate action (e.g., programs, services, availability/accessibility of resources), and any skill or resource required to perform a specific behavior. *Reinforcing factors* are rewards or punishments following or anticipated as a consequence of a behavior (e.g., social support, peer approval).

Thus, the qualitative interviews conducted in this study explored predisposing, enabling, and reinforcing factors related to genetic counseling/testing for ovarian cancer patients.

Methods

Setting

This study was conducted at a large, NCI-designated Comprehensive Cancer Center in the southeastern United States. The institution has dedicated clinics for gynecologic oncology (with 6 MDs and 6 APPs) and genetics (with 6 genetic counselors). The institution follows a traditional model of genetic counseling and testing, wherein a health-care provider refers a patient for genetic counseling, the patient is scheduled a separate in-person appointment with a genetic counselor for pre-test genetic counseling, and genetic testing results are disclosed by a genetic counselor in person or via telephone [23]. Clinical pathways have been developed to aid in the process of genetic counseling/testing referral. Both MDs and

APPs are able to place referrals for genetic counseling. Patients must travel to a satellite clinic building (separate from the gynecologic oncology clinic) for their genetic counseling appointment(s).

Procedures and Participants

All procedures were approved by the Institutional Review Board at the University of South Florida (Protocol #00035939). Based on our prior research [24, 25] we anticipated that 5–10 interviews would be required to reach saturation. Thus, our target sample size was 8 providers (including both gynecologic oncology providers and genetic counselors) and 8 ovarian cancer patients.

Eligible providers were (1) gynecologic oncology MDs or APPs, or genetic counselors; and (2) providing care to ovarian cancer patients. Providers were identified through institutional databases and informed of the study: (1) via email and (2) in-person at gynecologic oncology tumor board meetings. Those who expressed interest in study participation were contacted by a research team member who confirmed provider eligibility, obtained written informed consent, and scheduled a phone or in-person interview. Upon reaching our target sample size of 8 providers, we stopped enrollment.

Eligible ovarian cancer patients were: (1) female; (2) age ≥18; (3) seen for treatment between 01/01/2017 and 12/31/2017; and (4) English-speaking. Family history of cancer was not included as an eligibility criterion, as national guidelines recommend genetic counseling and testing for all women diagnosed with epithelial ovarian cancer, regardless of family history [9–12]. The institutional Collaborative Data Services Core was used to identify eligible patients who were then sent an introductory letter including instructions to contact the study team via phone or email if interested in study participation. Upon confirmation of interest and eligibility, patients were mailed informed consent documents. Those who completed informed consent documents and returned them via mail were scheduled for a phone or in-person interview.

Data Collection

During semi-structured interviews (see Supplemental Materials), participants were first provided with brief definitions of genetic counseling and genetic testing. They were then asked to describe their (1) experiences with genetic counseling and genetic testing; (2) perceptions of the benefits and barriers to genetic counseling and genetic testing for ovarian cancer patients; and (3) suggestions for improving the process of genetic counseling and genetic testing. All interviews were audio-recorded and transcribed verbatim. Patients and providers received a $50 gift card upon interview completion.

Data Analysis

Qualitative data analysis was based on the approach suggested by Lindlof and Taylor [26]. Raters (CC and LF) collaboratively developed a detailed codebook after initial transcript review. A codebook is a set of codes, definitions, and examples used as a guide to help analyze interview data [27]. In the present study, the codebook consisted of data-driven codes that emerged from the raw data. Grounded theory was used to let themes emerge and

the codebook was iteratively refined according to emergent themes. Eight transcripts (47%) were independently coded by both of the raters. Codes were assigned to phrases, sentences, or paragraphs to simultaneously interpret the text and break the text down into meaningful chunks or segments [28]. Applying codes to raw data enables the researcher to begin examining how their data supports or contradicts the theory that is guiding their research [27]. Coding disagreements were resolved through discussion until consensus was reached. The remaining nine transcripts were split between the two raters for independent analysis. Coding was conducted using MAXQDA v.12.

Following the completion of coding, the codes were organized into seven themes, which were classified based on categories from the PRECEDE-PROCEED model (i.e., predisposing, enabling, or reinforcing). The PRECEDE-PROCEED model was applied after the completion of coding to prevent overreliance on theory, which may limit the ability to see emergent findings in the data [29]. However, all codes did fit into PRECEDE-PROCEED domains. The relationship between the theory domains, overarching themes, and data-driven codes is presented in Table 1.

Results

Participant Demographics

Of eighteen eligible providers (MDs=6, APPs=6, genetic counselors=6), eight (8/18=44%) consented to participate, including two MDs (2/6=33%), two APPs (2/6=33%), and four genetic counselors (4/6=66%). Most were female (7/8=88%) and non-Hispanic White (6/8=75%), with an average age of 38 years (*SD*=12.9). They had been practicing an average of 10.2 years (*SD*=14.1). Providers estimated the number of ovarian cancer patients seen per year; gynecologic oncology provider responses ranged from 120 to 330 (*M*=233) and genetic counselor responses ranged from 30 to 48 (*M*=36).

Of the 103 eligible patients identified by the Collaborative Data Services Core, 30 (29%) were randomly selected for recruitment. Of the 30 patients who were approached regarding study participation, 11 (11/30=37%) expressed interest in participating and nine (9/30=30%) completed interviews. Most were non-Hispanic White (8/9=89%) and college graduates (6/9=67%), with an average age of 64 years (*SD*=10.7). Four patients (4/9=44%) had documentation in the electronic medical record of (a) discussion with a gynecologic oncology provider about available genetic services, (b) genetic counseling, and (c) genetic testing results; one patient (1/9=11%) had documentation for only a discussion with a gynecologic oncology provider about available genetic services. However, eight participants (8/9=89%) self-reported in qualitative interviews that they had completed genetic counseling/testing; patients who completed genetic counseling/testing outside of our institution may not have results documented in the electronic medical record.

Themes

Qualitative analysis identified several themes, revealing the ways in which ovarian cancer patients, gynecologic oncology providers, and genetic counselors perceive ovarian cancer-

related genetic counseling/testing. Tables 2–4 provide exemplar quotes from patients and providers for each theme.

A priori, we had considered gynecologic oncology providers and genetic counselors to be part of the same participant group. However, during the process of coding, the unique experiences of gynecologic oncology providers and genetic counselors became evident. As a result, we present them separately below and in Tables 2–4.

In addition, during the interviews we queried participants about genetic counseling and genetic testing as separate procedures. However, during the process of coding, we noted that participants (with the exception of the genetic counselors) did not typically distinguish between genetic counseling and genetic testing, and often confused the terms. During interviews, participants rarely identified unique barriers and facilitators for genetic counseling versus genetic testing. Thus, themes were considered to be consistent between genetic counseling and genetic testing and are presented as such.

Predisposing Factors

Theme 1: Patient knowledge is an important predisposing factor for genetic testing among ovarian cancer patients.: Patients and providers both indicated that patient knowledge of genetic counseling/testing plays a key role in whether or not those services are received. Several patients noted that they did not know that genetic testing was available to them, and felt that lack of knowledge would be a major barrier for other patients in getting tested. Patients expressed that the key knowledge gaps were in (1) existence of these services and (2) how genetic testing relates to ovarian cancer. In addition, patients felt that their knowledge about genetic counseling/testing was independent of their level of general education. One patient noted that she lacked knowledge about genetic counseling/testing, despite working in the medical field (Table 2, Row 1, Patient #24).

Providers, on the other hand, reflected more on patients' ability to understand and process information provided in the course of genetic counseling. Providers noted their concerns that genetic risk information is excessively complicated for some patients, but also emphasized that patients are willing to attend genetic counseling once their informational needs are met: "I think a lot of patients, once they understand why… it's as clear as can be. They don't question it." (Provider #3, MD)

Theme 2: Patient beliefs and attitudes also impact genetic counseling/testing preferences.: Patients and providers frequently noted that beliefs and attitudes would affect whether or not a patient has genetic counseling/testing. Some of these beliefs were focused on expectations about if/when providers would mention genetic testing, what genetic counseling/testing entails, or what their results will be. One genetic counselor described the situation of identifying an unexpected inherited mutation that increased cancer risk: "That can be really shocking for the family…There can be sometimes an unexpected emotional reaction because it's not something that we had a high suspicion of" (Provider #2, genetic counselor).

Enabling Factors

Theme 3: Providers and patients both recognize that insurance coverage and out-of-pocket cost is a major concern for ovarian cancer patients considering genetic counseling/testing.: Both groups discussed the challenges of estimating the "real cost" of testing for patients (Table 3, Row 1). While providers noted that the cost of genetic testing has decreased in recent years, patients and providers nonetheless emphasized that *any* financial obligation for genetic counseling/testing could be challenging in the context of cancer treatment, which is already extremely expensive. However, one genetic counselor noted that insurance coverage could be an enabling factor, allowing patients to consider testing who might not otherwise (Table 3, Row 1, Provider #5).

Theme 4: Availability and accessibility of genetic counseling/testing affect both patients and providers, but in different ways.: For patients, accessibility of genetic counseling/testing was primarily conceptualized as physical location. Both patients and providers stated that patients often travel a far distance to their appointments and that they do not want to travel for an additional genetic counseling/testing appointment. Furthermore, the genetics clinic is physically located at a different campus than the gynecologic oncology clinic. This was also noted as a barrier to patient engagement in genetic counseling/testing. Providers spoke to the difficulty of coordinating genetic counseling/testing appointments with other visits to the medical center, but noted that this is something that they try to do.

Providers discussed other logistical challenges related to accessing genetic counseling/testing, including ease of referrals, orders, or scheduling; competing demands or workload of provider; minimal or ineffective communication between care teams; and the limited availability of genetic counselors. Providers proposed some innovative solutions for these logistical challenges. For example, several providers mentioned the potential of electronic medical record automation for streamlining the referral process (Table 3, Row 2, Provider #2). Other suggested solutions included telehealth/virtual genetic counseling visits, embedding a genetic counselor into the gynecologic oncology clinic, having genetic counselors attend an interdisciplinary gynecologic oncology tumor board, enabling genetic counselors to propose an order to the physician via the electronic medical record, and making genetic testing status/results more visible in the electronic medical record. Providers noted that some of these solutions were already being implemented at our institution, but were unsure of their subsequent impact on referral and uptake of genetic counseling/testing.

Theme 5. Providers felt that the recommendation from a gynecologic oncology professional was critical, but patients presented a more balanced view that also emphasized the role of their own inquiry and advocacy.: Gynecologic oncology providers unanimously felt that their recommendation to undergo testing was important, though one APP noted that a recommendation from an MD may "make more of an impact" (Provider #8, APP). Genetic counselors felt that the way in which gynecologic oncology providers made their recommendations was nuanced; they noted the importance of phrasing the recommendation for genetic counseling/testing (Table 3, Row 3, Provider #1). Genetic counselors also reflected on the accuracy of information given to patients by providers. They identified their experiences with misinformation at the provider level, and shared their

efforts to educate not only gynecologic oncology providers but providers in general (Table 3, Row 3, Provider #1).

While some patients mentioned the impact of a provider recommendation on their decision to get genetic counseling/testing, many felt that they had to advocate for themselves in order to get the services that they needed. One patient described the provider recommendation and the patient self-advocacy as two complementary enabling factors (Table 3, Row 4, Patient #25). Interestingly, the theme of patient inquiry/advocacy was not raised in any interviews with gynecologic oncology providers or genetic counselors.

Reinforcing Factors

Theme 6: Ovarian cancer patients are motivated to pursue genetic counseling/testing in order to gain knowledge about genetic risks to self or family.: Both patients and providers emphasized that genetic counseling/testing would provide additional information to an ovarian cancer patient. Providers emphasized that genetic testing results were useful for informing a patient's personal treatment plan, and used anecdotes to demonstrate how patients are motivated to receive genetic testing because of the treatment implications (Table 4, Row 2, Provider #6). However, the implications of genetic testing for treatment were rarely discussed by patients. Rather, patients emphasized that this knowledge would be beneficial for their family members, enabling them to engage in preventive behaviors; this seemed to be the primary motivator for many patients to undergo genetic counseling/genetic testing.

Theme 7: Patients' emotional reactions to the idea of learning about genetic risk may deter them from pursuing genetic counseling/testing.: Patients and providers both noted the negative emotional responses that can come along with the recommendation for genetic counseling/testing. These negative emotions were conceptualized as barriers to genetic counseling/testing; patients may avoid receiving information about their genetic risk due to a desire to avoid these unpleasant emotions. Patients primarily focused on the emotion of fear, while providers described a wider variety of emotions (e.g., anger, fear, guilt).

Discussion

The current study explored patient and provider perspectives about genetic counseling/testing for ovarian cancer patients. Although prior research has identified sociodemographic characteristics associated with referral for genetic counseling and testing [15–19], this study is among the first to assess patient and provider-reported barriers and facilitators. Guided by the PRECEDE-PROCEDE framework, we identified predisposing, enabling and reinforcing factors related to genetic counseling/testing for ovarian cancer patients. The resulting themes represent domains that impact clinical practice and guideline-concordant care. Our findings are especially timely given the recently published guidelines from the United States Preventive Services Task Force and American Society of Clinical Oncology that recommend genetic counseling and germline genetic testing for all ovarian cancer patients [12, 13]. The American Society of Clinical Oncology guidelines also recommend that ovarian cancer patients be offered FDA-approved therapies based on genetic testing results. Given these guidelines and the ever-evolving therapeutic landscape, timely genetic counseling/testing is

critical for ovarian cancer patients and their providers to identify all potential treatment options and initiate cascade testing in family members [13].

Consistent with the extant literature demonstrating limited genetics knowledge among cancer patients [30, 31], all stakeholders in the present study discussed patient lack of knowledge as a key barrier to genetic counseling/testing. Commonly identified knowledge gaps included (1) the existence of genetic counseling/testing and (2) the relationship between genetic counseling/testing and ovarian cancer. Providers also noted the complexity of information provided in genetic counseling/testing.

Beyond self-reported lack of knowledge, interviews also revealed confusion and inaccuracy about genetic counseling/testing among patients. This is striking, given that eight of nine patients self-reported prior genetic counseling/testing. The remaining confusion about genetic testing – even after genetic counseling – supports providers' abovementioned concerns about the complexity of information provided in genetic counseling/testing. Thus, better communication regarding the genetic testing process and genetic testing results is needed. Patients, recognizing these knowledge deficits, strongly desired further education around genetic counseling/testing. While prior studies have reported on individuals' interest in genetic testing [32–34], these data extend prior findings to demonstrate patients' interest in education about cancer genetics more generally. Furthermore, patients may need additional, ongoing genetic education, even after completing genetic counseling/testing.

Patients and providers also identified a variety of beliefs and attitudes about genetic counseling/testing that might influence uptake of genetic services. These beliefs and attitudes can be broadly conceptualized according to Vroom's Expectancy Theory [35]. Vroom theorized that behavior is driven by beliefs about expectancy (whether a behavior will result in an outcome) and valence (whether the outcome is valuable or rewarding). The attitudes towards genetic counseling/testing described by stakeholders represent these categories. For example, expectancy beliefs might include thoughts about whether or not genetic counseling/testing will result in useful information (i.e., fatalism versus empowerment), while valence beliefs might include fear of genetic testing results. The qualitative data from this study indicate that both expectancy and valence beliefs should be considered for patient-level interventions targeting genetic counseling/testing. While many interventions targeting uptake of genetic counseling/testing among ovarian cancer patients have focused on structural or workflow issues, some do include a patient education component [16, 17, 36, 37]. Psychoeducation may address expectancy and valence beliefs, but future studies exploring intervention mechanisms are needed to test this hypothesis.

Gynecologic oncology providers' recommendation for genetic counseling/testing was a commonly-described enabling factor. Genetic counselors in this study emphasized that *how* the provider recommends genetic counseling/testing is crucial. When providers describe genetic counseling/testing as an essential service, rather than optional, patients are more likely to follow-through with genetic counseling/testing. Given the recent position statements from national organizations [12, 13] and the necessity of genetic testing results for therapeutic decisions, gynecologic oncology provider encouragement of genetic counseling/testing might be a critical "missing piece" in increasing uptake of these services.

However, provider knowledge of genetic counseling/testing may inhibit their ability to make appropriate recommendations. In a recent national survey, only 15% of gynecologic oncologists knew the number of genes associated with ovarian cancer risk, and only 66% recognized the term “cascade testing” (unpublished data, Mallen et al.). In our study, genetic counselors also noted needing to educate providers about genetics misinformation, which has also been documented in the literature among a variety of provider types and genetic testing types [38–41]. Thus, these data support the need for education about genetic counseling/testing at both the patient level *and* the provider level.

Patients felt their own inquiry and advocacy for genetic counseling/testing was a critical component in their receipt of genetics services. This information-seeking behavior is common among cancer patients, who often turn to multiple sources (e.g., the internet, support groups, medical providers) to gain information about individual or familial genetic risk [42, 43]. Interestingly, in the present study, no providers noted the importance of patient advocacy leading to genetic counseling/testing referral. Future studies might investigate this “communication gap” and further examine who initiates conversations about genetics, when these conversations are initiated, and the role of shared-decision making in these conversations [44–46]. Providers might also gain a better understanding of patients’ grasp of genetic counseling/testing by asking about patients’ motivations for undergoing testing. This conversation could elucidate patient hopes from genetic counseling/testing (including family and/or treatment use) as well as where patients are receiving information about genetic counseling/testing.

A final enabling factor described by all participants was insurance coverage and cost of genetic counseling/testing. Specifically, high costs and concerns about financial impact represented a significant barrier to genetic counseling/testing. This is consistent with prior findings demonstrating that the cost of genetic testing was the most important factor in forced decision-making experiments with ovarian cancer patients [47] and the growing recognition of financial toxicity of a cancer diagnosis [48]. Providers and patients alike desired more transparency from the health system about actual costs for patients, which would facilitate informed decision-making regarding the risk-benefit ratio of genetic counseling/testing [48]. However, it should be noted that this enabling factor is highly context-dependent; insurance coverage and cost may play less of a role at other institutions. Additional studies, including patients and providers from a variety of care settings, are needed in order to confirm or refute these results.

Regarding reinforcing factors, patients are highly motivated to pursue genetic counseling/testing when considering future risks to family members. This desire to help one’s family members is an actionable area to leverage for future interventions. While patients emphasized the benefits of genetic counseling/testing for family members’ cancer prevention, providers placed more emphasis on the implications of genetic counseling/testing for patients’ treatment plans. Interestingly, most patients did not connect concepts of genetic counseling/testing and treatment planning when they described the potential benefits of genetic counseling/testing. This suggests that education focused on the potential treatment implications of genetic counseling/testing is needed for patients, and providers should

ensure that they are incorporating genetic testing implications for family members into their discussions with patients.

Taken together, these themes demonstrate that barriers to genetic counseling/testing for ovarian cancer patients exist at multiple levels, including the patient (e.g., knowledge, emotional reactions), the provider (e.g., knowledge, workload), the organization (e.g., referral challenges), and the health care system (e.g., insurance/cost). Thus, interventions that aim to increase genetic counseling/testing among ovarian cancer patients will likely need to target multiple levels of influence. Participants in this study generated innovative solutions for addressing these barriers, some of which have been tested in prior studies. In previous trials, strategies including electronic medical record changes, workflow changes, care integration, and patient and provider education have resulted in a 40–352% increase in rates of genetics referral [16, 17, 36, 37]. Large, multisite dissemination and implementation trials are needed to understand which strategies are most effective for which types of care settings.

Strengths and Limitations

Strengths of our study include direct clinical applicability and a large volume of qualitative data. The process of genetic counseling and testing at our institution (e.g., referral to genetic specialists placed by primary team, pre-test genetic counseling, and post-test genetic counseling) does reflect the standard model of service delivery as defined by the National Society of Genetic Counselors [23] and recommended by the National Comprehensive Cancer Network [49]. Our findings are likely to generalize to other institutions that utilize the standard care delivery model of genetic counseling, and can be utilized to promote guideline-concordant care. Resulting themes represent targetable areas to enhance high-quality patient care and adherence to genetic counseling/testing in ovarian cancer patients. We also interviewed a diverse group of stakeholders including gynecologic oncology providers (both MDs and APPs), genetic counselors, and patients. The multidisciplinary participants also enable us to identify themes at the systems level in addition to the individual level.

Limitations must also be acknowledged. First, data came from only a single institution and may not be generalizable across all practice settings. Future research across multiple institutions is needed to validate the barriers and facilitators of genetic counseling/testing identified here. Additionally, our institution is an NCI-designated Comprehensive Cancer Center; thus, results may not reflect the typical gynecologic oncology practice setting. Smaller, community-based hospitals might face even more barriers than we identified in this high-resource setting. Second, although our institution adheres to the traditional model of genetic counseling and testing, we acknowledge that there are other service delivery models for genetic counseling and testing [50], to which these results may not apply. Third, only 30% of ovarian cancer patients approached regarding the study agreed to participate. This may be in part due to our recruitment approach: we sent a single letter via mail introducing the study and inviting participation. In other studies that have incorporated follow-up mailings and/or follow-up phone calls, we have observed higher participation rates [51, 52]. Because non-participants passively refused through non-response, we do not have data on

reasons for refusal. However, potential reasons for non-participation may include: (1) patient death, (2) seasonality (many patients at our institution are only local in the winter and may not have received recruitment mailings during the summer months), and (3) lack of time to participate due to active cancer treatment(s). Also, we hypothesize that patients who had not received genetic counseling/testing may have been less interested in or motivated to participate. This response bias is supported by the very high number of participants (89%) reporting that they had already participated in genetic counseling/testing (versus 20–30% reported in the literature [14]). Thus, results may be subject to selection bias; individuals agreeing to participate in a study of genetic counseling/testing may be more positive towards genetics than the general population. Finally, most of the patient participants were White (89%) and highly educated (67% college degree or more); these results may not be generalizable to other populations.

Conclusions

By using a rigorous theoretical framework (PRECEDE-PROCEDE) and synthesizing multidisciplinary perspectives from key stakeholders, we identified targetable areas for increased adherence to guideline-concordant care. Future studies should quantitatively examine the PRECEDE-PROCEED domains identified here in a large, representative sample of ovarian cancer patients and gynecologic oncology providers from multiple different institutions. This design would illuminate any differences in predisposing, enabling, and reinforcing factors by care setting. When integrated with the qualitative data presented here, results will inform specific multilevel intervention strategies. This line of research is particularly important given the practice-changing therapeutic options on the horizon, where genetics will relate to both treatment inclusion and prognostic predictions. Now more than ever, reducing barriers to genetic counseling/testing for ovarian cancer patients is a critical component of high-quality cancer care.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Conflicts of Interest: Dr. Wenham has participated in data safety monitoring, trial steering, advisory, and speaker activities for which he has received honoraria from Tesaro, Clovis, Genentech, Mersana, Marker Therapeutics, Ovation Diagnostics, AstraZeneca, and Merck. He is also a principal investigator for a number of sponsored clinical trials. Ms. Barton has participated in advisory activities for which she has received honoraria from AstraZeneca and Merck. No other authors have conflicts of interest to disclose.

List of Abbreviations:

MD	Doctor of Medicine
APP	Advanced practice professional

References

[1]. Hoskins PJ, Gotlieb WH. Missed therapeutic and prevention opportunities in women with BRCA-mutated epithelial ovarian cancer and their families due to low referral rates for genetic counseling and BRCA testing: A review of the literature. CA Cancer J Clin 2017;67:493–506. [PubMed: 28881380]

[2]. Liang MI, Wong DH, Walsh CS, Farias-Eisner R, Cohen JG. Cancer genetic counseling and testing: perspectives of epithelial ovarian cancer patients and gynecologic oncology healthcare providers. J Genet Couns 2018;27:177–86. [PubMed: 28785836]

[3]. Yang D, Khan S, Sun Y, Hess K, Shmulevich I, Sood AK, et al. Association of BRCA1 and BRCA2 mutations with survival, chemotherapy sensitivity, and gene mutator phenotype in patients with ovarian cancer. JAMA. 2011;306:1557–65. [PubMed: 21990299]

[4]. Naumann RW, Morris JC, Tait DL, Higgins RV, Crane EK, Drury LK, et al. Patients with BRCA mutations have superior outcomes after intraperitoneal chemotherapy in optimally resected high grade ovarian cancer. 2018;151:477–80.

[5]. Kwa M, Edwards S, Downey A, Reich E, Wallach R, Curtin J, et al. Ovarian cancer in BRCA mutation carriers: improved outcome after intraperitoneal (IP) cisplatin. 2014;21:1468–73.

[6]. Torre LA, Trabert B, DeSantis CE, Miller KD, Samimi G, Runowicz CD, et al. Ovarian cancer statistics, 2018. 2018;68:284–96.

[7]. ACOG Committee on Gynecologic Practice. Cascade testing: testing women for known hereditary genetic mutations associated with cancer. Obstet Gynecol Surv 2018;73:211–2.

[8]. Marchetti C, De Felice F, Palaia I, Perniola G, Musella A, Musio D, et al. Risk-reducing salpingo-oophorectomy: a meta-analysis on impact on ovarian cancer risk and all cause mortality in BRCA 1 and BRCA 2 mutation carriers. BMC Womens Health. 2014;14:150. [PubMed: 25494812]

[9]. Robson ME, Bradbury AR, Arun B, Domchek SM, Ford JM, Hampel HL, et al. American Society of Clinical Oncology policy statement update: genetic and genomic testing for cancer susceptibility. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2015;33:3660–7. [PubMed: 26324357]

[10]. Daly MB, Pilarski R, Axilbund JE, Berry M, Buys SS, Crawford B, et al. Genetic/Familial High-Risk Assessment: Breast and Ovarian, Version 2.2015. Journal of the National Comprehensive Cancer Network : JNCCN. 2016;14:153–62. [PubMed: 26850485]

[11]. Hampel H, Bennett RL, Buchanan A, Pearlman R, Wiesner GL. A practice guideline from the American College of Medical Genetics and Genomics and the National Society of Genetic Counselors: referral indications for cancer predisposition assessment. Genet Med 2015;17:70. [PubMed: 25394175]

[12]. US Preventive Services Task Force. Risk assessment, genetic counseling, and genetic testing for BRCA-related cancer: US Preventive Services Task Force recommendation statement. Obstetrical Gynecological Survey. 2019;74:720–1.

[13]. Konstantinopoulos PA, Norquist B, Lacchetti C, Armstrong D, Grisham RN, Goodfellow PJ, et al. Germline and Somatic Tumor Testing in Epithelial Ovarian Cancer: ASCO Guideline. 2020:JCO. 19.02960.

[14]. Randall LM, Pothuri B, Swisher EM, Diaz JP, Buchanan A, Witkop CT, et al. Multidisciplinary summit on genetics services for women with gynecologic cancers: A Society of Gynecologic Oncology White Paper. Gynecol Oncol 2017;146:217–24. [PubMed: 28596016]

[15]. Kurian AW, Ward KC, Howlader N, Deapen D, Hamilton AS, Mariotto A, et al. Genetic Testing and Results in a Population-Based Cohort of Breast Cancer Patients and Ovarian Cancer Patients. Journal of clinical oncology : official journal of the American Society of Clinical Oncology. 2019:JCO. 18.01854.

[16]. Uyar D, Neary J, Monroe A, Nugent M, Simpson P, Geurts JL. Implementation of a quality improvement project for universal genetic testing in women with ovarian cancer. Gynecol Oncol 2018;149:565–9. [PubMed: 29653687]

[17]. Kentwell M, Dow E, Antill Y, Wrede CD, McNally O, Higgs E, et al. Mainstreaming cancer genetics: a model integrating germline BRCA testing into routine ovarian cancer clinics. Gynecol Oncol 2017;145:130–6. [PubMed: 28162234]

[18]. Vadaparampil ST, Scherr CL, Cragun D, Malo TL, Pal T. Pre-test genetic counseling services for hereditary breast and ovarian cancer delivered by non-genetics professionals in the state of Florida. Clin Genet 2015;87:473–7. [PubMed: 24735105]

[19]. Mallen AR, Conley CC, Townsend MK, Wells A, Boac BM, Todd S, et al. Patterns and predictors of genetic referral among ovarian cancer patients at a National Cancer Institute-Comprehensive Cancer Center. Clinical Genetics. 2019.

[20]. Holloway I, Galvin K. Qualitative research in nursing and healthcare: John Wiley & Sons; 2016.

[21]. Hammarberg K, Kirkman M, de Lacey S. Qualitative research methods: when to use them and how to judge them. Human reproduction. 2016;31:498–501. [PubMed: 26759142]

[22]. Green L, Kreuter M. The precede–proceed model. Health promotion planning: an educational approach. 3rd ed. Mountain View, CA: Mayfield Publishing Company; 1999. p. 32–43.

[23]. Cohen SA, Gustafson SL, Marvin ML, Riley BD, Uhlmann WR, Liebers SB, et al. Report from the National Society of Genetic Counselors service delivery model task force: a proposal to define models, components, and modes of referral. Journal of Genetic Counseling. 2012;21:645–51. [PubMed: 22566244]

[24]. Vadaparampil ST, Quinn GP, Brzosowicz J, Miree CA. Experiences of genetic counseling for BRCA1/2 among recently diagnosed breast cancer patients: a qualitative inquiry. Journal of psychosocial oncology. 2008;26:33–52. [PubMed: 19042271]

[25]. Vadaparampil ST, Quinn GP, Miree CA, Brzosowicz J, Carter B, Laronga C. Recall of and reactions to a surgeon referral letter for BRCA genetic counseling among high-risk breast cancer patients. Ann Surg Oncol 2009;16:1973–81. [PubMed: 19408048]

[26]. Lindlof TR, Taylor BC. Sensemaking: Qualitative data analysis and interpretation. Qualitative communication research methods. 2011;3:241–81.

[27]. DeCuir-Gunby JT, Marshall PL, McCulloch AW. Developing and using a codebook for the analysis of interview data: An example from a professional development research project. Field methods. 2011;23:136–55.

[28]. MacQueen KM, McLellan E, Kay K, Milstein B. Codebook development for team-based qualitative analysis. Cultural Anthropology Methods. 1998;10:31–6.

[29]. Collins CS, Stockton CM. The central role of theory in qualitative research. International Journal of Qualitative Methods. 2018;17:1609406918797475.

[30]. Scherr CL, Christie J, Vadaparampil STJPhg. Breast cancer survivors' knowledge of hereditary breast and ovarian cancer following genetic counseling: an exploration of general and survivor-specific knowledge items. 2016;19:1–10.

[31]. Meiser B, Butow P, Barratt A, Gattas M, Gaff C, Haan E, et al. Risk perceptions and knowledge of breast cancer genetics in women at increased risk of developing hereditary breast cancer. 2001;16:297–311.

[32]. Cherkas LF, Harris JM, Levinson E, Spector TD, Prainsack BJPo. A survey of UK public interest in internet-based personal genome testing. 2010;5.

[33]. Collins J, Ryan L, Truby HJJohn, dietetics. A systematic review of the factors associated with interest in predictive genetic testing for obesity, type II diabetes and heart disease. 2014;27:479–88.

[34]. Graves K, Peshkin B, Luta G, Tuong W, Schwartz MJPHG. Interest in genetic testing for modest changes in breast cancer risk: implications for SNP testing. 2011;14:178–89.

[35]. Vroom VH. Work and motivation. Hoboken, NJ: Wiley; 1964.

[36]. Bednar EM, Oakley HD, Sun CC, Burke CC, Munsell MF, Westin SN, et al. A universal genetic testing initiative for patients with high-grade, non-mucinous epithelial ovarian cancer and the implications for cancer treatment. Gynecol Oncol 2017;146:399–404. [PubMed: 28610746]

[37]. Swanson CL, Kumar A, Maharaj JM, Kemppainen JL, Thomas BC, Weinhold MR, et al. Increasing genetic counseling referral rates through bundled interventions after ovarian cancer diagnosis. Gynecol Oncol 2018;149:121–6. [PubMed: 29402500]

[38]. Hamilton JG, Abdiwahab E, Edwards HM, Fang M-L, Jdayani A, Breslau ESJJogim. Primary care providers' cancer genetic testing-related knowledge, attitudes, and communication behaviors: A systematic review and research agenda. 2017;32:315–24.

[39]. Browner CH, Preloran HM, Casado MC, Bass HN, Walker APJSs, medicine. Genetic counseling gone awry: miscommunication between prenatal genetic service providers and Mexican-origin clients. 2003;56:1933–46.

[40]. Cragun D, Camperlengo L, Robinson E, Caldwell M, Kim J, Phelan C, et al. Differences in BRCA counseling and testing practices based on ordering provider type. 2015;17:51–7.

[41]. Joseph G, Pasick RJ, Schillinger D, Luce J, Guerra C, Cheng JKYJJogc. Information mismatch: cancer risk counseling with diverse underserved patients. 2017;26:1090–104.

[42]. Hay J, Kaphingst K, Baser R, Li Y, Hensley-Alford S, McBride CJPhg. Skin cancer concerns and genetic risk information-seeking in primary care. 2012;15:57–72.

[43]. Waters EA, Wheeler C, Hamilton JGJJohc. How are information seeking, scanning, and processing related to beliefs about the roles of genetics and behavior in cancer causation? 2016;21:6–15.

[44]. Silverman TB, Kuperman GJ, Vanegas A, Sin M, Dimond J, Crew KD, et al. An applied framework in support of shared decision making about BRCA genetic testing. AMIA Annual Symposium Proceedings: American Medical Informatics Association; 2018. p. 961.

[45]. Grimmett C, Pickett K, Shepherd J, Welch K, Recio-Saucedo A, Streit E, et al. Systematic review of the empirical investigation of resources to support decision-making regarding BRCA1 and BRCA2 genetic testing in women with breast cancer. 2018;101:779–88.

[46]. Vadaparampil ST, Cragun DJTbm. Shared decision making: Implications for return of results from whole-exome and whole-genome sequencing. 2018;8:80–4.

[47]. Davidson BA, Ehrisman J, Reed SD, Yang J-C, Buchanan A, Havrilesky LJJGor, et al. Preferences of women with epithelial ovarian cancer for aspects of genetic testing. 2019;6:1.

[48]. Yousuf Zafar S Financial toxicity of cancer care: it's time to intervene. Journal of the National Cancer Institute. 2016;108:djv370. [PubMed: 26657334]

[49]. National Comprehensive Cancer Network (NCCN). Genetic/Familial High-Risk Assessment: Breast, Ovarian, and Pancreatic (Version 1.2020). NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®)2019.

[50]. McCuaig JM, Armel SR, Care M, Volenik A, Kim RH, Metcalfe KA. Next-generation service delivery: a scoping review of patient outcomes associated with alternative models of genetic counseling and genetic testing for hereditary cancer. Cancers. 2018;10:435.

[51]. Vadaparampil ST, Malo T, De la Cruz C, Christie J. Do breast cancer patients tested in the oncology care setting share BRCA mutation results with family members and health care providers? J Cancer Epidemiol 2012;2012.

[52]. Vadaparampil ST, Quinn GP, Lee JH, Malo T, Zhao X, Miree C, et al. Satisfaction with physician recommendation for and information about genetic counseling among breast cancer patients. The breast journal. 2011;17:79–82. [PubMed: 21129092]

Table 1.

Relationship between theory domains and data-driven themes and codes.

PRECEDE-PROCEED Domain	Themes	Codes
Predisposing	Patient knowledge is an important predisposing factor for genetic testing among ovarian cancer patients	• Patient knowledge • Role of media and culture • Word of mouth • Patient education about genetics • Misinformation/confusion about genetic testing/ counseling
	Patient beliefs and attitudes also impact genetic counseling/testing preferences.	• Personal background • Perceived usefulness of genetic counseling/testing
Enabling	Providers and patients both recognize that insurance coverage and out-of-pocket cost is a major concern for ovarian cancer patients considering genetic counseling/testing.	• Insurance coverage • Cost of testing
	Availability and accessibility of genetic counseling/testing affect both patients and providers, but in different ways.	• Logistics • Health status • Systemic barriers • Accessibility of genetic counseling/testing
	Providers felt that the recommendation from a gynecologic oncology professional was critical, but patients presented a more balanced view that also emphasized the role of their own inquiry and advocacy.	• Provider recommendation/referral • Provider discussion • Provider knowledge • Patient inquiry/advocacy
Reinforcing	Ovarian cancer patients are motivated to pursue genetic counseling/ testing in order to gain knowledge about genetic risks to self or family.	• Tailored treatment • Perceived risk to self or family • Prevention focus
	Patients' emotional reactions to the idea of learning about genetic risk may deter them from pursuing genetic counseling/testing.	• Emotional reactions • Genetic discrimination/privacy

Table 2.

Representative quotes describing predisposing factors.

Predisposing Factors	Patients	Providers	
		Gynecologic Oncology (MDs and APPs)	Genetic Counselors
Knowledge	"Interviewer: Now, what do you think has prevented you from receiving the genetic counseling? "Interviewee: Um, well, I – I guess I didn't know there was such a thing." (Patient #15) "Interviewer: Now, what would prevent you or anyone from receiving genetic testing? Interviewee: Ignorance. Not [having] the knowledge. And in my case, if it wasn't for [my doctor] just casually saying, "did you get genetic testing", I didn't know to get it. And I'm a nurse. I'm a nurse." (Patient #24)	"I probably can't speak to this because, again, I don't do the counseling, but I wonder sometimes how much patients grasp all that information. So, is there a barrier in terms of patient education and their comprehension of this stuff?" (Provider #3, MD) "A lot of them don't know hat genetics are all about. I mean, most of them refer to the *BRCA* mutation; otherwise they probably don't have any knowledge." (Provider #8, APP)	"I think the patients don't have the education to know that they are eligible, or why it would be beneficial." (Provider #1) "It's hard to make sure that the patient understands the information. It's complicated information, and we try and make it as easy to digest as possible. But we're not getting informed consent because they're not understanding what we're actually doing." (Provider #2)
Beliefs and Attitudes	"Especially people that, you know what, they hear the word cancer – we're talking about a lot of demographics here. Certain people when they hear about cancer, they say, 'okay, I'm gone.' And they close a door." (Patient #24) "They [patients undergoing testing] may say, 'I don't really care. If I've got it, I've got it. So, you know, it doesn't make any difference'" (Patient #26)	"I would say that when I mention genetics, they're – some of 'em are probably – maybe that was unexpected. It was a surprise because they didn't think I was gonna mention that right off the bat." (Provider #3, MD) "Many patients don't like the idea [of genetic testing]... If there is a con to genetic testing, it is that patients are concerned what this information may do to them from other aspects, not the medicine of it but the social aspects of having a genetic mutation." (Provider #7, MD)	"So, I think some patients have an expectation that they're just coming in for a blood draw, when, in reality, it's an appointment where we discuss their personal family history, and we give them a risk assessment, and we make sure that they have information about what they could learn from the testing and implications for themselves and family members. So, I think one thing is some people just simply don't really know exactly what the appointment's going to be like." (Provider #5)

Table 3.

Representative quotes describing enabling factors.

Enabling Factors	Patients	Providers	
		Gynecologic Oncology (MDs and APPs)	Genetic Counselors
Insurance/Cost	"I do remember when I went for the testing that they said that there was a $100 [medical] bill that the insurance would not cover. And I think to some people if they don't have the financial ability that they would decline based on just not wanting to pay another fee. Since being ill and having to deal with any cancer is already expensive on its own... If someone knew that they were going to do something that was an optional treatment, let's say like genetic testing, and they're told that you're also gonna get another $100 bill. Some people would think that would not be worth it." (Patient #1) "Well, I mean, they didn't even tell me the cost of it up front. If somebody had said 4 or 5 thousand dollars, I would have, you know, tried to find an alternative way." (Patient #25)	"For some patients they may have to make the very realistic choices and say, 'Do I wanna spend my money on my growth factor for my chemo or this counseling visit?' And they may say, 'I just can't afford it.'" (Provider #3, MD) "The only negative would be if their insurance doesn't pay for it. They end up with a large bill. Obviously, people would not be inclined to do the genetic testing if their insurance is not going to pay and they end up with a few thousand dollar bill they can't pay. Yeah, I mean, cost is always going to be a big factor." (Provider #4, APP)	"If they don't know exactly how much it's gonna cost then that's a barrier and so I think just being more transparent in exactly how much this appointment costs will be a huge thing for our patients and that hopefully will lead to less cancellations." (Provider #2) "Sometimes cost can be a barrier for patients because they're already undergoing expensive cancer treatments and then we have to add this testing on, which may be $200, which, when they're not undergoing cancer treatment may be doable, but when they've got all these medical bills, maybe it's not doable." (Provider #2) "When they learn that [genetic testing] is something that would likely be covered, at least in part, by their insurance company or that there are more affordable options available, it's something that they're much more willing to consider." (Provider #5)
Logistics	"It was at another facility, or something. And it was not on the same day as my other treatment. It had to be done on a separate day which meant another trip and another location...It does take more effort to drive or make another appointment and take the time to do it." (Patient #1) "If they were able to combine it by just by having the blood sample taken at the same time as another appointment when I was getting other blood draws. That would have made it a no brainer and I would have had it done a lot sooner." (Patient #1)	"I don't know if they've been involved in any e-visits or virtual visits. It's obviously an area kind of ripe for that... I think it's a great thing to offer patients because I think that's maybe the only barrier is someone is three hours away and they're already coming here every three weeks for treatment." (Provider #3, MD) "Let's say a patient comes to us once for a second opinion and they go get the genetic screening and counseling and then we never see them again. Like I don't even know if they ever got that done. Because there's no follow up with that and half the time I don't know what those [genetic testing] results are." (Provider #4, APP) "Typically [genetic counseling] appointments are scheduled out like three months." (Provider #4, APP) "Let's say at our tumor boards we empowered the genetic counselor to not only write down who should be counseled, but they go back and they are able to propose an order to the physician. And then it's in [the electronic medical record], and then they just sign off on it." (Provider #3, MD) "I think having a [genetic counselor] on tumor board makes a big difference about how many referrals we're making." (Provider #4, APP) "I think that if there was a field [in the electronic medical record] that said genetics testing completed or not completed – and if it's in there it's	"It's never convenient for an ovarian cancer patient to come see us. I mean, it's not convenient for anyone really, but often times [ovarian cancer patients] are doing chemo, and then surgery, and then chemo again, so it's hard to find a good time in their treatment schedule to get them in to us." (Provider #2) "Within the pathology report, you know, have some sort of auto-populated section where if the person has ovarian cancer it kinda just pops up saying, "your patient meets [National Comprehensive Cancer Network] guidelines for genetic counseling and testing. Please consider referring your patient to a genetic counselor." So it's on the pathology report, which everybody looks at. Or, if they're eligible for genetic counseling, maybe there's something that pops up on their little patient portal, or the physician [electronic medical record] that says, "oh, they're eligible for genetic testing and genetic counseling." (Provider #1) "With scheduling, there are probably some things that could be improved. So, if we know that all patients with ovarian cancer should be referred, then maybe we can create a standard order that's part of what every provider does when completing their clinic note the first time they meet with a patient." (Provider #6) "I think having the genetic counselor at tumor boards is just a visible reminder and double check to all those providers. Someone is there advocating for the patients who really need to be seen for genetic counseling." (Provider #6) "We do have a genetic counselor who is in the [gynecologic oncology] clinic... I think having her based kind of in-clinic is something that reminds them. I don't know if maybe having someone to see these patients

Enabling Factors	Patients	Providers	
		Gynecologic Oncology (MDs and APPs)	Genetic Counselors
		buried because I've never seen it – that would be something I would look for to say, 'Okay, she's had genetics' or 'She hasn't had genetics.'" (Provider #8, APP)	in clinic with them at the same time would be helpful." (Provider #2)
Provider recommendation/ referral	"Interviewer: And, what prompted you to complete genetic testing? Interviewee: Well, the wonderful thing about [my doctor] is his/her nurses. They were like, okay, you're going to do this. Okay! But they were insistent. Interviewer: So, it was with the encouragement of the doctor and – and their team. Interviewee: It really was." (Patient #7) "[Patients] need encouragement from the physician to get whatever testing they need." (Patient #24)	"I think [my recommendation] is very important. I can think of actually one or two occasions in the last year that a patient was recommended counseling, like at tumor board but I hadn't had a chance to talk to the patient yet, and they were called from a scheduler, and the patient then called my nurse and said, 'Why am I doing this?' So, I think that a brief conversation from their provider can go a very long way." (Provider #3, MD) "I'm a nurse practitioner. So, I think if the physician provider also discusses it with them, that – that makes more of an impact." (Provider #8, APP) "From a provider standpoint, I really think one of the things we should be doing is making this a priority. If all providers strongly felt that genetic testing was a priority, we could probably be more cognizant in capturing these patients. And I think that one of the problems is probably we are missing opportunities to discuss genetic counseling and testing." (Provider #7, MD)	"The provider may recommend it, but they may phrase it in such a way that the patient thinks that it's not important. A lot of physicians at my last institution would say, "genetic counseling is optional." And it is optional. That's totally true, but the patient would a lot of [the] time take that wording to mean unimportant, or not necessary, or not beneficial. They'd say, it's something you can do, you don't have to. Well, that's absolutely true, but it can benefit people. I think sometimes that piece is kind of left out. I mean, anything's optional. Your surgery is optional, but it's still important." (Provider #1) "I think some [providers] may just feel like it's not a priority... I also wonder if it wouldn't immediately impact treatment or a surgical decision if maybe they think it's something that could wait for another time and then they simply never get back [to it]." (Provider #5) "I find [the provider recommendation] extremely important because sometimes, unfortunately, they're only following through because 'the doctor told me to'. So, if they have that type of established relationship and rapport, they understand that if the physician views it as important, they should too, and they should at least hear the information." (Provider #6) "There's always miseducation out there. I would do different educational events, and doctors would say, 'Oh, but what about genetic discrimination. If you get genetic testing, you'll never be able to have health insurance again.' I'd be like, 'Oh, we solved that problem ten years ago.' And they'd say, 'That's thousands of dollars, and no one can afford it.' And I'd say, 'Well, it's not anymore, and all the insurance covers it, and if you don't have insurance, the lab will do it for free.' And so there's a lot of outdated information, and misinformation." (Provider #1)
Patient inquiry/ advocacy	"I was the one that asked doctor, my oncologist. Because my cancer came back within 15 months, I wanted to know if there was any kind of other options. Could I speak to someone about it?" (Patient #24) "One of the barriers would be the doctors... I was the one who would ask him about treatment plans and alternatives and ask him about genetic testing. So, you know, I would definitely say the doctor is one factor. And the other one is just, you know, how well the client is her own advocate, or what friends or relatives are	N/A	N/A

Enabling Factors	Patients	Providers	
		Gynecologic Oncology (MDs and APPs)	Genetic Counselors
	advocating on behalf of the patient.” (Patient #25)		

Table 4.

Representative quotes describing reinforcing factors.

Reinforcing Factors	Patients	Providers	
		Gynecologic Oncology (MDs and APPs)	Genetic Counselors
Inform Family	"Well, I think if you have a cancer that runs in your family, I think you would want to know this so you could prepare your family that they would get check-ups maybe sooner than you did and more frequent. I would like my children to know if there were any problems that could be passed on to my children or even my grandchildren. That's the reason I had [genetic testing]." (Patient #11) "There"s nobody in my family before me with cancer. I have nobody – it's always been heart disease. So, there was no reason why I would have done it. But I have daughters, and I have to make sure that they're okay." (Patient #26)	"I think that, you know, they're obviously worried about their family members. They're worried about kind of how it's going to affect them as far as their personal cancer diagnosis and if these patients' family members are positive for a genetic mutation, what do they need to do with that information." (Provider #4, APP) "I think they want to understand the implications, not just for themselves, but really what does that implication of genetics mean regarding their disease but also regarding how it may affect family members." (Provider #7, MD)	"Anybody who's a parent is always concerned about the risk to their children and grandchildren... I think most of the parents are more concerned about the children than they are about themselves." (Provider #1) "There's even patients who are really excited about it, because they understand the benefit that it can serve themselves or family members... it can be viewed as something that is empowering. It's knowledge that previously wasn't known, that now the family can use to better provide management for those at risk." (Provider #6)
Tailored Treatment	"So, some of the medications that they're coming up with, I think, for the gene test – for – how it's helped me, is now I know that I'm *BRCA1*, and I can get into these trials, you know, or find the trials that are for people with *BRCA* mutations." (Patient #3) "If you have certain genetic traits or just certain genes for like ovarian cancer, I think that there might be additional or different treatments or clinical trials that would be open for you." (Patient #25)	"I think it opens up some other treatment planning as far as like different chemotherapies, clinical trials." (Provider #4, APP) "I think now that there's treatment available based on what your genetic status is, I think they're interested because of that." (Provider #7, MD)	"I think that if patients had a clear understanding of, 'This could impact your treatment in the future,' especially if their cancer isn't responding to other treatments, I think that that might sway whether or not someone would come to the appointment." (Provider #2) "Recently I had a patient who was very apprehensive about genetic counseling and testing. She had a diagnosis of ovarian cancer, and she had a family history, but just didn't really see how it could benefit her at the time, even though the provider had recommended it. She said to me, 'I don't have any children,' but she recognized the benefit for treatment. So, that was the thing that really motivated her. (Provider #6)
Emotional Reactions	"The fear of knowing. Two of my kids have said that they wouldn't want to get tested because they don't wanna know if they're going to get sick. They want to live their lives and then find out later... they were both like, "yeah, we don't wanna know when we're gonna get it... why ruin my life, when I could live my life and do what I wanna do?" (Patient #3) "Interviewer: What do you think could prevent somebody from going through the counseling? Interviewee: I think fear. Sometimes, not knowing and living in oblivion can make you a happy person! It is less fearful not to know than it is to know, sometimes." (Patient #7) "Uh, what would prevent people from doing it? I, I don't know. Sometimes people fear the information they will get." (Patient #25)	"Interviewer: And are there any negative outcomes? Interviewee: Yes. I think that the one that sticks out is the anxiety of going through this process. Some patients can get very anxious waiting for an appointment." (Provider #7, MD) "They're scared to find out if they're gonna have an increased risk for breast cancer or if their relatives or their daughters or nieces [are at increased risk] – some are very eager to have it; some don't want anything to do with it." (Provider #8, APP)	"Sometimes they become emotional and they can tear up or cry because they don't want to pass something onto their family." (Provider #2) "A patient who could have guilt if they start to understand that potentially it is something hereditary and there could be risk to other individuals in the family, whether that's siblings, or parents, or children. And then, you know, how you reconcile those types of feelings." (Provider #6) "So, sometimes people, when coping with their current cancer diagnosis say, "You know, I've already been through so much with this, I really can't deal with, you know, better understanding if I'm at an increased risk for colon cancer."" (Provider #6)