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Young Women's Perceptions Regarding Communication with Healthcare Providers About Breast Cancer, Risk, and Prevention

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Abstract

Background—Women younger than 45 years old have lower rates of breast cancer, but higher risk of recurrence and mortality after a cancer diagnosis. African American women are at risk for early onset and increased mortality; Ashkenazi Jewish women are at risk for genetic mutations leading to breast and ovarian cancer. Although younger women are encouraged to talk to doctors about their family history, little is known about these discussions.

Materials and Methods—In 2015, 167 women aged 18–44 years participated in 20 focus groups segmented by geographic location, age, race/ethnicity, and family history of breast and ovarian cancer. Transcript data were analyzed using NVivo 10 software.

Results—Although the majority of women talked to their doctor about breast and ovarian cancer, these conversations were brief and unsatisfying due to a lack of detail. Topics included family history, breast cancer screening, and breast self-examination. Some women with and without family history reported that healthcare providers offered screening and early detection advice based on their inquiries. However, few women took action or changed lifestyle behaviors with the intent to reduce risk as a result of the conversations.

Conclusions—Conversations with young women revealed missed opportunities to: enhance patient-provider communication and increase knowledge about breast cancer screening and surveillance for higher risk patients. Physicians, allied health professionals, and the public health community can better assist women in getting accurate and timely information about breast and ovarian cancer, understanding their family history to determine risk, and increasing healthy behaviors.

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Keywords

providers; young women; breast cancer; ovarian cancer

Introduction

Breast cancer affects women of all ages, with most cases diagnosed in women older than 50 years.¹ While women younger than 45 years only account for <10% of all cases,¹ their occurrences are often accompanied by higher risk of recurrence and death, compared to older women.^{2,3} This is true for African American women who have been identified as having increased prevalence at younger ages and increased mortality rates from breast cancer.⁴⁻⁶ Breast cancer at younger ages could be indicative of genetic mutations like *BRCA1/2*, which are associated with increased susceptibility to hereditary breast and ovarian cancer (HBOC).^{7,8} While the risk of having these mutations occurs in about 1 in 400 people in the general population, women of Ashkenazi Jewish descent are at higher risk.^{9,10} Recent studies have also reported higher-than-expected frequencies of *BRCA* mutations among young (<45 years) African American women living with breast cancer.¹¹

Younger women can talk to their doctors about their family history of breast and ovarian cancer and associated risk, ways to reduce risk (*e.g.*, breast feeding, limiting alcohol, maintaining a healthy weight, and avoiding exposure to carcinogens and radiation), and recommendations for genetic counseling and/or testing. Genetic counseling can help women understand their hereditary breast cancer risk and determine whether genetic testing is warranted to identify genetic mutations with hereditary links.¹² Younger women determined to be at higher risk may also benefit from discussions of early detection strategies through advanced screening or other medical interventions.

Unfortunately, existing research has identified several challenges to effective patient and provider communication about breast and ovarian cancer and poor uptake of action-oriented outcomes, including referral to genetic counseling and testing. These challenges include the following: lack of primary care providers (PCPs) knowledge about HBOC and limited experience in referring women for genetic counseling¹³⁻¹⁵; poor systematic collection of family history data^{16,17}; provider difficulty in communicating genetic risk¹⁸⁻²⁰; and poor patient understanding regarding HBOC, the genetic counseling and testing process, and the meaning of genetic testing results.²¹⁻²⁴ Some interventions to address these challenges include continuing medical education for providers and the inclusion of nurses, allied health professionals, and patient navigators in the delivery of communication. However, the evidence regarding effectiveness of these interventions has not been widely examined regarding breast cancer communication between young women and their providers.

While the aforementioned challenges have been examined, limited information exists regarding aspects of communication between providers and patients, including the types of healthcare providers (HCPs) with whom young women are talking about breast and ovarian cancer; catalysts for these conversations; topics discussed; tone and satisfaction of the conversations; and actions taken as a result. In addition, these factors have not been evaluated and compared across groups of women with and without a family history of breast

and ovarian cancer or those from specific racial/ethnic backgrounds which may predispose them to higher risk of breast cancer occurrence or breast cancer-related mortality. Our study examines these underexplored factors regarding patient and HCP communication about breast and ovarian cancer, related risk, and actions that can be taken to lower risk or detect breast cancer earlier in women at higher risk.

Materials and Methods

The Centers for Disease Control and Prevention's (CDC) "Bring Your Brave" (BYB) campaign²⁵ provides information and resources about breast cancer and related risk for women younger than age 45 by sharing real stories about young women affected by breast cancer. As part of a larger qualitative study for this campaign,²⁵ data from young women were collected during focus groups conducted in five U.S. cities over 1 month (Chicago, New York City, Birmingham, Sacramento, and Phoenix). Twenty focus groups were conducted, in part, to explore beliefs and perceptions regarding communication with HCPs about breast and ovarian cancer. Focus groups were conducted with women aged 18–44 years and segmented by race/ethnicity (Ashkenazi Jewish, African American, or other "general population/other racial or ethnic groups"), age (18–29 years vs. 30–44 years), and by any reported first or second degree relative, maternal, and/or paternal family history of breast or ovarian cancer (history vs. no history; Table 1).

Professional recruiting service firms arranged logistics and participants for the focus groups. All participants were screened to ensure respondents met inclusion criteria and to ensure heterogeneous demographic parameters (Table 2). Groups were then stratified by age, race/ethnicity, and family history (Table 1). Institutional Review Board exemption and Office of Management and Budget approval were received from the CDC and Oak Ridge Associated Universities. Written and verbal consent were obtained from participants during the screening process and before focus groups. Participants who met inclusion criteria were enrolled in the study and received an incentive (\$75).

Focus groups lasted 2 hours and were conducted by professional female moderators with relevant experience in cancer/chronic disease. All moderators used semistructured moderator's guides developed by the study team. Moderators were matched to focus groups for which they self-identified as the same race/ethnicity as participants. Trained research staff observed focus groups in person, *via* a two-way mirror, and through online streaming. Focus group discussions were audio recorded and transcribed.

Analysis

Two team members (B.S. and B.W.) reviewed transcripts for accuracy and completeness against discussion notes and audio recordings. Final transcripts were uploaded to QSR International's NVivo 10 software for analysis. Reviewers trained in qualitative thematic analysis reviewed the data and developed a codebook. Using the codebook, three researchers coded transcripts independently. A coding comparison query was run to determine agreement between coders and to test for quality assurance and accuracy (reliability rate 75%). Researchers analyzed coded responses to identify thematic differences and

similarities in perceived participant and HCP communication between ethnic and racial groups, those with presence or absence of family history, and younger and older age groups.

Results

Sample characteristics

Of 167 total participants, 41% lived in the western census²⁶ region ($n = 69$); 30% lived in the midwest ($n = 50$), 19% lived in the south ($n = 32$), and 10% lived in the northeast ($n = 16$) of the United States. Forty-one percent self-identified as being from racial/ethnic groups other than African American and Ashkenazi Jewish (“general population”; $n = 69$), 39% were African American ($n = 65$), and 20% described being of Ashkenazi Jewish descent ($n = 33$). About half were under 29 years old ($n = 84$) and the majority of participants reported having one or more relatives diagnosed with breast and/or ovarian cancer ($n = 89$; Table 1). While participants in family history groups were not required to have an affected relative diagnosed at a young age (under 50 years), several family history group participants did self-disclose having a female relative who was diagnosed with breast cancer at a young age.

Occurrence of patient-provider communication regarding breast and ovarian cancer and related risk

Responses are outlined below. Select responses (transcribed quotations) are available in Table 3. Alphanumeric designations in the text refer to relevant quotation numbers.

Across all segments (age, ethnicity, and family history), most women reported communicating with their HCPs about breast and ovarian cancer. Independent of race/ethnicity, women with and without a family history mentioned that women without a family history of breast or ovarian cancer would be less likely to need or want to talk to HCPs about breast or ovarian cancer (Table 3, c1, c2). While not the majority, some women in general population groups with a family history endorsed not wanting to discuss breast and ovarian cancer with their HCPs, despite possible risk.

Most women, across all focus group segments, reported having regular annual appointments with a HCP at which conversations about breast and ovarian cancer were most likely to occur. Conversations about breast and ovarian cancer were more likely to occur with obstetricians and gynecologists (OB/GYN) than with other types of PCPs. In addition to OB/GYNs and PCPs, women also reported speaking with nurses, herbalists, midwives, medical staff working for health insurance companies, and counseling specialists working at doctor’s offices.

Women with a family history described being the primary initiators of conversations regarding breast and ovarian cancer, but agreed that HCPs also initiated these conversations. Women without a family history reported that they did not routinely initiate communication as “it was not something they needed or wanted to talk about,” given that no close relative had been diagnosed. Differences in being the primary initiator were also seen based on age and race/ethnicity. Women aged 30–44 years were more likely to report HCPs initiated conversation, while women 18–29 years endorsed being initiators. African American women were slightly more likely to report initiating conversations with their HCPs compared to

respondents who identified as Ashkenazi Jewish or were part of other racial and ethnic groups.

Catalysts and barriers for patient-provider communication

Catalysts for communication. While most women, across all segments, communicated with their HCPs about breast cancer and ovarian cancer, the majority described these conversations as brief and lacking detail. Several women initiated conversations with HCPs after experiencing symptoms or health concerns they perceived to be related to breast and ovarian cancer, including lumps, uneven breast development, back pain, and chest acne. Most women with a family history of breast or ovarian cancer, independent of race/ethnicity, agreed that having a family history prompted them to speak with their HCPs (Table 3, c3, c4, c5). The majority of women across group segments agreed that they answer questions about family history of any medical illness on appointment intake forms. However, most women with and without family history of breast and ovarian cancer agreed that the forms did not prompt much in-depth conversation with their HCP about breast or ovarian cancer or related risk. Instead, women with a family history mentioned that more in-depth discussion with a provider might occur only after a woman is referred for screening by their HCP and if she receives an abnormal screening test result.

Barriers to communication—Some women reported avoiding communication with HCPs regarding breast and ovarian cancer. Ashkenazi Jewish women also reported not initiating conversations during annual doctors' visits due to lack of concern about the diseases, an assumption that the "HCP would bring it up if it was important," and limited consultation time with the doctor (Table 3, c6, c7). Some women from general population groups also described not wanting to discuss concerns about breast and ovarian cancer with their HCPs despite understanding risk, due to fear of getting tested and diagnosed with these cancers (Table 3, c8).

Topics discussed during patient-provider conversations

Breast health topics women most frequently mentioned discussing with their HCPs were related to clinical breast examination and recommended mammography screening ages, family history, and breast self-examination (BSE).

Clinical breast examination and recommended screening ages—Most women with a family history of breast and/or ovarian cancer and a few without reported speaking with their HCPs about clinical breast examinations and the recommended age to begin mammography. The reported HCP recommended age of initiation among women with a family history varied by race/ethnicity (African American women = 23–42 years; Ashkenazi Jewish women = 30–35 years; and women in the general population groups = 40–50 years).

Several 30- to 44-year-old African American women with a family history endorsed talking to their HCP about mammography and receiving a mammogram before age 40 years.

Women in this group who received a mammogram expressed feeling "happy" with their decision to get screened. Most women in this group, who did not receive a mammogram, reported frustration when they were advised to wait, even after expressing a strong desire to

have a mammogram. Some women in this group felt they were being prevented from doing what would be best for their health (Table 3, c9, c10). In some cases, they acknowledged questioning their HCPs judgment or concern for them as a patient. Reasons they were advised to wait ranged from being too young, the procedure not being covered by insurance (at their age), and being informed that they “did not need one.”

Family history and health concerns—Few women with a family history reported having conversations pertaining to counseling about the *BRCA* gene and/or genetic testing. Some Ashkenazi Jewish women without a family history mentioned that providers inquired about their ethnicity, informed them of associated risk for genetic diseases (e.g., Tay-Sachs), and suggested genetic testing to identify genetic mutations for diseases other than breast and ovarian cancer. Overall, HBOC risk was not usually brought up during these discussions (Table 3, c11). While the majority of Ashkenazi Jewish women stated that their HCPs were aware of their ethnic background, some 30–44 years old without a family history expressed frustration or concern that their HCPs never discussed HBOC risks specific to their Ashkenazi Jewish heritage. Women in this group felt that their HCPs should be aware of their increased risk of HBOC and discuss these concerns with them (Table 3, c12, c13).

Breast self-examination—Many women, across all groups, reported that their HCPs regularly taught and encouraged them to conduct BSE.

Other discussion topics—A few women mentioned discussing ovarian cancer risk and insurance coverage for breast cancer screening with their HCPs. Notably, few women in any of the focus group segments reported discussing preventive health behaviors related to breast or ovarian cancers with their HCPs.

Tone of conversations and related patient satisfaction

Several women across focus group segments described the tone of conversations with HCPs as “pleasant,” “comfortable,” “easy,” “reassuring,” and “casual/laid back.” While a positive tone to conversations with their HCPs was reported, women, especially those who were aged 30–44 years and those with a family history, regularly reported dissatisfaction with the content or outcomes of HCP conversations describing communication as “matter of fact” and “surface/basic.”

Family history—Many women with a family history (independent of race/ethnicity) felt their concerns were not always appropriately addressed by HCPs because of their young age (Table 3, c14, c15). In addition, some women with a family history felt that they did not get credible or satisfactory information or explanation of test results from their HCPs, which left them “frustrated” and/or “looking to other HCPs or sources for health information” (Table 3, c16, c17).

Age—The amount of time allocated for patient visits was commonly discussed as a reason for dissatisfaction, among 30-to 44-year-old women. These women felt the time constraints on HCP visits prevented them from having their health concerns addressed in a thorough and timely manner (Table 3, c18, c19). Only a few women expressed that their HCPs took time

to answer all their questions and address any concerns they had regarding breast and ovarian cancer-related topics.

Actions taken based on conversations with HCPs and reasons for inaction

Overall, few women mentioned actions they had taken as a result of breast cancer and ovarian cancer discussions with their HCPs. Some women, including those without a family history, reported that their HCPs offered screening and early detection advice based on their inquiries, but advice regarding age of screening initiation varied by race/ethnicity. Some women also described getting a mammogram or doing BSE, as recommended by their HCPs (Table 3, c20, c21, c22). Few women reported engaging in preventive behaviors (*e.g.*, exercise and healthy eating), researching health topics, and initiating conversations with family members after discussing breast and/or ovarian cancer with their HCP.

Ashkenazi Jewish women aged 30–44 years discussed actions they had not taken or would not take due to inability or unwillingness. Some women in this group mentioned that they had not received a mammogram because they were breastfeeding. Others who were advised to get genetic testing did not do so because they were only given pamphlets and educational materials by their provider without a more robust conversation about testing details and rationale, or they did not see the purpose in getting genetic testing if they were not willing to take surgical preventive measures, including prophylactic mastectomy (Table 3, c23).

Discussion

This analysis explored communication between young women and their HCPs regarding breast and ovarian cancer and hereditary risk. The majority of women in the study reported annual preventive care doctors' visits with a PCP or OB/GYN. In comparison, only 41% of women aged 18–29 years and 45% of women aged 30–49 years attend annual preventive care visits with PCPs or OB/GYNs.²⁷

While many women reported discussing breast and/or ovarian cancer during routine wellness visits, these conversations were often described as containing limited discussion about hereditary risk or prevention. The lack of detailed information provided may be a function of factors reported in our study, including women without a family history of breast and/or ovarian cancer feeling less concerned or having no desire to speak with a HCP about related topics, limited time during doctors' visits, and fear of discussing cancer and related risk. High levels of dissatisfaction were reported regarding the amount of tailored information shared by HCPs, especially among women with a family history. As several women in our study reported having a relative diagnosed with breast and/or ovarian cancer before age 50 years, women in these groups may have elevated risk and a subsequent need for more intensive discussions regarding screening, genetic counseling, and genetic testing in accordance with care guidelines and recommendations^{12,28} (when indicated).

Across groups, women reported that both they and their providers initiated discussions. However, family history of breast and ovarian cancer was a catalyst for patient-initiated communication with a provider. This is consistent with previous research showing women with a family history are more interested in initiating discussions about risk, genetic

counseling, and testing.^{29,30} Experiencing symptoms (*e.g.*, lumps and pain) or health concerns, in addition to having an abnormal screening test, were also reported catalysts for patient-initiated communication.

African American women and women aged 18–29 years were more likely to be the initiators, while HCPs primarily initiated conversations with women aged 30–44 years. As the incidence of breast and ovarian cancer is rare among women who are under the age of 29 years¹ and many breast cancer recommendations pertain to women who are older, it is possible that providers do not routinely initiate detailed discussions about breast and ovarian cancer given a number of other competing topics that are often covered during the standard medical visit (13–16 minutes).³¹ The onus for initiating discussions about breast and ovarian cancer, risk, and prevention may then fall on women who are under the age of 29 years. In addition, our finding that African American women were slightly more likely to initiate conversations with their HCPs (compared to respondents from Ashkenazi Jewish or general population groups) was encouraging given that women in this racial group are at higher risk for late-stage diagnosis and poorer outcomes when diagnosed.^{4–6}

Discussion topics

Women in our study talked to their HCPs about family history and hereditary health concerns, clinical breast examinations and recommended screening ages, and BSE. While completing family history intake forms at doctors' visits may have prompted women and their providers to discuss breast and ovarian cancer, these reported conversations largely did not address hereditary risk or BRCA screening for individuals with a family history of cancer.¹² While providers may be aware of *BRCA* testing and counseling, research has shown that few providers consistently recognize family history patterns as appropriate indications of the need for BRCA testing, leading to poor referral rates and, possibly, limited communication with patients regarding this topic.³² In the case of hereditary risk among Ashkenazi Jewish women, providers may also be more aware of genetic risk for diseases like Tay-Sachs and less aware of risks for HBOC related to *BRCA1/2*.

Regarding discussions about breast cancer screening, women with family history more often reported speaking to their HCP about the age they should receive a mammogram, possibly due to heightened awareness of potential risks for HBOC. Among women with a family history of breast or ovarian cancer, differences in information provided by HCPs about the age at which to first receive a mammogram varied by race/ethnicity. It is possible that African American (vs. those in the general population) women were informed about starting mammography at younger ages by their HCP due to heightened awareness or perceived risk of late-stage diagnosis and *BRCA* genetic mutations, leading to conversations about mammography at younger ages. African American women aged 30–44 years with a family history endorsed feeling happy after receiving a mammogram before age 40 years as a result of having a conversation with their HCP. However, some women in this group also reported frustration at not receiving a mammogram after their HCP discouraged them from getting screened before age 40 years because they were “too young,” the procedure was not covered by insurance (at their age), or other undisclosed reasons. Consistent with previous literature,

it is possible that HCPs may discourage patients from voicing their concerns, expectations, or requests for more information,³³ if the HCP does not feel that screening is indicated.

In all focus group segments, many women mentioned that their HCPs taught and encouraged them to conduct BSE. While existing guidelines do not frame determinations regarding BSE for high risk women who are not yet recommended to start mammographic screening due to age, United States Preventive Services Task Force does recommend against teaching BSE for all women.²⁸

Finally, patient-provider conversations reportedly lacked discussion regarding preventive health behaviors associated with breast and ovarian cancer risk reduction. This was not surprising given that research showing 82% of OB/GYN visits and 74% of visits to PCPs among women is not inclusive of counseling regarding obesity, exercise, tobacco use or exposure, or diet.²⁷ Health behavior counseling and related interventions are an important mechanism to address prevalent health-related behaviors in clinical settings. Subsequently, HCPs serve an important and integral role in providing counseling and motivating their patients in adopting health behavior changes.³⁴

Satisfaction with conversations and subsequent actions taken

Consistent with previous studies,³⁵ women were largely dissatisfied with their provider discussions due to lack of time during the visit, feeling discounted due to their young age, and the perception that information provided by their HCP was not credible or satisfactory. Women with family history reported feeling discounted due to their age, despite provider recommendations¹² to screen women with a family history tool designed to identify family history associated with increased risk *BRCA1/2* genetic mutation. Few women took actions to reduce breast and ovarian cancer risk, engaged in preventive methods, sought additional knowledge about related topics, or received genetic counseling or testing. HCP communication and recommendations have been associated with increased interest in and uptake of genetic counseling and testing among certain groups of women.^{30,36} Limited action taken among women in our study may reflect the dearth of received information about genetic counseling and testing during their HCP conversations.

Strengths and limitations

This study adds new perspectives to the research in this area, including examining perceptions regarding how often communication occurs between HCPs and their patients who are 18 through 44 years, satisfaction with topics discussed, and any actions taken among those women. The study also uniquely examines respondent communication patterns segmented by age, race/ethnicity, and existence of family history of breast and ovarian cancer. The study sample size is larger than average for qualitative studies, and women in the study represented diversity in economic status, education, marital and parental status, and geographic location. However, results are still based on a small sample of recruited respondents under age 45 years and may not represent the views of women over the age of 45 years or those with a personal history of breast and ovarian cancer. This study did not formally assess participant cancer risk, making actual risk of participants unknown. The study also excluded women who received genetic testing or counseling and, therefore, may

have been recognized by a HCP as potentially high risk. However, the study's intent was to examine provider communication and informational needs among women who might be at elevated risk based on their family history and who had not received genetic testing or counseling. This study, therefore, provides novel findings which can be used to adapt and develop content for educational interventions such as the CDC's BYB campaign for this specific group of women.

Conclusions

Although women access healthcare services regularly, HCPs may be missing opportunities for providing counseling on breast and ovarian cancer risks and preventive health behaviors. While interventions^{37–39} have been designed to support HCPs in offering evidence-based care and guidance and improving patient health literacy, their effectiveness has not routinely been evaluated among young women and those who may be at increased risk for breast and ovarian cancer. HCPs may benefit from additional training regarding communication with patients, especially those under 45 years and/or with a family history of breast and ovarian cancer, about risk, prevention, and genetic counseling and appropriate testing. In addition, women may benefit from receiving tailored information and educational materials about these topics from their HCP and/or other trusted sources.²⁵ As HCPs are continually tasked with addressing several health-related topics during brief medical visits, increased engagement of nurses, genetic counselors, patient navigators, and other allied health professionals may be important in providing more robust discussions with patients. Providing all women, including younger women, high-quality and up-to-date information about their breast and ovarian cancer risk is imperative. This requires sufficient patient and provider engagement and communication about overall risk, preventive health behaviors, and screening and surveillance options for women at increased risk.

CDC's BYB campaign²⁵ informs young women about their risk for breast and ovarian cancer and may improve their knowledge and awareness about HBOC and preventive health behaviors. Results from this study will be used to inform campaign efforts and communication strategies.

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Table 1

Focus Group Segmentation Strategy

Audience segment	Family history of breast or ovarian cancer		Focus group location (one group per location)
	Yes (n)	No (n)	
Ashkenazi Jewish women ages 18–29 years	9	—	New York City
	—	9	Chicago
Ashkenazi Jewish women ages 30–44 years	9	—	Chicago
	—	7	New York City
African American women ages 18–29 years	8	—	Birmingham
	9	—	Chicago
	—	7	Birmingham
	—	6	Chicago
African American women ages 30–44 years	9	—	Birmingham
	9	—	Chicago
	—	8	Birmingham
	—	9	Chicago
General population ages 18–29 years	9	—	Sacramento
	9	—	Phoenix
	—	9	Sacramento
	—	9	Phoenix
General population ages 30–44 years	9	—	Sacramento
	9	—	Phoenix
	—	6	Sacramento
	—	9	Phoenix

Table 2

Focus Group Inclusion and Exclusion Criteria

Inclusion criteria	Exclusion criteria	Within group characteristics
<ul style="list-style-type: none"> Female gender 18–44 years of age No history of breast or ovarian cancer No history of undergoing genetic counseling or testing regarding cancer-related concerns Own a smart phone^a Use of Internet for more than 2 hours each week^a African American/Black race for segmented groups in Birmingham and Chicago (Table 1) Ashkenazi Jewish for segmented groups in New York and Chicago (Table 1) 	<ul style="list-style-type: none"> Nonfemale gender 45 years of age and older Current or past diagnosis of breast or ovarian cancer Undergone genetic counseling with a licensed genetic counselor regarding cancer-related concerns Undergone genetic testing related to cancer or your risk for developing cancer Did not own a smart phone^a Did not use the Internet for at least 2 hours each week^a Employees or contractors for public health, like the CDC, local or state health department, or other public health organization Employed or contracted as Medical professional 	<p>Focus group participants had a mix of heterogeneous characteristics, including:</p> <ul style="list-style-type: none"> Education level, Income, Marital status, Parental status.

^aInclusion and exclusion criteria selected as data collected were also used to inform the “Bring Your Brave” campaign.²⁵

CDC, Centers for Disease Control and Prevention.

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Table 3
Patient-Provider Communication Regarding Breast and Ovarian Cancer and Related Risk

Theme	Supporting quote	Family history ^d	Race/ethnicity	Age, years	Location
Occurrence of a discussion about breast and ovarian cancer	(c1) "I don't think it's necessarily (to talk to a doctor). It's an uncomfortable topic and there's just no history (of breast or ovarian cancer) in my family."	No	General population	18-29	Sacramento
	(c2) "If I had a family history, maybe I would (talk to a doctor about breast or ovarian cancer), but I feel like I don't think about it as much."	No	Ashkenazi Jewish	18-29	Chicago
Catalysts to communication	(c3) "Mine happened (conversation with doctor) when my mom got diagnosed, like last year, and like I visited and talked to the doctor more in the last year than ever."	Yes	African American	18-29	Birmingham
	(c4) "Since I was 16 and my mom got breast cancer and my grandmothers' had it three times, I ask every year about it. I make them triple check."	Yes	Ashkenazi Jewish	18-29	New York
	(c5) "I've definitely approached my doctor because I know this gene is in my family so... and as I mentioned, I'm supposed to get tested for it."	Yes	General population	30-44	Phoenix
Barriers to communication	(c6) "I feel like it's not that I don't want to (talk to the doctor). I just don't think about it really."	No	Ashkenazi Jewish	18-29	Chicago
	(c7) "I figure I'm safe if they don't bring it up. I see the doctor once a year... everything's checked."	Yes	Ashkenazi Jewish	30-44	Chicago
Topics discussed: clinical breast examination	(c8) "Me... honestly no (I don't talk to my doctor) 'cause I don't wanna hear the answer that I have it."	Yes	General population	18-29	Sacramento
	(c9) "My physician said it's too early for me to get a mammogram. I've never had a mammogram, I'm only 35. I've actually been trying to get a mammogram since I was 25. And the first time I asked, they said your breasts are not developed. And I told them, 'Well, I have a history, it's a family history of breast cancer'. I want to know, because if you have to cut them off, cut them off, I'm fine. I'm totally fine with that. And they still said 'No, you have to wait'."	Yes	African American	30-44	Chicago
	(c10) "And my doctor asked me (family history) and I still didn't get no testing (clinical breast examination) done from there. I told her (I have family history of breast cancer) and she said I don't even need a mammogram. That's what I'm saying, and she knew that I had somebody in my family that had breast cancer, but she didn't even say I needed to be checked (clinical breast examination)."	Yes	African American	30-44	Birmingham
Topics discussed: family history and hereditary health concerns	(c11) "She (physician) did ask if I was of Ashkenazi descent. I said yes, so she did send me for the Tay-Sachs test. There were a couple of other genetic diseases that if you're a carrier and your husband is a carrier, then your child will be born with it. But breast cancer and ovarian cancer I think are not part of that discussion."	No	Ashkenazi Jewish	30-44	New York
	(c12) "I'm kind of like how could I not be told about this by any gynecologist? I mean if there's some sort of risk factor because of who I am, I should know about it I think."	No	Ashkenazi Jewish	30-44	New York
	(c13) "I never got anything either. Maybe because I was younger, and I was not looking to bear children yet or anything. They don't mention it (risk of HBOC or genetic mutation) and my doctor is Jewish too so I'm surprised that she didn't say anything, because I've never heard of this either. If they did offer me tests to see if I am positive or negative, I would take them."	No	Ashkenazi Jewish	30-44	New York

Theme	Supporting quote	Family history ^a	Race/ethnicity	Age, years	Location
Tone of discussions and patient satisfaction	(c14) "They're just like, 'Oh, you're OK, you're still 38'. It pisses me off because it's like I want to be able to prevent it before it happens. I mean I like her, she's a nice OB/GYN, but she's just like, 'Oh, you don't have to worry about it'. I'm like, 'I do worry about it'."	Yes	General population	30–44	Sacramento
	(c15) "So I don't think it's really regarding the insurance. It's just that we're younger, and they just disregard the situation in total. Because like a mammogram, yes, they are expensive because not too many young women really come up with breast cancer statistically. So they just disregard us overall."	Yes	African American	18–29	Chicago
	(c16) "I've had conversations with my doctor. Some of these doctors... I honestly feel like they don't know what they're talking about."	Yes	African American	18–29	Chicago
Actions taken after HCP discussion and reasons for inaction	(c17) "I was floored by the reaction I got from the radiologist who just 'foo-foo' d' me and told me there was nothing there. Then I went to my other doctor again today, my primary care, and she felt it, and she goes 'It's pretty obvious that it's there, so I don't know why she didn't know'. You know, it made me mad because you go in, and you make this appointment, and you take time off work to dedicate to find out and get answers and do what you need to do to ask questions or whatever, and it's like those are your 15 minutes."	Yes	General population	30–44	Sacramento
	(c18) "If I feel a pain and something's wrong with me, or whatever, I call my doctor to make an appointment. You (doctor) can't see me for three months? I can drop dead in three months. I can drop dead tomorrow. What am I supposed to do? Don't tell me to go to the emergency room. They're general. They're not going to do anything. [the emergency room doctor will say] 'Make an appointment with your doctor. I did'. It's not for three months."	Yes	African American	30–44	Chicago
	(c19) "The problem with that is they only have a certain amount of time for you—period. And if you go in there with a list of questions, [the doctor might say] 'Well, we're only here for this one, so we'll discuss this one. You can come back'. It's like, 'Well, I have these other questions'. [the doctor might say] 'Well, I have other patients, I'm on a time schedule'. So they go with the most severe thing and then move forward."	Yes	General Population	30–44	Sacramento
Actions taken after HCP discussion and reasons for inaction	(c20) "I always go home [after doctor's visit] and I share with my husband and we make sure we do the checks and I share it with my sister."	Yes	African American	30–44	Birmingham
	(c21) "Mm-hmm [received mammograms] My two sisters (the one is 23, and the other one's 25) and me."	Yes	African American	18–29	Birmingham
	(c22) "So I follow [the HCP's] plan, which is probably five to ten years earlier than you would normally do some of these [screening tests for cancer]."	Yes	Ashkenazi Jewish	30–44	Chicago
Actions taken after HCP discussion and reasons for inaction	(c23) "At the end of our visit, he (doctor) basically just sat in his room and said, 'There's this new test'. This was about four years ago. I guess it was a hot topic then. He gave me a pamphlet and said 'Would you be interested in taking this? Here's a form to fill out if you want to go for testing'. I didn't do anything with it. [The pamphlet mentioned fertility and the predisposition for <i>BRCA</i> gene mutation]. I didn't want to chop off my boobs. I didn't want to think about it too much. He's like 'You can know, or you cannot know'. I'm like 'I'll choose not knowing if I have it or not.'"	No	Ashkenazi Jewish	30–44	New York

^aFamily history refers to any history of breast and ovarian cancer.

HB0C, hereditary breast and ovarian cancer; HCP, healthcare provider.