Knowledge, Attitudes, and Interest in Breast-Ovarian Cancer Gene Testing: A Survey of a Large African -American Kindred with a BRCA1 Mutation[1]

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Abstract:

Background. This study assessed counseling and testing needs from the perspective of adult members of a large African-American kindred with a BRCA1 mutation.
Methods. Interviews were conducted with 95 male and female kindred members to elicit information on sociodemographics, attitudes toward health care providers, breast cancer screening behaviors, and religious/spiritual beliefs, as well as to evaluate psychological distress, beliefs, knowledge, and attitudes related to genetic testing.
Results. Knowledge about breast and ovarian cancer genetics was limited. Adherence to screening recommendations was low among females with no personal breast or ovarian cancer history. The majority (67%) wished to discuss risk factors with a health care provider. Most participants (82%) indicated that they would have a genetic test if it were available. Significant predictors of intent to undergo testing were having at least one first-degree relative with breast and/ or ovarian cancer (OR = 5.1; 95% CI = 1.2–20.9) and
perceived risk of being a gene carrier ?50%(OR = 64.3;
95%CI = 5.1–803.9) or reporting that they did not know their risk of being a gene carrier (OR = 10.9; 95%CI = 2.1–57.7). Cited barriers to testing included cost and availability.
Conclusion. There is a high interest level in genetic testing despite limited knowledge about cancer genetics among these high-risk African Americans. Our study provides information for designing a genetic education and counseling intervention for this and similar families.
Key Words: genetic testing; African American; breast cancer; screening.

INTRODUCTION

Approximately 2–5% of breast cancers and 10% of ovarian cancers can be attributed to mutations in the BRCA1 and BRCA2 genes [1,2]. Testing for BRCA1 and BRCA2 is commercially available and offers the opportunity to identify patients for whom genetic counseling maybe of value. Issues regarding insurability, confidentiality, and potential discrimination have been discussed [3,4]; however, little research on the clinical application of cancer-related genetic technology for ethnic minority populations has been done [S]. Offspring of a female or male BR CA1 carrier are at 50% risk of inheriting the altered gene. Female carriers of BRCA1 mutations have an estimated 46–85% lifetime risk of breast cancer and a 16–65% risk of ovarian cancer [6f10]. Furthermore, the risk for developing colorectal

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cancer in male and female BRCA1 mutation carriers and prostate cancer in male carriers may be increased [10,11].

Use of genetic counseling and testing for breast and ovarian cancer susceptibility is increasing in clinical settings throughout the United States [12,13]. Because most of the molecular epidemiologic research on BRCA1/BRCA2 mutations has focused on Caucasians and those of Ashkenazi Jewish origin [7f10], knowledge of the frequency and penetrance of these mutations in African Americans is limited. Furthermore, genetic counseling and testing programs developed for Caucasian populations may not be culturally sensitive. Thus, it is timely to examine factors that will influence genetic counseling and testing programs among individuals from diverse cultures and socioeconomic groups. Furthermore, due to the racial disparities in incidence and mortality rates for cancer in African Americans, it is critical to target this group for screening and prevention interventions.

Prior to developing a genetic counseling and testing protocol for adult members of an extended African- American kindred with a BRC,41 mutation, a needs assessment was conducted. This needs assessment evaluated adult members of the kindred. Here we describe: (a) their health care attitudes and practices; (b) their knowledge about breast and ovarian cancer susceptibility; (c) their beliefs and attitudes about breast and ovarian cancer and genetic testing; and (d) breast cancer screening behaviors. We also determined predictors of intent to have a genetic test. This kindred maybe the first African-American familywith a BR C,41 mutation to be studied in this manner.

MATERIALS AND METHODS

Study Population and Procedures

Ninety-five adults (all ?18 years of age) were interviewed between July 1998 and February 1999. Most live in a small Louisiana town; they are diverse in income, location (rural vs urban), and education. The kindred, known as K2099, includes six generations with 36 known cancer cases: 27 breast, 4 ovarian, 4 colorectal, and 1 prostate. The youngest ages of onset of breast cancer and ovarian cancer are 28 and 54 years, respectively. Forty-four percent of the participants participated in a prior study to isolate BR C,41 [14]. Although the specific mutation in BR C,41 was later determined, no further testing has been conducted on the Louisiana members of this kindred, and none of the relatives received research results or information about the genetics of hereditary breast and ovarian cancer. However, in the course of this psychosocial study, they were told that they were at increased risk for developing breast cancer due to family history. None of the participants reported having clinical BR C,41 testing prior to participation in the present study.

Eligibility criteria for our study included the ability to give written informed consent in English and biological kinship to a K2099 member. The study was approved by the University of Utah Institutional Review Board. Participants were given the option, when possible, of having interviews in person in their homes or in another acceptable location or by telephone. This strategy was suggested by family members during the planning phase of the study. Information about the study purposes and procedures was sent between July and October 1998. Those not interested in the study were requested to return a form indicating that they did not want to be

contacted further. Those who consented to participate completed a structured in-person (63%) or telephone (37%) interview.

Measures

The in-person or telephone administered questionnaires contained identical measures of sociodemographics, clinical variables, psychological distress, religious/spiritual beliefs, and attitudes toward genetic counseling and testing.

Background factors. Variables included age, gender, family identification number (to control for group-level variance attributable to immediate families), marital status, education, household income, history of cancer, and number of first-degree relatives with breast and/ or ovarian cancer.

Health care attitudes and utilization. Measures included presence or absence of a regular health care provider (HCP) or clinic, interpersonal aspects of health care among female members without cancer (unaffected), and utilization of breast cancer screening. The Interpersonal Aspects of Care Scale (Communication and Rapport Subscales) of the Adherence Determinants Questionnaire assessed and measured interactions with HCPs [15]. Each subscale contains four items rated on a 5-point Likert scale from strongly agree to strongly disagree. Internal consistency for our sample was acceptable for the total scale (a = 0.77). Cronbach's a coefficients for the Communication and Rapport subscales were 0.67 and 0.62, respectively. Participants were asked whether a HCP discussed personal or familial breast cancer risk with them and whether they wanted to talk to a care provider about familial cancer.

For unaffected females, breast cancer screening (i.e., mammography, clinical breast exam (CBE), and breast self-exam (BSE)) was ascertained by self-report. Adherence for unaffected female carriers was determined using guidelines developed for high-risk families by a taskforce convened by the Cancer Genetics Study Consortium [11]. These guidelines include the following: monthly BSE by age 18 to 21, education and instruction on BSE technique, annual CBE by age 25 to 35, and annual mammography beginning between ages 25 and 35 (about 5 years younger than the earliest age of onset of breast cancer in kindred members).

Psychological distress. The Center for Epidemiologic Studies Depression Scale (CES-D) [16] and the Revised Impact of Event Scale [17] were utilized. The 20-item CES-D asks individuals to rate the frequency with which they have experienced depressive symptoms, with an emphasis on affective components (e.g., hopelessness, sorrow) during the preceding 7 days. Ratings of the 4-point response scale are summed to yield a score ranging from 0 to 60, with higher scores indicating depressive symptoms. The scale has excellent internal consistency in both community populations (a = 0.85± 0.87) and our sample (a = 0.92).

The Intrusion Subscale of the Impact of Event Scale was used to measure the frequency and severity of intrusive thoughts about having cancer in the family and personal risk of cancer. Items are summed with possible scores ranging 0 to 35. Internal consistency was excellent in our sample (Cronbach's a = 0.90).

Knowledge and attitudes about breast cancer and BRCA1. Knowledge was assessed with a 9-item true± false scale adapted from a core set of instruments developed for the National

Institutes of Health National Center for Human Genome Research Cancer Genetics Studies Consortium [18]. Open-ended questions were used to elicit information on beliefs about the causes of breast and ovarian cancer and about perceived major benefits, limitations, and risks of genetic susceptibility testing. Perceived risk was assessed by asking participants to rate their chances of being an altered breast or ovarian cancer gene carrier on a scale of 0 to 100. Participants were also asked to rate the degree to which they agreed or disagreed with 23 Likert-style items (10 pro and 13 con), which were described as a "list of issues people might consider in deciding whether or not to take a genetic test" [19].

Religiosity/spiritual beliefs. Religious affiliation and a specific type of religiosity, God Locus of Health Control (GLHC), were assessed. The 6-item God Locus of Health Control scale assessed the belief that God is (or is not) either the locus of control of one's health status in general or the locus of control of one's specific disease status [20]. Internal consistency was excellent, with a coefficients ranging from 0.87 to 0.91 in prior studies and 0.85 in our sample.

BRCA1 testing intentions. We evaluated participants' readiness for testing based on self-reported intentions by using a measure adapted from a previous study [19]. The following information was presented orally: 'Scientists believe that, in some families, women who develop breast cancer have inherited a particular gene that makes them susceptible to cancer. It is possible to perform a blood test to determine which members of these families have this breast cancer gene. A woman who has the gene would have an extremely high risk of developing breast cancer in her lifetime. A woman who didn't have the gene would have the same risk of developing breast cancer as a woman with no family history of breast cancer. Imagine that this test was made available to you, what would your plans regarding the test be?° Five response options ranged from planning to take the test within the next 30 days to not planning to take the test within the next 6 months. A dichotomous variable, intent to have a genetic test, was created by recoding the variable assessing readiness to have a genetic test as planning to have a genetic test within the next 30 to 60 days or distant future vs all other replies.

Analysis

Descriptive statistics (i.e., frequencies and means) were used to describe the study population in terms of demographic characteristics, clinical factors, psychosocial responses, and genetic testing items. Subsequently, contingency table analysis (X^2 and Fisher's exact tests) for categorical variables and t tests for continuous variables were computed to examine associations between intention to have BRCA1 testing and the sociodemographic, clinical, and psychological variables. Two- sided P values <0.05 were considered statistically significant.

Logistic regression analysis with general estimating equations [21] was used to determine predictors of intention to have a genetic test while controlling for type of interview (i.e., in-person vs telephone) and correlated responses within families. Any variable having univariate associations ofP <0.25 with intent tohave a genetic test was a candidate for entry into the logistic model. Backwards elimination procedures were used to determine which variables were retained in the final model [22]. Variables that had a P < 0.10 were also included, as was type of interview (i.e., in person vs telephone).

RESULTS

Response Rate and Analysis of Response Bias

Of the 121 eligible K2099 members, 79% (n = 95) participated in the present study. Compared to nonparticipants, participants were more likely to be female (X^2 = 9.2; df = 1; P < 0.01) and to have participated in the prior linkage study (X^2 = 5.5; df = 1; P = 0.02). Respondents tended to be younger (x = 43 years; SD = 13.2) than nonrespondents (x = 50 years; SD = 15.5), although this difference was not statistically significant (t = 1.4; df = 106,P = 0.13). Geographic location (southeastern Louisiana vs other) (X^2 = 4.4; df = 1; P = 0.76) was not related to participation.

Background and Health Care-Related Factors

Characteristics of the study population are shown in Table 1. Participants were on average 43 years old (SD = 13.2; range = 18±78). The vast majority reported that they went to a specific HCP or clinic, where rapport

TABLE 1

Sociodemographic and Clinical Characteristics of the Study Population

Characteristic	% of participants
Gender, % female	77
Marital status, % married or living as married	58
Education	
Less than high school	18
High school graduate	20
Technical school or some college	43
College graduate/postgraduate degree	17
Yearly household income	
<$15,000	22
$15,000±29,999	21
$30,000±49,000	20
>$50,000	16
Not reported	21
Religious affiliations	
Catholic	78
Protestant	10
Other	12
Geographic residence, % living in southeastern Louisiana	83
Number of first-degree relatives with breast and/or ovarian cancer	
0	57
1	10
2	11
≥3	22
Has health insurance	83
Presence of a primary health care provider	90

Note. Percentages do not add to 100 because of missing values.

TABLE 2

Knowledge about Breast±Ovarian Cancer Genetics (n = 95)

Questions	% of participants answering incorrectly/ don't know
A woman who has an altered breast or ovarian cancer gene has a higher risk of breast or ovarian cancer than a woman who has a normal gene	40
A woman who does not have an altered breast or ovarian cancer gene can still get breast or ovarian cancer	43
A woman who has an altered breast or ovarian cancer gene has a 50% chance (1 in 2) of passing an altered breast or ovarian cancer gene to each of her children	49
A father can pass down alterations in the breast or ovarian cancer gene to his daughter	54
All women who have an altered breast cancer gene will get breast cancer	63
About 1 in 10 women has an altered breast or ovarian cancer gene	95
Having one's ovaries removed will definitely prevent ovarian cancer	71
Alterations in hereditary breast or ovarian cancer genes cause about one-half of all cases of breast cancer in the United States	75
Even if a woman does not have an altered gene, her children can still get it from their grandmother (their mother's mother)	96

and communication with health professionals were felt to be very high.

Twenty-eight percent of women 25–39 years indicated that they had had a mammogram within the past year; the most common reason given for not doing so was that they were “too young.' Other reasons were: “a mammogram was never scheduled,' “nothing was found during self-examination of the breasts,' “no lump was found,' and “fear.' Fifty-two percent of women ?40 years reported having had a mammogram within the past year; reasons for not doing so included: “not suggested by doctor,' “concentrating on spouse' s illness,' “forgot to schedule one,' and “haven' t taken the time.' Eighty percent of women ≥25 years and 63% of women ≥40 years reported having a CBE within the past year. One hundred percent of women between the ages of 18 and 24 reported performing BSE at least monthly, while 85% of women 25–39 years and 73% of women ≥40 years of age reported performing monthly BSE.

Less than half (48%) of unaffected females, and 18% of males, reported that a care provider had discussed their own or their female relatives' breast cancer risk with them. Overall, two-thirds of the participants indicated that they wished to learn more about their familial risk. The most common informational needs were understanding why a family is cancer prone, causes of cancer, estimation of risk, and measures to reduce risk.

Knowledge, Attitudes, and Psychological Variables

As per Table 2, participants' knowledge about the genetics of breast and ovarian cancer was limited. The average knowledge score was 3.2 (SD = 2.1; range = 0–7) out of a total of 9. Thirty-three percent of the items were answered correctly by the majority of participants. Only 5% knew that the population prevalence of hereditary breast and ovarian cancer gene mutations was not 1 in 9. Furthermore, 40% did not know that having an altered breast cancer gene increases the risk of breast and ovarian cancer, and 54% did not know that a hereditary breast and ovarian cancer gene mutation can be inherited from one' s biological father.

The most commonly cited cause of breast cancer was heredity. Other perceived causes of breast cancer were lifestyle factors (e.g., diet, smoking, and lack of exercise), environmental factors (e.g., pollutants from chemical plants and inhalation of baking soda or “scrub'), viruses, psychological stress, “spiritual condition,' “not taking care of self,' and injury to the breast.

When asked to rate their likelihood of being a breast cancer gene mutation carrier, 31% guessed that their chances were at least 50%, while 56% did not know. Similarly, 21% guessed that their chances of being an ovarian cancer gene mutation carrier were at least 50%, while 64% did not know.

Data concerning perceived advantages, limitations, and risks of genetic testing are shown in Table 3. More than half of the participants endorsed all of the advantageous items and 38%ofthe limitation and risk items.

Psychological distress was relatively high. Overall, the mean CES-D score was 15.0 (SD = 12.4); scores did not significantly differ by gender or cancer status (affected vs unaffected). Using the standard cutoff point for the CES-D scale (15/16), the prevalence of depressive symptoms was 41%. The median score on the Intrusion subscale of the Impact of Event Scale was 9.0 (range 0–35); scores did not significantly differ by gender or cancer status. Because the responses were not normally distributed, this measure was first divided into tertiles and then dichotomized as low/moderate distress (first and second tertiles; Intrusion subscale score = 0–12) and high distress (third tertile; Intrusion subscale score ≥13).

Factors Associated with Intent to Have a Genetic Test

If a BRCA1 test were made available, 82% of the participants indicated that they would seek genetic testing: 45% within the next 30 days, 35% within the next 6 months, and 2% in the more distant future. Fourteen percent indicated that they did not plan to take the test but could change their mind; 4% were unsure.

Sociodemographic and clinical factors associated with intention to have BRCA1 testing are shown in Table 4. Younger age was associated with interest in genetic testing (P = 0.02), as were a prior history of breast or ovarian cancer (P = 0.05) and one or more first-degree relatives with breast and/or ovarian cancer (P = 0.05). There were no significant associations between those who intend to and those who do not intend to have a genetic test with regard to gender, income, religion, having health insurance, having a primary care provider, provider rapport, and provider communication. Type of interview was not significantly associated with intent to have a genetic test (P = 0.68).

Table 5 presents cognitive and psychological variables associated with genetic testing intentions. Participants who believed that their chances of being a

TABLE 3

Perceived Pros and Cons of Genetic Testing (n = 95)

	Strongly agree/agree (%)
Pros	
Knowing that I carry the gene would motivate me to perform breast self-examination more frequently.[a]	92
If I were found to carry the gene, it would help my daughter(s) or sister(s) decide whether to undergo genetic testing.	91
Knowing that I carry the gene would help me decide whether to go for more frequent mammograms.[a]	90
Knowing that I carry the gene would help me decide whether to undergo preventive surgery.[a]	77
Knowing whether or not I carry the gene would help me make important life decisions (e.g., getting married, having children).	74
My sense of uncertainty about the future would be reduced if I knew whether or not I carried the gene.	68
Knowing whether or not I carry the gene would increase my sense of personal control.	67
Knowing that I do not carry the gene would greatly improve my quality of life.	66
My concerns about developing breast cancer would be reduced if I knew I did not carry the gene.[a]	60
Knowing that I do not carry the gene would improve how I feel about myself.	55
Cons	
My concerns about my female offspring developing breast cancer would increase if I knew that I carried the gene.	95
Knowing that I do not carry the gene would not be helpful since my offspring could still develop breast cancer.	83
Knowing that I carry the gene would cause me to worry more about other family members who could be carriers (e.g., mother, sisters, and daughters).	79
My concerns about developing breast cancer would increase if I knew that I carried the gene.[a]	75
Knowing that I do not carry the gene would not be helpful since I could still develop breast cancer.[a]	58
Knowing that I do not carry the gene would not reduce my concerns about developing breast cancer.[a]	45
If I were found to carry the gene, it would jeopardize my insurance coverage or lead to problems with my employers.	17
Knowing that I carry the gene would leave me in a state of hopelessness and despair.	16
Knowing that I carry the gene would worsen my quality of life.	14
If I were found to carry the gene, it would cause others to view me negatively.	14
I feel I already know my chances of getting breast cancer, so I wouldn't learn anything more from being tested.[a]	12
If I were found to carry the gene, it would lead to marital or family problems.	10
Testing is not worthwhile because it could yield inconclusive results about whether I carry the gene for breast cancer.	9

[a] Unaffected females.

TABLE 4

Intentions to Have a Genetic Test by Background and Health Care Variables

Variable	Intend to have a genetic test: No (n = 17) N (%)	Intend to have a genetic test: Yes (n = 78) N (%)	P
Sociodemographics			
Gender			1.00
Female	13 (76.5)	60 (76.9)	
Male	4 (23.5)	18 (23.1)	
Education			0.16
≤ High school	9 (52.9)	27 (34.6)	
> High school	8 (47.1)	51 (65.4)	
Religion			0.70
Catholic	12 (70.6)	59 (75.6)	
Protestant	2 (11.8)	11 (14.1)	
Other	3 (17.7)	8 (10.3)	
Marital status			1.00
Married or living as married	7 (43.8)	34 (43.6)	
Not married	9 (56.2)	43 (55.1)	
Income[a]			0.78
<$30,000	4 (23.5)	37 (47.4)	
≥$30,000	4 (23.5)	30 (38.5)	
Not reported	9 (53.0)	11 (14.1)	
Age, years[b]	52.5 (17.1)	40.7 (14.4)	0.02
Health care variables			
Health insurance			1.00
No	4 (23.5)	17 (21.8)	
Yes	13 (76.5)	61 (78.2)	
Primary care provider (PCP)			1.00
No	1 (6.2)	7 (21.8)	
Yes	15 (93.8)	61 (78.2)	
Prior history of breast and/or ovarian cancer			0.05
No	13 (76.5)	73 (93.6)	
Yes	4 (23.5)	5 (6.4)	
Number of first-degree relatives with breast and/or ovarian cancer			0.05
None	6 (35.3)	48 (61.5)	
≥1	11 (64.7)	30 (38.5)	
Communication with PCP[b]	14.4 (1.3)	14.2 (2.6)	0.85
Rapport with PCP[b]	15.3 (2.0)	15.5 (2.0)	0.75

Note. Percentages do not include missing data unless otherwise indicated.

[a] χ^2 test does not include those who did not report their household income.

[b] Data are means (SD).

mutation carrier were ?t50% (35.9%) were more likely to indicate interest than those who believed their risk was <50% (7.7%). Likewise, testing intentions were higher among participants who perceived their risk of ovarian cancer to be 50% or greater than among those who believed their risk was lower, although this association was marginally significant. Higher levels of cancer- specific distress were observed among participants who intend to have a genetic test than among those who do not intend to be tested (P = 0.05). Participants with depressive symptoms were more likely to indicate interest in genetic testing; however, this difference was

marginally significant (P < 0.10). Knowledge about familial breast cancer genetics and God Locus of Health Control score were not associated with genetic testing intentions.

Multivariate Analysis

The eight variables selected for logistic regression analysis with generalized estimating analysis included the following: age, education, prior history of breast and/or ovarian cancer, number of first-degree relatives with breast and/or ovarian cancer, perceived risk of being a carrier of an altered hereditary breast cancer gene, presence of depressive symptoms, knowledge about breast cancer genetics, and cancer-specific psychological distress. Perceived risk of being a hereditary ovarian gene mutation carrier was highly correlated with the variable assessing perceived risk of being a carrier of a breast cancer gene mutation (Pearson's r = 0.80); therefore, this variable was not entered into the model. Having at least one first-degree relative with breast and/or ovarian cancer (OR = 5.1; 95% CI = 1.2– 20.9), perceiving that the risk of being a gene carrier was ?t50% (OR = 64.3; 95% CI = 5.1–803.9), and not

TABLE 5

Intention to Have a Genetic Test by Cognitive and Psychological Variables

Variable	Genetic testing intention: No (n = 17) N (%)	Genetic testing intention: Yes (n = 78) N (%)	P
Perceived risk of being a carrier of an altered hereditary breast cancer gene			<0.01
<50	6 (35.3)	6 (7.7)	
>50	1 (5.9)	28 (35.9)	
Don't know	10 (58.8)	44 (56.4)	
Perceived risk of being a carrier of an ovarian cancer gene			0.07
<50	5 (29.4)	9 (11.5)	
≥50	1 (5.9)	19 (24.4)	
Don't know	11 (64.7)	50 (64.1)	
Depressive symptoms			0.10
No	13 (76.5)	42 (54.5)	
Yes	4 (23.5)	35 (45.5)	
Cancer-specific psychological distress			0.22
Low/moderate	13 (76.5)	46 (60)	
High	4 (23.5)	30 (40)	
Knowledge score[a]	2.5 (2.6)	3.4 (1.9)	0.12
God Locus of Health Control score[a]	26.6 (5.6)	26.1 (6.3)	0.77

[a] Data are means (SD).

knowing their risk (OR = 10.9; 95% CI = 2.1–57.7) were independent predictors of intention to get genetic testing for breast cancer. Although the variables family identification number and interview type were not significant predictors, they were retained in the models as control variables.

DISCUSSION

This cross-sectional survey provided insight into the knowledge deficits, needs, and desires of an African-American family with a BRCA1 mutation. Despite limited knowledge, many participants had a high level of interest about cancer susceptibility testing. This finding supports

prior studies of genetic testing interest in cancer predisposition testing among unaffected individuals, including African Americans [5,23f26]. A limitation of our study is that we measured intention to undergo genetic testing rather than actual behavior. Prior research has shown that interest in BR CA1/2 testing overestimated actual uptake among Caucasians [18,27f29]. Research on uptake rates among high-risk African Americans is an area for evaluation.

Few prior studies have assessed the influence of spirituality and religion on genetic testing decisions. A recent study by Schwartz et al. noted a positive association between spiritual faith and acceptance of genetic testing [30]. However, another recent study found no such association [27]. These study populations were predominantly Caucasian; data indicate that religiosity or spirituality may have a greater influence on health behaviors among African Americans [31]. We observed a negative association between beliefs about God as a controlling force over one's health and adherence to breast cancer screening guidelines among members of K2099 [32]. Thus, assessment of the effects of specific spiritual and religious beliefs and their influence on health behaviors awaits further research.

Insufficient communication with providers is not limited to members of high-risk families. A survey of breast cancer survivors found that only 8% had discussed genetic testing with HCPs [33]. Our observations revealed evidence of inadequate communication between the study subjects and their HCPs, despite generally favorable attitudes toward these providers. Few of the participants had discussed cancer causes and treatment, genetic testing, and personal or familial risk factors. Our observations highlight the need for a careful initial assessment of baseline knowledge, with the goal of enhancing understanding of specific information needs. Subsequent discussions could focus on individual beliefs and misconceptions, limitations of testing and concerns related to minimizing these limitations, informed consent issues, implications of test results, and risk factors for cancer. Previous research has shown that women from different socioeconomic classes tend to vary in the type of information desired [34. Thus, education and counseling should be tailored to the attitudes, education level, and socioeconomic status of the individual patient. Likewise, prior studies have shown that patients often wish to know their HCP's recommendations about whether or not genetic testing should be performed [35f36]; this attitude maybe especially prevalent in women from known high-risk families. When particularly vulnerable populations indicate that they want their HCPs to advise them about whether they should be tested, it does not necessarily follow that HCPs should give such advice. HCPs not equipped to provide genetic counseling should make referrals to qualified professionals who can provide specialized services. A recent study reported that even after genetic counseling and testing, utilization of breast cancer screening is suboptimal [37]. Moreover, adherence to screening recommendations in our study was poor. Given the high breast cancer mortality rates among African-American women [38], use of mammography among participants was disappointing; this finding is consistent with other studies [39]. A number of possible factors may be relevant; some relate to under referral by HCPs, while others may involve characteristics of participants. HCPs may lack knowledge about cancer genetics and screening guidelines for high-risk women and may not be taking detailed family histories to assess risk factors. In addition, physicians are less likely to recommend mammography for African-American women [39].

Some caution should be used when interpreting these findings. Our participants generally had favorable attitudes toward their HCPs in terms of communication and rapport. However, many African Americans have a distrust of the medical system; this may inhibit them from using medical services [40]. Thus, our findings may not reflect the beliefs, attitudes, and knowledge among other African Americans who carry a gene mutation associated with hereditary breast cancer. The odds ratios have wide confidence intervals and are imprecise, possibly due to the small sample size. The choice of in-person or telephone interviews may be suboptimal. However, this design was established in partnership with key informants of K2099 as a strategy to enhance recruitment. We did not observe statistically significant differences in responses between those who completed in-person versus telephone interviews.

In conclusion, our study provides important information about knowledge deficits as well as attitudes and beliefs to consider when designing a genetic education and counseling intervention for this kindred and other similar high-risk families. Our participants clearly wished to expand their knowledge in hopes of making optimal decisions about cancer screening and genetic testing. If high-risk individuals are to benefit from such programs, assessment of baseline knowledge levels must continue. Services should be tailored to the attitudes, beliefs, and educational level of recipients, as well as care providers who are often perceived as trusted information sources. It is vital that the views of high-risk groups such as this kindred be considered in the development and implementation of programs and clinical protocols intended for them. Issues such as genetic susceptibility, privacy rights, and informed consent may well be viewed in different ways by the providers and the recipients of information. Further research on the psychosocial and behavioral outcomes of genetic counseling and cancer predisposition will help guide culturally sensitive interventions that promote adherence to appropriate cancer prevention and screening guidelines and minimize adverse psychological and social consequences.

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