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Genetic counseling content: How does it impact health behavior?

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Abstract

Women with hereditary breast-ovarian cancer face decisions about screening (transvaginal ultrasound, CA125, mammography, breast exams) and proactive (before cancer) or reactive (after cancer) surgery (oophorectomy, mastectomy). The content of genetic counseling and its relation to these key health behaviors is largely unexamined. Ashkenazi Jewish women ($n = 78$) were surveyed through the process of genetic testing and had audiorecorded counseling sessions available for Linguistic Inquiry and Word Count analysis. Proportions for participant and counselor cognitive and affective content during sessions were used as primary predictor variables in linear mixed models for change in intentions for screening and treatment and in self-reported screening. Cognitive and affective content were important predictors of behavior. Counselor cognitive content was associated with ovarian screening. An interaction effect also emerged for CA-125, such that counselor cognitive content plus participant cognitive content or counselor affective content were associated with more screening. Teasing out the factors in risk communication that impact decision-making are critical, and affect from a risk communicator can spur action, such as cancer screening.

Keywords

BRCA1; BRCA2; cancer screening; genetic counseling; surgery

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'All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all patients for being included in the study.'

Hereditary mutations in *BRCA1* and *BRCA2* genes are associated with a lifetime risk of breast cancer as high as 85% and ovarian cancer as high as 40% in carrier women (Easton et al. 1995; Oddoux et al., 1996). Recent recommendations from the US Preventive Services Task Force include risk assessment and genetic counseling for *BRCA*-related cancers (Moyer et al., 2014). Features of hereditary breast-ovarian cancer may include: younger age of breast cancer onset (pre-menopausal), multiple primary cancers, multiple family members affected, and multiple generations affected (Fitzgerald et al., 1996; Oddoux et al., 1996). Facing an increased lifetime risk of breast-ovarian cancer and the threat of multiple primary cancers, women carrying *BRCA1* and *BRCA2* mutations may consider prophylactic surgery to remove unaffected breast and ovarian tissue (primary prevention) and may increase cancer screening (secondary prevention). Prophylactic removal of the ovaries (prophylactic oophorectomy) and breasts (prophylactic mastectomy) has been demonstrated efficacious in the prevention of ovarian and breast cancer, respectively (Finch et al., 2006; Hartmann et al., 1999). Particularly for those who have not had mastectomies and/or oophorectomies, cancer screening through mammography, clinical breast exams, pelvic exams, transvaginal ultrasounds (TVU), and CA-125s may be considerations (Miller et al., 1992; Nystrom et al., 2002; Olivier et al., 2006; Vasen et al., 2005). For women with *BRCA1* and *BRCA2* mutations, mammography, clinical breast exams, TVU and CA-125 are recommended annually or semi-annually starting at age 25-35 years (Burke et al., 1997).

Studies of cancer screening and prophylactic surgery decisions in the context of genetic testing for *BRCA1* and *BRCA2* mutations have found increased utilization of breast and ovarian cancer screening and prophylactic surgery following genetic counseling and testing (Beattie et al., 2013 2013; Botkin et al., 2003; Howard, Balneaves, & Bottorff, 2009; Peshkin et al., 2002; Scheuer et al., 2002; Miller, et al., 2005). In particular, studies have found increased rates of CA-125 and TVU utilization (Botkin et al., 2003; Mannis et al., 2013; Schwartz et al., 2003; Miller, et al., 2005) and of prophylactic surgery among carriers (Botkin et al., 2003; Loader, Shields, & Rowley, 2004; Lodder et al., 2002; Mannis et al., 2013). Despite these general findings, considerable variability in practices remain, and a significant minority of women fail to follow screening recommendations (Howard et al., 2009; Wainberg & Husted, 2004).

Individuals with a family history of breast-ovarian cancer have difficulty using empirical risk to guide health actions following genetic counseling and testing (Lerman et al., 2000). As a result of genetic counseling, one study found performance of clinical breast exams decreased (Meiser et al., 2001), and one study found that mammography did not change (Meiser et al., 2001) while another found mammography decreased (Schwartz et al., 1999). Other studies suggest that one to two years after genetic testing for *BRCA1*, both carriers and non-carriers increased breast cancer screening (Botkin et al., 2003; Dorval et al., 2011; Kinney et al., 2006; Morgan et al., 2009). Studies have also found those receiving positive and negative results have pursued prophylactic surgery (Botkin et al., 2003; Morris et al., 2001), particularly oophorectomy (Manis et al., 2013; Schwartz et al., 2012 Poggi, 2012). Yet, individuals with positive results and a family history of cancer were more likely to have screening and prophylactic surgery (Howard et al., 2009; van Driel et al., 2014 2014).

In spite of numerous studies of screening and surgery, the link between the content of genetic counseling and risk management is understudied. Higher anxiety and distress has been associated with increased CA125 utilization (Halbert et al., 2011) and risk-reducing mastectomy (Howard et al., 2009; Schwartz et al., 2012; Poggi, 2012). Those perceiving more benefits were more likely to have higher intentions to have prophylactic surgery (O'Neill et al., 2010). However, it is unclear if genetic counseling may help or hinder this decision-making process. Studies have found that mode of genetic counseling delivery (telephone vs. in-person) did not influence screening or surgery decisions (Doughty Rice et al., 2010), but the influence of genetic counseling content on screening and surgery is unclear. Indeed, <text removed> found an association between genetic counseling content and psychosocial factors (Ellington et al.; Ellington et al.; Kelly et al., 2014, in press), yet we identified no other studies linking genetic counseling content to risk management behaviors. Such relationships between communication and behavior would be expected based on models such as the Comprehensive Model of Information Seeking (Johnson, 1997) and Self-Regulation Model (Leventhal, Brisette, & Leventhal, 2003), which delineate key attentional, cognitive, and affective factors in health behavior.

In this prospective study of women at elevated risk for hereditary cancer, behaviors and intentions in the context of *BRCA1* and *BRCA2* genetic counseling and testing were examined. The aims of the current study are: (1) to describe baseline intentions for and uptake of surgery (i.e., prophylactic mastectomy and oophorectomy; lumpectomy and mastectomy in response to cancer) and cancer screening (i.e., mammography, clinical breast exams, pelvic exams, TVUs, CA-125); (2) to examine the change in cancer screening and surgical procedures in response to genetic counseling and testing; and (3) to examine the relationship of the content of genetic counseling in relation to change in cancer screening and surgical procedures.

MATERIALS AND METHODS

Participants

Ashkenazi Jewish women ($N = 107$) from approximately 70 families participated in a study investigating responses to counseling for *BRCA1* and *BRCA2* mutations. As the current study focuses on breast-ovarian cancer screening, only women with intact breast and ovarian tissue who proceeded to have genetic testing are included in the analyses ($n = 78$). Besides being Ashkenazi Jewish, participants met additional criteria to increase the probability of finding a *BRCA1* and *BRCA2* mutation. For example, women with a previous cancer diagnosis were eligible if they had breast cancer before age 50 or ovarian cancer at any age. Women without a previous diagnosis of cancer were eligible if they had a first or second degree relative with female early-onset or male breast cancer, ovarian cancer, or a *BRCA1* and *BRCA2* mutation.

Procedure

Prior to initiation of the study, approval was received from the internal review boards (ethical review) of the universities and medical centers involved in the research. Individuals contacted a genetic counselor who confirmed study eligibility through medical records. A

packet was mailed to eligible participants, including an explanation of the study, informed consent form, and a baseline questionnaire. Upon completion, participants scheduled an appointment with a genetic counselor. Genetic counseling and testing were provided free of charge by a board certified or board eligible genetic counselor ($n = 3$). Genetic counseling sessions were one to two hours and were guided by an outline of a standard cancer genetic counseling session (National Society of Genetic Counselors, 2004). Genetic counseling sessions were audiorecorded and transcribed. Approximately two days after genetic counseling, the genetic counselor telephoned the participant to inquire about the decision to have genetic testing. Those deciding to have testing signed an additional consent form. Blood was drawn and DNA was analyzed in a CLIA approved laboratory at the New Jersey Medical School for common, recurrent *BRCA1* and *BRCA2* mutations seen in the Ashkenazi Jewish population, which were *c.68_69delAG* and *c.5266dupC* on *BRCA1* and *c.5946delT* on *BRCA2* (Tonin et al., 1996).

One to three months following the decision to test, participants met with a genetic counselor to discuss their results. Individuals were considered having a positive result if any mutation was detected in the *BRCA1* and *BRCA2* genes. A negative result for an individual where a mutation had not been located in the family was essentially uninformative since other mutations in *BRCA1*, *BRCA2* or other breast-ovarian cancer genes may still be present. These participants were told their risk remained elevated above the general population. Individuals with an informative negative result were told their risk of cancer was equivalent to the general population. Six to eight months following genetic testing, participants were mailed a follow-up questionnaire with a return, stamped envelope, including psychosocial and screening assessments.

Measures

Demographic (e.g., age, education, income, marital status) and cancer history information (i.e., presence breast or ovarian cancer history) were collected at baseline and confirmed with medical record review, when available.

Prophylactic Surgical Procedures—Participants were asked a series of questions regarding their preferences for prophylactic surgery (i.e., prophylactic mastectomy in one breast, prophylactic mastectomy of both breasts, prophylactic oophorectomy) based on possible diagnostic scenarios. For example, women were asked: “If I find that I have cancer (again) in only one breast, I will have a prophylactic mastectomy of the other breast”. A five-item Likert-type response scale was used (i.e., strongly disagree-agree strongly) with the additional option of “I have done this.” Participants completed these at baseline and follow-up.

Reactive Surgical Procedures—Participants were asked a series of questions for surgery (i.e., lumpectomy, mastectomy, oophorectomy) in response to having breast cancer. For example, for lumpectomy, participants were asked the extent to which they agreed with the following statement: “If I find that I have breast cancer (again), I will have a lumpectomy (removal of just the area of cancerous tissue).” The same Likert-type format

was used with the option of “I have done this.” Participants completed these at baseline and follow-up.

Cancer Screening—Participants were asked how frequently they intended to perform and how frequently they actually performed screening for breast cancer (i.e., mammography, clinical breast exams) and ovarian cancer (i.e., pelvic exams, TVUs, CA-125). A sample of an intention question was: “I intend to have more frequent mammograms than are routinely recommended for women my age.” The same five-item Likert-type format was used. A sample of the frequency of actual performance question was: “What best describes how often you have a mammogram.” The statement had a seven-item response scale (never, once every five years or more, once every three years, once every two years, once a year, once every six months, and once every three months). These questions were asked at baseline and follow-up.

Emotion and Cognition—Transcripts of genetic counseling sessions were converted into quantitative data by calculating the frequency of particular types of words. Each transcript was divided into participant and genetic counselor content before conducting word count analyses. Linguistic Inquiry and Word Count (LIWC) software and dictionary was used to determine the word count structure for each speaker, allowing for over 70 preset linguistic categories, among which are affective, cognitive, social, and self dimensions (Pennebaker & Francis, 2001; Pennebaker & Booth, 2001), with established reliability, feasibility, and construct validity (Kahn et al., 2007; Pennebaker & Francis, 2001). An example of how cognitive content would be evaluated is:

Participant: Do you think this might cause cancer in the future?

Genetic Counselor: Research leads us to believe that this is an important risk factor for cancer.

Similarly, an example of how affective content would be evaluated is:

Participant: When my aunt and my grandmother developed cancer the same year, we were all worried that it might be genetic.

Genetic Counselor: Many people are concerned about having a *BRCA1* or *BRCA2* mutation.

LIWC has been used for analyzing transcripts (Graves et al., 2005) and spontaneous verbal communication (Mehl et al., 2003; Niederhoffer et al., 2002), and this automatic categorization is well-suited for providing insight into large textual data-sets, beyond the scope of time intensive qualitative analyses. Thus, separate proportions of emotion (e.g., worried, sad) and cognitive content (e.g., think, believe) for the genetic counselor and participants were calculated for each session; these represent parts of the representation of emotion and the representation of cognition, respectively. Proportions for participant cognitive and affective content, along with proportions for counselor cognitive and affective content, during the counseling sessions were calculated for analysis.

Analysis

Demographic and baseline data were compared for those with a personal history of cancer versus those without a personal history. T-tests compared those with and without cancer history and those with positive and negative results for each of the screening and surgery outcomes. Change scores (Follow-up – Baseline) were computed for intentions for each of the prophylactic and reactive surgical procedures and for both the intended and actual frequencies of performance of each of the cancer screening modalities. Linear Mixed Models were fit to each set of difference scores (i.e., intentions for prophylactic procedures, intentions for reactive procedures, intended frequency of screening, actual self-reported frequency of screening), with a variable to differentiate between the specific procedure or test (e.g. oophorectomy, bilateral mastectomy, or unilateral mastectomy for prophylactic procedures). Participant was included as a random effect within the model, since each participant had data on each of the questions in that section – one for each type of procedure/screening tests. Predictor variables included cancer history (personal vs. family only) and test result (carrier vs. non-carrier), along with the proportions of cognitive and affective words in the counseling sessions, from both the counselor and participant. Age and baseline intention/performance were included as covariates. Interactions were examined between the variable identifying the specific procedure/screening and the main predictors to test if the effects varied for the different procedure/screening types, and the interaction terms were included in the model where significant. Interactions between cognitive content and affective content of participant and counselor were also considered and included in the final model where significant. Residual diagnostics were examined to evaluate model assumptions such as normality and homoscedasticity.

RESULTS

Table 1 shows women with a personal history of cancer were older [$t(76) = -7.65, p < 0.001$] and had greater intentions for reactive lumpectomies [$t(73) = -2.13, p = 0.037$] and mastectomies [$t(74) = -2.13, p = 0.037$] than women without a personal cancer history. Additionally, those with a personal history of cancer had higher frequencies of mammograms [$t(72) = -2.71, p = 0.008$] and CA-125s [$t(71) = -2.41, p = 0.019$]. During the study, five women had surgery (both prophylactic mastectomy and oophorectomy: $n = 3$; mastectomy only: $n = 1$; oophorectomy only: $n = 1$). Each of these women tested positive for a *BRCA1* and *BRCA2* mutation, and none of them had a personal history of cancer. Table 2 shows that positive test results were associated with increases in intentions for prophylactic mastectomy of the other healthy breast if found to have cancer [$t(1,46) = -2.41, p = 0.020$], clinical breast exams [$t(1,46) = -3.08, p = 0.004$], TVU [$t(1,41) = -2.91, p = 0.006$], and CA-125 [$t(1,40) = -2.96, p = 0.005$] and increases in actual CA-125 screening [$t(1,38) = -2.04, p = 0.048$]. Negative results were associated with an increase in reactive mastectomy if they were found to have cancer [$t(1,34) = 3.20, p = 0.003$].

Table 3 shows the results of the regression models on intentions for prophylactic procedures, reactive procedures, or screening. For **prophylactic procedures**, baseline intentions, age, gene status, and counselor affect were significant. Older women tended to decrease in intentions for prophylactic procedures more than younger women [$t(144) = -2.38, p =$

0.019], and women testing negative also decreased in interest in prophylactic procedures (Least Square Mean (LSM) = -0.69 , $SE = 0.20$) compared to women testing positive, who only slightly increased ($LSM = 0.06$, $SE = 0.23$) [$t(144) = -4.21$, $p < 0.001$]. Overall, intentions to have unilateral mastectomy only slightly decreased ($LSM = -0.08$, $SE = 0.23$), compared to a bilateral mastectomy ($LSM = -0.53$, $SE = 0.24$) or oophorectomy ($LSM = -0.52$, $SE = 0.24$) [$t(144) = 2.62$, $p < 0.05$]. More counselor affective content was associated with a higher change in intention for prophylactic procedures ($t(144) = 2.27$, $p = 0.02$). For **reactive procedures**, women indicated that if they find they have breast cancer they are now less likely to have a lumpectomy ($LSM = -0.47$, $SE = 0.14$), as opposed to a mastectomy ($LSM = 0.31$, $SE = 0.14$) or oophorectomy ($LSM = 0.56$, $SE = 0.15$) which increased [$F(2, 136) = 15.41$, $p < 0.001$].

For **intentions to screen**, cancer history ($p = .018$), test result [$F(2,235) = 17.78$, $p < 0.001$], and procedure [$F(4, 235) = 5.64$, $p = 0.018$] were significant. Receiving positive results ($LSM = 0.75$, $SE = 0.15$) and having a personal cancer history ($LSM = -0.28$, $SE = 0.13$) were associated with increased intentions to screening. Receiving negative results ($LSM = -0.27$, $SE = 0.08$) or declining results ($LSM = -0.34$, $SE = 0.21$) were associated with decreased intentions to screen (with those testing positive increasing in intentions). Intentions for clinical breast exams increased over time ($LSM = 0.43$, $SE = 0.15$), whereas the other tests generally remained similar. More participant cognitive content was marginally associated with a higher intention to obtain more frequent screenings ($p = 0.051$).

Table 4 shows that aside from baseline variables, predictors of self-reported screening behavior were only significant for TVU and CA-125. Those who were younger ($p = 0.026$) or had a personal history of cancer ($p = 0.013$) showed greater increase in their self-reported frequency of CA-125. Women testing positive increased their self-reported frequency of TVU ($p = 0.012$) and CA-125 ($p = 0.003$). Linguistic data showed more impact on CA-125 than the other screening methods. Women with higher participant affective content showed less change in CA-125 ($Beta = -0.58$, $t(32) = -2.93$, $p = 0.006$). The effect of counselor cognition depended on counselor affect and participant cognition. Counselor cognitive content only had a slight negative effect when both counselor affect and participant cognitive content were both low ($Beta = -7.50$, $t(32) = -2.75$, $p = 0.010$), but the effect of counselor cognitive content increased as counselor affective content increased ($Beta = 1.01$, $t(32) = 2.93$, $p = 0.006$) and also when participant cognitive content increased ($Beta = 0.26$, $t(32) = 2.24$, $p = 0.032$). However, the effect of participant cognitive content overall relates to lesser CA-125 screening.

DISCUSSION

Our study examined change in screening and surgical practices in response to genetic counseling and testing for *BRCA1* and *BRCA2* mutations, and how the content of genetic counseling may be associated with these changes. Performance of cancer screening was high among our participants prior to counseling and testing. Over 80% of the women had a mammogram, clinical breast exam, and pelvic exam in the last year, and approximately 30% had transvaginal ultrasound and CA-125 in the past year. Those with a personal cancer history had higher mammogram and CA-125 utilization in the past year, higher than the

study by Peshkin *et al.* (Peshkin et al., 2002), which reported 65% ($n = 107$) of their sample reported obtaining a mammogram in the year prior. Our sample is relatively well-educated, middle to upper income and urban—all factors associated with a greater likelihood of cancer screening (Coughlin et al., 2005).

A number of factors played a role in changes in screening and surgery intentions and behavior in our study. Important to note, five women in our study had prophylactic surgery in the six months between receiving test results and our follow-up survey. It appears that women were using information from genetic counseling and testing to make these decisions, as supported by their anecdotal reports. Further, age appeared to be an important factor in these decisions. Those who were older were less likely to be interested in preventive measures (i.e., prophylactic surgery and screening) than those who were younger over the course of the study. Although a recent study by Saadatman et al. (2014) recommends continuation of intense screening in older mutation carriers, most of the women in our study did not receive positive results, making the higher level of utilization among younger women less clear. In addition, the medical benefits of prophylactic surgery are higher in younger (pre-menopausal) women than in older women, and this may affect intentions for prophylactic surgery utilization in younger women (Obermair et al., 2014). Further, those with a cancer history had greater increases in intentions to screen than those without, and these changes were most salient for transvaginal ultrasound and CA-125 behavior over the course of the study. Previous research indicates that women became more aware of the risks of ovarian cancer in genetic counseling (Kelly et al., 2004), and a number of studies have found that ovarian cancer screening increases as a result of counseling and testing (Botkin et al., 2003; Mannis et al., 2013; Schwartz et al., 2003).

Clearly, test results trump cancer history when examining the impact of genetic counseling and testing. Consistent with previous research, women testing positive increased in intentions and in actual CA-125 behavior (Howard et al., 2009; van Driel et al., 2014). Overall, those receiving negative results decreased in intentions for preventive measures such as screening and prophylactic procedures; although some may argue that these decreases were not as great as expected, perhaps contributing to uptake of prophylactic surgeries in women who are not objectively at elevated risk (Mannis et al., 2013; Ray, Loescher, & Brewer, 2005). These women may be at risk for other, unknown mutations, however, their risk may not be as high as they believe (Kelly et al., 2004; Ray et al., 2005). Further, more genetic counselor cognitive content was associated with greater intentions to screen, which may indicate that the genetic counselor was discussing the possible implications of screening.

Consistent with these findings of change in screening behavior in individuals as a response to genetic counseling, regardless of whether or not they tested and whether they received a positive or negative test result, we found that affective and cognitive content in counseling were important predictors of screening intentions (statistical trend) and ovarian screening behavior. Strikingly, greater participant affective and cognitive content, as well as greater counselor affective and cognitive content, when considered individually were associated with decreased CA-125 screening behavior. However, when interactions were considered, higher counselor cognitive content was associated with higher increases in reported CA-125,

particularly (1) when counselor affective content was high in addition to counselor cognitive content and (2) when participant cognitive content was high in addition to counselor cognitive content. This seems to indicate that when counselors are using cognitive words and when patients match in their proportion of cognitive words or when counselors are also using affective words, CA-125 screening behavior is increased. Although it is unclear why this pattern emerged, we speculate that matching in degree of cognitive discussion between counselor and participants may have resulted in greater degree of exploration of different types of screening, such as CA-125.

In addition, greater cognitive and affective content from the counseling may have portrayed greater emotion and urgency about the threat of cancer, resulting in participant “hot cognitions” as described in the Self-regulation model (Leventhal et al., 1997; Leventhal et al., 2003). The Self-regulation model posits that cognitive and affective factors play a key role in health behaviors, such that cognitions that are affectively-laden are most likely to be acted upon. This concept of hot cognition and its instinctual association with action is closely related to the concept of salience in the Comprehensive Model of Information Seeking (Johnson, 1997), such that cognitions that are affectively-laden may take preeminence in behavioral decision-making. Thus, new information in genetic counseling about the potential danger and threat to survival posed by ovarian cancer may have stimulated more discussion and resulted in greater screening. Examining the actual content and process of counseling is essential to better understanding this screening behavior.

Limitations and strengths of this study should be noted. First, this study only examined word counts of genetic counseling content, and without analyzing actual content, we cannot be certain of the meaning of the relationships of content to surgical and screening decisions. Second, self-report of cancer screening and surgical procedures were assessed, rather than medical record reports. Third, although power for within, repeated measures analysis was high and a number of differences were noted for carriers, the sample size may have resulted in inadequate power to adequately test some relationships, particularly those involving tests of interaction effects. Our study was also not powered to look at underlying counselor styles for cognitive and affective communication, and we did not assess the preferences of patients. Fourth, this sample was of a relatively high socio-economic status; populations of lower socio-economic status may have more barriers to utilizing screening and surgical options due to fewer resources. Strengths of this study include: a prospective, repeated measures design allowing assessment of change over time, a combination of assessment of behavior and intentions (potentially more sensitive to change), a combination of breast and ovarian cancer screening and surgical assessments, and inclusion of measures of the content of genetic counseling sessions.

In conclusion, individuals receiving genetic test results have a number of screening and surgical options to consider. Women testing positive showed increases in intentions for prophylactic surgeries and cancer screening following genetic counseling and testing, especially ovarian cancer screening; however, those receiving negative test results continued to opt for these less sensitive and specific screening tools. Further, the more that counselors included cognitive content and the more that the counselors included affective content and the more that participants matched counselors, or vice versa, in proportion of cognitive

content, the more likely participants were to have a CA-125. Although we cannot completely explain this finding, it is suggestive of the critical role of genetic counseling in testing and merits further research. Teasing out the factors in risk communication that impact decision-making are critical, and affect from a risk communicator can spur action, such as cancer screening.

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Table 1

Demographics and baseline response for personal history versus no personal history of cancer: percentage or mean (standard deviation)

	<i>No Personal History (n = 38)</i>	<i>Personal History (n = 40)</i>	Test Statistic
Marital Status			
Married	73.7%	72.5%	$\chi^2(1) = 0.01$
Not Married	26.3%	27.5%	
Age	39.2 (9.2)	57.2 (11.3)	$t(76) = -7.65^{***}$
Amount of school	16.8 (2.3)	16.6 (2.6)	$t(75) = 0.40$
Family income			
\$49,999 or less	21.6%	23.7%	$\chi^2(1) = 0.05$
\$50,000 or more	78.4%	76.3%	
Carrier			
Yes	21.0%	20.0%	$\chi^2(1) = 0.87$
No	65.8%	67.5%	
Declined	13.2%	12.5%	
Baseline Intention: Prophylactic Procedures (1=strongly disagree to 5=strongly agree)			
Mastectomy of other (non-cancerous) breast	3.5 (1.4)	3.1 (2.1)	$t(74) = 0.38$
Mastectomy of both Breasts	2.7 (1.5)	2.3 (1.5)	$t(73) = 1.13$
Oophorectomy	2.5 (1.2)	2.8 (2.1)	$t(73) = 0.46$
Baseline Intention: Reactive Procedures (1=strongly disagree to 5=strongly agree):			
Lumpectomy	3.3 (1.7)	4.5 (2.9)	$t(73) = -2.13^*$
Mastectomy	3.7 (1.4)	4.7 (2.6)	$t(74) = -2.13^*$
Oophorectomy	4.4 (0.9)	4.5 (1.4)	$t(70) = -0.30$
Baseline Intention: Screening Frequency (1=strongly disagree to 5=strongly agree)			
Mammogram	3.3 (0.2)	2.9 (1.4)	$t(73) = 1.42$
Breast Exam	4.0 (1.1)	3.7 (1.3)	$t(74) = 0.92$
Pelvic Exam	3.2 (1.2)	3.4 (1.1)	$t(75) = -0.94$
Transvaginal Ultrasound	3.2 (1.3)	3.0 (1.1)	$t(75) = 0.49$
CA-125	3.1 (1.2)	3.3 (1.2)	$t(72) = -0.69$
Baseline Screening Frequency (1=never to 7=once every three months)			

	<i>No Personal History (n = 38)</i>	<i>Personal History (n = 40)</i>	Test Statistic
Mammogram	3.9 (1.7)	4.8 (1.0)	$t(72) = -2.71^{**}$
Breast Exam	5.7 (0.6)	5.8 (1.1)	$t(73) = -0.48$
Pelvic Exam	5.2 (0.6)	5.1 (1.0)	$t(75) = 0.57$
Transvaginal Ultrasound	2.4 (1.9)	2.4 (1.7)	$t(73) = -0.17$
CA-125	1.8 (1.6)	2.9 (2.2)	$t(71) = -2.41^*$

*
 $p < 0.05$,

**
 $p < 0.01$,

 $p < 0.001$

Note: Screening behavior is based on self-report.

Table 2

Results from Linear Mixed Models (Parameter Estimates and Significance Tests) on Change Scores (Follow-up – Baseline) for Intention for Prophylactic Procedures, Reactive Procedures, and Screening Frequency)

	Test Result	Baseline	Follow-up	Difference	Standard Error of Difference
Type of Prophylactic Procedure (Intentions)					
Mastectomy of the Other (Healthy) Breast*	Negative	3.00	2.78	−0.22	0.16
	Positive	3.27	3.82	0.55	0.21
Mastectomy of Both Healthy Breasts	Negative	2.21	2.03	−0.18	0.18
	Positive	2.60	2.90	0.30	0.34
Oophorectomy	Negative	2.24	2.03	−0.22	0.17
	Positive	2.78	3.11	0.33	0.33
Type of Reactive Procedure (Intentions)					
Lumpectomy	Negative	2.94	2.97	0.03	0.18
	Positive	2.92	2.38	−0.54	0.54
Mastectomy**	Negative	3.29	3.80	0.51	0.16
	Positive	4.50	4.50	0.00	0.00
Oophorectomy	Negative	4.24	4.42	0.18	0.17
	Positive	4.54	4.62	0.08	0.14
Type of Screening (Intentions)					
Mammography	Negative	3.03	2.92	−0.10	0.18
	Positive	3.22	3.44	0.22	0.32
Clinical Breast Examination**	Negative	3.87	3.68	−0.18	0.16
	Positive	3.70	4.70	1.00	0.42
Pelvic Examination	Negative	3.11	2.81	−0.31	0.17
	Positive	4.00	4.13	0.13	0.23
Transvaginal Ultrasound**	Negative	2.94	2.60	−0.34	0.18
	Positive	3.88	4.75	0.88	0.40
CA-125**	Negative	2.97	2.53	−0.44	0.19
	Positive	3.88	4.75	0.88	0.40
Type of Screening (Behavior by Self-Report)					
Mammography	Negative	4.66	4.76	0.11	0.12
	Positive	4.00	4.30	0.30	0.21
Clinical Breast Examination	Negative	5.72	5.69	−0.03	0.10
	Positive	5.89	5.67	−0.22	0.15
Pelvic Examination	Negative	5.29	5.34	0.06	0.09
	Positive	5.63	5.50	−0.13	0.13
Transvaginal Ultrasound	Negative	2.36	2.52	0.15	0.19
	Positive	2.88	4.50	1.63	0.80
CA-125*	Negative	2.25	2.40	−0.03	0.19

	Test Result	Baseline	Follow-up	Difference	Standard Error of Difference
	Positive	3.63	4.50	1.00	0.49

[^]
 $p < .1,$

^{*}
 $p < 0.05,$

^{**}
 $p < 0.01,$

^{***}
 $p < 0.001$

Note: Screening behavior is based on self-report.

Note: Indicator variables were included to differentiate between the specific procedure or test, and with random effects included for each participant.

Table 3

Results from Linear Models (Parameter Estimates and Significance Tests) on Change Scores (Follow-up – Baseline) for Actual Screening Frequency for Mammogram, Clinical Breast Exam, Pelvic Exam, Transvaginal Ultrasound, and CA-125

Effect	Prophylactic Procedures		Reactive Procedures		Screening	
	Estimate	t value (df = 144)	Estimate	t value (df = 136)	Estimate	t value (df = 235)
Intercept	–2.42	–1.02	5.02	2.06	–1.29	–0.57
Baseline	–0.50	–7.38 ***	–0.55	–7.88 ***	–0.39	–6.92 ***
Age	–0.02	–2.38 *	0.00	–0.41	–0.02	–1.77 ^
Cancer History	0.35	1.80	–0.16	–0.82	–0.46	–2.37 *
Gene Status:						
Negative	–0.74	–4.21 ***	0.18	1.02	–1.02	–5.84 ***
Declined	–0.56	–1.95	0.20	0.73	–1.09	–4.16 ***
Positive	0.00	.	0.00	.	0.00	.
Procedure:	Oophorectomy		Lumpectomy		Clinical Breast Exam	
	0.01	0.04	–1.02	–5.24 ***	0.50	2.47 *
	Unilateral Mastectomy		Mastectomy		Mammography	
	0.44	2.62 *	–0.25	–1.40	0.10	0.52
	Bilateral Mastectomy		Oophorectomy		Pelvic Exam	
	0.00	.	0.00	.	–0.03	–0.13
					CA-125	
					0.03	0.13
					Transvaginal Ultrasound	
					0.00	.
Participant Affect	0.02	0.24	–0.01	–0.17	0.01	0.17
Counselor Affect	0.40	2.27 *	–0.20	–1.16	0.15	0.95
Participant Cognitive	0.02	0.55	–0.03	–0.77	0.08	1.96 ^
Counselor Cognitive	0.15	1.62	–0.07	–0.67	0.13	1.47

^
p < .1,

*
p < 0.05,

**
p < 0.01,

p < 0.001

Note: Screening behavior is based on self-report.

Table 4

Regression Results on Change in Actual Screening Frequency (by Self-Report)

	Mammogram		Clinical Breast Exam		Pelvic Exam		Transvaginal Ultrasound		CA-125	
	Estimate	t Value (df = 43)	Estimate	t Value (df = 43)	Estimate	t Value (df = 38)	Estimate	t Value (df = 36)	Estimate	t Value (df = 32)
Intercept	3.66	1.01	-1.42	-0.35	-1.52	-0.65	-5.59	-0.73	142.68	2.86 **
Baseline	-0.28	-3.09 **	-0.43	-2.23 *	-0.38	-3.88 ***	-0.43	-3.40 **	-0.26	-2.71 *
Age	0.01	1.03	0.02	1.25	0.00	0.06	-0.02	-0.53 *	-0.05	-2.34 *
Cancer History	-0.25	-0.90	-0.05	0.13	0.15	0.82	0.77	1.09	1.32	2.63 *
Gene Status:										
Positive	0.09	0.33	-0.07	-0.23	-0.05	-0.27	1.53	2.63 *	1.46	3.16 **
Declined	-0.36	-1.02	-0.75	-1.83 ^	-0.15	-0.69	-0.32	-0.44	1.24	2.02 ^
Negative	0.00	.	0.00	.	0.00	.	0.00	.	0.00	.
Participant Affect	0.02	0.21	0.05	0.41	-0.02	-0.30	-0.35	-1.56	-0.58	-2.93 **
Participant Cognitive	-0.08	-1.38	0.02	0.28	0.03	0.61	0.10	0.68	-5.06	-2.33 *
Counselor Affect	-0.15	-0.62	0.20	0.71	0.19	1.21	0.61	1.11	-17.26	-2.88 **
Counselor Cognitive	-0.07	-0.51	0.09	0.62	0.14	1.79	0.32	1.10	-7.50	-2.75 **
Counselor Affective × Counselor Cognitive									1.02	2.93 **
Participant Cognitive × Counselor Cognitive									0.26	2.24 *

1000 > *d*

,500 > *d*
*
,1 > *d*
^

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