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Women's Satisfaction with Genetic Counseling for Hereditary Breast-Ovarian Cancer:

Psychological Aspects

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Abstract

Women who participate in *BRCA1/2* cancer genetic counseling do so for a variety of reasons, including learning quantitative risk information about their chances of developing hereditary breast-ovarian cancer at some point during their lifetimes. For these women, obtaining pre-test and disclosure genetic counseling with a professional affords them numerous potential benefits, including adequate preparation for, and accurate interpretation of, their test results. In consequence, women commonly report being highly satisfied with their cancer genetic counseling experience, even if the information learned through testing suggests they are at increased cancer risk. This occurrence raises an interesting question, namely what are the psychological aspects of satisfaction with genetic counseling for hereditary breast-ovarian cancer in women? To answer this question, we administered the Genetic Counseling Satisfaction Scale (GCSS) to a convenience sample of 61 women participating in *BRCA1/2* pre-test genetic counseling, and re-administered the GCSS to approximately one-third of these women at disclosure. Available psychological data included personality, distress, and family functioning. In bivariate analyses, optimism and family functioning were positively associated with pre-test satisfaction. With respect to satisfaction at disclosure, general and cancer-specific distress were negatively associated with satisfaction. Our findings suggest that psychological aspects of satisfaction with cancer genetic counseling vary, with individual differences and family functioning playing a role at pre-test, and distress playing a role at disclosure. The implications for future research and clinical practice are discussed.

Keywords

hereditary breast and ovarian cancer; genetic counseling; genetic testing; satisfaction; psychology

INTRODUCTION

Genetic counseling and testing for *BRCA1/2* mutations afford women numerous potential benefits, including adequate preparation for and interpretation of their risk of developing hereditary breast-ovarian cancer [Lerman et al., 1996; Schneider, 1997]. Studies suggest that patients who participate in cancer genetic counseling are often satisfied with the counseling

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they receive as part of their care [Bleiker et al., 1997; Chen et al., 2002; DeMarco et al., in press; Nordin et al., 2002]. Prior work indicates that patient satisfaction with genetic counseling is not solely a byproduct of the medical information exchanged during counseling, but may result from the dynamic interplay between the intrapersonal functioning of the patient, and the interpersonal counseling environment [Shiloh et al., 1990; Veach et al., 1999]. For example, the listening skills, understanding, interest, and competence of the provider have all been studied as salient aspects of satisfaction with cancer genetic counseling [Holloway et al., 2004], as well as other affective, cognitive, and behavioral components of genetic care [Shiloh et al., 1990]. In a descriptive study by Stadler and Mulvihill [1998], a significant proportion of women participating in cancer genetic counseling reported high satisfaction and reduced cancer-specific distress following counseling. These and other findings have led some to suggest that a deeper exploration of the psychological aspects of genetic counseling is necessary in order to understand counseling outcomes, including patient satisfaction [Biesecker and Peters, 2001; Kessler, 1998; Stadler and Mulvihill, 1998; Weil, 2003].

Much of the research literature has focused on the outcomes of *BRCA1/2* testing, and not on cancer genetic counseling per se, but these outcomes are interrelated. Numerous studies have examined the psychological aspects of genetic counseling and testing for hereditary breast-ovarian cancer, including the impact of personality, distress, and family functioning on *BRCA1/2* testing outcomes [Lerman et al., 2002]. With respect to personality, a study by Audrain and colleagues [1997] conducted with a large sample of women interested in such counseling found that individual differences in women's optimism levels were significantly associated with pre-counseling distress, such that women with a tendency to view life's stressors in a less optimistic manner were more distressed. For these women, part of the distress surrounding *BRCA1/2* testing likely came from their uncertainty surrounding the ultimate interpretation and meaning of their test, such as whether or not they would likely test positive. As individual differences in women's tendencies to interpret and accept breast cancer information in a more positive and hopeful manner exist [Carver et al., 1994], it is conceivable that optimism may affect *BRCA1/2* counseling patients' satisfaction and overall well-being as well. Indeed, prior research suggests a strong relationship between individual difference variables and optimism with patient-provider satisfaction [Rose et al., 2002], and individual difference variables with health-related quality of life ratings in both cancer [Carver et al., 1993; Yu et al., 2001] and noncancer [Handler et al., 1997] populations. As such, optimism may be an important psychological aspect of women's satisfaction with genetic counseling for hereditary breast-ovarian cancer.

With respect to distress, basic behavioral research into patient satisfaction has identified that persons who are psychologically distressed are more likely to report being less satisfied with their receipt of health care services than are patients without distress [Greenley et al., 1982; Ruggeri, 1994]. Tercyak, Johnson et al. [2001] reported a negative association between distress and satisfaction among women participating in prenatal genetic counseling and testing. However, this issue has not been fully examined with respect to cancer genetic counseling.

With regard to family functioning and interpersonal relationships among patients and their extended family members, these too may shape a patient's genetic counseling experience. It has been well established that many patients undergo *BRCA1/2* genetic testing to obtain information for the benefit of their relatives [Green et al., 1997] and, therefore, family communication often plays a prominent role in the genetic counseling process [Biesecker et al., 1993; Croyle and Lerman, 1999; Schneider, 1997]. A recent study by Forrest et al. [2003] found genetic testing participants perceive informing their at-risk relatives about their test results as an important responsibility, but that fulfilling this responsibility is influenced

by dynamic characteristics of family functioning. Thus, it is possible that in addition to personality and distress, family functioning may also impact upon a patient's contentment with the genetic counseling process.

To date, only a few published studies have focused on the psychological aspects of patient satisfaction with genetic counseling for hereditary cancer per se. In a study by Holloway and colleagues [2004] conducted in Scotland with women referred for breast cancer risk counseling, the researchers found no association between distress and patient satisfaction with genetic consultation. Nordin et al. [2002] described the psychological functioning (including personality and distress) of 63 adult males and females referred for breast, ovarian, or colorectal cancer counseling and testing; participants completed a genetic counseling satisfaction rating form within a few days following pre-test education. The results suggested that dispositional monitoring (a stable personality-like trait) was inversely related to patient satisfaction with the informative aspects of counseling, but that the relationship between distress (an unstable situational state) and satisfaction was inconsistent. Unfortunately, given the heterogeneity and size of the sample and the study's design, it was not possible to determine if the pattern of results was the same or different for different cancer types, or if the pattern of results was the same or different throughout all phases of genetic counseling (i.e., pretest counseling, disclosure counseling).

In light of these issues, the objective of this study was to better understand the role of personality, distress, and family functioning in women's satisfaction with genetic counseling for hereditary breast-ovarian cancer. Specifically, this study sought to answer the question: What are the psychological aspects of satisfaction with genetic counseling for hereditary breast-ovarian cancer? It was hypothesized that participants with a tendency to view life's stressors in a more hopeful manner would be more satisfied with their genetic counseling experience given the complexity, ambiguity, and uncertainty that are involved in hereditary cancer risk assessment and communication. It was also expected that participants with less distress would be more satisfied given the impact of distress on satisfaction in prior studies. And finally, it was hypothesized that greater family functioning would be associated with satisfaction given the implications of counseling for one's relatives.

MATERIALS AND METHODS

The Georgetown University Medical Center institutional review board reviewed and approved this protocol. After being informed about the study, participants were asked to read and sign a written informed consent form that explained the nature and purpose of the study, as well as its likely risks and benefits.

Subjects

From 1999 through 2001, the Lombardi Comprehensive Cancer Center's Cancer Assessment and Risk Evaluation (CARE) Program served as the source of participants in this study. At the time this investigation was conducted, the CARE Program was a no-cost, comprehensive, patient education and cancer genetic counseling, and *BRCA1/2* testing research effort. Patient participation in the CARE Program and its testing component were voluntary and counseling followed a research protocol that was based on standards of clinical practice (e.g., pre-test and disclosure counseling [Schneider, 1997]). The CARE Program has served as host to a number of ancillary studies examining focal issues. In the ancillary study reported on herein, the focal issue was parent-child communication about *BRCA1/2* testing and genetic counseling outcomes.

In order to be eligible for this ancillary study, participants must have met the CARE Program's criteria for risk level, been English-speaking, mother to at least one child between

the ages of 8 and 17 years, and have already provided a blood sample for *BRCA1/2* mutation analysis through the CARE Program. A total of 82 women were identified as eligible and the overall study consent rate was 89%. However, data analysis was limited to the subset of 61 (74%) participants who were administered and completed a genetic counseling satisfaction measure.

Methods

All methods are described in Tercyak et al., 2002. Participants completed baseline psychological measures via telephone and were then scheduled to attend an in-person pre-test genetic counseling session with a genetic counselor or nurse educator. The pre-test session included qualitative risk assessments based upon personal and family history, details about the process of testing for *BRCA1/2* mutations, risk communication and interpretation of test results, cancer risks associated with *BRCA1/2* gene mutations, options for cancer prevention and surveillance, a discussion of the benefits and risks/limitations of testing, and information about the possible psychosocial impact of testing. Immediately following the pre-test session, participants were offered the opportunity to provide a blood sample for *BRCA1/2* mutation analysis. Separately, study personnel asked participants to complete a genetic counseling satisfaction measure in private. To promote honest and candid responses, participants were reassured of the confidentiality of their satisfaction reports and informed that their genetic counselor or nurse educator would not have access to their satisfaction information. When test results became available (approximately four weeks later), women were invited to an individual disclosure genetic counseling session which was scheduled at the participant's convenience. At the disclosure session, a more detailed discussion was undertaken regarding test result interpretation and risk communication and other issues raised during the pre-test session. Immediately following the disclosure session, participants were again asked to complete a genetic counseling satisfaction measure in the same manner, and with the same assurances, described above.

Measures

Sociodemographics—Age, race, marital status, education level, and family income were assessed.

Medical—Personal history of cancer (Yes/No) was identified for each participant via self-report, and *BRCA1/2* test results were also obtained (positive, true negative, uninformative).

Genetic Counseling Process—Study personnel recorded if participants were or were not accompanied to each of their pre-test and disclosure genetic counseling sessions (Yes/No), as well as the length of each session (≤ 60 minutes, > 60 but ≤ 90 minutes, > 90 but ≤ 120 minutes, >120 minutes).

Personality—The Life Orientation Test-Revised [LOT-R; Scheier et al., 1994] was used to assess individual differences in generalized optimism, or one's tendency to view life's stressors in a more hopeful (as opposed to a more pessimistic) manner. The LOT-R consists of 10 items rated along a 5-point Likert scale, where higher scores indicate greater optimism (mean [*M*] = 16.0, standard deviation [*SD*] = 5.5). The internal consistency of the LOT-R was 0.85.

Distress—General distress was measured using the short form of the Hopkins Symptom Checklist [HSCL-25; Hesbacher et al., 1980]. The HSCL-25 is a 25-item Likert scale that assesses the presence and severity of anxiety and depression symptoms experienced in the past month. Higher scores indicate greater distress (*M* = 38.1, *SD* = 10.2). The internal consistency of the HSCL-25 was 0.92. Cancer-specific distress was measured by the Impact

of Events Scale [IES; Horowitz et al., 1979]. The IES is a 15-item Likert scale frequently used to assess stress associated with a specific life event (in this case, having a family history of cancer). The IES measures intrusive thoughts and feelings, and avoidance of thoughts and feelings, related to the stressor and higher scores indicate greater distress ($M = 23.4$, $SD = 19.5$). The internal consistency of the IES was 0.88.

Family Functioning—Family functioning was measured by the Family Relationship Index [FRI; Holahan and Moos, 1986]. The FRI is commonly used to assess the perceived quality of social support among family members. It is a 27-item True/False measure that yields scores on three scales (Cohesion, Expressiveness, Conflict) that are combined to form an overall total score; higher scores indicate greater family functioning ($M = 84.8$, $SD = 11.3$). The internal consistency of the FRI total score was 0.92.

Satisfaction—Satisfaction with genetic counseling was assessed via the Genetic Counseling Satisfaction Scale [GCSS; DeMarco et al., in press]. The GCSS is a 6-item Likert scale that assesses patient satisfaction with the process and content of genetic counseling (i.e., understanding, knowledge, reassurance, session length, concern, value); higher scores indicate greater satisfaction (pre-test $M = 26.9$, $SD = 3.9$). The reliability and validity of the GCSS has been established with both prenatal [Tercyak, Johnson et al., 2001] and cancer genetic counseling [DeMarco et al., in press] populations, and has been found to be inversely related to anxiety [Tercyak, Johnson et al., 2001]. The internal consistency of the GCSS was 0.90.

RESULTS

Sample Characteristics

As shown in Table I, participants were, on average, 45 years-old. The majority were Caucasian, married or living as married, college graduates, and had an annual family income of \$75,000 or more.

Cancer History and *BRCA1/2* Test Results

A total of 32 participants (53%) had been diagnosed previously and treated for some form of breast-ovarian cancer. Twenty (33%) participants ultimately received positive *BRCA1/2* test results, 5 (8%) received true negative results, and 36 (59%) received uninformative results.

Session Attendance and Length

The majority of participants were unaccompanied by a relative or friend to their pre-test ($n = 43$, 71%) and disclosure ($n = 45$, 74%) genetic counseling sessions. The majority of participants ($n = 54$, 88%) had pre-test sessions that lasted from 60 to 120 minutes in length, and the majority ($n = 45$, 74%) had disclosure sessions that lasted up to 60 minutes in length.

Bivariate Relationships

The first step in the data analysis plan was to examine if sociodemographic, cancer history, and genetic counseling process variables were associated with pre-test genetic counseling satisfaction. This was determined via a Pearson product-moment correlation (for age) and Student's *t*-tests (for all other variables). No significant associations were found ($P < 0.05$). The next step was to examine if psychological variables (personality, general distress, cancer-specific distress, family functioning) were associated with pre-test genetic counseling satisfaction. This was determined via Pearson product-moment correlations. The results suggested that personality and family functioning were significantly associated with

satisfaction, such that participants with greater optimism ($r = .25$, $P = 0.03$), and those with greater functioning within their families ($r = .30$, $P = 0.009$), were more satisfied.

Finally, we explored changes in satisfaction from pre-test to disclosure via paired samples *t*-tests, and bivariate relationships between sociodemographic, medical, genetic counseling process, and psychological variables with satisfaction at disclosure via Student's *t*-tests and Pearson product-moment correlations. A total of 20 participants (33% of original sample) completed the GCSS at disclosure. Overall, there were no differences between participants who did and did not go on to complete a satisfaction measure at the second time point with respect to age, race, marital status, education level, family income, cancer history, or *BRCA1/2* test result, and there was a nonsignificant trend for satisfaction to increase over time from pre-test to disclosure, $t(19) = -1.70$, $P = 0.10$. None of the sociodemographic, medical, or genetic counseling process variables were associated with satisfaction at this time point. However, general ($r = -.50$, $P = 0.01$) and cancer-specific distress ($r = -.42$, $P = 0.03$) were significantly associated with satisfaction at disclosure, such that participants with greater distress were less satisfied.

Multivariate Relationships

Multivariate logistic regression analysis was used to determine the likelihood of personality's and family functioning's association with pre-test satisfaction, and distress's association with satisfaction at disclosure. To ease interpretation, a median-split procedure was performed on the satisfaction outcomes to divide the sample into those who scored at or above the median (i.e., those who more satisfied) from those who scored below the median (those who were less satisfied) at each time point. Participants with greater functioning within their families were about 6% more likely to be more satisfied at pre-test than were participants with poorer family functioning, (Odds Ratio = 1.06, 95% Confidence Interval = 1.003, 1.127, $P = 0.04$). The main effect of personality, and the interaction between personality and family functioning, were tested but were not significant. A similar model of satisfaction at disclosure utilizing distress scores was also tested and found to be nonsignificant.

DISCUSSION

The results of this study suggest that there were several psychological aspects of satisfaction with genetic counseling for hereditary breast-ovarian cancer. Specifically, optimism and family functioning were independently and positively associated with pre-test counseling satisfaction, and general and cancer-specific distress were independently and negatively associated with disclosure counseling satisfaction. These findings were consistent with our hypotheses.

In terms of pre-test counseling, it is not surprising that optimism would be associated with satisfaction, given the general findings in the behavioral and medical decision-making research literatures that when faced with uncertain outcomes, optimism and similar personality-like tendencies exert influence over satisfaction and health-related quality of life [Handler et al., 1997; Rose et al., 2002; Yu et al., 2001]. Thus, our results underscore the point that when examining patient outcomes in cancer genetic counseling, the potential influence of individual differences in personality should be taken into account. Audrain et al. [1997] in their study of optimism in cancer genetic counseling and testing also concluded that optimism plays an important role in mediating outcomes. Examples of outcomes may include risk perceptions, adherence to screening guidelines, and communication with at-risk relatives [Croyle and Lerman, 1999].

With regard to family functioning, our data suggest that this too is a potentially important area of inquiry. Claes et al. [2003] reported that estranged relationships with family members were commonly cited reasons why *BRCA1/2* testing participants did not communicate their test results to their relatives, and similar findings have been reported elsewhere [Hughes et al., 2002].

Researchers have explored various ways to assist genetic counseling professionals in assessing the complexities of family communication issues that arise during hereditary cancer risk counseling, and have done so in the hope of better preparing these professionals to incorporate this information into their practice [Daly et al., 1999]. Given the important role that family communication plays in *BRCA1/2* counseling and testing, it is conceivable that participants with poorer and more estranged relationships with their family members might react negatively to the suggestion that they inform at-risk relatives about their test results. These individuals may, in turn, report lower satisfaction with their genetic counseling experience. Though none of the studies mentioned above examined satisfaction with counseling per se, the results of the present investigation suggest that satisfaction with pre-test counseling is lower in the presence of poorer family functioning. The results of the multivariate analysis further confirm that this variable, in particular, accounts for a small but significant portion of satisfaction variance.

Unlike personality and family functioning, which were associated with pre-test counseling satisfaction, distress was associated with disclosure counseling satisfaction. As expected, participants with greater distress were less satisfied. This finding replicates an earlier observation among women participating in prenatal genetic counseling that noted an inverse relationship between baseline levels of distress and satisfaction with counseling [Tercyak, Johnson et al., 2001]. As articulated by Greenley et al. [1982], several possibilities exist to explain this finding, including the possibility that patients with greater distress are generally less satisfied. Indeed, a study by Hoff et al. [1999] confirmed distress as a robust predictor of patient satisfaction. Further evidence of the distress-satisfaction relationship comes from treatment studies, where the suggestion has been made that increasing satisfaction with information provided through psychoeducational interventions with patients with breast cancer can lead to decreased distress [Okamura et al., 2003]. Whether or not similar effects might be observed among women participating in genetic counseling for hereditary breast-ovarian cancer remains to be seen.

Perhaps more importantly, it is interesting that the pattern of results was different across time, despite relatively little change in overall satisfaction from pre-test to disclosure. This suggests that psychological aspects of satisfaction with cancer genetic testing vary, with individual differences and family functioning playing a role at pre-test, and distress playing a role at disclosure. The important distinction between pre-test counseling and disclosure counseling is that test results are known at disclosure, and disclosure of positive *BRCA1/2* test results can exacerbate distress immediately after counseling in the presence of certain personality-like traits [Tercyak, Lerman et al., 2001]. Though distress was not reassessed immediately at the time of disclosure in this study, the putative effects of personal history of cancer, *BRCA1/2* test results, and genetic counseling process variables on satisfaction were tested but not observed. This diminishes the likelihood that the observed association between distress and satisfaction at disclosure was due, in part, to these effects. Thus, genetic counseling professionals are encouraged to attend to premorbid distress levels in their patients as this distress may downwardly affect patients' perceptions of counseling as a satisfying encounter.

Nevertheless, medical and genetic counseling process variables do play an important role in shaping the disclosure session. For example, in this sample from the CARE Program, 74%

of disclosures took place within 60 minutes, but an additional 20% of disclosures lasted up to 90 minutes, and 6% lasted up to 120 minutes. Having a personal history of breast-ovarian cancer, and a positive test result were positively related to disclosure session length. Future research should explore the impact of these variables in a more in-depth manner.

In interpreting these results, one must keep in mind a number of limitations that apply to the setting, sample, and methods used. First, the CARE Program provided no-cost genetic counseling and testing to eligible participants, the sample was selected by convenience, it was not diverse with respect to sociodemographics, and it was relatively small and contained few participants receiving positive test results. As such, the generalizability of the findings is limited. Second, not all participants completed the GCSS at both time points. This adversely affected study power in that it could no longer detect bivariate relationships in the low range but only in the moderate range. Though no meaningful differences were detected between participants who did or did not go on to complete a GCSS at the second time point, the attrition rate further limits the generalizability of the findings. And finally, distress was measured at a single point in time, and it is likely that important information would be gleaned from linking distress assessments closer in time to satisfaction assessments to understand their temporal relationships.

In summary, the results of this study suggest that the psychological aspects of satisfaction with genetic counseling for hereditary breast-ovarian cancer in women include optimism, general and cancer-specific distress, and family functioning, with each exerting relatively more or less influence at different times during pre-test and disclosure genetic counseling. To the extent that genetic counseling research carefully attends to and incorporates this psychological information in an attempt to better assess professional practice impact, quality improvement in patient satisfaction may result. However, additional research is necessary to determine the most effective methods for doing so.

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TABLE I

Characteristics of Study Sample (N = 61)

	Mean (SD)	N (%)
Age	45.18 (5.07)	
Race		
Caucasian		54 (88.5)
African-American		4 (6.6)
Asian		1 (1.6)
Other		2 (3.3)
Marital Status		
Single		3 (4.9)
Married or Living as married		53 (86.9)
Divorced or Separated		5 (8.2)
Education		
High school		4 (6.6)
Partial college		6 (9.8)
College graduate		51 (83.6)
Annual Household Income		
Less than or equal to \$75,000		14 (22.9)
Greater than \$75,000		47 (77.1)
Cancer History		
Unaffected		29 (47.5)
Affected		32 (52.5)
Test Result		
Positive		20 (32.8)
True Negative		5 (8.2)
Uninformative		36 (59.0)