

Cognitive and Psychological Impact of *BRCA* Genetic Counseling in Before and After Definitive Surgery Breast Cancer Patients

Juliette Christie, PhD¹, Gwendolyn P. Quinn, PhD^{1,2}, Teri Malo, PhD¹, Ji-Hyun Lee, PhD^{2,3}, Xiuhua Zhao, MPH³, Jessica McIntyre, BA¹, Jennifer Brzosowicz, MS, CGC⁴, Paul B. Jacobsen, PhD^{1,2}, and Susan T. Vadaparampil, PhD^{1,2}

¹Department of Health Outcomes and Behavior, Population Science, Moffitt Cancer Center, Tampa, FL; ²Department of Oncologic Science, College of Medicine, University of South Florida, Tampa, FL; ³Department of Biostatistics, Moffitt Cancer Center, Tampa, FL; ⁴Lifetime Cancer Screening and Prevention Center, Moffitt Cancer Center, Tampa, FL

ABSTRACT

Purpose. To examine changes in cancer-related knowledge, distress, and decisional conflict from pre- to post-genetic counseling (GC) in before (BDS) and after (ADS) definitive surgery breast cancer (BC) patients.

Methods. Sociodemographic and clinical characteristics were collected at baseline; primary outcome data were collected before (T1) and after (T2) pretest GC. Within group changes for cancer-related knowledge, distress, and decisional conflict over genetic testing were compared by Wilcoxon signed-rank tests.

Results. Of 103 BC patients, 87 were ADS and 16 were BDS. Analyses revealed that both groups reported significant increases in knowledge between T1 and T2 (median change 4.2, $p = 0.004$, and 2.7, $p < 0.001$, for BDS and ADS patients, respectively). Overall cancer-related distress showed a downward trend between T1 and T2 for both groups and was significant for BDS patients ($p = 0.041$). Reports of BDS patients trended toward overall and subscale-specific increases in decisional conflict, with the exception of the uncertainty which trended downward, but did not reach significance. Overall decisional conflict decreased in ADS patients, approaching marginal significance ($p = 0.056$), with significant improvements in informed decision making (median change -12.6 , $p < 0.001$; i.e., pretest GC yielded improved knowledge of benefits, risks, and side effects of available options).

Conclusions. These pilot data suggest that pretest GC increases cancer-related knowledge for both BDS and ADS patients, decreases distress in BDS patients, and improves informed decision making in ADS patients. Future studies with larger sample sizes are needed to replicate these results.

In the 10 years after diagnosis, breast cancer (BC) survivors with a *BRCA* mutation are at a greatly increased risk of contralateral BC (50 %) and ovarian cancer (7–13 %) compared to patients without a *BRCA* mutation (15–20 % new primary BC risk; ~2 % ovarian cancer risk).^{1–5} The National Comprehensive Cancer Network's medical management recommendations vary in intensity and modality for BC survivors based on *BRCA* mutation status.⁶ Contralateral prophylactic mastectomy reduces contralateral BC risk by ~95 % and confers a BC-specific and all-cause mortality survival advantage for *BRCA* carriers.^{7,8} Prophylactic bilateral salpingo-oophorectomy reduces ovarian cancer risk by ~80 % and BC risk by ~50 %.^{9–11} A few studies have demonstrated a 50 % reduction in contralateral BC incidence for *BRCA* carriers when tamoxifen is provided, particularly for those without prior prophylactic bilateral salpingo oophorectomy.^{12–14} For *BRCA* carriers who choose surveillance to manage risk, biannual magnetic resonance imaging alternating with mammography is recommended.¹⁵ Given the role of *BRCA* status in BC treatment and risk management, high-risk BC patients may benefit from *BRCA* genetic counseling (GC) and genetic testing (GT) at or near the time of initial diagnosis.

The model for providing comprehensive *BRCA* testing typically begins with an in-person pretest GC session.^{15–19}

Patients meet with a trained health professional to obtain a risk assessment based on personal and family cancer history, receive education about hereditary breast and ovarian cancer (HBOC), and discuss the benefits and limitations of testing. Goals of this initial session are to determine the appropriateness of GT based on the patient's history and risk assessment, as well as to increase HBOC knowledge, aid in psychosocial adjustment, and assist with decision making regarding testing.^{20–24}

In general, pretest GC is associated with improvements in cancer-specific knowledge and minimal adverse psychological consequences.²⁵ However, women with cancer may be at an increased risk for distress, particularly if the GC and GT process occurs at a time near cancer diagnosis and treatment.^{26–28} Yet little is known about the specific impact of pretest GC on knowledge, psychosocial adjustment, and GT decision making in BC patients before or while undergoing treatment.²⁹

A recent study on BC patients approached for GC referral shortly after undergoing surgery demonstrated no increase in short-term psychological burden after GC.³⁰ What remains unclear, however, is how BC patients who have not undergone definitive surgery respond to pretest GC. For example, before definitive surgery (BDS), patients may feel overwhelmed by the additional risk information and surgical treatment implications presented during GC.³¹ Others may be concerned about the emotional impact of genetic vulnerability for themselves or their family at a time when distress is already heightened or perceive limited utility of GC for current treatment decisions.^{31,32} Despite the reality of these perceived barriers, the time surrounding a recent BC diagnosis is unequivocally both cognitively and emotionally taxing.³³ Thus, this group may not only perceive but also be at greater risk for distress, difficulty retaining information, and making decisions about GT after pretest GC compared to after definitive surgery (ADS) patients. Conversely, given the focus on risk assessment, discussion of immediate medical management

(i.e., surgery), and attention to patients' psychosocial status incorporated into a pretest GC session, it is also possible BDS patients may feel less distressed, experience greater information retention, and have less decisional conflict after pretest GC. To assess BDS and ADS pretest GC outcomes, we conducted a prospective, pilot study to examine the short-term impact of pretest GC on: (a) HBOC knowledge, (b) cancer-related distress, and (c) decisional conflict associated within each group.

METHODS

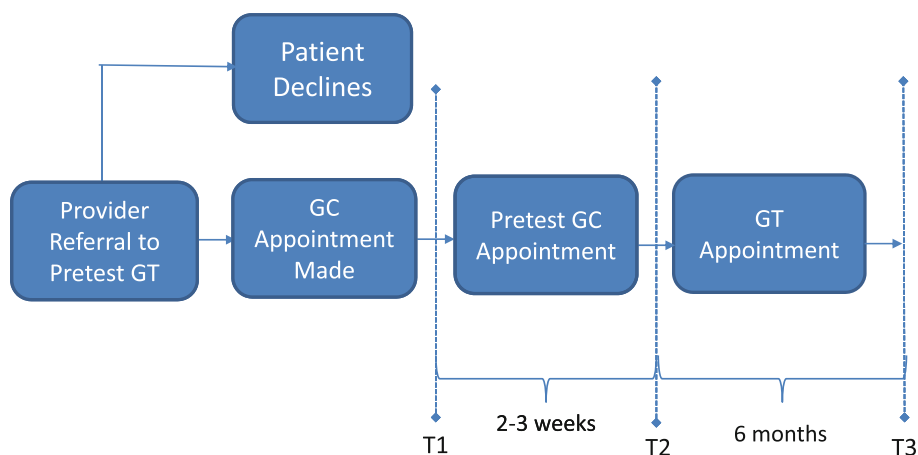
Participant Recruitment

As part of a larger, longitudinal study, data were collected: (a) after the pretest GC appointment was scheduled but before the GC session (T1), (b) within 2–3 weeks after participants completed the pretest GC (T2), and (c) 6 months after completing the T2 assessment (T3). The current report is focused on the short-term impact of pretest GC; therefore, analyses are based on T1 and T2 data (Fig. 1).

Upon institutional review board approval, recruitment began in April 2009 and ended in July 2010. Eligibility criteria included: (a) meeting National Comprehensive Cancer Network cancer genetics referral criteria, (b) ≥ 18 years of age; (c) confirmed personal BC diagnosis based on medical records review; (d) no previous participation in GC and/or testing for HBOC; (e) capable of speaking and reading standard English; (f) having a mailing address and working telephone number; and (g) having a GC appointment scheduled at Moffitt Cancer Center.

The study genetic counselor reviewed the GC appointment schedule weekly for women meeting study eligibility criteria. Eligible patients were mailed a study packet including an introductory letter with a toll-free number to opt out of further contact by the study team, the T1 survey, two consent forms, and a preaddressed envelope.

FIG. 1 Overview of study-related assessments. Current analyses are based on T1 (before pretest, or pre-, GC) and T2 (after pretest, or post-, GC) data



Approximately 1 week from the mailing date, patients who did not opt out were contacted via telephone to confirm receipt of study materials and to answer any questions they may have. For those not reachable by telephone before their scheduled GC appointment, the study coordinator met briefly with patients after their GC session to determine whether the T1 survey was complete. Those who did not complete the T1 survey before attending their pretest GC session were considered decliners.

For the first 6 weeks of study recruitment, patients who failed to attend their pretest GC appointment were considered ineligible. However, this strategy precluded the opportunity to include patients who rescheduled and attended their GC appointment. Thus, recruitment procedures were revised so that patients who scheduled a new appointment were mailed an additional packet. Patients who failed to reschedule their appointment between the date of their canceled appointment and July 2010 (end of data collection) were considered ineligible. Participants received a \$25.00 and \$20.00 gift card for completing T1 and T2, respectively.

Measures

Participants had the option of completing paper or web-based surveys. Data on sociodemographic and clinical characteristics were collected at baseline; primary outcome data were collected at T1 and T2.

Sociodemographic and Clinical Characteristics Sociodemographic and clinical characteristics obtained from patient questionnaires or medical records review included: age at diagnosis, current stage of BC (1, 2/3, 4, unstaged, other [e.g., unknown]), previous surgery (yes [i.e., breast conservation lumpectomy, unilateral mastectomy after biopsy, contralateral mastectomy after unilateral mastectomy, or bilateral mastectomy], no [have not had surgery]), and primary payor at diagnosis (private insurance, public insurance, no insurance, other). Additional data collected via self-report questionnaires included: education (high school or less; vocational school and some college; college graduate and beyond), total household income at time of diagnosis (<\$35,000, >\$35,000, ≤\$50,000, >\$50,000), marital status (married, other), and race (Black, white, other).

HBOC Knowledge A 15-item, adapted version of the National Center for Human Genome Research (NCHGR) Knowledge Scale was used to measure four aspects of HBOC genetics knowledge: (a) prevalence of *BRCA* gene mutations, (b) patterns of inheritance, (c) cancer risks associated with *BRCA* mutations, and (d) risk management options for women with a *BRCA* mutation.^{34–37} Items were scored as a 1 for correct and a 0 for incorrect or “don’t

know” responses, allowing for the calculation of an overall knowledge score ranging from 0–15. The scale had adequate internal consistency at baseline and after pretest GC (T1 $\alpha = 0.82$ and T2 $\alpha = 0.81$).

Cancer-Related Distress The 15-item Impact of Events Scale (IES) measure of current, subjective distress was used to assess the frequency of intrusive thoughts or avoidance related to a specific stressor.³⁸ Intrusion is characterized by repetitive thoughts, mental images, disturbing dreams, and repetitive behavior. Avoidance is associated with denial of consequences from an event, blunting feelings, and emotional numbness related to an event. Respondents were asked to indicate how frequently (0 = not at all, 1 = rarely, 3 = sometimes, 5 = often) they experienced each indicator of distress during the past 7 days due to their BC diagnosis. Overall cancer-related distress scores range from 0 to 75, intrusion subscale scores range from 0 to 35, and avoidance subscale scores range from 0 to 40. The IES has been found to be a reliable and valid instrument for cancer-related distress among women at increased risk for hereditary BC and was recently used in a study of newly diagnosed BC patients undergoing GC and GT.^{39–42} In the current study, Cronbach’s alpha for the overall distress scale was 0.92 and 0.92 at T1 and T2, respectively; $\alpha = 0.88$ and 0.91 for the intrusion subscale at T1 and T2, respectively, and $\alpha = 0.81$ and 0.82 for the avoidance subscale at T1 and T2, respectively.

Decisional Conflict The 16-item Decisional Conflict Scale (DCS) scale was used to assess patients’ decisional conflict over GT and includes five subscales: (a) perceptions of being informed (i.e., feeling informed about options, risks, and benefits; informed subscale), (b) degree of clarity regarding their personal values attached to the pros and cons of their decision (i.e., feeling clear about personal values attached to benefits and risks; values clarity subscale), (c) perception of decisional support (i.e., feeling supported by others in decision-making; support subscale), (d) degree of certainty about the particular health decision that is to be made (i.e., feeling clear about, certain of, and at ease with the best personal choice; uncertainty subscale), and (e) perceived effective decision making (i.e., perceptions about whether decisions are informed, are consistent with personal values, will be implemented, and are satisfactory; effective decision subscale).^{43,44} After subscale scores were summed and divided by the total number of items, one point was subtracted from each subscale’s total. These scores were then multiplied by 25, resulting in final scores ranging from zero (low decisional conflict) to 100 (high decisional conflict). This scale has been shown to be reliable and valid for individuals making a variety of health-related decisions.^{43,45–50} Cronbach’s α for the overall decisional conflict scale in the current study was 0.94 and 0.99

for T1 and T2, respectively; alpha values for the: (a) informed subscale were 0.90 and 0.97, (b) values clarity subscale were 0.91 and 0.98, (c) support subscale were 0.57 and 0.97, (d) uncertainty subscale were 0.85 and 0.97, and (e) effective decision subscale were 0.89 and 0.98, at T1 and T2, respectively.

Data Analysis

Descriptive statistics were summarized to characterize the total sample and each group. Scoring guidelines for each survey instrument were used to compute composite and subscale scores. Distributional characteristics of the composite and subscale variables for both patient groups were examined using histograms. Before conducting within-group analyses, Wilcoxon rank-sum tests were performed to assess differences between BDS and ADS patient groups: (a) at baseline, or pre-GC on HBOC knowledge, cancer-related distress, and decisional conflict (and all related subscales), and (b) on variables constructed to measure changes from pre- to post-GC reports on HBOC knowledge, cancer-related distress, and decisional conflict (and all related subscales). For each group, the changes from pre- to post-GC cancer-related knowledge, BC-related distress, and decisional conflict, including subscales where appropriate, were compared by Wilcoxon signed-rank tests. All tests were two-sided, with alpha set at the conventional level of 0.05. Statistical analyses were conducted by SAS 9.2 software (SAS, Cary, NC).

RESULTS

A total of 223 patients were identified. Of these, 87 patients did not meet eligibility requirements (e.g., previous participation in GC and/or testing for HBOC, rescheduled GC appointment more than three times, non-English speaking). Of the remaining 136 eligible participants, 114 consented and completed the T1 survey, resulting in an 83.8 % response rate. Of 114, there were 87 ADS patients (i.e., had undergone one or more surgeries) and 16 BDS patients (i.e., had not undergone definitive surgery) at T1. Eleven patients did not know whether they had undergone previous surgery at T1; these patients were excluded from the current analyses given study aims, resulting in a total of 103 patients across groups at T1. Ninety-three patients completed the T2 assessment.

As shown in Table 1, participants were, on average, 49 (range 24–69) years old. The majority was married (68.9 %), had previously undergone surgery (84.5 %), and had private insurance at the time of diagnosis (52.4 %). About 38 % of participants were diagnosed in stage 2/3. Approximately 81 % of participants were white, 49.5 % had college or postgraduate

degrees, and 37.9 % had a household income >\$50,000 before diagnosis.

There were no differences between groups at baseline or in changes from pre- to post-GC on HBOC knowledge, cancer-related distress, and decisional conflict (nor on any related subscales; data not shown).

As for within-group differences on study outcomes, both BDS and ADS patients showed significant increases in HBOC knowledge from pre- to post-GC (median change 4.0, $p = 0.004$, and 3.0, $p < 0.001$, for BDS and ADS patients, respectively; Table 2). With regard to psychological distress, results showed significant decreases in overall cancer-related distress ($p = 0.041$) and intrusive thoughts ($p = 0.014$) from pre- to post-GC for BDS patients. For ADS patients, there were nonsignificant downward trends for distress from baseline to post-GC ($p = 0.303$, $p = 0.274$, and $p = 0.646$ for median changes in overall distress, intrusion, and avoidance for ADS patients, respectively; Fig. 2).

In terms of decisional conflict regarding GT, BDS patient reports on overall and subscales of decisional conflict trended toward increases in conflict with the exception of the informed subscale of decisional conflict which trended downward; however, changes were not statistically significant (Table 2). ADS patients reported decreases in overall decisional conflict that approached marginal significance (median change -10.2 , $p = 0.056$, Table 2) and significant decreases in the informed subscale (median change -25.0 , $p < 0.001$).

DISCUSSION

Several studies have documented underutilization of GC and GT, particularly among newly diagnosed BC patients.^{51–55} This may be due, in part, to patient lack of understanding of how the GC and GT process can inform their current treatment decisions and/or concerns regarding the psychological impact of this process at an already stressful time.^{31,32} Similarly, healthcare providers may be concerned about a patient's ability to cope effectively with this process at a time when they are dealing with a new BC diagnosis.³³ However, no study to date has specifically explored whether BDS and ADS BC patients have similar responses to pretest GC. This pilot study assessed HBOC knowledge, cancer-related distress, and decisional conflict before and after pretest GC for *BRCA* mutations in high-risk BC patients who have and have not had definitive surgery. Although there were no differences between groups at baseline or in changes between T1 and T2 on study outcomes, there were several notable within-group changes.

Similar to the results of other studies assessing knowledge before and after pretest GC in women at increased

TABLE 1 Sociodemographic and clinical characteristics of study participants^a

Characteristic	Total sample (<i>n</i> = 103)	BDS (<i>n</i> = 16)	ADS (<i>n</i> = 87)	<i>p</i> ^b
Age at diagnosis (year)				
Mean ± SD	49.2 ± 10.7	45.9 ± 12.5	49.8 ± 10.2	0.173
Range	24–69	24–67	24–69	
Current disease stage				
Stage 1	26 (25.2)	1 (6.3)	25 (29.8)	0.078
Stage 2/3	39 (37.9)	9 (56.3)	30 (35.7)	
Stage 4	8 (7.8)	3 (18.8)	5 (6.0)	
Unstaged	21 (20.4)	3 (18.8)	18 (21.4)	
Other (unknown; bilateral breast)	6 (5.8)	0	6 (7.1)	
Primary payor at diagnosis				
Private insurance	54 (52.4)	9 (60)	45 (54.2)	0.136
Public insurance	31 (30.1)	2 (13.3)	29 (34.9)	
No insurance	2 (1.9)	1 (6.7)	1 (1.2)	
Other	11 (10.7)	3 (20)	8 (9.6)	
Education				
High school or less	15 (14.6)	1 (6.3)	14 (16.1)	0.662
Vocational school and some college	37 (35.9)	6 (37.5)	31 (35.6)	
College graduate and beyond	51 (49.5)	9 (56.3)	42 (48.3)	
Total household income before diagnosis				
≤\$35,000	28 (27.2)	4 (28.6)	24 (32.9)	0.866
>\$35,000 to ≤ \$50,000	20 (19.4)	4 (28.6)	16 (21.9)	
>\$50,000	39 (37.9)	6 (42.9)	33 (45.2)	
Marital status				
Married ^c	71 (68.9)	11 (68.8)	60 (69.0)	1.00
Other	32 (31.1)	5 (31.3)	27 (31.0)	
Race				
Black	8 (7.8)	1 (6.3)	7 (8.1)	1.00
White	83 (80.6)	13 (81.3)	70 (80.5)	
Other	12 (11.7)	2 (12.5)	10 (11.5)	

^a Data are presented as *n* (%) unless otherwise indicated. Percentages may not add up to 100 due to missing data

^b Wilcoxon signed-rank tests conducted to compare sociodemographic and clinical characteristics between groups

^c Includes common-law and living with domestic partner

risk of developing hereditary BC, both patient groups (BDS and ADS patients) reported increases in HBOC knowledge after GC compared to baseline.³⁰ These findings are encouraging, given increased patient knowledge is considered an important goal of pretest GC.⁵⁶

With regard to psychological distress, BDS patients experienced significant decreases in cancer-related distress and in intrusive thoughts between T1 and T2. These findings support previous research demonstrating reductions in baseline cancer worry after participation in pretest GC.⁵⁷ In this sense, pretest GC may be psychologically protective for BDS patients in terms of cognitive intrusion, rather than distressing. Although levels of cognitive avoidance declined after GC compared to baseline for BDS patients, changes were not significant. Reduction in psychological distress in ADS patients demonstrated a downward trend, but also did not reach significance.

These results are consistent with those reported by at risk, unaffected women and by women who have undergone surgery.^{30,58} Further research is needed to understand the impact of GC on cognitive avoidance.

Although not statistically significant, BDS patients reported increased levels of overall decisional conflict related to the decision to have GT. GC protocols may need to be adapted to meet specific needs and perspectives of BDS BC patients to ensure timely and effective decision making after pretest GC. For example, BC patients who decline *BRCA* GT may be more likely to report increased “cons” (rather than decreased “pros”) than those who choose to undergo GT.⁵⁴ Therefore, BDS patient–genetic counselor dialogue may need to focus on addressing perceived risks associated with GT and how those align with patient values and satisfaction.

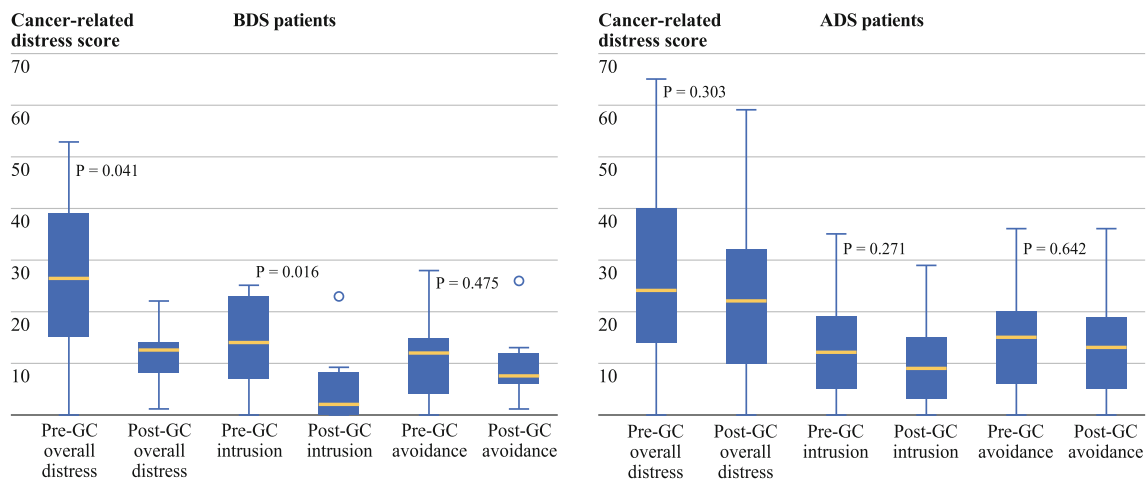
TABLE 2 Changes in cancer-related knowledge and decisional conflict regarding GT from pre- to post- GC in BDS and ADS patients

Characteristic	(n) Median [range]			<i>p</i> ^a
	Pre-GC	Post-GC	Change (post – pre)	
BDS patients (<i>n</i> = 16)				
HBOC knowledge ^b	(16) 7.0 [2–11]	(10) 10.0 [7–15]	(10) 4.0 [–1–8]	0.004
Overall decisional conflict	(15) 23.4 [0.0–60.9]	(11) 25.0 [0.0–100.0]	(10) 3.1 [–34–89]	0.748
Uncertainty	(15) 25.0 [0.0–58.3]	(11) 25.0 [0.0,100.0]	(10) 0.0 [–91.7–33.3]	0.625
Informed	(16) 29.2 [0.0–91.7]	(11) 25.0 [0.0,100.0]	(11) 0.0 [–41.7–75.0]	0.383
Values clarity	(16) 25.0 [0.0–58.3]	(11) 25.0 [0.0,100.0]	(11) 0.0 [–42–75]	0.818
Support	(16) 25.0 [0.0–50.0]	(11) 16.7 [0.0,100.0]	(11) 8.3 [–33–100]	0.406
Perceived effective decision making	(16) 25.0 [0.0–56.3]	(11) 25.0 [0.0,100.0]	(11) 0.0 [–50–100]	0.719
ADS patients (<i>n</i> = 87)				
HBOC knowledge	(85) 7.0 [0–14]	(78) 10.0 [1–14]	(76) 3.0 [– 10, 11]	<0.001
Overall decisional conflict	(83) 29.7 [0.0, 68.8]	(78) 18.0 [0.0, 100.0]	(74) –10.2 [– 48, 100]	0.056
Uncertainty	(87) 25.0 [0.0, 91.7]	(80) 16.7 [0.0, 100.0]	(80) 0.0 [– 100, 75]	0.660
Informed	(85) 50.0 [0.0,100.0]	(80) 25.0 [0.0, 100.0]	(78) –25.0 [– 75, 100]	<0.001
Values clarity	(87) 33.3 [0.0, 100.0]	(81) 25.0 [0.0, 100.0]	(81) –8.3 [– 75, 100]	0.075
Support	(86) 25.0 [0.0, 66.7]	(80) 16.7 [0.0, 100.0]	(79) –8.3 [– 50, 100]	0.206
Perceived effective decision making	(85) 25.0 [0.0, 62.5]	(79) 12.5 [0.0, 100.0]	(77) 0.0 [– 63, 100]	0.989

GT genetic testing, GC genetic counseling, BDS before definitive surgery, ADS after definitive surgery

^a Wilcoxon signed-rank tests conducted to compare changes in outcomes, including subscales, from pre- to post-GC in BDS and ADS patients

^b Scores for cancer-related knowledge range from 0 (no items correct) to 11 (all items correct); scores for decisional conflict range from 0 (no decisional conflict) to 100 (extremely high decisional conflict)

**FIG. 2** Changes in breast cancer-related distress (overall and by subscales) GC in before definitive surgery (BDS; *n* = 16; *top*) and after definitive surgery (ADS; *n* = 87; *bottom*) patients. Wilcoxon signed-rank tests were conducted to compare median changes over time

Conversely, trends suggest pretest GC decreases overall decisional conflict for ADS patients, with significant decreases in conflict regarding informed decision making (e.g., knowing the pros and cons of each option and which is most salient personally). It is possible that ADS patients gain increased understanding of the benefits and risks of previous and potential treatment and surgical options, thereby alleviating decisional conflict over GT and promoting future informative treatment decisions.

Results of the current study, however, should be examined in light of its limitations. First, the small sample size for BDS patients yielded limited statistical power for our analyses, potentially leading to Type II errors. However, our smaller sample of BDS patients likely reflects the current clinical reality that fewer newly diagnosed BC patients are being referred for and participating in pretest GC before undergoing surgical treatment.⁵⁵ It is also important to consider the heterogeneity that may exist

within our BDS group. It is possible that this group may include patients without an imminent surgical decision (e.g., women who may be undergoing neoadjuvant chemotherapy before surgical treatment). Upon reviewing medical records for the 16 BDS patients, clinic notes confirm that one of the 16 nonsurgical patients had surgery before the T2 assessment. In addition, we assessed whether any of these patients underwent surgery before T3 (post-GT). Eight of the 16 patients classified as nonsurgical at T1 and T2 had undergone surgery before the 6-month follow-up at T3 (post-GT). This study also did not have a comparison group of BC patients who did not receive pretest GC. Previous research including both an ADS and comparison group, however, suggest there are no differences between groups in general anxiety, depression, or breast-cancer related distress.³⁰ In terms of ADS patients, 30 % received GC at least more than 1 year after their diagnosis. Post-hoc analyses demonstrated that ADS patients who were diagnosed more than 1 year before GC experienced significantly different changes in distress and intrusion than those who were more recently diagnosed (data not shown). Examining effects of time since diagnosis on GC and GT outcomes, particularly within surgical patients, warrants future investigation.

Additionally, our study evaluated the impact of pretest GC. However, it is very likely that discussions and informal counseling regarding hereditary cancer risk began before the actual pretest GC session, namely with surgeons, medical oncologists, nurse navigators or other healthcare professionals involved in the care of BC patients. We conducted a post-hoc frequency analysis to assess the proportion of BDS and ADS patients who previously discussed GC with a healthcare professional. Approximately 94 % of BDS and 84 % of ADS patients reported discussing GC with a healthcare professional before attending the GC session. A Fisher's exact test was conducted to determine whether there were significant differences between groups regarding prior discussion of GC. Results suggest no significant differences between BDS and ADS groups in terms of prior discussion of GC ($p = 0.455$).

All patients in the current study were afforded an in-person pretest GC session by a master's prepared genetic counselor focusing in oncology, which may not reflect delivery of GC across the US.⁵⁹ However, differences in delivery may dissipate over time based on 2012 American College of Surgeons' Commission on Cancer accreditation guidelines that specify risk assessment and GC be offered by a qualified genetic professional as a clinical service to ensure patient-centered quality of care. Also, the majority of patients was non-Hispanic white; thus, findings from this study may not be generalizable to BC patients from other racial and ethnic populations. It is important to note as well that although BC patients in this study were referred for

GC based on NCCN and study criteria, patients may differ in terms of the number and types of criteria met. For example, some women may have been referred for early-onset BC (under age 50) and strong family history, whereas others may have been referred based on family history alone. These differences may affect GC outcomes. Therefore, future investigations should attempt to parcel out these effects.

Although BDS and ADS patients did not exhibit increases in psychological distress in this study, BC patients who are younger, single with little social support, less optimistic, employ maladaptive coping, report lower quality of life, or exhibit high distress at baseline are more likely to experience adverse psychological effects.³⁰ Future studies with larger, nationally representative samples of BC patients should examine multiple types of psychological distress (e.g., anxiety, depression) and the potential moderating effects of age; marital status; and personality, coping, and quality of life variables on BDS and ADS patient outcomes.

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REFERENCES

1. Graeser MK, Engel C, Rhiem K, et al. Contralateral breast cancer risk in *BRCA1* and *BRCA2* mutation carriers. *J Clin Oncol*. 2009;27:5887–92.
2. Malone KE, Begg CB, Haile RW, et al. Population-based study of the risk of second primary contralateral breast cancer associated with carrying a mutation in *BRCA1* or *BRCA2*. *J Clin Oncol*. 2010;28:2404–10.
3. Metcalfe KA, Lynch HT, Gadirian P, et al. The risk of ovarian cancer after breast cancer in *BRCA1* and *BRCA2* carriers. *Gynecol Oncol*. 2005;96:222–6.
4. Chen Y, Thompson W, Semenciw R, Mao Y. Epidemiology of contralateral breast cancer. *Cancer Epidemiol Biomarkers Prev*. 1999;8:855–61.
5. Brekelmans CT, Tilanus-Linthorst MM, Seynaeve C, et al. Tumour characteristics, survival and prognostic factors of hereditary breast cancer from *BRCA2*-, *BRCA1*- and non-*BRCA1/2* families as compared to sporadic breast cancer cases. *Eur J Cancer*. 2007;43:867–76.
6. Daly M, Axilbund JE, Bryant E, et al. The NCCN genetic/familial high-risk assessment: breast and ovarian clinical practice guideline, version 1.2006. <http://www.nccn.org/>. Accessed 1 Oct 2006.
7. Boughey JC, Hoskin TL, Degnim AC, et al. Contralateral prophylactic mastectomy is associated with a survival advantage in high-risk women with a personal history of breast cancer. *Ann Surg Oncol*. 2010;17:2702–9.
8. Domchek SM, Friebel TM, Singer CF, et al. Association of risk-reducing surgery in *BRCA1* or *BRCA2* mutation carriers with cancer risk and mortality. *J Am Med Assoc*. 2010;304:967–75.
9. Finch A, Beiner M, Lubinski J, et al. Salpingo-oophorectomy and the risk of ovarian, fallopian tube, and peritoneal cancers in women with a *BRCA1* or *BRCA2* mutation. *J Am Med Assoc*. 2006;296:185–92.

10. Rebbeck TR, Friebel T, Lynch HT, et al. Bilateral prophylactic mastectomy reduces breast cancer risk in *BRCA1* and *BRCA2* mutation carriers: the PROSE study group. *J Clin Oncol*. 2004;22:1055–62.
11. Rebbeck TR, Levin AM, Eisen A, et al. Breast cancer risk after bilateral prophylactic oophorectomy in *BRCA1* mutation carriers. *J Natl Cancer Inst*. 1999;91:1475–9.
12. Gronwald J, Tung N, Foulkes WD, et al. Tamoxifen and contralateral breast cancer in *BRCA1* and *BRCA2* carriers: an update. *Int J Cancer*. 2006;118:2281–4.
13. King MC, Wieand S, Hale K, et al. Tamoxifen and breast cancer incidence among women with inherited mutations in *BRCA1* and *BRCA2*: national surgical adjuvant breast and bowel project (NSABP-P1) breast cancer prevention trial. *J Am Med Assoc*. 2001;286:2251–6.
14. Narod SA, Brunet JS, Ghadirian P, et al. Tamoxifen and risk of contralateral breast cancer in *BRCA1* and *BRCA2* mutation carriers: a case-control study. Hereditary breast cancer clinical study group. *Lancet*. 2000;356:1876–81.
15. Daly M, Axilbund JE, Bryant E, et al. The NCCN genetic/familial high-risk assessment: breast and ovarian clinical practice guideline, version 1.2009. <http://www.nccn.org/>. Accessed 3 Dec 2009.
16. Earle CC. Failing to plan is planning to fail: improving the quality of care with survivorship care plans. *J Clin Oncol*. 2006;24:5112–6.
17. Hewitt M, Greenfield S, Stovall E. From cancer patient to cancer survivor: lost in transition. Washington, DC: National Academies Press, 2005.
18. American Society of Clinical Oncology policy statement update: genetic testing for cancer susceptibility. *J Clin Oncol*. 2003;21:2397–406.
19. Robson ME, Storm CD, Weitzel J, et al. American society of clinical oncology policy statement update: genetic and genomic testing for cancer susceptibility. *J Clin Oncol*. 2010;28:893–901.
20. Berliner JL, Fay AM. Risk assessment and genetic counseling for hereditary breast and ovarian cancer: recommendations of the national society of genetic counselors. *J Genet Couns*. 2007;16:241–60.
21. Fraser FC. Genetic counseling. *Am J Hum Genet*. 1974;26:636–61.
22. Bernhardt BA, Biesecker BB, Mastromarino CL. Goals, benefits, and outcomes of genetic counseling: client and genetic counselor assessment. *Am J Med Genet*. 2000;94:189–97.
23. Shiloh S, Avdor O, Goodman RM. Satisfaction with genetic counseling: dimensions and measurement. *Am J Med Genet*. 1990;37:522–9.
24. Pilnick A, Dingwall R. Research directions in genetic counselling: a review of the literature. *Patient Educ Couns*. 2001;44:95–105.
25. Braithwaite D, Emery J, Walter F, et al. Psychological impact of genetic counseling for familial cancer: a systematic review and meta-analysis. *J Natl Cancer Inst*. 2004;96:122–33.
26. Lerman C, Croyle RT, Tercyak KP, Hamann H. Genetic testing: psychological aspects and implications. *J Consult Clin Psychol*. 2002;70:784–97.
27. Meiser B. Psychological impact of genetic testing for cancer susceptibility: an update of the literature. *Psychooncology*. 2005;14:1060–74.
28. Hamann HA, Somers TJ, Smith AW, et al. Posttraumatic stress associated with cancer history and *BRCA1/2* genetic testing. *Psychosom Med*. 2005;67:766–72.
29. Vadaparampil ST, Miree CA, Wilson C, Jacobsen PB. Psychosocial and behavioral impact of genetic counseling and testing. *Breast Dis*. 2007;27:97–108.
30. Schlich-Bakker KJ, Warlam-Rodenhuis CC, van Echtelt J, et al. Short term psychological distress in patients actively approached for genetic counselling after diagnosis of breast cancer. *Eur J Cancer*. 2006;42:2722–8.
31. Vadaparampil ST, Quinn GP, Brzosowicz J, Miree CA. Experiences of genetic counseling for *BRCA1/2* among recently diagnosed breast cancer patients: a qualitative inquiry. *J Psychosoc Oncol*. 2008;26:33–52.
32. Geer KP, Ropka ME, Cohn WF, et al. Factors influencing patients' decisions to decline cancer genetic counseling services. *J Genet Couns*. 2001;10:25–40.
33. Nusbaum RH, Peshkin BN, DeMarco TA, Goodenberger M. *BRCA 1/2* testing in patients with newly diagnosed breast cancer. *Commun Oncol*. 2009;6:367–71.
34. Lerman C, Schwartz MD, Lin TH, et al. The influence of psychological distress on use of genetic testing for cancer risk. *J Consult Clin Psychol*. 1997;65:414–20.
35. Lerman C, Narod S, Schulman K, et al. *BRCA1* testing in families with hereditary breast-ovarian cancer. A prospective study of patient decision making and outcomes. *J Am Med Assoc*. 1996;275:1885–92.
36. Lerman C, Biesecker B, Benkendorf JL, et al. Controlled trial of pretest education approaches to enhance informed decision-making for *BRCA1* gene testing. *J Natl Cancer Inst*. 1997;89:148–57.
37. Hopwood P, Shenton A, Lalloo F, et al. Risk perception and cancer worry: an exploratory study of the impact of genetic risk counselling in women with a family history of breast cancer. *J Med Genet*. 2001;38:139.
38. Horowitz M, Wilner N, Alvarez W. Impact of Event Scale: a measure of subjective stress. *Psychosom Med*. 1979;41:209–18.
39. Vadaparampil ST, Ropka ME, Stefanek ME. Measurement of psychological factors associated with genetic testing for hereditary breast, ovarian and colon cancers. *Fam Cancer*. 2005;4:195–206.
40. Wevers MR, Ausems MG, Verhoef S, et al. Behavioral and psychosocial effects of rapid genetic counseling and testing in newly diagnosed breast cancer patients: design of a multicenter randomized clinical trial. *BMC Cancer*. 2011;11:6.
41. Thewes B, Meiser B, Hickie IB. Psychometric properties of the Impact of Event Scale amongst women at increased risk for hereditary breast cancer. *Psychooncology*. 2001;10:459–68.
42. Schwartz MD, Lerman C, Brogan B, et al. Impact of *BRCA1/BRCA2* counseling and testing on newly diagnosed breast cancer patients. *J Clin Oncol*. 2004;22:1823–9.
43. O'Connor AM. Validation of a decisional conflict scale. *Med Decis Making*. 1995;15:25–30.
44. O'Connor AM. User manual—decisional conflict scale. Ottawa: Ottawa Hospital Research Institute, 1993, updated 2010.
45. Cranney A, O'Connor AM, Jacobsen MJ, et al. Development and pilot testing of a decision aid for postmenopausal women with osteoporosis. *Patient Educ Couns*. 2002;47:245–55.
46. Man-Son-Hing M, Laupacis A, O'Connor AM, et al. A patient decision aid regarding antithrombotic therapy for stroke prevention in atrial fibrillation: a randomized controlled trial. *J Am Med Assoc*. 1999;282:737–43.
47. Stacey D, DeGrasse C, Johnston L. Addressing the support needs of women at high risk for breast cancer: evidence-based care by advanced practice nurses. *Oncol Nurs Forum*. 2002;29:E77–84.
48. Sawka CA, Goel V, Mahut CA, et al. Development of a patient decision aid for choice of surgical treatment for breast cancer. *Health Expect*. 1998;1:23–36.
49. O'Connor AM, Tugwell P, Wells GA, et al. A decision aid for women considering hormone therapy after menopause: decision support framework and evaluation. *Patient Educ Couns*. 1998;33:267–79.
50. O'Connor AM, Tugwell P, Wells GA, et al. Randomized trial of a portable, self-administered decision aid for postmenopausal

- women considering long-term preventive hormone therapy. *Med Decis Making*. 1998;18:295–303.
51. Trivers KF, Baldwin LM, Miller JW, et al. Reported referral for genetic counseling or *BRCA 1/2* testing among United States physicians: a vignette-based study. *Cancer*. 2011;117:5334–43.
52. Meyer LA, Anderson ME, Lacour RA, et al. Evaluating women with ovarian cancer for *BRCA1* and *BRCA2* mutations: missed opportunities. *Obstet Gynecol*. 2010;115:945–52.
53. Vadaparampil ST, Quinn GP, Miree CA, et al. Recall of and reactions to a surgeon referral letter for *BRCA* genetic counseling among high-risk breast cancer patients. *Ann Surg Oncol*. 2009;16:1973–81.
54. O'Neill SM, Peters JA, Vogel VG, et al. Referral to cancer genetic counseling: are there stages of readiness? *Am J Med Genet C Semin Med Genet*. 2006;142C:221–31.
55. Levy DE, Byfield SD, Comstock CB, et al. Underutilization of *BRCA1/2* testing to guide breast cancer treatment: black and Hispanic women particularly at risk. *Genet Med*. 2011;13:349–55.
56. Clarke A, Parsons E, Williams A. Outcomes and process in genetic counselling. *Clin Genet*. 1996;50:462–9.
57. Bowen DJ, Burke W, McTiernan A, et al. Breast cancer risk counseling improves women's functioning. *Patient Educ Couns*. 2004;53:79–86.
58. Meiser B, Halliday JL. What is the impact of genetic counselling in women at increased risk of developing hereditary breast cancer? A meta-analytic review. *Soc Sci Med*. 2002;54:1463–70.
59. Bellcross CA, Kolor K, Goddard KA, et al. Awareness and utilization of *BRCA1/2* testing among U.S. primary care physicians. *Am J Prev Med*. 2011;40:61–6.