HHS Public Access

Author manuscript

Breast J. Author manuscript; available in PMC 2015 October 13.

Published in final edited form as:

Breast J. 2011 ; 17(1): 79–82. doi:10.1111/j.1524-4741.2010.01027.x.

Satisfaction with Physician Recommendation for and Information About Genetic Counseling Among Breast Cancer Patients

Susan T. Vadaparampil, PhD, MPH, **Gwendolyn P. Quinn, PhD**, **Ji-Hyun Lee, DrPH**, **Teri Malo, MPH**, **Xiuhua Zhao, MS**, **Cheryl Miree, MS**, and **Jennifer Brzosowicz, MS, CGC**

Moffitt Cancer Center, Tampa, Florida

Abstract

To evaluate satisfaction with (a) the timing and strength of provider recommendation for and (b) information received prior to and during genetic counseling (GC) among breast cancer patients who attended GC before definitive surgery (BDS) or after definitive surgery (ADS). Satisfaction with provider recommendation for and information received about GC was evaluated among breast cancer patients who attended GC as part of their clinical care (n = 51). There were no significant differences among breast cancer patients who attended GC BDS or ADS in satisfaction with when the physician referred them for GC, the strength of recommendation for GC, the amount of information provided about the GC, and the information received in GC. From a clinical perspective, the optimal time for attending GC may be BDS. Nevertheless, breast cancer patients appear satisfied with physician recommendation of and information related to GC, regardless of when they attend.

Keywords

BRCA; breast cancer; genetic counseling; satisfaction

In the 10 years postdiagnosis breast cancer patients with a *BRCA1* or *BRCA2* (*BRCA*) mutation are at increased risk of contralateral breast cancer (~30%) compared to women without a *BRCA* mutation (~10%) (1). Additionally, patients with *BRCA* mutation have a 7–13% chance of developing ovarian cancer within 10 years after diagnosis (2). There is considerable evidence supporting the efficacy of prophylactic surgery (3) and chemopreventive agents (4) in reducing the risk of new primary breast cancers in mutation carriers. Thus, the breast oncology care setting represents an opportunity to identify and inform patients at increased risk for hereditary breast and ovarian cancer (HBOC) (e.g., women with early onset breast cancer, significant family history of breast and/or ovarian cancer [5]).

Genetic counseling (GC) provides patients with a detailed risk assessment for hereditary cancer, education and counseling about HBOC, and the advantages and disadvantages of

Address correspondence and reprint requests to: Susan T. Vadaparampil, PhD, MPH, 12902 Magnolia Drive, MRC-CANCONT, Tampa, FL 33612, USA, or susan.vadaparampil@moffitt.org..

genetic testing (GT). Despite standard referral criteria on personal and family cancer history (5), integrating risk appropriate referrals for and utilization of GC into breast oncology care is an ongoing challenge with tremendous variability in when women are identified, referred, and, attend GC (6).

Genetic counseling can be an important source of information for recently diagnosed breast cancer patients at increased risk for HBOC across multiple points in the breast cancer diagnosis, treatment, and survivorship continuum. GC before definitive surgery (BDS) can be useful in treatment planning and decision making (6). For patients after definitive surgery (ADS), the focus of information shifts to prevent future malignancies and risk to family members (6).

Uptake of GC among recently diagnosed breast cancer patients is strongly influenced by provider recommendation (7); however, there is no information about whether patient satisfaction with the timing of provider recommendation, the strength of the recommendation or information received prior to or during GC, varies based on whether GC occurred prior to or ADS. Women attending GC ADS may feel that if a provider recommended GC earlier or more strongly, they may have selected a different treatment option (8). Conversely, those attending BDS may have felt overwhelmed with the information given during GC and felt they should have been referred once their treatment was complete (9). Additionally, some women may have chosen to attend at a different time if they had been provided with additional information about GC. Finally, recently diagnosed breast cancer patients may desire emphasis on information that generally is not the main focus of a traditional GC session (e.g., counseling that is more tailored to the current breast cancer diagnosis, treatment, and/or follow-up) (6). This pilot study evaluated satisfaction with (1) the timing and strength of provider recommendation for and (2) information received prior to and during GC among breast cancer patients who attended GC BDS or ADS.

METHODS

Recruitment

Patients who attended *BRCA* GC BDS or ADS between 2003 and 2005 were identified using the Moffitt Cancer Center Genetic Counseling and Testing Service's clinical database. Eligibility criteria included women who: (a) were ≥18 years of age; (b) had no documented or observable psychiatric or neurological disorders that would interfere with study participation; (c) were capable of speaking and reading standard English; (d) underwent GC ≤2 years following their diagnosis of breast cancer; (e) had no history of cancer other than breast cancer, ovarian cancer, or basal cell skin carcinoma; (f) had a mailing address and working telephone number; and (g) provided written informed consent. Patients were classified as: (a) BDS (i.e., those who attended GC prior to completing definitive surgical treatment for their current breast cancer diagnosis) or (b) after definitive (i.e., those who completed definitive surgical treatment for their current breast cancer and underwent GC ≤2 years following their diagnosis of breast cancer). Eligible patients were mailed a study packet including a cover letter, consent form, questionnaire, and a postage paid envelope. Women who did not opt out via a toll-free number provided in the letter were given a

follow-up call by study coordinator. All patients were given a $25.00 honorarium upon completion of the study.

Sociodemographic characteristics assessed via self-report questionnaire included: race, age, marital status, and education. Clinical variables assessed via chart review were: cancer stage, subsequent *BRCA* testing, and first-degree relative with breast or ovarian cancer. Satisfaction with physician recommendation for GC was explored with two items that asked about timing and the strength of the recommendation for GC. Patients' satisfaction with information they received was assessed with two items that asked how satisfied they were with the information they received prior to attending GC and during GC. Participants were asked to respond to these items on a 4-point Likert scale.

Data Analysis

Analyses were performed with SPSS v. 17.0 using two-tailed tests of significance. Univariate analysis was used to compare those who attended GC before and ADS based on sociodemographic, clinical, and satisfaction variables. Chi-squared tests were conducted to examine differences in satisfaction between those who attended GC prior to and after definitive treatment. Due to high levels of satisfaction, participants who reported that they were "very satisfied" were compared to participants who reported another level of satisfaction.

RESULTS

Of the 106 potential participants mailed a study packet, 26 could not be reached and one had moved out of the country. Among the remaining 79 participants, 51 participated in the study (65% response rate). Of the 51 patients, 25 attended GC BDS surgery and 26 attended ADS. The majority were White, married, aged 40–49, possessed some college or technical school education, employed, had stage 2 breast cancer, subsequently had GT, and did not have a first-degree relative with breast or ovarian cancer (Table 1).

There were no statistically significant differences in satisfaction between those who attended GC prior to or after definitive treatment based on sociodemographic and clinical variables, or satisfaction with: timing of physician referral for GC, strength of recommendation for GC, amount of information provided about the GC and testing process, and the information received during GC (Table 2).

DISCUSSION

Overall, satisfaction with respect to both timing and strength of provider recommendation and information prior to and during GC was high. Although these specific issues have not been addressed in prior research, previous studies of breast cancer patients who attend GC show overall high levels of satisfaction in various domains (10). Women in our study who attended GC BDS did not differ with regard to satisfaction with timing and strength of physician recommendation for and information about GC compared to those who attended ADS.

This finding suggests factors beyond provider recommendation and information may impact when a breast cancer patient opts to attend GC. One possible explanation for the lack of differences may relate to patients' perceived emotional status near the time of a breast cancer diagnosis. A qualitative study of 26 breast cancer patients referred for GC at our institution showed that many patients felt emotionally overwhelmed, prompting them to delay GC (8). In a study of 102 Dutch breast cancer patients who declined *BRCA* testing, 19% felt GC should have been suggested at a later time point due to feeling overwhelmed by their current diagnosis and treatment (9). Another possible explanation is based on a qualitative study of nine patients from our institution suggesting that recently diagnosed breast cancer patients may not be fully informed about the purpose and implications of GC and/or testing for treatment. The majority were unaware that referral prior to definitive surgery for their breast cancer diagnosis may have allowed them to make different treatment choices (11). High satisfaction may reflect low knowledge about the implications of GC and/or testing for treatment decisions.

The limitations of our study include possible recall bias due to the retrospective study design. While, satisfaction studies can only take place once the service has occurred, women in our study completed GC between 2003 and 2005, but were not recruited until 2007. There may have also been an interaction between satisfaction with provider recommendation and GT result. However, GT results are not included in the medical record, limiting our ability to explore this issue. The participant pool was limited to patients at an institution following National Comprehensive Cancer Network Criteria guidelines for referral to a genetics professional (5), and may not be generalizable to patients receiving care in a setting not using these guidelines. Finally, the sample was homogenous with regard to race and ethnicity.

CONCLUSION

From a clinical perspective, the optimal time for attending GC may be prior to definitive surgical treatment. Yet, breast cancer patients appear satisfied with physician recommendation of and information related to GC, regardless of when they attended. However, this pilot study underscores the need for larger scale studies to ensure that high levels of satisfaction are based on an understanding of the implications of GC for treatment decision making and risk reduction.

Acknowledgments

This research was conducted with funding from the American Cancer Society (MRSG CPPB-111062). The work contained within this publication was supported in part by the Survey Methods Core Facility at Moffitt Cancer Center.

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Table 1

Demographic and Clinical Variables of Study Participants (%)

	BDS (*n* = 25)	ADS (*n* = 26)	Total (*n* = 51)
Race			
African-American	2 (8.0)	1 (3.8)	3 (5.9)
White	23 (92.0)	25 (96.2)	48 (94.1)
Marital status			
Single/divorced/widowed	9 (36.0)	4 (15.4)	13 (25.5)
Married	16 (64.0)	22 (84.6)	38 (74.5)
Age at diagnosis			
<40	8 (32.0)	3 (11.5)	11 (21.6)
40–49	11 (44.0)	12 (46.2)	23 (45.1)
50+	6 (24.0)	11 (42.3)	17 (33.3)
Education			
High school	4 (16.0)	2 (7.7)	6 (11.8)
Some college/technical school	10 (40.0)	14 (53.9)	24 (47.1)
>College	11 (44.0)	10 (38.4)	21 (41.1)
Employment status			
Not employed	9 (36.0)	8 (30.8)	17 (33.3)
Full/part-time employed	12 (48.0)	13 (50.0)	25 (49.0)
Other	4 (16.0)	5 (19.2)	9 (17.7)
Stage			
Ductal carcinoma in situ	4 (16.0)	5 (19.2)	9 (17.6)
Stage 1	3 (12.0)	1 (3.8)	4 (7.8)
Stage 2	10 (40.0)	13 (50.0)	23 (45.1)
Stage 3	8 (32.0)	7 (26.9)	15 (29.4)
Subsequently had GT			
Yes	21 (84.0)	17 (65.3)	38 (74.5)
No	3 (12.0)	6 (23.1)	9 (17.6)
Unknown	1 (4.0)	3 (11.5)	4 (7.3)
FDR has breast or ovarian cancer			
Yes	9 (36.0)	6 (23.1)	15 (29.4)
No	16 (64.0)	20 (76.9)	36 (70.6)

BDS, before definitive surgery; ADS, after definitive surgery.

Table 2

Satisfaction Related to GC by Timing of GC Groups (n = 51)

	BDS, *n* (%)	ADS, *n* (%)	Total, *n* (%)	p*
Physician recommendation				
Timing				
Very dissatisfied	2 (8.0)	2 (8.3)	4 (8.2)	0.94
Dissatisfied	2 (8.0)	0 (0.0)	2 (4.1)	
Satisfied	2 (8.0)	4 (16.7)	6 (12.2)	
Very satisfied	19 (76.0)	18 (75.0)	37 (75.5)	
Strength of recommendation				
Very dissatisfied	1 (4.3)	2 (8.3)	3 (6.4)	0.59
Dissatisfied	2 (8.7)	2 (8.3)	4 (8.5)	
Satisfied	3 (13.0)	4 (16.7)	7 (14.9)	
Very satisfied	17 (73.9)	16 (66.7)	33 (70.2)	
Information				
Prior to genetic counseling				
Very dissatisfied	0 (0.0)	0 (0.0)	0 (0.0)	0.37
Dissatisfied	3 (13.0)	1 (3.8)	4 (8.2)	
Satisfied	5 (21.7)	5 (19.2)	10 (20.4)	
Very satisfied	15 (65.2)	20 (76.9)	35 (71.4)	
During genetic counseling				
Very dissatisfied	0 (0.0)	1 (3.8)	1 (2.0)	0.59
Dissatisfied	1 (4.0)	0 (0.0)	1 (2.0)	
Satisfied	5 (20.0)	7 (26.9)	12 (23.5)	
Very satisfied	19 (76.0)	18 (69.2)	37 (72.5)	

* p-values are testing “very satisfied” versus all other levels of satisfaction, using Pearson’s chi-squared tests.

BDS, before definitive surgery; ADS, after definitive surgery.