Cancer Surveillance Behaviors in Women Presenting for Clinical *BRCA* Genetic Susceptibility Testing

Lois J. Loescher, PhD, RN, Kyung Hee Lim, PhD, RN, Ofri Leitner, MS, CGC, Jessica Ray, MS, CGC, Joyce D'Souza, RN, MSN, and Cary M. Armstrong, MS, CGC

People at risk for hereditary breast and ovarian cancer (HBOC) may consider having clinical *BRCA* cancer susceptibility testing to further elucidate their risk. They also may receive cancer surveillance recommendations from healthcare providers, yet little is known about their choices of surveillance behaviors. This study explored cancer surveillance behaviors in women at risk for HBOC who presented for clinical *BRCA* testing (i.e., commercial testing not provided as part of a research study). Specific aims were to (a) describe self-reported cancer surveillance behaviors and reasons for not engaging in behaviors, (b) compare surveillance behaviors with existing surveillance guidelines for high-risk individuals, and (c) evaluate associations of cancer surveillance behaviors with *BRCA* results.

Hereditary Breast and Ovarian Cancer

In the United States, 10% of patients with breast or ovarian cancer have HBOC (Lynch & Lynch, 1991) and 80%–90% of HBOC is attributed to mutations in the *BRCA1* or *BRCA2* cancer susceptibility genes (Thull & Vogel, 2004). *BRCA* mutation carriers have approximate lifetime risks of 50%–85% for breast cancer and 11%–65% for ovarian cancer (Easton et al., 2004; King, Marks, & Mandell, 2003). Mutation carriers diagnosed with breast cancer have a lifetime risk of developing contralateral breast cancer that is 53%–64% versus less than 2% risk in noncarriers (Lynch & Lynch; Rogozinska-Szczepka et al., 2004). Risk factors for HBOC include early-age onset of breast cancer; family history of breast cancer and ovarian cancer, particularly in first-degree or second-degree

Purpose/Objectives: To investigate cancer surveillance behaviors of women at risk for hereditary breast and ovarian cancer (HBOC) who presented for clinical *BRCA* cancer susceptibility testing, specifically to describe cancer surveillance behaviors and reasons for not engaging in behaviors, compare surveillance behaviors with existing surveillance guidelines, and evaluate associations of cancer surveillance behaviors with *BRCA* results.

Design: Cross-sectional, descriptive.

Setting: Genetic risk-assessment programs in a National Cancer Institute-designated comprehensive cancer center and a community cancer center, both in the southwestern region of the United States.

Sample: Purposive sample of 107 at-risk women.

Methods: Self-report survey.

Main Research Variables: Breast and ovarian cancer surveillance behaviors and *BRCA* test results.

Findings: Ninety percent of participants had a personal history of breast cancer; 84% had a negative *BRCA* result. About 60% of participants engaged in at least the minimum recommended breast cancer surveillance behaviors, but 70% had suboptimal ovarian cancer surveillance behaviors. Lack of physician recommendation was the most frequently reported reason for not having surveillance procedures. *BRCA* results were not associated with the breast cancer surveillance categories and the ovarian cancer surveillance recommendations.

Conclusions: Although most participants were not carriers of a mutation, the presence of other risk factors for breast and ovarian cancer dictates continued cancer surveillance. At-risk women may not be informed adequately about cancer surveillance.

Implications for Nursing: Healthcare providers should be aware of changing breast and ovarian cancer surveillance recommendations and counsel their at-risk patients accordingly.

relatives; evidence of disproportionately more multiple primary cancers; presence of a *BRCA* mutation in the family; or Ashkenazi Jewish ancestry (Frank et al., 2002; National Comprehensive Cancer Network [NCCN], 2007). Despite the high percentage of HBOC that is attributed to *BRCA* mutations, those cases account for less than 5% of all breast cancers, suggesting the existence of other breast cancer susceptibility genes (Oldenburg, Meijers-Heijboer, Cornelisse, & Devilee, 2007). *BRCA* mutations account for almost all ovarian cancers found in families with clusters of multiple breast and ovarian cancers (Gayther et al., 1999); however, mutations in other genes are implicated in a smaller percentage of ovarian cancers (Watson et al., 2001). Thus, people in families at risk for HBOC likely will be tested for *BRCA* mutations first.

BRCA Genetic Predisposition Testing

Professional organizations once endorsed limiting *BRCA* testing to a research setting (American Society of Clinical Oncology [ASCO], 1996; American Society of Human Genetics, 1994). However, guidelines have been revised and provide indications for which genetic counseling and genetic testing should be considered (ASCO, 2003). In the United States, full DNA sequencing of both the *BRCA1* and *BRCA2* genes is available commercially only through Myriad Genetics Laboratories, Inc.

BRCA testing provides a way to further evaluate risk of HBOC and an opportunity to begin cancer surveillance earlier in life (Burke, 2002). *BRCA* testing may identify presence of mutations (positive result; does not rule out contributions of other, untested susceptibility genes), show an absence of mutations (negative result; suggests involvement of other breast cancer susceptibility genes or absence of genetic predisposition, that is, sporadic cancer), or be inconclusive (gene variants of uncertain clinical significance that either have not been identified previously or have an unknown causal link to cancer) (Myriad Genetics Laboratories, Inc., 2007). A mutation cannot predict with certainty future breast or ovarian cancer; cancer may not occur because of incomplete penetrance or variable expressivity of the genes (Petrucelli, Daly, Bars Culver, Levy-Lahad, & Feldman, 2005).

Cancer Surveillance Strategies

Increased chances of cancer in people at risk for HBOC underscore the importance of cancer surveillance in that population (Scheuer et al., 2002). In general, intensive screening is warranted for *BRCA* mutation carriers and at-risk individuals younger than 40 years (Ghosh, Hartmann, & Brandt, 2004). The screening benefits (e.g., decreased mortality) of breast self-examination (BSE) and clinical breast examination (CBE) are not proven, even though a palpable breast mass heralds about 60% of all breast cancers (Kuschel, Lux, Goecke, & Beckmann, 2000). Mammography sensitivity in at-risk individuals is 33%–40%; however, mammography is problematic for younger people because of breast density and concern about cumulative radiation exposure (Andrieu et al., 2006; Gundry, 2005). Digital mammography in asymptomatic women was found to be significantly better at detecting breast cancer in women younger than 50 years, women with dense breasts, and women who were pre- or perimenopausal (Pisano et al., 2005). Another study of at-risk women who had CBE every six months and a yearly mammogram showed that those surveillance measures were less favorable with respect to tumor stage and sensitivity (overall 74%) in *BRCA* mutation carriers and in women younger than 40 years (Brekelmans et al., 2001). Breast ultrasound (BUS) rarely is used alone as a screening procedure, but it improves the specificity of mammography by characterizing suspicious breast masses (Madjar, Rickard, Jellins, & Otto, 1999). In at-risk women, particularly *BRCA* mutation carriers, magnetic resonance imaging (MRI) has higher sensitivity than mammography for detection of breast cancer but has lower specificity (Gundry). Observational data suggest that MRI can identify breast cancer in people with a family history (Saslow et al., 2007). Some investigators have proposed that MRI and mammography be staggered at six-month intervals for carriers of a *BRCA* mutation (Esserman & Hylton, 2005). Nevertheless, MRI as a screening tool for at-risk women requires further validation in larger clinical trials before definitive recommendations can be made (Saslow et al.).

Combining cancer surveillance modalities holds promise for women at risk for HBOC. A study of the use of MRI, BUS, mammography, and CBE in carriers of a *BRCA* mutation showed that the sensitivity and specificity of the procedures were 77% and 95% for MRI, 36% and 99.8% for mammography, 33% and 96% for BUS, and 9% and 99% for CBE, respectively. Combining all four screening modalities had a sensitivity of 95% versus 45% for combining only mammography and CBE (Warner et al., 2004).

Surveillance procedures for women at risk for ovarian cancer include pelvic examination, transvaginal ultrasound (TVUS), and testing with the serum marker CA125. Minimal evidence exists that those procedures detect ovarian cancer early. For example, the usefulness of pelvic examination depends on the examiner's skill performing a bimanual examination (Kuschel et al., 2000). TVUS has an estimated sensitivity of 80%–90% but also has a high false-positive rate (Kuschel et al.). Using thresholds of 30 U/ml or 35 U/ml, the sensitivity of CA125 testing followed by TVUS is 50% in at-risk women (U.S. Preventive Services Task Force, 2004). To date, no evidence shows that any of those

screening procedures reduces ovarian cancer mortality; however, some authors have suggested that people at risk for HBOC should have a pelvic examination, TVUS, and CA125 testing every 6–12 months (Sifri, Gangadharappa, & Acheson, 2004).

Cancer Surveillance Recommendations

Many professional organizations have published surveillance recommendations for people at high risk of breast or ovarian cancer. The recommendations are based on expert opinion and consensus or are evidence based (Saslow et al., 2007), yet they exhibit some inconsistency in their definitions of higher-than-average risk and in the types and frequencies of surveillance measures. The recommendations have several distinctions (see Table 1). For example, the American Cancer Society ([ACS], 2006b) recommends that asymptomatic people at higher risk of breast cancer (including those with past breast cancer) may benefit from surveillance strategies modified from those offered to people at average risk. In the wake of recent information regarding breast MRI screening for high-risk groups, the ACS added an evidence-based guideline for breast screening with MRI as an adjunct to mammography (Saslow et al.). The Cancer Genetics Study Consortium (CGSC) surveillance recommendations specifically target people with a *BRCA* mutation (Burke et al., 1997). The age groups in the CGSC recommendations reflect data from affected families showing that elevated breast cancer risk begins in the late 20s or early 30s. The NCCN algorithm builds on the ASCO and CGSC recommendations, but the NCCN (2007) specifically categorizes high-risk surveillance behaviors by cancer history, family history, or genetic predisposition.

Whether sufficient evidence exists to justify all of the strategies for at-risk women is a topic of debate (Saslow et al., 2007; Smith et al., 2003). Nevertheless, people with positive *BRCA* test results should be informed of the limited or equivocal evidence for cancer surveillance strategies. Likewise, their individual preferences should be taken into account in decisions for follow-up (Burke et al., 1997). Interpretation of negative *BRCA* test results and subsequent surveillance recommendations must take into account personal history of cancer as well as family history of cancers. When genetic testing is negative but an individual being tested has never had cancer, the risk of developing cancer and subsequent screening recommendations are based on family history. Whenever possible, genetic testing should be carried out on an index patient, a person who has been diagnosed with breast or ovarian cancer. When an index patient has a negative *BRCA* test result, recommendations are that mutation analysis be carried out on another affected relative because the index case may be a phenocopy (a phenotype that resembles the phenotype caused by a mutation). Phenocopies may be attributed to a variety of factors, including chance, environmental effects, another mutation in the family, or other modifier genes (Smith et al., 2007). Smith et al. (2007) showed that the breast cancer risk of a female first-degree relative of a carrier of a *BRCA* mutation who tests negative is 6.4% by age 50, compared with 2% in the general population. The authors contended that risk of cancer in women testing negative is sufficiently high to warrant mammogram surveillance initiated at age 35 years, according to the NCCN algorithms.

Inconclusive *BRCA* findings present a dilemma in regard to appropriate cancer surveillance recommendations (Dorval et al., 2005). For example, should women with an inconclusive or variant of uncertain significance test result, who still are at high risk by virtue of family history, undergo high-risk surveillance? Because of such issues, people at risk for HBOC may or may not choose to participate in clinical or self-screening activities (Kash, Holland, Halper, & Miller, 1992; Lerman et al., 1993, 1995; MacDonald, 2002). The current study sought to provide additional information about the surveillance behaviors practiced by women at high risk for HBOC and those who were presenting for clinical *BRCA* testing.

Materials and Methods

Study Design and Setting

This descriptive, cross-sectional study was conducted in two cancer genetic risk-assessment clinics: the Arizona Cancer Center (AZCC), a National Cancer Institute–designated comprehensive cancer center affiliated with the University of Arizona in Tucson; and the Virginia G. Piper Cancer Center (VGPCC), a community cancer center affiliated with Scottsdale Health Care in Arizona. Although no standardized method for cancer genetic counseling exists, genetic counselors at both institutions conducted risk assessment using similar formats.

Sample

The sample consisted of 107 women aged 18 years or older who were fluent in English reading and comprehension and were presenting for clinical *BRCA* testing for HBOC. The researchers restricted recruitment to women who had not previously had cancer genetic risk assessment and were having an initial counseling session at the AZCC or VGPCC between March 2004 and August 2006. Women were either self-referred for risk assessment and counseling or referred by their physicians. The women were either breast or ovarian cancer survivors or had no personal cancer history. Women with a history of breast cancer had to have at least one remaining breast and ovary (i.e., had not undergone risk-reducing surgery). Eligible participants met at least

Table 1. Recommendations for Breast and Ovarian Cancer Surveillance

Organization	BSE	CBE	Mammogram	BUS	Breast MRI	Pelvic Examination	TVUS	CA125
American Cancer Society								
• Asymptomatic person[a] (American Cancer Society, 2006b)	Explain risks and benefits; start prior to age 20.	More frequent; start prior to age 40.	Annually; start prior to age 40.	–	–	Not specified	Not specified	Not specified
• Women at increased risk[b] (Saslow et al., 2007)	–	Annually; start at age 30.	Annually; start at age 30.	Consider adding this procedure.	Annually; start at age 30.	–	–	–
American Society of Clinical Oncology (1996, 2003)	Monthly	Annually or semi-annually	Annually; start at age 25–30.	Not specified	Not specified	Not specified	Start at age 25–35.	Start at age 25–35.
Cancer Genetics Study Consortium (Burke et al., 1997)	Monthly; start in early adulthood.	Annually or semi-annually; start at age 25–35.	Annually; start at age 25–35.	Not specified	Not specified	Annually or semi-annually; start at age 25–35.	Annually or semi-annually; start at age 25–35.	Annually or semi-annually; start at age 25–35.
National Comprehensive Cancer Network (2007)	Encourage periodic BSE.	Every 6–12 months; start at age 25 for patients with HBOC and 5–10 years prior to youngest breast cancer case for strong family history or other genetic predisposition.	Annually; start at age 25 for patients with HBOC and 5–10 years prior to youngest breast cancer case for strong family history or other genetic predisposition.	Not specified	Annually; consider as adjunct to CBE and mammography.	Not specified	Not specified	Not specified

[a] The American Cancer Society (2006b) has recommended increasing frequency of these procedures in high-risk groups.

[b] For women meeting the following criteria: *BRCA* mutation carrier, or untested but with a first-degree relative who is a *BRCA* mutation carrier, or lifetime breast cancer risk at least 20%–25% defined by risk models that are largely dependent on family history

BSE—breast self-examination; BUS—breast ultrasound; CBE—clinical breast examination; HBOC—hereditary breast and ovarian cancer; MRI—magnetic resonance imaging; TVUS—transvaginal ultrasound

one of the following NCCN (2007) criteria for HBOC risk: (a) two or more first-degree relatives with cancer, (b) one first-degree and two or more second-degree relatives with cancer, (c) one or more family members diagnosed with cancer before age 50, (d) one or more family members with cancer in paired organs, (e) a male family member with breast cancer, or (f) Ashkenazi Jewish ancestry.

Procedure

Institutional review boards from both settings approved the study. At a woman's first genetic risk-assessment visit, the genetics professionals established eligibility of prospective participants and gave them a brochure that summarized the study. Women interested in participating were instructed to contact the investigators for more information. Upon doing so, women who agreed to participate were mailed consent forms and demographic questions to complete and return by mail. Participants signed two consent forms: one for the study and another that gave the genetics professionals permission to release participants' *BRCA* results to study personnel. Consent forms and demographic information were obtained before the participants received their *BRCA* test results, which usually occurred about one month later. Three months after participants

received their results, they received the surveillance behaviors survey to complete and return by mail. Based on the researchers' previous work, they determined that a three-month window provided participants with sufficient time to schedule or participate in recommended surveillance activities if they chose to do so (Ray, Loescher, & Brewer, 2005).

Measures

Demographic information and personal and family risk factors: Participants' characteristics were examined in terms of age, race, current marital status, education, household financial status, and occupation. The researchers identified specific risk factors for HBOC by tabulating which of the six eligibility criteria were met by each participant.

***BRCA* test results:** The researchers used the *BRCA* test results issued from Myriad Genetics Laboratories, Inc. The analytical sensitivity of full DNA sequencing of the *BRCA1* and *BRCA2* genes is estimated to be greater than 99%. For a patient with at least a 10% probability of a positive test based on a personal or family history of cancer, the chance of an incorrect test result is less than 1% (Myriad Genetics Laboratories, Inc., 2007).

Cancer surveillance behaviors: A self-report cancer surveillance survey used in a previous study (Ray et al., 2005) enabled the researchers to obtain information about the sample's breast and ovarian cancer surveillance activities. The surveillance behavior items in the original survey were derived from published recommendations for surveillance at the time and were agreed upon by a genetic counselor specializing in breast cancer risk, a nurse scientist with experience in cancer control, and a gynecologic oncologist (Ray et al.). The behaviors included BSE, mammography, BUS, CBE, pelvic examination, TVUS, and the CA125 blood test. For the current study, the researchers added breast MRI to reflect current recommendations. Queries about surveillance behaviors were structured as follows: When (date) did you last have a (mammogram, CBE, etc.)? What were the results of the (mammogram, CBE, etc.)? If you have not had a (mammogram, CBE, etc.), please tell us why not. To capture frequency of BSE, the researchers asked participants how many times they had performed BSE in the past four months. For the other procedures, the researchers assessed whether those reported had occurred within a year of responding to the survey.

The researchers viewed the NCCN (2007) breast cancer screening algorithm for women presenting for *BRCA* analysis who, at the time of initial assessment, do not know if they carry a *BRCA* mutation. The algorithm takes into account strong family history, genetic predisposition, and age (younger or older than 25 years). Using the algorithm as a framework, the researchers agreed upon three categories of breast cancer surveillance behaviors: minimum recommended, suboptimal, and optimal. Minimum recommended behaviors were having had at least one mammogram and CBE within the past year. Suboptimal behaviors were not having had a mammogram and CBE within the past year, or having only a mammogram, or having only a CBE. Optimal behaviors were yearly mammogram and CBE plus periodic BSE, plus, for women with a family history, breast MRI.

To categorize ovarian cancer surveillance behaviors, the researchers used information from the American Cancer Society (2006a, 2006b) and agreed on two categories: minimum recommended and suboptimal. Minimum recommended behaviors were having had a pelvic examination within the previous year and a TVUS and a CA125 blood test. Suboptimal behaviors were not having any test or examination or having only a pelvic examination, only TVUS, or only a CA125 blood test.

Data Analysis

The researchers used descriptive statistics to assess characteristics of the sample and individual and total cancer surveillance behaviors. They grouped reasons for not engaging in behaviors into categories. Using the chi-square test, they assessed associations of cancer surveillance behaviors with sample characteristics and *BRCA* results. Significance levels were set at 0.05. Data were analyzed with SPSS® (version 14.0).

Results

Characteristics of the Sample

Of the 153 women eligible for the study, 34 (22%) declined to participate, and 120 (78%) were enrolled. Of those, 13 (11%) did not return the survey because they did not have time to complete it and subsequently were dropped from the study. No significant differences existed in demographic characteristics between the dropouts and women who completed the study, with the exception of financial status. More than 50% of the participants were financially comfortable (57%), but more than 50% of dropouts reported no debt but lived paycheck to paycheck (62%). The final sample consisted of 107 women, having a mean age of 53.6 years (SD = 11.97). Most were white, married or partnered, well-educated, professionally employed or retired, and financially comfortable. Table 2 lists additional information about the sample.

Risk Estimates and *BRCA* Test Results

A negative *BRCA* test result was reported for 84% of participants, 8% had a mutation or positive result, and 8% had an inconclusive *BRCA* test result.

Table 2. Characteristics of the Sample

Characteristic	n	%
Age (years)		
$\bar{X}$ = 55.8	–	–
SD = 12.0	–	–
Race		
Non-Hispanic white or European	102	95
Latino or African American	5	5
Marital status		
Married or partnered	83	78
Divorced, separated, or widowed	17	16
Never married	7	7
Education		
College or higher	81	76
Associate degree or technical school	19	18
High school or GED	7	7
Income[a]		
Financially comfortable	76	72
Paycheck to paycheck, no debt	15	14
Many debts or need financial help	14	13
Occupation		
Professional	52	49
Retired	25	23
Housewife	18	17
Technician	7	7
Unemployed or student	5	5
Diagnosis		
Breast cancer	90	84
Ovarian cancer	5	5
Breast and ovarian cancers	1	1
No cancer history	11	10
Family risk factors for hereditary breast or ovarian cancer[b]		
One or more family members diagnosed with cancer before age 50	71	66
One first-degree relative and two or more second-degree relatives with breast or ovarian cancer	63	59
Two or more first-degree relatives with breast or ovarian cancer	49	46
One or more family members with cancer in paired organs	47	44
Ashkenazi Jewish ancestry	18	17
At least one male family member with breast cancer	3	3

N = 107

[a] Data missing from two participants

[b] Participants could report more than one risk factor.

Note. Because of rounding, percentages may not total 100.

Reported Cancer Surveillance Behaviors

Table 3 illustrates each cancer surveillance behavior reported by the participants. More than 87% of participants reported at least a yearly CBE, mammogram, or pelvic examination. Table 4 lists the reasons participants reported for not engaging in breast or ovarian cancer surveillance procedures. Approximately 50% stated that they did not do so because their physicians did not recommend the procedures. Of note was the finding that some participants confused the CA125 blood test with the *BRCA* test.

Figure 1 shows categories of participants' cancer surveillance behaviors that reflected the NCCN and ACS recommendations for ovarian cancer screening. Most participants performed the minimum recommended or optimal breast cancer surveillance behaviors (84%), but ovarian cancer surveillance behaviors were suboptimal (73%).

Association of Surveillance Behaviors With Sample Characteristics and *BRCA* Results

No significant associations were found between breast and ovarian cancer surveillance behaviors and sample characteristics of race, marital status, education, or income. No associations of *BRCA* results were found between the breast cancer surveillance categories derived from the NCCN algorithm (χ^2 =4.26, p = 0.37) and the ovarian cancer surveillance categories derived from ACS recommendations (χ^2 = 2.10, p = 0.35).

Discussion

The main findings of this study were that women in the sample, at risk for HBOC and having clinical *BRCA* testing, reported participating in at least the minimal breast cancer surveillance behaviors recommended by the NCCN. The women also reported ovarian cancer surveillance behaviors that were considered suboptimal based on ACS recommendations. No associations were found between *BRCA* test results and surveillance behaviors.

Characteristics of the Sample

More than 90% of the participants had a personal history of breast or ovarian cancer; thus, the findings cannot be generalized to women without a personal history. Ideally, people with cancer should have *BRCA* testing before unaffected family members; however, the current study did not ask participants whether they were the index cases being tested in their families (Burke, 2002; Sifri et al., 2004). Despite the high percentage of risk factors for HBOC, most participants (84%) had a negative *BRCA* test result, higher than the 62%–69% negative result rate found in other studies of high-risk women (Schwartz et al., 2002; Weitzel et al., 2003) but congruent with the fact that most results of *BRCA* testing are negative (Couch et al., 1997). Similar to other reports (Couch et al.; Weitzel et al.), *BRCA* mutations were identified in about 8% of the current sample. Another 8% had inconclusive *BRCA* test results, which were at the low end of the 9%–77% reported by others (Schwartz et al.; Weitzel et al.). The sociodemographic characteristics of the sample mirrored those found in other studies of HBOC and further limit the current findings to women who are non-Hispanic white, are partnered, are well-educated, have health insurance coverage, and can afford *BRCA* testing.

Table 3. Reported Breast and Ovarian Cancer Surveillance Behaviors

Behavior	n	%
Number of breast self-examinations during the past four months		
Fewer than four	54	51
Four or more	53	49
Clinical breast examination at least yearly		
Yes	99	93
No	8	7
Mammogram at least yearly		
Yes	94	88
No	13	12
Breast ultrasound		
Yes	85	79
No	22	21
Breast magnetic resonance imaging		
Yes	47	44
No	60	56
Pelvic examination		
Yes	104	97
No	3	3
Transvaginal ultrasound		
Yes	49	46
No	58	54
CA125 blood test[a]		
Yes	50	47
No	56	53

N = 107

[a] Data missing from one participant

Cancer Surveillance Behaviors

Most participants had a strong family history of cancer; subsequently, the researchers viewed the NCCN algorithm as an appropriate framework for assessing cancer surveillance behaviors. Use of the framework is a strength of the study in that other similar investigations (Braithwaite, Emery, Walter, Prevost, & Sutton, 2006; Claes et al., 2005; Emmons et al., 2000; McInerney-Leo et al., 2006) were devoid of such a framework. The current study also included assessment of BUS, breast MRI, and ovarian cancer screening, which have been under-reported in studies of women presenting for *BRCA* testing, yet some are present in existing surveillance guidelines.

Most women engaged in minimum recommended or optimal breast cancer surveillance behaviors according to categorization by the NCCN algorithm. This finding could reflect the fact that most of the sample had a history of breast cancer and likely had routine follow-up care. However, given that most were noncarriers of a *BRCA* mutation, their overall participation in surveillance behaviors was as much as threefold higher than that reported by others (Claes et al., 2005), indicating that some at-risk women are motivated to participate in surveillance, regardless of *BRCA* mutation status.

Similar to other studies (Emmons et al., 2000), half of the current sample reported performing BSE approximately once a month, but higher percentages were reported by MacDonald, Sarna, Uman, Grant, and Weitzel (2006) in their study of cancer screening behaviors in women seeking cancer genetic risk assessment and by Botkin et al. (2003), who found higher sustained levels of BSE in *BRCA1* mutation carriers and noncarriers. BSE findings are difficult to interpret. BSE is not advocated for average-risk women because insufficient clinical data link BSE to decreased mortality or increased rates of breast preservation (Smith et al., 2003). Whether this is the case for at-risk women, including those presenting for *BRCA* testing, remains unclear, owing to lack of large-scale randomized, controlled trials looking at the same endpoints. Almost all of the current participants were vigilant with mammography and CBE, and most had undergone BUS as an adjunct to screening; all percentages were higher than those reported in other studies of women with a strong family history of breast cancer (Emmons et al., 2000; Isaacs et al., 2002; MacDonald et al., 2006; Madlensky et al., 2005) or those undergoing genetic testing (Botkin et al.; Lerman et al., 2000). Most participants had not had a breast MRI, but at the time of data collection for this study, the position on breast MRI for cancer surveillance was less clear. Clinicians caring for women at risk for HBOC should be cognizant of current research findings on breast MRI and strongly weigh the benefits of that screening option for younger at-risk women (Wood, 2004).

Almost three-quarters of the participants reported suboptimal ovarian cancer surveillance behaviors based on ACS recommendations, with the remainder reporting the minimum surveillance behaviors. The unavailability of reliable screening measurements for ovarian cancer makes it difficult to ascertain whether any level of participants' surveillance behaviors was adequate. Given that 50% of women with ovarian cancer do not receive recommendations about symptom surveillance from healthcare providers (Donovan, Hartenbach, & Method, 2005), the current researchers were not surprised that most at-risk women in the study did not receive ovarian cancer surveillance recommendations. Additionally, most of the participants had a negative *BRCA* test result. A prospective study of *BRCA*-negative HBOC families showed that their risk of ovarian cancer is low; those investigators suggested that ovarian cancer risk-reduction strategies might need to be modified for women who test negative (Kauff et al., 2005). All but three of the current participants had a pelvic examination, which is higher than the number reported by others (Emmons et al., 2000; McInerney-Leo et al., 2006), but even that procedure is not routinely advised as a cancer surveillance tool (American College of Preventive Medicine, 2005). Fewer than half of the women had CA125 testing; other investigators have reported similarly low percentages

Table 4. Participants' Self-Reported Reasons for Not Engaging in Breast or Ovarian Cancer Surveillance Procedures

Behavior	n	%
Breast self-examination (N = 24)		
Not recommended by physicians	18	75
Do not like this examination	2	8
Unfamiliar with procedure	1	4
Forgot	1	4
Prefer professional examination	1	4
Healing from breast reconstruction	1	4
Mammogram at least yearly (N = 4)		
Not recommended by physicians	4	100
Clinical breast examination at least yearly (N = 4)		
Not recommended by physicians	4	100
Breast ultrasound (N = 22)		
Not recommended by physicians	21	95
No indication of abnormal conditions to warrant procedure	1	5
Breast magnetic resonance imaging (N = 59)		
Not recommended by physicians	56	95
Unfamiliar with procedure	2	3
No indication of abnormal conditions to warrant procedure	1	2
Pelvic examination (N = 2)		
Unfamiliar with procedure	1	50
Dislike procedure	1	50
Transvaginal ultrasound (N = 54)		
Not recommended by physicians	42	78
Unfamiliar with procedure	4	7
Not sure	4	7
No indication of abnormal conditions to warrant procedure	3	6
Dislike procedure	1	2
CA125 blood test (N = 55)		
Not recommended by physicians	29	53
Had genetic testing instead	9	16
Not sure	9	16
No indication of abnormal conditions to warrant procedure	5	9
Unfamiliar with procedure	3	6

[a] Not all participants who did not engage in behaviors reported reasons.

Note. Because of rounding, not all percentages total 100.

(Botkin et al., 2003; Isaacs et al., 2002; Lerman et al., 2000; MacDonald et al., 2006; McInerney-Leo et al., 2006). The inability of some participants to discriminate between *BRCA* testing and CA125 testing makes it difficult to judge the validity of this finding. It does, however, reflect the need to fully explain to at-risk women the difference between the two tests. Twice as many women in the current sample reported having TVUS than has been reported in other studies of at-risk women (Botkin et al.; MacDonald et al.; McInerney-Leo et al.), possibly reflecting a tendency for women with both a family and personal cancer history to have TVUS.

More than half of the participants not reporting a specific breast or ovarian cancer surveillance behavior indicated that they did not engage in the behavior because their physicians did not recommend it. This phenomenon also has been reported in studies of colorectal cancer surveillance in high-risk groups (Kinney et al., 2007; Yusoff, Hoffman, & Ee, 2002). Because current surveillance recommendations vary, healthcare providers may be uncertain about which recommendations to use for their high-risk patients. Nevertheless, the availability of clinical *BRCA* testing increases healthcare providers' professional responsibility to recommend evidence-based clinical management strategies (Daly, 2004). As a prerequisite for *BRCA* testing, all of the current participants had received cancer genetic risk assessment and subsequent surveillance recommendations from a genetics professional, a procedure that is highly advised by professional groups (ASCO, 1996, 2003; American Society of Human Genetics, 1994; NCCN, 2007; U.S. Preventive Services Task Force, 2004). With the recent trend toward online genetic testing (e.g., via DNAdirect [2005]), testing may be done in the absence of comprehensive risk assessment and genetic counseling. This raises concern about the type and quality of cancer surveillance recommendations given to people electing online testing.

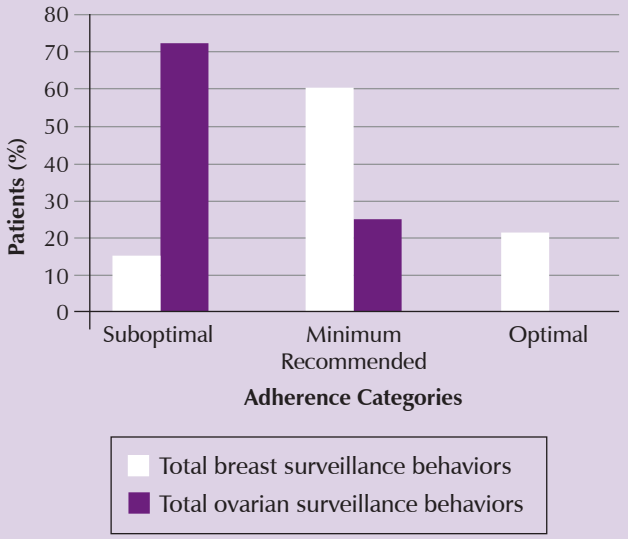
Limitations

Limitations of this study were the small sample size and lack of a comparison group. Participants were enrolled in the study prior to receiving *BRCA* results, and researchers did not anticipate the high percentage of negative results. The lack of statistical power to compare surveillance behaviors by test result is a limitation. Nevertheless, others have shown that *BRCA* test results do not necessarily predict cancer surveillance behavior (McInerney-Leo et al., 2006).

Implications

This study has several clinical and research implications. Women presenting for *BRCA* testing in a clinical setting may be at risk for HBOC, but each case is unique. Healthcare professionals should use existing evidence-based surveillance recommendations as a clinical framework for counseling, but they must choose the recommendations that best reflect a person's personal and family history of cancer and other risk factors for HBOC. This requires keeping current with recommendations that are updated on Web sites (e.g., NCCN) and published in other formats by professional organizations.

Prior to *BRCA* testing, healthcare professionals should query patients about current and past surveillance behaviors, including frequency and results of procedures. Of equal importance is patients' understanding of the procedures and their personal interpretation of the findings. This clarification is particularly important for more



Note. Adherence categories were derived from National Comprehensive Cancer Network (2007) breast cancer screening guidelines and American Cancer Society (2006a, 2006b) recommendations for ovarian cancer screening.

Figure 1. Categories of Breast and Ovarian Cancer Surveillance Behaviors
N = 107

controversial and less well-known procedures such as TVUS and CA125 testing. Surveillance behaviors in all women with strong risk factors for HBOC should be monitored carefully, regardless of *BRCA* test results. Such women could be at risk for mutations in other, as yet unknown, cancer susceptibility genes (Oldenburg et al., 2007).

The current findings provide descriptive information that can be used to generate and refine hypotheses for future studies of cancer surveillance behaviors in high-risk women. A need remains for more in-depth research on cancer surveillance behaviors in women with a diagnosis of breast cancer versus at-risk women without a history of cancer. To obtain the full spectrum of cancer surveillance behaviors of women undergoing *BRCA* genetic susceptibility testing, larger studies are required for analysis of behaviors according to test result. Most women have a negative test result; therefore, such research likely would require a collaborative, multicenter trial to yield sufficient numbers of participants with *BRCA*-positive or inconclusive test results. People with inconclusive findings are of particular interest because little information is available about provider recommendations to this group or their surveillance behaviors. As always, a great need exists to study these behaviors in less-advantaged socioeconomic groups that may not have access to surveillance procedures. The findings from the current study and future research will assist healthcare professionals in developing tailored cancer surveillance interventions for specific at-risk groups.

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Lois J. Loescher, PhD, RN, is an assistant professor in the College of Nursing at the University of Arizona and the Arizona Cancer Center, both in Tucson; Kyung Hee Lim, PhD, RN, is a postdoctoral fellow in the College of Nursing at the University of Arizona; Ofri Leitner, MS, CGC, is a genetic counselor at the Virginia G. Piper Cancer Center in Scottsdale, AZ; Jessica Ray, MS, CGC, is a genetic counselor at the Arizona Cancer Center; and Joyce D'Souza, RN, MSN, is a clinical nurse specialist and Cary M. Armstrong, MS, CGC, is a genetic counselor, both at the Virginia G. Piper Cancer Center. This research was supported, in part, by Phi Beta Psi local chapters (Sigma Kappa, Sigma Nu), the University of Arizona Foundation (Better Than Ever), National Institutes of Health (NIH)–National Institute of Nursing Research 1P20NR07794 (feasibility study), and NIH–National Cancer Institute 1K07CA106996. Loescher can be reached at loescher@nursing.arizona.edu, with copy to editor at ONFEditor@ons.org. (Submitted January 2008. Accepted for publication June 22, 2008.)

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