Cancer Screening and Risk-Reducing Behaviors of Women Seeking Genetic Cancer Risk Assessment for Breast and Ovarian Cancers

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Purpose/Objectives: To examine breast and ovarian cancer screening and risk-reducing behaviors of women seeking genetic cancer risk assessment (GCRA).

Design: Descriptive, cross-sectional.

Setting: An insurance-based clinic that serves high-risk patients in a southern California cancer center.

Sample: 134 women with breast or ovarian cancer (affected group) and 80 women with a family history of breast or ovarian cancer (unaffected group). The mean age of the sample was 48 years (range = 21–86), 79% were Caucasian, 66% were married, 60% were college educated, and 78% had children. Most affected women had early-stage disease. Unaffected women had a family history of breast (86%) or ovarian (14%) cancer.

Methods: Mailed surveys assessed pre-GCRA health behaviors and health and family histories.

Main Research Variables: Breast cancer screening (mammograms, clinical breast examination [CBE], breast self-examination), ovarian cancer screening (CA-125, pelvic ultrasound), and breast and ovarian cancer risk-reducing strategies (tamoxifen, bilateral mastectomy, oral contraceptive pills, bilateral salpingo-oophorectomy).

Findings: Twenty-one percent of the women who should have been having a mammogram had not had an annual examination as recommended, and 30% of affected women had not had annual CBEs. Few women took tamoxifen or oral contraceptive pills or had a bilateral salpingo-oophorectomy or bilateral mastectomy for cancer risk reduction. Twelve percent likely had unnecessary ovarian cancer screening. About 35% used other means, including herbs and homeopathy, for cancer prevention.

Conclusions: Nearly a third of the affected women had not had appropriate breast cancer screening. About 12% used unsubstantiated, potentially harmful cancer "prevention" measures (e.g., herbs).

Implications for Nursing: Nurses should assess clients' personal and family breast and ovarian cancer histories and promote cancer screening and risk-reducing behaviors that are appropriate for age and risk level.

Key Points . . .

- Genetic cancer risk assessment rapidly is becoming the standard of care for women with early-onset breast or ovarian cancer or a family history of these malignancies.
- Ensuring that women follow age- and risk-appropriate early-detection and risk-reducing strategies is crucial to minimizing cancer morbidity and mortality.
- Assessment of women's cancer screening and risk-reducing behaviors may help oncology nurses to identify areas for health promotion.

More than 211,000 U.S. women were diagnosed with breast cancer in 2005, and at least 40,400 women died as a result of the disease (Jemal et al., 2005). Ovarian cancer affected 22,220 women, with most cases found at a late stage, causing 16,210 deaths (Jemal et al.). Risk for breast and ovarian cancers varies widely in women with a personal or family history of the malignancies (Ziogas et al., 2000). Breast cancer risk for women with a single close relative who had the disease in her 70s is increased minimally above the general population's 2% risk by age 50 and 10% risk by age 80. However, the risk climbs to as high as 6% by age 50 and 21% by age 80 if the relative was affected in her 20s

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(Claus, Risch, & Thompson, 1994). Similarly, most women who have one or two close relatives with ovarian cancer have a 5%–10% risk for the disease, compared to a 1.6% general population risk. In striking contrast, however, 5%–10% of women have a very high risk for breast and ovarian cancers, most often attributed to an inherited mutation in the *BRCA1* or *BRCA2* gene (Easton, Bishop, Ford, Crockford, & the Breast Cancer Linkage Consortium, 1993). Breast cancer risk in this circumstance is about 30%–50% by age 50, escalating to as much as 87% by age 80 (Ford et al., 1998; Frank et al., 2002; Struewing et al., 1997), and the risk for a second primary breast cancer is 15%–60%, with the highest risk in younger women (Bernstein, Thompson, Risch, & Holford, 1992; Metcalfe et al., 2004; Robson et al., 2005). The associated risk for ovarian cancer ranges from 12%–54% (King, Marks, & Mandell, 2003). The incidence of *BRCA* mutations is higher (2.5%) in women of Ashkenazi (northern and central European) Jewish descent, as for most Jewish women in the United States (Struewing et al.).

Ensuring that women at increased cancer risk are following early-detection and risk-reducing strategies appropriate to their ages and risk levels is crucial to minimizing cancer morbidity and mortality. As such, genetic cancer risk assessment (GCRA) rapidly is becoming the standard of care for women with early-onset breast or ovarian cancer or a family history of these malignancies (American Society of Clinical Oncology, 2003; National Comprehensive Cancer Network, 2005). GCRA includes genetic counseling and education about cancer and genetics, genetic testing (as appropriate and desired), recommendations for risk-based cancer screening and risk-reducing options, psychosocial support, and discussion of healthcare implications for family members. Recognizing the value of GCRA, professional nursing organizations have published guidelines on the important role of nurses in GCRA, including assessment of cancer screening and risk-reducing behaviors (International Society of Nurses in Genetics, Inc., 1998; Oncology Nursing Society, 2004a, 2004b).

Breast and Ovarian Cancer Screening and Risk Reduction Strategies

National breast cancer screening guidelines include age and frequency recommendations for mammograms, clinical breast examination (CBE), and optional breast self-examination (BSE). Breast cancer risk reduction options for women at increased risk include the use of tamoxifen for five years (Fisher et al., 1998) and, for some, bilateral mastectomy or oophorectomy. For women who have had breast cancer, the standard of care includes annual CBEs and mammograms.

Screening for ovarian cancer is not recommended for women with average risk. Women at increased risk for the disease have options ranging from no screening to biannual CA-125 and pelvic ultrasounds to bilateral salpingo-oophorectomy with or without a hysterectomy; in fact, bilateral salpingo-oophorectomy is recommended for women with a *BRCA* mutation ("NIH Consensus Conference," 1995; SGO Committee, 2005). The American Cancer Society, National Comprehensive Cancer Network, National Cancer Institute, U.S. Preventive Services Task Force, and some disease-specific professional societies publish cancer prevention and screening guidelines regularly. Minor differences exist among the various guidelines, such as age to begin BSE; in addition, the National Cancer Institute and U.S Preventive Services Task Force omit the BSE recommendation. Aspects of the guidelines also have changed over time (National Comprehensive Cancer Network, 2005; Smith, Cokkinides, & Eyre, 2005). The American Cancer Society and National Comprehensive Cancer Network guidelines are displayed in Tables 1 and 2.

Strategies to reduce breast cancer risk include the use of tamoxifen and the removal of healthy breasts (Fisher et al., 1998; Narod et al., 2000; Rebbeck et al., 2004). Strategies to reduce ovarian cancer risk by 50%–96% include the use of oral contraceptive pills and bilateral salpingo-oophorectomy, which also may reduce breast cancer risk (Narod et al., 2002; Narod & Offit, 2005; Rebbeck, 2000; Schildkraut, Calingaert, Marchbanks, Moorman, & Rodriguez, 2002; SGO Committee, 2005).

Purpose

The purpose of the current study was to describe and compare the cancer screening and risk-reducing behaviors of women with a personal or family history of breast or ovarian cancer, prior to GCRA.

Conceptual Framework

The larger study from which this sample was drawn was grounded in Champion's (1993) adaptation of the Health Belief Model. Several studies, including a recent meta-analysis of 42 studies identifying that perceived risk was associated with mammogram screening and risk-reducing mastectomy, have found that the Health Belief Model construct of perceived susceptibility helps to predict early-detection and risk-reducing behaviors (Austin, Ahmad, McNally, & Stewart, 2002; Bosompra et al., 2000; Bunn, Bosompra, Ashikaga, Flynn, & Worden, 2002; Champion, 1987, 1993; Fishbein et al., 2001; Jacobs, 2002; Katapodi, Lee, Facione, & Dodd, 2004; McGarvey et al., 2003). MacDonald, Sarna, Uman, Grant, and Weitzel (2005) recently noted that women believed they were at increased risk for breast or ovarian cancer in the next 10 years. Consequently, they hypothesized that women who perceived themselves to be at risk would follow national cancer screening guidelines for breast cancer (BSE, CBE, mammogram) and might use measures to reduce cancer risk, and that women with a personal history of breast cancer would be more likely to engage in breast cancer screening than those without such a history. A family history of ovarian cancer was projected to influence screening for the disease and use of oral contraceptive pills or bilateral salpingo-oophorectomy for risk reduction.

Methods

Design

A prospective, comparative design was used to describe the pre-GCRA cancer screening practices and risk-reducing strategies of women who had a history of breast cancer (affected group) and women without the disease who had a family history of breast or ovarian cancer (unaffected group). Data were collected using a survey mailed in consecutive order to women when they scheduled a GCRA appointment. This report is part of a larger, longitudinal study investigating

Table 1. Previous Breast Cancer Screening and Risk Reduction Guidelines for Asymptomatic Women Who Have Not Had Breast Cancer (1997–1999)

Modality	Average Risk	Modest Family History	Suspected or Known Hereditary Risk	Issues
Annual mammogram	Begin at age 40.	Begin at age 40 or 10 years before earliest diagnosis.	Begin at age 25.	Breast density in young women may limit efficacy; magnetic resonance imaging or ultrasound may be used.
Annual clinical breast examination	Begin at age 40 (every three years for ages 20–39).	Begin at age 40 or 10 years before earliest diagnosis.	Begin at age 25; examination can be conducted semiannually.	None
Monthly breast self-examination	Begin at about age 20.	Begin at about age 20.	Begin at about age 25.	No proven benefit; the American Cancer Society changed this modality to optional in 2005.
Tamoxifen	Not applicable	Optional for women aged 35 or older with a five-year risk of 1.66% or more according to the Gail et al. (1989) model of breast cancer risk	Optional for women aged 35 or older with a five-year risk of 1.66% or more according to the Gail et al. (1989) model of breast cancer risk	Side effects include hot flashes, venous thrombosis, and uterine cancer risk.
Risk-reducing mastectomy	Not applicable	Not applicable	Optional, considered on an individual basis	Reconstruction, sexuality considerations, and small residual breast cancer risk

Note. Based on information from National Comprehensive Cancer Network, 2005; Smith, Cokkinides, et al., 2005.

characteristics, medical histories, and cancer-related health beliefs and behaviors of women scheduled for GCRA.

Operational Definitions

For the current study, the researchers used a set of definitions to characterize the participants (see Figure 1). The definitions are at least as stringent as those for women at high risk for breast or ovarian cancer published by the National Comprehensive Cancer Network (2005).

Sample and Setting

Participant description (i.e., demographics, health characteristics, family history, and health beliefs), sampling procedures, survey development, and content validity were reported previously (MacDonald et al., 2005). Participants were part of a larger study of primarily physician-referred, healthcare-insured women that was approved by an institutional review board. In the larger study, adult women with a personal or family history of breast or ovarian cancer were mailed a study packet, including a study invitation letter, consent, survey, prepaid return envelope, and standard pre-GCRA health and family history surveys in consecutive order when scheduled for a GCRA consultation. After two weeks, nonresponders were sent a second study packet. This article presents data from the 214 women who completed the study survey and signed the study consent prior to their initial GCRA consultation (41% response rate). The 214 women included 134 with a personal history of breast cancer (affected group) and 80 with a family history of breast cancer or ovarian cancer in at least one close relative (unaffected group).

Measures

Demographic data (i.e., age, ethnicity, marital status, education, and parity), reproductive history, prior surgeries and

Table 2. Previous Ovarian Cancer Screening and Risk Reduction Guidelines for Asymptomatic Women Who Have Not Had Ovarian Cancer (1997–1999)

Modality	Average Risk	Modest Family History	Suspected or Known Hereditary Risk	Issues
CA-125	Not applicable	Optional	Begin annually or semiannually from age 25–35.	Poor predictive value; false positives and negatives
Pelvic ultrasound	Not applicable	Optional	Begin annually or semiannually from age 25–35.	Poor predictive value; false positives and negatives
Oral contraceptive pills[a]	Not applicable	Optional	Optional	Possible increased breast cancer risk with long-term use
Bilateral salpingo-oophorectomy[b]	Not applicable	Optional	Consider on an individual basis; strongly recommended by age 35–40	Ends childbearing; menopausal symptoms; residual risk for primary peritoneal cancer

[a] May reduce ovarian cancer risk by as much as 50%, even in high-risk women (Narod et al., 2002)

[b] Premenopausal bilateral salpingo-oophorectomy may reduce breast cancer risk by greater than 50% (Narod et al., 2002).

Note. Based on information from National Comprehensive Cancer Network, 2005; Smith, Cokkinides, et al., 2005.

Unaffected: women without a personal history of breast or ovarian cancer

Affected: women with a personal history of breast or ovarian cancer

Close relative: a blood relative on the same side of the family who is a first-degree relative (parent, sibling, child) or second-degree relative (aunt, uncle, niece, nephew, grandparent); a third-degree relative (first cousin, great-aunt, great-uncle, great-niece, great-nephew) would be considered a close relative if less than two unaffected female relatives older than age 50 are between a woman and her closest affected relative (e.g., a women with no paternal aunts whose paternal uncle has an affected daughter [cousin]).

Modest family history: a woman who has a close relative with breast cancer after age 40 or after age 50 if of Ashkenazi Jewish descent or a close relative with ovarian cancer and no family history meeting hereditary risk criteria

Suspected or known hereditary risk among women who have had breast cancer: a woman diagnosed (a) before age 40 (before age 50 if of Ashkenazi Jewish descent), (b) before age 50 who had a second primary breast cancer at any age, or (c) at any age if a close relative had breast cancer before age 50 or was diagnosed with either ovarian cancer or male breast cancer

Suspected or known hereditary risk among women who have not had breast cancer: a woman with two close relatives diagnosed with breast cancer (a) before age 40 (before age 50 if of Ashkenazi Jewish descent), (b) before age 50 and had a second primary breast cancer at any age, or (c) at any age if a third close relative had breast cancer before age 50 or was diagnosed with either ovarian cancer or male breast cancer

Figure 1. Operational Definitions

Note. Based on information from National Comprehensive Cancer Network, 2005.

serious or chronic illnesses, cancer diagnoses (age at onset, cancer type, and treatment), and family history information (i.e., number of all first-, second-, and third-degree biologic relatives; gender; current age or age at death; cause of death; cancer type and stage; and age at onset) were obtained from mailed, self-report, standard health and family history surveys and confirmed by available medical or other records. Family history of ovarian cancer was confirmed by pathology reports, death certificates, or other documentation in most cases.

The study survey included 10–12 items assessing the use and frequency of cancer screening and risk-reducing behaviors derived from American Cancer Society and National Comprehensive Cancer Network guidelines (Daly, 1999; Leitch et al., 1997; Smith, Mettlin, Davis, & Eyre, 2000). Space was provided for the women to supply other responses or comments. Survey items were revised after prior pilot testing and in-depth interviews with 10 of the 50 pilot study participants (MacDonald, 2002). Content validity was established previously by an expert genetics and oncology judge panel (i.e., three nurse researchers, a physician, and a clinical research associate) until 100% agreement was reached. The survey was reviewed for content, readability, clarity, and time for completion (average of 17 minutes) by a female judge panel (i.e., three nonhealthcare professionals, a certified health educator, and a well-known expert GCRA nurse). Revisions incorporating participants' and reviewers' comments were made prior to full study implementation. Reliability ($p \leq 0.005$) was determined by test-retest of eight items not expected to change within a month (MacDonald et al., 2005).

Cancer screening: The two items for breast cancer screening, frequency of mammograms and CBE, were answered by checking once a year, twice a year, or other. BSE was measured on a single-item scale of seven options ranging from never to weekly, including other. Two yes or no items assessed the use of the CA-125 serum marker and pelvic ultrasounds to screen for ovarian cancer. Frequency was measured as once or twice a year or other. Women were asked to skip breast health items if they had undergone a bilateral mastectomy and ovary health items if they had had both ovaries removed.

Risk reduction: A single yes-or-no item assessed whether women took medication to reduce the risk of breast cancer. If they answered "yes," women were asked to indicate whether they took tamoxifen. A single yes-or-no item asked women whether they had had a healthy breast removed to reduce breast cancer risk. Finally, all women were asked to describe any other risk-reducing strategies they employed.

One yes-or-no item per category assessed the use of oral contraceptive pills, bilateral salpingo-oophorectomy, and any other means the women used to reduce ovarian cancer risk. Women who indicated that they took oral contraceptive pills were asked whether the pills were taken for birth control, ovarian cancer risk reduction, or another reason. Similarly, women who reported having one or both ovaries removed were asked whether the surgery was for risk reduction or another reason and whether the removal was in conjunction with a hysterectomy.

Data Analysis

Data were analyzed using SPSS® version 11.5 (SPSS Inc., Chicago, IL). Descriptive statistics were used to describe screening and risk-reducing behaviors. Differences in screening and risk reduction strategies among women with and without breast cancer were determined using Student's t tests and chi-square analysis. The differences were evaluated for (a) the entire sample, (b) the subset of women (n = 160) aged 40 or older for breast cancer screening, and (c) women with and without a family history of ovarian cancer for ovarian cancer screening and risk reduction. Because all subjects answered most of the applicable survey items, they were retained in the data set without substituting missing data. Responses that did not pertain to participants who had had both breasts (n = 15) or ovaries (n = 33) removed were excluded from analyses. A stratified, random sample of 214 nonresponders (134 affected and 80 unaffected) was selected and compared with responders on demographic characteristics.

Results

Sample

The mean age of the 214 participants was 47.9 years (range = 21–86). Most participants were Caucasian (79%), older than age 40 (75%), married (66%), and college educated (60%) and had children (78%). The only demographic difference between participants and nonresponders was that women in the affected group were about 4.5 years older than women in the unaffected group ($p = 0.02$). The mean age at breast cancer diagnosis was 44.3 years (range = 25–76, SD = 10.9). Most had early-stage breast cancer, including two who also had ovarian cancer. Eighty percent had a first- or second-degree relative with either breast or ovarian cancer. Of the 199 women who had not had a bilateral mastectomy, 69% (n = 138) were older than age 40. Overall, 29 women (14%) had a family history of ovarian cancer in a first- or second-degree relative. Nonresponder and responder demographics were similar, varying by only a few percentage points.

Cancer Screening and Risk-Reducing Strategies

Breast cancer screening: The breast cancer screening behaviors of women aged 40 or older, separated by affected or unaffected status, are displayed in Table 3. Twenty-one percent of the respondents (17% ≥ age 40) who should have had an annual mammogram did not do so, 19% (23% ≥ age 40) did not have a CBE by a doctor or nurse annually, and 40% (42% ≥ age 40) did not practice monthly (or more frequent) BSE.

Ovarian cancer screening: The ovarian cancer screening behaviors of all women, separated by affected or unaffected status, are displayed in Table 4. Fifty-eight percent of the respondents with ovaries (n = 69 of 118) reported having one or more CA-125 blood tests to screen for ovarian cancer and 29% (n = 46 of 166) reported having at least one pelvic ultrasound for this purpose. Of those having screening ultrasounds at least yearly, 32% (n = 10) had a family history of ovarian cancer and 10% (n = 3) had a personal history of breast cancer.

Breast cancer risk reduction: Thirty-nine percent of the affected women who had not had a bilateral mastectomy (n = 46 of 119) indicated that that they took medication to reduce breast cancer risk. Twenty-two percent (n = 10 of 46) reported that they took tamoxifen or raloxifene for this purpose. Ten percent (n = 14 of 134) of the affected women had had a contralateral mastectomy as a preventive measure. Forty-three percent of the respondents (n = 75 of 171) described other strategies they used in an attempt to prevent breast cancer, mostly dietary and alternative measures (see Table 5).

Ovarian cancer risk reduction: Twelve women indicated that they used oral contraceptive pills. Of them, 25% (n = 3), all in the unaffected group, did so to reduce ovarian cancer risk. Of the 33 women who had had a bilateral salpingo-oophorectomy, two did so as a preventive measure because of a family history of the disease and two had had the surgery for treatment of ovarian cancer (all four women were breast cancer survivors). The remaining 29 women had had a bilateral salpingo-oophorectomy for benign reasons such as fibroids. All but one of the women who had had a bilateral salpingo-oophorectomy were at least 40 years of age at the time of surgery. Eighteen percent (n = 6 of 33) had a family history of ovarian cancer. Thirteen percent (n = 20 of 158) of the respondents with at least one ovary indicated using other means (primarily diet and exercise) to try to prevent ovarian cancer.

Comparison of Affected and Unaffected Groups

The only significant difference found in breast cancer or ovarian cancer screening between the two groups was that, overall, unaffected women were significantly more likely to have at least an annual CBE, regardless of age (χ^2 [1] = 9.46, $p < 0.02$). This finding remained significant when analyzed among women at least 40 years of age.

The only significant difference found in risk-reducing strategies between the two groups was that women with a breast cancer history (n = 26 of 42) took a medication to reduce breast cancer risk significantly more often than unaffected women (χ^2 [1] = 27.17, $p < 0.0001$). The sample size was too small to determine differences in use of oral contraceptive pills or bilateral salpingo-oophorectomy to reduce ovarian cancer risk. No significant differences were found in ovarian cancer screening or risk-reducing behaviors when analyzed separately for the 29 women with a family history of ovarian cancer.

Table 3. Breast Cancer Screening Practices Among Women Aged 40 or Older

	Unaffected Women (N = 52)		Affected Women (N = 75)		
Screening Option	n	%	n	%	p
Annual mammogram[a]	47	90	59	79	0.094
Annual clinical breast examination[a]	47	90	51	68	0.005
Monthly breast self-examination[a]	28	54	46	61	0.465

[a] Some women reported more frequent screening.

Table 4. Ovarian Cancer Screening and Risk Reduction Practices

	Unaffected Women (N = 66)		Affected Women (N = 115)		
Option	n	%	n	%	p
CA-125 (n = 118)[a]	10	17	12	20	0.814
Pelvic ultrasound (n = 166)[a]	20	19	10	17	0.835
Oral contraceptive pills for risk reduction (n = 158)[b]	3	5	–	–	–

[a] Testing was conducted yearly, but some women reported more frequent screening.

[b] Sample size was too small for analysis.

Discussion

Breast Cancer Screening and Risk Reduction

To the researchers' knowledge, this is the first study to compare women's pre-GCRA breast and ovarian cancer screening and risk reduction behaviors to national guidelines. The findings of the current study indicate that nearly a third of the women at increased risk for breast cancer were not receiving adequate cancer screening prior to formal risk assessment. Of particular concern, women with a history of breast cancer had less breast cancer screening than the unaffected women. The data also suggest that some women were having unnecessary ovarian cancer screening. Additionally, most women did not use chemoprevention or surgical interventions to reduce their perceived high risk for breast and ovarian cancers. The investigators were unable to determine whether these findings were because of a lack of pre-GCRA education about cancer screening and risk-reducing interventions for women with a personal or family history of breast or ovarian cancer, the biases of their healthcare providers, or other reasons. The Health Belief Model construct of perceived susceptibility predicting early-detection behaviors appeared to be only partially supported for some behaviors, but was not supported regarding BSE. Additionally, the disturbing finding that women with a breast cancer history had less screening for the disease than unaffected women appears congruent with the recent finding that the women perceived themselves to have less breast cancer risk than the women who had not had the disease

Table 5. Other Strategies Women Reported Using to "Prevent" Breast Cancer

Strategy	n	%
Healthy diet	32	43
Exercise or yoga	16	21
Herbs or homeopathy	9	12
Reduce stress	9	12
Vitamins	9	12
Avoid alcohol	7	9
Pray or meditate	6	8
Avoid caffeine	3	4
Quit smoking	3	4
Miscellaneous (e.g., healthy lifestyle, educate self)	5	7

N = 75

Note. Multiple responses were possible.

(MacDonald et al., 2005). Perceived susceptibility does not appear to be predictive of risk-reducing behaviors for women because few used tamoxifen or surgical interventions.

In this sample of women with health insurance, the rate of yearly mammograms was higher than in two U.S. studies (i.e., < 75% in Botkin et al.'s [2003] and Isaacs et al.'s [2002] studies) offering free genetics counseling and testing programs but was slightly lower than the 89% adherence rate found in a government healthcare system study of 416 unaffected women with a family history of breast cancer who sought screening advice (Meiser et al., 2000). Review of the health and family history information of the current study's participants identified that the women were age and risk appropriate for annual mammography. Perhaps the women or, as has been suggested, their healthcare providers were unaware of the need for breast surveillance above general population screening guidelines (Tinley et al., 2004). This finding supports the important role of nurses in assessing the family history of cancer and cancer screening and risk-reducing behaviors of adult, female clients. Targeting women who do not adhere to national mammogram recommendations is an important area for nursing intervention.

The overall rate of CBE adherence in the current study (78%) was less than the rate found in both the free clinic (86%) and the government healthcare (90%) studies previously described (Isaacs et al., 2002; Meiser et al., 2000). Surprisingly and of concern, nearly a third of the affected women in the current study reported having a CBE less than annually. Because an annual CBE is the minimum standard of care for all women who have had breast cancer, researchers must explore the reasons that women were not having the proper follow-up. Promoting yearly CBE for these women is needed and is within the scope of practice for all nurses.

The revised American Cancer Society guidelines for women with average risk state that, because of a lack of sufficient data proving its benefits, BSE is optional (Smith, Cokkinides, et al., 2005). Nevertheless, the American Cancer Society purported that the benefits and limitations of BSE should be discussed with women beginning in their early 20s and that national guidelines for women at increased risk of breast cancer continue to recommend monthly BSE. The current study's investigators found that 40% of the participants did not perform BSE monthly. Nurses should provide BSE instruction for women who desire it and promote BSE among women with increased breast cancer risk. Oncology nurses also should be familiar with recently updated breast ultrasound and magnetic resonance imaging recommendations for high-risk women (Kriege et al., 2004; National Comprehensive Cancer Network, 2005) and the use of aromatase inhibitors (versus tamoxifen) for adjuvant treatment of most postmenopausal women with breast cancer (Smith, Dowsett, et al., 2005; Winer et al., 2005).

One study found that women presenting for *BRCA* testing used complementary and alternative medicines (DiGianni et al., 2003). Similarly, many of the current study's participants reported using various means to prevent cancer. A few mistakenly described screening measures as strategies for cancer prevention. Some of the reported strategies are supported by empiric literature, whereas others, such as the use of herbs, are not and may be counterproductive, especially in conjunction with other medications or health problems or when associated with unrealistic expectations (Boyle, Maisonneuve, & Autier, 2000; Cho et al., 2003; Kurzer, 2003; Lu, Anderson, Grady, Kohen, & Nagamani, 2000; Tavani et al., 2004; Wargovich, Woods, Hollis, & Zander, 2001). This finding illustrates that nurses must ask women about their use of complementary and alternative medicine and educate women not only about cancer screening and risk reduction but also about differences between screening and risk reduction and the potential adverse health outcomes from the use of herbs and other unproven modalities.

Thirty-eight percent of the women in the current study reported taking medication to reduce breast cancer risk, but only 7% stated that they took tamoxifen. Perhaps the women confused medications for risk reduction with those used for breast cancer treatment. Only two unaffected women reported taking tamoxifen (two reported taking raloxifene) to reduce breast cancer risk. At the time of the study, many participants would have been eligible to use tamoxifen as a risk-reducing measure or participate in the STAR (Study of Tamoxifen and Raloxifene) trial comparing tamoxifen to raloxifene (Fisher et al., 1998; Gail et al., 1989). If raloxifene is found to be at least as effective as tamoxifen, women's use of a risk-reducing medication could be influenced because raloxifene is not associated with endometrial hyperplasia or cancer.

Historically, women with a strong family history of breast cancer have been advised to have bilateral mastectomies as a preventive measure. Recent studies have found that this procedure is about 90% effective in preventing breast cancer, even for women at the highest risk level (Hartmann et al., 1999; Hartmann, Degnim, & Schaid, 2004; Rebbeck et al., 2004). Although many of the current study's participants had a strong family history of breast cancer, none of the unaffected women had had a bilateral mastectomy and only 14% of the affected women had had one for prophylaxis. Botkin et al. (2003) also found that no unaffected women had had this effective yet body-altering intervention.

Ovarian Cancer Screening and Risk Reduction

Because of the limitations (poor sensitivity and specificity) of ovarian cancer screening, guidelines for women at increased risk for ovarian cancer range from no screening to serum CA-125 and transvaginal ultrasound every six months (National Comprehensive Cancer Network, 2005; "NIH Consensus Conference," 1995). Most of the women in the current

study did not have a personal or family history of ovarian cancer or any other indication suggesting that screening was warranted, yet nearly 60% of the women reported having had screening at least once and about a third of the women did so yearly or more often. A few women mistakenly reported that they had yearly Pap tests to screen for ovarian cancer. In the free care Botkin et al. (2003) study, none of 97 women with at least one ovary had had CA-125 or pelvic ultrasound screening in the year prior to genetic testing. Although a much lower rate of CA-125 testing was found in another free genetic counseling and testing study (Isaacs et al., 2002), the authors reported nearly the same rate (about 30%) of having a screening ultrasound in the past year or in the women's lifetimes.

Only three women reported using oral contraceptive pills or other strategies to reduce ovarian cancer risk and none reported having had a bilateral salpingo-oophorectomy for this purpose; bilateral salpingo-oophorectomy use was not reported in the free care or government healthcare studies. Although the effect of current oral contraceptive pill formulations on breast cancer risk in women with a family history of the disease is unclear (Narod et al., 2002; Narod & Offit, 2005), oral contraceptive pill use and bilateral salpingo-oophorectomy have been shown to reduce ovarian cancer, the former by as much as 50% and the latter by at least 90% (National Comprehensive Cancer Network, 2005; "NIH Consensus Conference," 1995; Schildkraut et al., 2002; Whittemore et al., 2004). Experts disagree whether a hysterectomy is needed when bilateral salpingo-oophorectomy is performed for ovarian cancer risk reduction and whether hormone replacement is a safe option for women at increased cancer risk who have menopausal symptoms not alleviated by other means ("NIH Consensus Conference"; Paley et al., 2001). Importantly, bilateral salpingo-oophorectomy performed prior to menopause appears to markedly lower risk for both breast and ovarian cancers in high-risk women (Rebbeck et al., 2002); therefore, along with tamoxifen or another chemoprotective medication, bilateral salpingo-oophorectomy may be a more appealing alternative for high-risk, unaffected women contemplating the removal of healthy breasts.

Discussion of the benefits, limitations, and risks of chemoprotective medications, mastectomies, oral contraceptive pills, and bilateral salpingo-oophorectomy for cancer risk reduction is another area that may be within the scope of practice for nurse experts in GCRA and other advanced practice oncology nurses. Interested nurses can find in-depth discussion of these strategies in the referenced articles.

Limitations

Several study limitations should be discussed. The study findings may have been affected by the nonrandom design, demographically homogenous sample, inaccurate recall of past events, and low response rate (41%). The researchers speculate that the response rate was at least partly a result of unfamiliarity with the researchers and data collection burden, because many nonresponders subsequently enrolled in the study post-GCRA. In some cases, the researchers were not able to confirm a family history of ovarian cancer. Additionally, the sample size in some response categories such as the use of oral contraceptive pills, and comparison of CA-125 testing and pelvic ultrasounds to family history of ovarian cancer analyses, may have been too small to detect differences. The findings may not be generalizable to culturally diverse or less educated women. Reference to the Health Belief Model must be interpreted very cautiously because formal analysis to evaluate the model constructs was not undertaken.

Conclusion

This study adds to the limited data about the breast cancer and ovarian cancer screening and risk-reducing behaviors of women scheduled for risk assessment in a clinic that serves a high-risk population. Of specific concern is the finding that 24% of women with a breast cancer history did not have an annual mammogram and about 30% did not have an annual CBE. At least 40% of both affected and unaffected women did not practice BSE monthly. Results varied 2%–7% when analyzed by age (i.e., younger and older than 40 years). The findings also suggest that some women had received unwarranted ovarian cancer screening and used unsubstantiated and potentially harmful measures for cancer prevention.

Implications

All oncology nurses should (a) be aware of the importance of documenting at least a three-generation cancer family history, (b) be able to refer women for risk assessment, (c) assess cancer screening practices according to national guidelines, (d) assess cancer risk-reducing behaviors and the use of complementary and alternative medicines, and (e) ensure that women understand the differences between screening and risk reduction and the potential adverse health outcomes from the use of herbs or other remedies purported to prevent cancer. Advanced practice oncology nurses and nurse experts in GCRA can educate women, nurses, and other healthcare providers about age- and risk-appropriate cancer screening and risk-reducing strategies.

This study's findings need to be confirmed in heterogeneous, uninsured, ethnically diverse populations. Research also is needed to determine the impact of GCRA on cancer screening and risk-reducing behaviors and to develop and test nursing interventions.

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