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Development of the Breast Cancer Education and Risk Assessment Program

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Purpose/Objectives: To provide a description of the inception and evolution of the Breast Cancer Education and Risk Assessment Program.

Data Sources: Computerized database (e.g., Personal Family History Risk Assessment Model, Knowledge Assessment Tool, risk perception, evaluation form) and author experience.

Data Synthesis: A total of 749 women participated in the group education and risk-assessment program from March 1999 through March 2002. Advanced practice nurses provided information about calculated risks, corrected misperceptions among participants, and highlighted options available to decrease breast cancer risk. Knowledge scores improved, and, in general, participants were very satisfied with the content and comprehensibility of the educational session.

Conclusions: Results from the evaluation of the Breast Cancer Education and Risk Assessment Program suggest that group education is a viable and acceptable way to bring new advances in breast cancer prevention to large groups of women. The data sources support the conclusion that women can be effectively taught general breast cancer risk information in a group setting and be placed into specific risk categories to streamline discussion of risk-management options and relevant research studies.

Implications for Nursing: Advanced practice nurses are a vital link in the assessment of women at high risk for breast cancer, education, and appropriate referrals for management options and relevant clinical trials.

Key Points . . .

- ➤ The Breast Cancer Education and Risk Assessment Program is an effective and efficient method of providing information and identifying women at high risk for breast cancer.
- ➤ An integrated model that incorporates both personal risk factors and maternal and paternal family history of cancer was developed and may estimate more accurately the risk of developing breast cancer.
- ➤ Advanced practice nurses are a vital link in the assessment of women at high risk for breast cancer, education, and appropriate referrals for management options and relevant clinical trials.

An estimated 211,300 women in the United States will be diagnosed with breast cancer in 2003 (American Cancer Society, 2003). Although recent advances in diagnosis and treatment have reduced mortality rates, breast cancer remains the second leading cause of cancer deaths among women. An explosion of information has occurred in the areas of genetics, risk assessment, and risk reduction for breast cancer. Recently, considerable research efforts have focused on prevention of breast cancer. The Breast Cancer Prevention Trial, sponsored by the National Cancer Institute (NCI) and the National Surgical Adjuvant Breast and Bowel Project, demonstrated that tamoxifen, a selective estrogen receptor modulator (SERM), reduced the overall risk of invasive breast cancer by almost 50% (Fisher et al., 1998). The U.S. Food and Drug Administration's approval of tamoxifen for breast cancer prevention for high-risk women followed the announcement of these positive results in 1998. Along with the good news came the challenge to identify women for whom the potential benefits of tamoxifen would outweigh the risks.

In the Breast Cancer Prevention Trial, women were considered to be at high risk for the development of breast cancer based on one of the following criteria.

- Age of 60 years or more
- Age of 35–59 years with a five-year estimated absolute risk of breast cancer of at least 1.66%
- A diagnosis of lobular carcinoma in situ (LCIS)

Five-year risks were calculated using the Breast Cancer Risk Assessment Tool (BCRAT), a modification of the Gail Model that estimates absolute risk of breast cancer using age, menarche, age at first live birth, first-degree family history, number of breast biopsies, history of atypical hyperplasia, and race (Gail et al., 1989).

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Advances in breast cancer risk estimation, detection, and prevention highlight the pivotal role of risk assessment in primary care. Healthcare providers must become adept at evaluating breast cancer risk and providing appropriate counseling on risk-reduction strategies to women (Armstrong, Eisen, & Weber, 2000). Cancer risk assessment is very appealing. Patients who receive cancer screenings are motivated to learn their risk for developing cancer and what can be done to reduce that risk (Mahon, 1998). However, changes in the healthcare system have created an environment in which physicians may have less time to spend with patients (Bodenheimer, 1999). Therefore, the first areas to be cut by physicians in an effort to control costs might include prolonged discussions of health maintenance and prevention. Thus, healthcare providers are challenged to educate women adequately about their breast cancer risk and to identify the cohort of high-risk women who require more intense counseling in breast cancer risk reduction.

Breast Care Center at the National Naval Medical Center

Located in Bethesda, MD, the Breast Care Center (BCC) at the National Naval Medical Center (NNMC) is a facility jointly run by the NCI and NNMC. It was established in 1995 with a mission to provide state-of-the-art patient care, conduct clinical research, and pursue educational initiatives. Healthcare providers at the clinic see about 1,000 Department of Defense (DoD) patients (e.g., active duty, dependents, retired military) and diagnose about 10 cases of breast cancer per month. The BCC team is multidisciplinary, comprised of surgeons, radiation oncologists, medical oncologists, physical therapists, social workers, and nurses specializing in education, research, and genetics. Once the results of the Breast Cancer Prevention Trial were published, the BCC staff anticipated an increased need to provide a triage system to identify women at high risk for breast cancer and appropriately refer them to providers to discuss prevention options and risk-reduction strategies. However, the staff was unsure of which providers (e.g., surgeons, medical oncologists, family practitioners) should evaluate these women and what would be the most efficient method of identifying them.

The Breast Cancer Education and Risk Assessment Program

Purpose

In 1998, the Breast Cancer Education and Risk Assessment Program was created with the goals of providing breast cancer risk education to women in a group setting, identifying those at increased risk for breast cancer, and facilitating referrals for individualized risk-reduction counseling. The ultimate goal of the program is to assist women in understanding their personal risk for developing breast cancer and learning what options are available to decrease that risk. An educational session provides foundational knowledge for all who enter the program and allows for more appropriate identification of high-risk patients who need further consultation with providers who specialize in high risk. Such providers include medical and surgical oncologists and nurse practitioners who specialize in breast cancer care and counseling of high-risk women regarding breast cancer surveillance and risk-reduction options.

Development of the Program

The breast cancer risk assessment team, comprised of advanced practice nurses specializing in breast cancer education, genetics, and research and a medical oncologist-geneticist, held biweekly meetings over a four-month period to formulate the education and risk-assessment program. This included discussion of the content of the educational session based on the findings of Fisher et al. (1998), the definition and development of risk categories, and the process for referring high-risk patients to appropriate providers. The team agreed that the content of the educational session should include discussion of the natural history of breast cancer, known risk factors, an explanation of the Gail Model, breast cancer surveillance and chemoprevention trials, SERMs, and other risk-reduction strategies (see Figure 1).

Educational and Risk-Assessment Class

The 90-minute educational session is scheduled bimonthly and conducted by a master's-prepared education nurse within the BCC. Class size is limited to 20 women, and each woman is encouraged to bring a support person with her. Initially, the educational session was open to patients seen at the BCC who were either physician- or self-referred. One year after its inception, the class was opened to the broader community.

- What is cancer?
- Breast cancer risk factors
  - Age-specific versus lifetime risk
  - Breast cancer risk factors
    - Gender
    - Age
    - Pathology
    - Family history
    - Genetics
    - Ethnic background
    - Lifestyle and environment
    - Hormones
- Gail Model
  - What is it?
  - Calculation
- Clinical trials
  - Breast Cancer Prevention Trial
  - Multiple Outcomes of Raloxifene Evaluation
  - Study of Tamoxifen and Raloxifene
  - Selective Estrogen Receptor Modulator Study
  - Susceptibility to Breast Cancer
- Options for women at high risk for breast cancer
  - Regular surveillance
  - Chemoprevention
  - Prophylactic surgery
- Cancer screening
  - Breast self-examination
  - Clinical breast examination
  - Mammography
- Summary

Figure 1. Content of the Educational and Risk-Assessment Session

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The majority of participants continue to be referred by BCC providers, despite efforts to reach out to local hospitals. Registration and participation in the class are free of charge.

Prior to the class, participants complete a risk-assessment form, which includes the BCRAT (i.e., current age, age of menarche, age at first full-term pregnancy, ethnic background, number of previous breast biopsies, and history of atypical hyperplasia). Additionally, a detailed family cancer history questionnaire provides insight into potential hereditary breast cancer risk (see Figure 2). While the class is conducted, advanced practice nurses calculate BCRAT scores and assess the family histories. When the BCRAT score can be calculated (i.e., those who have a history of invasive breast cancer, ductal carcinoma in situ [DCIS] or LCIS are considered high risk without a BRCAT score), five-year and lifetime risks for breast cancer are determined. Each patient's risk is classified into one of three categories (average risk, slightly to moderately increased risk, and high risk) based on a risk-assessment model. At the end of the educational session, advanced practice nurses review the completed risk assessments individually with each participant, interpreting results and answering questions. Participants identified to be at high risk based on family history suggestive of a hereditary cancer syndrome are referred to the NCI's Clinical Cancer Genetics Program for genetic education and counseling.

Data Sources

Personal Family History Risk Assessment Model: Several models calculate the risk of developing breast cancer (Euhus, 2001); some are based predominantly on personal risk factors (e.g., BCRAT Gail Model), whereas others solely consider family history of breast cancer (Claus, Risch, & Thompson, 1994). Although each of these models has its strengths and limitations, a need clearly exists for an integrated model that incorporates both personal risk factors and maternal and paternal family history of cancer. Such a hybrid model may estimate more accurately the risk of developing breast cancer. Therefore, a working model for classifying risk based on both

Your estimated breast cancer risk calculation is based only on the information you provide on this form.

Menstrual history
Current age: _____
Age at first menstrual period: _____
Age at first full-term pregnancy: _____

Racial or ethnic background
☐ White (not Hispanic) ☐ Native American
☐ Black (not Hispanic) ☐ Unknown
☐ Hispanic ☐ Other
☐ Asian

Religion: _____

History of breast cancer

	No	Yes	Uncertain
Previous breast biopsies How many? _____	☐	☐	☐
Have any of your biopsies shown			
• Atypical hyperplasia?	☐	☐	☐
• Ductal carcinoma in situ?	☐	☐	☐
• Lobular carcinoma in situ?	☐	☐	☐
Have you ever had			
• Invasive breast cancer diagnosis?	☐	☐	☐
• Another cancer diagnosis? (specify) _____			

Family cancer history

Relative	Type of cancer (e.g., breast, ovarian, colon)	Age at diagnosis
Mother		
Father		
Sister #1		
Sister #2		
Sister #3		
Brother #1		
Brother #2		
Brother #3		
Daughter #1		
Daughter #2		
Daughter #3		
Son #1		
Son #2		
Son #3		
Mother's sister (maternal aunt) #1		
Mother's sister #2		
Mother's sister #3		
Mother's brother (maternal uncle) #1		
Mother's brother #2		
Mother's brother #3		
Father's sister (paternal aunt) #1		
Father's sister #2		
Father's sister #3		
Father's brother (paternal uncle) #1		
Father's brother #2		
Father's brother #3		
Mother's mother (maternal grandmother)		
Mother's father (maternal grandfather)		
Father's mother (paternal grandmother)		
Father's father (paternal grandfather)		

Full name: _____
Address: _____
_____
Date of birth: ___/____/_____
Daytime phone number: _____

Please check appropriate box.
☐ Military/dependent
☐ Civilian

Sponsor's social security number: _____

Figure 2. Personal Risk-Assessment Form

Note. Form courtesy of the National Cancer Institute and the Breast Care Center at the National Naval Medical Center.

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personal and family history was developed. It initially was created as a guideline to maintain consistency and accuracy among the nurses calculating patients' risks. Average risk was defined as five-year Gail Model calculation less than 1.7% with no family history of breast cancer. High risk was defined as any of the following: a five-year Gail Model calculation greater than or equal to 1.7%, any patient with a first-degree relative (i.e., mother, sister, father, daughter) diagnosed with premenopausal (younger than 50 years) breast cancer regardless of Gail Model score, or any patient with a history of infiltrating breast cancer, DCIS, or LCIS. Slightly to moderately increased risk was defined as an average five-year Gail Model score with a first-degree relative postmenopause (older than 50 years) or a second-degree relative diagnosed with breast cancer at any age or an average five-year Gail Model score with a history of atypical ductal hyperplasia or an average five-year Gail Model score with a first-degree relative diagnosed with premenopausal ovarian cancer. The slightly to moderately increased risk category is determined on an individual basis because those patients do not fall into a high-risk category but may have some risk factors that put them in a higher category than patients at average risk. Because risk assessment is considered to be a screening process, the risk-assessment team decided to err on the side of classifying a woman as having a slightly increased risk instead of average. Although this model has not been validated statistically, it has been used effectively and practically from March 1999 to the present to provide guidance for referral to providers who specialize in high-risk cases, referral to a genetics team, and entry into relevant research studies.

The Knowledge Assessment Tool (KAT) is a 10-item true-or-false questionnaire developed to assess baseline and posteducation knowledge. The questions address issues such as breast cancer risk factors, the Gail Model, SERMs, screening, heredity, and clinical research studies. The tool currently is being evaluated for content and construct validity.

Risk perception: Participants in the educational class are asked to rate their perceived risk of developing breast cancer as lower, about the same, a little higher, or much higher than that of the average woman. The data are obtained prior to and after the educational session.

Evaluation form: After the session, participants are asked to complete an evaluation form that asks about motivation for attending the class, satisfaction with the information provided, comprehensibility of information presented, and the referral source. This information provides the staff with feedback about the educational session, factors that motivate attendance, and topics of importance to participants.

Postprogram Follow-Up

Within two weeks after the class, the education nurse places a follow-up call to each participant to ask further questions and facilitate consultation with a provider who specializes in high-risk cases, if appropriate.

Results of Data Collection

Participant Demographics

Since the inception of the Breast Education and Cancer Risk Assessment Program, 749 participants have attended an educational session. All participants were women with a mean age of 54 years (range = 20–87). The majority (89%, n = 665) were Caucasian, 5% (n = 39) were African American, 3% (n = 24) were Asian, 2% (n = 17) were Hispanic, and 1% (n = 4) were from other ethnic backgrounds. In the first year, all participants were DoD enrollees. After enrollment was opened to the public and an article was published in the *Washington Post*, class attendance increased from 178 to 352 in its second year, with 21% of participants attending from the non-DoD community. Participation leveled off in the third year, with 219 attendees, the majority of whom were DoD referrals through the BCC.

Eighty-six percent (n = 644) of participants were classified as high risk, 6% (n = 44) were categorized as slight or moderate risk, and 8% (n = 61) were considered average risk (see Figure 3). Significantly more DoD participants were classified as high risk (89%, n = 595) than non-DoD participants (60%, n = 49), and a substantially greater proportion of non-DoD participants were classified as average risk (35%, n = 28) compared to DoD attendees (5%, n = 33) (see Figure 4). The referral process likely accounts for these differences; DoD participants generally were referred by healthcare providers at the BCC, whereas non-DoD participants generally were self-referred.

Participants' perceived risk of breast cancer prior to the educational class was compared to actual risk calculation as determined from information on the Personal-Family History Risk Assessment Model (see Figure 5). The majority of participants classified their risk of developing breast cancer as slightly increased (52%, n = 220), followed by high (23%, n = 97), average (20%, n = 82), and lower than the average woman (5%, n = 21). Calculated risks for this same cohort of women revealed that the vast majority of them were categorized as high-risk (86%, n = 360), followed by significantly less in the average (9%, n = 37) and slightly to moderately increased (5%, n = 23) categories.

Of the 595 women who were classified as high-risk after the class, 38% (n = 227) were referred to and seen by providers who specialize in high-risk cases. Seventy-five of those women (33%) chose to start SERM (tamoxifen n = 71,

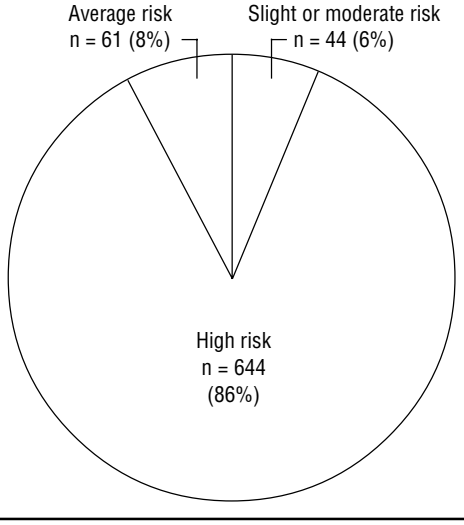

Figure 3. Risk Categorization of Class Participants
N = 749

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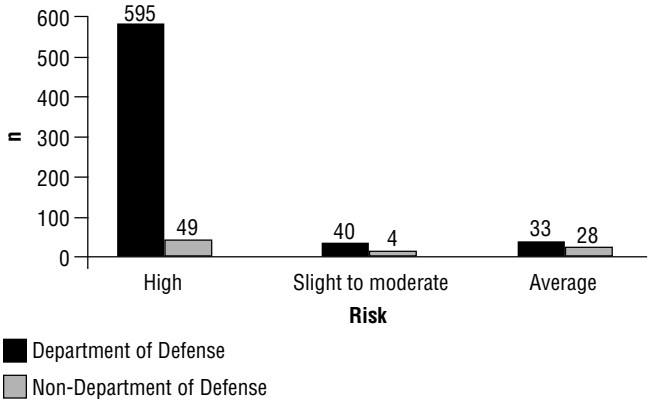


Figure 4. Risk Categorization of Class Participants by Department of Defense Status

N = 749

raloxifene n = 4), and 10 chose to participate in one of the chemoprevention trials (e.g., Study of Tamoxifen and Raloxifene, Capital Area Study Evaluating the Safety of Raloxifene in Premenopausal Women). In addition, after attending the educational class, 125 women chose to participate in one of the ongoing NCI or NNMC research studies.

The mean pretest score on the 10-item knowledge acquisition test was 63%, versus a mean post-test score of 91% (see Figure 6). The lowest pretest scores were on questions pertaining to breast cancer risk factors, the Gail Model, and SERMs. These questions also accounted for the most significant improvement in scores after the educational session.

Seventy-eight percent of participants (n = 585) who returned their postsession evaluations rated comprehensibility of information at 99% and satisfaction with information provided at 98%. Data were not obtained from 22% of participants (n = 164) who did not fill out the evaluation form.

Discussion

Although literature about the use of group education in breast cancer risk assessment is limited, clear benefits exist to providing this information in a group setting, from both a patient-centered and management viewpoint. The educational session of the Breast Cancer Education and Risk Assessment Program provides consistent baseline information about breast cancer risk factors, ongoing clinical trials, surveillance, and risk-reduction options to all participants. Information is presented in an evidence-based, unbiased format (e.g., results from clinical trials are discussed, benefits and risks of SERMs are covered). A small-group setting facilitates questions in an interactive, supportive environment. As evidenced by improvements in test scores and positive evaluations by participants and providers, the session is a valuable resource for attendees. From a management viewpoint, a previsit educational session streamlines appointments with healthcare providers who then can recommend individualized surveillance and risk-reduction options. Ultimately, this promotes efficiency and optimal use of providers' time.

In addition to the advantages of a group educational session, the risk-assessment portion of the class provides individualized information to participants. By informing women

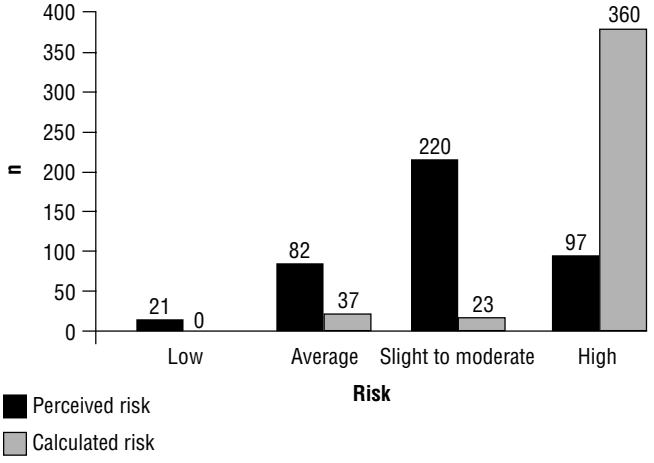
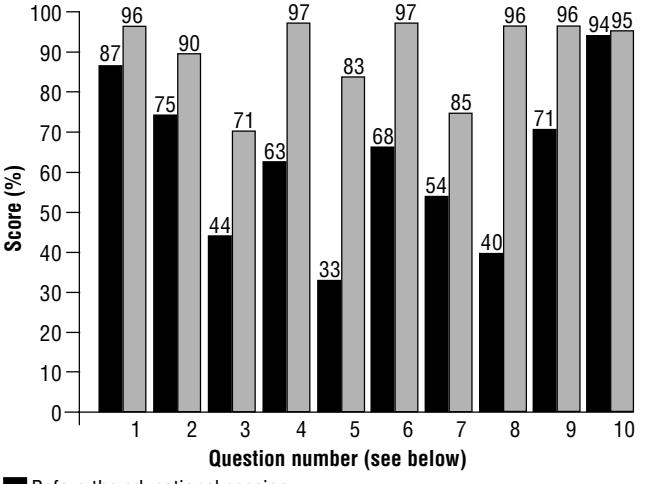


Figure 5. Perceived Versus Calculated Risk



True-or-False Questions

1. A woman's risk of breast cancer remains the same throughout her lifetime. (False)
2. For most women, the ordinary lumpiness they feel in their breasts does not increase their risk of breast cancer. (True)
3. Most women who develop breast cancer do not have any known risk factors. (True)
4. Most breast cancers are inherited. (False)
5. All known risk factors for breast cancer are included in the Gail Model. (False)
6. The medication tamoxifen can decrease the risk of breast cancer for women who are at increased risk for developing the disease. (True)
7. Tamoxifen should be prescribed for all women at increased risk for breast cancer. (False)
8. Raloxifene is approved for the treatment of osteoporosis and is being studied for use in breast cancer prevention. (True)
9. Most advances in breast cancer are the result of knowledge gained through clinical trials. (True)
10. A woman getting regular mammograms need not have clinical breast examinations. (False)

Figure 6. Scores on Individual Questions Before and After the Educational Session

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of their risk categorization, inaccurate risk perceptions may be adjusted and appropriate risk perceptions may be validated. For example, a woman who perceives her risk of breast cancer as high and whose calculated risk is average subsequently may have decreased anxiety and cancer worry (Alexander, Ross, Sumner, Nease, & Littenberg, 1996). Conversely, a woman who perceives her risk of breast cancer as low but actually has a high risk should be counseled about her risk and options. The identification of individuals at high risk for breast cancer provides a mechanism for referrals to healthcare providers who specialize in high risk; referrals to genetics teams for education, counseling, and genetic testing as appropriate; and opportunities to participate in research studies (e.g., chemoprevention trials). Because most advances in breast cancer prevention and treatment result from knowledge gained through clinical trials, increasing participation is imperative. Spilker and Cramer (1992) reported that prevention trials generally have an accrual yield of 1%–6%, whereas treatment trials generally yield 20%–27%. This demonstrates that accrual to trials in general, and prevention trials specifically, is lacking. Based on the numbers of women who participated in studies as a result of the educational session, the authors believe that education is one strategy to increase participation in some research studies.

The population seen in BCC at NNMC is predominantly Caucasian women. More vigorous and targeted marketing to women of other ethnic backgrounds might ensure a more diversified group. The significant number of women categorized as high risk from the educational and risk-assessment class participants likely reflects a referral bias. High-risk women are more likely to be referred to the class because of personal or family history risk factors for breast cancer than individuals who do not have any known risk factors. Although 38% of identified high-risk women visited providers who specialize in high risk, the remaining 62% did not. Why 62% chose not to is not known. Myriad possible reasons exist; one explanation is that perhaps the educational and risk-assessment class provided sufficient information. The educational background of class participants was not assessed, but this information would be helpful to design programs for the general community. Additionally, the risk-assessment model used in this program and the knowledge acquisition test have not been investigated for their content and construct validity and reliability because they were intended only as risk-identification tools. Further research should be conducted to validate the tool.

Summary

The Breast Cancer Education and Risk Assessment Program was designed to provide a broad-based educational program for women with personal or family history risk factors for breast cancer, individualized risk assessment, and, once identified, referrals for high-risk women to appropriate providers and relevant research studies. Three years after its inception, almost 800 women have attended an educational and risk-assessment class and have provided overwhelmingly positive feedback. The authors believe that this program has proven to be an asset to patients and providers alike and is easily adaptable for use in other settings. Group education with regard to breast cancer risk and risk-reduction options is not only feasible but also a highly effective method of disseminating important and relevant information.

Implications for Nursing

Advanced practice oncology nurses are in a unique position to educate and provide accurate risk assessment and counseling for women at increased risk for developing breast cancer (MacDonald, 1997). The Breast Cancer Education and Risk Assessment Program at NNMC allows nurses the opportunity to use assessment, planning, intervention, and evaluation skills. The program can be adapted for use in clinical settings by other advanced practice nurses working with high-risk populations. Additionally, validation of the Knowledge Assessment Tool and the proposed model of assessing risk could be investigated by nurse researchers in this and other patient populations. Advanced practice nurses are a vital link in assessment of women at high risk for breast cancer, education, appropriate referral for management options, and relevant clinical trials.

The authors wish to thank the BCC staff members for their assistance and support in making this program a success.

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