

Addressing the Support Needs of Women at High Risk for Breast Cancer: Evidence-Based Care by Advanced Practice Nurses

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Purpose/Objectives: To identify support needs of women at high risk for breast cancer and enhance an evidence-based service.

Design: Descriptive study.

Setting: A comprehensive, breast-health service for high-risk women.

Sample: 97 high-risk women with a 1.66% or greater five-year risk of breast cancer, atypical hyperplasia, lobular carcinoma in situ, or positive genetic screen.

Methods: A self-assessment questionnaire completed previsit and a satisfaction survey completed postvisit.

Main Research Variables: Women's perceived informational, emotional, and decisional support needs, current self-care practices, and satisfaction with the service provided.

Findings: Women under age 50 (n = 54) wanted information on breast cancer screening, risk of breast cancer, lifestyle options to lower risk, and hormone replacement therapy; older women (n = 43) wanted information on risk of breast cancer, lifestyle options, breast cancer screening, and chemoprevention. More than 75% of all women wanted information to help them make decisions on breast cancer prevention options, benefits, and risks. The satisfaction survey (N = 61) revealed that most women's needs were met.

Conclusions: Support needs were consistent with the literature that focused primarily on younger women seeking genetic counseling. Proactive planning assisted with addressing the needs of these women.

Implications for Nursing: A previsit questionnaire facilitates individualized proactive planning before the visit. However, further assessment of self-care practices and emotional needs is required. Interventions should evaluate outcomes, such as accurate risk perception, lifestyle changes, screening follow-through, and decision quality. Advanced practice nurses require specialized skills, including evidence-based risk communication, behavior modification, and decision support.

Key Points . . .

- ▶ Advanced practice nurses can facilitate proactive planning to identify the individualized informational, emotional, self-care, and decisional support needs of women at high risk for breast cancer.
- ▶ In addition to breast cancer prevention options, more younger than older high-risk women want information about hormone replacement therapy.
- ▶ Decision support is needed for women considering genetic testing, chemoprevention, and prophylactic mastectomy.
- ▶ With the rapidly evolving research in breast cancer prevention, the challenge is to maintain an evidence-based service for women at high risk for breast cancer.

occur in women over age 50, with only 22% occurring in women under 50 (National Cancer Institute [NCI], 2001). In addition to increasing age, other major risk factors for breast cancer include family history of breast cancer, prolonged menstrual history, nulliparity or giving birth to the first live child at age 30 or older, and history of atypical hyperplasia or lobular carcinoma in situ (Gail et al., 1989; Gross, 2000; Vogel, 2000). Prevention options for high-risk women may include healthy lifestyle practices, chemoprevention, prophylactic mastectomies, and breast cancer surveillance (Gross; Vogel). However, limited evidence is available to support many of these preventive measures. With the increasing complexity of knowledge in breast cancer prevention, advanced

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Breast health is an important concern for women. The high incidence of breast cancer, global breast health initiatives, and results of breast cancer chemoprevention trials have appeared to heighten the awareness of and concern about breast cancer risk. Most breast cancers

practice nurses (APNs) are challenged to understand and address women's support needs by maintaining an evidence-based practice that promotes health and prevents illness.

The High-Risk Breast Assessment Clinic at the Ottawa Regional Women's Breast Health Centre of the Ottawa Hospital is a new, comprehensive, breast-health service targeted specifically for high-risk women who are concerned about their breast cancer risk but not necessarily eligible for genetic counseling. Women seen in the clinic are eligible for a referral to the genetic counselor if they have a minimum 20% lifetime breast cancer risk, based on the Claus risk prediction model, or when a genetic mutation is known to be in their family (C. Gilpin, personal communication, November 30, 2000). Women are eligible for the High-Risk Breast Assessment Clinic if they meet any of the absolute criteria: (a) family history of breast or ovarian cancer in two or more first- or second-degree relatives, (b) breast cancer occurring in one first- or second-degree relative when bilateral or premenopausal in onset, (c) atypical hyperplasia, (d) lobular carcinoma in situ, or (e) a positive genetic screen. Women also are eligible if they have cumulative risk factors resulting in a 1.66% or greater five-year risk of breast cancer using the Breast Cancer Risk Assessment Tool (NCI, 2000).

An APN acts as the entry point to the clinic by reviewing all consults and telephoning women prior to mailing out a previsit questionnaire. Using the previsit questionnaire, a multidisciplinary team of breast-care experts consisting of an APN, oncologists, surgeons, a nurse research coordinator, a genetic counselor, radiologists, radiology technologists, and a social worker collectively determines the prevention and screening options for each woman and identifies team members most appropriate to provide counseling and care. Services include breast cancer risk assessment, options for breast cancer prevention and early detection, supportive care (e.g., information, emotional counseling, guidance in decision-making), clinical breast examination (CBE), diagnostic imaging, and clinical management recommendations. Follow-up care is based on women's breast cancer risk and tailored to women's selected prevention options. For example, a woman who is not performing breast self-examination (BSE) monthly because of lack of confidence is assessed for readiness to learn, may be shown a video and demonstration, and is reassessed if scheduled for a return visit. In collaboration with the multidisciplinary team, the APN provides leadership in the development, implementation, and evaluation of the clinical program.

The purpose of this continuous quality improvement project, undertaken by an APN and a graduate nursing student, was to further understand the support needs of women at high risk for breast cancer and enhance the evidence-based service within this new high-risk breast assessment clinic. This project involved a literature review on the support needs of high-risk women, identification of the needs of women at the new clinic, analysis of women's satisfaction with the clinic service, and identification of implications for practice, research, and the APN role.

Literature Review

Support is the provision of information, help, and emotional comfort to enhance coping and feelings of empowerment, make better health-related decisions, minimize dis-

tress, and promote health, self-care, and appropriate use of health services (Stewart, 1995). In this article, support includes addressing informational, emotional, self-care, and decision-making needs.

Informational and Emotional Support Needs

Support needs for high-risk women have focused predominantly on younger women referred for genetic counseling (Audrain et al., 1998; Hallowell, Murton, Statham, Green, & Richards, 1997; Hopwood et al., 1998; Lerman et al., 1996; Lloyd et al., 1996; Tessaro, Borstelmann, Regan, Rimer, & Winer, 1997), whereas only two studies identified the needs of women who were not seeking genetic counseling (Chalmers, Thomson, & Degner, 1995; Richardson, Mondrus, Deapen, & Mack, 1994). In six of these eight studies, personal risk interpretation was a need that was identified either directly by the women (Audrain et al.; Chalmers et al.; Hallowell et al.) or indirectly by inaccurate self-perception of risk (Hopwood et al.; Lloyd et al.; Richardson et al.). Other needs included information about breast cancer prevention and detection (Audrain et al.; Chalmers et al.; Hallowell et al.; Lloyd et al.), emotional support (e.g., allowing women to verbalize, providing specific strategies for managing stress, speaking with other women in similar situations) related to the psychological stress of being at risk (Audrain et al.; Chalmers et al.; Hopwood et al.; Lerman et al., 1996; Lloyd et al.), bereavement counseling to cope with having a family member with breast cancer (Chalmers et al.; Hopwood et al.; Lloyd et al.), and decision support for genetic testing (Audrain et al.; Tessaro et al.).

Self-Care and Decision Support Needs

The American Institute for Cancer Research (AICR) (1997) estimated that breast cancer risk can be reduced by one-third to one-half through healthy lifestyle practices. However, no recommendations exist specifically for high-risk women, and the efficacy of many lifestyle practices remains controversial given the limited and sometimes conflicting evidence (Freudenheim, 2001; Vogel, 2000). Primary prevention aimed at decreasing breast cancer risk that requires self-care includes limiting alcohol consumption (Longnecker, 1994), eating more fruits and vegetables (AICR; Gandini, Merzenich, Robertson, & Boyle, 2000), increasing physical activity (Friedenreich, Thune, Brinton, & Albanes, 1998; Verloop, Rookus, van der Kooy, & van Leeuwen, 2000), and avoiding excess body weight if postmenopausal (Trentham-Dietz et al., 1997).

Prophylactic mastectomy and chemoprevention are primary prevention options that are potentially difficult decisions. The decision for prophylactic mastectomy requires considering the psychological distress, risks of major disfiguring surgery, and benefit of lowering breast cancer risk by 90%–95% (Hartmann et al., 1999; Klijn, Janin, Cortes-Funes, & Colomer, 1997). In addition, the prophylactic surgery option usually is reserved for women with a genetic mutation (Armstrong, Eisen, & Weber, 2000). Women who decide to take tamoxifen for chemoprevention must weigh the potential benefits and potential harms. Potential benefits include breast cancer and bone fracture risk reduction, whereas potential harms include increased uterine cancer risk, side effects, and thromboembolic events, such as deep vein thrombosis, stroke, and pulmonary embolism (Chlebowski & Collyar, 1999; Fisher et al., 1998).

Project Methods

Secondary prevention employs strategies to calculate risk and screening to find cancer early (Mahon, 1995). Factors considered in breast cancer risk prediction models include advancing age, family history of breast cancer, menstrual history, age of first live birth, and history of atypical hyperplasia or lobular carcinoma in situ (Armstrong et al., 2000; Gail et al., 1989; Gross, 2000; Vogel, 2000). Women may decide whether to seek personal risk assessment. Risk assessment also includes assessing genetic susceptibility for women with a strong family history of cancer; these women may need decision support when considering genetic testing. In a study of 98 healthy women attending genetic counseling, 95% wanted information on genetic benefits, limitations, and risks; 63% wanted advice and recommendations for genetic testing; and 50% wanted to discuss personal values related to genetic testing (Audrain et al., 1998).

Another secondary prevention strategy is breast cancer screening. Evidence for screening in high-risk women is not available. Women need assistance understanding the variations of current guidelines as they relate to their individual risk status and make decisions about their personal plan for screening. Screening mammography lowers mortality from breast cancer in women aged 50–69 by 25%–30% and in women aged 40–49 by 15% (Kerlikowske, 1997; Swedish Cancer Society & the Swedish National Board of Health and Welfare, 1996). Monthly BSE is encouraged by most professional groups, despite a trial of 267,040 Shanghai women that revealed no change in mortality rates when women in the control group were compared with those who received BSE instruction (Thomas et al., 1997). The Shanghai study concluded insufficient evidence existed to recommend BSE.

Interpretation of the evidence has resulted in variations in screening guidelines. The American Cancer Society (2001) breast cancer screening guidelines stated that all women over age 40 should perform BSE monthly and have a yearly CBE and mammogram, whereas women aged 20–39 should perform BSE monthly and have a CBE every three years. The Canadian Cancer Society (2002) guidelines stated that women aged 50–69 should perform BSE regularly and have a CBE and mammogram every two years, whereas women aged 40–49 should perform BSE regularly and have a CBE every two years. Breast cancer screening guidelines in Ontario for high-risk women aged 40 and older with one or more relatives with breast cancer (or starting 10 years younger than the youngest affected relative, but not before 30 years of age) include BSE monthly, CBE every 6–12 months, and mammogram yearly (Ontario Cancer Genetics Network, 1999).

Summary

High-risk women want information on their personal risk for developing breast cancer and strategies for breast cancer prevention and early detection. Emotional support needs focus primarily on coping with the stress that occurs when a woman knows she is at risk and has a family member with breast cancer. High-risk women considering genetic testing need decision support. When making difficult decisions about chemoprevention and prophylactic mastectomy, women are likely to require support. However, most support needs identified in the literature were focused more narrowly on subgroups of high-risk women seeking genetic counseling. Minimal literature discussed the support needs of high-risk women in general.

Following telephone consultation with the APN, the self-assessment questionnaire was mailed to all women referred to the high-risk breast assessment clinic with instructions to return it within two weeks by mail, by fax, or in person. Clinic staff booked an appointment with the women within one month of receiving the questionnaire. The questionnaire provided the multidisciplinary team with information to calculate risk, identify individual support needs and expectations, identify current lifestyle and screening practices, and proactively plan care. The Ottawa Decision Support Framework (O'Connor et al., 1998) and knowledge of primary and secondary breast cancer prevention were used to guide its development.

To ascertain women's satisfaction with the service provided in the clinic, a semistructured satisfaction survey was mailed with a self-addressed, stamped return envelope. The survey was mailed in May 2000 to all women seen in the clinic between July 1999 and May 2000. The satisfaction survey, based on a survey by the Picker Institute (2000) and Picker Institute Europe (2002), was not psychometrically tested.

Project Results

Demographics

Researchers analyzed questionnaires for all 97 women seen between July 1999 and May 2000 to identify women's previsit needs and visit expectations. Of the 97 women, 54 were under age 50 with the typical women being 41 (range 25–49), having a 1.5% five-year risk of breast cancer (range 0.1%–4.0%), and having a family history of breast cancer with 78% having family histories that deemed them eligible for genetic counseling. The typical woman aged 50 and older was 57 years old (range 50–70), had a 3.3% five-year risk of breast cancer (range 0.7%–8.1%), and had a family history of breast cancer, with 54% eligible for genetic counseling. Most women were Caucasian (83% of the younger women versus 98% of the older), all spoke English, and most had completed postsecondary education (89% of the younger women versus 81% of the older).

Table 1. Self-Care and Screening Practices

| Practice | Age < 40 (N = 24) | | Age 40–49 (N = 30) | | Age 50+ (N = 43) | |
|------------------------------------|----------------------|----|-----------------------|----|---------------------|----|
| | n | % | n | % | n | % |
| Mammogram | | | | | | |
| Within one year | 7 | 29 | 19 | 63 | 37 | 86 |
| Greater than one year | 7 | 29 | 9 | 30 | 6 | 14 |
| Never had one | 10 | 42 | 2 | 7 | – | – |
| Clinical breast examination | | | | | | |
| Within one year | 20 | 83 | 22 | 73 | 36 | 84 |
| Greater than one year | 4 | 17 | 8 | 27 | 7 | 16 |
| Breast self-examination | | | | | | |
| Monthly | 10 | 42 | 15 | 50 | 20 | 47 |
| Every 2–6 months | 9 | 38 | 11 | 37 | 15 | 35 |
| Every 7–11 months | – | – | 2 | 7 | 2 | 5 |
| Once a year | 2 | 8 | – | – | 3 | 7 |
| Never | 3 | 13 | 2 | 7 | 3 | 7 |

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

Table 2. Lifestyle Practices

| Practice | Age ≤ 49 (N = 54) | | Age 50+ (N = 43) | | Both Groups (N = 97) | |
|---|----------------------|----|---------------------|----|-------------------------|----|
| | n | % | n | % | n | % |
| Consuming more than seven alcoholic drinks per week | 7 | 13 | 6 | 14 | 13 | 13 |
| Using tobacco | 5 | 9 | 3 | 7 | 8 | 8 |

Having had a mammogram within the previous year was reported by 86% of women aged 50 and older, 63% of women 40–49, and 29% of women under 40 (see Table 1). Women aged 40–49 were less likely to report having had a CBE within the last year (73%) compared with the older or younger groups of women (84% and 83%, respectively). Overall, 46% of the women stated that they practiced monthly BSE, although they reported varying degrees of confidence with their ability.

For all women, 13% consumed more than seven alcoholic drinks a week and 8% smoked (see Table 2). Physical activity, intake of fruits and vegetables, and body weight were not documented routinely; however, many women were observed to have excess body weight.

The main reason for referral was having a family history of breast cancer. Other reasons included confirmation as a breast cancer gene carrier or a desire for information on the current chemoprevention trial.

Support Needs

The most common information needs identified, in order of importance, by more than half of the women in both groups were personal risk factors, breast cancer screening, lifestyle options, steps in decision making about breast cancer prevention, chemoprevention trial, hormone replacement therapy, genetic testing, and the use of tamoxifen (see Table 3). The main differences for information needs were that more women under age 50 wanted to know about breast cancer screening (93% versus 77%) and hormone replacement therapy (70% versus 54%), whereas more older women wanted to know about the chemoprevention trial (72% versus 60%). Seventy-five percent of all women identified that information (e.g., options, benefits, risks) would be most helpful in making breast health-related decisions, whereas 62% identified needing guidance in how to consider personal values related to prevention options (see Table 4).

Table 3. Informational Support Needs

| Topics Women Wanted to Discuss | Both Groups (N = 97) | | | Age ≤ 49 (N = 54) | | | Age 50+ (N = 43) | | |
|--------------------------------|----------------------|----|------|-------------------|----|------|------------------|----|------|
| | n | % | Rank | n | % | Rank | n | % | Rank |
| Personal risk of breast cancer | 85 | 88 | 1 | 49 | 91 | 2 | 36 | 84 | 1 |
| Breast cancer screening | 83 | 86 | 2 | 50 | 93 | 1 | 33 | 77 | 3 |
| Lifestyle options | 83 | 86 | 2 | 48 | 89 | 3 | 35 | 81 | 2 |
| Decision making | 66 | 68 | 3 | 37 | 69 | – | 29 | 67 | – |
| Chemoprevention trial | 63 | 65 | – | 32 | 60 | – | 31 | 72 | 4 |
| Hormone replacement therapy | 61 | 63 | – | 38 | 70 | 4 | 23 | 54 | – |
| Genetic testing | 56 | 58 | – | 33 | 61 | – | 23 | 54 | – |
| Tamoxifen | 49 | 51 | – | 28 | 52 | – | 21 | 49 | – |
| Prophylactic mastectomy | 27 | 28 | – | 17 | 32 | – | 10 | 23 | – |

Satisfaction Survey

Sixty-one of the 97 (63%) satisfaction surveys were returned and analyzed. Ninety-three percent of the women were satisfied with their participation in decision making, 90% with the information provided, and 93% with the amount of emotional support (see Table 5). The high level of satisfaction was obvious in comments such as, “This clinic is exactly what I had been searching for after two immediate family members were diagnosed with breast cancer,” and “My appointment there has set high expectations of how healthcare can be provided.” One woman appreciated the emotional support and said, “I was very impressed by the emotional support which is given to a human being by very *human* beings.”

Despite the women’s high level of satisfaction, they had several suggestions for improvement. One woman asked for more “alternative solutions to be available other than Western-based medicine.” Another woman commented, “I was given excellent information and counseling and then sent on my way,” and she was surprised that follow-ups were not planned (women with a minimal increased risk are referred back to their physician with prevention options). One woman suggested that a take-home form be provided that summarized her estimated breast cancer risk and listed options. Finally, 100% of the women stated that they would recommend the clinic to family and friends.

Discussion

Support needs of high-risk women found in the previsit questionnaire were similar to those reported in the literature. The common information needs (e.g., personal risk of breast cancer, healthy lifestyle practices, screening guidelines) are consistent with those identified by women with a family history of breast cancer including younger women seeking genetic counseling (Audrain et al., 1998; Chalmers et al., 1995; Hallowell et al., 1997; Hopwood et al., 1998; Lerman et al., 1996; Lloyd et al., 1996; Richardson et al., 1994; Tessaro et al., 1997). The referring physician, however, may have influenced the need for information on chemoprevention. In this continuous quality-improvement project, women were satisfied with the information and emotional support provided, even though emotional support needs were not explicitly measured. In the clinic, some women discussed their distress related to a family history of breast cancer and consequently received emotional support or ongoing grief counseling. The literature review highlighted emotional and bereavement support needs and suggested that when these needs were not addressed, women experienced

Table 4. Decisional Support Needs

| Support Needs for Making Breast Health-Related Decisions | Both groups (N = 97) | | Age ≤ 49 (N = 54) | | Age 50+ (N = 43) | |
|--|----------------------|----|-------------------|----|------------------|----|
| | n | % | n | % | n | % |
| Information on options, benefits, and risks | 73 | 75 | 41 | 76 | 32 | 74 |
| Guidance in values clarification | 60 | 62 | 32 | 59 | 28 | 65 |
| Learning about sources of information and support | 47 | 49 | 28 | 52 | 19 | 44 |
| Information on how others have made the decision | 37 | 38 | 20 | 37 | 17 | 40 |

higher levels of psychological distress (Hopwood et al.; Kash, Holland, Osborne, & Miller, 1995; Lloyd et al.). Psychological distress was associated negatively with women's adherence to breast cancer screening (Kash, Holland, Halper, & Miller, 1992; Lerman, Kash, & Stefanek, 1994; Lerman et al., 1996).

The high level of adherence to screening mammography for women aged 50 and older at this clinic was consistent with women who were seeking genetic counseling (Evans, Blair, Greenhalgh, Hopwood, & Howell, 1994; Lloyd et al., 1996). The appropriate use of mammography in women under age 50 would require further investigation to determine which is consistent with risk-based recommendations (Ontario Cancer Genetics Network, 1999). At the high-risk breast assessment clinic, cancer prevention self-care needs included performing monthly BSE and establishing healthy body weight.

Women wanted guidance in decision making. More specifically, they wanted information on breast cancer prevention (e.g., options, benefits, risks), as well as help clarifying their values related to prevention options. These results are consistent with decisional support needs of women considering genetic testing (Audrain et al., 1998). After visiting the clinic, women felt comfortable asking questions and were satisfied with their involvement in decision making.

Implications for Practice and Research

Based on the results of this project, practice and research implications include three areas: assessment of needs, interventions to address needs, and further evaluation of the service.

Table 5. Satisfaction With Care

| Aspect of Care | Yes, Definitely/Completely | | Yes, Somewhat | | No Answer | | | |
|-----------------------------|----------------------------|----|------------------|----|-------------|---|------------------|---|
| | n | % | n | % | n | % | | |
| Informational needs met | 55 | 90 | 6 | 10 | – | – | | |
| Emotional needs met | 57 | 93 | 1 | 2 | 3 | 5 | | |
| Involved in decision making | 57 | 93 | 2 | 3 | 2 | 3 | | |
| Recommend clinic to others | 59 | 97 | 2 | 3 | – | – | | |
| | Excellent | | Very Good | | Good | | No Answer | |
| | n | % | n | % | n | % | n | % |
| Overall quality of care | 43 | 70 | 14 | 23 | 2 | 3 | 2 | 3 |

N = 61

Currently, the previsit questionnaire provides insight into the information and decision support needs and allows for individualized proactive planning. The questionnaire now includes further assessment of self-care practices such as body weight and exercise patterns. Nutritional intake is explored at the consultation visit. The assessment of emotional support needs and timing of such an assessment requires careful consideration. Lerman et al. (1996) measured breast cancer-specific distress using the Impact of Event Scale. This scale could be evaluated for its usefulness in clinical practice with measurement made at or before the first visit and again postvisit.

Interventions for women at the high-risk breast assessment clinic include verbal and written general information based on their informational, self-care, and decisional support needs. Subsequent to the findings in this project, a take-home package of personalized information is under development. With a clinical and research focus on nutrition as a prevention strategy, the accessibility to a dietitian, either through referral or as part of the team, is being explored. Yet, the establishment and maintenance of healthy lifestyle practices is a complex process with physical, psychological, social, and cultural implications (Pender, 1996). Therefore, further research is required to determine interventions to address the support needs of high-risk women. In a pilot study by Kash et al. (1995), 20 high-risk women were assigned to either a control group or a six-week psychoeducational intervention group that provided education about personal risk and breast cancer prevention and screening, facilitated problem solving by focusing on active coping, and provided emotional support. Women in the intervention group estimated their risk more accurately, had improved knowledge of breast cancer, and were more adherent to breast cancer screening. Finally, a decision aid consisting of an audio-guided booklet that provides information on breast cancer, risk factors, breast cancer screening, options to lower risk (e.g. lifestyle, tamoxifen, clinical trial), outcome probabilities, others' opinions, and guidance in decision-making was developed and is being evaluated. (Visit www.ohri.ca/programs/clinical_epidemiology/OHDEC/decision_aids.asp to learn more about decision aids and this booklet.) This aid is designed to help women aged 50 and older prepare for consultation with a breast health practitioner and make a decision about chemoprevention (Stacey, 2000).

Improvement in clinical programs requires continuous evaluation of outcomes. One option is to reevaluate support

Table 6. Advanced Practice Nurse Role in Addressing the Needs of High-Risk Women

| Need | Breast Cancer Prevention | Advanced Practice Roles | Women's Self-Identified Needs |
|---|--|---|--|
| Accessibility to health resources | Self-referral or physician referral to breast health services Educational resources Cultural sensitivity | Direct care Act as entry point. Collaborate with women to advocate for breast health. Develop educational resources that are appropriate culturally, socially, and educationally for the population. Develop programs in response to needs of high-risk women. | Practical needs Provide written plan for follow-up and summary of options. |
| Health promotion and illness prevention | Lifestyle practices (e.g., eating fruits and vegetables, physical activity) Avoiding carcinogens (e.g., alcohol, excess body weight, tobacco) Chemopreventive agents (e.g., tamoxifen, investigative therapy) Surgical interventions (e.g., prophylactic mastectomy) Risk identification (e.g., risk factors, genetic susceptibility) Breast cancer screening (e.g., mammography, clinical breast examination, breast self-examination) | Direct care Assess factors that have an impact on healthy lifestyle practices. Provide behavioral modification counseling. Promote self-efficacy. Encourage participation of significant others. Assess risk perception and risk. Determine genetic susceptibility. Provide pregenetic testing education. Interpret risk tailored to each woman. Provide bereavement counseling, organize programs or groups. Education Educate others on healthy lifestyle and screening guidelines based on level of risk. Research Provide evidence-based clinical practice. Participate in studies targeting health promotion. | Priority of information needs Personal risk of breast cancer Healthy lifestyle practice (e.g., physical activity, weight loss, limiting alcohol) Breast cancer screening (e.g., breast self-examination) Investigative agents |
| Appropriate use of technology | Chemopreventive agents Surgical interventions Genetic testing Information and Internet Appropriate means to provide information to women | Direct care Provide evidence-based information to women. Interpret new technologies. Enable women to make informed choices. Guide in decision making. Education Educate others on new technologies—risks, benefits, and impact on care and health. Research Evaluate impact of new technologies on health. Participate in supportive care research (e.g., breast cancer prevention decision aid). Leadership Learn about new technologies. | Decision support needs Provide information on options, benefits, and risks. Help clarify personal values. Guide in decision making for health-related decisions, such as chemoprevention, genetic testing, or prophylactic mastectomy. |
| Participation of consumers | Identify needs. Self-help groups Self-care Clients planning and making health-related decisions | Direct care Empower women to identify their needs. Use previsit self-assessment questionnaire to address their needs. Enable women to be active in planning and making health-related decisions. Collaborate Work with women to identify needs. Advocate for getting these needs met. Research Collate needs from previsit self-assessment. Administer satisfaction survey. Facilitate focus groups. Conduct participatory action research. Perform a community assessment. | Emotional needs Provide support in coping with the knowledge of being at high risk. Practical needs Facilitate women helping other women by participating in research and encouraging women to attend breast health programs. Provide further explanation for the previsit self-assessment |

needs after the visits using a questionnaire similar to the one for previsits. To further evaluate satisfaction with the service, subsequent surveys should be administered at consistent time points after their initial visits. Finally, other interventions in-

fluencing outcomes, such as lifestyle behavioral changes and adherence to screening, decisions made, and chemoprevention could be studied using a continuous quality improvement approach or more formal research.

Implications for the Advanced Practice Nurse Role

Given the complexity of knowledge and skills required in breast cancer prevention, APNs are challenged to maintain evidence-based practice when addressing the needs of high-risk women from both program and individualized perspectives. An oncology APN is a nurse who has graduate education with expanded clinical, theoretical, and research-based knowledge and skills that are used in the provision of care to individuals with an actual or potential diagnosis of cancer (Oncology Nursing Society, 2001; Spross & Heaney, 2000). Although the competencies of APNs are grouped into five main areas (i.e., clinical practice, education, collaboration/consultation, research, and leadership), the effective interaction, blending, and simultaneous execution of the skills, knowledge, judgment, and interpersonal attributes in highly complex practice environments are what characterize advanced nursing practice (Canadian Nurses Association, 2000; Hamric & Spross, 1989). At the High-Risk Breast Assessment Clinic, the APN contributes to program development and evaluation and partners with high-risk women to help them identify and meet their needs (see Table 6). Specialized skills required include risk communication, behavior modification, and decision support.

Risk communication: Helping women understand their risk for breast cancer is an important role for APNs (MacDonald, 1997). Risk perception was not routinely documented in the clinic, although the literature reports that women overestimate their risk for breast cancer, only contributing further to their emotional distress (Hopwood et al., 1998; Lloyd et al., 1996). Most women in the clinic stated that they were relieved because their actual risk was less than their perceived risk; perceived risk now is elicited on the previsit questionnaire. In another study, women had poor recall of their personal risk unless a letter was sent in follow-up to clinic counseling (Evans et al., 1994). To help women understand risk, APNs need to clarify women's perceptions of their risk and provide written and verbal explanations. APNs also can provide education about breast cancer genetic testing and verify women's eligibility for genetic testing. In one study, APNs proved to be equally effective in providing education about genetic testing when compared to genetic counselors (Bernhardt, Geller, Doksum, & Metz, 2000).

Behavior change: APNs can enable women to identify their needs for action and support women to adopt healthy lifestyle practices. Specific areas that require consideration are performing monthly BSE and weight management. Using the principles of behavior change theory, APNs can provide guidance in assessing multiple factors affecting healthy practices, providing appropriate counseling interventions, and evaluating outcomes through research (Bandura, 1997; Pender,

1996). In a review of studies using the concept of self-efficacy in cancer prevention, several studies demonstrated that higher self-efficacy predicted increased confidence in performing BSE and participation in breast cancer screening (Lev, 1997). APNs should consider the roles of others, such as dietitians, social workers, and exercise specialists in addressing the needs of high-risk women. Zimmerman and Connor (1989) found that family members had a positive influence on changing exercise and fat consumption behaviors.

Decision support: APNs can interpret new options, such as chemoprevention, that are available for high-risk women and enable women to make decisions that are informed, consistent with personal values, and acted on, and ones in which both the decision and process used to reach the decision are satisfactory (O'Connor et al., 1998). A theoretical approach that APNs could consider for guiding high-risk women in decision-making is the Ottawa Decision Support Framework (O'Connor et al.; Stacey, Jacobsen, & O'Connor, 1999). This framework uses a three-step process to assess determinants of decisions to identify needs, provide decision support to address suboptimal determinants, and evaluate the decision-making process and outcomes. Determinants of decisions include perceptions of the decision (e.g., knowledge of options, benefits, risks, expectations of outcomes, values associated with outcomes), perceptions of others, personal and external resources, and characteristics of the client and practitioner. Decisions about chemoprevention, genetic testing, and prophylactic mastectomy fit well with this framework, given that these decisions have no clear correct choice, they have uncertain outcomes, patients' values influence the decisions, and more effort is required for deliberation than implementation.

Conclusion

Given the informational, emotional, self-care, and decisional support needs of high-risk women and new prevention options, such as chemoprevention, breast cancer risk is an important but complex health issue. By addressing their needs, nurses can help women to understand their risk more accurately, feel reassured and satisfied with their care, and take steps forward in cancer prevention. This project indicated that risk management can be individualized and adaptive. APNs with advanced knowledge and skills that include program development, risk communication, behavior modification, and decision support have an important role in addressing the support needs of high-risk women and maintaining an evidence-based service.

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