Understanding contralateral prophylactic mastectomy decision making in women with early-stage breast cancer

By Minda J. Dwyer, ANP-c, MSN; Judith R. Greener, PhD, MA; and Sarah Bauerle Bass, PhD, MPH

A growing proportion of women with early-stage breast cancer without familial or genetic risk factors are electing contralateral prophylactic mastectomy (CPM)—even though the procedure is not clinically indicated and confers no clear survival benefit. Heightened emotions accompanying a breast cancer diagnosis can drive some women to make a quick decision to undergo CPM. Instead, these women should be encouraged to deliberate longer and choose the treatment most consistent with their needs and values. Nurse practitioners are well positioned to provide a holistic assessment of each woman's circumstances and assist her in making a treatment decision aligned with these circumstances. The purpose of this article is to identify and discuss strategies to guide women during the days and weeks following a breast cancer diagnosis—as they consider treatment options such as CPM.

KEY WORDS: **contralateral prophylactic mastectomy, CPM, early-stage breast cancer, treatment decision making**

Breast cancer, a complex and pervasive disease, is the most common cancer among women in the United States and the second most lethal cancer following lung cancer.[1] Most women diagnosed with breast cancer choose surgery as all or part of their treatment. On a continuum of most conservative to most radical, it ranges from breast-conserving surgery, which includes lumpectomy or partial mastectomy, to total mastectomy.[1] In recent decades, the proportion of women electing mastectomy to treat breast cancer, including contralateral prophylactic mastectomy (CPM), which removes the unaffected breast as well as the affected breast, has risen dramatically.[2,3] For women with early-stage breast cancer and without familial or genetic risk factors, CPM is not clinically indicated and does not confer a clear survival benefit.[4] Why then do so many women make this choice? Is there anything that nurse practitioners (NPs) can do to educate women regarding the possible harms of CPM?

A primary factor influencing the choice of CPM is fear, including generalized fear and anxiety about cancer.

Background

A review of SEER (Surveillance, Epidemiology, and End Results) registry data for the period 2002 to 2012 reflected an increase in the rate of CPM from 3.9% to 12.7% among women with stages I to III breast cancer.[5] This increase was consistent across all ages, races, and geographic locations, and this trend does not appear to have reached a plateau.[6] A National Cancer Database analysis showed that the increase in mastectomies between 1998 and 2011 among women with early-stage disease was driven by those electing CPM, from 5.4% in 1998 to 29.7% in 2011.[7] This increase in CPM rates, particularly among patients with early-stage disease, is reflected among women with ductal carcinoma in situ (DCIS), often considered stage 0 breast cancer. From 1998 to 2013, the rate of CPM among patients with DCIS undergoing mastectomy rose from 5.4% to 37.5%.[3]

Various organizations have published guidelines or opinions related to CPM. National Comprehensive Cancer Network (NCCN) guidelines discourage CPM in women who lack a genetic predisposition to breast cancer.[8] The American Society of Breast Surgeons' 2016 consensus statement concludes that, with the possible exception of women with known *BRCA1* or *BRCA2* mutations or elevated risk of a genetic mutation, CPM does not appear to be associated with a survival benefit.[9] Based on the absence of evidence demonstrating a benefit of CPM versus breast-conserving surgery and radiation, the decision to have bilateral breast removal is considered a patient-motivated, preference-sensitive decision rather than one driven by the healthcare community.[10–12]

The increase in the CPM rate is especially concerning as it relates to women with early-stage breast cancer who have a minimal annual risk for developing contralateral disease.[13] The procedure is associated with substantial physical risks, including lymphedema, surgical-site infections, and perioperative complications, particularly in the prophylactic breast. In addition, CPM and its increased morbidity incur higher healthcare costs—close to an additional $12,000 per woman compared with a unilateral mastectomy.[14–17] In the first study to prospectively address the psychosocial impact of CPM among patients with nonhereditary breast cancer, women who had CPM, compared with those who did not undergo CPM, experienced an overall decrease in quality of life (physical, social, emotional, and functional well-being) and an increase in body-image concerns at 18 months after surgery.[18] No difference in decisional regret between the groups was observed. Based on what is known about CPM and its potential adverse health consequences, healthcare providers (HCPs), including NPs, are advised to discourage CPM for women with cancer in one breast who are not considered to be at high risk for disease recurrence or a second primary cancer in the contralateral breast.[19,20]

Factors influencing the CPM decision

Literature focused on patient-reported and psychosocial individual-level information has added insight into factors that influence the CPM decision, as well as how these factors are addressed within the decision-making environment. Factors linked to women choosing CPM include a desire to avoid a future need for mammograms, overestimation of the risk of cancer in general or contralateral cancer in particular, a desire for breast symmetry after unilateral mastectomy, inadequate understanding of treatment, perceived survival benefit, use of CPM by high-profile celebrities, advice of friends and family, and rush to decision making.[21–29]

A primary factor influencing the choice of CPM is fear, including generalized fear and anxiety about cancer and concern about another cancer or recurrence.[26,28,30] For some women, fear drives a desire to be proactive and in control of their disease by quickly choosing surgically aggressive treatment

rather than weighing all available options.[31,32] For others, fear is tied to perception of risk, with concern about a potential future cancer in the contralateral breast or elsewhere in their body driving the decision. Although many women understand and/or have been counseled about the fact that CPM does not confer a survival benefit, they perceive any risk as unacceptable.[32,33] Finally, fear can manifest as a feeling of vulnerability to a future, inevitable cancer recurrence.[22,34] The CPM decision can falsely serve as a potential weapon against this inevitability.

Tempering emotional reactions to reach a reasoned decision

For many women, receiving a breast cancer diagnosis produces a dense fog of complex emotions through which they must navigate as they consider treatment options and make a decision.[31] With the heightened emotions that accompany a cancer diagnosis, fear in any form can drive women to make quick and pressured decisions.[35] Ager et al suggested that HCPs, when discussing potential treatment options with patients, assess these women's expectations for relief from cancer fear, tolerability for any level of risk, and perceived vulnerability to cancer.[36]

Literature has provided support for placing greater emphasis on managing women's emotional reactions to a breast cancer diagnosis within the context of helping them understand the risks and benefits of various treatment options. Particularly for women with early-stage breast cancer, HCPs can offer support during the decision-making process by creating an environment designed to ameliorate stress rather than heighten it. The objective is to prevent an impulsive, emotionally driven decision that is inconsistent with the patient's healthcare needs.[12] NPs are particularly well positioned to help patients select a treatment that is most concordant with their needs and values.

Clinical implications

Women with newly diagnosed early-stage breast cancer are best served clinically by a multidisciplinary team approach. In many cases, consultations with specialists in oncology, surgery, and perhaps plastic surgery are scheduled, along with an encounter with an NP as part of the clinical management team. This lattermost consultation can help women process all the information they are receiving.[37] It also gives NPs a unique opportunity to undertake a thorough, holistic assessment during this postdiagnosis period.

Elements of the NP encounter

Nurse practitioners are skilled in developing rapport and fostering a trusting relationship with patients that is characterized by respect, empathy, and authenticity.

Elicit key information

Active, nonjudgmental listening techniques help elicit key information from women as they move toward deciding on a treatment path. A well-timed encounter in the immediate postdiagnosis period can result in a therapeutic relationship in which NPs can truly "walk alongside" patients as sources of both information and support. The goal is to involve patients as active participants in the treatment decision process.[38] Elements in the initial clinical encounter should include:

- Knowledge: Assess patients' understanding of clinical information they have received, provide clarification as needed, particularly regarding risks/benefits of treatment options.
- Influence of others: Assess the role of patients' family and friends (advice and shared experiences, influences of media and social media).
- Practical factors: Assess patients' concerns regarding potential impact of treatment options on routine functioning at home and at work.
- Potential barriers to decision making: Assess patients' psychiatric status, identify the potential need for referral for additional psychiatric evaluation (eg, excessive anxiety, depression, sleep disorder related to diagnosis).
- Values and priorities: Assess patients' overarching attitudes to help determine their most important considerations.
- Decision-making styles: Assess patients' previous experiences with making decisions regarding their healthcare.

Encourage active involvement and taking time with decision making

Hack et al studied 205 women with breast cancer 3 years after diagnosis.[39] Women who reported active involvement in treatment decision making at baseline reported improved clinical outcomes, including better quality of life and physical and social functioning, compared with women less involved in decision making. This finding suggests the importance of assessing patients' understanding of information presented. NPs should guide women newly diagnosed with breast cancer to take time to think about the treatment decision, particularly because fear and anxiety, so common in the postdiagnosis period, can impair the ability to process treatment-related information.[35] During this initial clinical encounter, NPs should encourage patients to allow the intensity of these immediate reactions to subside before committing to a treatment path and deliberate longer to make

the treatment choice most consistent with their needs and values.[35]

Use tools

Use of decision aids can facilitate the assessment of patients' knowledge and preferences.[40] The Breast Cancer Surgery Decision Quality Instrument (BCS-DQI) is designed to assess the knowledge, goals, and concerns of patients with early-stage breast cancer, specifically as these relate to surgical intervention. The BCS-DQI consists of multiple-choice items related to three domains of breast cancer and treatment: knowledge regarding the disease and treatment options, goals/concerns, and involvement in the treatment decision-making process. One study that used the BCS-DQI to assess knowledge and preferences related to surgical treatment decisions in women with early-stage breast cancer found significant deficits in knowledge regarding disease and treatment options among participants. Many women felt that they were not sufficiently involved in their treatment decisions and that, in retrospect, their surgical treatment was not concordant with their goals.[41]

Another useful tool is the Decision Board, a visual aid that has demonstrated utility in presenting information related to adjuvant therapy options.[40] It consists of a series of panels, each depicting a treatment option along with potential risks and benefits. This tool can be used in a face-to-face encounter to inform patients of the range of treatment options available, clarifying the information as it is presented. Questions can be answered in real time to ensure that patients understand the answers.

Dealing with input from physicians/surgeons with regard to CPM

Oncologists' and surgeons' beliefs and communications regarding treatment options can influence patients' decision making. Results of two recent studies have suggested that many women who consider CPM are not knowledgeable about the procedure and do not have comprehensive discussions with their surgeons.[42,43] In addition, more patients were found to choose a procedure if they perceived that their surgeon recommended it—as compared with patients who felt that no recommendation was provided.[43]

Therefore, information presented to patients should include discussion about the potential risks and benefits of different treatment modalities, as well as the risks of disease recurrence without treatment. Some patients may have concerns about recently publicized information calling into question the clinical benefits of chemotherapy for many women with early-stage breast cancer, leading them to decide that surgery may be more beneficial.[44] The goal of the holistic evaluation then is to identify gaps in understanding and clarify information that is clinically relevant for patients, especially with regard to their treatment decision. The *Box* summarizes key information that should be presented to patients who are considering CPM in the setting of early-stage breast cancer.[38]

Other topics for discussion

The clinical review of relevant infor-

Box. Contralateral prophylactic mastectomy: Discussion guide for average-risk women[38]

For most women, the estimated risk of developing cancer in the contralateral breast is 2% to 6% over the next 10 years. Put another way, these women have a 94% to 98% chance of not getting cancer in the opposite breast over the next 10 years or more. In addition:

- Contralateral prophylactic mastectomy (CPM) will not improve women's cure rate for their known cancer.
- CPM will not reduce their risk of cancer recurrence at a distant site.
- Although CPM significantly reduces the risk of cancer on that side, it is not 100% protective. Strong evidence suggests that CPM reduces the relative risk of cancer in the contralateral breast by 90% to 95%. However, breast cancer risk is not completely eliminated with CPM. After CPM, the absolute risk of developing cancer on that side ranges from 0% to 1.5%.
- CPM will not reduce their need for adjuvant therapy, if indicated, for their known cancer.
- The risk of surgical complications at the surgical site (eg, bleeding, infection, healing complications, chronic pain) is approximately twice as high when CPM is performed.
- Complications of CPM may delay treatment for their known cancer, including chemotherapy and radiation that may be recommended after surgery.
- CPM results in permanent numbness of the chest wall (and nipple if preserved).
- Consultation with a plastic surgeon can provide women with detailed information on reconstructive procedures.
- CPM with reconstruction results in an increased number of operations and possibly a longer recovery time.
- Reconstruction procedures without CPM can provide breast symmetry and preserve sensation.
- CPM may have an adverse impact on physical, emotional, and sexual well–being. About 10% of women regret their decision to undergo CPM.
- Breastfeeding is not possible after CPM.
- Women who undergo CPM do not need mammograms or routine breast imaging for cancer screening after surgery.
- Continued close surveillance with mammograms or other breast imaging is a reasonable alternative to CPM.

mation should contain elements of self-care that patients can incorporate as part of a holistic approach to treatment. NPs can provide counseling on the role of lifestyle modification (eg, healthful diet, regular exercise, stress-reducing techniques, smoking cessation) to optimize clinical outcomes.[8]

A comprehensive discussion should include the role of imaging (magnetic resonance imaging of the breast, ultrasound of the breast, mammography), laboratory tests (histologic typing, pathology results, estrogen-receptor testing), and the full range of clinical interventions available (lumpectomy and radiation, mastectomy). The NCCN offers a thorough web-based resource that provides information about the disease and treatment options.[45] It contains tools to guide patients with regard to questions to ask HCPs, as well as links to decision aids, support groups, and other resources. Providing resources that patients can access as questions/concerns arise can foster their self-efficacy, resulting in decreased anxiety and an enhanced sense of control. It also may enhance the perceived benefits of making a decision guided by patients' own values and attitudes.[38]

Conclusion

The prevalence of CPM among women with early-stage breast cancer is a major health concern. Understanding the emotional milieu in which women deliberate about treatment options in the aftermath of a diagnosis of early-stage breast cancer calls for a mediating presence, which can be filled by an NP. NPs who work in women's health and oncologic settings can assist patients in making treatment decisions that are congruent with their needs and values. NPs also can offer appropriate tools to ensure women understand their treatment options, provide supportive care based on their fears and concerns, and offer a holistic assessment aligned with critical health realms. ●

Minda J. Dwyer is a Senior Clinical Quality Specialist at Optum Health. Judith R. Greener is Research Assistant and Sarah Bauerle Bass is Associate Professor of Social and Behavioral Sciences and Director of the Risk Communication Laboratory, both at Temple University, College of Public Health, in Philadelphia, Pennsylvania. **The authors state that they do not have a financial interest in or other relationship with any commercial product named in this article.**

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