



Practitioner Opinion on Contralateral Prophylactic Mastectomy: How Do We Steer a Patient-Driven Discussion?

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ABSTRACT

Background. Contralateral prophylactic mastectomy (CPM) is increasing despite a recent statement from The American Society of Breast Surgeons discouraging average-risk women with unilateral breast cancer (BC) from undergoing CPM. The objective of our study was to conduct a needs assessment of BC health practitioners to gather information about their opinions, attitudes, and experiences surrounding CPM.

Methods. The Ottawa Decision Support Framework was the theoretical framework for the development of the interview guide. Semistructured interviews were conducted until data saturation with a convenience sample of 16 BC practitioners (Ontario, Canada), including oncologic and reconstructive surgeons, medical oncologists, and nurse navigators.

Results. Nearly all practitioners identified the discussion regarding CPM as patient-initiated. The majority of practitioners (13/16) described their role as supporting the patient in the decision-making process. Practitioners described educating patients on the lack of survival benefit and in general discouraging CPM. Practitioners agreed that most patients demonstrate decisional conflict (11/16) as a

barrier to decision-making, and it is a challenge to realign patients' understanding and expectations. Almost all practitioners (15/16) identified a need for information materials to help educate patients on the risks and benefits of CPM and to help realign expectations.

Conclusions. Practitioners have identified CPM in average-risk women with unilateral BC as a patient-driven phenomenon that is on the rise, despite highlighting the increased risk of complications and lack of survival benefit. Our practitioner needs assessment identifies the need for a dynamic decision aid to help guide the shared decision-making process for practitioners and patients.

The risk of developing a contralateral breast cancer (BC) in a woman with average-risk, nonhereditary BC remains low at 0.3–0.5% per year.^{1,2} Yet, the rate of contralateral prophylactic mastectomy (CPM) has increased from 2% to 5–15% in the United States during the past 10 years.^{3–6} Many women report that reducing the risk of developing a contralateral BC and improving their survival are important factors when choosing to proceed with a CPM.⁷ However, CPM does not improve overall or disease-specific survival.^{8,9} CPM may offer a psychological benefit related to reduced worry over cancer recurrence, positive body-image, and contentment with quality of life.^{8,10}

The American Society of Breast Surgeons (ASBrS) recently published a position statement on CPM best practices and a framework for shared decision making. The consensus group concluded that CPM should be discouraged for an average-risk woman with unilateral BC, because most women will obtain no oncologic benefit from the procedure.¹¹ CPM is not associated with a survival

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benefit and doubles the risk of surgical complications when performed at the same time as the cancer surgery.¹² Conservation of the contralateral breast provides equivalent survival outcome and should be recommended to all appropriate candidates.¹² The ASBrS encourages patients to engage in an informed discussion with their surgeon discussing the risks and benefits of CPM with consideration of their personal values and preferences.¹¹ Shared decision making is important to address misconceptions of future cancer risk, risk/benefits of CPM, potential long-term outcomes of CPM on body image and sexuality, and to ensure patient preferences are considered.¹¹

The objective of our study was to conduct a needs assessment of Canadian BC practitioners, including surgeons, medical oncologists, and nurses, to gather information about their opinions, attitudes and experiences when recommending treatment and supporting their BC patients considering CPM.

METHODS

Semistructured interviews were conducted until data saturation with a convenience sample of BC practitioners. Data saturation was determined at the point when no additional new data or themes were being raised during practitioner interviews. Oncologic and reconstructive surgeons, medical oncologists, and nurse navigators were sampled. Practitioners were sampled from both academic and community practice settings in Ontario, Canada. This study was approved by the Sunnybrook Health Sciences Centre Research Ethics Board.

Interviews were audio recorded and conducted either in person or over the phone. Interview questions regarding CPM explored the initiation of the discussion, perceived patient challenges, challenges faced by the practitioner, advantages/disadvantages to CPM, roles in decision making, and the overall decision-making process. The discussion on CPM was focused on newly diagnosed cancer patients. The Ottawa Decision Support Framework (ODSF) was the theoretical framework for the development of the interview guide.¹³ The ODSF has been used to guide previous needs assessments of both individual and population decision-making. It has three main elements: (a) decisional needs, (b) decision quality, and (c) decision support. This study focuses on the first element, identifying decisional needs.

For interview questions with precoded responses, descriptive statistics (frequencies and percentages) were used to summarize the results. The responses to open-ended questions were reviewed and tabulated using descriptive statistics by a single reviewer.

RESULTS

Demographics

From July 2016 until July 2017 a sample of 16 BC practitioners was interviewed in Ontario, Canada. Practice locations included two urban academic centers in Toronto, Ontario, and five community hospitals. Practitioners interviewed were 62.5% female and from various BC disciplines (Table 1). Included in the sample were 11 surgeons (oncologic and reconstructive), 3 medical oncologists, and 2 nurses. Half of practitioners practiced in an academic setting (8/16) and the other half in a community setting. Responses did not differ based on practitioner specialty.

Initiating the Discussion Regarding CPM

The majority of practitioners interviewed (15/16) identified breast-conserving surgery versus mastectomy as the most important surgical decision that patients with unilateral BC have to make. Three practitioners additionally identified CPM as an important decision.

Nearly all practitioners (15/16) identified the discussion regarding CPM as patient-initiated. If the topic is raised by the patient, most practitioners discuss the lack of survival benefit or risk of contralateral BC (13/16).

“In general I tell them in the absence of a known inherited mutation that there is no impact on their survival from breast cancer by getting a prophylactic mastectomy on the other side” (Practitioner (Pt) 5).

TABLE 1 Practitioner demographics

Characteristic	No. (%)
Age	
30–39	6 (37.5%)
40–49	4 (25.0%)
50–59	5 (31.3%)
60–69	1 (6.2%)
Gender	
Male	6 (37.5%)
Female	10 (62.5%)
Practice discipline	
Surgical oncologist	6 (37.5%)
General surgeon	4 (25.0%)
Plastic surgeon	1 (6.2%)
Medical oncologist	3 (18.8%)
Nurse	2 (12.5%)

Some also discuss the cosmetic result or reconstruction options (5/16) and complications and risks of CPM surgery (4/16).

Four practitioners start the discussion by asking questions to understand the reasoning behind the interest to undergo CPM, and two practitioners refocus the discussion on treating the current BC. Although all practitioners have a discussion to inform and address misconceptions about CPM, four practitioners acknowledged that patients who are anxious about ongoing surveillance and biopsies may benefit psychologically:

“If they are very, very frightened about a new cancer and can’t imagine going through screening anymore they probably are relieved to be making that decision” (Pt 5).

Making the Decision for CPM

Eight different symptoms or signs of decisional conflict that patients may experience in regards to the decision about CPM were explored. The number of practitioners who agreed with each is summarized in Table 2. Practitioners agreed that anxiety regarding the cancer diagnosis and fear of recurrence are common feelings among patients.

TABLE 2 Making the decision for CPM

Patient experience	No. (%)
Perceived patient emotions	
Distressed or upset	13 (81.3%)
Physical signs of stress	13 (81.3%)
Constantly thinking about the decision	12 (75.0%)
Unsure about what to do	11 (68.8%)
Wavering between choices	10 (62.5%)
Questioning what is important	10 (62.5%)
Delaying the decision	8 (50.0%)
Worried about what could go wrong	6 (37.5%)
Patient decision-making challenges	
Confused from information overload	13 (81.3%)
Unsure about what to do	10 (62.5%)
Lacking information about options	10 (62.5%)
Lacking information on the chances of benefits and harms	10 (62.5%)
Unclear about what is important to them	9 (56.3%)
Feeling pressure from others	9 (56.3%)
Lacking motivation/not feeling ready to make a decision	7 (43.8%)
Lacking the ability to make a decision	6 (37.5%)
Feeling unsupported in the decision	4 (25.0%)

“I address the questions and that sometimes people have a fear of recurrence. And, that fear is actually not really founded based on current management. Because, we’ve improved. And, I talk about the fact that some people feel that anxiety related to recurrence of BC even in the setting of contralateral mastectomy, is not always relieved” (Pt 12).

Four practitioners specifically stated that patients present with misconceptions on CPM improving survivability. Some practitioners identified that patients feel more aggressive treatment in terms of more surgery is better, which is driven by fear of recurrence/death and an overestimation of their risk. Other reasons included competing information (4/16), such as from the media.

Practitioners agreed that most patients demonstrate decisional conflict (11/16) as a barrier to decision-making, and it is a challenge to realign patients’ understanding and expectations.

“I think it’s just the competing information they have from the world and family and friends, and what their medical practitioners are telling them and also their own experience with their body, and journey” (Pt 5).

Advantages and Disadvantages of CPM

The main described advantages and disadvantages to CPM are outlined in Table 3. Practitioners stated a reduction in patient anxiety as the greatest advantage of CPM and increased surgical complications as the greatest disadvantage. Six practitioners specifically identified that CPM eliminates patient anxiety surrounding ongoing breast imaging and biopsies.

“I’m finding more and more that the patient, even if they have had a complication or even if they completely understand the risks and complication rates being double. In their mind they are happier that they’re having bilateral if that was their initial choice” (Pt 14).

Roles in Decision-Making for CPM

The usual role of the practitioner and other individuals, such as a friend or family member, in the decision-making process was generally viewed as supportive. Table 4 summarizes the reasons that make it difficult and easier to support patients’ decision-making for CPM. The ideal patient was described as a well-informed patient who understands why they want it.

TABLE 3 Advantages and disadvantages of CPM

Practitioner responses	No. (%)
Advantages	
Reduced anxiety	15 (93.8%)
Improved symmetry and cosmesis	9 (56.3%)
Reduced contralateral breast cancer risk	5 (31.3%)
Ability to use smaller prosthesis	1 (6.3%)
Disadvantages	
Increased surgical complications	15 (93.8%)
Lack of survival advantage	7 (43.8%)
Impact on psychological well being	7 (43.8%)
Increased operative time and costs	3 (18.8%)
Losing ability to breast feed	1 (6.3%)

TABLE 4 Factors that help and hinder practitioners in supporting patients' decision

	No. (%)
Patient factors that hinder decision-making process	
Adamant/mind set on CPM and not listening to medical facts	5 (31.3%)
Not understanding the lack of survival advantage	3 (18.8%)
Extreme cancer fear/anxiety	2 (12.5%)
Psychiatric illness or extreme anxiety or cancer fear	2 (12.5%)
Conflicting advice from different practitioners	1 (6.3%)
Seeking alternative medicine	1 (6.3%)
Not enough time to give support needed	1 (6.3%)
Patient factors that ease the decision-making process	
Well informed	10 (62.5%)
Enough time to process the information	5 (31.3%)
Second opinion from another surgeon/colleagues	4 (25.0%)
Nursing/social work/psychological support	3 (18.8%)
Good social support system	2 (12.5%)
Open minded	1 (6.3%)

Decision-Making Process

All practitioners believed that counseling from a health care practitioner is beneficial for patients, and the majority identified a need for information materials to help educate patients on the risks and benefits of CPM and to help realign their expectations (Table 5). The type of content to be included in information materials for patients was discussed with practitioners. The majority of practitioners agreed that a description of invasive BC (15/16), treatment options (15/16), risks and benefits (15/16), and probabilities of the risks and benefits (14/15) was useful content to provide to patients.

TABLE 5 Decision-making process as identified by practitioners

	No. (%)
Patient's methods in decision-making	
Get support from others	16 (100.0%)
Get information on the chances of benefits and risks	14 (87.5%)
Get information on options	12 (75.0%)
Find ways to handle pressure	12 (75.0%)
Consider the personal importance of the benefits and risks	11 (68.8%)
Get information on how others go about deciding	8 (50.0%)
Beneficial resources in decision-making	
Counseling from health care practitioner	16 (100.0%)
Information materials	15 (93.8%)
Discussion groups of people facing the same decision	12 (75.0%)
Content for information materials	
Health condition	15 (93.8%)
Surgical options	15 (93.8%)
Risks and benefits	15 (93.8%)
Issues of personal importance	15 (93.8%)
Probabilities	14 (87.5%)
Format for information materials	
Booklet or pamphlet	15 (93.8%)
Internet	14 (87.5%)
Videos	10 (62.5%)

DISCUSSION

In our study, practitioners identified decisional conflict amongst patients during the decision-making process for CPM. A consensus statement from the ASBrS discourages the use of CPM in average-risk women with unilateral BC, although also calls for shared decision-making between the patient and practitioner.¹² In our needs assessment, practitioners identify CPM in average-risk women with unilateral BC as a patient-driven phenomenon that is on the rise, despite highlighting the increased risk of complications and lack of survival benefit.

Nearly all practitioners interviewed (15/16) identified CPM as a patient-initiated discussion. The topic is generally not raised in clinic discussions on unilateral BC treatment unless by the patient, yet there is a clear increasing interest and trend towards CPM. Parker et al. conducted a survey of women with early-stage unilateral BC before being seen at their first clinic visit that revealed 50% of women were moderately to extremely interested in CPM.¹⁴ A number of external influences, such as social network and media, affect the decision-making process for CPM.¹⁵ A study conducted by Jaggi et al. revealed a significant influence in surgeon recommendation and rate of

CPM.¹⁶ Patients who were counselled against proceeding with CPM underwent CPM significantly less frequently (1.9%) compared with those who received no recommendation (19.0%).¹⁶ Because CPM is not recommended for the treatment of unilateral BC in average-risk patients, we feel that it is not necessary for physicians to routinely bring up CPM as a treatment option in patients who are not inquiring about it.

Practitioners felt that patients overestimate their risk of developing contralateral BC, driven by anxiety and fear. Other studies also have concluded that average-risk women diagnosed with unilateral BC often overestimate their risk for contralateral BC.^{7,17,18} Abbott et al. revealed that women diagnosed with early-stage BC or DCIS overestimated their risk of developing contralateral BC with an estimated 10-year risk of 31.4% as opposed to actual 6.1%, a value that is likely even lower with the use of hormonal therapy.^{17,19} Women with a high perceived risk were found to have a higher level of psychological distress.¹⁷ Covelli et al. found that patients were choosing CPM as a way to “take control of cancer and manage their fear.”²⁰ Greater cancer worry has previously predicted which patients subsequently underwent CPM.¹⁴ Similarly, Musiello et al. found that fear and anxiety was the most common reason that women request CPM.²¹ Other characteristics previously found to be associated with an increase in CPM rate are young age, large tumor size, family history of BC, lobular histology, multicentric disease, and female surgeon.²²

The primary perceived advantages stated by practitioners for CPM were anxiety reduction and improved cosmesis and symmetry. A study by Agarwal et al. using data from the Surveillance, Epidemiology, and End Results database demonstrated a correlation between an increase in CPM and reconstruction.²² As CPM rate increased from 7.7 to 28.3% during 2000–2010, the proportion of women undergoing reconstruction increased from 18.7% to 46.5%.²³ Ashfaq et al. also demonstrated a strong association between CPM and reconstruction where 46% of women undergoing CPM also underwent reconstruction compared with only 15% of women who did not have CPM.²⁴ A desire for symmetry and improvements in reconstructive surgery outcomes are likely driving forces behind CPM. The parallel increase of bilateral reconstruction along with CPM is potentially troublesome in publicly funded healthcare systems where resources and funding are limited. Previous studies have demonstrated increased associated costs of bilateral mastectomy and immediate reconstruction compared with unilateral mastectomy and immediate reconstruction.^{25,26} In performing CPM, we are reducing the resources available to other patients with no survival benefit.

An increase in surgical complications was the most common disadvantage identified amongst practitioners for CPM followed by lack of survival advantage. Miller et al. found that patients undergoing CPM were 2.7 times more likely to suffer from a major complication involving rehospitalization or readmission compared with patients undergoing unilateral mastectomy.²⁷ Similarly, Osman et al. found a significant increase in 30-day complication rate for patients undergoing CPM with odds ratio of 1.9.²⁸ The ASBrS consensus statement reiterates that there is no known survival benefit associated with CPM and calls for enhanced decision-making guidelines.¹² A meta-analysis by Fayanju et al. similarly concludes that in the absence of hereditary risk factors, there is no survival benefit for CPM, and therefore it should not be offered.²⁹

The main limitation of this study is the relatively small sample size. However, data saturation was reached with this sample size—likely because most practitioners feel similarly about CPM. Despite being conducted in a single province in Canada, we feel that the results of this study are generalizable to other settings given the inclusion of community and academic practitioners. This study focuses on the challenges faced by practitioners during the decision-making process around BC surgery. In Canada, given the universal healthcare system, we did not inquire about decisional conflict secondary to the financial cost of the surgery/reconstruction. In a setting where there may be more financial burden on the patient, such as in the U.S. healthcare system, this may influence a patient against proceeding with CPM.

Our practitioner needs assessment identifies the challenges of shared decision-making around CPM. This is primarily a patient-led discussion that requires engagement of the patient and the practitioner to reach a values-based, educated decision. Patients also may identify other outcomes that they deem as important in choosing CPM, and it is important for practitioners to acknowledge and discuss these outcomes as well. A possible solution to realign patient expectations and improve informed decision-making around CPM may be a dynamic decision aid to help guide the decision-making process. A decision aid would potentially enhance patient knowledge and understanding of the benefits and risks of CPM while helping to realign patient expectations and clarify the patients' values.

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