

# Patient opinions on contralateral prophylactic mastectomy: A patient-driven discussion in need of tuning?

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**Background:** Rates of contralateral prophylactic mastectomy (CPM) are increasing among women with unilateral breast cancer despite low rates of contralateral recurrence and lack of survival benefit. We aimed to investigate the decisional needs and supports required to ensure adequate and quality decision-making by patients with breast cancer facing the decision regarding CPM.

**Methods:** In this qualitative study, we used semistructured interviews developed with the use of the Ottawa Decision Support Framework to investigate the decisional needs and supports of women (aged > 18 yr) with nonhereditary breast cancer who had previously discussed CPM with their care provider. Patients were recruited from 2 academic cancer centres in Toronto, Ontario. Interviews were conducted between June 2016 and October 2017. We analyzed responses to the open-ended questions iteratively and inductively to establish major themes within the results.

**Results:** Ten patients were recruited. Eight patients reported having initiated the discussion about CPM. Although most patients reported feeling supported, 6 mentioned some degree of decisional conflict. Cancer risk reduction was the most commonly reported perceived benefit of CPM (9 patients), followed by improved psychologic well-being (7). Most patients (8) did not mention the lack of survival benefit of CPM as a disadvantage of the procedure. Patients indicated that information resources (in 8 cases) and improved counselling from their health care team (in 7) would assist in decision-making.

**Conclusion:** Our findings illustrate the disconnect between true and perceived risks (i.e., surgical risk) and benefits (potential recurrence and survival benefit) of CPM, which is not being managed adequately despite support from the health care team. A decision aid may address unmet patient need by providing a reliable resource regarding the benefits and risks of this procedure, while helping patients understand their values and realign their expectations.

**Contexte :** Les taux de mastectomie prophylactique controlatérale (MPC) sont en hausse chez les femmes atteintes d'un cancer du sein unilatéral, malgré les faibles taux de récurrence controlatérale et l'absence d'avantage sur le plan de la survie. Notre objectif consistait à étudier les outils décisionnels et les mesures de soutien nécessaires pour permettre à ces patientes de prendre des décisions adéquates relativement à la MPC.

**Méthodes :** Dans cette étude qualitative, nous avons eu recours à des entretiens semi-structurés élaborés à l'aide du Modèle d'aide à la décision d'Ottawa pour analyser les outils décisionnels et les mesures de soutien nécessaires aux femmes (âgées de plus de 18 ans) atteintes d'un cancer du sein non héréditaire ayant déjà discuté de la MPC avec leur prestataire de soins. Les patientes ont été recrutées dans 2 centres universitaires de cancérologie à Toronto, en Ontario. Les entretiens ont été réalisés entre juin 2016 et octobre 2017. Nous avons analysé les réponses aux questions ouvertes de manière itérative et inductive afin d'établir des thèmes majeurs à partir des résultats.

**Résultats :** Au total, 10 patientes ont été recrutées, dont 8 ont indiqué avoir déjà entamé la discussion sur la MPC. La plupart des patientes ont affirmé se sentir soutenues, mais 6 ont dit avoir tout de même de la difficulté à prendre une décision. La réduction du risque de cancer est l'avantage de la MPC le plus souvent évoqué (9 patientes), suivi de l'amélioration du bien-être psychologique (7). La plupart des patientes (8) n'ont pas mentionné l'absence d'avantage sur le plan de la survie de la MPC parmi les inconvénients. Elles ont indiqué que des ressources d'information (dans 8 cas) et une amélioration du counseling de leur équipe soignante (dans 7 cas) les aideraient à prendre une décision.

**Conclusion :** Nos résultats illustrent un décalage entre les risques et avantages réels et perçus (risque opératoire d'une part; récurrence potentielle et avantage sur le plan de la survie de l'autre) de la MPC qui n'est pas géré de manière adéquate malgré le soutien de l'équipe soignante. Une aide à la décision pourrait permettre de répondre aux besoins des patientes si elle leur offre une ressource fiable pour mieux comprendre les avantages et les risques de l'intervention, pour apprécier leur valeur et pour moduler leurs attentes.

Over the past decade, rates of contralateral prophylactic mastectomy (CPM) have increased by 150% in the United States, and similar trends have been noted in Canada.<sup>1-4</sup> Although CPM has shown survival benefits secondary to reduction of contralateral breast cancer in women with hereditary breast cancer (*BRCA1* or *BRCA2*),<sup>5,6</sup> these findings are not consistent in those without a genetic predisposition.<sup>7-9</sup> The rate of cancer development in the contralateral breast among patients with non-hereditary breast cancer is about 0.3%–0.5% per year.<sup>10-13</sup> With this low risk, many providers view CPM as unnecessary in women with nonhereditary disease at average risk, given the surgical risk and concomitant morbidity. This view has been supported by previous meta-analysis and the American Society of Breast Surgeons owing to lack of oncologic benefit.<sup>14,15</sup>

Despite improvements in adjuvant treatment, leading to better disease control, many women are opting for more aggressive surgical therapy. Data from 2015 suggest that rising rates of CPM are driven largely by patient choice rather than clinical indication,<sup>16</sup> often related to concern about recurrence, hope for improved survival, and lack of appreciation of the potential benefits and risks.<sup>17</sup> Although CPM does not demonstrate improved overall or disease-specific survival,<sup>18,19</sup> potential psychologic benefits have been reported, including reduced concern over cancer recurrence and improved overall satisfaction.<sup>20-22</sup>

The decision-making process with respect to CPM is a challenge for both patients and physicians. Physicians require support to facilitate shared decision-making and help convey the risks and general lack of oncologic benefit. In addition, surgical decision-making should align with the patient's values. The objective of this study was to identify the decisional needs and supports required to ensure adequate and quality decision-making by patients with breast cancer facing the decision regarding CPM.

## METHODS

We conducted a patient needs assessment using semistructured interviews to establish decisional needs, values-based preferences and desired roles in decision-making regarding CPM, and to identify current and potential support strategies for overcoming barriers to informed and quality decision-making. Ethics approval was obtained from the Sunnybrook Health Sciences Centre Research Ethics Board.

### Interview guide

We developed an interview guide (Appendix 1, available at [www.canjsurg.ca/lookup/doi/10.1503/cjs.003420/tab-related-content](http://www.canjsurg.ca/lookup/doi/10.1503/cjs.003420/tab-related-content)) from a standard template for eliciting needs based on the Ottawa Decision Support Framework,<sup>23</sup> which has been validated in similar populations.<sup>24,25</sup> The framework has been used to guide previous needs

assessments of both individual and population decision-making.<sup>26</sup> It has 3 main elements: decisional needs, decisional support and decision quality. This study focused on identifying decisional needs, which includes understanding decision parameters (complexity, timeliness, barriers to decision-making), identifying decisional conflict, and identifying discrepancies in patient knowledge and expectations. In addition, we assessed current decisional supports (clinical counselling, discussion groups, decision aids or tools) to identify potential resources to address unmet needs of the patient and the care team.

### Participants

We recruited patients from cancer clinics in 2 tertiary hospitals (inner city, academic) in Toronto, Ontario, using purposive sampling. Potential participants were identified by study coordinators attending breast cancer clinics, and the treating physician (medical oncologist or breast surgeon) identified those who met our criteria. Treating physicians requested permission for the study coordinator to discuss possible participation in the study. If the patient agreed to be approached by the study coordinator, the study coordinator explained the study and obtained consent.

We reviewed all patients' charts retrospectively for demographic information and disease characteristics (American Joint Committee on Cancer stage), as well as the use of adjuvant therapy and surgical interventions. Patients were included if they were English-speaking women more than 18 years of age, had confirmed unilateral breast cancer (invasive or in situ), had discussed CPM during their decision-making consultation, and underwent unilateral or bilateral mastectomy. Patients were excluded if they had confirmed bilateral breast cancer or recurrent disease, or were known to have or were related to known carriers of *BRCA* mutation or other genetic syndromes (e.g., *TP53* mutation, *PTEN*, *PALB2*).

### Data collection

Interviews were conducted by Z.B. and A.E.S. at a tertiary cancer clinic in Toronto between June 2016 and October 2017, either in person or by telephone. Interviews were audio-recorded after informed consent was obtained.

### Data analysis

We used descriptive statistics to describe the results of interview questions with precoded responses (using frequencies and percentages). We analyzed responses to the open-ended questions iteratively and inductively to establish major themes within the results. The data were coded by a single author (Z.B.) using principles of thematic analysis, which were interpreted in collaboration with a study coauthor (A.S.S.). Data analysis was considered complete

when saturation of major themes was achieved, to depict a complete and logical narrative of the patient experience.

**RESULTS**

Ten patients with a mean age of 49 years (standard deviation 9 yr [range 34–70 yr]) were interviewed. They underwent initial surgery an average of 4 months after biopsy. Patients represented a diverse group of women across a range of ages, menopausal status, marital status and non-metastatic disease stages (Table 1). Five patients did not receive immediate reconstruction; however, 3 of these women were interviewed within 1 year of their primary surgery and had not yet made a decision about delayed reconstruction.

Patients were interviewed 3–95 (mean 32.5) months after their original breast cancer diagnosis as per date of biopsy; most interviews were conducted within 2 years of the date of diagnosis.

Most patients (8) reported that they had initiated the discussion regarding CPM; in 2 cases, the idea was introduced by the surgical team or primary care provider. Of those who self-initiated the conversation, 3 felt positive about bringing the topic up to their provider, 2 had mixed or neutral feelings about broaching the topic, and 3 described a negative experience.

[Doctor’s name] was open for discussion, [their] opinion is not to do [bilateral mastectomy] but of course have the discussion. (Patient 4)

I felt comfortable but a bit dismissed. ... “Just trust us, this is what’s best for you” rather than a more open discussion. (Patient 3)

The surgeon just said that it [CPM] wasn’t an option. I was frustrated. I just couldn’t understand why, if that’s something I chose to do, why I wasn’t able to do it. (Patient 8)

Among the patients who initiated the conversation regarding CPM, the idea arose from independent research through various sources (Internet, library, medical journals) (2 patients) or discussions with survivors (3); 3 patients came to the conclusion on their own:

It was just common sense. ... It’s very strange having only one breast. (Patient 8)

The decision surrounding CPM commonly resulted in varying degrees of decisional conflict, which included uncertainty, worry and physical symptoms of stress (Table 2):

It was a really conflicting period of time ... really debating back and forth what would be best. (Patient 3)

**Table 1. Demographic and clinical characteristics of participants**

Characteristic	No. (%) of participants n = 10
<b>Menopausal status</b>	
Premenopausal	6 (60)
Postmenopausal	4 (40)
<b>Relationship status</b>	
Married	8 (80)
Single	1 (10)
Divorced	1 (10)
<b>AJCC stage</b>	
I	4 (40)
II	2 (20)
III	4 (40)
<b>Surgery</b>	
Unilateral mastectomy	4 (40)
Bilateral mastectomy	6 (60)
<b>Reconstruction</b>	
Immediate	4 (40)
Implant	3 (30)
Tissue transfer	1 (10)
Delayed (tissue transfer)	1 (10)
No reconstruction	5 (50)
<b>Chemotherapy</b>	
Yes	8 (80)
Adjuvant	4 (50)
Neoadjuvant	4 (50)
No	2 (20)
Trastuzumab therapy	2 (20)
Endocrine therapy	5 (50)
Radiotherapy	5 (50)

AJCC = American Joint Committee on Cancer.

**Table 2. Decisional parameters surrounding contralateral prophylactic mastectomy**

Item	No. (%) of participants
<b>How participant felt when making decision about contralateral prophylactic mastectomy</b>	
Unsure about what to do	5 (50)
Worried what could go wrong	4 (40)
Physical signs of stress	4 (40)
Questioning what is important	3 (30)
Distressed/upset	2 (20)
Wavering between choices/changing mind	2 (20)
<b>Factors that made decision difficult</b>	
Lacked information about options, benefits, risks	4 (40)
Lacked information on chances of benefits and harms	2 (20)
Felt unsupported	2 (20)
Felt pressure from others	2 (20)
Information overload	1 (10)
Unclear about what was important	1 (10)
Lacked motivation/hot feeling ready to make decision	1 (10)
Lacked ability or skill to make decision	1 (10)

However, no participants reported that decisional conflict had delayed their decision.

Lack of information was the most commonly reported barrier to decision-making regarding CPM (4 patients) (Table 2). Four patients reported no decisional conflict, and 3 patients described feeling decisional conflict; 1 patient (patient 1) described the decision as “empowering.”

### Knowledge and expectations

Understanding of potential risks and benefits associated with CPM was poor (Table 3). Nine patients thought there was a significant reduction in cancer risk with CPM, 3 of whom described an associated improvement in survival and longevity. Only 2 patients mentioned the lack of survival benefit of CPM when prompted about disadvantages of undergoing the procedure. Seven patients cited improved psychologic well-being or decreased worry as an additional benefit, with thoughts that having CPM would “ease stress of worry” about a new cancer (patient 3). No longer requiring follow-up with mammography was also reported as a benefit, by 4 patients.

Six patients described an increase in the potential for risks or complications of undergoing CPM; however, the probability of those risks seemed poorly understood (Table 3). One patient described “this big long list of all the things that can happen,” serving largely legal purposes:

The doctors have a level of liability, and they have to tell you all the possible things that can happen. (Patient 10)

Some patients believed that having CPM would paradoxically decrease their risk of complications or make no difference:

I’d have to go through the operation all again. ... It’s better having it just one time. (Patient 9)

Improved cosmetic results (i.e., symmetry) was mentioned as a benefit to undergoing CPM by 4 patients, including those who underwent single or bilateral mastectomy, as well as those with immediate or delayed reconstruction. Women also expressed interest in undergoing bilateral mastectomy if potential balancing mastopexy were recommended after single mastectomy.

### Decisional support

Most patients (8) reported an overall feeling of support from family, friends or their health care providers. In addition to support from their care team, patients often involved spouses (6 patients), family members (6) and, less frequently, friends (4) and support groups (2). Roles varied from simply providing decisional support (in 7 cases) to

**Table 3. Participants’ knowledge and expectations regarding benefits and risk of contralateral prophylactic mastectomy**

Item	No. (%) of participants
<b>Perceived benefit</b>	
Reduced cancer risk	9 (90)
Improved psychologic well-being	9 (90)
Improved symmetry/cosmesis	6 (60)
No more follow-up (imaging, call-backs, procedures)	4 (40)
Improved longevity/survival	3 (30)
Reduced/no change in complication risk/recovery	3 (30)
<b>Perceived risk</b>	
Increased complication risk/recovery	6 (60)
Lack of survival advantage	2 (20)

**Table 4. Decisional support and resources**

Item	No. (%) of participants*
<b>Methods</b>	
Gathered information	8 (80)
From health care providers	5 (50)
From independent research	4 (40)
Information content	
Chances of benefits and risks	7 (70)
Options	6 (60)
How others go about deciding	5 (50)
Valuation/personal importance of benefits and risks	4 (40)
<b>Beneficial resources</b>	
Information materials	8 (80)
Health condition	8 (80)
Surgical options	8 (80)
Surgical benefits and risks	8 (80)
Probabilities of benefits and risks	8 (80)
Valuation/personal importance of benefits and risks	4 (40)
Guidance in deliberation	3 (30)
Counselling from health care practitioner	7 (70)
Discussion groups of people facing same decision	5 (50)
<b>Format</b>	
Booklet/pamphlet	8 (80)
Internet	4 (40)
Video	3 (30)

\*Participants could choose more than 1 response.

being more involved in a shared decision (in 5 cases). None of the patients reported having someone else make the decision for them.

Eight patients reported gathering information to inform their decision, either from health care providers or independently (Table 4). They felt that these information materials were needed to improve decision-making, reinforce information discussed during visits with their health care providers or assist in the visit itself:

If somebody tells you you have cancer, you’re not hearing much more. (Patient 10)

It would be great if there was take-home material to read. (Patient 3)

Seven patients supported multidisciplinary counselling (Table 4), with requests for clear delineation of risks and benefits, and how various options aligned with patients' values. Patients most commonly requested general information about disease, treatment options, and chances of benefits and risks, often in the form of something tangible that they could review at leisure (e.g., booklet, pamphlet) (Table 4):

Every bit of information that I got was useful, even the little pamphlets. (Patient 5)

Discussion groups with people in similar situations was viewed as useful by 5 patients.

## DISCUSSION

Our needs assessment showed that patients in our institution experienced elements of decisional conflict and barriers to shared decision-making regarding CPM. Although our participants experienced considerable emotional distress through the decision-making process, they reported receiving sufficient support from their family, friends and health care team.<sup>27</sup>

Overtreatment in cancer care is a complex, multifactorial problem. With a new cancer diagnosis, the treatment selected is strongly affected by a reflexive response to preserve survival. However, it has been shown that patients often misinterpret the absolute benefit of individual treatments.<sup>28</sup> Studies describe how patients undergo CPM largely in an effort to lower the possibility of cancer in the contralateral breast, with the intention of improving survival.<sup>17,27,29,30</sup> These patients overestimated the benefit of CPM, as did the majority of women in our study. Most patients overestimate the risk of recurrence and equate any recurrence with death.<sup>27,31–34</sup> There is a disparity between perceived and actual benefits of CPM, with most women confident in their understanding of the risks and benefits of each treatment option.<sup>27</sup>

Previous studies of CPM have been limited to the perception of surgical benefits and risk of recurrent cancer. Our patients had a limited comprehension of potential surgical complications of CPM, with several believing that the risk associated with double mastectomy was decreased or equivalent to that with single mastectomy. These beliefs were largely rooted in the underlying assumption of likely recurrence in the contralateral breast without double mastectomy, which would necessitate additional surgery and potentially increase surgical risk.

Although personal health decisions should be strongly influenced by objective probabilities of risks and benefits,

personal values and emotions also have an influence. In a previous survey of women who underwent CPM, participants described subjective feelings regarding CPM, with comments such as “it only changes things from eight percent to two percent, but I would rather be two percent.”<sup>35</sup> This may be partially attributable to the worry and anxiety around a new cancer diagnosis. In a study of perceptions of the severity of a health condition among university students, participants tended to disregard likelihood data and based their decisions on previous beliefs and current emotions when the consequences were worse.<sup>36</sup> Our data support this concept, with 90% of our participants indicating improved psychologic well-being as a reason for undergoing bilateral mastectomy. Moreover, anxiety around decision-making has been shown to further amplify misconceptions regarding perceived risks and benefits.<sup>33,34,37</sup>

As such, efforts to improve decision-making must go beyond counselling. Several meta-analyses and Cochrane reviews support the use of decision aids as tools to address concerns regarding medical decision-making, through effective communication of risks and benefits while recognizing individual patient valuation of these factors.<sup>38–41</sup> Decision aids have been shown across several randomized trials to improve patient education and increase their confidence in their knowledge.<sup>41</sup> Several studies have shown the positive impact of a decision aid in decision-making regarding breast-conserving surgery versus mastectomy in early breast cancer and the use of various adjuvant and neoadjuvant chemotherapy regimens.<sup>42–45</sup> Patients who receive decision aids often report improved satisfaction and decreased decisional conflict compared to those who receive standard counselling and information resources,<sup>43,46</sup> with these effects appearing most prominently in those who select more aggressive surgical interventions over conservative treatments.<sup>42</sup> Although there is evidence suggesting that patients who receive decision aids are more likely than those who do not to select more conservative treatment,<sup>43</sup> even when the decision about surgery is not altered, patients who receive decision aids still report greater well-being, with less regret and lower rates of depression after surgery, than those who do not receive such aids.<sup>47</sup>

Overall, our findings illustrate the disconnect between true and perceived risks (i.e., surgical risk) and benefits (potential recurrence and survival benefit), which is not being managed adequately despite support from the health care team. A decision aid has the potential to address the need for improved patient education and setting of expectations, while further clarifying the patient's needs and values to effectively guide deliberation and facilitate shared decision-making among the team. In our experience, patients are increasingly taking active roles in decision-making, by completing independent research and requesting materials from their care team. Patients show a willingness to engage in a resource that can address the concern

about misinformation adequately while the patient's individual assessment and values surrounding potential benefits and risks are considered. A decision aid is one possible solution that can be developed and studied to assess possible improvements to the quality of decision-making, health outcomes and psychologic well-being, and appropriate use and costs of services.

### Limitations

Previous studies on patient perspectives of the decision-making process regarding CPM have been limited to surveys, with inclusion of open-ended questions.<sup>27,30</sup> Our use of semistructured, in-person interviews builds on these findings to give accounts of individual, unique patient perspectives regarding the decision-making process. Purposive sampling of our study population allowed for a heterogeneous group of participants with regard to age, menopausal status, disease stage and treatment received.

Although the diversity of our sample may limit the overall generalizability of our findings, we believe it allowed us to describe a larger range of potential perspectives. Given the depth of data extracted from each encounter, sample saturation was sufficiently achieved with 10 patients. We observed a common and consistent rhetoric across various patient demographic characteristics, which would not necessarily have benefited from further sampling. The patient interview structure was designed by the physician care team, which may have introduced bias within the results. However, interviews were conducted and analyzed by a different team member to limit potential effects. Recall bias must be considered when interpreting these findings, as interviews were conducted up to 8 years after diagnosis. Several patients were still receiving or considering ongoing treatment (e.g., reconstructive revision, adjuvant therapy) at or beyond the average interview time after their original breast cancer diagnosis of 32 months.

### CONCLUSION

Our patient needs assessment identified key challenges surrounding shared decision-making regarding CPM. Decisional conflict was commonly reported, rooted in inadequate knowledge of potential risks and benefits, which led to treatment decisions that were misaligned with patient values. There is a clear need for reliable resources to assist in education and guidance in shared decision-making. Development of decision aids may address patient needs by improving their knowledge regarding the benefits and risks of CPM while realigning their values and expectations, which may improve decision quality.

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**Competing interests:** None declared.

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