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Perceptions, knowledge, and satisfaction with contralateral prophylactic mastectomy among young women with breast cancer: A cross-sectional survey

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Abstract

Background—There has been a dramatic increase in rates of contralateral prophylactic mastectomy (CPM), particularly among younger women with breast cancer, however little is known about how women approach the decision to undergo CPM.

Objective—To examine preferences, knowledge, decision-making, and experiences of young women with breast cancer who chose CPM.

Design—Cross-sectional survey.

Setting—Eight academic and community medical centers that enrolled 550 women diagnosed with breast cancer at age 40 and younger, between November 2006 and November 2010.

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Patients—123 women without known bilateral breast cancer who reported having a bilateral mastectomy.

Measurements—A one-time, 23 item survey that included items related to decision-making, knowledge, risk perception, and breast cancer worry.

Results—Most women (98%) indicated that the desire to lower the chance of developing a contralateral breast cancer (CBC) and to improve survival (94%) were extremely or very important factors in their decision to undergo CPM. However, only 18% indicated that women with breast cancer who undergo CPM live longer than women who do not. BRCA 1 or BRCA 2 mutation carriers more accurately perceived their risk of a CBC while women without a known mutation substantially overestimated this risk.

Limitations—The survey, administered a median of two years post-surgery, was not validated and some questions might have been misinterpreted by respondents or subject to recall bias. Generalizability of our findings might be limited.

Conclusions—Despite knowing that CPM does not clearly improve survival, women who have undergone the procedure do so, in part, to extend their lives. Many women overestimate their actual risk of developing breast cancer in the unaffected breast. Interventions aimed at improving risk communication in an effort to promote evidence-based decision-making are warranted.

Introduction

There has been a dramatic increase in rates of contralateral prophylactic mastectomy (CPM) among women treated for early breast cancer in recent years in the United States. In the late 1990s, between 4% and 6% of women who had mastectomies also underwent CPM, while in more recent years the reported range has increased to between 11% and 25% of women, a three to four-fold change (1–4).

The trend for bilateral mastectomy at diagnosis of unilateral breast cancer is particularly notable among young women, with younger age consistently identified as a predictor of CPM (1–5). Although mastectomy is a safe procedure and major complications are rare, there are cosmetic concerns as well as clinically significant potential long-term sequelae including numbness of the chest skin and chronic pain which may impact quality of life (QOL). With many women opting for reconstructive surgery, the potential for an extended recovery time, additional surgical complications, and decrease in strength or function due to muscles being moved or stretched must also be considered.

Most importantly, the value of the procedure for the majority of women with unilateral early stage breast cancer is unclear. While CPM markedly reduces the chance of developing a new cancer in the unaffected breast, the risk of a contralateral breast cancer (CBC) in most women (those without a clear cancer-predisposing mutation), is low: approximately 0.5–0.75% per year among women with early stage disease (6, 7). Moreover, this risk has decreased over time due to the widespread use of adjuvant therapy (8). In women with a family history of breast cancer but who do not harbor a known genetic predisposition, a recent study reported the 10 year cumulative risk of developing a CBC was <15% in women younger than age 40 at diagnosis of the index cancer (9). Among the youngest women in this study with a deleterious BRCA 1 or 2 mutation, the 10 year cumulative risks range ranged from approximately 24% to 31% (9). Findings are mixed as to whether contralateral mastectomy results in improved survival among high-risk women who have already had a first breast cancer (10, 11). This is likely because, not only is the absolute benefit from the procedure modest, but young women are at greatest risk, on average, of systemic recurrence and death from their initial breast cancer (12), and thus have a heightened competing risk. Undergoing CPM is not at all likely to impact on risk of the development of metastatic

disease from a woman's primary breast cancer. Thus, when considering CPM for women with early stage breast cancer, there is an inherent tension between the clinician's obligation to practice evidence-based medicine and "do no harm" by avoiding unnecessary procedures with a desire to respect the preferences of the patient.

Studies examining the decision to undergo CPM have been limited, especially among younger women with breast cancer. There is little available data related to the decision-making process, including how well-informed women were about CPM when they made the decision. In this study, we sought to describe perceptions, knowledge, and satisfaction with CPM among participants enrolled in a large, prospective cohort study of women diagnosed with breast cancer at age 40 and younger. A better understanding of how patients approach the decision to undergo CPM can potentially inform clinicians who are counseling young women with early stage disease about their local therapy and preventive decisions.

Methods

Design Overview

The Helping Ourselves, Helping Others: Young Women's Breast Cancer Study (YWS) is a prospective cohort study established to explore biological, medical, and QOL issues specific to young women diagnosed with breast cancer. Following enrollment, women are mailed surveys twice a year for the first three years following diagnosis, and then annually for an additional seven years. Beginning in November 2010, a one-time, supplementary questionnaire ("CPM survey") was mailed to women who enrolled in the cohort between November 2006 and November 2010 and reported a bilateral mastectomy on any survey completed within the first year after diagnosis. This study was approved by the Institutional Review Board at the Dana-Farber/Harvard Cancer Center and other participating sites.

Study Participants

As of November 2010, study enrollment sites for the YWS included 9 academic (n=4) and community (n=5) hospitals located in Eastern Massachusetts and a single academic site in Toronto, Canada. The CPM sub-study was open only to women enrolled from centers in Massachusetts. Eligibility criteria for the YWS include being English-speaking and a diagnosis of breast cancer at or under 40 years of age. For the sites in Massachusetts, women are identified within six months of diagnosis using the Rapid Case Identification Core of the Dana-Farber/Harvard Cancer Center and subsequently invited to enroll in the study.

Of the 550 women enrolled between November 2006 and November 2010, 159 women (29%) from 8 of 9 participating centers reported having a bilateral mastectomy between September 2006 and November 2010 (Figure 1). The response rate was 83%, with 132 women completing the CPM survey. An additional 9 women were excluded from the analytic sample for the following reasons: bilateral breast cancer, diagnosed either prior to (n=3) or following surgery (n=4) and bilateral prophylactic indications, defined as having a bilateral mastectomy without knowledge of a cancer in either breast prior to surgery, with a cancer detected only after surgery, (n=2). In total, 123 women were included in this analysis.

Measurements

Socio-demographic and Disease Characteristics—Age, race, ethnicity, marital status, education, employment, and insurance status was self-reported by participants on the baseline survey, which was completed an average of approximately five months following diagnosis. Genetic mutation information (BRCA 1 or 2, mutation of uncertain clinical significance, not tested or unknown, no mutation) and family history of breast and ovarian cancer was also self-reported on the survey completed by participants one year after

diagnosis. Women with a BRCA 1 or 2 mutation or who reported having a mutation of uncertain clinical significance were categorized as “mutation carriers” while all others were considered “non-carriers.” Medical record review was used to ascertain stage, grade, HER2, hormone receptor status, as well as to reconcile missing socio-demographic information and verify self-report of genetic testing results. Medical record review was not used to ascertain whether diagnostic procedures (e.g., MRI, ultrasound) were used prior to surgery to exclude the possibility of contralateral disease.

The CPM Survey—The CPM survey (see Appendix) consisted of 23 items related to decision-making, knowledge, risk perceptions, and breast cancer worry. This was a one-time, cross-sectional, survey developed specifically for this study, based on the expert knowledge of co-authors (M. Morrow, A. Partridge, K. Sepucha) with extensive experience measuring decision-making, risk perceptions and knowledge outcomes in breast cancer patients.

Decision-making—Women were presented with a comprehensive list of potential reasons for undergoing CPM, including cosmetic, preventive, genetic, and cancer-related (i.e., fear of recurrence, history of abnormal mammography/MRI) and asked to indicate on a five-point scale (extremely important; very important; somewhat important; not at all important; not sure) to what degree these factors played a role in their decision. This scale was also used to assess the influence of different sources of information (i.e., physicians, nurses, family and friends, and media) in relation to the decision to undergo CPM. The SURE scale is composed of four items from the Decisional Conflict Scale (13) that measures patients’ uncertainty about which treatment to choose and factors contributing to uncertainty (feeling uninformed, unclear values, and unsupported in decision-making).

The SURE scale has been shown to have modest reliability and good construct validity in a sample of English-speaking patients as well as a sample of French speaking patients facing treatment decisions (14). Scores range from 0–4 with lower scores indicating higher decisional conflict.

Satisfaction with the decision was evaluated on a scale of 0–10 (0=not confident; 10=extremely confident) measuring respondents’ confidence regarding whether the choice to undergo CPM was the right one for them. A second question asked women whether they would still choose CPM if making the decision again (yes; definitely; yes, probably; no, probably not; no, definitely not; not sure). Women were also asked to indicate if their experience with several surgical and QOL outcomes, including pain, cosmesis, sense of sexuality, and recovery from reconstruction, was better than expected, worse than expected, or about what they expected.

There was a single item about who first brought up the idea to have CPM (i.e., patient, oncologist, surgeon, family, or friend). Additional items aimed to assess the extent of discussion with a physician regarding the risk of contralateral cancer, reasons to undergo or not undergo CPM, and personal feelings about CPM. Responses regarding these discussions were graded as a lot, some, a little, or not at all.

Knowledge, Risk Perception, and Breast Cancer Worry—Respondents were asked to estimate how many women out of 100 with early breast cancer would: 1) develop breast cancer in the contralateral breast following either a single mastectomy or lumpectomy with radiation; 2) develop recurrent breast cancer in the chest wall in the breast removed prophylactically. Other items pertaining to breast cancer knowledge were adapted from the Breast Cancer Surgery Decision Quality Instrument (15) and included an estimate about how many women diagnosed with and treated for early breast cancer will eventually die of

breast cancer (most vs. about half vs. most will die of something else) and an item about differences in breast cancer survival by treatment type (mastectomy vs. bilateral mastectomy vs. lumpectomy with radiation).

Items measuring risk perception included how much (a lot; some; a little; not all) respondents thought having the “other breast” removed would reduce the subsequent risk of a CBC and whether the chance of their cancer returning was higher, lower or about the same as other women with early stage breast cancer.

Additionally, there was an item about how worried women currently were about breast cancer (a lot; some; a little; not at all) and another relating to past concern (extremely; very; somewhat; a little; not concerned at all) about being diagnosed with a CBC in the future.

Statistical Analysis

As the aim of this study was to better understand how women approached the decision to undergo CPM, the analyses we conducted are primarily descriptive. Means, medians, and frequency distributions were calculated for continuous and categorical outcomes, respectively. For the measures of risk perception and knowledge, results were stratified by mutation carrier status. For items with a response rate of less than 100%, the number of respondents who answered the question is specified. To assess whether results would differ when excluding high-risk women, we repeated the above analyses excluding women who were identified as mutation carriers (n=34). All analyses were conducted in SAS version 9.2 (SAS Institute, Cary, N.C.).

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Results

Study Population Characteristics

Patient and disease characteristics for the study population are presented in Table 1. Women completed the survey an average of 2.1 years (range: 0.1–4.3 years) after undergoing CPM and median age at breast cancer diagnosis was 37 (range: 26–40). Ninety-four percent of women had reconstructive surgery. Most women had either a Stage I or Stage II breast cancer and 60% of tumors were estrogen receptor (ER) positive.

Approximately one-quarter of women were carriers of either a BRCA1 or BRCA 2 mutation. Twenty-six percent had a first degree relative and 62% had a second or third degree relative who had been diagnosed with either breast or ovarian cancer. Among mutation carriers, 41% had a first-degree relative with breast or ovarian cancer; among non-carriers this proportion was 20% (Appendix Table 1). A majority of women (56%) with a mother or sister with breast or ovarian cancer were not mutation carriers (Appendix Table 2). A higher proportion of women who had CPM were mutation carriers or had a family history of breast or ovarian cancer than women who did not report a bilateral mastectomy (Appendix Table 3 and Appendix Table 4).

Decision-making

Table 2 lists the responses to the items that assessed the importance of various factors that might have played a role in the decision to undergo CPM. Almost all women (98%) surveyed said that the desire to lower the chance of developing a CBC was an extremely or

very important reason. A similarly high proportion of women ranked peace of mind (95%), desire to improve survival/extend life (94%), feeling at increased risk of CBC (87%), and desire to prevent breast cancer from spreading to other places in body (85%) as extremely or very important factors in their decision. Few women reported advice from family or friends or abnormal screening tests (i.e., MRI, mammogram prior to surgery) as important reasons for choosing CPM. Appendix Table 5 includes importance of family history as a reason to have CPM, among women with and without a positive family history for breast or ovarian cancer.

Overall satisfaction with the decision was high: 80% of women were extremely confident in their decision to undergo CPM and 90% of respondents would definitely choose CPM if deciding again. When making the choice to undergo CPM, among the women who responded to these items (n=120), almost all felt they knew the risk and benefits of each option (97%), were clear about which benefits and risks mattered most (96%), had enough support and advice to make the choice (92%), and felt sure CPM was the right choice for them (93%). Overall, 87% of respondents scored 4 out of 4, indicating no decisional conflict as measured by the SURE scale.

Physicians were the most important sources of information for the decision, followed by family and friends). Of the women who responded (n=120), more than half (n=68) said they were the first to bring up the idea of having their contralateral breast removed. While 80% (97/121) of women reported that they spoke with their doctors to at least some extent about the reasons for undergoing CPM, only 51% (62/122) said their doctors similarly discussed the reasons not to have this surgery.

Many women reported that several outcomes associated with surgery were worse than what they had expected (Table 3). Thirty-three percent reported that the number of surgeries/procedures needed was worse than expected and 28% said that numbness/tingling in the chest was worse than they had thought. With respect to QOL outcomes, 42% reported that their sense of sexuality was worse than they expected following surgery and close to one-third said self-consciousness about appearance was also worse than expected.

Breast Cancer Risk Knowledge and Perception

Table 4 details risk knowledge and perception by mutation carrier status. Regarding the risk of developing a CBC without CPM, mutation carriers estimated a median of 20 out of 100 women, and non-carriers a median of 10 out of 100 women would develop a cancer in their other breast in the 5 years after unilateral breast cancer treatment. Regarding the risk of developing a chest wall recurrence, both mutation carriers and non-carriers estimated a median of 5 out of 100 women would develop a chest wall recurrence despite having both breasts removed in the 5 years after treatment.

Over half of women (56%) without a genetic mutation thought the chance of their cancer returning was about the same, 19% thought this chance was higher and 20% thought this chance was lower, compared to other women with early stage breast cancer. In contrast, among mutation carriers, 21% thought this risk was about the same as other women, while 32% approximated this risk to be higher and 41% to be lower than other women. Among mutation carriers, 94% thought that removing the unaffected breast would lower their chance of developing a CBC by a lot; among non-carriers, 67% responded that removing the unaffected breast would reduce their risk of CBC by a lot.

A higher proportion of non-carriers (84%) compared to mutation carriers (74%) correctly answered that most women with early breast cancer will die of something other than breast cancer. While most carriers (71%) and non-carriers (73%) responded that that there is no

difference in survival among the different treatment options, a higher proportion (24%) of women with a mutation (vs. 15% of non-carriers) responded that women who have a bilateral mastectomy would live longer.

Breast Cancer Worry

Eighty-seven percent of women (110/126) reported that they had been extremely or very concerned about being diagnosed with a CBC in the future. Among women who responded to the item concerning current breast cancer worry (n=118), 90% were at least a little worried about their breast cancer at the time of the survey.

When all analyses were run excluding women who had a BRCA mutation or who reported a mutation of uncertain clinical significance (n=34), the results did not change substantially (Appendix Tables 6–12).

Discussion

To the best of our knowledge, our study is the largest to date examining decision-making, risk perceptions and psychosocial aspects relating to CPM among young women with breast cancer. Among both those at increased risk for CBC due to a cancer-predisposing mutation as well as among non-carriers, a desire to reduce the risk of CBC, obtain peace of mind, and improve survival were all cited by most women as important reasons for undergoing CPM. While mutation carriers had a more accurate perception of their risk of a CBC without CPM as well as about the efficacy of CPM as a risk-reducing strategy, non-carriers substantially overestimated their risk of developing a CBC without CPM.

The 28.5% prevalence of CPM in our cohort exceeds the prevalence reported in the general breast cancer patient population, and supports prior studies that have found younger women are more likely to undergo CPM (1–5, 16). A recent review of the literature found several studies that describe increasing rates of CPM (1, 2, 4, 5, 17) predictors of undergoing CPM (3, 18–22) and selected outcomes related to CPM, such as satisfaction with and QOL following surgery (23–29). Few studies, however, have specifically reported about the decision-making process and perceptions about how CPM might influence outcomes such as disease recurrence and survival.

A large majority of women ranked both desire to improve survival/extend life and a desire to prevent metastatic disease as extremely or very important reasons for choosing CPM. However, most women did understand that having a bilateral mastectomy would not lead to an extension of survival. This discordance suggests some degree of cognitive dissonance: most women acknowledge CPM does not improve survival, however anxiety and fear of recurrence are likely influencing women during the decision-making process, leading them to identify their desire to extend life and prevent metastatic disease as among the most important reasons for undergoing CPM. Interestingly, women with a positive mutation were more likely to identify a survival benefit associated with having a bilateral mastectomy. Results from a recent study (30) suggest that prophylactic mastectomy alone might improve survival among women with BRCA mutations, however this has not been conclusively established as an effective mortality reduction strategy in the absence of oophorectomy in high-risk women (31).

Our results indicate that women who are not at increased genetic risk overestimate the actual chance of developing a contralateral cancer, with non-carriers estimating a median of 10 women out of 100 would develop a CBC without CPM within five years, which exceeds the actual risk of approximately 2–4% over five years (1,6–7). Other studies of women with DCIS or invasive cancer have also documented overestimation of risk of a CBC, as well as

recurrent disease (32–34). Both mutation carriers and non-carriers overestimated their risk of a chest wall recurrence in the unaffected breast after CPM, which is estimated to be <1% (35, 36) over five years, thus underestimating the benefit of the procedure. Almost all mutation carriers were also more likely to perceive CPM as greatly reducing the chance of a CBC compared to only 67% of non-carriers. Additionally, only half of all women said their doctor had talked at least to some degree about reasons not to have CPM, suggesting that women, particularly those who do not have a genetic mutation, may not be informed by their health care provider that the risk of a CBC is relatively low. Alternatively, some women may be told but are unable to comprehend their low risk, may simply not remember it accurately, or are unable to contextualize how this risk is relevant to them, possibly as a consequence of anxiety. Risk perceptions have been associated with anxiety in other breast cancer settings, including in women who are at risk but have not developed the disease (32, 37, 38).

In our study, physicians were identified as the most important sources of information, however only one-third of women cited a desire to follow a doctor's recommendation as an extremely or very important factor in their decision, with only one respondent listing physician recommendation as the single most important reason for undergoing CPM. This finding is supported by recent studies, where patient-driven decision-making has been identified as an important determinant of likelihood to have a mastectomy (39, 40).

Our findings suggest a potential role for interventions that ensure women are sufficiently informed and the actual risk of contralateral disease is effectively communicated, particularly in the context of other competing risks, such as metastatic recurrence. There is some evidence that decision aids can help improve the quality of the decision-making process, specifically by reducing decisional conflict and enhancing knowledge (41–43). In one randomized trial, breast conserving surgery was more frequently the treatment chosen by women randomized to the decision-aid intervention (44). Given the relationship between anxiety and overestimation of breast cancer risk, simply providing information might not be sufficient for women with high levels of distress (32, 45). Better supportive care and management of anxiety surrounding diagnosis will likely enhance the effectiveness of any decision-aid intervention.

The impact of CPM on outcomes such as body image and sexuality should be an important consideration given young women are more likely to experience impaired QOL compared to older women following a breast cancer diagnosis (46–50). Many women in our sample reported that the effect CPM had on their appearance was worse than they expected, which is consistent with findings from several other studies, where issues related to appearance and image persisted, in some cases, many years after surgery (26, 27). While a substantial proportion (42%) of women reported that their sense of sexuality following CPM was worse than expected, other studies have not found sexual problems to be prevalent. In a large retrospective study, Frost et al. (26) reported that only 23% of women related CPM to sexual relationship problems. In a recent prospective analysis that measured sexual functioning in 60 women before and after CPM (27), no significant changes between the pre and post surgical periods were detected.

Our study has limitations. While several items included were from validated measures or used in prior studies, the CPM survey itself is not a validated instrument. It is also possible that respondents might have misinterpreted certain survey items. The potential for recall bias must also be considered, as the survey was completed an average of two years after surgery and some women might not accurately recall the details about how they approached their decision to undergo CPM.

Our study population was mostly white, non-Hispanic and college-educated and therefore the generalizability of our findings might be limited. It is possible that in a more diverse population, perceptions, reasons and knowledge about CPM might differ. A relatively large number of women also reported a family history of breast cancer, a factor that might influence surgical choices. Further, we only surveyed women who had CPM, and it is not clear whether responses are different from women who did not have CPM. Since this study sampled participants from an ongoing prospective cohort study, ongoing research includes exploring factors associated with other surgical choices and whether these differ between women who undergo CPM and those who do not.

Additional clarification of conflicting responses, specifically, the inconsistencies between the importance of improved survival as a reason for choosing CPM while acknowledging CPM is not associated with better survival outcomes, would be helpful. Future investigations might include focus groups or collection of qualitative data, with the goal of elucidating the role of cognitive biases in making treatment decisions.

While this is a cross-sectional, descriptive study, our findings provide important information about an understudied area and highlight the fact that many women have misperceptions about breast cancer risk. We believe this points to a need for better risk communication strategies in an effort to ensure that treatment decision-making is truly evidence based, while remaining patient-centered.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

1. Tuttle TM, Habermann EB, Grund EH, Morris TJ, Virnig BA. Increasing use of contralateral prophylactic mastectomy for breast cancer patients: a trend toward more aggressive surgical treatment. *J Clin Oncol.* 2007; 25(33):5203–9. [PubMed: 17954711]
2. Tuttle TM, Jarosek S, Habermann EB, Arrington A, Abraham A, Morris TJ, et al. Increasing rates of contralateral prophylactic mastectomy among patients with ductal carcinoma in situ. *J Clin Oncol.* 2009; 27(9):1362–7. [PubMed: 19224844]
3. King TA, Sakr R, Patil S, Gurevich I, Stempel M, Sampson M, et al. Clinical management factors contribute to the decision for contralateral prophylactic mastectomy. *J Clin Oncol.* 2011; 29(16): 2158–64. [PubMed: 21464413]
4. Jones NB, Wilson J, Kotur L, Stephens J, Farrar WB, Agnese DM. Contralateral prophylactic mastectomy for unilateral breast cancer: an increasing trend at a single institution. *Ann Surg Oncol.* 2009; 16(10):2691–6. [PubMed: 19506956]
5. Yao K, Stewart AK, Winchester DJ, Winchester DP. Trends in contralateral prophylactic mastectomy for unilateral cancer: a report from the National Cancer Data Base, 1998–2007. *Ann Surg Oncol.* 2010; 17(10):2554–62. [PubMed: 20461470]
6. Brewster AM, Parker PA. Current knowledge on contralateral prophylactic mastectomy among women with sporadic breast cancer. *Oncologist.* 2011; 16(7):935–41. [PubMed: 21672945]
7. Murphy JA, Milner TD, O'Donoghue JM. Contralateral risk-reducing mastectomy in sporadic breast cancer. *Lancet Oncol.* 2013; 14(7):e262–9. [PubMed: 23725708]
8. Nichols HB, Berrington de Gonzalez A, Lacey JV Jr, Rosenberg PS, Anderson WF. Declining incidence of contralateral breast cancer in the United States from 1975 to 2006. *J Clin Oncol.* 2011; 29(12):1564–9. [PubMed: 21402610]

9. Reiner AS, John EM, Brooks JD, Lynch CF, Bernstein L, Mellekjaer L, et al. Risk of asynchronous contralateral breast cancer in noncarriers of BRCA1 and BRCA2 mutations with a family history of breast cancer: a report from the Women's Environmental Cancer and Radiation Epidemiology Study. *J Clin Oncol.* 2013; 31(4):433–9. [PubMed: 23269995]
10. van Sprundel TC, Schmidt MK, Rookus MA, Brohet R, van Asperen CJ, Rutgers EJ, et al. Risk reduction of contralateral breast cancer and survival after contralateral prophylactic mastectomy in BRCA1 or BRCA2 mutation carriers. *Br J Cancer.* 2005; 93(3):287–92. [PubMed: 16052221]
11. Boughhey JC, Hoskin TL, Degnim AC, Sellers TA, Johnson JL, Kasner MJ, et al. Contralateral prophylactic mastectomy is associated with a survival advantage in high-risk women with a personal history of breast cancer. *Ann Surg Oncol.* 2010; 17(10):2702–9. [PubMed: 20853163]
12. Adami HO, Malaker B, Holmberg L, Persson I, Stone B. The relation between survival and age at diagnosis in breast cancer. *N Engl J Med.* 1986; 315(9):559–63. [PubMed: 3736639]
13. O'Connor AM. Validation of a decisional conflict scale. *Med Decis Making.* 1995; 15(1):25–30. [PubMed: 7898294]
14. Legare F, Kearing S, Clay K, Gagnon S, D'Amours D, Rousseau M, et al. Are you SURE?: Assessing patient decisional conflict with a 4-item screening test. *Can Fam Physician.* 2010; 56(8):e308–14. [PubMed: 20705870]
15. Sepucha KR, Belkora JK, Chang Y, Cosenza C, Levin CA, Moy B, et al. Measuring decision quality: psychometric evaluation of a new instrument for breast cancer surgery. *BMC Med Inform Decis Mak.* 2012; 12:51. [PubMed: 22681763]
16. Ellsworth WA, Bass BL, Skoracki RJ, Heller L. Breast reconstruction in women under 30: a 10-year experience. *Breast J.* 2011; 17(1):18–23. [PubMed: 21155919]
17. Stucky CC, Gray RJ, Wasif N, Dueck AC, Pockaj BA. Increase in contralateral prophylactic mastectomy: echoes of a bygone era? Surgical trends for unilateral breast cancer. *Ann Surg Oncol.* 2010; 17 (Suppl 3):330–7. [PubMed: 20853055]
18. Graves KD, Peshkin BN, Halbert CH, DeMarco TA, Isaacs C, Schwartz MD. Predictors and outcomes of contralateral prophylactic mastectomy among breast cancer survivors. *Breast Cancer Res Treat.* 2007; 104(3):321–9. [PubMed: 17066320]
19. Metcalfe KA, Lubinski J, Ghadirian P, Lynch H, Kim-Sing C, Friedman E, et al. Predictors of contralateral prophylactic mastectomy in women with a BRCA1 or BRCA2 mutation: the Hereditary Breast Cancer Clinical Study Group. *J Clin Oncol.* 2008; 26(7):1093–7. [PubMed: 18195327]
20. Yi M, Hunt KK, Arun BK, Bedrosian I, Barrera AG, Do KA, et al. Factors affecting the decision of breast cancer patients to undergo contralateral prophylactic mastectomy. *Cancer Prev Res (Phila).* 2010; 3(8):1026–34. [PubMed: 20647335]
21. Arrington AK, Jarosek SL, Virnig BA, Habermann EB, Tuttle TM. Patient and surgeon characteristics associated with increased use of contralateral prophylactic mastectomy in patients with breast cancer. *Ann Surg Oncol.* 2009; 16(10):2697–704. [PubMed: 19653045]
22. Chung A, Huynh K, Lawrence C, Sim MS, Giuliano A. Comparison of patient characteristics and outcomes of contralateral prophylactic mastectomy and unilateral total mastectomy in breast cancer patients. *Ann Surg Oncol.* 2012; 19(8):2600–6. [PubMed: 22396004]
23. Geiger AM, West CN, Nekhlyudov L, Herrinton LJ, Liu IL, Altschuler A, et al. Contentment with quality of life among breast cancer survivors with and without contralateral prophylactic mastectomy. *J Clin Oncol.* 2006; 24(9):1350–6. [PubMed: 16549829]
24. Nekhlyudov L, Bower M, Herrinton LJ, Altschuler A, Greene SM, Rolnick S, et al. Women's decision-making roles regarding contralateral prophylactic mastectomy. *J Natl Cancer Inst Monogr.* 2005; (35):55–60. [PubMed: 16287886]
25. Montgomery LL, Tran KN, Heelan MC, Van Zee KJ, Massie MJ, Payne DK, et al. Issues of regret in women with contralateral prophylactic mastectomies. *Ann Surg Oncol.* 1999; 6(6):546–52. [PubMed: 10493622]
26. Frost MH, Slezak JM, Tran NV, Williams CI, Johnson JL, Woods JE, et al. Satisfaction after contralateral prophylactic mastectomy: the significance of mastectomy type, reconstructive complications, and body appearance. *J Clin Oncol.* 2005; 23(31):7849–56. [PubMed: 16204003]

27. Unukovych D, Sandelin K, Liljegren A, Arver B, Wickman M, Johansson H, et al. Contralateral prophylactic mastectomy in breast cancer patients with a family history: A prospective 2-years follow-up study of health related quality of life, sexuality and body image. *Eur J Cancer*. 2012; 48(17):3150–6. [PubMed: 22695071]
28. Frost MH, Hoskin TL, Hartmann LC, Degnim AC, Johnson JL, Boughey JC. Contralateral prophylactic mastectomy: long-term consistency of satisfaction and adverse effects and the significance of informed decision-making, quality of life, and personality traits. *Ann Surg Oncol*. 2011; 18(11):3110–6. [PubMed: 21947589]
29. Tercyak KP, Peshkin BN, Brogan BM, DeMarco T, Pennanen MF, Willey SC, et al. Quality of life after contralateral prophylactic mastectomy in newly diagnosed high-risk breast cancer patients who underwent BRCA1/2 gene testing. *J Clin Oncol*. 2007; 25(3):285–91. [PubMed: 17159191]
30. Sigal BM, Munoz DF, Kurian AW, Plevritis SK. A simulation model to predict the impact of prophylactic surgery and screening on the life expectancy of BRCA1 and BRCA2 mutation carriers. *Cancer Epidemiol Biomarkers Prev*. 2012; 21(7):1066–77. [PubMed: 22556274]
31. Domchek SM, Friebel TM, Singer CF, Evans DG, Lynch HT, Isaacs C, et al. Association of risk-reducing surgery in BRCA1 or BRCA2 mutation carriers with cancer risk and mortality. *JAMA*. 2010; 304(9):967–75. [PubMed: 20810374]
32. Partridge A, Adloff K, Blood E, Dees EC, Kaelin C, Golshan M, et al. Risk perceptions and psychosocial outcomes of women with ductal carcinoma in situ: longitudinal results from a cohort study. *J Natl Cancer Inst*. 2008; 100(4):243–51. [PubMed: 18270338]
33. Liu Y, Perez M, Aft RL, Massman K, Robinson E, Myles S, et al. Accuracy of perceived risk of recurrence among patients with early-stage breast cancer. *Cancer Epidemiol Biomarkers Prev*. 2010; 19(3):675–80. [PubMed: 20160274]
34. Abbott A, Rueth N, Pappas-Varco S, Kuntz K, Kerr E, Tuttle T. Perceptions of contralateral breast cancer: an overestimation of risk. *Ann Surg Oncol*. 2011; 18(11):3129–36. [PubMed: 21947590]
35. Mamounas EP, Anderson SJ, Dignam JJ, Bear HD, Julian TB, Geyer CE Jr, et al. Predictors of locoregional recurrence after neoadjuvant chemotherapy: results from combined analysis of National Surgical Adjuvant Breast and Bowel Project B-18 and B-27. *J Clin Oncol*. 2012; 30(32):3960–6. [PubMed: 23032615]
36. Dominici LS, Mittendorf EA, Wang X, Liu J, Kuerer HM, Hunt KK, et al. Implications of constructed biologic subtype and its relationship to locoregional recurrence following mastectomy. *Breast Cancer Res*. 2012; 14(3):R82. [PubMed: 22621306]
37. Liu Y, Perez M, Schootman M, Aft RL, Gillanders WE, Ellis MJ, et al. A longitudinal study of factors associated with perceived risk of recurrence in women with ductal carcinoma in situ and early-stage invasive breast cancer. *Breast Cancer Res Treat*. 2010; 124(3):835–44. [PubMed: 20446031]
38. Apicella C, Peacock SJ, Andrews L, Tucker K, Daly MB, Hopper JL. Measuring, and identifying predictors of women's perceptions of three types of breast cancer risk: population risk, absolute risk and comparative risk. *Br J Cancer*. 2009; 100(4):583–9. [PubMed: 19209174]
39. Katz SJ, Lantz PM, Janz NK, Fagerlin A, Schwartz K, Liu L, et al. Patient involvement in surgery treatment decisions for breast cancer. *J Clin Oncol*. 2005; 23(24):5526–33. [PubMed: 16110013]
40. Hawley ST, Griggs JJ, Hamilton AS, Graff JJ, Janz NK, Morrow M, et al. Decision involvement and receipt of mastectomy among racially and ethnically diverse breast cancer patients. *J Natl Cancer Inst*. 2009; 101(19):1337–47. [PubMed: 19720966]
41. O'Brien MA, Whelan TJ, Villasis-Keever M, Gafni A, Charles C, Roberts R, et al. Are cancer-related decision aids effective? A systematic review and meta-analysis. *J Clin Oncol*. 2009; 27(6):974–85. [PubMed: 19124808]
42. Belkora JK, Volz S, Teng AE, Moore DH, Loth MK, Sepucha KR. Impact of decision aids in a sustained implementation at a breast care center. *Patient Educ Couns*. 2012; 86(2):195–204. [PubMed: 21665420]
43. Waljee JF, Rogers MA, Alderman AK. Decision aids and breast cancer: do they influence choice for surgery and knowledge of treatment options? *J Clin Oncol*. 2007; 25(9):1067–73. [PubMed: 17369570]

44. Whelan T, Levine M, Willan A, Gafni A, Sanders K, Mirsky D, et al. Effect of a decision aid on knowledge and treatment decision making for breast cancer surgery: a randomized trial. *JAMA*. 2004; 292(4):435–41. [PubMed: 15280341]
45. Lerman C, Lustbader E, Rimer B, Daly M, Miller S, Sands C, et al. Effects of individualized breast cancer risk counseling: a randomized trial. *J Natl Cancer Inst*. 1995; 87(4):286–92. [PubMed: 7707420]
46. Howard-Anderson J, Ganz PA, Bower JE, Stanton AL. Quality of Life, Fertility Concerns, and Behavioral Health Outcomes in Younger Breast Cancer Survivors: A Systematic Review. *J Natl Cancer Inst*. 2012
47. Janz NK, Mujahid M, Lantz PM, Fagerlin A, Salem B, Morrow M, et al. Population-based study of the relationship of treatment and sociodemographics on quality of life for early stage breast cancer. *Qual Life Res*. 2005; 14(6):1467–79. [PubMed: 16110927]
48. Kroenke CH, Rosner B, Chen WY, Kawachi I, Colditz GA, Holmes MD. Functional impact of breast cancer by age at diagnosis. *J Clin Oncol*. 2004; 22(10):1849–56. [PubMed: 15143077]
49. Baucom DH, Porter LS, Kirby JS, Gremore TM, Keefe FJ. Psychosocial issues confronting young women with breast cancer. *Breast Dis*. 2005; 23:103–13. [PubMed: 16823173]
50. Wenzel LB, Fairclough DL, Brady MJ, Cella D, Garrett KM, Kluhsman BC, et al. Age-related differences in the quality of life of breast carcinoma patients after treatment. *Cancer*. 1999; 86(9): 1768–74. [PubMed: 10547550]

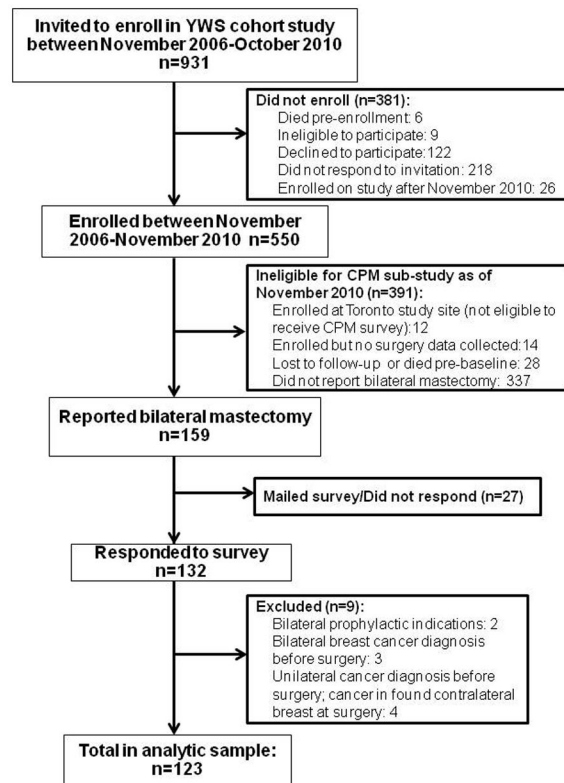


Figure 1.
Study flow diagram

Table 1

Patient and tumor characteristics (n=123)

Median age at diagnosis in years (range)	37 (26–40)
Median time since CPM in years (range)	2.1 (0.1–4.3)
	N (%)
Race	
White	113 (92)
Other	7 (6)
Missing/Did not wish to provide	3 (2)
Married/living as married	
Yes	101 (82)
No	19 (15)
Missing	3 (2)
College education	
Yes	104 (85)
No	14 (11)
Missing	5 (4)
Employed full time	
Yes	45 (37)
No	75 (61)
Missing	3 (2)
Medically insured	
Yes	118 (96)
No	1 (1)
Missing	4 (3)
Estrogen receptor (ER) status	
ER+	74 (60)
ER–	49 (40)
Her-2 Neu status	
Her-2 Neu+/indeterminate	42 (34)
Her-2 Neu–	75 (61)
Missing	6 (5)
Stage	
0	8 (7)
I	41 (33)
II	56 (46)
III	17 (14)
IV	1 (1)
Reconstructive surgery	
Yes	116 (94)

No	7 (6)
First degree relative with breast or ovarian cancer	
Yes	32 (26)
No	87 (71)
Unsure	4 (3)
Second degree relative with breast or ovarian cancer	
Yes	76 (62)
No	38 (31)
Unsure	9 (7)
Mutation status	
No mutation	74 (60)
BRCA1 +	22 (18)
BRCA2 +	8 (7)
Mutation of uncertain significance	4 (3)
Not tested/Unknown	15 (12)

CPM, contralateral prophylactic mastectomy

Table 2
Importance of reasons identified by women for choosing contralateral prophylactic mastectomy*

	Extremely important	Very important	Somewhat important	Not at all important	Not sure	Missing
	N (%)	N (%)	N (%)	N (%)	N (%)	N (%)
Desire to lower the chance of getting breast cancer in "other breast"	102 (83)	18 (15)	1 (1)	1 (1)	-	1 (1)
Desire for peace of mind	98 (80)	18 (15)	5 (4)	1 (1)	1 (1)	-
Desire to improve my survival/extend my life	97 (79)	18 (15)	3 (2)	5 (4)	-	-
Desire to prevent breast cancer from spreading to other places in my body	85 (69)	20 (16)	5 (4)	13 (11)	-	-
Feeling at increased risk of getting cancer in the "other breast"	81 (66)	26 (21)	9 (7)	5 (4)	2 (2)	-
Worry that screening wouldn't find cancer in the other breast	39 (32)	21 (17)	32 (26)	28 (23)	3 (2)	-
Have a strong family history of breast cancer	35 (28)	11 (9)	10 (8)	57 (46)	2 (2)	8 (7)
Desire to have both breasts look the same after surgery	34 (28)	36 (29)	34 (28)	18 (15)	1 (1)	-
Have known genetic change (mutation) such as BRCA 1 or BRCA 2 mutation	32 (26)	2 (2)	2 (2)	73 (59)	3 (2)	11 (9)
Desire to follow my doctor's recommendation	22 (18)	16 (13)	35 (28)	45 (37)	1 (1)	4 (3)
Desire to make breasts look better	13 (11)	20 (16)	29 (24)	57 (46)	4 (3)	-
Advice from family/friends	6 (5)	11 (9)	38 (31)	66 (54)	-	2 (2)

* Additional items related to diagnostic work up (e.g., MRI, ultrasound) and a history of prior chest radiation due were queried but not included in the above table.

Table 3

Women's reported experiences in relation to expectations associated with CPM

	Worse than expected N (%)	About what you expected N (%)	Better than expected N (%)	Does not apply N (%)	Missing N (%)
Cosmetic results	34 (28)	55 (45)	31 (25)	1 (1)	2 (2)
Pain at surgical site	31 (25)	49 (40)	37 (30)	4 (3)	2 (2)
Number of surgeries/procedures needed	41 (33)	68 (55)	10 (8)	1 (1)	3 (2)
Numbness or tingling in chest	35 (28)	63 (51)	19 (15)	5 (4)	1 (1)
Self-conscious about your appearance	38 (31)	49 (40)	28 (23)	5 (4)	3 (2)
Sense of sexuality	52 (42)	48 (39)	17 (14)	4 (3)	2 (2)
Worry or anxiety about breast cancer	28 (23)	63 (51)	29 (24)	1 (1)	2 (2)
Amount of follow up imaging or tests	14 (11)	61 (50)	32 (26)	14 (11)	2 (2)
Recovery from reconstruction surgery*	33 (27)	39 (32)	41 (33)	2 (2)	8 (7)
Complications or problems from reconstruction surgery*	26 (21)	34 (28)	30 (24)	24 (20)	9 (7)
Filling up expanders*	28 (23)	32 (26)	29 (24)	25 (20)	9 (7)

* only applicable to women who had reconstruction (n=116)

Table 4

Breast cancer knowledge and risk perception by mutation carrier status

	Mutation carriers (N=34)	Non-carriers (N=89)
Risk of developing a CBC without CPM in the five years after treatment (Number of women out of 100)[*]		
Median	20	10
Mean	23.1	16.7
Range	0–65	0–90
Risk of developing a chest wall recurrence with CPM in the five years after treatment (Number of women out of 100)[†]		
Median	5	5
Mean	10.1	9.0
Range	0–50	0–98
Do you think the chance that your cancer will come back is higher, lower, or about the same as other women with early stage breast cancer?	N (%)	N (%)
Higher	11 (32)	17 (19)
Lower	14 (41)	18 (20)
About the same	7 (21)	50 (56)
Missing	2 (6)	4 (4)
How much did you think that having the “other breast” removed would lower your chance of getting breast cancer in that breast or chest area in the future?		
A lot	32 (94)	60 (67)
Some	2 (6)	21 (24)
A little	-	7 (8)
Not at all	-	1 (1)
With treatment, about how many women diagnosed with early breast cancer will eventually die of breast cancer?		
Most will die of breast cancer	1 (3)	-
About half will die of breast cancer	7 (21)	14 (16)
Most will die of something else	25 (74)	75 (84)
Missing	1 (3)	-
On average, which women with early breast cancer will live longer?		
Women who have a mastectomy	-	8 (9)
Women who have a lumpectomy and radiation	1 (3)	1 (1)
Women who have a bilateral mastectomy	8 (24)	13 (15)
There is no difference	24 (71)	65 (73)
Missing	1 (3)	2 (2)

* n=3 mutation carriers and n=3 non-carriers did not answer this question

† n=3 mutation carriers and n=2 non-carriers did not answer this question