

Psychosocial factors associated with the uptake of contralateral prophylactic mastectomy among *BRCA1/2* mutation noncarriers with newly diagnosed breast cancer

Jada G. Hamilton^{1,2} · Margaux C. Genoff¹ · Melissa Salerno³ · Kimberly Amoroso³ · Sherry R. Boyar^{3,5} · Margaret Sheehan³ · Megan Harlan Fleischut³ · Beth Siegel³ · Angela G. Arnold³ · Erin E. Salo-Mullen³ · Jennifer L. Hay^{1,2} · Kenneth Offit^{3,4} · Mark E. Robson^{3,4}

Received: 31 October 2016 / Accepted: 18 January 2017 / Published online: 1 February 2017
© Springer Science+Business Media New York 2017

Abstract

Purpose Women who are newly diagnosed with breast cancer may consider contralateral prophylactic mastectomy (CPM) to reduce their future risk of cancer in their unaffected breast. Pre-surgical *BRCA1/2* genetic testing can provide valuable risk information to guide this choice. However, little is understood about why *BRCA1/2* mutation noncarriers, who are generally not at substantially elevated risk of contralateral disease, select CPM.

Methods We examined the uptake of CPM among breast cancer patients identified as *BRCA1/2* mutation noncarriers ($n = 92$) as part of a larger prospective study of the impact of pre-surgical *BRCA1/2* testing. Data obtained from self-report questionnaires and patient medical records were used to examine associations between theoretically relevant background and psychosocial factors and *BRCA1/2* mutation noncarriers' decisions to undergo CPM.

Results Among *BRCA1/2* mutation noncarriers, 25% ($n = 23$) elected to undergo CPM. Psychosocial factors including a self-reported physician recommendation for CPM, greater perceived contralateral breast cancer risk, and greater perceived benefits of CPM were all significantly associated with the uptake of CPM.

Conclusions A sizeable minority of *BRCA1/2* mutation noncarriers choose to undergo CPM after learning their mutation status through pre-surgical genetic testing. *BRCA1/2* mutation noncarriers' cognitive perceptions and social influences appear to be important in shaping their decisions regarding CPM. This work highlights the importance of several psychosocial factors in influencing patients' surgical decisions. Future research is needed that examines the formation of *BRCA1/2* mutation noncarriers' beliefs regarding their disease and available treatment options, and that characterizes the physician-patient communication that occurs in this complex decision-making context.

✉ Jada G. Hamilton
hamilto@mskcc.org

- ¹ Behavioral Sciences Service, Department of Psychiatry & Behavioral Sciences, Memorial Sloan Kettering Cancer Center, 641 Lexington Avenue, 7th floor, New York 10022, NY, USA
- ² Department of Psychiatry, Weill Cornell Medical College, Cornell University, New York, NY, USA
- ³ Clinical Genetics Service, Department of Medicine, Memorial Sloan Kettering Cancer Center, New York, NY, USA
- ⁴ Department of Medicine, Weill Cornell Medical College, Cornell University, New York, NY, USA
- ⁵ Division of Medical Genetics, Department of Genetics & Genomic Sciences, Icahn School of Medicine at Mount Sinai, New York, NY, USA

Keywords Breast cancer · Decision-making · Genetic testing · Prophylactic mastectomy · Prevention

Introduction

In addition to complex treatment decisions, newly diagnosed breast cancer patients must make choices about managing their future cancer risk. One option they may consider is contralateral prophylactic mastectomy (CPM) to minimize the likelihood of developing cancer in their unaffected breast. This decision is somewhat time-sensitive because outcomes are optimized when a woman chooses to undergo CPM early in her treatment course, as she can then avoid risks associated with multiple surgeries and radiation

that would compromise breast reconstruction options if she later chose to have a prophylactic mastectomy. The uptake of CPM has increased substantially, with estimates of uptake ranging from 11–18% in recent years [1–4].

Pre-surgical *BRCA1/2* genetic testing can provide valuable risk information to guide patients' decisions about CPM. This is because *BRCA1/2* mutation carriers have an elevated risk of developing a new contralateral breast cancer (CBC) in their unaffected breast. Ten years after their index diagnosis, women who are carriers of pathogenic *BRCA1/2* mutations have a 27–37% chance of developing CBC [5–7]. Conversely, *BRCA1/2* mutation noncarriers face a much lower 10-year CBC risk of 5–10% [6, 8–10]. Following pre-surgical *BRCA1/2* testing, mutation carriers are consistently more likely to opt for CPM than are patients with uninformative or negative genetic test results [11–15]. Yet, in spite of their lower levels of objective risk, some women identified as *BRCA1/2* mutation noncarriers also choose to undergo CPM [11–17].

The psychosocial factors that may motivate *BRCA1/2* mutation noncarriers to select CPM are not well understood. Past work suggests that demographic and medical factors, including younger age [13, 15], marital status [14], and family history of breast [11, 13] and ovarian cancer [15], are associated with *BRCA1/2* mutation noncarriers' use of CPM. Schwartz and colleagues [11] also observed that *BRCA1/2* mutation noncarriers who reported that their physician had recommended genetic testing and had recommended CPM were more likely to undergo the surgery. Limited evidence suggests that psychological factors may also influence noncarriers' decisions. In a retrospective survey, *BRCA1/2* mutation noncarriers cited feeling at increased CBC risk, and the desire to reduce CBC risk, obtain peace of mind, and improve survival, as important reasons for choosing CPM [18]. Qualitative interviews conducted with breast cancer patients without *BRCA1/2* mutations following completion of CPM also identified influential decision-making factors including patients' subjective evaluation of the risks and benefits of the various treatment options, ability to maintain or improve breast appearance, and potential to avoid future cancer surveillance and worry [19]. The need exists, however, for studies that prospectively examine how such perceptions of the harms and benefits of CPM or emotional distress about breast cancer may be associated with subsequent CPM uptake among *BRCA1/2* mutation noncarriers.

With the present study, we sought to extend past work by examining the CPM decision-making process among newly diagnosed breast cancer patients identified as *BRCA1/2* mutation noncarriers through pre-surgical genetic testing. Specifically, we aimed to determine the frequency of CPM uptake, and to identify psychosocial factors

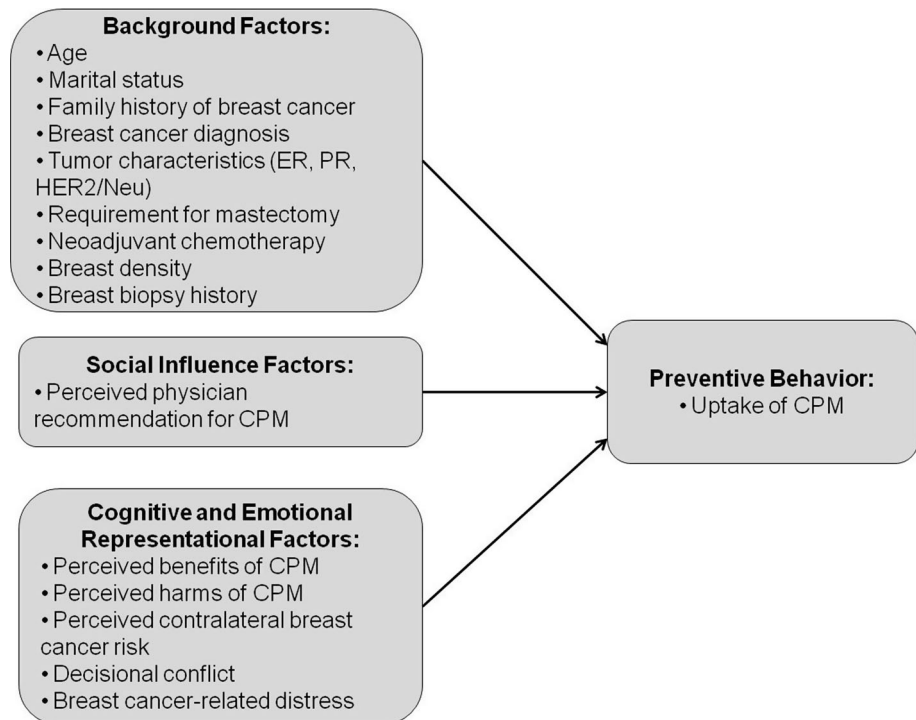
contributing to this decision. We evaluated a conceptual model of CPM decision-making (Fig. 1), with the selection of psychosocial factors guided by past empirical work [11, 13, 14, 19–21] and the Preventive Health Model (that identifies various factors that can influence an individual's decision about preventive behavior) [22, 23]. These factors can include background (e.g. sociodemographic characteristics and medical history), representational (e.g. cognitive perceptions and emotional responses), and social influences (e.g. interpersonal relationships and support). We hypothesized that background factors including family history of breast cancer and younger age (which are most relevant to absolute CBC risk [9]), marital status, and an invasive cancer diagnosis would be associated with CPM uptake. We further hypothesized that noncarriers' cognitive and emotional representations of CPM would be relevant such that those who perceived greater CBC risk, experienced less decisional conflict, and reported greater breast cancer-related distress would be more likely to choose CPM. Given past qualitative work suggesting the importance of perceived treatment benefits and risks to this decision-making context [19], we also predicted that greater perceptions of benefits and lower perceptions of harms of CPM would be associated with uptake. Finally, we hypothesized that the social influence of a perceived physician recommendation for CPM would be associated with CPM uptake.

Methods

Participants and procedures

Data were collected as part of a larger prospective study of the impact of pre-surgical *BRCA1/2* testing among newly diagnosed breast cancer patients. The Memorial Sloan Kettering Cancer Center Institutional Review Board approved the study protocol. Eligible participants included English-speaking women aged 18 or older with a diagnosis of invasive breast cancer or ductal carcinoma in situ (as a primary malignancy or as a second diagnosis if a CBC and the first cancer was not treated with mastectomy) who had not completed definitive surgical treatment and were deemed appropriate for genetic testing based on National Comprehensive Cancer Network criteria [24] (i.e. breast cancer diagnosed at age 45 or younger; bilateral breast cancer first diagnosed at age 50 or younger; breast cancer diagnosed at any age with a male relative with breast cancer; breast cancer diagnosed at age 50 or younger with either at least one relative with breast cancer diagnosed at age 50 or younger or at least one relative with ovarian cancer; or of Ashkenazi Jewish ethnicity with breast cancer diagnosed at age 60 or younger).

Fig. 1 Conceptual model of decision-making about contralateral prophylactic mastectomy (CPM). This model describes psychosocial factors including background factors (e.g. sociodemographic characteristics and medical history), social influence factors (e.g. interpersonal relationships and support), and representational factors (e.g. cognitive perceptions and emotional responses) that may influence the decision to undergo CPM (adapted from [22, 23])



Participants were recruited at the time of their surgical consultation. All participants provided written informed consent and underwent a consultation with a genetic counselor trained in hereditary cancer risk assessment. Participants could then choose to provide a DNA sample for pre-surgical *BRCA1/2* testing or defer genetic testing until a later time. All participants chose pre-surgical testing. Following genetic testing (Ashkenazi founder mutation testing or full sequencing with large rearrangement testing, as appropriate), participants returned for a genetic counseling session that included the disclosure of the results, and discussion of cancer risk management options and individualized screening recommendations. Prospective data for the present study were obtained from a written self-report questionnaire completed by participants after receiving their *BRCA1/2* results and before their surgical treatment, and from review of participants' medical records.

Measures

Perceived benefits of CPM were assessed with five investigator-designed items (e.g. "it might improve my chances of surviving breast cancer"). Participants rated their agreement with each item as a reason to have CPM on a five-point Likert scale (response options: 1 = "not at all a good reason for me" to 5 = "a very good reason for me"). Responses were summed to create a scale score ranging

from 5 to 25, with higher values indicating greater perceived benefits of CPM (Cronbach's $\alpha = 0.86$).

Perceived harms of CPM were assessed with five investigator-designed items (e.g. "I would feel disfigured after surgery"). Participants rated their agreement with each item as a reason to not have CPM (response options: 1 = "not at all a good reason for me" to 5 = "a very good reason for me"). Item responses were summed; higher values indicate greater perceived harms of CPM ($\alpha = 0.91$).

Perceived CBC risk was assessed with one item. Participants indicated how many of 100 women like them "will get breast cancer in their other breast in the next 10 years" (response options: "less than 5," "between 5 and 10," "between 10 and 15," "between 15 and 20," "between 20 and 25," and "more than 25"). Responses were recorded to reflect perceived CBC risk consistent with that of a *BRCA1/2* mutation noncarrier (0 = "10 or fewer women") or higher (1 = "More than 10 women").

Decisional conflict was assessed with the 16-item Decisional Conflict Scale [25], which measures perceptions of uncertainty in choosing decision options; degree of feeling uninformed, unclear about personal values, and unsupported in decision-making; and perceptions of the effectiveness of decision-making regarding CPM ($\alpha = 0.96$). Scores range from 0 to 100; higher values indicate greater decisional conflict.

Breast cancer-related distress was assessed with the 15-item Impact of Event Scale [26], which measures the

presence of intrusive thoughts ($\alpha = 0.86$; scores range from 0 to 35) and avoidance ($\alpha = 0.76$; scores range from 0 to 40) regarding the participant's breast cancer diagnosis.

Perceived physician recommendation for CPM was assessed with one item: "Has your doctor recommended that you have a prophylactic mastectomy?" (response options: yes/no).

Uptake of CPM at the time of each participant's surgical treatment was abstracted from medical records (response options: yes/no).

Sociodemographic and medical factors abstracted from medical records included age, race, Ashkenazi Jewish ethnicity, marital status, family history of breast cancer, breast cancer diagnosis, hormone receptor status (ER, PR, and HER2/neu) of the diagnosed breast cancer, whether a mastectomy was required for treatment of the affected breast, whether neoadjuvant chemotherapy was used, number of previous breast biopsies, and breast density.

Data analysis

Data were analyzed using SPSS version 22.0. Descriptive statistics were computed for all variables. To describe participants' perceptions of the benefits and harms of CPM, *t*-tests were used to compare responses on the individual items from each measure among those who did and did not choose CPM. Chi square significance tests and *t*-tests were used to examine bivariate associations between psychosocial, sociodemographic, and medical factors with the outcome of CPM uptake. Any variables significantly ($p \leq 0.05$) associated with CPM uptake were then included as predictors in a multivariable logistic regression model. All statistical tests were two-tailed with $\alpha = 0.05$.

Results

Sample characteristics

Data were available for 102 women who underwent pre-surgical *BRCA1/2* testing; eight tested positive for a pathogenic *BRCA1/2* mutation, two were found to have a variant of uncertain clinical significance, and 92 tested negative for a pathogenic *BRCA1/2* mutation. None of these 92 women were tested for known familial mutations. These 92 "*BRCA1/2* mutation noncarriers" comprise the present study sample (Table 1). Participant ages ranged from 29 to 59 (median = 43), and the majority were White/Caucasian (83.7; 4.3% of the participants were Black/African American, 4.3% were Asian, and 7.6% declined to answer). Almost two-thirds (62.2%) of the sample reported a family history of breast cancer, with

participants reporting a median of one other affected family member (range: 0–5).

Uptake of CPM

Twenty-five percent of the *BRCA1/2* mutation noncarriers (23/92) elected to undergo CPM following pre-surgical genetic testing. In comparison, 88% (7/8) of the patients identified as *BRCA1/2* mutation carriers and 0% (0/2) of those with a variant of uncertain clinical significance in the larger study chose to undergo CPM.

Psychosocial correlates of the CPM decision

Among the sample of *BRCA1/2* mutation noncarriers, 90.2% (83/92) provided responses to the self-report questionnaire including the psychosocial variables. Questionnaire nonresponders did not differ from responders in age, Ashkenazi Jewish ethnicity, cancer diagnosis, or CPM uptake; however, nonresponders were less likely to be married/partnered than responders (44.4 vs. 77.1%, $p = 0.05$).

We first examined *BRCA1/2* mutation noncarriers' cognitive perceptions of the benefits and harms of CPM (Fig. 2). Participants perceived the ability to reduce their chances of getting breast cancer again, improve their chances of surviving breast cancer, and decrease their worry about breast cancer as the greatest benefits of CPM. Participants who chose to undergo CPM endorsed each of the benefits more strongly than did those who chose to not have the surgery, with the greatest differences observed for the benefits of feeling good about the surgery and regretting not having the surgery. In general, participants did not strongly endorse any of the harms of CPM. No significant differences in the perceptions of harms were observed between those participants who did and did not choose CPM.

Next, we examined the extent to which the hypothesized psychosocial factors were associated with *BRCA1/2* mutation noncarriers' surgical decisions. Bivariate (Table 1) and multivariable (Table 2) analyses confirmed several of the hypothesized associations. The social factor of perceiving that one's physician had recommended CPM was significantly associated with the decision to undergo CPM. Furthermore, the cognitive representation factors of perceiving greater CBC risk and perceiving greater benefits of CPM were both significantly associated with CPM uptake. However, the cognitive representation factors of perceived harms of CPM and decisional conflict, and the emotional representation factor of breast cancer-related distress were not significantly associated with noncarriers' surgical decisions (all $ps > 0.05$). In addition, although the medical factor of breast density was associated with CPM

Table 1 Characteristics of newly diagnosed breast cancer patients identified as *BRCA1/2* mutation noncarriers

Characteristic, mean \pm standard deviation or <i>n</i> (column %)	Total sample (<i>n</i> = 92)	Chose CPM (<i>n</i> = 23)	Did not choose CPM (<i>n</i> = 69)	<i>p</i> ^a
Age (median; range)	43; 29–59	42; 30–55	44; 29–59	0.15
Ashkenazi Jewish ethnicity (yes)	52 (56.5)	12 (52.2)	40 (58.0)	0.63
Marital status (married/partnered)	68 (73.9)	18 (78.3)	50 (72.5)	0.58
Family history of breast cancer				0.80
No family history	35 (38.0)	8 (34.8)	27 (39.1)	
Second-degree relative(s) only	30 (32.6)	7 (30.4)	23 (33.3)	
First-degree relative(s), with or without second-degree	27 (29.3)	8 (34.8)	19 (27.5)	
Cancer diagnosis				0.56
DCIS	20 (21.7)	6 (26.1)	14 (20.3)	
Invasive	72 (78.3)	17 (73.9)	55 (79.7)	
Estrogen receptor (ER) status				0.23
Positive	68 (73.9)	20 (87.0)	48 (69.6)	
Negative	12 (13.0)	1 (4.3)	11 (15.9)	
Unknown	12 (13.0)	2 (8.7)	10 (14.5)	
Progesterone receptor (PR) status				0.59
Positive	62 (67.4)	17 (73.9)	45 (65.2)	
Negative	14 (15.2)	2 (8.7)	12 (17.2)	
Unknown	16 (17.4)	4 (17.4)	12 (17.4)	
HER2/neu status				0.74
Positive	12 (13.0)	2 (8.7)	10 (14.5)	
Negative	63 (68.5)	17 (73.9)	46 (66.7)	
Unknown	17 (18.5)	4 (17.4)	13 (18.8)	
Number of previous breast biopsies	1.3 \pm 0.60	1.4 \pm 0.66	1.3 \pm 0.54	0.40
Mastectomy required (yes)	9 (9.8)	3 (13.0)	6 (8.7)	0.69
Neoadjuvant chemotherapy (yes) ^b	1 (1.2)	1 (4.5)	0 (0)	0.26
Breast density				0.04
Predominantly fatty/Scattered densities	18 (19.6)	1 (4.3)	17 (24.6)	
Heterogeneously dense/Extremely dense	74 (80.4)	22 (95.7)	52 (75.4)	
Perceived benefits of CPM ^c	17.9 \pm 5.5	21.9 \pm 3.2	16.6 \pm 5.4	<0.001
Perceived harms of CPM ^c	10.7 \pm 5.7	10.7 \pm 5.5	10.6 \pm 5.8	0.97
Perceived CBC risk ^c				0.03
10 or fewer women out of 100	34 (41.0)	4 (20.0)	30 (47.6)	
More than 10 women out of 100	49 (59.0)	16 (80.0)	33 (52.4)	
Decisional conflict ^c	25.8 \pm 21.0	25.5 \pm 25.0	25.9 \pm 19.8	0.94
Breast cancer-related distress ^c				
Intrusion	16.7 \pm 8.5	18.1 \pm 7.4	16.2 \pm 8.8	0.39
Avoidance	17.0 \pm 7.8	18.0 \pm 7.3	16.6 \pm 8.0	0.51
Perceived physician recommendation for CPM (yes) ^c	13 (15.7)	9 (45.0)	4 (6.3)	<0.001

CPM contralateral prophylactic mastectomy, CBC contralateral breast cancer

^a *t* test used to compute *p* value for continuous variables, Pearson χ^2 significance tests used to compute *p* values for categorical variables

^b Data missing for seven participants

^c Total *n* = 83 (of which 20 chose CPM and 63 did not choose CPM)

uptake in the bivariate analysis ($p = 0.04$), it did not remain significant in multivariable analysis ($p = 0.26$) and was thus excluded from the final model. Similarly, none of

the other sociodemographic and medical factors were significantly associated with noncarriers' surgical decisions (all $ps > 0.05$).

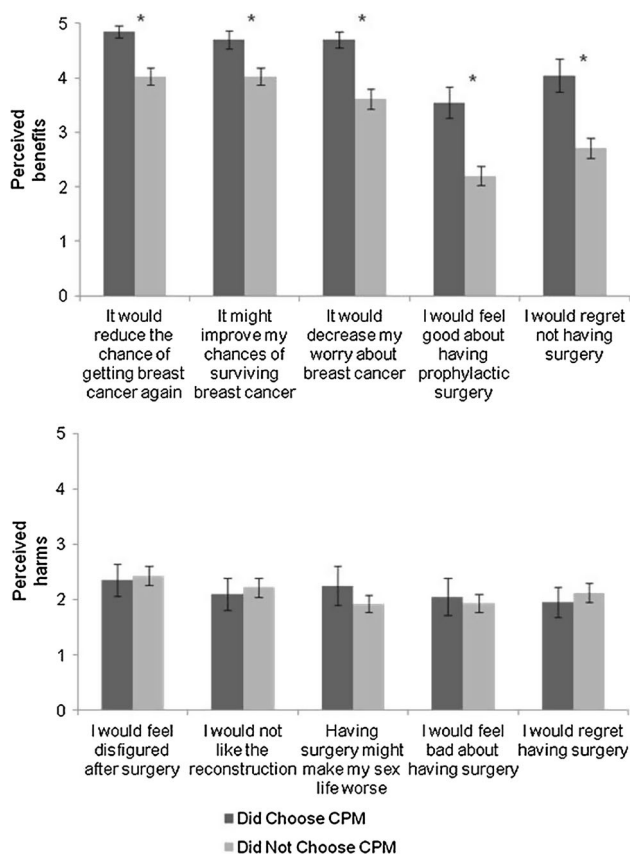


Fig. 2 Perceived benefits and harms of contralateral prophylactic mastectomy (CPM) among newly diagnosed breast cancer patients identified as *BRCA1/2* mutation noncarriers through pre-surgical genetic testing ($n = 83$). Error bars correspond to the standard error of the mean. Asterisks indicate significant differences in perceived benefits of CPM between those who did and did not choose CPM ($p \leq 0.005$)

Discussion

The present study examined CPM uptake among newly diagnosed breast cancer patients identified as *BRCA1/2* mutation noncarriers through pre-surgical genetic testing. Although *BRCA1/2* mutation noncarriers generally do not face substantially elevated CBC risk, we observed that 25% of these patients chose to undergo CPM. This figure is

substantially lower than that observed among *BRCA1/2* mutation carriers in our larger study (88%), and is consistent with a few other studies of CPM in noncarriers following pre-surgical *BRCA1/2* testing [11, 12, 15, 17]. However, this level of uptake is somewhat higher than estimates in the general population of women with breast cancer, which suggest that approximately 11–18% of patients ultimately choose CPM [1–4]. This difference may be attributable in part to the fact that study participants were generally younger (ages 29–59) than is typically observed in a population ascertainment.

In an attempt to explain why *BRCA1/2* mutation noncarriers chose to undergo CPM, we also examined how psychosocial factors consistent with the Preventive Health Model [22, 23] contributed to patients’ decision-making. Contrary to our predictions, the examined background sociodemographic and medical factors (which included age and family history, factors most relevant to absolute CBC risk [9]) and emotional factor of breast cancer-related distress were not associated with CPM uptake. Rather, several cognitive representations and social influence factors were most relevant. Results demonstrate that *BRCA1/2* mutation noncarriers perceive various benefits of CPM, and these perceptions influence choice of this cancer risk management strategy. Conversely, noncarriers appear to give less weight to the potential harms of CPM, as these beliefs do not contribute to their decision. This observation is noteworthy because CPM is associated with serious physical risks including increased surgical site and post-operative complications as compared to unilateral mastectomy [27–29], and is also associated with psychological complaints regarding physical appearance, sexuality, and feelings of femininity among a minority of patients [18, 30, 31]. Why study participants appear to be less concerned about harms of CPM is unclear, although one study noted that physicians are more likely to discuss reasons for having CPM as opposed to reasons for not having CPM with breast cancer patients who are *BRCA1/2* mutation noncarriers [18]. Such findings suggest that patients may benefit from interventions such as decision aids or physician-directed prompts in the electronic

Table 2 Multivariable logistic regression model of psychosocial factors associated with the decision to undergo CPM among *BRCA1/2* mutation noncarriers ($n = 83$)

Independent variable	Odds ratio	95% CI	<i>p</i>
Perceived benefits of CPM	1.38	1.11–1.70	0.003
Perceived CBC risk			0.018
10 or fewer women out of 100	1.00 (ref)		
More than 10 women out of 100	6.59	1.39–31.33	
Perceived physician recommendation for CPM			0.007
No	1.00 (ref)		
Yes	10.98	1.94–61.96	

CPM contralateral prophylactic mastectomy, CBC contralateral breast cancer

medical record that encourage the discussion and deliberation of both the advantages and disadvantages of CPM to promote informed treatment decisions.

As hypothesized, patients' cognitive perceptions of personal CBC risk also contributed to the decision to undergo CPM. Theoretical and empirical work supports the role of heightened disease risk perceptions in influencing adoption of health protective behaviors [32–35]. However, breast cancer patients can overestimate their likelihood of developing CBC [18, 36]; indeed, in the present study, 59% of participants overestimated their 10 year CBC risk. Evidence is mixed regarding the efficacy of existing educational interventions, including genetic counseling, for improving patients' subjective understanding of their cancer risk [37, 38]. Newly diagnosed breast cancer patients, in particular, face numerous communication challenges that may interfere with their ability to process or accurately recall this risk information (e.g. exposure to a large amount of complex medical information, the need to make important decisions in a short time period, receipt of conflicting messages from various healthcare providers). Thus, these individuals may benefit from research to develop and test targeted, novel educational and risk communication approaches that promote accurate disease risk perceptions, and consequently, more informed treatment and risk management decision-making.

The social influence factor of perceived physician recommendation for CPM was also associated with patients' surgical choices. Physicians are a primary source of information and advice for breast cancer patients facing treatment decisions [18, 39]. Furthermore, patient-reported physician recommendations for CPM have been previously associated with CPM uptake in a prospective study of newly diagnosed *BRCA1/2* mutation noncarriers [11] and a retrospective study of breast cancer patients who had the surgery [21]. In the present study, perceived physician recommendation for CPM was the strongest predictor of the CPM decision; however, this finding should be interpreted cautiously as only a small proportion of participants (16%) reported that their physician made this recommendation. These participants were treated by different physicians (six different medical oncologists and surgeons among the 13 participants reporting a physician recommendation). Yet, we lack any information about the actual clinical communication that occurred between participants and their physicians—for instance, it is not clear to what extent physicians may have strongly recommended CPM, or simply mentioned it as an available option. Future observational research incorporating qualitative and quantitative methods is needed to examine the content of physician-patient communication regarding CPM and other breast cancer treatment options and to understand what aspects of this communication may shape

patients' perceptions of their physicians' opinions and preferences.

This study represents one of the first attempts to prospectively evaluate how theoretically informed psychosocial factors influence *BRCA1/2* mutation noncarriers' decision-making about CPM. However, this study has several limitations. Data were collected from a small sample of primarily younger, Caucasian patients at a single cancer center. Study participants may also have been more willing to consider CPM than patients who decline pre-surgical genetic testing (although it is routine surgical practice at our center to refer all high-risk patients for genetic testing and participants were offered the option of deferring genetic testing until after their treatment but none chose to do so); such potential selection bias may have influenced the study results. Thus, the generalizability of these findings to more diverse patients and treatment settings requires further study. Furthermore, the small sample size likely contributed to the wide confidence intervals observed for the associations between perceived CBC risk and perceived physician recommendation with CPM uptake. Future studies utilizing larger, more diverse samples would provide more precise estimates and greater insight into the role of these psychosocial factors in patients' decision-making. Established, well-validated measures were used to assess several of the psychosocial factors. However, novel measures and single-item measures were also used, and the reliability and validity of such items are unknown. In addition, the measures of perceived benefits and harms of CPM may not have assessed the full range of issues that patients and their physicians consider in this decision-making context. Relevant medical factors including the hormone receptor status of the cancer, necessity of mastectomy and neoadjuvant chemotherapy for treatment of the affected breast, and participants' history of breast biopsies and breast density were included in the analyses; however, additional clinical data that may contribute to contralateral disease risk (e.g. history of benign disease in the contralateral breast) and therefore inform decision-making were not available. Finally, no data were available regarding the outcomes of this decision (e.g. surgical complications, regret, satisfaction), although such longitudinal data would provide valuable insight into the CPM decision-making process among *BRCA1/2* mutation noncarriers.

In spite of these limitations, these results can guide future research. We observed that social influences, namely physician recommendations, shape *BRCA1/2* mutation noncarriers' decisions about CPM. However, it remains possible that other individuals, such as a patient's spouse/partner, family members, and close friends, also influence this decision [21]. These individuals could provide direct feedback about the appropriateness of CPM, or

indirectly influence a patient's decision by shaping her cognitive representations, including her perceptions of future disease risk [40, 41]. Research should investigate the development of *BRCA1/2* mutation noncarriers' beliefs about their CBC risk and the benefits and harms of CPM, with a particular emphasis on the interpersonal communication that occurs in this decision-making context. Studies could utilize observational methods (e.g. recordings of discussions between patients and physicians) and collect data from multiple individuals (e.g. patients and spouses/partners) to examine how others' perspectives can inform and interact with women's past experiences, emotions, and beliefs to influence their cancer risk management decisions.

Conclusions

Study results demonstrate that a sizable minority of recently diagnosed breast cancer patients who learn that they are *BRCA1/2* mutation noncarriers through pre-surgical genetic testing will nonetheless elect to undergo CPM. These patients' CPM decisions are influenced by psychosocial factors including their cognitive perceptions about the benefits of CPM and their CBC risk. In addition, patients' physicians can exert a powerful social influence on their decision-making about CPM. Future research is needed that examines the formation of patients' beliefs regarding their disease and available treatment options and that characterizes the communication between patients and physicians regarding these issues. Such work could inform the development of educational, risk communication, and decision-making interventions to assist newly diagnosed breast cancer patients with making informed cancer risk management decisions.

Acknowledgements This study was supported by award C026591 (PI: Mark E. Robson, MD) from the New York State Department of Health, NCI P30 CA008748, Robert and Kate Niehaus Center for Inherited Cancer Genomics, and the Breast Cancer Research Foundation.

Compliance with ethical standards

Conflicts of interest The authors declare that they have no conflict of interest.

Ethical approval This research complies with the current laws of the country in which it was performed (United States). All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Human and animal rights This article does not contain any studies with animals performed by any of the authors.

Informed consent Informed consent was obtained from all individual participants included in the study.

References

- Jagsi R, Jiang J, Momoh AO, Alderman A, Giordano SH, Buchholz TA, Kronowitz SJ, Smith BD (2014) Trends and variation in use of breast reconstruction in patients with breast cancer undergoing mastectomy in the United States. *J Clin Oncol* 32(9):919–926. doi:10.1200/jco.2013.52.2284
- Kurian AW, Lichtensztajn DY, Keegan TH, Nelson DO, Clarke CA, Gomez SL (2014) Use of and mortality after bilateral mastectomy compared with other surgical treatments for breast cancer in California, 1998–2011. *JAMA* 312(9):902–914. doi:10.1001/jama.2014.10707
- Tuttle TM, Habermann EB, Grund EH, Morris TJ, Virnig BA (2007) Increasing use of contralateral prophylactic mastectomy for breast cancer patients: a trend toward more aggressive surgical treatment. *J Clin Oncol* 25(33):5203–5209. doi:10.1200/jco.2007.12.3141
- Kummerow KL, Du L, Penson DF, Shyr Y, Hooks MA (2015) Nationwide trends in mastectomy for early-stage breast cancer. *JAMA Surg* 150(1):9–16. doi:10.1001/jamasurg.2014.2895
- Robson M, Svahn T, McCormick B, Borgen P, Hudis CA, Norton L, Offit K (2005) Appropriateness of breast-conserving treatment of breast carcinoma in women with germline mutations in *BRCA1* or *BRCA2*: a clinic-based series. *Cancer* 103(1):44–51. doi:10.1002/cncr.20728
- Robson ME, Chappuis PO, Satagopan J, Wong N, Boyd J, Goffin JR, Hudis C, Roberge D, Norton L, Begin LR, Offit K, Foulkes WD (2004) A combined analysis of outcome following breast cancer: differences in survival based on *BRCA1/BRCA2* mutation status and administration of adjuvant treatment. *Breast Cancer Res* 6(1):R8–r17. doi:10.1186/bcr658
- Metcalfe K, Lynch HT, Ghadirian P, Tung N, Olivotto I, Warner E, Olopade OI, Eisen A, Weber B, McLennan J, Sun P, Foulkes WD, Narod SA (2004) Contralateral breast cancer in *BRCA1* and *BRCA2* mutation carriers. *J Clin Oncol* 22(12):2328–2335. doi:10.1200/jco.2004.04.033
- Rhiem K, Engel C, Graeser M, Zachariae S, Kast K, Kiechle M, Ditsch N, Janni W, Mundhenke C, Golatta M, Varga D, Preisler-Adams S, Heinrich T, Bick U, Gadzicki D, Briest S, Meindl A, Schmutzler RK (2012) The risk of contralateral breast cancer in patients from *BRCA1/2* negative high risk families as compared to patients from *BRCA1* or *BRCA2* positive families: a retrospective cohort study. *Breast Cancer Res* 14(6):R156. doi:10.1186/bcr3369
- Reiner AS, John EM, Brooks JD, Lynch CF, Bernstein L, Mellekjær L, Malone KE, Knight JA, Capanu M, Teraoka SN, Concannon P, Liang X, Figueiredo JC, Smith SA, Stovall M, Pike MC, Haile RW, Thomas DC, Begg CB, Bernstein JL (2013) 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* 31(4):433–439. doi:10.1200/jco.2012.43.2013
- Malone KE, Begg CB, Haile RW, Borg A, Concannon P, Telled L, Xue S, Teraoka S, Bernstein L, Capanu M, Reiner AS, Riedel ER, Thomas DC, Mellekjær L, Lynch CF, Boice JD Jr, Anton-Culver H, Bernstein JL (2010) Population-based study of the risk of second primary contralateral breast cancer associated with carrying a mutation in *BRCA1* or *BRCA2*. *J Clin Oncol* 28(14):2404–2410. doi:10.1200/jco.2009.24.2495

11. Schwartz MD, Lerman C, Brogan B, Peshkin BN, Halbert CH, DeMarco T, Lawrence W, Main D, Finch C, Magnant C, Penanen M, Tsangaris T, Willey S, Isaacs C (2004) Impact of BRCA1/BRCA2 counseling and testing on newly diagnosed breast cancer patients. *J Clin Oncol* 22(10):1823–1829. doi:[10.1200/jco.2004.04.086](https://doi.org/10.1200/jco.2004.04.086)
12. Lokich E, Stuckey A, Raker C, Wilbur JS, Laprise J, Gass J (2014) Preoperative genetic testing affects surgical decision making in breast cancer patients. *Gynecol Oncol* 134(2):326–330. doi:[10.1016/j.ygyno.2014.05.028](https://doi.org/10.1016/j.ygyno.2014.05.028)
13. Wang F, Amara D, Peled AW, Sbitany H, Foster RD, Ewing CA, Alvarado M, Esserman LJ (2015) Negative genetic testing does not deter contralateral prophylactic mastectomy in younger patients with greater family histories of breast cancer. *Ann Surg Oncol* 22(10):3338–3345. doi:[10.1245/s10434-015-4745-3](https://doi.org/10.1245/s10434-015-4745-3)
14. Howard-McNatt M, Schroll RW, Hurt GJ, Levine EA (2011) Contralateral prophylactic mastectomy in breast cancer patients who test negative for BRCA mutations. *Am J Surg* 202(3):298–302. doi:[10.1016/j.amjsurg.2011.04.001](https://doi.org/10.1016/j.amjsurg.2011.04.001)
15. Elsayegh N, Kuerer HM, Lin H, Gutierrez Barrera AM, Jackson M, Muse KI, Litton JK, Albarracin C, Afrough A, Hortobagyi GN, Arun BK (2014) Predictors that influence contralateral prophylactic mastectomy election among women with ductal carcinoma in situ who were evaluated for BRCA genetic testing. *Ann Surg Oncol* 21(11):3466–3472. doi:[10.1245/s10434-014-3747-x](https://doi.org/10.1245/s10434-014-3747-x)
16. Rosenberg SM, Ruddy KJ, Tamimi RM, Gelber S, Schapira L, Come S, Borges VF, Larsen B, Garber JE, Partridge AH (2016) BRCA1 and BRCA2 mutation testing in young women with breast cancer. *JAMA oncol*. doi:[10.1001/jamaoncol.2015.5941](https://doi.org/10.1001/jamaoncol.2015.5941)
17. Elsayegh N, Profato J, Barrera AMG, Lin H, Kuerer HM, Ardic C, Litton JK, Tripathy D, Arun BK (2015) Predictors that influence election of contralateral prophylactic mastectomy among women with ductal carcinoma in situ who are BRCA-negative. *J Cancer* 6(7):610–615. doi:[10.7150/jca.11710](https://doi.org/10.7150/jca.11710)
18. Rosenberg SM, Tracy MS, Meyer ME, Sepucha K, Gelber S, Hirshfield-Bartek J, Troyan S, Morrow M, Schapira L, Come SE, Winer EP, Partridge AH (2013) Perceptions, knowledge, and satisfaction with contralateral prophylactic mastectomy among young women with breast cancer: a cross-sectional survey. *Ann Intern Med* 159(6):373–381. doi:[10.7326/0003-4819-159-6-201309170-00003](https://doi.org/10.7326/0003-4819-159-6-201309170-00003)
19. Rendle KA, Halley MC, May SG, Frosch DL (2015) Redefining risk and benefit: understanding the decision to undergo contralateral prophylactic mastectomy. *Qual Health Res* 25(9):1251–1259. doi:[10.1177/1049732314557085](https://doi.org/10.1177/1049732314557085)
20. Beesley H, Holcombe C, Brown SL, Salmon P (2013) Risk, worry and cosmesis in decision-making for contralateral risk-reducing mastectomy: analysis of 60 consecutive cases in a specialist breast unit. *Breast* 22(2):179–184. doi:[10.1016/j.breast.2012.06.005](https://doi.org/10.1016/j.breast.2012.06.005)
21. Soran A, Ibrahim A, Kanbour M, McGuire K, Balci FL, Polat AK, Thomas C, Bonaventura M, Ahrendt G, Johnson R (2015) Decision making and factors influencing long-term satisfaction with prophylactic mastectomy in women with breast cancer. *Am J Clin Oncol* 38(2):179–183. doi:[10.1097/COC.0b013e318292f8a7](https://doi.org/10.1097/COC.0b013e318292f8a7)
22. Myers RE (2005) Decision counseling in cancer prevention and control. *Health Psychol* 24(4 Suppl):S71–s77. doi:[10.1037/0278-6133.24.4.s71](https://doi.org/10.1037/0278-6133.24.4.s71)
23. Myers RE, Ross E, Jepson C, Wolf T, Balslem A, Millner L, Leventhal H (1994) Modeling adherence to colorectal cancer screening. *Prev Med* 23(2):142–151. doi:[10.1006/pmed.1994.1020](https://doi.org/10.1006/pmed.1994.1020)
24. Daly MB, Axilbund JE, Buys S, Crawford B, Farrell CD, Friedman S, Garber JE, Goorha S, Gruber SB, Hampel H, Kakkalmani V, Kohlmann W, Kurian A, Litton J, Marcom PK, Nussbaum R, Offit K, Pal T, Pasche B, Pilarski R, Reiser G, Shannon KM, Smith JR, Swisher E, Weitzel JN (2010) Genetic/familial high-risk assessment: breast and ovarian. *J Natl Compr Canc Netw* 8(5):562–594
25. O'Connor AM (1995) Validation of a Decisional Conflict Scale. *Med Decis Making* 15(1):25–30. doi:[10.1177/0272989x9501500105](https://doi.org/10.1177/0272989x9501500105)
26. Horowitz M, Wilner N, Alvarez W (1979) Impact of Event Scale: a measure of subjective stress. *Psychosom Med* 41:209–218
27. Silva AK, Lapin B, Yao KA, Song DH, Sisco M (2015) The effect of contralateral prophylactic mastectomy on perioperative complications in women undergoing immediate breast reconstruction: a NSQIP analysis. *Ann Surg Oncol* 22(11):3474–3480. doi:[10.1245/s10434-015-4628-7](https://doi.org/10.1245/s10434-015-4628-7)
28. Miller ME, Czechura T, Martz B, Hall ME, Pesce C, Jaskowiak N, Winchester DJ, Yao K (2013) Operative risks associated with contralateral prophylactic mastectomy: a single institution experience. *Ann Surg Oncol* 20(13):4113–4120. doi:[10.1245/s10434-013-3108-1](https://doi.org/10.1245/s10434-013-3108-1)
29. Osman F, Saleh F, Jackson TD, Corrigan MA, Cil T (2013) Increased postoperative complications in bilateral mastectomy patients compared to unilateral mastectomy: an analysis of the NSQIP database. *Ann Surg Oncol* 20(10):3212–3217. doi:[10.1245/s10434-013-3116-1](https://doi.org/10.1245/s10434-013-3116-1)
30. Frost MH, Hoskin TL, Hartmann LC, Degnim AC, Johnson JL, Boughey JC (2011) 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* 18(11):3110–3116. doi:[10.1245/s10434-011-1917-7](https://doi.org/10.1245/s10434-011-1917-7)
31. Frost MH, Slezak JM, Tran NV, Williams CI, Johnson JL, Woods JE, Petty PM, Donohue JH, Grant CS, Sloan JA, Sellers TA, Hartmann LC (2005) Satisfaction after contralateral prophylactic mastectomy: the significance of mastectomy type, reconstructive complications, and body appearance. *J Clin Oncol* 23(31):7849–7856. doi:[10.1200/jco.2005.09.233](https://doi.org/10.1200/jco.2005.09.233)
32. Orom H, Kiviniemi MT, Shavers VL, Ross L, Underwood Iii W (2013) Perceived risk for breast cancer and its relationship to mammography in Blacks, Hispanics, and Whites. *J Behav Med* 36(5):466–476. doi:[10.1007/s10865-012-9443-z](https://doi.org/10.1007/s10865-012-9443-z)
33. Katapodi MC, Lee KA, Facione NC, Dodd MJ (2004) Predictors of perceived breast cancer risk and the relation between perceived risk and breast cancer screening: a meta-analytic review. *Prev Med* 38(4):388–402. doi:[10.1016/j.ypmed.2003.11.012](https://doi.org/10.1016/j.ypmed.2003.11.012)
34. Dillard AJ, Couper MP, Zikmund-Fisher BJ (2010) Perceived risk of cancer and patient reports of participation in decisions about screening: the decisions study. *Med Decis Making* 30(5 suppl):96S–105S. doi:[10.1177/0272989x10377660](https://doi.org/10.1177/0272989x10377660)
35. Weinstein ND (1993) Testing four competing theories of health-protective behavior. *Health Psychol* 12(4):324–333
36. Abbott A, Rueth N, Pappas-Varco S, Kuntz K, Kerr E, Tuttle T (2011) Perceptions of contralateral breast cancer: an overestimation of risk. *Ann Surg Oncol* 18(11):3129–3136. doi:[10.1245/s10434-011-1914-x](https://doi.org/10.1245/s10434-011-1914-x)
37. Smerecnik CMR, Mesters I, Verweij E, De Vries NK, De Vries H (2009) A systematic review of the impact of genetic counseling on risk perception accuracy. *J Genet Couns* 18(3):217–228. doi:[10.1007/s10897-008-9210-z](https://doi.org/10.1007/s10897-008-9210-z)
38. Dieng M, Watts CG, Kasparian NA, Morton RL, Mann GJ, Cust AE (2014) Improving subjective perception of personal cancer risk: systematic review and meta-analysis of educational interventions for people with cancer or at high risk of cancer. *Psychooncology* 23(6):613–625. doi:[10.1002/pon.3476](https://doi.org/10.1002/pon.3476)
39. O'Leary KA, Estabrooks CA, Olson K, Cumming C (2007) Information acquisition for women facing surgical treatment for

- breast cancer: influencing factors and selected outcomes. *Patient Educ Couns* 69(1–3):5–19. doi:[10.1016/j.pec.2007.08.002](https://doi.org/10.1016/j.pec.2007.08.002)
40. Hamilton JG, Lobel M (2015) Psychosocial factors associated with risk perceptions for chronic diseases in younger and middle-aged women. *Women Health* 55(8):921–942. doi:[10.1080/03630242.2015.1061094](https://doi.org/10.1080/03630242.2015.1061094)
41. Montgomery GH, Erblich J, DiLorenzo T, Bovbjerg DH (2003) Family and friends with disease: their impact on perceived risk. *Prev Med* 37(3):242–249. doi:[10.1016/S0091-7435\(03\)00120-8](https://doi.org/10.1016/S0091-7435(03)00120-8)