

## RESEARCH COMMUNICATION

# What Made Her Give Up Her Breasts: a Qualitative Study on Decisional Considerations for Contralateral Prophylactic Mastectomy among Breast Cancer Survivors Undergoing BRCA1/2 Genetic Testing

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## Abstract

**Objective:** This qualitative study retrospectively examined the experience and psychological impact of contralateral prophylactic mastectomy (CPM) among Southern Chinese females with unilateral breast cancer history who underwent BRCA1/2 genetic testing. Limited knowledge is available on this topic especially among Asians; therefore, the aim of this study was to acquire insight from Chinese females' subjective perspectives. **Methods:** A total of 12 semi-structured in-depth interviews, with 11 female BRCA1/BRCA2 mutated gene carriers and 1 non-carrier with a history of one-sided breast cancer and genetic testing performed by the Hong Kong Hereditary Breast Cancer Family Registry, who subsequently underwent CPM, were assessed using thematic analysis and a Stage Conceptual Model. Breast cancer history, procedures conducted, cosmetic satisfaction, pain, body image and sexuality issues, and cancer risk perception were discussed. Retrieval of medical records using a prospective database was also performed. **Results:** All participants opted for prophylaxis due to their reservations concerning the efficacy of surveillance and worries of recurrent breast cancer risk. Most participants were satisfied with the overall results and their decision. One-fourth expressed different extents of regrets. Psychological relief and decreased breast cancer risk were stated as major benefits. Spouses' reactions and support were crucial for post-surgery sexual satisfaction and long-term adjustment. **Conclusions:** Our findings indicate that thorough education on cancer risk and realistic expectations of surgery outcomes are crucial for positive adjustment after CPM. Appropriate genetic counseling and pre-and post-surgery psychological counseling were necessary. This study adds valuable contextual insights into the experiences of living with breast cancer fear and the importance of involving spouses when counseling these patients.

**Keywords:** Breast and ovarian cancer - qualitative - prophylactic mastectomy - BRCA1 and BRCA2 - genetic testing

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## Introduction

Women who carry a mutation of BRCA1 or BRCA2 gene have an increased lifetime risk of breast cancer as high as 50-85% (Matloff et al., 2000; Antoniou et al., 2003; King et al., 2003). The annual risk for contralateral cancer for mutated BRCA1 or BRCA2 carrier is increased by approximately 3% and the overall risk may be as high as 52% by age 70 years. Options for carriers include early and regular surveillance, chemoprevention, and prophylactic surgery. Given the significant increased risk of contralateral breast cancer for young breast cancer female patients with a strong family history, prophylactic mastectomy is the most effective method for breast cancer risk management. It can reduce the risk of breast cancer by more than 90% in women at high risk (Hartmann et al., 1999; Domchek et al., 2006), and there is an increasing trend in its introduction as a preventative option for high-

risk individuals. (Lloyd et al., 2000, Bebbington et al., 2003).

Despite its known efficacy and benefit, such radical procedure involves complex decisional process and related psychological distress including types of mastectomies and choices of breast reconstructions; each with different pros and cons, recovery time, surgical, cosmetic, and psychosocial implications (Bebbington et al., 2003; Björkman et al., 2008). For those who had prior breast cancer history, the decision of going through CPM may stimulate previous experience and result in a more complicated decisional process and psychological reactions.

Prevalent research publications are usually based on Caucasian cohorts when studying the implications of prophylactic mastectomy for high-risk individuals. Contemporary studies usually focused on impact such as post-surgery adjustment, pain syndromes, cancer risk perception, body image, intimacy and sexuality issues;

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which are common issues that patients have to endure (Lerman & Croyle, 1994).

Immediate neuropathic pain and related sensations after mastectomies are commonly experienced by patients; some may develop chronic pain conditions. Despite improved surgical techniques which attempt to reduce severe nerve injuries after breast surgery (Björkman et al., 2008), women can still experience a combination of symptoms (pain, lymphoedema, paresthesia, strange sensations, and muscle weakness) in the breast area or in the ipsilateral arm that have detrimental effects on the overall quality of life (Marchettini et al., 2001; Reuben et al., 2004; Rothmund et al., 2004). Research has shown that patients who underwent different types of Myocutaneous Flaps Reconstruction (e.g. Deep Inferior Epigastric Perforator [DIEP] Flap, Transverse Rectus Abdominis Myocutaneous [TRAM] Flap) might also experience different degrees of post-surgery and chronic pain (Gill et al., 2004).

Another impact of prophylactic mastectomy is its effect on body image and intimate relationships. Psychosocial studies found that breast cancer surgeries are potentially traumatic to women's body image. An integrative review on 13 studies indicated that up to one-half of the women suffer a negative effect on body image and lead to changes in sexuality (McGaughey, 2006). Sexual problems after prophylactic mastectomy are common (Payne et al., 2000; Bresser et al., 2006; Brandberg et al., 2008). Some studies (DudokdeWit et al., 1997; Bebbington et al., 2003) have suggested that women tended to be reluctant to confront possible sexual problems before the surgery, and rated prevention of cancer risk as the priority. A qualitative study found that considerable amount of females was surprised at the lack of physical sensation in their breast up to 18 months post-operatively and how it negatively affected their sexual activities or marital relationships (Bebbington et al., 2003).

Reduction in breast cancer risk is one major benefit of prophylactic mastectomy. Some studies evaluated women's subjective perception of their risk of breast cancer before and after prophylactic mastectomy (Lodder et al., 2002). One study found that BRCA1 carriers estimated their risk of breast cancer to be, on average, 69% before surgery and significantly decreased to 41% after surgery. BRCA2 carriers estimated their risk of breast cancer to be 69% prior to surgery and 45% after surgery.

Due to different cultural background and perception, continuing impact of prophylactic surgery experienced by Asians may be different from Caucasian populations. There is a lack of relevant data on Asian, especially Chinese cohorts, on long-term impact of CPM among high-risk female breast cancer survivors. There is a need for up to date research that seeks to explore the experiences of these risk-reducing procedures among Asians, for which the cultural expectations and medical practice can make the experience different from their Caucasian counterparts.

The aim of the present study was to explore impact of CPM from the subjective account of high-risk unilateral breast cancer survivors following a genetic BRCA1 or BRCA2 diagnosis. This is the first study to adopt a qualitative methodology and provide a discovery-

orientated dimension from the perspective of Asian (Chinese) females.

## Materials and Methods

### Background

Between Aug2007-Aug 2010, 596 eligible females had genetic counseling and testing of BRCA1/2 gene by a breast surgeon and genetic counselor with training in cancer genetics and clinical psychology under the Hong Kong Hereditary and High Risk Breast Cancer Programme (www.HRBCP.org, hereafter referred as the Programme). The Programme is the only registry in Hong Kong collecting the most representative sample of high-risk breast cancer patients in the territory. The criteria and procedures of genetic counseling and testing service by the Programme were described in a previous study (Kwong et al., 2010).

### Procedure

This study was approved by the ethics committees of The University of Hong Kong and all participating sites. Among the 596 females, those who had CPM after BRCA1/2 genetic testing were being invited to participate in a face-to-face or telephone interview individually using a semi-structured questionnaire by a trained qualitative interviewer. Questions were open-ended with emphasis on encouraging self-initiated sharing on 5 main facets:

1. reasons of decision and their evaluations about such decision
2. what procedures they decided to do in the end
3. perceived immediate impact
4. perceived chronic impact
5. perceived breast cancer risk after CPM

The whole data set was transcribed in verbatim. Scores were calculated while qualitative data was subjected to a series of systematic analyzing process based on The Grounded Theory (Glaser & Strauss, 1967). Content was constantly compared to develop conceptualizations of the possible relations between various pieces of data, and result in the derivation of different themes.

## Results

### The Characteristics of the Study Population

Eleven female BRCA1/BRCA2 mutation carriers (10.2% of female carriers of the Programme) and 1 female non-carrier (< 1% of female non-carriers of the Programme) with a history of unilateral breast cancer who subsequently had CPM since the establishment of our programme in 2007 were recruited during study period. Table 1 summarizes the basic sociodemographic and clinical characteristics of the sample.

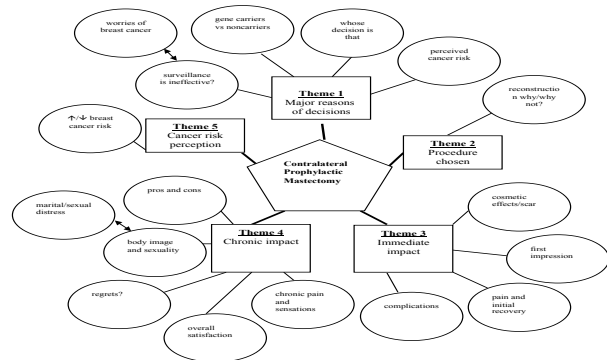
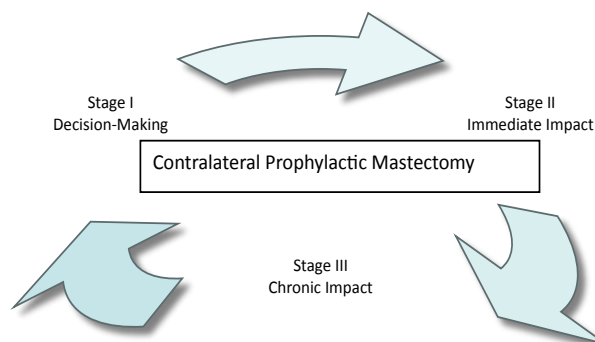
All 12 eligible women gave informed consent and took part in a 40 minute face-to-face or telephone interview depending on their geographical restrictions and preference (Response rate: 100%).

### A Stage Conceptual Model

Initial themes were identified by one researcher (AC) and then verified by a second researcher (AK) who

**Table 1. Demographic Information and Clinical Characteristics (N = 12)**

Characteristics	N (%)	Mean (range)
Women	12(100%)	-
Age (years)		-47 (34-55)
Married/ co-habitant	6 (50%)	-
Age of diagnosis of CA breast (years)		-39 (24-50)
Time since completion of CPM (in months)		-21 (11-34)
Reconstructive surgery with CPM	6 (50%)	-
Confirmed BRCA1/2 mutated gene carrier	11 (92%)	-

**Figure 1. Thematic Flow Chart****Figure 2. Conceptual Framework Explaining the Experience of CPM**

independently coded interviews. By the analyzing process of The Grounded Theory, 5 main themes were derived in the end (Figure 1). Narratives from the interviews were then reviewed using a stage conceptual framework on how the participants made sense of the whole process of CPM starting from I) Decision-making, II) Immediate impact, to III) Long-term impact of CPM (Figure 2).

**Stage I: Decision-Making.** Types of CPM and Reconstruction, half of the participants opted for reconstruction, all of which were performed at the same setting as the CPM. Half of the females who opted for reconstruction (n = 3/6) were married, while the other half had never been married or had been single before the surgery. Table 2 depicts the types of surgery that participants underwent.

Positive BRCA1 or BRCA2 results and hence heightened risks and fear of contralateral breast cancer were major reasons for CPM (91.7%; n = 11/12). Anxious feelings such as “feel like carrying a bomb”, “miserable”, “worries”, “scare of getting another breast cancer” are commonly experienced by the sample. The strong sense of worries on the possibilities of getting cancer on the other breast could not be relieved by normal mammography/

**Table 2. Types of Prophylactic Mastectomy and Reconstruction**

	Without reconstruction N = 6 (50%)	With reconstruction N = 6 (50%)
Types of Prophylactic Mastectomy	N (%)	N (%)
Mastectomy	4 (33.3%)	-
Mastectomy with reconstruction (1 X latissimus dorsi [LD] flap, 1 X silicone implant)	-	2 (16.7%)
Areola sparing mastectomy	1 (8.3%)	-
Areola sparing mastectomy with reconstruction (1 X silicone implant)	-	1 (8.3%)
Nipple sparing mastectomy	1 (8.3%)	-
Nipple sparing mastectomy with reconstruction (1 X DIEP flap, 2 X silicone gel implant)	-	3 (25%)

ultrasound results. Periodic surveillance, although non-invasive, was perceived as stressful by various participants.

“Surveillance was neither inconvenient nor painful but it was a periodic reminder that I was carrying a cancer bomb...physically surveillance may seem non-invasive but psychological it was difficult (to deal with)...”

“I cried every time after each stressful mammogram!”

“I just wanted to have the surgery once and for all. Surveillance felt like taking examinations. You passed this time but then what about next?” “The anxiety was agonizing.”

Reasons for non-carrier to choose CPM, one married participant who had cancer on her right breast at the age of 43 decided to undergo left nipple sparing prophylactic mastectomy with total reconstruction and free DIEP flap although her genetic test result was negative.

“I decided to do this (CPM) even before getting the genetic results. The left breast has recurrent benign conditions... the periodic check-up was stressful. I was tired of living under constant fears, and wanted to get it done and over with. I decided to do it although I was negative (genetically). I would not have to think twice if I have a second chance.”

Some 75% of the interviewees stated that they made their own decision to undergo CPM. Only 25% involved family in making the decision. Although most interviewees perceived that they made the right decision and showed no regrets, they thought the decision was personal and expressed reservations on recommending such procedure to those with similar medical background.

“...have to consider her psychological well-being and whether her partner supports her.”

“People have different psychological state and background... I thought I made a good decision but does not mean others would feel the same.”

“Only professionals can judge whether she is physically and psychologically suitable... It is not something you can decide for others.”

**Stage II: Immediate Impact of CPM.** The majority of the present cohort (83.3%; n = 10/12) did not experience any post-surgical complications. Most of the reconstruction surgeries (83.3%; n = 5/6) were successful without serious

complications. Only one participant experienced serious flap cyanosis and eventually flap failure on the CPM side. She had to be re-operated for exploration and removal of flap.

All participants described the pain they endured during the recovery period after the procedure as “bearable” and “as expected”. The prior mastectomy as breast cancer treatment for more than half of the interviewees (58.3%) had enabled them to adopt realistic expectation during the initial recovery and adjustment period.

All participants could recall the first time they saw their post-CPM breast area. Almost all participants (91.7%) described the first impression as “acceptable”, “OK”, or “Not too bad”. Successful reconstruction and implants also contributed to better adjustment towards the surgical outcomes.

*“First impression was OK. I did research from internet. They actually looked better than I expected.”*

*“My breasts looked alright...best at first with the implants when they were still swollen up...looked more perky. They started to shrink afterwards.”*

*“It was OK. I had been living without my left breast (Modified Radical Mastectomy) for more than 12 years so nothing could scare me.”*

Reconstruction and Implants, among the half of the interviewees who underwent reconstruction, 50% (3/6) stated that they were satisfied with the procedure. The other half declared that they would rather forgo implants if they could choose again.

*“...no regrets (on CPM). But the implants gave me uncomfortable stretchy sensations from my shoulders down to my armpits...mastectomy alone might have been better.”*

*“I would rather forgo the implants. I heard that they hinder the accuracy of mammogram and that made me nervous.”*

*“I would rather not have the reconstruction. The flap failed and I ended up having 2 additional operations.”*

Regarding cosmetic effects and scars, participants were asked to indicate whether they are satisfied with the appearance of the breasts after the CPM on a Likert scale (1: very dissatisfied, 2: dissatisfied, 3: average, 4: satisfied, 5: very satisfied). The average score for those who had a successful reconstruction was 3.6, while that of those who either did not have reconstruction or the reconstruction procedures failed was 2.86. Three participants (25%) suffered from keloid scars and they thought that the scars substantially affected the cosmetic outcome of the surgery.

**Stage III: Chronic Impact of CPM.** Participants were asked to indicate their overall satisfaction of the CPM at the time of the interview on a likert scale (1: very dissatisfied, 2: dissatisfied, 3: average, 4: satisfied, 5: very satisfied). The average score was 3.83. Two-third (66.7%; n = 8/12) rated that they were either satisfied or very satisfied with the procedure. The woman who experienced flap failure was the only participant who stated her overall satisfaction of the prophylactic mastectomy as dissatisfactory.

Although serious pain syndromes were not reported by the participants, they still experienced a combination of symptoms including numbness, stretchy sensations, and

muscle weakness in the breast area or in the ipsilateral arm. Different degrees of sensation loss on the breast were commonly experienced. Most of them either lost half or most of the sensation of the breast after CPM. As conveyed, the numbness would gradually decrease but some participants still claimed to experience such sensations after 2-3 years. All interviewees agreed that the mentioned sensations were manageable and just mildly affected daily life.

Regarding impact on sexual life and marriage, among those who were still sexually active after the surgery (50%, n = 6/12), all of them stated that they were sensitive to the reaction of their spouses after the CPM. Spouses' attitudes and support contributed to the overall adjustment of the women.

*“He looked a bit shocked. I think he was scared the first time he saw my body!”*

*“He read medical information with me so he was psychologically prepared and looked calm.”*

*“Women are sensitive, from his reactions the first time we had sex (after CPM), I knew that he did not mind.”*

*“Initially I felt bad as I am no longer complete as a woman. He reassured me and said nothing else really matters as long as I am healthy. Our sex life is still alright.”*

Half of the married females who were still sexually active after CPM perceived that their husbands touched their breasts less in general (be it the “cancer breast” or the side that underwent CPM) during sex even up to 3 years after the procedure.

*“He touched my breasts obviously less comparing to the past. He touched my ‘cancer’ side significantly less. He said he’s afraid that he might hurt me. I had explained to him that it was fine but he is still touching my breasts less now.”*

*“I did have a feeling that he avoided touching them (breasts) now. Maybe I am too sensitive. I have not brought it up though.”*

Among those who are married but were sexually inactive after the CPM (50%; n = 3/6), the lack of sexual activities had already started before CPM. Reasons include decrease of libido after cancer treatment, menopause, or fatigue. Only one participant thought that CPM (without reconstruction) had serious negative impact towards her sex life, with sexual activities significantly decreased after CPM. Sexually-inactive single participants appeared to adjust better to the cosmetic results of the surgery.

*“I have been single for more than 20 years. My priority is my own survival, not whether my breasts would look great to others.”*

*“I no longer need to worry about breast cancer. CPM (without reconstruction) did not bother me at all. No one needs to see them except myself.”*

Regarding regrets and second thoughts, most (75%) of the participants were satisfied with their decisions and stated that they had no regrets at all. This 75% of participants stated that they would make the same choice again if there was a second chance.

With perceived benefits of CPM, as reservation towards the efficacy of periodic surveillance is obvious, most participants admitted that they were constantly



worrying about their risk of contralateral breast cancer before the procedure. Nearly all of them perceived the psychological relief of breast cancer worry as the major benefit of CPM. The secondary benefit is being able to abstain from stressful periodic surveillance.

*"I have offloaded a big burden. I was constantly worrying about getting cancer before and suffered from insomnia. Now the problem is gone!"*

*"I can finally stop worrying whether the doctor would find a lump again and start living a normal life!"*

*"I no longer carry a cancer bomb!"*

Some of those who already had simple mastectomy on one of their breasts before as cancer treatment actually appreciated the sense of balance after CPM.

*"(My breasts) feel and look better than having only one breast actually."*

*"Now that my breasts are similar I can wear more types of clothes. I can do more activities now such as swimming."*

Concerning breast cancer risk perception After CPM, all participants (100%) agreed that CPM had decreased their risk. The present study found that BRCA1 mutated gene carriers estimated their risk of breast cancer to be, on average 20%, while BRCA 2 mutated gene carriers estimated their risk of breast cancer to be, on average 15.7 % after surgery. The only female who had a negative genetic result and opted for CPM and total reconstruction still estimated her breast cancer risk to be 50% after prophylactic surgery. The participants tended to slightly over-estimate their breast cancer risk even after CPM and removal of bilateral breasts.

Regarding need for counseling following CPM, a considerable amount of the participants (75%) highlighted the importance of professional psychological support. It was supported by women who did not experience overt psychological distress, *"Not all women are as strong as me. I think it would be beneficial if there's mandatory professional psychological service provided."* Some of them indicated that although they felt *"well prepared"*, *"spouses should be helped to understand CPM and have realistic expectation on its results"*.

## Discussion

This study is the first to report the long-term impact of CPM for an Asian (Southern Chinese) cohort who had undergone BRCA 1 and BRCA2 genetic testing adopting a qualitative methodology. Our previous study showed that Hong Kong Chinese BRCA mutation carriers are more likely to choose intensive surveillance as a major option for cancer risk management (Kwong et al., 2010). Prophylactic mastectomy rate (including completion mastectomy and contralateral prophylactic mastectomy) was found to be about 20% overall in all mutation carriers, which is in the mid range compared with that of international studies (Metcalf et al., 2011).

A number of stages describing the experience of CPM were identified in the present study. Such conceptual model may enhance the understanding of the process that these women underwent and provide a structural framework to illustrate the specific distress they endure.

One major theme was that undergoing CPM is perceived as a significant and personal decision. Most interviewees agreed that the decision was not an easy one, but they perceived it as a necessary action to decrease their perceived breast cancer risk. From the narratives, all participants appeared to prioritize the elimination of contralateral breast cancer risks at the decision-making stage, and saw CPM as a "life-saving" strategy for survival. Few of them mentioned about the cosmetic concerns and its impact on their sexuality as important elements in their initial decision-making process. A minority of participants did not even involve their spouses in the decision-making process. This also gave insight to the need of involving husbands or partners in the counseling process.

An important force that facilitated their decision was the fears of getting contralateral breast cancer again. Although periodic surveillance (mammography, breast ultrasound, breast MRI) is a much less physically invasive option than prophylactic mastectomy, most of the participants felt that it was a psychologically stressful procedure. Surveillance was perceived as a cyclical reminder of their genetic predisposition and hence heightened breast cancer risks. Their prior experience of going through intensive cancer treatment such as chemotherapy and radiotherapy also underlay their plea for a more efficacious remedy, if not closure. Reduction of breast cancer risk and related worries dominated the decision process of our cohort.

The present Chinese cohort shared similar results with previous findings on their Caucasian counterparts that women tended to be reluctant to confront possible sexual problems at the decisional-making stage. However, the physical and psychological impact emerged right after the procedure. A minority of interviewees stated that they had some regrets on the decision but perceived that it was still the right thing to do. This sense of cognitive dissonance has not been vividly reported by other qualitative studies, but may be one of the possible sources of psychological distress for these patients. Future research can examine whether this is due to the high compliance to the recommendations of clinicians which is a cultural characteristics of Chinese.

Despite going through proper genetic counseling and testing service, a minority still over-estimated their breast cancer risk after CPM. The only female who underwent CPM despite a negative genetic result still estimated her breast cancer risk as 50%. Clinicians may need to reassure these patients by clarifying their subjective perception of breast cancer risk during pre-surgery sessions.

Another important finding is that some interviewees were still coping with the psychological impact up to nearly 3 years post-CPM. There is currently no mandatory psychological service for high-risk females going through prophylactic mastectomy in Hong Kong. Psychological service at governmental hospitals in Hong Kong is normally provided upon patients' request or based on clinicians' referrals. There may be patients who are suffering in silence chronically without professional intervention.

It would be beneficial if professional pre-surgery psychological service is available to assist in decision-making, assess the baseline of patient's psychological

status, ventilate pre-surgery anxieties, ensure they have realistic expectations of the procedure, and screen potential candidates who may need continuous psychological assistance after surgery. In order to enhance patients' overall adjustment, such service may be valuable if spouses are involved, and emphasis should be put on psychological preparation of realistic expectation of cosmetic results, as well as how to be better caregivers. The high response rate of the present study also delineated that these females were eager to share their experiences. Patient support groups may be a good source of informational and social support for them.

The strength of the study is the multi-institutional sources of referrals for genetic counseling and testing for patients and families at high risk of breast cancer. Our programme was established in 2007 to provide such services to that of international standards by trained specialists in cancer genetics and clinical psychoncology, and to establish in a research database on Asian cohorts. Mutation carriers are generally compliant in returning to our high-risk clinic for further management.

There are intrinsic limitations to any retrospective study such as the current type. It only collected data at one point in time without pre-surgery baseline data. We cannot dispute possibilities that some participants might already have experienced psychological distress before the procedure. The retrospective nature also negates the ability to detect a response shift. Knowing that, information from a prospective database was incorporated, and interview questions were designed to differentiate perceptions with specification in context before and after the procedure.

Moreover, this study includes a rather small cohort of patients because it is only 3 years into the establishment of the program. Our previous publication showed that only about 20% of BRCA1 or BRCA2 mutated gene carriers had opted for prophylactic mastectomy. By estimation, the present study had already recruited the representative sample of patients who underwent CPM after genetic testing in Hong Kong. There is also possibility that some patients may change their minds and decide to undergo CPM at a later time.

This study still provides valuable information regarding the long-term physical and psychological implications of prophylactic mastectomy among high-risk Southern Chinese. Thorough genetic counseling with a detailed discussion on different preventative options is crucial. Clinicians need to ensure that women's decisions to have such surgery are based on accurate perceptions of their own risk and informed considerations of the efficacy and outcomes of such procedure.

The authors are planning a prospective study to examine the risk and protective factors for long-term adjustment of different types of prophylactic mastectomy and reconstruction. It will guide the development of a structured psychological support service to meet the specific needs of these patients.

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