

Title: “It felt like unfinished business, it feels like that’s finished now”: Women’s experiences of decision making around Contralateral Prophylactic Mastectomy (CPM)

Running title: Decision making around Contralateral Prophylactic Mastectomy

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Abstract:

Objectives: Increasing numbers of women in the UK are choosing to have a Contralateral Prophylactic Mastectomy (CPM) after diagnosis of breast cancer. Whilst research suggests that many experience high rates of psychological wellbeing after CPM, professional guidelines suggest CPM is 'not required' for the majority of unilateral breast cancer patients and some individuals consider the surgery to be controversial. Existing research has explored patients' reasons for seeking CPM, however, little is known about their experiences of decision making. This study aimed to investigate women's experiences of decision making around CPM in the UK. *Methods:* Semi-structured qualitative interviews were conducted with twenty-seven women, recruited through breast cancer support charities. All participants had CPM in the UK after a diagnosis of unilateral breast cancer, ductal carcinoma in situ (DCIS) or invasive ductal carcinoma. Data was analysed using thematic analysis. *Results:* Two main themes were generated from the analytic process: 'sanity check' ('battling for CPM', 'feeling stigmatised', 'seeking similar others'), and 'reclaiming the body' ('being true to self', 'moving forward'). Women described defending their decision to have CPM, concerns that their thoughts about surgery may be considered 'abnormal', and seeking support from peers. The decision to have CPM was discussed in terms of their future relationship with their body and moving forward after cancer. *Conclusions:* This study highlights the importance of interactions with healthcare professionals in the decision-making experience, the role of peer support, and the need to fully understand the potentially complex and multifaceted nature of each woman's decision to seek CPM.

Keywords: cancer; oncology; breast cancer; prophylactic mastectomy; decision making

Background

Data suggests that women diagnosed with unilateral breast cancer are increasingly choosing to undergo Contralateral Prophylactic Mastectomy (CPM), with rates of CPM amongst women having a mastectomy in the United States increasing from 4.2% to 11% [1] between 1998 and 2003. Whilst equivalent figures are not currently available for the United Kingdom, a similar increase is believed to be present [2], with patients requesting CPM for reasons relating to fear of future breast cancer, feelings of vulnerability and a desire for symmetry [3].

The benefits of CPM for women who are found to be negative for a BRCA mutation are controversial in the medical community. CPM is believed to reduce the risk of contralateral breast cancer by up to 90% [4]; however, many argue that the oncological benefit is negligible in patients who are not thought to be at increased risk of recurrence, with the population risk of CBC currently believed to be 0.5% per year [5]. Existing professional guidelines echo this perspective, with guidelines by the UK's Association of Breast Surgeons (ABS) suggesting that "for the majority of women with unilateral breast cancer, contralateral mastectomy is not required" [6]. In addition, guidelines from the American Society of Breast Surgeons (ASBS) and a consensus statement reached by Canadian medical specialists, have suggested that CPM is discouraged for women with unilateral breast cancer, and an average risk of contralateral breast cancer, due to the lack of oncologic benefit [7,8]. In contrast, research exploring women's reasons for requesting CPM are more complex than these statements may suggest. Studies suggested that motivations for CPM may be related to personal experience [9] and perceptions of objective risk were not generally the motivating factors for patients' or surgeons' decision making, with women requesting CPM for reasons related to subjective vulnerability and breast symmetry [10].

There is a growing literature suggesting that women who have had CPM are highly satisfied with their decision and experience high rates of psychological wellbeing [11]. However, those who are dissatisfied with CPM have been found to report adverse body image, poor cosmetic results and a perceived lack of education regarding the alternatives [3]. These findings emphasise the importance of ensuring women have access to information and support when considering CPM, in order that

they can make a fully informed decision [11], and a decision aid for women considering the procedure has recently been found to be both acceptable and feasible in Australia [12]. However, there remains a paucity of research exploring women's experience of this decision-making process, particularly in the UK.

Research to date highlights the complexity of this decision, with influences from objective risk, subjective risk, vulnerability, appearance, and education; and highlights the need for an in-depth understanding of their experiences when faced with this choice. This is important if we are to ensure they are appropriately supported in making fully informed decisions. In light of the lack of research exploring the process of decision making amongst the increasing numbers of women undergoing the surgery, this exploratory study aimed to investigate women's experiences of CPM decision making and treatment in the UK.

Methods

Design

Semi-structured qualitative interviews were used to explore women's experiences of CPM decision-making. They were conducted by the first author, an experienced qualitative researcher, who has supported close family members with breast cancer but has no personal experience of CPM. Participants had chosen to have CPM after a diagnosis of unilateral breast cancer, ductal carcinoma in situ (DCIS), or invasive ductal carcinoma. Participants were required to be female, aged 18 or over, have received treatment in the UK, and have sufficient fluency in English to take part in an interview conducted in English. All participants were required to provide written informed consent. Telephone interviews were conducted in order to enable women from a wide geographical area to take part, and to encourage open communication regarding a sensitive topic.

Procedure

This research received a favourable ethical opinion from the authors' institution (approval number: HAS.17.09.017). Recruitment was carried out in collaboration with three national UK charities providing support to women who have had, or are currently having, treatment for breast cancer ('Flat Friends UK', 'Breast Cancer Care' and 'Macmillan Cancer Support'). Adverts were placed on the charities' social media

pages or online forums, with participants invited to contact the researchers if they were interested in taking part. An interview guide was developed by DH and NP on the basis of previous research in this area and the aims of the current study. This guide was reviewed by trustees at 'Flat Friends UK' and the Service User Research Partnership at 'Breast Cancer Care' (see Table 1), and further refined by PT and NP after conducting several interviews with participants. All interviews were audio recorded and transcribed verbatim, and analysis was conducted by hand. Mean interview duration was 32 minutes (range 15-50 minutes).

Data analysis

A thematic analysis of the data was conducted by VSW, with supervision throughout the analytic process and agreement on the final themes from PT. Analysis was conducted from a relativist approach where the authors view knowledge as relative to individuals and cultures, and acknowledged that participants' experiences were told from their own perspectives. Whilst the author's prior knowledge and experiences inevitably influence the subsequent qualitative analysis, efforts were made to focus the analysis on the data collected and to reflect on any assumptions that may come from this experience. Analysis followed five steps, including: 'data familiarisation', 'initial coding generation', 'searching for themes', 'reviewing and refining themes' and 'theme definition and labelling' [13]. There was no discrepancy in the themes between the two readers.

*****TABLE 1 HERE*****

Results

Twenty-seven participants from across the UK took part in semi-structured interviews, with a mean age of 50 years (range 33-65 years) and mean duration since surgery of 25 months (range 1-103 months). Further demographic information is displayed in Table 2 and all names used in this publication are pseudonyms.

*****TABLE 2 HERE*****

Two main themes were generated from the analytic process. The first of these is 'Sanity check', with subthemes 'Battling for CPM', 'Feeling stigmatised' and 'Seeking similar others'. The second theme is 'Reclaiming the body', with subthemes 'Being

true to self' and 'Moving forward'. Each of these superordinate themes, and their accompanying subthemes, are presented below (see Table 3 for details of all themes and subthemes, with demonstrative quotes).

TABLE 3 HERE

Theme 1: Sanity check

The first theme, 'Sanity check', encompasses the process of requesting CPM from healthcare professionals ('Battling for CPM'), the experience of being asked to meet with a psychologist whilst making this decision ('Feeling stigmatised') and normalisation of the decision through contact with peers ('Seeking similar others').

Battling for CPM

Women often found they were met with resistance when initiating discussions about CPM with healthcare professionals and, whilst some were pleasantly surprised at the willingness of their clinicians to consider CPM, others reported a far longer and more challenging process, at what was already a very difficult time.

“...you're at your weakest lowest point, you've just come out of chemo, you feel absolutely horrendous and battered, and then you've got to go through a fight...” – *Samantha*

Women referred to the process of requesting CPM as a 'fight' or a 'battle', and described feelings of abnormality in their desire for the surgery. Such feelings were exacerbated by the reactions of healthcare professionals to their request.

“I completely felt like I was the only one who had ever suggested it” – *Michelle*

Participants were also highly aware of the need to present their reasons for CPM clearly in order to avoid negative perceptions from healthcare professionals and further challenges to their request. For example, Rachel believed healthcare professionals would associate any discussion of recurrence with an impulsive 'knee jerk' reaction, and wanted to make it clear to staff that this was not her motivation.

“I was very careful not to talk about reoccurrence, because I knew that then they might decide that I was making a knee jerk psychological decision to have the breast removed to protect my life and it wasn't about that.” – *Rachel*

Feeling stigmatised

Several women were asked by their breast team to see a psychologist as part of their decision-making process, and this was perceived by some as further evidence that staff doubted their decision-making abilities and led some to feeling stigmatised. For many, this appointment represented a 'hoop' that they needed to jump through, rather than a useful therapeutic process.

“when you say you want to have the other breast off and they said ‘well you need to see a psychologist’, it makes you feel like, it’s another thing that backs up that you feel like a freak, because if you were going for a reconstruction you don’t have to see that psychologist, so it’s like they’re questioning your sanity...” - *Deborah*

As seen here, women who did not want breast reconstruction often viewed this consultation as being discriminatory. It was suggested that women who wanted a unilateral mastectomy and breast reconstruction would not be required to see a psychologist, despite this decision also regarding a substantial and invasive surgical procedure that alters the body’s appearance and has associated risks. Importantly, not all women shared this feeling and the request to see a psychologist was described by participants more positively when it was framed as a routine part of the treatment pathway and an opportunity to discuss their feelings around the decision and surgery.

Seeking similar others

Feelings of isolation appeared common in the decision-making process and, for many women, the reactions of healthcare professionals led them to seek out others who had had similar experiences. Many joined online forums or social media groups for women who had been diagnosed with breast cancer, where they were reassured that their thoughts regarding CPM were similar to others.

“...if it hadn’t been for that online social media support group I would have still felt months later like I was the only person” - *Michelle*

Women felt that connecting with others who were, or had previously been, in a similar situation allowed them to ‘normalise’ their decision and reduce the sense of

being alone, as well as giving them space to openly discuss their decision without fear of judgement.

Theme 2: Reclaiming the body

An important element of the decision-making process for many participants was considering the relationship they wished to have with their body in the future and how this would be impacted by CPM. For some, this was about symmetry and reconciling their internal self-image with their external appearance ('Being true to self'), whilst for others it was about addressing the psychological distress that they associated with their remaining breast and a distrust in available surveillance methods ('Moving forward'). These two elements formed an important part of many women's decision making around CPM and together form the theme 'reclaiming the body'.

Being true to self

Symmetry was a key factor in many women's decisions to have CPM and they discussed its importance in relation to both psychological and physical issues. This symmetry was particularly important for women who did not want breast reconstruction, who made the comparison between CPM and reconstructive procedures. These women described both procedures as offering the opportunity for symmetry, whilst stressing that living symmetrically flat felt like the correct choice for them.

"It was after about a year of looking in the mirror, the flat side was the right side, you know, it was the great big boob left hanging there that looked wrong"
- *Deborah*

Whilst women acknowledged that others may prefer to have reconstructive surgery or live with one breast, they suggested this was not in line with how they saw themselves and described symmetry as reconciling the difference between their own self-image and the reality of their appearance.

"Because I was finding the remaining breast psychologically quite damaging. I could look down at my scar without any issue at all, but seeing that remaining breast was, not horrifying, but upsetting to me. And I can't tell you why, I

wasn't looking down thinking I wish I had two, I was looking down thinking it looks stupid..." - *Claire*

In addition, symmetry allowed them freedom to pursue physical activities (such as running, yoga and horse riding) with a confidence and comfort that they did not feel was possible with one breast, with or without a prosthesis.

"Like this, I can go to yoga and I can turn upside down without a worry, having one great big boob and one flat side, I would have been in a shell, I wouldn't have been happy.." - *Amanda*

Moving forward

For some women, CPM also offered a means to address the psychological distress they felt relating to their remaining breast and to move forward with their future. Some felt that their relationship with their breasts had changed since their cancer diagnosis, and that their breasts had in some ways let them down:

"in a way I kind of felt they'd wronged me" - *Melanie*

Others felt it was methods to detect cancer that had failed them and they could no longer trust surveillance methods to detect future cancers,.

"...you cannot satisfactorily assure me through screening that I don't have breast cancer on the other side, because even knowing that I had a lump under my arm and you were actively looking for something, you still couldn't find it with mammogram and ultrasound, and mammogram and ultrasound are all you will offer me going forward..." - *Dawn*

Women made a clear distinction between anxiety surrounding future recurrence and anxiety relating to the prospect of future radiotherapy or chemotherapy. When some women expressed concerns that their remaining breast could pose a risk of future cancer, they described clinical staff reassuring them of the availability of treatment. However, it was the prospect of future treatment that prompted anxiety for many, and thus this sentiment did not act as an appropriate reassurance.

"...And you know they said 'well we can screen you and we can, you know, you can go through treatment again', but treatment was hideous and I just wanted my life back..." - *Zoe*

For many of these women, any risk of future recurrence and repeating their experiences of cancer treatment was intolerable. CPM represented a means for them to overcome these anxieties and move forward in their lives. Participants often spoke about how this anxiety could never be removed completely, but how it was significantly reduced after surgery.

“It felt like unfinished business, it feels like that’s finished now.” - *Rachel*

Conclusions

This study identified two major themes in women’s experiences of decision making around CPM: ‘Sanity check’ and ‘Reclaiming the body’. As explored in the first of these themes, women often found the process of deciding to have CPM challenging, both in determining what decision was ‘right’ for them and in negotiating treatment with healthcare professionals. Participants overwhelmingly reported satisfaction with their decision, reflecting the existing literature on this topic [11]; however, the process of requesting CPM was characterised by some as a ‘fight’ or ‘battle’, and women were keen to avoid being characterised as making a decision based on a ‘knee jerk reaction’. This process led some to feel isolated or stigmatised in seeking this surgery and women often sought support from others in a similar position to them or who had already made this decision. In such forums, women could validate and normalise their decisions to have CPM, as well as receiving emotional support from others. Peer support groups are widely regarded as a valuable resource, with existing research suggesting that internet mediated support groups allow patients to access practical and experiential information [14,15], foster communities of peer support [16] and may lead to improved psychological wellbeing [17,18]. This study has highlighted the importance of such support (whether face-to-face or online) for women making decisions regarding CPM, particularly in a context where women describe feeling isolated and that they are ‘fighting’ for their choice to have CPM. These results also reflect the experiences of younger women deciding against breast reconstruction, who have described feeling unusual for their choice and who suggest that peer support may have reduced their feelings of isolation [19]. In addition, many women faced difficulties communicating their wishes to healthcare professionals and some reported feeling stigmatised when referred for psychological support in making their decision. This may also reflect a broader stigma associated with referral to

psychological services and demonstrates the importance of clinicians carefully communicating such a referral to normalise or positively frame the experience.

The second theme in this analysis, 'Reclaiming the body', captures the complexity of women's motivations for decision making. Women discussed the decision to have CPM in terms of the relationship they wished to have with their body in the future, an effort to reconcile their internal self-image with their external appearance, and as part of a process to move forward from this period in their lives. Women described their own motivations for surgery in terms of their perception of their breasts, their appearance and their future relationship with their body. These findings reflect previous research suggesting that women often request CPM for cosmetic reasons [10], and sit in stark contrast to much of the CPM literature which has focused primarily on patients' objective risk perception. This study found that a key motivation to have CPM was women's desired future relationship with their body, as well as reducing the psychological distress associated with their remaining breast. These findings highlight the complex multi-faceted nature of decision making around CPM and indicate a need to fully understand each woman's motivation for surgery. Whilst the roles of appearance and body image in decision making about surgery to remove the cancer and/or recreate a breast shape have been explored in previous qualitative research [19–22], the current study has shown they are also important in decision making around CPM.

Study limitations

Whilst it was necessary to explore this topic with women who have previously had CPM, in order to explore their journey through health care services and how they felt about their experiences since, there is also a risk of recollection bias in asking participants to reflect upon an experience retrospectively. Moreover, as a decision they had already made and no longer had control over, there is the possibility that their reports of experiences could have been biased to positively appraise their choice to have CPM, thereby 'bolstering' their decision [23]. Further research would benefit from exploring the decision-making experiences of women who considered CPM but ultimately chose not to go ahead, investigating their reasons not to pursue surgery. Prospective research could ascertain whether levels of satisfaction or regret may be influenced by the pre-surgical decision making process.

Clinical implications

Participants often highlighted feelings of conflict when discussing CPM with their clinicians, suggesting that clear and sensitive communication around this treatment pathway is important to patients' experiences of decision making and wellbeing. Clinicians need to be aware of the complexity of women's motivations for CPM and mindful of how referral to psychological services are framed in order to avoid feelings of stigma. It is suggested that women could benefit from signposting to appropriate peer support when making treatment decisions; service providers might usefully consider their role in facilitating these peer support networks.

Summary

Women in this study described the challenge of defending their decision to have CPM, concerns that their desire for surgery might be considered 'abnormal' and often sought support and reassurance from others who have been in a similar situation. Their decision to have CPM was related to the future relationship they wanted to have with their bodies, allowing them to achieve symmetry, reduce the distress they associated with their remaining breast, and move forward. This study highlights the importance of interactions with healthcare professionals in the decision making experience, the role of peer support, and the need to fully understand the potentially complex and multifaceted nature of each woman's decision to seek CPM.

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Conflict of interest statement

No conflict of interest has been declared by the authors.

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Data availability statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Table 1. Questions included in the interview protocol

Interview protocol
<p><i>Questions in this schedule were used as a guide and may have been added or removed depending on individual participant's responses.</i></p> <ul style="list-style-type: none">- Could you start by giving me an overview of your diagnosis and treatment?- What were your reasons for having CPM?- How did you make that decision?- Do you remember who first initiated the discussion about CPM?- Do you feel that you were actively engaged in the decision making process? Did you have breast reconstruction following CPM?- What advice would you give to women considering CPM?- What advice would you give to breast care teams caring for women who are considering CPM?- How do you feel about the outcome of surgery?- Finally, is there anything else you would like to say about your experience or anything we discussed today?

Table 2. Participant demographic information.

		Number of participants (%)
Diagnosis	Breast cancer	18 (66.7%)
	Ductal Carcinoma in Situ	1 (3.7%)
	Multiple diagnoses (e.g. Breast cancer and DCIS)	8 (29.6%)
Ethnicity	White	26 (96.3%)
	Mixed/multiple ethnic group	1 (3.7%)
Been told they had increased risk of future breast cancer	Yes	10 (37%)
	No	15 (55.6%)
	Don't know	2 (7.4%)
Treatment provider	National Health Service (NHS)	25 (92.6%)
	Private provider	2 (7.4%)
Had breast reconstruction	No	19 (70.4%)
	Yes – immediate	8 (29.6%)
	Yes - delayed	0 (0%)

Table 3. Themes and sub-themes, with demonstrative quotes.

Theme	Subtheme	Participant quote
Sanity check	Battling for CPM	"...you're at your weakest lowest point, you've just come out of chemo, you feel absolutely horrendous and battered, and then you've got to go through a fight..." – Samantha
	Feeling stigmatised	"when you say you want to have the other breast off and they said 'well you need to see a psychologist', it makes you feel like, it's another thing that backs up that you feel like a freak, because if you were going for a reconstruction you don't have to see that psychologist, so it's like they're questioning your sanity..." - Deborah
	Seeing similar others	"...if it hadn't been for that online social media support group I would have still felt months later like I was the only person" - Michelle
Reclaiming the body	Being true to self	"It was after about a year of looking in the mirror, the flat side was the right side, you know, it was the great big boob left hanging there that looked wrong" - Deborah
	Moving forward	"It felt like unfinished business, it feels like that's finished now." - Rachel